Factors Affecting Assessment, Uptake and Adherence to Physical activities in people with dementia: An inclusive approach

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by

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Table of Contents

List of Tables and Figures

Abstract

Dementia is a growing problem worldwide. There is no available long term effective treatment and many cases of dementia remain undiagnosed. Within this context, appropriate, accurate and reliable cognitive assessments are important in informing the process of diagnosing dementia, and monitoring the effects of subsequent interventions. Previous research has often researched the journey of dementia in stages. This thesis, however, was guided by inclusivity, a concept applied to encapsulate the need for the inclusion of all individuals across the whole journey of dementia. Assessments utilised during diagnostics should be cross-culturally applicable, easy and quick to administer, inexpensive, non-invasive and able to identify changes in cognitive functioning. Little research has explored cognitive assessments for people with intellectual disabilities, a growing group at high risk for experiencing dementia at a younger age. Moreover, physical activity could be a key intervention for people with dementia, with the potential to slow cognitive symptoms and promote independence. However, meta-analyses show mixed outcomes for the success of physical activity interventions. This may partly be due to low levels of engagement and adherence. Therefore, both cognitive assessments and physical activity, including factors influencing adherence, are important aspects of the journey of dementia, which require more research with an inclusive approach.

This thesis was divided into 2 parts to reflect the underpinning paradigms that informed the investigations in each part. Hence, a mixed methods approach is used to investigate more inclusive practices in dementia diagnostics, intervention assessment and delivery of physical activity. Applied quantitative methods were used in part 1 to assess the accuracy of a battery of cognitive assessments (Mini Mental State Examination or MMSE, Hopkins Verbal Learning Test or HVLT, Verbal Fluency or VF, and the novel: Cognitive Computerized Test Battery for Individuals with Intellectual Disabilities or CCIID) in informing dementia diagnostics for individuals with (n=30) and without (n=25) intellectual disabilities (chapters 4 and 5). The same cognitive tests were then utilised to assess the acute effects of a physical activity intervention compared to a psychosocial control activity using a cross-over design involving people with dementia (chapter 6).

The second part of the thesis informed by critical realism, but continuing the inclusive approach began by exploring the barriers and facilitators to physical activity for people with dementia (chapter 7). Novel mobile methods of interviewing were applied to explore the perspectives of people with dementia towards physical activity (chapter 8). These walking interviews were also discussed in comparison to more traditional seated interviews for their application in understanding the perspectives of people with demenita. This was only the second study to conduct walking interviews with people who have dementia, but the first to discuss physical activity within this context. Chapter 9 then sought to investigate the perspectives of professionals who work to provide physical activity for and with people who have dementia. This study investigated how professionals navigate barriers and facilitate adherence to physical activity for people with dementia within the community, and hence offers a discussion of practical solutions to barriers identified in the literature and from interviews with people with dementia.

The findings from the initial investigations in this thesis showed that participants with and without a pre-existing cognitive impairment who had dementia scored significantly lower on all included cognitive assessments (MMSE, VF, HVLT, Series and Jigsaw subtests and total CCIID) than their age-matched counterparts. Receiver Operating Characteristic analysis revealed that all included assessments significantly classified those who had dementia, with a high accuracy of above 0.80 for all assessments with all populations. Assessments were well tolerated by all participants, including those with an intellectual disability.

Acute cognitive benefits of physical activity were demonstrated over and above a psychosocial control using an order balanced cross-over design. An increase in cognitive scores was visible on the MMSE, VF, HVLT, Series and Jigsaw subtests and total CCIID after engaging in a short bout of resistance band physical activity versus a bingo (psychosocial) activity. This study confirms earlier research with resistance band physical activities in promoting memory in older people with and without dementia, but adds another new sensitive planning and logical reasoning test (CCIID) which could be important for early stages- or different types- of dementia. This study shows that the same well tolerated cognitive tests can be used for the initial screening and subsequent assessment of interventions.

Systematic literature review (chapter 7) revealed that people with dementia have problems adhering to regular physical activity. The following thematic analysis of walking interview data with people who have dementia in chapter 8 revealed four key themes as to why this might be. The themes were: i) competition, ii) physical activity across the lifespan, iii) injury and decline; and iv) barriers to physical activity. The themes indicated that competitive aspects of physical activities can be encouraging or discouraging depending upon the individual participating, by giving the activity purpose, whether this is through competition or an activity goal, more people with dementia are interested in repeatedly engaging. Furthermore, injuries and decline in physical functioning frequently impacted participants' ability to enjoy physical activity. This often led to adapted physical activities rather than traditional sports that participants described enjoying earlier on in their lives. Each participant also discussed different logistical barriers outside of physical capabilities that limited their consistent participation in physical activity.

The final study of the thesis, in chapter 9, analysed interviews with professionals, and offered methods of navigating the barriers highlighted by people with dementia; and discussed the potential for professional engagement with dementia care to increase physical activity participation and inclusively deliver interventions. This often meant providing a personalised activity that includes social interaction for the participants to further engage with, and benefit from. The professionals discussed the structure of the context in which physical activity is provided for people with dementia.

Overall, this thesis argues for inclusive practices for people with dementia regardless of pre-existing cognitive ability, from diagnosis through to strategies for sustaining interventions that could offer substantial benefits. The empirical chapters are potentially limited by the small numbers of participants per study (n=9-25). However, this also allowed for in-depth analyses. The findings demonstrate the need for increased communication between healthcare professionals and people with dementia to offer more inclusive practices that can give greater insight into our understanding of dementia, as well as offer better care throughout the journey of dementia for all individuals.

Chapter 1

Introduction

Aspects of this chapter have been published in:

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Chapter 1 - Introduction

Dementia is a worldwide health pandemic. Approximately 47 million people globally were living with dementia in 2015; with this number projected to triple by 2050 (Livingston et al, 2017). Ninety five percent of all cases start over the age of 65 (Reitz & Mayeux, 2014). Although dementia is not a part of the natural course of ageing, the risk for developing dementia does increase with age. Hence, the need for identification and diagnosis becomes more pressing as the population is ageing worldwide. Characterised by progressive and severe cognitive impairment, dementia leads to significant interference with social and occupational functioning (APA, 1994). There are numerous types of dementia. The most common of which, Alzheimer's disease (AD), accounts for 50% to 60% of all cases (Todd et al, 2013). Other types of dementia include Vascular dementia, Frontotemporal dementia and dementia with Lewy Bodies, alongside other less frequently occurring types. Differences in presentation and everyday functioning can be clinically observed between the varying types, but overlap in neuropathology is common (e.g. Venkat, Chopp & Chen, 2015; Park, Harvey, Johnson & Farias, 2015; Kosaka, 2017). Longitudinal studies have also increasingly recognised the importance of mixed pathologies as a factor in the development of dementia (Kapasi, DeCarli & Schneider, 2017).

Individuals with AD experience multiple clinical symptoms that gradually start and become more severe over a period of years. Memory decline is often one of the first symptoms. There are two key pathological mechanisms that are most likely implicated in AD. The first, the amyloid-β (A β) peptide is aggregated extracellularly into neuritic plaques (e.g. Jansen et al, 2015). The time lag between amyloid pathology and dementia prevalence suggests a long pre-clinical phase of the disease (Visser & Tijms, 2017). Similarly, the presence of this pathology does not always equate to a clinical diagnosis, as many individuals can have pathology without any symptoms (e.g. Jansen et al, 2018).

The second implicated mechanism is p-tau protein that accumulates intracellularly as neurofibrillary tangles (e.g. Reitz & Mayeux, 2014). The associations between neuropathological changes and cognitive functioning are yet to be fully clarified. Although amyloid plaques play a key role in the AD pathogenesis, the severity of cognitive impairment correlates best with the burden of neocortical neurofibrillary tangles (Nelson et al, 2012), but vascular changes are also often present (Hogervorst, Bandelow, Combrinck, Irani, & Smith, 2003). Previously, pathologies suspected as being implicated in dementia were confirmed at post mortem examination (e.g. Connor et al, 1998). More recent advances in molecular imaging has meant it is possible to identify specific dementia pathologies during the diagnostic process (Livingston et al, 2017). Many national dementia guidelines therefore suggest that structural neuroimaging should constitue part of routine clinical assessment. Reality, however, presents a more inconsistent clinical picture, with different areas reporting variance in the use of imaging during the diagnostic process (e.g. Vernooj et al, 2019; Gardeniers, Wattjes, Meulen, Barkhof & Bakker, 2016); potentially due to limited access, training or cost. Considering the inconsistencies in practical use of imaging, diagnosis is more frequently determined through less costly methods of clinical assessment, such as assessment of cognition, family history, alongside clinical judgement.

This chapter gives background on current dementia research, introduces the process of diagnosing dementia; and makes the case for inclusive dementia diagnostics. The available treatments following a diagnosis are discussed, alongside potential psychosocial and behaviour interventions. One such interventions identified to be most promising is physical activity. Therefore, this chapter concludes by suggesting the need for physical activity to be facilitated for people with dementia, and describing how the thesis subsequently explores these topics.

1.1 Current Dementia Research and the Person with dementia

Early dementia research lacked a focus on people with dementia (e.g. Downs, 1997), instead portraying the person only through their neurobiology or neuropsychological (in)ability (Cotrell & Schulz, 1993; Cheston & Bender, 1999). The importance for older people to remain in control of their lives and maintain their voice was recognized in the 1990s (e.g. Thursz, Nusberg & Prather, 1995), but has substantially increased in importance since. In 2012 in the United Kingdom, the Prime Minister’s challenge on Dementia (Department of Health, 2012) documented the context of ‘better research’ to be aimed for and mandated the inclusion of people with dementia in the conduct of research. Researchers have since called for people with dementia to have ‘meaningful’ involvement in research (Murphy, Jordan, Hunter, Cooner & Caser, 2015); and although assessment and measurement are still critical;

attention is being increasingly given to the participants and their experience of dementia (Bruce, Beuthin, Sheilds, Molzahn & Schick-Makaroff, 2016). This growth in research involvement has extended to varying roles: initially acting as participants in interview based studies (e.g. Gibson, Dickinson, Brittain & Robinson, 2015), people with dementia have since been referred to as the experts on patient and public involvement (PPI) panels. As experts on PPI panels, people with dementia are directly involved in generating ideas for research, advising researchers, consultating on and co-designing research projects (Gove et al, 2018).

This increased research emphasis on people, rather than pathology, is reflected throughout a variety of sectors including care, policies and community based campaigns and groups. Many apply the term ‘person centred approach’ to encapsulate this emphasis on the individual. This approach, however, is frequently confused and applied interchangeably with simple personalisation (Brooker, 2015). Originally defined by Thomas Kitwood (1997), the person centred approach involves numerous considerations aimed at treating individuals as individuals. Thomas Kitwood’s definition was later refined and further expanded upon by Brooker (2003). This later definition aimed to better illustrate the four threads in which person centred approach could be applied. The first thread describes how valuing people with dementia and those who care for them is essential to achieving a person centred approach. The next thread describes how people with dementia should be treated as individuals. The third thread asks that the world be looked at from the perspective of people with dementia. The final thread states that people with dementia should be provided with an enriched social environment to allow them opportunity for personal growth. This definition has therefore been labelled the VIPS definition, as an acronym for Valuing care, Individual care, Perspectives and Social environment (Brooker, 2003).

Since Brooker sought to better establish a clear definition of person centred care (PCC), an abundance of literature has discussed this concept. Many of these publications, however, are descriptive, often based on clinical experiences, personal opinions and anecdotal evidence (Edvardsson, Winbald & Sandman, 2008); with researchers often highlighting a distinct lack of empirical studies available (e.g. Kogan, Wilber & Mosqueda, 2016). Similarly, measurement tools that have been developed to assess the person centred-ness of interventions for older people and those with dementia, can be critiqued for not being tested past the initial development phase and therefore have limited validity, reliability and applicability (Edvardsson & Innes, 2010). This has resulted in widespread use of person-centred intervention and training manuals that are not evidence based (Fossey et al, 2014) and the application of PCC frequently being led by ‘personal understanding’ of the concept and how to translate it into practice (Backman et al, 2020).

Despite the earlier critiques of PCC, more recent studies have identified numerous benefits for older adults and those with dementia through the implementation of PCC in practical settings, such as residential homes. These include reducing agitation, neuropsychiatric symptoms, depression and improving quality of life (Chenoweth et al, 2009; Kim & Park, 2017; Chenoweth et al, 2019). The benefits noted throughout the literature were identified within residential care settings, with little research exploring alternative settings such as during an intervenetion or the diagnosis process. Therefore, despite indications that all aspects of the dementia journey could be guided by a person-centred approach, the evidence thus far only supports the application of PCC in specific care settings. PCC can be likened to other approaches that also value the individual being cared for, such as humanising approach to healthcare (e.g. Todres, Galvin & Holloway, 2009; Borbasi, Galvin, Adams, Todres & Farrelly, 2013). However, much like PCC these alternative approaches are yet to be explored across the journey of dementia, rather than just during residential care.

Several approaches, including PCC and humanising care, despite their discussed shortfalls do have synonymous considerations for treating individuals as individuals. This is an appealing prospect to consider for the whole journey of dementia, including during diagnosis. Even more so when the context of current dementia research is considered, whereby people with dementia are frequently described as a homogenous group with little differentiating them from one another (Ludwin & Capstick, 2015). Individuals with dementia also experience increased social isolation and segregation following a diagnosis (e.g. Bryden, 2015) and failure to take individuality into account has been found increase social isolation, exacerbate symptoms and hasten deteriation (Hancock, Woods, Challis & Orrell, 2005). In order to consider people with dementia as individuals

People with dementia are a diverse group of individuals whose life experiences and outlooks are unique (Ludwin & Capstick, 2015). Diversity is hence a key consideration of the treating people with dementia as individuals. Therefore, when seeking to better understand the journey of dementia, then it is crucial to consider the breadth of individuals that could be involved with that journey. In the case of the diagnostics phase of the journey of dementia then consideration should be made for all individuals who might be at risk of requiring a diagnosis. Therefore, flowing from previous understandings of person centredness, but accompanied by the consideration for the diversity of individuals who experience the journey of dementia, the overarching concept of inclusivity is applied to the dementia research laid out in this thesis. Inclusivity can be defined as the inclusion of all individuals across the whole journey of dementia. The application of inclusivity, in this thesis, begins with inclusive dementia diagnostics.

1.2 Inclusive dementia diagnostics

Diagnosis is not a one-off event, but rather a process (e.g. Hellstrom & Torres, 2013; Peel, 2015), that involves collecting information from different sources over an extended period of time. Information gathered during diagnostics includes - but is not limited to - behaviour, symptoms, family history, and direct cognitive assessment longitudinally. Some studies have suggested that collecting information using imaging and assessing cerebrospinal fluid (CSF) biomarkers could further improve diagnostic accuracy (e.g. Bayer, 2018). However, the clinical validity and utility of these biomarkers are not well evidenced (Frisoni et al, 2017). Moreover, CSF biomarker procedures are invasive and uncomfortable. Utilising biomarker measurement for diagnostics is currently tenuous and expensive.

The information gathered from various sources including observations, carers' input, medical and psychiatric evaluations, neuropsychological and neurological testing is then collated and the clinician applies clinical judgement alongside diagnostic criteria to reach a diagnosis consensus between several involved specialists. Diagnostic criteria are determined by various internationally recognised psychological or healthcare governing bodies. Revised diagnostic criteria in the United States have recently re-termed dementia as Major Neuro-Cognitive Disorder (MNCD - APA, 2013). Research so far has suggested that the new DSM V criteria are broader in their categorisation than earlier categories (Eramudugolla et al, 2017). Medical bodies in the United Kingdom, most relevant to this thesis, have maintained use of the term dementia (e.g. NICE, 2019). Hence, for the purpose of this thesis the term dementia shall be utilised, but readers should be aware that some research discussed may refer to the alternate DSM V criteria of MNCD.

Due to the diverse range of information gathered and the variety of sources that are contacted to do so, dementia diagnosis is a time-consuming process. Not only time consuming, diagnostics is a complex process of clinical decision making. Clinical decision making extends beyond just determining the diagnosis itself. Currently, the timing of a diagnosis has been raised as a contentious issue for numerous reasons. In the UK Department of Health report (2013), for instance, it was estimated that 45% of patients who might meet the criteria for dementia in any given population still do not receive a formal diagnosis or receive it too late to be clinically useful. Moreover, at the end stage of the disease it can be clinically difficult to discriminate between different pathologies and effective treatment strategies (Kalaria, 2016). It is for that reason that most national and international health authorities, such as the World Health Organisation, call for an early diagnosis (e.g. Waite, 2012). Esralew, Janicki and Keller (2018) also argue that early identification of signs and symptoms of cognitive and functional decline is a vital first step in managing the course and progression of dementia and providing quality care; indicating an early diagnosis as paramount.

Le Couteur and colleagues (2013), however, recommend caution over delivering a diagnosis too efficiently, as services may be overrun and unable to support newly diagnosed families. Clinicians also need to be vigilant when determining a diagnosis, as identifying the correct subtype of dementia may be wrong in 20% or more cases (Bayer, 2018). Having said that, dementia remaining undetected altogether has been suggested to significantly contribute to healthcare utilization and costs of care in older adults (Wray, Wade, Beehler, Hershey & Vair, 2014). Researchers have therefore leant towards the term ‘timely’ diagnosis (Brooker, La Fontaine, Evans, Bray & Saad, 2014), as this proposes that there is an appropriate time for a diagnosis, which can be determined by the clinician alongside other key stakeholders such as caregivers and family members. There is potential for a timely diagnosis to offer opportunities for early intervention, implementation of coordinated care plans and better management of symptoms. Further down the line a timely diagnosis can offer cost savings to healthcare services, as well as the potential to delay institutionalisation for the person with dementia (Dubois, Padovani, Scheltens, Rossi & Dell’Agnello, 2016).

Healthcare research has thus been critical of the overall diagnostic process (e.g. Bunn et al, 2012; Iliffe, Manthorpe & Eden, 2003, Koch & Iliffe, 2010; Moore & Cahill, 2013). Interviews with caregivers have found that a diagnosis does not systematically respond to a significant worsening of symptoms and is therefore not necessarily the starting point for caregiving (Brossard & Carpentier, 2017). The potentially negative impacts of a diagnosis on the patient and the caregiver is the most prominent concern raised across the literature (e.g. Bunn et al, 2012). Further, concerns for the lack of service provision available for people with dementia have been voiced, specialist services are particularly overloaded and are not necessarily always tailored to individuals' needs (Bunn et al, 2012; Sampson et al, 2018).

In spite of all of the highlighted concerns, catastrophic reactions to a diagnosis of dementia are relatively uncommon (Moore & Cahill, 2013), in part because diagnosis is delivered in such a way as to mitigate this (Peel, 2015). Therefore, irrespective of the timing of diagnosis the overall importance of a diagnosis remains high. Through diagnosing, the patient, caregivers, families, services and resources can experience a wide range of benefits that far outweigh any potential concerns (e.g. Moore & Cahill, 2013). For instance, this could include the initiation of treatment, including pharmacological and psychosocial interventions, that could delay time to dependency and admission to nursing homes (Leung et al, 2011).

As outlined earlier, when gathering information clinicians will assess the cognitive status of the person; this assessment is required longitudinally to identify changes in cognitive functioning over time. In the UK, there is a lack of agreement on which tests should be used for identifying dementia (Hunt & Hyde, 2017). The clinician determines the diagnostic tools that are applied, but considering the breadth of available assessments this is a carefully considered decision. Researchers have argued that cognitive assessments should not be used in isolation to confirm or exclude disease (Creavin et al, 2016). Thus, it is common practice to utlise several cognitive assessments that usually measure different aspects of functioning to inform the overall process of achieving a diagnosis.

The many considerations that clinicians when selecting an appropriate instrument include, but are not limited to, the setting in which the assessment was originally developed and validated, as well as the setting in which the assessment will be administered during diagnostics (Ismail & Mortby, 2017). Cognitive assessments can be critique for not being inclusive and therefore being biased by various participant characteristics such as race, ethnicity, culture, education and language (e.g. Mayeda, Glymour, Quesenberry & Whitmer, 2016; Ojeda, Aretouli, Pena & Schretten, 2016; Devenney & Hodges, 2017). If such characteristics are not accounted for or the chosen instrument has not been developed or validated for an individual with those characteristics, then the potential interpretation that can be made from cognitive scores are limited. Moreover, many cognitive assessments have associated copyright concerns which can impact their potential for use.

Tsoi and colleagues (2015) found that the most commonly used cognitive assessment at the time was the Mini Mental State Examination (MMSE – Folstein, Folstein & McHugh, 1975). The MMSE is an example of a cognitive assessment that assesses global cognitive functioning and is useful at highlighting areas that may require further investigation. Despite the widespread use of the MMSE, it is neither the most accurate, nor the most efficient tool with which to evaluate cognitive disorders (Mitchell, 2017). The main application of the MMSE is in screening or ruling out those without cognitive based disorders, it is unable to act a confirmatory tool for dementia and should not be used in isolation (Creavin et al, 2016; Mitchell, 2017). Alternative cognitive assessments are therefore utilised either in place of the MMSE or following the initial screening. Other examples of assessments of global cognitive functioning include the Montreal Cognitive Assessment or MoCA (Nasreddine et al, 2005) and the Addenbrookes Cognitive Examination – revised or ACE II (Mioshi, Dawson, Mitchell, Arnold & Hodges, 2006).

Alongside assessment of global cognition, investigating specific areas of functioning that are implicated in varying subtypes of dementia can better inform accurate diagnosis. One of the earliest observable symptoms of dementia are memory issues (Grenfell-Essam, Hogervorst & Rahardjo, 2018), this is most notable for Alzheimer’s disease (e.g. Sperling et al, 2010). Therefore, alongside assessment of global cognitive functioning, clinicians additionally opt for a direct assessment of memory too, such as the Wechsler Memory Scale, for example, that has been developed to measure varying aspects of memory (Wechsler, 2009). Verbal word lists, such as the Hopkins Verbal Learning Test (HVLT, Brandt, 1991) and the California Verbal Learning Test (CVLT – Delis, Kramer, Kaplan & Ober, 1987) are also examples of memory tests, but this time with a specific focus on verbal memory. Verbal memory assessments however, may be problematic if the individual has a hearing impairment or specific linguistical difficulties.

Although deciding on an appropriate cognitive assessment can be a complex process, cognitive assessments are beneficial as they are a quick and useful way to assess cognitive functioning (Ashford et al, 2006). Most crucially, for many patients, cognitive assessments are also non-invasive, making them more tolerable than biomarker procedures. The breadth of diagnostic test accuracy evidence is mixed and there is no one brief cognitive assessment that clearly emerges as superior to others, in terms of test accuracy (Hunt & Hyde, 2017). As a result, review has called for further validation of cognitive assessments currently in use to better advance dementia diagnostics (e.g. Velayudhan et al, 2014). More recent discussions have suggested the potential for cognitive assessments to screen population-wide for dementia, as this may identify individuals with unrecognised dementia (Harrawood, Fowler, Perkins, LaMantia & Boustani, 2018). This issue is controversial, however, as the feasibility of a population wide screening programme is questionable (Brayne & Davis, 2012).

Overall the process of diagnosing dementia is under continuous revision, and is widely debated in both clinical and academic contexts. In line with many other services and experiences for people with dementia, memory clinics aim for a person centred and inclusive approach in order to offer most benefits to the individuals involved. Manthorpe and colleagues (2013), however, found that few participants in their study of diagnosis experienced the process as patient centred. As dementia can affect a wide range of individuals, the process of diagnosing dementia should be inclusive. Accordingly, dementia diagnostics should identify symptoms in all individuals that may require a diagnosis. This includes populations that are not currently captured by general population diagnostics. Individuals with intellectual disabilities (ID) are one such population.

The International Summit of ID and dementia has recently called for national plans and policies pertaining to dementia to increase the inclusion of individuals with ID in services, support, research and care practices and policies (Watchman et al, 2017). Research has shown that the life expectancy of individuals with ID is steadily increasing (e.g. Holst, Johansson & Ahlström, 2018); which has been attributed to improvements in medicine and quality of life (Janicki, Ackerman & Jacobson, 1985; Eyman, Call & White, 1991). Although age at death for individuals with ID is still younger than individuals from the general population, the difference between these populations has decreased (Arvio, Salokivi & Bjelogrlic-Laakso, 2017). Consequently, individuals with ID are in a position of marked concern for diseases such as dementia, and there is an increased need for accurate dementia diagnostics within this population.

Adjacent to concerns stemming from increases in the life expectancy of people with ID, the risk of dementia for individuals with ID has also been emphasized. Individuals with ID and

Down’s Syndrome (DS) have been shown to have a higher risk of developing AD than the general population (e.g. Nieuwenhuis-Mark, 2009). More recent data has confirmed high risk levels for dementia among people with DS, with no differences between the severity of the intellectual disability (McCarron et al, 2017). Findings from genetic studies have suggested that the complex etiology of DS and the triplication of the amyloid precursor protein (APP) gene on chromosome 21 has resulted in DS being considered a potential model of early-onset dementia (Rohn, McCarty, Love & Head, 2014). Almost all adults with DS over the age of 35-40 years show neuropathological changes characteristic of AD (Deb & McHugh, 2010), including senile plaques and neurofibrillary tangles. Although this does not necessarily reflect a clinical diagnosis, genetic evidence has highlighted similarities between the neuropathology of the two conditions. Less is known about the neuropathology of individuals with ID who do not have DS.

