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The Development of an assessment of freedom for people living with dementia.

A mixed methods study.

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Abstract

Within the UK over 850,000 people live with dementia, 650,000 remain in their homes with the support of 600,000 carers. A problem faced by community dwelling PLWD is that of becoming lost when leaving their home. Carers may restrict the freedom of PLWD due to concerns about their safety. Leaving the home unsafely is a significant risk for PLWD with up to a third of people living with the condition becoming lost at some point. This is a frightening and distressing experience which may lead to injury and anxiety. However, when involved in research people living with dementia have identified the benefits of being involved with their local community and environment. For those whose condition is more advanced being able to walk may be calming and reduce agitation and distress. The issue of freedom for people living with the dementia is then a difficult balance between the benefits of risk and safety. This research developed an assessment of freedom for people living with dementia and a theoretical model of freedom. The acronym FREEDEM was used for the assessment.

Methods

This PhD used an exploratory sequential mixed methods approach to develop FREEDEM. A theoretical model of freedom was initially developed from philosophy. A scoping review collated relevant literature to identify the elements of this assessment. Thirty semi structured interviews were carried out with people living with dementia, carers, and occupational therapists. In these interviews the definition of freedom was explored and how this changed as the condition progressed. This data was used to refine the theoretical model of freedom. Results from the interviews and scoping review were synthesised using triangulation to inform the development of FREEDEM. The assessment components were then subjected to a Delphi study. Results from the Delphi study were used to finalise FREEDEM. Patient and public involvement was integrated into the research process, including study documentation and topic guide design.

Results

This assessment includes the assessment of risk, early warning systems, carer education, social groups, and telecare technology. The theoretical model identified that elements of the definition of freedom from PLWD included freedom of movement, social integration, choice of activities and relational autonomy. People living with dementia demonstrated an ethic of care towards their carers and the wider community at a point when they had capacity, and insight into the implications of their condition. This was manifested as a concern for both their carers and the wider community if they became lost. This ethic of care changed as the condition progressed. This then led to a situation where freedom may be sought, and carer's freedom may be compromised as a result. Carers considered their freedom was defended or conceded depending upon their prior relationship with the PLWD and other demands upon their time.

Conclusion

In the event the freedom of the person living with dementia is restricted they are potentially deprived of their liberty. A legal authorisation may be required for the carer's actions. Rather than this formal authorisation the assessment aims to facilitate freedom for people living with dementia thereby avoiding the needs for a judicial process. Instead, the person living with condition will be assessed by an occupational therapists who will carry out an assessment which facilitates their freedom and provides support to their carers' in facilitating this freedom.

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Presentation at EEE virtual conference 30th April 2020. *What is freedom for people living with dementia.*

TEAMS Presentation to pre doctoral Clinical Fellows University of Nottingham 18th November 2020 *What a pre doctoral programme fellowship* can do for you.

Posters

Engage Enthuse Empower Conference 13th June 2019 at Crowne Plaza. *The Development of an assessment of Freedom.*

Table of abbreviations

CRPD	International Convention for the rights of disabled people
CPN	Community Psychiatric Nurse
DOLS	Deprivation of Liberty Safeguards
DOL	Deprivation of Liberty
ECtHR	European Convention on human rights
HCOP	Healthcare of older person
JBI	Joanna Briggs Institute
LPS	Liberty Protection Safeguards
MCA	Mental Capacity Act
MCAA	Mental Capacity Amendment Act
MDT	Multi-disciplinary team
MeSH	Medical subject headings
MOCA	Montreal cognitive assessment
NHS	National Health Service
PIS	Participant Information sheet
PP1	Patient and public involvement
PLWD	Person/people living with dementia
RCT	Randomised controlled trial
RGN	Registered General Nurse
UK	United Kingdom
WHO	World Health Organisation

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Chapter one. Introduction

This thesis sets out the development of an occupational therapy (OT) assessment of freedom for community dwelling people living with dementia (PLWD). The assessment is intended to facilitate freedom for those PLWD who have care from family or friends. To represent the core components of the assessment, the acronym FREEDEM (Based on freedom and dementia) was selected. FREEDEM is supported by a theoretical model of freedom for PLWD, which will facilitate the clinical reasoning used in the assessment process.

This introductory chapter will identify the background to this thesis, including the prevalence of dementia and significant social, functional, and economic implications of the condition. The chapter considers the literature linked to leaving home unsafely and how this relates to symptoms of dementia. The potential harm to PLWD who leave unsafely will be set out together with the impact of leaving unsafely on carers. Also, the psychosocial reasons for wishing to leave home and the benefits of doing so will be reviewed. The potential role of OTs in implementing the assessment will be introduced. Each element of the study's aims and objectives will be presented together with the thesis structure and theoretical background.

1.1 Rationale why study freedom?

A dictionary definition of freedom defines this concept as "the condition or right of being able to do whatever you want to without being controlled or limited" (Cambridge English Dictionary 2020). From a philosophical perspective, there may be multiple facets to freedom. In a philosophical context, freedom can also be defined as the absence of constraints on the individual imposed by other people. Freedom has also been defined as being able to pursue and achieving willed goals (Berlin 1969). Law and philosophy tend to use the term liberty, while freedom is arguably more common parlance. The terms liberty and freedom will be treated as synonymous throughout this thesis.

Freedom may incorporate religious, social, political, and press freedom (Flathman 1987, Berlin 2002). Freedom may be expressed at a social level. This expression may occur through social interaction with others. Freedom may also be expressed in the choice to join with groups of people (Oppenheim 2004). These groups may share a political or cultural perspective. This shared perspective may be expressed through the media, shared activities, religious or cultural practices (Flathman 1987, Pearson 2013). Freedom is then a potentially multifaceted concept. Freedom may be constrained by a lack of legal protections for free speech or the active banning of interest groups. A degree of legal protection is arguably necessary to protect these freedoms and regulate situations where freedoms conflict (Pearson 2013, Queiroz 2018).

Freedom may also be constrained for those perceived as vulnerable, and the law may protect these freedoms or allow for such constraints. Vulnerable groups include people who are unable to make a decision due to cognitive impairment. Freedom is not a straightforward issue as those living with cognitive impairment are entitled to protection from harm, which is a risk of freedom (Manthorpe and Martineau 2011). Restrictions may include preventing people with cognitive problems from marrying, making a will, or engaging in activities perceived as dangerous (Voskou 2018). The freedom of PLWD occurs in the context of caring relationships where they may be prevented from leaving their home by carers concerned about risks such as getting lost (Robinson et al 2007, Bantry White and Montgomery 2014 b). This then potentially prevents engagement in activities of choice and freedom of movement. Concerns have been expressed by PLWD that their carers will favour safety over autonomy (Robinson et al. 2007, Bantry-White and Montgomery 2014a). Health care professionals have also been criticized as being risk averse. Robinson (2007) identified this risk aversion amongst staff was impacted by fear of litigation, which created the potential of overly restrictive practices. Assessment of risk by healthcare professionals may not be centred upon the individual living with dementia and their wishes and preferences (Clarke et al. 2010). No studies could be identified where PLWD, or carers were asked to define their freedom and which elements of freedom are of the most significant importance to them. We do not know what expectations PLWD may have of their carers in facilitating or restricting their freedom. The research aims to address this and incorporate these views into the theoretical model of freedom and assessment.

1.2 What is dementia?

Dementia is the generic name for a collection of chronic and progressive conditions, characterised by forgetfulness and other abnormalities in cognition, of sufficient severity to interfere with everyday activity. Dementia commonly causes impairment in memory function, but in isolation, this is not sufficient to give rise to a diagnosis (Robinson, Tang, and Taylor 2016). The ICD-10 classification (World Health Organisation 2016) identifies symptoms in which 'there is the 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'. These conditions impact upon the structure and biochemistry of the brain (Pujades-Rodriguez et al 2018). Progressive damage to the brain occurs in all types of dementia; however, damage may be more discreet in specific types of the condition, such as frontotemporal dementia, which impacts on the frontal lobes (Bang et al 2015, Livingstone et al 2020).

1.3 Subtypes of dementia

The pathology of different types of dementia may overlap, meaning the distinction between subtypes is questionable in some patients. Many PLWD have one or more subtypes. This may lead to difficulties in diagnosis. It is estimated that up to eighty percent of dementia has a mixed element (Jellinger and Korcyzn 2018). The symptoms of dementia are variable but there is a significant overlap in symptoms between the most prevalent subtypes.

Despite the mixed element to most dementias, PLWD are often offered a single subtype diagnosis (Jellinger and Korcyzn 2018). Alzheimer’s disease is the most prevalent subtype diagnosed, accounting for approximately 70 % of all dementia diagnosed in the UK (Prince et al 2014). Approximately 17% of cases of dementia diagnosed in the UK are primarily vascular (NHS digital 2018). A smaller percentage of PLWD are diagnosed with subtypes, which occur less frequently. These include Lewy Body dementia (approximately 4%). The defining characteristic is Parkinsonism (slowness, stiffness, and tremor). Approximately 2% of dementias are Frontotemporal dementia (FTD). FTD is a progressive condition where atrophy is primarily located in the brain's frontal and temporal areas (Stopford et al 2012). FTD is three biological conditions, these three sub types of dementia have similar pathology and symptoms, primary progressive aphasia, semantic dementia, and frontotemporal dementia. The remaining subtypes form over 100 different conditions and account for under 5% of cases.

1.4 Symptoms of dementia

There are two major groups of symptoms in dementia, symptoms of cognitive dysfunction and behavioural and psychological symptoms. This section sets out some symptoms which occur frequently and the potential functional impact of the symptoms.

1.4.1 Memory loss

Memory loss is often the most reported and easily identified symptom of dementia (Robinson, Tang, and Taylor 2015). Memory is not a single cognitive ability and divides into episodic, semantic, working, and remote. Episodic memory involves retaining memories about recent or past events and experiences. Creating and recollecting these memories depends on the ability to encode the memory, store the memory, and retrieve it. (Easton and Eacott 2015, Gui et al. 2017). While episodic memory may be significantly impaired in dementia, long term memories may remain intact. Remote memory is the memory of events in the long ago past (Easton and Eacott 2015). Semantic memory relates to general knowledge, including knowledge of facts. Impairment in semantic memory prevents the PLWD from learning new things (Budson et al 2005). Working memory is linked to attention. The capacity of working memory requires attention but only allows us to hold a few pieces of information. As the condition progresses, remote memories may dominate the consciousness of the PLWD (Budson et al 2005, Star et al 2005). Attempts may be made to resume old routines such as collecting children from school or attempting to find a previous address. At this point, the condition is likely to be presenting significant functional difficulties.

1.4.2 Visuospatial skills

Visuospatial skills may be defined as the use of vision in the perception and location of objects in our environment and the spatial relationships between them. Dementia may cause deterioration of visuospatial skills, including object and space perception. Difficulty in processing information around objects and space can create disorientation and impair way-finding abilities. Visuospatial deficits may be linked to topographical memory (Thiyagesh et al 2009, Pengas et al 2012, Jedynak et al 2013), the ability to remember familiar places and orientate oneself in place. These difficulties may impact navigation skills and create difficulties for a PLWD finding their way home from familiar and unfamiliar locations (Banks 2010). In the earlier stages of dementia, driving may deteriorate partly because of a deterioration in visuospatial skills that impact judging the distance between vehicles at speed and the position of a vehicle on the road. Perceptual deficits include a deterioration in dealing with visuospatial cues (Jedynak et al., 2013).

1.4.3 Attention

Attention is divided into three subtypes, selective attention, divided attention, and sustained attention. Selective attention is the ability to filter out multiple stimuli to focus on a particular stimulus. Sharing attention across competing stimuli requires divided attention. Sustained attention is the ability to maintain attention to stimuli over time. Dementia tends to impact selective and divided attention rather than sustained attention (Chiu et al 2004). Attention is the basis of working memory and is required for executive function, including decision making, problem-solving, and planning. Deficits in attention may be classified as elements of a loss of higher executive function but problems with sustaining attention may be linked to all cognition dimensions (Chiu et al 2004, Kowlanski et al 2012). Reduced selective attention will prevent the PLWD from completing tasks. A deterioration in divided attention may reduce focus and hinder task completion.

1.4.4 Disorientation in time and place

Orientation is a mental function that processes the relations between the self and places, time, and people. Orientation is a complex cognitive function, and it is hypothesised that a cognitive map develops of time, place, and person (Eggers Norburg and Elkman 2005, Jedynak et al 2013). This map can be referred to in order to create orientation. Disorientation in time and place may occur in dementia and be particularly pronounced in an unfamiliar environment. Disorientation may cause a loss of recognition of an environment and an inability to recognise the correct time of day or date. As dementia progresses, it may not be possible for the PLWD to identify other people, including close family (Eggers Norburg and Elkman 2005, Jedynak et al 2013). Orientation in time allows for an understanding of past events and planning for the future. Orientation is not fully understood as a mental function but is vital to everyday tasks such as shopping, social interaction, and safety as a driver or pedestrian (Jedynak et al 2013)

1.4.5 Executive function

Executive functions are sometimes referred to as higher functions. These are sophisticated cognitive processing tasks. These skills involve the integration and processing of information across different areas of cognition (Peres 2008). Deterioration in executive function will typically be a cluster of symptoms that present a challenge for the PLWD and carers (Giovanni et al 2007, Thyagessh et al 2009). These skills can be divided into organisation which includes, for example, planning, problem solving, and abstract thinking. Day to day tasks that are complex such as cooking, may be impacted. Such tasks may appear straightforward but require planning, problem solving, and processing of different pieces of information to complete successfully (Peres 2008). Wayfaring skills may be impacted and the likelihood of becoming lost will increase. Deterioration in the ability to plan means that it is more difficult to find the way between two points (Giovanni et al 2007, Thyagessh et al 2009).

1.4.6 Regulatory functions

Regulatory functions are concerned with emotional control and initiating actions (Mioshi et al 2010). Dementia may cause difficulty in controlling emotions, which may result in alterations in patterns of behaviour. There may be an absence of insight into symptoms, an inability to learn from experiences, and a lack of concern for others. These symptoms may impact upon the ability to identify risk. The impairment of regulatory functions may overlap with behavioural and psychological symptoms of dementia (Van der Lind et al 2016, De Oiveria et al 2015).

1.4.7 Behavioural and psychological symptoms of dementia (BPSD)

These symptoms have a high prevalence in dementia, and nearly all people with dementia have at least one of these symptoms during the condition. These include apathy and indifference. This may produce an apparent lack of motivation to begin new activities or continue usual ones. There may be a reduction in social participation and initiation of activities (Van der Lind et al. 2016, Tiel et al 2019). Anxiety is sometimes a symptom of dementia and may result in avoidance of situations that provoke increased anxious feelings. Other symptoms may include irritability, agitation, labile moods, and sleep problems (Dickerson, Ducharme, and Onyike 2016). Such symptoms have adverse effects on both PLWD and caregivers' quality of life and are associated with increased costs of care (Mioshi et al 2010, Dickerson Ducharme and Onyike 2016). There may be low mood and difficulty in controlling emotions, emotional expression, and concern for others may decrease. Mood may be low or fluctuant and change rapidly. In the later stages of the condition, hallucinations may develop, which may be visual or auditory, and paranoia may be present (Lovheim et al 2008, Sava et al 2009).

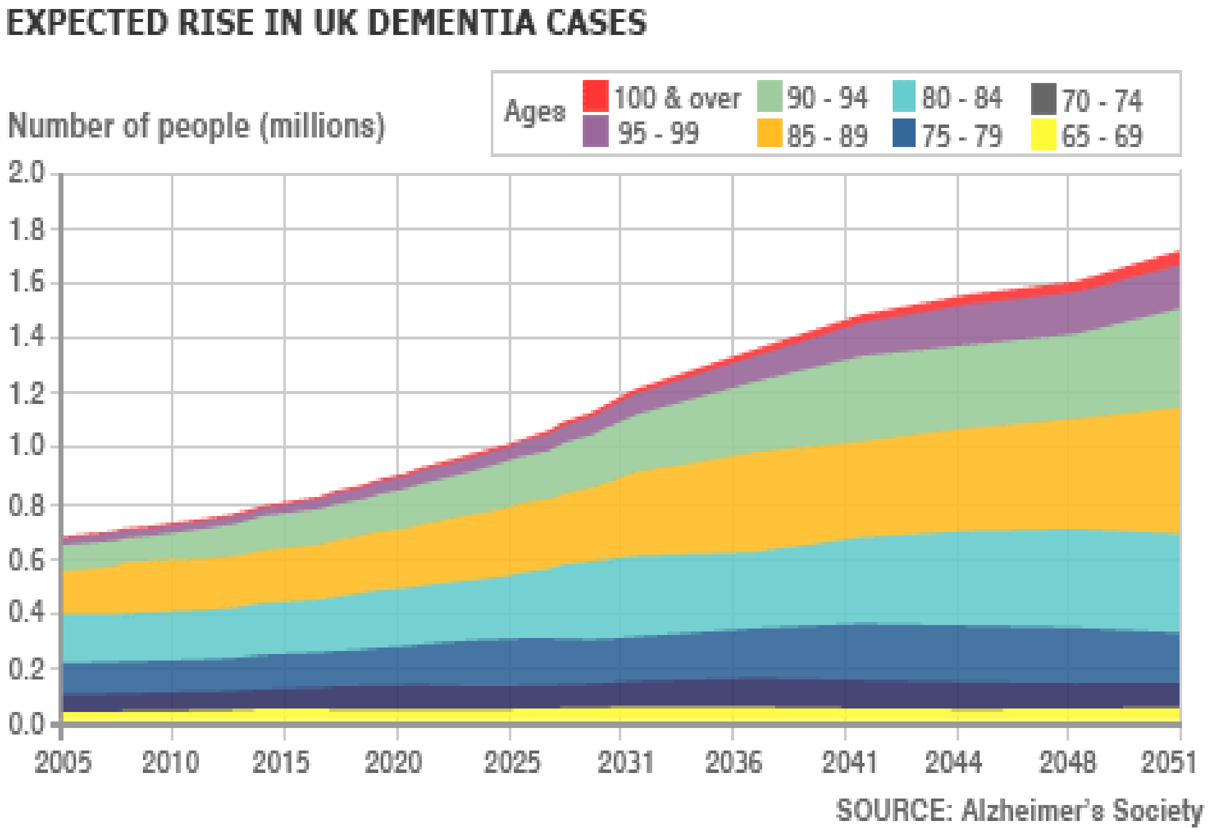
When dementia has progressed significantly, agitation and irritability may cause attempts to seek freedom. PLWD may pace and engage in repetitive movement to leave areas without being able to state their intended purpose (Algase 2007a). At this stage there will be a loss of insight into the cognitive loss (Dickerson, Ducharme, and Onyike 2016). This lack of insight and extent of cognitive deterioration may cause the PLWD to leave an area as there may be no awareness that this is unsafe.

1.5 Prevalence of dementia

Approximately 850,000 people in the UK live with dementia (Department of Health 2020). The rate of diagnosis in December 2020 is estimated at 62.4 %, meaning that a precise determination of the number of people living with the condition cannot be provided (Department of Health 2020). While there is evidence of a decrease age specific incidence (Matthews et al 2013, Department of Health 2020), the overall pattern is one of increasing prevalence as the population ages with a rate of new diagnosis of over 200,000 cases per year. Two thirds of PLWD in the UK live in the community (Wittenburg et al 2019). 600,000 informal carers provide the necessary support to ensure ongoing community tenure (Department of Health 2020).

Dementia is a syndrome which has an increasing incidence as people age. Whilst 2% of those who are between 65-69 years old live with dementia, this rises to 20% of those between 85 and 89 (Dementia statistics Hub 2019). The condition is not exclusive to older people and is found in approximately one in every 1400 people under 65 (Public Health England 2019). In 2016 15.4 % of deaths in women were attributable to dementia and 8 % of men (Registrar General 2019). Dementia is the UK's leading certified cause of death. Individual prognosis is uncertain due to variability in condition progression, subtype, and time taken to diagnosis (Registrar General 2019). Following diagnosis, most people diagnosed will live between 18 months and 10 years (Xie, Brayne and Matthews 2008, Pujades-Rodriguez et al 2018). Deterioration during this period is variable. The leading causes of death in PLWD as reported in a cohort study in Pennsylvania (Matthews et al 2013), included cardiovascular disease (47.5%), pneumonia (12.3%), cancer (12.3%), stroke (9.3%), and sepsis (5.1%). It is apparent that many patients diagnosed with dementia have significant comorbidities that may contribute to functional difficulties.

As demographic ageing and age-specific prevalence remain unchanged, the total number of people with dementia in the UK would increase to over 1 million by 2025 and over 2 million by 2051 (Prince et al 2014). This growth would be caused solely by the ageing of the population. As the incidence of the condition increases with age, any improvements in life expectancy are inevitably tied to an increase in the number of PLWD. It is possible that improvements in risk factors such as education standards, cardiovascular health and activity levels may reduce the age specific incidence of dementia and accordingly, current projections cannot be made with certainty (Matthews et al 2013, Wittenburg et al 2019). Projections for the potential demographic changes in the number of PLWD are set out in figure one.



SOURCE: Alzheimer's Society

Figure one. Expected rise in UK dementia cases.

1.6 Cost of dementia

In Dementia UK, the second edition (2014) Prince et al estimate the cost of dementia in the UK to be £26.3 billion. This figure reveals how dementia impacts on social and financial aspects of the lives of PLWD and their carers. These cost subdivide into £4.3 billion to the NHS and £10.3 billion to social care. Of this £10.3 billion, £4.5 billion is paid out by publicly funded social care, and £5.8 billion is paid privately. A further £11.6 billion is attributed to the unpaid cost of family care. A total of £17.4 billion of the entire figure is borne by those who live with dementia and their unpaid carers. These figures are more marked when considering community dwelling people who live with dementia. For those living in the community, 74.9% of their care costs are represented by informal carer’s unpaid care.

It is to be anticipated that as the condition progresses, so do the costs associated with care. The total societal costs associated with Alzheimer's disease in the UK over 18 months were £25,865 for patients with mild dementia at baseline, £30,905 for moderate dementia, and £43,560 for the moderately severe to severe group (Lennox Smith et al 2018). Within the most prevalent conditions**,** dementia is unusual in having lower health costs but higher social costs. In a cost of illness study (Luengo-Fernandez et al 2011), dementia was estimated to have the lowest health care costs, £1.2 billion, compared to £4.0 billion for cancer, £2.2 billion for coronary heart disease and £1.6 billion for stroke. The costs placed on the social care system by dementia (£9.3 billion) far outweighed the social care costs of cancer, coronary heart disease, and stroke. These figures reveal how of all the major diseases in the UK, dementia carried the greatest financial cost to those who live with the condition and provide care**.** These costs reflect both the extent of unpaid care provided and the financial consequence if informal carers cannot entirely meet care needs. The potential increased cost of dementia is set out in figure two.

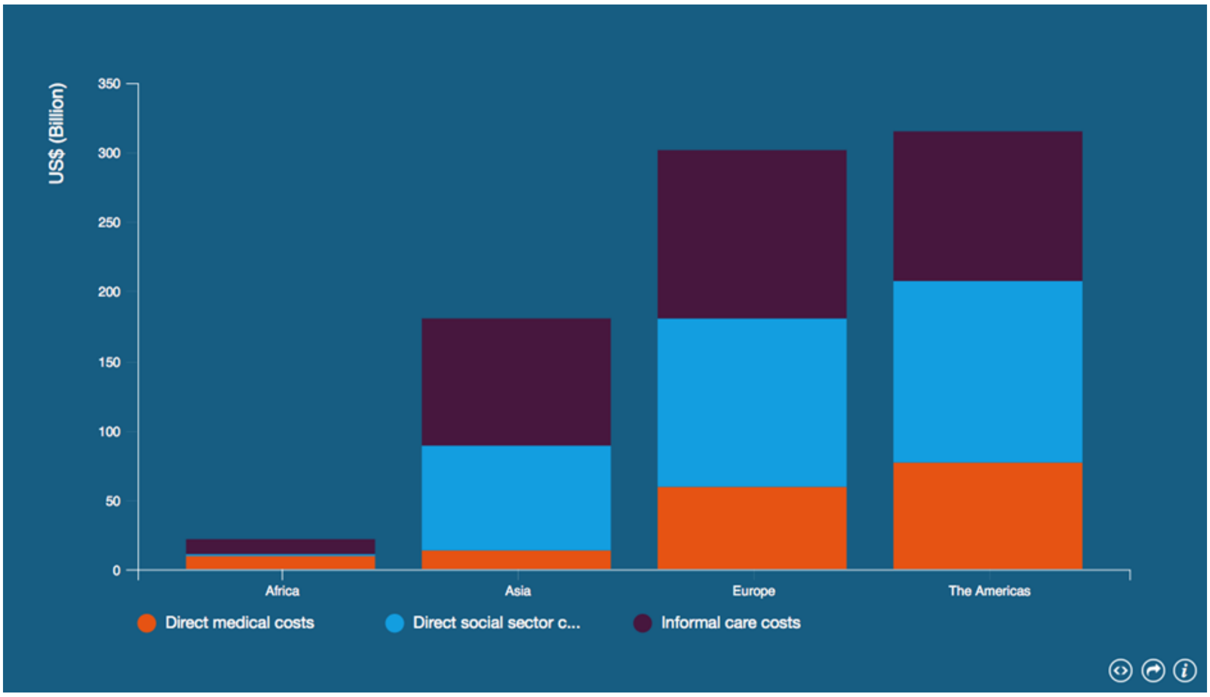


Figure Two: International Cost of Dementia

1.7 Dementia and carers

Fifty percent of those living with dementia in the community receive over 35 hours of family care a week (Wimo et al 2002, Alzheimer's Association 2007). Dementia is a progressive condition, and the amount of care provided may vary significantly depending upon the symptoms experienced. Such care may comprise essential activities of daily living such as providing meals, help with washing and dressing, and managing medication and continence (Springate and Tremont 2014). Carers may also ensure continued emotional support, social involvement and support the development and maintenance of valued roles for the PLWD (Wimo et al 2002).

Providing care may be made more difficult due to the physical health issues of carers. Many carers are older themselves with health issues. While carers may derive satisfaction from providing care, the experience can also prove physically, socially, and economically detrimental (Price et al 2014). Carers have an increased rate of depression and stress over non-carers, and these impacts are more significant when caring for someone with dementia than other long-term conditions (Springate and Tremont 2014, Warren et al. 2016). The risk of institutionalisation for PLWD is significantly reduced by living with a resident carer (Esika et al., 2013). While non-resident carers may not have such an effect upon institutionalisation their care may still be essential to the wellbeing of PLWD and serve to maintain their independence. The impact of dementia on a family's finances is illustrated by NHS England quotes in a presentation in response to the 2014 dementia survey.

"Financial support is our greatest need to continue to pay for Mum's care. We have exhausted all my father and mothers' assets and now are exhausting our own. We are forecasting bankruptcy and the inability to support our own families and businesses"
(NHS England 2014)

The lower health costs and higher social costs of dementia have clear implications for the extent of care provided as the condition progresses. The implications for carer's may be an intertwined combination of financial, social, and emotional factors. Caring for a person who lives with the condition may be life-altering and mirror the impact upon those who live with dementia**,** creating significant emotional and physical pressure (Chenoweth et al 2016, Ledgerd et al 2016).

"Unfortunately, I have decided to leave my employment as my mum does not even know who I am, or my sister is at times. I feel that my mum needs us now because my mum has supported me and my sister for such a long time as we lost our dad over 46 years ago when I was 6, and my sister was 9. She has always stood by us. I would like

to know more about dementia and how to cope with it as I get very stressed." (NHS England 2014).

1.8 Epidemiology of leaving unsafely.

To substantiate the need for FREEDEM, it is necessary to establish the prevalence of PLWD leaving their homes in a way their carers may consider unsafe. There are no precise numbers of PLWD who will become missing each year. The National Police Improvement Agency (NPIA) (2011) estimates at least 40,000 people with dementia in UK will go missing for the first time every year. Earlier studies use the term wandering (Edgerley and Dominic 1998, Klein et al 1999). This term (wandering) was commonly used to describe the activities of PLWD who left their home. The terminology has changed; what was formally seen as wandering has been redefined as walking, an activity that maintains physical and mental health (Algase et al 2007). PLWD may become lost after leaving home to engage in a range of activities. A minority of those who go missing will do so repeatedly. Becoming lost and wandering are not the same thing (Rowe et al 2003). Within this section, the terminology used will be true to the original research, but the term wandering will be in parenthesis.

The prevalence of "wandering" is unclear, with reported rates varying between 17.4 % (Klein et al 1999) to 63% (Hope et al). These significant variations may arise due to whether the research is longitudinal, definitions of wandering, and the physical environment of the PLWD (Kwak Yang and Koo 2015, Rowe et al 2010). Leaving unsafely or "wandering" has been the topic of longitudinal studies, which have revealed that the prevalence of this increased over time as symptoms progressed**.** In a study of 1312 participants, 26 % of patients with Alzheimer's disease left unsafely, and 18 % of those with vascular dementia (Cooper & Mungass 1993). Rates were lower in the earlier stages of the condition (12% Alzheimer's disease and 9% vascular dementia). These were higher as the condition progressed (37% Alzheimer's disease, 28% vascular dementia). Other studies also identified that the likelihood of "wandering" increased with symptom progression. In a study (Klein et al 1999) of 638 community dwelling participants diagnosed with dementia, 17.4 % had "wandered". This data was obtained in a case control investigation at a single point in time**.** A 12-month prospective study of assistive technology identified that 25 % of a small sample of 52 people attempted to leave unsafely (Rowe et al 2010). In a veteran's study of community dwelling people living with early-stage dementia over a two-year period, 26 % (N=37) of carers reported wandering on the part of the PLWD they cared for (Barratt et al 2016). Three visits occurred across the period of the study, and at each point, approximately 15% of carers reported: "wandering."

Leaving unsafely and getting lost are different constructs. A longitudinal study of PLWD in the community identified that getting lost incidents occurred with greater frequency than studies asking questions about wandering (Pai & Lee 2016). Within the two groups in this study, one had previous getting lost incidents (N=95), and the other group did not (N=90). At the second time point, 2.5 years later, within the group who had become lost previously, 38 participants had new instances of getting lost, while a third of the group who had never been lost had incidents of becoming lost (N=30). The study aimed to correlate features of dementia with incidents of getting lost. These incidents occurred in people who often continued to be carrying out day-to-day activities independently and did not necessarily recur.

1.9 The consequences of getting lost

The international consortium on missing and wandering incidents identified the antecedents of leaving home unsafely (Rowe et al 2015). Missing incidents differed in frequency (regular versus isolated incident), timing (unpredictability v occurring within a predictable time frame), and nature (occurring within normally conducted activities rather than being temporarily disorientated). In the earlier stages of dementia, people become lost while carrying out everyday activities. The first incident may be difficult to predict as it occurs in the context of everyday activities such as shopping, visiting friends, and leisure activities. These people could not be defined as leaving their homes unsafely as this initial incident was difficult to predict as the point of exit.

While studies on becoming lost may be small scale and be confined to specific geographical areas, certain shared factors arise (Flaghtey 1996, Bantry White 2014a). Mode of transport, weather conditions, and length of time missing were all factors that may lead to increased mortality and harm (Rowe and Bennett 2003). Rowe et al (2011) suggest that the nature of the area is critical. Serious harm is more likely to occur when the PLWD lives alone and is missing for a far greater period before the alarm is raised. Also, those who live in rural areas are at greater risk (Rowe and Glover 2001). It is notable that when people are found, it is because their behaviour is noticed, not because they have asked for help. There is limited data on the proportion of those who leave home unsafely becoming injured. In 2010 Rowe et al conducted a study of injuries and unattended home exits. The purpose of the study was to identify the hazard rate of leaving unsafely and resulting injuries (Rowe et al 2010), 25% of the study (N=13) participants had unattended home exits (Leaving the home in an unsafe manner), of whom 2 had soft tissue injuries**.** In a retrospective observational study (Bantry White and Montgomery 2014a), it was identified that of PLWD who were reported as missing to the police 16% (N=45) of those reported returned home of their own accord. Two missing people (0.7%) were found dead, and 4.6% sustained an injury (N = 13). This paper identifies that the balance between risk and freedom is complex. At one end of this spectrum, significant harm may result from leaving unsafely and becoming lost. While for those who returned home independently after their absence was reported to the police carers, fears and restrictions on freedom may not be justified.

The consequences of becoming lost are more significant when the person living with dementia is driving. In a 2010 exploratory study, Hunt Brown and Gilman conducted an extensive online search for published or reported incidents over a 10-year period (August 1998- August 2008) in which an older adult diagnosed with dementia became lost while driving. The study findings are set out in table 1.

Table One: Outcome of people living with dementia becoming lost when driving.

Driver outcome	Age (standard deviation)	Passengers	Someone in vehicle injured
Group One (N=70) Uncertain or not found	77.56 (6.74)	1	

Group two (N=116) found alive	78.87 (7.17)	7	35
Group three (N=32) found dead	78.54 (7.54)	3	

Those found alive had been missing for an average of 1.99 days, while for those found dead, there was an average of 26.76 days until a body was found. The causes of death included drowning after driving into water, road traffic accidents, and exposure either within the vehicle or while seeking help. The study found many people drove off the road and mistook an alternative surface such as a boat ramp for a road. Becoming lost whilst driving appears to have a similar aetiology to becoming lost on foot. People who became lost while driving were driving to or from familiar places such as shops, relatives' homes, and a doctor's office and choir practice. Family members considered the PLWD safe to drive.

It is acknowledged within this study that many instances of PLWD who become lost while driving do not result in any form of media report. The study also illustrates how adverse outcomes may be linked to the geography of an area. Of those outcomes where more details were reported, a remote area is mentioned in eight cases. The study took place in the US, and some reports came from areas with low population density and isolated or abandoned roads.

To summarise this data, it appears that up to a third of PLWD may become lost at some point but relatively few of these people are physically harmed. It is unclear what the cause of the safe return to people's homes may be, but it seems probable that carer vigilance is linked to this. It is also possible the wider community, including neighbours and local shops, may be involved in returning people home safely. There is a role for the emergency services, paramedics, the police, or search and rescue to return people to their homes (Greene et al 2019).

1.10 The impact on carers

Significant demands may be placed upon informal carers by leaving unsafely on the part of the PLWD. Greene et al (2019) interviewed 12 family caregivers of PLWD to identify what factors led them to report the person they cared for was missing. Carers identified feelings of responsibility and guilt, worry, and anxiety over the PLWD becoming lost. Such an experience may create increased vigilance and constant supervision. There may be a reluctance to leave the PLWD alone due to the perception that they may become lost. The cause of crisis in caring for someone who lives with dementia may be multi-factorial, leaving unsafely has been identified as one of the top ranked risk factors for crisis (Toot et al 2015, Ledgard et al 2015). Leaving unsafely occurs at a point where other behavioural factors such as agitation, delusions, and sleep disturbance are causing increased pressure upon carers. (Vroomen et al 2013). The level of care provided may significantly impact the freedom of the person providing care. Managing the possibility that the PLWD may become lost creates a conflict for carers balancing the potential for harm and the maintenance of freedom for the PLWD (Robinson et al 2007). Carers have identified that their own anxieties may contribute to significant restrictions on the freedom of the PLWD (Bantry-White and Montgomery 2014).

1.11 Psychosocial reasons for leaving/walking about

Rowe (2003, p34) identifies that 'people who wander may never become lost and those who never wander may become lost'. There is a distinction between walking, a normal and everyday pursuit for PLWD and getting lost. PLWD who wish to leave their home may be seeking exercise, companionship, or stimulation. Walking can carry significant social and physical benefits (Robinson et al. 2007, Cerdervall et al. 2015). Walking has also been linked to decreased agitation amongst those with early to middle stage dementia (De Olivera et al 2015). While mobilising may not have the same level of purposefulness amongst PLWD when the condition is more advanced, walking and exercise have been linked to reduced behavioural and psychological symptoms from dementia (Tible et al 2017).

When those living with dementia have been included as research participants in studies relating to restrictions upon freedom (Robinson et al 2009, Clarke et al 2010), they have spoken of the need for independence and concerns over carer surveillance. Participants identified the impact of remaining in the home on friendships and identified reasons such as social interactions as reasons to go outside. While some participants accepted limitations placed upon them by carers (Clarke 2010, Bantry-White & Montgomery 2015), others stressed the importance of fresh air and autonomy.

Being a member of a neighbourhood has been linked to social connections, which create a sense of belonging (Department of Health 2010, Maples 2011). Neighbourhoods provide an immediate social context, and for community dwelling PLWD, a familiar environment has been linked to a sense of attachment and offers the potential for freedom of movement (Cerdevall et al 2015). The wishes of PLWD to leave their home cannot be perceived as significantly different to those who do not live with the condition and reflect a need for PLWD to be socially included (Department of Health 2010).

1.12 Disability rights movement

The rights of PLWD to freedom can be linked to a social perspective on disability. Such a perspective called for an acknowledgement that social and attitudinal barriers create disability. This perspective became the basis of the British social model of disability (Oliver 1990). This perspective has shifted through an acknowledgment that for conditions such as dementia, it cannot be argued that limitations to freedom are not at least partly attributable to the condition rather than society (Shakespeare, Zellig, and Mittler 2019). The cognitive elements of dementia may have accounted for the initial exclusion of PLWD from the social model (Gilliard et al 2005). However, increasingly dementia is regarded as included within a social model of disability that incorporates a rights-based perspective (Shakespeare, Zellig, and Mittler 2019). The concept of the right to freedom as defined by PLWD is integral to this thesis.

1.13 Person centred care

The history of dementia contains important shifts in the ways PLWD have been viewed and treated. In the current social and medical context, there is a body of policy, educational literature, and law that supports the concept of person-centred care (Health and Social Care Act regulations 2014, NHS Confederation 2018). Kitwood's theory of person-centred care changes the priorities of care so that at the centre of all decisions and tasks is the PLWD. Personhood is central to this theory and is described as "a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997, p. 8). Brooker (2006) outlined that the following four key components are integral to a person-centred care approach for PLWD.

1. A value base that asserts the value of all human life regardless of age and cognitive ability
2. An individual approach that recognizes uniqueness
3. seeing the world from the perspective of the person with dementia, to understand the person’s subjective experience and behaviour.
4. Providing a social environment which meets the fundamental psychological needs of people living with dementia.

In Person-Centred Dementia Care: Making Services Better, Brooker (2006) expanded upon these components and identified key indicators or practices for each of the four components. While many of these components were only relevant to institutional care to be consistent with these key indicators, FREEDEM should be consistent with the values, wishes, and preferences of PLWD. To achieve this, the history, lifestyle, and culture of the person should be understood. All these elements may be linked to their attitude to freedom and potentially their expectations of carers.

Personhood is, however, decontextualized as the focus is upon the PLWD rather than identifying broader relationships. The commitment to the PLWD offers a starting point, which is individual rather than relational. Within a relational perspective, personal relationships are a key contextual element of the experience of the PLWD (Morhardt and Spira 2013, De Witt and Fortune 2019). Freedom may occur within the context of a negotiation with the person who provides care, and so the interpersonal element of care cannot be ignored (Springate and Tremont 2014). Interdependence and interconnectedness may maintain or degrade identity and freedom. The behaviour and attitudes of carers towards the PLWD may undermine their personhood. In the context of freedom, this may be an overprotective carer who is excessively concerned with risks and limits the freedom of the PLWD. The proposed assessment will incorporate a person-centred approach whilst acknowledging the importance of relationships with carers to the PLWD and in supporting or denying freedom in the context of relational care (Soklarides et al 2016).

The concept of person-centred care was updated in 2016 (Brooker and Latham 2016). Most of this book is dedicated to a care home setting and how care should be provided. In addition, the relationship between the carer and the PLWD has less focus than within the concept of relational care. In view of this, the proposed assessment will be underpinned at a theoretical level by the concept of person centre care supplemented by relationship centred care. Relationship centred care is a concept founded on four principles (Soklarides et al 2016).

1. Personhood matters.
2. Affect and emotion are important.
3. Relationships do not occur in isolation.
4. Maintaining genuine relationships is necessary for health and recovery and is morally valuable.

Relationships in a healthcare context can include those between the PLWD, clinicians the family and community. These relationships are interconnected and form the framework through which relational care may be implemented (Nolan et al 2004, Sprague 2008). Rather than negating person-centred care this is supplemented by a relational perspective upon the provision of care and the acknowledgement of the importance of carers in supporting the PLWD. This wider perspective also acknowledges the importance of the community and the relationship between the community and the PLWD. Throughout this thesis where the theoretical framework of relationship centred care is used this will incorporate the concepts of personhood.

1.14 Occupational Therapy

It is proposed that the professional group implementing the assessment will be occupational therapists (OTs). OTs are an Allied Health Profession. Within the UK, OTs qualify through completion of a BSc degree. In the UK, once qualified, the OT must be registered with the Health Professions Council to practice (Health Professions Council 2020). The degree qualifies an OT to work in either physical or mental health settings. OTs work in both acute and community health and within social care. There are over 30,000 OTs currently practising in the UK. The Royal College of Occupational therapy (2019) defines the role of the profession as “providing practical support to empower people to facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them. This support increases independence and satisfaction in all areas of life”.

1.14.1 Occupational therapists and PLWD

OTs are extensively involved with PLWD and their carers. This role extends to both inpatient and community work. In the UK, there is a history of OTs forming part of the multidisciplinary team in memory clinics and older adults' mental health services (Hall and Skelton 2012). There is also an OT presence in community rehabilitation services for PLWD and working-age dementia services (Swinson et al 2016, Wenbourn et al 2016). Within these roles, OTs assess cognition and capacity on both an informal and formal basis. The profession is experienced in assessing the function of PLWD and provides adaptations and rehabilitation (Gitlin et al 2005, Graf et al 2006, Gitilin et al 2008, Gitlin et al 2010). OTs also work with carers and provide education, advice, and support for people providing care (Hall and Skelton 2012). Despite this experience OTs have been participants in studies that identified an over-cautious approach to the freedom of PLWD (Clarke 2010). The assessment could help address any lack of positive risk taking amongst the profession while also being consistent with OTs' underlying skills.

1.14.2 Occupational therapy assessments

The College of Occupational Therapy identifies over 160 different assessments that may be carried out by OTs (College of Occupational Therapy 2016). These relate to diverse areas, including mental health issues and a variety of physical conditions. The College identifies that some generic assessments are used, and a generic community occupational therapy assessment is set out in appendix 11.11. Such an assessment provides details of the home, social circumstances, and baseline function of the PLWD.

This assessment may be available as information to build upon in completing an assessment of freedom. The critical factor assessed in such assessments is the function of the person assessed. This may include the ability to carry out activities of daily living linked to domestic tasks such as cooking, cleaning, and shopping (Swinson et al 2016). These tasks are often referred to as domestic activities of daily living (DADL). Personal care may comprise washing, dressing, and grooming. These activities are abbreviated to personal activities of daily living (PADL). Mobility, physical and cognitive function are frequently assessed (Swinson et al 2016). No assessment could be identified which addressed freedom for PLWD.

1.15 Overview of the research

1.15.1 Aims and objectives.

This PhD study's primary aim was to empirically explore the idea of freedom as it relates to PLWD and develop an assessment and model of freedom for community dwelling PLWD. The following objectives will be tied to the content of each chapter in table two. The objectives of this study were to:

1. Explore the philosophical and legal definitions of freedom.
2. Explore how people living with dementia and their carers define freedom.
3. Develop a theoretical model of freedom for people living with dementia.
4. Identify what components of an assessment may support freedom for people living with dementia.
5. Identify the current role of occupational therapists in ensuring freedom for people living with dementia.
6. Develop a person-centred assessment of freedom.

1.15.2 Thesis structure

Table Two: Thesis Structure.

Chapter	Objective Met	Methods and content
One	6	Provides the link between dementia and leaving home unsafely. Describes the role of carers in supporting people living with dementia and in potentially restricting freedom. Describes the concept of person-centred care.
Two	2	Sets out the legal position regarding deprivation of liberty for community dwelling people living with dementia. To identify the legal elements of the assessment.
Three	1,2,3	Explores philosophical definitions of freedom and how these definitions could be linked to the development of a theoretical model of freedom to support the assessment.
Four	5	Presents a scoping review that identifies potential assessment components to support liberty for people living with dementia.
Five	2,3,4	Describes the methods used in the primary research. The justification and rationale for a mixed methods approach are set out. The methods used for the recruitment of participants and collection and analysis of data are explained.

Six and seven	1, 3,5, 6 7	Presents interview findings linked to the theoretical model of freedom derived from people living with dementia, carers, and occupational therapists. The completed model of freedom is constructed from interview data. Chapter seven identifies the methods used for the development of the assessment and the data used to develop the assessment from the semi structured interviews.
Chapter 8	6,7	Describes the methods for the Delphi study and the outcome of the study. The finalised assessment is set out in this chapter.
Chapter 9		Summarises the research findings and identifies strengths and weaknesses in the research. Presents a discussion of issues identified with implications for clinical work, research, direction of future research, and concludes the thesis.

1.15.3 Methods

The philosophy of pragmatism underpinned the research methods on the basis that this approach has been tied to the use of mixed methods. This is because pragmatism is not centred upon a single version of the truth and is accordingly sufficiently flexible as a philosophy to incorporate a mixed methods approach (Feilzer 2010, Hall 2013). A sequential exploratory mixed methods design was used to address the study aims and objectives. This design begins with a qualitative exploration of a topic before commencing a second quantitative stage (Cresswell and Plano Clarke 2011). This design has been used to develop an instrument such as the proposed assessment following the qualitative stage and has been called the instrument development design (Cresswell Fetters and Morgan 2004).

Mixed methods research (MMR) was used as the flexibility of mixed methods allowed for the incorporation of legal, philosophical, and clinical concepts around freedom (Biesta 2008, Anderson and Denscombe 2010). A mixed method approach also allowed for the incorporation of qualitative and quantitative research into the assessment development.

1.15.4 Chapters content

The thesis has two introductory chapters. This chapter sets out the prevalence of dementia in the UK and how the condition may be linked to leaving home unsafely. The chapter also sets out the role of carers in supporting PLWD and potentially depriving them of their freedom. The role of OTs in working with PLWD is also introduced. Chapter two will set out the current law in England and Wales relating to DOL and will situate the assessment in relation to the process of authorising a DOL. Chapter three will consider the underpinning epistemology of this thesis and philosophical concepts linked to freedom. The theoretical model of freedom for PLWD will be provisionally developed in chapter three following consideration of these philosophical concepts. In chapter four, a scoping review is then set out to identify the potential elements of the assessment. The assessment is developed further through data obtained in semi-structured interviews. The methods for these interviews are explained and developed in chapter five. Thirty semi-structured interviews were carried out with PLWD, carers, and OTs. The findings of these interviews are set out in chapters six and seven. This data is used to develop the assessment of freedom and amend the philosophical, theoretical model of liberty. The assessment is refined further in a Delphi study. Participants in this study element are carers for PLWD, mental health nurses, registered general nurses, social workers, OTs, physiotherapists, and doctors. The thesis concludes with a discussion providing an overview of the research's findings and research methods, strengths and weaknesses, and implications for further research.

1.15.5 Situating the researcher

The interpersonal context may impact on the research processes (Holmes 2010, Burkitt 2010). I will write in the first person in reflective or reflexive writing in this thesis as these sections are concerned with personal insights. Reflexivity relates to the extent to which the researcher’s own views and opinions impact upon the research process. Our positions and interest may influence all stages of the research process. By identifying these positions, it is possible to illuminate this influence. Parahoo (2006 p37) defined reflexivity as ‘the continuous process of reflection upon the researcher’s values and preconceptions behaviour or presence and those of participants which can affect the responses offered and their interpretation.’ To avoid this, a reflexive stance involves developing insight into the self and how this impacts upon the research project.

Within a reflexive approach, my personal history is relevant. I worked as a solicitor for 10 years specialising in litigation. I retrained to be an OT in 2003-2005. Since 2005 I have worked with PLWD and their carers regularly. During this period, I helped care for my sister, who had a diagnosis of motor neurone disease with Fronto-temporal dementia. She lived with my mother so that her husband could continue to work as she could not be left alone safely. This was partly because she had a two-year-old son at the point of diagnosis. She liked to go for a walk with him, which was not safe as she had limited speech and reduced cognition. The trigger for her moving in with my mother was going out with my nephew while my brother-in-law was at work and being returned home by the police.

My mother was the primary carer. She lost a significant amount of her freedom during this time. When I became aware of the proposed change in the law relating to DOL, I considered it in the context of my own family. I would not have wanted any more to be asked of my mother and would have been angry if a clinical staff member had told her to facilitate my sister’s liberty or sought to obtain approval for a DOL.

I recognise that as a former solicitor, and OT I was confident in my ability to manage situations for my own family. An element of being a solicitor is decisiveness, and I felt there was a clear balance to be struck between my mother's freedom and my sister's. I found this an easy decision to make and helped by spending time with my sister and nephew so my mother could go out. This experience shaped the legal element of the research question but recognising my own views, and I will utilise this insight to avoid developing collection or interpretation of data from a perspective that is wholly my own. This insight was made possible using reflexivity. Reflexivity allowed me to be aware of my effect on the research process and outcomes (Alvesson and Sköldberg 2000). By recognising my own perspective, I also acknowledge that my experiences cannot be excluded entirely and might be positive as it gives insight into carers situation. Personal history and standpoint can be regarded as a resource if it provides relevant knowledge (Braun and Clarke 2019). What is essential is an insight into this personal experience and how it may influence data interpretation. I will revisit reflexivity in the context of research methods, interpretation of data, and the conclusion to this thesis.

1.16 Summary

This chapter defines the most common types of dementia and sets out the prevalence of dementia in the UK. The most common subtypes of dementia are identified. The epidemiology of leaving the home unsafely is set out together with a literature review on the consequences of becoming lost. It is identified how carers may restrict the freedom of PLWD and how attempts to leave may cause carer stress and crisis. It is also identified that being able to leave the home and participate in activities of choice continues to be important to PLWD. The chapter introduces the complex decisions that carers may need to make in balancing risk and freedom. The role of OTs in implementing the proposed assessment is set out. The structure and content of the thesis have been explained. In chapter two, the history of the law relating to DOL and proposals for legal reform will be linked to liberty for those who live with dementia in the community.

