

Non-delivery of homecare for older people in Scotland: A multi-method study

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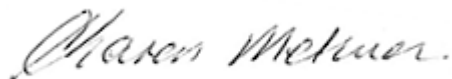
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A handwritten signature in cursive script, appearing to read "Sharon McMurdo".

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COMPETING INTERESTS

This study was funded by the Faculty of Health Sciences and Sport at the University of Stirling. I was fully responsible, in conjunction with the guidance provided by my supervisors, for the study design, fieldwork and analysis. I had no connection, professional or otherwise, with the large independent homecare service provider or Glasgow City Council.

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ABSTRACT

Background: A large homecare service provider for older people in one region in Scotland reported concerns of an increasing incidence of non-delivery of homecare for older people. Non-delivery denotes planned care that care workers attempted to deliver but, for whatever reason, were not able to gain access to the service user to provide care. Concerns exist that, if not addressed, incidences will continue to increase, with negative implications for the wellbeing of older people and for service provision. This thesis presents an account of the research performed to address these concerns.

Aims: To identify the extent of non-delivery of homecare for older people, to establish the characteristics of those most likely to refuse or avoid homecare, and to explore the reasons why, for some older people, care was more likely to be refused or avoided.

Methods: Using a multi-method approach, and in two studies this doctoral thesis was designed to answer the research question: *'What is known about non-delivery of homecare for older people in Scotland?'*

The first study adopted a quantitative approach, linking data from a large homecare service provider in one region in Scotland, to individual-level hospital in-patient data (SMR01) to help establish the extent of non-delivery of homecare and to characterise those most likely to refuse or avoid care delivery within a discrete three-month time-period. The second study employed a qualitative design, drawing on individual interviews and a focus group discussion with older people receiving homecare, to explore in depth the reasons why, for some older people, care might be refused or avoided.

Findings: This is the first study to explore the patterns and reasons for non-delivery of planned homecare. This research established that non-delivery of homecare was a problem for a few older people only. Using framework analysis, the findings revealed an unexpected propensity to accept rather than refuse homecare. Moreover, the presiding values of older people are to live at home, to be independent and to remain connected, and homecare was viewed as a means to protect these values. However, homecare did not always meet these expectations, and the findings revealed that older people would accept the compromises involved in being a homecare recipient in order to live at home rather than relinquish this independence.

Three key findings, which presented as paradoxes are: i) older people would refuse homecare if it was unsatisfactory, yet, despite having this experience, very few actually refused; ii) older people valued their independence above staying at home, yet they would inadvertently relinquish their independence to the care service to stay at home; and iii) whilst non-delivery of homecare places older people at risk, these same assumed risks are those associated with the provision of poor quality care. Ultimately, although independence was considered important, living at home was crucial and the presiding motivating factor to accept homecare.

The findings of this study are timely and relevant as they link into current governmental initiatives to keep people at home for as long as possible with appropriate and sustainable homecare at the core of national outcomes.

Recommendations: Based on these findings, the study will inform future research, practice and policy, and all those interested in improving homecare for older people, notably: homecare service providers, local authorities, and government bodies. This study is particularly relevant considering the effects of COVID-19, the impact of which has affected the way in which care is delivered. As for now, living at home is the most effective way of shielding vulnerable people.

Keywords: Older adults, older people, homecare, non-delivery, negative health implications

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ABBREVIATIONS AND DEFINITIONS

CDG	Care Development Group
CHI Number	Community Health Index Number
COSLA	Convention of Scottish Local Authorities
CQC	Care Quality Commission
DHSSPS	Department of Health, Social Services and Public Safety
GP	General Practitioner
HLE	Healthy Life Expectancy
IoRN	Indicator of Relative Need
IPA	Interpretive Phenomenological Analysis
LPAC	Local Privacy Advisory Committee
NA	No Access
NCS	National Care Service
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NHIR	National Institute for Health Research
NRS	National Records of Scotland
OECD	Organisation for Economic Co-operation and Development
ONS	Office for National Statistics
PPC	Patient and Client Council
PPI	Patient and Public Involvement
PVG	Protecting Vulnerable Groups
RCB	Robertson Centre for Biostatistics
RCN	Royal College of Nursing
SCIE	Social Care Institute for Excellence
SIMD	Scottish Index of Multiple Deprivations

SMR01	Scottish Morbidity Record 1
SOP	Standard Operating Procedures
SPSS	Statistical Package for Social Sciences
SR	Service Refusal
SREC	School Research Ethics Committee
SSSC	Scottish Social Services Council.
UK	United Kingdom
VPN	Virtual Private Network
WHO	World Health Organisation
Service user	Person receiving homecare
Participant	Person in the study sample
Care worker	Person providing paid homecare
Kinship carer	Family/friend carer

Introduction – Setting the Scene

I worry about her all the time – she’s alone all day, and I’m working so far away. By the time I get to hers, it’s often past seven o’clock, and sometimes she’s been sitting in that chair since goodness knows when. I can tell when the carers have been there, because they leave me notes, but sometimes they are so far behind, they are only coming to in to make her tea when I arrive to put her to bed. Once, I was sure nobody had been, so I called to complain. It turned out that she had refused to buzz them into the flat. I have to give the carers their due, they did try, they even got the neighbour to try to convince her, but she is so stubborn! She flat out refused to open the door! I began to wonder what would happen to her if I wasn’t there – what would happen to someone else who didn’t have someone like me to check up on them and put them to bed? And then I began to wonder, what does the homecare service do if someone refuses care? After all, it is their human right, isn’t it? It’s a real worry.

(Vignette of a conversation with the daughter of an older person who received homecare)

This thesis originated out of a plea to respond to this question – what happens when older people refuse homecare services? How often does this happen? How does the homecare service cope with these situations? What causes people to refuse care? In the instance described above, the homecare service provider was approached for informal conversations about their wider concerns, if any, relating to this issue, and they revealed that this was indeed something that was greatly troubling, and a situation that caused much anxiety and distress, particularly when the older person was not home to receive care. The fundamental requirement of maintaining the safety and wellbeing of older people demands that the care provider is able to carry out that responsibility, and any incidence of refusal of care disrupts the effective running of an often over-stretched service. Starting from this basic question, this thesis set out to explore the homecare service delivery for older people in the largest healthcare region in Scotland by first revealing the extent to which refusal of care occurs. From this original investigation, the results led the research into a very different and unexpected direction, but one which revealed much insight into the experiences of older people who are in receipt of homecare services.

My own background provided me with a keen interest in pursuing this research. As a registered general nurse, the majority of my professional career has involved caring for older people in hospital and in the community. A particular interest in advocacy and palliative care for this often vulnerable group of people culminated in my participation in research studies at both undergraduate and postgraduate level. Both of my parents have dementia and, as legal advocate for their health and wellbeing, I have experienced first-hand the challenges associated with procuring the necessary care at home for them. It is this experience and my interest in the care that older people receive at home generally that has influenced my further interest in the research study presented in this thesis.

As I was in the later stages of writing this thesis, the world was in the midst of the COVID-19 pandemic. This disease has affected millions of people worldwide, with the most susceptible being those ‘aged 60 years and over, and those with underlying medical problems like high blood pressure, heart and lung problems, diabetes, obesity or cancer’ World Health Organisation (WHO 2020, n. p.). The research presented in this thesis includes people who belong to this group, offering timely insight that is linked closely with their experiences and which can help to inform and improve the way in which their care is delivered. This chapter sets the scene and helps provide context to the research.

Globally, the number of people aged 65 and older is increasing (WHO 2017). In particular, people aged 85 years and over represent the fastest growing age group (WHO 2017). Evidence highlights that older people want to stay in their own homes and depend on individually designed homecare provision to do so for as long as possible. In addition, they place high value on their independence (Gilleard and Higgs 2008; Leach et al. 2013; McNeil and Hunter 2014). A study in New Zealand consisting of 121 older adults ascertained that older people want choices about where they age and viewed the home as a place of attachments and feelings of security (Wiles et al. 2011). The UK government had a pre-COVID vision to be the best place in the world to grow old and to help people to remain healthy, active and independent (Public Health England 2019). The Scottish Government (2019a) recognises that meeting the needs of an ageing society, many with co-morbidities and complex needs, presents a concern for

policy makers and care providers. This is the context within which the research presented in this thesis was conducted.

The Scottish Government is also committed to supporting older people ‘to live independently in their own homes for as long as they wish to do so’ (Scottish Government 2016, p. 3). Various initiatives have helped to monitor progress towards this aim. Most recently, the Scottish Government, in collaboration with COSLA (Convention of Scottish Local Authorities), described their shared vision of a care service as one that protects people’s human rights, a service that is person-led and flexible according to individual needs, and ensures that people live safely and independently at home while remaining connected to the community (Scottish Government 2019a).

This research germinated from informal discussions with a large homecare service provider in Scotland who raised concerns over the rising incidence of non-delivery of homecare services for people aged 65 and older with little information to explain the reasons for this. Reports of non-delivery automatically initiated follow-up by the homecare service provider to establish the whereabouts and welfare of missing service users, which was time-consuming and costly. Hence, the homecare service provider was concerned that, if this trend continued, non-delivery could have negative implications for service users.

An initial scoping review of the literature highlighted limited research on non-delivery of homecare. This study explores issues relating to non-delivery of homecare. Described as an arm’s-length service, the services delivered by this leading homecare service provider are purchased by Glasgow City Council and accessed through primary care or following hospital discharge. The majority (94%) of their clients are aged over 65 years and receive up to five visits a day from care workers at home. In this study, homecare refers to social or domiciliary care involving personal support with activities of daily living and essential domestic tasks. This particular homecare service provider classifies non-delivery of homecare as either: Service Refusal (SR), where the service user refused care, for whatever reason, at the point of delivery; or No Access (NA), which denotes that, for whatever reason, the care worker had not gained access to the service user to provide care. Collectively, non-delivery pertains to care that care workers attempted to deliver, rather than to care that the care worker omitted to deliver.

Global ageing

Most countries in the developed world have accepted the chronological age of 65 years and over as the definition of the older person (WHO 2017). According to Kydd and Fleming (2015, p. 2), ‘the term ‘old’ is a nebulous concept’, one which differs according to retirement age, state pension age and changes in longevity. For the purpose of this doctoral thesis, people aged 65 and over are classified as older people.

Globally, the population is ageing. In almost every country, the proportion of people aged 65 and older is faster growing than any other age group. Furthermore, the number of oldest old people, those aged 80 and over, is expected to increase three-fold by 2050. The reason for this growth is in part due to an increase in longevity (WHO 2017).

United Kingdom (UK) ageing

Global trends are broadly consistent with UK national trends. Between 2015 and 2017, life expectancy at birth for people in the UK was 79.2 years for men and 82.9 years for women (Office for National Statistics (ONS) 2018a). People aged 65 and older represented 18 percent of the population in 2018, and this proportion is expected to increase to 26 percent in 25 years. The fastest increase is seen in people in the 85+ years age-group, who accounted for 2 percent of the population in 2016, and this proportion is projected to double by 2041 (ONS 2018a).

Scotland: A different picture

Scotland has one of the lowest life expectancies in Western Europe, lower than the rest of the UK, with the major causes of death being cancer, dementia and circulatory disease (National Records of Scotland (NRS) 2018). Between 2015 and 2017, life expectancy at birth was 77 years for men and 81.1 years for women. Presently, 19 percent of Scotland’s population are aged 65 and over. However, the number of people aged over 65 years is projected to nearly double by 2029 (Scottish Government 2018a). Although the number of older people is set to rise, the projected population growth in Scotland is less than that of the rest of the UK (NRS 2018).

Despite Glasgow having similar levels of socio-economic deprivation to other larger cities in the UK, such as Liverpool and Manchester, it is not fully understood why Scotland, and Glasgow in particular, have lower life and healthy life expectancy rates,

with premature deaths up to 30 percent higher and all other deaths 15 percent higher across the whole population, a phenomenon termed ‘the Glasgow effect’ (Walsh et al. 2010; Livingston and Lee 2014). These statistics are of particular interest for this thesis, as the homecare service provider, with whose collaboration the research was conducted, with concerns for increasing incidence of non-delivery, provides the majority of homecare to older people who live in the Greater Glasgow and Clyde area.

The changing demographic in age has been strongly influenced by the baby boomer generation, with those born between 1946 and 1954 and those born between 1961 and 1964 representing two distinct waves (McNeil and Hunter 2014). Baby boomers represent a group of post-war babies with distinctive experiences that differentiate them from previous generations. Referred to as the ‘bridging generation’, this group reflects a general aversion to ageing, preponderance towards warding off the passage of time and a preference for strong independence (Gilleard and Higgs 2008). Baby boomers have high expectations of the life they have left to live and where they are going to live it. They want to stay in their own home for as long as possible (Leach et al. 2013) and be independent of family and friends (McNeil and Hunter 2014).

Longevity contributes to the changing health status for this ageing demographic (ONS 2018b). In addition to longevity is Healthy Life Expectancy (HLE). Estimating how many years that people may live in a healthy state before their health deteriorates is of particular interest to policy makers and service providers. Preparation time is vital to implement the necessary changes to support older people with reducing health to live at home. In Scotland, between 2015 and 2017, the HLE at birth was projected to be 62.3 years for men and 62.6 years for women. However, women can expect to live more years in poor health than men due to a greater life expectancy (NRS 2018). These estimations are critical in considering the care of older people, as it is the years beyond the healthy status that provide a challenge for care provision (NRS 2018).

Deprivation significantly impacts both life expectancy and HLE. People living in disadvantaged areas can expect to have a lower life expectancy and almost double the number of years lived in a non-healthy state than their more affluent counterparts (NRS 2018). Older people living in Scotland have a lower life expectancy and suffer the worst ill-health in the western world (Scottish Government 2018a). These health disparities are considered in part due to a combination of low socio-economic status (smoking,

alcohol misuse, injection drug use and obesity), high levels of stress, and even cold weather (Cowley et al. 2016).

The recent spread of COVID-19 has had an unparalleled effect on the world's health, claiming the lives of many (Scottish Government 2020). To stem the spread of this virus, people were asked to stay at home and socially distance themselves from others, initially for 12 weeks. People over the age of 70 years and those with underlying health conditions are particularly vulnerable to the damaging effects of this virus; thus, homecare provision has been scaled back to limit unnecessarily spreading the virus. As a consequence, the Coronavirus Act (2020) makes provision to respond to an emergency. Under section 17 of the 2020 Act, assessment for health and social care has been eased to meet the most urgent needs of the population (Scottish Government 2020). Despite these emergency measures being put in place, reducing homecare services to essential visits only is likely to have an impact on service users' wellbeing: in particular, loneliness can have a hugely detrimental effect, especially for those who live alone (Gov.UK. 2020).

The growing number of older people, many living with an increasing number of multi-morbidities, presents the Scottish Government with a challenge to provide the care necessary to support them at home and to reduce pressures in acute settings. Moreover, older people want to stay at home for as long as possible and expect a system of care that enables them to stay connected to their community (Scottish Government 2018a). In response to this challenge, the Scottish Government launched initiatives reflecting the needs of this population: in particular, supporting people's choice to stay at home with appropriate care. The pre-COVID-19 policy and legislation, which regulated the care provision in place while my research was carried out, reflect this position, as described in the next section.

Pre-COVID-19 policy and legislation

By 2021, the Scottish Government aims to reduce the number of hospital days and, in particular, emergency admissions, by at least 20 percent by improving community care. Therefore, investing in health and welfare to support older people to live at home remains one of the key challenges facing policy makers and care providers (Scottish Government 2018a).

In 2011, the Scottish Government aimed to develop a strategy to explore the housing needs of the ageing population to provide people the opportunity to live at home with the appropriate support to enjoy full and positive lives that also meet their needs. To achieve this aim, the Scottish Government worked with stakeholders to develop policy and practice. Their vision and commitment is that: ‘Older people are valued as an asset, their voices are heard and older people are supported to enjoy full and positive lives in their own home or in a homely setting’ (Scottish Government 2018a, p. 3).

As part of the National Clinical Strategy for Scotland, ‘The 2020 Vision’ (Scottish Government 2011a) focussed on preventative, anticipated and supportive self-management to enable independent living at home. The 2020 vision includes a system of integrated services between health and social care to enable people to live at home with minimal risk of re-admission to hospital (Scottish Government 2011a). Thereafter, another initiative, ‘Reshaping Care for Older People – A Programme for Change’, helped to monitor this change (Scottish Government 2011b) followed by an update paper (Scottish Government 2012a). Part of the 2020 vision involves overseeing integration of adult health and social care with a joint sharing of budgets, accountability for services, person-centred and outcome-focussed care, concentrating on optimising independence and wellbeing for older people while living at home. Placing people at the centre of care and promoting a person-led service is at the core of their mission (Scottish Government 2012b, Health and Social Care Act 2012).

The Scottish Government (2017a) developed standards to be used as a guideline for how to achieve high quality care that reflects the way everyone should expect to be treated. These standards are underpinned by the five principles of dignity, compassion, being included, receiving responsive care and support, and wellbeing. Presently, and in collaboration with COSLA, the Scottish Government launched their self-directed support implementation plan for 2019–2021 to promote the rights of people to direct their own care and to live as independently as possible and for as long as possible (Scottish Government 2019a). This on-going initiative started with the passing of the Social Care (Self-Directed Support) (Scotland) Act 2013, which reinforced human rights-based values and the principles of respect, fairness, independence, freedom, safety, involvement, collaboration, informed choice, participation and dignity (Human Rights Act 1998).

As defined by the Scottish Government (2019b, n.p.), ‘social care support is about supporting people to live independently; be active citizens; participate and contribute to society; and maintain dignity and human rights’. In practical terms, social care is support that helps people on a day-to-day basis, including, but not limited to, help with washing, bathing, getting dressed, going to bed, meal preparation and medication administration. As well as physical care needs, social care includes the assessment of psychological, emotional and social care needs and the procurement of the necessary interventions to ensure these needs are met. Although social care is available to people of all ages and in different environments who need extra support, the majority is delivered to people aged 65 and over within their own home. With the increase in the ageing population, the demand for homecare, to keep people living at home for as long as possible, is expected to grow (Equality and Human Rights Commission 2012). In particular, care is needed that caters for people with complex needs (Duff and Hurlley, 2012), where one or more co-morbidities are present (Social Care Institute for Excellence (SCIE) 2014), such as diabetes, heart disease, arthritis, mobility and mental health issues (Patmore and McNulty 2005).

Homecare

In Scotland, homecare is provided jointly by the NHS and local authorities. Unlike the rest of the UK, Scotland provides free nursing and personal care, subject to assessment of need. Therefore, people living at home may be in receipt of both health and social care. There are 48,800 people aged 65 and over receiving homecare in Scotland who account for two-thirds of all social care provision (Scottish Government 2017b). Over the last decade, local authorities have purchased homecare services from private organisations, which now provide 33 percent of homecare hours and this is set to increase in response to the increase in demand (SCIE 2014). Sixty-five percent of service users receive less than 10 hours of care per week and only 7 percent receive more than 20 hours of care per week (Scottish Government 2018b). People who live alone with high intensity care are more likely to have repeated hospital admissions than those with similar needs living in a care home (Bardsley et al. 2012). This suggests that people living alone at home with complex needs might require extra support to prevent unnecessary hospital admissions.

The topic of this thesis focuses on social care delivered at home to people aged 65 years and older. The advent of the provision of free personal care for older people (Scottish Government 2002) ensured that everyone who was assessed as needing care would receive it, irrespective of income or living arrangement. Personal care includes physical, emotional, counselling and psychological support, as well as help getting washed and dressed, and providing support in activities of daily living and essential domestic tasks (NICE 2015). However, according to a survey by Scottish Care, a membership organisation and the representative body for over 400 independent social care services in Scotland, tasks relating to the ‘social’ element of care, to help tackle the issues of social isolation and loneliness, was of low priority, with lack of time for each visit being the main barrier (Scottish Care 2015). In their report, Scottish Care state that ‘the outcomes a person wants for their life; to keep in touch with friends, to continue to be engaged in a pursuit or activity, to continue to be involved in their community and its organisations, are as fundamental as the mechanics of food and drink’ (Scottish Care 2017, p. 10). Recommendations from their survey include a new model of care, with the focus placed on preventative care to keep people living in their homes for longer and out of hospital to reduce the cost of unplanned hospital admissions.

Key points:

Concerns for non-delivery of homecare: Informal discussions with a main homecare service provider highlight a concern for a rising incidence of non-delivery of homecare for older people and concerns for adverse health outcomes associated with non-delivery.

Age and health: Although global ageing is on the increase, life expectancy and healthy life expectancy in Scotland, aggravated by deprivation and addictions, are the worst in the western world. This generation of older people, greater in numbers than ever before, many with complex needs, have high expectations of living well, well into old age.

Expectations of care: Older people want to live at home and expect good quality homecare to make this happen. Present policy supports independent living at home with a package of homecare based on an assessment of needs. However, meeting the needs of older people with long-term and complex needs remains a concern.

Initiatives: The Scottish Government aims to reduce hospital days and emergency admissions by improving community care. Older people with complex needs require

extra support to prevent unnecessary hospital admissions. Older people have a right to direct their own care, and to live as independently as possible and for as long as possible. They have a right to decide where they want to live and receive care pertinent to their needs.

Considering all of the key points discussed above, this thesis presents a unique exploration of the patterns and reasons for non-delivery of planned homecare among older people in one city council in Scotland. This is the first study to do so. Drawing on both quantitative and qualitative research methodologies over two individual research studies, I have synthesised the findings from both the analysis of data gathered within a large healthcare database and extensive interviews with participants who are directly affected by these issues in their day-to-day lived experiences.

Structure of the thesis

The thesis is organised into five chapters as outlined below.

Chapter 1: Scoping review of non-delivery of homecare. This chapter includes the methods, results and discussion of the scoping review and the implications for future research. The research questions are formulated.

Chapter 2: Methodology - Philosophical positioning, pragmatism and multi-methods. This chapter discusses the methodology and philosophical underpinnings for Study 1 and Study 2.

Chapter 3: Quantitative Study – A study of the frequency of non-delivery of homecare using data linkage (Study 1). This chapter introduces the quantitative study and includes the methods, results and discussion.

Chapter 4: Qualitative Study – An exploratory study of the reasons for non-delivery of homecare (Study 2). This chapter introduces the qualitative study and includes the methods, findings and discussion.

Chapter 5: Conclusion – A consideration of the findings of both studies in combination to describe how each contributes to a better understanding of non-delivery of homecare. This chapter determines the extent to which the studies have answered the research aims and research questions and how these insights are positioned within the existing

literature. My original contribution to knowledge is stated, and implications for future research, practice and policy are presented. Finally, I reflect on the research process, the research findings and my journey through this doctoral research process.

CHAPTER 1: Scoping review of non-delivery of homecare

1.1 Introduction

As described in the introductory preface to this thesis, informal conversations with a large homecare service provider, based in a large city in Scotland, revealed concerns for the delivery of homecare. Of particular concern were occurrences when the older person was not at home to receive their care or when care was refused at the point of delivery. These concerns prompted the necessity of developing research to explore this issue further.

Informed by my involvement in previous research studies, along with my own nursing background and personal experience of social care provision, I recognised a significant gap in published knowledge relating to issues around non-delivery of homecare for older people in general. As such, it was necessary to explore and map out any existing research in order to determine the scope and reach of the literature relating to the factors that contribute to non-delivery of homecare. Thus, a scoping review was initially performed.

The question for this scoping review was: *‘What is known about non-delivery of homecare for older people?’*

1.2 Methods – Scoping Review

A scoping review provides the framework necessary to explore research from a variety of sources and is a rigorous and transparent means of mapping research that others may follow (Pham et al. 2014). The main objective was to explore and map existing evidence on non-delivery of homecare for older people. An initial search of the university library catalogue and within Google Scholar was conducted, using the basic search terms, ‘non-delivery’, ‘homecare’ and ‘older adult’. This revealed limited data published or unpublished on the topic, therefore, a systematic scoping review method was chosen to explore the literature further, as this approach is best suited when little evidence is expected (Munn et al. 2018).

1.2.1 Relevant studies

The search strategy aimed to find all published academic material and grey literature (New York Academy of Medicine 1999) relating to non-delivery of homecare. The following electronic databases were accessed: CINAHL Complete, Health source, MEDLINE, PsycINFO and SocINDEX, Social Sciences Abstracts, and Sociological Abstracts. A range of keywords using Medical Subject Headings (MeSH) terms helped capture the relevant literature. Due to the limited prior research on this topic, the chosen search terms were broad enough to capture published and unpublished reports from a variety of sources (Arksey and O'Malley 2005). The question for this review was broken down into its core components to constitute the initial keywords. These were 'non-delivery', 'homecare', and 'older adults'. In order to extract relevant data, similar terms for each component were identified and added to the list of search terms. Truncation helped to avoid having explicitly to include all possible variants in the search strategy. Truncation is a searching technique used in databases in which a word ending is replaced by an asterisk enabling variations of a word to be searched for simultaneously, thus widening the search.

The following definitions of key concepts are provided to help clarify their meanings in relation to how the terms are used in this thesis and in the scoping review. For the scoping review searches, the term 'older adult' was chosen, as it is the term most used in the literature. However, elsewhere throughout the thesis, the term 'older people' is used to refer to people aged 65 and older, as it is the preferred term to refer to this group within policy and legislation. This group accounts for 75 percent of all social care received in Scotland (Scottish Government 2017b). 'Homecare' refers to social/domiciliary care provided at home. 'Non-delivery of homecare' refers to care that, for whatever reason, care workers were unable to deliver. 'Care workers' refers to paid carers, and 'kinship carers' refers to family and friends who are providers of care.

Search terms:

Due to differences in terminology relating to the care of older people, a variety of possible truncations of keywords were chosen as search terms, as follows:

eld*(elderly, elder, elders) OR age*(aged, ages, aging) OR old* (older, oldest) adult OR 65* (sixty-five) and older OR service user* (users) OR retire* (retired) OR senior

citizen OR geriatric* (geriatrics) OR pension* (pensioners) AND homecare OR homecare service* (services) OR homecare delivery OR social care OR social care delivery OR domiciliary care OR mainstream care OR reablement care OR elder care AND non-delivery of homecare OR service refusal* (refusals, refuser(s), refusing) OR no access OR service avoidance OR missed visit* (visits) OR non-uptake of social care OR service rejection OR service non-use OR service barrier* (barriers) OR service access OR inappropriate service* (services) OR avoidance of help NOT care home* (homes). Each keyword/phrase was run independently before merging all combined 'OR's with combined 'AND's and 'NOT's.

Zetoc Alert, a global search service, provided regular notifications of current relevant publications from a variety of journals for consideration and possible inclusion. The final pool of literature was sent to Ref Works, as the preferred reference data manager, for review and possible inclusion.

Inclusion criteria:

Papers to be included in this review were those that related to older adults, aged 65 years and older (irrespective of diagnosis). In addition, those that related to homecare and non-delivery of homecare (care which care workers, for whatever reason, were unable to deliver) were included, and both academic literature and grey literature were searched. No date restriction was made, but only papers written in English were selected.

The PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analysis) Statement (Moher et al. 2009) is a widely-used method for the transparent reporting of systematic review and meta-analyses in healthcare research. While this scoping review is not designed specifically to evaluate healthcare interventions, the PRISMA selection process provides a robust and reliable model for identifying relevant evidence in a scoping review. The PRISMA flowchart (Figure 1) presented below highlights the selection process adopted here, which developed from an initial output of 71 records to the final 13 papers selected for review. This process can be followed through the four stages of 'identification', 'screening', 'eligibility' and 'included'.

Selection process

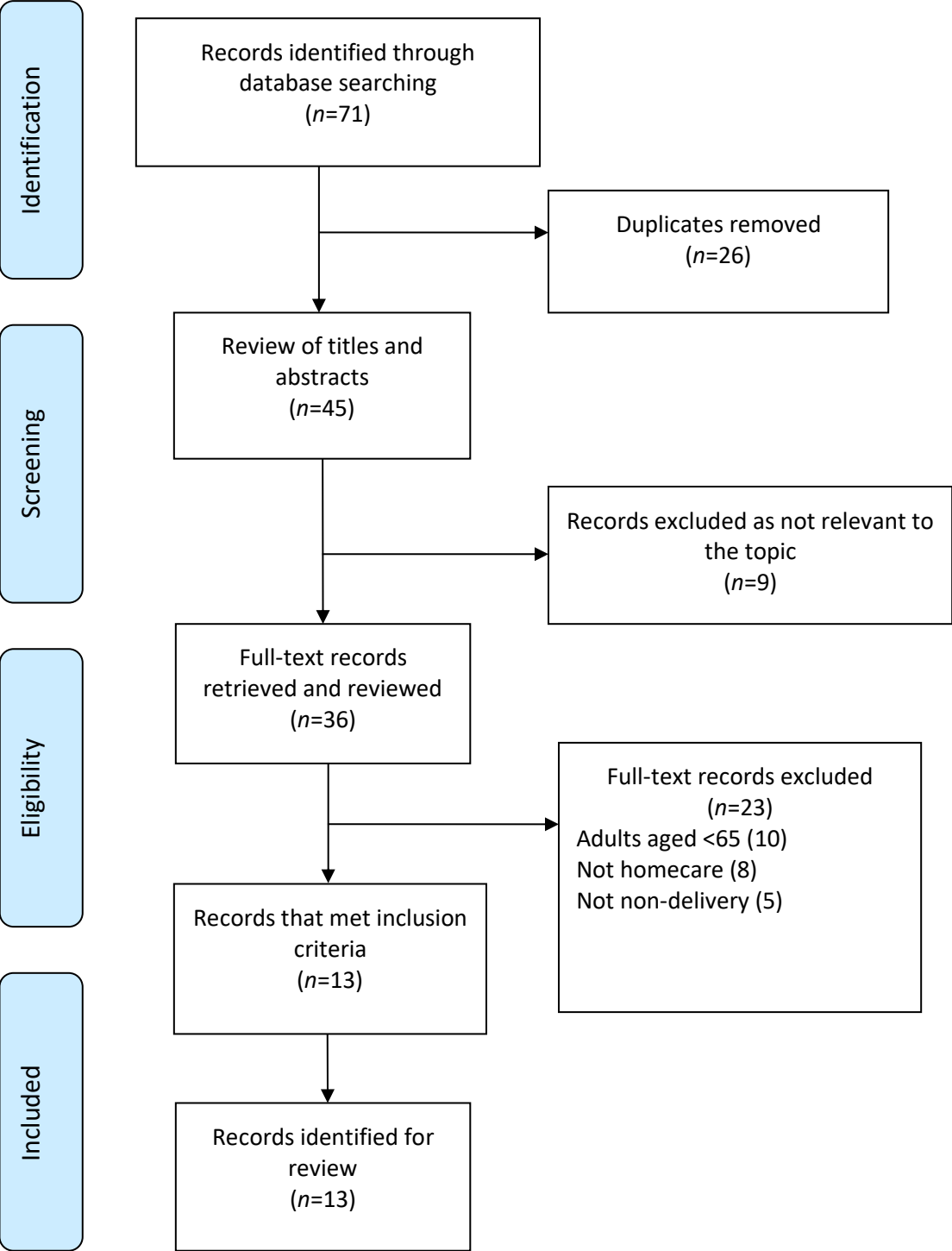


Figure 1: PRISMA flowchart (Moher et al. 2009)

Seventy-one papers were identified for inclusion. Following the removal of 26 duplicates, 45 titles and abstracts were reviewed, resulting in the exclusion of another nine papers, as they were not relevant to the topic area. Where there was insufficient evidence in the title and abstract alone to make a decision, the full text was retrieved

($n=36$). The 23 papers excluded at the eligibility stage failed to meet the inclusion criteria because the population did not relate to older adults aged 65 and over (10), homecare (8), or non-delivery of homecare (5). The 13 finally-selected papers, presented in Table 1, highlight the study aims, research design, analysis and relevant findings for each paper.

These 13 papers considered aspects of care for older adults and their kinship carers living in the community and comprised 10 qualitative studies, two quantitative studies and one mixed-method study. One paper was a meta-synthesis and another began by reviewing 48 studies and another was a literature review. Three studies focussed on community/family caregivers only, and recruited 109, 113, and 430 participants aged 65+, respectively. The remaining seven studies in which 65+ year old service users took part recruited 15, 18, 20, 30, 50, 68 and 293 participants, respectively: the median number of older adult participants was 30. For inclusivity, papers were accepted irrespective of service users' diagnosis. However, it was recognised that older adults diagnosed with dementia and with complex needs (Moholt et al. 2020) could have had an impact on the care that was received.

Included evidence originated from the UK ($n=6$), Australia ($n=4$), Canada ($n=1$), the USA ($n=1$) and Norway ($n=1$). Although there was very little research relating to non-delivery of homecare for older adults, all of the papers ($n=13$) discussed, in part, reasons why older adults living at home might decline offers of help (refusal), unwillingly either accept or seek offers of help (reluctance), or avoid offers of help or non-uptake (avoidance). The terms refusal, reluctance and avoidance were implicit within the literature. Exploring the differences between these terms helped to establish the nuances behind non-delivery of care. Overlaps existed between descriptions of what was considered reluctance, avoidance and refusal of services. Unless specifically identified in the title or abstract, other papers were assigned to one of the above three categories according to the relevance of their findings and what they contributed to the research knowledge.

Refusal of homecare was discussed, at least in part, in seven papers (Bowes and Dar 2000; Brodaty et al. 2005; Innes et al. 2005; Themessl-Huber et al. 2007; Durand et al. 2009; Stirling et al. 2010; Moholt et al. 2020). Reluctance to accept home-based support was evident in three papers (Kenning et al. 2017; MacLeod et al. 2017; Lindquist et al.

2018). The remaining papers focussed specifically on help-avoidance and why older adults and their kinship carers (family/friend carers) chose not to seek help (Strain and Blandford 2002; Howse et al. 2004; Phillipson et al. 2013).

Sub-groupings within the above studies concentrated on older adults within ethnic minority groups (Bowes and Dar 2000; Kenning et al. 2017), those living in rural and remote parts of Scotland (Innes et al. 2005) and those living with dementia (Bowes and Dar 2000; Brodaty et al. 2005; Innes et al. 2005; Durand et al. 2009; Stirling et al. 2010; Phillipson et al. 2013; Kenning et al. 2017; MacLeod et al. 2017; Moholt et al. 2020).

Table 1 presents a summary of each published paper with respect to: *What is known about non-delivery of homecare for older people?* The ‘Relevant findings’ column describes those findings that relate specifically to non-delivery of homecare.

Table 1: Selected studies

Author/Year/Title/Journal/ Country	Study Aims/Purpose	Study Design	Analysis	Relevant Findings
<p>Bowes and Dar (2000)</p> <p>Researching social care for minority ethnic older adults: Implications for some Scottish research</p> <p><i>The British Journal of Social Work</i>, 30 (3), pp. 305–321</p> <p>Scotland</p>	<p>To explore the issues raised by research on patterns of welfare and mutual care among older Pakistani people and their families with particular reference to their use or lack of use of social care services</p>	<p>Qualitative study</p> <p>Interviews x 3 with:</p> <ul style="list-style-type: none"> i) Pakistani older adults aged 55–90 ($n=30$) ii) Social work department staff ($n=9$) iii) South Asian staff working in community-based groups ($n=7$) 	<p>Thematic analysis</p>	<p>Families of older Pakistani people preferred to ‘look after their own’</p> <p>Evidence of institutional racism</p> <p>Differences in attitude and desire to work with ethnic minority groups</p>
<p>Strain and Blandford (2002)</p> <p>Community-based services for the taking but few takers: Reasons for non-use</p> <p><i>The Journal of Applied Gerontology</i>, 21 (2), pp. 220–235</p> <p>Canada</p>	<p>To examine the reasons for not using nine community-based services and the characteristics associated with these reasons among a sample of 293 older person–caregiver dyads in a Canadian province</p>	<p>Qualitative study</p> <p>Random selection of older person–caregiver dyads ($n=293$)</p> <p>Cognition assessed using the modified Mini-Mental State Examination (MMSE)</p>	<p>Logistic regression</p>	<p>Reasons for non-uptake:</p> <p>Caregiver perspective: older adults’ health did not necessitate use, family and friends provided care, unaware of services available and older adults did not like or want services on offer or were not eligible for services</p> <p>Older adults’ perspective: alternative offers of help, fear of loss of independence</p>

				Characteristics of non-use: caregiver cognitive impairment associated with not using home services. Male caregivers and those with less education more likely to be unaware of available services
Howse et al. (2004) Help-avoidance: Why do older adults not always seek help? <i>Reviews in Clinical Gerontology</i> , 14 (1), pp. 63–70 UK	To explore the evidence about older adults' refusal or non-uptake of health and social services Why some may refuse or avoid help despite being aware of need	Qualitative study Literature review	Thematic analysis	Reasons to refuse or avoid: Alternative sources of help, social or financial barriers to access, unsuitability of the help available, psychopathological refusal to acknowledge need, denial of need and social identity of older age High refusal of services among older adults who need it most
Brodaty et al. (2005) Why caregivers of people with dementia and memory loss don't use services <i>International Journal of Geriatric Psychiatry</i> , 20, pp. 537–546 Australia	To develop a typography of the characteristics of caregivers of community dwelling people with dementia or memory loss who do not use services and investigate the reasons for non-use	Literature review of 48 studies used to develop typography of caregivers' non-use of services and applied to sample of community-based caregivers (n=109)	Cross-tabulation	1 in 3 caregivers used no services in spite of need because: i) They did not consider a need for the service ii) Care recipients' reluctance to use services iii) Lack of knowledge about services In the process of applying for services Physical disability and contact with social worker were associated with service use Service availability or affordability not considered barriers to service use

<p>Innes et al. (2005) Dementia care provision in rural Scotland: service users' and carers' experiences <i>Health and Social Care in the Community</i>, 13 (4), pp. 354–365 Scotland</p>	<p>To understand service use from the perspective of service users with dementia and their carers in 8 rural areas in Scotland Shared experiences of what makes a good service Explored perceived gaps in services Advocate the collective 'voice' from both service users with dementia and their carers</p>	<p>Qualitative study Interviews with service users with dementia ($n=15$) and their carers ($n=16$) Service users who have dementia ($n=14$) participated in one of three focus groups Note that 50% of kinship carers in this study were aged 70 and older with health problems of their own</p>	<p>Thematic analysis</p>	<p>Twenty-six participants refused services on offer to them or those they care for with dementia due to unsuitability and ill-timing of the service on offer. They preferred to have family involvement instead. Refusal of services even when needed because of:</p> <ul style="list-style-type: none"> i) distress to service users ii) feelings of guilt iii) desire to remain at home iii) perceptions of coping iv) protecting privacy <p>Gaps include lack of transport and availability of day and respite care and homecare. Other gaps include personal care and support for the person with dementia. Need for well-trained staff they can communicate with. Including the views of people with dementia a central feature of this research Control of services is a central issue in this study. Services need to reflect the needs of the service users and their carers</p>
<p>Themessl-Huber et al. (2007) Frail older adults experiences and use of health and social care services <i>Journal of Nursing Management</i>, 15,</p>	<p>To highlight older adults' experiences and expectations of services and the consequences for</p>	<p>Qualitative study Purposive sample Interviews with people aged 80 and older</p>	<p>Framework analysis</p>	<p>Reasons to refuse services: Don't want to bother people, abandoning independence, embarrassed and humiliated and want familiar faces</p>

<p>pp. 222–229 Scotland</p>	<p>service provision, service development and research</p>	<p>(<i>n</i>=18) with history of multiple hospital admissions (more than 2) from four Scottish Health Board areas</p>		<p>Service changes needed because they do not cater for their individual needs. Own frailties prevent enjoyment of service uptake and services need to be more flexible</p>
<p>Durand et al. (2009) Domiciliary and day care services: Why do people with dementia refuse? <i>Aging and Mental Health</i>, 13 (3), pp. 414–419 UK</p>	<p>To explore why older adults with dementia who live alone refuse domiciliary and day care To examine the relationship between willingness to accept day services and depression Selection made through the use of the MMSE score above 11 and the Cornell Scale for depression in dementia</p>	<p>Qualitative study Convenience sample Interviews of older adults over age of 65 with a diagnosis of dementia (<i>n</i>=50) and their informal carers, living alone in the community. Informal carers helped service users to complete the interview. Informal carers were asked to rate the service users' willingness to accept help</p>	<p>Thematic analysis</p>	<p>Common reasons why service users refused domiciliary and day care services: i) believed they did not need services ii) believed they liked being on their own iii) believed they would not enjoy it Persistent refusers' reasons to refuse day services: i) feared meeting new people ii) feared losing independence iii) feared being institutionalised Willingness to accept care is unrelated to cognitive function, or depression. No link was found between depression and a willingness to accept care. People with greater memory loss are more likely to accept care Misconceptions about day services need to be addressed. Study highlights importance of asking service users with dementia their reasons for refusal</p>

<p>Stirling et al. (2010)</p> <p>Measuring dementia carers' unmet need for services - an exploratory mixed method study</p> <p><i>BMC Health Services Research</i>, 10, 122</p> <p>Australia</p>	<p>To explore the relationship between different types of carer service need using Bradshaw's typology</p> <p>To explore the link between measures of carer burden (normative need), service use (expressed need) and carers' stated need (felt need)</p>	<p>Mixed method study</p> <p>20 community dwelling pairs of dementia carers and people with dementia</p>	<p>Bivariate descriptive analysis</p> <p>Case analysis</p>	<p>Carers (felt need) did not correlate with service use (expressed need) implying a high level of unmet service need which could lead to service refusal</p> <p>Carers (felt need) important indicator of service need. Therefore, services should be based on carers' stated need (felt needs) rather than on service use (expressed need)</p>
<p>Phillipson et al. (2013)</p> <p>Why carers of people with dementia do not utilise out-of-home respite services</p> <p><i>Health and Social Care in the Community</i>, 21 (4), pp. 411–422</p> <p>Australia</p>	<p>To investigate carer beliefs regarding out-of-home respite services and why some carers do not utilise them</p>	<p>Quantitative study</p> <p>Questionnaires ($n=113$) to examine factors associated with non-use of services using the Theory Planned Behaviour within the Anderson Behavioural Model</p>	<p>Binary logistic regression</p>	<p>They claim this to be the first study to explore these issues. Although carers report high need for respite care, their use is low. Carers believe that service use would result in negative outcomes for the care recipient with dementia. This belief is associated with delays in accessing health services. Recommend carer service beliefs should be addressed through service improvement and promotion that emphasises benefits for both carers and care recipients</p>
<p>Kenning et al. (2017)</p> <p>Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of</p>	<p>To systematically review qualitative studies and to perform a meta-synthesis around barriers and</p>	<p>Qualitative study</p> <p>Twenty-eight studies included in meta-synthesis</p>	<p>Meta-ethnographic analysis</p>	<p>Two overarching themes:</p> <ul style="list-style-type: none"> i) 'Inadequacies' linked to service level barriers ii) 'Cultural habitus' linked to personal/cultural barriers

<p>qualitative studies</p> <p><i>BMC Psychiatry</i>, 17, 316</p> <p>UK</p>	<p>facilitators to accessing care for dementia in ethnic minority groups</p>			<p>Stigma of mental health and dementia. Asian family caregivers felt shame and guilt if others provided care. Therefore reluctant to seek help. Issues of trust, anxiety and reluctant to let people to let strangers into their home. Beliefs about western medicine, institutional racism and negative carer experiences</p>
<p>MacLeod et al. (2017)</p> <p>“There isn’t an easy way of finding the help that’s available.” Barriers and facilitators of service-use among dementia family caregivers: a qualitative study</p> <p><i>International Psychogeriatrics</i>, 29 (5), pp. 765–776</p> <p>Australia</p>	<p>Family caregivers of people with dementia have unmet needs regarding their care giving role but remain reluctant to utilise services to reduce their burden</p> <p>To examine the barriers and facilitators of service use among family caregivers of people with dementia</p>	<p>Qualitative study</p> <p>Semi-structured interviews with family caregivers ($n=24$) of community-dwelling people with dementia</p>	<p>Thematic analysis</p>	<p>Six main barriers and three facilitators across many types of services and supports:</p> <p>Barriers: Inability to find information about relevant services/supports. Poor quality or mistrust of services. Inflexible services. Caregivers’ beliefs about obligation as the care giving role and resistance by care recipient</p> <p>Facilitators: Good communication with care recipient. Access to expert point of contact. Positive service-affirming beliefs</p>
<p>Lindquist et al. (2018)</p> <p>Overcoming reluctance to accept home-based support from an older adult perspective</p> <p><i>The American Geriatrics Society</i>, 66 (9), pp. 1796–1799</p>	<p>To understand older adults’ perceptions about accepting help at home, in particular fears related to the potential loss of</p>	<p>Qualitative study</p> <p>Community-dwelling adults aged 65+ ($n=68$). Focus groups sought participants views and experiences of their</p>	<p>Constant comparative analysis</p>	<p>Reluctance to accept home-based support associated with concerns over an inability to complete tasks, perceptions of being a burden to others, lack of trust in others and loss of control</p> <p>Strategies to overcome reluctance</p>

USA	independence To examine possible strategies of overcoming refusal to accept home-based support	future health care options, including a potential reluctance to accept help in the home		include reframing independence to interdependence, contributing to others, overcoming the initial task Addressing the above reasons and promoting the strategies may lead to fewer unmet home-based needs
Moholt et al. (2020) Factors affecting the use of home-based services and out-of-home respite care services: A survey of family caregivers for older persons with dementia in Northern Norway <i>Dementia</i> , 19 (5), pp. 1712–1731 Norway	To explore the use and predictors of use of home-based and out-of-home respite care services available to older home-dwelling persons with dementia as reported by caregivers	Cross-sectional survey Family caregivers (n=430) Predictors of service use were examined	Bivariate correlation, multiple linear regression and Poisson regression analyses	Services are utilized where there is high caregiver burden, e.g., dementia Characteristics: (Person with dementia) advancing age, living alone and living in urban areas and those who are able to live alone for short periods of time (Caregiver) with increasing age, a family member, high educational level and in full-time employment Greater need for respite care with long duration of care giving and higher care-giving demands

1.3 Results

The 13 papers highlighted in this review refer to refusal of homecare, reluctance to accept homecare and avoidance of homecare. Only refusal and avoidance behaviours refer to non-delivery, whereas those who reluctantly accept homecare service still received it. To understand these features, I examined the extent of non-delivery, the characteristics of those most likely to experience non-delivery and the reasons for non-delivery of care. Sub-themes within the literature included older adults living in urban or remote rural locations, those who lived alone or with others, people from ethnic minority groups and people with dementia.

1.3.1 Refusal/Reluctance/Avoidance

Howse et al. (2004), in their literature review, identified refusal of homecare where services were explicitly refused, reluctantly accepted, or avoided, whereby people did not put themselves forward for care, but did not provide much distinction between these categories. This distinction remains an important factor and one that requires exploration. Previous research points to these distinctions but also does not make them clear (Strain and Blandford 2002; Themessl-Huber et al. 2007).

An early qualitative study explored social care for ethnic minority older adults in Glasgow, with concerns that the ethnic and cultural preferences of older Pakistani people were not being met, leading to subsequent refusal of services (Bowes and Dar 2000). With cultural and language barriers, service providers were losing touch with people at the very point when help was needed. However, there was a propensity for families from ethnic minority groups to 'look after their own', ensuring their needs were being met. Durand et al. (2009) identified high levels of service refusal among people with dementia and depression who lived alone. This qualitative study relates older adults' refusal with misconceptions about services on offer, with 60 percent of older adults identified as 'persistent refusers' (people who refused regularly).

Brodaty et al. (2005) identified service refusal amongst people with dementia and their kinship carers. Findings across 48 studies helped to develop a typology of kinship carers' non-use of services. The main reasons reported were perceived lack of need and older adult refusal. From a different perspective, Innes et al. (2005) explored dementia care provision in rural Scotland for older adults with dementia and their caregivers. This

study included the viewpoint of participants from both groups. Refusal of care services was linked to unmet needs in 35 out of 45 participants. Likewise, another study in rural Scotland identified a link with service refusal and caregiver unmet needs (Stirling et al. (2010). Caregivers in this study were informal carers, such as friends and family.

Themessl-Huber et al. (2007) interviewed older adults about their experiences of health and social care services and found a tendency to refuse care that was not person-centred. This was the only study to seek the viewpoint of older adults exclusively regarding the service they received. In order to better inform older adults about the services on offer, Lindquist et al. (2018) developed an online tool to help easier navigation around service availability. This qualitative study sought to understand reluctance among older adults to accept home-based support and, in particular, their fears about loss of independence. Macleod et al. (2017) explored barriers and facilitators of service use among kinship carers (friends and family) of people with dementia. In the same year, Kenning et al. (2017) explored the barriers and facilitators to access dementia care within ethnic minority groups with reluctance among older adults to utilise services.

Help-avoidance was identified as part of a spectrum of rational help-seeking behaviour, which included alternative offers of help and refusal to acknowledge need (Howse et al. 2004). Strain and Blandford (2002) found that kinship carers did not use community-based care services because they believed the services were neither wanted nor needed. A later study by Phillipson et al. (2013) investigated why carers of people with dementia tend not to use out-of-home respite services. They found that carers believed that service use would result in negative outcomes for the person affected by dementia. In contrast, Moholt et al. (2020) explored the use and predictors for use of home-based and out-of-home respite care services among kinship carers and found a greater use of respite care where there were higher caregiving demands.

Although refusal, reluctance and avoidance of homecare for older adults and their kinship carers are discussed separately, an overlap exists between the behaviours. Whereas refusal of services is most frequently referred to, reluctance to accept, if not addressed, could lead to care refusal. Acceptance of homecare depends largely on the health status of older adults, and whether they live with another person or they live alone.