Evidence has been observed through cross sectional study design for an increased risk of developing dementia for individuals with ID (Cooper, 1997; Strydom, Chan, King, Hassiotis and Livingston, 2013). Opposing studies, applying a longitudinal design, have found risk of dementia to be equivalent to, or lower than, the general population (e.g. Zigman et al, 2004). The highlighted contradictions in prevalence rates could be best explained by methodological differences between the few studies available (e.g. Strydom, et al, 2010). Although Cooper and colleagues (1997) based their estimates on samples representative of service users, it can be criticised for applying a cross-sectional study design and therefore could be overestimating the prevalence of dementia. Zigman and colleagues (2004) conversely could be culpable of underestimating dementia prevalence. Despite a longitudinal design, the sample chosen in their study is less representative than previous research as criteria for inclusion were more restrictive, convenience sampling was applied and all subtypes of dementia are not included. Researchers are yet to fully address the controversies in our understanding of dementia prevelance rates for individuals with ID without DS. This is especially so when consideration is made for the numerous factors that can implicate an individuals risk for developing dementia. One such factor is cognitive reserve, the concept that has been proposed to account for the disjunction between degree of brain damage and clinical presentation (e.g. Stern, 2009). The concept of reserve heavily relies on the idea that there can be individual differences in how cognitive tasks are processed, which is particularly important to highlight when considering inclusivity within the process of diagnosing dementia. Researchers have proposed that individuals with ID have a lowered cognitive reserve than that of their cognitively healthy counterparts (e.g. Evans et al, 2013), which could support the hypothesis that individuals with ID are more vulnerable to diseases such as dementia. However, without further prevalence studies addressing the medthodological flaws highlighted in previous research it is unclear whether individuals with ID without DS do have an increased risk of dementia than that of their cognitively healthy counterparts. Regardless of these contradictions in prevalence estimates, it can be concluded that dementia is equally concerning for individuals with ID, as those without, and thus more inclusive diagnostic practices are required.

There are complications when diagnosing dementia for individuals who have an ID, as dementia and related pathology is manifested in areas of functioning that are more than likely already impaired by the ID (Holland, 2000). Encouragingly, it is possible to apply cognitive assessments if the selected assessments do not incur floor effects and have a broad enough spread of questions to capture a range of levels of functioning. Doing so will enable dementia diagnostics to be a more inclusive process. Aylward, Burt, Thorpe, Lai and Dalton (1997) identified the lack of standardized criteria and diagnostic procedures for individuals with ID as the principal disablement to progress in the understanding and treatment of dementia in this group. By reaching a consensus, benefits in assessment efficiency and communication between healthcare professionals could be achieved. Zeilinger and colleagues (2013) in their review of the literature have, therefore, emphasised the need for a consensus on the diagnostic tool utilised to identify dementia for people with intellectual disabilities.
Adults with ID may also have specific needs for dementia related care that, if unmet, can lead to diminished quality of life (Watchman et al, 2017). It is therefore important to consider individuals with ID when looking to improve and develop the process of dementia diagnostics. Benefits could be further magnified if cognitive assessments used in the general population could be replicated for people with ID.

1.3 Treatment and care for people with dementia

Regardless of pre-existing functioning, once diagnosed with dementia some form of treatment should follow. Discouraging results from clinical trials performed in individuals with AD have shown that modifying treatments for Alzheimer’s disease would require far earlier diagnosis, prior to symptom onset, to optimise their potential benefits (Molinuevo, Minguillon, Rami & Gispert, 2018). Research has not identified any type of treatment that can cure dementia and pharmaceutical options are yet to improve cognitive scores on tests, such as the Mini Mental State Examination (MMSE) (e.g. Tzeng et al, 2017). In the absence of disease modifying treatments, the current course of treatment aims to help people with dementia manage their symptoms. While the current prescriptions aim to manage the symptoms of dementia, these have no substantial long term impact on disease progression (Andersen et al, 2018).

Use of certain pharmacological treatments, whether for primary cognitive symptoms or behaviour management in dementia, are common in people with dementia living at home (e.g. Oesterhus et al, 2017). These drugs, however, often incur increased risk of mortality and morbidity (Maher et al, 2011; Schneider, Dagerman & Insel, 2005; Nielsen, Lolk, Rodrigo-Domingo, Valentin & Andersen, 2017). With limited benefits available through pharmaceutical treatments and well documented risks, alternative treatment options aim to maintain functioning of the person with dementia and offer caregiving support to families. Respite care, for instance, offers the opportunity for the primary caregiver to have a break from caregiving. This is often cited as essential support which can delay or prevent the need for institutionalisation (O’Shea, Timmons, O’Shea, Fox & Irving, 2017; Maayan, Soares-Weiser & Lee, 2014). This option, unfortunately, only temporarily alleviates the caregiver (Gresham, Heffernan & Brodaty, 2018), and does not offer longer term effective treatment to the individual with dementia.

1.4 The role of physical activity for people with dementia

As discussed, the shortcomings of current dementia treatments are clear. Physical activity could offer an auxiliary solution. Although not currently considered a treatment (Schutzer & Graves, 2004), the potential for physical activity to benefit the health and wellbeing of people with dementia and act as a treatment is compelling, and shall be discussed throughout this section (Junge, Ahler, Knudsen & Kristensen, 2018). Prior to dementia onset during midlife, evidence consistently indicates positive cognitive effects of physical activity; with many studies suggesting physical activity as a vital tool in preventing dementia (e.g. Hogervorst, 2017; Jang & Na, 2016). The evidence for the cognitive effects of physical activity once an individual has dementia are less compelling. The physical benefits of engaging with physical activity for people with dementia are well evidenced, including increases in fitness, physical function, balance and decrease in concern about falls (Lamb et al, 2018; Heyn, Abreu & Ottenbacher, 2004; Taylor et al, 2017).

The most recent clinical trials looking at the effects of physical activity on cognition and mental health for people with dementia have found conflicting results. Lamb and colleagues (2018) for example, delivered a moderate to high intensity aerobic and strength training programme and found that the rate of cognitive decline for individuals with dementia did not slow after 12 months (Lamb et al, 2018), meaning there was no cognitive benefit observable from the engagement with the physical activity. This study offered supervised physical activity twice a week for four months followed by two months of activity at home before the first follow-up cognitive assessment was completed. Participants' were offered adherence support throughout and overall compliance was reported as 65%. This predominantly involved telephone calls during the two months of unsupervised home-based activity. The cognitive effects of the supervised activity, however, were not measured immediately after adherence to the programme. Although measures were put in place, there was no guarantee that participants completed the advised amount and intensity of physical activity once unsupervised. Moreover, smaller studies have found contradicting results, and have argued that physical activity does have cognitive benefits (e.g. Acroverde et al, 2014). These findings should therefore be interpreted with caution and further research undertaken to better understand the effects.

Literature reviews examining the cognitive effects of physical activity for people with dementia have reflected these mixed results. Heyn and colleagues found cognitive benefits of physical activity for people with dementia (Heyn, Abreu & Ottenbacher, 2004). Early cochrane reviews found insufficient evidence for the cognitive effects of physical activity for people with dementia (e.g. Forbes et al, 2008). This could be attributed to the strict inclusion criteria that Cochrane apply to their reviews which, as a result, do not include smaller studies. A later update of the same review, however, including the most recent research at the time concluded that there is promising evidence that physical activity can have a significant improvement on ability to perform activities of daily living, and possibly cognition as well (Forbes, Thiessen, Blake, Forbes & Forbes, 2013). This could suggest that studies completed since 2008 have found physical activity to benefit the cognition of people with dementia to a greater extent than earlier research.

As indicated by the change in conclusion by Forbes and colleagues from 2008 to 2013, more up to date discussions have more consistently found positive effects of physical activity. It can be noted that there have been methodological improvements in the conducting of studies included in more recent reviews. Most crucially this can be observed in the reporting of appropriate data, as many of the earlier physical activity studies were not included into meta-anlaysis calculations (e.g. Forbes et al, 2008) due to a lack of required data to be able to understand the cognitive outcomes of the trials. Guitar and colleagues, for instance, in their review found trends toward improvements in executive functioning scores, the aspects of cognitive functioning most impaired by AD, with four assessed studies showing significant improvements in these cognitive scores (Guitar, Connelly, Nagamatsu, Orange & Muir-Hunter, 2018). A recent meta-analysis also demonstrated positive cognitive effects of physical activity for people with dementia (Groot et al, 2016). However, Brasure and colleagues (2018) still maintain that insufficient evidence is available, suggesting the need for further investigation.

On further expection it is apparent that studies included in the earlier review by Forbes and colleagues consist mainly of studies conducted within residential or nursing home settings, whereas studies that have indicated more positive effects, such as those contained in the review conducted by Guitar and colleagues (2018) include studies conducted with individuals who have dementia but are still living within the community. This could suggest a disparity in the both the severity of dementia and how long individuals have had dementia between those included in the reviewed studies. As literature has found individuals to have had dementia for longer when they are admitted to residential care facilities than those still living in the community (e.g. Luppa, Luck, Brähler, König & Riedel-Heller, 2008) as well as living situation being related to the severity of dementia at diagnosis (e.g. Sibley et al, 2002). This suggests that individual differences in how long people have had dementia as well as how severe their dementia may be, could impact the extent to which they benefit from physical activity engagement. However, this is not the only individual difference impacting cognitive response to physical activity.

Various mechanisms have been proposed for the potential improvements in cognitive functioning observed in many studies and reviews. Boyle and colleagues found that physical activity is independently associated with greater whole brain and regional brain volumes, as well as reduced ventricular dilation (e.g. Boyle et al, 2015). In earlier research Silbert and colleagues (2003) proposed that the rate of ventricular volume enlargement can be used to monitor disease progression. This suggests that the brain regions directly negatively impacted by the dementia are also positively impacted during physical activity.

What is not yet clear is the rate at which physical activity impacts the cognition of people who have dementia. Studies with healthy older adults have identified cognitive benefits following a single session of physical activity (e.g. Won et al, 2019). Interestingly, the cognitive benefits Won and colleagues observed were localised to known semantic networks and therefore did not just reflect a general increase in blood flow. Although these findings are yet to be replicated for individuals who have dementia. Studies tha thave been conducted with those who have dementia suggest uncertainty when it comes to determining the appropriate amount of physical activity that people with dementia should engage with to benefit cognition. Reviews have consistently reported insufficient evidence to conduct subgroup analyses that could explore this question (e.g. Guitar et al, 2018). Therefore, to the author’s knowledge previous studies have not explored the immediate or acute effects of physical activity for individuals who have dementia. In the outlined reviews and studies physical activity effects were investigated only after a minimum of four weeks. Exploring the acute effects of physical activity could further the argument for physical activity being promoted as a treatment, as benefits might be immediately observable, stimulating subsequent uptake and adherence.

1.5 Current issues with physical inactivity

Despite the potential benefits of engaging in physical activity, it is rarely viewed as a necessary prescription medicine (Schutzer & Graves, 2004). When we consider healthy older adults, around the world one out of five are still classed as physically inactive (e.g. Dumith, Hallal, Reis & Kohl, 2011). Although the literature varies in prevalence estimates across countries, the percentage of older adults participating in physical activity has been shown to be as low as 2.4% in some studies (Sun, Norman & While, 2013). The reasons for this inactivity are yet to be fully explored. Some studies have suggested barriers that inhibit physical activity participation. Van Alphen, Hortobagyi and van Heuvelen (2016) systematically reviewed the literature and found 35 of these barriers. Prominent barriers included physical and mental limitations and difficulties with guidance and organisation of physical activity by caregivers (van Alphen, Hortobagyi & van Heuvelen, 2016). Barriers that are specific to people with dementia have also been explored. Innes and colleagues (2016) for example suggested that the ability to undertake leisure activities is subject to a greater range of barriers for people with dementia that are structured in a hierarchical manner (Innes, Page & Cutler, 2016). This highlights the severity of the barriers to physical activity people with dementia could be experiencing, and suggests that this topic should be addressed in order to aid people with dementia to access physical activity.

Behaviour change techniques discussed in psychological studies have sought to establish not only what the barriers to physical activity people with dementia are experiencing, but also how these barriers can be navigated (e.g. van Alphen, Hortobagyi & van Heuvelen, 2016). Researchers have been utilising behaviour change techniques alongside physical activity programmes, potentially as a solution to adherence concerns. Three of these techniques have shown potential for improving behaviour outcomes including goal setting, social support and using a credible source (Nyman, Adamczewska & Howlett, 2018). Although this recent research is promising, the overall efficacy of behaviour change techniques with physical activity is contentious, as little research has examined this with people with dementia thus far. Similarly, a wide range of adherence support strategies are being included in physical activity interventions for people with both mild cognitive impairment and dementia; as with behaviour change techniques, however, researchers argue that efficacy is currently limited (van der Wardt et al, 2017).

Lack of participation in physical activity and adherence to available physical activity programmes could also account for variance across the literature in the physical activity effects shown for people with dementia. Evidence-based physical activity interventions may improve health status for people with dementia but cannot be fruitful without adherence, which has shown to be problematic thus far (van der Wardt et al, 2017). To better understand the impact that physical activity could have as a potential treatment, uptake and adherence of physical activity for people with dementia warrants further investigation. To remain inclusive, people with dementia should be sought as experts during this process, as well as service providers who work with people who have dementia and therefore have an accumulation of practical knowledge about dementia.

1.6 Aims of this Research

The literature thus far indicates that research should be progressed through better establishing appropriate cognitive assessments to be utilised during an inclusive process of dementia diagnostics, as well as assessing the acute effects of physical activity interventions. Developing a greater understanding of the potential cognitive benefits of physical activity could offer a solution to current shortfalls of treatments for dementia. Moreover, developing an understanding of how this physical activity can be delivered to people with dementia is required, in order to increase participation in physical activity. This advancement in our understanding of physical activity can be best established through the perspectives of people with dementia and the professionals who deliver physical activity programmes. It would be particularly beneficial to conduct research with people who have dementia using novel methods, most notably walking interviews, that could offer a deeper insight into their physical activity experiences, applying inclusive practices throughout.

This thesis aims to research with people who have dementia inclusively, taking into consideration the person centred approach and providing most potential benefits for those individuals. The research questions hence seek to increase inclusivity in the process of diagnosing dementia, available treatment options, physical activity assessments and accessibility. The main research questions guiding this thesis are:

1. Can cognitive assessments in dementia diagnostics be more inclusive?
2. To what extent can physical activity have positive acute effects for people with dementia, and therefore potentially act as a treatment for dementia?
3. What are the barriers to participation in physical activity for people with dementia and how can these be navigated?

In order to address these research questions the objectives of the subsequent thesis are therefore threefold:

i) To investigate cognitive functioning across a wide range of individuals in order to better establish inclusive, reliable and valid cognitive assessments that could also inform dementia diagnostics in vulnerable adults.

ii) To use the same cognitive assessments to evaluate the benefits of physical activity in vulnerable individuals with dementia to develop inclusive physical activity protocols that benefit a wide range of people.

iii) To assess the best ways people with dementia can better take up physical activity as a potential intervention to treat dementia using inclusive methods and practices.

Table 1.1. outlines the purpose of each chapter. Chapter 2 outlines the methodological background that underpins this research as well as the methods that are applied to investigate each research question. The first research objective is then explored throughout chapters 3, 4 and 5. Initially through the use of a systematic literature review of cognitive assessments utilised to inform dementia diagnostics for individuals with intellectual disabilities. This is followed by two studies that explore the use of the cognitive assessments that are outlined in chapter 2, to inform dementia diagnostics for individuals with intellectual disabilities with and without dementia in chapter 4, and then with individuals without a pre-existing impairment, but with and without dementia in chapter 5. The second objective is investigated in chapter 6 through the use of cognitive assessments before and after a short bout of physical activity. The final objective is explored in extensive detail in chapters 7, with a discussion of individuals' willingness to take up physical activity, and chapter 8 with a systematic literature review exploring adherence to physical activity for people with dementia. The final objective is investigated in chapters 9 and 10. Chapter 9 describes the attitudes people with dementia have toward physical activity using walking interviews with people with dementia. Chapter 10 then discusses the role professionals have in facilitating physical activity for people with dementia and how their involvement can navigate barriers highlighted around adherence. This thesis then concludes with a discussion of how these findings translate to clinical practice and suggestions for future research.

Table 1.1 Outline of chapter contents

Chapter	*Purpose*
2 - Methodology	To outline the methodology guiding this research and to explain the division of the thesis into two parts.
Part 1	
3 – Systematic Review of Cognitive Assessments to inform dementia diagnostics for individuals with intellectual disabilities	To systematically evaluate the use of cognitive assessments in previous research to infom dementia diagnostics for individuals with intellectual disabilities.
4 – Cognitive Assessments for Dementia Diagnostics: A cross-sectional study of those with intellectual disabilities with and without dementia	To investigate the feasibility, accuracy, sensitivity and specificity of selected cognitive assessments in identifying those with intellectual disabilities with and without dementia at initial assessment and 6-month follow-up.
5 - Cognitive Assessments for Dementia Diagnostics: A cross-sectional study of those with and without dementia	To investigate the feasibility, accuracy, sensitivity and specificity of the same cognitive assessments in identifying those with and without dementia from a sample of individuals who do not have a pre-existing impairment.
6 – Acute cognitive effects of physical activity for people with dementia	To establish the acute cognitive effects of a short bout of physical activity for people with dementia and age-matched controls. Also to establish whether physical activity shows cognitive benefits over and above a psychosocial control activity.
Part 2	
7 – Systematic literature review exploring adherence to physical activity for people with dementia	To establish how much people with dementia are currently adhering to physical activity interventions and discuss the potential factors highlighted in the literature that could affect these adherence rates.

8 – Persepctives toward physical activity: walking interviews with people who have dementia	To explore physical activity from the perspectives of people with dementia while conducting light physical activity in the form of walking interviews and conventional seated interviews.
9 – Physical activity for people with dementia: professionals' perspectives	To investigate the role professionals have in facilitating physical activity for people with dementia.
10 – Discussion	To discuss the implications of the findings throughout the thesis and the real world context in which these findings are situated.

Chapter 2

Methodology

Chapter 2 – Methodology

The research conducted throughout this thesis aims to develop a more inclusive approach to dementia diagnostics and physical activity delivery. This thesis further aims to develop a more in-depth understanding of the accessibility individuals with differing levels of pre-existing functioning have to dementia diagnostics and physical activity interventions, as this is situated under the banner of inclusivity. In order to facilitate the best possible research, this chapter first examines the research pathway that led to the development of both the research contained within this thesis but also the personal development of the researcher too. The philosophical perspectives of the researcher that underpin this research will be described, next, followed by a justification for presenting this thesis in two parts. Lastly, the methods that follow these key methodological decisions are discussed.

2.1 Reflections and Research Pathway

This reflective piece and the appropriate sections of this thesis that align to later philosophical development shall use first person narrative, this is intentionally applied to reflect the paradigmatic lens that informed these sections of the thesis. In essence, it is a crucial point to highlight that throuhgout this thesis I developed in both understanding of the topics at hand, but also my overall understanding of the philosophical perspectives that underlie the whole research process. Having studied psychology prior to undertaking the work in this thesis and specifically cognitive psychology, I was late to explore the philosophy of scientific research. Following an initial plan for the subsequent chapters that involved an entirely quantitative approach looking at cognitive assessments to first determine whether an individual was a case or control and then using those same assessments to assess the cognitive effects of physical activity in a large randomized controlled trial or RCT with individuals who have dementia. However, initial attempts at conducting said trial resulted in numerous barriers to a successful data collection. Firstly, gatekeepers presented as very opposed to individuals with dementia within the community taking part in cognitive assessments. There was a lot of concern for the discomfort this places upon the person with dementia and their caregiver and not wanting to inflict this uneasiness outside of a doctor’s office. Participants themselves seemed happy to participate but the logistical barriers seemed too much. I sought recommendation from the literature and offered adherence support in the form of telephone calls. This was, however, unsuccessful as adherence to the home based physical activity was not forthcoming. With this in mind I began to ask participants for more information about why they were not able to engage. I generated a lot of ‘soft’ knowledge around the barriers and facilitators that people with dementia have towards physical activity and so I set out to better understand the story of physical activity for people with dementia. With this unexpected shift in overall thesis goal came a key development in my philosophical understandings of myself as a scientist and the research I wanted to conduct. I formulated a plan, situated in critical realism, a philosophy that I felt much more aligned to. Guided by both my primary supervisor and a new secondary supervisor, I was able to better understand the gaps in the story of the dementia journey, from diagnosis to physical activity and navigating that journey day to day. With this, I came to the conclusion that regardless of any potential benefits of people with dementia engaging with physical activity, if individuals are unable to engage then no positivist explorations situated within cognitive psychology would be informative and of impact. Hence, exploring the perspectives of those with dementia and those that are positioned to help people with dementia to be physically active became of paramount importance.

This divergence from an earlier understanding and earlier research plan is a strength of the subsequent thesis because through this work I was able to address key questions that were otherwise unanswered within current literature. This thesis has flowed from both positivism and critical realism, but more crucially is able to develop a deeper understanding of the inclusivity that is required in both the cognitive asssessments that inform diagnosis and assess physical activity as well as the perspectives that could help individuals with dementia to benefit from current cognitive understandings of physical activity. However, as this personal development resulted in philosophical development this thesis is divided into two parts to reflect the two lenses that underpinned the research conducted at that time. The first part offers earlier research informed by positivism. The second part offers a critical realist exploration with substantial potential for translation to practical application. By dividing the final thesis into two parts it is clear which paradigm each study is situated and therefore the implications for the conclusions that are drawn from this.

2.2 Positivism

Philosophical perspectives, whether implicit or explicit, guide and shape research. These are the worldviews that researchers hold about the nature of the world and the relationships within it (e.g. Broido & Manning, 2002). It is through these worldviews that three key decisions are made. The first is ontology, the study of being, the second epistemology, the nature of knowledge; and the third is the concrete methodologies, that can put these beliefs into action (e.g. Broido & Manning, 2002). This chapter unpicks the perspectives that have guided this thesis, as this facilitates maximum understanding in order for methods to be replicated. Together these three domains (ontology, epistemology and method application) form the researcher’s paradigmatic lens. A reflexive approach was also applied throughout the thesis to continue to understand the decisions and perspectives that developed alongside the research being conducted.

Justification is hence provided for the adoption of a mixed methods strategy and using a variety of methodological tools, including systematic reviewing; cross-over design intervention studies; focus groups; semi-structured interviews; and mobile methods for interviewing. Associated decisions regarding data collection tools, such as cognitive assessments, as well as methods of analysis that follow are similarly identified and justified. Throughout the thesis, the way in which each approach and method is applied is discussed for each study.

This thesis is presented in two parts. The first is embedded in the philosophical perspective of positivism. Since it’s inception, the dominant narrative of Psychology is situated within positivism through it’s insistence that studies in psychology are objective and generalisable (Breen & Darlaston-Jones, 2010). Therefore, much of what we know about cognitive processes is understood through experimental studies (e.g. Chow, 1992). This is as many early psychologists, such as Wundt, poised psychology as a natural science which meant it was inherently experimental and required a lot of introspection within a laboratory setting (e.g. Blumenthal, 1980). Therefore, the concrete methods that followed were quantitative. In the first half of this thesis the quantitative chapters 3, 4, 5 and 6 were informed by the researcher’s earlier studies in psychology.

2.3 Critical realism

The second part of this thesis is embedded in critical realism and is guided, as such, using critical realism as the theoretical framework. Critical realism is a movement in philosophy, human sciences and cognate disciplines; and in the last quarter century since its inception has become a fully international and multi-disciplinary movement (Archer, Bhaskar, Collier, Lawson & Norrie, 2013). A critical realist approach uses a unique and stratified ontology to distinguish between three differing layers of knowledge: the ‘real’, the ‘actual’ and the ‘empirical’ (e.g. Schiller, 2016). A critical realist ontology is what differentiates critical realism from other philosophies, such as positivism, as it considers an independent reality (Bergin, Wells & Owen, 2008; Hedlund-de Witt, 2013). Through this layered reality, critical realists seek to explore causative mechanisms for what is experienced and observed (Walsh & Evans, 2014).

Causation is generative; a number of factors are required to cause a specific outcome, factors need to be in the right combination, at the right time and in the right context (Harwood & Clark, 2012). Take the example of baking a cake for instance, all of the ingredients together are causative mechanisms and are required to make a cake, but without the context of a hot oven at the right time, when the mixture has been mixed, the causative mechanisms cannot be generative. Mechanisms can also counteract each other, potentially rendering neither as generative (Danermark et al, 2002). This means that understanding the context in which mechanisms occur can be crucial in understanding whether those mechanisms have a generative effect. In our basic example of the cake if we added too much flour and too few eggs the ingredients that could otherwise be generative, counteract each other and do not produce a cake. In the context of this thesis, whether the appropriate physical activity is delivered at the right time will impact whether older adults with dementia will adhere to physical activity longer term. If the selected physical activity is not appropriate for the individuals taking part then the mechanisms that could otherwise be generative, delivery of physical activity and when it is delivered, counteract each other to reduce physical activity participation.

In critical realism, the ‘real’ domain contains the structures and the mechanisms that generate phenomena (e.g. McEvoy & Richards, 2006) and is independent of human thought, awareness and even existence (Modell, 2009). It represents the physical or material world. The actual domain suggests that whether humans experience phenomena or not it still happens (e.g. Longhofer and Floersch, 2012). The empirical domain includes the information humans get from research as well as various theories that we create about natural and social phenomena (Danermark et al, 2002; Miller & Tsang, 2011; Oladele, Clark, Richter & Laing, 2013). The empirical domain is transitive, meaning knowledge is a human construct that is subject to change over time as experience develops (Pratt, 2011).

Human speculations and perceptions in the empirical domain are considered to be fallible representations of the real domain (Clark, Lissel & Davis, 2008). Therefore, it is only possible to know what we experience both directly and indirectly. Only fully closed systems, such as in an experiment conducted in a vacuum, a context in which researchers sometimes attempt to recreate, could possibly yield universally valid patterns of interplay between the causal events associated with real objects and mechanisms, which would result in law-like associations in the actual world (Bhaskar, 1998a). However, most social settings are highly complex and far from being closed systems. The actualisation of generative mechanisms are thus dependent upon the variable conditions at that time (Bhaskar, 1998b; McEvoy & Richards, 2006). With this in mind, this thesis considers the context in which each study is conducted and argues the contexts and mechanisms that are required to best facilitate timely diagnosis and assessments of physical activity treatments and adherence to consistent physical activity. Additionally, without the ability to observe a fully closed system, this thesis can only discuss the generative mechanisms that could be acting upon the social setting being studied.