2 Chapter Two - Legal Introduction

2.1 Introduction.

This chapter sets out the provisions of the Mental Capacity Act 2005 (MCA, 2005) and the 2019 Mental Capacity Amendment Act (MCAA 2019). However, it is essential to note that the MCAA (2019) implementation will not occur until April 2022. Accordingly, areas linked to implementation cannot be concluded within this thesis (Whately 2020). It is beyond the scope of this thesis to analyse the MCA (2005) or amendments to the Act in detail. Instead, this chapter sets out an overview of the legal position relating to freedom for people who lack capacity. The assessment of capacity and best interests will be explained together with the development of the law relating to DOL. The legal position relating to freedom in private homes will be considered. The potential implications of legal changes introduced in the MCAA 2019 upon those who live with dementia and their carers will be set out linking the legal position to chapter one. This chapter will also identify how FREEDEM could be linked to this legal amendment.

2.2 Aims and objectives of this chapter.

The aims and objectives of this chapter are:

Aim

1. To provide the legal background to this thesis.

Objective

2. To provide an overview of the Mental capacity Act 2005
3. To set out the development of the law leading to the Mental Capacity Act 2019.
4. To discuss the legal implications of deprivation of liberty in a domestic setting.

2.3 Sources of UK law

The MCA (2005) is an example of statute, the highest form of UK law. An alternative domestic source of law is common law. Common law arises from judicial court decisions which come within a court hierarchy. This rises from the County Court to the High Court and ultimately the Supreme Court, the highest UK court (Slapper and Kelly 2015). Statutes are subject to interpretation which occurs through legal challenge within the court structure. Sources of UK law are set out at figure three.

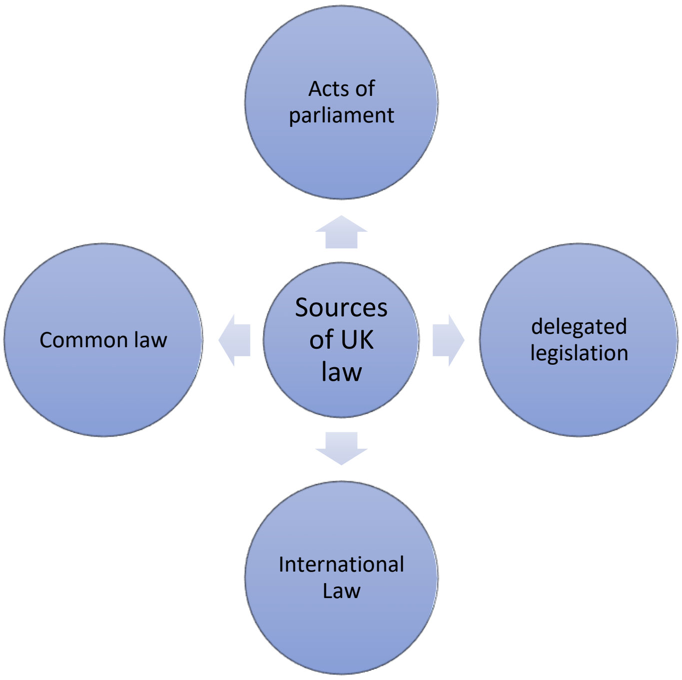


Figure three: sources of UK Law.

For devolved powers to the Scottish and Northern Irish assemblies' laws impacting directly upon those countries, including the law relating to Mental Capacity and DOL fall within those assemblies' powers (Birrell & Gray 2017). In contrast, Wales has secondary legislative power only and remains within a Welsh/English legal structure. Wales has more limited legislative powers than the Scottish or Northern Ireland assemblies and continues to be bound by statutes passed at Westminster relating to Mental Capacity (Holden 2007).

The MCA 2005 established the Court of Protection, which oversees cases concerning DOL. Most decisions under the MCA do not require a court decision, but when such a decision is necessary, the Court of Protection has jurisdiction over matters relating to the

MCA. There is a right of appeal from the Court of Protection to the Court of Appeal and then sometimes to the Supreme Court.

2.4 The International dimension

2.4.1 The European Convention on Human Rights

The European Court of Human Rights provides a route of appeal outside the UK for issues relating to freedom. This Court is outside the European Union and will not be impacted by the UK leaving the European Union (International Justice Resource Centre 2018). The Court is intended to protect the rights of citizens of countries who are signatories to the European Convention on Human Rights (International Justice Resource Centre 2018). The convention was set up in the aftermath of the Second World War in response to the atrocities of the war. Britain is a signatory to the European Convention of Human rights (ECHR) (Council of Europe 1950). The ECHR has been given domestic effect in the UK by The Human Rights Act (1999); however, the article is still relevant as citizens of signatories have a right of appeal from domestic courts to the ECHR if they consider their human rights as set out in the ECHR have been breached (The repeal bill white paper 2017). Article five of the ECHR, which concerns, DOL is particularly relevant for present purposes. This article states that everyone has the right to liberty and security of the person. The article sets out the situations in which lawful detention may occur, for example, the detention of people of unsound mind under Article 5(1) e.

2.4.2 The United Nations Convention on the rights of persons with disabilities (CRPD)

At an international level, the CRPD (UN 2014) has been called an important legal shift in acknowledging the rights of people with disabilities (Kayess and French 2008, Lang et al 2011). The convention situated disability within a social model and lays out the rights of all human beings regarding those who live with disabilities. The convention seeks to protect, "the inherent dignity, worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice, and peace in the world." (Article one CRDF 2014). Internationally commentators have identified violations of rights of people with disabilities such as failing to seek consent to treatment (Dhir 2005), the use of restraints and unethical inclusion in research (Kayess and French 2008). Such treatments cannot be consistent with the concepts of dignity and inalienable rights, which the convention seeks to promote. An international perspective prevents a scheme founded upon individual governments and provides a mechanism to address identified abuses. The United Kingdom has ratified the convention. Ratification is an international act whereby a state consents to be bound by the terms of a treaty. The treaty is not, however, legally enforceable. (United Nations 2014). Amongst the rights protected by the CRDF is the right to freedom. The potential expansion of the CRDF into domestic law is a contested and debated issue (Davidson et al 2015, Bartlett 2020). Article 14 conveys the provisions of the convention linked to freedom and states that "parties shall ensure that persons with disabilities, on an equal basis with others: (a) Enjoy the right to liberty and security of person; (b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty" (CRPD 2014). These provisions identify the rights of PLWD, which extend beyond domestic law.

2.5 The Mental Capacity Act 2005

The MCA (2005) provides the circumstances when a decision can be made in the best interests of a person who lacks capacity. This framework is intended to provide protection and empowerment of people who lack capacity on issues such as their care and treatment. The MCA (2005) is founded upon five key principles. The first of these is a presumption of capacity; this ensures that there must be a demonstrable lack of capacity before rights or freedom of action is affected. Rights and freedom of action are not defined in either the statute or MCA guidance. Decisions must be made in the least restrictive way. Any interference with these rights must be in the person's best interests. The core principles are below in box one.

Box one: core principles of MCA 2005

A person must be assumed to have capacity unless it is established, he lacks capacity.

A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success.

A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

An act done or decision made, under this Act for or on behalf of a person who lacks capacity must be done or made, in his best interests (Best Interests is defined further within this act).

Before the act is done, or the decision is made, regard must be had as to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

2.5.1 Assessment of Capacity

Capacity is the legal ability to make decisions. It is specific to the decisions being made, and the time the decision is taken (MCA Code of Practice 2007). Guidance for the assessment of capacity is set out in sections 2 and 3 of the MCA (2005). The Mental Capacity Act Code of Practice (2007) sets out additional guidance. The factors considered are as follows.

Box two: Assessment of Capacity.

For the purposes of the Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

It does not matter whether the impairment or disturbance is permanent or temporary.

A lack of capacity cannot be established by reference to –

- A person's age or appearance
- Or a condition of his, or aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity.

In proceedings under this Act or any other enactment, any question about whether a person lacks capacity within the meaning of this Act must be decided on the balance of probabilities.

Capacity will need to be assessed where a person appears to be unable to make a particular decision at a particular time because their mind or brain is affected by illness of disability. Dementia is a condition in which capacity on specific decisions may be lost as the condition progresses (Emmett et al 2013, Pennington et al 2018). Lack of capacity may not be a permanent condition. Dementia may fluctuate or increased cognitive impairment may occur because of fatigue or ill health. The following factors are relevant to the assessment of capacity.

Box three: Factors relevant to assessment of capacity

For the purposes of section 2 a person is unable to make a decision for himself if he is unable to:

- Understand the information relevant to the decision.
- To retain that information,
- To use and weigh that information as part of the process of making the decision or to communicate his decision (whether by talking using sign language or by any other means).
- A person is not to be regarded as unable to understand the information relevant to a decision if he is unable to understand an explanation or it given to him in a way that is appropriate to his circumstances (using simple language, visual aids, or any other means).
- The fact that a person is able to retain the information relevant to the decision for a short period only does not prevent him from being regarded as able to make a decision.
- The information relevant to the decision includes information about the reasonably foreseeable consequences of (a) deciding one way or another (b) failing to make a decision.

2.5.2 Best Interests

It is a basic principle under the MCA that acts done, or decisions made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests (MCA 2005). It must also be considered whether capacity will be regained and when this may occur. The involvement of the PLWD must be facilitated so far as reasonably practicable. The factors which must be considered are set out in box four. These categories are not closed if there are other factors that should be considered in making a best interest decision.

Box four. Best Interests factors to consider.

The persons past wishes and feelings (and in particular any written statement made by the person when they had capacity),

The beliefs and values which would be likely to influence his decision if he had capacity and the other factors, he would be likely to consider if he were able to do so.

He must take into account if it is practicable and appropriate to consult them, the views of –

Anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

Anyone engaged in caring for the person or interested in his welfare,

Any donee of a lasting power of attorney granted by the person, and any deputy appointed for the person by the court.

2.5.3 Criticisms of the Mental Capacity Act.

It is beyond the scope of this thesis to analyse the MCA 2005 in detail. The Act has been praised as enshrining rights for people lacking the capacity to be involved in decision making and empowering clinical staff to make decisions consistent with the wishes of those who lack capacity (Manthorpe et al 2009, 2011). Criticisms of the Act in a clinical setting have been primarily focussed upon the level of understanding of the Act amongst clinical staff and difficulties with practical operationalisation and consistent implementation (e.g., in the assessment of capacity, or determining best interests) (Phair and Mansthorpe 2012, Samsi et al 2011a, 2011b Emmett et al 2012). Research suggests carers have limited understanding of the Act with knowledge confined more to specific aspects such as a power of attorney or financial planning (Samsi and Manthorpe 2011a, Manthorpe et al 2012).

2.6 Deprivation of Liberty

2.6.1 What is a deprivation of liberty?

The MCA (2005) contains the original framework for authorising a DOL for a person who lacks capacity. The MCAA 2019 amends the original DOL provisions. The 2019 Act is an addition to, rather than a replacement of the MCA 2005. The MCA 2005 and MCAA 2019 apply in England and Wales. Comparable legislation occurs within other countries addressing similar decision-making powers and protections for people who lack capacity, such as The Adults with Incapacity Act (Scotland) (2000). This research is set within the framework of a specific jurisdiction but has broader implications as it addresses international concerns in the context of dementia, such as those contained in the CRDF.

The legal definition of DOL is derived from the caselaw of the ECHR. There are three elements within the assessment of whether a person is deprived of their liberty (Guzzardi v Italy 1980 Series A No 39),

Liberty has an objective element (The person is confined to a particular place for a non-negligible period of time).

The subjective element (The person has not consented to the control placed upon them or lacks capacity to consent)

and the state element (The DOL may be directly or indirectly attributed to the State).

The following elements are relevant, the **duration, effect manner and degree, and intensity of the restriction** (Guzzardi v Italy 1980 Series A No 39). These elements remain relevant in a domestic setting. The type of restriction within this setting may include telecare technology (sensor mats at doors or placed randomly to monitor movement or GPS tracking to find the person if they become lost (Bantry White and Robinson 2014b). Doors may also be locked, or there may be constant supervision and monitoring (Robinson et al 2007). The restriction may include, for example, confining the PLWD to one room within the home. A blanket restriction is more likely to be perceived as a DOL The final element is the degree or intensity of each restriction. For example, supervision by a carer in a domestic setting may be intermittent or constant and intrusive.

2.6.2 The Deprivation of Liberty Safeguards

People who live with a cognitive impairment may lack capacity to consent to treatment or care. Providing this care may involve depriving these people of their liberty. In a hospital or care home, DOLS protects the rights to liberty of those who lack capacity. A decision to deprive someone of their liberty must be authorised by an approved legal process as otherwise, such a deprivation is unlawful. The framework for these safeguards is set out in the MCA (2005) and is designed to ensure a structure through which a person may lawfully be deprived of their liberty. The DOLS code explains how to identify how a person is deprived of their liberty and how the deprivation may be avoided. It is important there is a clear pathway for authorisation as the person being deprived of their liberty is deprived of their article five rights. The DOL safeguards does not automatically apply to people outside organisations that are linked to the State. The deprivation must be imputable to the State for the DOLS to be applicable. Imputability may arise as a result either of the State's direct involvement in the person's detention, or of the State's positive obligations to protect the person against interferences with their liberty carried out by private persons. (Law Commission 2017) There is then limited distinction between a DOL in an institutional setting and a private DOL, as the private deprivation may be imputable to the State.

The liberty protection safeguards (LPS) form the replacement scheme for DOLS. It is intended that the safeguards should offer a simplified scheme for the approval of deprivations of liberty in all settings (Law Commission 2017). The scheme should redress elements of the DOLS which have been criticised, including the resource intensiveness and time taken to process an application to approve a DOL. Any, DOL including private deprivations of liberty, will be authorised within health and social care with a right of appeal to the Court of protection in disputed cases (Griffiths 2020). The subsequent paragraphs set out the development of DOLS and how the LPS is intended to address shortfalls in the DOLS scheme.

2.6.3 The development of the law relating to deprivation of liberty.

2.6.3.1 The Bournewood case

The roots of the current legal position within the UK originate with the Bournewood case. The DOLS amendment to the MCA originated with the ‘Bournewood’ case (HL v UK 45508/99 [2004] ECHR 471). The case concerned a young man with learning difficulties on the autistic spectrum known by his initials HL throughout the proceedings. He was fostered successfully by an older couple but, during a day centre visit, became distressed and agitated. He was admitted to Bournewood hospital as a voluntary patient. HLs foster parents challenged the decision to hold him at Bournewood. At first instance (The High Court), it was ruled that the detention was lawful as HL had made no attempt to leave the hospital. The detention was lawful as no restraint would occur until HL had attempted to leave, and the applicant had done something to prevent this. It should be noted that HL was heavily sedated while an inpatient and had impaired communication, which would have impacted his ability to express a wish to leave.

The Court of Appeal revised this decision by holding that a lack of active dissent did not imply consent, and HL should have been detained under a section of the Mental Health Act (1983). The House of Lords (the highest English Court and predecessor to the Supreme Court at the time) rejected this decision holding there must be an actual rather than potential restraint. This judgement appears to have been partly attributable to public policy considerations**.** It was argued that if the Court found that HL was unlawfully detained, potentially thousands of voluntary patients who lacked the mental capacity to consent to remain in a hospital would then require sectioning under the Mental Health Act 1983. HL was released back into the care of his foster parents, but the case was pursued to the European Court of Human Rights to obtain a declaration that HL had been deprived of his liberty within the meaning of article 5 of the European Convention on Human Rights (HL v. UK 2004 - App no 45508/99; 40 EHRR 761). The Court found that HL had been detained and rejected the majority verdict of the House of Lords, finding the distinction between actual and potential restraint was insufficient to prevent a breach of article 5 of the convention. Under Article 5(1)(e), detention may be lawful if imposed in a way consistent with the law. The Court contrasted the safeguards applicable to mental health admissions under the Mental Health Act with the lack of a legal mechanism for the authorisation of the detention and admission of compliant patients lacking capacity. The absence of this procedural framework for the DOL for those lacking capacity became known as the ‘Bournewood Gap.'

2.6.3.2 The Statutory Development of Deprivation of Liberty

Following the Bournewood decision, the UK government launched a consultation process to develop a procedural legal framework to rectify the gap identified in Bournewood. (Department of Health 2005). This framework would then bring the law in England and Wales into compliance with Article 5 ECHR. This consultation extended the scope of enquiry beyond patients who were voluntary inpatient rather than those detained under a section of the Mental Health Act 1983 to those detained to residential homes and hospitals. The MCA was amended to contain legal provisions relating to DOL for those who lack capacity on the 1ST of April 2009. The amendments were debated in the House of Lords but there was no debate in the House of Commons (Hargreaves 2009), creating a lack of parliamentary scrutiny. This amendment was intended to provide an administrative process and judicial safeguards for those who lack capacity who are potentially deprived of their liberty. This legal amendment applied only to emanations of the State.

2.6.3.3 Cheshire West and The Acid Test

The test for whether a person was deprived of their liberty was subsequently interpreted in the cases of Cheshire West (1. P by his litigation friend the official solicitor appellant v Cheshire West and Chester Council and another. 2. P and Q by their litigation friend the official solicitor appellant’s v Surrey County Council respondents 2014). These cases became collectively known as Cheshire West. The cases concerned people with learning difficulties living in assisted care settings in the community. The case set out the acid test for whether a person was deprived of their liberty. This test stated that a person was deprived of their liberty if they could not consent to their care and treatment, were under continuous supervision and control, and would be prevented from leaving if they attempted to do so. The test encompassed those who were actively trying to leave and those who were not attempting to. The case concerned people who lacked capacity on their choice of residence and care regime but were making no attempt to leave. The test for these people was would they be prevented from leaving if they attempted to do so.

Lady Hale gave the lead judgment and set her rationale out as follows "The local authorities who are responsible for them have no doubt done the best they could to make their lives as happy and fulfilled, as well as safe, as they possibly could be. But the purpose of article 5 is to ensure that people are not deprived of their liberty without proper safeguards. These safeguards will secure that the legal justifications for the constraints which they are under are made out in these cases, the law requires that they do indeed lack the capacity to decide for themselves where they should live and that the arrangements made for them are in their best interests. It is to set the cart before the horse to decide that because they do indeed lack capacity and the best possible arrangements have been made, they are not in need of those safeguards" (Paragraph 56 (1) P by his litigation friend, the official solicitor appellant v Cheshire West and Chester Council and another. 2. P and Q by their litigation friend the official solicitor appellant's v Surrey County Council respondents 2014).

In addition to the acid test, the significance of Cheshire West is that it addresses deprivations of liberty outside the DOLS. Cheshire West confirmed that those living in a variety of settings are entitled to the protection of article 5 ECHR. The distinction between those in care homes and hospitals and those in a non-care home setting now became a procedural one as the mechanism for approving a DOL was not the same as the framework for the DOLS. In 2014 a streamlined procedure was created to provide a more straightforward pathway for authorisations of DOL in the community (Ruck Keene et al 2017). This procedure is sometimes referred to as a community DOL or the Re X procedure. This procedure is designed to approve a DOL in a setting other than a hospital or care home and was intended to be administratively streamlined for cases that were not contested. Alternatively, for those cases where there are other welfare issues, it is possible to make a welfare application to the Court of Protection (Ruck Keene et al 2017). An authorisation for a DOL may be an element of such a welfare application.

2.7 Critiques of the deprivation of liberty provisions

The problems identified with the DOLS provisions are extensive and beyond the scope of this thesis. However, the difficulties in the practical application of the provisions may impact upon the enforcement and effectiveness of the Liberty protection safeguards, and so it is helpful to identify some of the most common criticisms in the form of administrative and financial implications, the scope of the DOLS provisions and lack of patient benefit.

In 2014 The House of Lords compiled a post-legislative scrutiny report on the MCA 2005 (Great Britain Parliament 2014). The task undertaken by the House of Lords was to answer the question of whether the Act was working as Parliament intended. This report praised the Act itself but identified problems with its implementation. The report stated that the sections relating to DOL were not fit for purpose. It was identified that clinical staff were often unclear about who needed authorisation resulting in both blanket applications and missing cases in which authorisation was clearly required. There was evidence of limited application as staff were unclear about how to implement the safeguards. It was recommended that a comprehensive review of the safeguards be carried out with a view to replacing them with provisions that were compatible in style and ethos to the rest of the MCA. A potential statutory amendment was proposed, and the law commission was tasked with redrafting the provisions of the MCA relating to DOL.

2.7.1 Financial/Administrative implications

The House of Lords report identified potential significant expense with limited evidence of benefit to those whose DOL was approved. It was noted that the safeguards appeared to have limited benefit in end-of-life care and critical care settings. This limited benefit occurred in the context of multiple competing funding priorities in health and social care. Over 70% of applications were not approved within the statutory time limit. The system to authorise DOLS was unable to cope under the strain of the number of applications for authorisation.

The Cheshire West case resulted in an increase in the number of applications for authorisation from settings other than care homes/hospitals. Also, there has been a steady increase in applications from the care home and hospital setting. There were 217,235 applications for DOLS received during 2016/17, an increase of 11 percent on 2015/16. In 2015/16, the number of completed applications was 105,000. In 2016/2017 152,000 applications were completed (NHS digital 2018). The increasing number of applications has created significant pressure on the systems for authorisations of a DOL. The reported backlog of cases that were not completed as of year-end 2017 increased by 7 percent to 108,545 over the year (NHS digital 2018). The law commission impact assessment (2018) places the cost of fully operationalising DOLS scheme at £348.40 million per annum.

2.7.2 Lack of patient benefit

The law commission (2017) identified that the DOL provisions focused on article 5 of the ECHR to the exclusion of Article 8, a right to family life. This was compounded by the limited scope of the DOLS provisions. The provisions did not apply to private homes, assisted living schemes, or sheltered accommodation as deprivations in these settings would not be imputable to the State.

The House of Lords report also identified that the safeguards appeared to have limited benefit in end-of-life care and critical care settings. In these settings, the safeguards made no difference to the clinical care of the patients. The patient's freedom could not be exercised purely because of their medical condition, and the DOLS were effectively an administrative process which consumed resource but conferred no benefit.

2.7.3 Complexity

The provisions have been criticised as difficult to follow in contrast to the MCA, which has been praised for its relative simplicity. The DOLS provisions are almost as long as the remainder of the MCA. Six separate applications must be completed including an assessment of age, capacity, and best interests. The forms required to complete the six assessments run to over 20 pages (Law Commission 2017). It is apparent that the process is both complicated and bureaucratic (and expensive)

2.7.4 Scope of the DOLS Provisions

Other deprivations of liberty, such as in a private home or assisted living scheme, would require a welfare application to the Court of Protection (Rucke-Keene et al 2017). This then raises the issue of the accessibility of the Court and the extent to which PLWD can access the Court to ensure their freedom (Law Commission 2017). The majority of those living with dementia live in the community supported by carers who are family or friends (Wittenburg et al 2019, Department of Health, 2020). It is probable that for these people being deprived of their liberty may not come to the attention of health or social care staff, who could then commence the process of authorisation for a private DOL. This potentially results in a lack of protection for most PLWD, many of whom lose capacity on decisions pertaining to liberty.

2.8 The Mental Capacity Amendment Act

2.8.1 Law Commission Reports

The law commission submitted their second report containing proposals for statutory change to the Department of Health for approval in March 2016 (Law Commission 2017). The Department rejected the Law Commissions original report submitted in 2015 on the grounds that it produced a cumbersome framework for the enforcement of DOLS. The second law commission report set out a simplified regime introducing the Liberty protection safeguards (Law Commission 2017). In July 2018, the government published the Mental Capacity (Amendment), Bill. After an extensive debate in the Houses of Lords and Commons, the Bill passed into law in May 2019. The amendment replaced the DOLS with the liberty protection safeguards (LPS). Much of the LPS replicates the previous position. There is no deviation from the Acid Test. The deprivation must be imputable to the State. However, the number of assessments has been reduced to three, the capacity assessment, the medical assessment, and the necessary and proportionate assessment. It is intended that the liberty protection safeguards (LPS) should offer a simplified scheme for the approval of deprivations of liberty in all settings (Law Commission 2017). The scheme should redress elements of the DOLs which have been criticised, including the resource intensiveness and time taken to process an application to approve a DOL.

2.9 What are the process and assessments for the LPS?

Any DOL including private deprivations of liberty, will be authorised within health and social care with a right of appeal to the Court of Protection in disputed cases (Griffiths 2020). Whilst the detail of the process of the implementation are awaited some elements are apparent. The responsible body will make arrangements for the LPS assessments. This body will be either a local authority or a health organisation (Griffiths 2020). It is anticipated that anyone will be able to make a referral to the responsible body. Such a referral should produce identification of the appropriate body to assess the deprivation of liberty (Department of Health and Social care 2020a). This body will then be obliged to investigate the potential deprivation of liberty through a process which could initially be informal (a telephone call or email).

2.9.1 Representation and support

Once the referral is received by the responsible body representation throughout the assessment and approval process must be arranged for the person lacking capacity. This may be representation from a family member, or someone close to the person being potentially deprived of their liberty. Alternatively, if no such representation is available an independent mental capacity act advocate (IMCA) could be identified (Department of Health and Social Care 2020b). The role of the IMCA, relative or friend is to support the person lacking capacity through the process of assessment under the LPS. The responsible body (health or social care) must take practicable steps to ensure the process is understood by the representative and person potentially deprived of their liberty (Department of Health and Social Care 2020a).

2.9.2 Assessments and authorisations.

The LPS assessments will be arranged by the responsible body (the capacity assessment, the medical assessment, and the necessary and proportionate assessment) (Department of Health and Social Care 2020c). These assessments will be accompanied by a consultation with the person deprived of their freedom, and other individuals such as family members. Following the consultation, a preauthorisation review will be completed. This must be carried out by someone not involved in the persons day to day care or treatment. The review must determine if the conditions of authorisation for the deprivation of liberty are met. The review will be carried out by an approved mental capacity professional (AMCP) if there is any objection by the person deprived of their liberty (Department of Health and Social Care 2020a). Further clarification of the AMPC role is awaited in terms of which cases the AMCP is obliged to accept. The AMCP must meet with the person deprived of their liberty and (unless not appropriate or practicable to do so) and complete further consultation.

The authorisation conditions set out by the Department of Health 2020a are that:

1. the person lacks capacity to consent to the arrangements.
2. the person has a mental disorder, as defined by the Mental Health Act 1983
3. the arrangements are necessary and proportionate; that is, the arrangements are necessary to prevent harm to the person and proportionate to the likelihood and seriousness of the risk of harm to the person.

Following completion of the preauthorisation review an authorisation may be provided. for a period of up to 12 months with reviews every 12 months thereafter. Following this an authorisation can be renewed for 36 months if appropriate. Further details on when this three-year review may be appropriate will be clarified in the code of practice (Department of Health 2020a). In addition, there will be a programme of reviews to assess if the authorisation is still required and these reviews may be unscheduled. Such unscheduled reviews may be caused by significant changes in the condition of the person who lacks capacity. This may result in termination of the authorisation if for example the person no longer needs to be deprived of their liberty. The person deprived of their liberty or anyone else such as the IMCA, family or appropriate person may challenge the authorised arrangements through appeal to the court of protection.

2.9.3 How will this process operate in a domestic setting?

There is no suggestion this process or the assessments will differ due to the context of a domestic setting. However, the family member who could potentially be the authorised person may be involved in depriving the PLWD of their freedom creating a situation of potential conflict. The open-door policy for a referral for approval of a DOL means that health and social care staff including OTs may be involved in referring a potential deprivation of liberty to the relevant body for authorisation.

The role of OTs in assessing cognition and capacity may support a basic element of the assessment in that the person must lack capacity on decisions relating to freedom. The OT assessment set out in enclosure 11.11 and the FREEDEM assessment will provide background which may establish if the PLWD is deprived of their liberty. This may establish the nature and extent of the potential deprivation and whether the actions taken are reasonable and proportionate. The role of the FREEDEM assessment in supporting the assessments under the LPS is considered further in chapter nine of this thesis.

2.9.4 The role of the Best Interests Assessor

The Best Interests Assessor (BIA) carries out one of the DOLS assessments, the best interests' assessment. Under the LPS, there will be no best interest assessment. The role of BIA is replaced by the approved mental capacity professional. It is anticipated that existing BIAs will be fast-tracked into this role. The three assessments will be carried out by other health or social care staff and reviewed by an approved mental capacity professional (AMCP) in a pre-authorisation assessment. AMCPS will also be involved in cases where it is believed the person potentially deprived of their liberty objects to their care and treatment or place of residence. The case may also be referred by the responsible body (a health authority or social care) to the AMCPs if there are, for example, procedural concerns (Griffiths 2020).

2.10 The legal position in the domestic setting

The Liberty Protection Safeguards apply to all settings, including domestic homes. The guidance on the Liberty Protection Safeguards, which will contain details of implementation, will not be available until 2022 (Whately 2020). However, it remains the case that such deprivation must be imputable to the State (Law Commission 2017, p. 25). While case law is relevant to the DOL provisions, the link between these provisions and the liberty protection safeguards means that this case law will continue to be relevant in identifying when a DOL may be authorised in a private home. However, the bulk of the jurisprudence relates to institutions that can be identified as emanations of the State. Despite this, within Cheshire West paragraph 71, Lord Neuberger said: "…It is a fair point that the Strasbourg court has never had to consider a case where a person was confined to what may be described as an ordinary home. However, I cannot see any good reason why the fact that a person is confined to a domestic home, as opposed to a hospital or other institution, should prevent her from contending that she has been deprived of her liberty ". Despite this, jurisprudence relevant to domestic situations is extremely limited. Attempts to identify Court of Protection cases were made by a search of the Court Hub. Other relevant case law was sought at Mental Health law online and the British and Irish Legal Information Institute. Westlaw and Lexis Nexis and the comments and database at 39 Essex Chambers were also searched.

In the case of W City Council V Mrs L (EWCOP 20 2015), the potential for a deprivation of liberty to occur in a private home was considered. The case raised the issues of (a) whether Mrs L's care arrangements constituted a deprivation of her liberty; and (b) if so, whether the State was responsible for such deprivation of liberty; and (c) if so, then whether the Court should authorise such deprivation of liberty and what the arrangements for continuing authorisation should be.

Mrs L was a 93-year-old lady with Alzheimer's disease. She lived in a first floor flat. She had left her flat on a previous occasion and walked away from her home in inappropriate clothing. Following this, fencing was installed around her garden, and a new gate was installed. She was able to leave the flat, but the garden gate was difficult for her to open. There was also telecare in place to ensure that her daughter was alerted if she left the property at night. It was held that while the arrangements constituted restrictions on Mrs L's liberty, they did not quite meet the standard for a DOL. The judge held that the level of family involvement was such that any deprivation was in any event not imputable to the State. The family's strong role diluted this state input in the form of a care package.

The issue of how a private deprivation of liberty could be imputable to the State was contained in the judgement in the case of Staffordshire County Council v SRK & Another

[2016] EWCA Civ 1317. A financial settlement had been made in a personal injury action for a claimant who had a head injury. This settlement was subsequently approved by the Court of Protection as the claimant lacked the capacity to make decisions relating to the settlement. The knowledge of the settlement that the Courts acquired through this approval meant that although the claimant was residing in his own home with a private care package, an authorisation for DOL was sought and granted. The State does not have direct responsibility because of a local authority investigating an alleged deprivation of liberty, or by the actions of the CQC: "Such steps are part of the supervision and regulation of private providers of care and do not found a sufficient direct participation by the State as a decision-maker, provider or otherwise in the creation and implementation of SRK's (private) deprivation of liberty within Article 5" (para 131). The State can be responsible because of direct involvement with the individual and knowledge that there has been a failure to comply with positive obligations under Article 5 ECHR. It was also noted in the judgement that section 64(6) of the MCA (2005) made it possible for a deprivation of liberty to occur in a private setting.

2.11 Discussion

2.11.1 Safeguarding

An overly protective family may restrict the freedom of the person they care for, while a family less involved with their relative may afford greater freedom while failing to ensure such freedom is safe. Protection of people who have lost capacity may be dealt with as a safeguarding issue. The provisions of safeguarding in the UK are set out in the Care Act 2014. In the context of safeguarding principles, a lack of protection for an adult with care and support needs would be identified as a safeguarding issue. Under the Care Act, a local authority has a duty to make enquiries where there is reasonable cause to suspect an adult with care and support needs is being abused and neglected, or there is suspicion of abuse or neglect (Care Act s 42). To prevent someone from leaving their home has the potential to be a safeguarding issue. Carers allowing someone to leave their home in the knowledge that this may result in car accidents, falls, and getting lost may result in the attention of safeguarding.

Each local authority must set up a Safeguarding Adults Board, which is a multi-agency body to help and protect adults in its area (Care Act 2014). These boards have a duty to arrange for case reviews where there has been a serious safeguarding incident. There is a central registry of serious case reviews (Manthorpe and Martineau 2011), and no reviews were identified linked to the freedom for PLWD, and the level of risk and harm sustained due to families not restricting that freedom. Both within safeguarding and jurisprudence, there are limited data upon the impact of restrictions of freedom in a domestic setting.

The legal consequences of allowing freedom that is potentially dangerous have attracted less legal attention than the risk in an institutional setting. For example, prosecutions linked to PLWD leaving care homes unsafely are brought under the Management of Health and Safety at Work Regulations**,** which are applicable to employers' obligations while running a business. In 2012 Rose Court Lodge in Mansfield Nottinghamshire was prosecuted following the death of George Chicken. George, who had a diagnosis of dementia, left the home through a first-floor fire escape door, and fell down a set of concrete steps suffering a fractured skull and dying of his injuries two days after the fall. The home manager received a nine-month jail sentence suspended for two years. The company that owned the residential home received a £1.5 million fine. These statutes would not be applicable to PLWD in a domestic situation because their care was provided by a family.

Neglect by carers in a domestic setting may amount to a criminal offence under section 44 of the Mental Capacity Act 2005 (ill-treatment or neglect of a person lacking capacity). The number of prosecutions under the Act is described as extremely low (Samuel 2013, Preston Shoot 2017). In the alternative, there is a theoretical risk of a carer depriving a PLWD facing civil or criminal action, if they prevent the person, they care for from leaving. The law commission acknowledged the difficulties of addressing confinement where there is no direct state involvement (Law Commission 2017). The person concerned may be able to bring a claim in tort (a civil wrong) for false imprisonment. This tort would not apply to a person who did not by their actions express or manifest a wish to leave their home or was not aware that they would be prevented from leaving if they attempted to do so (Purpura 2013). An acceptance that neglect may masquerade as freedom justifies the inclusion of potential safeguarding issues within the assessment. Safeguarding teams may also be involved if there is overly restrictive care and, in the absence of a formal judicial process, may be involved in ensuring freedom.

2.11.2 The Acid Test in a domestic setting

The number of people who the law deems are deprived of their liberty has been increased because those who are not actively seeking freedom are included in those who are deprived of their liberty. In Cheshire West, Lady Hale stated, ". We should not let the comparative benevolence of the living arrangements with which we are concerned blind us to their essential character if indeed that constitutes a deprivation of liberty" (Page 15 para 35 P v Cheshire West). The acid test does not distinguish between those actively trying to leave and those who are not. In a dissenting judgement in the Cheshire West Case Lord Clarke did not agree that the parties, in that case, had been deprived of their freedom, instead of finding that restrictions upon their lives were dictated by their own cognitive impairments. The limitations upon autonomy and freedom of movement were for their own protection rather than done with the purpose of restricting their liberty. Lord Clarke argued that authorising the purported DOL made no difference to the care of the applicants. If the authorisations for a DOL make no difference to the care of the person who has restricted freedom, then the law affords limited benefit in these cases. If the person is apparently content in their own home, but their freedom is restricted, It is difficult to anticipate how such situations would come to the attention of health or social care professionals who may begin the process of authorisation for a DOL. For situations where the family or friends provide care and are already under significant pressure, there may be no realistic possibility of such an approval enhancing the level of freedom of the PLWD.

2.11.3 Implementation of the LPS

How the LPS will be fully implemented cannot be set out as this time as the guide to implementation is awaited. It appears however that initially deprivations of liberty will be authorised through health or social care providers, with a route of appeal to the Court of Protection (Griffiths 2020). The guide to the implementation of the liberty protection safeguards is awaited. A private DOL may arise if a carer is continuously present and dependent on the degree of supervision and control exercised. A DOL may occur in the absence of a care package or any form of state funding. Of the 650,000 PLWD in the community, up to 30% will leave their homes and become lost at some point (Rowe et al 2010, Rowe et al 2011, Pai and Lee 2016). This may impact their future freedoms, and for those with concerned carers, freedoms may be restricted. There is no overall way to establish the proportion of people with a DOL imputable to the State who are referred to the Court of protection for approval of the DOL through the route of a welfare order (Series, Fennel and Doughty 2016). However, from the limited jurisprudence, it appears that it is an exceedingly small proportion of those PLWD for whom liberty may be restricted. This may not change when the LPS are implemented, resulting in variable legal protection for the rights of those who live with dementia.

2.11.4 Rights of Appeal

It is intended that the authorisation process under the LPS should counterbalance the powers of health and social care professionals (Law Commission 2017). This may be of greater importance when the person lacking capacity remains in their home cared for by an unpaid carer. In these instances, it may be more important that a carer can access rights of application and appeal to the Court of Protection. It seems unlikely that such rights of appeal and participation will be fully achieved under the LPS. In practice, the route of applying for a welfare order is currently inaccessible to the person lacking and their family (Series Fennel and Doughty 2016). Court of Protection health and welfare proceedings offer limited opportunities for the participation of the person of who lacks capacity (Series Fennel and Doughty 2017). In the absence of a clear legal appeal pathway for those carers who may be concerned about decisions made regarding the freedom of a PLWD, these decisions will rest with the clinical or health staff familiar with implementation routes rather than carers. If appeals to the Court of Protection provide a familiar and well-trodden mechanism for these decision makers to achieve their aims, there is little chance for carers and those living with dementia to participate in appeals against the decisions of health or social care professionals.

2.11.5 Resource Implications

An inquiry by the House of Lords Select Committee on the MCA described them as 'not fit for purpose,' finding that the safeguards were sometimes used to control the person who lacked capacity rather than facilitating their rights. Over 70% of applications were not approved within the statutory time limit. The system to authorise DOL was unable to cope under the strain of the increased number of applications. The Liberty Protection Safeguards is intended to introduce a proportionate means of authorising DOL. It is part of the safeguards that people lacking capacity and deprived of their liberty with a stable condition will require a review of authorisations of that deprivation every three years rather than annually. In addition, the authorisation under the LPS can be carried from setting to setting (MCAA 2019). This would potentially reduce the need, for example, for a hospital to make a fresh application to authorise a DOL for care home residents. Despite these welcome reductions in resources, the LPS will be expanded to 16- and 17-year-olds creating an additional need for resources (MCAA 2019). The LPS will impose fresh demands upon health and social care rather than a legal structure that has creaked under the weight of the DOL provisions.

2.11.6 Potential assessment role.

Chapter one identified literature linked to the demands of providing care. The difficult balance between freedom and safety was introduced. An application for authorisation of a DOL could be prevented if the freedom of the PLWD is enhanced. An assessment that supports carers may provide a welcome contribution in balancing problematic decisions regarding risk and freedom. A potential legal challenge regarding the safeguards is that unpaid carers cannot be compelled to facilitate freedom. There is no contractual basis upon which family carers could be compelled to ensure the PLWD is able to leave their home safely. In addition, in a shared domestic setting, a locked door may be for the benefit of residents other than the person living with dementia. It is difficult to envisage how a right to freedom for the PLWD could be weighed against the concerns about the personal security of other family members. In the event a carer lives with a PLWD, it would be open to the carer to argue that they had a legal entitlement to lock doors in their own home. An assessment that includes the perspective of carers and highlights the benefits of freedom will provide a route for negotiation with carers who cannot be legally compelled to facilitate freedom.

2.12 Summary

The chapter has set out the development of the law linked to DOL and an overview of the legal position in the domestic setting. It remains to be seen how the implementation of the LPS will be framed. No definition of freedom is contained in the LPS. A potential definition of liberty would underpin this assessment and ensure freedom beyond that afforded by a legal remedy. By ensuring this freedom, the assessment may reduce the need for any authorisation under the LPS, thereby enhancing freedom beyond that required by law.

3 Chapter Three - Epistemology and Philosophical definition of freedom

3.1 introduction.

To aid clarity, this chapter is divided into two sections. The first sets out the epistemology chosen; this section outlines how the philosophy of pragmatism informed the research methods. This chapter will then explore the philosophical definition of liberty and the links between philosophical debates relating to liberty and the freedom of PLWD. These concepts will be developed in the context of the clinical literature and the philosophical concepts of relational autonomy. The ethics of depriving PLWD of their liberty will be considered from the perspective of ethics of care.

A theoretical model of freedom will be developed, which will inform the questions in the interview phase of this research in chapter six of this thesis. The data obtained in that phase will be used to amend the proposed theoretical model of freedom for PLWD in this chapter. The model potentially provides new meanings to older philosophical concepts using historicism, a structure for updating philosophical concepts. This model provides a theoretical background through which clinicians can understand the freedom of people who live with dementia in the context of relational autonomy. This will support the clinical reasoning of OTs in carrying out the assessment of freedom. Also, the model will provide a shared language and understanding of what freedom may mean.

3.2 Aims and objectives of this chapter.

Aim.

1. To begin developing a theoretical model of freedom for people living with dementia.

Objective.

1. To set out the underpinning epistemology of the doctoral research.
2. To describe a philosophical definition of freedom.

3.3 Methodology rationale

Philosophy may provide a method of understanding the knowledge claims that underlie research methods. Epistemology is defined as the philosophical enquiry into the nature and scope of human knowledge, including the distinction between genuine knowledge and belief (Benton and Craib 2011). An epistemological perspective is concerned with what can be known and how the researcher’s perspective impacts upon the creation of knowledge. Different research methods vary in their assumptions about what can be known and the construction of knowledge (Guba and Lincoln 2005, Mertens 2012). These assumptions may impact the methodology of a study and the methods used to address the research question. Implementation of methods without philosophical clarity may lead to ambiguities in research purpose and findings (Feilzer 2010). A philosophical perspective provides a structured methodological framework that gives coherence to the chosen methods (Guba and Lincoln 2005). Accordingly, there is a need for philosophical clarity to identify the researcher's epistemological and ontological interpretation of method and methodology.

To develop FREEDEM, the interventions and assessments which may facilitate research participants views of freedoms will need to be identified. To have a breadth in elements of the assessment and model, a mixed methods framework is adopted. The philosophy of pragmatism underpins the research methods. Mixed Methods Research (MMR) has been linked to the philosophy of pragmatism because there are multiple ways to define a truth, which can be linked to practical solutions to social problems (Hall 2013). Pragmatism is concerned with the world that an individual inhabits and the selections of meanings and outcomes that make the most sense (Biesta 2010a). Pragmatism focuses on what makes a difference and what works (Malachowski 2010). This philosophy originated in the United States around 1870. The first generation of classical pragmatists included Charles Sanders Pierce and William James, who developed and popularised pragmatism as a philosophy. Initially, pragmatism focussed on the nature of meaning and truth (Rorty 1979). The second nineteenth-century classical stage of pragmatism led by John Dewey was influential in applying this philosophy to areas as diverse as social improvement and education (Haack 2006).

A further fundamental element of pragmatism is the rejection of dualism. In philosophy, this divides reality into two independent principles, particularly mind and matter. Dualism is the philosophical position that mind and body are separate from each other and that mental phenomena are, in some respects, non-physical in nature (Rorty 1979). Dualism is described as assumptions about the physical world and why this is different from the world of the mind. Pierce rejected dualism and instead set out the pragmatic maxim, 'Consider what effects which might conceivably have practical bearings, we conceive the object of our conceptions to have. The goal of enquiry is to justify the beliefs developed, and there is then no further question relating to their truth' (Pierce p239 1968). From its origin's pragmatism has been concerned with what is tangible and practical. However, the use of pragmatism in the context of mixed methods needs to be justified as otherwise, it may be unclear how pragmatism guides enquiry and interpretation of data. The identification of pragmatism as a philosophy may otherwise be superficial and simplistic and based on a 'what works' philosophical position (Johnson and Onwuegbuzie, 2004, Feilzer 2009).

Pragmatism languished in the mid-20th century until the revival by contemporary pragmatists (Malachowski 2010). It is the philosophy of the contemporary pragmatist Richard Rorty which informs this thesis. In terms of neo pragmatism in Philosophy and the Mirror of Nature (PMN), Richard Rorty set out a deconstruction of modern epistemology. He argued that the central problem of modern epistemology relied upon a concept of the mind as mirroring an external reality mind independent reality. Rorty rejected this and instead argued that knowledge was understood once we recognised how society defines a belief. What Rorty offered as an account of knowledge was an ability to criticise and revise our view of the world through the development of language. Knowledge is achieved when we understand the social justification of belief and thus have no need to view it as accuracy of representation. (1979 p170).

Rorty did not accept that there were central truths independent of the human mind that corresponded to reality. Instead. truth was best perceived as that which can be agreed upon by public discourse; this discourse has the power to increase human solidarity. Within this discourse is the potential to form and develop a range of beliefs Rorty also rejected foundationalism epistemology. Foundationalism is a view about the proper structure of one’s knowledge or justified beliefs. Some beliefs are known or justifiably believed only because some other beliefs are known or justifiably believed. Rorty questioned whether claims to knowledge could be traced to a set of foundations. He objected strongly to the concept that philosophy could ever be foundationalist and offered no privileged insight into knowledge.

Rorty argued that research should not aim to provide an accurate account of how things are in themselves but rather aim for utility. This leads to pluralism as there is no single right answer, but there can be categories of experience that may be identifiable and shared. Pluralism has been defined as accepting a multiplicity of realities in contradiction to dualism, which has been rejected by all strands of pragmatism (Malakowski 2010).

Howe (1988) identifies that researchers need not choose between competing philosophical perspectives or research methods in accepting this version of the truth. Howe rejects this false dichotomy between research methods and instead promotes pragmatism as an alternative view so that researchers may move past questions and conversations about ''whether combining positivistic and interpretivist elements is legitimate to how this combination can be accomplished'' (Howe p. 14). Pragmatism then forms a bridge between different research traditions allowing for the incorporation of qualitative and quantitative methodologies.

Pragmatism has been linked to mixed methods as a justification for combining research from a qualitative and quantitative tradition on the basis that pragmatism allows for multiple truths rather than a single truth (Biesta and Burbles 2003, Biesta 2010). No single view of reality accounts for all phenomena. Pluralism allows for differing viewpoints rather than an assertion that there is only one truth. Both objective and subjective inquiry attempts to produce knowledge that best corresponds to, or represents, reality (Rorty, 1999, p. xxii). This then does not assert quantitative and qualitative methods are the only research methods that reflect reality or create knowledge in isolation, and both methods may be incorporated into answering a research question. To develop FREEDEM, the interventions and assessments which may facilitate these freedoms will need to be identified. To have a breadth in elements of the assessment and model, a mixed methods framework is adopted. There are three distinct groups of participants in the interview stage of this study. It is accepted each group and individual participant may define their lived experience differently. Patterns of experience may, however, be identified. Issues relating to freedom occur in a social context including the relationship between carers and those who live with dementia.

3.3.1 Critiques of relativism

The primary charge against neo pragmatism and particularly Rorty is that of relativism. Pluralism offers a potentially endless range of realities and values. This recognition and acknowledgment of differing perspectives and values mean that there is potentially no distinction between right and wrong (Gary 1998, Malakowski 2010). Relativism professes to understand all. Thereby resulting in potential moral stagnation as there is a lack of conflict and debate, which may reduce progression and development at multiple levels (Gary 1998, Sandiou 2018). Rorty argues this pluralism of values is freedom and a way of identifying multiple perspectives that may address social problems. However, pluralism potentially avoids challenges between differing perspectives without a need for justification of the values adopted. To address this, Rorty argues that projects of individual self-development should occur in the private sphere. Any values held which result in cruelty to others or a denial of their rights cannot be justified (Rorty 1989).

While pragmatism can be critiqued for allowing multiple viewpoints. The link between pragmatism and pluralism does not exclude shared descriptions of experiences and values. Shared meanings and categories of experience can arise and be identified through varied research traditions. (Biesta 2010, Mertens and Hesse Biber 2012). In keeping with this, the researcher commences the research with some knowledge of the research context but remains open to a new experience that develops through participants.

3.3.2 Methodology and Reflexivity

Reflexivity is tied to the production of knowledge. It is not a method but could be perceived as an approach that ensures good practice throughout the research process. The researcher's relationship to the topic, including their history and preconceptions, can give rise to the investigation into the nature of enquiry (Mruck and Breuer 2003, Holmes 2010). Knowledge and understanding are grounded in the history and culture of the individual. This mirrors the neo pragmatism view that questions regarding reality and knowledge production need to be identified through a historicist lens. That is to say that we are products of a particular time in history. (Rorty 1979). As knowledge is situated, theory develops in a cultural, social, and historical context (Hardaway 1998). Reflexivity has a second layer that researchers are also a product of their personal history. This is linked to our interactions 'our subjectivity becomes entangled in the lives of others' (Denzin, 1997: 27) both the researcher and participant are products of a social world, and the intersection of the two creates new knowledge. The role of reflexivity is partly to enable the researcher to have insight into her own cultural, social, and historical context and how this may impact the methods of recruitment, data collection, and interpretation (Williams and Morrow 2009). Reflexivity has been used to examine the overall research question and aims. This thesis's introductory chapter contains reflections upon the law and how personal views regarding the LPS have developed from a reflexive position.

3.4 Isaiah Berlin’s positive and negative liberty

Within pragmatism, there is no central debate upon how freedom may be defined. The seminal debate regarding liberty has stemmed from Isaiah Berlin's work upon positive and negative liberty (Berlin 1969). Philosophers including Kant and John-Stuart Mill theorised upon the meaning of freedom, but within a 20th-century context, Isaiah Berlin examined, defended, and expanded the concept (Ignatieff 1998, Putterman 2006). Berlin was from a Latvian Jewish family and moved to the UK at eight years of age. He was an undersecretary in the British Embassy in Washington DC during the Second World War, and this experience informed much of his written work. He was horrified by Nazi ideology but was equally critical of communism. He considered that philosophy had a political role, and the rejection of comment on current political affairs could contribute to nationalism (Ignatieff 1998). 'When ideas are neglected by those who ought to attend to them--that is to say, those who have been trained to think critically about ideas--they sometimes acquire an unchecked momentum and an irresistible power over multitudes of men that may grow too violent to be affected by rational criticism' (Berlin p192. 1969).

