

An evaluation of the feasibility of the
routine measurement of quality of life
of people with dementia in care homes
using DEMQOL-Proxy

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Abstract

Background: A third of people with dementia in the UK live in care homes and there has been an increasing focus on the quality of care provided to them. One possible strategy to monitor and improve care is by routinely measuring and therefore understanding better the quality of life (QoL) of residents, but this is seldom done in practice. In this thesis the potential of routine measurement of QoL in care homes is investigated.

Method: The study had four iterative stages. (i) Qualitative interviews with care staff and focus groups with care home managers were carried out to understand staff views about measuring QoL as a part of routine care. Brief guidance for implementing routine QoL measurement into care practice was developed. (ii) The ability of care staff to use a QoL instrument without the need for interviewer-administration was then assessed. (iii) Based on these findings, DEMQOL-Proxy was adapted into a new version, DEMQOL-CH, for use in care homes. This instrument was tested to determine if care staff could use it appropriately. (iv) In the final stage, a preliminary assessment of routine QoL measurement was completed including a limited assessment of the psychometric properties of DEMQOL-CH when used in routine care practice by care staff.

Results: The qualitative interviews and focus groups showed that staff were positive about measuring QoL and fitting a QoL instrument into routine practice. There was a belief that measuring QoL could provide beneficial outcomes for staff and residents with the potential for positive impacts on the quality of care provided to residents. Systematic error was identified when staff self-completed the DEMQOL-Proxy without an interviewer. The DEMQOL-Proxy was modified to create DEMQOL-CH, this reduced the error, producing a version that could be used more accurately by care staff. Care staff were able to rate resident QoL routinely in care practice with an average frequency of monthly ratings for each resident. In a limited evaluation, when used in care homes by care staff DEMQOL-CH showed acceptable psychometric properties with satisfactory reliability and validity and a clear factor structure.

Conclusions: The research presents preliminary data on the acceptability, feasibility and performance of routine QoL measurement in care homes using an adapted version of DEMQOL-Proxy called DEMQOL-CH. Results provide a proof of the concept that routine measurement of QoL may be possible in care homes. Research is needed to refine and test

the methodology further and to explore the potential for benefits to residents, staff, and care homes in more representative populations.

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Abbreviations

CDR	Clinical Dementia Rating Scale
COSMIN	Consensus-based Standards for the selection of health measurement instruments
CQC	Care Quality Commission
DCM	Dementia Care Mapping
HRQoL	Health related quality of life
Independent researcher (SD)	Stephanie Daley
QoL	Quality of life
Researcher (LH)	Laura Hughes
Reviewer (NF)	Nicolas Farina
Reviewer (TEP)	Thomas E Page
sMMSE	Standardised mini mental state examination

Terminology

Definition of terms used in the thesis

There are terms used in this thesis where there are a number of options that are used in the literature. For simplicity and clarity, the author has chosen one term to use throughout this thesis. These are outlined below:

Family carer: in this thesis the term “carer” is used according to the Carers UK definition: “someone of any age providing unpaid support to family or friends”. “Family carer” is sometimes held to be problematic because not all unpaid care is provided by families, however on balance it is the term used here to include carers who related and unrelated to the person with dementia. The term “informal carer” is not used because the term “informal” is seen by many carers to belittle the carer role. We acknowledge that there are concerns with the use of the term “carer” in dementia but we have chosen not to use the terms “supporter”, “carer/supporter” or “caregiver” as the main term since there is still greater general understanding of the term “carer”

Care staff: is the term used to refer to formal carers who are paid to provide care, either in a person’s own home, or in a care setting. Formal carers may also be called professional or paid carers. Here, care staff is used in reference to all staff in care homes (e.g. manager, care assistant, nurse, activities coordinator) unless specifically stated.

Care home: Although there are difference between care and nursing homes, the term care home is used to refer to both unless explicitly distinguished.

Routine measurement: The term routine measurement in this thesis is used to refer to the regular systematic measurement of QoL as part of normal care practice. ‘Routine’ may be used in the literature to mean long-term or repeated measurement for a period of time.

Measurement and assessment: In this thesis the terms measurement and assessment are used. Assessment is defined as making a judgement about someone or something, whereas measurement is the act of assigning a number to a characteristic of an object or phenomenon. It may be argued, because of its subjective nature, that QoL can be assessed but not measured. However, for clarity, in this thesis measurement is used to refer to the act of completing QoL or other instruments (e.g. care staff measuring resident quality of life and using the instrument).

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Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

Laura Hughes

Chapter 1: Introduction

1.1 Context

Dementia is an umbrella term used to describe a set of neurodegenerative diseases that result in the deterioration of cognitive functions such as memory, reasoning, communication, and personality. Other areas of functioning are also affected by dementia, such as social relationships, mood, and physical abilities which can lead to decreases in mobility and the ability to carry out activities of daily living (ADLs) (Alzheimer's Society, 2017). Dementia therefore has an enormous impact on the person diagnosed with the illness as well as upon their family, friends, and wider society. There are medications that attempt to maximise cognitive functioning, and there are medications available for managing the symptoms related to dementia such as agitation and depression but there is, at present, no cure or disease-modifying treatment for dementia.

Currently, there are approximately 850,000 people living with dementia in the UK. Due to an ageing population, the number of people with dementia is expected to increase to over a million by 2025 (Alzheimer's Society, 2014; Banerjee, 2015). The cognitive, social, and functional consequences of dementia often result in the person with dementia relying upon care and support from family carers and health and social care services to live as independently as possible. The progressive course of dementia means that the large majority of people may initially be able to live reasonably independently in the community. Over two thirds of those with dementia live in the community (Alzheimer's Society, 2014). However, as the symptoms of dementia progress, needs can escalate and people with dementia themselves and their family carers may find it harder to cope. In addition, multimorbidity, the presence of two or more long-term conditions, is also common in older age, with 65% of those aged 65-84 and 82% of those 85 and over affected. In dementia, the prevalence of multimorbidity is even higher (Banerjee, 2015). With increasing needs, limitations in family support available, and the presence of other chronic illnesses it can become necessary for people to move into a care home to receive extra care and support.

Due to the impact of dementia on the person and the increasing numbers of people with dementia, improving the quality of care for those with dementia has become of increasing interest to researchers and policy makers. This is demonstrated by the development of the national Dementia Strategy for England (Department of Health, 2009) and the G8 Dementia Summit Agreements internationally (Department of Health, Prime Minister's Office, 2013).

Approximately 416,000 elderly people live in care settings in the UK (National Institute of Health Research, 2016). With population ageing this number is expected to increase (Prince et al., 2014). As people age, and their needs increase, moving into residential care or nursing homes may be necessary. Many people move into care homes because they can no longer live independently in their own home. This may be for a number of reasons such as declining physical abilities, illness, or cognitive impairment brought about by conditions such as dementia. It is estimated that anywhere between 50% to over 80% of people living in care homes have a dementia or some degree of cognitive impairment (Abrahamson, Clark, Perkins, & Arling, 2012; Jagger & Lindesay, 1997; Livingston et al., 2017; Macdonald, Carpenter, Box, Roberts, & Sahu, 2002).

With expected increases in the number of people with dementia in care there has been growing concern over the quality and variability of care provided to those that live in care homes (Care Quality Commission, 2017a). This has led to a focus on how to assure and improve the quality of care provided in care homes and therefore the quality of life (QoL) of those living in care settings. It has been suggested that one possible way of improving the quality of care for those living in care is through the understanding of and measurement of their QoL (Abrahams et al., 2012). This may allow the provision of person centred care that can be tailored to individual needs. As a broad measure of overall well-being, QoL and its measurement has become an important area of research in care homes to understand the impact of care and specific interventions on people living in care settings (Crespo, Quirós, Gómez, & Hornillos, 2011), including those with dementia (Aspden, Bradshaw, Playford, & Riazi, 2014).

However, challenges exist in the measurement of QoL in care homes in routine practice; appropriate instruments and implementation plans are needed to ensure that the use and uptake of routine QoL measurement is successful. In terms of translation of research findings into clinical practice, implementation is often unsuccessful because of implementation error, where the research practice does not accord with what is possible in routine care, thus obstructing the implementation of routine measurement (Vernooij-Dassen & Moniz-Cook, 2014) leading to poor uptake (Lawrence & Banerjee, 2010; Fossey et al., 2014; Lawrence, Fossey, Ballard, Ferreira, & Murray, 2015). There is a need to include staff in the development and implementation of instruments to be used by them as it acknowledges their expertise (Lawrence & Banerjee, 2010) and provides an understanding of their preferences and concerns which can be designed in at the outset to enhance implementation and limit

obstacles and barriers (Lawrence et al., 2015). At present there is very little evidence on the routine measurement of QoL in care homes and little in the way of involvement of care staff in generating effective ways to implement such measurement.

Instruments that measure QoL are normally only used in care homes in specific research projects (Selai & Trimble, 1999), rather than as a part of routine care practice. A number of dementia-specific QoL instruments have been developed in recent years, however, most of these were developed and evaluated in community dwelling populations, rather than in care homes (Bowling et al., 2015). Few of the dementia-specific instruments have been used by care staff to routinely measure resident QoL. There is a lack of evidence that these instruments can be implemented into routine care practice or that they can be used effectively by care staff to measure resident QoL and obtain routine QoL ratings. Starting to address these gaps in the evidence base is the focus of this thesis.

1.2 Overall aims of the thesis

The overall aim of the research is to evaluate the feasibility of the routine measurement of QoL in care homes using DEMQOL-Proxy.

The specific aims of the thesis were:

1. To determine the feasibility of implementing routine QoL measurements into care home practice.
2. To assess if DEMQOL-Proxy can be used by care staff without the need of an interviewer to administer it.
3. To assess the use of a QoL instrument in routine practice and whether routine QoL measurement by care staff is possible.

1.3 Research setting and researcher context

This research took place in care homes in East Sussex, England. The PhD student (LH) was responsible for completing all the work in this thesis. LH has a background of working as a care worker in the care sector and those experiences led to an interest in pursuing a research

career in dementia and QoL. Working in the social care sector provided LH with a deep understanding of how care homes operate, the working environment, and staff working conditions. This helped inform the focus of the research contained in this thesis. LH is aware of the pressures that staff are under to deliver good quality care in a context of time and resource constraints; this influenced her view that using any instrument introduced in routine care practice would need to be quick and easy to use. Low staffing levels and high resident need mean that it can often be difficult for staff to complete mandatory tasks within the time available. LH was clear that any instrument introduced into practice needed to be sensitive to this. LH's experience working in care homes provided understanding and common ground to build relationships with staff and residents alike.

1.4 Stages of the study

The aims presented above were addressed in the four study stages below. Figure 1.1 outlines the aims of the research overall and of each stage. The exploratory nature of the research called for an iterative study. Each stage of the study was carried out in chronological order; each informed the next, either in part or wholly, and determined the emergent direction of the research. The way that findings from each stage informed the next is highlighted at the end of the chapters describing each stage (Chapters 4-7).

Stage 1 assessed the feasibility of adding a QoL instrument into routine care practice (research aim 1). The receptiveness of care staff toward measuring QoL was an important first aspect to explore. If care staff were not open to measuring QoL, or if they did not believe that it was potentially beneficial or appropriate, the study would have needed to take a different approach. To achieve this, care staff views about measuring QoL and about using a QoL instrument were explored through individual qualitative interviews and discussion groups. The interviews explored what staff thought they might gain from measuring QoL routinely, and what they thought the residents might gain from having their QoL measured routinely. The barriers and facilitators to measuring QoL and implementing it into care practice were also explored. This stage produced guidance to inform future care home research generally, and the current study specifically. The findings from this stage informed and were assessed in Stage 2.

Stage 2 assessed whether an existing QoL instrument, DEMQOL-Proxy (Smith et al., 2005), could be used by care staff (research aim 2). DEMQOL-Proxy is a well validated interviewer-administered dementia-specific measure of health related QoL. It was developed and validated in a mixed population including people living in care homes. However, the instrument has not been used by care staff as a self-administered instrument. This stage aimed to assess whether care staff could use the DEMQOL-Proxy instrument independently. The agreement between the standard administration method (interviewer-administered) and new administration method (self-administered) was assessed. The findings from this stage required the next stage of the study.

Stage 3 aimed to further understand whether care staff could use a QoL instrument independently, without the need of an interviewer (research aim 2). Findings from stage 2 highlighted the need to alter the structure of the DEMQOL-Proxy questions to emphasise the QoL aspect of the questions and so improve validity. This resulted in the creation of an adapted self-administered version of DEMQOL-Proxy: DEMQOL-CH. As in Stage 2, agreement between the two instruments was assessed. Better agreement was found, suggesting DEMQOL-CH can successfully be used by care staff as a self-administered QoL measure. The findings from this stage informed Stage 4.

Stage 4 aimed to answer research aim 3. This stage was concerned with the feasibility of measuring QoL routinely. The adaptation of DEMQOL-Proxy into DEMQOL-CH required an initial assessment of the psychometric properties of DEMQOL-CH. Care staff used DEMQOL-CH on a routine basis, the validity and reliability of DEMQOL-CH when used routinely by care staff was examined. The number and frequency of QoL ratings made by care staff was assessed to enable an assessment of whether routine QoL measurement by care staff is possible.

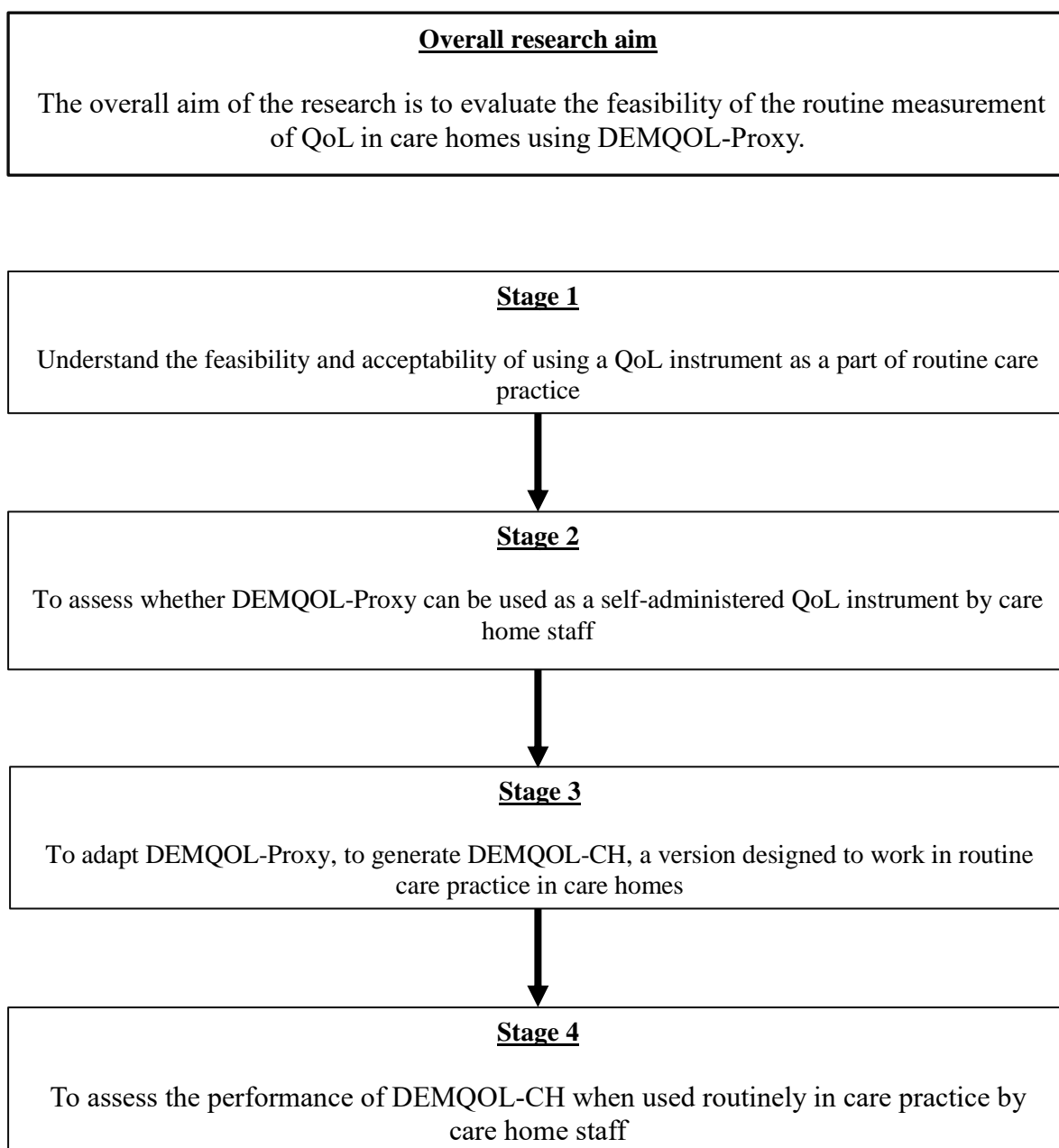


Figure 1.1 Outline of the aims of the thesis overall and for each stage of the study.

1.5 Structure of the thesis

The thesis is set out over eight chapters. The four stages of the study are contained in chapters 4 to 7. The content of each chapter is as follows:

Chapter 1 provides an introduction and context of the research including the overall thesis aims and structure.

Chapter 2 provides a review of the literature relating to the aims and content of the thesis. This provides a rationale for the research undertaken in the thesis.

Chapter 3 provides the broad methodology for the thesis including sample and setting, instruments used, and recruitment and data collection procedures. The detailed methodology specific to each stage is included in each relevant chapter.

Chapter 4 (Study Stage 1). This chapter is concerned with overall study aim 1, which is to understand care staff views about measuring resident QoL as a part of routine care practice and using a QoL instrument. This was achieved through qualitative interviews and discussion groups with care staff and managers. The findings from this were used to inform the introduction of DEMQOL-Proxy into practice in the following stages.

Chapter 5 (Study Stage 2). This stage is concerned with overall study aim 2. To determine if an existing instrument could be used by care staff themselves. DEMQOL-Proxy (Smith et al., 2005) was completed by care staff. This was completed first as a self-administered instrument and then as an interviewer-administered instrument (the standard method of administering DEMQOL-Proxy), the agreement between the two was assessed to determine if DEMQOL-Proxy could be used with validity as a self-administered instrument. The findings from this showed that alterations to the instrument were needed.

Chapter 6 (Study Stage 3). This stage is concerned with overall study aim 2. Findings from Stage 2 (chapter 5) showed poor agreement between the two administration methods of DEMQOL-Proxy. The instrument was therefore adapted to improve agreement between the self- and interviewer-administered versions. Findings showed improved agreement between the two instruments. Thus, an adapted version of DEMQOL-Proxy was created, DEMQOL-CH. This new version of the instrument had a new administration method and altered question structures.

Chapter 7 (Study Stage 4). This stage is concerned with overall study aim 3 above. To assess the use of a QoL instrument in routine practice and whether routine QOL measurement is possible. Findings from Stage 3 (chapter 6) showed that adapting DEMQOL-Proxy to create DEMQOL-CH improved agreement and meant that care staff could use DEMQOL-CH as a self-administered QoL instrument. Because DEMQOL-CH has restructured questions and a different administration method compared to DEMQOL-Proxy this established a need to assess, at least in a preliminary manner, the reliability and validity of the instrument when used by care staff. This chapter also investigates the frequency of QoL ratings made by staff.

Chapter 8 provides a discussion of the findings taken together, including the overall contribution to knowledge made by the thesis. The overall strengths and limitations are discussed, as are the implications for policy, practice, and future research directions.

Figure 1.2 provides an overview of the stage addressed in each chapter and the research aim that each stage addressed.

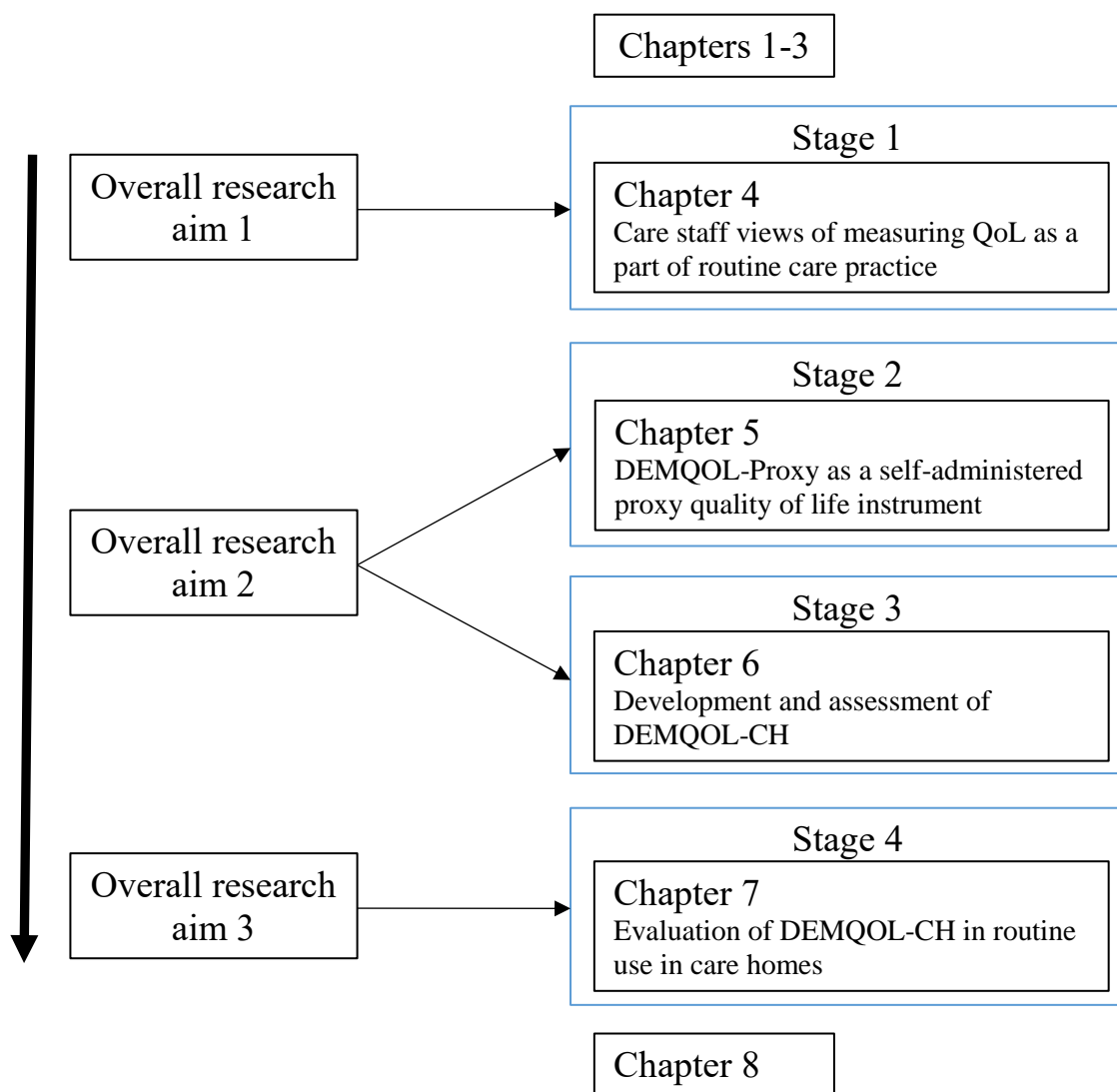


Figure 1.2 Overview of layout of chapters and stages and the research aim that each stage addresses. The arrow indicates that each stage was carried out in chronological order, with each stage informing the next

1.6 Rationale for instrument choice

This research was carried out in the Centre for Dementia Studies whose Director (Sube Banerjee) was the lead for the DEMQOL development programme and the main supervisor of this PhD project. The further development of the DEMQOL system is one of the goals of the Centre for Dementia Studies and the funding for this studentship was based on this. The instrument used in this study was DEMQOL-Proxy (Smith et al., 2005). It was therefore chosen for this evaluation largely on *a priori* grounds. DEMQOL-Proxy is a widely used instrument for measuring the QoL of people with dementia, it has good psychometric properties and is the product of thorough development (Bowling et al., 2015; Smith et al., 2005). The validity and reliability of DEMQOL-Proxy has shown acceptable psychometric properties in people with mild, moderate, and severe dementia (Smith et al., 2005). DEMQOL-Proxy is freely available and has acceptable usability.

Chapter 2: Literature Review

This chapter discusses the measurement of QoL in dementia. A narrative review of the literature considers the challenges that exist in effectively measuring QoL in people with dementia and how these challenges impact on the measurement of QoL in care homes. A systematic review of QoL instruments for use in care homes is provided to determine the characteristics and feasibility of the instruments available to measure QoL in care homes. Literature on routine and longitudinal measurement of QoL in care homes is discussed. The challenges and knowledge gaps identified form the basis of the rationale for the research presented in the thesis, as outlined at the end of the chapter.

2.1 Quality of life

Quality of life is a multidimensional construct defined by the World Health Organisation (WHO) as a person's perception of their well-being in relation to their goals, culture, values, expectations and concerns (WHOQOL Group, 1995). It is a subjective multidimensional concept which encompasses psychological, physical and social well-being (Birren, Lubben, Rowe, & Deutchman, 1991). A number of factors can contribute to this sense of well-being such as good health, social and occupational environments, financial stability, spirituality, and social and personal relationships.

Health related quality of life (HRQoL) is a part of overall QoL but is distinct in that it relates to those aspects of QoL that are affected by a health condition or illness (Perales et al., 2014). Schipper and colleagues defined HRQoL as "the functional effects of an illness and its consequent therapy upon the patient, as perceived by the patient" (Schipper, Clinch, McMurray & Levitt, 1996). It is about a person's perception of the impact of an illness or disease on their daily life. HRQoL, like overall QoL, is multidimensional incorporating physical, psychological and social functioning (Smith et al., 2005).

When a person is ill almost every aspect of their life may become health related (Guyatt, Feeny, & Patrick, 1993), and this is especially relevant in the case of dementia which is so very pervasive and wide-ranging in its impacts. It is important that we understand the impact of dementia on a person's life overall not just the cognitive and functional deficits that people with dementia experience (Abrahamson et al., 2012). Assessments of QoL can be used as

broad measures of overall outcome and to estimate the impact and cost effectiveness of medication and other interventions for the symptoms of dementia and for disease modification (Selai & Trimble, 1999). QoL has become an important area of research in care homes to understand the impact of interventions on people with dementia living in care (Aspden et al., 2014).

2.2 Care Homes

As people age, and their needs increase, moving into residential care or nursing homes can allow individuals to maximise their independence. Nursing homes provide healthcare delivered by trained nurses, as well as personal care provided by care staff (non-medically trained); residential care homes provide personal care only. For the purposes of this thesis the term ‘care home’ is used to refer to both residential care and nursing homes unless explicitly stated.

There are approximately 16,000 care homes in England (Care Quality Commission, 2017b). Care homes provide care for people with a broad range of abilities and functional impairments. In the UK, care homes are required to register with a governing body to be permitted to deliver care to older adults, some homes are also registered to provide care to people with dementia, and some are registered to offer specialist categories of care such as, Alzheimer’s disease, sensory impairment, and mental health. Homes are registered with the Care Quality Commission (CQC) in England, the Care Inspectorate in Scotland (formally known as Social Care and Social Work Improvement Scotland), the Care and Social Services Inspectorate in Wales, and the Regulation and Quality Improvement Authority in Northern Ireland. These organisations are the independent regulators and inspectors for health and adult social care. All care homes are required to register and adhere to a set of core care standards. In England, the CQC inspect, monitor and regulate services to ensure that services like care homes provide safe, effective, compassionate, high quality care (Care Quality Commission, 2017b).

Homes are inspected by a group of trained inspectors and people who have experiences with care services. They assess whether care homes meet the required standards and give each home a rating based on their findings of either ‘outstanding’, ‘good’, ‘requires improvement’, or ‘inadequate’. If homes are failing to provide adequate care, CQC can take

action to protect residents from harm, help services improve, and hold care home providers to account for their failures. This can be achieved either through providing warnings, making changes to a home's registration, placing homes into special measures where they are closely supervised, issuing fines, or prosecuting care home providers or individuals who may have caused harm or danger.

As noted in the last chapter, there are 416,000 people living in care homes in the UK (NIHR, 2016) and up to 80% of them may have a dementia (Jagger & Lindesay, 1997; Alzheimer's Society, 2014). This includes those care homes not specifically registered for dementia care (Macdonald, Carpenter, Box, Roberts, & Sahu, 2002). A recent large scale study found that 86% of care home residents had dementia (Livingston et al., 2017).

There has been growing concern about the quality of care provided to people with dementia in the UK (Downs, Capstick, Baldwin, Surr, & Bruce, 2009), this has been further highlighted in recent reports from the charity Independent Age (2017b), and the Care Quality Commission (2017a). These reports outline the current state of care in England and the regional variations in care quality across the country. The findings of these reports show that although the majority of care services provide 'good' care (77%), 19% require improvement and 2% are inadequate. And it is estimated that the 2% of services rated as inadequate provide care to almost 20,000 people. These large numbers of people receiving inadequate care highlights the need for improvements in care provision and maintaining good care.

There are approximately 1.3 million jobs in the local authority and private sectors of social care (Skills for Care, 2017). In care homes, care is provided by a variety of different staff, which typically includes a manager, deputy manager, nurses (in nursing homes), senior care assistants, and care assistants. The social care workforce is predominantly female (82%) with an average age of 42 years (Skills for Care, 2017), and around a fifth of care staff come from outside of the UK, with many care staff coming from lower socioeconomic backgrounds and having few qualifications (Luff, Laybourne, Ferreira, & Meyer, 2015).

2.3 Improving quality of care and QoL in care homes

One way of improving the quality of care for people living in care homes is through adopting a person-centred approach to care. Traditionally, the provision of care has used a task centred

approach (Argyle, 2012) that focussed heavily on the biomedical model of care (Edvardsson, Petersson, Sjogren, Lindkvist, & Sandman, 2014). Person-centred care is a psychosocial approach to dementia care (Chenoweth et al., 2009) that aims to move toward a holistic approach to care where the psychological needs of the individual are central (Edvardsson et al., 2014; Li & Porock, 2014), where there is a focus on the individuality of the person, not their impairments (Halek, Dichter, Quasdorf, Riesner, & Bartholomeyczik, 2013). Person-centred care in dementia is firmly based in the fundamental work of Tom Kitwood and based on the principle of personhood (Kitwood, 1997). Personhood describes the qualities of being an individual person, and is bestowed on an individual to show respect, recognition, and trust. Showing respect, recognition and trust enhances the personhood and well-being of the individual. However, if this is not shown personhood reduces, leading to ill-being (Mitchell & Agnelli, 2015). Kitwood proposed a set of psychological needs which are important for maintaining and enhancing personhood. These are: comfort, attachment, inclusion, occupation, and identity. Meeting these needs allows humans to feel relaxed, secure, at ease, valued, and of use (Bradford Dementia Group, 2005) If people with dementia are not able to meet these psychological needs themselves because of cognitive impairment, they must rely on family, care staff and the care environment to meet these needs (Kitwood, 1997). If staff are unable to or unsuccessful in meeting these needs for people then their personhood and well-being will diminish. Brooker furthered this approach to person-centred care and set out four key components for meeting the psychological needs of people with dementia. These are: valuing people with dementia and those who care for them; treating people as individuals; looking at the world from the perspective of the person with dementia; and providing a positive social environment in which the person living with dementia can experience relative well-being (Brooker, 2003).

Adopting a person-centred approach and using the approach outlined by Brooker (2003) allows care staff to move away from focusing on tasks and focus more on the experiences of the person with dementia instead (Downs, 2013), thus providing opportunities for staff to meet the psychological needs of the person with dementia and enhance their well-being. In practice, one way of achieving person-centred care is through the use of personalised care plans and life histories. This provides, among other things, information about the person's individual likes, preferences, and needs. This information can help care staff to see the person with dementia as an individual and not just as someone with a disease. This is particularly important for behavioural symptoms of dementia. Behavioural symptoms of

dementia such as agitation are argued to be a result of unmet need, staff-resident interaction, or resident-environment interaction and not just as an inevitable symptom of dementia (Edvardsson, Winblad, & Sandman, 2008). Information about the person's individuality, preferences and their life history can assist staff to identify the reason for the behaviour and make changes to enhance well-being.

Dementia Care Mapping (DCM: Bradford Dementia Groups, 2005) is a useful and widely used tool for realising person-centred care (Surr et al., 2016) (see *Section 3.4.3* for a full description of DCM). DCM can help to identify and assess factors that influence resident behaviour, the quality of staff-resident interactions, resident QoL, and resident well-being. This information can be used to tailor care to individual needs and make changes to care practice where necessary (Chenoweth & Jeon, 2007; Innes & Surr, 2001). DCM empowers care staff to reflect on their individual practices and the practice of the home overall in order to improve the quality of care for people with dementia. The DCM process outlined below can be used for quality monitoring and improvement, provide individual assessment and care planning for residents, organise and reorganise daily activities and events for resident benefit, and highlight staff training and development needs (University of Bradford, 2015). Because of its potential to improve the provision of person-centred care in care settings, the use of DCM is recommended by the National Institute for Clinical Excellence/Social Care Institute for Excellence as a practice development tool (NICE & SCIE, 2006).

DCM is an observational tool for use in care settings, it helps promote and enhance the provision of person-centred care through a set of six cyclical phases: 1) briefing care staff, management, and residents; 2) DCM systematic observation; 3) data analysis and report writing; 4) feedback to care staff and management; 5) action planning by care staff and management based on findings from DCM; and 6) realising the action plan (Dichter et al., 2015; Halek et al., 2013).

Each stage of the DCM process has the potential to enhance the achievement or improvement of person-centred care. The active inclusion and engagement of care staff in all aspects of DCM is encouraged so that staff are accountable in their role in realising person-centred care (Halek et al., 2013). In the observation phase trained mappers observe and record what happens to residents every five minutes over the mapping period. Mappers record the type of behaviours and a mood and engagement score for each behaviour is recorded. Over the whole mapping period a picture is built up of the individual and their relative well and ill-

being from the information recorded. This allows care staff to witness how residents spend their day and the effect this has on their mood and engagement, and consequently, how this affects their well-being. In addition to what happens to residents, mappers also record any personal enhancers and personal detractors that may occur in each five-minute interval. Personal enhancers and detractors are behaviours and interactions displayed by care staff towards the resident; these behaviours either enhance or undermine a resident's personhood and the core psychological needs of comfort, identity, attachment, inclusion, and occupation. Observations made using DCM are analysed and written in report format. This includes individual and aggregate well-being scores for the observed residents. DCM can therefore be used as a measurement as well as an intervention. The findings show the frequency that behaviours occur and the percentage of time that residents spend in different mood states, i.e. different intensities of positive or negative mood and engagement. This can be used to tailor changes to residents' individual care to reflect their personal needs. Any instances of personal enhancers or personal detractors observed are also included; these are useful in identifying training needs of staff. The information in the report is fed back to care staff. Importantly, a positive feedback approach is used so that care staff do not focus on what was 'wrong' with the care, or they do not relate the findings to themselves negatively. Through a positive approach care staff are instead encouraged to interpret the findings in relation to the residents' lives and the impact that the findings could have on resident well-being (Brooker & Surr, 2006). Findings from DCM observation and discussions in feedback sessions can be used in the action plan phase to make appropriate changes to individualised care for residents and care practices in general. For example, care staff can plan changes to resident care plans to reflect their preferences and unmet needs observed during the DCM session. Similarly, information from observations, particularly any evidence of personal detractors, can be used to improve the interactions between care staff and residents. This can inform the need for additional training for care staff. If care staff understand how interactions affect the psychological needs of residents, they can make positive changes to support residents to meet these needs. Following this, the action plan is implemented and identified changes are actioned. The inclusive and non-threatening approach of the DCM process is beneficial to implementing changes in care practice. The positive approach is intended to reduce resistance to negative feedback and to encourage willingness to change (van de Ven et al., 2012). Care staff are encouraged to see that making changes to aspects of care can have positive benefits for residents, and are likely to be more receptive to changes because of the positive approach adopted.

Providing person-centred care has significant positive benefits for residents such as life satisfaction, adjustment to care home placement, QoL, agitation, and neuropsychiatric symptoms (Ballard et al., 2018; Yoon, 2018). Training care staff to provide person-centred care has benefits for provided care such as improved gentleness, more verbal support, and a greater sense of ease (Hoeffler et al., 2006). These potential positive outcomes of person-centred care have resulted in widespread adoption of a person-centred approach in many countries (Harding, Wait, & Scrutton, 2015). As such, providing person-centred care is a national priority in the UK, and is one of the fundamental standards of care that all homes must adhere to (Care Quality Commission, 2017b). However, as the reports by CQC and Independent Age highlight, there is still large variability in care. This raises concerns about the implementation and efficacy of person-centred care in care homes. Person centred care is mandated but DCM is not. There is variability in the working practices in care homes (Argyle, 2012), and despite the introduction of policy changes to implement person-centred care, there is a disparity between policy and practice (Colomer & de Vries, 2016). This likely stems from a lack of consensus about what person-centred care actually is and how to deliver it (Brooker, 2003; Harding et al., 2015). The perspective of what constitutes person-centred care can vary among researchers, with some perceiving person-centred care as individualised care or a set of specific techniques to use (Brooker, 2003), and some perceiving it to be simply the provision of good care (Colomer & de Vries, 2016). There is also confusion among healthcare professionals as to what person-centred care is, which can result in superficial use of the term and unsubstantiated claims that person-centred care is practiced or achieved (Harding et al., 2015).

Another pathway to improving the quality of care in care homes proposed is through the routine use of measurement and understanding of the QoL of people in care homes to inform care provision at an aggregate and an individual level. The outcomes of QoL measurement and person-centred care are likely to be complementary as they both focus on the individual (Winzelberg, Williams, Preisser, Zimmerman, & Sloane, 2005). As Edelman and colleagues assert, “The very act of inquiring about the quality of life of persons with dementia recognizes them as individuals rather than merely as care recipients” (Edelman, Fulton, Kuhn, & Chang, 2005a, p.27). Therefore, an integration of QoL measurement into routine care practice could have positive benefits by enhancing the provision of person-centred care which consequently could improve the QoL experienced by care home residents.

2.4 Measuring quality of life in dementia

2.4.1 Approaches to measuring QoL in dementia

There are two main options for measuring QoL in any disorder, generic or disease-specific approaches. There are also particular methodological issues when measuring QoL in dementia; the use of self-report, proxy-reports and observation tools all have their own benefits and challenges. These are discussed below.

2.4.1.1 Generic measurement

Broadly, QoL can be measured using either generic or disease/condition specific strategies (Patrick & Erickson, 1993). The generic strategy uses instruments applicable across different diseases and treatments. Instruments such as the 36 item Short Form Survey (SF-36; Stewart, Hays, & Ware, 1988), 12 item Short Form Survey (SF-12; Ware, Kosinski, & Keller, 1996), and the EuroQol five dimensions questionnaire (EQ-5D; Brooks & EuroQol Group, 1996) are generic instruments. These instruments ask a person to rate their general health and aspects of their life that are affected by their health status. In the SF-36 and SF-12, for example, respondents are asked to rate their general health and different health constructs such as limitations in physical and social activities and usual roles due to emotional and physical problems. The EQ-5D asks the respondent to rate their own health that day from worst imaginable to best imaginable health state. Five questions ask about mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.

Generic instruments allow for comparison of outcomes across diverse patient groups with different diseases and treatments as they capture general health constructs (Ware & Sherbourne, 1992). But generic instruments can fail to address disease-specific elements crucial to QoL in that particular condition and may not be sensitive enough to detect changes in outcome (Fitzpatrick, Davey, Buxton, & Jones, 1998; Patrick & Erickson, 1993). To address these limitations, disease-specific instruments have been developed, including items directly relevant to the condition, to be more responsive to change over time and with intervention.

Given the complexity of dementia and its impacts on the individual affected, significant positive or negative impacts of interventions may be missed by the use of generic tools (Jones, Edwards, & Hounsome, 2012). This complexity is evidenced by the finding that there appears to be no simple linear association between severity of dementia as measured by increasing cognitive impairment or activity limitation and decreasing QoL (Banerjee et al., 2009; Hoe, Hancock, Livingston, & Orrell, 2006; Moyle, Murfield, Griffiths, & Venturato, 2012). This means that measures of ADL or cognition cannot be used as a substitute measurement of QoL.

2.4.1.2 Disease-specific measurement

Taken together, this means that a disease-specific approach to QoL in dementia is likely to be of value so that an accurate assessment can be made that encompasses the complexity of dementia and the changes that can occur over time as the illness progresses (Banerjee, 2006; Smith et al., 2005; Thorgrimsen et al., 2003).

Dementia-specific frameworks and models have been proposed which give a broader account of QoL in dementia which do not rely on an entirely health and function approach. The approaches to QoL in dementia that researchers adopt influence and shape the instrument created (Missotten, Dupuis, & Adam, 2016). Broadly, instruments discussed in the systematic review (*See Section 2.6*) in general and DEMQOL-Proxy specifically, which is used in the research presented in this thesis, are based on a small number of QoL models. Some instruments use more than one model but it is often not clear what conceptual framework instruments are based on, and what assumptions are made (Bowling et al., 2015; Missotten et al., 2016).

A number of instruments are based solely or in part, on work of Lawton (Missotten et al., 2016). Lawton proposed that QoL in dementia is a multidimensional construct made up of four core components; two subjective components of perceived QoL and psychological well-being; and two objective components of behavioural competence and objective environmental quality (Lawton, 1983, 1994). Lawton places emphasis on including both objective and subjective components to provide a fuller picture of QoL. Stating that because people with more severe dementia cannot provide reliable reports of their subjective experiences, it may only possible to collect information on the objective aspects of QoL. The

influence of Lawton's work can be seen in instruments such as QUALID (Weiner et al., 1999), ADRQL (Rabins, Kasper, Kleinman, Black, & Patrick, 1999), DQoL (Brod, Stewart, Sands, & Walton, 1999), QUALIDEM (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007), and QOL-AD (Logsdon, Gibbons, McCurry, & Teri, 1999). The definition of QoL used in DCM (Bradford Dementia Group, 2005) is similar to Lawton's (Missotten et al., 2016).

Brod and colleagues (1999), adopted a health-related QoL definition that states QoL is a multidimensional concept encompassing social, psychological and physical domains (Birren, Lubben, Rowe, & Deutchman, 1991), with HRQoL distinguishable from QoL as it only includes aspects of QoL that are affected by a health condition. Brod et al. used elements of Lawton's QoL model to develop the DQoL instrument. The authors proposed a model that included psychological well-being as the primary outcome. Although Brod and colleagues were in agreement with Lawton's argument that QoL is made up of subjective and objective components, the authors emphasised the need to collect this information by means of self-report of QoL only. The definition of HRQoL was also used by Smith and colleagues in the development of the DEMQOL system (Smith et al., 2005). The authors based this on the definition by Bullinger and colleagues which states "health related quality of life... focuses more on the impact of a perceived health state on an individual's potential to live a subjectively fulfilling life" (Bullinger, Anderson, Cella, & Aaronson, 1993, p. 452). DEMQOL includes five conceptual domains: daily activities and looking after self; cognitive function; health and well-being; social relationships; and self-concept. The DEMQOL system includes a self-report and a proxy-report and the developers argue that both should be used as complimentary instruments, although the proxy report is useful for people who can no longer provide a self-report of their QoL such as those with severe dementia.

Another approach used is the adaptation-coping model developed by Dröes and colleagues (Dröes, van Mierlo, van der Roest, & Meiland, 2010). The definition of QoL used in this model is that dementia-specific QoL is a multidimensional evaluation of the person-environment system of the individual in relation to adaptation to the consequences of dementia (Dichter, Ettema, et al., 2016). The adaptation-coping model was developed to explain behaviour problems of people with dementia as a consequence of the successful or unsuccessful adaptation to a set of seven adaptive tasks thought to be important domains of QoL: dealing with own disability; developing an adequate care relationship with the staff; preserving emotional balance; preserving a positive self-image; preparing for an uncertain

future; developing and maintaining social relationships; and dealing with the nursing home environment. This model was used to inform the development of the QUALIDEM instrument (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007b). QUALIDEM places emphasis on the importance of the environment in determining QoL. As such, both of these instruments are designed specifically for use in care settings. QUALIDEM has similar view to those of Lawton, that people with more severe dementia may not be able to provide a report of their own QoL. However, the authors of QUALIDEM do not advocate for the use of objective external measurement of QoL, instead, they argue that QoL measurement is best achieved through proxy-reports of QoL, thus allowing the inclusion of people with more severe impairments, and providing usable longitudinal data in order to assess changes to QoL over time (Dichter, Bartholomeyczik, Nordheim, Achterberg, & Halek, 2011).

An approach with similarities to the adaptation-coping model, is that underpinning DCM. The DCM tool is based on Kitwood's psychosocial theory of dementia care (Kitwood & Bredin, 1992) and is grounded in a person-centred approach to dementia care (Brooker, 2005), described earlier. Kitwood and Bredin (1992) describe four sentient states that are significant in dementia, these are: sense of personal growth, sense of agency, social confidence, and hope; all of which can be affected by the care process. In this theory it is argued that although the progression of dementia can lead to declines in functions such as cognition, it does not in itself result in a degeneration of the person psychologically and emotionally. Rather, it is the result of a negative psychosocial environment that the individual lives in. The care environment and the interactions of residents in their environment are central in improving and maintaining the well-being of residents. The developers of DCM created an instrument that focuses on the care environment and interactions. DCM is an observational tool, the developers recognised the difficulties of obtaining self-reports from people with more severe dementia (Bowling et al., 2015), the DCM approach allows the inclusion of people who cannot provide self-reports of QoL. And similar to the QUALIDEM instrument, DCM places emphasis on the environment and its effect on the QoL and well-being experienced by people with dementia.

These approaches attempt to capture the subjective aspects of QoL in dementia, not just objective aspects such as health status. In these dementia-specific models and instruments there is less focus on the health and functional/role aspects of the illness and more emphasis on areas that appear to matter to those with dementia such as social aspects and the impact of disability, not just the severity of the disability. These conceptual models benefit from the

input of people with dementia, in that they were not just developed based upon information from the general population and not based purely upon the opinions of carers or professionals (O'Rourke, Duggleby, & Fraser, 2015).

2.4.2 Methodological challenges in measuring QoL in dementia

Measuring QoL in dementia can be accomplished from three different measurement perspectives. These are self-report, proxy-report and (non-participant) observation.

2.4.2.1 Self-report

It is well understood that QoL is a subjective concept, it is therefore argued that the 'gold standard' of measuring such a subjective construct is through self-report (Moyle & Murfield, 2013; Selai & Trimble, 1999). Self-report QoL instruments ask the person with dementia to rate their own QoL. Some authors believe that because of the subjective nature of QoL, only self-reports give a reliable reflection of QoL. Despite the potential for more missing data with self-reports, some suggest that measurement of correct domains and a focus on item clarity and simplicity can improve instruments using a self-reported perspective (Brod et al., 1999). Because of this, instruments such as the Dementia Quality of Life (DQoL) (Brod et al., 1999) were developed with only a self-report version.

However, it is not always possible to obtain a valid or reliable self-report of QoL due to impairments of memory, attention, and insight which can all be caused by dementia (Logsdon, Gibbons, McCurry, & Teri, 2002). Cognitive impairments could mean that the person with dementia may not fully understand some QoL concepts (Rabins & Black, 2007). Furthermore, it may not be possible to obtain a self-report of QoL at all due to language and communication difficulties which can have an impact on people with dementia, particularly those in more advanced stages of the condition (Weiner et al., 1999). As a result, many self-report questionnaires only have acceptable validity and reliability in mild and moderate dementia (Bowling et al., 2015), even though it has been found that those with mild to moderate (Trigg, Jones, & Skevington, 2007) and some with severe dementia (Thorgrimsen et al., 2003) can provide accounts of their own QoL.

2.4.2.2 Proxy report

Many authors have reported that residents in care homes, even those with severe dementia, can provide reliable self-reports of their own QoL (Crespo, Hornillos, & Gómez, 2013; Hoe, 2005; Logsdon et al., 1999, 2002; Moyle et al., 2012; Spector & Orrell, 2006; Thorgrimsen et al., 2003), however, there is large variability in the percentage of people with dementia who are able to complete self-report instruments, with studies ranging from as low as 25% up to 98%.

In circumstances where the person with dementia is unable to give a valid self-report, a proxy-report of QoL may be used in its place. A proxy is a person who knows the person with dementia well enough to be able to give an account of their QoL. Where the person with dementia is still able to give a self-report, a proxy report may be collected in addition to a self-report to provide a broader understanding of the individual's QoL. This is dependent on the instrument used and whether it contains both self- and proxy-report versions; tools such as the DEMQOL system (Smith et al., 2005) and the Quality of Life in Alzheimer's Disease (QOL-AD) (Logsdon et al., 1999) have self- and proxy versions that can be used as complementary measures, and where needed, for proxy instruments to be used as a substitute when self-report is not possible.

As mentioned above, it has been argued that we cannot rely on proxy-reports as they do not capture subjective QoL. One of the more common arguments for not using proxy instruments are the reported discrepancies between self- and proxy-reports of QoL (Banerjee et al., 2009). Proxy-reports of QoL have been shown to be lower compared to those reports given by the person with dementia (Arlt et al., 2008; Vogel, Mortensen, Hasselbalch, Andersen, & Waldemar, 2006). It is often assumed that people are not able to accurately reflect upon their QoL resulting in discrepancies between scores (Brod et al., 1999). However, these differences could be a result of something known as the 'disability paradox', where a person's functional status and perceived well-being are discordant; they report good QoL despite having functional impairments or disabilities. There are often negative perceptions of people with disabilities and it is presumed that they do not experience a good QoL as those without disabilities (Albrecht & Devlieger, 1999). This has also been found in dementia where those without dementia do not think it is possible for a person to experience good QoL with a diagnosis of dementia. The disability paradox may result in differences between self- and proxy QoL ratings, thus highlighting the need for further education and understanding of the experiences of people with dementia for those caring for them and for wider society.

The differences observed between self- and proxy-reports could also be a result of the type of questions in instruments. Lukovits & McDaniel, (1992) found better agreement between family and staff carer reports of behavioural disturbance for observable and easy to define behaviours. Similarly, QoL assessments between proxy and self-reports have shown more disagreement for unobservable, less objective aspects of function (Novella et al., 2001; Sprangers & Aaronson, 1992).

Despite the differences found between self- and proxy QoL reports, moderate to good agreement has been observed with agreement typically better in more recently and more robustly developed QoL instruments (Smith et al., 2005). The viewpoint that proxies take when completing QOL instruments may affect the reliability of proxy-reports. There are two ways for proxy respondents to answer questions on instruments, a proxy-patient and a proxy-proxy perspective (Pickard & Knight, 2005). A proxy-patient viewpoint is where the proxy responds as they think the person with dementia would respond, proxy-proxy is where the proxy gives their own perspective of the person with dementia's QoL. Better agreement has been found between self- and proxy-reports when a proxy-patient viewpoint is used rather than a proxy-proxy viewpoint (McPhail, Beller, & Haines, 2008). Thus, instruments should try to achieve a proxy-patient perspective if the aim is to obtain a more accurate account of the person with dementia's (subjective) QoL.

2.4.2.3 Observation

With the inherent subjectivity of QoL assessment and the discrepancies found between self- and proxy-reports, it has been proposed that observational tools of behaviour could be used (Selai & Trimble, 1999). Observational tools allow the observer to directly observe and document how often particular behaviours and events occur and the enjoyment gained from them, or to observe how positive or negative social interactions and activities are for an individual.

Lawton (1994) stated that people with more severe dementia are unable to give a reliable account of their subjective QoL, and that measurements of externally observed behaviours are important for measuring QoL. It is argued that due to the higher proportion of people with severe dementia in care homes in comparison to the community, observational tools should be used there (Barca, Engedal, Laks, & Selbæk, 2011). This would resolve the

limitations of self-reports in severe dementia, and potential disagreements between self- and proxy-reported QoL.

One of the advantages of observational instruments such as DCM (Bradford Dementia Group, 2005), QUALIDEM (Ettema et al., 2007a), and Quality of Life in Late-stage Dementia (QUALID) (Weiner et al., 1999) is therefore that they can be used for people with all severities of dementia. Observation of behaviours and activities without attempting to gain a self-report means that people with severe dementia can be included. Some systematic reviews of QoL instruments for dementia recommend using an observational instrument such as the QUALIDEM for severe dementia (Aspden et al., 2014; Schölzel-Dorenbos et al., 2007).

However, observational tools may not fully reflect an individual's QoL as they only provide a snapshot of an individual's QoL at any given time, and they also rely on objective behaviours and actions which may not capture other important aspects of QoL. Also, observational tools are often time consuming and costly to complete (Bowling et al., 2015).

2.4.3 Instruments for measuring QoL in dementia

A number of HRQoL instruments have been developed specifically to measure QoL in dementia. A recent comprehensive review (Bowling et al., 2015) identified 16 dementia-specific QoL instruments. These instruments have varying levels of validity and reliability, and are validated in various settings (community and care homes), and with different populations such as people with mild, moderate and severe dementia. Most self-report instruments have no or questionable reliability and validity for people with severe dementia. The psychometric properties of many proxy-reported tools were good for mild and moderate dementia but poor for people with severe dementia.

Some of the more widely used instruments identified in the review were: the QOL-AD (Logsdon et al., 1999); DQoL (Brod et al., 1999); Alzheimer Disease Related Quality of Life (ADRQL) (Rabins, Kasper, Kleinman, Black, & Patrick, 1999); DEMQOL (Smith et al., 2005); QUALIDEM (Ettema et al., 2007a); QUALID (Weiner et al., 1999); and DCM (Bradford Dementia Group, 2005). These instruments have been identified in at least two other reviews (Moyle & Murfield, 2013; Ready & Ott, 2003). These instruments are discussed in more detail in *Section 2.6*

2.5 Measuring QoL in care homes

Measurement of QoL in care homes is usually carried out as part of specific research studies to assess the outcomes of interventions. However, as we have discussed above, understanding QoL in care homes is not just about measuring the impact of specific interventions; there is an increasing interest in measuring QoL in order to understand what determines good QoL and how to improve QoL and quality of care for people living with dementia in care homes more generally (Barca et al., 2011; Moyle & Murfield, 2013). (Moyle & Murfield, 2013).

However, QoL in care homes is relatively under-researched area (Hall, Opio, Dodd, & Higginson, 2011). QoL is often presumed to be related to quality of care, leading to care quality indicators being accepted as an indication of QoL (Abrahamson et al., 2012). To improve the quality of care and QoL for people living in care homes it should be understood that, while importantly connected, QoL and quality of care are not the same thing. Care quality is in itself difficult to measure but is not a substitute measure of QoL; good QoL is one of the important outcomes that we hope to secure by providing good quality of care. To ensure that people in care homes can receive high standards of care as well as experience good QoL benefits from an understanding of how QoL can be measured in care homes and be used as a part of routine care practice.

As mentioned earlier, quality of care is assessed by regulators and inspectors such as the CQC. Care inspectors use a tool called the Short Observational Framework for Inspection (SOFI) to help assess and understand the well-being and interactions of care home residents (University of Bradford, 2016). This tool was developed by The Bradford Dementia Group and is based on DCM (Bradford Dementia Group, 2005). SOFI is used as a practice development tool; it is not used solely as a tool for measuring QoL, it is one of the approaches used by inspectors as evidence of compliance to set care standards (Care Quality Commission, 2017b). Care inspections assess outcomes such as ‘respecting and involving people who use services’, ‘care and welfare of people who use services’, ‘meeting nutritional needs’, ‘safeguarding people who use services from abuse’, ‘management of medications’, and ‘suitability of staffing’. These areas, although related and important to the QoL of people living in care homes, focus more on care practice than QoL.

Measurements of QoL are rarely carried out in care homes solely to understand the QoL experienced by residents, and there is little evidence of routine measurements carried out in care homes as a part of normal care. One study by Magennis and Chenoweth, (2009) assessed the value and practicality of routine measurement of QoL in care homes. The authors found that there is little value in individual QoL measurement unless staff are motivated and able to address the identified issues affecting resident QoL. Staff in the study reported that resident QoL could be improved by employing more care staff, increasing activities, and having more consistent allocation to job roles, but could not identify anything they could do as staff to improve resident QoL. This study was limited however as QoL was not measured routinely, only two measurements took place, this may not have been sufficient for staff to make a judgement on the benefits of measuring QoL. The authors however did discuss how routine measurement of resident QoL could potentially motivate staff to implement the changes needed to improve QoL.

Other potential benefits to routine QoL measurement have been proposed, care staff could use QoL instruments to identify the effect of interventions on residents under their care, relatives of residents could be given data in addition to that on the physical health of their relatives, and care inspectors and regulators could use QoL instruments to make inspection findings more relevant, and have greater positive impact (Edelman et al., 2005a). Further, routine measurement of QoL could allow homes to monitor changes to resident QoL over time and provide staff with more understanding of the lives of the residents they care for (Magennis & Chenoweth, 2009). It could also allow the comparison of QoL in different homes at an aggregate level.

2.5.1 Challenges in measuring QoL in care homes

2.5.1.1 Implementing change in care homes

Implementing changes, such as introducing the routine use of a new instrument into care homes can be difficult to accomplish. Unsuccessful implementation may often be attributed to an implementation error; where the practical difficulties of conducting research or making changes in the routine of the care homes interferes with the implementation of the tool

(Vernooij-Dassen & Moniz-Cook, 2014) and leads to poor uptake of the change (Lawrence & Banerjee, 2010; Fossey et al., 2014; Lawrence et al., 2015).

The challenging work conditions of care staff have been well documented; they are low paid with high stress (Hussein, 2010; Low Pay Commission Report, 2016). Asking care staff to take on extra work may be difficult to achieve and asking those that employ them to make that extra time available may also be difficult. Engaging with and including staff may improve implementation of changes (Lawrence et al., 2015). Staff are fundamental to implementing changes in practice and would be key if a new instrument were to be introduced into routine practice. Including staff in the development and implementation of such changes acknowledges their expertise (Lawrence & Banerjee, 2010) and listening to and engaging with staff provides an understanding of their preferences and concerns, which can then be acted upon at the outset of research to enhance implementation and limit obstacles and barriers (Lawrence et al., 2015).

2.5.1.2 Methodological and practical challenges

As discussed in *Section 2.4.2* methodological challenges exist in measuring QoL in dementia. In general, these challenges are similar in attempting to measure QoL in care homes and may even be compounded due to the higher prevalence of impairments in care home residents. These need to be considered when determining what approach to use and what type of instrument to use. A review of QoL instruments for use in care homes recommended using a dementia specific QoL instrument for people with dementia and a generic HRQoL instrument for people without dementia (Aspden et al., 2014). However, using two different instruments to measure QoL would not allow a single overall assessment over time. Dual measurement in this situation may lead to confusion and a lack of clarity in the interpretation of scores, and would also be dependent on an accurate diagnosis of a dementia, rates of which are currently 67% in the UK (Department of Health, 2016). Many without a formal diagnosis of dementia in care homes, will in fact have dementia. In addition, the questions contained in QoL instruments need to be appropriate for care settings. Some instruments not developed specifically for use in care home settings can contain inappropriate questions. As Hall et al. (2011) argue, they often reflect the opportunity to perform a function rather than the ability to perform it.

The prevalence of people living in care homes with dementia is so high that the use of generic QoL instruments would be limited. Furthermore, self-reports of QoL would be useful for a limited number of care home residents due to severity. As dementia progresses it may not be possible to obtain self-reports of QoL resulting in changing to collecting proxy-reports. However, as mentioned, making changes in care practice can be difficult, and staff are often overburdened with lack of time being one of the biggest barriers. Attempting to introduce two different report-types of QoL instrument into routine practice would be a real challenge and one likely to cause confusion as to whether a self-report or proxy report is most suitable for each resident. The ideal would be to use a single instrument that could be used for all residents. Practical issues also need to be considered such as the accessibility of the instruments, difficulty of administration problems, monetary and time costs.

2.6 Systematic review of dementia-specific QoL instruments for use in care homes

Previous reviews have assessed the available dementia-specific QoL instruments (Bowling et al., 2015; Ready & Ott, 2003) and QoL instruments for use in care homes (Aspden et al., 2014). A review of dementia-specific QoL instruments for use in care homes has not been carried out and this is what is presented here. As discussed earlier in *Section 2.4* selecting an instrument that has good psychometric properties is important in order to ensure that the instrument accurately and consistently measures the desired outcome. Adapting the questionnaires for use in different settings and populations, not only may affect the accuracy of the instrument but may also have implications in terms of feasibility. Previous systematic reviews have focussed on reviewing and reporting the psychometric properties of identified instruments (Aspden et al., 2014; Bowling et al., 2015; Ready & Ott, 2003); no review has examined the usability of instruments such as the availability, cost, or ease of use. For routine use in care homes instruments need to be readily available, free or low cost, easy to use and interpret, and appropriate for the setting.

A systematic review of the literature was therefore carried out to identify dementia specific QoL instruments validated for use in care homes. This review reports on the feasibility of each instrument as well as their psychometric properties.

2.6.2 Methods

2.6.2.1 Protocol and registration

The protocol for this review is registered in the International Prospective Register of Systematic Reviews (PROSPERO) – 42017046272

2.6.2.2 Inclusion criteria

Studies were included in the review if they met the following criteria: 1) they described the development and/or evaluation of an instrument, or described the adaptation and evaluation of an existing instrument for a care home population; 2) the instrument was a dementia-specific QoL instrument, studies only evaluating generic health-related QoL instruments in care home populations were excluded; 3) the study population included residents living in a care home (including nursing homes), and data on this group was presented separately from any other studied; and 4) studies were published in English. There were no exclusion criteria based on diagnosis, or non-diagnosis, of dementia.

2.6.2.3 Search strategy

Articles were identified from initial searches in four electronic databases: PubMed, PsychINFO, Web of Science, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL). All searches were conducted in January 2017. There were no restrictions on date of publication. The following four combined search terms were used: 1) “quality of life” OR QOL OR “health related quality of life” OR HRQOL OR HRQL, AND 2) dementia OR Alzheimer’s, AND 3) residential facilities OR residential OR care institutions OR long-term care OR nursing homes OR care homes OR residential care homes, AND 4) measure development OR valid* OR reliab* OR accuracy OR feasibility OR scale. Lateral searches resulted in the inclusion of eight articles. Lateral searches involved checking the references of included studies (snowballing), and further searching for identified measures on PubMed and Google search engine. Two independent reviewers (LH & NF) screened article titles and abstracts against the predefined inclusion criteria. Full

text articles were sought for all relevant studies. Any disagreements regarding inclusion were resolved through discussion by the two reviewers.

2.6.2.4 Data extraction

Two reviewers (LH & TEP) independently extracted the following data for studies that met the inclusion criteria: name of instrument, country, language of instrument, sample characteristics (i.e. age, gender) study design, measurement domains, number of items, response format, and evidence of reliability and validity.

The reviewers also extracted and collected the following data about the usability of each instrument: existence of a dedicated website, user guide available, restrictions of use, cost, required training, cost of training, time to complete instrument, need for specialist software for scoring and interpretation, guidance available for scoring and interpretation, and appropriateness of questions for a care setting. This information was collected via internet searches and email contact with original authors.

All information was collected February 2017.

2.6.2.5 Quality assessment

The methodological quality of the studies was assessed using the COnsensus based Standards for the selection of health Measurement INstruments (COSMIN) checklist (Mokkink et al., 2010). This is a standardized tool which assesses the measurement properties of health-related instruments across nine domains (internal consistency, reliability, measurement error, content validity [including face validity], construct validity [subdivided into structural validity, hypotheses testing, and cross-cultural validity], criterion validity and responsiveness) with each domain rated using 5-18 items. Each item is rated as ‘excellent’, ‘good’, ‘fair’, or ‘poor’ quality. A methodological quality score for each measurement property is obtained by taking the lowest rating of any item in that box (“worst score counts”). Two independent reviewers (LH & TEP) assessed the methodological quality of the included studies using the checklist. Studies will not be excluded based on COSMIN scores.