Through critical realist thought this thesis attempts to clarify the various circumstances or contexts under which a particular event is likely to occur, or a particular explanation is likely to be valid (Bhaskar, 1998b; Modell, 2009). So in the initial studies this involves identifying the most inclusive cognitive assessments that, if acceptable in varying contexts, can advance dementia diagnostics and assessment of intervention effects. Subsequently this involves clarifying the contexts in which people with dementia can best access physical activity. The key process by which such clarifications are generated in critical realist analysis is known as abduction, which is a form of inference that uses emerging empirical observations to generate a hypothesis that will account for those observations, accepting that the premises do not actually guarantee the conclusions that are being drawn from them. Hence, throughout this thesis, there are various analytical techniques applied to generate hypotheses about these data. For example, in Chapters 8 and 9 thematic analysis will be utilised to better understand and draw contextual conclusions about physical activity for people with dementia; with the caveat that these conclusions are not guaranteed. It is possible to gain knowledge of actual events and structures but these are theories not a ‘mirror image’ of reality (Danermark et al, 2002).

Epistemologically, critical realism asserts that it is not possible to attain a view of reality that is unobstructed by a number of other factors, rather that an understanding of the world will always be constructed from a combination of an individual’s experiences, perceptions and standpoints (Maxwell & Mittapalli, 2010). Furthermore, there is a deeper reality, the real domain, underpinning that which we can observe and experience, the actual domain, or what we can know or interpret, the empirical domain (Schiller, 2016). The role of research is to therefore to explain social phenomena that are experienced in the empirical domain (Frauley & Pearce, 2007). Scientists, guided by critical realism, are trying to approximate the truth of the world through research, but in doing so remain cognizant that all knowledge derived in this way is ultimately fallible and could be proven incorrect by subsequent studies. Critical realism, therefore, insists upon the premise that reality is a social construct, because as humans we can only know what we have experienced or what has been represented to us (Pratt, 2011).

The real world, and all generative mechanisms that interact to result in the events we may or may not actually experience, will always be much greater than that which we can actually know (Collier, 1994; Eastwood, Jalaludin & Kemp, 2014). In fact, critical realism emphasises that, given that humans only experience a subset of complex interactions between causal powers, only context-bound assertions about ‘truth’ or knowledge can be advanced. For instance, in a particular study people with dementia may have adhered to physical activity for a period of several months, but in another study people with dementia consistently dropped out of the activity and did not complete physical activity. It is the context under which these participants were delivered physical activity that could impact their participation. Was the physical activity guided, completed with friends or individually? Was the physical activity class a long journey away from some participants’ homes or was it readily available in their residential area? All of these circumstances impact on whether the provision of physical activity is a generative mechanism in increasing physical activity or whether other barriers counteract the provision of physical activity. Therefore, the only assertions we can make here is that under the circumstances in that particular study, physical activity is increased for people with dementia, we can not conclude that just by providing physical activity, engagement will increase. The advancement and validation of our scientific knowledge claims are a matter of clarifying the contingent circumstances under which a particular explanation is likely to hold (Modell, 2009). Thus, throughout this thesis the context of the inquiries being undertaken are detailed, as these determine what can be inferred from this research.

Overall, critical realism warrants the use of both quantitative and qualitative methods. Through quantitative methods, researchers can strive to establish statistical associations, which may be evidence of deep structures. Alongside, qualitative methods that investigate people’s own explanations of such underlying structures and their causal impact. Using a mixed methods approach in this way allows an evaluation of statistical associations between cognitive assessments and their potential for use in diagnostics and intervention assessment. This can then be followed by interviews with a variety of participants to better understand how people with dementia can benefit from interventions. Hence, there is no single method best suited to critical realist inquiry (Fletcher, 2017). The best methods for each study should be determined by its guiding theoretical and conceptual framework, which is treated as fallible and subjected to inherent critique throughout the process (O’Mahoney & Vincent, 2014). The concrete methods applied throughout this thesis are varied, as each serve to further our understanding of the context in which inclusive diagnostics and interventions can be accessible for people with dementia.

The remainder of this chapter discusses the methodological considerations that apply to the subsequent thesis and offers justification for these methodological choices. Considering the importance of the context of this research in developing our understanding of the mechanisms that could be acting within this social setting, the wider implications of these choices are also discussed.

2.4 Methods Applied in this Thesis

This section describes the methods applied throughout this research. The various sections discuss literature reviewing, ethics, participants, cognitive assessments, physical activity protocol, uptake of physical activity, adherence to physical activity, interviews with people with dementia and finally, interviews with professionals.

2.4.1 Literature review

A literature review is a summary of a subject field that supports the identification of specific research questions (Rowley & Slack, 2004). Conducting a literature review is therefore an important step in understanding previous research, prior to undertaking any new research. In the process of planning the research in this thesis an understanding of previous literature was developed. It was found that cognitive assessments, although habitually utilised for people from the general population experiencing declines in memory, are rarely utilised in diagnostic practice for people with a pre-existing cognitive impairment or intellectual disability. However, systematic literature reviews have been previously critiqued for their shortfalls in correlating findings to practical healthcare settings (e.g. Clegg, 2005). The lack of current practical application leaves a gap in the previous understanding of cognitive assessments for people with intellectual disabilities. Therefore, the first method applied in this thesis is systematic literature reviewing.

Due to the inclusive principles guiding this research, and the novelty of the use of cognitive assessments inclusively, a greater understanding of previous research is required prior to undertaking any further planned studies. Furthermore, systematic reviews of cognitive assessments have been hailed for summarizing the accuracy, sensitivity and specificity of diagnostic tests in a systematic and transparent way (Leeflang, 2014). The discussion of findings from previous research is presented in chapter 3 and chapter 8. The findings may be suggesting underlying deeper structures associated with the cognitive functioning of people with intellectual disabilities who may or may not have dementia. However, it is acknowledged that the discussion of such is in the empirical domain and merely serves as a starting point in which to better understand inclusive diagnostic practice.

2.4.2 Ethics

Once a literature review had been conducted and research questions developed, appropriate ethics were sought for each study. The first ethical procedure was approved through the National Health Service (NHS) National Research Ethics Service (NRES) East of England committee. This ethics enabled recruitment of individuals with intellectual disabilities, with or without, dementia for the purpose of the study detailed in chapter 4 involving participants completing a battery of cognitive assessments. All other studies contained in this thesis were approved by Loughborough University ethical committee. These separate approvals, overall, facilitated the recruitment of individuals with dementia, aged-matched controls and professionals who work with people who have dementia.

The cognitive and linguistic difficulties inherent for individuals with dementia with or without intellectual disabilities increased the potential for participants in these studies to experience vulnerability throughout the research process. Literature review has highlighted a lack of consensus or guidelines addressing ethical concerns relating to research conducted with people who have dementia (West, Stuckelberger, Pautex, Staaks & Gysels, 2017). For this thesis, although ethical approval was given for each of the studies before initialising any research, the researcher took a relational ethical approach. This considers ethics to be a continuous process throughout all stages of the research. This type of relational ethics foregrounds the need for researchers to be sensitive to interactions and imbalances of power between researchers and participants (e.g. Palmer, 2016). This predominantly required ongoing communication with the participants, and the application of reflexive practice throughout all research endeavours. These key principals put the experiences of the participants at the forefront of all activities related to the production of this thesis and aligned well with the overarching inclusive approach.

A more specific example of the applied provisions involved all participants being given equal access to the study information with symbol accessible information sheets (Appendix 1). Furthermore, caregivers were asked to assent (Appendix 2), as well as participants to consent (Appendix 3) to participation as a way of further confirming that individuals were happy to participate, particularly in cases where cognitive difficulties could impede the participants' ability to consent.

2.4.3 Participants

Two differing methods of recruitment were utilised for this thesis. The first involved recruitment from an NHS sample of individuals with intellectual disabilities. Participants were included in the study in chapter 4 if they had a diagnosis of Intellectual Disability as defined by the ICD-10 criteria as this is the criteria that clinicians in the Leicestershire memory clinic apply to inform their diagnoses of intellectual disability. ICD-10 criteria propose that ID are lifelong conditions that manifest during the development years and are characterised by below-average general intellectual functioning, alongside limited adaptive functioning (e.g. Carulla et al, 2011). Participants were also aged 30 above and had a completed Dementia Questionnaire for Learning Disabilities (DLD - Evenhuis, Kengen & Eurlings, 2007) in their case notes completed by an appropriate caregiver or informant as a part of routine assessment with the clinician prior to chosing to take part in the study. Research has shown that dementia onsets substantially earlier with people who have a pre-existing intellectual disability (e.g. Prasher & Mahmood, 2019), therefore age 30 was selected for recruitment to reflect the earlier age at onset observed within this cohort. Prior to completion of the DLD, potential physical complications were ruled out. Participants were excluded (i) if they did not have an appropriate carer or person who knew the patient well enough to act as personal consultee (required if the patient lacked capacity to give informed consent); (ii) if they lacked the ability to complete the study assessments and/or could not follow the instructions required to do so; (iii) or if they did not have a carer or person willing or able to provide the informant information. Participants completed a demographic and health questionnaire upon enrolling in the study to ensure individuals were healthy to participate and met inclusion criteria (Appendix 4).

The second set of recruitments were based in the community. The participants sought for the remaining studies were recruited from charity-led events, groups, coffee mornings, church-led support groups and University hosted public outreach days. Community outreach groups and events were chosen based on their proximity to the University and their potential for interest in the studies being run. Participants were included if: they were community dwelling; aged 65 and over; and able to consent for themselves. Consent was gathered using an information sheet and consent form for each study. Appendix 5 gives an example of the form used for the physical activity study. Participants with dementia were sought as well as age-matched controls. As participants were recruited from community settings, dementia status was self-reported on a demographic and health questionnaire that participants filled out during their first study visit (Appendix 6). However, it was required that the participants had received this diagnosis from a GP or clinician. Recruitment methods often resulted in participants enrolling as a couple, with the caregiver of the person with dementia participating as the age-matched control.

Previous research has consistently highlighted methodological issues with participant selection in dementia research. Most notably, risk of illness, death and study attrition from drop-outs or individuals that refused to continue participation are all heightened for individuals with impaired cognition or dementia (e.g. Weuve et al, 2015). This prominent issue presented numerous challenges throughout all studies. Final samples for each study are discussed in more detail within the relevant chapters, however it is worth noting these methodological challenges and the practical implications that follow as a result of the specific populations asked to participate in this research.

To offer a brief overview of the participants who did participate in this thesis. 7 participants with intellectual disabilities and dementia were compared to 23 control participants with intellectual disabilities, but without dementia, in the study detailed in chapter 4. Twenty-five participants in total took part in the studies contained in chapter 5 and 6 looking at the diagnostic utility of cognitive assessments followed by the assessment of acute physical activity effects, this included 15 individuals with dementia and 10 age-matched controls without a pre-existing impairment. The study detailed in chapter 7 examining the uptake of physical activity, included 48 participants; further demographic details of which are described within the chapter. The interview study in chapter 9 included nine individuals, five of whom had dementia and the remaining four of which were caregivers and spouses to those with dementia. The final study, detailed in chapter 10, included 13 participants who were all professionals that worked with people who have dementia. As stated, only the 30 participants who took part in the study in chapter 4 were recruited through the National Health Service (NHS); all other participants were recruited through community events and groups related to dementia.

2.4.4 Cognitive Assessments and accompanying analytical techniques

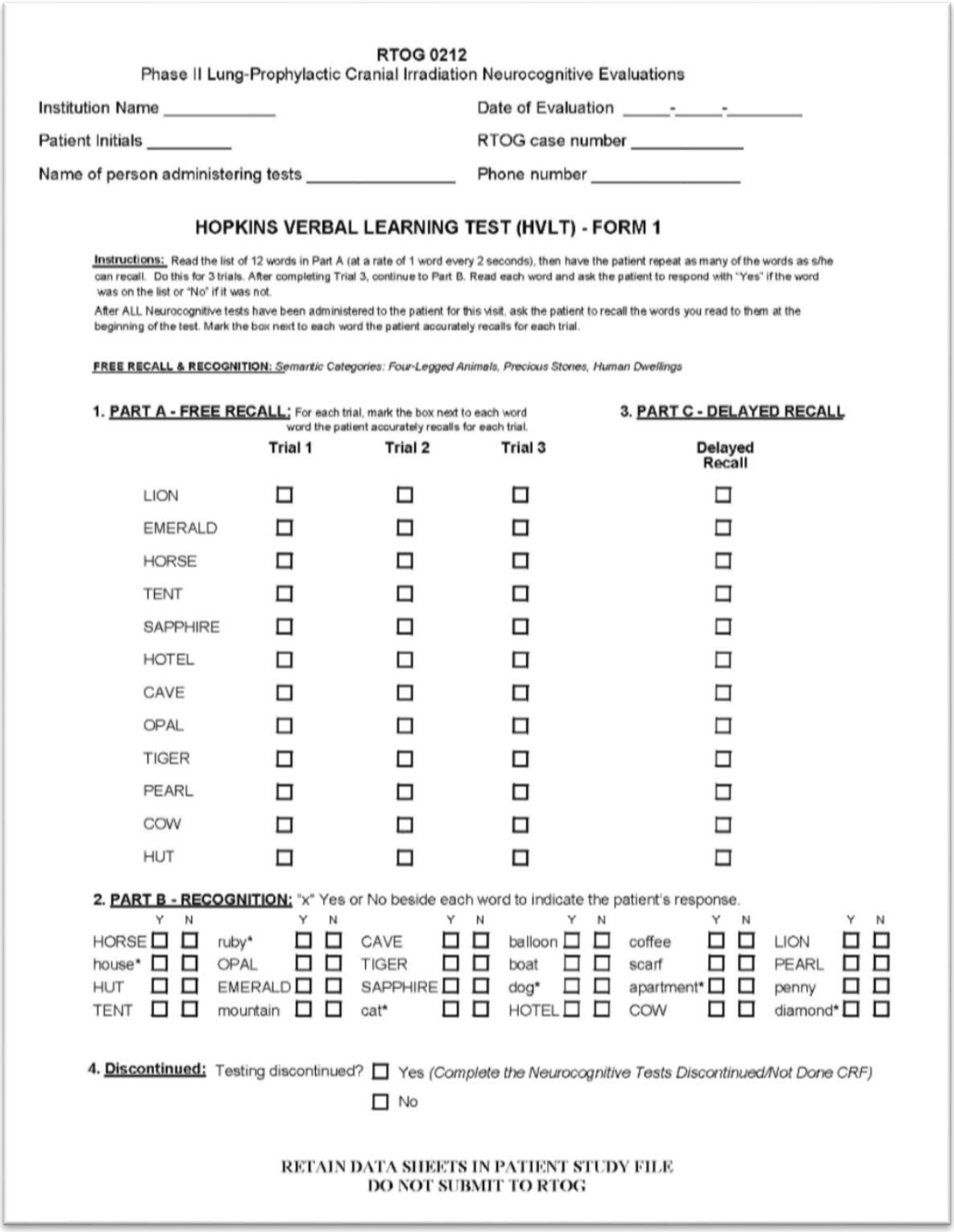
Dementia diagnosis is a continuously changing process, following any updates to diagnostic manuals and research initiatives. Presently, biomarkers are suggested to be the most accurate assessment of dementia pathology (e.g. Frisoni et al, 2017). However, it is suggested that neuropsychological assessments are equally valuable and arguably more affordable and less invasive than cognitive biomarkers of disease (Weissberger et al, 2017). The current diagnostic process in the UK is initiated with a probable diagnosis from a local doctor followed by a referral to a specialist memory clinic, as seen in the cases discussed in Plejert, Jones and Peel (2017). Either with the local doctor, or in a specialist clinician in a memory clinic, neuropsychological assessments are administered to examine the individuals' cognitive functioning. Considering that dementia specialist services are often reported to be overloaded (e.g. Iliffe, Manthorpe & Eden, 2003); Tong, Thokala, McMillan, Ghosh & Brazier (2017) have suggested having the local doctor administer such assessments as a more cost effective alternative to relying on memory clinics. This is yet to be consistently applied in practice.

Throughout this thesis cognitive assessments are utilised to further our understanding of how dementia can be diagnosed inclusively, and how interventions can impact the cognitive functioning of these individuals. The subsequent three studies, detailed in chapters 4, 5 and 6, apply a cognitive test battery as a data collection tool. This test battery is comprised of a group of cognitive assessments selected based on literature reviewing and previous practical experience in the applied cognitive research group at Loughborough University. The assessments include: i) the Hopkins Verbal Learning Test (HVLT – Brandt, 1991), ii) the Verbal Fluency (VF – McCarthy, 1972), iii) Mini Mental State Exam (MMSE – Folstein, Folstein & McHugh, 1975) and iv) the Cognitive Computerised Test Battery for Individuals with Intellectual Disabilities (CCIID – Van der Wardt, Hogervorst & Bandelow, 2011). The next section of this chapter offers a discussion of the included assessments. This describes the administration of each test, appropriate cut-offs and previous uses. The order in which these assessments are presented reflect the order participants completed each assessment.

2.4.4a) Hopkins Verbal Learning Test (HVLT – Brandt, 1991)

Memory problems have often been identified as the earliest symptom of Alzheimer’s type dementia (e.g. Jonker, Geerlings & Schmand, 2000; Grenfell-Essem, Hogervorst & Rahardjo, 2018). Therefore, memory assessments are frequently used to initially identify dementia. Systematic review and meta-analysis confirm that memory measures have high diagnostic accuracy for the identification of Alzheimer’s type dementia (Weissberger et al, 2017). The meta-analysis Weissberger and colleagues (2017) conducted also identified similar diagnostic accuracy for immediate and delayed memory tasks. In a clinical context, immediate memory tasks require much less time compared to delayed tasks, which is desirable for both the clinician and the patient. Therefore, this thesis includes assessments of immediate memory in the relevant studies detailed in chapters 4, 5 and 6. Primarily the HVLT free recall section, as this specifically assesses short term (immediate) verbal memory. This section of the HVLT only takes 10 minutes to complete and involves the researcher reading a list of 12 words aloud and then asking the participant to repeat as many words as they can remember. This is repeated over three trials and the number of words recalled is noted. Figure 2.1 shows the scoring sheet in which words recalled are tallied.

Figure 2.1 Hopkins Verbal Learning Test Scoring Sheet



RTOG 0212
Phase II Lung-Prophylactic Cranial Irradiation Neurocognitive Evaluations

Institution Name ____________
Date of Evaluation _____-_____-________
Patient Initials _________
RTOG case number ____________
Name of person administering tests ________________
Phone number ________________

HOPKINS VERBAL LEARNING TEST (HVLT) - FORM 1

Instructions: Read the list of 12 words in Part A (at a rate of 1 word every 2 seconds), then have the patient repeat as many of the words as s/he can recall. Do this for 3 trials. After completing Trial 3, continue to Part B. Read each word and ask the patient to respond with "Yes" if the word was on the list or "No" if it was not.

After ALL Neurocognitive tests have been administered to the patient for this visit, ask the patient to recall the words you read to them at the beginning of the test. Mark the box next to each word the patient accurately recalls for each trial.

FREE RECALL & RECOGNITION: *Semantic Categories: Four-Legged Animals, Precious Stones, Human Dwellings*

1. **PART A - FREE RECALL:** For each trial, mark the box next to each word word the patient accurately recalls for each trial.

3. **PART C - DELAYED RECALL**

	Trial 1	Trial 2	Trial 3	Delayed Recall
LION	☐	☐	☐	☐
EMERALD	☐	☐	☐	☐
HORSE	☐	☐	☐	☐
TENT	☐	☐	☐	☐
SAPPHIRE	☐	☐	☐	☐
HOTEL	☐	☐	☐	☐
CAVE	☐	☐	☐	☐
OPAL	☐	☐	☐	☐
TIGER	☐	☐	☐	☐
PEARL	☐	☐	☐	☐
COW	☐	☐	☐	☐
HUT	☐	☐	☐	☐

2. **PART B - RECOGNITION:** "x" Yes or No beside each word to indicate the patient's response.

	Y	N		Y	N		Y	N		Y	N		Y	N		Y	N
HORSE	☐	☐	ruby*	☐	☐	CAVE	☐	☐	balloon	☐	☐	coffee	☐	☐	LION	☐	☐
house*	☐	☐	OPAL	☐	☐	TIGER	☐	☐	boat	☐	☐	scarf	☐	☐	PEARL	☐	☐
HUT	☐	☐	EMERALD	☐	☐	SAPPHIRE	☐	☐	dog*	☐	☐	apartment*	☐	☐	penny	☐	☐
TENT	☐	☐	mountain	☐	☐	cat*	☐	☐	HOTEL	☐	☐	COW	☐	☐	diamond*	☐	☐

4. **Discontinued:** Testing discontinued? ☐ Yes *(Complete the Neurocognitive Tests Discontinued/Not Done CRF)*
☐ No

RETAIN DATA SHEETS IN PATIENT STUDY FILE
DO NOT SUBMIT TO RTOG

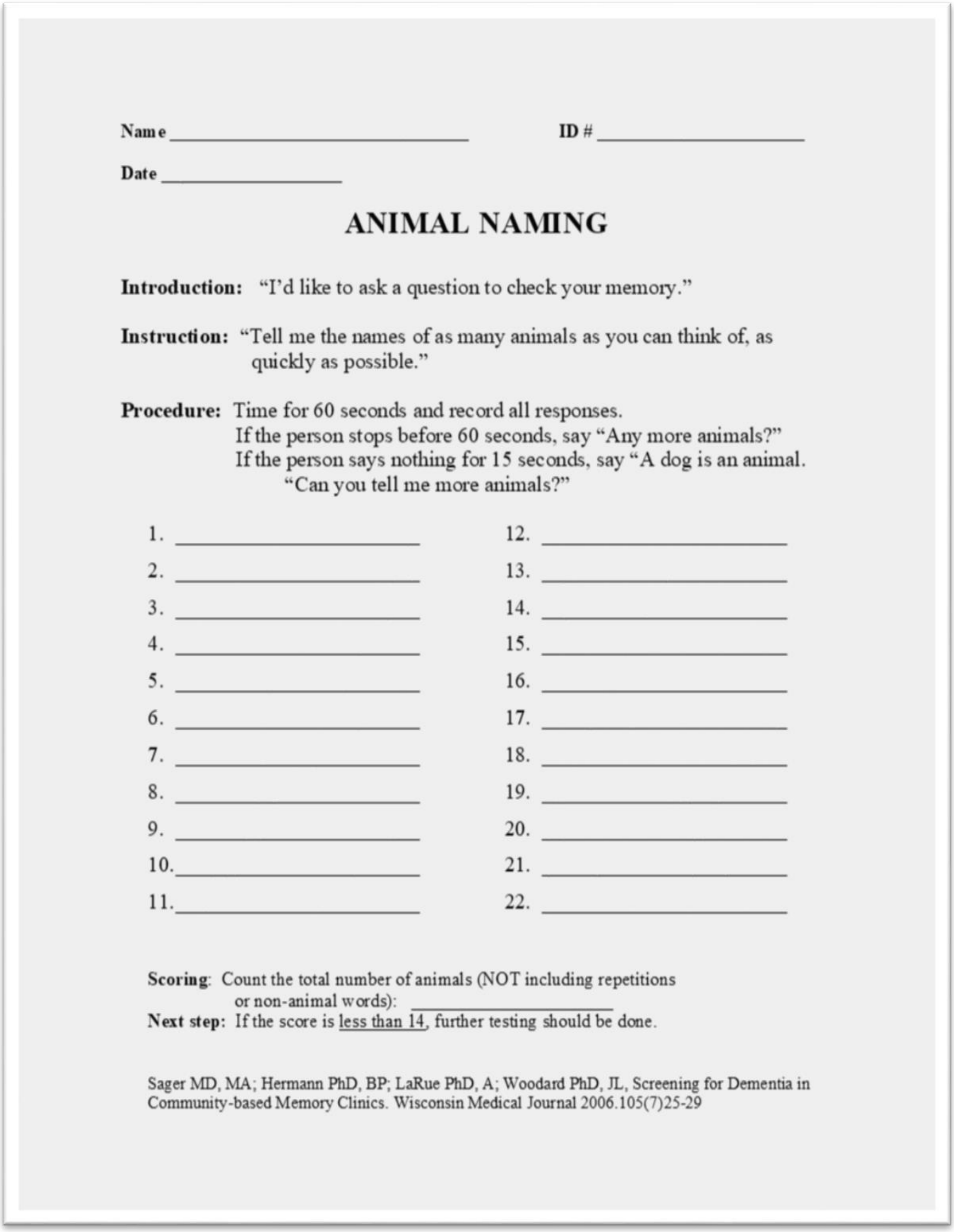
Research has found the HVLT is valid and reliable at detecting dementia, across both cultures and different age populations (Xu, Xiao, Rahardjo & Hogervorst, 2015; Grenfell-Essem, Hogervorst & Rahardjo, 2018). Additionally, previous application of the HVLT has shown it to be less sensitive to education than alternative cognitive assessments (Hogervorst, Combrinck, Lapuerta, Rue, Swales & Budge, 2002), which further benefits its potential for application as it has high diagnostic accuracy regardless of the participants' level of education. A cut-off of 16 to 18 words recalled immediately across the three trials has been found to identify dementia cases from controls with sensitivity varying from 87% to 95% and specificity from 77% and 98% (Xu, Rahardjo, Xiao & Hogervorst, 2014). This suggests that if a participant scores beneath 16 there is presence of a memory problem. Different cut-offs are also able to identify varying levels of cognitive impairment, however these scores are less evidenced thus far (for review see Xu, Rahardjo, Xiao & Hogervorst, 2014).