3.5 Freedom and Pluralism

In common with the pragmatists, Berlin did not regard philosophy as producing fundamental universal truths. He considered the role of philosophy was to consider the organisation of experience. These categories of experience shape our sense of the world. These experiences and the categories that develop are not pre-determined. Berlin (1958, 1969) was opposed to determinism (the argument that human beings do not possess free will and their thoughts and actions are pre-determined by forces over which they have no control). Berlin was concerned with pluralism, which ensured individual choice and respected dignity. A pluralism of values was intrinsic to Berlin's ideas (Hardy 2002). These systems of value are ‘beliefs about how life should be lived, what men and women should be and do’ (1990, p1–2). There are multiple values that may conflict, but which are not wrong. Values are human creations.

Pluralism accepts the existence of multiple potentially conflicting values. Individuals may be faced with conflicts over values, but there is not a single correct choice. A choice may serve these values while conflicting with other values that are no less important or interests that are neither more nor less true and important. Berlin (1967) identified that liberty as a value may conflict with other values. Such conflicts are the essence of being human and to avoid such conflicts in favour of a more unified and less complex construction of reality is to deny the world we know. He accepted that the realisation of some values must involve the sacrifice of others (Hardy 2002). While recognising this compromise, Berlin was influenced by humanism and held that avoiding harm to humans is the first moral priority. This pluralism was guided by liberalism: 'The first public obligation is to avoid extremes of suffering.' He insisted that moral collisions, even if unavoidable, can be softened, claims balanced, compromises reached. The goal should be the maintenance of a 'precarious equilibrium' that avoids, as far as possible, 'desperate situations' and 'intolerable choices (1990 18-19). There is, within this pluralism, a moral viewpoint that some values are intrinsically good and universally valid. Liberty, for example, was a genuine value for all human beings. This pluralism is central to ideas about liberty as providing for freedom of choice. This freedom links to the concept of free will. Free will involves the power of self-determination and the power to choose another course of action. The agent themselves must choose to act as if compelled; the action is not theirs. Positive and negative liberty represent a definition of this value. That freedom is an exercise of free will and choices deriving from that free will.

3.6 Philosophical Definitions of Freedom

3.6.1 Negative liberty

In Berlin's analysis, negative freedom is primarily concerned with external interference by external bodies or factors. Central to this is the absence of coercion by others. This is the external nature of negative liberty, the freedom from coercion and restrictions put in place by others. The concept of negative liberty has been broadened by theorists of liberty in an argument that it is achieved not only by non-interference with rights but by conditions that ensure non-interference is guaranteed (Skinner 1993, Shnayderman 2012*)*. Such conditions may arise because of laws, a bill of rights, a constitution, or a political structure that prevents an arbitrary exercise of power. This may include a separation of the powers of the legislative, executive, and judiciary function and citizens participating in society in a way that promotes civil and public order. On this view, negative freedom can arise only in a society with a political structure that guarantees the independence of its citizens (Neldin 2005)**.** This view contrasts with the liberal standpoint, which holds that freedom is a natural state and that law and political authority restrict freedom. From this perspective, negative liberty is enhanced by a reduction in state activities, particularly laws which impact freedom (Galston 2002, Crowder 2007).

3.6.2 Positive Liberty

Positive liberty is the fulfilment of individual purposes. Positive freedom is concerned with internal factors affecting the extent to which autonomy and free will can be practised by individuals or groups. Once a person is free of external constraints, their autonomy, and free will may still be restricted. The choice of activities or engagement in political or social groups of choice goes beyond the removal of external constraints. Autonomy is comprised of authenticity and competency. Competency includes the ability to process information, form intentions, and engage in voluntary action. Authenticity requires self-government in that a person's choices and actions are her own and are determined by her values, character, and desires. In the sense of authenticity and competency, autonomy is a facet of positive liberty (Christman 1988, Dworkin 1989).

Autonomy is linked to a culture of individualism in self-definition, law, and political structures (Dworkin 1998, Noddings 2004). In a Western context, autonomy has been defined as "the state and condition of self-governance or leading one's life according to reason values or desires that are authentically one's own." (Taylor 2017 p38). A negative definition of autonomy would identify that individuals are protected from intrusion by others, which then ensures that people make independent decisions. In the context of positive liberty, autonomy gives effect to the Western, post-Enlightenment idea that an adult person is a bounded individual who can live her life freely in accordance with her self-chosen plan and ideally independently from controlling influences (Dworkin 1988). Berlin’s perspective on autonomy was expressed as follows, “I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be the instrument of my own, not of other men’s acts of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes, which are my own, not by causes which affect me, as it were, from outside.” (Berlin 1958 p12). The reference to free will within this quotation represents the alternate element of positive freedom. Belin opposed the concept of determinism which would assert that actions and thoughts are pre-determined by forces beyond the control of the individual. Instead, Berlin argued that free will was inconsistent with determinism and fundamental to liberty. Freedom concerns not only the absence of intrusion but also individual effectiveness as an agent. Agency is the capacity of a person to act. Effective agency is manifested in internal or psychological capacities to govern oneself and in the ability to carry out wishes through action. A person who faces no restrictions in the form of intrusion or constraint may still be unable to act in any meaningful way if unable to carry out choices once the external constraint is removed (Berlin 2002).

The concept of positive liberty has polarised philosophers regarding the extent to which the state should be concerned about these internal factors (Pettit 1996, 1999). Positive liberty has been criticised as leading to the possibility of authoritarian rule. This concern has arisen from the concept of the divided self. The higher self is rational and capable of moral action and judgement. This rational and insightful self has also been defined as the true self. This self has been compared to a lower self, the self which may dominate in the case of basic needs (food, shelter, safety), addiction, or uncontrolled impulses. Positive freedom is achieved when the higher rational self is predominating, and choices are made rather than being driven by need. The concept of the divided self continues into the argument that some are more rational than others and know for others what is in their true interests (Berlin 2002 Simohny 2016). This argument can then be used to dominate others by telling them what they must do, supposedly for their own good.

Berlin (1969) identified and acknowledged how the concept of positive freedom could be distorted. He argued that there was a link between positive and negative freedom and that protecting the rights of the individual (negative freedom) avoided the potential for totalitarianism. Berlin considered that both autonomy and non-interference by both the state and other individuals were needed for positive freedom to be possible.

3.6.3 Are negative and positive liberty commensurable?

Negative liberty is described as *freedom from* the absence of constraints on the individual imposed by other people (Berlin 1967). Positive liberty is described as *freedom to* pursue and achieve willed goals. In addition, positive liberty is autonomy or self-rule rather than dependence (Berlin 1967). In a social context positive liberty continues to be a highly relevant concept. The concept of choice is integral to positive liberty. These choices may be dependent on context as social progress and technological advances may create opportunities which increase choice. Such choice can, for example, be exercised in the context of healthcare (Goodwin 2014). A lack of health funding would prevent the purchase of a range of technologies which could treat health conditions. This could then be perceived as a lack of choice. This progression in healthcare may however increase what could be perceived as governmental interference. This may occur in the context of government imposing constraints upon behaviours that are negative to health (such as banning smoking in public places) and increasing taxation to provide access to technologies. This situation represents both an increase in freedom thorough choice (positive freedom) and potential constraints upon freedom by increased government involvement in people's lives and restrictions upon choices through increased taxation and redistribution of wealth (Goodwin 2014). The conflict can also be clearly seen in relation to Covid -19 restrictions. Freedom from disease has restricted freedom to pursue activities of choice illustrating that positive and negative liberty may conflict and be incommensurable.

Alternatively, the supposed conceptual distinction between negative and positive freedom has created debate amongst philosophers. It is argued freedom (or liberty) is plastic and flexible and there are multiple ways in which elements of that notion could be conceptualised (Flathman 1987, Nelson 2005). Freedom cannot then be unpacked into positive and negative liberty and is a more complex and multi-faceted concept. This perspective argues that positive liberty is not conceptually distinct from its negative counterparts (Nelson 2005) and that liberty can always be understood in a negative fashion, with disagreements over its meaning amounting really to disputes over the meaning of "constraint." A conception of liberty can then be developed comprised entirely of negative freedom, that includes internal constraints that operate to prevent emergence of a true, authentic self from emerging (Nelson 2005, Christman 2005a).

Despite this, if freedom is perceived only as negative it is merely as a set of opportunities afforded by removing constraints from action and thought. If there is a lack of taxation and government investment in opportunities to develop the self this may give rise to injustice (Christman 2005a). Instead, such opportunities may be available only to those with the means to pay for potential choice such as private healthcare or education. Christman (2005a) argues that to fail to argue for both negative and positive liberty is to see freedom as nothing more than the removal of certain interferences. This ignores potential inequalities, and arguments for institutions concerned with redressing inequalities. Positive freedom is then a crucial component of the articulation of principles of justice and the resistance to certain forms of oppression linked to poverty and restricted choice (Christman 2005a 2005b).

The freedom and ability to make choices between values that may conflict is central to the morality of the individual. In this context, negative and positive liberty are values that must be balanced. Liberty may conflict with other values such as safety, security, public order, or the liberty of another. Berlin accepted (1967) that liberty might have to be restricted in some cases in the purpose of equality and justice to protect some sections of society or individuals against victimisation. This reflects the potential dispute between values within pluralism. Despite accepting situations in which liberty should be compromised, Berlin was intrinsically liberal in maintaining that individual liberty continues to be a political issue.

3.6.4 Liberalism

Liberalism as a political philosophy is linked to non-interference. This perspective favours individual liberty over the role of central government. A more extreme stance than liberalism is libertarianism; this stance opposes almost all economic and personal governmental interference in the life of an individual. For liberals at a political level, the state's role in enhancing positive freedoms is regarded as prescriptive and interference, which restricts rather than enhances liberty (Dworkin 1988, Christman 2005b Shnayderman 2012). The ideal is a reduction in state activities. This includes the involvement of the state in organising activities that are consistent with state aims. Such activities may exclude individual choice. Central to this concept of liberty is an absence of restriction or coercion. A liberal state would ensure such coercion did not occur. Liberalism is based upon some values which Belin recognised as universal (Berlin 1967). Within this viewpoint, autonomy, and an ability to act according to free will are integral elements of positive liberty. For Berlin, non-interference, and autonomy both comprised elements of freedom (Berlin 2002). While Berlin was broadly liberal, he accepted a state structure could be used to ensure negative liberty by legally protecting a zone of non-interference. He was on account of this relatively moderate in his liberal views.

3.6.5 Republican Freedom

In contrast to a liberal view, a republican conception of liberty as non-domination has been described as 'not living at the mercy of others,' 'not subjected to another's will' (Pettit 1996, pp. 576, 2003, p. 394). Republican power structures guarantee non-domination even if the individual is interfered with as those structures constrain the interference. Liberty can accordingly be equated with non-domination and a political structure. 'What constitutes domination is the fact that in some respect, the power-bearer has the capacity to interfere arbitrarily, even if they are never going to do so.' (Pettit 1997, p. 63) This leads to the role of law; within this republican tradition, just law makes us free regardless of the imposition of restrictions on our conduct as these laws prevent domination. The interference of law or social rules is acceptable if interference is not arbitrary. Pettit (1997) and Skinner (1993) argue that if someone else holds a power that is not exercised, this still represents a loss of liberty. Law is a central means by which there may be constraints upon such power and through which liberty may be achieved.

3.6.6 Tripartite freedom

A further definition of freedom is offered by MacCallum (1967). The subject is free from constraints to do, be or become certain things. This definition comprises three elements, an individual, conditions that prevent, and something the individual could be or do. Within this definition, MaCallum argued that freedom is always for someone; it is also freedom from potential constraint and is the freedom to do or not do something. There is a purpose within this freedom that is frustrated by the constraining conditions. A statement about freedom in this context will identify the agent, constraints, and limitations to freedom and the purpose for which the agent may seek freedom. This structure moves away from a positive or negative construction of liberty. Rather the emphasis may be upon specific aspects of the triad, not a negative or positive view. Berlin argued that it is not necessary to specify that a person need not know a purpose in seeking freedom. Rather, 'A man struggling against his chains or a people against enslavement need not consciously aim at any definite further state. A man need not know how he will use his freedom; he just wants to remove the yoke. So do classes and nations.' (Berlin 1953 p43).

3.7 Historicism

3.7.1 Hegelian Historicism

An updating of philosophical concepts is a form of historicism. Historicism holds that rather than there being a set of fundamental philosophical principles that human societies and activities are defined by their history. These activities and the society in which they occur can only be understood in the context of their history. Hegel also argued that societies both build on and react to what has gone before (Beiser 1993, Rockmore 2003). Berlin's philosophy was brought about by his background, choices, and circumstances. These personal circumstances, combined with the historical events occurring in the mid-20th century, shape his thoughts regarding liberty. Berlin's development of negative and positive liberty concepts was linked to how individual freedoms could be facilitated or denied by the structure and ideology of government. Using Hegelian historicism Berlin's concepts of freedom can be built on to encompass a current clinical understanding of legal, political, and social attitudes to the rights of PLWD.

The concept of positive and negative liberty also has a social and personal dimension (Christman 2005 a). To develop a model of freedom, it will be necessary to combine elements of political and social philosophy with literature related to people who live with dementia and their carers. While Berlin's theory of liberty sets out a structure for freedom, it is questionable whether this structure can be applied to PLWD without amendment. In the context of positive freedom, Berlin argued for freedom on the basis that he was 'a thinking, willing, active being, and bearing responsibility for my choices.' (Berlin 1958 p 17). He stated that he was able to explain these choices, 'by references to my own ideas and purposes. I feel free to the degree that I believe this to be true and enslaved to the degree that I am made to realize that it is not' (Berlin 1958 p17). As PLWD experience increasing cognitive impairment, they may lose the ability to plan, or rationalise choices using necessary information, or explain their choices (Star et al 2005, Budson et al 2008), but this alone does not amount to a justification for depriving someone of their freedom. The background to the development of concepts such as negative and positive liberty is rooted in sociohistorical circumstances. It could be anticipated that historicism would identify shifting attitudes to the rights of people living with a cognitive impairment through developments in language with consequent legal amendments.

3.7.2 Neo Pragmatism and Historicism

Within neo pragmatism a historicist view upon philosophy was developed by Richard Rorty. Rorty argued that philosophical problems might appear or change shape because of new assumptions or vocabularies (Rorty 1979). This interpretation of philosophy is historicist in that philosophy has no essential nature that separates it from social events. Rorty maintained that once Darwinian evolutionary theory was accepted, the only distinction between humans and animals was language. From this, Rorty identified that language forms a part of a linguistic, historical narrative. Rather than a focus on truth, the issue is one of a shifting development in culture and history led by linguistics (Rorty 1979). "Roughly, the ironist is a nominalist and historicist who strives to retain a sense that the vocabulary of moral deliberation she uses is a product of history and chance—of her having been born at a certain time in a certain place" (Rorty 1998. p307). Rorty defines an ironist as someone who is not metaphysical. By metaphysical Rorty means attempts to gain access to the true reality of things to discover the overriding truth to human existence. Identifying this overriding truth provides an answer to the knowledge of the mind and world and defines the nature of reality. The ironist challenges this concept and argues instead that knowledge and identity are contextual. This means that the development of law and language, and social attitudes occur within a context different from that Berlin experienced. To develop a current theoretical model, both language and current social attitudes must be incorporated for the model to be consistent with the current context within health and social care.

This time and place is one in which the rights of people with disabilities and language used to describe those people and their choices has developed in terms of a concern for equality and rights to ensure this. This has occurred alongside the development of a legal structure intended to provide a mechanism for the enforcement of those rights, such as the MCA 2005. This legal evolution has been accompanied by a change in social and political perspectives. The protection of human rights within Europe was in response to the human rights violations of the Second World War and the development of a human rights agenda that would avoid any repetition of those offences. The European Convention on Human Rights (1950) was then followed by legislation relating to discrimination on the grounds of race or gender (Race Relations Act 1976, Sex discrimination Act 1975). Legislation to provide protection to people who may be discriminated against on the grounds of disability (Disability discrimination Act 1995) culminating at a national level in the Equalities Act 2010 and at an international level in the United Nations Convention on the rights of persons with Disabilities (United Nations 2006).

Alongside these legal developments, there have been developments in language which have influenced professional and social views to the freedom of PLWD. For example, there has been a reaction to the use of the word 'wandering'. The term became less acceptable when the issue of using the term walking rather than wandering was raised in 2006 by the publication of 'Dementia walking not wandering – fresh approaches to practice' (Marshall and Allan 2006). This linguistic shift illustrates how our care for PLWD has become increasingly person focussed. The term wandering has come to be perceived negatively as it implies purposelessness. It is now argued that it should be understood PLWD may wish to walk, and this wish should be respected even if their purpose in doing so is not understood (Marshall 2006). This illustrates Rorty's argument that ‘Rational criticism of knowledge claims can only proceed on a historicistic basis, that is, in the light of the problems and existing social norms human beings possess during particular epochs. (Rorty 1979 p319).

3.8 The Theoretical Model

Potential areas of a new theoretical model will be identified in the following section of this chapter. The concept of negative and positive liberty will be combined with the clinical literature to produce a framework for the model. The concept of autonomy will be reviewed and addressed in the context of relationships with carers. The issue of ethics will also be addressed as there is an ethical issue in depriving a PLWD of their liberty. This ethical issue will be addressed within the relationship between the PLWD and their carer through ethics of care. The theoretical model will be represented by an image that incorporates the updated, philosophical concepts.

3.8.1 A Feminist Perspective?

Ethics of care originated within feminist theory (Gilligan 1982). This raises the possibility of a feminist element to the proposed theoretical model. This would require the identification of a type of feminism and the extent to which it could be incorporated into care. The adoption of a feminist perspective requires evidence that there is oppression or discrimination in terms of the type or amount of care provided by women with consequent economic or social disadvantage (Ashton and McKenna 2018). The last reliable UK data which might identify such discrimination concerning care was derived from the 2011 UK census (Office for National Statistics 2011). While overall, the gender gap in care revealed a higher proportion of unpaid care work carried out by women (2.9 % in England and 3.9% in Wales) in older adults defined as 65 years older or more, the percentage of men providing care exceeds the number of women. There is also evidence that men are less likely to seek support or services (McDonnell and Ryan 2013, Greenwood and Smith 2015) and that the number of very old carers (over the age of 85) is significantly weighted towards male carers. Women are more likely to give care but also receive care (Eurostat 2019). It would be difficult to sustain a feminist perspective upon care for PLWD in the light of these figures.

3.8.2 Dementia and Relational Autonomy

The idea that those who live with dementia are in a state of autonomy from those who care for them is inconsistent with the social, emotional, and financial interdependent and interrelatedness of those who live with the condition and those who provide care (Prince et al 2014, Ledgard et al 2014). Such a construct of individuality is contradicted by the dependence of those cared for upon their carer's and the mutual demands of the caring relationship. Furthermore, the capacity to have reflective thought is necessary for autonomy (Berlin 1969). Such insight may not be possible for those who live with dementia, meaning that autonomy within the sense put forward by Berlin cannot be achieved by those who live with the condition. Autonomy in the context of providing care can instead be perceived as having a choice of action (Nedelsky 1989, Westlund 2009). A PLWD must enjoy a significant range of viable options and retain authority over her social circumstances to be autonomous. Within this the person living with dementia maintains their choices and free will (Westlund 2009). Definitions of autonomy, which rely on self-guided reasoning and critical reflection upon choices, cannot be consistent with a cognitive impairment, which may impact upon reasoning and reflection.

A relational approach identifies that human beings are interdependent and interconnected. The self is defined by social relationships and structures such as families and social groups (Christman 2005a, Westlund 2009). This understanding of autonomy identifies that others do not only define us, but our choices and actions may be dependent upon them. Relational autonomy may facilitate freedom by enabling activities that would not be possible in isolation. People are at once defined and develop in the context of these relationships (Nedelsky 1989, Westlund 2009). This view of autonomy contrasts with a more traditional philosophical perspective of self-reliance and independence.

Relational autonomy does not comprise a single viewpoint, and there is debate regarding the definition of relational autonomy and the extent to which autonomy may be defined, facilitated, or undermined by social relationships (Westland 2009). A radical viewpoint regarding relational autonomy argues that the relational aspect is essential to a definition of autonomy. Such a definition is questioned on the basis that it implies social relationships necessarily enhance autonomy. Relationships with carers may be problematic and may limit as well as facilitate autonomy (Nedlesky 1989, Westland 2009). The autonomy of a carer may be reduced if they are unable to exercise freedom of choice or action because of their caring responsibilities. Combined with this, there may be a reduction in the autonomy of the PLWD both because of carer overprotectiveness and symptoms of the condition.

A caring relationship based on restrictions on the PLWD could be perceived as paternalistic. Paternalism within this context is defined as interfering with the freedom of the PLWD without their consent or against their will motivated by the aim of advancing their good (Benson 2005, Murgic et al 2015). While traditional philosophical concepts of autonomy may not be consistent with cognitive impairment autonomy does stand theoretically as a barrier to unchecked paternalism. Debates regarding autonomy extend beyond philosophy and impact ethical, political, and moral theory as well as legal freedoms (Sjostrand et al 2013). In the context of care for a PLWD, the ethics of depriving a person of their freedom are consistent with a branch of ethics that acknowledges a caring relationship, such as ethics of care.

3.8.3 Ethics of care

The branch of ethics that acknowledges relationships and dependencies is ethics of care. Carol Gilligan defines ethics of care as, “An ethic grounded in voice and relationships in the importance of everyone having a voice, being carefully listened too in their own right on their own terms and heard with respect (paying attention, listening, responding) and to the cost of losing connection with oneself or others (Gilligan 2011) Ethics forms a branch of moral philosophy, the area of philosophy which determines what is right and wrong in contexts including political, social and health decisions. In the context of a caring relationship, ethics of care developed from feminist theory and challenged an objective ethical viewpoint (Gilligan 1982, Barnes and Henwood 2015). This branch of ethics has been perceived as intricately linked to private areas of life, such as caring relationships between people linked by family or social ties.

Fundamental underpinning principles of ethics of care may lead to a recognition of relational interdependence, the maintenance of caring and just relationships that afford rights to both parties, and the beliefs that lead to respectful care (Petterson and Hem 2011 Murgic et al 2015,). A focus on social relationships, interdependency, and identity are specific features of care ethics that form the basis of a theoretically distinct concept (Held 2006, Engster 2007). The issue of care ethics also raises issues of how widely drawn such relationships should be. Does the theory require we adopt an attitude of justice to all people, or is it sufficient to extend to friends and family? The literature on carer stress renders this debate theoretical and unrealistic. The demands of care may be so extensive that there is not time, finance, physical or emotional energy to be concerned about issues other than those faced in the immediate caring relationship (Lacey et al 2012, Toot et al 2013, Prince et al 2014).

In the context of caring for someone who has dementia, there may be mutual care if, for example, an elderly person with limited mobility is caring for a cognitively impaired person with excellent mobility, but in much of the literature on the provision of care, this flows in only one direction, from the carer to the PLWD. Accordingly, a basic needs approach to providing care is used (Engster 2010). Care is defined as an activity which does not require the presence of any particular emotion, “everything we do to help individuals to meet their vital biological needs, develop or maintain their basic capabilities, and avoid or alleviate unnecessary or unwanted pain and suffering, so that they can survive, develop, and function in society” (Engster 2007, p28).

Relational autonomy and ethics of care are intrinsically related. Autonomy for PLWD is consistent with providing care that respects the fundamental right to freedom for PLWD. In most cases, care defined in keeping with care ethics flows in one direction, from the carer to the PLWD. At other levels, however, the ongoing maintenance of the cared for person may satisfy an emotional need, a need for continued company, and the fulfilment of an accepted responsibility on the part of the carer (McConaghy and Caltabiano 2005, MacWarren 2016). Consequently, there is a fluctuating interlinked autonomy and freedom set within the context of ethics of care, which underpins the issue of freedom for PLWD.

3.8.4 Carers and negative liberty

Carers may restrict the freedoms of the PLWD. This may be achieved by locked doors or constant surveillance (Robinson 2007, Bantry White and Montgomery 2010). Technology may also be used, including mobile phone apps and telecare technology, so that the PLWD is under continuous monitoring. Telecare technology may enhance watchfulness and increase anxiety by making carers constantly aware of the activities of the PLWD (Robinson et al 2009, Bailey et al 2013). This may then serve to increase the degree of carer anxiety and supervision. Restrictions to the freedom of carers may mirror those of PLWD. Constant supervision requires the carer also limiting themselves to the home or an area within it. If the carer leaves with the person living with the PLWD, they may have no choice about where they go being instead restricted to the location chosen by the PLWD. These situations create a potential intertwined loss of liberty. Berlin (1967, 2002) did not explore the issue of cognitive impairment and freedom. It is only by using historicism that the concept of negative liberty can be redrawn to encompass the shared loss of freedom of a carer and a person living with dementia.

The relational aspect of autonomy serves to reduce and potentially extinguish carers' negative freedom as there may be situations where a carer has no zone of non-interference by another person. What could be perceived as a zone of non-interference from others is lost if supervision and care must always be provided. For example, this could occur if a carer continues to ensure that a PLWD who attempts to leave unsafely has access to an unlocked door. This means that the carer must always be present as the PLWD may attempt to leave and requires supervision. It is possible that the situation faced by carers will differ depending on whether they live with the person with dementia. Interviews will explore the extent to which negative liberty is impacted on those who are resident with the PLWD and apart from them. In terms of negative liberty, the interviews will also explore whether the anxiety and watchfulness of carers who provide care at a distance impacts their negative liberty.

3.8.5 Carers and positive liberty

Positive liberty has been defined in foregoing chapters as linked to autonomy and free will. A concept of autonomy tied to independence and being a bounded individual is not consistent with the provision of care. Alternatively, there may be caring relationship where there is mutual dependence between the PLWD and their carer. In either event the reliance created by dementia is inconsistent with the concept of a bounded individual and more consistent with relational autonomy and ethics of care.

Choice is integral to the concept of free will. Within dementia, positive liberty may be restricted due to the progression of the condition as choices may be significantly reduced. Memory loss, anxiety (Matthews et al 2013), apathy (Ciprani et al 2014), or justified fear of falling (Algase et al 2007) are some components of the condition which may impact positive liberty. A carer may also be constrained from exercising choice to achieve any fulfilment of individual purpose by the demands of providing care. In these circumstances, the carer and cared for have an interlinked loss of positive liberty. The extent to which the positive liberty of both the PLWD and their carer will be linked to the progression of the condition and how this manifests itself. The positive liberty of the carer may be affected by a loss of employment, social interaction, and a decrease in choice of activities (Prince et al 2014). In terms of positive liberty, the interviews will also explore whether the anxiety and watchfulness of carers who provide care at a distance impacts upon their liberty.

Situations linked to positive liberty have been considered within which the person applying the restrictions is of a kindly and non-interfering disposition This interference is still detrimental to freedom (Pettit 1999). The apparent dominant party, the carer, also experiences a loss of freedom, which increases as the condition of the PLWD progresses, and greater assistance or supervision is required to ensure safety. It may also be that the carer will ensure the person living with dementia is able to attend activities, social and leisure activities they have always enjoyed. Such opportunities are consistent with a relationship-centred definition of care and may be opportunities for continued social inclusion and the maintenance of identity. During this time, they may be accompanied by a carer who at the same time does not have the freedom to pursue activities of their choice.

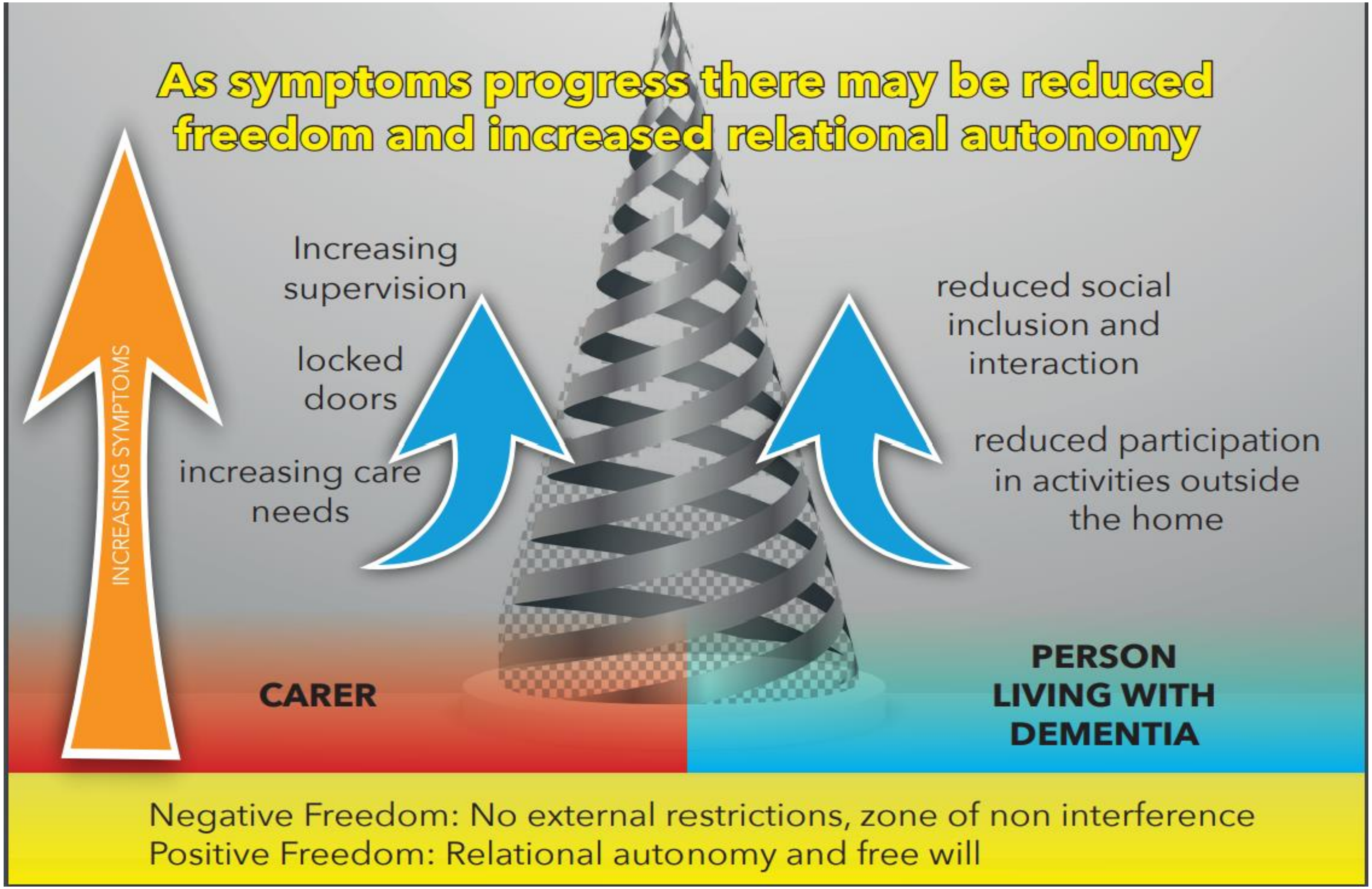
To extend the concept of positive liberty to PLWD also requires that a philosophical concept from political philosophy is applied to an individual situation. Christman (2005b) suggests that positive liberty can be construed as a concept that impacts individuals. This bypasses some of the liberal objections to the concept of positive liberty at state level. This concern about state involvement to facilitate positive liberty may be reduced when the concept is applied to an individual relationship between carers and PLWD.

3.9 Theoretical model and interviews

The provisional theoretical model is depicted in figure 7. The entirety of the proposed model will be challenged in the interview stage of this study. The interviews with PLWD and carers will collect data on whether the proposed view of negative and positive liberty is consistent with their lived experience. Participants will be asked to define freedom and comment on how dementia or providing care will impact freedom. The interviews will also ascertain whether autonomy is perceived as relational and whether ethics of care represents the ethical theory most consistent with the data. The semi structured interviews with staff will help identify the extent to which the model will support the clinical reasoning and conceptual views of freedom. The finalised model is intended to support the decision making of clinical staff working with carers and PLWD. The model will assist in identifying that freedom may be a shared concept in which the freedom of carer's and PLWD occurs within a relational framework. This understanding will facilitate the clinical reasoning underpinning the proposed assessment. The issue of freedom and the intertwined nature of freedom for PLWD and their carers can potentially be conceptualised more clearly through a visual representation.

3.10 Summary

This chapter has set out the underpinning epistemology of the research methods adopted. The importance of pragmatism in justifying a mixed methods approach is set out. Berlin's interpretation of negative and positive liberty has been identified and discussed. Alternative definitions of liberty have been identified. The role of autonomy as relational has been discussed. The theoretical basis of ethics of care is identified and linked to the provision of care for PLWD. The provisional model of freedom will support the development of the topic guides in that stage of the research. The interview questions and schedule will deal with issues around freedom and autonomy for PLWD and their carers. The interviews will identify views upon the law linked to freedom for people who live with dementia and whether this is consistent with a republican or libertarian perspective upon liberty. This data obtained from the interviews will be utilised to adapt the proposed model.



As symptoms progress there may be reduced freedom and increased relational autonomy

Negative Freedom: No external restrictions, zone of non interference
Positive Freedom: Relational autonomy and free will

4 Chapter Four - Literature review

4.1 Introduction.

A thorough understanding of the research evidence relating to assessments and interventions that may facilitate freedom is required to develop the assessment. The literature identified will be used to develop elements of a codebook, which will be developed further in the interview stage of this study. Freedom is defined in accordance with the principles of positive and negative liberty set out in chapter three. The purpose of this chapter is to collate the literature, which will form the basis of the assessment of freedom for PLWD. To achieve this, the rationale for the review and chosen method will be set out. This includes the methods for the literature search, which are identified and justified.

4.2 Review Methods

Literature reviews in research contain numerous methods to collect or synthesise data to further understand an issue. In recent years, the type of literature reviews has expanded significantly, and terminology linked to reviews has become complex (Strauss 2016a). This expansion of the categories of literature review has been brought about in part by the acknowledgement that different phenomena may need to be addressed by different forms of evidence and methods of synthesis (Pluye and Hong 2014, Pluye et al 2016, Strauss 2016 b). In a quantitative integrative approach, data would be pooled and summarised through statistical methods (Pluye and Hong 2014). In a qualitative review, interpretative approaches may be used to synthesise concepts creating a new understanding of concepts or phenomena. While systematic reviews remain the gold standard, if little is known about a topic and the breadth of literature is wide, the method may be overly restrictive (Strauss 2016 c). Each method has advantages and disadvantages, and the method should be selected based upon the question that is being asked. Grant and Booth (2009) set out a typology of literature reviews identifying the underpinning theory, strengths, and weakness of the methodology each of 14 types of review. Based upon these typologies, a scoping review was identified as most closely meeting the review's aim.

There is no single accepted definition of a scoping review or wholly accepted method (O'Brien et al 2014, Daunt Van Mosel and Scott 2013), but Colquhoun et al (2014) provided a broad definition. A scoping review or study is a "form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge (O’Brien et al. 2014). Scoping reviews differ from systematic reviews as an element of their function is to map available evidence rather than appraising methodological quality (Peters et al 2020). This provides a broader theoretical framework than a systematic review but may not achieve such depth. However, this broader framework allows for a diverse range of literature and methodologies (Arksey and O'Malley, 2005, Pham et al 2014, Peters et al 2020). The review seeks to identify interventions and assessments relating to the impact of a core concept, deprivation of liberty, which has potential clinical, philosophical, and legal implications. Accordingly, literature will originate within different knowledge bases. Consequently, a scoping review method was selected as the value of such reviews lies partly in bringing forward evidence from differing or heterogeneous sources (Peters et al 2020). This method allows for the inclusion of legal opinion and grey literature, which may contribute significantly to the assessment's development by providing a diversity of literature. The inclusion of such literature would not be possible in more traditional methods of review. Pham et al (2014) identified most studies used the framework proposed by Arksey and O'Malley (2005). The following steps have been selected as these are supported by both JBI (Peters et al 2020) and Arksey and O’Malley (2005). These are:

1. Formulating the research question
2. Identifying relevant literature
3. Selecting studies
4. Charting the data
5. Collating reporting and summarising the results and

6. Consultation which will in this research be carried out with patient and public involvement groups.

4.2.1 Research Question

The primary review question is:

What assessments or interventions facilitate or restrict the liberty of community-dwelling people who live with dementia?

Secondary questions are:

- What evidence is there of identified interventions being implemented by occupational therapists?
- To what extent can theoretically similar research methods bridge interprofessional boundaries between legal and clinical literature?
- What are the ethical and legal issues of the identified interventions or assessments?

4.2.2 Scoping Review Objective

The main objective of the review is to identify components that will be in the proposed assessment of freedom for PLWD.

Population Concept and Context

The research question is informed by 1) The population (PLWD who have carers). 2) Concept (Liberty) 3) Context (community-dwelling). To increase the relevance of literature identified, transparency and reproducibility terminologies are defined further. "Carer" is defined consistently with the Care Act (2014), an adult who provides or intends to provide care for another adult. An adult is not to be regarded as a carer if the adult provides or intends to provide care under or by virtue of a contract or as voluntary work. The context is the private residence of people who live with dementia. This excludes residential settings including nursing and residential homes and hospitals. Freedom is defined in the context of the philosophical structure identified by Belin (1968) and reinterpreted as an intertwined concept of negative and positive liberty, which includes the PLWD and their carer in chapter three of this thesis (paragraphs 3.10.2-3.10.5).

4.2.3 Inclusion criteria

The scoping review question and objective are inextricably tied to the MCA 2005, which contains the relevant legal framework regarding DOL The act is intended to assist and support people who might lack capacity and to discourage those who care for them from being overly restrictive or controlling (Great Britain Parliament 2014). The MCA provides a definitive anchor point of legal change in a time of debate over inclusion, empowerment, and participation of those who live with dementia. Accordingly, all empirical and theoretical peer reviewed and grey literature from the date of the act will be included that examines the research question from the key date of 1st January 2005, the year the MCA 2005 was made publicly availability, until the current day. The change in social and clinical attitudes to people who live with dementia means an earlier date may result in literature representing out of date practice. This would result in evidence inconsistent with inclusion and empowerment of those who live with dementia contributing to the assessment tool.

Specifically, each publication must:

(a) Be an empirical or theoretical publication from the clinical or legal literature containing an abstract and clear stated purpose.

(b) Include the concept of liberty and similar terms (Freedom, restrictions, social integration, and risk) in the context of dementia and the community.

(c) Contain (i) An assessment (ii) An intervention (iii) An evaluation of either or (iv) A comment upon the ethical implications or acceptability of the intervention or assessment.

(d) Grey literature will also be searched and included based on relevance. Grey literature and case law will be reviewed in the absence of an abstract.

Stages in the development of an intervention will be reviewed and included if meeting the inclusion/exclusion criteria.

4.2.4 Exclusion Criteria

All studies published prior to 01/01/2005, the year of publication of the Mental Capacity Act. Restrictions impacting upon publication such as accepted but not published/in press will not be applied. Clinical conditions other than dementia will be excluded.

4.2.5 Search Strategy Stages

4.2.5.1 Stage One

The initial stage involved a limited initial search of three online databases, MEDLINE, CINHAL and Lexis Law. CINHAL has been credited with containing qualitative nursing and allied health profession (Wright al 2014) whilst MEDLINE offers a more general health-based perspective. Lexis has an international element and is accordingly being used in the initial stage (Sampson et al 2009)

Search terms in stage one will include keywords and terms related to:

1. Dementia such as Alzheimer's disease, cognitive impairment, confusion
2. Keywords relating to carers to include family, spousal informal/unpaid care, carer stress.
3. Keywords linked to liberty to include liberty, freedom, risk, outdoor mobility, telecare technology, becoming lost, wandering.
4. Keywords linked to deprivation of liberty to include supervision, monitoring, locked doors, and restraint.

This initial search will uncover literature, which can then be analysed to develop search terms further. During this stage, law journals will be identified which may contain additional relevant literature that informs the scope of available research.

4.2.5.2 Stage Two

The second stage comprised an analysis of the text words contained in the title and abstract of retrieved papers identified in stage one and the index terms used to describe the articles Identified keywords and index terms are then used to carry out a second search across included databases. These keywords will include the interventions and assessments identified. Word strings were developed representing the inclusion criteria.

Terms within the strings were combined using Boolean operators, 'OR' to combine terms within groups or, 'AND' to combine groups. These groups are set out in figure four.

Population	Concept	Context
Dementia	Deprivation of liberty	Community
Alzheimer's disease	Supervision	Home
Vascular dementia	Monitoring	House
Lewy body dementia	Locked doors	Dwelling
Frontotemporal dementia	Restraints	Accommodation
Early onset dementia	Telecare technology	Family
Cognitive impairment	Wandering	Carer
	Safety	Environment
	Liberty	
	Freedom	

Figure four: Word strings

4.2.5.3 Stage three

For this stage, multiple sources, including professional peer reviewed journals, books, case law and statute were accessed through MEDLINE (OVID), University of Nottingham online catalogue, and CINHAL, EMBASE and Web of Science were searched. In addition, West Law, Lexis library index and Ingenta connect were used to identify legal documentation which could provide insights. Grey literature was located through the search for unpublished studies including conference proceedings, the websites of relevant organisations including NHS choices, the Alzheimer's society, and dissertations.

4.2.6 Selecting studies

A single reviewer screened titles and abstracts. Literature that clearly did not meet inclusion/exclusion criteria was excluded. A single reviewer identified the full text of potential articles and extracted the data. Duplicate studies were removed during this process. Studies were then screened using an extraction form set out in appendix 11.1. The extraction form was trialled with three sources and reviewed with the supervisory team. A second reviewer, a 2nd year PhD student then screened twenty percent of the articles using the same extraction form. The use of a second reviewer is suggested in the JBI methodology (Peters 2020). Disagreements were resolved through discussion. The identified literature was then discussed with the supervisory team and a total of 57 studies were included. This process is set out in the PRISMA flow diagram at figure five.

PRISMA 2009 Flow Diagram

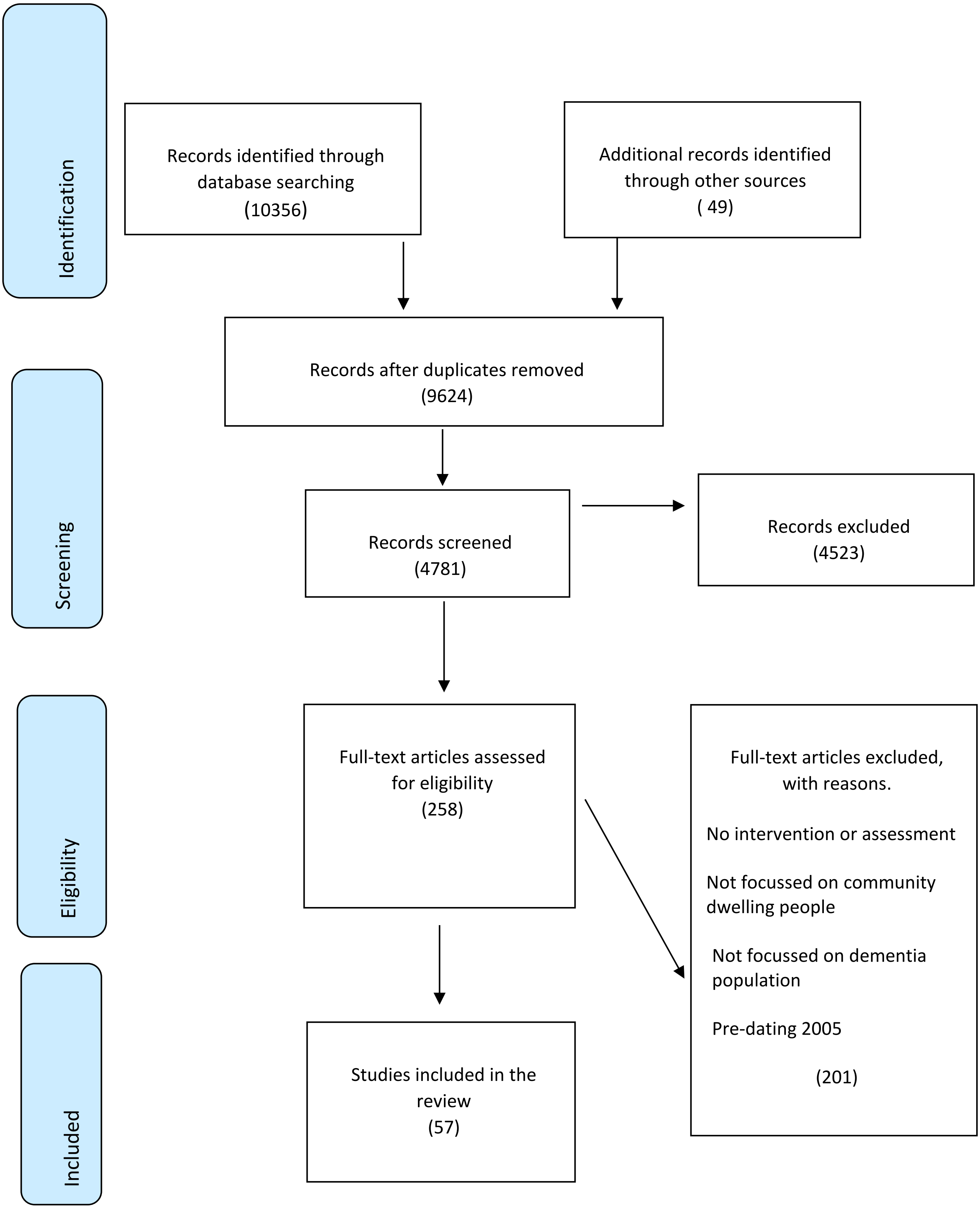


Figure Five: PRISMA Flow diagram

4.2.7 Charting the Data

Table three below sets out the articles by geographical distribution.

Continent/region.	Number of publications.
United Kingdom.	19
North America.	22
Europe.	10
Australasia.	3
South America.	1
Multi-national collaborations.	2

Table Three: Literature by geographical distribution.

4.2.8 Dates of literature

The literature spanned from 2005 until the end of 2020. Publication by year is set out in figure eight.

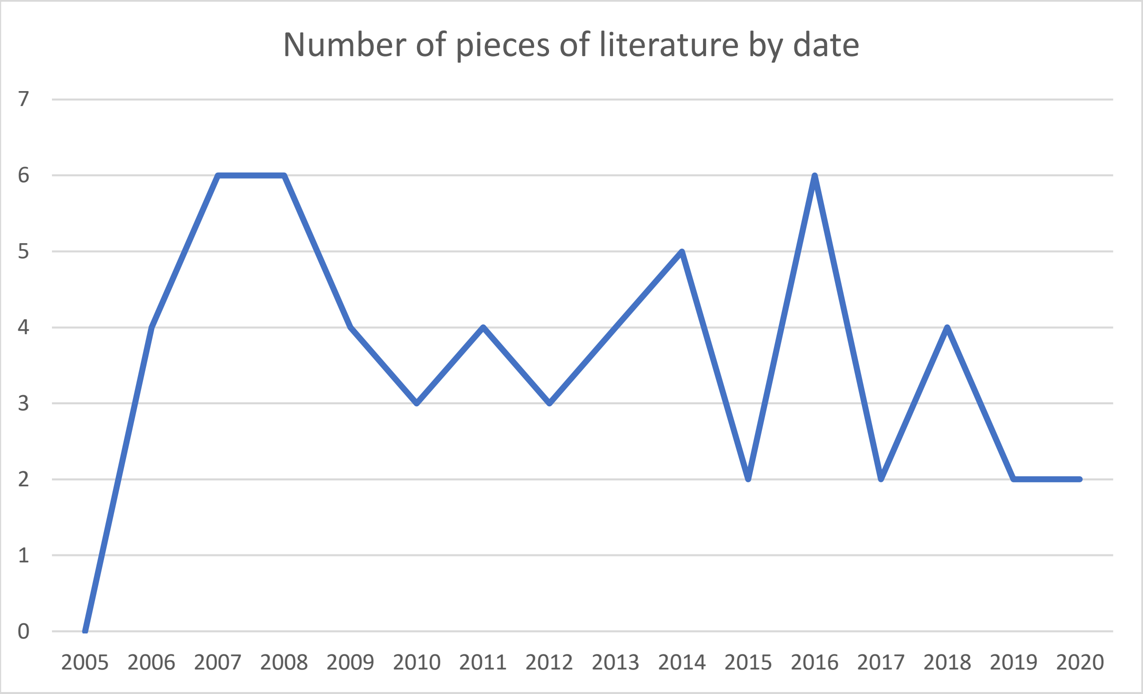


Figure Six: publications by date.

4.3 Findings

Literature identified came under the following categories, alert systems, telecare technology, driving, carer education, social inclusion, and risk assessment. For clarity, under the following results, the assessment/intervention, how it is related to liberty and which group has implemented the assessment/intervention is set out. Literature relating to any ethical debate is identified, followed by analysis of whether the literature consistent with the philosophical and theoretical underpinnings of the thesis. The legal literature is discussed separately.

4.3.1 Alert Systems

Alert systems comprise a variety of assessment/interventions designed to return a missing PLWD to their home if lost. Four papers considered ethical implications and described these systems (Carr et al 2010, Tobias, Wasser, and Fox 2013, Peronito et al 2017, Gengrerich and Davis 2017). One grey piece of literature was identified (Metropolitan Police 2020). This literature described the UK alert system of the Herbert Protocol. These interventions may be carried out before a PLWD leaves their home unsafely, or to locate them once missing and may provide reassurance that facilitates continuing community freedom.

An intervention of alerts was identified in the UK (The Herbert Protocol) and the United States (Medic Alert + Safe Return program, Project Lifesaver International PLI), and the newest Program, Silver Alert) (Carr et al 2010, Wasser and Fox 2013, Peronito et al 2017, Gengrerich and Davis 2017). The US National Silver Alert Act (2011) ensures a coordinated response to finding missing PLWD, including notification of the police and media with the intention that the public will also be alerted. Safe return uses a community network of the police and members of the Alzheimer's association together with a database of health issues and an identifying bracelet or necklace giving details of the person and their health condition. Project Lifesaver international uses a transmitter and tracking equipment as well as police notification. The Herbert protocol is a UK paper-based system containing details of the person's social and medical history and a photograph (Metropolitan Police 2020).

In the US, these interventions are implemented by private companies (Silver Alert, Project Lifesaver international), whilst medic alert and safe return is run by a voluntary agency (Peronito et al 2012). These interventions are also implemented by carers, healthcare professionals, those who run the companies, and those agencies responsible for searching for missing people (Peronito et al 2012, Tobias, Wasser, and Fox 2013). While in the UK, the grey literature identifies the Herbert Protocol is routinely used by British police forces in partnership with other agencies, including the NHS and Alzheimer's Society (Metropolitan Police 2018). It is unclear how effective these alerts are in finding those who become lost, or whether caregiver vigilance is the major factor in returning missing PLWD to their homes (Peronito et al 2017).