2.6.2.6 Data synthesis

A narrative synthesis approach was adopted to assess the practicalities for the QoL instruments for use in care homes. No formal frameworks or criteria exist for the assessment of the pragmatic properties of QoL instruments for use in care homes. Therefore, a set of criteria deemed to be important for using QoL instruments in this setting was created; these are based upon the working structure and practices of care homes in the UK. Information on the availability, usability, and appropriateness of instruments was collected.

2.6.3 Results

2.6.3.1 Search results

Initial database searches identified 616 articles, 269 were removed after duplicate deletion, leaving 347 articles. However, after title and abstract screening one more duplicate was identified and removed, this meant that 346 original articles were identified from the initial search. Title and abstract screening resulted in the exclusion of 308 articles. Full text papers of the remaining 38 articles were sought. After reviewing full texts, 19 articles met the inclusion criteria. Eight additional articles were identified from lateral searches. Two of the articles from lateral searches were subsequently removed as they did not report the results of care home population sub-analyses. Figure 2.1 illustrates the study selection process.

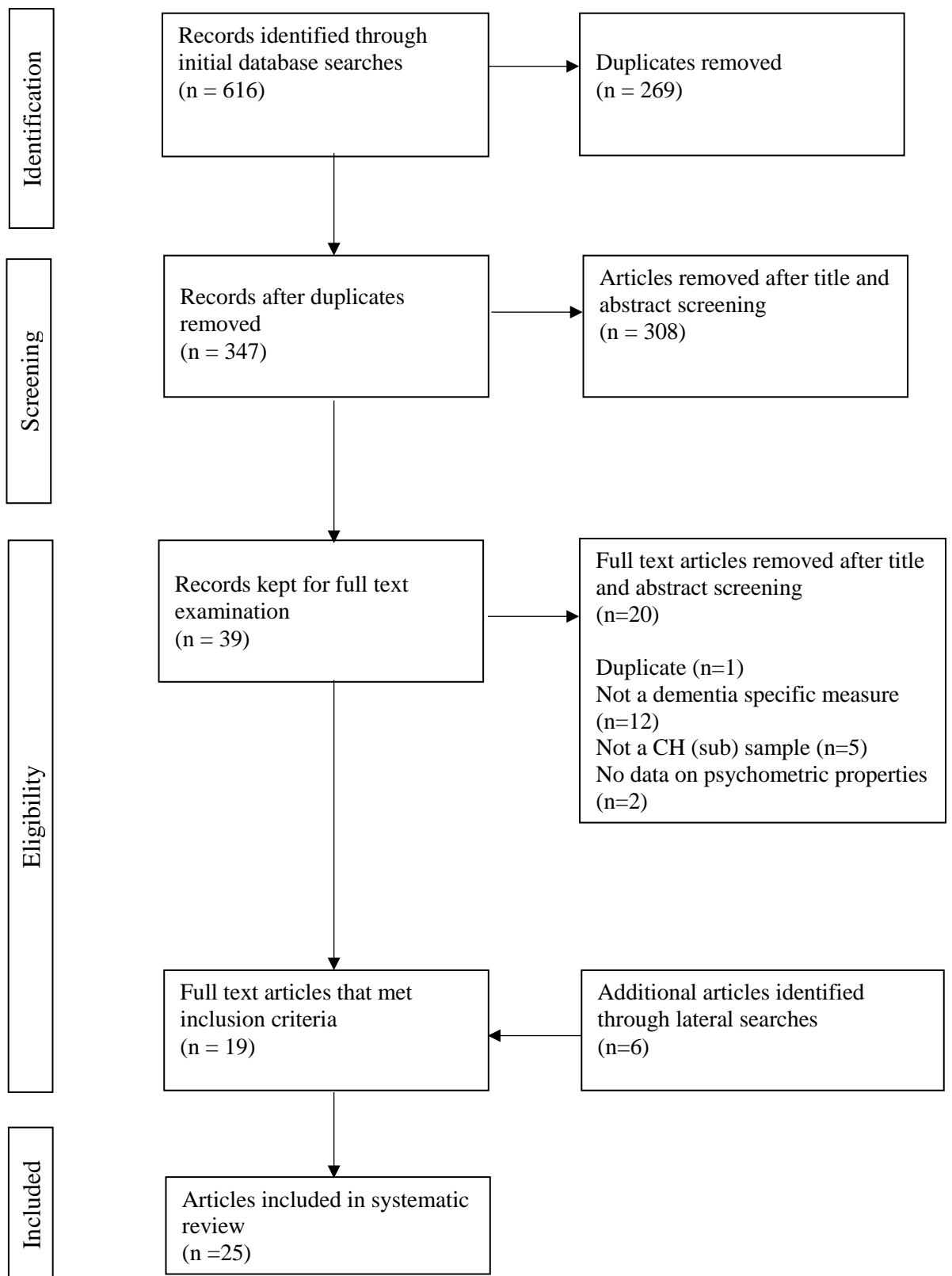


Figure 2.1. Flow diagram of study selection

In total 25 studies were included in the systematic review, these reported on 9 different QoL instruments for use in care homes. Instruments consisted of: DQoL (Brod et al., 1999), QOL-AD (Logsdon, Gibbons, McCurry, & Teri, 1999), Quality of Life in Alzheimer's Disease nursing home version (QOL-AD NH; adapted by Edelman and Fulton, unpublished work), QUALIDEM (Ettema et al., 2007b), QUALID (Weiner et al., 1999), DCM (Bradford Dementia Group, 2005), ADRQL (Rabins, Kasper, Kleinman, Black, & Patrick, 1999), ADRQL revised (Kasper, Black, Shore, & Rabins, 2009), and the Quality of Life in Dementia (QOL-D; Albert et al., 1996). The number of times instruments were identified (from most to least) were:

- QUALIDEM (n = 7)
- QUALID (n = 6)
- QOL-AD NH (n = 6)
- DCM (n = 5)
- DQoL (n = 4)
- ADRQL (n = 3)
- ADRQL revised (n = 1)
- QOL-AD (n = 1)
- QOL-D (n = 1)

2.6.3.2 Study characteristics

The sample size (residents) of these studies ranged from 20 (Beer, Bosboom, Almeida, & Flicker, 2009) to 973 (Bouman et al., 2011). The sample size for studies that included and reported proxy information (n = 10) ranged from 29 (Dichter, Wolschon, Meyer, & Köpke, 2016b) to 381 (Crespo et al., 2011). The studies recruited from the United Kingdom (n=8), the United States (n=2) Netherlands (n=3), Spain (n=4), Germany (n=5), Sweden (n=1), and Norway (n=2).

2.6.3.3 Methodological quality of studies

Table 2.1 shows the score from the COSMIN checklist. Seventeen of the studies had at least one domain rated as 'poor' quality. The measurement domain that received the highest

number of poor ratings was internal consistency (12 of 25 studies). Twenty studies had at least one domain rated as 'fair' quality, and the measurement property that received the highest number of 'fair' ratings was reliability. Six studies had at least one domain rated as 'good' quality. The measurement domains rated as 'good' quality were internal consistency (5 ratings), reliability (1 rating) and structural validity (1 rating). Three studies had at least one domain rated as 'excellent' quality (Bouman et al., 2011; Dichter et al., 2013; Mjorud et al., 2014). The measurement domains rated 'excellent' quality were internal consistency (1 rating) and structural validity (3 ratings).

The greatest number of measurement domains rated by any study was seven (Falk, Persson, & Wijk, 2007; Garre-Olmo et al., 2010), both of these were for the QUALID instrument. The least was zero (Kasper et al., 2009) for the ADRQL. The ADRQL instrument was included in the review as the study assessed the psychometric properties of the ADRQL and ADRQL revised but did not carry out a sub-group analysis of care home residents with the ADRQL. Seven studies only rated one measurement domain, these were: QOL-AD NH (Beer et al., 2009; Dichter, Wolschon, et al., 2016), QUALIDEM (Dichter et al., 2014; Ettema et al., 2007b), ADRQL revised (Kasper et al., 2009), and DCM (Edelman et al., 2005; Sloane et al., 2007).

Table 2.1

Results of COSMIN checklist for assessing the methodological quality of studies. Scores range from poor to excellent

Study	QoL instrument	Internal consistency	Reliability	Measurement Error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	Responsiveness
Adler and Resnick, (2010)	DQoL	Poor	Fair	•	•	Fair	•	•	Poor	•
Beer et al., (2009)	QOL-AD NH	•	Poor	•	•	•	•	•	•	•
Bouman et al., (2011)	QUALIDEM	Excellent	Fair	•	•	Excellent	•	•	•	•
Clare et al., (2014)	QUALID	Fair	•	•	•	Fair	•	•	•	•
Crespo et al., (2011)	QOL-AD NH	Poor	Fair	•	•	•	•	Poor	•	•
Dichter et al., (2011)	QUALIDEM	Good	•	•	•	Fair	•	Poor	•	•
Dichter et al., (2013)	QUALIDEM	Excellent	•	•	•	Excellent	•	•	•	•
Dichter et al., (2014)	QUALIDEM	•	Fair	•	•	•	•	•	•	•
Dichter et al., (2016a)	QUALIDEM	Poor	Fair	•	•	•	•	•	•	•
Dichter et al., (2016b)	QOL-AD NH	•	•	•	•	•	•	Fair	•	•
Edelman et al., (2005)	QOL-AD NH	Good	•	•	•	Poor	Poor	•	•	•
	DQoL	Good	•	•	•	Poor	Poor	•	•	•
	ADRQL	Poor	•	•	•	Poor	Poor	•	•	•
	DCM	•	•	•	•	•	Poor	•	•	•
Ettema et al., (2007a)	QUALIDEM	•	•	•	•	•	Fair	•	•	•
Ettema et al., (2007b)	QUALIDEM	Poor	Good	•	Fair	Good	•	•	•	•
Falk et al., (2007)	QUALID	Fair	Poor	•	•	Fair	Poor	Poor	Poor	Poor
Fossey et al., (2002)	DCM	Poor	Fair	•	•	Poor	Poor	•	•	•
Kasper et al., (2009)	ADRQL	•	•	•	•	•	•	•	•	•
	ADRQL revised	Poor	•	•	•	•	•	•	•	•
Leon-Sallas et al., (2011)	QOL-AD	Poor	Poor	Fair	•	•	Fair	•	•	•
Mjorud et al., (2014)	QUALID	Good	•	•	•	Excellent	•	•	•	•
Moyle et al., (2012)	DQoL	Poor	•	•	•	•	Fair	•	•	•
	QOL-AD NH	Poor	•	•	•	•	Fair	•	•	•

Study	QoL instrument(s)	Internal consistency	Reliability	Measurement Error	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	Criterion validity	Responsiveness
Roen et al., (2015)	QUALID	Poor	Fair	•	•	•	Poor	Poor	•	•
Sloane et al., (2005)	QOL-D	Poor	Fair	•	•	•	Poor	•	•	•
	QOL-AD NH	Poor	Fair	•	•	•	Poor	•	•	•
	ADRQL	Poor	Fair	•	•	•	Poor	•	•	•
	DQoL	Poor	Fair	•	•	•	Poor	•	•	•
	DCM	•	Fair	•	•	•	Poor	•	•	•
Sloane et al., (2007)	DCM	•	Fair	•	•	•	•	•	•	
Villar et al., (2015)	DCM	Good	Poor	•	•	Fair	Fair	•	•	•
Weiner et al., (2000)	QUALID	Poor	Poor	•	•	Poor	Fair	•	•	•

• = no information/not measured

2.6.3.4 Quality of life instruments identified

From the 25 studies nine instruments were identified. Three instruments had both a self-report and proxy-report questionnaire, one instrument was a self-report questionnaire, four instruments were proxy report questionnaires, and one instrument was a proxy observation tool. The number of measurement domains ranged from one (QOL-AD, QOL-AD NH, QUALID) to nine (QUALIDEM 37 item version).

Six instruments were developed for use in care homes (QUALID, QUALIDEM, DCM, ADRQL, ADRQL revised, and QoL-D), one was adapted specifically for use in care homes and evaluated (QOL-AD NH) and two instruments were evaluated for use in care homes (QOL-AD, and DQoL). The number of items in each instrument ranged from six (affect subscale of QOL-D) to 47 (ADRQL).

The characteristics of each identified instrument are shown in Table 2.2.

Table 2.2

Characteristics of identified instruments

Instrument	Mode of administration	Measurement Domains	No of items	Response format
DQoL	Self-report interview	Sense of Aesthetics, Feelings of Belonging, Negative Affect, Self-esteem, Positive Affect	29	5-point Likert scale
QOL-AD	Self-report interview and proxy report questionnaire	Quality of life	13 items	4-point Likert scale
QOL-AD NH	Self-report interview and proxy report questionnaire	Quality of life	15 items	4-point Likert scale
QUALIDEM	Proxy report questionnaire	Mild to severe: Care relationship; Positive affect; Negative affect; Restless tense behaviour; Positive self-image; Social relations; Social isolation; Feeling at home; Having something to do. Very severe: Care relationship, positive affect, negative affect, restless tense behaviour, social relation, social isolation	Mild to severe - 37 items, Very severe – 18 items	4-point scale
QUALID	Proxy report interview	Quality of life	11 items	5-point Likert scale
DCM	Proxy observation	Behaviour Category Code (BCC); Well-/Ill-Being Value (WIB); Interaction; Degeneration; Personal detraction	24 behaviour category codes	WIB recorded on 6-point scale from -5 to +5
ADRQL	Proxy interview	Social interaction; Awareness of self; Feelings and mood; Enjoyment of activities; Response to surroundings	47 items.	Dichotomous agree/disagree

Instrument	Mode of administration	Measurement Domains	No of items	Response format
ADRQL Revised	Proxy interview	Social interaction; Awareness of self; Feelings and mood; Enjoyment of activities; Response to surroundings	40 items,	Dichotomous agree/disagree
QoL-D	Self- and proxy-report (unsure if interviewer-administered or self-administered)	Activity, Affect	Activity subscale: 15 items, Affect: 6 items	Activity: 3-point scale Affect: 5-point scale

2.6.3.5 Psychometric and feasibility properties of the QoL instruments

2.6.3.6 Psychometric properties

The instrument with the most comprehensive evaluation of psychometric properties across the nine domains of the COSMIN checklist was QUALID with seven domains assessed in two separate studies. The DQOL, QOL-AD, QUALIDEM, and DCM had four domains assessed in at least one study. The instrument with the least domains assessed were QOL-AD NH (n = 3), QOL-D (n = 3), ADRQL (n = 3), and ADRQL revised (n = 1).

Reliability

Internal consistency was reported in 20 of the 25 studies. All nine instruments had internal consistency reported in at least one study. Instruments that were reported on the most were QUALID (6 studies with poor to good ratings), and QUALIDEM (5 studies, poor to excellent quality ratings).

Fifteen studies reported test retest or inter-rater reliability of eight of the instruments. The most assessed instruments were QUALIDEM, QUALID, and DCM (4 studies). QUALIDEM was rated fair to good, QUALID and DCM were both rated poor to fair. QOL-AD NH was assessed in three studies (poor to fair), DQoL was assessed in two (fair), and the QOL-AD (poor) ADRQL (fair), and QOL-D (fair) were assessed in one study. QUALID and QOL-AD were the only instruments to have measurement error assessed; both were given fair quality ratings.

Validity

Content validity was assessed in QUALIDEM only, it was rated as fair quality. Structural validity was assessed in six instruments, the instruments most assessed were QUALID, rated in five studies with poor to excellent ratings, and QUALIDEM, rated in four studies with fair to excellent ratings. The DQoL and DCM were rated in two studies with fair to poor ratings for both. QOL-AD NH and ADRQL were assessed once with poor ratings.

Hypothesis testing was carried out for eight instruments. The most assessed instruments were QUALID and DCM, they were assessed in four studies with poor to fair ratings. DQoL and

QOL-AD NH were assessed in three studies with poor to fair ratings each. ADRQL was assessed in two studies with poor ratings, QUALIDEM and QOL-AD were assessed once with fair ratings, QOL-D had one poor rating.

Cross cultural validity was assessed for three instruments. QUALID and QOL-AD NH were both assessed twice. QUALID had poor ratings, QOL-AD NH had a poor and a fair rating. QUALIDEM was assessed once and had a poor rating. Criterion validity was assessed for two instruments. QUALID was assessed twice, both with poor ratings, DQoL was assessed once with a poor rating. Only the QUALID was assessed for responsiveness, this had a poor rating.

2.6.3.7 Feasibility properties

The availability and usability of each of the instruments is outlined in Table 2.3. Availability of instruments includes how accessible they are from reputable sources, any costs involved and any training required. Usability covers the ease that instruments can be used and scored, including the time needed to complete and information available for scoring. All information was taken from dedicated websites, where available, or the instruments themselves. For instruments that were not accessible information was gathered from the literature where available.

Availability

Four of the instruments were accessible (QOL-AD, QUALIDEM, ADRQL revised, and DQoL). The self-report version of the QOL-AD was available at the end of the original paper. Both self and proxy versions of the instrument were available from the MAPI-research trust website which is a website repository of clinical outcome assessments. This website requires that an account be set up to be able to request and download the instrument. There is no cost for the instrument for non-funded academic researchers, costs are incurred for commercial use or funded research (see Table 2.3), and there is no mandatory or suggested training to use the instrument. QUALIDEM was available from contact with the author of the German version of the instrument. The English language version of the instrument is also available at the end of the English user guide, although there is not

dedicated website, there is an official website affiliated with the author of the German version of the instrument that the user guide is available from. A simple internet search provides access to the English language version. There are no costs or training required to use QUALIDEM. The ADRQL revised instrument was available from the MAPI-research trust website and also through contact with the original author. ADRQL revised has costs for commercial and non-funded academic research uses through the MAPI-research trust site (see Table 2.3). Detailed information about the ADRQL and ADRQL revised is available on a dedicated website. Training is recommended before using the instrument, this is free to use and is found on the website.

The DCM tool is not available unless specific training is carried out, the author completed this training so had access to the instrument. Training for DCM costs £975 and takes 3 days to complete, a full user guide is available after training is complete. There is a dedicated website that provides detailed information about the instrument development and aims. DQoL was available by contacting the original author directly, there are no costs or training required to use the instrument.

Four instruments were not accessible. The ADRQL instrument was not available from an official source as it has been replaced by the ADRQL revised instrument, it may be possible to access through contact with the original author. Information about the instrument is available on a dedicated website, similar to the ADRQL revised, a free training video is available and recommended for training. QOL-AD NH is not available as it was informally adapted from another instrument. It is assumed that researchers or clinicians wishing to use the instrument must have to access and adapt the QOL-AD by referring to the available literature. QUALID was not accessible through internet searches or contact with original authors. A copy of the QUALID was however identified through internet searches but was not available from an official source, it was therefore not possible to determine if this was an original version of the instrument. No information regarding costs or training were available. The QOL-D instrument was also not accessible, there is little information available about QOL-D, including any costs or training needed.

Usability

Information about the usability of each instrument was available for all instruments except the QOL-D. Most of the identified instruments can be completed in little time, approximately

5 - 10 minutes, with the exception of DCM. DCM observations can be carried out for up to 6 hours. QUALID takes the least amount of time to complete, only needing five minutes. The QOL-AD and QOL-AD NH both take 5 minutes for the proxy report and 10-15 minutes for the self-report. DQoL and QUALIDEM take 10 minutes, and ADRQL and ADRQL revised takes 10-15 minutes to complete.

The time frame that QoL is meant to be measured in is stated clearly for five of the instruments. Four of the instruments had reasonable time frames; QUALIDEM is completed for the previous week for the English and German version of the instrument, and two weeks for the Dutch instrument; ADRQL and ADRQL revised were both to be completed for the previous two weeks; and the QUALID completed for the previous week. DCM is completed by observing activities that occur in present time. Three instruments had unclear time frames stated. DQoL does not state a specific time frame to be measured, each question starts with 'recently, how much have you enjoyed ...'. Similarly, the QOL-AD and QOL-AD NH report that QoL should be measured for 'present time (e.g. within the past few weeks)'. The time frame to be measured is unknown for the QOL-D as no information is available.

Scoring information was available for all instruments except QOL-D. A separate scoring guide or information was available for DCM. ADRQL, ADRQL revised, and QUALIDEM also have separate guides as well as information on each instrument. DQoL scoring instructions are available on the original paper only. The rest of the instruments have the scoring information on the instrument themselves.

None of the instruments require specialist software to carry out scoring as they only require simple mathematic skills to complete. There is however a specially formatted spreadsheet available for DCM to make scoring easier for users.

Table 2.3

Availability and usability properties of each identified instruments

Instrument	Availability				Usability			
	Dedicated website	User guide	Cost of instrument	Training required (cost)	Time to complete	Time frame to measure	Specialist software required?	Scoring guide
DQoL	No	No	Free	None	10 minutes	Recently	Not stated	Scoring instructions in original paper (Brod et al., 1999)
QOL-AD	No *	Yes, and instructions on instrument	Free to non-funded academic researchers ^a	None	5 mins proxy 10-15 mins self-report	Present time (e.g. within the past few weeks)	No	Yes
QOL-AD NH	No	Yes, and instructions on instrument	Free to non-funded academic researchers ^a	None	5 mins proxy 10-15 mins self-report	Present time (e.g. within the past few weeks)	No	Yes
QUALIDEM	No	Yes	Free	None	10 minutes	2 weeks Dutch version, 1 week English and German versions	No	Yes, on instrument and in user guide
QUALID	No	No	Not known	Not known	5 minutes	1 week	No	Yes, scoring instructions on instrument

Instrument	Availability				Usability			
	Dedicated website	User guide	Cost of instrument	Training required (cost)	Time to complete	Time period to measure	Specialist software required?	Scoring guide
ADRQL	Yes	Yes, and instructions on instrument	Free to non-funded academic researchers ^b	Recommended use of ADRQL training video (free)	10-15 mins	2 weeks	No	Yes
ADRQL Revised	Yes *	Yes, and instructions on instrument	Free to non-funded academic researchers ^b	Recommended use of the ADRQL training video (free)	10-15 mins	2 weeks	No	Yes
QoL-D	No	Not known	Not known	Not known	Not known	Not known	Not known	Not known
DCM	Yes	Yes	Free after training	Mandatory 3 day training (£975)	Up to six hours observation	Present time	Not required but available	Yes

All data presented accurate from February 2017

* Not a dedicated website but available from MAPI trust repository.

^a Non-funded academic researchers - free

Funded academic researchers - €300 per study and €50 per language

Commercial users – Royalty fees €1000 per study and €50 per language. Distribution fees €1000 per study and €50 per language

^b Non-funded academic researchers - free

Funded academic researchers - €300 per study and €50 per language

Commercial users – Royalty fees 10,000 USD per study and 500 USD per language. Distribution fees €700 per study and €300 per language

2.6.4 Discussion

Twenty-five studies were identified that assessed 9 dementia specific QoL instruments in care homes. The psychometric and feasibility properties were extracted to assess the practical use of these instruments in care homes by care home staff. Taken together, the findings are potentially useful in showing that there are few high quality instruments available that can reasonably be used by care staff for the routine measurement of QoL in care homes.

Overall, there was limited information about the psychometric properties of most instruments with many elements not assessed. COSMIN scores that were assessed had relatively low ratings with the majority of ratings being poor or fair. The instruments with the most psychometric evidence were QUALID and QUALIDEM; they were identified in the most studies and had the most domains of the COSMIN checklist assessed. The instruments with the least psychometric information available were the ADQRL revised, and QOL-D, these instruments were only identified in one study each and had the least amount of COSMIN domains assessed.

The availability and usability of instruments was varied among instruments. Although some were accessible to the author through internet searches and by contacting original authors directly, accessibility of instruments for care staff would be significantly more difficult. Furthermore, instruments need to be obtained from trustworthy sources to ensure that the instrument is the correct version and has not been adapted. It is understandable that authors want to control access to protect the developed instrument to ensure that they are used correctly. However, the consequences of this may mean low utilisation of instruments, and altered versions that have been made available may accidentally be accessed and used. In carrying out this review, we found two instruments from unofficial sources, one of which had a section missing that was significant for correct scoring of the instrument.

Of all the instruments that were available for this review the QOL-AD, QUALIDEM, and ADRQL revised were accessible via simple internet searches, the DQoL was only accessible from the original author directly and DCM was already accessible to the author through completion of the required training. The QOL-AD NH and ADRQL are available to a degree, requiring adaption of the instrument or requesting it from the original author.

The most psychometrically assessed and most accessible instrument identified in this review was QUALIDEM. The instrument was easily accessible and free to use, and all information regarding administration and scoring is available in an extensive user guide. The amount of time to administer the instrument and the time frame to measure are both reasonable without putting too much burden on respondents. However, although an English language version of QUALIDEM is available it has not been validated in an English sample as far as can be determined from this review. The QUALID and QOL-AD NH instruments had more extensive psychometric assessment carried out but they were not easily accessible. These instruments could potentially be useful in routine care home use as they are quick to complete or administer and easy to use. The scoring and interpretation of QoL are simple to carry out. The instruments however would need to be more accessible for care homes.

Other instruments that were easily available were QOL-AD, DQoL, and ADRQL revised. However, these instruments all had poor psychometric assessment and were identified in very few studies. These instruments are all quick to administer and easy to score and interpret. More extensive assessment is needed before it can be determined if they could be used effectively in care home settings. The ADRQL and QOL-D were not available and had poor psychometric quality ratings; they were also identified in very few studies in this review. DCM is one of the more widely known observational tools for use in care homes. It had a moderate amount of psychometric assessment in the studies in this review. However, it is expensive to train to use the instrument and also time consuming to complete.

Some instruments that were included in previous reviews were identified and subsequently excluded from this review because they did not meet the set criteria. The Philadelphia Geriatric Centre Affect Rating Scale (PGC-ARS: Lawton, Haitsma, & Klapper, 1996) and the Resident and Staff Observation Checklist Quality of Life measure (Sloane et al., 1991) were not included in this review despite being included in a review by (Aspden et al., 2014) as they were not assessed to be measures of QoL. The PGC-ARS is a measure of affect and RSOC-QOL was developed as a measure of physical and chemical restraint. Similarly, the Quality of Life Assessment Schedule (QOLAS) (Selai, Trimble, Rossor, & Harvey, 2001) was included in the review by (Bowling et al., 2015) as one of the dementia specific QoL instrument, however, the QOLAS was not specifically developed for use in people with dementia, it was adapted and evaluated for use with people with dementia after its initial development.

One of the limitations to this review is that only articles published in English were included. This could have excluded instruments that were developed or evaluated in other languages.

Conclusion

The number of high quality accessible instruments available for use in care homes is low. Psychometric analysis of instruments was generally poor with a limited number of psychometric elements assessed for each instrument in any single study. Furthermore, the quality ratings of each instrument were weak with very few receiving excellent or good ratings. Instruments with the best psychometric assessment were not available to access, and those that were available had some of the poorest quality and most limited assessment. DCM adopted a very different approach from the other instruments as an intensive observational instrument with strong conceptual underpinning. However, the relatively high costs and need for specific training, as well as the person time needed for the observations to be completed were assessed as limiting its utility as a regular measure of QoL in care homes. Its use as a quality improvement intervention was beyond the scope of this review.

Findings indicate that there is a potential need for instruments of high quality that are easily available to use in care homes. This is particularly important for people who wish to use them in a non-research or clinical capacity. Care home staff wishing to introduce a QoL instrument into routine practice may not know what instruments are available, they may not know what to look for or how to access a high quality instrument that is usable, easy to use and interpret. The conclusion of the review was that there would be value in the development of an instrument that measures the QoL of care home residents well and which is suitable for routine use by care staff.

2.7 Studies assessing QoL in dementia

2.7.1 Routine measurement of QoL

To date, only one study has assessed the routine measurement of QoL in care homes (Magennis & Chenoweth, 2009). The aim of the study was to understand what influenced residents' QoL, and to assess any possible benefits and the practicality of routine QoL

measurement. Qualitative and quantitative methods were used. Sixty-eight residents and 26 care staff from one care home in Australia took part in the study. Residents assessed their own QoL using the self-report QOL-AD instrument, this was administered by an interviewer (research staff). Residents that had low QoL (i.e. those that rated four or more items on QOL-AD as poor or fair) (N=20) were asked further questions about their QoL such as, what impacted on their QoL, and what could improve it. Care staff then rated the QoL of these residents using the proxy-report QOL-AD. After staff had rated the residents' QoL, a member of the research team facilitated discussions with staff about their ratings in order to come to a consensus on the QoL rating. It is unclear whether the care staff all rated the same residents for the same time or if one member of staff rated a subset of residents. Once consensus was reached, staff were informed of the residents' self-reports of QoL. Staff then developed plans to improve resident QoL.

After six months, resident QoL was measured again by self-report, 16 residents were available at follow-up and staff focus groups were carried out to discuss how QoL could be improved for residents. The statistical findings showed that staff and resident QoL ratings were similar, the only significant differences were for the subscales 'mood' and 'relationship with friends', where staff rated 'mood' higher and 'relationship with friends' lower compared to resident self-reports. For self-reports at follow-up, in comparison to baseline, there were significantly lower scores for the subscales 'relationships with staff', 'relationships with friends', and 'ability to make choices'. Individually, scores at follow-up showed that five residents had better QoL, three remained the same, and eight had lower QoL. Qualitative findings showed that very few residents were able to determine ways that the care home could improve their QoL. Findings from staff meetings and focus groups showed that although the staff were supportive of the idea of trying to improve resident QoL, they had reservations about the effectiveness of the approach used in the study. Staff were uncertain about whether measuring resident QoL would be useful because they could not identify ways that they could improve it. The only ways identified by staff were by employing more staff, having consistent job assignment, and having more variety of activities for residents. The authors stated that they had hoped residents would have identified ways that their QoL could be improved to motivate staff. However, because they could not identify anything and stated that they were satisfied with their current care staff may have felt that did not need to do anything. Half of the staff learned something new about a resident from taking part in the study; they reported learning more about residents' mood.

Because of this, and the finding that staff and resident QoL scores were similar, the authors suggested that the cost of conducting resident interviews could not be justified because staff were already aware of resident issues and had good knowledge of residents. Furthermore, because the ways of improving QoL identified by staff were out of care staff control, the authors concluded that implementing routine QoL measurement is not likely to be an effective way to improve QoL. The authors suggested that the issues known to affect QoL in care homes, such as loneliness, should be focussed on as it may be easier to make improvements to QoL. Although this study attempted to determine the benefits of measuring QoL, and tried to gain insight into resident and staffs views, this study however did not really implement the routine measurement of QoL. Self-reported QoL were only collected at two time-points with one staff measurement of QoL. It can be argued that this is a before/after design rather than routine measurement. Furthermore, a single time frame of 6 months was used between measurements.

2.7.2 Longitudinal studies of QoL in care homes

A series of longitudinal studies conducted by different researchers from 2003 to 2014 have assessed changes to QoL over time, with some evaluating the factors that predict QoL changes.

The first of these studies was by Lyketsos and colleagues which assessed changes in QoL of people living in a care setting over a two year period (Lyketsos et al., 2003). Using the proxy ADRQL instrument, participant QoL was measured at baseline and again two years later. Participant cognitive function (mini mental state examination (MMSE) (Folstein, Folstein, & McHugh, 1975), depression, non-mood behaviour disturbance, and physical dependency were also measured. ADRQL was administered to a proxy, however, the authors do not state if the proxy was a family carer or care staff. There were 120 participants at baseline, 47 were available for follow-up. As the authors hypothesised, there was a small significant decrease in QoL at follow-up for total ADRQL score. Significant decreases were also found for the 'social interaction' and 'awareness' subscales, and there was a trend toward significance for the 'enjoyment of activity' and 'response to surroundings' subscales. The only improvement was a non-significant increase in QoL for the 'feelings and mood' subscale of ADRQL. Exploratory linear regression analysis was used to assess baseline predictors of change in ADRQL scores. Baseline variables were: age; gender; education;

ADRQL; MMSE; MMSE change; physical dependency; behavioural disturbance; depression; and duration of residence. The only significant predictor was ADRQL baseline score, a one point increase on baseline score was associated with a mean 0.6 points less decline at follow-up. The hypothesis that change in QoL would be associated with a change in dementia severity was not supported. The authors noted that despite the decrease in QoL scores, at the individual level, almost half of the participants (49%) improved or remained the same at follow-up. The authors concluded that the ADRQL appears sensitive to change over time, supporting the use of ADRQL and other proxy QoL instruments as suitable outcome measures for intervention studies. The results of the study may not be generalizable as all residents were recruited from one care home, they included people from both an assisted living and skilled nursing area of the home. The authors acknowledged this. They also stated that the home provides high quality care with a focus on improving QoL, this could have resulted in the small changes to QoL and the finding that half of the residents had no change or an improvement in QoL. The high loss to follow up, through death and the infrequency of the assessments (two years apart) limit the inferences that can be made.

The second longitudinal study of QoL in dementia was carried out in care homes in Japan (Funaki, Kaneko, & Okamura, 2005). This small study assessed 25 residents who had moved into a care home within the previous three months. The two homes used were group homes, which are usually small groups of five to nine people living together in small-scale homes. The authors assessed changes in QoL scores after residents had moved into these types of home and focussed on occupation tasks and the environment as factors that could change QoL. The QOL-D is an observational instrument, it was used to measure QoL of residents at baseline and again at follow-up three months later. Other factors measured included: activities of daily living (ADL); instrumental activities of daily living (IADL); housekeeping tasks and items, this measures housekeeping items such as cooking, shopping, laundry, and cleaning; dementia severity; and sociodemographic data such as age, gender, type of dementia and duration of residence. A significantly higher QoL was found at follow-up compared to baseline for total QOL-D score. A significant difference was also found for the subscale 'vivid communication with surroundings'. The authors suggested that increases in the subscale 'vivid communications with surroundings' demonstrated that residents' communication with others had improved after moving into the group home. The only significant predictor of QoL was housekeeping items; if residents performed an increasing number of housekeeping items such as cooking and laundry they had higher QoL. The

authors concluded that providing residents with an opportunity to have a role and a sense of competence can aid in improving QoL as it encourages self re-evaluation.

A study by Selwood, Thorgrimsen, & Orrell, (2005) assessed changes to QoL over a one year follow-up using three different self-report QoL instruments. Two dementia-specific self-report instruments, QOL-AD and DQoL, and one generic self-report HRQoL instrument, EQ-5D, were used at baseline and follow-up. Fifty-eight participants from inpatient, day hospital, care home, and nursing home settings were included in the study. At follow-up participant depression, cognitive function, and anxiety were also measured. It was hypothesised that QoL would not change significantly and not be predicted by baseline QoL. Considering the challenges that can be present when using self-reports of QoL the authors also appropriately included completion rates for each instrument. It was found that 60% of participants could complete the DQoL, but only 37% could complete the QOL-AD and EQ-5D. No statistically significant changes to mean QoL were found for any of the instruments. Individually, changes to QoL for QOL-AD showed that 27.6% had higher QoL, 44.8% remained the same, and 27.6% had lower QoL. At follow-up, correlations between QoL, anxiety and depression were significant, with higher depression and anxiety scores correlating with lower QoL. No significant relationship between cognitive function and QoL was found for either the DQoL or QOL-AD. The authors carried out correlations of baseline and follow-up scores for DQoL and QOL-AD and found them to be highly correlated. Higher QoL scores for DQoL and QOL-AD were found for people that lived alone in comparison to those that lived with a relative or in residential care, though the QoL scores were very similar for all groups. Because some participants' living arrangements had changed during baseline and follow-up the authors assessed the association with QoL but found no relationship. The authors concluded from their own findings and with reference to those of the individual QoL findings from Lyketsos and colleagues (2003) that decline in QoL is not certain. And similar to Lyketsos et al., (2003), the only predictor of QoL change was baseline QoL. Finally, the authors suggested that the QOL-AD was better for use in future studies and in clinical settings as it can be used in people with low MMSE scores. However, in this study the authors excluded people that could not complete the QOL-AD instrument, potentially excluding those with more severe dementia. This study used self-reports instruments. The authors stated that the main caregiver was also asked to help complete some scales; there was no evidence if the caregiver was a family carer or care staff in a care home. Similarly, the scales that the caregiver assisted with were not specified.

Missotten et al., (2007) examined changes to QoL of 356 people over a two year period. They included people that lived at home and in care homes. Similar to Lyketsos et al., (2003), they measured QoL using the proxy-reported ADRQL instrument. QoL was measured at baseline, one year, and two year follow-up. The person with dementia's family carer or a member of care staff completed the ADRQL. The authors state that family carers completed the instrument in collaboration with a researcher, there was no statement as to whether care staff were administered the instrument or completed it independently. Other factors assessed were: cognitive function using MMSE and the cognitive scale (CAMCOG) of the Cambridge Examination for Mental Disorders of the Elderly (Roth et al., 1986); ADLs; IADLs; dementia severity (CDR); and behaviour. The correlation between the clinical variables and QoL was assessed, as was the explanatory effect of clinical variables on QoL. At follow-up 127 people were assessed. The findings showed that QoL increased at year one follow-up and decreased at year two follow, although year two remained higher than baseline scores. The only statistically significant difference was between baseline and the first year follow-up. For the five subscales of ADRQL there was a significant difference for the subscale 'response to surroundings' and 'feelings and mood'. MMSE score correlated with QoL at baseline, ADL score and dementia severity correlated at year one follow-up, and all clinical variables (MMSE, IADLs, ADLs, and dementia severity) were correlated at two year follow-up. They found that at baseline, 5.9% of the variance in QoL was accounted for by dementia severity (MMSE), whereas at year two follow-up 40% of the variance was accounted for by dementia severity (MMSE and CDR), yet there was no significant difference in QoL between baseline and two year follow-up. The authors conclude that other factors, such as physical and social environment which were not measured, probably played a significant role in explaining QoL, and that there is no direct relationship between the clinical factors measured and QoL.

A study by Hoe et al., (2009) investigated changes to QoL of care home residents in a 20 week follow-up study using the self- and proxy-report versions of the QOL-AD instrument. Care staff of the homes completed the proxy QOL-AD instrument. The authors also measured different clinical factors to determine which ones predicted changes in QoL. These were: cognitive function (MMSE); dementia severity (CDR); challenging behaviour; residents' needs; dependency; depression; anxiety; and ADLs. 192 people from 24 care homes were followed up. No significant differences between QoL were found between baseline and follow-up for either self-report or proxy-report. At an individual level, for self-

report 27.1% had no change, 34.4% had better QoL, and 38.6% had worse QoL. Improvements in self-reported QoL were associated with less baseline anxiety, lower baseline QoL, and a decrease in depression and anxiety at follow-up. Improvements in proxy-reported QoL was associated with lower anxiety and QoL at baseline, and decreased depression and anxiety at follow-up. For self-reported QoL, once all other variables were controlled for, lower QoL at follow-up was predicted by higher baseline QoL, less depression and anxiety symptoms at baseline, and worsening depression and cognition. For proxy-report, lower QoL at follow-up was predicted by higher baseline QoL, and less dependency at baseline. Increasing dependency and worsening depression were also significant predictors. The authors concluded that although there was no difference between baseline and follow-up, the QOL-AD instrument is suitable for detecting changes in individual QoL. They also suggested that in future studies individual QoL scores should be measured as well as the sample mean. The authors also suggested that improvements to cognition and mood may lead to improvements in QoL. Almost half of the residents (48.9%) had an unrecorded QoL score, and only 36.5% of residents were able to complete the QOL-AD at both baseline and follow-up, whereas 94.8% of staff were able to. This highlights the challenge of using self-report instruments for longitudinal follow-up.

Oudman & Veurink, (2014) conducted a two year follow-up study using the proxy QUALIDEM instrument. They measured the QoL of nursing home residents at baseline and once again two years later. This was the first study to only use residents in a skilled nursing facility with advanced dementia; residents lived in a psychogeriatric ward of a nursing home. Advanced dementia was determined using the Reisberg Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982), residents with a score of more than 5, indicating more severe impairment, was used. The authors stated that they did not include people with end stage dementia, a GDS score of 7, as QoL at this stage is not well understood. Seventy-five residents were recruited into the study, 36 were followed-up two years later. Socio-demographic variables (e.g. age, gender, dementia diagnosis) of residents were collected, no other clinical or environmental variables were measured. QUALIDEM was completed by the same care staff at baseline and follow-up. There was no significant difference between baseline and follow-up QoL scores; although the authors pointed out that there was a trend toward significance for overall QoL and for the 'social relationship' subscale. A mean increase of 3.4% was found, and on average, QoL improved for 59.4% of residents. The biggest increase in subscales were for 'feeling at home', 'social isolation', and 'negative

affect'. The 'feeling at home' subscale had the strongest change. Decreases in social isolation and improvements in feeling at home were suggested to be caused by residents accepting or adapting to their situation, and additionally, that people with more severe dementia have less expressive behaviours, such as shouting and rejecting others, leading to less social isolation. The authors concluded that despite cognitive deterioration in severe dementia, QoL is stable or can improve.

The most recent longitudinal study that assessed changes to QoL was carried out by Beerens et al., (2015) across eight different countries. They assessed the impact of resident-related factors on change in QoL. Participants were residents who had moved into a care home within the previous one to three months. The QOL-AD (self- and proxy-report) instrument was used. Only residents who could complete the instrument at baseline and follow-up were included. Proxy respondents were care staff in the care homes, if the care staff did not have sufficient knowledge of the resident a family carer was used. However, the authors did not state in the results whether family carers or care staff had completed the instrument. Other variables measured were: cognition; comorbidity; ADLs; depression; neuropsychiatric symptoms, e.g. hyperactivity, mood/apathy, psychosis, and anxiety. There were 343 resident self-reports and 332 proxy-reports of QoL were measured at baseline and follow-up. There were no significant changes to QoL for either self or proxy-reported QoL. The difference between the self- and proxy-reports were found to be significantly different, although not clinically relevant. Individual changes to self-reported QoL, compared to baseline were: 25.4% had worse QoL; 44.0% had no change; and 30.6% had an improvement to QoL. For proxy-reports: 25.6% had lower QoL at follow-up; 48.8% had no change; and 25.6% had improved QoL. Analysis of the explanatory variables showed that a decrease in self-reported QoL at follow-up was associated with higher QoL and better cognition at baseline. Lower proxy-reported QoL at follow-up was associated with higher baseline QoL, more dependency for ADLs at baseline, an increase in ADL dependency between baseline and follow-up, more depressive symptoms at baseline, and an increase in depressive symptoms between baseline and follow-up. The authors concluded that the QoL of residents new to care homes does not decrease after admission, however, there were changes at an individual level.

Studies investigating the routine use of DCM to investigate QoL are also limited. Thornton, Hatton, & Tatham, (2004) argued that relatively little research has been carried out with care staff, who are trained to use DCM, to assess the quality of care they provide to residents.

Although acceptable levels of inter-observer agreement have been found in DCM studies, they have typically used mappers who are professionals trained in research methods, or mappers connected to the developers of DCM, the Bradford Dementia Group. In their study Thornton and colleagues assessed DCM when used by care staff. Sixty-four residents on an NHS continuing care ward or attendees of a day hospital were recruited to the study. Participants had a broad range of cognitive function and physical dependency. Eight members of staff who had been trained to use DCM and had been using it for over two years were recruited as mappers. Resident dependency was measured. Continuous time sampling (CTS) (Bowie & Mountain, 1993), another observational method to record behaviours, was used by the authors. DCM and CTS were carried out simultaneously. Mappers observed the same residents at the same time and the inter-observer reliability was assessed. The authors found low inter-observer reliability between care staff using DCM. They attributed this mainly to the complexities of using DCM. The authors did acknowledge that variation in training could have resulted in poor reliability; there is no follow-up system to ensure mapping is conducted effectively. Although this study did not assess the routine or longitudinal use of DCM it assessed its use by care staff.

Another study that assessed the use of DCM with care staff was conducted in German nursing homes (Dichter et al., 2015). This study was a pragmatic quasi-experimental trial assessing the effect of DCM as an intervention to improve resident QoL and challenging behaviour. Nine nursing homes were recruited into the study. Three groups were formed based on their experiences with DCM in the past. Group A had prior experience with DCM having had mapping sessions performed by outside mappers, group B had an interest in DCM but had never used it, and group C was a control, the QUALIDEM instrument was integrated into their usual care. Groups A and B had two staff trained as mappers for the study. The primary outcome was QoL using the QOL-AD (proxy) instrument, and challenging behaviour. The secondary outcome was also QoL using QUALIDEM. Functional ability and institutional characteristics such as staff/resident ratio were also collected. Data were collected at baseline, six months, and 18 months. DCM was carried out between the time-points. Two hundred and seventeen residents were recruited at baseline and more were recruited throughout the study resulting in 453 people recruited and followed up. The results showed that QoL was not significantly different between the three groups across the three time-points. QoL measured by QOL-AD and QUALIDEM both decreased between baseline and 18 month follow-up for groups A and B but increased for

group C. The authors acknowledged that their sample was diverse and that differing levels of support for staff to implement the intervention may have affected the results. The authors concluded that it was disappointing that DCM as an intervention showed no improvements in resident QoL over an 18 month period.

2.7.3 Summary

This section outlines studies which have assessed routine or longitudinal measurement of QoL. This highlights the current methodologies employed by researchers to assess QoL longitudinally. The primary aim, particularly for longitudinal studies, is to determine if QoL changes over time and to determine what causes these changes. Clinical variables such as dementia severity, mood, anxiety, dependency, and depression are often the focus of assessments when attempting to understand the factors that affect QoL ratings. However there are conflicting findings for the effect of these variables. Few studies identified dementia severity as a predictor of QoL. Those that did find a relationship found that dementia severity only explained a small amount of variance in ratings. Similarly, the effect of other clinical variables account for a small percentage of the variance in QoL ratings. Studies that used proxy-reported instruments, particularly those that used both family and care staff provided little evidence or discussion of the differences between the two proxy ratings, except to assess to what degree the self- and proxy-reports agreed. Similarly, when care staff were used, studies did not state the type of care staff that completed the instruments.

The focus on clinical variables and the way that proxy ratings of QoL were assessed in the above studies demonstrates that the main motivation of QoL assessments is to understand the factors of the person with dementia that affect QoL ratings or evaluate a specific intervention. Even when proxy respondents were used there was a lack of assessment of proxy factors associated with QoL ratings, particularly in care staff. A number of previous studies have assessed the effect of proxy factors and found that stress (Winzelberg et al., 2005; Zimmerman et al., 2005) and burden (Grske, Meyer, & Wolf-Ostermann, 2014) can affect care staff QoL ratings, and family carers own QoL can affect proxy ratings (Arons, Krabbe, Schölzel-Dorenbos, van Der Wilt, & Rikkert, 2013). Despite this however, proxy factors are often neglected.

The findings from the studies outlined above also highlight the challenges of long-term use of self-report instruments. Those that used a self-report instrument only included people with lower dementia severity or only analysed the results of those who could complete the instruments at baseline and follow-up. Studies with less strict criteria found that relatively low percentages of people were able to complete the follow-up assessment, ranging from 36.5% (QOL-AD) up to 60% (DQoL). Variability in response rates have been found in other studies using self-reported instruments (Edelman et al., 2005; Hoe, 2005; León-Salas, Logsdon, Olazarán, & Martínez-Martín, 2011; Logsdon et al., 1999, 2002; Moyle et al., 2012; Sloane et al., 2005; Spector & Orrell, 2006; Thorgrimsen et al., 2003; Zimmerman et al., 2005), as a result, it has been suggested that approaches other than self-report be used for people that are or may become unable to assess their own QoL (Crespo et al., 2013). The findings from Thornton et al., (2004) and Dichter et al., (2015), support the use of care staff to carry out such assessments.

Most studies found no changes to QoL over time; whereas small increases and decreases to QoL were found by some. This does not appear to be a fault of the instruments as different studies using the same instrument found different results. Changes to individual QoL scores demonstrate the variability of QoL for individuals over time. Even though mean QoL may show no changes or overall decreases or increases, there is a need, as Hoe et al., (2009) suggested, to look at individual scores as well. Such examination of individual scores will encourage a focus on the individual, echoing the aims of person-centred care. Also these findings may simply demonstrate that cognition and activity limitation are not major drivers of life quality in dementia (Banerjee et al., 2009).

Whilst Magennis and Chenoweth claimed to assess routine QoL measurement (Magennis & Chenoweth, 2009), limiting the measurement to two-time points is likely to fall short of the definition of 'routine'. It is suggested that the routine use of QoL instruments in care homes could be useful in identifying the benefits of clinical interventions (Hoe et al., 2009). Although many of the studies reported here attempted to assess and understand the changes to QoL, the question remains of the value of the measurement of QoL at one or two time-points.

2.8 Rationale for the research

The need for improvements in care provision has been well documented in the literature, there are also suggestions that there may be potential benefits in routine measurement of QoL in care homes. Knowing the QoL of those living in care, could allow potential improvements to be made to the care provided to residents.

Despite the recognition that measuring QoL in care homes could provide useful insights and improvements to care quality, there exists little research into the systematic routine measurement of QoL in care homes. This may be a product of the availability and usability of QoL instruments or of the challenges surrounding the implementation of such instruments into routine practice. The use of self-report instruments is problematic because not everyone can complete them and using a mix of self- and proxy-reports is more likely to cause confusion than shed light on how to intervene to improve QoL. We have proofs of concept that care staff can measure QoL by proxy rating using a variety of instruments but no evaluations of their use in routine practice.

However, no studies have examined the feasibility of measuring QoL as a part of routine care practice and none have worked with care staff to find out how to accomplish this goal. Magennis and Chenoweth asked care staff about their views of measuring resident QoL only after the fact (Magennis & Chenoweth, 2009). Research evaluating the feasibility of routine QoL measurements in care practice could have important implications for resident and staff outcomes and the quality of care provided. The research presented here attempts to make a contribution to this process.

Chapter 3: Aims and methodology

This chapter provides an overview of the aims of the study and the methodology used in the thesis. A methods section is also included in each chapter outlining the sample and setting, recruitment, and data analysis procedures of each stage. A brief discussion of the results is provided at the end of each chapter with a full discussion presented in Chapter 8.

3.1 Aims

3.1.1 Overall thesis aims

The overall aim of the research was to evaluate the feasibility of the routine measurement of QoL in care homes using DEMQOL-Proxy.

The overarching research aims are:

1. To determine the feasibility of implementing routine QoL measurements into care home practice.
2. To assess if DEMQOL-Proxy can be used by care staff without the need of an interviewer to administer it.
3. To assess the use of a QoL instrument in routine practice and whether routine QoL measurement by care staff is possible.

3.1.2 Study stage aims

The research was carried out in four stages. The aims of each stage are:

Stage 1 (research aim 1). To understand the feasibility and acceptability of using a QoL instrument as a part of routine care practice

Stage 2 (research aim 2). To assess whether DEMQOL-Proxy can be used as a self-administered QoL instrument by care home staff.

Stage 3 (research aim 2). To adapt the DEMQOL-Proxy, to generate DEMQOL-CH, a version designed to work in routine practice in care homes.

Stage 4 (research aim 3). To assess the performance of DEMQOL-CH when used routinely in care practice by care home staff

Detailed aims specific to each stage are provided in individual chapters.

3.2 Methodological considerations

3.2.1 Instrument choice

In this study the evaluation of the feasibility of routine care home QoL measurement is based on a proxy-rated disease-specific QoL instrument, the DEMQOL-Proxy. As noted above this research was carried out in the research group that had developed the DEMQOL system where the further development of the DEMQOL system is one of its goals. It was therefore chosen for this evaluation largely on a priori grounds. Other QoL instruments identified in the systematic review in *Section 2.6* could have been used instead. The review shows all to have their own limitations. We could have used a second QoL instrument alongside DEMQOL-Proxy to provide a head-to-head comparison. But it was felt that this would have imposed too great a burden on the care staff and taken the evaluation away from the inclusion of a simple instrument into routine care. Instead, for validation we chose the best available observational method (DCM), this was completed by the author in order to impose no additional burden on the care workers. In terms of the rationale for DEMQOL-Proxy, the rationale for using a dementia-specific proxy-report QoL instrument was:

Dementia specificity:

The high prevalence of dementia in care homes means that a dementia-specific instrument is likely to be appropriate for most residents.

Using a dementia-specific instrument means that those with undiagnosed dementia will not be excluded.

Proxy-reporting:

Will not exclude those unable to complete self-reports due to more severe dementia, or communication impairments.

Will allow consistent measurement over time using one instrument.

Will not over burden staff.

Easier interpretation of QoL over time using one instrument.

Owned by care staff.

DEMQOL-Proxy is a widely used measure for assessing the QoL of people with dementia, with good psychometric properties and is the product of thorough development (Bowling et al., 2015; Smith, et al., 2005). Validity and reliability of DEMQOL-Proxy evaluation has shown acceptable psychometric properties in people with mild, moderate, and severe dementia (Smith et al., 2005).

DEMQOL-Proxy has not been specifically validated in care settings and so was consequently not identified in the review carried out in Chapter 2. In terms of feasibility it was chosen because:

It is quick to administer, taking approximately 5-10 minutes via interview format to proxy respondents

It has a simple 4 point Likert scale response format

It has a specific time period to be measured, respondents are asked to report on the previous week

It has high accessibility, with an official dedicated website providing comprehensive information regarding the development and administration of the instrument

It is free to use with no formal training required

A detailed interviewer manual is available that gives instructions for administration and provides responses to possible queries

A free downloadable scoring tool is available

3.3 Sample and settings

Eight care homes in East Sussex, England took part in this study. Three care homes took part in Stages 1, 2, and 3. Five further care homes took part in Stage 4. Six of the homes were privately owned, one was local authority owned and one was voluntary/not for profit. The eight homes together had the capacity to care for 267 residents with an average of 33 beds. The smallest home had 17 beds and the largest had 50. The number of homes recruited to the study was selected to be manageable for the timeframe of the study and the resources of the researcher.

All staff were eligible for participation, regardless of what type of shift they worked (i.e. day or night shift) and whether they worked full-time or part-time. All residents were eligible to take part in the study regardless of dementia diagnosis or severity.

3.4 Measures and materials

Throughout this study a small set of qualitative and quantitative measures and materials were administered to staff and residents. These are outlined below, the stage or stages that each measure was used in is stated at the end of the measure description.

3.4.1 Staff measures and materials

Staff demographics: (Appendix D). A demographic information sheet was used to collect demographic and occupational characteristics of staff. Demographic characteristics included age, gender, ethnicity, and English language fluency. Staff were asked whether English was their first language, if it was not they were asked to rate how well they think they spoke English. Occupational characteristics included: job role, time working in the care home and the care sector, hours and days worked per week, resident contact and resident knowledge. This was completed at consent in Stage 1 and Stage 4. Staff in Stage 2, and Stage 3 were already consented into the study so they had already completed demographic information sheets.

Staff information sheets: (Stage 1 Appendix I) (Stage 4 Appendix J). Staff were provided with information sheets during recruitment at Stage 1 and Stage 4. Staff from Stage 1 also took part in Stages 2 and 3 but were already consented into the study, thus, there are two information sheets for the study. All staff were provided with an information sheet to read, the information sheet contained details about the study, what would be expected of them, and what would happen if they chose to take part.

Staff consent forms: (Stage 1 Appendix K) (Stage 4 Appendix L). During recruitment staff were provided with consent forms which detailed what staff participants were consenting to do if they took part in the study. Staff completed this if they wished to take part. Similar to the information sheets, there are two, one for staff in Stage 1, and one for staff in Stage 4.

Qualitative interview guide: (Appendix C). An interview topic guide of six questions with follow-up questions/prompts was created by the researcher and reviewed by an independent qualitative researcher. Questions covered the benefits and barriers of measuring QoL as a part of care practice, and staff confidence. Questions were chosen with regard to the time available for staff since they were interviewed during their working day when time is limited. Interviews and focus groups were audio recorded using an Olympus WS-831 digital voice recorder. Interviews were carried out in Stage 1 only.

DEMQOL-Proxy: (Smith et al., 2005): *DEMQOL-Proxy* is a 31-item interviewer-administered proxy instrument which measures the QoL of people with dementia. The questions in *DEMQOL-Proxy* are derived from five conceptual domains: *health and well-being, cognitive functioning, daily activities, social relationships, and self-concept*. *DEMQOL-Proxy* has a two-factor model structure comprising ‘emotion’ and ‘functioning’; in the questionnaire these are organised into three sections. The first section asks about ‘feelings’ (emotion), the second about ‘memory’ (functioning), and the third about the ‘everyday life’ (functioning) of the person with dementia over the previous week. The ‘feelings’ section asks whether the person has experienced particular emotions such as being cheerful, sad, and frustrated. The ‘memory’ section asks how worried the person has been about aspects of their memory, such as forgetting things that happened a long time ago, forgetting people’s names, and having difficulty making decisions. The ‘everyday life’

section asks how worried the person has been about particular aspects of their everyday life, such as keeping themselves clean, using money to pay for things, and not having enough company. Questions are answered by a proxy such as a family carer or care home staff of the person with dementia. Questions are answered on a four-point Likert-type response scale (*a lot, quite a bit, a little, and not at all*), there is an additional overall QoL question also answered on a four point Likert-type scale (*very good, good, fair, and poor*), this question is not included in the calculation of QoL. Items are scored from one to four with a score range of 31 to 124 with higher overall scores indicative of better QoL.

One change was made to DEMQOL-Proxy for this study, the original DEMQOL-Proxy asked the proxy to think about ‘your relative’, the version used in this study asked the proxy to think about ‘the resident’

An additional 5-point Likert-type question was added to the end of DEMQOL-Proxy that asked the respondent to rate how confident they felt in completing each QoL assessment (not confident at all, not very confident, neither confident nor unconfident, confident, and very confident). DEMQOL-Proxy was used in Stage 2 and Stage 3.

DEMQOL-CH: (Appendix E). DEMQOL-CH is a 31 item self-administered QoL questionnaire. This is an adapted version of DEMQOL-Proxy. It is completed by a proxy without an interviewer to administer. The proxy respondent reads the instructions and each question and marks their response on the questionnaire. Questions are answered on a four-point response scale (*a lot, quite a bit, a little, and not at all*), there is an additional overall QoL question answered on a four point Likert-type scale (*very good, good, fair, and poor*), this question is not included in calculating the QoL score. Items are scored from one to four with a score range of 31 to 124 with higher overall scores indicative of better QoL. An additional short training guide is added to the front of DEMQOL-CH that is designed to assist staff in completing the instrument correctly (see below).

There was an additional 5-point Likert-type question added to the end of DEMQOL-CH that asks the respondent to rate how confident they felt in completing each QoL assessment (not confident at all, not very confident, neither confident nor unconfident, confident, and very confident). DEMQOL-CH was used in Stage 3 and Stage 4.

DEMQOL-CH instructions for administration: (Appendix H). A short guidance note for completing DEMQOL-CH was created and given to staff with DEMQOL-CH. This was adapted from the original DEMQOL-Proxy interviewer manual instructions for administration. The instructions were created with input from and reviewed by experts in the field of dementia (Psychologist, Care home manager, Old Age Psychiatrist). Instructions were created so that it is suitable for use by professional caregivers in a care setting when rating resident QoL. The instructions include: the aim of the DEMQOL-CH, how to complete DEMQOL-CH, and advice/prompts for any possible queries that may arise. This was used in Stage 3 and Stage 4.

Staff study experience questionnaire: (Appendix F). A study specific questionnaire was used to assess staff satisfaction of using DEMQOL-Proxy and of taking part in the study. This had open ended questions about staff experiences of using DEMQOL-Proxy and the perceived effects it had on staff insight into resident QoL. The questionnaire includes nine statements that staff were asked to rate on a 5 point Likert-type scale from strongly agree to strongly disagree, statements include ‘The DEMQOL-Proxy met my expectations’ and ‘I do not feel I could accurately complete the DEMQOL-Proxy’. This questionnaire was given to care staff who used DEMQOL-Proxy at the end of Stage 3. A version for DEMQOL-CH was also created and given to staff at the end of Stage 4 who had used DEMQOL-CH (Appendix G).

3.4.2 Resident measures and materials

Resident information sheet: (Stage 1 Appendix M) (Stage 4 Appendix N). Residents were provided with information sheets at the beginning of Stage 1 and Stage 4. Residents from Stage 1 also took part in Stages 2 and 3 but were already consented into the study, thus, there are two information sheets for the study. All residents were provided with an information sheet to read, the information sheet contained details about the study, what would be expected of them, and what would happen if they chose to take part.

Resident consent forms: (Stage 1 Appendix O) (Stage 4 Appendix P). During recruitment residents were provided with consent forms which detailed what resident participants were consenting to do if they took part in the study. Residents completed this if they had capacity and wished to take part. Similar to the information sheets, there are only two, one for residents in Stage 1, and one for residents in Stage 4.

Standardised mini mental state examination (sMMSE) (Molloy et al., 1991): The sMMSE is a 20 item questionnaire which assesses specific domains of functioning in older adults. The sMMSE covers cognitive domains including orientation to time and place, short and long term memory, registration, recall, constructional ability, language, and ability to understand and follow commands. The researcher administers the questionnaire, scoring for each item that the person gets correct. The scores range from 0 to 30, although it is possible to adjust the scoring for people with other impairments not attributable to a cognitive impairment, such as physical disabilities, or for people with problems with language abilities or those who do not speak English fluently. The sMMSE has better reliability compared to the original Mini Mental State Examination (Folstein et al., 1975), with clearer guidelines for the administration, scoring, and time limits for responses which reduces scoring variation (Molloy et al., 1991). sMMSE scores range from 30 (normal cognition) to 0 (severe dementia), studies often use arbitrary cut-offs to determine severity (Pernecky et al., 2006), largely these are: <10 = severe, ≥ 10 = mild/moderate dementia (Smith et al., 2005). The sMMSE was used in Stage 4 only.

3.4.3 Researcher measures

Clinical Dementia Rating Scale (CDR) (Morris, 1997): The CDR is a 5 point scale used to characterise the severity of impairment in six domains of functional performance related to dementia. The domains assessed are memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care. The person with dementia is assessed on each domain and categorised as either 0 - none, 0.5 - questionable, 1 - mild, 2 - moderate, or 3 - severe. The domain scores are based upon interview data and researcher judgement. A short interview is carried out with an informant and the person with dementia separately to determine and assess particular information about the person with dementia such as their date of birth occupation etc. The researcher uses this and observations of the

person with dementia to make a judgement on the scoring for each category. These scores are then calculated using a sum of boxes scoring algorithm which is a weighted score based on memory. This provides a global score of dementia severity from normal to severe (0 = normal, 0.5 = questionable, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia). The CDR and MMSE have been found to have good agreement for identifying the stage of dementia (Perneckzy et al., 2006). CDR was used in Stage 4 only.

Dementia Care Mapping (DCM) (8th ed.) (Bradford dementia group, 2005): DCM is an observational tool designed for use in communal or ‘public’ areas within care settings. DCM is often used for assessment, practice development and staff training, quality assurance, and research. DCM attempts to measure the positive and negative aspects of the psycho-social environment (Brooker, Foster, Banner, Payne, & Jackson, 1998) and has been used in care practice to develop and improve person-centred care, and in research to assess QoL (Barbosa, Lord, Blighe, & Mountain, 2017; Brooker, 2005). A trained person, known as a mapper, sits in communal areas and observes between 1 and 6 people for a period of time anywhere from 2 to 6 hours. The mapper documents what happens to each person, or what each person is doing, in 5 minute intervals for the mapped period. This includes any interactions between the residents, staff, and visitors. Two sets of related data are recorded:

Behaviour Category Codes (BCCs) are a record of the behaviours shown/experienced or types of activities carried out. There are 23 possible BCCs in the 8th edition of DCM, these can be summarised into two categories; type 1 are positive behaviours such as expressive activities which have high potential for well-being, and type 2 are negative behaviours such as being socially withdrawn which have low potential for well-being.

