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**Research in Care Homes
Issues of participation and citizenship**

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Abstract

Across Scotland, there is a lack of research in care homes. This thesis explores this topic by examining links between inclusion, participation in general and participation in research and whether those who work and live in the care home environment experience social citizenship.

Using a national survey and interviews with residents, staff, relatives and experts in care home research, this thesis investigated whether participation generally was linked to participation in research for residents, staff and visitors in a care home setting. The thesis further explored how social citizenship functions in a care home environment and whether there is a link between participation and citizenship.

The findings suggest there is a lack of general participation which is connected with the leadership style and management within the care homes. There is misunderstanding about research and legislation amongst the care home staff, residents, visitors, as well as the junior research staff which inhibited staff and resident participation. Furthermore, citizenship is not experienced universally by residents or staff due to disempowerment, and exclusion occurs amongst residents due to age, frailty and dementia. By facilitating good leadership, communication and relationship-building such issues may be overcome.

In addition, the analysis suggests a link is evident between inclusion, participation and citizenship. Where choice is provided and residents have their social position maintained, as well as have a degree of responsibility for shaping events, this leads to participation and inclusivity as described in Bartlett and O'Connor's (2010) definition of social citizenship. Furthermore, if inclusion is adapted for cognition and frailty, then participation leads to the experience of social citizenship, encouraging a culture which can welcome research.

The explicit emphasis on inclusion and participation in research has enabled this under-researched area of participation and experience of social citizenship in care homes to be more fully explored.

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Chapter 1 Introduction

Across Scotland, there is a lack of research in care homes. This thesis explores this topic by examining links between inclusion, participation in general and participation in research and whether those who work and live in the care home environment experience social citizenship.

There are over 900 care homes for people aged over 65 in Scotland providing care to approximately 32,000 residents (Information Services Division (ISD), 2014). Of these residents, the Scottish Care Home Survey in 2014, identified that 65% had dementia. Twenty-five percent of people living with dementia in Scotland are in a care home (Alzheimer Scotland, 2016). With this in mind, the realisation of the importance, both politically (Scottish Government, 2016; Department of Health, 2015; Scottish Government, 2013; Department of Health, 2013) and sociologically, (Carmody, Traynor and Marchetti, 2015; Prorok, Horgan and Seitz, 2013; Brooker, 2004; Sabat, 2001) of dementia research in all settings is growing despite Government spending on dementia research still lagging behind other major disease areas such as cancer and heart disease (Alzheimer's Research UK, 2013). With the growing interest in and emphasis on dementia research following the G8 summit (Department of Health, 2013) and in particular an increasing emphasis on encouraging care homes to participate in research (NIHR, 2013), this is an area which requires more examination of issues for those in a care home setting.

The thesis has four core aims:

Firstly, I aimed to explore the opportunities to contribute to research, for people who live or work in a care home, including those people who have dementia.

Secondly, I aimed to consider factors affecting care home staff and residents which may influence participation in general and in research, including social attitudes regarding people with dementia.

Thirdly, I aimed to explore how participation generally links to participation in research for residents, staff and visitors in a care home setting.

Finally, I aimed to explore how citizenship works in a care home environment and whether there is a link between inclusion, participation and citizenship within the care home environment.

This thesis explores issues of participation and citizenship within the context of a care home, particularly for residents with dementia. The research questions are as follows:

Research Question 1 - How do people who live and work in a care home participate generally and in research?

Research Question 2 - Which factors in the care home influence participation generally and in research?

Research Question 3 - What aspects of social citizenship can be observed and what influences social citizenship within a care home?

Research Question 4 – To what extent can we establish a link between participation generally and in research and social citizenship?

Using findings from my field work, this thesis will address the research questions posed to generate new ways of thinking and enhance understanding about citizenship, participation and inclusion in research within a care home environment.

BACKGROUND

There has been an increase in interest around how much dementia research there is nationally. The Prime Minister's challenge on dementia (Department of Health, 2012) and 'Dementia 2020' (Department of Health, 2015) sought to involve 10% of people with a diagnosis of dementia in research. This target was not being met, with participation rates around 4% in England and 1% in Scotland (Law, Russ and Connelly, 2014) but there continues an investment in dementia research by both the UK and the Scottish Government. Furthermore, Scotland's National Dementia Strategy:2016-2019 (Scottish Government, 2016) has outlined a commitment to research stating a continuation of support to research through funding with the objective of bringing together the range of dementia research interests in Scotland and maximising the impact of, and funding opportunities for, research. In the United Kingdom, the James Lind Alliance, a group acting as an independent facilitator who undertake priority setting partnerships with charities, people affected by a particular disease, carers, clinicians and lay people, carried

out a priority setting partnership which published its results in mid-2013 (Alzheimer's Society and James Lind Alliance, 2013). This process aimed to identify the unanswered questions in dementia research, which resulted in a short list of 10 priorities for dementia research. Interestingly, 6 of the top 10 priorities involved people with dementia in a care home setting (Alzheimer's Society and James Lind Alliance, 2013). This may indicate that the issue of research in care homes is a priority in research.

The increase in research interest in dementia has recognised that there is a significant proportion of people with dementia living in care homes. In December 2013, to coincide with the G8 summit on dementia research (Department of Health, 2013), the Economic and Social Research Council (ESRC) announced, along with the National Institute for Health Research (NIHR), that it had awarded £20 million to six research projects which will significantly add to the understanding of dementia. Of the six projects funded, one study is specifically targeting people in care homes and four others will involve people in care homes. The NIHR also established ENRICH (Enabling Research In Care Homes) (Davies et al, 2014; NIHR, 2015) to assist in bringing research into the care home sector and helping care homes to be 'research ready'.

The landscape in dementia research is therefore becoming more inclusive. Moreover, a sample of Scottish people with dementia and their carers expressed that not participating in dementia research was a form of deprivation (Law, Russ and Connelly, 2013). In this study participants expressed the opportunity to participate in research must be offered to all people with dementia wherever they are living therefore the increase in inclusivity is welcomed. This thesis furthers this work by enabling those who live and work in a care home, including those people with dementia, to be involved.

The premise of this thesis centres on three core concepts: inclusion, participation and social citizenship. These concepts are explored in detail, considering factors affecting the care home which influence participation in research and social attitudes regarding people with dementia. Other forms of inclusion and participation, such as inclusion and participation in day-to-day living in the care home will be explored to assist in understanding these issues. I will investigate whether inclusion and participation are linked, because inclusion is seen as necessary to be able to participate (Dewar, 2005; Brannelly, 2006). This thesis explores whether care home residents can participate and exercise their citizenship within the context of a care home, in the form of social citizenship

whether or not they have dementia. This thesis will generate new ways of thinking and enhance understanding about social citizenship and participation in general and in research within a care home environment. It will provide a greater understanding of issues of social citizenship to inform and enrich future research conduct and involvement of people with dementia living and working in care homes.

CONTEXT AND DEFINITIONS

The research reported in this thesis was conducted in care homes. A care home in Scotland is a residential setting where a number of older people live, usually in single rooms, and has access to on-site care services. A home registered simply as a care home will provide personal care only, such as help with washing, dressing and giving medication. Some care homes are registered to meet a specific care need, for example dementia or terminal illness. Dual-registered homes no longer exist, but homes registered for nursing care may accept people who just have personal care needs but who may need nursing care in the future. For the purposes of this study, all the homes are referred to as 'care homes'.

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language (Alzheimer's Association, 2016). Dementia is caused when the brain is damaged by diseases such as Alzheimer's disease or a series of strokes. Dementia can also be caused by trauma and anoxia which are not diseases (Burns and Iliffe, 2009). For this thesis, for the resident to be classified as having dementia, they should have a formal diagnosis of dementia made by a clinician.

'Participation' and 'inclusion' are terms I have used throughout the thesis and it would be useful for the reader to understand the context in which I use these terms. 'Inclusion' is described as a passive "presence rather than activity" by Bartlett and O'Connor (2010:44) whereas participation recognises agency and active involvement (Kitwood, 1997). When discussing participation there are two types of participation of interest to this thesis – one is participation in society and the other is participation in research. Notably Bartlett and O'Connor (2010) recognised one person's methods of participation may differ from another's which is a consideration for my thesis because of differing groups of interest i.e. staff, residents, residents with dementia and relatives.

Moreover this thesis is concerned with the link between inclusion, participation and social citizenship and what citizenship means to people who live and work in a care home environment. Therefore it includes a critique of citizenship in the

literature review to explore different models used. The context and definition used for citizenship for the purposes of this thesis, is social citizenship:

> "Social citizenship can be defined as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level" (Bartlett and O'Connor, 2010:37).

This was chosen as the most fitting definition found for those living in a care home. I will discuss in more detail the rationale for this choice in the literature review.

OVERVIEW OF THESIS CHAPTERS

The project has been conducted to enhance understanding of inclusion, participation and social citizenship, in the context of a care home environment, including those people living and working in a care home, some of whom may have dementia.

I have collected data which has enabled me to conduct an analysis of the issues surrounding inclusion, participation and citizenship in a sample of care homes. In this thesis, I will explore whether care homes are involved in any depth in research. I will explore whether participation and inclusion in general, in these care homes is present or lacking and which factors such as organisational issues, policies and legislation, environment, staffing and leadership can influence this within the care home. I will study social citizenship for people who live and work in a care home environment and how this concept affects people who have dementia. I will investigate whether participation, inclusion and citizenship are linked and whether improved participation, inclusion and citizenship might increase research participation within this community of people. My data will enable me to develop the line of reasoning and add to the literature that inclusion, participation and citizenship may be linked.

Chapter 2 is a review of the literature which details how the literature was accessed and assimilated over three different time points during the project. The review of the literature describes the initial exploratory approach to finding literature and how this process was refined during the subsequent literature reviews to yield papers of interest to the subject of the thesis.

The literature focuses on some factors which may influence inclusion, participation and citizenship in a care home environment such as legislation, policiesand gatekeeping, by ethics committees or care home managers. It also identifies factors affecting care homes such as the physical environment, leadership, communication and work-force support which may be either facilitative or constraining to inclusion and participation generally and in research in a care home. This thesis contextualises in wider debate through the literature, the issues of differing citizenship models and how the model of social citizenship relates to inclusion and participation in research, within the care home environment. The literature review examines participation generally and then more specifically relating to research within a care home environment. It examines the concept of personhood and how this relates to inclusion, participation and citizenship. Above all, the literature helps to frame the idea that inclusion, participation and citizenship may be linked and that involvement in research for those living and working in a care home environment is contingent on the levels of participation and citizenship experienced by the people involved.

Chapter 3 is the methods chapter and describes the research design and execution for this thesis to answer the research questions posed. The research is carried out in 2 phases:

Phase 1, included a national survey of all care homes in Scotland and key informant interviews. The national survey was sent to all available care homes in Scotland, to gauge care homes' present and previous involvement in research and which factors were facilitative or constraining to research. The key informant interviews were one-to-one semi-structured interviews with researchers who were experts in the field of research in care homes.

Phase 2, included the identification of 3 care homes for the fieldwork phase of the study, including interviews, focus group and general observation. This phase included interviews with the manager, staff, residents and visitors including one resident in each care home who had dementia, about their views on research, being involved and included in the care home and what citizenship meant to them. Included in this chapter is the ethical review process including submission to two different ethical committees, and the selection process for the care homes and participants.

To explore the research questions required the views of people who live and work in the care home environment including those living with dementia. The

methods chapter finishes with a section on the strengths and limitations of the processes including the interviews and how they were crucial in understanding the link between participation, inclusion and citizenship and the communication tools used and how the insights from their use inform the next chapter – the findings.

Chapter 4 outlines the findings from the national survey of the care homes in Scotland, the key informant interviews, the general observations and the care home interviews. I will show from the national survey that there was a scarcity of research on any subject in care homes. The key informant interviews suggested that the manager was key to facilitating research and staff attitudes were dependent on the manager's leadership. I will show that consideration of physical environment, physical capabilities and emotional issues of residents and staff within the care home environment, coupled with the qualities of the staff involved in research in care homes were paramount to overcoming barriers and maximising facilitators. These findings strengthen the argument of how policies and legislation can be a barrier to research, that several factors affect research involvement and that research participation is related to inclusion and participation in general as well as citizenship. The analysis of the findings is discussed in the discussion chapter.

The discussion chapter draws together the findings of the national survey, the key informant interviews, the care home interviews and observations made during the field work. I have further developed the debate around factors which firstly, affect general participation for residents, residents with dementia and for staff and affect research participation. I debate citizenship and how it is experienced in care homes and I debate that general inclusion and participation in care homes is linked to research participation, inclusion and citizenship. Finally I present an overview of the key arguments.

Chapter 6 concludes the arguments of my thesis. It considers the implications of my research, what research should follow on from this and the strengths and limitations of the thesis.

This introduction has outlined the intended aims, arguments and research questions of this thesis, using a chapter-by-chapter summarisation. Having provided an overview of the thesis and its structure, the next chapter will present the literature review.

Chapter 2 Literature review

Introduction

This chapter details the three literature reviews that were conducted and reviews the evidence from the literature on inclusion, participation, citizenship and research for those living and working within a care home environment, including people with dementia. The first literature search was a general background search to scope the extent of the literature on care home research and concepts of citizenship, inclusion and participation (see Table 1). The second literature search was conducted following the national survey and key informants interviews, which enabled the review to be more systematic and targeted by categorising the literature into subject topics of interest. The third literature review was completed following the fieldwork to try to capture any recent literature of interest and to include it in the review of evidence.

Each literature search was an iterative process, building on the knowledge gained during the fieldwork and the analysis of the findings of the thesis so far. An adjunct to the formal literature searches was the more informal methods of discovering literature: from experts in this field during informant interviews recommending literature; through supervision at Stirling University; and by taking opportunities at conferences and meetings to talk to people who had knowledge around this area. The literature was read over the course of the thesis and the analyses of the literature were amalgamated to inform and contribute to the arguments in the thesis. Table 1 details the criteria used and outputs of the literature searches.

TABLE 1 LITERATURE REVIEWS 1, 2 AND 3

Literature review 1 – General background search to scope extent of literature			
Search terms	**Search engines and date criteria used**	**Numbers of papers yielded**	**Number of papers used and subject headings**
Dementia, Alzheimer's, participation, inclusion, consent, research, care homes, nursing homes, residential homes, citizenship	CINAHL, Sociological Abstracts via ProQuest and OVID No date restrictions	Not noted	As this was a scoping exercise to gauge the extent of the literature it was more informally conducted and numbers of papers were not counted.
Literature review 2 – Focussed search of the literature following initial fieldwork			
Search terms	**Search engines and date criteria used**	**Number of papers yielded**	**Number of papers used and subject headings**
Dementia, Alzheimer$, participation, inclusion, consent, capacity, research, care homes, nursing homes, residential homes, citizenship, human rights	ASSIA, CINAHL, ProQuest Hospital collection, Psych Articles, Social Services abstracts	317	55 participation in research and inclusion and exclusion generally; 12 on citizenship and human rights; 26 on care homes and research; 10 on agency, communication, capacity and consent and dementia.
	Ovid, Medline, Embase	17	
	University of Stirling: British humanities Index, International Bibliograph of the Social Science World Wide Political Science Abstracts and Sociological abstracts	26	
	CINAHL, Psychology and Behavioural sciences collection and Psychinfo No date restrictions	22	
		Total 382	**Total 103**

Literature review 3 – Search using the same criteria as review 2 following completion of the fieldwork			
Search terms	**Search engines and date criteria used**	**Number of papers yielded**	**Number of papers used and subject headings**
Same as 2	Same as 2	51	9 on participation in research and inclusion and exclusion generally;
	Google scholar	11	3 on citizenship and human rights;
	Theses	9	4 on care homes and research; 2 on agency, communication, capacity and consent and dementia.
		Total 71	**Total 18**

LITERATURE REVIEW 1

The first literature review was a background search to scope the extent of the literature and to guide the next stages. It searched on both the University of Stirling and NHS Knowledge network databases of CINAHL, Sociological Abstracts via ProQuest and OVID search form using search terms of "dementia", "Alzheimer's", "participation"," inclusion"," consent", "research", "care homes", "nursing homes", "residential homes" and "citizenship" tested in a range of combinations to yield key papers, books and policy documents (see Table 1). Key documents were used as a source for further literature such as INVOLVE Evidence Bibliography 5 (INVOLVE, 2014), the PIECE-Dem report (Brooker et al, 2011) and the CHOICE report (Killett at al, 2013). The topics of interest in linking inclusion, general participation, research participation and citizenship within this community of people is fundamental for this thesis. This first literature review was a general search of the literature and the output was not recorded.

LITERATURE REVIEW 2

The second literature review was structured as described in Table 1 following NHS ethical approval of the research. The issues of capacity and consent became more relevant following the key informant interviews. ASSIA, ProQuest Hospital collection, Psych articles and social services abstracts were searched using the terms "dementia", "Alzheimer$", "participation"," inclusion"," consent", "capacity", "research", "care homes", "nursing homes", "residential homes",

"citizenship" and "human rights" and then were searched in combinations with an output of 317 possibly relevant papers. This process was repeated using Ovid, Medline and Embase which yielded 17 further papers. The same search terms were used in the University of Stirling's databases of British Humanities Index, International Bibliography of the Social Science World Wide Political Science Abstracts and Sociological Abstracts with an output of 26 articles of interest. Finally searched was CINAHL, Psychology and Behavioural sciences collection and Psychinfo yielding a further 22 papers. There were no date restrictions entered into the search terms. This led to a total of 103 papers of interest: 55 on participation in research and inclusion and exclusion generally; 12 on citizenship and human rights; 26 on care homes and research; 10 on other relevant subjects such as agency, communication, capacity and consent and dementia.

LITERATURE REVIEW 3

The third literature review was performed at the end of the fieldwork stage. The review used the same databases and search terms as Literature review 2 and had an output of 51 papers. Google Scholar was used as a supplementary search tool and this revealed a further 11 papers of interest by using key papers already reviewed and using the 'similar articles' tab below the article of interest. Finally, there was access to a recent unpublished doctoral thesis (Watson, 2015) yielding a further 9 papers. The literature review is presented with a summary and conclusion to follow.

The care home environment

The care home population is getting older with a corresponding increasing frailty. The average age of the population of care homes in Scotland has increased between 2005 and 2014 by 14% in the 85 to 94 age group. This age group now represent nearly half of the long stay residents in care homes (ISD, 2014).   The World Alzheimer Report found that the focus for research in care homes was predominately on care and researchers found that encouraging people to participate in research was more difficult due to frailty(Alzheimer's Disease International (ADI), 2013). In keeping with the ADI report Mitchell and Koch (1997) described involving those residents who have advanced frailty and confusion who were unable to articulate their needs, with the researchers concluding that this was a very difficult process requiring sensitivity from them.

Mjorud et al (2014) found the severity of dementia is associated with reduced quality of life for people within the care home environment.

Care homes are moving away from being an alternative form of housing for frail older people towards being viewed as a "location of last resort for individuals with high support needs towards the end of life" (Lievesley, Crosby and Bowman, 2011:3). The afore-mentioned researchers' care home census carried out by BUPA in 2009 showed that care home residents are predominately female and aged over 65 years, with 75% experiencing some form of neurological disorder. Similarly, Wild and Kydd (2016) in their literature review on culture change in care homes found people entering care homes were doing so because they can no longer manage at home due to physical or mental health deterioration.

Care homes have improved in comfort and quality since the researcher, Peter Townsend's (1962) seminal work 'The Last Refuge' where he described visiting and reporting on 173 public, voluntary and private care homes for older people in England in the early 1960's. One of the major changes since that time is the shift from public to private sector provision with NHS and Local Authority places declining significantly from the mid-1980s to 1998 (Lievesley, Crosby and Bowman, 2011). This decline in public provision continues with the latest care home census showing the numbers of residents who are in NHS or Local Authority care home to have decreased by 33% between March 2000 and March 2014 (ISD, 2014). Researchers continued to be interested in whether the quality of care had improved in proportion to the comfort and quality of environment, as benchmarked in Townsend's research (Bowers, Fibich and Jacobson, 2001; Edwards, Courtney and Spencer, 2003). Furthermore, Gaugler (2016) shows that although quality of care topics may have evolved to include contemporary issues such as hand washing and bariatric provision for society's increasing obese population, quality of care in all respects, is still an important concern for researchers.

Furthermore, residents who were assisted in their acceptance and adaptation to their living situation in the care home had a more positive attitude and were more able to make active decisions about participation in the life of the care home (Bradshaw, Playford and Riazi,2012). Similarly, Killett et al (2013) found that person-centred activity and engagement with residents developed within the culture of the care home was integral to inclusion of residents.

Evans and Goodman (2009) noted the heterogeneity among care homes a view shared by Killett et al (2013) and Zimmer (1985). An 'enormous diversity' is described in Lawrence et al's (2012) meta-synthesis of 39 papers describing the aspects of successful implementation of psychosocial interventions in care homes. The variability of the care homes was noted meaning researchers have to take into consideration there may be great differences amongst the homes and their residents. This was described by Jenkins et al (2016) and shared by Luff, Ferreira and Meyer (2011)

Tune and Bowie's (2000) study of 46 care homes found that the physical care home environment can be both a facilitator and a constraint to research with the environment generally being good, but the provision of reality orientation cues, such as calendars and large faced-clocks, being poor. Similarly Popham and Orrell (2012) found the influence of the physical environment on residents' ability to participate in activities within the care home and also to have some privacy to communicate with others was a significant factor in active participation. Popham and Orrell (2012) researched what matters for people with dementia in the care homes and found that the identified themes included activity and interaction, freedom and safety, dignity and privacy, design and environment were all aspects which mattered to people. Furthermore, Higgins (2013) described the difficulties in maintaining privacy during interviews, and similarly Hall, Longhurst and Higginson (2009) found the environment problematic in finding opportunities to conduct interviews. On the other hand in Bradshaw, Playford and Riazi's (2012) systematic review on quality of life in care homes they found among other things that meaningful daily life facilitated by a conducive physical environment contributed to residents having feelings of autonomy and greater control.

Luff, Ferreira and Meyer (2011) argued the core function of the care home is to provide care. Likewise, the Alzheimer Society (2009) observed that providing specialist care is the main function of care homes. Other researchers identified different types of care: one which may be 'task-centred care' (Wilson-Brown and Davies, 2009) or 'person–centred care' (Kitwood, 1997). Furthermore, Mead and Bower (2000) and Brownie and Nancarrow (2013) observed that person-centred care is the goal striven for in care homes. The core focus on care may make it difficult to incorporate a research focus and more general concepts of citizenship.

COMMUNITY

The idea of community and people living in care homes is discussed by Davies and Brown-Wilson (2007a) where the concept of a 'community' within the care home setting is illustrated. They reference social exchange theory where Emerson (1976) described this as: "a two-sided mutually contingent and mutually rewarding process involving 'transactions' or simply 'exchange'" (Emerson, 1976:336). Both Baldwin (1978) and Thye, Lovaglia and Markovsky (1997) found the use of power in the exchanges between staff and residents was a negative aspect in their interactions. Trybou et al (2014) recognised a positive aspect when social exchange theory is applied to nurses and care assistants in care homes. They found that if staff perceive a high level of social exchange then they will be prepared to work more productively in the organisation. These power exchanges are important when considering the effect on participation.

Furthermore, Nelson (2000) argues that the structure of dependence and control inherent in care homes can eliminate the fair exchange in the framework of social exchange theory. This is explored in more detail in Higgs and Gilleard's (2015) observations of the 'abjection' experienced by residents and staff working in care homes, where abjection defines people without power.

CONDUCTING RESEARCH IN CARE HOMES

The literature suggests there are constraints in conducting research before even entering the care home environment. Luff, Ferreira and Meyer (2011) found the importance of preparing the care home for the impending research by communicating with the manager and the care home staff was crucial to success. Hubbard, Downs and Tester (2003) reiterated this with the emphasis on planning ahead highlighted. Likewise, McMurdo et al (2011) found that research participation by older people needed careful consideration when planning time and place for research, so that people could attend.

Munk and Murphy (2012) and Tolhurst (2014) described the process of gaining approval as subject to repeated criticisms by researchers. Jenkins et al (2016) contributes to this viewpoint describing the difficulties encountered, such as lack of understanding of social sciences based research projects from the committee members, in gaining ethical approval through the NHS Research Ethics Committee system.

Some researchers e.g. Warner et al (2008) and Jenkins et al (2016) have cast doubts on the clinicians' and researchers' concepts of capacity and its

assessment. It is a topic which is acknowledged in the literature as troublesome to researchers in how they interpret the legislation. Dewing (2007), Luff, Ferreira and Meyer (2011) and Dewar (2007) described interpreting the legislation for a group of people, such as those with more advanced dementia living in care homes. Later in the chapter I will discuss the application of legislation in care homes.

Lack of time to do research was one of the reasons given by both staff (Jenkins et al, 2016) and residents (Heath, 2007) to other researchers when they encountered difficulties in encouraging people to participate in their research. Hall, Longhurst and Higginson (2009) found one difficulty in conducting research was seizing opportunities to speak to residents and staff within their busy daily routine. Likewise, Zermansky (2005) described the time window in which a researcher could talk to residents as short. Similarly, Mold et al (2008) when studying the needs of minority ethnic older residents in care homes found that the most repeated excuse for not participating, from managers, was lack of time as well as suspicion around the reason for the research.

Sensory impairment has been reported in conducting research and how this could impact on the ability of residents to participate and communicate with the researcher and with each other. Jenkins et al (2016) found this could be due to both vision and hearing loss. Cook, Brown-Wilson and Forte (2006) described difficulties in enabling interviews to be conducted due to noise intrusion from other residents. They observed televisions, radios and music systems being played with the volume turned up loud which further disabled those with hearing impairments to engage with the researcher. The researchers agreed that the staff play a vital role in ensuring the environment is optimal to enable the resident to be fully engaged (Jenkins et al, 2016; Cook, Brown-Wilson and Forte, 2006; Barba, 2002).