The following section highlights the characteristics of those likely to experience non-delivery, and explores the more specific reasons for non-delivery and the extent of non-delivery identified in the literature.

1.3.2 Characteristics/Reasons/Extent

Information on the characteristics of older adults most likely to experience non-delivery of homecare was limited. Strain and Blandford (2002) identified the characteristics of kinship carers of older adults who refused services as being more likely to be men with less education. Likewise, Brodaty et al. (2005) developed a typology of some of the characteristics of kinship carers and people with dementia who were more likely to accept services. Characteristics included older adults of advancing age and those who lived alone in urban areas. Kinship carers included those of advancing age, being a family member, educated and in full-time employment.

Reasons to refuse care were plentiful and descriptive but differed according to the person who was doing the reporting. Older adults gave one view of their own care experience, whereas kinship carers had a different view, based on their own experiences. Where there was reduced capacity, for instance, with dementia, kinship carers made decisions on the older adult's behalf. Kinship carers refused care because they did not consider a need for the service or the service was unsuitable for their needs, being ill-timed and inflexible (Innes et al. 2005), and they were unaware of the existence of some services or had difficulty accessing services (Brodaty et al. 2005). Kinship carers wanted to protect the privacy of older adults living at home (Innes et al. 2005). They felt guilty if they did not provide the care themselves (Bowes and Dar 2000), even though many were themselves over the age of 70 with health-related concerns of their own (Innes et al. 2005).

Reasons for non-delivery of care from the viewpoint of older adults differed from those given by kinship carers. Durand et al. (2009) identified why older adults refused care services and identified two groups; refusers, and persistent refusers. Those within the refuser group believed that they did not need services, they liked being on their own and that they would not enjoy services anyway. Persistent refusers, those who regularly refused care, did so because they feared meeting new people. They feared losing their independence and admission into a care home. However, Durand et al.'s (2009) study was carried out in older adults diagnosed with dementia and so is unlikely to be similar

among all older adults. Other concerns for the lack of uptake of care services included denial of need and the cost of the service (Howse et al. 2004). Moreover, the older adults perceived that the services would not cater for their individual needs and could infringe on their independence (Themessl-Huber et al. 2007).

As above, the main focus of the findings pertained to reasons for non-delivery (refusals). The discussion which follows provides a deeper exploration of the nuances around this phenomenon.

1.3.3 Reasons for non-delivery of homecare

The many reasons for non-delivery of homecare are described under their respective headings; barriers of identity, barriers of independence, service barriers, and access barriers. These headings emerged from my analysis of the literature. The first two encapsulate non-delivery as a personal choice and relate to the attitudes and beliefs that older adults hold about themselves and others. The latter two headings include service appropriateness and a lack of awareness of services available.

Barriers of identity:

How people perceive themselves and how others might perceive them makes up their identity (Lindquist et al. 2018). Acceptance of homecare depends upon the individual's self-awareness and acknowledgement of needing care. Two papers identified an association between 'identity' and the uptake of care (Themessl-Huber et al. 2007; Lindquist et al. 2018). A problem exists in that older adults do not always identify themselves as being 'older'. When asked, older adults tend not to relate to their age and often express a preference not to spend time with others of a similar age. Furthermore, they do not want to be the recipients of charity or to be a burden upon others (Lindquist et al. 2018).

Denial of advancing age was evident, with many respondents genuinely perplexed to be considered old enough to be a part of a study regarding homecare requirements (Howse et al. 2004; Lindquist et al. 2018). To clarify, the identity of being an 'older adult' relates to the views of the society in which one lives. In western society, where youth and productive aging are valued, older adults reject images of getting old themselves, yet readily judge others based on these stereotypes (Townsend et al. 2006). A correlation exists between the stigma of old age and the negative uptake of homecare

among those who need it most. Kenning et al. (2018) identified an added burden of stigma attached to people with dementia where kinship carers often displayed feelings of guilt and shame if they were not seen to care for their own relatives and, as a result, would rather deny the need for care than accept service help. In addition, older adults from ethnic minority groups had concerns about western medicine and fear racism (Bowes and Dar 2000). Older adults stigmatise themselves by avoiding services if they view ill-health as a normal part of ageing and a burden to be borne (Howse et al. 2004). Likewise, refusal of help is likely if they view themselves as a burden (Themessl-Huber et al. 2007; Lindquist et al. 2018) or frail and incapable (Themessl-Huber et al. 2007). De-stigmatising dementia and older age would overcome some of the barriers to service use (Brodaty et al. 2005).

The most frequently mentioned concern within the literature reviewed was the loss of independence, especially when it was relinquished to others. The following heading discusses this and other barriers to independence.

Barriers to independence:

Living at home and independence are the desired goals for most people as they get older (Scottish Government 2019b). For some, homecare services help to keep people living in their own homes for longer and are received without question or concern. For others, accepting homecare is likened to abandoning independence and therefore a reason to refuse services (Themessl-Huber et al. 2007; Lindquist et al. 2018). The fear of loss of control by relinquishing independence is a strongly held belief (Strain and Blandford 2002; Lindquist et al. 2018). As independence decreases, a reluctance to accept services increases (Lindquist et al. 2018). Even when older adults struggle in their daily lives, they repeatedly decline services.

Lindquist et al. (2018) explored a reluctance to accept home-based support among community-dwelling older adults aged 65 and older ($n=68$) in the USA. This qualitative study revealed concerns over losing the ability to complete tasks. They feared being taken advantage of and of relinquishing control if others were to make decisions on their behalf. Participants in this study proposed 'reframing independence' as one of three strategies to help overcome service refusal. Reframing 'independence' to 'interdependence', and acceptance that people continually depend on each other throughout their lives, helped to validate the use of services. The two remaining

strategies included ‘contributing to others’ and ‘overcoming the initial ‘ask’.

Contributing to others relates to the acceptance of help from others who wish to provide it. A commonly felt theme concerned difficulties regarding the initial request for help for fear of rejection (Lindquist et al. 2018). Lindquist et al. (2018) claimed theirs was the first study to explore older adults’ refusal to accept home-based help. To my knowledge, there has been no similar research conducted since then.

Trust is the key component of a positive relationship and considered more important than skills or qualifications (Themessl-Huber et al. 2007; Kenning et al. 2017; Lindquist et al. 2018). Older adults living with complex needs with greater need for services preferred to seek help from family or friends rather than initiate services from caregivers as strangers (Strain and Blandford 2002; Themessl-Huber et al. 2007), or mistrusted care workers (Themessl-Huber et al. 2007; MacLeod et al. 2017; Lindquist et al. 2018), even in an emergency. Communication and friendship were valued over skills and professional qualifications.

For older adults who depended on others to keep them at home, decisions to accept or refuse care were sometimes removed from them by others speaking for them. Care was refused or accepted by friends and family because they felt their health did not necessitate its use or because they considered it their responsibility to provide care (Strain and Blandford 2002; MacLeod et al. 2017). Often, the higher the caregiver burden, the more likely they would be to refuse services (Themessl-Huber et al. 2007), suggesting a reduction in caregiver burden might increase service use. Continued independence remained central to the papers reviewed. Services were accepted because living at home meant independence; or refused because of the fear of losing their independence (Strain and Blandford 2002; Themessl-Huber et al. 2007; Durand et al. 2009; Lindquist et al. 2018). What was clear in the research was that supporting people to live independently is the key to effective homecare service provision.

Service affordability, inflexibility, suitability and alternative offers of help are discussed under the following heading; service barriers.

Service barriers:

Concerns exist about a fragmented system of care with an inappropriate and inflexible service (Howse et al. 2004), an inability to find relevant information, and about poor

care quality with staff unqualified to provide the necessary care (MacLeod et al. 2017). The authors suggest that alternative offers of help from kinship carers as a preferred option to accepting help from professionals as strangers formed the most common reason for refusal (Howse et al. 2004).

Strain and Blandford (2002) examined reasons for non-use of community-based services among a sample of 293 older person-caregiver dyads. In this Canadian study, the kinship carer was unaware of service availability and therefore unintentionally denied older adults the care they needed. This was more common among male kinship carers and those with less education. Kinship carers intentionally refused care because they perceived it to be not needed or because they thought it was their job to provide care. Arguably, the kinship carer, as overseer of services sought, accepted or refused, created a barrier to often much-needed professional care.

A later Scottish study explored frail older adults' experiences and use of health and social care services (Themessl-Huber et al. 2007). The findings highlighted that frail older adults, as high users of services, had concerns that their needs were not being met by the service they received, with one in four older adults requesting a change to the type and quality of care they received to avoid cancellation of services (Themessl-Huber et al. 2007). In particular, there was a need for a flexible service that did not interfere with routines and habits and a service that was available when needed, but otherwise remained inconspicuous.

Alternative offers of help, inappropriate care and denial of need formed the main reasons for refusals of care. Older adults' expectations of homecare did not always match that given, leading to disappointment (Howse et al. 2004). Adverse effects of not using community-based services were not investigated in this study but were recognised as a potential topic for future research. The financial implications of accepting care were also identified as a reason to refuse care and sometimes used as a way of protesting against the cost of care (Strain and Blandford 2002; Lindquist et al. 2018). Conversely, Brodaty et al. (2005) identified service cost as a non-barrier to service acceptance. Moholt et al. (2020) found that one in three kinship carers refused services because they believed services were not needed, older adults were reluctant to use services and service times were inflexible.

Lack of information, knowledge gap and unmet needs are discussed under the following heading; access barriers.

Access barriers:

Whereas service barriers highlight problems associated with the service itself, access barriers relate to service availability. Stirling et al. (2010) explored the link between measures of normative, expressed and felt need for carers and found a disconnect between carers' stated needs (felt needs) and service users' needs (expressed needs), which implied a high level of unmet need, leading to possible refusal of services. They suggested that providing services based on carers' felt needs rather than their expressed needs could prevent service refusals. Unmet needs among kinship carers of people with dementia were explored by MacLeod et al. (2017). Identifying the barriers and facilitators of service use helped to explain kinship carers' reluctance to utilise services. Barriers included concerns for the poor quality and mistrust of services and their beliefs about the caregiving role and resistance by older adults to accept services from any other source. Facilitators included having good communication with the older person and having access to an expert point of contact. Likewise, Kenning et al. (2017) identified the barriers and facilitators to accessing care for people with dementia among ethnic minority groups. A meta-synthesis of 28 studies identified two overarching themes, 'inadequacies' and 'cultural habitus'. Inadequacies, linked to service level barriers, included better need for education and a redesign of the information literature to make it more inclusive, whereas cultural habitus recognised the impact of cultural beliefs and expectations on service uptake. The aim of that study was to better understand the relationship between barriers and facilitators. One of their findings suggested that, although not separate entities, the two concepts lend themselves to interventions at a service level.

Howse et al. (2004) identified a lack of information regarding available help and a cause of service non-use specifically among kinship carers of older adults with cognitive impairment. Care was often measured against assistance required for Aids of Daily Living (ADL) and Instrumental Aids of Daily Living (IADL) (Strain and Blandford 2002). They found that, when a variety of services are used, some or all may be refused, often as a result of the perceived benefits and harms involved; a perception of being ineligible for a service and having difficulty in using the service. This was the only

study within this review to describe the characteristics associated with non-use of services from older adults and their kinship carers.

It was recognised that the collective ‘voice’ of older adults regarding individual concerns would be advantageous as older adults are themselves best placed to provide a comprehensive view of their own health status and needs (Themessl-Huber et al. 2007). Older adults want to be involved in research and decision-making (Howse et al. 2004). Moreover, the collective ‘voice’ of older adults in research, encouraged by policy-makers, helps to design a service that best suits individual needs. However, this is unlikely when service providers, those considered ‘experts’ and even kinship carers continue to take the lead role in decision-making.

If service uptake is to be improved, research has to reflect the views and concerns of older adults about the services they receive (Themessl-Huber et al. 2007). Alternatively, if older adults do not relate to being older, it is likely that their needs would go unmet with an increased chance of re-admission into hospital, or admission into a nursing home (Themessl-Huber et al. 2007). A major barrier to service provision was due to perceptions about services on offer and about those providing care. Beliefs were rooted in negative experiences of homecare or perceptions of a service not yet experienced (Phillipson et al. 2013). Kinship carers believed they had an obligation to provide care themselves to their older family members (Bowes and Dar 2000; Innes et al. 2005; Kenning et al. 2017). There was resistance from care recipients to accept care (MacLeod et al. 2017) because of inflexible services, mistrust of caregivers and of the service generally (Strain and Blandford 2002; Howse et al. 2004; Brodaty et al. 2005; Innes et al. 2005; MacLeod et al. 2017; Lindquist et al. 2018). Care recipients felt embarrassed and humiliated (Themessl-Huber et al. 2007), with concerns about care workers’ qualifications and level of training and letting strangers into their home (Kenning et al. 2017).

Living in rural and isolated areas provided another barrier to service provision. Innes et al. (2005) investigated rural care provision for people affected by dementia and their carers and found gaps in service provision. The ‘community spirit’ in these remote areas of Scotland negated the need for external care provision. Moreover, care was often refused by family members because of feelings of guilt that they were ‘not doing their job’.

1.4 Discussion

The main objective of the scoping review was to explore and map existing evidence on non-delivery. The main findings revealed that the reasons for non-delivery were well documented, but differed between older adults and kinship carers, the characteristics of those most likely to experience non-delivery of homecare was limited and the extent of non-delivery of homecare was unknown. The main strength of this scoping review was the method used and the ability to include a wide range of literature from a variety of sources. In contrast, the lack of available literature on non-delivery of homecare was the main limitation to this scoping review.

Initially, a search of the university library catalogue and Google Scholar, using basic search terms, 'non-delivery', 'homecare' and 'older adult' revealed that there is very limited data published on the topic. As a result, I decided to conduct a systematic scoping review, as the parameters of this approach are best suited when little evidence is expected (Munn et al. 2018). Therefore, the scoping review question remained as broad as possible and the inclusion criteria were made as inclusive as possible to help capture all available evidence from a variety of sources (Arksey and O'Malley 2005). The PRISMA flowchart selection process aided the identification of the most relevant evidence. The final selection of papers, presented in tabular form, provide a summary to effectively highlight each study's aims, research design, method of analysis and relevant findings.

This scoping review started from a suggestion that non-delivery is growing, but revealed that more data are needed to establish the full extent of the problem. Knowing the extent of the problem would help policy makers and service providers to understand the complexities behind non-delivery of homecare for older adults.

The intention of the scoping review was to identify types of data in a given field, and identify key characteristics related to the topic area and gaps in the knowledge-base. This scoping review captured nuances that would not necessarily be revealed with other approaches (Arksey and O'Malley 2005) because data derived from grey literature and online agencies were included. Unlike a traditional or systematic review, a scoping review removes the need to appraise the literature critically. This allowed the inclusion of any literature relating to the topic area, focussing on the breadth of data, irrespective of its source (Munn et al. 2018). This approach was particularly valuable, given the

anticipated lack of pertinent literature on non-delivery of homecare. However, this focus did not negate the need to follow a structured approach. Therefore, a five-stage methodological framework, advocated by Arksey and O'Malley (2005), helped to guide this review. Performed in an iterative process, this framework allowed for the revisiting of each stage more than once to establish what was known about the topic area and to identify gaps in the literature. In line with the scoping approach, and given the scarcity of papers, the focus of my review was to report the findings from each paper rather than try to synthesise them (Arksey and O'Malley 2005). This review helped to confirm current homecare practice, identify areas which need further exploration and formulate my research questions (Munn et al. 2018).

1.4.1 Strengths and limitations

The scoping review approach limited the ability to assess the quality of the evidence formally, as the emphasis was on the breadth rather than depth of data (Tricco et al. 2016). However, Pham et al. (2014), in their review of 344 scoping reviews, found this to be a study limitation in only 16 percent of all reviews included.

Synthesis was not a focus within this review (Arksey and O'Malley 2005). Instead, the aim was to explore the range of research activity around non-delivery of homecare for older adults, irrespective of any other factors. Initially, following the systematic review methodology, an extensive search of relevant databases using broad search terms was undertaken. Methodological information on the population, data collection, interventions and outcomes were extracted, which helped interpret the evidence (Bunn et al. 2016). Although it was possible that not all relevant evidence was discovered, I was confident that the parameters of this scoping strategy unearthed enough material to provide a comprehensive review of the existing evidence pertaining to non-delivery of homecare for older adults.

Each paper was accepted according to its association with the topic area and ability to answer the review question. Non-delivery of homecare as a term was infrequently mentioned. What this review revealed was a focus on care that was not delivered because service users refused it, reluctantly accepted it or avoided it. Reasons to refuse, accept or avoid care were well documented. The extent of the problem of non-delivery remained unknown. The inclusion criteria focussed on older adults, irrespective of diagnosis. Each paper included, but not exclusively, people with frail and complex

needs, people affected by dementia, people who lived alone, and people who lived in rural areas.

Half of the papers originated from outside the UK with limited application to health and social care within the UK. The most recent study claimed to be the first to explore reluctance to accept home-based support (Lindquist et al. 2018). This study, from the USA, identified reasons for refusal and proposed strategies to overcome it. However, the care system in the USA is quite different to that of the UK, with different cost implications and eligibility criteria pertinent to that country. The same disconnect may be discerned in the remaining papers from Australia, Canada and Norway. Nevertheless, the papers included in this review provided valuable insight into the issues they faced regarding home care.

1.4.2 Research gap

This literature review highlights distinct gaps in knowledge. Although reasons for non-delivery of home care were well documented, the reports emanate from the care worker or kinship carer perspective. The characteristics of those most likely to experience non-delivery were not adequately covered. Likewise, the older adults' perspective was not adequately covered in the research process. However, the extent of non-delivery was unknown and research within the UK was not adequately covered, requiring further research.

1.4.3 Implications of the results for this thesis

This scoping review provided some key information to inform our understanding of non-delivery of home care for older adults. However, the scoping review represented limited data with further research required. Unravelling the complexities of non-delivery required an understanding of the importance of independence and the need to stay at home; relationships with others, beliefs, fears, attitudes and service appropriateness. This multi-layered issue provided a challenge for policy-makers and service planners in their drive to improve home care for older adults in the community.

Out of the 13 selected papers, only three studies exclusively sought older adults' views of home care experienced (Howse et al. 2004; Themessl-Huber et al. 2007; Lindquist et al. 2018). Five of the included studies focussed on kinship carers and their role as caregivers, including their reluctance or non-use of home care or respite care (Brodsky et

al. 2005; Stirling et al. 2010; Phillipson et al. 2013; Macleod et al. 2017; Moholt et al. 2020). The selected papers discussed wholly or in part issues of refusal, reluctance or avoidance of homecare services for older adults. These terms were used interchangeably to describe similar behaviours. However, refusal of services was the main currency.

The reasons for service refusals were well reported, with loss of independence and unmet need a cause for concern, in particular, when linked to care provided within an inappropriate, untimely and inflexible service. Alternative offers of help from friends and family were welcomed by older adults. A lack of trust in care workers endorsed the preference to be cared for by family members rather than carers as strangers, especially among ethnic minority groups where the emphasis was on ‘caring for your own’.

Differences existed between the views of older adults and their care workers on the homecare required; differences that needed to be addressed if service uptake was to improve. Older adults refused because of concerns about an unsuitable service and the fear of losing independence. They preferred to be looked after by their own family in their own home. Kinship carers refused homecare because of concerns for an unsuitable service and because they felt they should provide care themselves. Refusal of services was high, even where there was high caregiver burden.

Despite these different views, there was a tendency for researchers to ask those providing the care rather than those in receipt of it. Across most of the studies, the ‘voice’ of older adults in research was missing. This highlights a distinct lack of knowledge in the literature, as they alone can provide a subjective view of their own needs and requirements (Twigg and Martin 2015). Where possible, research that is sensitively designed can incorporate the views of older adults, even those with high care needs (Velzke and Baumann 2017); research that can improve service suitability, satisfaction and, ultimately, sustainability.

Based on the findings of the scoping review, the following research questions were formulated.

1.5 Research Questions

Overall research question – *What is known about non-delivery of homecare among older people in Scotland?*

Research Question 1 – *What is the extent of non-delivery of homecare among older people?*

Research Question 2 – *What are the characteristics of older people most likely to experience non-delivery?*

Research Question 3 – *What are the reasons for non-delivery of homecare among older people?*

1.6 Chapter Summary

This chapter reports the findings of a scoping review exploring what was known about non-delivery of homecare for older adults. Overall, the findings suggest that the literature specific to non-delivery of homecare for older adults is limited. This initial scoping of the literature revealed an evidence gap in relation to non-delivery of homecare. Most of the papers included in this review focussed on the delivery of homecare rather than on non-delivery. Non-delivery was instead reported as part of research on homecare delivery. What was revealed was a growing concern over older adults' dissatisfaction with service provision. Further research to explore non-delivery of homecare from an older adult's perspective would inform and improve future service provision.

The results of this scoping review helped to effectively inform appropriate research questions within which to frame the scope and processes of the research presented in this thesis. Identifying the gaps in the evidence, particularly in relation to the extent of non-delivery of homecare for older adults and the lack of research drawn from the older adults' perspective, has allowed me to make an original contribution to the knowledge.

Chapter 2 identifies and discusses the methodology best suited to answer the research questions identified by this review.

CHAPTER 2: Methodology – Philosophical positioning, pragmatism and multi-methods

2.1 Introduction

This chapter presents the study aims and explores the philosophical positioning of the research and the researcher. The methodological approach is presented and justified in the context of the paradigms within which this research is situated. This research necessitated the conducting of two studies to answer the three research questions, while adopting a multi-method approach.

2.1.1 Research aims

This study set out to identify the extent of non-delivery of homecare for older people, to establish the characteristics of those most likely to experience non-delivery and to explore the reasons for non-delivery of homecare.

2.1.2 Philosophical positioning

Initially, and as part of the process of research design, the philosophical considerations relating to this research, based on its ontological and epistemological underpinnings, were contemplated. Any individual's beliefs, shaped by our own ontological (existence) (Crotty 1989) and epistemological (knowledge) premises (Guba and Lincoln 1994), will guide a researcher's views of the world (Maxwell 2012). These beliefs help to shape our methodological decisions, including data collection and analysis (Creswell and Plano Clark 2011).

Worldview:

A worldview, also known as a paradigm, is associated with a particular methodology (Byrne and Humble 2007) and, as Brannen (2005, p. 7) writes, 'methodological choice does not exist within a philosophical void'. My worldview is that the world we experience exists independently of us and that our understanding of this world is inevitably a construction, unique to our own individual standpoint. However, we are all in and of the same world. We each build our own understanding of it and responses to it out of our own experience of it (Maxwell 2012). My worldview, based on my past experiences as well as the aim of the research and research questions, influenced the selection of quantitative and qualitative research within this multi-method study.

The logic supporting my first mode of inquiry was to establish the incidences of non-delivery and the number of people accounting for them, which required a quantitative approach. Positivism, as the underpinning paradigm in quantitative research, assumes that reality is an external construct and can be observed and replicated under similar circumstances (Lapan et al. 2012). Positivists claim that objective and value-free inquiry within quantitative research is possible, as facts and values are distinct and objectively measurable (Blaikie 2007). Unlike the positivist viewpoint, I believe that the research process, and thus the researcher, is value-laden, which has the potential to influence the outcome. Therefore, every safeguard was made to reduce the impact of researcher bias within the quantitative element of the research. Research Question 1 and Research Question 2 were situated within the positivist paradigm.

The logic supporting my second mode of inquiry was inductive; rather than starting with a set hypothesis, knowledge was generated throughout the process of the research. Interpretivism, as the underpinning paradigm associated with qualitative research, is exploratory in nature (Guba and Lincoln 1994), provides a sense of process (Bryman 2012), and helps to establish meaning in social situations and to understand the ‘world of human experience’ (Cohen and Manion 1994, p. 36). The third research question was situated within this paradigm.

Figure 2 provides a visual illustration of the philosophical underpinnings of this study.

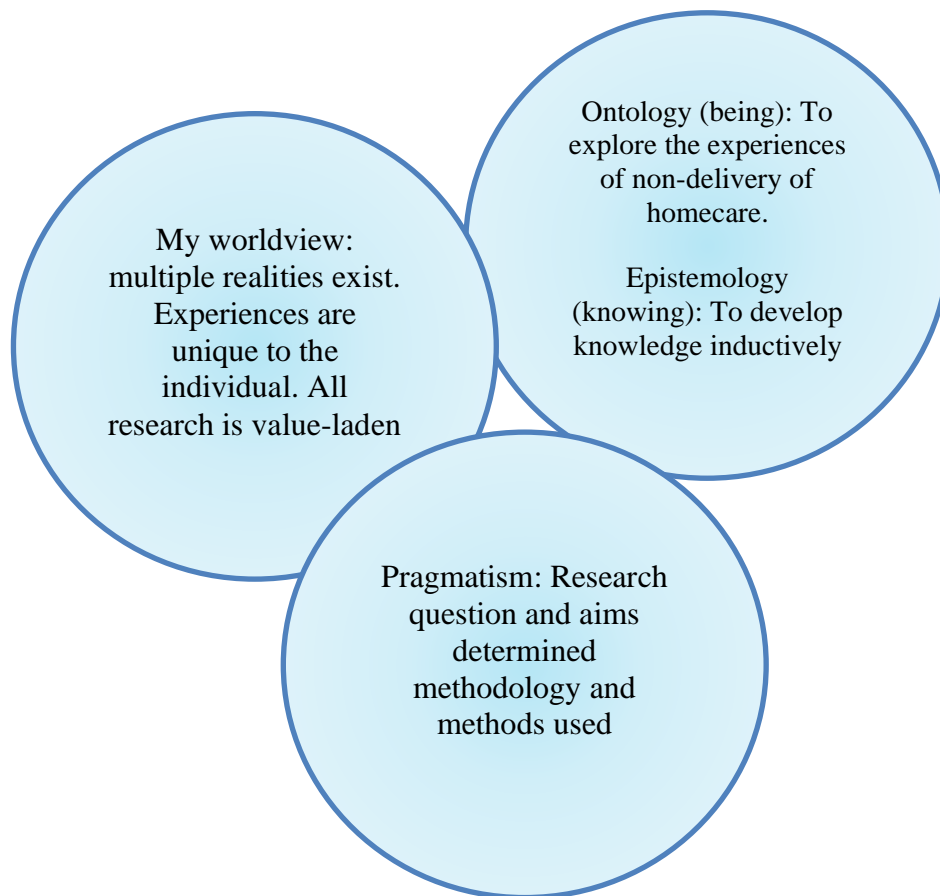


Figure 2: Philosophical underpinnings of these studies

Pragmatism:

Despite drawing on both positivist and interpretivist paradigms, it was important for me to guard against the rigid confines imposed by paradigms which limit capturing philosophical diversity (Pernecky 2016). According to Morgan (2014), pragmatism goes beyond the confines of epistemology and ontology and concentrates on beliefs that are connected to actions, focussing on the how, why and what of research. Pragmatism allows for different worldviews and different assumptions, as well as different forms of data collection and analysis (Creswell 2003). Some traditionalists advocate for qualitative research driven by a theoretical framework (Reeves et al. 2008). Taking a pragmatic approach, the dialectic stance assumes all paradigms offer something, and that multiple paradigms in a single study contribute to a better understanding of the phenomenon being studied (Greene and Hall 2010). Moreover, using a range of approaches produces better quality work, with each approach adding to an enhanced understanding of the research in question (Seale et al. 2007). With due consideration, a

pragmatic approach allowed me to focus on identifying the most appropriate methodology and methods to help answer the research questions posed.

Pragmatic research studies naturally divide into mixed-methods and multi-methods (Morse 2003). Having established the need to include both quantitative and qualitative research, the benefits or otherwise of both approaches were deliberated. Although the language used to describe these two approaches is similar, the sub-divisions are methodologically very different. Mixed-methods, associated with the pragmatic paradigm, involves data collected simultaneously or sequentially with the integration of data at more than one stage of the study to answer the same research question (Creswell 2003), thus adding depth and breadth to findings of complex social phenomena (Tashakkori and Teddlie 2003). Conversely, a multi-method approach utilises different methods to help answer distinctly different research questions (Morse 2003). This was therefore the chosen methodology for this research.

Multi-methods:

Increasingly, research involving complex social contexts requires more than one method in order to answer the questions relating to the ‘what’ and the ‘how’ of the issue being studied (Creswell 2013, p. 3). The initial research questions raised in this thesis necessitated the quantitative exploration of a large set of data, analysed with descriptive statistics to reveal the extent of the issue as well as to provide some general information about the characteristics of those who are most affected. However, one of the drawbacks of a quantitative research model is that it may not allow for an in-depth exploration of the understandings of the individuals who experience the effects of the issue (Morse 2003). Therefore, it was necessary to draw on multiple methods to explore both the breadth and depth of the problem.

The scoping review revealed that non-delivery of homecare had presented as an under-researched and complex topic area within the literature. Therefore, the research questions required a methodology which allowed the freedom to utilise the approach best suited to answer three distinctly different research questions (Bryman 2016). There are other methodological approaches that combine quantitative and qualitative research that might have been adopted for this study. However, a multi-method design was best suited for the following reasons. A multi-method design involves quantitative and qualitative projects which are relatively complete on their own, each maintaining its

own worldview integrity (Morse 2003). Thus, because quantitative research is framed in terms of numbers, or quantifiable measures which can be analysed statistically (Creswell 2014), this was considered to be a suitable method for the first study, as its aim was to determine the *extent* of non-delivery of homecare among older people, as well as identify their *characteristics*. Alternatively, qualitative research is a generic term that refers to a group of methods and ways of collecting data. Qualitative research helps to make sense of complex data, gain new insights and provide a deeper understanding of phenomena (Brannen 2005). This was therefore deemed the most appropriate for the second study as it provided the necessary in-depth exploration of the reasons for non-delivery of homecare among older people. For this line of inquiry, a deeper understanding of the issue was more important than the recruitment of large samples (Ritchie et al. 2014).

Multi-method research studies analyse highly complex social phenomenon which are driven by two separate logics of inquiry requiring different approaches to different research questions (Greene 2015). Anguera et al. (2018), in exploring the literature to compare multi-methods and mixed-methods research, emphasise that the definitions of each are conceptually overlapping and described using vague terms. The main difference found between the two is that mixed-methods research requires the integration of the findings. However, the integration the findings achieved in two separate research methods relies on the purpose of the research being to gain insights into one research objective. This does not apply where different methods are used to explore different objectives (Anguera et al. 2018), as is the case in this multi-method study described here. The complexity of the research presented in this thesis necessitated multiple research objectives, thus, despite the ambiguity presented in both definitions, I chose the term 'multi-methods' to describe the design of the methods adopted here. Chapter 5 considers the insights generated by both studies in combination and discusses the different outcomes in relation to the research questions to make conclusions about the inferences that can be made.

My multi-method study therefore comprised two study designs to answer three pre-specified research questions. The first study (Study 1) utilised quantitative research to identify the extent of non-delivery of homecare and to establish the characteristics of those most likely to refuse or avoid homecare. The second study (Study 2), informed by

findings from the first, utilised qualitative research to explore reasons for non-delivery from the service user perspective. Each study was analysed separately. Each had its own aims and research design. Following completion of both studies, the findings of each were considered together to establish to what extent the overall study aim had been met. Morse (2003) describes how such use of multiple methods or data sources can be employed to develop a comprehensive understanding of complex phenomena. Figure 3 demonstrates the process followed for this multi-method study.

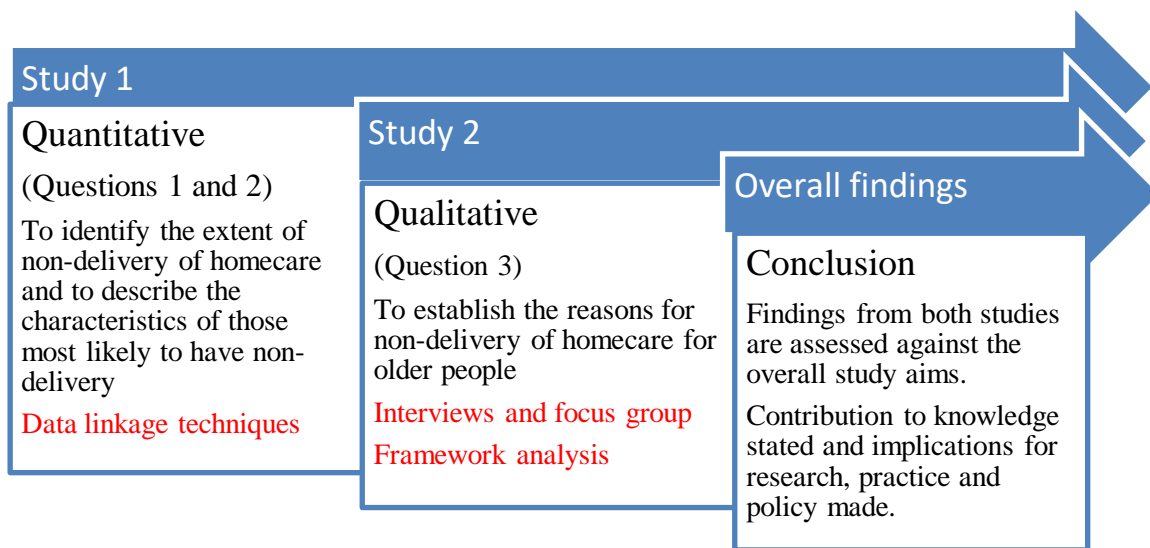


Figure 3: Research process of this multi-method study

2.2 Chapter Summary

This chapter has presented the overall aims of the research, its methodology and the methods applied. My own philosophical positioning was reflected in my choice of pragmatism, as it ensured that the research questions drove the research rather than it being theoretically driven. The research questions could not be readily answered by a single-study design. Therefore a multi-method approach was adopted in two studies. A multi-methods approach was deemed most appropriate to answer the research questions. Study 1 was designed specifically to answer Research Questions 1 and 2, and Study 2 was designed to answer Research Question 3. The design of each study was outlined in this chapter, however, a more detailed account of the practical considerations of each study is provided at the beginning of their relative chapters (Chapters 3 and 4).

In the chapter relating to Study 1 (Chapter 3), older people are referred to as service users because they had all received or had been assessed as needing homecare, whereas their voluntary participation in Study 2 (Chapter 4) warrants their being described as participants. Those providing paid homecare are referred to as care workers. Each study, alone and together, informed the debate on non-delivery of homecare.

Chapter 3 introduces Study 1, the quantitative study.

CHAPTER 3: Quantitative Study – A study of the frequency of non-delivery of homecare using data linkage (Study 1)

3.1 Introduction

This chapter describes in more detail the method, including data linkage techniques, adopted as well as the results and discussion for the quantitative study (Study 1). This was the most suitable approach to explore the extent of non-delivery of homecare for older people, as well as the characteristics of those most likely to experience non-delivery (Research Questions 1 and 2).

3.1.1 Rationale

Informal conversations with a large homecare service provider revealed concerns for the delivery of homecare for older people and about whether they were actually receiving the care planned for them. This homecare service provider supplied 98 percent of all homecare to people in Greater Glasgow and Clyde, the majority to people aged 65 years and older. They were keen to establish the reasons for non-delivery to prevent its escalation.

In Scotland, healthcare policy has advocated the integration of health and social care services since the Community Care and Health (Scotland) Act was enacted in 2002, which introduced powers for NHS boards and councils to work together more effectively. In 2012, the Scottish Government published the results of a consultation for proposals to advance the integration of health and social care provision in Scotland (Scottish Government 2012), which contributed to the enactment of the Health and Social Care Act (2012). Subsequently, the Public Bodies (Joint Working) (Scotland) Act 2014, introduced new guidance, allowing a significant reform of how care is delivered, and making arrangements for the sharing of data across care providers to ‘ensure services are well integrated and that people receive the care they need at the right time and in the right setting’ (Audit Scotland 2015, p. 5). As such, this has created opportunities for the drawing of data from multiple sets of registers and databases for the purposes of improving care as well as for conducting research.

3.1.2 Research questions

This record-linkage study between homecare provision for, and hospitalisations of, older people was designed to answer the first two research questions:

Research Question 1: *What is the extent of non-delivery of homecare among older people?*

Research Question 2: *What are the characteristics of older people most likely to experience non-delivery?*

A major homecare service provider helped to facilitate the first study: it granted permission to access its records of homecare delivery and non-delivery across a three-month time period (September to November 2013) among service users aged 65 years and older. Thereafter, the data were ‘cleaned up’, ready to be sent for data linkage with a healthcare dataset, the Scottish Morbidity Record 1 (SMR01), which contained hospital admissions only, to identify a study cohort of older people who had not been hospitalised and whose reasons for non-delivery of homecare (if applicable) were not because they had been in hospital. This period captured individuals as they moved in and out of care provision, some at the beginning, and some at the end of their care package. Collectively, this timeframe had fewer bank holidays or other organisational reasons, such as statutory holidays, that might affect uptake of homecare. A reduction in homecare before, during and after major holidays such as Christmas was recognised. Importantly, the patterns of homecare service could alter pre- and post-hospital admission.

The homecare organisation holds an operational database which documents all those in receipt of homecare and care received. The data held include socio-demographic information which comprised part-Post Code (4 digits), Date of Birth (DOB), Gender, Age, Visit frequency, Ethnic group, Living group and SIMD (2016) (Scottish Index of Multiple Deprivation).¹ Data relating to service users’ clinical diagnosis and co-morbidities were not available. Within the dataset, there is an entry for every homecare visit, including the type of service provided, the frequency of service provision and incidence of No Access (NA) or Service Refusal (SR). NA refers to incidents where the

¹ The Scottish Index of Multiple Deprivation (2016) is a relative measure of deprivation across 6,976 small areas (or data zones). More information can be obtained on the SIMD website (<https://www.gov.scot/collections/scottish-index-of-multiple-deprivation-2020/>).

care worker was unable to gain access to the service user at the point of delivery. SR refers to a service that was refused by the service user at the point of delivery. Other relevant data included adverse events, such as hospital admissions and deaths, records of falls and GP call-outs.

The success of linking data between two previously unlinked datasets was as yet unknown, as homecare data had never previously been linked to hospitalisations data. Therefore, it was necessary to first test the possibility of linking previously unlinked data across a social and a healthcare dataset. Thereafter, it would be possible to identify the extent of non-delivery of homecare and to establish the characteristics of older people who were most likely to experience non-delivery of homecare.

3.2 Methods

Working in collaboration with the University of Stirling, a major homecare service provider and Glasgow City Council, the possibilities of data linkage were explored using two previously unlinked datasets (data from NHS Greater Glasgow and Clyde, drawing on the national healthcare dataset, SMR01, and a dataset drawn from a homecare service provider) to identify the extent both of non-delivery of homecare and of hospitalisations and to establish the characteristics of older people most likely to experience non-delivery of homecare over a three-month timeframe.

For verification, this main homecare database needed to be linked to SMR01 to exclude assuredly all those who had been admitted to and discharged from hospital. Data linkage between the homecare dataset and SMR01 (NHS Greater Glasgow and Clyde) identified all of those with admissions into hospital during the study period. Elimination of this subgroup enabled us to identify the population of all those whose homecare visit schedules were relatively stable.

Data linkage was undertaken by Glasgow Safe Haven, a physical and electronic space within which the necessary levels of security are provided to support access to local healthcare data for service and research purposes (NHS Greater Glasgow and Clyde 2020). Developed by NHS Greater Glasgow and Clyde, and referred to as a data warehouse, the Glasgow Safe Haven was primarily created to support the secondary research use of clinical data. Moreover, as a secure environment, it allowed me to access anonymised linked data for my analyses. Glasgow Safe Haven, supported by the

Scottish Government through the Chief Scientist's Office, is a partnership with the Robertson Centre for Biostatistics (RCB) at the University of Glasgow. Governance of the data usage is performed via a Local Privacy Advisory Committee (LPAC), whose primary function is to protect the privacy and confidentiality of patients. The Glasgow Safe Haven IT infrastructure has embedded Standard Operational Procedures (SOP) and Caldicott Guardianship, already in place, allowing for approved linkages and access to anonymous NHS data through the University of Glasgow's Virtual Private Network (VPN). This facility permitted me to access linked datasets via dumb terminals for unconsented anonymous linked datasets within the RCB system. Logging on remotely, enabled access to the linked data, which are stored but could not be removed and are only accessed by those with the authority to do so.

To help ensure that the study was on track and meeting its objectives, a study steering group was established, consisting of professionals with a vested interest in the study, as described below. While it was considered prudent to include those directly affected by the topic under study (INVOLVE 2020) in the group, Glasgow City Council prohibited older people with experience of homecare and non-delivery from being approached directly for recruitment onto a steering group.

3.2.1 Steering group

A steering group of 12 key stakeholders, including representatives from the homecare service provider and Glasgow City Council, met regularly every few weeks to monitor the progress of the study. A steering group ensured participation from 'experts' to ensure the protocol was followed and to provide advice where necessary to guide the research (NIHR 2010). People invited to join the steering group included homecare managers, discharge managers, fieldwork managers and a systems analyst. Four meetings with up to six people attending any one meeting provided constructive comments on the design of the quantitative study. The venue was within easy access for all steering group members. As lead researcher, I sent out an agenda prior to each meeting, chaired the meeting, and took minutes. Once drafted, the minutes were sent to each member for validation and comment before being adopted.

3.2.2 Lay-user involvement

In preparation for conducting the research, I obtained membership to the Disclosure Scotland PVG (Protecting Vulnerable Groups) scheme and completed an Occupational Health Check. This allowed me to recruit a group of older people as lay members onto a discussion group to help define the scope of the study, which informed the protocol. This also allowed me to involve those who are directly affected by the topic of study in the research, despite not being able to include them in the steering group. This small group of people had experience of homecare, but not necessarily from this particular homecare service provider. As requested, Glasgow City Council were provided with the details of the themes and questions that would be explored during the discussion group, the frequency and whereabouts of the venue for the meetings, and the number of people who would be participating. One meeting took place. The process of recruiting participants to this group follows.

The day care unit manager provided interested people with a flyer (Appendix 1). The flyer provided information on the study and invited those eligible to join the discussion group. People aged 65 years and older with experience of homecare, who were able to understand the purpose of the meeting and able to communicate and provide consent, were eligible to be included in the lay-user group.

3.2.3 Other meetings

Various meetings with people outwith the steering and lay-user discussion group also helped to refine the study design. Meetings with homecare managers and a systems analyst enabled a better understanding of the procedures pertaining to homecare delivery and, in particular, the process, that care workers followed in the event of non-delivery. This included contacting next of kin, family and friends and then, where necessary, the police.

3.2.4 Ethical approvals and permissions

Ethics approval for this study was obtained from the University of Stirling, Glasgow City Council and the homecare service provider who participated in the research. A three-way data sharing agreement was set up to represent the interests of all parties, a process that proved long and complex. The Glasgow Safe Haven data linkage service, in connection with NHS Greater Glasgow and Clyde Health Board, carried out all data

linkage. Individual approvals to conduct the study were obtained from the School of Nursing and Midwifery Research Ethics Committee (SREC) at the University of Stirling (Appendix 2), the homecare service provider (Appendix 3), Glasgow Safe Haven (Appendix 4) and the University of Glasgow VPN (Appendix 5). Lawyers employed by Glasgow City Council worked on a three-way joint data sharing protocol that represented the interests of all of the above stakeholders (Appendix 6).

Data linkage was required to connect the records of people within two otherwise separate datasets, which is an exceedingly valuable research method.

3.2.5 Data linkage

Data linkage refers to a situation where ‘information from two or more records of independent sources are brought together as they are perceived to belong to the same individual, family, event or place’ (Brook et al. 2008, p. 19). Linking data between homecare and healthcare datasets enabled a better understanding of the issue of non-delivery of homecare.

Initially, a homecare dataset was linked with the SMR01, including only Glasgow and Clyde NHS data, and which contained information relating to hospital admissions only. The two datasets were linked in order to identify dates when people were in hospital. The problem with data linkage between these two datasets was that a lack of common patient identifiers impeded linkage across both datasets. The first stage to linkage was therefore to allocate a CHI (Community Health Index) number to each of the homecare data records. The CHI number is a unique 10-digit patient identifier by which all healthcare datasets in Scotland are indexed, and is allocated to patients when they register with a GP in Scotland. CHI numbers, attached to service users’ healthcare data records, were allocated to homecare data by the Glasgow Safe Haven and then record-linked to a CHI-indexed database of inpatient hospital admissions called SMR01 (ISD Scotland 2017). The process of allocating CHI to homecare data, completed by Glasgow Safe Haven, follows.

Allocation of CHI to homecare data:

The master homecare file contained 7376 service users. CHI numbers were allocated to all people within the three-month sample, irrespective of whether they had a history of non-delivery. Homecare service users have a unique identification number allocated to

them, but not a CHI number. To ensure anonymity, Glasgow Safe Haven allocated CHI numbers from the CHI Master Patients Index to the homecare service user records.

Probabilistic linkage methods were used to make the CHI number attribution for homecare service users. Glasgow Safe Haven typically uses probabilistic linkage methods for specified data items (name, address and date of birth) for the allocation of CHI from the CHI master patient index. An algorithm computes a score which reflects a number, which in turn reflects the probability that the records referred to the same person. However, inaccuracies and inconsistencies for some records hindered this process. When this occurred, the Glasgow Safe Haven statisticians manually linked the data.

CHI-seeded data linked to SMR01

Following the above allocation of CHI numbers to service user records, the next stage involved deterministic linkage to the Glasgow portion of SMR01 (inpatient hospital admission).

3.2.6 Data processing

The number of homecare visits where care was received was compared with visits where the care worker had attempted to deliver homecare but, for whatever reason, was unable to. The homecare service provider categorised non-delivery as either No Access (NA) or Service Refusal (SR). Collectively, this information helped identify the extent of non-delivery in both categories. Profiles of those with and without non-delivery of homecare were examined. Further explanatory data, from care worker records, provided an opportunity to ascertain the exact reasons for non-delivery of homecare. However, data on the underlying need for care, or comorbidity and diagnosis, were not available.

Care workers documented each visit. The documentation was specific to this homecare service provider and included a comprehensive list of codes relating to delivery and non-delivery of homecare. Access to the meanings of the codes was essential in enabling me to decipher the data. Each time a service user was visited, whatever the outcome, a record of that visit was made electronically by the care worker who visited.

Records of 7376 people who had received homecare within the three-month period were anonymised and made available for interrogation through the University of Glasgow

VPN (Virtual Private Network). The database was accessed by logging on remotely and using SPSS for Windows and ACCESS software packages. Thereafter, records of people under the age of 65 were identified and removed from the sample.

Characteristics of older people most likely to experience non-delivery of homecare were then described. The extents of NA, SR and both were calculated and the results presented in tabular form. Associated descriptive data provided an opportunity to further investigate the exact reasons for non-delivery from the care workers' perspective. Randomly selected ten-percent samples of records for both NA and SR provided limited information relating to some of the reasons for non-delivery of homecare. A ten-percent randomly selected sample of 417 incidences (not individuals) of NA was created from 4170 incidences (not individuals) of NA. Likewise, a ten-percent randomly selected sample of 96 incidences (not individuals) of SR and any reasons given were created from 960 incidences (not individuals) of SR. To quantify the results, a count was made for each reason given (and for sub-categories of reasons) and then converted into percentages. Creating a sub-sample was a practical means of extrapolating manageable data from a large sample. Random selection ensured that the quality of the data was not affected. Written free text within these ten-percent sub-samples provided an opportunity for me to identify some of the reasons for NA and SR. Initially, the reasons were coded according to the reasons given and then placed alongside others with similar content and then put into categories. These results are presented in diagrammatic form in the next section.

3.3 Results

3.3.1 Data linkage process

The following section describes the process and results of the data linkage, which was conducted in four sweeps. The master homecare file contained 7376 service users.

Sweep 1:

Probabilistic CHI allocation based on demographic data supplied. This allocation process initially produced 3493 matches. Errors in original homecare data, in particular, inconsistencies in the order of first names and surnames, incomplete postcodes and dates of birth, and a few potentially duplicate service users, affected the ability to link these records using algorithms. A manual check on the first 100 service users on the

homecare file against the data emanating from SMR01 proved problematic with many mismatches. A mismatch occurs where there is a failure or a discrepancy in correspondence between individuals from both datasets. The Glasgow Safe Haven statisticians classified these discrepancies as either major or minor, depending on the likelihood of the match.

Proceeded to Sweep 2:

Manual identification of duplicate and mismatched service users. Following CHI matching, any mismatches were sorted into Major = 103 and Minor = 671 mismatches.

Proceeded to Sweep 3:

Manual identification and removal of mismatched subjects. A true match was achieved if all but a minor data error fitted with that recorded on the SMR01 health data, therefore, using this method, all 671 minor mismatches were deemed to be matches. The 103 major mismatches required deeper exploration into demographic characteristics. All but three were matched using this method. A total of 3490 records of people within the population had been CHI-matched so far.

Proceeded to Sweep 4:

Manual identification of unmatched subjects. As the above CHI linkage methods had yielded the best results, it was decided to match the remaining 3886 as carried out in Sweep 3. Where there was a major mismatch, archived demographic data were ‘drilled into’ to match against older records. This process removed unmatched service users ($n=405$) and matched a further 3481 service users, resulting in a total of 6971 successful individual matches. Therefore, out of the original master homecare file containing 7376 service users, this gave a 94.5 percent linkage success rate.

The final dataset, resulting from the four sweeps, contained 6971 linked matches and was anonymised, encrypted and transported to the University of Stirling via ACCESS.

Prior to analysis, all those younger than 65 years and all those with ‘no age’ were removed from the database ($n=212$), leaving 6759 linked service users. All those who had been in hospital during the three-month period ($n=1944$) were also removed to ensure that hospitalisation would not account for records of non-delivery. This gave a total of 4815 linked service user entries which were then ready for analysis.