2.4.4b) Verbal Fluency (VF – McCarthy, 1972)

Similar to the HVLT, the Verbal Fluency offers an assessment of immediate semantic memory recall (e.g. Ardilla, Ostrosky-Solis & Bernal, 2006; Goñi et al, 2011). Verbal Fluency has been noted to also measure various aspects of executive functioning and crystalised intelligence (Shao, Janse, Visser & Meyer, 2014). However, it has been shown to be not only sensitive to dementia (e.g. Henry, Crawford & Phillips, 2004), but also able to distinguish between varying types of cognitive impairment (Zhao, Guo & Hong, 2013). Moreover, VF is sensitive to exercise effects and therefore is suitable for use at different timepoints in the dementia journey (e.g. Clifford, Bandelow & Hogervorst, 2009). The Category/Semantic version of the Verbal Fluency specifically has been shown to be valid and reliable for populations of older adults (e.g. Shao, Janse, Visser & Meyer, 2014) and in discriminating between those who are healthy, have a mild cognitive impairment or Alzheimer's disease (Ramanan, Narayanan, D'Souza, Malik & Ratnavalli, 2015; Pakhomov, Eberly & Knopman, 2018). Canning and colleagues (2004) found that a score of 15 or below was 20 times more likely to be a patient with Alzheimer's disease than a healthy control. This score showed both high sensitivity and specificity and thus suggests a cut-off of 15 will distinguish between those with dementia and those without.

In the semantic or category Verbal Fluency test the participant is given a category name, for example animals or fruit and vegetables, and asked to name as many words in that category as they can in one minute. The researcher then times the participant and notes down how many words they recall on the scoring sheet (Figure 2.2). The participants' score is the total number of words they recall in one minute.

Figure 2.2 Verbal Fluency (Animals) Scoring Sheet



Name ______________________ **ID #** ____________________

Date ____________________

ANIMAL NAMING

Introduction: "I'd like to ask a question to check your memory."

Instruction: "Tell me the names of as many animals as you can think of, as quickly as possible."

Procedure: Time for 60 seconds and record all responses.
If the person stops before 60 seconds, say "Any more animals?"
If the person says nothing for 15 seconds, say "A dog is an animal.
"Can you tell me more animals?"

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________
11. ____________________
12. ____________________
13. ____________________
14. ____________________
15. ____________________
16. ____________________
17. ____________________
18. ____________________
19. ____________________
20. ____________________
21. ____________________
22. ____________________

Scoring: Count the total number of animals (NOT including repetitions or non-animal words): ____________________
Next step: If the score is less than 14, further testing should be done.

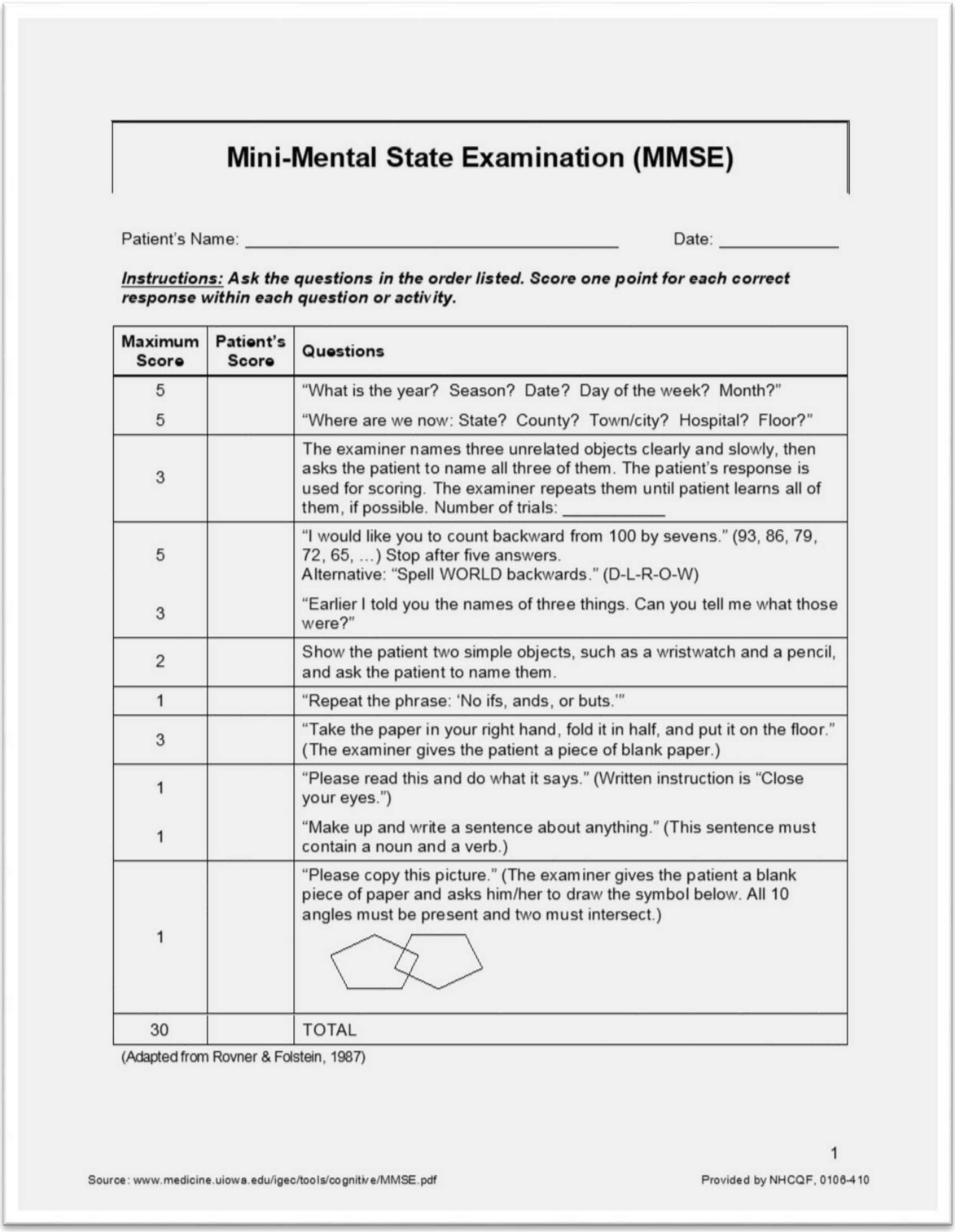
Sager MD, MA; Hermann PhD, BP; LaRue PhD, A; Woodard PhD, JL, Screening for Dementia in Community-based Memory Clinics. Wisconsin Medical Journal 2006.105(7)25-29

2.4.4c) Mini Mental State Examination (MMSE – Folstein, Folstein & McHugh, 1975)

The MMSE takes a snapshot of overall cognition and is the best known and most often used cognitive screening tool in dementia diagnostics (Arevalo-Rodriguez et al, 2015). In the MMSE, the participant is asked a series of 20 questions, some requiring actioned responses such as ‘Close your eyes’ and others just a verbal answer. The researcher then notes down and scores the participants’ responses on the scoring sheet (Figure 2.3). The participants’ total score is out of a potential 30 points. This test takes 8 minutes to administer and therefore is easy to apply in a practical setting.

The MMSE is currently the principal instrument for observing symptoms related to dementia and has been shown to be valid and reliable for populations of older adults and in discriminating between those who are healthy, have a mild cognitive impairment or Alzheimer’s disease (e.g. Tsoi, Chan, Hirai, Wong & Kwok, 2015). Various cut-offs have been proposed throughout the literature for optimal diagnostic potential. Literature reviews have shown that the most common cut-off scores for dementia were 23 and 24 with high sensitivity and specificity (Tsoi, Chan, Hirai, Wong & Kwok, 2015; Creavin et al, 2016). Additionally, the MMSE has been shown to have comparable diagnostic performance across geographic regions and recruitment settings (e.g. Tsoi, Chan, Hirai, Wong & Kwok, 2015). The MMSE has been previously criticised as it is not the most accurate tool for dementia diagnostics. However, it does provide a benchmark against which newer tools can be compared (Mitchell, 2017).

Figure 2.3 Mini Mental State Examination Scoring Sheet



Mini-Mental State Examination (MMSE)

Patient's Name: ________________________________ Date: ____________

***Instructions:* Ask the questions in the order listed. Score one point for each correct response within each question or activity.**

Maximum Score	**Patient's Score**	**Questions**
5		"What is the year? Season? Date? Day of the week? Month?"
5		"Where are we now: State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible. Number of trials: ___________
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, …) Stop after five answers. Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)
30		TOTAL

(Adapted from Rovner & Folstein, 1987)

1

Source: www.medicine.uiowa.edu/igec/tools/cognitive/MMSE.pdf

Provided by NHCQF, 0106-410

2.4.4d) The Cognitive Computerized Test Battery for Individuals with Intellectual Disabilities (CCIID – van der Wardt, Hogervorst & Bandelow, 2011)

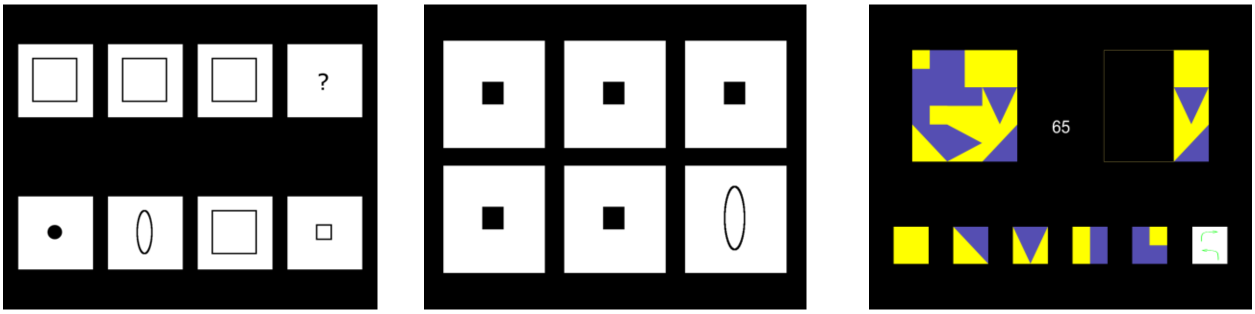
The CCIID assesses inductive reasoning and visuospatial skills. Participants complete three subtests on a laptop computer. The researcher helps support the participant with learning how to complete each subtest but otherwise the participant is able to complete the cognitive test battery unaided. The CCIID is comprised of 3 subtests that are described in Table 2.1.

Table 2.1 Subtests of the CCIID

Subtest	*Ability tested*	*Description*
Series	Inductive Reasoning	Three shapes are presented to the participant on a touch screen computer. There is a large range of items, which vary in degree of difficulty, therefore some items may be all the same shape whereas others are transforming. The participant is asked to choose the option that makes the fourth shape and completes the series.
Odd One Out	Inductive Reasoning	The participant is presented with six shapes. Five of the shapes are either the same or share a feature that groups them together. The participant is asked to identify the shape that is the ‘odd one out’ or is most different from the other five shapes.
Jigsaw	Visual-Spatial Abilities	Jigsaw is based on existing block design tests. The participant is presented with a box containing a set of geometric shapes on a touch screen computer. They are asked to replicate the geometric shapes next to the presented box using single colour or patterned squares given to them. The patterned squares can be rotated and moved into different positions, the participant is also able to change their mind as they go along, the jigsaw is only finished when the participant clicks the finished button.

The CCIID test battery completes the scoring and therefore the researcher needs to merely note down the score after the participant has completed the assessment. Overall the test takes roughly twenty minutes to complete and, due to the automation, is easy to administer in a practical setting.

Figure 2.4 Series subtest, Odd One Out subtest and Jigsaw subtest of the CCIID.



The CCIID is a cross-cultural instrument, which has been previously validated in groups of individuals who already have a cognitive impairment due to various different intellectual disabilities. This research (van der Wardt, Hogervorst & Bandelow, 2011) found the CCIID to be tolerated well by individuals who have an intellectual disability as well as healthy controls. Appropriate cut-off scores for this cognitive assessment are yet to be established and will be discussed in Chapters 4 and 5.

The three studies in which the cognitive assessments are included (in chapters 4, 5 and 6), first assess the diagnostic potential for these assessments, and secondly, the potential for these assessments to detect the immediate cognitive effects of a short bout of physical activity. The context of these studies are crucial as they lay the foundations for an increase in inclusivity during dementia diagnostics.

2.4.5 Analysing cognitive scores

Quantitative methods of statistical analysis were applied to understand the potential for cognitive assessments to diagnose of dementia and to detect changes in cognition relating to physical activity participation. Non-parametric tests of difference were consistently applied to these data due to small sample sizes. Tests such as the Mann Whitney U test and Spearman's rank correlations allow an understanding of the differences and associations between demographic factors, such as participants' age, and diagnostic test scores. Chi-square tests were applied when demographic factors were categorical. When assessing diagnostic suitability, Receiver Operating Characteristic (ROC) analysis were applied. ROC analyses show the accuracy, sensitivity and specificity of a particular test to detecting whether a participant is a case or a control. For the studies detailed in chapter 4 and 5 ROC analyses, conducted for each cognitive assessment individually, showed whether the test accurately assessed whether the participant had a diagnosis dementia or if they did not. Despite small sample sizes, when assessing the cognitive effects of the interventions parametric tests were applied. Due to this being select sample with limitations on the potential for recruitment, previous research looking at physical activity for people with dementia have also applied an ANOVA with numbers as small as 13 participants without dementia being compared to 9 participants with dementia across timepoints and interventions (e.g. Yerokhin et al, 2012). Although larger sample sizes are desirable it was decided to compare resistnace band physical activity with the psychosocial control of bingo, through a mixed measures 3 x 2 x 2 ANOVA. This assessed the difference using three factors: (i) within subjects: time – before, immediately after or six months after, (ii) between subjects: intervention – physical activity or social control and (iii) between subjects: participant group – whether the participant had dementia or not. Multiple linear regression (MLR) were also applied to indicate which predictor variable influenced performance on each of the cognitive assessments.

2.5 Methods of understanding Uptake and Adherence of Physical activity

Participants were shown a demonstration of physical activity at a public outreach event or workshop. The demonstration showed a series of four resistance band exercises to be completed while seated, as pictured in Figure 2.5. This specific physical activity was tailored to ensure the appropriateness and accessibility for all individuals regardless of current physical ability. The full programme is described in the information booklet given to participants at public outreach events (Appendix 9). Each activity targeted a different part of the body with added strength given through the use of resistance bands.

Figure 2.5 Pictures of the four seated resistance band physical activities

Adherence to physical activity has been discussed alongside numerous physical activity studies. Therefore, a literature review was conducted to better understand the adherence of people with dementia to physical activity in previous studies, contained in chapter 7. Whether participants take up physical activity and whether they then adhere to that activity is crucial in understanding whether physical activity is a feasible intervention for people with dementia. Following chapter 7, the next two studies, detailed in chapters 8 and 9, develop a deeper understanding of the contexts of physical activity and the ways people with dementia may access physical activity through the perspectives of people with dementia and the varying professionals that work with these individuals.

2.6 Interviews and the accompanying analytical techniques

Research to date has shown interviews to be a feasible method for giving voice to people with dementia (e.g. Gillies, 2000; Borley & Hardy, 2017). Chapter 8 presents data from interviews with people with dementia and chapter 9 follows on, using interviews with professionals who work with people with dementia. Conventionally, interviews are conducted in a seated position between an interviewer and interviewee. Mobile methods, however, offer a novel method of collecting data about movement whilst on the move (Büscher, Urry & Witchger, 2010; Ross, Renold, Holland & Hillman, 2009). The study detailed in chapter 8 consisted of both walking interviews, a mobile method of interviewing, and seated interviews with people with dementia. Concerns could be raised about the logistical challenges that come along with moving whilst talking (e.g. Carpiano, 2009), such as risk for falls. Having said that, Kullberg and Odzakovic (2017) have successfully carried out walking interviews with people with dementia. Potential benefits of discussing a movement based topic whilst moving that have also been pointed to in earlier mobile methods research (e.g. Carpiano, 2009; Trell & Van

Hoven, 2010). This, therefore, suggests that this method is both feasible and beneficial for discussing physical activity with individuals with dementia.

Participants with dementia who had taken part in earlier studies detailed in chapters 4, 5 and 6 were invited to be interviewed. Participants were allocated to either a seated or walking interview based on a number of factors, namely their personal preference and the weather conditions on the day of their interview. Due to ethical and safety provisions caregivers were invited to participate in the interview alongside the person with dementia. It was the decision of both the person with dementia and the caregiver whether they did so. This was maintained for both types of interviews in order to not introduce any further differences between the interview types. A semi-structured interview schedule was used as a basis for the conversations had during the interviews (Appendix 11). The interviews were audio recorded and transcribed verbatim, and the subsequent analysis is described below and detailed in chapter 8.

The study in chapter 9 also applied interview methods. These were conducted over the phone or face to face with professionals that work with people with dementia. Participant availability and preference determined how the interview was conducted. A semi- structured interview technique was used with the purpose of learning more about the professionals' experiences with barriers to physical activity, how they sought to navigate those barriers and the outcomes they observed as a result. The questions posed to professionals required them to reflect holistically on their experiences of working with people with dementia (Appendix 12).

Both chapters 8 and 9 applied a thematic analysis guided by the six steps laid out by Braun and Clarke (2006). In both instances this involved an initial familiarisation of the dataset. Codes were then generated inductively, meaning there was not a coding framework applied to these data. Codes were then grouped to aid in generating themes. Themes were perceived as reflexive which meant they were continually reviewed prior to being named and defined (Braun & Clarke, 2019). Lastly, the analysis was written up, offering an in-depth discussion of people with dementias' experience with physical activity in chapter 8 and professionals' experiences in chapter 9. In chapter 9, the themes were described in the context of theoretical concepts and current understandings of the topic. This gives the subsequent data the context needed to understand how and when professionals are able to facilitate physical activity for people with dementia and the strategies that are used to do so.

In chapter 8, however, analysis was extended to include the impact the methods that were applied had on the production of the data. During the initial familiarisation and coding of the data detailing the experiences of people with dementia the influence of the type of interview conducted was noticeable. In consideration of this novel walking approach for people with dementia, it was therefore decided to conduct a second analysis to offer a discussion of the methodology. The interview scripts were therefore re-coded to comment on the methodology and how this influenced the discussion of physical activity. These codes were then grouped into two columns. The first was for seated interviews and the second for walking interviews. These codes, alongside researcher diary notes, were then used to inform a discussion of the impact of these modes of interview seen in these data. This was then written up as a detailed description of the differences between the interview types, perceived during data collection by the researcher and shown in the analysis of the transcripts. This discussion intends to add a further layer of understanding as to whether discussing physical activity while being physically active is an inclusive method that is feasible and ultimately beneficial for people with dementia.

2.7 Conclusions

Overall, the mixed methods approach taken to this thesis allows for a broader and deeper examination of the research questions outlined in chapter 1. The critical realist underpinnings allow for the use of quantitative methods to analyse cognitive assessments to inform dementia diagnostics that is inclusive of all individuals that could be impacted by the onset of dementia, as well as assess physical activity effects. This is then followed by the qualitative methods that examine physical activity for people with dementia. The combination of these methods and approaches has resulted in a broad and varied research enquiry that offers an in depth understanding of the topics being discussed. According to critical realism, the explanations drawn from this thesis can only be understood under the contingent circumstances in which the knowledge was produced. The methods applied to this research, therefore, align well with the critical realist stance taken as they are designed to offer the a broad and deep understanding of the circumstances in which the topics being discussed occur.

PART 1

Chapters 3 - 6

Chapter 3

Systematic Review of Cognitive Assessments to inform dementia diagnostics for individuals with intellectual disabilities

Aspects of this chapter have been published in:

Elliott-King, J., Shaw, S., Bandelow, S., Devshi, R., Kassam, S., & Hogervorst, E. (2016). A critical literature review of the effectiveness of various instruments in the diagnosis of dementia in adults with intellectual disabilities. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*.

Chapter 3 – Systematic Review of Cognitive Assessments to inform dementia diagnostics for individuals with intellectual disabilities

3.1 Introduction

An intellectual disability (ID), similar to the UK specific term learning disability, onsets during the developmental period and is characterized by impairments of general mental abilities that impact adaptive functioning in three main domains: conceptual, social and practical (APA, 2013). Various studies discussed throughout this review refer specifically to Down Syndrome (DS). This is the most common genetic disorder seen in clinical practice. DS is caused 94% of the time by non-disjunction of chromosome 21, and 3-5% of the time by translocation. The IQ of people with DS falls within the mild to moderately severe ID spectrum (Stanton & Coetzee, 2004).

Improvements in living circumstances and medicine has results in an increase in the life expectancy of individuals with ID (Janicki, Ackerman & Jacobson, 1985; Eyman, Call & White, 1991) equalling life spans of those of the general population (Patja, Iivanainen, Vesala, Oksanen & Ruoppila, 2000). Consequently, adults with ID are in a position where age-related illnesses are becoming a greater concern. The most notable of these illnesses is dementia, for which an individual’s age is the strongest risk factor (e.g. Daviglus et al, 2011). Dementia is a cognitive impairment that gradually onsets, is progressive and leads to interference with social and occupational functioning (DSM IV, 2000). Furthermore, individuals with ID often experience onset of ageing characteristics earlier than in the general population (Lin, Wu, Lin, Lin & Chu, 2011) and this is reflected in age of dementia diagnosis. Onset of dementia usually occurs among older adults over the age of 65, however in individuals with DS onset is usually around the early 50s (Janicki & Dalton, 2000).

Literature has shown substantial conflict in prevalence estimates of dementia in ID populations with and without DS when compared to the general population. At the International Summit on ID and Dementia in 2016, key researchers noted that our understanding of the differences in trajectories of dementia in people with DS, compared to individuals with ID without DS is lacking (McCarron et al, 2018). Dementia has been shown to be common in older adults with ID, but prevalence rates reported differ according to the diagnostic criteria applied (Strydom, Livingston, King & Hassiotis, 2007). In people who have ID but do not have DS Cooper (1997) found diagnosis of dementia to be substantially higher than the general population, 21.6% of participants were diagnosed with dementia, compared to 5.7% that was expected in a group with this age structure. This was further supported by Strydom, Chan, King, Hassiotis and Livingston (2013), who highlighted an incidence rate of dementia to be five times higher than older adults in the general population. Other studies have shown prevalence rates to only be comparable or higher than in the general population (e.g. Strydom et al, 2010). Additionally, opposing studies have shown risk of dementia to be equivalent to or lower than in the general population (e.g. Zigman et al, 2004). Thus, highlighting the divergence in the understanding and application of dementia diagnostics for individuals with ID, that numerous studies have pointed to as accentuating the differences in prevalence estimates.

Stronger evidence has been established regarding dementia rates in individuals with ID and DS. Incidence of early onset dementia of the Alzheimer’s type has been shown to be higher than in the general population (e.g. Bush and Beail, 2004). Genetic findings have suggested that due to the complex etiology of DS and the triplication of the amyloid precursor protein (APP) gene on chromosome 21, DS could be considered a model of early-onset dementia (Rohn, McCarty, Love & Head, 2014). Almost all adults with DS over the age of 35-40 years show neuropathological changes characteristic of AD (Deb & McHugh, 2010), including senile plaques and neurofibrillary tangles. Although this does not necessarily mean a clinical diagnosis, genetic evidence has merely begun to highlight similarities between the neuropathology of the two conditions. Unsurprisingly however, individuals with DS in many cases, have been shown to be at higher risk of developing Alzheimer’s disease than the general population (e.g. Nieuwenhuis-Mark, 2009).

There is a need for further clarification of the difference in prevalence rates between the three populations, individuals from the general population with no pre-existing impairment, individuals with ID but without DS and individuals with ID and DS. Regardless of comparisons to the general population, evidence does show that the prevalence rates of dementia in ID increase dramatically between the ages of 40 and 60 years (Holland, 2014). Therefore, dementia diagnostic assessments should be targeted at this age group or before.

There are inherent difficulties in assessing cognition to inform dementia diagnostics in people with intellectual disabilities (Holland, 2014). The complicated process of assessment is remarkably more complex in individuals with ID as dementia and related pathology is manifested in areas of functioning that are, more than likely, already impaired by the intellectual disability (Holland, 2000). Novel methods for informing diagnosis and care are beginning to emerge (e.g. Schaap, Dijkstra, Finnema & Reijneveld, 2018). However, evidence is limited and it remains that there is currently no consensus, in the literature or in practice, on how dementia diagnosis should be informed in ID populations (e.g: Moran, Raffii, Keller, Singh & Janicki, 2013).

Assessments within the general population often involve direct cognitive tests that indicate progressive cognitive decline in areas such as short-term and long-term memory, orientation, communication and mood, among others. These tests are frequently not appropriate for individuals with ID as they often require abilities that individuals with ID may find more difficult due to their pre-existing impairment. Assessments are seldomly developed for use in ID populations and therefore they do not reliably screen for dementia in this group (Zeilinger, Stiehl & Weber, 2013). Moreover, there are no normed data for this population and thus results cannot be interpreted meaningfully (Moran et al, 2013). Consequently, floor effects are often observed on the chosen test and problems of accuracy in diagnosis ensue. There are three potential assessment methods that practitioners can apply to help inform diagnosis. These include a single test that directly assesses the individual’s cognitive functioning, a test battery which comprises of multiple tests that assess a range of cognitive functions and, lastly, informant reports which are completed by a carer or close relative who can report on the individual’s functioning. This could include informant reports of behaviour, as similar reviews have found behavioural assessments to equally contribute to informing the process of dementia diagnostics (McKenzie, Metclafe & Murray, 2018).