Gatekeeping in care homes can have an effect on research due to researchers not being able to access participants. King and Horrocks (2010) offer a useful definition of gatekeepers in research as:

> "Someone who has the authority to grant or deny permission to access potential participants and/or the ability to facilitate such access." King and Horrocks, 2010:31

Brown-Wilson et al (2013) found that the gatekeepers were vital to the success (and failure in some parts) of their study while Hellström et al (2007) found that

gatekeepers were able to exclude people with dementia in participating in research and forewarn researchers to be aware of informal gatekeepers. Brown-Wilson et al (2013) experienced gatekeeping which was excessive and disabling to their research from the next-of-kin of people with dementia, by not allowing people with dementia to participate in their research. On the other hand, Higgins (2013) in her study on how to involve people with dementia in research, while acknowledging that gatekeeping provides the appropriate safeguards when researching this vulnerable group of people, also states the challenge for researchers is to ensure that a paternalistic and exclusionary approach is overcome.

Meanwhile, gatekeepers may be resistant to allowing the researcher access to the resident because of their interest in the person they are 'protecting' as found in Jenkins et al's (2016) paper in overcoming challenges to conducting research in care homes. People act as gatekeepers to protect the person who is in their care. Some insights are offered by Sherratt, Soteriou and Evans (2007) to the negotiations needed with gatekeepers such as the use of skills in communication and preparation to overcome this. The researchers say that the study should not be invasive and should be directly applicable to caregiving or management issues. Likewise, McNeely and Clements (1994) argue that gatekeepers will be more likely to support this non-invasive type of research.

LEADERSHIP AND HOW THIS INFLUENCES PARTICIPATION IN RESEARCH IN CARE HOMES

The literature suggests that good leadership can encourage research, support participation, engender citizenship and promote a positive culture in care homes. Moiden (2002) discussed the importance of a mixture of leadership styles, with democratic and autocratic styles used at the appropriate moments, seen as the best type of leadership i.e. knowing when to use what. Furthermore, Scott-Cawiezell (2005) showed that leadership in care homes is essential to sustain improvements and was related to lower staff turnover, better working environments, good communication and stronger links between staff. Furthermore, Killett et al (2013) illustrated that good leadership engenders staff involvement in decisions and a positive culture of inclusiveness within the care home. Importantly, Scott-Cawiezell (2005) noted the manager's influence is crucial in promoting participation in care homes for all those who work and live in the care home. Similarly, Davies and Brown-Wilson (2007b) observed that good

leadership can encourage research, promote participation and engender citizenship in care homes.

Supporting this view point is Pennington, Scott and Magilvy (2003) who discuss the importance of good leadership in the care home as vital for the creative culture and growth of staff enrichment as a positive movement. Similarly, Brownie and Nancarrow (2013) and Wild and Kydd (2016) found the manager played an integral role in the culture of the care home and therefore its accessibility to researchers and the ideas and participation in research. They found that successful changes in culture have been ascribed to good leadership and stable management within the care home environment. Similarly, Goodman et al (2011) and Jenkins et al (2016) found that spending time with the managers in forming relationships time well spent in fostering research and increased care home input in research.

Anderson, Issel and McDaniel (2003) reported that involving staff in the decision-making process led to better outcomes for the residents served. They found that practices instigated by the manager to increase communication and interaction amongst people led to better resident outcomes, a finding shared by Froggatt, Davies and Meyer (2009). They found that relationship–orientated behaviours by the care home leader led to better resident outcomes with less falls. Furthermore relationship-orientated leadership defined by maintaining good relationships with staff, led to a positive culture in the care home. While Moyle et al (2003) found that job satisfaction was related to workplace flexibility but managers had to put in strategies to maintain this.

Conversely, poor leadership could lead to sources of job dissatisfaction with instances of poor planning and poor explanation of decisions that affect the care home (Moiden, 2002). Kane et al (1997) previously found that negative staff attitudes which emanate from poor leadership created disempowered staff. More recently, Bailey et al (2015) found that poor leadership breeds a culture of negative power dynamics which would find the supporting of participation in any activity for residents problematic. Similarly, Wild and Kydd (2016), found poor leadership can perpetuate an unhealthy culture which is demeaning to the residents. Both Wild and Kydd (2016) and Cleary (2004) found the culture of the care home can be influenced externally by the corporate policies that are imposed on the care homes and this is particularly relevant in care home 'chains'. As Jenkins et al (2016) described, this could be a factor in the care homes

participating in research as the chain management has to be consulted and agree to any research participation

Communication and relationships

COMMUNICATION

The literature enables us to enhance our understanding of how relationships flourish and develop in the care home environment. It assists us in having an appreciation of the relevance of communication and how it can augment relationships between the workforce and people who live in the care homes, whereby we are more likely to understand what would enable people in this environment to engage in research. In Killick and Alan's (2001) seminal book on communicating with people with dementia, they explain that good communication is a facilitator for inclusion and participation in all activities within the care home.

Several researchers argue the implications of positive communication. Burgio et al (2001) observed communication-based interventions were found to improve residents' ability to engage socially, which would have implications for participation. Likewise, Aveyard and Davies (2006) and Williams, Kemper and Hummert (2016) found positive communication a significant facilitator to inclusion and participation of people living and working within a care home environment. While Jenkins et al (2016) described the importance of good communication when overcoming challenges in research in care homes. Furthermore, Scott-Cawiezell (2005) discusses the influence of good clear communication on participation in decision-making for all those living and working in a care home. This resonates with the idea of the importance of communication:

> "the need to listen and hear what people have to say and to respond in a meaningful way that respects personal preferences and with a negotiated form of agency taking account of the rights and responsibilities of citizenship" (Gilmour and Brannelly, 2010:245).

The links between enabling participation and enabling citizenship are becoming apparent through the lens of communication and how positive communication can support inclusion, participation and social citizenship.

ETHIC OF CARE

Brannelly (2006) highlighted the practice of care underpinned by an ethic of care, which was argued to strengthen and enhance citizenship for those with dementia and to facilitate participation in care. Likewise, Barnes and Brannelly (2008) say that an ethic of care based on attentiveness, competence and trust, responsibility

and responsiveness all increase the understanding between the practitioner, the person with dementia and their families and increase the participation of the person with dementia in many aspects of their daily lives. Furthermore, Goodman et al (2011) and Higgins (2013) suggest this ethical approach may enable participation of people with dementia and other care home residents in research due to increased levels of understanding and an enhanced sense of belonging and citizenship.

The converse of this is the ethical implications of poor communication and where it can distort power relationships and any interactions the person with dementia has with those around them (Killick and Alan, 2001). This aspect is relevant for those who are residents in a care home as they are lacking in power not by being a resident but also a person with dementia, meaning that their status could be seen to be lower than other residents (Jervis, 2002). This may fundamentally affect the person's ability to experience citizenship, as social citizenship as defined by Bartlett and O'Connor (2010) is based on the premise of freedom from discrimination, to have recognition of the person's social position and upholding of personhood. People with dementia may find it more difficult to be heard because of their low status and may experience disempowerment due to communication difficulties (Williams et al, 2009). This is supported by the findings of the Alzheimer's Society survey of 4,084 carers, care home workers and managers which concluded that people with dementia were excluded from activities of the home because of the label 'Dementia' (Alzheimer's Society, 2008).

The exclusion of those with dementia may contribute to people not experiencing social citizenship. The idea that "relationships become the context in which persons and communities develop and survive" (Davis, 2000:296), is of relevance to the concept of inclusion, participation in general and in research and citizenship in care homes. Developing positive relationships can help to understand the subjective experience i.e. "the perceptions and meaning of the person with dementia" (Bartlett and O'Connor, 2010:26). Also, the interactional environment such as participation in activities and the use of physical space and the sociocultural context which recognises ethnic positioning, gender and socioeconomic positioning on a person's autonomy and independence (Bartlett and O'Connor, 2010), all of which are central to understanding participation and social citizenship.

DEMENTIA

The special role of communication and the importance of being able to communicate meaningfully with people with dementia are highlighted by Killick and Alan (2001). They suggest that there has been a prevalent culture of ignoring what the person with dementia has to say, which undermines their personhood and eventually leads to behaviours which challenge the onlookers such as withdrawal, disturbed language and lack of competence, which in turn "magnify our own distorted responses, which triggers deeper distress and disorganisation in the individual" (Killick and Alan, 2001:19). This leads to a downward spiral of malignant communication with the person with dementia and taints any future ability to communicate in a meaningful way.

Kitwood (1997) described the observation of personhood being undermined in care settings as 'Malignant Social Psychology' which could include the person with dementia being intimidated, not responded to, infantilised, labelled, disparaged, blamed, manipulated, invalidated, disempowered, disrupted, objectified, ignored, mocked, banished and outpaced. The concept of malignant social psychology and development of personhood grew from the observations of the way people with dementia were inhibited and treated in the care home environment (Brown-Wilson et al, 2013). Williams et al (2009) evidenced that 'elderspeak' (infantilising communication used by care staff) can increase resistiveness. Higgs and Gilleard (2015) reflect on how the abjection of people with dementia in care homes goes hand in hand with an ambivalent relationship between the carer and the cared for.

The concept of personhood has effectively brought the person with dementia into the frame (Kitwood, 1997). Personhood and participation are intertwined when attempts are made to understand the subjective experience of dementia (O'Conner et al, 2007). Flesner and Rantz (2004) found the issue of mutual respect and empowerment through person-centred care was advocated as a tool for positive change which aided communication and created empowered staff and residents. It is necessary to understand the subjectivity of participation –each individual will be able to participate but it will be to different degrees depending on the person's abilities and interest. One group of researchers advocate "well-designed research studies are essential to inform the development of high-quality person-centred care" (Jenkins et al 2016:23) and in doing this, ensuring there is some form of involvement from the people being researched (INVOLVE, 2012). Personhood and the assumption and perceptions of loss of personhood precedes

other losses such as claims to liberty, privacy and the right to choose (Behuniak, 2010). Such losses are intrinsically linked into the loss or absence of inclusion, participation and citizenship as well as personhood.

There is still stigma surrounding dementia. Goffman (1963) wrote about social identity and stigma theorising that stigma is society's attitudes towards the attributes of a problem such as dementia, as not being normal. It is the relationships with others not the attributes which contribute to the experience of stigma: "There is a special kind of relationship between attribute and stereotype" (Goffman 1963:5). Researchers argue that stigma distorts services at all levels for people with dementia, concluding that non-stigmatising care focuses on personhood and relationships (Benbow and Jolley, 2012). Garand et al (2009) found a stigmatising impact of diagnostic labelling of people with dementia for research purposes and participation which had an effect on families and further stigmatised the person with the label.

Research involvement is a form of engaging agency and invoking citizenship (Boyle, 2014). People with dementia can be perceived by others to lack the ability to initiate social action and therefore lack agency (Boyle, 2014). This perceived lack of agency, as a negative social attitude, may be central in contributing to the exclusion of people with dementia in care homes. Agency theory (Emirbayer and Mische, 1998) relies on rationality, language and intentional action, one or more of which may be lacking in a person with dementia. Boyle (2014) describes the extant cognitive abilities of people with dementia as under recognised and therefore argues that agency is presumed to be lacking. This finding is reflected by researchers in care homes in North Europe showing that the proportion of those with dementia is around 80% (Heggestad, Nortvedt and Slettebo, 2013). Their study revealed that people in care homes were not given a voice to explore what is important to them. The assumptions made of older people not participating in research or other decisions is because "growing older inevitably results in reduced capacity for involvement" (Dewar, 2005:48) would further exclude people from engaging in research.

FAMILY, STAFF AND RESIDENT RELATIONSHIPS
The family's relationship with staff is important in many aspects of the residents care but of interest to this project is how this relationship may enable participation. Caron, Griffith and Arcand's (2005) study which looked at the implications of decision-making at the end-of-life in dementia in long term care

settings found that the dimension which emerged as vital to the family carer experience was the relationship with the health care provider. Meanwhile, Hertzberg and Ekman (2003) and Maas et al (2004) showed that there could be conflict and misunderstanding between staff and families in care homes.

Aveyard and Davies (2006) found that staff had the responsibility for acting on proposals within the care home, including the implementation of the research project, but frequently failed to draw on the expertise of the family carer. This limited the ability to establish the research within the care home as families objected to the resident's input if they had not been involved.

Dissatisfaction was utmost when there was poor communication between the family carer and the care staff. Several researchers identified that care home staff can find their relationships with family members challenging (Utley-Smith et al, 2009; Pillemer et al, 2003; Hertzberg, Ekman and Axelsson, 2001). This may have consequences for the ability of researchers to establish themselves in this setting of mistrust.

That said, Sumaya-Smith (1995) described the 'surrogate family bond' that develops between the carer and the resident. This is expanded upon by Grau, Chandler and Saunders (1995) who studied the importance of staff and their ability to communicate well and form positive interpersonal relationships with residents and the impact on the residents' perceptions of quality of care and well-being. Ghusn et al (1996) suggested that positive relationships, such as being respected for the past and having a sense of being needed are the basis for quality long term care while Anderson et al (2005) and Scott-Cawiezell (2005) found that positive communication and good team work will enhance decision-making and the experience for residents. Williams, Kemper and Hummert (2016) and Anderson et al (2005) found evidence that enhancing communication skills fostered good relationships between families and care home staff. This emphasis on the importance of positive relationships with staff enhancing residents' well-being was reflected recently by Eldh et al (2015) who observed that the sense of accomplishment and fulfilment experienced by staff enhanced their relationship with the residents, with reciprocal compassion being noted.

Brown-Wilson and Davies (2009) considered how relationships developed in the care home environment and found there were three approaches to care delivery: individualised task-centred; resident-centred; and relationship-centred. The implications of these approaches are the varying support of social citizenship and

participation for residents: the individual resident is involved in each of the approaches to differing levels, with the least amount of resident input in task-centred care to the most amount of resident input in relationship-centred care. This may have implications for participation generally and in research as enabling these skills might enhance participation in research by understanding and utilising the approach of relationship-centred care.

The literature underlines the importance of communication and relationships between staff and residents. Negative social attitudes and stigma towards people with dementia may have a detrimental effect on residents' ability to participate in general and to experience social citizenship and therefore influence these residents' inclusion, participation generally and in research, and ultimately citizenship. The literature suggests there are implications for any researchers wanting to base their research in care homes, as the ability of the staff and residents to communicate with each other as well as with the researcher may have an impact on the quality of the research carried out.

Workforce support, education and training

The literature suggests workforce support is central to enabling a culture of change and innovation which welcomes participation of residents and encourages the workforce in embracing research. Bostick et al (2006) found the workforce is at the heart of the care home and may be the difference between a good, well-performing care home and a poor-performing care home. This finding was shared by Fitzpatrick and Roberts (2004) and Meyer (2007). Similarly, Luff, Ferreira and Meyer (2011) found evidence that within a care home environment a well-supported workforce who are motivated in their work provide better care to residents. This is supported by the Alzheimer Society (2009) and Gilster (2002) on their insights into quality care in care homes research.

In contrast to a well-supported workforce, negative power dynamics described by Thye, Lovaglia and Markovsky (1997) that can be inherent within care homes between staff and residents as described by Baldwin (1978) may be attributed to the lack of empowerment of staff. This coupled with more contemporary observation by Higgs and Gilleard (2015) when discussing the power dynamics of the fourth age that staff in care homes are poorly paid, doing 'dirty work' may be a factor in high staff turnover. More seriously, insidious abusive relationships can occasionally develop (Higgs and Gilleard, 2015).

QUALITY OF CARE AND EDUCATION

Quality of care is linked to a well-educated workforce, which is of relevance to the core points of this project examining inclusion, participation and social citizenship and how quality of care can affect this. Nolan et al (2008) highlighted the role of training and education in achieving change in care homes and found it was more than the training and education of staff that raised standards in care homes. Wild and Kydd (2016) attributed the change to raising the role and status of care homes using a relationship–centred approach to care, acknowledging the needs of everyone involved in the care home. This included residents, visitors and staff all of whom made a difference. Similarly, Bostick et al (2006) found that a well-staffed, well-educated workforce in a care home could provide improved quality of care. Whereas Hantikainen (2001) found that it was an intrinsic change of staff attitudes with a greater understanding of the needs of residents, which could enhance the avoidance of the use of restraint, thereby improving quality of care.

Birnie (2003) found that introducing an educational programme, free of charge to care homes engendered collaboration and a greater understanding of the difficulties faced within the care home environment. Furthermore, Hasson and Arnetz (2011) advocate that staff training can improve the quality of life for people with dementia, a finding supported by Beeber et al (2010). O'Kell (1995) and Davis (2000) both reported the need for staff to be supported to be able to provide quality care. Further examples include Fitzpatrick and Roberts (2004) who discuss providing an education programme to health care support workers which had an impact on their self-worth and ultimately their quality of care. Similarly, Williams et al (2009) found that communication training could enhance care by reducing resistiveness especially when 'elderspeak' is addressed during the training. This evidence contributes to the debate that a care home with a well-supported workforce who have received a particular level of training and education will provide better care as previously established by Wicke et al (2004) and Nolan et al (2008).

One school of thought is that care home staff cannot be successful agents in empowering residents (Kane et al, 1997) if they feel they are not empowered themselves (Higgs and Gilleard, 2015). Parsons et al (2003) found that care assistants were frustrated by the lack of career opportunities, inadequate supervision and poor communication between staff and management. More recently, Bailey et al (2015) found disempowerment of staff was evident among care assistants because they were seen as less able than the registered nurses

in dealing with the public. Tolson et al (2011) showed education programmes in care homes could have positive short term effects but then were difficult to maintain in the longer term. Despite this researchers agreed that education of the work-force was a positive attribute and one could argue a positive factor in inclusion, participation and citizenship of all who work and live in the care home and needs to be considered as a possible influence to enable research and engender social citizenship.

TRAINING IN RESEARCH

Training care home staff in what to expect from their involvement in a research project may be advantageous. Entwistle et al (1998), in examining lay perspectives and health research, showed the importance of training for both the health professionals and the participants who may be involved in research. These findings are echoed by Smith et al (2008) on user involvement in nursing, midwifery and health visiting research, where the researchers found that there was much to learn about what user involvement is, what works best and why, as well as the importance of the researchers' own education and training. Similarly, Minogue et al (2005) found that service users and carers, in an NHS mental health trust, involved in research found the experience enjoyable and valuable and the numbers participating increased because of their direct involvement.

Participation

In Chapter 1 there is a definition of inclusion and participation. I argue my perspective of the difference between the two concepts are as follows: Inclusion is about being part of something, but not necessarily actively so it could be a name on a list or being a group member, whereas participation is an activity-based concept – where the person is involved actively.

PARTICIPATION AND SOCIAL NETWORKS

Scharf et al (2001) described participation as how well people were connected within their own social networks:

> "Participation and integration refers to older people's embeddedness in social networks, and the extent to which older people contribute to or draw upon the social capital that exists in their neighbourhoods" (Scharf et al, 2001:316).

This relates to the sociological literature on participation of older people and some of the possible reasons for exclusion and non-participation within a care

home environment. It is difficult to be embedded in social networks when you have been removed from those networks built up over a life time and placed within a care home. Scharf, Phillipson and Smith (2005) noted that dementia can make these social networks even more difficult to maintain.

Gillard et al (2010) showed concerted efforts have been made, at a policy level, to explore the impact of public involvement on service development in a wider health and social care arena. Furthermore, there has been recognition both politically (Department of Health, 2012) and within the research community (Brodie et al, 2011; Gillard et al, 2010) that participation in research is a positive development. Law, Russ and Connelly (2014) showed efforts to encourage people to participate in research were evident. The increasing interest both politically and within research around the potential benefits of user involvement have been noted with particular reference to social policy development (Department of Health, 2012; Beresford, 2002). However, Dewar (2005) and Help the Aged (2007) demonstrated that this ideal had not reached the care home population. Similarly, Backhouse et al (2016) indicated social policy development has not filtered through to the population of interest for this study i.e. older people living in care homes. The lack of social policy development mirrors the apparent lack of social networks and absence of social capital for residents within the care home environment.

PARTICIPATION FOR PEOPLE WITH DEMENTIA

The challenges of participation for people in care homes are significant. This challenge is magnified for people in care homes with dementia. Issues include the description of loss and exclusion due to issues of frailty (Wild and Kydd, 2016), staff misunderstandings (Jenkins et al, 2016) and stigma of dementia (Hellström et al, 2007). Engaging people with advanced dementia in research has been examined in the literature by Cowdell (2008) who notes that one must adopt ethical principles. Dewing (2007) reported that if ethical principles were applied sensitively and flexibly it was possible to engage older people with advanced dementia in research using careful planning, understanding of personhood and process consent methodology. Similarly, being treated with dignity was cited as the best predictor of older people's satisfaction and increased participation in activities (Burack et al, 2012).

STAFF PARTICIPATION

Staff need to be considered when discussing participation in research in care homes as staff have a variety of reasons why they may be motivated to participate in research. This links back to the earlier exploration of workforce support, leadership, positive communication and team work highlighted by researchers such as Scott-Cawiezell (2005) in her work on sustaining change in leadership in care homes and Brownie and Nancarrow (2013) in their work on culture change and leadership. However, if staff are mistrusted and mistrusting in their role in the care home as outlined by Higgs and Gilleard (2015) then participation in research will be very difficult for staff or by staff. For care home staff to participate in research in the care home they have to be supported to do so by both the care home manager and the research staff.

CARERS

There has been extensive work in the clinical trials field around carer involvement, which has relevance to this thesis. The literature suggests motivations for carers to encourage relatives to participate in clinical trials were helping them to feel better but also the hope of a cure and to live longer (Mastywyk, 2003; Elad, Treves and Drory, 2000). Grill and Karlawish (2010) found several positive factors associated with clinical trial involvement for both people with dementia and their carers such as having access to specialists who explained about informed consent, gaining access to new treatments and feelings of altruism. Law, Russ and Connelly (2013) found that 'being asked' was a very important motivation to participate and this included asking carers. This learning can be directly relevant to encouraging carers to participate in research, as well as those who live and work in care homes.

Methodological challenges

In describing the methodological challenges of conducting a study in a care home Hall, Longhurst and Higginson (2009) found challenges included finding opportunities to conduct interviews, the involvement of care home staff and maintaining privacy during interviews. These issues are reflected in the work of Zermansky (2005) and Higgins (2013). Moreover, Aveyard and Davies (2006) described that staff felt challenged by the university staff in their midst, which was echoed by Jenkins et al (2016) as a methodological issue.

Furthermore, a methodological challenge to be considered is the possibility of 'Social desirability bias' as described by Crowne and Marlowe (1960). Social desirability is described as how survey respondents may answer questions in a way that will be viewed favourably by others, rather than answer with what they actually think or feel. Researchers are well advised to have an understanding of social desirability bias and be aware that there is a possibility of this challenge so that if answers appeared biased or are contradicted by further findings that this could be the mechanism at work.

Another complex methodological challenge is enabling people with an impaired memory to participate, especially in research. Dewing (2007) describes a method which enables people with severe dementia to be involved in research. The Process Consent Method (Appendix 3) shows how to include people with issues of capacity and allows someone with severe dementia to participate. The Process Consent Method is described in 5 stages, which start from: seeking permission of access; to establishing capacity; to providing information about the study; to on-going consent monitoring; to feeding back and supporting the person with dementia. Additionally, researchers could use Talking Mats™ (Murphy et al, 2010), a method to pictorially present situations which are simple to understand and respond to, in an effort to facilitate participation.

INCLUSION

As I will explore whether participation and citizenship are linked and that to increase research participation would need improved inclusion within this community of people, one of my aims is to explore inclusion in more depth. Inclusion (see definition earlier in this chapter) is an overarching theme, when researchers examine good and poor experiences in care homes. Killett et al (2013) found a shared purpose, a sense of connectedness, activity and engagement including inclusion of the residents in choice and decisions were some of the important factors, a finding shared by Goodman et al (2011). One school of thought from Brannelly (2011) is that it is the responsibility of the staff to ensure inclusion.

Goodman et al (2011) and Brodie et al (2011) advocate for the promotion of research that includes participants in the conception, planning and execution of research including research in care homes. There is literature that emphasises the importance of including and involving people with dementia in research

(Darling and Parra, 2013) from conception of the idea to delivery (INVOLVE, 2012).

EXCLUSION

Higgs and Gilleard (2015) highlight the deliberate inclusion in many aspects of public life for those in the 'Third Age' i.e. those who are in their early retirement, contrast starkly with those people who are described as being in their 'Fourth Age'. Scourfield (2007) argues there is a consequent disenfranchisement of people in the fourth age from society in general which contributes to a loss of identity, reduced personhood, low self-esteem and consequently a loss of personal identification. He argues that there needs to be a movement to ensure effective inclusion of those in care homes whereas Higgs and Gilleard (2015) contest that once a person is in the fourth age they are separated from society:

> "a socially negotiated boundary demarcates the fourth age from the rest of society, where the usual attribution of agency, responsibility and social citizenship seem to no longer apply" (Higgs and Gilleard, 2015:96).

Higgs and Gilleard (2015) imply that those in care homes no longer have a connection with society at large and furthermore this is when institutionalisation may become a spectre for those in a care home and inclusion from society may be removed. This exclusion has an influence on how people experience citizenship in a care home environment and will therefore be explored in this study.

EXCLUDING PEOPLE WITH DEMENTIA

Meehan, Meyer and Winter (2002) showed a general exclusion and isolation of residents with dementia in care homes. Rocha et al (2013) corroborated these findings in their study of people with dementia living in care home facilities having severe activities limitation and participation restriction. There were residents who said that they had wanted to be included in activities but were just not asked.

Furthermore, dementia is cited as a source of strain and negativity in caring for people in a care home environment by Brodaty, Draper and Low (2003). Contemporary researchers Baillie, Sills and Thomas (2016) describe a continued negative social attitude towards residents with dementia by professional staff and this is supported by the findings of Garrie, Goel and Forsberg (2016). Similarly, as discussed above, Brodaty, Draper and Low (2003) hypothesised that people with dementia may find it more difficult to be heard because of their low status while Killick and Allan (2001) identified disempowerment due to communication

difficulties. Likewise, the Alzheimer's Society (2008) supports this view of people with dementia having a lower status and therefore being less likely to participate in activities within the care home environment. Similarly, Brownie and Nancarrow (2013) identified a constraint to participation for those in a care home environment who are subject to any behaviours which undermine personhood. I will explore how inclusion with the subsequent positive or negative consequences may be linked to citizenship.