Well-/ill-being scores (WIB) provide an indication of the participant’s ‘well-being’ or ‘ill-being’ determined by the mood and engagement displayed for each recorded BCC. These are recorded on a six point ordinal scale (-5, -3, -1, +1, +3, +5). -5 represents worst ill-being with participants showing great signs of negative mood and withdrawal, +5 represents highest well-being with participants showing very high positive mood and deep engagement. +1 represents a neutral score where no overt signs of positive or negative mood are present.

DCM is a multi-component tool. In addition to collecting information about resident well-being, DCM is also as a practice development tool. The process of DCM contains three steps, these are, observation, feedback, and action planning (van de Ven et al., 2012). Mappers collect and record information about what happens during the mapping period. This includes any personal detractors and enhancers displayed by staff towards residents; these are behaviours that either undermine or enhance the resident's personhood. Observations and analyses from mapping sessions are written in a report format and feedback is provided to care staff and management. This allows for an action plan to be created based on the findings. Action plans are created by care staff for the individual and the group. Consequently, action plans are the tools that provide staff with the opportunity to implement person-centred care in practice. In this study feedback and action planning were not carried out as DCM was used as a measure of validation only.

In this study, mapping was conducted over a continuous three hour period. Each mapping session incorporated the hour before lunch as this has been found to be representative of the rest of the day when using other observational tools (Macdonald, Craig, & Warner, 1985), and also DCM (Fossey et al., 2002). Based on previous studies that evaluated DCM with other instruments (Sloane et al., 2005) the following DCM indices were calculated: mean well-ill-being (WIB) score, percentage of positive WIB scores (+3 or +5), and the percentage of behaviours observed that were 'good' behaviours (BCC Type 1).

3.5 Procedures

Brighton and Sussex Medical School research sponsorship was granted in May 2015. National Research Ethics (reference: 15/IEC08/0042) was granted in August 2015 (Appendix A and B). Ethical approvals cover all stages of the research in this thesis.

3.5.1 Recruitment

Homes were identified through meetings with East Sussex and Brighton care home in-reach teams; these are specialist multi-disciplinary teams who work with care homes to improve QoL of people with dementia. Through contact with these teams the researcher was able to

meet with care home managers to provide information about the study and invite those that were interested to contact the researcher. Most care home managers showed an interest in taking part. Homes were also identified through word of mouth from other researchers and care home managers.

3.5.2 Consent

In each of the homes care staff were provided with information about the study, given the opportunity to ask any questions, and invited to take part. If they wished to take part they were given a consent form to read and sign.

Care home residents were assessed to determine whether or not they had the capacity to consent to the study. All residents, regardless of capacity, were provided with information about the study. Residents that were assessed as having capacity were asked if they wished to take part in the study. If they wanted to take part they were given a consent form to read and sign. Residents were also asked who they would wish to act as a personal consultee for them should the need arise. If residents were assessed as not having the capacity to consent a personal consultee was sought in the first instance, if a personal consultee was not available then a nominated consultee was approached.

A personal consultee was a person that knew the resident sufficiently; the consultee acted in the best interests of the resident and based on their knowledge of the resident, decided if they would have wanted to consent if they could. If the consultee determined that the resident would have wanted to consent, and the resident showed no sign of dissent, the consultee signed a declaration form. If there was no identifiable personal consultee, or if the personal consultee did not think they could carry out the role, a nominated consultee was allocated. A nominated consultee was selected by the researcher; a nominated consultee was a person that knew the resident sufficiently who had no interest in the outcome of the research.

3.5.3 Data collection procedure

A brief summary of the data collection procedures for each stage is outlined below. More detailed information about the data collection procedure for each stage can be found in corresponding chapters.

In Stage 1 individual qualitative interviews were carried out with care staff and focus groups were carried out with care home managers. Methodology and results are presented in Chapter 4.

In Stage 2 care staff rated resident QoL using DEMQOL-Proxy as an interviewer-administered instrument and as a self-administered instrument. Staff completed DEMQOL-Proxy (self-administered) first and then DEMQOL-Proxy (interviewer-administered) after an interval of approximately 6 hours. The methodology and results of this stage are presented in Chapter 5.

In Stage 3 the DEMQOL-CH instrument was developed. Care staff rated resident QoL using the DEMQOL-CH instrument and the DEMQOL-Proxy instrument (used as an interviewer-administered instrument). Staff were randomly allocated to complete DEMQOL-CH or DEMQOL-Proxy first, instruments were completed with an interval of approximately 6 hours between measurements. At the end of Stage 3 all staff that had taken part in Stages 1, 2 and 3 were given the DEMQOL-Proxy experience questionnaire to complete. The methodology and results of this stage are presented in Chapter 6.

In Stage 4 care staff routinely rated resident QoL using DEMQOL-CH. Resident dementia severity was assessed by the researcher using the sMMSE and CDR tools. A DCM observation was carried out in each home. At the end of Stage 4 staff were given the DEMQOL-CH experience questionnaire to complete. The methodology and results are presented in Chapter 7.

3.6 Analysis

A brief summary of the analysis techniques used is outlined below. Detailed information about the analyses used in each stage can be found in the corresponding chapters.

In Stage 1 all interviews and focus groups were analysed using thematic analysis. Data were transcribed and subject to thematic analysis following the 6 stages set out by Braun & Clarke, (2006), please see *Section 4.1.1* for more detail.

In Stage 2 acceptability and data quality of DEMQOL-Proxy (interviewer-administered and self-administered) was assessed by examining descriptive statistics and calculating floor and ceiling effects and percentage of missing data. Reliability of both versions of DEMQOL-

Proxy was assessed by internal consistency analysis. Agreement between DEMQOL-Proxy interviewer-administered and self-administered was assessed using Bland Altman plot analysis (Altman & Bland, 1983; Bland & Altman, 1996). See *Section 5.1.4.4* for more detail.

In Stage 3 the acceptability and data quality of DEMQOL-CH was assessed by examining descriptive statistics. Reliability was assessed by internal consistency analysis. Agreement between DEMQOL-CH and DEMQOL-Proxy (interviewer-administered) was assessed using Bland Altman plot analysis.

In Stage 4 the frequency of QoL measurement were described and presented graphically. The number of QoL ratings made for each resident in each home over the follow-up period of the study were presented. The mean QoL of each care home over the follow-up period were also presented. The psychometric properties of DEMQOL-CH were assessed. Reliability of DEMQOL-CH was assessed using internal consistency, test retest, and inter-rater reliability analysis. Validity was assessed by exploratory factor analysis and correlations between DEMQOL-CH and DCM scores. Known-groups differences for people with mild, moderate and severe dementia were assessed. Regression analysis was carried out to assess demographic and occupation characteristics effects on QoL ratings by care staff.

All qualitative data analysis was conducted with the aid of NVivo software (QSR International, 2012). All quantitative analyses were carried out using the Statistical Package for the Social Sciences (SPSS) version 22 (IBM Corp., 2013) and version 24 (IBM Corp., 2016).

3.7 Ethical considerations

Involvement in this research was not anticipated to cause pain or discomfort to resident or care staff participants. There are however other ethical considerations to acknowledge.

Consenting residents with dementia, both with and without capacity has potential ethical implications. The researcher ensured that sufficient time was available to talk to residents about the research and carry out mental capacity assessments. The researcher was trained in assessing mental capacity. Residents without capacity were included in the study. Those without capacity had a personal or nominated consultee in place, residents without an

identifiable consultee were not included in the study. Personal consultees were also invited to take part in the study. This may raise issues in circumstances where there is discordance between the resident and consultee. For example, a consultee may think that the resident would have wanted to take part in the research and wants to take part as a consultee, whereas the resident may show signs of dissent. The feelings and views of the resident are always considered first and foremost, thus, the resident would not be included in the study.

Another potential ethical issue is if harm or abuse was reported to or observed by the researcher during the study. Should this happen a standardised procedure was in place. This procedure required the researcher to immediately inform the clinical lead who would notify the relevant services responsible for the resident. If the resident was in imminent danger the researcher would contact the emergency services. This procedure was made clear to care home managers prior to recruitment.

The final potential ethical consideration was taking staff away from their caring duties; all staff participation occurred during their working shift. There was a risk that this could impact on resident care. To minimise this the researcher limited the time burden as much as possible on staff. Meetings between the researcher and care staff were concise and short and at a time that suited the staff and the situation of the home on the day of the visit. In addition, care staff were aware that if they needed to see to their duties during any visits with the researcher they could, the researcher would wait for them or arrange another meeting if needed.

Chapter 4 Stage 1: Care staff views of measuring QoL as a part of routine care practice

This chapter addressed aim 1 of the research (see *Section 1.2*), which is to determine the feasibility and acceptability of implementing a QoL instrument into care practice. To achieve this, we sought to use qualitative methods to explore this with care staff. This included individual qualitative interviews with care staff and focus groups with care home managers. If care staff believe there to be little value in measuring QoL or if their views about measuring QoL are otherwise negative there would be implications for their engagement in the research and the long-term implementation of QoL measurement. So it was important that care staff views were obtained to determine whether it is feasible to implement routine QoL measurement into routine practice and guide and inform the research and implementation strategies. See Figure 4.1 for detail of stage aims and relation to overall thesis aims.

The aims of this stage were:

1. To discover how staff feel about integrating a QoL instrument into their current practice.
2. To understand the fit between the instrument and care practice, and the factors influencing this.
3. To create guidance for routine QoL measurement in different care homes in this research and more widely based on interview and focus group findings.

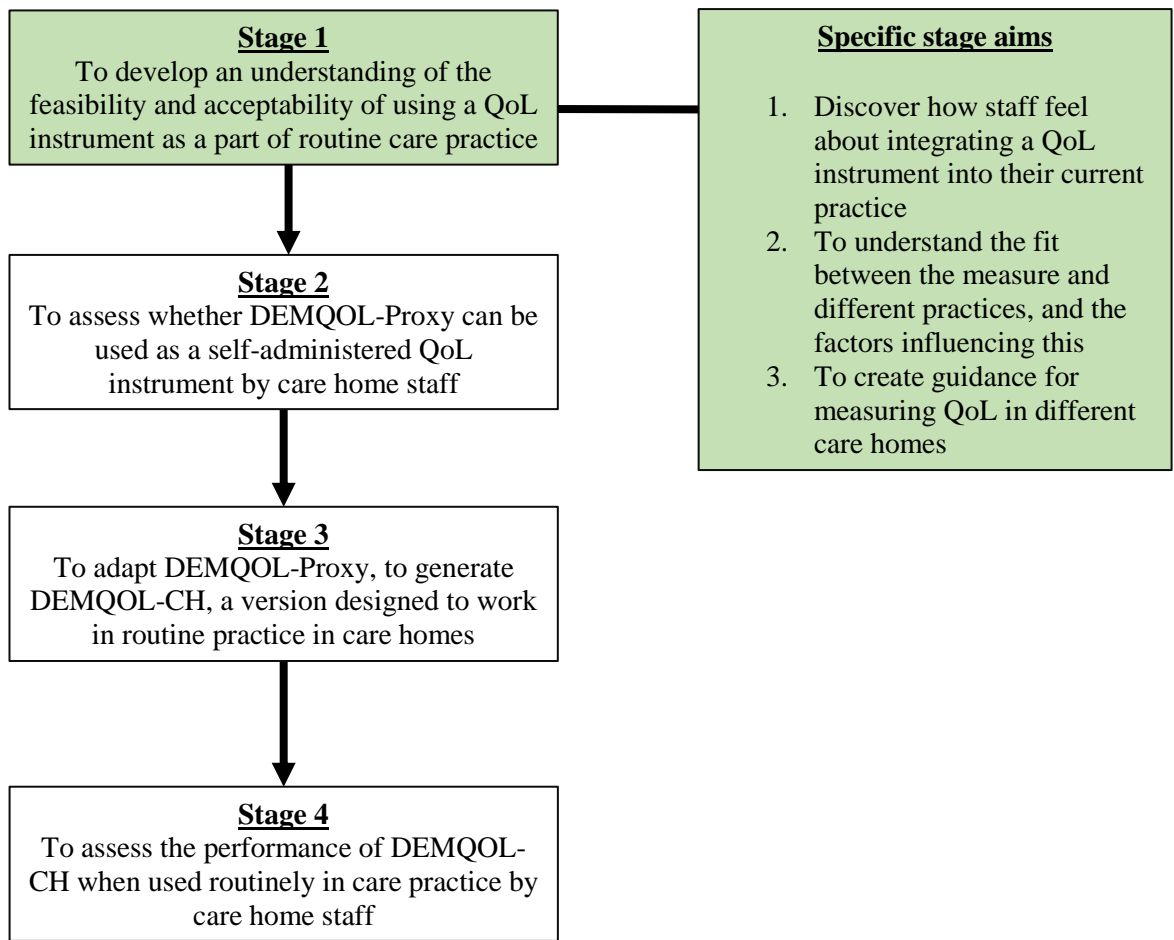


Figure 4.1. Aims of each stage of the study. Stage 1 is expanded to show the specific research aims of the stage.

4.1 Methodological considerations

4.1.1 Research design

A qualitative design was used to understand the views of care staff about using a QoL instrument as a part of routine practice. Using a qualitative approach enables an understanding of the important factors and issues as experienced by the participant (Patton, 2002).

4.1.2 Thematic analysis

Thematic analysis is a method used to analyse qualitative data, identifying and analysing patterns (themes) within data. A theme is an important meaning or response within the data that relates to the research question (Braun & Clark, 2006). Thematic analysis organises and describes the data in rich detail. For the current study this approach was chosen rather than other qualitative approaches because specific research questions were outlined prior to data collection, the research is not bound by a theoretical framework, nor is it attempting to test or create a theory. Thematic analysis was used to answer the research questions posed whilst also allowing for exploration of the data to discover other important and meaningful themes that were provided by staff. Thematic analysis follows the six phases set out by Braun and Clarke (2006), these are:

- 1) Familiarisation with the data: transcription of raw data, repeated reading of the data, searching for meaning/patterns, noting initial ideas.
- 2) Generation of initial codes in a systematic fashion. Identify aspects of the data which form the basis of themes across the dataset.
- 3) Searching for themes within the collated codes. Sorting different codes into potential themes.
- 4) Reviewing themes to ensure they fit with the coded extracts and the dataset as a whole.

- 5) Defining and naming themes to refine each theme and ensure clear definitions and names for each theme.
- 6) Report the findings giving a concise, coherent, and interesting account providing evidence of the themes.

4.1.3 Sample size rationale

In qualitative research there is no systematic method to calculate the appropriate sample size for a study. Many authors base sample size on the occurrence of data saturation where additional participants will not add anything meaningful to the data analysis. However, guidelines set out by Malterud and colleagues suggest that sample size could be based on information power; the more information a sample has that is relevant to the research means less participants are needed. The authors suggest that this can be based on five criteria: 1) the aim of the study, broad aims require larger samples; 2) sample specificity, a sample with characteristics specific to the aim of the study requires lower sample sizes compared to a non-specific sample, this is also by recruitment strategy; 3) use of established theory, a study that applies established theory for planning and analysis will need a smaller sample size than a study that does not use an established theory 4) quality of dialogue, a strong dialogue between participant and researcher will need a smaller sample size whereas a weak dialogue will need a larger sample size; and 5) analysis strategy, a cross-case analysis requires more participants compared to a case analysis (Malterud, Siersma, & Guassora, 2016).

In this study a large sample size was appropriate. Based on the five criteria above the study 1) had a broad aim, 2) a convenience sample of participants were recruited, 3) no established theory was used, 4) the dialogue was a mix of strong weak, and 5) the analysis was carried out on a cross-case basis, it was deemed that a large sample size was needed to capture enough relevant information.

4.2 Method

4.2.1 Sample and setting

Three care homes in East Sussex (England) participated in Stage 1 of the study. The care homes were homes for older adults that provide care without nursing care. Care homes that were included were chosen because the managers engaged with the researcher and were keen and enthusiastic about the home and staff taking part in QoL research. The number of care homes included in the study was selected to be manageable for the timeframe of the study and the resources available, namely researcher time. The three homes were all registered to provide care for older adults; one of the homes was registered for specialist Alzheimer's dementia care; one was registered for dementia, mental health conditions, and learning disability care; and one was registered for old age, physical disability, and sensory impairment. In total across the three homes there were 52 care staff employed, the three homes had the capacity for a total of 81 residents. All staff were eligible for participation, regardless of what type of shift they work (i.e. day or night shift) and whether they worked full-time or part-time. Bank care staff were included in the study if they worked regularly in the homes, this was self-reported by bank care assistants.

Staff characteristics are presented in the results section.

4.2.2 Materials

Qualitative interview guide: (Appendix C). An interview topic guide of six questions with follow-up questions/prompts. Questions covered the benefits and barriers of measuring QoL as a part of routine practice, and staff confidence. Questions asked are outlined in Table 4.1. These questions were chosen with regard to the time available for staff since they were interviewed during their working day when time is limited.

A topic guide was not created for focus groups with managers as the results of the interviews were the topics to be discussed. Interviews and focus groups were audio recorded using an Olympus WS-831 digital voice recorder.

Table 4.1

Individual qualitative interview questions

Q1	As a member of staff what do you think you will gain from taking part in this study and what would you like to gain?
Q2	What do you think the benefits will be for the residents by having their QoL measured regularly as a part of their care?
Q3	Where do you see this quality of life measure fitting into your care practice?
Q4	Do you feel confident in your ability to reliably rate the residents' QoL? a. If yes, can you think of anything which would affect your confidence? Either making you more or less confident? b. If no, why do you think that is so, what do you think would improve your confidence?
Q5	Do you think there are any particular characteristics of residents or types of residents that you would find it difficult to rate the QoL of?
Q6	What barriers do you think there would be in completing a QoL measure as a part of your normal care practice? a. What do you think would make it easier or what would reduce the barriers? b. Why do you think that would be?

4.2.3 Procedures

4.2.3.1 Recruitment and consent

The researcher met with two care home in-reach teams covering Brighton and Hove, and East Sussex to provide details of the study with the hope of accessing appropriate care homes to take part in the study. The researcher was invited to speak to care home managers at two different care home manager forums, where managers from care homes within the local area came together to discuss different aspects of care. The researcher presented the study and its aims to managers and invited those who were interested to contact the researcher or provide contact details. Most care home managers showed an interest in taking part, three care homes were selected. Staff from each care home were invited to take part in the study and consent to taking part in interviews and to measure resident QoL. Staff were given an information sheet to read and provided with the opportunity to ask questions. Staff completed the consent form if they wished to take part. See Appendix I and Appendix K for care staff information sheet and consent form.

4.2.3.2 Qualitative Interviews

Interviews were used to understand care home staff perceptions of using a QoL instrument as a part of routine practice, to determine where they saw it being able to fit, and what factors might affect this. Focus groups could have been carried out with care staff to allow a more detailed discussion about staff views and to explore differing staff views. However, there was an identified risk that all participants would not have an opportunity to voice their opinions equally, or that some participants would feel unable to speak honestly or openly with others present.

At the beginning of each interview, all staff were introduced to DEMQOL-Proxy (Smith et al., 2005) as an example of a well-developed QoL instrument (Bowling et al., 2015). The researcher showed a copy of DEMQOL-Proxy to each staff member and explained the instrument to them. Interviews were carried out in 2015. All interviews were carried out in the care homes where staff worked. All interviews were audio recorded and lasted for approximately 10 to 15 minutes.

4.2.3.3 Focus groups

Two focus groups were conducted with care home managers to discuss the findings from the interviews and to obtain clarification on the best method for implementing the instrument (e.g. frequency of ratings and the pairing of staff and residents) based on the opinions of staff. It was intended that one focus group would be carried out to include all managers but unforeseen circumstances meant that the manager and deputy manager from the third home could not attend. Therefore the first focus group continued as intended and a second one was conducted at a later date for the managers that were unable to attend. This presented an opportunity for an iterative process to determine if consensus was achieved between the different homes. From now, focus groups will be referred to as ‘discussion groups’ throughout the thesis as there were not enough participants to justify the use of the terminology ‘focus group’, as this usually requires at least four to six people.

Discussion groups were carried out in early 2016 by the researcher. The first discussion group was carried out at Brighton and Sussex Medical School, the second was carried out at one of the participating care homes. In the first discussion group, findings from interviews were presented to managers using a PowerPoint presentation and a discussion facilitated. This included a presentation of the themes and some quotes from the interview findings. In the second discussion group, the interview findings and the first discussion group findings were presented using a PowerPoint presentation to the managers and a discussion facilitated. This presentation included a presentation of the themes from the interviews and themes from the first manager discussion group. This process is illustrated in Figure 4.2.

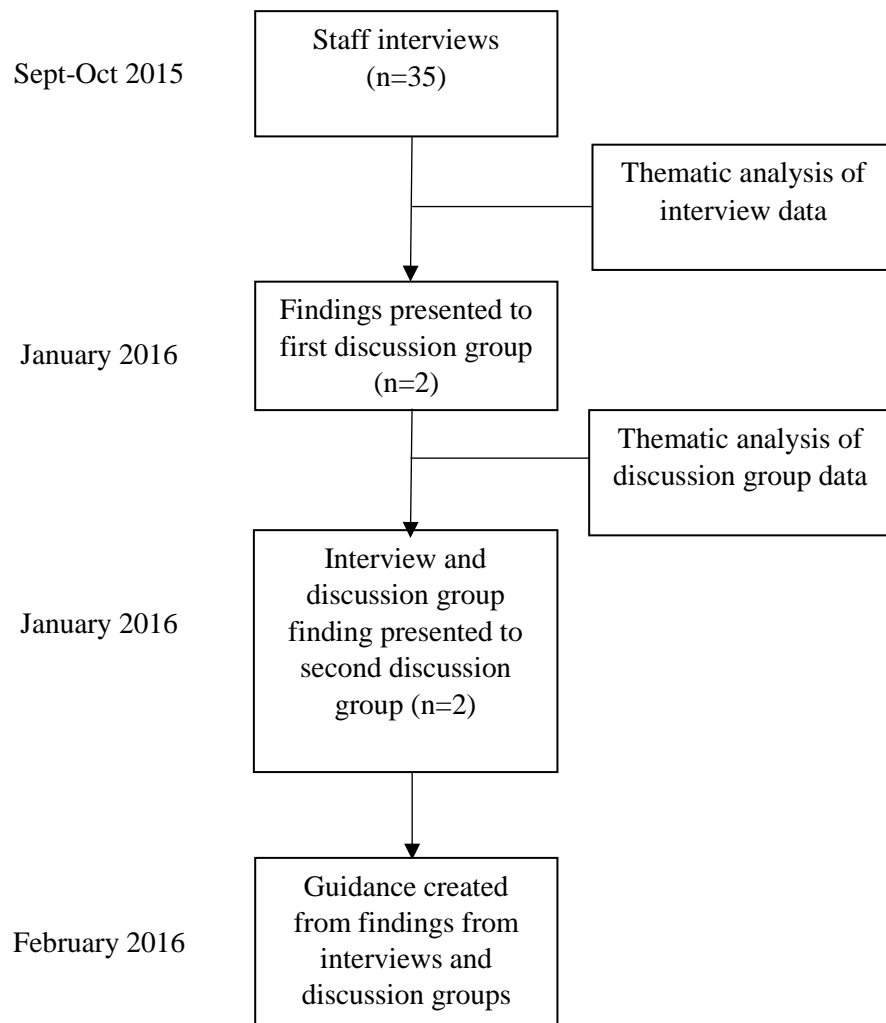


Figure 4.2. Flow diagram of the process of individual interview and discussion group data collection. The dates of each activity are indicated

4.2.4 Analysis

All interview and discussion group transcripts were analysed using thematic analysis (Braun & Clarke, 2006). The researcher (LH) met with an independent researcher (SD) during data collection and analysis. The first 3 transcripts were independently manually coded by LH and SD who then met to discuss and agree upon an initial list of codes. Remaining transcripts were analysed and coded by LH. LH and SD met frequently to discuss any additional codes that were generated and to discuss themes within the collated codes. Themes were reviewed (by both LH and SD) to ensure fit with the coded extracts and the dataset as a whole, and to develop clear definitions and names for each theme.

All data analysis was supported by the use of NVivo 10 (QSR International, 2012) for organising and reviewing themes.

4.2.5 Rigour and reflexivity in the qualitative research process

LH met ten times with SD for supervision during the data collection, and throughout and beyond data analysis. Robustness of the qualitative data were ensured through these meetings and discussions with SD. These meetings not only allowed review of the coding of themes to enhance rigour, they also supported the process of reflexivity. LH was able to reflect upon her own position as the researcher and the experiences of having worked in the care sector for many years. Expectations and previous experiences will impact upon and influence the direction of the research and the interpretation of the data. These meetings allowed LH to explore how this might impact upon the research and interpretation of the data and results. A brief summary of meetings between LH and SD is included in Appendix T. Findings from thematic analysis were not presented to participants to check or comment on. LH attempted to ensure robustness with open and honest discussion with SD surrounding her thoughts of and experience in the care sector.

4.3 Results

4.3.1 Sample characteristics

Forty-four care staff consented to take part in the study; Interviews were conducted with 35 of the consented staff. See *Figure 4.3* for diagram of participant numbers at each stage. A range of staff members were interviewed including managers, senior care assistants, care assistants, and full and part time staff. The characteristics of interviewed staff are shown in Table 4.2.

Two discussion groups were carried out with the managers of the three care homes. The first discussion group included a manager from two of the care homes. The second discussion group included the manager and deputy manager from the third care home. Characteristics of managers are shown in Table 4.3.

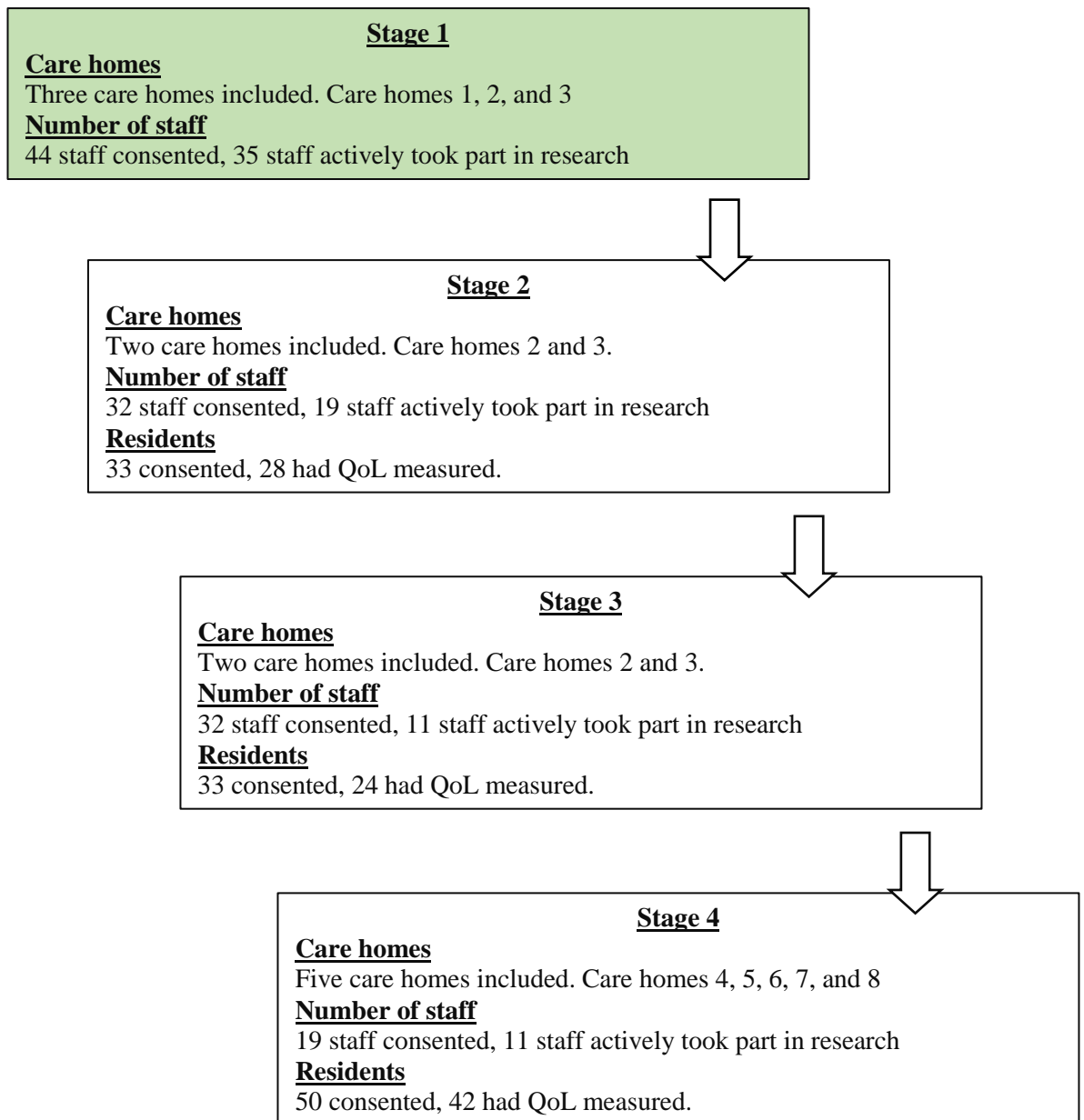


Figure 4.3. Diagram of number of care homes, staff, and residents included in each stage of the study. Current stage highlighted in green. Each stage is broken down by number of staff and residents consented and number who actively took part in the research, i.e. collected QoL data or had QoL measured

Table 4.2

Socio-demographic and occupational characteristics of interviewed care home staff in Stage 1 (n=35)

Variables	Mean (SD)(Range)	n	%
Age	40.0 (12.2) (17-58)	34	
Gender			
Female		32	91.4
Male		3	8.6
Ethnicity			
White British		24	68.6
White other		4	11.4
Other Asian background		3	8.6
Other black background		2	5.7
Black or black British African		1	2.9
Other ethnic group		1	2.9
Job Role			
Manager or deputy		5	14.3
Senior care assistant		10	28.7
Care assistant		17	48.6
Bank care assistant		3	8.6
Experience in care			
Time working in care home (months)	41.9 (42.7) (0.5 -180.0)		
Time working in care sector (years)	11.4 (10.2) (0.08 - 40.0)		
Hours and days worked per week			
Hours	34.6 (9.0) (15-50)		
Days	4.2 (1.2) (2-6)		
Keyworker			
Not applicable		14	41.2
Keyworker		13	38.2
Non-keyworker		7	20.6
Language			
English as a first language		25	71.4

Table 4.3

Socio-demographic and occupational characteristics of managers in discussion groups (n=4)

Variables	Mean (SD)(Range)	n	%
Age	43.7 (14.4)(27-52)	3	
Gender			
Female		3	75.0
Male		1	25.0
Ethnicity			
White British		4	100.0
Experience in care			
Time working in care home (months)	117.0 (54.0) (72 – 480)		
Time working in care sector (years)	23.7 (14.1) (8 - 40)		
Hours and days worked per week			
Hours	46.8 (2.4)(45-50)		
Days	5.3 (0.5)(5-6)		
Language			
English as a first language		4	100.0

4.3.2 Key themes identified from qualitative interviews

From the analysis, two overarching themes were identified:

1. Perceived gains, and
2. Implementation.

In terms of perceived gains, overall there was a great deal of positivity towards using an instrument, with a perception that it could provide positive outcomes for both staff and care home residents. This positivity and benefit also appeared to be an important feature in how the staff saw the instrument fitting into practice and of overcoming barriers and concerns to implementation.

The theme of implementation encompassed staff perceptions of how the instrument would fit into current practice and the identification of factors which could enhance or hinder its adoption. A summary of the interrelated sub-themes are shown in Table 4.4, these themes will be discussed in detail.

Table 4.4

Summary of qualitative interview themes and sub-themes

Themes	Content
<u>Perceived gains</u>	
Learning opportunity	Learning more about residents and resident feelings, knowledge and understanding of residents and their QoL, improving awareness of the concept of QoL, comparing ratings of QoL between staff
Improvements for residents	Improving QoL, QoL improvements as an outcome of staff knowledge and learning, wanting to improve QoL, being unable to improve QoL, doing more than tasks
Feedback on and enhancement of knowledge	Enhancing documentation, changing focus, enhance practice; including highlighting new points etc. to focus on
<u>Implementation</u>	
Fit into current practice	Positivity about fitting in, fitting into specific areas of practice, what will make it fit; including the ease of use and simplicity of the instrument and staff knowledge of residents, individual staff ownership
Staff confidence	Uncertainty, feelings of confidence, time working in care home, time spent with residents
Concerns and uncertainties	Uncertainties about current knowledge, anxiety about doing the right thing
Challenges	Resident communication and expression, overcoming challenges, no challenges
Barriers	Time, overcoming barriers, staff as a barrier; including staff willingness and new staff, time spent with residents

4.3.2.1 Theme one: Perceived gains

The majority of care staff interviewed highlighted the gains and benefits of measuring the QoL of residents as a part of routine practice and using a QoL instrument into their current practice. Three potential benefits were identified: a) learning opportunity for staff; b) improvements for residents; and c) feedback on and enhancement of current practice.

Sub-theme 1: Learning opportunity

The use of a QoL instrument was seen by many as a learning opportunity for care staff. Staff suggested that the instrument would improve their knowledge and they would be able to learn more about individual residents in order to have more understanding and insight into the lives of residents generally.

'I think it'll give us a better understanding of the residents' needs I think, and their QoL how we can improve it. I think that's what we'll gain from it' (senior care assistant, P7c)

Other care staff made several references to more specific learning points such as being able to understand resident QoL more.

'I'd like to gain a better understanding of the difference between a quality of care and quality of life, and how that implicates people's life in care home' (manager, P9c)

And specifically knowing whether or not the residents have a good QoL.

'It would just be interesting to see if they have got a good quality of life' (senior care assistant, P1c)

'You, know, if somebody's upset, to see overall, if their quality of life is good' (manager, P1a)

Staff also discussed the potential of using the instrument to understand the feelings of residents. There was a perception that an instrument would allow staff to have more insight and understanding of how residents feel, and as a method of understanding residents more than they are currently able to.

'You can really, really think about how they're feeling. Because you don't often as a carer get that, well not that time, but you don't often concentrate exactly on how they (residents) are feeling and how their QoL is' (senior care assistant, P1c)

'I would be able to gain the thought of the other residents, like to take a step in their shoes and know how they're feeling, understand them more and what they're going through' (care assistant, P16a)

Care staff perceived that using the instrument would help them to have increased awareness of what QoL is.

'I think it gets lost and I think sometimes staff aren't really aware of what QoL means exactly. If somebody's had the basics taken care of and they're sitting quietly, em, I think it will be very good for people that em the staff who are caring for them are maybe having to think a bit more broadly about...' (Support worker, P11a)

And that the instrument could be used as a prompt for staff to think of QoL more.

'I think it can, well, it can be used as a tool with paperwork, or, I think, when you're getting somebody up in the morning you can see yourself how they (residents) are ... and just making you aware that that tool is available at any time ... and I think it will make the staff more aware so you've got it in your mind all the time' (manager, P1a)

The final learning opportunity was the benefit of comparing QoL ratings. Staff suggested that it would be interesting to see the differences between staff perceptions and ratings of QoL.

'Em, I think it would be good to get a detailed reflection on people's (residents) feelings and on their, what their, on their experiences, what they're going through and very interesting to see what other staff think about the same people I'm getting to know' (support worker, P11a)

And also to see and understand the differences in residents' QoL as it may change over time.

'Um, be more aware of seeing changes in the residents I suppose with their moods and that, and whether we can step in and help them in any way to maybe uplift them or find out exactly what, you know if they're a bit low or something, see if we can get to the bottom of why that is' (care assistant, P2b)

When discussing the potential outcomes of using a QoL instrument some staff also discussed points which may be unrealistic or unattainable in terms of what could be expected from the QoL instrument.

'Maybe I will be given some ideas or guidelines to improve the quality of their life' (nurse, P4b)

Sub-theme 2: Improvements for residents

Many staff identified potential benefits which they believed residents would gain from having their QoL measured regularly. One area of improvement was an increase in resident QoL.

'Well it's about the quality, improving the quality of life of the residents, so that will be nice if we can achieve that' (senior care assistant, P3a)

Improvements in resident QoL were often seen in relation to how staff saw their own role as individual staff members in affecting the residents' lives. Improvements to QoL were seen as an outcome from knowing and understanding residents more, and of having more insight and awareness of residents and their QoL.

'Well of course if we measured them (resident) we would know if they're happy here or if they're sad, then we could do something about it' (senior care assistant, P19a)

'Hopefully all the staff will be aware of the measurement of their (residents) quality of life and how we can, again, improve things for that resident' (manager, P10c)

A genuine desire to improve QoL for residents and to improve care also came across in some of the descriptions.

'We so want to make her quality of life good but it is quite difficult' (Nurse, P4b)

'... so that we can have more insight into the care we can offer' (senior care assistant, P1b)

Although some staff voiced concern that they may not be able to improve the QoL of all residents. It was suggested that despite it being informative to know about QoL, it may not always be directly beneficial to residents due to the residents' general mood or diagnosis.

'There are some residents I may change, there are some residents that may just be exactly the same' (senior care assistant)

There were several descriptions of staff being able to move beyond the task oriented routines of care, to deliver more person-centred care by considering residents' feelings and the impact that the provided care has on this.

'Yes, yeah, to actually think oh actually, Mrs D when you look at this (the DEMQOL-Proxy), her quality of life is actually quite poor, she may be well looked after but actually not actually getting much out of life. And it might make them (staff) more aware of what, what we can do to improve things' (manager, P10c)

'Um, I think it will make us take more notice of the residents, not that we don't, but rather than just going in and doing their care, by asking them questions how do you think they feel about it? It would, sort of looking at it from a different angle sort of thing, if you know what I mean?' (Care assistant, P6b)

There were also some points made by staff which may be unrealistic or unattainable in terms of the potential outcomes for residents.

'I think, um, maybe they will get um, less agitated, if they get what they want, or you know, um, they might eat better and sleep better' (senior care assistant, P3a)

Sub-theme 3: Enhancing current practice and knowledge

There were a number of descriptions and discussions about the ways in which measuring QoL and introducing it into current practice could enhance the current knowledge of staff.

'It's gotta be good, if people are asking more questions and listening more, then great' (support worker, P11a)

The use of a QoL instrument was seen as enhancing the methods currently used in each home for measuring and monitoring the well-being of residents. This included changing the way staff recorded aspects of the residents' lives and what aspects they might focus upon.

'well when you kind of got it on paper it's, it's much easier to see than trying to, when you're kind of just discussing it ...it's easier to look back and you can compare notes, where you got little tick boxes it's easier to refer back to, whereas if you're just chucking ideas around its not recorded properly.' (Manager, P9a)

'But some of the questions ...they could be different questions that we (staff) could talk about' (care assistant, P3b)

The use of an instrument of QoL could also enhance current practices within each home.

'There could be things that we're missing, um, yeah, that could enhance their life couldn't it? ...maybe small things' (senior care assistant, P2a)

'The care home in reach team have already given us the PAL tool (Pool Activity Level tool is used to assess level of ability of cognitively impaired people. It allows planning of activities based on needs to help carers plan meaningful engagement), um, that I think will go hand in hand a lot of the time ...we use that to cross reference into the care plan it will also go hand in hand with their quality of life' (manager, P9c)

4.3.2.2 Theme two: Implementation

This theme related to how the QoL instrument could be implemented into everyday practice. This included the ways in which the instrument could fit in, the aspects of the instrument which make this possible to fit, concerns and uncertainties as well as barriers and challenges.

Sub-theme 1: Fit into current practice

There was substantial discussion within the interviews about how the QoL instrument could fit into current practice and the conditions required for this to happen.

Staff suggested that they could see the instrument fitting into practice. They provided very specific times and places in which they could see it fitting into their own practice based on typical duties in a shift or work pattern.

'On Wednesdays particularly I do a lot of form work, because I do the special care (providing one-to-one care for those with specific needs) for the whole morning' (care assistant, P12a)

'And I know we tend to move around a lot as well, but certain carers like (other staff member) will only work on 39 (a section of the home) , so she'd be good with them ...whereas I float around quite a lot' (care assistant, P6b)

When discussing the factors which might help the instrument fit into practice so that it would be used, staff acknowledged that if the instrument was seen as useful and beneficial then it

was more likely to be used as staff would be more likely to finding the time and ways to make it fit.

'It's having the time to get everything done ...but if it's going to be, you know, beneficial it's worth it isn't it?' (senior care assistant, P2a)

'Yeah I could fit it in if needed be, yeah if I needed it and it works, use it' (night senior care assistant, P11c)

Ease of use was identified as a factor, several staff expressed that the instrument itself appeared easy to use, and as such were positive about it fitting in; on the basis that it was not too complicated or too time consuming to use.

Participant: *'if it's not too much, I don't want to say too much effort, but if it's not too...'*

Researcher: *'Too burdensome on your (time)?'*

Participant: *'or too complicated, which we can do maybe weekly but easily, then yeah, that'd be perfect, I mean if it's, obviously if, as you've seen today we can be very busy so sometimes we don't have the time, but if it's easily done weekly we, you know, we can manage that easy, and it'll be perfect for this kind of setting'* (care assistant, P6c)

'Yeah, yeah, don't think, I think it would be fine. So long as it doesn't take too long to actually fill out and stuff I should think it should ...yeah, should be able to find the time to do it' (care assistant, P2b)

The ease of use of the instrument was also seen as important in overcoming potential barriers and helping the instrument fit into practice.

'Eh, it would only be time fitting it in, but I mean I think it's gonna be pretty str- as you say, it's not as though we're gonna be doing it on a daily basis or anything like that so, and not on every resident ... every day or anything, so I don't think there'd be a barrier really; I think everything should be okay ... and it's um, you know the fact it's just ticking, and it's not long winded, you know' (care assistant, P2b)

Many staff could see the instrument being implemented successfully because they know the residents well enough to be able to rate their QoL.

'No I think, because we're a small home we know the residents quite well, so I think, we're in a position where we are able, I mean this is like, we are like a big family, so we're able to, we're able to make, I think, quite accurate decisions, I think' (care assistant, P6c)

'I'm just trying to think if any of our residents are like that? And we know them, because we can see by their manner, the way they talk to us in the morning if they're feeling happy or not, so' (care assistant, P6b)

The perception of staff's own role in enhancing resident QoL was evident. Many spoke of the way in which they saw themselves as personally responsible for or important in the residents' QoL and making it better.

'If I can make things easier for them, life's better for them isn't it?' (night senior care assistant, P11c)

'Whatever I am able to do, I will do' (nurse, P4b)

Staff also described the impact that lower resident QoL would have on them and how they would feel.

'I think only the fact, like you said, if it comes back and their quality of life isn't as good as you thought it was, then I think it would get me down and then I would obviously try and improve that in a way' (senior care assistant, P1c)

The theme of individual staff ownership also emerged when staff discussed how the instrument could fit into practice and potential barriers. Staff saw themselves as instrumental in the QoL instrument fitting into practice.

'I think that the only issues will be in yourself, how, how you're gonna portray how they're gonna answer them questions and if you're worried you're gonna answer it wrong for them. I think the only barrier would be yourself, not thinking how they're gonna answer the questions' (senior care assistant, P1c)

'I don't think there's any barriers if it's me doing it' (senior care assistant, P5c)

Flexibility was discussed by staff as an important factor for them being able to complete the QoL instrument. There was a perception that if the way the instrument was used was flexible and staff did not feel pressurised to complete it on specific days or times then it would be more accepted.

'As long as you don't say I want it done on this day at this time, if it's flexible we can do it around us, then it shouldn't be a problem' (care assistant, P6b)

'If we said we're going to do it in the week commencing next week ... and suddenly this happens I'll say, "that's fine, don't feel under pressure we'll do it the following week" ...I think it's flexible enough to be able to do that' (manager, P7b)

Sub-theme 2: Staff confidence

Staff confidence appeared to be a factor in using the QoL instrument. Staff expressed some uncertainty in measuring QoL.

'Yeah ... I do, hope so' (senior care assistant, P2a)

'At this stage probably not, because I would probably doubt myself but I have, I think, I feel confident knowing the residents well enough to have a go. That's probably where I feel comfortable saying' (manager, P9c)

Many described feeling confident enough to measure resident QoL. On exploration, staff reported that they believe they *should* feel confident because of the amount of time that they have worked in the care home.

'Yes, yeah I feel confident; I think I've been here long enough to, yeah' (care assistant, P4c)

'I've been here long enough, I know 'em well enough, I've spent one on one time with all most of them so (senior care assistant, P11c)

When asked what could affect confidence staff talked about the amount of time they spend with residents and the effect this would have. They recognised that there are variations in the amount of time they spend with different residents, and that this could affect their confidence.

'I don't think so. Obviously like where if you talk to a resident more than the other then might have a bit more confidence and less in someone else, but apart from that, yeah it'll be fine' (care assistant, P4c)

'I think if you asked me I could confidently tell you about people who I know well' (support worker, P11a)

Sub-theme 3: Concerns/uncertainty

Concerns and uncertainties were discussed by staff. One of the main themes which emerged was uncertainty about current knowledge and practice.

'Because you, if we can pick up on any problems or if they're unhappy about anything. Hopefully we do anyway, but' (care assistant, P6b)

'If it's not measured I suppose then, you're not gonna know if they have got good quality of life. Erm, I mean I know seeing them and entertaining them, doing activities etcetera etcetera will improve their quality of life but, you still don't know deep down if they are happy in their environment etcetera' (senior care assistant, P1c)

Another point to emerge was anxiety about doing things correctly with staff concerned about measuring QoL accurately/correctly.

'So it'll be a case of observe them a bit more I think and initially keep an eye on them a bit more, and hoping I could answer the questions how they feel they would answer them. Maybe look at their care plans more in depth so you know their background more as well' (senior care assistant, P1c)

'I think that I would probably be biased, that would be my biggest concern would be bias because obviously staff would be biased to the home, so they would be try-, hopefully, if they were going to be biased any way it would be towards the home so they could make sure, you know, you would like to think they all had a good quality of life because we work for that you know, and I would hate for that to implicate them or me filling out one of these questionnaires. So that would probably be my only concern' (manager, P9c)

Sub-theme 4: Challenges

Two main challenges were identified from the interviews; communication and expression. For some staff, no barriers were identified.

Concern was expressed about rating the QoL of residents who are unable to communicate verbally, with the perception that it would be harder to rate. In particular, that it would be difficult to understand the feelings of residents.

'Some people aren't able to communicate whereas other people are better, so to measure how someone is feeling without actually them vocalising sometimes it might be hard' (care assistant, P21a)

Staff identified that they could use non-verbal means to overcome challenges associated with communication, however, they also described the difficulty of rating residents who have no non-verbal communication.

'Yes, well, especially those residents who can't, you know, express what they want any more ...so we have to judge it by non-verbal cues, you know' (senior care assistant, P19a)

'Erm, maybe like facial expressions, like some residents don't make as many, as much facial expressions as others' (care assistant, P13a)

Interestingly, some staff acknowledged that there are always ways to assess how residents are feeling.

'I guess the people who find it more difficult to communicate ...um, it might be a bit difficult ... But, they've all got their own way of communicating' (care assistant, P12a)

'But you can tell with their moods' (care assistant, P3b)

The second challenge related to the expressiveness of residents. Staff discussed the difficulty of measuring those who do not or are unable to express their emotions. This was not necessarily due to communication problems but because of certain mental health conditions as mentioned by some staff. Staff identified dementia, schizophrenia, depression, and mental health as some of the factors involved, however no single condition was mentioned as a main challenge.

'This particular lady for instance just sits and watches television and doesn't really interact very much. The first question "is she cheerful?" I would say she never shows that she's cheerful.' (Manager, P10c)

'Yeah, the mental health. The ones with mental health problems I think that mask often how they're feeling.' (Manager, P10c)

Finally, some staff did not perceive there to be any challenges to measuring resident QoL. It was unclear whether this was because they did not genuinely think there were any challenges, whether there was an element of embarrassment, or if they could not think of any at that time.

'No, I think, I think that I can do it' (care assistant, P14a)

'Mmm, no. There probably are. I mean I could say things like you know severe dementia but then that's kind of the point isn't it? No, probably not' (manager, P5b)

Sub-theme 5: Barriers

Staff were asked about any barriers they perceived there to be in measuring QoL. The most often expressed barrier was time, with staff discussing that there was never enough time to do what they need to do.

'Just time limits probably, I think, sometimes. There's not much time' (care assistant, P12a)

'Well yeah the usual restraints like time' (Care assistant, P6c)

Despite time being identified as a key barrier, staff also described the way that the barrier could be overcome. They said that the instrument seemed easy to use so therefore they could see it being used in practice despite time being limited, or similarly, thinking of a specific time to complete the instrument allowed staff to see how the barrier could be overcome.

'It would only be time fitting it in, but I mean I think it's gonna be pretty, as you say, it's not as though we're gonna be doing it on a daily basis or anything like that so, and not on every resident' (care assistant, P2b)

'Only time really ...if we've got the time to do it, we're usually pretty quiet in the afternoon so that would be a good opportunity then' (care assistant, P6b)

Other staff described and discussed there being no barriers in completing the QoL instrument as a part of practice. This was seen as a relation to seeing themselves as pivotal in making it work and in overcoming any potential barriers.

'Em no I don't think so, I used to have to do a lot, I used to work for the NHS with learning disabilities and we used to have to do everything, so no there's probably not a lot that' (care assistant, P8c)

Staff were also identified as a potential barrier to the implementation of the instrument. This included staff willingness (to use the instrument), staffing levels, new staff and differing staff ideas of what QoL is. Methods of overcoming barriers were also identified.

'Em, [pause] well if the staff can't be bothered, but then I, I don't think anybody who has signed up to it, has that attitude, they see it as a positive thing' (manager, P7b)

'No, maybe not really, only when sometimes when it gets short staffed you know ...then we won't be able to, do it' (senior care assistant, P19a)

Finally, concern about not spending enough time with residents was identified. Staff recognised that they have different levels of knowledge of residents depending on the amount of time they spend with residents or how close they are to particular people. It was recognised that to measure QoL they need to know the residents well enough and to spend time with them, especially around the time that they are required to rate the residents.

'Um, maybe, it depends on whether you've been interacting with that particular person in the last week ...I mean sometimes you will help them get up in the morning and sometimes you just don't spend so much time with them' (care assistant, P17a)

Researcher: *'Do you think it might be hard for you to rate them if you maybe don't know them that well?'*

Participant: *'Well (resident), I only see him for five minutes in the morning when he's shaving, so, it's not really a lot of time' (night senior care assistant, P11c)*

4.3.3 Key themes identified from discussion groups

From analyses of the two discussion groups two overarching themes were identified; Benefits and Implementation. The themes are closely related to themes found in the individual interviews, this was expected because managers were asked to comment on the findings from the interview analysis and discuss them further.

The theme of benefits related to the benefits that manager believed there to be in measuring QoL. The theme of implementation encompassed specific ways that the instrument could fit into practice and how it could link into or become embedded into current practice. A summary of the interrelated sub themes is presented in Table 4.5 and the themes are discussed in detail.

Table 4.5

Summary of manager discussion group themes

Themes	Content
Benefits	Proving and justifying practice: assessing effects of practice on QoL, staff improvements, staff change
Implementation	Embedding and linking into practice, frequency of measuring QoL, and practicalities of measuring QoL

4.3.3.1 Theme one: Benefits

Managers discussed some of the benefits of using the QoL instrument. Two potential benefits were identified, these were a) proving and justifying practice and b) staff improvements.

Sub-theme 1: Demonstrating and reinforcing current good practice

Using the QoL instrument was seen by managers as a means of being able to prove and reinforce practice. To prove to themselves and others that they are trying to make improvements.

It was suggested that by recording resident QoL staff would be able to show themselves that they do know how the residents feel, that they are doing everything they can, and that by using a QoL instrument it would allow them to document residents QoL correctly.

Manager 1: yeah, because we kind of do it, you kind of do it now anyway ... don't we?

Manager 2: we do

Manager 1: but it's not really written down even though

Manager 2: it's not a formal

Manager 1: we'll just do it, we'll come downstairs and say 'oh she's not very well today' or 'there's something not right with her but I'm not sure what it is' and actually, we're doing it, and you've got the proof written

'yeah so, "how do you know you're doing your best?" I'm sure that's a question you're gonna get [directed to manager 1 about CQC inspections], you say "well actually we measure it" (manager 2)

Managers also described that knowing about resident QoL would be interesting in itself, whether or not they could improve it, and that it might help to be able to understand what affects residents' QoL.

'can I just, can I just say there is a diverse line that had occurred to me, that you can improve the quality of, how do I put this, even medicines you can improve the quality of their life. Now we might be doing it at the moment, but isn't it quite nice that we could, prove that the reactions we do, our response to the need, erm or our contact

with the GP has actually improved the quality of their life, if we could measure that, I think that would be great' (manager 2)

Researcher: *'So you would be interested in looking at the effect on QoL of particular areas in care?'*

Manager 2: *'yes, yes, I think we could do that, I think we could do that'*

Manager 1: *'I think that would be very good, between health and social care ... you know like when they go to hospital and they take, stop all their medication and then their QoL goes down but they might be well for a little while [laughs] ... and vice versa'*

Sub-theme 2: Staff improvements

The second benefit discussed by managers was staff improvement. Managers agreed that the findings from interviews were positive. The positivity shown by staff, and their desire to learn more, showed that staff want to make improvements.

I think it shows they're em, looking to go out of the task orientated as well, because you know care homes were very very task orientated and trying to bring them out of that is quite difficult, so it shows that they are starting to think, there's other things they can do other than getting their care done, doing this, doing that (manager 1)

And that by using the QoL instrument it may change the way they work.

Manager 2: *well it could change carers' attitudes or their approach or something, no matter how small it is...*

Manager 1: *it's better than nothing*

Manager 2: *...it will improve, they'll recognise triggers more easily ... and what the responses are to the triggers that have caused the change in behaviour, it's not physical*

4.3.3.2 Theme two: Implementation

Managers discussed the implementation of the QoL instrument into routine care practice, this relates to specific ways of using the instrument and what may make it fit effectively into practice. There were five main points: a) linking and embedding into practice; b) frequency of measurement; c) valuing and considering staff; d) staff and resident closeness; and e) who should measure QoL.

Sub-theme 1: Linking and embedding into practice

There was extensive discussion about embedding the instrument into current practice. Managers identified that it could be used in the same way as or alongside other tools which are currently used in the homes.

Manager 3: *'it could even go in their red files couldn't it? (Directed to manager 4 about documentation files kept by senior care assistants) Because they've got a week of ADLs in there'*

Manager 4: *'yes, yes'*

Manager 3: *'so we could even tie it in with the weeks recording'*

'Like as the care plans, it all works together, you review their QoL as you review the PAL (checklist) (Pool activity level, Pool, 2017), and the care plan all at the same time, unless there's a call for it to be done more frequently than that' (manager 3)

Managers described linking QoL measurement into current practices and ways of working in the homes.

'Yeah but if you take one of the CQC fundamental standards which is em response to changing needs you could certainly link in if this works, QoL to that very nicely' (manager 2)

'Because actually, moving kind of a little bit forward, what you want is that you want to fit it in however many times a week, month or whatever. And then if somebody is doing a resident or getting them up in the morning, if they're worried about them, they would automatically do that, come downstairs and say I'm a bit worried I've just done a quick, em, survey, whatever you call it, and I'm worried about them and then it goes further. Because that's what you want isn't it?' (manager 1)

And finally, managers questioned and discussed embedding QoL measurement into practice long-term, they discussed what would happen during and after the study.

I suppose it's um, getting better at something, but where's this going after? Is there a training for staff? Will there be training for new staff? You know, so that it keeps, if you're gonna do something like this is it gonna be continued which would enhance all their learning ... QoL is really important isn't it and we're all looking for something to make their QoL better, and if this is a good study would it then go on you know, to be something that was known, I don't know, Brighton and Hove or whatever (manager 1)

And discussed embedding QoL measurement into existing training and induction procedures to enhance its use long term.

'I'm sure if it's successful and it works it could be embedded in quite a lot of the areas of training that we do anyway' (manager 2)

'It could be a part of the induction couldn't it as a basic sort of documentation procedure ... yeah, and you'll be a key worker, you'll be expected to do this, this'll be the paperwork you fill in' (manager 3)

Sub-theme 2: Frequency of ratings

Managers discussed the frequency of measuring QoL. They expressed an eagerness to measure QoL regularly, with the belief that because QoL can change often there is a need to measure it more regularly than monthly.

'I think QoL should be done quite regularly, because that can change so differently can't it? So I think you need to look at the time span between, if you're gonna do it, because monthly I mean if I did it every month I mean I could have one person that is euphoric one month and the next month they can be right down, so it would be quite difficult to quantify' (manager 1)

Manager 2: *'it can change daily cant it? I just think we could have a realistic time span, I think'*

Manager 1: *'maybe once a week or something like that is probably feasible'*

Managers also expressed that more frequent measurements would allow staff to become more comfortable in using the instrument and improve their confidence

'I just worry if, you do it at the beginning monthly, a bit like assessing somebody, they can go off the boil, so if they do it, because they're going to be slightly nervous doing it in the first place the staff, even with support, then they have to wait a month, it will be almost I think in a month like starting again ... do you see what I'm saying? ... so you know, we've got to build up some confidence in the staff, familiarity with it in order for them to then feel relaxed about it and probably give accurate results' (manager 2)

And finally, there was much discussion surrounding using the instrument at varying times. Managers expressed a desire to measure QoL frequently but understood that staff time and burden must be considered in the frequency of ratings. Some managers therefore believed that the QoL instrument could be used more frequently when needed and less frequently when not needed.

'yeah, you know when you're worried about somebody (resident) and they're losing a lot of weight you do it on a very regular basis, and then when things are going fine then you leave it monthly kind of thing. When you're worried about someone you do it every day or every week so, because you see when somebody's not happy actually, most of the time' (manager 1)

Some managers did not agree completely with measuring more frequently than monthly but did agree that responding to changing needs would be interesting.

'I would do it monthly as a standard review but there would be known triggers that cause you to review it. So there might be, like with the care plans you review it on account of a change, so a new fall, a change in moving and handling a change in mental health. And we did have Stop and Watch Tool, have you heard of that?' (manager 3)

But that long term it may be more feasible to do a monthly review.

'I think it would be, especially for research purposes, I would suggest yeah, we would do it probably every few days or once a week, just to get the processes of em assessing somebody else's QoL in, because you might do one assessment now and one next week and because of re-reading the paperwork it could be totally different next week or something. So yeah I would be up for that, I, long term future prospects I would see it being embedded into a monthly review' (manager 3)

Sub-theme 3: Valuing and considering staff

Managers described valuing staff in the implementation of the instrument. It was believed that in order for the instrument to be implemented effectively staff need to be valued for the work they do.

Manager 2: Yeah, and it's not just, just that, it's just that, you know well done, you're doing a great job and this is what

Manager 1: yeah, yeah, you mustn't forget, yeah,

Manager 2: and we're moving forward

Manager 1: to keep reminding them

Manager 2: and we're moving forward because all of you

Manager 1: have been working really hard

And making sure they do not feel disheartened by unrealistic expectations.

'I think just one thing we need to emphasise to, obviously not (manager 1) and I or the deputies, but to some of the other staff, is to not have too high an expectation, because I don't want them to feel that you know, they've failed. Make sense?' (manager 2)

One way identified by managers of being able to keep staff motivated and to keep the momentum of the study and QoL measurement going was staff participation. Managers suggested involving staff in group discussion between staff from the different homes.

Manager 1: I think that's really good, I mean we're having a staff meeting soon so maybe we could incorporate one of your visits

Manager 2: I wonder if we could have a joint meeting. Not all the people who you're going to use, between our two homes? ... There would be something very different

Manager 1: and they could kind of interact together and, yeah, I don't mind, I think it could be good

Manager 2: rather than, being, us facilitating it with a bit of bias. I think that would be very interesting

Manager 2: and it goes outside the home

Manager 1: and it shows that, it kind of makes them feel they, they are doing a good job ... because they're talking to another home that's doing the same thing

Sub-theme 4: Staff and residents closeness

In the interviews it emerged that how close staff feel to some residents might affect their ability to rate QoL. Managers discussed the effect that the closeness between staff and residents might have on the reported QoL. There was concern that this may adversely affect the results.

'But there could be a personal element involved as well couldn't there? That somebody (staff) will rate them (resident) higher because they want to be seen to be, better than they are, but not the resident, the carer ... I want them, because I know them so well I'm going to give them high scores' (manager 2)

But also that it may be favourable to rating quality of reliably.

Manager 1: *I mean that can work both ways, can't it? Because if you know somebody really well and they're kind of favourite, we don't use that word, we shouldn't, but actually you know that person and if they're down you'll know that straight away*

Manager 2: *absolutely, definitely*

Manager 1: *so in a way that could work for this study as well*

Managers also expressed that staff need to know the residents well enough to rate QoL properly.

'You know you've got new people coming into the business all the time so, you're not going to ask somebody that hasn't done it for a long time to do something like that straight away, you'll wait until they know a bit more about the residents and, so, you know, you should be able to deal with that' (manager 1)

Sub-theme 5: Who should measure QoL?

There were discussions about who would be the best person to measure resident QoL. Managers identified keyworkers (equivalent depending on the staffing structure within the home), as the people they believe would be most appropriate to measure QoL.

'I do because I can see them (deputy care assistant who act as keyworkers) doing it when they have a report to fill out each week on all their deputies, on all their residents and I can see them, because they know that resident' (manager 1)

4.4 Discussion

In this chapter, aim 1 of the overall thesis was addressed; this aim was to determine care staff's views of the feasibility of implementing routine QoL measurement into practice.

The findings showed two overarching themes of 'gains' and 'implementation'. These were both important for understanding how care staff felt about rating the QoL of the people they care for, how they felt about using a QoL instrument as a part of routine care practice, and also how the care staff perceived the instrument fitting into practice. Staff identified positive outcomes for both themselves and for residents. The outcomes for residents were seen as a consequence of increased staff knowledge; resident improvements would come about because staff would have better insight into residents' QoL, feelings and emotions. The perceived positive outcomes were central to staff overcoming any potential barriers to implementing QoL measurements. Staff identified time as the most likely barrier to them being able to implement measurements into their own practice but they believed that they could overcome this because the potential benefits were worthwhile. The findings suggest that the positivity about using a QoL instrument was due in part to the apparent ease of use of the DEMQOL-Proxy instrument and the benefits that using it might provide.

A heterogeneous sample in terms of staff job role was used in this stage of the study. Purposeful sampling is often preferred in qualitative and mixed-methods studies as it allows the inclusion of information-rich cases, thus providing the opportunity to learn about the important issues central to the research (Patton, 2002). The purpose of the study was to understand the views of staff who provide care and support to residents. Including managers, senior care assistants, and care assistants provided views from all relevant workers in the care homes. The inclusion of activity co-ordinators would have been useful as they also provide support to residents and can spend a large amount of time with residents. However, no activity co-ordinators were employed in the homes included in this stage of the study; other care staff carried out this role instead.

The inclusion of and engagement with care staff and management in the current study is not only an important aspect of working effectively with care home staff in the implementation of routine instruments within care settings, it is also key to effectively conducting research with care workers in care settings.

From the findings we are able to develop a short guidance that will be used throughout the study to assist with the implementation of the QoL instrument into routine care practice.