Several reviews to date have explored the different instruments available to inform the process of diagnosing dementia for individuals with ID. McGuire and colleagues (2006), for example, first collated instruments available for individuals with intellectual disabilities, however can be criticised for not applying a systematic approach to evaluation of the available instruments. Zeilinger and colleagues (2013) later collated instruments that are both a direct assessment of the individuals with ID, as well as an indirect assessment, i.e. through an informant report. This review was strengthened by it’s consideration for whether the assessment had been developed for individuals with ID specifically or just for the purpose of dementia diagnostics generally. Zeilinger and colleagues (2013) however, can be critiqued for not considering the time each assessment takes to administer, as this has impact on the suitability of that assessment for clinical application.

This review aimed to critically appraise existing instruments used in the diagnosis of dementia in individuals with ID. The instruments are coded according to whether they are (1) a direct cognitive test, (2) informant report or (3) a test battery. The benefits of each type of test is then discussed. This review builds on previous reviews by presenting an up to date overview of the instruments available, as well as discussing instruments that have been proposed for diagnostics in adults with ID, but have yet to be established as such. This could include instruments that are designed for use in the general population, in the intellectually disabled populations or in people who have already been diagnosed with dementia. This review therefore could aid clinicians to extend their knowledge of the potential cognitive assessments available, discuss non-cognitive assessments being utilized and give recommendations based on previous literature.

3.2 Methods

3.2.1 Literature Search

A systematic literature search was conducted in four databases; PubMed, Science Direct, Google Scholar and PsycInfo. These databases were selected due to the depth and breadth that they offer in literature searching as well as their relevance to the reviewed topic. The search string included various terms for (1) the measure of interest (e.g. Alzheimer’s disease, Dementia, Dementia of Alzheimer’s type) as well as (2) the output of interest (e.g. diagnosis, assessment, instrument, screening tool). The search was performed once for the (3) specified population (e.g. intellectual disability, learning disability, mental retardation) and again for (4) Down Syndrome, due to the well documented increased risk of dementia of Alzheimer’s type in this sub-group of individuals with ID. Table 3.1 shows the logic of the search strategy. References of included studies were also hand-searched, in order to include further relevant studies. Both English and non-English publications were sought after, however due to searching being conducted in English, publications that had been originally written in English or translated into English were able to be included.

Table 3.1: Search String Logic:

	Output	Measure	Population
Synonyms	Informant report, direct test, test battery, diagnosis, diagnostic, screening, assessment, tool, questionnaire, Scale	Dementia, Alzheimer's disease, Dementia of Alzheimer's type	Intellectual Disability, Learning Disability, Mental Retardation, Developmental Disability, Down Syndrome, Downs Syndrome.
Combined and Truncated	Inform* OR Informant Report* OR diagnos* OR screen OR screening* OR instrument* OR tool* OR Assess* OR questionnaire OR Scale*	Dement* OR Alzheimer*	((Intellectual* OR mental* OR learning OR developmental*) AND (disab* OR retard*)) OR (Down* AND syndrom*)

Relevant studies were identified and selected using the following inclusion criteria. Identified studies should be suitable dementia assessments for individuals with ID; this included informant reports, independent direct cognitive tests or test batteries. Test batteries were included with both cognitive assessment and non-cognitive assessment reported by an informant. Direct cognitive tests that are not yet used for dementia assessment, but test a specific aspect of cognitive functioning like memory, intelligence or orientation in an intellectually disabled population were included. Participants in selected studies included participants with ID that were classified as mild, moderate, severe, with or without the presence of Down Syndrome. Included studies compared individuals with ID to individuals with ID who have already been diagnosed with dementia.

Studies were excluded if the instruments presented were not suitable for use in ID or DS populations. The instrument did not need to have been used for the purpose of diagnosis as of yet, but if it has been shown to be tolerated well by participants with ID and has been suggested for use in dementia assessment, then it was considered in this review. Diagnostic checklists and criteria were excluded, as this review aimed to assess instruments that assess an individual with ID's functioning, either via an informant or directly, to aid the practitioner to complete checklists and criteria for dementia diagnosis. Checklists, although helpful when making the final decision regarding diagnosis require heavy input from trained clinicians. This review sought to identify assessment methods that can be completed prior to input from the clinician as this will give the opportunity for diagnosis to be made more efficiently. Medical tests or studies focusing on biological or genetic markers were excluded, due to their differential emphasis in the diagnostic process. Studies looking at interventions and treatments were also excluded due to lack of relevance to the diagnostic process.

3.2.2 Extraction of Information and Coding of Instruments

Selection and coding of studies was completed by two independent researchers, with a third independent researcher consulted when discrepancies arose. Instruments were extracted from included studies and coded according to whether they were (1) Direct Cognitive test completed by the individual with ID, (2) an Informant Report completed by a Carer or Consultee on behalf of the individual with ID or (3) a Test battery consisting of multiple tests. Test batteries contain many different independent direct cognitive tests and informant reports, to avoid repition, if the instrument was included in a battery it is described in table 4 even if it is applicable to table 2 or 3. Instruments were further coded to highlight the level of ID and whether DS was present or not during the specified study. Tables therefore are displayed with Non DS participants denoted first, starting with Mild ID, then moderate and, finally, severe. Following this, studies that compared ID participants without DS to participants with equivalent level of ID and DS. Lastly, the tables display studies conducted with participants who have ID and DS.

3.3 Results

The literature searches conducted in all 4 databases yielded a total of 9840 studies. After excluding duplicates, screening titles and abstracts 74 studies remained. These were assessed in full text, a further 34 studies were excluded at this point for not meeting the inclusion criteria. 36 studies remained and their references were hand searched manually, identifying 12 additional relevant studies; resulting in a total of 48 studies being included. An overview of the search and results is shown in Figure 3.1.

A total of 44 instruments were found in the 47 included studies. There were 33 instruments to be completed by the individual and 11 to be completed by the Carer or Consultee. Of the 33 tests completed by the individual, 10 test batteries were identified and 23 independent direct tests were identified. In the following sections the instruments extracted are described in further detail. All studies were conducted within a clinical or applied setting. A clinical setting refers to a healthcare setting in which a GP, physician or clinician would conduct the assessment. An applied setting refers to a community setting in which the participant is most familiar; the most frequent of which was a residential or nursing home.

3.3.2 Direct Cognitive Tests

Twenty-three instruments coded as direct cognitive test batteries were identified during the literature search; these are listed in Table 3.2. They each assess an aspect of cognitive functioning, hypothesized to be associated with dementia, and therefore are useful assessment during dementia diagnostics. Various aspects of memory were the cognitive function most often assessed. Memory domains included visual recognition, visual spatial, explicit, recall and cued recall. Numerous tests sought to take a snapshot of overall cognitive functioning. Alternatively, the individual cognitive domains that were tested included learning, various aspects of language, object recognition, executive function and intelligence, among others. Floor effects were still observable on many tests, when participants were classed as having severe ID, reducing the potential for those assessments to be utilised in practice (e.g: PCFT - Kay et al, 2003; MMSE – Deb & Braganza, 1999; CAMCOG – Hon, Huppert, Holland & Watson, 1999). When a study found floor effects this was noted in the comments column of Table 3.2.

Figure 3.1: A PRISMA Flow Diagram detailing the search strategy and results

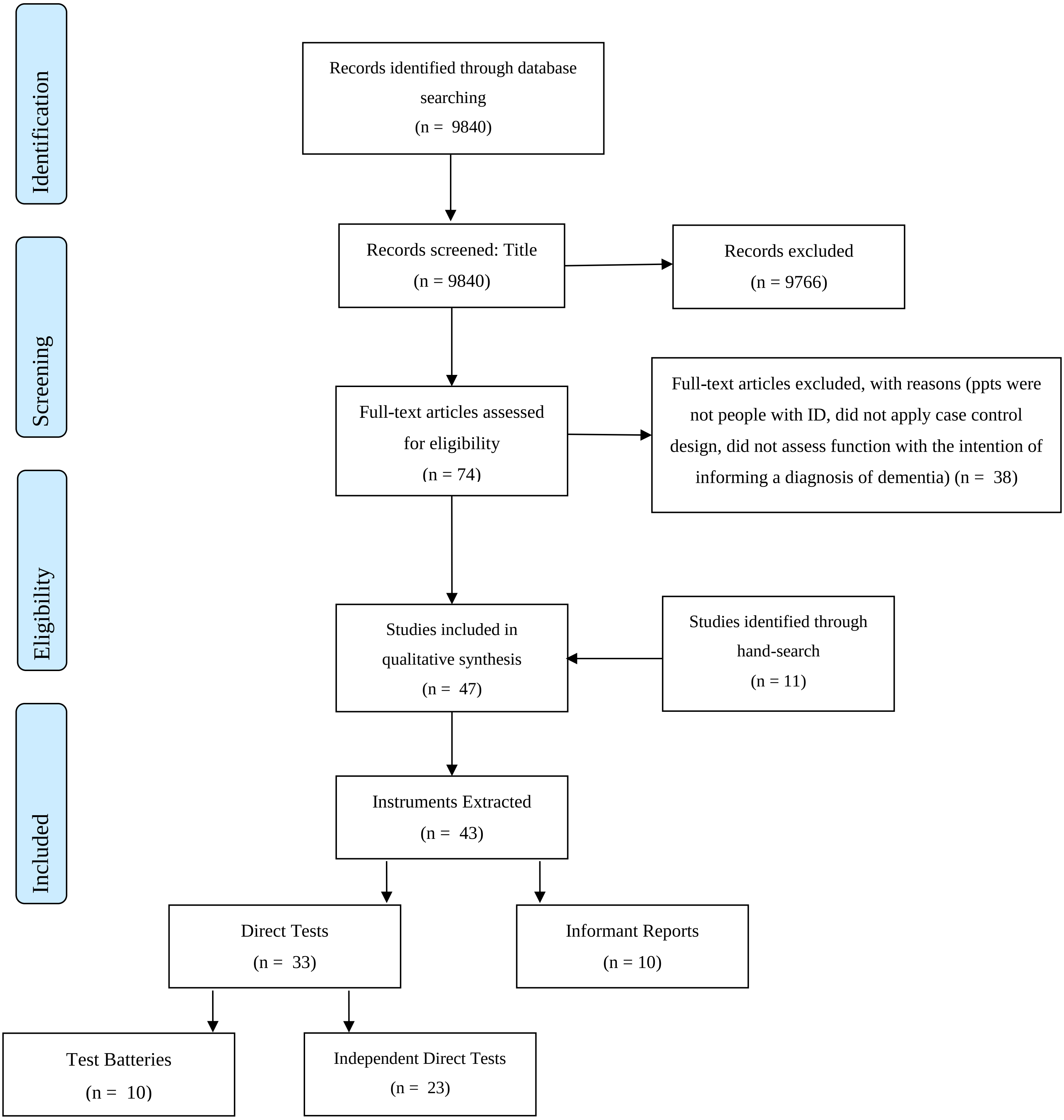


Table 3.2 Direct Cognitive Tests

Author (Year)	**Country and Setting (clinical or applied)**	**Test Name**	**Ability Tested**	**Ppts**	**Type of ID**	**Groups**	**Outcome (what was sig?) ><**	**Comments**
McDaniel, McLaughlin (2000)	US – Applied setting (quiet room in their unit)	**Dementia Rating Scale (DRS) (Mattis, 1988)**	General Cognitive Ability	84 ppts Aged: 14-60	Mild ID (n=32) Moderate ID (n=42) Severe ID (n=10)	1 = Mild 2 = Moderate 3 = Severe	1 > 2 (sig) on Total Score and all subtests except Construction 2 > 3 (sig) on all measures.	DRS can provide info about the cognitive strengths and weaknesses of individuals with ID. DRS can be administered to a wide range of individuals with ID.
Pyo, Ala, Kyrouac & Verhulst (2010)	US – Applied Setting (separate room with a family or staff member present to make ppts feel more comfortable)	The revised Picture Recognition Memory Test (r-PRMT) (Pyo, Kripakaran, Curtis, Curtis & Markwell, 2007)	Visual Recognition Memory	59 ppts (26 cases, 33 controls) Age: 40+	Moderate to severe	1 = DAT cases with DS (n= 15) 2= DAT cases without DS (n=11) 3= Controls with DS (n=9) 4=Controls without DS (n=24)	Controls > Cases on r-PRMT Controls with non-DS etiologies scored much lower with a wider score spread, resulting in significant overlap with the score distribution of DAT cases. Effect sizes indicated that ppts with DS were 5.35 for r-PRMT immediate and 4.44 for r-PRMT delayed which were significantly larger compared to non-DS	r-PRMT may be effective at identifying DAT among moderate to severe from DS, however high false positive rate.

							ppts who showed effect sizes of 0.73 and 1.02, respectively.	
		The Modified Objective Memory Test (OMT)	Recall Memory				Cases = Controls on OMT (no sig difference)	
		Test for Severe Impairment (TSI) (Albert & Cohen, 1992)	Mental Status as a whole, including immediate memory recall and delayed recall.				Cases = Controls on TSI (no sig difference)	
		The Neuropsychology (NEPSY) Comprehension of Instructions (Korkman, Kirk & Kemp, 1998)	Language Comprehension				Cases = Controls on The NEPSY (no sig difference)	
Shultz, Aman, Kelbley, LeClear, Burt, Primeaux-Hart, Loveland, Thorpe, Bogos, Timon, Patti & Tsiouris (2004)	US – Applied Setting (designated rooms at ppts' group homes or workshops)	The Shultz Mental Status Exam	Overall Mental Status	38 ppts Aged: 45-74	ID without DS (32%) and ID with DS (68%)	Cases = Dementia Controls = Non dementia	Both performance tasks discriminated between groups. The performance tasks were related to dementia and IQ, but not age or sex.	Both the Shultz Mental Status Exam and the paired associate learning task were able to detect cases vs controls and therefore could be informative when diagnosing dementia in ID.
		Paired Associate Learning Task (modified from Taylor, Sandman, Touchette, Hetrick & Barron, 1993)	Visual Spatial Explicit Memory					

Krinsky-McHale, Devenny & Silverman (2002)	US – Potentially a clinical setting but this is not specified.	Selective Reminding Test (SRT) (Buschke, 1973) Modified for use in this population (Hill, Wisniewski, Devenny-Phatate & Silverman, 1988)	Explicit Memory	155ppts	Down Syndrome vs individuals with ID but no DS. Equivalent level of ID between groups.	Cases 1 = DS with DAT Controls 1 = DS without DAT Cases 2 = ID without DS with DAT Controls 2 = ID without DS without DAT	Cases 1 < Controls 1 & Cases 2 < Controls 2 on long-term storage and retrieval processing abilities	These declines preceded other DAT symptoms, in most cases by more than 1 year & sometimes up to 3 years. Results confirm SRT can detect affected memory processes during early dementia in adults with DS.
Das, Divis, Alexander, Parrila & Naglieri (1995)	Canada and US – Applied Setting (Quiet rooms located in a workshop, group or independent living setting)	**Dementia Rating Scale (DRS) (Mattis, 1988)**	General Cognitive Ability	63ppts Age: 40-49 or 50-62	Down Syndrome vs individuals with ID but no DS. Equivalent level of ID between groups.	Younger Cases = DS aged 40-49 Younger Controls = non-DS aged 40-49 Older cases = DS aged 50-62 Older controls = non DS ages 50-62	Older Cases < younger cases, younger controls, older controls	Older DS individuals performed most poorly on the tasks involving planning and attention. DRS indicates good clinical utility. PPVT-r also discriminated effectively. Matrix was found to be too difficult for individuals with moderate to
		Peabody Picture Vocab Test – revised (PPVT-r)(Dunn & Dunn, 1981)	Receptive Vocabulary					
		Matrix – Analysis Test – expanded form (Naglieri, 1985)	Non verbal measure of intelligence					

								severe ID to complete.
Nelson, Scheibel, Ringman & Sayre (2007)	US – Clinical Setting	Simple Visual Discrimination	Visual Discrimination Learning	19 ppts Age: 24-55 Mean = 40	Down Syndrome			Results demonstrated good reliability and validity of select tests.
		Reevarsal Learning	Executive Function				Reevarsal and Landmark 0: Sensitivity 71.43 Specificity 72.73	Sensitivity and Specificity not given for tests individually.
		Delayed non-match to sample	Object Recognition				Delayed non-match to sample and landmark 4: Sensitivity 72.73 Specificity 27.27	
		Landmark Stimulus- Response task	Spatial Learning and Memory				Landmark 4: Sensitivity 75 Specificity 60	
McCarron, McCallion, Reilly & Mulryan (2014)	Ireland & US – Clinical Setting (Memory clinic)	Downs Syndrome Mental Status Exam (DMSE) (Haxby, 1989)	Overall Mental Status	77ppts Aged: 35+	Down Syndrome	Cases = dementia Controls = non dementia	Average age of diagnosis = 55.41 (SD=7.14) Median survival = 7 years after diagnosis Cases sig older than controls	DMSE was effective at picking up changes in functioning 1 year prior to diagnosis.
Kay, Tyrer, Margallo-Lana, Moore, Fletcher, Berney &	UK – Clinical Setting	Prudhoe Cognitive Functioning Test (PCFT)	Overall Mental Status, including: orientation, recall, language,	87 ppts Aged: 20+	Down Syndrome	No dementia cases participated, the sample was made up of	PCRT sig. correlated with Adaptive Behaviour Scale (ABS – Nihira, Lambert & Leland, 1993) given to carers.	PCFT = reliable quantitative measure of cognitive function in DS. Floor effects suggests that

Vithayathil (2003)			praxis and calculation.			individuals with DS only.	PCRT sig. correlated with degree of ID More subjects with high levels (i.e. profound to untestable) of ID obtained very low or zero scores on PCFT.	PCRT is limited to detecting cognitive decline to those who are less disabled.
Devenny, Zimmerli, Kittler & Krinsky-McHale (2002)	US – Applied Setting (Quiet rooms in ppts' day programme or at their residence)	Cued Recall Test (CRT) (Buscke, 1984; Grober & Buschke, 1987)	Cued Memory Recall	160ppts	Down Syndrome	Cases = with DS and early stage DAT Controls = DS with no DAT Controls2 = ID no DS and no DAT	Cut-off value of ≤23 on the TS = sensitivity: 94.7%, specificity: 93.9%, positive predictive value: 81.9% when cases compared to controls2.	Usefulness of CRT needs to be confirmed with longitudinal data. Memory declines can occur several years prior to DAT identification.
Tyrrell, Cosgrave, McCarron, McPherson, Calvert, Kelly, McLaughlin, Gill & Lawlor (2001)	Ireland – Potentially a clinical setting but not clearly stated.	**Downs Syndrome Mental Status Exam (DMSE) (Haxby, 1989)**	Overall mental status.	285 ppts Aged: 35-74 mean age ±SD = 46.5 ± 8.2 years	Down Syndrome	Cases = DS with dementia Controls = DS without dementia	Sig different Median scores in Cases vs Controls for DMSE.	
		Test for Severe Impairment (TSI) (Albert & Cohen, 1992)	Mental Status as a whole, including immediate memory recall and delayed recall.				Sig different Median scores in Cases vs Controls for TSI.	No Floor or Ceiling effects in individuals with moderate and severe ID.
Deb & Braganza (1999)	UK – Setting not	**The Mini Mental State Exam (MMSE) (Folstein,**	Overall Mental Status	62 ppts Aged: 35+	Down Syndrome	Cases = DS with	MMSE could only be completed by 34 (55%) ppts with DS.	MMSE not able to be

	clearly stated.	**Folstein & McHugh, 1975)**				Dementia (n=26) Controls = DS without dementia (n=36)	30ppts got MMSE score less than 24 (the usual cut- off for the diagnosis of possible dementia), 23ppts (77%) (of the 30) did not have a diagnosis of dementia.	administered to all ppts with DS. And did not accurately identify cases or controls.
Hon, Huppert, Holland & Watson (1999)	UK – Applied Setting (Ppts' home or day centre)	Cambridge Cognitive Examination (CAMCOG)	Overall Cognitive Functioning	74 ppts Aged: 30+	Down Syndrome	1 = Younger DS 2 = Older DS	CAMCOG scores = well distributed. 8 ppts (11%) scored 0. 1 > 2 (sig) on total CAMCOG score 1 > 2 (sig) on 6 out of 7 subscales.	CAMCOG useful unless ID is severe. May need some modifications to make it more accessible. Better than MMSE as well.
Pennington, Moon, Edgin, Stedron & Nadel (2003)	US – Applied Setting	Cambridge Neuropsychological Test Automated Battery, Paired Associates Learning (CANTAB-PAL- Robbins, 1994)	Visual-Spatial Explicit Memory	56ppts	Down Syndrome	1 = Children without DS 2 = Children with DS	Study was not assessing dementia but does show that the test is well tolerated in DS populations.	CANTAB-PAL was designed for use for assessing dementia in general population. But this study indicates that CANTAB-PAL may be able to be used in assessment of dementia in ID.
Boada, Alegret, Buendia,	Spain – Clinical Setting	The Mini Mental State Exam (MMSE) (Folstein,	Overall Mental Status	45ppts Age: 40+	Down Syndrome	Cases = Alzheimer's	MMSE performance sig. correlated with total and cognitive	MMSE= useful for assessing cognition.

Hernandez, Vinas, Espinosa, Lara, Guitart & Tarraga (2008)		Folstein & McHugh, 1975)				disease (AD) Cases2 = Potential AD Control = Absence of AD	DMR scores as well as SIB scores.	
Tests highlighted in bold indicate repeated use within studies. **Table Abbreviations: ID= Intellectual Disabilities, DS= Down Syndrome, DAT = Dementia Alzheimer's Type** **ppts= participants vs= compared with, *Age is denoted in years.*** **DRS=Dementia Rating Scale, r-PRMT=Revised Picture Recognition Memory Test, OMT=Modified Object Recognition Test, TSI=Test for Severe Impairment, NEPSY=The Neuropsychology Comprehension of Instructions, SRT=Selective Reminding Test, PPVT-r=Peabody Picture Vocab Test revised, DMSE=Down's Syndrome Mental Status Examination, PCFT=Prudhoe Cognitive Functioning Test, CRT=Cued Recall Test, MMSE=Mini Mental State Examination, CAMCOG=Cambridge Cognitive Examination, CANTAB-PAL=Cambridge Neuropsychological Test Automated Battery- Paired Associates Learning**								

3.3.3 Informant Reports

The informant reports found in the studies in this review are detailed in Table 3.3. A total of 11 informant reports were reviewed. The informant reports nearly all assessed either behaviour, dementia status or daily functioning. These are non-cognitive symptoms of dementia that indirectly indicate changes in cognitive functioning and have been highlighted as able to inform dementia diagnostics throughout the literature. However, informant reports are frequently not specifically designed for this purpose (McKenzie, Metcalfe & Murray, 2018). The most notable benefit of informant reports is that they do not require the individual to complete any tests that they could potentially find distressing. This is particularly favoured when the individual has a more severe ID. All informant reports in table 3.3 were shown to be effective during the process of dementia diagnostics, except for the Activities of Daily Living Questionnaire (ADL – Mahoney & Barthel, 1965), which was not found to be effective in this population (Lin et al, 2014). The Dementia Questionnaire for Mentally Retarded people (DMR -Evenhuis, 1992), which has been renamed as the Dementia Questionnaire for people with Learning Disabilities (DLD – Evenhuis, Kengen & Eurlings, 2007) and Adaptive Behaviour Scale (ABS – Nihira, Lambert & Leland, 1993) were shown to be most effective when used together, as they can cover a wide range of factors affected by dementia. This suggests that both adaptive behaviour and general cognitive functioning that are assessed with these two scales are useful during the diagnostic process.

Table 3.3 Instruments based on Informant Reports

Author (Year)	Country and Setting (clinical or applied)	Test Name	Ability tested	Ppts & Age	Type of ID	Groups	Outcome (what was sig?) ><	Comments
Zeilinger, Gartner, Janicki, Esralew & Weber (2016)	US – Applied (in large residential care homes)	The National Task Group – Early Detection Screen for Dementia (NTG-EDSD)(Esralew et al, 2013)	Dementia Status	221 carers	ID. All participants are cared for.	All participants were paid carers so no groups applied here.	Four feasibility dimensions of use of the NTG-EDSD were reported on by carers. However, data from the NTG-EDSD was not assessed directly. All feasibility dimensions were rated good to very good and 80% of the carers found the NTG-EDSD useful or very useful in the early detection of dementia.	Reliability and Validity of the instrument for clinical use in aiding dementia diagnostic assessment was not assessed. Therefore, further research is needed before use of this instrument.
Lin, Lin, Hsia, Hsu, Wu & Chu (2014)	Taiwan – Setting is not clearly stated but potentially an applied setting.	**Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) (Deb, Hare, Prior & Bhaumik, 2007)**	Dementia status	459 ppts Aged: 45+	ID of varying degree	Cases = Dementia Controls = Non-dementia	Was used to identify cases and controls in this study. 16.3% of ppts in this study were identified as being diagnosed with dementia based on the DSQIID.	Although originally designed for use in DS is an effective tool for diagnosing dementia in ID.

