

University of East Anglia

Does a personhood and citizenship training workshop delivered to residential care home staff have the potential to affect the wellbeing of residents with dementia?
Intervention development and feasibility testing of a cluster randomised controlled trial

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Abstract

Aim: To test the feasibility of a definitive cluster-randomised controlled trial, comparing the effect of a personhood and citizenship training intervention for care home staff, with training as usual, on the wellbeing of residents with dementia.

Background: A third of people with dementia live in residential care, a sector with high staff turnover challenging the continuity of care. Most care homes provide only basic mandatory training. It is important that training interventions are robustly tested, and that outcomes are relevant to care home residents with dementia.

Methods: *Phase one:* The PERSONABLE dementia workshop intervention was informed by four focused discussion groups consisting of residential care home staff (n=12) and family members (n=3). Subsequently, PERSONABLE was piloted with care staff (n=5) and further amendments made to the content and delivery. *Phase two:* Participants were (i) care home residents with dementia, and (ii) staff working in any role with at least weekly face-to-face contact with residents. Care homes were randomly allocated to (i) PERSONABLE, or (ii) training as usual. PERSONABLE comprised five reflective exercises facilitated by a mental health nurse. The primary outcome (residents) was the mean change from baseline in Dementia Care Mapping™ wellbeing/ill-being score. Secondary outcomes were recorded at the level of care home member of staff. The Personhood in Dementia Questionnaire measures staff attitudes to personhood. A perceived competence visual analogue scale assessed how able staff felt caring for residents who have dementia. Feasibility outcomes captured i) the recruitment and attrition of care homes, residents and staff members, ii) the acceptability of the intervention, iii) the acceptability of the chosen outcome measures.

Results: Six care homes were recruited and a total of 40 residents and 118 staff members. Four residents were lost to follow-up. In the PERSONABLE arm 26 staff completed both baseline and follow-up measurements compared to 21 in the training as usual arm. Twenty-nine staff attended PERSONABLE, comprising 20 care workers, seven ancillary staff and two administration staff. Although it is not possible to infer effectiveness from this feasibility study, the direction of effect moved towards slightly more positive wellbeing/ill-being scores for residents allocated to the PERSONABLE arm.

Discussion: Engagement of care homes, residents and staff in this trial was encouraging. Simplification of study methods may help retain sufficient staff in a definitive randomised controlled trial aiming to draw inferences about effectiveness. This study found that Dementia Care Mapping™ works effectively as an outcome measure but needs further refinement to accurately capture any possible effect of a training intervention.

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Table 1: Abbreviations

Outcomes	
DCM™	Dementia Care Mapping™
ME	Mood and engagement score (DCM™)
BCC	Behaviour category codes (DCM™)
GBCC	Grouped behaviour category codes (DCM™)
PD	Personal detracting interaction (DCM™)
PE	Personal enhancing interaction (DCM™)
WIB	Well/ill-being score (DCM™)
PDQ	Personhood in dementia questionnaire
VAS	Visual analogue scale
TESS-RC	Therapeutic environment screening survey
Research terms	
RCT	Randomised controlled trial
PPI	Patient and public involvement
TAU	Training as usual
QUIS	Quality of interaction schedule
Organisations	
ENRICH	Enabling research in care homes
CQC	Care quality commission
DOH	Department of health
DSM	Diagnostic and statistical manual
NHS	National health service
DEEP	Dementia engagement and empowerment project
EMI	Elderly mentally infirm (care homes)
People	
AA	My primary supervisor
BP	My secondary supervisor
JW	My NHS manager
SJ	A peer who helped with the focused discussion groups
JF	The second observer for DCM™

Chapter one: Thesis introduction

1.1 Thesis structure

This thesis describes the study in six chapters. I occasionally employ a first person narrative, which is intended to add a personal perspective to the description of this study (Wertz et al., 2011).

1. Chapter one: an introduction to the thesis, providing an overview of the thesis structure and a personal reflection describing the origins of my idea for the study.
2. Chapter two: a literature review is presented to narrate the evolution of the two main theories of this thesis, personhood and citizenship. The literature review describes the context of residential care, highlighting research which seeks to investigate the composition of these environments. Additionally, there is an appraisal of how the components which make up usual residential care, can affect the provision of personhood and citizenship theory.
3. Chapter three: this chapter will outline phase one of the study, intervention development. This chapter contains the methods, analysis, results and interpretation pertinent to intervention development. It will describe the development of the intervention, using stakeholder feedback, focused discussion groups and piloting.
4. Chapter four: this chapter describes the methodology for phase two of the study. Phase two tested the feasibility of a definitive randomised controlled trial at the level of care home, resident, staff and intervention.
5. Chapter five: this chapter will present the findings from phase two. This study tests the feasibility of a randomised controlled trial. Therefore the analysis not only performs between group comparisons, but will integrate reporting of the feasibility outcomes.
6. Chapter six: the final chapter will take the reader through a discussion of the results. The discussion will attempt to make meaning of the study as a whole and relate this to the research questions and study aims. The implications of the study for residential dementia care and future research are discussed.

1.2 The reflection of a community nurse

Working as a community dementia nurse I often visited residential care homes. Usually following a GP referral to review medication prescribed to a resident with a dementia diagnosis. Professionally I found these referrals problematic. Despite feeling the solution to the distress of the resident was not pharmaceutical, I often found myself caught in conversations dominated by a biomedical discourse. Conversations which admittedly increased my feelings of clinical competence and perceived efficacy. I initially perceived practical nursing strategies as clinically inferior. Such strategies might have included: personalisation of care environments to aid orientation; promoting low noise care to improve communication; review of diet, fluid and physical activity; increasing opportunities for social inclusion; and helping staff to accurately interpret the experience and subsequent behaviour of residents.

I found it challenging when attempting to convey such care planning suggestions to large groups of staff. The care home would report demands on time and high staff turnover as a barrier to knowledge sharing aimed at improving the continuity of care and the resident experience. With these factors in mind, I began to offer group supervision during staff handovers. I centred discussion, of the referred resident, around the Kitwood (1993b) model of personhood because it provided an all-encompassing framework to gather information and collectively inform subsequent care planning.

I was surprised by how well the group supervision was received, it elicited an enthusiastic dialogue between residential care staff about the people for whom they cared. Solutions to the behaviour, of the referred resident, seemed to flow naturally. Sometimes there were no apparent solutions, but a better acceptance of the situation due to a deepened understanding of the person experiencing a dementia.

Once the group supervision had been delivered, there seemed only a temporary change in care delivery. After a few months I frequently observed a return to normal practice. This was not always the case, making me question what qualities the more engaged care homes possessed. One residential care home integrated the personhood model into their care planning; frequently hosting community events within the residential home, engaging residents in the personalisation of their

environments and promoting a culture of positive risk taking. All components which might promote a sense of freedom, identity and purpose for the residents. When I began exploring an area to research for my thesis the integration of personhood theory into care environments seemed worthy of further investigation. It was not until I embarked on this further investigation that I encountered citizenship theory.

1.3 Thesis overview

Residential care homes are complex environments with many interacting components. This organisational complexity can detract from the smooth testing of interventions delivered as part of randomised controlled trials (Kuske et al., 2009). Systematic review has highlighted some factors hindering the effectiveness of interventions delivered within residential care homes (Spector et al., 2016, Surr et al., 2016a). Reoccurring themes limiting intervention delivery include, high staff turnover, low staff morale, limited time, sparse physical resources, and a reluctance of staff to prioritise research over their day-to-day work (Low et al., 2015). Care home studies, delivering educational interventions, as part of a randomised controlled trial, frequently report poor staff attendance (Chenoweth et al., 2009) typically due to the time commitment being too burdensome (Beer et al., 2011a). Despite an indication that specific dementia training is beneficial, the limited time and resources apparent within residential care mean that it is usual for training to only meet basic mandatory requirements. Mandatory training directed at staff working within care homes does not usually consider personhood and citizenship, two fundamental theories perhaps crucial to the delivery of good quality dementia care (Spector et al., 2016). These two interrelated theories, when implemented within dementia care environments, could guide a provision of care which is personalised and recovery orientated.

Most care home studies, particularly trials, target interventions solely at care workers, or those who have clinical contact with residents (Kuske et al., 2009, Beer et al., 2011a, Chenoweth et al., 2009). Using a randomised controlled trial methodology this study attempted to explore the feasibility of delivering a dementia workshop intervention to all care, ancillary and administrative staff. The intervention was aimed at improving staff members' applied knowledge of personhood and citizenship. Furthermore, the study explored whether the application of personhood and citizenship theory, by the

workforce, resulted in changes to the wellbeing and behaviour of the residents they supported.

The intervention was called PERSONABLE an amalgamation of the underpinning theoretical concepts of personhood (PERSON) and citizenship (ABLE).

Chapter two: Literature review

2.1 Literature review structure

A narrative review of the available literature was conducted to explore and evaluate the existing evidence in similar or related contexts, seeking to identify interventions comparable to the one used in this study. Furthermore, the literature review sought to explore and inform the theoretical underpinning of this study. A format for narrative reviews suggested by Green et al. (2006) has been followed. This structure facilitated a deeper understanding of relationships between historical and current practices surrounding personhood and citizenship.

To inform the methods for testing the feasibility of an intervention, this review needed to explore the basis of concerns reported by trials already conducted: difficulty recruiting residents with dementia, high participant attrition, staff engagement with interventions, perceived problems navigating ethics for people lacking capacity and an institutional nihilism of an area with poor expected benefit to cost (Peri et al., 2008). To address these broad issues the literature review covered four key domains 1) the theoretical paradigms of personhood and citizenship, 2) observational wellbeing measures, 3) the care home workforce, and 4) care home dementia training interventions, reflective of personhood or citizenship principles, delivered within randomised controlled trials.

A categorised narrative approach (Green et al., 2006) to studies identified in the literature review helped to identify how researchers have integrated theoretical narratives into the current evidence base. This narrative approach was employed when exploring the theoretical paradigms of personhood and citizenship, observational measures and the exploration of the care home workforce. A more structured appraisal has been performed of studies which are similar to the intended focus and methodology of this study. Reflecting on the processes used by similar studies helped formatively develop this study. In particular, there was an iterative relationship between this literature review and this studies development of the intervention. This interaction was crucial when the idea for the intervention was evolving and was complemented by a narrative approach. Prior to completion of the

thesis the literature searches were rerun to ensure the discussion chapter was informed by the most current available evidence.

A systematic approach to a literature review may have been too specific, and not sensitive to the broad theoretical paradigms, when contextualised within complex care environments. Furthermore, preparatory literature searches indicated a sparsity of similar studies and it was a concern that a systematic review might be dominated by one or two larger trials. Feasibility testing for a definitive randomised controlled trial would need to explore the many interacting variables within residential care, therefore a broad and detailed understanding of the literature was warranted. The results of the literature review have been written as one fluid piece of work, which integrates the evidence into a broader story of the historical development of the personhood and citizenship of people with dementia.

2.1.1 Search strategy: care home interventions, reflective of personhood or citizenship principles, delivered within randomised controlled trials

A more structured approach was undertaken when searching for controlled trials testing the effect of interventions containing an element of person-centred care, personhood or citizenship. The initial search strategy was conducted using blocks of terms relating to the PICOS framework (Saaq and Ashraf, 2017) (Table 2). This very specific search strategy did not return many relevant results. When studies appearing in the reference lists of the located studies were reviewed in more detail, it became apparent that many authors had omitted the study design from the title and therefore did not appear in my original search. Furthermore, specific terms relating to resident outcomes were more varied than anticipated, meaning the initial search lacked sensitivity. The initial search including outcome measures did not capture studies with terms measuring adverse resident outcomes such as 'aggression', 'restraint' or 'anxiety'. Similarly, when specific staff outcomes were included in the search terms the increased precision of the search was at the expense of reduced sensitivity.

Taking these initial observations into account and to help ensure relevant studies were captured by the search strategy, an approach recommended by the Centre for Reviews and Dissemination was utilised (University of York, 2008). This guidance recommends omitting aspects of a PICOS search strategy that limits sensitivity, whilst

maintaining the ones that will capture the key characteristics. Subsequently, terms relating to methodology, outcomes and the theoretical underpinning of personhood and citizenship were withdrawn because they were too specific and key studies, with comprehensively structured study titles, were not being detected. This refined approach was discussed with a subject specialist librarian and further changes were made. Subsequently, a block of terms relating to a key characteristic, study settings, was introduced to keep the search focused on the specific location of investigation. Using this refined method for study searches yielded a much larger quantity of papers. This refined approach required a greater amount of detailed investigation of study abstracts and full reports. However, the strategy was more inclusive and helped underpin this study's procedures and intervention development.

Table 2: Search terms

Participants			
Resident	Staff	Intervention	Setting
Dement*	Staff	Training	Residential care
Alzheimer*	Workforce	Education	Nursing home
Cognitive impair*	Personnel	Development	Long term care
Memory	Employee*	Learn*	Care home
	Care work*	Program	Supported housing
	Care staff	Teach*	
	Nursing assistant	Instruction	
		Knowledge	

The terms in (Table 2) were entered into electronic databases using the operator 'AND' between the blocks of terms relating to participants (resident OR staff), interventions and study settings. The operator 'OR' was used for synonyms within each block of terms, a standardised approach recommend by Eriksen and Frandsen (2018). Electronic searches of the following databases were conducted: Science Citation Index, Social Sciences Citation Index, MEDLINE Complete, Academic Search Complete, Complementary Index, CINAHL Complete, PsychINFO, Directory of Open Access Journals and Science Direct. Duplicates were removed, and the remaining results were reviewed for appropriateness by title using a PICOS framework. When items relating to PICOS were missing from the study title further clarification was sought and study abstracts and full reports were reviewed. Studies were then further

appraised against inclusion and exclusion criteria. The final studies for inclusion were agreed with a second reviewer (AA).

2.1.1.1 Quality rating and critical appraisal

To get detailed information on the training interventions, the final papers were examined using a data extraction tool adapted from the Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 (Higgins JPT and Green S, 2011). This tool was used to provide a standardised approach to extracting data on study interventions and trial procedures. The final papers were assessed for quality (Table 3) using the 'Quality assessment tool for quantitative papers' (Effective Public Health Practice Project, 2007) as recommended within the Cochrane handbook (Schünemann H et al., 2013). Furthermore, the 'Quality assessment tool for quantitative papers' has been explored within a systematic review and appraised as a valid measure for a variety of quantitative studies (Deeks J, 2003). This quality assessment tool was chosen because it comprehensively covers areas relating to study bias, design, confounders, blinding, data collection methods, attrition, intervention integrity and analysis. Each section is given a score 1 (strong), 2 (moderate) and 3 (weak). Using this three-point scale, an overall score is usually agreed by two reviewers. For this review I conducted the initial appraisal independently and then agreed the final scores in consultation with a second reviewer AA.

2.1.1.2 Inclusion criteria

Studies were included for review if they met all of the following criteria:

- They were cluster randomised controlled trials, randomised controlled trials or controlled trials.
- The resident participants had a diagnosis of dementia.
- The staff participants were employed by the residential care home in any role.
- Training interventions were provided to residential care staff and contained an element of either personhood or citizenship theory.
- Outcome measurements were related to resident wellbeing or staff knowledge of dementia, attitudes to dementia, staff wellbeing and perceived competence.
- Studies published in peer-reviewed journals and available in English.

- Conducted between the years of 1989 and 2020, a wide parameter designed to capture all studies with interventions reflective of personhood or citizenship.

2.1.1.3 Exclusion criteria

Studies were excluded from the review if they met any of the following criteria:

- Participants with dementia were community dwelling and using the care home for day care.
- Training intervention did not include an element of person-centred care broadly reflective of personhood or citizenship principles.
- Where the distinction between the use of DCM as an intervention and as an outcome measure could not be determined (for example where DCM feedback was provided that could potentially affect intervention delivery).



Figure 1: 'Spot the cat' by George Sidebottom (c1890)

Figure 1 is a painting of 'The Retreat' a psychiatric hospital in York. The painting shows adults, children and animals. They are engaged in leisure activities occurring inside the walls of the hospital. The person on the bed has been brought outside and included in the social activities. It is hard to tell who is a resident and who is an employee. The depiction was painted by a resident of the institution, George Sidebottom.

2.2 The resident

"I am hungry for the life that has been taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness, and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for!"

George Thomas (a person with dementia), in Cohen and Eisdorfer (2002, page 31).

George is one of an estimated 815,827 people with dementia living in the United Kingdom, approximately 291,000 of these people live in residential care (Office for National Statistics, 2014). The diversity of this population has been highlighted, underpinning a need for adaptive and individualised care (CQC, 2014b). A census of care residents conducted between 2001 and 2011 identified a growing ethnic and religious diversity (Office for National Statistics, 2014). A diversity especially apparent in urban areas like London which had the biggest growth of ethnic populations in care homes (9.4%), compared to other areas of the United Kingdom (Office for National Statistics, 2014, Office for National Statistics, 2015). Gender is another notable demographic difference seen between people residing in care homes, with an estimated 2.8 females for every male (Alzheimer's Society, 2014). Understanding the demographic variation of care home residents helps to avoid blanket assumptions derived from study data, assumptions which might obscure the need for a tailored approach to care (Tamar and Iliffe, 2012).

A sustainable approach to caring for diverse residents might be to help staff explore and understand the individual for whom they care (Mohler et al., 2018). However, larger trials conducted in care homes face challenges when attempting to accurately describe and convey the experience of individual residents to care staff. Luff et al. (2015) conducted a thematic analysis of contributions from 57 members of the National Care Home and Research and Development Forum. They undertook this research to gain detailed insights into the broad themes highlighted as problematic by previous research conducted in care homes. One identified theme was the difficulty of finding outcome measurements which accurately capture the resident experience and are acceptable to the rest of the care home environment. A factor which can be

compounded by limited staff time, busy routines, variable observer competence and poor retention of participants.

Much of the evidence which details the individual experience of being a resident within a care home comes from smaller studies (Goodman et al., 2011). This is partly because of difficulty recruiting sufficient numbers of residents with dementia into large trials (Luff et al., 2015). In a comparative study conducted in eleven care homes, Crespo et al. (2012) explored resident quality of life, recruiting 184 relatives and 197 staff but only 102 residents. Importantly, Crespo et al. (2012) concluded each group of participants appraised the experience of the residents differently.

Choosing research outcomes which represent the experience and wishes of residents with dementia can be challenging. Cooney et al. (2009) differentiate between quality of care and quality of life, arguing that for a resident quality of care, as it is currently measured, will not always positively correlate to quality of life. Using a grounded theory approach and interviewing 101 residents they found that residents value autonomy, choice, control and meaningful activities over the professional delivery of care. A desire to maintain autonomy when moving into residential care has been explored (Jaffe and Wellin, 2008), with residents expressing fundamental challenges to their perceived independence and sense of worth. Phenomenological exploration of resident autonomy has suggested the challenges they face when moving into residential care are predominantly emotional; 'loss, isolation, uncertainty, fear, and a sense of worthlessness' (Clare et al., 2008).

To combat these negative emotions, other authors have highlighted the importance of people with dementia maintaining a sense of purpose when moving to a residential care home (Krizaj et al., 2016). Conducting interviews of six Slovenian care home residents Krizaj et al. (2016) captured the desire for purpose in the quote of one resident, who commented they would like to 'hold on to what I do'. This statement brings to life a need for residential care to purposefully reflect the world outside the walls of the residential home. However, maintaining an environment which is reflective of the 'outside' community is not straightforward. Attempting to respect the privacy and autonomy of residents whilst actively promoting socialisation is challenging; with many different people living in a relatively small space. Many

residents prefer personal informal socialisations and opportunities to talk, rather than larger organised activities (Andersson et al., 2007). However, the delivery of personalised opportunities for activity, which aims to improve the social, mental and physical wellbeing of residents, can often be regarded by staff as problematic due to the busy routines within residential care (Henwood et al., 2017).

The busy routines of staff is not the only factor affecting the provision of holistic care to residents. The MARQUE study explored the relationship between resident behaviour and staff coping (Laybourne et al., 2019). Collecting data for 1566 staff and 1483 residents the MARQUE study concluded that increasing the amount of time staff spent with residents did not improve resident agitation. They suggested training in new approaches to resident care combined with interventions supporting staff coping, would be more positively influential on resident behaviour.

Although many care homes make attempts to facilitate community diversity, exploring the efficacy of this approach is not necessarily reflected in the evidence base. There have been recent attempts within research to increase awareness of dementia in younger generations (Gibson et al., 2018), acknowledging children constitute a normal part of any community (Baker et al., 2018). However, the effect of children visiting residential care homes has not been explored, with research focusing on the negative impact of children supporting family members who have dementia (Lindgren et al., 1999, Millenaar et al., 2014). To better provide a diverse and familiar community environment many care homes have pets and there has been some exploration of the effect of animals on the wellbeing of residents with dementia, in particular the use of dogs (Karefjard and Nordgren, 2019). Although a recent meta-analysis (Zafra-Tanaka et al., 2019) concluded that current studies are not powered to detect a positive effect of interventions testing the effect of animals in care homes.

Reflecting on the painting by George Sidebottom (Figure 1) community diversity can take many forms. With this in mind, it could be that addressing the gaps in care home community diversity may generate opportunities for people with dementia to maintain their sense of identity and belonging.

2.2.1 The autonomy and selfhood of people with dementia

Challenges to the autonomy of a person and their sense of self do not necessarily begin with a move from living at home to living with support in residential care. This experience can be rooted at an earlier point in the disease (Bentwich et al., 2018). Currently in England it is estimated that 48% of people with dementia have a formal diagnosis (Alzheimer's Disease International, 2015). Banerjee and Wittenberg (2009) in an economic analysis of early diagnosis, explored the societal, financial and personal impact concluding that early diagnosis can result in improved quality of life, a reduced need for residential care and fewer general hospital admissions. However, there can also be negative effects of the diagnosis, which can permeate a person's journey with the disease (Smith et al., 2018). People receiving a diagnosis have reported a perceived loss of control and loss of rights originating in the diagnostic process (Campbell et al., 2016, Iliffe et al., 2003). Themes common throughout the literature exploring the diagnostic process include grief, guilt, shame disempowerment, and a loss of their sense of self (Campbell et al., 2016, Robinson et al., 2005). These themes are also expressed by people with dementia living in residential care (Garcia et al., 2014, Robinson et al., 2005, Marshall et al., 2015), representing a continuum of socially driven disempowerment which was seminally illustrated by Kitwood (1990).

A move to a residential care home can often occur against the expressed wishes of those with dementia, but justified as being in their best interests (Falk et al., 2013), exacerbating a perceived loss of autonomy and purpose (Kenkmann et al., 2017). These feelings can be made worse by the reality of residential care, in which it remains usual for people with dementia to have limited freedoms, which would be available to them outside of the walls of the care home (Mitchell et al., 2016). The importance of reducing the dichotomy between the outside community and the inside of residential care has been explored and there have been improvements to resident wellbeing when initiatives to integrate the outside community are employed (van Hoof et al., 2016). In this respect, and when done appropriately, the workforce can act as facilitators of resident autonomy, bridging the imaginary gap between the outside community and the front door of the care home.

2.3 Residential care staff

There are some demographic trends apparent in the residential care home workforce who attempt to provide personalised care for residents with dementia. The care home workforce is often inexperienced (Adams, 2001). Difficulty recruiting staff means that often care homes employ people completely new to care who require a period of training and development before they are proficient within their new roles (Surr et al., 2017). Strong clinical leadership seems to improve care standards, notably when care is led by a qualified nurse, approaches to care can be less risk adverse (Jacobson, 2005). Jeon et al. (2013) suggested that a greater registered nurse presence could have improved the effective implementation and use of their educational dementia care-planning tool. A nursing outreach intervention delivered within dementia care facilities, over a one year period, identified that intervention sites had lower attrition of staff (Borbasi et al., 2011). The authors attributed the reduced attrition to improved staff confidence when implementing care plans for complex physical, social and mental health needs, although this observation was concluded from focus group feedback rather than blinded quantitative data (Borbasi et al., 2011).

Despite these observations, employing a registered nurse in residential care homes is rare because it is expensive and not compulsory. Residential care homes which are registered as 'Elderly Mentally Infirm' (EMI) employ a registered nurse competent in mental health care. However, they usually have additional managerial responsibilities, which limits their face-to-face contact time with residents (Dwyer, 2011). Practical implementation of resident care planning is mostly undertaken by residential care home staff with varying levels of experience, knowledge and skill (Karlsson et al., 2009). In addition to these issues there is a poor retention of registered nurses working in residential settings. The Care Quality Commission (CQC, 2014b) cites a total staff turnover rate of 32% in the first year of employment. Reportedly, this is the highest of any social care role, yet having familiar staff and established routines in care improves outcomes for residents with dementia (Hong and Song, 2009). The CQC (2014b) found other negative effects of high staff turnover on residents, including inconsistent care standards and an increased risk of general hospital admission. The report proposes some possible explanations for a high staff turnover are poor perceived career progression, low remuneration, a high percentage of preretirement

nurses working in residential settings, poor training provision and a professional inclination to work for the NHS (CQC, 2014b).

As well as clinical staff, the effect of differing staff roles can be viewed in a broader context. The Centre for Policy on Aging (1996) has long since identified the significant amount of time ancillary and administration staff spend in face-to-face contact with residents who have dementia. In a repeated measures study which recruited 41 acute hospital staff, 35 of whom worked in nursing roles, Surr et al. (2016a) suggested that future trials which test training interventions should target staff working in non-direct care roles. Surr et al. (2016a) elaborated that it is usual for staff working in non-direct care roles to only receive basic foundation training surrounding the care of people with dementia. Yet typically research has not sought to involve these staff groups and a broader consideration of specific roles is yet to evolve (Spector et al., 2016).

2.3.1 The parameters of the residential care staff role

If a person moves into residential care the care role usually transitions from the family member to the care staff (Ray et al., 2015). When appraising the quality of the care delivered by a member of care home staff, there is disagreement as to what constitutes the provision of good care (CQC, 2014b). Where time pressures clash with individualised support, there remains a perceived divide between 'person-centred care' and 'task focused care' (Orchard et al., 2017). Often when described these two phrases are dichotomised into different entities (Lea et al., 2018). However, these two concepts can be viewed as the same, yet performed in different ways. Therefore, task focused care should not be blind to the person and person-centred care will inevitably involve 'tasks'. Importantly, both scenarios can be performed in a person-centred manner.

The transformation in viewing the paradigm of care, from a product to a philosophy, is explored by Skog et al. (1999). They describe the effect of education on the perceptions of trainee medical professionals working with people who have dementia. In a yearlong exploration of care, Skog et al. (1999) observed the transformative process of reflective education. The medical trainees began viewing residents through a staff perspective, which was focused on tasks to be achieved. As they learnt more they changed to an educational perspective, where the trainees learnt about the

disease of the people for whom they were providing care. Finally the trainees found a humanistic perspective, brought about by a more reflective and personal understanding of the residents. A perspective which elicited changes to their work and directly enhanced the autonomy of the residents.

Yet, the problems associated with care do not solely occur on a personal level. Barriers to understanding the purpose of the provision of care, provided by staff, occur on many levels; government policy, local service provision, care home processes and the individual preferences of residents (Cepoiu-Martin and Bischak, 2017, Hadjri et al., 2015, Ballard, 2010). These barriers can conflict with the ideals of person-centred care and create challenges when attempting to provide personalised care.

2.4 Residential care homes

Currently, approximately 550,000 informal carers support people with dementia who live in the community (DoH, 2013a). However, despite an emphasis on community care and assessment, which is aimed at reducing residential care need (Banerjee and Wittenberg, 2009), the proportion of people living in residential care continues to rise, currently estimated to be 291,000 people (Office for National Statistics, 2014). A figure estimated as higher 311,730 in a report jointly undertaken by Kings College London and the London School of Economics for the Alzheimer's Society (2014). The CQC (2014a) acknowledge many residential and nursing homes need to improve care delivery and have set standards surrounding safe, effective, caring, responsive, and well-led care. Yet there remains contention over how these standards are measured and whether they are the appropriate benchmarks for appraising the delivery of care (Cooney et al., 2009).

There are organisational factors within residential care, which can compromise the delivery of quality care; high staff turnover, a lack of registered nurses, weak or inconsistent leadership, poor staff training provision and the physical constituent parts of a care home (CQC, 2014a). These are factors which also seem to affect the willingness and ability of care homes to participate in research. Iliffe et al. (2017) describes care homes who effectively manage complex organisational factors as being more 'research receptive'. Exploring some of these factors, Luff et al. (2015) acknowledges the complexity of conducting research within care homes suggesting

researchers consider how the cognitive and physical frailty of residents, pressure on staff and the unique components of the care home environment might impact upon their research. Luff et al. (2015) proposed that, where possible, these issues can be mediated by working in partnership with participants. Collaboratively developed interventions which seek to address barriers to care may help improve outcomes for care home residents, staff and organisations.

With regard to the physical environment of care homes, there are many integral components which might influence the experience of the residents and staff; lighting, mirrors, structural barriers, bathrooms, furniture, bedrooms, odour, walkways, noise, outside space, quiet spaces and communal areas (Sloane et al., 2002). Research has explored the influence of some, but not all, of these factors on the provision of care.

2.4.1 The physical environment of the residential care home

The components which comprise the physical care home environment, and their effect on the resident with dementia, have been studied by several authors. In an exploration of 30 care homes, walkways which physically restrict the ability of a person with dementia to mobilise and explore, were observed to lessen the ability of these residents to complete five wayfinding tasks (Marquardt and Schmiege, 2009a). Marquardt and Schmiege (2009b) describe the environmental exploration of people with dementia as 'wayfaring', an alternative term to 'wandering'. Their rationale for a differing term is that people with dementia walk with a purpose and do not aimlessly 'wander'. Hope and Fairburn (1990) created a descriptive typology, which explored the underlying meaning and purpose behind the 'wandering' of people with dementia. Gaining an understanding of the agency and meaning which motivates the wayfaring of a resident could help care staff personalise residents care plans. Marquardt and Schmiege (2009b) noted that understanding and encouraging wayfaring, helped to maintain a better level of physical and cognitive function. In a comparative study of 40 healthy elderly people and 30 people with dementia, an increase in physical fitness was shown to enhance the wellbeing and executive function of participants with varying severities of dementia (Hollamby et al., 2017). A health and fitness focus could be an emerging need within care homes given the growing popularity of this hobby in the general population (Shigdel et al., 2019). In addition to the physical and cognitive

benefits, a systematic review and meta-synthesis of 45 studies, encompassing interviews with 672 people with dementia, reported that encouraging the free movement of residents, can promote opportunities for 'social and emotional restoration' (Forsund et al., 2018). A focus which may enhance the opportunities for residents to explore their expression of citizenship or personhood.

A diversity of indoor and outdoor spaces has been identified as beneficial, this diversity has been referred to as 'gradation' (Barnes, 2006). Using a cross sectional approach to thirty eight care homes, Barnes (2006) observed improved quality of life, wellbeing and environmental engagement in care homes which provided gradation. They used the observational measure Dementia Care Mapping™ (DCM™) to observe 452 residents, which indicated that gradation improved the 'environmental control' of a person with dementia. In this context, environmental control was defined as meaningful interaction with the physical surroundings.

Access to outside space can be limited for residents who have dementia. Promoting free-flowing movement in outside space is considered by Chalfont (2015), who describes the nurturing quality of adapted outdoor dementia friendly environments. Using the term 'culturally adapted' to imply personally tailored environments, which Chalfont (2015) asserts improves the ability of a person with dementia to 'alleviate stress by maintaining what is natural and familiar' the latter statement implies that care environments may improve if they reflect the wider society outside of the residential care home walls. Chalfont's observations seem to concur with the findings of the study by Marquardt and Schmiege (2009b), that surroundings which provide opportunities for people with dementia to practice usual activities, can promote wellbeing by improving overall cognitive and physical function. Gardening activity programmes have been reported as reinforcing the agency, identity and sense of community of those with dementia (Noone and Jenkins, 2017, Lee and Kim, 2008, Lerner, 2005). In a study of twenty three residents, sleep quality, levels of distress and cognition were demonstrated to significantly improve when exposed to a five week gardening intervention (Lee and Kim, 2008). Although these studies cannot determine whether it was the gardening activity, the social component or the physical nature of gardening that was the key ingredient. When considering the physical make up of a

residential care home, the generalised therapeutic benefit of outdoor activities is worthy of consideration.

Although noise can be a subjective experience, a care home is often filled with non-therapeutic noise from televisions, door bells, bedroom or toilet alarms, vacuum cleaners, music, staff and residents. The negative impact of non-therapeutic noise can be exacerbated by: cognitive disorder, sensory impairment, poor hydration and being in an unfamiliar environment (Umeda-Kameyama et al., 2014, Flaherty and Little, 2011, Burke and Travaline, 2006). The negative effect of noise on a person with dementia has been broadly explored in a narrative article, which discussed the challenges of busy and sometimes loud care environments (Dewing, 2009). More specifically, excessive background noise has been identified as a factor having a profound negative impact on the word recall ability of people with Alzheimer's disease, when compared to healthy elderly people exposed to the same disturbance (Belleville et al., 2003). Gussekloo et al. (2003) describe the effect of excessive background noise as 'sensory overload' reporting this phenomenon as an accelerant to distressed behaviours of residents with dementia. Another study differentiated between positive and negative noise, analysing the effect of different types of noise on the level of distress of a person with dementia, and observing improvements in cognition, behavioural distress and activities of daily living when intervention group participants were exposed to twenty minutes of calm 'white noise' consisting of ocean, rain, wind, and running water sounds (Lin et al., 2017). Dewing (2009) identifies the conflict between taking positive risks to reduce offensive noise and maintaining a safe environment. The most obvious conflict is the use of persistent alarms to notify staff when a resident requires assistance.

Natural light is important for both physical and mental wellbeing (McCurry et al., 2011, Figueiro et al., 2011). However, being exposed to an adequate amount of natural light can be an issue for people residing in care homes because of physical disability, low staff numbers to facilitate access to the outside, a resident being fearful of leaving the indoors, care home architecture, inclement weather and institutional patterns of care (Bantry White and Montgomery, 2016, Furumiya and Hashimoto, 2015, Bantry White and Montgomery, 2015). Much of the existing research focuses on synthetic lighting

interventions (Figueiro et al., 2015). Studies which explore natural light are limited (Dewing (2009) and it is usual for natural lighting to be considered only as a constituent part of the reported outdoor interventions (Edwards et al., 2013, White et al., 2017, Charras et al., 2017). Too little or too much artificial light can potentially cause either 'sensory underload' or 'sensory overload', both of which impact on the wellbeing of residents (Dewing, 2009). The effect of low-level synthetic "bluish-white" lighting, which is designed to promote circadian stimulation during the daytime was observed for 14 nursing home residents who had this lighting intervention installed in their bedrooms for four weeks (Figueiro et al., 2014). This small study concluded that the correct level of light at the right time of day was particularly important when attempting to promote healthy circadian rhythms, which subsequently improved the levels of agitation and depression experienced by the participating residents (Figueiro et al., 2014). To promote healthy sleep, orientation and occupation, lighting within residential care needs to be responsive to the seasons of the year and weather patterns (Wahnschaffe et al., 2017). The type of light, in particular 'blue light' has been identified as influencing activity, anxiety and depressive symptoms (Hopkins et al., 2017). Specifically, excessive 'blue light' can increase activity during the night, increasing incidence of distressed behaviour among residents, conversely, the same lighting intervention was reported to reduce the overall level of anxiety felt by the residents (Hopkins et al., 2017). Placement of lighting is important, well-lit walkways lower the risk of falling, although the light is only one factor and it is also important that the walkway is clearly defined, with perceptual cues, to encourage accurate spatial awareness (Figueiro et al., 2011).

2.5 Current training

The Cavendish report (DOH, 2013b) recommended increasing the minimum training requirement and ongoing supervision for care home staff. Subsequently a care certificate was developed by multiple stakeholders: Skills for Health, Skills for Care and Health Education England (Health Education England, 2015). The certificate, currently not mandatory, acknowledges the need for improved monitoring of staff training. Employees undertaking the certificate report having to complete the workbook on their days away from work (Health Education England, 2015). The certificate aims to

improve the values of the non-regulated care-force, and the behaviour and competences required to deliver effective care. The care certificate covers fifteen key competencies using a workbook which should be completed by the employee over twelve weeks (Argyle et al., 2017). The certificate is subsequently assessed by a 'suitably trained professional'. However, the professional is not specified and staff designated to supervise the care certificate report difficulty finding the time to understand and complete the assessment paperwork (Argyle et al., 2017).

Despite the high number of care home residents having a form of dementia, it is unusual for person-centred dementia training to be provided to staff within their mandatory training. This calls into question the frequent claims of 'person-centred' care on provider websites (CQC, 2014a). When person-centred training is delivered it can often misinterpret the underpinning personhood theory and is not always supported by an evidence base (Fossey et al., 2014). Some public bodies, such as the Social Care Institute for Excellence (2019) have attempted to bridge this gap by providing online training for staff working in any role. These online courses can count towards credits needed for the care certificate (Health Education England, 2015). This accessibility to dementia training is a step forward, however, Surr et al. (2017) has highlighted a need to bridge the gap between learning theory and applying the theory into practice, which for inexperienced staff may require a supervisory mechanism.

Reflective approaches to training are common place in contemporary health care, yet a reflective approach is not as apparent within trial interventions, which can focus on education surrounding the disease process or management of distressing symptoms (Spector et al., 2016). Reflective practice is a crucial component of training for registered health professionals (Anderson et al., 2018), it provides a safe method for people to explore the components of their role which they find frustrating or problematic and to explore strategies for change (Anderson et al., 2018). Reflective behaviour adjustment is theorised by Schon (1991) who proposed a process of 'reflecting on action' could promote a more competent 'reflecting in action' approach to care. In a participatory mixed methods case study of 32 health care staff and 12 senior managers working in 24 different health settings, Fuller et al. (2015) concluded that reflective practice directly enhanced behaviour transformation. They suggested

reflection provided a non-confrontational method for discussing sensitive organisational issues.

Dementia Care Mapping™ (DCM™) is a measure of resident behaviour, wellbeing and staff interactions (Kitwood and Bredin, 1992, University of Bradford, 2010). DCM™ attempts to marry observations of residents with staff reflection. When undertaking DCM™ the observer feeds back observations on resident behaviour and staff interactions to the workforce, so they might adapt their care practices (Yasuda and Sakakibara, 2017, van de Ven et al., 2013). Because of the iterative relationship between DCM™ observation and feedback given to staff, the intervention and the observational measurement are interlinked (Dichter et al., 2015, Beavis et al., 2002). An example of this iterative relationship is seen in the CADRES cluster randomised controlled trial conducted by Chenoweth et al. (2009). The study took place in 15 care homes in Sydney Australia. Five receiving an intervention based on the DCM™ training manual (University of Bradford, 2010), five receiving a training intervention covering DCM™ care plans and five receiving usual care. Outcome measurements were the therapeutic environment screening survey for nursing homes, the quality of interactions schedule, the Cohen-Mansfield agitation inventory and the quality of life in dementia questionnaire. On first appraisal the DCM™ based intervention and outcome measures seemed separate. However, further investigation of the report found that DCM™ observation was also carried out and fed back to staff to help them reflect on their work with residents. This literature review found no studies which totally separated the interventional reflective feedback component of DCM™ from the observational component (Thornton et al., 2004, Surr et al., 2018a).

The reflective approach to training within DCM™ has proved effective in changing staff behaviour (Chenoweth and Jeon, 2007). However, as with other approaches to staff training the significant time needed to successfully implement DCM™ has proved a barrier to implementation (Chenoweth et al., 2009, Griffiths et al., 2019). Reflective approaches have been used in other training interventions designed by Meziane et al. (2018) and Browning and Cruz (2018). Both training interventions were designed to help staff reflect on and cope with the distress they felt in difficult clinical

environments. The separate studies each concluded there was a positive relationship between reflective practice and a reduction in staff distress.

2.5.1 Dementia training interventions in research

Many researchers who have designed dementia training for interventions include a component of personhood and to a lesser extent citizenship principles (Low et al., 2015). A systematic review of 19 studies (Spector et al., 2016) indicated that typically training interventions are delivered face-to-face, either by a qualified professional or by a designated care home staff member. A tendency towards taught dementia training has been challenged by Surr and Gates (2017) who highlight a staff preference for interactive and reflective training which helps them to explore their understanding of assessment and its practical application.

An exception to face-to-face training was used in a study by Beer et al. (2011a) which tested the effect of a multifactorial dementia training intervention on the quality of life of 351 residents living in 39 care facilities in Western Australia. The training intervention was face-to-face for the 450 care worker participants, with under ten percent completing the entire educational program. In their intervention development study Beer et al. (2009) acknowledged the need for training to account for the busy schedule of the general practitioner participants. To mitigate the time burden on general practitioners the researchers offered an online version of the training. Despite this adaptation only 16 of the 27 general practitioners completed the adapted training, low concordance which Beer et al. (2011a) stated negated any positive effect of the training on the residents with dementia.

The complexity of studying life in residential care, makes it difficult to identify relationships, between staff training and subsequent outcomes related to residents or the workforce (Low et al., 2015). The systematic review by Low et al. (2015), of sixty-three intervention studies, suggested small targeted interventions are better received by staff than global changes. This review observed that interventions are often hindered by high staff turnover, large workloads and subsequent pressure on staff. Because of the apparent complexities in residential care, the many interacting variables have to be viewed holistically. For example, it has been broadly suggested that increasing provision of training for staff, improves staff wellbeing and lowers staff

turnover (Grant et al., 1996, Rajamohan et al., 2019). However, to understand which types of training interventions are effective in mediating these issues, the influence of the diverse factors in care homes need further clarification (Spector et al., 2016).

In studies testing the effect of training interventions it can be difficult to attribute subtle changes in outcome measurements to the intervention (Beer et al., 2011a). This can be compounded by a sparsity of measures which audit the baseline level of usual person-centred training provided by the included care homes (Griffiths et al., 2018). At a staff level, because of the time commitment needed for cluster trials implementing a training intervention, often studies do not make their projected care home recruitment target (Ballard et al., 2017, Whitaker et al., 2014). This might partly be attributed to the burden of training delivered within trials being passed onto staff, who already feel overburdened by attending training or completing online courses in their non-work time (Surr et al., 2018b). It would seem the type of training and the method for delivery is of particular importance when attempting to increase the acceptability of an intervention (Beer et al., 2009). At an organisational level, it would seem that training interventions have greater engagement when staff participation is supported by strong leadership (Quasdorf and Bartholomeyczik, 2017).

The WHELD trial (Ballard et al., 2017) attempted to negotiate the burden of training on staff by offering a psychosocial or exercise intervention, in tandem with a reduction in resident anti-psychotic medication. Each care home was offered person centred training, which comprised of dissemination of psychosocial training attended by two dementia champions at each site. There was a hundred percent recruitment of dementia champions at each site. How many other staff received the information dispersed by the two dementia champions is not clear. In addition to the psychosocial intervention, participating care homes were randomised to one or more supplementary interventions; a social intervention, an antipsychotic review or a personalised exercise intervention. The WHELD study (Ballard et al., 2017) suggested a statistically significant improvement in resident health-related quality of life, although the content and intensity of each of the interventions is not clearly described within the reports. This absence of intervention clarity makes it difficult to appraise how much of the effect can be attributed to the psychosocial and exercise

interventions, or the clinical consultations which occurred when reviewing the antipsychotic medication (Ballard et al., 2016).

Studies testing training interventions in residential care settings commonly use a series of classroom-based sessions as a platform to teach staff about person-centred care (Spector et al., 2013b). Shorter, standalone training interventions were not apparent in the literature; a majority of interventions consisted of taught hour long training sessions delivered over a period of weeks or months. Face-to-face classroom training was the most predominant approach taken (Testad et al., 2016, Kuske et al., 2009, Teri et al., 2005). As well as face-to-face training, eLearning (Beer et al., 2011a), individualised staff coaching (Ballard et al., 2018), staff development of emotion-focused interventions (Berendonk et al., 2019) and prompt cards (Deudon et al., 2009) were used, although all of these methods were reinforced with classroom training.

Despite evidence underpinning the effectiveness of brief or much shorter interventions (Brown et al., 2019, Klemperer and Hughes, 2017) none of the interventions solely took this simpler approach. Brief interventions have demonstrated statistically significant effects in trials delivering interventions for smoking cessation, with reports highlighting that staff felt brief interventions better enabled patients to understand the key focus of the suggested strategies (Marshall et al., 2019). The closest to brief or very brief interventions were in the trial conducted by Ballard et al. (2018), in which tailored staff coaching was offered to staff allocated to the intervention group. In focus groups conducted after completion of the trial, the tailored coaching was reported by staff (Griffiths et al., 2019) as helpful when attempting to apply the new knowledge to their daily work. These short flexible interventions were offered in addition to classroom training for two dementia champions in each of the 69 participating care homes. In the trial by Berendonk et al. (2019) 171 mini emotion-focused interventions were developed by care staff. Prior to developing these interventions staff were provided with two days of classroom training and implementation of the interventions was supported by research staff.

Aside from suggestions on training structure and delivery, some of the included studies suggested organisational changes which might increase the likelihood of an intervention's successful implementation. Ballard et al. (2018) propose interventions

which target culture change might increase the likelihood of training uptake. Addressing care home culture change has been reported to improve adherence to interventions once trials have ended (McCallion et al., 1999). Furthermore, promoting systemic changes in care home culture could create the right environment for implementation of non-pharmacological interventions, which have been suggested as preferable in the management of resident distress (Deudon et al., 2009). Flexible interventions which adapt to organisational barriers have been observed to be effective (Kuske et al., 2009). However, it remains important within a cluster design that sufficient numbers of staff are exposed to an intervention to ensure adequate study power (Schrijnemaekers et al., 2002).

The success of training interventions is also complicated by the many differing roles working in and with residential care homes (Griffiths et al., 2019). To reflect the diversity within a residential care community, Beer et al. (2009) recruited and delivered an intervention to a range of health care professionals. However, because of the time commitment of the protracted intervention, conducted over seven one-hour sessions, the researchers reported difficulty getting sufficient numbers of staff to attend the sessions. Furthermore, Beer et al. (2009) reported that collaborative inter-professional implementation of theory learned in training was challenging because of geographical and communicative barriers. In a critique of the current evidence surrounding training about dementia, delivered in care homes, Surr and Gates (2017) suggest that the suitability of training interventions to meet the needs of non-clinical staff groups have yet to be extensively tested. Using a small sample of 68 'non-direct care workers', who do not provide physical resident care, Irvine et al. (2013) piloted dementia eLearning, finding some positive influence on the knowledge, attitudes, self-efficacy, and behavioural intentions of participants.

Whichever staff role is being addressed, if definitive testing indicates a training intervention is effective it still needs to be practical within current health and social care working environments (Varney, 2018). An extensive resource heavy six month training intervention combined with mental health nurse liaison visits demonstrated an improvement in depressive symptoms among residents with severe dementia (Proctor et al., 1999). However, despite the reported efficacy of case management by

mental health nurses when liaising with residential care homes (Orrell et al., 2007), current community mental health teams have limited resources to facilitate prolonged and flexible interventions possibly because of the greater number of people being assessed for a timely dementia diagnosis or review of their presentation (Piercy et al., 2018). Similar time pressures, perceived or actual, have been reported by other researchers as reducing the willingness of staff participants to engage in research (Low et al., 2015).

In addition to limited time in which to deliver training, demonstrating links between person-centred training, changes in staff care practices and the wellbeing of people with dementia can be problematic (Mansah et al., 2008). Researchers have used 'train the trainer' interventions to convey person centred principles to the workforce (Rajkumar et al., 2016). In principle this method has appeared successful, however, it remains problematic to measure the exact 'information dose' or to attribute any applied changes in care practices to the intervention (Shen et al., 2018). More formalised approaches have been taken. To help measure the possible effect of an intervention Smidt et al. (2009) have advocated the use of the Kirkpatrick model, a training appraisal tool. The model can be used to evaluate whether the learning provided by training is applied within the organisation, and if so, at what level (Dorri et al., 2016). Similarly, ensuring the fidelity of the intended purpose of the intervention can be challenging when conducting cluster trials where the care home is the unit of randomisation but a mixture of people are responsible for delivering the intervention (Ballard et al., 2016).

As well as the dose of the intervention, there is difficulty deciding what constitutes a positive or negative change in the interaction between a member of staff and a resident (Kim and Woods, 2012). Hunter et al. (2013b) has explored the impact of person-centred training and developed a Personhood in Dementia Questionnaire (PDQ), intended to evaluate knowledge and application of personhood principles by health providers. They concluded that health provider beliefs about dementia do have the potential to increase the incidence of positive psychosocial approaches to care planning and care behaviour, specifically a reduction in the use of anxiolytic medication to manage distressing behaviour. Several authors have demonstrated

positive associations between a provision of person-centred training and increased employee wellbeing, reducing reported staff 'burnout' (Astrom et al., 1990, Zimmerman et al., 2005). Noel et al. (2000) concludes that not only does increased training improve staff retention but it also improves the wellbeing of care home residents, however, the methods by which training can be practically implemented is not addressed.

A table of eleven key studies is summarised in Table 3. These are the only randomised controlled trials, located by this literature review, which have tested personhood and citizenship training interventions aimed at improving resident outcomes. Trials basing their intervention around DCM™ were excluded. This is because when DCM™ is used as a measurement, it is routinely interrelated to the interventional component, the reflective feedback. This is even the case in studies which claim DCM™ as the outcome measure (Chenoweth and Jeon, 2007).

2.5.2 Quality of controlled studies testing the effect of interventions reflective of person-centred care, personhood or citizenship

The quality of the studies located within the literature was assessed using the 'Quality assessment tool for quantitative papers' (Effective Public Health Practice Project, 2007) (Table 3). The majority of studies were assessed as either being of 'moderate' quality (Deudon et al., 2009, Beer et al., 2011a, Finnema et al., 2005, Berendonk et al., 2019) or 'low' quality (Kuske et al., 2009, McCallion et al., 1999, Teri et al., 2005, Visser et al., 2008, Schrijnemaekers et al., 2002). Only two studies were assessed as being of 'strong' quality (Ballard et al., 2016, Ballard et al., 2018). Delivering psychosocial interventions presents obvious problems when attempting to maintain blinding of participants and researchers to outcome measurements, randomisation and intervention delivery. These challenges can be partially overcome when the number of clusters becomes large enough to protect the anonymity of participants (Ballard et al., 2018). This is because in smaller trials it is likely the researchers will become familiar with identifiable participant characteristics and despite attempts to distance the researcher blinding can be compromised (McCallion et al., 1999, Kuske et al., 2009, Visser et al., 2008).

Clarity about how interventions differ from the comparator group was also not clear in many of the trial reports (Berendonk et al., 2019, Deudon et al., 2009, McCallion et al., 1999, Teri et al., 2005, Visser et al., 2008). Given that a majority of these studies were small in size, lack of clarity about what constituted usual care made it difficult to attribute differences between groups to the effect of the intervention. Overall, there are numerous challenges in conducting quality trials within residential care home settings: blinding of participants and researchers, selection bias, high attrition in intervention and control groups, lack of engagement with interventions and data collection methods not being appropriately tailored to the research question or setting. This could imply that further feasibility testing would be beneficial to further inform trial designs, when applied within a residential care setting.

Table 3: Controlled studies testing the effect of interventions reflective of person-centred care, personhood or citizenship

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
Berendonk et al. (2019)	Cluster RCT <i>Intervention:</i>	<i>Clusters:</i> Nursing homes (n=20)	Baseline and eight weeks post intervention	2	Proportionally low attendance at training (n=68)
The DEMAIN study Germany	Two-day face-to-face training intervention. Teaching staff to create emotion-focused mini interventions which could be provided to residents <i>Comparator:</i> Training as usual	<i>Participants:</i> Residents with dementia (n=84) Staff caregivers (n=180)	<i>Staff:</i> Job strain and satisfaction <i>Residents:</i> Thematic analysis of care notes for residents receiving mini interventions		Intervention group job satisfaction increased compared to control group

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
Ballard et al. (2018)	Cluster RCT	<i>Clusters:</i> Care homes (n=69)	Baseline and nine months post intervention	1	Statistically significant improvement in resident quality of life
The WHELD study	<i>Intervention:</i> Orientation phase: One full time WHELD therapist allocated to nine care homes. Providing information to staff and nominated WHELD champions over two whole days over one month. Intervention phase: Eight months of 'off-site' training delivered to WHELD champions. Intervention covered person-centred care, information sharing, care planning, evidence surrounding anti-psychotic medication, understanding resident behaviour and inter-professional working.	<i>Participants:</i> Residents with dementia (n=847)	<i>Residents:</i> Primary: Proxy-rated quality of life Secondary: Agitation, cognitive deterioration, depression, quality of staff interactions, pain scale		Increase of positive care interactions between baseline and follow-up
UK	<i>Comparator:</i> Training as usual				

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
Ballard et al. (2017)	Cluster RCT factorial design	<i>Clusters</i> Care homes (n=16)	Baseline and nine months post intervention	1	Intervention group 50% reduction in anti-psychotic use
The WHELD study	Care homes assigned to social intervention (n=8), delivered by two 'dementia champions'	<i>Participants</i> Residents with dementia (n=277)	<i>Residents</i> Depression, agitation		Statistically significant reduction in depressive symptoms when antipsychotic review was combined with social interventions personalised to the needs of each care worker
UK	<i>Intervention two</i> Care homes assigned to exercise intervention (n=8)	Staff – 'dementia champions' (n=32)			
	<i>Intervention three</i> Care homes assigned to anti-psychotic review (n=8)				
	<i>Comparator:</i> Care homes receiving person-centre training (n=16)				

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
Beer et al. (2011a) The DIRECT study Australia	Cluster RCT <i>Intervention:</i> Education for designated dementia champions and eLearning for the General Practitioner participants <i>Comparator:</i> <ul style="list-style-type: none"> - Care staff and GPs in education group - Care staff education, GP control - Care staff control, GP education - Care staff control, GP control 	<i>Clusters:</i> Residential care homes (n=39) <i>Participants:</i> Residents with dementia (n=351) Clinically trained professionals, managers and care staff (n=450) General Practitioners (n=16)	Baseline and four weeks and six months post intervention <i>Staff:</i> Staff attitudes <i>Residents:</i> Self and proxy-rated quality of life	2	No statistically significant changes in resident outcomes Only 10% of the 326 staff participants attended all face-to-face training

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
Deudon et al. (2009) France	Cluster RCT <i>Intervention:</i> 90 minute training on dementia and use of 'how to' training cards. Staff were supported by trainers who gave advice on dementia management, using person-centred principles, during a two hour visit twice a week for first month and then once a week for second month <i>Comparator:</i> Training as usual	<i>Clusters:</i> Nursing homes (n=16) <i>Participants:</i> Residents with dementia (n=306) Staff participation not reported	Baseline and eight and twelve weeks post intervention <i>Residents:</i> Agitation inventory	2	Statistically significant reduction in resident agitation

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
Kuske et al. (2009) Germany	Cluster RCT <i>Intervention:</i> Three month educational intervention, designed to improve interactions between residents and caregivers <i>Comparator:</i> Relaxation intervention to promote staff mindfulness and stress reduction	<i>Clusters</i> Nursing homes (n=6) <i>Participants</i> Residents with dementia (n=210) Staff caregivers (n=96)	Baseline and immediately after intervention and six months post intervention <i>Staff</i> Caregiver knowledge of dementia care and caregiver perceived competence when caring for people with dementia	3	Statistically significant improvements in caregiver knowledge and perceived competence

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
<p>Visser et al. (2008)</p> <p>Australia</p>	<p>Cluster RCT: Pilot study</p> <p><i>Intervention:</i> Education program consisting of eight one hours units run twice a week and thirty minute peer support program after each unit</p> <p><i>Comparator:</i> Training as usual</p>	<p><i>Clusters:</i> Care homes (n=3)</p> <p><i>Participants:</i> Residents with dementia (n=76)</p> <p>Staff (n=52)</p>	<p>Baseline and three and six months post intervention</p> <p><i>Residents:</i> Agitation and quality of life</p> <p><i>Staff:</i> Staff attitudes and burnout</p>	<p>3</p>	<p>Behaviourally based education program did not result in statistically significant changes to behaviour management practices or reduce staff burnout</p> <p>Non-statistically significant improvement in staff behaviour management skills</p>

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
<p>Finnema et al. (2005)</p> <p>Netherlands</p>	<p>Cluster RCT</p> <p><i>Intervention:</i> Two half day courses explain emotion-orientated care</p> <p><i>Comparator:</i> Usual care working in accordance with guidelines from Dutch Association of nursing Home Care</p>	<p><i>Clusters:</i> Nursing homes (n=14)</p> <p><i>Participants:</i> Residents with dementia (n=146)</p> <p>Nursing assistants (n=99)</p>	<p>Baseline and seven months post intervention</p> <p><i>Residents:</i> Depression, agitation and morale</p> <p><i>Staff:</i> Organisational stress and general health</p>	<p>2</p>	<p>Statistically significant improvement in staff emotional adaptation and staff stress reactions</p>

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
Teri et al. (2005)	Cluster RCT	<i>Clusters:</i> Assisted living residences (n=15)	Baseline and eight weeks post intervention	3	Statistically significant differences reported for residents in depression, anxiety and behaviour
The Star study USA	<i>Intervention:</i> Two half-day workshops and four individualised sessions. Staff taught person-environment approaches to care through social learning theory <i>Comparator:</i> Training as usual	<i>Participants:</i> Residents with dementia (n=120) Staff (n=114)	<i>Residents:</i> Depression, anxiety, memory, behaviour, agitation, behaviours and neuropsychiatric symptoms <i>Staff:</i> Sense of competence		

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
Schrijnemaekers et al. (2002) Netherlands	Cluster RCT <i>Intervention:</i> Four hours of clinical lessons on dementia. Eight care workers in each home given emotion focused six day training program <i>Comparator:</i> Training as usual	<i>Clusters:</i> <i>Care homes</i> <i>(n=16)</i> <i>Participants:</i> Residents with dementia <i>(n=151)</i> Staff participation not reported	Baseline and three, six and twelve months post intervention <i>Residents:</i> Behaviour, agitation and activities of daily living	3	No statistically significant differences between groups for all outcomes

Authors and setting	Design and intervention	Study sample	Outcomes	Blinding and quality rating	Key findings
<p>McCallion et al. (1999)</p> <p>USA</p>	<p>Cluster RCT: Pilot study</p> <p><i>Intervention:</i> Four 45 minute communication skills group workshops and four 30 minute individual sessions offered to staff</p> <p><i>Comparator:</i> Training as usual</p>	<p><i>Clusters:</i> Care homes (n=2)</p> <p><i>Participants:</i> Residents with dementia (n=88)</p> <p>Staff participation not reported</p>	<p>Baseline and three and six months post intervention</p> <p><i>Residents:</i> Cognitive deterioration</p> <p><i>Staff:</i> Knowledge of Alzheimer's disease and mental health symptoms</p>	<p>3</p>	<p>Statistically significant improvement in depression scores</p> <p>Lower staff turnover in intervention group</p>

2.6 The context of personhood and citizenship

Often, the symptoms of dementia are described purely in the context of a neuropathological process (Wolters and Ikram, 2018). The social and emotional impacts are frequently labelled as secondary symptoms of the biologically rationalised disease (A et al., 2018). However, large scale population studies have suggested there may be social and psychological causes, contributing to the prevalence of the disease (Wu et al., 2017, Matthews et al., 2013). A growing body of evidence highlights the effect of factors aside from neurodegeneration, which could be prevented or minimised, in particular the effect on cognition and wellbeing of those in restricted social networks (Santini et al., 2015).

Healthcare predominantly works with the paradigm that the wellbeing of people with dementia can be medically improved, which negates a focus on social and psychological approaches to care. This dominance is embedded in the current World Health Organisation definition of dementia (WHO, 2012, page 7):

‘Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in a large number of conditions primarily or secondarily affecting the brain’.

It might seem logical that dementia be described in terms of the impact it has on a person’s brain function and subsequent cognitive function. Indeed many of the most notable symptoms of dementia can easily be attributed to deterioration of brain structures (A et al., 2018). However, it may also be the case that the underlying causes for these apparently neurological symptoms are caused by, or exacerbated by, a deterioration in the socialisation, purpose and agency of the person with dementia (de Vugt and Droes, 2017). When viewed using this broader framework, the neuropathological changes can be seen as a symptom, rather than the cause, the neuropathological focus obscuring a recovery orientated approach (Jha et al., 2013,

Adams, 2010). When regarded as a purely neuropathological event, it is understandable that the accompanying lack of definitive evidence to explain the causes of dementia, maintains the disease as seemingly insurmountable. However, when reviewing historical explanations for dementia these issues were not always the case.

Millennia ago, philosophers debated whether cognitive decline was a normal part of aging or an atypical disease. Solon (Circa 630BC), a statesman concerned with Athenian moral decline, wrote that judgement can be impaired by old age (Boller and Forbes, 1998). Later Cicero (44BC), a Roman philosopher and statesman, suggested deteriorating cognition was not solely a normal part of aging (Cicero, 44BC).

In the late 1800s, the question of whether cognitive decline was usual in older age drove clinical enquiry. Alois Alzheimer (1864-1915) is often credited with the first neuropathological description of a person experiencing pre-senile dementia, August D a 52-year-old woman from Frankfurt (Fischer, 1987, Small and Cappai, 2006). Understanding the debate of whether pre-senile and senile dementia were part of the same disease is important, because as Innes (2009) states it drove dementia enquiry into a biological realm, a bias, which they assert is reflected by contemporary dementia research and care. Highlighting the competition within medical research during this period, Alois Alzheimer's recognition has been described as politically endorsed by his mentor Emil Kraepelin, a prominent 18th century physician, notable for categorising mental disorder. In 1998 the slides of August D's brain autopsy were found and analysis confirmed she had what we now call Alzheimer's disease (Graeber et al., 1997).

The pre-senile/senile debate continued to fuel the medical discourse of dementia as a biological entity in the 19th and 20th centuries, dissuading contemporary focus from social or psychological perspectives (Cotrell and Schulz, 1993). In 1976 Dr Robert Katzman wrote a seminal paper 'The Prevalence and Malignancy of Alzheimer's Disease' (Khachaturian, 2008) suggesting that pre-senile and senile dementia were a continuum of one disease (Blumenthal, 1979). Harding and Palfrey (1998) state the motivation for this distinction was a desire to quantify dementia as a disease, not part of normal aging, and focus the medical communities' consensus on dementia. Once

the neuropathological debate gained a more united focus researchers began to once again explore psychosocial explanations for dementia (Innes, 2009, Bartlett and O'Connor, 2007).

The detailed history of dementia (Tay et al., 2015), suggests the disease was not always considered a purely biological process (Amaducci et al., 1986). There is no disputing the many contemporary studies, which demonstrate a correlation between neurological disease or vascular disease and cognitive decline (Mar et al., 2015, Knopman et al., 2018). Therefore, it might be instinctive to attribute alternate explanations for dementia to a historical lack of neuro-anatomical understanding (Roth et al., 1966, Monsell et al., 2015). However, when reading the history of dementia (Beach, 1987, Fischer, 1987, Amaducci et al., 1986, Innes, 2009) the apparent open-mindedness to alternative realms, which reportedly contribute or cause a dementia, is enlightening. Boller and Forbes (1998) list some of the causal factors, of dementia, which were proposed by the 19th century physician Esquirol. At first glance some are seemingly bizarre, however, many have been explored and indicated as causal by contemporary researchers (Wu et al., 2013): head injury, dietary excesses, fears (mental ill health), wine abuse, unhappy love, poverty and mania.

Esquirol used a biopsychosocial framework to describe the causal factors which he suggests lead to dementia, whether he deliberately or intuitively used this framework is unclear, but important, because it shows an inclination to a holistic view when attempting to understand dementia. Innes (2009) states the subsequent 19th and 20th century focus on describing dementia on a neuropathological level was driven by an understandable desire to locate the disease processes and cure dementia. In recent epidemiological studies, social deprivation has been positively correlated to dementia incidence, although the term 'social deprivation' could encompass many different variables; diet, smoking, alcohol consumption, illicit drug use, pollution or poor family support (Ferri et al., 2005, Matthews et al., 2013, Azarpazhooh and Hachinski, 2018). Towards the end of the 20th century, the dementia discourse again expanded and began to seek biopsychosocial explanations for causes of dementia aside from a purely neuropathological realm (Lawton, 1980, Rabins, 1988, Weitzel-Polzer and Rasehorn, 1988). During this era terms which dehumanise and disempower people with

dementia remained prevalent within the literature. For example, one paper exploring psychosocial interventions, calls people living in care homes ‘inmates’ (Weitzel-Polzer and Rasehorn, 1988). Contemporarily the language used remains a challenge to the individual identity of people who have a dementia and media headlines continue to use provocative phrases such as ‘dementia time bomb’, ‘dementia epidemic’ and ‘living death’ (Peel, 2014). Arguably these soundbites might instigate government pressure, prompting sufficient funding of dementia care and research. However, widespread negative discourse could also pose a challenge to the personhood and citizenship of individuals who have dementia (Panke-Kochinke et al., 2015).

2.7 Personhood

2.7.1 Defining personhood

This study has defined personhood, so it can be used as a framework with a specific utility, which is for a third party to understand the personhood of another. The intervention proposed in chapter three, attempted to convey two theories to residential care staff, personhood and citizenship. This study has attempted to develop autonomous definitions for each theory. It was intended that this approach would improve the understanding and application of these two theories for staff working with care home residents who have dementia.

In this study, ‘personhood’ is broadly defined as ‘the state of being a person’. This definition is literally formed from the prefix ‘person’ and suffix ‘hood’, which relates to a ‘state, condition, character or nature’ (OED, 2019). To further understand the ‘state’ of being a person, an identity focused definition of personhood has been employed (Higgs and Gilleard, 2016). This study has attempted to isolate the components which might comprise a person’s identity so that staff have a mechanism to appraise and plan care which promotes personhood. Although many facets of being human arise from interacting with other people (Cassel, 1982), this study’s definition attempts to distil each component of a personhood identity from other people and the environment. This is a pragmatic approach and acknowledges that a person can never be completely distilled from the people around them, the contextual environment or the time and situation (Dewing, 2008, Post et al., 2006). Neither can the components that constitute the state of being a person be completely separated

from each other (Baldwin, 2007). However, this approach was intended to help staff consider each domain of resident personhood, and better place the person with dementia as the agent of their own personhood.

There exist many interpretations of personhood. In recent years the term has been popularised in relation to the care of people with dementia. Arguably common use of the term 'person-centred care' in health and social care, has diluted the original utility of personhood theory, and the phrase can often be attached to clichéd 'how do you like your tea' interpretations of the concept (Cooke, 2018). However personhood theory is implemented, its delivery within care environments is likely to improve when staff have frequent access to supervisory support, aimed at enriching their understanding of personhood (Willemse et al., 2015). Personhood models are often framed as 'listening aids', to improve the understanding of a healthcare worker when interacting with a person who has dementia, but might also have difficulty expressing themselves (Washburn and Grossman, 2017). In this respect modelling of personhood can be used as a mechanism for another person to understand an individual's state of being (Tomaselli, 1984). A state which is constantly affected by social interaction (Kontos et al., 2017, Reed et al., 2017), the environment, and the stasis of an individual (Kitwood, 1990). However, it could also be argued that personhood is not something to be 'bestowed' or given, moreover a state which ultimately exists and is owned within the person (Miller, 2018). Practically, it is possible these two perspectives can be combined, as occurs in collective action models of empowerment (Drury et al., 2005). In this case, the collective action of an informed workforce seeking to facilitate empowering opportunities for people with dementia to find and express their own personhood (Bosco et al., 2019).

2.7.2 Personhood and community

The psychiatrist Ronald Laing argued that the state of being of a person, or their personhood, is interactional and environmental (Laing, 1990). He proposed that the experience of being human, and the resulting behaviours are entirely driven by an individual's experience of the world (Laing, 1990). This conceptualisation of what it means to be human relates to dementia personhood theory. Laing persistently states that to maintain selfhood, a person needs the therapeutic support and mirroring of a

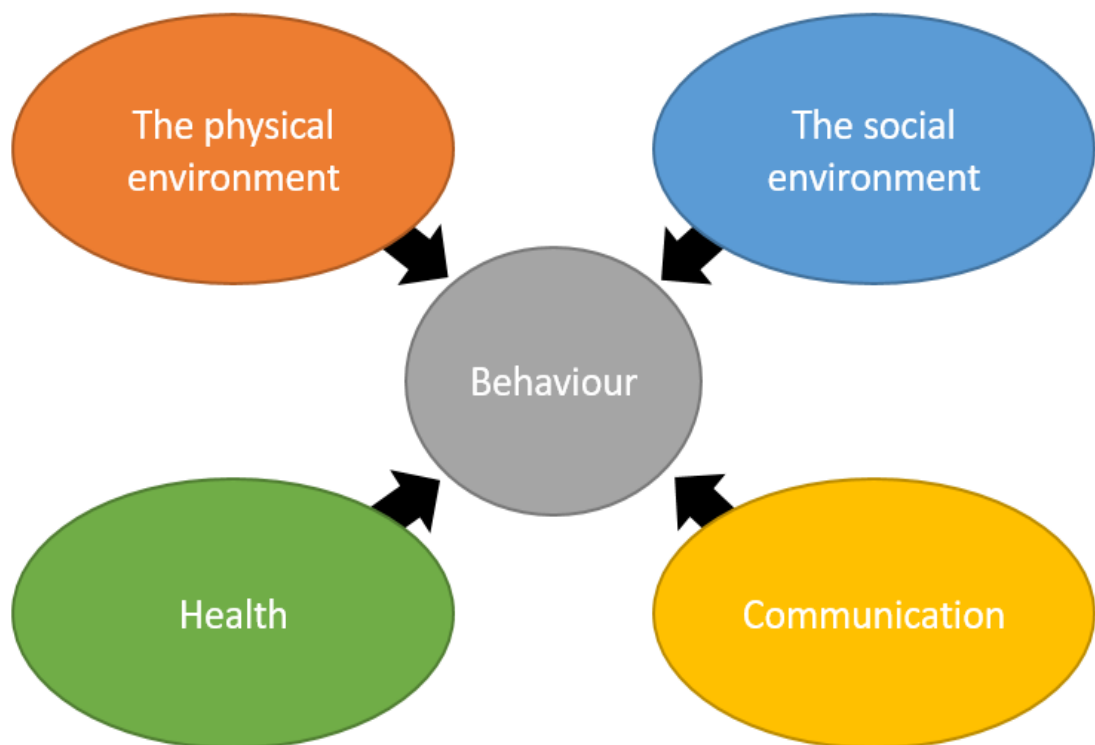
community (Laing, 1990). A stance which has been reflected in contemporary research demonstrating improved wellbeing and the increased life expectancy of people accessing supportive social networks (Lee et al., 2017, Santini et al., 2015). To enact his theory concerning the benefit of a therapeutic community, Laing created a residential community 'Kingsley Hall' for individuals with schizophrenia. Those in charge of care at Kingsley Hall sought to provide the usual activities which would be available in the outside community (Crossley, 1998). Basaglia criticised the approach of Laing, stating that care which isolates from the community outside of the institution walls would decrease opportunities for recovery from mental disorder (Fusar-Poli et al., 2011). More recently, in a comparison of four care settings, Woodward (2018) found improved resident quality of life in the care settings which had more frequent visits from community volunteers. Basaglia acknowledged a need for institutional care but insisted care should eventually enable individuals to reintegrate back to their community (Fusar-Poli et al., 2011).