This guidance can be divided into three key points:

1. Instrument fit – The implementation of a QoL instrument should be able to fit within existing practices.
2. Training, environment and culture – Successful use of the QoL instrument in a care home is dependent on the staff. They need to be trained in using the instrument and have the confidence to use it. Ensuring that management supports the staff in using the instrument routinely is vital to success.
3. Rater choice – A member of staff may not feel that they are adequately able to measure a resident's QoL, irrespective of the number of contact hours. It is important to consider who the best person to measure a resident's QoL is, as it is likely to effect the accuracy and validity of the instrument.

4.4.1 Strengths and limitations

In this stage of the study the main strength was the inclusion and engagement of care staff in the research process which was achieved by using a qualitative approach. The use of interviews in this study allowed an understanding of the important aspects of fitting a QoL instrument into practice and what the perceived benefits were to the care staff and residents from the perspective of staff. By getting staff to identify the benefits themselves, rather than being told what the potential benefits could be, we may have increased their sense of autonomy. The addition of manager discussion groups after the qualitative interviews provided an opportunity to discuss the practical details of fitting in the QoL instrument effectively. Including those that are central to successful implementation will enhance the possibility of implementation. This helped identify how successful implementation of QoL instruments could be achieved in care homes.

The findings of this stage need to be considered in light of the study limitations. Question two in the individual interview topic guide was positively framed. This may have affected care staff responses by limiting the ability of staff to express negative views. Consequently, this could have affected the analysis and findings of the data; a strong theme of positive benefits for residents and staff was found, this may be a function of the positively framed

question. Different views might have been found if the question was asked in a more neutral manner. As mentioned previously (*Section 4.2.3.2*), individual interviews were chosen over focus groups for care staff to ensure that all staff were given the opportunity to voice their opinion. Focus groups could have provided more information about differing staff views on implementing QoL measurement into practice and could have provided a broader discussion between staff about practical ways to implement the instrument. Findings from thematic analysis were not presented to participants to check or comment on. LH attempted to ensure robustness with open and honest discussion with SD surrounding her thoughts of and experience in the care sector. Asking participants to comment on or check the findings can help to improve robustness and quality of the data. Time limits of the study did not make processes such as these possible.

4.4.2 Reflexivity

Throughout this stage of the study, and beyond, LH was aware of her role in completing the study as well as her previous role working in the care sector and how these impacted on the research process.

Because of LH's experience in care and experience of working with care staff she expected that care staff would show some positivity to measuring QoL but also expected a degree of apprehension and some negativity. The findings showed largely a positive response with few to no negative discussions. This expectation and finding was discussed with SD during supervisory meetings. Similarly, LH believed that some participants would perceive no benefits or gains for staff, or that staff would state that they had enough knowledge about the residents already so would not learn anything else. The findings however showed that staff believed they would have a number of benefits from measuring QoL and they would learn a lot about different aspects of the residents. LH was able to discuss these expectations and findings with SD to explore the implications on the interpretation and presentation of the research findings.

4.4.3 Conclusion

In summary, the answer to the three aims of this chapter were as follows:

- Aim 1 - Qualitative interviews and discussion groups show that care staff have positive views of measuring QoL as a part of care practice and believe there will be positive outcomes for both themselves and residents.
- Aim 2 - To effectively fit QoL measurement into care practice utilising existing practices would be beneficial and potentially lead to better implementation in the short and long-term.
- Aim 3 - A short guidance, as outlined above, was created that can guide research in implementing QoL instruments into care practice.

4.4.3.1 Implications for the next stage

Findings from this stage of the study were used to inform the next stage of the study. We found that care staff perceive that their ability to effectively rate resident QoL is likely to be affected by their subjective confidence in measuring that resident, and that this is related to the amount of time that staff spend with residents. To address these findings and to ensure an appropriate approach to implementing a QoL instrument is achieved, in the next stage of the study care staff were only asked to rate residents that they felt confident in rating. The relationship between staff confidence and the amount of time spent with residents will be assessed to gain more understanding of the relationship between staff resident contact time and staff subjective confidence in rating residents. No ethical issues arose in this stage of the study.

The findings reported in this chapter are further discussed in Chapter 8. The next chapter assesses DEMQOL-Proxy when used by care staff to determine if it can be used without the presence of an interviewer.

Chapter 5. Stage 2: DEMQOL-Proxy as a self-administered proxy quality of life instrument in care homes

This chapter addresses overall aim 2 of the thesis, assessing if DEMQOL-Proxy can be used independently by care staff as a self-completed instrument, without the need of an interviewer to administer it.

DEMQOL-Proxy was originally developed to be administered to a proxy respondent by an interviewer. A proxy respondent is someone who knows the person with dementia well enough, such as a family carer or care staff, who can think about and report on different aspects of the person with dementia's life. The interviewer asks the proxy to think of the person with dementia, and respond to each question as they think the resident would respond. The interviewer reads out the questions, asks the proxy to respond, and the interviewer notes the response on the questionnaire.

It is argued that using interviewer-administered questionnaires can enhance the accuracy of responses (Bowling, 2005). The interviewer can ensure the questions have been administered correctly and that questions are interpreted correctly by using follow-up questions. However, in routine practice in care homes, relying on an interviewer to administer the questionnaire to a proxy is not feasible. The aim of this study is to evaluate the feasibility of routine measurement of QoL in normal care practice. This would require care staff to rate resident QoL independently, without a third party interviewer. Requiring a trained interviewer to administer the instrument to care staff would potentially make this unfeasible since it would be time consuming and costly. In this thesis we therefore test if care staff are able to complete the DEMQOL-Proxy independently without an interviewer present.

As described in Chapter 4, the amount of time care staff spend with residents, and care staff's perceived confidence in rating particular residents were found to be important in enabling staff to complete the DEMQOL-Proxy. This chapter aims to further understand care staff confidence; to assess the relationship between subjective confidence in rating particular residents and the amount of time spent with those residents, and to assess how confident staff feel in using DEMQOL-Proxy both as an interviewer-administered and a self-administered instrument.

Specifically, the aims of this stage were:

1. To compare the data quality and acceptability of DEMQOL-Proxy when used as an interviewer-administered and self-administered instrument.
2. To assess how confident care staff feel in completing DEMQOL-Proxy (both self-administered and interviewer-administered), and to assess the relationship between perceived confidence in rating residents and the amount of time staff have spent with residents.
3. To assess the agreement in QoL measurements between DEMQOL-Proxy (interviewer-administered) and DEMQOL-Proxy (self-administered).
4. To understand the agreement/differences between DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered) by assessing the differences in mean scores of the two factors (emotion and functioning) between instruments.
5. To assess care staff experiences of using DEMQOL-Proxy to measure residents' QoL.

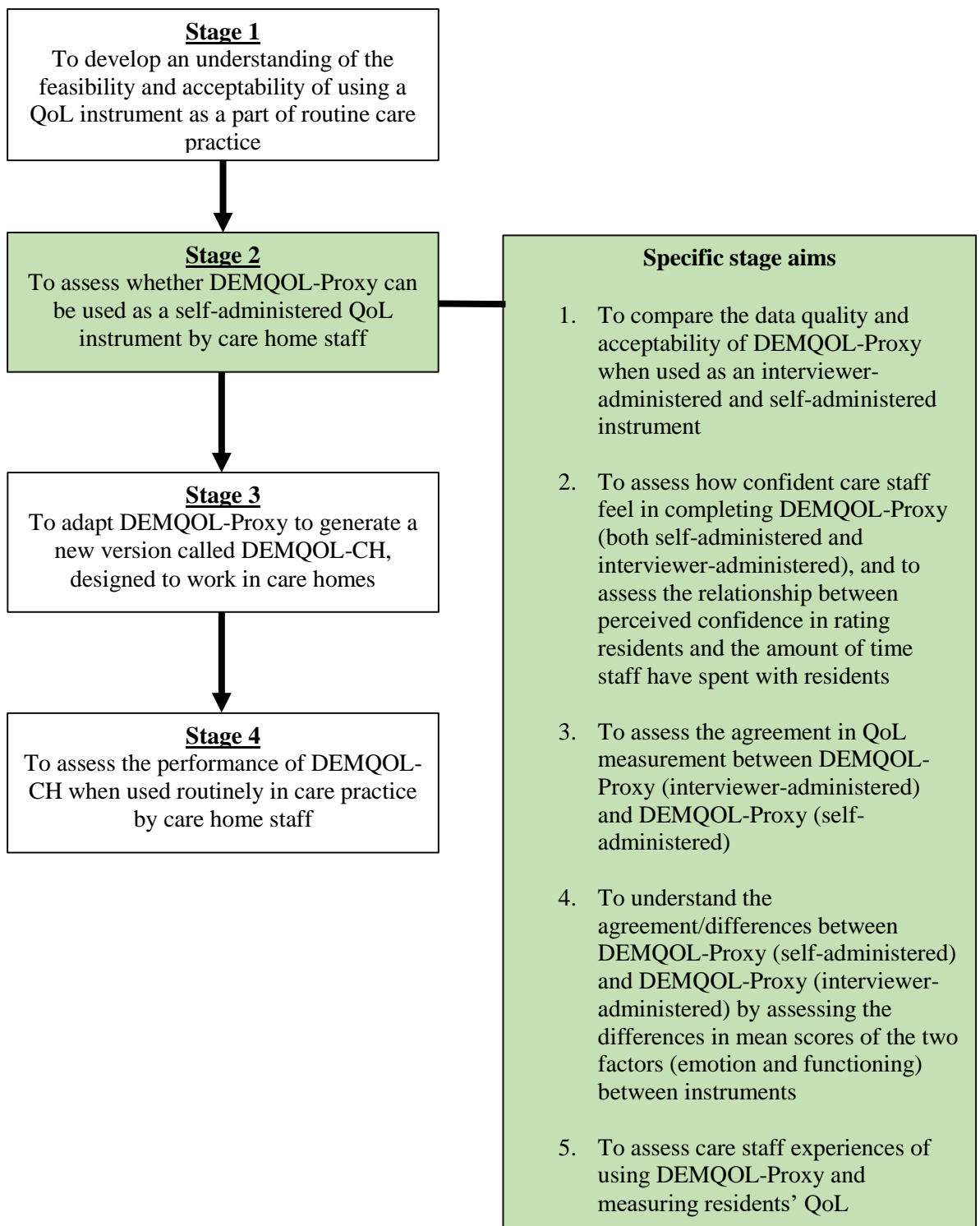


Figure 5.1. Aims of each stage of the study. Stage 2 is expanded to show the specific research aims of the stage

5.1 Method

5.1.1 Research design

A cross-sectional study design was used in this stage of the study.

5.1.2 Sample and setting

Two of the care homes from Stage 1 took part in this stage of the study (see Section 4.2.1 for full details of the homes). One of the homes stopped participation because of staffing problems. Across the 2 homes, 40 care staff were employed and had the capacity for 57 residents. All staff were eligible for participation, regardless of what type of shift they worked (i.e. day or night) and whether they worked full-time or part-time.

Staff characteristics are presented in the results section.

5.1.3 Quantitative Measures

The following measures were included in this stage: Staff demographics, DEMQOL-Proxy, and a DEMQOL-Proxy study experience questionnaire. See *Section 3.4* for full descriptions of measures.

5.1.4 Procedures

The following recruitment and data collection procedures were used.

5.1.4.1 Recruitment and consent

Staff

The same care homes and care staff from Stage 1 (*see Section 4.2.3.1*) were involved in this stage of the study and the same consents applied (see Appendix I and K for care staff information sheet and consent form).

Residents

Care home residents were asked to consent to allow the care home staff to measure their QoL. Care home residents were assessed to determine whether or not they had the capacity to consent to the study. Residents that were assessed as having capacity were given information about the study and asked if they wish to consent to the study (see *Section 3.5.1* for a full description of the capacity and consultee process used). All residents, regardless of capacity, were given an information sheet about the study (Appendix M). Those with capacity were provided with a consent form to sign if they agreed to take part (Appendix O). For residents without capacity a personal or nominated consultee was contacted. Based on their knowledge of the resident the consultee declared the resident into the study if they thought the resident would have wanted to have taken part.

5.1.4.2 Data collection procedure

Staff were asked to categorise the consented residents based on how confident they subjectively felt about measuring each resident's QoL. Staff were asked to rank the order of residents from highest to lowest for confidence in rating QoL. For example, if there were 15 residents consented into the study each care staff ranked the residents from 1 to 15, with 1 meaning most confident and 15 meaning least confident. This was used instead of a Likert-type scale of confidence to ensure that staff did not put all residents at one end of the confidence scale. It was necessary to obtain confidence ratings as many care staff previously stated that they felt confident in rating all residents but also stated that they spend more time with some residents than others and knew those residents better.

Staff measured the QoL of residents they ranked as feeling highly confident. Staff were given a small number (approximately five) of DEMQOL-Proxy's at a time to complete. Staff measured resident QoL using the self-administered method first followed by the interviewer-administered method with a time interval of approximately 6 hours between each measurement. The time interval was selected to not be too large so staff would be measuring a similar time frame but would be long enough so that they would not simply repeat their previous measurement. Another approach would have been to alternate administration where half the staff would have completed the self-administered instrument first and half the interviewer-administered instrument first. This was not carried out in order to avoid learning effects and because our primary focus was on determining if care staff would be able to use

DEMQOL-Proxy without additional assistance. The researcher met with each member of care staff prior to completing DEMQOL-Proxy to provide them with the instruments and explain how to complete the DEMQOL-Proxy. The information given to staff was based on the original DEMQOL-Proxy interviewer manual.

At the end of this element of the study staff were asked to complete the DEMQOL-Proxy study experience questionnaire. Staff completed this independently and returned it to the researcher once completed.

5.1.5 Statistical analysis

The following analyses were carried out to assess the use of DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered) by care home staff.

5.1.5.1 Acceptability and data quality

Missing data and floor and ceiling effects were assessed for DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered). Descriptive statistics for both administration conditions were compared, scores for DEMQOL-Proxy from the original development were used as a means of benchmarking. The criterion for acceptability and data quality was <5% missing data and floor and ceiling effects <10%.

5.1.5.2 Reliability (internal consistency)

Internal consistency is a measure based on the correlations between different items in a test. It measures whether groups of items that propose to measure the same general construct produce similar scores. Internal consistency can be assessed using Cronbach's alpha (α). Cronbach's α examines scores between each test item and the sum of all other items, providing a coefficient of inter-item correlations. Scores range from 0 to 1, stronger relationships suggest higher internal consistency, the higher the score, the higher the consistency. It is generally accepted that an alpha of 0.70 or greater is acceptable. Cronbach's alpha's for the self-administered and interviewer-administered versions were calculated and compared to each other, and these were compared to the original DEMQOL-Proxy findings

by Smith and colleagues (2005). A Cronbach's alpha of ≥ 0.70 was considered acceptable for internal consistency analysis.

5.1.5.3 Confidence

Staff ranked the residents in their care in order of confidence at rating their QoL, where 1 was most confident and higher numbers indicated lessening confidence. Staff also rated the amount of time spent with each resident on a scale of 1 to 10, where 1 was least time and 10 was most time spent with the resident. Scores for contact time were reverse coded to make analysis and interpretation of results clearer. The correlation between confidence and time was calculated.

Each DEMQOL-Proxy (self-administered and interviewer-administered) had an additional confidence question on a five-point Likert scale on the final page of each questionnaire. This asked staff to rate how confident they felt in completing that particular questionnaire from not at all confident to very confident. Mean and median confidence scores were calculated. A Wilcoxon matched pairs signed rank test was used to assess any differences in care staff confidence between the two administration methods.

5.1.5.4 Agreement between DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered)

To assess the agreement between the two versions of the instrument, and to determine if a self-administered DEMQOL-Proxy can be used instead of an interviewer-administered DEMQOL-Proxy, a correlation and paired t-test analysis was conducted to assess the relationship between the two administration conditions. A Bland Altman plot analysis was carried out on QoL scores to assess the agreement between the two instruments.

Bland-Altman plot analysis is a standard statistical approach to assess the agreement between two methods of clinical measurement (Altman and Bland, 1983; Bland and Altman, 1986; Mantha et al, 2000). Using this approach, for each QoL rating the new score (DEMQOL-Proxy Self-administered) is subtracted from the standard score (DEMQOL-Proxy Interviewer-administered), representing the "measurement error" observed within that set of ratings. The mean of these differences is computed, along with a standard deviation. A 95% confidence limit, mean ± 1.96 SD, is then computed, called the "limits of agreement." This represents the limits in which we can be 95% confident that the measurement error will

lie. If the limits of agreement are contained in, or narrower than what would be a clinically or statistically acceptable measurement error, it can be concluded that the new instrument can be used interchangeably with the standard instrument. A 95% confidence interval was computed for the mean difference. A threshold of 5 points was chosen as the clinically accepted measurement error for changes in QoL scores estimated as half a standard deviation (SD) of the total scale (Norman et al., 2003).

To test for proportional bias a linear regression line was fitted to the Bland Altman plot. Proportional bias means that the two measurements do not agree through the range of scores. It is argued that if the slope of the regression line is not significantly different from zero there is an absence of proportional bias. The difference between the two administrations were regressed on the average of the two scores to assess whether they agreed across the range of measurement.

5.1.5.5 Differences in factor means

To explore further the differences between scores on DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered) the differences in means for each of the two factors (emotion and functioning) were assessed for the two.

Quantitative data was analysed using SPSS version 22 (IBM Corp., 2013).

5.1.5.6 Study experience questionnaire

To understand how care staff felt about using the DEMQOL-Proxy and measuring QoL, staff completed an experience survey questionnaire. Descriptive statistics of questionnaire responses were calculated.

Responses to open ended questions are summarised. Thematic analysis was initially planned, however, due to the small number of responses only a summary was possible.

All statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS), version 22.

5.2 Results

5.2.1 Staff characteristics

Of the 40 staff in the two care homes, 32 consented to take part in the study but only 19 staff completed QoL questionnaires. See *Figure 5.2* for diagram of participant numbers at each stage. Characteristics of the 19 care staff are shown in Table 5.1 Care staff were mainly female and white British. On average, staff had worked in the care home for 31 months, and in the care sector for 8 years. On average staff worked for 33 hours a week over a 3.9 day week.

To assess differences between consented staff who did and did not complete QoL questionnaires paired t-test analyses were carried out for continuous variables (e.g. age, number of years working in the care sector), and Chi square analysis was carried out for categorical data (e.g. gender, ethnicity, job role). There was a significant difference in number of hours worked per week ($t = -2.564$, $df = 46$, $p = 0.014$); staff who completed QoL questionnaires worked more hours worked per week than staff who did not complete questionnaires. No other statistically significant differences between key demographics were found, $p > 0.05$.

Four care staff completed the study experience questionnaires. Staff characteristics are presented in Table 5.2. Staff were mainly female, White and on average worked in the care home for 65 months and in the care sector for 16 years.

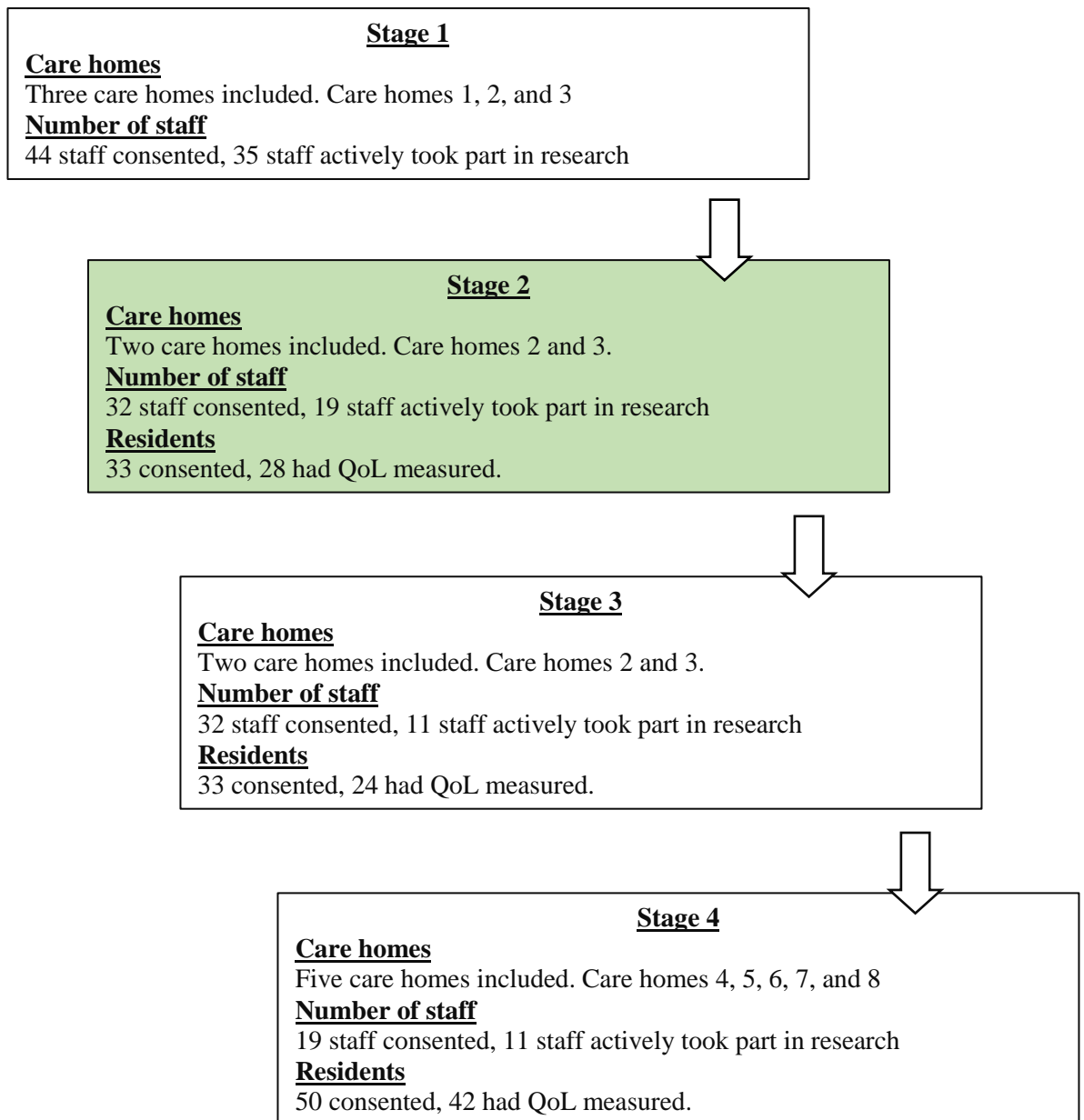


Figure 5.2. Diagram of number of care homes, staff, and residents included in each stage of the study. The current stage is highlighted in green. Each stage is broken down by number of staff and residents consented and number who actively took part in the research, i.e. either collected QoL data or had QoL measured

Table 5.1

Socio-demographic and occupational characteristics of care staff in Stage 2 (n=19)

Characteristic	Mean (SD) (Range)	n	%
Age	37.2 (13.0) (16-58)		
Gender			
Female		16	84.2
Male		3	15.8
Ethnicity			
White British		13	68.4
White other		3	15.8
Other Asian background		1	5.3
Other black background		1	5.3
Other ethnic group		1	5.3
Job role			
Manager or deputy		4	21.0
Senior care assistants		9	47.4
Care assistants		6	31.6
Experience in care			
Time working in CH (months)	38.1 (35.2) (3.0 – 144.0)		
Time working in care sector (years)	11.3 (8.9) (0.08 – 30.0)		
Hours/days worked per week			
Hours per week	37.6 (8.8) (12-47)		
Days per week	4.2 (0.9) (2-5)		
Keyworker			
Keyworker		7	36.8
Non-keyworker		1	5.3
Not applicable		11	57.9
Language			
English as a first language		15	78.9
Resident knowledge			
% of staff who answered yes to the question “do you feel they know residents well enough to rate QoL?”		19	100.0
% of residents that staff feel they know well enough	80.2 (22.2) (40.0-100.0)	12	

Table 5.2

Socio-demographic and occupational characteristics of care staff who completed the study experience questionnaire (n=4)

Characteristic	Mean (SD) (Range)	n	%
Age	36.0 (12.6) (25-52)		
Gender			
Female		3	75.0
Male		1	25.0
Ethnicity			
White British		3	75.0
White Other		1	25.0
Job role			
Manager		1	25.0
Assistant manager		1	25.0
Senior care assistant		1	25.0
Care assistant		1	25.0
Experience in care			
Time in CH (months)	65.8 (57.0) (23.0-144.0)		
Time in care sector (years)	16.0 (13.2) (1.9-30.0)		
Hours/days worked per week			
Hours per week	40.5 (7.1) (30-45)		
Days per week	5.0 (0) (5-5)		
Keyworker			
Not applicable		4	100.0
Language			
English as a first language		1	25.0
Resident knowledge			
% of staff who answered yes to the question “do you feel they know residents well enough to rate QoL?”		4	100.0
% of residents that staff feel they know well enough	93.9 (5.8) (90.0 – 100.0)	3	

5.2.2 Resident capacity and consent

There were 58 residents residing in the two care homes. The researcher assessed the capacity to consent of each resident. Seventeen (29 %) had capacity to consent, 38 (66 %) did not have capacity, and 3 (10 %) were unable to be assessed. Figure 5.3 illustrates the percentage of those with and without capacity who were consented into the study or had a consultee declaration.

Overall, 33 (57%) residents were consented into the study. Four residents died prior to QoL assessments being carried out. This left 29 residents in two homes, of these, 28 had their QoL measured by care staff.

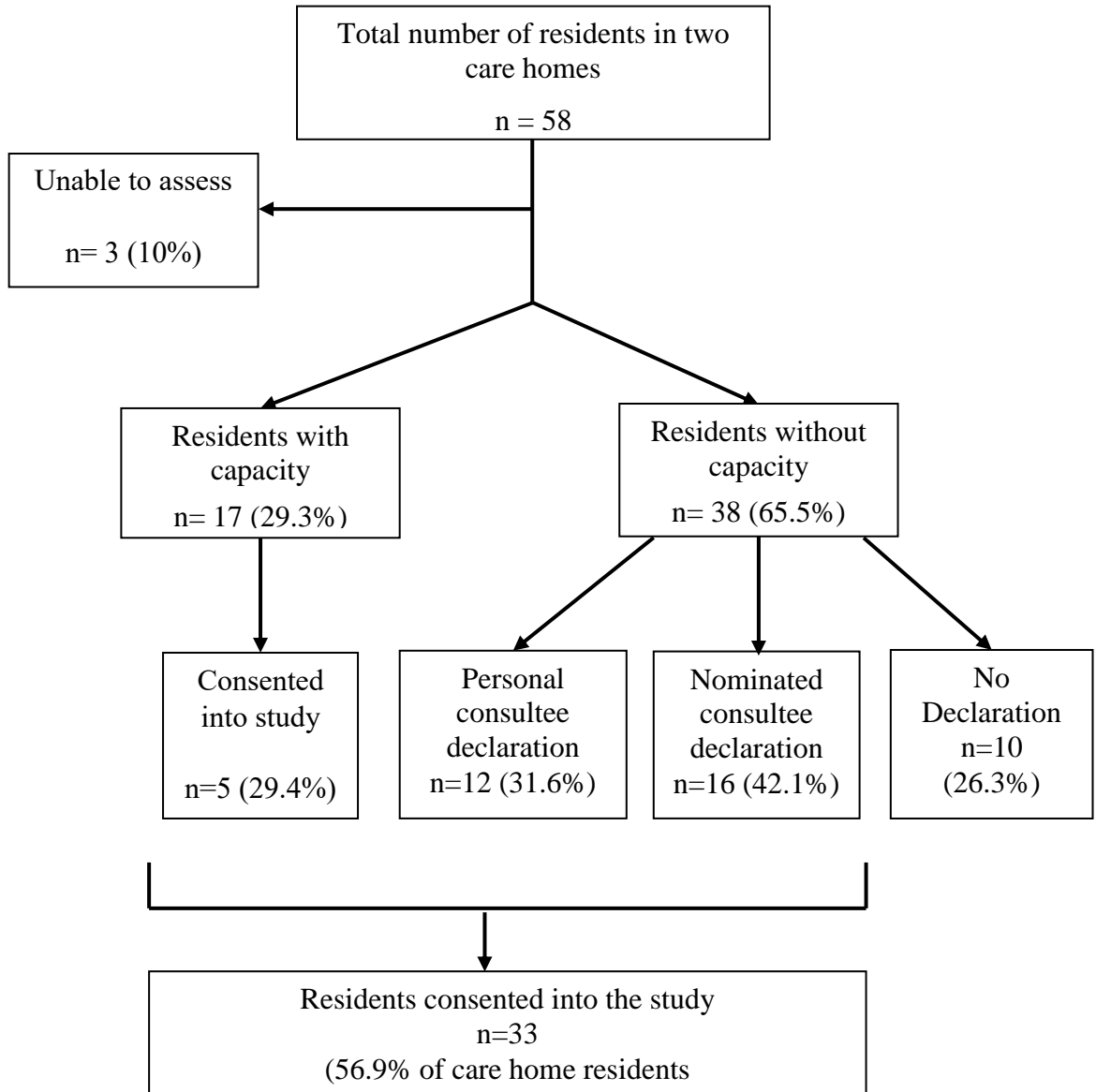


Figure 5.3. Resident capacity and consents for Stage 2. This figure illustrates the number of residents with and without capacity in the two care homes and the percentage that consented (or were declared by a consultee) to take part in the study

5.2.3 Number of QoL ratings

A total of 92 pairs of QoL ratings were made using DEMQOL-Proxy self-administered and DEMQOL-Proxy interviewer-administered conditions.

Of the 19 care staff, seventeen completed five QoL ratings, one completed four ratings, and one completed three ratings. All ratings were for individual residents (staff only rated each resident once). This is illustrated in Table 5.3

Of the 33 residents consented into the study, 28 had their QoL measured by care staff. One resident had their QoL rated by six staff, three were rated by five staff, six were rated by four staff, twelve were rated by 3 staff, five were rated by two staff, and one resident was rated by one care staff. This is illustrated in Table 5.4 All ratings were individual, this is further illustrated in a clustered bar chart, see Appendix Q.

Table 5.3

Number of unique QoL ratings made by each member of care staff

Care home number	Staff number	Number of unique resident QoL ratings
1	1	5
1	2	5
1	3	5
1	4	5
1	5	5
1	6	5
1	7	4
1	8	5
1	9	5
1	10	5
1	11	5
2	12	5
2	13	5
2	14	3
2	15	5
2	16	5
2	17	5
2	18	5
2	19	5
n = 19		Total ratings n = 92

Table 5.4

Number of times each residents had their QoL rated

Care home number	Resident number	Number of QoL ratings
1	1	4
1	2	3
1	3	2
1	4	3
1	5	2
1	6	2
1	7	3
1	8	4
1	9	4
1	10	3
1	11	3
1	12	3
1	13	2
1	14	4
1	15	3
1	16	3
1	17	5
1	18	1
2	19	3
2	20	2
2	21	4
2	22	3
2	23	5
2	24	6
2	25	3
2	26	5
2	27	3
2	28	4
	n = 28	Total ratings n = 92

5.2.4 Statistical analyses results

5.2.4.1 Acceptability and data quality

Table 5.3 shows the acceptability and descriptive statistics of the self-administered and interviewer-administered versions of DEMQOL-Proxy. These results are displayed alongside descriptive scores from the original DEMQOL-Proxy development findings by Smith and colleagues (2005). Missing scores and floor and ceiling effects were all within the acceptable range. The data was slightly skewed to the left for both instruments (-0.53 Self-administered and -0.49 Interviewer-administered).

5.2.4.2 Reliability (internal consistency)

The interviewer-administered version of DEMQOL-Proxy had high internal consistency (Cronbach's $\alpha = 0.86$, $n = 92$). The self-administered version of the instrument also had high internal consistency (Cronbach's $\alpha = 0.93$, $n = 92$) these were consistent with the originally developed interviewer-administered version of DEMQOL-Proxy (Cronbach's $\alpha = 0.89$). See Table 5.5.

Table 5.5

Descriptive statistics, acceptability, and data quality of interviewer-administered, self-administered and original version of DEMQOL-Proxy

Scale	Reliability ^a (95% CI)	% missing	Score range		Mean (SD)	Floor/ceiling effect		Skew
			Scale	Sample		% Floor	% Ceiling	
Interviewer-administered ^b	0.85 (0.81-0.89)	0	31-124	75-118	100.85 (10.12)	0	0	-0.54
Self-administered ^c	0.91 (0.90-0.95)	0	31-124	65-116	95.99 (15.31)	0	0	-0.49
DEMQOL-Proxy original ^d	0.89	1	31-124	55.8-118.83	92.14 (13.65)	0	0	-0.48

^a Internal consistency Cronbach's alpha

^b All n = 92

^c All n = 92

^d n = 99 except Reliability n = 98, Data from Smith et al., (2005). Confidence intervals unavailable for original data

5.2.4.3 Confidence

Because the distribution of scores were skewed. Spearman rather than Pearson's correlations were calculated. There was a significant weak positive correlation between staff confidence in rating the residents' QoL and contact time; as time spent with residents increased, so did confidence ratings. ($r_s = 0.29$, $n = 276$, $p < 0.001$, one-tailed).

The mean rating for staff confidence in completing each individual DEMQOL-Proxy instrument was 3.94 ($SD = 0.71$, range 2-5) for interviewer-administered and 3.82 ($SD = 0.92$, range 2-5) for self-administered. The median confidence score was 4 ('confident') for both interviewer-administered and self-administered instruments (scale range 1-5). A non-parametric Wilcoxon matched pairs signed rank test showed there were no significant differences between the confidence means of the two instruments ($z = -1.35$, $p = 0.18$).

5.2.4.4 Agreement between DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered)

Because the scores were not normally distributed, a Spearman's correlation was used instead of a Pearson's correlation. For QoL score means there was a significant correlation between the DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered) instruments ($r_s = 0.65$, $n = 92$, $p < 0.001$, one-tailed). Figure 5.4 shows this relationship.

However, paired samples t-test showed a significant difference between the means ($t = 3.82$, $df = 91$, $p < 0.001$), indicating a bias between the two different administration conditions.

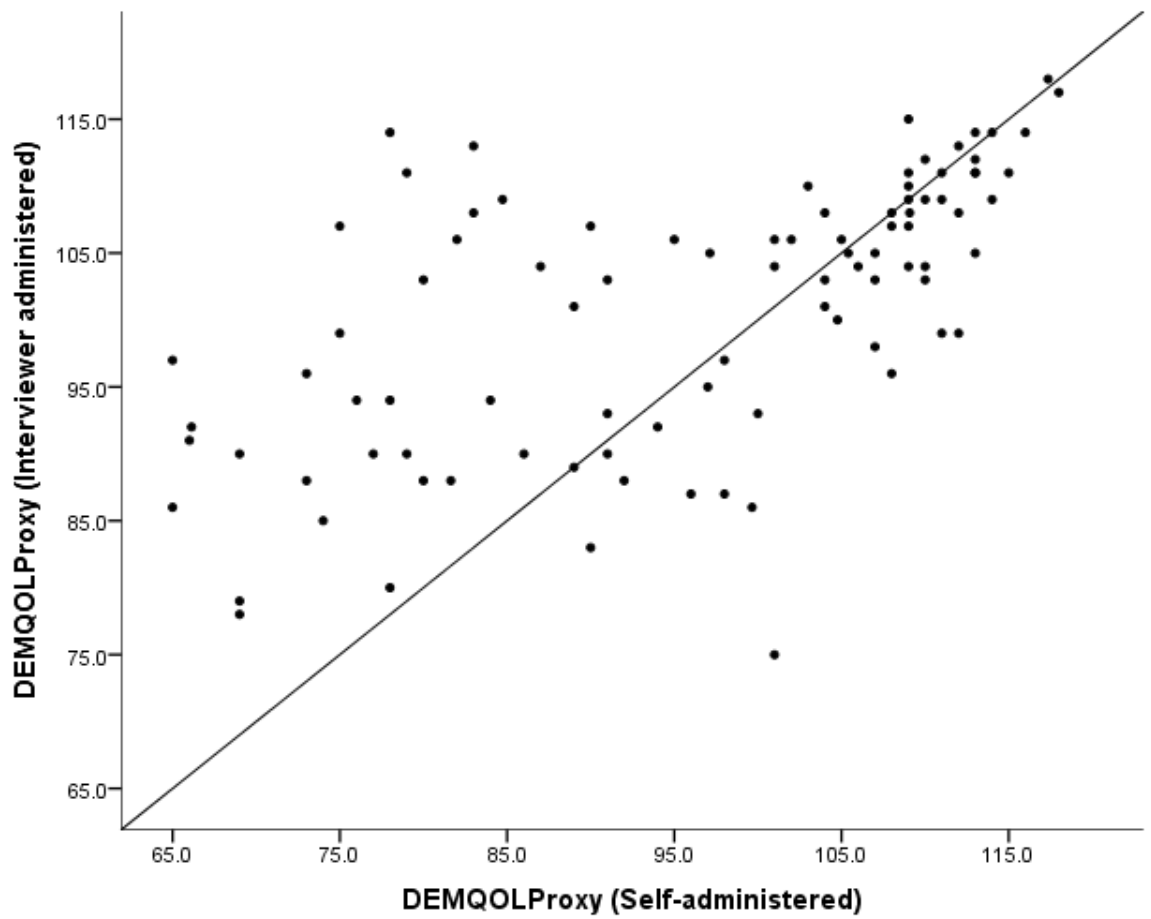


Figure 5.4. Scatterplot of the correlation between DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered) scores

Bland Altman plot analysis (Figure 5.5) showed that the mean difference between the QoL scores was 4.86 (SD=12.21, 95% CI: 2.33 to 7.39). Mean difference is shown by the red dashed line, lower and upper confidence intervals are indicated by green dotted lines.

The limits of agreement were calculated as the mean difference \pm 1.96SD. The upper and lower limits of agreement were 28.79 (95% CI: 24.53 to 33.05) and -19.07 (95% CI: -14.81 to -23.33) respectively, upper and lower limits of agreement are represented by the blue dashed lines, 95% confidence intervals represented by green dotted lines.

There was evidence of proportional bias, the scatters of differences were not uniform. The slope of the regression line on the Bland-Altman plot differed significantly from zero (t (90) = -5.08, p<0.001), this is shown in Figure 5.6.

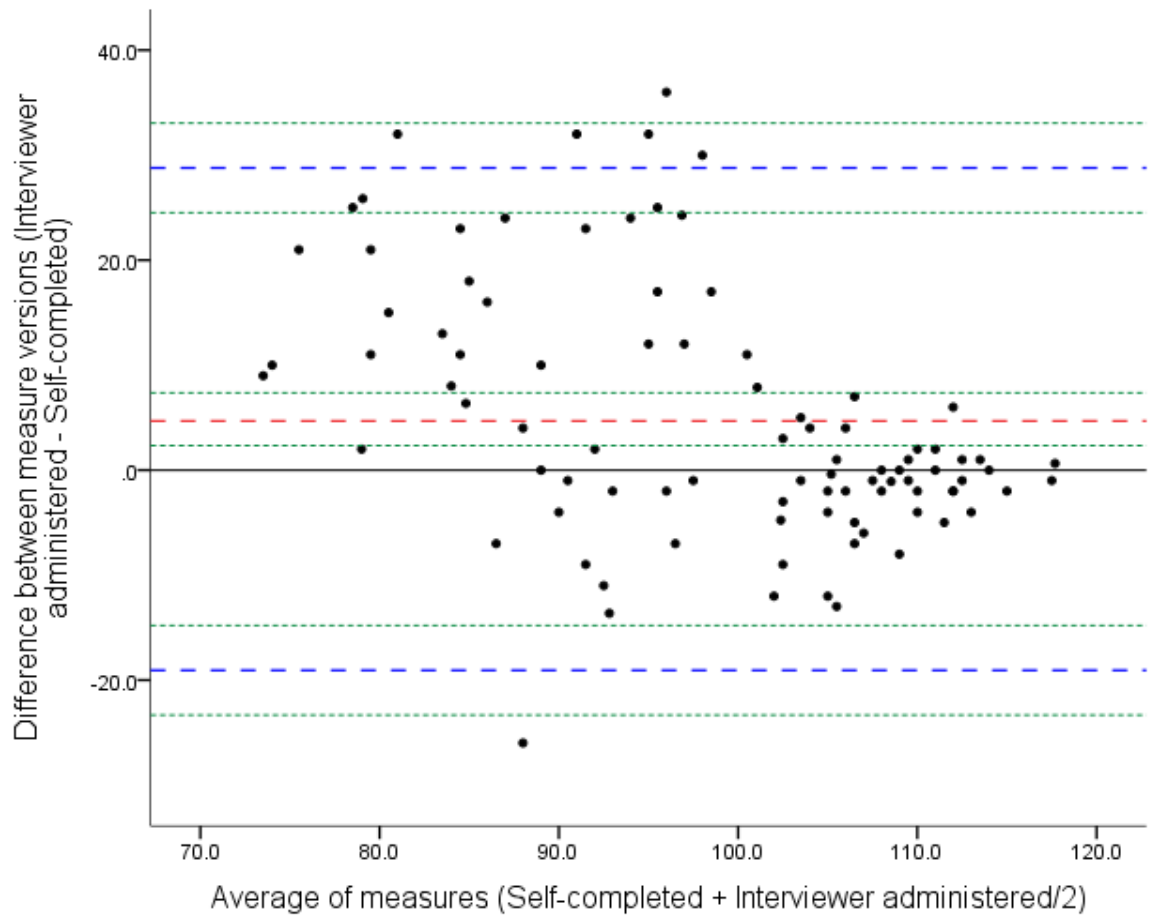


Figure 5.5. Bland Altman plot of agreement between DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered). A difference of zero would indicate perfect agreement as indicated by the black line. The mean difference between the two instruments is indicated with a red dashed line, the upper and lower 95% limits of agreement are indicated with the blue dashed lines, with 95% confidence intervals indicated by green dotted lines

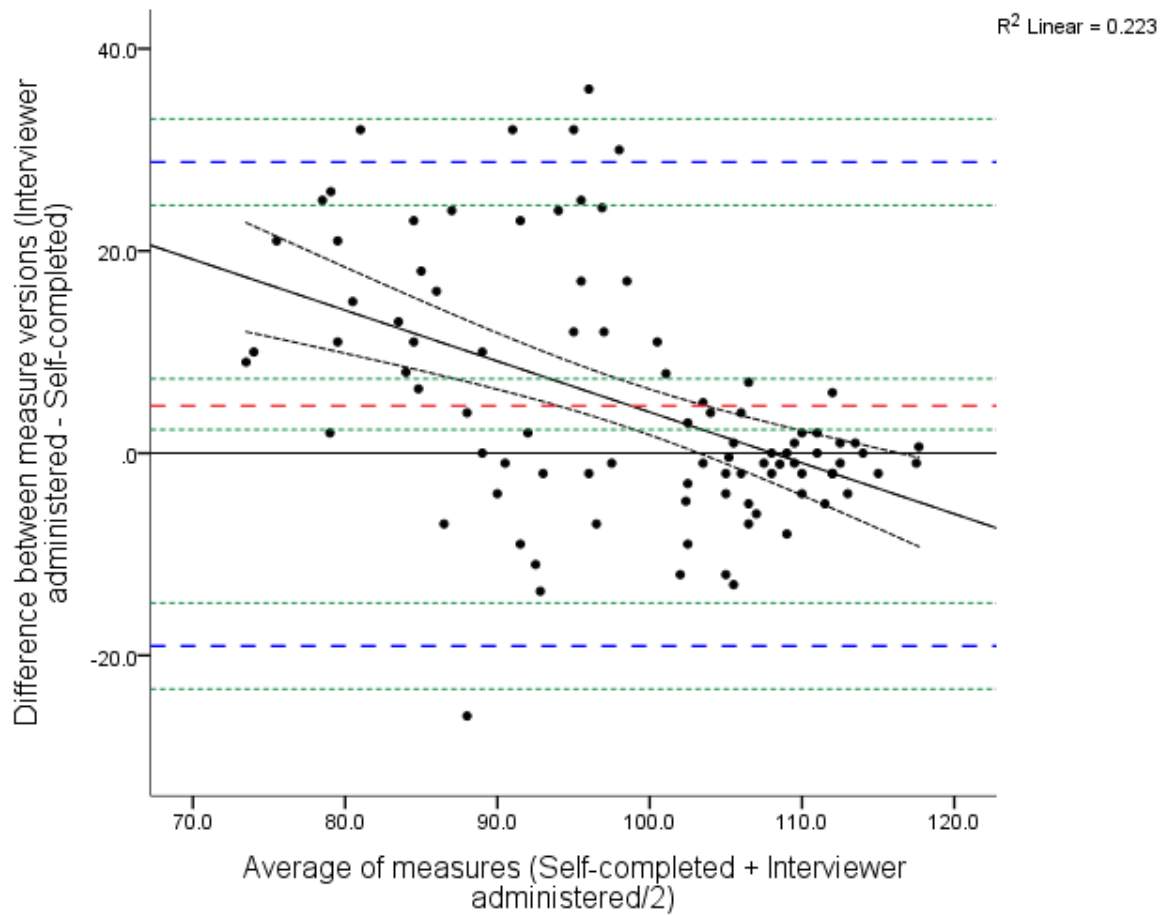


Figure 5.6. Bland-Altman plot showing evidence of proportional bias. This is the same plot as Figure 5.4 including the regression line. The solid black line represent the regression line, with 95% confidence interval limits represented by the black dotted lines

5.2.4.5 Differences in factor means

The means of the two factors were calculated for each administration condition. The ‘emotion’ factor had mean scores of 30.08 (SD = 4.98) for DEMQOL-Proxy (interviewer-administered) and 29.93 (SD = 4.72) for DEMQOL-Proxy (self-administered). The ‘functioning’ factor had mean scores of 63.73 (SD = 7.74) for DEMQOL-Proxy (interviewer-administered) and 59.31 (SD = 11.08) for DEMQOL-Proxy (self-administered).

Because the assumption of normality was violated non-parametric analyses were used. A Wilcoxon matched pairs signed rank test was conducted to determine whether there was a difference in the QoL scores for DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered) for known factors (emotion and functioning).

Results of the analysis show that there was no significant difference between the ‘emotion’ factor ($z = -0.139$, $p = 0.889$) for the two instruments. A significant difference was however found between the two instruments for the ‘functioning’ factor, with a greater number of lower QoL scores for the self-administered instrument than the interviewer-administered instrument. This is shown in Table 5.6

Table 5.6

Wilcoxon matched pairs signed rank test of differences between DEMQOL-Proxy (self-administered) and DEMQOL-Proxy (interviewer-administered) for the 'emotion' and 'functioning' factor

Self-administered – interviewer-administered	Ranks	n^a	Mean rank	Z score	Significance (2 tailed)
Factor 1 Emotion	Negative	38	43.99	-0.139	0.889
	Positive	44	39.35		
	Ties	10			
Factor 2 Functioning	Negative	53	46.96	-4.173	0.000
	Positive	27	27.81		
	Ties	12			

- a. First line: Self-administered < interviewer-administered.
 Second line: Self-administered > interviewer-administered.
 Third line: Self-administered = interviewer-administered.

5.2.4.6 Study experience questionnaire

Questionnaire statements

Descriptive statistics of the two dichotomous questions show that all respondents believed that using a QoL instrument increased their insight into resident QoL. Three of the four participants would recommend the instrument for measuring QoL for residents, with one remaining undecided.

Descriptive statistics of the nine questionnaire statements are shown in Table 5.7. For the statements there was an overall positive response to using the DEMQOL-Proxy with most respondents agreeing that they enjoyed using the instrument and did not believe that it was too complicated to use. One respondent reported that they did not feel that they could accurately complete the instrument and one respondent reported that there were too many questions to complete.

Open-ended questions

Q1) In your opinion, what was the best aspect of the DEMQOL-Proxy instrument?

Staff believed that one of the positive aspects of using DEMQOL-Proxy was that it helped increase their understanding of residents by giving them time to reflect upon residents' QoL. Staff also felt that the ease of completing of the instrument was an important positive aspect.

Q2) What improvements do you think could be made to DEMQOL-Proxy?

The only recommended improvement was to do with the similarity of questions. One care staff perceived some of the questions to be very similar or repetitive.

Q3) Do you think the DEMQL-Proxy instrument has increased your insight into the QoL of the residents?

It was believed that using the DEMQOL-Proxy instrument raised awareness of what QoL is and prompted staff to consider other aspects of residents' lives that are important. Staff also discussed that using the DEMQOL-Proxy instrument made them realise that they need to spend more time with residents and that completing the instrument gave them time to reflect on QoL.

Q4) Would you recommend DEMQOL-Proxy as a measure of QoL for residents?

Staff were positive about recommending DEMQOL-Proxy as a QoL instrument with one commenting that a particularly positive aspect is that it will encourage staff to reconsider their approach and focus in individual QoL.

Table 5.7

Responses to questionnaire statements by care home staff on study experiences

Statement	Responses	Whole sample (n=4)
DEMQOL-Proxy met my expectations	Agree	2
	Neither agree nor disagree	2
Overall I enjoyed completing DEMQOL-Proxy	Strongly agree	2
	Agree	2
Regularly assessing QoL is important	Strongly agree	2
	Agree	2
There were too many QoL questions to complete	Agree	1
	Disagree	3
I would have preferred to complete the DEMQOL-Proxy less frequently	Neither agree nor disagree	3
	Disagree	1
The DEMQOL-Proxy was too complicated to use	Disagree	3
	Strongly disagree	1
Completing DEMQOL-Proxy helped me to do my job more effectively	Agree	1
	Neither agree nor disagree	2
It changed the way I think about the QoL of the residents	Strongly agree	1
	Agree	1
	Neither agree nor disagree	2
I did not feel I could accurately complete the DEMQOL-Proxy	Neither agree nor disagree	1
	Disagree	3

5.3 Discussion

In this chapter we addressed aim 2 of the overall thesis; we assessed whether DEMQOL-Proxy could be used as a non-interviewer-administered instrument by care home staff. Following the assessment of acceptability and reliability of the data, correlation analysis, and agreement plot analysis, the data suggest that, despite acceptable data quality and correlation analyses, there is poor agreement between DEMQOL-Proxy (interviewer-administered) and DEMQOL-Proxy (self-administered).

Findings from agreement analysis and from observations suggest that staff were misinterpreting some of the questions of the instrument. One reason for this could be the way that the questions of DEMQOL-Proxy are structured. DEMQOL-Proxy questions are structured with a time frame, stem, and item; the time frame and stem are written in a sentence preceding the items and responses for each section. The functioning factor questions, separated over 2 sections, ask the respondent 'how worried' the person with dementia has been. This is located at the top of each section above the individual items and response options. It appeared that care staff may neglect to read this first part of the stem for each question in the self-administered instrument resulting in misinterpretation of the question, and leading to the poor agreement observed. If care staff misread the stem and item there is a possibility that they recorded their response based on the resident's **functional ability rather than their QoL** as they would have not read the section that asked 'how worried' the resident had been.

Findings from the experience questionnaires are very difficult to interpret due to the very small number of interviews, however those that responded were positive about measuring QoL as a part of care practice and about using the QoL instrument itself. Although some staff thought a few of the questions appeared similar they felt that overall the instruments were easy to use and would recommend them for routine use as a part of care.

5.3.1 Strengths and limitations

One of the strengths of this stage of the study was the assessment of staff confidence. Findings from Stage 1 (Chapter 4) showed that staff believed the amount of time they spent with residents would affect how confidently they could rate residents QoL. The relationship

between contact time and subjective feelings of confidence was assessed and a weak but significant relationship was found. One of the potential limitations of this stage of the study is order bias. All staff completed the self-administered version of the instruments first and the interviewer-administered version second. If administration had been alternated better agreement might have been observed since those who had completed the interviewer-administered version first might have carried over more understanding about how the questions should be answered. As noted above, we chose not to do this to avoid such learning effects to determine if care staff were able to take an already established instrument and use it without additional or assistance beyond the standardised manual available for DEMQOL-Proxy. The findings highlight the need for clear instruction and guidance for care staff to complete self-report QoL instruments. Another potential limitation is that a heterogeneous sample, in terms of staff job role, was used in this stage of the study. A sample of managers, senior care assistants, and care assistants were recruited into the study. A more homogeneous sample might have allowed more simple generalisability of the findings to that specific group. In the study reported above the different staff may spend differing amount of times with and have different relationships with residents, potentially increasing variance in findings. However, the staff included in the study are representative of the social care sector workforce overall (Skills for Care, 2017) in terms of age, gender, and proportion of job roles. In addition, it is unknown which type of staff member, if any, is more able to or effective at measuring QoL as a part of care practice. This study aimed to provide broad preliminary data and provide insights into the feasibility of routine QoL measurement. More explicit assessment of different care staff ability to rate QoL is needed in future studies. Finally, as noted above the small sample size and the highly selected population of care homes and staff will limit generalisability of the findings. However, the overall aim of the work of the thesis in general was to conduct a broad study demonstrating ‘proof of concept’ and providing information for the design and conduct of further definitive and more directly generalisable research.

5.3.2 Conclusion

In summary, the answer to the five aims of this chapter were as follows:

- Aim 1 - the data quality and acceptability of DEMQOL-Proxy when used as a self-administered and interviewer-administered versions were comparable between themselves and with the development sample.
- Aim 2 - care staff were confident in using DEMQOL-Proxy in both an interviewer and a self-administered format, there was a weak but positive relationship between subjective confidence in rating residents' QoL and the amount of time that staff spent with residents.
- Aim 3 - agreement between DEMQOL-Proxy (interviewer-administered) and DEMQOL-Proxy (self-administered) versions was found to be poor, scores on the interviewer-administered instrument were significantly higher than scores on the self-administered instrument.
- Aim 4 - differences were found between the two instruments for the functioning factor with significantly higher scores for the interviewer-administered instrument.
- Aim 5 - care staff felt positively about using DEMQOL-Proxy and believed it could be a useful instrument in practice.

Overall, results from this stage show that there are important limitations in using the DEMQOL-Proxy, in its current form as a self-administered instrument by care staff. Examining why some questions were answered differently when using DEMQOL-Proxy as an interview-administered compared to self-administered questionnaire suggested that care staff do not read the questions in accordance with original guidelines. This suggests that in order to enable the instrument to be used as a self-administered instrument by care staff in care homes then there is a need to modify the framing of the questions to enable them to be considered as required. No ethical issues arose in this stage of the study.

5.3.2.1 Implications for the next stage

The next chapter outlines the process of altering the structure of questions in DEMQOL-Proxy, and assesses the impact this has on agreement between the two instruments.

Chapter 6 Stage 3: Development and assessment of DEMQOL-CH

This chapter addresses aim 2 of the thesis which is to assess if an existing QoL instrument can be used independently by care staff. The aim of this chapter is to explore further the differences in QoL scores between DEMQOL-Proxy when used as an interviewer-administered instrument compared with being self-administered (see Stage 2 in Chapter 5) and to examine if simple changes to the questionnaire result in an instrument that can be used independently by staff.

In Chapter 5 lower scores were observed when staff completed the DEMQOL-Proxy (self-administered) compared to completing the DEMQOL-Proxy (interviewer-administered). One possible explanation for this is that staff may have misinterpreted the questions and answered some of the DEMQOL-Proxy (self-administered) questions based on the functional abilities of residents rather than the QoL experienced by residents, leading to lower scores. It appeared that the sections of DEMQOL-Proxy that contained questions from the functional factor were particularly affected, this may have been due to the structure of the questions influencing the way staff answered the questions. To overcome this, DEMQOL-Proxy was adapted to form a new version, DEMQOL-CH. Agreement between DEMQOL-CH (self-administered) and DEMQOL-Proxy (interviewer-administered) was then assessed.

The specific aims of this stage were:

1. To create DEMQOL-CH by adapting the DEMQOL-Proxy instrument.
2. To assess the agreement between DEMQOL-CH and DEMQOL-Proxy to determine if a self-administered instrument (DEMQOL-CH) can be used instead of an interviewer-administered instrument (DEMQOL-Proxy) in care homes with acceptable psychometric performance.

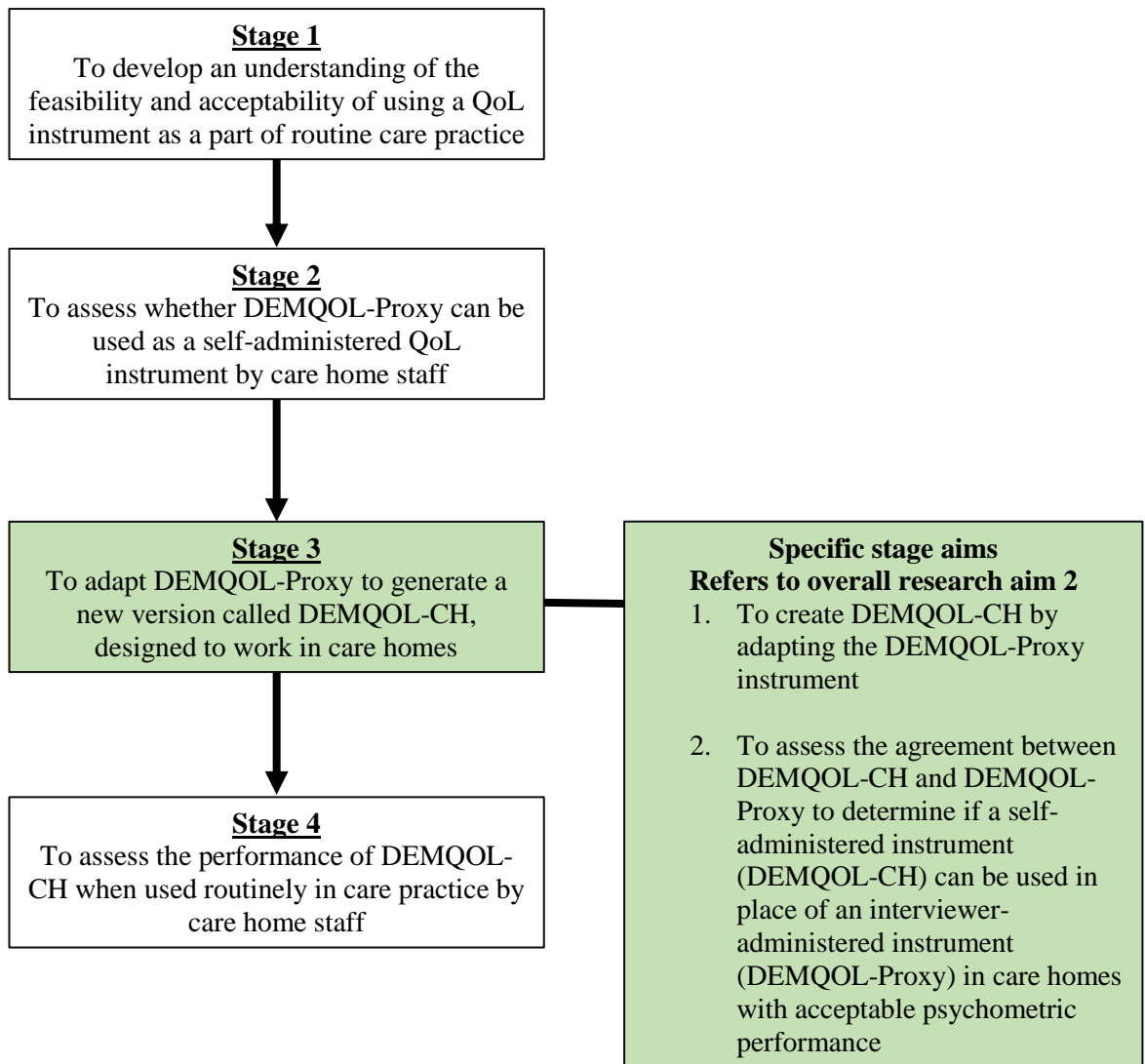


Figure 6.1. Aims of each stage of the study. Stage 3 is expanded to show the specific research aims of the stage

6.1 Deriving DEMQOL-CH

When the DEMQOL system was originally developed, the authors (Smith et al., 2005) assessed the appropriateness of the structure of the questions, including the question stem and response option format, by pre-testing a number of different stem and response options. Table 6.1 shows an example of the first question of each section of DEMQOL-Proxy.

As described in the original article, the DEMQOL-proxy is divided into three sections, these are, ‘feelings’, ‘memory’, and ‘everyday life’, capturing two underlying factors. As can be seen in Table 5.1, the questions contain a time frame, stem, main item, and response choice. The DEMQOL-Proxy questionnaire contains two different question stems, these are: “*How often has (your relative) felt...*” for the ‘feelings’ questions, and “*How worried has (your relative) been about...*” for the ‘memory’ and ‘everyday life’ questions. The time frame of ‘In the past week’, and the response options of ‘a lot’, ‘quite a bit’, ‘a little’, and ‘not at all’ are the same for all three sections (see Table 6.1).

Smith and colleagues (2005) raised concerns about whether participants would use the stem of the questions. For example, would participants use the stem “How worried would you say (your relative) has been about...” or would they answer the main item question of the stem and base their response on function? The authors reported that although it was not always clear whether participants had used the stem, there was evidence that they had distinguished between function and QoL when completing the original DEMQOL and DEMQOL-Proxy. These concerns were mainly for the DEMQOL instrument rather than the DEMQOL-Proxy instrument as it is used with people with dementia who may struggle to distinguish between reporting functional abilities and reflecting on their feelings. It is reasonable to assume that respondents completing the DEMQOL-Proxy would have fewer problems distinguishing between the two. A fundamental decision taken by the developers was therefore to make DEMQOL and DEMQOL-Proxy interviewer administered instruments. When administering the DEMQOL and the DEMQOL-Proxy, the interviewer reads the time frame, stem and item for each question to the respondent. The interviewer also ensures, by using follow-up questions, that the respondent has correctly understood the nature of each question. As such, the interviewer acts as a means of ensuring accurate and appropriately framed data is collected.

DEMQOL-Proxy has been assessed using family carers as a self-administered instrument, and was found to have comparable validity and reliability to the original DEMQOL-Proxy (Hendriks, Smith, Chrysanthaki, & Black, 2016). This paper used family carers who were living with the person with dementia, and the authors did not assess directly the agreement between the DEMQOL-Proxy as an interviewer or self-administered instrument. Instead, they compared the psychometrics against those of the original DEMQOL-Proxy evaluation. In this study, as reported in Chapter 5, the reliability of the DEMQOL-Proxy when self-administered was comparable both to the interviewer-administered version and the original DEMQOL-Proxy, but there was poor agreement.

As discussed above, there are likely to be differences when care staff use a self-administered QoL instrument compared to an interviewer-administered one. The busy nature of care work may affect the way that care staff read the DEMQOL-Proxy and report QoL, with a risk that care staff may not use the stem of each question correctly and report only on the main item question. To minimise the potential for the DEMQOL-Proxy to be incorrectly completed by self-reporting care home staff, we therefore adapted the format of the questions so that respondents read all of the components (i.e. time frame, stem, and item) of the questions, thus enhancing the likelihood that they answer questions based on QoL, not on function. This adaptation of the DEMQOL-Proxy resulted in a new version of the instrument, the DEMQOL-CH.

Table 6.2 illustrates the structure of the DEMQOL-CH questions. As the DEMQOL-CH is used as a self-administered (not an interviewer-administered) instrument the structure of the new question encourages the respondent to read all important parts and respond appropriately. The stem is one of the more important parts of the question structure as it prompts the respondent to answer the question based on subjective feelings, not functional abilities. Therefore, in DEMQOL-CH, the stem is combined with the item (see Table 6.2), with the intention that this will ensure that respondents read the stem for every question.

All other aspects of the instrument remained the same as DEMQOL-Proxy.