Citizenship

As highlighted in Chapter 1, citizenship is a key focus of this thesis. I have chosen Bartlett and O'Connor's (2010) model of social citizenship as the model I refer to during my thesis. To understand the merits of this model requires a wider understanding of other concepts of citizenship and how they apply to people living in a care home. Some of the concepts of citizenship will be critiqued to enable a comparison of models and a justification of why I have chosen the model of social citizenship for this group of people living and working in care homes, some of whom have dementia.

CONCEPTS OF CITIZENSHIP - A CRITIQUE

The traditional view of citizenship (Marshall, 1950) describes a three strand model of civil, political and social rights and responsibilities, with the emphasis being on the maintenance and promotion of citizenship through state systems and institutions. There are limitations to this traditional view which overlooks the influence of social movements:

> "A very traditional view of citizenship fails to take account of the citizen-driven campaigns for social change" (Bartlett and O'Connor, 2010:31).

As I will explore, Bartlett and O'Connor (2010) show that social citizenship recognises that there is not a 'fixed' way of being a citizen and embraces differences in values, beliefs, sexualities, lifestyles, cultures and in world views. Thinking about citizenship in this broadened view allows us to accept that everyone can be a citizen in some form or other, no matter where they live.

Marshall's definition of citizenship is much criticised for its lack of inclusion of the individual (Marshall, 1950). In the description of the lived experiences of citizens with dementia who campaign for social change (Bartlett, 2014) there is an emphasis placed on identity and citizenship and the importance of inclusion. Lister (1997) recognised the exclusionary forces that influenced citizenship in

women also influenced other social divisions such as those with frailty, disability or old age.

When considering the public face of citizenship in care homes, with the political agenda of inclusive citizenship for all and the private face of citizenship with the exclusionary forces working against people who are older or infirm, such as those with dementia, one can appreciate the public/private divide This perspective resonates with the argument that participation links to inclusion and citizenship within the care home environment.

A further concept of citizenship explored was Cohen's (2009) concept of semi-citizenship which describes a model of citizenship encapsulating the idea that there is a 'middle ground' for those people who may have been excluded by the traditional model.

Several researchers have argued that people with dementia have been 'positioned as passive actors' due to their difficulties in communicating and their cognitive deficits. This denies the person with dementia the ability of having active citizenship (Brannelly, 2011). Furthermore, Boyle (2008) says it is impossible for people to have citizenship if practitioners are unable to see the person with dementia as socially alive and able to participate. Both these assumptions may influence the citizenship experienced by people living in care homes by firstly not recognising citizenship because of a person's cognitive difficulties and secondly not being recognised as a citizen because of the onlooker's ignorance of personhood, participation and citizenship needs.

Furthermore, McIntyre and McDonald (2012) have suggested that citizenship may be difficult to achieve in the marginalised and misunderstood group of people with dementia who are living in a care home environment. Likewise, Craig (2004) has contended losing the ability to exercise the fundamental aspects of citizenship was an insidious process which was imposed on care home residents. Furthermore, Bartlett (2014) noted that citizenship appears difficult to achieve in the marginalised and misunderstood group of people who are living in a care home environment, and is magnified in people with dementia. Likewise, Higgs and Gilleard (2015) in their work on understanding the 'fourth age' and loss of agency due to placement within a care home, whether this placement was voluntary or not, found citizenship was lacking.

Craig (2004) articulates the framing of citizenship for older people as the ability of individuals to operate as citizens. This is despite being beyond traditionally held

notions of citizenship but acknowledging a level of social exclusion of those no longer in the labour market. Craig's (2004) research describes the process of losing the ability to exercise the fundamental aspects of citizenship due to issues associated with independence and mobility, preservation of identity, dignity, control and choice. This is echoed by Hewitt, Draper and Ismail (2013) who found that the institutionalisation of the residents resulted in there being little or no citizenship, with the residents having lost all ownership and any willingness to participate in research.

Semi-citizenship seems to fit for those people within a care home environment but I would argue not as comprehensively and inclusively as social citizenship. The power dynamics which are seen in citizenship in society (Bartlett and O'Connor, 2007) have a resonance to the citizenship debate for those in an institution such as a care home. Literature shows that there has been a shift in the debate around citizenship which introduces the idea of social participation recognising that citizenship is a practice as well as a status (Gilmour and Brannelly, 2010). Hitherto, Shotter (1993) argued that we needed to 'belong' to our community and to be actively involved. More recently, Higgs and Gilleard (2015) endorsed this conception of belonging as an indicator of involvement in a community. Understanding and approaching citizenship as a social practice is more fitting with the population of interest to this study.

CITIZENSHIP AND HUMAN RIGHTS

Citizenship can be further complemented and understood when viewed within a human rights lens which promotes the rights of everyone to being treated as equal (Scottish Human Rights Commission, 2016). As there are parallels between citizenship and human rights this will be examined to establish where the human rights agenda and citizenship are juxtaposed, as this will have a bearing on whether participation and inclusion in general is lacking due to external factors such as organisational issues, policies and legislation affecting care homes.

There has been much work on ensuring people's human rights are adhered to from the first publication of the European Convention on Human Rights (Council of Europe, 1950), followed by the Human Rights Act (Home Office, 1998) and the Scotland Act (Scottish Government, 1998). There has been a growing movement in Scotland to ensure that all areas of public service in Scotland ensure consideration of a human rights based approach. This can be evidenced

by the development of Scotland's National Action Plan for Human Rights (SNAP) developed and overseen by the Scottish Human Rights Commission which is described as being a roadmap for the realisation of all internationally recognised human rights (SHRC, 2016). SNAP outlines a number of outcomes and priorities around enshrining a human rights based approach into every area of people's lives in Scotland including for those living in care homes. Despite this, Kelly and Innes (2013) contest in their research on human rights, citizenship and dementia nursing care that there is a paucity of societal human rights awareness.

Alzheimer Scotland has a commitment to ensuring all "legislation, policy and strategies affecting people living with dementia are underpinned by human rights" (Alzheimer Scotland, 2014). This commitment was preceded by the Charter of Rights (Alzheimer Scotland, 2009) which outlined the commitment to empower people with dementia to ensure their rights are recognised and respected.

While not wishing to denigrate the policy intentions, it is important to demarcate the difference between policy and empirical evidence gained from high quality research. This is a gap I have identified, where there is much reference in literature about policy but as Kelly and Innes (2013) indicate there is little research evidence about the application and understanding of human rights in relation to dementia. Policy is necessary to ensure everyone understands the rights of people; but to measure this understanding and whether policy has been implemented requires good audit and research, which has still to catch up on the policy around human rights and dementia.

LEGISLATION

There is legislation in Scotland aimed at ensuring vulnerable people such as those with dementia are protected. This includes: The Mental Health (Care and Treatment) (Scotland) Act 2003 (Scottish Government, 2003); The Adult Support and Protection (Scotland) Act 2007 (Scottish Government, 2007); and The Adults with Incapacity (Scotland) Act 2000 (Scottish Government, 2008). Enshrined in the principles of this legislation are the ethical issues that arise when conducting research in care homes. In Scotland, The Adults with Incapacity Act says it must be generally presumed that an adult is capable of making personal decisions and stresses the importance of people not assuming, because someone has dementia that means they are incapacitated to make decisions for themselves. The Act is also clear on its aims, which are to protect people who are unable to

make decisions and has defined principles which can be followed by anyone authorised to make decisions on someone else's behalf.

The Adults with Incapacity Act (Scottish Government, 2008) has a defined section of legislation which outlines what people can do about involving people in research who do not have capacity to consent. The Act clearly outlines the conditions which must be fulfilled for a person who is not able to give consent due to their lack of understanding: the research is likely to produce real and direct benefit to the adult; the adult does not indicate unwillingness to participate in the research; the research has been approved by the Ethics Committee; the research entails no foreseeable risk, or only a minimal foreseeable risk, to the adult; the research imposes no discomfort, or only minimal discomfort, on the adult; and consent has been obtained from any guardian or welfare attorney who has power to consent to the adult's participation in research or, where there is no such guardian or welfare attorney, from the adult's nearest relative (Scottish Government, 2008).

As some of the Key Informants I spoke to were living and working in England and their experiences were based on the English laws it is worth mentioning the Mental Capacity Act (UK Government, 2005). The Mental Capacity Act is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals who live in England and Wales. The principles are similar to the Adults with Incapacity Act in Scotland (Boyle, 2008) and there have been some comparisons between the acts (Stanley and Manthorpe, 2009) however, essentially they have a very similar purpose i.e. to protect the rights of people who have lost capacity to make their own decisions.

Researchers and research bodies recognise the importance of obtaining informed consent from people with dementia (Higgins, 2013; Wood et al, 2013; Luff, Ferreira and Meyer, 2011; Maas et al, 2002; Franzi, Orgren and Rozance, 1994) as well as other considerations such as competency and fluctuating impairment (Zermansky et al, 2007; High, 1992). Dewing (2007) believed that consent should be viewed as an inclusive and particularistic event whereas Hellström et al (2007) and Sherratt, Soteriou and Evans (2007) found it to be an exclusionary process. Whereas Moore and Hollett (2003) found that there was a pervasive paternalistic attitude to people with dementia and people may be excluded from research because of a presumed lack of capacity but also Slaughter et al (2007) noted that not being involved in research reinforces the

negative stereotypes associated with dementia. McCormack's (2003) research said that people with dementia are largely excluded from research due to the consent process. On the other hand, there has been some excellent high-quality research which has included the views of people with dementia and researchers have taken a considerable amount of care and effort to ensure people living in a care home, some of whom have dementia, are included in research (Jenkins et al, 2016; Killett et al, 2013; Brooker et al, 2011; Help the Aged, 2007) with careful planning it is possible to conduct high-quality research in care homes.

When the use of policy and legislation is considered in relation to involving people in research in care homes, the issue of consent and capacity is made more complex, dependant on who is the welfare guardian or nearest relative. Reed, Cook and Cook (2004) observed that the right to participate versus the care home's duty to safeguard the vulnerable can be a difficult issue to resolve. Similarly, High (1992) noted difficult to resolve issues around ethical considerations in decision-making. Even when legislation is used, as noted by Black, Wechsler and Fogarty (2013), with the appointed welfare guardian or nearest relative brought into play there can be tension between the ethical standard of best interest versus substituted judgment.

The literature highlights the importance of correct use of legislation but also the complexities of interpretation and implementation of the legislation.

Summary of the literature review findings

THE CARE HOME

The literature highlighted how researchers should approach care homes, the planning that should take place beforehand, the difficulties with gaining ethical approval and what to expect from the environment and how to maximise this. These were recognised as factors in maximising participation. The importance placed on positive leadership within the care home and how this intertwined with good communication was linked to participation and citizenship. The literature identified what the pitfalls were, in terms of lack of research participation and inclusion with a resultant lack of citizenship, if there was poor communication and a lack of leadership. The importance of positive relationships with staff, residents and family members and how this was also intertwined with communication and participation was identified in the literature. Lastly the impact of workforce support, education and training was considered and how this could impact both

positively and negatively on issues of participation in research in care homes.

PARTICIPATION AND INCLUSION

Participation and inclusion were examined through focusing on participation generally and then more specifically relating to research within a care home environment. The literature shows that participation in dementia research in Scotland is supported in policy and protected in law but this message does not seem to have filtered through to the population within care homes. There are challenges in involving staff. There is evidence of exclusion from clinical trials for those people in care homes and generally exclusion of people with dementia, more so in care homes. There are benefits to participation and it was found that asking people to be involved was a useful tool in enabling people to participate, along with other tools which aid inclusion and participation.

The literature review examined the concept of personhood and how participation is linked to citizenship, supporting the suggestion of citizenship being linked to participation in research and how the care home environment, including leadership, communication and work-force support can be either facilitative or constraining to research in a care home. I intend to explore how participation, inclusion and citizenship are linked. There was no specific evidence in the literature of the link showing that increased research participation is linked to participation, inclusion and citizenship within this community of people. This is what I intend to add to the literature through this thesis.

CITIZENSHIP

The literature supports the use of social citizenship as the model of choice for this population. The literature considered the interlinking of citizenship and human rights for those in the care home environment. There is reference to those excluded from citizenship in the feminist literature including those who are elderly or infirm. The literature also discusses how citizenship is experienced for residents in a care home. Once in a care home, the literature showed there is loss of the fundamental aspects of citizenship particularly for those with dementia.

The literature shows an understanding of citizenship in many forms but there is little detail about citizenship and its application to people in care homes specifically, which is where my thesis address a gap in the literature.

Capacity and consent issues for older people living in care homes who may have memory problems have legislation to protect them. The literature showed that despite the specific legislation there may be misunderstanding about issues involving capacity and consent, within research. The literature pointed to some possible directions in interpreting legislation for those with a more severe dementia. There were examples in the literature of people being excluded from research due to the consent process and by overprotective gatekeeping but also acknowledgement that there was some excellent research in care homes. The process of consent should be inclusive but the literature describes the difficulties of applying the legislation and that capacity and consent difficulties can exclude people, particularly those with dementia.

Conclusion

The literature reviewed raises questions that have not been fully explored about inclusion, participation and citizenship within a care home setting and how they are interlinked and relate to participation generally or in research. The review has raised issues of interest and gaps firstly, in concepts of inclusion and participation including: research participation; gatekeeping; leadership; communication; social citizenship; and workforce support. Secondly about what affects general participation: for residents and their relatives; for residents with dementia; and for staff. Thirdly what affects research participation such as: legislation and how it is interpreted; the physical environment; planning ahead. Fourthly the issues of citizenship and how the model of social citizenship has been used to illustrate citizenship within care homes. Finally, the perspective of whether inclusion, participation and citizenship are linked has not been explored specifically in the literature which this thesis primarily aims to address. There is a need for systematic exploration rather than incidental reflection on issues of inclusion, participation in general, in research and social citizenship for people living and working within a care home environment.

The research questions have been shaped by the literature review. I have inserted them below to remind us of how the research questions relate to the literature with the intention of addressing some of the gaps found when reviewing the literature of interest.

As previously outlined in chapter 1, this thesis has four research questions:

Research Question 1 - How do people who live and work in a care home participate generally and in research? This allows us to explore participation across a spectrum of contexts.

Research Question 2 - Which factors in the care home influence participation generally and in research? This thesis is a systematic exploration of these factors in a focused study.

Research Question 3 - What aspects of social citizenship can be observed and what influences social citizenship within a care home? This allows me to examine this issue in a novel way to contextualise questions of participation.

Research Question 4 – To what extent can we establish a link between participation generally and in research and social citizenship? The thesis will synthesis the literature and analyses of the findings to explore this.

I have shown through the literature review that there is a need for focused research which contextualises the issues of inclusion, participation and citizenship and how they relate to participation generally and in research, within the care home environment. In the next chapter (Chapter 3), I will describe the methods used to answer these research questions and in turn fulfil the aims of the thesis.

Chapter 3 Methodology and methods

Introduction

This chapter will outline in detail, the methodology and methods used to inform and gather data and to answer the research questions posed. The chapter will describe: the methodology used; the ethical approvals process; the process of the national survey of care homes; the semi-structured interviews with key informants; the semi-structured care home interviews; the general observation within each of the care homes. It will also describe the selection criteria, communication tools used and the methods chosen of data analysis.

All copies of the ethical approvals, information sheets and consent forms are available upon request.

METHODOLOGY

The selection of methodology must arise from the problem faced and therefore a careful selection of the research questions and how they were to be addressed required some forethought (Flick, 2007). I chose to use an interpretivist approach to the methods of data collection.

The interpretivist approach, whereby there is an understanding that others hold a different worldview (Creswell, 2009), is a description of the world view of 'social constructivists'. Crotty (1998) summarised constructivism whereby the researcher is seeking to understand the subject of research in context and culture. Therefore, the researcher will engage with the participants by personally gathering the information thus gaining an understanding of the culture, context and social perspective of the participants. Through this process the meaning of the research arises (Robson, 2011). For this thesis, by taking a constructivist view, I planned to understand the social reality of people who live and work within a care home and gain a richer understanding of their interpretation of what citizenship and research meant to them.

Furthermore, the choice of interpretivism comes from the realisation that my stance when embarking on the journey of the Doctorate in Applied Social Research was firmly within the positivist camp. My previous degree (Master's in Public Health) was quantitatively-focused encouraging the realist ontology with an empiricists epistemology. I measured facts. This was evident in my choice of

employment as a manager of a clinical research network. The journey from positivist to interpretivist started when I began the part-time doctorate. I have learned there is a different world view to consider and that there are socially constructed ontologies with different realities. I engaged with the constructivist epistemology which resonated with my emerging world view i.e. that there are competing accounts – none of them wrong, just different. I found that using and interpretivist approach to this research enabled me to give expression to all the players involved in this research, which I could not have done using a positivist approach.

For this reason, a predominately qualitative study design was chosen. Although some quantitative research methods are used. Creswell and Plano Clark (2007) explain the methods chosen for this study cannot be called a mixed-methods design as the approaches are not used in tandem, therefore I will refer to the methods used as a multiple-methods approach. Multiple-methods of data collection were used to enable a broad examination of the opportunities to contribute to research, for those living and working within a care home. "The use of multiple-methods reflects an attempt to secure an in-depth understanding of the phenomena in question" (Denzin and Lincoln, 2005:5). Having established my stance as an interpretivist researcher this will enable me to explore the opportunities to contribute to research, for people who live or work in a care home, including those people who have dementia by attempting to capture the many facets of peoples' world views within the care home environment.

I will consider factors affecting the care home which influence participation in research. This will be realised using the survey, the key informant interviews and the semi structured interviews within the study care homes. I will explore how participation in research links to participation in other social domains for residents, staff and visitors in a care home setting. I will explore how participation links to inclusion and citizenship within the care home environment and will develop an understanding of how those links operate and what their consequences may be. This will be accomplished using all the data collection methods described and using the literature to substantiate the findings.

The people involved and interviewed in this research help to construct their reality and helped me to make sense of their world. Robson (2011) articulates how the differing views of those included in the research coupled with my own experiences of doing the research all enhance the findings: "There are as many realities as there are participants, including the researcher" (Robson, 2011:24).

These methods of enquiry will allow us to formulate answers to the research questions outlined in the previous chapter.

The data collection methods that were used were a national survey, semi-structured interviews, and general observations and the datasets are compared to find commonalities and differences and enable an enriched understanding of the resultant findings (Flick, 2007). A quantitative and qualitative approach are used in the survey to allow the presentation of quantitative descriptive statistics complementing a qualitative research method of enquiry (Fowler, 2002). A qualitative research method is used exclusively in the other data gathering method of interviews. This is designed to focus on "giving voice to those who live experiences no one else would know about directly" (Lapan, Quartaroli and Riemer, 2011:9). This enables the exploration of the experiences and lived reality of people living and working within a care home environment around the issues of research participation, inclusion, and citizenship.

SAMPLING

My sampling strategy was based on both a probability sample (survey), and a non-probability sample (key informant and care home interviews).

The probability or representative sample (Robson, 2011) used for the care home survey, aimed to approach all care homes in Scotland who had provision for housing older people. A representative sample was achieved by using a combination of intelligence from the Care Inspectorate, Scottish Care (2015) and ENRICH (NIHR, 2015). This is further expanded upon in the next section describing Phase 1 field work. I intended to use simple statistics to display the findings.

The non-probability sampling strategy used for the key informant selection was purposive sampling (Robson, 2011) whereby I wanted to talk to researchers who had experience of carrying out research in care homes. I decided on my target number of interviews prior to commencement of approaching key informants. Most accepted the invitation to be interviewed but those who could not be interviewed for whatever reason where substituted with other key informants until I reached my target of eight interviews.

The sampling strategy for selecting the care homes to be approached to take part was non-probability convenience sampling. Due to constraints of time I had to approach care homes which were within easy driving range of my home as all the

interviews were to be carried out within a limited time frame i.e. evenings or weekends. The participants within the care homes to be interviewed were chosen using a convenience sampling strategy. The sampling depended on who was willing to talk to me on any given day, who was visiting, who was on duty, had they read the consent information and whether they had time to talk to me.

REFLEXIVITY

To understand fully the decisions made about which methods were chosen and why, I exercised reflexivity during the research process from the conception of the thesis subject matter, to performing the research tasks required in the execution of the research methods, to the writing up of the findings. Bryman (2008) offers a good definition of reflexivity which resonates with my own experience:

> "a reflectiveness among social researchers about implications for the knowledge of the social world they generate of their methods, values, biases, decisions and mere presence in the very situations they investigate" (Bryman, 2008:698).

The project takes a worldview (Creswell, 2009) with recognition of aspects of my being an interpretivist researcher, which is explained well by Bryman (2008)

It is also approached as a critical researcher, a stance involving recognition that political and social structures shape and hold power over the lives of individuals (Schensul, 2011). During the time in the study care homes I was in the role of an observer which meant I was an interviewer also making some observation of people in everyday contexts which allowed some evaluation of the social context and environment (Brooker, 1995) but involved no participation in the daily activities in the care home. Bryman (2008) encapsulates my approach as an interpretivist researcher:

> "Understanding of the social world through an examination of interpretation of the world by its participants" (Bryman, 2008:366)

My background was also a consideration in the methods chosen and the subject of study, as the previous experience in nursing and management roles, as well as the personal roles of mother, daughter, wife and friend shaped the initial decision to study within care homes as this was an area which I had an interest in. A presupposition of my expectations of what care homes were like could have introduced bias into my findings but this was minimised due to my reflexivity prior, during and following care home visits for research purposes. I used a reflective

field note journal to capture my thoughts and feelings and felt I was aware of this potential bias due to my preconceived ideas about care homes. This reflexivity was an important aspect of the study proceedings to present a cogent view of my findings.

I acknowledge that I have extensive familiarity and expertise of the NHS systems of care for people with dementia, as this is the field I practiced in as a nurse and manager for the last 30 years. This may have created preconceived ideas of how people should be cared for in a care home based on my own experience in a very different setting – the NHS. There is also my interest in research inclusivity with a desire to enable people with dementia to be involved in any research no matter where they lived or how developed their illness was. This desire was with the best intentions but may have been a value-laden intention which I became aware of during the interview process due to the practical difficulties of including everyone in research.

A good example of my preconceived idea of 'good research practice', which illustrates reflexivity of my practice background with extensive nursing and professional expertise came to light when I decided to use Talking Mats (Murphy, et al 2010) as a vehicle for enhancing my interviews with people with dementia. I had heard of this tool to enhance communication and further read about it during the literature review. I thought it would be an ideal opportunity to enrich my own research by demonstrating how well it worked in a care home environment with people with dementia. I attended the training to use Talking Mats and had sessions with the developers who were conveniently based on the University of Stirling campus. I had a special set of cards to use which was shaped to the research I had planned.

In practice, it did not work for my research. I found that some people became impatient and even angry with the cards and with me. This may have been for a variety of reasons: Firstly, because Talking Mats is used as a communication tool for people with mild to moderate dementia and the people I interviewed had more severe dementia. Secondly, I was a novice at using this tool and may have been using it incorrectly despite attending the training. Thirdly, it may have been the environment in which I was using the tool i.e. in a busy area of a care home, which was distracting for the participant. I had to make decisions based on my knowledge and experience of working with people with dementia to abandon these sessions.

The paradigms of political and social structures are apparent within a care home environment where larger systems of dominance and control are in evidence from the policies and legislations which are inherent in this environment. It has been necessary to understand the worldview of the residents, carers and staff through interviews and conversation as well as recognising the constraints by the system that the people are subject to in the care home. The data was collected at national level through the national survey and at an individual level, through one-to-one semi structured interviews and a focus group (Schensul, 2011). Some of the findings are based on the results of a national survey and expert evidence from key informant interviews. The multi-site study of care homes was based on a naturalistic premise of studying and interviewing residents, staff and visitors going about their daily business in the care home and aiming to understand their reality around participation, inclusion and citizenship and how this related to their experience of research.

VALIDITY

I used various techniques to ensure the accuracy and credibility (validity) of the data. This is an important step in the process of qualitative research (Creswell, 2009) and I have outlined the steps I took below. Miles and Huberman (1994) provide a pertinent description of validity:

> "The meanings emerging from the data have to be tested for their plausibility, their sturdiness, their confirmability – that is their validity." (Miles and Huberman, 1994:22)

To safeguard validity, I checked the transcriptions for any mistakes as they were returned to me. I made notes on a daily basis and have provided an example of my notes from one of my research analysis days as follows:

> Summary of today
>
> Read through key informant interviews. Wrote thoughts on paper attributing them to each key informant and page to trace them back again. Read my protocol and looked for information on what I had hoped to gain from the key informant interviews. Checked the guide sheet (see appendix 2) – did it match to the interviews? Used the notes page to start assembling codes. Tried to do a mind map of themes looking at perspectives of staff, researchers and residents with communication, attitudes and capacity issues as top themes. Feel positive and will look at information gathered and themes again tomorrow. (Emma Law, 10th August, 2015)

I have provided an account of the steps I used in this project when dealing with the data gathering and analysis. I have noted the decisions I made and why I

made them as the data analysis proceeded and I have provided in Appendix 4 a chart which outlines the codes I used.

Phase1: The fieldwork was conducted between May 2014 and September 2014. Phase 1 received ethical approval from the University of Stirling, School of Applied Social Science, by letter from the Chair of the Ethics Committee on 14th of April 2014. The University ethics process for phase 1 was straightforward and some very good feedback was received about the quality of the application which noted that the information sheets and invitations to participants were very clear and comprehensive.