More recently similar approaches to the re-enablement of people with dementia have been attempted. For example, the Dutch 'dementia village' in Weesp, which endeavours to provide care in a seemingly normal community environment (Jenkins and Smythe, 2013). Clinical and non-clinical staff wear everyday clothes, the village has a positive approach to risk and residents are grouped together based on their interests and background. However, this enterprise which seeks to enable people with dementia has not gone uncriticised. Some authors have felt that the approach restricts the autonomy of the residents by obscuring the 'real' community and creating segregation masquerading as inclusion (Haeusermann, 2017). This observation deserves exploration, as it distinguishes between healthcare attempting to understand a persons' reality even if it does not match our own, and deliberately imposing a false reality (Hyden and Samuelsson, 2018). An ethnography of community dementia care has clarified the importance of integration with the greater community outside of an institution (Phinney et al., 2016). These authors observed the enriched wellbeing of a person with dementia when the focus is not on dementia, but of belonging and having a social purpose (Phinney et al., 2016). Other emerging terms have similar problems, 'Dementia Friendly Communities' is a phrase designed to help

people with dementia feel more supported within their community (Heward et al., 2017). However, the term has been criticised for emphasising difference rather than belonging, and the simplified term ‘communities’, which are collaborative, have been suggested as sufficient (Phinney et al., 2016).

During the 1980s personhood theory was beginning to be specifically applied to the care of people with dementia. Stokes and Goudie (1990) were two authors attempting to model the effect of extrinsic influences, on the internal state and resultant behaviour of the person with dementia (Figure 2).

Figure 2: Model of behaviour, in Stokes and Goudie (1990)



Relating to care homes, the Stokes and Goudie (1990) model begins to specifically address the components of an environment which might influence the behaviour of a resident with dementia. The model helps the reader to consider the influence of the architecture, staff interactions, resident health and the social make-up of the care setting on a resident. The model represented an important academic shift in attitude towards education describing a personalised approach to care, for those working in care environments. This way of viewing resident behaviour helped to focus the

tailoring of care for people living in supported environments and instigated an influence on the type of research conducted in care homes. During this period, terms like personhood became more widely used in relation to the care of people with dementia (Ryden and Feldt, 1992). There did however, remain a predominant use of a dementia disease paradigm for quantitative studies performed within care homes (Aronson et al., 1992).

2.7.3 Tom Kitwood and Personhood

Tom Kitwood was not the only author to explore theories of personhood in relation to mental health, neither was he the first author to apply this theoretical ideology to dementia care (Kitwood and Bredin, 1992). However, his contribution is extremely important and influential. Baldwin (2007) highlights some crucial factors to consider when critically appraising Kitwood's work: Kitwood died prematurely aged 61 years. It is likely his conceptualisation of dementia would have significantly altered had he lived longer. His work was constructed in an era when it was not usual to challenge the disease paradigm of dementia, and at times his narrative diplomatically reflects concessions to this effect. His work was constructed when it was not usual to diagnose people with dementia at an early stage in the disease, therefore much of his work concentrates on people with severe dementia who might have difficulty fully articulating their experience.

2.7.3.1 *What is human?*

In 1970 Tom Kitwood wrote his first book 'What is human' (Kitwood, 1970). Within the first page he acknowledges 'the problem of the elderly' specifically referring to increased life expectancies. He does not comment further about elderly people or write about dementia in this book. He describes himself as a 'convinced Christian' and acknowledges the bias this creates, stating he prefers to write with bias than pseudo objectivity. Later in his life Kitwood renounced his Christian faith (Baldwin, 2007). At this point Kitwood stated his arguments were heavily influenced by biology, which he explains is because his studies have 'led me that way'. When summarising his exploration of what it means to be human he is pragmatic, arguing that an altered human experience is not possible without acknowledging 'man's moral failure', asserting that human behaviour is best changed through 'social action', at this time

he was not specifically referring to care environments, rather a comment on human behaviour.

His 1970 book begins to articulate Kitwood's emerging interest in Personhood. This work charts the beginnings of what would later become his creation, the observational tool Dementia Care Mapping™ (DCM™). A comprehensive explanation of DCM™ will be provided in the methods chapter. Within the book 'What is Human?' Kitwood acknowledges the importance of understanding what is real and applies this to understanding individuality. He states that untrue forces, or insincere actions, within a society 'reduce him (people) to something less of a person'. Kitwood later elaborated on the 'untrue forces' suggesting the popular conviction that cellular degeneration was the sole cause of dementia dictated an unhelpful 'doublespeak' in the care of people with dementia, a 'doublespeak' which lessened the focus on social perspectives. The term 'doublespeak' refers to a discourse described by George Orwell (1950) to describe a dominant discourse which obscures truth. Kitwood (1970) refers to the status of feeling valued within a society 'human beings can have friendship, can love, can find a meaning in their existence, can live and die in hope', an observation which later translates into his commentary on dementia.

2.7.3.2 Kitwood and malignant dementia care

Between 1989 and 1993 Kitwood made clear the problem of viewing dementia entirely in terms of a 'disease'. In one early paper Kitwood (1989) introduced the hypothesis that cognitive decline has a non-linear relationship with brain atrophy or other pathologies. Kitwood suggested the traditional reductionist neuropathological explanation, severity of cognitive decline caused by brain changes, was not correlated to neurodegeneration observed post autopsy, an assertion that was reinforced, but not conclusively, by more recent autopsy research (Pillai et al., 2016). Writing to persuade a medical audience, he proposed a framework to hypothesise which other factors might contribute to an unpredictable path of cognitive decline. Kitwood described the cognitive decline of people with dementia when exposed to social detractors: absence of social networks, poverty of conversation, negative social discourse in particular those seen within care environments or broader social constructs (Kitwood, 1989). Kitwood and Bredin (1992) later asserted these social

factors accelerate existing cognitive decline in the absence of any neuropathological change. Kitwood (1990), taking a holistic biopsychosocial view of what constitutes the personhood of someone with dementia, highlighted that the disease or neurological component is entwined in many other variables, all of which comprise an understanding of the personhood of someone experiencing dementia. Importantly he did not refute the neuropathological component of personhood, merely arguing the importance of other factors when understanding the state of personhood experienced by an individual.

Kitwood (1989) explored social interaction, proposing conceptual scenarios in which a person with dementia cognitively adapts, both negatively and positively. Interestingly, he introduces explanations of pseudo cognitive change dependent on factors other than neurological damage. Kitwood defines pseudo cognitive change as a change to cognition that is not due to neurological degeneration, highlighting factors affecting cognition which, if addressed, could be rectifiable:

- 1) Pseudodementia: that a person can recover from dementia-like syndromes such as clinical depression or delirium.
- 2) Apparent precipitation: the observation that significant life events, for example the death of a family carer, can highlight an apparent decline in the cognition of the person with dementia. However, on closer inspection the decline seems to be an 'unmasking' of an existing state, previously masked by family support.
- 3) Catastrophic decline: a dramatic change in an acutely unfamiliar and negative environment can result in a sudden decline of cognition. Kitwood provides the example of someone with dementia moving from their home to a 24 hour care environment with rigid regimes, lacking resources and demotivated staff.
- 4) Moderate or transitory 'rementia': the concept of 'rementing' describes the effect of restoring the impact of 'apparent precipitation' and 'catastrophic decline'. If the social environment is therapeutic, 'high ratios of caregivers to sufferers, close personal attention and free expression of emotion', then Kitwood suggests a person with dementia's cognition can improve or 'rement'.

Within the early work of Kitwood (1989) the essence differs from his later papers. In his 1989 paper 'Brain, mind, dementia: with particular reference to Alzheimer's disease' Kitwood concludes his work as 'bland' and in need of development, which gives a sense of him knowing his ideas are the beginning of a theoretical path. It is during this early period that he begins to use the term 'personhood' when speaking about people with dementia, albeit in conjunction with a neuropathological focus. His later work in the 1990s looks for a broader explanation of the experience of being human. His theoretical advancement is mirrored by a change in the discourse of his work; as time passes he less frequently uses disabling terms like dementia 'sufferer' or 'managing' a person with dementia. Kitwood's changing terminology perhaps mirroring a positive societal shift in attitudes towards people with dementia in the late 20th century (Blumenthal, 1979).

In 1990 Kitwood first proposed a brief equation to describe the personhood of someone with dementia (Figure 3). The equation was specifically proposed as a way of describing the effect of a negative discourse, sometimes apparent within care homes, on the personhood of someone with dementia:

$$\text{Senile Dementia} = \text{Neurological impairment} + \text{Malignant Social Psychology}$$

Figure 3: Kitwood's 1990 formula describing the effect of negative social discourse on dementia

This 1990 equation was based on Kitwood's early observations that cognitive decline appeared to accelerate in malignant care environments, noting that malignant care was commonly unconscious, institutional behaviour. At this point in his work he seems to begin moulding his earlier observations on the power of social action. He does this by facilitating institutional reflection to prompt changes in care practice. This reflective practice marked the beginning of his evolution of Dementia Care Mapping™. Considerable amounts of Kitwood's investigation discussed and provided algebraic equations to explain the dialectics of dementia in care environments. Although these equations are descriptive rather than mathematical, they help illustrate the various undesirable discourse patterns apparent in care homes during the late part of the 20th

Century. Kitwood was particularly focused on the mechanism which sustained malignant care practice and discourse, which he suggested was a result of care staff viewing people with dementia solely within a disease paradigm. He argued such attitudes negated any emphasis on personhood in the care environment (Kitwood, 1989). He reasoned the institutional neuropathological focus reduced the sense of 'self' experienced by people with dementia.

In his 1993 editorial 'Person and process in dementia' Kitwood (1993b) proposed a new equation to model the personhood of those with dementia (Figure 4). He proposed the equation was necessary to provide a framework to influence care environments by more effectively personalising care for people with dementia:


$$\text{Senile Dementia} = \text{Personality} + \text{Biography} + \text{Health} + \text{Neurological impairment} + \text{Social Psychology}$$

Figure 4: Kitwood's 1993 personhood formula

The two equations remain descriptive of the factors which contribute to the presentation of the disease of dementia. In particular reference to the 1993 model, Kitwood does not always articulate the 'equation' as a model of personhood and sometimes gets side-tracked by justifying the model as an explanation for cognitive impairment. Interestingly, his earlier book 'What is human?' more explicitly describes personhood, albeit not in relation to dementia and not using a specific model (Kitwood, 1970). It would seem when beginning to speak about dementia and personhood that Kitwood does not completely step away from a disease paradigm of dementia. Although, this observation seems semantically based as his underlying message of personhood remains intact. During this period, it is possible he was still attempting to persuade a medical audience of the authenticity of his ideas or possibly he was in a transformative phase of his investigation. Mostly, Kitwood presents the constituent parts of his equation using a humanistic approach, yet the end point of the equation remains a description of the 'physical manifestation of dementia' (Kitwood and Bredin, 1992).

2.7.3.3 Social psychology

Kitwood's emphasis on social psychology is possibly the most notable component of his theory. There is increasing evidence to suggest a link between poor social networks and a negative impact on, mortality, wellbeing and prognosis of dementia (Santini et al., 2015, Wu et al., 2016). The change of the term 'Malignant Social Psychology' in his 1990 paper to his use of 'Social Psychology' in 1993, more objectively positioned the language in the equation to acknowledge when social interaction 'enhances or diminishes'.

Despite his acknowledgement of 'enhancing' social discourses, the 1993 paper is focused on negative social discourse occurring within care settings and the resulting impact on the person with dementia. At this time, Kitwood categorises ten differing types of negative social interactions that occur between care staff and people with dementia (Kitwood, 1993b, pages 542 and 543):

'Treachery, disempowerment, infantilization, condemnation, intimidation, stigmatization, outpacing, invalidation, banishment and objectification'.

Developing his idea in his book 'Dementia reconsidered: The person comes first', Kitwood dichotomises his observation, and balances social interactions which detract with ten enhancing interactions (Kitwood, 1997a, pages 90 and 91):

'Recognition, negotiation, collaboration, play, stimulation, celebration, relaxation, validation, holding and facilitation'.

Theorists have expanded on one component of the enhancing interactions, validation. The benefit of acknowledging the emotional state of a person with dementia 'validation' was identified and turned into a form of therapy by an American social worker Naomi Feil (Feil, 1982). This was during a period when it was more usual to use reality orientation, a therapy designed to orientate people with dementia to our reality, or consensus reality. Although effective in improving cognitive and behavioural outcomes (Spector et al., 2000, Akanuma et al., 2011), reality orientation has been criticised for its disempowering nature because it confronts the reality of the person with dementia, a reality which might not match that of the consensus reality (Woodrow, 1998). Confronting the cognitive ability of someone with a dementia has been explored and a negative effect on self-esteem has been indicated, it being more

important to promote hope and optimism than to highlight deficit (Cheston et al., 2015). However, some views of reality orientation can be reductive, viewing the sole purpose of reality orientation as a cognitive exercise to help remember dates and places. When delivered as part of Cognitive Stimulation Therapy, the components which make up reality orientation are sensory prompts rather than direct verbal challenges to the reality of the person with dementia; familiar music, pictures, smells or textures (Tsoi et al., 2018, Cheung et al., 2018, Luyten et al., 2018). This constructive approach to developing therapeutic sensory orientation, with people who have dementia, embraces the enhancing principles set out by Kitwood (1997a) and is more in line with contemporary dementia recovery models (Jha et al., 2013).

Much of Kitwood's framing of social psychology is externally driven, describing the actions of care staff on the personhood of those with dementia (Kitwood, 1993b). This is in conflict with the other four domains of his personhood equation; neurological impairment, biography, health and personality, which he describes as constituent parts owned by the person. When considering personhood, understanding social psychology as something entirely external of the person, driven by others, rather than intrinsically influenced is limiting. Attempting to understand how a person with dementia prefers to seek, or not seek, social interaction could be more reflective of their personhood because it is intrinsically owned (Graham, 2017).

In some of his later work, Kitwood explored positive social interactions (Kitwood, 1998), or positive person work (Kitwood, 1997a). However, when considering positive person work, Kitwood continues to frame personhood as initiated and given by the carer, rather than reacting to attempts by a resident to enact their personhood within a responsive environment (Murray and Boyd, 2009). Brooker and Latham (2016) have developed positive person work in their VIPS model, which consists of four person-focused elements 1) valuing people, 2) promoting individual lives, 3) understanding personal perspectives and 4) developing positive social environments. In a single site non-controlled study Passalacqua and Harwood (2012) tested the effect of the VIPS model delivered within four separate one hour workshops, finding improvements in caregiver depersonalisation of people with dementia and enhanced caregiver communication skills. The VIPS model has been more rigorously tested in a

randomised controlled trial (Røsvik et al., 2011), the authors concluded that positive person work is more achievable when delivered within small units of staff. Furthermore, Røsvik et al. (2011) proposed that positive person work, delivered by staff using the VIPS model, is most effective under strong leadership which directs a consensus amongst staff to work in a certain way.

2.7.3.4 Neurological impairment

Reflecting on Kitwood's change from 'Malignant Social Psychology' to the more neutral term 'Social Psychology', it could be hypothesised that the 'Neurological Impairment' component of the equation may have undergone a similar evolution, if not for Kitwood's early death. 'Neurological Impairment' remains the only overtly diminutive term within the personhood equation. Kitwood seemingly used 'Neurological Impairment' to reflect the medical dialogue of that era, maybe to evoke engagement with medical academics. Opposing the medical model was not common in this era (Kitwood et al., 2007) and maybe Kitwood was attempting to cautiously bridge the theoretical boundary between the biological and biopsychosocial. Concerning Personhood, exploration of neurological strengths as well as impairments has been a well-received approach when applied to intervention development led by people with dementia (Judge et al., 2010). Viewing 'neurological impairment' as one component, rather than the only component affecting the behaviour of a person with dementia may provide a more balanced appraisal of the elements constituting personhood.

2.7.3.5 Health

Kitwood (1993b) included 'Health' in his personhood equation to acknowledge the effect health states may have on the cognition of a person. Indeed, some acute health states such as infection or cardiac events may have a dramatic effect on cognition (Morandi et al., 2019). However, solely focusing on the effect of a health condition on cognition can obscure a personhood perspective. A personhood focus on 'health' could help describe the effect of a health state on the sense of autonomy, identity and purpose experienced by an individual.

This is mirrored within some dementia research. One of the most cited reasons for people with dementia transitioning from home to residential care is the inability of those around them to cope with incontinence (Hope et al., 1998, Thomas et al., 2004).

The impact of this symptom is not initially on cognition but rather lower self-worth and increased distress (Melendez et al., 2018), impacting on a person's sense of self or personhood. A secondary symptom of these factors could be lowered cognitive performance (Jaffe and Wellin, 2008). Similarly, limited mobility which impairs the ability of a person with dementia to socialise or interact with the environment could affect their perceived freedom and autonomy, resulting in reduced wellbeing and possibly leading to a reduced cognitive performance (Forsund et al., 2018).

2.7.3.6 Biography

In simplistic terms Kitwood (1993b) explained that 'Biography' needed to be included in his personhood equation to provide a context for a personal history. He suggested this enabled people using the model to contextualise their understanding of the person with dementia, in particular their ability to cope with 'loss, crisis, and change'. Kitwood (1993a) hypothesised that a biography could paint a road map of the life, of a person, leading up to the beginning of the disease, that some people may arrive at this point with good resources and resilience, but others may have experienced a series of traumatic life events. He suggested this may lower their ability to cope with a given situation, such as a dementia diagnosis. An observation complemented by a recent cohort study, which observed how those with low resilience due to previous trauma are more likely to experience poor mental health (Joyce et al., 2018).

More recently the practice of collecting 'life stories' has been explored using an in-depth case study conducted across four care settings (McKeown et al., 2015). The study used semi-structured interviews, observations, conversations and field notes to holistically appraise the use of life stories for people with dementia. The authors concluding that the practice of collecting a life story should account for personal disclosures, the accuracy of the information if informed by a proxy and an over-reliance on life story work to inform present care decisions.

2.7.3.7 Personality

Kitwood (1993b) discusses the effect personality will have on a person's ability to cope with crisis, loss and change, which may have been illustrated in their 'Biography'. When commenting on the 'Personality' component of Kitwood's equation Baldwin (2007) has called personality traits 'resources for action'. 'Personality' is perhaps one of the more complex components of Kitwood's personhood model, in his later work

Kitwood attempts to expand and categorise his description of personality and how this might affect personhood (Kitwood, 1997a). A development which has been criticised for further medicalising his theoretical explanation for personhood (Baldwin, 2007). It is possible that by demarcating 'Personality', Kitwood was attempting to clearly articulate a boundary between the constituent parts of his personhood equation. For instance, differentiating between, social psychology and personality, can be problematic (Kitwood, 1993a). Understanding the relationship between external influence of social factors and an internal personality driven response, is a key aspect of Kitwood's work (Kitwood, 1990). Kitwood highlights the importance of distinguishing between the inability of a person to cope with a situation because of their underlying personality and not being able to cope because of a negative social discourse, or challenging social environment (Kitwood et al., 2007). He explains that often a person with dementia can be incorrectly attributed personality traits based on their reaction to negative care interactions, subsequently being labelled as difficult or aggressive (Kitwood et al., 2007).

An approach to personhood which adapts to the demands of the care environment, could better place an intervention to positively promote the psychology of the person with dementia (Keady, 2018). Kitwood addressing the psychological needs of the person with dementia, highlighted that each person may require differing input depending on their personality type (Kitwood, 1997b). The cause and effect of social interaction with third parties on the psychology of the person with dementia has been raised by Raineri and Cabiati (2016). This interaction between socialisation and personality further highlights the difficulty of isolating components which might comprise an assessment of personhood and promote psychological wellbeing (Baldwin, 2007). This interaction is an important consideration when attempting to develop an unambiguous model for personhood, which could be used by care staff. Confronting the theoretical ambiguity when interpreting personhood, it might be pragmatic to consider the specific application of the personhood model.

[2.7.4 The critical discussion surrounding Kitwood's ideas and research](#)

When exploring literature discussing personhood, Higgs and Gilleard (2016) suggest that personhood can be understood using frameworks of morality, consciousness,

rationality, identity, agency and reflexivity. This study has concentrated on elements of personhood relating to identity to help staff view the person with dementia beyond the disease of dementia. Critically reviewing the direction of person-centred care, Dewing (2004) appraises frameworks used to understand the personhood of people with dementia. Dewing (2004) highlights the model proposed by Kitwood (1993b) as most common. Kitwood referred to this model as a 'conceptual basis which acknowledges personhood fully' (Kitwood, 1993b). In the same paper, Kitwood (1993b) also describes the model as a platform for understanding 'the clinical manifestation of dementia'. This phrasing has been criticised for distancing the model from an understanding of the person, placing the person who has dementia as a condition to be understood (Tolhurst and Weicht, 2018). The 'clinical manifestation of a person' could be a more accurate interpretation, a 'manifestation' which could encompass but not be dominated by the disease of dementia. When reframed in this way, the model proposed by Kitwood is more representative of this study's definition of personhood and provides a simple method for exploring the identity of an individual and their 'personhood'. This theoretical framing helped inform the development and implementation of personhood so it could be operationalised in relation to people working with residents who have dementia.

Kitwood frequently describes the effect of human interaction on personhood, famously describing personhood as 'a standing or status that is bestowed upon one human being, by others' (Baldwin, 2007, Kitwood, 1997a). This has been criticised for indicating a hierarchy within personhood, through the endorsement of another person (Mitchell and Agnelli, 2015, Tolhurst and Weicht, 2018). Dewing (2008) highlights that when positioning personhood as something to be given or 'bestowed', Kitwood takes power from the person with dementia and gives it to those in care roles. A focus on the effect of care staff interactions on the personhood of someone with dementia is prevalent throughout Kitwood's work. This focus initially centres on care staff (Kitwood, 1990) and then permeates into explorations of psychotherapeutic relationships (Kitwood, 1997b). Although this focus seems an attempt to address negative staff interactions, the emphasis on third parties, rather than the agency of

the person with dementia, obscures a formulation of personhood that is driven by the person with dementia.

Despite an apparent focus on the external influences, there are conflicting incidences when Kitwood makes reference to personhood as something which can be autonomously driven by the person with dementia (Kitwood and Bredin, 1992). These contradictions are acknowledged by him, shown in an acceptance that deep theoretical concepts like personhood are hard to define and distil (Kitwood and Bredin, 1992). Appraising the underpinning intention of Kitwood's work on personhood, Dewing (2008) suggests he locates his interpretation of personhood in promoting staff to nurture a moral concern for people with dementia. However, as the discussion surrounding dementia has evolved and people are being diagnosed at an earlier point, the theoretical understanding of personhood is increasingly directed by the perspectives of people with dementia, who can inform which approaches to personhood are most favourable and important to them (Cowdell, 2006).

Reviewing studies using accounts of people with dementia, Hennelly et al. (2019) found themes highlighting the importance of identity and agency when people with dementia define and maintain their personhood. Tolhurst and Weicht (2018) further endorse the 'agential scope' of the person with dementia. This reframing of personhood from something to be 'bestowed' (Kitwood, 1997a) to something which can be generated by the individual, could be useful if they are supported by staff to enact this volition. This challenges the focus on malignant social psychology expressed by Kitwood (1990) in which the emphasis is on personhood being diminished by negative social discourse and actions, rather than staff as agents positioned to assist residents attempts to initiate personhood. Although this distinction is somewhat semantic, it remains an important refocusing and could help place the resident with dementia in a position of power, as the agent of personhood and not a product of negative staff behaviour. Repositioning carers as resources for personhood has been explored in a systematic review and qualitative synthesis of twenty study reports (Hennelly et al., 2019). The review concluded that carers comprise a platform for a person with dementia to initiate, relate and express their own personhood. Similarly, Milte et al. (2016) argued that personhood is supported rather than bestowed or

given. They drew this conclusion from an analysis of interviews with fifteen residents with dementia, which highlighted the positive effect when an environment enables the physical and social freedom for people with dementia to express their personhood.

Adams (1996) provides a critical review of Kitwood's work, acknowledging his contribution to dementia research. One criticism made by Adams (1996) is that Kitwood provides little insight into the research methods he uses to formulate and inform his theories. The strongest criticism, by Adams (1996), of Kitwood's work concerns the reporting of a larger study of 44 participants, in which Adams (1996) disagrees with Kitwood's proposition that there exists a correlation between negative life events and cognitive deterioration. Similarly, Keady et al. (2003) observe frequent contradictions within Kitwood's work, stating that his theoretical explorations are often presented as narrative thought patterns, rather than rooted in study data. Kitwood (1993b) describes himself as an 'ethnogenic' researcher. Adams (1996) points to the quality of the data underpinning this approach and cites one paper (Kitwood, 1990) which transforms interview data from two family members. Adams (1996) concludes that although these interviews lasted two hours, the breadth and subjectivity of the data was insufficient to draw generalisable conclusions. Whatever the criticisms of Kitwood's work, it remains highly significant, influencing many contemporary interpretations of person-centred care (Mitchell and Agnelli, 2015) such as, the 'very important persons' (VIPS) model (Brooker and Latham, 2016) or the person-centred nursing framework (McCormack and McCance, 2006).

2.8 Citizenship

Various models of citizenship exist, which attempt to capture the diversity of individuals and their living circumstances (Bartlett et al., 2016). Citizenship models have focused on human rights (Kelly and Innes, 2013), legal rights (Boyle, 2008), physical care equality (Graham, 2004), minority group equality (Birke, 2000) and gender equality (Hunter et al., 2016). This breadth of theoretical scope means citizenship remains a complex concept to standardise and apply across diverse contexts and populations (Bartlett, 2016).

2.8.1 Defining citizenship

For this study, citizenship is defined as the way in which a person enacts their personhood in the wider community. This can include the seeking of purpose, rights and roles. This is a person focused framing of citizenship, in which the person with dementia is the agent (Brannelly, 2011). The definition was intended to help staff be responsive to, or create opportunities for, residents to construct and enact their own citizenship. Similar to the commentary on personhood (Dewing, 2008, Tolhurst and Weicht, 2017), Ursin and Lotherington (2018) argue that viewing citizenship as something given to a person negates that person's agency in creating their own citizenship. When viewed as self-initiated, citizenship can be understood as something sought and led by the person with dementia, positioning staff as catalysts, not enforcers, of resident citizenship. However, this working definition (Ursin and Lotherington, 2018) of citizenship is pragmatic, agreeing with other authors who recognise the need for support, and a social platform, when a person with dementia attempts to enact their citizenship (Bartlett, 2014, Bartlett and O'Connor, 2007). Bartlett (2014) acknowledges that these attempts can either be supported or hindered by the understanding and engagement of the surrounding community, and although community is defined in its broadest sense within Bartlett's work, this framing could also be applied to residential care home communities.

The person-focused framing of citizenship used in my study was influenced by Birt et al. (2017) who describe citizenship as a social function enacted by individuals within a specific community. Bartlett and O'Connor (2007) take a more pragmatic view of the enacting of citizenship, acknowledging the limits of the theory for people with very advanced dementia. For this group of people Bartlett and O'Connor (2007) argue that the staff supporting the person with a late stage dementia may play a more active role in supporting their citizenship, naming this strategy the 'bi-directional' enactment of citizenship. Thematically analysing transcripts from 61 interviews, 12 of which were with people with dementia, Keyes et al. (2019) acknowledge the need for 'interdependency' when a person with dementia is attempting to express their citizenship. When attempting to nurture a citizenship friendly partnership, Hughes (2019) describes the benefit of an authentic and genuine relationship between a

person with dementia and those who care for them. Hughes (2019) suggests that a cooperative relationship requires reflection and adaptation from the person in the caring role, to monitor when their intervention 'swamps' the authenticity of the person with dementia. If a facilitative relationship is developed between staff and residents it is possible this will lead to greater resident wellbeing by creating an atmosphere which enriches opportunities for expression of citizenship.

2.8.2 The difference between citizenship and personhood

Using the available literature I have attempted to define and categorise personhood and citizenship pragmatically. This approach acknowledges the similarities and differences between the two theories. The core principle utilised when I was investigating each concept was to construct distinct workable definitions. Although the line between personhood and citizenship is not always clear (Bartlett and O'Connor, 2007), when personhood and citizenship are viewed as separate but related concepts, each with functions and limitations, they have a better chance of being integrated into study interventions designed to help care staff operationalise the two theories.

This literature review, and a systematic review (Spector et al., 2016), found no existing research exploring care home staff training specifically tailored to citizenship theory. However, this is possibly because 'personhood' is often used as a universal term, encompassing aspects of citizenship (Bartlett and O'Connor, 2007). There exists a theoretical overlap between the terms citizenship and personhood. The suffixes 'hood' and 'ship' have nearly interchangeable meanings, therefore 'citizenhood' is not dissimilar to 'personship'. Bartlett and O'Connor (2007) have acknowledged this theoretical connection. They state the greater purpose of 'citizenship' theory is to catalyse and focus attention on the rights of people with dementia, using the metaphor of citizenship as a theoretical 'lens' on personhood. Although their model only refers to personhood, Radha Krishna and Alsuwaigh (2015) provide a 'ring theory' model which combines the shared components of personhood and citizenship; innate, individual, relational and societal.

Despite the similarities, if kept separate the two theories could have autonomous functions, arising from their subtle but useful differences. Personhood theories usually attempt to describe the ephemeral experience of being human, drawing on past and present existence to help understand a current state of being (Nowell et al., 2013). In contrast citizenship theory usually situates the individual in a wider social context, which addresses a specific group or community boundary. Wiersma et al. (2016) have differentiated the two theories as ‘seeing the person’ (personhood) and ‘seeing the person as an active social agent’ (citizenship). These observations are further defined by Birt et al. (2017), who suggested that citizenship theory was evolved from the actions of marginalised groups. In this respect citizenship theory has helped consideration of the agency, purpose, identity and rights of a person, and how these are promoted within and by a community (Birt et al., 2017). Despite their interconnectedness the two theories are not always symbiotic and Dougherty (1992) has discussed the friction that can occur when individualism (personhood) exceeds the capacity of communalism (citizenship).

Table 4: The key components of personhood and citizenship as defined in this study

Personhood	Citizenship
Identity focused	Community focused
Internal attributes	Societal attributes
Individualism	Communalism
Agency within self	Agency with others

After reviewing the available literature, Table 4 was constructed to help describe how I have differentiated between personhood and citizenship. The categorisation of the two theories was informed during the formative stages of the literature review by grouping the key observations from the located literature on both personhood and citizenship. Patterns in the reports were then reviewed with a small group of academics experienced in these two theories. The primary difference between personhood and citizenship, for the purposes of this study, is that personhood pertains to the identity of the individual, exploring how the individual is understood beyond their current social and physical environment (Higgs and Gilleard, 2016).

Comparatively, citizenship introduces a community focus, a social platform in which an individual may enact their personhood. This interaction between personhood and citizenship is further described by Bartlett and O'Connor (2007). They propose that citizenship theory helps move from an identity focused understanding of personhood, to a broader conceptualisation which encompasses social and political factors. When using this framework to understand citizenship, Bartlett and O'Connor (2007) suggest that people with dementia become active individuals within a community. Looking at citizenship through a predominantly rights based paradigm, Bartlett and O'Connor (2007) maintain citizenship as something to be bestowed on people with dementia by those in positions of power. When taking this stance, Bartlett and O'Connor (2007) are challenging a fundamental societal power imbalance, similar to the motivation of Kitwood when describing personhood as bestowed (Baldwin, 2007, Kitwood, 1997a). However, these comparable stances could undermine the personhood and citizenship of people with dementia by indicating they are less likely to be agents with power, unless power is given or relinquished by a third party (Bartlett, 2016).

Placing the power of enacting these concepts in the hands of a third party, limits the potential functionality of personhood and citizenship theory. Addressing the distribution of power in residential care homes can be problematic (Scales et al., 2017). Care staff may face challenges when attempting to support and respond to a resident expressing individual agency (personhood), for example a resident attempting to leave the care home, assist with care staff duties or during meal times. When the resident interacts with other residents, expressing a communal agency (citizenship), these challenges could amplify, increasing the perceived need for staff to exert control and power (Bartlett, 2016). It is at this point that staff may be presented with the challenge of balancing individualised support, with the demands of communal living. When individualism and communalism interact, one solution is a strengths based approach (Mullan and Sullivan, 2016, McGovern, 2015). Strengths based approaches, which acknowledge the individual (personhood) and communal (citizenship) attributes of a resident have successfully improved outcomes for residents and care staff (McGovern, 2015). If these two theories can be pragmatically

separated and delivered to care staff it is possible subsequent changes to their work will create more opportunities for both resident personhood and citizenship.

2.8.3 Modelling citizenship

Baldwin and Greason (2016) coined the term 'citizenship as practice' and have categorised four approaches to practising the citizenship of people with dementia. First, meta-citizenship where organisations or government elicit political reform at a national level. Second, macro-citizenship where individuals improve the welfare of vulnerable groups, on a communal or national level. Third, midi-citizenship, where organisations take action to improve their collective citizenship. And finally, micro-citizenship, where individuals expressing their personal citizenship, or supporting others to express their citizenship within an organisation.

When considering 'meta, macro and midi citizenship' it is common to frame citizenship theory using a rights based paradigm (Bellamy, 2008). A rights based citizenship approach has helped bring about change in rights attributed to marginalised populations; ethnic minorities, class, gender and people with learning disabilities (Kacmar et al., 2011, Bartlett et al., 2016, Joshi, 2011, King, 2001).

One attempt to model rights-based citizenship within dementia care is PANEL, described in the Alzheimer Scotland (2009) manifesto, the five component model comprises of:

- Participation of people with dementia in directing decisions concerning their human rights.
- Accountability of those responsible for the respect, protection and fulfilment of human rights.
- Non-discrimination and equality of people with dementia.
- Empowerment to know your rights and how to claim them.
- Legality in all decisions through an explicit link with human rights legal standards in all processes and outcome measures.

Using a purely rights-based approach to promote citizenship in people with dementia can obscure other components of the theory which may prove helpful (Clarke, 1996). When populations gather to exercise their rights they form a new community boundary, with a focused purpose (Bellamy, 2008, Harmer and Orrell, 2008). In this scenario the collective action of individuals transcends the boundaries of the four citizenship categories 'meta, macro, midi and micro' defined by Baldwin and Greason (2016). Phinney et al. (2016) have proposed a more malleable definition of citizenship, explaining the status cannot be categorised into a 'fixed status'. Flexible citizenship is powerfully seen within the discourse and self-advocacy of participants in the 'Race for Life' cancer campaign. A powerful enterprise illustrating the positive impact of individual involvement on societal citizenship. Specifically, the campaign aims to raise public awareness of a previously stigmatised group by their self-directed discourse, created when groups run together wearing pink, personifying cancer into a beatable entity, 'cancer we are coming to get you' (Cancer Research UK, 2015).

2.8.4 Challenges to citizenship

Such vigorous citizenship campaigns are less apparent in subaltern groups who may lack the ability to self-advocate, or their attempts to self-advocate are misunderstood (Lewis, 2011). Often people with dementia are not attempting to explicitly exercise their rights. Using a purely rights based citizenship paradigm can obscure more

personal characteristics of the utility of citizenship, such as a desire of someone to enhance their selfhood or identity (Pillay, 2013).

Legislation exists to promote the citizenship of people who find it difficult to self-advocate. The Mental Capacity Act (Department of Health, 2005) dictates that a persons' capacity to make a decision should be presumed until demonstrated otherwise. In qualitative interviews Manthorpe et al. (2014) found that dementia nurses were more likely to apply the Mental Capacity Act (DH, 2005) to grand events of care which restrict freedoms, rather than more day-to-day decisions to promote citizenship or personhood. Martin and Hickerson (2013) reported a tendency of healthcare workers to presume a lack of mental capacity before an assessment has been carried out. However, on a smaller scale when used correctly within a care setting, the everyday application of the Mental Capacity Act can increase the enablement of independence (Boyle, 2008). It has been argued that if well intentioned communities act paternalistically towards people with dementia, that a culture of risk avoidance can further disable the person with dementia, by limiting opportunities for meaningful community engagement (Peel, 2014). This relationship between risk avoidance and disablement is sometimes mirrored in residential care. Taylor et al. (2018) report some health care workers feel deskilled, or overburdened, when using the Mental Capacity Act (2005). This attitude reportedly lessens the likelihood of professionals taking positive risks to promote challenging activities for people under their care.

2.8.5 Citizenship in research

In contrast to, or maybe in response to, the problems apparent when implementing the Mental Capacity Act in healthcare, dementia citizenship research has flourished. The proliferation of citizenship research seems to have occurred alongside one objective of the National Dementia Strategy (DoH, 2009), to diagnose people at an earlier point in the disease, when they may be more able to consent to participation. However, people with more severe dementia, who may lack the capacity to consent to participation face challenges being represented in research (Long, 2017). These challenges to autonomous participation are mostly procedural, complicated by high staff turnover and busy care environments which challenge effective communication

(Goodman et al., 2011). Ultimately, these challenges reduce the research voice of residents who are not able to consent to participation (Murray, 2013).

Around the time of the National Dementia Strategy, the publication of the 'Out of the Shadows' report described an initiative by Alzheimer Scotland (2009) to increase the active community participation of newly diagnosed people with dementia. A citizenship focus continued to gain momentum and in 2016, the research journal 'Dementia' dedicated a whole issue to citizenship, presenting citizenship in the context of care homes, sexuality, politics, dementia friendly communities, research involvement and feminist perspectives (Baldwin and Greason, 2016, Kontos et al., 2016, Sonnicksen, 2016, Phinney et al., 2016, Bartlett, 2016). Recently more positive discourses depicting people with dementia have appeared, possibly because of an interaction between a citizenship research focus, policy and public and professional attitudes (de Vugt and Droes, 2017).

If explained in a constructive way a citizenship focus to the care of residents with dementia could help target the use of personhood theory. Increased attention on the citizenship of residents who have dementia could inform care planning. A repositioning of citizenship alongside personhood theory, rather than acting as a 'lens' for personhood (Bartlett, 2016). This repositioning could better promote the components which comprise a person with dementia, as an able individual living within a care home community (Harmer and Orrell, 2008).

2.9 Research questions

1. Does a personhood and citizenship training workshop delivered to residential care home staff have the potential to affect the wellbeing of residents with dementia?
2. Is it feasible for a cluster randomised controlled trial to test the effectiveness of an intervention?

2.9.1 Specific feasibility questions

2.9.1.1 Participation

1. What is the response and non-response of participants during recruitment, intervention participation and outcome measurement?
2. What is the number of, and reasons for, the attrition of residents?
3. What is the number of, and reasons for, the attrition of staff?

2.9.1.2 Intervention

4. Will a collaboratively designed intervention be acceptable to participants?
5. Does the intervention have the potential to improve the knowledge and application of personhood and citizenship theory by staff?
6. Does a personhood and citizenship intervention have the potential to improve the wellbeing of residents with dementia?

2.9.1.3 Measurement

7. Does Dementia Care Mapping™ capture any possible effect of changes in staff or resident behaviour as a result of a personhood and citizenship intervention?
8. Are the chosen outcome measures acceptable and useful to participants?

Chapter three: Development of an intervention

3.1 Introduction

This chapter demonstrates how the PERSONABLE intervention, a reflective dementia workshop evolved. The intervention idea was rooted within observations from my clinical experience, when I would frequently visit care homes to meet residents who had dementia. Arising from this personal beginning the intervention was systematically scrutinised by several formative processes. The preliminary stakeholder input helped me to construct a draft version of the intervention. Following this the intervention was further informed by focused discussion groups. This structured process helped me to tailor the language and content to a specific population, people who work within residential care homes. After the focused discussion groups, I piloted the refined version of the intervention with a group of residential care staff. I made further amendments in tandem with feedback received from an independent observer. At this point the intervention was complete and ready to test within phase two of this study, the feasibility testing of a randomised controlled trial.

3.2 Focused discussion groups

I chose focused discussion groups to help refine the working idea for the intervention. The focused discussion groups were intended to allow a variety of professionals and family members of residents to comment on predetermined themes relating to the proposed dementia workshop. Additionally, I believed focused discussion groups would help illuminate any interactional issues between staff, which might inform the smooth operation of phase two of the study, when the intervention would be delivered to staff to test the feasibility of a randomised controlled trial (Barbour and Kitzinger, 1999).

3.3 Reflective practice

The intervention is novel not only because of the reflective content, which veers away from a traditional taught emphasis on the care of people with dementia, but also because it was delivered to residential care staff working in a variety of roles. I proposed the inclusion of a mixture of roles to help staff reflect on their joint work as a care home community. Interventions which have focused on taught knowledge can often overlook the reflective component necessary to safely explore challenging care

scenarios (Mansah et al., 2008). Additionally, the literature review indicated a reflective process to staff training could help facilitate transformation by bridging the gap between the training and its application to care (Beer et al., 2011b).

3.4 Intervention development

Including the opinions of all core groups of staff working within residential care was intended to prompt a rounded approach to any adjustments made as a result of the intervention. This idea was partly rooted within my observations from clinical practice that well-performing care homes seemed to have cohesive staff relationships. Similar interventions to PERSONABLE have been determined as not feasible when incorporating insufficient input from stakeholders who work in the environment in which interventions are targeted (Iliffe et al., 2014). Therefore, it was important that the engagement of people with direct experience, of the considered phenomena be included in development of PERSONABLE. I believed this group were best placed to identify issues surrounding residential care processes which might inhibit successful delivery of an intervention (Vastine et al., 2005).

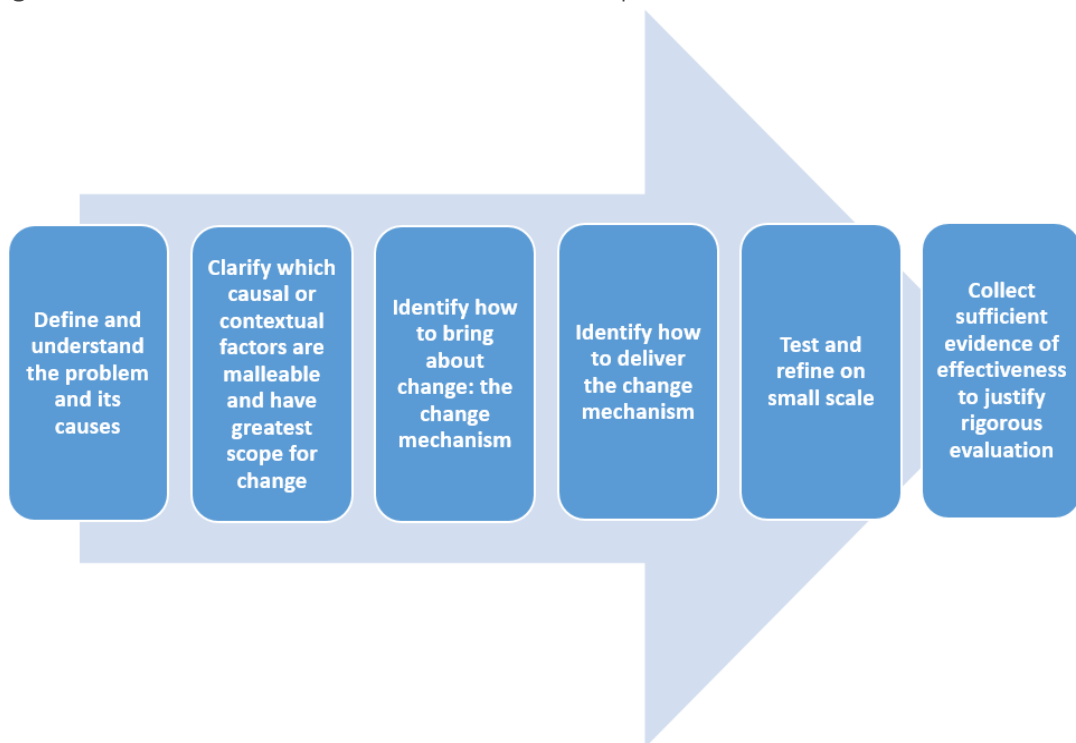
3.5 Intervention idea and initial development

To aid a systematic approach to intervention development, I used the Six Steps in Quality Intervention Development model (6SQuID) (Wight et al., 2016). The 6SQuID model (Wight et al., 2016) enables a systematic process of intervention refinement (Bartholomew et al., 1998). Using this model aided a linear exploration of the components to be considered when attempting to deliver an intervention within residential care. The 6SQuID model aided my analysis of mechanisms for change, specifically when I was considering organisational barriers. Furthermore, the 6SQuID model complemented the evolution of the intervention by methodically synthesising theory with organisational behaviour. Practically this meant I could more effectively plan the integration of the personhood and citizenship intervention, into the complexities of a residential care home. I considered alternative models of intervention development. The PRECEDE–PROCEED Model⁸ focuses on capturing the possible effect of an intervention on a specified behaviour (Onken, 2011). This approach could have been useful when attempting to explain any causal mechanisms between the intervention, the resident and staff behaviour (Onken, 2011). However,

the PRECEDE-PROCEED model does not incorporate a structured approach to intervention development, which was imperative when recording the steps taken to design this novel intervention. Another model I considered was 'The Framework for Design and Evaluation of Complex Interventions to Improve Health' (Campbell et al., 2000). I rejected this model because it has phases specifically designed for testing the intervention within a definitive trial, which was beyond the scope of this study (Campbell et al., 2000). The 'Intervention Mapping' model is another framework of intervention refinement, which I considered; the model provides an iterative process between problem identification, change management and analysis (Bartholomew et al., 1998). However, to use this model I would have had to have attended an international course, which was not feasible given available time and resources.

The 6SQuID model is split into six sequential stages of refinement (Figure 5):

Figure 5: 6SQuID model of intervention development



3.5.1 Define and understand the problem and its causes

Barriers to conducting intervention studies in care homes, were illuminated when conducting the literature review. These included high staff turnover, low staff morale, limited time, sparse resources, reluctance of staff to engage in research, inconsistent

leadership and difficulty recruiting residents who lack capacity to consent to participation (Hall et al., 2009, Low et al., 2015, Wight et al., 2016). Exploration during the literature review aided my understanding of the possible relationships between these organisational barriers and prompted me to consider strategies to overcome these.

In addition to my reading of the literature relating to training interventions, the initial development of the intervention was influenced by my work as a community mental health nurse visiting care homes. The idea of using a framework to help staff understand personhood had occurred to me during my work as a mental health nurse working with care homes. During the initial phase of my doctoral studies I had spent time scoping the literature appraising the use of personhood within care homes, this had provided me with several ideas for a platform, which might convey personhood theory to staff and in turn help residents with dementia. I reflected on key themes surrounding the implementation of training arising from the literature review, initial presentations I had conducted in the early part of my doctoral studies, frequent discussion with my academic peer group and researchers working in the field of dementia care. Additionally, I used ideas from training I had attended whilst working as a mental health nurse, which helped me consider possible platforms for conveying personhood and citizenship theory to staff.

When searching the literature using a more structured approach I was surprised that despite the large number of studies exploring training in care homes, the authors predominantly reported little or no effect of the interventions. The training interventions were diverse, and all seemed to take different approaches to the delivery of knowledge surrounding dementia. When reviewing in more detail the style, content and mode of delivery taken in other similar randomised controlled trials it was apparent that many other studies took a protracted approach to the delivery of training (Ballard et al., 2018, Teri et al., 2005, Beer et al., 2011a, Kuske et al., 2009, Berendonk et al., 2019). Other studies included in the literature review had taken a more brief approach to the individual training sessions, but these had still been delivered on several occasions over the course of weeks (McCallion et al., 1999, Visser et al., 2008) or months (Deudon et al., 2009). It occurred to me that a short and more

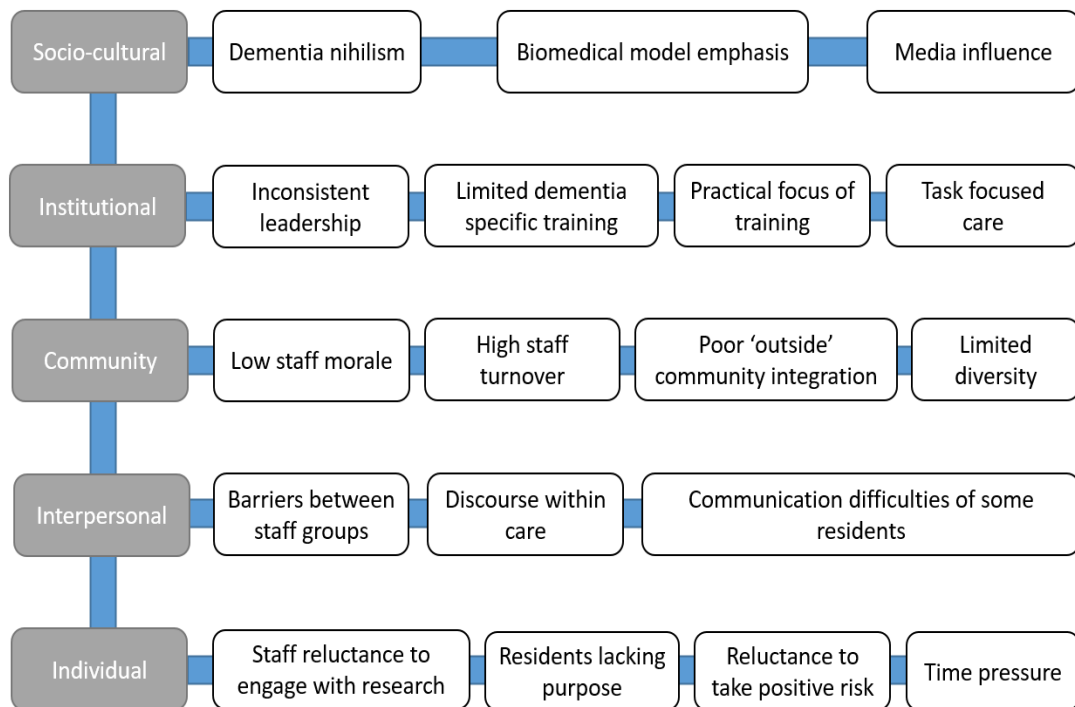
simplistic approach to personhood and citizenship training had yet to be explored. Furthermore, although there were many interventions which attempted to convey the principles of personhood to staff, this study found none which explicitly covered citizenship principles.

Once training had been decided as a platform to convey personhood theory to staff, I began to formulate a starting point for the training. Given the limited time I had to develop the intervention, I wanted something uncomplicated and something that I was confident I could deliver across several care homes. I had used the personhood model proposed by Kitwood (1993b) in my professional work and for this reason I decided to use this model as a starting point. I was aware that attempting to convey both personhood and citizenship in one exercise might dilute the underlying message; therefore, in conjunction with my supervisory team and academic peers, all of whom were experienced in dementia care, I constructed an initial starting point for reflective exercises to help convey personhood and citizenship theory to care home staff in the focused discussion groups.

3.5.2 Clarify which causal or contextual factors are malleable and have scope for change

I used a process matrix (Figure 6) to explore the factors pertinent to residential care, which might affect the implementation of an intervention. The links between the matrices were informed by the literature review, which helped me to anchor development of the intervention within the existing evidence base.

Figure 6: 6SQulD model process matrix: links within the evidence base



The process matrix illuminates the components, for which evidence exists, highlighting the relationships between the factors within care homes which might be obstructing the successful testing of training related to dementia (Grant et al., 1996). Exploring some of these relationships, Jeon et al. (2012) attempted to evaluate the success of an intervention within residential care. However, they reported severe under recruitment of staff participants compared to their protocol projections, citing a perceived lack of spare time to participate in research. The authors explained that although staff appreciated research was important, it was not in the forefront of their busy day-to-day priorities (Jeon et al., 2012). Other similar studies located by the literature review consistently reinforced the pressures on staff time as a fundamental characteristic of the residential care environment (Easton et al., 2016).

3.5.3 Identify how to bring about change: the change mechanism

The limited time in which staff working in residential care have to undertake training, was increasingly becoming apparent as a key determinant of staff uptake of a delivered intervention. However, training had been demonstrated as effective in improving staff and resident outcomes when it could be delivered efficiently (Spector et al., 2016). With this in mind, time as a commodity was central when deciding what

platform for training should be used to introduce the theories of personhood and citizenship to staff. Using the process matrix helped keep my personal observations rooted in the context of the available evidence base.

The existing evidence surrounding training interventions within care homes provided a framework for this study to progress from and adapt accordingly (Beer et al., 2009, Whitaker et al., 2014, Beer et al., 2011a). Currently few studies describe a specific theoretical approach when delivering dementia training interventions, resulting in a broad range of methods and interpretations when attempting to convey person-centred principles to care staff (Spector et al., 2016). The available literature consistently cited difficulties when delivering training interventions within residential care, despite the encouraging reported effects of training on staff and residents (Scerri and Scerri, 2017, Schepers et al., 2012, Mullan and Sullivan, 2016). These difficulties have included high staff turnover, organisational care priorities, demands on staff in busy working environments and cumbersome formats of training (Fossey et al., 2014, Beer et al., 2011a).

Studies (Fossey et al., 2014, Kuske et al., 2007) have attempted differing modes of training delivery, face-to-face, staff champions, online courses and flexible approaches to the time of intervention delivery. Researchers have also considered the need for interventions to be 'very brief' to fit with the demands of busy healthcare environments (Pears et al., 2016). These approaches to study methods were intended to address organisational time and resource barriers encountered when attempting to deliver interventions to sufficient staff. Despite these attempts delivering training within residential care remains a challenge, leaving studies underpowered to make definitive assumptions (Ballard et al., 2017, Chenoweth et al., 2009, Whitaker et al., 2014).

As part of my consideration of effective change mechanisms, the potential barriers, identified within literature searches, which might obstruct the successful delivery of an intervention were discussed with my supervisory team (AA and BP). Referring to the available evidence, we explored possible change mechanisms for conveying information about personhood and citizenship to staff: care plans on whiteboards in resident bedrooms or the staff office, a train the trainer system, a work book to be

completed independently by staff, a training application for smart phones and face-to-face training. The available evidence suggested face-to-face training as the most practical method for conveying information to healthcare staff (Beer et al., 2009). In conjunction with this observation we agreed that face-to-face training would be an adaptable method for conveying theory to a diverse audience. However, as a group we agreed the intervention would have to be constructed differently to previous attempts in other studies to aid sufficient uptake when delivered. PERSONABLE would need to be designed sympathetic to the pressures apparent within residential care.

3.5.4 Identify how to deliver the change mechanism

Before progressing the intervention any further I presented the working idea to a group of professionals familiar with the demands of residential care. I presented to them the issues cited within the literature review, the intended audience and a proposed outline of exercises which might deliver the theories of personhood and citizenship (Table 5).

Table 5: Preliminary idea for reflective exercises

Exercise one	Understanding Kitwood's (1993) personhood model
Exercise two	Understanding citizenship: the journey to work
Exercise three	Case study: what is important?
Exercise four	Change one action for 30 days pledge

Feedback from the group focused on the structure, language and content of the initial idea. The comments made it possible for me to develop the working idea. I began to construct reflective exercises, which would comprise the skeleton training intervention. This represented version one of the training intervention (Figure 7).



Figure 7: Version one of PERSONABLE constructed following feedback from a group of health care professionals

At this point, I named the intervention PERSONABLE. 'PERSON' highlighting the importance of knowing the person you are caring for (Personhood), and 'ABLE' reflecting the significance of respecting the agency of people with dementia (Citizenship); together it was hoped the staff recipient would become more PERSONABLE. Since this point, I have reflected on the appropriateness of the PERSONABLE title, and whether it embodies personhood and citizenship, I present my thoughts on this in chapter six.

3.5.5 Test and refine on a small scale and collect sufficient evidence of effectiveness to justify rigorous evaluation

Once I had a working idea for PERSONABLE, ethical approval for focused discussion groups, was sought, and subsequently approved by, the university Faculty of Medicine and Health Research Ethics Committee (appendix one). This marked the start of my structured data collection to inform and develop the PERSONABLE intervention. In the focused discussion groups I presented the working idea for PERSONABLE to all groups in the same format. At this point by reflecting on the knowledge gained from feedback and supervision the structure of PERSONABLE had been further refined. I felt exercise two in Figure 7 had too many active components, confusing the key teaching points. I subsequently revised and split this exercise into two separate entities, exercises three and four in Figure 8. Additionally, I had the idea of asking the staff to consider their own personhood using the Kitwood (1993b) model, exercise one in Figure 8. I hoped this adjustment might encourage staff to reflect on an appraisal of their personhood, versus that of a resident.

To help explore the proposed intervention, current training and the practical delivery of an intervention I developed a topic schedule. Due to the deliberate heterogeneity of the groups I made some adaptations to these topic schedules (Table 6). Following my analysis and synthesis of the data from the focused discussion groups I made further adjustments to the content and structure of PERSONABLE. Next I piloted the refined PERSONABLE with a group of residential care staff. The pilot was completed in its entirety and observed by AA. Once the pilot was complete both the residential care staff and AA provided feedback and further amendments were made. Development of the PERSONABLE workshop was then complete and ready to be fully tested within phase two of the study.

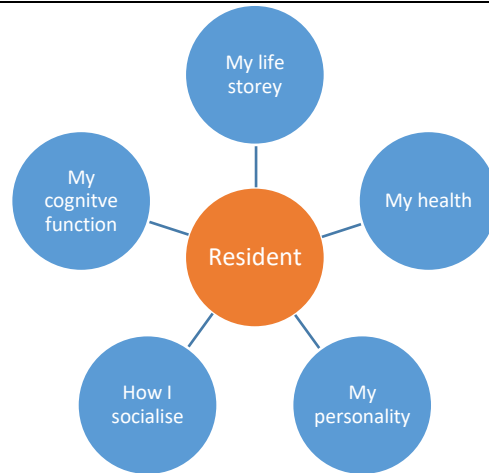
Exercise one: staff personhood

- 1) By the blue circles list words which describe you
- 2) Which domain is most important?



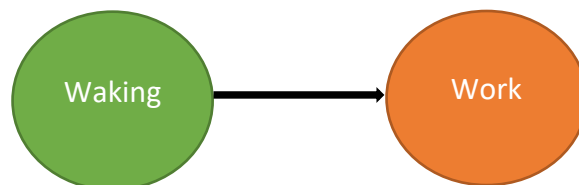
Exercise two: resident personhood

- 1) By the blue circles list words which describe a resident for whom you care
- 2) Which domain is most important?



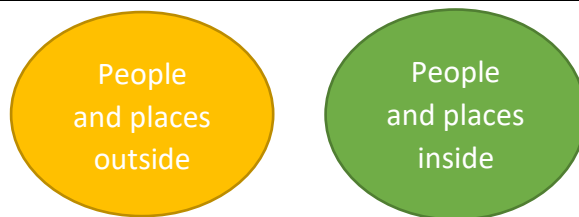
Exercise three: waking to work

- 1) List the choices you made and landmarks you saw on your journey to work



Exercise four: outside to inside

- 1) In the yellow circle list the people and places you saw on your last day off
- 2) Do the same in the green circles for your last shift



Exercise five: the pledge

- 1) Write down one action you will change for the next 30 days

The Pledge

For the next 30 days I will

Figure 8: Version two of PERSONABLE presented to the focused discussion groups

3.6 Phase one methods

3.6.1 Phase one: study design

In February 2016 the university ethics committee for the faculty of medicine and health sciences approved phase one of the PESONABLE intervention study (Figure 9). Four focused discussion groups and one pilot group were undertaken to assist in the development of PERSONABLE, a dementia workshop, intended for use with residential care home staff.

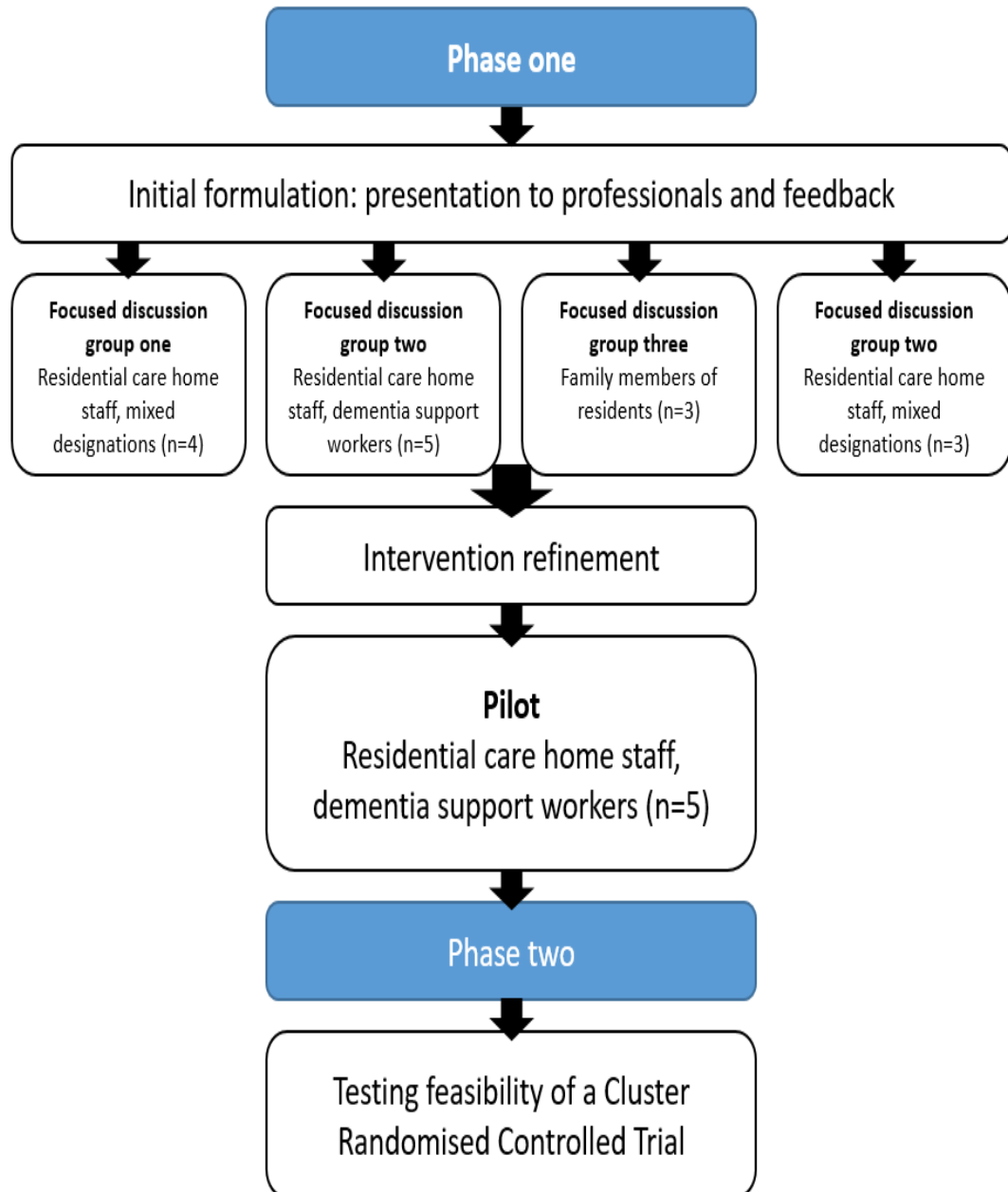


Figure 9: Intervention development flow diagram

3.6.2 Recruitment and consent to focused discussion groups

To aid recruitment I referred to a list of potential care providers in Norfolk and Suffolk and approached potential participants via a targeted mail strategy. The care home point of contact was sent the study information leaflets and a covering letter, detailing the purpose and implications of participation in the focused discussion group. A follow-up telephone call was made to the care home point of contact to discuss potential participation forty-eight hours after expected receipt of the study invitation material.

Three care homes agreed to take part, one in a coastal town (setting one) and two located in the suburbs of a city (settings two and three). None of these care homes were used in phase two of this study. Setting one had an active family support group which ran from their premises once a month. I sought permission to present a summary of the study at the family/friend support group, through the care home management team and administration. For all other focused discussion groups of residential care home staff, I spoke to the point of contact at each care home and enquired if they had a regular team meeting which I might attend to briefly present a summary of my proposed focused discussion group study.

In each location, potential participants were given time to consider their involvement in the focused discussion groups. Participant information sheets were provided and I sought written consent to participate on the day of the focused discussion groups. To allow further questions and clarification of points which family members and friends or residential care home staff might not feel comfortable raising in a group, I gained family members, friends and residential care home staff consent on an individual basis immediately before the focused discussion groups whilst SJ, a doctoral student with a nursing background, welcomed people to the event.

3.6.3 Focused discussion group and pilot group settings

3.6.3.1 *Setting one*

This care home, located in a small coastal town in a rural area, scored 'Good' in a 2013 Care Quality Commission inspection. The main building of the care home comprised a forty bedrooled nursing unit on the ground floor and a forty bedrooled residential unit within the lower ground floor. Additionally, there was a twelve bedded residential home located twenty metres from the main building. All three units accommodate

people with varying degrees of dementia. The twelve bedded home provides care for people with more severe dementia running day care and support groups for people with dementia and their families.

3.6.3.2 Setting two

This purpose-built care home, located in the outskirts of a city, opened in 2015. In a 2018 CQC inspection the home scored 'Requires Improvement'. The home provides specialist dementia care, residential care and nursing care and is split accordingly into living spaces on three floors. Each living space provides support to approximately twenty-six people. The building has a large reception area with a café, and wide corridors. Within each living space the communal areas are circular and brightly lit by large floor to ceiling windows. Each living space has a large wall mounted TV, surrounded by chairs. There is a kitchenette for use by residents and an accompanying dining area behind a partition wall.

3.6.3.3 Pilot setting: setting three

Once the PERSONABLE intervention had been refined using the data gathered from the four focused discussion groups, a draft final version was tested in full at a residential care home, independent of the first two settings. This care home was a purpose-built single level building in the suburbs of a city. In a 2016 CQC inspection the home scored 'Good'. The home provides care to people with and without dementia. It has very broad walkways, leading to forty single bedrooms for residents. There was a central atrium which comprised a nursing station, a hair salon, café/bar and three seating areas. There were patio doors which led onto an enclosed garden.

3.6.4 Participants

I recruited female and male participants from varying designations and caring roles. This had the intention of providing a broad range of feedback, reflective of both professional and lay perspectives. Additionally, I recruited a small group consisting of carers of people with dementia. For each group I proposed a sample of six people, allowing for attrition on the day of the focused discussion groups, but not so large a group as to intimidate the less confident participants (Neugroschl et al., 2014).

3.6.5 Focus group discussion procedure

3.6.5.1 Location

I undertook the focused discussion groups in private rooms at each of the residential care homes.

3.6.5.2 Structure

The focused discussion groups lasted approximately one hour and were facilitated by me. I am a nurse and at this point I was in my second year of my doctoral studies. Within the ground rules at the beginning of the focused discussion groups, I asked participants to avoid personally identifying the residents they support. I attempted to promote a relaxed atmosphere, to help participants feel at ease sharing their views on potentially sensitive topics. The direction of the discussion and the time and priority given to the suggested topics was guided by discussion group participants. I attempted to encourage all participants to provide their views, but contribution to discussion was not compulsory. On occasion I used prompts to elicit more of the groups experience and to direct discussion when it veered too far from the discussion objective of informing development of PERSONABLE.

3.6.5.3 Observation

Because of my limited resources, only focused discussion groups one and two were observed by SJ, who was independent of the study and setting. During these focused discussion groups SJ made notes on the group dynamic and the delivery of the workshop exercises.

3.6.5.4 Question schedule

I used a standardised list of topics for each group. However, I specifically selected subject areas to elicit the differing experience specific to each diverse group (Table 6). I asked groups one and four, groups of mixed roles, more questions which explored how their differing roles affected their interactions with residents who have dementia. I asked group two, all care workers, more questions exploring the training they received in their role as care workers. I asked group three, family members, questions designed to understand what attributes they wanted from people who care for their family or friend. All groups were asked for their opinion on the language which would be used to adapt the five domains in the Kitwood model of personhood (Kitwood, 1993b) and for feedback on the provisional ideas for the workshop exercises.

Table 6: Topic guide for phase one focused discussion groups

	Focused discussion group one (mixed roles)	Focused discussion group two (care workers only)	Focused discussion group three (family members)	Focused discussion group four (mixed roles)
Explore how differing roles affect the care that is provided	Yes			Yes
Explore what participants feel is important when attempting to provide good care	Yes	Yes	Yes	Yes
Feedback on PERSONABLE exercises	Yes	Yes	Yes	Yes
Practicality of delivering PERSONABLE	Yes	Yes		Yes
Discuss the types of training staff currently receive	Yes	Yes		Yes
Explore how training is undertaken: cost, when completed and which staff receive training	Yes	Yes		Yes
Explore types of training participants might expect staff to have undergone			Yes	

3.6.6 Analysis method

Focused discussion groups were undertaken to get a range of personal experiences, which might inform the development of the PERSONABLE intervention. To aid transparency, all focused discussion group data has been stored and analysed within the research software NVivo 11. The selected framework analysis methodology, is particularly suited to analysing cross-sectional descriptive data (Smith and Firth, 2011). For consistency I have used the terms recommended within framework analysis, indexes, charting, mapping, rather than the coding terms used within NVivo 11 (nodes and cases). To keep analysis sensitive to the broad range of discussions an inductive approach to the analysis of the transcribed text has been used. The text was indexed line by line and allocated one index per line. The indexes were placed under headings deductively based on the focused discussion group question schedule. Once organised, the individual indexes were explored for a deeper meaning. Using the inductive and then deductive approach helped me to describe the breadth of the data, whilst also keeping the analysis focused, by specifically indexing the transcripts. Furthermore, this strategy helped to chart and map the views expressed by the diverse sample.