Table 6.1

DEMQOL-Proxy time, stem, and item structure of original instrument.. One example from each section of questions (e.g. feelings, memory, and, everyday life)

Time frame ^a	Stem	Item (examples from each section)^a	Response
In the past week	How often has (your relative) felt...	Happy	A lot, quite a bit, a little, not at all
In the past week	How worried would you say (your relative) has felt about...	His/her memory in general	A lot, quite a bit, a little, not at all
In the past week	How worried would you say (your relative) has felt about...	Keeping him/herself clean	A lot, quite a bit, a little, not at all

Table 6.2

DEMQOL-CH time, stem and item structure with Stem and Item combined into one sentence. One example from each section of questions (e.g. feelings, memory, and, everyday life)

Time frame ^a	Stem and Item (examples from each section)^a	Response
In the past week	How often has (the resident) felt happy	A lot, quite a bit, a little, not at all
In the past week	How <u>worried</u> has (the resident) been about his or her memory in general	A lot, quite a bit, a little, not at all
In the past week	How <u>worried</u> has (the resident) been about keeping him/herself clean	A lot, quite a bit, a little, not at all

- a: Top = example of 'Feelings' questions
- Middle = example of 'Memory' questions
- Bottom = example of 'everyday life' questions

6.2 Method

6.2.1 Research design

A cross-sectional study design was used.

6.2.2 Sample and setting

Two care homes (the same from Stage 2) were involved in this stage of the study. Arguably, it would have been beneficial to conduct this stage of the study with a separate sample who had no experience with the DEMQOL-Proxy instrument. However, the constricted timescale of the studentship meant it was not feasible to recruit extra care staff from additional care homes without restricting or affecting subsequent stages of the study. Across the 2 homes, 40 care staff were employed and had the capacity for 57 residents. All staff were eligible for participation, regardless of what type of shift they worked (day or night shift) and whether they worked full-time or part-time.

Staff characteristics are presented in the results section.

6.2.3 Quantitative Measures

The following were used in this stage of the study: DEMQOL-Proxy, DEMQOL-CH, and DEMQOL-CH instructions for administration. See *Section 3.4* for a full description of measures.

6.2.4 Procedure

6.2.4.1 Recruitment and consent

The same care homes and care staff from Stage 2 took part in this stage of the study (see Appendix I and K for care staff information sheet and consent form). The same residents that consented or were declared into the study in Stage 2 took part in this stage of the study (see Appendix O and N for resident information sheet and consent form). Recruitment and consent procedures as outlined in *Sections 3.2.3.1* and *4.1.3.1* were used.

6.2.4.2 Data collection procedure

As in Stage 2 (Chapter 5) staff rated the QoL of residents that they felt confident in rating; this was taken from the confidence rankings given by staff, as described in *Section 5.1.4.2*. Staff completed both the DEMQOL-Proxy and the DEMQOL-CH instruments. Staff were randomly allocated to one of two conditions:

- Condition 1: DEMQOL-CH completed first, then DEMQOL-Proxy;
- Condition 2: DEMQOL-Proxy completed first then DEMQOL-CH.

Staff were randomly allocated to these conditions, this was not based on staff and resident pairs; residents could be rated by staff in either condition. The time interval between DEMQOL-CH and DEMQOL-Proxy measurements was approximately 6 hours.

6.2.5 Statistical analysis

6.2.5.1 Acceptability and data quality

Missing data and floor and ceiling effects were assessed for DEMQOL-CH and the DEMQOL-Proxy. The descriptive scores of both instruments were calculated and compared against each other. The criterion for acceptability and data quality was set at <5% missing data and floor and ceiling effects <10%.

6.2.5.2 Reliability (internal consistency)

Internal consistency was assessed for the DEMQOL-Proxy and DEMQOL-CH using Cronbach's α (Cronbach, 1951), the criterion for acceptable reliability was a coefficient equal to or higher than 0.70.

6.2.5.3 Confidence

Each DEMQOL-Proxy and DEMQOL-CH had an additional confidence question on a five point Likert scale on the final page of each questionnaire that asked staff to rate how confident they felt in completing that particular questionnaire from not at all confident to

very confident. Descriptive statistics of confidence ratings for the two instruments were produced and differences assessed using a Wilcoxon signed rank test.

6.2.5.4 Agreement between DEMQOL-CH and DEMQOL-Proxy.

To assess the agreement between DEMQOL-Proxy and DEMQOL-CH and to determine if the self-administered DEMQOL-CH can be used instead of the interviewer-administered DEMQOL-Proxy, a correlation and paired t-test analysis was conducted to assess the relationship between the two instruments. A Bland Altman plot analysis (Bland & Altman, 1996) was carried out on QoL scores to assess the agreement between the two instruments.

The mean difference and standard deviation between the two instruments was computed along with the 95% limits of agreement (mean \pm 1.96 SD). A 95% confidence interval (CI) was computed for the mean difference.

As in Chapter 5, the threshold of 5 points was chosen as the clinically accepted measurement error for changes in QoL scores, estimated as half a standard deviation (SD) of the total scale (Norman, Sloan, & Wyrwich, 2003). (In the following analyses, the DEMQOL-Proxy SD was 9.57, and DEMQOL-CH SD was 9.72.) Proportional bias was checked by linear regression analysis. The difference between the two instruments was regressed on the average of the two instruments to assess whether they agreed throughout the range of measurement.

6.2.5.5 Analysis of order of administration conditions

Analysis of variance (ANOVA) of DEMQOL-CH and DEMQOL-Proxy

A mixed-group factorial analysis of variance (ANOVA) was performed to examine the effect of DEMQOL-CH and DEMQOL-Proxy order of administration on QoL scores.

Differences in confidence scores between conditions

Descriptive confidence scores for both instruments in each condition were calculated. Differences in confidence scores for the instruments in each condition were analysed using a Wilcoxon signed rank test.

Statistical analysis was conducted using SPSS version 22 (IBM Corp., 2013).

6.3 Results

6.3.1 Staff characteristics

Thirty-two care staff consented to take part in the study from the two care homes. Eleven care staff took part in the research and collected QoL data. See *Figure 6.2* for a diagram of participant numbers for each stage. Staff were those already consented into the study. Staff characteristics are shown in Table 6.3. Care staff were predominantly female (n=10) and white British (75%). Staff on average worked in the care home for 37 months and the care sector for 12 years.

To assess differences between the samples of each condition paired t-test analyses were carried out for continuous variables (e.g. age, number of years working in the care sector), and Chi square analysis was carried out for categorical data (e.g. gender, ethnicity, job role). Between groups, there was no significant differences between key demographics (age, gender etc.) with $p>0.05$.

6.3.2 Resident consent

There were 58 residents residing in the two care homes. Thirty-three residents consented to take part in the study. Twenty-four residents had their QoL assessed by care staff.

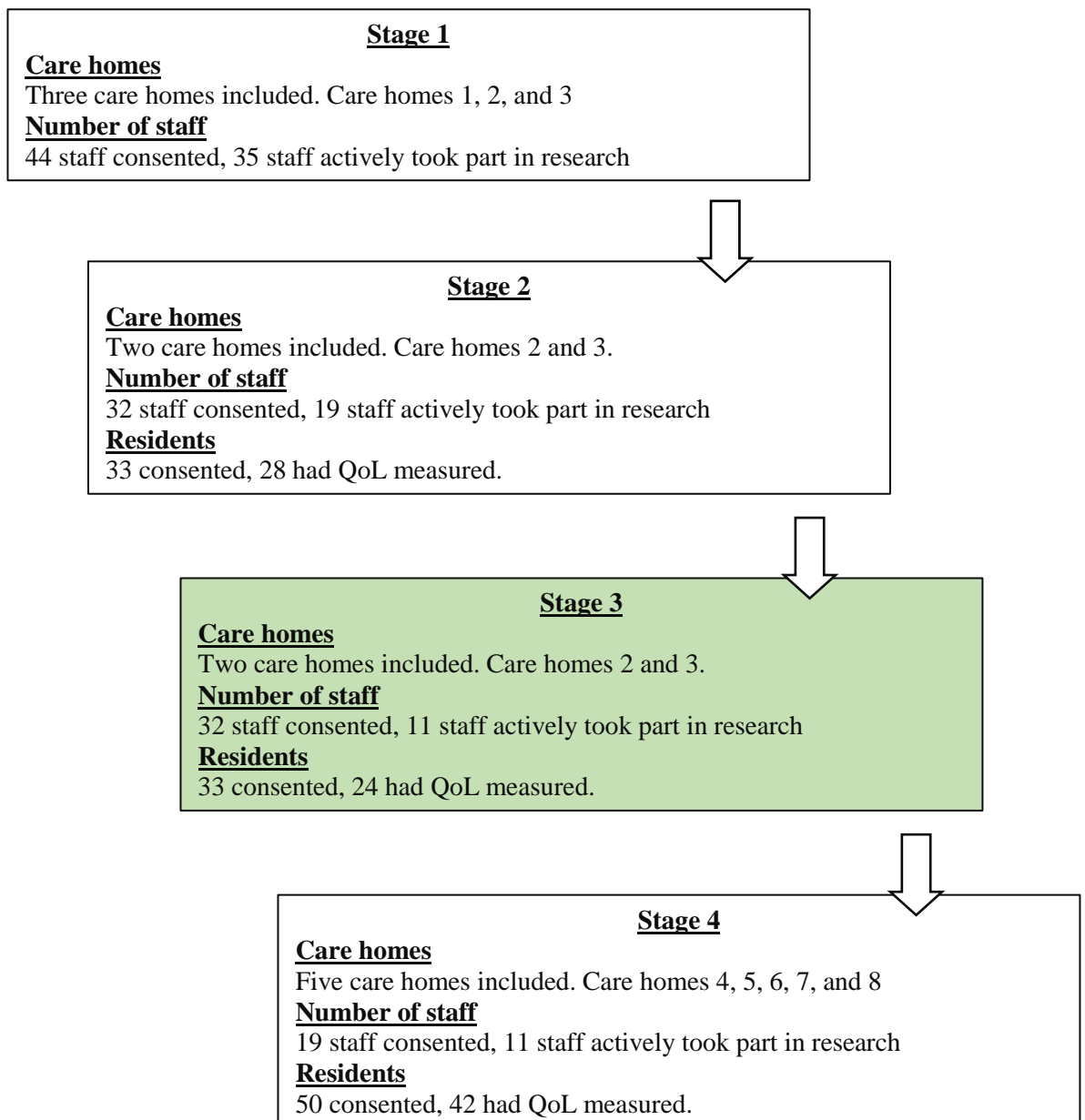


Figure 6.2. Diagram of number of care homes, staff, and residents included in each stage of the study. The current stage is highlighted in green. Each stage is broken down by number of staff and residents consented and number who actively took part in the research, i.e. either collected QoL data or had QoL measured

Table 6.3

Socio-demographic and occupational characteristics of care staff in Stage 3 (n=12)

Characteristic	Mean (SD) (Range)	n	%
Age	34.8 (11.9) (16-52)		
Gender			
Female		9	81.8
Male		2	18.2
Ethnicity			
White British		9	81.8
White other		1	9.1
Other Asian background		1	9.1
Job role			
Manager or deputy		3	27.3
Senior care assistants		6	54.6
Care assistants		2	18.2
Experience in care			
Time working in CH (months)	38.5 (43.1) (3.0 – 144.0)		
Time working in care sector (years)	13.3 (9.7) (0.50 – 30.0)		
Hours/days worked per week			
Hours per week	39.3 (10.2) (12-47)		
Days per week	4.4 (0.9) (2-5)		
Keyworker			
Keyworker		6	54.5
Not applicable		5	45.5
Language			
English as a first language		9	81.8
Resident knowledge			
% of staff who answered yes to the question “do you feel they know residents well enough to rate QoL?”		11	100.0
% of residents that staff feel they know well enough	71.2 (28.0) (40.0-100.0)	7	

6.3.3 Number of QoL ratings

A total of 51 pairs of QoL ratings were made using DEMQOL-CH and DEMQOL-Proxy instruments. Eleven staff rated 24 residents' QoL.

Of the 11 staff who completed QoL ratings seven completed QoL ratings for five residents and four completed QoL ratings for four residents. See Table 6.4. All ratings were for individual residents, i.e. staff only rated a resident once.

The 24 residents were rated on average two times with a range of one to five ratings. This is detailed in Table 6.5. All ratings were individual, i.e. residents were not rated by the same staff member more than once.

QoL ratings are illustrated in a clustered bar chart, please see Appendix R.

Table 6.4

Care home number	Staff number	Number of unique ratings made
1	1	4
1	2	5
1	3	5
1	4	5
1	5	4
2	6	4
2	7	5
2	8	5
2	9	5
2	10	5
2	11	4
		Total ratings n = 51

Number of unique QoL ratings made by each member of care staff

Table 6.5

Number of times each residents had their QoL rated

Care home number	Resident number	Number of unique QoL ratings
1	1	2
1	2	1
1	3	1
1	4	1
1	5	1
1	6	2
1	7	3
1	8	1
1	9	1
1	10	1
1	11	1
1	12	3
1	13	2
1	14	3
2	15	3
2	16	1
2	17	4
2	18	2
2	19	5
2	20	4
2	21	2
2	22	1
2	23	3
2	24	3
		Total ratings n = 51

6.3.4 Statistical analysis of DEMQOL-CH and DEMQOL-Proxy

6.3.4.1 Acceptability and data quality

Table 6.6 shows the acceptability and descriptive statistics of DEMQOL-Proxy and DEMQOL-CH. Missing scores and floor and ceiling effects were within the acceptable range. Data was slightly skewed to the left for both instruments, with a larger skew for the DEMQOL-Proxy (-0.67) than for the DEMQOL-CH (-0.23). However, the data were normally distributed.

6.3.4.2 Reliability (internal consistency)

DEMQOL-Proxy and DEMQOL-CH both had high internal consistency. DEMQOL-Proxy Cronbach's $\alpha = 0.84$ (95% CI: 0.76 – 0.89), DEMQOL-CH Cronbach's $\alpha = 0.85$ (95% CI: 0.79 – 0.91), $n = 51$ for both.

6.3.4.3 Confidence

The median score was used as the measure of central tendency for confidence scores as the scores are ordinal and data were skewed. The median for both instruments was 4. A Wilcoxon signed rank test showed no differences in confidence between the two instruments ($z = -0.44$, $p=0.66$).

Table 6.6

Descriptive statistics, data quality and acceptability of the DEMQOL-Proxy and DEMQOL-CH

Scale	Reliability ^a (95% CI)	Score range			Floor/ceiling effect			
		% missing	Scale	Sample	Mean (SD)	% Floor	% Ceiling	Skew
DEMQOL-Proxy ^b	0.84 (0.76 – 0.89)	0	31-124	75 – 117	99.30 (9.57)	0	0	-0.67
DEMQOL-CH ^c	0.85 (0.79 – 0.91)	0	31-124	80 - 117	99.66 (9.72)	0	0	-0.23

^a Cronbach's alpha
^b All n = 51
^c All n = 51

6.3.4.4 Agreement between DEMQOL-CH and DEMQOL-Proxy.

A Pearson's correlation analysis showed a strong statistically significant correlation between DEMQOL-Proxy and DEMQOL-CH ($r = 0.89$, $n = 51$, $p < 0.001$, one tailed) (Figure 6.3).

A paired samples t-test showed that there was no statistically significant difference between the means of the two instruments ($t = -0.57$, $df = 50$, $p = 0.57$).

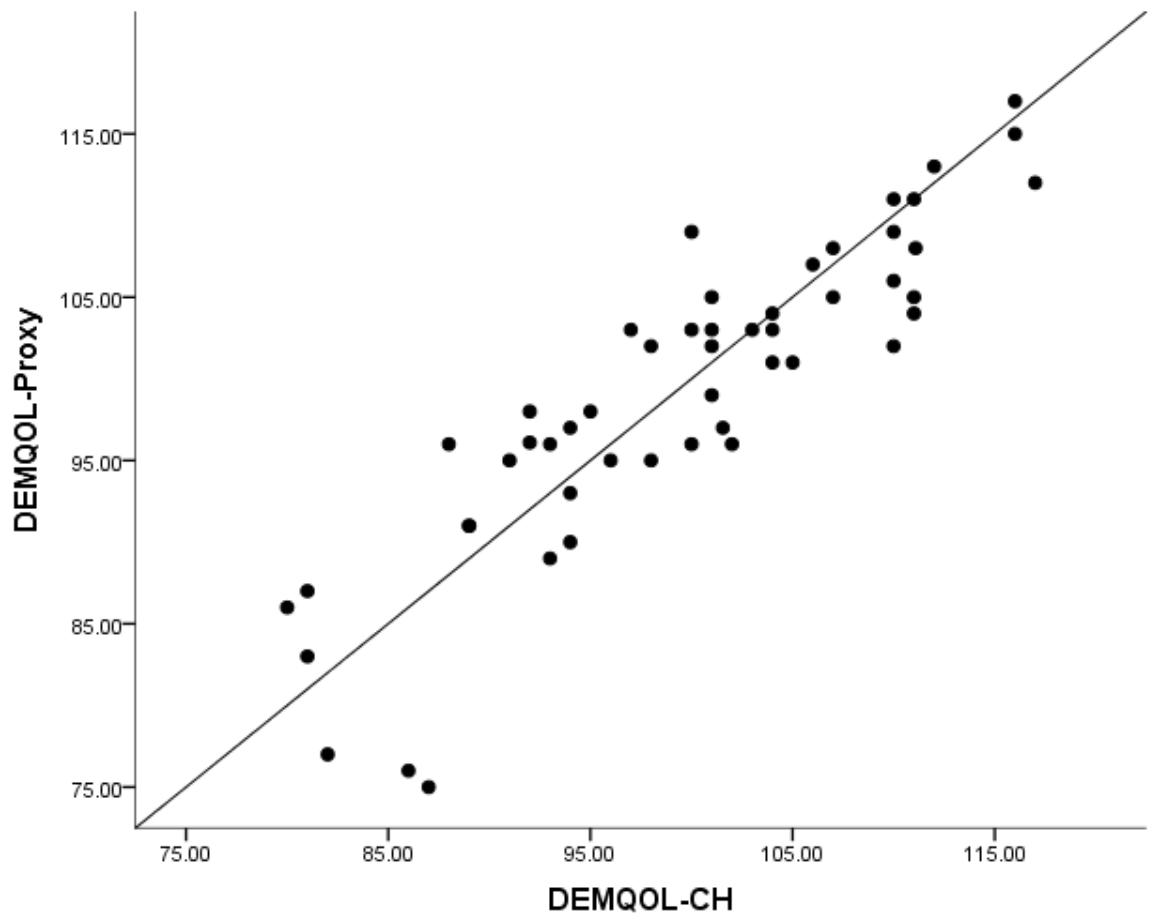


Figure 6.3. Scatterplot of the positive correlation between DEMQOL-CH and DEMQOL-Proxy scores

Bland Altman analysis (Figure 6.4) showed the mean difference between the scores was -0.36 (SD = 4.53). The mean difference is represented by the red dashed line. Upper and lower 95% CI of 0.91 and -1.64 are shown by the green dotted lines.

The upper and lower limits of agreement, calculated as the mean difference \pm 1.96 SD, represented by the blue dashed lines were 8.51 (95% CI, 6.37 to 10.65) and -9.24 (95% CI, -7.1 to -11.38).

There was no evidence of proportional bias; the scatter of differences were uniform throughout the range of measures. The slope of the regression line on the Bland-Altman plot did not differ significantly from zero ($t(50) = -0.23$, $p = 0.819$), this is shown in Figure 6.5.

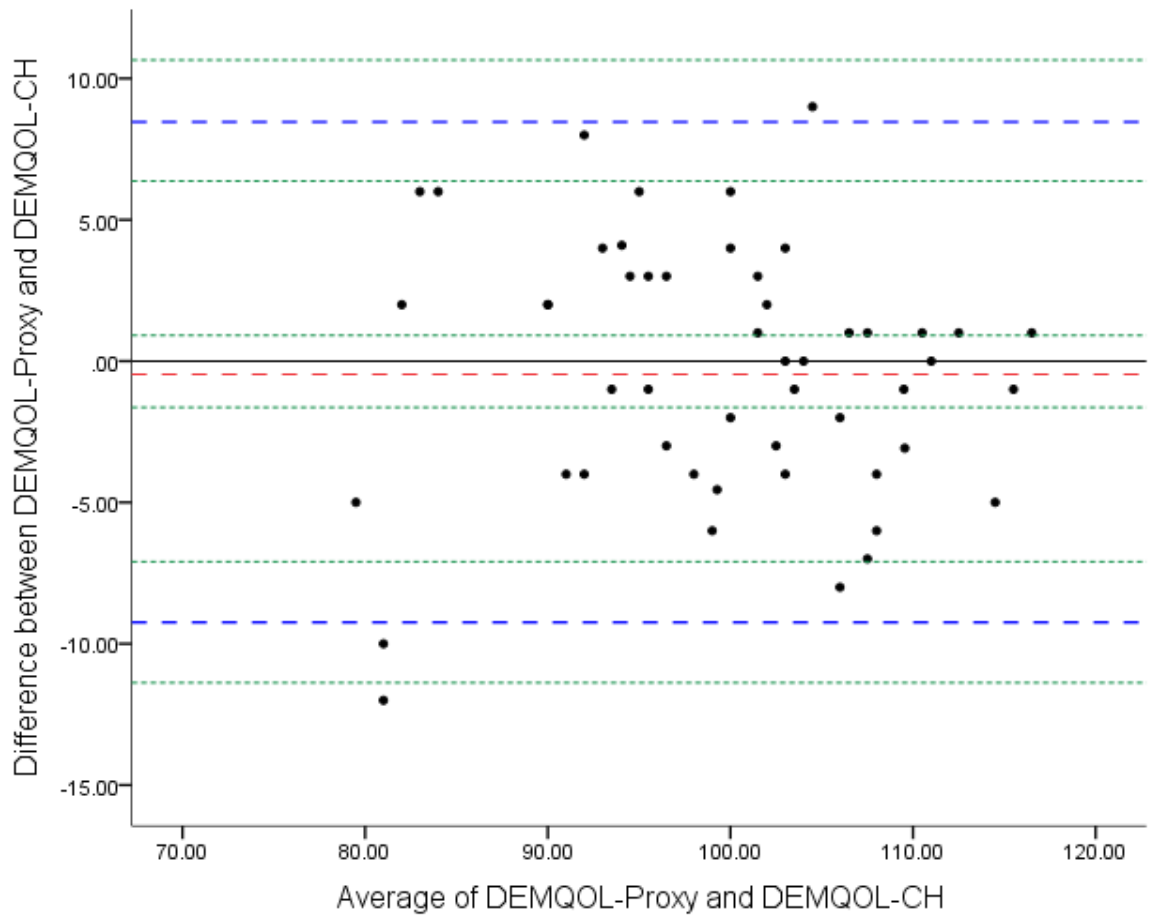


Figure 6.4. Bland Altman plot of agreement between DEMQOL-Proxy and DEMQOL-CH. A difference of zero would indicate perfect agreement as indicated by the black line. The mean difference between the two instruments is indicated with a red dashed line, the upper and lower 95% limits of agreement are indicated with the blue dashed lines, with 95% CI indicated by green dotted lines

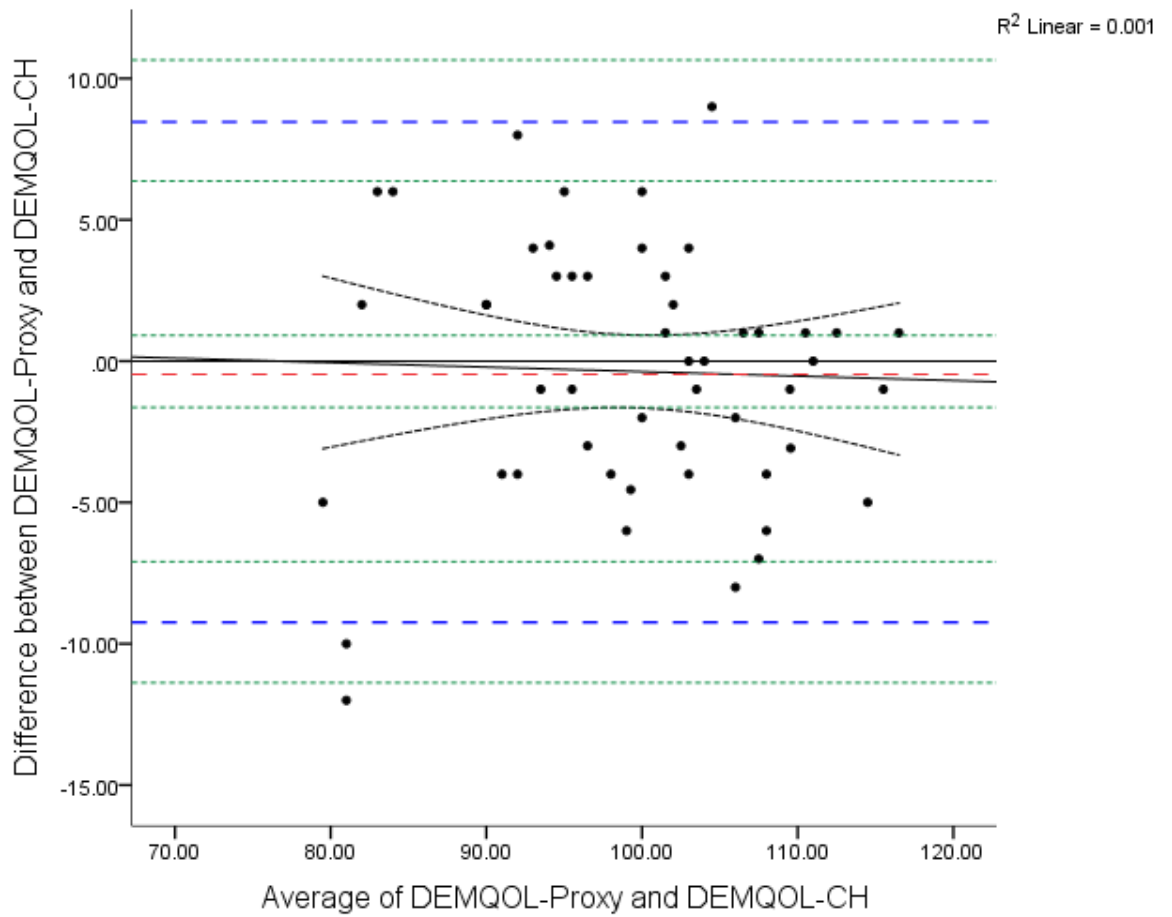


Figure 6.5. Bland-Altman plot showing evidence of proportional bias. This is the same plot as Figure 6.4 including the regression line. The solid black line represent the regression line, with 95% confidence interval limits represented by the black dotted lines

6.3.4.6 Analysis of conditions

Analysis of variance (ANOVA) of DEMQOL-CH and DEMQOL-Proxy

The mean scores of each condition were 101.83 (SD = 7.43) for condition 1 and 96.83 (SD = 11.06 for condition 2. These scores and the mean scores for both instruments in each condition are shown in Table 6.7.

The ANOVA results (Figure 5.4) show no main effect of time of administration, with no difference in scores between time 1 and time 2 ($F(1, 98) = 0.16, p = 0.692, \text{partial } \eta^2 = 0.002$).

There was a significant main effect of condition ($F(1, 98) = 7.21, p = 0.009, \text{partial } \eta^2 = .07$), with condition 1 means significantly higher than condition 2.

There was no significant interaction between time and condition ($F(1, 98) = 0.05, p = 0.828, \text{partial } \eta^2 < 0.001$), as illustrated in Figure 6.6.

Table 6.7

Means and standard deviations of DEMQOL-Proxy and DEMQOL-CH in each condition, and means and standard deviation of each overall condition

Instrument	Condition 1^a mean (SD)	Condition 2^b mean (SD)
DEMQOL-Proxy	102.00 (6.41)	96.25 (11.60)
DEMQOL-CH	101.67 (8.44)	97.40 (10.71)
Overall condition	101.83 (7.43)	96.83 (11.06)

^a Condition 1: DEMQOL-CH completed then DEMQOL-Proxy

^b Condition 2: DEMQOL-Proxy completed then DEMQOL-CH

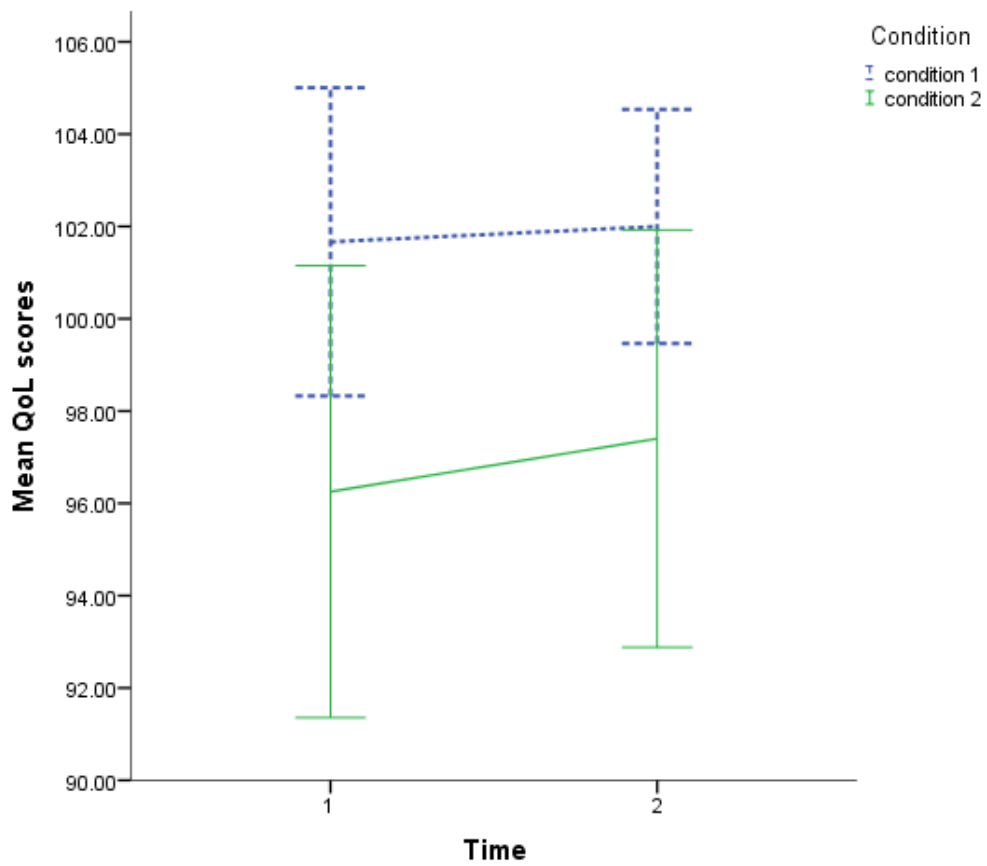


Figure 6.6. DEMQOL-CH scores by time (Time 1 = first, Time 2 = second) and condition (Condition 1: DEMQOL-CH completed then DEMQOL-Proxy. Condition 2: DEMQOL-Proxy completed then DEMQOL-CH). Vertical lines represent upper and lower 95% confidence intervals

Differences in confidence scores between conditions

The confidence ratings staff reported for each instrument in each condition were recorded; the median was used as a measure of central tendency. Figure 6.7 shows the frequency of scores for the two instruments in conditions 1 and 2.

For condition 1 the confidence score was 4 for DEMQOL-Proxy and DEMQOL-CH instruments. For condition 2 the median confidence score was 3 for the DEMQOL-Proxy and 3 for the DEMQOL-CH. There was a wider range of scores reported for condition 2 compared to condition 1.

A Wilcoxon sign rank test showed no statistically significant differences in confidence scores between the two instruments for condition 1 ($z = -0.45$, $p = 0.66$) or condition 2 ($z = -0.25$, $p = 0.80$).

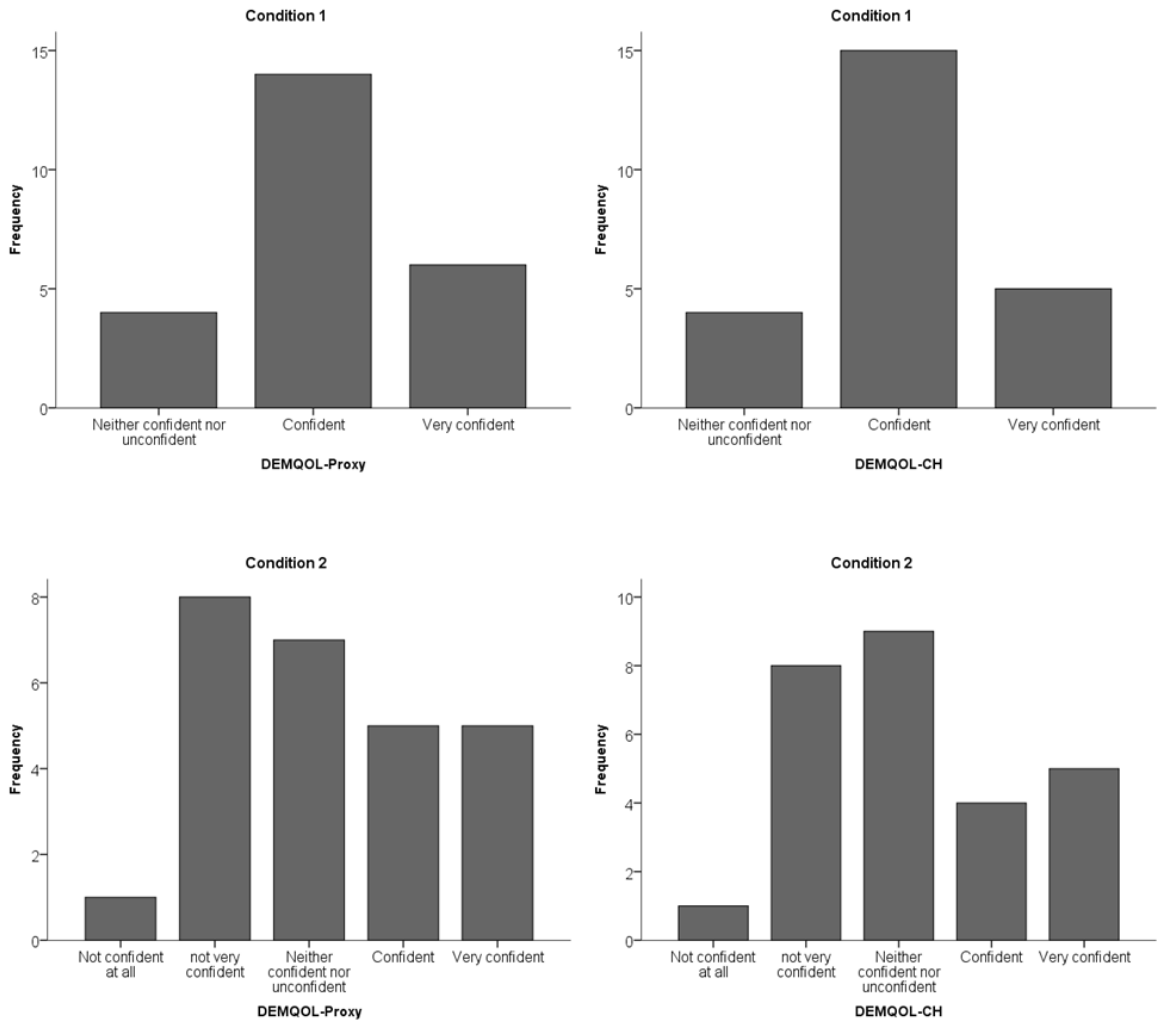


Figure 6.7. Mean confidence in using DEMQOL-CH and DEMQOL-Proxy in condition 1 and condition 2

6.4 Discussion

In this chapter we assessed whether making changes to the question structure improved agreement. Aim one of this chapter was to highlight the QoL aspect of questions by adapting the DEMQOL-Proxy to create a self-administered instrument for use in care homes by care staff called DEMQOL-CH. Aim two was to determine these changes in DEMQOL-CH improved agreement between DEMQOL-CH and an interview-administered DEMQOL-Proxy.

The stem and item structure of the questions were altered to highlight the QoL aspects of the questions. It was expected that highlighting that the questions were to be answered based on QoL and not function would mean that there would be better agreement. DEMQOL-CH was compared with DEMQOL-Proxy administered by an interviewer, who can ensure that the respondent has understood the questions, to replicate the conditions and performance of the original instrument. We hypothesised that the changes would result in better agreement between DEMQOL-Proxy and DEMQOL-CH, so indicating that changes made to the DEMQOL-CH prompted respondents to focus on QoL.

Overall, the data above show good agreement between DEMQOL-CH and DEMQOL-Proxy, and better agreement than between the interviewer and self-administered versions compared in the last chapter. This suggests that the changes to the structure of the questions had a positive effect on the way that staff completed the DEMQOL-CH. The order effects notwithstanding, we conclude from these analyses that there is preliminary evidence to suggest that the self-administered DEMQOL-CH can be used instead of the interviewer-administered DEMQOL-Proxy (the gold standard) in care homes by care home staff without the use of interviewer-administration.

6.4.1 Strength and limitations

One of the strengths of this stage of the study is that it builds directly upon the negative findings of the last chapter. It addresses the concerns raised by highlighting the QoL aspect of the questionnaire questions in the new version DEMQOL-CH. This enables the instrument to capture the information it is intended to capture in this specific setting.

The findings of this study need to be viewed in light of the limitations. As in the last chapter the main limitation is the small number of participants who completed all elements of this stage of the study and their highly selected nature. Some staff had left employment and some were not available due to annual leave and as discussed in the last chapter there was high heterogeneity in the sample. This limits the inferences that can be made from the findings. Another limitation is that the staff included in this stage of the study were also included in the previous stage; care staff therefore had experience of using the DEMQOL-Proxy instrument. This could have affected the way staff completed the instruments and could have affected the confidence they felt in using the instruments. Consequently, this could have increased the possibility of better agreement between the two versions of the instrument. An alternative approach would have been to recruit new participants who had not completed any of the instruments previously; different results may have been observed if new staff were recruited. Unfortunately, the timing of the studentship and the resources available limited the opportunity to do this. It must be stressed that these findings can in no way be considered definitive and there is a need for further research that will investigate agreement between DEMQOL-Proxy and DEMOQL-CH with staff who have no previous experience with either instrument and its performance in care home in larger more generalisable populations. However, the data generated here are encouraging that the DEMQOL-CH may be worth investigating in such future studies. A final potential limitation is that a heterogeneous sample in terms of staff job role was used in this stage of the study. A convenience sample of managers, senior care assistants, and care assistants was recruited into the study. A more homogeneous sample allows more generalisability of the findings, the different characteristics of staff such as job role may have effects on factors such as time and quality of time spent with residents. This could affect the results seen above.

6.4.2 Conclusion

The answers to the two research aims of this chapter were as follows:

- Aim 1 - small changes were made to the structure of the questions of the instruments. These changes highlight the QoL aspect of the questions by prompting respondents to read the important parts of the question. This generated a new version of DEMQOL-Proxy called DEMOQL-CH.

- Aim 2 - after the changes were made agreement between the interviewer-administered DEMQOL-Proxy and DEMQOL-CH was assessed, good agreement was found between the two instruments.

No ethical issues arose in this stage of the study.

6.4.2.1 Implications for the next stage

Because DEMQOL-CH is a new version of an existing instrument, with altered question structure and a different administration method, its psychometric properties need to be assessed. Therefore, in the next chapter the validity and reliability of DEMOQL-CH when used in routine practice by care staff is assessed.

Chapter 7 Stage 4: Evaluation of DEMQOL-CH in routine use in care homes

This chapter addresses aim 3 of the thesis, which is to assess the use of a QoL instrument in routine practice and whether routine QoL measurement by care staff is possible. See Figure 7.1 for details of the stage aims and the corresponding overall thesis aims.

In Chapter 6 changes were made to DEMQOL-Proxy to create a self-administered version of the instrument called DEMQOL-CH. This resulted in good agreement between the instruments and suggests that with these changes in place, DEMQOL-CH can be used instead of an interview-administered DEMQOL-Proxy as a self-administered QoL instrument in care home settings.

DEMQOL-CH, although similar to DEMQOL-Proxy, has an altered questionnaire structure and a new administration method. Moreover, the purpose of DEMQOL-CH in this study is for the routine measurement of QoL in a care home population using care staff as the proxy respondent. In the original DEMQOL-Proxy development and validation by Smith and colleagues (2005) only 19% of people included in the study lived in a care setting. Also, as discussed in previous chapters, DEMQOL-Proxy was developed as an interviewer-administered instrument. The use and application of such patient-centred outcome measures are changing, there is a growing interest in obtaining routine outcome assessments in social care to make positive changes to service delivery (Black, 2013). Such goals require the re-evaluation of these instruments to ensure they are suitable for their new intended application (Hendriks, Smith, Chrysanthaki, Cano, & Black, 2017). Thus, the changes made to the structure and administration of the instrument and the change in target population mean we need to evaluate the validity and reliability of DEMQOL-CH.

The aim of this chapter is therefore to investigate the psychometric performance and use of DEMQOL-CH as a self-administered proxy measure of QoL in routine care practice in care homes.

The specific aims of this stage of the research were:

1. To assess the frequency that care staff can rate resident QoL.
2. To assess the psychometric properties of DEMQOL-CH.
3. To assess what factors affect QoL ratings when completed by care staff.
4. To assess differences in QoL of residents by severity of cognitive impairment.

5. To assess care staff experiences of using DEMQOL-CH and measuring resident QoL.

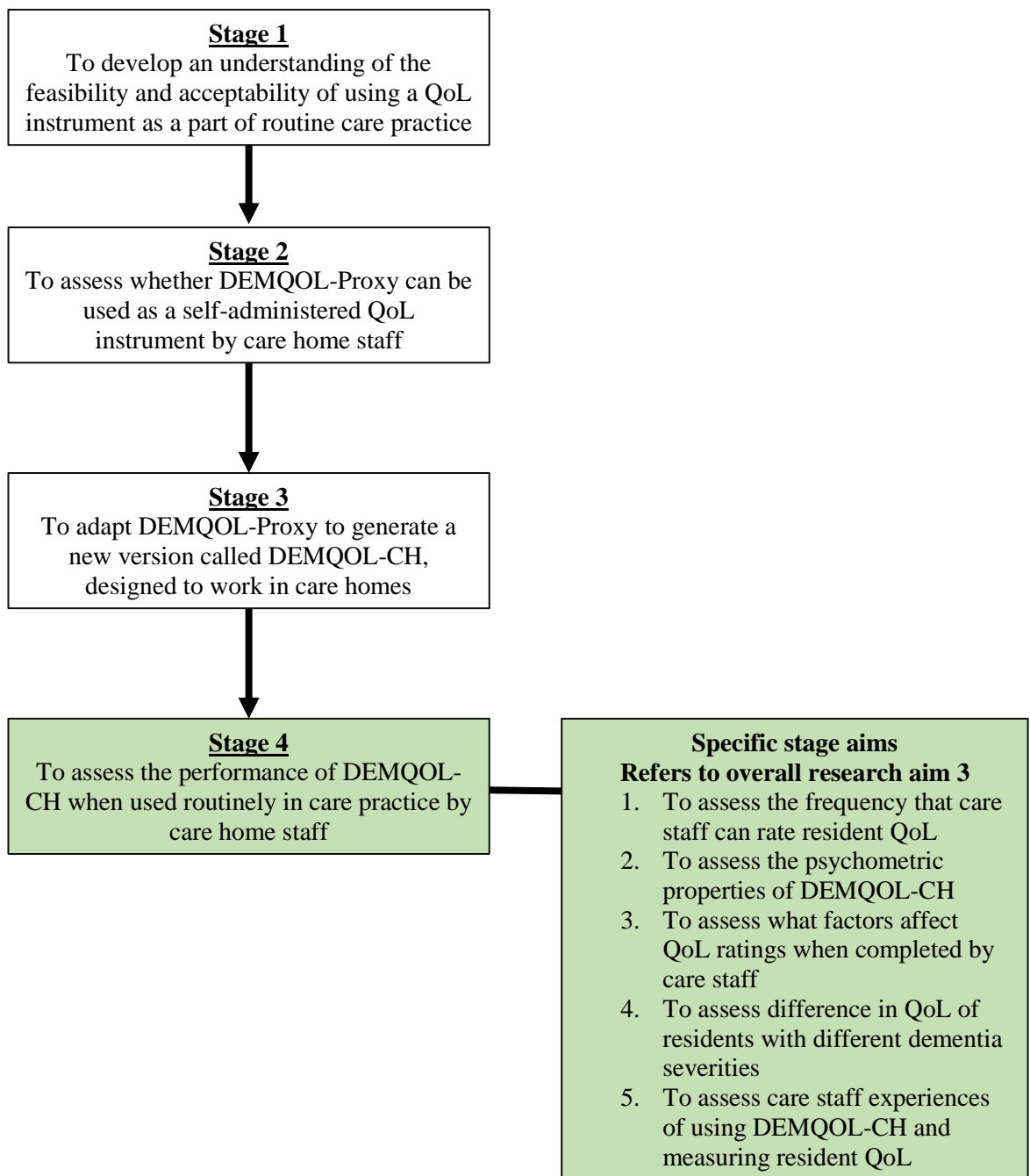


Figure 7.1. Aims of each stage of the study. Stage 4 is expanded to show the specific research aims of the stage

7.1 Method

7.1.1 Research design

A cross-sectional and cohort design was used for the psychometric assessment and the descriptive elements of this stage of the study.

7.1.2 Sample and setting

Five care homes in East Sussex, England participated in this stage. Care homes in Stage 4 were identified through initial contact in 2015 with two Care Home In-Reach teams covering Brighton and Hove and East Sussex (see *Section 4.2.3.1* for more information). Additional homes were identified through word of mouth from other researchers and from managers of care homes. The care homes all provided residential care for older adults. Four of the five homes provided nursing care. All homes were registered with Alzheimer's disease as a specialist care category. The care homes were chosen as the managers showed an interest in taking part in the research project, (please refer to *Section 4.2.3.1* for more detail). Staff from each care home were invited to take part in the study and to consent to measuring resident QoL routinely using DEMQOL-CH.

Across the five homes there were approximately 100 care staff employed to provide care for residents, the homes had a capacity for a total of 222 residents, however, one home was at 50% capacity as it was newly built, and one home was at reduced capacity due to refurbishment works. All staff were eligible for participation, regardless of what type of shift they worked (day or night) and whether they worked full-time or part-time. Agency staff and casual workers on zero hour contracts (bank care staff) were excluded from the study due to the potential of increased heterogeneity in care staff characteristics, including the level of contact with residents, motivation, and available time.

Staff characteristics are presented in the results section.

7.1.3 Quantitative measures

The following measures were used:

Care home staff: demographic information; DEMQOL-CH, with instructions for administration attached, and DEMQOL-CH study experience questionnaire.

Residents: Standardised mini mental state examination (sMMSE).

Researcher: Clinical dementia rating scale (CDR). Dementia care mapping (DCM). DCM was conducted over a continuous three hour period. Each mapping session incorporated the hour before lunch as this has been found to be representative of the rest of the day when using DCM (Fossey et al., 2002) and other observational tools (Macdonald et al., 1985). Based on previous studies that have evaluated DCM with other QoL instruments (Sloane et al., 2005), the following DCM indices were calculated: mean well-/ill-being (WIB) score, percentage of positive WIB scores (+3 or +5), and the percentage of behaviours observed that were ‘good’ behaviours (BCC Type 1).

Please see *Section 3.4* for full descriptions of measures.

7.1.4 Procedures

7.1.4.1 Recruitment and consent

Staff

Care staff were invited to take part in the study and to consent to measuring resident QoL routinely. Staff were given an information sheet to read and provided with the opportunity to ask questions. Staff completed the consent form if they wished to take part. See Appendix J and Appendix L for care staff information sheet and consent form.

Residents

Care home residents were assessed to determine whether or not they had the capacity to consent to the study. Residents that were assessed as having capacity were given information about the study and asked if they wish to consent to the study. If a resident did not have capacity a personal consultee was sought in the first instance. See *Section 3.5.1* for a full description of the capacity and consultee process used. All residents, regardless of capacity,

were given an information sheet about the study (Appendix N). Those with capacity were provided with a consent form to sign if they wanted to take part (Appendix P). Care home residents were asked to consent to allow the care home staff to measure their QoL, to have their cognitive function assessed by the researcher, and to possibly be observed by the researcher during a DCM session.

7.1.4.2 Data collection procedure

Staff

Staff were asked to rank the residents based on how confident they felt in rating the QoL of each resident. As in Stage 2, (see *section 5.1.3.2*), staff ranked residents from most to least confident in rating QoL. All staff rated QoL using DEMQOL-CH. Initially staff were asked to rate residents they felt more confident with (based on confidence rankings). As staff completed more DEMQOL-CH instruments and became more familiar with the instrument they were asked to also rate residents that they had ranked lower in confidence.

Staff were asked to complete regular QoL ratings for consented residents. Discussions with each staff member were carried out to determine how long it would take to complete a set of five DEMQOL-CH assessments. Instruments were given to care staff and collected after the time period determined.

To assess inter-rater reliability care staff independently completed the DEMQOL-CH for the same residents for the same time period. To assess test-retest reliability staff completed several DEMQOL-CH instruments for the same residents with a time period between each measurement. It was not always possible to control the time period between measurements as staff were often busy, occasionally staff would forget to complete the DEMQOL-CH measurements and then not be at work for some time due to allocated days off or vacation time.

In a normal validation study participants are asked to complete a set number of ratings in a set timeframe. However, the main aim of this thesis was to determine if care staff could complete the DEMQOL-CH routinely as a part of normal care practice. Therefore, staff were provided with the instruments and asked to complete them routinely and the statistical analysis was carried out on this data. Another appropriate method would have been to collect

a set of data from staff to use for the psychometric analysis, and then ask staff to collect routine QoL data. However, there would have been an insufficient number of staff to collect enough data to carry out a robust analysis.

At the end of Stage 4 staff were asked to complete a questionnaire which asked them questions about their experience of using the DEMQOL-CH and taking part in the study. Characteristics of staff who completed the questionnaire are presented in the results section.

Residents

Residents had their cognitive function and dementia severity assessed using the sMMSE and CDR. These instruments were administered by the researcher in the care home in a quiet setting. These were completed once at the beginning of the study. The sMMSE was carried out in a quiet place in each home, either a quiet room or the residents own room. The sMMSE was completed as far as possible for each resident, including those with more severe impairments. Residents that were at end of life stages and unresponsive were not administered the sMMSE, the CDR was completed for all residents based on the researcher's observations and through an interview with a member of staff who knows the resident.

Researcher

DCM was carried out by the researcher in each of the homes involved in the study on one occasion. This was completed towards the end of QoL data collection. When assessing convergent validity it is normal practice to use an instrument that measures the same or similar constructs as the instrument being developed or evaluated. In many QoL studies questionnaires such as QOL-AD and DQoL are used as validation instruments. In this study however, there was a need to limit the burden on care staff; there was also a potential issue that using other QoL questionnaire could influence or effect results on DEMQOL-CH and cause confusion as to the differences between the instruments. It was therefore decided to use a non-participant observation method. DCM has had concurrent validity assessed against other QoL instruments and thus could be argued to be measuring similar constructs.

7.1.5 Statistical analysis

Statistical analyses were carried out for the baseline and whole sample dataset as indicated by the specific attributes being tested.

7.1.5.1 Frequency of QoL ratings

To understand whether routine QoL measurement is possible in care homes the number and timing of QoL ratings made by care staff were recorded by resident, these were presented graphically. The number and frequency of QoL ratings made by care staff were generated for all residents in the study by individual homes.

7.1.5.2 Psychometric analysis

The acceptability, reliability and validity of DEMQOL-CH was assessed using the methods and criteria described below.

7.1.5.3 Acceptability and data quality

Missing data and floor and ceiling effects were assessed for DEMQOL-CH. Descriptive statistics for the whole sample, baseline and first follow-up were compared. The criterion for acceptability and data quality was <5% missing data, and floor and ceiling effects <10%.

7.1.5.4 Reliability analysis

Reliability was assessed on the basis of internal consistency, test-retest, and inter-rater reliability analysis.

Internal consistency: Internal consistency was assessed using Cronbach's alpha (α). A more detailed description of internal consistency and Cronbach's α can be found in Chapter 5 section 5.1.4.2. Cronbach's α was calculated for the whole sample and the baseline sample.

A Cronbach's α of ≥ 0.70 was considered acceptable for internal consistency analysis (DeVon et al., 2007).

Test-retest reliability: Test-retest reliability assesses the stability of an instrument when it is administered to, or completed by respondents on two different occasions. Intra-class correlation (ICC), using a two-way mixed-effects model of absolute agreement, was used to assess test-retest reliability (Koo & Li, 2016). ICC scores range from 0 to 1 with scores closer to 1 indicating a stronger correlation. The criterion for good reliability is ≥ 0.75 (Koo & Li, 2016) The time period between measurements ranged from 1 to 12 weeks. Correlations were calculated for the whole sample and for separate time periods grouped into 2 week periods.

Inter-rater reliability: Inter-rater reliability is used to assess the degree to which different respondents or observers agree on ratings of an instrument. Inter-rater reliability was also assessed using ICC. To assess agreement between raters an ICC using a one-way random effects model was calculated. The criterion for good reliability was ≥ 0.75 (Koo & Li, 2016). Ratings made up to 7 days apart were included in the analysis.

The researcher provided pairs of care staff with DEMQOL-CH instruments at the same time, they were asked to complete the instruments for the same residents independently. It was not possible to guarantee that staff completed the DEMQOL-CH instruments for the same time period. The dataset was examined and organised so that ratings between staff could be compared. Ratings up to 7 days apart were analysed.

7.1.5.5 Validity analysis

Factor analysis

Exploratory factor analysis was carried out to evaluate the dimensionality of the DEMQOL-CH instrument. All factor analyses used unweighted least squares extraction as it is more appropriate for smaller sample sizes and provides better estimates (Wollins, 1995). Direct

oblimin, an oblique rotation, was used as some correlation between factors was expected (Costello & Osborne, 2005).

Suitability of the data for factor analysis was checked using Keiser–Myer-Olkin (KMO) statistic. KMO shows the proportion of variance that could be caused by underlying factors. A score of >0.5 indicates that the data is suitable (Field, 2013). Bartlett’s test of sphericity was calculated to test the null hypothesis that there is no relationship between the variables. This should be statistically significant ($p<0.05$).

Initial analyses were run to obtain eigenvalues, the criterion for eigenvalues is ≥ 1.0 . The scree plot was then inspected to determine the number of factors that should be retained. Item loadings of ≥ 0.40 were considered an acceptable standard in the analysis (DeVon et al., 2007). To assess the fit of the factor model the difference between the observed correlations and the model-based correlations were analysed. No more than 50% of the residuals should be > 0.05 (Yong & Pearce, 2013).

Analyses were carried out for the whole dataset first and the baseline data to see if the factor structure held and to provide support for the factor structure.

Convergent validity

Convergent validity is the extent to which a construct is correlated with a measure of the same or similar constructs. Assessment is based on correlations between the constructs; strength of correlations is based on the similarity of the measured constructs in each instrument. In this study we assessed the convergent validity of DEMQOL-CH by examining the correlations with DCM indices of mean WIB score, % WIB +3 or +5 and % BCC Type 1. The whole dataset of QoL scores were used for this analysis. The use of only baseline data would not have been appropriate due to the time between baseline data collection and DCM observation.

Based on previous research (Sloane et al., 2005) it was hypothesised that positive moderate correlations (approximately 0.30 - 0.50) between DEMQOL-CH and DCM would be found as DEMQOL-CH is a proxy instrument and DCM is an observational tool.

Known-groups differences

Known-groups difference is the extent to which an instrument can differentiate between groups that are known to be different. There is some evidence of differences in QoL between people with and without cognitive impairment (Hendriks et al., 2016; Smith et al., 2005). In this study there was an insufficient number of people without dementia, therefore only people with questionable, mild, moderate and severe dementia were included in the analysis. Further, the understanding of the relationship between QoL and dementia severity is not fully established or understood (Smith et al., 2005), similarly, there are conflicting results regarding the differences in QoL between people with different severities of dementia. Therefore, known-groups difference was investigated on an exploratory basis to assess any differences in QoL between people with different dementia severities.

Severity was based on CDR scores. Because the data were not normally distributed a non-parametric Kruskal-Wallis test was used to assess if there were any differences between the different dementia severities. Kruskal-Wallis test is the non-parametric equivalent of a one-way ANOVA.

Differences between groups was also assessed for the whole dataset and baseline dataset.

7.1.5.6 Overall QoL scores

Question 32 of DEMQOL-CH (see Appendix E) asks respondents to think about all of the questions they were asked about the resident in the previous 31 questions and rate the resident's overall QoL. This is rated as either 'very good', 'good', 'fair', or 'poor'.

In this analysis the relationship between the response to question 32 and the QoL score were assessed to determine correspondence (i.e. do respondents arbitrarily assign an overall QoL category based on their own judgement, or do their responses mirror those of the QoL score obtained). It was expected that the 'positive' QoL categories ('very good', 'good') would have higher QoL scores than the 'negative' QoL categories ('fair', 'poor').

For clarity, the term 'overall QoL category' is used to refer to question 32, this is a separate question not used in the analysis to obtain the QoL score. QoL score is derived from the first 31 items in the DEMQOL-CH.

The score of each overall QoL category was calculated. The data were not normally distributed, however, as a one-way ANOVA is robust to violations of normality it was used to investigate if there were any differences between the overall QoL categories. Data for the whole and baseline sample is reported.

Differences between QoL score and overall QoL category were also compared for different dementia severities for the whole dataset using one-way ANOVA.

7.1.5.7 Regression analysis

A hierarchical regression analysis was carried out to assess which factors accounted for the most variance in predicting DEMQOL-CH scores. Multiple regression assesses the relationship between an outcome and predictor variables, and assesses the effect that changes to the predictor variables have on the outcome variable.

Prior to conducting the analysis, the assumptions of hierarchical regression were tested. A three step hierarchical multiple regression was conducted with total QoL as the dependent variable. Resident characteristics (resident gender and dementia severity) were entered at Step 1, the variables related to time spent with residents and time working in care (time working in the care home, time working in the care sector, hours worked per day) were entered at Step 2. Staff confidence in completing each DEMQOL-CH was entered at Step 3.

7.1.5.8 Study experience questionnaire

To understand how care staff felt about using the DEMQOL-CH instrument and measuring QoL staff completed an experience survey questionnaire. Descriptive statistics of questionnaire responses were calculated.

Responses to open ended questions are summarised. Thematic analysis was initially planned, however, due to the small number of responses only a narrative summary was possible.

All statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS), version 24.

7.2 Results

7.2.1 Sample characteristics

7.2.1.1 Care staff

Nineteen staff consented into the study. However only 11 staff completed DEMQOL-CH instruments. See *Figure 7.2* for a diagram of participant numbers for each stage of the study. Characteristics of the sample who completed DEMQOL-CH instruments are shown in Table 7.1. Staff were mainly female, white British, and the majority were employed as care assistants.

To assess differences in demographics between consented staff who did and did not complete DEMQOL-CH assessments, paired t-test analyses were carried out for continuous variables (e.g. age, number of years working in the care sector), and Chi square analysis was carried out for categorical data (e.g. gender, ethnicity, job role). No statistically significant differences were found for key demographics (age, gender etc.) between the two groups with $p > 0.05$. However the small sample size limits such significance testing.

Four care staff completed the study experience questionnaires. Staff characteristics are presented in Table 7.2. Staff on average worked in the care home for 26 months and in the care sector for 5 years.

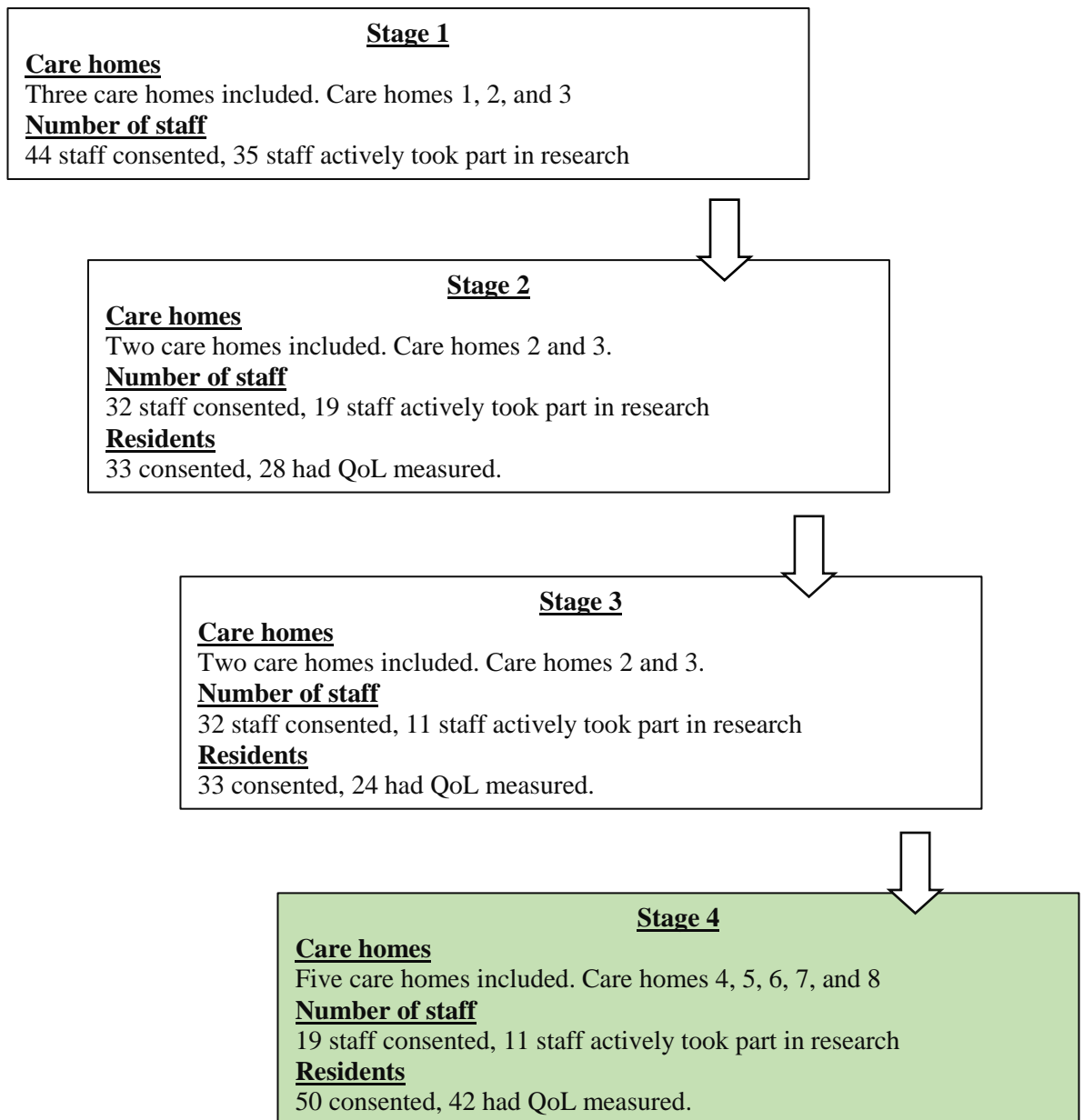


Figure 7.2. Diagram of number of care homes, staff, and residents included in each stage of the study. The current stage is highlighted in green. Each stage is broken down by number of staff and residents consented and number who actively took part in the research, i.e. either collected QoL data or had QoL measured

Table 7.1

Socio-demographic and occupational characteristics of care home staff in Stage 4 (n=11)

Characteristic	Mean (SD) (Range)	n	%
Age	46.0 (18.0) (21-68)		
Gender			
Female		10	90.9
Male		1	9.1
Ethnicity			
White British		6	54.5
White other		2	18.2
Other ethnic group		1	9.1
Job role			
Nurse		3	27.3
Care assistants		6	54.6
Activity coordinator		2	18.2
Experience in care			
Time in CH (months)	47.7 (68.4) (2.0 – 240.0)		
Time in care sector (years)	11.9 (12.6) (0.67 – 36.7)		
Hours/days worked per week			
Hours per week	39.6 (11.2) (26-80)		
Days per week	4.4 (0.8) (3-5)		
Keyworker			
Keyworker		4	36.4
Not applicable		6	54.5
Language			
English as a first language		7	63.6
Resident knowledge			
% of staff who answered yes to the question “do you feel they know residents well enough to rate QoL?”		11	100.0
% of residents that staff feel they know well enough	82.3 (22.7) (33.0-100.0)	8	

Table 7.2

Socio-demographic characteristics of care home staff who completed study experience questionnaires (n=4)

Characteristic	Mean (SD) (Range)	n	%
Age	36.8 (12.6) (23-51)		
Gender			
Female		4	100.0
Ethnicity			
White British		2	66.7
Other ethnic group		1	33.3
Job role			
Nurse		1	25.0
Care assistant		1	25.0
Activity coordinator		2	50.0
Experience in care			
Time in CH (months)	26.0 (12.6) (2.0-48.0)		
Time in care sector (years)	5.1 (4.5) (1.0-11.6)		
Hours/days worked per week			
Hours per week	30.4 (3.8) (27-35)		
Days per week	4.25 (1.0) (3-5)		

7.2.1.2 Residents

Resident capacity and consent

There were 164 residents in five care and nursing homes at the start of Stage 4. The researcher assessed each resident's capacity to consent. Seventeen (10.4%) could not be assessed, 50 (30.5%) had capacity, and 97 (59.1%) did not have capacity. (See Figure 7.3)

Resident characteristics

Fifty residents consented to take part in the study or had a personal or nominated consultee in place. Eight residents died or moved out of the home prior to data collection. CDR ratings for the remaining 42 residents show that one resident (2%) had no dementia, 14.3% (n =6) had questionable dementia, 23.8% (n =10) had mild dementia, 19.0% (n = 8) had moderate dementia, and 40.5% (n = 17) had severe dementia. Fifteen residents (30.0%) were able to or willing to complete the sMMSE, therefore, this is not included in the analyses. The resident without dementia was not included in the following analyses as sub-group analysis cannot be carried out. Therefore, a total of 41 residents had their QoL measured and analysed.