Phase 2: Since I had planned to talk to people who had dementia and therefore may not have capacity to consent to being involved in research there was an application to the National Research Ethics Scotland A Committee who are specialists in examining proposals for people who do not have capacity to consent. The participant information sheets were specifically designed for the population: easy-to-read; large print; a simple, jargon free explanation of the project; and a picture of me. The information sheets were then given to 5 members of the Scottish Dementia Clinical Research Network (SDCRN) patient and public involvement (PPI) group for their review and comments were made and acted upon, including making the information even less jargonised and ensuring the format was in booklet form. The ethics committee did not approve the use of these information sheets and said that all the information to be used in the care homes had to use their template. This was duly changed and the application was granted full ethical permission from the National Research Ethics Scotland A Committee (reference 14/SS/1076) on the 5th of November 2014. Approval was given from local NHS Tayside R&D following national approval. This was given on the 7th of November 2014.

Subsequently, I received a complaint from one of the resident's family members about the poor quality of the participant information sheet including its readability and format. The previous version of the patient information sheet rejected by the ethics committee but approved by the PPI group was given to the relative for their perusal. They thought this was a much better way to introduce this research to the residents of the care home. A substantial amendment was applied for with the National Research Ethics Scotland A Committee to allow a more user-friendly version of the participant information sheet, including larger print and a picture of

me, given in booklet form and distributed to participants. This was approved on the 4th of May 2015, (14/SS/1076, AM01) with the proviso that the original Scotland A REC approved materials were given in conjunction with the user-friendly version. In practical terms this was belatedly received as I was nearing the end of the study care homes interview phase of the fieldwork. Jenkins et al (2016) expound that Research Ethics Committees' are inconsistent, lengthy, daunting, submission forms are complex, and have a preference and more understanding of quantitative studies, a view shared by other researchers (Tolhurst, 2014; Munk and Murphy, 2012) and I concur with this perspective based on my experience during this process.

Phase 1 Fieldwork

NATIONAL SURVEY OF CARE HOMES

Phase 1 of the study involved a survey of all care homes for older people in Scotland. A survey was chosen to allow representation of views from many care homes about the issues of participation in research. It explored factors which influenced the care home staff and the residents, to participate in research and the perceived constraints to participation. By using a survey (Appendix 1), a snapshot of views (Flick, 2007) was able to be gathered from all areas from the large geographical spread of Scotland

The survey which I designed asked some basic demographic details of the care home and more specifically about present or previous involvement in research. It was a self-administered questionnaire survey. The survey was cross-sectional in design, with data collected once, within a 16-week period between May and August, 2014. As described in the previous section, it used both closed and open questions. A reminder was sent by email to increase response rate and the survey closed in August 2014.

The survey was addressed to the manager of the care homes and was conducted primarily as an online survey, supplemented by a postal survey if the email addresses were not available. Bryman (2008) outlined advantages of using an online survey such as: low cost; faster response; attractive formatting; and fewer unanswered questions. However, disadvantages include: a low response rate; the survey is restricted to an online population; it requires motivation to fill in and return; and the respondent may question the anonymity and confidentiality of

their responses. For my study the advantages of using an online survey, such as low cost and faster response time, outweighed the disadvantages outlined above.

The survey was included as an insert in the Scottish Care Bulletin (Scottish Care, 2015), Scottish Care being an organisation which represents the independent care sector in Scotland and represents more than 400 independent care homes with a mailing list of approximately 650 care homes. The insert had details of how to participate both online and by post. The Care Inspectorate were contacted and they provided a list of all care homes in Scotland including email addresses with the proviso that it was out of date and that care home managers tended to move on fairly quickly in some areas therefore some of the email addresses would not be valid. Duplicates were removed which had already been sent to the Scottish Care group. All postal returns were sent to a prepaid address which only the Scottish Dementia Clinical Research Network (SDCRN) administrator and I could access (SurveyMonkey®, 2014). All the surveys were entered onto an Excel data sheet and were coded for source to ensure that there were no duplicate replies from care homes. In all there were 139 returns, 92 online and 47 by post, (14% return rate from 650 care homes) from care homes spanning Scotland (see chapter 4 for the national survey analysis and findings).

KEY INFORMANT INTERVIEWS

Key informant interviews were chosen to add "depth, nuance, complexity and roundness" (Mason, 2007:65) to understanding the experiences of participation in research in care homes, as described by people who are considered experts in this field and have already carried out this type of research within the United Kingdom. They were identified through reading key care home research papers and through contacts I had made with people who were previously engaged in care home research. Eight key informant interviews were conducted with researchers who have participated in care home research, within the United Kingdom. The key informant interviews were conducted during June, July and August 2014. Once approached, the potential key informant was sent the participant information sheet and consent form to consider. If they chose to participate they were offered the opportunity to see the proposed questions prior to their interview. Three of the eight interviewees chose to have the questions in advance. All the interviews were conducted as semi-structured interviews with the pre-determined questions acting as a guide (See Appendix 2). As Silverman (2010) outlined, semi-structured interviews are a method of eliciting the perceptions of the interviewees around the subject of interest i.e. participation

and inclusion, using the key informants' experiences and knowledge to inform the thesis. Interviews allow a depth of enquiry not available using a survey (Robson, 2011).

The advantages of using a semi-structured interview over the more structured survey described earlier is that it is very flexible and the interview can be shaped to capture interesting insights depending on who is being interviewed (Gilbert, 2008). Also, interview skills to can be used to maximise the information gathered such as probing and clarifying points and is a powerful tool for the researcher to utilise:

> "Interviewing is one of the most common and powerful ways in which we try to understand our fellow humans" (Fontana and Frey, in Denzin and Lincoln, 1994:697-698).

The disadvantages of using semi-structured interviewing is that it can be time consuming, taking on average one hour per interview and if the interview is face-to-face then there is the travel time and cost of travel to consider too. For each hour of interview captured on a digital recorder it takes an average of eight hours to transcribe it for a professional transcriber (Silverman, 2010) and longer if the researcher is transcribing it. I chose to use semi-structured interviews as a method to gather a variety of perspectives from researchers of differing seniority, with whom I could probe and question further during the interviews. I minimised the cost in time and money by conducting some interviews by phone and had the cost of the transcribing agreed beforehand.

Six of the interviews were conducted as face-to-face interviews, at a place of the key informant's choosing. Two were conducted as telephone interviews. This was the interviewees' choice as I offered to travel to the interviewees' place of work. For the telephone interviews, the consent form was sent in advance then posted back. Consent was discussed, item by item, on the phone and recorded both in writing by and using the digital recorder. The interviews lasted around an hour each. All the interviews were recorded using a digital recorder and then transcribed for analysis (see chapter 4 for the key informant interviews analysis and findings).

Phase 2 Fieldwork

The information gathered in phase 1 informed phase 2 through preliminary analysis of the information from the national care home survey. This had been read and transferred on to an Excel spread sheet with comments included. This

confirmed the expected outcomes from the survey – that there was very little research going on nationally - and enabled me to change the inclusion criteria for the choice of care homes for phase 2 to include care homes who had no previous experience of research. Following the preliminary analysis of the national survey, the dearth of research activity with care homes was identified and therefore the choice of care home was less dependent on previous research experience and more on whether the care home was willing to participate. The key informant interviews gave me some insight into accessing care homes and reiterated the importance of good communication prior and during access to the care homes. Phase 2 involved using semi-structured interviews in the care home setting with residents, staff and relatives or visitors.

IDENTIFYING THE CARE HOMES

The care homes identified allowed me to explore activities and processes on individual care homes, which are referred to as the 'study' care homes (Robson, 2011). The study care homes were bound by time and activity (Creswell, 2009) meaning they were similar in care-provision and were studied in the same time period spanning 8 months. The three care homes were identified following consultation with the Care Inspectorate (Care Inspectorate, 2012) to ensure that any 'failing home' as categorised by the Care Inspectorate was not put under undue pressure to also participate in research. It was intended that the care homes would be chosen depending on their current or previous research activity and if they were enrolled with ENRICH (NIHR, 2015). This did not happen as previous research experience was lacking in most of the care homes.

INCLUSION AND EXCLUSION CRITERIA

To be included in the study, participants were either a resident, a member of staff, a visitor or family member of a resident in the study care homes. In each of the study care homes I wanted to talk to someone who had a diagnosis of dementia; therefore one of the resident interviewees had a diagnosis of dementia. See Table 2 for the inclusion and exclusion criteria applied to the selection of care homes and individuals within care homes.

TABLE 2: INCLUSION AND EXCLUSION CRITERIA

Inclusion/Exclusion	Factors
Inclusion criteria (care home)	• The care home is situated in NHS Tayside Board area • The care home is registered for providing care for older people with the Care Inspectorate • The care home manager is willing to participate and facilitate the research
Inclusion criteria (individuals)	• All participants will need to be able to speak and understand English • If the resident has a formal diagnosis of dementia and does not have capacity to consent for themselves they must have a representative who can consent on their behalf
Exclusion criteria (care home)	• The care home is under special attention by the Care Inspectorate • The care home is not situated in NHS Tayside board's area
Exclusion criteria (individuals)	• People who are experiencing mental ill health such as depression • Anyone who is acutely ill or very frail • People who are unable to speak English due to the lack of access to a translator • Inexperienced care workers who have been working in the caring role for less than 1 month

GETTING TO KNOW THE CARE HOME STAFF, RESIDENTS AND RELATIVES

I contacted each of the care homes to discuss with the manager the proposed timeline for the fieldwork and to disseminate materials available to the care home. These included a poster specifically prepared for the care homes, which included an outline of the research, the University logo and a prominent picture of me. Participant information sheets were made available for staff, residents and visitors and given to the care home prior to fieldwork starting. Managers were requested to talk about the impending research at any meetings with staff, relatives or residents.

I arranged to meet with the care home manager to conduct the first interview with them and to be introduced to other people living and working within the care home. This was an opportunity to be shown around the care home and get a feel for the general atmosphere in each care home. The reflective field note journal was started for each care home visit at this first meeting (see later section on 'General observation and communication').

SELECTION OF RESIDENTS, STAFF AND FAMILY/CARER

Any residents who fitted the inclusion and exclusion criteria (see Table 4) and wished to participate within each care home were identified in collaboration with the care home manager, senior care staff and relatives. I requested that the manager identified one resident with dementia who may be willing to be interviewed, to allow their relatives or power of attorney to be contacted in advance to request permission for the interview. The manager could give an indication if the resident had any indicators of well or ill-being and what would be the best method of approach.

The first staff interview in the care home was with the manager. Following guidance from the care home manager, staff were invited to participate in advance and were provided with information about the study. Most interviews with the staff were opportunistic i.e. it would be staff on duty, in the time that I was within the care home, who were invited to participate by the manager or their deputy. No-one who was approached refused to be interviewed and even when there was a full explanation given about the research, with the staff's right to voluntarily withdraw consent explained, no-one refused to be involved.

Family members, carers or regular visitors were invited to participate, individually, as directed by the care home manager. This invitation was supplemented by a more general invitation in the form of a poster on the public notice board and flyer handed to carers as they visited their relatives or friends. This ensured that people who may be regular visitors, but were not the nearest relative in the residents' care plan or records, were included in the research if they wished. As with the staff selection, this was opportunistic and would depend on who was visiting during my time in the care home. In total, there were 33 interviews: 15 staff; 6 relatives of residents; 9 residents; 3 residents with a formal diagnosis of dementia.

FEASIBILITY

Three care homes were approached, and all three homes initially contacted were keen to participate. The sample size was determined by the feasibility of the size of the thesis, and is not a probability sample. The sample size of study care homes and participants was chosen to reflect the range of views required to explore the issues of interest. In each of the three care homes identified, I invited a variety of participants for the purposes of the semi-structured interviews: The care home manager; a minimum of 2 members of staff; at least 1 family member

of a resident; and at least 2 residents, who had the capacity to consent, and one resident who had a diagnosis of dementia.

SEMI-STRUCTURED INTERVIEWS

Semi-structured interviews were chosen to gain insight into the respondents' perceptions of participation, inclusion, and their views on whether they felt citizenship within the care home environment (Silverman, 2010). All interviews ranged from 10 minutes to an hour in length. In total, there were 33 interviews. The questions explored were formed from the initial findings of the semi-structured interviews of the key informant interviews in phase 1 (See Appendix 2). All the interviews were recorded using a digital recorder and then transcribed for analysis (see chapter 4 for the analysis of the care home interviews).

The staff on duty were consulted on the day of my visit about the ability of residents to participate on that day. The interviews were conducted in a sensitive manner with no-one approached who was distressed or who communicated to me, in any way that they did not wish to participate. For those residents who had dementia, all permissions were sought from either the resident's Power of Attorney, if they had that in place, or their nearest relative. Twice I had to withdraw because both residents were becoming agitated during the interview; once because of fatigue and once because of difficulty hearing.

The interview process was explained to the interviewee, describing to them their right to withdraw their consent at any time, explaining that the conversation would be recorded but would remain confidential with pseudonyms used and that anything disclosed about abuse would have to be acted upon. Dewing's (2007) Process Consent Method was used in all the interviews with residents, as described in the literature review and in Appendix 3.

FOCUS GROUP

In each of the three study care homes I planned to facilitate one focus group, to explore some of the issues arising from the key informant interviews and care home survey of Phase 1 and the semi-structured interviews of Phase 2. Focus groups are a useful technique to increase the efficiency of the qualitative data collected (Bryman, 2008) as they allow the collection of data from several people at once. The group dynamics can help to focus on the important topics at hand and there is group stimulation where participants are empowered by the other group members (Robinson, 1999). Focus groups involving staff, residents and

residents' relatives were to be carried out after all the semi-structured interviews had been completed.

Despite repeated efforts, two of the care homes could not facilitate focus groups. There were various reasons that the focus group attempt was not successful. The forward planning required, as it required the staff to ask people in advance if they would be willing to be involved was a factor. Also, not understanding what a focus group meant – one care home managed to get two care workers together so they were interviewed together but this did not constitute a focus group. On three occasions, I arrived to lead the focus group to find the care home had forgotten I was coming and no-one could participate that day. Some of these difficulties experienced when trying to use a focus group are reflected by Gilbert (2008). One care home enabled me to lead a focus group and the results and analysis have been incorporated into the semi-structured interview analysis, as the same questions were used to guide the focus group as were used in the semi-structured interviews (See Appendix 2).

GENERAL OBSERVATION AND COMMUNICATION

I used the time spent in the care homes, while arranging and conducting interviews, with residents, staff, family and friends of residents in observing the interactions between people. This was completed in an informal manner with no note-taking done while in the care home about what was observed. Reflections on interactions were written in a reflective field note journal, as soon as practical, preferably the same day, of each day spent within the care home environment. The reflective field notes were not included in the analyses of data and were used to enhance reflexivity, as described earlier in the chapter. The original intention was to gather and analyse the field notes of observations in a more formal manner using Townsend's parameters from his survey which enabled a measure of an institution's quality such as physical amenities, staffing and services, means of occupation, freedom of daily life and social provisions (Townsend, 1962). Although Townsend's work was done more than 50 years ago it is still relevant in our modern society as the parameters set were as important then as they are now. The observational reflections were used to enrich the interviews by enhancing the understanding of the context of the interviewees. The reflections were useful to gain insight into the 'feel' of the care home and to have a time for reflection following the interviews. Using the general observations coupled with an awareness of the principles of the National Care

Standards for Care Homes (Scottish Government 2008), I was able to gauge the general state of observable emotional well-being of residents including their level of engagement and the style of staff interaction and communication with people living in the care homes. I did not analyse the field notes in a more formal manner due to my personal time constraints.

For this thesis, communicating with people within the care home setting, including those with dementia, is central to finding out how people perceive the issues of inclusion and participation. It required my skills to facilitate communication to enable the person within this setting to be heard. I used a variety of tools to enable this. I have 30 years' experience of communicating with people with dementia of all levels and have held senior posts in the NHS, primarily concerned with the care and treatment of people with mental health issues and dementia. These skills were used with relatives, care workers, managers and with people with advancing dementia. Dewing (2007) describes the necessary communication skills of the researcher in the use of the Process Consent Method (Appendix 3), as paramount to the success of involving those with dementia in research. This was a technique employed successfully in the three interviews with people with dementia and in the other interviews with residents. I completed the approved training for TalkingMats™ (Murphy et al, 2010) to facilitate some discussions. This is a communication framework developed in the University of Stirling to enable those with communication difficulties to air their views. It is designed for those with moderate dementia to be able to participate in research. It has been found to work well in the care home setting (Macer, 2011). It is low technology and consists of a series of picture symbols which allow the person being interviewed to place symbols against a visual scale. The developers of TalkingMats™ were involved in the design of the symbols to maximise the value of using this tool for this thesis. Its use in this context was helpful for six interviews because it gave a framework for me and the person being interviewed to follow, which kept the discussion focused. The data collected using the methods described has been discussed in the following section.

DATA ANALYSIS

As demonstrated in the previous section, the multiple-methods of data collection produced data from various sources which then required analysis. Miles and Huberman (1994) describe data analysis as:

> "three concurrent flows of activity: data reduction; data display and conclusion drawing/verification" (Miles and Huberman, 1994:21).

This description corresponds to how the data was managed for this thesis. The process was driven by thematic analysis using data reduction as the tool i.e. condensing large amounts of data into smaller, easier to segments.

The data gathered from the survey, which included descriptive statistics and text, the eight key informant interviews and the 33 interviews with people working and living in care homes, plus the observations used for context only, written in the reflective field note journal amounted to a large amount of data. Robson (2011) notes that the volume of data can easily become overwhelming. The strategies used to manage this amount of data require thorough planning prior to starting to gather the data, which is why I chose the types of data gathered and the number of interviews. Miles and Huberman (1994) advocate that data reduction activity is part of the analysis process as there is much skill involved in summarising data which requires the researcher to be on the lookout from the start of the data gathering for issues of interest, patterns and themes (Robson, 2011). The data reduction process enabled large amounts of data from the survey results, interviews and observation to be simplified through reading and selecting relevant parts of the data, which then resulted in summaries of coded and themed data. This process was accomplished by using techniques for data reduction: I used my reflective field note journal to summarise each interview, immediately after the interview had taken place and revisited this summary after the interview had been transcribed; I used memos, written in the reflective field note journal and electronically in my iPad notes section to capture other intuitive thoughts about the data capture process; I used thematic coding analysis (described in more detail later in this chapter). It makes sense of the data by ordering it but also verifying the validity of the findings.

The survey results were displayed on an excel spreadsheet for analysis with some demographic information gathered. A thematic analysis approach was used for answers to the questions requiring a narrative response. The survey allowed me to start the analysis process by displaying the data as soon as it was gathered and reading it over to see if any themes were emerging from the initial

data. It enabled me to shape the questions I wanted to explore in more depth with the key informants.

The semi-structured interviews were recorded, transcribed and then analysed using a thematic analysis approach. Notes were taken in the reflective field work journal and on my iPad about any anomalies noticed or information which I found relevant to the process, at the time of each interview. The interviews were transcribed by a professional transcriber who provided each transcript within less than a week of receiving the recorded interview. This was useful as the interview would still be fresh in my memory and when I checked the transcript I could add in any nuances or information from the field notes directly on to the Word document transcription.

The next stage was coding of data. This involved using both a printed version of the transcribed interview and working with an electronic version on Microsoft Word. I have kept a note of the process I used which was: read through each interview; write thoughts and comments in the margin; summarise each interview; read again; think of commonalities; which themes are emerging; what did you expect to see – what were your assumptions; what did you not expect to see.

There are many pages of corresponding detailed notes which I dated, and which I have retained with the interviews and daily I would summarise what I had done and what I expected to do the next day. This approach is advocated in Robson (2011) as a systematic and detailed way to approach large amounts of qualitative data, which requires a detailed explanation as provided above, on the actual procedure of the analysis.

This process was then followed by identifying topics or themes (Creswell, 2009). As described above, the data was read to identify codes. My detailed written notes show that I identified 54 codes for the eight key informant interviews alone. These numerous codes were refined over time by the formulation of an index of themes, which emerged from the material (see Appendix 4). I used Microsoft Word and colour-coded sections within the text, using the themes and sub-themes as identified in Appendix 4.

I was able to modify the questions during the interview, so when a line of enquiry was of interest to the subject of participation, inclusion or citizenship, this could be followed, unlike during the survey.

The amount of data gathered was immense and as previously described, care had to be taken to manage the number of interviews with the needs of the study and my time available in gathering and analysing all the data. During interviews with the staff, it was noted that the interviewee would generally be a bit tense at first and would then relax into the interview. It was only at the end when the digital recorder was switched off, that often staff would divulge some very interesting insights into the workings and relationships within the care home which they had not volunteered during the interview. Robson (2011) noted this 'hand on door' phenomenon, when interviewing people and using a consistent approach to how it is dealt with was an important factor. Any information disclosed at the end of the interview, after the digital recorder had been switched off could not be used in the analysis of the interviews due to the constraints of the consent given but could be used to contextualise the interview.

CONCLUSION

The methodology used to underpin the methods of data gathering has enabled me to gather worthwhile and interesting data to address the aims of the thesis and to answer the research questions posed. The ethical approvals required from both the University of Stirling and the NHS Research Ethics Committee were necessary for this research but highlighted the difficulties inherent in the NHS system which is more focused towards providing approvals for clinical research and not social research as described by Tolhurst (2014), which was clear during the process and the subsequent need for an amendment.

My description of the analysis process demonstrates the systematic approach to the thematic analysis, which in turn makes sense and takes meaning from large amounts of qualitative data. Using the methods described of the national survey, the semi-structured interviews and the general observations gathered in the reflective field work journal enabled the aims of the thesis to be investigated in-depth. These aims were: to explore the opportunities to contribute to research, for people who live or work in a care home, including those people who have dementia; to consider factors affecting care home staff and residents which may influence participation in general and in research including social attitudes regarding people with dementia; to explore how participation generally links to participation in research for residents, staff and visitors in a care home setting; to explore how citizenship works in the care home environment and whether there is a link between inclusion, participation and citizenship within this environment.

These aims were to allow the research questions to be answered and this will be deliberated in more detail in the discussion chapter. The insights gained from the methodology and methods used in phases 1 and 2 are outlined in the following chapter on the findings of the study.

Chapter 4 Findings

Introduction

This chapter presents the findings from the national survey of care homes in Scotland, the key informant and study care home interviews. The national survey findings are presented first followed by the key informant interviews and finally, the findings from the study care home interviews are detailed. The findings from the focus group are incorporated into the study care home interview findings. I explore how the findings enrich our understanding of participation and inclusion in research. The impact of the findings on, and link to, social citizenship will be considered in greater detail in the discussion chapter.

Findings of the national survey of care homes in Scotland

A survey (Appendix 1) was sent to all the Health Board areas in Scotland to ascertain the broad trends of care home research in Scotland. Care homes in 11 health boards returned a total of 139 surveys, a representative sample of Scottish care homes and which amounted to a 14% return rate. Nine responses were excluded from all analysis due to missing data. The criteria applied to exclude a survey were: missing health board AND missing bed numbers AND missing numbers of people diagnosed with dementia. This information was necessary to allow comparisons of the care homes. There were other fields with missing data but there was enough information in the data set to allow these surveys to remain in the analysis. Some of the fields allowed more than one answer per question so the number of answers varied, depending on the answers provided. Due to the 14% return rate (139 returns from a possible 923 homes) and missing data, this survey cannot be generalised to the overall population of care homes in Scotland but provides an indication of the trends in attitudes to research within those which answered the survey. The survey gathers the perspective of staff working in the care homes as this is who the survey was aimed at. It is worth noting that it is likely that those who are most interested in research are the most likely to respond to the questionnaire which will have implications for the findings.

NUMBER OF CARE HOMES INVOLVED

The 130 care homes included in the analysis have been further categorised into small, medium, large and very large depending on the number of beds available in each care home. This was the simplest way to classify the care homes. The

largest care home had 180 beds which was 80 more than the second largest at 100 beds, which is why it was stratified into the very large category, so that it would not skew the findings. The other categories of care home size being small, medium and large had similar numbers within each category. See table 3 below.

TABLE 3: SIZE OF CARE HOME CATEGORISED BY NUMBER OF BEDS

Care home size	Number of beds (range)	Number of care homes
Small	8 - 30	40
Medium	31 - 50	43
Large	51-100	46
Very large	101-200	1
Total		130

NUMBER OF STAFF INVOLVED

Table 4 shows the number of staff, including qualified staff, in each of the categories of care home. Qualified staff were staff who had a recognised nursing qualification, such as Registered Mental Nurse (RMN) or Registered General Nurse (RGN) or a Scottish Vocational qualification (SVQ).

TABLE 4: NUMBERS OF STAFF IN THE CARE HOMES

Care home	Number of staff range (mean)	Number of qualified staff range (mean)	Percentage of qualified staff (%)	Number of care homes with no qualified staff
Small (n=40)	2 – 43 (18)	0-43 (14)	79	3
Medium (n=43)	15 – 61 (39)	0-48 (18)	42	2
Large (n=46)	20 – 150 (75)	0-75 (26)	36	1
Very large (n=1)	140	81	58	0

Table 4 shows a small number of the care homes did not have qualified staff working in them. The percentage of qualified staff was larger in the smaller homes. What we might draw from this is that the smaller homes may have an

increased complexity of residents who are frailer and require more nursing care than some of the larger care homes with smaller percentages of qualified staff. There were no qualified staff in 6 homes: we may surmise that these homes are 'residential' care homes which have residents who require little nursing care needs. The literature showed that there has been an increase in frailty over the past 15 years which is why care homes with no qualified staff are so few (ISD, 2014).

### NUMBER OF RESIDENTS WITH A DIAGNOSIS OF DEMENTIA

Table 5 shows the number of residents that had a formal diagnosis of dementia, and those the respondent thought had dementia. Column 2 shows the percentage of people with an actual diagnosis of dementia whereas column 3 shows the number the respondent judged to have dementia. Column 4 shows the percentage difference. These are expressed as a percentage of the total number of residents in the care home. It showed that consistently across the different sizes of care homes, the percentage of those who did not have a formal diagnosis of dementia but the respondent judged to have a memory problem was higher than the numbers formally diagnosed with dementia.