The authors of 'Framework' Ritchie and Spencer (1999), later referred to as 'Framework analysis', suggest five analytical stages; familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation.

3.6.6.1 Familiarisation

Because of the relatively small quantity of data from the four focused discussion groups it was possible for me to become immersed in the data (virtually) from the point of collection. Once data collection was complete, I continued familiarisation by listening to the audio recordings. Then I transcribed the audio recordings verbatim and, once completed, reread the transcriptions. I mediated my subjectivity during this phase of familiarisation by a cycle of structured reflection (Halpern, 2009), enhanced by my frequent discussions with AA, BP and SJ. To enrich my understanding, the contextual data (gathered by SJ and AA) from the observations was extensively reviewed. Observational data helped to affirm or dismiss my interpretations whilst analysing the focused discussion group data.

3.6.6.2 Identifying a thematic framework and indexing

My thematic framework was based around 'a priori' themes derived from the interview schedule. A strategy recommended by Ritchie and Spencer (1999) when collecting data for a specific purpose. In this case, refinement of the PERSONABLE intervention. The four thematic headings were:

1. Personhood and citizenship
2. PERSONABLE feedback
3. Staff characteristics
4. Current training.

The inductive analysis created multiple indexes from the transcribed text. These I grouped under the thematic headings mapping the range of participant views. This approach was inclusive of non-confirming data, which helped moderate my subjectivity, creating a more neutral analysis when mapping the polarities of each thematic heading (Halpern, 2009).

3.6.6.3 Charting

I created four charts, one for each thematic heading. The charts organised the indexed data into cases (individual participants). The indexed cases were then organised within a table (appendix two). This process helped me to focus analysis on the range of prevailing opinions expressed by the diverse participants.

3.6.6.4 Mapping and interpretation

Charting the data by participant type meant I could group individual participants by their job role, or relationship if family members. The next step of the framework analysis assisted my mapping of the range of individual case data within the staff groups: managers, ancillary staff, care workers and for family members (Table 8, pages 102 to 104). Mapping the data by job role helped inform changes to PERSONABLE to suit a potentially diverse population, by illuminating patterns or gaps within the different groups' experience, knowledge and application.

3.7 Phase one findings: focused discussion groups

3.7.1 Participants

Table 7: Focused discussion group and pilot group participant characteristics

	Management	Care worker	Administration	Maintenance	Family member	Male	Female
Focused discussion group one	1	1	1	1		1	3
Focused discussion group two		5				1	4
Focused discussion group three					3	1	2
Focused discussion group four	1	2				1	2
Pilot group		5				1	4

3.7.1.1 Focused discussion group one

Focused discussion group one had four participants, three female and one male. Participant one worked in the care home's day care services, participant two was an administrator, participant three was the care home's general manager and participant four was the maintenance person.

3.7.1.2 Focused discussion group two

Focused discussion group two had five participants, comprising of four females and one male. All were support workers based in the specific residential unit for people with dementia. The participants worked in the same role in the same facility.

3.7.1.3 Focused discussion group three

Focused discussion group three had three participants, two female and one male. They all attended the family carer group. All participants cared for their spouses and had varying experiences of their spouses receiving paid carer support; day care, home care and respite.

3.7.1.4 Focused discussion group four

Focused discussion group four had three participants, two female and one male. There were two care workers and a relations manager. One care worker had six months experience working with people with dementia and the other had over two years. The relations manager was responsible for promoting the care home to the public and organising events that occurred within the care home. She had a background in psychology but under twelve months experience of working with people who have dementia.

3.7.1.5 Pilot group

The pilot group consisted of five participants, four female and one male. All participants were care workers with varying levels of experience of working with people with dementia and their families.

3.7.2 Focused discussion group data

Below (Table 8) is a summary framework chart summarising the range of views expressed by staff working in different roles, and family members.

Table 8: Range of focus group views by job role or relationship

Staff role	Personhood and citizenship	Current training	Staff characteristics	PERSONABLE feedback
Management	<ul style="list-style-type: none"> • More likely than other staff groups to feel competent when care planning for positive risks which promote resident independence and purpose 	<ul style="list-style-type: none"> • Reported difficulty training large numbers of staff • Managerial staff the first to receive personhood training • Managerial staff distribute knowledge gained from personhood training to care workers 	<ul style="list-style-type: none"> • Commented that staff can lack reflective ability • Observed that staff can be task focused • Managers dominated the focus group dynamic 	<ul style="list-style-type: none"> • Commented the waking to work exercise promoted resident choice but did not make them think of community • Enjoyed the reflective nature of the exercises • Preferred term 'how I learn' to 'my brain function' or 'my cognitive function'

Staff role	Personhood and citizenship	Current training	Staff characteristics	PERSONABLE feedback
Care workers	<ul style="list-style-type: none"> • Frequently acknowledged the importance of knowing a resident's life history • Choice was usually considered in relation to food or clothing but not in relation to agency and taking positive risks 	<ul style="list-style-type: none"> • Usually have to complete training in own time • Frequent use of eLearning • Have to travel for advanced personhood training, limited to a few staff • Most training infrequent and in-house • Difficulty getting large groups of staff together for training 	<ul style="list-style-type: none"> • Reported acceptance of constructive criticism • Keen to reflect on practice but not always easy due to time • See tasks as separate from personhood and citizenship focused care 	<ul style="list-style-type: none"> • Would have liked more prompts and examples to aid understanding of pledge • Case study had difficulty imagining a scenario not based on their direct experience • Preferred 'how I learn' to 'my cognitive function' or 'my brain function' • Felt waking to work exercise highlighted choice but did not make them think of community diversity
Ancillary staff	<ul style="list-style-type: none"> • Reported anxiety dealing with distressed residents • Did not see role as care • Described frequent interactions with residents • Had more time to watch and reflect on care 	<ul style="list-style-type: none"> • No opportunities for personhood or citizenship training • Most knowledge gained from experiential learning 	<ul style="list-style-type: none"> • View themselves as separate from the care workers • Frequently demonstrated reflective ability 	<ul style="list-style-type: none"> • Preferred reflective learning to knowledge based learning

Staff role	Personhood and citizenship	Current training	Staff characteristics	PERSONABLE feedback
Family members	<ul style="list-style-type: none"> • Acknowledged importance of knowing resident life history and health issues • Highlighted practical issues, such as ill health and resources can limit access to the community 	<ul style="list-style-type: none"> • Would expect staff to have training for clinical interventions but not other interventions 	<ul style="list-style-type: none"> • Stated that humanistic characteristics of patience, humour and kindness more important than knowledge of care staff 	<ul style="list-style-type: none"> • Preferred term cognitive function' to 'neurological impairment' • Would have difficulty expressing 'learning style'

3.7.3 Describing the range of focused discussion group data

Charting the qualitative data helped me to begin the mapping process, and subsequently group the indexes to demonstrate the range of data as a whole. For this part of the analysis the data has been split into those aspects which enhance, or detract from, the thematic headings (Figure 10).

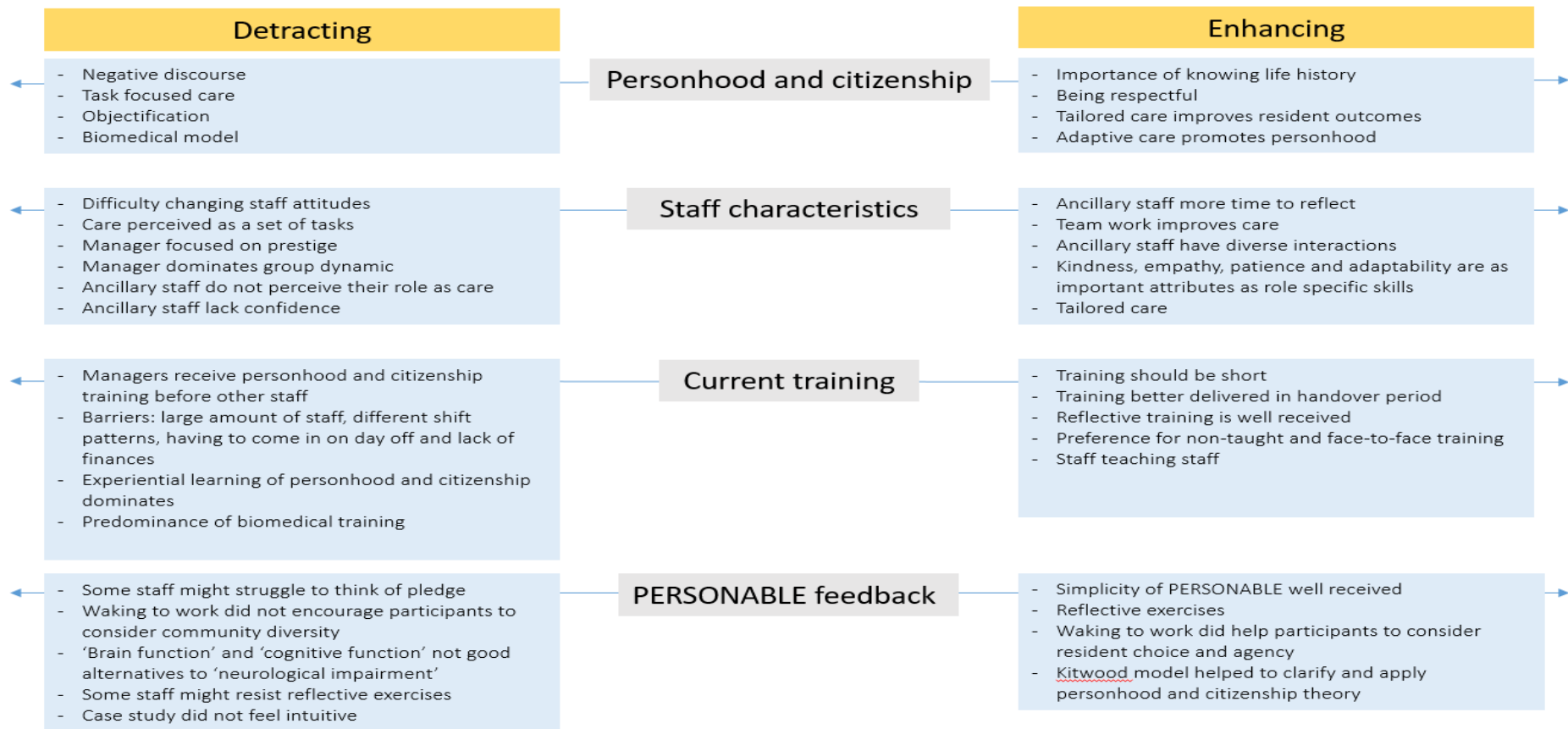


Figure 10: Range map of focused discussion group data

3.7.4 Personhood and Citizenship

The focused discussion groups helped to clarify the current level of understanding of personhood and citizenship theory. Staff and family participants demonstrated awareness of personally tailored care, which needs to adapt to the challenging environments in which they provide care. However, their discussions also unearthed potential barriers to the implementation of the theoretical ideals of personhood and citizenship. There were frequent references to people with dementia which objectified them, *'you do it in the dementia wing'* (General Manager) or used a negative discourse to describe the behaviour of the people for whom they care *'strange random requests'* (Administrator). There was also a tendency, apparent in all groups, to rely on a disease model to explain the behaviour of residents with dementia, *'there is this conflict between what I call her Alzheimer's mind and her for want of a better mind her normal mind'* (Family member). The use of the disease model of dementia was reflected in the dementia training which was reported as typically provided, *'this is the brain, this is different types of dementia'* (Care worker).

3.7.5 Staff characteristics

The focused discussion groups provided evidence of the effect of cohesive team work, which when apparent was reported to improve resident outcomes. The specific characteristics of staff groups, which enhanced care, were cited within their discussions, in particular, one manager commented that ancillary staff have more opportunity to watch care, which they proposed gave this staff group an opportunity to reflect on ways in which they might improve provided care. Despite frequent contact with residents, ancillary staff presented with varying degrees of confidence in their interactions with residents who have dementia, *'I worry about what do I say, I just...am I making it worse...then I think 'I know, I'll call the care staff'* (Administrator).

A lack of reflective practice was reported as a barrier to adaptive care *'I think there are some people that think they are perfect'* (General Manager). Staff being able to adapt their care seemed role specific and job role appeared to influence the type of interactions occurring between staff and residents. Interestingly, it was the ancillary staff who reported more opportunity to engage in diverse interactions with residents *'well I have to go into their rooms and actually organise things, put pictures up, so obviously I discuss things with them, talk to them'* (Maintenance person). In

comparison because of organisational pressures placed on staff care workers predominantly appeared focused on physical care, *'bring them in again, they have baths...have chiropodist and then we take them home in the afternoon'* (Care worker). Pertinently, 'tasks' and what constituted 'person-centred care' were often described as separate entities. The dichotomising of tasks and person-centred care was also apparent within ancillary staff comments *'I do have a care role, give them a cup of tea, biscuits that sort of thing'* (Maintenance person).

In some focused discussion groups it seemed compartmentalisation of tasks and person-centred care was influenced from a managerial level *'there's still an element of tasks that have to be dealt with when you're looking after residents'* (General Manager). There were two managers within the focused discussion groups, they demonstrated the most academic understanding of personhood and citizenship. However, they frequently dominated the group, often taking the lead if there was a pause in the discussion *'I'll start, shall I cos I've possibly done the most training really'* (General Manager), and *'I'll start then, my role is as a customer relations manager'* (Relations manager).

3.7.6 Current training

Participants universally agreed that because of the large size of care home workforces, any training needed to be short. They suggested that training preferably be delivered within quiet periods, such as the afternoon staff handover period, *'I think no more than probably two hours, I think probably two hours maximum is probably the best thing for any training'* (General Manager), *'obviously any training is time off the floor for the actual employees, so you know, that time has to be covered somehow'* (Care worker). Participants frequently reported a preference for interactive training, *'face to face personally in a group such as this, in a group with someone that's training us in a particular way that is practical to what we do'* (Care worker). One participant reported benefitting from training which helped them empathise with the resident experience, *'I think as it (training) progress we need to progress and learn some different like behaviours and the emotional journey'* (Care worker). When speaking about the different ways in which knowledge was filtered through their organisations, participants endorsed the use of staff feeding back to staff when they had been on

dementia specific training. It appeared this process usually occurred top down, with senior staff feeding back to other members of the team *'so I thought if we sent the two dementia home team leaders...it's not training like classroom training, its coaching to teach you how to coach'* (Relations manager). Regardless of role, staff commented that often they learnt to care for residents by experiential learning, *'I had a lot of, a lot, of bad experience and I learnt off that as well'* (Care worker). Experiential learning formed the totality of the dementia training for all of the participating ancillary staff, *'the answer is I've really learnt on the job and by observation obviously'* (Maintenance person).

3.7.7 PERSONABLE Feedback

The focused discussion groups consisted of a range of staff and family members of residents. The small groups seemed to create a comfortable atmosphere for sharing personal experiences and views. However, the small number of participants may have limited the completeness of the data obtained. With this in mind all focused discussion group data was reviewed with my supervisory team, to agree any changes to the intervention, at points where there was not enough data to establish a participant consensus. The question schedule was used as a starting point for each group; it was designed to help ensure each group covered key topics necessary to inform intervention development, rather than a pure standardised approach. This method meant that as the focused discussion groups progressed and new insights became apparent I could seek further clarification from subsequent groups. For example, when the first two groups universally agreed that a predefined case study was not going to be as effective as reflecting on real care events, this component was omitted from the next two groups.

Discussing the data already obtained with my supervisory team the working model evolved into an exercise which might more directly help staff think about resident personhood in relation to their experience and behaviour (as developed in exercise three: resident personhood). This adaptive approach made best use of the limited time in which to gain feedback on the evolving workshop exercises. Furthermore, by the time I facilitated the last two groups, a large amount of data surrounding current training provision had been obtained which meant I could explore the finer details of

the evolving exercises, such as the language, structure of the exercises and cross checking previous suggestions made by each group.

After the focused discussion groups were concluded, several changes were made to the terms used within the model originally proposed by Kitwood (1993b). These changes were made in keeping with my working definition of personhood. The adaptations adhered to four main principles i) that changes should help people working with those who have dementia to better understand personhood ii) to keep the appraisal of personhood focused on the person with dementia, rather than external influences, and iii) to develop a model of personhood, which acknowledges the strengths as well as the limitations of the person with dementia iv) that changes to the model of personhood should help staff to separate and consider personhood in isolation from citizenship.

The following discussion describes how the focused discussion group data shaped and adapted the original terms of 'neurological impairment' and 'social psychology' used by Kitwood (1993b). Terms relating to 'health', 'personality' and 'biography' have been discussed in less detail because there was greater consensus when these terms were presented to the focused discussion groups.

The participants fed back positively on the reflective and interactive nature of PERSONABLE, *'this is exactly the sort of thing that I think works really well, is to actually make the staff think about what they do and how the person with dementia can feel exactly the same'* (General Manager). One ancillary participant liked the simplicity of the workshop, *'I think that programme is just nice and I think it's not being negative when I say it's quite simple to follow'* (Maintenance person). Participants reported that the 'waking to work' exercise helped them to consider resident choice, *'it makes you think about how many decisions you make and just how complex it is, when you stop and think about all the processes you go through'* (Care worker). However, consensus was the 'waking to work' exercise did not make them think of diversity within the community, *'I can see with the steps that it's more about choice, but I didn't think about community with it'* (Care worker).

The first two focused discussion groups were asked if a case study would help them apply the workshop content to their roles. Staff fed back that a case study might be

helpful if it was personal to their experience rather than constructed by the facilitator. The language within the exercise was discussed, especially within the exercises using the adapted Kitwood (1993b) model. When presenting to the group of professionals before seeking ethical approval for the focused discussion groups, they had felt the terms 'neurological impairment' and 'social psychology' would be a barrier to the understanding of care staff. Subsequently, after discussion with my supervisory team and research colleagues, the working terms 'cognitive function' and 'how I socialise' were selected as a starting point for the focused discussion groups.

When reviewing the focused discussion group feedback, terms relating to neurological impairment such as, cognitive function, cognitive impairment and brain function, provoked the most discussion. There was also the least consensus between participants for this domain. There was agreement amongst participants that the term 'cognitive function' limited an appraisal of those with dementia because of its negative 'impairment' connotations. There was consensus from the participants that the ambiguous term 'brain function' would not broaden care staff understanding of people with dementia, some participants felt this medicalised term might be difficult for less experienced care staff to interpret. The first three focused discussion groups went through a process within their discussions which illuminated alternative terms. One participant from the family member group introduced the idea that 'cognitive function' could be seen as an ability to process information '*are you really trying to find out how they absorb information?*' (Family member). This led to a group discussion of the intended audience and the proposition by a group member that a lay audience might better understand the concept of learning. One group member commented '*I think brain function is the better one*' (General Manager) but this was not the prevailing opinion, '*brain function, because even brain function makes it sounds like it's not, there's other things implied from that*' (Family member). Alternatives were explored, '*I think learning style*' (Care worker), '*I think it's difficult to complete learning style...I'd understand it but wouldn't necessarily understand how to express it*' (Family member), '*I'm making an assumption about the age of the person but generally that's a generation, they would know learning style*' (Relations manager).

Following from this discussion the consensus was that a term relating to 'learning style' might enable care staff to consider the positive and negative cognitive function of people with dementia. When I took the original terms, and this new term, to focus group four the consensus was that 'learning style', may '*appeal to a wider range of people*' (General manager). The participants in focused discussion group four agreed terms relating to 'brain or cognitive function' were '*just too wide*' and that this group of terms might act as a barrier to staff who '*don't really understand what it (the brain) does*' (Care worker). Once focused discussion group data had been analysed and before the piloting of the workshop the various responses to the terms were reviewed with my supervisory team; we agreed the term 'how I learn' was in keeping with the agency based definition of personhood developed during the literature review. It was also agreed that 'how I learn' was accessible to care staff and focused on the strengths of the individual with dementia. Importantly, the term 'how I learn' had the potential to broaden discussion surrounding this domain of personhood and place the person with dementia in a more powerful position.

These comments provided the final piece of feedback needed to adapt the language used to describe the five domains of the adapted personhood model proposed by Kitwood (1993b) (Figure 11 and Table 9). Changes to the language were made in tandem with consideration of the effect each change would have on the underpinning personhood and citizenship theory, as defined and used in this study. The interpretation of focused discussion group data moved away from aspects of Kitwood's model (Kitwood, 1993b) which might limit a strengths based appraisal of a personhood domain such as 'neurological impairment'. Those aspects of the model which drew focus away from the individual, such as 'social psychology' were also challenged and targeted for development. Changing 'neurological impairment' to 'how I learn' was intended to focus care staff on the neurological strengths of the person with dementia, whilst also helping to reposition them as agents with potential, rather than individuals with deficit. Changing 'social psychology' to 'how I socialise' was also changed in response to focused discussion group feedback, this change was intended to reposition the person with dementia as a person with choice and power in their social choices. The change was also a step to distinguishing the adapted

personhood model from citizenship theory by refocusing on the individual, rather than the impact of third parties.

Figure 11: Adaptation for care home staff of Kitwood's personhood model

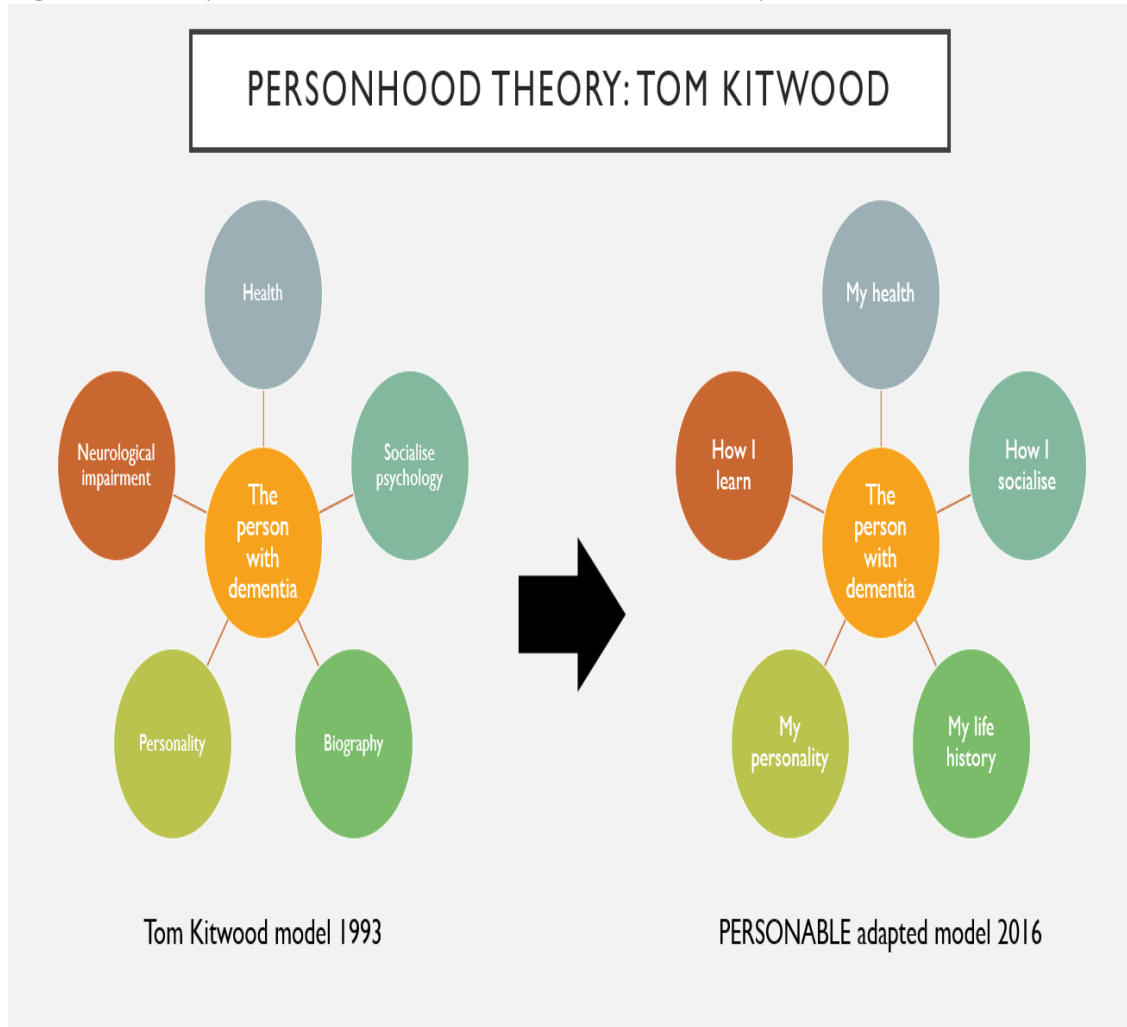


Table 9: *PERSONABLE adaptations after conducting the focused discussion groups*

Adapted component	Rationale and source of data
<p>Waking to work exercise</p> <p>Changing the order of the exercises. Moving the <i>'waking to work'</i> exercise to the beginning of the workshop.</p>	<p>The <i>'waking to work'</i> exercise was designed to help staff consider resident choice. It had previously been designed to address resident choice and community diversity, however, all groups commented that the exercise did not make them think about the community diversity <i>'it highlighted more about choice but not what you said about the community'</i> and <i>'it's more about choice than (the community)'</i>. When reflecting on the focused discussion group data, many staff understood the principle of resident choice <i>'loads of choices that we can make every day and take for granted'</i>. Participants naturally considered resident choice in many areas without much prompting <i>'just because somebody's got dementia or is not well doesn't mean they want poor food'</i> and <i>'they always have the power to choose their clothes and of course we don't always show their whole wardrobe because it's too much for them'</i>. Given the familiarity of staff with the need to promote resident choice, this seemed a good place to begin the workshop before moving onto the more challenging concepts.</p>
<p>Exercises two and three: Personhood</p> <p>Replacement term for <i>'neurological impairment'</i>. Term <i>'neurological impairment'</i> changed to <i>'cognitive function'</i> following feedback from professionals prior to focused discussion groups. Following focused discussion group feedback <i>'Cognitive function'</i> changed to <i>'How I learn'</i>.</p>	<p>Some disagreement between participants for this domain. Consensus from all groups that terms should not imply disablement. All groups felt terms relating only to the brain could imply physical disablement rather than purely cognition <i>'brain function, because even brain function makes it sounds like it's not, there's other things implied from that'</i>. All groups felt the term should not be medical so that a person with limited experience could understand and utilise the term, when I asked <i>'would you understand the term cognitive function?'</i>, one participant replied <i>'a lay person wouldn't'</i>. One family member suggested <i>'my learning style'</i>, which led to discussion exploring the positive utility of viewing the person with dementia as having the capacity to learn <i>'are you really trying to find out how they absorb information?'</i>. Changing from <i>'cognitive function'</i> to <i>'how I learn'</i> was discussed with my supervisory team and a group of doctoral students familiar with my study. There was consensus that <i>'how I learn'</i> was the term best placed to convey the personhood and citizenship focus of the workshop.</p>

Adapted component	Rationale and source of data
<p>Exercises two and three: Personhood</p> <p>Replacement term for central circle of personhood model denoting 'staff' and 'resident'. The terms 'staff' and 'resident' replaced with one term 'who am I?' for both exercises.</p>	<p>When reviewing the transcripts I was prompted to consider keeping all terms in exercises two and three the same. A participant in focused discussion group two implied they perceived the assessment of personhood as the same regardless of whether the person has dementia or not '<i>I probably looked at this and thought of myself before I thought of anyone with dementia</i>'. A participant in group one also commented that '<i>you shouldn't really talk to people who have got dementia any different than somebody who hasn't got dementia</i>'. This led me to consider that the central circle should have the universal phrase 'who am I?' for both staff and residents. A universal term denoting human personhood which would reflect the identity focused definition of personhood used within this thesis.</p>
<p>All exercises</p> <p>Colour of circles. After the focused discussion groups were completed all the different coloured circles were changed to light blue.</p>	<p>This was changed after personal reflection and discussion with my supervisory team about my choice of colours and attempting to design a neutral and standardised intervention in which discussion and reflective processes were the focus, rather than visual presentation. This change was with the exception of the central circles in exercises two and three, which were designed to stand out.</p>
<p>Exercises two and three: Personhood</p> <p>Adding of white circles to rank personhood domains. After the focused discussion groups a blank white circle was added to each domain of the personhood model.</p>	<p>The focused discussion groups prompted the idea to ask staff to rank the importance of each personhood domain presented in exercises two and three. One participant introduced the idea of some of the personhood domains being more influential than others '<i>you get probably number one 'my life history' even with the dementia in the middle stage</i>'. This also was based on staff comments implying that staff viewed the assessment of resident personhood as having a different function to their own '<i>I was thinking about reflecting on myself first and was answering these in my head about me, I didn't really think about anybody else</i>' and '<i>any kind of (resident) behaviour can be the result of these things not quite sitting right</i>' and '<i>health, the personality, the activity, are they enjoying it, is it because they're enjoying as we put them together, so actually having some background to it</i>'.</p>

Adapted component	Rationale and source of data
<p>Outside to inside exercise</p> <p>Changing of language to simplify to key concepts. After the focused discussion groups the language in the two circles of the <i>'outside to inside'</i> exercise was simplified from <i>'people and places: inside and outside'</i> to just <i>'inside'</i> and <i>'outside'</i> in each circle.</p>	<p>This adaptation was made after the observer of the focused discussion group (SJ) made observations that certain participants would spend a lot of time reading the text of the exercises. After reviewing this observation with my supervisory team it was agreed that minimal words should be included on the worksheets, with the aim of improving staff engagement with the reflective discussions.</p>
<p>The Pledge</p> <p>More detail added to the pledge instruction. After the focused discussion group the wording of the pledge was changed from the simple statement 'For the next 30 days I will' to 'Within the next 30 days I will change one thing about the way I work. It may improve my understanding of a resident who has dementia. Or I might introduce something from the outside community into the care home'.</p>	<p>The exception to the principle of keeping words to a minimum was the final pledge exercise. This decision was based on feedback in the focused discussion groups that some staff might have difficulty thinking of a pledge <i>'if they can't see it, just a few examples and they may come up with'</i> and <i>'if there's examples there, you can sort of say 'I see where that's coming from' and maybe something new'</i>. The text was adjusted to provide more guidance but examples were not given because I felt this would not give an indication of whether staff had engaged with and understood the content of the workshop.</p>

3.8 Piloting of the PERSONABLE intervention

Once focused discussion group data had been analysed and discussed with AA, BP and SJ, I conducted a pilot group of the near finalised PERSONABLE intervention. Each of the five exercises was delivered in their entirety following a process map of each exercise (Table 10). Following the previous stages of development PERSONABLE had been shortened and one key theme had been assigned to each exercise. Each exercise lasted approximately 12 minutes. The process map was based on Carl Rogers theory of action learning (Rogers, 1986). This specific framework was chosen to complement the applied nature of PERSONABLE and to ensure each exercise had a clear format and purpose. Participants were given a simple workbook containing illustrations of each of the five exercises. The order of the exercises had been adjusted to provide a more accessible progression of the theoretical application of personhood and citizenship principles. No written instructions were given to encourage participant discussion rather than reading. The pilot was observed by AA who made notes on my delivery of the exercises. Being observed, and the feedback received, helped me further refine my personal delivery of PERSONABLE in line with the attributes for facilitating reflection suggested by Rogers (1986).

3.8.1 Process mapping of exercises prior to piloting of PERSONABLE

Exercise	Initial learning state	Reflecting	Generalising	Transferring	Altered learning state
1 Resident choice: from waking to work	The participant's current experience and knowledge about residents with dementia	Reflecting on choices made between 'waking and work' related to people, places or activities	What did these choices give you?	Does your experience regarding choice differ from the experience of a resident with dementia?	A participant might begin imagining how their freedoms could be replicated for residents
2 Understanding personhood: Kitwood model - staff	Continuing the inward reflection of exercise one	Exploring components comprising a person, using the adapted Kitwood personhood model	Prompts to explore what parts of the model are most fundamental to participants	Does the participant personhood status alter as they move into differing social environments?	Participants have reflected on how experience forms personhood and citizenship
3 Understanding personhood: Kitwood model - resident	Participants are orientated to what components comprise their individual personhood	Using the same adapted Kitwood model but this time reflecting on a resident with dementia for whom they care	Which parts of the model are most important when understanding the resident?	Does the personhood model help them understand the experience of the resident?	An enriched understanding of the resident for whom they have applied the personhood model
4 Community diversity: from outside to inside	Working towards an understanding of personhood in the context of a community (citizenship)	What opportunities do you have on your days off? What people, places, objects or activities did you see?	Elaborate on the participants experiences. What types of experience gave you most contentment?	Discussion to contrast staff opportunities with the opportunities of the residents they support	Participants may begin to consider disparities between the community outside and inside of the care home walls
5 Into action: the pledge	Participants may feel open to exploring strategies to implement their observations into the care they provide	Considering a pledge which will embrace learning from the personhood and citizenship exercises	Is the change something which is feasible within the care home context?	Participants transforming principles of personhood and citizenship into their work	Measured when the researcher returns and completes the follow-up measurements

Table 10: Workshop process mapping using an adapted model of Carl Rogers learning theory (Rogers, 1986)

3.8.1.1 Exercise one: waking to work

In this exercise participants were asked to reflect on all the choices they had made between waking and work and to make brief notes in the workbook (Figure 12). This exercise was placed first because I recalled that participants within the focused discussion groups had all broadly understood the principle of enabling resident choice, therefore it was felt to be a safe starting point.

The focused discussion group data suggested staff predominantly understood resident choice in the context of 'tasks', concerning food, dressing and washing. This presented an opportunity to deepen citizenship discussion by exploring the deeper benefit of providing choice. The pilot group were encouraged to consider the sense of purpose and agency that an improved array of choices might provide.

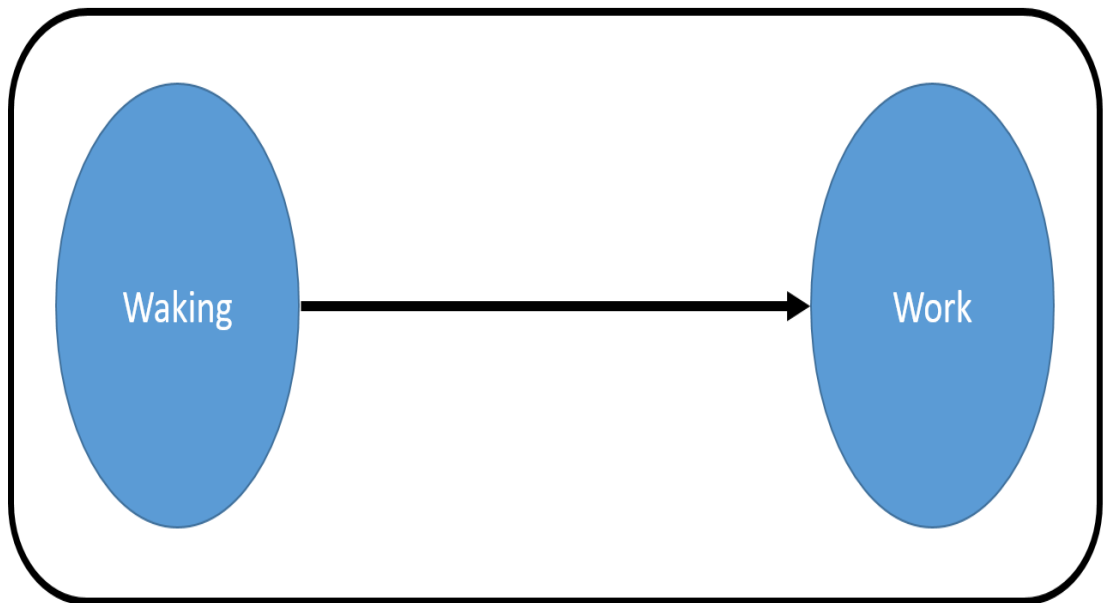


Figure 12: 'Waking to work' reflective exercise

3.8.1.2 Exercise two: reflecting on self

For this exercise, I asked participants to populate the adapted Kitwood personhood model using themselves as the person to be considered (Figure 13). They were then asked to rate each domain in the white circles, a score of 1 representing the most important domain when describing themselves and 5 the least important. The idea of getting participants to initially reflect on themselves using the Kitwood model was to prompt a period of introspection to help them consider how personhood can be the same regardless of a disease a person is experiencing. Pilot participant feedback indicated staff universally understood this exercise.

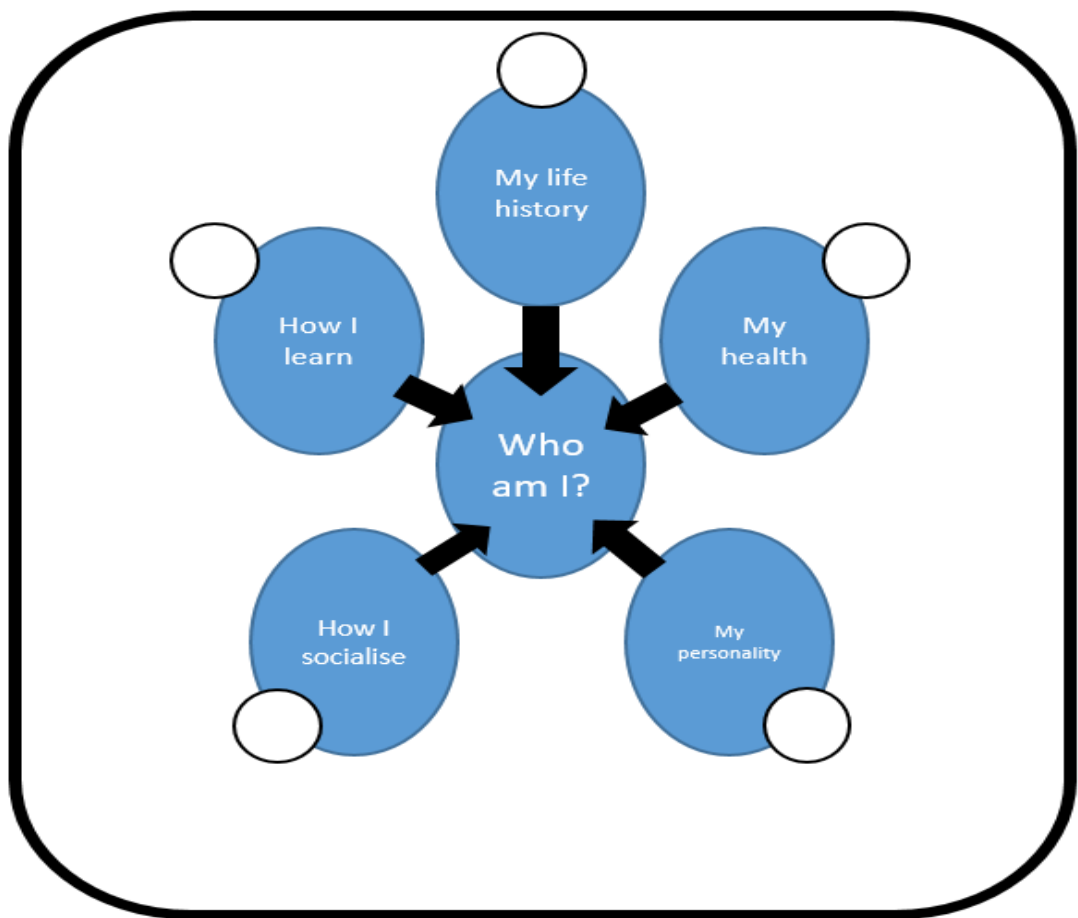


Figure 13: Adapted Kitwood model of personhood for staff to reflect on themselves

3.8.1.3 Exercise three: reflecting on resident

For this exercise I asked participants to complete the same adapted Kitwood model as in exercise two, but this time in relation to a resident (Figure 14). The white circles were again numbered (1-5) provoking a discussion of any differences in the importance they placed on domains in relation to themselves or the residents in their care. It was intended that exercise three would promote a transformative process for the participants. Exercise three would now include a case discussion, replacing the initial separate case study, which was dropped early in the development of PERSONABLE because it had proved excessively time consuming and did not chime with the participants own experiences. It was felt that a more applied case discussion would naturally occur within exercise three. The inclusion of a resident case discussion using the Kitwood model drew out my nursing persona, during this exercise I became overly instructional attempting to draw conclusions on behalf of the participants. AA noted this hindered participants' reflections and their application of the exercise to their personal experiences. This was an important observation, when conducting the pilot, because it was positioning me as an educator rather than a facilitator for reflection. Nurturing a much more facilitative approach would aid consistency of delivery across the intervention sites.

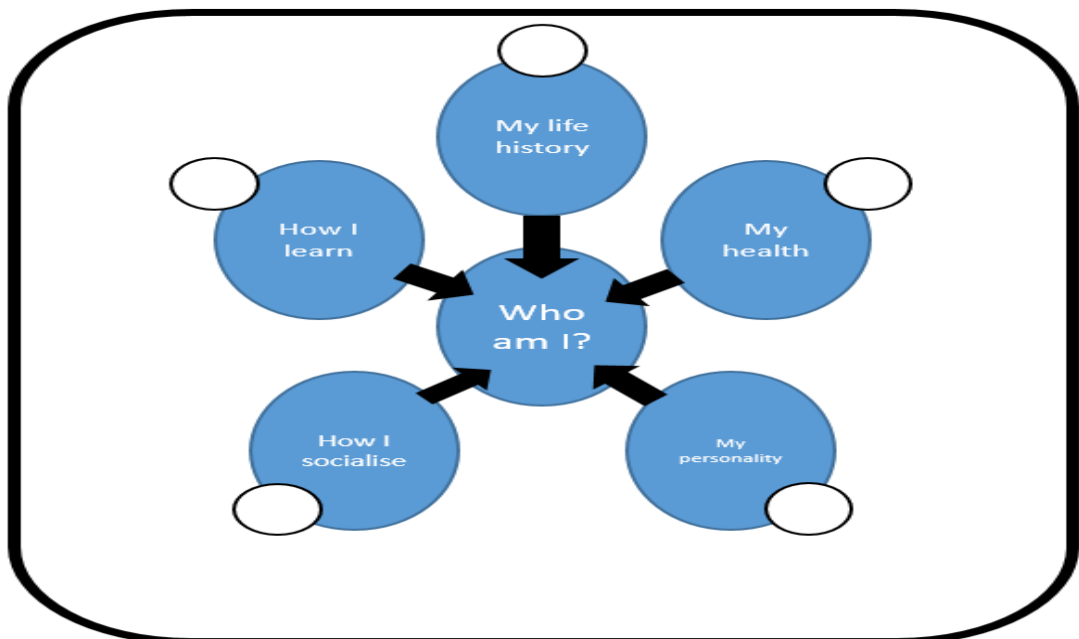


Figure 14: Adapted Kitwood model of personhood for staff to reflect on a resident

3.8.1.4 Exercise four: from outside to inside

The purpose of exercise four was to explore citizenship in relation to the diversity apparent within the community outside of the care home (Figure 15). Additionally, I intended exercise four to encourage participants to consider the interface between the care home and the wider community, considering this broadened the application of the citizenship theory delivered by PERSONABLE. Delivery of the exercise went smoothly. From the engagement with the exercise, it was apparent that a reflective process helped participants to visualise the disparity between the diverse communities outside of the care home walls and how, in general, this diversity was not reflected within residential care homes. Some participants seemed to have difficulty broadly reflecting on their day off, concentrating more on the things they did rather than the diversity of their environment or people they saw. However, the pooled group discussion mitigated these omissions and broadly covered the key learning points needed to deliver citizenship theory. Barriers to community integration identified within the previous focused discussion groups were used in the pilot as prompts to provoke a wide-ranging exploration of citizenship. I believed broadening the discussion at this point would help the participants to identify strategies to overcome obstacles to community integration. This exploration would pave the way for the final 'into action' process within the next exercise.

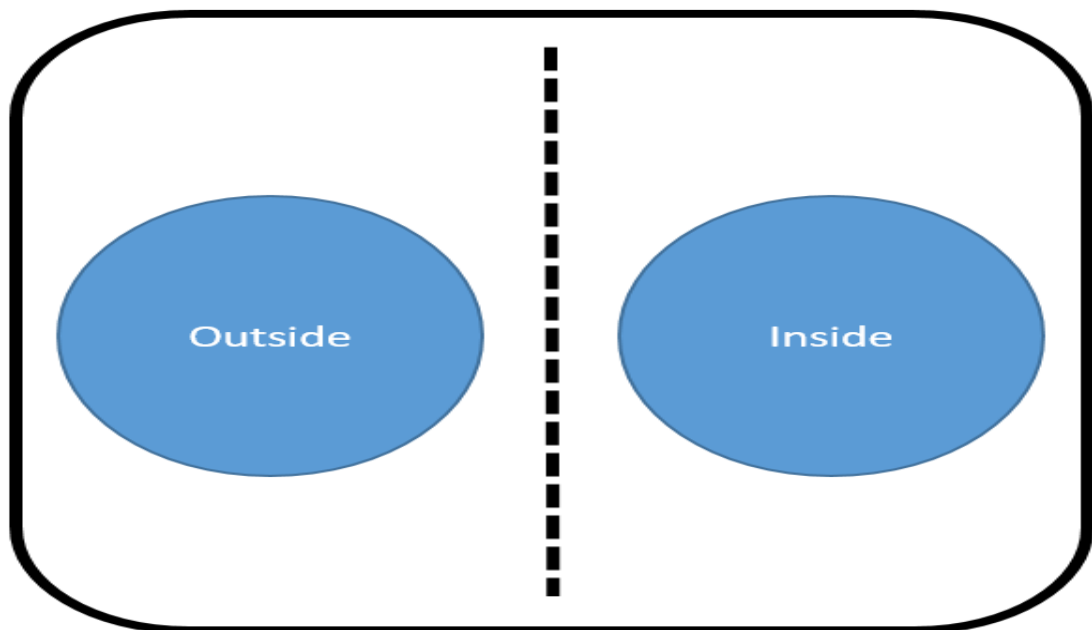


Figure 15: The 'outside to inside' reflective exercise

3.8.1.5 Exercise five: the pledge

I had envisioned this exercise would act as a transformative platform for staff to adapt their reflections into an action. The instruction was for staff to think of one thing, in relation to the previous exercises, they might change about their work within the next thirty days and to note the pledge down on the provided workbook sheet (Figure 16). Some focused discussion group participants had felt prompts might be necessary to help participants who would struggle to think of an idea for change. However, I decided against explicit prompts and used open ended direction. I believed this approach would give a better indication of whether the staff had understood the underpinning personhood and citizenship theories conveyed within the workshop.

<h2 style="color: #4F81BD;">The pledge</h2>	For the researcher
<p>Within the next 30 days I will change one thing about the way I work. It may improve my understanding of a resident who has dementia. Or I might introduce something from the outside community into the care home</p>	
<hr/> <hr/>	

Figure 16: The PERSONABLE pledge

3.8.1.6 *The Finalised PERSONABLE workshop*

Following analysis of the focused discussion and pilot group data, further adaptations were made to the language and presentation of the exercises and the PERSONABLE intervention was finalised (Figure 17) (appendix three).

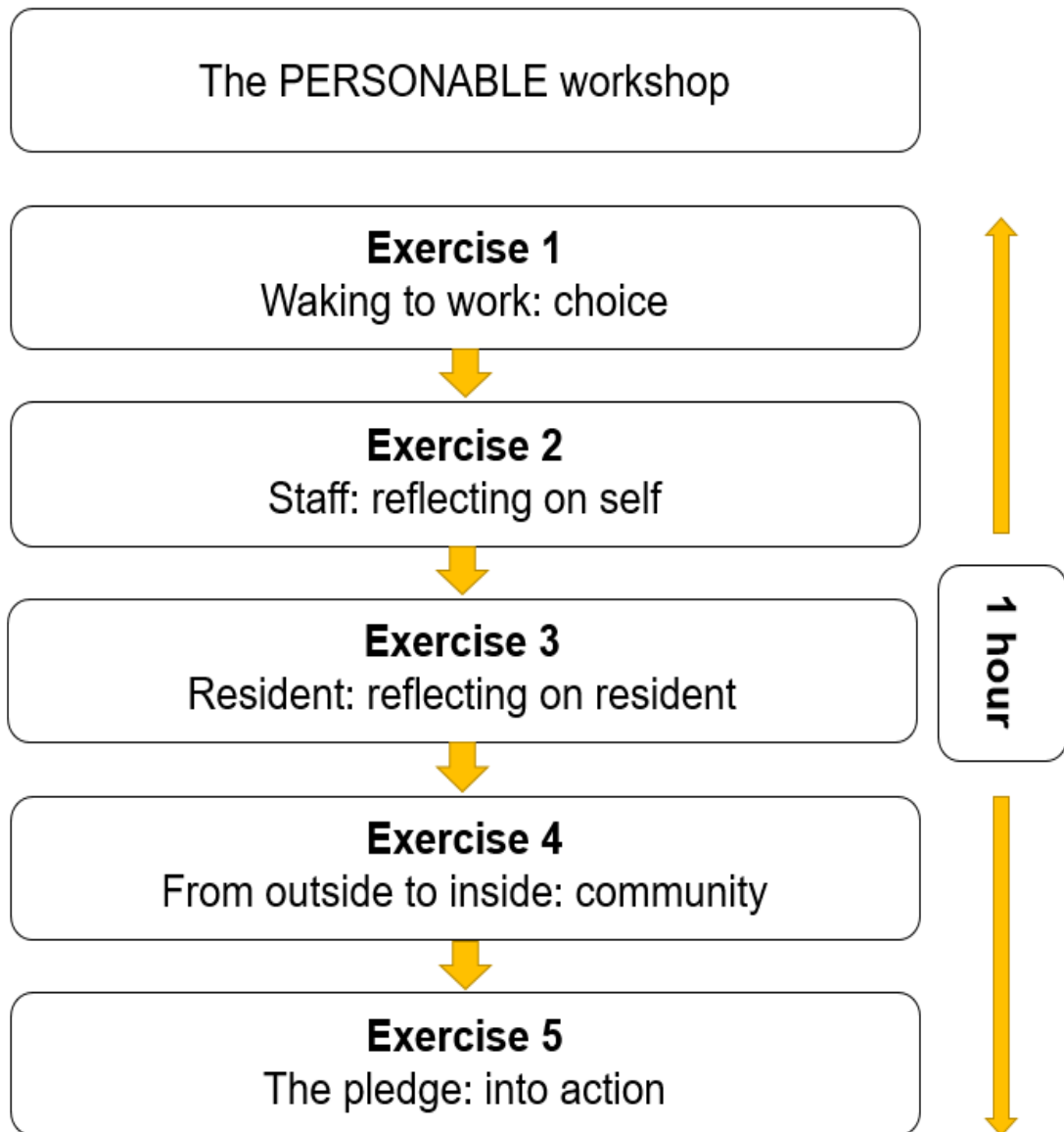


Figure 17: The finalised PERSONABLE workshop

3.9 Phase one summary

Table 11: Transforming the phase one data into adaptations to PERSONABLE

	Phase one summary	Adaptations to PERSONABLE	Exercise
Personhood and citizenship	Staff not understanding choice as a tool for resident agency	Highlight choice as a tool for resident agency	One
	Staff using disease model to rationalise resident behaviour	Behaviour modelled in the context of personhood	Two and three
Staff characteristics	Negative discourse in relation to residents	Adapt language used to deliver PERSONABLE	All
	Influence of managerial staff on group dynamic	Phase two to exclude managers from PERSONABLE	All
	Staff dichotomising 'tasks' and 'person-centred care'	'Tasks' performed in a 'person-centred manner', added as a prompt to discussion	Three
	Ancillary staff lacking confidence in dementia care	PERSONABLE to provide safe space for discussion	All
	Some staff exhibiting a lack of reflective practice	PERSONABLE to encourage personal reflection	All
	Care workers experiencing difficulty finding time to engage in personhood or citizenship activities	Add prompt that personhood and citizenship can be integrated into day-to-day care	Three and five
Current training	Limited time to complete training	PERSONABLE kept under one hour in length	All
	Staff expressed a preference for face-to-face interactive training	PERSONABLE reflective focus and delivered in a personal manner which encourages group discussion	All
	Senior members of staff usually receive training first	PERSONABLE delivered equally across staff groups	All
	Ancillary staff not receiving specific dementia training	Encourage ancillary staff to attend PERSONABLE	All

	Phase one summary	Adaptations to PERSONABLE	Exercise
PERSONABLE feedback	Positive feedback on the simplicity of PERSONABLE	Changes to PERSONABLE embracing clarity of purpose	All
	Community diversity discussion lacking	Community diversity introduced as discussion prompt	Four
	Fictional case study poorly received by participants who felt it did not relate to their work	Case study to be dropped and incorporated into an existing exercise	Three
	Alternative term to 'neurological impairment' discussed	Consensus that 'learning style' promoted a strengths based approach to understanding cognition	Two and three
Facilitation	Facilitator assuming a teaching role	Adjusted the delivery to encourage personal reflection	All
	Facilitator providing lengthy explanations for each exercise	Introductions to exercises shortened and discussion prompts simplified to a single theme for each exercise	All
	One participant felt that staff might need prompts to complete the pledge	Prompts for the pledges not provided. Pledges thought to provide an indication of participant understanding of the purpose of PERSONABLE	Five

3.9.1 Pilot sample

People from differing professional and personal backgrounds were purposively recruited to the three focused discussion groups. This strategy elicited different views on the same themes, providing a richer understanding of the broad issues within the participating residential care homes. Each arising issue needed to be considered prior to testing feasibility of the PERSONABLE intervention in phase two of this study. Of note was how specific staff roles affected the knowledge and application of personhood and citizenship, and how this affected staff interpretation of the PERSONABLE intervention.

3.9.2 Managerial

In group one, the general manager spoke about the steps they would have to take to promote the citizenship of residents. These steps included organising meetings to assess if a resident was safe to access the community independently. The general manager in focused discussion group one demonstrated greater confidence than other staff when positively assessing risk. Her confidence might be attributed to being a registered nurse, being in a position of authority, higher level training or that she had worked at the care home for thirty-three years.

These characteristics were mirrored by the relations manager in focused discussion group four. They frequently demonstrated a more academic understanding and application of the exercises when compared to other participants. However, the confidence of management staff was tangibly to the detriment of the other members of the group, who were observed to withdraw from discussion when the managers asserted their viewpoints.

Regarding the language within the workbook. One manager preferred the term 'brain function' to 'neurological impairment', another preferred 'learning style'. Both managers thought the pledge a useful transformative component but agreed there might be resistance from some residential care staff who did not readily acknowledge when they needed to reflect and adapt their working practice.

3.9.3 Care workers

Care workers did not frequently discuss the citizenship of residents. When citizenship was addressed, they perceived the busy nature of their role as a limiting factor for creating opportunities to promote the citizenship of residents. Focused discussion

group two, comprised entirely of care workers. This group spoke frequently about encouraging resident choice, usually contextualised to encouraging residents to make decisions about food and clothing. Care workers commented that perceived risk to the residents often stopped them providing activities which might facilitate resident citizenship. The care workers would often discuss personhood in relation to the life history and neurological impairment of a resident, but did not intuitively apply other components of the Kitwood (1993b) personhood model, such as how a resident's personality, health or social preferences might influence their experience and behaviour. Care workers reported the prospect of a case study felt confusing and cumbersome. They appreciated the need for a discussion to apply the principles of personhood and citizenship and suggested this exploration could occur as a component of the exercise using the Kitwood (1993b) model to explore the personhood of a resident for whom they care. The care workers participating in the piloting of PERSONABLE welcomed the idea of the pledge stating it gave them a chance to improve their current way of working. However, they acknowledged some staff might be resistant to the introspection necessary to complete the pledge, an observation which helped me understand how I might deliver the exercise when it came to phase two of this study.

3.9.4 Ancillary staff

This small group reported the least access to personhood and citizenship training, relying solely on experiential learning. Despite frequent direct contact with residents who have dementia, the maintenance person felt he did not have a caring role and reported having no specific training in the care of residents who have dementia. Even so, he intuitively utilised a reflective approach to provide care to residents, which was in line with current personhood and citizenship theory. Conversely, the administrator, who also had no specific dementia training, expressed a lack of confidence when interacting with residents who she perceived as 'aggressive'. She stated she would often call care support staff to assist her with situations she perceived as complex; one particular example was when residents were waiting for taxis to help them to access the community. In this respect she reported a different role to other ancillary staff, a role of gatekeeper to the front door of the care home. She commented how this particular role affected the perceived freedom (citizenship) of some residents.

This was in contrast to the maintenance person who mostly reported providing facilitative services which might enhance the citizenship of a resident. Although ancillary staff had frequent contact with residents, generally they did not define their role as care provision. Data indicated this was because they did not have a physical care role. Additionally, ancillary staff have the ability to exit a situation with a resident which they find challenging. The ancillary staff participants demonstrated an understanding of the exercises presented and expressed a preference for reflective and interactive training.

3.9.5 Family members

Out of all the participants family members most frequently spoke about the importance of topics related to personhood and citizenship; two of them had no formal dementia training, but had experiential knowledge of dementia. One family member had worked as a dementia support worker. When speaking about personhood, the family group was the only group that focused on health as a component of personhood. The family members group discussion centred on the desirable intrinsic attributes of a person who might care for their family member and the quality of the environment in which they might be cared for: quality of the food giving a person dignity and excessive noise and poor lighting increasing distress. Family members often commented that kindness, humour and patience were more desirable in residential care home staff than professional qualifications. This group felt that the term 'cognitive function' was understandable but felt participants might need prompts to help them understand how to express this term, they felt 'brain function' might imply something physiological.

3.10 Phase one conclusions

Within the pilot the refined exercises were well received, however, it was noted by the observer that my delivery was at times instructional rather than facilitative. An instructional approach clouded the intended interactive nature of PERSONABLE by placing me as an educator, compromising the ability of the participants to reflect on the exercises. In some of the exercises I tended to provide protracted instructions; for the finalised version it was concluded that facilitation and direction should be concise and focused on a single theme for each exercise.

The workshop ran to time and each exercise took approximately the same amount of time to complete. Some participants spent quite some time writing on the exercise sheets; I decided that to promote engagement that in future sessions the instruction 'brief notes' would help participants from thinking they had to write lengthy statements for each reflective exercise.

After all the stages of intervention refinement, PERSONABLE was developed into a brief reflective workshop with a broad appeal (appendix 3). The overall purpose to convey knowledge of the theories of personhood and citizenship was ratified by the discussions provoked by the exercises. The delivery of the workshop was developed to be standardised, so it might be delivered in a replicable manner.

By adjusting the style of presentation, the role of the person delivering the intervention changed from educational to facilitative. This adjustment was observed to better promote a more reflexive approach which may improve the efficacy of the intervention in phase two of this study.

Chapter four: Methods

4.1 Introduction

This chapter describes the methods used for phase two of the study, which was to test the feasibility of (i) the intervention developed within phase one; and (ii) a definitive cluster randomised controlled trial. A cluster randomised controlled trial was chosen to adjust for known and unknown confounders within residential care homes (Campbell and Walters, 2014). The need for feasibility work was to address questions around the potential barriers that may be encountered with experimental research within residential care, such as participant recruitment, intervention attendance and staff turnover. Many people living with a moderate or severe dementia will reside in residential care homes. Organisational challenges surrounding available resources can inhibit the engagement of people with dementia, staff and care homes in research conducted within these environments (Beer et al., 2011a). There is a consistently reported difficulty in recruiting and retaining sufficient staff and residents within randomised controlled trials conducted in care homes (Low et al., 2015). Active research projects can be hindered by a real or perceived lack of time of staff, residents and owners (Peri et al., 2008, Froggatt et al., 2020), with understandably essential day-to-day routines taking priority (Beer et al., 2011a). This study was designed in recognition of these potential challenges. The methods used were chosen to streamline the research process, so that the perceived burden might be reduced or better understood. This approach has been reported as having the potential to improve the capacity of residential care homes to successfully facilitate, and take part in randomised controlled trials (Cohen-Mansfield, 2016, Froggatt et al., 2020).

As well as gaining a better understanding of any organisational issues, there were also challenges deciding how to numerically capture any possible effect of personhood and citizenship theories which a training intervention might attempt to convey. This chapter presents a rationale for the chosen outcome measures used to quantitatively appraise the potential impact of an intervention delivering the theories of personhood and citizenship.

4.2 The characteristics of pilot and feasibility studies

Many attempts have been made to categorise the specific characteristics of feasibility and pilot studies. Eldridge et al. (2016) conducted a Delphi review, at an international

research conference. Their Delphi review was intended to define the characteristics of feasibility and pilot studies. However, they reported a reluctance of the expert panel to assign mutually exclusive definitions to either 'feasibility' or 'pilot' studies. Morris and Rosenbloom (2017) define feasibility as exploring whether something 'can and should' be done. They assert that a pilot study is a subset of feasibility that tests the research design and part or all of an intervention on a smaller scale. An alternative categorisation is proposed by Whitehead et al. (2014) who suggest differing features between pilot and feasibility studies. They note that pilot studies are usually conducted once it is likely a definitive trial will take place. In this respect Whitehead et al. (2014) recommend that pilot studies flow from initial feasibility testing, which may have indicated a definitive trial is possible. However, they highlight that pilot studies undertake further refining and testing of study methods after a feasibility study has been conducted. In this respect the proposal by Morris and Rosenbloom (2017) that feasibility studies do not include parts of an intervention felt too rigid, and the literature seemed to suggest the two methods represent an ongoing process of refinement. A broader purpose of feasibility studies could be to focus on and explore any components of study methods which might affect the viability of a pilot study or definitive trial. In this respect feasibility studies need to be flexible to adapt this focus dependent on observations made by previous studies (Whitehead et al., 2014). Paying attention to this process of refinement, Whitehead et al. (2014) suggest pilot studies are better placed to more accurately estimate sample sizes should a definitive trial be indicated.

After considering the literature surrounding feasibility and pilot studies, the research questions for this study were adapted from the NIHR (2019) framework for feasibility studies. This framework suggests the key objectives of feasibility studies are to explore:

- The willingness of participants to be recruited and randomised
- The acceptability of, and adherence to, an intervention
- The number of eligible participants

- The acceptability of proposed outcome measures, including follow-up and response rates
- The time needed to collect and analyse study data

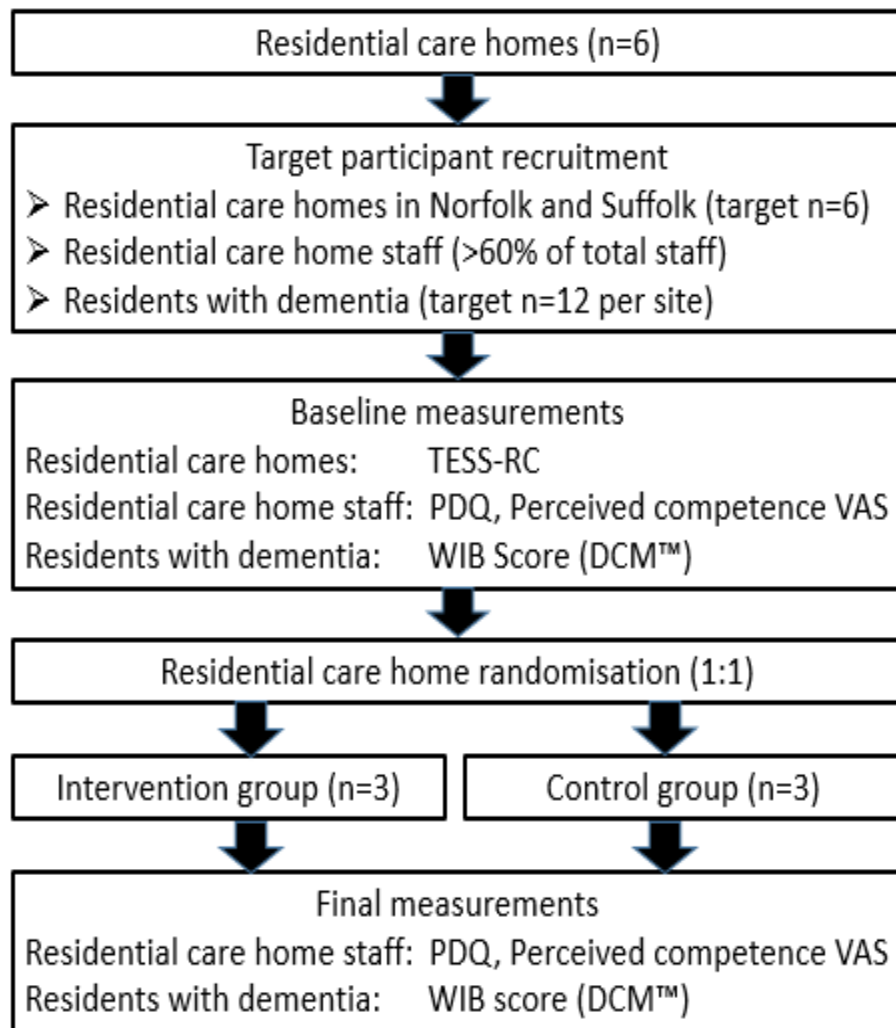
Referring to the NIHR (2019) framework helped to tailor the research aims and questions in a systematic manner. Additionally, this framework helped to provide a structure for exploring the feasibility of the PERSONABLE intervention.

4.3 Trial design

The study design was a cluster randomised controlled trial, comparing and testing the feasibility of a dementia workshop (PERSONABLE) delivered to residential care staff with Training as Usual (TAU) (Figure 18). The randomised controlled trial methodology used in this study intervened at the level of staff member but observed outcomes at the level of the resident. The alternative would have been to randomise staff members but this would have been impractical as it would have restricted care of residents in the home to particular staff members in one particular arm of the study. With this in mind, a cluster randomised controlled trial design was chosen for this study primarily to avoid intervention contamination (Magill et al., 2019). When conducting the literature review, studies which attempted to randomise within (rather than between) the unit of care home, highlighted the difficulty of distilling participants who had not been randomised to the intervention (Knight et al., 2019). Broadly, contamination appeared to occur because of interactions between a community of different staff during collaborative daily duties (Keogh-Brown et al., 2007). In addition to possible intervention contamination, during the piloting of DCM™ in phase one of the study, I observed that keeping track of which staff had been randomised to which arm of the trial might prove difficult in larger care homes. My unfamiliarity with staff, might have been further compounded by the reportedly high staff turnover in care homes (CQC, 2014b). Choosing a cluster design was intended to complement the exploration of feasibility in relation to high staff turnover by gathering data across a more diverse array of care homes (Magill et al., 2019).

There are other important methodological considerations, aside from intervention delivery, which might inform the feasibility of a future cluster randomised controlled

trial. Bland and Kerry (1997) describe the effect of a clustering approach to randomisation, explaining that trial participants must be considered within a cluster and can no longer be treated as independent individuals. The methodological 'cost' of this is less precision in terms of estimates of effect in comparison to a study of the same size, which has used simple randomisation. Steins Bisschop et al. (2015) explain this loss of power as due to cluster randomised controlled trials needing to account for the variability between each cluster. The extent of variability between clusters effectively reduces the size of the sample (Broderick, 2017). Qualitative methods are frequently used within care homes to clarify resident and staff attitudes to intervention provision and study procedures (Griffiths et al., 2019). However, with such care home research being a relatively new area of investigation, there remains a need to explore intervention feasibility on a larger scale (Surr et al., 2016b). Although there is varying success of cluster trials conducted within residential care homes, the contemporary evidence is evolving and beginning to highlight fundamental methodological issues, consideration of which are further developing the evidence base. In light of the limited number of high quality trials conducted in residential care homes, further investigation of feasibility is necessary.



Abbreviations

DCM™	Dementia care mapping, an observational wellbeing measurement tool
WIB score	A component of DCM™, the average of the aggregate wellbeing and ill-being scores
TESS-RC	The therapeutic environment screening scale for residential care
PDQ	The personhood in dementia questionnaire
Perceived competence VAS	A visual analogue scale for the perceived competence of staff

Figure 18: Phase two study flow diagram

4.4 Trial registration

Before recruitment commenced the trial was registered on the international standard randomised controlled trials network (ISRCTN), ID ISRCTN13641553 (Corner, 2017).

4.5 Eligibility criteria

4.5.1 Care home criteria

Residential care homes were restricted to those in the east of England. They were included if they provided care for people with dementia. Nursing homes, or those solely providing palliative care were excluded because of the high probability of physical illnesses or acute confusion.

4.5.2 Resident inclusion criteria

Residents were included if they had a diagnosis of dementia, demonstrated capacity to consent to participation in the study, or had a consultee as outlined within the terms of the Mental Capacity Act 2005 (Department of Health, 2005). A personal or nominated consultee was asked to provide advice and inform a decision to include a resident who had been assessed to lack capacity to consent to participation in the study. Residents were excluded if they were receiving palliative care or had an acute illness.

4.5.3 Staff inclusion criteria

Staff were eligible if they were employed at the residential care home and worked on a full or part-time basis. Staff employed in any role such as care worker, ancillary, maintenance or administrative positions were included and had a minimum of weekly face-to-face contact with residents. Staff were excluded if they were agency or bank staff or if they worked in a senior management position in the care home.