Table 2 identifies the socio-demographic characteristics of the study population and describes the profile of the sample with or without non-delivery within the three-month study period.

Table 2: Socio-demographic characteristics of the study population (n=4815)

Socio-demographic Characteristics	Study Population
Gender:	<i>n</i> (%)
Female	2789 (58.0)
Male	1213 (25.2)
Not known	813 (16.8)
Total	4815
Age:	
65–74	738 (15.3)
75–84	1925 (40.0)
85–90	1305 (26.3)
91–95	641 (13.0)
96–100	172 (5.0)
101–108	34 (0.7)
Total	4815
Ethnic Group:	
White British	3798 (78.9)
Ethnic minority	47 (1.0)
Not known	970 (20.2)
Total	4815
SIMD:	
1 (most deprived)	2652 (55.1)
2	885 (18.4)
3	403 (8.4)
4	309 (6.4)
5 (least deprived)	329 (6.8)
Not known	237 (4.9)
Total	4815
Living Group:	
Living alone	2241 (46.5)
Living with another pensioner	908 (18.8)
Living with other people	346 (7.2)
Not known	1320 (27.5)
Total	4815
Intended visits per week	
1–7 visits	1579 (32.8)
8–14 visits	1305 (27.2)
15–21 visits	767 (15.9)
22–28 visits	1085 (22.5)
29–35 visits	79 (1.6)
Total	4815

Key: SIMD Scottish Index of Multiple Deprivations

The total study population ($n=4815$), within the three-month study period, comprised twice as many women than men. Further data show that a further 137 women were aged >95 years with 25 women aged >100, the oldest being 108. In comparison, the majority of men 541 (44.6%) were aged between 75 and 84 years with a gradual reduction in the number of men in all age categories thereafter, with only two men >100, the oldest being 104. This reflects the longevity advantage that women have over men. Service users' mean age was 83 years. Overall, the mean age across both genders was 83 years.

For the 3845 service users whose ethnicity was known, all but 47 (1%) were white British. Almost half, 2241 (46.5%), of the study population lived alone, and over half, 2652 (55.1%), lived in the most deprived areas of Greater Glasgow and Clyde (SIMD 1). The SIMD (2016) deprivation category is a postcode measure derived from multiple aspects of deprivation, including employment, income, health, education, access to services, levels of crime and housing. SIMD is a ranking based on the full postcode, with category 1 = most deprived, and category 5 = most affluent (SIMD 2016).

Deprivation is associated with a lack of resources and opportunities, poor health and low income. No data were available on diagnosis or co-morbidities, which could have provided a more comprehensive view of service user needs.

With a maximum of 35 intended homecare visits per week available, 1579 (32.8%) had between one and seven visits a week, while 79 (1.6%) had between 29 and 35 visits per week, with the mean number of visits being 16. There were incomplete data entries: for 17 percent, gender was left blank; for 20 percent, ethnicity was left blank; for 27 percent, living group status was left blank; but SIMD characterisations were unavailable for only five percent. Collectively, this represented a notable incompleteness of data.

Having established the characteristics of those within the study population with or without non-delivery, Table 3 shows the proportion of people with incidence of No Access (NA) or Service Refusal (SR) combined, as well as NA only and SR only.

Table 3: Proportion of people with incidence of non-delivery (NA or SR)

(Sept, Oct, Nov) Incidence	NA/SR combined People <i>n</i> (%)	NA People <i>n</i> (%)	SR People <i>n</i> (%)
All care received	3211 (66.7)	3404 (70.9)	4388 (91.1)
1 NA/SR	1203 (25.0)	1099 (22.8)	347 (7.2)
2-3	191 (3.9)	150 (3.1)	42 (0.9)
4-5	96 (1.9)	79 (1.6)	15 (0.3)
6-10	66 (1.4)	47 (0.9)	16 (0.3)
11-20	32 (0.7)	26 (0.5)	4 (0.1)
21-50	13 (0.3)	7 (0.1)	3 (0.1)
51-100	3 (0.1)	3 (0.1)	0 (0.0)
Total	4815 (100.0)	4815 (100.0)	4815 (100.0)

The first row, illustrated in green, demonstrates the numbers of people and percentages of those who had received all care planned for them. The first column (far left) shows the incidence of NA or SR over the three-month study period.

The second column shows the proportion of people with at least one incidence of either NA or SR. The third column shows the proportion of people with at least one incidence of NA only. The fourth column shows the proportion of people with at least one incidence of SR only.

The first row (presented in green) shows that 3211 people (66.7%) received all the care that had been planned for them, leaving 1604 older people (33.3%) with at least one incidence of non-delivery of care (NA or SR). The second column shows that a quarter ($n=1203$) of the older people (25.0%) had one incidence of non-delivery and 191 older people (3.9%) had between two and three incidence of non-delivery. Thereafter, this trend continued, whereby fewer older people accounted for higher frequencies of non-delivery.

The third column shows that 1099 older people (22.8%) had one incidence of NA and 150 older people (3.1%) had between two and three incidence of NA. As before, a trend continued whereby fewer older people accounted for higher frequencies of NA. The fourth column shows that 347 older people (7.2%) had one incidence of SR and 42 older people (0.9%) had between two and three incidence of SR. Again, a trend continued whereby fewer older people accounted for higher frequencies of SR.

In summary, the majority of older people in this three-month sample received all care planned for them. For those who had experienced non-delivery, whether NA, SR, or both, most had experienced only one incident. High incidence of non-delivery occurred for the very few, with, for example, one older person having 44 incidences. The maximum number of care visits a day is five. Therefore, recorded missed visits could represent only a portion of one day. Although the problem of very high incidence of non-delivery existed for a few older people only, it has to be taken into account that the number of instances of non-delivery depended on the number of planned deliveries.

Using SPSS (Statistical Package for Social Sciences) for Windows, the database was further interrogated to establish the characteristics of service users with either NA or SR. A record of 'not known', or where the data were missing, was due to the incompleteness of the homecare data. The following table (Table 4) shows socio-demographic data for older people within the study population of 4815 people with incidence of NA ($n=1411$), and people with incidence of SR ($n=427$), with three times as many documented incidence of NA (29.1%) than SR (8.9%). The former was three times as many as the latter.

The data helped to reveal whether there were differences of non-delivery by gender, age, ethnic group, SIMD, living group and visit frequency.

Table 4 illustrates the number (n , %) of people with at least one NA or SR. The second and third columns show the socio-demographic characteristics of people with either, NA and SR, respectively, with percentages of the total number for that demographic group.

Table 4: Socio-demographic characteristics of people experiencing non-delivery (NA and SR)

Socio-demographic Characteristics	People with both NA and SR	People with at least 1 NA	People with at least 1 SR
Gender:	<i>n</i>	<i>n</i> (% of population)	<i>n</i> (% of population)
Female	2789	899 (32.2)	264 (9.4)
Male	1213	457 (37.7)	136 (11.2)
Not known	813	55 (6.8)	17 (2.0)
Total	4815	1411 (29.3)	427 (8.9)
Age:			
65–74	738	250 (33.9)	74 (10.0)
75–84	1925	580 (30.1)	181 (9.4)
85–90	1305	373 (28.6)	110 (8.4)
91–95	641	161 (25.1)	51 (8.0)
96–100	172	42 (24.4)	8 (4.7)
101–108	34	5 (14.7)	1 (3.0)
Total	4815	1411	427
Ethnic Group:			
White British	3798	1113 (29.3)	333 (8.8)
Ethnic minority	47	14 (29.8)	4 (8.5)
Not known	970	284 (29.3)	90 (9.3)
Total	4815	1411	427
SIMD:			
1 (most deprived)	2652	786 (29.6)	228 (8.6)
2	885	266 (30.0)	69 (7.8)
3	403	104 (25.8)	40 (10.0)
4	309	88 (28.5)	24 (7.8)
5 (least deprived)	329	89 (27.0)	43 (13.0)
Not known	237	78 (40.0)	23 (9.7)
Total	4815	1411	427
Living Group:			
Living alone	2241	715 (32.0)	224 (10.0)
Living alone with another pensioner	908	208 (23.0)	68 (7.5)
Living with other people	346	89 (25.7)	27 (7.8)
Not known	1320	399 (30.2)	108 (8.1)
Total	4815	1411	427
Visit frequency per week:			
1–7 visits	1579	282 (18.0)	89 (5.6)
8–14 visits	1305	468 (36.0)	112 (8.6)
15–21 visits	767	278 (36.2)	97 (12.6)
22–28 visits	1085	361 (33.3)	122 (11.2)
29–35 visits	79	22 (27.8)	7 (9.0)
Total	4815	1411	427

The following section provides an analysis of the findings for these socio-demographic characteristics, as they correspond with the likelihood of non-delivery.

3.3.2 Patterns of non-delivery by patient characteristics

Gender: Men were more likely than women to have non-delivery of homecare services. The proportion of men (37%) experiencing at least one incidence of NA was greater than the proportion of women (32%) experiencing at least one NA. With incidence of SR, the same trend applies.

Age: The likelihood of non-delivery reduced with increasing age. In the age group 65–74 years, 34 percent of people had at least one NA. Thereafter, the proportion decreased with increasing age. In the age group spanning 65–95 years, 8–10 percent had at least one SR. Figures for those in the older categories were lower (5% and 3%).

Ethnic group: The likelihood of having non-delivery was approximately the same across both ethnic groups. The results by ethnic group showed that 29 percent of white British people had experienced at least one NA. Likewise, 29 percent of people from ethnic minority groups had experienced at least one NA. Similarly, eight percent of people from white British groups and eight percent of people from ethnic groups had experienced at least one SR.

SIMD (Scottish Index of Multiple Deprivation): It was difficult to determine a relationship between SIMD and incidence of non-delivery. In every quintile, between 27–30 percent experienced at least one NA, with the people within the higher figures (29–30%) living in the most deprived areas (SIMD 1 and 2). By comparison, in every quintile, between 7–13 percent experienced at least one SR, with the people within the higher figure (13%) living in the least deprived area (SIMD 5).

Living group: The likelihood of having non-delivery of care was greater for those who lived alone. Almost one-third of those who lived alone had at least one NA. A similar pattern was found for SR, whereby 10 percent of those who lived alone had experienced at least one SR, compared with 7–8 percent of those who lived with another.

Visit frequency: The likelihood of having non-delivery of care was greater for those who had between 15 and 21 visits per week. A smaller proportion (18%) of those with fewer visits per week (1–7) had experienced at least one NA compared with between 28–36% of those with greater numbers of visits. In the case of SR, a similar picture applied.

The above results established that the likelihood of non-delivery varied by socio-demographic characteristics. This information helped to build up a profile of those who were most likely to experience non-delivery, information that could alert care workers early to prevent non-delivery of planned care in future. The small variations in the data suggested that those most likely to experience non-delivery were male, aged between 65 and 74 years, who lived in the most deprived areas (SIMD 1 and 2), lived alone and received between 15 and 21 care visits a week. Alternatively, and reassuringly, those in the older age groups who had a greater need for care were actually receiving it.

Incidences of NA were greater than those for SR. Although both were of concern, reports of NA initiated a follow-up procedure to ensure service user whereabouts and safety. Further explanatory text in home data records provided an opportunity to delve into some of the reasons for NA and SR. In order to do this, ten-percent randomly selected sub-samples of all incidence of NA and SR were created. Random selection from the study population provided an equal opportunity for study inclusion, which is a particularly valuable strategy to adopt when dealing with large numbers (Creswell 2014).

3.3.3 Reasons for no access (incidence)

A ten-percent randomly selected sample of 417 incidences (not individuals) of NA was created from 4170 incidences (not individuals) of NA. To quantify the results, a number was allocated to each reason and sub-categories of reasons and converted into percentages. These results, based on the categories I defined, are presented in a bar chart below (Figure 4).

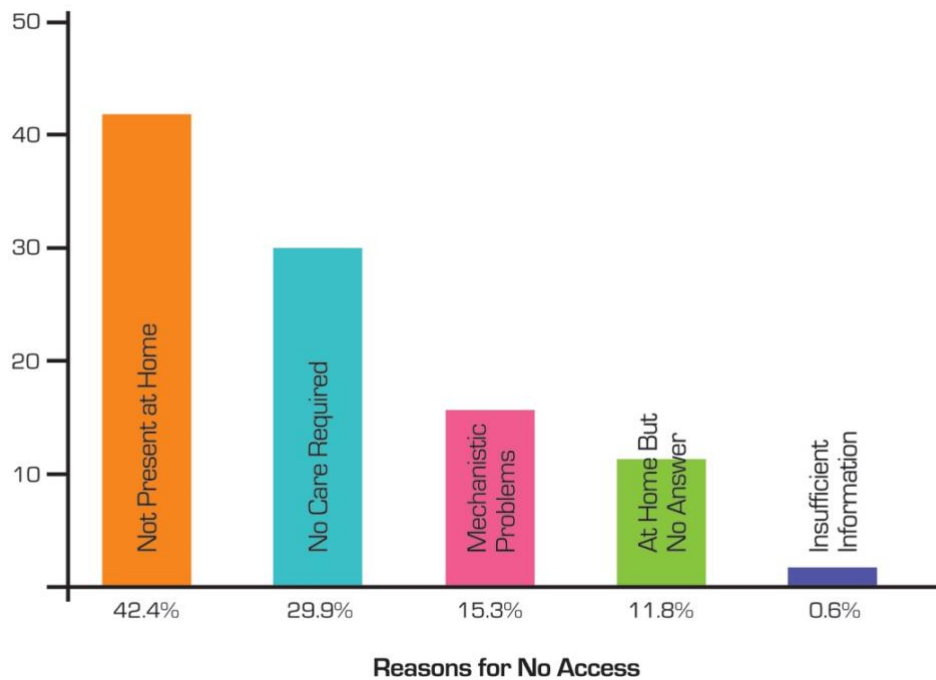


Figure 4: Reasons for No Access in 10% of randomly selected cases

Figure 4 illustrates the five main reasons for NA. ‘Not Present at Home’ represents the largest theme (42.4%). ‘No Care Required’ accounted for 29.9 percent of NA. Arguably, if care workers knew that no care was required, this should then have been recorded under ‘service refusals’. ‘Mechanistic Problems’ (15.3%) included problems with the phone, doorbell, buzzer or key safe system, affecting the carers’ ability to contact service users or gain access to the home. The key safe system relates to the key to the service user’s home being left in a safe place, available to the carer. ‘At Home, But No Answer’ accounted for 11.8 percent of NA, where the service user was in the house but, for various reasons, did not know that the carer was attempting to gain access. The reasons given included: not hearing the phone, doorbell, knock on the door or buzzer; being asleep; being upstairs; and, occasionally, not being well. The smallest theme, ‘Insufficient Information’ (0.6%), represented where there was not enough information in the records to establish the reasons for NA. A report of NA automatically initiated further investigation into the reasons for it in order to establish the whereabouts of the service user. These sub-categories are illustrated below in Figure 5.

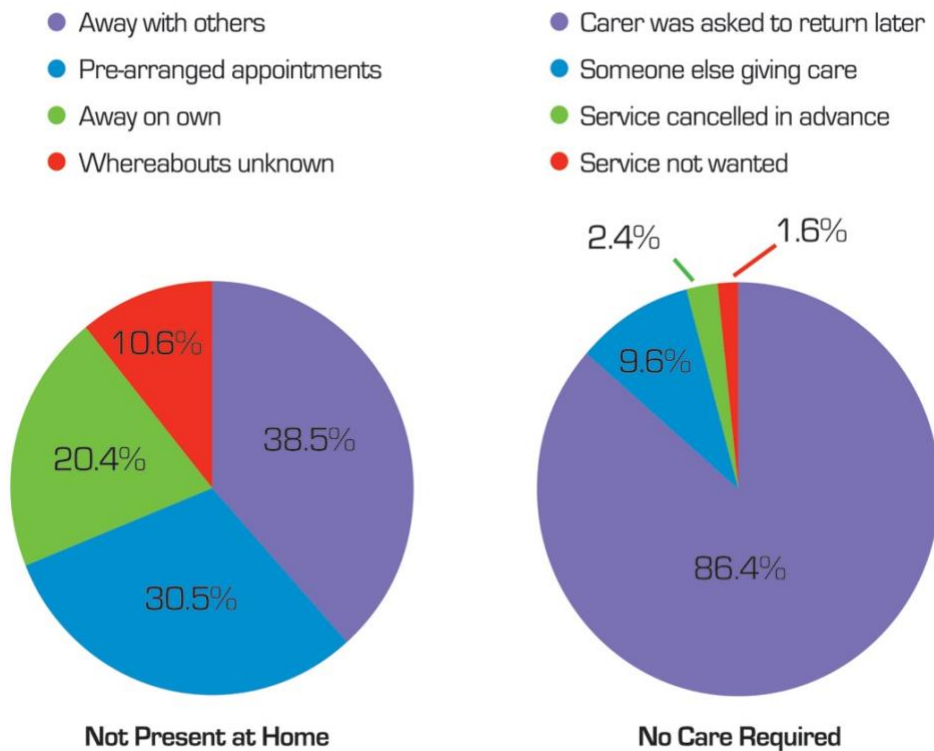


Figure 5: Sub-categories within Not Present at Home and No Care Required

Figure 5 illustrates the sub-categories within two main reasons for NA; ‘Not Present at Home’, and ‘No Care Required’. ‘Not Present at Home’ was sub-divided into four sub-themes; ‘Away with others’ (38.5%), ‘Pre-arranged appointments’ (30.5%), ‘Away on own’ (20.4%), and ‘Whereabouts unknown’ (10.6%). Pre-arranged appointments at the GP, hospital and chiropodist, if known by the carer in advance, should not initiate an access attempt, whereas it was possible that being away by themselves or with others may not have been pre-planned. There was nothing in the records to establish the whereabouts of a small percentage of service users. ‘No Care Required’ was likewise sub-divided into four sub-categories, as follows: ‘Carer asked to return later’ (86.4%), ‘Someone else giving care’ (9.6%), ‘Service cancelled in advance’ (2.4%), and ‘Service not wanted’ (1.6%). A family member more often than the service user requested that no care was required at that time and that the carer was to return later to provide care. A small percentage (2.4%) of service users had cancelled the service in advance, but this message had not been received by the carer. Where the care service was not wanted, no further reasons were available.

The data were explored within the category they were assigned to. However, it was clear that some of the reasons given for NA should have been documented under reasons for SR instead.

3.3.4 Reasons for service refusal (incidence)

Following the same process as conducted with the NA data, a ten-percent randomly selected sample of 96 incidences (not individuals) of SR, and any reasons given were created from 960 incidences (not individuals) of SR. To quantify the results, a number was allocated to each sub-category and then converted into percentages. The proportions of the reasons for SR are represented in a bar chart (Figure 6).

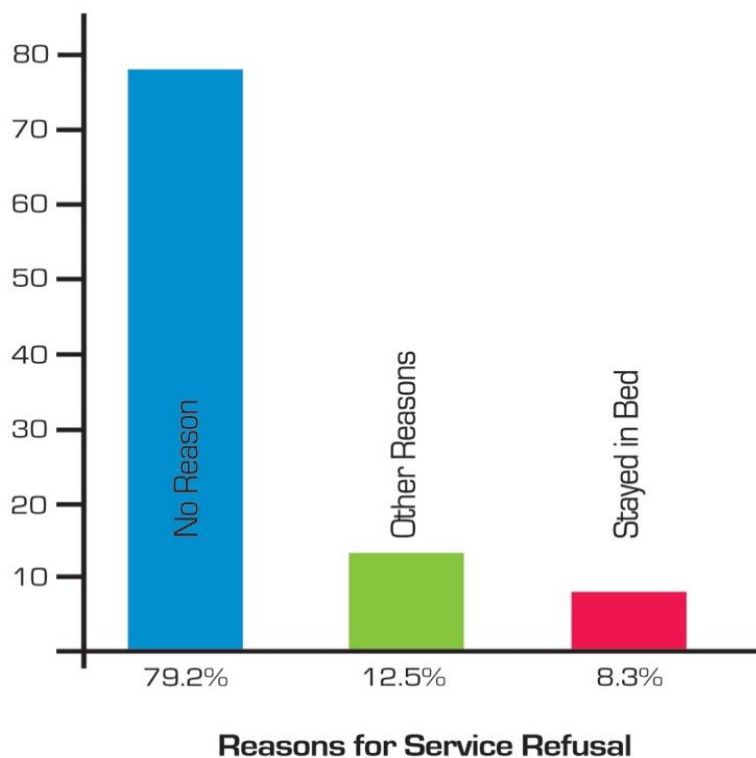


Figure 6: Reasons for Service Refusal

Figure 6 illustrates there were 'No Reasons' available for SR in 79.2 percent of reported incidences. However, 'Other Reasons' were given for 12.5 percent of reported incidences, including going to the pub, going to mass/church, waiting for a taxi, carer too late, able to care for themselves, and not needing care at that time. The remaining 8.3 percent of incidences of SR were due to service users who wished to 'Stay in Bed'. It was evident that care workers had differing interpretations of NA and SR.

Apart from reasons for non-delivery, other concerns were documented. For instance, on two occasions, help was sought from the next of kin because meals had been repeatedly refused, with one individual refusing breakfast for a week. On three occasions, carers were actively refused entry into the home. One spoke to the service user through the door, one pushed the care worker away and one jammed their foot in the doorway to prevent the carer entering their home.

In summary, the analysis identified the extent of non-delivery of homecare for people aged 65 years and older and described the characteristics of those who are most at risk of non-delivery of homecare. Further explanatory data helped to establish some of the reasons for non-delivery of homecare services. Reasons for NA were identified, but reasons for SR were unclear. Category ambiguity, and missing, incomplete and inconsistent explanatory data, hindered the analysis

3.4 Discussion

This discussion section focuses on the process involved in data linkage. The findings and quality of the data generated from the homecare service provider are deliberated and recommendations to improve service uptake are made. The benefits of service user involvement in research are considered, and the strengths and limitations of this study are highlighted. Finally, the findings from Study 1 are explored in relation to how they emphasised the need for further qualitative research to explore the reasons for non-delivery in more critical depth, while foregrounding the service user perspective.

Despite the recent legislation and policy reform, information sharing between health and social care agencies in the UK using data linkage techniques is in its infancy (Maguire et al. 2018). Increasingly, data linkage techniques have been utilised across dissimilar data sources with various linkage success rates (Karmel and Rosman 2008; Bardsley et al. 2012). Innovatively, this linkage study was the first time that linkage had been attempted in Scotland between data from this particular homecare service provider and a healthcare dataset, and the chosen variables and their subsequent analysis was a hugely successful endeavour. As a new resource, the success rate of the data linkage process carried out in Study 1 is an outcome that will be of some note and interest to future adult social care linkage projects.

The analysis of the data identified the extent of non-delivery of homecare for people aged 65 years and older and described the characteristics of those who are most at risk of non-delivery of homecare. Further explanatory data helped to establish some of the reasons for non-delivery. Reasons for NA were identified, but reasons for SR were unclear. In addition, category ambiguity, and missing, incomplete and inconsistent explanatory data, hindered the analysis process.

Extent of Non-Delivery:

The initial analysis process in Study 1 demonstrated that two-thirds of service users aged 65 and older received the homecare for which they had been assessed. For the remaining third, the problem of high incidence of non-delivery existed for a few people only. In particular, one person had 44 incidences of non-delivery. For those with non-delivery there were three times as many documented incidences of NA than SR, creating a problem for care workers establishing the whereabouts of potentially vulnerable people.

As each service user could have up to five homecare visits each day with a maximum number of possible visits at 35 per week, each incidence of non-delivery may only be a proportion of one day. From the study population, 25 percent of service users had just one incidence of non-delivery over the three-month period. Thereafter, a downward trend in both NA and SR categories continued, with fewer numbers of people accounting for larger incidence of non-delivery. A reassuring correlation existed between people with high numbers of weekly visits and less incidence of non-delivery, as demonstrated in Table 4. This suggests that those with more complex needs, requiring a high care package, received all their care.

Explanatory text, recorded by care workers following each visit, helped to establish some of the following reasons for non-delivery.

Reasons for No Access:

Explanatory text attached to most of the NA records indicated that the majority of the reasons for NA were because service users were not at home when the delivery of care was attempted (service users were out on their own, out with others, pre-arranged appointments or whereabouts unknown). Of particular concern was that no care was

delivered for 125 attempted visits during the entire study, with service users' whereabouts unknown and with no record of any follow-up procedure. Better communication between care worker and service user could have prevented unnecessary concerns for the safety and wellbeing of missing service users. Lesser problems involved system failures, such as door bells not working, which meant that people were at home, but that they could not hear the door bell ringing.

The second most prevalent reason was that the service user did not require care at that time. A wasted journey could have been avoided when the carer was asked to return later, someone else was giving the care, the service was not wanted, or the service had been cancelled in advance. The latter was a failure of communication within the organisation. Although a small percent of service users stated that 'Someone else was giving care', it was not known whether service users within the 'No Care Required' category were receiving care from others and that was why they did not require care at that time. Mechanistic problems were unavoidable but, once identified, easily rectified.

Reasons for Service Refusals:

From the 96 incidences of SR, there was no explanatory text available to establish why in 79 percent of cases. Perhaps this was due to carers not asking the reason why, or perhaps because it was deemed unnecessary as long as service users' whereabouts were known. Either way, this represented a distinct gap in the knowledge. The next category represented miscellaneous one-off reasons for SR, while a small but significant group of reasons pertained to the service user staying in bed (8%). Earlier than expected visits could have contributed to this finding, with a concern that leaving potentially vulnerable people alone, without delivery of care, could have negative health implications.

Categories of Non-Delivery:

At this point it is worth reiterating that the categories of NA and SR are specific to this particular homecare service provider. Other organisations may have a different system of documenting non-delivery. Reports of NA were made when care workers were unable to access the service user at the planned place of care delivery. SR was reported when the service user refused care at the point of delivery. Each category was analysed separately. However, there was an overlap of information within these categories, with

reports of NA which should have been recorded in the SR category and vice versa. This made it difficult to accurately assess the incidence in both categories.

Another concern pertained to reports of non-delivery where no explanatory text was provided. The analysis revealed this to be the case in over three-quarters of the reasons for SR, requiring further investigation. Reasons for NA were only known once the service users' whereabouts had been established, in other words, after follow-up. Alternatively, all those who refused care did so at the point of delivery or before. A particular concern was for those whose whereabouts were unknown, which initiated an often time-consuming investigation to ensure their whereabouts and safety. Adopting a better system of documentation would help ensure a standardised system to guide practice.

Clearly, it was difficult to establish accurately the problem of non-delivery from the data. What was revealed suggests that the extent of non-delivery was not as great a concern as anticipated by the homecare service provider, with only a few service users accounting for a large incidence of non-delivery of homecare. Because the incidence of NA was greater than SR but with little to differentiate between the two categories, caution is required when making assumptions regarding the extent of and reasons for non-delivery within their respective categories.

Conversely, the analysis and development of the typology of those most at risk of non-delivery of homecare was more robust. Out of a study population of 4815 service users, the small variations in the data reveal that those more likely to experience non-delivery were male, people aged between 65 and 74, and those with between 15 and 21 scheduled visits per week. It was perhaps not surprising that those with fewer visits had fewer incidences of non-delivery. There was a 10 percent higher proportion of NA among those who lived alone than if they lived with another, suggesting that those who lived alone should be closely monitored to ensure their needs were met. Further research on the reasons for NA would help to prevent potentially vulnerable people living alone who are not receiving care. In addition, the likelihood of NA was higher among people who lived in the most deprived areas (SIMD 1 and 2). However, the likelihood of SR was higher among those who lived in the least deprived areas (SIMD 5), with limited information to substantiate the reasons for this in 79 percent of cases. In particular, 40 percent of SIMD entries were unknown for incidence of NA, and 30

percent of living group entries (whether they live alone or with others) were unknown, representing a significant limitation for data analysis.

According to SIMD (2016), Glasgow has 13 of the 20 most deprived areas in Scotland, with Glasgow City being the most deprived in all categories. Although there had been a gradual reduction in deprivation of late, there remained a noticeable relationship between areas of high deprivation and the prevalence of long-term health problems and disability, with people living in these areas being twice as likely to report ill-health (SIMD 2016).

As requested, the homecare service provider was provided with a report which identified that the extent of non-delivery of homecare was not as great a concern as they had anticipated, and that, reassuringly, most had received all the care planned for them. Suggestions that were made to the homecare service provider, arising from this research, included ensuring that socio-demographic data are fully documented to initiate easier linkage for future projects. Other recommendations I made comprised the design and production of an operational manual to guide daily practice, including a revised system of coding non-delivery that better reflected NA and SR and a standardised follow-up procedure in the event of non-delivery. Care workers trained in record-keeping and being part of research to improve service-user satisfaction would motivate care workers to ensure complete and consistent documentation. In addition, it was recommended that improved communication with service users and their families could also potentially prevent unnecessary visits and time-consuming follow-ups to establish the safety and whereabouts of individuals. Finally, it was suggested that knowing the key characteristics of those most likely to experience non-delivery would enable close monitoring of those who are most at risk of non-delivery, thus ensuring that care is delivered to those who needed it.

Service user involvement:

Service user involvement was intended to be a central part of this research (Dewar 2005; Douglas et al. 2018; INVOLVE 2020). The study design included soliciting the views and opinions from service users about the value of the study and to inform the research process. The intention was to invite a group of service user representatives to participate in a steering group alongside care workers and other interested parties. However, a caveat within the data-sharing agreement prevented the use of data to

identify and recruit older people from the linked study onto a steering group. Using the homecare data to actually identify and recruit people with high levels of non-delivery required a whole different layer of ethics and governance. Glasgow City Council had their own concerns about including service users within a steering group, with concerns that this may be seen as tokenistic, with a perceived imbalance of power between service users and service providers (Dewar 2005). Moreover, they felt that the use of organisational language and jargon could have an impact on their level of understanding (Dainty et al. 2007).

There is evidence to support the benefits of service user participation in every aspect of the research process, from informing the design of the study to the evaluation and validation of the results (Dewar 2005; Douglas et al. 2018; INVOLVE 2020). Cowdell (2008) advocates the usefulness of actively engaging older people in the research process, even if they are cognitively impaired. From the service user perspective, the greatest driver to participate is the motivation to ‘have their say’ on matters that could directly affect them (Dewar 2005). Moreover, service user involvement in research has been welcomed for the development of health and social care policy (Douglas et al. 2018). The NHS National Institute for Health Research has developed a framework for good practice for promoting meaningful public involvement in research (INVOLVE 2020). One of the principles, in practice, advocates the inclusion of at least two public members as key partners throughout the research process, including being on steering groups. Moreover, public involvement opportunities should be made accessible to all, including people from diverse, hard-to-reach groups, providing that the relevant information is free of acronyms and devoid of jargon.

For the above reasons and with Glasgow City Council permission, I approached a day centre, within the same region where the data was drawn for the qualitative study, to initiate a lay-user discussion group. Initial contact was made by phone with the day centre manager to establish the likelihood of service user participation. In all, five women, aged 65 and older who had received homecare, agreed to participate in a one-off discussion to comment on the scope of the research. Following a brief introduction of the study aims and objectives, it was established that all five individuals consented to continue as part of this discussion.

The participants in this discussion were posed an open question; ‘*What are your views of the research we are doing?*’ and invited to comment. The discussion group agreed that the research was of value. There was consensus that most people might have to have homecare at some time, but their focus was more on the importance of remaining independent and the participants viewed homecare as a way of achieving this. They did, however, acknowledge the importance of being provided with the right type of homecare, for instance, care that meets their needs. They proceeded to tell their own stories, whereby the care delivered was not always what they expected, including late visits. No one disclosed any incidence of service refusal. Initially, the process of data linkage was explained in as plain a language as possible. However, it was evident that they found the concept confusing. Thereafter, I tried to offer clarification by asking whether they understood and if they had any questions. No comments or objections were made regarding the linkage process, and there were no concerns regarding client confidentiality. On reflection, although I attempted to simplify the explanation of data linkage, a lack of interest or understanding in the linkage element of the research process was observed. This perhaps reflected the views of those who felt it was tokenistic to ask them. However, I believe their contribution to the process of the study was invaluable, and that the participants appreciated being a part of a study that could help improve care for themselves or others.

Another researcher (my supervisor) helped facilitate the discussion with me. At regular intervals, we summarised what had been said and sought clarification of understanding from participants. Notes were taken after the discussion to avoid distracting the flow of the conversation and results corroborated between us (Appendix 7). Likewise, the session was not recorded to keep it as informal as possible. The aim of the discussion group was to obtain the views of those who could likely appreciate the impact of this research on those participating. Moreover, the INVOLVE (2020) organisation recognises the importance of including Patient and Public Involvement (PPI) in research that in some way affects them. In order to monitor the wellbeing of group members, the day centre manager remained present but inconspicuous throughout the discussion. As she knew them well, the manager was alert to any signs of distress or tiredness in the discussion group participants. The meeting adopted an informal tone, with refreshments provided, and took one hour to complete.

Data linkage:

This quantitative study successfully linked data between two previously unlinked datasets with a 94.5 percent success rate. The homecare service provider, University of Stirling and Glasgow City Council had not collaborated on a joint research project before. Ethics approval from the University of Stirling, School of Health Sciences was granted quickly. In contrast, joint approvals and permissions to link data proved to be complex and time-consuming and took two years to complete, due to the necessity to develop a suitable data sharing protocol, upon which all parties agreed, and one where everyone was represented equally. The University of Stirling funded the homecare service provider to prepare the data in readiness for linkage and made remunerations to the Glasgow Safe Haven to perform the linkage. One of the reasons for conducting the data linkage was to remove all those from the study population who had been in hospital during the three-month study period from the data analysis. Further removal of all those under the age of 65 years provided a sample of people with and without incidence of non-delivery.

As is common practice within other data linkage studies (Bardsley et al. 2012; Witham et al. 2014; Porter and Morrison-Rees 2015), time was taken to tidy up the homecare data to make them ‘research ready’. Inconsistent and missing entries were a concern, and poor grammar and spelling in the detailed records proved to be a barrier to understanding certain aspects of the reasons for non-delivery of homecare services. Providing homecare service staff with training on the benefits of recording high-quality data for research is likely to provide improved data submissions and less complicated linkage possibilities in future (Witham et al. 2014).

Although in its relative infancy, data linkage techniques are increasingly used across health and social care datasets with various linkage success rates. For example, an English study used a range of health and social care databases to determine the proportion of older people who accessed hospital and social care with a linkage success rate of between 78 and 95 percent (Bardsley et al. 2012). Witham et al. (2014) documented the process of data linkage between health and social care datasets, using CHI numbers to initiate linkage with a 99.8 percent linkage success rate. A later study used data linkage to explore the correlation between social care and admissions to hospital in Wales with a match rate of 91 percent (Porter and Morrison-Rees 2015).

Data linkage is not without its problems and controversies. Disagreement over privacy issues has identified concerns relating to breach of confidentiality and security (Flowers and Ferguson 2010; Douglas et al. 2017) versus the view that data linkage conserves patient privacy (Holman et al. 2008). These concerns justified the time needed to carefully consider and debate the ethical implications of the data linkage process in this study and to obtain the necessary approvals and permissions to ensure anonymity. Linkage projects rely on using a set of common identifiers between two datasets. Concurrent with another study (Maguire et al. 2018), data linkage proved to be problematic in the absence of CHI numbers being attached to the homecare data, preventing the use of a computer-generated algorithm. Therefore, the process of linkage relied on manually linking the data between these two datasets. In spite of this issue, it was reassuring that a 94.5 percent linkage success rate was achieved.

3.4.1 Strengths and limitations

Strengths: To my knowledge, this was the first study to utilise data linkage in order to explore non-delivery of planned homecare for people aged 65 and older in Scotland. Likewise, this was the first time that data linkage techniques had been used between these two datasets. This study has shown that it is feasible to record-link health and social care data for a small well-defined project. Although approvals were time-consuming to obtain, the data linkage process was fairly straightforward, involving the probabilistic allocation of CHI numbers to social data and then the deterministic linkage of that data to SMR01 data that were already CHI indexed. In spite of the problems associated with linkage, for this study, the 94.5 percent success rate indicates that this was a worthwhile undertaking. The results also suggest that there is a potential for future linkage projects.

Working remotely, anonymous data were interrogated and the extent of non-delivery within a three-month timeframe was identified. The results of this study identified patterns of non-delivery, which revealed that the majority of older people received all the care that had been planned for them. In particular, older people and those with more frequent weekly care visits were less likely to experience non-delivery of care. The identification of the characteristics of those most likely to experience non-delivery can therefore enable close monitoring of those at risk of non-delivery.

Patient and Public Involvement was enhanced by the inclusion of those within the steering group and the service user involvement group to establish the parameters of the research and to keep the study on track. The explanatory text provided some of the reasons for non-delivery which, although limited, pointed towards the need for further qualitative research to explore critical reasons for non-delivery in more depth. The findings of this study, presented here, are an accurate reflection of the data available from this three-month sample based on the data provided.

My preliminary analysis of the quantitative data in the linkage presented an opportunity to further interrogate the data while the dataset was available to assess whether a link exists between non-delivery of homecare and emergency hospital admissions. Building on my earlier analysis, my primary supervisor, who has extensive experience in complex statistical analysis, used case-control methodology to determine whether non-delivery was a risk factor for hospital admission. In the logistic regression analysis, those who had an emergency hospital admission in the calendar month following the study period were identified, and, after controlling for age and gender, and using emergency hospital admissions as the dependent variable, non-delivery was found to be a risk factor. My initial findings from the quantitative linked study (Study 1), and the extended study completed by my primary supervisor, were published in the online journal, *Quality in Ageing and Older Adults* (Evans et al. 2019). While the findings of this further analysis did not contribute directly to responding to the research questions in my thesis, they do strengthen the concern for non-delivery of homecare and its associated negative health implications.

Limitations: This study was restricted to older people with no hospital admission. Arguably, this population ($n=4815$) may be healthier and less vulnerable than those who were removed from the sample ($n=1944$), as they had not required hospitalisation, and this represents a key study limitation. The initial premise of performing data linkage between this particular social care dataset and a healthcare dataset was to identify and remove all of those participants whose non-delivery was due to being in hospital, thus identifying a population of people whose homecare visits were relatively stable. However, if, as demonstrated in Evans et al. (2019), non-delivery of homecare is a risk factor for hospital admissions, then the removal of people within this sub-sample from the study could lead to an underestimation of the incidences of non-delivery and

therefore represents a study limitation. Alternatively, inclusion of this sub-sample as they moved in and out of hospital over the three-month time-period would have provided a prime opportunity to identify more people with incidence of non-delivery and could have initiated a fuller discussion of non-delivery of homecare.

Time was an issue: in the quantitative study, obtaining ethical approval and permissions, ones that represented all stakeholders equally, proved time-consuming and costly. As a particular concern, maintaining client confidentiality required resolution. Having completed this once, the development of future research protocols may be less time-consuming and thus less costly. Likewise, it was time-consuming to tidy up the data in readiness for linkage, as incomplete and inconsistent care worker documentation following each attempted visit resulted in large amounts of missing data. More time was needed than anticipated to plan and deliver research involving people from hard-to-reach groups. Specifically, a large amount of time was needed to develop successful relationships with participants and gatekeepers.

The study population was drawn from one large homecare service provider that provides the majority of homecare to older people in one major City Council. Therefore, it is questionable whether the findings from this study resonate with other organisations providing care or whether they are transferable to other settings. However, the intention in Study 1 was not to generalise the findings, but to establish the patterns of non-delivery for this one particular service provider. Although the numbers of participants included in this study were large, the timeframe, over three months, provided a snapshot of non-delivery. Future research over a longer period of time could ascertain whether the patterns identified are concurrent with those observed in this study.

Approvals required to link and access anonymous record-linked data proved to be time-consuming and complex. Permissions were required from the University of Stirling, the homecare service provider and Glasgow City Council. Glasgow Safe Haven had existing standards embedded in their operating procedures, thus the lack of a common identifier between both datasets relied on other means of data linkage. Although the end result yielded a successful match percentage, had there been a more consistent approach to recording homecare data, linkage techniques using algorithms would have speeded up the linkage process. As such, there are wider implications of this data-linking exercise, as my experiences of the process, and the results, indicate that better methods

for maintaining accurate databases in the social care setting should be designed in collaboration with the organisations who maintain national databases, such as SMR01. Collaborative cross-agency working and accurate and consistent data entry is crucial for facilitating the linkage of meaningful datasets in order to provide accurate platforms on which research can be conducted. Ultimately, this would inform care services and improve the integration of health and social care. Training care workers to be well-versed in data recording, storage and transfer would ensure that data was ‘research ready’ in preparation for future data linkage projects (Witham et al. 2014).

Care workers are required to record electronically the outcome of each visit made. However, this was not always the case. Missing and incomplete data hampered analysis due to category confusion. Designing a more distinct coding system will provide clarity and avoid ambiguity of the terms for non-delivery. Non-delivery was categorised as NA or SR where a care worker attended but did not deliver care. In practice, there was no clear distinction between them. However, NA were greater in number than SR, which initiated a time-consuming and costly investigation to establish the whereabouts of ‘missing’ service users. For those with high levels of SR, there was little explanatory evidence available to establish the reasons why. Instances where visits that were missed entirely due to non-attendance by the care worker were not recorded and their frequency remained unknown. This absence of information in the records indicated that further research was necessary to determine the reasons so as to inform how the homecare service provider might minimise the number of undelivered visits.

Finally, it is worth considering whether non-delivery is associated with certain health conditions. Access to clinical diagnosis and co-morbidity could have provided the means to establish a link with health status and reasons for non-delivery.

Validity is a concept that is judged by how accurately the findings reflect the data or whether the research actually measured what it intended to measure (Polit and Beck 2012). In part, therefore, validity relies on the accuracy and completeness of the data provided for linkage and the corroboration of findings throughout the process of generating codes and analysis. Future research involving this particular homecare provider would benefit from having access to data that are ‘research ready’, including better standardisation of NA and SR categories.

Even considering the inconsistency of the data obtained from the homecare dataset, the findings revealed enough information to identify that the problem of non-delivery was an issue for a few people only. Had it been permitted, the voice of service users within a steering group would have brought greater validity to the research, which was for them and about them. This quantitative study answered part of the overall research question, but failed to identify fully the reasons for non-delivery. In addition, what was known came from only the care worker perspective. This provides further justification for the conducting of a qualitative study to explore in more depth the reasons for non-delivery while foregrounding the service user perspective.

3.5 Chapter Summary

Informal conversations with a large homecare service provider revealed concerns for an increasing incidence of non-delivery of homecare where older people were not at home when their care was due and where care was refused at the point of delivery. With their concerns for service provision and for service user wellbeing, my research was welcomed to identify the extent of non-delivery and the characteristics of those who are most at risk of non-delivery of homecare.

This quantitative study proved to be valuable. However, the research identified significant gaps that required further investigation. A qualitative exploratory study provides the opportunity to research in-depth the problem of non-delivery by asking the views of service users in receipt of homecare. Adopting a qualitative approach in the next steps therefore enabled me to engage with service users to further explore the issues revealed in this quantitative data linkage study.

Chapter 4 introduces that qualitative study.

CHAPTER 4: Qualitative Study – An exploratory study of some of the reasons for non-delivery of homecare (Study 2)

4.1 Introduction

Chapter 4 describes this qualitative, exploratory study and presents the methods, findings and discussion associated with this element of the thesis. Thus far, the quantitative research, described in Chapter 3 (Study 1), has provided answers to Research Questions 1 and 2. However, these findings posed further questions. As outlined in the methodology section in Chapter 2, in order to obtain a more in-depth understanding for the reasons for non-delivery of homecare services for older people, qualitative methods are more suitable. The methods adopted for Study 1 were useful for identifying the extent of non-delivery; however, there are certain drawbacks, such as not being able to obtain the thoughts and experiences of the older people in relation to the reasons for non-delivery of services. Therefore, by adopting a qualitative approach and foregrounding the older person's perspective, the study reported in this chapter (Study 2) allowed me to respond to the third research question by exploring the reasons for non-delivery of homecare in greater depth.

Because this chapter presents the processes of the qualitative study, it is written in the first person. Within the positivist paradigm associated with quantitative research, reporting traditionally involves distant, impersonal prose and the use of the third person in academic writing (Tang and Suganthi 1999). Conversely, in keeping with the epistemologies of qualitative research, this chapter is written using the first person to reinforce the understanding that qualitative research is a process of interpreting the data through the lens of my own understandings and research practices (Denzin and Lincoln 2017) and in pursuit of reflexivity (Webb 1992). Therefore, the use of the first person in the qualitative narrative within Study 2 recognises the writer's presence by putting the 'I' in identity (Tang and Suganthi 1999).

As Webb (1992) suggests, the neutrality of the third person is unreliable when applied to qualitative research because it eliminates the social elements of the research process. The interpretivist paradigm acknowledges that research is value-laden. Therefore, as Wertz et al. (2011, p. 9) suggest, 'the goal of using composite first person narrative is to

express the insights gleaned through qualitative research in a way that is accessible to all in a way that will add to the knowledge of a certain phenomenon’.

4.2 Methods

4.2.1 Study rationale

Having identified key elements relating to the extent of non-delivery of homecare services and the characteristics of those most likely to experience it, this chapter describes the qualitative study that was designed to further explore reasons for and experiences of non-delivery. Older people in receipt of homecare were interviewed about their experiences according to their preference: individually, as a pair, or within a focus group.

This qualitative study explored reasons for non-delivery from an older person’s perspective. In alignment with Study 1, it would have been judicious to recruit those with experiences of non-delivery of homecare who had been identified and included in the quantitative study. However, for data protection and ethical reasons, their data were anonymised. At this juncture, it was decided to recruit from a similar population to those included in Study 1.

Further discussions with the homecare provider and members of the steering group ascertained that older people, who visited community day centres, were likely to receive some level of homecare, which would provide a convenient sample of older people who had similar characteristics. Therefore, community day centres were approached for recruitment. This provided an opportunity to probe reasons for non-delivery further, but, this time, from an older person’s perspective.

The categories NA and SR generated by the homecare service provider in Study 1 were deliberately not used within this study. If older people had experienced non-delivery, follow-up questions ascertained the context: for instance, they were asked whether they were away from home at the time the care worker arrived or whether they had refused homecare and for what reason. The participants’ responses to these questions contributed to answering the third research question, and provided an opportunity for these older people to relate their own experiences of homecare.

4.2.2 Research aim

The aim of Study 2 was to explore reasons for non-delivery of homecare from the perspective of older people.

4.2.3 Research question

Having addressed primary Research Questions 1 and 2 in Study 1, this qualitative study addressed the third research question: *What are the reasons for non-delivery of homecare for older people?*

This third research question was an exploratory one which required an in-depth exploration of the older people's experiences of non-delivery; those who met the inclusion criteria below. The definition of non-delivery had been established as homecare that had not been delivered because the older person, for whatever reason, was not available when planned care was due. Non-delivery does not, however, refer to care that care workers, for whatever reason, did not deliver.

4.2.4 Inclusion criteria

People considered for inclusion in Study 2 were those aged 65 and older with experience of homecare, irrespective of the type, length or location of homecare received; who could understand the purpose of the study and were able to give written or verbal consent; and who were able to speak and understand English and lived in or around the Greater Glasgow and Clyde region.

Inclusivity: People with or without age-related memory loss might have wished to participate in this study. Therefore, careful thought was given to the design of this research to accommodate older people who were affected by cognitive difficulties. With this in mind, it was important to ensure the safety of those within the study and to safeguard them against coercion or being influenced in any way to participate.

Therefore, potential participants were given ample time to consider participation in the study and, if they so desired, to seek advice from others. Moreover, it was important to assure the older people that, if they did not want to participate, or if they decided to withdraw from the study at any time, their taking part in the study would not affect their current care provision. Prior to participation, consent was sought from each older person, which ensured that they understood the study and their part in the research process (McMurdo et al. 2011).

4.3 Sampling and Recruitment

4.3.1 Convenience sample

Convenience sampling is an approach in which selection is made on the basis of who is available (Ritchie et al. 2014). Given the concerns for recruitment from hard-to-reach groups, discussed later in this chapter (Section 4.3.3), convenience sampling was considered to be the most appropriate means of recruitment. Convenience sampling involves recruitment from a population which is easily accessible, inexpensive and efficient (Etikan et al. 2016). In addition, this approach focuses on specific locations and draws on existing relationships to pursue recruitment opportunities (Valerio et al. 2016). Approaching day centres enabled the recruitment of several people from one location, thus reducing unnecessary time spent approaching people individually at home. Although there were no existing associations, time was taken to develop positive relationships with day centre managers.

As a type of nonprobability sampling, convenience sampling is usually described as a process whereby not everyone has an equal chance of being included, limiting generalisability to the broader population (Valerio et al. 2016). However, the sample within this study consisted of people drawn from a wide range of ages; between 65 and 94 years. Some lived alone whilst others lived with another, and, furthermore, they each had various care needs and care packages (see Table 5 in Section 4.7). Arguably, the needs of those who were younger would be quite different from those who were older, however, the ability to draw on the experiences of a wider variety of older people promoted greater inclusion in this research study.

There were several day centres in and around Glasgow providing day care to older people at the time this study was conducted. Day centres in Glasgow were selected according to their postcodes, half of which had been categorised as being in the most deprived SIMD areas. Including day centres with postcodes that correlated to the known postcodes of older people in the Study 1 helped to establish methodological rigour between the two studies (Tobin and Begley 2004). An opportunity to speak to people who possibly had received homecare from the same organisation as that included in Study 1 was true with all but one participant, who had a private homecare service arrangement.