		Activities of Daily living Questionnaire (ADL) (Mahoney & Barthel, 1965)	Daily functioning				Disability level and comorbidity can explain 10% of the ADL score variation. Dementia conditions can only explain 3% of the ADL score variation in the study.	ADL would not be an effective tool for diagnosing dementia in ID
de Vreese, Mantesso, Bastiani, Marangoni, Gomiero (2011)	Italy – Applied setting	Assessment for Adults with Developmental Disabilities Scale (AADS-I) (De Vreese et al, 2011)	Behaviour	63 ppts	All ID included		Good reliability and validity found.	Useful for detecting dementia if used longitudinally.
Kirk, Hick & Laraway (2006)	UK – Setting is not clearly stated.	**Dementia Questionnaire for Mentally retarded people (DMR) (Evenhuis, 1992)**	Dementia status Behaviour	88 ppts Aged: 40+	Varying ID (n=76) And DS (n=12)	All ppts completed both tests	DMR significantly related to ABS	Would need to use both to assess an individual for dementia diagnosis as neither covers the full range of factors effected by dementia.
		The Adaptive Behaviour Scale (ABS) (Nihira, Lambert & Leland, 1993)					ABS significantly related to DMR	2 questionnaires showed significant relationships.
Shultz, Aman, Kelbley, LeClear,	US – Applied Setting (Rooms at	The Dementia Scale for Down Syndrome (DSDS)	Dementia Status	38 ppts Aged: 45-74	ID without DS (32%) and ID	Cases = Dementia	Both dementia scales discriminated between groups.	All informant reports used were able to detect cases vs controls and

Burt, Primeaux-Hart, Loveland, Thorpe, Bogos, Timon, Patti & Tsiouris (2004)	group homes or workshops)	**Dementia Questionnaire for Mentally retarded people (DMR) (Evenhuis, 1992)**	Dementia Status		with DS (68%)	Controls = Non dementia	The dementia scales were not related to premorbid IQ, age, or sex.	therefore could be informative to clinicians looking to make a decision regarding dementia diagnostics for people with ID.
		Reiss Screen for Maladaptive Behaviour (Reiss, 1987)	Adaptive Behaviour				Various Reiss Screen subscales also discriminated between groups.	
Prasher, Farooq and Holder (2004)	UK – Setting is not clearly stated.	Adaptive Behaviour Dementia Questionnaire (ABDQ) (Prasher, Farooq & Holder, 2004)	Behaviour	150 ppts (83 male 67 females) Mean Age: 44	Down Syndrome	Cases = Diagnosed DAT during 5 year study Controls = remained non dementia throughout.	The scale has good reliability and validity. Overall accuracy = 92%.	First tool designed specifically for detecting DAT in DS.
Lin, Chen, Hsu, Lin, Lin, Tang, Wu, Chu & Chou (2014)	Taiwan - Setting is not clearly stated but potentially an applied setting.	**Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) (Deb, Hare, Prior & Bhaumik, 2007)**	Dementia Status	196 ppts Aged: 15- 48	Down Syndrome	Younger = adolescent ppt Older = adult ppts	Older > Younger on DSQIID scores. Older age (p = 0.001) and comorbid conditions (p = 0.003) were significantly associated with DSQIID scores. Age (p < 0.01), Severe disability level (p<0.05) and Comorbid condition (p<0.01) significantly explained 13% of	DSQIID used well to diagnose dementia here in DS but need to consider other demographic factors that play a large influence on dementia status.

							variation in DSQIID scores after adjusting for sex, education level and multiple disabilities.	
Ball, Holland, Huppert, Treppner, Watson & Hon (2004)	UK – Setting is not clearly stated.	Modified version of Cambridge examination for mental disorders of the elderly (CAMDEX)	General Cognitive Functioning	74ppts at first visit and 56ppts at repeat 6 years later Aged: 30+	Down Syndrome		CAMDEX-based diagnosis of AD shown to be consistent with objectively observed cognitive decline (good concurrent validity) and to be a good predictor of future diagnosis. Inter-rater reliability was good with Kappa > 0.8 for 91% of items and >0.6 for all items.	Modified CAMDEX informant interview useful when diagnosing dementia in ID and DS.
McCarron, McCallion, Reilly & Mulryan (2014)	Ireland & US – Clinical Setting (Memory clinic)	Daily Living Skills Questionnaire (DLSQ) (National Institute of aging, 1989)	Daily Functioning	77ppts Aged: 35+	Down Syndrome	Cases = dementia Controls = non dementia	Over 14 year followup average age of diagnosis = 55.41 years (SD=7.14). Median survival of 7 years after diagnosis. Cases older than controls (sig) Decline in DLSQ score was shown 3-4 years prior to diagnosis. Presence of dementia also associated with epilepsy and sensory impairments.	Changes in DLSQ indicated diagnosis 3 to 4 years apriori. More effective than direct tests used (DMSE and TSI) Also informative about variables that are associated with dementia diagnosis.
		Dementia Questionnaire for Mentally retarded people (DMR)					Among instruments used DMR most sensitive to tracking change in symptoms over time prior to diagnosis, reporting changes 5 years prior to	DMR most effective at reporting changes in functioning.

		(Evenhuis, 1992)					diagnosis. Direct tests used only reported changes 1 year prior to diagnosis.	
Deb, Hare, Prior, Bhaumik (2007)	UK – Setting is not clearly stated.	**Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) (Deb, Hare, Prior & Bhaumik, 2007)**	Dementia Status	193 ppts Aged: 23 – 77 Mean age = 55	Down Syndrome		Sensitivity = 0.92 and Specificity = 0.97 On DSQIID score of 20. Internal consistency (a1⁄4 0.91) for all its 53 items, and good test -retest and inter-rater reliability. Good construct validity was established by dividing the items into 4 factors.	Valid and Reliable Screening method for Dementia in DS.
Kay, Tyrer, Margallo-Lana, Moore, Fletcher, Berney & Vithayathil (2003)	UK – Clinical Setting	Adaptive Behaviour Scale (ABS)	Behaviour	87 ppts Aged: 20+	Down Syndrome	No dementia cases participated, the sample was made up of individuals with DS only.	Significantly correlated with direct test Prudhoe Cognitive Functioning Test (PCFT – see table 1) ABS correlated significantly with the degree of ID.	Was able to obtain scores for all levels of ID including profound, whereas the direct test was not able to.
Deb & Braganza (1999)	UK – Setting is not clearly stated.	**Dementia Questionnaire for persons with Mentally Retardation (DMR) (Evenhuis, 1992)**	Dementia Staus	62 ppts Aged: 35+ with DS.	Down Syndrome	Cases = Dementia (n=26) Controls = non dementia (n=36)	DMR and DSDS showed good positive correlation. A similar positive correlation was found between the overall DSDS score and the scores in the main subcategories of the DMR.	Informant scales, rather than the direct tests, were more useful for the diagnosis of dementia in people with an intellectual disability.

		Dementia Scale for Downs Syndrome (DSDS – Gedye,1995)	Dementia Status				Direct test used (MMSE) could not be completed by all ppts.	

Tests highlighted in bold indicate repeated use within studies.
Table Abbreviations: ID= Intellectual Disabilities, DS= Down Syndrome, DAT = Dementia Alzheimer’s Type
ppts= participants, vs = compared with, ***Age is denoted in years.***
NTG-EDSD= The National Task Group – Early Detection Screen for Dementia, DSQIID=Dementia Screening Questionnaire for Individuals with Intellectual Disabilities, ADL=Activities of Daily Living, AADS-I= Assessment for Adults with Developmental Disabilities Scale, DMR= Dementia Questionnaire for Mentally retarded people, ABS=Adaptive Behaviour Scale, DSDS=Dementia Scale for Down Syndrome, ABDQ= Adaptive Behaviour Dementia Questionnaire, CAMDEX= Modified version of Cambridge examination for mental disorders of the elderly, DLSQ=Daily Living Skills Questionnaire.

3.3.4 Test Batteries

There were 10 test batteries identified in the literature search, DS. The remaining battery was designed for individuals in the general population who already have severe dementia, rather than for use as an assessment battery. Eight of the batteries contained sections for informant reports as well, whereas 2 of the batteries just focus on just the participant's cognitive abilities. The test batteries varied in length from 20 minutes (Severe Impairment Battery), up to 4 hours (Das Naglieri Cognitive Assessment System).

Table 3.4 Test Batteries

Author	Battery Name - designed for…	Informant Reports contained in Battery	Ability Tested	Direct Tests contained in Battery	Ability Tested	Ppts, Age & Group	Type of ID	Outcome and Comments
Burt & Aylward (2000) - USA	Working Groups Battery – designed for dementia diagnosis in ID.	-DMR (Evenhuis, 1992) - The Dementia Scale for Downs Syndrome (DSDS - Gedye, 1995) - Reiss Screen for Maladaptive behaviour (Reiss, 1987) - Scales of Independent Behaviour – revised (SIB-R) (Bruininks, Woodcock, Weatherman & Hill, 1996) -AAMR Adaptive Behaviour	- Dementia Status - Dementia Status - Emotional/ Motivational Changes - Behaviour - Behaviour - Differential Diagnostics (Stress)	- Test for Severe Impairment modified (TSI – Albert and Cohen, 1992 and Cosgrave et al, 1998) - Stanford Binet Sentences (Thorndike, Hagen & Sattler, 1986) - Fuld modified (Seltzer, 1997) - Spatial Recognition Span (Moss, Albert, Butters & Payne, 1986) - Autobiographical Memory - Orientation (Aylward & Burt, 1998) - Boston Naming Test (Kaplan, Goodglass, & Weintraub, 1983) -McCarthy Verbal Fluency	-Memory and Other Cognitive decline - Immediate recall - Immediate and delayed recall - Immediate spatial recognition - Autobiographical memory - Orientation to time and place - Expressive vocabulary - Language fluency - Receptive language - Fine motor speed	None reported in first study – reliability studies did follow…. - Pyo, Kripakaran, Curtis, Curtis & Markwell (2007) showed good reliability on the Autobiographical memory and Orientation tests. - Pyo, Curtis, Curtis & Markwell (2009) only looks at orientation and shows significant differences between DAT group and controls but Orientation tests alone are not reliable for diagnosis. - Pyo, Ala, Kyrouac & Verhulst (2010) showed autobiographical memory tests to be reliable.		**1-1.5 hours to administer.** Longitudinal administration is crucial to observing clinical change.

		Scale: Residential and Community (Nihira, Lambert & Leland, 1993) - Stress Index		(McCarthy, 1972) - Simple commands (modified from Haxby, 1989) - Purdue Pegboard modified (Tiffin & Asher, 1948) - Developmental Test of Visual Motor Integration (Beery, 1997)	- Perceptual motor skills			
Palmer (2006) - USA	Not given – designed for dementia assessment in individuals with Mental Retardation.	- The Early Signs of Dementia Checklist (Visser, Aldenkamp, Van Huffelen & Kuilman, 1997)	- Dementia Status	- The Color Trials Test (D'Elia, Satz, Uchiyama, & White, 1996) - The Boston Naming Test (Kaplan, Goodglass, & Weintraub, 1983) - The Controlled Oral Word Association Test (COWAT – Spreen & Strauss, 1998) - The Fuld Object Memory Evaluation (Fuld, 1980)	- Visual Attention and Concentration - Expressive Vocabulary (Agnosia) - Language: sematic fluency - Memory and Learning	22 ppts Aged: 33-66 *Groups:* Cases=Dementia Controls = matched for IQ, age, presence of DS and sex but no dementia present.	Mild or Moderate ID.	**2-2.5hours to administer.** Cases < Controls in all areas assessed.

Van der Wardt, Bandelow & Hogervorst (2011) – UK, applied setting	Cognitive Computerised Test Battery for Individual's with Intellectual Disabilities (CCIID) – designed to assess IQ in individuals with ID.	N/A	N/A	- Corsi Block Tapping Test (Crosi, 1972) - Series - Odd one out -Jigsaw	- Visual/Spatial Working Memory - Inductive Reasoning - Inductive Reasoning - Visual/Spatial Abilities	Reliability and Validity studies were conducted in various ID populations and showed the CCIID to be a valid and reliable instrument for testing IQ.	ID all levels	**30 minutes to administer.** Originally designed as an IQ test for verifying eligibility for Paralympic sporting events, but has been suggested for use in dementia assessment – not yet tested however for this purpose.
Silverman, Schupf, Zigman, Devenny, Miezejeski, Schubert & Ryan (2004) – US, applied setting (ppts' residence or day programme facility)		- Informant Interviews conducted based on a clinical record review of the participants medical history. - The Dementia Questionnaire for Mentally Retarded persons (Evenhuis, 1992).	- Medical history - Cognitive abilities and social skills - Description of functional abilities	- IBR evaluation of Mental Status (Wisniewski & Hill, 1985) - Downs Syndrome Mental Status Examination (Haxby, 1989) – including expanded memory section. - Test of Severe Impairment (TSI – Albert & Cohen, 1992) - The Peabody Picture Vocabulary Test –	- Orientation - Overall Cognitive Functioning - Overall Cognitive Functioning - Receptive Vocabulary - Verbal Fluency	273 ppts Aged: 45+ After testing grouped into: 1) No dementia 2) Questionable 3) Possible dementia 4) Definite dementia 5) Declines with complications	All levels of ID.	**2 hours to administer.** 18 month longitudinal analysis presented. Findings suggest that by conducting a full assessment of cognitive abilities like presented here, diagnosis of dementia can be made a lot more rapid and accurate.

		- Part 1 of the American Association on Mental Deficiency Adaptive Behaviour Scae (ABS – Nihira, Foster, Shellhaas & Leland, 1974) - Reiss Screen for Maladaptive Behaviour (Reiss, 1987)	- Screening for possible depression, psychosis & behaviour problems.	Revised (PPVT – Dunn & Dunn, 1981) - Verbal Fluency Test (McCarthy, 1972) - The Beery Visual Motor Integration Test, long form (Beery & Buktenica, 1989) - Block design subtest of WISC-R (Wechsler, 1974) - Selective Reminding Test (Buschke, 1973)	- Construction abilities - Visual Spatial Memory - Episodic Memory			
Das, Divis, Alexander, Parrila, & Naglieri (1995) – US and Canada, applied setting (quiet rooms in workshops, group or independen	Das Naglieri Cognitive Assesment System – designed to assess cogntivie decline due to ageing among individuals with Downs Syndrome.	N/A	N/A	- Planned search (Teuber, Battersby & Bender, 1949) - Matching numbers (Naglieri & Das, 1987) - Number finding (Das & Mishra, 1995) - Expressive Attention (Das & Mishra, 1995) - Receptive Attention	- Visual search and planning - Planning -Attention, Vigilance - Expressive attention - Recpetive Attention - Language - Simultaneous processing memory	63 ppts Aged: 50 -62 *Groups:* 1) Young DS (n=16) 2) Old DS (n=16) 3) Young Non DS (n=16) 4) Old Non DS (n=15)	ID with DS or ID without DS with equivalent level of ID.	**1.5 – 4 hours to administer** – a lot of variation in time taken. 2 < than all other groups on all tasks. Seen most on tasks requiring planning and attention.

t living setting)				(Naglieri & Das , 1987) - Simultaneous Verbal - Figure Memory -Word Series - Color ordering -Speech rate	- Recall Memory - Spatial Memory - Speech rate (Verbal Fluency)			
Crayton, Oliver, Holland, Bradbury & Hall (1997) - UK	Neuropsychological Assesment of dementia in adults with intellectual disability – designed for dementia assessment in Downs Syndrome.	Cognitive test battery was compared to… - Vineland Adaptive Behaviour Scale (VABS – Sparrow, Balla & Cicchetti, 1984)	- Adaptive Behaviour	- British Picture Vocabulary Scale (BPVS – Dunn, Dunn, Whetton & Pentilie, 1982) - Orientation (taken from Cambridge Mental Disorders of the Elderly Examination – CAMDEX: Roth et al, 1986) - Picture Naming (taken from BPVS) - Picture Identification (taken from BPVS) - Acting on request - Card Sorting task	- Receptive Language - Orientation - Aphasia - Agnosia - Receptive Language - Executive Functions - Visual Memory - Recognition - Spatial Abilities - Object recognition	70 ppts Aged: 28+ Mean Age: 42.8 *Groups:* 1) under 40 years old 2) between 40 and 49 years 11 months old 3)aged3 50 +	DS	**1.5 hours to administer.** VABS and all neuropsychological tests negatively correlated (sig) – preexisting global cog impairment shown on these tests No difference between age groups (1,2&3) on neuropsychological deficits. – because of screening method used before study. 2 & 3 < 1 performance on memory tests

				Computerised tests: - Visual Memory - Pattern Recognition - Spatial Recognition - Matching-to-sample -Delayed response - Conditioned associative learning	-Delayed response - Conditioned associative learning			(sig) Results suggest sensitive tests that were used could be useful in dementia diagnostic process.
Oliver, Crayton, Holland, Hall & Bradbury, (1998) – UK	Different test batteries were collated, including the CANTAB and CAMCOG, plus extra tests added for the purpose of this study. (Please see across) – designed to detect age related cognitive change in DS.	- Vineland Adaptive Behaviour Scale (VABS – Sparrow, Balla & Cicchetti, 1984)	- Adaptive Behaviour	- Visual Memory battery (part of Cambridge Neuropsychological Automated Test Battery – CANTAB, see Sahakian et al, 1988), only 2 sections analysed in this study, delayed response and conditioned associative learning tasks. - Orientation section of CAMCOG (part of the Cambridge Assessment for	- Learning and Memory - Aphasia and Agnosia - Apraxia	57 ppts Aged: 30+ *Groups:* 1) No cognitive deterioration 2) Cognitive deterioration3) Moderate cognitive deterioration 4) Severe cognitive deterioration	DS	**Doesn’t state how long the battery took to administer.** 28.3% of ppts showed severe cognitive deterioration, like apraxia or agnosia. A higher prevalence of these impairments was associated with older age. Rate of cognitive deterioration also □ w/ age & degree of pre-existing cognitive

				Mental Disorder in the Elderly – CAMDEX) Asked to name 14 pictures of everyday objects and identification following a verbal instruction. Also asked to carry out simple actions on a verbal cue (e.g. clap your hands). -The British Picture Vocabulary Scale (BPVS) (Dunn, Dunn, Whetton & Pentilie, 1982) - Extra verbal memory test added to batteries used. (adapted from the Memory for Sentences Test – Terman & Merrill, 1960) - Extra procedure added at the start of the memory for objects test, involving naming,	- Receptive Language - Verbal Memory - Memory			impairment. Deterioration in memory, learning and orientation preceded the acquisition of aphasia, agnosia and apraxia. Pattern of cognitive deterioration seen with individuals who have DS in this study is comparable to the pattern reported in individuals who have Alzheimer’s disease but do not have DS.

				identification, immediate recall and delayed recall.				
Jozsvai, Kartakis & Collings (2002) – UK, Clinical Setting	Not given – designed to assess cognitive decline in DS.	- The Dementia Scale for Downs Syndrome (DSDS – Gedye, 1995)	- Dementia status	- The Peabody Picture Vocabulary test revised (PPVTr – Dunn & Dunn, 1981) Battery included: - Information and Orientation Questions (IO) - Block Design Test (BD – from WISC-R: Wechsler, 1974) - Fuld Object Memory Evaluation (FULD – Fuld, 1978; 1980) - Grocery List (GL) - Boston Naming Task (BNT – Kaplan, Goodglass & Weintraub, 1983) - Test of Apraxia (PX)	- Receptive Vocabulary, Verbal Intelligence - Orientation -Visuo-constructional praxis - Immediate and Delayed memory - Category Fluency - Expressive Vocabulary - Apraxia	35 ppts Aged: 28+ *Groups:* Cases = diagnosed DAt using DSDS (n=12) Controls = without DAT (n=23)	DS - Does not include more severe ID in sample	**Doesn't state how long the battery took to administer.** FULD and IO shown to be most useful tests in battery – must be wary of practice effects though. BNT and BD, most effected by aging & had least diagnostic ability.
Johansson & Terenius	Not given – designed to assess dementia in DS.	Informants were interviewed with questions regarding the ppts abilities		- Spatial Tests of Memory - Verbal tests of Memory including: objects to be remembered, auditive		9 ppts Aged: 26 – 56	DS	**Ppt section took 1.5 – 2 hours to administer.**

(2002) - Sweden		in the following aspects and any changes observed in these abilities: 1) Change (global changes in ppt) 2) Support 3) Learning Adaptability		learning, visual learning, supported learning, sensing items inside a bag, Where did I put it? - Other cognitive tests included: - Understanding pictures - Simplified Arithmetic - Telling the time on a clock - Ability to estimate time taken - Understanding of cause and effect - Drawing ability - Proper prepositions - Copying pictures with and without the original - Agnosia: what did you draw? - Word Fluency - Routine Decisions - Understanding reverse order - Arranging a coffee break - Naming (aphasia, agnosia & apraxia) -Long term Memory Questions included: - Biographical questions - Memory of the dys preceding the interview - Past and present friends and staff at residential and occupational settings - Semantic Memory - Prospective Memory	*Groups:* 1) No Decline 2) Possible Decline 3) Decline		Advocates a combination of testing and interviewing in order to gain a full clinical picture.
Witts & Elders (1998) – UK,	Severe Impairment Battery (SIB - Saxton,	- Vineland Adaptive Behaviour Scale	- Adaptive Behaviour	*Battery Tests Focus on:* - Attention - Orientation -Language	33 ppts Mean Age = 36	DS	**20 minutes to administer.**

applied setting (adult training centres.	McGonigle, Swihart & Boller, 1993**) –** designed to assess cognitive functioning of those with severe dementia client.	(VABS - Sparrow, Balla & Cicchetti, 1984)		- Memory - Visuo-perception - Construction - Praxis -Social Interaction Carers provide most of the info for the battery.			Good reliability and validity found. No Floor Effects encountered. Should be used longitudinally.

Tests highlighted in bold indicate repeated use within studies.
Table Abbreviations: ID= Intellectual Disabilities, DS= Down Syndrome, DAT = Dementia Alzheimer's Type
□**=** ***increases*****, < = less than, ppts= participants, vs = compared with**
DSDS=The Dementia Scale for Downs Syndrome, SIB-R=Scales of Independent Behaviour – revised, DMR=Dementia Questionnaire for Mentally Retarded people, AAMR=Adaptive Behaviour Scale: Residential and Community, TSI=Test for Severe Impairment modified, COWAT=The Controlled Oral Word Association Test, CCIID=Cognitive Computerised Test Battery for Individuals with Intellectual Disabilities, PPVTr=Peabody Picture Vocabulary Test – Revised, ABS=Adaptive Behaviour Scale, BPVS= British Picture Vocabulary Scale, VABS= Vineland Adaptive Behaviour Scale, CAMDEX= Cambridge Mental Disorders of the Elderly Examination, CANTAB= Cambridge Neuropsychological Automated Test Battery, CAMCOG= Cambridge Cognitive Examination, BD=Block Design Test, BNT=Boston Naming Test, FULD=Fuld Object Memory Evaluation, GL=Grocery List, IO=Information and Orientation Questions, PX=Test of apraxia, SIB=Severe Impairment Battery.
Age is denoted in years.

3.4 Discussion

In this review instruments that are used in the assessment of dementia in individuals with intellectual disabilities (ID) were systematically collated and appraised. This review has also presented information regarding the available instruments in an accessible and condensed form that clinicians can easily use to inform decisions during the process of dementia diagnostics for individuals with ID. Furthermore, strengths and weaknesses of each type of instrument were discussed.

The three categories of diagnostic instruments presented are direct cognitive tests, informant reports and test batteries. Previous reviews agree that consensus needs to be reached in order to advance assessment of dementia in ID (e.g. Zelinger et al, 2013). Clinicians currently lean towards using instruments that they are previously familiar or comfortable with, however this is resulting in disparity in the instruments being utilized across clinical settings. By reaching a consensus, benefits will be observed in assessment efficiency, communication between health professionals and treatment. Earlier treatment has been suggested to maintain the highest possible level of cognitive functioning while dementia is mild (Seltzer et al, 2004).

Many studies agreed that memory impairment is crucial to dementia diagnosis and therefore included assessments of various aspects of memory in their recommendations of instruments. Some studies chose to assess other cognitive domains either alongside memory assessments or instead of, for instance, tests of orientation, language, intelligence, executive functioning, to name a few. Although Crayton, Oliver, Holland, Hall and Bradbury (1997) observed a similar clinical progression in the participants with ID and dementia that is often seen in individuals with dementia but no pre-existing ID, researchers have highlighted the current limitations in our understanding of the trajectories of dementia (McCarren et al, 2018). The numerous different cognitive domains tested in the included studies further emphasise how onset, course and progression of dementia can notably differ from person to person.

With this in mind, it is vital to consider the level of intellectual disability that the assessments are best suited to. It is important to also note that instruments often differ in their applicability to clinical or applied settings. All instruments discussed can be administered in both settings; however, some instruments are better suited to one setting or the other. In any case, level of distraction, how comfortable the participant is and accuracy of information gathered should consistently be scrutinised when deciding where to administer various instruments.

3.4.1 Direct cognitive Tests

Evaluation of the direct cognitive tests found many instruments that are appropriate for application with people who have ID. Studies assessed various comparisons between types of ID, including those with ID and DS and those with just ID. The evaluated instruments are, therefore, applicable to a range of levels of ID and could be utilised across varying levels of ID, which is important for inclusivity within the assessment process.

Multiple studies indicated good clinical utility for the Dementia Rating Scale (DRS - Mattis, 1988) and the Downs Syndrome Mental Status Exam (DMSE - Haxby, 1989). McCarron, McCallion, Reilly & Mulryan (2014), commented that the DMSE was particularly useful in detecting cognitive changes one year prior to dementia diagnosis and therefore could also be useful in early detection. Studies looking at the DRS only included a total of 147 participants (Das, Davis, Alexander, Parrila & Naglieri, 1995; McDaniel & McLaughlin, 2000), whereas studies examining utility of the DMSE included 362 participants (McCarron, McCallion, Reilly & Mulryan, 2014; Tyrrell et al, 2001). Further research, using these assessments, and particularly the DRS, would be beneficial in increasing the sample sizes and adding weight to the preliminary evidence available thus far. There were no studies that found the DRS or the DMSE to be unsuitable for informing inclusive dementia diagnostics. Both instruments in the reported studies were utilized in applied and clinical settings in the reported studies. This indicates their flexibility in application and potential for informing dementia diagnostics.