4.6 Recruitment and consent

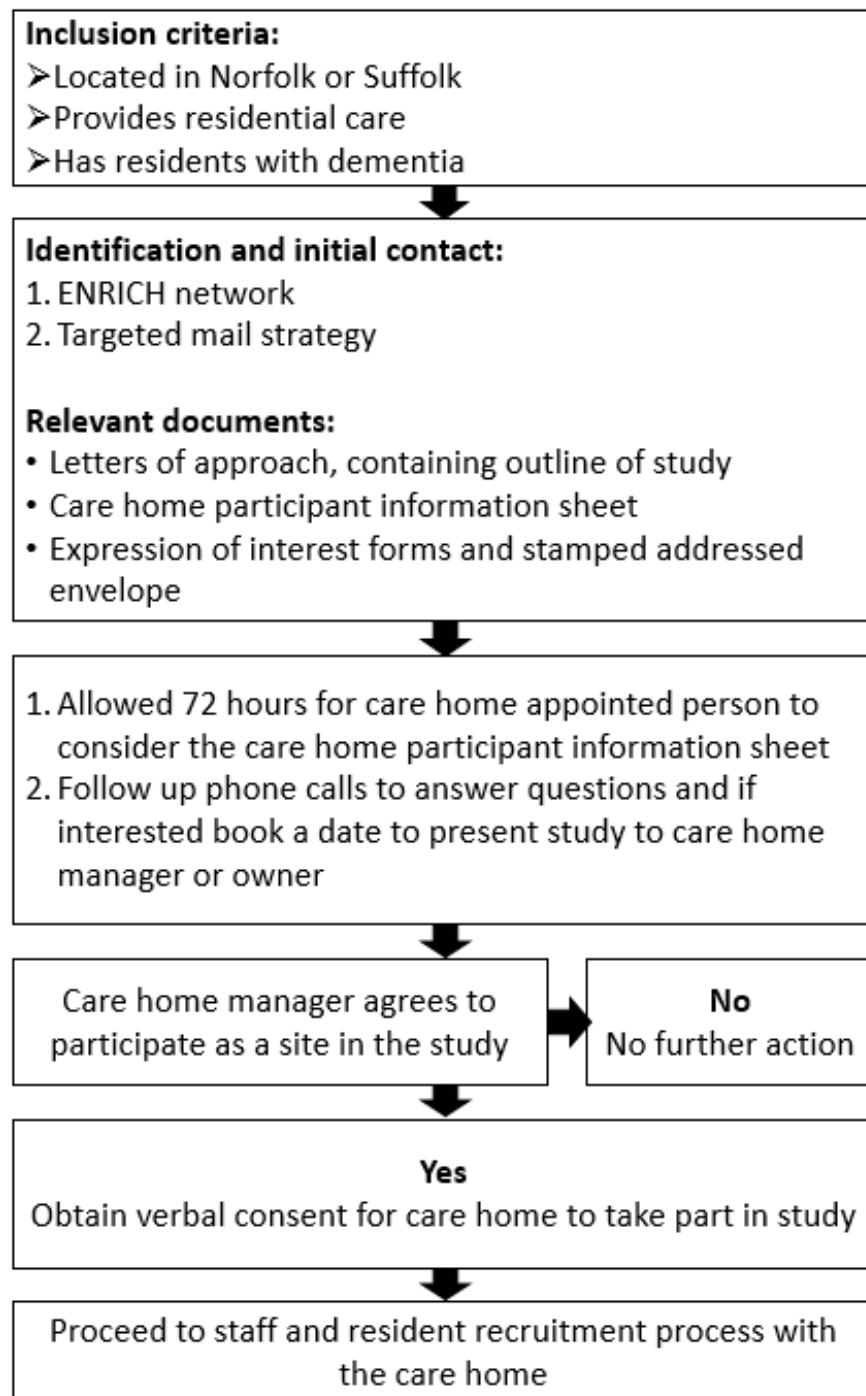
4.6.1 Residential care homes

The care home manager or owner was asked to act as a gatekeeper and provide permission for care home participation. I took the following steps when conducting the recruitment of care homes, these steps are summarised in Figure 19.

1. Residential care home participant sites were identified using the Enabling Research in Care Homes (ENRICH) network. ENRICH have a database of care homes ready and enthusiastic to take part in research. Residential care homes which were not registered with ENRICH were identified using the online AgeUK public access website (AgeUK, 2017). This website lists care homes and gives their contact details.
2. Identified residential care homes were sent care home participant information sheets (appendix four) and study leaflets (appendix five) and a covering letter (appendix six) detailing the study.
3. Three working days after expected receipt of study information, a follow-up telephone call was made to the care home manager or owner.
4. If the care home manager was agreeable, consent was obtained to access the care home.
5. Permission was sought for me to attend the care home team meeting and briefly present a summary of the proposed study to staff.

Recruitment of care homes ceased once permission was given to access six different residential care homes which had sufficient numbers of staff and residents to fulfil the recruitment targets.

Figure 19: Care home recruitment flow diagram

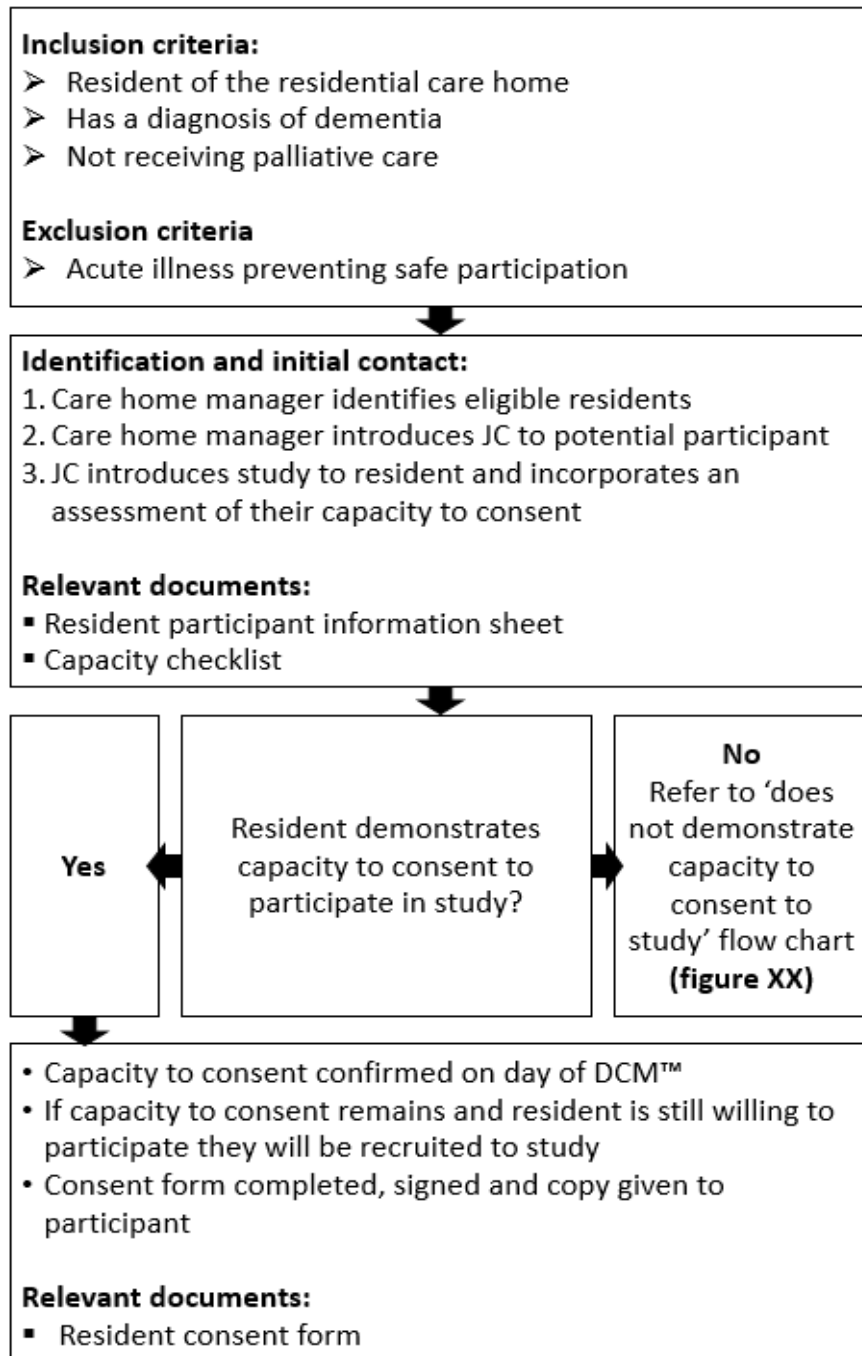


4.6.2 Residents with dementia

Residents were eligible if they had moderate to severe dementia. This inevitably affected their ability to consent to participation in this study. I assessed resident capacity drawing on my clinical experience of the assessment of mental capacity, as defined within the Mental Capacity Act (DoH, 2005). Additionally, I was guided by the Department of Health (2008) guidance on the recruitment of people who may lack capacity to consent to participation in research. To recruit resident participants I took the following steps which are summarised in Figure 20.

1. The care home manager was asked to identify residents who have dementia.
2. When an appropriate resident was identified, the care home manager gained permission from the resident for me to speak with them about the study and they were given resident participant information sheets for their consideration (appendix seven).
3. When agreeable, I explained my study to the resident. I presented the information in a way which I felt best suited the needs of the person I was speaking with, and in a manner which gave them the best chance of understanding the purpose of the study. If the resident showed an interest in participation and was agreeable, I performed an assessment of their capacity to consent to the study based on a standardised form provided by my NHS manager (appendix eight). The capacity assessment drew on the knowledge of those most familiar with the resident.
4. If the resident demonstrated the capacity to consent to participation in the study and wished to take part then they were asked to sign a consent form (appendix nine).
5. On the day of data collection, I checked assent prior to commencement of any observation.

Figure 20: Recruitment of residents

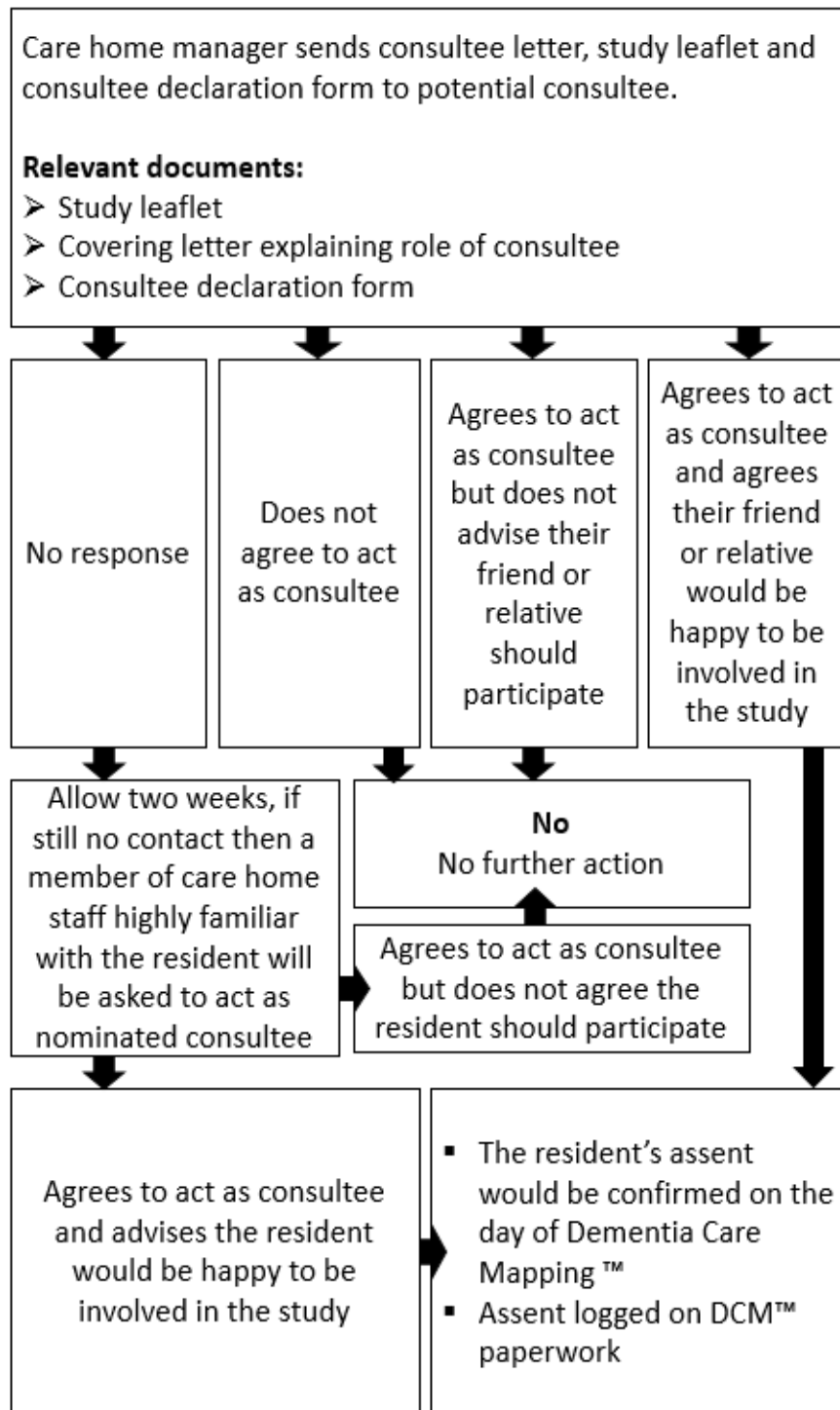


4.6.3 Consultee process

When residents were assessed not to have the capacity to consent to participation in the study, the opinion of a consultee was sought. Preferably this was a family member or close friend (personal consultee) or if not, an identified member of the care team (nominated consultee). When navigating the consultee process I took the following steps, these are summarised in Figure 21.

1. If the resident did not demonstrate the capacity to consent to participate then I requested that the care home manager sent a covering letter (appendix ten), a study leaflet (appendix five) and a consultee declaration form (appendix eleven) to the potential consultee.
2. If they agreed to act as consultee but felt the resident would not like to take part in the study, the resident was not to be included. If they agreed to act as consultee and felt the resident would like to take part, then the resident could be included, so long as they assented to observation on the two days of data collection.
3. If the potential consultee did not respond (they were given two weeks), then a staff member very familiar with the resident was asked to act as nominated consultee and offer their opinion as to whether the resident would like to be included in the study.

Figure 21: Consultee flow diagram

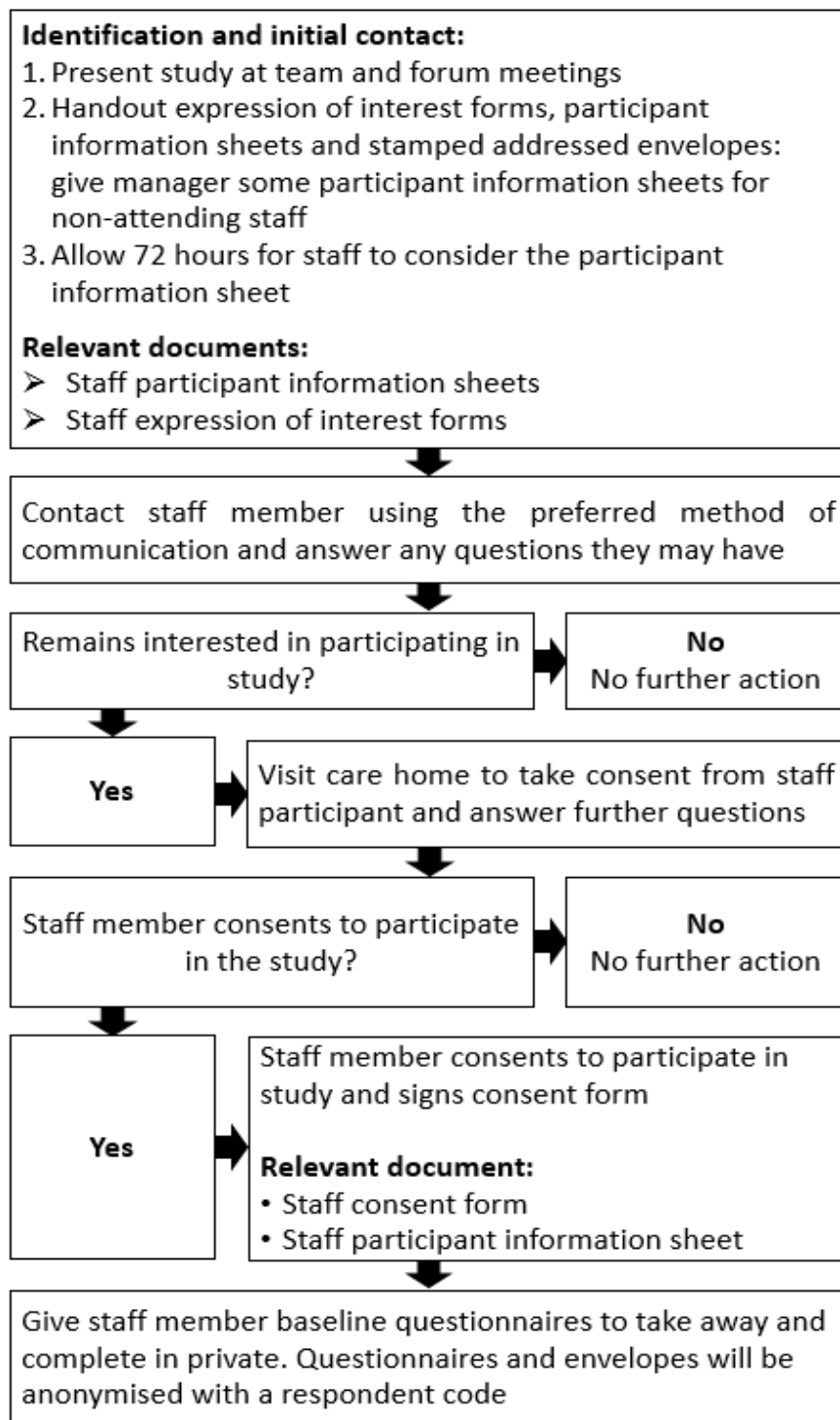


4.6.4 Residential care staff

Staff recruitment began once the care home manager or owner had consented to participation, of the care home, in the study and it had been established the home provided care for a sufficient number of residents with dementia to meet the required sample size. When conducting the literature review for this study a reportedly high attrition of staff was observed by other similar studies (Beer et al., 2011a, Chenoweth et al., 2009, Kuske et al., 2009). Therefore, this trial allowed staff to join at baseline, at intervention delivery or at follow-up. It was hoped this approach to participation would help more comprehensively capture feasibility and describe the flow of staff through the trial. To recruit staff members I took the following steps, which are summarised in Figure 22.

1. If acceptable, I presented a summary of the study at care home team meetings or staff handovers. During these presentations potential participants were given participant information sheets (appendix twelve) to take away and read and expression of interest forms (appendix thirteen) should they wish to take some time before agreeing to participate in the study. I gave the manager expression of interest forms and study information leaflets for members of staff who may have missed the presentations but would be present on the days when observations would be taking place.
2. Before consenting to participation staff were given the opportunity to ask questions relating to the study.
3. If staff remained happy to consent to participation in the study they signed study consent forms (appendix fourteen). Consent was re-confirmed on the days of DCM™ observation.
4. There was no further contact with the control group care homes until follow up measurements were to be collected. For the intervention group, on the day of the dementia workshop participant information leaflets were available.

Figure 22: Staff recruitment flow diagram



4.7 Resident measurements

4.7.1 Dementia Care Mapping™

Dementia Care Mapping™ (DCM™) is an observational method which attempts to interpret the fundamental meaning behind the non-speech, and speech, communication of those who have dementia. DCM™ was originally developed by Kitwood and Bredin (1992). This method of observation was designed to help gain an understanding of a person with severe dementia so that their experience might be more accurately interpreted (Innes and Surr, 2001). Originally DCM™ was designed to advocate the needs of the person severely affected by dementia (Whitlatch, 2001, Whitlatch, 2013). The observational interpretation of DCM™ could then be fed back to staff, who can more astutely adapt their care behaviour (Janicki and Keller, 2015). When considering the available literature it seemed that DCM™ could help facilitate the inclusion of those residents with dementia who are less likely to be able to consent to participation, and who may have difficulty verbalising their experience (Brooker and Surr, 2006). DCM™ achieves this by attempting to impartially observe (Buetow, 2019), record and narrate an authentic interpretation of the experience of residents, an interpretation which is reflective of the theoretical underpinning of the intervention relating to personhood and citizenship.

4.7.1.1 Usual procedure for Dementia Care Mapping™

Dementia Care Mapping™ was originally developed as a practice evaluation tool to understand and measure quality of care for people with dementia. For this study, the most recent 8th edition of DCM™ was used (Brooker and Surr, 2006). For practitioners to use DCM™ an accredited course must have been undertaken, usually four days long. I completed the course in 2011. Surr et al. (2020) conducted a cluster RCT (EPIC) of 50 care homes. They recruited 726 residents, which reduced to 261 residents at 16 months follow-up. Two members of staff were trained to undertake DCM™, however, only 26% of trained staff completed a cycle of DCM™. The primary conclusion of the EPIC trial (Surr et al., 2020) was that DCM™ was not cost effective when conducted by care home staff.

Primarily an observational tool, DCM™ attempts to describe the experience and behaviour of people with dementia and then feedback observations to staff so they can adapt the care they provide. Additionally, DCM™ describes the underlying nature

of interactions that occur between people with dementia and the people who care for them. For this study the reflective feedback element was omitted, this was to explore the use of DCM™ as an outcome measure independent from the reflective intervention.

For this study observations were carried out on any day between Monday and Friday, the observation period was four hours at baseline and another four hours at follow-up. The four-hour period was usually between 10:00hrs and 14:00hrs but this timing varied slightly to accommodate different care home routines. The observation period was set to always include the pre-lunchtime period, which (Fossey et al., 2002) suggest is most correlated to the overall observation period. On the day of DCM™ the observer introduces themselves to the residents and staff who are going to be observed. A typical observation period is four to six hours. As I was the sole person conducting baseline and follow-up measurements across all six sites this study used four hours of observation. Every five minutes the observer assigns a behaviour category code (BCC) and a mood and engagement score (ME) for each resident participant on a data sheet. They also can make brief notes on each participant throughout. As obtaining a qualitative description was not the intention of this study, only very brief notes were taken, which was intended to maximise the potential for including and observing a greater number of residents. To maintain the dignity of people with dementia, DCM™ only takes place in public areas, this approach also helps to maintain a focus on care provided in the social-psychological environment (Brooker et al., 2013). If, through the observation period any resident (including people not having their experience 'mapped') shows signs of distress at the presence of the observer, the researcher ceases observation. It was agreed with the Social Care Research Ethics Committee, during the ethical review and approval process, that the care home team would immediately be made aware of any resident exhibiting significant distress, denoted by a -5 score, and their participation in the study would cease.

DCM™ comprises three elements: Mood and Engagement (ME), Behaviour Category Codes (BCC) and Personal Enhancing or Personal Detracting (PE or PD) interactions between staff and residents.

4.7.1.2 Mood and Engagement score (ME)

The ME score refers to two dimensions of the ‘mood’ (M) and ‘engagement’ (E) levels of the observed person. Mood is traditionally rated between +5 (positive mood), and -5 (negative mood). Engagement is rated between +5 (very engaged) and -3 (disengaged). Currently DCM™ denotes neutral mood or engagement with a +1 score. A -5 value was not used in this study; ethical approval was given on the basis that any extreme distress requiring a -5 score would be immediately reported to the care home team and data collection stopped for that resident (Table 12).

Because DCM™ was originally developed from feedback to staff on care practices, it focuses on capturing the positive aspects of the care environment. For each five-minute time frame the observer records the highest observed mood or engagement score. For example, if a participant was observed as low in mood but very engaged with a task, the observer would score for the engagement observed. Additionally, DCM™ operational rules state that an observer must score the highest ME value within the five-minute time frame, so if a participant is sleeping for the majority of the time frame but wakes up in the last thirty seconds, the observed ME value for the last thirty seconds would be recorded.

Table 12: Mood and Engagement (ME) score range

DCM™ Mood and engagement score range
+5
+3
+1
-1
-3
-5

*Grey shading denotes that a score of -5 was not used for this study

4.7.1.3 Behaviour Category Code (BCC)

There are twenty-three different BCCs (Table 13) designed to describe the behaviour of people with dementia.

Table 13: Behaviour Category Codes

Code	Name	Behaviour description
A	Articulation	Interacting with others
B	Borderline	Being socially involved, but passively
C	Cool	Being socially uninvolved, withdrawn
D	Doing for self	Engaging in self-care
E	Expression	Engaging in an expressive or creative activity
F	Food	Eating, drinking
G	Going back	Reminiscence and life review
I	Intellectual	Activity prioritising intellectual abilities
J	Joints	Engaging in exercise or physical sports
K	Kum and go	Independent walking, standing, moving
L	Leisure	Engaging in leisure, fun and recreation
N	Nod, land of	Sleeping, dozing
O	Objects	Displaying attachment to or relating to inanimate
P	Physical care	Receiving practical, physical or personal care
R	Religion	Engaging in religious activity
S	Sex	Engaging in sexual expression
T	Timalation	Direct engagement of the senses
U	Unresponded to	Attempting to communicate but not receiving a response
V	Vocational	Engaging in work or work-like activity
W	Withstanding	Repetitive self-stimulation
X	X-cretion	Episodes related to excretion
Y	Yourself	Talking to oneself, or an imaginary person
Z	Zero option	Fits none of the existing categories

The twenty three BCCs are split into four groups, each group describing the potential of the behaviour for positive mood or engagement (Table 14). Each group was assigned a numerical value from lowest potential group to highest potential group (zero to three).

Table 14: BCC Potential for positive mood or engagement

Group	Behaviour category codes	Value
High potential categories	A,D,E,F,G,I,J,K,L,O,P,R,S,T,V,X,Y	3
Moderate potential categories	B	2
Low potential categories	C,U,W	1
No potential categories	N	0

For each five-minute time frame, an observer must score the behaviour with the highest potential for mood or engagement. For example, if a person has been withdrawn (C) for most of the time frame but becomes very interested in a leisure (L) activity towards the end of that time frame, then leisure (L) would be recorded, because it has the highest potential for mood or engagement.

4.7.1.4 *Personal enhancers and personal detractors*

DCM™ attempts to describe the type and nature of interactions which occur between the staff and those they care for. The use of personal enhancers and detractors is descriptive of the nature of the staff interaction rather than a numerical measure of interaction quality. There are seventeen personal enhancing staff interaction categories and seventeen detracting staff interaction categories (Table 15). It is usual to only use these codes when an interaction of interest has taken place. However, for this study to capture the breadth of interactions across all sites, all interactions occurring between staff and resident were recorded. Because of the high number of interactions anticipated from taking this approach the rating of the thirty-four different interactions was condensed. Enhancing interactions were recorded as +1 and detracting interactions as -1.

Table 15: Table of personal detractors and personal enhancers

Personal detractors	Personal enhancers
Undermines comfort needs	Supporting comfort needs
PD1 Intimidation	PE1 Warmth
PD2 Withholding	PE2 Holding
PD3 Outpacing	PE3 Relaxed pace
Undermines identity needs	Supporting identity needs
PD4 Infantilisation	PE4 Respect
PD5 Labelling	PE5 Acceptance
PD6 Disparagement	PE6 Celebration
Undermines attachment needs	Supporting attachment needs
PD7 Accusation	PE7 Acknowledgement
PD8 Treachery	PE8 Genuineness
PD9 Invalidation	PE9 Validation
Undermines occupation needs	Supporting occupation needs
PD10 Disempowerment	PE10 Empowerment
PD11 Imposition	PE11 Facilitation
PD12 Disruption	PE12 Enabling
PD13 Objectification	PE13 Collaboration
Undermines inclusion needs	Supporting inclusion needs
PD14 Stigmatisation	PE14 Recognition
PD15 Ignoring	PE15 Including
PD16 Banishment	PE16 Belonging
PD17 Mockery	PE17 Fun

4.8 Justification for using DCM™ to interpret the experience of the resident

4.8.1 Outcome measure choice and the consideration of alternative outcome measurements

After development of the PERSONABLE intervention in phase one of this study it seemed important to choose a measure which would capture the experience of participating residents and any possible changes to staff working practices. It was likely that participating residents would have significant cognitive impairments, therefore, an observational measure rather than a questionnaire seemed necessary (Algar et al., 2016). Indeed, many wellbeing measures use exclusion criteria based on the severity of dementia (Hughes et al., 2019). Therefore the decision was that an observational measure should be adopted, which could record the resident experience in relation to the concepts of personhood and citizenship.

Quantitative observational tools measuring the wellbeing of people with dementia were located when conducting the literature review and when meeting with research groups familiar with observational measures. Several reviews have explored the many observational measures, which seek to quantify and describe the experience of a person with severe dementia (Algar et al., 2016, Keady, 1996, Dooley et al., 2015). Some observational measures were not considered because they capture the behaviour of the resident related to a specific activity, such as art in the 'Behaviour Observation' tool (MacPherson et al., 2009) and the 'Greater Cincinnati Well-being Observational Tool' (Rentz, 2002). Observational measures which had not been widely used (Bruce, 2000) or had not been peer reviewed (Gottlieb-Tanaka et al., 2008) were not considered.

An observational approach needed to be mindful of the influence of observer bias, which can have a significant effect on the recording of observational measures (Mahtani et al., 2018). One way to limit observational bias is by using a period of training to improve interrater agreement and making attempts to blind the researcher collecting observational data from group allocation (Mahtani et al., 2018). Therefore this approach was adopted for this study, I review the success of this approach within the discussion chapter of this thesis.

Table 16: Measures considered for use in this study

Measure	Description	Appropriateness
Staff		
Personhood in dementia questionnaire (Hunter et al., 2013a)	Measures carer personhood knowledge. 20 items rated between strongly agree and strongly disagree. Includes reverse coding questions.	Specifically measures carer personhood knowledge. Nature of questions means citizenship knowledge is also addressed. Valid and reliable.
Sense of competence questionnaire (Schepers et al., 2012)	Measures carer perceived competence. 27 items rated on a five-point scale. Questionnaire covered three domains 1) Satisfaction with the care recipient, 2) Satisfaction with one's own performance, 3) Consequences of involvement in care for the personal life of the caregiver	Measurement pertains to carer attitudes rather than knowledge. Limited measurement of personhood or citizenship. Validity poor for domains one and two. Low validity for domain three
Confidence in dementia scale (Elvish et al., 2014)	Measures carer confidence working with people and dementia. Nine item self-report questionnaire rated on a five-point Likert scale	Measures carer confidence, rather than the concepts of personhood or citizenship. Good internal consistency
Knowledge in dementia scale (Elvish et al., 2014)	Measures carer knowledge of dementia. 16 point self-report questionnaire, scored using agree (1) disagree (0)	Brief measure, which might suit needs of study. However, limited measurement of personhood or citizenship. Good internal consistency
The Alzheimer's disease knowledge scale (Carpenter et al., 2009)	Measures carer knowledge of dementia. 30 items rated as true or false. Covers risk factors, assessment, symptoms, life impact, caregiving and management	Questions relate to specific carer skills rather than measuring the concepts of personhood or citizenship. Adequate reliability and validity
Dementia attitudes scale (O'Connor and McFadden, 2010)	Measures carer attitudes to dementia. 20 items rated on a five-point scale	Limited measurement of personhood or citizenship. Good reliability and validity

Measure	Description	Appropriateness
Dementia knowledge assessment tool (Toye et al., 2014)	Measures carer knowledge of dementia. 25 items rated by Yes/No/Unsure.	Designed for use in aged care environments. Designed as a quiz. Based on a medicalised formulation of dementia symptoms. Good reliability and validity.
Personhood questionnaire (Kurokawa et al., 2013)	Measures personhood knowledge of carers. 17 items which were rated on a five-point Likert scale.	Designed for elderly people and not exclusively people with dementia. Valid and reliable.
Care home		
Therapeutic environment screening survey (Sloane et al., 2002)	Measure of usual care environment. 31 items. Binary and continuous rating scales.	Can be adapted for a less invasive assessment of care environments. Can be completed in less than thirty minutes. A version for nursing homes and separate version specifically for residential care homes. Good validity and reliability.
Environment assessment tool (Waller et al., 2017)	Measurement of suitability of environment for people with dementia. 59 items rated on a five-point scale. Qualitative notes required to substantiate rating.	Specifically addresses environment in relation to a person with dementia. Time consuming and requires supporting qualitative notes.
Sheltered Care Environment Scale (Lemke and Moos, 1987)	Measurement of sheltered care environment. 63 items rated with Yes/No responses. Tool measures seven dimensions: cohesion, conflict, independence, self-disclosure, organisation, resident influence, and comfort.	Focuses on the social capital of a care environment. Measure not specifically designed for use with people who have dementia. Good reliability and validity.
Care home checklist (AgeUK, 2019)	A checklist to inform a carer's opinion on a care home. 87 items not rated but logged with a tick if domain is present.	Partly addresses environment in relation to dementia care. Not a quantitative measure and not tested for validity or reliability

Measure	Description	Appropriateness
Resident		
Dementia Care Mapping™ (University of Bradford, 2010)	Observational measure, originating from practice development. Collects data on the experience of a person with dementia 1) Behaviour category codes, 2) Mood and engagement score, and 3) Staff detracting or enhancing interactions. Observer can collect qualitative notes to substantiate the quantitative data.	Person focused and specifically measures the resident experience. Rigorously tested within many research studies. Good validity and reliability reported.
Quality of Interaction Schedule (Dean et al., 1993)	Quantitative observational measure focusing on staff interactions. Staff interactions assigned one of five categories reflecting either positive, neutral or negative interactions: positive social, positive care, neutral, negative protective and negative restrictive.	Records interactions using a person-centred approach. Challenges to consistent observer agreement reported.
Behaviour observation tool (MacPherson et al., 2009)	Rates the engagement of the person with dementia on a scale of very engaged, engaged, neutral, disturbed, disengaged. Observations recorded for every two minute time frame.	Specifically developed to code behaviour of people with dementia during art gallery visit. Does not specify behaviour when recording level of engagement.
Greater Cincinnati wellbeing observational tool (Rentz, 2002)	Measures seven domains of wellbeing for people with dementia: attention, pleasure, negative affect, sadness, self-esteem and normalcy.	Recommended to observe only up to three people. Lack of specificity of behaviour when coding.
Bradford wellbeing profile (Bradford Dementia Group, 2008)	A simpler tool than DCM™ and centred on the wellbeing of a care home resident. Domains; communicates wants, needs and choices; makes contact with other people; shows warmth or affection; shows pleasure or enjoyment; alertness, responsiveness; uses remaining abilities; expresses self-creativity; is cooperative or helpful; responds	Requires further training. Less domains than DCM™ but still complicated method of observation. Behaviour domains are subjective.

Measure	Description	Appropriateness
	appropriately to people/situations; expresses appropriate emotions; relaxed posture or body language; sense of humour; sense of purpose; signs of self-respect. Domains rated on a scale 0 (no sign), 1 (some sign) and 2 (significant sign).	

*Blue shading denotes the measurements that were chosen for use in this study

4.8.2 Involvement of people with dementia in research studies

Following the National Dementia Strategy (DoH, 2009), there was an increased focus on the rights of people with dementia, a focus which was reflected in greater funding for dementia research (Alzheimer's Society, 2014). Despite better research capacity generated by the National Dementia Strategy (DoH, 2009), there has been a dearth of care home resident accounts, either interpretive or first-hand (Backhouse et al., 2016). Reacting to this sparsity, both quantitative and qualitative researchers have adapted their methodologies to better represent the views of people with a diagnosis of dementia, who may find it difficult to fully articulate their views and experience (Goodman and Davies, 2012).

Public health groups specifically promoting the research participation of those with dementia have been established. The Enabling Research in Care Homes (ENRICH) network promotes care home engagement in research and is part of the National Institute for Health Research (2015). The ENRICH network have constructed strategies which promote the research capacity of residential care, and in tandem, cites the increased inclusion of residents with dementia as a priority (Goodman and Davies, 2012). The Dementia Engagement and Empowerment Project (DEEP) is a national initiative funded by the Joseph Rowntree Foundation (Joseph Rowntree Foundation, 2018). The initiative purposefully seeks to increase the direct involvement of people with dementia, in policy and research development, attempting to reduce an apparent disparity in the interpretation of patient and public involvement (PPI) (Charlesworth, 2018, Bethell et al., 2018). It also provides an extensive network of people with dementia to meet and provide peer support. I approached the DEEP project, however, they indicated problems recruiting people with dementia and regionally DEEP had no one with dementia enrolled to provide feedback on emerging studies, so this avenue was not further pursued (The Dementia Engagement and Empowerment Project, 2015).

A systematic review of care home resident engagement in research also reported difficulty recruiting people with dementia to directly guide and provide input into dementia research (Backhouse et al., 2016). This paper reported that many of the

studies included in the review specified a diagnosis of dementia as participant exclusion criteria, citing cognitive impairment as a barrier to understanding and participation. Although care homes may accommodate significant proportions of people who lack the capacity to consent to involvement in research, inclusion can occur on different levels and impaired cognition need not be a limiting factor when conducting definitive trials (Boyle, 2008).

4.8.3 Capturing the experience of residents who have dementia

The challenges of accurately representing the experience of people with severe dementia has been acknowledged (Surr et al., 2018a). At a progressed stage of the disease, people with dementia may have difficulty communicating their experience verbally (Innes and Surr, 2001). This has meant that the inclusion of people with dementia can be incorrectly perceived as a burden to the smooth running of trials (Suijkerbuijk et al., 2015). Typically, if people with dementia are viewed as not able to contribute to research, the opinion of a proxy can be sought. However, using a proxy to inform outcome measures can distance the perspective of people with dementia (Vogel et al., 2012).

Furthermore the use of proxy informants is not in line with the standards for individual autonomy set out within the Mental Capacity Act (DoH, 2005) in England and Wales. This act states no one can truly know the person's experience other than the person themselves. If staff and family are feeling overburdened by their care role they typically rate the quality of life of the person they care for as lower (Robertson et al., 2017, Bradford et al., 2013). The experience of people with dementia reported from a proxy perspective can differ qualitatively as well as quantitatively. Family members have been reported to more readily base their assessment of the wellbeing of a person they care for, using a paradigm of physical disablement or cognitive decline as opposed to a holistic description of mental wellbeing (Moyle et al., 2012, Arons et al., 2013a, Vogel et al., 2012). Conversely, Robertson et al. (2017) suggested that overall ratings by a proxy were reflective of resident wellbeing, however, their study also used a paradigm of physical and cognitive disablement to define resident quality of life. Viewing quality of life in this manner can negate other factors such as emotional wellbeing or perceived identity (Perrin et al., 2014). Despite different perspectives,

self and proxy reported quality of life are often conflated (Suijkerbuijk et al., 2015). Acknowledging the challenges of proxy accounts, there remains the real dilemma of accurately capturing the experience of those whose ability to communicate their experience verbally is severely affected by the disease. It is suggested a person removed from the emotional impact of providing care might perform a more objective assessment (Western and Tomaszewski, 2016).

4.8.4 Interpreting behaviour and 'non speech' communication

Various approaches have been taken to objectively understand the expression and behaviour of residents with dementia who may have difficulty verbally expressing themselves. One intention of this study was to explore outcome measures which might advocate for people with dementia who have difficulty articulating their experience. A phenomenological study, conducted with residents living in residential care (Clare et al., 2008), explored the challenge of interpreting 304 transcribed conversations with residents with dementia who had difficulty with verbal communication. Clare et al. (2008) highlighted the balance between gaining an authentic first-person account versus losing information which could not be communicated by the resident.

Another phenomenological exploration of smaller samples has focused attention on the understanding of residents 'non-speech' communication (Walmsley and McCormack, 2014). Generally researchers have struggled to find a method for interpreting 'non-speech' communication which can be categorised and translated into larger quantitative descriptions (McLean et al., 2017). The Quality of Interaction Schedule (QUIS), is a quantitative observational measure focusing on staff interactions, as opposed to concentrating on the underlying experience of the person with dementia (McLean et al., 2017, Dean et al., 1993). McLean et al. (2017) reported challenges to consistent observer agreement, an observation reflecting wider limitations of observational measures rather than specifically relating to QUIS (McLean et al., 2017). To explore strategies to assist interrater agreement, video recordings have been observed and rated using the 'Verbal and Non-verbal Interaction Scale' (Williams et al., 2017). Williams et al. (2017) reported improved

observer agreement when data familiarisation was aided by pausing the video and observers could discuss their views on the interaction.

4.9 Resident demographic data

The only demographic data obtained for the resident participants was their gender. Other resident data on cognitive ability, physical ability or disability, social function and usual emotional state may have been desirable. However, it was decided when writing the study protocol that because of the complexity of managing many levels of data collection across six care homes that: (i) requesting access to resident notes would add another layer of intricacy and may have impacted on resident recruitment and participation; (ii) that performing an audit of resident notes across sites might not have provided comparable information; and (iii) liaising with health practitioners such as general practitioners and practice nurses to obtain accurate data would extend the practical resources of this study.

4.10 Residential care home staff

4.10.1 Personhood in dementia questionnaire

The beliefs of staff surrounding personhood were measured using the Personhood in Dementia Questionnaire (PDQ) (Hunter et al., 2013b). The choice of tools which specifically measure personhood knowledge and attitudes was limited (Table 16). To operationalise the observations made when conducting the literature review and to inform the feasibility testing conducted in this study, measures exploring changes in staff attitudes to, and understanding of, personhood and citizenship were considered. It appeared necessary to choose measures which could involve some level of blinding; therefore, a questionnaire seemed the most appropriate method to achieve this objective (Copeland et al., 2019). Additionally, it was important to choose staff measures, which were sympathetic to the busy schedules in care homes reported by the care staff who participated in the phase one focused discussion groups. The primary objective of including staff measures was to assess the extent of engagement with trial procedures. A secondary purpose was to explore the suitability of the specific tool in capturing changes in staff knowledge and attitudes gained from PERSONABLE. This meant that ideally the measurement tool should be sensitive to personhood and citizenship. The 'Sense of Competence in Dementia Care' questionnaire explores staff perceived competence (Schepers et al., 2012). Similarly, the 'Confidence in Dementia

Scale' and 'Knowledge in Dementia Scale' (Elvish et al., 2014) measure staff confidence and knowledge. However, these tools were broadly framed in relation to general role competence or confidence and not specifically relating to a specific understanding of personhood or citizenship. 'The Alzheimer's Disease Knowledge Scale' (Carpenter et al., 2009) specifically tests staff knowledge surrounding dementia; however, the tool covers risk, assessment, diagnosis, symptoms, disease progression, life impact, caregiving and treatment but does not explore either personhood or citizenship. The 'Dementia Attitudes Scale' (O'Connor and McFadden, 2010) explores 'social comfort' and in this respect was more suited to an appraisal of personhood and citizenship approach. However, this measurement tool also includes a section on 'dementia knowledge', which was not reflective of the content of PERSONABLE.

One other measure exploring personhood knowledge was located (Kurokawa et al., 2013). However, this 'Personhood Questionnaire', derived from a study of 314 healthcare staff, examines the personhood of 'elderly' people who did not all have dementia. The PDQ created by Hunter et al. (2013b) consists of twenty statements about the personhood of people with dementia (appendix fifteen). A member of staff can rate between strongly agree and strongly disagree. Although the questionnaire refers solely to personhood, many of the questions also encapsulate citizenship theory. All the questions are phrased in accessible lay person language and terminology. The tool has been tested and found to be both valid and reliable (Hunter et al., 2013b). Permission to use the tool was granted by the PDQ chief investigator (Hunter et al., 2013b).

Items within the PDQ requiring a reverse score were assigned a suitable inverse value. To create an absolute zero, scoring was adjusted from the original 1-7 scale to a new 0-6 scale. To provide a more accessible reporting range the personhood in dementia questionnaire total score was adjusted so it would report on a zero to 100 scale thereby representing a percentage of maximum score.

4.10.2 Perceived ability to care: visual analogue scale

How able the staff felt to care for residents who have dementia was measured using a visual analogue scale, which I designed and piloted with a group of five undergraduate nurses. The undergraduate nurses gave feedback on the language of

the question and presentation of the scale. The visual analogue scale asked the question 'how able do you feel to care for residents who have dementia?'. The question was designed to prompt staff to consider the two terms 'care' and 'ability'. Below this question, the participants were asked to mark a cross denoting their answer, on a plain line ten centimetres wide (appendix sixteen).

4.10.3 Staff demographic data

At the point of care home consent, and prior to any baseline measurements, a figure for staffing levels was obtained from the care home manager. Further information on staff gender, job role and overall months of experience was included within the baseline and follow-up questionnaires. The reason for loss to follow-up was given by the care home manager and recorded for all staff who had completed a baseline questionnaire but not follow-up.

4.11 Residential care home

At baseline only, the quality of the usual care environment was measured using the Therapeutic Environment Screening Survey for Residential Care (Sloane et al., 2002) (TESS-RC) (appendix seventeen) and was restricted to the parts of the questionnaire pertaining only to public areas of the care home. The CQC rating from the most recent inspection was also recorded to provide context during the analysis.

In the formative stages of this study discussions were held with researchers experienced in process evaluation. They raised the importance of measuring and describing the baseline quality of usual care provided by care homes. This advice concurred with literature surrounding process evaluation, which highlighted the benefit of measuring usual care to help evaluate any differences between trial arms once care homes have been randomised (Young et al., 2019). There are few measures which evaluate the quality of the care home environment in relation to dementia care (Calkins, 2018). When considering what is important when evaluating a care environment Calkins (2018) proposes that historically measurements have been too focused on resident safety, rather than resident freedom and environments which support the expression of individuality and purpose (Newman, 1989, Pastalan, 1993). Waller et al. (2017) created the 'environmental assessment tool' in conjunction with The Kings Fund. This tool qualitatively appraises a care environment and assigns

numerical scores to specific domains related to the care environment. The tool relates these domains to five aspects of dementia care that may improve wellbeing: familiarity, meaningful activity, orientation, legibility and wayfaring. Although the 'environmental assessment tool' (Waller et al., 2017) tool focused on aspects of the care environment which might reflect personhood or citizenship, it was anticipated that there would be insufficient time available on the days when this assessment would be needed to be completed. To ensure the observational data was of high quality and collected ethically, it was decided that reaffirming consent, or assent, with participants and ensuring all necessary resources were available would take precedence and there would be insufficient time to also complete such a detailed questionnaire. This assessment tool was therefore not used.

4.12 Measurements collected at baseline

After recruitment and gaining consent from participating care homes, residents and staff baseline assessments were undertaken. All the baseline measurements, DCM™, PDQ, VAS and TESS-RC were collected by me prior to randomisation in all six sites. In addition to these quantitative measurements, contextual information surrounding the study setting was obtained from the care home manager. This included an overview of the care home ownership, operating procedures, number of resident bedrooms and number of staff at that time.

4.13 Random allocation

Randomisation occurred in blocks of two. Once two sites were recruited and baseline measures complete, they were randomised on a 1:1 basis (PERSONABLE intervention: training as usual). The random allocation to PERSONABLE or control group was performed by a third party (AA) using site study codes. Participating care homes were randomly assigned using the 'ralloc' command in Stata version 12.

4.14 The PERSONABLE intervention: a reflective dementia workshop

The domains suggested within the TIDieR model (Hoffmann et al., 2014) have been used to formally describe the way in which the developed intervention (PERSONABLE) was conducted. The steps taken to develop PERSONABLE are fully reported in Chapter

two. Prior to beginning this feasibility study, four focused discussion groups of residential care staff and family carers of residents with dementia were conducted. Participants gave feedback on the proposed dementia workshop. Feedback was used to inform changes to the structure and content of the workshop, which was then piloted before embarking on phase two of the study.

4.14.1 The name of the intervention

The dementia workshop was named PERSONABLE to reflect both an understanding of the person (resident with dementia) and promoting their enablement; reflecting the essence of personhood and citizenship theory.

4.14.2 The purpose of the intervention

The PERSONABLE dementia workshop is a reflective training intervention, designed to improve the workforce understanding of the theories of personhood and citizenship in relation to the care of residents with dementia. PERSONABLE sought to help residential care home staff of any designation to reflect on their work with people who have dementia. It aimed to improve insight into how to understand residents living with dementia holistically as a person rather than reductively as a person with a condition. Furthermore, PERSONABLE was designed to help participants consider how they might consider the autonomy of a resident and promote a sense of community within the residential care environment.

4.14.3 Location of intervention and resources required for delivery

PERSONABLE required minimal physical resources other than simple worksheets illustrating the five exercises (appendix three). The worksheets helped the facilitator to visually guide participants through the PERSONABLE workshop. A private room within the residential care home was required in which to deliver PERSONABLE to staff.

4.14.4 The person facilitating the intervention and mode of delivery

The PERSONABLE dementia workshop was facilitated face-to-face by myself across all sites allocated to the intervention arm. PERSONABLE was designed to be brief and require minimal staff resources, so if it ultimately proved effective it could be easily replicated in other care homes. Although I am an experienced mental health nurse specialising in the care of people with dementia, my role within the intervention was to facilitate reflection and discussion rather than convey knowledge about dementia.

4.14.5 Intervention tailoring, duration and frequency

The PERSONABLE dementia workshop is a simple reflective intervention and was developed in phase one of this study. The consensus from staff involved in phase one was that in order to attract sufficient staff, PERSONABLE should last under an hour. It could then fit into the quiet period after staff handover when early and late shift staff would both be on shift in the home. Participants who worked at sites randomised to the intervention arm received the PERSONABLE intervention once per participant. The PERSONABLE intervention was offered on several dates at each site to ensure sufficient numbers of staff were exposed to the intervention. However, due to care home pressures, the care homes randomised to the PERSONABLE arm all requested to run PERSONABLE on only one date in each home.

4.14.6 Fidelity of the intervention

In phase one of this study, I had spent time standardising the PERSONABLE intervention content, so that it could be delivered true to design and consistently across all intervention sites. In particular, it was important that PERSONABLE could deliver its core themes, in a standardised manner, to care home staff diverse in age, experience and role (Campbell et al., 2000). The intervention was piloted before the trial and PERSONABLE was further developed, this time concentrating on a consistent style of facilitation. All training was delivered by me as I was independent of all the residential care homes. A uniform plan was followed describing how to deliver each exercise, which listed learning objectives and discussion prompts. I guided exploration within the workshop but did not offer my own opinions on the exercises, rather encouraging reflective discussion and gently prompting all group members to participate in the discussion.

4.14.7 Structure of intervention

The PERSONABLE dementia workshop consists of five consecutive elements, each lasting approximately twelve minutes, depending on discussion.

4.14.7.1 Exercise one 'from waking to work': choice and purpose

Staff were asked to pause and reflect on the choices they had made between waking up that morning and arriving at work. They were asked to write a few words along a line on a worksheet to remind them of the various choices they had made between waking and work. The objective of this reflective exercise was to help staff explore the

everyday choices they make, what these choices mean to them, how it might feel without these choices and how these everyday choices might be replicated for a person with dementia living in residential care.

4.14.7.2 Exercise two 'reflections on personhood': reflecting on staff personhood

An adapted version of the Kitwood (1993b) personhood model was used, which lists five domains comprising an assessment of the personhood of an individual. Staff were asked to list a few words in each of the five domains which best described them. This exercise was intended to steer participants to reflect on how they would like to be understood by someone who does not know them well. At the end of the exercise they were asked to rank the five personhood domains from one to five and record their answer in the small white circles. A score of one represented the domain which best described them and five the least reflective.

4.14.7.3 Exercise three 'reflections on personhood': reflecting on resident personhood

Using the same adapted Kitwood (1993b) personhood model as in exercise two, participants were asked to think of a person with dementia for whom they care and list a few words under each heading which best described the resident. The purpose of this part of the exercise was to exactly follow the reflection from exercise two but to now place staff in the shoes of the person with dementia. As with exercise two they were asked to rank the domains. They were asked to consider whether the way in which they ranked the importance of the five domains: how I learn, my personality, my health, my life history and how I socialise, differed from the way in which they ranked their own and, if so, why.

4.14.7.4 Exercise four 'from outside to inside': replicating community diversity

A reflective exercise to help participants consider the richness of the community they experience outside of the care home walls. Participants were asked to reflect on their last day off and write down a few words which described the diversity of the people, places and activities they saw. They were asked to consider how these experiences might be replicated within the residential care home for people with dementia.

4.14.7.5 Exercise five 'the pledge': reflection into action

Participants were asked to consider all they had explored in the previous four exercises and to pledge to change one thing about their work within the next thirty

days. The facilitator did not guide the participants, enabling them to formulate their own ideas for what might constitute a change to their work.

4.14.7.6 Potential benefit of the proposed intervention

The PERSONABLE dementia workshop is different to other workshops apparent in the existing research because (i) it was brief, lasting no longer than an hour, (ii) it invited all staff, working in any designation in the home to participate, and (iii) it encouraged staff to reflectively consider the personhood and citizenship of residents. The workshop exercises aimed to take participants through a reflective process ending in the commitment to change something about their work which reflected the principles of personhood and citizenship. The pledge was a crucial component designed to give the intervention the best chance of effecting a change to the personhood and citizenship of residents. A reflective approach was taken in response to initial stakeholder feedback. Additionally, adopting a reflective approach to training is supported by recent research (Zhang et al., 2017). Reflection has demonstrated a modest but positive effect on the wellbeing of care staff and staff retention (Garner et al., 2012, McCabe et al., 2007). Using a logical framework model (Haddon, 1972, Weeks et al., 2012) (Table 17) and drawing on the literature review and phase one of the study, it was hypothesised that positive changes in care staff work practice, might subsequently improve the wellbeing of residents with dementia (Beer et al., 2011a).

Table 17: Logical framework model charting the potential relationship between staff training and resident wellbeing (Haddon, 1972)

	Summary	Objectively verifiable indicators	Verification methods	Important assumption
Goal	To explore the feasibility and possible effect of PERSONABLE within the residential care home environment	To identify factors which might facilitate or hinder the smooth running of a definitive randomised controlled trial	To collect care home, staff and resident data at the point of baseline and follow-up measurement and intervention delivery	That participant flow throughout the trial will inform conclusions about the feasibility of a definitive trial
Purpose	To deliver PERSONABLE to residential care home staff which will prompt them to adapt their caring behaviour	That staff engage with the training and adapt their knowledge and attitudes towards personhood and citizenship	To collect data which explores the knowledge and attitudes of staff towards the theories of personhood and citizenship	That improvements in the knowledge and attitudes of staff will translate into improve resident wellbeing
Results	The improved wellbeing of residents who have dementia	The expression of resident wellbeing and behaviours reflective of personhood and citizenship will be enhanced	An observational measure which can collect data for residents who may find it difficult to verbalise their experience	That the chosen observational measure will capture changes to resident and staff behaviour
Activities	Deliver PERSONABLE to staff who support residents with dementia	Changes to the promotion of resident personhood and citizenship by staff	An observational measure which can capture changes to the approach of staff	Adapted staff behaviour after attending PERSONABLE will improve resident wellbeing

4.15 Training as usual

The control group received training as usual (TAU). The current provision of usual training delivered to staff was explored within the literature review and the phase one focused discussion groups. Discussion indicated that residential care homes usually provided: (i) mandatory training with very limited dementia specific content; (ii) occasional dementia specific training which is usually delivered to staff by others who have attended courses; and (iii) usually no dementia specific training for ancillary staff.

4.16 Follow-up outcome measurements

All follow-up measurements were assessed ten weeks post randomisation to give time for intervention delivery and a period for the staff to complete their pledges. All measurements taken at baseline, at the level of staff and residents, were repeated using the same collection procedure.

4.16.1 Primary outcome measure – Dementia Care Mapping™

The primary outcome measure was the mean of the wellbeing/ill-being (WIB) score for each resident participant. The WIB score is the mean of the aggregate wellbeing and ill-being score, which was recorded every five minutes, per four-hour DCM™ period. DCM™ was carried out at baseline prior to randomisation and again ten weeks after randomisation.

4.16.2 Secondary outcome measures

4.16.2.1 Residents

The secondary outcomes for residents were the mean score of the grouped BCCs and the mean of personal enhancing interactions for each resident.

4.16.2.2 Staff

The secondary outcomes for staff participants were the mean scores for the PDQ and VAS for each participant completing questionnaires.

4.16.3 Feasibility outcomes

The feasibility of undertaking a definitive trial was assessed by adapting the research questions listed at the end of the literature review. These were categorised into three domains:

4.16.3.1 Feasibility of participation

1. Measuring the response and non-response during recruitment, intervention participation and of outcome measures.
2. Measuring the number of, and reasons for, the attrition of residents.
3. Measuring the number of, and reasons for, the attrition of staff.

4.16.3.2 Feasibility of the intervention

4. Testing the acceptability of the PERSONABLE intervention in a residential care environment.
5. Exploring the potential effect, on staff, of the PERSONABLE intervention on the knowledge and application of personhood and citizenship theory.
6. Exploring the potential effect of the PERSONABLE intervention on the wellbeing of residents with dementia.

4.16.3.3 Feasibility of the measurements

7. An appraisal of DCM™ as an outcome measure.
8. The acceptability and usefulness of the outcome measures to participants.

4.16.4 Interrater agreement

Inter-rater agreement was assessed at follow-up. Together with a researcher (JF) independent of the study, I carried out DCM™ at two of the recruited care homes at follow-up, one in the intervention group and one in the control group. JF is experienced in the application of DCM™ and is involved in the training of DCM™ practitioners.

4.16.5 Trial sequence

The six participating care homes were randomised (1:1) in blocks of two (Table 18). This approach was to help practically manage the trial and avoid overlap between the various stages of the trial. Each block consisted of one training as usual and one intervention care home.

Table 18: Sequence of events in trial

Week	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Block one	Baseline measurement (DCM™, TESS-RC, PDQ, VAS)		Randomise	PERSONABLE delivered (intervention group) or training as usual (control group)		Time to implement PERSONABLE pledges. Intervention group only			Follow-up measurement (DCM™, PDQ, VAS)					
Block two			Baseline measurement (DCM™, TESS-RC, PDQ, PC VAS)		Randomise	PERSONABLE delivered (intervention group) or training as usual (control group)		Time to implement PERSONABLE pledges. Intervention group only			Follow-up measurement (DCM™, PDQ, VAS)			
Block three					Baseline measurement (DCM™, TESS-RC, PDQ, PC VAS)		Randomise	PERSONABLE delivered (intervention group) or training as usual (control group)		Time to implement PERSONABLE pledges. Intervention group only			Follow-up measurement (DCM™, PDQ, VAS)	

4.16.6 Participant withdrawal

Participant attrition was recorded as feasibility data to inform the viability of a definitive trial.

4.16.7 Sample size

This study tested the feasibility of a larger scale randomised controlled trial and therefore was not powered to determine superiority of the PERSONABLE intervention compared to training as usual.

Care home: target of six sites.

Staff: informed by the observations on recruitment from a similar study, which reported low engagement with their intervention (Beer et al., 2011a), this study aimed to recruit 60% of total staff members at each site. This proportion was judged to be sufficient to assess feasibility outcomes and give an indication of any effect on resident outcomes.

Residents: to allow for attrition due to being unwell or absent on the day of DCM™ up to twelve residents in each of the six recruited care homes were recruited. Between six and eight were actually selected for observation on the days of DCM™. Six to eight resident participants was thought to be manageable because DCM™ piloting (Figure 23) indicated that not all residents would be in view at the same time during the two four-hour observation periods. For the majority of baseline and follow-up observations I was the only person collecting DCM™ data. Therefore, which residents were chosen was based on who was most likely to spend their time in the communal areas of the care home. It was thought possible to recruit more residents in the larger of the participating care homes. Attempts were made to keep the overall baseline sample size in the intervention and control arms equal.

4.17 Piloting of Dementia Care Mapping™

4.17.1 Piloting stage one: acute general hospital

As a formative exercise I spent a day mapping on a ward in an acute general hospital, with a nurse (JW). JW is a DCM™ trainer and has been involved in the data collection for a large cluster randomised controlled trial, using DCM™ as the primary outcome measure (Griffiths et al., 2019). This exercise helped me revise my knowledge of DCM™ and identify pertinent factors which might be an issue when collecting DCM™ in phase two of the trial, notably; mapping in confined areas, coding unusual events such as bay curtains being drawn and interrater agreement when mapping with someone new.

4.17.2 Piloting stage two: care home

Following on from this formative exercise I undertook a period of mapping in a care home (setting two) which had hosted one of the phase one focused discussion groups. This care home was not used in phase two of the trial. Two hours of DCM™ piloting occurred in April 2017 between 09:50 and 11:50hrs. DCM™ was carried out by me independently. The primary and secondary outcomes for phase two of the study were quantitative, for this reason and to increase the capacity to include more residents I chose not to make extensive qualitative notes for each resident. Six care workers were on shift, plus two activity coordinators and one care manager. Based on this observation and previous experience of mapping in other environments it was decided to observe ten residents, a mixture of both male and female.

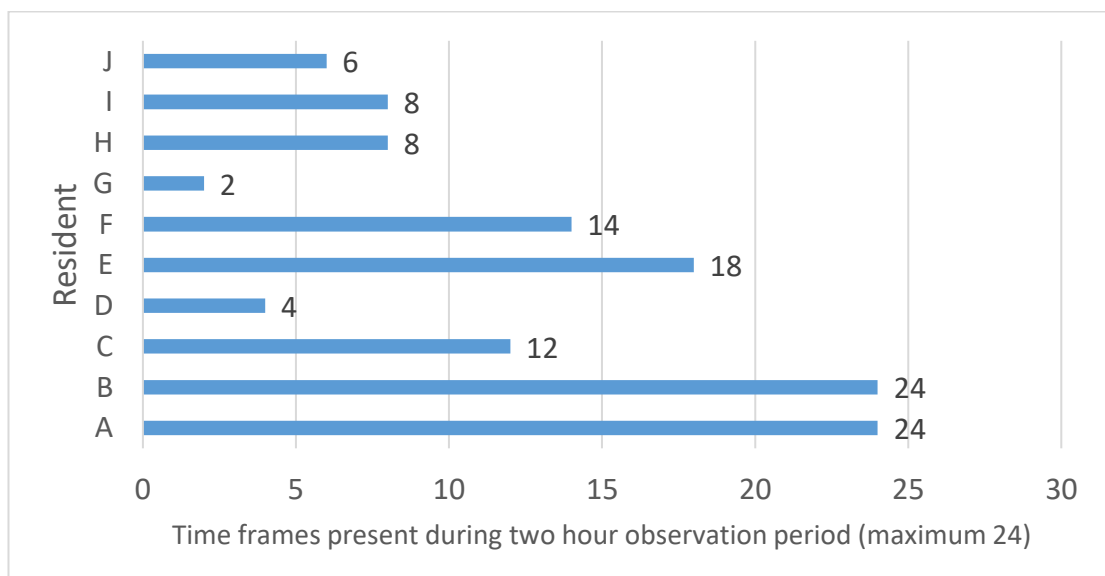


Figure 23: Resident flow during stage two DCM™ piloting exercise

4.17.3 Interpretation of DCM™ pilot

Only two residents spent the entire twenty-four time frames in clear view (Figure 23). Of the ten residents observed six were present for less than fifty percent of the possible twenty-four time frames, spending differing amounts of time either in the lounge area or walking in other areas of the home. At one point the activity coordinators took two residents to another area of the unit for an organised activity; at this point I made the decision to stay with the majority of observed residents to get an impression of whether this approach would give a broad overview of care.

All care homes vary in their size, architecture and levels of residents and staff, therefore this exercise could only descriptively inform resident sample size. I observed that DCM™ data collection quality was satisfactory when six or less residents were present during a time frame, noticing the accuracy of data reducing dramatically when more than eight residents were present during any given time frame. Reflecting on the DCM™ pilot, I concluded that a minimum of six participants and a maximum of eight residents would be suitable upper and lower targets for observation in phase two of the trial. These were conservative estimates because an excessive number of resident participants would affect data integrity should resident movement not be as free flowing as in the pilot. Another consideration highlighted by the pilot was the challenge of interrater agreement when two people map together for the first time. This challenge has been reflected in a study by Thornton et al. (2004) who observed interrater disagreement was more frequent than agreement when two observers had not previously mapped together. To explore this phenomenon I made the decision to employ a second researcher, with whom I had not previously mapped, aiming to conduct DCM™ observation with them in one control and one intervention home at follow-up.

4.18 Blinding

4.18.1 Blinding at baseline

At baseline residents were blinded to group allocation but not to DCM™ measurement. Staff were blinded to group allocation when completing PDQ and VAS. I was blinded to group allocation. By using staff participant codes and a third party to collect the questionnaires I was blinded to which staff completed questionnaires.

4.18.2 Blinding during randomisation

The third party (AA) undertaking randomisation was blind to care home identity at the point of allocation.

4.18.3 Blinding of PERSONABLE intervention

Due to the nature of the intervention, staff were not blind to their participation in the intervention and I was not blind to which staff attended the intervention. Attempts were made to keep JF, the second dementia care mapper, unaware of care home allocation. However, during one visit she was made aware by comments made by the care manager. When completing DCM™ in the intervention home JF was blind to which specific staff had attended PERSONABLE.

4.18.4 Blinding at follow-up

At follow-up residents were not blind to group allocation or DCM™ measurement. Staff were not blinded to group allocation. I was not blinded to group allocation. By using staff participant codes and a third party to collect the questionnaires I was unaware as to which staff completed follow-up questionnaires. At follow-up the second rater (JF) was not blind to trial arm allocation.

4.19 Data management

Questionnaire, DCM™ and TESS-RC data was inputted into Excel spreadsheets and then imported to the Statistical Package for the Social Sciences (SPSS version 25). Data entry was checked twice for each participant. All participants were allocated a code, which was used to link baseline and follow-up study data. Personal identifying details on consent forms were stored separately from observation and questionnaire data. All paper copies of participant data were stored securely in a locked cupboard in a designated office with a key code door.

4.20 Analysis

As the study is not a definitive randomised controlled trial the aim of the analysis was not to determine evidence of effect but to descriptively represent potential changes within confidence intervals. Prior to all analysis all data was formatted within SPSS (version 25). Given the complexity of the files this was an extremely lengthy process, especially for the DCM™ data. An abridged version of the SPSS syntax is presented in appendix nineteen. Baseline characteristics including TESS-RC, resident and staff variables are described in the results chapter for each trial arm using descriptive statistics. For all staff and resident outcomes hierarchical mixed effects linear regression models were performed. Clusters were used as the unit of analysis. Using the care home cluster as the unit of analysis helped to account for any variability of individual staff and resident participants (Gold et al., 2019). Within the mixed effects model the inference of treatment effect was dependent on the outcome at baseline. To account for the effect of random variables, fixed effects were added to the models. Initially, all resident and staff outcomes were adjusted for baseline. Following this analysis additional fixed effects were added to the model to further explore predictive relationships in the context of the confidence intervals. Analysis used 95% confidence interval.

4.20.1 Primary outcome

4.20.1.1 *Dementia Care Mapping™: mean of the well/ill-being score (WIB)*

A mixed effects linear regression model was used to report change between baseline and follow-up mean WIB score. In this model the fixed effects were the allocation (arm), baseline WIB and resident gender. The random effect was the unit of care home.

4.20.2 Secondary outcome analysis

4.20.2.1 *Resident DCM™: personal enhancers (PEs)*

Very brief field notes were made for each interaction occurring between residents and staff. These notes informed the allocation of an interaction as either enhancing or detracting. The field notes have provided context to the quantitative data.

4.20.2.2 *Resident DCM™: grouped behaviour category codes (GBCC)*

A mixed effects linear regression model was used to report change between baseline and follow-up mean for the grouped behaviour category codes. Using the assigned

values for BCC grouping (3 high potential, 2 medium potential, 1 low potential and 0 no potential), data was treated as ordinal. In this model the fixed effects were the allocation (arm), baseline grouped behaviour category codes and resident gender. The random effect was the unit of care home.

4.20.2.3 Interrater agreement and the DCM™ concordance coefficient

Interrater reliability testing is recommended to help those conducting DCM™ to evaluate how much comparable data is being produced (University of Bradford, 2010). Usually it would occur prior to formal DCM™ investigation and can help minimise observational practices which do not reflect the operational rules set out within the DCM™ manual (University of Bradford, 2010). Once observation is complete data can be examined for agreement within each time frame for each participant. This process is undertaken for Behaviour Category Codes and Mood and Engagement scores separately and then combined (University of Bradford, 2010). A concordance coefficient is calculated by dividing the actual agreement score by the maximum possible agreement score and then multiplying by one hundred. It is suggested that each pair of mappers should achieve 70% concordance to map for evaluation purposes and 80% concordance to map for research purposes (University of Bradford, 2010).

4.20.2.4 Residential care home staff: personhood in dementia questionnaire (PDQ)

A mixed effects linear regression model was used to report change between baseline and follow-up mean PDQ score. To aid reader clarity and include an absolute zero, the scale of the data obtained using the questionnaire was adjusted from a 20-140 to a 0-100 scale. In this model the fixed effects were the allocation (arm), staff gender, months experience and job role. The random effect was the unit of care home.

4.20.2.5 Residential care home staff: visual analogue scale (VAS)

A mixed effects linear regression model was used to report change between baseline and follow-up mean VAS score. All data was recorded, reported and analysed on a 0-100 scale. In this model the fixed effects were the allocation (arm), staff gender, months experience and job role. The random effect was the unit of care home.

4.20.2.6 PERSONABLE intervention: data from exercises two and three

All staff attending PERSONABLE provided ratings of the Kitwood (1993b) Domains within exercises two and three. Rating the five domains from one to five, one

representing the domain most reflective of their personhood and five the least reflective domain. To explore differences between these two sets of ordinal data from the same sample of staff the Wilcoxon signed rank test was used.

4.20.2.7 Clustering

Clustering was assessed by estimates of the intraclass correlation coefficient, the proportion of total variance accounted for by the between variance. This was estimated for each mixed model. If this could not be estimated due to problems with model convergence, covariates were removed to reduce the risk of overfitting. If the intraclass correlation coefficient could still not be estimated then clustering was presented graphically.

4.21 Ethical considerations

4.21.1 Residents

During recruitment all residents were presumed to have the capacity to consent to the study (Department of Health, 2005). This meant that residents were approached and autonomously consulted about the study before approaching staff or family members. My approach was sympathetic to the possibility that some residents may have lacked the capacity to consent to participation.

The method of data collection meant observing residents in their home environment. From the perspective of the resident this approach to data collection had the potential to feel invasive. Assent of the residents was taken on the days of observation and checked regularly to minimise any possible distress as a result of my presence. Additionally, should residents have become very distressed it was written into the study protocol that resident observation would immediately cease and staff informed.

4.21.2 Staff

The consent process sought to ensure that staff did not feel obliged to take part in the study. I attempted to maintain a balance between being proactive in my attempts to include staff and giving them autonomy in their decision to participate. Visiting the participating homes prior to commencement of the study helped to familiarise staff with the study. This helped to give them sufficient time to make an informed decision surrounding participation. Once the study had begun any staff members who no

longer wanted to participate were able to withdraw their consent with no impact on their working practice.

4.21.3 Care homes

A proactive approach to care home recruitment was taken. To ensure care homes had the capacity and resources to meet the demands of the study I spent time speaking with managers and owners to fully inform them of the commitment required for participation. This helped to ensure that participating care homes would be prepared should they experience external pressures during the study, such as inspections or staff changes.

4.21.4 Ethical agreement

Prior to commencing phase two, approval was sought and granted by the National Social Care Ethics Committee: REC reference 17/IEC08/0008 (appendix eighteen).