Recruiting from four day centres, rather than focussing on one, increased the chance of finding people from typically hard-to-reach groups who met the inclusion criteria (Schilling and Gerhardus 2017). Centre managers were keen to shield those they felt were most vulnerable and so automatically excluded those with a known diagnosis of dementia. I did not have access to individuals' previous medical history, apart from what was disclosed during the interviews. However, it was unknown whether others with memory loss, who were initially considered for recruitment, might be undergoing investigations for dementia.

Ultimately, I wanted to speak to anyone with the necessary characteristics who were willing to be interviewed, without any further selection process required. This process of selection may have created a potential bias, which would have influenced my ability to draw inferences about a wider population and therefore represented a potential study limitation (Etikan et al. 2016). However, as this was not the intended aim of the research, this limitation was not detrimental to the validity of the results.

4.3.2 Sample size and saturation

The issue of how many people should be recruited onto this qualitative study was deliberated. Unlike sampling methods in quantitative research, which aim to include large numbers and achieve statistical representation over a wide population, qualitative research involves small samples of people who are studied in depth (Miles and Huberman 1984). The object of my research was not to be able to conduct a large-scale research project, but to explore reasons for non-delivery from a small population in great depth. However, it is still important to consider the implications of how the number of participants may affect the rigour of the research (Morse 2015).

The concept of saturation in relation to the appropriate point in time to stop recruiting participants and collecting data was also considered. Saturation is a means of establishing whether the research question had been sufficiently answered and determining when no new data are likely to emerge (Creswell 2014; Etikan et al. 2016). It is therefore the data that reach saturation and not the number of study participants (Morse 2015), negating the need to be bound by recruitment numbers. Therefore, rather than pre-determining a target number of participants, recruitment continued while earlier interviews were being transcribed and analysed (Saunders et al. 2018). Recruitment of new participants ended when no new themes were revealed in the

interviews. While acknowledging the need to establish when to end recruitment and data collection, of equal importance was the presence of a rigorous and coherent process of data condensation and interpretation (Bowen 2008). Therefore, this iterative process of conducting early analysis alongside data collection helped to guide the decision to use framework analysis.

Reaching saturation is frequently considered a guarantee of qualitative rigour (Morse 2015). It is used to discern when to discontinue data collection and start analysing (Saunders et al. 2018). Following this process necessitated that I adopted a fluid approach to recruitment, whereby participants were recruited until what was said provided no new knowledge (Saunders et al. 2018).

4.3.3 Hard-to-reach groups

Age can form a barrier to recruitment and study participation (Schilling and Gerhardus 2017). With age comes the likelihood of increased frailty, including visual and hearing loss, and cognitive and functional difficulties (Witham and McMurdo 2007; Habicht et al. 2008). Moreover, illness, discomfort, fatigue, hospital appointments, mistrust of the research process and competing obligations further compound recruitment opportunities and, in particular, problems associated with transport to places where research might take place (Moreno-John et al. 2004; Witham and McMurdo 2007; Mody et al. 2008; Patterson et al. 2011; Watts 2012; Ellard-Gray et al. 2015).

Older people are also less likely to put themselves forward for participation because of self-imposed ageism, the research is of no perceived benefit to them, or they feel unworthy of the attention spent on them (Witham and McMurdo 2007; Mody et al. 2008; Patterson et al. 2011). Moreover, concerns over attrition rates due to illness and hospitalisation, especially at the end-of-life, have meant that some researchers choose to recruit old, but healthy, people instead (Mody et al. 2008; Ridda et al. 2010). Therefore, unlike many other groups in society, older people are not always given the opportunity to participate in studies that directly affect them, which leads to under-representation or even absence from social and clinical research (Adams et al. 1997; Barnes et al. 2005; McMurdo et al. 2005; Witham and McMurdo 2007; Habicht et al. 2008; Davies et al. 2010; Ridda et al. 2010; McMurdo et al. 2011; Watts 2012), especially when they are frail (Harris and Dyson 2001) and aged 85 and older (Davies et al. 2010). Under-

representation of older people in research is therefore a major concern, especially for those with impaired decision-making capacity, which denies them from making a contribution to society through research (Shepherd et al. 2019).

It is perhaps not surprising that the complexities of recruitment and retention deters researchers from including older people in research projects (Ellard-Gray et al. 2015). Despite these challenges to recruitment, Ellard-Gray et al. (2015) recognise the benefits of research that involves hard-to-reach, hidden groups as a means to positively influence their wellbeing, increase their visibility and give them a voice. They view recruitment as a process of engagement based on trust. Something as simple as introducing myself as a nurse who was doing the research rather than a researcher had a positive impact on communication and in building rapport with the participants. Likewise, using simple language and appealing for their support in the invitation flyers and information sheets made them more personable and user-friendly, for instance, using an inviting tone, such as 'I would really like to talk to you!' (Appendix 8).

Within this study, engaging people from hard-to-reach groups proved problematic, which was perhaps surprising, given the increasing numbers of older people who are in receipt of homecare. Age-related conditions and increasing morbidity further hampered recruitment possibilities. In addition, day centre managers acted as gatekeepers, using their ability to either block or allow access to potential recruits. Success or failure depended on their perception of the value of the research. This further strengthened the need for building personal relationships early in the research process.

4.3.4 Gatekeepers and recruitment

Initially, a Community Development Officer, working with a UK-based charity which helps support and educate older people and their carers, identified community older people's forum groups for possible recruitment. Thereafter, I was invited to one such group to talk to several senior representatives of local groups. As appointed members, their role was to disseminate pertinent information back to members of their group. This enabled older people who were less able or willing to attend themselves to remain informed and to have a 'voice' through their appointed representative (Carey and Asbury 2016). Time was taken to liaise face-to-face to explain the purpose of the research and to allay any anxieties. Face-to-face interactions are ten percent more

effective as a recruitment tool over that of the telephone or questionnaire (Witham and McMurdo 2007; Patterson et al. 2011).

Following a successful first meeting, older people's forum group representatives took the information flyers to distribute among their members. Unfortunately, the opportunity to recruit ceased at this point. Resistance from group representatives to mediate between me, as the researcher, and the target group became a barrier to recruitment. Perhaps due to a lack of personal interest, the group representatives disseminated less enthusiastically to other potential recruits. Thereafter, community day centres were approached. Day centres provided day and respite care for older people who would not otherwise have the opportunity to leave their home, most of whom were in receipt of homecare. The intention was not to exclude those outwith day centres but to recruit people who possess the characteristics necessary for study inclusion.

Community day centres:

Four day centres in the Greater Glasgow and Clyde area were approached for recruitment. As charitable organisations, each day centre provides weekly support, friendship and care to older people, including transport to and from home, lunch and activities. The aim of this service is to prevent loneliness and isolation by providing each person with a link to the community.

Initial contact was made with community day centre managers. Time was taken to liaise with each manager, as positive recruitment relied on their full co-operation and successful navigation through the following three stages of recruitment: set-up, alliance, and exchange (Patterson et al. 2011).

1. Set-up: Identify and contact

Once the four community day centres were identified, consideration was given to foster good relationships with the managers of each centre, to ensure that they understood and realised the potential of the research. As an initial introduction, contact was made by phone and then in person. A good alliance at this stage depended on effective communication, including resisting the temptation to 'bother' gatekeepers with unnecessary contact and requests (McFadyen and Rankin 2016). Forward planning at this stage allowed for minimal contact at a time that was convenient to them.

2. Alliance: Connect and engage

Time was taken to secure good relationships. Effective communication, again, was vital. Following an initial introductory telephone call with the centre manager, arrangements were made to discuss the research further. A sense of a shared goal was established, one grounded in the desire to invite older people to be involved in research that might be of benefit to them or others (Patterson et al. 2011). The centre managers demonstrated a concern that the purpose of the study would not have a negative impact on the welfare of the people in their care. In particular, they filtered out those with cognitive difficulties from recruitment possibilities. Early identification of fall-prone individuals, people with mobility difficulties and wheelchair users helped to procure a safe environment for them, including the availability of lifts and accessible toilet facilities. Likewise, the timing of data collection ensured that day centre activities and meal times were uninterrupted (Creswell and Creswell 2018).

3. Exchange: Request and resolve

It was also imperative that I established good relationships with day centre managers, which led to positive interactions with potential participants. Establishing and maintaining a relationship based on trust and understanding helped centre managers endorse me as somebody to be trusted. The benefits of taking the time needed to develop secure relationships with centre managers positively affected recruitment thereafter (Patterson et al. 2011).

Having established good relations with centre managers, the process of recruitment followed.

4.3.5 Recruitment

Once the research (and me, as the researcher) had been assessed as being suitable, day centre managers were keen to support the research in any way that they could, but they had a tendency to filter out those they felt could not or would not wish to participate. As demonstrated by these gatekeeping tendencies, the view that older people are vulnerable and in need of protection is often misplaced (McMurdo et al. 2011). Gatekeeping occurs wherever access to someone or something is allowed or denied by a third party (Patterson et al. 2011). According to McFadyen and Rankin (2016), gatekeepers have a key role to play in recruitment.

Good relationships with day centre managers helped recruitment opportunities and initiated contact with other day centre managers. Key to successful relations and subsequent recruitment relied on the day centre managers understanding and recognition of the benefits of the research, their ability to communicate with others and their motivation. Ultimately, this successful liaison with day centre managers secured my access to potential participants. Only those who possessed the characteristics of interest were invited to take part in a discussion explaining the research and what they could expect from participating in the study.

A poster providing taster information about the study (Appendix 8) was placed in an easily accessible position in the day centre. All those who met the inclusion criteria were invited to attend a forthcoming discussion on possible participation. Returning at the specified date, I answered any questions that groups of interested people had (Dibartolo and McCrone 2003). Information sheets were also distributed at that time (Appendix 9), and ample time was provided for the potential participants to discuss the research with family and friends before making the decision about whether to participate (McMurdo et al. 2005). Although older people are apt to listen to the views of their family and caregivers, they were still likely to make their own decision in the end (Witham and McMurdo 2007). The contact details of people who were interested in principle were taken (Appendix 10), and arrangements were made to contact them a week later at a mutually convenient time, using their preferred means of communication.

Pre-arranged visits to day centres coincided with days when most people frequented the centre. Returning at a mutually convenient time, when there was continued interest to participate, written consent was obtained for people to attend either an individual interview (Appendix 11) or take part in a focus group (Appendix 12). Participants indicated at this point whether they would like to have a friend or family member with them during the data collection process. One person, who had been diagnosed with early onset dementia, decided to participate and chose to have his daughter present because of his short-term memory loss to help 'fill in the gaps' of his memory.

All aspects of the recruitment process were tracked by way of a recruitment diary in order to maintain accurate records and keep the study on track (Mody et al. 2008). Once recruited, the older people were referred to as participants.

4.3.6 Incentives

Providing incentives have been shown to increase recruitment and retention rates by up to ten percent (Moreno-John et al. 2004). For this study, it was decided, with ethical approval, to provide a travel fund of up to £10 per person if needed. Reimbursement of travel costs also helps to improve recruitment rates by up to ten percent (Kreuger 1994, 1998). In addition, each community organisation was given a single donation of £50 as a ‘thank you’ for their time. This token was considered acceptable in establishing a relationship of trust and was viewed as desirable by all involved (Dibartolo and McCrone 2003).

Recruitment and retention rates remain higher for older people when there is an interest in the topic area, for personal reasons, and where the research may affect them in some way (Patterson et al. 2011). Dedyne et al. (2018) assessed older peoples’ incentives to participate in nutritional and exercise programmes. They found that motivation to participate could be attributed to interpersonal factors and health beliefs: in particular, if they perceived it would be of benefit to themselves and others. Notably, altruistic reasons, including a desire to support research to help others, as well as a hope for personal benefit and the opportunity to access treatment not readily available, make up most of the reasons that people give when agreeing to participate (Singer 2002; Moreno-John et al. 2004; Tolmie et al. 2004; Dibartolo and McCrone 2003).

4.4 Data Collection

Preliminary conversations with older people in receipt of homecare highlighted a reluctance to disclose incidences of non-delivery. Experience of non-delivery was therefore not part of the inclusion criteria. Instead, interview questions were specifically designed to explore the context of homecare delivery with ample opportunity provided to disclose incidence of non-delivery. Moreover, at this juncture it was not known how many, if any, participants had had non-delivery of homecare.

4.4.1 Semi-structured interviews

For this study, in-depth, semi-structured interviews provided the means to answer specific research questions and obtain the depth of insight required (Walliman and Appleton 2009). A semi-structured format in the form of a natural conversation helped to develop a relationship between the participants and me, one that was based on trust

(Walliman 2006). I had a genuine interest in their stories and wanted to listen. Face-to-face interactions were preferable to ensure on-going understanding and to monitor any adverse effects that the experience of taking part in an interview might have for the participants (Walliman 2006). This allowed me to monitor visual cues and body language, such as tiredness or disengagement, or confusion over questions asked (Creswell and Creswell 2018). Each interview was audio-recorded. I also kept a fieldwork diary to record all aspects of the research process (Creswell 2016). In particular, notes were taken immediately after the interviews to capture non-verbal cues.

The interviews provided the opportunity for participants to ‘tell their story’. There are three types of interviews; structured, semi-structured, and unstructured. Arguably, a structured interview would be too tight to answer the research questions, restricting the responses given. Conversely, an unstructured interview allows total freedom without any restriction imposed on the direction of the conversation. However, the use of a semi-structured interview helps answer key questions with minimal interruption from the researcher (Gill et al. 2008). This is particularly important when time is limited and where participants are unable or unwilling to sit for long. Semi-structured interviews were therefore considered to be the most appropriate means of data collection. Initial interview questions were asked and, alongside prompts and question guides, I allowed the conversation to progress naturally (Creswell and Creswell 2018).

Initially, rapport-building questions helped to put participants at ease with me, the equipment and each other (Quine 2017). An informal conversation aimed to ensure that everyone felt comfortable and safe enough to be able to talk without concerns for breach of confidentiality. Before each interview, I restated the purpose of the interview and the role that I had, as the researcher, in this process. Managing expectations of being interviewed can prove problematic (Quine 2017). One participant saw this as an opportunity to obtain help and advice from me, as the researcher. In this instance, I reiterated the role that I had and informed the day centre manager so that their concerns could be addressed.

4.4.2 Focus group

Focus groups increase the quality of participant responses and actively empower and engage participants in the research process (Velzke and Baumann 2017). Moreover, focus groups help to reflect the social realities within a particular group of people with

shared experiences (McLafferty 2004). Although each participant would have had experience of homecare, they were each likely to have a different perspective on that experience. Previous research suggests that an optimum number of people to include in a focus group is between 5 and 6 participants (Bloor et al. 2001). A larger group size may preclude everyone from having the opportunity to speak and a smaller group may deter participants from speaking freely and thus yield a more limited discussion (Streubert and Carpenter 2007). Prior to commencing, the purpose of the focus group was re-iterated using a preamble sheet (Appendix 13). Verbal re-iteration is shown to benefit older people's ability to remember prior written information (Tun and Wingfield, 1997). On-going consent was re-established at this stage. The parameters of the focus group were highlighted, including the participants' right to withdraw from the focus group at any time without any repercussions. While it is sometimes beneficial to involve a second researcher to take notes during a focus group, because I was audio-recording the discussion (Bloor et al. 2001), I facilitated the focus group alone.

Focus groups are particularly valuable where sensitive topics are discussed and they also provide a mechanism whereby marginalised groups are helped to voice their opinions and concerns (Carey and Asbury 2016). With this in mind, efforts were made to ensure that the four participants within the focus group had an opportunity to speak and that no one member dominated the group. It was crucial that, as facilitator of the focus group, I honed my listening skills or, as Carey (2016, p. 731) explains, was able 'to listen behind the words'. This expression is linked to the researcher's reflexive ability to ascertain the meaning behind what was said or not said and record these observations in a fieldwork diary.

The focus group approach means more than the convenience of a shared discussion in one sitting. A concern exists for participants within a focus group where there is a lack of mutual trust between them affecting their ability to speak honestly (Carey and Asbury 2016). However, within this study, four people who chose to be part of a focus group did so under their own volition. The reasons given were because they knew one another, they felt comfortable with one another and trusted one another, and they did not feel judged (Hennink et al. 2020). One of the aims of conducting a focus group for my research was not to obtain consensus of opinion, but to obtain a wide range of experiences. Adopting this strategy facilitated the sharing of ideas and allowed me to

chart the changing of opinions during the process of group discussion, which further adds to the validation of the research findings (Hennink et al. 2020).

Unlike an individual interview, the focus group increases the depth and clarity of the discussion in a relatively quick time. This depends on the participants themselves, the relationship between them, and on having the right environment within which to be able to share ideas safely (McLafferty 2004). This required forward planning to ensure that the venue was familiar, comfortable and accessible.

The semi-structured interview format, outlined below, was guided by probes and prompts drawn from the research questions. Open-ended questions helped to focus the discussion (Kreuger 1998).

4.4.3 Interview questions

Both the focus group and the individual interviews were guided by the following semi-structured interview questions (see also Appendix 14).

Question 1: *What are your experiences of homecare received so far?*

Supplementary questions:

Who provides your homecare? (Organisation and individual)

How often do you receive homecare?

What does your homecare consist of?

What aspects of your homecare do you find positive?

What aspects of your homecare do you find negative?

What, if any, changes would you make to the care you receive?

Question 2: *What are your experiences of not receiving planned homecare?*

Supplementary questions:

What reasons might you have for refusing homecare? (Actual and hypothetical)

Where were you when planned homecare was due?

Question 3: *What health effects, if any, have you experienced as a result of not receiving homecare?*

Supplementary question:

How has non-delivery of homecare impacted your health?

To ensure the clarity of the questions and to identify any ambiguities, the interview questions were piloted with two of my contacts, who work within and are familiar with care services for older people. The questions were descriptive, as they focussed on the how, what and where of non-delivery. The questions were designed to be succinct, but broad enough to capture the nuances associated with non-delivery, and the supplementary questions helped to guide the conversation to avoid straying too far off-track (Doody and Bailey 2015). The first question sought to establish the context of homecare. The second question was only relevant if homecare had not been received as planned. However, the supplementary questions explored actual and hypothetical reasons to refuse homecare. The third question explored health implications associated with non-delivery, which was only posed to participants if care had not been delivered.

4.4.4 Context and equipment

Interviews were conducted in a convenient location to prevent unnecessary travelling, especially for those with mobility problems or travel concerns. The venues for the interviews were mutually arranged between participants and day centre managers. The majority chose to take part at the day centre, with only one participant preferring to be interviewed at home. Forward planning was required to ensure that interviews did not interfere with meal times and activities. Participants were told that the length of their interview would be at their discretion, but would last no longer than 45 minutes.

An audio-recorder was placed in a central point between the participant(s) and me. Participants were told when it was switched on and when it was switched off. Prior to data collection, the audio-recorder was tested to ensure that it was in full working order. I facilitated the interview by beginning with a general opening question, then progressing to more specific ones, only intervening to keep the topic on track. The questions I asked were short, using simple unambiguous language. Spoken sentences using complex syntax can prove problematic for older people with possible working memory limitations (Tun and Wingfield 1997). Where there was reluctance to answer a question, I moved on to the next question. To help in this process, I referred to the question guide (Appendix 14). Field notes were taken after data collection to capture the essence of the discussion and to record any non-verbal cues that I had observed (Arthur and Nazroo 2003).

The audio-recordings enabled me to return repeatedly to the original data. Listening to the recordings alongside reading the transcriptions helped to immerse me in the data. The audio recordings of the interviews were transferred onto a password-protected single computer to which I had sole access.

4.4.5 Member validation

Member validation is a process whereby participants are invited to comment on the study findings, adding significantly to the validity and trustworthiness of findings (Doyle 2007). Seeking clarification of my understanding ensured that the essence of the interview was captured, which further increased the validity of the findings. After each interview and focus group, I summarised and paraphrased that which had been said while clarifying any areas of confusion. For the individual interviews, the participants were asked immediately afterwards whether they felt that the paraphrased summaries resonated with their own experiences, without which they might be left feeling overlooked and unnoticed (Birt et al. 2016). This provided an opportunity to ‘double check’ the meanings behind the data, which is required for performing in-depth interpretive analysis (Ritchie et al. 2014). The focus group provided a different level of validation of findings through the process of shaping and re-shaping ideas through interaction with other members of the focus group. As such, I observed this process as it happened and recorded this form of validation in my fieldwork diary.

4.5 Ethics Approval and Consent

Initially, ethics approval was sought to approach older people for recruitment through a community older people’s forum group, as described in Section 4.3.4. Having failed to recruit through this group, the necessary ethics permissions were sought and obtained to broaden recruitment opportunities. Ethics approval was therefore sought and obtained from the School Research Ethics Committee (SREC) at the University of Stirling only (Appendix 15).

Because the initial plan for recruitment via the older people’s forum groups did not transpire, a further application was made to SREC to help extend recruitment opportunities. An amendment to the existing permissions was granted to approach community day centres for recruitment purposes (Appendix 16). Issues pertinent to research in this area required that particular attention was given to avoiding perceived

coercion to take part, participant confidentiality, sensitive topic areas, and causing any potential distress to older people, as well as researcher safety.

4.5.1 Risk management in ethics

The main risks identified for this study were four-fold, and these were carefully considered and measures put in place to address each of them, as described in the summary below.

- 1) *Perceived coercion to take part* (Creswell and Creswell 2018). Eligible people entered the study at their own volition. They were informed that they were free to withdraw from the study at any time without any warning or reason given with no repercussions for any care received.
- 2) *Breach of confidentiality*. Participants were assured that their anonymity and confidentiality would be upheld. At no point during the analysis or in reports of the findings, such as in a thesis or journal publication, would any participant be identified.
- 3) *Sensitive issues and participant distress*. Participants could potentially become distressed when talking about health-related issues and sensitive subjects. In tune with possibly sensitive subjects, interviewing skills, such as open questions and active listening, were employed. During the focus group, as it consisted of four individuals only, and because it was audio-recorded, I facilitated it alone. I have prior experience of facilitating focus groups and in discussing sensitive topics. Participants were informed that they did not need to answer questions that could cause distress and were free to leave the focus group or terminate the interview at any time. As a trained nurse, I had the skills and ability to identify and alleviate any distress.
- 4) *Researcher safety*. Risk associated with performing this research was rated as being very low. Where there may be cause for concern for safety, the interview would be discontinued. A lone worker policy ensured my safety, whereby I contacted my supervisor before and after each interview. If my supervisor did not receive a text message within two hours of the start of the interview, she would attempt to contact me. If contact was not established, the police would have been alerted.

People may wish to participate in research when they consider their contribution could make a difference to either themselves or others. Initial contact with older people who have experienced homecare has shown a desire to be included in the conversation about matters that directly affect them (Schilling and Gerhardus 2017). As a group that is so often overlooked in being included in research projects, it is important to include older people in research, particularly when they are directly affected by the topic of study. Therefore, the value of performing this research study far outweighs the relatively low level of risk determined here. In addition to the ethics considerations outlined here, I also performed the research in accordance with the University's Code of Good Research Practice (University of Stirling 2016).

4.5.2 Informed consent

Another ethical concern was that of informed consent. As a legal requirement, informed consent was obtained prior to the start of data collection. Obtaining consent from a group of people with possible cognitive limitations has its complications. The following steps were taken into account in order to obtain informed consent from all participants. First, I ensured that all participants had at least 24 hours to read the participant information sheet and consent form before confirming with them that it was fully understood and that they were fully aware of the part that they played in the research process before being asked to sign the consent form. I ensured that each form was signed and dated with a copy retained by the participant. During the early recruitment stages and throughout the data collection period, the study was fully described to the participants in plain language. Participants were also reminded that their participation was voluntary and that they could withdraw at any point without giving a reason and that their personal data would subsequently be removed from the study (Data Protection Act 1998), and that their participation, or not, would not make any difference to the homecare they presently received. In addition, their consent was confirmed, verbally, on an on-going basis throughout the research process, just prior to the start of the interview/focus group. The design of this study took into account the influence that memory loss may have had on the participants' contributions by using sensitive questioning and allowing the opportunity for people to take the time to consult their relatives and friends about the study and to act as their aide memoire if needed (Witham and McMurdo 2007). This approach was also reflected in the consent forms (Appendices 11 and 12).

4.5.3 Confidentiality and anonymity

All data were kept confidential. Personal data obtained during interviews were anonymised by assigning participants with unique pseudonyms (see Table 5, Section 4.7). The views of participants, expressed in focus groups, were not linked to individuals, nor were individual participants identified in research reports or publications. Original copies of the consent forms, which contained personal information, were stored in a locked cabinet in the University of Stirling. Other personal data were stored on a password-protected university computer.

4.5.4 Reflexivity

The researcher forms an integral part of the research process itself; from the development of the research questions through to the analysis of the data and presenting their understanding of the findings. Throughout Study 2, I conducted all of the interviews, noted my observations, and kept a reflexive diary. This practice allowed me to reflect on and acknowledge the influence that I had on every stage of the research process (Creswell 2016).

In embarking on this research study, I arrived with my own set of assumptions, based on my past experiences in various clinical environments as well as in the community. Acknowledgement of these assumptions ensured that I took this into account through the process of practising 'reflexivity'. As an important aspect of all research, reflexivity allowed me to reflect on the effect that my presence, values and experience may have on the decisions that were made in guiding the research process (Creswell 2014). In fact, as Agee (2009, p. 431) proposes, 'the idea of qualitative inquiry as a reflective process underscores the strengths of a qualitative approach'. Therefore, reflexivity was an important element of the research, highlighting that the relationship between the research and the researcher is mutually reinforcing (Alvesson and Sköldbberg 2009).

By undertaking the interviews, I played an integral part in influencing the research process. According to McNair et al. (2008), the clinician as researcher is well placed to access participants and knowledge and a valuable resource in the field of research. Contrary to the view that researchers should distance themselves from the research process, McNair et al. (2008) point out they are an inevitable feature of data collection and interpretation. Therefore, it was better to acknowledge pre-existing views in the

process of reflexivity so that this awareness could be drawn upon as an asset to the research and its outcomes.

Throughout the findings chapter, boxes containing vignettes, based on my observations, illustrate the processes that helped me to reflect on some aspects of the interviews that were not evident within the transcriptions. For instance, during one interview, the participant appealed to me to help them solve a problem they were having. As I have a working knowledge of the field of study, I was sensitive to their situation but, as a researcher, I was required to stay impartial. However, this inside knowledge provided critical insights which helped me to contextualise what had been said in the interviews. I realised that their expectations of me might influence what they disclosed during interview. Acknowledging this bias helped me to reflect upon my competing interests as a researcher and as a nurse. Reid et al. (2018) recommend practising reflexivity before embarking on the research and throughout the process of research, which was a strategy that was immensely helpful in my own practices.

The majority of participants had age-related communication difficulties, affecting their speech and hearing. Experience in caring for older people helped me to understand some of the issues facing older people receiving care and for care workers delivering care. This experience helped facilitate the free flow of conversation and promote effective engagement. While there may be merits in terms of effective engagement and communication in eliciting depth in conversation, I was also mindful that my own prejudices could influence my understanding of what is being said (Creswell 2014). To avoid this potential bias, I approached each interview with an open perspective. I found conversations, once the audio-recorder had been switched off, helped to create an accurate picture of what was really happening and was as valuable as transcribed data. Although the interviews were transcribed professionally, I repeatedly listened to the recordings while reading the transcriptions, thus helping me to become fully immersed in the data.

4.6 Data Processing

Each interview was uploaded to the software application, NVivo 11 (QSR 2016). NVivo, a computer assisted analysis software package, is frequently used to help manage and sort large amounts of qualitative data to facilitate analysis (Bazeley and

Jackson 2013). Additionally, Excel and Word helped to organise, manage and document the stages of analysis.

Digital copies of the audio-recordings, transcriptions documents, and transcriptions of my field notes and reflexive diary were stored on a password-protected university computer and original copies were stored in a locked cabinet at the University of Stirling. Only myself, and my PhD supervisors, had access to the raw data. Participant anonymity was assured and participant names and personal details are not reported in this thesis, nor shall they be in any future publications. At the end of the study, this research data was stored securely on encrypted servers and will be destroyed after five years, according to University of Stirling data management and security procedures.

The transcriptions of the data were undertaken by a professional transcriber and saved as Microsoft Word documents. The interviews were transcribed using the ‘full verbatim’ method of transcription. Inclusion of pauses, interruptions, laughter and emphasis provided a clear meaning of what was said and the context in which it was said and acted as an aide memoir for the researcher given the plethora of data generated (Creswell 2016). Transcriptions were given large margins to facilitate the addition of hand-written coding and reflective accounts.

4.6.1 Framework analysis

Research Question 3 and the need to understand the experience of non-delivery from the unique experience of the individual underpinned my decision to use framework analysis. The framework analysis approach guides the collection and analysis of data with a focus on ensuring that descriptions and interpretations made were firmly grounded in and supported by the data, thus enabling the voices of the older people to be heard (Ritchie et al. 2014).

Data for analysis included those generated from interview transcriptions as well as observations of interactions seen and heard during and after the interviews, as recorded in my fieldwork and reflexive diaries. Observations included gestures, tone, remarks and overall impressions. The resulting data were rich, descriptive and plentiful, and the volume necessitated the application of an analytical tool to help make sense of the data without losing their meaning; a tool that would help to identify themes and sub-themes.

Framework analysis (Ritchie et al. 2014) was selected as the most appropriate approach to manage and analyse this large amount of data systematically.

Framework analysis enables the abstraction of data from surface description to in-depth interpretation. Initially, staying close to the raw data helped to capture the essence of the data and their original meaning. Thereafter, the identification of higher-order categories helped to explain linkages and patterns within the data. The disadvantages of framework analysis included that it was time-consuming and resource-intensive, requiring input from a team of researchers familiar with the approach (Gale et al. 2013). Three researchers were involved in this doctoral study; as the doctoral student, I performed the primary analysis, and my two PhD supervisors, one of whom is an experienced qualitative researcher and analyst, were closely involved in extensive and detailed discussions as the analysis progressed.

As a systematic, iterative and flexible process, framework analysis also allowed for the modification of its model. Indeed, Ritchie et al. (2014) encourage users of their approach to modify it according to their needs, taking care not to take shortcuts through its five stages. The process of framework analysis ranges from data management through to abstraction and interpretation. My own process for data management involved the production of labels, themes and sub-themes in their descriptive form. Thereafter, abstraction and interpretation moved the data through descriptive to interpretive findings. Figure 7 represents the five stages of framework analysis suggested by Ritchie et al. (2014), which I adopted as a guide for performing my own analysis.

Data management \longleftrightarrow Abstraction and interpretation

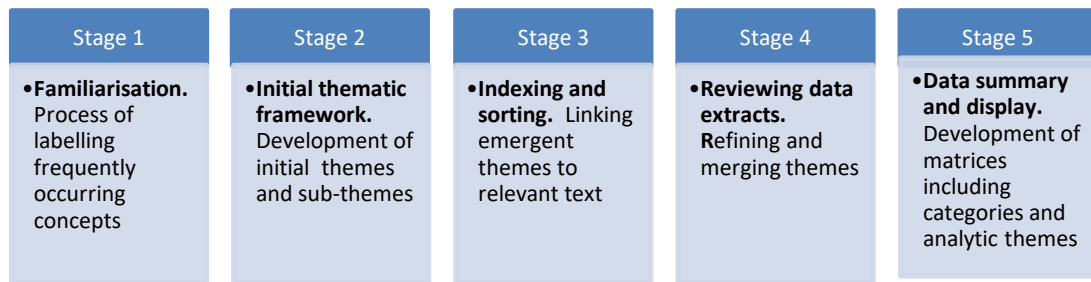


Figure 7: Framework analysis

The first four stages of the analysis was an iterative process, which helped me to identify patterns, similarities and differences between the participants' accounts, allowing me to develop themes and categories. The fifth and final stage involved the development of matrices specifically linked to the categories and analytic themes identified in the first four stages. The following section describes the five stages of framework analysis in greater detail. At each step, the development of labels, themes and sub-themes was corroborated by my supervisor.

1. Familiarisation:

Establishing my familiarity with the data involved listening to the recordings several times, documenting pauses and inflections, while simultaneously reading and re-reading field and observational notes. Labels were attached to frequently occurring concepts or areas within a randomly selected sample of six of the twelve transcriptions by identifying areas that looked or sounded alike and that were relevant to the study aims and objectives. My supervisor, who was familiar with the process of framework analysis, likewise compiled a list of labels from the same sample of transcriptions. Comparisons were drawn between the two sets of labels, and these were discussed until an agreement on the most suitable set was reached. This process was repeated with the remaining transcripts.

2. Initial thematic framework:

This second stage involved the 'pooling' of labels to form initial themes and sub-themes. Any labels that were not pertinent to the study aims were removed. This time-consuming iterative process helped to develop initial themes and associated sub-themes

with descriptions to ensure clarity of understanding which was then corroborated by my supervisor.

3. Indexing and sorting:

The initial thematic framework, which had been established by myself and my supervisor, was applied to the remaining six transcriptions. I did this by creating headed columns based on the initial framework. Thereafter, indexing and sorting refers to the process of linking emergent themes back to the relevant text, keeping the themes firmly grounded in the raw data. This process ensured that all data were correctly placed under the most relevant themes. Verbatim extracts helped to illustrate the themes generated through the analysis.

4. Reviewing data extracts:

This stage ensured that no important themes were missing. Revisiting the initial thematic framework and associated data allowed the opportunity for further refinement and merging of themes and sub-themes. During this stage, the data were reviewed to ensure that important themes were not missing from the framework and that less relevant ones were removed. Where there was any overlap between sub-themes, these were merged to form one theme.

5. Abstraction and interpretation:

The last phase of framework analysis involved the development of categories and analytical themes with the aim of identifying a range of perceptions pertaining to non-delivery of homecare, from the perspective of older people. To make sense of the data, summaries were identified and listed against their relevant sub-theme within the matrix. Thereafter, elements were identified from the data summaries, followed by the formation of categories from condensed elements. Finally, all of the categories emanating from each matrix were revisited. All those that were similar were merged together and renamed as analytic themes. The analytic themes formed the basis for generating discussion of the findings.

4.7 Findings

The findings highlight three main concepts: the value of home, the value of independence, and the value of connectivity. These concepts are fundamentally

important and the reasons why homecare was rarely refused. Although unexpected, these findings add substantially to present knowledge on the delivery of homecare for older people. With people living longer than ever before, these findings provide valuable information to help policy makers and care workers in their drive to deliver homecare that keeps people in their homes for as long as possible.

For the purpose of this study, the people included within the study sample aged between 65 and 92 years old are classified as older people. However, far from being a homogeneous group, their characteristics are as disparate as those within any other age range with different care needs. As suggested by Kydd et al. (2020), the re-banding of people in ten-year cohorts (60–69, 70–79, 80–89, 90–99 and 100+) would certainly have more accurately provided a sample of people with similar needs. However, while acknowledging that the complexity of the needs will differ greatly between these multiple cohorts, these differences are not the focus of the research presented here, and the range in age of the participants was sufficiently varied so as not to over-represent any one band over another.

A summary of the socio-demographic characteristics of the older people who were recruited to the study, using their pseudonyms, and identifying their participation in an Individual Interview (II), a Paired Interview (PI) or within a Focus Group (FG), is presented below in Table 5.

Table 5: Socio-demographic characteristics and interview type for older people recruited to the study

Pseudonym	Age	Gender	Living status	Interview type II, PI, FG*
Helen	74	F	Lives alone	PI (no. 1)
Kirsty	68	F	Lives alone	PI (no. 1)
Ros	85	F	Lives alone	PI (no. 2)
Jan	65	F	Lives alone	PI (no. 2)
Betina	88	F	Lives alone	FG
Maggie	89	F	Lives with husband	FG
Issy	76	F	Lives alone	FG
Elizabeth	82	F	Lives alone	FG
Jock	76	M	Lives alone	II
Morag	75	F	Lives alone	II
Arthur	73	M	Lives alone	II
Steve	77	M	Lives alone	II
Flora	73	F	Lives alone	II
Ivy	79	F	Lives alone	II
Ina	75	F	Lives alone	II
Ellie	74	F	Lives alone	II
Bob	94	M	Lives with wife	II

*II – individual interview; PI – paired interview; FG – focus group

The next section expands on each of the stages of framework analysis that I followed, providing a critical exploration of the benefits of adopting this approach in relation to the findings that emerged at each stage. Reflective boxes, punctuated throughout this section and the following presentation of the findings, highlight my own thoughts and reflections gathered during the process of conducting the analysis.

Becoming familiar with the data is the first and arguably the most crucial step in framework analysis (Ritchie et al. 2014). In total, 12 transcriptions (1 focus group of 4 people; 2 paired interviews and 9 individual interviews) containing interviews with seventeen participants were examined. These transcriptions were read in conjunction

with listening to the interview audio-recordings. This process was repeated several times, which helped to fill most of the gaps within the transcriptions where understanding was a problem due to language use, and to better understand the actions and behaviours of the participants (Miles and Huberman 1984). Immersion into the data promoted familiarity, and notes were jotted down in the margins of the transcriptions along with my initial thoughts and impressions. Field notes and reflexive diaries were read alongside transcriptions to identify non-verbal cues, such as facial expressions.

Reflection: *Committing my thoughts to paper.* Jotting down ideas and thoughts helped me keep abreast of every aspect of the project, including day-to-day planning and interactions that might impact, influence the project.
Date: 13.5.15

Stage 1: Familiarisation

In the initial stage, having read and re-read six randomly selected transcriptions line-by-line, a label or paraphrase was attached to particular passages of interest. Labelling involved the identification of frequently occurring concepts or ideas related to the interview questions. Taking a broadly inductive approach allowed a preliminary list of labels to be assigned to data. Labels, not pre-defined, were kept as descriptive as possible to keep them close to the raw data. This process yielded a long list of labels pertinent to the research questions and identified topics of recurrent interest across the dataset. After reaching consensus through independent examination and labelling of the six transcriptions, this stage formed the first part of the audit trail, promoting the reliability, trustworthiness and transparency of the process (Ritchie et al. 2014). Where there was disagreement, the labels were either removed or relabelled accordingly. Fifty-eight labels were created. Table 6 provides a summary of the most frequently occurring labels.

Table 6: Frequently occurring labels

Fear of institutional care	Unexpected care given	Inappropriate care given
Insufficient care time	Feeling lonely	Physical care needs
Care service late	Desire to live at home	Rushed care visits
Care boundaries	Anxiety	Put out the bins
Homecare wanted	Carers as friends	Others' needs take priority
Changes in care at short notice	No continuity of care	Care refusals
Being liked and being cared for	Carers are liked	Carers that care
Homecare provides company	Unlikely to complain	Unsure of carers' role
Social isolation	Unlikely to refuse care	Connective care needs
Independence valued	Dependence on carers	Grateful for care given

Having reached consensus on these labels, all areas that shared similar characteristics were grouped together to form an initial thematic framework.

Stage 2: Initial thematic framework

Constructing an initial thematic framework involved the development of initial themes and sub-themes. Once again, consensus was achieved through collective agreement between me and my supervisor, creating meaningful but preliminary thematic connections. The identified areas were then renamed as an 'initial theme' and each was given a description to ensure clarity. Likewise, each label was renamed as an 'initial sub-theme'. This iterative process involved necessary changes to ensure that the initial themes and sub-themes best represented the data and were relevant to the study objectives. Figure 8 illustrates how NVivo 11 helped in the process of refinement of moving from labels to themes. Six out of the twelve transcriptions were processed in this way (that is, in NVivo 11) and taken back to the remaining transcriptions to help develop the framework. The framework structure thus changed as other themes emerged.

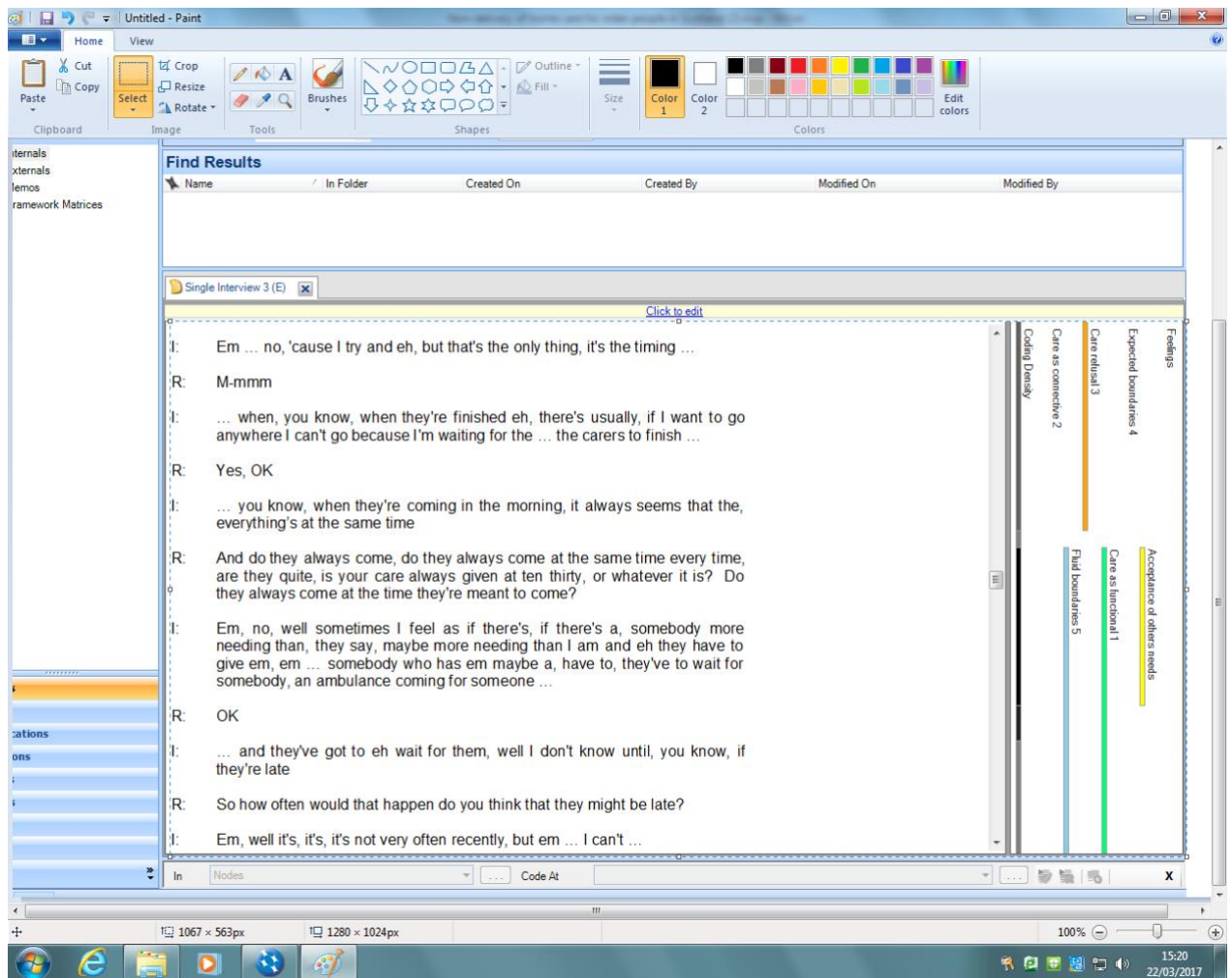


Figure 8: NVivo extracts

Table 7 below illustrates the initial thematic framework that was collectively generated and agreed. This includes the identification of five initial themes, along with their descriptions and three associated initial sub-themes. At this stage, each theme was deemed to be of equal importance.

Table 7: Initial thematic framework

Initial themes	Initial sub-themes
1. Care values	
Description: Value of living at home	<ul style="list-style-type: none">• Living at home• Independence versus dependence• Fear of institutional care
2. Care expectations	
Description: Expectations of care wanted and received	<ul style="list-style-type: none">• Attributes of care• Continuity of care• Physical/domestic care
3. Care time	
Description: Experience of an unwanted service	<ul style="list-style-type: none">• Unreliable care time• Insufficient care time• Changing patterns of care
4. Care boundaries	
Description: Boundaries of care received	<ul style="list-style-type: none">• Accepting care• Refusing care• Limitations of care
5. Care connectivity	
Description: Value Of connecting with others	<ul style="list-style-type: none">• Loneliness and isolation• Carers and company• Being liked and being cared for

This initial thematic framework was applied back to the remaining six transcriptions and relevant data extracts in preparation for the next stage, indexing and sorting.

Stage 3: Indexing and sorting

Indexing and sorting illustrates where each theme was referred to in the data by linking emergent themes back to the relevant text (Ritchie et al. 2014). This process ensured that all data were correctly placed under the most relevant themes. Verbatim interview quotations, annotated with pseudonyms to protect the anonymity of the participants, were used to illustrate themes.

This lengthy process helped to bring data ‘about the same thing’ together, or, as Saldana (2009, p. 8–9) suggests, data that are judged to ‘look alike’ or ‘feel alike’. This required copying and pasting into a word document and being careful not to lose the content and context of the data from the original transcriptions to ensure the meaning was not lost. Simple and descriptive themes identified at this stage were a result of going back and forth within and between transcriptions.

One of the benefits of framework analysis was the constant revisiting of the data to ensure that the themes and sub-themes correctly represented the data. Therefore, it was decided to postpone Stage 3 until after completion of Stage 4.

Stage 4: Reviewing data extracts

This stage provided the opportunity to review the data to ensure themes within the initial thematic framework best represented the data. Changes made to the framework, as a result of the process of refinement and merging, are highlighted in Table 8.

Changes made to initial themes 1, 3 and 5 are indicated in red text. These changes reflect the sequence of importance according to participants’ ranking. Issues of care connectivity, including ‘carers and company’ and ‘being liked and being cared for’, were elevated to the first theme ‘Care values’, whereas ‘Care tensions’, between care wanted and care received, although of importance, were generated deductively by me alone, and were therefore discussed last. In this analysis, tensions were particularly evident between independence versus dependence, homecare versus institutional care and homecare versus loneliness.

Table 8: Revised thematic framework

Initial themes	Initial sub-themes
1. Care values	
Description: Value of home and homecare	<ul style="list-style-type: none">• Living at home and independence• Carers and company• Being liked and being cared for
2. Care expectations	
Description: Expectations of care wanted and received	<ul style="list-style-type: none">• Attributes of care• Continuity of care• Physical/domestic care
3. Care time	
Description: Unwanted care time	<ul style="list-style-type: none">• Unreliable care time• Insufficient care time• Changing patterns of care
4. Care boundaries	
Description: Boundaries of care received	<ul style="list-style-type: none">• Accepting care• Refusing care• Limitations of care
5. Care tensions	
Description: Tensions between care wanted and care received	<ul style="list-style-type: none">• Independence versus dependence• Homecare versus institutional care• Homecare versus loneliness

Illustrations follow for each of the above five themes, presented with an accompanying narrative. The narrative focuses on each individual's story to 'provide a better understanding of phenomena in the context of people's own accounts of their personal development and histories' (Ritchie et al. 2014, p. 17). Interesting verbatim quotations, highlighted in italics, capture the essence of what was said under the relevant sub-themes. Individual experiences and quotes, however isolated, were given equal merit and consideration. Therefore, as Ritchie et al. (2014, p. 317) suggest, 'if an element is mentioned only once it still contributes to a full description of the phenomena in question'.

4.7.1 Care values

Living at home and independence:

In answer to the question, *What does living at home mean to you?*, the most frequent response emphasised the wish to remain at home, which was viewed as a means of remaining independent. Retaining independence was why people accepted homecare and formed a central theme within the data.

I've always done things for myself ... yes that's important (Morag)

Oh aye ... I think it's great ... independence ... I like my own independence. (Helen)

Many participants volunteered their wish to remain at home before being asked, and expressed how able they were to live on their own:

Staying at home, well I would'nae like to leave this place cos I'm really quite able still. (Jock)

It is very, very [emphasis] important. (Helen)

I love my own house. I live on my own. It's not a problem. I can go down the stair any time I want tae ... and I can put the telly back on and I plug it in and that. (Morag)

The majority of participants lived at home alone. One participant lived with her husband at home. As her primary carer, he provided help with daily activities to ensure they could live at home together for longer. Another participant, in receipt of homecare himself, provided help to his wife, a role he took to ensure they could likewise stay at home. Talking on behalf of both himself and his wife, Bob stressed the importance of being able to live at home.

Bob: *I think it keeps yae in yer ain environment.*

Int: *And how important is that to you?*

Bob: *Oh that's a lot. It's a big yin for me. Yes I want tae try and stay in my own house as much as we can...*

Reflection: *Assertive.* Out of all the participants, Bob was the most assertive. He seemed to 'own' the care provided, perhaps because he paid for it privately
Date: 20.1.15

Bob was the primary carer for his wife. He employed his own carer, mainly for household chores, while providing care for his wife himself, a role he considered crucial to maintaining their independence.

Carers and company:

Most participants were glad to see any of the carers, not one in particular, even with a time-limited visit: *Well it's good for them coming in and having a talk tae me and that and then they go away* (Morag). One participant reported that he was lonely and could not go outside unless he was accompanied and saw care workers' presence as more than just company: *I need them to take me to the shops. It's more than company* (Jock). Participants also need carers for company: *If I don't get out of the house with them then I don't have any company at all* (Ivy). Moreover, they described how they enjoy it when carers take time to sit and chat with them: *Sitting even for a wee while meant that I could have a chat with someone* (Steve).

The need for company for some meant taking a long bus journey to travel to the day centre to seek the company of others: *It's a long way to go but it's worth it to have someone to talk to* (Kirsty). The following section illustrates how participant narratives suggest the belief that if their carers liked them, they would more likely receive extra help and favours from them.

Being liked, being cared for:

Participants wanted to like their carer: *I like the people ... the ladies that came ... they were very nice and they're still nice to me when I meet them on the bus* (Ros). Moreover, they wanted their carers to like them. Carers being nice to them was used as a gauge to determine whether they were liked: *They know me and they're nice to me* (Jan), as was the receiving of gifts: *They buy me gifts back from their holidays 'cause they like me* (Kirsty).