Four studies considered ethical issues relating to the alert systems. The primary objection is that of excessive levels of surveillance, which may compromise the freedom of PLWD (Carr et al 2010, Wasser and Fox 2013, Peronito et al 2017, Gengrerich and Davis 2017). Potentially the restrictions imposed are above the level required for safety. All four studies also identified that the restrictions were balanced against the risks if the PLWD left their home unsafely. No study identified any specific abuse of the alert systems, and all studies acknowledged the balance between the liberty of PLWD and the concerns of carers. These ethical concerns can be encompassed by the philosophical model adopted for this research as the alert systems may represent a restriction of the negative liberty of PLWD. The increased level of vigilance required of carers who do not use such systems will represent a restriction upon the negative and positive liberty of those who provide care and potentially a significant stressor for PLWD and their carers. There is no evidence that such schemes either facilitate or deny liberty to PLWD. The acid test would not be breached by the holding of personal data in a private home. Furthermore, the degree of supervision and control over the person who lives with the condition is absent once they are missing so no authorisation would be required.

4.3.2 Telecare

Telecare is defined as “support and assistance provided at a distance using information and communication technology. It is the continuous, automatic and remote monitoring of users by means of sensors to enable them to continue living in their own home "(Telecare Services Association 2018). For a PLWD, such interventions may comprise satellite tracking, which may allow a person to be located via GPS signals via a mobile phone, and infrared technology, which may identify if a PLWD has left or remains in an area beyond a designated period (Plastow 2006, Martin et al 2013). These physical devices may comprise mats that sound an alarm when stepped on, pressure sensors on beds and chairs to identify if the PLWD has moved in the home. Such interventions may enhance the confidence of PLWD in leaving their homes and contribute to remaining in their homes for longer. Two papers identified ethical issues (Plastow 2006, Dahlke and Ory 2020). Five qualitative papers were identified (Robinson et al 2007, Landau et al 2009, Bantry-White and Montgomery 2010, McCabe and Innes 2013, and Bantry-White and Montgomery 2014). Three quantitative papers were included (Pot et al 2010, Hattinck et al 2014, Forsyth et al 2019) and two mixed methods studies (Meiland et al 2012, Martin et al 2013).

The literature identified addressed GPS (Pot et al 2012, Bantry White and Montgomery 2010, 2014b, Innes and McCabe 2013, Meiland et al 2012 Landau et al 2010) and combinations of telecare interventions (Robinson et al 2007, Martin et al 2013, Mackenzie et al 2013, Hattinck et al 2016, Forsyth et al 2019). OTs are identified as involved in assessing for and prescribing telecare in opinion articles (Plastow 2006), but otherwise psycho geriatricians and social workers are mentioned (Landau et al 2010). Family carers felt the decision regarding GPS tracking should ultimately be made within the family, and only in the case of dispute should a healthcare professional be involved (Landau et al 2010, Bantry-White and Montgomery 2010, 2014a). Plastow (2006) was the only article that dealt with the ethics of the technology in the absence of any empirical research.

Two quantitative papers focused on the feasibility, effectiveness, and acceptability of the technology (Hattinck et al 2016 Pot 2012). Qualitative papers (Bowes et al 2018, Robinson 2007 Robinson et al 2009, Landau 2010, Bantry-White and Montgomery 2010, Martin et al 2013, McCabe and Innes 2013 Bantry-White and Montgomery 2014) and mixed methods (Mackenzie et al 2013) identified the ethical implications of the technology. The absence of quantitative research in this area has been identified in literature reviews (Davis et al 2013). It is unclear why the body of literature in this area is mainly qualitative.

Ethical debates arose around the balance between liberty and safety (Bantry White et al 2010, Bantry White and Montgomery 2014b, Laudau et al 2010). However, carers also supported covert usage for those who lacked capacity (Bantry White and Montgomery 2010). Within groups of health care professionals, the balance between risk and freedom was influenced by a fear of litigation (Robinson et al 2007). Whether relatives were more focused on freedom than professional staff varied between studies (Robinson 2007, Landau 2010). The ethical issues of covert usage and freedom being curtailed were debated in all studies. Further interesting ethical issues were identified by Dahike and Ory (2020) in the ability of PLWD and carers to access telecare technology due to issues of resource and technological ability in older people.

There was limited generalisable evidence of telecare technology's effectiveness in preventing PLWD from becoming lost or being found if they left home unsafely. This is a significant gap in the existing body of literature. However, all studies identified the potential for this technology to enhance the liberty of PLWD. The inclusion of an assessment of the potentially liberty enhancing elements of telecare would appear to be justified.

Telecare technology would potentially require approval under the LPS. The Acid Test would be breached if the technology were used to provide continuous supervision and control, and the PLWD was not free to leave by virtue of the technology. Whether a DOL had occurred would depend upon the duration, effect manner and degree, and intensity of any restriction achieved using telecare technology. However, the technology may also facilitate freedoms as families may be less anxious, and monitoring may decrease in consequence. Some family carers reported a reduction in stress as they felt able to relax supervision and allow greater freedoms. For PLWD, attitudes were mixed as some people felt safer and others under greater surveillance (Robinson et al 2007, Landau et al 2010).

4.3.3 Risk Assessment.

The issue of liberty for PLWD is combined with a potentially significant risk of harm. PLWD may experience risks from attempting to leave unsafely, such as falling and exposure (Hope et al 2001). Alternatively, there may be barriers to entering specific areas of the home or constant supervision due to safety issues relating to fire and electricity (Walker et al 2007, Rowe et al 2011 Harvey et al 2015). The interventions linked to risk are the construction of risk by health professionals, carers and PLWD (Clarke et al 2009, Clarke et al 2010, Clarke et al 2011) and the assessment of leaving unsafely and the harm caused to those who do. This literature centres on the Algase community wandering scale (AWS) (Algase et al 2007b), an assessment that attempts to predict the chance of PLWD leaving home unsafely and adverse outcomes. Literature relating to the wandering scale is quantitative (Algase et al 2007b). The broader assessment of risk is addressed in qualitative literature (Clarke et al 2009, 2010) and mixed methods (Clarke et al 2008). There is no evidence of any specific professional group carrying out the interventions. Clarke et al (2010) discuss health professionals in generic terms, and the wandering scale contains no specific recommendations as to which group of health professionals should use it.

Post 2007, the AWS has shown strong construct validity in an outpatient setting and takes 10-20 minutes to complete (Marcus et al 2007). A systematic review on the effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia was included (Robinson et al 2007) as ethical issues relating to the restrictions placed on those who live with dementia were explored. The issue of subjective adaptations to prevent a PLWD from leaving a day centre unsafely were discussed in a case study (Daza et al 2013). However, the ethical implications of the artificial barriers were not explored.

The balance between risks and freedom is central to the safe liberty of PLWD. The method of assessment of risk by health professionals and carers is integral to decisions about liberty. Clarke et al (2009) conducted focus groups with managers in health and social care and equivalent voluntary sector organisations focussing on identifying the understanding of risk by practitioners. In a symbolic interactionist qualitative study (Clarke et al 2010), the primary areas of risk were identified. Five contested territories arose from the data, friendships smoking, going out, domestic arrangements, occupational and activity. The participants were PLWD, carers, and practitioners. This second paper in the series recommends that risk assessment encapsulates the purpose and interplay of risk in contested territories. Clarke et al (2011) identified that the construction of risk might create an emphasis on physical safety, which is overly restrictive of the rights of PLWD. The study identified that healthcare professionals who participated were more skilled at assessing risk than facilitating independence. Their focus was upon the assessment of certain and concrete factors rather than a recognition that those who live with dementia are in a constant position of fluctuating function.

The search also identified a potentially highly significant policy document-nothing ventured, nothing gained (Department of Health 2010). This document provides advice on the management of risk and how this can facilitate independence. The document is lengthy and extremely broad, covering a wide range of potential risks in a variety of settings. The document is aimed at clinical staff and accepts the findings in Robinson et al (2007) that healthcare professionals are more likely to be over cautious in assessing risks compared to family carers.

In the context of assessment development, a balance between risk and safety is integral to the issue of freedom, given the risk to life or significant injury. The assessment could incorporate carers concerns about risk while also supporting the liberty of PLWD. It would be appropriate to consider both risks in a negotiated partnership incorporating relational and person-centred care. This would include an assessment of the risks of leaving unsafely together with carer strategy in the event this occurs.

4.3.4 Social inclusion

The diminution of the social world external to the home has been identified as a source of loss and stress for PLWD and carers (Judge et al 2009). As the condition progresses, a loss of friendships and social activities may be experienced, which results in increased isolation (Keyes et al 2016). However, PLWD have identified social and recreational activities as those which they would most welcome support in the initial stages of the condition (Chester et al 2016). Carers report that they are unable to access safe community spaces and appropriate social interaction for the person who lives with the condition (Innes et al 2016). This reduces the occasions on which the carer/PLWD dementia can leave their home. Maintaining such contact through social groups potentially increases the frequency of a community-based interaction, and the space itself may be suitable for offering appropriate activities and a calm, safe space (Keyes et al 2016). Two qualitative studies were identified (Schake and Zank 2006, Giebel 2016), a single mixed methods study (Willis Semple and De Vaal 2018) and four qualitative studies (Harris and Caparella 2014 Keyes et al 2016, Osman Tischler and Schneider 2016, Van Rijn, Meiland and Droes 2019).

The search identified five pieces of research containing interventions Harris and Caporella (2016) developed an inter generation choir to reduce the stigma of Alzheimer’s disease and social isolations. This intervention was intended to reduce the stigma faced by people living with the condition. Group singing was also identified in the context of Alzheimer’s society groups in a qualitative study (Osman, Tischler and Schneider 2016). Giebel et al (2014) identified the importance of social relationships to a sense of wellbeing in PLWD. The study aimed to amend the Interview for Deterioration for Daily Living Activities in Dementia, a validated instrumental activities of daily living scale (IADL) by incorporating social aspects. The study identifies that IADL were impaired to varying degrees and that impairments relating to social activities particularly relate to wellbeing in PLWD. Impairments in social function were linked to increased carer stress.

Willis et al (2018) identified the economic value of peer support for PLWD and informal carers in a social return on investment study (SROI). SROI is a form of economic analysis that collects data on the economic and clinical inputs and outputs and outcomes of an intervention, which becomes an SROI. The study considered three peer support groups to evaluate the social value of outcomes in relation to investment. A reduction in isolation and loneliness was a significant outcome for PLWD. Carers reported a reduced level of stress and a reduction in burden of care. In a qualitative study, Keyes et al (2016) identified the value of peer support groups in positive emotional and social impact, while Schake and Zanke (2006) identified a statistically significant reduction in carer stress from a day care programme for PLWD. Keyes et al (2016) identified the benefits of a peer support programme, which PLWD found supportive and understanding. The law commission have suggested that day centres could be incorporated into the care plan relating to DOL (Law Commission report 2017). These groups may sit within the voluntary sector. It is doubtful whether this statutory amendment has the power to compel independent companies to provide a service in the absence of any contractual obligation.

4.3.5 Carer Education.

Without the support of carers, many PLWD would be unable to remain in the community, thereby losing their homes and freedoms (Prince et al 2014). Nineteen papers were identified. The literature identified in this area was predominantly quantitative (fourteen papers) with no qualitative studies, two mixed-methods papers (Dam et al 2007, Chenoweth et al 2016), and one paper where the methods were unclear (Sarna and Thompson 2008). Literature in this area is comprised educational or psychosocial interventions in person or via the internet (Dam et al 2007, Gallagher-Thompson et al 2008, Chiu et al 2009, Van der Rost 2010, Smith et al 2011, Cristancho-Lacroix et al 2015, Van Mierlo et al 2015, Chenoweth et al 2016, Kurtz et al 2016) or phone (Winter and Gitlin 2006). Some interventions contained elements delivered face to face (Farran et al 2007, Sarna and Thompson 2008, Gavrilova 2009, Kurtz et al 2016, Pihet and Kipfer 2018) and an element of contact via internet platforms (Chiu et al 2009). One paper (Ducharme et al 2011) provided workbooks to carers that could be completed when convenient. Such interventions comprise information about dementia as a condition, management of challenging behaviour, support in decision making including the law, and emotional support. These interventions could also provide evidence about the benefits of continued community involvement and any legal duty to facilitate liberty.

In the context of assessment development, such interventions would provide support to carers and would also incorporate information about freedom and any legal duties the carer is placed under. The assessment may also support positive risk taking through the provision of information. In a 2018 mixed methods study, carers and PLWD identified their preferences information attributes (Chester et al 2018). Carers identified that information on coping with dementia and sessions dealing with feelings and concerns represented the main attributes preferred when the PLWD was in the early stage of the condition.

The interventions identified were varied, including coaching (Chenoweth et al 2016) and skill-building (Farran et al 2007, Gitlin et al 2008). Information focused on delivering interventions around providing advice about dementia, legal advice, providing care and managing problem behaviours (Sarna and Thompson 2007, Devor and Renvall 2007 Logsden, McCurry and Teri 2007, Dias et al 2008 Gavrilova et al 2008). Other interventions were delivered remotely. DVDs were used as an intervention to provide information about memory and communication with PLWD (Smith et al 2011, Liddle et al 2012). Online interventions provided details of services and information about caring for PLWD (Chiu et al 2009, Van der Rost et al 2010 Van Merlo et al 2015) Dam et al (2018) developed Inlife. Life is a tool for social support, and information could be used by both carers and PLWD. Only one study involved a dyadic component for carers and PLWD, this included exercise for the PLWD and skills training and coping strategies and skills in caring for carers (Prick et al 2016)

There was limited information about which professional group implemented the interventions. Doctors implemented the 10/66 intervention for carer givers purely because this was the group who could be accessed. The intervention comprises information and resources for carers in low- and middle-income countries (Gavrilova et al 2009). OTs and social workers designed the online intervention in Chiu et al (2009) and tailored activity programme (Gitlin et al 2008). In Farran et al (2007) nurses and social workers implemented the intervention. In Liddel et al (2012), the intervention was overseen by two researchers with either speech pathology or psychology qualifications Admiral nurses (Sarna et al 2008) and social workers (Winter and Gitilin 2006) were also identified as professional groups.

Online interventions are unlikely to be perceived as unethical, as are coaching and skill-building. The educational elements of the component could provide the opportunity to provide information about the liberty protection safeguards and the benefits of freedom and community inclusion for PLWD. The elements of individual coaching, training, and support have the potential to reduce carer stress and promote PLWD remaining with the community, thereby increasing their liberty.

4.3.6 Driving

Difficulties driving may be linked to a loss of understanding of signs, using the wrong lane, turning incorrectly, and becoming lost (Hunt et al 2010). These issues are a consequence of decreased visuospatial awareness and memory loss. In addition, a lack of insight into driving deficits and impaired judgement may cause road traffic accidents, while losing a licence may have a significant impact on the freedom and independence of PLWD (Carr and Ott 2010). All literature identified was quantitative other than two papers. The methods used in Byzuski et al (2013) were unclear, and a single qualitative paper was included (Stasiulis et al 2020). Identified literature subdivides into the correct method referring a patient for an assessment of safety to drive and the process of assessment and decision making to either voluntarily or compulsorily remove a licence. There is also a small body of literature relating to compensatory strategies and support for PLWD and their carers once a licence has been voluntarily or compulsorily removed. Referrals for formal assessment came primarily from Doctors (Ranchet et al 2005), whilst the driving assessments were carried out by OTs. They had often completed additional qualifications to provide specialist assessments (Eby et al 2011). An unknown proportion of PLWD will stop prior to any form of formal assessment and there is a legal requirement to report a diagnosis of dementia to the DVLA (Gov.UK 2018).

Literature included in-vehicle technology (Eby et al 2012), use of a standard note template for both driving and firearms (Lo Conte et al 2008), implementation and evaluation of a continuing education project (Meusner et al 2006), the distinction between fitness to drive decisions in on-road assessors and physicians (Ranchet et al 2016), guidelines developed from a consensus process (Versijpt et al 2017), and the development of a standardised road test (Lincoln et al 2009) and analysis of specific specialist tests of driving performance (Vella and Lincoln 2006, Lincoln and Radford 2012). A validation study Byzeuski et al (2013) developed a toolkit that clinical staff could use in conjunction with carers and the PLWD. A web-based driving cessation toolkit to support decision making for the decision to stop driving was developed by Stasiulis et al (2020). It is apparent that a degree of unreliability is present in the majority of assessments and assessment tools used (Ranchet et al 2016 Vella & Lincoln 2014), meaning that the correct assessment tool to use to decide on the safety of the PLWD is not clear cut. The literature in this area was almost exclusively quantitative except for Byzeuski et al (2013) and Stasiulis et al (2020).

During the assessment process, if the PLWD was still driving it would be appropriate to instigate the use of a toolkit. This could be used in conjunction with carers and PLWD acknowledging the joint nature of the decision to stop driving and the implications of the loss of freedom that the withdrawal of a driving licence may entail. Given the social impact of removing a licence for some drivers (Meuser et al 2006) and the significance of the safety issues for other road users and the PLWD, it is appropriate to involve assessing potential driving risks within the assessment process. The importance of driving in maintaining independence and freedom means that the development of alternative transport plans would also logically form an element of the assessment.

4.3.7 Legal Literature

It is notable that no empirical literature was identified from a legal perspective. The literature identified was doctrinal; this is research which states what the law is (Vibhute

& Aynalem 2009). Legal research may also focus upon a comparison of the law across different legal, geographical areas (Jurisdictions), whether the law is applied in practice, and the potential impact of law. All these forms of research are secondary, based upon documentation, and create a framework for enquiry that is unique to the law (Van Hoeck M 2013). This research tradition is entirely different to the research methods commonly used in health and social care research. An empirical research framework is also theoretically used within the law (Leeu and Smheets 2016), but the application of these methods is a new development within legal research. This may in part, account for the lack of relevant legal research. There is no methodological reason why convergence cannot occur. This is a potential area for legal/clinical research to develop further.

The silence of the legal literature has implications for the development of the assessment. Over twenty percent of MPs have been practising or academic lawyers (Hyde 2015), and a culture and understanding common to lawyers is likely to form a part of the thinking of MPs from other disciplines. The assessment will likely be substituted for a more reductionist approach to defining freedom unless dissemination is targeted at potentially unusual routes, including parliamentary structures, legal journals, and all parliamentary group on dementia.

4.4 Mapping of results.

The results of the scoping review are set out at Table three. The map is consistent with the recommendations of JBI (Peters et al 2020) but is also adapted to the purpose of this thesis. The map identifies the pieces of literature included in the review, the methods adopted, the populations identified, and the assessment/intervention or review of the effectiveness or acceptability of either. The exception to this is those papers that comment on the ethics of an identified intervention or assessment.

Table Four. Mapping results. Alert systems

Number of paper	Authors and date.	Location of Research.	Assessment/intervention.	Method.	Participants.
1	Carr (2010).	North America.	Silver Alerts.	Discussion of ethical implications.	N/A
2	Petonito G et al (2012).	North America.	Silver Alerts.	Narrative review and ethical implications.	N/A
3	Tobias, Wasser, and Fox (2013).	North America.	Silver Alerts.	Opinion. Ethical implications.	N/A
4	Gergerich E, and Davis L (2017).	North America.	Retrospective analysis of silver alerts.	Opinion and ethical implications.	N/A
5	Metropolitan Police (2018).	UK.	Herbert Protocol.	Grey literature information provision.	N/A

Telecare Technology.					
Number of paper.	Authors and Date.	Location of research.	Assessment/intervention.	Methods.	Participants.
6	Plastow (2006).	UK.	Telecare technology.	Opinion piece on ethics of telecare.	N/A.
7	Robinson et al (2007).	UK.	Telecare technology.	Qualitative study. Focus groups considering issues around the use of telecare technology and other interventions which restrict freedom.	Clinical staff social worker (N=1) Occupational therapist(N=1) Old age Psychiatrist (N=1) Clinical psychologist.
8	Bantry White and Montgomery (2010).	UK.	Telecare technology.	Qualitative study. Ten semi structured interviews with carers looking at the impact of telecare.	Carers (N=10).
9	Landau et al (2009).	Australasia.	Telecare technology as GPS and RFID.	Qualitative study. Four focus groups considering attitude to telecare.	Family caregivers (N=36) Voluntary group facilitators (N=20). Multidisciplinary health workers (N=12).

Number of papers.	Authors.	Location of research.	Intervention/assessment.	Methods.	Participants.
10	Pot, Willemse and Horjus (2010).	Europe.	Telecare GPS tracking.	Quantitative pilot study is focused on the feasibility, acceptability, and effectiveness of a three-month use of Global Positioning System (GPS) by care receivers and caregivers.	Dyads of carers and people living with dementia (N=56).
11	Meiland, et al (2012).	Multinational.	A new digital multifunctional device, the COGKNOW Day Navigator (CDN).	Mixed Methods semi-structured interviews and questionnaires for both the PLWD and carer. Observations of PLWD using the CDN, a diary and list filled in by the carer (meant to inventory problems and positive experiences in using the CDN).	Four to six dyads of persons with dementia and their informal carers participated in each of the three evaluation cycles at each test site. Field test 1 (N=16) Field Test 2 (N=12) Field test 3 (N=12).

Number of papers	Authors	Location of research	Intervention/assessment	Methods	Participants
12	McCabe and Innes (2013).	UK.	GPS tracking.	Qualitative study. Focus groups.	People living with dementia (N=12) carers (N=3) older people (N=5).
13	Martin et al (2013).	UK.	Novel telecare intervention for night-time needs promoting orientation.	Mixed methods semi structured interviews and device monitoring.	People living with dementia and their carers are participants Number unclear.
14	Hattink et al (2014).	Multinational.	The Rosetta multi-functional telecare device to promote orientation and social inclusion and safety.	Randomized-controlled trial (RCT) among people with MCI and dementia and their carer's. a pre-test–post-test control group design.	People living with dementia and mild cognitive impairment (N=30) and carers (N=30).
15	Bantry White & Montgomery (2014b).	UK.	GPS tracking.	Explored ethics of telecare in semi structured interviews with carers.	Carers (N=10).

16	Forsyth et al (2019).	UK	The ATTILA An assistive technology and telecare device to maintain independent living at home for people with dementia.	Randomised controlled trial of ATT assessment and installation, Intervention received ATT.	Intervention group (N=248) Control group (N=247).
Number of papers.	Authors.	Location of research.	Intervention/assessment.	Methods.	Participants.
17	Dahlke and Ory (2020).	North America.	Intelligent assistive technology.	Explores ethics of different types of technology. Literature review.	N/A.

Assessment of risk.					
Number of paper.	Authors.	Location of research.	Intervention/assessment.	Methods.	Participants.
18	Algase et al (2007).	North America.	Three versions of wayfinding effectiveness scale.	Quantitative study evaluating three versions of the Wayfinding Effectiveness Scale (WES), developed to differentiate problems of wayfinding, and wandering behaviour of community-residing elders with dementia (EWD), in 266 dyads.	Carers (N=133) reported as dyads (N=266).
Number of paper.	Authors.	Location of research.	Intervention/assessment.	Methods.	Participants.

19	Clarke et al (2008).	UK.	Development of a risk management framework.	Mixed methods. Questionnaires and comments to understand the construction of risk. Part of a larger project.	Respondents to the questionnaire were service/home managers (N=28), nurses (CPN, Registered Mental Health Nurses, clinical nurse leads) (N=7), other health care professionals (N= 2) and dementia care co-ordinators (N=2).
20	Clarke et al (2009).	UK.	Development of a risk management framework.	Qualitative study aiming to understand the construction of risk for people with dementia, their carers, and clinical staff.	165 interviews with people who live with dementia (N=55), carers (N=55) and nominated staff members (N=55).
21	Clarke et al (2011).	UK.	Risk assessment and management framework.	Qualitative study practice development research methods derived in part from action research reported here formed one part of a multisite multi-phase study.	The participants had a variety of professional backgrounds, including social work, occupational therapy, podiatry, and nursing. Numbers of each profession not specified (N=20).

Social groups

Number of paper	Authors	Location	Intervention/assessment	Methods	Participants
22	Schake and Zank (2006).	Europe.	Day care services.	Quantitative study longitudinal changes in caregiving stress (treatment group) to corresponding changes in non–day care users (control group).	Control groups carers (N=43) Intervention group carers (N= 37) Significant attrition remaining control group (N=19) Intervention group (N=18).
23	Harris and Caparella. (2014)	North America.	Intergenerational Choir.	Mixed methods study semi structured interviews, focus group and observations.	Semi structured interviews with students (N=13) Focus groups with people who live with dementia (N=13).
24	Keyes et al (2016).	UK.	Peer support.	Qualitative analysis of peer support for people living with dementia.	Semi structured interviews with PLWD (N=46) Carers (N=68) and staff/volunteers/stakeholders (N=82).

Number of paper.	Authors.	Location.	Intervention/assessment.	Methods.	Participants.
25	Giebel (2016).	UK.	Revised interview for deterioration in activities of daily living for people living with dementia.	investigated instrumental activities of daily living deficits in mild dementia by exploring the relationship between instrumental activities of daily living initiative and performance and general cognition.	Twenty dyads people living with dementia (N=20) and carers (N=20).
26	Osman Tischler and Schneider (2016).	UK.	Dementia Choir.	Qualitative semi structured interviews.	Participants living with dementia (N=20).
27	Willis Semple and De vaal (2018.)	UK.	Peer support.	Mixed methods A Social Return on Investment (SROI) analysis with peer support groups for people living with dementia.	Focus groups (N=14) people living with dementia. Interview participants carers (N=8) Group staff (N=7).

28	Van Rijn and Meiland (2019).	Europe.	Volunteering and peer support	Qualitative multiple case study.	Semi structured interviews with key figures/stakeholders (N=22).

Carer Education

Number of paper.	Authors.	Location.	Intervention/assessment.	Methods.	Participants.
29	Winter and Gitilin (2006).	North America.	Telephone-based support group.	Quantitative. Evaluated the feasibility and effectiveness of professionally led telephone-based support groups.	103 female carers (N=103).
30	Farran et al (2007).	North America.	compared caregiver skill building to the provision of information.	Quantitative. An analysis of a subgroup of caregivers who participated in a randomized clinical trial	Subgroup of carers (N=143).
31	Devor and Renvall (2007).	North America.	Seminars for carers.	Quantitative. A community-based seminar series aiming to reduce caregiver burden and overload and increase competence.	Family carers (N=300).

Number of paper.	Reference.	Location.	Assessment/intervention.	Methods.	Participants.
32	Dam et al (2007).	Europe.	(1) the development of an online social support intervention Inlife, and (2) the evaluation of the feasibility of this intervention and the measurements to assess its effectiveness.	Mixed methods interviews focus groups and feasibility testing.	Carers interviews (N=10). Focus groups experts and web designers (N=6) three think aloud interviews. (N=3) Pilot study with carers (N=25).
33	Logsden, Mc Curry and Ten (2007).	North America.	Support groups for carers.	Randomized controlled clinical trial comparing early-stage support groups with a wait-list control condition.	Dyads of carers and people living with dementia (N=150).
34	Gitlin et al (2008).	North America.	Tailored intervention programme.	Pilot study.	Carers intervention arm (N=30) Control arm (N=30).
35	Sarna and Thompson (2008).	UK.	Educational intervention.	Method not specified.	Admiral nurses number not specified.

Number of paper.	Reference.	Location of research.	Assessment/intervention.	Method.	Participants.
36.	Dias et al (2008).	Australasia.	Caregiver education and training including leaving unsafely (10/66 intervention).	Randomised controlled trial.	Dyads of people living with dementia and carers Intervention group (N=41) Control group (N=40).
37.	Gallagher Thompson (2008).	North America.	CBT intervention programme coping with caregiving (Intervention arm) or telephone support control arm.	Randomised controlled trial.	Carers. Hispanic/Latino and White Women, Control (N=87) Intervention (N=97).
38.	Gavrilova et al (2009).	Europe.	Caregiver education and training including leaving unsafely (10/66 intervention).	A single blind parallel group randomized controlled trial.	Carers. Intervention group (N=30) Usual treatment (N=30).

39.	Chiu et al (2009).	North America.	Internet based carer support for Chinese Canadians.	Mixed methods usability study followed by qualitative interviews.	Usability study (N=3) Demographic and questionnaire data (N=28) Interviews (N=10).
40.	Ducharme et al (2011).	North America.	Psycho education individual programme with carers.	Experimental design with random assignment.	Intervention group (N=62.). Control Group (N=49).
Number of paper.	Reference.	Location of research.	Assessment/intervention.	Method.	Participants.
41	Guerra et al (2011).	South America.	10/66 Intervention.	Randomised controlled trial.	Carers Intervention Group (N=29). Control group (N=29).
42	Van Meirlo et al (2015).	Europe.	Digital interactive social chart.	Quantitative cluster randomised controlled trial.	Intervention group carers (N=41). Case managers (N=13). Control group carers. (N=32)

					Case managers (N=14).
43	Cristancho Lacroix (2015).	Europe.	Web based psycho educational programme.	A unblinded randomized controlled trial considering efficacy and acceptability.	Carer participants (N=49).
44	Chenoweth et al (2016).	Australasia.	Coaching for carers.	Mixed methods in a pre/post-test/follow-up design. Outcome measures and semi structured interviews.	Carer participants (N=91).
45	Kurz et al (2016).	Europe.	An internet-based information and skill-building program for family carers.	Quantitative. Multi-centre, randomised, controlled, single-blind trial.	Carer participants (N=292).
Number of paper	Reference	Location of research	Assessment/intervention	Method	Participants
46	Prick et al (2018).	Europe.	A multi component dyadic intervention received home-based physical exercise training, psychoeducation, communication skills training, and pleasant activities training.	Randomised controlled trial of dyads.	Dyads of a PLWD and Carer (N=111). Intervention group (N=57) Comparison group dyads (N=54).

47	Pihet and Kipfer (2018).	North America.	Group intervention focusing on coping with the daily stress of dementia caregiving.	Mixed Methods Feasibility trial a one group pre- and post-test design 1) the feasibility of implementing the program in two regions of Switzerland, 2) the effects of the program, and 3) the participants' use of the trained strategies in daily life. Quantitative and qualitative post intervention reports.	Carers (N=18).

Driving					
Number of paper	Reference	Location of research	Assessment/Intervention	Methods	Participants
48	Meuser et al (2006).	North America.	Aimed to develop and evaluate a multimedia workshop curriculum about driving assessments and driving retirement.	Quantitative pre and post-test to identify effectiveness of workshop.	147 participants. Physicians (N=26) nurses or physician's assistant (N=17) OTs, physiotherapists (N=61) social workers or psychologists (N=43).
49	Loconte et al (2008).	North America.	Use of a standardised note template.	Quantitative identified if Standardised template would identify people living with dementia who own guns and are still driving.	Physicians and social workers. (N=44) across two site
50	Eby et al (2011).	North America	In-vehicle technology to identify driving behaviours in early dementia.	Quantitative data from drivers who do not have dementia and PLWD to identify differences in driving behaviour	PLWD (N=17).

Number of paper.	Reference.	Location.	Assessment/intervention.	Methods.	Participants.
51	Byzeuski et al (2013).	North America.	Toolkit to assist with decision making.	Unclear. The aim of this project was to develop a toolkit to assist persons with dementia (PWD) and their caregivers, in planning for retirement from driving.	Developed by an interdisciplinary team of professionals including nurses, social workers, OTs, geriatric medicine, and rehabilitation medicine numbers not given.
52	Lincoln Taylor and Radford (2012).	UK.	The Nottingham neurological driving scale used for people living with dementia.	Quantitative study comparison of driving ability between two groups.	People living with dementia (N=118) controls 30.
53	Lincoln Taylor and Radford (2014).	UK.	Nottingham neurological driving ability.	Quantitative study analysing interrater reliability.	People living with dementia (N=6).

Number of paper	Reference	Location of research	Assessment/intervention	Method	Participants
54	Vella and Lincoln (2014).	UK.	The Rookwood Driving Battery and the Dementia Drivers Screening Assessment.	The aim was to assess the concordance between the classifications (pass/fail) of the RDB and DDSA in individuals with dementia, and to compare any discordant classifications against on-road driving ability.	People living with dementia (N=24).
55	Ranchet et al (2016).	North America.	Fitness to drive recommendations.	Quantitative Investigate the agreement between medical and practical fitness-to-drive recommendations in 68 active drivers with dementia.	Physicians (N=57) and fitness to drive assessors (not specified).
56	Versijpt et al (2017).	Europe.	Consensus process.	Reviews what is known from both literature and existing guidelines and proposes a consensus recommendation tailored to the Belgian situation, agreed by both AD experts and the Belgian Road Safety Institute endorsed by	Numbers unclear AD experts and the Belgian Road Safety Institute endorsed by the Belgian Medical Association.

				the Belgian Medical Association.	
57	Stasiulis et al (2020).	North America.	Development of a driving toolkit.	Semi structured interviews.	Staff participants (N=15).

4.5 Summary of findings

The aim of this scoping review was to identify and map relevant literature that could be used to form the elements of the FREEDEM assessment. The literature identified was multinational and derived from a diverse range of methods. This was the first scoping review to collate literature on assessments/interventions which may facilitate liberty for PLWD. The studies identified different potential elements of the assessment of freedom.

While PLWD were participants in some studies, their views were only sought in a minority of studies. Only one study considered risk in the context of PLWD (Clarke 2009). It is also important to consider the nature of participation. For example, assessing the driving of a PLWD does not identify how that driving may be essential to freedom or an integral part of identity. However, these findings illustrate that in specific areas, there is limited research with PLWD as active participants able to provide their views.

In addition to the actual areas identified, the issue of the ethics of the proposed element of the assessment was considered. The purpose of this is that an assessment that would be unethical is unlikely to be tolerated by either carers or PLWD. It is unlikely OTs would use such an assessment or regard it as consistent with their code of practice. The only area in which significant ethical issues were addressed was that of telecare technology.

Policy documents were identified linked to the assessment of risk and dementia friendly communities (Department of Health 2010, Morgan, and Williamson 2014). These documents were linked to the area of positive risk and social integration and may help inform the content of the assessment and the approach to implementation, one of positive risk taking rather than an over cautious approach that may restrict freedom. An approach to risk which is positive should not negate a focus upon the individual who lives with dementia. The PLWD may also have comorbidities, which could be physical or psychological and may impact upon their wish or ability to seek freedom. The condition's progress may significantly impact the elements of risk that a carer will tolerate and the extent to which the PLWD dementia wishes to participate in the risks. A person-centred approach requires insight into the individual rather than a generalised approach to risk.

The PLWD may fluctuate across shorter periods of time and may behave differently in terms of cognition and physical abilities (Robinson 2007, Rowe 2010). There may be significant changes in the ability to exercise choices linked to freedom. Accordingly, the weighting of different assessment elements will vary according to how the symptoms of dementia impact the person living with the condition. While the progression of symptoms cannot be anticipated, it is still essential that the PLWD and their carer be involved in decisions regarding freedom. This is consistent with the concept of a relationship centred model of care.

4.6 Strengths and weaknesses of method

A strength of this literature review was the use of a scoping methodology, which produced diverse evidence. A review confined to qualitative, quantitative, or mixed methods research would have failed to identify a considerable proportion of the literature identified. This would then present a narrower view of the potential areas of the assessment. While it is argued that a systematic review is the gold standard (Puye 2016, Strauss 2016a) in evidential terms, such a review with narrower criteria than a scoping review would not have identified the range of literature collected and reviewed or uncovered the ethical opinion-based literature. While it was difficult to locate relevant legal literature, the potential divide in terms of method highlights an area for the potential development of research.

It is not the purpose of a scoping review to appraise quality (Strauss 2016b, Peters 2020), but this could be regarded as a weakness. The literature identified was diverse, and it was difficult to identify methods from some of the papers included. Quality appraisal would have excluded these papers. The focus within scoping reviews is upon the aggregation of data rather than the analysis of the data obtained (Peters 2020). The data obtained in this review were too heterogeneous to allow for a successful synthesis. It may be that a specific assessment of quality of literature within scoping reviews will need to be addressed with method specific quality assessments which have not yet been developed (Levac, Colquhoun, and O'Brien 2010). Whilst the lack of quality appraisal is a frequent criticism of scoping reviews (Struass 2016 b and c) the breadth of evidence uncovered is a strength and helps to form a starting point for areas of the assessment, which can then be refined through further stages of the study.

A limitation of this study is that the papers recovered were all in English. This is partly because if search terms in English are used, results are returned in the same language. Two German papers were retrieved, but neither met the inclusion/exclusion criteria. However, some of the literature points out the effects of dementia in economic systems where there are fewer resources. The 10/66 intervention was the subject of trials in Russia, South America, and India. The 10/66 intervention is intended to support carers in middle- and low-income countries (Dias et al 2008, Gavrilova et al 2009). There is some geographic diversity in the identified sources of literature, which identifies how the assessments and interventions may provide support to PLWD and their carers in a variety of cultures. However, the predominance of English papers must be acknowledged.

4.7 Development of a codebook

The development of FREEDEM will be derived partly from the literature identified in this chapter. The method to achieve this will be through the development of a codebook. The codes are developed from the findings of the literature review. These codes will be supplemented by the theoretical underpinning of relationship and person-centred care as set out in chapter one of this thesis and the legal elements of the assessment identified in chapter two (the assessment of capacity and safeguarding). The findings of the literature review supplement these areas.

4.8 Codebook content

A structure was developed for the codebook using three components, the code name, a definition of the code, and an example. This structure has been used in other research (Decuir-Gunby, Marshall, and Mcculloch 2011). Coding using a codebook is iterative and results in revisiting the original codes, which can be removed or supplemented during data analysis.

Code one is derived from person-centred care principles, which form an element of relationship centred care set out in chapter one. The assessment of cognition capacity and safeguarding are derived from the legal requirements in chapter two (Codes two, three, and four). The remaining items are derived from the findings in this literature review. These codes and the codebook will impact on elements of the data analysis. The codebook is set out in table five.

Table Five: Codebook

Code Name.	Definition of code.	Example.
1. Person centred care.	Treating people as individuals with dignity and focussing on what they can do (National Service Framework 2009). Relationship centred care.	Placing the wishes, feelings, culture, and history at the centre of the assessment process.
2. Assessment of cognition.	The examination was conducted to determine the level of cognitive function.	The Montreal Cognitive Assessment.
3. Assessment of capacity.	Assessment of ability to make a decision to leave the home safely.	Assessment under section 2 of the MCA (2005).
4. Safeguarding.	Protecting an individual's health, wellbeing, and human rights. Protecting them from harm and neglect or exploitation.	Financial exploitation of people living with dementia in the community.
5. Alert systems.	The Herbert Protocol.	The standardised information used to identify a PLWD who is missing.
6. Telecare technology.	Remote care for a person living with dementia.	Global positioning systems enabled tracker devices.

Code Name.	Definition of code.	Example.
7. Assessment of risks.	A process of evaluating the potential risks of a PLWD leaving their home.	Assessing risk of getting lost or dealing with traffic.
8. Social groups.	Day centre provision.	Centres that provide day services for PLWD.
9. Carer education.	Educational groups.	Educating carers about the benefits of freedom for PLWD.
10. Driving.	Driving a motor vehicle.	Supporting PLWD to consider alternative transport options if safe.

4.9 Summary

The assessments and interventions included in the review are alert systems, telecare, driving, carer education, assessment of risk, and social inclusion. OTs role in carrying out assessments or interventions was ambiguous, and accordingly, the interview stage of this study will include questions regarding this profession's role. The codebook developed will be used to facilitate the areas for questions within the interview stage of this study. There are multiple publications relating to DOL within the legal literature but no empirical research that contributes to the assessment's clinical perspective and development. The literature review suggests there is more to be done in research terms to bridge the clinical/legal divide, and this is a potential future direction for research.

5 Chapter Five Methodology and Methods

5.1 Introduction

This chapter presents the methodology and methods of the qualitative interview stage of this research. This is the qualitative stage of a sequential mixed methods study design. To aid clarity, the chapter is divided into three sections. The first sets out the overall methodology and methods chosen. This is followed by a second section on the study procedures, including the sampling strategy and recruitment of participants. The methods for recruitment and data collection of thirty semi-structured interviews are explained in this section. Details of the ethical approvals received for this element of the research are provided. The management of data, including the analysis of data, is set out in the third section. The use of field notes to promote reflexivity, the importance of transcribing, and how data quality was ensured are discussed in this section. This section also identifies the methods used for a hybrid analysis of interview data. Within sections dealing with reflexivity, both methodology and methods are addressed. To structure this element of the research and address research quality the COREQ guidelines were utilised (Tong, Sainsbury, and Craig 2007). A copy of the completed criteria is available at appendix 11.13. This chapter commences with the aims and objectives of this element of the study.

5.1.1 Aim

To identify the methodology and methods for the interview stage of the study.

5.1.2 Mixed Methods Research

Chapter three set out the epistemology underpinning this study. This study uses mixed methods research (MMR) to develop the theoretical model and the assessment of freedom. MMR represents a relatively recent development in research methods. In MMR, 'a researcher or team of researchers combine elements of qualitative and quantitative approaches for the broad purpose of breadth and depth of understanding and corroboration.' (Johnson and Onwuegbuzie 2004). MMR can address different facets of a single research question providing insights into differing features of a phenomenon (Guba and Lincoln 2005). The precise definition of MMR is contested, and there are ongoing debates about the structure and sequence of data order and method for the synthesis of qualitative and quantitative data (Biesta 2010, Cresswell and Plano Clarke 2017). The continued development of the approach has led to flexibility in philosophy and methodology (Hathcoat and Meximer 2015, Fetters and Molina-Azorin 2020). As set out within the literature review in chapter four, the diversity of data sources in this research requires a method that allows for flexibility around both these diverse data sources and the synthesis of data. Also, the breadth of legal, clinical, and philosophical views upon freedom justifies an inclusive method. MMR has been used to collect and integrate data across research methods and interprofessional boundaries (Mayoh and Onwuegbuzie 2013, Fàbregues, Paré, and Meneses 2019). Despite the extensive debates over MMR's structure, it is argued that the method may produce and inform a completer and more comprehensive picture of complex phenomena than a single method (Fàbregues, Paré, and Meneses 2019). MMR's flexibility and breadth provide a potential method for the in-depth exploration of the issue of liberty.

5.1.3 Interpretivism in Mixed Methods

An interpretivist approach has been used in the qualitative element of mixed methods studies (Cresswell et al 2006, McChesney and Aldridge 2019). Within the qualitative element of this research an interpretivist perspective will be used. The core elements of interpretivism are subjectivity and reflexivity. Interpretivism aims to understand rather than explain or critique (Willis 2007). From an interpretivist perspective, the study of phenomena must be addressed by the subjective meaning of human experience (Bryman 2012).

Knowledge is created by individuals, their interactions with each other and the world. This perspective accepts that knowledge is socially created. Meaning and understanding are produced by people and their subjective interpretation of their world and experiences (Willis 2007, Bryman 2012). As meaning making is acknowledged to be subjective, those different participants will develop different meanings of a specific phenomenon creating potentially individual and varied constructions of reality. The participants' experience must be understood from within to retain the integrity of the phenomena being investigated (Cresswell 2006). Interview questions should observe a degree of flexibility as an inflexible external structure may reflect the researcher's viewpoint as opposed to that of the participant (Kaushik and Walsh 2019). An acceptance of these varied constructions of reality is the reason for using semi-structured interviews. An interpretative approach allows for an interview technique, which is most successful in uncovering the depth of understanding while not dictating style or content (Bryman 2012, Hathcoat and Meximer 2015). In keeping with this, a flexible approach to the development and amendment of the topic guide and reflexive approach will be used during the qualitative stage of this research. A qualitative approach to research interviews is consistent with identifying individual meanings and differing constructions of reality (Braun and Clarke 2006, Creswell 2007).

The use of a neo pragmatist stance allows for an acceptance that PLWD and their carers may construe reality differently. This strand of Pragmatism does not negate the value of data in which contradictions are identified as an individual viewpoint is accepted (Malakowski 2010, Halliwell and Rassumen 2014). At the same time, it is accepted that patterns may emerge through the interpretation of experience. An approach derived from neo pragmatism situates this research in the context of current debates about freedom. The interviews will not be conducted on the basis that freedom can be perceived and defined only from a philosophical perspective. Instead, PLWD will define their own freedom, and it will be identified if there is any commonality in their lived experience in terms of freedom. Carers will also offer their experiences and provide information about how their freedom has been impacted at a later stage of the condition. OTs can provide an overview of the way which the profession facilitates freedom. The staff may be impacted by both internal and external influences. These influences may be professional, personal or at an organisational level and derived from trust and government policy. An interpretivist approach means that data can be obtained from different participants, and differing views are not seen as a lack of a single truth but rather facets of a phenomenon (Biesta 2010).

Where the passage of time is an element of the research, interpretivism allows for differing perspectives and interpretations of experience. For example, the interview data obtained from PLWD was at an early stage of the condition. Carer interviews were at a point where the people they cared for had progressed much further along the spectrum of symptoms caused by dementia. This represented stages along the trajectory of a progressive condition. The differences the passage of time makes can be incorporated if an interpretivist approach is used, as a phenomenon can be viewed from different perspectives along a trajectory of symptoms from dementia.

5.1.4 Triangulation of data

This research structure presented the opportunity to triangulate data to develop and refine FREEDEM. Within the mixed methods literature, there has been extensive debate regarding the role of triangulation in laying claim to greater validity and a more comprehensive picture (Mertens and Hesse-Biber 2012, Denzin 2012). Flick (2018) defines triangulation as the observation of a research issue from more than two points. There are multiple methods of triangulation, including data from differing sources and using several investigators to ensure consistency in interpretation (Fielding 2012). In this element of the study methodological triangulation will be used. The quantitative and qualitative data identified in the literature review will be triangulated with the data from the semi structured interviews. This is a between methods form of triangulation where both qualitative and quantitative data contribute to the assessment development (Bryman 2012, Fielding 2012). This type of triangulation has the benefit of redressing the weaknesses in a single method.

5.1.5 Confirmation, Refutation, and Complementary Findings

Confirmation and refutation may occur when data is triangulated. If the findings across qualitative and quantitative studies are consistent, confirmation has occurred (Fielding 2012). When the relationship between quantitative and qualitative data reveals findings that diverge or are in direct opposition to each other, refutation has occurred (Fielding 2012). However, it has been questioned whether confirmatory validation is achievable as the same phenomena may not be observable from the differing viewpoints afforded by MMR (Denzin 2010). Convergence cannot be achieved if the researcher takes the standpoint that differing methods answer different facets of research questions. If the different research traditions address different facets of the phenomena in question (freedom for PLWD and how this could be facilitated), the findings could not be confirmatory or repudiatory. Also, using triangulation to provide evidence of confirmability may mute the possibility of dissonance between the quantitative and qualitative elements of the research. Instead, the finding could be complementary. Complementary findings provide information on different facets of a research question without being dissonant (Mertens and Hesse-Biber 2012, Fielding 2012).

5.1.6 Inductive, Deductive, and Abductive Framework

In research, induction and deduction are approaches to logic and address the approach to research along a continuum. Theory derived from data is classed as inductive, whereas a deductive approach begins with a theory (Alvesson and Skoldberg 2009). Abduction combines both elements and can begin with an empirical or theoretical framework, which is developed and refined. Qualitative research tends to be derived from an inductive approach, while deduction is commonly linked to quantitative research (Azunga 2018). Neither induction nor deduction are easily defined or isolated concepts (Alvesson and Skoldberg 2009). Developing a quantitative hypothesis may require an understanding of the clinical or social background of the hypothesis proposed. While qualitative research may, for example, involve the identification of a phenomenon that is pre decided by the researcher rather than arising from data (Azunga 2018). Pragmatism can be used as a guide not only for top-down deductive research design but also for inductive, or abductive research. (Morgan, 2007) Within pragmatism, Pierce suggested an alternative, that the process of enquiry began with abduction, the tentative development of new ideas and hypotheses (Misak 2013). Abduction involves making an inference from a set of circumstances, which is the best possible explanation (Alvesson and Skoldberg 2009).

The interview stage of the doctoral research could not be labelled as either firmly inductive, deductive, or abductive. The development of the theoretical model was achieved through the exploration of explanatory patterns within the data obtained and the reflexive development of the topic guides. The codebook framework for development of FREEDEM represents a more deductive element of the research, as it was formed to some extent from a starting point of law and theory. However, the codebook also illustrates the mixture of inductive and deductive elements in the research, as this initial coding will be reviewed through the analysis of interview data.

5.2 Study Methods

5.2.1 Semi structured Interviews

The method for obtaining data was semi structured interviews. A structured interview asks pre-determined questions with no deviation. Such an approach has been used in quantitative research (Woo O'Boyle and Spector 2017). A more flexible approach allowed the topic area to be adapted for PLWD. Symptoms such as verbal impoverishment, attention deficits, and fatigue may all be symptoms of dementia and can be accommodated by flexibility in the interview structure and questions (Panegyres Berry and Burchell 2016). Despite this, to address liberty, some structure is required as issues such as the legal position is pre-determined and could not be explored in a wholly flexible interview. Accordingly, a semi structured interview with topic guides was used as the method of data gathering.

A semi-structured interview method allowed the narrowing of topics to those of the greatest relevance and interest to this phase of the research (Cresswell 2007, Bryman 2012). Questions identifying the phenomena of interest could be prepared ahead of time. While some topics that were pre-determined, the interview format allowed for a degree of flexibility to explore complex issues around freedom. Interviews were carried out in a way consistent with current guidance on interviewing PLWD (Samsi and Manthorpe 2020). For example, for people experiencing a degree of verbal impoverishment, family members were present who could help to prompt answers. Questions were simplified where for example, PLWD were not able to answer abstract questions.

5.2.2 Ethical approvals

Before the commencement of recruitment, an integrated research application (IRAS) form and study documents were completed. The university sponsor approved the application. The application for NHS research ethics approval was submitted to the Health Research Authority, who then sent it to Bradford and Leeds research ethics committee. A copy of the approval is in appendix 11.8. The study also received Health

Research Authority approval (Appendix 11.7). The study received local trust approval from Nottinghamshire Healthcare trust and Nottingham City care.

Participants' medical or personal information obtained because of this study was considered confidential. All participants were asked whether they authorised others to see and/or hear their data for specific purposes. These purposes were detailed on the participant information sheet (PIS). A sample PIS is at appendix 11.4.

5.2.3 Development of Topic Guide

An interview protocol was developed. This protocol included the interview structure (appendix 10.2) and topic guides set out in appendices 10.51-10.53. The interview began with introductions including my role as an OT and doctoral researcher, an explanation of the research, and answering any questions. The participants were assured of confidentiality and anonymity. Consent and the option to withdraw, and how the results would be used were also explained. It was explained that the interview would be recorded and how data would be used**.** This information was contained in the PIS but was reiterated at the beginning of the interview. It was also explained that reflective field notes were being maintained, and these would remain confidential.