Chapter five: Results

5.1 Introduction

This chapter presents the results of the second phase of the study. It begins by reporting the participation of care homes, residents and staff. The chapter continues with a description of the study settings. Baseline measurements are explored and any differences between trial arms identified. To explore the feasibility outcomes surrounding the acceptability of the intervention, this chapter reports the engagement of staff with the PERSONABLE intervention. The follow-up measurements are discussed for each measurement at the level of care home, residents and staff. The formatting and analysis of data required the creation of a significant amount of syntax within SPSS (version 25). An abridged version of this syntax is presented in appendix nineteen.

5.2 Trial participation

5.2.1 Care home

All six sites were recruited with the agreement of managers and owners between the 4th of May 2017 and the 20th of June 2017. A table of the characteristics of approached care homes is reported in Table 19. Response during recruitment was encouraging, which made it possible to purposefully target care homes with varied characteristics: urban and rural, privately or corporate owned and sites of varying size. Twenty-seven care homes were approached for inclusion in the study. There was no response from fifteen care homes. Seven care homes on the ENRICH 'research ready' database were approached. Five of these homes were recruited to the study and one care home on the ENRICH database was approached but did not respond. Only one care home that was recruited did not appear on the ENRICH database of 'research ready' care homes. One care home declined to take part because they were already participating in another study. Another care home expressed interest but then declined because data collection would have coincided with a CQC inspection. Two care homes were not recruited to the study because they had similar characteristics to the homes which had already been recruited. One care home expressed interest just after the final care home had been recruited to the study. Baseline and follow-up measurements were all successfully assessed on the dates agreed with the participating care homes.

5.2.1.1 Care home recruitment

Table 19: Characteristics of approached residential care homes

		Care homes approached n=27	Care homes recruited n=6
Number of bedrooms	Median (IQR ¹)	32 (21.0 - 43.0)	18.5 (14.3 - 36.5)
CQC rating	Outstanding (n)	3	0
	Good (n)	21	5
	Requires improvement (n)	3	1
	Special measures (n)	0	0
Setting	Rural (n)	12	4
	Town (n)	8	0
	City (n)	2	0
	Coastal town (n)	5	2
ENRICH active ²	Yes	7	5
	No	20	1

¹Interquartile range

²Care homes active within the ENRICH database of research ready care homes

5.2.2 Staff

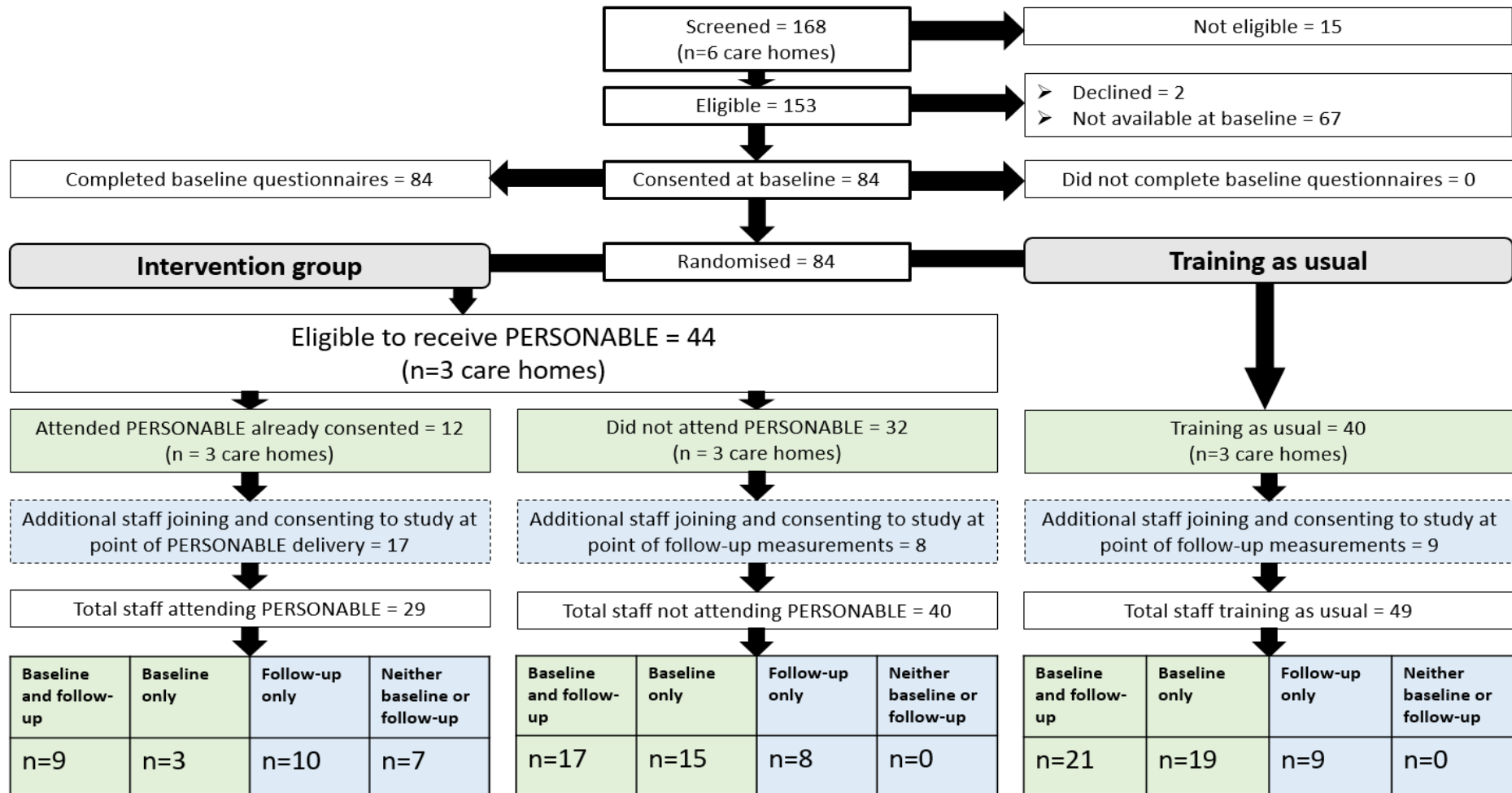
Care home staff were recruited between the 14th of June 2017 and the 30th of October 2017. The flow of staff is illustrated in Figure 24.

Of the 168 staff screened for eligibility in the study, 154 met the eligibility criteria set out in the protocol. Only two staff declined to take part. 68 staff were not available at baseline because of a staggered shift pattern, holiday or sickness. At baseline 84 staff consented to participation in the study and completed baseline measurements prior to randomisation.

In the PERSONABLE arm (n=44 at baseline) a further 17 staff joined the study after randomisation to participate in PERSONABLE. During follow-up measurements eight staff joined the study but had not attended PERSONABLE. In care home three (PERSONABLE arm) the general manager left employment before baseline measurements and the deputy manager left employment between baseline and follow-up measurements.

In the TAU arm (n=40 at baseline) a further nine staff joined the study at follow-up. In care home four (TAU arm) the deputy manager left employment shortly after baseline measurements were completed. In care home six (TAU arm) the general manager was in the process of leaving employment during follow-up measurements.

Figure 24: Flow of staff through the feasibility trial



*Green and blue shading highlights which completed measures relate to each stage of the trial

5.2.2.1 Measurement compliance

A total of 118 staff participated in the study. Of staff working in those homes allocated to the PERSONABLE intervention, 69 staff participated compared to 49 staff in the TAU arm. Information on measurement compliance is diagrammatically represented in Figure 24 and further summarised in Table 20. Staff who completed both baseline and follow-up questionnaires varied slightly between arms, PERSONABLE (n=26) and TAU (n=21). There was larger variation, between trial arms, of staff that completed follow-up questionnaires when they had not completed baseline questionnaires, PERSONABLE (n=18) and TAU (n=9). A small proportion of participants (n=7) did not complete either baseline or follow-up measurements, these were all staff that had attended PERSONABLE.

Table 20: Measurements (PDQ and VAS) completed by staff within each trial arm

Measurements completed	PERSONABLE n (%)	Training as usual n (%)
Baseline only	18 (23.0)	19 (25.3)
Follow-up only	18 (23.0)	9 (12.0)
Both	26 (33.3)	21 (28.0)
Neither	7 (9.00)	0
Total	69	49

5.2.2.2 PERSONABLE attendance

PERSONABLE was delivered successfully at the three sites randomly allocated to receive the intervention (Table 21). All care homes requested that PERSONABLE be delivered during the staff handover period just after lunch. Because of organisational pressures, none of the intervention care homes wanted to facilitate more than one session of PERSONABLE. Of the 69 staff recruited to participate in the trial, and randomised to the intervention arm, 29 attended PERSONABLE. Across the three intervention sites, care workers (n=20) were predominant in attendance. However, in care home three there was greater ancillary staff (n=7) attendance with PERSONABLE than care workers (n=4). Only two participating staff from the 'other' job group attended PERSONABLE, both were from care home three. This was a wait list trial and the care homes randomised to the TAU arm were offered PERSONABLE once all follow-up data had been collected. However, despite PERSONABLE being offered at this point and the initial interest of the individual managers, all three TAU care homes did not further pursue my verbal and written offers.

Table 21: Attendance at PERSONABLE by staff role (intervention arm)

	Attended PERSONABLE ¹ n (% ²)	Not attending PERSONABLE ¹ n (% ²)
CH2		
Care workers	7 (24.1)	8 (20.0)
Ancillary	0	2 (5.00)
Other	0	0
CH3		
Care workers	4 (13.8)	15 (37.5)
Ancillary staff	7 (24.1)	2 (5.00)
Other	2 (6.90)	2 (5.00)
CH5		
Care workers	9 (31.0)	9 (22.5)
Ancillary staff	0	0
Other	0	2 (5.00)
Total	29	40

¹Number of participating staff attending or not attending PERSONABLE

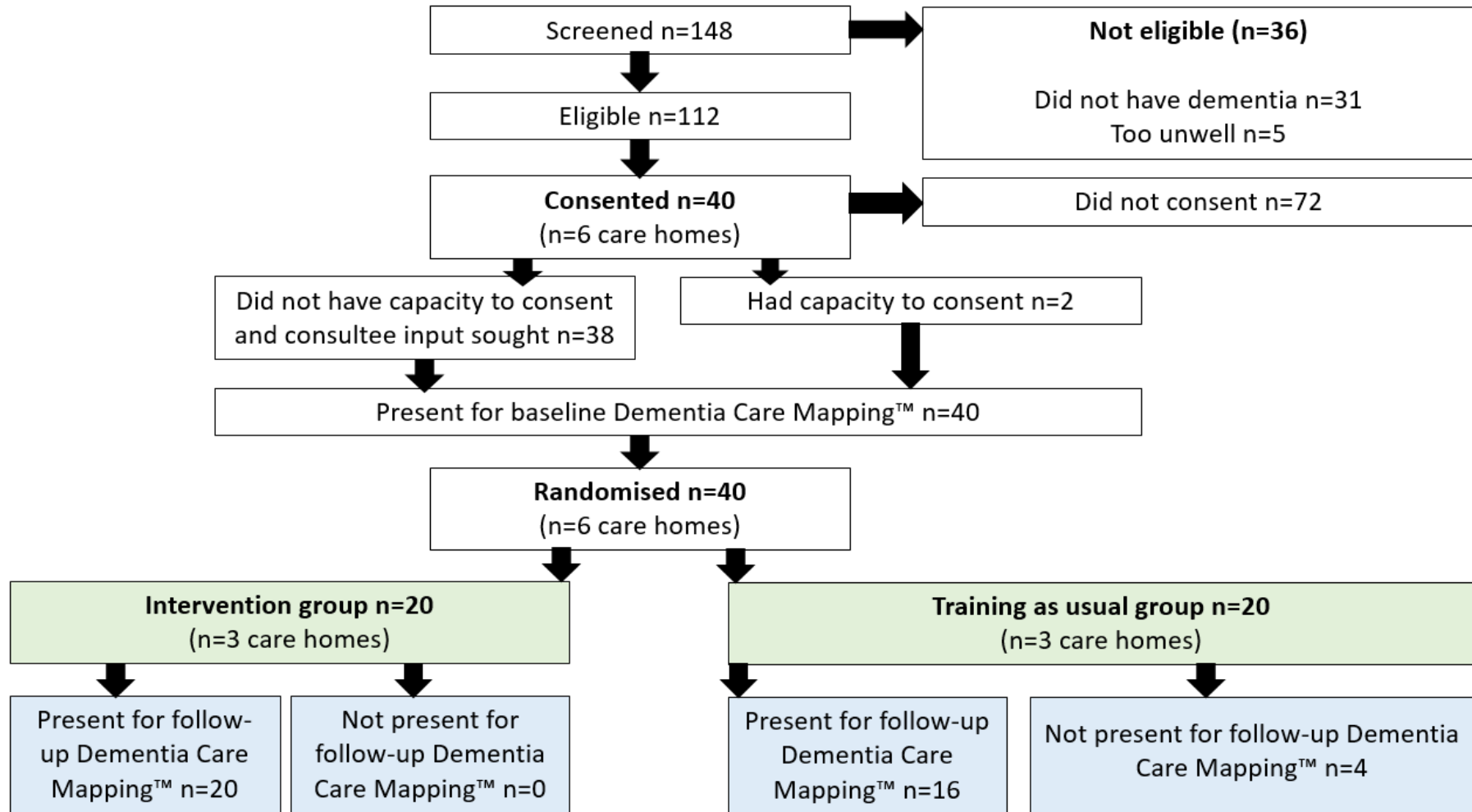
²Percentage of participating staff attending or not attending PERSONABLE

5.2.3 Residents

Residents were recruited between the 1st of June 2017 and the 27th of July 2017 (Figure 25). Only two residents were assessed as having the capacity to consent to participation in the study. The other residents (n=38) were recruited following the consultee process previously described in the methods chapter. In the TAU arm there was one missing case. This was a gentleman who was consented to the study but excluded before baseline measurements commenced because of an uncertainty surrounding his dementia diagnosis.

Before being approached for inclusion in the study the suitability of potential participants was discussed with the care home manager. In discussion with the care home manager, those residents with a higher level of care need, who might be less able to verbally express themselves were targeted for recruitment. Baseline measurements were collected for all participating residents.

Figure 25: Resident flow through feasibility trial



5.3 Study settings

The descriptions of the care home settings are based on field notes made on the days of observation. An account of the social atmosphere at baseline is presented below, the social atmosphere at follow-up is presented later in this chapter.

Wuest et al. (2015) highlight the contextual importance of describing the settings in which feasibility studies are carried out. With this in mind, the participating residential care homes are described using an adapted version of the Stokes and Goudie (1990) model. The Stokes and Goudie (1990) model is pertinent because it helped to frame resident behaviour in the context of the physical environment, the social environment and staff communication.

5.3.1 Care home one

5.3.1.1 *The physical environment of the care home*

The first site was a small privately owned care home (n=21 bedrooms) located on a busy road in a large seaside town, providing support to people with and without dementia. The home scored 'good' across all five domains in their most recent CQC report. The home is a single storey modern building. At the front of the building there is a courtyard used for car parking. A small alleyway leads to the front door of the care home. To the left of the entrance there is a large communal lounge with arm chairs placed all around the walls. The lounge has extensive windows overlooking the car park and main road. The lounge is carpeted, pictures of landscapes hang on the walls and there is a television in one corner of the room. To the right of the entrance to the home is an 'L' shaped dining room with seating for approximately thirty people. The dining room has an adjoining kitchen, in which resident meals are prepared. Directly opposite the dining room are two small rooms, a clinic and office space for care workers and another smaller office for the two managers. Leading from the entrance area are narrow and dimly lit corridors. The bedrooms of the residents are located along the main corridor, which winds around the perimeter of a central courtyard garden. Each bedroom has a single bed, a small toilet, a sink area and patio doors which open onto the central courtyard garden.

5.3.1.2 *The social environment of the care home during baseline observation*

Baseline observation occurred on the 14th of June 2017 between 1000 and 1400hrs, on a warm and sunny day. The care home employed a total of 28 staff. All staff were

female, as were both managers. The care home staff were a mixture of managerial, care and ancillary workers. At baseline, there were two managers, four care workers, one ancillary staff and two volunteers present during the observation period. All care staff wore purple uniforms. Observation took place predominantly in the patio garden. I positioned myself in the corner of the patio area, giving me a clear view of all participating residents whilst they were in the garden. For the first hour of observation two entertainers sung to the residents. At lunchtime fish and chips were delivered to the care home and all residents ate in the garden. Residents did not use the lounge area during the observation period and therefore the television was turned off. The two managers left their office periodically to speak with residents in the garden. After lunch, three of the participating residents retired to their bedrooms, the others remained in the patio area.

At baseline, the communication that occurred between the staff and the residents was mostly performed in a neutral manner, mainly surrounding care tasks. There were very few examples of interactions where staff demonstrated a higher level of aptitude reflecting a personhood or citizenship approach. Staff spent more time communicating with the less impaired residents and were observed to have difficulty when attempting to communicate with the more severely cognitively impaired residents.

5.3.2 Care home two

5.3.2.1 *The physical environment of the care home*

The second site was a small and privately owned care home (n=15 bedrooms) situated on a village green in a rural village, providing support to people with and without dementia. The home scored 'good' across four domains and 'outstanding' for leadership in their most recent CQC report. The building is a Victorian conversion set over two levels. At the entrance of the home there is a small patio area with potted flowers. The home has a small lobby area at the foot of some stairs. To the left of the lobby area is a lounge with large bay windows and five armchairs. The lounge displays many photos of the residents, there are two tall stacked book shelves and a wall mounted television located over an open fireplace. To the right of the entrance is another lounge with bay windows, eight arm chairs and some wall mounted pictures of nature. A small corridor leads from this lounge to a toilet and then another corridor

leads to another very small lounge area, where there is a fish tank and two budgies in a cage. This lounge is linked to another corridor leading to a resident bedroom. On the ground floor, and straight on from the main entrance along a narrow corridor are four more resident bedrooms. The dining room is at the end of this corridor and has seating for approximately twenty people. The dining room has four tables, a door to the kitchen and patio doors opening onto a small courtyard garden. On the second floor are the rest of the resident bedrooms, a clinic room and two very small offices, one for the owner and another for the care home manager. All bedrooms have large windows, some overlooked the village green and some a hardware store at the rear of the care home.

5.3.2.2 The social environment of the care home during baseline observation

Baseline observation took place on the 15th of June 2017 between 1015 and 1415hrs, on a warm sunny day. The care home employed 22 members of staff. All care staff were female. The home had a female manager and a male owner. There were 19 staff employed as care workers. Three staff members worked in a dual role of care worker and chef. The home employed a cleaner who visited daily. All care staff wore a purple uniform. At baseline, there was one owner, one manager, three care workers, one ancillary staff and one volunteer present during the observation period. The residents with dementia sat in the larger lounge, a lone male resident without dementia sat in the other smaller lounge. For the majority of the observation period I positioned myself in the dining room, where I had the best chance of remaining inconspicuous. This was also the area with the most resident activity. There were no loud alarms, only the occasional ring of the front door bell. One gentleman left the home during baseline observation to go for a walk in the village, using his walking frame. Later that day the owner took the same gentleman swimming at a local pool. Before lunch one care worker led an activity making lemonade, she encouraged all residents to join in regardless of their cognitive or physical abilities. At meal times staff ate with residents at the dining tables. Lunch was served in a dedicated dining room. After lunch a volunteer visited for one hour and spent time talking to residents. The female manager was often observed to be involved directly in resident care. The home had a free roaming cat, a fish tank and some budgies in a cage, no residents used the small lounge during the baseline observation period.

At baseline, many staff demonstrated a higher level of communication which reflected a personhood and citizenship approach to care. There were numerous examples of the verbal validation of residents by staff and their use of communication intended to promote a feeling of belonging, humour, fun, warmth and recognition. With the more severely cognitively impaired residents staff remained inclusive and frequently used non-verbal communication when interacting with these residents.

5.3.3 Care home three

5.3.3.1 *The physical environment of the care home*

The third site was a large national corporate owned care home (n=53 bedrooms) located in the countryside near a small village, providing support exclusively to people with dementia. The home scored 'good' across all five domains in their most recent CQC report. The home is a very large Victorian building set over two floors. Access to the home is via a long driveway, which divides the fenced gardens. The entrance of the home has ornate pillars framing a heavy double door opening onto a tiled lobby area, with seating for residents and visitors. The management and administration offices are either side of the front entrance. Through the entrance there is a large central atrium with two sofas. The atrium leads into the two separate areas for high and low dependency care. The two areas are separated by a windowed door which can be accessed with a key code. Despite the physical separation, staff can move between the two areas, as can some residents for meal times. Turning left from the central atrium there is a corridor leading to the back of the home from which there is access to laundry and staff rooms. At the end of the corridor and through the key coded door is an open plan dining area with seating for approximately sixty people. Most residents from the high and low dependency units spend their time in this area. The dining area has a small kitchenette in the corner and five dining tables. Towards the back of the dining room there is a large seating area, a wall mounted television and sliding patio doors leading to a patio garden. The second floor of the care home comprises entirely of resident bedrooms, connected by a series of corridors.

5.3.3.2 *The social environment of the care home during baseline observation*

Baseline observation occurred on the 6th of July 2017 between 1000 and 1400hrs, on a warm sunny day. The care home employed a mixture of male and female staff (n=43). There was a general manager and deputy manager, both female. Staff worked

in a combination of care work, ancillary, administration and maintenance job roles. The care staff wore casual clothing. At baseline, there was one manager, nine care workers, four ancillary and one member of administration staff present during the observation period. I positioned myself in the large open plan lounge and dining area, where the majority of participating residents were located. The door to the courtyard garden was open but not used by the residents. There were frequent, prolonged and loud alarms to alert staff when residents would need assistance. The television was on at a high volume. When not involved in resident care, the staff congregated around a kitchenette unit and completed paperwork, they also spent long periods looking at provided mobile phones to track care tasks on specifically designed software. Meals arrived on a trolley and were dispensed from the kitchenette to residents who were seated at dining tables or in arm chairs. No organised or impromptu activities were observed to take place and the managers did not enter the observation area.

At baseline, none of the interactions reflected a personhood or citizenship approach. Care workers seemed preoccupied with completing care tasks and then logging these tasks on a software application on the provided mobile phones. Care workers seemed to have difficulty communicating with the residents who were more severely cognitively impaired. Staff tended to congregate away from the residents at the kitchenette area, where they mostly discussed the distribution of care tasks.

5.3.4 Care home four

5.3.4.1 *The physical environment of the care home*

The fourth site was a medium size national corporate owned care home (n=31 bedrooms) located in a rural village. The home provides support exclusively to people with dementia. The home scored 'good' across all five domains in their most recent CQC report. The building is partly Victorian and partly modern. It is set in large grounds surrounded by fields and trees. The entrance opens onto a small waiting area linked to an office for the management and administration staff. Through a key code activated door the waiting area leads into a wide hallway. The hallway is a complete circle connecting the two care areas of the home. The first area providing accommodation for residents with mild dementia and the second area for people with more complex needs associated with their dementia. These two areas are connected by another key code activated door. Despite this physical divide the two areas are not

autonomous, with staff working between either care area on any given shift. Following the corridor clockwise in the first care area the only communal room is a medium sized lounge and dining area with seating for approximately twenty people. The room has a television mounted on one wall and some pictures of landscapes and animals hanging on the walls. The lounge has patio doors giving access to an enclosed courtyard about the size of a tennis court and surrounded by the inner walls of the care home. From the lounge area the corridor circles to the second care area and along this corridor are more resident bedrooms. The lounge of the second care area has seating for approximately twenty people and patio doors opening onto the courtyard garden. Unlike the first area, this one has a separate dining room and a small corridor which leads to the rest of the resident bedrooms towards the back of the care home.

5.3.4.2 The social environment of the care home during baseline observation

Baseline observation occurred on the 13th of July 2017 between 1025 and 1425hrs, on a sunny and hot day. Observation occurred in the lounge of the first care area for residents with more complex care needs. The care home employed a mixture of male and female staff (n=34). There was a general manager and a deputy manager, both female. Staff worked in a combination of care work, ancillary and activity coordinator job roles. Care staff wore casual clothing. At baseline, there was one manager, three care workers, two ancillary and one administration staff present during the observation period. I positioned myself in the lounge area, which had a good view of the majority of participating residents throughout the four-hour period. Some participating residents were observed to be using the patio garden for walking or just sitting in the sun. Throughout baseline observation the television was on at high volume. At lunchtime food was served from a hot food trolley. For meals, the small dining area was used by a few residents, the rest of the residents remained seated in armchairs. The lunch period was very hectic, noisy and two members of staff had a heated discussion in front of the residents about the care routine. To monitor care tasks the staff used an application on provided mobile phones. This meant they spent long periods of time checking and entering data into these devices. During the baseline observation period there were no organised activities. Towards the end of the observation period some music was playing on the television and one resident, who was a participant in the study, was given a musical rattle. The management staff

were not seen in the observation area during baseline measurement. At baseline, the staff made frequent attempts to communicate with residents, most of which occurred during interactions with food or drinks.

5.3.5 Care home five

5.3.5.1 *The physical environment of the care home*

The fifth site was a very large regional corporate owned care home (n=89 bedrooms) located in a small town in a coastal setting. Owned by a regional corporation of care homes and providing support exclusively to people with dementia. The home was rated as 'good' across all five domains in their most recent CQC report. Accommodation for residents is split into six separate autonomous areas, each with their own staff team and space for approximately twelve residents. The glass-fronted main entrance to the building overlooks the car park and a neighbouring housing estate. Once inside there is an expansive central atrium, with a small seating area, vending machines, an administration office and a staircase leading to a hair salon and more offices on the second floor. All care areas are of similar design and wrap around the huge courtyard garden. The courtyard backs onto a primary school, separated by a tall fence. The area where the study was conducted is set over one floor and has twelve resident bedrooms. The front of this care area has a key pad activated door, which opens onto a horse shoe shaped central corridor wrapping around a central block comprising of two toilets, a small lounge, a staff office and a laundry room. On the other side of the corridor is an entrance to the main lounge. The lounge has six arm chairs and two sofas arranged around a wall mounted television. Large patio doors connect the lounge to the rear courtyard. At the end of the corridor is a dining room, which has seating for approximately twenty people and a small kitchenette area.

5.3.5.2 *The social environment of the care home during baseline observation*

Baseline observation occurred on the 26th of July 2017 between 0945 and 1345hrs, on a sunny day. Observation occurred in the main lounge area, the room was bright due to the large patio windows. The care home employed a mixture of male and female staff to work on this unit (n=13). The home had a general manager and deputy manager, both female. Each of the six units had a supervisor who would oversee the operation of several units and staff team. Two activity coordinators were employed to

provide support across all six units. All care staff wore blue uniforms. At baseline, there were two care workers and two ancillary staff members present during the observation period. I positioned myself just outside the lounge area and had good visibility because of the open plan design, at lunchtime I sat with the residents in the separate dining room. During baseline observations the television was on at a low volume. Although it was a sunny day the doors to the patio garden remained closed and residents did not request access. Towards the end of the morning shift the staff wrote their notes in the lounge area with the residents. More able residents were encouraged to get their own drinks from the kitchen. Neither the care home manager nor deputy manager visited the unit during baseline observations.

At baseline, there were frequent examples of personal enhancing interactions. Frequently these enhancing interactions surrounded belonging and empowerment. Staff communicated proactively with residents and spent all their time in the large communal lounge with the residents. The staff had a very informal approach to their care and would often use humour to engage the residents, the humour suggested an individualised understanding of the residents with whom they were communicating. The staff were observed to make attempts to communicate with residents who were more severely cognitively impaired.

5.3.6 Care home six

5.3.6.1 *The physical environment of the care home*

The sixth site was a small privately owned care home (n=14 bedrooms), located in a rural village. The care home provides care exclusively to people with dementia. The care home was rated as 'requires improvement' in four domains, and 'good' for the care domain in their most recent CQC report. The building is Victorian and set over two floors. In front of the entrance there is an oval car parking area. Two white pillars frame the green front door. Once inside there is a small lobby area, with stairs leading up to the second floor. To the left of the entrance is a lounge with armchair seating for approximately ten people. This lounge has a floor standing television and some pictures of wildlife on the walls. There is one small window and patio doors which lead into a garden area. To the right of the entrance is a second similar sized lounge, this lounge also has a small window and patio doors leading to the second garden. A narrow corridor leads from the entrance to the back of the care home, from which

stem two small offices, one for the management and owner and another for the care workers. Towards the end of the corridor there is a toilet with a thin sliding door and three resident bedrooms. Opposite the toilet is the main dining room which has three tables and seating for approximately twelve people. The small kitchen is attached to the dining room and some patio doors open onto a rear garden. Upstairs, joined by a narrow corridor, are the rest of the resident bedrooms.

5.3.6.2 The social environment of the care home during baseline observation

Baseline measurement occurred on the 27th of July 2017 between 1000 and 1400hrs, on a warm but overcast day. The care home employed a mixture of male and female staff (n=13). The home employed one female care manager. The owners were a married couple. The home employed 10 care workers, a chef, a maintenance person and a cleaner. All care staff wore purple uniforms. At baseline, there were two owners, one manager, two care workers, two ancillary staff and one maintenance person present during the observation period. The current owners had recently bought the Victorian care home, which was still undergoing renovation after being closed for a period of months. The renovation of the interior of the care home was mostly complete, however, the garden and conservatory were full of DIY debris and therefore not accessible to residents. For observation I alternated between the two small lounge areas and the separate dining room. I moved between these three areas depending on where most residents were situated. Most residents spent their time in the lounge situated to the left of the entrance, which had a television on throughout the observation period. The second lounge area was darker and had a cage containing two budgies. There were no organised activities. The care manager spent most of her time in the management office. A maintenance man employed by the care home spent much of his time speaking with residents and helped one resident with their lunch. At baseline the male owner spent a small amount of time speaking with residents and joined them for lunch in the dining room.

At baseline, the majority of interactions surrounded care tasks such as providing drinks or food to the residents. These were performed in a mostly unexceptional manner. Staff seemed to have difficulty communicating with residents when they exhibited distress and spent more time with residents who had a naturally relaxed disposition.

5.3.7 Care home staffing levels during baseline and follow-up DCM™ observations

The observations were carried out at a similar time of day across all study sites. However, there was some variation in staff shift patterns which may have affected staffing levels when conducting the observations. The majority of care homes used an early, afternoon and night time shift pattern. Overall, the PERSONABLE arm had a greater total number of staff on shift, during baseline and follow-up measurements, when compared to the TAU arm (Table 22). A difference possibly proportional to the larger number of residents residing in the care homes randomised to the PERSONABLE arm.

With the exception of care workers the other staff groups were balanced between trial arms. The total amount of care workers present during observation differed between trial arms. The PERSONABLE arm having 14 at baseline, and 15 at follow-up. This was compared to the TAU arm which had nine at baseline and 11 at follow-up.

Table 22: Total number of staff on shift within each trial arm, during DCM™ observation period

	PERSONABLE		Training as usual	
	Baseline	Follow-up	Baseline	Follow-up
Owners	1	1	2	2
Management	2	3	4	4
Care workers	14	15	9	11
Ancillary staff	7	7	5	5
Other	1	1	2	2
Volunteers	1	0	2	0
Total	26	27	24	24

5.4 Groups at baseline

Baseline data was collected on three levels; care home, resident and staff (Table 24).

5.4.1 Care home

The TESS-RC was the standardised measure used to assess care home quality at baseline. A breakdown of the TESS-RC domain scores is presented in (Table 23). The mean number of care home bedrooms was slightly higher in the PERSONABLE arm (26.0) compared to the TAU arm (22.7). The aggregate TESS-RC score was somewhat higher in the PERSONABLE arm (49.3) compared to the TAU arm (38.7) (potential range of 1-73). Care homes in the PERSONABLE trial arm scored higher in seven of the TESS-RC questionnaire domains: maintenance, cleanliness, safety, lighting, personalisation, noise and outdoor areas. Scores for the PERSONABLE and TAU trial arms were equivalent in three domains: dementia specific design, odours and toilet access. In two domains the TAU arm scored higher than the PERSONABLE arm: plants and appearance of residents.

Table 23: Components of the Therapeutic Environment Screening Survey for Residential Care (TESS-RC)

TESS-RC categories	Potential score range	PERSONABLE mean (SD)	TAU mean (SD)
Dementia specific design	1-2	1.67 (0.58)	1.67 (0.58)
Maintenance	0-4	3.67 (0.58)	3.00 (1.00)
Cleanliness	0-4	3.33 (1.56)	2.67 (0.58)
Odours	0-2	1.00 (1.00)	1.00 (0.00)
Safety	0-5	4.33 (0.58)	3.67 (0.58)
Lighting	0-12	9.67 (1.53)	7.34 (0.58)
Personalisation	0-13	6.67 (1.53)	3.67 (0.58)
Noise	0-16	10.34 (2.52)	8.00 (1.72)
Plants	0-2	0.33 (0.58)	0.67 (1.15)
Outdoor areas	0-7	5.33 (1.78)	3.67 (1.53)
Appearance of residents	0-2	1.33 (0.58)	1.67 (0.58)
Toilet access	0-2	1.67 (0.58)	1.67 (0.58)
Total	1-73	49.3	38.7

5.4.2 Staff

At baseline, the mean working full-time equivalent of staff was slightly higher in the PERSONABLE arm (26.3) compared to the TAU arm (25.0). The two arms of the trial had a greater number of female staff than men. The PERSONABLE arm had a total of 62 female and six male staff participants. The TAU arm had a total of 44 female and five male staff participants. One participant did not report their gender in the questionnaire.

More care worker staff participated in the PERSONABLE arm (n=52) compared to the TAU arm (n=36). This was partly because of staff attending PERSONABLE who did not complete baseline or follow-up questionnaires (n=7). Ancillary staff participation was higher in the PERSONABLE arm (n=11) compared to the TAU arm (n=8). In the 'other' staff job group the PERSONABLE arm had greater participation (n=6) compared to the TAU arm (n=3). The mean months of experience for staff was slightly higher in the PERSONABLE arm (29.4) compared to the TAU arm (24.9). The mean score for the VAS (potential range of 1-100) was balanced between groups at baseline, PERSONABLE (85.0) and TAU (83.3). For the Personhood in Dementia Questionnaire the mean score (potential range of 0-100) was similar in the two trial arms (PERSONABLE 89.5 versus TAU 86.6).

5.4.3 Residents

At baseline, in the PERSONABLE arm, there was a higher percentage of female (80%) resident participants, compared to male (20%). The percentage of female (55%) residents to male (45%) was more balanced in the TAU arm.

At baseline, the mean of the aggregate wellbeing/ill-being (WIB) score was higher in the PERSONABLE arm (0.09) compared to the TAU arm (0.06). There was balance between trial arms in the behaviour category codes with a high potential for the mood or engagement of residents: at baseline, residents in the PERSONABLE arm had a total of 454 behaviours with high potential for mood or engagement, compared to 445 high potential behaviours in the TAU arm. The total number of behaviours with medium (286) and low (46) potential for mood or engagement in the PERSONABLE arm was greater compared with the TAU arm, which had a total of 179 behaviours with medium potential for mood or engagement and 10 with low potential. Total observed

behaviours with no potential for mood or engagement were much greater in the TAU arm (152) than in the PERSONABLE arm (46).

At baseline, personal enhancing interactions were broadly balanced between arms. The total enhancing interactions for the PERSONABLE arm was 165 and for the TAU arm 152. At baseline, personal detracting interactions occurred much less frequently, but in similar quantities between trial arms with three total detracting interactions in the PERSONABLE arm compared to a total of two detracting interactions in the TAU arm.

Table 24: Groups at baseline

Level of data				PERSONABLE	Training as usual
Resident	Gender		Female, n (%)	16 (80.0)	11 (55.0)
			Male, n (%)	4 (20.0)	9 (45.0)
			Missing cases	n	1
Observation	WiB score ²		Mean (SD)	1.12 (0.21)	1.19 (0.50)
	Personal detractors		n (%)	3 (1.79)	2 (1.30)
	Personal enhancers		n (%)	165 (98.21)	152 (98.7)
	High potential behaviours ¹		n (%)	454 (54.6)	445 (56.6)
	Medium potential behaviours ¹		n (%)	286 (34.4)	179 (22.8)
	Low potential behaviours ¹		n (%)	46 (5.5)	10 (1.3)
	No potential behaviours ¹		n (%)	46 (5.5)	152 (19.3)
Staff	Gender	Female	n (%)	62 (90.5)	44 (89.8)
		Male	n (%)	6 (9.5)	5 (10.2)
		Missing cases	n	1	
	Months experience		Mean % (SD)	29.4 (13.3)	24.9 (8.8)
	Staff role	Care worker	n (%)	52.0 (75.4)	36.0 (74.9)
		Ancillary	n (%)	11.0 (15.9)	8.00 (17.6)
		Other	n (%)	6.00 (8.7)	3.00 (7.5)
		Missing cases	n	2.00	
PDQ (0-100)		Mean (SD)	89.5 (10.8)	86.6 (11.3)	
VAS (0-100)		Mean score (SD)	85.0 (18.7)	83.3 (16.2)	
Care home	Total WTE staff		Mean (Range)	26.3 (13-43)	25.0 (13-34)
	Total bedrooms		Mean (Range)	26.0 (12-51)	22.7 (16-31)
	TESS-RC		Mean (Range)	49.3 (33-58)	38.7 (37-42)

¹Total number of behaviour category codes during baseline observation, grouped by the potential for positive mood and engagement

²Based on revised -2 to 2 scale inclusive of zero

5.5 Findings from the PERSONABLE intervention

In exercises two and three of the PERSONABLE workshop participants were asked to rank the five domains of the adapted Kitwood (1993b) personhood model. In exercise two they did this with respect to their own personhood and in exercise three with respect to the personhood of a resident they cared for. A score of one denoted the most representative domain of their personhood and a score of five the least representative. The mean ranks for participants completing the exercises is reported in Table 25. The participants rated ‘my life history’ and ‘my personality’ as the top two most important domains for themselves and residents respectively.

To explore the participant’s perception of their personhood versus that of the resident a Wilcoxon non-parametric test was used to examine any relationships within the same sample. There was a statistically significant difference in two domains, where health was considered of greater importance for ‘resident personhood’ ($p=0.02$) and personality of greater importance for ‘own personhood’ ($p=0.03$).

Table 25: Staff personhood domain rankings for exercises two and three

	n	You ¹		Resident ²		p value ³
		Mean rank	SD	Mean rank	SD	
My personality	29	1.64	1.04	2.38	1.36	.03
My life history	29	2.12	1.11	1.92	1.29	.41
How I socialise	29	3.00	0.93	3.12	0.91	.67
My health	29	3.88	1.17	3.04	1.00	.02
How I learn	29	4.04	0.96	4.44	1.16	.28

¹Kitwood personhood model domain ratings for the staff participant’s view of themselves

²Kitwood personhood model domain ratings for the staff participant’s view of their chosen resident

³Wilcoxon signed ranks test

5.5.1 PERSONABLE pledges

In exercise five, all participants attending PERSONABLE were asked to complete pledges, these are presented in Table 26. This table also captures the two staff who declined to make pledges, and the two staff who made pledges which were not reflective of personhood or citizenship. Eleven staff participants made pledges that reflected personhood, seven of these related to learning more about a resident's life history. Thirteen pledges related to citizenship and ideas for improving the diversity of the care home community were most popular. One ancillary member of staff made a pledge to promote the agency and purpose of a resident and said they would 'give a resident a duster'.

Table 26: Pledges made by staff in exercise five of PERSONABLE

Role	Pledge
CSW	I would like to improve my ability to communicate more easily with residents, a blowing bubbles game
CSW	To learn more about residents as only been here two months
Ancillary	Try to chat more about things they have done during their life and learn more about them
CSW	Ask family members about life history
Ancillary	Try to take time to watch and get to know resident
CSW	More 1-2-1 time with residents
CSW	I try to make sure I learn more and understanding
CSW	Find out more of the resident's life history e.g. old jobs, family, lifestyle
CSW	To know more about the residents look into life history, see hobbies
CSW	Look into residents life histories more
CSW	Box for thing for a gentleman who stimulation may help
CSW	5 minute rummage boxes, spend a little more time just chatting
CSW	Try to encourage people without dementia to understand dementia
CSW	Helping others with the understanding of dementia
CSW	Enjoy tea and lunch break with a resident
Ancillary	Bring in my grandchildren
Other	I will get in touch with Dementia Friendly Community in...to see what they suggest
Ancillary	Bring flowers in to put about the home
Ancillary	Improve resident make cake skills
CSW	Bring in my niece/pets to visit more often to cheer up residents
Ancillary	Give a resident a duster
Ancillary	Water plants with residents

Role	Pledge
Ancillary	Bring in one of my dogs
CSW	To control my emotions, reading care plans regularly, to introduce activities relevant to bring my children in and dogs
CSW	Reading care plans more regularly. Bring my children in for a visit
CSW	Help someone drink a bit more fluid
CSW	To bring ways of getting residents to drink more and enjoy their fluids
CSW	Declined to complete pledge
CSW	Declined to complete pledge
Blue: pledge reflective of personhood	
Green: pledge reflective of citizenship	
Yellow: pledge not reflective of either theory	
Pink: declined to complete a pledge	

5.6 Follow-up

5.6.1 Settings at follow-up

The physical environment of the participating care homes did not change between baseline and follow-up measurements. However, at follow-up there were some changes to the social environments of the care homes.

5.6.1.1 The social environment of care home one during follow-up observation

Follow-up observation occurred on the 13th of September 2017 between 1000 and 1400hrs, on a cool overcast day. There were two managers, six care workers and one ancillary staff present during the observation period. Because of the cooler weather residents spent most time in their bedrooms or sitting in the open plan dining area. I spent most of the observation period in an area to the edge of the dining room, which had an unobstructed view of the majority of residents. During the observation period a loud persistent alarm frequently sounded to alert staff when residents needed assistance in their bedrooms. During the follow-up period the two managers spent the majority of the observation period in their office.

5.6.1.2 The social environment of care home two during follow-up observation

Follow-up observations took place on the 6th of September 2017 between 0945 and 1345hrs, on a cool cloudy day. There was one owner, one manager, five care workers and one ancillary staff member present during the observation period. The staff commented that it was unusual to have so many care workers on shift that day. As with baseline, I positioned myself in the dining room. One care worker led a reminiscence activity and encouraged all residents to participate by giving each of them a different task. One resident was recovering from a hip operation and despite her limited mobility, staff made attempts to actively include her in the organised activities. At lunchtime, staff ate with residents at the dining tables. The manager spent most of her time upstairs with a male resident (not a participant) receiving palliative care. The owner of the care home spent most of the observation period completing paperwork in his office.

5.6.1.3 The social environment of care home three during follow-up observation

Follow-up observation occurred on the 19th of October 2017 between 1020 and 1420hrs, on a cold and rainy autumn day. My observation took place in the same large lounge and dining area as at baseline. There were two managers, eight care workers,

four ancillary and one member of administrative staff present during the observation period. I was accompanied by the second DCM™ observer (JF) who sat next to me throughout the observation period. The care atmosphere was mostly similar to that on the day of baseline measurements, however, on this occasion the television volume was lower. As with baseline there were no organised or impromptu activities facilitated by staff and the management did not enter the observation area during the period of assessment. Most of the social interactions revolved around the provision of food and were performed in an unexceptional manner.

5.6.1.4 The social environment of care home four during follow-up observation

Follow-up observation occurred on the 18th of October 2017 between 1045 and 1445hrs, on a cool overcast day. I positioned myself in the same place as during baseline observation. I was accompanied by the second DCM™ observer (JF) and we sat together. The cooler weather meant that residents spent all of their time indoors. There was one manager, three care workers, two ancillary and one member of administrative staff present during the observation period. The television was on at a high volume. There were no organised activities, however, towards the end of follow-up measurements one care worker played a game of cards with a participating resident. Neither of the managers visited the unit during the observation period.

5.6.1.5 The social environment of care home five during follow-up observation

Follow-up observations occurred on the 23rd of October 2017 between 0935 and 1335hrs, on a cool autumn day. There were two care workers and two ancillary staff members present during the observation period. I took the same positions for observation as at baseline. As with baseline observation most of the residents spent their time in the main lounge area, either watching the television or speaking to care staff. During the lunch period residents were given jobs such as helping to lay the tables and clear the tables once lunch was over.

5.6.1.6 The social environment of care home six during follow-up observation

Follow-up observation occurred on the 25th of October 2017 between 1000 and 1400hrs, on a cold day. There were two owners, one manager, two care workers, one ancillary staff and one maintenance person present during the observation period. I alternated my position for observation, as at baseline, depending on the position of the residents. The care routine was similar to that observed during baseline

assessment. Staff would come and speak briefly with residents in between care tasks but there were no formal activities. The care manager was present during observation but said she was leaving employment that week and spent most of her time in the staff administration office. The two owners were present, their interactions with the residents were infrequent, mostly they stayed in the management office which had a 'staff only' sign on the door.

5.6.2 Loss to follow-up

5.6.2.1 Staff

In total 37 staff were lost to follow-up, 18 in the PERSONABLE arm and 19 in the TAU arm (Table 27). Most of the staff lost to follow-up were those who had left employment, 13 of whom were from care homes in the PERSONABLE arm and 10 from those in the TAU arm. Of the 13 staff that had left employment in the PERSONABLE arm 11 were from care home three and six from care home four in the TAU arm. Care home six had the largest proportion of staff leaving employment between baseline and follow-up measurements, five of a total of 13 employed staff.

Staff who were away from work, for holiday or had prolonged gaps in their shifts, was balanced between trial arms. Only two participants declined to complete follow-up questionnaires when they had already completed baseline questionnaires, both of these were in the TAU group.

Table 27: Reason for staff loss to follow-up by trial arm

Reason for loss to follow-up	PERSONABLE n (% ¹)	Training as usual n (% ¹)
Followed up	69	49
Lost to follow-up	18	19
Away	5 (27.8)	5 (26.3)
Declined	0	2 (10.5)
Left employment	13 (72.2)	10 (52.6)
Retired	0	1 (5.3)
Sickness	0	1 (5.3)

¹Percentage of recruited participants in each trial arm

5.6.2.2 Residents

Four residents were not available at follow-up; one resident in care home two who at follow-up was receiving palliative care and three residents in care home six who had moved to different care homes between baseline and follow-up measurements. At

follow-up, a resident in care home two was recovering from a hip operation but remained included in the study because she was being actively rehabilitated within the communal areas of the care home and her level of attention and cognition did not seem altered from the baseline observations.

5.6.2.3 *Care homes*

No care homes were lost to follow-up.

5.6.3 *Follow-up outcome measures*

There were a total of 36 residents and 44 staff who provided baseline and follow-up data to compare outcomes between the two trial arms. This study was not powered to make statistical inferences about effectiveness, however, the statistical tests needed to make such inferences in a definitive trial have been carried out, and reported on, to explore their suitability. For all primary and secondary outcomes, the baseline measurement has been used as a constant fixed effect in the two adjusted mixed effects models. As expected all baseline measurements were predictive of follow-up measurements (Jotheeswaran et al., 2010).

5.6.4 Resident: primary outcome

5.6.4.1 Wellbeing/ill-being score (WIB)

Table 28: Adjusted change in Wellbeing/ill-being (WIB) scores between baseline and follow-up by trial arm.

	n ¹	Coefficient	p value	95% CI ⁴	
				Lower	Upper
Adjusted²					
PERSONABLE vs TAU	36	0.30 ⁵	0.34	-0.32	0.75
Baseline WIB	36	1.34 ⁶	0.02	0.15	1.35
Adjusted³					
PERSONABLE vs TAU	36	0.10 ⁵	0.90	-1.05	1.22
Baseline WIB	36	2.13 ⁶	0.00	1.10	3.20
Male vs Female	36	-0.42 ⁵	0.07	-0.90	0.03

Mixed effects model, random effect of care home

WIB score is based on scale of -3 to +5

¹Number of resident participants present for baseline and follow-up measurements

²Mixed effects model adjusted for baseline, intraclass correlation coefficient = 0.35

³Mixed effects model adjusted for baseline and gender, intraclass correlation coefficient = 0.38

⁴Based on the estimated $\pm 1.96 \times SE$

⁵Mean difference

⁶Estimated difference per one unit increase

The mixed effects linear regression model using the outcome measure WIB was based on 36 residents. When adjusted only for baseline differences the direction of effect moved towards more positive WIB scores for residents allocated to the PERSONABLE arm (mean difference 0.30 95% CI -0.32 to 0.75). When additionally adjusted for gender, this positive direction of effect lessened slightly (mean difference 0.10, 95% CI -1.05 to 1.22).

5.6.5 Resident: secondary outcomes

5.6.5.1 Behaviour category codes grouped by their potential for mood or engagement

Table 29: Adjusted change in the Grouped Behaviour Category Code (GBCC) scores between baseline and follow-up by trial arm.

	n ¹	Coefficient	p value	95% CI ⁴	
				Lower	Upper
Adjusted²					
PERSONABLE vs TAU	36	0.06 ⁵	0.90	-0.78	0.90
Baseline GBCC	36	0.41 ⁶	0.4	0.02	0.80
Adjusted³					
PERSONABLE vs TAU	36	0.05 ⁵	0.90	-0.78	0.88
Baseline GBCC	36	0.40 ⁶	0.046	0.007	0.80
Male vs Female	36	-0.04 ⁵	0.84	-0.48	0.40

Mixed effects model, random effect of care home

GBCCs are based on scale of 3 (high potential) to 0 (no potential)

¹Number of resident participants present for baseline and follow-up measurements

²Mixed effects model adjusted for baseline, intraclass correlation coefficient = 0.21

³Mixed effects model adjusted for baseline and gender, intraclass correlation coefficient = 0.20

⁴Based on the estimated $\pm 1.96 \times \text{SE}$

⁵Mean difference

⁶Estimated difference per one unit increase

The mixed effects linear regression model using the Grouped Behaviour Category Codes was based on 36 residents. When adjusted only for baseline differences the direction of effect moved fractionally towards more positive WIB scores for residents allocated to the PERSONABLE arm (mean difference 0.06, 95% CI -0.78 to 0.90). When additionally adjusted for gender, the positive direction of effect was still negligible but lessened very slightly (mean difference 0.05, 95% CI -0.78 to 0.88).

5.6.5.2 Personal enhancing or detracting interactions

Table 30: Number and proportion of interactions occurring at baseline and follow-up

Trial arm	Interaction	n ¹	Baseline n (%)	Follow-up n (%)
PERSONABLE	Enhancing	960	165 (17.2)	177 (18.3)
	No interaction	960	792 (82.5)	776 (81.0)
	Detracting	960	3 (0.30)	7 (0.70)
TAU	Enhancing	960	152 (15.8)	108 (11.2)
	No interaction	960	806 (84.0)	835 (87.0)
	Detracting	960	2 (0.20)	17 (1.80)

¹Total number of possible interactions

There were a possible 960 five minute time frames for which interactions could be recorded (Table 30). For the majority of the 960 possible time frames ‘no interactions’ were observed. At baseline, this was mostly balanced between groups, PERSONABLE (n=792) and TAU (n=806). At follow-up, there was a bigger discrepancy, PERSONABLE (n=776) and TAU (n=835).

The majority of interactions recorded during observation were ‘enhancing’. At baseline, the proportion of enhancing interactions was balanced between the PERSONABLE (n=165) and TAU (n=152) arms, however, at follow-up the PERSONABLE (n=177) arm had a much greater amount of enhancing interactions recorded compared to the TAU (n=108) arm. In both arms there were very few detracting interactions recorded at baseline. At follow-up the overall amount of detracting interactions increased slightly in each arm of the trial, 17 in the TAU arm compared to the seven in the PERSONABLE arm.

5.6.5.3 DCM™ field notes

Reviewing the field notes made during baseline and follow-up measurements most interactions, detracting or enhancing, involved the provision of food or drink (n=238), interactions involving communication between staff and residents were the next most common (n=211) and those involving leisure (n=71), personal care (n=49) or mobility (n=41) were less frequently observed. Twenty interactions did not have a field note attached. This was typically because of time pressure during busy observational periods or when having to consult the DCM™ handbook (University of Bradford, 2010).

Although the majority of interactions were recorded as enhancing, the brief qualitative DCM™ notes for each interaction indicated a large proportion of these interactions were 'neutral' in quality. These types of interactions were not overtly detracting, and needing a code to record the interaction, had been assigned as enhancing. Examples of these types of interactions were captured in the brief DCM™ field notes 'brought food, nothing exceptional', 'offered food, nothing exceptional', 'helped to move, nothing exceptional', 'acknowledged, nothing exceptional' or 'offered drink, nothing exceptional'.

The DCM™ field notes captured examples of staff performing care interventions in a truly enhancing manner. One example was an attendee at PERSONABLE who at follow-up skilfully facilitated a conversation between two very impaired residents during the lunch time period. Some of the interactions reflected an empowering citizenship approach, such as a member of care worker staff asking a resident to help hand out some lemonade they had made during an activity, or a resident who was encouraged to help tidy up after lunch. Some staff encouraged residents to maintain their independence 'you know where the fridge is if you want another glass of milk' or 'come look what is on the menu'.

The truly enhancing interactions mostly occurred during organised or informal social activities, for example a staff member noticing a resident was not participating in an activity and making efforts to include them. Humour was sometimes used therapeutically, one staff member joked with a resident, who she knew well, about 'chatting up' the ice cream man.

There were only a few examples of truly enhancing interactions when staff were performing tasks related to personal care or the provision of food, one example was when medication was being administered in a warm clear manner that did not rush the resident. Another example was a member of staff giving a resident a drink and making a considered attempt at non-verbal communication because the resident spoke only Farsi.

One care home provided a platform for a personhood approach by having staff and residents eat their meals together. This resulted in frequent examples of staff acknowledging the personhood of the residents, 'you're vegetarian aren't you?' and

a more humorous approach 'what would your maid use that (vintage kitchen tool) for?'. However, on one occasion some staff in this home seemed to view eating lunch with residents as a break from their work and were observed ignoring the residents whilst speaking between themselves.

Generally, in participating homes, many of the detracting interactions surrounded meal times or care tasks. Often notes like 'brought drink not acknowledged', 'tried to help resident with food despite her (resident) being able to do this herself', 'brought food, no words', 'counting with food, like you might with a child' or 'asked if wanted cup of tea in an infantilising manner', 'you're unwell because you do not take your medication' were recorded.

Ancillary and 'other' staff groups were observed interacting with residents. Because observation occurred in the communal areas opportunities to observe these interactions were limited. This was because ancillary and 'other' staff tended to work in other areas of the care homes such as resident bedrooms, kitchens or office space. The type and quality of the interactions varied. Detracting interactions were recorded when kitchen staff were observed bringing meals to residents but not speaking to them, and often care workers would be observed trying to 'feed' residents who could do this activity themselves.

As with care workers the language used to communicate with residents varied, one maintenance person was observed frequently using infantilising language, whereas a cleaner was observed talking about a necklace a resident was wearing in a warm and genuine manner. Some ancillary staff demonstrated a natural interest in the biographies of residents and would often be observed talking to residents about their life histories.

5.6.6 Staff: secondary outcomes

5.6.6.1 Personhood in Dementia Questionnaire (PDQ)

Table 31: Adjusted change in the PDQ score between baseline and follow-up by trial arm.

	n ¹	Coefficient	p value	95% CI ⁴	
				Lower	Upper
Adjusted²					
PERSONABLE vs TAU	44	2.84 ⁵	0.22	-1.80	7.50
Baseline PDQ	44	0.47 ⁶	<.001	0.24	0.70
Adjusted³					
PERSONABLE vs TAU	44	3.10 ⁵	0.21	-1.90	8.08
Baseline PDQ	44	0.47 ⁶	<.001	0.22	0.71
Male vs Female	44	-0.30 ⁵	0.97	-16.4	15.8
Experience	44	-0.01 ⁶	0.60	-0.04	0.02
CSW staff	44	7.51 ⁵	0.11	-1.90	16.90
Ancillary staff	44	11.8 ⁵	0.07	-1.00	24.6
Other staff	44	-7.51 ⁵	0.11	-17.0	1.80

Mixed effects model, random effect of care home

PDQ measured on a continuous scale of 0 to 6 for each of the 20 questions

¹Number of staff participants completing baseline and follow-up questionnaires

²Mixed effects model adjusted for baseline

³Mixed effects model adjusted for baseline, gender, experience and job role

⁴Based on the estimated +/- 1.96 x SE

⁵Mean difference

⁶Estimated difference per one unit increase

The mixed effects linear regression using the outcome measure PDQ was based on 44 staff who returned both baseline and follow-up questionnaires, which contained sufficient information for analysis. When adjusted only for baseline differences the direction of effect moved towards more positive PDQ scores for residents allocated to the PERSONABLE arm (mean difference 2.84, CI 95% -1.80 to 7.50). When additionally adjusted for gender, experience and staff role the direction of effect moved more positively in the direction of the PERSONABLE arm (mean difference 3.10, CI 95% -1.90 to 8.08).

In the context of the small sample and feasibility protocol, the 'ancillary' variable suggests that working in an ancillary role could be an influential factor affecting the direction of effect in favour of the PERSONABLE arm (mean difference 11.8, CI 95% -1.00 to 24.6).

5.6.6.2 Visual analogue scale (VAS)

Table 32: Adjusted change in the VAS score between baseline and follow-up by trial arm.

	n ¹	Mean difference	p value	95% CI ⁴	
				Lower	Upper
Adjusted²					
PERSONABLE vs TAU	44	-0.13 ⁵	0.97	-7.60	7.34
Baseline VAS	44	0.76 ⁶	<.001	0.51	1.02
Adjusted³					
PERSONABLE vs TAU	44	1.85 ⁵	0.61	-7.73	8.27
Baseline VAS	44	0.50 ⁶	<.001	0.48	1.04
Male vs Female	44	-1.40 ⁵	0.92	20.7	32.7
Experience	44	0.01 ⁶	0.73	-0.05	0.06
CSW staff	44	28.2 ⁵	<.001	12.3	44.0
Ancillary staff	44	28.3 ⁵	0.01	7.42	49.2
Other staff	44	-28.3 ⁵	0.01	-49.2	-7.42

Mixed effects model, random effect of care home

Measured on a 0-100 continuous scale

¹Number of staff participants completing baseline and follow-up questionnaires

²Mixed effects model adjusted for baseline

³Mixed effects model adjusted for baseline, gender, experience and job role

⁴Based on the estimated +/- 1.96 x SE

⁵Mean difference

⁶Estimated difference per one unit increase

The mixed effects linear regression model using the outcome measure VAS was based on 44 staff who returned both baseline and follow-up questionnaires, which contained sufficient information for analysis. When adjusted only for baseline differences the direction of effect moved towards slightly more positive VAS scores for staff allocated to the TAU arm (mean difference -0.13, 95% CI -7.60 to 7.34). When additionally adjusted for gender, experience and staff role the direction of effect changed and moved towards more positive VAS scores for staff allocated to the PERSONABLE arm (mean difference 1.85, 95% CI -7.73 to 8.27). Although it is not possible to infer effectiveness from this feasibility study, there is an indication that job role might be associated with VAS score.

5.6.6.3 Clustering

The intraclass correlation coefficients for all mixed models based on resident outcomes ranged from 0.20 to 0.47. On the basis of a mean of six residents to each care home (cluster) this would translate to a design effect of between 2.02 and 3.37. This is the factor by which the sample size based on a non-clustered trial design would need to be inflated by.

Clustering of staff participants within care homes could not be assessed through an estimate of the intraclass correlation coefficient due to problems with model convergence. Covariates were dropped to see if overfitting was the cause of this but to no effect. Baseline PDQ and VAS are presented in Figure 26 and Figure 27 below. These suggest that while the median scores for both measures were broadly similar across all six homes, the variation among staff members was much less in two of the homes.

Figure 26: Baseline PDQ

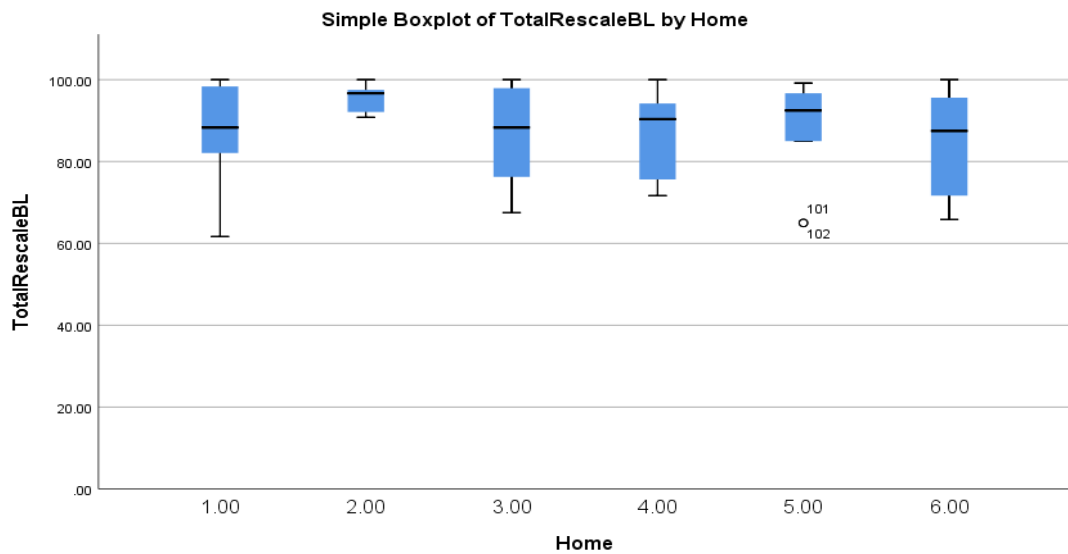
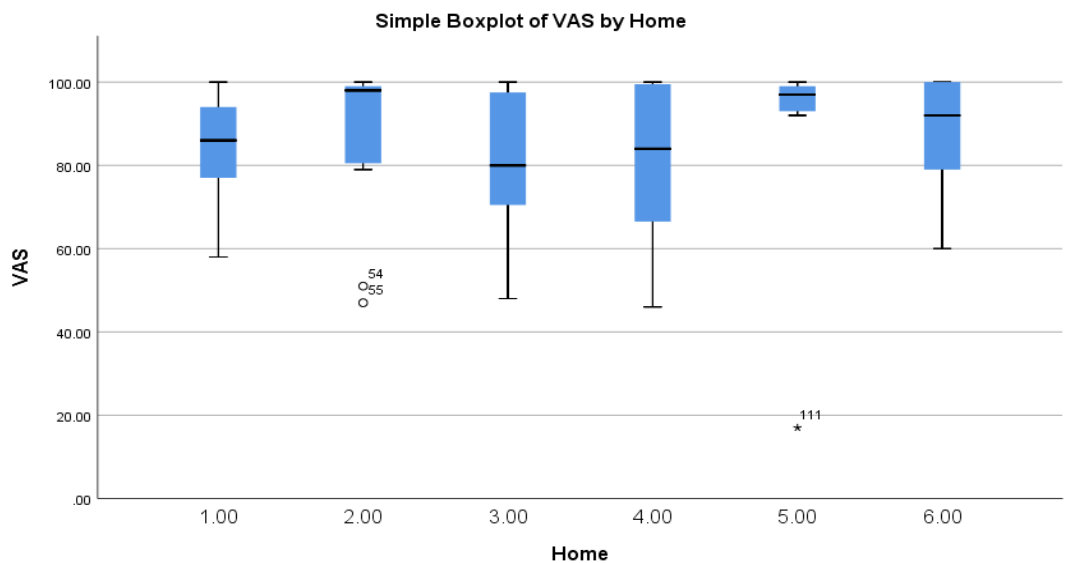


Figure 27: Baseline VAS



5.6.7 Interrater DCM™ agreement

JF and I performed interrater agreement for a total of eight hours. Our agreement and non-agreement is summarised in Table 33. The raw interrater data is presented in appendix 20. After accounting for breaks this constituted 84 five-minute time frames. During this period the behaviour category codes 'going back (G)', 'intellectual (I)', 'religion (R)', 'sex (S)', 'X-Cretion (X)' and 'zero option (Z)' were not observed and therefore not recorded by either JF or myself. The code 'joints (J)' were not recorded by myself and recorded on one occasion by JF. During the eight hours of observation, the second observer (JF) recorded a greater variety of codes (17) compared to my coding (12).

We had the most agreement for the behaviour category codes 'borderline (B)', 'food (F)' and 'withstanding (W)'. We had some agreement for the behaviour codes 'articulation (A)', 'doing for self (D)', 'kum and go (K)' and 'land of nod (N)'.

We frequently disagreed when coding for 'borderline (B)', 'land of nod (N)' and 'yourself (Y)' when incidences of an action by a resident, representing a high potential behaviour, may have been more subtle. Disagreement also frequently occurred during busy meal times or when food was combined with another high potential behaviour.

The DCM™ concordance coefficients are presented in Table 33. We had low agreement for the behaviour category codes in each of the intervention and control groups. We agreed for only 40 out of 178 time frames in the intervention group and 23 out of 161 time frames in the control group. This equated to very low concordance co-efficients, 22 for the intervention group and 14 for the control group. We broadly had better agreement for the mood and engagement scores, and both agreed for 109 out of 178 time frames in the intervention group and 79 out of 161 in the control group. This equated to modest concordance co-efficient values of 61 for the intervention group and 49 for the control group. The combined behaviour category code and mood and engagement score concordance co-efficients were low, 42 for the intervention group and 32 for the control group. Our agreement for the intervention group (second day of observation) was noticeably better compared to the control group (first day of observation) in all domains

Table 33: Interrater agreement and concordance co-efficient, expressed as percentages

Behaviour category code agreement						
Participant	BCC Agreement		Total possible agreement BCC		Concordance co-efficient BCC	
	Intervention	Control	Intervention	Control	Intervention	Control
1	6	11	40	42	15	26
2	9	0	41	5	22	0
3	16	2	41	38	39	5
4	0	5	15	35	0	14
5	9	5	41	41	22	12
Group	40	23	178	161	22	14
Mood and engagement score agreement						
Participant	ME Agreement		Total possible agreement ME		Concordance co-efficient ME	
	Intervention	Control	Intervention	Control	Intervention	Control
1	22	28	40	42	55	67
2	35	1	41	5	85	20
3	23	21	41	38	56	55
4	11	14	15	35	73	40
5	18	15	41	41	44	37
Group	109	79	178	161	61	49
Combined behaviour category code and mood and engagement score agreement						
Participant	Overall Agreement		Total possible agreement		Overall concordance co-efficient	
	Intervention	Control	Intervention	Control	Intervention	Control
1	28	39	80	84	35	46
2	44	1	82	10	54	10
3	39	23	82	76	48	30
4	11	19	30	70	37	27
5	27	20	82	82	33	24
Group	149	102	356	322	42	32

Cohen’s weighted Kappa coefficient (Cohen, 1968) was used to explore our agreement (Table 34). According to the scale presented by Cohen (1968) we had very poor agreement for mood and engagement scores and poor agreement for behaviour category codes. However, there was good agreement when the behaviour category codes were grouped by their potential for wellbeing.

Table 34: Interrater agreement using Cohen’s weighted Kappa coefficient

Level of DCM™ data	Mean Kappa	Range	
		Minimum	Maximum
Behaviour category code agreement (individual) ¹	0.23	0.12	0.33
Behaviour category code agreement (grouped) ¹	0.61	-0.143	1.00
Mood and engagement score agreement ¹	-0.02	-0.10	-0.05

¹Cohen's weighted kappa coefficient

Chapter six: Discussion

6.1 Introduction

The first part of this chapter is modelled around the research questions. These are explored in the context of the literature review and study findings. After addressing the research questions the discussion critically examines how personhood and citizenship was enacted within the study and how this relates to current approaches to the provision of care in residential care homes. Discussion of the quantitative findings draw on the brief field notes collected while conducting DCM™ observation. A discussion of the limitations and strengths of the study is presented. This is followed by the implications of this study for future research, proposing how adjustments might be made to navigate the boundaries of this investigation. The discussion continues with a personal reflection where I shall attempt to review my experience of conducting the study. Finally, a conclusion is presented which attempts to summarise this study.

6.2 Feasibility of participation

6.2.1 What is the response and non-response of participants during recruitment, intervention participation and outcome measurement?

6.2.1.1 Care home

There was a positive response from the care homes approached for inclusion in this study. This was not anticipated because difficulty with care home recruitment had been reported by similar studies identified in the literature review (Rajkumar et al., 2016, Beer et al., 2011a). The general willingness of care homes to participate enabled some purposeful sampling of study sites during recruitment. Having this flexibility assisted when attempting to represent an apparent diversity of residential care homes (Office for National Statistics, 2014, Office for National Statistics, 2015). During initial approaches managers reported the opportunity for staff training as a key motivation for participation.

Care homes who performed best in the TESS-RC, did not necessarily reflect the observations by Iliffe et al. (2017) that higher quality care homes are more 'research receptive'. During the recruitment process the most receptive group of care homes were those rated as 'good' or 'requires improvement' by the CQC. Although, further information obtained during discussions with managers at the point of care home consent, clarified that 'outstanding' care homes were i) more likely to already have

person-centred training in place, or ii) were currently involved in other research studies. The latter point suggests that care homes have a limited capacity to support more than one research study at any given time. The tendency of care homes who have previously been involved in research to be more agreeable to further approaches was captured during the recruitment phase of this study. Care homes on the ENRICH 'research ready' database were the most likely to agree to participation, with five of the six recruited care homes appearing on the database. Additionally, there was only one non-response to approaches for inclusion in the study from the homes on the ENRICH database, compared to fifteen non-responses for those approached through other sources.

Despite the demands of busy care environments, there was good engagement with PERSONABLE at the level of care home. This engagement was evidenced in practical adjustments facilitated by the care home management to facilitate the study procedures. For the three homes allocated to PERSONABLE, the two larger care homes hosted the workshop in dedicated meeting rooms and the smaller home used an empty resident bedroom. The two larger care homes utilised a senior care worker to promote attendance at PERSONABLE on the day of the workshop. In comparison, the smaller care homes used the care manager to promote attendance at PERSONABLE. The manager involvement seemed more proactive and they were observed to begin promoting the workshop in the weeks leading up to PERSONABLE. The active engagement of the manager resulted in extra staff attending on their day off. Given the high levels of staff turnover (CQC, 2014b) and reflecting on the concerns expressed by staff in phase one of the study I wondered what might encourage staff to attend on their day off (for example a sense of duty, a willingness to learn, interest in research or perhaps more cynically, pressure from higher management). When staff reported completing training on their days off, in the phase one focused discussion groups, they seemed to passively accept this as part of their job. Although staff consistently report undertaking training surrounding dementia in their free time, their attitudes to this practice is not elaborated within the evidence base (Fossey et al., 2014, Kuske et al., 2007).