TABLE 5: PERCENTAGE OF RESIDENTS WITH A DIAGNOSIS OF DEMENTIA OR MEMORY PROBLEM

Care home	Percentage of residents with a diagnosis of dementia (%)	Percentage of residents judged by respondent to have a memory problem (%)	Difference (%)
Small (n=40)	64	77	13
Medium (n=43)	60	75	15
Large (n=45)	55	76	21
Very large (n=1)	46	54	8
Total (n=130)	56% (Mean)	71% (Mean)	15% (Difference)

The literature shows that the numbers of people in care homes with dementia are estimated at 69% (Alzheimer's Society, 2014) therefore the estimates for the number of people with dementia or a memory loss problem in care homes are consistent with the literature, at an average of 71% from 130 care homes.

**FIGURE 1: WHO MAKES THE DECISION TO PARTICIPATE IN RESEARCH?**
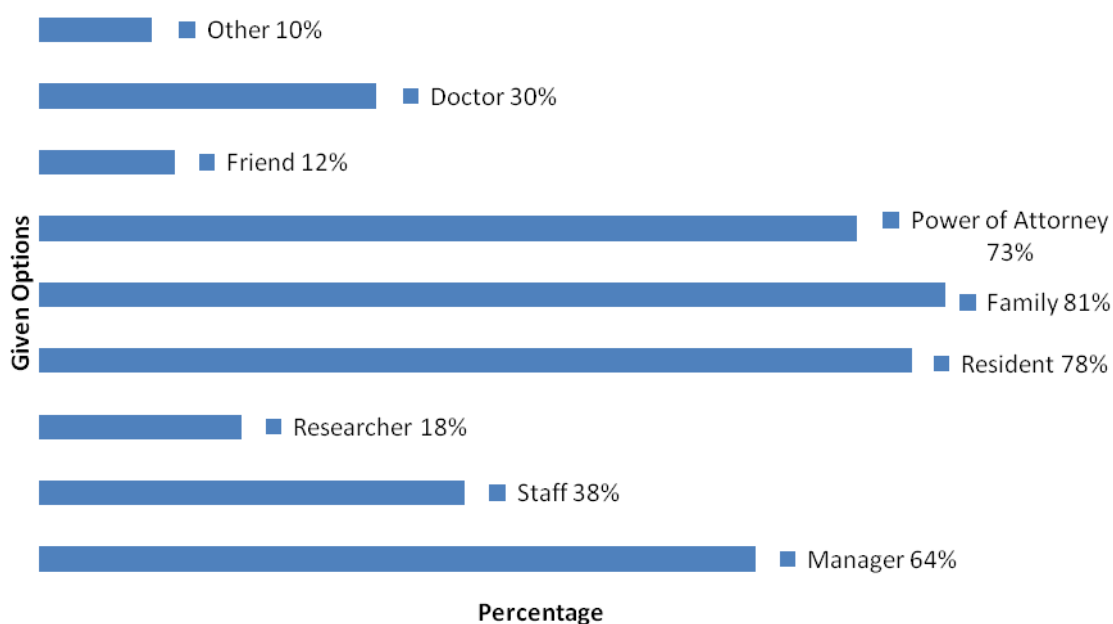
Questionnaire respondents were given a list of options of whom they would expect to be involved in the decision of residents participating in research. They could choose multiple answers and the results are displayed in Figure 1, which shows the percentage of times the given option was chosen as a possible response. The most popular choice from the respondents, of the person to be involved in the decision of being involved in research was the family (81%), followed by the resident (78%) and then power of attorney (73%). The manager features highly here at 64%, and this is an interesting finding, as the manager was found to be the most influential gatekeeper regarding research involvement by the key informants, as will be discussed in later sections. This is consistent with Brown-Wilson et al (2013) and Hellström et al's (2007) findings whereby the gatekeeping by the care home manager was an influencing factor in accessing care home for research. This will be discussed in the next section.

INFLUENCING FACTORS

Figure 2 shows the factors that participants reported would influence the decision for the residents to take part in research. This question was asked with given categories, of which the respondent could choose as many as they thought were relevant. Respondents were given space for free text.

**FIGURE 2: FACTORS INFLUENCING THE DECISION TO PARTICIPATE IN RESEARCH**
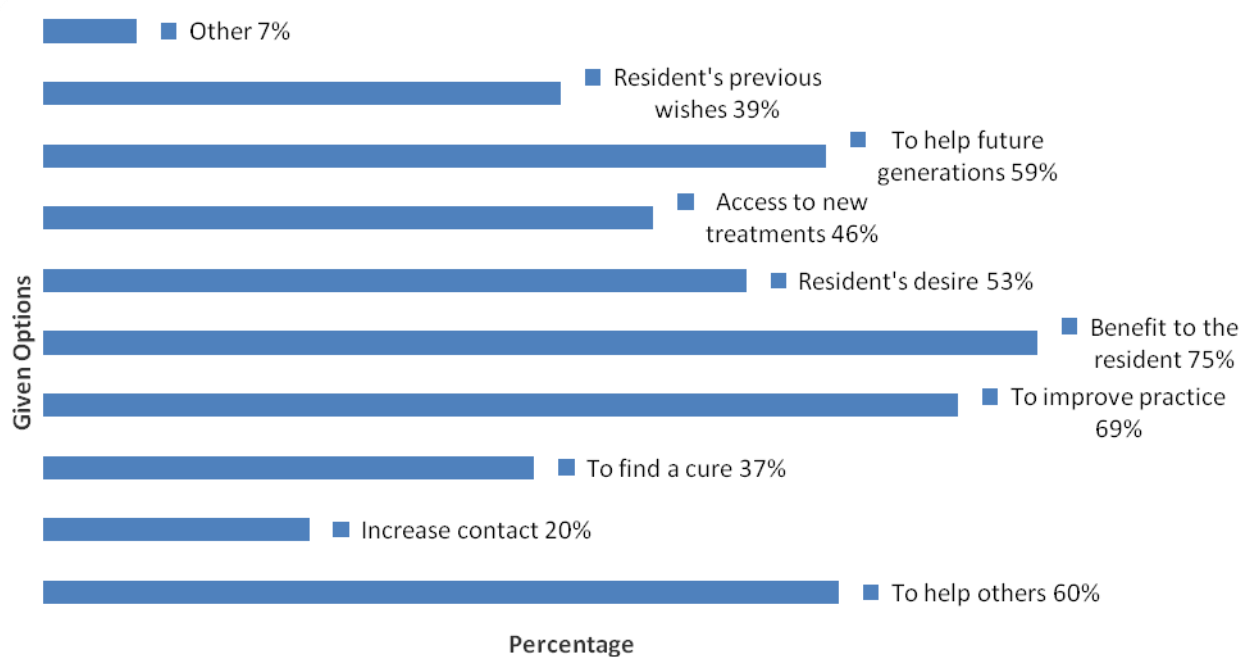
The most popular choice of factors which would influence the respondents' decision for the resident to take part in research was benefit to the resident (75%). This was followed by the ability to improve practice (69%), to help others (60%) and to help future generations (59%) as other popular choices. Free text comments included: "amount of time involved would be a priority"; "residents would have time for social inclusion and would happily take part" and "depends on type and reason for research". The free text comments echoed the fixed-choice answers in the survey, reiterating the importance of time, both lack of time of staff and the perceived amount of time residents would have to participate, and the staff's perception of the importance of the research and whether they would choose to take part or not. This tentatively reflects that there may be some experience of social citizenship if people are able to participate in research.

Figure 3 shows answers given to the question of "What would encourage staff to put themselves, their staff or their residents forward for research in their care home?"

**FIGURE 3: FACTORS WHICH WOULD ENCOURAGE RESEARCH**
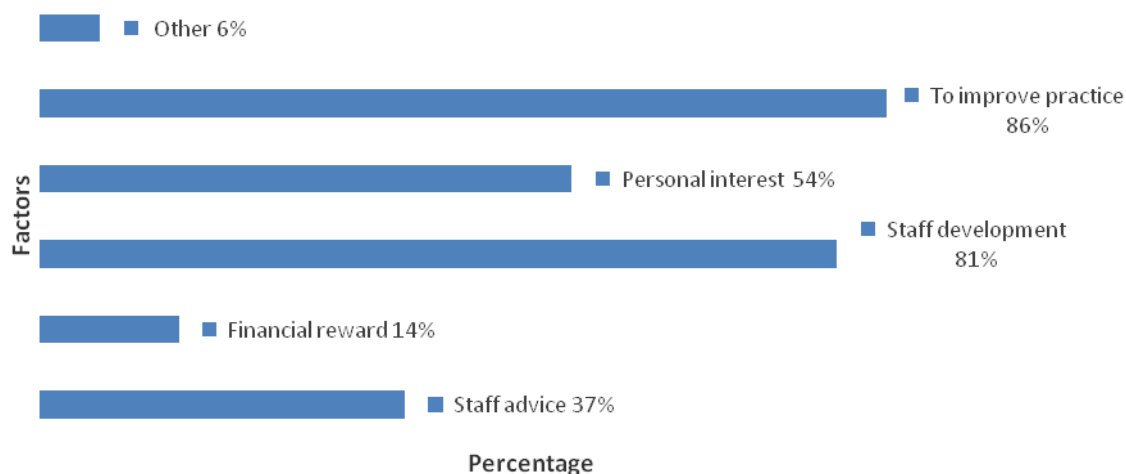
The most common choice was the opportunity to improve practice (86%) with staff development also being chosen as an important factor in encouraging people to participate in research (81%). This question was asked with given categories, of which the respondent could tick as many as they thought were relevant. They were also given space for free text. Comments included: "Raise profile of dementia and the vitality and fun which takes place within a dementia friendly environment"; "free holidays"; "residents may feel they are doing something worthwhile"; and "to help the home's staff development and training". There were some positive additonal comments such as "raising the profile of dementia", "feelings of worthiness" and "helping staff development and training". The comment about "free holidays" was more difficult to interpret without speaking to the respondent – they could have meant that their perception of research involement could mean they would get time off their normal duties, without having to take holidays. Furthermore my findings suggest that to facilitate staff development and to improve practice – the top choices - would require good leadership. The findings also suggest that social citizenship may be experienced, when considering that Bartlett and O'Connor's (2010) definition of social citizenship recognises growth and development in life which would include staff development. It is worth noting the findings support the importance of facilitating staff development and improving practice which require good

leadership in keeping with the literature: Scott-Cawiezell (2005) showed that good leadership was an important factor in encouraging research in the care home environment, a finding shared by Davies and Brown-Wilson (2007b).

DISCOURAGING FACTORS

The respondents were asked to give reasons why they might not want to participate in research or might discourage others from doing so. This question was asked to enable the respondents to write any ideas about what would discourage them.

FIGURE 4: WHAT DISCOURAGES RESPONDENTS FROM PUTTING FORWARD THEMSELVES, THEIR STAFF OR THEIR RESIDENTS?
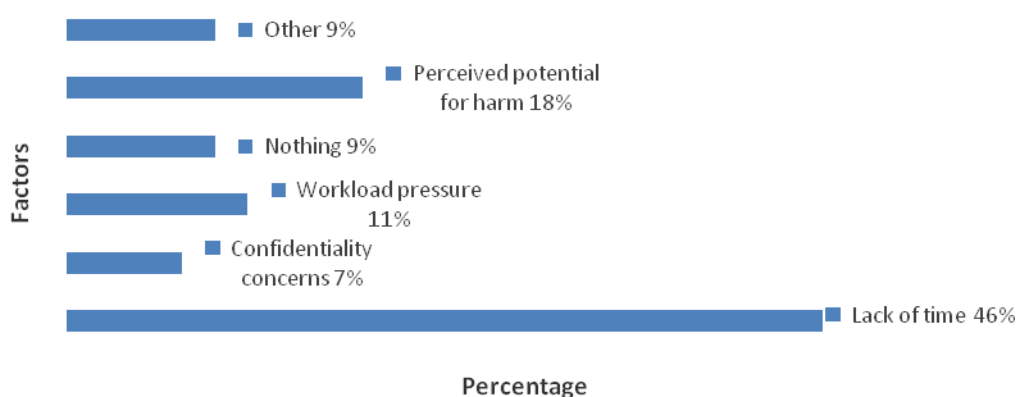
73 respondents wrote about why they might be discouraged from putting themselves, their staff or their residents forward for research. The responses were categorised using a thematic analysis approach. See Figure 4 for the responses. The most frequent responses were references to a lack of time to participate in research (46%). The second most popular choice was a worry that the research, in some way, might be harmful to the resident (18%). I further examine these issues in my discussion chapter.

FURTHER QUESTIONS

The respondents were asked if their care home had been involved in any research of any type. If they indicated they had been, they were asked to provide any details of the research including: who was involved; the name of the lead

researcher; the topic area of the research; how many participants there were; and when the research was carried out.

Of the 130 respondents, only ten could recall any research carried out in their care home. Of these ten only five could remember the name of the lead researcher. Seven of the ten projects were dementia related. Only three could give a date of when the research was carried out.

The survey has shown, in the care homes which responded, that only 7% of the care homes had been involved in any research previously.

The respondents were given an opportunity to give further comment at the end of two of the questions and any further comments were asked for at the end of the survey. Few respondents chose to comment but this is one of the comments that articulates the lack of research in care homes:

> "Care homes are the obvious base for undeveloped area of research in gerontology and the oldest old".

From other comments the findings suggest respondents would like to see more research in dementia but acknowledge that there are other considerations which have a bearing on research, such as keeping core service running.

SUMMARY

The survey achieved a 14% return, which is an acceptable return rate for an on-line and postal questionnaire (Barach and Holton, 2008). The findings suggest there was very little research going on in care homes, of any type, in Scotland as only 7% of the care homes who responded had any research to report over the past few years.

It was the managers who generally answered the survey and it was noted that some may have answered as they thought the researcher wanted to hear but this was at odds with the findings. Crowne and Marlowe's (1960) social desirability bias is a possible explanation for this and is explored in more detail in the literature review.

The care homes who did respond seemed positive in their views about what would encourage them to put themselves, their staff or residents forward for research with over 60% of responses citing staff advice and staff development as factors, which is a learning point for researchers wanting to encourage care homes to participate in research. Lack of time and workload pressure together

amounted to 42% of the reasons given which would discourage people to participate in research.

The survey was not able to gather any evidence from those care homes who chose not to respond, about research participation. One could argue that the more motivated care homes may be more likely to encourage participation in research and may experience social citizenship for their residents and staff. It was these homes who would respond to a survey about research participation. Therefore, the survey cannot be generalised to the overall population of care homes, but provides a good indication of the views of those who were willing to respond.

Findings of the key informant interviews

INTRODUCTION

The key informant interviews were designed to increase understanding around participation and inclusion in research. As described earlier the extent that this is linked to social citizenship is explored in more detail in the discussion chapter. The key informant interviews were useful in helping to understand some of the barriers and facilitators to conducting research within a care home environment from the perspective of researchers who have worked there. Furthermore, the experiences of the key informants helped to inform the research practices in the execution of the fieldwork for this thesis.

Eight key informants were interviewed; some having had many years of experience and one having attended over 50 care homes in their research career. On the other hand, some of the researchers were very new to this type of research and for one researcher this was their first experience of being in a care home environment. This perspective of both experienced and inexperienced researchers highlighted some of the perceived barriers and facilitators to research, depending on experience.

The findings of the key informant interviews are presented in the themes into which they were categorised following analysis. Themes emerged following the process described in the methods chapter and are as follows: managers and staff attitudes to researchers; communication and relationship building; capacity and consent; physical and emotional issues.

MANAGER'S AND STAFF ATTITUDES TO RESEARCHERS

All key informants found that the care home managers' attitudes and the type of leadership they provided to staff was a pivotal factor in both facilitating and hindering research. Key informants gave instances of when the managers had a positive and negative influence on the research. Here is one of the positive examples:

> "A really helpful thing is the care home manager being on board and making sure their staff are informed." Key Informant (KI)3

This idea of inclusion and being on board from the manager is important in allowing this commitment to filter to the staff. Conversely, the negativity expressed from a manager could affect how all the staff reacted to researchers:

> "I feel the one thing we always walk away from is if the individual care home manager doesn't want to take part because there's just no point." KI5

Difficulties arose when the managers were not interested and this lack of interest was conveyed to the researchers by lack of respect for the researcher's time, not enabling the researcher to contact relatives or not telling staff about the proposed study. Researchers expressed that they did not want to include these homes because of the cost implications due to the extra time it would take to engage with the home and therefore complete the research. The negative side to this, as expressed by more than one key informant, is that the homes excluded, due to the manager's negative attitudes, disregards all the people living and working within those homes who may have wanted to take part and have had interesting and valid perspectives to add to the research. Furthermore, one would expect there to be little social citizenship experienced by staff or residents, whereby social citizenship can be distinguished by people's ability to shape events.

The importance of leadership within the care home was further expressed in the verbalisation of some of the negative attitudes displayed by staff of the homes towards the researchers. The researchers found it frustrating when they felt they were low priority to the staff with instances of being left waiting for long periods of time, feeling:

> "Completely unimportant." KI1

There was evidence of researchers facing hostility from staff. The way that researchers overcame this was to understand where the hostility comes from:

> "People can be hostile but they are just being defensive and are just worrying about their job safety." KI2

Researchers found that the fear and negativity expressed as hostility could also be a fear of the new or the unknown. Zero hours' contracts were also cited as reasons for staff hostility and an unwillingness to do anything more than the job required.

It helped when researchers could understand that staff would warm to the researcher after a few visits and that building a rapport and a reputation of:

> "being nice to work with." KI7

would help with the progress of the study in that care home.

If the manager's attitude was positive and facilitating to the researcher it seemed they had much more success in being able to gain entry to the care home.

> "It helps if the care home manager introduces you, as you feel like you have validity in being there." KI4

This introduction to the care home residents and staff enabled researchers to talk to staff, and be included in meetings, and subsequently facilitated residents, relatives and staff in participating.

COMMUNICATION AND RELATIONSHIP BUILDING

The importance of good communication and of relationship building was spoken about by all the key informants. The forms of communication ranged from: providing good written information such as posters for the walls and notice boards; information sheets which were simplified and easy to read; and going along to staff meetings to ensure everyone knew about the intended research and felt involved in it. It was felt unanimously by the key informants that the staff were key to being able to complete the research:

> "Communication with the staff is the most important thing in terms of getting things done." KI3

The balance of views from the interviews implied that not giving enough information could have an adverse effect on the care home staff's understanding of what was expected from the staff, residents and relatives within that home.

Building relationships with managers, staff, relatives and residents was discussed. The key informants described building trust by explaining the research process in detail with assurances of anonymity to all participants whether staff or residents:

> "You speak to family of people, yeah family of people with dementia who want to know why you are doing the work you are doing almost as a way to trust you." KI4

Doing thorough preparation before going in to the care home was another important aspect of relationship building. Good preparation, some researchers felt, helped to dispel the feelings of negativity:

> "With staff it's persistence and it's just back and back I think, you know, wearing them down or they get used to us, you build a relationship." KI1

This importance of direct contact and how this helped to facilitate the research was further explored by the researchers. Some felt that face-to-face contact was crucial in building relationships and aiding communication with staff and relatives:

> "Spend time to tell people about the research, to tell people about ourselves…you're not just a nice friendly visiting face, you are there for something that they have a right to be involved with or not be involved with." KI6

A dictatorial form of communication from the managers was seen by the researchers as a negative influence with staff informed they were to be involved in research without the necessary understanding of what they were involved in:

> "They're basically just being told they have to do it rather than sort of being completely on board." KI1

The key informants suggested that understanding and identifying who the gatekeepers were, could assist in the research process in care homes. It was suggested that the gatekeeper was not always the obvious person i.e. the manager:

> "You think you've done your gatekeeping with your top management but then you end up working or negotiating with a yet another set of people." KI7

Understanding why there may be reluctance from potential participants would assist in helping the person to become involved:

> "People are right to be cautious really about what they sign, you know. They've been signing away some big things lately when somebody's moved into a care home." KI8

The wider implications implied here for any participant from a care home, including relatives and residents who may potentially be involved in the research, is the unseen and unknown events that precipitated the admission to the care home.

> "A good piece of research would have all sorts of procedures for ongoing monitoring of different kinds of resistance or avoidance to research and then stances for responding to that." KI8

As illustrated by Key Informant 8, above, good communication in both written and spoken form is key to letting the care home know about the impending research including: who the researchers are; why they are there; who they want to speak to; time limitations of the research; and any feedback planned.

CAPACITY AND CONSENT

The findings around capacity and consent suggested a difference of attitude depending on the experience of researchers. The balance of views implied that this is because the issues of capacity and consent are difficult, time consuming and fraught with intricacies and problems in interpreting, communicating and applying relevant legislation to others. The more experienced researchers had built up a reservoir of knowledge and skill throughout the years in dealing with many of the different scenarios that can arise during this fraught and bureaucracy loaded process:

> "In a very sensitive environment with lots of vulnerable people and often the staff are vulnerable just as much as the residents, one has to be very, very processual and flexible and articulate in applying and re-applying consent." KI8

The less experienced researchers verbalised the difficulties they experienced including: understanding and then applying capacity legislation; who to seek help from; talking to relatives about capacity; the difference of opinions between the junior researcher and care home staff about residents' capacity. For example:

> "I think the capacity thing is definitely difficult. I'm very comfortable working out if someone has what I would discern to be mental capacity but I'm not as comfortable trusting someone else's judgement on it." KI3

The more experienced researchers acknowledge the difficulties faced and the frustrations around capacity and consent processes:

> "With residents it almost seemed like the kind of paperwork of the consent process was just a little bit overwhelming." KI6

Capacity and consent issues were fraught with problems and it became clear that more junior researchers required support from their senior colleagues to enable them to feel comfortable with the processes required.

The following quote resonated with my own experiences of the ethical consent process:

> "I don't think there's an easy solution and I can see why we have now very thorough procedures for achieving ethical consent but I think for the level of risk involved in the sorts of research we are doing, it often feels like it's a bit of a sledgehammer to crack a nut." KI7

Processes of capacity and consent in this study are discussed in detail in the methods chapter and in the legislation section of the discussion chapter.

PHYSICAL AND EMOTIONAL ISSUES

The findings suggested that the physical environment of the care home could be both a possible facilitator and barrier to research. The availability of private, quiet areas to talk to people was discussed as an important facilitator, as was the physical layout of the care home. Having to interview people in busy, noisy, large public rooms with distractions of television, radio or other residents was a barrier. One key informant noted that due to mandatory change in practices such as moving and handling, some homes were not fit for the purpose they were originally intended for.

Respondents emphasised the importance of assessing if a resident was very physically frail, hard of hearing or experiencing any pain as all these issues would affect the ability of the resident or relative in sustaining an interview. This would affect the types of research this resident could be involved in.

Fluctuations in the emotional or cognitive state of residents were factors identified which could adversely affect the interview. Key informants recognised that these could be very dependent on the time of day, or just how that resident was feeling on that particular day:

> "People can just not be in a very good mood or perhaps they've had a rough night's sleep or you might be suddenly bringing back memories." KI7

The quality of the research staff was recognised as an important factor in the research process. Senior key informants evidenced the need to have researchers who could relate to people with dementia and their families, as well as the staff who look after them. One key informant said their background as a nurse was

useful. There was recognition among the researchers of the 'human work' involved in being a researcher:

> "Being respectful of all the people who are involved in the life of the care home from the quietest resident to the youngest member of staff to the noisiest and oldest, you know. To recognise that you need to go in with a bag of respect." KI7

All this evidence is indicative of the key informants' views on the importance of the qualities required in the research staff who will be working with this vulnerable group of people, to ensure that the facilitators to enable involvement and participation in research are maximised and barriers recognised and minimised.

SUMMARY

The key informant interviews enabled me to study some of the factors as detailed which may influence participation in research from a researcher's perspective.

The key informants recognised that the manager was key to facilitating research and staff attitudes were dependent on the manager's leadership. Two-way communication, in different forms, was vital to success or failure of a research project.

Capacity and consent issues seem to be the most contentious for the key informants and described as stretching the competencies of junior research staff. This finding supports my argument that policies and legislation surrounding research and participation for those living and working in a care home environment, although designed to protect people can also be a barrier to research.

Consideration to physical environment, physical capabilities and emotional issues of residents and staff within the care home environment coupled with the qualities of the staff involved in research in care homes was seen as paramount to overcoming barriers and maximising facilitators.

To further elucidate our understanding of how participation in research is linked to participation assisting in the understanding of how those links operate and what their consequences are in the next section I will detail the findings of the care home interviews with residents, staff and visitors. How participation and inclusion are linked to social citizenship will be explored in the discussion chapter.

Findings of the care home interviews

INTRODUCTION

This section outlines the study care home interviews. Appendix 4 outlines the overall themes and sub-themes of the interviews. These were drawn from a detailed and in-depth analysis of the interviews. Each theme is examined in turn, and I consider how each theme and sub-theme can relate to the overall research questions. The findings are summarised here and how the findings relate to inclusion, participation in general, in research and social citizenship are explored in the discussion chapter. The findings from my general observations captured in the reflective field note journal and personal notes are intertwined with the findings from the care home interviews as outlined in the methods chapter.

There were 33 interviews in total, with 6 of these interviews completed in a focus group setting. Table 6 outlines the number of interviews, in which care home and with whom.

TABLE 6: DESCRIPTORS OF PARTICIPANTS OF INTERVIEWS IN 3 CARE HOMES

CATEGORY	CODE	CARE HOME 1	CARE HOME 2	CARE HOME 3	TOTAL NUMBER OF INTERVIEWS
MANAGER	M	1	1	1	3
REGISTERED NURSE	RN	0	1	1	2
JUNIOR CARE STAFF	JCS	0	0	4	4
SENIOR CARE STAFF	SCS	3 (1)*	2	1	6
RELATIVE OF RESIDENT	Rel	4 (1)*	1	1	6
RESIDENT WITH NO DEMENTIA	Res	6 (4)*	3	0	9
RESIDENT WITH DEMENTIA	ResD	1	1	1	3
TOTAL		15	9	9	33
FOCUS GROUP	FG	(6)*			
	*Figures in brackets were people involved in the focus groups				

Table 6 provides an illustration of the codes used for staff, residents and relatives.