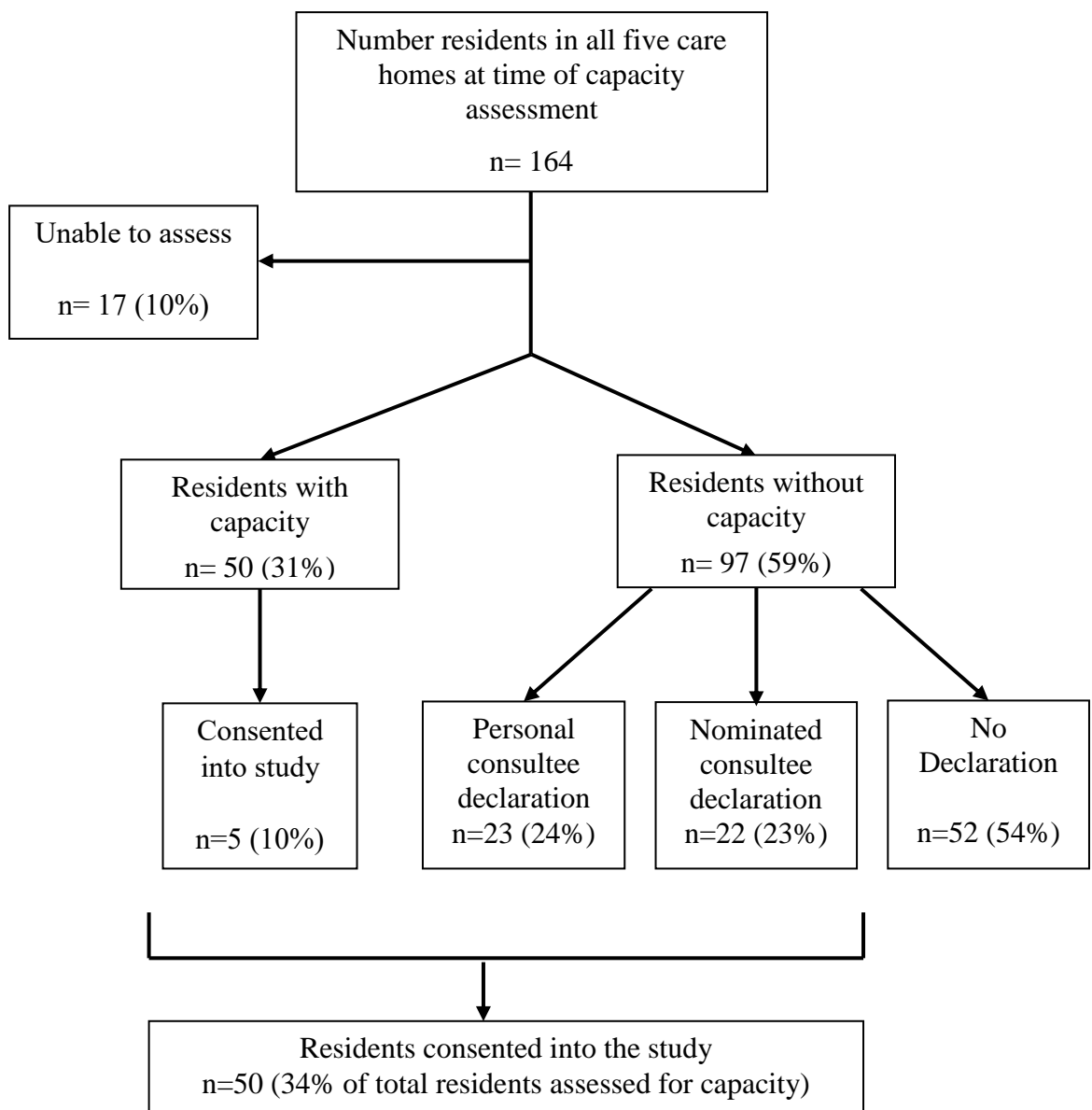


Figure 7.3. Resident capacity and consent for Stage 4. This figure illustrates the number of residents with and without capacity in the five care homes and the percentage that consented (or were declared by a consultee) to take part in the study

7.2.2 Frequency of QoL ratings

A total of 154 QoL ratings were made across five homes on the 41 residents. Care home 5 only carried out baseline ratings, results from this home are not presented here. Therefore, a total of 150 QoL ratings were made for 36 residents across four homes. The follow-up period for the whole study was eight months. Individual QoL scores for each residents are presented in Figure 7.4.

The number of QoL ratings for each resident in each home are presented in Figure 7.5. Table 7.3 shows the actual number of ratings for each resident, Table 7.4 shows the actual number of ratings made by each member of care staff. QoL ratings are illustrated in a clustered bar chart, please see Appendix S.

Care home 1 rated QoL for a four-month period. Twelve residents were rated on average four times each over this time. See Figure 7.6.

Care home 2 rated QoL for a four-month period. Five residents were rated on average three times each. One resident was only rated at baseline. See Figure 7.7.

Care home 3 rated QoL for a four-month period. Fourteen residents were rated on average five times in the four-month period. See Figure 7.8.

Care home 4 rated QoL for two months. Four residents were rated twice in this period. See Figure 7.9.

The change in mean QoL for each home is presented in Figure 7.10.

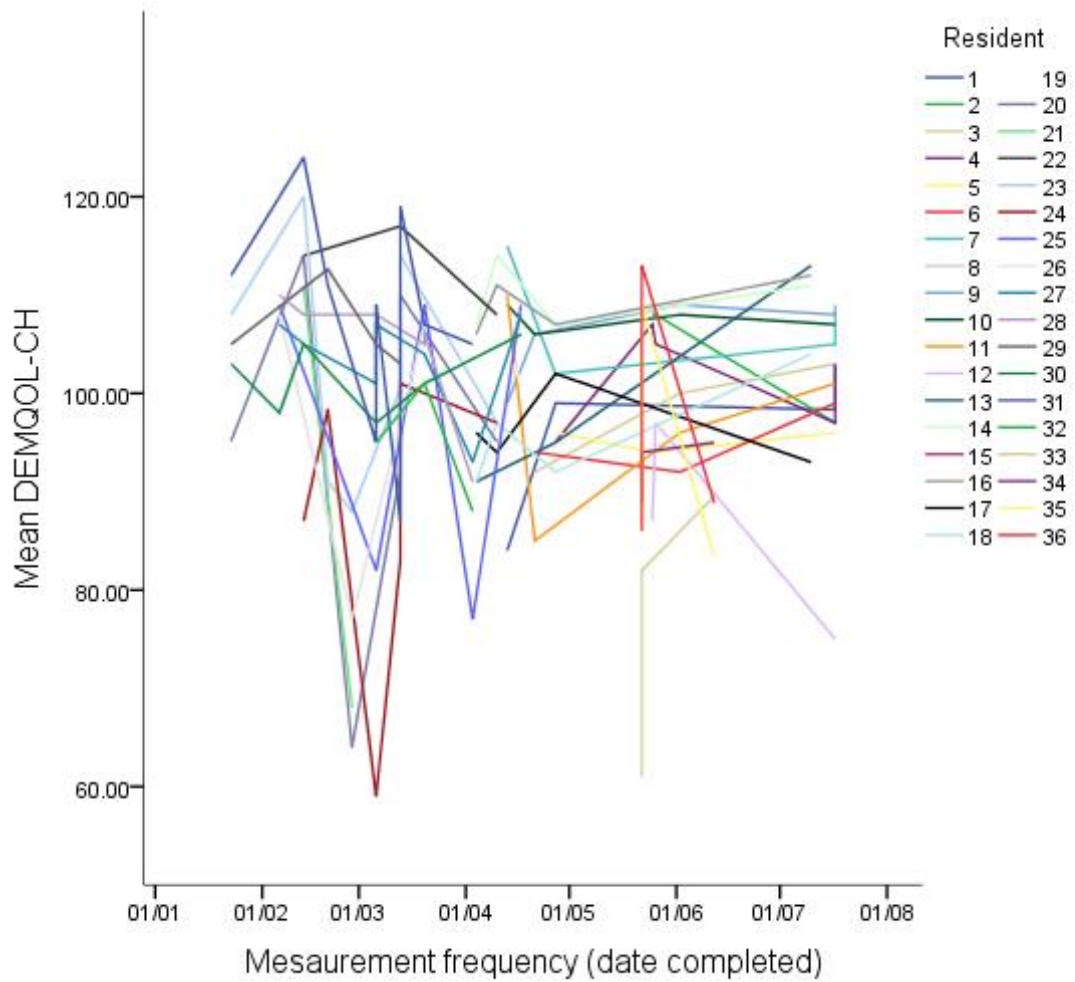


Figure 7.4. Frequency of QoL ratings for all residents. This figure illustrates the QoL ratings for 36 residents in 4 care homes over 8 months. Each resident is represented by a separate line. The x axis represents each month from January to August 2017

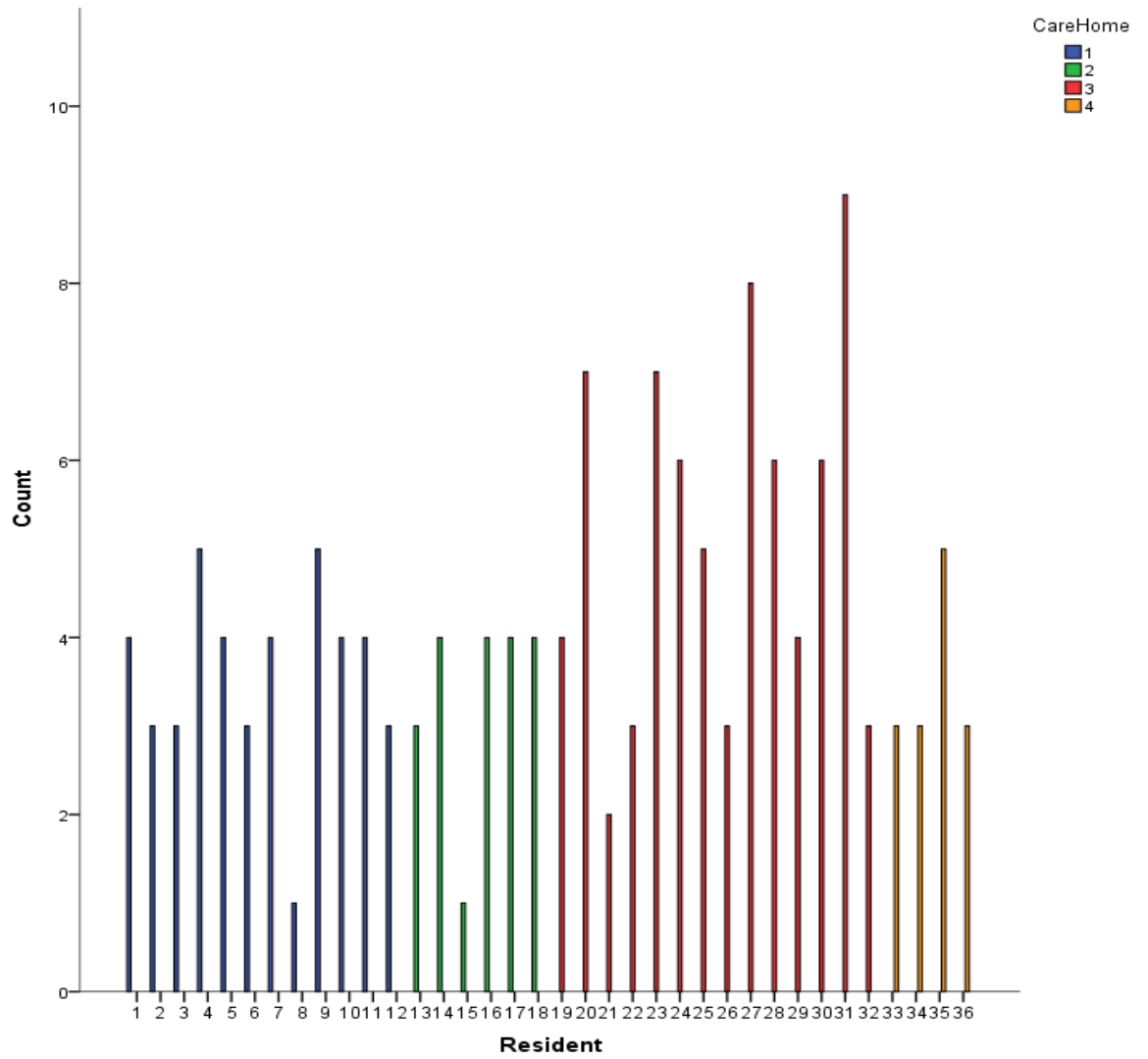


Figure 7.5. Bar chart of QoL rating frequency for each resident over an 8 month period

Table 7.3

Number of times each residents had their QoL rated

Care home number	Resident number	Number of QoL ratings
1	1	4
1	2	3
1	3	3
1	4	5
1	5	4
1	6	3
1	7	4
1	8	1
1	9	5
1	10	4
1	11	4
1	12	3
Total		43
Average		4
2	13	3
2	14	4
2	15	1
2	16	4
2	17	4
2	18	4
Total		20
Average		3
3	19	4
3	20	7
3	21	2
3	22	3
3	23	7
3	24	6
3	25	5
3	26	3
3	27	8
3	28	6
3	29	4
3	30	6
3	31	9
3	32	3
Total		73
Average		5
4	33	3
4	34	3
4	35	5
4	36	3
Total		14
Average		4
		Total ratings n = 150
		Average ratings = 4

Table 7.4

Number of unique QoL ratings made by each member of care staff

Care home number	Staff number	Number of ratings
1	1	21
1	2	22
Total		43
Average		22
2	3	10
2	4	10
Total		20
Average		10
3	5	19
3	6	30
3	7	9
3	8	15
Total		73
Average		18
4	9	5
4	10	9
Total		14
Average		7
		Total ratings n = 150
		Average ratings = 15

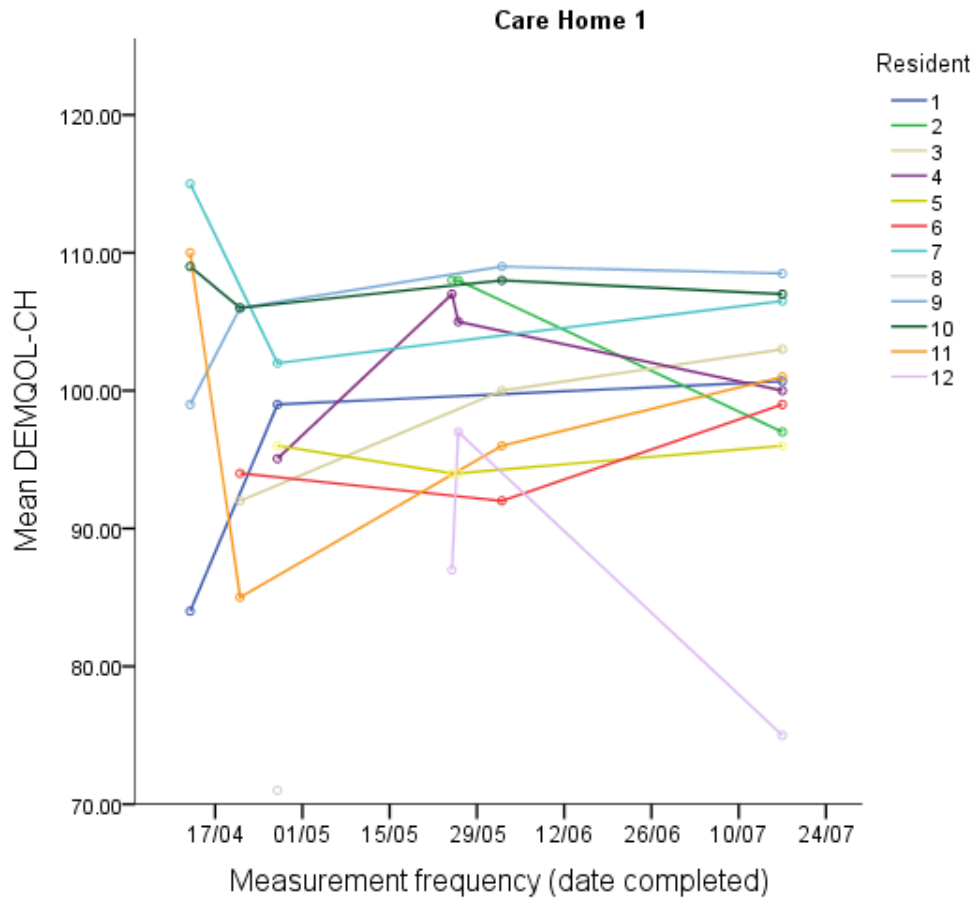


Figure 7.6. QoL ratings for care home 1. This figure illustrates the QoL ratings made for 12 residents over 4 months. Each line represents one resident. The x axis represents the date of measurement

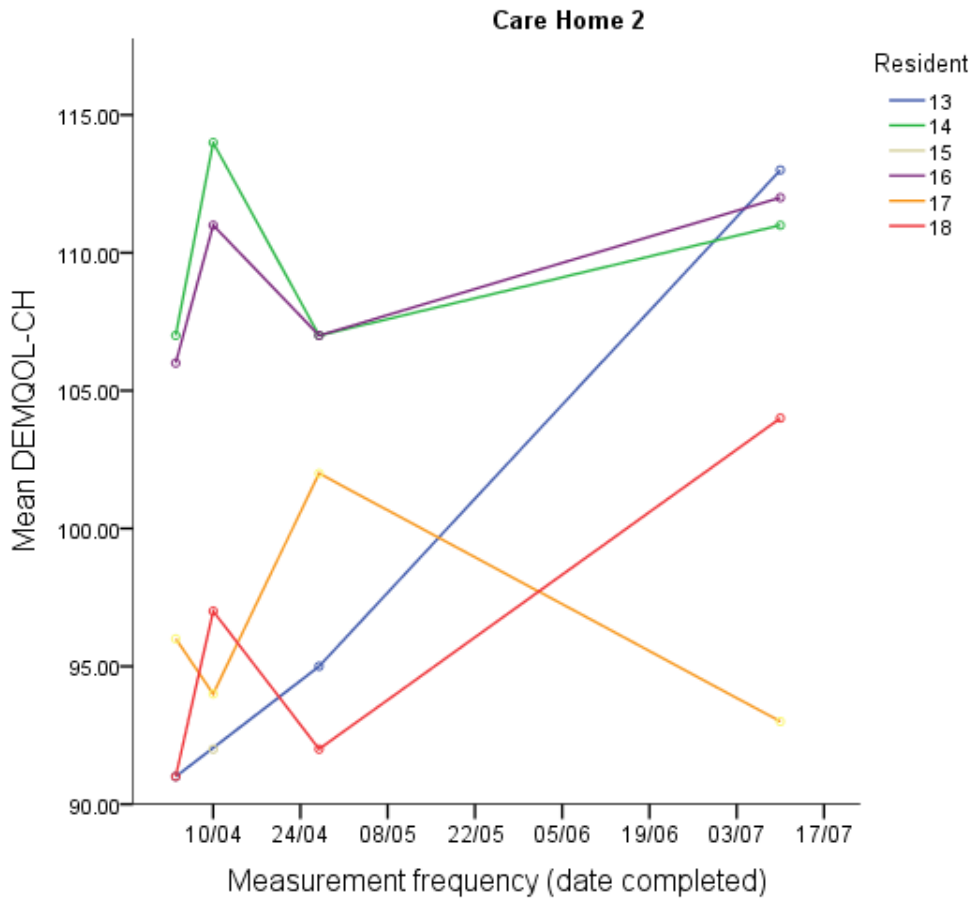


Figure 7.7. QoL ratings for care home 2. This figure illustrates the QoL ratings of 5 residents over 4 months. Only five of the six residents in this home had their QoL rated more than once. The x axis represents the date of measurement

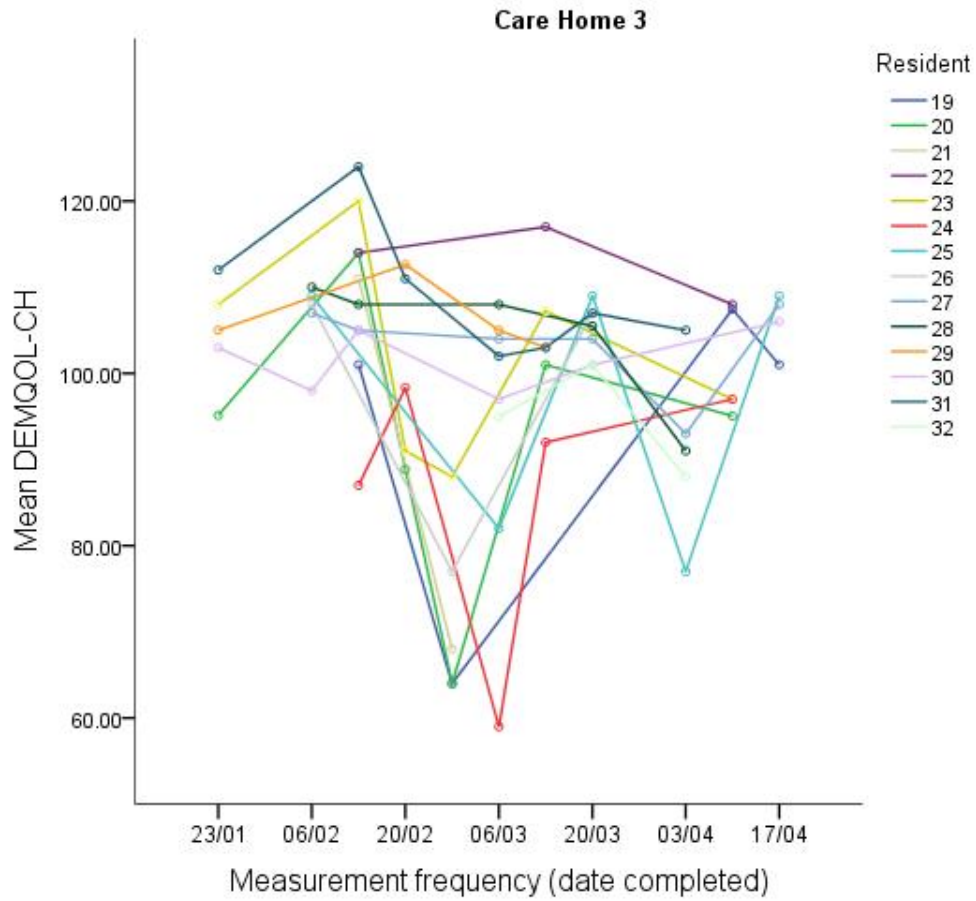


Figure 7.8. QoL ratings for care home 3. This figure illustrates the QoL ratings for 14 residents over 4 months. Each line represents one resident. The x axis represents the date of measurement

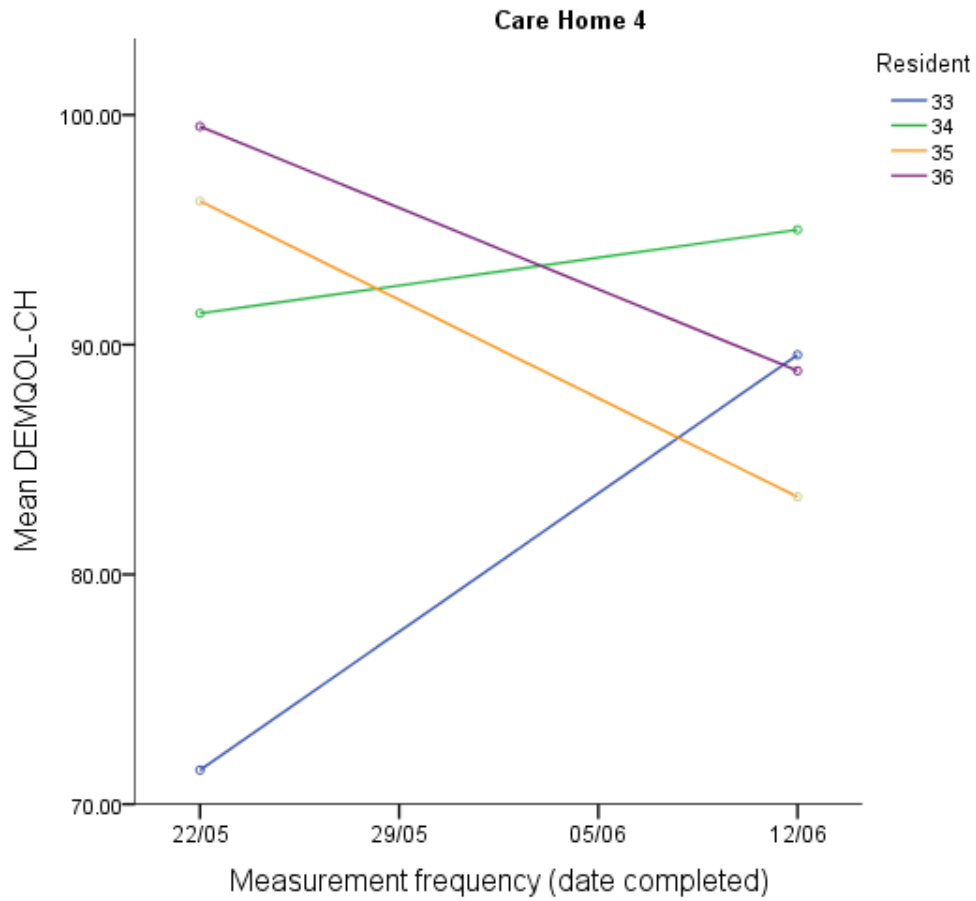


Figure 7.9. QoL ratings for care home 4. This figure illustrates the QoL ratings made for 4 residents over 2 months. Each line represents one resident. The x axis represents the date of measurement

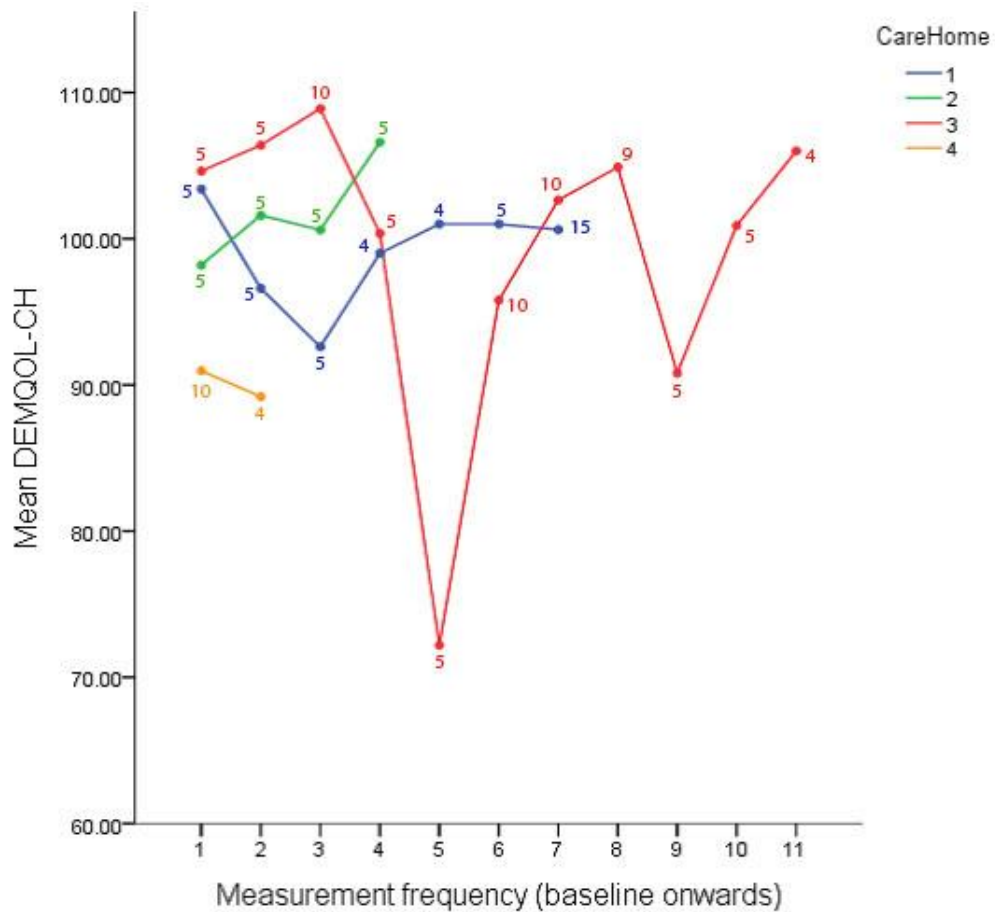


Figure 7.10. QoL ratings for each care home throughout the study. This figure illustrates the mean QoL for each home throughout the study. Each line represents an individual home. The x axis represents each measurement time-point. The number of ratings made at each time point is shown

7.2.3 Reliability

7.2.3.1 Acceptability and data quality

Table 7.5 shows the descriptive statistics of DEMQOL-CH for the whole dataset, baseline, and first follow-up datasets. Missing scores and floor and ceiling effects were within acceptable ranges for both datasets.

Baseline data were not normally distributed, therefore a non-parametric Kruskal-Wallis test was carried out to assess if there was a statistically significant difference between baseline, first follow-up, and second follow-up scores.

Results showed that there were no statistically significant differences ($\chi^2(2, n = 152) = 2.64, p = 0.267$).

7.2.3.2 Internal consistency

Internal consistency was good to excellent for all three datasets. Cronbach's α and 95% confidence intervals (CI) of DEMQOL-CH for the whole, baseline and follow-up datasets are presented in Table 7.5.

Table 7.5

Descriptive statistics, data quality and acceptability of DEMQOL-CH for different dementia severities, for whole sample, baseline, and first follow-up

	n	Reliability (Cronbach's alpha) (95% CI)	% missing	Score range			Floor/ceiling effect		
				Scale	Sample	Mean (SD)	% Floor	% Ceiling	Skew
Whole dataset	154	0.90 (0.88 – 0.92)	0	31-124	59 – 124	98.78 (12.36)	0	0.60	-1.06
Questionable	10	0.96 (0.92 – 0.99)	0		62 – 117	90.20 (19.86)	0	0	-0.05
Mild	47	0.89 (0.84 – 0.93)	0		64 – 124	100.14 (11.84)	0	2.1	-0.49
Moderate	30	0.89 (0.82 – 0.94)	0		60.97 – 115	99.93 (11.25)	0	0	-1.49
Severe	67	0.90 (0.86 – 0.93)	0		59 - 112	98.36 (11.56)	0	0	-1.43
Baseline data	88	0.92 (0.89 – 0.94)	0	31-124	59 – 124	97.00 (14.38)	0	1.1	-0.86
Questionable	8	0.96 (0.90 – 0.99)	0		62 - 114	85.50 (19.05)	0	0	0.38
Mild	25	0.90 (0.83 – 0.95)	0		64 - 124	99.95 (13.76)	0	4	-0.62
Moderate	16	0.92 (0.86 – 0.97)	0		60.97 - 115	98.75 (13.80)	0	0	-1.42
Severe	39	0.91 (0.87 – 0.95)	0		59 – 111	96.39 (13.31)	0	0	-1.17

	n	Reliability (Cronbach's alpha) (95% CI)	Score range			Floor/ceiling effect			
			% missing	Scale	Sample	Mean (SD)	% Floor	% Ceiling	Skew
First follow-up	56	0.84 (0.77 – 0.90)	0	31-124	77 – 119	101.62 (8.75)	0	0	-0.58
Questionable	2	0.83 (0.02 – 1.00)	0		101 – 117	109.00 (11.31)	0	0	-
Mild	17	0.87 (0.76 – 0.94)	0		83.38 – 119	102.13 (9.86)	0	0	-0.32
Moderate	12	0.82 (0.64 – 0.94)	0		88.87 – 112.63	101.17 (8.34)	0	0	-0.25
Severe	25	0.86 (0.76 – 0.93)	0		77 - 112	100.89 (8.25)	0	0	-1.32

7.2.3.3 Inter-rater reliability

For ratings made up to 7 days apart the ICC for inter-rater reliability was 0.40 (95% CI = 0.06 – 0.65) (n = 31).

7.2.3.4 Test-retest

Test-retest reliability for the whole sample had an ICC of 0.65 (95% CI = 0.50 – 0.76). ICCs when separated into 2 week time interval groups ranged from 0.30 to 0.75. See Table 7.6 for correlations of whole sample and separate time intervals.

Table 7.6.

DEMQOL-CH: ICCs for test-retest reliability for whole sample and for grouped time intervals

Time	n	Intra-class correlation (ICC)	95% Confidence intervals	
			Lower bound	Upper bound
Whole sample	74	0.65	0.49	0.76
1 to 2 weeks	9	0.75	0.22	0.94
3 to 4 weeks	34	0.72	0.51	0.85
7 to 8 weeks	19	0.30	-0.18	0.66
12 weeks	12	0.56	0.001	0.85

7.2.4 Validity

7.2.4.1 Factor analysis

The Keiser-Meyer-Olkin (KMO) measure for sampling adequacy was 0.84 for the whole data sample and 0.82 for the baseline data sample. This indicated that the sample was suitable for factor analysis. Bartlett's test of sphericity was significant for the whole sample ($\chi^2(465)$, = 3106.14, $p < 0.001$) and for the baseline sample ($\chi^2(465)$, = 2126.16, $p < 0.001$).

For the whole dataset, 6 factors with eigenvalues greater than 1 were identified, these explained 68.0% of the variance. The screeplot (Figure 7.11) suggested that either a 5-factor or a 4-factor structure were probable. After examining the 6-factor, 5-factor, and 4-factor solutions, the 4-factor solution was chosen as it provided a clearer factor structure.

The 4-factor solution accounted for 58.8% of the variance. Examination of the model fit showed there were 135 (29%) non-redundant residuals. The 4 factors were labelled as follows: Factor 1, functioning (15 items, $\alpha = 0.92$); Factor 2, positive emotions (5 items, $\alpha=0.84$); Factor 3, negative emotions (6 items, $\alpha=0.88$); and Factor 4, engagement (5 items, $\alpha= 0.85$). One item (getting in touch with people) cross loaded onto Factor 1 and Factor 4 above the criterion of 0.40. It was agreed through discussion with the wider research team that the item 'getting in touch with people' fitted better conceptually in Factor 4. One item (keeping him/herself clean) did not load onto any factor above 0.40 but loaded onto factor 1 with a loading of 0.386.

Factor loadings after rotation are shown in Table 7.7. Loadings of <0.3 are not included in the table.

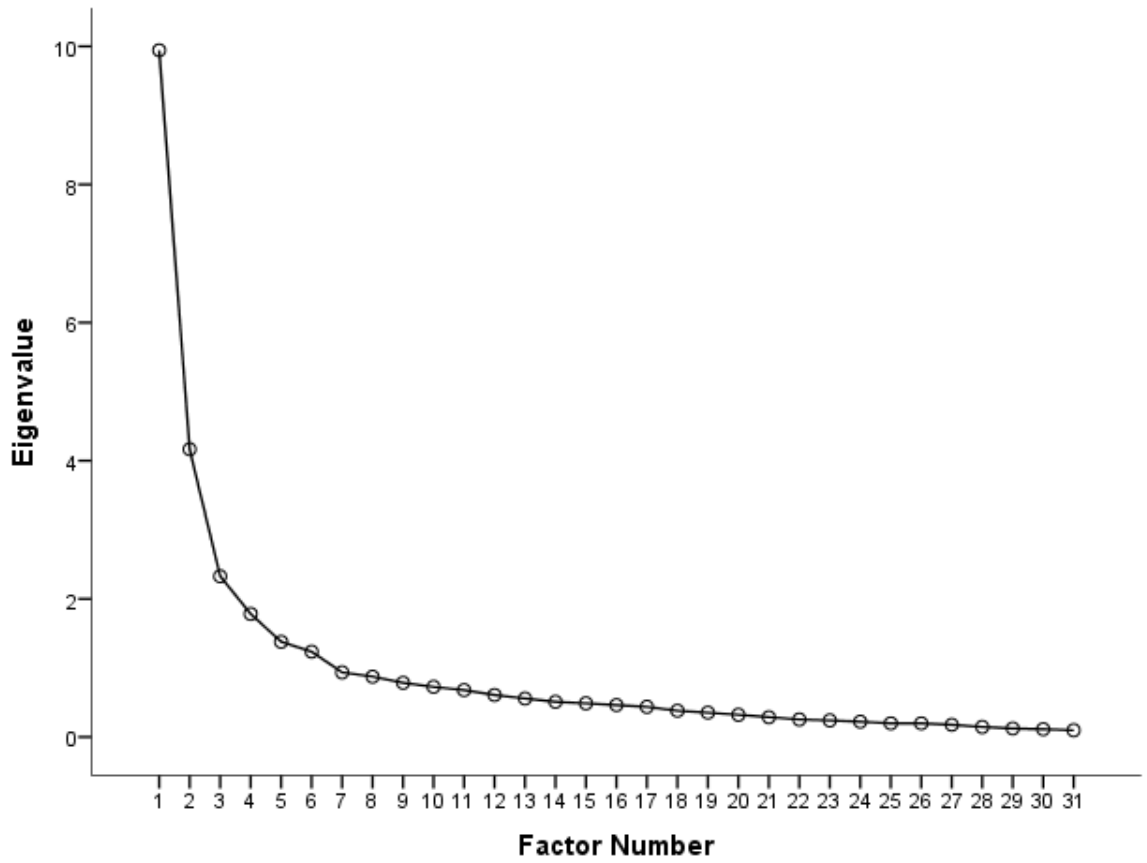


Figure 7.11. Scree plot for whole sample dataset ($n = 154$). The scree plot suggests either a five or four factor solution is probable

Table 7.7

Rotated factor loadings (N=155) for whole sample dataset

Summary description of question	Factor			
	1 Functioning	2 Positive emotion	3 Negative emotion	4 Engagement
Memory in general	0.792			
Things taking longer than they used to	0.761			
Things that happened a long time ago	0.750			
Forgetting what day it is	0.718			
Looking after finances	0.717			
Things that happened recently	0.660			
Thoughts being muddled	0.642			
Forgetting where he/she is	0.618			
Using money to pay for things	0.598			
Difficulty making decisions	0.509			
Getting in touch with people	0.500			-0.404
Forgetting people's names	0.491			
Getting what they want from the shops	0.487			
Keeping him/herself looking nice	0.425	-0.318		
Keeping him/herself clean	0.386			
Full of energy		0.831		
Cheerful		0.766		
Lively		0.742		
Have things to look forward to		0.649		
Content		0.529		
Distressed			-0.850	
Frustrated			-0.713	
Irritable			-0.713	
Worried or anxious			-0.679	
Sad			-0.595	
Fed up			-0.548	
Not being able to help others				-0.843
Not playing a useful part				-0.800
Not having enough company				-0.698
Physical health				-0.559
Making self understood				-0.412
Cronbach's alpha (95% confidence interval)	0.92 (0.90-0.94)	0.84 (0.80-0.88)	0.88 (0.85-0.91)	0.86 (0.83-0.89)

For the baseline dataset 7 factors were identified with eigenvalues greater than 1 which explained 74.7% of the variance. Similar to the whole dataset, the scree plot (Figure 7.12) suggested either a 5 or 4-factor structure. After examining the different factor structures the 4-factor solution was preferred, accounting for 62.4% of the variance. Examination of the model fit showed there were 159 (34%) non-redundant residuals.

The 4 factors were labelled as follows: Factor 1, functioning (15 items, $\alpha = 0.93$, 95% CI = 0.91 – 0.95); Factor 2, positive emotions (5 items, $\alpha = 0.84$, 95% CI = 0.78–0.89); Factor 3, negative emotions (6 items, $\alpha = 0.91$, 95% CI = 0.87-0.93); and Factor 4, engagement (5 items, $\alpha = 0.86$, 95% CI = 0.81 – 0.90).

Similar to the whole sample dataset the item ‘getting in touch with people’ loaded onto Factors 1 and 4, although this did not load above the criterion of 0.40 for Factor 4. It was also agreed that this item fits better in Factor 4 compared to Factor 1. Two items (‘forgetting people’s names’ and ‘making self understood’) did not load onto any factor above the criterion of 0.40.

Factor loadings after rotation and Cronbach’s alpha for scales are shown in Table 7.8. Factor loadings of <0.30 are not included.

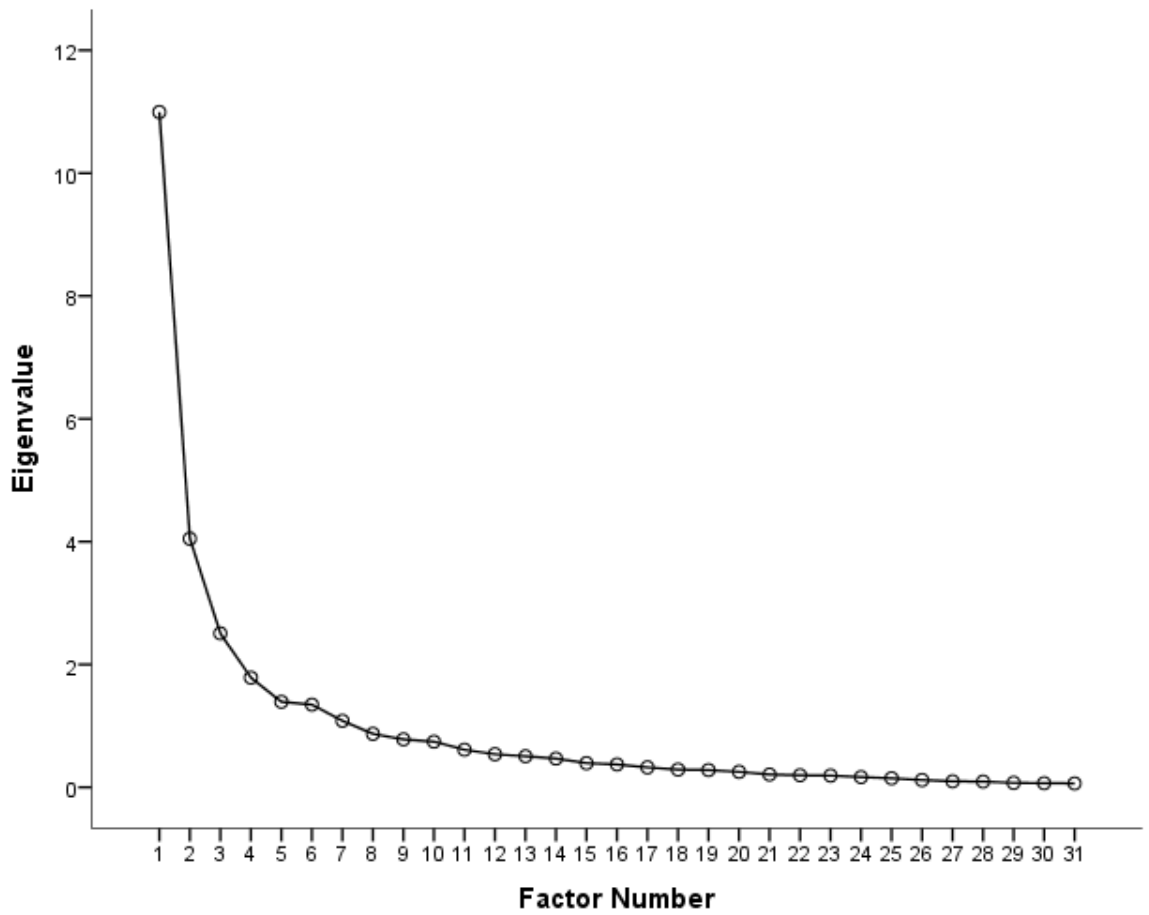


Figure 7.12. Scree plot for baseline sample ($n = 88$). The scree plot suggests either a five or four factor solution are probable

Table 7.8

Rotated factor loadings (N=89) for baseline dataset

Summary description of question	Factor			
	1 Functioning	2 Positive emotion	3 Negative emotion	4 Engagement
Things that happened long time ago	0.830			
Looking after finances	0.825			
Things taking longer than they used to	0.804			
Using money to pay for things	0.752			
Memory in general	0.712		-0.329	
Forgetting what day it is	0.593			
Thoughts being muddled	0.590			
Getting what want from shops	0.555			
Getting in touch with people	0.513			-0.396
Things that happened recently	0.507		-0.38	
Difficulty making decisions	0.450			
Keeping self looking nice	0.425	-0.305		
Forgetting where he/she is	0.418		-0.326	
Keeping self clean	0.400			
Forgetting people's names	0.355		-0.321	
Full of energy		0.802		
Cheerful		0.796		
Lively		0.670		
Things to look forward to		0.638		
Content		0.620		
Distressed			-0.888	
Irritable			-0.779	
Frustrated			-0.727	
Sad			-0.668	
Worried or anxious			-0.660	
Fed up			-0.592	
Not being able to help others				-0.894
Playing a useful part				-0.887
Not having enough company				-0.771
Physical health	0.321			-0.562
Making self understood				-0.321
Cronbach's alpha	0.93	0.84	0.91	0.88
(95% confidence interval)	(0.90-0.95)	(0.78-0.89)	(0.87-0.93)	(0.83-0.91)

7.2.4.2 Convergent validity

The association between DEMQOL-CH and DCM indices are presented in Table 7.9. Only residents with mild and moderate dementia were available for observation using DCM.

Correlations between DEMQOL-CH and mean well-/ill-being (mean WIB) and the percentage of WIB scores that were positive (% WIB +3 or +5) were low ($r_s = 0.06$, $n = 35$ $p = 0.369$, and $r_s = 0.00$, $n = 35$ $p = 0.50$, one-tailed, respectively). A weak statistically significant positive correlation was found for DEMQOL-CH and the percentage of observed 'good' behaviours (% BCC Type 1) ($r_s = 0.34$, $n = 35$ $p = 0.024$, one-tailed).

No statistically significant correlations were found for those with mild dementia, however, there was a trend toward significance with $p = 0.06$ for all DCM indices.

For those with moderate dementia a strong positive correlation was found between DEMQOL-CH and mean WIB score ($r_s = 0.67$, $n = 13$ $p = 0.006$, one-tailed) and a moderate positive correlation between DEMQOL-CH and % BBC Type 1 ($r_s = 0.55$, $n = 13$ $p = 0.026$, one-tailed).

Table 7.9

Correlations (Spearman's r) between DEMQOL-CH and DCM indices. Results shown for whole sample, and mild and moderate dementia severity sub-samples. No analyses carried out for severe dementia severity

	Dementia Care Mapping		
	WIB mean	% WIB +3 or +5	% BCC Type 1
DEMQOL-CH Total score	0.06	0.00	0.34*
Mild	0.41	0.41	0.41
Moderate	0.67**	0.14	0.55*

Notes: WIB = well- and ill- being score, BCC = behaviour category codes.

Full sample $n = 35$, Mild sample $n = 22$, Moderate sample $n = 13$

* = $p \leq 0.05$

** = $p \leq 0.01$

7.2.4.3 *Known-groups differences*

Table 7.5 shows the mean scores for questionable, mild, moderate, and severe dementia groups for the whole dataset, baseline and follow-up dataset. For the whole data and the baseline dataset the mean QoL score was lowest for questionable and highest for mild dementia. (See also Figure 7.13).

Results of the Kruskal-Wallis test show that there were no statistically significant differences between the dementia severity groups for the whole dataset ($\chi^2(3, n = 154) = 1.80, p = 0.614$) or baseline dataset ($\chi^2(3, n = 8) = 3.71, p = 0.294$).

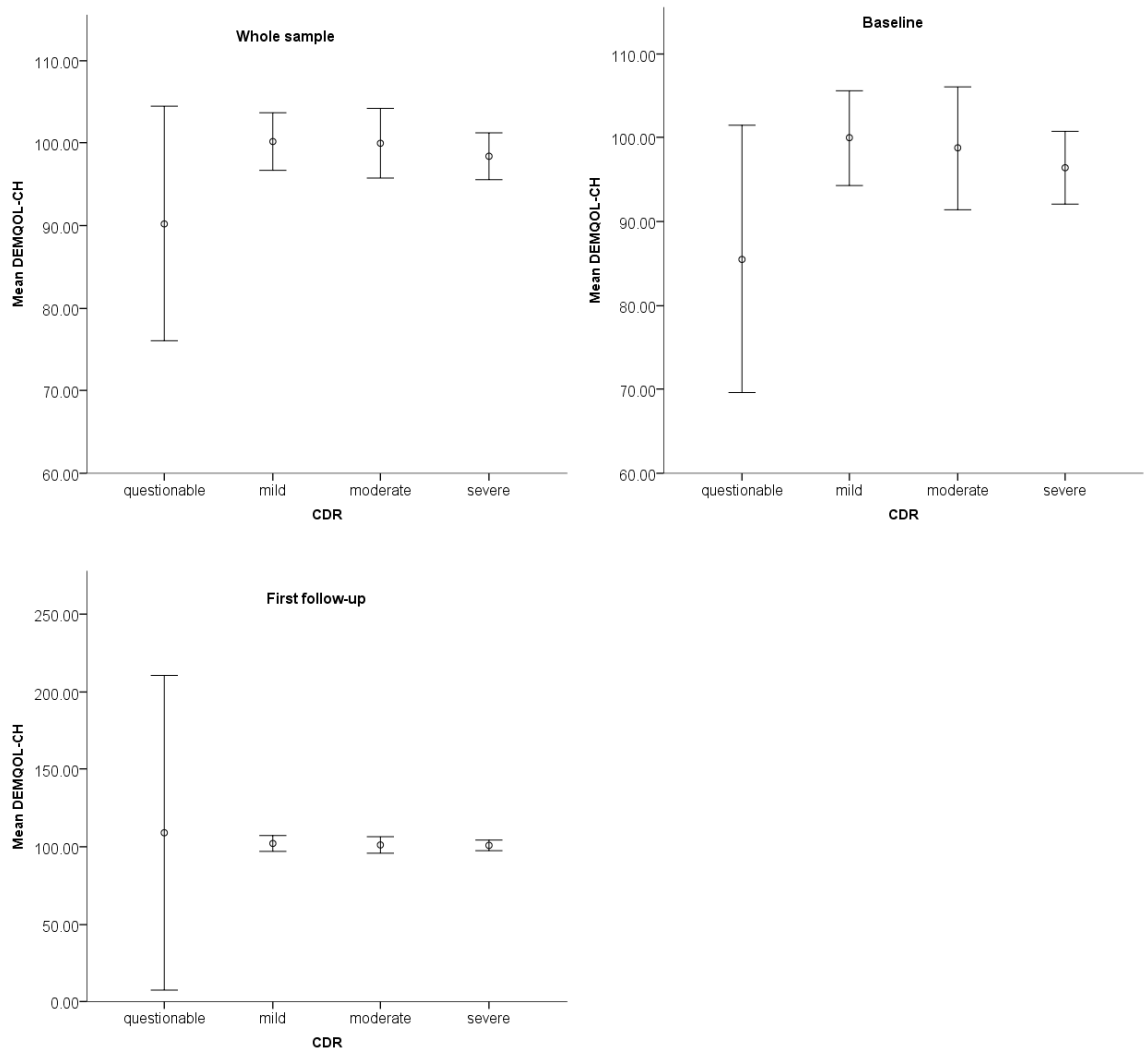


Figure 7.13. Mean DEMQOL-CH QoL scores of different dementia severities. Mean scores with 95% confidence intervals for questionable, mild, moderate, and severe dementia for the whole, baseline, and first follow-up data samples

7.2.5 Overall QoL scores

Descriptive statistics showed, as expected, that positive overall QoL categories ('very good', and 'good') had higher QoL scores than negative categories ('fair', and 'poor'), see Table 7.10.

Results of a one-way ANOVA for the whole sample showed a statistically significant difference between the overall QoL categories ($F(3,150) = 574.90, p = 0.009$). A Tukey post hoc test showed that QoL scores were significantly higher for the 'very good' category in comparison to the 'poor' and 'fair' categories ($P < 0.05$).

For the baseline dataset a statistically significant difference was also found ($F(3,84) = 1018.19, p = 0.001$). A post hoc Tukey test showed that QoL scores were significantly higher for the 'very good' category in comparison to the 'poor' and 'fair' categories ($p < 0.05$). And 'good' was significantly higher than the 'poor' category ($p < 0.05$).

Table 7.10

Mean DEMQOL-CH QoL score for each overall QoL category

Overall QoL	n	Mean QoL (SD)
Whole sample		
Poor	31	95.30 (13.33)
Fair	62	96.49 (12.66)
Good	40	101.58 (10.44)
Very good	21	104.60 (10.65)
Baseline		
Poor	15	87.40 (14.92)
Fair	37	95.16 (14.42)
Good	21	99.45 (11.20)
Very good	15	106.74 (11.47)

Descriptive statistics for overall QoL categories for different severities are outlined in Table 7.11. No residents with moderate dementia were rated as having poor overall QoL, residents with severe dementia had more 'poor' and 'fair' overall QoL category ratings.

The positive overall QoL categories ('very good' and 'good') had higher QoL scores than negative ('fair' and 'poor'), with the exception of severe dementia, where the 'very good' overall QoL category had a lower QoL score. See Figure 7.14.

A one-way ANOVA found a statistically significant difference for questionable ($F(3,6) = 1011.48, p = 0.006$) and mild ($F(3,43) = 418.93, p = 0.024$) dementia severities. A Tukey post hoc analysis for questionable dementia showed that QoL scores were significantly higher for the 'very good' category compared to 'poor' and 'fair' categories ($p < 0.05$). QoL scores were also significantly higher for the 'good' category compared to 'poor' and 'fair' ($p < 0.05$)

Post hoc test could not be carried out for mild dementia as there were less than two cases in one of the groups.

Table 7.11

Mean DEMQOL-CH QoL score for each overall QoL category. Separate columns for each dementia severity

	Questionable M(SD)	n	Mild M(SD)	n	Moderate M(SD)	n	Severe M(SD)	n
Whole dataset								
Poor	66.50 (6.36)	2	77	1	-	-	98.01 (10.70)	28
Fair	78.00 (10.00)	3	94.34 (9.40)	9	98.78 (12.03)	18	97.54 (12.97)	32
Good	104.33 (11.37)	3	100.08 (12.14)	23	101.22 (7.76)	9	107.49 (2.06)	5
Very good	111.00 (4.24)	2	105.61 (9.75)	14	103.00 (18.19)	3	93.57 (2.22)	2

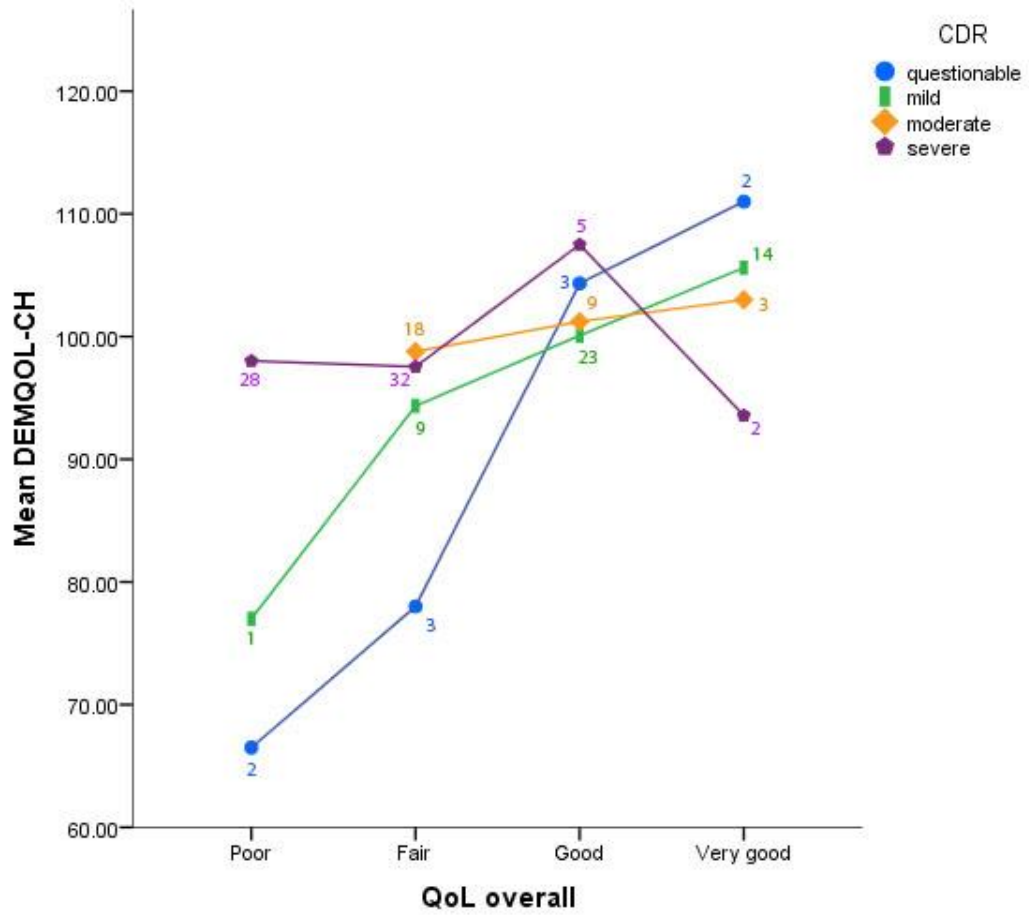


Figure 7.14. Total DEMQOL-CH QoL scores of each overall QoL category for different dementia severities

7.2.6 Regression analyses

The tests of hierarchical multiple regression found that the assumption of normality was violated with a negative skew (-1.06, standard error = 0.19) on the dependent variable (QoL). Square root transformation of the QoL variable resulted in approximately normal data (skew = 0.25) (Tabachnick & Fidell, 2007). An examination of correlations between the remaining variables (Table 7.12) revealed that none of the independent variables were highly correlated. Collinearity statistics (Tolerance and VIF) were all within acceptable limits (Brace, Kemp & Snelgar, 2006). An analysis of the Mahalanobis distance score indicated no multivariate outliers.

The hierarchical multiple regression showed that at Step 1, resident gender and resident dementia severity did not contribute significantly to the regression model ($F(4,112) = 1.97$, $p = 0.103$), accounting for just 3.2% of the variation in QoL. The introduction of the time variables explained an extra 11.1% of the variation in QoL. This change in R^2 was significant ($F(7,109) = 3.76$, $p = 0.001$). Finally, adding staff rating confidence to the regression model explained an additional 10.3% of the variance in QoL and this change in R^2 was significant ($F(8,108) = 5.74$, $p < 0.001$). See Table 7.13 for a summary of the hierarchical linear regression analysis results.

When all ten predictor variables were included in Step 3 of the regression model there were only 3 significant predictors of QoL, these were: time working in the care home ($p < 0.05$), hours worked per day, and confidence (both $p < 0.001$).

Table 7.12

Correlation matrix of study variables in hierarchical regression analysis

	QoL	Resident gender	Severe	Questionable	Mild	Moderate	Time in care home	Time in care sector	Hours worked per day	Confidence using DEMQOL-CH
QoL	1.000									
Resident gender: Male	0.043	1.000								
Severity: Severe	-0.125	-0.048	1.000							
Severity: Questionable	-0.164*	-0.253*	0.222*	1.000						
Severity: Mild	0.128	0.266*	0.591**	0.195*	1.000					
Severity: Moderate	0.108	-0.100	0.394**	0.130	0.347**	1.000				
Time in care home	-0.130	0.164*	0.083	0.124	0.066	-0.264*	1.000			
Time in care sector	-0.070	-0.248*	0.096	0.053	0.001	-0.156*	-0.429**	1.000		
Hours worked per day	-	-0.096	0.031	-0.059	-0.051	0.061	0.100	0.100	1.000	
Confidence using DEMQOL-CH	0.301**	0.288**	0.019	0.219*	0.056	-0.245*	-0.013	-0.096	0.139	-0.145
										1.000

* = $p < 0.05$, ** = $P \leq 0.001$

Table 7.13

Summary of hierarchical regression analysis for variables predicting QoL

Variable	β	t	R	R²	Adjusted R²	ΔR^2
Step 1			0.257	.066	.032	0.066
Resident gender: Male	0.112	1.154				
Severity: Questionable	-0.139	-1.425				
Severity: Mild	0.180	1.749*				
Severity: Moderate	0.141	1.407				
Step 2			0.441	0.19	0.143	0.129**
Resident gender: Male	0.120	1.191				
Severity: Questionable	-0.244	-2.522				
Severity: Moderate	0.015	0.145				
Severity: Severe	-0.207	-2.045*				
Time working in care home	-0.183	-1.748				
Time working in care sector	-0.025	-0.235				
Hours worked per day	-0.320	-3.643				
Step 3			0.546	0.298	0.246	0.104**
Resident gender: Male	0.058	0.601				
Severity: Questionable	-0.175	-1.900				
Severity: Moderate	0.077	0.793				
Severity: Severe	-0.085	-0.851				
Time working in care home	-0.283	-2.791*				
Time working in care sector	0.095	0.931				
Hours worked per day	-0.384	-4.577**				
Confidence using DEMQOL-CH	0.356	3.995**				

* = $p < 0.05$, ** = $p \leq 0.001$

7.2.7 Study experience questionnaire

Questionnaire statements

Descriptive statistics of the two dichotomous questions show that all respondents believed that using a QoL instrument increased their insight into resident QoL and would recommend the instruments for measuring QoL for residents.

Descriptive statistics of the nine questionnaire statements are shown in Table 7.14. There was an overall positive response to using the DEMQOL-CH instrument with all respondents agreeing that they enjoyed using the instruments, they did not believe that the instrument was too complicated to use. There were positive responses to the statement ‘Completing the DEMQOL-CH helped me to do my job more effectively’ with most respondents agreeing strongly.

Open-ended questions

Q1) In your opinion, what was the best aspect of the DEMQOL-CH instrument?