Participants felt that, if they were liked by their carer, they would more likely receive 'extras'. 'Extras' denote care or tasks provided outwith the expected boundaries of care.

Extras were considered to be a positive addition, and participants welcomed the contribution they made. Participants did not expect them, as they were at the discretion of each carer, but included tasks such as bed-making, running errands and, of note, the putting out of rubbish bins for collection. It was often the more mundane tasks that were most appreciated: *She empties my bin, she always makes time ... just managed to squeeze it in* (Jan). Being liked meant that she would get her bed made: *I know that they don't always make beds but they do for me 'cause they like me!* (Ivy). Running errands was the norm for some carers: *She runs errands for me, if I ask her* (Kirsty).

Some participants were keen to ensure they were not seen as a problem. Participants perceived that if they were 'no bother' to their carers, they would probably be liked and receive help over and above what was planned for them. There was a perception that being compliant receivers of care would ensure they were liked and that they would receive help over and above what was planned for them.

They would come in three times a day, I remember they weren't supposed to make the bed but they did make the bed and I think they liked me 'cause there wasn't very much to do and I liked them and when they stopped I was sorry and when I meet them as I do, they're always nice to me because I wis'nae any bother to them. (Ros)

Just going that 'extra mile' meant much, especially when it was offered and not asked for.

There was one woman, she was a kinda older woman and eh she made a cup of tea [raising voice] and I said oh none of them [strong emphasis] have offered to do anything like that! (Ellie)

Alternatively, some participants actively engaged with their carers to initiate favours. Asking for favours was more frequent where participants considered the carer as a friend first and as a carer second.

They become more a friend than a carer. That's right, you get to know them. (Maggie)

I says, "Eh ... can I ask yae tae dae me a big favour?" She says, "What's that?" I says, "You would'nae mind going tae the chip shop and getting me a single fish would yae?" If I run out of milk they'll go tae the shop and get me it. (Kirsty)

Kirsty knew that her physical disability initiated carers to help with shopping if she asked for it.

Sometimes, the professional relationship between carer and participant spilled into that of friendship with evidence of the reciprocal giving and receiving of gifts:

One of them carers brought me slippers eh a nice cardigan and chocolates ... and I give them stuff. (Morag)

I always buy her a gift when I go on my holidays, just a fridge magnet. (Ellie)

One of the key questions asked of the participants was about their expectations of care. Reports of satisfaction of the care service were interspersed with concerns of an unexpected and uncertain service.

4.7.2 Care expectations

Attributes of care:

Participants regarded kindness and consideration as key attributes of good care. Moreover, a good carer would help them to feel safe and confident.

The positive thing about having good carers is that you feel safe, it gi'es [gives] me mair [more] confidence. (Arthur)

Participants expressed appreciation of the time and effort taken by some carers to ensure that they were dressed and presentable as keeping up standards of hygiene and appearance was important to them.

Eh, just wi' no' being able tae get myself dressed and a' that. I know I'm going to be dressed and I'm going to be presentable. (Issy)

Another participant was unhappy that a carer, from the befriender service, sent to accompany her out of the house, did not make her decisions for her. This physically agitated participant viewed her carer as someone who would relieve her of any decision-making, an area she struggled with on a day-to-day basis.

You know ... helping me and things like that, you know, instead o' saying, "I don't know, I can't help you wi' that," you know, like that kind of thing. (Flora)

A tension existed between independence versus a relief from decision making. Her perception of the role of the carer was different to that which was provided, leaving her feeling disappointed with the service.

And we go out for walks as well and then go to the shops, she just goes to do her shopping and then she's actually supposed to be with me in case anything – God forbid – happens, a few times things, I have taken dizzy turns and I'm shouting on her and I don't know where she is, she's away tae the other end o' the shop picking her shopping up. (Flora)

Reflection: *Expectations.* Flora had high but false expectations of the interview. She hoped that I was able to help her to improve her situation and reduce her anxiety. This was the most difficult interview for me. I explained to her my role as researcher and referred her to the day centre manager for after-care. Thereafter, I explained my role as researcher prior to future interviews
Date: 28.6.15

Flora was the only participant to receive befriender care while all others received help for physical care and domestic care.

Continuity of care:

Ideally, participants expected care that was delivered by professional, friendly carers, preferably the same carers, who they knew and who knew the routine and could be left to get on with the job.

Well, the same person knows where everything is, and how to switch on the shower... you know, the routine ... (Ellie)

This was emphasised further by another participant.

I've had the same girls fae I started getting the carers, there's one girl in particular, I've had her all the time, constant, you know, sometimes its morning, lunch or tuck time and that, big G, she's a lovely lassie. (Kirsty)

Reference was made to the lack of continuity of care, tempered with satisfaction of the carer.

Well I get sometimes different people now and again, you know, but eh they're seem to be a good lot o' women, they're good at their job, you know what I mean, they make sure that I get my pills you know.
(Ivy)

I don't always get the same carer which is a nuisance as I have to retrain them. (Ellie)

By retraining, Ellie meant that she had to spend time explaining to each new care worker where everything was and what she expected of them. In fact, she needed to train, rather than retrain them. For Ellie, the continuity of care worker was very important.

Physical care/domestic care:

Physical and domestic care includes help with tasks such as washing and dressing, meal preparation, housework and medication administration. The majority of participants had been assessed for and were receiving care, including help with washing, getting up and going to bed. There were however, reports of uncertainty regarding the role of the carer, with confusion over what to expect at each visit, having little or no influence on the outcome.

I do my own washing, right and I take it down the stairs, spin dry it and I try tae iron it ... They say, "You've got far too much, we can'nae do it." I says, "But that's your job, that's what you're getting paid for." (Jock)

Many participants expressed appreciation for efforts taken by some homecare workers: *They are really good them carers, always make an effort* (Maggie). There was general satisfaction with the visits, and expectations were reached in the majority of cases, namely, checking that their clothes were clean and that they were eating properly; that the house was tidy and that they 'behaved themselves', although the meaning of the latter was never qualified.

They make sure I've got clean clothes, make sure I'm behaving myself ... and eating properly. Somebody that just mair or less comes in and makes sure I'm a' right, makes sure I've got clean clothes, you know, the house is tidy enough. They have a good look roond aboot and make sure everything's a' right and I've got food in the hoose and that. (Arthur)

Participants expected to receive physical care and viewed it as being important for their physical wellbeing. Likewise, they expected to receive domestic care and housework.

Time spent on each visit was another issue frequently expressed. Unreliable visit times included an earlier or later than expected care service, insufficient time allocated per visit and the impact that this had on the participant's wellbeing.

4.7.3 Care time

Unreliable care time:

Carers arriving later than expected had an impact on the wellbeing of participants. One told how waiting for a frequently late care service affected her plans for her day, adding to her social isolation: *If I want to go anywhere I can't go because I'm waiting for the carers to finish* (Ellie). Another partially sighted participant had signed up to go to reading and writing classes in the evening, but had to cancel them because she was having to wait for her carer to come, who was invariably late: *Because I had to wait for her again, I cannae go to my reading and writing classes* (Morag). For this participant, learning to read and write was very important. Having learning difficulties meant that, when she was young, there was little in the way of literacy support and she did not have the confidence until now to do anything about it. Her disappointment was clear to see.

As well as affecting social life and cognitive development, unreliable visit times negatively impacted physically, with people waiting to be helped to go to bed and getting cold in the process: *About two and a half hour I'm sitting with my, my nightdress on and its, it's, it's [emphasis] cold, I get cold ... it's kinda long tae wait.* (Ellie)

Not many participants complained about an unreliable service. However, one participant made a stand against what he felt was unacceptable visit times when a carer visited later than he had expected, leaving him waiting for his pre-breakfast medication. Jock conveyed his annoyance that his carer questioned why he thought being late was not good enough.

Once I lost the head wi' one o' them, I said, "This is not good enough," ... She said to me, "What do you mean it was not good enough?" I said, "Quarter to nine o'clock in the morning to settle the inside o' my stomach before I eat anything but look at the time it is now, it's a quarter to ten, you start at eight o'clock." (Jock)

Limited care time:

It was almost considered a given that the care participants received, improved their physical wellbeing, however, not enough time was allowed to provide the homecare that had been planned. Visit times could last up to one hour, with the majority of visits taking half an hour, depending on what was to be done and who was doing it: *Maist o' the ladies stay about 20 minutes, half an hour* (Arthur). The timing of each visit was a key concern expressed, with visits sometimes being earlier or later than expected:

Sometimes they would come in for say half an hour and other times maybe they're only in ten minutes, it depends on what they're going to do. (Betina)

Concerns raised included restricted time allocation for visits, leaving participants feeling rushed: *I feel rushed ... I need more time* (Ellie). The general consensus was that more time should be allocated during and between home visits with concern that time taken up in travelling results in less time spent with them.

I think there should be more time given for the people for travelling time, there should be more time, and there's not enough time given to the patient itself. (Ros)

Another frequently expressed concern regarded the time that carers spent completing paperwork during each visit, which was considered to impact negatively on care provision: *They seem to have an awful lot o' writing up to do* (Ellie). This further reduced the time spent providing care: *By the time they write up all their reports and everything, it's just a quick shower* (Steve). Steve looked forward to his weekly shower and appeared visibly disappointed that it was so quick.

The following section highlights how changes in care provision were often made without participants' consultation or collaboration.

Changing patterns of care:

There was evidence of changes made to care visits without participants' prior consultation or collaboration.

I was supposed to get somebody else out on the Sunday but they stopped and they never sent anybody in her place and I wasn't informed. (Issy)

Changes in care involved the reduction of care visits received, or, in some cases, the complete cessation of visits without prior consultation.

Unexpected changes in care affected participants' day-to-day plans and, for Flora, this was a frequent occurrence.

She was on holiday and they never replaced anybody and no phone call to tell me ... and eh, it does affect me because I plan, I'm looking forward for them to come so I can go to the shops with them. (Flora)

For this participant, going to the shops gave her the opportunity to both get out of the house and to have company. Having someone to talk to, if only for a short time, helped to reduce her feelings of isolation and loneliness.

One reason for care changes was because the perceived needs of the participant had altered: *All of a sudden, because I could do my own personal care it was stopped (Jan)*. There was uncertainty as to who had made this decision. All she knew was that she had had no prior knowledge of the changes made to her care plan. Staffing problems involving sickness or holiday cover formed another reason for changes in care provision.

Most of the changes in care provision were made at short notice.

Last week she just phoned me in the morning before nine o'clock. "L is not coming." I said, "What about somebody replacing her?" I said, "You should have at least informed me beforehand somebody's not coming, 'cause I had planned my day," and then she said, "Oh, sorry about that," and eh, "She just won't be coming today, she'll come next week," and when she goes on holiday as well I don't have anybody replacing her, she was off for two weeks and it's quite a long time being without somebody. (Flora)

Unlike most, Flora did not readily accept last-minute changes to her care and made sure her carers knew that she should have been informed.

For another, care cessation encouraged self-reliance: *I did miss it. It was inconvenient but I just picked myself up and as they say 'dust yourself down' and get on with it (Jan)*. She accepted the decision without question. Uncertain patterns of care proved to be more than inconvenient.

Unexpected changes to care provision had negative health consequences. For one participant, the sudden cessation in care provision had a profound effect.

I just started panicking, I was in a helluva shock that day, 'cause eh I was just shaking and trembling and could'nae get tae the shops and a' that, cause I do start taking these panic attacks. (Flora)

This participant relied on her care visits as the only means to get out of her house. She was clearly upset by this and the prospect of having a panic attack.

Of note was that, in spite of changes in care provision, often without prior notification and associated participant dissatisfaction, there were few reports of service refusals. On the contrary, participants were more likely to accept the care on offer, irrespective of the quality of care provided. The following section illustrates the reasons why refusals are unlikely, why care is more often than not accepted, as well as the limitations of care.

4.7.4 Care boundaries

Accepting care:

Some participants accepted care because of the greater concern that refusal may affect them living in their own home. Care was more often than not accepted in case refusal of services meant that it would not be on offer again.

If you feel you don't want it they will turn round and if you don't want it ... you don't need us and say what's the point of us coming in. (Ros)

A tension was evident between the need for independency versus the dependency on homecare and the fear of losing it.

Although not a prevalent theme, there was a disregard for the amount of paperwork involved in the acquisition of care which required the help of agencies to help in its completion.

I just get fed up wi' a' the forms you get sent in; we got somebody from the health service to come and help us with them, cause it's ridiculous the amount and they're asking the same question. (Morag)

Refusing care:

Most participants were very explicit about the reasons why they might refuse care when the care worker attempted to deliver care. In reality, they rarely refused care because of the greater concerns that: i) this may affect them living in their own homes (*If I refuse carers coming in tae my hoose [house] I might not be able to live there for very long* (Ivy)); or ii) if care was refused, it may not be offered again. In this study, only two participants described refusing planned care. Helen refused care because of the arrival of a male carer to provide stoma care in place of the expected female carer, and Kirsty refused care because of her experience of inappropriate caring.

Helen refused a male carer to provide stoma care because of his gender and her own embarrassment.

One day my, my bell went and I goes to the door and this wee man's standing wi' his bunnet on he says eh, "I'm from homecare dear, are you Mrs O?" I says, "Yes," I said, "But you're no coming tae me son." (Helen)

When asked how this made her feel, Helen replied that she felt embarrassed: *I did'nae know the wee man and I would'nae feel so embarrassed if I was in the hospital* (Helen). There was better acceptance of a male carer within a hospital setting than that of a male carer in a home setting.

Kirsty reported an incident of service refusal where she was given a dry shower. She proceeded to explain what she meant by this.

You've heard o' dry shampoos ... have you ever heard o' a dry shower? So she gets my wee scrunchie and she puts this gel oan it and she hands me one and I'm looking at it and I had tae rub this doon oer me without water 'cause she doesn't want to get wet ... so once we'd done that, then she put the shower on, so I phoned up about it, I says, "Don't send me that girl again," ... I says, "I've heard o' dry shampoos," I says, "But my God, that's the first time I've had a dry shower." (Kirsty)

Reflection: *Passive.* Helen furtively, almost apologetically, told her story which I doubt she would have disclosed had Kirsty not first told of her incidence of service refusal
Date: 5.8.15

In this instance, the participant contacted the homecare service provider and asked them not to send that care worker to her again. Others were less likely to report their concerns. One man expressed why he might refuse care if his wife's privacy was compromised: *Just make sure my wife gets privacy when it comes to showers and such like, you know, keep her clean* (Bob); or if they did not get on with the care.

You might not actually want that particular individual ... well if she's no pleasant, you're no wanting anybody coming in like that you know.
(Elizabeth)

Limitations of care:

A strong sense of empathy was evident amongst participants. Waiting patiently, knowing that the reason for a late visit could be due to others having a greater need at that time, formed a prevalent theme: *I don't like to complain, there are other people much worse than me* (Ellie).

Participants proved much more forgiving when told that the reason for being late was due to others needing more urgent attention.

Int: *Do they always come at the time they're meant to come?*

Flora: *Em, no, well sometimes I feel as if there's somebody more needing than I am and they have to wait for somebody, an ambulance coming for someone ...*

Ellie: *Well, it could be any time ... I think I'm the last in her line ... if there's anybody else needing more attention ... like em if they need to be given medication that's given priority.*

Although there was concern and sometimes annoyance about having to wait for carers to arrive, generally, all participants accepted without question that other people may have a greater need and were keen to express that this was the reason for a late visit.

It's not that they're unreliable it's just that perhaps they've got so many other people to see. (Helen)

and I was usually up and I had made my breakfast the time they'd come ... because they were coming round other folks. (Jan)

Well actually they've got quite a few people tae dae, it's no' just me.
(Ina)

Participants were keen to help their carers if lateness was due to carers being with others: *They would come in the house but I had already made my bed ... cos I try to help them* (Jan).

These poignant examples reveal that tensions exist between the benefits of receiving homecare and a concern for the implications of not accepting it.

4.7.5 Care tensions

Independence versus dependence:

The analysis revealed a tension between the desire for independence to live at home and the dependence on homecare services to enable this. According to one participant, the ability to be self-sufficient depended on how positive her attitude was towards the task. This situated the onus and responsibility with her. Even when the task was becoming more difficult, they apportioned the blame to themselves if they did not remain positive.

Sometimes you feel like you want more help, sometimes you feel you just want to get on and try and do it yourself ... you know, trying to think positive that you can do things ... but it's getting more difficult all the time. (Flora)

Nonetheless, many participants ensured they received the optimum care possible in the time given. For example, in recognition that visits were time-limited, participants tried to maximise the time spent with their carer, by being ready for their arrival.

Well I've got, always got to be ready, you know, just to be ready for them coming. (Ellie)

For the girls coming in, I've got things a' ready for them. (Kirsty)

Some participants voiced concerns that if they were seen as being too independent their care package may be stopped. However, at the same time, they wanted to be as independent as possible and to do as much for themselves as they could.

So I don't lose her, I'll do o' the housework myself. (Steve)

I do a heck of a lot which I should'nae be doing ... I help staff before they arrive. (Jock)

Independence is very important to me but I don't want to lose my carer as she helps me in so many ways. (Maggie)

The value that participants placed on independent living appeared to be related directly to the concern for alternative institutionalised, dependent care. Institutional care was considered to be the alternative to homecare and distasteful to most.

Homecare versus institutional care:

Participant discussion around care homes revealed complex interrelated dimensions. Throughout the interviews, participants frequently expressed strong and significant concerns, irrespective of the discussion topic. Living at home was viewed as a means of avoiding living in institutional care and was therefore deemed important: *Oh aye, I like to be at home, I don't want to go in'tae a home or anything like that* (Flora).

Humour was used as a tool for relaying an upsetting narrative: *They may as well shoot me, take me and shoot me* [Laugh] (Elizabeth). All other participants within the group concurred: *I says, "Well I'm no wanting tae go in a home," I tell them, "I'll live in my house as long as I'm fit tae do it"* (Morag). Although interspersed with humour, this sentiment was shared by all within the discussion group that institutional care had to be avoided at all costs.

Living in a care home was linked to loss of independence and deterioration.

They seem to lose something ... independence I know a lot o' people who've went in'tae homes and they've had mair care than I get and I get quite a bit and they seem tae go doonhill. (Arthur)

One participant, describing negative media reports of life in a care home, endorsed the perception of care home residents as being 'poor people' and the carers as being 'terrible'. This further affirmed their insistence to live at home and their resistance to alternative institutional care.

I've heard of some poor people that pay to stay in some care homes, I don't mean like this, a day centre ... a care home, it was on the television recently and it was terrible what they were doing to them, the carers, you know supposedly carers ... (Steve)

Participants who spoke about living in a care home as an alternative to living at home, spoke about it in negative terms. The potential loss of independence and loneliness meant that they would more likely accept the homecare on offer in spite of their satisfaction or otherwise of the homecare service received.

They don't always do what I thought they should do but I still want them to come 'cos it keeps me independent and gives me company.
(Ivy)

Loss of independence by being admitted into institutional care was a key concern, a concern they offered without being asked.

Reflection: *Fear.* I was surprised how every participant expressed their dislike for being admitted into a care home, without being first asked. Such was the strength of feeling! It wasn't part of the interview schedule. It was almost as if they thought I had some influence on their destiny.
Date: 12.8.15

Homecare versus loneliness:

Participants held a belief that homecare and the company of carers reduced loneliness and isolation. Almost all participants expressed their fear of social isolation and described living at home with little or no contact with anyone on a daily basis: *I won't see anybody ... I won't speak to anybody ... nobody would come tae my door* (Ros). Being in the house without the chance of getting out was linked to feeling isolated: *If I don't get out of the house then there's isolation* (Issy). Homecare offered the opportunity to connect with someone and provided temporary respite from feelings of loneliness and isolation.

Well she comes in for a couple of hours, you feel that at least somebody's there with you ... you know, for a few hours and then she's got to go and that's it, you feel isolated again, you know ... I just feel lonely, you know, you're on your own again. (Ellie)

I look forward to someone coming because I'm, I'm, I'm very [emphasis] lonely. (Betina)

For those who lived alone, loneliness was a particular issue and formed a prevalent theme: *Well I quite like them coming, 'cause it's company* (Ros). Keeping busy to prevent loneliness was no substitute for the company of others: *I can keep myself busy wi' things I'm having to do, but I still feel lonely* (Kirsty).

4.7.6 Emotional impact of receiving homecare

The participants appreciated the care they received that went beyond what was planned for them. General satisfaction in all aspects of homecare received was reported from the one participant who employed their own carer. The remaining participants, who received council-run homecare, reported varying degrees of satisfaction/dissatisfaction in the homecare service they received.

Recurring themes across the dataset included being ‘appreciative’ of the care they received to help them stay at home for as long as possible and ‘grateful’ if they were liked by their carer and received favours. Other themes included ‘accepting’ that others’ needs may be greater, leaving them waiting for their care, and ‘unhappy’ if their care had been changed without their prior knowledge or consultation. In addition, participants described being ‘concerned’ about the possibility of losing their independence by being admitted into institutional care. A dominant theme was of ‘loneliness’, because they had little company on a day-to-day basis and therefore looked forward to the carers’ visits. Loneliness overrode all other concerns about the service the participants received: *I don’t see anyone on a day-to-day basis; and nobody ever comes to my door* (Kirsty), and for that reason, the participants looked forward to their carer’s arrival. The participants recognised that homecare helped them to remain independent and in their own homes for longer and, for this reason alone, were grateful for the service provided. Participants expected a reliable, timely service with professional and friendly carers. They expected to be admitted into a care home should they require more care than they got at home and feared the loss of independence associated with alternative care home living.

Although not necessarily advocated by Ritchie et al. (2014), sorting the narrative under the five relevant themes helped in preparation for the development of the matrices revealed in Stage 5.

Stage 5: Data Summary – Development of Matrices

So far, the process of framework analysis (Stage 1–4) had enabled the visiting and revisiting of the raw data to establish initial themes and sub-themes. Changes made during this process (highlighted in red in Table 8) were as a result of re-evaluating the headings to ensure they were an accurate representation of the data.

The final stage in the data management process involved the development of a series of five matrices, one for each theme, progressing from descriptive to interpretive accounts. The matrices illustrate the process of data refinement from themes to sub-themes to elements to categories and, finally, to analytic themes.

Table 9 presents Matrix Theme 1, 'Care Values', and illustrates these by providing extracts under each sub-theme. This matrix was selected to demonstrate the process. For further illustration and to promote an understanding of how other themes and subthemes were developed, the remaining matrices can be found in Appendix 17.

Table 9: Matrix Theme ‘Care Values’

Theme 1: Care Values		
Sub-theme Living at home and independence	Sub-theme Carers and company	Sub-theme Being liked and being cared for
Participants want to have homecare to be able to stay in their own home: <i>I want to have homecare cos I think it keeps yae in yer ain environment</i> (Bob)	The need for company for some means taking a long bus journey to go to the day centre to seek the company of others: <i>It’s a long way to go but it’s worth it to have someone to talk to</i> (Kirsty)	Carers being nice to them is used as a gauge to determine if they are liked: <i>They know me and they’re nice to me, so they like me</i> (Jan)
Participants express how they are still able to live at home: <i>Staying at home, well I would’nae like to leave this place cos I’m really quite able still</i> (Jock)	Participants are glad to see their carer, even with a time-limited visit: <i>Well it’s good for them coming in and having a talk tae me and that and then they go away and there’s no time</i> (Morag)	If they are liked by the carer they are more likely to receive ‘extras’. Extras denote care or tasks provided outwith expected boundaries of care: <i>She likes me. She empties my bin, she always makes time ... just managed to squeeze it in</i> (Jan)
Participants want to be able to do what they want, whenever they want in their own home: <i>I love my own house. I live on my own. I can go down the stair any time I want tae ... and I can put the telly back on and I plug it in and that</i> (Morag)	One participant could not go outside unless he is accompanied. He saw his carer’s presence as more than company: <i>I need them to take me to the shops. It’s more than company</i> (Jock)	Being liked means that she will get her bed made by the carer on a regular basis: <i>I know that they don’t always make beds but they do for me ‘cause they like me!</i> (Ivy)
Living at home for as long as possible is a prime consideration: <i>Oh that’s a lot. It’s a big yin for me. Yes I want tae try and stay in my own house as much as I can</i> (Ivy)	Participants enjoy it when carers take time to sit and chat with them: <i>Sitting even for a wee while meant that I could have a chat with someone</i> (Steve)	If they are liked they will receive help over and above what was planned for them: <i>They would come in three times a day, I remember they weren’t supposed to make the bed but they did</i> (Ros)
	Participants need carers for company: <i>If I don’t get out of the house with them then I don’t have any company at all</i> (Ivy)	Participants use the receiving of gifts as a gauge to determine if they are liked: <i>They buy me gifts back from their holidays ‘cause they like me</i> (Kirsty)

Plain text: indicates my summary. *Text in italics*: indicates direct quotation from participants.

The next stage of analysis, abstraction and interpretation, provided a deeper interpretation of the data.

4.8 Abstraction and Interpretation

While some data remained at the descriptive level, other themes were taken to a higher level of generality; from explicit meanings grounded in the raw data, to implicit explanations generated by inferences made. According to Ritchie et al. (2014), interpretation requires drilling down into the meanings made, in order to gain a deeper understanding of the phenomena.

This process required the breaking down and recombining of ideas at a higher level of interpretation. Dey (1993) refers to this process as splitting and splicing. Questions asked at this stage included: What does each theme mean? What are the meanings underpinning it? What conditions gave rise to it? So far, the focus had been on identifying data that were similar and the subsequent development of themes. However, this drilling down revealed other more complex connections, which improved my understanding of the meanings, those that underpinned the participants' experiences of homecare. As such, some of the previously identified participant quotations will appear again in this analysis to revisit these experiences to reveal these deeper understandings.

Abstraction and interpretation involved two stages; the development of categories, and of a final thematic framework.

Development of Categories:

The development of categories involved a process whereby detected elements were drawn from data summaries for each matrix. Selecting the first sub-theme, 'Living at home and independence', Table 10 provides an example of how detected elements were identified from the data summaries.

Table 10: Sub-themes to elements ‘Living at home and independence’

Data Summaries for Sub-theme: Living at home and independence	Detected Elements
Participants want to have homecare to be able to stay in their own home: <i>I want to have homecare cos I think it keeps yae in yer ain environment</i> (Bob)	<ul style="list-style-type: none"> • Want to live at home • Homecare is valued
Participants express how they are still able to live at home: <i>Staying at home, well I would'nae like to leave this place cos I'm really quite able still</i> (Jock)	<ul style="list-style-type: none"> • Able to stay at home alone
Participants want to be able to do what they want, whenever they want in their own home: <i>I love my own house. I live on my own. I can go down the stair any time I want tae ... and I can put the telly back on and I plug it in and that</i> (Morag)	<ul style="list-style-type: none"> • Want to be independent • Living at home alone is not a problem
Living at home for as long as possible is a prime consideration: <i>Oh that's a lot. It's a big yin for me. Yes I want tae try and stay in my own house as much as I can</i> (Ivy)	<ul style="list-style-type: none"> • To live at home for as long as possible • Living at home is valued

The identified elements were then compared to see which of them related to the same idea or issue. All related elements were grouped together and referred to as categories.

Table 11 demonstrates the outcome of this process.

Table 11: Elements to categories ‘Living at home and independence’

Detected Elements	Categories
<ul style="list-style-type: none"> • Want to live at home • Able to stay at home alone • Want to be independent • Living at home alone is not a problem • To live at home for as long as possible • Living at home is valued 	<p>Elements relate to wanting to live at home independently for as long as possible</p> <p>Category: Home means independence</p>
<ul style="list-style-type: none"> • Homecare is valued 	<p>Element relates to valuing homecare to be able to live at home</p> <p>Category: Homecare valued</p>

Tables 12 to 15 demonstrate the same process carried out for the remaining two sub-themes relating to ‘Care values’: ‘Carers and company’, and ‘Being liked and being cared for’.

Table 12: Sub-themes to elements ‘Carers and company’

Data Summaries for Sub-theme: Carers and company	Detected Elements
The need for company for some means making a long journey to seek the company of others: <i>It’s a long way to go but it’s worth it to have someone to talk to</i> (Kirsty)	<ul style="list-style-type: none"> • Prepared to travel to seek company
Most participants are glad to see their carer, even with a time-limited visit: <i>Well it’s good for them coming in and having a talk tae me and that and then they go away and there’s no time</i> (Morag)	<ul style="list-style-type: none"> • Glad to see carer • Good to talk even if time-limited • ‘There’s no time’
One participant could not go outside unless he was accompanied. He saw his carer’s presence as more than company: <i>I need them to take me to the shops. It’s more than company</i> (Jock)	<ul style="list-style-type: none"> • Unable to go out unless accompanied • Carers seen as more than company • Carers needed to take them to the shops
Participants enjoy it when carers take time to sit and chat with them: <i>Sitting even for a wee while meant that I could have a chat with someone</i> (Steve)	<ul style="list-style-type: none"> • Enjoy chatting to the carers even for a short time
Participants need carers for company: <i>If I don’t get out of the house with them then I don’t have any company at all</i> (Ivy)	<ul style="list-style-type: none"> • Carers get them out of the house • Carers provide company

Table 13: Elements to categories ‘Carers and company’

Detected Elements	Categories
<ul style="list-style-type: none"> • Glad to see carer • Carers seen as more than company • Prepared to travel to seek company • Carers provide company 	Elements relate to the need for company Category: Company needed
<ul style="list-style-type: none"> • Enjoy chatting to carers even for a short time • Good to talk even if time-limited • ‘There’s no time’ 	Elements relate to the need to talk Category: Good to talk
<ul style="list-style-type: none"> • Carers get them out of the house • Unable to go out unless accompanied • Carers needed to take them to the shops 	Elements relate to a dependency on carers to get them out and about Category: Care dependency

Table 14: Sub-themes to elements ‘Being liked and being cared for’

Data Summaries for Sub-theme: Being liked and being cared for	Detected Elements
Carers being nice to them is used as a gauge to determine if they are liked: <i>They know me and they’re nice to me, so they like me</i> (Jan)	<ul style="list-style-type: none"> Participants think carers like them if their carers are nice to them
If they are liked by the carer they are more likely to receive ‘extras’. Extras denote care or tasks provided outwith expected boundaries of care: <i>She likes me. She empties my bin, she always makes time ... just managed to squeeze it in</i> (Jan)	<p>If carers like them they:</p> <ul style="list-style-type: none"> Put their rubbish bins out for collection Provide ‘extras’ Make time for them
Being liked means that she will get her bed made by the carer on a regular basis: <i>I know that they don’t always make beds but they do for me ‘cause they like me!</i> (Ivy)	<ul style="list-style-type: none"> Carers make the bed if they like them
If they are liked they will receive help over and above what was planned for them: <i>They would come in three times a day, I remember they weren’t supposed to make the bed but they did</i> (Ros)	<ul style="list-style-type: none"> Carers make their bed even though they are not supposed to
Participants use the receiving of gifts as a gauge to determine if they are liked: <i>They buy me gifts back from their holidays ‘cause they like me</i> (Kirsty)	<ul style="list-style-type: none"> Carers buy them gifts if they like them

Table 15: Elements to categories ‘Being liked and being cared for’

Detected Elements	Categories
<ul style="list-style-type: none"> Participants think their carers like them if carers are nice to them Carers put their rubbish bins out for collection Carers provide ‘extras’ Carers make time for them Carers make their bed if they like them Carers make their bed even though they are not supposed to Carers buy them gifts if they like them 	<p>Elements relate to being liked and receiving extra care not necessarily planned for</p> <p>Category: Being liked and being cared for</p>

Matrices representing the remaining four main themes can be found in Appendix 17. Collectively, the information gained from all the matrices helped to develop the final thematic framework.

4.8.1 Final thematic framework

In developing the final thematic framework, the categories were revisited and all those with commonalities were placed together. The identification of key concepts reduced the data further still, while verbatim quotations ensured these key concepts stayed true to the original meaning. Table 16 illustrates the process of moving from categories to key concepts and, finally, analytic themes. Analytic themes were derived by examining the key concepts drawn from the categories. At this stage, my analysis moved away from the language used by the participants to developed more abstract themes, which helped me to achieve a greater level of integration within the data and in the representation of the data.

Finally, the data were reduced to two analytic themes: ‘Care values’, and ‘Care burdens’. The ‘Care values’ theme represents positive aspects of homecare that participants value, while ‘Care burdens’ represents aspects of homecare that participants consider negative. Each theme has an associated inference; ‘being with’, and ‘doing to’.

Table 16: Final thematic framework

Categories	Key Concepts	Analytic Themes
Home means independence	Homecare valued <i>“I’ll live in my house as long as I’m fit tae do it”</i>	Care values <i>‘being with’</i>
Homecare valued	***	
(Homecare) contact reduces loneliness	Independence valued <i>“I can go down the stairs and put my own telly on”</i>	
Continuity of care	***	
Independence valued	***	
Physical care	Physical and domestic care <i>“They help me wash and clean the house”</i>	
Domestic care	***	
Being liked and being cared for	Being liked, being cared for	

<p>Carers valued</p> <p>Care acceptance</p> <p>Care priorities</p> <p>Consistent care</p> <p>Good care and caring</p> <p>Good to talk</p> <p>Humour as coping strategy</p>	<p><i>“They make my bed cos they like me”</i></p> <p>***</p> <p>Others needs take priority <i>“There are other people much worse than me”</i></p>	
<p>Changing care patterns</p> <p>Waiting for care</p> <p>Lonely, housebound, alone</p> <p>Negative care outcomes</p> <p>Independence versus dependence</p> <p>Negative perception of care home admission</p> <p>Avoidance of care home living</p> <p>Uncertain care expectations</p> <p>Service refusal</p> <p>Continuity of care lacking</p> <p>Care tensions</p> <p>Care dependency</p> <p>Unreliable visit time</p>	<p>Effects of care changes <i>“I started to panic”</i></p> <p>***</p> <p>Independence versus dependence <i>“Independence is very important to me but I don’t want to lose my carer”</i></p> <p>***</p> <p>Fear of care home admission <i>“Well I’m no wanting tae in a home”</i></p> <p>***</p> <p>Care expected <i>“Makes you feel safe”</i> versus Care given <i>“I don’t want a male carer”</i></p> <p>***</p> <p>Fear of refusing services <i>“If you don’t want it ... you don’t need us”</i></p> <p>***</p> <p>Loneliness, isolation and connectivity <i>“I won’t see anybody... I won’t speak to anybody”</i></p> <p>***</p> <p>Unreliable visit time <i>“I feel rushed ... I need more time”</i></p>	<p>Care burdens <i>‘doing to’</i></p>

4.8.2 Developing understanding

Care values – being with:

Care values represent all those that participants value, namely; their independence, living at home, and receiving the right type of care at the right time. 'Being with' formed a core component of a care value where participants welcomed the opportunity that homecare presented to allow them to connect with someone, even for a limited time. Rarely the primary reason for providing homecare, 'being with' was often the welcome 'spin-off' from physical care visits and viewed as an opportunity to connect with people even for a short time: *Well it's good for them coming in and having a talk tae me and that and then they go away, then there's no time* (Morag). Participants looked forward to their carer's visits to prevent loneliness and, in some cases, isolation, and they appreciated it when carers took the time to have a chat with them.

Well she comes in for a couple of hours, you feel that at least somebody's there with you ... you know, for a few hours and then she's got to go and that's it, you feel isolated again, you know... I just feel lonely, you know, you're on your own again. (Ellie)

Participants liked 'being with' their carer. They hoped that they would get on with their carer as they valued being with someone for company, especially for those who had little else in the form of day-to-day interactions: *I look forward to someone coming because I'm, I'm, I'm very [emphasis] lonely* (Betina). They welcomed the opportunity to share a joke and used humour to convey concerns: *Well they may as well shoot me rather than go into a nursing home* (Elizabeth). Participants disliked having different carers who they had to get to know and re-train: *I don't always get the same carer which is a nuisance as I have to retrain them* (Ellie). However, having someone was preferable to having no one: *I would rather have them here for company than no one at all* (Jan).

The desire for independence and the need for company meant that participants were tolerant of care received that was outwith the care they expected or wanted. In particular, participants were tolerant of unexpected changes in care provision and inconsistent care-giving: *They don't always do what I thought they should do but I still want them to come 'cos it keeps me independent and gives me company* (Ivy).

Occasionally, carers were viewed as friends rather than carers with a relationship that spilled into that of friendship which participants appreciated: *They become more a friend than a carer. That's right, you get to know them* (Maggie). They felt that if they were liked by the carer, they would more likely than not receive extra attention, often in the form of favours, such as picking up shopping for them or putting the refuse bins out for them. A theme of going that extra mile resonated within this study. Some carers ran errands or did extra chores, which was appreciated by participants: *She empties my bin, she always makes time ... just managed to squeeze it in* (Jan). Most participants were grateful for help with mundane tasks that they struggled to do.

Care burdens – doing to:

Care burdens represent unwanted and unwelcome homecare, fear of care home admission and loss of independence, care tensions and service refusals. 'Doing to' represents two opposing aspects of homecare provision. Firstly, the benefits of the care provided allowed the participants to lead their lives at home. Conversely, there were drawbacks associated with the limitations of receiving an inappropriate care service that does not involve them in the decisions made about them and for them. 'Doing to', presents a dichotomy between the positivity of being helped with necessary daily physical tasks, and the negativity of having a care service into which they had little input. 'Doing to' comprised care of a physical and domestic nature, a service that focussed on Aids for Daily Living (ADL). In general ADLs consist of ensuring day-to-day activities are accomplished, such as getting people up and dressed and making their breakfast. Ideally, people are empowered through help and support to help themselves. Participants recognised this as a necessary service, one which helped them stay at home for longer. Looking presentable and being in their own environment, was of equal importance.

Eh, just wi' no' being able tae get myself dressed and a' that. I know I'm going to be dressed and I'm going to be presentable. (Issy)

I think it keeps yae in yer ain environment. (Bob)

Although there was evidence of satisfaction with reports of a timely and efficient service, there was compelling evidence to the contrary:

I feel rushed ... I need more time. (Ellie)

There was little mention of physical and domestic care as comprising a collaborative event with an agreeable package of care delivered at a mutually convenient time. On the contrary, participants received care that they had little input into, including ill-timed, unreliable visits impacting negatively on their health and wellbeing, such as having to wait for a late visit and getting cold.

I finally get up at half past seven ... about two and a half hour I'm sitting with my, my nightdress on and its, it's, it's [emphasis] cold, I get cold ... it's kinda long tae wait. (Ellie)

A recurring reason given by carers for being late was because care given to others had taken longer than expected. Participants frequently viewed others needs as being greater than theirs and accepted this without question or complaint: *I don't like to complain, there are other people much worse than me* (Ellie). This illustration of empathy for the needs of others was commonplace. For people with limited capabilities, help with daily activities is important. However, participants need to be involved in the care they receive and the decisions made regarding the type and timing of that care, therefore, 'doing to' can be both beneficial and detrimental. Although the majority of care has a physical focus, of equal importance is the care that focuses on the psychological, emotional and spiritual aspects of being human with the focus on 'being with'. Presently, homecare focuses on 'doing to', with the much-preferred option of 'being with' a far cry from present-day homecare services.

4.8.3 From mapping to conceptual typologies

Where categorisation is about identifying formal relations within the data, linkage is based on searching for patterns of association in the data based on how things interact (Ritchie et al. 2014). This involved identifying connections between typologies, either within or between the data. The reason that data hangs together in a certain way relies on either explicit accounts from the participants or explanations made implicitly by the researcher.

Thus far, the data had progressed through five stages of framework analysis, as detailed by Ritchie et al. (2014), with 'Care values' and 'Care burdens' identified as the two main analytic themes. The initial (revised) thematic framework identified connections and tensions explicit within the data. Throughout the process of analysis, these

connections and tensions have been condensed and relabelled to provide a better understanding of them.

4.8.4 Connections

Table 17 presents connections in order of importance, based on the frequency of reporting and emphasis.

Table 17: Connections between themes

Home, homecare and independence
Care homes and dependence
Homecare and connectivity

Home, homecare and independence: Participants were explicit in the view that living at home helped maintain their independence: *If I live at home then I'll be able to make my own decisions and do what I like* (Jock). For those who required it, homecare helped to keep people living at home and independent: *I know that I have to have help at home but that keeps me independent* (Ivy).

Care homes and dependence: Just as independence was associated with living at home, living in a care home was associated with increased dependency. Participants were explicit in the view that being admitted into a care home meant loss of independence: *If I go into a home I know I'll no be able to do what I want ... I'll lose my independence* (Jan).

Homecare and connectivity: Another key benefit to receiving homecare was the company that carers provided. Although not a primary reason for the provision of care, the fringe benefits included someone to talk to, especially for those who lived alone. Participants were explicit in the view that the company of carers was as important as care provided: *I need them to help me get dressed in the morning but I really like talking to them* (Elizabeth). *It stops me feeling lonely* (Jan).

4.8.5 Tensions

Tensions were identified early on in the process of analysis. Tensions identified within the initial (revised) thematic framework were condensed and re-categorised into three main tensions that impact directly on acceptance or refusal of care. Three main tensions existed between: i) homecare wanted versus unwanted inconsistencies in homecare provision; ii) accepting homecare to maintain independence at home versus relinquishing independence to the homecare service to stay at home; and iii) ‘being with’ versus ‘doing to’. Table 18 illustrates these tensions in the horizontal. Vertically, the left-hand side of the table illustrates desirable aspects that would likely contribute to homecare acceptance. The right-hand side of the table illustrates less desirable aspects that would likely drive homecare refusal. Each acceptance factor thereby exists in a state of tension with a refusal factor.

Table 18: Tensions affecting acceptance or refusal of homecare

Homecare acceptance	Tension	Homecare refusal
Homecare wanted	Versus	Unwanted inconsistencies in homecare provision
Accepting homecare to maintain independence at home	Versus	Relinquishing independence to homecare service to stay at home
Being with	Versus	Doing to

Within these new connections and tensions made, significant concepts were evident, concepts that participants valued as being important to them. These concepts were ‘the value of home,’ ‘the value of independence’ and ‘the value of connectivity.’

4.9 Discussion

This discussion section focuses on the research process, including the challenges to recruitment, in particular, hard-to-reach groups. The findings are deliberated and assessed against the research question, and the strengths and limitations of this study are highlighted.

Ultimately, nine participants chose to be interviewed individually, four participants chose to be interviewed in pairs, and another four chose to be part of a focus group. This resulted in the generation of a total of twelve interview transcriptions. Returning at the mutually arranged time, verbal consent to confirm continued agreement was obtained to establish on-going approval prior to interview, which is a particularly pertinent strategy to adopt for those with cognitive difficulties. As described above, one participant chose to have his daughter present to help fill in the gaps due to his memory loss. He had recently been diagnosed with early onset dementia and had lapses in memory, which he wanted his daughter to help him with. He was, however, able to understand the purpose of the research and give consent. An opportunity to speak to people who possibly had received homecare from the same homecare service provider as that included in Study 1 was true with all but one participant, who had a private homecare service arrangement.

Unfortunately, the venue was not always conducive for either privacy or comfort, and finding a suitable place to perform the interviews proved difficult. A pre-interview visit to each day centre helped identify a place for interviewing. However, these were not always suitable. Ideally, seating would have been arranged in a circle with the researcher within the circle, reducing the perceived imbalance of power (Stewart and Shamdasani 2015). However, on one occasion, the only space available for the focus group was the cloakroom, which was just big enough to accommodate four people with mobility problems, one in a wheelchair, one using a walker frame and two with walking sticks, with space enough to ensure visual contact with each other. On another occasion, an interview was conducted in a corridor leading to the toilets. Although it was quiet for most of the time, the interview was stopped and the audio-recorder paused every time someone passed by, which interrupted the tone and flow of the conversation. An inability of the participants to sit for long periods of time was observed, with one participant terminating their interview earlier than expected because of discomfort. A comfortable, less noisy environment with interruptions kept to a minimum and an interview lasting longer than the average 30 minutes may have elicited further disclosures of non-delivery.

Initially, rapport-building questions helped to put participants at ease with me, the equipment and each other (Quine 2017). An informal conversation aimed to ensure that everyone felt comfortable and safe enough to be able to talk without concerns for

breach of confidentiality. Before each interview, I restated the purpose of the interview and the role that I had, as the researcher, in this process. Managing expectations of being interviewed can prove problematic (Quine 2017). One participant saw this as an opportunity to obtain help and advice from the researcher. In this instance, I reiterated the role that I had and informed the day centre manager so that their concerns could be addressed.

Although the framework analysis approach was selected, other approaches to qualitative data analysis were considered. Grounded theory adopts an inductive approach, and deals with emerging issues previously unknown with the aim of generating new theory, guided by the analysis (Lawrence and Tar 2013). However, because the aim of this research was not to derive and assemble any new theories and concepts relating to homecare and non-delivery of homecare, this approach was discounted. Interpretive Phenomenological Analysis (IPA) was also considered because of the central concern of the meanings an individual ascribes to events which are only accessible through an interpretative process (Smith et al. 2009). This approach would fit with the aim of the investigation; to explore in-depth the experiences of homecare and service refusal from the unique perspective of those who experienced it. However, the specified ontological and epistemological underpinnings of IPA as an approach did not align with those of my own research (Larkin et al. 2006), whereas the clearly defined steps, such as those suggested by Ritchie et al. (2014), did. Another approach considered was thematic analysis, which provided the means to generate themes and sub-themes. However, this method is usually considered to be more appropriate for larger sets of data than that available here (Miles and Huberman 2001). One potential drawback of adopting thematic analysis is that its theoretical basis has been criticised for its lack of rigour, being too flexible an approach to be scientific (Popay et al. 2006). However, framework analysis offers its own strengths, each of which promote rigour. For example, framework analysis can be undertaken both during and after the data collection process by incorporating a reflexive element to the research. This enhances the transparency of the method and is useful for producing conclusions that can be directly related back to the original data (Ward et al. 2013). In addition, this method is useful when novice researchers are being supported and guided by more experienced supervisors, as it provides a clear map of how the data have migrated between the stages of analysis and interpretation to improve the dependability of the research (Ward et al. 2013).

Within thematic analytical approaches, framework analysis (Ritchie et al. 2014) stood out as the most appropriate method for the following reasons. Framework analysis has been progressively used in health and social research with specific research questions and large amounts of data requiring management, organisation and analysis (Srivastava and Thomson 2009). Gale et al. (2013), in their review of its use in health research, found framework analysis to be flexible in that it is not affiliated to any particular epistemological, philosophical or theoretical approach. Ward et al. (2013) found it to be systematic, flexible and rigorous; offering clarity and transparency in the form of generating an audit trail. The addition of a matrix allowed for constant comparative techniques across and between data, allowing an in-depth understanding of data (Gale et al. 2013). More recently, framework analysis has been successfully used in health research relating to chronic conditions (Olson et al. 2016), cardiac rehabilitation (Pedersen et al. 2017) and coeliac disease (Satherley et al. 2017).

The findings are now discussed in relation to answering Research Question 3. To reiterate, the findings highlight the concepts of the value of home, the value of independence and the value of connectivity.

Research Question 3

The findings from this qualitative study helped in part to respond to Research Question 3: *'What are the reasons for non-delivery of homecare?'* Although actual reports of non-delivery were limited, this line of inquiry revealed an unexpected paradox between care refusal and care acceptance, whereby care was more likely to be accepted than refused. The reasons why participants did or would refuse care included inconsistent or unsatisfactory care with carers they did not like. Although the majority of participants reported instances of this, only a minority actually refused care because of it.

Clearly, a disparity existed between what participants said, what they did and what the data revealed. In particular, retaining independence was their principal wish. However, the analysis revealed a willingness to sacrifice some of their independence to the care service in order to stay at home. Therefore, although independence was important to the participants, living at home was crucial. The analysis revealed a greater need for them to stay at home; to remain independent and to have the company of their care workers to keep them from feeling lonely. The participants believed that they should accept

homecare to ensure these needs are met. Most participants strongly expressed their concern that, if they were not able to manage at home, then they might be admitted into a care home. For this reason, care was accepted, irrespective of its quality.

The process of framework analysis helped to ensure that the data were kept close to their original meaning and that the categories were described as accurately as possible, considered descriptive. Thereafter, the analysis became interpretive, as the researcher explored the meanings behind the data. Providing a deeper understanding of the meaning behind the data was potentially open to interpretive bias (Ritchie et al. 2014). To avoid this, each interview was approached with an open perspective; this was also facilitated by the interviews being transcribed by a professional transcription typist.

The process of framework analysis can be viewed as being on a continuum, as illustrated in Figure 9.

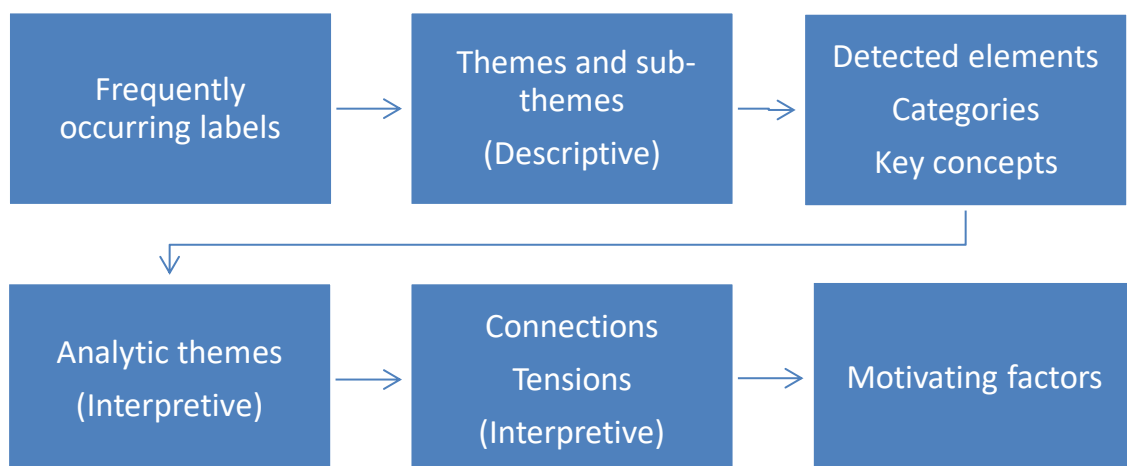


Figure 9: Process of data analysis

Responses from the following three interview questions helped answer Research Question 3. Adopting a pragmatic approach allowed the research question to be the focus of this investigation (Sandelowski 2000).