Topic guides were developed with a PLWD and their carer. Two community OTs also provided feedback. The most complex questions in the topic guide were reviewed with a qualitative researcher after the first four interviews. Following this, additional questions and prompts were developed, which are set out in the supplementary section of the topic guide at appendix 11.6. The wording of questions linked to the law was reviewed. More challenging questions were also asked about telecare technology and the role of carers.

5.2.4 Patient and public involvement

The definition of patient and public involvement used is by INVOLVE (INVOLVE 2015). INVOLVE is part of the National Institute for Health Research. ‘The changes, benefits and learning gained from the insights and experience of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiatives ‘. The role of INVOLVE is to promote active public involvement in health and social care research.

Patient and public participation helped to adapt academic language into more understandable plain English (INVOLVE 2015). PPI groups may identify if research addresses an important need and is also potentially empowering or disempowering (Scottish dementia working subgroup 2014). Study documents may be rewritten to ensure they are in plain English, and interview questions may be reframed to ensure they are understandable. PPI involvement has been framed in terms of rights in the context of dementia, "nothing about us without us" (Bryden 2015).

Initially, a small group of people was brought together to form a PPI group. This was two carers for PLWD, an OT working with PLWD, and a senior nurse responsible for the DOLS and safeguarding. Both the carers left the group as the people they were caring for became more dependent, and sadly both died within the first year of the doctoral fellowship. This group therefore disbanded. Instead, the research utilise the University of Nottingham's Dementia and Frail older person's PPI group, who provided general feedback on the direction of the research. The Alzheimer's society also gave PPI support. The PIS and topic guide were considered by two carers and two PLWD involved with the Alzheimer's society before commencing the interviews. These documents were then amended to simplify the questions/language used. Attempts to involve PPI groups in 2020 were frustrated by the COVID-19 pandemic and the cancellation of meetings. Instead, the University of Nottingham PPI group referred to above moved online and was used for ongoing PPI.

5.2.5 Sampling framework

A purposive stratified sampling framework was used to recruit ten PLWD, ten OTs, and ten carers. Involving a variety of participants allows for insight into potentially complex issues linked to liberty from multiple perspectives. Purposive sampling identifies and selects specific individuals who are members of a group with experience of the phenomena in question (Suri 2011). This framework was stratified to ensure three groups of participants with specific characteristics were selected to meet inclusion and exclusion criteria (Suri 2011, Benoot Hannes and Bilsen 2016). Sampling and data collection were concurrent as the interview topic guide continued to evolve as data was collected and analysed.

There is no established guide to the number of qualitative interviews required in a study. The nature and size of the sample should be justified by reference to the research question and aims (Vasileiou et al 2006). A common method of justification for the sample size given was to achieve saturation of data. This can be defined as a point where no added information or themes can be identified from additional data (Guest Bunce and Johnson 2006, Nelson 2017). There are recommendations that rather than a minimum number of participants, the number of interviews should reflect the methods used and be transparent (Marshall et al 2013, Robinson 2014). Using separate groups of participants presented the opportunity to obtain differing views upon liberty for PLWD. A sample of 30 participants comprised of 10 from each group was decided upon to attempt to reach saturation and depth in the data obtained.

5.2.6 Inclusion Criteria

The need for the perceptions of PLWD regarding liberty meant that it was imperative that people living with the condition were central to this research. The PLWD interviewed needed to have experience of leaving their homes safely and have insight into why this was safe. This was so they could provide information on their current freedom, future freedom, and factors they were considering in exercising it. The assessment is intended to be based in the community, and hence it was essential that participants were community dwelling. It was also necessary that participants were able to consider freedom in the context of a potential carer who may need to provide support in the future.

Carers are intertwined with issues about facilitating or depriving a PLWD of their liberty (Clarke 2010). The carers needed to have experience of the person they cared for leaving their home in a way the carer considered unsafe. How leaving unsafely was defined formed an element of the interview questions. This was because such experience would provide insight into freedom for PLWD and how the assessment would provide support.

OTs were interviewed as it was intended this profession would implement the assessment. The reason for this is the skills of this group of healthcare professionals in assessing capacity, cognition, and the home, community, and social circumstances of

PLWD (Gitlin et al 2005, Graf et al 2006, Gitilin et al 2008, Gitlin et al 2010. It was accordingly essential that the views of OTs were integral to the content of the assessment. The OTs needed to have a depth of clinical experience and work in a community setting to understand the assessments and interventions which would support the freedom of community dwelling PLWD. An inexperienced therapist would not have sufficient expertise in the assessment of PLWD. However, it will be a part of the interview with OTs whether they feel the profession has the necessary skills to complete an assessment of freedom. The following are the inclusion/exclusion criteria for the study.

5.2.6.1 People living with dementia.

- A diagnosed dementia.
- In receipt of or potentially in receipt of care not provided through a contract of employment or voluntary work.
- Community dwelling.
- Capable of leaving their home independently.

5.2.6.2 Carers

- The carer provides care for a person living with a diagnosed dementia in the community.
- The care is not provided through a contract of employment or voluntary work.
- The cared for person has leaves or attempts to leave their home.
- The carer is to be an adult over the age of 18 but no other age limit is set.

5.2.6.3 Occupational Therapists

- OT participants are registered with their professional body, the Health Professions Council.
- Participants have worked with people living with dementia and their carers for a period of over 1 year as a registered occupational therapist.
- The OT currently works on a community team who work with people living with dementia and their carer’s.

5.2.6.4 Exclusion Criteria

- Occupational therapists within their preceptorship year.
- Non-English speaking.

5.2.7 Recruitment of PLWD

PLWD were recruited through Join Dementia Research (JDR), an online register of volunteers who are willing to take part in dementia research. JDR was developed by The National Institute for Health Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer's Research UK, and Alzheimer's Society. JDR allows people to register their interest in participating in dementia research and be matched to suitable studies. The website matches research volunteers with the study inclusion/exclusion criteria in a specified geographical area. A wording for information about the study was agreed with the study coordinator from JDR. Participants were drawn from an area with a radius of 20 miles from the University of Nottingham. 36 JDR volunteers were approached to obtain 10 participants. All participants were contacted by email by the researcher. An email was sent to volunteers outlining the study. If the volunteer expressed an interest in participating, the PIS was emailed. Participants were then contacted a minimum of 24 hours later to organise an interview.

Details of the participants living with dementia are set out in table six. The subtype of dementia was identified on JDR and confirmed with participants in the interview. The potential carer is the person who might provide care in the event it is required. This was also checked at the interview. Eight interviews with PLWD took place in their homes of the participants and two in a room in a hospital OT department. For eight participants, the person who would potentially provide them with care was present in the interview with their consent.

Table six: Participants living with dementia.

Diagnosis.	Age and gender.	Date of diagnosis.	Potential Carer.
1. Alzheimer's disease.	76 male.	2012.	Wife.
2. Alzheimer's disease.	79 male.	2018.	Wife.
3. Alzheimer's disease.	73 female.	2014.	Daughter.
4. Alzheimer's disease.	73 male.	2014.	Wife.
5. Alzheimer's disease.	61 female.	2018.	Husband.
6. Alzheimer's disease.	57 female.	2017.	Husband.
7. Alzheimer's disease.	76 male.	2012.	Wife.
8. Mixed dementia.	77 male.	2016.	Wife.
9. Alzheimer's disease.	76 male.	2015.	Wife.
10. Mixed dementia.	73 male.	2016.	Wife/daughter.

5.2.8 Recruitment of Carers

OTs who worked in a large hospital identified carer participants on 11 healthcare of older people (HCOP) wards of a large teaching hospital. The researcher attended a team meeting and explained the background of the study. The initial approach was through a member of the OT team who approached the potential participant and explained the study. The details of the carers were collected through daily attendance at OT team meetings. Potential carer participants were provided with a PIS by the researcher at ward visiting times. The carers were then offered 24 hours to read through the study documents. Some carers wished to be interviewed on the same day and this was arranged.

It was anticipated that the family rooms on wards would be used for interviews with carers. Family rooms would normally be free for meetings with families, but because of winter bed pressures, these rooms were occupied by patients. One interview took place in a rehabilitation facility. Seven Interviews took place at the homes of carers. Two interviews took place in the occupational therapy department. The shortest carer interview was 47 minutes and the longest an hour and 5 minutes. Details of carers are set out in table seven.

Table Seven: Carer participants.

Diagnosis of PLWD who is cared for.	**Date of diagnosis.**	**Age of PLWD who is cared for.**	**Carers Age.**	**Relationship to person living with dementia.**
1.Vascular dementia.	2015	94	68	Daughter.
2.Lewy Body dementia.	2014	74	69	Ex-wife.
3. Vascular dementia.	2018	76	43	Nephew.
4. Vascular dementia.	2018	84	70	Sister-in-law.
5. Mixed dementia.	2008	72	74	Husband.
6. Mixed dementia.	2015	89	60	Daughter.
7. Vascular dementia.	2016	92	89	Brother.

8. Vascular dementia.	2018	85	70	Friend.
9. Alzheimer’s disease.	2016	83	53	Daughter.
10. Alzheimer’s disease.	2017	84	52	Daughter.

Five potential participants identified by OTs did not meet the inclusion criteria. In three cases this was because the PLWD had not attempted to leave the home unsafely. Two potential participants who said they would be willing to take part in the study then declined after reading the PIS. This was not solely because they were concerned about participating in the study. In both cases it had been decided that the PLWD would not return home, and this had distressed the carer too much for them to be involved in the study.

5.2.9 Recruitment of Occupational therapists

OTs were recruited from Nottinghamshire community teams who work with PLWD and their carers' in a community setting. The purpose of the inclusion /exclusion criteria for OTs was to ensure therapists with adequate experience were identified. The local collaborator was a clinical specialist OT who recruited the participants. With their consent, she sent forwarded their email addresses. Participants worked for memory assessment clinics, intensive recovery intervention service teams, and community beds teams. The interviews took place after the interviews with carers and PLWD were concluded. This was partly because of the time taken to get local approval. However, a beneficial consequence was access to the views of carers and PLWD first. This ensured that the situations faced by carers and PLWD could be explored with clinical staff. Interviews took place in the workplace of the OTs (seven interviews), two took place in a hospital occupational therapy department, and one took place in a participant's home. The demographics of the OT participants are set out in Table eight. Interviews took between 43 Minutes and 1 hour and 10 minutes.

Table eight: Occupational therapy participants.

Current team,	Band.	Years working with people living with dementia.
Community Mental Health Team.	6	7
Intensive Recovery Intervention Service.	6	10
Community Mental Health Team.	6	7
Community Mental Health Team.	6	6
Community Mental Health Team.	6	3
Community re-enablement team.	7	14
Intensive Recovery Intervention Service.	6	14
Intensive Recovery Intervention Service.	5	6
Mental Health Intensive Recovery Service.	6	8
Working age dementia service.	6	19

5.2.10 Obtaining informed consent

An essential element of the interview was obtaining informed consent. All participants signed a consent form (appendix 11.3) following consideration of the PIS. The most complex issue around consent was ensuring the PLWD had capacity.

MCA guidance states that capacity must be assumed unless there are grounds to believe someone does not have the capacity (MCA code of practice 2007). Capacity was relevant to two separate areas of the research. Firstly, the capacity to give informed consent to be a participant and secondly to have capacity on the issue central to the research, whether the person had the capacity on the issue of leaving their home safely. As a result of the MCA guidance on a presumption of capacity, it would have been inappropriate to carry out a formal assessment of participants without some evidence of a lack of capacity.

The formal two-stage capacity test first asks if there is an impairment in the mind or brain (such as dementia) and that because of that impairment, the person is unable to make a decision. The second stage of the capacity assessment has multiple stages. Firstly, can the PLWD understand information relevant to the decisions to be taken, that is, the decisions to leave their home and participate in the research? Secondly can the person retain the information relevant to that decision for long enough to make the decision? Could the participants remember that they were consenting to take part in an interview and retain information about whether they were safe to leave home? Third were the participants able to use and weigh the information relating to the decision? That is, does this person understand the consequences of deciding one way or another? Did the participants understand that the interview data would be kept confidential and the purpose of the interviews? Were participants able to use and weigh information linked to deciding to leave the house? The final stage is the ability to communicate the decision. One participant had a noticeable degree of verbal impairment but expressed his views and participated in the interview.

There was no doubt that the people interviewed had the capacity to decide to leave their homes. Only one participant had been lost, but that was on a cruise ship, and he commented it was an easy place to get lost, and he found his way back to his cabin. Seven participants travelled around with no adaptations or precautions, and none had ever become lost. Two other participants had not become lost but had taken precautions; dog walking routes were always the same, and a regular walk had been adapted to avoid the countryside. Another participant took his mobile phone, which had several applications that meant he could be found. This was in response to low mood and a threat of self-harm rather than becoming lost. This information showed that participants who had concerns about getting lost had recalled they were worried about this, had communicated this concern to their potential carer, and had then understood that they might get lost and put strategies in place. This showed an ability to use and weigh the factors linked to potentially becoming lost.

In terms of consenting to the interview, the PLWD either met at a predesignated location or met at their homes. We discussed Join Dementia Research and if they had been involved in any other studies. I asked them to tell me about the studies, and all were able to explain the studies and the consent process. All except two had taken part in other studies. Three had been interviewed previously. The two that had not taken part in any studies had both stopped working within the last year and were able to deal with abstract concepts. All could explain the details of their homes, the areas they lived in, and who their potential carers were.

5.2.11 Data Collection

Undertaking an interview requires active engagement and agreement, both in terms of collecting valid data and agreeing to the recording and processing of the data. Interviews were digitally audio recorded and transcribed by the researcher with consent from the participants. Recordings were deleted once this process was complete. Data including these transcripts, consent forms, and field notes were managed in accordance with the Data Protection Act 2018. All personal data was removed from study documents to ensure anonymity and confidentiality, including the transcriptions and reflective field notes.

Initially, neutral subjects were discussed with PLWD to ensure these participants felt comfortable and in control. The interview protocol and topic guide provided a structure that facilitated interview fluidity and a focus on key areas. Despite this, the responses and direction of such interviews could not be predicted, and the interviews were flexible in length and topic.

5.2.12 The use of a vignette

A vignette is a ‘Short scenarios in written or pictorial form, intended to elicit responses to typical scenarios’ (Hill 1997 p177). The scenario was adapted from the experience of a participant. Participants were informed that that the vignette was drawn from the actual experience of a carer participant. The technique offered a way of exploring potentially distressing issues for PLWD around the progression of the condition and how this may impact on the level of care and supervision required. The vignette also allowed for the exploration of beliefs and attitudes towards freedom in the context of an example of potential harm due to leaving unsafely. This highlighted when restrictions on freedom may be perceived to be acceptable. OTs' answers were potentially constrained by their employer's instructions (that PLWD should not be locked in) and the policy of positive risk taking. The vignette allowed for exploration of these policy considerations and how the issue of risk may be tied to restrictions on freedom. In addition, there was the potential to explore issues around the implementation of the law linked to the DOL in a domestic setting.

5.3 Data Management

5.3.1 Data security

Written data were stored in a locked, secure area of the university. Electronic data was stored on a University of Nottingham password protected computer server. This complied with protocols for information governance approved by the research sponsor and the research ethics committee.

5.3.2 Data Quality

In establishing quality in qualitative research, Lincoln and Guba (1989) identified the concept of trustworthiness. Willliams and Morrow (2009) offered some clarity to this concept by proposing categories to establish the trustworthiness of the data. These include the integrity of the data and the balance between reflexivity and subjectivity. To ensure a structure for quality for the qualitative element of the thesis, the COREQ guidelines were used (Tong, Sainsbury, and Craig 2007). A copy of the guidelines setting out which elements were complied with is in appendix 11.13.

The integrity of the data is enhanced if it is of sufficiently rich quality to support the choice of interpretation. This interpretation occurs when the data is transformed from raw data into the production of meaning (Morse 2009, Priest Roberts, and Woods 2002). To achieve this, the corpus of data obtained had to be consistent with the approach used. This choice must be justified as, by its nature, the approach used excludes other approaches and potential interpretations (Wiliams and Morrow 2009). The quantity must also be sufficient to fill out the themes with sufficient data so that the interpretation becomes plausible. This generates trustworthiness of data as the interpretation is based on sufficient data to give the themes depth (Williams and Morrow 2009, Hadi and Kloss 2016).

To ensure data of sufficient depth, the topic guide was reviewed with an experienced qualitative researcher. The development of the topic guide and prompts was also discussed in supervision Transcripts were shared with the supervisory team, and their feedback was used to improve the quality of subsequent interviews. The most significant improvement in depth of data was brought about through reflection on the interviews during transcription. It was possible to identify where answers could have been explored in more depth and where additional areas could have been identified. As themes emerged, questions were refined, and more questions were, for example, asked about how identity was defined and how this definition changed through the progression of dementia.

5.3.3 The balance between subjectivity and reflexivity

This balance involves the researcher's subjective interpretation of the participants' voices. Within this, the researcher brings their own knowledge and perspective to the interpretation while also being open to a new understanding of the knowledge (Williams and Morrow 2009). It was essential to recognise that the participants interpreted their reality, and that the researcher’s interpretation represented a reinterpretation of that reality; ‘the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world’ (Smith 2004, p. 40). Understanding this may produce an acceptance of an interpretation that is not consistent with the researcher's preconceived notions (Anderson 2008)**.** Whether this occurs is dependent on whether the researcher’s interpretation achieves the correct balance between subjectivity and reflexivity (Finlay 2002, Anderson 2008). The maintenance of a critical distance from the material obtained and the interpretation of data can enhance the balance between subjectivity and reflexivity (Mauther and Douchet 2003). A failure to achieve distance may result in the researcher placing too much emphasis upon their own views, knowledge, and understanding rather than basing the interpretation of data within the views of the participants (Pope Zealand and Mays 2000, Mruck and Breuer 2003).

5.3.4 Field Notes

Field notes provide a source of contextual information. For a novice researcher, field notes may provide a framework for observations to enhance research skills. Field notes can enhance data and provide rich context (Emerson, Fretz and Shaw 2011, Charmaz and Belgrave 2012). Such notes are an element of rigorous qualitative research. (Tong, Sainsbury, and Craig 2007). While the use of field notes is encouraged by these recommendations, there is no single structure for using such notes. A set of recommendations by Phillip and Lauderdale (2018) to structure the field notes into the setting, participants, the interview, and critical reflections upon the interview was used. The main priority identified was the improvement of qualitative interview skills. Field notes were made immediately after the interviews while recollections were still fresh. This immediate recollection was supplemented by listening to the tapes and noting additional information, for example, whether participants were interrupted by the researcher, whether verbal cues were noted, and if interruptions from family members needed to be dealt with more effectively. Participants wanted to talk after the tape was turned off. Any unrecorded data formed an element of field notes and was not included in the final analysis. Participants were made aware of this. These notes also encouraged reflection and identified how interview skills could affect the process of data collection.

The values of the field notes were threefold: Firstly, the field notes were used to facilitate coding. Secondly, the topic guide was revised, and this contributed to the development of the theoretical model. These revisions came about through reviewing the interviews when constructing field notes and transcription of the data. Thirdly, writing the field notes also created a short pause in data collection. This was used to reflect upon the data collected and how the interview style impacted this collection of data.

5.3.5 Data Transcription

In some qualitative research, the analysis only begins once the data are transcribed. An alternate perspective is that data analysis begins with the transcription of data (Tilley 2003, Bird 2005). For a doctoral researcher conducting the interviews and carrying out the transcription can provide immersion in the data and valuable experience. Transcription may be a stage in the analysis and interpretation of data. It has been argued that the same person should carry out transcription and analysis of data (Lapadat and Linsay, 1999, Bailey 2008). Chafe (1995: p61) stated, 'One cannot fully understand data unless one has been in on it from the beginning. Certainly, as a doctoral researcher carrying out the interviews, then transcribing them gave access to a depth of understanding of the data and the first stage in developing interpretations. Transcription also helped to improve interview technique. It was possible to identify that some areas could be explored more fully with participants. It was apparent that at the fourth and fifth interviews, topics began to be explored in more depth, and the data seemed to be richer. During transcription, potential new areas to discuss in the interviews were identified, and the topic guide was amended in consequence. The areas of identity and passage of time were discussed in greater detail, and these became major elements of the interpretation.

5.4 Researcher Position

In chapter one, paragraph 1.16.5, I indicated that reflective sections of this thesis would be written in the first person. This section of the thesis linked to the researcher position and interpretation of data is written in the first person. A researcher may belong to the groups they are researching. I am an OT and was a carer. It could be expected I would share an understanding with the profession I work for and the people providing care. I could be defined as either an outsider from the groups interviewed, or an insider based on previous knowledge and experience. Insiders are members of an organisation; they are embedded and familiar with politics but may take much for granted and fail to observe familiar things (Thompson and Gunter 2011). Outsiders are not directly connected and are not a part of the setting or situation studied. A fresh perception of events is possible, but nuances that are familiar to the insider may be lost. This dichotomy between the insider and outside has been challenged, and instead, relationships are perceived as occurring on a continuum rather than dichotomous (Dwyer and Buckle 2009). I find this more convincing. I occupied a multi-faceted identity as an OT and former solicitor, carer, and now researcher. Questions were asked about the law, and I disclosed my legal background to participants. I did this, to be honest, and provide a degree of confidence to understand the legal position. I felt that this would contribute to classification as an outsider, however with some OT participants, I felt identity of interests, and this resulted in more informal interviews that relaxed and appeared frank. The most informal interview with an OT took place in her home, and our shared experiences of providing care to a family member resulted in a discussion about the gap between policy and practice. This debate was less clearly framed in other interviews. The location and shared individual experience produced a depth of data and allowed the participant to go beyond trust policy in her responses.

The researcher is central to knowledge production. Rather than conceal this, an interpretivist approach allows for an acknowledgement of the self in research and encourages honesty. To recognise the self within the process of collecting and interpreting data, reflexivity is required (Pope Zealand and Mays 2000, Mruck and Breuer 2003). Only by acknowledging pre-determined beliefs, values, and perceptions as someone who had been a carer and was both an OT and former solicitor could I understand how these first-hand experiences would shape these aspects of the research process. These past experiences and my current role as an OT influenced my choice of questions and perceptions. The purpose of reflexivity is to step beyond usual practices and routines and approach interviews with self-awareness (Williams and Morrow 2009). An essential element of the insider/outsider debate is how the status of the researcher impacts upon the research process. (Dwyer and Buckle 2009 I situated myself in chapter one, as the researcher's position impacts on all stages of the research from initial research design, data collection, and analysis. Continuing to be aware of this perspective has allowed me to interpret data with an awareness of my own knowledge and experience.

5.5 Data Analysis

Interview data linked to the theoretical model's production were analysed using the six stages of thematic analysis identified by Braun and Clarke (2006, 2012,2016**).** This approach is an analytic method rather than a methodology and offers a theoretical independence and flexibility that is potentially consistent with a mixed methods study. These stages are as follows:

1. Familiarity with data: Firstly, becoming familiar with the data. Data was transcribed, read, and reread to obtain familiarity. Initial ideas were obtained through familiarisation and transcribing and noted down.

2. Generating initial codes: Using NVivo, initial codes were developed. These were then reviewed and systematically developed across the entire data set.

3. Searching for themes: Initial codes were developed into potential themes and reviewed with the supervisory team. Data was gathered relevant to each potential theme from codes. A theme represented a patterned response or meaning which is identified across the dataset.

4. Reviewing themes: Ensuring themes work in relation to the coded extracts and the entire data set. A thematic map of the analysis was generated.

5. Defining and naming themes: Ongoing continuing analysis took place to refine themes and the overall analysis. There was continuing clarification, definition, and naming of each theme.

6. Producing the report: The final analysis involved selecting the most compelling extract examples for the report and the final analysis of these extracts. The analysis was be tied to the research question and literature, producing a chapter of the thesis.

5.5.1 Method of analysis

The method has been described as providing a basic foundation in qualitative data analysis and is accordingly a useful starting point for a doctoral student (Braun and Clarke 2012). The method also contains sufficient detail for clarity in terms of the steps taken and providing a structure to work within. The method was updated into reflexive thematic analysis (Braun and Clarke 2019). Reflexive thematic analysis asks for researchers to state their approach at the outset for clarity. The approach is organic and iterative and the steps in coding identified above can be used flexibly. With this form of thematic analysis, the interpretation moves beyond the obvious meanings within the data to find a meaning based upon the researcher’s interpretation (Braun and Clarke

2019). Data linked to the development of the theoretical model was developed using this level of interpretation. Braun and Clarke (2019) identify that thematic analysis may be sematic where the interpretation is more literal, and there is greater fidelity with the spoken words of the participants. The focus is upon what is explicitly stated. This semantic approach was used in relation to the development of the assessment.

The choice of an inductive or deductive position impacts upon data coding and interpretation. Data can be coded to provide an answer to a specific research question (Braun and Clarke 2019). At this stage of the interpretation, coding might be attached to a theoretical question such as the element of the proposed theoretical model or contributing to the development of the assessment. The model is provisional, and questions directed at developing this were flexible and varied between participants. For this element of the research, a more latent thematic analysis was carried out in defining elements of freedom, and data was interpreted beyond a semantic level. This open and exploratory approach is consistent with a position of induction. The purpose of this approach is to identify and communicate underlying attitudes, assumptions, and meanings (Braun and Clarke 2019). Where the approach is more deductive, such as the development of FREEDEM from a provisional codebook, interpretation can occur at a more semantic level (Alversson and Skoldberg 2009). A semantic approach identifies the immediate meaning to structure of the data. The interpretation of data is hybrid in approach, and the two separate interpretations (semantic and interpretative) may occupy distinct positions on the inductive deductive continuum. Knowledge is capable of revision and improvement, and the development of knowledge is not confined to a semantic or interpretative approach; either can produce new knowledge (Biesta and Burbules 2003).

5.5.2 Process of analysis

The process of analysis began with the transcription of data. Extensive analysis also began in the field with the use of field notes for note taking and reflection. The data transcription meant that the data was familiar, and patterns began to emerge before the data was transferred to NVivo 12 software. This software made the volume of data manageable and offered a consistent and transparent way of managing data. All interview transcripts were uploaded to NVivo. The field notes were maintained as a separate document, which was used to track the development of themes. While a significant amount of the analysis was done without the software, interpretation was finalised on NVivo.

Data was initially analysed on NVivo using nodes. Nodes were used to organise data from each individual transcript. Nodes were then developed across transcripts, and repetitions were reduced to a smaller number of nodes. In relation to the definition of freedom and facets of freedom, the nodes became more theoretical and interpretative. Once there had been a thorough review of individual transcripts, broader patterns were identified, refined, and reduced. The pattern became one of larger nodes that represented themes with sub-themes that represented the interpretation of data. The first level node linked to definitions of freedom was developed before coding on NVivo began. The other first level nodes linked to time and identity and carers freedom were developed during the interpretation of data. The supervisory team supported the development of themes. Visual representations of the interpretation of data are set out in the results chapter in tables nine, ten and eleven.

The initial interpretations were compared back to the original transcripts to ensure they were consistent with the participants' meanings. The overall aims and research objectives were also revisited to support the development of themes and subthemes. The field notes were referred to regularly to ensure the roots of each identified theme could be traced and explained. This allowed me to be sure whether what was being identified was a subjective account or an interpretation of the data**.** For the corpus of data linked to the existing codebook, I reviewed each interview to identify whether it was consistent with the codes developed or if these codes needed to be revisited or broadened. Data was also considered in the context of policy and to what extent this impacted upon the codes developed. Theory and policy were reviewed again where data appeared to be contradictory or address a silence within the identified codes. This created an iterative process of review of items that were included in the Delphi study.

5.6 Summary

This chapter has set out the methods and methodology used for the collection and analysis of interview data. The results from this phase of the research will be set out in chapters six and seven of this thesis. The data obtained in the interviews was analysed to form the assessment and to develop the model of freedom for PLWD. The use of interpretivism in the context of a mixed method study and pragmatism was explored. The importance of reflexivity was identified. Whilst this is generally of importance in ensuring quality in qualitative research (Williams and Morrow 2003) it is potentially of greater relevance due to first-hand experiences and the insider/outsider role of both being a former carer and OT. These roles shaped the initial research question and highlighted the importance of reflexivity in data collection.

6 Chapter Six - Findings

6.1 Introduction

This chapter sets out the findings of the semi structured interviews. The assessment is supported with a theoretical model setting out different dimensions of freedom. The model includes the input of cares PLWD and OTs into supporting or denying freedom for PLWD. To achieve this, thirty semi-structured interviews were carried out to identify different facets of freedom. By involving different groups of participants diversity of experience and commonalities between groups could be identified and used to shape the assessment and model. Data linked to the theoretical model is set out in chapter six with the development of the assessment set out in chapter seven.

6.1.1 Aims and objectives.

Aim

To develop the theoretical model of freedom

Objectives

1. To identify carer's (i) experience of deprivation of liberty and (ii) views upon the elements of FREEDEM.

2. To obtain the views of people who live with dementia upon (i) their own freedom, (ii) expectations of informal carers in facilitating freedom (iii) how freedom should be defined (iv) what elements FREEDEM should contain.

3. To define OTs current views upon freedom for people living with dementia.

Participants had experience of different points along the trajectory of symptoms of dementia. PLWD had insight into the pressure of providing care and showed concern for their potential carers. The elements of care provided, and extent of care were linked to condition progression and could not be fully foreseen by PLWD at the time of interview. Carers were interviewed at a point where symptoms of dementia had progressed significantly. Carers provided insights into the type and extent of care provided and the impact this had upon freedom. The data obtained was from different points along the timeline of stages in the condition and the nature of care as the condition progresses.

For carers freedom was compromised at both a physical and emotional level. The sacrifice of freedom was either made willingly or freedom was defended. Some participants simply could not provide more input due to the demands of work or other caring responsibilities. For these carers, their own freedom and that of the person they cared for may be compromised. The data identified conceded and defended freedom as facets of carer's freedom. These elements of freedom are set within the context of the changes in identity of the PLWD and how the passage of time and condition progression impacts upon freedom. The themes of time and identity link the data from the PLWD and carers.

OTs provide data linked to freedom from extensive experience of working with PLWD and their carers. These therapists were also able to offer data showing how policy considerations impacted upon their decisions regarding freedom for PLWD and their expectations of carers. Potential inconsistencies in clinical decision making were explored using a vignette. This highlighted how this group of staff apply clinical reasoning to high-risk situations around freedom and when restrictions upon freedom were justified.

The data obtained was extensive and to detail all the data obtained would be beyond the scope of this thesis. In keeping with the overall aim of the research the focus was upon those elements of the data which would support the development of the assessment and model. The chapter commences with a worked example of the coding process which sets out how nodes in NVivo 12 were used to interpret data. Three tables provided are followed by a worked example of how the codes were developed into the overriding theme and sub themes. Three levels of analysis occurred for the issue of carers freedom and the themes of time and identity whereas for PLWD there was more complexity, and four levels of analysis were required. The following chapter will set out the elements of the data most pertinent to the research question and development of the theoretical model.

Table 9: Stages in thematic development on NVivo.

First Level Node.	**Second Level Node.**	**Third level Node.**	**Overriding themes.**
What is freedom for people living with dementia?	Doing what I want. Going where I want. Finding my way home. Being safe. Not getting lost. Being independent. Our freedom not mine (relational autonomy). A social thing.	Positive Elements of Freedom**.**	The most important element of freedom is the choice to continue to walk outdoors and engage in activities of choice. It is also the choice to close the door and remain within the home if that feels safe. Freedom has boundaries and was encircled on a continuum by the idea of safety, activities which involved significant risk of harm were not freedom.
	The police being called. Not upsetting my family. Not bothering Neighbours. Safeguarding. Fear of becoming lost and consequences. Physical dysfunction. Anxiety.	Constraints affecting freedom	An ethic of care in the context of freedom from people living with dementia.

Table 10: Stages in thematic development on NVivo.

First Level Node.	**Second level node.**	**Overriding theme.**
Progression of dementia and impact on identity.	Family relationships (the best mum). Outgoing. Caring for others. A life of work.	Shifting identify in the context of symptom progression and the passage of time.
	Day to day. She has changed. I do not see it.	
	What would she think? Who she is or who she was? She is not my mum. I am grieving.	
	She does not know me. She does not care about me. Aggression. A red line.	

Table 11: Stages in thematic development on NVivo.

First level Node.	Second level node	Overriding themes
Carers freedom.	Constant presence. Always on my mind. Keeps me awake. Heightened awareness.	Conceded Freedom. AND Defended Freedom.
	I hardly have any. Giving up work. Not seeing friends. Losing future. I never leave her.	
	Carving out time. Defending time. Balancing demands.	
	When I meet my freedom. Social activities. Family time. Back to work. As I was.	

6.1.2 What is freedom for PLWD.

The definitions of freedom set out in Chapter 3 are based on philosophical concepts that are not explicitly linked to the experience of living with dementia or providing care. The concept of freedom and its potential definitions are debated in both philosophical and legal literature (Berlin 1969, Law Commission 2017). No statutory definition of freedom is provided within the Liberty Protection Safeguards (MCAA 2019). Within the legal literature, the 'acid test' states that a person is deprived of their liberty if they lack capacity, are not free to leave, and are under continuous supervision and control (Law Commission 2017). This definition is concerned with the absence of freedom rather than a positive definition of what freedom may be. A theoretical, philosophical, or legal perspective upon freedom may not be consistent with the lived experience of those with a diagnosis of dementia or those who provide care,

The research originated from the perspective that freedom is a positive right that should be defended. While this may appear self-evident, two participants born outside the UK were incredulous about the level of concern regarding freedom for people who live PLWD. One Black and Minority Ethnic participant living with dementia had lived in South Africa in the apartheid era, and the other, a carer, had lived in Poland in the communist era. Both regarded freedom as an intrinsic part of living in the UK. If Rorty's historicism is accepted, then freedom is situated in a cultural and social context. The definitions offered by participants occur within a specific time and place, which may impact upon their perceptions of freedom.

The elements of the definition of freedom that were prioritised by participants living with dementia were the ability to leave the home, to engage in occupations of choice, including social interactions, and to do so safely. Being safe included being able to find the way home. Participants living with dementia did not wish to cause problems to others by leaving, including carers and services such as the police. The PLWD who provided this definition had capacity and were functionally independent. The carer participants supplemented this definition with data from a time when symptoms from dementia had progressed significantly. OTs offered a professional view on freedom derived from clinical experience. This experience varied from memory assessment clinic staff who worked with people at an early stage of the condition and community staff who worked with people whose dementia was more advanced and had a more significant impact on function.

Participants living with dementia described their definition of the important facets of freedom. Their involvement is consistent with recommendations that PLWD should be involved in research that impacts them (Bryde 2016, Wilkinson and Novak 2019)**,** and rather than imposing a definition, their views should have primacy.

"Walking my dogs whenever I want to. I know my way, and I follow the same routes." PLWD 1

“It is going out and when I am out doing what I want to do.” PLWD 5

“That you can safely go anywhere and that you can get home and you will not cause any problems for any of the other people out there.” PLWD 7

The activities identified included involvement in a dementia choir, dog walking, involvement in the dementia rights movement, and driving around the UK to see family. No participant mentioned being free if they had a choice of activities within their home and access to all areas of the home. These definitions also represented a duality between two aspects of freedom, one sought and the other unwanted where restrictions upon freedom may be justified. The sought aspect is to be able to continue leaving the home safely and engage in activities of choice including social interaction. To do so unsafely and be exposed to risk was not considered freedom. It was not freedom if this included causing a nuisance to others, and if leaving the home was a cause of fear and potential harm. Restrictions upon freedom may be justified if there is great potential risk.

The question of how freedom should be defined was greeted with silence by some participants before a response was given. If OTs or carers were finding the question difficult, they were asked to consider how they would define their own freedom and whether that was or should be different from the definition PLWD may have. All PLWD were asked when they felt free and what they were doing that made them feel this.

Carers and PLWD were more inclined to mention safety, and OTs were more inclined to mention risk.

“So, when she was better going out and doing what she wanted the same as for me. Now it is getting out with help being safe she cannot do it on her own. Feeling safe”. Carers P10.

"What a question. Freedom is the choice of where they go, what they do and who with but then when people stop making wise choices, and then I suppose it is the least restrictive thing you can do". OT 1.

Safety could be compromised by physical dysfunction as well as wayfinding abilities and verbal loss. The primary concern of carers and OTs was that the person living with dementia would become lost. Carers and PLWD were not aware of the same policy frameworks as OTs (Department of Health 2010, Morgan and Williamson 2014)**.** While such frameworks have the benefit of ensuring consistency in clinical practice, it is also possible policy considerations would dictate the definition of freedom and how carers may constrain this. OT participants were all from a single employer who had informed them that locking PLWD in their homes was unacceptable, and this policy combined with the employer's instructions potentially impacted upon definitions of freedom.

6.1.3 The continuum of freedom

As set out in chapter six, a vignette was used to identify the views of participants to a situation where a PLWD had become lost and was missing overnight. It should be noted that the actions of the staff concerned were not correct in that an application should have been made to the Court of Protection for approval of the potential DOL.

Vignette

This man cares for his wife and had done so for ten years. He gets up with her in the night to take her to the toilet, washes, and dresses her, feeds her, and never leaves her. He takes her out when he can. She is independently mobile. They live on a busy road in a rural area. She left their house and garden and became lost on more than one occasion. This time she left when he was preparing food. It was evening time. She was out overnight. The police helicopter was involved in searching her and many people in the village where they live. She was found in a ditch near her home the next morning. Following this, he asked for help. Two staff came out from social services and told him that if he locked the house door and the gate, he was depriving her of her liberty. He was very upset about this. What are your views on this (PLWD and carers), or what would you do (OTs)?

Figure 12: Vignette.

OT participants all recognised the degree of risk in the vignette and accepted this was a situation where the door or gate may need to be locked with the purpose of ensuring the PLWD did not leave. One OT said the defining factor for her was whether the PLWD and carer were locked in together or if someone was locked in alone. Whilst this is understandable, the PLWD the vignette is based on someone who made concerted attempts to leave although her husband was present. Participants all recognised the degree of risk and accepted this was a situation where the door or gate may need to be locked with the purpose of ensuring the PLWD did not leave. The vignette was useful as it provoked discussion and ensured that therapists were required to respond to a realistic and high-risk situation.

“I would have said lock the gate if you want to, I will deal with legal issues later because she is in a pretty risky situation and locking a gate is not a big deal, and I would say that is fine." OT 2

"She is not being deprived of her liberty he is depriving her of death by truck when you have done everything you can to make things better for your partner, and someone comes along who is half your age and tells you that. What I would be looking at what is her aim when she goes out, what is her aim when she does that". OT 3

Carers and PLWD were incredulous about the actions of the social care staff. Only one carer thought there was some potential justification in leaving the gate open. He was the oldest carer at 89, and he refused to lock his sister's door despite several episodes of her leaving her home unsafely and hospital admissions due to her being found in the street at night. Otherwise, carers stressed safety.

"I would rather she was safe rather than die in some field somewhere. I would rather she was locked in and safe because I would want to be locked in and safe rather than be out and confused and frightened". Carers P6

This vignette also triggered a debate about the continuum of freedom. Continuum is defined as a sequence in which there is a limited distinction between adjacent elements, but the extremes are quite distinct. At one end of the continuum was the desired continued safe freedom. The vignette represented the other extreme and highlighted the distinct difference between arguing that freedom should be defended and the consequences of leaving the home unsafely. This clarified when restrictions upon leaving the home were justified. No participants felt that a definition of freedom could incorporate being lost, frightened, and cold as it is probable the person living with dementia had been in this situation. None felt this person was free by spending the night in a ditch. What is attained was not consistent with participants concept of freedom and accordingly constraints such as locked doors and gates were justified. The vignette also highlighted that the carer could be perceived as failing to take care of the safety of his partner if he unlocked the gate when they lived on a busy road.

Symptoms of dementia could impact the level of freedom the PLWD expressed a preference for. For those experiencing symptoms of dementia such as anxiety and apathy, the ability to leave the home may represent a frightening, disorientating, and unwanted experience. Some carer participants reported the person they cared for had reduced attempts to leave the home because of physical dysfunction or because they had become increasingly frightened or disinterested.

"5 minutes later, she says there is no food in the house, so I tell her that there is, and she does not need to go out and she does not seem to want to go out often she will say

as long as she can stay in the bungalow, she is happy, and I wonder if she is frightened". Carers P3.

6.1.4 Negative Freedom

Negative liberty comprises the barriers to freedom. These may be physical barriers or legal constraints upon movement. An overview of negative freedom is set out in chapter three. The vignette and participants responses to it identified that for some PLWD, the absence of barriers creates such elevated risk that it is not consistent with participants' definition of freedom. This aspect of freedom represents a 'freedom from' in the sense that there is a freedom from harm, which could include getting lost and physical injury, and is a differently defined within the data than the definition than the philosophical concept of negative freedom. Participants considered the absence of physical barriers potentially leads not to freedom but the risk of significant physical harm and distress to both the PLWD and the carer. Participants did not consider leaving the home could be defined as freedom when there was a risk of harm, including anxiety, falling, and becoming lost. These risks justified a degree of restriction.

"It depends on the stage you are at, and we do have someone at the dementia tea dance, and his wife calls him a runner. You should think about the person, their state of mind, and where they live, do they live with fields around you have just forgotten to assess the individual and consider the risks involved. If the risks are very high well, locking the door might be the only way" PLWD 10.

These restrictions purely to prevent harm cannot be equated with negative liberty. This has then been summarised as 'opposing' rather than 'negative' elements. This is consistent with the idea that negative liberty is partly comprised of a zone of non-interference. A carer impinges upon this zone by restricting freedom, but this is because of the necessity of the provision of care. The provision of care was not considered within the philosophical debate regarding a zone of non-interference.

6.1.5 Positive Freedom

Positive freedom is defined in chapter three as the fulfilment of individual purposes. Positive freedom is concerned with internal factors affecting the extent to which autonomy can be practised by individuals or groups. In terms of participants living with dementia, the concept involved pursuits, including social dimensions of freedom and favoured activities. Social groups such as those run by the Alzheimer's society offered choirs, walking, swimming, and DIY. Some participants had become actively involved in these groups for PLWD doing activities that could be equated with positive liberty. For other participants, the symptoms of dementia had produced a reduction in their activities. This was on account of low mood, apathy, and verbal impoverishment. For all PLWD, positive freedom had shifted and either increased due giving up work or for one participant involvement in a dementia rights movement.

"We looked at running a workshop for people where we were the experts, because we have dementia and we all came away three feet off the ground we had such topics such as dying well and talked about involvement of people living with dementia in making decisions we had talks in the morning then in the afternoon we split up into groups and did different things and there was a gardening section and there was a pub and because we all felt like our feet were not touching the ground we organised something else and this time we called it the big conversation." PLWD 3.

Others wish to continue to have a routine or an awareness of deterioration in their condition. For one participant, routines had been adopted following an incident where he considered ending his own life due to low mood following his dementia diagnosis. These routines offered him continued social integration and stability through the routine.

"On Tuesday I go to dementia friendly pottery, and on Wednesday I go to swimming for people who have dementia then it is a day off on Thursday, and then on Friday I go to men's shed that is every other Friday, the other Friday I go to a dementia friendly tea dance." PLWD 10.

How do those activities link to freedom?

It is feeling included being with other people who know you have dementia and help. Talking to them and enjoying their company PLWD P10

There was evidence that low mood and restricted freedom increased as symptoms progressed. One participant had deliberately shrunk his world to reduce risk and what he perceived as a burden upon his family. He achieved this by leaving his primary social group, moving to a gated community, and giving up his driving licence. OTs also identified a shrinking of the world of PLWD.

"Life becomes more constrained, and right at the end, the only things left is for people to come really close into them. There is a little bubble around them, and there are a series of losses and one less thing they can do, and it is a balance between safety and wanting to do things". OT 1

At this stage, positive liberty may be restricted by the progression of the condition. Positive liberty then fluctuates across the course of symptom development and the wishes of the PLWD. The impact of the condition upon others also affected the choices made by people living with dementia regarding their own freedom. A choice to reduce freedom could be impacted by a wish not to cause inconvenience to others. This ties into the following sub theme of 'being a nuisance. '

6.1.6 Being a nuisance

Carers and PLWD were mindful of being what was described by one participant as ' a nuisance.' An awareness of this was facilitated by a family history of dementia and insight into how the condition may progress.

“Well, the police, for one, if I got lost, I would not want them to look for me. They have better things to do than that". PLWD 2

This participant had previous experience of caring for his mother when she lived with dementia and became lost frequently. He recounted annual visits to the police station to give cards and presents to officers who had brought his mother home. He did not consider his own freedom was worth the risk that other agencies would become involved in attempting to return him home.

Carers also identified that the behaviour of people of PLWD might affect others, and this may result in restrictions to the liberty of the person who is cared for. Carers were concerned about the risk of offence to neighbours as well as potential involvement of services.

"Since July, they have told us she has been knocking on doors asking for tea and bread, that sort of thing, and they said they did not mind, but if it is late, say 11.30 at night, and she is knocking on doors, and I think they have got fed up and they want her gone". Carers P4.

Rather than a definition of freedom, this is linked to the prioritisation of freedom. At what point is individual freedom for a PLWD no longer sufficiently valuable to be protected, relative to the consumption of resources and disruption to other people? Instead, restrictions upon freedom were accepted to prevent this level of community involvement. Rather than this being resented by participants living with dementia, they were willing to accept restrictions upon their freedom if this imposed upon the freedom of others.

6.1.7 Loss of freedom and not wanting to be a burden.

PLWD did not wish to impact upon the freedoms of those who provided care. However, all those interviewed had capacity and were functionally independent. The willingness and necessity for PLWD to accept help from the people providing care may increase as symptoms progress. This can result in a degree of freedom for PLWD, which may be greater than that of the people providing care. This contradicts the earlier wishes of PLWD, but such change happens due to the progression of the condition, which may reduce insight into carer’s needs**.** At an earlier stage, however, participants living with dementia did not wish their carers to facilitate their freedom.

"Other family members have their own lives to lead, and I do not think it is fair to ask other people to give up part of their life to make sure someone else can go out and have that freedom. That is not right. There has to be an area where we say that is enough, and there is a need for additional support". PLWD P5

For carers, a distinction was drawn between preventing people from leaving and actively facilitating freedom. It was felt that the level of freedom a PLWD should have was a day-to-day issue. Fluctuations in the PLWD meant that it was possible to facilitate aspects of freedom on some days, while on other days, it would then be challenging. Carers also faced variable demands upon their own time, meaning that their ability to support freedom was changeable. It was identified that any formal expectation that carers would facilitate freedom was unenforceable, regardless of any sense of moral obligation. One carer participant who worked as a solicitor succinctly summarised her position.

“I would put it conversely something should be done if freedom is actively denied but compelling family members, I do not think you can. it would be very hard to compel family to do anything positive”. Carers P9

Therapists were inclined to say that carers should, where possible, facilitate freedom for the person they cared for. Facilitating freedom goes beyond not locking a person in their home. Instead, it was perceived as desirable to ensure the door was unlocked and the person could leave safely.

"Yes, it reasonable to ask, having that expectation can have a negative effect on the carer so it is not as cut and dried, and there is a reasonable expectation for the person to do that if they can." OT 2

These views were not consistent with any compulsion. As set out in chapter two, carers cannot be legally compelled to support freedom. The willingness of carers to support freedom is linked to defended and conceded freedom identified within this chapter.

6.1.8 Relational autonomy

Relational autonomy can be defined as the extent to which we define ourselves by our interactions with others and how autonomy may be linked to this (Walter and Ross 2014). Autonomy does not comprise freedom in its entirety but was identified as an element of positive freedom by Berlin (1969). To be autonomous, a PLWD must enjoy viable options and retain authority over her social circumstances (Christman 2005b). With one exception, PLWD felt their freedom was linked to carers and identified the importance of social relationships to both freedom and self-definition.

"We were brought on this earth not to be alone; we would not have the power of speech we would not be able to communicate otherwise. We are interconnected. It is a fundamental part of what we are". PLWD 3.

As dementia progresses, facilitating the positive freedom of another person may be achieved but may impact the person who provides care. By prioritising the needs of the PLWD, the carer may compromise their freedom and autonomy to the benefit of the PLWD. For these carer's local cafes and garden centres featured widely as safe places to go. For carers, whose own freedom was almost utterly compromised the quality of freedom provided to the person they provided care to was a source of satisfaction. One carer providing both day and night-time care found the local café a place of safe social interaction for her and her mother.

"She was 89, and we have a lovely café, and it is a Greek lady and her boyfriend, and they sang happy birthday in 3 languages, and they have really taken to her, and the young lady who runs the café and she has a friend who has recently had a baby, and when mum comes she rings her friend and they bring the baby and mum loves the baby, and they put the baby on her lap which is lovely, and it makes mum really happy while we have our coffee." Carer P6

From carers data it was apparent that the relationality of freedom increased as the condition progressed. Once people PLWD were unable to leave safely independently, the extent of their freedom was dependent upon the person who provided care. This could result in a situation where the PLWD continued to have some positive and negative freedom while the carer had little. Alternatively, both the carer and PLWD may lose freedom. During this period, the PLWD may lose capacity on the issue of leaving the home safely and going out could be challenging for carers. For one carer, the level of supervision required made it difficult to leave the home for any length of time. He said he would like to go to the pub with his wife, but if he turned his back to go to the bar, she would be gone. Trips out were challenging due to the level of vigilance required.

"A few weeks ago, Poppy and her partner were making pizza at Melton Park, and I took the children up there, and Janet, and it was quite difficult she did not want to stop

with me and the children. She got quite difficult, so I ended up having to bring her away, bringing her home." Carer P5.

6.1.9 Dementia and Ethics of Care

Chapter three of this thesis discussed the role of ethics of care in relation to PLWD. This branch of ethical thought places emphasis on social relationships, interdependence, and identity (Held 2006, Engster 2007). Barnes (2015) argued that ethics of care needs to be understood in three ways: as a way of conceptualising personal and social relations, as a set of values or moral principles, and as a practice in recognising care as a necessity for all. Care ethics also blurs the boundaries between the givers and receivers of care and places care for others in the context of relationships (Ward 2011, Brannelly 2011). The data suggest that PLWD display concern for their carers and the wider community. While the PLWD has insight, they are aware of the impact their condition may have upon the people providing care and this community. The concern for the wider community is identified in the sub theme of 'being a nuisance.' The wish of PLWD not to involve their carers in facilitating their freedom is indicative of a level of respect and care which is consistent with an ethic of care from the person living with dementia to their carers. To negate the concerns of PLWD towards their wider community and carers is potentially to disempower them. Instead, the ethic of care demonstrated flows from the PLWD to the wider community and their carer. This occurs in the context of the change of identity, which may mean that personal and social relationships may change significantly as the condition progresses.