This study was a 'wait list' trial. When follow-up measurements were complete the care homes randomised to TAU were offered PERSONABLE. Interestingly, despite enthusiasm for the workshop expressed during recruitment, all three care homes allocated to the TAU arm did not accept the offer of the PERSONABLE workshop. This was despite face-to-face, telephone and email prompting. The reduced enthusiasm of all care homes towards the end of the trial was tangible. The reduced enthusiasm was possibly reflective of observations made by Luff et al. (2015) who suggested retention of participants lessens as their perceived 'research burden' increases. At this point participating care homes seemed to move onto other care priorities.

At the level of care home there were no objections to any of the outcome measurements. As with the intervention, outcome measures were specifically chosen to limit the burden on participants, responding to observations made in other trial reports appraising overly cumbersome assessments (Beer et al., 2011a). Another threat to research engagement cited in the literature review was unstable leadership (Spector et al., 2016). In one care home both the general and deputy managers left employment between baseline and follow-up measurements. This affected the continuity of measurements and was in stark contrast to the positive engagement seen in care homes with stable leadership. Positive leadership connected care home resources, especially during recruitment and the overseeing of staff questionnaires. In addition to positive leadership, these research processes were greatly enhanced when supported by engaged administrative staff.

6.2.1.2 Residents

Recruitment of residents was successful, which had not been expected when reflecting on the current evidence base (Beer et al., 2011a, Chenoweth et al., 2009). Most of the residents who were approached did not demonstrate the capacity to consent to participation in the study and consultee advice was sought and gained in relation to these residents. All residents assented to observation on the days of DCM™. There was no dissent by any of the residents during the observation periods. During DCM™ observation some residents communicated with me, enquiring about my presence in the care home. On these occasions I ceased DCM™ observation to briefly provide an explanation, conscious that my desire to collect resident data did

not impact on their autonomy. There was no attrition of residents in the PERSONABLE arm. This seemed supported by the general research willingness of the managers from care homes in the PERSONABLE arm. Overall, this willingness was less apparent in the three care homes allocated to the TAU arm.

When managers were positively engaged with the research process this improved the recruitment and retention of resident participants, something also noted in an editorial by Iliffe et al. (2017). The specific mechanism for the positive effect of 'research informed' management was seen in one of the care homes allocated to the PERSONABLE arm. The manager and owner understood the value of engaging with the intricacies of trial procedures during the recruitment process, which enhanced the suitability of recruited residents and resulted in no attrition between baseline and follow-up measurements.

6.2.1.3 Consultees

The personal consultee process was the most procedurally complex level of recruitment. As part of my clinical role I had frequently performed assessments of capacity using the Mental Capacity Act (Department of Health, 2005). In these instances the Mental Capacity Act (Department of Health, 2005) was being used to positively advocate the independence of people with dementia. In relation to this study, my experience was similar to the observations of Murray (2013) who suggested early career researchers are more likely to conservatively assess the capacity of potential participants.

Most residents were assessed as not having capacity to participate in the study and a personal consultee was sought. This meant the navigation of several systemic issues within the care homes: high staff turnover, difficulty passing information between staff working differing shift patterns and staff having different priorities than research administration. All these factors were identified in the literature review as limiting resident participation (Goodman et al., 2011). In addition to these difficulties I observed that when administrative staff made the initial approach to personal consultees, successful approaches seemed dependent on administrative staff having previous knowledge of study procedures. Mostly administrative staff were not familiar with research procedures and obtaining accurate information surrounding the

personal consultee process was difficult to capture. This unfamiliarity, contributed to less proactive attempts to engage potential personal consultees and by default there was follow-through to approaching nominated consultees. These experiences partly concur with Long (2017) and Murray (2013) who observed complex ethical procedures lessening engagement with the personal consultee process. Furthermore administrative staff explained that potential personal consultees routinely deferred decisions to the care home manager, perceiving this decision as something requiring professional endorsement. Reflecting on the comments made by family members in the phase one focused discussion groups, this deferment could be family carers preferring to relinquish the administrative aspects of their care roles, choosing to concentrate on emotional care. If true, this is an interesting transformation because the literature review had suggested family carers found it difficult to think of emotional care, whilst their relative was living with them (Chester et al., 2018).

The complexity of the consultee processes for this study created a tension between, the principle expressed by Long (2017) of giving a voice to people with dementia, and the principles set out in the Mental Capacity Act (Department of Health, 2005) which helps ensure their inclusion is legal and ethically sound. The intricacy of the consultee process has been acknowledged in large randomised controlled trials conducted in care homes (Goodman et al., 2011). For this study the consultee protocol stated a two week cut-off point when seeking a personal consultee, at which point the opinion of a nominated consultee was sought. Although the opinion of a personal consultee is preferable, having a cut-off helped resident recruitment because it allowed me to move forwards with recruitment when replies from consultees were not forthcoming. Complex consultee processes may affect the ability of larger trials to recruit sufficient participants if the demand on resources exceeds the boundaries of the study grant (Goodman et al., 2011).

6.2.1.4 Staff

Staff engagement was monitored during all stages of the trial. In total, 118 staff participated in some capacity either by completing measurements at baseline, follow-up or both or by attending PERSONABLE. There were 35 staff employed by the participating care homes who did not participate in the trial in any manner. The

barriers affecting the ability of staff to fully engage with the trial were mostly reflective of those identified in the literature review (Beer et al., 2011a), most notably their busy work schedule. Solutions to the impact of the pressured nature of care work have been elaborated in a process evaluation by Fossey et al. (2019), who stressed the benefit of 'strong local leadership' when promoting the engagement of staff in clinical trials. When conducting this study, leadership did not always come from the designated manager. Some care workers and administrative staff were observed to take on leadership roles, positively impacting on the engagement with this study.

Of the 69 staff participating in the group allocated to the intervention arm 29 attended PERSONABLE. Most staff attending PERSONABLE were those designated to work on the day the workshop was delivered. Griffiths et al. (2019) focused on the effect of a perceived 'burden of trial participation' by managers who might have other priorities such, as high staff turnover or external care inspections. This was reflected in the results of this study, where care homes with stable leadership had better engagement of staff in the study. Conversely, one of the care homes who had significant changes to management had fifteen care worker non-attenders at PERSONABLE (Table 21), the highest number of non-attenders in the trial.

Staff response to study questionnaires was positive, with 111 staff completing baseline, follow-up or both baseline and follow-up measurements. At follow-up some staff stated they had previously completed the questionnaires and had to be prompted that the design of the study necessitated completion of the questionnaires on two occasions. This highlights the need for clear and accessible strategies to inform staff of research processes (Goodman et al., 2011). An issue not raised in the literature (to my knowledge) was that staff in the control arm seemed to find study processes particularly difficult to understand, not having the PERSONABLE workshop as a reference point. Generally, the poor appreciation of trial procedures was compounded by a lack of engagement with the lengthy study information required to inform their consent. To minimise the impact of this I frequently briefed staff on the structure of the trial, in person.

Capturing the views of staff attending a training intervention is important to provide researchers with the best indication of intervention implementation (Beer et al.,

2011a). Seven of the 29 staff who participated in PERSONABLE did not complete questionnaires at baseline or follow-up. To increase engagement, questionnaires were deliberately designed to have the least impact on staff time. Despite these adjustments time remained an issue for staff consenting to participation on the day of PERSONABLE. These staff indicated to me that they did not have sufficient time to attend the workshop as well as complete a questionnaire.

Stable or unstable leadership did not influence the agreement of staff to be observed during DCM™ measurement. No staff objected to observation at either baseline or follow-up. Interestingly, staff seemed accustomed to observation by a third party. I wondered if this willingness was an active desire to engage in research (Long, 2017), as opposed to being passively engaged because they felt obliged. The research willingness of staff is an area which might benefit from further exploration to inform their future engagement. Conversely, the pattern of staff disengaging from research is well documented, however, the underpinning reasons remain broadly categorised under pressures within the working day (Griffiths et al., 2019).

6.2.2 What is the number of, and reasons for, the attrition of residents?

A total of four residents were lost to follow-up. Only one resident participant was lost to follow-up due to ill health and no residents were lost to follow-up because of death. After reviewing the literature at the start of this study a much greater attrition of residents to death or illness had been anticipated (Beer et al., 2011a). This had resulted in a generous estimation of residents needed to be recruited to gather sufficient feasibility data.

Residents moving from one care home to another was a factor not identified when reviewing similar studies (Beer et al., 2011a, Ballard et al., 2017). Three residents from one care home (TAU arm) were lost to follow-up because they were on respite at the point of baseline measurements and had moved from the care home before conducting follow-up measurements. At the point it became apparent that these residents were on respite it was too late to recruit three other residents. The manager for this care home was due to leave employment and was not engaged with the processes of this study, such as the need for baseline and follow-up measurements. This highlights the benefit of having 'research informed' management when

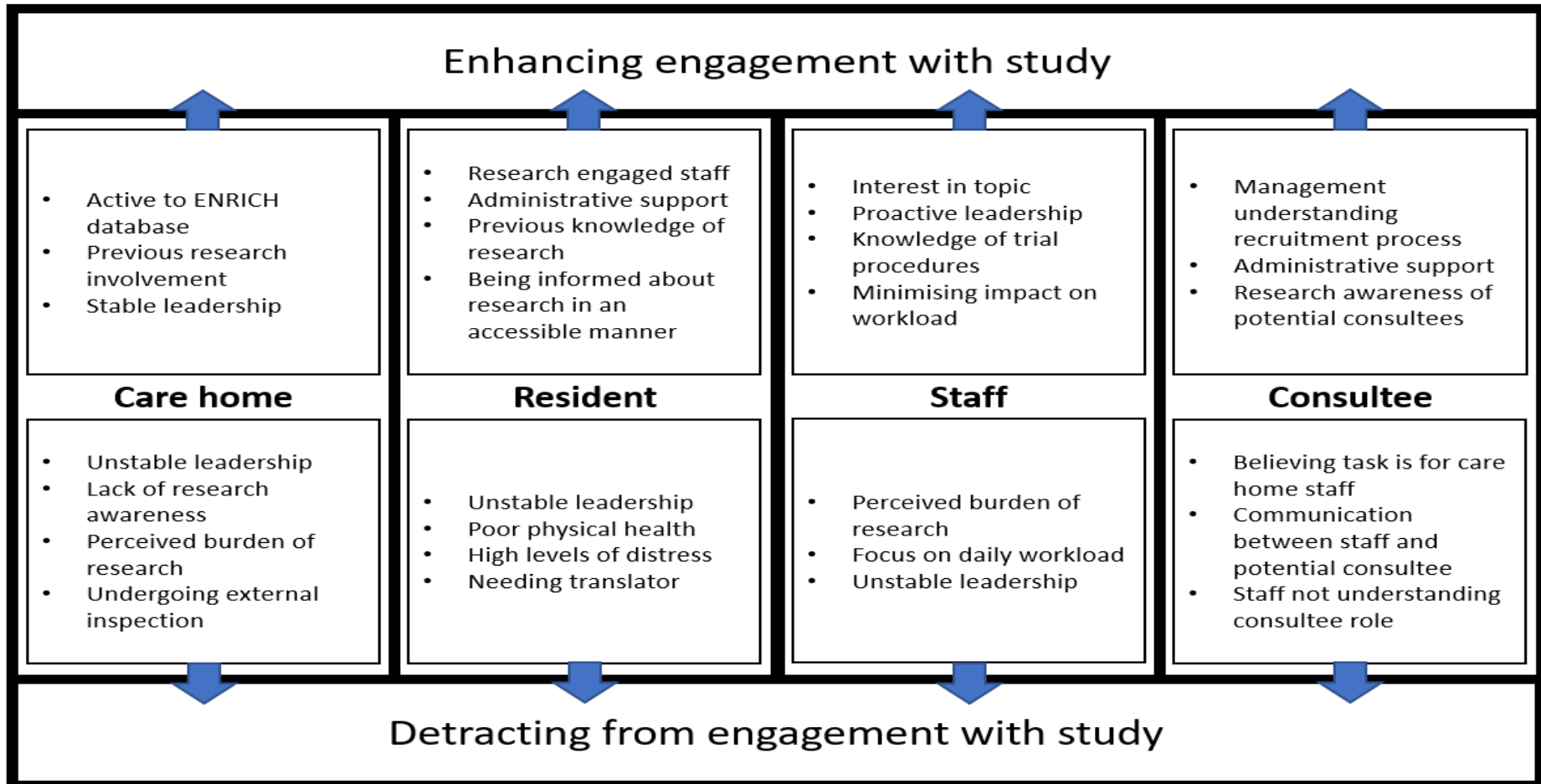
conducting trials in care homes, although this approach might not capture an apparent variability in the quality of care homes (Fossey et al., 2019).

6.2.3 What is the number of, and reasons for, the attrition of staff?

There was a similar level of staff lost to follow-up in the two trial arms, which given the small number of clusters is encouraging for future trials in care homes. Across the study sites there were twenty-three staff who left employment between baseline and follow-up measurements, a period of approximately ten weeks; this was the most common reason for the attrition of staff participants. Staff retiring or being away from work were two other, although less dominant, factors affecting participation, which were not identified from reviewing similar studies (Ballard et al., 2017, Chenoweth et al., 2009, Beer et al., 2011a).

Notably, staff attrition appeared influenced by changes in care home leadership. The care home which lost the general and deputy managers between baseline and follow-up measurements, lost eleven participating staff at follow-up, the greatest number across all six sites. The negative impact of a manager leaving employment was mirrored in another care home, which had proportionally the largest number of staff lost to follow-up. These examples of changes to leadership further highlighting a proposed link between unstable leadership and poor staff engagement with trial procedures (Goodman et al., 2011).

Figure 28: Diagram summarising factors which enhanced and detracted from participant engagement with this study



6.3 Feasibility of the intervention

6.3.1 Will a collaboratively designed intervention be acceptable to participants?

The PERSONABLE intervention was deliberately designed to be brief and requiring no preparation from staff. This approach was based on observations from other studies, which reported poor engagement with trials when procedures increase the perceived workload of staff (Chenoweth et al., 2009, Ballard et al., 2017). Reviewing the impact of the design and delivery of PERSONABLE on the willingness of staff to participate, the brevity and timing of the workshop were reported by staff as being influential in their decision to attend. It was the case that managers who integrated themselves into the daily care routines were more effective when raising awareness of the PERSONABLE workshop. This has developed observations made by Quasdorf and Bartholomeyczik (2017), who compared 28 interviews conducted with care managers, observing a relationship between proactive leadership styles and improved research engagement.

There were several barriers which may have reduced the subsequent impact of PERSONABLE on residents. One barrier was in keeping with existing research, which highlighted the poor engagement of staff with lengthy interventions (Beer et al., 2011a). Responding to concerns expressed by several managers surrounding the time commitment required to engage with PERSONABLE, the workshop had been offered to each care home in the intervention arm on one occasion and not three as stated within the study protocol. This approach attempted to balance the need to disperse information on personhood and citizenship to enough staff, whilst limiting their perceived burden (Chenoweth et al., 2009, Beer et al., 2011a).

Given that the workshop occurred on one occasion at each site, the proportion of staff attending the intervention was encouraging; with 42% of participating staff (intervention arm) taking part in PERSONABLE. However, when viewed in the context of the total number of available care home staff, participation is less encouraging. One care home had proportionally better attendance of ancillary staff at PERSONABLE compared to care workers. When attending the workshop these ancillary staff reported greater flexibility in their workload than the attending care workers, who commented that other care workers were helping a distressed resident. In the two other care homes allocated to the PERSONABLE arm, when attempts were made to

promote the attendance at PERSONABLE to ancillary and 'other' staff groups, they made comments indicating a belief that PERSONABLE was not the sort of training they could attend. Across all intervention sites, attendance from 'other' staff groups was low and both participants were from the same care home. The low representation of ancillary and 'other' staff groups in one of the smaller care homes was due to the care home employing only one member of ancillary staff. To mitigate the narrow staff mix the manager and owner had diversified their role, undertaking administrative, domestic and care tasks. Inclusion of ancillary and 'other' staff groups has been proposed by Surr and Gates (2017). However, strategies to increase their participation have not yet been fully explored, despite their fundamental role in resident care (Surr et al., 2017). Typically, in previous similar studies only experienced care workers or supervisory staff have been used as 'dementia champions' (Ballard et al., 2017). However, given the reportedly flexible nature of the work undertaken by participating ancillary and 'other' staff, they seem ideally suited to undertake joint work as champions with care workers.

6.3.2 Does the intervention have the potential to improve the knowledge and application of personhood and citizenship theory by staff?

When adjusted for gender, experience and staff role the direction of effect changed and moved towards more positive PDQ and VAS scores for staff allocated to the PERSONABLE arm. For the staff that attended PERSONABLE there was good engagement with the content of the workshop. The simple message within each exercise and the reflective nature of PERSONABLE prompted dynamic discussions between participants. Only two participants did not complete the brief tasks designated within the workbooks. To promote free flowing discussion, managers had been excluded from participating. One aim of PERSONABLE was to provide a safe environment for staff to explore and suggest ideas to better facilitate the personhood and citizenship of residents with dementia. This approach attempted to broaden discussion and promote reflective practice (Spector et al., 2016).

When facilitating PERSONABLE, some obstructions to the fluid discussion of personhood and citizenship were observed. Exercise four explored and contrasted staff views of the community in and outside the care home. One participant suggested introducing animals to diversify the care home community. This proposal was opposed

by a member of the administrative team, who stated the manager had ruled out having animals in the home. This proxy statement of authority closed this line of exploration despite my attempts to encourage staff to further explore this interesting idea.

Considering the implementation of pledges more actively involving managers may have encouraged staff participants to form a plan for implementation. This interaction with management staff could have occurred after PERSONABLE had been attended by staff. This might have promoted an integrated approach to leadership. The positive impact of engaging management in the implementation of a cycle of reflective learning has been considered (Griffiths et al., 2019), identifying the role of managers in appraising the skills of staff to facilitate adaptations to care because of an intervention. Using managers to review the skills and preferences of care workers could be further expanded by engaging staff working in ancillary and 'other' roles in the active components of intervention delivery.

Twenty-nine staff attended PERSONABLE, which was encouraging given the limited resources available. There was high attrition of staff allocated to the PERSONABLE arm. This meant that many staff who had attended PERSONABLE had left employment between intervention delivery and follow-up measurements. The high staff turnover increased the likelihood of staff who had attended PERSONABLE being absent on the day of follow-up DCM™ measurement, reducing the possibility of observation capturing changes to care. For the two smaller care homes allocated to the PERSONABLE arm there was less attrition of staff, increasing the likelihood of staff who had attended PERSONABLE being present on the day of follow-up measurement. Greater resources would have been required to increase the DCM™ observation periods and the subsequent sensitivity of DCM™ to PERSONABLE implementation (Chenoweth et al., 2009).

This study used DCM™ in a novel way by separating the outcome measure from the interventional reflective feedback of DCM™. The literature review indicated that although some researchers describe DCM™ as the outcome measure, it remains dependent on the reflective feedback given to staff after observation (Chenoweth and Jeon, 2007). Typically in DCM™ research this feedback constitutes the 'active'

component, or intervention, used to deliver personhood theory to staff, who then make changes to their working practices (Ervin and Koschel, 2012). Generally, staff had no difficulty separating the use of DCM™ as an outcome measure from the PERSONABLE workshop. However, one care manager who was qualified in using DCM™ did question why there was no reflective feedback, prompting an informative discussion on the methodology of this study.

The idea for the PERSONABLE pledges, in exercise five, was to bridge the gap between theoretical reflection and its application to care. All but two of the pledges made by participants reflected either personhood or citizenship. Not giving staff verbal or written examples of pledges challenged staff to demonstrate their interpretation of the theoretical principles delivered within PERSONABLE. This reflexive approach to the pledges attempted to step away from more prescriptive educational methods (Testad et al., 2016, Beer et al., 2011a). Only two participants declined to write a pledge, one participant stated they could not think of a pledge and another did not give a reason. Two participants made pledges about hydration which did not seem reflective of the content or principles explored in PERSONABLE. One of these participants copied their pledge from her colleague who had been a champion for another study promoting the hydration of residents.

Staff pledges which reflected personhood were mostly attempts to understand the life history of the residents. There were no pledges which demonstrated a broader understanding of the adapted personhood model explored in exercises two and three. Interestingly, many ancillary staff demonstrated a high level of citizenship awareness and much of their vibrant discussion during PERSONABLE centred on the rights and identity of the residents. This was surprising given the lack of personhood and citizenship training this group of staff receive (Irvine et al., 2013). It is possible ancillary staff have more freedom in their working day to seek supervisor support, which Willemse et al. (2015) asserted can improve the person-centred care provided by staff. I discussed with one manager the reason why ancillary staff might demonstrate an aptitude for citizenship and she hypothesised that ancillary staff have a greater amount of time to observe care practices. Indeed, one member of ancillary staff pledged to take time to 'watch' the care environment. Comparatively, because of the

demands during a normal working day, there can be a tendency of care workers to focus on the sometimes challenging demands of direct care tasks involving residents (Orchard et al., 2017).

Reflecting on the time which might be required to carry out pledges, those embodying personhood which added to the existing workload of staff, usually involved spending time with residents in addition to usual care. This resonated with the observations of Bosco et al. (2019) who identified a need for additional staff resources when promoting the co-production of resident personhood. Conversely, pledges reflective of citizenship frequently introduced resources into the care environment from the outside community such as, organisations, children, animals and objects. If facilitated by care home management and owners, citizenship approaches could promote the involvement of the community in residential care, embedding resident citizenship in the wider community (Birt et al., 2017).

The facilitation of resident citizenship was considered by one ancillary member of staff who pledged to 'give a resident a duster'. This pledge helped reposition the resident from a 'recipient' of care to a 'contributor', creating a role and purpose for the resident within the care home community (Phinney et al., 2016). This type of pledge embodies a transformative process, asserted as aiding the transition of a resident from a 'liminal' state to one promoting their identity (Birt et al., 2017). In this respect the pledge of 'giving a resident a duster' (citizenship) could have helped transition the resident from a 'dementia identity', to a 'personhood identity'. When the relationship between personhood and citizenship is viewed in this way, citizenship is not only an adjunct to personhood (Bartlett and O'Connor, 2007), but an action and power catalysing personhood.

Exercises two and three had been designed to help explore personhood, by asking staff to consider their own personhood (exercise two) and then that of the resident (exercise three). The idea for this exercise had originated from research discovered within the literature review, which identified the benefit of a transformative process when staff make attempts to understand residents as individuals (Reed et al., 2017). The domain 'how I learn' had replaced 'neurological impairment' from the original personhood model proposed by Kitwood (1993b). The change from 'impairment' to

'learning' was to try and reposition this domain of the model as strengths based, encouraging a recovery focus (Judge et al., 2010). Staff ranked 'how I learn' as the least descriptive domain of personhood, for themselves and for the resident. This is an interesting ranking of the 'how I learn' domain because during DCM™ observation 'learning' had provided opportunities for enriching resident personhood and citizenship. An example of this relationship was a resident being very engaged when being taught to use the internet, on a tablet, to search for a lemonade recipe. For the 'my health' domain there was a statistically significant difference, with staff ranking the importance of 'my health' higher for residents than themselves. Optimistically, this might imply that staff acknowledge the impact of ill health on the personhood of an older population (Kitwood et al., 2007). A less empowering explanation is that staff view residents as defined by their health conditions (Kitwood et al., 2007).

6.3.3 Does a personhood and citizenship intervention have the potential to improve the wellbeing of residents with dementia?

This study tested the suitability of its primary outcome, the WIB, when attempting to measure the effect of PERSONABLE on the wellbeing of residents. The study was not powered to detect statistically significant changes in outcomes. However, the analysis provides an indication of the direction of effect, which did move slightly towards more positive WIB scores for residents allocated to the PERSONABLE arm. The field notes made when conducting DCM™ observation do occasionally capture incidences when staff members who had attended PERSONABLE were interacting with residents in a manner promoting personhood or citizenship. However, there were not enough of these incidences to provide a comparison between field notes collected at baseline and follow-up.

When adjusted for gender the direction of effect for the primary outcome (WIB) moved positively in the direction of the PERSONABLE arm. Further emphasising the importance of collecting sufficient demographic data for the analysis of a cluster randomised controlled trial (Campbell and Walters, 2014). These observations of the potential effect on the wellbeing of the residents should ultimately be viewed in the context of the limitations of the study. The effect of the intervention would have been impacted by limited blinding, low study power and the sensitivity of the primary outcome in capturing the effect of PERSONABLE.

6.4 Feasibility of the measurements

6.4.1 Does Dementia Care Mapping™ capture any possible effect of changes in staff or resident behaviour as a result of a personhood and citizenship intervention?

6.4.1.1 *Mood and engagement score*

A decision was made during the formulation of this study to explore whether wellbeing as measured by DCM™ would work as a primary outcome measure in a definitive trial. For many years there has been a strong evidence base underpinning the use of DCM™ to measure the wellbeing of people with dementia living in residential care homes (Brooker, 2005). However, there is some debate about what constitutes wellbeing and how this might be captured by observations conducted as part of a research study (van der Steen et al., 2001, Jonker et al., 2001).

DCM™ prioritises whether a score for mood or engagement is recorded within any given five minute time frame (University of Bradford, 2010). When used as a tool to gather information and then feedback to staff this mechanism is helpful because it allows the observer to comment on the experience which was most beneficial for the wellbeing of a resident, whether that be 'mood' or 'engagement'. For this feasibility trial, treating 'mood' and 'engagement' as one level of data limited how accurately the data represented the actual experience of the participating residents. Although mood and engagement both affect wellbeing, they are fundamentally different concepts (Thornton et al., 2004). The limitations of combining these two concepts in a research context was illustrated within the brief field notes collected during DCM™. One resident was very engaged with a jigsaw puzzle for the majority of baseline and follow-up measurements, however, his mood when doing the jigsaw puzzle was sombre. For this resident engagement was recorded as the predominant factor, giving this participant a high overall WIB score, despite his sombre mood. When used to transform and inform care, recording the better of the 'mood' or 'engagement' scores works well, ensuring staff concentrate on the component that has the most potential for wellbeing. However, in a research context this approach omits a perspective pertinent to the experience of a resident. After I had completed all follow-up DCM™ measurements I thanked the resident doing the jigsaw for letting me observe the care he received, during this conversation he informed me he had worked as a 'draftsman'. This information expanded my understanding of his personhood, providing an

explanation for his engagement with the jigsaw puzzle. Importantly, when telling me about this career he smiled profusely for the first time in the eight hours I had been observing.

A separation of 'mood' and 'engagement' could help provide a more accurate representation of DCM™ data collected to represent the experience of a person with dementia. This approach might better capture variation in the resident experience occurring in different clusters, and more completely detect important effects of an intervention.

6.4.1.2 Behaviour category codes

The behaviour category codes have a strong influence on the ME score of participants (Innes and Surr, 2001). Consistent with previous research I observed an abundance of the behaviour code 'borderline (B)' at both baseline and follow-up, representing a participant being passively engaged in their environment (Thornton et al., 2004, Sloane et al., 2007). Although the behaviour category code 'borderline (B)' can attain a higher ME score, it is usual for this behaviour code to be assigned a neutral value. The essence of the 'borderline (B)' behaviour code is that someone is passively engaging with their environment (University of Bradford, 2010). Behaviour category codes are further explored in the section discussing the inter-rater observations conducted as part of the study.

6.4.1.3 Personal enhancers and personal detractors

When DCM™ is used as a practice development tool every interaction between staff and residents is not routinely recorded. Interactions are only documented when they stand out as important, either by meaningfully enhancing or detracting from the resident experience. In an attempt to capture the effect of PERSONABLE the approach to the recording of enhancing and detracting interactions for this study was different and recorded every interaction that occurred. As explored in the results, the brief field notes captured some changes to the approach of staff who had attended PERSONABLE.

Because of the large number of residents to be observed in the settings, before baseline measures were conducted a decision to use a binary system to record staff interactions was chosen. When DCM™ was piloted in phase one of the study the

emphasis was on exploring how many resident experiences could be accurately recorded using DCM™. There were few staff interactions during the piloting of DCM™ and after discussion with my supervisory team and a DCM™ trainer, it was agreed that assigning binary values would broadly capture changes to staff behaviour. Towards the end of baseline observation, across the six study sites, it became apparent that many interactions were neither positive nor negative and that a neutral code might better describe patterns in staff interactions. However, at this point it was decided to continue with the original binary recording of staff interactions to maintain parity across study sites.

DCM™ is designed for use with people with dementia who find it hard to verbalise their experience (Baldwin, 2007). The positive impact of a recovery approach, on the wellbeing of people with mild cognitive impairment has been reported in a pilot randomised controlled trial (Jha et al., 2013). When recording enhancing and detracting interactions at baseline and follow-up, I frequently noted that staff were more readily engaged with residents who appeared to have a higher level of cognitive function. This pattern of care was especially apparent during meal times, when staff would sit with residents who appeared less impaired, speaking with them whilst eating their meal. Staff appeared less ready to employ a recovery approach when interacting with residents with more advanced dementia. Staff appeared less confident and to struggle to communicate with this group of residents.

There were some exceptions. At baseline a care worker in one of the TAU care homes used a flower to visually prompt a conversation with a resident with very severe dementia, by saying 'look at this lovely flower'. At follow-up a care worker who had attended PERSONABLE used simple conversation prompts, gestures and facial expressions in an attempt to facilitate discussion between residents during the lunch period. These approaches shifted the focus from the performance of a task to the promotion of personhood and citizenship using a recovery approach (Judge et al., 2010). It is encouraging that a recovery approach is being adopted with people newly diagnosed with dementia (Jha et al., 2013). However, there is a need to explore how to extend this with people who might have a more advanced dementia, requiring a higher level of staff skill and awareness (Adams, 2010).

6.4.1.4 *Interrater reliability*

Prior to undertaking DCM™ with the second observer (JF) I had not spoken with her about the DCM™ operational rules. The operational rules of DCM™ are designed to standardise the implementation of the tool (Cooke and Chaudhury, 2013). Few studies that use DCM™ conduct the measure without a period of consolidation between observers prior to collecting trial data (Thornton et al., 2004). Spending time together is aimed at reducing disagreement between observers; however, even when observers have formative discussions prior to conducting DCM™ there remains considerable disagreement (Surr et al., 2018a). Within a process evaluation Surr et al. (2019) observed that agreement improves when mappers receive appropriate time to discuss mapping and coding practices supported by a suitably trained person. This was certainly the case when I was refreshing my DCM™ competence with an expert mapper (JW) at the beginning of my doctoral study. The cost of employing the second observer (JF) was £200 a day and limited the time available to conduct consolidation of DCM™ procedures prior to the day of data collection. However, JF and I went through an active process of mediation that complemented our schedule:

- 1) We travelled together for an hour to the care homes, during which time we discussed our use of DCM™ and its application within care homes.
- 2) JF is an expert mapper and has been involved in running DCM™ courses. She is passionate about the observational measure and quickly identified when my mapping did not reflect the guidance in the DCM™ handbook (University of Bradford, 2010).
- 3) We took frequent breaks together during the mapping period which increased opportunity for reflection on the observation period.

On the first day these factors did not seem to have an impact on our agreement and the weighted Kappa scores were poor. The following day we again drove to the second site. The time we had spent together on the previous day and reflecting that night seemed to have a mediating effect on our agreement and there was a modest improvement to the Kappa scores. Although the change in weighted Kappa scores was small, the increased opportunities for reconciling interactions and reviewing the DCM™ handbook (University of Bradford, 2010), seemed to have prompted an

improved understanding of the way in which we operationalised the DCM™ procedural rules.

One of the biggest differences in our coding was the ME value we were each assigning when coding for 'food (F)'. This was a pertinent difference given that the largest proportion of resident behaviours surrounded food. The DCM™ manual (University of Bradford, 2010) attempts to explain the interpretation of behaviours surrounding food, stating that the engagement score should be higher if accompanied by a positive mood. Despite this clarification some subjectivity remained between our interpretation of the levels of mood and engagement we assigned to behaviours surrounding food.

One of the key attributes of DCM™ is the range of codes which are available to accurately describe the experience of the people being observed. However, the breadth of behaviour codes complicates levels of agreement between observers (Thornton et al., 2004, Innes and Surr, 2001). For this study, when the behaviour category codes were grouped and analysed by their 'potential for wellbeing' observer agreement dramatically increased. However, grouping the behaviour category codes loses the sensitivity of the measurement when describing resident behaviour. Some consolidation of behaviour codes might be an alternative approach which could acknowledge this limitation whilst improving agreement between observers.

Reflecting on my experiences conducting interrater reliability testing I initially felt despondent by the lack of agreement between JF and myself. During our brief formative discussions I was aware that my use of DCM™ was not as informed as JFs and because this was my study I had felt that I was somehow not appropriately qualified to be conducting this observation. JF was very supportive during the observations, but each time we discussed the measure my confidence in the way I was conducting DCM™ diminished. I could feel myself second guessing every code I entered for each time frame and rather than concentrate on observation and referring to the DCM™ handbook (University of Bradford, 2010) I would spend much time attempting to second guess what JF would be coding. Reflecting on their DCM™ practice, Mansah et al. (2008) has highlighted that actively engaging in reflection during DCM™ prompted them to engage in more cross checking activities, such as

referring to the DCM™ handbook or speaking with someone experienced in DCM™ measurement. This was certainly my experience. I had done some mapping with JW in phase one of the study, had this resource been more available throughout my study my mapping accuracy may have improved. In the context of larger cluster trials, maintaining adequate training for researchers conducting DCM™ who might live in different areas, may still be a worthwhile investment (Chenoweth et al., 2009). Refined approaches to DCM™ have been attempted (Fulton et al., 2006) and although these adaptations to the measurement produce good results, they could compromise the original purpose of the measure, to sensitively describe the experience and behaviour of a person with dementia. One solution might be to tailor the measure to the environment and omit behaviour codes not relevant to the surroundings. This approach has been used successfully in a study conducted on a neurology rehabilitation ward in an acute general hospital (McIntosh et al., 2012). Reflecting on my use of DCM™ during the interrater agreement, adapting the codes might have given us more flexibility to focus on and agree our approach to the remaining codes.

6.4.2 Are the chosen outcome measures acceptable and useful to participants?

6.4.2.1 Personhood in dementia questionnaire

The Personhood in Dementia Questionnaire (PDQ) is the only measure this study found which specifically measures staff attitudes to personhood and citizenship principles in relation to people with dementia (Hunter et al., 2013b). When reviewing the questions in the PDQ it clearly covers topics pertinent to citizenship, and therefore was ideally suited to the purpose of this study. The possible difficulty of staff engagement with questionnaires delivered within a trial has been reported (Beer et al., 2011a). The PDQ was accessible to staff participants taking approximately ten minutes to complete. The PDQ was well received by staff, with few objections to the length of the questionnaire or content of the questions. The small time commitment necessary to complete the PDQ is one possible reason for the good staff response to questionnaires. Some staff annotated the questionnaires to indicate frustration with what they felt were ambiguous questions; however, this occurred on only three questionnaires.

When designing the study there were problems finding measures which might accurately capture changes in staff knowledge. Historically, measures used to assess staff knowledge in this area concentrated on a medicalised understanding of dementia (McCallion et al., 1999, Spector et al., 2013a). Scerri and Scerri (2019) highlight that many staff measures which seek to explore staff knowledge can be too focused. They recommend a more global approach when measuring staff knowledge. This view is shared by Spector et al. (2016) who suggest that the nature of measuring a change in staff knowledge is 'abstract' and indicate that this is further complicated by brief measurement tools, which are not equipped to measure global concepts. Furthermore, statistically significant changes in resident outcomes do not always seem to correlate to statistically significant changes in staff knowledge, attitude or wellbeing (Teri et al., 2005). Even when staff measures are absent from trials, statistically significant changes in resident outcomes still provide sufficient evidence of intervention effect (Deudon et al., 2009).

6.4.2.2 Visual analogue scale

Temple et al. (2004) suggest visual analogue scales can be an effective way to measure broad concepts, such as mood and anxiety. Arons et al. (2013b) acknowledges that one shortcoming of a visual analogue scale is the differing way in which a person completing the scale might interpret a more theoretically detailed question. This could apply for the question used within this study, which although brief had been deliberately designed to capture a broad range of interpretations by staff. Arons et al. (2013b) highlight that visual analogue scales are more susceptible to changes in participant mood and circumstances than traditional questionnaires. Sabbagh et al. (2000) propose that different interpretations of VAS questions can be mediated by the use of broader questions and support qualitative interviews to explore the meaning behind the interpretation of questions. If time had of allowed, this would have been an interesting approach to take with the VAS used by this study to gain a better understanding of how different staff groups perceive care.

The question 'how able do you feel to care for residents who have dementia' seemed to be interpreted in different ways depending on staff role. Very little is currently known about the varying attitudes to care of different staff groups (Spector et al., 2016). Some ancillary and 'other' staff made comments which indicated they did not

think the term 'care' applied to their work. The higher VAS score for care workers suggests they have no difficulty perceiving their role as the provision of care, or that they believe they have a high level of competence. If staff interpret their roles as having different underlying purposes this might create friction between staff groups when individual staff objectives interact (Harmer and Orrell, 2008). From the results of this study it seems that care homes which had more permeable borders between staff roles facilitated an approach to care which better complemented personhood and citizenship principles.

Within the mixed regression there was some evidence of the predictive influence of staff role. There was a statistically significant effect of staff role on the VAS score, with ancillary and 'other' staff reporting less perceived ability to care for residents with dementia. This significance should be viewed in the light of the sample size and wide confidence intervals. However, it does give an indication of statistical effect and possibly indicates differing attitudes to care. This would be an interesting area for a more thorough appraisal if a definitive trial were to take place.

6.4.2.3 Therapeutic Environment Screening Survey – Residential Care (TESS-RC)

The TESS-RC was chosen to help document the physical make-up of the residential care environment and DCM™ provided a description of the social environment. These two aspects helped constitute an appraisal of usual care in line with the model proposed by Stokes and Goudie (1990).

Overall the homes allocated to PERSONABLE scored higher in the TESS-RC, a pattern not reflected by their most recent CQC reports. Individually, the care homes who had changes in leadership between baseline and follow-up scored lower on the TESS-RC. The physical and social make-up of the care homes seemed interlinked, and it appeared that a stable social environment, reflected by better staffing levels and retention, enhanced the personalisation of the physical environment, captured by the TESS-RC.

However, a thorough exploration of the personalisation of the care homes was partly obscured. To help maintain resident dignity, it was agreed with the Social Care Ethics Committee that the TESS-RC questions pertaining to the bedrooms of the residents would not be completed, these questions were shaded grey in the TESS-RC (appendix

seventeen). Therefore, a significant part of the appraisal of usual care was missing. This restriction might have reduced the sensitivity of the TESS-RC to the nuances of each care setting. Reflecting on my clinical experience, bedrooms are an important component when appraising the personalisation of the care environment. Gaining an insight surrounding bedrooms may have provided an improved insight into the participating care homes attitudes to resident personhood.

I had chosen the TESS-RC because it was a quantitative measure and when reviewing the questionnaire I felt there would be sufficient time to complete this measure on the days of baseline DCM™ observation. For this reason I had rejected the use of the 'Environmental Assessment Tool' created by Waller et al. (2017). However, when it came to completing the TESS-RC and preparation for DCM™ baseline observations, I had allowed much more time than was necessary and therefore considered that I could have completed the 'Environmental Assessment Tool' (Waller et al., 2017). The measure might have provided a more thorough appraisal of the residential care homes because it specifically assesses an environment in relation to the provision of person-centred care. The TESS-RC is a feasible measure and reflecting on the participating care homes in this study, this measure did appear to reflect the quality of the care homes. However, if a definitive trial were to be conducted the use of the 'Environmental Assessment Tool' (Waller et al., 2017) would be more in keeping with the nature of a person-centred intervention, because it is specifically designed for use with people who have dementia who live in residential care settings.

6.4.3 Summarising the overall feasibility of a definitive randomised controlled trial

6.4.3.1 Recruitment

I recruited a total of nine separate care homes, 138 staff and 40 residents, across phases one and two of this study. Compared to the experience of others (Beer et al., 2011a, Chenoweth et al., 2009) recruitment was positive and relatively straightforward. The main limiting factor was the time I could reasonably give to ensuring recruitment adhered to the specified trial procedures. The training intervention seemed to be a draw for care home participation, staff recruitment was improved by using existing staff with knowledge of the trial to promote the study and

resident recruitment was improved when a personal or nominated consultee was available. The conclusion for this aspect of the trial is that recruitment for a definitive trial delivering an intervention is feasible at the level of care home, staff and resident. However, adaptations to simplify recruitment procedures, whilst also maintaining ethical integrity, may help to promote staff and resident participation, should a definitive trial be conducted.

6.4.3.2 Blinding and bias

A relatively large amount of cluster randomised controlled trials have been conducted in residential care settings. However, a simpler approach to study outcomes measuring any possible effect of a personhood and citizenship intervention, has not yet been explored. The randomised controlled trial is often purported as the gold standard of scientific rigour (Ahuja, 2019, Tibboel, 2016). However, in the context of residential care homes it is not always easy to adhere to the underlying principles of this methodology. During the various parts of the feasibility study I encountered significant problems either implementing or maintaining the blinding of researchers and participants. This occurred during baseline and follow-up measurements, randomisation and intervention delivery. Blinding of myself to group allocation and attendance at PERSONABLE was possible for the PDQ and VAS data. However, to a certain extent this was compromised when I was creating the initial spreadsheets of questionnaire data. This was because I had to separate the consent forms, which had participant names on them, from the questionnaires which had numerical codes intended to provide some anonymity. The presence of another autonomous person to separate the consent forms from questionnaire data would mitigate this issue and could be factored into any grant application for a definitive trial. Blinding was not possible for DCM™ observation because I was aware of group allocation and could remember which staff had attended PERSONABLE; this had a clear impact on the validity of the data. However, in a definitive trial independent DCM™ observers could be employed, although steps would need to be taken to ensure staff were aware not to inform the observers of their group allocation.

The increased possibility of selection bias during care home recruitment was considered and accounted for by attempting to recruit homes that varied in term of

the environments they provided for residents. Avoiding bias in staff and resident selection was a greater challenge. This was because managers were responsible for the initial introduction to residents and staff and those willing to engage with the study were more likely to participate. Attempts were made to encourage a wide variety of participants through conversations with managers and by making myself available to speak with staff who were perhaps more ambivalent about participation. Further consideration of the effective shielding of research staff to intervention allocation is desirable if blinding is to be successfully achieved within a definitive trial.

6.4.3.3 Baseline measurements

I conducted all the baseline measures. On the morning of DCM™ baseline measurements there was sufficient time to undertake the TESS-RC without compromising data quality. This gave me an opportunity to familiarise myself with the care home structure prior to observation taking place. Conducting DCM™ in care homes which were not used to this measure took extra time to make sure managers, staff and residents were all aware of the nature of my presence. Once DCM™ data collection began all baseline measurements were conducted with very few difficulties. Across the six care homes there were only two occasions when staff or residents sought further clarification of my presence. No member of staff or resident expressed their reluctance to be observed or withdraw from the observation. Not having access to resident records did mean a reliance on managers to know whether participating residents had a diagnosis of dementia; this resulted in one resident having to be withdrawn from the study when it became apparent that their diagnosis was not clear. However, this was in line with the ethical approval obtained as there was no access to resident records.

When conducting baseline measurements, levels of engagement with the PDQ questionnaire and VAS were positive. Staff members were willing to fill in the questionnaires - there was only one instance where a member of staff expressed an open desire not to complete a questionnaire although this member of staff did consent to being observed during DCM™. Despite the expressed positive engagement of the staff who were approached, the overall proportion of employed staff completing baseline measures was lower than expected. A definitive trial might need

to consider even briefer staff measures or possible incentives to participate. If briefer staff measures were adopted, resources could then be placed in other areas of the trial such as intervention delivery or qualitative data. Another solution might be to assign a member of the staff to collaborate and promote awareness of study measurements. This could also promote engagement with study measurements, when one staff member informally took this role, during baseline measurements, I observed better staff engagement. The conclusion for this aspect of the trial is that with further consideration and adaptations baseline measurements are a feasible component of a definitive trial.

6.4.3.4 Randomisation

For this study randomisation was conducted by AA. Care homes were given anonymised study site codes and then randomised using the 'ralloc' command in Stata version 12. Even though AA was familiar with the trial and acted as primary supervisor for the study, he was unaware of how a code number related to an individual home when conducting the randomisation process. This aspect of a definitive trial is feasible.

6.4.3.5 Intervention

Attendance at PERSONABLE was low (n=29) when viewed as a proportion of the total staff population across participating care homes. This was in part due to a high staff turnover in some of the care homes allocated to the intervention. The reasons for non-attendance seemed to be related to four issues: i) the intervention being delivered on a day when staff were not working ii) staff not feeling motivated to attend the training iii) not having sufficient staff to cover work whilst other staff attended PERSONABLE and iv) staff not realising PERSONABLE was open to all staff; this point especially related to administration and maintenance staff. I had reflected on the evidence located in the literature review and specifically developed the intervention to fit with busy care home routines. Despite this adaptation, poor engagement with training seems to be a pervasive pattern in care home research (Beer et al., 2011a, Romeo et al., 2019).

Different approaches to managing the lack of engagement with training delivered within trials conducted in care homes has been exhaustively considered, see for example the systematic literature reviews conducted by Spector et al. (2016) or Surr et al. (2017). A more tailored approach to training has been reported by the authors

of the WHELD trial as successful (Fossey et al., 2019). The WHELD trial took an individualised approach when delivering training, similar to that of a clinician visiting a care home, or provision of individual staff coaching. On first appraisal, this approach does not reach as many staff; however, being a more targeted method could help ensure staff are receiving information in a manner and at a time which is responsive to their needs. This is a strategy which a standardised method of training cannot achieve. A more personalised approach might be especially effective when attempting to help those staff most in need of training or those most likely to implement knowledge gained from a personalised intervention. Reflecting on the successful methods used in the WHELD study (Fossey et al., 2019, Ballard et al., 2018), if the content of PERSONABLE could be adapted to be delivered in a more personalised manner, away from traditional classroom teaching, then it is feasible that this aspect of a definitive trial would be possible.

6.4.3.6 Follow-up measurements

I conducted all follow-up measurements with the exception of the inter-rater reliability testing conducted by JF at two homes during follow-up. As with the baseline measures, DCM™ was broadly accepted by the participants, there was a very small attrition between baseline and follow-up of residents due to death or ill health. However, it should be acknowledged that I only used the observational components of DCM™, which did not require many resources from the care home staff and residents, other than their good will in letting me observe them. Surr et al. (2020) reported much less engagement with DCM™ when care staff were asked to undertake the DCM™ training, observation and subsequent feedback to staff.

The engagement of staff with the PDQ and VAS follow-up measurements was poor. This lack of engagement was largely due to a total of twenty-three participating staff leaving employment in approximately ten weeks between baseline and follow-up measurements. Furthermore, ten participating staff were away from work due to sickness, holiday or shift patterns and therefore did not complete follow-up measurements. The very high proportion of staff leaving employment is a concern for a definitive trial; however, it is likely to be an ongoing issue and given that a cluster design already challenges study power, consideration of whether staff measures are a barrier to trial success is crucial.

Placing further emphasis on the part of my process evaluation which captured engagement with intervention content and study measurements would have helped me better understand the components of intervention delivery with which staff engage. This may have better informed and mapped out the recommendations for definitive trial procedures by providing richer insights into the difficulties staff face when attempting to implement knowledge gained from an intervention. In view of the high attrition to follow-up measurements, greater mapping of staff engagement would be required to aid clarity when it came to data analysis. This might include conducting outcome measurements at a greater number of time points, shortening the length of time between study measurements, making measurements more brief, or completing measurements before and after an intervention is delivered.

6.5 Utility of this study for resident personhood

The personhood model proposed by Kitwood (1993b) comprises four domains directly relating to the individual: health, biography, neurological impairment and personality. The social psychology domain is different because it refers to the discourse and behaviour of third parties towards the person with dementia (Kitwood, 1993b). The personhood model (Kitwood, 1993b) was adapted after the literature review, focused discussion groups and the piloting of PERSONABLE. After these steps, I remodelled Kitwood's conceptualisation of personhood to encompass the ideas of Tomaselli (1984) who described personhood as an internal state generated by external influences. A description similar to the relationship between behaviour and environmental experience proposed by Laing (1990). This remodelling had prompted me to consider further reflective exercises in the PERSONABLE workshop to help staff consider external influences. A process which also helped me explore what constituted an 'external influence'.

Models of personhood usually provide a framework to help an individual understand the personhood of a third party (Sakamoto et al., 2017). A fundamental factor influencing the usefulness of a personhood model is how effective the model is in assisting staff to empathise with the personhood of a resident (Vikstrom et al., 2015). Reflecting on the resident participants it seems logical to appraise personhood before considering external influences. Once someone has completed an appraisal of

individual personhood, the model could be expanded to acknowledge the impact of external influences like social and physical environments. This approach provides a bridge between the personhood model proposed by Kitwood (1993b) and the behavioural model of Stokes and Goudie (1990).

During baseline and follow-up measurements, a fluidity between intrinsic personhood and environmental influences seemed to be improved when the social and physical borders, between the staff and residents, were dissolved. A good example of this phenomenon is the care home in which care workers ate their meals with the residents, where numerous personhood enhancing interactions were observed.

The relationship between an individual and their environment is modelled by Radha Krishna and Alsuwaigh (2015) in their 'ring theory' model of personhood. This model allows personhood to be initially separated from the environment by considering 'innate' and 'individual' personhood, before the 'relational' personhood is understood in the context of the 'societal' environment. This was one reason why the PERSONABLE exercises had placed the consideration of personhood before an exploration of the residential community.

6.6 Utility of this study for resident citizenship

Citizenship applied to the care of people with dementia is a relatively new paradigm and not yet widely discussed in clinical practice, therefore the theory was new to me when beginning my doctoral studies in 2015. This created a challenge when exploring the theoretical relationship between personhood and citizenship.

My understanding of citizenship, and how it varied from personhood, was informed by my initial theoretical investigation (Bartlett et al., 2016, Birt et al., 2017). My theoretical understanding evolved through observations made when conducting the practical elements of this study and discussions with other researchers. The phase one focused discussion groups shaped my understanding of the enacting of citizenship within the residential care community. The analysis of focused discussion group data helped me further differentiate citizenship theory from personhood theory, observing themes and key characteristics. At this point, I understood the features of citizenship as a person having autonomy and purpose within a community.

During phase two my understanding of citizenship, and how it related to personhood, developed further. After completing baseline measurements I wondered why certain care homes implemented the theories of citizenship better than others. This thought process initially occurred by noticing a change in myself when moving between my different social environments: being a father, a researcher or a runner. I felt my self-expression change as I moved between these social environments. It occurred to me that each of these social environments has a boundary, a citizenship boundary in which my personhood is enacted. It seemed to me, the enacting of my personhood was citizenship.

The different citizenship boundaries affected the way in which my personhood was enacted. Reflecting on the term 'gradation' proposed by Barnes (2006) to describe diverse physical environments, the diversity of social environments could be referred to as 'social gradation'. To account for social gradation I would adapt my behaviour to different people, rules and conventions. Sometimes this adaptation felt comfortable and sometimes it felt restrictive. The realisation of a citizenship boundary made me reflect on how living inside just one boundary might affect my wellbeing, if the boundary is rigid and limits my access to the things which give me joy and a purpose.

Occasionally I observed a friction between the enacting of citizenship and individual personhood. This is similar to the conflict between individualism and communalism, described by Dougherty (1992). The interaction between individualism and communalism was sometimes an issue for residents exercising their personhood within the care home boundary. This was apparent for an Iranian participant who had different cultural expectations surrounding meal times. In this respect an established citizenship boundary was divisive and required the mediation of staff.

Without realising it I had been experiencing the friction between personhood and citizenship in the language I adopted when writing the literature review. Having spent time deliberating whether to use the term 'person with dementia' (personhood) or 'resident with dementia' (citizenship), I found that I more frequently used the term 'resident with dementia'. In hindsight I preferentially used this term to acknowledge the rights of the resident, set in the context of their residential care community.

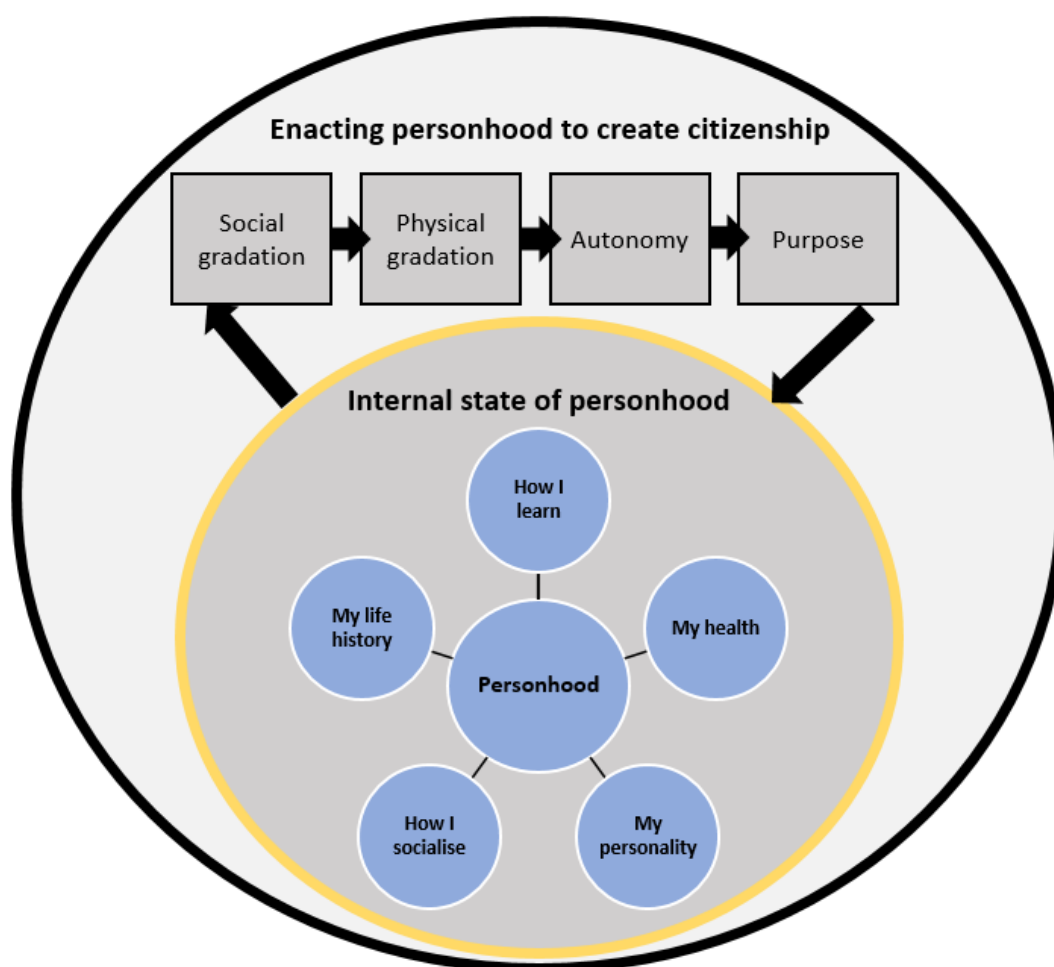
Reflecting further on this preference I feel there is no perfect answer, only the realisation that the two phrases have a different agency.

Extra staff resources were often required to bridge the gap between personhood and citizenship. One resident was observed having a conversation with a care worker and requesting to leave the care home, expressing her wish to be autonomous and return to the citizenship boundary of her family home, where she had not lived in many years. The care worker demonstrated great skill in this instance using validation (Neal and Barton Wright, 2003) to broaden their conversation and explore the underlying reasons why the lady wanted to leave. The open conversation provided useful information about the work the woman used to do, which she reported enjoying and smiled during this interaction. This simple interaction positively acknowledged the personhood of this resident, enhancing her diminished citizenship state. The resident had felt better understood as a person and her observed mood and engagement score had increased. For a period of time after this interaction the resident appeared more comfortable within what she had felt was an unfamiliar citizenship boundary, the care home.

This example mirrors the 'ring theory' of personhood proposed by Radha Krishna and Alsuwaigh (2015), the care worker had considered the 'innate' and 'individual' personhood of the resident, then enacted 'relational' personhood in their interaction. The result of this process being the improved 'societal' personhood of the resident. It is possible that citizenship is 'societal personhood', the enacting of personhood within the boundary of a specific community.

Based on my evolving understanding of the two theories, I have attempted to illustrate the circular relationship between the internal state of personhood and the enacting of citizenship within a community boundary (Figure 29). The yellow circle denotes the boundary of personhood, and the black circle the citizenship boundary.

Figure 29: The components of, and relationship between, personhood and citizenship



Other citizenship boundaries were observed within the care homes. I frequently observed rigid boundaries between residents and staff. In one care home some residents spent much of their time in their bedrooms. The care home manager stated that the residents had the capacity to decide where to spend their time. However, residents appeared to be in greater spirits when in the dining room at lunchtime.

In the same care home two residents came to the staff office to enquire when an activity would take place and were told the activity had been cancelled and the residents returned to their bedrooms. In this instance, the discourse between the staff and residents seemed to create invisible citizenship boundaries between resident, communal and staff space. Seemingly, the residents felt they needed an invitation to

join the communal areas, restricting any positive effect of social or physical gradation (Barnes, 2006).

There were differences in the use of citizenship between staff working in different roles and barriers between staff groups were observed. Typically ancillary staff performed tasks in the environment such as cleaning or food preparation, rather than performing tasks to the residents. This means that when in the company of residents, ancillary staff more often positioned residents as 'accomplices' to care rather than 'objects' of care. One ancillary staff member was seen giving a resident participant some towels to fold up and place in a cupboard, which the resident seemed to enjoy. Care workers had more rigid routines and often this limited approaches used with residents. However, some care staff were skilled in the promotion of citizenship and were observed to promote the inclusion of residents in care tasks such as laying tables and serving drinks. These types of care interventions were observed to directly improve resident wellbeing, possibly by giving residents a sense of purpose.

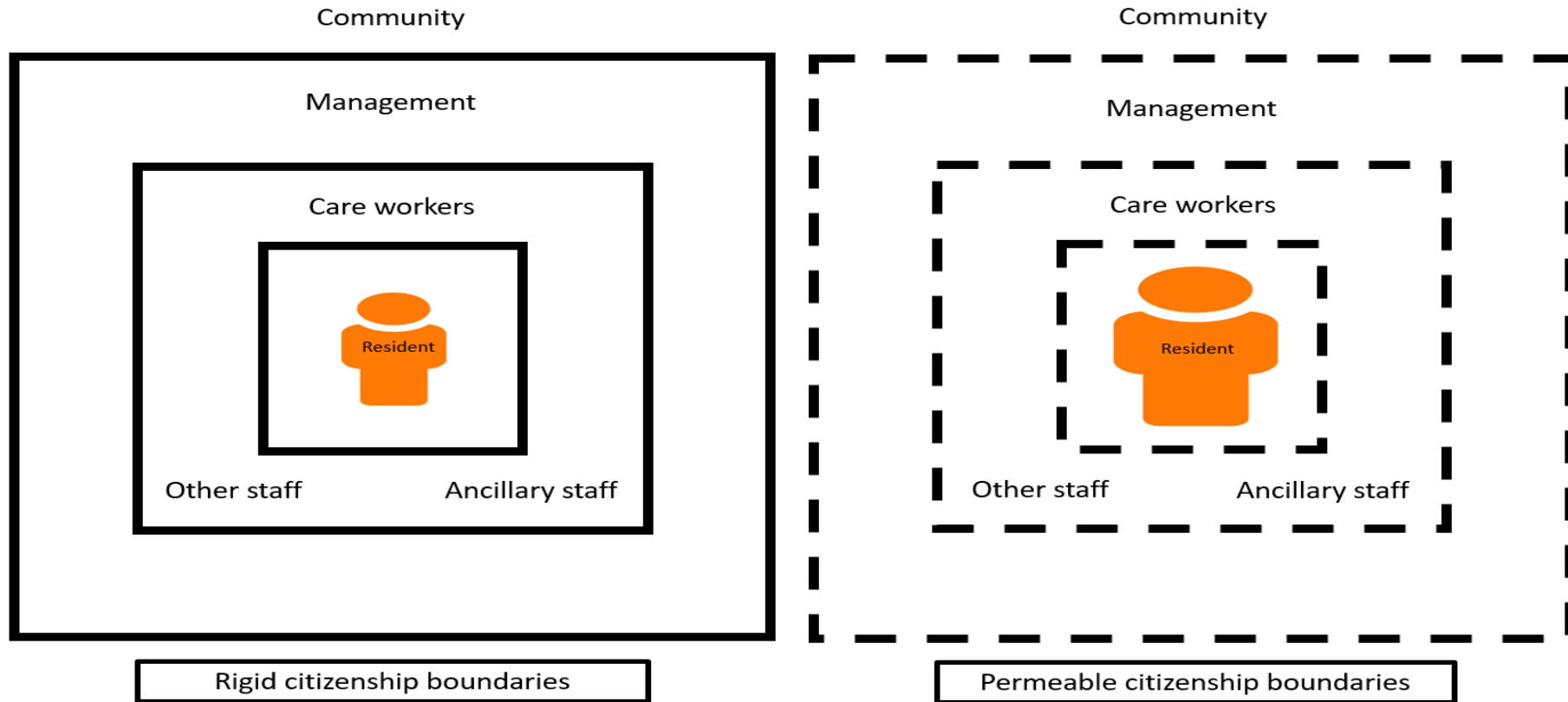
Staff who combined citizenship with the tasks they had to perform were in the minority. Usually, pressure on care worker time and demanding institutional routines impacted on the ideal of engaging residents in everyday tasks. In one care home a resident was observed independently eating their breakfast, but during the busier lunch period a care worker spoon fed the same resident. My accompanying note read 'tried to help resident with food despite her (resident) being able to do this herself'. Other barriers to the utility of citizenship were observed on a technological level, and in two participating care homes staff inputted the completion of care tasks into a mobile phone application, a task which took considerable time and detracted from time spent with residents. In comparison, staff in another care home wrote resident notes collaboratively with the residents in the lounge area.

Those care homes which had more frequent enhancing interactions, reflective of citizenship, all seemed to have common denominators, strong links with the community outside of the care home walls and managers who integrated themselves into the day-to-day care of residents. Permeating the barriers between the care home and the 'outside' seemed to promote an enriched sense of community within the care home. An observation reinforced by a comparative thematic analysis discovered in the

literature review (Woodward, 2018). This study compared four care settings, observing 2170 staff and resident interactions. The study concluded an improved resident quality of life in the hospice setting, which had more frequent visitors from the outside community. Concerning my study, when conducting DCM™ observation in one of the care homes a lady visited from the 'outside' community. She brought home made scones and sat with some of the residents preparing the scones. During her visit the simple activity and her conversation about the village outside the care home walls had a connective effect between staff and residents.

Strong links between the wider external community and the internal community of the care home, increased opportunities for enhancing interactions which might promote citizenship. Figure 30 illustrates the possible effect of rigid and permeable citizenship borders on the personhood of residents with dementia. The illustration, which draws on observations made when conducting this study, attempts to describe the positive effect on resident personhood when the citizenship boundaries between the outside community and the inside community of the care home are permeable. Furthermore, when the citizenship boundaries between the different staff groups are permeable the opportunities for resident personhood could be further increased.

Figure 30: Modelling the effect on personhood of rigid and permeable citizenship boundaries



*The personhood of the individual living in a 'rigid citizenship' boundary is proposed to be more restricted (represented with a smaller orange resident)

6.7 Summary of study strengths and limitations

The discussion chapter has attempted to interpret the results of this study. In this section I will draw together this interpretation by discussing the strengths of the study. Limitations of the study will also be discussed to explore how adjustments to my approach might have more comprehensively explored the research questions.

6.7.1 Study design

Throughout the formative stages of the study, I frequently encountered a trade-off between collecting more data and designing study methods enabling me to keep the study on schedule. I could appreciate the significant time commitments of care home, resident and staff recruitment, resident capacity assessments, undertaking the consultee process and the conducting and analysing the measurements. I was mindful of not overcommitting my resources and compromising the quality of the work I would undertake. There remain many components of a cluster randomised controlled trial methodology in need of further exploration, refinement and clarification (Froggatt et al., 2020). Expanding the amount of good feasibility studies which numerically capture issues with recruitment, engagement with interventions and exploration of the appropriateness of outcome measurements is fundamental to progressing understanding (Froggatt et al., 2018).

However, there were occasions when a mixed methods approach might have complemented this study, such as an appraisal of the feasibility of study measures and staff opinions on PERSONABLE. However, as the only person undertaking this complex methodology, I believed that a mixed methods approach would not be viable without deviating from the study schedule. Undertaking this study has highlighted that some qualitative work could have been integrated into study methods without generating significant extra work at the point of data collection. However, from the phase one qualitative work I learnt that even small quantities of data, which might not take long to collect, generate a significant time burden in relation to analysis. When I had to make decisions surrounding collecting more qualitative data to inform study feasibility, my approach was always pragmatic and to keep my research methods workable and achievable. This approach accounted for the proposed scale of the study, which was conducted almost entirely by myself and involved: undertaking two different ethics procedures, recruiting three care homes (phase one), six care homes

(phase two), twenty care staff and family members (phase one), 118 care home staff (phase two) and 40 care home residents (phase two), as well as delivering the intervention to three care homes.

This study used the gold standard design of a randomised controlled trial. Care homes are challenging environments in which to conduct trials. Rather than attempt a definitive trial, this study has generated evidence that can inform a definitive trial, thereby increasing the probability of success. Cluster randomisation was targeted at the level of care home. Based on the successful recruitment of care homes and the retention of all sites during the trial, randomisation appeared to be acceptable.

The intraclass correlation coefficients suggest that there is some variation in terms of both residents and staff between care homes. Interestingly, this variation was less in the two care homes with the highest TESS-RC scores. Understanding that variation exists will allow for a more precise power calculation that takes account of the clustered nature of the study design.

6.7.2 Ethical approval

For phase one of the study ethical approval was sought through the university ethics committee. This committee is unable to grant permission for the inclusion of people who may lack capacity, such as those with dementia. During intervention development it would have been helpful to find out from people with a dementia diagnosis what types of staff interactions are usual and how these interactions might better promote personhood and citizenship.

The ideal of including people with a dementia diagnosis in the formative stages of this study was obstructed by some current undefined conventions in research. The decision to approach the university ethics committee had been a response to ambiguous information when investigating the nature of Patient and Public Involvement. This practice seemed to be diffusely explained by the various professionals and public bodies I approached (Charlesworth, 2018, Bethell et al., 2018). In addition to the varied information surrounding patient and public involvement there was an absence of resident representatives to approach and none were available in the East of England (The Dementia Engagement and Empowerment Project, 2015). Given these disparities, I was not confident that I could collect and use

patient and public involvement data meaningfully or ethically, and I decided to go through a more formal university ethical clearance procedure.

For phase two of the study I sought ethical approval from the Social Care Research Ethics committee, a Health Research Authority committee, based in London. Drawing on the experience of other researchers who had previously submitted applications to this body I had taken advice to keep my protocol simple. This fitted with my plan of not overburdening the participants and being able to complete the study to schedule. However, the ethics committee meeting went much smoother than I had anticipated. I had deliberately not asked the ethics committee for permission to access resident notes at the care home. I made this choice after speaking to a professional who has sat on university and national ethics committees who felt obtaining this information would be problematic. Furthermore, the literature (Goodman et al., 2011) indicated the process of assessing capacity and approaching consultees might make recruiting sufficient residents to the study challenging. In hindsight I wonder if I could have asked the ethics committee to suggest an alternative way to overcome the practical barriers to collecting further resident information. This omission limited the variables used when adjusting the mixed effects regression model. Having this information may have helped identify patterns within the data, possibly indicating the influence of resident characteristics on the direction of effect of PERSONABLE.

6.7.3 Recruitment

Generally there was good participation from care homes, residents and staff. There were a total of thirty five staff, employed by the six care homes, who did not participate in the study. Capturing the reasons why staff did not participate in the study would have more completely informed an appraisal of the feasibility questions. However, this is problematic as information could not be sought directly from non-participating staff, which would have meant a reliance on conjecture from managers and other staff.

Another group who did not engage with this trial were people approached to be personal consultees. I had been aware that getting a response to requests for personal consultees might be a difficult part of the study (Goodman et al., 2011). However, there is limited evidence of the specific reasons for the non-engagement of personal

consultees making it difficult to plan this part of the study (Goodman and Davies, 2012, Goodman et al., 2011). At the point I asked administration staff to approach consultees I also relinquished control, which made keeping track of this part of the study problematic. Interestingly, after finishing data collection I was approached by a researcher from another university who requested general figures for my consultee process. They stated there was very little existing research which explored the difficulties of engaging consultees in the research process.

6.7.4 Intervention

Most of the limitations surrounding the design of PERSONABLE were explored during its development in phase one of this study. However, there were some additional issues which came to light in the practical delivery of PERSONABLE during phase two. Reflecting on the literature review (Beer et al., 2011a, Ballard et al., 2016) and feedback from the focused discussion groups PERSONABLE had been deliberately designed to be brief. This was a response to the reported time pressure on care home staff. PERSONABLE was delivered on one occasion at each care home allocated to the intervention arm. This was less than the three times per care home proposed in the study protocol, a reduction brought about at the point of recruitment when care home managers stated that three sessions would not be practicable or feasible. During the formative phases of the study, I had considered other ways to disperse information from the workshop to staff who did not attend, such as the staff 'champions' used in similar studies (Ballard et al., 2016). However, the brief intervention was intended to be something simple which could be practically implemented within care homes, should it ultimately prove beneficial. Additionally, I wanted to isolate the workshop from other 'active' components. Attempting to evaluate the feasibility of an intervention with multiple active components would not have been practical given my limited resources (Fossey et al., 2019, Ballard et al., 2017).

The PERSONABLE workbooks were deliberately brief and requested little information from staff, which aimed at optimising the opportunity for reflective discussion. Feedback pertinent to the content and delivery of PERSONABLE had been collected when conducting the pilot within phase one. However, collecting further information

in the context of phase two might have provided additional data on the acceptability of the workshop. Evaluation of a training intervention is a complex area which is site specific and influenced by the subjectivity of individual staff (Griffiths et al., 2019).