Interview question 1: *What are your experiences of homecare received so far?*

The first interview question was designed to initiate context for the delivery and possible non-delivery of homecare. The participants had an assessed package of care

which they had little input into and were rarely consulted when changes were made. The care they received focussed on physical needs rather than connective (emotional) needs. The participants recognised the need for physical, functional care, but appreciated the company of their carers to stop them from feeling lonely, a situation many found themselves in, especially for those who lived alone. Participants were keen to share their experiences of the service they received, which ranged from satisfaction of care that met their needs to dissatisfaction through ill-timed visits and lack of continuity of carers. The underlying concept of 'being with' pertains to the need for company. Participants appreciated this as a positive spin-off from the usual physical, functioning care (doing to) that most assessments were based on. Participants recognised that they need to accept the 'doing to' in order to obtain the 'being with'.

Interview question 2: *What are your experiences of not receiving homecare as planned?*

The second interview question specifically targeted experiences of non-delivery and was broad enough to establish some of the reasons for refusing care. Another disparity existed between care that was refused and that which was accepted. The majority of homecare was actually delivered, although often it was too late or too brief. During one paired interview, both participants disclosed experiences where they had refused homecare. Once one participant disclosed service refusal, and the other followed. These disclosures came at the beginning of the data collection process, with no further reports of refusal thereafter.

4.9.1 Reasons to refuse homecare

Reasons to refuse care were limited. Therefore, participants were asked why they might refuse care hypothetically. The reasons given included receipt of poor quality care by a carer they did not like and inconsistent care. A disconnect existed between what they said and what they did, as, irrespective of care given, they would be more likely to accept than refuse care. Hypothetical imagery in the form of vignettes has previously been used to explore beliefs versus action (Jenkins et al. 2010). Drawing on their own experiences, participants were invited to imagine how the central character of the vignette might behave in a given situation. This was then compared with the participants' responses to similar situations in everyday lived events, and little

distinction was found between the two. Within this study, participants themselves were the central characters, suggesting that their reports of hypothetical imagery might be closer to their actual reality. A study by the Care Quality Commission (2013) reported on a survey designed to establish people's willingness to report concerns about the standard of care in the health and social care sector. They found that most people were generally satisfied with the care they received. Therefore, instances of complaint-making were low. Resistance to making a complaint was attributed to: i) being seen as a trouble maker; ii) it would not make a difference anyway; and iii) nothing would improve as a result. Conversely, my study identified levels of dissatisfaction with the care received. It was not known whether people had officially complained, as this was not the focus of the investigation. However, refusals as a demonstration of dissatisfaction were few and disproportionate to the reports of care concern.

In my study, it took one participant to tell of their service refusal before the other one, who had up until that point described being satisfied with the service, decided to disclose their experience of when they had likewise refused. It has to be questioned whether others, when interviewed together, might have had the same group effect. Helen, who lived alone, apologetically refused a male carer entry into her home to change her colostomy bag. Kirsty, with significant physical disabilities, due to arthritis, explained how she reported a care worker for inappropriate caregiving. Kirsty felt rushed and had not benefited from a shower without soap or water. Both accounts initiated service refusal because of the effect that homecare had on them physically and emotionally. In order to help explain the actions of Helen and Kirsty, literature on the ageing body and caregiving is explored here.

Twigg (2006) identifies the complex interplay between the ageing body, gender and care. Her seminal work, conducted over many years, focuses on the role of the body in the subjective experience of ageing. She argues that the ageing body is socially and culturally constructed and that the views of the ageing body are formed and given meaning within and by culture (Twigg and Martin 2015). This includes the resistance to getting older and ageism reflecting societal views on the physicality of the ageing body and the naked ageing body (Twigg 2006). This helps to explain why caregiving focuses on physical aspects rather than psychological aspects of care. An earlier study refers to care work as bodywork, as it centres on bodily deficits requiring personal and intimate

care. As a measure of need, scores are given to assess mobility, continence and Activities of Daily Living (ADL) (Twigg 2000). Kirsty's care worker failed to provide the basics of providing physical care to help keep her body clean, therefore, any enjoyment gained as a result of this activity was denied her. For Helen, physical care to change her colostomy bag was on offer, but the psychological impact of having a male carer perform this task, when they were alone, was enough for her to refuse care.

From a feminist perspective, paid and unpaid care has traditionally resided within the realms of women. However, men are increasingly joining the care sector as care workers (Twigg 2006). There is a general expectation that men working in the care sector are expected to occupy high-status positions, which distances them from service users, whereas women are expected to occupy low-level care worker positions requiring direct physical contact with service users (Twigg 2004). These socially bound expectations suggest that homecare is less likely to be refused if the care worker is female and is arguably a reason why Helen was resistant to accept care from a male care worker. In order for Helen to have her colostomy bag changed, she would need to expose some of her naked body. According to Twigg (2004, p. 68), 'Women represent the body in terms of male desire', indicating why, for Helen, exposing even a small amount of flesh would be unacceptable, particularly in the context of her home: *I did'nae know the wee man and I would'nae feel so embarrassed if I was in the hospital* (Helen). In other environments, male care workers are rarely permitted to give personal care to women, as being naked and exposed can be demeaning and undermining (Twigg 2003). However, good care practice should mitigate these concerns. Helen did not wish to be exposed to a male care worker, irrespective of how proficient he claimed to be, because they were alone.

Kirsty's refusal of care related to the activity of showering. Kirsty had expected to have a shower using soap and water. The omission of both did not match her expectations. The level of help that Kirsty required left her dependent on others and arguably very vulnerable to a power imbalance that can exist between the older person's naked body and the inevitably younger and clothed care worker (Twigg 2004). However, in this case, Kirsty felt strongly enough to do something about it: *So I phoned up about it, I says don't send me that girl again* (Kirsty). Twigg's research deconstructs the social bath and makes the distinction between a social bath and a medical bath (Twigg 1997).

The medical bath is one to make clean, it is considered a necessity for the welfare of the individual, performed by people with often formal qualifications. Conversely, the social bath, often given by unskilled low paid care workers, is viewed as not being absolutely necessary, something to be enjoyed, to be taken time over, to help de-stress and to invigorate (Twigg 2011). The notion of the social bath therefore sits well with the ideology of the home as a place of relaxation and personal control with carers as visitors. Unfortunately, for Kirsty, she had neither the benefit of a health nor a social bath (shower).

Where there were no admissions of service refusal, participants were asked to imagine a situation where they might refuse homecare and why. Hypothetical imagery included that unwanted care workers and unwelcomed care would justify service refusal. However, further questioning established instances of just that, and yet they chose not to refuse. This created a tension between accepting homecare, irrespective of its quality, in order to live at home on the one hand, while refusing it and running the risk of it not being on offer again on the other. Consequently, although participants were explicit about the reasons why they might refuse care, in reality, they rarely refused as, ultimately, they had many more reasons to accept.

4.9.2 Reasons to accept homecare

Reasons to accept homecare include the desire to live at home, to remain independent, to enjoy the company of care workers, and to avoid living in institutional care. Pivotal to the participants' acceptance of homecare was their fear of admission into a care home with perceptions of poor quality care, uncaring staff and the ultimate loss of independence (Quine and Morrell 2007). This fear overrode many concerns about a care service that failed to meet expectations and formed another reason why few complaints were made. Participants were provided with a time-limited service with time factored in between and during visits with minimal provision for alterations to that format. Unavoidable travel hold-ups required a shorter visit as care workers tried to make up time lost. Yet again, participants would readily accept unacceptable levels of care in order to live at home for as long as possible, suggesting that, for some, poor care is better than institutional care.

Interview question 3: *What negative health implications, if any have you experienced as a result of not receiving homecare?*

This study found that negative health implications were associated with delivery and non-delivery of homecare. However, the question remains why some people continue to accept homecare while others refuse it. The findings of this study revealed negative health implications associated with a rushed, inflexible and often late care service impacting on physical and psychological health. For instance, care workers provided care to several people needing to go to bed at the same time and, consequently, some would go later or earlier than expected. Twigg (1999) refers to 'bodytime' and service time being in conflict, especially for older people who are confined to home, where most people expect to rise and go to bed at a time that suits their bodily needs, yet homecare often disrupted the times of these activities.

For one participant, an unreliable service affected their opportunity to continue with reading and writing classes, thus denying them the chance to become literate. For another, cessation of services at short notice meant that they were unable to go out to the shops, causing anxiety in the process. Two adverse outcomes, experienced as a result of an unreliable service, included becoming cold while waiting for homecare, and feeling hungry while waiting for their meals to be prepared. Regardless of this, participants continued to accept homecare. Those who actually refused felt that the impact of an unwanted service necessitated service refusal. However, there was no obvious connection between what would be accepted and what was refused.

As discussed earlier, connections evident within the data centred on the need for continued independence and the factors that enhanced or lessened it. The participants reported that staying independent was singularly the most important aspect of their lives and the main reason why homecare was accepted. However, an unexpected connection revealed that, too often, independence was readily relinquished to a homecare service that was neither wanted nor welcomed in order to stay at home for as long as possible. Therefore, although independence was important, living at home was crucial.

These concerns influenced the participants' acceptance of homecare rather than their refusal of it and formed a core finding. In fact, the participants provided twice as many

reasons to accept homecare as to refuse it. Ultimately, the findings from this study identified three main values which are: the value of home, the value of independence, and the value of connectivity. These are the presiding motivating values in the lives of this particular group of individuals. They are crucial to their wellbeing and to their attitudes towards the receipt of homecare. However, homecare has an impact on these values. The following concepts are discussed separately but are inextricably linked as facets of what participants ultimately value: the values that underpin the acceptance or refusal of homecare.

4.9.3 The value of home

Participants expressed their wish to remain at home for as long as possible. Most people want to remain at home as they age as this can positively affect their wellbeing (Scottish Government 2018a). However, home is more than a physical space, home is valued as a place of memories, safety and refuge, and promotes a sense of belonging, expression, independence and autonomy (Gillsjö et al. 2011; Prieto-Flores et al. 2011; Wiles et al. 2011) and control (Eloranti 2009). Older people want to be given choices about where they live and how they age. In contrast, Eisele et al. (2015) argue that being cared for at home can be socially and economically challenging and suggest that some groups might benefit from residential care.

Tanner et al. (2008) further conceptualise the home environment as having three primary modes of experience; the physical home, the social home, and the personal home. The physical home consists of the layout and design of the dwelling. The social home represents significant relationships with others within the home, and the personal home is a place of self-expression, identity and personal control. For older people with cognitive difficulties, the home represents feelings of identity, security and familiarity (Wiles et al. 2011). Living at home while ageing heightens these attachments. Crucially, home is somewhere they could not imagine living without (Gillsjö et al. 2011). It is no surprise that, at an age when losses are a part of life, the home is strongly protected.

Homecare is aimed at keeping people in the place of their choice (Hillcoat-Nalletamby 2014). The participants in this study who received homecare recognised that they had a need and welcomed the opportunity to receive care to enable them to stay at home. However, for some, the constant invasion of care workers threatened their deeply valued privacy and the relationship they had with their home (Twigg 2006). Homecare,

within this study, impacted both positively and negatively on the physical, social and personal home environment. The participants assumed that if they received care at home they would be less likely to need admission into hospital or institutional care.

Nevertheless, they also acknowledged that living at home well into old age was unlikely and accepted the inevitability of having to leave their home at some point. This was considered the ultimate sacrifice, with the loss of so many attachments and special meanings (Eloranti 2009).

For those who needed assistance, receiving homecare was a viable option. Homecare includes intimate hands-on activities, such as washing, bathing and toileting. Bodywork and bodily care represents the main activities in homecare and the main focus in social care (Twigg 2006). However, concerns surround the uncertainty of the role of the care worker. Waiting for a late service because others had more pressing care needs was readily accepted, even if it adversely affected their own health and social care needs. Waiting passively for care workers to arrive, shifted the balance of power, with each participant willing to accept care, irrespective of its type or timing (Twigg 2004).

The home is central to the lives of those living there, but can be transformed from a private space to a public arena through the provision of homecare, which further detaches the participant from what they have always thought of as their home (Steward 2000). Unlike the hospital, the home environment is rarely designed to provide care (Twigg 2006). Homecare frequently changes the physical environment to accommodate hoists, commodes and other equipment to help with the activities of daily living. The purpose of these modifications is to help increase physical function and independence and strengthen the home as a place of security and safety (Tanner et al. 2008).

Alternatively, this can mean, for the participants in this study, a change in position to becoming an ill and dependent consumer of services with limited control, rather than a consumer of services with a sense of control (Angus et al. 2005; Twigg 2011).

One participant, who privately employed their own care worker, viewed themselves as an employer, whereas the rest considered themselves as consumers of a service paid for by others. The council-funded participants appeared to adopt a passive role, not only in their choice of language, but also in their actions. They showed a greater tolerance to compromising within a service that was neither wanted nor welcomed. Conversely, the one who paid for their care displayed more control and authority. This seemed to arise

from a shift in the care/caregiver dynamic, where, if the participant paid for the care, their expectations were higher, and alternative arrangements could be made if these were not being met.

The receipt of care giving has been linked with oppression and passivity (Fine and Glendinning 2005). Indeed, most participants passively accepted the care that they were given, irrespective of its quality. Even those who refused homecare relayed their story quietly during interview, ensuring that no one was listening. This change in behaviour can in part be explained by how older people view themselves and their relation to others.

An English study (Townsend et al. 2006) examined older people's contrasting images of how people viewed themselves and others. They explored how these images affect self-identity and self-management of getting old in a society which has ambivalent views of old age. Three different groups were identified; the older people perceived themselves as heroes, villains, or victims. Positive connotations associated with heroes included the value they placed on interdependency and reciprocity. 'Heroes' belied their years, were fitter and more active, and had a positive outlook on life. They remained independent against considerable odds and were viewed as exemplars of how life should be led as an older person. While acknowledging the effect of ill-health, criticism was aimed at the 'villains', those who were physically more able to go out but were giving up on life and refused to be helped. Villains were considered by others to be moaning, complaining and inactive people, someone to be distanced from. Finally, 'victims' were to be pitied. They were primarily people with dementia who needed to be looked after. Townsend et al. (2006) concluded that two different but persistent parodies exist between older people; one associated with ill-health and mental decline, and the other characterising those who coped well with transition into older age. Recognition that these caricatures persist amongst the attitudes of older people helps to understand how people cope with the changes imposed upon their sense of self and to their environment as they age, and sheds some light on why some people in my study accepted homecare while others refused it.

4.9.4 The value of independence

The stereotypical view of old age is of weak and dependent members of society (Kydd and Fleming 2015). Conversely, the findings from this study highlight that participants

value their independence and view living at home with homecare with increased independence (Hillcoat-Nalletamby 2014). Homecare is essential for good physical, emotional and cognitive health. It also denotes self-reliance and successful ageing (Beswick et al. 2010). Not surprisingly, therefore, homecare is more likely to be accepted, as it promotes independence and choice, and empowers people to have a voice regarding the care they receive (Callaghan and Towers 2014; Scottish Government 2018a). Independence is the ultimate goal of care provision (Fine and Glendinning 2005). Alternatively, the provision of care can itself deepen dependency (Fine and Glendinning 2005), which can unwittingly create an unequal relationship between the disproportionate power of the care worker versus the powerless dependency of the participant (Orme 2001). However, for some, this was a situation they liked to perpetuate to relieve them of day-to-day responsibilities.

The participants in this study willingly accepted homecare as a means to live independently. However, a deeper understanding of the findings showed that, although independence was highly valued, perceptions were distorted. Crucially, a level of independence was surrendered during visits, but then regained when home activities reconvened. In contrast, Hillcoat-Nalletamby (2014) suggests that, by receiving homecare for physical support, independence need not be compromised. Furthermore, independence, linked to self-determination, is enhanced through the provision of resources to help fulfil daily needs. Alternatively, the presence of care workers and medical equipment, as an unwanted invasion, is not always welcome (Twigg 2006).

In this study, there was evidence that participants wished to stay as independent as possible for as long as possible and recognised homecare as a way to achieve this. Independence was highly valued and protected, as participants endeavoured to stay in control of the care they received. Therefore, to help busy care workers, prior to their arrival, participants would attempt to undertake some of their own care, tempered with a concern that if they were seen to be too able, the service might be stopped altogether. Although the majority of participants adamantly refused to relinquish their independence, there was, for some, a fine balance to be made between striving to maintain their independence and risk losing homecare and relinquishing some independence in order to continue with homecare. However, there was no evidence of a service that had been stopped because participants had been too independent. The

participants acknowledged the value of the input they received from friends and family to help keep them at home. This position of interdependency as a reciprocal relationship exists between those who require assistance and those who provide it, and should be based on mutual dependence, exchange and partnership. A position of interdependency between care worker and participant is therefore the preferred option (Barnes et al. 2005).

As part of an initiative to optimise the quality of life for older people in Scotland, the Scottish Government developed a framework to keep people healthy, active and independent for longer (Cohen et al. 2014). Independence, at the core of this framework, is measured against a range of fundamental personal care needs, function and dependency. From a policy perspective, the measurement of care and dependency helps to procure the necessary intervention in order to receive appropriate care. To assess levels of dependency, Cohen et al. (2014) used the indicator of relative need (IoRN), which is a validated measurement tool designed to assess ADL, personal care, food preparation and mental wellbeing (ISD Scotland 2015). Measuring the need for care based on dependency differs between objective assessments made by professionals and subjective assessments gathered from service users, with significant differences found between the two (Ahlqvist et al. 2014). Objective assessments identify threats to independence relating to co-morbidities and conditions that contribute to disability. Conversely, subjective assessments identify threats to independence, such as a reduction in physical activities, not managing heavy lifting and housework, polypharmacy, and obesity. Present assessment practices using the IoRN measurement tool are based on objective assessment exclusively. Arguably, both have their place, as, without care based on the service user's subjective assessment, older people will continue to experience a reduced sense of their own independence (Burr and Mutchler 2007). Therefore, service users should be listened to when assessing their capability of living at home (Ahlqvist et al. 2014).

Eisele et al. (2015) argue that being cared for at home can be socially and economically challenging and suggest that some groups might benefit from residential care. Participants in this study perceived admission to a care home as the ultimate sacrifice of independence and abhorrent to most. This was despite the risks associated with failing health, mobility and physical functioning. Therefore, it is possible that participants did

not feel that they had relinquished their independence to the care service as suggested. Even if homecare interrupts independent living, this was still preferable to living in a care home with increased interruptions to their independence more likely. Ultimately, the participants in this study acknowledged that they may have to sacrifice some of their independence to live at home, but would relinquish control to the care system in order to do so. Although independence was important, living at home was crucial and why homecare was rarely refused.

Quine and Morrell (2007) explored the correlation between the fear of being admitted into a care home and loss of independence. They found that the proportion of older people with concerns about losing their independence was larger than those with specific concerns about care home admission. Interestingly, participants in this study expressed the same fear without any prompting. Most held a stereotypical image of a care home as a bad place whereby, once they were admitted, there was 'no going back'. For this reason, even short-term respite care was avoided. Two earlier studies highlight similar distaste for care homes. An Australian study found that older women would rather die than live in a nursing home (Salkeld et al. 2000). An even earlier study demonstrated that 80 percent of older people looked at admission to a care home with extreme displeasure (Salvage et al. 1989). However, people continue to be admitted to care homes, but at a much later stage in their lives, usually as they near death, and thus require end-of-life care (Bally and Jung 2015), which can be negatively associated with loneliness and isolation and feelings of helplessness (Fleming et al. 2010). These negative connotations, and the general tendency for people to associate care homes with the end of life, may further account for the participants' reluctance to be admitted, even for periods of respite care.

The above research relates specifically to perceptions of the negative impact of living in institutional care. Other research reveals that admission to a care home can have a positive influence. For example, when focussing on the perceptions of those who had experienced the transition to institutional care, Callaghan and Towers (2014) found that older people living in a care home reported feeling more in control over daily life than those receiving care at home with an increased sense of control and psychological wellbeing. They recognised that encouraging enablement and increased control over

their own lives for older people should be a policy priority for social care services in the UK.

4.9.5 The value of connectivity

Tensions within this study are intersected by social isolation and loneliness. The majority of participants lived alone and, although they frequently visited the day centre, they all stressed how lonely and, in some cases, isolated they felt, and welcomed their carers' visits for company. Even if they did not like their carers, it was better than seeing no one. Such was the strength of their need for company.

Participants in this study enjoyed the opportunity to meet others, even during a short homecare visit. For some, this was the only connection they had with anyone on a day-to-day basis, and a reason why care workers should avoid undelivered care visits, especially for those who live alone (Steptoe et al. 2013). Likewise, they expressed appreciation in being part of this study. Being able to connect with someone was crucial to their wellbeing. Connecting was not exclusively a physical construct, as a phone call or a 'Skype' call was also much valued. As one participant said: *It's just being able to talk to someone ... it's better than just watching the telly.* (Flora).

Current literature highlights connections between loneliness and isolation as being interrelated but different concepts. The literature highlights a lack of concurrent definition, but the following examples have been selected to provide context to this discussion. Social isolation refers to a lack of interactions, social support structures and engagement with the wider community (Gardiner et al. 2018). Loneliness is a personal, subjective and individual experience of being separated from others (Bandari et al. 2020). Social isolation can be objectively measured, reflecting the lack of contact with other people. In contrast, loneliness is a subjective experience, one which is unique to the individual.

Cotterell et al. (2018) confirm the importance of treating social isolation and loneliness as separate concepts, as each have independent predictors and health effects. Knowing this helps to assess those most at risk. Moreover, loneliness and social isolation are growing public health concerns in our ageing society. A recent study found that '50% of individuals aged over 60 are at risk of social isolation and one-third will experience some degree of loneliness later in life' (Fakoya et al. 2020, p. 2). However, loneliness is

more frequently researched (Bandari et al. 2020), perhaps due to the serious threat that loneliness presents as a major health problem, when combined with deteriorating physical health, living alone at home and having poor social connections (Teuton 2018).

Hillcoat-Nalletamby (2014) found that the potential for social isolation was greater for those who lived alone. The negative health effects are depression, cardiovascular disease and dementia (O’Luanaigh and Lawlor 2008), which can also lead to early institutionalisation (Savikko 2008), a situation which the participants in this study were vehemently opposed to. Likewise, loneliness was a concern for those who lived alone, and can have a negative impact on mental and physical health (Courtin and Knapp 2015), in particular, depression and cardiovascular disease (Bandari et al. 2020) and a greater susceptibility to commit suicide (Malcolm et al. 2019). Loneliness, as an under-researched area, changes according to culture and setting, affecting more women than men, and those with low socio-economic status (Bandari et al. 2020).

Katz et al. (2011) document personal relationships, social interaction and good relationships with formal carers as being crucial to psychological wellbeing. The delivery of homecare is therefore seen as a valuable optimising strategy to increase much-needed social interaction to prevent both social isolation and loneliness (Baltes 1996). In contrast to these findings, my study found that, in spite of visiting care workers and having the company of others during day centre visits, social isolation and feelings of loneliness persisted. Unfortunately, data regarding the participants’ medical status was unavailable to me for this study. It was therefore not known what effect living alone without much social interaction had on their physical and psychological health, apart from what was offered during the interview. Participants who lived alone reported feeling lonely most of the time and the opportunity to connect with someone they did not even like during a rushed visit was preferable to being alone. Participants did, however, have high expectations of a long-term caring relationship with the same care worker they knew and trusted, providing a sense of connectedness beyond the delivery of clinical healthcare tasks (Gethin-Jones 2013). Unfortunately, this was seldom the case, and the lack of consistency of care workers remains a cause for concern, although the effects of COVID-19 may change this.

Bandari et al. (2020) acknowledge loneliness as a subjective experience, with tensions between those who live alone who did not feel lonely and those who live with others

who felt lonely. This discrepancy was not evident in my study, as most participants lived alone and felt lonely. Bandari et al. (2020) developed a protocol to help define loneliness among older people living in the community. This Iranian study acknowledged that loneliness carried with it a stigma, which made older people more reluctant to talk about it. Therefore, without the support structures needed to combat loneliness, older people were less resilient to the effects of loneliness.

Hagan et al. (2014) investigated the effectiveness of social therapeutic interventions to reduce loneliness in older people and found limited evidence of the effectiveness of one-to-one interventions, with group interventions as the preferred mode. In response to the stigma associated with loneliness, they suggested that, in order to create a more inclusive society, stronger social communications are required that engage with older people. With communication increasingly relying on technology, further research is required to investigate more sophisticated means of indirect communication.

Protocols have been developed to help reduce social isolation and loneliness in older people (Landeiro et al. 2017) and to explore the association between loneliness/social isolation and key health-related behaviours in older people (Malcolm et al. 2019). By assessing the quality of evidence, their aim is to inform stakeholders in tackling the growing challenges arising from loneliness and social isolation. Alternatively, evidence regarding the prevention of social isolation for older people remains scarce (Cotterell et al. 2018).

In response to the increasing reports of social isolation and loneliness, various strategies have been developed in Scotland to help tackle the issue. The Scottish Government made a commitment to reduce social isolation to alleviate loneliness amongst older people living in the community. Working alongside other organisations, a National Social Isolation Strategy was developed to ensure a holistic approach is established to tackle problems of loneliness and isolation (Scottish Government 2018b). 'A Connected Scotland' (Scottish Government 2018b) is a strategic approach that endorses building stronger social connections. Empowering communities to build partnerships, promote positive attitudes, and tackle stigma can create opportunities for people to connect and will build supporting infrastructure that fosters connections. Findings from a longitudinal pilot study, Healthy Ageing in Scotland (HAGIS) (Douglas et al. 2017), have informed policies that aim to reduce instances of loneliness and isolation among

older people in Scotland. The profile of someone who is more likely to experience social isolation and loneliness in Scotland was characterised as being female, in a broad range of ages, and married with poor educational attainment.

The Scottish Government recognise loneliness as a major public health issue, with older people at increased risk (Teuton 2018). Many people go through the week without a visit or call from anyone. As an ageing group, many have experienced social decline and the death of a partner and friends (Brooke and Jackson 2020). These feelings of loneliness and social isolation have been exacerbated by the recent COVID-19 pandemic. In order to keep older, more vulnerable, people safe, people over the age of 70 years have been asked to stay at home and avoid contact with others, in many instances for months at a time (Scottish Government 2020). For many, this will have a further impact on their current feeling of loneliness and isolation. Guidance is available on maintaining health and wellbeing during the social restrictions of COVID-19, but, for some, access to this information, most of which is available through social networks, is not an option. Therefore, the recruitment of volunteers provides meaningful telephone support to help those through this period of social isolation and loneliness (Brooke and Jackson 2020). Family and friends who are no longer able to provide informal care rely on social care to look after their relatives. Nationally, the Coronavirus Act (2020) emergency legislation suspends the statutory obligations of local authorities to conduct detailed assessments of care and support needs and to meet these needs. Unfortunately, while the need for social care rises, staffing levels are affected by illness and quarantine, with far reaching implications for older people with high social care needs, with increased risk of death and deteriorating physical and mental health (Comas-Herrera et al. 2020). Suggestions to mitigate the psychological effects of social isolation include social prescribing by involving community groups and charities to improve social connectivity (Razal et al. 2020).

To summarise, in order to protect the three values of home, independence and connectivity, defended so fervently, the participants in this study accepted homecare irrespective of its quality. This research has exposed some of the limitations of homecare, yet participants continued to accept rather than refuse it in order to meet functional and connective needs. 'Doing to' formed the main focus of homecare assessment and practice, while 'being with' was a much needed and sought-after aspect

of homecare, especially for those who lived alone. Shifting the focus from ‘doing to’ to ‘being with’, similar concepts to ‘doing for’ and ‘doing with’ (Brown et al. 2006), highlights a care service that is service-driven, endorsing dependency, to one that is client-driven, endorsing independence. The following sections consider ‘doing to’ as a care burden and ‘being with’ as a care value.

Doing to (care burden)

‘Doing to’ represents unwanted and unwelcome homecare, aspects of care of an often physical nature. Participants expected to be involved in decisions made about the care they received but rarely had an opportunity to contribute (NICE 2015). Participants accepted that occasionally other people’s needs may leave them waiting for their care to be delivered, further impacting on limited visit time. Participants expected a physical focus to care but welcomed the opportunity to connect with their care workers, even if only for a short time. For some, especially those who lived alone, feeling lonely and isolated was a daily experience. Maximising the time spent with another person during the homecare visit was therefore crucial to their psychological wellbeing.

Unfortunately, due to increasing pressures on care services, recommended time allocation per visit was not always adhered to further compounding this problem (NICE 2015).

Being with (care value)

‘Being with’ represents care that enhances feelings of connectivity; care that participants treasure and appreciate. Care values are divided into functional care and emotional care. Functional care encompasses a service that is timely, consistent and appropriate to their assessed needs. The participants want a homecare service that enables them to live at home without affecting their privacy, independence and social life. Emotional care encompasses care that is a reliable service and not rushed, delivered by professional, friendly carers, who they know and like. Limited visits left little time for conversation, but instead depended on chat generated during other tasks. They were grateful to their care workers, who many saw as friends. The barriers of the professional relationship sometimes merged into one of friendship, a dynamic endorsed by participants, as they benefitted from care they considered to be ‘extras’.

Current guidelines suggest that the care that is delivered should be designed around the needs of the individual (NICE 2015). This includes a flexible service that meets their changing needs (SCIE 2014). As consumers, the participants are entitled to exercise control (Callaghan and Towers 2014) and to have an active involvement regarding the care that they receive (NICE 2015). There was little in my study to substantiate the presence of this right. This study identified a service which was predominantly service-centred with participants rarely consulted prior to changes being made to their care provision or when decisions were made about them. Nevertheless, they appeared to be grateful for homecare, even if it was unreliable, delivered by care workers they did not like, and, once again, they passively accepted it. They demonstrated a great deal of empathy for the needs of others and accepted without complaint if the reason for a late service was due to this. Participants in this study had few expectations of homecare, as to receive it was enough. For some, poor care was better than none.

The findings of my study clearly identified a central tension between elements that enhance (positively influence) homecare acceptance and elements that impede (negatively influence) homecare acceptance, yet homecare is rarely refused. Positive elements that enhance service acceptance include the need to stay at home for as long as possible, the need for independence and the need for company. Negative elements that impede service acceptance were unwanted care or care workers, the fear of alternative institutional care and the fear of being lonely. Contrary to the participants' perceptions of what they value most, the findings from this study illustrate that home is in fact significantly more valued than independence. Participants would readily compromise their independence by accepting an unreliable service to live at home. Ultimately, these are the reasons why homecare is more likely to be accepted than refused.

4.9.6 Strengths and limitations

Strengths: truth value and trustworthiness

The notion of the value of trustworthiness in qualitative research has been questioned, because validity and reliability cannot be assessed in the same way as it can with quantitative research (Shenton 2004). Therefore, the strength of the qualitative research findings has been assessed against Leung's (2015) criteria for truth value and trustworthiness in qualitative research.

Truth value: Truth value requires the clear and accurate presentation of participants' perspectives, devoid of the researcher's personal experiences and biases (Leung 2015). Although I agree that truth value requires a clear and accurate presentation of the participants' perspectives, it is difficult to eradicate completely the researcher's personal experiences and biases. I argue that the process of reflexivity at every stage of this qualitative study became as important as the findings themselves to assess truth value. Reflexivity, embedded in framework analysis, acknowledges the researcher's presence and the possible impact that this may have on the findings (Ritchie et al. 2014). Moreover, in this study, adopting a framework analysis approach ensured that the themes generated were as a result of revisiting the data in its original form. Interpretation of the themes relied on my ability to see past what had been said and to dig deeper into meanings and assumptions made. Therefore, it is possible that my personal and professional experiences as a trained nurse and of caring for older people may have introduced some element of bias to the research process.

Reflexivity is a process whereby the researcher acknowledges any pre-determined values and opinions they hold, how these could influence interpretation, and their potential to change the direction of research (Creswell 2013). Research is never value-free, and reality cannot be accurately captured, as the views of those doing the research are value-burdened (Bryman 1988). In an attempt to reduce any bias associated with this, I engaged with the process of reflexivity throughout the study, which included reflecting on my thoughts and acknowledging any assumptions that I had in relation to delivery and non-delivery of homecare.

I have had previous professional experience in caring for older people and was able to take into account the likelihood that I might obtain limited responses due to reduced cognition or poor health. However, this pre-understanding may also have biased the research (Miles and Huberman 2001). Keeping an open and reflective mind helped guard against any potential bias. Having spent thirty years with an interest in the long-term care of older people, both academically and professionally, I have developed a set of experientially based assumptions as a result of my practice. These assumptions include a present deficiency related to nursing and caring which may at times be overly paternalistic. This is manifested through age-related stigma and a lack of individual centred care, which may have influenced the data analysis and interpretation. By

engaging with the process of reflexivity, I was acutely aware of the importance of the careful wording of questions during the interviews to prevent leading the participants. For instance, an open-ended question format was used and, where necessary, clarification was sought to avoid the temptation to assume understanding. Revisiting the audio-recordings and transcriptions helped to de-mystify areas of confusion. I engaged with all participants and conducted the interviews personally, while keeping field notes and a reflexive diary. As no research is assumption-free, my own feelings and reflections thus become part of the data, further adding to the knowledge base (Phan 2007). As Alaszewski (2006) argues, keeping research diaries allow for creative thought and allows the researcher access to areas which may prove difficult to record or observe due to their sensitive nature.

Trustworthiness in qualitative research refers to its methodological soundness and adequacy (Rolfe 2006). Trustworthiness signifies that others must be able to trust that the researcher reached alignment between data collection, analysis and reporting (Thomas 2017). The use of constant comparative techniques ensured the trustworthiness of the findings in the research presented here (Guest et al. 2006). Data collection involved in-depth, semi-structured interviews and one focus group, supported by field notes and observations. NVivo was used to help organise and manage the data. Framework analysis provided transparency by generating an audit trail, whereby others could judge the consistency of the data analysis (Creswell 2014) and the trustworthiness of the findings (Ritchie et al. 2014). Ensuring alignment thus helped increase the validity of the findings. Further, the trustworthiness of the findings from this study can be assessed in terms of its credibility, transferability, dependability and confirmability (Polit and Beck 2012), as discussed below.

i) Credibility refers to the ‘truth’ of the findings (Shenton 2004). The more characteristics shared between findings, the greater the increase in their validity (Robinson 2013). The use of semi-structured interviews and a focus group revealed both concordant and opposing elements, which, in turn, strengthened the credibility of the findings from this study. Prior to the start of data collection, interview questions and focus group guides were piloted to ensure that the questions were easily understood and unambiguous (Creswell and Creswell 2018). Abbreviations were avoided, as was technical language and jargon. Interviews were scheduled with ample time left between

them to allow the researcher to digest what had been said and to make field notes. Of particular interest and value was the information gleaned after the audio-recorder had been switched off, when the participant revealed what they had wanted to say all along.

ii) Transferability refers to the extent to which the findings can be generalised to other settings or groups (Polit and Beck 2012). In this study, data were collected from older people who visited day care centres in Scotland's largest city, which limits transferability to other settings: for example, rural settings. Conversely, the focus of this study was on the depth of inquiry, irrespective of the number of participants (Polit and Beck 2012). Nevertheless, it is possible that the findings may resonate with and enlighten other homecare service providers in other cities who are looking to improve homecare provision.

iii) Dependability of the findings was enhanced by the transparency of the research process, methodology, data collection and analysis. Framework analysis provided transparency by creating an audit trail whereby others could judge the consistency of data analysis (Creswell 2014). Framework analysis ensured that themes remained grounded in the raw data and the participants' original meaning. Following the descriptive stage, higher-order interpretive concepts, strongly supported by the data and narrative account, were assumed. Revisiting transcribed data repeatedly by listening to the interview recordings ensured that the voices of the participants were understood and accurately represented during the process of analysis (Ritchie et al. 2014).

iv) Confirmability was assured by documenting the process of checking and rechecking the data. The process that I followed during the analysis is presented clearly in this chapter. I was aware of the possible disconnect between descriptive findings based on original excerpts and an interpretation of the meaning behind the data.

Epistemologically, the experience of each participant was accepted as their reality (Birt et al. 2016). Measures were therefore taken to guard against the possibility that the process of interpretation could increasingly distance the findings from the participants' original meaning (Grbich 2006).

Following the completion of each interview, I asked each participant to validate my understanding of what they had said, including any interpretations made. Member validation ensures that original meanings and perspectives are represented accurately

and are not affected by the researcher's understanding and interpretation (Lincoln and Guba 1985; Tong et al. 2007; Morse 2015). Although validation of the interview findings were sought immediately after the completion of the interview, a system of member validation checks post-interview could have further endorsed the reliability and transferability of the findings and would have been of particular value if used to evidence change in practice (Crilly et al. 2006). However, for some participants, recalling memories of their experiences proved to be difficult, especially for those with memory problems. Observing body language and non-verbal cues helped gain an understanding of what was being said and meant.

Graham (2001) suggests that memory is a composite of imagination, experience and what is going on in the current position. Therefore, when a participant describes their experiences, they rely on recall. They create a picture from their current picture rather than play a tape of past events. They reflect on the event and not in the event, reconstructing their memories as they are telling them, further distancing their experience from reality. Therefore, validating findings immediately post-interview was perhaps more reliable. Unfortunately, it was not possible to return to participants at a later date to validate study findings, as all four day centres were permanently closed soon afterwards due to council funding cuts.

Limitations: Recruitment and sample size

This qualitative study presents several challenges affecting truth value and trustworthiness. Although the interview schedule was designed to explore non-delivery of homecare, the participants did not possess the characteristics needed to explore this issue in depth, with an over-reliance on hypothetical reasons for non-delivery. Due to appropriate anonymity constraints for unconsented record-linkage, the opportunity to ask service users, identified in Study 1, about why they refused homecare was blocked. Therefore, this second study established reasons for refusal from a group of older people who had experienced homecare but not necessarily non-delivery. At the recruitment stage, it was impossible to know who had actually refused care without asking them during the interview. The paucity of non-delivery due to acceptance of care on offer was because they feared the consequences of refusing or because they were satisfied with care received. Despite this paucity, the chosen methods of data collection

and analysis provided meaningful insights into the experiences of older people who are in receipt of homecare services, as well as those who experienced non-delivery.

It is important to recognise potential difficulties around a small sample size in qualitative research (Vasileiou et al. 2018). This perhaps reflects the difficulty of recruiting older people from hard-to-reach groups with age-related illnesses and disabilities. This was further compounded by the presence of gatekeepers' active protection of the interests of those they care for. My liaison with gatekeepers was successful, but recruitment opportunities remained limited. Recruiting a group of older people, as service users, with known experience of non-delivery from the beginning may have yielded different results and could potentially have improved the transferability of the findings to other settings.

Saturation can be reached during sampling, data collection or analysis (Saunders et al. 2018). Data saturation in Study 2 was reached when participants provided the same information again and again, and where nothing new was added. Therefore, data saturation was determined by the frequency of what was said rather than the number of participants making the report. Another form of saturation considered here was theoretical saturation. The concept of theoretical saturation has its origins in grounded theory (Glaser and Strauss 1967), for which the sole purpose of the research is to develop theory with no a priori assumptions, thus allowing the data to drive the research. After careful consideration of the suitability of each approach, a hybrid form of saturation was deemed to be the one most applicable to Study 2 (Saunders et al. 2018), one which combined elements of data saturation and theoretical saturation. The development of theory was not a prior consideration. However, it is worth noting that saturation of data at a deeper level of interpretive analysis helps to provide the validity needed to develop theory (Hennink et al. 2017).

Because the participants were interviewed and the data were analysed simultaneously, it was easy to identify any repetition in the data, which helped guide the development of labels and themes. However, I also considered that saturation was reached at a more meaningful level of interpretive analysis, as seen within the framework approach (Saunders et al. 2018). Concerns exist that saturation, as a measure of 'completeness', may not have been reached or is not enough. However, rather than consider saturation as the ability to reach a final limit, after which point it is impossible to reveal new

insights, it may be more helpful to consider it as reaching ‘a *sufficient depth* of understanding’ that will allow the researcher to draw inferences from these insights (Nelson 2016, p. 556, emphasis in original).

Arguably, within this study, the repetition of information suggested that saturation had been reached at the level of analysis. Alternatively, as this qualitative study focussed on the unique experience of the individual, saturation of the data was not necessarily something to strive for (Saunders et al. 2018). Although the data took an unexpected turn away from reasons for non-delivery of homecare, the range of experiences of homecare, both similar and dissimilar, revealed critical insight into the issues pertaining to homecare provision.

The dearth of research in this field makes these findings worth noting and presents a revealing time-limited three-month snapshot of the experiences of homecare to highlight the complexities of the home/independence balance that older people seek. The data generated in this research, and its analysis, provide a positive contribution to current research and reveals valuable insight into some of the reasons why care was accepted rather than refused. One of the defining aspects of this qualitative research study was that the research question changed during the course of inquiry. As Agee (2009) proposes, research questions in qualitative research serve as a starting point only and will change throughout the course of the research process to reflect an increased understanding of the problem. The initial formulation of Research Question 3 helped to focus on the problem of non-delivery however, because only a few participants reported experiences of homecare refusal, the focus of inquiry changed direction to focus on establishing the reasons why care was rarely refused.

Thus, the overall research question served only to direct further inquiry into the unexpected (Agee 2009) and, therefore, the change in direction enabled a deeper understanding about why, for some participants, homecare was more often accepted and, hypothetically, why care might be refused. According to Agee (2009, p. 432), ‘good research questions, are part of a reflexive and iterative inquiry and are usually developed or refined in all stages of a reflexive and iterative inquiry’. Therefore, the framework analysis approach, with its embedded reflexivity and iterative analysis processes, aligned well with this qualitative study. These unexpected turns in the direction of the research therefore served only to enrich the findings.

4.10 Chapter Summary

This study set out to explore reasons for non-delivery of homecare, but instead found that homecare was more likely to be accepted than refused. It might be argued that the findings were limited in terms of being able to answer Research Question 3, as non-delivery was not as key an issue as previously thought. However, what the findings did reveal, was that older people preferred to accept homecare, irrespective of its quality, in order to remain at home. This is a key finding, which reveals an interesting paradox: while the service providers acknowledge and are concerned that non-delivery of homecare places the older people at risk, it is the same assumed risks of poor care and a desire to stay at home to maintain independence that are the very factors that both prevent them from refusing care and actually refusing it. The findings provide a valuable and original contribution to the research, with implications for the chosen methodology.

Older people accepted the compromises involved in being a homecare recipient and accepted care burdens and ‘doing to’ for the benefit of care values and ‘being with’ in order to remain at home. This study identified three core concepts which service users most value. These were: the value of home, the value of independence, and the value of connectivity. Homecare was likewise valued as a means to protect these values and was accepted, even if considered poor, as the service users’ central motivation was to continue to live at home. Therefore, poor care was better than none. Reasons why homecare was/would be refused were consistent, yet, only a minority actually refused. The reason why some refused care whilst others accepted it remains unclear, necessitating further research.

Chapter 5, as the concluding chapter, considers the findings of both studies in combination, and discusses the inferences that can be made.

CHAPTER 5: Conclusion – A consideration of both studies in combination to describe how each contributes to a better understanding of non-delivery of homecare

5.1 Introduction

This chapter considers the findings of both studies in combination to describe how they informed and guided the research process to respond to the research questions and to describe how each contributes to a better understanding of non-delivery of homecare. The implications for practice, policy and research are identified, and my original contribution to knowledge is stated. Finally, I reflect on my doctoral research journey, as described in this thesis.

This thesis started from the informal conversations held with a large homecare service provider who had concerns about the delivery of homecare for older people and about whether they received the care that was planned for them. Concerns were also expressed for the wellbeing of older people who were not at home when care was due or when care was refused at the point of delivery. These concerns prompted a request for research, upon which this doctoral thesis was based, to explore this issue further.

As demonstrated throughout both Study 1 and Study 2, there was limited empirical evidence to support the assumption that non-delivery of homecare was a major concern, with the majority of older people actually receiving all their homecare. What this multi-method study did reveal, however, was a much more nuanced understanding of the reasons why older people tend to accept care rather than refuse it; specifically, to stay at home for as long as possible with independence and to have the company of their care workers to prevent them from feeling lonely.

The scoping review of the literature, presented in Chapter 1, revealed that the reasons for service refusals were well reported, with loss of independence and unmet need a cause for concern, in particular, in relation to the provision of an inappropriate, untimely and inflexible service. Alternative offers of help from friends and family were welcomed by older people. A lack of trust in care workers endorsed the preference to be cared for by family members rather than carers as strangers, especially among ethnic minority groups, where the emphasis was on ‘caring for your own’. The majority of the reported reasons for non-delivery emanated from care workers or friends and family of

the older people, rather than the older people themselves. The literature recognised this as a limitation, one which this thesis addressed by including older people, where possible, at every stage of the research process. The scoping review described the characteristics of those who had experienced non-delivery within the limited articles available, but the extent of non-delivery was unknown, necessitating further exploration.

This knowledge gap allowed me to formulate the research questions:

Research Question 1 (Study 1): *What is the extent of non-delivery of homecare among older people?*

Research Question 2 (Study 1): *What are the characteristics of older people most likely to experience non-delivery?*

These research questions guided the design of Study 1, which successfully established the incidence of non-delivery within a discrete sample of the population as well as determined the characteristics of those who are most likely to refuse care. Exclusion of those who had been hospitalised from the sample may have created an element bias. However, the results echoed similar concerns identified in the literature. For example, the majority of older people in Study 1 actually received all their care with a few ‘persistent refusers’ (Durand et al. 2009) accounting for the most incidences of non-delivery. These results differ from a study conducted by Brodaty et al. (2005), who found that older people and those who lived alone were more likely to accept their planned care. Older people reported having a preference for seeking help from family and friends rather than from a care worker they mistrusted, which is also a common theme in the literature (Strain and Blandford 2002; Themessl-Huber et al. 2007; MacLeod et al. 2017; Lindquist et al. 2018).

The data linkage method adopted in Study 1 provides justification for the use of similar projects in the future, involving previously unlinked health and social care datasets. In addition, Study 1 highlights the complexities of obtaining approvals for analysing across different datasets, and provides a valuable blueprint for future data linkage research projects.

Despite the irregularities in missing and incomplete data that hampered the analysis, the results revealed a comprehensive report of the incidence of non-delivery within a

discrete sample of older people in Glasgow. These results filled a gap in the knowledge in two ways: first, by establishing the extent of non-delivery, which, up until this point, had not been fully identified; and second, by clearly describing the process for successful data linkage between two previously unlinked datasets without a common identifier, a process which will be of interest to future adult social care linkage projects.

The available data in the records in Study 1 were not suited to exploring a more detailed understanding of the reasons for non-delivery of homecare. Study 2 was therefore designed to explore the reasons for non-delivery in more depth and from the older person's perspective. Adopting a qualitative methodology, Study 2 explored the unique experiences of older people in receipt of homecare and whether they ever refused, using Research Question 3 as a starting point:

Research Question 3 (Study 2): *What are the reasons for non-delivery of homecare among older people?*

Study 2 provided an opportunity to ask those in receipt of homecare about their experiences of the care they received and whether they ever refused homecare. Framework analysis guided every aspect of data collection and analysis, safeguarding the integrity of the findings. The five stages of framework analysis (Ritchie et al. 2014) focused on describing the data by categorising initial coded data that were similar. Framework analysis was selected because it enabled further exploration of the data and a deeper understanding of non-delivery and the meanings behind what had been said. This process of drilling down revealed other complex connections, which would not have been revealed had the analysis stopped at the descriptive stage. Specifically, tensions and contradictions were evident between what participants stated during their interviews and what they had done. These paradoxes revealed more about why they might accept homecare rather than refuse it. The use of matrices, specific to the framework approach, provided a means whereby others can judge the validity of the inferences made deductively. Therefore, not only did the framework analysis process validate the findings, but the findings validate the selection of framework analysis as the approach most appropriate to help answer the research questions posed, as described in Section 4.9.

This doctoral research study has revealed three unexpected paradoxes as key findings, which are of particular interest to all associated with the provision of homecare. A

minority of older people reported on their experiences where they had refused homecare. It was at this juncture that the research took an unexpected turn, which revealed more insightful reasons why, for some, homecare was accepted rather than refused. In an attempt to maintain the focus of the research topic, I asked all those who had not refused care to explain why they might do so, hypothetically. This revealed the first paradox between what they said they would do and what the data revealed.

Paradox 1:

Older *people* in this study said that they would refuse homecare if it was inconsistent or unsatisfactory with carers they did not like, yet, irrespective of that perception, only a minority actually refused their homecare.

This research has revealed a tendency to accept rather than refuse homecare because of older people's greater need to stay at home and to maintain their independence and their concerns of being admitted into a care home with the loss of home and independence. Of concern was the discrepancy between what they said and what they did. What remains unknown is why some people refuse homecare whilst others accept.