Additionally, the modified version of the Selective Reminding Test (SRT – Hill, Wisniewski, Devenny-Phatate & Silverman, 1988) was shown to have good utility in early detection, identifying cognitive changes between 1 and 3 years prior to dementia diagnosis (Krinsky-McHale, Devenny & Silverman, 2002). Although there were no studies opposing this conclusion, this was only shown in one study of 155 participants, therefore further research is required to support the clinical utility of the SRT.

Discrepancies in the effectiveness of the Mini Mental State Exam (MMSE – Folstein, Folstein & McHugh, 1975) and the Test for Severe Impairment (TSI – Albert & Cohen, 1992) were apparent. For instance, Boada, Alegret, Buendia, Hernandez, Vinas, Espinosa, Lara, Guitart & Tarraga (2008) were able to show the MMSE discriminated effectively between those with ID and those with ID and dementia. Similarly, Tyrrell and colleagues (2001), found this using the TSI. However, studies are inconsistent as Deb and Braganza (1999) found the MMSE to show no significant difference between people with ID with and without dementia. Pyo, Ala, Kyrouac & Verhulst (2010) also found no significant difference with the TSI.

This review found the DRS, DMSE and SRT to be most effective, however the current sample sizes do not justify firm conclusions and further research should seek to replicate these findings in larger sample sizes. Several studies noted the importance of tests being administered longitudinally, as there are no normative data for individuals with ID as of yet. If applied longitudinally, clinicians can observe cognitive decline, which could be informative. Having said that, Margallo-Lana et al, 2007, suggest that longitudinal follow-up is not useful in people with severe ID. Test selection should be carefully tailored to the level of functioning of the individual and the setting in which the testing is being administered.

3.4.2 Informant Reports

Informant reports evaluated non-cognitive domains, such as activities of daily living and functioning, as individuals with dementia find many activities of daily living difficult due to decline in episodic memory (Mokhtari et al, 2012). Informants are often positioned to observe these changes and reports on everyday functioning, prospectively or retrospectively, have been shown to be more effective than reporting on changes in memory (Jamieson-Craig, Scior, Chan, Fenton & Strydom, 2010). Non-cognitive concepts have also been highlighted to hold greater significance to individuals with ID and their carers, than cognitive assessment (Cooper & Prasher, 1998). Although the effectiveness of informant reports often varies from study to study (e.g. Jorm, 1997), in the studies reviewed here informant reports were shown overall to be an effective way of informing dementia diagnostics. Informant reports are well suited to individuals who have severe ID. A variety of both clinical and applied settings were utilized in the reviewed studies and no studies commented on the setting being inappropriate for the assessment, but again level of distraction and accuracy of data should be considered when deciding administration setting.

In all of the studies that compared informant reports to direct cognitive tests, informant reports were shown to be more effective than cognitive assessments (McCarron, McCallion, Reilly & Mulryan, 2014; Kay et al, 2003; Deb & Braganza, 1999). The Daily Living Skills Questionnaire (DLSQ – National Institute of aging, 1989) was noted to be effective in early detection, showing changes indicative of dementia 3 to 4 years prior to diagnosis. The Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID – Deb, Hare, Prior & Bhaumik, 2007) was administered to a total of 848 participants the reviewed studies and each found the questionnaire to be informative. Lin et al (2014), also noted further demographic factors that influence dementia status do need to be considered alongside DSQIID administration.

Results on the Activities of Daily Living Questionnaire (ADL – Mahoney & Barthel, 1965) were better explained by disability level and comorbidity than dementia status. Therefore, this was the only informant report of those reviewed found to be unsuitable for use in dementia diagnostics for people with ID.

3.4.3 Test Batteries

The reviewed test batteries contained both direct cognitive tests and informant reports. All batteries were effective in discriminating between individuals with ID and dementia and those with ID without dementia, and none described floor effects, suggesting potential for clinical utility. Jozsvai, Kartakis & Collings (2002), found the Boston Naming Task (BNT - Kaplan, Goodglass & Weintraub, 1983) and the Block Design Test (BD from WISC-R – Wechsler, 1974) contained in their test battery to be affected by participant age. Thus, these two tests were shown to have least diagnostic utility out of tests contained in the battery used in this study. If a practitioner was to select this test battery it is advised that these tests be removed.

The Cognitive Computerised Test Battery for Individuals with Intellectual Disabilities (CCIID – Van der Wardt, Bandelow & Hogervorst, 2011) is yet to be studied for the purpose of dementia diagnostics in individuals with ID. However, the CCIID has been validated in adults with ID. Moving forward this battery should be assessed in a sample of individuals with ID and dementia prior to clinical utility. Similarly, the Das Naglieri Cognitive Assessment System is yet to be assessed comparing those with ID and dementia to ID without dementia. Das, Divis, Alexander, Parrila & Naglieri (1995) assessed cognitive decline that results from ageing and occurs among adults with DS, using this test battery and found the battery to be effective at detecting age related cognitive decline. Research has not yet assessed its utility in discriminating between dementia cases and controls in an ID or DS sample. Further research is therefore warranted to determine the usefulness of this battery in aiding with dementia diagnosis.

Test batteries often assess a range of cognitive abilities without relying on informants. Consequently, in order to best inform dementia diagnostics administering a test battery longitudinally can highlight any decline and track cognitive functioning to best aid a clinician in making a diagnostic decision. Although dementia related information and technology is growing in ID (Watchman & Janicki, 2017), there are numerous practical implications that need to be considered. Many require touch screen laptops, which are costly if the technology is not already available to the clinician. The laptops would also need to be near an available plug socket in order to administer tests without interruption, which may not be practical in an applied setting. This limits the potential for test batteries to be utilised. Paper and pen versions of certain cognitive assessments are available, which means if it is not feasible to have technology then the same concept of assessing a range of cognitive functions can be applied. All test batteries presented require further testing to validate their clinical utility in an appropriate sample, particularly those batteries that have concerns noted above.

3.4.4 Combining Methods

Previous reviews argue a combination of methods can best inform dementia diagnosis in individuals with ID (e.g. Burt et al, 2005). Johansson and Terenius (2002), describe how cognitive testing and informant interviewing could be the most effective way to combine methods and gain a full clinical picture. Combining methods for diagnosis, although effective, may be time consuming. Therefore, the chosen combination of methods should be carefully considered. This further supports the recommendation of the use of a test battery to aid diagnosis, as a number of batteries presented contain informant reports, alongside cognitive assessments.

3.4.5 Limitations of this Review

This review does have limitations. Most notably, instruments that compiled the test batteries were not evaluated individually as direct cognitive tests. To improve this research instruments used within the batteries could be assessed individually as well as part of the battery. However, due to the benefits of test batteries discussed in this review, it was felt that information about test batteries would be more beneficial to clinicians, as a whole.

3.4.6 Conclusion

In summation, it can be recommended that when diagnosing dementia in individuals with ID an assessment of multiple areas of cognitive functioning is undertaken; as no one area of functioning can account for the onset of dementia for individuals with ID. In order to achieve this a combination of methods could be applied, either through test battery assessment alongside informant reports or a battery that contains informant reports to provide valuable information on the daily functioning of the individual, as well as an overall assessment of cognition. Tables provided highlight previous validation of test batteries, and prior to selecting a battery, a clinician should review the literature presented. Particularly considering the length of the test battery, the severity of ID of the individual being assessed and the setting in which the assessment will be administered. It may be advised to complete a shorter instrument when the ID is more severe. In this case, the CCIID or the SIB each take 30 minutes or less. Regardless, breaks should be offered to participants throughout any testing and it is also possible to split testing sessions into multiple shorter sessions.

Completing a test battery that specifically contains both informant reports of daily functioning and assesses a full range of cognitive abilities is advised. This can enable clinicians to gain a more in-depth account of participants' functioning and symptoms; and best inform a diagnostic decision. This chapter contributes to our understanding of how dementia diagnostics has been informed, through varying assessments, in previous research and practice. The next study, described in chapter 4, applies these cognitive assessments. To further our understanding of dementia diagnostics, scores on the cognitive assessments (described in chaper 2) will be compared between individuals with intellectual disabilities who have dementia and those who do not have dementia. This will then be further extended in chapter 5 with individuals who do not have a pre-existing ID. This research offers the potential to better inform dementia diagnostics, whilst increasing the inclusivity of the diagnostic process.

Chapter 4

Cognitive Assessments for Dementia Diagnostics: A cross sectional study of those with intellectual disabilities with and without dementia

Aspects of this chapter have been published in:

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Shaw, S., Susch, M., Elliott-King, J., Kassam, S., Devshi, R., Xin, X., Bandelow, S., & Hogervorst, E. (2017). Verbal Memory and the Diagnosis of Dementia: A Critical Literature Review Exploring the Clinical Utility of the Hopkins Verbal Learning Test for the Detection of Dementia. Costa, A., & Villalba, E. (Eds)., *Horizons in Neuroscience Volume 26* (pp. 29-56). Hauppauge, New York: Nova Science Publisher.

Chapter 4 - Cognitive Assessments for Dementia Diagnostics: A cross sectional study of those with intellectual disabilities with and without dementia

4.1 Introduction

Dementia is becoming an increasing concern for individuals with intellectual disabilities. Inherent difficulties with identifying dementia within this population were discussed throughout chapter 3. At present, there is no current consensus on how to diagnose dementia in ID, but research suggests that consensus needs to be reached in order to advance assessment of dementia in ID (Zeilinger, Stiehl & Weber, 2013; Elliott-King et al, 2016). The literature review detailed in chapter 3 recommended the use of a combination of cognitive assessments, either through a test battery or a test battery and an informant report, in order to assess a range of cognitive functuions in which to inform dementia diagnostics. The lack of standardization of diagnostic procedures for individuals with ID is impeding progress in the understanding and treatment of dementia in this patient group (Aylward, Burt, Thorpe, Lai and Dalton, 1997). Diagnostic efficiency and standardization is advantageous as it can facilitate communication between health professionals, decrease burden on healthcare professionals time; and lead to earlier treatment, which can result in maintaining the highest possible level of cognitive functioning while the dementia is mild (Seltzer et al, 2004). Moreover, the timing of a diagnosis is important to the dementia caregiver in providing an explanation for difficulties experienced and allowing earlier organization of care, future planning and caregiver education to mitigate the problems that are inherent when living with undiagnosed and unrecognized dementia (Ng, Martin-Khan, Farrow, Beattie & Pachana, 2016).

Diagnosis in the general population often involves direct cognitive testing that reflects progressive cognitive decline in areas of functioning, such as short-term and long-term memory, orientation, communication and mood, among others. These tests should assess a range of cognitive functions in order to gain a quick overview of the functioning of the individual, such as the Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975). Alternatively, tests could examine a specific cognitive domain that has been shown to be associated with certain types of cognitive impairments, such as verbal learning and memory as tested with the Hopkins Verbal Learning Test (HVLT) (Brandt, 1991). The MMSE has been shown to be sensitive to education, which could be problematic for individuals with ID. The HVLT, however, has been shown to be less sensitive to education (Hogervorst, Combrinck, Lapuerta, Rue, Swales & Budge, 2002). Although there is significant debate across the literature, Crayton, Oliver, Holland, Hall and Bradbury (1997) observed similar clinical progression in the ID participants with dementia to individuals with dementia from the general population.

Furthermore, the numerous cognitive domains affected by dementia and related cognitive disorders highlight how onset, course and progression of dementia can substantially vary from person to person, irrespective of any pre-existing cognitive impairment. Therefore, where possible, individuals with ID should complete assessments that correspond with those used in the general population and vice versa. This could aid communication and understanding of dementia pathology in both populations. There are many potential improvements to dementia diagnostics for people who have a pre-existing ID through this approach. As recommended by review of the literature, using a test battery could be the most efficient solution that assesses a range of cognitive functions in an efficient manner. Using a test battery that is designed for application in ID populations may be able to offer a solution to diagnostic difficulties. The Cognitive Computerised Test Battery for Individuals with Intellectual Disabilities or CCIID (van der Wardt, Bandelow & Hogervorst, 2011) could be an example of a suitable test battery. Diagnosis is however, not a one-off event, but a process involving longitudinal assessment (e.g. Hellstrom & Torres, 2013), this is so that any cognitive assessments can be compared from one timepoint to the next to determine if the individual is experiencing decline in their cognitive functioning, an inherent characteristic of dementia. Therefore, it is important to consider if a cognitive assessment can detect the decline associated with dementia as well as identifying who most likely has dementia and who does not.

The current study aimed to evaluate the potential for the CCIID to assess cognitive abilities in Leicestershire service users who have an ID; to establish accuracy, sensitivity and specificity of the HVLT and the CCIID in distinguishing between individuals with ID and dementia and those with ID without dementia for the purpose of informing inclusive dementia diagnostics; to compare accuracy, sensitivity and specificity of HVLT total score to

CCIID composite and subtest scores to establish which instrument is best suited to aid clinicians during dementia diagnosis in individuals with ID; and to evaluate the feasibility of the CCIID and the HVLT to be used in support of the diagnostic process at 6 month follow-up assessment for individuals with ID.

It is important to consider demographic factors such as age, ID severity and level of education, that could confound to affect any differences observed between those with a diagnosis of dementia and those without. As this is a really specific clinical population, that are hard to reach, it may not be feasible to perform any further analysis to account for demographic factors, however, these are considered and discussed and future studies across multiple regions may be able to more effectively control for confounding variables. Based on previous research and pilot data it was hypothesized that the proposed cognitive assessments would be well tolerated by individuals with ID, both with and without dementia; and that controls would score more highly on the HVLT total score, CCIID subtests: Series, Odd One Out and Jigsaw, as well as the CCIID composite score, than ID dementia patients at both baseline and follow-up.

4.2 Methods

4.2.1 Participants

Thirty people with ID were recruited from the Leicestershire Partnership Trust ID services within the East Midlands region of England, 7 of whom had been diagnosed with dementia. Individuals with ID and dementia were found to be significantly older than participating ID controls, but the groups did not differ in level of ID severity. Participants were eligible for inclusion in the study if they had a diagnosis of Intellectual Disability as defined by the ICD-10 criteria; were aged 30 above and had a completed Dementia Questionnaire for Learning Disabilities (DLD) in their case notes. Prior to completion of the DLD potential physical complications are ruled out. Participants were excluded (i) if they did not have an appropriate carer or person who knows the patient well enough to act as consultee (required if the patient lacked capacity to give informed consent); (ii) if they lacked the ability to complete the study assessments and/or could not follow the instructions required to do so; (iii) or if they did not have a carer or person willing or able to provide the informant information. This study was approved by National Health Service National Research Ethics Service (NRES) committee East of England. Informed consent was obtained using the form shown in Appendix 3.

4.2.2 Instruments

During the testing session the participants completed the total free recall section of the HVLT (Brandt, 1991) and then all subtests of the CCIID (van der Wardt, Bandelow & Hogervorst, 2011), starting with the Series, followed by the Odd One Out and finishing with the Jigsaw. The tests were administered by two researchers who were trained in delivering the tests to individuals with ID. Testing took roughly 45 minutes in total, however, participants were offered breaks throughout resulting in variations in testing time between participants. A health questionnaire was given to carers during this time, which provided descriptive information on the participants. The assessments then taken were described in detail in chapter 2. Each subtest gave an individual score. The CCIID also gave a total score, that totals all three subtest scores, which indicates the level of overall cognition in the assessed areas.

4.2.3 Statistical Analysis

A cross – sectional case-control study design was employed to compare individuals with ID that were diagnosed with dementia to ID controls. A Mann Whitney U analysis evaluated the differences between ID dementia and ID controls on demographic factors and assessment scores. Spearman's rank correlations were then used to further investigate the associations between demographic variables and test scores. Following this, Receiver Operating Characteristic (ROC) were used to highlight the accuracy, sensitivity and specificity of the assessments on whether the participant had ID and dementia or was an ID control. Multiple Linear Regression (MLR) models were completed to indicate which predictor variables influenced performance on each of the cognitive assessments. The sample was then matched for age statistically and analyses were repeated to see whether the assessments were still able to discriminate between ID dementia and ID controls.

Due to a small sample size being available for data collection at follow-up assessment, subsequent analyses were not possible. However, descriptive statistics for the follow-up data that was collected are presented. All analyses were conducted in SPSS 23.0 and a p-value of <0.05 was applied throughout.

4.3 Results

Descriptive statistics and Mann-Whitney U tests of difference for all participants, the ID dementia (n=7) and ID controls (n=23) are presented in Table 4.1. The first hypothesis was that the selected cognitive assessments would be well tolerated by individuals with ID both with and without dementia. This was supported by initial inspection of the data, as all participants achieved scores on the assessments. Although, the jigsaw may be of concern as both groups achieved very low scores.

Table 4.1 – Descriptive Statistics

	ID dementia	**ID Control**	**Total**	**Mann Whitney U (p value)**
N	7	23	30	-
Mean Age in years (SD)	54.17 (6.70)	44.83 (9.40)	46.76 (9.64)	**27.00 (p=0.02)***
Severity (n):				65.00 (p=0.80)
Mild	2 (33.3%)	7 (30.4%)	9 (31.0%)	
Moderate	3 (50.0%)	15 (65.2%)	18 (62.1%)	
Severe	1 (16.7%)	1 (4.3%)	2 (6.9%)	
Mean Total CCIID Score (SD)	7.50 (1.29)	18.53 (11.19)	16.43 (10.96)	**12.00 (p=0.05)***
Mean Series Score (SD)	3.00 (0.00)	8.21 (5.00)	7.30 (4.95)	**8.00 (p=0.01)***
Mean Odd One Out Score (SD)	4.00(1.15)	10.73(9.94)	9.57 (9.37)	31.00 (p=0.54)
Mean Jigsaw Score (SD)	1.00(0.00)	1.5 (0.65)	1.41(0.62)	12.00 (p=0.18)
Mean HVLT Total (SD)	0.57 (1.51)	4.57 (5.12)	3.63 (4.82)	**34.50 (p=0.02)***
Gender (n):				77.50 (p=0.86)
Male (%)	4 (57.1%)	14 (60.9%)	18 (60%)	
Female (%)	3 (42.9%)	9 (39.1%)	12 (40%)	

* indicates a significant result ($p \leq 0.05$)

ID dementia and ID controls differed significantly in Series scores, total CCIID scores and total HVLT scores. The Odd One Out and Jigsaw subtests, however, did not show any significant differences between groups. Therefore, further analysis were conducted using only the Series subtest, total CCIID and total HVLT scores.

Table 4.2: Spearman's rank correlation matrix

	ID Severity	Age	Diagnosis	Series Score	Total CCIID	Total HVLT
ID Severity	-					
Age	rho=0.113 p=0.56	-				
Diagnosis	rho=0.048 p=0.81	**rho=0.428** **p=0.02***	-			
Series Score	rho=0.149 p=0.51	rho=-0.361 p=0.09	**rho=-0.531** **p=0.01***	-		
Total CCIID	**rho=-0.541** **p=0.01***	rho=-0.407 p=0.08	**rho=-0.443** **p=0.04***	**rho=0.723** **p≤0.00***	-	
Total HVLT	rho=-0.325 p=0.085	**rho=-0.536** **p≤0.00***	**rho=-0.443** **p=0.01***	**rho=0.432** **p=0.04***	**rho=0.551** **p=0.01***	-

* indicates a significant result (p≤0.05)

Table 4.2 shows correlational analysis that was undertaken to further investigate the associations between descriptive statistics and outcome variables. Significant Spearman's rank correlation confirmed the association between diagnosis and age. Being ID dementia or ID control was also significantly associated with Series, total CCIID and total HVLT scores. ID Severity was correlated with total CCIID score, highlighting a sensitivity of the CCIID to different levels of severity. The HVLT was highly correlated with age, indicating a possible age bias on HVLT scores which was explored further. All three cognitive assessments were correlated with each other.

Table 4.3 shows Receiver Operating Curve (ROC) analysis that was conducted to investigate the accuracy, sensitivity and specificity with the suggested optimal cut-off scores for the Series subtest scores, CCIID total scores and HVLT total scores. The ROC curves were produced by plotting the sensitivity against the specificity for each cognitive assessment in discriminating between ID dementia and ID controls.

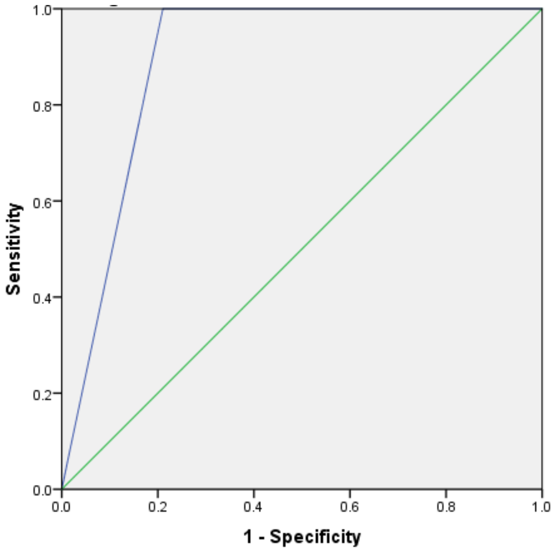
Table 4.3: ROC Analysis for Series, Total CCIID and Total HVLT

	Area	Std. Error	95% CI	P value	Cut-off	Sensitivity	Specificity
Series	0.90	0.07	0.76-1.00	0.02*	**3.5**	**100%**	**79%**
					4.5	100%	74%
Total CCIID	0.82	0.09	0.64-1.00	0.05*	**11.0**	**100%**	**65%**
					13.5	100%	59%
Total HVLT	0.79	0.08	0.62 – 0.95	0.02*	**4.5**	**100%**	**53%**
					5.5	100%	35%

*** indicates a significant result (p≤0.05)**

Figure 4.1 shows the ROC curve for the Series subtest, a large area under the curve of 0.90 was shown and a cut-off score of 3.5 would detect 100% of the ID dementia and identify 79% of the ID controls correctly.

Figure 4.1 ROC Curve for Series Subtest



Diagonal segments are produced by ties.

Figure 4.2 shows the ROC curve for the total CCIID scores, showing a large area under the curve (0.82). A cut-off score of 11.0 showed the highest sensitivity and specificity within this sample of 100% and 65%, respectively.

Figure 4.2 ROC Curve for Total CCIID

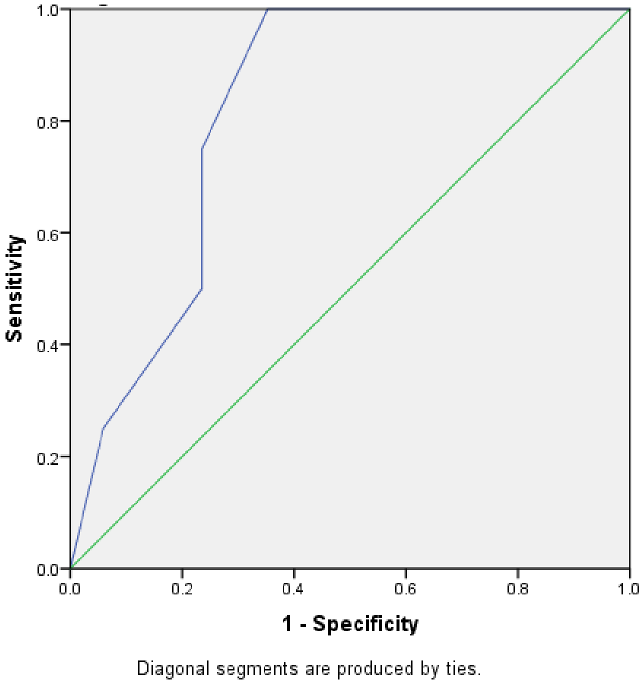
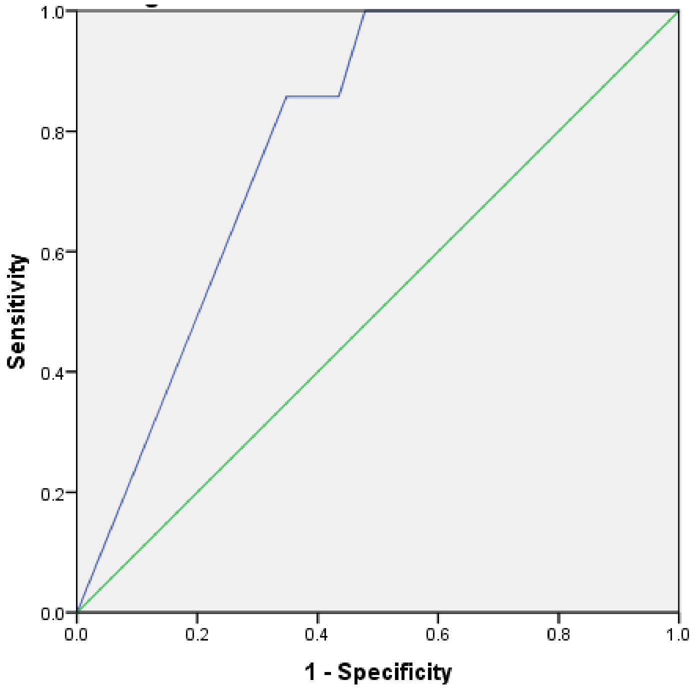


Figure 4.3 shows the ROC curve for the total HVLT scores, showing an area under the curve of 0.79. A cut-off score of 4.5 showed the highest sensitivity and specificity within this sample of 100% and 52%, respectively.

Figure 4.3 ROC Curve for Total HVLT



Diagonal segments are produced by ties.

The hypothesis that ID controls would score more highly that people with ID and dementia was supported for the HVLT, Series and total CCIID through initial investigation of the correlations between diagnosis and cognitive score as well as the ROC analyses that confirm the accuracy, sensitivity and specificity of each test. Following ROC analyses, three multiple linear regression analyses were run, applying a stepwise backward method to establish which predictor variables explained the variance in Series, total CCIID and HVLT scores. Stepwise backward method involves starting with all candidate variables, which in this case was gender, age, diagnosis and severity of ID, and removing non-significant variables from the model.