One of the positive aspects of using DEMQOL-CH was that staff felt it was easy to use. Staff also felt that it not only provided further insights into residents QoL, it also highlighted areas of their own practice that are important, such as time, and that staff believe they need to spend more time with residents.

Q2) What improvements do you think could be made to DEMQOL-CH?

One member of care staff perceived some of the questions to be too vague. Apart from this, no other staff had any suggested improvements.

Q3) Do you think the DEMQOL-CH instrument has increased your insight into the QoL of the residents?

Staff believed that using the instrument highlighted other important aspects of the residents’ lives that they need to consider more, such as their life history.

Q4) Would you recommend DEMQOL-CH as a measure of QoL for residents?

Overall staff were positive about recommending DEMQOL-CH as a QoL instrument.

Table 7.14

Responses to questionnaire statements by care home staff on study experiences

Statement	Responses	Whole sample (n=4) n (%)
DEMQOL-CH met my expectations	Strongly agree	1 (25.0)
	Agree	3 (75.0)
Overall I enjoyed completing DEMQOL-CH	Strongly agree	1 (25.0)
	Agree	3 (75.0)
Regularly assessing QoL is important	Strongly agree	3 (75.0)
	Agree	1 (25.0)
There were too many QoL questions to complete	Neither agree nor disagree	1 (25.0)
	Disagree	3 (75.0)
I would have preferred to complete the DEMQOL-CH less frequently	Neither agree nor disagree	1 (25.0)
	Disagree	3 (75.0)
The DEMQOL-CH was too complicated to use	Disagree	1 (25.0)
	Strongly disagree	3 (75.0)
Completing DEMQOL-CH helped me to do my job more effectively	Strongly agree	3 (75.0)
	Neither agree nor disagree	1 (25.0)
It changed the way I think about the QoL of the residents	Strongly agree	4 (100.0)
I did not feel I could accurately complete the DEMQOL-CH	Agree	1 (25.0)
	Strongly disagree	3 (75.0)

7.3 Discussion

This chapter addressed aim 3 of the overall thesis, to assess the use of a QoL instrument in routine practice and whether routine QoL measurement by care staff in care homes is possible. We assessed the frequency of QoL ratings made by care staff, and assessed the psychometric properties of the DEMQOL-CH instrument when used as part of routine care.

The findings provide a proof of concept that it is possible for staff to rate resident QoL routinely in care homes. Regular measurement of QoL was possible for four of the five homes included in the study. Three of these homes rated QoL for four months and were able to carry out several ratings for each resident. One home carried out measurements for two months but were still able to obtain ratings for residents for each month. The changes to individual QoL over time observed in the graphs presented demonstrate the potential for capturing variations in QoL that may be missed by less frequent QoL measurement.

Findings from the psychometric analysis show excellent internal consistency and acceptable test-retest reliability, however, inter-rater reliability was below the set criterion. A clear 4-factor structure of DEMQOL-CH was found for the whole sample, which was strengthened by finding the same structure in the baseline data. Convergent validity for the whole sample was as expected for the percentage of 'good' behaviours observed, the other DCM indices were however poor. No significant differences were found between the dementia severities which is in line with the evidence base on the lack of correlation between dementia severity and QoL (Banerjee et al 2009). Regression analysis showed that a small proportion of the variance in QoL ratings was associated only with care staff factors.

Some analyses were carried out separately for both the whole sample and the baseline sample. This was to provide evidence of the robustness of the findings. The findings show few differences between the two samples, suggesting that regardless of whether repeated data or single time-point data are used the results are largely comparable. It must be noted however that these differences were not tested statistically. The acceptability and data quality were similar for both samples, mean QoL was similar, as were the scale ranges. The only noteworthy difference was a marginally higher percentage of missing values for the baseline data. Internal consistency results for the baseline and whole sample were both excellent, with equivalent 95% confidence intervals. The factor structure of the whole sample and baseline sample was the same with comparable Cronbach's alphas for each factor and similar

percentage of variance accounted for. There was a slight difference in the items that failed to load onto any factor, one item did not load for the whole sample, whereas two different items did not load for the baseline sample data. Scores for the know groups difference analysis showed similar scores for the two data samples. Finally, the scores for the overall QoL scores analysis also showed similar scores between the two data samples.

Overall the results show that DEMQOL-CH has acceptable psychometric properties in this sample and provides limited preliminary support for the use of DEMQOL-CH as a self-administered QoL instrument in care homes, however, further research in larger and more representative populations is needed.

Findings from the study experience questionnaires show that staff were positive about using DEMQOL-CH and believed that measuring QoL had given them more insight into resident QoL and had provided them with other areas to focus on or things to think about. However, the small sample size limits the conclusions that can be drawn.

7.3.1 Strengths and limitations

One of the strengths of this element of the study is that it is the first to implement the routine measurement of QoL in care settings and assess the psychometric properties of the instrument when used as intended. Despite the small number of care staff participants and residents included in the study the findings provide tentative evidence that QoL measurement can be carried out routinely by care staff and be implemented into normal care practice. Future studies need to identify and assess ways in which care homes can use this information to benefit residents and to realise the potential of the information obtained to enhance care quality.

The findings reported above need to be considered in light of the limitations. The small sample size and the selected nature of the respondent care home and care staff group limits generalisability and significance testing. The small sample size in this stage of the study will increase the possibility of type II error. There were a sufficient number of QoL ratings to perform the analyses of the study, however, these were carried out on repeated measurements. A small number of staff rated residents' QoL on more than one occasion. Repeated measurements of QoL allowed an evaluation of the feasibility of care staff

completing routine measurements over time, however, this could have negatively affected the findings from the psychometric analysis. There is likely to be a lack of independence in the observations which will affect the findings presented. Future studies should aim to evaluate the psychometric properties of DEMQOL-CH in large, independent, representative samples with a specified frequency of repetition. Similarly, only a small number of participants completed the study experience questionnaires. Some staff had left employment and some were not available due to annual leave, this limits the inferences that can be made from the experience questionnaire findings.

As discussed above, the small and non-random recruitment of staff and homes into this study limits the generalisability of its findings. The sample of homes included in the study was small and all were from one geographical area. Therefore, the homes will not be representative of care homes nationally. The homes were not unusual in any way in terms of their size or staffing structure, however, most of the homes had been in contact with the care home in-reach team. This team is invited into care homes to assist with any challenges that staff may face with residents or training. This may show a willingness to accept assistance and make necessary changes to care provision to improve care practice. This may not be observed in homes who have not requested outside assistance and advice. In addition, the sample of participants included in this stage of the study were heterogeneous, consisting of nurses, care assistants, and activity co-ordinators. Unlike previous stages of the study no senior care assistants or managers were consented into the study. This sample is not representative of the social care sector as a whole, and will not be representative of other homes; particularly care homes that do not employ nurses or activity co-ordinators, not all homes employ these staff, whereas in this study they made up three quarters of the sample. This limits the generalisability of the findings, future studies should include larger samples of more representative staff to provide more robust findings.

Psychometric analysis was based on routine QoL measurements. In psychometric studies it is common practice that participants collect a small set of data for a specified period of time only and psychometric analyses are carried out. However, in this thesis the overall aim was to evaluate routine QoL measurement in care practice. Therefore, in this stage of the study routine QoL measurements were collected by staff and psychometric analysis carried out on this data to understand the properties of the instrument when used in the field under normal circumstances. There may have been differences in results if data were collected in a

different way. Future studies using DEMQOL-CH would benefit from assessing the properties of the instrument in non-routine use.

DCM was used to assess convergent validity. It would have been possible to use another proxy measure of QoL such as the QOL-AD or QUALIDEM. However, there was a need to limit the burden on care staff as much as possible. Future evaluations of DEMQOL-CH should assess convergent validity with instruments such as QoL-AD or QUALIDEM, they may be more comparable to DEMQOL-CH.

7.3.2 Conclusion

To summarise, the answers to the research aims of this stage were as follows:

- Aim 1 - care staff were able to collect regular QoL ratings for residents. On average, staff could collect monthly resident QoL ratings and completed 15 QoL ratings. Residents, on average, had four QoL ratings made for them over the period of the study.
- Aim 2 - psychometric properties of DEMQOL-CH was assessed including reliability and validity analyses. DEMQOL-CH reliability was acceptable, with acceptable data quality and test-retest reliability and excellent internal consistency. Inter-rater reliability was poor. In terms of validity, DEMQOL-CH demonstrated a clear 4-factor, however, convergent validity was lower than expected.
- Aim 3 - there were no differences in QoL between the different dementia severities.
- Aim 4 - care staff were positive about using DEMQOL-CH, most believed that using DEMQOL-CH and measuring QoL helped them to do their job more effectively.

No ethical issues arose in this stage of the study.

These results are discussed in detail in Chapter 8.

Chapter 8 Discussion

This thesis describes the preliminary development and evaluation of the feasibility of routine measurement of QoL of people with dementia in care homes using a proxy QoL instrument. This chapter synthesises and discusses the findings presented in preceding chapters and considers the strengths and limitations of the study overall.

8.1 Summary

The aim of this thesis was to evaluate the feasibility of the routine measurement of QoL in care homes. The specific aims were:

1. To determine the feasibility of implementing QoL measurement into care home practice.
2. To assess if DEMQOL-Proxy can be used by care staff without the need of an interviewer to administer it.
3. To assess the use of a QoL instrument in routine practice and whether routine QoL measurement by care staff is possible.

The research presented in this thesis is the first to provide a preliminary demonstration of the potential for the modification of an existing instrument to work in care homes and the feasibility of routine QoL measurement in care homes.

Qualitative findings demonstrated that routine measurement of QoL by care staff would be possible and was positively received by staff. They believed that measuring QoL in routine care practice might lead to improvements in quality of care and QoL. It was then found that DEMQOL-Proxy, an instrument developed to be administered by an interviewer, generates additional error when used as a self-administered instrument by care staff in care homes. The structure of DEMQOL-Proxy needed to be modified to be used with acceptable reliability without an interviewer so that the questions are read and interpreted correctly. This was achieved by creating a modified instrument, DEMQOL-CH. DEMQOL-CH was tested and found to have acceptable levels of reliability and validity that are comparable to other candidate QoL instruments that might be used in care homes. Preliminary data on the feasibility of its use in care settings by care staff were generated.

This thesis therefore provides a proof of concept that routine QoL measurement in care homes by care staff may be feasible and acceptable. Such an approach might provide care staff with insights into how to improve the QoL of residents. Such measurement would also allow the routine comparison of different homes and interventions in care homes.

8.2 Care staff attitudes to and experience of routine QoL measurement

Little previous research has explored the opinions of care staff about measuring QoL as a part of routine care practice. The data from this project are limited by the small sample size and the selected nature of the study population, but care staff were positive about measuring QoL as a part of routine care and they believed there were potential benefits and positive outcomes for both staff and residents. Care staff saw themselves as responsible for resident outcomes, with a belief that resident QoL is largely reliant on their own knowledge and actions. Learning more about the residents was seen as a way to enable them to improve their knowledge and therefore help them to improve residents' QoL. The care staff interviewed articulated a clear desire to measure QoL to inform and improve the content of care.

Staff were realistic about not always being able to improve resident QoL, but they stated that simply measuring QoL and knowing the QoL status of individual residents would be better than not knowing at all. These findings provide new insights and a different perspective of the potential benefits of measuring QoL as an outcome that may be meaningful and useful. Many would argue that the primary aims of measuring QoL is to be able to improve it, so measuring QoL would be largely for the benefit of residents. As such, a large proportion of studies have assessed what causes changes in QoL. These have assessed clinical (Beerens et al., 2015; Hoe et al., 2009; Lyketsos et al., 2003), and environmental and care provision factors (Funaki et al., 2005; Zimmerman et al., 2005) that might affect QoL. The one study that investigated the routine measurement of QoL in care homes concluded that routine measurement of QoL in itself was not enough to improve QoL and that staff need to be empowered to make the necessary changes (Magennis & Chenoweth, 2009). The changes they identified as needed were seen as largely institutionally determined and so beyond the means of a care worker to deliver. The findings in this thesis however suggest that understanding the benefits and outcomes for staff may also be important. Empowering staff

to make institutional changes would be of benefit. However, the data here suggest that there remains the potential for routine measurement of QoL to provide a focus for reflection on individual residents and their QoL to facilitate person-centred care. Also, aggregated measures might present a quality marker for the home as a whole over time and in relation to other care homes.

One of the aims of person-centred care is to change the culture of care in homes to improve the experience and well-being of residents. One of the ways that this can be achieved is by moving away from exclusive focus on completing tasks and instead trying to understand the experience of residents (Downs, 2013). Some of the potential benefits of measuring QoL identified by care staff here are clearly supportive of the delivery of person-centre care. Staff believed that measuring QoL would help them to move away from merely focussing on the tasks they do for residents and focus more on what matters to the QoL of the residents which they found hard to capture otherwise. Other perceived benefits discussed included: improvements to staff knowledge and understanding of residents and their feelings; awareness of what QoL is; and awareness and understanding of the difference between QoL and quality of care.

These potential benefits were identified prior to collection of QoL data so are evidence of what staff think could be achieved, not what would be achieved. However, in the study experience questionnaires, conducted after routine QoL measurement, staff reported that measuring QoL led them to reflect more on residents, and to recognise they need to spend more time with residents. It is unclear if these findings suggest that staff were not as confident or able to rate resident QoL as they initially thought, or that that they thought that spending more time with residents might improve their QoL. Properly integrated into routine practice, QoL measurement could promote reflective practice, even if only to highlight residents who might need more attention. Care staff reported they had an increased understanding and awareness of QoL and of the residents' individual needs. Developing an awareness of the difference between QoL and quality of care was discussed. This demonstrates that staff were aware, or becoming aware, that quality of care is not a measure of QoL by itself. Staff also recognised what they do not currently focus on when thinking of residents' QoL. They discussed that measuring QoL made them more aware of factors such as how a resident's past will affect their QoL now. Task focussed routines often dominate in care settings, despite the drive for person-centred care, the findings of this study indicate that

getting staff to measure QoL could raise awareness of residents' needs, their QoL, and how to improve it. The aims of person-centred care and QoL measurement are complementary, i.e. focussing on the individual resident (Winzelberg et al., 2005), and so measuring QoL as a part of routine care practice could help to enhance and inform person-centred care provided by care staff. Although only a small number of staff completed the experience questionnaires, they provide a tentative demonstration of the potential outcomes of measuring QoL which would benefit from further assessment in future studies.

Care staff felt that the best part of the instruments was their ease of use. This was one of the key findings from qualitative interviews, where staff believed that because the instrument appeared easy to use and provided potential benefits, they could foresee overcoming the barriers they identified. Although there were mainly positive discussions of the instrument some staff did report that some of the questions were similar and some vague. Future work on the DEMQOL-CH instrument would benefit by looking at item reduction, which could also address concerns with 'time poor' members of staff.

It is important to note that this research did not assess changes in staff attitudes, awareness, or care practice. This was in part to reduce the burden of the research on care staff. It was judged that the inclusion of additional measures would have increased the staff time needed to the point where it may have affected homes' willingness to participate in and compliance with completing the QoL instrument. A number of studies have assessed the effect of care staff factors on QoL assessments, but few have assessed the impact that measuring QoL has on staff. Most studies which have, have assessed this using DCM. This is logical since DCM is both a measure of QoL and an intervention to improve quality of care, (Barbosa et al., 2017; Brooker, 2005). These studies have reported: declines in staff stress; reduced staff burnout; less negative emotional reactions; and improvements in job satisfaction (Jeon et al., 2012; van de Ven et al., 2013). Chenoweth & Jeon (2007) investigated the effect of DCM on resident QoL and found no significant effect but did find that staff and resident interactions had improved. Further studies of the effects of routine QoL measurement including both staff and resident outcomes are needed.

8.3 Barriers and facilitators to implementation of routine QoL measurement

Staff views provided useful insights into how to introduce QoL measurement into routine care practice, and identified factors that might enhance or impede implementation. Findings from the implementation literature has found that time is the most prominent barrier to implementing changes to care practice (Vernooij-Dassen & Moniz-Cook, 2014). Time was the biggest barrier that care staff identified in stopping or affecting them being able to introduce routine QoL measurement into their practice. This is reasonable as time constraints in care and nursing homes, as well as in health and social care overall, are well-documented. Staffing levels and the nature of caring, especially in nursing homes where residents have more functional impairments (Bowman, Whistler, & Ellerby, 2004), can be burdensome on staff. Time as a barrier to implementation is usually seen as an organisational factor (Grol & Grimshaw, 2003). However, in this study there was little staff discussion of organisational factors in terms of others being responsible or of needing organisational involvement in the success of implementing routine QoL measurement. Staff appeared to have a sense of personal responsibility, not only towards the residents' lives by improving or maintaining their QoL, but also towards the success of implementing the QoL measure in practice. These findings are different to those from the implementation literature, where such organisational factors have been found as key to successful implementation (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005; Weiner, Amick, & Lee, 2008).

Staff also discussed how the amount of time they spend with residents affects their confidence and ability to rate resident QoL. This has previously been identified as a likely factor affecting the accuracy of proxy QoL ratings (Addington-Hall & Kalra, 2001). Addington-Hall and Kalra, (2001) suggest that this is likely to be a small effect as the important factors affecting proxy ratings are still unknown. However, the identification of this barrier by staff shows the importance it has to them in their ability to rate QoL.

Care staff were concerned about their ability to accurately rate the QoL of residents with communication problems. Communication difficulties are common in care home residents (Hawes et al., 1995). Effective communication between staff and residents is essential when providing person-centred care (McGilton et al., 2017), and has been related to higher resident QoL (Zimmerman et al., 2005). Staff thought that it might be more difficult to know and

understand how some people feel as those with impairments of verbal and non-verbal communication find it harder to convey their emotions. In practice however, when staff completed the QoL measurements they noted that although it was difficult, and that they had to think more carefully about questions regarding feelings, they were able to rate the QoL of people with communication impairments. Staff in Stage 4 (Chapter 7) also commented that it was more difficult to complete the feelings section of questions on DEMQOL-CH for people that do not communicate, but that they could complete them. The differences between QoL ratings of people with and without communication impairments was not assessed in this study, this may be of benefit to future research to further investigate if it has an effect on care staff QoL ratings.

8.4 Frequency of QoL ratings

When considering the routine measurement of QoL, how often QoL feasibly could or should be measured needs to be considered. In most studies of QoL in dementia the frequency of QoL measurement is determined by the design of the research and the intervention being evaluated. For example: studies aiming to describe the QoL of a particular group will measure QoL cross-sectionally at one time-point; intervention studies measure QoL before and after an intervention; and longitudinal studies measuring change of QoL over time measure QoL, at a minimum, at baseline and with one follow-up. (Magennis & Chenoweth, 2009), in their study of routine QoL measurement, measured QoL at only two time-points and provided no rationale for this frequency. However the utility of the measurement will be determined by their frequency of completion, especially if there is value in generating a dynamic picture of QoL in individuals and homes.

The feasibility of the routine use of outcome measures in mental health care (Slade, Thornicroft, & Glover, 1999; Thornicroft & Slade, 2000) and specialist community dementia services (Higginson, Jefferys, & Hodgson, 1997) has been discussed. It is generally accepted that routine use of QoL instruments would be beneficial in terms of improving patient outcomes. However, these papers seldom consider how often such routine measurements could be carried out. It is not known how often routine QoL assessments could be carried out in care homes, and what would be the most beneficial for residents and staff. No studies have asked care staff how often this could be done. Care staff views about the frequency of

measurement are important for the implementation of routine QoL measurement, particularly when care staff will be the ones completing the measurements. Discussions in the qualitative study showed that staff preferred frequent QoL measurements to monitor change. In order to reduce care staff burden there were also discussions about using a QoL instrument as a response to changing needs tool. This often occurs in care homes where a change in the needs of a resident prompts more frequent monitoring or assessment for a period of time; for example, more frequent assessment of an individual's weight may be prompted by sudden weight loss or illness. Care staff thought that if frequent (e.g. weekly or fortnightly) QoL measurements were too burdensome on staff then a minimum monthly measurement of QoL could be carried out with more frequent measurements for individual residents when needed. This approach however would rely on a systematic method of determining what would necessitate more frequent QoL measurement.

In stage four of the study staff in four of the five care homes were able to rate resident QoL repeatedly over a period of two to four months. On average, care homes were able to complete monthly QoL ratings for residents. In practice, some staff struggled to find the time to complete the instruments within the set time frame. When providing staff with the QoL instruments the researcher discussed how long a period of time it would take for them to complete a set of five instruments, taking about ten minutes each to complete. The modal answer was a period of a week. Further empirical investigations are needed into the value of more or less frequent QoL measurement and the effect of staff occupational characteristics (e.g. job role and hours worked per day) on staff engagement with and ability to implement routine QoL measurement into their individual practice. An important limitation of this study was the inclusion of a heterogeneous sample of nurses, care assistants, and activity-coordinators; furthermore, not all types of staff member completed QoL ratings (e.g. managers and senior care assistants). Further investigations using larger more representative samples of care staff are needed to assess the frequency of QoL ratings that can be achieved and to determine if there are any differences between staff groups.

Care homes are very busy places with routines to follow and particular tasks to complete, this makes it important that there is flexibility and feasibility in measurement. Although staff discussed being able to move away from more task-oriented routines and focusing more on QoL, the tasks remain. This was debated by managers in the discussion groups; working with existing practice in the home would enhance the long-term use of the instrument.

As outlined in Chapter 4, from the qualitative study we were able to infer some practical guidance to support the effective introduction of a QoL instrument into routine practice in a care setting. This guidance was used in this study and was effective in supporting implementation. There were three key points:

1. *Instrument fit* – The use of the QoL instrument should fit within existing practice.
2. *Training, environment and culture* – Successful use of the QoL instrument in a care home is dependent on the staff. They need to be trained in using the instrument and have the confidence to use it. Ensuring that management supports the staff in completing it routinely is vital to success.
3. *Rater choice* – A member of staff may not feel that they are adequately able to rate a particular resident's QoL, irrespective of the number of contact hours. It is important to consider who the best person to measure a resident's QoL is, as it is likely to affect accuracy and validity.

8.5 Self versus interviewer administration

In Stage 2, care home staff were asked to complete an interviewer and self-administered version of the DEMQOL-Proxy. Poor agreement was found between the two instruments. Data quality, acceptability, and reliability of the DEMQOL-Proxy (self-administered) were all comparable to that of the original DEMQOL-Proxy, and internal consistency, was marginally better. Poor agreement however demonstrated that there were problems with using DEMQOL-Proxy in its original form as a self-administered instrument for care home staff. However it was clear from the qualitative work that for routine measurement of QoL in care homes only a self-administered instrument would be feasible.

Interviewers play an important role in administering questionnaires in research studies, they ensure that the questions are read out fully and are interpreted correctly by the respondent. In contrast to the findings in this research, in their study of a self-administered version of DEMQOL-Proxy, Hendriks et al., (2016) found that family carers could indeed complete the instrument reliably without an interview to administer it. However, the authors acknowledged that while DEMQOL-Proxy was completed without an interviewer, clinic staff were available to respond to any questions from proxy respondents. Such staff needed to understand the purpose of the instrument to enable it to be completed correctly.

The finding here of good reliability but poor agreement highlights the need for a fuller assessment of agreement between two instruments, not just a comparison. In the study by Hendriks and colleagues the authors assessed the psychometric properties of a self-administered DEMQOL-Proxy as per the original DEMQOL-Proxy development and compared their results to those of the original (Hendriks et al., 2016). However, they did not assess if the scores would have been similar to scores from the interviewer-administered version. This study evaluated the agreement between the self-administered and interviewer-administered versions of DEMQOL-Proxy beyond simple correlation between scores, or comparison to the original instrument.

In analyses, the agreement between two variables or instruments is often tested by correlation analysis; however, two instruments designed to measure the same phenomenon would be expected to strongly correlate (Giavarina, 2015). As the same constructs were being measured in this study, albeit using different administration methods, a significant correlation would be expected. This was found with a statistically significant moderate positive correlation between DEMQOL-Proxy (interviewer-administered) and DEMQOL-Proxy (self-administered). Therefore, the use of either instrument is likely to result in similar findings. However, correlation measures the strength of the linear relationship between two variables and how they relate to each other, not their agreement. If two instruments obtain the same rating every time they are administered, when plotted, the data points will fall along the line of equality, indicating agreement. Correlation however will be seen if the data points fall along any straight line, regardless of slope or origin point (Altman & Bland, 1983; J. Martin Bland & Altman, 2010; Rankin & Stokes, 1998).

One definition of a clinically meaningful difference in QoL scores is half a standard deviation of the total scale score (Norman et al., 2003); this has been widely used in other QoL studies (e.g. Beerens et al., 2015; Bosboom, Alfonso, & Almeida, 2013; Hoe et al., 2009). In this study, the conservative threshold of 5 points was selected as a half of the standard deviation of DEMQOL-Proxy (interviewer-administered) (SD= 10.12). On average, in this study, DEMQOL-Proxy (self-administered) measured 4.86 QoL points lower than DEMQOL-Proxy (interviewer-administered). This difference in QoL falls within the determined threshold of 5 points but only just. Suggesting there may be differences in scores sufficient to impact clinical interpretations and justifying further investigation of the

differences between the two instruments. Also, the use of such arbitrary cut-offs should be made with caution, particularly when considering the holistic and personal nature of QoL.

To understand the differences between the QoL scores of the two instruments the factor level scores of the questionnaire were compared. A Wilcoxon matched pairs signed ranks test showed that the 'functioning' factor had significantly different scores between the two instruments, with respondents scoring the functioning factor lower when using the self-administered instrument. There was no significant difference for the emotion factor. One possible explanation of these results is the misinterpretation of questions by staff, or incorrect reading of questions. It was observed by the researcher when administering the DEMQOL-Proxy (interviewer-administered) that staff may have been interpreting and answering the questions incorrectly when they completed the DEMQOL-Proxy (self-administered). For example, when a member of care staff responded to the question 'how worried would you say the resident been about his/her memory in general' with 'a lot' the researcher asked a follow-up question such as 'how much does that worry them?', very often they would respond that it does not worry the resident, but that the resident has memory problems and therefore would change their response to 'not at all'. If a resident had functional impairments but did not worry about those impairment this may have resulted in marked differences in the two scores as the scoring for DEMQOL-Proxy is 'a lot' (score 1) 'quite a bit' (score 2) 'a little' (score 3), and 'not at all' (score 4).

From the agreement analysis results, and observations, it seemed likely that staff had misinterpreted or misread some questions in the self-report instrument, and had reported on whether the resident had a functional impairment, not on the QoL experienced. This was most probably a function of the stem and item structure of the questionnaire. If the stem and item were misread it is likely that the questions would be answered based on function rather than QoL. Concerns about the way the stem and item could be used were noted by Smith and colleagues (2005) when developing the DEMQOL system. They found no evidence that this happened with interviewer-administration.

To improve agreement, minor changes were therefore made to DEMQOL-Proxy to create DEMQOL-CH. A short guidance statement was added to outline the aim of the instrument. This was placed at the beginning of DEMQOL-CH. As QoL in dementia is concerned with the impact an impairment has on a person's life, and not about whether the impairment is present, it was important to emphasise that the questions in DEMQOL-Proxy and

DEMQOL-CH are concerned with the resident response. The questions were restructured to emphasise this.

These findings have to be interpreted in light of the study limitations. Staff were not randomised for completion of the DEMQOL-Proxy (self-administered) or DEMQOL-Proxy (interviewer-administered) instruments. All staff completed the DEMQOL-Proxy (self-administered) instrument first, followed by the DEMQOL-Proxy (interviewer-administered) instrument. This could have affected the findings reported above. In particular, lower staff confidence in using the self-administered instrument could have resulted in the lower reported QoL. In addition, it should be noted that a heterogeneous sample of participants completed the instruments. This may affect the generalisability of the findings.

8.6 Emphasising QoL

DEMQOL-Proxy was therefore adapted to create a self-administered instrument for use in care homes by care staff, DEMQOL-CH. Following this, the agreement between DEMQOL-CH and DEMQOL-Proxy was assessed to evaluate if the DEMQOL-CH could be used instead of DEMQOL-Proxy in care settings. The data suggested that agreement was acceptable and so provided preliminary support for the use of DEMQOL-CH as a self-administered proxy QoL instrument by care home staff. Analyses of DEMQOL-CH showed that the data quality was acceptable; floor and ceiling effects and the percentage of missing data were within set limits. Reliability assessed in terms of internal consistency showed a good Cronbach's alpha. There were also strong correlations and good agreement between the two instruments; these were better than those reported in Chapter 5. Bland Altman plot analysis showed a mean difference of -0.36, well within the 5 point cut off for clinically relevant change, and there was no evidence of proportional bias; the instruments agreed equally throughout the spread of scores. This data suggest that the changes made to the DEMQOL-CH is an improvement of using a self-administered DEMQOL-Proxy in care home settings.

It is not surprising that care staff focus on resident functional ability as well as QoL when completing QoL instruments, particularly a self-administered instrument where misinterpretation can occur since there is no external interviewer to guide. One of the

primary roles of care staff is to monitor and report resident functional abilities and any changes. Although there is conflicting evidence (Banerjee et al., 2009), some studies have identified associations between proxy QoL scores and functional ability (Bosboom, Alfonso, Eaton, & Almeida, 2012; Crespo, Hornillos, & Bernaldo de Quiros, 2013; Edelman et al., 2005a; Gonzalez-Salvador et al., 2000; Hoe et al., 2009; Logsdon et al., 2002), where higher functional impairments were associated with lower proxy QoL scores, or were more closely associated with proxy scores than with self-reports. Despite all staff who completed the self-completed DEMQOL-Proxy being given basic training and the standardised instructions, it is still likely that there was miscoding. Interviewer administration reduces the likelihood of incorrect answers due to misinterpretation of the questions as the interviewer can prompt the respondent and ensure they have understood the question correctly by using follow-up questions. This is an issue with self-completed questionnaires, and is one of the trade-offs when using this mode of data collection. The further possible explanation of the differing results between the two instruments is the bias present between different modes of administration; interviewer-administered QoL instruments have been found to provide more favourable QoL scores over self-administered instruments (Cheung et al., 2006; Lyons et al., 1999; Weinberger et al., 1996), participants may feel the need to please the researcher and inflate the QoL report (Cheung et al., 2006).

Overall, the data showed good agreement between DEMQOL-CH and DEMQOL-Proxy, suggesting that the changes to the structure of the questions and the additional training had a positive effect on the way that staff completed the DEMQOL-CH. Although it is unclear whether improvements in agreement were due to the additional structured guidance given to staff, or the changes made to DEMQOL-CH, or a combination of the two.

The findings of this stage of the study need to be considered in light of the limitations. Staff who took part in this stage of the study also participated in the previous stage. Therefore, they had experience of DEMQOL-Proxy both as a self and interviewer administered instrument. This could have influenced the improvement in agreement that was observed. In addition, similar to the previous stage, the sample was heterogeneous which may limit generalisability.

8.7 Psychometrics

Findings from the psychometric analysis of DEMQOL-CH (Chapter 7) show that the overall validity and reliability of the instrument are comparable to that of other available instruments. DEMQOL-CH also has an added advantage of simplicity of use by care staff, promoting the possibility of routine use in care settings. If the COSMIN criteria (Mokkink et al., 2010), as used in *Section 2.6* are applied to the methods and findings of Chapter 7, DEMQOL-CH performs as well as other instruments for use in a care home setting. Four of nine psychometric domains were assessed: internal consistency; reliability (inter-rater and test-retest); structural validity; and hypothesis testing. Based on the COSMIN criteria, DEMQOL-CH would score ‘good’ on internal consistency and structural validity, Reliability and hypothesis testing would both be scored as ‘fair’. In the systematic review in *Section 2.6* it was found that the four of the nine QoL instruments had four domains assessed. Internal consistency scores ranged from poor to excellent, reliability ranged from poor to good, structural validity ranged from poor to excellent, and hypothesis testing ranged from poor to fair. It should be noted that across the psychometric properties of DEMQOL-CH, a larger sample size would have increased the scores based on the COSMIN criteria.

If the reliability results of DEMQOL-CH are compared to those obtained for the instruments identified in *Section 2.6*, DEMQOL-CH performs better than most other instruments for internal consistency, and is comparable for test-retest reliability. Internal consistency of DEMQOL-CH was excellent for the whole sample ($\alpha = 0.91$) and good to excellent for the different dementia severities. The range of scores of instruments used in care homes were: QOL-AD NH self-report (0.86 – 0.91); QUALIDEM (0.82 – 0.90); DQoL subscales (0.84 – 0.95); ADRQL (0.29 – 0.85); DCM (0.55); QOL-D subscales (0.57-0.79); QUALID (0.67 – 0.79); and QOL-AD self-report (0.86 - 0.90). Test-retest of the other instruments and their time intervals were: QUALIDEM (1 week = 0.70 – 0.89; 3 weeks = 0.86); QUALID (2 days = 0.80; 9 days = 0.83); and QOL-AD 3 weeks = 0.83). DEMQOL-CH was slightly lower (1-2 weeks = 0.75; 3-4 weeks = 0.72) but still good to acceptable reliability (Koo & Li, 2016), with an appropriate time interval (Waltz, Strickland, & Lenz, 2010). Inter-rater reliability of DEMQOL-CH (0.40) was lower than other instruments, although there was a wide range of scores for some of the instruments: QOL-AD NH (0.33 – 0.99); QUALIDEM (0.47 – 0.90); QUALID (0.69 – 0.95); QOL-AD (0.51); QOL-D (0.95 – 0.99); ADRQL (0.99); DQoL

(0.91); and DCM (0.28 – 0.80). Overall, DEMQOL-CH reliability is as acceptable as other instruments that have been validated in care settings.

Acceptability was high for DEMQOL-CH with no missing data and low floor/ceiling effects for all datasets (whole sample, baseline, and first follow-up). Reliability was assessed in terms of internal consistency, test-retest, and inter-rater reliability. High Cronbach's alpha indicated that the items are related to a similar underlying construct. These findings are comparable to those of the originally developed DEMQOL-Proxy (Smith et al., 2005) and also of the self-administered version of DEMQOL-Proxy assessed by Hendriks et al., (2016).

It could be argued that because DEMQOL-CH is adapted from DEMQOL-Proxy it is a different instrument. However, the differences between the two instruments are marginal, and do not differ in terms of content. The findings in this study can be compared to those of DEMQOL-Proxy. Exploratory factor analysis found a four factor structure of functioning, positive emotion, negative emotion, and engagement that accounted for 58.7% of the variance for the whole sample, this factor structure held for the baseline sample and accounted for 62.4% of the variance. Factors for the whole sample and baseline sample were comparable, providing support for this factor structure of DEMQOL-CH. These factors are different to those found in previous analyses of DEMQOL-Proxy. Smith and colleagues, in the DEMQOL-Proxy development, found a 2 factor structure of functioning (cognition and everyday activities) and emotion (positive and negative emotion) (Smith et al., 2005). Mulhern and colleagues found a 5-factor structure of cognition, negative emotion, daily activities, positive emotion, and appearance (Mulhern et al., 2012). In their study, there were eight items that did not load or cross-loaded so were not included. Lucas-Carrasco and colleagues validated a Spanish version of DEMQOL-Proxy and found a 4-factor structure of memory, negative feelings, positive feelings, and everyday life (Lucas-Carrasco et al., 2010). It is of interest to note that the original DEMQOL-Proxy study found a 2 factor solution whereas more recent studies have found four and five factors solutions. Furthermore, the findings of this study show separate positive and negative emotion factors, this was also found in the studies by both Mulhern et al., (2012) and Lucas-Carrasco et al., (2010).

There are a number of reasons that could explain why a different factor structure was found in this study. Firstly, all of the studies mentioned above involved people from different settings such as the community, day centres, memory clinics, or day hospitals. In the original DEMQOL study less than 20 percent of participants were from care homes (Smith et al.,

2005). The studies by Mulhern and colleagues and Lucas-Carrasco and colleagues only included people living in the community (Lucas-Carrasco et al., 2010; Mulhern et al., 2012). DEMQOL-Proxy has never been assessed in a solely care home population, this is the first study to do this. A care home environment is very different to living at home. People living in care homes might have different priorities to those living in the community, and they could be affected by different aspects of care and the care home. In this study, a factor called 'engagement' was found; this included items that are relevant to interacting and engaging with others and being involved. Social engagement and activity in care home residents is often limited, many are not provided with the opportunity to engage socially (Chung, 2004; Kolanowski, Fick, Campbell, Litaker, & Boustani, 2009; Tak, Kedia, Tongumpun, & Hong, 2015). The engagement factor found in this study included items related to socially engaging with others, suggesting it is an important aspect of QoL in care homes. These findings are in line with previous studies where social interaction was identified as an important aspect of QoL (Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013; Cahill & Diaz-Ponce, 2011) and quality of care (Beerens et al., 2016; Willemse et al., 2015) for people with dementia in care homes. Physical health was also included in the engagement factor, this may have arbitrarily loaded onto the engagement factor or it could demonstrate that physical health is an important aspect of engagement. Actual or perceived problems with physical health could impair an individual's ability or motivation to socially engage.

Secondly, the instrument in this study had a different administration method compared to previous studies. DEMQOL-Proxy has always been used as an interviewer-administered instrument, except in the study by Hendriks and colleagues who used family caregivers to complete DEMQOL-Proxy as a self-administered instrument (Hendriks et al., 2016). The authors however did not assess the factor structure of DEMQOL-Proxy when administered using a self-administered method, it is therefore unknown if this had an effect on the factor structure. Thirdly, the instrument was completed by care staff only. All of the studies mentioned above who assessed the psychometric properties of DEMQOL-Proxy used family or informal carers. In research more widely most studies using QoL instruments usually use family carers to complete proxy questionnaires, some also use care staff in addition to family carers. This is the first study to assess DEMQOL-Proxy using only care staff as proxy respondents. Finally, most QoL instruments do not have stable factor structures. A search of QoL instruments when used in a variety of settings shows variability in the number of factors found, even when used in the same country. Similarly, the systematic review in Chapter 2

found variability in factor structures for instruments when used in similar settings. For example, DQoL had two and five factor solutions when used in care settings and a three factor solution when used in the community, QUALID had between one and three factor solutions when used in care settings. This instability in factor structures could be due in part to the type of analysis carried out; it is argued that classical test theory methods such as factor analysis are not the most robust method of analysis and that other methods such as item response theory are more appropriate (Hendriks et al., 2017). Most of the studies discussed in Chapter 2 used factor analysis. Future research needs to assess the goodness of fit of the 4-factor structure using confirmatory factor analysis; it would also be informative to analyse DEMQOL-CH using Rasch methods in place of or in conjunction with factor analysis.

No studies using DEMQOL-Proxy have assessed the inter-rater reliability of the instrument. A study by Aguirre and colleagues assessed QoL ratings between DEMQOL and DEMQOL-Proxy scores as a form of inter-rater reliability (Aguirre, Kang, Hoare, Edwards, & Orrell 2016). They found no significant correlation for mild dementia ($ICC = 0.56, p = 0.15$) or for moderate dementia ($ICC = 0.61, p = 0.07$). In this study poor inter-rater reliability was found for DEMQOL-CH. The reason for this is unclear. It could be due to small sample size; as it was difficult to determine when care staff would complete the instruments. The data had to be checked after data collection for ratings that could be included in the analysis, resulting in a small sample. Another possibility is that different staff may focus on different aspects of QoL from one another, and different staff characteristics may also have effected QoL ratings. Although results from the regression analysis found that staff occupational characteristics accounted for a very small proportion of the variance in QoL ratings, poor reliability between staff could represent other unmeasured characteristics of staff affecting ratings. Some studies investigating the effect of staff characteristics on QoL measurement have found that care staff proxy ratings of QoL can be affected by factors other than sociodemographic or occupational characteristics. Winzelberg and colleagues found that attitudes towards residents with dementia and staff work stress were significantly associated with staff QoL ratings using the QOL-AD (Winzelberg et al., 2005). Zimmerman and colleagues also found a significant association of staff attitudes to people with dementia using the QOL-AD and ADRQL instruments; staff work stress was only statistically significant for the ADRQL instrument (Zimmerman et al., (2005). Poor inter-rater reliability could have implications for long-term use in care settings, particularly where there is high

staff turnover. If characteristics, such as those discussed above, affect staff QoL ratings it could mean that some staff are more effective at measuring QoL than others. This could have an effect on the implementation of routine QoL measurement in care settings if staff with particular characteristics are needed to be able to give reliable ratings. Furthermore, poor-inter-rater reliability will be a problem with the high turnover of care staff in the care sector. Even if care homes work to improve the inter-rater reliability of care staff QoL measurements, high staff turnover may compromise this improved reliability when staff members leave the care home. Future studies would benefit from further investigating different staff characteristics and the effect these have on QoL ratings, particularly for inter-rater reliability analysis. In this study inter-rater reliability in different dementia severities was not assessed.

The small sample size in this study makes the results of these reliability tests unstable. Test-retest analysis for the whole sample was below the set criterion with a correlation of 0.64. Results for time intervals of one to two weeks and three to four weeks had acceptable reliability of 0.75 and 0.72 respectively; although there were only 9 cases for the one to two week period. Reliability was poor at seven to eight weeks, ratings at 12 weeks were just above the minimum value of acceptable reliability (0.56) (Portney & Watkins, 2009). This fits with the generally accepted time interval of two weeks to one month for test-retest assessment (Waltz et al., 2010), with measurements longer than this resulting in worse reliability due to real change being likely in this time.

Convergent validity analysis using DCM for the whole sample found that DEMQOL-CH correlated with the percentage of observations that had a Type I behaviour category code (BCC), these are behaviours that are “good”, e.g. conversation or using intellectual abilities. This was in the hypothesised direction. The mean well-/ill-being score (WIB) and the percentage of WIB values representing highest possible state of well-being (+3 or +5) were not significantly correlated. For mild dementia, no statistically significant correlations were found, although there was a trend toward significance. For moderate dementia a stronger than expected correlation for mean WIB score and percentage BCC Type I was found. This might suggest that DCM and DEMQOL-CH are measuring different constructs. Although DCM and DEMQOL-Proxy have both shown good concurrent and convergent validity with the same instruments in other studies. Concurrent validity of DCM has been assessed in multiple studies. Significant correlations with mean WIB scores have been found for QOL-

AD and ADRQL (Edelman, Fulton, & Kuhn, 2004). Fossey et al., (2002) found a significant correlation between DCM indices and a generic proxy paper and pencil QoL test (Blau, 1977). Sloane et al., (2005) assessed correlations between the three DCM indices used in this thesis (mean WIB, % WIB +3 or +5, % BCC Type I) with QOL-AD (self and proxy) and ADRQL (proxy). They found better correlations with proxy-reports than with self-reports. Lower correlations were found for percentage WIB +3 or +5 compared to percentage BCC Type I and mean WIB scores; these findings are similar to the ones reported for this study, percentage WIB +3 or +5 correlated moderately with mild dementia only. Convergent validity of DEMQOL-Proxy has been assessed using similar QoL instruments: moderate correlation was found for the generic health-related QoL instrument, EQ-5D proxy (The EuroQol Group, 1990) and a self-administered version of DEMQOL-Proxy (Hendriks et al., 2016); moderate correlations were found with QOL-AD (proxy) for mild to moderate dementia but weaker correlations for severe dementia (Smith et al., 2005); and Lucas-Carrasco and colleagues found good to moderate correlations with a Spanish version of DEMQOL-Proxy and the physical, psychological, and environment subscales of the generic WHOQOL-BREF QoL instrument (Lucas-Carrasco et al., 2010; WHOQOL Group, 1995). This demonstrates that DEMQOL-Proxy has good validity with a variety of instruments of QoL, and it is not unreasonable to assume that DEMQOL-CH would provide similar results.

Considering that DCM and DEMQOL-Proxy both have good correlations with other dementia specific QoL instruments it is unclear why correlations between DCM and DEMQOL-CH were lower than expected. There are a number of limitations to using DCM as a validation instrument; the constructs being measured by the instruments and the administration method could have affected the correlation between the instruments. Although DCM has been used in research as a measure of QoL, the instrument is more often used for practice development, quality assurance, and staff training to develop and improve person-centred care (Barbosa et al., 2017; Brooker, 2005). Secondly, DCM was completed by the researcher whereas DEMQOL-CH was completed by care staff. It would have been possible to use another dementia specific proxy measure of QoL such as the DQoL, QOL-AD or QUALIDEM. However, in the current study there was a need to limit the burden on care staff and mimic routine practice as much as possible. The inclusion of other QoL instruments could therefore have influenced the evaluation. Regardless, future evaluations of DEMQOL-CH should assess convergent validity with instruments such as QUALIDEM. Although DQoL and QOL-AD were used for the original DEMQOL-Proxy development the

QUALIDEM instrument may be the most appropriate instrument to use for DEMQOL-CH as it was developed to be used in care settings, has good psychometric properties, and can be used for people with severe dementia.

Known-groups differences analysis found no significant differences between the dementia severity groups. This is unsurprising as there is growing evidence that good QoL can be experienced by people with all dementia severities (Banerjee, 2006; Brod et al., 1999; Smith et al., 2005). The small sample size of people with questionable dementia showed large 95% confidence intervals, this is likely due to the small sample size for this group and may have affected the results obtained. The results therefore should be interpreted with some caution. Differences in people with and without cognitive impairment have been reported (Hendriks et al., 2016), further investigation of DEMQOL-CH including people without dementia is recommended to further explore its ability to distinguish between groups.

It must be noted that the sample sizes used for the psychometric evaluation of DEMQOL-CH were smaller than is normally used for definitive psychometric analysis. There were a sufficient number of observations to perform the analyses, however, these were carried out on repeated measurements. Thus, the findings need to be taken with caution as there is a lack of independence in the observations which could affect the findings presented. Future studies should evaluate the psychometric properties of DEMQOL-CH using independent data from large representative samples. These findings must be considered as tentative and preliminary. They are however encouraging.

8.8 Predictors of QoL ratings

The only significant predictors of QoL, as measured by hierarchical linear regression analysis, were: the amount of time staff had worked in the care home; the number of hours staff worked per day; and staff confidence. Lower QoL was associated with the amount of time that staff worked in the care home and number of hours worked per day, whereas higher QoL was associated with staff confidence. The finding that only 24.6% of the variance in QoL was accounted for by these factors demonstrate that DEMQOL-CH when used by staff is not just a measure of staff bias. Dementia severity was not a predictor of QoL. There were no statistically significant differences in mean QoL between the different dementia

severities. This adds to the literature that the association between dementia severity and QoL is not straightforward and that QoL does not inevitably decline with more cognitive impairment. Although some studies have found a relationship between the two (Barca et al., 2011; Hoe et al., 2009; Mjørud, Kirkevold, Røsvik, Selbæk, & Engedal, 2014), numerous other studies and reviews have found that dementia severity is not associated with, or a predictor of, QoL (Banerjee, 2006; Banerjee et al., 2009; Fuh & Wang, 2006; Logsdon, Gibbons, McCurry, & Teri, 2002; Lyketsos et al., 2003). It was also found that the more hours staff worked per day and an increasing amount of time that staff worked in the care home (in months) was negatively associated with QoL. Taken together, this could suggest that higher staff and resident contact results in lower QoL ratings by staff. This has been found in previous studies where more stable staff and resident assignment, i.e. more time spent together, has been related to lower QoL (Zimmerman et al., 2005); the authors were unsure as to whether stability affected staff attitudes, leading to poor ratings, or if it actually affected resident QoL. Another study found that the number of days that staff worked before carrying out a QoL rating related to lower reported QoL (Gräske, Meyer, & Wolf-Ostermann, 2014). The regression analysis carried out in this study found that increased staff confidence was associated with higher QoL. It is unclear if staff confidence was related to their confidence in rating the QoL instrument, or their confidence in rating the particular resident. Results in Chapter 5 found that the confidence staff felt about rating residents' QoL was significantly positively correlated with the amount of time they had spent with residents. Collectively, the findings reported in this thesis, and findings from previous studies, show that further investigation is needed to fully understand the relationship between staff and resident contact, and confidence, and the affect this has on staff QoL ratings.

Staff confidence as a predictor of QoL is a notable finding from the regression analysis. Previous studies assessing differences between care staff proxy-reports of QoL with those of family proxies or self-reports have suggested that a "key" person such as a resident's keyworker should be used (Crespo et al., 2011; Hoe et al., 2006). It was thought that keyworker staff would have better knowledge about the resident they are a keyworker for as they spend more time with them. However, from discussions with care staff key-workers do not always have the greatest knowledge of the resident. Similarly, being a keyworker to a resident does not guarantee that the staff member and resident spend more or 'quality' time together. Findings in Chapter 4 suggested that the amount of time spent with residents and

the subjective confidence that staff feel about measuring resident QoL may be more important and a more suitable criteria for allocating staff to residents in QoL assessments.

Staff confidence was also one of the findings to come out of the qualitative study, it appeared to influence different aspects of introducing a QoL instrument into practice, from the practicalities of completing the instrument, to staff feelings of who they could complete the instrument for. Furthermore, staff confidence has been found to be an important factor in caring for people with dementia (Hughes, Bagley, Reilly, Burns, & Challis, 2008) and also associated with higher QoL scores using the QOL-AD (Winzelberg et al., 2005). Although Winzelberg et al., 2005) assessed staff training confidence, the authors highlighted the importance of confidence when training staff to meet resident care needs using person-centred care, and emphasised the similarities between the aims of person-centred care and QoL measurement. It can be concluded that holding the title of keyworker is not in itself grounds to allocate staff to residents when measuring QoL, the other factors identified need to be taken into consideration as well. Future research should investigate whether there is a confidence, knowledge, or contact threshold for staff to accurately rate residents' QoL.

It is important to note that this research did not assess staff factors such as QoL, burden, and attitudes. This was to reduce staff burden with the main aim of the study to develop a way to implement routine QoL measurement into care practice. Assessing the effects of staff characteristics on QoL ratings should be a focus in future studies. A number of studies have found that a proxy's own QoL (Arons et al., 2013; Schiffczyk, Jonas, Lahmeyer, Müller, & Riepe, 2011), burden (Gomez-Gallego, Gomez-Amor, & Gomez-Garcia, 2012; Gräske et al., 2014), burnout, and satisfaction with life (Gräske et al., 2014) can affect proxy ratings of QoL of the person with dementia. It is not possible to know whether these factors affected care staff ratings of QoL in this study, future studies would benefit from investigating this.

8.9 Engaging with care homes and care staff

Care homes are special environments that require a particular approach when conducting research. Guidelines are available that provide information on how to work with care homes and care home staff to ensure that research is conducted effectively (Luff, Ferreira, & Meyer, 2011; Luff et al., 2015; NIHR, 2016). Inclusion of care staff in the process of determining

the best way to measure QoL as a part of routine practice was important to enable the effective introduction of the QoL instrument. Acknowledging the views of care staff at the outset of research has been found to aid in implementation (Lawrence, Fossey, Ballard, Moniz-Cook, & Murray, 2012), and care staff are the people most qualified to determine where and when QoL measurements could be used realistically in care practice.

Acknowledging staff and working with them collaboratively will affect the engagement staff have with the research (Lawrence & Banerjee, 2010). Variable engagement with staff may have had an impact on the findings reported in this thesis with fewer than expected QoL measurements. Overall, engagement with staff was positive, although engagement with staff in Stage 4 of the study was more challenging than in earlier stages. Observations made during the research suggest that staff in Stages 1, 2, and 3 were more engaged in the study than staff in Stage 4. This was in terms of their positivity and engagement towards the study and the presence of the researcher, and in terms of their positivity and willingness to engage in the research. This is reflected in participant numbers; many more staff were consented into the study in the first stages (80% of employed staff) than in Stage 4 (approximately 20% of employed staff). Engagement in general could have been elevated because a neutral party was involved, staff may also have had a desire to help as they knew the project was a part of a PhD studentship. Finally, staff were aware that the researcher had worked in the care home sector and had an understanding of the job that they carry out, this could have influenced the relationship that was developed. Participation and engagement could have been lower if any of these factors were different.

There are several potential reasons why there was a difference in engagement between the different stages. In the first stages of the study it was possible to build up good relationships with staff; this may have been because of more time spent with individual staff when completing qualitative interviews. Qualitative interviews were not carried out in the second stage of the study which could have affected the perception of level of involvement needed by staff. As Luff et al., (2015) suggested, care homes and researchers need time to become familiar with one another. Highlighting the benefits of an intervention or new instrument promotes 'buy in' from staff (Kilbourne, Neumann, Pincus, Bauer, & Stall, 2007), meaning that they will be more likely to adopt the new instrument. Qualitative interviews in Stage 1 allowed staff to identify the benefits themselves, potentially increasing their positivity, and affecting their engagement with the research process in general. In Stage 4 staff did not take

part in qualitative interviews, instead they were told of the potential benefits that measuring QoL could have, but did not have the opportunity to identify them for themselves, this could have resulted in the poorer engagement with the study at this stage.

Management influence may have affected engagement. Similar to care staff, managers in the first stage of the study appeared more engaged, not only with the research and the researcher, but also with their own staff and the expectations they had of their involvement in the study. The managers in the first stage of the study seemed more eager to encourage their staff to actively take part and were more positive about what their staff would be able to achieve. Conversely, in the second stage of the study the managers of the care and nursing homes appeared to step back from the research, to distance themselves and allow the researcher to engage and encourage staff. The managers were less involved in the research overall. In this study a 'bottom up' approach was adopted by involving staff in the implementation. This was in an attempt to improve engagement and implementation. However, it appeared that staff may need encouragement from managers to engage fully with the research and be allowed to allocate their time to complete QoL instruments; a 'top-down' approach from managers is needed as well. The CQC State of Care (2015/2016) report highlights strong visible leadership as a major factor for delivering high quality care and making improvements in care. This is in line with the findings reported here. In homes where managers were more engaged, staff appeared more engaged and were more likely to want to be involved in the study and find the time to complete the DEMQOL-CH.

Organisational support would be important for the introduction of a QoL instrument into routine care practice. When investigating barriers to nursing staff using research to change practice, (Retsas, 2000), found that organisational support was the most important factor in relation to staff finding time to use and conduct research. This is an important aspect for future care home research, care and nursing home managers need to be engaged and communicate their intentions with the research project to their staff, researchers do not have any authority or influence over care staff and their involvement with research, it is an informed choice made by staff as to whether they want to volunteer to take part. If staff have little knowledge about the research there may be hesitation and poorer engagement. Care home researchers have found that if managers effectively communicate the aims and importance of the research with staff and are enthusiastic about the research, staff will be more prepared for the researcher visits (Luff et al., 2015).

Finally, the different types of home may have affected staff engagement. In Stage 4 there were more nursing homes than in the first stages, residents in nursing homes often have more impairments and require more assistance from staff to carry out ADLs. The subsequent effects of this could mean higher levels of stress and staff burden, consequently, affecting staff engagement.

8.10 Routine QoL measurement

It has been argued that routine measurement of QoL could have positive impacts on the quality of care experienced by residents in care homes (Edelman et al., 2005). It has also been suggested that frequent measurement of individual QoL should be investigated to provide a clearer understanding of the changes to QoL over time (Hoe et al., 2009). However, the question of whether or not routine QoL can be accomplished has not been previously investigated. The findings from qualitative analysis reported above show that care staff positively received the idea of routine QoL measurement; the findings in Chapter 7 demonstrate that it is possible that routine QoL measurement can be completed in practice, albeit in a highly selected group of care homes.

In four of the five care homes, staff were able to rate resident QoL repeatedly over a period of two to four months. On average, care homes were able to complete monthly QoL ratings for residents. The graphs presented in Chapter 7 present some of the ways that care homes could use routine QoL data. Care homes could track and monitor QoL over time in order to understand changes to resident QoL. Such data could aid staff in determining and understanding changes to individual resident QoL and what may affect QoL, it could also provide a means of understanding changes to QoL of the home overall. Care providers who deliver care in multiple care homes could monitor and track the QoL of homes simultaneously over time. An example of how routine measurement of QoL can provide insights into the factors that affect care can be seen in the findings in care home 3 (Figure 6.5). Changes to resident QoL in care home 3 were evident, there were decreases in QoL for a number of residents over one particular time period. This was also seen clearly in the comparison between homes in Figure 6.6. During the study the manager of the care home resigned, leaving the home without a manager for a period of time that corresponds to the dip observed. These findings support the CQC state of care report 2013/2014, which showed

that the absence of a registered care home manager can negatively affect the quality of care provided in homes compared to homes with a manager in place (Care Quality Commission, 2014). These are speculative findings, the study design does not allow us to prove that the absence of the manager had a direct effect on resident QoL, or via changes to staff mood and morale which had a subsequent effect on the QoL ratings made by staff. Regardless of this, if such changes are observed then such data would be of help to the management and leadership teams in their mission to improve the QoL of their residents and the quality of care provided by their staff.

These longitudinal data highlight the variability that can occur in resident QoL scores over time. During qualitative interviews in Stage 1, care staff and managers discussed wanting to measure QoL as frequently as possible as they believed that residents experienced regular changes in QoL. The figures in Chapter 7 summarising the QoL scores in the individual care homes, particularly for care homes 1, 2, and 3 show that care staff were correct, some individual QoL ratings did show change over time. These findings suggest that there may be considerable variability in homes which may be missed in longitudinal studies which only measure QoL on two occasions (Beerens et al., 2015; Clare, Woods, et al., 2014; Hoe et al., 2009; Oudman & Veurink, 2014; Selwood et al., 2005). (Missotten et al., 2007) assessed QoL at three time-points and found an increase and a subsequent decrease in QoL. Many residents had similar QoL ratings recorded at baseline and for the final rating, but they also had several changes in QoL between these time-points. If only one follow-up measurement was obtained this information would have been missed.

As discussed in Chapter 2, it has been suggested that carrying out routine QoL measurements as a part of care practice could have potential positive outcomes such as improvements to resident QoL and improvements to the provision of care. This was one of the possible areas that could have been addressed in a study such as the one presented in this thesis. However, the work presented here focussed primarily on the feasibility of implementing a QoL instrument into care practice and the development and evaluation of an appropriate instrument for use in care homes. This is in line with the Medical Research Council (MRC) guidance on the development, evaluation, and implementation of complex interventions. The four key elements of a development and evaluation process are: feasibility/piloting, evaluation, implementation, and development. These do not have to be carried out in a linear or cyclical sequence, researchers can choose to carry out particular elements as needed for

the research aims or carry out more than one element concurrently (Craig et al., 2008). Addressing the feasibility of implementation in the current study will allow future studies to put more focus on other aspects of routine QoL measurement in care homes; findings and lessons from this study can be implemented in future investigations of inter-rater reliability and care staff and resident outcomes, for example.

The present study provides data on the proof of the concept that routine QoL measurement is feasible. It should be noted that staff turnover is likely to effect the implementation of a QoL instrument into routine care practice. In this study staff turnover resulted in variability in the numbers of staff consented into the study at different times. This was evident in the number of staff available to complete the experience surveys at the end of the study stages. Staff turnover is a prevalent and growing problem in the care sector (Care Quality Commission, 2017a; Skills for Care, 2017) and is likely to affect the use and implementation of any instrument or training in routine care practice. However, if the implementation and use of such instruments is free or less costly, non-burdensome, easy to use and train, and fit within current training and routines, the effect of staff turnover should be minimised.

8.11 Ethical considerations

Possible ethical considerations were discussed in Chapter 3, *Section 3.7*. No other unforeseen ethical issues or challenges emerged in the study.

8.12 Limitations and strengths of the study

The findings in this thesis need to be interpreted in light of the limitations of the research design. A number of limitations specific to the findings have been discussed above. The overall limitations and strengths of the study will now be considered.

In this study the feasibility of implementation and psychometric evaluation of DEMQOL-CH were combined. Because of the exploratory nature of the research project it was not possible to predict what would happen through the study programme and what, if any, changes would need to be made to the study as the research progressed. The need to adapt DEMQOL-Proxy to create DEMQOL-CH arose from the data generated in Stage 2.

Subsequent changes made to the instrument and the alternative administration method required re-evaluation of the psychometric properties of DEMQOL-CH when used by care staff. Therefore, instead of solely investigating the feasibility of routine measurement and implementation of a self-administered DEMQOL-Proxy, there was a need for new psychometric evaluation of DEMQOL-CH in the last stage of the study in addition to documenting the frequency of QoL ratings that were achievable by staff.

We adopted a staff-driven model to determine how frequently measurements might be made. There are implications of allowing the rate and timing of measurements to be chosen by care staff. This was beneficial to assessing the feasibility of any form of routine measurement. It was hoped this flexibility would reduce burden and help in take up by homes. However, this will have had consequences for the robustness and ease of interpretation of the findings. It would have been easier if we had stipulated that measures should be taken on a monthly basis and any study in the future can do so now we have demonstrated, even in our selected group, that such a frequency of measurement is possible.

It can be argued that our decision to combine the feasibility and psychometric evaluation in a single study did not provide a sufficient amount of time for either. As discussed above, the exploratory nature of the study dictated the progress, it would have been possible to extend the feasibility study and perform the psychometric analysis in a separate study in the future. However, the aim of this study was to provide broad preliminary data about the feasibility of routine QoL measurement by care staff, this necessitated the psychometric re-evaluation of the instrument after changes were made to the structure of questions and the administration method. A smaller than expected number of participants completed QoL measurement in the care homes. If a separate study was conducted this could have been rectified and a larger sample recruited, thus improving the robustness of the study and its findings. However, we did not have the time to do this within the resource constraints of the studentship and the PhD. We chose to sacrifice depth for breadth of inquiry in this study, as such we can say a little about a lot, rather than be definitive about any single element. As such this work needs to be seen as the beginning, rather than the end of a research process.

The small sample sizes and the potentially unrepresentative nature of the sample will also have affected the validity of the results obtained. As mentioned earlier, recruitment into stage 4 of the study was lower than expected and lower than earlier stages. Small sample sizes reduce the stability of estimation of the psychometric parameters and may lead to Type II

error when statistical significance is tested. To try and increase the sample size care home staff were encouraged to take part in the study by the researcher throughout the study, newly employed staff were also asked to take part. Unfortunately due to the nature and timescale of the study a deadline of recruitment was needed. Particularly, staff needed to have knowledge of the residents when measuring QoL, therefore recruiting new staff to the study in the latter stages was not possible. It was also not possible to recruit participants from further care homes. However, this study does provide unique preliminary data on the feasibility of implementing routine QoL measurement into care practice, and has identified ways that participant recruitment may be enhanced in future studies. Larger and more representative participant samples in terms of staff and residents is needed in future studies of the psychometric performance of DEMQOL-CH in care homes.

A relatively large number of staff participated in the qualitative interviews, and the findings highlighted a number of important potential outcomes for residents and staff, including making improvements to care. However, only eight care staff completed the study experience questionnaire, although the results were positive with staff believing they had more insight into residents' lives the results should be taken with caution. Only a small number of staff were available to complete the survey, these staff may be unrepresentative in that they agreed to complete the survey. Staff views of the outcomes of measuring QoL may therefore not be representative of the care workforce in the recruited homes or of homes in the social care sector in general. Care assistants and senior care assistants make up a large portion of the care workforce (Skills for Care, 2014), however, despite this, senior care assistants were underrepresented in the experience questionnaire group.

The small and non-random recruitment of participant staff and homes into this study will have limited the generalisability of its findings. The sample of homes included in the study was small and were all from one geographical area; the homes therefore are not representative of care homes nationally. Despite this, the occupational and demographic characteristics of care staff included in the study were consistent with staff in the social care sector (Skills for Care, 2017). The care homes were included in the study if staff were engaged with the research and were willing to take part., and all homes had good CQC reports and none were under any special measures. Different results might be found with homes that were underperforming or with staff that were not as engaged in the possibility of research and/or the routine measurement of QoL. The homes were not unusual in terms of

their size or staffing structure, however, it could be argued that they are unusual in that they were willing to engage in research. In addition to this, most of the homes had been in contact with the care home in-reach team; this team is invited into care homes to assist with any challenges that staff may face with residents or training. This may show a willingness to accept assistance and make necessary changes to care provision to improve care practice. This may not be observed in homes who have not requested outside assistance and advice. Future studies need to assess routine QoL measurement in a larger more representative sample of care homes.