Theme 1- Facilitators and constraints to participation

INTRODUCTION

How the environment impacts on residents' abilities to participate in their everyday lives and other facilitators and constraints to participation such as making choices, communicating, building relationships with others and being supportive is explored further in the following subthemes. Appendix 2 shows the questions asked when interviewing residents, staff and relatives. People were asked if they were included, able to participate and what kind of choices they were offered.

SUB-THEME 1A– ENVIRONMENT

Facilitators to participating in everyday events within the care homes were included with physical aspects of the environment such as the ambience, space and comfort described by all interviewed. Having a private area in which to talk to residents, staff or relatives was helpful to facilitate discussion and enabled me to carry out research and assist participation in research. Having personal belongings was expressed by residents as an important aspect of care home living with one resident with dementia expressing:

> "Luckily we can choose …….I am very, very happy in my room. I've got my life around me." ResD1

There was evidence of people being aware of the impact of their surroundings, talking about access to space and fresh air, mentioning the smells and sounds. At some point to varying degrees in all the study care homes there were uncontrollable noise levels due to other people shouting or being agitated, the television was left on and staff were noisy at times.

One manager verbalised the difficulties of care home living:

> "I don't think we're there and I think, I mean, this isn't a huge place…but large communal living has its limitations with people." MRN3

This was echoed in other interviews with people remarking about the size and layout of the care home having an impact on which type of residents could live there, the need to be mindful of others due to communal living and the lack of privacy, which impacted on visits from relatives.

There was discussion about the inability to control the environment in which people had to live and work. There was a feeling of imprisonment articulated by one member of staff due to the environment:

> "Sometimes you feel like you're in a jail (laughs) because you're locked in here constantly." JCS32

This feeling of being confined, articulated by the staff member, gives some insight on how the residents and relatives might feel when the door is continuously locked for safety reasons.

One of the care home relatives talked about the problems of isolation because of people voluntarily staying within their rooms:

> "I'd like mum to join in more but she doesn't feel she can so… She's quite isolated really. Aren't you, Mum? You're quite isolated because you stay in your room." Rel14

How the environment impacts on participation in research was an area of discussion found in the key informant interviews and is reflected here in the care home interviews.

Environment has a direct impact on participation and allows us to further explore how participation in research links to participation in general. Some of the interviews were conducted in noisy communal areas, with the television on in the background. This was distracting and difficult to navigate for both the interviewer and interviewee. The impact of the environment is further explored in the following subthemes of choice.

SUB-THEME 1B - CHOICE

Being offered choice in the many aspects of day-to-day living was seen as an important aspect of life in all of the care homes, by all of the people interviewed. There were examples of choices offered in some of the more mundane areas of life – such as enabling residents to participate in the simple decisions around choice of food to eat, what to wear or what the day is going to be spent doing.

There was evidence from residents and relatives that having a choice of what to do was an important aspect of participation in the care home, with the proviso that they could also choose *not* to do something:

> "I like to take part and the outings, you can go every Thursday. It's voluntary of course and it's perfectly free. So it's… and so I think…. and I mean we get some wonderful outings. We don't have to go, you see." Res11

There was evidence of choices offered including what to eat from staff, relatives and residents themselves:

> "Yes, you get the… well… there's the likes of sausage in a casserole. I'm not so keen on that. They gave me meat instead of…. yesterday, they gave me meat instead of sausage. So I had an alternative there and then there is always a salad if you want a salad. I'm not really a salad man (laughs)." Res22

Other aspects of choice discussed were: what type of music people liked; whether they wanted to have families involved in meetings; which newspapers people preferred to read; what type of redecoration people would prefer; where they would prefer to eat; if they would choose to have a 'long lie'; and what television programme they chose to watch. These types of choices link to including people in decisions about their everyday lives which is encapsulated in Bartlett and O'Connor's (2010) social citizenship.

Staff did talk about being able to access training and that this was a matter of choice. Staff articulated why choice was important to people's well-being and that staff needed to allow time to be spent on enabling choice. There was a description of how choice could be perceived and understood by the resident:

> "Probably giving them more choice and having more time to take in understanding as well. About how the resident's actually feeling. Ken*, just taking time to even, like, when you're walking down the corridor, a resident's walking, just like speak to them, ken, giving them that, like, 'oh someone's speaking to me' kind of thing. Even saying "Hi", you can see it brightens up their face ….." JCS33

'Ken' is a common colloquialism in the East of Scotland meaning 'you know'.

This observation was made by one of the junior carers. In the same care home in an interview with another junior carer there was further reasoning as to why choice was important:

> "I think we try to promote choice. I mean, it is important, because it's their life." JCS34

The evidence would suggest from observations made during the interviews and what the interviewees said, that offering choice to residents could be especially problematic as their dementia progresses. The type of choices on offer could decrease to basics:

> "That's what they are mainly involved with, you know, like activities and what they want to eat for that day or what they want to do for that day for activities and…Yeah, basically the basics, day-to-day basics. That's when they get involved." SCS3

And despite the insightful reasoning of why choice is important to the residents in the care home there was evidence that due to busyness of staff, choice was compromised:

> "….yeah there probably has been times that we've… there's not… they've not got what they've wanted but, ken, they don't like it, they've just been given it anyway." JCS32

The resident who expressed their feelings about how they ended up in the care home was an example of where choice had been removed and one could sense the feeling of powerlessness that this person had about their situation:

> "I was just dumped here. I think it's not what I prefer but it's what's done." ResD1

Choice did not seem to feature in this resident's life and their experiencing social citizenship would be hard to imagine for this person. It should be remembered that many of the residents are not in the care home through choice but necessity:

> "Now I've heard a lot on the telly a lot about different homes and how they were ill-treated and that but I can't see anything wrong with this place at all, as far as I am concerned you know. I'd rather be at home, mind." Res22

The findings contribute to the literature that being offered choice in some of the more mundane areas of life can be interpreted as an example of participation. Choice is a factor in the care home which, one could argue, may be related to participation. The findings show that choice may be compromised for those people with dementia. The findings also support that choice in care homes may be lacking in some instances. This will be explored in more depth in the discussion chapter. Being able to offer and receive choice relates to the next sub-theme of communication, because the choice has to be communicated to the intended recipient or conveyed by the recipient.

SUB-THEME 1C – COMMUNICATION

There were illuminating examples of where positive communication between staff, residents and relatives could facilitate feelings of participation. Relatives gave examples of being told about things verbally, by phone, as they happened and how this made them feel involved in the care of their loved one despite being geographically distant:

> "People phone me anytime anything happens with dad that's relevant, whether it be an accident or just because he's had a visit from the District Nurse and there is something they think I should know. So I feel very much part of the loop that people include me proactively without me coming having to knock on doors and ask questions, that I'm always kept informed of what's happening to dad. So for these various reasons, I feel very involved." Rel13

Other examples of communication were the description of the use of communication tools, such as: an 'Ideas Book'; using feedback through a suggestion book; a written weekly chart of events going to all the residents and relatives; as well as the importance of enabling feedback through a questionnaire:

> "They like one-to-one so we do have letters that go out, you know, questionnaires for the residents and that can be things like, you know, 'what do you think of the food?' Good, bad, poor, excellent, you know. There's a list and they tick the boxes and then it's things like 'what do you think of the cleanliness of the home?' So it's all sections to do with housekeeping. You know, 'Do you think it's clean?' 'What's the ambiance like?' Things about the carers. 'Are they nice and friendly?' You know, 'are they good, poor, adequate?' you know." SCS12

Staff described how they would maximise communication with residents through verbal methods such as: using eye contact and doing this by talking to people on their level, so if someone is in a chair kneeling down to be able to talk to them; not talking 'over' someone to a colleague or other resident; talking to people using the correct tone, speed and pitch of voice; the content of speech being made easy to understand by avoiding jargon; and talking to people about what was happening, which some staff thought was particularly important during hands-on care of a resident.

One of the non-verbal methods of communication noted by one of the relatives, in relation to the staff was their positive use of touch:

> "It's nice to see them giving them a cuddle and things like that, you know." Rel3

The staff recognised that the use of ordinary clothes instead of uniform helped to take away the clinical feel and helped to make the care home homelier; having a friendly face and encouraging a feeling of calm also went towards positive communication.

The importance of communication and how this facilitates participation within the care home setting between staff and everyone they come in contact with, including their colleagues, is summed up by the following:

> "I think being able to communicate well, like really well with each other is important for me because we're helping people with their lives and it's important that we are able to communicate with each other and with other people, like, that are coming into the home and their relatives, if they've got any concerns to be able to help them." JCS34

Some of the constraints identified were the physical aspects of difficulties in communication such as: difficulty in hearing; poor understanding of the person with dementia; the person losing their verbal skills due to dementia; and fatigue of the resident:

> "It can be difficult communicating with somebody that is losing their verbal skills. They can't tell you what's wrong." SCS21

Another constraint in communication was that residents expressed in all three care homes that 'not being asked' was a barrier to participating in activities. This would have an impact on people being able to experience social citizenship as this may be an exclusionary act if people are not asked.

Contradictory evidence was found in one care home of what the manager believed about the abilities of the staff and what the staff were actually capable of. The manager talked about their staff not reading books in general and seemed dismissive of their abilities:

> "To be realistic, a lot of the carers I have, don't read books." MRN3

But this was in the same care home that there was a clearly described understanding of the importance of communication as illustrated by *JCS34* above. The understanding of the pointless, meaningless and cursory styles of communication that were observed and commented on, by one of the junior staff,

about the senior care home staff talking to the residents was an interesting observation in itself:

> "They have a conversation but it's like, 'Hi, how are you doing today. You're looking, like, well.' and stuff like that but it's not like, ken, 'What do you want to do today?' or 'How are you feeling today?' It's just like, sort of, the usual questions, like, I don't know, it's hard to explain. Ermmm (pause)." JCS33

This view of inadequate communication was supported by one of the residents with dementia who was able to express her feelings about communication saying:

> "Could do more. Not great." ResD3

A common problem encountered by managers and reflected by residents, relatives and other staff was the difficulties in getting relatives to attend meetings. When one manager was asked why this could be the reply was:

> "I don't know. I've never asked them and they don't know either. I've tried having it week days, week nights, weekends so the people who work....... but it doesn't make any difference." MRN2

Understanding why people did not attend meetings may help in understanding more about participation in other areas of the care home life, such as participating in research.

To be able to communicate effectively in all aspects of living, is important to enable one's needs, wishes, thoughts and feelings to be conveyed to another. In the context of a care home it is particularly important because of the possible 'interference' in communication: misunderstandings; physical barriers such as poor speech or hearing; volume; interruptions; illness such as dementia. One could argue that if there is a barrier to communication because of a misbelief in the abilities of staff, as demonstrated by one manager this can cause misunderstandings. If the recipients do not understand or hear the message then it compromises the ability to participate. Facilitating participation and enabling positive communication led to the awareness of supportive management as discussed in the next sub-theme.

SUB-THEME 1D – SUPPORTIVE MANAGEMENT

Supportive management is a factor in enabling participation, as a supportive manager can enable, facilitate and lead by example, their staff, relatives and residents in their care. Evidence of supportive management was seen in all the care homes including the discussion and importance of encouraging learning in

their staff. This was reiterated by the staff interviewed in the care homes, all of whom were able to say, to varying degrees of certainty, that they would be supported by their manager if they wanted to do further education.

There was much discussion and evidence of the supportive management in CH1, from relatives, about the importance of good leadership including: high visibility of the manager; time spent with the residents; putting the needs of the residents above the staff; and taking time to meet with potential residents and their families. This is well-illustrated by one relative:

> "The general welcoming demeanour of all the staff, the grounds, the building, the physical aspect of it and just the feel for the people they've got here which I think really stems from the top. This person is a wonderful manager." Rel13

There were statements from each of the managers about how they liked to be perceived as visible and approachable. They talked about how they liked to have 'an open door' meaning they were accessible to all in the care home. One described how she liked staff to have their lunch in her office, rather than the staff room.

The evidence was clear in CH1 from the interviews with staff, relatives and residents alike that the manager was, indeed, visible and was named and praised by all, as someone who liked to facilitate learning, listened to the staff and residents and seemed aware of the difficulties in maintaining a degree of input when combined with their management duties:

> "Myself and my deputy, trying to, it's difficult in this job, at this level to actually be as involved as you would really like or you should be with your residents. I think it's still important to make sure that you're out there and you're seen and you're approachable and you make people know that you're there and that's why my office door is open so that people can come and hopefully keep it an open, open forum all the time." MRN1

There was mention of the manager, by name, in CH2, from relatives, with one relative interviewed saying she had been listened to about a problem she had encountered. Staff said they would be supported if they wanted to do further learning and the manager was keen to promote learning in their care home and be visible:

> "I don't believe in being a matron who sits in an office somewhere that you have got to make an appointment to see. That's why my office is there at the front so people can pop in and see me any time." MRN2

In the interviews in CH3, staff did not mention the manager by name, only by the title 'manager' and that staff seemed unsure if they would be fully supported if they wanted to do further training. This manager evidenced their own lack of learning:

> "I've maybe got a wee bit stale myself. I haven't done anything myself for a while."   MRN3

Some of the junior staff expressed their frustration at not being listened to and not having a vehicle to support what they had to say:

> "They could listen to us more and maybe take on what we say a little bit more as well. So it does feel a bit rubbish at times when that happens." JCS32

They expressed their anger at being ignored and not listened to and could only see the way forward in approaching the management as a group, as none of them felt strong enough or listened to enough, to be able to do this as individuals.

Having supportive management links directly to communication the good communicators were the managers who were seen as supportive by staff, residents and relatives alike. It also links to choice, as the people interviewed mentioned the choices available to them due to decisions and support directly from the manager. It therefore could be argued that this links to experiencing social citizenship for staff and residents. This will be further explored in the discussion chapter. As demonstrated in the previous sub-theme of communication, supportive management facilitates participation, whereas the converse is observed too – non-supportive management appeared to generate discontent and anger among the staff, which became a barrier to participation. The positive attributes seen in supportive management are achieved, partly, in building relationships, as discussed in the next sub-theme.

SUB-THEME 1E– BUILDING RELATIONSHIPS

There was evidence of the importance of the key worker's role in facilitating positive relationships i.e. developing trust between the key worker and the resident. The key worker is the carer allocated to a particular resident to oversee aspects of their care and to provide continuity. A good relationship between the keyworker and resident was a factor in being able to assist understanding and facilitate good lines of communication, trust and rapport. This was reflected in interviews with staff, residents and relatives. This positive relationship building is acknowledged by a relative who described how he perceived the treatment of his father:

> "I think the friendliness of the staff towards dad. It's not just a question of 'Do you want me to take you to the toilet?' or 'Do you want to eat lunch in the dining room?' It's kneeling down in front of him or sitting with him." Rel13

Other staff talked about the general feel of the care home as important to relationship building. There were descriptions in all three care homes, of homeliness and the residents, carers and relatives described as a family unit:

> "I think they feel part of a…. we're like an extended family so they've come in and they'll make new friends with other residents that are here so we end up with what we like to think of as one big, happy family." RN3

Various approaches were articulated by staff, in helping them to build, what in their views, were positive relationships with both residents and relatives: that there is a need for patience and understanding; that dealing with people in a sensitive way helps understanding between two people; that being sympathetic to people was a useful tool to engender a rapport; having empathy; compassion; affection; devotion; respect; being valued; and treating people with dignity. In the staffs' view these were all components of building positive, respectful relationships which in turn may enable good communication and allow choice, and facilitate participation and inclusion.

A constraint to participation due to relationships breaking down was in evidence in the description of tension being caused, when staff did not meet the expectations of the relatives. Staff described how they felt relatives misunderstood the complexities experienced by the care staff working in the care home environment. For example, one member of staff expressed frustration towards relatives:

> "You shouldn't do that because she was like this, she was like this… blah blah blah' and we try to explain that this is her now. I understand what you're saying, she was like this before but we have to care for her as she is now." SCS3

Misunderstanding dementia was another area of tension for the care home staff as they felt that relatives did not realise what happens in the course of dementia:

> "There are so many that really even to this day don't know what dementia is all about. We get it even with families coming in with their mothers and they find it very hard to cope with it. They just really don't know, you know, what it's all about." SCS22

Relationship breakdown between staff and residents as discussed in some of the interviews may negatively influence participation and inclusion because of the lack of communication as explored in the literature review.

Building positive relationships may be a further step in realising and optimising participation within the care home environment. How staff in care homes behave towards each other, their residents, their relatives and other visitors, including researchers, may have implications for how participation is experienced. To be able to have residents involved and participating within the care home environment, it may be necessary to have all the components of choice, communication, supportive management bound by positive relationship building already in place within the care home environment. This is further explored in the discussion chapter.

Theme 2 – Inclusion and participation

INTRODUCTION

Some of the semi-structured questions in the interviews (see Appendix 2) asked staff, residents and relatives if they were involved in general aspects of the care home and more specifically in research. Asking all those interviewed if they had been given the opportunity to be involved in various activities, including research, may give some insight into the level of inclusion experienced. How people were involved and included in activities within the care home may provide a link to their abilities to be included in research as well as possible confirmation of the facilitators and constraints to participation in general and in research.

SUB-THEME 2A –MEETINGS AND EVENTS

Staff, residents and relatives were asked if they had the opportunity to attend meetings. The meetings or events were defined as any group which was attended by their peers, facilitated by another person or organised for a special event such as a party. If they did attend meetings or events, they were asked if they felt involved and included in activities within the care home because of their attendance. There was evidence from one care home where people felt completely involved in a relatives' meeting organised by the manager of the care home and which was held regularly and minuted:

> "I'm invited to regular friends' and relatives' meetings. I'm always made very welcome and kept well informed." Rel13

Staff and residents of this care home (CH1) articulated their involvement in regular meetings held specifically for their group. The manager described the staff meetings she held regularly, which was further evidenced during the interviews with the staff. This was the only care home which managed to organise the focus group involving staff, residents and relatives, which gave some very concrete evidence of the ability of this care home to involve and include people in activities within the care home. This may provide some evidence of the link between a general attitude of involvement and involvement in research.

The other care home managers said they had difficulty getting engagement at meetings. This was evidenced in the sub-theme of communication, above, when one of the managers, when asked why people did not attend, said she had not asked people. This manager went on to say that said attendance was improved if they had meetings combined with functions such as the Christmas party.

Staff in CH2 and CH3 did not agree that meetings were inclusive or held regularly. The problems identified were the meetings were not well attended or advertised widely enough:

> "Only one relative always comes and it's not exactly well put out. I mean if, I don't think some of the relatives even know that it actually goes on so, anyway, it could be broadcasted a bit more." JCS32

When asked about staff meetings, one member of staff could not remember when the last one had been held.

Events discussed were attendance at events such as bingo nights, quiz nights, tea dances. One resident said he had enjoyed the pre-dinner drinks event which was organised by the staff in the care home but explained it had been stopped due to non-attendance and disruption from other residents.

Inclusion in activities within the care home link to the facilitators and constraints to participation and its sub themes of environment, choice, communication, supportive management and building relationships because all of these elements may be required in the care home to ensure individuals are included, whether they are residents, staff or relatives. This enables us to explore the link between inclusion in activities in general and participation in research for residents, staff and visitors in a care home setting. These findings may help us to develop our understanding of how those links operate and what their consequences are and how participation links to inclusion and then to social citizenship within the care home environment. This is further examined in the discussion chapter. Examining activities within the care home is connected with the effect of external factors to the care homes.

SUB-THEME 2B – EXTERNAL ACTIVITIES

As a measure of inclusion and participation beyond the boundaries of the care home, participants were asked if they felt connected to the community outside. This was to examine how external factors could influence participation and its links to inclusion within the care home. For example, all the care homes talked about how they invited local schools in for carol concerts at Christmas. One of the care homes asked local people to give presentations and all had local events displayed on their notice boards.

There was reference in all the care homes of how they had managed to involve local schools in events throughout the year. Residents in all of the care homes expressed an interest and enjoyment of contact with younger people and

described the importance of keeping in touch with the younger generations. One good example of this was given in CH2:

> "We did a sensory garden and the girls from the school came to do a mural and they brought pictures and the residents got to choose what picture they thought would be nicest." MRN2

CH1 had helped to promote inclusion of relatives as lay inspectors with the Care Inspectorate directly because of their involvement in the care home meetings. There was evidence of their residents being involved in staff interviews and in showing potential residents and their relatives around the home. This is a good example of social citizenship whereby the residents and relatives social standing is recognised and they are encouraged to grow, participate and have a responsibility for sharing events at a societal level (lay inspectors) within the environs of the care home.

In all three care homes people expressed a desire to be in contact with people and organisations out with the care home in some capacity but articulated uncertainty about how to do this. One resident expressed an unfulfilled wish to have more contact with the local community but thought that there would be difficulties because of their frailty, in fulfilling this wish.

> "The last thing you want to do when you come in here is feel as if you are in a ghetto. You want to feel that you are still part of the community." Res15

How external organisations may affect the care home's ability to facilitate participation and inclusion in general and in research will be further explored and examined in more detail in the discussion chapter. Being involved in internal and external activities, one could argue, may lead to inclusion and participation and this is explored in the next sub-theme about feeling a sense of involvement.

Participants expressed that feeling involved in what is going on around you is fundamental to a feeling of inclusion and may increase the likelihood of participation. There was evidence of feeling involved and how that made people feel included:

> "Everybody includes you. You feel wanted." ResD3

There was further evidence of people being invited to join in and how that made them feel included in the care home and why it was important to them to feel like this:

> "It's still about maintaining their life, not being shut in a room or forgotten because you're old… it's maintaining a life." Rel12

There were observations from relatives about how they felt involved in social activities within the care homes from playing a simple game of dominoes and being able to involve other residents to being able to eat a meal with their relative. One relative described the pleasure at being invited to the care home's Christmas meal. It was recognised as important to gauge what level of involvement people wanted:

> "It depends on what level, we try to find out what level of involvement they want. Some just want to visit." MRN3

One of the managers described how people began to call others by their first names and that there was camaraderie among groups of relatives who would otherwise not have met were it not for the common factor of their loved one being in the care home. There was evidence of staff feeling that the residents were an extended family. And in each of the care homes there was evidence staff felt a loyalty to the care home and to the residents they looked after with expressions of how much they enjoyed their jobs:

> "I enjoy working here. When I'm at home, I want to come back to work if I'm off for holidays because it's just a nice feeling here with everybody." SCS12

Conversely, there was evidence of residents feeling excluded when they expressed feelings of isolation and being ignored:

> "I mean it's not everybody that talks to you, they pass you by." Res23

Memory loss and dementia may be a constraint to inclusion and participation from both the person who has the memory loss, their relatives and from the care staffs' perspective:

> "They always get invited to go on activities but they've never been on any yet. I think basically because if Mum's put out of her comfort zone, she gets all the more confused." Rel2

There was evidence of negative attitudes towards people with dementia and the disruption they caused to other residents but conversely, there was also evidence of the efforts that people went to, to ensure people with dementia were involved in activities within the same care home.

The findings help us to understand how participation links to inclusion and social citizenship within the care home environment and develop an understanding of how those links operate and what their consequences are. This is why it was important to understand the feelings of inclusiveness felt by the participants. Being involved may engender a feeling of belonging and a sense of social citizenship.

These findings suggest that inclusion may be linked to participation and the identified areas within Theme 1 - the facilitators and constraints to participation – due to the impact of the environment, of choice, of good communication, of having a supportive manager and in building relationships and how all these components then intertwine with the internal and external activities of the care home. How people feel involved and included is evidenced within the theme of inclusion. There were some examples of internal and external factors affecting the care home which influence participation e.g. involvement in meetings, maintaining links with the community. Participation and inclusion are further explored in Theme 3 – research involvement – and to understand how all these factors impact on how residents, staff and visitors become involved in research.

Theme 3- Research participation

INTRODUCTION

Research involvement was a key interest for me at the start of the thesis. As the semi-structured interviews progressed I realised that there seemed to be a general lack of understanding and mystification around research and what it was. This was typified by people saying they did not feel able to participate in research despite their participating in research by agreeing to be interviewed by me and checking they understood this through the consent process. People were asked directly if they were involved in research in the semi-structured interviews and this was an important aspect of gauging people's perceptions of research and what it meant to them. Research involvement, participation and how this links to social citizenship are key to this thesis and will be explored in more depth in the discussion chapter. The understanding of what is meant by 'research' was a useful outcome of the findings and is explored next.

SUB-THEME 3A- UNDERSTANDING RESEARCH

During the interviews, there was evidence of some understanding of research and the impact it had on the lives of people in the care home. There was also evidence in some of the interviews that people did not really understand what research meant. It is worth noting that all the people interviewed were involved in research by agreeing to be interviewed but as note-worthy is that some people expressed that they did not think they could be involved in research. There was reference to reading Care Inspectorate reports being termed as 'research'. Some staff said that training was a type of research:

> "Well, we obviously do the E-learning on the computer which is like you've got your dementia, your method of handling, theory and your Health and Safety and just like there's loads of ones. We've done Person Centred Care." JCS32

One resident said that they could never be involved in research and thought that they had to have a high level of intelligence, when asked if they thought they could be involved in research:

> "I'm no' very clever right enough." Res22

This perspective has implications for researchers, in the explanations they give to potential participants about what they are doing. This person *(Res22)* , who did not have cognitive problems, and was taken through the informed consent process step-by-step did not seem to realise that they were actively involved in research despite having been given a participant information sheet and time to discuss it with me and their relatives. They signed the consent form and had further explanation given at the beginning of the interview of what was expected.

As a researcher in the care home environment one had to question whether there was sufficient articulation about what was meant by 'research'. And if not, was there sufficient explanation to the staff, residents and relatives about the impact of the time being spent in the care home on this activity. From these findings one must question if there is sufficient understanding from the research community of the impact researchers have on the environments they enter. The significance for residents, staff and visitors of what research means is important for their participation in the research. This is further explored in the discussion chapter. Understanding research links to the next sub-theme of the importance of research.