When constructing the draft research protocol for phase two of the study I had included some semi-structured interviews with staff. This approach has previously been taken in a process evaluation of a training intervention (Fossey et al., 2019). This process evaluation was published after I had made the decision not to conduct interviews; however, to a certain extent the report supports my concern that in face-to-face evaluations staff can feel obliged to give responses favourable to the intervention. The semi-structured interviews were proposed to be undertaken with staff that had attended PERSONABLE to gain an insight into their thoughts surrounding the intervention. When the protocol was complete and the full feasibility trial procedures were outlined, I took the decision to remove the semi-structured interviews. I made this choice because I felt that PERSONABLE had been adequately reviewed for the purposes of feasibility testing by the staff and family members attending the focused discussion groups. However, once follow-up measurements were complete I reflected on this choice and realised that a separate evaluation could have added context by reviewing PERSONABLE as it was delivered in phase two of the study. During follow-up measurements, I realised that a simple feedback form could have been included with the follow-up measurements. This feedback form would have gained simple qualitative data on the acceptability of the intervention, outcome measurements and associated trial procedures. A feedback form could also have provided insights into whether the staff who attended PERSONABLE implemented the pledges, or what barriers they had when attempting to implement their pledges. Furthermore, including a feedback form in the follow-up measurement packs might have helped participants to feel that they could give more honest feedback compared to face-to-face semi-structured interviews or solely relying on observational measurements (Hrobjartsson et al., 2012).

6.7.5 Measurements

I have been periodically using DCM™ in my clinical practice since 2011. However, more recently I have been using the tool less since moving from a ward-based environment to a community setting. On the ward DCM™ is routinely carried out when people with dementia are admitted. When I decided to use DCM™ as the outcome measure for this study, I spent time reviewing the DCM™ handbook (University of Bradford, 2010). Additionally, my line manager (JW) within the NHS was an expert DCM™ mapper and involved in a trial in which she trained care home staff in the use of DCM™ (Griffiths et al., 2019). I spent much time going over the operational rules and procedures of DCM™ with my NHS line manager, after which we spent a day mapping on a ward in an acute general hospital. In phase one I spent time on my own piloting DCM™ in a care home to further develop my confidence and skill. Despite being thorough in taking steps to refresh my knowledge I still lacked confidence in my ability with this outcome and had to frequently refer to the DCM™ handbook to check specific rules and coding. When undertaking the interrater reliability with JF, an experienced mapper and trainer, it was reassuring that they also frequently had to refer to the DCM™ operational handbook (University of Bradford, 2010).

Dementia Care Mapping™ has an extensive evidence base (Surr et al., 2018a). This study only used DCM™ as an observational measurement, omitting the reflective feedback usually given to staff after observation. Separating the data collected when performing DCM™ from the feedback given to staff was intended to explore whether DCM™ was sensitive to changes to the resident experience reflective of adaptations made to staff behaviour as a result of PERSONABLE. Every staff interaction with a resident was recorded, in an attempt to capture any changes in staff behaviour between baseline and follow-up measurements. However, because DCM™ was mostly carried out in the communal areas of the care home, observation did not capture interactions occurring in the more sensitive areas of the care home, such as resident bedrooms. One care worker in a care home allocated to PERSONABLE reported that she had spent much of the afternoon in a resident bedroom creating a life history with the resident. On another occasion a resident was being supported by an ancillary member of staff to change her bed linen, although I could hear the interaction it was out of sight and could not be recorded. Additionally, it is possible that interactions

occurring within resident bedrooms might better reflect an enhanced application of care promoting personhood and citizenship, such as the skilled performing of direct care tasks whilst integrating these theoretical principles.

When observing residents there was a struggle when attempting to collect accurate data for the large number of participating residents. Studies explored in the literature review (Beer et al., 2011a, Ballard et al., 2017) had suggested significant resident attrition might occur between baseline and follow-up measurement. This had prompted a generous estimation of the required resident sample size. On occasion, the need to check the wide variety of resident behaviours in the DCM™ handbook (University of Bradford, 2010) lessened my observational attention. The limitation was not necessarily on the quality of the data captured rather the amount of data that was missed when spending time consulting the handbook (University of Bradford, 2010). Piloting of DCM™, in phase one, had indicated that when observing, not all residents would be present at any given time. However, whilst observing residents in phase two of the feasibility trial generally there was less movement of the residents and therefore a greater number of residents were present.

DCM™ has 34 different classifications of interactions, which can be recorded as enhancing, highly enhancing, detracting or highly detracting (University of Bradford, 2010). During the piloting of DCM™ in phase one of this study I was aware that the large quantity of enhancing or detracting codes was impractical. To optimise the practicality of collecting frequent interactions this study dichotomised the 34 classifications into a binary value representing positive and negative interactions. The 34 classifications provide a rich description of the underlying nature of interactions between staff and residents (Chenoweth and Jeon, 2007). Although the binary approach lost the descriptive quality, it helped me to accurately capture the large quantity of interactions. This would not have been possible using the 34 interaction codes described in the DCM™ handbook (University of Bradford, 2010). This binary approach to the recording of interactions was limited because there was no function for recording interactions which were neutral in nature. This resulted in the majority of interactions being recorded as 'enhancing'. During observation I made brief field

notes of each interaction, and when reviewing these notes, interactions of a neutral nature were the most frequent.

Currently, when using DCM™ some researchers have used additional measures, such as the Quality of Interaction Schedule, to quantitatively capture the quality of interactions (McLean et al., 2017). To avoid the use of multiple measurements the enhancing, highly enhancing, detracting or highly detracting scale currently used by DCM™ could be adapted to include a neutral value. This would create a five point scale, similar to the one used within the Quality of Interaction Schedule (McLean et al., 2017). Using this approach for DCM™ might increase the number of residents recruited to trials using this measure, increasing study power and better describing variation between arms of a trial as a result of an intervention (Campbell and Walters, 2014). However, reducing the choice of interactional codes would restrict the nuanced descriptions provided by the original 34 interaction codes.

Formal evaluation of the acceptability of the visual analogue scale was not conducted. A more formal validation of the visual analogue scale could have informed the feasibility of this study and provided insight into whether staff perceive their work as 'care'. However, during this part of the study there was insufficient time available for this as I was attempting to work to a deadline relating to ethical approval. This seemed an important framing of the question when asking the staff who would be working in various roles within the residential care homes. A more detailed process evaluation of this outcome measure may also have included an appraisal of how staff perceive specific study measurement designs, such as questionnaires or visual analogue scales. Only two people did not complete the VAS and one participant indicated that they did not have the time to complete the lengthier PDQ but did complete a VAS. The positive engagement with the VAS might indicate some acceptability of this simpler approach to measurement.

I designed the VAS prompt question: 'How able, do you feel, to care for residents with dementia?' to be open to interpretation from staff working in different roles. In the formative stages of this study, the prompt question had been presented to a small group of nursing students; their feedback was helpful in refining the VAS question and

amending the language for a lay audience. Given that study measures need to be accessible to staff, it might have been beneficial to conduct a more focused approach to the construction of the prompt statement. I had considered incorporating the VAS question into the focused discussion groups. However, after discussion with my research peers and supervisory team I decided to keep the focused discussion groups centred on development of the intervention in order to ensure I gained sufficient data to develop the workshop. On reflection, further evaluation of the VAS is one instance where it would not have been a significant burden on my resources to include an appraisal of this measure. This appraisal could have been included towards the end of the focused discussion groups once enough data about the proposed intervention had been collected.

6.7.6 Researcher bias

Buetow (2019) highlights the difficulty researchers with a clinical background may have in setting aside their unconscious bias. I had anticipated this phenomenon and had considered how my previous experience visiting care homes might affect my ability to be objective. Throughout the study I used a simple reflective approach based on the Johari window (Sutherland, 1995). This process helped me to consider aspects of my unconscious bias with which I might not normally be familiar. I am quite used to reflecting within my nursing role and I felt aware of how my previous role could influence my thought processes. Comparatively, in my researcher role I tended to reflect 'on action' rather than the more instinctive 'in action' reflection I use in my clinical role (Schon, 1991).

Positively, I had taken practical steps to remove the effect of bias. Particularly, the coding system I had designed to anonymise staff participants. This system was particularly effective at eliminating bias from my data collection and analysis for the PDQ and VAS. Removing bias from DCM™ was much harder. This was the case even in relation to third parties not related to any other part of the study procedures. I had not anticipated how difficult it would be to completely blind the second observer (JF) from care home allocation and in future trials staff and managers would have to be more comprehensively briefed about this requirement.

My personal bias manifested itself in my reticence to record detracting interactions during baseline measurements. During this period I felt grateful to all the care homes for agreeing to participate in the study, a gratitude which made me subconsciously reluctant to assign interactions as detracting. When returning to complete follow-up measurements and having had time to reflect and consciously expose this bias, I concluded that my appraisal of staff interactions at baseline, for all care homes, had been generous.

Before baseline measurements I had considered how to remain impartial in other areas of DCM™ observation (Buetow, 2019). I had reflected that my unconscious bias could manifest itself at follow-up in a positive appraisal of resident ME values in homes allocated to the PERSONABLE arm. Interestingly, this awareness had the paradoxical effect of making me more conservative in my appraisal of resident ME values. This was partly to avoid bias to care homes allocated to the PERSONABLE arm, and partly a personal curiosity about whether the experiment would have an effect. Bias, whether unconscious or conscious is a factor when conducting any observational measure (Buetow, 2019) and an awareness of this bias helped mediate my internal dialogue.

6.8 Recommendations for future research

6.8.1 Participants

The effect of leadership has been broadly highlighted by studies which explore factors aiding or hindering trials taking place in residential care homes (Fossey et al., 2019, Griffiths et al., 2019). However, the specific characteristics of leadership which effectively supports the implementation of an intervention has been highlighted as needing further investigation (Griffiths et al., 2019).

This study has had good engagement from ‘ancillary’ staff. This involvement has uncovered an aptitude of some ancillary staff in a citizenship approach, despite their limited training. Currently the evidence base exploring the effect of staff role on the care provided is small (Willemse et al., 2015). Given the apparent opportunities for collaborative work and the barriers that are created when differing staff roles work within rigidly defined boundaries, further exploration of the interaction between differing staff roles may inform an exploration of intervention feasibility.

6.8.2 Intervention

Marrying an intervention delivering the theories of personhood and citizenship with a randomised controlled trial methodology was complex. This study used several layers of data in an attempt to explore whether the chosen outcomes had the potential to capture the effect of staff training on the experience of residents. To capture the effect of an intervention participant sample sizes need to be sufficient, but also the time frames used for observational measures need to be sensitive to sometimes brief interactions, which might reflect knowledge gained from an intervention (Campbell and Walters, 2014). To enhance the ability of a quantitative approach to capturing these subtleties, qualitative elements may help capture changes to the nuances of care resultant from an intervention.

DCM™ is suited to capturing intervention effect because it records so many details of provided care and the resident experience. However, this complexity can also detract from the consistency of the data, which limits the number of residents who can be observed. Therefore, to better evidence intervention effect DCM™ may benefit from adaptations to streamline the data collection process. Adaptations which will inevitably impact on the sensitivity of DCM™ in describing the resident experience (Innes, 2003).

6.8.3 Measurements

DCM™ is an established method for collecting data which describes the experience of people with dementia (Surr et al., 2018a). The observational measure is able to capture and describe the specific behaviours of people with dementia (Chenoweth and Jeon, 2007). However, the measurement has been criticised for its complexity and subsequent low agreement between observers (Thornton et al., 2004). More research using DCM™ as an outcome measure rather than an intervention will help establish its validity and reliability.

For DCM™ to better capture the effect of a standalone intervention this study suggests a number of adaptations. These suggestions acknowledge that DCM™ is trademarked and ownership of the tool resides with University of Bradford (2010). However, an illustration of the suggested adaptations is presented in Figure 31:

- Separate mood and engagement (ME) scores into separate measures to better reflect the experience of the person with dementia.
- Each timeframe to record the most predominant behaviour code, rather than the one which has the most potential for mood or engagement, giving better variation and discrimination in the behaviour codes recorded in study sites.
- Record the most predominant ME score rather than the highest score.
- Introduce a 'neutral' code for interactions which fall between enhancing, highly enhancing, detracting and highly detracting, which may better describe differences in the care provided in multiple study sites.
- Introduce a specific code for no interaction to assist with analysis.
- Introduce codes for particular staff roles to provide a better illustration of the effect of multidisciplinary working.

Figure 31: Suggestions for amended DCM™ data collection tool

	10:00	10:05	10:10	10:15	10:20	10:25	10:30	10:35
Interaction¹	E	N	N	D	E	N	D	N
Staff role²	Anc.	CW	CW	-	Admin	-	Anc.	-
Mood³	+3	+1	+1	-3	-1	+1	-1	-1
Engagement³	+1	+1	+1	+3	-3	-1	+1	+3
Behaviour category code	A	A	A	L	L	L	A	D

Hypothetical data has been added to the chart to illustrate the utility of the proposed amendments

¹Codes for enhancing (E), neutral (N), detracting (D) interactions

²Role of staff recorded in separate row to better describe patterns in care relating to job role

³Separate rows to record both mood and engagement

The PDQ (Hunter et al., 2013b) was the only tool identified which specifically explored the knowledge and attitudes of staff surrounding personhood. The measure did not specifically seek to measure levels of knowledge and attitudes towards citizenship, although this was implied in some of the questions. Citizenship is an emerging theory in the care of people with dementia and this study has shown that the two concepts can be framed as theoretically distinct. Therefore another measure, or an adapted PDQ, integrating the measurement of personhood and citizenship would be helpful, especially as an adjunct to DCM™ when measuring changes in staff working practices and attitudes. Further work is clearly needed in this area, underpinned by additional research.

6.8.4 The key contributions to knowledge of the PERSONABLE intervention study

6.8.4.1 Dementia Care Mapping™

Despite much evidence in support of DCM™ as a practice development tool, this study has concluded that the tool, and its many intricate levels of data recording, is too complex when used as an outcome measure. The underpinning theory is impressive, and the behaviour codes give the observer great flexibility when attempting to describe the experience of someone with dementia. However, this flexibility creates a real challenge when gathering observational data, because it hinders interrater reliability and undermines the confidence we can have in it as a reliable outcome measure. There are very few studies, like this one, which have conducted DCM™ interrater reliability testing with little preparation between observers (Thornton et al.,

2004). Although it was not planned, the limited amount of time that myself and JF had to review our respective DCM™ practices was very informative. Initially I was disappointed that our agreement was poor. Our levels of agreement only became acceptable when codes were grouped by their potential for wellbeing and this negates the descriptive detail of DCM™. I am relatively experienced in DCM™ and JF is very experienced, but despite our familiarity with the measure we had frequent differences of opinion. Even when later referring to the DCM™ guidance (University of Bradford, 2010) we did not completely agree on our coding of behaviours or mood and engagement scores. The complexity of data collection detracted from my ability to keep accurate records of people who had attended PERSONABLE; a simpler observational tool may allow more time to record changes in staff behaviour because of an intervention. This might enable researchers to forgo staff measures and place more resources into a refined observation measure, which might then have a better chance of capturing behaviour change because of an intervention.

6.8.4.2 Intervention

This study was conducted to test the feasibility of delivering a personhood and citizenship training intervention using a cluster randomised controlled trial design, in a care home setting. Whilst analysing focused discussion group data, in phases one of this study, it was apparent that staff had a narrow understanding of personhood, usually restricted to the resident's biography. Furthermore, staff were reluctant to engage in activities which promoted citizenship because these would usually involve an element of positive risk taking. There were challenges when attempting to integrate the theories of personhood and citizenship into an intervention. The reflective approach used by PERSONABLE seemed to help convey these theories to staff in an accessible and meaningful way and their understanding of the interrelated theories is reflected in pledges by staff participants. The pledges indicate that staff, working in any role and with differing levels of experience, understood the content and possible applications of PERSONABLE. This study has helped move personhood and citizenship training forward by clearly differentiating the two theories; this was intended to better equip staff to understand and implement personhood and citizenship principles. Theoretically this is an important step forward and will help inform the confusing overlap between the two theories; this is especially important

when personhood and citizenship are considered in the context of their practical application.

PERSONABLE had clear themes for each exercise and the workshop lasted no longer than one hour in each of the three intervention sites; this was deliberate and different to methods utilised by other training interventions discovered during the literature review. Simplification of the intervention was a deliberate attempt to craft the intervention to the demands of the busy care environment; however, it is difficult to tell whether this simplified approach to training enhanced staff attendance at PERSONABLE. The relatively low attendance at PERSONABLE highlights that interventions which are designed sympathetically to the demands of busy care environments do not necessarily result in greater attendance. This observation is new and important, and it could be that training delivered to residential care staff needs an even simpler and more reflexive approach, which could be more sympathetically tailored to the daily fluctuations in care homes. There is also a need for care home owners to accept some responsibility in providing protected time for staff to engage with good quality training. Currently interventions predominantly focus on the fidelity of delivery (Hanson et al., 2016), an approach possibly adopted because of a perceived need for standardised interventions delivered within randomised controlled trials. One example of the requirement for a flexible approach to training delivery was when I turned up at an intervention care home to implement PERSONABLE and some kitchen staff could not attend because of work pressure. In this instance the intervention key themes might have been delivered to these staff more flexibly and could have involved very brief interventions or short conversations. This would reflect the flexible methods of intervention delivery used by Ballard et al. (2018), where an individual practitioner provided brief tailored psychosocial interventions to individual members of staff. When I initially became aware of this intervention, I had been frustrated that the intervention was not more defined. However, having reflected in the context of what I now know, the approach taken by Ballard et al. (2018) is not dissimilar to the way in which I work when I visit care homes as a community mental health nurse and could have merit for potential use as a method in further research.

6.9 Personal reflection

To explore my personal experience when carrying out this study I have used a model of reflection recommended by Christopher Johns (2009). He proposed that reflection is not an academic exercise and should creatively help a person frame and understand a situation. In his reflective model Johns (2009) suggests a person might explore the aesthetics and empirics of a situation, considering both personal impact and subsequent reflexive actions.

6.9.1 The aesthetics of my investigation

I started my doctoral study in 2015. I didn't really know what a PhD was. If I'm really honest I didn't know 'doctoral' related to the term PhD. I had completed an MSc in clinical research two years before and had sworn 'no more study'. I'm glad I was not true to my words.

Visualising myself being interviewed for this doctorate I was full of fear. I had seen prospective candidates exiting the interview room, all looking more suitable. But I obtained a place. In October 2015, grateful and full of pride I began my PhD.

I remember the task of the doctorate seeming BIG. Like stepping into a huge desert without a map. No academic landmarks. I couldn't visualise the components of the PhD. It felt daunting. The way I usually navigate complex situations is by trying to isolate, visualise and understand the constituent parts. Some of these had rather foggy undefined boundaries, for example patient and public involvement, DCM™ as an outcome measure, ethics procedures, the theories of personhood and citizenship and the characteristics of prospective participants.

I feel tangible discomfort when things aren't defined and clear. This discomfort is usually alleviated through contextual investigation. I experienced a constant struggle between the discomfort and the calming effect of investigation. Writing this final part of my thesis, I feel I know my topic. But I've reached the end of the desert and now the map has changed. I have further to go. I'll drop the desert metaphor now.

6.9.2 The empirics of my investigation

The uneasiness of doing something which was not familiar to me was lessened by several practical factors. I had a colleague start their doctorate at the same time and sharing the same office we spent many lunch hours discussing and exploring our ideas,

our difficulties, and the things which were working well. Another PhD student was one year ahead of me, and was able to give valuable procedural advice throughout my studies, especially in relation to my ethics applications.

My strong supervisory team at the university provided very regular support, which challenged my thinking. My ways of viewing current healthcare had become quite fixed from my many years of clinical practice. Still being employed by the NHS I was lucky to have a manager in this organisation who oversaw the dementia research department in my NHS trust. This professional relationship helped me keep my reflections during the study rooted in the reality of clinical practice.

In addition to these inter-professional factors, my iterative relationship with the literature review helped guide my investigation. Continually returning to the literature, at each stage of the study, enabled me to see the literature in a new light. This was challenging in the initial stages when differentiating between personhood and citizenship. Reflecting on this period of my study, I can physically feel the resistance I had to citizenship, which in relation to people with dementia was a new theory.

During my initial investigation into personhood and citizenship I was aware of my bias. I felt citizenship theory was an attack on Tom Kitwood's personhood theory. I felt defensive of his work. Ironically this desire to defend Kitwood's work drove my investigation into citizenship. Eventually, I was able to clearly differentiate between the two theories, having initially been convinced personhood and citizenship were synonymous.

This belief had been challenged in stages. Firstly the literature review increased my awareness of citizenship. Around this time I wrote a book for my daughter (Corner, 2015) about the citizenship of someone with early dementia. This process helped me reflect on the utility of citizenship and how it might be enacted for someone with dementia. Whilst conducting the study, focused discussion groups helped me understand how citizenship approaches are currently used by staff. Finally when collecting data in phase two of the study I began to see the broader vision of how citizenship relates to people who have dementia.

6.9.3 How it affected me personally

Fear dominated my investigation when recruiting participants and collecting data. I was worried because of the complexity of the study that some parts would not run smoothly. The thought of failure challenged my pride. I tried to remind myself that the components of the study which did not run smoothly would inform feasibility outcomes. However, early in the study I fell into the trap of viewing the study as a definitive trial, wanting the study to show an effect of the intervention.

My desire for success was mediated by a process of reflection. This mostly took the form of the frequent discussions with my peers and supervisory team. I got better and better at receiving challenging feedback, seeing the comments as an opportunity to positively influence the study and not a challenge to my competence (pride).

By the time I had begun data collection I was conscious I was overcorrecting my positive bias towards PERSONABLE. Having a self-deprecating nature, I found it amusing that this part of my character was leaving my pencil and being transformed into data, then crossed out and corrected and then again questioned. This is why you need blinding.

6.9.4 The reflexivity of my investigation

I'm used to speaking with a variety of professionals in the course of my clinical work. My role changed when I was visiting care homes as a researcher. As a nurse I visit care homes to offer advice and support, temporarily adding resources to the environment. As a researcher I am asking for help from the care home, potentially detracting from their resources. Aware that my presence as a researcher was adding to the burden of care staff I felt I was imposing on their time. This awareness may have presented in a disposition indicating to care managers that I understood the demands of their work. Acknowledging the pressures of running and working in a care home may have enhanced the recruitment of participants.

In other ways I found my appreciation of the demands of the care environment difficult to manage. My appreciation of care home engagement definitely made me more reluctant to record detracting interactions at baseline. It wasn't until follow-up measurements that I had untangled my gratitude to care homes from my desire to collect accurate data.

My awareness of the purpose of research has changed during this study. I have learnt research is not purely a quest for a magical 'p value'. For studies to successfully recruit and retain participants, I have noticed the need for researchers to understand the various pressures of potential participants. This realisation has helped me reflect on how I might improve my approach as a researcher, be more PERSONABLE.

This makes me reflect on the title of the intervention. If I was naming the intervention now I might not call it PERSONABLE. This title for the intervention could have been received as condescending by staff. They may already have viewed themselves as enabling a person-centred approach, promoting resident autonomy.

Now, I might have called the intervention PURPOSEFUL. This title is more resident focused and embodies the ultimate utility of the intervention. However, hindsight is a useful tool, I had to conduct this study to fully understand the importance of having purpose when attempting to lead a fulfilling life.

6.10 Conclusion

This study concludes that, with some methodological adjustments, a definitive trial is feasible. The success of future definitive trials will rely on the tailoring of study methods to meet the demands of busy residential care homes with high staff turnover. This approach may involve the simplification of recruitment strategies, interventions and outcome measurements.

For this study, an approach which was sympathetic to the demands of the residential care environment helped to:

- Improve the attractiveness of the study at first point of contact with the care home.
- Assist with the retention of each cluster (care home) during changes to management.
- Keep the burden on residents low by using an observational measure and collecting minimal demographic data.
- Keep the burden on staff low by using brief questionnaires and collecting minimal demographic data.

For a definitive trial there needs to be a balance between collecting sufficient information to make meaningful conclusions and overburdening study participants. The sheer size of the care home population suggests that thoughtful and energetic efforts to overcome the challenges of research in this complex environment can yield high powered studies that will ultimately improve the care of residents. Using a flexible approach that does not compromise methodological rigour may improve recruitment and retention of participants. Delivered interventions do not necessarily need to be lengthy or extensive. In phase one of this study, staff were less enthusiastic about the engagement with, and use of, interventions when they did not fit into their busy work routine.

An increase of trials conducted in care homes could help researchers, care home staff and residents learn from both success and failure when these challenging investigations are undertaken. The parts of this study which did not run to plan were those which were not intuitive for participants: the need for blinding, the consultee process and the understanding of staff that there is a need for both baseline and

follow-up measurements. A greater research presence in care homes may help to familiarise residents, owners, managers, staff, family members and ethics committees with the steps necessary to undertake successful trials.

A more creative use of technology, that is unobtrusive, but does not compromise the ethical basis of a study, might help to improve the accessibility of study information which details, outcome measurements, intervention delivery and study consent. An approach which might release the researcher from the large quantities of paperwork so they can be more proactively engaged with answering questions about the purpose and requirements of the study.

To be successful the information gathered when conducting training interventions, delivering personhood and citizenship principles within care homes, needs to be effectively communicated with the professional bodies who currently dictate training requirements, such as the care certificate (Health Education England, 2015). A more integrated relationship between research and professional bodies might ensure the minimum requirement set within mandatory training includes personhood and citizenship theory. The inclusion of these two theories in mandatory training could help a larger proportion of care home staff, working in any role, to understand and develop their valuable 'care' contributions, to better embed personhood and citizenship theory into practice.

"I am hungry for the life that has been taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness, and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for!" (George Thomas, a person with dementia (Cohen and Eisdorfer, 2002, page 31).

Reflecting on this quote from the beginning of the literature review, refocusing current training might help the many people like George Thomas to regain the parts of their lives which provide the most fulfilment. Conveying personhood and citizenship principles to the entire care workforce may benefit the hundreds of thousands of people experiencing what we currently call 'dementia', a condition for which there is no known cure. Yet there is a cure, a cure for diminished personhood and citizenship.

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Appendices

7.1 Appendix one: university ethics approval

Faculty of Medicine and Health Sciences Research Ethics Committee



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18th July 2016

Dear Jason,

Project Title: Focused discussion group to assist refinement of a dementia workshop intervention intended for use with care home staff.

Reference: 2015/2016 - 94

The amendments to your above proposal have been considered and I can confirm that your proposal has been approved.

Please could you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance and also that any adverse events which occur during your project are reported to the Committee. Please could you also arrange to send us a report once your project is completed.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'P. We'.

Dr Maggie McArthur
Deputy Chair
FMH Research Ethics Committee

Cc Supervisor Tony Arthur

7.2 Appendix two: framework analysis of focused discussion group data

Participant		Index
Focus group one	Personhood and Citizenship	
General manager	<p>'...you know (the resident) had lived in (place name) all his life, all his married life...erm...he had been the organist for all the local churches and he would walk from village to village on a Sunday...'</p> <p>'...that past histories can have a huge impact on people's lives...'</p>	Importance of life history
	'...you may need to take a little bit more time for explanation but they shouldn't be talked to like children...I think like a proper adult...'	Respectful care
	'...and you do it in the dementia wing...'	Negative discourse
	'...he kept going back there (to his previous home)...and knocking on the door...the people who lived there were nice and understood...they'd let us know he'd been there...'	Facilitators to community integration
	'...I mean you know we try and encourage our residents to go out...'	
	'...sometimes we restrict what they do because we become too protective and we you know...'	Risk avoidance
	'...I think sometimes we are too over caring and we forget they are still able to do things...'	
Administrator	'...we take their post rounds so we see people...go into their rooms...'	Community within the care home
	'...we have a little shop, also they want to come buy something...'	
	'...strange random requests...'	Negative discourse
Care worker	'...there's not one person got I would say, the same dementia...I don't find, you have to approach each individual differently...'	Tailored care
	'...I've found that you shouldn't really talk to people who have got dementia any different than somebody hasn't got dementia...'	Respectful care

	'...bring them in again, they have baths, join in the activities...have chiropodist and then we take them home in the afternoon...'	Task focused care
	'...a lot of that really is to give their carers a rest as well, especially if people have got dementia...'	Objectification
Maintenance person	'...well I have to go into their rooms and actually organise things, put pictures up, so obviously I discuss things with them, talk to them...'	Respectful care
	'...basically I'm just there to make sure that they are happy with their environment really...'	
Focus group two		
Care worker one	'...their job can come through as well...how they've been as a person...'	Importance of life history
	'...this is the brain, this is different types of dementia because with you know, I think as it progress we need to progress and learn some different like behaviours and the emotional journey...'	Biomedical model
Care worker two	'...I come up with the idea of Frozen (Disney film), which was the thing, everyone was doing Frozen, so the Frozen day was launched and so I kind of got the two together to encourage the children to come in (to the care home)...'	Facilitators to community integration
	'...where the family comes in because we have to glean a lot of information from the family because it's not always possible in the late stages to get everything that is real...'	Importance of life history
Care worker three	'...if you don't have enough information about the person who is coming onto the unit...'	Importance of life history
	'...we've got the this is me, with all their life history and all the information on kind of like brief history, but we don't always get a lot of information, sometimes we do...'	
Care worker four	'...I had go through to get different type of dementia and all that...'	Biomedical model

Focus group three		
Family member one	'...we try to bring back happy occasions, we talk about music and I think sometimes his mind is very locked so you have to sort of remind them of past conversations...'	Reminiscence
	'...they asked me to fill in the blanks and I thought that was good because then they've got a background of that person haven't they...'	Importance of life history
Family member two	'...because for somebody that never want to go (to day care), he's very happy when he get there, they greet him nicely...'	Respectful care
	'...I have to say my main reason for wanting it is he's got other people than me...'	Care diversity
	'...somebody with a soft voice he'll chat to but anybody with a harsh voice he switches off straight away...'	Interactional diversity
	'...I think most of the people with him in the afternoon were ladies...erm...and it's not that he doesn't like chatting to ladies, he's just not a chatty person, he was sitting enjoying the scenery but he hasn't got anyone to talk to...'	Lack of diversity
	'...it's very hard actually to understand, you're so involved...my husband quite childlike so maybe he likes being treated like a child...'	Infantilising statement
Family member three	'...you get probably number one 'my life history' even with the dementia in the middle stage...'	Biomedical model
	'...fortunately the phase does pass and there is this conflict between what I call her Alzheimer's mind and her for want of a better mind her normal mind...'	
	'...I tried to find diversionary tack ticks like simply taking her out for a walk...'	Adaptive care
	'...I cannot let her go out on her on own, because she's quite convinced she's okay but she isn't she just simply get lost...'	Barriers to community integration
Focus group four		
Relations manager	'...because you can ask someone during the round, when they take the order, two hours later at lunch time, and we've got 20 shepherd's pies and 2 fish and chips 'I don't want that, I want fish and chips...'	Task focused care

	'...we have a mother and toddlers group come here once a month...'	Community within the care home
Care worker one	'...if you start to show the plate of shepherd's pie and fish and chips they choose shepherd pie, after that they start to do with plate normal plate and we show both, as soon as they have they have the choice, it's done, they eat and they're happy and no stress...'	Task focused care
Care worker two	'...like my colleague said we help with personal care and moving during the day, assisting to the toilet, cleaning everything...er...we help them with meals...'	Task focused care
	'...there was this guy who was up all night, we thought it was just because you know of his dementia, he doesn't know what time of day it is, but we found out he worked nights for years so he's going to awake at night...'	Importance of life history
	'...show them you're not really giving them a real choice, they might recognise certain things, if you say fish and chips to them, they'll know what that is but some might say Chinese stir fry...'	Tailored care
Staff characteristics		
Focus group one		
General manager	'...so I think with that for people to actually think about what they do and change something, that's not something that we do easily, we don't reflect on our work practices as much as we should but when we do we don't like seeing negative or detrimental things that we are doing...'	Reflective ability
	'...we have had to deal with some challenging times as well so yeah...but it's about working together...'	Benefit of team work
	'...not to be so task focused and be a bit more person centred isn't something that you can just do overnight...'	Difficulty of changing staff attitudes
	'...nursing staff, there's still an element of tasks that have to be dealt with when you're looking after residents, you know, that have nursing needs...'	Care perceived as a set of tasks

	<p>'...been awarded the butterfly award at level three with dementia care matters, which meant they had to come and observe us...erm...and they did that on both sides (care units)...so I could get an understanding of what level we were over here (the residential unit)...as compared to the (dementia unit)...</p>	<p>Manager focused on status of care home</p>
	<p>'...I'll start, shall I cause I've possibly done the most training really...'</p>	<p>Manager dominates group dynamics</p>
Administrator	<p>'...I worry about what do I say, I just...am I making it worse...then I think 'I know, I'll call the care staff'...'</p>	<p>Not feeling skilled in care of people with dementia</p>
	<p>'...so mainly in the main office we probably deal even more with the relatives...'</p> <p>'...we might interact to some extent with some of the residents, but I wouldn't know a lot about the histories (of residents) because we don't go in and have a sit down and a cup of tea and a chat to the residents, you know, but I'll learn more from their, their, siblings or children or what we interact more with I guess...'</p>	<p>Ancillary diversity of interactions</p>
Maintenance person	<p>'...you just have to take them as they are...and just try to be as kind, we have dementia in the street now...understanding people...'</p>	<p>Kindness is a quality carers should have</p>
	<p>'...I do have a care role, give them a cup of tea, biscuits that sort of thing...'</p>	<p>Care perceived as a set of tasks</p>
	<p>'...no...well...sometimes they think I'm a carer, which...so erm...no but I think their, once they get to know me they're quite happy really...erm...that's strange really, someone of my size walking into their room, not what they're expecting really...'</p> <p>'...it must be frustrating dementia, when you think all those years you've been independent and self-reliant and you get to this point, must be very frustrating for the people...'</p>	<p>Empathic care</p>

	'...they've travelled all over the world, gone mountain climbing and then all of a sudden you end up like this, it must be very frustrating for them, you know, I think any understanding of that is only helping people do their job really...'	
	'...if you don't understand dementia you think, well if you can't remember five minutes ago, if he goes out, can he remember where he came from? But, he had no problem with that...'	Care should be reflective
Focus group two		
Care worker two	'...constructive criticism is always fine...'	Reflective ability
Care worker three	'...a lot of that is as it happens sort of you come across something and you deal with it and you see a problem and you think I can talk about this...'	Being adaptable
Focus group three		
Family member one	'...friendly nurse, smile, they greeting warmth, you can't beat all that...warmth and understanding and compassion...'	Patience, warmth and compassion
	'...I said at least she live in a happy world and we have good laughs together and I don't know what we were laughing about but just to keep her happy, she was in a happy life I thought, so I thought I'll laugh with her (chuckles)...'	Kindness is a quality carers should have
	'...I would say they make a nice friendly atmosphere, I don't really think skills come into it, I think just getting on with them is the main thing...'	Personal attributes over skills
	'...that's very difficult sometimes to understand where they are coming from but I think when you analyse it all that's very often from the past you just have to try to get to their level, a level of understanding really...'	Empathic care
	'...I'd have to reassure myself first that there is good security in that residential home...'	Care should be safe
Family member two	'...but you just have to keep taking through practice and realise that perhaps it's happening, where you could just think 'oh they're being difficult', my husband has never been really unpleasant but he's not a social person...'	Need patience when caring

	'...so you need the nursing care but not all the time probably just somebody who was caring for them and who says 'you look well this morning' when they see the nurse...'	Personal attributes over skills
	'...I think that's up to the individual care when you've got somebody like that...I just like the friendliness...'	
Family member three	'...I think the carer takes a long time to develop the requisite patience...that's certainly my experience and still trying, still learning and it depends how you feel at any one time as a carer, you might be tired...'	Need patience when caring
	'...you've got me thinking of a person to come in and do ironing but with empathy and chat with (<i>names wife</i>)...yes...'	Kindness is a quality carers should have
Focus group four		
Relations manager	'...I'll start then, my role is as a customer relations manager...erm...so initially I'm the first point of contact I suppose...'	Manager dominates group dynamic
Care worker one	'...like my colleague said we help with personal care and moving during the day, assisting to the toilet, cleaning everything...er...we help them with meals...'	Care perceived as a set of tasks
Care worker two	'...basically as a care assistant and then obviously you're responsible for their personal care, you're responsible for helping them at meal times...'	Care perceived as a set of tasks
	'...other people throughout the home might not have that opportunity so it would probably be more difficult for them, so maybe a bit of guidance around, don't just think of, if you don't work directly with people with dementia, these are the sorts of things you might need to do, I think if I didn't work in this role, if I worked in the kitchen or worked in reception...'	Not viewing ancillary staff as in a caring role
Current training		
Focus group one		
General manager	'...I think no more than probably two hours, I think probably two hours maximum is probably the best thing for any training...'	Training should not be long

	'...I think afternoons or late mornings are the best times because obviously the care environment is at its busiest first thing in the morning...'	Best time to deliver training
	'...the (care group) has decided to go with David Sheard's butterfly approach and, and, philosophy really (<i>continued to explain managers received training first</i>)...'	Managers receive dementia training before care workers
	'...I think the barriers for this home in particular is the amount of staff that we have here, and getting them all trained...'	Barriers to training
	'...I have done his year-long...erm...dementia matters course...erm...plus I've also done quite a lot of...erm...observational training where I'll sit in a room and just do observations...'	Current person-centred training
	'...a guy came to do some dementia training and he made us close our eyes and then he started to talk and we had to be like a person with dementia that was and you had to imagine that you were sitting in a room and these strangers came in...'	Reflective exercises in training
	'...it's about I think giving them the training that makes them open up a little bit...'	Preference for non-taught training
Administrator	'...I've seen like a trial were they almost do like a sensory deprivation...'	Reflective exercises in training
Care worker	'...I think er...my father's (dementia) was the most challenging...I had a lot of, a lot, of bad experience and I learnt off that as well...'	Experiential learning
Maintenance person	'...the answer is I've really learnt on the job and by observation obviously...'	Experiential learning
	'...because you know you can sit there and you can have a projector which tells you about all the different dementias...'	Biomedical training
Focus group two		
Care worker one	'...unless you have a workshop and do so many and then a manager could do a different day for those who didn't attend...'	Best time to deliver training
	'...our general manager has done it, our deputy manager has...they've done it and	Managers receive

	they're working through the (dementia unit) to do it, the seniors and they're hoping to get the carers down to do it but I do find, I did feel a better person coming out of it...'	dementia training before care workers
	'...so you either come in on your day off or stay afterwards or it may not be enough people go and attend it, depends how many people they want on a workshop, if it was say six then that wouldn't work with all of us, because you're covering all three shifts...'	Barriers to training
	'...I think one of its cost as one of our training has to go through the (names employer), so they set all the training up...'	Financial barrier to training
	'...the first book is erm sort of all about the brain and sort of all the different types of dementia...'	Biomedical dementia training
	'...started from the basic again, this is the brain, this is different types of dementia because with you know...'	
	'...face to face personally in a group such as this, in a group with someone that's training us in a particular way that is practical to what we do...'	Face-to-face training
	'...I went every month for a year and it was called the emotional journey and it didn't start on the basics it just went and you learnt all about the person...'	Current person centred training
Care worker two	'...you have a six month window to complete it (the dementia workbook), you have six months to do it...'	Staff having to do training in their own time
	'...both went on a erm...a course with the dementia alliance so we're both trained coaches so we do a bit of training with the (dementia unit) people...'	Staff teaching staff
	'...as it happens sort of you come across something and you deal with it and you see a problem and you think I can talk about this...'	Experiential learning
	'...yeah reflect on yourself first...'	Reflective exercises in training

Care worker three	'...I found that very interesting because you came back and you thought well you have to look at yourself, how do you look at you own emotions to situations so you can understand the residents, and I found that a very good course...'	Reflective exercises in training
Care worker four	'...I did dementia training when I started...erm...like six month dementia training, I had go through to get different type of dementia and all that...'	Biomedical dementia training
Care worker five	'...just generally busy and finding time to get things done...'	Barriers to training
	'...we do and there's usually three books we have to work through...'	Staff having to do training in their own time
	'...because when I first started here I didn't really know anything about dementia, so learning all the different types of dementia and what they can each be and all that it did help me...'	Biomedical dementia training
Focus group three		
Family member one	'...you just gain them as the situation arise, as something arise you have to logically try and deal with it...'	Experiential learning
Focus group four		
Relations manager	'...here are three group I think of it but the good thing about this is its not training like classroom training, its coaching to teach you how to coach...'	Staff teaching staff
	'...it would have been lovely if everyone could have gone on the course but there would be nobody in the home running things so I thought if we sent the two dementia home team leaders...'	
Care worker one	'...so sometimes we can't come, so in one month wait or two months wait we've got the same training and with me and I think with the others ones, I think they've got the training when we are all on...'	Barriers to training
	'...my last module, I'm in the Open University, is about dementia as well...'	Staff paying for own training
	'...I had more experiences working on the floor with...give us all the experience because we have team leader and he	Experiential learning

	knows something and he help with dementia, this is the best environment we can have, is working on the floor with them...'	
Care worker two	'...well I know they were trying to put training in the evenings but it's not very easy to get training in...'	Best time to deliver training
	'...I suppose it's just down to your time because if you're not, the company are good, they do offer lots of training courses, they do offer, if you're not on, on that day then sometimes...'	Barriers to training
	'...the only thing from the company's point of view are erm...you know, obviously any training is time of the floor for the actual employees, so you know, that time has to be covered somehow...'	Barriers to training
	'...it is sometimes difficult to get people from the night shift on to training courses because they usually run during the day and that's when gonna be asleep and that sort of thing, so I think that's quite difficult to get night staff onto all of the training. Just because if it's in between shifts for them...'	Barriers to training
	'...I've completed an eLearning model on dementia...'	Staff having to do training in their own time
	'...one of the main team leaders on the dementias unit wants to give us more training on coping strategies and how to deal with people with dementia and their behaviour...'	Staff teaching staff
	'...I've also attended a one day training course so that just explains a bit more about the condition about the disability and how it affects people, how it affects families, the different types of dementia...'	Biomedical dementia training
PERSONABLE feedback		
Focus group one		
General manager	'...I think brain function is the better one...'	Suggests 'brain function' as better than 'cognitive function'

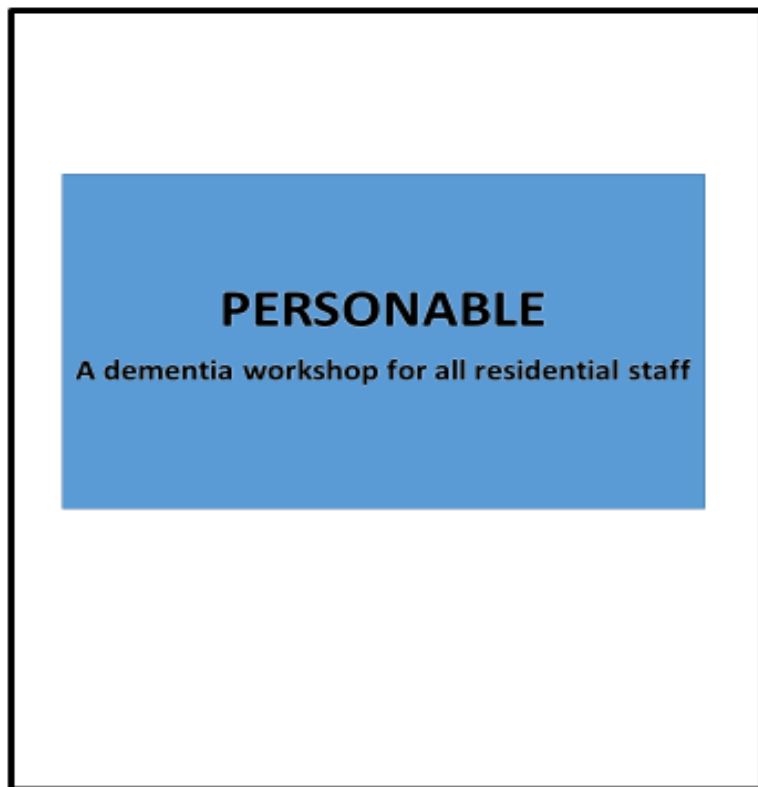
	'...but I think there are some people that think they are perfect...'	Barrier – staff lacking desire to be reflective
	'...I think that's something you could use in your basic dementia training, I think that's a really good exercise to incorporate into that to make people think...'	Positive feedback about exercise one
	'...some don't want to...'	Respecting resident choice
	'...this is exactly the sort of thing that I think works really well, is to actually make the staff think about what they do and how the person with dementia can feel exactly the same...'	Exercise one – positively making staff empathise
	'...how do we in the home make our residents feel included in the community, what do we do, do we do anything...'	Exercise 1 – importance of putting learning into action in the care home
	'...I'm just not sure how that would relate to the community...'	Exercise 1 – not helping staff think of community
	'...yeah it did, the basic things you do in life, you get in the morning and have a shower...'	Exercise 1 – Did help participants consider autonomy
Maintenance person	'...I think that program is just nice and I think it's not being negative when I say it's quite simple to follow...'	Positive that exercises were simple to follow
	'...there is those people who think they don't need extra training but I find that you know, any help that you can get is welcome...'	Barrier – staff lacking desire to be reflective
Focus group two		
Care worker one	'...loads of choices that we can make every day and take for granted...'	Respecting resident choice
	'...I like a cup of tea if my partners there, you know...he bring me one...but that's done routinely and you don't really think like that do you...'	Respecting resident choice

	'...so actually I think to me that making you look in a person centred place and promoting their rights as a citizen...'	Exercise 1 – helped participants consider autonomy
Care worker two	'...if it's something constructive, then you think yeah we can do it like that and probably keep doing it forever as opposed to thirty days...'	Happy to do pledge
Care worker three	'...it's good feedback as well, if you pledge to do that and you see a difference then...'	The pledge exercise encourages reflection
	'...just a few examples and they may come up with, may get them thinking at least they may not follow the list but they may be, see other things going through the list, get some ideas...'	Promotes for pledges
	'...I think that's good, it does make you think you know, as you were going through things I do in the morning and you completely take all that for granted...'	Respecting resident choice
Focus group three		
Family member one	'...brain function, because even brain function makes it sounds like it's not, there's other things implied from that...'	Difficulty with the term learning style
Family member two	'...I think it's difficult to complete learning style...'	Difficulty with the term learning style
	'...I'd understand it but wouldn't necessarily understand how to express it...'	
Focus group four		
Relations manager	'...I'm making an assumption about the age of the person but generally that's a generation they would know learning style, there would be people who have done on the job training, we all know, we're in a different generation where we are used to that terminology, they would know learning style, are you a visual person, do you have to repeat it a hundred times to learn it, do you have to do it to learn it?...'	Positive comment about learning style term
	'...what would you do differently after today? But I mean, it quite a good idea, it really puts an idea in your mind about how you might be able to do things...'	Happy to do pledge

	'...I don't think it did, I think it highlighted more about choice but not what you said about the community...'	Exercise 1 – did not help staff consider diversity of community
	'...it makes you think about how many decision you make and just how complex it is, when you stop and think about all the processes you go through...'	Exercise 1 – Did help participants consider autonomy
Care worker two	'...I think learning style...'	Exercises – positive feedback language used
	'...I think you should leave it up to the individual and how they work...'	Staff shouldn't have prompts for pledges
	'...I think everyone should be able to think of one thing they would probably do a bit differently, they may help to look after the people, it doesn't have to be a major think does it?...'	Happy to do pledge
	'...I suppose I would just modify it a bit, say for the next month, yours is like every day you're at work whereas mine isn't so it would be something like, for the next month every time I do interact with someone who has dementia I will ask them how their day is going...'	
	'...I get where you're going with this, where as I can see with the steps that it's more about choice, but I didn't think about community with it...'	Exercise 1 – did not help staff consider diversity of community
	'...because you always do it, you just take for granted what the person with dementia, you know, it's much more difficult for them...'	Exercise 1 – Did help participants consider autonomy

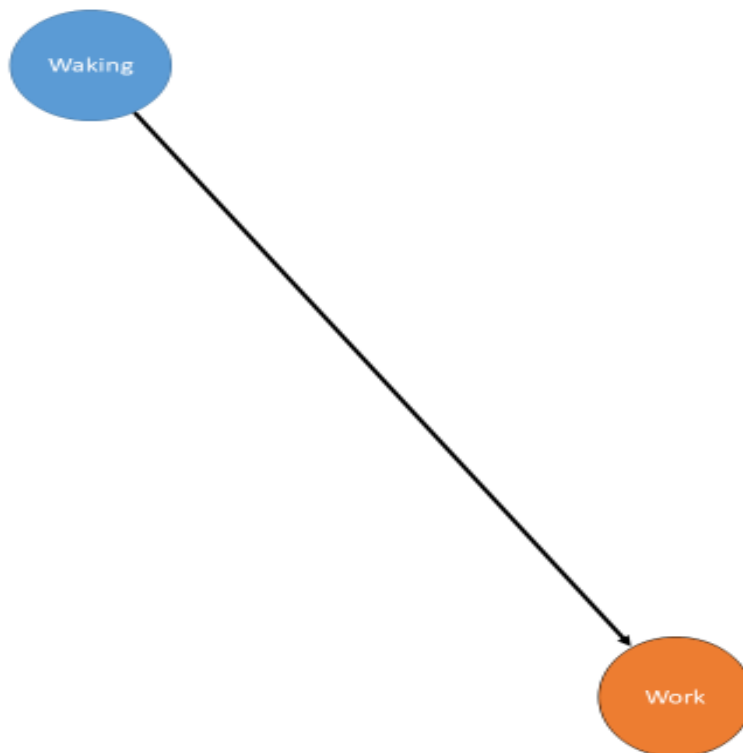
7.3 Appendix three: final version of PERSONABLE

7.3.1 Front page



7.3.2 Exercise one

Exercise 1: from waking to work



7.3.3 Exercise two

Exercise 2: understanding you



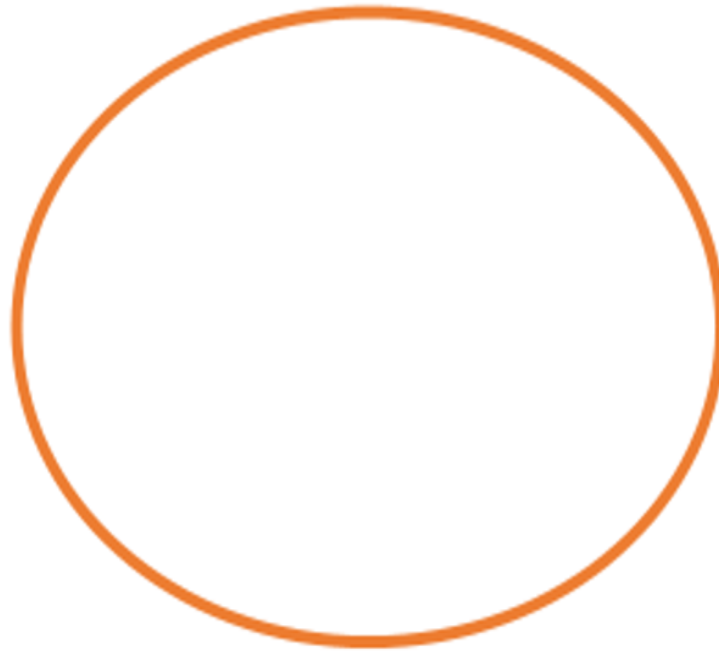
7.3.4 Exercise three

Exercise 3: understanding the resident



7.3.5 Exercise four

Exercise four: From outside to inside



7.3.6 Exercise five

The pledge	For the researcher
<p>Within the next 30 days I will change one thing about the way I work. It may improve my understanding of a resident who has dementia. Or I might introduce something from the outside community into the care home</p>	
<hr/> <hr/>	

The pledge	For you
<p>Within the next 30 days I will change one thing about the way I work. It may improve my understanding of a resident who has dementia. Or I might introduce something from the outside community into the care home</p>	
<hr/> <hr/>	

7.4 Appendix four: care home participant information sheet

Doc B, participation information sheet (care home)

Version 2.0. Date 27/03/2017



Collaboration for leadership
in applied health research
and care
East of England

Participant information sheet for residential care homes

Study title

Can a dementia workshop delivered to residential care home staff affect the wellbeing of residents with dementia? A feasibility study

Why am I being approached?

Your residential care home is being invited to take part in a research study. Before you decide whether you are happy for this care home to be a part of this study please read the following information carefully. If anything is unclear please contact Jason Corner using the contact details at the end of this document.

Background and purpose of this study

As you are aware care homes provide a significant proportion of care for older people with dementia. When providing personalised support for someone with dementia it is important to understand them as an individual and provide opportunities to promote their rights and provide a sense of community.

In this research study I will deliver a dementia workshop to residential care staff and measure whether this has the potential to affect the wellbeing of residents with dementia.

What does taking part involve?

If this care home takes part, then, with your permission, I will invite your staff to be participants in the study. This will take the form of a written invitation to individual members of staff. I am able to come and speak to staff about the study face-to-face. Members of staff who agree to take part will be asked to complete a short questionnaire on two occasions approximately 10 weeks apart, the questionnaires should only take 10 minutes to complete. In addition, staff members will be invited to attend a one-hour dementia workshop that will take place after the first questionnaire or the second.

The dementia workshop will be facilitated by Jason Corner, a PhD student at the UEA and a registered nurse. A convenient time will be agreed with you. The workshop can be run on more than one occasion. The dementia workshop should take place in an area of the care home where the staff will be able to talk openly without being interrupted. The workshop is designed to help staff members think about the people they care for and to plan an action to change about their work as a result of something they have learnt in the workshop.

In this study, some care homes will receive the workshop prior to the second questionnaire being sent out, and the others will receive the workshop after. This will allow us to compare staff knowledge and attitudes between those that have received the workshop prior to the second questionnaire and those that have not.

I will also be conducting Dementia Care Mapping. This will take the form of observing staff and residents over a four hour period, on two separate occasions, in the public areas of the home in order to assess residents' well-being. If your staff do not wish to be observed I will

respect this and liaise with you to make alternative arrangements for my data collection.

What are the benefits of taking part?

You or your staff will not benefit directly from participating. However, taking part in a research study may help staff to reflect on care practices and may improve the way they work with residents who have dementia. Your agreement to using your residential care home as a study site will help provide valuable insights into dementia education within residential care homes.

What are the possible disadvantages and risks of taking part?

Discussions about dementia can provoke sometimes distressing emotions. Should your staff find any of the discussion upsetting they can leave the dementia workshop immediately. Jason will be available after the dementia workshop for a conversation and to direct them to available support.

Will information be kept confidential?

Yes. All information you or your staff give, such as names and locations will remain completely confidential. Results may be published in research journals and presented at conferences. No information that can lead to anyone being identified will be used in any report or publication that this study produces. You and your staff should be aware that at the University of East Anglia contributions to research studies are stored for 10 years.

Confidentiality may be broken in circumstances where any disclosure causes concern for the welfare of interviewees or the welfare of others.

If this should happen I will talk to you or your staff directly before taking any further action.

Does the care home I manage have to take part?

No. Your participation is entirely voluntary. If you decide to take part in this study you may withdraw at any time. However, you should be aware that should you wish to withdraw your residential care home from the study after participating in the dementia workshop then anonymized contributions will be retained. Full participation by care home staff in the dementia workshop will be appreciated but your staff may opt out of any part and at any point.

What if something goes wrong?

In the event of a problem occurring or if you are not happy you can talk to Jason who will try to resolve any difficulties. Alternatively, you can contact the project supervisor whose contact details are at the end of this information sheet. If you wish to speak to, or have a complaint, you may contact someone independent to the project, their contact details are also provided below.

Ethical approval for the study

This study has been reviewed and permission granted by the social care research ethics committee.

What do I do next?

If you would like more information, or wish for your residential care home to take part in this study please return your expression of interest form in the stamped addressed envelope provided. Jason will call you to confirm you have received details about the study.

Alternatively, you can contact Jason using the details below. Thank you for taking the time to read this information sheet.

Lead Researcher Contact details	Project Supervisor Contact details	Independent Person Contact details
<p>Jason Corner University of East Anglia Rm 0.07 Edith Cavell Building Norwich Research park NR4 7TJ</p> <p>Tel: <u>01603592597</u></p> <p>Email: j.corner@uea.ac.uk</p>	<p>Professor Antony Arthur University of East Anglia Rm 1.12 Queens Building Norwich Research park NR4 7TJ</p> <p>Email: antony.arthur@uea.ac.uk</p> <p>Tel: 01603 591094</p>	<p>Professor Eneida Mioshi University of East Anglia Rm 1.07 Queen's Building Norwich Research park NR4 7TJ</p> <p>Email: e.mioshi@uea.ac.uk</p> <p>Tel: 01603593300</p>

7.5 Appendix five: study leaflet

What will happen to the data that the study collects?

The data will be kept confidential and analysed by the researcher. The findings of the data will be written up in a PhD thesis and for publication in scientific journals.

Who has reviewed the study to make sure it is safe?

All materials and procedures for the research have been reviewed by the Social Care Research Ethics Committee to make sure they are safe for all the participants.

Who to talk to about problems or concerns with the observations?

If you have any problems or concerns, please talk to Jason if he is on site or at the contact details provided. If the problem with the research is urgent and then please contact the manager or a senior member of staff.

Complaints can be made to Professor Eneida Moshi at: Email: e.mioshi@uea.ac.uk,

Tel: 01603 593300

University of East Anglia

About the researcher

This research project is part of a PhD doctoral degree being undertaken at the University of East Anglia supervised by Professor Antony Arthur, antony.arthur@uea.ac.uk and Bridget Penhale, b.penhale@uea.ac.uk. It is intended that the study will be written up in the form of a PhD thesis and the findings will be published in scientific peer reviewed journals.

If you would like any information then please contact Jason in person, or at the details below:

Jason Corner

Email: j.corner@uea.ac.uk

Web: <https://www.uea.ac.uk/health-sciences/people/profile/j-corner>

Phone: 01603592597

University of East Anglia

Edith Cavell Building 0.07

School of Health Sciences

Norwich Research Park

Norwich

Norfolk

NR4 7TJ

Does a dementia workshop delivered to care home staff affect the wellbeing of residents with dementia?



Researcher: Jason Corner

What the study is about

This study will deliver a dementia workshop to care home staff and explore whether the workshop affects the wellbeing of residents who have dementia.

What the study involves at this care home

Care home staff will be invited to attend a dementia workshop, which seeks to help staff reflect on the care they provide. For this study six care homes are being used. Three will be randomly selected to receive the dementia workshop. When all data has been collected the three care homes not randomly selected will be offered the dementia workshop.

The researcher, Jason, will be present within the care home and will sit quietly observing the day to day workings of the care home. Jason will make anonymised notes on the care that is provided at the care home and the wellbeing of the residents with dementia.

The study will involve observations of communal areas within the care home. Jason will only make notes about staff and residents who have given their permission. Some residents may need a close friend or relative, who knows them well, to help the decision to include them in the study.

What the research means for you:

Residents and staff

- You do not have to do anything if you do not want to, for staff participation in the dementia workshop is entirely voluntary
- Jason will only take observations from residents and staff who have given written permission
- Residents or staff can withdraw permission at any time during the research
- Not taking part or withdrawing from the research will in no way have an effect on receipt of any services or employment

What will happen and when?

Weeks 1-2	Staff and residents will be asked if they would like to take part in the study
Weeks 2-4	Staff: Jason will ask staff to complete two short questionnaires Residents: For four hours Jason will observe and make notes on six residents who have dementia Care home: Jason will also make brief notes on the care home.
Weeks 4-6	If your care home is one randomly selected to receive the dementia workshop, Jason will deliver the dementia workshop to your staff, at an agreeable time
Weeks 6-12	Staff will have a chance to use what they have learnt in the workshop
Weeks 12-14	Jason will ask staff to complete the two questionnaires again and complete an

Your details will remain confidential

During the observations, if any information is taken that can lead to someone being identified, it will be removed from all observation notes and all information will remain confidential. Your name will be replaced with a randomly selected number. If you complete a questionnaire, again, no identifying information will be taken. A more detailed information sheet will be provided to you should you agree to complete the questionnaire.

If you want to take part in the research, an information sheet will be provided which gives more details. No one will be identified in any way from any data or in any reports that come from this research.

Everything I observe or you say is confidential unless you tell us something that indicates you or someone else is at risk of harm. I would discuss this with you before telling anyone else. All data will be kept securely for 10 years as required by university policy.



7.6 Appendix six: care home covering letter

Document A, letter of approach (care home)

Version 1. Date 18/02/17



Collaboration for leadership
in applied health research
and care
East of England

 Jason Corner
School of Health Sciences
University of East Anglia
0.07 Edith Cavell Building
Norwich Research Park
NR4 7TJ
Tel: 01603 592597
Email: j.corner@uea.ac.uk

(Correspondent address)

Date

Dear [name of care home manager or owner],

Re: Potential participation in a dementia care research study

My name is Jason Corner and I am currently studying for a PhD at the University of East Anglia. As part of my doctoral work I am conducting a study of people with dementia living in care homes. I am seeking to recruit care homes in Norfolk and Suffolk.

My study seeks to explore the effect on residents of a one-hour dementia workshop delivered to residential care staff. Details of the workshop, alongside what would be expected of study participants, are contained in the information sheets enclosed.

I will try and contact you in approximately one week to see whether you would like any further information about the study. I am happy to come and meet you if that would be more convenient, in which case please complete the enclosed 'expression of interest' form.

Many thanks for your interest,

Jason Corner

One page only

IRAS Project ID: 204927



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Participant Information Sheet (Resident with Memory Problems)

Does a workshop delivered to care home staff affect the wellbeing of residents with memory problems?

Who is running this project?

- Jason Corner, a student at the University of East Anglia
- He is supervised by Professor Antony Arthur and Bridget Penhale

What is the project for?

- This study wants to know whether staff training can improve the day to day lives of residents with memory problems

Why have I been invited to take part?

- Because you are living at (insert care home name) and because you have problems with your memory

What will it involve?

If you agree to take part:

- Jason will visit you at (insert care home name) and ask permission to observe you and the care you receive for four hours on two separate occasions
- Jason will make some brief notes about the care you receive

Why might I prefer not to take part?

- If you feel uneasy at any time then Jason will stop observing you
- Taking part is entirely voluntary
- Whether you take part has no effect on your care or support

How will your information be protected?

- Your name will not be used in any reports
- All information from the visits will be kept in a securely locked place
- All information is kept for 10 years, as required by the University of East Anglia

- Everything I observe or you say is confidential unless you tell me something that indicates you or someone else is at risk of harm. I would discuss this with you before telling anyone else.

Who has reviewed this study?

The study has been reviewed and approved by the Social Care Research Ethics Committee. They are a group of people who check proposed research to make sure it is helpful, fair and unlikely to cause harm.

Who can I contact if I have questions?

On the next page are contact details for Jason and his supervisor, Professor Antony Arthur. There are also contact details for someone independent of the research study, in case you wish to make a complaint. You can use these contacts at anytime.

Lead Researcher Contact details	Project Supervisor Contact details	Independent Person Contact details
<p>Jason Corner University of East Anglia Rm 0.07 Edith Cavell Building Norwich Research park NR4 7TJ</p> <p><u>Tel: 01603592597</u></p> <p>Email: j.corner@uea.ac.uk</p>	<p>Professor Antony Arthur University of East Anglia Rm 1.12 Queens Building Norwich Research park NR4 7TJ</p> <p>Email: antony.arthur@uea.ac.uk</p> <p>Tel: 01603 591094</p>	<p>Professor Eneida Mioshi University of East Anglia Rm 1.07 Queen's Building Norwich Research park NR4 7TJ</p> <p>Email: e.mioshi@uea.ac.uk</p> <p>Tel: 01603593300</p>

7.8 Appendix eight: capacity assessment form



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MENTAL CAPACITY ACT (2005) ASSESSMENT

1. Individual's details

Name: _____

Date of birth: ____ / ____ / ____

Location at time of assessment: _____

2. Research Study Title (in full)

Note: Before deciding that someone lacks capacity to make a particular decision, it is important to take all practical and appropriate steps to enable that person to make that decision themselves.

3. Two-Stage Test of Mental Capacity (See MCA (2005) Code of Practice Chapter Four)

- a. Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent) Provide evidence.

Note: If a person does not have such an impairment or disturbance of the mind or brain, they will not lack capacity under the Act.

- b. Does that impairment or disturbance mean that the person is unable to make the decision in question; at the time it needs to be made?

Can the person:	(Circle one)
a) Understand the information relevant to the decision?	Yes No
b) Retain that information?	Yes No
c) Use or weigh that information as part of the process of making the decision?	Yes No
d) Communicate his/her decision (whether by talking or other means)?	Yes No

Provide evidence in respect of the person's ability in relation to each of these four elements of the test:

Note: If a person cannot do one or more of these four things, they are unable to make the decision.

4. Outcome of Mental Capacity Test (Tick one only)

On the balance of probabilities, there is a reasonable belief that:

The person **has** capacity to make this particular decision at this time

Or

The person **does not have** capacity to make this particular decision at this time

Details of assessor

Assessor (PRINT): _____ Date: _____ Time: _____

Signature: _____ Designation: _____

Document H, MCA assessment form. IRAS Project ID: 204927. Version 1: Date 18/01/2017

7.9 Appendix nine: resident consent form



Collaboration for leadership
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Informed Consent Form (Person with Memory Problems)

Does a workshop delivered to care home staff affect the wellbeing of residents with memory problems?

- I have read and understood the participant information sheet and this consent form
- I have had a chance to ask questions about taking part in this study.
- I will be given a copy of both forms for my own records
- I do not have to take part in this study and have the right to withdraw from this study at any stage without giving any reason without this affecting my status as a resident at (name of residential care home).

Please initial in the boxes and sign below.

I agree to take part in this study.

I agree to be observed by a researcher

Name of participant: _____

Signature of participant: _____

Signature of researcher: _____

Date: _____

Contact details: Jason Corner, School of Health Sciences, University of East Anglia,
Norwich, NR4 7TJ. Email: j.corner@uea.ac.uk Telephone number: 01603 592597

7.10 Appendix ten: consultee covering letter

IRAS Project ID: 204927

[Care setting headed paper with contact details]

Date

Dear [Name of potential consultee]

[Name of care setting] is working in partnership with Jason Corner, a researcher at the University of East Anglia (UEA) on a study which explores the effect of a dementia workshop delivered to the care home staff.

As part of this research, Jason will be undertaking observations of residents and staff located in the communal areas of the care home to explore what helps residents with dementia live contentedly. All observations will remain anonymous and no identifying information will be recorded. Observations will be taken on two separate days and for four hours on each day, these times will be arranged with the care manager first. Everything observed is confidential unless the researcher witnesses something that indicates someone is at risk of harm.

An important part of this research is the ethical considerations of everyone involved. It is important that only people who are willing and happy to be included in these observations are included. Anyone who does not want to be included in the research just has to let a member of the care staff or the researcher know and they will not be involved in any of the research, this will in no way affect the services that they receive here.

You are being approached as you are someone who may be willing to act as a consultee for [name of resident] who we believe lack the capacity to decide whether they wish to participate in this research. The role of acting as a consultee is entirely optional, and [name of resident] does not have to take part in the study. If you do not act as the consultee this will have no effect on any services that are being provided to [name of resident].

The role of a consultee is to provide advice about what you feel the wishes of the resident with regard to taking part in this research project. You are not being asked to consent on behalf of the person who lacks capacity, but you are being asked to try and set aside any personal views you may have about the research and consider only the past and present views of the person who lacks capacity with regard to this study. At any stage you can advise the researcher that the person who lacks capacity would not want to be included in the study and the researcher will respect that advice. If a resident has fluctuating capacity, and loses capacity during the course of the research observations, then they will continue to be included in the study unless you as the consultee advise otherwise. This is also the case if [name of resident] shows any

Document K, covering letter consultee

Version 1

18/01/2017

signs of discomfort with the research, in which case they would not be included in the study with immediate effect.

If you agree to act as a consultee for the resident, then you are asked to sign the consultee declaration form provided at the end of this letter and return it to us at the address provided, or to [name of care setting], the declaration form also asks you to consider whether [name of resident] would be happy to be included in this research study.

It is important to note that only observations in communal areas of the care home will take place, and no one will be identified at any stage. Residents who are being observed will be reminded of the research every time Jason comes to conduct the research and if they ever show any indication that they do not want to take part then they will not be included. I have included an information leaflet about the research. If you have any questions or would like to discuss the research then you can either contact myself or the researcher, Jason, via the details located on the information leaflet.

If you have any complaints about the research, there is a person who is independent to the research who would be willing to deal with the complaint. The contact details are:

Address:

Professor Eneida Mioshi
University of East Anglia
Rm 1.07 Queen's Building
Norwich Research Park
NR4 7TJ
Email: e.mioshi@uea.ac.uk
Tel: 01603 593300

Thank you for taking the time to read this information.

Yours sincerely

[Care manager name]

[Signed by care manager]

Document K, covering letter consultee

Version 1

18/01/2017



Participant information sheet for residential care home staff

Study title

Can a dementia workshop delivered to residential care home staff affect the wellbeing of residents with dementia? A feasibility study

You are being invited to take part in a research study because you are a member of staff of a participating care home. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully. If there is anything that is unclear or if you would like more information, please contact Jason Corner using the contact details at the end of this document.

Background and purpose of this study

As you are aware many people with dementia reside in residential homes, which provide care for a variety of people who because of their dementia need a greater level of support. The support you provide can take many forms. When providing personalised support for someone with dementia it is important to understand them as an individual and provide opportunities to promote their rights.

In this research study I will deliver a dementia workshop to residential care staff and measure whether this affects the wellbeing of residents with dementia.

Why am I being approached?

You have been asked to take part in this study because you provide support for people with dementia. You might be employed in any capacity (for example, care work, administration, kitchen and cleaning), but you should have direct interaction with residents on at least a weekly basis. Senior managers are not being recruited to participate in the workshop.

What does taking part involve?

If you agree to take part you will be asked to complete a short questionnaire on two occasions approximately 10 weeks apart. Completing the questionnaire should take no longer than 10 minutes. In addition, you will be asked to attend a one-hour dementia workshop taking place after the first questionnaire or the second.

The dementia workshop will be facilitated by Jason Corner, a PhD student at the UEA and registered nurse. A convenient time will be agreed with your manager. The dementia workshop will take place in an area of the care home where you will be able to talk openly without being interrupted. Jason will guide participants through four exercises which make up the dementia workshop. The exercises are designed to help staff members think about the people they care for and to plan an action to change about their work as a result of something they have learnt in the workshop.