Heterogeneity of the sample with respect to staff job roles could have affected the results found. In quantitative research a homogeneous sample is preferred as findings can be more generalizable. However, in this study there were limited numbers of staff available in the included care homes, all staff were invited to take part in the study regardless of job role. Including all staff in the study may be evidence of a 'whole' home approach to measuring QoL, however, there could be inherent differences in the way staff measure QoL as a consequence of their job role. Differences in factors such as staff-resident relationships and amount of time staff spend with residents could be markedly different for staff employed in different job roles. This could have affected the findings in this study, particularly, this could have contributed to the poor inter-rater reliability found in Stage 4. Future studies would benefit from comparing QoL ratings from staff employed in different job roles, investigations of differences in staff opinions of what good a QoL is would also be of interest to determine if there are any differences in staff that could affect QoL ratings.

The literacy levels of care staff were not assessed as a part of the study, the researcher did however meet with each member of staff during the consent process to ensure they understood the aims of the research. In addition, staff whose first language was not English were asked if the language and terms used in the participant forms and QoL instrument were understood.

Chapter 2 of the study discussed that routine measurement of QoL has the potential to play a role in improving the QoL and quality of care of people living in care settings. This study did not assess the changes to QoL over time, nor did it assess changes to the quality of care provided to residents. The aim of the study was to provide broad preliminary data about the feasibility of routine measurement of QoL. The potential effects of measuring QoL routinely were not assessed in this study. Rather, the findings from this study have provided proof of

the concept that this could be achieved, and that there exist potential positive outcomes in doing so. Future research is needed to determine the outcomes of routine QoL measurement for staff, residents, and the quality of care provided.

There is evidence that a proxy's own QoL (Arons et al., 2013; Schiffczyk et al., 2011), and burden (Gomez-Gallego et al., 2012; Gräske et al., 2014) can affect ratings of QoL of the person with dementia. No measures of care staff QoL, burden, or stress were collected in the study, it is therefore not possible to know if this had an effect on the QoL ratings made by staff.

An initial hope in this study was to invite relatives of consented residents to take part in the study and to complete QoL assessments of their relative residing in the care home. Unfortunately contact with family members was difficult to organise, family members either lived far from the home or had limited visitation times resulting in difficulties contacting family members. Therefore, family ratings of QoL were not collected. Future research would benefit from assessing if there are any differences between family and care staff proxy ratings using DEMQOL-CH.

People without dementia were not excluded from taking part in the study. However, only one person that consented into the study did not have dementia. This is in line with previous findings (Jagger & Lindesay, 1997; Livingston et al., 2017), but limits the interpretations that can be made about the ability of DEMQOL-CH to assess the QoL of residents without dementia in care homes.

The main strength of the study was the inductive approach used to engage with care homes and care home staff. The use of interviews in this study allowed an understanding of the important aspects of fitting a QoL instrument into practice and what the perceived benefits were to the care staff and residents from the perspective of staff. Getting staff to identify the benefits themselves, rather than being told what the potential benefits could be, may have had a greater effect on staff by increasing their sense of autonomy. The addition of manager discussion groups after the qualitative interviews provided an opportunity to discuss the practical details of fitting in the QoL instrument effectively. Including those that are central to successful implementation will enhance the possibility of implementation. This method of approach showed how successful implementation of QoL instruments could be achieved. This study is not a definitive study of the value of introducing routine QoL measurement

into care homes. However, it is a proof of concept that has developed a method that may be used in care homes and which can now be subject to further evaluation, development and use.

8.13 Implications

8.13.1 Implications for policy

There are no direct identifiable implications for policy from the findings of this thesis. The thesis does however provide the foundation for future research that could have potential impacts on policy in care homes. One potential future implication is the introduction of routine QoL measurement as one of the fundamental standards of care. The fundamental standards of care, set out by the CQC, stipulate that everybody has the right to expect certain standards of care. One of these standards is the right to receive person-centred care. Care homes have to provide evidence that person-centred care is being delivered. This is often accomplished through ensuring each resident has a personalised care plan in place that details each individual's specific needs, interests, and wishes. As discussed above, providing person-centred care and measuring and understanding QoL are complementary as they both aim to provide more understanding of the individual. The inclusion of routine QoL measurement as a set national standard that care homes must adhere to could aid care homes in providing or improving person-centred care nationally. However, to achieve broader implementation more extensive research is required into the areas covered in this thesis.

8.13.2 Implications for practice

Because of the preliminary nature of the research reported here there are no definitive implications for practice from the findings. There are however four points to consider for practice and implementation in care homes.

D). Changing practice in care homes to include routine measures of QoL could be achieved by using existing routines and practices in the home and by introducing an instrument that has been developed to work with the constraints of time that are inherent in care homes.

II). There is a need for a top-down and bottom-up approach when implementing changes to care practice so that staff feel heard, but also have the guidance and leadership needed in place to enable the changes to be made. In this study a bottom-up approach was used to engage with care home staff and to enhance implementation. The recruitment numbers, particularly in Stage 4 of the study where management involvement was limited, highlight that although this approach is necessary. The involvement of management is fundamental to enable staff to make real changes to their practice, to justify staff time, and to encourage staff.

III). There is room for improvement to staff knowledge and understanding of residents experiences. Staff require ways of documenting and reflecting on resident's experiences and QoL other than those currently available to them. Staff reported that they believed they would learn more about residents by measuring their QoL. Further exploration of these outcomes will provide more insight into the effect of measuring QoL on care staff and person-centred care, and how this could affect residents long-term.

IV). The time constraints on care staff need to be considered when implementing new instruments into care practice for both their uptake and their use. If instruments are too complex or time-consuming to use there is a risk that such instruments will not be implemented effectively, it is also possible that they would be completed incorrectly due to staff having to complete them too quickly.

8.13.3 Implications for future research

The findings and discussion reported in this thesis have highlighted future research questions:

1. Evaluation of the implementation and use of DEMQOL-CH in larger groups of more representative care and nursing homes is needed to provide evidence of the robustness of the instrument and the approach. Most of the care homes in this study were smaller homes that had the capacity for approximately 20-30 residents, and the larger care homes included were not at full capacity. Implementing DEMQOL-CH in more and larger care homes would provide a more representative view of the potential value and feasibility of routine QoL measurement in care homes.

2. This thesis covers residential care homes and nursing homes, however, differences in implementation and use of DEMQOL-CH between the two types of homes was not assessed. This was because of the imbalance of different homes recruited into the study; more homes provided nursing care in the final stage of the study. Assessment of differences between the two types of homes would benefit in future research. Although there is evidence of an overlap in residents dependency between the two types of home, there is higher dependency in nursing homes (Bowman et al., 2004); this may have effects on staff burden and stress resulting in variable engagement with, and ability to perform, QoL measurements.
3. More work is needed to determine the optimum frequency of measurement of QoL using this system.
4. The effect of care staff characteristics, attitudes to dementia, work stress, and burden on the ratings of QoL generated need to be investigated.
5. There would be value in assessing the effect that measuring QoL has on care staff and on residents.
6. Research is needed into the use of DEMQOL-CH in those without dementia in care homes. Similarly, assessment of care staff views and abilities of measuring QoL of people without dementia using DEMQOL-CH would provide useful insights into the practicality of the instrument for common use regardless of dementia diagnosis.
7. Further research would be useful on the differences between family carer and care staff QoL ratings.
8. Additional psychometric assessment in larger and more representative samples of residents and care staff is needed to determine more information on the validity and reliability of the instrument. The finding of poor inter-rater reliability of DEMQOL-CH needs to be assessed in a larger sample size and in conjunction with assessment of staff characteristics. This will provide an understanding of whether different staff characteristics are affecting the ratings. The convergent validity of DEMQOL-CH using other proxy-reported QoL instruments would also be useful.
9. Item reduction of the instrument may aid in the usability of DEMQOL-CH in routine care practice as a shorter instrument would be less burdensome.
10. The acceptability and utility of routine use of DEMQOL-CH in care homes needs to be determined

11. The agreement between DEMQOL-CH and DEMQOL-Proxy with staff who have no previous experience with either instrument should be investigated.
12. It would be useful to generate a simple user-friendly database that could be used in care homes to enter, score, and graphically present DEMQOL-CH data and its changes over time.

8.14 Conclusion

This thesis contributes new findings to the literature on the measurement of QoL in care homes. The aim of this study was to generate preliminary data on the feasibility of routine QoL measurement in care homes. Despite the small number of participants, this was achieved, and this is the first study to provide evidence that routine QoL measurement in care homes is feasible. This may lead to positive outcomes for care staff and residents, and potential improvements to care through the routine measurement of QoL but this study was not designed to investigate such outcomes. The findings of the research highlight factors that may aid implementation in future studies to ensure wider engagement and participation. It provides useful insights into implementing routine QoL measurement into care practice and methodological considerations for those wanting to implement new practices into care homes. The findings reported here provide a proof of the concept that a QoL instrument can be introduced into routine care practice and that implementation is enhanced by working collaboratively with care staff and managers in the process to enhance positivity and engagement. It provides a description and a preliminary validation of a promising instrument and approach that can be used in future care home research and practice. The method and results used in this study illustrate that QoL instruments may need to be modified when they are used for self-completion of proxy-reports by care home staff in care homes.

Overall, the research provides a distinct contribution to knowledge in the following areas:

- 1) Identification of care staff views of measuring QoL as a part of care practice and factors influencing implementation.
- 2) Development of guidance for implementing instruments into care practice.
- 3) Identifying that QoL instruments need to be properly framed to ensure accurate completion of self-administered proxy instruments.

- 4) Identifying that staff engagement and participation is dependent upon management input and encouragement.
- 5) Development of a promising instrument for the routine collection of QoL data as a part of normal care practice.
- 6) Demonstration that care staff can repeatedly collect high quality longitudinal QoL data.

A definitive method for the routine measurement of QoL has not been created, rather, the first data to demonstrate that routine QoL could be feasible has been generated. Despite small numbers of participants in the study and high staff turnover in care settings, we present tentative evidence that the use of a simple and easy to use instrument as a part of care practice is feasible. More research is needed to evaluate and optimise implementation, but the data presented show the potential positive contribution routine QoL measurement could have on improving the QoL of people living in care homes.

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Appendix A. University sponsorship

BSMS Research Governance & Ethics Committee (RGEC)
Chair: Professor Kevin Davies
Deputy Chair: Professor Bobbie Farsides
Secretary: Miss Caroline Brooks
Tel: 01273 872855 c.e.brooks@bsms.ac.uk
Applications and general enquiries: rgec@bsms.ac.uk



Brighton and Sussex Medical School
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15/05/2015

Prof Sube Banerjee
Brighton and Sussex Medical School
Trafford Centre
University of Sussex
Falmer
Brighton
BN1 9RY

Dear Prof Banerjee

Full Study Title: Quality of Life in Care Homes
RGEC Ref No. : 15/096/BAN

I am writing to inform you that the Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) which met on **Wednesday 13th May 2015** has now assessed your application. On our recommendation the University is willing to take on the role of **Research Sponsor** for the duration of the study. Additionally, the Committee made the following comments for further improvement of the IRAS submission:

- It was unclear what the 'Centre for Dementia Studies (BSMS) guidelines for fieldwork' were. The Committee advised that the Centre's guidelines should adhere to and reflect University level policy to ensure they are fit for purpose. (This should also be clarified in the IRAS Form).
- Question A31. The time allowed for a participant to decide whether to take part in the study is for as long as it is feasible to withdraw – for e.g. until anonymisation of the data/publication etc.
- In the Participant Information Sheet 'Routine measurement of QoL in care homes Personal Consultee Information Sheet/ 21.04.2015/Stage 2 Version 1.1' track changes appeared on page 2 and throughout the document. Please can this be removed.
- Question A56. the statistician providing support to the project will be Dr Stephen Bremner, who has recently joined BSMS, and he should be contacted before his name is added to the study.
- Questions A76-1, A76-2 and A76-3: The standard wording in response to these sections is: "The University of Sussex has insurance in place to cover its legal liabilities in the unlikely event harm should arise from this study."

Your project has been allocated the following reference: **15/096/BAN** please quote this on all correspondence.

Conditions of Approval

Please note that you cannot commence this study until you have been given a favourable opinion by an appropriate NHS Research Ethics Committee (REC) (National Research Ethics Service). The approval will cover the period stated in your application to that committee, and will be extended in line with any amendments agreed by the REC.

A favourable opinion must be gained from the appropriate Research Ethics Committee within 6 months of the issue date of this letter. Any delay beyond this may require a new review of the project.

If your project receives an unfavourable ethical opinion from an NRES REC, you must submit the revised protocol to RGEC for sponsorship approval prior to re-submission.

Indemnity

The study will be indemnified by the University of Sussex.

Please obtain the Public Liability Certificate, Employers Liability Certificate and Professional Negligence Certificate which are available from the University of Sussex insurance webpage: <http://www.sussex.ac.uk/finance/services/corporateaccounting/insurance>.

NHS Management Permission (R&D Approval)

In addition to a favourable opinion from NRES you will also need to obtain NHS Management Permission (also referred to as R&D Approval) for each NHS site where you will be conducting the research or recruiting patients.

If your research will also be conducted on University of Sussex or Brighton premises, you will be granted management approval by this committee following notification of a favourable opinion from NRES.

Amendments

Any amendments to the project dated after the issue of this approval letter must also be submitted to the BSMS Research Governance and Ethics Committee for approval in order for sponsorship to be valid. Please submit your application for an amendment to the Committee (via rgec@bsms.ac.uk) using the 'Request for an Amendment Form'.

Monitoring

The Medical School has a duty to ensure that all research is conducted in accordance with the University's Research Governance Code of Practice. In order to ensure compliance the department undertakes random audits. If your project is selected for audit you will be given 4 weeks notice to prepare all documentation for inspection.

It is your responsibility to inform me in the event of early termination of the project or if you fail to complete the work.

I wish you luck with your project.

Yours sincerely



Professor Kevin Davies
Chair of the BSMS Research Governance and Ethics Committee

Appendix B. Ethical Approval



Social Care REC

Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 972 2568

06 August 2015

Miss Laura Hughes
Brighton and Sussex Medical School
Trafford Centre
University of Sussex
Brighton
BN1 9RY

Dear Miss Hughes

Study title:	Development and evaluation of a methodology for the routine measurement of quality of life in care homes.
REC reference:	15/IEC08/0042
IRAS project ID:	171671

Thank you for your letter of 29 July 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC during the week commencing 03 August 2015. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Barbara Cuddon, nrescommittee.social-care@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

The Committee approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Clarify on the participant information sheets (PISs) for consultees (personal and nominated) making it clear that, while Quality of Life is a subjective phenomenon, asking carers or care workers who know the person well to try to answer the questions from the point of view of the people with dementia is the best approach to getting an insight into quality of life. This will make it clear that the questionnaire is about the quality of life of the person with dementia, but also acknowledge that it is the carers'/care workers' opinions.
2. Add to all the PISs that the study has also been approved by the Social Care REC.
3. Amend the process for appointing consultees so that consultees are only approached for those without capacity. Participants with capacity can be approached to identify a consultee who can be approached if they lose capacity. Amend any relevant documentation.
4. Amend the complaints statement in the PISs, to, for example, 'If you want to complain about any aspect of the research, please contact.....'
5. Remove the reference on the PISs, under the section on confidentiality that non-anonymised questionnaire information can be seen by ethics committees. Add a list of all those who can see this data.
6. Add tick boxes to the Consultee declaration forms
7. Forward the PISs and consent forms for carers, who are also going to be asked to complete the proxy questionnaires in stage 2.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Guidance on Research Governance approval for social care organisations is available from the Research Governance Framework: Resource Pack for Social Care, 2nd Edition, April 2010 and can be found at:
<http://www.hra.nhs.uk/resources/before-you-apply/non-nhs-recs/national-social-care-research-et-hics-committee/>

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra_studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee decided that the research did not require Site-Specific Assessment at non-NHS sites as it involved no clinical interventions and all study procedures at sites would be undertaken by the CI's team.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	1.1	09 June 2015
Covering letter on headed paper [Response to committee comments]	1.2	29 July 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University Indemnity Certificate]		15 September 2015
IRAS Checklist XML [Checklist_19062015]		19 June 2015
IRAS Checklist XML [Checklist_29072015]		29 July 2015
Letter from sponsor [Sponsorship approval letter]	1	15 May 2015
Non-validated questionnaire [Staff study experience survey]	1.1	21 April 2015
Non-validated questionnaire [Staff demographic information]	1.1	21 April 2015
Non-validated questionnaire [Family/friend study experience survey]	1.1	21 April 2015
Non-validated questionnaire [Family/friend demographic information sheet]	1.1	21 April 2015
Non-validated questionnaire [patient capacity to consent form stage 1]	1.0	24 July 2015
Other [Letter to GP]	1.1	21 April 2015
Other [Cv for Academic Supervisor Professor Sube Banerjee]		
Other [CV for Academic Supervisor Naji Tabet]		
Participant consent form [Family/friend consent form]	1.1	30 May 2015
Participant consent form [staff consent sheet stage 1]	1.1	27 July 2015
Participant consent form [resident consent form stage 1]	1.0	24 July 2015
Participant consent form [personal consultee declaration sheet stage 1]	1.0	27 July 2015
Participant consent form [nominated consultee declaration sheet stage 1]	1.0	27 July 2015
Participant consent form [staff consent sheet stage 2]	1.1	27 July 2015
Participant consent form [nominated consultee declaration sheet stage 2]	1.2	27 July 2015
Participant consent form [personal consultee declaration sheet stage 2]	1.2	27 July 2015
Participant consent form [resident consent form stage 2]	1.2	27 July 2015
Participant information sheet (PIS) [staff information sheet stage 1]	1.2	27 July 2015
Participant information sheet (PIS) [Simplified information sheet stage 1]	1.0	27 July 2015
Participant information sheet (PIS) [Resident information sheet stage 1]	1.0	24 July 2015

A Research Ethics Committee established by the Health Research Authority

Participant information sheet (PIS) [Personal consultee information sheet stage 1]	1.0	24 July 2015
Participant information sheet (PIS) [Nominated consultee information sheet stage 1]	1.0	27 July 2015
Participant information sheet (PIS) [staff information sheet stage 2]	1.2	27 July 2015
Participant information sheet (PIS) [nominated consultee information sheet stage 2]	1.2	27 July 2015
Participant information sheet (PIS) [resident information sheet stage 2]	1.2	27 July 2015
Participant information sheet (PIS) [personal consultee information sheet stage 2]	1.2	17 July 2015
REC Application Form [SC_Form_19062015]		19 June 2015
Research protocol or project proposal [Protocol]	2.2	29 July 2015
Summary CV for Chief Investigator (CI) [Laura Hughes CV]	1	10 June 2015
Validated questionnaire [DEMQOL-Proxy staff]		
Validated questionnaire [DEMQOL-Proxy family/friend]	1	10 June 2015
Validated questionnaire [Clinical dementia rating scale]		
Validated questionnaire [Standardised mini mental state examination]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form

available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

15/IEC08/0042

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Martin Stevens
Chair

Email:

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"*

Copy to: Kevin Davies

Appendix C. Qualitative interview guide

-
- Q1** As a member of staff what do you think you will gain from taking part in this study and what would you like to gain?
- Q2** What do you think the benefits will be for the residents by having their QoL measured regularly as a part of their care?
- Q3** Where do you see this quality of life measure fitting into your care practice?
- Q4** Do you feel confident in your ability to reliably rate the residents' QoL?
- c. If yes, can you think of anything which would affect your confidence? Either making you more or less confident?
 - d. If no, why do you think that is so, what do you think would improve your confidence?
- Q5** Do you think there any particular characteristics of residents or types of residents that you would find it difficult to rate the QoL of?
- Q6** What barriers do you think there would be in completing a QoL measure as a part of your normal care practice?
- c. What do you think would make it easier or what would reduce the barriers?
 - d. Why do you think that would be?
-

Appendix D. Demographic information sheet for care staff



CARE HOME STAFF DEMOGRAPHIC INFORMATION SHEET – STAGE 1

Participant Number:

Care home ID number:

Age:					
Gender:					
Ethnicity:	<table border="0"> <tr> <td>White British Irish Other white background</td> <td>Asian or Asian British Indian Pakistani Bangladeshi Other Asian background</td> </tr> <tr> <td>Black or Black British Caribbean/African/ Other Black background</td> <td>Other ethnic group Please specify</td> </tr> </table>	White British Irish Other white background	Asian or Asian British Indian Pakistani Bangladeshi Other Asian background	Black or Black British Caribbean/African/ Other Black background	Other ethnic group Please specify
White British Irish Other white background	Asian or Asian British Indian Pakistani Bangladeshi Other Asian background				
Black or Black British Caribbean/African/ Other Black background	Other ethnic group Please specify				
Job role:					
Time working in care home (months):					
Time working in care overall (months):					
Hours worked per week:					
Days worked per week:					
Are you a key worker?					
Is English your first language?	<p>Yes No</p> <p>If No: How well do you feel you speak English? Please circle</p> <p>Very well Well Not well Not at all</p>				
Do you have contact with all residents?	<p>Yes No</p> <p>If No, approximately what percentage of residents do you have contact with? _____</p>				
Do you feel you know the residents well enough to rate their wellbeing?	<p>Yes No</p> <p>If yes, approximately what percentage of residents do you feel you know well enough to rate their wellbeing? _____</p>				

1

Appendix E. DEMQOL-CH instrument

Date: ___/___/___	Resident name: _____	How many hours contact time (approx.) did you have with the resident in the previous week? _____
Staff: _____	Care home: _____	(Contact time can be any interaction or observation with the resident, such as talking, providing personal care, activities etc.)

DEMQOL - CH

Instructions: *Read each of the following questions (in bold) verbatim and show the respondent the response card.*

I would like to ask you about _____ (the resident's) life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how _____ (the resident) has felt in the last week. If possible try and give the answer that you think _____ (the resident) would give. Don't worry if some questions appear not to apply to _____ (the resident). We have to ask the same questions of everybody.

Before we start we'll do a practice question; that's one that doesn't count. (Show the response card and ask respondent to say or point to the answer). In the last week how much has _____ (the resident) enjoyed watching television?

a lot quite a bit a little not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about _____ (the resident's) **feelings**. In the last week:

- | | | | | | |
|-----|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 1. | would you say that _____ has felt cheerful? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 2. | would you say that _____ has felt worried or anxious? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 3. | would you say that _____ has felt frustrated? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 4. | would you say that _____ has felt full of energy? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 5. | would you say that _____ has felt sad? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 6. | would you say that _____ has felt content? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 7. | would you say that _____ has felt distressed? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 8. | would you say that _____ has felt lively? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 9. | would you say that _____ has felt irritable? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 10. | would you say that _____ has felt fed-up? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 11. | would you say that _____ has felt that he/she has things to look forward to? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Next, I'm going to ask you about _____ (the resident's) **memory**. In the last week:

- | | | | | | |
|-----|--|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 12. | how worried would you say _____ has been about his/her memory in general? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 13. | how worried would you say _____ has been about forgetting things that happened a long time ago? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

- | | | | | | |
|-----|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 14. | how worried would you say _____ has been about forgetting things that happened recently? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 15. | how worried would you say _____ has been about forgetting people's names? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 16. | how worried would you say _____ has been about forgetting where he/she is? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 17. | how worried would you say _____ has been about forgetting what day it is? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 18. | how worried would you say _____ has been about his/her thoughts being muddled? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 19. | how worried would you say _____ has been about difficulty making decisions? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 20. | how worried would you say _____ has been about making him/herself understood? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Now, I'm going to ask about _____(the resident's) **everyday life**. In the last week

- | | | | | | |
|-----|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 21. | how worried would you say _____ has been about keeping him/herself clean (e.g. washing and bathing)? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 22. | how worried would you say _____ has been about keeping him/herself looking nice? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 23. | how worried would you say _____ has been about getting what he/she wants from the shops? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 24. | how worried would you say _____ has been about using money to pay for things? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

- | | | | | | |
|-----|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 25. | how worried would you say _____ has been about looking after his/her finances? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 26. | how worried would you say _____ has been about things taking longer than they used to? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 27. | how worried would you say _____ has been about getting in touch with people? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 28. | how worried would you say _____ has been about not having enough company? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 29. | how worried would you say _____ has been about not being able to help other people? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 30. | how worried would you say _____ has been about not playing a useful part in things? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 31. | how worried would you say _____ has been about his/her physical health? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

We've already talked about lots of things: _____ (the resident's) feelings, memory and everyday life. Thinking about all of these things in the last week:

- | | | | | | |
|-----|--|------------------------------------|-------------------------------|-------------------------------|-------------------------------|
| 32. | how would you say _____ would rate his/her quality of life overall? ** | <input type="checkbox"/> very good | <input type="checkbox"/> good | <input type="checkbox"/> fair | <input type="checkbox"/> poor |
|-----|--|------------------------------------|-------------------------------|-------------------------------|-------------------------------|

** items that need to be reversed before scoring

Please answer the question below

HOW CONFIDENT DID YOU FEEL IN COMPLETING THE QUESTIONNAIRE?

Not confident at all	Not very confident	Neither confident nor unconfident	Confident	Very confident
1	2	3	4	5

Appendix F. DEMQOL-Proxy staff study experience questionnaire

Care Home Staff Study Experience Survey

We are evaluating the outcome of the research project you took part in. Specifically, the questions below ask about your experience and opinions about the quality of life questionnaire (the DEMQOL-Proxy). Your responses are confidential and will not be shared with others.

To be completed by the researcher

Participant ID:

Date:

Care home ID:

1. In your opinion, what was the best aspect of the DEMQOL-Proxy questionnaire?

2. What improvements do you think could be made to the DEMQOL-Proxy? Either in the questions asked or the way it was administered.

3. Do you think completing the DEMQOL-Proxy has increased your insight into the quality of life of residents?

Yes

No

Please explain:

4. Please assess the following statements based on your experiences of taking part in the research study and measuring quality of life as a part of your caring role.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The DEMQOL-Proxy met my expectations	1	2	3	4	5
Overall I enjoyed completing the DEMQOL-Proxy	1	2	3	4	5
Regularly assessing residents' quality of life is important	1	2	3	4	5
There were too many quality of life questions to complete	1	2	3	4	5
I would have preferred to complete the DEMQOL-Proxy less frequently	1	2	3	4	5
The DEMQOL-Proxy was too complicated to use	1	2	3	4	5
Completing the DEMQOL-Proxy helped me to do my job more effectively	1	2	3	4	5
Completing the DEMQOL-Proxy changed the way I think about the quality of life of the residents in my care	1	2	3	4	5
I did not feel I could accurately complete the DEMQOL-Proxy	1	2	3	4	5

5. Would you recommend the DEMQOL-Proxy as a measure of quality of life for residents?

Yes

No

Please explain:

6. Any other comments, suggestions or thoughts?

Thank you for taking the time to complete this survey and thank you for taking part in the study

Appendix G. DEMQOL-CH staff study experience questionnaire

Care Home Staff Study Experience Survey

We are evaluating the outcome of the research project you took part in. Specifically, the questions below ask about your experience and opinions about the quality of life questionnaire (the DEMQOL-CH). Your responses are confidential and will not be shared with others.

To be completed by the researcher

Participant ID:

Date:

Care home ID:

1. In your opinion, what was the best aspect of the DEMQOL-CH questionnaire?

2. What improvements do you think could be made to the DEMQOL-CH? Either in the questions asked or the way it was administered.

3. Do you think completing the DEMQOL-CH has increased your insight into the quality of life of residents?

Yes

No

Please explain:

4. Please assess the following statements based on your experiences of taking part in the research study and measuring quality of life as a part of your caring role.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The DEMQOL-CH met my expectations	1	2	3	4	5p
Overall I enjoyed completing the DEMQOL-CH	1	2	3	4	5p
Regularly assessing residents' quality of life is important	1	2	3	4	5p
There were too many quality of life questions to complete	1	2	3	4	5n
I would have preferred to complete the DEMQOL-CH less frequently	1	2	3	4	5n
The DEMQOL-CH was too complicated to use	1	2	3	4	5n
Completing the DEMQOL-CH helped me to do my job more effectively	1	2	3	4	5p
Completing the DEMQOL-CH changed the way I think about the quality of life of the residents in my care	1	2	3	4	5p
I did not feel I could accurately complete the DEMQOL-CH	1	2	3	4	5n

5. Would you recommend the DEMQOL-CH as a measure of quality of life for residents?

Yes

No

Please explain:

6. Any other comments, suggestions or thoughts?

Thank you for taking the time to complete this survey and thank you for taking part in the study

Appendix H. DEMQOL-CH proxy instructions for administration

DEMQOL-CH - Instructions for administration

Aim of the questionnaire

- It is the resident/service user's feelings and understandings that are of interest. There are no right or wrong answers
- How people feel about things that happen every day are important. Things such as the activities that people do during the day, how they feel, and their relationships.
- Do not answer questions in terms of ability/function, it is about how much the resident/service user worries about the activities.
- **You will need a DEMQOL-CH questionnaire for each resident**

Completing the questionnaire

- Read the instructions on the front of the questionnaire.
- Read and complete the practice question.
- Read each question exactly as it is written
- Mark only one response for each question
- At the end, go back to any missed items
- **Complete each questionnaire by yourself, do not ask other members of staff or the resident/service user.**

Possible queries

I don't understand a question

If you are struggling with the meaning of the question re-read the question again, including the stem and item. Base your answer on what you think the question means.

I don't know the answer or I am unsure of an answer

It can be hard to choose a response, choose the response option that most applies to the resident/service user. All the questions are very important, please try to answer all of the questions.

Can I get the resident/service user to complete it with me?

Understanding the feelings of people who live in care and nursing homes is the aim of the questionnaire. Some people may not be able to provide this information themselves because of memory or other impairments. Therefore, getting care staff opinions is the best way to obtain a consistent measurement of how residents/service users feel.

I am unsure how the resident/service user is 'feeling'

You probably know the resident quite well, just give the answer that best describes how you think the resident has felt.

I don't understand the general quality of life questionnaire at the end

Carefully re-read the stem and the question again. Think of how the resident/service user would rate their quality of life overall, thinking about the resident/service user's life in the last week, would you say it was . . . very good, good, fair, or poor?

Appendix I. Care home staff information sheet for stage 1



CARE HOME STAFF INFORMATION SHEET

Routine measurement of quality of life in care homes

You are being invited to take part in a research study that aims to develop a method to measure residents' quality of life that can be routinely completed by care home staff.

Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please read this information carefully and discuss it with others if you wish.

Please ask a research team member if anything is not clear or if you would like more information.

Part One of this sheet explains the purpose of the study and what will be asked of you if you decide to take part.

Part Two of this sheet gives further information on how the study will be carried out.

Part One

What is the purpose of the study?

To work with care homes and care staff to develop a method so that residents' quality of life can be routinely measured and assessed as a useful part of normal care practice.

Why have I been chosen?

People being asked to take part in this study work as members of care staff in a residential care or nursing home for older adults, including people with dementia.

Do I have to take part?

No. It is entirely up to you to decide if you would like to take part in the research. If you do decide to take part in the research you will be given this information sheet to keep and be asked to sign a consent form.

If you do decide to take part, you are free to withdraw *at any time without giving a reason*. If you decide not to take part or withdraw from the study the terms of your employment will not be affected.

What will happen to me if I take part?

You will be asked to complete a questionnaire to gather demographic information and details about your role in the care home. You will also be asked to participate in a short interview with the researcher and a focus group with other staff members to gather your opinions on the development of a quality of life questionnaire, how it should be used in the care home. After the focus group discussions you will be asked to complete a quality of life questionnaire for residents on a routine basis. The frequency in which you complete this questionnaire will be based upon the discussions and views of staff during the interviews and focus group. The questionnaire should only take 10 minutes to complete.

All research activities will be completed during working hours. You will be asked to complete the quality of life measure individually, not as a part of a team. You will be routinely followed up for a maximum of 6 months.

You will be given the results of the quality of life questionnaire in feedback session with the researcher.

This completes Part One of the Information sheet. If the information in Part one interested you and you are considering participating in the study, please continue to Part Two and read the information carefully before making a final decision

Part Two

Will my taking part in this study be kept confidential?

Yes, however, during the focus groups you will be asked to discuss topics in the presence of colleagues, the information will be transcribed and analysed by the researcher. The information gained will be kept anonymous from those not involved in the focus groups. During the study, your information will be labelled or 'coded' with a participant number, not your name, so that you cannot be identified. All data will be stored securely.

When processing and storing information, we will comply with the Data Protection Act 1998 to protect your confidentiality.

Only a small number of researchers will have access to your personal information (e.g. name, address) to be used for contact purposes only (e.g. to arrange visits). All personal information will be stored separately to results in a secure location.

By agreeing to take part in this research, you will be agreeing to your focus group and questionnaire information being seen by other people who check that the research has been conducted correctly. These people include members of the immediate research team such as the researcher's academic supervisor. Anonymised data may be seen by Brighton and Sussex Medical School (the funders of the research). Anyone who works with your information agrees to hold it in confidence.

Everything you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What will happen to the results of the research study?

When we have collected all the results for this study we will analyse them and then publish and present the results. You will not be identified in any publication or presentation.

What are the possible benefits of taking part?

We hope that during the completion of the questionnaire you get a better insight into the factors that affect the wellbeing of residents in your care. Ultimately, we hope that a valid measure of quality of life can be created and used in a care home setting so that staff are able to monitor their residents' wellbeing.

If you would like to receive updates on the research then please tick the appropriate box on the consent form.

Will there be any risks or other implications of taking part in this study?

There are no risks or health implications to you or the residents by taking part in this research. All information we obtain as part of this study will be anonymised and kept confidential.

What if there is a problem?

If you are unable to attend a researcher visit (for whatever reason) please let them know. In most circumstances the visit can be rearranged at a time convenient for you.

If you would like to withdraw from taking part in the research then please contact a member of the research team. Additionally, if you think that any of the residents are becoming distressed due to taking part in the study please inform a member of the research team. Any resident becoming distressed because of the study will be immediately removed from the research. All data collected from the research will be kept for analysis and publication purposes unless otherwise requested. If you do decide to withdraw consent for the use of your data, such data will be deleted from the research and will not be used in any subsequent analysis.

In the unlikely event that you are harmed due to our negligence, you are encouraged to approach us through the research team. Normal legal processes are also open to you. If you wish to complain about any aspect of the research then please contact Ms Isla Kate Morris, University of Sussex Research Governance Officer (Email: i.morris@sussex.ac.uk, Tel: 01273 872748).

The Universities of Brighton and Sussex have insurance in place to cover their legal liabilities in respect of this study.

What if I would like to find out the results of the study?

All participants will be provided the opportunity to attend a 'findings meeting' at the end of this part of the study (Stage 1). If you would like to learn more about the findings (including that of Stage 2), please tick the appropriate box at the bottom of the consent form. At the end of the study (mid 2017), we will post you a short summary of the results for you to keep.

Who is funding the research?

The study is funded by Brighton and Sussex Medical School.

Who has reviewed the research?

The study protocol was reviewed and approved by the Brighton and Sussex Medical School Research Governance and Ethic Committee.

This study has been reviewed and approved by the Social Care Research Ethics Committee.

Contacts for further information

If you require any further information about this study then please do not hesitate to contact Laura Hughes (Tel: 01273 873132 or Email: L.J.Hughes@bsms.ac.uk)

Thank you for reading this information sheet.

Appendix J. Care home staff information sheet for stage 4

CARE HOME STAFF INFORMATION SHEET

Routine measurement of quality of life in care homes

You are being invited to take part in a research study that aims to develop a measure of residents' quality of life that can be routinely completed by care home staff.

Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please read this information carefully and discuss it with others if you wish.

Please ask a research team member if anything is not clear or if you would like more information.

Part One of this sheet explains the purpose of the study and what will be asked of you if you decide to take part.

Part Two of this sheet gives further information on how the study will be carried out.

Part One

What is the purpose of the study?

To work with care homes and care staff to develop a method so that residents' quality of life can be routinely measured and assessed by care home staff as a useful part of normal care practice.

Why have I been chosen?

People being asked to take part in this study work as members of care staff in a residential care or nursing home for older adults, including people with dementia.

Do I have to take part?

No. It is entirely up to you to decide if you would like to take part in the research. If you do decide to take part in the research you will be given this information sheet to keep and be asked to sign a consent form.

If you do decide to take part, you are free to withdraw *at any time without giving a reason*. If you decide not to take part or withdraw from the study the terms of your employment will not be affected.

What will happen to me if I take part?

You will be asked to complete a questionnaire to gather demographic information and details about your role in the care home. You will also be asked to complete quality of life questionnaires for some of the residents in your care on a routine basis. You may be asked to rate the quality of life for some residents on a monthly basis as a minimum and on a weekly basis as a maximum. You will be asked to rate those residents that you are familiar with, e.g. those you feel confident in rating the quality of life of and those that you have spent time with in the week prior to rating. All research activities will be carried out during your working hours. You will be asked to complete the quality of life measure individually, not as a part of a team.

At the end of the study you will be asked to provide feedback on your experiences of using the quality of life questionnaire.

You will be followed up for a maximum of 6 months.

You will be given the results of the quality of life questionnaire in feedback sessions with the researcher.

This completes Part One of the Information sheet. If the information in Part one interested you and you are considering participating in the study, please continue to Part Two and read the information carefully before making a final decision

Part Two

Will my taking part in this study be kept confidential?

Yes. The information gained will be kept anonymous. When processing and storing information, we will comply with the Data Protection Act 1998 to protect your confidentiality. During the study, your information will be labelled or 'coded' with a participant number, not your name. All data will be stored securely.

Only a small number of researchers will have access to your personal information (e.g. name, address) to be used for contact purposes only. All personal information will be stored separately to results in a secure location.

By agreeing to take part in this research, you will be agreeing to your questionnaire information being seen by other people who check that the research has been conducted correctly. These people include members of the immediate research team such as the researcher's academic supervisor. Anonymised data may be seen by Brighton and Sussex Medical School (the funders of the research). Anyone who works with your information agrees to hold it in confidence.

Everything you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What will happen to the results of the research study?

When we have collected all the results for this study we will analyse them and then publish and present the results. You will not be identified in any publication or presentation.

What are the possible benefits of taking part?

We hope that during the completion of the questionnaire you get a better insight into the factors that affect the wellbeing of residents in your care. Ultimately, we hope that a valid measure of quality of life can be created and used in a care home setting so that staff are able to monitor their residents' wellbeing.

If you would like to receive updates on the research then please tick the appropriate box on the consent form.

Will there be any risks or other implications of taking part in this study?

There are no risks or health implications to you by taking part in this research. All information we obtain as part of this study will be anonymised and kept confidential.

What if there is a problem?

If you are unable to attend a researcher visit (for whatever reason) please let them know. In most circumstances the visit can be rearranged at a time convenient for you.

If you no longer would like to take part in the research then please contact a member of the research team. Additionally, if you think that any of the residents are becoming distressed due to taking part in the study please inform a member of the research team. Any resident becoming distressed because of the study will be immediately removed from the research. All data collected from the research will be kept for analysis and publication purposes unless otherwise requested. If you do decide to withdraw consent for the use of your data, such data will be deleted from the research and will not be used in any subsequent analysis.

In the unlikely event that you are harmed due to our negligence, you are encouraged to approach us through the research team. Normal legal processes are also open to you. If you would like to make a complaint about any aspect of the research please contact Dr Antony Walsh, University of Sussex Research Governance Officer (Email: rgoffice@sussex.ac.uk, Tel: 01273 872748).

The Universities of Brighton and Sussex have insurance in place to cover their legal liabilities in respect of this study.

What if I would like to find out the results of the study?

All participants will be provided the opportunity to attend a 'findings meeting' at the end of the study. If you would like to learn more about the findings of the study, please tick the appropriate box at the bottom of the consent form. At the end of the study (mid 2017), we will post you a short summary of the results for you to keep.

Who is funding the research?

The study is funded by Brighton and Sussex Medical School.

Who has reviewed the research?

The study protocol was reviewed and approved by the Brighton and Sussex Medical School Research Governance and Ethic Committee.

This study has been reviewed and approved by the Social Care Research Ethics Committee.

Contacts for further information

If you require any further information about this study then please do not hesitate to contact Laura Hughes (Tel: 01273 873132 or Email: L.J.Hughes@bsms.ac.uk)

Thank you for reading this information sheet.

Appendix K. Care home staff consent form for Stage 1



Care Home Staff Consent Form

Routine measurement of quality of life in care homes

Initial as appropriate

1. I have read the information sheet on the above project (dated 27 July 2015) and have been given a copy to keep. I have been given the opportunity to ask questions about the project.

2. I consent to take part in interviews and focus groups with the researcher and other members of staff. The interviews and focus groups will be audiotaped for transcription purposes.

3. I understand that taking part in the focus group involves discussing topics in the presence of colleagues. I understand that the data will be anonymised so I cannot be identified by those not involved in the focus group

4. I agree to complete quality of life measures on behalf of the residents in my care.

5. I understand that I will not benefit financially.

6. I know how to contact the research team if I need to

7. I understand that I can change my mind and refuse to take part at any time, without reason and without it affecting my employment.

Appendix L. Care home staff consent form for Stage 4



Care Home Staff Consent Form

Routine measurement of quality of life in care homes

Initial as appropriate

1. I have read the information sheet on the above project (dated 09 June 2016) and have been given a copy to keep. I have been given the opportunity to ask questions about the project.
2. I consent to complete quality of life measures on behalf of the residents in my care. This will be on a regular basis for a maximum of 6 months.
3. I agree to complete a small set of questionnaires which include my opinions of the quality of life questionnaire.
4. I understand that I will not benefit financially.
5. I know how to contact the research team if I need to.
6. I understand that I can change my mind and refuse to take part at any time, without reason and without it affecting my employment.
7. I understand that all information obtained as part of this study will be anonymised and kept confidential. All data will be stored securely in a separate location to personal information.

8. I am satisfied that the researcher has explained the project and has provided an opportunity to ask questions. The researcher has answered all questions fully.

I would like to receive regular updates about the findings of the study.

.....
Name of person giving consent **Signature** **Date**

.....
Name of researcher **Signature** **Date**

Thank you for agreeing to take part in this research

Appendix M. Care home resident information sheet Stage 1



CARE HOME RESIDENT INFORMATION SHEET

Routine measurement of quality of life in care homes

You are being invited to take part in a research study which aims to develop a method that will allow care staff to routinely measure the quality of life of people living in care and nursing homes.

Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please read this information carefully and discuss it with others if you wish.

Please ask a research team member if anything is not clear or if you would like more information.

Part One of this sheet explains the purpose of the study and what will be asked of you if you decide to take part.

Part Two of this sheet gives further information on how the study will be carried out.

Part One

What is the purpose of the study?

The purpose of this study is to develop a method so that care staff can regularly assess the quality of life of care home residents as a part of normal care practice. This will help to improve the understanding of the quality of life experienced by people with memory problems in care and may help in the maintenance and improvement of quality of life.

Why have I been chosen?

People being asked to take part in this study live in residential care and nursing homes for older adults.

Do I have to take part?

No. It is entirely up to you to decide if you would like to take part in the research. If you do decide to take part in the research you will be given this information sheet to keep and be asked to sign a consent form.

If you do decide to take part, you are free to withdraw at any time without giving a reason.

Note. If you decide not to take part in the research or if you later decide to withdraw, this will not affect the standard of care you receive.

What will happen to me if I take part?

You will not have to do anything directly for this study, you will not be asked to complete any measures. The care home staff will complete a quality of life measure called the DEMQOL-Proxy. This measure is used by a proxy to assess your quality of life; it will be used along with other tools already used by the care home to assess wellbeing.

This completes Part One of the Information sheet. If the information in Part One interested you and you are considering participating in the study, please continue to Part Two and read the information carefully before making a final decision

Part Two

Will my taking part in this study be kept confidential?

Yes. Information for use by the researcher will be kept confidential. During the study, your information will be labelled or 'coded' with a participant number, not your name. All data will be stored securely. When processing and storing information, we will comply with the Data Protection Act 1998 to protect your confidentiality.

Only a small number of researchers will have access to your personal information (e.g. name, address) to be used for contact purposes only. All personal information will be stored separately to results in a secure location.

By agreeing to take part in this research, you will be agreeing to your information being seen by other people who check that the research has been conducted correctly. These people include members of the immediate research team such as the researcher's academic supervisor. Anonymised data may be seen by Brighton and Sussex Medical School (the funders of the research). Anyone who works with your information agrees to hold it in confidence.

Everything you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What will happen to the results of the research study?

When we have collected all the results for this study we will analyse them and then publish and present the results. You will not be identified in any publication or presentation.

What are the possible benefits of taking part?

The results from the study are unlikely to directly useful to you. However, we hope that the results of the study may inform care staff of the quality of life of residents and may be used to improve or maintain quality of life.

If you would like to receive updates on the research then please tick the appropriate box on the consent form.

Will there be any risks or other implications of taking part in this study?

There are no risks or health implications to you by taking part in this research. All information we obtain as part of this study will be anonymised and kept confidential.

What if there is a problem?

If you no longer would like to take part in the research then please contact a member of the research team or inform a member of staff. All data collected from the research will be kept for analysis and publication purposes unless otherwise requested. If you do decide to withdraw consent for the use of your data, such data will be deleted from the research and will not be used in any subsequent analysis.

In the unlikely event that you are harmed due to our negligence, you are encouraged to approach us through the research team. Normal legal processes are also open to you. If you would like to make a complaint about any aspect of the research please contact Ms Isla Kate Morris, University of Sussex Research Governance Officer (Email: i.morris@sussex.ac.uk, Tel: 01273 872748).

The Universities of Brighton and Sussex have insurance in place to cover their legal liabilities in respect of this study.

What if I would like to find out the results of the study?

If you would like to learn more about the findings of the study, please tick the appropriate box at the bottom of the consent form. At the end of the study (mid 2017), we will post you a short summary of the results for you to keep.

Who is funding the research?

The study is funded by Brighton and Sussex Medical School.

Who has reviewed the research?

The study protocol was reviewed and approved by the Brighton and Sussex Medical School Research Governance and Ethic Committee.

This study has been reviewed and approved by the Social Care Research Ethics Committee.

Contacts for further information

If you require any further information about this study then please do not hesitate to contact Laura Hughes on 01273 873132 or L.J.Hughes@bsms.ac.uk

Thank you for reading this information sheet.

Appendix N. Care home resident information sheet for Stage 4



CARE HOME RESIDENT INFORMATION SHEET

Routine measurement of quality of life in care homes

You are being invited to take part in a research study which aims to develop a method that will allow care staff to routinely measure the quality of life of people living in care and nursing homes.

Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please read this information carefully and discuss it with others if you wish.

Please ask a research team member if anything is not clear or if you would like more information.

Part One of this sheet explains the purpose of the study and what will be asked of you if you decide to take part.

Part Two of this sheet gives further information on how the study will be carried out.

Part One

What is the purpose of the study?

The purpose of this study is to develop a method so that care staff can regularly assess the quality of life of care home residents as a part of normal care practice. This will help to improve the understanding of the quality of life experienced by people with memory problems in care and may help in the maintenance and improvement of quality of life.

Why have I been chosen?

People being asked to take part in this study live in residential care and nursing homes for older adults.

Do I have to take part?

No. It is entirely up to you to decide if you would like to take part in the research. If you do decide to take part in the research you will be given this information sheet to keep and be asked to sign a consent form.

If you do decide to take part, you are free to withdraw at any time without giving a reason.

Note. If you decide not to take part in the research or if you later decide to withdraw, this will not affect the standard of care you receive.

What will happen to me if I take part?

The care home staff will complete a quality of life measure called the DEMQOL-Proxy. This measure is used by a proxy to assess your quality of life; it will be used along with other tools already used by the care home to assess wellbeing. You will be asked to complete a brief questionnaire to assess functions such as memory, attention and language; this will take no more than 20 minutes. A subset of people living in the home may be asked to consent to being observed by the researcher. If you are asked to take part in this you will be observed by the researcher only in communal areas of the care home. You will not be required to change your day-to-day schedule. This type of

observation tool usually lasts from 1 to 6 hours, however, in the current study it is expected to last less than 6 hours.

This completes Part One of the Information sheet. If the information in Part One interested you and you are considering participating in the study, please continue to Part Two and read the information carefully before making a final decision

Part Two

Will my taking part in this study be kept confidential?

Yes. Information for use by the researcher will be kept confidential. During the study, your information will be labelled or 'coded' with a participant number, not your name. All data will be stored securely. When processing and storing information, we will comply with the Data Protection Act 1998 to protect your confidentiality.

Only a small number of researchers will have access to your personal information (e.g. name, address) to be used for contact purposes only. All personal information will be stored separately to results in a secure location.

By agreeing to take part in this research, you will be agreeing to your information being seen by other people who check that the research has been conducted correctly. These people include members of the immediate research team such as the researcher's academic supervisor. Anonymised data may be seen by Brighton and Sussex Medical School (the funders of the research). Anyone who works with your information agrees to hold it in confidence.

Everything you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What will happen to the results of the research study?

When we have collected all the results for this study we will analyse them and then publish and present the results. You will not be identified in any publication or presentation.

What are the possible benefits of taking part?

The results from the study are unlikely to directly useful to you. However, we hope that the results of the study may inform care staff of the quality of life of residents and may be used to improve or maintain quality of life.

If you would like to receive updates on the research then please tick the appropriate box on the consent form.

Will there be any risks or other implications of taking part in this study?

There are no risks or health implications to you by taking part in this research. All information we obtain as part of this study will be anonymised and kept confidential.

What if there is a problem?

If you are unable to attend a researcher visit (for whatever reason) please let them know. In most circumstances the visit can be rearranged at a time convenient for you.

If you no longer would like to take part in the research then please contact a member of the research team or inform a member of staff. All data collected from the research will be kept for analysis and publication purposes unless otherwise requested. If you do decide to withdraw consent for the use of your data, such data will be deleted from the research and will not be used in any subsequent analysis.

In the unlikely event that you are harmed due to our negligence, you are encouraged to approach us through the research team. Normal legal processes are also open to you. If you would like to make a complaint about any aspect of the research please contact Ms Isla Kate Morris, University of Sussex Research Governance Officer (Email: i.morris@sussex.ac.uk, Tel: 01273 872748).

The Universities of Brighton and Sussex have insurance in place to cover their legal liabilities in respect of this study.

What if I would like to find out the results of the study?

If you would like to learn more about the findings of the study, please tick the appropriate box at the bottom of the consent form. At the end of the study (mid 2017), we will post you a short summary of the results for you to keep.

Who is funding the research?

The study is funded by Brighton and Sussex Medical School.

Who has reviewed the research?

The study protocol was reviewed and approved by the Brighton and Sussex Medical School Research Governance and Ethic Committee.

This study has been reviewed and approved by the Social Care Research Ethics Committee.

Contacts for further information

If you require any further information about this study then please do not hesitate to contact Laura Hughes on 01273 873132 or L.J.Hughes@bsms.ac.uk

Thank you for reading this information sheet.

Appendix O. Care home resident consent form for Stage 1



Resident Consent Form

Routine measurement of quality of life in care homes

Initial as appropriate

1. I have read the information sheet on the above project (24/07/2015) and have been given a copy to keep. I have been given the opportunity to ask questions about the project.
2. I give permission for the care home staff to assess my quality of life using the DEMQO-Proxy quality of life measure
3. I understand that I will not benefit financially.
4. I know how to contact the research team if I need to.
5. I am satisfied that my welfare and interests have been properly safeguarded.
6. I understand that I can change my mind and refuse to take part at any time, without a reason and without my care, medical treatment or legal rights being affected.
7. I understand that all information obtained as part of this study will be anonymised and kept confidential. All data will be stored securely in a separate location to personal information.
8. I am satisfied that the researcher has explained the project and

Appendix P. Care home resident consent form for Stage 4



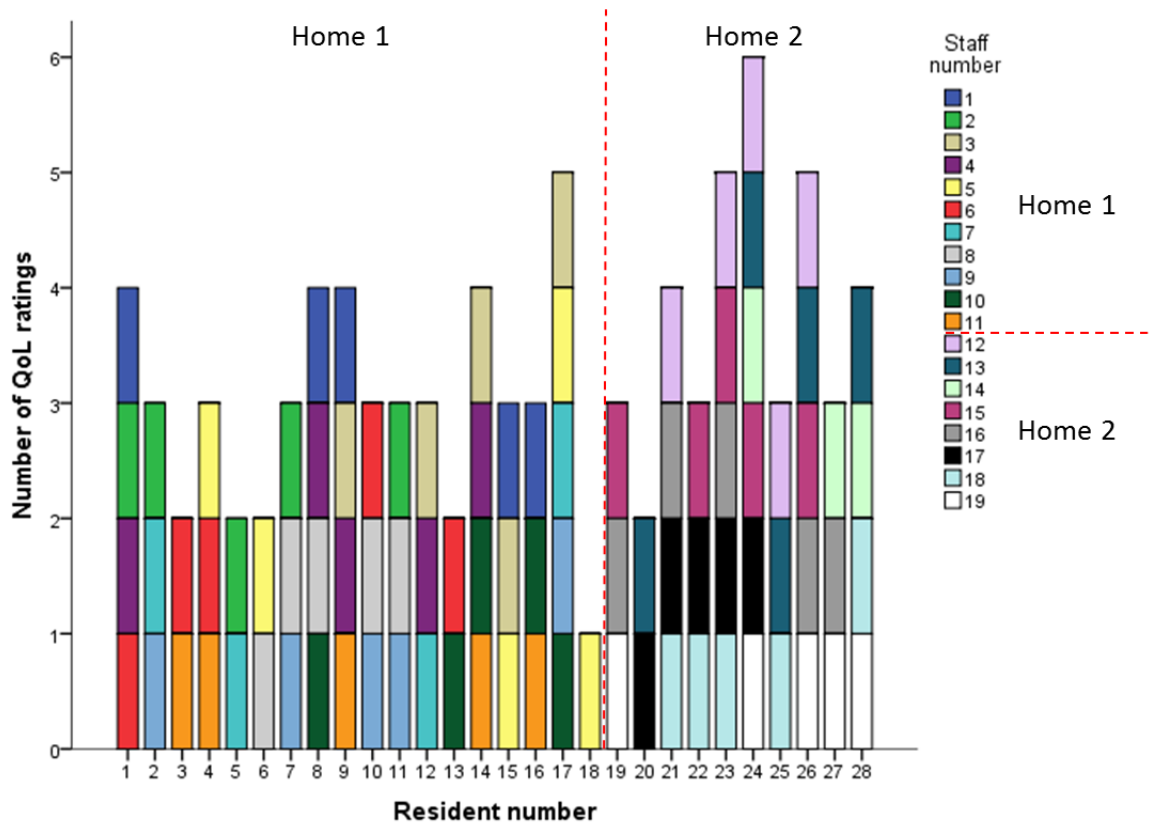
Resident Consent Form

Routine measurement of quality of life in care homes

Initial as appropriate

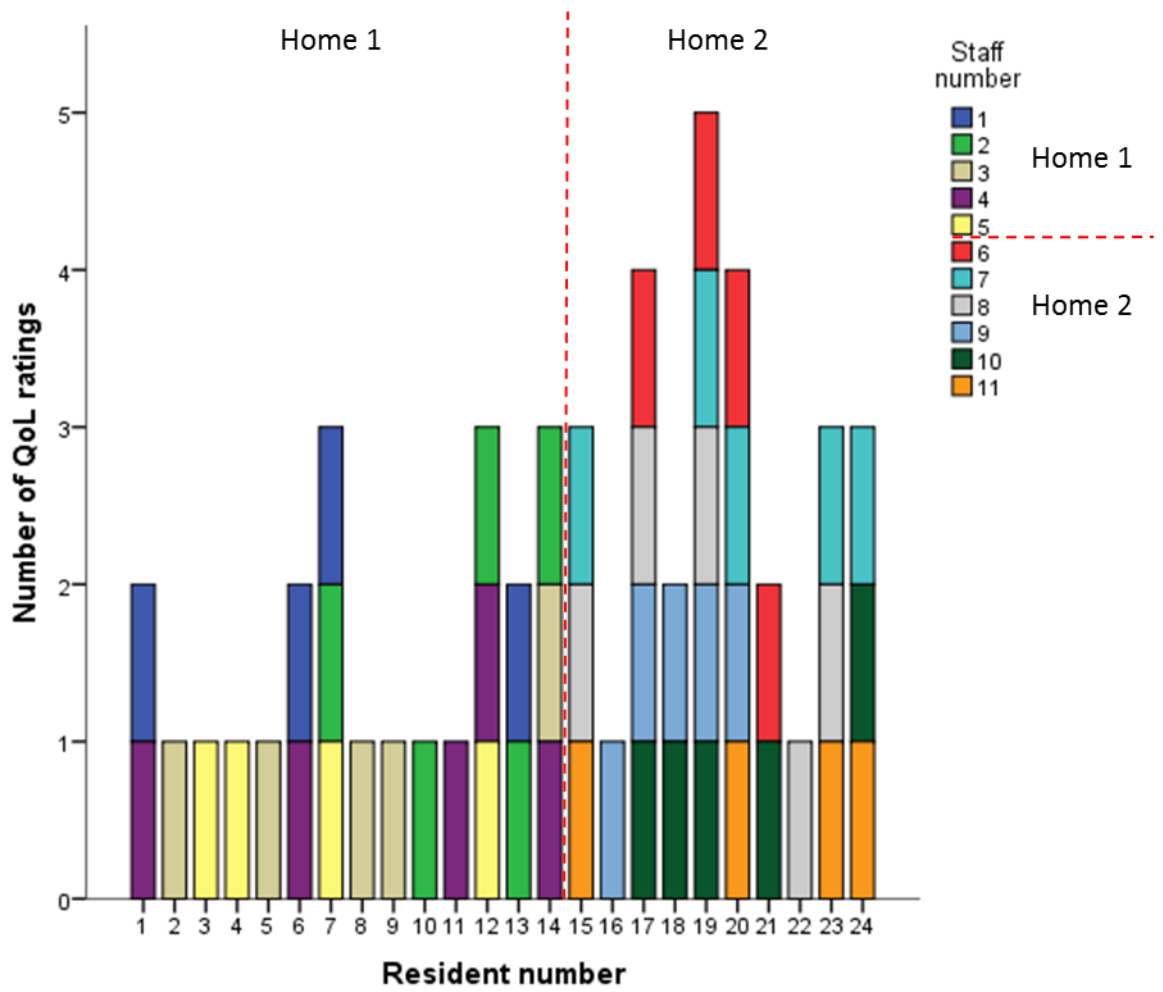
1. I have read the information sheet on the above project (dated 27 July 2015) and have been given a copy to keep. I have been given the opportunity to ask questions about the project.
2. I agree to have areas of functioning (such as memory and language abilities) assessed by the research team
3. I give permission for care home staff to assess my quality of life using the DEMQOL-Proxy quality of life measure
4. I give permission for members of the research team to observe me in communal areas of the care home
5. I understand that I will not benefit financially.
6. I know how to contact the research team if I need to.
7. I am satisfied that my welfare and interests have been properly safeguarded.
8. I understand that I can change my mind and refuse to take part at any time, without a reason and without my care, medical treatment or legal rights being affected.

Appendix Q: Cluster bar chart of QoL ratings for Stage 2



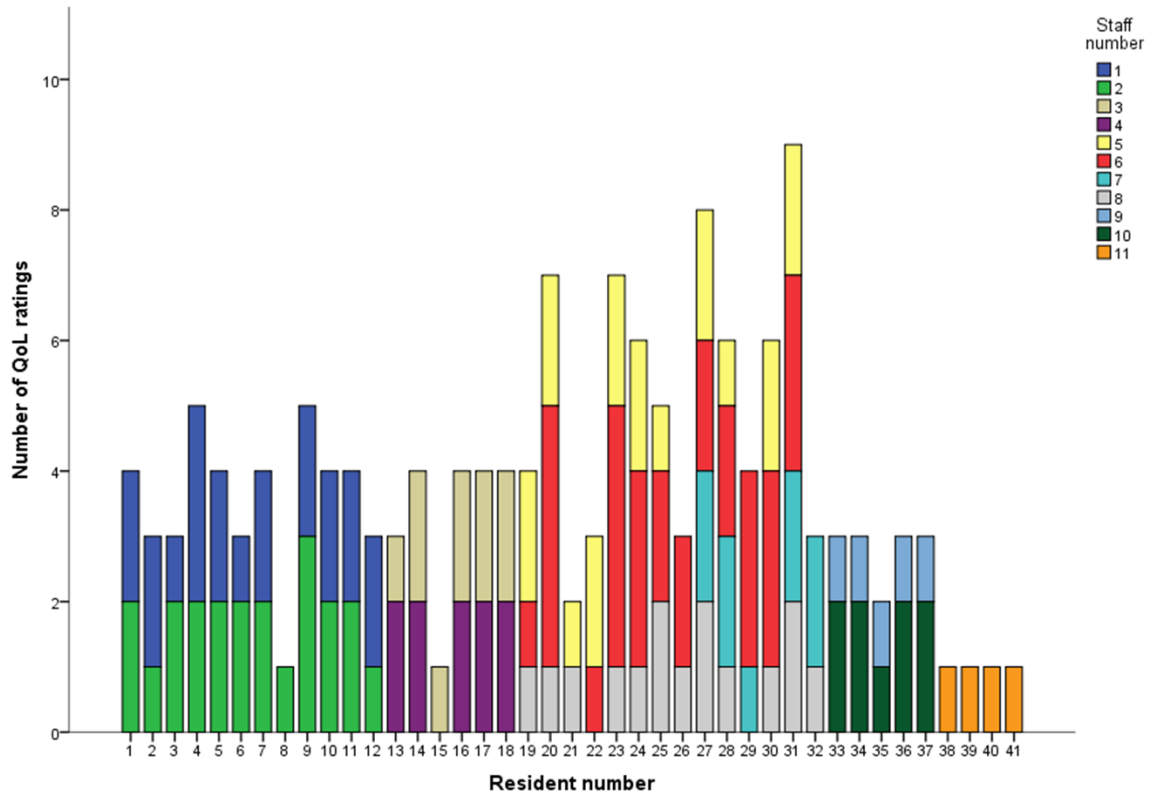
Cluster bar chart showing the number of ratings made for each resident by each member of care staff in Stage 2.

Appendix R: Cluster bar chart of QoL ratings for Stage 3



Cluster bar chart showing the number of QoL ratings made by each member of care staff for each resident in Stage 3.

Appendix S. Cluster bar chart of QoL ratings for Stage 4



Cluster bar chart showing the number of QoL ratings made by each member of care staff for each resident in Stage 4

Appendix T. Summary of meetings with qualitative supervisor in Stage 1

October 2015

Organised independent analysis of three transcripts, to discuss coding at next meeting.

Nov 2015

Discussion of independent coding of transcripts. Good agreement and discussion about coding.

Nov 2015

Catch up to see how things are progressing and to determine if there are any issues or concerns.

Dec 2015

Meeting to go over analysis and writing of results. Able to discuss my feelings on the findings from the analysis.

Dec 2015

Discussion of findings and organising focus group meeting with care home managers. Plan presentation for focus group. Talked to qualitative supervisor about focus group process.

Jan 2016

Finalised focus group presentation.

Jan 2016

Analysis and findings from focus group discussed, plan and presentation for second focus group made.

Feb 2016

Discussion of second focus group findings and plan of chapter writing. Organised date to send chapter for review. Discussion of creating a short guidance from findings.

April 2016

Meeting to go over qualitative chapter progress.

May 2016

Meeting to discuss qualitative chapter final version.