Older people's experiences of homecare revealed mixed reports of satisfaction and dissatisfaction. Continued care acceptance did not necessarily mean that they were satisfied with the care given. Although they were grateful for a service that kept them living at home with carers they liked, ill-timed care and inconsistency of carers had an impact on their overall satisfaction. Whether care was accepted or refused, a sense of passivity prevailed among most participants, which was demonstrated when they apologetically refused care or passively accepted the poor quality of care on offer.

Paradox 2:

Although older people said that they valued their independence above staying at home, they would inadvertently relinquish that independence to the care service in order to stay at home; therefore, the value of home was greater than that of independence.

The findings from this study supported the idea that living at home and being independent is the desired goal for older people (Scottish Government 2019b) and that the acceptance of homecare allows them to live at home for as long as possible and to be independent. The literature focuses on independence as being the key to the

acceptance of homecare (Themessl-Huber et al. 2007; Lindquist et al. 2018). However, this study revealed instead that the home is the critical focus and the main reason why homecare was more often accepted by older people, regardless of its quality.

Elements that positively enhanced service acceptance included the need to stay at home, to be independent and to remain in control of their lives. Conversely, elements that negatively impeded homecare acceptance included the fear of being alone and the fear of alternative admission into institutional care. This was also reflected in the literature. Quine and Morrell (2007), in their Australian large cross-sectional study, found that, apart from losing physical health, the greatest fears of community-dwelling people aged 65 years and older were for the loss of their independence and for nursing home admission. Alternatively, Callaghan and Towers (2014) found that older people living in a care home reported feeling more in control over daily life than those receiving care at home.

In my research, the reality was that homecare did not always meet the participants' needs, especially their emotional needs, but the opportunity to connect with someone, even during a short visit, was better than none.

Paradox 3:

Whilst non-delivery of homecare places the older person at risk, the same assumed risks are those associated with the provision of poor quality care. The desire to stay at home, and to maintain independence, are the very factors that prevent them from refusing care and actually accepting it.

Contrary to initial concerns, older people compromised on the homecare service they received in order to stay at home and to be independent. They accept the care burdens (doing to) in order to receive the care values (being with) to reduce feelings of loneliness and isolation. The need for company was often greater than the necessity for functional care, although this was rarely factored into the assessment process. In short, there was an impression of 'doing to' with the much preferred option of 'being with' a far cry from present homecare experiences. Therefore, this research highlights the need to consider both functional needs and connective/emotional needs equally in the assessment process and in the final care package.

This research foregrounds an older person's perspective in research that is about them and for them. Experience of homecare for some older people is poor. In accordance with MacLeod et al. (2017), concerns exist about a homecare service that is stretched and presently unable to fully meet the physical, social and emotional needs of the people for whom they care.

The paradoxical nature of the findings in this research are supported by ambiguities revealed in other recent studies within older people's care across multiple settings, for example, Ericson-Lidman (2019) reveals that living in a nursing home can be experienced as both safe and lonely at the same time, and describes this perception as 'struggling between a sense of belonging and a sense of alienation' (p. 148). Similarly, the findings in this thesis are supported by those of Breitholtz et al. (2013), who describe how older people are both aware of their dependence on others, but wish to remain independent. They highlight the importance of continuity in routines while acknowledging that care needs will shift over time, and also advocate for establishing trust in the caring staff (Breitholtz et al. 2013) to promote autonomy and person-centred care.

Although Study 1 informed the development of Study 2, each study alone was designed to answer specific research questions which, collectively, added to the development of new knowledge (Morse 2003). The barriers to contacting older people whose data were included in Study 1 necessitated the recruitment of older people who visited day centres for Study 2. This provided a means to include a similar demographic population to those within the first study. As the homecare service provider in Study 1 was the major provider of homecare to older people in Greater Glasgow and Clyde (98%), it was likely that those recruited to participate in Study 2 received homecare from this same company.

Each study was methodologically very different, however, several similarities existed between the results of Study 1 and Study 2, which supports the strength of the findings overall. For instance, it was reassuring that most people received all care that was planned for them, especially those who were in greater need of care. However, of concern were those for whom non-delivery of care was a problem, for example, those who lived alone. With an increased risk of adverse health outcomes and mortality associated with social isolation and loneliness (Steptoe et al. 2013), it was important

that undelivered home visits were kept to a minimum, particularly for people living alone. Being alone and feeling alone was a key reason why care tend not to be refused. In accordance with the literature (Steptoe et al. 2013; Hillcoat-Nalletamby 2014; Courtin and Knapp 2015; Cotterell et al. 2018; Thomas et al. 2018; Teuton 2018; Bandari et al. 2020), this study found that loneliness was reported as a concern. Arguably, older people did have regular contact with people during their homecare visits and during day centre visits. Therefore, for the majority of older people within this study, their concern was for their potential loneliness, should their homecare be stopped.

Although one study enlightened the other, caution is required when making claims best suited to a mixed-method study, as the potential for the generalisation of the findings to other settings is limited (Creswell and Plano Clark 2017) due to restricted recruitment opportunities. However, the purpose of this research was not to enable generalisation of the findings; instead, the research inquiry was borne out of a need to focus specifically on one organisation to inform their service provision. As such, this research produced unique insight into the experiences of a specific group of older people and revealed a greater understanding of the complex relationships between the home, homecare and independence, providing a meaningful platform on which further research may establish whether these findings resonate with other homecare service providers.

5.2 My Original Contribution to the Knowledge

This research has made several significant contributions to knowledge relating to homecare delivery for older people; not only in terms of its findings, but also in relation to the methods which were applied in performing it. This multi-method study has provided insight into an area of research that, up until now, has had little consideration within the literature. In particular, the research has extended knowledge on the extent of non-delivery and the reasons for not refusing it. To my knowledge, this was the first study to explore patterns and reasons for non-delivery of planned homecare among older people in one city council in Scotland.

Successful data linkage

Innovatively, this linkage study was the first time that linkage had been attempted in Scotland between data from this particular homecare service provider and a healthcare

dataset (SMR01), and the chosen variables and their subsequent analysis was a hugely successful endeavour. This study extends existing limited knowledge on the use of data linkage (Bardsley et al. 2012; Witham et al. 2014; Porter and Morrison-Rees 2015) between two previously unlinked datasets, without a common identifier, providing a blueprint for future linkage projects. This has huge implications for other researchers who may wish to explore connections between the care provided in social care and health care, particularly as the integration of health and social care policy becomes embedded.

Research that foregrounds the perspectives of older people

This research is among a limited number of studies on non-delivery of homecare for older people which sought an understanding of their unique experience of non-delivery of homecare (Howse et al. 2004; Innes et al. 2005; Themessl-Huber et al. 2007; Durand et al. 2009; Lindquist et al. 2018). Moreover, this research adds to the increasing body of knowledge which includes Patient and Public Involvement (PPI) in research to help improve the quality, relevance and ethical conduct of research in this area (Cowdell 2008; Douglas et al. 2018; Gove et al. 2018; INVOLVE 2020). With a much-needed shift in perspective from care worker to the older person as service user, this research foregrounds older people's perspectives. It situates these within research that is about them and for them and has provided a platform for older people to voice their experiences of the delivery of homecare and of non-delivery.

Homecare is rarely refused

The findings from this research further advance an understanding of why care is rarely refused. An unexpected finding shifted the focus away from service refusal to acceptance; however, acceptance of homecare was highly complex, with nuanced tensions between a service which older people said they would refuse and that which was accepted. Care was rarely refused because of: i) their concerns for loneliness; and ii) their greater concern for living in institutional care with its associated loss of home and independence. Therefore, older people would rather accept poor care than be provided with institutional care.

The value of home is their principal wish

Similar to existing literature (Scottish Government 2018a), this study revealed that older people value the need to live at home and the need for their independence. However, as revealed in this thesis, although older people's independence was highly valued, this was often inadvertently surrendered to the care service in order to stay at home. Again, this links in with the 'doing to' finding, whereby older people accept, passively, the care they receive that is untimely or inconsistent which interferes with their daily plans and activities. Moreover, most people accept care without complaint or refusal because of their greater need to live at home. Ultimately, this study revealed that living at home was the biggest motivating factor to accept homecare, irrespective of its quality. Although the quality of care remains a cause for concern, the findings from this research point towards a preference to accept poor care rather than have no care at all.

5.3 Implications for Research, Practice and Policy

In light of the insights revealed in this study, the following implications can be drawn within three areas. The suggested changes for research, practice and policy illustrated here can positively influence the care experience for older people living at home.

5.3.1 Implications for research

This multi-method study points to the need for further research in the following areas.

Non-delivery as inclusion criteria:

Although Study 1 was initially designed to explore reasons for non-delivery; lack of detail relating to reports of non-delivery prevented me from exploring the reasons. Securing permission to identify and recruit people with experiences of non-delivery, and including these characteristics as part of the inclusion criteria, would have honed the purpose of the research from the beginning. However, as it would be unlikely to gain ethics approval to disclose the identity of those with non-delivery, other recruitment opportunities would need to be sought. In the absence of actual experiences of non-delivery, people were asked why they might refuse homecare hypothetically. As illustrated in section 4.9.1, although this study has shown similarities in actual and hypothetical imagery, further direction for research should include people with actual experiences of non-delivery of homecare. Future research may also benefit from adopting a broader approach to recruitment to capture experiences of non-delivery from

a larger population sample, which may negate the need to explore hypothetical refusals. Moreover, reasons why some refused care whilst others accepted remain unclear and why people would rather accept poor care than no care requires further exploration.

Member validation:

Future research would benefit from the embedding of member validation practices within the research design, either immediately post-interview or after the findings have been established. I recognise that challenges of attrition could affect this process, and so preferred to focus on member validation immediately post-interview.

To ask older people to recognise their voice in the transcriptions is part of the reflexive process and helps guard against researcher bias (Twigg and Martin 2015; Velzke and Baumann 2017; Scottish Government 2018a). It was unfortunate that the four day centres were closed due to cuts in funding, preventing further contact with the participants for validation purposes. This is indicative of the problems regarding research with hard-to-reach groups and where attrition is high due to ill-health and morbidity.

Data linkage:

This novel study (Study 1), presented in Chapter 3, provides a blueprint for future linkage projects. The findings highlight the need to ensure that data are ‘research ready’ to initiate successful linkage between two previously unlinked datasets. However, the process of linkage had its challenges. The lack of a common identifier between datasets impeded linkage, further demonstrating the importance of complete and consistent recording to initiate probabilistic linkage. Regardless of these challenges, the two datasets were successfully linked with a 94.5 percent success rate. Stakeholders acknowledged the benefits of this linked study to inform and improve homecare provision and may be receptive to future research using linked data.

Non-delivery of homecare:

There was limited evidence on non-delivery of homecare. Instead, the findings point towards a much more complex and nuanced relationship between the desire to live at home and the need to accept care, regardless of its quality, rather than refuse it. Therefore, further research is needed to establish why, in the event of an unwanted service, some people continue to accept care while others refused it. Of interest is why

the person paying for their care privately was the only one who reported complete satisfaction. Further research is warranted to establish the difference in satisfaction with services between those who pay for it and those who rely on funded care.

The findings from this research revealed that negative health implications were associated with the delivery of care rather than with refusal of care. Further research incorporating the health status of the individual would establish a possible correlation between existing health issues and the likelihood of service refusal.

5.3.2 Implications for practice

Care worker training:

Arguably, the most important aspect of this research is the influence it could have on homecare practice. In order to keep people at home for as long as possible, people require a homecare workforce that is skilled and valued. However, it is the care organisation's responsibility to procure the necessary training to help care workers, many of whom work in relative isolation from their peers, to support and provide care to people who live at home. Under the Scottish Social Services Council (SSSC 2016) regulations, the code of practice stipulates that employers are required to ensure that care workers have the necessary skills and knowledge to undertake their roles, including the increased use of technology (Scottish Government 2017c). The findings of this thesis, suggests that care workers need to have specialist knowledge to better care for older people who are looked after within their own home.

This research highlights the value that older people place on their home, their independence and being with others. Care workers who are versed in these motivating factors could help to provide a service that is likely to be accepted rather than refused. As guests in someone else's home, they should be mindful of a potential power imbalance and the negative impact of this. Care workers should include older people in every aspect of the care that is given. They should recognise the importance of independence, even within a reciprocal relationship of interdependency. The care they provide should be delivered in a timely and appropriate manner with any changes to care made in collaboration with each older person.

Care workers should also be made aware of the negative impact that a care service could have on an older person's sense of home. In particular, the presence of medical

equipment that can change the perception of home should be kept to a minimum (Twigg 1999). Likewise, a care worker's presence can be perceived as an invasion of privacy and an unwanted interruption to daily life. Therefore, care workers invited in as visitors may help reduce the power imbalance. Care workers should recognise that some older people want help to make decisions, whereas others want to be autonomous. Where possible, care workers should ensure that older people are encouraged to make their own decisions about areas that affect them. An understanding of the complexities of independence and interdependence helps to provide the flexible balance between helping and 'doing to'. Understanding the impact that an untimely visit arrival has on an older person's wellbeing can help reduce the negative health implications associated with it.

Homecare recommendations:

This research provided one particular homecare service provider with recommendations that can guide and influence their practice. The benefits of facilitating accurate and comprehensive care registries are vast, and meaningful analysis of the data can promote service improvement based on the identification of variations in practices, processes and outcomes (Nelson et al. 2016). In the UK, patient-focused registries have contributed to improved outcomes in the care of people affected by cardiovascular disease, stroke, cancer, and joint replacement (Nelson et al. 2016). The recommended changes in documentation practices in homecare services will facilitate a greater understanding of the reasons for any disruption in care provision and the conditions present that contribute to these disruptions. Putting measures in place to improve communication between care workers and older people will also help to avoid unnecessary, time-consuming and costly repeat visits to establish the whereabouts of 'missing' older people. Improved documentation practices would also ensure the standardisation of coding and provide clarity in determining what constitutes No Access and Service Refusal. Consistency of coding would also prevent unnecessary visits to determine the whereabouts of the older people, as service users, and ensure their wellbeing, and would provide more opportunities for comparing between different registries. In addition, staff training is recommended to ensure that care workers are aware of the importance of recording complete and coherent documentation following each visit and to guide follow-up actions needed in the event of non-delivery.

A report of the research findings was given to the homecare service provider who initiated this research. The problems that were identified regarding incomplete and missing data revealed a need to train homecare managers and care workers in the importance of ensuring that their registry entries are completed in full to create a comprehensive dataset and so that such analyses can be interpreted with more confidence in future.

As this homecare service provider provided the majority of homecare for this group, it is difficult to know whether the results would be similar for other homecare service providers. Although the findings provide analysis for one city in Scotland, future research needs to build on these findings. As an exploratory study, it is not proposed that any generalisation to the broader population can occur.

5.3.3 Implications for policy

Homecare service providers:

Incidence of service refusals can, for homecare service providers, prove extremely time-consuming and costly. Care workers have a protocol to follow when the older person is absent from the place of caregiving to ensure their whereabouts and safety. As reported by the homecare service provider, all too often, due to poor communication with the older person, care workers spend a significant amount of time searching for absent service users. A clearer system, based on effective communication with older people who are service users and their kinship carers, would help reduce these concerns, especially when the reasons for No Access are as a result of being away with others or because someone else is providing the care.

Recommendations made to the homecare organisation also included the development of an operational manual to guide daily practice regarding a follow-up procedure in the event of non-delivery and improved documentation to ensure a standardised system of coding with reasons for non-delivery clearly explained. Early identification of those who are at risk of non-delivery could be a useful indicator of vulnerable older people, as service users, who are in need of increased surveillance and would prevent unnecessary call-outs to determine the whereabouts of 'missing' older people.

Local authorities:

The number of older people living in the community continues to grow (Scottish Government 2018a). People prefer to live at home, but the present homecare service provider is stretched and unable to fully meet the needs of those for whom they care. If this situation continues, service refusals may increase, negatively impacting older people, as service users, and homecare service providers.

Local authorities purchase external homecare services to meet the increasing challenges of providing care to older people who live at home. Working in collaboration with homecare service providers, they have joint responsibility for the people they care for. This study revealed the benefit of research to help inform and improve services, without which service refusals might increase. Presently, the assessment of the need for homecare is based on physical and domestic needs. This research clearly shows that there is an equivalent need for social contact to prevent loneliness and social isolation. The implications of this need are now more pronounced, considering the context of the COVID-19 pandemic. Rushed visits prevent the opportunity for care workers to connect with older people in any meaningful way. The allocation of more time for homecare visits and more travel time in between visits is required in order to deliver the care that older people need.

Governmental policy:

The Scottish Government has made a commitment to provide homecare for all those who have been assessed as needing it, to enable people to live at home and to keep them out of hospital for as long as possible (Scottish Government 2018a). However, the needs of the ageing population are changing, and present care worker training and education does not reflect these needs (Scottish Government 2021).

Presently, the Adult Social Care Independent Review (Scottish Government 2021) recognises the social care workforce to be undervalued and poorly paid, with poor support provided for care workers in terms of their employment, learning and development. Their aim is to develop a National Care Service (NCS) to support positive experiences and outcomes for people who use services, including the establishment of a national organisation for training and development. They recommend a national job evaluation exercise to assess the skills, qualifications, responsibilities and contribution,

which is presently on-going. The findings of this thesis provide timely support towards establishing better education and training for care workers who provide care to older people who wish to live at home for as long as possible.

And finally ...

Ultimately, the overall research question, '*What is known about non-delivery of homecare among older people in Scotland?*', requires further research to explore the gaps in the knowledge that this doctoral research study has identified. This study highlights critical concerns that call for changes in practice for homecare service providers as well as the need to elicit change in policy. Obtaining the views of older people provided a previously untapped opportunity to explore their unique experiences of homecare and non-delivery. Although there are limitations, this doctoral research study provides significant insight into the issues facing care providers who are currently delivering homecare to older people, based on the views of older people. Collectively, both studies demonstrate an important potential for further innovative research, using data linkage, into the quality of social care, in particular why some people refuse while others accept homecare. This study provides a model that could be implemented in other care settings in other cities to further explore non-delivery of homecare for older people.

The Scottish Government's vision and commitment remains that 'older people are valued as an asset, their voices are heard and older people are supported to enjoy full and positive lives in their own home or in a homely setting' (Scottish Government 2018a, p. 3). This does not preclude the need for care homes. However, the influence of COVID-19 has shifted the balance of care from the care home to the home. As lockdown has prevented admissions into care homes, people are being cared for within their own home to protect them from this virus (Scottish Government 2020). Therefore, I believe that the findings from this research have come at a poignant time, as the nature of homecare is changing. Older people still want to remain in their home for as long as possible, but the experience of COVID-19 has now endorsed the importance of this to prevent the devastating effect that this pandemic has had on the this arguably very vulnerable group of people, and the NHS and social care.

5.4 Researcher's Reflections

My professional experience and personal interest in caring for older people placed me in a strong position to perform this doctoral research.

As a registered general nurse and as an SVQ assessor for health and social care, most of my professional career has been involved in ensuring the best outcomes for older people living in a hospital or community setting. I have witnessed first-hand the issues that care workers face in delivering care that is person-centred within a service with limited resources. Personally, I have advocated for elderly friends and family whose wish was to stay at home, but have encountered opposition based on cost and lack of resources. A culmination of my interest in caring for older people initiated study for a Bachelor's degree in Nursing and an MSc in Palliative Care. My progression to study towards a PhD was perhaps a natural one, as this topic relates so well to my previous interests, experiences and concerns.

The journey to completion of this thesis has been a challenging but enlightening one. Throughout the process I have developed my research skills. This was aided by an interim position as Research Fellow, exploring the educational needs of homecare workers caring for older people (Cunningham et al. 2019). As a researcher, my preference lies within the qualitative domain. Qualitative research allows in-depth exploration of complex phenomena, irrespective of the number of individuals it may account for. Adopting a pragmatic approach helped me to ensure that the research question remained at the forefront of my inquiry, which in turn dictated the most appropriate research design to answer these questions, without having the constraints of being attached to other methodological approaches.

I found the quantitative research process to be a challenge, but the benefits to this multi-method study far outweighed the challenges I experienced in doing it. This study highlights the need for more empirical research on non-delivery of homecare. This study also provides a valuable opportunity to access linked data for almost all 65-year-olds and older who receive care in Scotland's largest city.

I was comfortable undertaking the qualitative study, as this is the method that I was most familiar with. As previously stated, my worldview is that we are all in and of the same world. However, I also believe that we each build our own understanding of the

world and responses to it out of our own experience of it (Maxwell 2012). Knowing this helped me to guard against assumptions and bias by embracing reflexivity. On the one hand, I remained objective to allow participants the opportunity to speak freely, avoiding the temptation to impact the conversation. I was aware of the possibility of influencing the outcomes based on my own experiences. On the other hand, my experience with older people, some with cognitive difficulties, helped me to delve deeper into their multi-nuanced responses. This helped to identify connections and tensions within the data not immediately evident. In addition, I found that further conversations, once the audio-recorder had been switched off, helped to create an accurate picture of what was really happening and were just as valuable as the transcribed data.

Reflexivity is a strong component in framework analysis. Revisiting transcriptions and being immersed in the data ensured that the themes and categories stayed close to their original meanings and revealed any unnecessary researcher contamination. There were times during the study when data took an unexpected turn. Surreptitious struggles between perceptions and reality were evident, for instance, when what was said was in direct conflict with what the data revealed. I expected to hear more experiences of non-delivery of homecare, because I knew that community services were under pressure. As a nurse, it was sometimes difficult to hear negative reports of an inadequate service. However, I was reassured that the findings of my research have positive implications for indicating the need to recognise the benefits of including older people's voices and to act on these insights to facilitate older people to live at home and remain independent for as long as they wish.

Epilogue:

Perhaps I won't worry about her so much now. Although she was more likely to accept the homecare provided, I understand why she sometimes doesn't let the care workers in to help her. It's not just because they arrived late, as she understood that others needed as much care as she did and it wasn't that she didn't want yet another different care worker that she had to get to know. In fact, she enjoyed the company of her care workers without which she would feel lonely. She was, however, worried that if the care workers thought she couldn't cope by herself in her own home, she may end up being

admitted into a care home. If this happened, her fear was that she might lose the two things most important to her; her home and her independence. I am sure that it is for these reasons that she would accept homecare.

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Appendices

My Research Needs You!

Hello. My name is Karen Methven. I am from the University of Stirling where I do research in Health Care.



I would like to know what patients or service users think about a piece of research I am currently doing. I am interested in homecare for older adults and why some people do not always receive the homecare that is planned for them.

If you would like to comment on this research project, I would be pleased to invite you to **come along to a group discussion** of around 4-5 people.

I am *particularly* interested in your views as you may have had homecare yourself.

The discussion would last for no more than one hour and it would take place in the day centre with refreshments provided. Future discussions will be 6 monthly. We may meet up again before the end of the project if you want to comment further. If you are interested please tell the unit centre manager and a suitably convenient date and time for the first discussion will be arranged.

Thank you



UNIVERSITY OF
STIRLING

SCHOOL OF
NURSING, MIDWIFERY
AND HEALTH

Appendix 2: University of Stirling approval

JP/SG

14 February 2013

Karen Methven
Clinical Academic Fellow
School of Nursing, Midwifery and Health
University of Stirling
Stirling
FK9 4LA



UNIVERSITY OF
STIRLING

SCHOOL OF
NURSING, MIDWIFERY
AND HEALTH

Email: nursingmidwifery@stir.ac.uk
Web: www.nm.stir.ac.uk

John Paley
Chair
School Research Ethics Committee

School of Nursing, Midwifery and Health
University of Stirling
Stirling FK9 4LA

Tel: +44 (0) 1786 466399
Fax: +44 (0) 1786 466333
Email: john.paley@stir.ac.uk

Dear Karen

Patterns of delivery of home care and associations with adverse outcomes in older people.

Thank you for submitting this application, which was discussed at the meeting on February 13 2013.

I am happy to inform you that the study has been ethically approved.

However, we would like to draw your attention to one methodological ambiguity. At various points, including the *Aims*, the application suggests that you will be evaluating the relation between patterns of home care and health care outcomes (measured, for example, by hospital admissions). In other places, including the *Analysis*, it suggests that you will be identifying factors associated with non-delivery of home care, the implication being that the non-delivery will be the dependent variable in the regression.

So there are two sets of relations here: (a) factors affecting delivery and non-delivery, and (b) how delivery and non-delivery affect health outcomes.

There is no reason, of course, why you should not do both: treat non-delivery as a dependent variable and identify independent variables associated with it; and treat outcomes as the dependent variable, and examine patterns of non-delivery as the independent variable(s). As it stands, however, the proposal is not clear about what you intend.

This is not something you need to get back to us about. It's just something we thought worth pointing out.

Highland Campus:
Centre for Health Science
Old Perth Road
Inverness IV2 3JH

Tel: +44 (0) 1463 255655
Fax: +44 (0) 1463 255654

Stirling Campus:
Stirling
FK9 4LA

Tel: +44 (0) 1786 466340
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Western Isles Campus:
Western Isles Hospital
MacAulay Road
Stornoway Isle of Lewis HS1 2AF

Tel: +44 (0) 1851 708243
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The University of Stirling is recognised as a Scottish Charity with number SC 011159

Appendix 3: Homecare Service Provider Approval

Dear Sir/Madam

LETTER OF SUPPORT

RECORD-LINKAGE OF HEALTH AND HOMECARE DATASETS: ASSOCIATION BETWEEN NON-DELIVERY OF HOMECARE AND ADVERSE OUTCOMES IN OLDER ADULTS

Allow me introduce ourselves; we are [REDACTED] Scotland's leading facilities management and care provider. Our operation is based in the centre of Glasgow although we provide services to organisations across the west of Scotland and throughout the United Kingdom. We are a limited company 99% owned by Glasgow City Council and provide a range of homecare services on behalf of Glasgow City Council's Social Work Services. Over 7000 Glaswegians receive support from our homecare staff on a daily or weekly basis with 80% of our homecare population aged 65 or over. We have 2700 homecare workers who undertake 70,000 visits per year; approximately 6900 visits are delivered each week with an average of 9.6 hours per person. We are therefore, clearly a key player in keeping older adults at home longer.

We are delighted to be associated with the proposed studentship application and have been in discussion with the researchers for over a year now. We share their commitment to homecare and keeping older adults at home longer. Consequently, we believe the proposed studentship would considerably enhance our knowledge of our homecare population and assist us in better understanding the thorny and often complex issue of non-delivery of homecare. We would then be in a position to consider appropriate interventions that could enhance our homecare service provision thereby potentially reducing adverse events/outcomes and keeping older adults at home longer. We hope you will be able to support the application.

We are fully supportive of the proposed application and would fully co-operate and support the proposed research with access to our homecare dataset, homecare workers and homecare population. We are confident that Dr Evans and [REDACTED] will ensure that the successful doctoral candidate will carry out the research in a robust, systematic and ethical manner. Moreover, our existing working relationship will ensure that the research is grounded in a 'real life' problem with the findings being translated quickly into practice.

We sincerely

[REDACTED]



WoSRES
West of Scotland Research Ethics Service

Ms Flood
NHS Greater Glasgow and Clyde
NHS Safe Haven
Boyd Orr Building
University Avenue
Glasgow
G12 8QQ

West of Scotland REC 4

Ground Floor, Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT
www.nhsqgc.org.uk

Date 7 June 2012
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail XXX

Dear Ms Flood

Title of the Database: NHS Greater Glasgow & Clyde Safe Haven
Linked Research Database
REC reference: 12/WS/0142

The Research Ethics Committee reviewed the above application at the meeting held on 1 June 2012.

Ethical opinion

The Committee thanked [REDACTED] and [REDACTED] for attending the meeting and the following was discussed:

1. The Committee asked for background regarding the database and xxx explained that funding has been received from the Chief Scientists Office to set up the database in partnership with the University of Glasgow and that it will fall within the remit of the Health Information and Technology Department (HI&T) for NHS Greater Glasgow and Clyde.
2. The Committee asked how requests for data will be handled and Ms Flood explained that the applicant will be sent the data which answers their requests which will be sent to their e-mail address and also to the safe haven. Applicants will also sign a confidentiality statement regarding the use of the data they receive. Also any publications which includes data received from the database will be published on the database website.
3. The Committee asked for information regarding how the database is backed up and Ms Flood explained that the normal procedures already in place by the HI&T Department will be followed.
4. The Committee had concerns regarding the leaflet entitled "Confidentiality - it's your right" not being disseminated as widely as supposed and Dr Armstrong informed the Committee that the Local Privacy Advisory Committee plan to have an awareness campaign and will consider the best ways to make the leaflet available.
5. The Committee asked if "approved" researchers who will have access to the database will be only be from the University of Glasgow and Dr Armstrong explained that this is not the case and in fact said that the Scottish Health Informatics Programme are attempting to define what an "approved" researcher will be and through the programme anyone who will be accessing the database will have done a training course on data and privacy. Potentially an "approved" researcher can be anyone in Scotland who has completed the course.
6. The Committee noted that initially only data from the past 5 years would be integrated into Safe Haven. The dataset would be updated periodically and additional datasets would be added at the direction of the Local Privacy Advisory Committee (LPAC).
7. The Committee noted the request for generic consent for projects using the information created within Safe Haven. The Committee noted that the LPAC would have an important role in assessing whether requests for data meet the criteria set outwith the application. Requests for data that lie outside the governance arrangements (e.g. requests for data that contain sensitive information), would have to be submitted as a specific project for REC approval).
8. The Committee noted that it is possible to flag up electronically, those who wish to withdraw consent for inclusion of data within the datasets. The mechanism for withdrawal of consent must be made explicit in the information made available to the public.

The members of the Committee present gave a favourable ethical opinion of the above research database on the basis described in the application form and supporting documentation.

Duration of ethical opinion

The favourable opinion is given for a period of five years from the date of this letter and provided that you comply with the standard conditions of ethical approval for Research Databases set out in the attached document. You are advised to study the conditions carefully. The opinion may be renewed for a further period of up to five years on receipt of a fresh application. It is suggested that the fresh application is made 3-6 months before the 5 years expires, to ensure continuous approval for the research database.

Additional conditions of approval

In addition to the standard conditions attached, ethical approval is subject to the following:

1. The Committee require more information regarding who will review and approve requests for data held.
2. The Committee noted that the lay member mentioned in Q8-1 of the IRAS REC application form, is not truly lay and suggested that an active lay member from the West of Scotland Research Ethics Service should be recruited to sit on the Local Privacy Advisory Committee.
3. The Committee had concerns that the leaflet entitled "Confidentiality - it's your right" may not be disseminated as widely as supposed and suggested that this should be made available on the database website. The leaflet is dated 2007 and should be updated. It should specify the mechanism for an individual to withdraw consent for their data to be used.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Other: Hospital Information Leaflet (Appendix B)	3	-
Other: Local Privacy Advisory Committee Guidance Notes (Appendix D)	0.2	-
Other: Applicant's CV	-	14 May 2012
Protocol for Management of the Database	1.0	25 April 2012
REC application	-	21 May 2012
Summary of Research Programme(s)	1.0	-

Research governance

A copy of this letter is being sent to the R&D office responsible for NHS Greater Glasgow and Clyde.

Under the Research Governance Framework (RGF), there is no requirement for NHS research permission for the establishment of research databases in the NHS. Applications to NHS R&D offices through IRAS are not required as all NHS organisations are expected to have included management review in the process of establishing the database.

Research permission is also not required by collaborators at data collection centres (DCCs) who provide data under the terms of a supply agreement between the organisation and the database. DCCs are not research sites for the purposes of the RGF.

Database managers are advised to provide R&D offices at all DCCs with a copy of the REC application for information, together with a copy of the favourable opinion letter when available. All DCCs should be listed in Part C of the REC application.

NHS researchers undertaking specific research projects using data supplied by a database must apply for permission to R&D offices at all organisations where the research is conducted, whether or not the database has ethical approval.

Site-specific assessment (SSA) is not a requirement for ethical review of research databases. There is no need to inform Local Research Ethics Committees.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

Here you will find links to the following:

- a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
- b) Annual Reports. Please refer to the attached conditions of approval. c) Amendments. Please refer to the attached conditions of approval.

12/WS/0142

Please quote this number on all correspondence

Yours sincerely



**for Dr Brian Neilly
Chair**

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
Approval conditions

Copy to: R&D Office, Tennent Building, Western
Infirmary Ms Isobel Brown, Greater Glasgow
Health Board

Appendix 5: University of Glasgow VPN

Glasgow Clinical Trials Unit
Form 14.011A
v1.0



Virtual Private Network (VPN) Access Request Form

1.0 VPN Policy

1.1 Access Policy

Centre Staff refer to SOP 14.010 Teleworking.

1.1.1 Non-Centre Staff only

- a. By using VPN technology with personal equipment, users must understand that their machines are an extension of the Centre's network, and as such are subject to the same rules and regulations that apply to Centre owned equipment, i.e., their machines must be configured to comply with the following:
 - All computers connected to Centre's network via VPN must use up-to-date virus-scanning software and virus definitions.
 - All relevant security patches must be installed.
- b. Users of this service are responsible for the procurement and cost associated with acquiring basic Internet connectivity, and any associated service issues. VPN services work best over broadband connections. External equipment and software will not be supported by Centre IT staff.
- c. It is the responsibility of the user with VPN privileges to ensure that unauthorized users are not allowed access to the Centre's network.
- d. VPN access is controlled using a username and password authentication. For non-Centre staff these will be assigned by rcbitsupport@glasgowctu.org. The password must comply with the Centre's Password Policy. Each VPN user must have a unique profile. Shared profiles are not permitted.

1.2 VPN restrictions

- a. VPN services are to be used solely for Centre business and/or academic support purposes. All users are subject to auditing of VPN usage.
- b. When actively connected to the Centre's network, the VPN will force all traffic to and from the remote node through the VPN tunnel.
- c. Centre network access for non-Centre personnel will be limited to the resources to which they need access. Open access for these accounts will not be permitted.

1.3 VPN Disclaimers

I will:

- a. access datasets only for the purposes specified for the project;
- b. safeguard datasets and any usernames and passwords associated with it;
- c. abide by any other conditions notified to me by the Principal Investigator/regulatory bodies or the Centre;
- d. Notify the Centre immediately if any security breach or incident is suspected (via rcbitsupport@glasgowctu.org)
- e. Treat all access to data/files/documents as confidential.

I will not:

- a. make copies of any data/documents/files;
- b. issue anyone with any data/files/documents from the Centre's network;
- c. allow others to access the Centre's network using my credentials;
- d. login using my credentials and allow any non-authorised person(s) to view or access data
- e. attempt to link any data to other datasets outwith the project's approvals;
- f. attempt to identify any individual record (individual, household, business etc.) in any dataset, or to claim to have done so;
- g. transfer any other data/documents/files other than those agreed and outwith any regulatory or legal approvals;
- h. release or publish any information or results which identifies any individual record or may lead to the identification of any individual record;

1.4 Policy Enforcement

This policy regulates the use of all VPN services to the Centre's network. To maintain security, VPN services will be terminated immediately if any suspicious activity is found. Service may also be disabled until the issue has been identified and resolved.

Non-Centre employees and vendors are directly responsible for damage as a direct result of policy violation. Intentional and non-intentional violation will result in termination of service and may result in further action depending on the damage done.

1.5 Declaration

I certify that I have read all of the above clauses, that I understand that I am accountable for correct and responsible use of the data and data access system via VPN, and that I understand that my failure to comply with these will result in withdrawal of my access to the dataset and any other sanctions that may be determined.

Signature: 

Date: 24.11.14

Checked and approved by: _____

Appendix 6: Data sharing protocol

GLA 005-002

PROTOCOL ON SHARING PERSONAL DATA

between

GLASGOW CITY COUNCIL, a local authority incorporated under the Local Government etc (Scotland) Act 1994 and having its Chief Office at City Chambers, George Square, Glasgow (hereafter "GCC")

and

UNIVERSITY OF STIRLING, a university established in Scotland by charter dated 14th December 1967, (and registered as a charity in Scotland, registration number SC011159) of Stirling, FK9 4LA (hereafter "The University").

and



WHEREAS:-

- The University is conducting a study into patterns of delivery of home care services;
- The Research (as hereinafter defined) can best be conducted and the benefits which this Research will lead to best be attained through researchers from the 'Safe Haven' having access to personal data relating to home care service users, and of which personal data GCC and/or [REDACTED] are jointly the data controllers and matching that personal data from GCC and [REDACTED] with personal data held

by the Health Board to produce Anonymised Data, Data matching will be done utilising researchers at the "Safe Haven" infrastructure described below;

- Only Anonymised Data will be transferred or made available to the University by the researchers at the Safe Haven.
- The University is responsible for ensuring that its use of the Safe Haven complies with the requirements of this Agreement; and
- GCC, [REDACTED] and the University are determined to ensure that the transfer of Anonymised Data to the University is done in accordance with all applicable laws and with full regard to the rights of the Service Users concerned.

NOW THEREFORE IT IS AGREED AS FOLLOWS:-

DEFINITIONS.

- 1.1. In construing this Protocol the following expressions shall have the meanings hereby assigned to them except where the context otherwise requires:-

"Agreement and/or Protocol" means this agreement between GCC, [REDACTED] and the University together with the two schedules annexed hereto.

"Anonymised Data" means the information generated by the researchers at the Safe Haven by matching Personal Data from GCC and [REDACTED] with Personal Data held by the Health Board to produce statistical or other information in such a format that it is no longer possible for any person to identify any particular individual or individuals from the information in that format.

"Health Board" means Greater Glasgow and Clyde NHS Board, an NHS Board established in terms of National Health Service (Scotland) Act 1978 (as amended) and having its Head Office at JB Russell House, Gartnavel Royal Hospital Campus, Glasgow G12 0XH

"Service User" means any individual information relating to whom will be processed in terms of this Agreement.

"Service User Personal Data" means Personal Data relating to a Service User.

"Data", "Personal Data", "Sensitive Personal Data", "Data Controller" and "Processing" shall have the meanings ascribed to them respectively by the Data Protection Act 1998.

"the Parties" means GCC, [REDACTED] and the University and "Party" shall mean any of them as the context requires.

"Research" means the research into patterns of delivery of home care services, as more particularly described in Schedule 1.

"Safe Haven" means the data repository and associated data matching software and algorithms owned and managed by the Health Board, used for purposes of research involving medical data.

- 1.2. Except where the context requires, words imparting the singular shall include the plural and words imparting male gender shall include the female (and vice versa).

2. OVERARCHING PRINCIPLES AND GENERAL DESCRIPTION OF PROJECT.

- 2.1. GCC and [REDACTED] shall release the Personal Data to the Safe Haven in terms of the data sharing conditions spelled out in Clause 5 and Schedule 1.
- 2.2. It shall be a fundamental principle of this Protocol that the confidentiality of Service User Personal Data is paramount. The Parties agree that no use shall be made of Service User Personal Data which is inconsistent with the terms of this Protocol and the rights of confidentiality of the Service Users of that Data, except to the minimum extent required by law or to the extent that a particular Service User has expressly consented to that further use. The Parties agree to use their reasonable endeavours to safeguard the confidentiality of the Service User Personal Data, which duty of confidentiality the Parties expressly recognise subsists after death.
- 2.3. Information is exchanged between the Parties purely for the purposes of facilitating the Research.

3. DATA PROTECTION NOTIFICATION AND CONTROL.

- 3.1. GCC and [REDACTED] are initially jointly the Data Controllers of the Service User Personal Data.
- 3.2. The Parties confirm that each has a valid notification under the Data Protection Act 1998 and that this notification includes reference to the fact that Service User Personal Data is held and may be disclosed to the other Parties.
- 3.3. The Parties undertake not to allow the said notification to lapse or be amended in a way which would render it inconsistent with Clause 3.2 for the duration of this Protocol.
- 3.4. The Safe Haven shall become Data Controller of the Service User Personal Data at the point where the Service User Personal Data is released by GCC and [REDACTED] to the Safe Haven.
- 3.5. The Parties agree, and record their agreement within this clause, that in terms of the requirements of the fair processing notice code contained in Schedule 1 Part II paragraph 2 of the Data Protection Act 1998, it would involve disproportionate effort to expressly notify each Service User about the Research. GCC will include a reference to the Research within the privacy statement on the GCC website.

4. AUDIT AND INSPECTION, INDEMNITIES ETC.

- 4.1. The University hereby agrees to indemnify GCC and [REDACTED] for any losses or expenses incurred by GCC or [REDACTED] as a result of the University failing to comply with the terms of this Agreement (which, for the avoidance of doubt, shall include the reasonable costs of defending any action brought by or on behalf of the Information Commissioner including criminal prosecution or the imposition of a civil penalty).
- 4.2. GCC and [REDACTED] may with prior written notice, jointly undertake an audit of the University and any sub-contractor to ensure compliance with the agreed contractual standards. GCC and [REDACTED] undertake not to use or disclose any confidential information belonging to the University or any third parties acquired in the course of such audit.

- 4.3. The University will advise GCC and [REDACTED] as soon as is reasonably possible of any security breaches within its own organisation which involves or could reasonably impact on the Service User Personal Data.
- 4.4. The University will ensure that all staff or students who are involved in processing Personal Data receive the appropriate training in data protection procedures, identify and keep records of training received by such staff and contents of all courses. The University shall ensure that no other agents or employees of the University (i.e. other than those who have received this training and are part of the patterns of care delivery research team) are given access to the Service User Personal Data.
- 4.5. Any Service User Personal Data inadvertently accessed by the University from the Safe Haven will be immediately deleted from its computers and memory sticks, and the Safe Haven will be promptly advised of the inadvertent access in order that appropriate actions can be taken by the Safe Haven to remove such external access to the Service User Personal Data from its systems .
- 4.6. GCC must give prior written authorisation (on behalf of itself and [REDACTED]) for any transfer or disclosure of Service User Personal Data or the Research data outside the European Economic Area.

5. CONDITIONS ON RELEASE OF THE RESEARCH DATA

- 5.1 The Council and [REDACTED] shall release the Service User Personal Data to the Safe Haven on the conditions contained in the remainder of this Clause 5. The manner and format of the release of the Service User Personal Data will be in accordance with the information governance standards set out in Schedule 2 so as to ensure adequate Data security during the process of the transfer and proper use of the Data on receipt by the Safe Haven.
- 5.2 The Parties agree that since the processing envisaged by this Agreement is purely for research purposes and falls within the exception set out in Section 33 of the Act, it is neither necessary nor appropriate to seek the consent of the Service Users to their Personal Data being transferred from GCC and [REDACTED] to the Safe Haven.

- 5.3 The University hereby confirms that the Anonymised Data will be used solely for purposes of research which complies with the conditions listed in Section 33(1) and Schedule 3 paragraph 8 of the Data Protection Act 1998. In particular, the University undertakes not to make any attempt to identify or contact any person to whom the Anonymised Data relates.
- 5.4 The University shall use the Anonymised Data solely for the purposes of the Research described in Schedule 1. Any substantive addition or alteration to the research aims shall require the prior approval of GCC and [REDACTED].
- 5.5 Once the Service User Personal Data have been converted into statistical or other information in such a format that it is no longer possible for any person to identify any particular individual or individuals from the information in that format, the University shall be at liberty to use this information as it sees fit.
- 5.6 The University shall include an appropriate acknowledgement of the roles of GCC and [REDACTED] in this project in any literature it produces as a consequence of the Research project to which this Agreement relates.

6. DEALING WITH SUBJECT ACCESS AND FOI REQUESTS.

- 6.1 The following clauses shall apply if a Service User or someone duly authorised to act on their behalf makes a request to the University in terms of Section 7 of the Data Protection Act 1998 (hereafter a "subject access request") for any information contained within the Service User Personal Data.
- 6.2 The University shall, in any case, be free to advise the person making the subject access request that, in relation to information of the sort which is transferred in terms of this Agreement, the request might be better addressed to GCC and/or [REDACTED].
- 6.3 Notwithstanding any other provision in this Agreement, the Parties acknowledge that the existence of this Agreement may be subject to requests made pursuant to the Freedom of Information (Scotland) Act 2002 ("FOISA") and, subject to any applicable

exemptions as determined by the receiving Party of the FOISA request, the content of this Agreement may be disclosed pursuant to FOISA. Before disclosing any information relating to this Agreement in response to a request for information made pursuant to FOISA, the Party in receipt of the FOISA request shall, as soon as reasonably practicable after receiving such request, notify the other Parties of such request. The other Parties may make representations as to whether, and on what basis, the information requested is covered by an exemption under FOISA and thus should not be disclosed. The Party in receipt of the FOISA request shall consider reasonably any representations made to it by the other Parties before reaching a decision whether to disclose the information requested. However, in all cases, it is for the Party in receipt of the FOISA request alone to determine whether or not to disclose the information. Further, the Party in receipt of the FOISA request shall not be obliged to notify the other Parties where it has already decided that it does not intend to disclose the information because FOISA does not apply to the request or because an exemption under FOISA can be applied. If the Party in receipt of the FOISA request makes a decision to disclose the information it shall notify the other Parties of this decision in advance of the disclosure being made.

7. DURATION AND VARIATION.

- 7.1. This Protocol shall come into force immediately on being executed by all Parties.
- 7.2. This Protocol shall last until such time as the Research is completed, unless terminated or superseded in terms hereof.
- 7.3. Notwithstanding the termination or expiry of this Protocol, any duties of confidentiality or restrictions on permitted types of processing of Personal Data imposed on the Parties or in respect of staff or agents hereunder shall subsist indefinitely.
- 7.4. Any Party may terminate this Protocol on giving six months' written notice to the other Parties of their intention to do so.
- 7.5. This Protocol may be terminated or varied by the written agreement of the Parties.

- 7.6. This Protocol shall terminate on the execution by the Parties (or their successors) and coming into force of another Protocol on sharing Personal Data which is expressly stated to supersede this Protocol.
- 7.7. Any Party may terminate this Protocol by notice in writing immediately if:-
- 7.7.1. an other Party shall be in breach of any of the terms of this Protocol which, in the case of a breach capable of remedy, shall not have been remedied by that other Party within 21 days of receipt of a written notice specifying the breach and requiring its remedy; or
- 7.7.2. an other Party shall be incompetent, guilty of gross misconduct and/or any other serious or persistent negligence in the carrying out of its duties hereunder.

8. **MUTUAL INDEMNITIES.**

- 8.1. This Clause 8 shall apply in the event of a material breach by any Party of its obligations hereunder (whether or not such a material breach results in any other Party terminating or purporting to terminate this Protocol) where such breach results in harm or distress to any third party.
- 8.2. In the event that the third party who has suffered harm as a result of such a material breach seeks damages (whether at common law, under Section 13 of the Data Protection Act 1998 or otherwise) from a Party or Parties which was/were not in material breach of its or their obligations, that Party or those Parties shall be entitled to be indemnified by the Party in material breach of its duties hereunder.
- 8.3. The indemnity referred to in Clause 8.2 shall include the reasonable costs which any Party being indemnified has incurred in resisting or defending the claim for damages.
- 8.4. The duty to indemnify shall extend to extra judicial settlement of the claim for damages only where the Party in breach has consented to the settlement.
- 8.5. The duty to indemnify shall include the reasonable costs of any appeal against an initial adverse decision of the Court (whether by reclaiming motion or otherwise) only where the Party in material breach has consented to the taking of the appeal.

9. DISPUTES.

- 9.1. The Parties agree to act in good faith at all times and attempt to resolve any disputes arising as a result of their respective rights and duties hereunder on an amicable basis
- 9.2. In the event that the Parties are unable to resolve the dispute amicably, the matter shall be referred to a mutually agreed mediator. If the identity of the mediator cannot be agreed, a mediator shall be chosen by the Dean of the Royal Faculty of Procurators in Glasgow.
- 9.3. If mediation fails to resolve the dispute or if the chosen mediator indicates that the dispute is unsuitable for mediation, the matter shall be referred to arbitration. The arbiter shall be mutually agreed or, failing agreement, chosen by the Dean of the Royal Faculty of Procurators in Glasgow. The decision of the arbiter shall be final.
- 9.4. For the avoidance of doubt, this Section 9 shall apply to the duties contained in Part 8 hereof (mutual indemnities) as it applies to the rest of this Protocol.

10. FEES

- 10.1. The University will pay £3,000 (THREE THOUSAND POUNDS) to [REDACTED] in connection with [REDACTED] work in supplying the data required in terms of this Protocol and will also be responsible for meeting the fees for the Safe Haven, such payment to be made following the University being invoiced for this sum by [REDACTED] and in accordance with the payment terms set out in that invoice. No other fees or other form of payment or recompense are due to or by any Party in terms of this Agreement.

11. **GOVERNING LAW.**

11.1. This Protocol shall be governed by Scots law and the Parties hereto submit to the exclusive jurisdiction of this Scottish Courts: IN WITNESS WHEREOF these presents consisting of this and the nine preceding pages together with the two Schedules annexed hereto are executed as follows:

SCHEDULE 1: THE RESEARCH

This is the Schedule 1 referred to in the foregoing Data Processing Agreement and Protocol on Sharing Personal Data between Glasgow City Council, [REDACTED] and the University of Stirling.

Details of the research, and the information to be released:

Spanning four years, the purpose of this study is to determine the patterns of delivery of home care, the extent of non-delivery and associated adverse health consequences. It will also suggest possible reasons why people might not receive the home care which was planned for them. The research findings will inform the development of an appropriate intervention to reduce non-delivery of home care.

The specific aims of the study are as follows:

- To record-link [REDACTED] dataset with routine health care data in Scotland (SMR1 inpatient hospital admissions and GRO death data).
- To describe patterns of delivery of home care and the extent of non-delivery of home care
- To evaluate the associations between non-delivery of home care and adverse health outcomes

In the first quantitative phase, the sample will be the total population of people assessed for [REDACTED] during the months of September, October and November 2013. The demographic data (below) will help create the profile of [REDACTED] service users.