6.2 Changes in identity across time

When the PLWD was initially diagnosed, there may be only slight changes in cognition and behavioural and psychological symptoms (Van der Lind et al 2016). As symptoms progressed, insight could decrease, resulting in changes in mood, personality, and behaviour. Carers were asked about the person they cared for before the onset of dementia. Several participants talked fondly of the person they cared for in a family or employment role, sometimes adding their sadness at how that person was lost. One participant identified that the PLWD she cared for still had insight despite significant cognitive impairment and was distressed by the potential loss of his home and condition progression.

“He knows that he is going downhill."

How do you know that he knows that?

"He says this is no life, and I cannot disagree. This is the life we have got, and we make the most of it, yes, but from being someone who was so out there and only using the house to sleep, and he has either been working or playing golf or whatever. He ran his own business; he knew everybody it is so sad" Carers P2.

Restrictions on carer's freedom are precisely what people in the earlier stages of dementia did not wish to accept. Some participants living with dementia did not wish to be what they perceived as a burden. There was also a feeling that the needs of the PLWD should not be prioritised over those of carers. The following quote illustrates these concerns in the context of a father's relationship with his children. He was very animated during this exchange, and it was clear that he felt strongly about dependency and his children prioritising his need for freedom over their own activities.

“Should family have to help someone continue to have freedom?

I feel very, very strongly you do not have your children to help.

Never expect help or ask for it I am sure it would be forthcoming, but they should not have to

What would bother you about your children helping?

They have their own lives they cannot put me first. They have work and children of their own that needs to come first” PLWD 7.

The data raised the issue about changes in identity and whether decisions regarding freedom should be made based upon the previous wishes of a person when they had capacity or when the progression of dementia means that the decisions made are different. For example, a PLWD may seek freedom at the expense of carers contradicting earlier wishes. The Cambridge English Dictionary (2020) defines identity as who a person is or the qualities of a person that make them different from others. Identity can be perceived from a biological perspective. From this perspective, our identity over time is dependent on the continuation of physiological processes (Olson 1997). Within this continued existence, a person may change but maintains the same identity.

In contrast, a psychologic identity depends on the continuity between changes. The ability to recall previous states is fundamental as without this, it is argued there is a break in the chain of identity, and the person living with dementia is transformed into someone else (Dresser 1986, 1995, Fookes 2020). The data obtained does not contradict the perspective that PLWD should be respected at their current level of cognitive function, and their wishes and preferences should be identified regardless of symptom progression. The symptoms from dementia can then be regarded as occurring within a trajectory rather than as a sudden shift in identity where decision-making should be wholly within the carer or staff's remit. This does not mean that the changes in personality are not a source of grief to carers.

"I think my mum should be able to come and go as she chooses from her flat, but if she wants to go out in her slippers in the pouring rain that is what she should be allowed to do, but then I think about my mum as she was, such a proud person and so determined to keep herself and her home nice and she would be just horrified to think of that her state of affairs." Carers P9.

As symptoms progressed, the PLWD would exhibit less care for their carers. This may be linked to changes in personality and mood. In three cases, there was physical aggression from the PLWD directed to their carer. For this carer, this could be linked to her mother forgetting who family members were. She became upset talking about how her mother had changed and how she felt she was both present and absent.

"She swears and throws things, tries to hit me, and then I just get out of the way, and then she does not remember she has done it, and so there is nothing to do about it. I say, why did you do that, and she will say, what have I done? She does not even know she has done it. It is the same with people visiting, so my brother has been, and she tried to hit him with a pan, and she denied it, and then she will get angry because she does not believe he has been there."

How do you deal with the aggression?

"Well, sometimes it is not my mum that is what I think, she has gone and then sometimes she is back but not often now" Carers P10.

OTs made clinical decisions based on how the person presented on assessment. There was no suggestion that the PLWD should be treated as separate from their previous self. Instead, there was a continuation of identity which acknowledged the changes in the person living with dementia and the impact on carers.

"I said about your dad who he was, who he is, and who he still needs to be. It is quite obvious he is not retaining information, and I said he cannot remember things long enough to make a decision, and that is at a point where it could be determined he has not got capacity, and what has changed in the 10 minutes since we said that nothing your dad is still your dad." OT 8.

6.3 Dementia and time

PLWD and carers were asked whether they were planning ahead or if they lived day to day. The level of memory and insight of participants living with dementia was variable, and this resulted in reduced planning for some participants. Five participants out of ten living with dementia had relatives who were living with or had died with dementia. The extent to which this impacted on planning was dependent on variable levels of insight participants had into their condition. Some were not concerned by the progression of a relative's condition seeing this as being in isolation from their own symptoms, and the changes in their cognitive function. However, for two participants, experience of another family member living with dementia impacted on their current views and wishes for their care.

"so, when my mum had Alzheimer's my dad could not cope with her and she got difficult with him, and he is a difficult men and they would shout and he just got worse and worse and he did not keep her clean and she died because he could not keep her clean and I wouldn't want my kids and my husband to do that, have to look after me if I behaved like that." PLWD 6.

For carers, once the demands of care were significant, they lost a future perspective upon the provision of care. The all-consuming nature of care can mean that it is difficult to have an overview of the trajectory of symptoms, and both the level of care and restriction of freedom may be the consequence of day-to-day experience rather than longer term planning. This issue was addressed directly with participants.

"We were just going day by day, and we still are." Carers P5.

Carer responses to questions about time were striking in the level of consistency. Time can be experienced through calendars and clocks but also through the past, present, and future orientation (Safford et al 2005, Jowsey 2016). Carers providing extensive amounts of care were bound by the immediate needs of the PLWD and did not have a concept of future time until the caring was interrupted by hospital admission. OTs identified that care could become all-consuming and supported the development of insight by carers for putting boundaries in place regarding the extent of care they were willing to provide. This insight may allow carers to develop an awareness of how their freedom and that of the person they provide care to may be decreasing. In addition, exploring this issue with carers at an earlier stage could prevent a crisis such as a hospital admission to identify when home was no longer an option. In the following quotes, a carer who had looked after her mother identified how the day-to-day passage of time had been interrupted by a single event of leaving unsafely and a fall. She had cared for her mother for a period of five years in an annex at her home. Initially, she described how the demands of care crept up on her.

"*Well, it is funny when you are living with someone you don't see that actual moment you are doing it almost by osmosis," Carers P1.*

The decision to no longer provide care was brought about by after her mother tried to leave to go back to a childhood home. She had fallen outside in the garden before being able to reach a busy road. This was linked to a definite point when the realisation was care could no longer be provided.

"It is for us we are worried about her safety going forward, almost like a red line we have crossed about our ability to care for her. "Carers P1.

OTs were more familiar with this situation. They identified that the way time passed for carers was linked to decision making, and it was hard for carers to see they could no longer provide the level of care necessary to maintain someone in their home.

Do you think there is an incremental nature to care?

"Yes, we used to do co-dementia training. It is a carers group, and we had a lady who helped us run the course, and she said a CPN said to her she could not do it anymore and I should feed it back to people more and make it clear to them they do they cannot see it. Sometimes people need someone to tell them. One situation I was involved in, he became physically aggressive. His daughter did not want her to let her dad go, and the daughter got quite emotional, and he had to go into care. There was quite a protracted admission, and they had to accept it" OT 1.

6.4 Carers' freedom

Carers described providing varying levels and types of care. This was dependent on the carer's willingness to provide care and the need of the PLWD, and their willingness to accept care. The dimensions of care identified were assistance with personal care (washing, dressing, grooming) and assistance with domestic activities of daily living. These activities include providing food, shopping, and housework. Carers were also involved with supervising medication and dealing with incontinence. This may include help using the toilet, the management of the changing of continence pads, washing soiled bedding, and in one case supervising someone who was unable to clean themselves after using the toilet due to deteriorating cognition. Three carers were involved in manual handling. For two, this was helping people up after frequent falls. Finance became a problem when the PLWD was unable to manage money. All carers were involved in helping to manage money for the PLWD. There was also a category of care termed 'overnight care.' This is for people who had to get up regularly in the night due to the needs of the person they cared for. This included carers who got up when the people they cared for had fallen or needed support with continence. In addition to these essential and life-sustaining elements of care, carers provided companionships and social opportunities. The dimensions of care can be linked to positive freedom. However, if the extent of the care takes several hours a day or constant supervision, this may reduce these opportunities. The following participant provided extensive night and daytime care as a live-in carer for her mother. This resulted in fatigue for both her and her mother.

“Would she go to a group with you?

No Deanne (sister) was better at taking her to groups, so by the time you got her up and dressed, you would have to have shopping and lunch, and out you would be wacked so regular groups it is not easy to have the mental energy, and she would not play ball anyway for almost everything you would have to chivvy her along," Carers P6.

6.4.1 Constant Presence

For carers, the person they cared for had a constant presence regardless of their physical location. They were constantly on the minds of the people who provided care. In the views of therapists, physical proximity may reduce some elements of the stress upon carers as the physical absence of the person who is cared for may be a source of worry and anxiety. Three carers laughed when they were asked if the PLWD was always on their minds. This was explained when they said they had not realised, until asked that the person they cared for was never away from their thoughts. There was a constant physical presence for co-resident carers (four carers) but worries about what might be happening were not as significant as for those who were not present. This meant that even those carers with more physically distant relationships experienced a shift in what could be termed mental freedom. The risk of PLWD leaving unsafely impacted upon the level of concern for carers who were not physically present.

"And the thing is I am not sleeping very well because she was so poorly when I came in it is keeping me awake at night, and I am so frightened for her at home really that she could get run over or lost, and that keeps me awake." Carers P9

OTs recognised the extent of care provided and the impact this could have upon the freedoms of carers. There was an awareness that while there may be implications of lack of time and physical demands upon resident carers, the anxieties of carers who were non-resident may be more significant.

"Yes, further way is worried more, and there is an aspect of guilt." OT 4

The guilt referred to arose from a lack of physical presence and an inability to do more for the PLWD. Regardless of the degree of physical presence, the lives of carers were changed by the act of providing care, and restrictions upon carer’s freedom may occur at differing levels of care provision. Carers had varying degrees of willingness to compromise their own freedom.

6.4.2 Conceded and Defended Freedom

Carers are divided into those who willingly gave up their freedom to provide care and those who did not wish to or could not. For those who could not provide extensive care, this could be because of work commitments or other caring responsibilities such as children. For these participants, freedom was either defended or conceded. Caring was entered into willingly by some other participants, and freedom was almost entirely sacrificed. The impact on carer’s freedom may be incremental and occur as care increases or may occur suddenly due to the increasing needs of the PLWD. For one carer, a move into her mother's home was perceived as the only option due to the number of calls to the police and hospital admissions.

"I thought someone has got to be with her to stop her from doing this. She is doing this every day because she cannot remember people numbers, but she can remember 999, and so I thought, well, the easiest way to stop her doing it is to be with her". Carers P 6

For some carers, there was an active choice to ring-fence areas of freedom and a reluctance to engage in additional care. What is significant is that carers felt they needed to state what freedom they wished to preserve. These carers could not be forced to give up their homes or break family ties and responsibilities but felt a need to justify a decision that would not be made by people not providing care. Two carers were caring with some reluctance one was the ex-wife of the person living with dementia who was living with him because he owned a share of the family home (participant carer 2). The other cared for a sister-in-law who she had never been close to (carers participant 3). Caring relationships occurred against the backdrop of the previous family relationship. A working history influenced both these carers; one had worked as a nursing auxiliary and the other as a nurse. For the participant who had worked as a nurse (P3), she was understandably keen to maintain time with other family members. These decisions regarding freedom were made in contrast to the participants who give up any idea of their own freedom.

"Saturday morning, I take my granddaughter and her brother into Arnold, and I am not stopping that. My granddaughter has special needs, and I will not stop that. I will not give that time up", Carers P3.

Conflicting demands impacted on decision making around care and freedom. Carers were not always attempting to prioritise their own freedom. Rather than this, it was an attempt, which appeared almost impossible, to juggle the demands of work, family, and care for others. Carer's needs became lost in the demands placed upon them. This was because of necessity, for example employment and for some carer's other family obligations.

"The idea of a relaxed night away is gone, and with the family holiday I stressed about cancelling that, and then I agreed with Debbie (paid carer) to go in every day, and I would call her every day, but you know every day I needed to ring her every day, and you know working full time, and it is a very demanding job, and I take my son to football on a Saturday, but the washing is always piling up, and I quite enjoy housework, but I do not do any, and it is always Oh God what are we going to eat tonight." Carers P9.

6.4.3 Meeting my future

Carers also had the possibility of independence in the future. As carers were interviewed when the person, they cared for was a hospital in-patient, this was something that some had considered. Six of the carers had organised or were considering placement in a care home. The admission represented a crisis, which had helped to make this decision that admission to a care home was necessary. This could occur suddenly because of what appeared to be a single incident. In reality, the admission was part of a chain of events and changes in the level of provision of care required. One participant cared for her mother and reported a step change, which would mean far greater supervision levels as she lived on a busy road.

"There are French doors out to the garden, and my husband walked round the side of the house, and she was there, and she had got dressed, and she had fallen and had smashed her glasses, and she was leaving the house to go to Glasgow that is where she was born." Carers P1

The potential care home admission left carers with a significant amount of time and raised the possibility of a future with greater freedom. Carers plans were not extensive as it had not been possible to anticipate when they would stop providing care. This issue is likely to be tied to the passage of time for those who provide the most care within the dimensions identified. An almost complete loss of freedom for this group meant that they were faced with sudden decisions about how their time was spent.

"There is a gardening club in the next village, and there is a walking group in the village. I would like to do that sort of thing. there is no way I could do those things now", Carers P2.

"I thought I would volunteer helping children to read or conservation work or helping older people with their gardens jobs that need doing that sort of thing just bitting and bobbing about," Carers P5.

For some carers who were not considering a care home, there was no possibility contemplated of any life beyond caring. This could be a source of regret or distress at frustrated opportunities and the possibility of a different relationship with the PLWD. For one participant, this was a source of great grief and a sense of loss at the retirement he planned with his wife. He was very distressed throughout the interview and wept when he talked about the lost plans for their future together.

"Well, when we retired, we had plans to get a caravan and go round the country, and well, well, it never happened because of the dementia. I am sorry I get upset when I talk about it". Carers P6.

6.5 Legal change and decision making about freedom.

It is currently possible to refer a PLWD to the Court of Protection for authorisation for a DOL that is imputable to the state**.** The implementation of the law relating to DOL in a private domestic setting was exceedingly rare and tended to be connected to other welfare issues. Views were sought from all participants about the state's potential to be involved with people living within their own homes. This issue was linked to decision-making about freedom and whether decisions should be made primarily by families or healthcare professionals and a judicial process.

PLWD were keen to maintain some independence from the state, feeling that their families were able to support them in decision making. They felt either that decision should remain within the family or the family's wishes should have primacy over those of external professionals. This decision was made with capacity on freedom and reflected the concern that carers would be more aware of the wishes of those they provided care to when the condition progressed rather than clinical staff.

"In principle in someone's home, no because it is someone from outside making a decision. In a care home, well, if I ended up there, I would not care, so yes, I agree with that, but in a private home, no, no in principle". PLWD 2.

"If Helen needed to lock the door for some reason, knowing her as I do, there would be a very good reason; I am lucky I have a caring family. I would trust them to make that decision." PLWD 7.

The major reason given for this view was that carers knew and cared for the PLWD. It was also identified that services were not available twenty-four hours a day, whereas a carer might be. Carers felt their views should have primacy but were more willing than PLWD to accept the input of services. Carers were generally accepting of the legal position but placed emphasis on how professionals should communicate and be involved. There was a clear understanding of the responsibility of restricting liberty and how this may impact upon the person with dementia. The legal position offered potential clarity and support in decision making.

"I guess outsiders could have a part to play, say if they have seen something work for someone else well maybe those things could work for you, but otherwise family because you know the person best." Carers 2.

All participants acknowledged that families differed, and the extent of outside involvement would depend to some extent upon the family. OTs identified that the level of input they provided was linked to the individual family, and that this also determined their approach to issues around freedom. Therapists felt an individualised approach was needed due to variable levels of support for the PLWD.

"Can we ask family carers to facilitate liberty?

A lot want to we are not asking them for anything they would not be prepared to give.

Can we ask them to do more?

Yes, and we do if they want to care. Yes, we would ask this of them because neglect might be a strong word, but if a family member is coming round daily and there is not much food in the fridge, and what there is out of date if you are adopting that role, then you need to fulfil it." OT 8.

It was identified that carers could be extraordinarily stressed, and a role of therapists in this situation was to support decision making. The difficulty this presents in terms of the law is that the legal position does not have the same degree of flexibility as a person-centred approach by an experienced therapist.

"It is a really hard dynamic when people want to support and keep people safe, and there is no right or wrong, and we might be in a balance where someone might change, and their presentation might change, and it is not a straight road there are bumps and navigating that change as a family member." OT 6.

The closest response to inflexibility was determined by policy and employers' instructions considerations. This suggested locking someone in was never acceptable. The view was also that carers should ensure the freedom of those they provided care to.

"If they want to be involved in providing care to them, then yes, I do think so, and if they will not, they have to accept the input and decision making of services it is not ok to just lock the door." OT 6.

The purpose of the vignette was to give a situation where the policy issues were highlighted and allow therapists to show their clinical reasoning in a high-risk situation. This identified that presented with this level of risk OTs made a compromise.

The definition of the concept of republican and liberal freedom is set out in chapter three. These views do not support the concept of republican or liberal freedom. Within republican freedom, the extension of a just law into the home would not be regarded as preventing freedom provided a democratic government structure was available (Pettit 1996, 1999, 2003). While within liberal freedom, such an intervention would be an example of the law interfering in what should be a private domain (Skinner 1992, 1993). There was a recognition that advice would help but at the same time an acknowledgment that families differ and that their willingness and ability to support freedom was variable. Liberal and republican freedom did not acknowledge the implications of this variability, meaning that positive and negative liberty were more realistic ways to approach the issue of freedom.

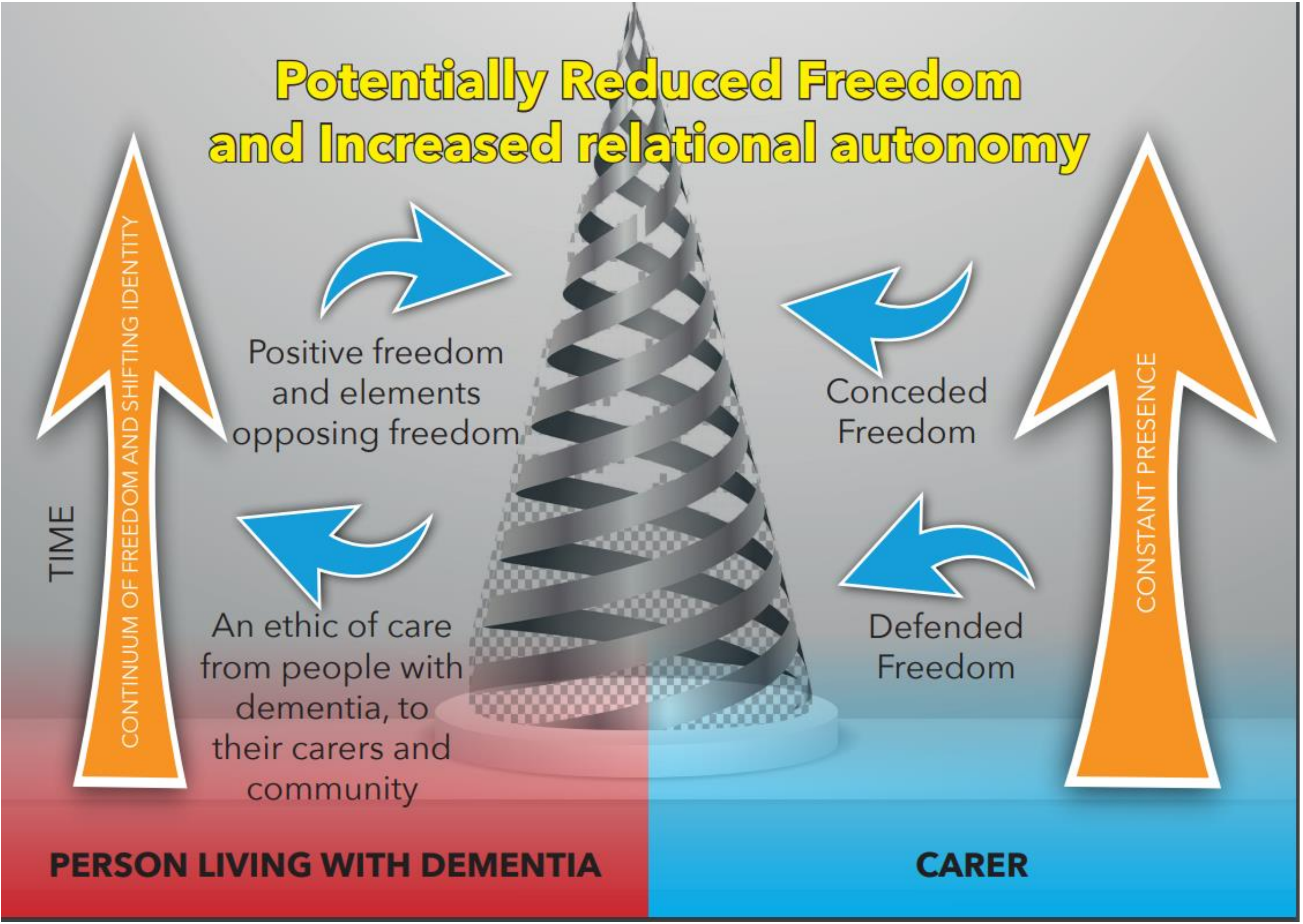
6.6 The model

Chapter three of this thesis sets out the purpose of theoretical models**.** A theoretical model identifies the area of interest and how a set of concepts are linked to this. The model represents a tool for organising information allowing for the visualisation and understanding of an interplay of complex factors identified in the empirical findings of the interview stage of the data. Some of these concepts are linked to the legal situation together with the philosophical concepts identified in chapter three. The model sets out some of the factors at play which may impact on the freedom of PLWD The inclusion of health-based perspectives allows for the complexity of the issue to be addressed and gives insight into the model's potential acceptability into clinical practice. The model is designed to dovetail with the assessment and inform the definition of freedom for PLWD.

The model is set out in diagrammatic form. The model addresses the issue of defended and conceded freedom from carers. Identifying this at a clinical level may allow for frank conversations about the carer’s willingness to support freedom. The issue of the ethic of care form PLWD to their wider community and carers may be an area that could be addressed in the context of best interest’s decision-making regarding freedom. The concept of relational autonomy helps to emphasise the importance of a caring relationship and how the freedom of the PLWD and carer are intertwined.

6.7 Summary

This chapter sets out elements of the data from the semi structured interviews. This data has been used to amend the provisional theoretical model of liberty. The data identified a definition of freedom and the facets of that definition. The chapter addressed the issues of the passage of time and changes to the identity of PLWD. The amendments to the DOL provisions were addressed with the participants and linked to the decision-making of carers and OTs. The themes identified were used to amend the provisional model of liberty set out in chapter three. This model will support the assessment of liberty set out in the following chapter.



Potentially Reduced Freedom and Increased relational autonomy

Positive freedom and elements opposing freedom

An ethic of care from people with dementia, to their carers and community

Conceded Freedom

Defended Freedom

PERSON LIVING WITH DEMENTIA

CARER

7 Chapter Seven Assessment Development

7.1 Introduction

This chapter sets out the findings of the semi-structured interviews linked to assessment development. Data was synthesised from the theoretical basis of the legal chapter (chapter two), scoping review (chapter four), and semi-structured interviews (chapter five) to develop the dimensions and content of the assessment. A provisional codebook was developed from literature review findings. The areas within the codebook were developed further through interview data. This structure is consistent with *t*he mixed methods sequential explanatory structure proposed by Plano-Clarke and Cresswell (2011).

7.2 Chapter aims and objectives.

Aim

The aim of this chapter was to develop the dimensions of the Delphi questionnaire.

Objectives

1. To synthesise the scoping review and semi-structured interview findings to develop potential assessment dimensions.
2. To synthesise legal elements of the assessment with semi-structured interview findings.
3. To define OT's current role in facilitating freedom for people living with dementia.

7.3 The rationale for assessment development method.

The assessment was developed using methods that mirror the development of a health-based scale. A scale can be defined as a set of items that each express different dimensions of a construct. The scale is then summed, achieving a total score that describes the individual's characteristics *(*Panagiotakas 2009). An assessment is flexible and more suited to the complexity of freedom for PLWD. There are potentially a wide variety of outcomes from a process of assessment rather than the numeric conclusion to a scale (Bowling 2017). The numbers interviewed in this research are lower than would be usual in the development of scale items. The smaller number of participants is consistent with a qualitative interpretivist approach to interviews where it is intended to obtain a depth of experience from participants (McChesney and Aldridge 2009). However, the structure of clinical scale development provides a useful and well-established framework that can be utilised. These stages in the development of the assessment are set out in Box 5 below.

Box Five: Stages in Scale Development

Stages in Assessment Development

- Research the intended meaning and breadth of the theoretical concept.
- Select appropriate conceptual labels and definitions.
- Identify potential dimensions and items.
- Conduct qualitative research to generate dimensions and items.
- Use expert feedback to refine the assessment.

(Boateng et al 2018. Morgando et al 2018)

7.3.1 Stage One: Research the intended meaning and breadth of the theoretical construct

The first stage of assessment development is to research the intended meaning and elements of a theoretical construct. The theoretical construct in this research is freedom for PLWD. Within scale development, the scale must be sensitive to the theoretical concept underpinning the scale (Panagiotakos 2009, Carpenter 2018). To be consistent with this element of scale development, FREEDEM must be sensitive to the underlying theoretical model of freedom for PLWD. FREEDEM gives effect to the practical steps which can be taken to address a potential loss of freedom in the context of the relationship between carers and PLWD.

7.3.2 Stage Two: Select appropriate conceptual labels and definitions.

Chapter four set out the development of a codebook from potential assessment components derived from literature, relationship centred care, and law. To develop conceptual labels, a series of codes were set up containing the areas identified in the literature review and linked to the concept of relationship-centred care and legal requirements. The codebook identified several potential areas for the assessment. These dimensions were as follows: early warning systems, telecare technology, assessment of risk, carer education, social integration, and driving.

7.3.3 Stage three identify potential dimensions and items.

The codes were developed further through the data from the semi-structured interviews to develop the provisional areas of FREEDEM. Legal requirements supplement these areas of the assessment. If a PLWD has capacity, then consent would need to be sought for any assessment. If the person lacks capacity on the issue of leaving their home, it would be necessary to identify this to carry out assessments in their best interests (MCA Code of Practice 2007). Assessing cognition gives an insight into capacity. The OT conducting the assessment would also need to be satisfied whether a DOL had occurred and if there was any necessity to refer the PLWD for authorisation for such a deprivation.

7.3.4 Stage four. Conduct qualitative research to generate dimensions and items.

The qualitative research conducted was semi-structured interviews. The topic guide contained questions about the potential assessment areas identified in the literature review. These questions were put to all participants. This meant that the acceptability of areas of the assessment to carers and PLWD could be identified. The ethical dimensions of elements of the assessment were raised and discussed to obtain differing perspectives. OTs were the most influential participants in developing areas of the assessment. Depth was added to existing areas, which arose from the perspective of OTs who currently assure the freedom of PLWD. The provision of aids and adaptations which might facilitate freedom was added to the dimensions of the assessment.

7.4 Analysis of data.

Coding of qualitative data can be done through differing levels of interpretation. Data linked to the definition of freedom were analysed using reflective thematic analysis (Braun and Clarke 2019). Data linked to assessment development was analysed at a semantic level. A semantic interpretation identifies the literal meaning of the data rather than underlying themes (Decur-Gunby et al 2011, Braun and Clarke 2019). The interview data relating to the model of freedom is an example of interpretative analysis, whereas, for the assessment development, the interview participants were asked specific questions derived from the literature review, and their answers are described (Decur-Gunby et al 2011). This is an example of coding driven by existing theory. This type of coding is not a predetermination of what the interview data will find. Instead, coding allowed for the reconceptualization of the findings identified in the literature review. Before interview data was coded a series of nodes were put onto NVivo representing the codebook dimensions. This was used as a framework for development of the assessment dimensions. Interview data was linked to the potential areas of FREEDEM.

7.5 Synthesis of data.

Assessment components were generated using data synthesised from the scoping review and semi-structured interviews. Data was synthesised using triangulation to identify complementary, convergent, and dissonance areas of FREEDEM identified in the literature review and the interviews (Denzin 2012, Flick 2018). Where there was convergence, the items were included. It was also identified if the data obtained was complementary and broadens the scope of identified items. Where there was a dissonance, this was discussed with the supervisory team and produced a wording on the Delphi questionnaire, which maximised a diversity of views. The exception to this structure is the legal requirements of the potential assessment components. These components are elements of the assessment, which include the assessment of capacity and cognition. For these elements, the interview data may change the way in which these facets of FREEDEM are implemented by staff. Following this discussion, the semi-structured interview findings linked to each assessment dimension will be set out in a table summarising the synthesis findings and which components will be taken forward to the Delphi study in the final empirical component.

The initial elements of these themes are linked to legal requirements and are derived from chapter two rather than the literature review.

7.6 Elements of Assessment

7.6.1 Assessment of cognition

This assessment component is linked to the legal requirement to assess capacity set out in chapter two of the thesis and form item two within the codebook.

All OT participants interviewed carried out both formal and functional assessments. The specific cognitive assessments mentioned in the interviews included the Montreal Cognitive Assessment (MOCA), Assessment of motor and processing skills (AMPS), and Large Allen cognitive screen (LACLS). These assessments identify cognitive deficits set out in chapter one, including cognitive, behavioural, and psychological symptoms of dementia. The individual needs of the PLWD determined the choice of assessment. The additional details from the data were complementary and provided details of the clinical reasoning behind the choice of assessment. There was a recognition that cognition assessment could be identified as threatening or distressing and that assessments with a more functional approach were less likely to upset the PLWD.

"We do the AMPS particularly if someone is struggling in a testing environment and has anxiety or there are issues around language or culture." OT 10.

Specific cognitive deficits such as memory impairment could create scores on formal testing, which created an inaccurate picture of function in a familiar environment. This highlighted that a functional assessment was of value and supplemented the overall understanding of the PLWD in a way that could not be achieved with a formal assessment.

“Well, her MOCA was nine, and that sounds bad, doesn't it, but it did not stop her coming to the door with a full face of make-up on and cooking a roast dinner. The formal assessment is one part of the picture". OT 8.

A rigid and prescriptive approach to assessment is not centred upon the individual patient and their symptoms**.** This reflects interviewees' concern that an individual approach was required, and PLWD may have distinct cultural and educational backgrounds, which would impact the choice of assessment. In addition to the legal requirements of FREEDEM, the approach to the choice of assessment was consistent with the person-centred element of relational care (Soklaridis et al 2016). Leaving staff with no discretion may ensure consistent practice but would prevent OTs tailoring assessment to the individual.

"Different services use different assessments as long as it reflects language, cultural, educational level. I think that clinical reasoning is important, and we cannot expect that everyone will react in the same way to one tool, or it will always be suitable and as a service, it is necessary to be able to use more than one tool as things may be suitable at different points". OT 6.

In the Delphi study, it was proposed that the choice of cognitive assessment would not be prescribed but rather left to the clinical judgement of the OT carrying out the assessment.

7.6.2 Assessment of capacity

This dimension of the assessment is a legal requirement rather than an issue of expert opinion. Information regarding the assessment of capacity is set out in chapter two of this thesis. Despite this, data was obtained on OTs role in assessing capacity as this is tied to OTs familiarity with the MCA 2005 and may highlight training needs to complete the assessment. Critiques of the MCA identified in chapter two (Manthorpe et al 2011, Samsi, Manthorpe, and Rapaport 2011) have highlighted implementation issues. However, the data suggested some depth of knowledge linked to the assessment of capacity amongst the OT participants. This understanding does identify a level of clinical expertise and supports the choice of this profession to carry out the assessment. All OT participants assessed capacity as a regular part of their clinical practice. Most of the assessments were informal and were carried out on every occasion there was interaction with the patient. The MCA code of practice (2007) preserves explicitly the right to make informal assessments of capacity. All participants did not carry out the formal assessment; this depended upon experience and role.

"Sometimes I will sit down and do something more formally if there is a specific question probably capacity on choosing where they lived, that is the most common one or managing medication that happens a lot too." OT 2.

"I am often the person who assesses capacity using the two stage test, and it is almost a foreign language for some of my colleagues, and I spend a lot of time banging the drum for it because often they will complain social workers are not listening to them, but I do not have a problem with that because I give them a formal in-depth assessment which they can take straight to panel and that supports the decision whichever way it goes." OT 3.

Given the potential impact of a loss of freedom, a formal assessment of capacity may be appropriate, and this will form an element of the Delphi questionnaire. If an application is to be made for formal approval of DOL, a formal assessment of capacity will be required. OTs ability to carry out the assessment of capacity on the issue of leaving home will be crucial to assessment implementation.

7.6.3 Risk assessment

Specific areas of risk were identified and discussed with OTs PLWD and carers. Dimensions of risk identified included road safety, outdoor mobility, orientation in time and place, time of day when leaving, clothing, and ability to lock and unlock the doors. The increased risk of a rural environment was also noted. These extended the single dimension of risk set out in the codebook, which defined the concept of risk in the context of positive risk-taking. Data obtained from the OTs was influenced by national policy on positive risk-taking and the concept of 'nothing ventured, nothing gained.' This document (Manthorpe and Moriarty 2010) was identified in the literature review and incorporated in making the codebook making FREEDEM consistent with health and social care policy. The literature review also identified (Clarke et al. 2009, 2011) that staff were sometimes more competent at assessing risk than finding solutions. The following paragraphs identify both the assessment of specific risks and solutions proposed by OTs. The interview findings were confirmatory otherwise. Carers considered the freedom of the person they cared for was of importance. These decisions were made in the absence of any knowledge of the policy documents. The data from carers suggests that the staff responses were not only determined by a policy decision at national and local levels. Instead, there is a general presumption in favour of freedom as a socially acceptable value (Flathman 2003). The multiple dimensions of risk identified for potential inclusion in the assessment are summarised in table 12.

"We have a risk assessment as part of our core documents, and then we have a positive risk framework, which means that we work with patients positively, so if the patients have risks, we will document those in the care plan that is based on nothing ventured nothing gained." OT 7.

"I mean, if you are caring for somebody, you want to know where they are, but if that person is capable of going out and they want to go out, they should be allowed to go out." Carers 7.

Data became more complex and challenging to synthesise when specific examples were given. Faced with a vignette developed from a carer participant's data, eight of the OTs accepted that a door might need to be locked if the risks were very significant. One OT who recognised this said seeing her mother caring for her grandmother who was living with dementia had changed her view. She did not see how her mother would be able to cope if the doors were not locked on occasion.

"I think the party line is do not lock the doors and if you can think of a better solution that is great but if there isn't one and that is the only way to manage and to keep the person at home then for short periods if they seem content it might be the best option and the one a carer can cope with." OT 9.

Two carers locked the door and hid the key, one because of night-time leaving combined with frequent falling and inappropriate clothing and the other because of his wife becoming lost and being missing overnight. Both these carers were resident and provided an extensive amount of both day and night-time care. Both considered these restrictions were justified given the degree of risk and concern for other community members

"My granddaughters were staying, and so I had left the key in the door, and Abby was up early, and he had taken his pad off, and Abby came running upstairs saying granddad is outside with a bare bottom, so I had to jump up and go and fetch him. I still do not lock the door during the day, but I do at night". Carers 2.

PLWD offered a different view, which is explored in the previous chapter. There was significantly less concern from PLWD about doors being locked by family carers in the future than from OTs. These views may appear to directly contradict those of OTs and carers but leaving unsafely occurred at a point within the progression of symptoms when actions were no longer consistent with these wishes. This issue of people being locked in is addressed in the concluding section of the assessment, where legal approval needs to be sought for some PLWD being locked in if this amounts to a deprivation of liberty, which would require authorisation.

7.6.3.1 Road safety

This dimension came within the broad area of risk assessment identified in the codebook. From the interview data, it was identified that road safety problems for pedestrians living with dementia included walking in the road and walking in front of oncoming vehicles. These issues may be linked to depth and distance perception and an inability to process vehicles approach due to visuospatial deficits. The interview data identified that a lack of road safety could only be resolved by the participation of another person, either carer, volunteers, or staff members. This only worked if the PLWD was willing to accept the supervision of another person. If this was not the case, road safety problems were likely to lead to restrictions on freedom. This dimension of risk tended to be perceived as one that could lead to a move to a care home. Carers and OTs both identified the significant risks associated with this dimension of the assessment.

"We did a road safety assessment on him, and it was just no good he went to step out in front of a motorbike, and he could not process the depth and distance of approaching objects, and that was that the only option for home was locking him in and he would try to get out, and we just could not do it." OT 6.

"We are on a country road, but it is very busy. She would be 5 seconds away from it to our mind unless John and I did 12 hours shifts. That is the only way we could do it". Carer 1.

One OT had obtained additional benefits to pay for a worker who would walk with a PLWD. In this case, the patient's wife was not physically capable of walking with him, but his road safety created significant risks to himself and other road users.

"This was about allowing him to walk more regularly, and he had to have someone walk with him, and he accepted that, and it is not always accepted some people feel very upset by that loss of independence." OT 1.

7.6.3.2 Time of day, clothing, and location.

Leaving at night was a concern for OTs and carers. As was leaving home without clothing suitable for poor weather. Understandable risks were identified, such as exposure and falling at a time when there are fewer people to observe a fall. If the PLWD was not orientated in time and place, the risks of getting lost were far more significant, and becoming lost at night had potentially profound consequences. Policy documents identified did not address the risks associated with potential exposure, but the review of the literature linked to PLWD becoming lost when driving identified this risk (Hunt Brown and Gilman 2010)

"It is more of an issue at night and not wearing appropriate clothing." OT 1.

"June stopped her the other night because she was going outside and had no cardigan or coat, so it has happened more than I realised. It is just chance they noticed her. She has been lucky". Carers P4.

The issue of time of day and clothing were linked to more general environmental issues. Two PLWD recognised that living in a rural area created potential risks and had adapted their routines. One lived on the edge of a city with a network of footpaths on his doorstep. He had stopped the countryside walks he loved due to concerns about becoming lost.

So, I just walk in a straight line to the shops and back and it is partly because you (his wife) worry, and I do not want that. I still walk everyday but just in that straight line there and back. PLWD 6.

7.6.3.3 Locking and unlocking doors

The progression of dementia and an inability to seek help or problem-solve led to situations where there were more significant restrictions on liberty. What remained of outdoor mobility had to be supervised. The issue of risk occurs alongside the progression of symptoms in the PLWD. The most problematic risks occurred in people with the most severe impairments. In these cases, there was no suggestion of positive risk-taking, and it had to be accepted that doors were locked. For these people, an application may need to be made for authorisation for their deprivation of liberty. Interestingly, in this example, there was no suggestion that the PLWD was deprived of her liberty and the team's aim was to find her and return her to her home.

"We had a lady who lived with her husband, and he was there 24/7, and she got out, and she was only in her early sixties and very physically fit, and she had been a mental health nurse, and one of the team had worked with her. He rang up and said she had gone, and everyone got in their cars and went out, and we found her with a man who had rung the police, and he realised something was wrong, and he did not want to scare her because she had no speech by then". OT 7.

Some PLWD may be unable to leave their homes due to an inability to unlock doors. This item was not identified in the literature review or codebook but was addressed by OTs and carers. The type of door a person has may impact on whether they are able to leave. Their ability to find keys and use them may be central to being able to leave the home.

"There is another lady she was not locked in, but it was because she could not find her key and she would get very upset also, I would say try your handbag, and she would find it there so effectively she was locked in," OT 1.

At the same time, as the carer's quote below indicates, the nature of the door entry/exit system may make it easier for a PLWD to leave. In this example, the PLWD had extremely limited vision and significant history of falls. This had resulted in falls both inside her flat and leaving her home alone and falling. Neighbours were involved on an almost daily basis in checking her whereabouts, and a non-resident carer was acutely aware of the risks. She was determined that her sister-in-law should be transferred to a residential setting, and the ease with which she could leave her building was a factor in this.

"now there is an electric door, so if you touch the button at the side it opens, and if she goes out, she might not take her keys, and we were going back to the flat, and she said it does not work anymore, and I showed her how to do it with the key fob and before there were two doors she would need to push open, but now it is easier for her to get out." Carers 4.

The issues identified justify the inclusion of the ability to lock/ unlock doors and as a potential assessment item.

7.6.4 Community inclusion

The code initially developed was confined to organised groups. From the interview data, this dimension divides into community-based groups, which the PLWD and sometimes carers could attend, and social inclusion in local communities. This social inclusion could include dog walking, interacting with neighbours, and shopping. Reduction in social contact, the loss of friendships, and increasing social isolation were identified in the literature review (Judge et al 2009, Keyes et al 2016, Chester et al 2016). This individual inclusion could facilitate safety when leaving the home and ongoing social contact. Interview data was confirmatory with this literature.

"It used to be that the family was part of the community, and people talked to each other, but now people lead such busy lives, but people locally know me because of the dog." PLWD 3.

"Here, the chemists know me, the shop keepers know me, and people look out for me, so that is a help." PLWD 10.

Continued social contact outside the home could be facilitated by carers and sometimes could be a source of mutual social interaction and a stress-free time for both. Both cafes and garden centres were mentioned as places where carers felt they could go with a PLWD.

OTs identified social inclusion at an individual and community level. Therapists indicated they would review the interactions of PLWD with others in their community to identify risks and appropriate social opportunities. This may include the ability to handle money and whether the PLWD could manage to plan and pay for shopping. The level of understanding in communities termed dementia-friendly may reduce isolation and support community participation. A community response may facilitate safety and chosen activity.

"The family were concerned about a relative going out on their own, and she lives in a part of the city where there is a robust network of shops who seem to really get it. This area has been on the news a few times, and shops have this arrangement, and they will ring a family and say they have been in and taken a few bits, and they will ring the family, and they will come in and pay, and if they are not well that is noticed", OT 2.

Personal social inclusion is partially comprised of personal interactions in the community of the PLWD finds themselves. Neighbours form a part of this community, and both helped to facilitate liberty and, on occasions, served as a form of safety net when the PLWD left home unsafely. Neighbours could, however, be risk adverse and anxious about the PLWD leaving their home and could both interfere with the freedom of the PLWD and cause concern for carers and professional staff, again identifying that an individual approach and assessment is required. The variability of the neighbours means that it would not be appropriate to include neighbours as a standardised element of the assessment, but in terms of general awareness of the environment of the PLWD neighbours may provide some support for freedom.

"Well, they can be terrible, and they can be great some of the warden-aided places can be great. It is difficult you cannot give them much information, and they feel a bit shunned by us. Some neighbours are better than door sensors". OT 4.

7.6.5 Formal Groups

In addition to informal community networks, this area of the assessment was split into the traditional day centre environment and groups linked to specific activities such as men’s sheds (A group for older men run by Age UK), singing for the brain, and swimming for people living with dementia. The literature review identified such groups as a positive source of advice and social inclusion for PLWD and their carers and a respite source for carers. The literature review identified confirmatory benefits but not the range of group activities the participants engaged in.

"It (the choir) is there for the power of music we thought it would finish, but it has gone from strength to strength, and we meet up for friendship, and it does not alleviate the symptoms, but it makes you a more social person," PLWD 4.

"Groups provide social inclusion and interaction and stimulation. Families will say they cannot remember going, and I will say out in that moment when they were there they got so much out if it, and if families go along, they can see that". OT 8.

Carers, PLWD and OTs all identified that experiencing the benefit from such groups was a very individual thing. People who disliked group situations would not benefit. However, for those who enjoyed group activities, these groups represented an opportunity for social engagement and interaction.

"There were long spells when they were doing nothing, and no one was talking to each other, and after we had eaten, I like to wipe up and tidy away." PLWD 1.

"She does not mix with people, she will not open up, but if it is a lovely sunny day, she would stop to chat to people she knows but not strangers." Carer P7.

The OTs identified that voluntary sector organizations like the Alzheimer's Society provided valuable groups but that services were fragmented and variable. Staff are likely to be aware of what is available in their area and need to exercise local knowledge and clinical reasoning in making these referrals. To be consistent with the person-centred elements of relational care (Clarke et al 2020), the proposed assessment needs to encompass the personality, interests, and wishes of the PLWD. Where consistent with person centred care, the assessment process would require a referral for such groups. This may comprise a formalised referral or be an element of the information provided at the point of diagnosis. The issue of continued involvement in local communities and organised groups in a way consistent with the wishes of the PLWD will form an element of the proposed assessment and be taken forward to the Delphi questionnaire.

7.6.6 Carer education

Information provision identified within the literature review focused on interventions around advice about symptoms of dementia, providing care, legal advice, and managing problem behaviour (Sarna and Thompson 2007, Devor and Renvall 2007, Dias et al 2008, Gavrilova et al 2008, Logsden, McCurry and Teri 2007). Within the interview, data participants were willing or keen to receive advice about freedom for the person cared for. Both PLWD and carers had the experience of formal taught sessions providing information about the condition. Formal sessions were run by memory cafes and voluntary sector organizations. Formal sessions were supplemented by literature, which was considered useful to varying degrees but did not always replace personalised contact.

"I saw the doctor and the social worker, and the doctor said she would leave some leaflets, and she did not. So, I went away and found out about it all online, and I told the rest of the family it was a terminal condition, and then I went and had a chat with Gill about her wishes. I told her about what the doctor had said and that it was serious. She said she wants to stay in the bungalow till she dies and what she wants at her funeral". Carer P4.

The delivery or content of information could also contribute to low mood. Four participants living with dementia had experienced a problem with low mood, and in two cases, this was tied to how the diagnosis was communicated. Some participants felt they had received more information than they wanted, meaning that any assessment of freedom would need to be delivered in a way that was acceptable to PLWD and their carers.

"Well, I have chucked quite a few books out, to be honest, and it is one day at a time, and I know my brain will deteriorate, and it is not too good now. I do not want any more information". PLWD 6.

Education and advice regarding freedom were provided individually and could be incorporated into care plans. The OTs provided this one-to-one tailored information and support depending on the needs of the individual carer. The OTs were involved in encouraging families not to restrict freedoms, and through this, they incorporated some of their recommendations in care plans.

"We did have one lady, and the dog walking was in her case plan, and she liked to walk the dog, and she always went on the same route, and that was more of an education thing for them to understand that was important to her." OT 8

OTs all identified that working closely with carers and providing information was an element of their work. This provides an interaction that could be developed to include the potential for carers to facilitate freedom. Carer education will be a potential element of the assessment and will form an element of the Delphi questionnaire.

7.6.7 Telecare technology

The definition of telecare technology and an overview of the types of technology relating to PLWD leaving their homes unsafely is set out in the literature review in chapter four of this thesis. The provision of telecare formed a potential code within the codebook. Within the body of literature, there are significant ethical issues identified (Bowes et al 2018, Robinson et al 2009, Landau 2010, Robinson 2007, Martin et al 2013 Bantry-White and Montgomery 2010, Bantry-White and Montgomery 2013, Bantry-White and Montgomery 2014) These ethical debates were linked to surveillance of the PLWD sometimes in circumstances where they were not able to consent. PLWD had mixed opinions. Some people felt safer due to the use of telecare and others under greater surveillance (Robinson et al 2007, Landau et al 2010). The ethical issues of covert usage and freedom being curtailed were debated in all studies.

During the interviews, PLWD, their carers and OTs were asked about their views upon whether telecare technology would enhance liberty or was ethically unacceptable. For those who were utilizing telecare technology (carers), their experiences of using the technology were sought. When alternatives were used (primarily mobile phones), these were discussed. The interview data identified a broad acceptance of GPS tracking. Participants living with dementia and carers did not identify any ethical concerns but identified the potential benefits. This data was accordingly contradictory in terms of the literature review findings, but the positive views towards telecare justified inclusion in the assessment.

"Yes, that might be useful on the basis of that it is a jolly good idea it is just they forget where they live that is a brilliant idea. You are doing it for their benefit". Carers P1.

"That sounds good actually. Yes, that is a really good idea. It would give me the chance of going out on my own you would know where I was". PLWD P1

Four participants living with dementia mentioned using phone apps or carrying the phone with them. These people all had capacity and had exercised choice. It is possible that the increasing acceptance of mobile phone usage even amongst older people may have contributed to the acceptance of telecare. Telecare offered the possibility of addressing ethical concerns about locking a PLWD in their home. It was felt that this course of action was significantly more unacceptable ethically than the level of surveillance inherent in tracking a PLWD.

"I want my mum safe, but now the biggest ethical decision I faced is her alone locked in the flat. That would be the worst thing". Carers 9

OTs were more reserved about the benefits of telecare technology. Participants did not have authority to order GPS tracking but would tend to assess for it and recommend the technology to families in appropriate circumstances. On occasions, a formal assessment would be required and referred for, concerns centred on the practicalities of the systems and the need for an appropriate assessment.

"It has a place, and it can help someone to be independent, but it needs to be properly assessed by someone who understands the options and the risks. It does not replace people or support networks, and it needs to be for a clear reason for a set period of time and reviewed". OT 10.

Carers who used the technology recognised both the practical benefits and problems if systems failed. One participant who did not live with the person he provided care to felt the telecare had significantly affected his stress levels. This occurred because of problems with the company monitoring the technology and the constant vigilance the system produced. In this case, the family were considering removing the alarms and felt their vigilance and daily visits provoked less anxiety and were of more significant practical benefit for their aunt.

"She (the social worker) said we do not want to restrict her freedom, and we don't, she has always been very independent, and we do not want her going into a home, but the sensors I find I am checking constantly to see what room she is in and then the alarm going off at 2.15 am and it was a false alarm and that company, they have done nothing so what good is that. I looked to see she was up last night, but I am trying not to monitor it all the time because it is a constant worry, and the sooner, they are gone, the better". Carers 3

In telecare's potential assessment area, the data and literature were more contradictory than in any other potential assessment area. The enthusiasm for telecare amongst PLWD and carers was inconsistent with the ethical concerns in the literature. If PLWD had significant concerns about the ethics of telecare, this would jeopardise the inclusion of telecare in the proposed assessment. Instead, telecare will form a proposed assessment area.