In this study, some care homes will receive the workshop prior to the second questionnaire being sent out, and the others will receive the workshop after. This will allow us to compare staff knowledge and attitudes between those that have received the workshop prior to the second questionnaire and those that receive it afterwards.

I will be conducting Dementia Care Mapping. This will take the form of observing staff and residents for four hours on two separate occasions, in the public areas of the home in order to assess residents' well-being. The focus of dementia care mapping is on the residents, not the staff but should you wish not to be observed you can let Jason know and he will reorganise the observations so that you are not included against your wishes.

What are the benefits of taking part?

You may not benefit directly from participating. However, taking part in a research study may help you to reflect on your own care practices. Your participation will help shape future research studies and provide valuable insights into dementia education within residential care homes.

What are the possible disadvantages and risks of taking part?

Discussions about dementia can provoke sometimes distressing emotions. Should you find any of the discussion upsetting you can leave the workshop immediately. Jason will be available after the dementia workshop for a conversation and to direct you to possible sources of support.

Will my information be kept confidential?

Yes. All information you give such as names and locations will remain completely confidential. Results may be published in research journals and presented at conferences. No information that can lead to anyone being identified will be used in any report or publication that this study produces. You should be aware that at the University of East Anglia contributions to research studies are stored for 10 years at the University of East Anglia. Confidentiality may need to be broken in circumstances where a disclosure causes concern for the welfare of interviewees or risk of harm to others.

Do I have to take part?

No. It is up to you, your participation in this study does not affect your rights of employment. Your participation is entirely voluntary. If you decide to take part in this study you can withdraw at any time, without giving a reason. However, you should be aware that should you wish to leave the study after participating in the dementia workshop then your anonymized contribution will be retained. Your full participation in the workshop will be appreciated but you may opt out at any time.

What if something goes wrong?

In the event of a problem occurring you can talk to Jason who will try to resolve any difficulties. Alternatively, you can contact the project supervisor (Professor Antony Arthur). If you wish to speak to, or have a complaint, you can contact someone independent of the project (Professor Eneida Mioshi). All contact details are provided below.

Ethical approval for the study

This study has been reviewed and approved by the Social Care Research Ethics Committee.

What do I do next?

If you would like more information, or wish to take part in the dementia workshop please return your expression of interest form in the stamped addressed envelope provided; alternatively, you can contact Jason using the details below. Thank you for taking the time to read this information sheet.

Lead Researcher Contact details	Project Supervisor Contact details	Independent Person Contact details
Jason Corner University of East Anglia Rm 0.07 Edith Cavell Building Norwich Research park NR4 7TJ Tel: <u>01603592597</u> Email: j.corner@uea.ac.uk	Professor Antony Arthur University of East Anglia Rm 1.12 Queens Building Norwich Research park NR4 7TJ Email: antony.arthur@uea.ac.uk Tel: 01603 591094	Professor Eneida Mioshi University of East Anglia Rm 1.07 Queen's Building Norwich Research park NR4 7TJ Email: e.mioshi@uea.ac.uk Tel: 01603593300

7.13 Appendix thirteen: staff expression of interest forms



Collaboration for leadership
in applied health research
and care
East of England

I am conducting a research study at the University of East Anglia. You are being invited to consider participating in the study. Details of what participation would involve are provided in the care home staff participant information sheet. If you would like to find out more about the study please contact **Jason Corner**



Jason Corner
University of East Anglia
Edith Cavell Building, 0.07
School of Nursing Sciences
Norwich Research Park
Norwich NR4 7TJ



01603 592597



j.corner@uea.ac.uk

Alternatively, fill in this contact slip and Jason will contact you in the next few days:

I am interested in hearing more about the dementia workshop, and I am happy for Jason to contact me. My preferred times to be contacted are:

Name:

Address:

Telephone:

E-mail:

I would prefer to be contacted by: Telephone

Post

Email

7.14 Appendix fourteen: staff consent forms



Collaboration for leadership
in applied health research
and care
East of England

Informed Consent Form (Staff member)

Does a dementia workshop delivered to residential care home staff affect the wellbeing of residents with dementia?

- I have read and understood the participant information sheet and this consent form
- I have had a chance to ask questions about taking part in this study
- I will be given a copy for my own records
- I do not have to take part in this study and have the right to withdraw from this study at any stage without giving any reason without this affecting my employment.

Please initial in the box and sign below.

I agree to take part in this study.

Name of staff member: _____

Signature of staff member: _____

Signature of researcher: _____ Date: _____

Name of researcher
Address:

Jason Corner
0.07 Edith Cavell Building
Norwich research park
University of East Anglia
Norwich NR4 7TJ

Email/Telephone: j.corner@uea.ac.uk / 01603 592597

7.15 Appendix fifteen: personhood in dementia questionnaire

<p>Instructions: Consider how true each statement is, and choose the rating that best applies. Remember that your response can only be used if you mark <u>one</u> and <u>only one</u> circle per item.</p>	Disagree strongly	Disagree quite a bit	Disagree Slightly	Neither agree nor Disagree	Agree slightly	Agree quite a bit	Agree strongly
1. Residents with dementia have a sense of purpose.	0	0	0	0	0	0	0
2. Most residents with dementia are still capable of making some informed choices about their lives.	0	0	0	0	0	0	0
3. Residents with dementia have a basic right to make any choices they can about their care.	0	0	0	0	0	0	0
4. Residents with very advanced dementia are so low-functioning that they are no longer persons.	0	0	0	0	0	0	0
5. Residents with end-stage dementia can no longer contribute to the world in any meaningful way.	0	0	0	0	0	0	0
6. Residents with dementia contribute to a sense of community within our long-term care facility.	0	0	0	0	0	0	0
7. All residents with dementia should be treated with respect.	0	0	0	0	0	0	0
8. Residents with advanced dementia are no longer true participants in life; instead, they watch from the sidelines.	0	0	0	0	0	0	0
9. It is possible for residents with dementia to connect with each other in meaningful ways.	0	0	0	0	0	0	0
10. Residents with dementia want to socialize with the people around them.	0	0	0	0	0	0	0

<p>Instructions: Consider how true each statement is, and choose the rating that best applies.</p>	Disagree extremely	Disagree quite a bit	Disagree Slightly	Neither agree nor Disagree	Agree slightly	Agree quite a bit	Agree extremely
11. Residents with dementia can continue to play an important role in their families.	0	0	0	0	0	0	0
12. Some residents with dementia have had an important role in my life.	0	0	0	0	0	0	0
13. Providing stimulation such as music is very helpful for a resident with end-stage dementia.	0	0	0	0	0	0	0
14. As dementia advances, residents with dementia no longer experience basic feelings such as pleasure.	0	0	0	0	0	0	0
15. Residents with end-stage dementia have some awareness of what is happening around them.	0	0	0	0	0	0	0
16. Residents with dementia who whine a lot should be isolated.	0	0	0	0	0	0	0
17. The needs of residents who still have awareness of their environment should take priority over the needs of those who have less awareness.	0	0	0	0	0	0	0
18. Residents with advanced dementia are no longer persons like you and me, because they do not think and reason logically.	0	0	0	0	0	0	0
19. Residents with dementia have feelings about their experiences.	0	0	0	0	0	0	0
20. Most residents with dementia feel the same range of emotions as I do.	0	0	0	0	0	0	0

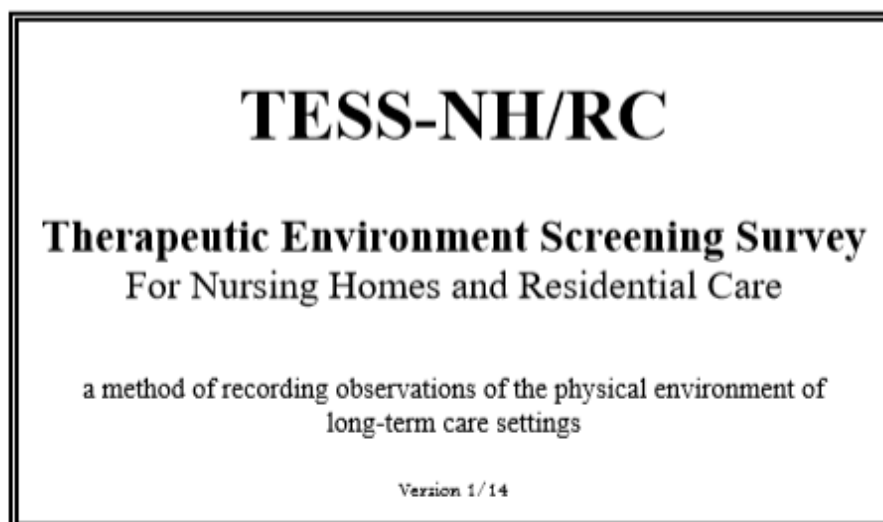
7.16 Appendix sixteen: visual analogue scale

How able, do you feel, to care for residents with dementia?

Mark your answer with a cross on the line below

Not able  Very able

7.17 Appendix seventeen: therapeutic environment screening survey



Developed by the Program on Aging, Disability and Long-Term Care, of the Cecil G. Sheps Center for Health Services Research, at the University of North Carolina at Chapel Hill

Contact Info:

Philip D. Sloane, MD MPH
Sheryl Zimmerman, PhD
Sheps Center for Health Services Research
University of North Carolina at Chapel Hill
CB#7590, 725 Airport Rd
Chapel Hill, NC 27599-7590

Email: Drs. Sloane or Zimmerman
psloane@med.unc.edu; sheryl_zimmerman@unc.edu



CLEANLINESS

3. Rate the general cleanliness of each of the following areas.

	*a.	*b.	c.	d.
	Activity/ Dining Areas	Halls	Residents' Rooms	Residents' Bathrooms
			# rooms with feature	
Very clean	2	2		
Moderately clean	1	1		
Poor level of cleanliness	0	0		
Number of rooms observed				

(T3a-T3dno)

ODORS

4. To what extent are odors of bodily excretions (urine and feces) present in public areas and in residents' bedrooms?

	*a.	*b.
	Public Areas	Residents' Rooms
	# rooms with feature	
Rarely or not at all (0-5%).....	2	
Noticeable in some areas (6-74%).....	1	
Noticeable throughout much or all of the area (75-100%).....	0	
Number of resident rooms observed		

(T4a-T4bno)

SAFETY

*5. Rate the floor surface in the halls.

- No slippery and/or uneven surfaces..... 2
- Mostly free of slippery and/or uneven surfaces..... 1
- Slippery and/or uneven surfaces..... 0

(T5)

6. To what extent are handrails present in this area?

	a.	b.
	Hallways	Bathrooms # rooms with feature
Extensively	2	
Somewhat	1	
Little or none	0	
Number of resident bathrooms observed		

(T6a-T6bno)

7. To what extent are call buttons present in resident rooms and bathrooms? (Count call button as present for both room and bathroom if resident wears a device that summons staff.)

- a. _____ # rooms with call buttons (T7a) b. _____ # bathrooms with call buttons (T7b)
- c. _____ # rooms observed (T7c) d. _____ # bathrooms observed (T7d)

8. Exit control:

a. Total number of exits out of the area _____
(include exits that are controlled or uncontrolled from outdoor areas) (T8a)

b. Number of exits that are controlled for unauthorized resident exit _____
(exclude doors that lead to outdoor areas; include any exits from the outdoor areas) (T8b)

9. Is the front door of the building controlled for unauthorized resident exit?

No0

Yes1

(T9)

LIGHTING

*10. Rate the light intensity in hallways, activity areas, and residents' rooms.

	a.	*b.	*c.
	Hallways	Activity/ Dining Areas	Residents' Rooms # rooms with feature
Ample	2	2	
Good	1	1	
Barely adequate/inadequate	0	0	
Number of rooms observed			

(T10a-T10cno)

11. To what extent is glare present in hallways, activity areas/dining, and residents' rooms?

	a.	b.	c.
	Hallways	Activity/ Dining Areas	Residents' Rooms # rooms with feature
A little or none	2	2	
In a few areas	1	1	
In many areas	0	0	
Number of rooms observed			

(T11a-T11cno)

12. Is lighting even in the hallways, activity/dining areas and in residents' rooms?

	a.	b.	c.
	Hallways	Activity/ Dining Areas	Residents' Rooms # rooms with feature
Even throughout the area	2	2	
Mostly even throughout the area	1	1	
Uneven; many shadows throughout the area	0	0	
Number of rooms observed			

(T12a-T12cno)

13. Assess the following light levels using the light meter held approximately 30 inches from the floor. Take readings in two hallways and two activity/dining areas

	<u>Reading</u>
a. Hallway #1:	
1) Brightest area (no closer than 3' from window).....	_____
2) Darkest area.....	_____
3) Center of hallway.....	_____
	(T13a1-T13a3)
b. Hallway #2: Check if there was: only one hallway <input type="checkbox"/> no hallways <input type="checkbox"/>	
1) Brightest area (no closer than 3' from window).....	_____
2) Darkest area.....	_____
3) Center of hallway.....	_____
	(T13b1-T13b3)
c. Activity/dining area #1:	
1) Brightest area (no closer than 3' from window).....	_____
2) Darkest seating spot.....	_____
3) Center of area.....	_____
	(T13c1-T13c3)
d. Activity/dining area #2: Check if there was only one activity area <input type="checkbox"/>	
1) Brightest area (no closer than 3' from window).....	_____
2) Darkest seating spot.....	_____
3) Center of area.....	_____
	(T13d1-T13d3)

PHYSICAL APPEARANCE/HOMELIKENESS/PERSONALIZATION

14. Which of the following describes the predominant configuration of the hallways?

No hallways; rooms open into living (common) area.....	2
Short hallways.....	1
Long hallways.....	0

(T14)

*15. To what extent do the activity/dining areas contain furniture, decorations, and other features that give them a homelike (residential as opposed to institutional) atmosphere?

Very homelike (75% or more of activity/dining areas are "residential").....	3
Moderately homelike (50-74% of the activity/dining areas are "residential").....	2
Somewhat homelike (25-49% of activity/dining areas are "residential").....	1
Not homelike (less than 25% of the activity/dining areas are "residential").....	0

*16. Is there a kitchen located within the area that is available for activities and/or for resident/family use? (sink, stove/micro, fridge, countertop)

Kitchen facility available for use.....	2
Selected kitchen appliances available for use.....	1
No access to kitchen appliances or no kitchen available.....	0

(T16)

*17. To what extent are pictures and mementos present in the residents' rooms?

	# rooms with feature
At least three personal pictures and/or mementos are present for each resident	
Number of resident rooms observed	

(T17-T17no)

18. To what extent is/are the following present in resident rooms?

	# rooms with feature
a. Non-institutional furniture	
b. Individual heating controls	
c. Individual air conditioning controls	
d. Telephone or telephone connection	
Number of resident rooms observed	

(T18a-T18no)

*19. Are opportunities for stimulation easily available for residents in activity/dining areas and hallways?

	a. Tactile	*b. Visual
Extensively	3	3
Quite a bit	2	2
Somewhat	1	1

7 of 11

None	0	0
------	---	---

(T19a-T19b)

ORIENTATION/CUEING

20. How many resident bedrooms have the following cues?

a. Entrance to Resident Bedroom:	# rooms with feature
1) doors routinely left open	
2) resident name on/near door (2")	
*3) current picture of resident on/near door	
*4) old picture of resident on/near door	
5) objects of personal significance on/near door	
Number of resident rooms observed	

(T20a1-T20a6)

b. Bathroom Entrance from Resident Bedroom	# rooms with feature
1) door open and toilet visible from resident bed (or toilet/commode in room and visible from bed)	
2) door open, but toilet not visible from bed	
3) picture, graphic, or sign (to indicate bathroom) visible from bed	
Number of resident rooms observed	

(T20b1-T20b6)

c. Cue to any Activity/dining area from outside Resident Bedroom Entrance	# rooms with feature
1) an area is visible	
2) a visual cue for an area is visible	
Number of resident rooms observed	

(T20c1-T20c6)

PRIVACY

21. Number of private bedrooms:

	# rooms with feature
Private bedroom	
Number resident rooms observed	

(T21-T21no)

22. What access to a toilet is available to occupants of resident rooms?

Type of access directly from room	# rooms with feature
a) Private toilet	
b) Semi-private toilet	
c) Shared toilet	
d) No direct toilet	
Number of bedrooms observed	

(T22a-T22no)

23. Is there a bathtub and/or shower in resident bedroom bathrooms (a-c above)?

	# resident rooms with feature
a) Yes, there is a bath and/or shower	
b) No bath or shower in bathroom	
Number of bedroom bathrooms observed	

(T23a-T23no)

24. Are residents routinely able to lock doors to resident rooms, apartments, or suites?

	# rooms with feature
a) Door can be locked from the inside (bolt, hook, etc.)	
b) Door can be locked from the outside (bolt, hook, etc.)	
Number of resident rooms observed	

(T24a-T24bno)

NOISES

25. During the observation interval, what was the status of the television in the main activity/dining area?

- The television was on all of the time for an activity..... 4
- No television present..... 3
- The television was off all of the time..... 2
- The television was on some of the time..... 1
- The television was on all of the time..... 0

(T25)

*26. During the observation interval, to what extent did you hear any of the following noises?

	a. Resident Screaming or Calling Out	b. Staff Screaming or Calling Out	c. TV/ Radio Noise	*d. Loud Speaker or Intercom	e. Alarm or Call Bells	f. Other Noises (machines, outdoor noises, etc.)
None present	2	2	2	2	2	2
Some present	1	1	1	1	1	1
Major distraction	0	0	0	0	0	0

(T26a-T26f)

PLANTS

27. To what extent are plants present in the area?

	a	b
	Activity/ Dining Areas	In residents' rooms
		# of rooms with feature
Extensively	2	
Somewhat	1	
Not at all	0	
Number of resident rooms observed		

(T27a-T27bnc)

OUTDOOR AREAS

28. Is there an outdoor area that is directly accessible to residents?

- Outdoor area adjacent; residents may go out on their own..... 3
- Outdoor area adjacent; staff must unsecure door and accompany residents.... 2
- Outdoor area present, but is away from area..... 1
- No outdoor access present..... 0

(T28)

29. Overall, how attractive and functional is/are any outdoor area(s)?

	a.	b.
	Attractive	Functional
Very	2	2
Somewhat	1	1
Not at all	0	0
No outdoor areas	9	9

(T29a-T29b)

RESIDENTS' APPEARANCE

*30. To what extent does the appearance of ALL residents in public areas reflect attention to individual identity and pride (hair styled/combed; extras such as jewelry, watches, belts; street clothes when up and about)?

- Extensively (75% or more of the residents well dressed and groomed)... 2
- Quite a bit (25-74% of the residents well dressed and groomed)..... 1
- Little (fewer than 25% of the residents well dressed and groomed)..... 0

(T30)

ACCESS TO PUBLIC TOILET FROM MAIN ACTIVITY AREA

31. What access to a public toilet is available from the main activity/dining area?

- The main activity area has a public toilet visible from the area..... 2
- The main activity area has a public toilet near (within 25' of) the area... 1
- The main activity areas have no public toilet nearby..... 0

(T31)

IMPRESSIONS

a) Note any striking, unique, or unusual features of this facility/area:

b) Note any things that were unusual about the day of your visit (e.g., certification visit, key people absent, unusual weather, holiday, etc.).

c) Other comments:

7.18 Appendix eighteen: social care ethics committee approval



Social Care REC

Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 972 2568

04 April 2017

Mr Jason A Corner
School of Health Sciences
University of East Anglia
Norwich
NR4 7TJ

Dear Mr Corner

Study title: Does a citizenship and personhood workshop (PERSONABLE) delivered to residential care home staff affect the wellbeing of residents with dementia? Intervention refinement and feasibility testing of a cluster randomised controlled trial.

REC reference: 17/IEC08/0008

IRAS project ID: 204927

Thank you for your letter of 29 March 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

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 opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

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

I confirm that the committee has 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

A Research Ethics Committee established by the Health Research Authority

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.

Advice Only – Not part of the Ethical Decision

The Committee recommend that the participant information sheet for residents is amended as follows:

1. The section 'Why might I prefer not to take part?' is retitled as 'Do I have to take part?' and the bullet points reordered, so they read:
 - Taking part is entirely voluntary
 - Whether you take part has no effect on your care or support
 - If you feel uneasy at any time then Jason will stop observing you

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions 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 within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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 the HRA. 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

Non-NHS sites

Site Specific Assessment

The Committee decided that the research did not require Site-Specific Assessment at non-NHS sites as it involves no clinical interventions and all study procedures at sites would be undertaken by the Chief Investigators' team and the Committee was satisfied that the risk to participants is likely to be negligible, and the study procedures will not significantly interfere with participants' freedom of action or privacy or be unduly invasive or restrictive.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Poster for days of data collection]	V2	27 March 2017
Covering letter on headed paper [Covering letter for ethics]	V1	19 January 2017
Covering letter on headed paper [Covering letter for ethics]	V1 (responses)	27 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor indemnity letter]	1	16 January 2017
IRAS Checklist XML [Checklist_13022017]		13 February 2017
IRAS Checklist XML [Checklist_29032017]		29 March 2017
IRAS Checklist XML [Checklist_04042017]		04 April 2017
Letters of invitation to participant [Letter to potential consultee]	1	18 January 2017
Letters of invitation to participant [Care home letter of approach]	1	18 February 2017
Other [Primary supervisor CV]	1	19 January 2017
Other [Secondary supervisor CV]	1	19 January 2017
Other [Care home expression of interest]	1	18 January 2017
Other [Expression of interest form staff]	1	18 January 2017

Other [Consultee declaration form]	1	18 January 2017
Other [MCA assessment form]	1	18 January 2017
Participant consent form [Resident consent form]	1	18 January 2017
Participant consent form [Staff consent form]	1	18 January 2017
Participant information sheet (PIS) [Study information leaflet]	1	18 January 2017
Participant information sheet (PIS) [Care home PIS]	V2	27 March 2017
Participant information sheet (PIS) [Staff PIS]	V2	27 March 2017
Participant information sheet (PIS) [Resident PIS]	V2	27 March 2017
REC Application Form [SC_Form_25012017]		25 January 2017
Research protocol or project proposal [Study protocol]	V2	27 March 2017
Summary CV for Chief Investigator (CI) [Chief investigator CV]	1	19 January 2017
Validated questionnaire [Personhood in dementia questionnaire]		16 January 2017
Validated questionnaire [TESS RC environment screen questionnaire]		16 January 2017

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

5

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/IEC08/0008

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

A handwritten signature in blue ink that reads "PP Barbara Avelin". The signature is written in a cursive style.

Dr Martin Stevens
Chair

Email: nrescommittee.social-care@nhs.net

Enclosures: *After ethical review – guidance for researchers*

Copy to: Mr Graham Horne

7.19 Appendix nineteen: SPSS syntax

7.19.1 Variable codes Dementia Care Mapping™

Variable name	Variable description
V1.1 to V48.1	Baseline personal enhancers and detractors
V1.2 to V48.2	Baseline Behaviour Category Codes (BCCs)
V1.3 to V48.3	Baseline Mood and Engagement score (ME)
v1 to v48	Baseline BCCs recoded from letter to numerical value
FUv1.1 to FUv48.1	Follow-up personal enhancers and detractors
FUv1 to FUv48	Follow-up BCCs recoded from letter to numerical value
FUunique	Unique code for each resident
vR1.3 to vR48.3	Baseline ME score recoded using revised scale
FUvR1.3 to FUvR1.3	Follow-up ME score recoded using revised scale
BGv1 to BGv48	Baseline BCCs grouped by potential for ME
FUBGv1 to FUBGv48	Follow-up BCCs grouped by potential for ME
BLPositivecount	Baseline sum of positive PE and PDs
BLPegativecount	Baseline sum of negative PE and PDs
FUPositivecount	Follow-up sum of positive PE and PDs
FUNegativecount	Follow-up sum of negative PE and PDs
cmissBL	Baseline sum of missing PE/PD values during the 48 time frames
cmissFU	Follow-up sum of missing PE/PD values during the 48 time frames
BLBCC1Count to BLBCC23Count	Baseline sum of each individual BCC for each resident
FUBCC1Count to FUBCC23Count	Follow-up sum of each individual BCC for each resident
Dropout1	Loss to follow-up
TotalmissingBL	Baseline total missing values on all three levels. Maximum missing values is 3x48=144
TotalmissingFU	Follow-up total missing values on all three levels. Maximum missing values is 3x48=144
Losstofollowup	Loss to follow-up expressed as a binary variable
PEMinusPDBL	Baseline aggregate score of PE/PDs
PEMinusPDFU	Follow-up aggregate score of PE/PDs
BCCBL0 to BCCBL3	Baseline sum of BCCs by their potential for ME grouping
BCCFU0 to BCCFU3	Follow-up sum of BCCs by their potential for ME grouping
BLWIB	Baseline wellbeing/illbeing score (WIB)
FUWIB	Follow-up wellbeing/illbeing score (WIB)
WIBChangescore	Follow-up WiB minus baseline WIB

7.19.2 Formatting of raw Excel DCM™ data

To reduce the large amount of syntax presented in this appendix, lists of variables have been condensed, without this the syntax would have exceeded 50 pages of text. When variables have been condensed the abbreviation is highlight in red.

7.19.2.1 Delete unused cells imported from Excel file

```
DELETE VARIABLES V51 TO V74.
```

7.19.2.2 Delete time variable. Time will be distinguished by observation periods 1-48

```
DELETE VARIABLES Time.
```

7.19.2.3 Switch formatting within Excel of variables to cases

```
Casestovars
```

```
/id=ParticipantName.
```

7.19.2.4 Change scale variable to nominal variable. Variables ending 0.1 relate to Personal detractors or enhancers. Ending 0.2 relate to Behaviour Category Codes. Ending 0.3 relates to Mood and Engagement score

```
alter type V3.1 (repeat up to V48.3) (f8.2). Execute.
```

7.19.2.5 Recode BCCs from letter codes to corresponding numerical code

```
RECODE V3.2 (repeat up to V48.2). Execute.
```

7.19.2.6 Create new variable for care home and time

```
COMPUTE Home=1 (repeat for all six homes). EXECUTE.
```

7.19.2.7 All variables change to nominal and create new variable 'unique' participant code

```
STRING temp (a4).
```

```
Compute temp = SUBSTR(ParticipantName,2,1).
```

```
ALTER TYPE temp(f2).
```

```
Compute unique = home*10+temp.
```

```
EXECUTE.
```

```
DELETE VARIABLES temp.
```

```
EXECUTE.
```

7.19.2.8 Merging separate care home files. Baseline

```
ADD FILES /FILE=*
```

```
 /FILE='E:\Data\Resident\DCM\SL Baseline 31052018.sav'.
```

```
EXECUTE.
```

(Repeat for all other care home data files)

7.19.2.9 Merging separate care home files. Follow-up

```
ADD FILES /FILE=*  
/FILE='E:\Data\Resident\DCM\SL Followup 31052018.sav'.  
EXECUTE.  
(Repeat for all other care home data files)
```

7.19.2.10 Merging baseline and follow-up files

```
GET  
FILE='U:\PHD\AA Thesis\data\Resident\DCM Baseline merged files\Baseline merged  
files 31052018.sav'.  
DATASET NAME DataSet1 WINDOW=FRONT.  
GET  
FILE='E:\Data\Resident\DCM Follow up merged files\DCM Follow up merged  
12062018.sav'.  
DATASET NAME DataSet2 WINDOW=FRONT.  
GET  
FILE='E:\Data\Resident\DCM Follow up separate files\OL Follow up 31052018.sav'.  
DATASET NAME DataSet3 WINDOW=FRONT.  
DATASET ACTIVATE DataSet1.  
DATASET CLOSE DataSet3.  
MATCH FILES /FILE=*  
/FILE='DataSet2'
```

7.19.2.11 To sort cases by arm. Split the file by arm and turn split file off

```
SORT CASES BY Arm.  
SPLIT FILE SEPARATE BY Arm.  
SPLIT FILE off.
```

7.19.2.12 Delete original baseline mood variables

Delete variables v1.3 to 48.3.

7.19.2.13 Delete original FOLLOW UP mood variables

Delete variables FUv1.3 (repeat to FUv48.3).

7.19.3 Transforming and grouping raw data

7.19.3.1 Baseline behaviour groups grouped into high medium and low potential behaviours

```
RECODE v1 (repeat to v48) (1=3) (2=2) (3=1) (4=3) (5=3) (6=3) (7=3) (8=3) (9=3)  
(10=3) (11=3) (12=0) (13=3) (14=3) (15=3) (16=3) (17=3) (18=1) (19=3) (20=1) (21=3)  
(22=3) INTO BGv1 (repeat to BGv48).  
EXECUTE.
```

7.19.3.2 Follow up behaviour grouped into high medium and low potential behaviours

```
RECODE FUv1 (repeat to FUv48) (1=3) (2=2) (3=1) (4=3) (5=3) (6=3) (7=3) (8=3) (9=3)  
(10=3) (11=3) (12=0) (13=3) (14=3) (15=3) (16=3) (17=3) (18=1) (19=3) (20=1) (21=3)  
(22=3) INTO FUBGv1 (repeat to FUBGv48).  
EXECUTE.
```

7.19.3.3 Frequency of ME score by group at baseline and follow-up

MULT RESPONSE GROUPS=\$BLMoodEngage (vr1.3 (repeat to vr48.3) (-3,2))
\$FUMoodEngage (fuvr1.3 (repeat to fuvr48.3) (-3,2))
/FREQUENCIES=\$BLMoodEngage \$FUMoodEngage.

7.19.3.4 Frequency of BCC at baseline and follow up, by arm

MULT RESPONSE GROUPS=\$BaselineBCCGroup (bgv1 (repeat to bgv48) (0,3))
\$FollowupBCCGroup (fubgv1 (repeat to fubgv48) (0,3))
/FREQUENCIES=\$BaselineBCCGroup \$FollowupBCCGroup.

7.19.3.5 Group PE and PD, baseline and follow-up together but not in same table

MULT RESPONSE GROUPS=\$BLPEandPD (v1.1 (repeat to v48.1) (-1,1)) \$FUPEandPD
(fuv1.1 (repeat to fuv48.1) (-1,1))
/FREQUENCIES=\$BLPEandPD \$FUPEandPD.

7.19.3.6 Frequency of BCCs per resident

COUNT BLBCC3=BGv1 (repeat to BGv48) (3).
VARIABLE LABELS BCCCount 'How many of each BCC3'.
EXECUTE.

Count BLBCC2=BGv1 (repeat to BGv48) (2).
VARIABLE LABELS BCCCount 'How many of each BCC2'.
EXECUTE.

Count BLBCC1=BGv1 (repeat to BGv48) (1).
VARIABLE LABELS BCCCount 'How many of each BCC1'.
EXECUTE.

Count BLBCC0=BGv1 (repeat to BGv48) (0).
VARIABLE LABELS BCCCount 'How many of each BCC0'.
EXECUTE.

7.19.3.7 Baseline WIB (Wellbeing Illbeing score)

COMPUTE BLWIB = (mean(vr1.3 (repeat to vr48.3))).
EXECUTE.

7.19.3.8 Follow-up WIB

Compute FUWIB =(mean(fuvr1.3 (repeat to fuvr48.3))).
EXECUTE.

7.19.3.9 Count of enhancing and detracting staff interactions per resident baseline

COUNT BLPositiveCount=v1.1 (repeat to v48.1) (1.0).
VARIABLE LABELS BLPositiveCount 'Staff interactions'.
EXECUTE.
COUNT BLNegativeCount=v1.1 (repeat to v48.1) (-1.0).
VARIABLE LABELS BLNegativeCount 'Staff interactions negative'.
EXECUTE.

7.19.3.10 Count of enhancing and detracting interactions per resident follow-up

```
COUNT FUPositivecount=FUv1.1 (repeat to FUv48.1) (1.0).  
VARIABLE LABELS FUPositivecount 'Staff interactions FU positive'.  
EXECUTE.
```

```
COUNT FUNegativecount=FUv1.1 (repeat to FUv48.1) (-1.0).  
VARIABLE LABELS FUNegativecount 'Staff interactions FU positive'.  
EXECUTE.
```

7.19.3.11 New missing data variable for PE and PDs for BL and FU

```
COUNT  
cmissBL = V1.1 To V48.1 (MISSING).  
execute.  
COUNT  
cmissFU = FUv1.1 To FUv48.1 (MISSING).  
execute.  
FREQUENCIES VARIABLES=cmissBL cmissFU  
/ORDER=ANALYSIS.  
execute.
```

7.19.3.12 New variable baseline BCC '1-23' behaviour code count per resident

```
COUNT BLBCC1Count=v1 (repeat to v48) (1.0).  
EXECUTE.  
(repeat for all 23 BCCs)
```

7.19.3.13 New variable follow up behaviour code category (1-23) count per resident

```
COUNT FUBCC1Count=FUv1 (repeat to FUv48) (1.0).  
EXECUTE.  
(repeat for all 23 BCCs)
```

7.19.3.14 Split file by arm prior to loss to follow-up analysis

```
SPLIT FILE by arm.
```

7.19.3.15 Loss to follow up

```
COUNT Dropout1=FUv1.1 (repeat to FUv48.1) (SYSMIS).  
EXECUTE.  
FREQUENCIES VARIABLES=Dropout1  
/ORDER=ANALYSIS.
```

7.19.3.16 Total missing values BL and FU within each case for all three blocks of variables

```
COUNT TotalmissingBL=v1.1 (repeat to v48.1) (SYSMIS).  
VARIABLE LABELS TotalmissingBL 'total missing on three levels'.  
EXECUTE.  
COUNT TotalmissingFU=FUv1.1 (repeat to FUv48.1) (SYSMIS).  
VARIABLE LABELS TotalmissingFU 'total missing on three levels'.  
EXECUTE.
```


7.19.3.17 Create binary variable for loss to follow up

```
COUNT Losstofollowup=TotalmissingFU(144).  
VARIABLE LABELS Losstofollowup 'Number of residents missing at follow up'.  
EXECUTE.
```

7.19.3.18 PE and PD aggregate score

```
COMPUTE PEMinusPDBL=BLPositivecount - BLNegativeCount.  
EXECUTE.  
COMPUTE PEMinusPDFU=FUPositivecount - FUNegativecount.  
EXECUTE.
```

7.19.3.19 Mean of BCC groups. Baseline and follow up

```
compute BLBCCGRPMean=(MEAN(BGv1 (repeat to BGv48))  
EXECUTE.  
compute FUBCCGRPMean=(MEAN(FUBGv1 (repeat to FUBGv48)).  
EXECUTE.
```

7.19.3.20 BCC group count baseline

```
COUNT BCCBL0=BGv1 (repeat to BGv48) (0.00).  
VARIABLE LABELS BCCBL0 "BCC '0' score count".  
EXECUTE.  
COUNT BCCBL1=BGv1 (repeat to BGv48) (1.00).  
VARIABLE LABELS BCCBL1 "BCC '1' score count".  
EXECUTE.  
COUNT BCCBL1=BGv1 (repeat to BGv48) (2.00).  
VARIABLE LABELS BCCBL2 "BCC '2' score count".  
EXECUTE.  
COUNT BCCBL1=BGv1 (repeat to BGv48) (3.00).  
VARIABLE LABELS BCCBL3 "BCC '3' score count".  
EXECUTE.
```

7.19.3.21 BCC group count follow up

```
COUNT BCCFU0=FUBGv1 (repeat to FUBGv48) (0.00).  
VARIABLE LABELS BCCFU0 "BCC '0' score count".  
EXECUTE.  
COUNT BCCFU1=FUBGv1 (repeat to FUBGv48) (1.00).  
VARIABLE LABELS BCCFU1 "BCC '1' score count".  
EXECUTE.  
COUNT BCCFU2=FUBGv1 (repeat to FUBGv48) (2.00).  
VARIABLE LABELS BCCFU2 "BCC '2' score count".  
EXECUTE.  
COUNT BCCFU3=FUBGv1 (repeat to FUBGv48) (3.00).  
VARIABLE LABELS BCCFU3 "BCC '3' score count".  
EXECUTE.
```

7.19.3.22 Delete the participant that did not have dementia and no data was observed or recorded

```
SELECT IF not (TotalmissingBL=144 and TotalmissingFU=144).  
EXECUTE.
```

7.19.3.23 WiB change score.

```
COMPUTE WiBChangescore=FUWIB - BLWIB.  
EXECUTE.
```

7.19.3.24 Sum of BCC by 'potential for mood and engagement'. Baseline and follow-up

```
compute BLBCCGRPSum=(sum(BGv1 (repeat to BGv48)).
```

```
EXECUTE.
```

```
compute FUBCCGRPSum=(sum(FUBGv1 (repeat to FUBGv48) ).
```

```
EXECUTE.
```

7.19.3.25 Aggregate score of BCC grouping

```
COMPUTE BCCGRPChange=FUBCCGRPSum - BLBCCGRPSum.
```

```
EXECUTE.
```

7.20 Analysis

7.20.1 Mixed effects regression model

7.20.1.1 Unadjusted WIB

```
MIXED FUWIB WITH Arm
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.2 Adjusted WIB

```
MIXED FUWIB WITH Arm BLWIB Gender
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm BLWIB Gender | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.3 Unadjusted PE/PD

```
MIXED FUPositivecount WITH Arm
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.4 Adjusted PE/PD

```
MIXED FUPositivecount WITH Arm BLPositiveCount Gender
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm BLPositiveCount Gender | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.5 Unadjusted BCCGroup

```
MIXED FUBCCGRPMean WITH Arm
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.6 Adjusted BCC by group

```
MIXED FUBCCGRPMean WITH Arm BLBCCGRPMean Gender
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm BLBCCGRPMean Gender | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.7 Adjusted PDQ

```
MIXED TotalRescaleFU WITH Arm TotalRescaleBL Experience Gender
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm TotalRescaleBL Experience Gender | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.8 Unadjusted PDQ

```
MIXED TotalRescaleFU WITH Arm TotalRescaleBL Experience Gender
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm TotalRescaleBL Experience Gender | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.9 Unadjusted VAS

```
MIXED FVAS WITH Arm
```

```
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.10 Adjusted VAS

```
MIXED FVAS WITH Arm VAS Experience Gender
/CRITERIA=CIN(95) MXITER(100) MXSTEP(10) SCORING(1)
SINGULAR(0.000000000001) HCONVERGE(0,
  ABSOLUTE) LCONVERGE(0, ABSOLUTE) PCONVERGE(0.000001, ABSOLUTE)
/FIXED=Arm VAS Experience Gender | SSTYPE(3)
/METHOD=REML
/PRINT=G SOLUTION
/RANDOM=INTERCEPT | SUBJECT(Home) COVTYPE(VC).
EXECUTE.
```

7.20.1.11 Number for PDQ adjusted

```
REGRESSION
/MISSING LISTWISE
/STATISTICS COEFF OUTS R ANOVA
/CRITERIA=PIN(.05) POUT(.10)
/NOORIGIN
/DEPENDENT TotalRescaleFU
/METHOD=ENTER Experience Arm Gender TotalRescaleBL Home.
EXECUTE.
```

7.20.1.12 Number for WIB adjusted

```
REGRESSION
/MISSING LISTWISE
/STATISTICS COEFF OUTS R ANOVA
/CRITERIA=PIN(.05) POUT(.10)
/NOORIGIN
/DEPENDENT FUWIB
/METHOD=ENTER Arm BLWIB Gender.
EXECUTE.
```

7.20.1.13 Number for PE/PDs

```
REGRESSION
/MISSING LISTWISE
/STATISTICS COEFF OUTS R ANOVA
/CRITERIA=PIN(.05) POUT(.10)
/NOORIGIN
/DEPENDENT FUPositivecount
```

```
/METHOD=ENTER Arm BLPositiveCount Gender.  
EXECUTE.
```

7.20.1.14 Number for VAS

```
REGRESSION  
/MISSING LISTWISE  
/STATISTICS COEFF OUTS R ANOVA  
/CRITERIA=PIN(.05) POUT(.10)  
/NOORIGIN  
/DEPENDENT FVAS  
/METHOD=ENTER Arm VAS Experience Gender.  
EXECUTE.
```

7.20.1.15 Number for BCCs

```
REGRESSION  
/MISSING LISTWISE  
/STATISTICS COEFF OUTS R ANOVA  
/CRITERIA=PIN(.05) POUT(.10)  
/NOORIGIN  
/DEPENDENT FUBCCGRPMean  
/METHOD=ENTER Arm BLBCCGRPMean Gender.  
EXECUTE.
```

7.20.2 Interrater agreement

7.20.2.1 To merge interrater datasets

```
DATASET ACTIVATE DataSet4.  
DATASET CLOSE DataSet5.  
GET  
FILE='U:\PHD\AA Thesis\data\Resident\SecondraterdataYH\SecondraterYH  
29032019.sav'.  
DATASET NAME DataSet6 WINDOW=FRONT.  
DATASET ACTIVATE DataSet6.  
DATASET CLOSE DataSet4.  
GET  
FILE='U:\PHD\AA Thesis\data\Resident\Secondrateroakland\SecondraterOaklands  
29032019.sav'.  
DATASET NAME DataSet7 WINDOW=FRONT.  
DATASET ACTIVATE DataSet6.  
  
SAVE OUTFILE='U:\PHD\AA  
Thesis\data\Resident\Secondrateroakland\SecondraterYH 29032019.sav'  
/COMPRESSED.  
  
SAVE OUTFILE='U:\PHD\AA  
Thesis\data\Resident\Secondrateroakland\SecondraterYH 29032019.sav'  
/COMPRESSED.  
MATCH FILES /FILE=*
```

```
/FILE='DataSet7'.  
EXECUTE.
```

7.20.2.2 Interrater agreement BCC

```
DATASET ACTIVATE DataSet1.  
CROSSTABS  
/TABLES=v1C BY v1  
/FORMAT=AVALUE TABLES  
/STATISTICS=KAPPA  
/CELLS=COUNT  
/COUNT ROUND CELL.
```

(Repeat for all 42 time frames)

7.20.2.3 Interrater agreement: ME values

```
CROSSTABS  
/TABLES=vR1.3C BY vR1.3  
/FORMAT=AVALUE TABLES  
/STATISTICS=KAPPA  
/CELLS=COUNT  
/COUNT ROUND CELL.
```

(Repeat for all 42 time frames)

7.20.2.4 Interrater agreement BCC grouping

```
CROSSTABS  
/TABLES=FUBGv1C BY FUBGv1  
/FORMAT=AVALUE TABLES  
/STATISTICS=KAPPA  
/CELLS=COUNT  
/COUNT ROUND CELL.
```

(Repeat for all 42 time frames)

7.20.2.5 Check reliability

```
RELIABILITY  
/VARIABLES=FUBCCGRPMeanC FUBCCGRPMean  
/SCALE('ALL VARIABLES') ALL  
/MODEL=ALPHA  
/ICC=MODEL(RANDOM) TYPE(CONSISTENCY) CIN=95 TESTVAL=0.
```

7.20.2.6 T-Test

```
T-TEST PAIRS=FUBCCGRPMeanC FUWIBC WITH FUBCCGRPMean FUWIB (PAIRED)  
/CRITERIA=CI(.9500)  
/MISSING=ANALYSIS.
```

7.21 Personhood in Dementia Questionnaire (PDQ) and VAS analysis

Variable	Variable description
Participants	Unique participant code
B1 to B20	Baseline score for each of the PDQ questions
F1 to F20	Follow-up score for each of the PDQ questions
VAS	Baseline Visual Analogue Scale (VAS)
FVAS	Follow-up Visual Analogue Scale (VAS)
B4R, B5R, B8R, B14R, B16R, B17R, B18R	Baseline reverse coded questions
F4R, F5R, F8R, F14R, F16R, F17R, F18R	Follow-up reverse coded questions
BLTotal	Baseline mean of question scores
FUTotal	Follow-up mean of question scores
Role_num	Numerical code for differing job roles
Job_group	Differing job roles grouped into three sub groups: care worker, ancillary and other
Experience	Staff experience in months
BLsum	Baseline sum value of question answers
cmissBL	Baseline sum of missing answers to questions
cmissFU	Follow-up sum of missing answers to questions
TotalRescaleBL	Baseline PDQ score changed to 0-100 scale
TotalRescaleFU	Follow-up PDQ score changed to 0-100 scale
respB	Baseline response to questionnaire
respF	Follow-up response to questionnaire
response	Overall responses by group. 0=Neither, 1=Baseline only, 2=Follow-up only, 3=Both
Drop_num	Grouped by reason for dropout. 1=Away, 2=Declined, 3=Left, 4=Retired, 5=Sick
changePDQ	Change score for PDQ
changeVAS	Change score for VAS

7.21.1 Formatting of raw Excel PDQ and VAS data

7.21.1.1 Creating variable for home (codes 1 to 6)

```
RECODE Participants (100 thru 199=1) (200 thru 299=2) (300 thru 399=3) (400 thru 499=4) (500 thru 599=5) (600 thru 699=6) INTO Home.  
EXECUTE.
```

7.21.1.2 Creating variable for trial arm

```
RECODE Home (1=0) (2=1) (3=1) (4=0) (5=1) (6=0) INTO Arm.  
EXECUTE.
```

7.21.1.3 Change the string variable 'sex' into the string variable 'gender'

```
AUTORECODE VARIABLES=Sex.  
/INTO Gender  
/BLANK=MISSING  
/PRINT.
```

7.21.1.4 Turns role into numeric variable

```
AUTORECODE VARIABLES=Role  
/INTO Role_num  
/BLANK=MISSING  
/PRINT.
```

7.21.1.5 Collapse new role numeric variable into 3-level job group variable

```
RECODE Role_num (1=3) (2=3) (3=2) (4=1) (5=2) (6=2) (7=2) (8=1) (9=2) (10=2) (11=1) (12=3) (13=1) INTO Job_group.  
EXECUTE.  
DATASET ACTIVATE DataSet3.
```

7.21.1.6 Changing baseline and follow-up reverse code questions into correct value

```
RECODE B4 B5 B8 B14 B16 B17 B18 (7=1) (6=2) (5=3) (4=4) (3=5) (2=6) (1=7) (ELSE=SYSMIS) INTO B4R B5R B8R B14R B16R B17R B18R.  
EXECUTE.
```

```
RECODE F4 F5 F8 F14 F16 F17 F18 (7=1) (6=2) (5=3) (4=4) (3=5) (2=6) (1=7) (ELSE=SYSMIS) INTO F4R F5R F8R F14R F16R F17R F18R.  
EXECUTE.
```

7.21.1.7 Checking reverse coding using crosstabs

```
CROSSTABS  
/TABLES=B4R BY B4  
/TABLES=B8R BY B8  
/TABLES=B4R BY B4  
/TABLES=B8R BY B8  
/TABLES=B4R BY B4  
/TABLES=B8R BY B8  
/TABLES=B4R BY B4  
/TABLES=B8R BY B8
```

```

/TABLES=B4R BY B4
/TABLES=B8R BY B8
/TABLES=B4R BY B4
/TABLES=B8R BY B8
/TABLES=B4R BY B4
/TABLES=B8R BY B8
/TABLES=B4R BY B4
/TABLES=B8R BY B8
/TABLES=B4R BY B4
/TABLES=B8R BY B8
/FORMAT=AVALUE TABLES
/CELLS=COUNT
/COUNT ROUND CELL.

```

7.21.1.8 Calculate mean of PDQ questions, baseline and follow-up. Adjusting by -1 to use a 0-6 scale

```

COMPUTE
BLTotal=(MEAN(B1,B2,B3,B4R,B5R,B6,B7,B8R,B9,B10,B11,B12,B13,B14R,B15,B16R,B
17R,B18R,B19,B20))-1.
EXECUTE.

```

```

COMPUTE
FLTTotal=(MEAN(F1,F2,F3,F4R,F5R,F6,F7,F8R,F9,F10,F11,F12,F13,F14R,F15,F16R,F17R
,F18R,F19,F20))-1.
EXECUTE.

```

7.21.1.9 PDQ Change score

```

COMPUTE Change=FLTTotal-BLTotal.
EXECUTE.

```

7.21.1.10 Baseline and follow-up. Rescaling PDQ score to a 0-100 scale

```

Compute TotalRescaleBL=(((MEAN.17(B1 to B3, B4R, B5R, B6, B7, B8R, B9 to B13,
B14R, B15, B16R to B18R, B19, B20))-1)/6)*100.
execute.

```

```

Compute TotalRescaleFU=(((MEAN.17(F1 to F3, F4R, F5R, F6, F7, F8R, F9 to F13,
F14R, F15, F16R to F18R, F19, F20))-1)/6)*100.
execute.

```

7.21.1.11 Transform sum of BL variable from 0-6 to 1-7, hence -1

```

COMPUTE BLsum =
(SUM(B1,B2,B3,B4,B5,B6,B7,B8,B9,B10,B11,B12,B13,B14,B15,B16,B17,B18,B19,B20)
)-1.
EXECUTE.

```

7.21.1.12 To get descriptives for the 0-100 rescaled values

```

DESCRIPTIVES VARIABLES=TotalRescaleBL

```

/STATISTICS=MEAN SUM STDDEV RANGE MIN MAX.

7.21.1.13 Create variables for number of missing items, check no duplicates in participants and identify Duplicate Cases

```
SORT CASES BY Participants(A).
MATCH FILES
  /FILE=*
  /BY Participants
  /FIRST=PrimaryFirst
  /LAST=PrimaryLast.
DO IF (PrimaryFirst).
COMPUTE MatchSequence=1-PrimaryLast.
ELSE.
COMPUTE MatchSequence=MatchSequence+1.
END IF.
LEAVE MatchSequence.
FORMATS MatchSequence (f7).
COMPUTE InDupGrp=MatchSequence>0.
SORT CASES InDupGrp(D).
MATCH FILES
  /FILE=*
  /DROP=PrimaryFirst InDupGrp MatchSequence.
VARIABLE LABELS PrimaryLast 'Indicator of each last matching case as Primary'.
VALUE LABELS PrimaryLast 0 'Duplicate Case' 1 'Primary Case'.
VARIABLE LEVEL PrimaryLast (ORDINAL).
FREQUENCIES VARIABLES=PrimaryLast.
EXECUTE.
```

7.21.1.14 Delete PrimaryLast

```
DELETE VARIABLES PrimaryLast.
EXECUTE.
```

7.21.1.15 Create a variable that indicates level of participation (baseline/follow-up both)

```
COUNT
cmissBL = B1 To B20 (MISSING).
execute.
COUNT
cmissFU = F1 To F20 (MISSING).
execute.
FREQUENCIES VARIABLES=cmissBL cmissFU
  /ORDER=ANALYSIS.
execute.
```

7.21.1.16 Check VAS missing

```
FREQUENCIES VARIABLES=FVAS VAS
  /FORMAT=NOTABLE
  /ORDER=ANALYSIS.
```

```
DESCRIPTIVES VARIABLES=VAS FVAS
  /STATISTICS=MEAN STDDEV MIN MAX.
```

7.21.1.17 Create a couple of temporary variables that include VAS in missing count

```
COUNT
totmissB = B1 To B20 VAS (MISSING).
execute.
COUNT
totmissF = F1 To F20 FVAS (MISSING).
execute.
FREQUENCIES VARIABLES=totmissB totmissF
  /ORDER= ANALYSIS .
```

7.21.1.18 Create response variables

```
RECODE totmissB (21=0) (ELSE=1) INTO respB.
EXECUTE.
RECODE totmissF (21=0) (ELSE=1) INTO respF.
EXECUTE.
CROSSTABS
  /TABLES=respB BY respF
  /FORMAT=AVALUE TABLES
  /CELLS=COUNT
  /COUNT ROUND CELL.
```

7.21.1.19 Tidy up variables.

```
DELETE VARIABLES totmissB totmissF.
EXECUTE.
```

7.21.1.20 Create one variable that shows whether somebody participated in one or other or both or neither baseline and follow-up

```
COMPUTE response=0.
IF ((respB = 1) & (respF = 0)) response=1.
IF ((respB = 0) & (respF = 1)) response=2.
IF ((respB = 1) & (respF = 1)) response=3.
EXECUTE.
VALUE labels
response
0 'neither'
1 'bl only'
2 'fu only'
3 'both'.
execute.
```

7.21.1.21 Crosstabs of missing data variable

```
CROSSTABS
  /TABLES=respB BY response
  /FORMAT=AVALUE TABLES
```

```
/CELLS=COUNT
/COUNT ROUND CELL.
CROSSTABS
/TABLES=respF BY response
/FORMAT=AVALUE TABLES
/CELLS=COUNT
/COUNT ROUND CELL.
```

7.21.1.22 Seven participants with no data are all attendees of intervention. Make that a numeric variable

```
compute Attend=0.
recode AttendedPERSONABLE ('Yes'=1) into Attend.
Execute.
FREQUENCIES VARIABLES=AttendedPERSONABLE Attend
/ORDER=ANALYSIS.
```

7.21.1.23 How many attenders at PERSONALBE by job role

```
CROSSTABS
/TABLES=Attend BY Job_group
/FORMAT=AVALUE TABLES
/CELLS=COUNT
/COUNT ROUND CELL.
```

7.21.1.24 Tidy up variables

```
DELETE VARIABLES AttendedPERSONABLE.
EXECUTE.
CROSSTABS
/TABLES=Arm BY Attend
/FORMAT=AVALUE TABLES
/CELLS=COUNT
/COUNT ROUND CELL.
```

7.21.1.25 Sort out missing codes in new variables of old string variables

```
RECODE Gender (3=SYSMIS).
EXECUTE.
FREQUENCIES VARIABLES=Gender.
Execute.
```

```
Frequencies VARIABLES Role Role_num.
Execute.
RECODE Role_num (14=SYSMIS).
Execute.
```

```
DELETE VARIABLES Sex Role.
EXECUTE.
```

7.21.1.26 Check Role and Collapsed category

```
CROSSTABS  
  /TABLES=Role_num BY Job_group  
  /FORMAT=AVALUE TABLES  
  /CELLS=COUNT  
  /COUNT ROUND CELL.
```

Move home level variables

```
SORT CASES BY Home.  
SPLIT FILE SEPARATE BY Home.  
EXECUTE.  
DESCRIPTIVES VARIABLES=beds WTE  
  /STATISTICS=MEAN STDDEV MIN MAX.  
EXECUTE.  
SPLIT FILE OFF.  
DELETE VARIABLES beds WTE.  
EXECUTE.
```

7.21.1.27 Converting loss to follow-up to numeric value

```
AUTORECODE VARIABLES=Dropout  
  /INTO Drop_num  
  /BLANK=MISSING  
  /PRINT.  
RECODE Drop_num (6=SYSMIS).  
Execute.  
FREQUENCIES VARIABLES=Dropout Drop_num.  
Execute.  
Delete variables Dropout.  
Execute.
```

7.21.1.28 Check dropout against respF

```
CROSSTABS  
  /TABLES=Drop_num BY respF  
  /FORMAT=AVALUE TABLES  
  /CELLS=COUNT  
  /COUNT ROUND CELL.
```

7.21.1.29 Create two change variables

```
compute changePDQ=TotalRescaleFU-TotalRescaleBL.  
compute changeVAS=FVAS-VAS.  
execute.
```

7.21.1.30 Tidy up dataset

```
DESCRIPTIVES VARIABLES=Change changePDQ changeVAS.  
execute.  
Delete variables change.  
execute.
```

7.21.1.31 Cross reference against consort diagram

```
SORT CASES BY Arm.  
SPLIT FILE LAYERED BY Arm.  
CROSSTABS  
  /TABLES=response BY Attend  
  /FORMAT=AVALUE TABLES  
  /CELLS=COUNT  
  /COUNT ROUND CELL.
```

7.21.1.32 Create new variable for individual job groups to perform adjusted and unadjusted cluster analysis

```
RECODE Job_group (2=1) (1=0) (3=0) INTO Ancillarybinary.  
EXECUTE.  
RECODE Job_group (1=0) (3=1) (2=0) INTO Otherbinary.  
EXECUTE.
```

7.21.2 Graphs for intraclass correlation coefficients

```
GGRAPH  
  /GRAPHDATASET NAME="graphdataset" VARIABLES=Home TotalRescaleBL MISSING=LISTWISE  
REPORTMISSING=NO  
  /GRAPHSPEC SOURCE=INLINE.  
BEGIN GPL  
SOURCE: s=userSource(id("graphdataset"))  
DATA: Home=col(source(s), name("Home"), unit.category())  
DATA: TotalRescaleBL=col(source(s), name("TotalRescaleBL"))  
DATA: id=col(source(s), name("$CASENUM"), unit.category())  
GUIDE: axis(dim(1), label("Home"))  
GUIDE: axis(dim(2), label("TotalRescaleBL"))  
GUIDE: text.title(label("Simple Boxplot of TotalRescaleBL by Home"))  
SCALE: linear(dim(2), include(0))  
ELEMENT: schema(position(bin.quantile.letter(Home*TotalRescaleBL)), label(id))  
END GPL.
```

```
GGRAPH  
  /GRAPHDATASET NAME="graphdataset" VARIABLES=Home VAS MISSING=LISTWISE  
REPORTMISSING=NO  
  /GRAPHSPEC SOURCE=INLINE.  
BEGIN GPL  
SOURCE: s=userSource(id("graphdataset"))  
DATA: Home=col(source(s), name("Home"), unit.category())  
DATA: VAS=col(source(s), name("VAS"))  
DATA: id=col(source(s), name("$CASENUM"), unit.category())  
GUIDE: axis(dim(1), label("Home"))  
GUIDE: axis(dim(2), label("VAS"))  
GUIDE: text.title(label("Simple Boxplot of VAS by Home"))  
SCALE: linear(dim(2), include(0))  
ELEMENT: schema(position(bin.quantile.letter(Home*VAS)), label(id))  
END GPL.
```

7.22 Care home analysis

Variable	Variable description
V2-V22	Component questions of the TESS-RC
Total	Total of TESS-RC questions
Arm	Trial arm
Beds	Total number of beds in care home
WTE	Total of whole time equivalent staff
Total rescale	Rescale of total score to percentage

7.22.1 Therapeutic environment screening survey

7.22.1.1 Total score by rows

total of rows

7.22.1.2 Create new variable for sum of individual TESS-RC questions

compute newvar = sum (v2 to v22).

7.22.1.3 Assign each care home to trial arm

RECODE carehome (1=0) (2=1) (3=1) (4=0) (5=1) (6=0) INTO arm.

7.22.1.4 Median and mean and range of TESS RC

CTABLES

```
/VLABELS VARIABLES=Total Arm DISPLAY=LABEL
```

```
/TABLE Total [MEAN MEDIAN RANGE] BY Arm
```

```
/CATEGORIES VARIABLES=Arm ORDER=A KEY=VALUE EMPTY=EXCLUDE.
```

7.22.1.5 Median and range of beds in each arm

CTABLES

```
/VLABELS VARIABLES=Beds Arm DISPLAY=LABEL
```

```
/TABLE Beds [S][MEDIAN, RANGE] BY Arm [C]
```

```
/CATEGORIES VARIABLES=Arm ORDER=A KEY=VALUE EMPTY=EXCLUDE.
```

7.22.1.6 Median and range of WTE in each arm

CTABLES

```
/VLABELS VARIABLES=WTE Arm DISPLAY=LABEL
```

```
/TABLE WTE [MEDIAN, RANGE] BY Arm [C]
```

```
/CATEGORIES VARIABLES=Arm ORDER=A KEY=VALUE EMPTY=EXCLUDE.
```

7.22.1.7 Converting to 0-100 scale, can use either syntax

```
COMPUTE TotalRescale = (Total-0)*(100/73).
```

```
COMPUTE TotalRescale2=(Total-0)/73*100.
```

```
EXECUTE.
```

7.22.1.8 Within group mean of number of staff

split file by arm.

execute.

```
DESCRIPTIVES VARIABLES=WTE
```


/STATISTICS=MEAN STDDEV.

7.22.1.9 Within group mean of number of bedrooms

DESCRIPTIVES VARIABLES=Beds

/STATISTICS=MEAN STDDEV.

7.22.1.10 Within group mean of Visual Analogue Scale

Split file by arm.

DESCRIPTIVES VARIABLES=VAS

/STATISTICS=MEAN STDDEV RANGE MIN MAX.

7.22.1.11 Table of care home recruitment

SAVE OUTFILE='U:\PHD\AA Thesis\data\care home\Recruitment 230052019.sav'

/COMPRESSED.

FREQUENCIES VARIABLES=No_bedrooms Setting CQC_rating

/NTILES=4

/STATISTICS=MEDIAN SUM

/ORDER=ANALYSIS.

FREQUENCIES VARIABLES=Beds_participatinghomes

/NTILES=4

/STATISTICS=MEDIAN SUM

/ORDER=ANALYSIS.

FREQUENCIES VARIABLES=ENRICH

/STATISTICS=SUM

/ORDER=ANALYSIS.

7.23 PERSONABLE analysis

7.23.1 Wilcoxon test

EXECUTE.

DATASET CLOSE DataSet11.

GET

FILE='U:\PHD\AA Thesis\data\Workshop\kitwooddomainrating18032019.sav'.

DATASET NAME DataSet12 WINDOW=FRONT.

NPAR TESTS

/WILCOXON=Learn_you Social_you Health_you History_you Personality_you WITH
Learn_resi Social_resi

Health_resi History_resi Personality_resi (PAIRED)

/STATISTICS DESCRIPTIVES

/MISSING ANALYSIS.

7.23.2 Paired samples T-Test

T-TEST PAIRS=Learn_you Social_you Health_you History_you Personality_you WITH
Learn_resi

Social_resi Health_resi History_resi Personality_resi (PAIRED)

/CRITERIA=CI(.9500)

/MISSING=ANALYSIS.

7.24 Appendix twenty: DCM™ interrater agreement raw data

Care home four (control group): DCM™ interrater raw data and agreement

Participant		JF DCM™ data																																																				
1	BCC	F	F	A	F	F	C	P	F	F	L	L	L	C	L	L	L	L	L	A	F	F	F	F	N	F	F	N	F	B	D	F	F	F	F	F	F	F	L	B	F	V												
	ME	+1	+1	+1	+3	+1	-1	+1	+3	+3	+1	+3	+1	-1	+1	+1	+1	+3	+3	+1	+1	+1	+1		+1	-1		+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+3	+1	+1	+1	+1									
2	BCC																																									L	L	L	L	L								
	ME																																											+1	+3	+3	+3	+3						
3	BCC	P	D	K	A	D	K	F	D	A	D	P	K	L	Y	Y	Y	Y	Y	F		Y	K	K	A	F	F	F	Y	Y									Y	Y	Y	Y	Y	K	K	Y		Y	Y					
	ME	+3	+1	+1	+1	+1	+3	+1	+1	+1	+1	+1	+1	+1	+3	+1	+3	+3	+3	+3	+3		+3	+1	+1	+3	+1	+3	+3	+3	-3									+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1			
4	BCC	D	F	O	O	D	O	F	F	K	A	K	K	Y	Y	N	N	F	F	F	N	K	K	K	K	D	F	F	F	B	B	B	D									F	F	F	D	K	K	B	B	B				
	ME	+3	+3	+3	+3	+3	+3	+1	+3	+1	+3	+1	+1	+1	+1						+1	+3	+3	+3	+3	+3	+3	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1		
5	BCC	D	C	D	F	F	P	D	P	N	C	N	N	N	N	B	D	O	O	O	N	N	N	N	N	D	F	C	K	O	O	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N				
	ME	+1	-1	+1	+3	+3	+3	+1	+1																																													
Participant		JC DCM™ data																																																				
1	BCC	F	D	D	F	A	A	F	F	F	F	F	F	B	N	N	B	D	D	B	F	B	B	B	D	B	B	B	D	D	D	F	F	F	F	A	B	B	B	P	B	B	B	F	B									
	ME	+1	+1	+1	+3	+1	+1	+1	+1	+1	+1	+1	+1	+1			+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1			
2	BCC	B	N	N	D	B	A	F	A	F	N	N	N	A	N	B	B	L	N	N	N	N	N	N	N	N	N	N	N	N	N	F	F	F	F	A	B	B	B	P	B	B	B	F	B	B								
	ME	+1			+1	+1	+1	+1	+1	+1				+1		+1	+1	+3													+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1		
3	BCC	F	B	T	F	A	A	Y	F	F	A	B	K	K	K	A	K	K	K	A	K	K	K	A	K	K	K	K	K	A	F	F	F	F	F	F	B	B	Y	N	N	N	N	N	N	N	N	N						
	ME	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1		
4	BCC	B	G	A	D	A	A	B	F	A	A	B	K	K	K	A	K	K	K	A	K	K	A	A	K	K	K	K	K	K	F	F	F	F	B	K	K																	
	ME	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+3	+1	+1	+1	+1	+1	+1	+1	+1	+1	+3	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1		
5	BCC	N	D	B	P	D	B	F	N	N	N	D	N	N	N	D	K	K	B	N	D	D	K	K	D		B	P	B	N	K	F	F	F	F	F	F	F	F	F	F	F	F	A	B	D	B	B	B					
	ME		+1	+1	+1	+1	+1	+1				+1				+1	+1	+1	+1	+1	+1	+1	+1	+1		+1	+1	+1		+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1		
Participant		Observer agreement for each time frame																																																				
1	BCC	1	0	0	1	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0				
	ME	1	1	1	1	1	0	1	0	0	1	0	1	0	0	0	1	0	0	1	1	1	1	1	0	1	0	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1		
2	BCC																																																					
	ME																																																					
3	BCC	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0		
	ME	0	1	1	1	1	0	1	1	1	1	1	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
4	BCC	0	0	0	0	0	0	0	1	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
	ME	0	0	0	0	0	0	1	0	1	0	1	1	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
5	BCC	0	0	0	0	0	0	0	0	1	0	0	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	ME	0	0	1	0	0	0	1	0	1	0	0	1	1	1	1	1	1	1	0	1	0	0	0	0		1	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Care home three (intervention group): DCM™ interrater raw data and agreement

Participant		JF DCM™ data																																																
1	BCC	C	N	K	B	A	B	C	N	N	A		B	A	B	C	D	F	B	D	B	D	D	F	C	F	F	F	F	F	F	F	F	F	F	B	B	B	D	D	E	E	A							
	ME	-1		+1	+1	+1	+1	-1			+1		+1	+1	+1	-1	+1	+1	+1	+1	+1	+1	+1	+1	-1	+1	+3	+3	+3	+3	+3	+3	+3	+3	+3	+3	+1	+1	+1	+1	+1	+1	+1	+1	+1					
2	BCC	T	D	T	T	F	P	T	T	K	K	A	A	D	D	D	B	D	D	D	D	D	D	F	F	F	B	B	D	B	D	A	B	D	T	D	B	D	A	D	D	T	D							
	ME	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+3	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	-1	-1	-1			
3	BCC	Y	W	W	W	W	W	W	W	W	Y	Y	Y	Y	W	Y	Y	W	W	W	D	D	W	W	W	W	W	F	F	F	T	P	C	F	F	N	D	E	E	E	E									
	ME	+1	+1	+1	+1	+1	+1	-1	+1	+1	+1	-1	-1	-1	-1	-1	-1	-1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	-1	+3	+3		+1	+1	+1	+1	+1								
4	BCC	F	F	F	F	F	D	D	C	F	B	C	C	F	F	P																																		
	ME	+1	+1	+1	+1	+1	+1	+1	-1	+1	+1	-1	-1	+1	+1	-1																																		
5	BCC	B	B	B	B	L	L	U	L	B	L	L	L	L	L	L	L	L	L	F	F	F	F	F	F	B	L	L	B	B	L	L	B	L	F	F	B	L	L	L	B	J								
	ME	+1	+3	+3	+3	+3	+1	-1	+1	+3	+1	+1	+1	+1	+1	+1	+1	+1	-1	-3	-3	-3	-3	-3	+1	-1	-1	+1	+1	+1	+1	+1	+1	+1	+1	+1	-3	-1	+1	+1	+1	-1	+1	+1						
Participant		JC DCM™ data																																																
1	BCC	B	B	B	B	B	A	B	B	B	B	A	B	B	B	N	B	B	B	B	A	Y	Y	A	A	A	Y	Y	Y	Y	A	B	B	A	A	Y	B	K		Y	B	B								
	ME	+1	+1	+1	+1	+1	+1	+3	+1	+1	+1	+1	+1	+1	+1		+1	+1	+1	+1	+1	+1	+1	+1	+3	-1	-1	-1	-1	+1	+1	+1	+1	+1	+1	+1	+1	-1	+1	+1		-1	+1	+1						
2	BCC	B	D	D	D	B	D	B	B	F	B	B	B	U	P	B	B	B	B	U	A	D	B	F	F	D	D	D	D	D	B	B	F	F	B	B	F	D		B	B	B								
	ME	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	-1	+1	+1	+1	+1	+1	-1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1				
3	BCC	W	C	W	W	N	W	F	W	W	W	W	W	W	W	W	W	N	W	W	C	W	W	W	W	W	W	B	B	F	W	F	B	B	W	Y	B		B	F	N									
	ME	+1	-1	+1	+1		+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1		+1	+1	-1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1				
4	BCC	D	D	B	B	T	Y	B	F	B	D	B	B	B	B	D	B	B	B	T	T																													
	ME	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1																														
5	BCC	A	P	B	B	B	B	B	B	B	B	N	B	F	B	N	B	B	B	B	F	F	F	N	B	B	N	N	N	B	B	B	N	B	N	N	N	N		B	B	F								
	ME	+1	+1	+1	+1	+1	+1	+1	+1	+1	+1		+1	+1	+1		+1	+1	+1	+1	+1	+1	+1		+1	+1				+1	+1	+1		+1									+1	+1	+1					
Participant		Observer agreement for each time frame																																																
1	BCC	0	0	0	1	0	1	0	0	0	0	0	0	1	0	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0			
	ME	0	0	1	1	1	1	0	0	0	1		1	1	1	0	0	1	1	1	1	1	1	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
2	BCC	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1	0	1	1	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
	ME	1	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	0	1	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
3	BCC	0	0	1	1	0	1	0	1	1	1	0	0	0	0	1	0	0	1	0	1	0	0	1	1	1	1	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	ME	1	0	1	1	0	1	0	1	1	1	0	0	0	0	0	0	0	1	0	1	1	0	1	1	1	1	1	0	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
4	BCC	0	0	0	0	0	0	0	0	0	0	0	0	0	0																																			
	ME	1	1	1	1	1	1	0	1	1	0	0	1	1	0																																			
5	BCC	0	0	1	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	ME	1	0	0	0	0	1	0	1	0	1	1	0	1	1	1	0	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0