Access to [REDACTED] data will enable interrogation of their dataset regarding the characteristics of home care delivery in Greater Glasgow. This dataset will be record-linked to health care datasets. For record-linkage to occur, CHI numbers will be allocated to [REDACTED] records. The CHI number is a unique 10-digit patient identifier by which all health care datasets in Scotland are indexed, and is allocated to patients when they register with a GP in Scotland. The NHS Glasgow Safe Haven will use probabilistic linkage methods for specified data items (name, address and date of birth) for the allocation of CHI numbers to [REDACTED] data. [REDACTED] data will then be linked to the CHI Master Patients Index.

Patterns of delivery of home care will be described followed by an examination of the records of non-delivery of care (No Access and Service Refusals) over the study period and the number of people accounting for them. The socio-demographic and clinical characteristics (age, sex, SIMD, health condition) of people with particularly high levels of non-delivery of home care will be identified.

Once sent to the NHS Glasgow Safe Haven, the data will be record-linked to National NHS datasets on hospital admissions and entry into nursing homes. The appropriate record-linked data will be anonymised and encrypted before the final research dataset is passed to the researcher for analysis.

The data will be analysed by Karen Methven, PhD student, School of Nursing, Midwifery and Health, University of Stirling, under the supervision of Dr Josie Evans, Dr Nicola Cunningham and Dr May McCreddie.

The final research dataset will contain information from three main data sources, individual demographic data, [redacted] data and data from SMR1 inpatient hospital admissions. Descriptive analysis will characterise the home care population served by [redacted] and the levels of home care provided. The intention is to define and describe the underlying population in terms of age, sex and previous medical history; also characterising the changing nature of the population, as people move in and out of different levels of care provision, alongside frequent inpatient hospital admissions. The records will then be examined for non-delivery of care (No Access and Service Refusals) over the study period and the number of people accounting for them. Simple regression analysis techniques will investigate the factors associated with non-delivery of care.

A second phase of this study will seek the views and experiences of service users and their carer's. Although not known at this stage, it is anticipated that the outcome of phase 1 will inform the design of the second phase.

Demographic data

- Name including middle and surname
- Post Code (4 digits)
- DOB (+ full year)
- Sex
- Ethnic group
- Lives alone/living group (code or description)
- Health conditions noted
- Background
- Function and ability (text)
- Risk category-8 categories
- Case category-8 categories. Over 65's in one category
- Housing status-tenant/owner/blank
- Date first received [redacted] care

Type of home care

- Reablement or mainstream
- Personal care/meal prep
- One or two workers – (Moving and Handling, Health and Safety)
- Escalation of home care – summary provided
- Weekly care provision in hours
- Time categories:
 - Time in/out
 - Breakfast 8 – 11
 - Lunch 11- 4
 - Tea 4 – 8
 - Tuck 8 – 10
 - Overnight 10 – 8
- Any adverse events noted (hospital admissions, falls, GP call outs, TMAV)

Non-delivery of home care data

- No access (i.e. nobody there)
- Service refusal (i.e. do not want service)
- Cancellation of service

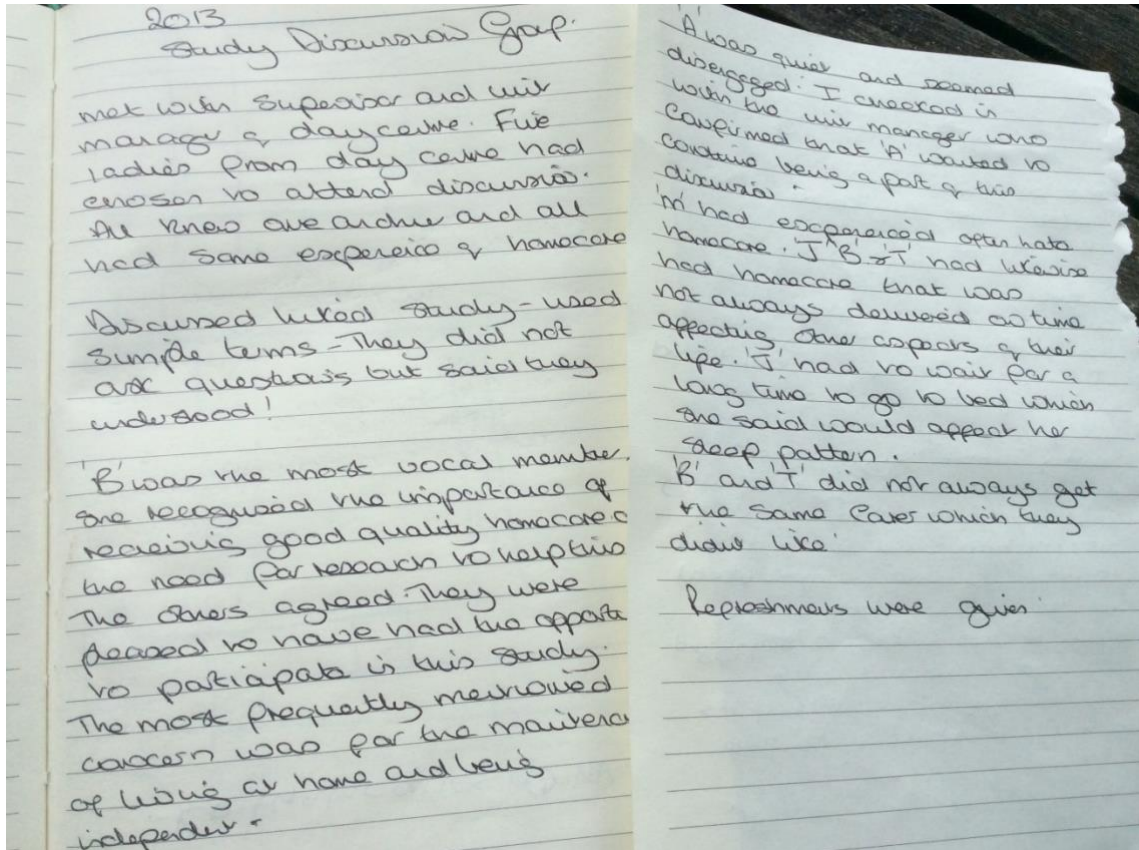
SCHEDULE 2: INFORMATION GOVERNANCE

This is the Schedule 2 referred to in the foregoing Data Processing Agreement and Protocol on Sharing Personal Data between Glasgow City Council, [REDACTED] and the University of Stirling.

Information Governance

- 1.1. Data will be supplied to the Safe Haven by [REDACTED] (on behalf of [REDACTED] and GCC) in a format meeting the Safe Haven's requirements to allow the data to be manipulated and matched within the Safe Haven's systems.
- 1.2. The Safe Haven will implement a back-up system which will allow deletion of the data once the research is completed.
- 1.3. Non-anonymised data will be held at all times within the Safe Haven infrastructure and will be subject to Safe Haven's security and access protocols. GCC's Asset Governance Manager (or appointee) will join the Safe Haven governance board for purposes of any discussions concerning access to and use of the data supplied by GCC and [REDACTED] under this Agreement.
- 1.4. [REDACTED] will supply the data to the Safe Haven either through SFTP or on encrypted memory stick.
- 1.5. At the conclusion of the Research (or termination of this ISP if earlier), the Safe Haven shall ensure that all Service User Personal Data are securely deleted from its IT systems and paper records securely destroyed. This shall not prevent the University from keeping wholly anonymised statistical data derived from the Service User Personal Data.

Appendix 7: Discussion group field notes





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If you are aged 65 and older and have homecare....

I would really like to talk to you!

Hello, my name is Karen Methven and I am a nurse researcher at the University of Stirling. I am interested in hearing about your experiences of homecare.

There are more people aged 65 and older than ever before, many of whom have care at home. However, recent research has shown that not everyone receives the homecare that has been planned for them.

If you would like to hear more about my research, I will be visiting you on.....during one of your meetings to tell you more about it.

Afterwards, if you would like to help me with this research, I will invite you to a group discussion of around 5-7 people who like yourself have also been invited to take part.

Or

If you prefer, I can visit you in your own home to discuss the same topic on an individual basis.

Should you have any queries before then please contact me by phone: 01786 466347 or by e-mail: k.e.methven@stir.ac.uk

Thank you

Appendix 9: Participation information sheet



UNIVERSITY OF
STIRLING

Participation Information Leaflet

Experiences of homecare delivery for people aged 65 and older in Scotland

Hello. My name is Karen Methven and I am a nurse researcher at the University of Stirling. I would like to invite you to take part in a research project looking into experiences of homecare delivery. For you to decide whether or not to take part, it is important that you understand why we are carrying out this study and what exactly it involves if you agree. This leaflet should help explain what we are doing so please take time to read it carefully and discuss it with others if you wish. If there is anything you are unsure about or you want to find out more please ask us for more information.

Who is involved? Apart from myself, I am supported by two supervisors, both from the School of Health Sciences at the University of Stirling.

What is the study about? I am interested in the delivery of homecare for older adults and why some people do not receive the homecare planned for them. I hope my study will help improve future homecare services.

Homecare is defined as providing care of a personal nature e.g. washing, dressing and toileting. Homecare is often provided by social services or privately.

What's in it for me? An opportunity to share your experiences to help us understand more about what older adults need to be supported to live at home.

Refreshments will be available during the discussion group. You can be reimbursed for up to £10 for travel expenses.

So what happens? If you are interested in taking part, you can be part of a discussion group or be interviewed on your own.

The venue for the discussion group will beYou will be given a choice of three dates to attend the discussion group. With your permission, the discussion group and interview will be audio-recorded and notes will be taken. Everything you say will be kept confidential and anonymised. So for example there will be no link made between your name and what you say, so no one will be able to identify you.

If anything is brought up during the interview or discussion group that gives cause for concern (such as for your safety or the safety of others) then I would discuss this with you and with my supervisors at the University of Stirling to agree the next steps.

Who's going to be there? If you attend a discussion group, there will be me, the main researcher and a fellow researcher who will take notes. If you want a one-to-one interview, it will be me and you are welcome to bring a support person.

How long does it take? About an hour.

What will happen to the results of the research study? The overall findings of this research will be presented as part of my doctoral thesis. The findings may be published in a relevant academic policy practice journal. You will not be identified in any way in either. The information from the study i.e. recordings will be kept in a secure environment within the University of Stirling and then destroyed after ten years.

Do I have to take part? No. You have been given this information leaflet because it provides more information about the study. If you are interested, please complete the Contact Sheet. I will contact you in one week to find out if you still wish to take part. If you no longer wish to take part, you may let me know.

Who has designed and reviewed the study? The study has been designed by me, Karen Methven from the University of Stirling. The University of Stirling has also sponsored and funded this research. The School Research and Ethics Committee (SREC), at the School of Health Sciences, University of Stirling, have examined this study proposal and have raised no objections from the point of ethics.

Further information: For further information, contact Karen Methven at the School Health Sciences, University of Stirling k.e.methven@stir.ac.uk (Tel: 01786 466347). I would be happy to discuss any queries you may have. If you wish to speak to an independent advisor about the study, or if you have any complaints, please contact Professor Andrew Watterson, School of Health Science, University of Stirling a.e.watterson@stir.ac.uk (Tel 017864 66283).

Thank you for reading this information sheet and for considering taking part in this study group.



Contact Sheet

Karen Methven
Clinical Academic Fellow

School of Health Sciences

University of Stirling

Study Title: Experiences of homecare for people aged 65 and older in Scotland

I invite you to consider whether or not you would like to be a part of the above study by completing this form. Thank you.

If you **are** interested in being a part of this study and to see if you are eligible, please *tick* the box below and complete your contact details

I would like to be contacted

Name:

First name.....

Phone Number:

Last name

House.....

Mobile.....

Address:

House name.....

E-mail.....

Street.....

Town.....

County.....

Post Code.....

From the details above, what is your preferred means of communication?.....

I look forward to contacting you in the next few days to talk with you further.

Appendix 11: Interview consent form



UNIVERSITY OF STIRLING

INTERVIEW CONSENT FORM

Title of Project: Experiences of Homecare for People Aged 65 and Older in Scotland

Names of Researcher: Karen Methven

	PLEASE	INITIAL
BOX		
1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.		<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without home care or my rights being affected.		<input type="checkbox"/>
3. I agree to the interview being audio-recorded and notes to be taken.		<input type="checkbox"/>
4. I understand that the relevant information collected (i.e. recordings of the interview and notes taken after it) may be accessed by the researcher and research team at the University of Stirling. I give permission for those individuals to have access to these materials.		<input type="checkbox"/>
5. I give permission for information that does not identify me to be documented in research reports and/or publications and presented in teaching/presentations.		<input type="checkbox"/>
6. I understand that the recordings and notes from my interview will be kept in a secure place within the University of Stirling and destroyed after ten years.		<input type="checkbox"/>
7. I agree to take part in this study.		<input type="checkbox"/>

Name of participant
Signature

Date

Name of person taking consent
Signature

Date

When complete, 1 for participant; 1 for researcher site file (original)



FOCUS GROUP CONSENT FORM

Title of Project: Experiences of Homecare for People Aged 65 and Older in Scotland

Names of Researcher: Karen Methven

PLEASE INITIAL BOX

- 1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without home care or my rights being affected.
- 3. I agree to the discussion group being audio-recorded and for a researcher to take notes during it.
- 4. I understand that the relevant information collected (i.e. recordings of the discussion group and notes taken during it) may be accessed by the researcher and research team at the University of Stirling. I give permission for those individuals to have access to these materials.
- 5. I give permission for information that does not identify me to be documented in research reports and/or publications and presented in teaching/presentations.
- 6. I understand that the recordings and notes from my interview will be kept in a secure place within the University of Stirling and destroyed after ten years.
- 7. **I agree to take part in this study.**

Name of participant
Signature

Date

Name of person taking consent
Signature

Date

When complete, 1 for participant; 1 for researcher site file (original)

Appendix 13: Focus group preamble

FOCUS GROUP PREAMBLE

Introduction:

Hello, thank you for coming here today and taking part in the study. My name is Karen Methven and I am a researcher at the University of Stirling. As you are aware I am interested in finding out more about homecare for people aged 65 and older. My role here is to ask you a number of questions about this topic and get some discussion-going amongst yourselves. I don't have a particular opinion about homecare, so please feel free to be as honest as you can. The focus group today will run for about 45 minutes. I will be recording the session and you have already provided consent for me to do this. My colleague will sit amongst you to take down notes of the discussion. Everything you say will be both confidential and anonymised. So, if for example you mention a person's name or place, this will be removed from the paper transcript. In addition, when we write up the report, if we do record a quote from yourself, your name will have been removed so no one will be able to identify you. Please could you turn off all mobile phones before we start.

Housekeeping:

Whereabouts of the toilet facilities, exits in the event of a fire alarm and refreshments.

Before I start, I just need to draw your attention to some important points.

- The sessions will be audio-recorded
- The tapes will be transcribed onto paper
- All identifiable information will be removed
- To make it easier for me to transcribe the tape it is important that only one person talks at a time and no one talks over the top of the other person
- I am interested in a range of opinions and so please do not be afraid to voice your opinion. There are no right or wrong answers. However, please also respect the opinion of others.
- Please let me know if you get upset about anything we are talking about. I will turn off the microphone and my colleague will take you out of the room and sit with you.

Appendix 14: Question guide

FOCUS GROUP AND INTERVIEW QUESTION GUIDE

I have arranged this meeting with you today because you have had some experience of homecare. I would like to gain an insight into your experience of homecare.

I would like you to talk as descriptively as possible, expand on all your ideas (even though you think it is not related), ask me to clarify anything you don't understand and most importantly this is not a test.

Can I begin by asking:

Main question:

1. What are your experiences of the homecare you have received so far?

Supplementary questions:

- Who provides your homecare? (Organisation and individual)
- How often do you receive homecare?
- What does your homecare consist of?
- What aspects of your homecare do you find positive?
- What aspects of your homecare do you find negative?
- What if any, changes would you make to the care you receive?

Main question:

2. What are your experiences of not receiving care that was planned?

Supplementary questions:

At the point of service delivery -

- What reasons might you have for refusing homecare?
- Why might you refuse carers entry into your home?
- Where were you when planned homecare was due?

Main question:

3. What health effects, if any, have you experienced as a result of not receiving homecare?

Supplementary questions:

These questions will probe where relevant the answers to supplementary questions above.

Appendix 15: Ethics approval letter

PH/SN

10 December 2015

Karen Methven
Clinical Academic Fellow
University of Stirling
Room 2T1
RG Bomont Building
Stirling FK9 4LA

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Web: <http://www.stir.ac.uk/health-sciences/research/ethics/>

Professor Pat Hoddinott
Chair
School Research Ethics Committee

School of Health Sciences
University of Stirling
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Tel: +44 (0) 1786 466404
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Dear Karen

**Patterns and experiences of non-delivery of home care for people aged 65 and older in Scotland: A mixed method study
SREC 15/16 – Paper No.45 – Version 1**

Thank you for responding the SREC correspondence of 9 December 2015, and enclosing a revised application.

I note that you have undertaken the minor amendments requested, and am now pleased to advise that your study has been formally approved.

May I remind you of the need to inform SREC prior to making any amendments to this protocol, of any changes to the duration of the project and provide notification of study completion. A site file of all documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the SREC page of the School's website.

<http://www.stir.ac.uk/health-sciences/research/ethics/>

Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

**Ref: SREC 15/16 – Paper No.45 – Version 1
Please quote this number on all correspondence**

Yours sincerely



PROF. PAT HODDINOTT
(Chair)
School of Health Sciences Research Ethics Committee
Cc *Dr J Evans, Supervisor*

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Appendix 16: Minor amendment approval



PH/SN

4 February 2016

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Stirling FK9 4LA

Web: <http://www.stir.ac.uk/health-sciences/research/ethics/>

Professor Pat Hoddinott
Chair
School Research Ethics Committee

School of Health Sciences
University of Stirling
Stirling FK9 4LA

Tel: +44 (0) 1796 466404
Fax: +44 (0) 1796 466333
Email: shs.ethics@stir.ac.uk

Dear Karen

**Patterns and experiences of non-delivery of home care for people aged 65 and older in Scotland: A mixed method study
SREC 15/16 – Paper No.45 – Version 1**

Thank you for your email correspondence of 27 January 2016, in which you request an amendment to your SREC application in order to broaden your recruitment possibilities.

You have advised that you would like to recruit from Community Day Care Centres for older people in addition to Clydebank Seniors Forum and Clackmannanshire Older Peoples Forum.

Following consideration, and taking into account that that you do not require to apply to NHS ethics, I am happy to approve this as a minor amendment, with the condition that the recruitment processes and methods are unchanged from those approved by committee.

**Ref: SREC 15/16 – Paper No.45 – Version 1
Please quote this number on all correspondence**

Yours sincerely

PROF. PAT HODDINOTT
(Chair)
School of Health Sciences Research Ethics Committee
Cc: *Dr J Evans, Supervisor*

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Stornoway Isle of Lewis HS1 2AF

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The University of Stirling is recognised as a Scottish Charity with number SC 011159

Appendix 17: Development of matrices

Table 19: Matrix Theme ‘Care Expectations’

Theme 2: Care Expectations		
Sub-theme Attributes of care	Sub-theme Continuity of care	Sub-theme Physical/domestic care
<p>Participants regard kindness and consideration as key attributes of a good carer. Moreover, a good carer helps them to feel safe and confident: <i>Being kind and considerate. The positive thing about having good carers is that you feel safe, it gi'es me mair confidence</i> (Arthur)</p>	<p>Participants express appreciation that continuity of the same carer ensures they are dressed and presentable: <i>Eh, just wi' no' being able tae get myself dressed and a' that. I know I'm going to be dressed and I'm going to be presentable by the same carer</i> (Issy)</p>	<p>Unsure of the role of the carer and confusion regarding what to expect at each visit: <i>I do my own washing, right and I take it down the stairs, spin dry it and I try tae iron it...They say you've got far too much washing for us to do, we can'nae do it I says but that's your job, that's what you're getting paid for</i> (Jock)</p>
<p>Participants expect care to be delivered on time by the same carer, who they know and who knows the routine and could be left to get on with the job: <i>Well the same person knows where everything is, and how to switch on the shower... you know, the routine</i> (Ellie)</p>	<p>Reference made to the lack of continuity of carers, tempered with satisfaction of the carer: <i>Well I get sometimes different people now and again, you know, but eh they're seem to be a good lot o' women, they're good at their job, you know what I mean, they make sure that I get my pills you know</i> (Ivy)</p>	<p>Carers check that their clothes are clean, they are eating properly; the house is tidy and that they ‘behave themselves’ (although the meaning of the latter was never qualified): <i>They make sure I've got clean clothes, make sure I'm behaving myself ... and eating properly. Somebody that just mair or less comes in and makes sure I'm a' right, makes sure I've got clean clothes, you know, the house is tidy enough</i> (Helen)</p>
<p>Flora's perception of the role of the carer is different to that which is provided leaving her feeling disappointed with the service: <i>And we go out for walks as well and then go to the shops, she just goes to do her shopping and then she's actually supposed to be with me in case anything – God forbid – happens. I have taken dizzy turns and I'm shouting on her and I don't know where she is, she's away tae the other end o' the shop picking her shopping up</i> (Flora)</p>	<p>Lack of continuity of carer is a nuisance as new ones need training: <i>I don't always get the same carer which is a nuisance as I have to retrain them</i> (Ellie)</p>	<p>Carers ensure everything is alright: <i>They have a good look roond aboot and make sure everything's a' right and I've got food in the hoose and that</i> (Arthur)</p>

<p>One participant viewed the carer as someone who relieves her of decision making, an area she struggles with on a day-to-day basis: <i>You know... helping me and things like that, you know, instead o' saying "I don't know, I can't help you wi' that," you know, like that kind of thing. I wanted her to make the decisions for me</i> (Flora)</p>	<p>Continuity of care is emphasised: <i>I've had the same girls fae I started getting the carers, there's one girl in particular, I've had her all the time, constant, you know, sometimes its morning, lunch or tuck time and that, big G, she's a lovely lassie</i> (Kirsty)</p>	<p>Participants are assessed and receive care with a predominately physical focus including help with washing, getting up and going to bed: <i>I was told I would have help with getting up in the morning 'cos it isn't easy, washing and the like and then back to bed at night</i> (Helen)</p>
---	--	---

Plain text: researchers summary. *Text in italics*: direct quote from participants

Table 20: Sub-themes to elements 'Attributes of care'

Data Summaries for Sub-theme: Attributes of Care	Detected Elements
<p>Participants regard kindness and consideration as key attributes of a good carer. Moreover, a good carer helps them to feel safe and confident: <i>Being kind and considerate. The positive thing about having good carers is that you feel safe, it gi'es me mair confidence</i> (Arthur)</p>	<ul style="list-style-type: none"> • Carers are kind and considerate • Carers make them feel safe and confident
<p>Participants expect care to be delivered on time by the same carer, who they know and who knows the routine and can be left to get on with the job: <i>Well the same person knows where everything is, and how to switch on the shower... you know, the routine</i> (Ellie)</p>	<ul style="list-style-type: none"> • Same carer • Consistency of care
<p>Flora's perception of the role of the carer is different to that which is provided leaving her feeling disappointed with the service: <i>And we go out for walks as well and then go to the shops, she just goes to do her shopping and then she's actually supposed to be with me in case anything – God forbid – happens. I have taken dizzy turns and I'm shouting on her and I don't know where she is, she's away tae the other end o' the shop picking her shopping up</i> (Flora)</p>	<ul style="list-style-type: none"> • Tensions between care expected and care received • Service disappointment
<p>One participant viewed the carer as someone who relieves her of decision making, an area she struggles with on a day-to-day basis: <i>You know... helping me and things like that, you know, instead o' saying "I don't know, I can't help you wi' that," you know, like that kind of thing. I wanted her to make the decision for me</i> (Flora)</p>	<ul style="list-style-type: none"> • Someone to help them with decision making

Table 21: Elements to categories ‘Attributes of care’

Detected Elements	Categories
<ul style="list-style-type: none"> • Carers are kind and considerate • Carers make them feel safe and confident • Same carer • Consistency of care 	<p>Elements relate to consistent kind and considerate care making them feel safe and confident</p> <p>Category: Consistent care</p>
<ul style="list-style-type: none"> • Tensions between care expected and care received • Service disappointment • Someone to help them with decision making 	<p>Elements relate to care tensions and service disappointment</p> <p>Category: Care tensions</p>

Table 22: Sub-themes to elements ‘Continuity of care’

Data Summaries for Sub-theme: Continuity of Care	Detected Elements
<p>Participants express appreciation that carers ensure they are dressed and presentable: <i>_ Eh, just wi’ no’ being able tae get myself dressed and a’ that. I know I’m going to be dressed and I’m going to be presentable (Issy)</i></p>	<ul style="list-style-type: none"> • Appreciation of care given • Being dressed, clean and presentable
<p>Reference made to the lack of continuity of carers, tempered with satisfaction of the carer: <i>Well I get sometimes different people now and again, you know, but eh they’re seem to be a good lot o’ women, they’re good at their job, you know what I mean, they make sure that I get my pills you know (Ivy)</i></p>	<ul style="list-style-type: none"> • Different carers • Good caring
<p>Lack of continuity of carer a nuisance as new ones need to be trained: <i>I don’t always get the same carer which is a nuisance as I have to retrain them (Ellie)</i></p>	<ul style="list-style-type: none"> • Lack of continuity of carer a nuisance • Retraining staff •
<p>Continuity of care is emphasised: <i>I’ve had the same girls fae I started getting the carers, there’s one girl in particular, I’ve had her all the time, constant, you know, sometimes its morning, lunch or tuck time and that, big G, she’s a lovely lassie (Kirsty)</i></p>	<ul style="list-style-type: none"> • Continuity of care valued

Table 23: Elements to categories ‘Continuity of care’

Detected Elements	Categories
<ul style="list-style-type: none"> • Lack of continuity of carer • Lack of continuity a nuisance • Retraining staff • Different carers 	<p>Elements relate to lack of continuity of care</p> <p>Category: Continuity of care lacking</p>
<ul style="list-style-type: none"> • Appreciation of care given • Good caring • Being dressed, clean and presentable 	<p>Elements relate to good carers and caring</p> <p>Category: Good care and caring</p>

Table 24: Sub-theme to elements ‘Physical/domestic care’

Data Summaries for Sub-theme: Physical/domestic Care	Detected Elements
<p>Unsure of the role of the carer and confusion regarding what to expect at each visit: <i>I do my own washing, right and I take it down the stairs, spin dry it and I try tae iron it...They say you’ve got far too much washing for us to do, we can’nae do it I says but that’s your job, that’s what you’re getting paid for</i> (Jock)</p>	<ul style="list-style-type: none"> • Uncertain care expectations
<p>Carers check that their clothes are clean, they are eating properly; the house is tidy and that they ‘behave themselves’ (although the meaning of the latter was never qualified): <i>They make sure I’ve got clean clothes, make sure I’m behaving myself ... and eating properly. Somebody that just mair or less comes in and makes sure I’m a’ right, makes sure I’ve got clean clothes, you know, the house is tidy enough</i> (Helen)</p>	<ul style="list-style-type: none"> • Clean clothes • House tidy • Eating properly
<p>Carers ensure everything is alright: <i>They have a good look roond about and make sure everything’s a’ right and I’ve got food in the hoose and that</i> (Arthur)</p>	<ul style="list-style-type: none"> • Food in the house • ‘Everything is alright’
<p>Participants are assessed and receive care with a predominately physical focus including help with washing, getting up and going to bed: <i>I was told I would have help with getting up in the morning ‘cos it isn’t easy, washing and the like and then back to bed at night</i> (Helen)</p>	<ul style="list-style-type: none"> • Care with a physical focus • Washing, getting dressed, going to bed

Table 25: Elements to categories ‘Physical/domestic care’

Detected Elements	Categories
<ul style="list-style-type: none"> Uncertain care expectations 	<p>Element relates to uncertain care expectations</p> <p>Category: Uncertain care expectations</p>
<ul style="list-style-type: none"> House tidy Food in the house ‘Everything is alright’ Clean clothes 	<p>Elements relate to good domestic care</p> <p>Category: Domestic care</p>
<ul style="list-style-type: none"> Care with a physical focus Washing, getting dressed, going to bed Eating properly 	<p>Elements relate to physical care</p> <p>Category: Physical care</p>

Table 26: Matrix Theme ‘Care Time’

Theme 3: Care Time		
Sub-theme Unreliable visit time	Sub-theme Insufficient visit time	Sub-theme Changing patterns of care
<p>The timing of each visit is a key concern with visits earlier or later than expected: <i>Sometimes they would come in for say half an hour and other times maybe they’re only in ten minutes, it depends on what they’re going to do</i> (Betina)</p>	<p>Time taken travelling between houses results in less care time: <i>I think there should be more time given for the people for travelling time. There’s not enough time given to the patient itself</i> (Ros)</p>	<p>Changes in care provision at short notice means a break in service: <i>I don’t have anybody replacing her, she was off for two weeks and it’s quite a long time being without somebody</i> (Flora)</p>
<p>Unreliable visit time and physical impact: <i>I finally get up at half past seven ... about two and a half hour I’m sitting with my, my nightdress on and its, it’s, it’s [emphasis] cold, I get cold ... it’s kinda long tae wait</i> (Ellie)</p>	<p>Concerns raised regarding restricted visit time, leaving participants feeling rushed: <i>I feel rushed ... I need more time</i> (Ellie)</p>	<p>Care changes without participant prior consultation affects day-to-day plans and for Flora this is a frequent occurrence: <i>Last week was the same and the week before that as well, she was on holiday and they never replaced anybody and no phone call to tell me. I couldn’t get out to the shops</i> (Flora)</p>
<p>Waiting for her carer to arrive affects Morags opportunity for self-development: <i>Because I had to wait for her again, I can’t go to my reading and writing classes</i> (Morag)</p>	<p>Paperwork affects time spent providing care: <i>By the time they write up all their reports and everything, it’s just a quick shower</i> (Steve)</p>	<p>Care changed because the perceived needs of the participant had altered: <i>All of a sudden, because I could do my own personal care it was stopped</i> (Jan)</p>
<p>Jock conveys his annoyance regarding late carer: <i>He is often late. This is not good enough</i></p>	<p>Waiting for carers: <i>If I want to go anywhere I can’t go because I’m waiting for the</i></p>	<p>Sudden absence in care provision has a profound effect: <i>I just started panicking,</i></p>

(Jock)	carers (Ellie)	<i>I was in a helluva shock that day, 'cause eh I was just shaking and trembling because they didn't come to me (Flora)</i>
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Plain text: researchers summary. *Text in italics*: direct quote from participants

Table 27: Sub-themes to elements 'Unreliable visit time'

Data Summaries for Sub-theme: Unreliable visit time	Detected Elements
The timing of each visit is a key concern with visits earlier or later than expected: <i>Sometimes they would come in for say half an hour and other times maybe they're only in ten minutes, it depends on what they're going to do (Betina)</i>	<ul style="list-style-type: none"> • Unexpected visit time • Short visits • Long visits
Unreliable visit time and physical impact: <i>I finally get up at half past seven ... about two and a half hour I'm sitting with my, my nightdress on and its, it's, it's [emphasis] cold, I get cold ... it's kinda long tae wait (Ellie)</i>	<ul style="list-style-type: none"> • Unreliable visit time • Waiting and getting cold • A long time to wait •
Waiting for her carer to arrive affects Morags opportunity for self-development: <i>Because I had to wait for her again, I can'nae go to my reading and writing classes (Morag)</i>	<ul style="list-style-type: none"> • Carer often late • Self-development affected
Jock conveys his annoyance regarding late carer: <i>He is often late. This is not good enough (Jock)</i>	<ul style="list-style-type: none"> • 'Being late is not good enough'

Table 28: Elements to categories 'Unreliable visit time'

Detected Elements	Categories
<ul style="list-style-type: none"> • Unexpected visit time • Long visits • Short visits • Unreliable visit time 	<p>Elements relate to unreliable visit times</p> <p>Category: Unreliable visit times</p>
<ul style="list-style-type: none"> • Carer often late • A long time to wait • 'Being late is not good enough' 	<p>Elements relate to having to wait to receive homecare</p> <p>Category: Waiting for care</p>
<ul style="list-style-type: none"> • Waiting and getting cold • Self-development affected 	<p>Elements relate to effects of an unreliable service</p> <p>Category: Negative care outcomes</p>

Table 29: Sub-themes to elements ‘Insufficient visit time’

Data Summaries for Sub-theme: Insufficient visit time	Detected Elements
Time taken travelling between houses results in less care time: <i>I think there should be more time given for the people for travelling time. There’s not enough time given to the patient itself</i> (Ros)	More visit time needed More travel time needed
Concerns raised regarding restricted visit time, leaving participants feeling rushed: <i>I feel rushed ... I need more time</i> (Ellie)	Restricted visit time Participants feel rushed More time needed
Paperwork affects time care time: <i>By the time they write up all their reports and everything, it’s just a quick shower</i> (Steve)	Paperwork affects care time
Waiting for carers: <i>If I want to go anywhere I can’t go because I’m waiting for the carers</i> (Ellie)	Waiting for carers to arrive

Table 30: Elements to categories ‘Insufficient visit time’

Detected Elements	Categories
<ul style="list-style-type: none"> • More visit time needed • More travel time needed • Paperwork affects care time • Restricted visit time • More time needed • Participants feel rushed • Waiting for carers to arrive 	<p>Elements relate to the need for more time during and between visits</p> <p>Category: More time needed</p>

Table 31: Sub-themes to elements ‘Changing patterns of care’

Data Summaries for Sub-theme: Changing patterns of care	Detected Elements
Changes in care provision at short notice means a break in service: <i>I don’t have anybody replacing her, she was off for two weeks and it’s quite a long time being without somebody</i> (Flora)	<ul style="list-style-type: none"> • Changes in care at short notice • Absence of care
Care changes without participant prior consultation affects day-to-day plans and for Flora this is a frequent occurrence: <i>Last week was the same and the week before that as well, she was on holiday and they never replaced anybody and no phone call to tell me. I couldn’t get out to the shops</i> (Flora)	<ul style="list-style-type: none"> • Affects day-to-day plans • Lack of communication • Repeated absence of care

Care changed because the perceived needs of the participant had altered: <i>All of a sudden, because I could do my own personal care it was stopped</i> (Jan)	<ul style="list-style-type: none"> • Sudden changes in care provision
Sudden absence in care provision has a profound effect: <i>I just started panicking, I was in a helluva shock that day, 'cause eh I was just shaking and trembling because they didn't come to me</i> (Flora)	<ul style="list-style-type: none"> • Sudden absence of care • Panic

Table 32: Elements to categories 'Changing patterns of care'

Detected Elements	Categories
<ul style="list-style-type: none"> • Absence of care • Repeated absence of care • Lack of communication • Sudden changes in care provision • Sudden absence of care • Panic • Affected day-to-day plans 	<p>Elements relate to care changes at short notice without prior warning</p> <p>Category: Changing care patterns</p>

Table 33: Matrix Theme 'Care Boundaries'

Theme 4: Care Boundaries		
Sub-theme Accepting Care	Sub-theme Refusing Care	Sub-theme Limitations of Care
Care accepted because of the greater concern that refusal may affect them living in their own home: <i>If I refuse carers coming in tae my hoose I might not be able to live there for very long</i> (Kirsty)	Helen refuses care from a male carer because of his gender and her embarrassment: <i>One day my, my bell went and I goes to the door and this wee man's standing wi' his bunnet on he says eh "I'm from homecare dear, are you Mrs O?" I says "yes," I said "but you're no coming tae me son". I was so embarrassed</i> (Helen)	Unlikely to complain about an unreliable service because other peoples' needs are worse: <i>I don't like to complain, there are other people much worse than me</i> (Ellie)
Participants accepted care services in case they were not offered it again: <i>If you feel you don't want it they will turn round and if you don't want it ... you don't need us and say what's the point of us coming in</i> (Ros)	Kirsty reported an incident where she was given a dry shower: <i>You've heard o' dry shampoos ... have you ever heard o' a dry shower? So I phoned up about it, I says "don't send me that girl again" ... I says "I've heard o' dry shampoos," I says "but my god, that's the first time I've had a dry shower."</i> (Kirsty)	Recognition that other people have a greater need for care: <i>It's not that they're unreliable it's just that perhaps they've got so many other people to see</i> (Helen)

Care accepted unless they didn't get on with the carer: <i>You might not actually want that particular individual ... well if she's no pleasant, you're no wanting anybody coming in like that you know</i> (Elizabeth)	Bob refuses care if their privacy is compromised: <i>Just make sure my wife and I get privacy when it comes to showers and such like, you know, keep us clean</i> (Bob)	Unlikely to complain because they understand that there are other people that need a visit: <i>Well actually they've got quite a few people tae dae, it's no' just me</i> (Ina)
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Plain text: researchers summary. *Text in italics*: direct quote from participants

Table 34: Sub-theme to elements 'Accepting care'

Data Summaries for Sub-theme: Accepting care	Detected Elements
Care accepted because of the greater concern that this may affect them living in their own home: <i>If I refuse carers coming in tae my hoose I might not be able to live there for very long</i> (Kirsty)	<ul style="list-style-type: none"> Care accepted to help them live at home for longer
Most participants accept care in case they are not offered it again: <i>If you feel you don't want it they will turn round and if you don't want it ... you don't need us and say what's the point of us coming in</i> (Ros)	<ul style="list-style-type: none"> If care refused, it might not be on offer again 'If you don't want it, you won't need it'
Care accepted unless they didn't get on with the carer: <i>You might not actually want that particular individual ... well if she's no pleasant, you're no wanting anybody coming in like that you know</i> (Elizabeth)	<ul style="list-style-type: none"> Care accepted unless they didn't like carer

Table 35: Elements to categories 'Accepting care'

Detected Elements	Categories
<ul style="list-style-type: none"> Care accepted to help them live at home for longer If care refused, it might not be on offer again 'If you don't want it, you don't need it' Care accepted unless didn't like carer 	<p>Elements relate to reasons why care is accepted</p> <p>Category: Care acceptance</p>

Table 36: Sub-theme to elements 'Refusing care'

Data Summaries for Sub-theme: Refusing care	Detected Elements
Helen refuses a male carer because of his gender and her embarrassment: <i>One day my, my</i>	<ul style="list-style-type: none"> Wrong gender Embarrassed

<i>bell went and I goes to the door and this wee man's standing wi' his bunnet on he says eh "I'm from homecare dear, are you Mrs O?" I says "yes," I said "but you're no coming tae me son". I was so embarrassed (Helen)</i>	
Kirsty reported an incident of service refusal where she was given a dry shower: <i>You've heard o' dry shampoos ... have you ever heard o' a dry shower? So I phoned up about it, I says "don't send me that girl again" ... I says "I've heard o' dry shampoos," I says "but my god, that's the first time I've had a dry shower."</i> (Kirsty)	<ul style="list-style-type: none"> • Dry shower • Incident reported • 'Don't send me that girl again'
Bob refuses care if their privacy was compromised: <i>Just make sure my wife and I get privacy when it comes to showers and such like, you know, keep us clean (Bob)</i>	<ul style="list-style-type: none"> • Privacy compromised

Table 37: Elements to categories 'Refusing care'

Detected Elements	Categories
<ul style="list-style-type: none"> • Wrong gender • Embarrassed • Dry shower • Incident reported • 'Don't send me that girl again' • Privacy compromised 	<p>Elements relate to reasons why care might be refused</p> <p>Category: Service refusal</p>

Table 38: Sub-themes to elements 'Limitations of care'

Data Summaries for Sub-theme: Limitations of care	Detected Elements
Unlikely to complain about an unreliable service because other peoples' needs are worse: <i>I don't like to complain, there are other people much worse than me (Ellie)</i>	<ul style="list-style-type: none"> • Care accepted even if unreliable • 'Other people worse than me'
Recognition that other people have a greater need for care than them: <i>It's not that they're unreliable it's just that perhaps they've got so many other people to see (Helen)</i>	<ul style="list-style-type: none"> • Many other people to see with greater care need
Unlikely to complain because they understand that there are other people that need a visit: <i>Well actually they've got quite a few people tae dae, it's no' just me (Ina)</i>	<ul style="list-style-type: none"> • Other people to see • Unlikely to complain • Understanding

Table 39: Elements to categories ‘Limitations of care’

Detected Elements	Categories
<ul style="list-style-type: none"> • Care accepted even if unreliable • ‘Other people worse than me’ • Other people to see with greater care need • Other people to see • Unlikely to complain • Understanding 	<p>Elements relate to priority care to those with a greater need and the effect this has on others.</p> <p>Category: Care priorities</p>

Table 40: Matrix Theme ‘Care Tensions’

Theme 5: Care Tensions		
Sub-theme Homecare versus loneliness	Sub-theme Independence versus dependence	Sub-theme Homecare versus institutional care
<p>Participants describe living at home with little or no contact with anyone: <i>I won't see anybody... I won't speak to anybody...nobody would come tae my door. I wish they would</i> (Ros)</p>	<p>Being independent is important: <i>Oh aye ... I think it's great ... independence ... I like my own independence</i> (Helen)</p>	<p>Humour helps to express what they feel about institutional care: <i>They may as well shoot me, take me and shoot me</i> [Laugh] (Elizabeth)</p>
<p>Being in the house without the chance of getting out is linked to feeling isolated. Participants look forward to the company of their carers to reduce their loneliness: <i>If I don't get out of the house then there's isolation.</i> (Issy). <i>I look forward to someone coming because I'm, I'm very [emphasis] lonely</i> (Betina)</p>	<p>Tensions exist between wanting to be independent and being dependent on homecare services to remain at home: <i>Sometimes you feel like you want more help, you feel like you want to get on and try and do it yourself but it's getting more difficult all the time</i> (Flora)</p>	<p>Living at home for as long as possible is preferable to living in institutional care: <i>Well I'm no wanting tae in a home" I tell them, "I'll live in my house as long as I'm fit tae do it"</i> (Morag)</p>
<p>Keeping busy to prevent loneliness is no substitute for the company of others: <i>I can keep myself busy wi' things I'm having to do, but I still feel lonely</i> (Kirsty)</p>	<p>In recognition that visits are time-limited, participants maximise the time spent with their carer, by being ready for their arrival: <i>Well I've got, always got to be ready, you know, just to be ready for them coming</i> (Ellie). <i>For the girls coming in, I've got things a' ready for them</i> (Kirsty)</p>	<p>Participants' link living in institutionalised care to dependency and deterioration: <i>They seem to lose independence. I know a lot o' people who've went in'tae homes and they've had mair care than I get and I get quite a bit and they seem tae go doonhill</i> (Arthur)</p>

<p>Homecare offers the opportunity to connect with someone and provides temporary respite from feelings of loneliness and isolation: <i>Well she comes in for a couple of hours, you feel that at least somebody's there with you</i> (Ellie)</p>	<p>Participants voice concerns that if they are viewed as being too independent then their care package may be stopped: <i>Independence is very important to me but I don't want to lose my carer as she helps me in so many ways</i> (Maggie)</p>	<p>Negative media reports of life in a care home endorse the perception of care home residents as 'poor people' and carers as 'terrible': <i>I've heard of some poor people that pay to stay in some care homes, I don't mean like this, a day centre...a care home, it was on the television recently and it was terrible what they were doing to them, the carers, you know supposedly carers</i> (Steve)</p>
<p>Loneliness is an issue for those who live alone: <i>Well I quite like them coming, 'cause it's company. I live alone and I get lonely</i> (Ros)</p>		

Plain text: researchers summary. *Text in italics*: direct quote from participants

Table 41: Sub-themes to elements 'Homecare versus loneliness'

Data Summaries for Sub-theme: Homecare versus loneliness	Detected Elements
<p>Participants describe living at home with little or no contact with anyone: <i>I won't see anybody... I won't speak to anybody...nobody would come tae my door. I wish they would</i> (Ros)</p>	<ul style="list-style-type: none"> • Little or no contact with anyone • No visits • Any contact will do
<p>Being in the house without the chance of getting out is linked to feeling isolated. Participants look forward to the company of their carers to reduce their loneliness: <i>If I don't get out of the house then there's isolation. (Issy). I look forward to someone coming because I'm, I'm very [emphasis] lonely</i> (Betina)</p>	<ul style="list-style-type: none"> • House bound isolation • Carer contact reduces loneliness
<p>Keeping busy to prevent loneliness is no substitute for the company of others: <i>I can keep myself busy wi' things I'm having to do, but I still feel lonely</i> (Kirsty)</p>	<ul style="list-style-type: none"> • Keeping busy is no substitute for the company of others
<p>Homecare offers the opportunity to connect with someone and provides temporary respite from feelings of</p>	<ul style="list-style-type: none"> • Homecare provides the opportunity to connect • Homecare provides temporary respite from feeling lonely and isolated

loneliness and isolation: <i>Well she comes in for a couple of hours, you feel that at least somebody's there with you</i> (Ellie)	
Loneliness is an issue for those who live alone: <i>Well I quite like them coming, 'cause it's company. I live alone and I get lonely</i> (Ros)	<ul style="list-style-type: none"> • Living alone and loneliness • Carers provide company

Table 42: Elements to categories 'Homecare versus loneliness'

Detected Elements	Categories
<ul style="list-style-type: none"> • Little or no contact with anyone • No visits • Any contact will do • Keeping busy is no substitute for the company of others • House bound isolation • Living alone and loneliness 	<p>No contact Category: Lonely, housebound and alone</p>
<ul style="list-style-type: none"> • Homecare provides temporary respite from feeling lonely and isolated • Homecare provides the opportunity to connect • Carer contact reduces loneliness • Carers provide company 	<p>Homecare as a means to prevent loneliness and Category: (Homecare) contact reduces loneliness</p>

Table 43: Sub-theme to elements 'Independence versus dependence'

Data Summaries for Sub-theme: Independence versus dependence	Detected Elements
Being independent is important: <i>Oh aye ... I think it's great ... independence ... I like my own independence</i> (Helen)	<ul style="list-style-type: none"> • Independence valued
Tensions exist between wanting to be independent and being dependent on homecare services to remain at home: <i>Sometimes you feel like you want more help, you feel like you want to get on and try and do it yourself but it's getting more difficult all the time</i> (Flora)	<ul style="list-style-type: none"> • Tensions exist between independence and dependence • Sometimes want to do it themselves • Sometimes need more help
In recognition that visits are time-limited, participants maximise the time spent with their carer, by being ready for their arrival: <i>Well I've got, always got to be ready, you know, just to be ready for them coming</i> (Ellie). <i>For the girls coming in, I've got things a' ready for them</i> (Kirsty)	<ul style="list-style-type: none"> • Maximise the time spent with carer by being prepared for them

Participants voice concerns that if they are viewed as being too independent then their care package may be stopped: <i>Independence is very important to me but I don't want to lose my carer as she helps me in so many ways</i> (Maggie)	<ul style="list-style-type: none"> • Concern that homecare might be stopped if seen to be too independent • Don't want to lose carer
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Table 44: Elements to categories 'Independence versus dependence'

Detected Elements	Categories
<ul style="list-style-type: none"> • Independence valued 	<p>Element relates to the value of independence</p> <p>Category: Independence valued</p>
<ul style="list-style-type: none"> • Tensions exist between independence and dependence • Sometimes want to do it themselves • Sometimes need more help • Concern that homecare might be stopped if seen to be too independent 	<p>Elements relate to tensions between living at home and being independent and the dependence on homecare in order to live at home</p> <p>Category: Independence versus dependence</p>
<ul style="list-style-type: none"> • Maximise the time spent with carer by being prepared for them • Don't want to lose carer 	<p>Elements relate to carers presence</p> <p>Category: Carers valued</p>

Table 45: Sub-theme to elements 'Homecare versus institutional care'

Data Summaries for Sub-theme: Homecare versus institutional care	Detected Elements
Humour helps to express what they feel about institutional care: <i>They may as well shoot me, take me and shoot me [Laugh]</i> (Elizabeth)	<ul style="list-style-type: none"> • Humour used to express fear of institutional care • Humour used as a coping strategy •
Living at home for as long as possible is preferable to living in institutional care: <i>"well I'm no wanting tae in a home" I tell them, "I'll live in my house as long as I'm fit tae do it"</i> (Morag)	<ul style="list-style-type: none"> • Living at home is considered preferable to institutional care • Want to live at home for as long as possible
Participants' link living in institutionalised care to dependency and deterioration: <i>They seem to lose independence. I know a lot o' people who've went in 'tae homes and they've had mair care than I get and I get quite a bit and they seem tae go doonhill</i> (Arthur)	<ul style="list-style-type: none"> • Institutional care linked to dependency • Institutional care linked to deterioration
Negative media reports of life in a care home endorse the perception of care home residents as 'poor people' and the carers as 'terrible':	<ul style="list-style-type: none"> • Negative media reports • 'Poor' care home residents • 'Terrible' carers

<p><i>I've heard of some poor people that pay to stay in some care homes, I don't mean like this, a day centre...a care home, it was on the television recently and it was terrible what they were doing to them, the carers, you know supposedly carers (Steve)</i></p>	
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Table 46: Elements to categories 'Homecare versus institutional care'

Detected Elements	Categories
<ul style="list-style-type: none"> • Humour used as a coping strategy • Humour used to express fear of institutional care 	<p>Element relates to the use of humour as a coping strategy to express fear of institutional care</p> <p>Category: Humour as coping strategy</p>
<ul style="list-style-type: none"> • Living at home considered preferable to institutional care • Want to live at home for as long as possible 	<p>Elements relate to the avoidance of institutional care</p> <p>Category: Avoidance of institutional care</p>
<ul style="list-style-type: none"> • Institutional care linked to dependency • Institutional care linked to deterioration • Negative media reports • 'Poor' care home residents • 'Terrible' carers 	<p>Elements relate institutional care to increased dependency, deterioration and poor care</p> <p>Category: Negative perception of institutional care</p>