SUB-THEME 3B – IMPORTANCE OF RESEARCH

All the interviewees were asked if they thought research was important and each answered that they thought it was important for a variety of reasons. Some said that they realised that research may help to improve treatments for people in care homes. Others expressed that research would assist to increase understanding of the experiences of people with dementia living in care homes. Some of the residents expressed altruistic reasons in that although research may be too late to help them it could help others. One resident said that research was a means to contribute and to keep active and interested in what was going on around them:

> "I think it's extremely important. If one is in a place like this, one must contribute oneself. You can't just sit and wait for things to be done for you. You've got to use your own ideas and you've got to keep yourself alive and awake and contribute to anything which is offered you."
> FGRes15

Other reasons to contribute to research and its importance were: to increase awareness; to learn; to provide feedback about how staff were performing; to improve practice; and to provide concrete evidence and answers. One relative expressed their thoughts around the importance of research:

> "All research is important because if some good comes out of it then, I don't have a problem being involved in it. You know what I mean? So, no, I think research is a good thing." Rel2

There was evidence that getting feedback from the research was an important aspect of the process as this enabled people to learn and understand how they could improve and to feel involved and part of the research process.

> "I haven't had any feedback yet. I was told I would get feedback….I would like to know as to how that progressed." MRN1

The emergence of the importance of research as a theme has allowed us to explore the opportunities to contribute to research, for people who live or work in a care home, including those people who have dementia. The interviews highlighted some of the facilitators to participation in research, such as altruism; if people fundamentally think research is a good thing, then their participation in research is facilitated by this idea. No-one said they thought research was not a good thing but there was some evidence of how some might find it onerous; one of the main constraints to research was given as lack of time and this is explored in the following sub-theme.

SUB-THEME 3C - TIME

The importance of planning research time into the busy schedule of the care home day was talked about, as was the need for more time to be able to participate in research, particularly from the staff. Some did not see how it could fit into the routine, despite being sure that it was an important aspect of life in a care home:

> "I'm not entirely sure of that because it depends really on whether we can fit that in to the routine of the home but provided there is a space to do the research, I think, yeah, there will be, yes." SCS3

The findings showed that staff saw the benefits of having a researcher seeing their residents as this provided valuable one-to-one time with residents, which they could not always give them:

> "Someone to just sit with them and have a one-to-one because sometimes it is difficult to spend that one-to-one time. We do our best but it can be hard sometimes." SCS11

This also provided evidence about staff understanding of research which is connected to the sub-theme of research understanding above, as this member of staff saw the researcher as someone who could fulfil a role of companionship, which would not be the purpose of a researcher visiting someone in the care home, although one-to-one time may be a positive outcome.

The awareness of the support needed from management to allow research to be carried out and that staff were reliant on their managers to be released was apparent. There was also recognition that staff needed to support their managers to be able to fulfil any duties required of the research:

> "If you become involved in stuff like that, you do need to support your manager. You do perhaps need more time so your time on the floor would have to be considered and covered but that's not our problem though." SCS11

The managers in all three care homes were all very supportive towards the need for research and talked about how they would facilitate it in their own area. One aspect which was a common theme in the key informant interviews was the issue of ensuring that the care home staff knew when the researcher was coming and this is echoed by a member of staff:

> "Well, as long as we knew when you were coming, we can work round that." MRN2

The issue of time or lack of time, as viewed by the care home staff, can have a direct impact on the ability of researchers to enable people to be involved in research for the care home community. Time constraints were a factor in enabling people to participate in research. Conversely, the key informants' experiences of being kept waiting and lack of time allowed to do research in an environment which can be difficult to negotiate and isn't 'research ready' also has an impact on participation in research and is further explored in the discussion chapter.

SUB-THEME 3D –INVOLVEMENT

There was evidence from the interviewees that some felt there was a duty in being involved, as this would help to improve services.

> "That's why I wanted to be involved in the research because I know we don't always get it right." MRN1

The benefits of being involved were explored. It was acknowledged that services are not perfect, and that research involvement would encourage staff to learn in

an 'act of openness'. One staff member talked about the evidence required for registration with the care Inspectorate, which was seen as a secondary gain from being involved in research. All the care homes talked about the benefits to the residents in being involved and that residents were happy to get involved in research:

> "Somebody was coming in on a weekly basis and she would see certain people. She would go and see them on her own and then she would come back and discuss that with us, ask certain questions. How many falls had they had? Did they do certain things for themselves? You know, to see if that was perhaps causing falls etc. So they were happy to get involved, our residents usually were." SCS11

This statement highlights, as well as the willingness of residents to be involved in research, the understanding that staff have of what researchers do when they are seeing people within the care home. This is further explored in the next sub-theme.

There was some evidence in two of the care homes of local audit and local surveys which showed that the care homes encouraged local feedback via questionnaires. These questionnaires were enabled due to the supportive manager who was keen to find out what residents and relatives thought of the care home and links to the facilitators and constraints to participation explored in the findings in Theme 1 – the facilitators and constraints to participation - and supportive management.

There was acknowledgment that research involvement was not always easy due to constraints such as shortage of time and lack of knowledge and that the actual process of research could be worrying for some:

> "I think with anything new, the interviews might be taped and might be scary for some of them but I know there's quite a few relatives here whose people have dementia and who would be quite keen to join in." MRN2

These findings help to build the evidence towards the link between participation, inclusion and the experience of social citizenship highlighting the facilitators to participation, the residents participating and the social citizenship experienced when people are involved and included.

Conclusion

There are some important insights in the findings which inform the research questions, and are summarised here. From the three main methods of data collection used the overall findings are presented with an indication of how they relate to the research questions.

From the national survey, there is confirmation, from the care homes who responded, that there is little research going on. Those who did respond were positive about research and cited staff advice and development as a facilitator to research interest and involvement and lack of time and workload pressures as a constraint to research involvement. This enabled exploration of the opportunities to contribute to research, for people who live or work in a care home, including those people who have dementia.

There was consideration of factors affecting the care home which may influence participation in general, in research and social citizenship. Participation was explored in general areas of care home activity and indicators of how it may link to participation in research for residents, staff and visitors in a care home setting were explored.

The semi-structured interviews with the key informants provided evidence of the barriers and facilitators to research. Managers and staff attitudes may have a bearing on whether research was part of the culture. Leadership and communication were both described as key components of whether there was participation in research. Capacity and consent understanding and implementation may be crucial to securing the inclusion and participation of residents in the care home. This includes those with dementia who may be overlooked and disenfranchised from research and other activities in the care home. This leads me to explore, in the discussion chapter, whether inclusion and participation would enable people to have experience of citizenship. Finally, the physical environment and peoples' physical capabilities were important in enabling research participation.

The study care homes, including semi-structured interviews and general observations were enlightening about the facilitators and constraints to research participation first hand. The impact of the environment and the choices that residents and staff were able to make were emphasised. The importance of communication in many forms was highlighted. The influence of supportive

management and leadership to all those who live and work in the care home was highlighted. The significance of relationship building was also seen as a factor in enabling participation.

Discussion with all those who live and work in the care home through the semi-structured interviews provided an understanding of the importance to this group of research and some of the misunderstandings surrounding research. It enabled an exploration of some of the issues directly affecting people in care homes, some of whom have dementia, with regards to research, such as time pressures and reasons for participating.

These findings have enabled a further the exploration of how participation may link to inclusion and where social citizenship lies within the link between participation and inclusion within the care home environment. In the discussion chapter I will develop our understanding of how those links operate and what their consequences may be. My findings together with the literature are considered in the discussion chapter next.

Chapter 5 Discussion

Introduction

The focus of this thesis was to examine the concepts of inclusion and participation in the context of a care home environment and how these relate to research participation and social citizenship of people in a care home. In this chapter I will be drawing together the findings of the national care home survey, the key informant interviews and the study care home interviews. During the field work I sought the views of three groups of interest within the care home environment: residents, some of whom had dementia; staff; and relatives of residents. I aim to relate these findings to the literature, building on existing knowledge and contributing new insights about participation in general everyday activities and participation in research, in care homes. I will explore how social citizenship is experienced in care homes and whether participation and social citizenship may be linked.

The thesis had four core aims and to contextualise the ensuing discussion it would be useful to revisit these: Firstly, I aimed to explore the opportunities to contribute to research, for people who live or work in a care home, including those people who have dementia. Secondly, I aimed to consider factors affecting care home staff and residents which may influence participation in general and in research. Thirdly, I aimed to explore how participation generally links to participation in research for residents, staff and visitors in a care home setting. Finally, I aimed to explore how citizenship functions in a care home environment and whether there is a link between inclusion, participation and citizenship within the care home environment. Furthermore, I will recap the research questions posed:

Research Question 1 - How do people who live and work in a care home participate generally and in research?

Research Question 2 - Which factors in the care home influence participation generally and in research?

Research Question 3 - What aspects of social citizenship can be observed and what influences social citizenship within a care home?

Research Question 4 – To what extent can we establish a link between participation generally and in research and social citizenship?

I have presented the discussion of the findings coupled with the literature, considering how inclusion and participation, research participation, gatekeeping, communication and workforce support are important topics in the debate. I then progress to discuss what affects general participation for residents and their relatives, for residents with dementia, and for staff. The discussion moves on to deliberate what affects research participation through examination of legislation, physical environment and the importance of planning ahead. I finish the discussion on issues of citizenship and what links inclusion and participation to social citizenship. Finally, I outline the key arguments of my thesis.

INCLUSION AND PARTICIPATION

To experience inclusion in something implies less activity than participation, as one might not actively participate – take part – but could be included e.g. by being on a list (See Chapter 1 for definitions of inclusion and participation). My findings section (see Chapter 4) explored inclusion and its relationship to participation as staff, residents and relatives talked about how they experienced inclusion in many aspects of the care home activities such as meetings, and external activities out with the home. Despite positive examples of inclusion there were still many instances given of residents, staff and relatives feeling they were not included in decisions about the home or activities within it. Some people felt they could be more involved and experience more inclusion. My findings suggest inclusion in activities in the care home is a complex process as Goodman et al (2011) suggests.

Notably Bartlett and O'Connor (2010) recognised one person's methods of participation may differ from another's which is a consideration for the findings of my thesis because of differing groups of interest i.e. staff, residents and relatives. My research suggests that despite the literature showing that some residents are more able to make active decisions about participation in the life of the care home (Bradshaw, Playford and Riazi, 2012) there is a paucity of meaningful participation in general day-to-day activities for residents. My findings explored some of the reasons for this e.g. poor environment and poor leadership amongst other factors, which will be discussed in more detail later in this chapter.

RESEARCH PARTICIPATION

Research participation would involve being actively included in a research project. In a care home setting that would mean different things to the different groups of interest. For a care home manager, it could mean facilitation of their care home to be involved in research such as joining the ENRICH network of research ready care homes (ENRICH, 2016), or acting as the gatekeeper for residents in their charge to enable them to participate in research. For staff members, it may be acting as a gatekeeper or offering to participate if there is a study in their care home. For residents, it is offering or accepting if asked, to be part of a research study in their care home. For people with dementia it is no different than other residents unless one has a diminished understanding due to dementia and therefore have capacity issues. In that case, someone (their nearest relative or guardian) may decide on their behalf whether they participate depending on their wishes before the onset of illness. For the relatives, it is helping to facilitate the research participation by judicious gatekeeping or indeed, participating as a carer in research.

The literature (Luff, Ferreira and Meyer, 2011; Alzheimer Society, 2009) and findings (Chapter 4) enable us to draw conclusions that research is not a priority for care home staff or residents. My research suggests the amount of research that has been taking place in care homes in Scotland is slight in comparison to the number of care homes, the population therein and the breadth and complexity of the issues encountered within them. Nonetheless, the literature demonstrates there are some excellent contemporary care home research projects in the UK. For example, Killett et al (2016) have studied how organisational cultures affect residents' experiences within a care home environment and Jenkins et al (2016) looked at how researchers could overcome the challenges of conducting research in care homes. Notwithstanding this, my findings from the national survey of care homes suggest there are few care homes involved in any depth in research in Scotland.

My own research was an example of inclusion and participation of care homes in research. The three care homes approached were all very welcoming to the idea of being involved in research. Despite my own the reservations about gatekeeping as illustrated in the literature (Jenkins et al, 2016; Brown-Wilson et al, 2013; Higgins, 2013), in practice I found that gatekeeping was minimal and that people were trusting of my approach. I took care to ensure that people knew

my professional background and that I was a registered nurse with all the professional implications that entails.

Despite this my findings suggest there is a paradox in care home research. While there is wide agreement that more research is needed to improve care, research is not a priority for care home staff or residents. Furthermore, I would argue that without the opportunity to participate in research, such as those given to the care homes I approached, improvements to care provided may be protracted. In the next sections, integrating my findings with the literature I focus on factors that firstly influence general participation and then research participation within the care home environment.

GATEKEEPING AND LEADERSHIP

Historically, Cleary (2004) argued that organisational issues such as bureaucracy out with care homes' control were problematic for researchers, in accessing residents within the care home. This is shared in my findings about gatekeeping particularly in care home chains, where researchers had to navigate a chain of command before even getting through the door of a care home. This meant that researchers had a further layer of bureaucracy to navigate in their negotiations with care home chain senior managers. Drawing on the literature (Hubbard, Downs and Tester, 2003; Luff, Ferreira and Meyer, 2011) there is recognition of the preparation that is required prior to entering the care home but I would argue that negotiating with the senior management, particularly in a chain of care homes, is fundamental to success. My own experiences were of the three care homes approached one was a chain and two were independently owned. The chain had to check with the senior management of the chain but there were no barriers to using any of the care homes in this research. This may have been because I used my contacts within the NHS to connect with each care home, which immediately established trust.

Furthermore, once through that door, my findings showed that despite the relatives and residents being cited as the most important of the decision makers according to my national survey, the key informant interviews suggested that it was the manager who was the actual gatekeeper in most instances. This is in keeping with Killett et al (2013) and other researchers (see the literature review section on Leadership) which found the manager was central to the culture and ethos of the care home including acting as a gatekeeper.

I found the importance of the manager to be the case in my own research. The manager was instrumental to the success of the research and in each of the three care homes I had their full support: Firstly, I had developed a good rapport with the managers by disclosing my background as a nurse. Secondly, I took time to explain the positive aspects of having a researcher in their care home and provided a poster they could display to show everyone that their care home was engaged in research. Thirdly, all of the managers saw engagement in research as a positive development for their care home particularly when feeding back to the Care Inspectorate.

However, gatekeeping may come from sources other than the care home manager. It may be a relative, a friend or another resident – 'you don't want to talk to her' was said to me on one occasion from one resident about another. My findings were echoed in the literature (McNeely and Clements, 1994; Brown-Wilson et al, 2013) with evidence that gatekeepers may come from unsuspected sources, such as relatives and junior staff. It is a challenge for researchers to ensure that a paternalistic and exclusionary approach is overcome. My research suggests that some of the methods described in this thesis such as good communication skills, the process consent method (Dewing, 2007), or the use of Talking Mats™ (Murphy et al, 2010) could assist researchers to overcome some of the exclusionary challenges of gatekeeping described.

There was a recurrent theme in the literature (Jenkins et al, 2016; Brownie and Nancarrow, 2013; Goodman et al, 2011; Davis and Brown-Wilson, 2007b) of the importance of the manager and their styles of leadership, in the overall functioning of care homes. My study extends the literature on how the manager's role in the care home can play an integral role in the culture of the care home and the importance of the manager in their role of facilitating inclusion, participation generally and in research. My research suggests the different leadership styles encountered within the study care homes reflected the significance of leadership. On the one hand, one of the study care homes, where the leadership style observed was inclusive and pioneering in its level of innovation and research inclusion, had previously been involved in a number of research projects. Conversely, in another study care home, the manager acknowledged they were out of touch with up-to-date research in their field. This care home had not been involved in any research previously. The manager had not attended any educational events and the level of exclusion and discontentment voiced by the

staff was striking. This demonstrates the link between participation generally and participation in research.

Disempowerment of staff was evident in my findings and I would suggest this relates to a lack of social citizenship as encapsulated by Bartlett and O'Connor (2010) where the essence of the practice and status of social citizenship for staff was absent. This may have been because there was a deficiency of opportunities to participate for staff, residents and their relatives in decisions which would shape events for all of these groups. The findings indicate that the management style has a bearing on the type of culture experienced by the staff. In turn, the management style has an impact on the residents in the care home. If it is positive and inclusive for the staff then the residents and relatives are more likely to experience inclusion, whereas if it is negative and exclusionary then there is an impact on the level of inclusion experienced by the residents and relatives.

My findings show if staff, residents or relatives are excluded from activities or making decisions within the care home there may be a culture of exclusion, which would not support participation in general or in research. As highlighted above, my findings add to the literature indicating inclusion and participation and ultimately social citizenship is very much led by the manager, their management style and the culture they create throughout the care home.

COMMUNICATION, POWER AND SOCIAL CITIZENSHIP

Mutual empowerment and respect increase communication and interaction with residents, producing better resident outcomes (Flesner and Rantz, 2004; Kitwood, 1997). Likewise, good communication has been shown to be a facilitator for inclusion and participation for all activities within the care home (Killick and Allen, 2001).

My research suggests that communication is a powerful aid to research when used well. It can enhance the experience for the researcher and the participants as well as the care home staff. During the interviews I observed many forms of communication e.g. written, verbal or non-verbal, and noted in the findings how communication could enhance both the staff's and the resident's experience of decision-making and participation. Killett et al (2013) recognise the relevance of communication and how it can enhance relationships between the workforce and those people who live in the care homes. My findings suggest that good communication, where the resident or staff member is listened to, responded to appropriately, treated with respect and dignity and able to air their views to a receptive audience, can enhance their experience of social citizenship, where

there is upholding of the persons rights and the essence of social citizenship is upheld. A good example of this in action was during the focus group where by the group could air their views to a receptive audience. I could see the application of social citizenship in practice through good communication. Indeed communication is at the core of social citizenship as described by Bartlett and O'Connor (2010).

In contrast, the literature shows that poor communication has been cited as a reason for high staff turnover and relationships breaking down between staff, residents and their families (Higgs and Gilleard, 2015). My research extends this view when I considered the impact that poor communication had on staff and residents, such as feeling ignored (resident) or feeling undervalued (staff) as described in more detail in the findings section of the care home interviews. Likewise, Killick and Alan (2001) described the negative power relationships and the effect this would have on the resident and all those around them. My findings advance this idea of the distorted power balance and an erosion of trust between firstly, staff and relatives, and secondly, staff and management. This evolved into a constraint to participation in general and in research activities for both the residents and staff. This links to social citizenship whereby the ability to grow and participate is hampered and the experience of social citizenship is minimised.

With these findings of the impact of positive and negative communication as outlined above, my research suggests the use of communication in all its forms when executed well is a significant facilitator to participation in general and in research activities. This was observed where communication was generally positive and the residents, relatives and staff spoke enthusiastically of the opportunities afforded to them in the care home. This was reiterated by the key informants who described the importance of good communication for participation generally and recognised the significance of communication in enabling participation in research, whether they were staff, relatives or residents.

Conversely, negative or poor communication is not just detrimental to participation but to the overall culture of the care home. The literature review highlighted how poor communication could alienate, disempower and belittle residents. The literature also highlighted how poor communication could erode social citizenship for residents (Utley-Smith et al, 2009; Bartlett and O'Connor, 2010). My research extends this idea by studying those who live and work in care homes and concluding that poor communication was a factor in the residents not experiencing social citizenship and the staff feeling aggrieved and disempowered

by poor communication, therefore not experiencing social citizenship either. I have extended the analysis of social citizenship by approaching residents and staff in an integrated way which adds a further dimension to the literature. Further to the contribution to the overall culture in the care home is the issue of workforce support for staff within the care home and the impact workforce support has on participation and in experiencing social citizenship, which I will discuss next.

WORKFORCE SUPPORT

My study suggests that workforce support enables a culture of change and innovation allowing all who live or work in the care home to participate in a meaningful way. The literature supports my findings that a well-educated and supported workforce can promote inclusion and participation (Bostick et al, 2006; Luff, Ferreira and Meyer, 2011; Hasson and Arnetz, 2011), thereby promoting social citizenship.

Furthermore, to enable a well-supported workforce the manager requires good leadership and management skills, as previously discussed. My findings showed that support of staff from the manager was found in varying degrees within the three study care homes. The more support in the form of training and education, visible management and recognition of the staff's input received by staff, the higher performing the care home was, in the opinions of the staff, residents and relatives questioned. My findings indicate the manager of a care home is pivotal in the culture of the care home. In furthering the literature the culture can be perceived as a facilitator or constraint to participation in general or in research as the findings illustrated.

Similarly, support for the workforce was discussed at length by the key informants as an important factor to staff's, relative's and resident's perception of well-being. Nevertheless, the study care home which did not have evidence of on-going education and training had some of the most insightful staff comments around the importance of choice and communication for the well-being of their residents. This suggests that despite a lack of education and training opportunities, some staff were able to uphold the practice of social citizenship.

My research suggests that a well-supported workforce has a bearing in facilitating research inclusion and participation, particularly if staff are informed of opportunities and understand the relevance of doing research. For care homes to be able to maximise their potential in their opportunities to engage in research, the care home may have to know about the research and have a connection with

researchers. The well-supported staff were in the high-performing care home (as indicated in the Care Inspectorate listings) who had participated in research, were registered with ENRICH (2015) (See Chapter 1 background on ENRICH) and were interested in being involved in other studies. In furthering this debate, it could be suggested that this investment in the workforce is a facilitator for encouraging participation generally and in research, as staff are more open to new ideas and innovative practice. Finally, the practice of social citizenship requires opportunities for participation to enable enrichment and growth in one's personal experience of life. This can be facilitated by supportive management and a well-educated work-force who understand the importance of participation in whichever form it takes.

What affects general participation?

FOR RESIDENTS AND THEIR RELATIVES

The extent to which residents and relatives in care homes are able to participate may be dependent on a number of key factors. These are outlined in the literature review chapter on Participation and include supportive management and positive leadership (discussed above), a well-educated workforce (discussed above) as well as understanding what constitutes participation.

In order to illuminate one aspect of participation, social networks (Scharf, Phillipson and Smith, 2005) are described in the literature review as central to general participation, and are difficult to establish and maintain when in a care home. This is because of the loss experienced by both the resident and the relative of the networks and ties within the community that the person once had. I noted that residents and staff expressed a wish to remain connected to the outside community and not become ghettoised within the confines of the care home.

The establishment of new social networks and forming new relationships is difficult as Bradshaw, Playford and Riazi (2012) showed. Likewise, my findings indicated the care home environment was not conducive to privacy or intimacy. There was a presumption of loss of agency highlighted in the literature by Boyle (2014) and echoed in the findings. Frailty and cognitive health were also factors both in the literature and the findings here that people experience barriers to participate generally.

My findings outlined many examples of exclusion from the key informants, care home staff, residents and relatives. I noted during the field work that although some residents and relatives would have liked to be included in activities and be able to participate, there were sometimes restrictions such as the person's frailty or cognition that were beyond the capabilities of the staff. Regrettably, most researchers agree that residents with dementia are much less likely to participate, whether in general or research, as discussed in the next section.

FOR RESIDENTS WITH DEMENTIA

The literature shows the challenges of participating for people in a care home are amplified for those with dementia (Wild and Kydd, 2016; Jenkins et al, 2016; Hellström et al, 2007; Cowdell, 2008; Dewing, 2007). My research indicates the difficulties of including people with dementia in day-to-day activities, due to misunderstanding, loss of speech or hearing, lack of time and other work priorities are widespread. This can lead to the exclusion of residents in many aspects of the care home's activities and indeed, having dementia was exclusionary in the care homes studied, with instances of people with dementia being overlooked and ignored by staff.

In the interviews there was a degree of negativity expressed by some staff, in looking after people with dementia. Similarly, there was evidence that some staff did not see the person with dementia as someone who could contribute. This has been described in the literature by Higgs and Gilleard (2015) as a constraint to participation and a loss of personhood (Kitwood, 1997). Furthermore, the key informants discussed the negative impact on their ability to conduct research in an environment which was dismissive of the people being cared for, due to their level of dementia. Conversely, the findings showed that residents without dementia acknowledged that some may have difficulties due to dementia but ensured they were not stigmatised because of it. My findings support Davis's (2000) that relationships within communities of people become more relevant and important for the constituents of that community i.e. the community of residents in the care home.

My research suggests that negative social attitudes towards people with dementia, which was seen within the care home environs, coupled with exclusionary actions such as not involving people in making choices or asking if people wanted to be involved in planning their day to day activities were factors in excluding people in general. This may relate to the lack of participation

observed in the study care homes for people with dementia. These negative attitudes found among some care home staff may have wider implications for people with dementia, as it may be a gauge of the wider negative attitudes people have about those with dementia. Having dementia is relevant for those who are residents in a care home as they are lacking in power not just by being a resident but a resident with dementia, meaning that their status could be seen to be lower than other residents.

This brings to the fore the exclusionary practices and attitudes towards people with dementia relayed in the findings in this research, which clearly link lack of inclusion and participation with a lack of experience of social citizenship in this group of residents. The literature and findings highlight the importance of communication for this group but also indicate that because of having dementia they are more prone to negativity from care home staff leading to exclusion and discrimination (Killick and Alan, 2001; Kitwood, 1997; Brown-Wilson et al, 2013; Higgs and Gilleard, 2015). This would indicate that people with dementia, due to exclusion, have difficulties in practicing or experience social citizenship.

FOR STAFF

There was evidence in the literature (Scott-Cawiezell, 2005; Brownie and Nancarrow, 2013; Higgs and Gilleard, 2015) that staff need to be supported to participate by positive communication, strong leadership and management (as discussed earlier). My findings indicate that negative power dynamics were still a feature in the modern care home environment. Staff would occasionally talk about residents in disparaging terms. Furthermore, one of the managers talked about staff in judgemental terms. There was a feeling of mistrust towards the senior staff seeming to come from the junior staffs' feeling of exclusion in the decision-making in the care home. There was a lack of opportunities for junior staff to interact with senior staff. This finding supports Higgs and Gilleard (2015) in their contention that the context of 'dirty work' in care homes may be a factor in negative power dynamics forming, with the majority of the 'dirty work' being performed by the junior staff.