7.6.8 Driving

The data obtained in this section was entirely confirmatory with the literature identified in the sense that PLWD recognised deterioration in their driving ability or had been assessed for medical licences. Four had stopped driving due to insight into deterioration in their driving ability. Four continued to drive on medical licences.

PLWD may experience increasing difficulty driving safely, such as turning incorrectly, travelling at an unsafe speed, and becoming lost (Hunt et al 2010). Difficulties driving may be caused by decreased attention, reduced visuospatial awareness, and memory loss. These driving ability reductions may not be recognised by the PLWD and who may then be involved in a road traffic accident due to driving unsafely (Hunt, Brown, and Gilman 2010). In a consequence of a reduction in road safety, licences may be surrendered or removed. While this may help maintain public safety, losing a driving licence may impact the freedom and independence of PLWD (Carr and Ott 2010).

OTs interviewed were not involved in driving assessments but identified potential risks of a PLWD continuing to drive and made appropriate referrals or discussed the risk with carers. Participants living with dementia linked driving to freedom but identified risks that had caused participants to stop driving. Only one who had been told he was safe in a driving assessment had decided to stop anyway.

"I went for an assessment and passed, but we had already decided I might not see a problem in time, and I would think I was alright, and I would not be, and if I hurt anyone because I was not safe, that would be terrible, so we decided I had to stop." PLWD 9.

Three further participants had made their own decision to stop driving before licences were removed through a recognition that their driving was deteriorating,

"I found myself driving up the A610 at 140mph, and I did not realise I was doing it and alright. It was the middle of the night, but the speed limit is 40, and it frightened me, and so I have given it up". PLWD 2.

Participants living with dementia identified that continuing to drive was perceived as an element of freedom. Driving allowed participants to leave their homes. Driving was more than a means of transport and was within itself a chosen and enjoyed the activity. The model of liberty developed identifies that choice of activity is a component of freedom.

"I do not have a lot of freedom, and that is because I do not have a car." PLWD 6.

Difficulties arise when the PLWD wishes to continue to drive, and carers perceive they are unsafe. Three carers had the experience of the PLWD continuing to drive unsafely, and in two cases, this led to accidents. The difficulty for carers was the degree of interpersonal conflict created by trying to stop the PLWD from driving if they became unsafe. If they were not stopped, the implications were the potential for injury to the PLWD and other road users. The examples provided suggested a significant loss of road safety. If carers are responsible for making decisions regarding driving, this can cause friction between the carer and the PLWD. In these two cases, the issue of continuing to drive was a source of anxiety for carers, and it was anticipated that attempting to stop the person from driving would create significant friction.

"We took the keys off her, and that was the awful thing. We knew she should not be driving, but if we had tried to take her car keys off her, she would have gone mad. So, who do you go to? What do you do? Who can help? We did not what to do. We knew she needed to stop, but we could not just take the keys off her". Carers 5.

OTs were aware of both the risks of a road traffic accident and the potential loss of freedom that a PLWD may experience. These therapists were not responsible for the actual driving assessment, which is carried out in specialist centres but identified if there was a potential problem and then made appropriate referrals.

“Only in terms of identifying the risk and ensuring the DVLA is notified. I have often had conversations with family members it is often the carers who make the decision”. OT 1.

The literature review identified a study (Byzeuski et al 2013) that developed a toolkit that clinical staff could use in conjunction with carers and the PLWD**.** Such a toolkit may facilitate decision-making about stopping driving and facilitating the freedom of those who have chosen to stop driving or been forced to stop. This may include identifying public transport links and voluntary and private transport provisions. This creates the potential to enhance the freedom of PLWD while maintaining safety.

7.6.9 The Herbert Protocol

The Herbert Protocol is a national scheme that involves carers of people who may become lost to complete a paper form containing information about the person before the person becomes missing. The form includes details about the person's appearance, medications, and previous routines. The protocol allows for those searching to have access to vital information. Proactive use of the form prevents delay in providing this information and removes the stress of providing these details when a person is missing. The use of the protocol was described in the literature identified (Metropolitan Police 2019), but there is no evidence of its effectiveness or the views of PLWD, carers, or staff upon its use.

OTs identified that a proactive approach to completing the protocol was potentially helpful, but this was dependent on the symptoms of the PLWD. At a certain point in the progression of the condition, it could not be anticipated where the person might go if they left their home. However, if previous routines were no longer followed, it was possible the protocol could provide details of the person, including their personal appearance and how to approach them to cause the least alarm. Completion of the protocol was considered to be ethically acceptable. Some OTs already used the protocol, but this varied between services.

"We often use this it. We give it to family members to fill in, and I always say some of it will not be appropriate, and it is a way of gaining ownership and control". OT 3.

"Yes, and the post-diagnostic team they use it, and I do not know how helpful it would be it differs from area to area." OT 10.

Carers identified no issues with the completion of the protocol. In some cases, the living environment of the PLWD virtually guaranteed they could not become lost, but in other cases, the potential value of the protocol was identified.

"Yes, that would be a great idea, but there are not many police around here, so it might be more getting neighbours to help." Carer 2.

"That would be very useful otherwise. You are reacting to rather than planning". Carer 1

Identification of the missing person and information about their medical history is a logical and relatively uncontroversial step in finding them. The literature review is complementary in the sense that the protocol is identifiable from the grey literature and utilised in clinical practice.

7.6.10 Outdoor Mobility

One area not identified in the literature review was the assessment of outdoor mobility. This may identify a risk of falls and increasing problems mobilising die to dementia or comorbidities. This assessment would need to be combined with an understanding of cognitive impairment as the PLWD may have lost the ability to learn how to use a new walking aid or lack the insight to recognise declining mobility. OTs did not define specific areas neatly. Instead, outdoor mobility was one of several areas that would be assessed.

What sort of assessments do you do?

"Assessments around outdoor mobility and risks so looking at things like road traffic awareness and any areas likely to cause falls and the environment generally kerbs and uneven surfaces and it gives you an idea if they are well known in their neighbourhood, and people will be aware of them going out, and I will look at the level of insight are they are aware if they are struggling with their mobility." OT 4.

7.6.11 Equipment

Outdoor mobility was tied to the provision of equipment. This provision could be walking aids, wheelchairs, adaptations to the entrances of properties to facilitate PLWD getting in and out of their home. The provision of equipment is a central element of the role of OTs.

Do you provide equipment to facilitate freedom?

"Yes, yes, of course."

What sort of equipment?

"Walking aids, ramps, wheelchairs, that sort of thing" OT 5.

The research position of the insider potentially impacted this area of the data. Providing equipment and adaptations is so central to OT practice that initially, therapists were not questioned about these interventions. This illustrates that key areas to produce data may be omitted by an insider researcher who will fail to perceive interventions that are so commonplace that both parties assume an understanding. This assumption means that there is a silence as neither the insider researcher nor the participant perceives the necessity to explore an unarticulated shared understanding. It was only on reviewing the data that questions were introduced about equipment and freedom.

7.7 Should FREEDEM be an OT Assessment?

The data suggested OTs had limited awareness of the DOLS safeguards and the LPS. All the OTs were from a single employer who provided training on the MCA but not on DOLS. As the implementation guidance for the LPS was not available at the time of the interview, this was understandable.

Have you had any training about DOLS or training about DOL in people's own homes?

“No”

Have you heard about the liberty protection safeguards?

“No, I have heard of DOLS but nothing like that” OT 2.

Two participants had heard about the possibility of legal change but were not aware of any details or how their clinical practice might be impacted.

“I do not have to use DOLS because I am in the community, and I started looking into it and saw there was this kind of thinking that it would be in the community, and it is not quite there yet, and I was thinking I need this.” OT 4.

Two participants identified that other healthcare professionals would seek OTs advice when it came to decisions around freedom. The healthcare professionals mentioned were nurses. This may be linked to community teams' composition, comprised mainly of OTs and Mental Health nurses. The specific skills included the assessment areas identified, such as understanding of cognitive impairment and risk and how continued social inclusion could be facilitated.

When it comes to facilitating freedom, do you think that is something OTs should do?

"Yes, I do. I think we have the right skills and experience. I think the nurses in MHSOP (Mental Health Services for Older People) refer to OT colleagues for advice on these sorts of issues anyway" OT 3.

“Yes, more or less people’s habits and routines and the nurses see it and say to us sometimes there is nothing we can do but a lot of work for the OTs” OT 7.

This data suggests that the core skills to implement the assessment are present, but training would be required both in the assessment itself and in understanding DOL in the domestic setting.

7.8 Development of Delphi Elements

The assessment components were then subjected to a modified Delphi consensus. Intervention components that reached predefined consensus levels were included in the final assessment. The above elements form the provisional assessment, which will be refined through the Delphi element of the overall research design. Exposing the assessment to experts is the final stage in the development of the assessment. The table below sets out below the outcome of the interviews and which areas are taken forward to the Delphi study.

Table twelve. Components of Delphi Questionnaire.

Delphi component.	**Justification for inclusion.**	**Confirmatory/complementary/refutatory/silent where applicable.**
Assessment of cognition.	Assessment of cognition may be relevant to safety and capacity in relation to specific decisions.	Linked to legal requirements.
Assessment of Capacity.	Capacity may be assessed formally or informally. A legal requirement. A formal assessment would be required if the PLWD requires authorisation of the deprivation of liberty.	Legal requirement.
The history, lifestyle, culture, and preferences of the PLWD.	Theoretical basis through relationship and person-centred care. Assessment of freedom should be person focused and identify preferences culture history and lifestyle, rather than the therapist or organisation.	Facilitates a person-centred approach to the assessment process.
Identify the values wishes and preferences of the PLWD relating to their freedom.	Values wishes and feelings are elements of person-centred care.	Person centred care as an element of relational care is an underpinning theoretical component of the assessment process.

Delphi component.	**Justification for inclusion.**	**Confirmatory/complementary/refutatory/silent where applicable.**
The assessment should contain details of the recent history of leaving the home to identify if the PLWD is unsafe doing this.	The risks of leaving unsafely may be identified by previous events.	Complimentary from semi structured interviews with occupational therapists.
The assessment should identify the previous routines of the PLWD as these may affect their choice of route/activities on leaving home.	Occupational therapists identified that routines may identify the location of the PLWD.	Confirmatory from occupational therapists and carers.
Hazards on leaving the home. Outdoor mobility. Road safety. Orientation in time and place. Is the area urban or rural?	These risk assessments are identified in the data. These assessments were tied to the concept of positive risk-taking set out in the policy documents.	Derived from policy and semi structured interviews. Complementary in that the areas identified were more extensive than is detailed in the literature.

Delphi component.	**Justification for inclusion.**	**Confirmatory/complementary/refutatory/silent where applicable.**
Shopping Ability to manage money.	Shopping is an important activity of daily living. Problems with managing money can be used as the basis to involve shop keepers in ensuring the person living with dementia is still involved in their community.	Linked to the issue of community integration identified in policy documents and complementary with semi structured interviews.
Safeguarding concerns.	This is a legal requirement set out in the Care Act (2014).	Legal requirements in terms of safeguarding. Also, may impact upon risk taking and restrictions upon freedom.
Activities the PLWD enjoys.	This is a fundamental element of the assessment process. The assessment is centred around the PLWD.	A person-centred element of the assessment. Complementary with interview data but must be based on the personality and wishes of the PLWD.
Carers ability to support these activities.	This element is tied to the theoretical model of freedom of people living with dementia.	A degree of dissonance between interview participants meaning this element should go forward.
Carers need advice/education about the positive risks for a PLWD when leaving the home	Derived from policy documents in the literature review.	This element was identified in the literature review and data from the interviews was complementary.

Delphi component.	**Justification for inclusion.**	**Confirmatory/complementary/refutatory/silent where applicable.**
integration with the community if this is consistent with the wishes of the PLWD.	Identified from all interview participants, Consistent with policy documents.	Policy documents literature and interviews. Complementary.
The assessment should identify if there are day centres or peer support groups providing activities the PLWD enjoys.	Identified from the literature review and interview data.	Confirmatory but identified must be person centred
The assessment of freedom should include telecare products including GPS trackers and door monitors.	Identified from the literature review and police recommendations in the UK.	Refutatory in the sense no ethical concerns arose but this does not preclude this from the assessment process.
The assessment of freedom should identify types of transport other than driving.	Consistent with driving toolkit derived from literature. Also, safety on public transport.	Derived from literature review and interviews. Complementary.

Delphi component.	**Justification for inclusion.**	**Confirmatory/complementary/refutatory/silent where applicable.**
The assessment should include the completion of the Herbert protocol.	Policy driven by police forces on a national basis.	Policy driven and aimed to empower carers. Complementary with interviews.

7.9 Discussion

The synthesised findings identify a range of elements for inclusion within the Delphi questionnaire. This represents the final stage within the development of FREEDEM which is using a consensus method to refine the assessment. This included addressing the psychological and physical factors which may impact on freedom regardless of the risk of leaving the home unsafely. These factors can be present because of the awareness of dementia and the distress this may cause or because of increased apathy which form a psychological element of the condition (Yeager and Hyer 2008, Noblis and Hussain 2018). The presence of comorbidities which may impact on mobility as well as inclination to leave the home impacted upon decision making regarding freedom.

The approach to freedom was strongly influenced by the policy documents identified in the scoping review (Morgan and Williamson 2014). These documents constrained elements of the clinical reasoning of therapists and it was only through use of a vignette that these issues could be addressed. Clinical reasoning is an element of the role of therapists and is essential to the provision of well reasoning clinical decision making (Department of Health 2010). Clinicians' practice may be constrained by resource implications such as the shortage of community groups for PLWD. The issues around resource allocation may impact on the way FREEDEM is utilised. Whilst a suitable group may be sought which is aligned to a person-centred approach to assessment it may not be possible to identify such a group. Onward referrals from the assessment process will occur within the context of local resources.

The interview data derived from OTs contributed more to the potential areas of the assessment than carers or PLWD. Data from PLWD and carers contributed more to the development of the theoretical model. OTs were inevitably drawing upon the experience of working with many PLWD and carers. These participants were familiar with assessing PLWD and making referrals to other agencies where necessary but did not share the lived experience of those they worked with.

The interview data added to areas of the codebook by providing detail in specific areas. These included risk in which a variety of different dimensions were identified. The new area for assessment which was added to the questionnaire was the provision of aids and adaptations to support freedom. The provision of rails at doors, and equipment such as wheelchairs may have a significant impact on freedom and if acceptable to the PLWD could provide a mechanism by which they could continue to visit their community. This area of the assessment reveals how easily the familiar may be missed if researching your own profession and is tied to the debate on how a researcher is identified as an insider or outsider (Asselin 2003). OTs asked about adaptations were surprised as they provided these items as such a regular and familiar part of their daily work. This does not negate the importance of this provision, or the potential for these interventions enhancing freedom.

7.10 Summary

These two chapters set out the results of the semi structured interviews and form the basis of the Delphi questionnaire. The data obtained offers insights into freedom for PLWD and how that freedom may be defined. The data also provides evidence of the impact of care upon the freedom of carers and how the presence of the PLWD is an enduring one regardless of their physical proximity. The intertwined freedom of the PLWD and their carer was also identified and how as dependency upon carers increased the freedom of both was affected. The development of the assessment will now be taken forward in a Delphi study in which the assessment elements will be exposed to an inter professional group to achieve consensus upon the contents of the assessment.

8 Chapter Eight - The Delphi Study

8.1 Introduction

The preceding chapter identified steps in the development of FREEDEM. This chapter sets out the use of a consensus method to refine the FREEDEM assessment. The methods used for a Delphi consensus study and the results of the Delphi element are explained. The strengths and weaknesses of the Delphi method are addressed in the context of this study. This discussion includes focussing upon the definition of an expert within Delphi studies. The chapter will then lead to the development of the finalised assessment.

8.2 Aims of this chapter.

- To refine the FREEDEM assessment through a consensus method.

8.3 Consensus Methods

A consensus method was identified to expose FREEDEM to a wider audience and provide a basis to refine the assessment. Different consensus methods, including the consensus conference and nominal group technique, were considered. A consensus conference involves the presentation of evidence by experts to a lay panel. An audience of members of the public and the panel can then question the experts (Halcolme, Davidson and Hardacre 2008). The nominal group technique is a group process for identifying problems and solutions (Waggner Clarke and Davey 2016). Everyone gives their responses individually in writing, and there is a vote.

While these two consensus methods have the benefit of fast results, both involve face-to-face meetings of participants. However, participants who are clinicians may have insufficient time to be involved in either conferences or meetings. The same applies to carers, particularly those providing the most demanding care levels who would not have time to participate by attendance in person. Also, any face-to-face method may result in some health staff's seniority or personal characteristics, causing some individuals to dominate the discussion (Hasson and Keeney 2011).

The Delphi technique was chosen as it allows participants to respond at a convenient time and may generate a geographical spread of participants. Delphi studies have four main elements: participants are defined as experts, there is anonymity between participants, responses are sought iteratively, and classically responses are analysed for evidence of consensus (Diamond et al 2014, Treveylan and Robinson 2015).

8.4 Study Design

This Delphi used a process of email questionnaire completion. All recruitment and responses were dealt with by email. Hasson and Keeney (2011) define such a Delphi as a modified e-Delphi. Such a Delphi may be easier to complete as no postage is required, so there are no demands to leave the home within a specified time frame. Feedback on the rounds was structured with the intention of gaining consensus on the content of the assessment. In a classical Delphi, the first round would have asked the participants to identify freedom and the potential elements of the assessment (Hasson and Keeney 2011). Instead, participants' definition of freedom was set out, and potential components of FREEDEM in table twelve comprised the questionnaire.

8.5 Reporting

The Delphi study was reported in line with the Conducting and Reporting DELphi Studies (CREDES) checklist. (Junger et al 2017). A copy of the completed checklist is available in enclosure 11.14.

8.6 Development of the Delphi questionnaire

The findings from the data synthesis from the theoretical background of person-centred care, literature review, semi structured interviews, and legal requirements were used to generate statements for the first Delphi round. These statements were reviewed by the supervisory team before the Delphi study commencing. A full copy of the questionnaire can be found in Appendix 11.9.

Items 1-3 were developed due to the potential legal requirements of the study, and 7-25 were all derived directly from the literature review and interviews. Questions 4 and 5 were developed from the concept of relational/person-centred care. Question 6 recognises that freedom may be unattainable due to physical or psychological dysfunction. A significant number of PLWD have comorbidities (Bunn et al 2014, Callaghan et al 2014), which may impact on their ability to seek freedom. These conditions may include physical limitations that impact upon mobility. Psychological barriers may include anxiety or apathy, which may be pre-existing or linked to dementia as a symptom of the condition (Noblis and Husain 2018). It may be that the PLWD is content in their home environment and simply does not wish to leave. A person-centred perspective should be accepting of the individual wishes of the PLWD.

8.7 Piloting the questionnaire

The Delphi questionnaire was trialled with a group of inpatient OTs and two community therapists. The questionnaire was also piloted with a community nurse specialised in DOL and an adult director of social services responsible for coordinating the implementation of the LPS. Piloting the Delphi questionnaire is recommended by the CREDES guidelines (Junger et al 2017). This addresses the adequacy of the information provided to complete the questionnaire. Comments were requested on the design and layout, and clarity of the questionnaire. The comments were generally favourable but based on feedback during the pilot tests there were some minor changes in the wording and content. A copy of the finalised questionnaire is available at appendix 11.5.

8.8 Methods.

8.8.1 Inclusion criteria

Participants were clinical and social care staff, including OTs, nurses, doctors, physiotherapists, and social workers with greater than five years' experience working with PLWD and their carers. Expert carers were classed as people who had provided care for more than 3 years to a PLWD. To be eligible, participants were 18 years of age or older.

8.8.2 Sampling

A purposive sampling strategy was used to select participants with the appropriate level of expertise. Based on the inclusion criteria, a panel was identified of expert carers and clinical experts in the field of dementia. A sample of 30 participants was aimed for to ensure sufficient participants were remaining if any attrition occurred. There is no firm guidance for the number of participants in a Delphi study. This sample was aimed for to be able to identify differences in perspective between carers and clinicians. Such a sample size is consistent with multiple other Delphi studies (Diamond et al 2014).

8.9 Recruitment

Potential clinical panellists were contacted with an invitation email. Expert clinicians were OTs recruited through the specialist section of the College of Occupational Therapists, nurses, and geriatricians working in clinical teams with experience of working with PLWD and their carers. Nurses were also recruited through the Royal College of Nursing and geriatricians and psychiatrists through the British Geriatrics Society. Social workers were recruited through the British Association of Social Workers. An advert was placed on the relevant forums, and potential participants then contacted the researcher. For participants in local teams with the necessary level of clinical experience, local collaborators assisted with recruitment. Once a staff member made contact by email, the questionnaire was forwarded to them with a participant information sheet. A total of 27 staff participants responded.

8.10 Ethical Approval

The Yorkshire and the Humber - Bradford Leeds Research ethics committee gave ethical approval for the semi structured interviews in this study on the 12th of September 2019 (Appendix 11.8). The committee requested that the Delphi study questionnaire be referred to them as a major amendment. This step was taken, and REC approval was given on the 9th of June 2020 and is set out in appendix 11.7. Local approval was provided by Nottinghamshire healthcare research ethics department. Participants were notified that the completion and return of the Delphi questionnaire would be taken as informed consent.

8.11 Round one

A copy of the questionnaire was provided by email. Clinicians were asked for information on their clinical background and profession, current workplace, experience of working with PLWD and their carers and number of years working in this area. Carers were asked about the diagnosis of the person they care for and how long they have provided care. A synopsis of stages 1-2 of the research was provided to panellists on page one of the Delphi questionnaire. Carers were also provided with information explaining some elements of the assessment, including a definition of telecare and the assessment of cognition. Each question was rated using a four-point Likert scale for the potential to facilitate liberty and provide support to carers. A space for additional comments was provided so panellists could justify their responses or seek clarification on uncertain statements. Panellists were given a period of three weeks to complete the questionnaire with weekly email reminders. Panellists' identities were not disclosed to each other by the researcher. The supervisory team and PPI group reviewed the new assessment to ensure consistency with the feedback from phase one.

It was initially planned for there to be two Delphi rounds; however, a consensus was reached in a single round on all items in the questionnaire. The Delphi study's original plan was that all statements that reached consensus would be removed from the subsequent questionnaire and would form the basis of the assessment. The assessment was accordingly finalised from the single Delphi round.

8.12 Determining consensus

The most common method of agreement was identified by Diamond et al (2014) as a level of agreement expressed as a percentage, followed by a proportion of participants agreeing within a rating range which is pre specified. In keeping with Diamond's recommendations, the following definition of consensus was developed prior to the Delphi study's commencement. Two rounds were initially proposed.

Box 6: Definition of consensus.

- Consensus agreement was confirmed by the combined median scores of strongly agree and agree.
- Consensus was defined by a score of important (3) or very important (4).
- Statements achieving a consensus of >75% representing a score of 4 (Very Important) or 3 (Important) on the Likert Scale are included in the assessment.
- Items are not to be included in the assessment if there is a consensus score of < 75% of neither important or unimportant (2) or unimportant (1).

8.13 Data Management

The questionnaire was sent out as a word document. Data was stored on a secure encrypted password protected cloud storage area. The email addresses of participants were only retained until it was ascertained that consensus was reached.

8.14 Results

Table 13: Delphi panellists' characteristics staff.

Health care Professionals (N=16).			
Profession.	Total Number of participants.	Number dual qualified as BIA.	Number working as academics.
Occupational therapists.	10	3	
Registered general nurses.	6	1	1
Mental Health Nurses.	2		

Physiotherapists	2		
Social workers	2		
Geriatricians	2		
Psychiatrists	1		
Psychiatrists clinical/academic	1		1
Place of work			
Community	19		
Acute Care	2		
Higher Education	1		
Two or more places	4		

Number of years working with people living with dementia.			
Mean.	20		
Standard deviation.	18.8		
Median.	20		
Range.	5-35		

Table 14: Delphi Panellist' characteristics carers.

Carers N=12.	
Number of years providing care.	
Mean.	6.54
Standard deviation.	3.43
Median.	5
Range.	3-15
Age of Carers.	
Mean.	66.7
Standard deviation.	7.8
Gender.	Female N=10 Male N=2

Table 15: Level of consensus for round one all participants.

Item Number.	Item Content.	Consensus Level of Agreement.	Consensus level reached.
1.	The assessment of freedom should include a formal assessment of cognition.	89.4%	Yes
2.	Cognition should be assessed functionally for example through meal preparation or shopping.	100%.	Yes
3.	The assessment should contain a formal assessment of capacity on the issue of leaving the home.	94.7%	Yes
4.	The assessment should contain details about the history, lifestyle, culture, and preferences of the person living with dementia.	89.5%	Yes
5.	The assessment should identify the values wishes and preferences of the person living with dementia relating to their freedom.	100%	Yes
6.	Whether freedom is reduced through choice or is caused by physical or psychological	92.1%	Yes

	dysfunction should be assessed.		
7.	The assessment should contain details of the recent history of leaving the home to identify if the person living with dementia is unsafe doing this.	97.4%	Yes
8.	The assessment should identify the previous routines of the person living with dementia as these may affect their choice of route/activities on leaving home.	95%	Yes
9.	The assessment should include hazards which may make it difficult for the person living with dementia to leave the home safely e.g., steps at the entrance to the home.	97.4%	Yes
10	The assessment of freedom needs to include an assessment of the outdoor mobility of the person living with dementia.	89.1%	Yes
11	The assessment of freedom ought to include road safety of the person living with dementia including route taken remaining on the pavement, road crossing, safely (ability to judge depth and distance and speed)	94.7%	Yes

12	The assessment should contain details of orientation in time and place when away from the home.	89.4%	Yes
13	The ability of the person living with dementia to lock or unlock the door on leaving and returning should be included in the assessment.	86.8%	Yes
14	If the person living with dementia is leaving the house to shop the ability to manage money to make a purchase should be assessed.	86.8%	Yes
15	Any safeguarding concerns relating to leaving the home and engaging in activities of choice should be identified.	97.3%	Yes
16	Activities relating to freedom that the person living with dementia enjoys should be identified and form part of the assessment.	100%	Yes
17	The assessment should identify carer's capability and willingness to support the identified activities.	97.3%	Yes
18	The assessment of freedom should include whether carers need advice/education about	94.7	Yes

	the positive risks for a person living with dementia when leaving the home.		
19	The assessment of freedom should facilitate integration with the community if this is consistent with the wishes of the person living with dementia.	91.9%	Yes
20	The assessment should identify if there are day centres or peer support groups providing activities the person living with dementia enjoys.	89.4%	Yes
21	The assessment of freedom should include an assessment of whether the area is urban or rural.	78.9%	Yes
22	The assessment of freedom should include telecare products including GPS trackers and door monitors.	86.8%	Yes
23	The assessment of freedom should identify if the person living with dementia is still driving and if any advice or referral relating to this is required.	97.3%	Yes
24	The assessment of freedom should identify types of transport other than driving.	91.1%	Yes

25	The assessment should include the completion of the Herbert protocol.	84.2%	Yes

This Delphi reached consensus in a single round, and accordingly, no second round was necessary. 38 participants were recruited, comprising 12 carers and 26 staff. 34 health and social care staff participants responded to the recruitment adverts. Of these, two responded following the deadline, and four had less than five years of clinical experience of working with PLWD. A further two fell outside the professions that were to be recruited. Both were speech and language therapists**.** Of the 26 panellists, most worked in the community (77 percent), followed by those working across the community and inpatient setting (15 %). The remaining two participants were primarily academics. The mean time working with PLWD was 20 years. All participants worked within the United Kingdom.

Carers were recruited from Join Dementia Research via their online recruitment. 132 potential participants were identified. Details regarding Join Dementia Research are set out in chapter five. Of these, it was identified that 14 potential participants were unsuitable. Two had no access to email, and the remainder either no longer provided care or had no concerns that the person they cared for would attempt to leave the home unsafely. Of the remainder, 102 did not respond to the email inviting them to participate. Three questionnaires were sent out but not completed. The remaining 12 participants were included in the final analysis.

Reaching consensus in the first round may, in part have occurred as 38.4 percent of staff participants were OTs or dual qualified as a best interest's assessor/ OTs. The items in the questionnaire were derived from the work of OTs, and it is not unexpected that this group of therapists would be strongly in agreement with the proposed assessment. It was notable that while the number of doctors was lower (15.38%) (Geriatricians and psychiatrists), the majority of answers which were deemed unimportant (1) or neither important nor unimportant (2) came from this group of healthcare professionals. Carers responses reached consensus in a single round. This highlights that panel composition may be of significance in whether a Delphi study reaches consensus. In the light of this, the results were broken down further. If the Delphi questionnaire's responses are dependent on the nature of expert participants, this has implications for the definition of an expert within Delphi studies. The responses of carers are set out at table 16, other staff at table 17 and OTs at 18.

Table 16: Level of consensus carers

Level of consensus carers			
Item Number	Item Content	Consensus Level of Agreement	Consensus level reached
1.	The assessment of freedom should include a formal assessment of cognition.	100%	Yes
2.	Cognition should be assessed functionally for example through meal preparation or shopping.	100%	Yes
3.	The assessment should contain a formal assessment of capacity on the issue of leaving the home.	100%	Yes
4.	The assessment should contain details about the history, lifestyle, culture, and preferences of the person living with dementia.	74.9%	No

5.	The assessment should identify the values wishes and preferences of the person living with dementia relating to their freedom.	100%	Yes
6.	Whether freedom is reduced through choice or is caused by physical or psychological dysfunction should be assessed.	83.3%	Yes
7.	The assessment should contain details of the recent history of leaving the home to identify if the person living with dementia is unsafe doing this.	100%	Yes
8.	The assessment should identify the previous routines of the person living with dementia as these may affect their choice of route/activities on leaving home.	91.6%	Yes
9.	The assessment should include hazards which may make it difficult for the person living with dementia to leave the home safely e.g., steps at the entrance to the home.	97.4%	Yes
10	The assessment of freedom needs to include an assessment of the outdoor mobility of the person living with dementia.	91.6%	Yes

11	The assessment of freedom ought to include road safety of the person living with dementia including route taken remaining on the pavement, road crossing, safely (ability to judge depth and distance and speed).	100%	Yes
12	The assessment should contain details of orientation in time and place when away from the home.	100%	Yes
13	The ability of the person living with dementia to lock or unlock the door on leaving and returning should be included in the assessment.	91.6%	Yes
14	If the person living with dementia is leaving the house to shop the ability to manage money to make a purchase should be assessed.	91.6%	Yes
15	Any safeguarding concerns relating to leaving the home and engaging in activities of choice should be identified.	100%	Yes
16	Activities relating to freedom that the person living with dementia enjoys should be identified and form part of the assessment.	100%	Yes
17	The assessment should identify carer's capability and willingness to support the identified activities.	91.6%	Yes

18	The assessment of freedom should include whether carers need advice/education about the positive risks for a person living with dementia when leaving the home.	91.6%	Yes
19	The assessment of freedom should facilitate integration with the community if this is consistent with the wishes of the person living with dementia.	87.5%	Yes
20	The assessment should identify if there are day centres or peer support groups providing activities the person living with dementia enjoys.	68.75%	No
21	The assessment of freedom should include an assessment of whether the area is urban or rural.	68.75%	No
22	The assessment of freedom should include telecare products including GPS trackers and door monitors.	87.5%	Yes
23	The assessment of freedom should identify if the person living with dementia is still driving and if any advice or referral relating to this is required.	100%	Yes

24	The assessment of freedom should identify types of transport other than driving.	93.75%	Yes
25	The assessment should include the completion of the Herbert protocol.	75%	Yes

Table 17: Level of agreement results for Delphi round one staff excluding OTs.

Level of consensus staff excluding occupational therapists.			
Item Number	Item Content	Consensus Level of Agreement	Consensus level reached
1.	The assessment of freedom should include a formal assessment of cognition.	75%	Yes
2.	Cognition should be assessed functionally for example through meal preparation or shopping.	100%	Yes
3.	The assessment should contain a formal assessment of capacity on the issue of leaving the home.	93,75	Yes
4.	The assessment should contain details about the	93.75%	Yes

	history, lifestyle, culture, and preferences of the person living with dementia.		
5.	The assessment should identify the values wishes and preferences of the person living with dementia relating to their freedom.	93.75%	Yes
6.	Whether freedom is reduced through choice or is caused by physical or psychological dysfunction should be assessed.	93.75%	Yes
7.	The assessment should contain details of the recent history of leaving the home to identify if the person living with dementia is unsafe doing this.	93.75%	Yes
8.	The assessment should identify the previous routines of the person living with dementia as these may affect their choice of route/activities on leaving home.	93.75%	Yes
9.	The assessment should include hazards which may make it difficult for the person living with dementia to leave the home safely e.g., steps at the entrance to the home.	93.75%	Yes

10	The assessment of freedom needs to include an assessment of the outdoor mobility of the person living with dementia.	93.75%	Yes
11	The assessment of freedom ought to include road safety of the person living with dementia including route taken remaining on the pavement, road crossing, safely (ability to judge depth and distance and speed).	76.25%	Yes
12	The assessment should contain details of orientation in time and place when away from the home.	68.75%	No
13	The ability of the person living with dementia to lock or unlock the door on leaving and returning should be included in the assessment.	81.25%	Yes
14	If the person living with dementia is leaving the house to shop the ability to manage money to make a purchase should be assessed.	81.25%	Yes
15	Any safeguarding concerns relating to leaving the home and engaging in activities of choice should be identified.	93.75%	Yes

16	Activities relating to freedom that the person living with dementia enjoys should be identified and form part of the assessment.	100%	Yes
17	The assessment should identify carer’s capability and willingness to support the identified activities	93.75%	Yes
18	The assessment of freedom should include whether carers need advice/education about the positive risks for a person living with dementia when leaving the home.	87.5%	Yes
19	The assessment of freedom should facilitate integration with the community if this is consistent with the wishes of the person living with dementia.	100%	Yes
20	The assessment should identify if there are day centres or peer support groups providing activities the person living with dementia enjoys.	91.6%	Yes
21	The assessment of freedom should include an assessment of whether the area is urban or rural.	91.6%	Yes
22	The assessment of freedom should include telecare products including GPS trackers and door monitors.	91.6%	Yes

23	The assessment of freedom should identify if the person living with dementia is still driving and if any advice or referral relating to this is required.	91.6%	Yes
24	The assessment of freedom should identify types of transport other than driving.	83.3%	Yes
25	The assessment should include the completion of the Herbert protocol.	100%	Yes

Table 18: Level of agreement results for Delphi round one Occupational Therapists.

Level of consensus occupational therapists			
Item Number	Item Content	Consensus Level of Agreement	Consensus level reached
1.	The assessment of freedom should include a formal assessment of cognition.	100%	Yes
2.	Cognition should be assessed functionally for example through meal preparation or shopping.	100%	Yes

3.	The assessment should contain a formal assessment of capacity on the issue of leaving the home.	90%	Yes
4.	The assessment should contain details about the history, lifestyle, culture, and preferences of the person living with dementia.	100%	Yes
5.	The assessment should identify the values wishes and preferences of the person living with dementia relating to their freedom.	100%	Yes
6.	Whether freedom is reduced through choice or is caused by physical or psychological dysfunction should be assessed.	100%	Yes
7.	The assessment should contain details of the recent history of leaving the home to identify if the person living with dementia is unsafe doing this.	90%	Yes
8.	The assessment should identify the previous routines of the person living with dementia as these may affect their choice of route/activities on leaving home.	100%	Yes
9.	The assessment should include hazards which may make it difficult for the person living with dementia to leave the home safely e.g., steps at the entrance to the home.	100%	Yes

10	The assessment of freedom needs to include an assessment of the outdoor mobility of the person living with dementia.	100%	Yes
11	The assessment of freedom ought to include road safety of the person living with dementia including route taken remaining on the pavement, road crossing, safely (ability to judge depth and distance and speed).	100%	Yes
12	The assessment should contain details of orientation in time and place when away from the home.	100%	Yes
13	The ability of the person living with dementia to lock or unlock the door on leaving and returning should be included in the assessment.	90%	Yes
14	If the person living with dementia is leaving the house to shop the ability to manage money to make a purchase should be assessed.	100%	Yes
15	Any safeguarding concerns relating to leaving the home and engaging in activities of choice should be identified.	100%	Yes

16	Activities relating to freedom that the person living with dementia enjoys should be identified and form part of the assessment.	100%	Yes
17	The assessment should identify carer’s capability and willingness to support the identified activities.	100%	Yes
18	The assessment of freedom should include whether carers need advice/education about the positive risks for a person living with dementia when leaving the home.	100%	Yes
19	The assessment of freedom should facilitate integration with the community if this is consistent with the wishes of the person living with dementia.	90%	Yes
20	The assessment should identify if there are day centres or peer support groups providing activities the person living with dementia enjoys.	90%	Yes
21	The assessment of freedom should include an assessment of whether the area is urban or rural.	90%	Yes
22	The assessment of freedom should include telecare products including GPS trackers and door monitors.	80%	Yes

23	The assessment of freedom should identify if the person living with dementia is still driving and if any advice or referral relating to this is required.	100%	Yes
24	The assessment of freedom should identify types of transport other than driving.	100%	Yes
25	The assessment should include the completion of the Herbert protocol.	90%	Yes

8.15 Discussion

8.15.1 How can expertise be defined?

The differing results from carers, OTs, and other health and social care professionals raise the question of who is an expert? Should one group of participants be viewed as more expert than another? The Cambridge dictionary definition of an expert is a person with a high level of knowledge or skill in a subject or activity. There is limited literature defining experts in the context of a Delphi study. (Kenney et al 2001, Mullen 2003) Keeney et al (2011) warn that If panellists lack specialist knowledge, qualifications, and track records in the field, the method may be undermined. It seems likely that carers have expertise in an individual PLWD rather than the professional overview of a clinician, which will involve working with many PLWD. This definition of expert presupposes professional expertise, whereas Hardy (2004) identifies that participants may be experts by experience as with the carers within this panel. Experts may be defined through their level of knowledge not linked to a formal qualification. A qualification within a clinical setting may not be equivalent to expertise (Hasson et al 2001).

The level of expertise of participants may be a factor in determining the level of consensus. The Delphi sought to recruit panellists with clinical experience; this form of potential expertise is different from seeking experts who have publications in the relevant field. The reason for this recruitment strategy is that the assessment is to be used in a clinical setting, and clinicians' views are therefore of importance.

8.15.2 Homogenous or heterogenous panels

It is assumed that a Delphi panel that is sufficiently broad will ensure that consensus may be reached across a range of levels of experience. The perspective of a participant with limited experience will be minimized by the responses from a more experienced majority. What is absent from the literature is when the levels of consensus vary across professional groups. This Delphi includes a comparison between differing health and social care professions and carers. This reveals a significant degree of consensus within the participants who are carers (Consensus on all items other than 20 and 21) and staff other than occupational therapists (consensus on all items other than item 12). OTs reached a consensus on all items.

Baker et al (2006) identified that it is unusual to include direct comparisons between separate groups of participants within the same panel. The semi structured interviews took place with carers and OTs. The proposed assessment is based on the findings of these interviews. It is not surprising then that the assessment reached such a high degree of consensus in these two groups. The issue that arises from this is in terms of the implementation of the assessment in a multi-disciplinary setting where other professions may disagree with the content of the assessment.

There is a discussion over when the Delphi sample should be heterogeneous as in the current sample or homogeneous. This issue is tied to the definition of an expert. A wider heterogeneous sample frame can encompass a wider definition of an expert. Such an approach to sampling with a Delphi study runs contrary to the original methods as the first predictive Delphi involved small numbers of participants (Hasson and Keeney 2011). A small homogenous sample may access, for example, participants involved in higher level policy decisions. It is suggested the experience of participants in such a Delphi should be such that the findings cannot be disputed (Kenney et al 2001 Keeney and Hasson 2011). However, such a group may fail to produce a diversity of views.

The assessment would need to be acceptable to carers and PLWD. The inclusion of carers could be perceived as a potential strength but is not consistent with some definitions of expert within the Delphi literature (Kenney et al 2001, Mullen 2003). The results also suggest that the assessment may be more acceptable to carers than to the wider multi-disciplinary team. This Delphi is unusual in the inclusion of both a multi-disciplinary perspective and the inclusion of carers.

8.15.3 Strengths and weaknesses of the Delphi technique.

The study enabled a diverse group of health and social care professionals and carers to contribute to the development of FREEDEM. This group's diversity highlights one flaw with the Delphi method in that there is no clear definition of an expert. Two carers commented that they found the questionnaire hard to understand. The language familiar to clinicians may not be familiar to carers. At the same time, carers are experts in the lived experience of providing care, and their views should be acknowledged.

PLWD were not recruited to the panel. Some definitions of an expert may preclude carers or those who live with dementia. This exclusion is inconsistent with the current research agenda from, 'research on' to 'research with' PLWD (Thomas and Milligan 2018). An accessible Delphi study has been developed with people living with dementia (Morbey et al 2019). To address this, it was originally intended that the Delphi study would be discussed with a PPI group involving PLWD, but such groups were cancelled due to the Covid-19 pandemic.

Reaching consensus in a single round prevents participants from having exposure to other expert views and debates. The Delphi technique was originally conceived to obtain a range of expert opinions. This is not achieved in a Delphi, which reaches consensus in a single round. Participants were asked to identify if there were any additional comments at the conclusion of the Delphi questionnaire. Participants commented on the amount of time the assessment may take and the potential resource required, but there was no additional suggestion for the inclusion of items. The finalisation of the assessment was made possible by the reaching of consensus within a single round.

8.16 Summary

This chapter sets out the methods used for the development of the consensus method and the variable views of differing groups of participants. The definition of an expert in the context of a Delphi study was considered and how this definition may be linked to a homogenous or heterogeneous panel of participants. The chapter also considered the strengths and weaknesses of the Delphi technique in the context of this study. The implications of reaching a consensus in a single round were discussed. The finalised assessment is set out in appendix 11.12. The finalisation of the assessment was made possible by the reaching of consensus within a single round.

9 Chapter Nine - Discussion and Conclusion.

9.1 Introduction

This chapter contains an overview of the key findings of the research. The balance between risk and freedom, and the implications of positive risk taking will be considered in the light of these findings. The strengths and limitations of the research methods are identified and explored. The clinical implications of the proposed assessment will be discussed. The implementation of the assessment and potential future research are set out. Finally, there will be a conclusion to the study and a reflection upon the researcher's position.

9.2 Overview of key findings.

The primary objective of this research was to develop the FREEDEM assessment. The assessment was supported by a theoretical model of freedom. This was initially developed from philosophy. FREEDEM includes the concept of person-centred care and potential legal elements. The scoping review collected additional elements for the assessment. The provisional assessment components were used to create a codebook. Both provisional assessment components and the theoretical model were amended when data was collected from PLWD, carers, and OTs. Through semi-structured interviews with PLWD and their carers the most essential elements of freedom were defined and incorporated into a theoretical model. The data obtained in the interviews was synthesised with the findings of the literature review. This was combined with elements of the law and person-centred care to develop the FREEDEM assessment. The draft assessment was validated further in a Delphi study, which reached consensus and allowed for the final assessment development.

9.2.1 Definitions of freedom

A definition of the most important facets of freedom for PLWD was important as it is difficult to protect what has not been defined. The literature review could not identify any empirical data which sought to define freedom for community dwelling PLWD. The area in which freedom had been extensively debated was within philosophy. In this area, the term liberty was generally used. The development of the concepts of positive and negative liberty by Isaiah Berlin (Berlin 1967) was used as a framework for the initial development of a theoretical model of liberty. Berlin identified the two types of liberty may be incommensurable (Berlin 1967). In the context of current events such as the COVID 19 epidemic the philosophical discussion has value in demonstrating the potential incommensurability of two versions of liberty. In this context the freedom from disease impacts upon the freedom to engage in activities of choice.

The research has greater implications for the definition of negative liberty in that external constraints may be necessary for protection. In addition, where the risks of leaving the home are great what freedom is attained has a cost that may would regard as disproportionate. The freedom from constraints gave rise to a risk of exposure, distress and disorientation which could not be equated with a definition of negative liberty. The importance of historicism was acknowledged, and the philosophical concepts of positive and negative liberty were updated (Berlin 1967, Berlin 2002).

Participants living with dementia defined the most important facets of their freedom. Freedom includes the ability to leave the home and to pursue chosen activities. There was a social element to activities identified, such as dance and swimming groups. Other valued activities included taking holidays and dog walking. Freedom has boundaries and was encircled by the idea of safety. For all participants living with dementia, the condition had impacted upon freedom. One felt she had greater freedom, as she had stopped working and acquired two dogs. Being able to walk the dogs whenever and wherever she wished was tied to her definition of freedom. Another was involved in the dementia rights movement and felt her freedom had increased. Four other participants living with dementia felt there had been no significant changes in their level of freedom. They described continuing freedom of movement, social involvement, and involvement in activities of importance.

Literature suggests that PLWD experience a shrinking of their world (Robinson et al 2007, Duggan et al 2008). Participants were, however, at an early stage of the condition, and the carers interviewed felt that those at a later stage had lost a significant degree of freedom. Literature linked to freedom is predominantly based in care home settings (Driessen, Van der Klift and Krause 2017, Steele et al 2020). However, activities linked to freedom in a community setting were identified by participants and in the literature, including involvement in choirs for PLWD (Harris and Caparella 2014, Osman Tischler and Schneider 2016). Freedom of movement and the meaning of neighbourhood was also addressed in literature. In a walking study (Odzakovic et al 2018), it was identified that freedom of movement in the context of neighbourhoods may be tied to personal history, community, and identity, illustrating that facets of freedom have a personal subjective element. In Nothing Ventured Nothing Gained (Department of Health 2010), it was suggested there were core elements to freedom, and the facets identified may represent some of the most significant core elements.

The definition of freedom from PLWD was impacted by the wish to be free from harm. This was highlighted most clearly in the interviews using a vignette in which a PLWD had become lost and spent the night in a ditch. The purpose of this was to explore how the issue of risk may be tied to restrictions on freedom. This resulted in the identification of the continuum of freedom for PLWD. At one end of the continuum was the safe and desired freedom. At the other end of this continuum was a significant risk and a situation that participants did not consider freedom. That of being able to leave the home but becoming lost and risking serious harm. This resulted in a reframing of the concept of negative liberty. Rather than this being a freedom from barriers to attaining freedom, it represented freedom from becoming lost, cold, frightened, potential physical injury, and potential issues around safeguarding. Literature suggests that of those who become lost, there are risks of physical harm. These risks were identified in the context of the literature reviewed in chapter one of this thesis. Risks included exposure and for a small number of those who became lost death (Rowe et al 2010, Bantry White and Montgomery 2014a). However, in the Bantry White and Montgomery study only two deaths occurred out of 281 incidents. This small number of tragic deaths still highlights how difficult a balance may be between risk and safety.

Freedom was also contextual. No participant mentioned freedom to marry, to vote, engage in their religion or economic issues. In terms of marriage, this may be because nine participants living with dementia were married. As previously noted, this thesis is set in a Western democracy in a time when some potential facets of freedom may be assumed. This situating of the concept of freedom is consistent with the neo-pragmatism definition of ironist and historicism (Rorty 1998).

9.2.2 Who should make the decisions about freedom?

The PLWD all had capacity to participate in the interview and on the issues around freedom. All but one participant felt that families should make decisions about their freedom at a later stage of the condition. This participant felt that the family should do so in conjunction with professionals. Two carers considered that the decisions about freedom for the person they cared for should be theirs entirely if the person did not have capacity. The reason for this was that staff were not there all the time and did not know the person cared for as well as the carers did. Otherwise, carers were willing to make decisions with support or information from staff. OTs felt they either worked with families, or the family led on such decisions. It was understandably identified that families vary significantly in the level of support provided, which would determine the OT's actions and the level of input required.

9.2.3 Shifts in Identity and ethics of care.

The PLWD interviewed were all at an early stage of the condition. Carers provided care to PLWD at a later stage in the condition. This allowed for insights into freedom along the trajectory of symptoms. Freedom over time was linked to symptoms and changing identity, facets of freedom fluctuated over time.

The concerns of PLWD for both the people they cared for, and their wider community was consistent with the principles of ethics of care. In this context, ethics of care was defined as conceptualising people as profoundly affected by and involved in relations with others (Noddings 2013). Noddings (2013), also believed that people are, to some extent, defined by social relationships. The freedom of the person living with dementia does not then occur in isolation from those around them, including their carers and the wider community**.** This ethic of care identified in PLWD may dissipate as the condition progresses. This raises the issue of shifting identity and how the progression of dementia may impact seeking freedom has upon others. Identity may be defined as the character and purpose of an individual (Cadell and Claire 2010). Interviewing PLWD who had capacity on their place of residence and ability to leave the home and interviewing carers who provide care later in the condition allowed for insights into this shift in identity along the trajectory of symptoms.

9.2.4 Freedom and risk

While the PLWD has insight and independence, they will be able to self-regulate the degree of risk they face by altering activities and hobbies. These lifestyle alterations were very apparent in the interviews, with both a narrowing and expansion of the worlds of PLWD. This was dependent upon individual personality, previous family experience of the condition and progression of symptoms**.** A willingness to take risks may be a crucial part of self-identity (Gilmour et al 2003, Clarke et al 2010). A US study of university students (Wang et al 2009) identified that an individual propensity to take risks is influenced by life history. If identity is determined as an individual's character and purpose, this may change across time as symptoms progress. Risk may mean different things to different people (Wang et al 2009, Clarke et al 2010). Risk is based on social and cultural perspectives, and so no single approach can be adopted to the measurement and definition of risk (Mitchell and Glendinning 2007, Dickens et al 2018). OT participants carried out a range of risk assessments that were individualised and so did not contain a generic approach to risk.

A person-centred approach forms an element of relational care (Rockwell 2012). Adopting an approach to both risk and freedom begins with understanding what is important to the PLWD (Kitwood, 1997, Baldwin and Capstick, 2007). The wishes and preferences of the PLWD must be central to the decision-making process for this to be person-centred. This approach would not begin with risk, but with the individual and what has been, and is important to them. One aspect of tailoring risk enablement strategies to freedom would be to consider how individual PLWD have approached risk throughout their lives. (Wang et al 2009, Clarke et al 2010) Within this approach, to be person centred the needs of the PLWD should be met by meeting psychological needs for comfort, identity, occupational, acknowledgement, and inclusion (Kitwood 1997, Baldwin and Capstick, 2007). A shared approach to risk between clinicians, carers, and PLWD in the context of relational care has the potential to avoid misunderstandings and ensure joint decision making (Rockwell 2012).