My research reveals that negative power dynamics could create a culture of exclusion which could permeate to the interactions with the residents. A dynamic such as this may disable Bartlett and O'Connor's (2010) concept of social citizenship for staff, based on recognition of social position, upholding of rights and a degree of responsibility for shaping events. These are counteracted when

there are negative power dynamics at play. My findings advance the literature to include staff in the concept of negative power dynamics and how this can interact and interfere with staff's ability to participate and experience social citizenship within their workplace of a care home.

What affects research participation?

The analysis of the findings strongly indicated there was a lack of participation in research found in the care homes. From the national survey it was discovered that only 7% of the care homes who responded had actually been involved in any research over the past ten years. When choosing the care homes with consideration and inclusion in this research, as described above only one of the three homes chosen had been previously involved in research It was clear that there was little research on-going in the study care homes but a willingness to be involved was expressed by the survey respondents. I was able to gain useful insight around research participation from the key informants' interviews.

My own experience of being a researcher within a care home where people expressed that they were not involved in research was paradoxical. Even though I had explained that I was a researcher and had followed the consent process with each individual involved in an interview, to inform my research there still seemed to be a misunderstanding of what research is. This is reflected in the findings as I was able to explore some of the factors of why research participation and inclusion were not perceived to be prominent in the study care homes despite me actually carrying out research in these care homes.

LEGISLATION

Firstly, one issue which may influence the extent that residents or staff may be involved in research was gatekeeping via the Ethics Committees. The difficulties encountered with the Ethics Committee were shared by the key informants who described their difficulties in navigating Ethics Committees as a major source of frustration, actually impinging on their ability to carry out research, in some instances, because of the restrictions put on them. As one of the key informants highlighted, it is a difficult line to follow when you must have ethical approval to approach the care home but need to prepare the care home in advance of your arrival. On the other hand the Ethics Committees are there as a source of information for researchers and are constituted to safeguard the rights, safety, dignity and well-being of research participants, independently of the researchers.

Such difficulties navigating the ethics committee system mirrored my own experiences. A lack of familiarity with qualitative research was evident in the NHS Ethics Committee. This is further elaborated in the methods section of my thesis.

Secondly, a barrier to research participation is the misunderstandings from both the research community and care home staff around the use of policies and legislation for capacity and consent issues. My findings revealed there were issues around capacity and consent emphasised in the key informant interviews, where there was uncertainty about how the legislation should be interpreted. Each key informant interviewed had found the use and understanding of the legislation for capacity and consent was a barrier to research participation in different ways. Capacity and consent issues required careful consideration especially amongst junior research staff due to their unfamiliarity with the legislation and uncertainness of its use in practice.

My findings indicated the key informants' greater seniority and experience increased their understanding of the issues at stake especially around the issue of consent. Furthermore, the more experienced researchers were more able to describe how to overcome barriers of interviewing vulnerable people in a care home but still found the bureaucracy and interpretation of the legislation difficult to negotiate. They indicated there has to be two-way trust between the researchers and care homes. I would argue the confidence and ability of the researcher to carry out the research in a professional manner, would have a bearing on an individual care home's confidence to participate in future research i.e. if they have a bad experience then they would be less likely to allow research to be carried out in their home in future. In my own research, I ensured that I was fully conversant about the legislation that I used and explained in detail the importance of the consent process. I was confident to do this because of my professional background in mental health nursing. So although I was acting as a junior researcher I had a professional background which prepared me for this type of research. I would suggest that it was clear from the more junior researchers that they needed support from senior staff in the understanding and use of this legislation, to help prevent exclusion of people with dementia in research. My findings add to the literature (Jenkins et al 2016; Goodman et al, 2011) about the importance of good supervision and support for junior research staff within the care home environment and the impact of the legislation when considering inclusion of participants in research.

PHYSICAL ENVIRONMENT

My research indicates the physical care home environment can be both a facilitator and a constraint to research participation. My findings imply that the physical environment was of great significance to everyone interviewed and issues concerning the physical environment were noted in my observations. In my experience as a researcher, first impressions included the locked door, the smell on arriving at the care home door, the noises from within. Once in, the noise of the care home such as clattering, other residents, shouting (staff and residents) television playing, hoovering, music playing, crockery clashing, staff chattering. The layout of the care home was another factor such as spaces to see and talk to people privately. Also, the physical capabilities of the residents (hearing, sight, mobility) was an important factor for research participation with more than one of my interviews conducted in the sitting room of the care home with the television on, during visiting time. This was because, in one case, the person being interviewed was in a reclining chair and it would have been too difficult for her and the staff to move them out to a private room. Immediate judgments may be made of the type of care home one is entering depending on sounds, smells and visual clues. Therefore, the environment may be a determinant of the whole ethos of the care home. As my findings illustrate it is the starting point of a relationship with the care home and all those who one may encounter, such as the manager, the staff, the residents, other visitors.

 The literature showed much diversity between care homes (Lawrence et al, 2012; Luff, Ferreira and Meyer, 2011; Evans and Goodman, 2009). The key informants expressed that they found the physical environment generally a constraint to research participation. Likewise, the residents said there was a lack of privacy, which was echoed by the staff. Popham and Orrell's (2012) work suggests that a significant factor in actively participating with others is privacy which is afforded by the environment. This factor links to the lack of social networking discussed earlier in the thesis. During my field work in the care homes I was interviewing people in public areas for a variety of reasons. This leads me to conclude that the physical environment is more of a constraint than a facilitator in conducting research within the care home, with the importance of planning ahead magnified due to this.

The key informants expressed there had to be months of preparation to get to know the staff and ensure they understood about the research proposed. Some of the key informants expressed the importance of face-to-face time with people in their preparations and how this enabled everyone to understand what was being proposed. The analysis of the findings established that staff in the care homes had to get used to the researcher in their midst. There was discussion in both the key informants and the care home interviews about researchers having meetings with care home staff, relatives, managers, and residents and how this should be costed into the study, as this time in preparing the ground for researchers was invaluable. I can corroborate this finding from conducting this piece of research field work for my thesis with the preparation time and attention to detail an important factor in completing the field work on time. I did find that the interview schedule had to be flexible and that I had to change plans at very short notice because the person I had intended to interview was not available but having a contingency plan helped to mitigate this.

In conclusion, I would argue that the preparation of the care home by contacting the manager and staff, well in advance as well as reminders immediately prior to commencing the research is time well invested by the researchers. This in turn, facilitates the care home to participate in the research as fully informed of the researcher's expectations of the care home as well as preparation of the all those who live and work within the care home.

Issues of citizenship

In the literature review (Chapter 2) I critiqued the different models of citizenship within the care home population. Bartlett and O'Connor (2010) indicated that social citizenship recognises that there is not a 'fixed' way of being a citizen and embraces differences in values and beliefs. At this juncture, a reminder of the definition of social citizenship is valuable:

> "Social citizenship can be defined as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level." (Bartlett and O'Connor, 2010:37)

For the purposes of this thesis I chose social citizenship as the best description to portray how people who live and work in care homes experience citizenship as it allowed me to accept that everyone can be a citizen in some way or other, no matter where they live. The findings indicated that on more than one occasion it was expressed to me that the resident was in the care home because they had been 'placed' there. Although they found the care home comfortable they expressed a loss of their sense of ownership, lack of choice and ultimately social citizenship.

Brannelly (2011) argued that it is difficult for people to experience citizenship if practitioners are unable to see the person with dementia as socially alive and able to participate. As previously discussed in this chapter, the exploration of how negative social attitudes to dementia can permeate into a care home environment is important for us to understand where some of the barriers to participation and inclusion lie. It also helps us to understand how negative social attitudes have a potential for negative influences on people who live and work in a care home environment to experience social citizenship.

My findings indicate staff and residents expressed a desire to belong and gave examples of what made them feel they belonged to the care home community. Conversely, both residents and staff gave many examples of feeling excluded, marginalised and ignored. Furthermore, staff seemed not to recognise the loss experienced by the residents. This detracts from staff's and resident's ability to experience social citizenship.

My research suggests that the exclusion of residents whether they have dementia or not, and their absence of social citizenship may be attributed to the lack of understanding about their needs and rights as citizens in the care home. It suggests that the concept of citizenship is not upheld amongst people living in care homes and that there is little preservation of citizenship once a person is living in the care home environment.

Furthermore, the findings about the importance of the managers' leadership style discussed earlier in this chapter helps us to understand why enabling residents to participate generally and in research could facilitate inclusion, participation and citizenship more broadly. Residents who expressed difficulties in exercising the most basic of choices such as what time they ate, or when they went to bed would find their likelihood of being able to participate in research questionable.

Likewise, I argued earlier in this chapter that disempowerment amongst staff may relate to a lack of social citizenship found in care homes. And that this disempowerment was influenced by the manager, their management style and the culture they create throughout the care home. The literature and the findings concur that the manager is a key person within the care home environment and is able to exert considerable influence on their staff, residents and the whole ethos and culture of the care home. The relevance of this finding in relation to the extent that staff and residents in care homes can participate in research should not be underestimated, as it implies the extent of a manager's influence on the ability of individual care homes, staff members or residents to become involved in research is great.

In support of this argument, I discovered there was a power dynamic in evidence following analysis of the findings from the key informants and the care home interview participants, when discussing the influence of staff such as managers' attitudes to researchers and the importance of supportive management. Where a manager was facilitative and positively responded to research there was the greatest uptake of involvement in research i.e. the study care home where the focus group was organised. I would argue the manager's leadership style strongly facilitates inclusion, influences participation generally and in research, and may ultimately empower social citizenship for all who live and work in the care home.

Linking inclusion, participation and citizenship

This thesis contributes to the argument that involvement of staff, residents and relatives requires inclusion in decisions and participation in events within their community. My thesis has contributed to the literature through analysis of the findings of the national survey, the key informants and the care home interviews and through the general observation that there is little involvement of residents in decision-making. Decisions are made by staff and management about almost all aspects of the residents' day without involving the residents, in most cases. Social citizenship is based on inclusion in whatever form it can be practiced and this lack of inclusion and participation seen in the care homes and in the literature about care homes has a direct bearing on people's abilities to engage in activities, due to a loss of citizenship.

Key implications

RESEARCH

There is a lack of research in care homes. Residents are excluded because of age, frailty and dementia. Staff are excluded because of poor leadership, management and lack of staff development opportunities. The lack of research extends from what is known already about clinical research where older people are not included in clinical trials on investigational medicinal products (CTIMPS) to social research as established in the current study, due to difficulties of time and cost, complexities in navigating the legislation, a shortage of funding and a paucity of expertise in this field. On the other hand, there are instances of high quality research developments particularly in the discipline of social research by expert care home researchers who are leading the field (Killett et al, 2013; Brooker et al, 2011; Help the Aged, 2007). Furthermore, there are positive moves to enable research in care homes using a national policy initiative to prepare care homes for research (NIHR, 2015). I would recommend that researchers prepare thoroughly before approaching care homes, just as care homes can be encouraged to prepare for research and learn the lessons from the established, experienced researchers in this field.

INCLUSION AND GENERAL PARTICIPATION

There is a lack of inclusion and general participation for residents in care homes because of various factors including the physical environment, task-orientated routines, and lack of trained staff: not just registered nurses but staff who have received specialist training for people with cognitive difficulties.

Management style and leadership of the care home are important factors which could engender a positive culture and inclusiveness of staff, residents and visitors when executed well but the reverse could be seen when there was poor management and leadership in the care home environment. Furthermore, workforce support such as education and inspiration from leaders could be seen as a positive dynamism encouraging innovative practice and participation for all.

Issues of gatekeeping both from the management structure of the care home, the manager themselves or others in the care home, including relatives, staff or other residents may prevent inclusion and participation. To improve this, there needs to be good leadership, and well-informed and educated staff with an understanding of dementia and difficulties such as frailty. This applies to the leadership in the care home and the leadership of the research team and may encourage and

increase research participation.

RESEARCH PARTICIPATION

There is a dearth of research participation observed in my thesis. I have argued that it follows if there is little general participation then there is minimum research participation and this link was established in the study care homes. Furthermore, research is misunderstood by residents and staff and there are suspicions of the motives of researchers. There is little time for research and it is not prioritised when the ethos of the care homes is to provide care. Exclusionary gatekeeping was observed as described above in care homes and from Ethics Committees too (Jenkins et al, 2016).

For research participation, my findings show that there needs to be preparation of the care home residents and staff to enable their valuable contribution to the research process be maximised by the researchers. My research showed the importance of supporting junior research staff by more senior researchers to relay their understanding of the legislation, its uses and limitations. Furthermore, the physical environment can be challenging but by planning ahead and preparing the care home for the researchers' input, the challenges of the physical environment can be overcome. Ultimately my research showed there needs to be preparation of the staff and residents prior to the research, identification of the gatekeepers and regular feedback to the residents and staff on the process and the outcome of the research.

SOCIAL CITIZENSHIP

Objectively and subjectively, in most cases care home residents do not experience social citizenship but are merely housed within the institutions where they reside. I do not mean to imply that the care is poor or that residents are poorly treated but my findings suggest that to enable residents to experience social citizenship, residents need to be experiencing inclusion and participation in all aspects of the day-to-day activities within the care home, including opportunities to take part in research. This extends to all residents, some of whom may be more challenging to include and enable to participate because of their altered cognition.

My research found there was evidence of discrimination towards residents with dementia. There was scant recognition of the social positions of residents. There were very few opportunities to grow and participate in life within or out with the

care home for the residents or for staff. There was little evidence that residents or staff, other than the manager could shape events at a personal or societal level. It is in the care home's interest and in the manager's capacity to explore ways of including everyone; staff, residents and relatives. This would enable the concept of research to be sown on fertile ground.

More positively, my findings indicated that relationship building is linked to inclusiveness and nurturing a facilitative culture and was seen as a positive act which enabled social citizenship in this group. This was facilitated by good communication practice and supporting the workforce to learn and contribute to the environment they worked in to ultimately improve it for the residents they care for. I would recommend all those involved in care homes, whether they are staff, residents, relatives or researchers to seek learning opportunities, whether formal or informal and to enhance communication within this group as best they can, maximising the resources they have available to them.

The link

My research suggests that understanding the links between inclusion, participation, and citizenship will enable research participation to be promoted. The links become more defined when factors such as choice, upholding residents' social position and having a degree of responsibility for shaping events, lead to participation and inclusivity which is described in Bartlett and O'Connor's (2010) definition of social citizenship. This link becomes more apparent if general participation is embraced for residents, in whichever way is most suitable for each resident, considering their frailty and cognition. In enabling this staff would feel more involved and would experience participation within the care home. Such a culture of participation at all levels is likely to foster positivity towards research involvement. The link between participation, research and citizenship is perceptible.

Chapter 6 Thesis Conclusions

Introduction

I will conclude with how the arguments have been developed and shaped during the thesis by examining the literature and using the research questions to guide the enquiry and shape my analysis of the key findings. I will consider the strengths and limitations of this thesis and what research could follow on from it.

During this thesis I have built the argument that inclusion, participation and social citizenship are linked. I explored what it looks like to experience social citizenship in a care home by critiquing citizenship and from this analysis chose social citizenship as the model most appropriate to apply to people living and working in care homes. Notably, this thesis has explored whether care home residents can participate and exercise their citizenship within the context of a care home, particularly if they have dementia, and found that generally residents are unable to do this for many of the reasons discussed.

The thesis also examined if staff, using the model of social citizenship as applied to people living and *working* in a care home, are able to experience social citizenship and it was found, generally, that social citizenship could not be demonstrated for staff, from the findings.

I explored how participation in research links to participation in other social domains for residents, staff and visitors in a care home setting and found that those who participated generally in day-to-day activities were more likely to be able to participate in research. This led to increasing my understanding of how participation links to inclusion and social citizenship within the care home environment and I was able to find evidence of how those links operate and what their consequences are for social citizenship, inclusion and participation.

My findings show that the relationship, practice or status of social citizenship, where there should be freedom from discrimination was not uniformly found. There was evidence that people with dementia were discriminated against. The opportunities to grow and participate in life were rare but where there was a culture of including people in general by providing choice and seeking opinion or enabling research activities led to feelings of inclusion and facilitated participation.

Finally, if residents and staff are included in many aspects of the care home regime, including opportunities to participate in life in the care home to the fullest,

while being a resident or a member of staff in that care home, then they are more likely to experience social citizenship. Inclusion and participation in whatever form, my research suggests, are inextricably linked to social citizenship and ultimately may improve research participation.

This thesis adds new information to the current literature on inclusion, participation generally, participation in research, and social citizenship. It has recognised the link between inclusion, participation and experiencing social citizenship for residents and staff by establishing that the culture in the care home which allows people to be included in decisions and activities, to grow and participate in life to their fullest potential enables a culture which allows research to flourish.

STRENGTHS AND LIMITATIONS OF MY THESIS

The strengths of my thesis include the explicit focus on inclusion and participation in research in contrast with other literature where this is incidental. This is contextualised in the wider literature about methodological issues in research and adds to the literature about the issues of participation, inclusion and links to the experience of citizenship for the care home population. Furthermore the strength of my thesis lies in the exploration of where the link between these concepts lie, as this is a largely overlooked area in the literature that has not been specifically explored before now. I have been able to bring together different strands of evidence that have helped piece together a complex and difficult to research area.

The limitations of my thesis include the small number of study care homes included in the research as it was a small-scale study as part of a professional doctoral thesis. Coupled with this was not addressing the care homes and people therein, who didn't respond to the survey, which may have led to response bias (Creswell, 2009). This meant that the survey respondents, while in no way diminishing the strength or validity of the findings in these homes, were not truly representative of the entire population of care homes in Scotland. Also, a more complex questionnaire design might have enabled me to carry out more

detailed inferential statistical analysis. I did not achieve my aim of organising a focus group within each care home which may have been due to the issues of lack of preparedness, priority of care over research and lack of leadership as discussed in the previous chapter. Despite these limitations I have been able to add to the literature on a topic which warranted further exploration.

WHAT RESEARCH AND APPLICATIONS SHOULD FOLLOW FROM THIS THESIS?

The research could be replicated on a larger scale to further augment the findings of the link between inclusion, participation and social citizenship. There could be research into how to engage care homes in research, overcoming the difficulties of lack of time, suspicion of the reasons for the research, the hard to reach care homes and the hard to reach populations within care homes such as some of the staff, residents and relatives I was unable to talk to. There could be research on the misunderstanding of the legislation which protects vulnerable people in care homes. There could also be enquiry into what skills and tools are available to enable researchers to research in the care home environment as care home researchers are a minority in the social and clinical research world. In addition, there could be research into the University and NHS ethics committees and the impact their decisions have as well as their understanding of the impact they have on the practical and ethical conduct of inclusive research.

There are many practical applications of this research: Firstly, encouraging simple ideas to include care home residents in choices within the care home, which can be beneficial to all. This may increase both residents and staff members' feelings of inclusiveness by involving them in such simple activities involving choices e.g. what to wear, what to listen to on the radio or television, what drink to have. All these choices may encourage a sense of citizenship which in turn can enable a research culture to develop.

Secondly, for managers of care homes to be open to the idea of research within their domain. This can be facilitated by allowing researchers into the care home with the knowledge of the benefits this can bring. These benefits include feelings of inclusion and participation amongst residents, staff and relatives, as well as a sense of citizenship. Another benefit is the positivity to all involved with the care home about the inclusion in research, both internally; care home specific newsletters etc. and externally; the Care Inspectorate report. Registering with ENRICH would enable the care homes and managers to be open to research by being 'research ready'.

Thirdly, the research shows us that researchers themselves must be prepared before approaching a care home for inclusion: If there are junior research staff, they should have access to supervision from a more senior member of the research team; to thoroughly prepare themselves and the care home for their approach, months before the intended research is to happen; and to ensure that the necessary ethics are applied for, again months before the intended research

is to happen. The preparation time has been shown to be crucial for success in the research process.

Fourthly, the research has shown that understanding the legislation and being able to apply it is a useful skill, both for the care home staff and for researchers working in this field, particularly around capacity and consent. The research team must be able to apply this legislation with confidence. There should be expertise within the care home staff who are looking after vulnerable people with dementia. Issues of capacity and consent or the knowledge of where to ask for help if issues arise can be accessed through links with the local old age psychiatry service or the social work department mental health officer.

Lastly, the research shows the importance of understanding dementia for residents, for staff and for visitors. This means understanding the different types of dementias e.g. Alzheimer's, Vascular dementia, Lewy body dementia (Burns and Iliffe, 2009); as well as the likely progression and likely changes to the person who has dementia. This will help staff to understand the barriers they may face in involving people with dementia within the care home; but also, enable them to overcome these barriers using a variety of skills and ideas which are available to help maximise involvement. If the care home can invest in a learning module such as the acclaimed University of Stirling's education flagship course of best-practice learning programme designed for care homes (Dementia Services Development Centre, 2017), this would be an advantage to everyone living and working within the care home environment.

This thesis has been the culmination of many years of work and has led me to explore aspects of care home interaction as well as allowing me access to some of the UK's leading researchers in this field. I have had the opportunity to talk to many people who live, work and visit care homes, which has been an honour for me. My research has led me to conclude that more work needs to be done in this area of research of how inclusion, participation and citizenship are closely linked and to advocate that people living in care homes are fully involved and included in the place where they live, as is laid out in the definition of social citizenship.

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Appendix 1: National survey of care homes in Scotland

1. Which Health Board area are you based in ?

2. What type of Care Home are you ?

3. How many beds do you have ?

4. Approximately how many full-time staff do you have working in your Care Home ?
How many are qualified staff (RMN, RGN, SVQ) ?

5. Approximately how many residents have a formal diagnosis of dementia ?

6. Approximately how many of your residents do you think have problems with their memory ?

7. Has your care home been involved in any research of any type, including dementia research ?   Yes   No

8. If Yes,

What was the name of the study ?

What medical condition / disease area was researched ?

When was the study ?

Who was the lead researcher ?

9. Who decides which residents can take part in research within your care home ?
Choose as many answers as are appropriate.

Manager	Resident	Resident's friend
Staff	Resident's family	Doctor
Researcher	Power of Attorney	Other

_____

10. What factors influence the decision for the resident to take part in research?
Choose as many answers as are appropriate.

To help others	To improve practice	Access to new treatments
Increase contact	Benefit to the resident	To help future generations
To find a cure	Resident's desire	Resident's previous wishes

Comments / other reasons

11. What would encourage you to put forward yourself, your staff or your residents for research in your care home?
Choose as many answers as are appropriate.

Staff advice   Personal Interest
Financial reward   To improve practice
Staff development   Other

Comments / other reasons

12. What would discourage you from putting forward yourself, your staff or your residents for research in your care home?

Thank you for taking the time to complete this questionnaire.

Appendix 2: One to one interview topic guide

Key informants:

Tell me about your experiences of research within a care home environment? How many care homes have you visited? How was your research received?

When you were recruiting care homes into a study what made it easier? What made it more difficult?

Were there gate keepers? If so how did you get through the "gate"? Were residents included in the decision?

If residents were unable to consent what did you do?

Did you experience any negativity to your presence? If so how did you combat that? What made it easier?

Did the research go as planned?

Any general comments of facilitators or constraints to participation?

Any further insights into your experiences of research in care homes that we may have overlooked?

Staff:

Tell me about any research you have been involved in?

Can you give examples of when the residents have been involved and included in the decisions made around the Care Home?

If someone has memory problems, are you able to describe what is done to make sure they are involved and included?

What support do you get, to help you to enable the residents you look after be involved and included in decision-making and the Care Home in general?

Would you be supported by others in the Care Home if you got the chance to be involved in research?

What could be done better? What is done well?

Resident:

What makes you feel included in the Care Home where you now live?

What kind of choices are you offered?

What about others around about you – Staff, other residents – can you tell me how they help you to feel included?

Tell me about any research you have been involved in?

What could be done better? What is done well?

Resident representative:

Can you give examples of when the residents have been involved and included in the decisions made around the Care Home?

Can you tell me about the kind of choices are you or your relative is offered?

If your relative has memory problems, are you able to describe what is done to make sure they are involved and included?

Tell me about any research you or your relative has been involved in?

What could be done better? What is done well?

Appendix 3: The Process Consent Method

The Process Consent Method (Dewing, 2007) is described as 5 stages:

• Stage 1 - The preparation involves seeking permission of access to the person with dementia from staff, relatives or other named persons and involving them in this decision. This may take some time and a high degree of skill from the researcher.

• Stage 2 – Establishing the basis for capacity –capacity can be situational and variable. Factors which must be considered: The person's usual presentation; the person's usual level of well/ill-being; how a decrease in well-being may be triggered; how it can be recognised; any other triggers in conversation which indicate the persons needs have changed. The use of interpretation of facial expressions is described as useful as is the establishment of how the person usually "consents" to a range of day-to-day activities.

• Stage 3 –Initial consent - following preparations as described in stage 1 and 2 the researcher then should seek initial consent by providing information to the person using the persons favoured way of communicating. Detailed notes are taken. The researcher must be clear that they can justify, with evidence, that consent has been given.

• Stage 4 – On-going consent monitoring - which involved revisiting the initial consent at regular intervals – this can even be within the same session. This can be aided by an objective observer who knows the person well enough to act as a validator. This could be the resident's key worker or representative.

• Stage 5 – feedback and support – This should be agreed with the person with dementia prior to feedback to staff or carers about what discussion or information exchange has taken place.

Appendix 4: Cross cutting themes and sub themes from the care home interviews

	Inclusion	Positive expressed emotions	Facilitators to participation	Constraints to participation	Negative expressed emotions	Research involvement
	Sub themes					
A	Feel part of the CH community	Compassion	Supportive manager	Lack of choice	Undervalued	Importance
B	Staff meetings	Dignity	Altruism	Environment	Negativism towards dementia	Feedback
C	Residents meetings	Respect	Choice	Poor communication	Not listened to	Want to be involved
D	Relatives meetings	Homely	Communication	Personal choice	Not supported	Local audit
E	Feeling involved	Valued	Education	Non-supportive manager	Other	Capacity
F	Capacity	Friendly	Environment	Other		Time needed
G	Other	Big happy family	Staff			Misunderstandings
H		Happy	Relationship building			
I		Devotion to job				
J		Nice feel				
K		Affectionate				