For the majority of the participants living with dementia the approach to risk was cautious, and safety was a crucial aspect of freedom**.** While the continued involvement of PLWD in activities enjoyed prior to diagnosis was important to some participants, this was not the wish of all, and some had reduced participation in activities outside the home. Choice and control may mean a reduction in activities outside the home or an increase or maintenance of such activities.

9.2.5 Carer’s Freedom

As dementia progresses those living with the condition may attempt to leave the home unsafely impacting on the freedom of carers. Carers may also provide an increasing level of care. Data obtained from carers identified the provision of care has consequent implications for carers’ freedom. Carers may provide care due to pre-existing bonds with the PLWD. This care may be provided in the context of lifelong close and loving relationships or out of a sense of duty or obligation (Steadman Treamont and Davis 2007). While prior relationships may not link directly to the nature of care required, it may determine whether the carers will seek to preserve some freedom. For some carers, their own freedom may be defended out of necessity as there may be other responsibilities, which means that the carer cannot provide support for the freedom of the PLWD. These may be responsibilities such as care for children, other family members or employment. Carers may provide care reluctantly. One carer interviewed was providing care to a sister-in-law because she was a nurse, and it was felt that she was the appropriate family member to give this care, despite her reluctance to do so. She made it quite apparent that she had never liked her sister-in-law and yet was providing both daily care and facilitating a degree of freedom. Another was caring for her ex-husband, with whom she shared a home. The relationship had ended because of his infidelity, and he had returned to the family home because he owned a part of it and had a legal right to do so. Such more emotionally distant relationships may also give rise to a carer's wish to preserve their freedom.

The data obtained identified that during the provision of care, the PLWD becomes a constant presence in the carer's life regardless of physical presence. This constant awareness tended to be worse in those who were not resident with the PLWD. This was accepted by the clinical staff interviewed, who identified that a carer who was present may have greater demands in terms of the extent of the care provided but would be less anxious due to the presence of the PLWD. The possibility of a future without care was not contemplated by some carers. For others, a hospital admission provides insight into how life might be without the provision of care. The passage of time was linked to care in that plans were not made for the future until the hospital admission brought this issue into sharp focus. The literature on the freedom of carers was sparse, but multiple studies identify the potential demands of care, including the loss of significant amounts of time and potentially freedom (McConaghy and Caltabiano 2005, Springate and Freidman 2014, Ledgard et al 2015). However, carer's freedom is on Berlin's construction (Berlin 1967), a fundamental value. The answer appears to be in adopting a compromise where carers' rights are recognised and balanced against the rights PLWD. Berlin accepted a degree of compromise between competing rights to freedom may be necessary (Berlin 2002).

9.2.6 Relational autonomy

The data obtained highlighted how those living with dementia experienced autonomy in relationships with carers and how freedom was a shifting concept that became more linked as the condition progressed. PLWD all identified their freedom was linked to that of their carers. Carers were to varying extents willing to prioritise the freedom of PLWD over their own, but freedom may be conceded or defended depending upon the other demands upon the carer. (Dewing 2008, Robinson et al 2007). The traditional concept of autonomy was based upon independence and self-determination (Berlin 2002), which is unlikely when a significant degree of care is required. The freedom of both the PLWD and the carer are interlinked in a relationship more consistent with a relational view of autonomy (Held 2006).

There may be complete independence at an early stage of dementia, and decisions may be made jointly. As symptoms progress, the carer will be increasingly involved in making decisions until a point where the PLWD retains little independence. Carers may continue to involve the PLWD in decision making and seek to maintain their autonomy when they no longer have capacity to make a decision (Tyrell et al 2006, Dickens et al 2013). The intertwined autonomy of the carer and PLWD brings a relational perspective to living with dementia. This is reflected in the theoretical model and the FREEDEM assessment in the inclusion of both a person centred and relational approach to the assessment of freedom.

9.2.7 The Policy Implications

The study was timely given increasing concerns about positive risk taking for PLWD in relation to their freedom. This is illustrated in the Department of Health publication Nothing Venture Nothing Gained (2010). This document was consistent with the Joseph Rowntree Foundation document - How can positive risk-taking help to build dementia friendly communities (2014). Both documents had a significant impact on the clinical practice of OTs. The policy of positive risk taking accepts a social perspective in which freedom for PLWD is partially determined by social attitudes rather than an underlying condition. In these policy documents, the taking of risk is argued for as a positive experience.

Within the risk enablement section of nothing ventured, nothing gained (2014), all problems can be neatly solved by assessing risk and putting plans into place. For the carers interviewed, decisions to restrict freedom were nuanced and linked to the person's condition and environment. Carers spoke of their own fears of harm to the person they cared for when attempting to balance freedom with safety. There is a gap between theory and practice in that neat solutions are not always possible. The difficult compromises that Berlin identified between the conflicting rights of diverse groups concerning freedom are still pertinent (Berlin 1978) but are unacknowledged within the policy document. The issue of positive risk taking is laudable provided it is consistent with the wishes of the PLWD and achievable for their carers.

9.2.8 The social model of disability

A social perspective on disability argues that disability is created by social and attitudinal barriers rather than physical or cognitive dysfunction (Oliver 1990. 2013). It is questionable whether a social model of disability is wholly consistent with the experience of most people who live with dementia. Priestly and Rabiee (2002) identify that whilst the majority of people in the UK who live with a disability are over the age of 65, the Disability Rights movement has primarily been involved with the rights of younger disabled people. It has been suggested that there is a degree of ageism within the social model of disability and consequently within the disability rights movement (Thomas and Milligan 2018). This has resulted in the exclusion of PLWD. The rights of PLWD tended to be progressed within organisations exclusively for PLWD, rather than the broader disability rights movement (Thomas and Milligan 2018). Dementia as a disability may be perceived as being not wholly based within a social model (Shakespeare, Zellig, and Mittler 2019). Some impacts of the condition upon cognition, mood, personality, and physical function are not socially determined and instead sit within physical changes to brain matter, creating these symptoms. However, a societal response may still ensure greater freedom by increased understanding of dementia and a stance of person-centred respect for those living with the condition. In addition, a supportive environment such as a dementia friendly community may support continued social integration as the symptoms of dementia progress (Morgan and Williamson 2014, Shakespeare, Zellig and Mittler 2019),

9.3 Implications for clinical practice.

9.3.1 How the assessment tool might map onto the specific assessments under the MCA/LPS

The FREEDEM assessment has the potential to be linked to the implementation of the LPS. This includes OTs being involved in specific assessments under the MCA/LPS including the assessment of cognition, capacity, and best interests. OTs are involved with both informal and formal assessments of capacity (Swinson, Wenborn and Hines 2013) and these assessments could be linked to the capacity assessment within the LPS. The FREEDEM assessment would provide information about the potential risks of the individual leaving their home and this would inform the reasonable and proportionate assessment within the LPS (MCAA 2019). By identifying the risks of leaving the home it would be apparent if any restrictions upon freedom were reasonable and proportionate. The inclusion of carers views within the assessment process would support the consultation duties within the LPS by identifying which parties should be consulted, and what their role may be in supporting or denying freedom to the PLWD.

All OT interviewees were experienced in assessing capacity and cognition. The familiarity with DOLS and the LPS was more limited, and this may in the future be an area of development for OTs. The assessment potentially leads to a greater level of involvement from OTs in assessing freedom and the LPS. In future training upon the safeguards may need to be a core element of the training for OTs.

9.3.2 Risk Taking

The practice of OTs was tied to policy documents advocating positive risk taking (Department of Health 2010, Morgan, and Williamson 2014). Elements of this include identifying and mitigating risk and then deciding whether the reduced risk should be taken in view of the benefits. This led to a focus on freedom and gave support to clinical decision making around risk. However, the danger was that a focus on policy would prevent the therapist from exercising individualised clinical reasoning.

The assessment would potentially support this individualised clinical reasoning and lead to a degree of consistency in clinical practice. This would be a more significant level of guidance for less experienced staff members and would be a source of training and support for clinical decision making. However, much within the assessment would be familiar to experienced OTs and was derived from their best practice. There would be a more limited need to have extensive training on the assessment dimensions for experienced staff and more on the legal position.

There is an emphasis in policy documents on a multi-disciplinary approach to risk and risk-taking, which is not consistent with a profession specific approach to risk (Department of Health 2010, Grand, Casper and MacDonald 2011). This emphasis on a multi-disciplinary approach within policy is recommended in the absence of evidence of its effectiveness in the context of freedom. It is intended to consider the assessment's acceptability and feasibility as the next step in its development to begin developing the evidence base for a profession-specific approach. The involvement of other professions may occur later in the development of the assessment.

9.4 Research implications

The research took place within a time of fast-paced legal change with implications for freedom. The research was shaped by this legal change (MCAA 2019) and the initial inability to predict how the law might be amended and subsequently enforced. Carrying out research in a fast-moving policy or legal environment may produce research that is timely and relevant. The research may be able to have greater integration in a time of change when clinical practice is shifting. However, there is no ethics pathway for the research, ensuring that such research could be carried out and completed in a timely way to ensure this relevance (NHS research ethics 2020). The risk is then that such projects, while highly relevant would not be well-timed, reducing the likelihood of research implementation. One viable way forward is consideration of the research question and aims of the research proposal. Such research may need to be narrowed to staff participants impacting on the ethics pathway. Alternatively, the aims of the research may need to be generalised beyond the specific issues linked to policy or legal change. In this case, the research had to be broadened from the initial proposal linked primarily to the legal amendment. The definition of facets of freedom developed was wider than any legal definition proposed, and accordingly, the implications of the assessment go beyond legal approval for a DOL.

9.5 PPI

A key element of this research was the involvement of PPI to shape and develop the assessment. A PPI group was used, which contained PLWD and carers. This was done to ensure that while PLWD were not participants in the Delphi study, they would continue contributing to the assessment development. OTs also piloted the assessment, which contributed to the development of the process maps and the Delphi questionnaire. The greatest challenge related to PPI was the impact of Covid -19 upon these groups. Some ongoing PPI input was obtained from a local group for PLWD and their carers'. These sessions offered the opportunity to expose the assessment to a broader audience. In addition, the University of Nottingham's Dementia and Frail older person's PPI group resumed online meetings. Their feedback helped to provide direction to the research. The group reviewed study documents, and their insights helped to amend the interview topic guide.

9.6 Research method strengths and weaknesses

9.6.1 Mixed Methods Research

The use of mixed methods forms an established framework, which was a strength. A sequential explanatory mixed methods approach was used. This has been called the assessment development structure (Cresswell and Plano Clarke 2011). MMR was chosen to allow for the incorporation of a policy and legal perspective. Mixed methods approaches are widely used in health research and allow for a breadth of research methods (Biesta 2010, Hathcoat and Meimer 2015). MMR includes the strengths of both qualitative and quantitative research. There have been criticisms of such an approach as seemingly attempting to integrate research methods from differing traditions, which could be deemed incompatible. This is due to differing traditions of date collection and interpretation and epistemological viewpoints. This can be reconciled using a neo pragmatic standpoint to research methods (Biesta 2010). Neo pragmatism does not prescribe any specific research method to create knowledge. Knowledge and progress are linked to the development of language which is not exclusive to any single research method (Rorty 1979). MMR is identified as particularly useful in addressing complex issues such as incorporating philosophy, law, and dementia in the current thesis (Kaushik and Walsh 2019). The sequential exploratory approach adopted allowed for the building of the assessment and theoretical model through stages.

To include PLWD, it was necessary to assess capacity and ensure participants felt comfortable discussing issues linked to future care and freedom. The depth of data sought could be appropriately obtained using qualitative methods; however, the literature review identified research from all research traditions, and excluding quantitative literature would have presented less breadth in the overall research findings. Within a purely quantitative approach to the issue of liberty, it would be difficult to achieve this depth of data and ensure that the views of the person living with dementia were included fully.

9.6.2 Involvement of people living with dementia.

This research began from the perspective that PLWD should be involved in research which affects them. This is consistent with current guidance on the inclusion of PLWD in research (The Scottish Dementia Working Group Research Sub-group 2014). Some participants had a degree of memory impairment, difficulty with abstract concepts and speech. Freedom is a very abstract concept, but those participants having difficulty with abstraction could still account for changes in their lives linked to freedom that informed research findings. One participant had some word finding difficulty but was able to talk round topics when he could not find the precise word. Inclusion of this group of participants was a clear strength and gave the research a degree of credibility it would not have otherwise. It also ensured the research was not paternalistic, as the views of PLWD were integral to the definition of principal elements of their freedom.

It is also possible that the selection criteria impacted upon the facets of freedom that participants identified as important. All participants had capacity upon leaving their homes and were at an early stage of their condition. All left their home regularly and were free to use all areas of their homes as they wished. OTs frequently advise that PLWD are prevented from using the stairs meaning that a whole floor of a house is unavailable to the occupant. In extreme cases the stairs may be walled off (Fraker et al 2014). Alternatively, the nature of a rooms use may be changed. Cookers may be disconnected microwaves and kettles may be removed (Fraker et al 2014). Baths may be taken out and replaced with showers. Such an impact on a private home could be perceived as a loss of freedom. Potentially participants with a more significant level of cognitive impairment would have considered being able to use all areas of their homes and choose activities within the home are facets of freedom.

9.6.3 The use of Guidelines

The research was reported using established guidelines. For the qualitative element of the thesis, the COREQ guidelines were used (Tong, Sainsbury, and Craig 2007). For the quantitative element, the Delphi study, guidelines for Delphi studies' conduct and reporting were utilised to provide structure and clarity (Junger et al 2017). The scoping review used the Joanna Briggs institute guidelines to provide a structure to the literature review (Peters et al 2020). The use of such frameworks helps guide a doctoral researcher and provides structure to the thesis elements. The frameworks also have implications for quality and provide input into the development of research skills by identifying vital elements of components of the research.

9.6.4 Feasibility Study

Within the timeframe available, it was not possible to develop a thorough feasibility study to identify issues around the assessment's acceptability and feasibility. This was to some extent attributable to the timing of the implementation of the liberty protection safeguards. It was initially planned the safeguards would be implemented in October 2020, but during this research, the timescale was delayed to 2022 (Whately 2020). This meant that refining the assessment to be linked to the development of the safeguards was not possible. The development of the FREEDEM through a feasibility study will be carried out during post-doctoral work.

9.6.5 Profession Specific Interviews

It was also a possibility that the assessment could be critiqued on the basis that it is to be carried out by OT rather than being a multi-disciplinary document. This was not an issue identified in the Delphi stage or interview stage but as the clinical interviewees were OTs and a substantial minority of the Delphi participants were also in this group, there is the possibility of a shared professional identity being an element of the production of FREEDEM (Kasperiuniene and Zydziunaite 2019). To address this in a future post-doctoral stage of the research, the assessment could be opened to a broader group of professionals. For example, mental health nurses could complete elements of the assessment, and it would be possible to identify any differences in the completion of the assessment between professional groups. It would also be possible to involve other healthcare professionals in a wider PPI group to identify if OTs should exclusively complete the assessment.

9.6.6 Interviews with carers present.

The participants living with dementia were interviewed with their carer in eight of the ten interviews. Consent for the carer to be present was obtained in all cases. Decisions about who should be present in an interview may affect the nature of the data gathered (Norlyk, Haahr and Hall 2016). Arguably, interviewing the PLWD alone would allow the person to express their thoughts and feelings without judgment from their partner (Eriksson Asplund and Svelund 2010). As some of the questions were about expectations of the carer, it might be that their presence affected how the questions were answered. Despite this, one participant had a degree of aphasia, which caused word finding difficulties, His wife kindly rephrased questions in a far blunter way than the role as a researcher allowed resulting in an answer. Guidance on carrying out interviews with PLWD (Samsi and Manthorpe 2020) suggests there is no correct answer, and the only option is to be transparent about the method used and recognise the potential advantage and disadvantages in the presence of a carer.

9.6.7 BAME Participants

Some of the study did not represent the cultural diversity of the UK population. Of the participants living with dementia, one participant was born in South Africa, and one carer defined herself as Polish not British. Both had the experience of regimes which they regarded as oppressive compared to the UK. Both wondered why I was asking about freedom in a country they regarded as free. Research suggests that there may be more intensive family support within specific cultural groups (Bottesford, Clarke and Gibb 2011), which may impact expectations of carers and PLWD to the extent that freedom should be prioritised. This potentially represents an area for research by a team with the appropriate cultural knowledge and standpoint.

9.7 Future research implications

To progress the current research, the assessment's acceptability and feasibility will need to be explored further. Exploratory studies play an essential role in refining assessments and interventions before carrying out a full trial. Such a study may be a pilot or feasibility study, and there is debate within the research community about how these terms may be defined (Arain et al 2010, Eldridge et al 2016). Eldridge et al (2016) propose that in a feasibility study, the question should deal with whether something can be done. Whether we should proceed with it and how. A pilot study asks the same questions but is a smaller version of the potential main trial (Ariane et al 2010, Thabane et al 2010). There is some ambiguity regarding the characteristics of such studies, but NIHR have provided a definition of feasibility and pilot studies. The definition of feasibility and pilot studies is set out in the box below.

Box seven: NIHR Definition of Feasibility and Pilot Study

- Standard deviation of the outcome measure which is needed in some cases to estimate sample size.
- Willingness of participants to be randomised.
- Willingness of clinicians to support recruitment.
- Numbers of eligible patients' carers or other appropriate participants
- Characteristics of the proposed and, in some cases, feasibility studies might involve designing a suitable outcome measure.
- Follow up rates responses to questionnaires adherence/compliance rates ICCS in cluster trials etc.
- Availability of data or the usefulness or limitations of a particular dataset
- Time needed to collect data.
- Pilot studies are smaller versions of the main study used to assess if all the components can work together. It is focused on the main study processes, for example, to assess if recruitment, randomisation, treatment, and follow-up assessments can work together. It resembles the main study in many respects, including an assessment of the primary outcome. In some cases, this will be the first phase of the substantive study, and data from the pilot phase may contribute to the final analysis; this can be referred to as an internal pilot, or at the end of the pilot study the data may be analysed and set aside as a-so called external pilot.

This definition provides a useful starting point to address concerns about a lack of clarity in the definitions of pilot and feasibility studies. Several issues would need to be addressed in a feasibility study prior to moving onto a pilot study. This would include using the assessment in a clinical setting and exploring the assessment's acceptability to carers and PLWD. There is an ongoing lack of agreement within the research community as to which outcome measure to use to evaluate effectiveness in psychosocial research

(Harrison et al 2016, Moniz- Cook 2008). The identification of a suitable measure would need to take place in future research.

This thesis does not contain an economic assessment, but this is an element that could be explored post doctorly. There is no recent economic analysis of the deprivation liberty safeguards (Shah et al 2011), but in cases imputable to the state, solicitor fees may total many thousands of pounds, in addition to the expense of the court time and time of the healthcare professionals involved. The expense of the DOLS was given as one reason for their amendment. An economic analysis would identify the cost effectiveness of the assessment compared to the expense of the judicial process.

9.8 Thesis Conclusion

9.8.1 Reflexivity and reflection

This research has identified the importance of reflexivity. I used reflexivity to challenge my preconceptions about the potential views of carers. In this context, I considered I came to the research occupying two primary roles as an OT and former carer. Both roles had the potential to impact upon the collection and interpretation of data. As an OT, I was aware that the profession is not mentioned at all in the MCA guidance (2007) or law commission impact assessment on the LPS (Law Commission Impact Assessment 2017). I considered and still that OTs have a set of valuable skills to contribute to the FREEDEM assessment. This perspective is that of an insider, and I believe the feasibility of the assessment should be opened to other professional groups to challenge the role of OTs further.

I consider, however, that the role that had the greatest influence was that of a former carer. I interviewed one OT who had also provided care, and she indicated this had impacted on her views relating to freedom. I used the field notes to identify how my experience as a former carer affected my views and could impact data collection. One event during this time is very memorable. On a family holiday, my sister went out taking her three-year son with her. At that point, she had little speech. The place we were staying was a farm cottage with farm animals and a stream running outside. My mother and I went to find her, and my mother was frightened. We found my sister and nephew on the village green where my nephew had made friends with three older men who seemed to find him very entertaining. They had kept him chatting because they were worried about him being out with my sister. He was not frightened at all. Neither had been at actual risk, but we could not have known that.

I still believe it would have been acceptable to lock my sister in rather than allow her to leave with a small child. However, I also feel locking her in alone at other times was acceptable. This is because I feel my mother was entitled to lock the doors to go shopping or take the dogs for a walk. I do not feel that a carer needing short breaks is unreasonable. If the doors were not locked my sister would go out and leave all the doors open. I believe a carer is entitled to take these short breaks knowing the PLWD is safe, and the security of their home is not compromised.

Reflexivity is not only about a moment-to-moment interaction but also is an element of the broader research design. Caring gave rise to this research question, and these experiences were a resource that helped me understand the carers better. The carers interviewed had views different from mine. They all took any potential loss of freedom for the person they cared for cautiously and regarded reducing freedom as a significant and complex decision. In our case, a young child's involvement may have made decisions more straightforward, but I did not find restricting my sister's freedom a difficult decision to make even when her son was not involved. Despite this, the carer participant's different opinions and views could be expressed and identified as reflexivity gave me insight into my feelings and experiences. This allowed me to hear and explore views different from my own.

9.8.2 Aims and objectives.

The following are the aims and objectives set out in chapter one:

1. Explore the philosophical and legal definitions of freedom.
2. Explore how people living with dementia and their carers define their freedom.
3. Develop a theoretical model of freedom for people living with dementia.
4. Identify what components of an assessment may support freedom for people living with dementia.

5. Identify the current role of occupational therapists in ensuring freedom for people living with dementia.
6. Develop a person-centred assessment of freedom.

This thesis has explored the philosophical and legal definitions of freedom. More is known about how PLWD and their carers define freedom. A theoretical model of freedom for PLWD has been developed. A person-centred assessment of freedom has been produced containing a person centred and relational element. The role of OTs in ensuring freedom for PLWD is clearer. In the influential report Nothing Venture Nothing Gained (2010), it was noted that there was little research to rely upon about interventions that enhanced positive risk-taking beyond risk assessments. The assessment provides a person-centred range of potential solutions to enhance this freedom. Data about how elements of freedom may be enhanced for PLWD is a core element of this thesis contributing to filling this gap in knowledge. The intertwined freedom of PLWD and carers has been set out and adds some new knowledge to the body of research relating to dementia and care in a domestic setting. This includes additional information about the constant presence of the PLWD in some carers thoughts whether they are physically present or not. This was a small study completed primarily by a doctoral researcher, and accordingly, there is potential to research the issue of freedom and dementia further. In particular, PLWD and carers' views about how the assessment could be implemented to enhance freedom from a potential future research direction.

9.9 Summary

This chapter has set out an overview of the research and conclusion. The chapter includes a critique of the methods used and future potential direction for the research. A reflection is provided on how the researcher's experiences are linked to the research question and the use of reflexivity. The overall findings and methods are set out and strengths of weaknesses of the research are reviewed in the context of relevant literature.

It is intended that the assessment will guide clinical reasoning and provides a framework to ensure freedom is maximised. The issue of liberty cannot be decided on a binary basis. Rather, a complex process of clinical reasoning would be involved, which would be impacted by the individual, family, and extent of the local area and community resources.. The assessment may also address freedom for those who have capacity but for whom their capacity is borderline. In either case, the assessment has the potential to enhance freedom for those who may not come to the attention of services and for whom legal protection may not be enforced. It remains to be seen whether the implementation of the LPS will enhance this freedom and how this might be achieved.

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10.1 Statutes

Adults with Incapacity Act (2000) https://www.legislation.gov.uk/asp/2000/4/contents

Care Act 2014 available from http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Data protection act 2018 available from https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted

Disability Discrimination Act 1995 https://www.legislation.gov.uk/ukpga/1995/50/part/II

Equalities Act 2010 available from: https://www.legislation.gov.uk/ukpga/2010/15/contents

Health and Social Care Act (2014) https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Human Rights Act available from https://www.equalityhumanrights.com/en/human-rights/human-rights-act

Management of Health and Safety at Work Regulations (2019) https://www.legislation.gov.uk/uksi/1999/3242/contents/made

Mental Capacity Amendment Act (2019) HMSO available from www.legislation.gov.uk/ukpga/2005/91/contents

Mental Health Act 1983 https://www.legislation.gov.uk/ukpga/2007/12/contents

Race Relations Act 1976 https://www.legislation.gov.uk/ukpga/1976/74/enacted

Sex Discrimination Act (1975) HMSO available from: https://www.legislation.gov.uk/ukpga/1975/65/enacted

The Mental Capacity Act (2005) HMSO available from: https://www.legislation.gov.uk/ukpga/2005/9/contents

10.2 Caselaw

Essex County Council v RF (2015)

Guzzardi v Italy (1980 Series A No 39), 7367/76, [1980] ECHR 5, (1980) 3 EHRR 333

HL v. UK (2004) - App no 45508/99; 40 EHRR 761

P v Cheshire West and Chester Council and another; P and Q v Surrey County Council [2014] UKSC 19

Rochdale Metropolitan Borough Council v (1) KW by her friend Celia Walsh (2) PK (3) MW Court of Protection 2014 case number 1245518

Staffordshire County Council v SRK & Another [2016] EWCA Civ 13

11 Appendices

11.1 Data extraction form

Data extraction form	
Review Details	
Scoping review title	
Review Objectives	
Review Question	
Reviewer	
Date	
Inclusion/Exclusion Criteria	
Population (People who live with Dementia)	
Concept (assessments or interventions linked to freedom)	
Context (Community Private Dwelling)	
Publication Information	
Study unique ID number	
Citation details	
Country	
Demographics	
Population/Sample	
Study design	
Interventions/Assessments Yes/No	
Describe the intervention/assessment	
Conclusion	
Include **Exclude (provide rationale)**	
Additional comments	

11.2 Interview Protocol

Introductions

- Introduce self and explain current job role. Thank participant for agreeing to be involved.
- Check participant information sheet has been read.
- Reassure participant of confidentiality and anonymity.
- Remind that interview will be recorded.
- Check if participants have any questions.
- Sign consent form if appropriate.

For participants living with dementia

- Talk about involvement in other research studies and discuss.
- Discuss home and area.
- Check their home circumstances.
- Check diagnosis.
- Review their understanding of research study.

Closing

- Thank for participation and remind how data will be used.
- Ask for feedback on interview if appropriate.

11.3 Consent Form

CONSENT FORM

Version 1.0 Date 3.06.2019

Title of Study: The development of an occupational therapy assessment of liberty for people living with dementia.

REC ref:

Chief Investigator: Doctor Sarah Goldberg

Name of co-investigator: **Cathy Brewin**

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number 1.0 dated xxxx for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group, and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to this data and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the final report or other publications ☐

5. I agree to take part in the above study. ☐

________________________ _________________ ________________________

Name of Participant Date Signature

________________________ _________________ ________________________

Name of Person taking consent Date Signature.

Participant Information Sheet For people living with dementia.

11.4 Sample participant information sheet

(Final version 1.0: 15.07.2019)

IRAS Project ID: 257586

Title of Study: The development of an occupational therapy assessment of liberty for people living with dementia.

Name of Chief Investigator: Doctor Sarah Goldberg.

Local Researcher: Cathy Brewin

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

As dementia progresses it becomes more difficult to make some decisions. This includes decisions about whether it is safe to leave home. Carers may prevent those they care for from leaving or prevent access to some areas of the home to keep them safe. This may place restrictions upon the freedom of people who live with dementia. The purpose of the study is to develop an assessment of liberty which ensures people who live with dementia have freedom and supports carers in providing care. The purpose of the study is to develop an assessment that ensures people who live with dementia have freedom and supports carers in providing care.

Why have I been invited?

You are being invited to take part because you have a diagnosis of dementia I wish to hear about your experiences of providing care and how this has affected you I wish to hear your views about your own freedom as the condition of your loved ones has progressed, and your views on the proposed legal change. We are inviting ten participants like you to take part.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

If you agree to take part

- You will have a confidential interview of up to one hour. I will ask you about your views on freedom for people living with dementia, your experience of your cared for person attempting to leave the home unsafely and your views of the change in the law. This interview will be recorded and can take place in a confidential area on a hospital ward or your home.

- You may be asked for a follow up interview if we agree their would-be further information you could provide or if the first interview is making you tired.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

I do not think there is any risk to taking part in the study as all I need is some time to interview you. The topics I am discussing may be distressing as we need to talk about dementia and the impact this has on you. I have experience of working with people living with dementia so please do not worry if you become distressed. If you need any further support or advice your GP can organise this. I can also provide you with details of organisations that can provide support and advice.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to facilitate the freedom of people who live with dementia.

What happens when the research study stops?

The results of this study will be submitted to peer review journals and be presented at conferences and included in a PhD thesis. It is expected this will be towards the end of 2020. We will send you any publications arising from this research if you wish to see these. If so I will need to obtain consent from you to hold your details You will not be identified in any report/publication.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting PALS (Patient Advice and Liaison Service) telephone 0800 183 0204.

In the event that something does go wrong, and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security), and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for 7 years after the end of the study so that we are able to contact you about the findings of the study. This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time, your data will be disposed of securely. During this time, all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's, and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I do not want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the research study?

The results of this study will be submitted to peer review journals and be presented at conferences and included in a PhD thesis. It is expected this will be towards the end of 2020. We will send you any publications arising from this research if you wish to see these. You will not be identified in any report/publication.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by The National Institute for Health Research

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Bradford and Leeds Research Ethics Committee.

Further information and contact details.

Co-investigator Name: Cathy Brewin Tel. Number: 07437 327639 email Catherine.brewin@nottingham.ac.uk Chief Investigator: Name: Doctor Sarah Goldberg Tel. Number: 0115 8230543 email sarah.goldberg@nottingham.ac.uk

1.5 Topic Guides

5.1 People living with dementia.

Topic	questions and prompts	Aims addressed
Home and social circumstances	Is this your home. How long have you lived here? Who do you live with	Demographics/ description
Introductory understanding of diagnosis	When did you receive your diagnosis? How does dementia affect you day to day? Who provides care now or in the future? How is their health/do they work/provide care to anyone else?	Description
Freedom/Liberty	Do you go out as much as you used to? How do you think this may change as your condition progresses? How do you define your freedom? What activities are linked to freedom	3(i)

Decisions about current and future care	How do you feel about needing care in the future? Have you thought about your future care and what would happen if you could not make your own decisions	3 (i) and (ii)
The liberty protection safeguards	How do you define your freedom? How important is this even if you think it might not be safe. Who should make decisions about your freedom if this becomes difficult for you? How do you decide if something is safe to do? Should decisions about your freedom ever be made outside your family? Should your carer have a duty to make sure you are free to do what you want to? How would you want to be kept safe if you were trying to leave unsafely	3 (i) and (ii)
Assessment	How would you feel about using a GPS tracker to make sure you can get home? The tracker is a device that could tell you where you were and guide you home.	3(iii) and 5
	Do you still drive, have you considered stopping	3(iii) and 5
	Do you worry about increasing risks from leaving home	3(iii) and 5
	Have you/your carer had any advice about dementia	3 (ii) and 5
	Do you think social groups for people living with dementia would help you to go out?	

	What are the most important parts of your freedom? Is there anything else you can think of which would help you to have greater freedom as you condition progresses?	3 (i) and 5
Generic Prompts	How do you feel about that? What happened next? Why do you think that happened? Can you tell me anymore about that? Have you talked about this with your career?	

11.5.2 Topic Guide: Carer.

Topic	**Questions and prompts**	**Aims addressed**
Home and social circumstances **Descriptive**	Tell me about the person you care for. How long have you provided care for? Does anyone help you to provide care? What do you do for the person you care for – can you take me through a typical day? Can you describe your home to me	Demographics/description
Leaving unsafely	Has your cared for person attempted to leave unsafely. Can you describe what happened? How did you feel? What would you do next time? Has this changed how closely you supervise the cared for person	Aim 2 (i) and 2 (iii)
Carers liberty/PLWD	Do you ever manage to go out? Do you need to restrict the areas of the house your cared for person goes into? How do you define your freedom? How has your freedom changed since you have become a career? How do you define freedom for the person you care for	Aim 2 (i) and 2(iii)

Carer stress	Do you ever find caring stressful, if so which elements of providing care? Do you get up in the night to provide care? Do you feel your social contacts have reduced?	Aim 2 (i) and 2 (iii)
Assessment	Did your cared for person drive. What impact did stop driving have? Would an alarm system or GPS tracking help you/them to have more freedom? How would you feel about your cared for person using such a device? Are you aware of the Herbert protocol – if yes, how was it helpful? Would a social group/peer support help you both to leave the home? Do you feel having more information about dementia would have helped you provide care? How do you feel about balancing risks and freedom for your cared for person	Aim 2 (ii) and 5
Prompts	How do you feel about that? What happened next? Why do you think that happened? Can you tell me anymore about that? Have you talked about this with x?	

11.5.3 Topic Guide: Occupational Therapist

Topic	Questions and prompts	Aims addressed
Professional Background	How long have you been qualified for? How long have you worked with people living with dementia and their carers	Demographics/inclusion criteria
MCA knowledge and practice	What is your role with PLWD and their carers? How do you assess cognition? What are your experiences of assessing capacity? Are you involved in best interest's decision making? What training have you received on the MCA? What do you know about the LPS?	Aim 4(i)
Freedom	How do you define freedom? How do you consider dementia impacts on people's freedom?	Aim 4 (ii) and (iii)

	What is your understanding of freedom and how does this apply to PLWD and their carers? How are carers freedoms impacted by providing care? What are you experiences of working with people who try to leave the home unsafely? (Can you give me an example) What advice do you give to carers if someone is trying to leave home unsafely? Do you ever advise carers to restrict people to specific areas of the home	
Assessment telecare	Do you prescribe telecare – what kind? How does it help to promote freedom	Aim 3 (iii) Aim 5 and 6
Driving	Are you involved in decisions about people continuing to drive? What interventions are you involved in when people stop?	Aim 3 (iii) 5 and 6
Herbert protocol	Do you complete this with PLWD/carers? How useful do you find it	Aim 3(iii) Aim 5 and 6

Risk assessment	How do you assess the risk that people may leave their homes unsafely? Do you use any standard tools and do you find these useful	Aim 3 (iii) Aim 5 and 6
Peer support	Do you refer PLWD or carers to peer support groups/online support? If so, how are these groups useful in supporting carers/PLWD	Aim 3 (iii) Aim 5 and 6
Carer education	What education about dementia do you provide to carers to provide care? Do you provide information on carer education resources	Aim 3 (iii) 5 and 6
Other assessments/interventions	What other assessments or interventions can you think of which might facilitate freedom	Aims 3(iii) 5 and 6

11.6 Supplemental topic areas to explore.

Additional questions

Vignette all participants.

What would you do (OT)?

What do you think about that (PLWD and carers)?

Carers

What were they like when they were well?

How have the changes in their personality/behavior affected you?

Should decisions be made on how she was/is?

Do you plan or take things day to day?

What do you plan to do if you are no longer providing care?

PLWD

Telecare

The technology is the same for offenders and PLWD is that acceptable?

OTs

Should decisions be made based on how the person was or how they are now?

Are carers more worried if they do not live with the PLWD (Why is this

11.7 Health Research Authority Approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Doctor Sarah Goldberg
School of Health
Sciences, Medical School
University of Nottingham
NG7 2UH

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

13 September 2019

Dear Dr Goldberg

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The development of an occupational therapy assessment of liberty for people living with dementia. A mixed methods study**
IRAS project ID:	**257586**
Protocol number:	**19053**
REC reference:	**19/YH/0275**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set, and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below. Your IRAS project ID is **257586**. Please quote this on all correspondence.

Yours sincerely,
Hayley Henderson
Approvals Manager

Email: hra.approval@nhs.net

Copy to: *Ms Angela Shone, Sponsor Contact*

11.8 Research Ethics Committee Approval major amendment

NHS
Health Research
Authority

09 June 2020

Ms Catherine Brewin
Nottingham University NHS Trust
Occupational Therapy Department Nottingham City
Hospital Hucknall Road
NG5 1PB

Dear Ms Brewin

Study Title: The Development of an occupational therapy assessment of liberty for people living with dementia. A mixed methods study.
REC reference 19/YH/0275.
Protocol number: 19053
Amendment number: Substantial Amendment 1.29/04/2020.
Amendment Date 11 May 2020.
IRAS project ID: 257586

The above amendment was reviewed at the meeting of the Sub-Committee held by correspondence.

Ethical Opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved Documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Non-validated questionnaire [Delphi]	1	30 April 2020
Notice of Amendment (non-CTIMP)	Substantial Amendment 1, 29/04/2020	11 May 2020

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19.

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

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.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and- improving-research/learning/

Yours
sincerel
Sarah Prothero
y pp

Dr Janet Holt Chair

E-mail: bradfordleeds.rec@hra.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to *Ms Catherine Brewin, Nottingham University NHS Trust*

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee Attendance at Sub-Committee of the REC meeting held by correspondence.

Committee Members:

Name	*Profession*	*Present*
Mrs Jenny Foggin	Senior Governance & Corporate Affairs Officer	Yes
Dr Janet Holt (Chair)	Associate Professor in Healthcare Ethics	Yes

Also, In Attendance:

Name	*Position (or reason for attending)*
Miss Jane Harker	Approvals Administrator
Miss Sarah Prothero	Approvals Officer

11.9 Health Research Authority Approval.

NHS
Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle Upon Tyne

12 September 2019

Ms Catherine Brewin
Researcher/PhD student
Nottingham University NHS Trust.
Occupational Therapy Department.
City Hospital.
NG5 1PB

Dear Ms Brewin.

Study title: The development of an occupational therapy assessment of liberty for people living with dementia: A mixed methods study.
REC reference: 19/YH/0275
Protocol number:**19053**
IRAS project ID: 257586

Thank you for your letter of 12th September 2019. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 11 September 2019.

Documents received.

The documents received were as follows:

Document	*Version*	*Date*
Other [Response to conditions of favourable opinion]		12 September 2019
Participant information sheet (PIS) [PLWD]	1.2	12 September 2019
Participant information sheet (PIS) [Carers]	1.2	12 September 2019
Participant information sheet (PIS) [OT]	1.2	12 September 2019

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Delphi advert]	1.0	15 July 2019
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only)		18 July 2019
Interview schedules or topic guides for participants [Carer]	1.0	15 July 2019
Interview schedules or topic guides for participants [Occupational Therapists]	1.0	15 July 2019
Interview schedules or topic guides for participants [Patient]	1.0	15 July 2019
IRAS Application Form [IRAS_Form_22072019]		22 July 2019
Letter from funder		11 April 2018
Letter from sponsor		18 July 2019
Other [Response to conditions of favourable opinion]		12 September 2019
Participant consent form [Consent form]	1.0	15 July 2019
Participant information sheet (PIS) [Delphi PIS]	1.0	15 July 2019
Participant information sheet (PIS) [Carers]	1.2	12 September 2019
Participant information sheet (PIS) [OT]	1.2	12 September 2019
Participant information sheet (PIS) [PLWD]	1.2	12 September 2019
Research protocol or project proposal [Protocol V1.0]	1.0	15 July 2019
Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [CV SG]		01 May 2019
Summary CV for student [CV CB]		03 June 2019
Summary CV for supervisor (student research) [CV SG]		03 June 2019

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

Yours sincerely

Thomas Fairman
HRA Approvals Manager

Email nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Copy to: *Miss Charlotte Davis, Nottingham University Hospitals Trust*

11.10 Invitation to participate in a Delphi study.

Division of Health Sciences

University of Nottingham QMC Campus,

Derby Road,

Nottingham NG7 2UH

E mail: Catherine.brewin@nottingham.ac.uk

Dear

I am writing to invite you to participate in a Delphi Study on the topic of the development of an occupational therapy assessment of freedom for people who live with dementia. The purpose of this study is to develop a person-centred assessment tool which provide freedom for people who live with dementia and support for carers. It is proposed occupational therapist will carry out the assessment. As an established expert in this field or someone who has expertise as a carer for a person living with dementia, I are keen to gain your views on freedom for people living with dementia and how the elements of the assessment could support this.

Specifically, I would like you to answer two short online questionnaires. Both questionnaires should take approximately 20 minutes to complete. The first questionnaire will include a number of questions about freedom. The second questionnaire will include a summary of the group’s responses, how it is assessed and what are the essential elements of the assessment. The second questionnaire will be used to assess your agreement with the answers. There will be room for you to ask additional questions. I will be grateful if you would complete each questionnaire within two weeks. Further details are provided in the attached participant information sheet.

Your expertise would be extremely beneficial in developing a credible, clinically relevant, and patient-centred assessment tool and would be very grateful if you would consider participating in this Delphi study. If you would like to contribute, please inform us by email or telephone and we will forward the instructions for the first Delphi round. If you wish to take part but do not have access to a computer or the internet, we will be able to provide paper copies.

This study is part of a PhD funded by the National Institute of Health Research at the University of Nottingham and Nottingham University Hospitals NHS Trust. Please do not hesitate to contact us if you require further information.

Yours sincerely,

Catherine Brewin

HEE/NIHR Clinical Doctoral Research Fellow

11.11 Occupational Therapy Assessment

Name *Address* *NHS number* *Diagnosis*		*Family contact details* *Address* *Phone number* *Relationship*
Who does patient live with?		
Type of home		
Entrance		
Stairs		
Mobility		
Transfers *Chair* *Bed* *Toilet*		
Signed *Dated*		

Name *NHS number*		
PADL *Bath/shower washing dressing and grooming.*		
DADL *Meal preparation, shopping, housework*		
Pressure Care (Braden Scale)		
Continence		
Cognition		
Signed *Dated*		

11.12 FREEDEM assessment

Name

Address

Diagnosis

Date of birth

Assessment	Outcome
Has cognition been formally assessed?	
Outcome of formal/informal assessment of capacity relating to leaving the home.	
Can the person assessed exit their home independently?	
Is freedom reduced through choice or is this caused by physical or psychological problems?	
What is the outdoor mobility of the person assessed?	
What is the recent history of leaving the home?	
Is the person assessed leaving to carry out previous routines on a specific route?	
Signed	Dated

What is the history, lifestyle, culture, and preferences of the person assessed?	
Is the PLWD able to lock or unlock the door on leaving and returning.	
Is the area urban or rural?	
What is the road safety of the person assessed? (Remaining on pavement, crossing the road, dealing with hazards)	
Is the person assessed orientated in time and place when away from the home?	
Can the person assessed manage money?	
Are there any safeguarding concerns relating to leaving the home and engaging in activities of choice?	
What are the values, wishes and preferences of the person assessed relating to their freedom?	
Signed	Dated

What is carer's capability and willingness to support these wishes and preferences?	
Do carers need advice/education about the positive risks of leaving the home?	
Could integration with the community be facilitated?	
Are there any suitable day centres or peer support groups available?	
Would telecare products be suitable including GPS trackers and door monitors?	
Is the person assessed still driving? Are any referrals relating to transport required?	
Has the Herbert protocol been completed?	
Does the person assessed need to be referred for approval for a deprivation of liberty?	
Signed Dated	

11.13 Completed Coreq checklist.

Number/item	Description	Reported on page
Domain 1: research team and reflexivity		
1. Interviewer/facilitator	Which author/s conducted the interviews?	50
2. Credentials	What were the researcher's credentials?	50
3. Occupation	What was their occupation at the time of the study?	50
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have?	50
6. Relationship with the study participants established		50
7. Participant's knowledge of the interviewer	What did the participants know about the researcher?	50
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	50
Domain 2: study design		
9. Methodological orientation and theory	What methodological orientation was reported to underpin the study?	44. 45.46.47.48
10. Sampling	How were participants selected?	51, 52.53

11. Method of approach	How were participants approached?	54, 55,56,57
12 Sample size How many participants were in the study	How many participants were in the study	51
13 Nonparticipation	How many participants dropped out reasons?	None
14 Setting of data collection	Where was the data collected?	55, 57.59
15.Presence of non-participants	Was anyone else present besides the participant and the researcher/ s?	54
16. Description of sample	What are the important characteristics of the sample?	54 55 56 57
17. Interview guides	Were questions, prompts guides provided by the author?	235-242
18. Repeat interviews	Were repeat interviews carried out?	N/A
19. Audio/visual recordings	Did the research use audio visual recordings to collect the data?	50
20. Field notes Were field notes made before or after the interview	Were field notes made during/and or after the interview?	After 62
21. Duration	What was the duration of the interview?	55, 57
22. Data Saturation	Was data saturation discussed?	51
23. Transcripts returned	Were transcripts returned to participants?	No
Domain 3: Analysis and Findings		
24. Number of data coders	How many data coders coded the data?	67

25. Description of the coding tree	Did authors provide a description of the coding tree?	71, 72,73
26. Derivation of themes	Were themes identified in advance or derived from the data?	65,66,67
27. Software	What software was used to manage the data?	67
28. Participant checking	Did participants provide feedback on the findings?	No
29. Quotations presented	Were participants quotations identified to illustrate the themes/ findings. Was each quotation identified?	74-123
30 Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31 Clarity of major themes	Were major themes clearly presented in the findings?	74-123
32 Clarity of minor themes	Is there a description of minor cases or discussion of minor themes?	81, 82

11.14 Checklist of the conduct and reporting of Delphi Studies.

		Page location in the main document
Rationale for the choice of Delphi study	Justification	133
Planning and Design	Planning and process	133/4
	Definition of consensus	136
Study Conduct	Information input	136
	Prevention of bias	131
	Interpretation and processing of results	136
	External validation	N/A
Reporting	Purpose and rationale	131
	Expert panel	134
	Description of the methods	131-135
	Procedure	134-135
	Definition and attainment of consensus	136
	Results	136
	Discussion of limitations	157

	Adequacy of conclusions	N/A
	Publication and dissemination	Ongoing

1.15 Delphi Questionnaire

An occupational therapy assessment of freedom for people living with dementia (FREEDEM) – Delphi questionnaire Round one.

Introduction

Thank you for agreeing to take part in this questionnaire. The purpose of this questionnaire is to generate consensus on the items that should be included in the occupational therapy assessment of freedom for people living with dementia. The assessment has been developed from literature and interviews with people living with dementia, carers, and occupational therapists. The assessment is being designed for use in a person’s home by occupational therapists when working with people living with dementia who have a family carer. The assessment will be in addition to the usual occupational therapy assessment, which will contain details of the persons home and social circumstances. You invited to take part because you have significant experience of working with or caring for people who live with dementia.

Definition of freedom

Freedom is defined by people living with dementia in semi-structured interviews as leaving the home and participating in activities of choice (freedom to do what you want). Safety (freedom from harm) outside the home was also considered important including returning home safely. Please use this definition when ranking the statements below.

Instructions

Please consider the importance of the following 25 statements in contributing to the development of an assessment of freedom of people living with dementia. Below each statement is an explanation to clarify the statement where necessary. You will be asked to rate each statement with a 4-point scale where items are ranked from unimportant (1) that the item should be included in the assessment to very important (4). There is a space below each statement for you to make comments to justify your rating of the item or to identify where more clarification is needed.

Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.
1. The assessment of freedom should include a formal assessment of cognition. A cognitive assessment may help to identify if the person living with dementia has capacity. These assessments may include the Montreal Cognitive Assessment (MOCA), assessment of motor and processing skills (AMPS) and large Allen cognitive screen (LACLS).				
Comments				
2. Cognition should be assessed functionally for example through meal preparation or shopping. **A functional assessment may be used to identify problems with cognitive functioning for example memory, planning, sequencing, and recognising items involved in a task.**				
Comments				

Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.
3. The assessment should contain a formal assessment of capacity on the issue of leaving the home.				
Comments				
4. The assessment should contain details about the history, lifestyle, culture, and preferences of the person living with dementia.				
Comments				

Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.
5. The assessment should identify the values wishes and preferences of the person living with dementia relating to their freedom.				
Comments				
6. Whether freedom is reduced through choice or is caused by physical or psychological dysfunction should be assessed.				
Comments				
Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important	3. Important.	4. Very important.

		or unimportant.		
7. The assessment should contain details of the recent history of leaving the home to identify if the person living with dementia is unsafe doing this.				
Comments				
8. The assessment should identify the previous routines of the person living with dementia as these may affect their choice of route/activities on leaving home.				
Comments				
Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important	3. Important.	4. Very important.

		or unimportant.		
9. The assessment should include hazards which may make it difficult for the person living with dementia to leave the home safely e.g., steps at the entrance to the home.				
Comments				
10. The assessment of freedom needs to include an assessment of the outdoor mobility of the person living with dementia.				
Comments				
Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important	3. Important.	4. Very important.

		or unimportant.		
11. The assessment of freedom ought to include road safety of the person living with dementia including route taken remaining on the pavement, road crossing, safely (ability to judge depth and distance and speed)				
Comments				
12. The assessment should contain details of orientation in time and place when away from the home.				
Comments				

Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.
13. The ability of the person living with dementia to lock or unlock the door on leaving and returning should be included in the assessment.				
Comments				
14. If the person living with dementia is leaving the house to shop the ability to manage money to make a purchase should be assessed.				
Comments				

Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.
15. Any safeguarding concerns relating to leaving the home and engaging in activities of choice should be identified.				
Comments				
16. Activities relating to freedom that the person living with dementia enjoys should be identified and form part of the assessment				
Comments				

Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.
17. The assessment should identify carer's capability and willingness to support the identified activities.				
Comments				
18. The assessment of freedom should include whether carers need advice/education about the positive risks for a person living with dementia when leaving the home.				
Comments				

Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.
19. The assessment of freedom should facilitate integration with the community if this is consistent with the wishes of the person living with dementia.				
Comments				
20. The assessment should identify if there are day centres or peer support groups providing activities the person living with dementia enjoys.				
Comments				

Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.
21. The assessment of freedom should include an assessment of whether the area is urban or rural.				
Comments				
22. The assessment of freedom should include telecare products including GPS trackers and door monitors.				
Comments				
Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.

23. The assessment of freedom should identify if the person living with dementia is still driving and if any advice or referral relating to this is required.				
Comments				
24. The assessment of freedom should identify types of transport other than driving.				
Comments				
Please place an X in the box that identifies how important the item is to the assessment of freedom	1. Unimportant.	2. Neither important or unimportant.	3. Important.	4. Very important.

25. The assessment should include the completion of the Herbert protocol. Available from https://www.ageuk.org.uk/calderdaleandkirklees/about-us/latest-news/articles/2018/the-herbert-protocol/				
Comments				

Do you have any additional comments about the assessment of freedom for people living with dementia?

What is your profession ……………………………………………………………………………………………

How many years have you worked with people living with dementia………………….?