Table 4.4 shows the results of the first MLR seeking to explain variance in Series subtest scores. Entering all of the variables incurred a determination coefficient of 0.362 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression analyses, which represented the best explanatory independent variables were significant ($F_{(4,17)} = 3.91$, $p=0.02$) and explained 67% of the variance in Series scores (R Square). The final variables included in the model were age, gender and ID severity. Age and ID severity significantly contributed to the model. Older participants achieved lower scores than younger participants. Dementia diagnoses was included in the analyses, however, as diagnosis did not significantly contribute to the model it was removed as a part of the stepwise backward method and therefore not included in the final model.

Table 4.4 –Multiple Linear Regression for Series Subtest

	Beta	95% CI	P value
Constant		9.10 – 30.64	≤0.00*
Age	-0.48	-0.52 – -0.06	0.02*
Gender	-0.33	-7.07 – 0.61	0.61
ID Severity	0.40	0.13 – 6.19	0.04*

* indicates a significant result (p≤0.05)

Secondly, a MLR was conducted to assess the variance in Total CCIID scores, see Table 4.5. Entering all variables incurred a determination coefficient of 0.368 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression, which represented the best explanatory independent variables were significant ($F_{(2,17)} = 6.53$, p=0.01) and explained 66% of the variance in total CCIID scores (R square). The final variables included in the model were Dementia diagnosis and ID severity. The model excluded age and gender. Only ID severity significantly contributed to the model, whereas Dementia diagnosis did trend towards significance.

Table 4.5 – Multiple Linear Regression for Total CCIID Scores

	Beta	95% CI	P value
Constant		22.58 – 46.28	≤0.00*
Diagnosis	-0.36	-22.43 – 0.64	0.06
ID Severity	-0.56	-15.75 – -2.88	0.01*

* indicates a significant result (p≤0.05)

Lastly, a MLR was conducted to assess the variance in Total HVLT scores, see Table 4.6. Entering all of the variables incurred a determination coefficient of 0.153 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression, which represents the best explanatory independent variables were significant ($F_{(1,27)} = 6.06$, p=0.02) and explained 18% of the variance in total HVLT scores (R square). Only age was left as the final variable included in the model. The model therefore excluded diagnosis, gender and ID severity suggesting that age-dependent cut-offs would be needed for optimal dementia diagnoses using the HVLT.

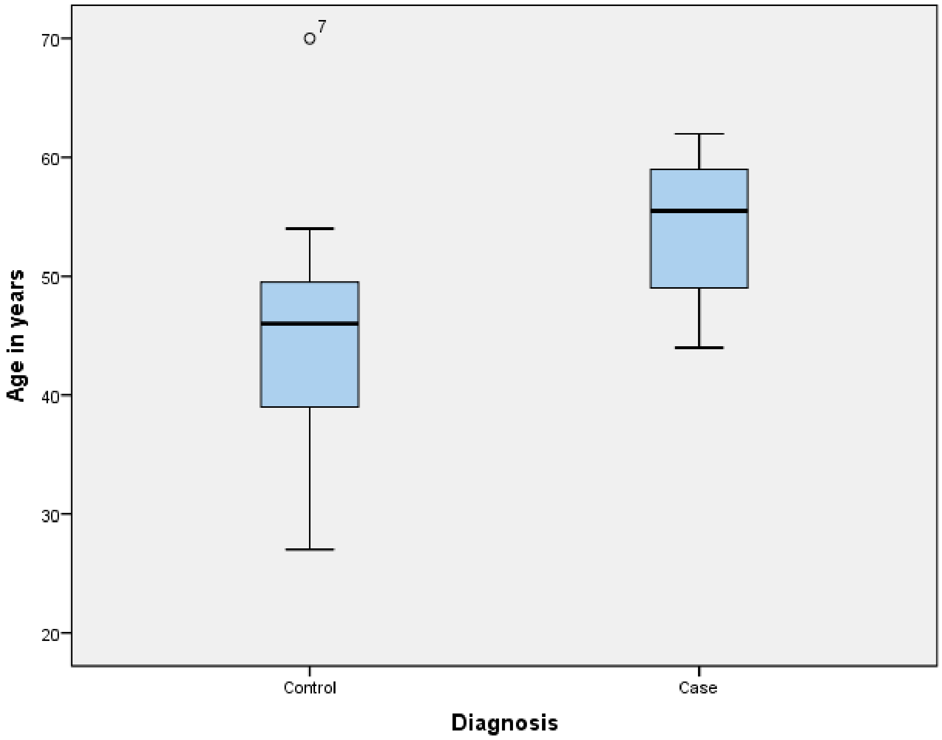
Table 4.6 – Multiple Linear Regression for Total HVLT Scores

	Beta	95% CI	P value
Constant		5.27 – 22.44	0.003*
Age	-0.43	-0.40 – -0.04	0.02*

* indicates a significant result (p≤0.05)

The models shown in tables 4.4, 4.5 and 4.6 were not consistent with correlations carried out earlier in the analysis. This could be due to the small sample size included in the study potentially making the models unstable. Therefore, further inspection of the groups was conducted. The age range of the ID dementia group, 27 to 70 years old, differed from ID controls, ranging from 44 to 62 years old, but this did not appear problematic. However, on further inspection of box plots ID dementia were as a group much older as a group than ID controls, highlighting a systematic age difference between the groups. See figure 4.4.

Figure 4.4 Age comparison of cases and controls



In order to match for age in subsequent analysis, a filter was applied to exclude participants with an age less than or equal to 44 years old or greater than or equal to 62 years old. Descriptive statistics for the age matched sample are displayed in table 4.7 below. In this sub-sample, age was no longer significantly different between ID dementia and ID controls. Series scores remained significantly different, regardless of sample alterations, but HVLT and total CCIID were no longer significantly different between groups. This suggests an age bias for these assessments.

Table 4.7 – Descriptive Statistics for Age matched sample

	ID dementia	ID Control	Total	Mann Whitney U (p value)
N	6	12	18	-
Mean Age in years (SD)	54.17 (6.70)	49.42 (3.26)	41.00 (5.15)	21.00 (p=0.16)
Severity (n):				33.00 (p=0.74)
Mild	2 (33.3%)	2 (16.7%)	4 (22.2%)	
Moderate	3 (50.0%)	9 (75.0%)	12 (66.7%)	
Severe	1 (16.7%)	1 (8.3%)	2 (11.1%)	
Mean Total CCIID Score (SD)	8.00 (1.00)	14.55 (8.82)	13.14 (8.24)	11.00 (p=0.39)
Mean Series Score (SD)	3.00 (0.00)	6.64 (3.61)	5.86 (3.53)	**4.50 (p=0.05)***
Mean HVLT Total (SD)	0.67 (1.63)	2.25 (3.05)	1.72 (2.72)	23.00 (p=0.17)
Gender (n):				33.00 (p=0.74)
Male (%)	3 (50.0%)	5 (41.7%)	8 (44.4%)	
Female (%)	3 (50.0%)	7 (58.3%)	10 (55.6%)	

* indicates a significant result (p≤0.05)

Descriptive statistics were then further analysed using Spearman’s rank correlation analysis, as shown in table 4.8. Total HVLT remained correlated with Age, despite the age match alterations, suggesting an independent effect of age on HVLT assessment scores in this sample.

Table 4.8: Spearman's rank correlation matrix for age matched sample

	ID Severity	Age	Diagnosis	Series Score	Total CCIID	Total HVLT
ID Severity	-					
Age	rho=0.118 p=0.64	-				
Diagnosis	rho=-0.082 p=0.75	rho=0.342 p=0.16	-			
Series Score	rho=0.157 p=0.59	rho=0.067 p=0.82	**rho=-0.541** **p=0.05***	-		
Total CCIID	rho=-0.328 p=0.25	rho=-0.017 p=0.96	rho=-0.240 p=0.41	**rho=0.776** **p≤0.00***	-	
Total HVLT	rho=-0.059 p=0.86	**rho=-0.523** **p=0.03***	rho=-0. 363 p=0.17	rho=0.386 p=0.17	rho=0.365 p=0.20	-

* indicates a significant result (p≤0.05)

In the age matched sample, the Series subtest was the only assessment that showed a significant correlation with Dementia diagnosis. ROC analysis for the Series subtest indicated an area under the curve of 0.86. A cut-off score of 3.5 showed the highest sensitivity and specificity within this sample for the Series subtest of 100% and 73%, respectively. When a cut-off of 4.5 was applied the sensitivity remained at 100% but the specificity dropped to 64%, so the most optimal cut-off was 3.5 (Figure 4.5).

Figure 4.5 ROC Curve of Series for Age matched sample

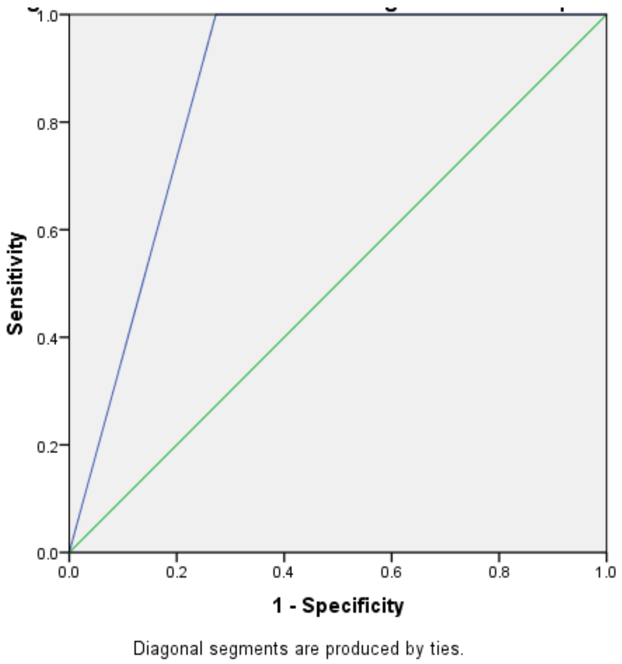


Table 4.9 shows results of an MLR seeking to explain variance in Series subtest scores within the age matched sample. Entering all of the variables incurred a determination coefficient of -0.092 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression, which represented the best explanatory independent variables were not significant ($F_{(4,9)}$ = 0.726, p=0.60). Neither diagnosis, age, gender or ID severity significantly explained the variance in Series scores. However, the sample due to matching was most likely too small to run these analyses.

Table 4.9 –Multiple Linear Regression for Series Subtest in Age matched sample

	Beta	95% CI	P value
Constant		-32.63 – 43.73	0.75
Diagnosis	-0.40	-0.906 – 2.50	0.23
Age	-0.02	-0.69 – 0.66	0.96
Gender	-0.06	-6.34 – 5.50	0.88
ID Severity	0.24	-2.57 – 5.15	0.47

* indicates a significant result (p≤0.05)

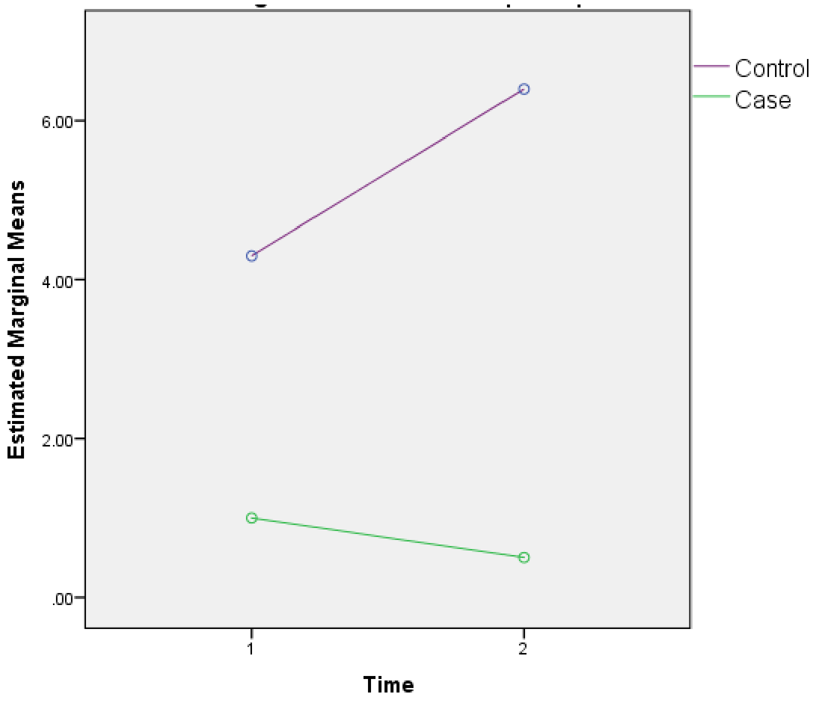
Following assessment of baseline scores comparing ID dementia to ID controls, 6 month follow-up assessments were examined on the full sample. Due to various reasons including illness, death, sleep patterns and lack of availability due to other activities and family visits not all participants could be followed up. Due to the resultant small sample size, further analyses were not possible with these data. However, considering the importance of follow-up data in indicating the suitability of a cognitive assessment to detect cognitive decline over time and inform dementia diagnosis, the means of the current follow up are presented in table 4.10.

Table 4.10 – Descriptive Statistics for Follow-up analysis

	ID dementia	ID Control	Total
N	1	2	3
Series	7.00	8.50 (6.36)	8.00 (4.58)
N	0	2	2
Total CCIID	-	12.5 (6.36)	12.5 (6.36)
N	4	10	14
Total HVLT	0.50 (1.00)	6.40 (5.85)	4.71 (5.62)

As the HVLT was completed by the most participants of those that completed follow-up assessments, figure 4.6 was used to visually assess the potential for differences in HVLT scores at baseline and follow-up. Although this cannot suggest at any effects at this stage, visually a slight worsening of HVLT scores for individuals with dementia can be observed, alongside an improvement for healthy controls. This therefore suggests that the HVLT could offer potential for follow-up investigation during the diagnostics process, but this would need to be investigated in subsequent studies with larger sample sizes in order to draw firm conclusions.

Figure 4.6 HVLT Follow-up comparisons



4.4 Discussion

The present study aimed to assess and evaluate the accuracy, sensitivity and specificity of the Computerised Cognitive test battery for Individual's with Intellectual Disabilities (CCIID) and the Hopkins Verbal Learning Test (HVLT) in line with the first overarching objective of this thesis. The study further aimed to evaluate the potential utility of the proposed cognitive tests at follow-up assessment. Performance on the CCIID and total HVLT for 7 individuals with ID and dementia were compared to 23 ID controls at baseline. The results of this comparison suggest that ID dementia participants achieve lower scores on the Series subtest of the CCIID, the total CCIID score and the total HVLT score than ID controls at baseline. Unfortunately, numbers of participants able to complete follow-up assessments were limited (n=14) so statistical analyses were not possible, however, inspection of the means suggests the need for future studies to investigate the potential for these tests to also be applied longitudinally throughout the process of diagnosing dementia.

Findings from this study are consistent with previous findings, which indicate that patients with dementia score lower on these cognitive assessments compared to controls in both individuals with ID and individuals without (e.g. Hogervorst, Combrinck, Lapuerta, Rue, Swales, Budge, 2002; Deb and Braganza, 1999). This is unsurprising considering the progressive nature of cognitive decline associated with dementia. Results for controls are similar to other studies, as people without ID and no dementia also showed an average improvement of the HVLT at follow-up even after a 2 to 3 year interval (Schrijnemaekers, de Jager, Hogervorst & Budge, 2006).

Jamieson-Craig and colleagues (2010) highlighted the reliance on informant reporting in dementia diagnostics in ID. For instance, this is seen in the Dementia Screening Questionnaire for Individuals with ID, which has been heavily advocated in place of cognitive assessments (e.g. Gomiero et al, 2017). Our study, however, has shown that it is possible to effectively use direct and objective cognitive test batteries to support clinicians in the process of dementia diagnostics, if the correct tests are used and if cut-offs pertinent to individuals with ID are applied. This study suggests the potential for the CCIID, Series subtest and total HVLT scores to be useful in informing clinical judgement, but will require further investigation in order to be able to advise clinical use.

Many earlier uses of direct tests incurred floor effects when participants were classified as having severe ID, meaning cognitive tests are frequently limited in their potential for practical usage (e.g. PCFT - Kay et al, 2003; MMSE – Deb & Braganza, 1999; CAMCOG – Hon, Huppert, Holland & Watson, 1999). This, however, was not the case with the CCIID and HVLT. This can be attributed to the suitability of using the CCIID and HVLT to assess the cognition of individuals with ID. The CCIID was designed to be used cross-culturally and has been validated in numerous ID populations (van der Wardt, Bandelow & Hogervorst, 2011). The HVLT, although used cross-culturally (e.g. Xu, Xiao, Rahardjo & Hogervorst, 2015), has rarely been utilized in an ID population. Yet, by using only the total free recall section in this study, the HVLT was suitable for ID participants and was found to be tolerated well by both individuals with ID and dementia and those without dementia.

Out of the subtests completed for this study the Series and the HVLT showed the most promise for clinical utility. The Series subtest score, which examines inductive reasoning, showed a significantly high accuracy and could detect 100% of individuals with ID and dementia and identify 79% of ID controls accurately. This suggests that the Series subtest alone could be informative. When the sample was matched for age, the Series subtest still identified 100% of ID dementia and 73% of ID controls. This suggests that the Series subtest is accurate at detecting individuals with ID and dementia and ID controls regardless of age, highlighting its potential for clinical use.

Additionally, this study indicated that there is potential for the HVLT to be utilised within this population, following further study. The HVLT gave a sensitivity of 100%, with a lower specificity of 52%. Previous research in the general population has shown the HVLT to have good diagnostic utility, be tolerated well and applicable across cultures. However, demographic factors, such as age, can alter the accuracy of the HVLT (e.g. Hogervorst, Xin, Rahardjo, & Shifu, 2014), which was demonstrated within this sample as well. The specificities observed across all subtests were lower than those that are usually observed within the general population. This could be due to severity of intellectual disability, as well as other demographic factors that could impact cognitive scores, not being matched across the two groups. Therefore, in order to further support the indications of these tests being feasible for use with individuals with ID, future research needs to investigate these demographic factors in more detail.

Prior studies have shown severity of ID to influence scores on cognitive assessments (e.g. Kay et al, 2003). The sample examined in the present study did not differ between ID dementia and ID controls in ID severity, gender or education level, indicating a well matched sample. However, similar to previous findings (e.g. Sinai, Hassiotis, Rantell & Strydom, 2016) the ID dementia group in this study were significantly older than ID controls. The systematic age differences observed in this sample influenced outcomes observed on the HVLT. In order to account for the age specific effects, adjusted cut-off norms for the HVLT could be applied. In the general population, the application of age specific cut-offs has been suggested as important for those with early onset Alzheimer’s disease, who are under sixty-five years old, as well as for those who have advanced age of above eighty years old (Vanderploeg et al, 2000). Previous research has applied age specific cut-offs to the HVLT (e.g. Shi et al, 2012). This has resulted in up to a four point difference in total HVLT cut-off scores needed to be used to obtain maximum discriminative capacity (Shi et al, 2012).

Considering that the HVLT has been rarely employed in samples of individuals who have an ID, age specific cut-offs for the purpose of dementia diagnostics are yet to be explored. The evidence provided in this study, however, suggests that investigating age specific cut-offs during dementia diagnostics for individuals with ID may be more clinically useful than applying a general cut-off score. This was unfortunately beyond the scope of this study, due to the small sample size. Nevertheless, to achieve maximum clinical utility of the HVLT, in both the general population and those with a pre-existing intellectual disability, age specific cut-offs should be researched further.

The HVLT and the Series test present the opportunity to apply a more inclusive approach to dementia diagnostics. The HVLT has been consistently applied to dementia diagnostics in the general population. Using the same test for individuals with ID could offer an avenue for memory clinics and ID specialists to increase inclusivity thoughout the process of dementia diagnostics. This in turn could incur benefits in communication and understanding of the course and progression of dementia across populations, which was noted, in chapter 3, as a limitation in current understanding of dementia (McCarron et al, 2018). The Series test has been shown to have good correlations with traditional IQ tests, such as the WAIS (van der Wardt, Bandelow and Hogervorst, 2011), and with further investigation could be considered for use in all dementia diagnostics. Future research should seek to explore the Series test separately, as a potential screening tool for dementia for individuals who do not have a pre-existing ID.

This study, as with many in its field, is limited by the small sample size. In a larger sample it would be possible to further investigate the effect of age on the various cognitive assessments and establish a definitive cut-off for both Series and HVLT to be introduced into clinical practice. Future research should, therefore, seek to further validate the proposed cognitive assessments within a larger sample of individuals with ID. The potential for clinical utility demonstrated in this study suggests that it may be possible to reach a consensus on the use of cognitive assessments to inform diagnostics for individuals with ID.

The lack of current standardized criteria and diagnostic procedures is agreed to be impeding progression in both the understanding clinicians and researchers have of dementia in ID, and the potential treatments available for people with ID and dementia. (Aylward, Burt, Thorpe, Lai & Dalton, 1997). Establishing a suitable diagnostic tool that can be used in clinical and research settings alike, could lead to substantial benefits in assessment efficiency, communication between healthcare professionals and in available treatment. Studies have shown that earlier treatment can maintain the highest possible level of cognitive functioning while the dementia is mild (Seltzer et al, 2004). Therefore, further study is warranted to maximize the benefit of the current findings to clinical settings.

Overall, both the CCIID and the HVLT have been shown to distinguish between individuals with and without dementia in an ID population and could offer potential for clinical utility. These initial findings suggest that the Series subtest could be most effective as a stand-alone assessment but clinicians could also consider the use of the Series and HVLT together for an efficient battery of cognitive assessments to inform diagnosis, following further assessment within a larger sample. This chapter, alongside findings from the literature discussed in chapter 3, has demonstrated the potential for cognitive assessments to be applied during the process of dementia diagnostics for individuals with ID. The next chapter builds upon this research by identifying whether the same instruments can also assess the cognition of individuals without a pre-existing ID and successfully identify those with dementia and those without. Applying the same cognitive assessments for all individuals could be crucial in informing a more inclusive approach to the process of dementia diagnostics.

Chapter 5

Cognitive Assessments for Dementia Diagnostics: A cross sectional study of those with and without dementia

Chapter 5 - Cognitive Assessments for Dementia Diagnostics: A cross-sectional study of those with and without dementia

5.1 Introduction

Dementia is currently under detected and underdiagnosed; with diagnosis rates estimated at only 50% in higher income countries and 5-10% in lower income countries (e.g. Lian et al., 2017). Recent governmental focus on dementia based strategies in the UK has led to a positive change since 2005, with increases being shown in diagnostics rates and the quality of drug treatment being provided (Donegan et al, 2017). As laid out by the Prime Minister's challenge on Dementia (Department of Health, 2012) accurate and early diagnosis is a national priority and remains so currently, with a further need to focus on diagnostic timeframe and referral rates. There is however, no mandated timeframe for either a referral to specialist services or to the point where an individual receives a specific diagnosis (Meskarian, Monks, Chappell & Kipps, 2017). Without a mandated timeframe many individuals, who are potentially distressed by symptom onset and the resultant disruption caused to daily life, remain without an understanding or explanation of why this is happening, and what can be done to help.

The need for a timely diagnosis has been consistently reinforced by the numerous benefits of early detection discussed in the literature. Most notably are the opportunities for early intervention, implementation of coordinated care plans, offering greater support to the caregiver, reducing the risk of misdiagnosis, better management of symptoms, increased patient safety, higher cost savings and postponement of institutionalisation (Dubois et al, 2016; Chang & Silverman, 2004). Moreover, cognitive impairment may manifest substantially earlier than previous research proposed, in the preclinical phase of Alzheimer's disease up to 18 years prior to diagnosis (Rajan, Wilson, Weuve, Barnes & Evans, 2015). Between four and five years prior to diagnosis a prominent increase in rate of cognitive decline is observable (Rajan et al, 2017). The arguments for assessment as early as possible, during the preclinical phases of dementia, although heavily debated are strong as early assessment allows for earlier detection and monitoring of cognitive status longitudinally.

The international landscape of dementia diagnostics is continuously changing. US researchers have changed their classification of dementia in the latest update of the diagnostic and statistical manual (from the DSM 4 to the DSM 5). This new approach has relabelled MCI and dementia, as Mild and Major neurocognitive disorders (NCD). Researchers, in the US predominantly, hope that as the use of these criteria becomes more widespread, a common international classification for these disorders could emerge, thus promoting efficient communication among international clinicians and researchers which is, at present, problematic (Sachdev et al, 2014). Changes in classification has resulted in a 127% increase in diagnosis relative to the DSM 4 (Eramudugolla et al, 2017). This is because the additional cases being identified since the change in classification have less severe memory, language and instrumental activities of daily living (IADL) impairments compared to cases meeting DSM 4 criteria for dementia. Therefore, the presence of additional cases being identified highlight that the DSM 5 is broader in its categorisation (Eramudugolla, Mortby, Sachdev, Meslin, Kumar & Anstey, 2017). Tay and colleagues have also found a 39.7% increase in the frequency of dementia diagnoses using DSM 5 criteria. However, overall agreement is only moderate between the different operational definitions (Tay et al, 2015). This suggests that the two criterian, DSM 4 and DSM 5, do not always align in the diagnoses clinicians reach when applying the differing classifications.

In the UK, the DSM classification is not the only criteria considered when diagnosing dementia. The ICD-10 (World Health Organisation, 1992) is an alternative classification system that is often applied outside of the US; in this system dementia is maintained as the umbrella term to describe cognitive impairment, alongside mild cognitive impairments. Thus, many clinicians in the UK opt to refer to the ICD-10 and the earlier DSM 4 rather than applying the newer DSM 5 classificiations. Participants were asked to self-report their diagnoses and the participants in this study, and others throughout this thesis, labelled their GP or memory clinic derived diagnosis as “dementia”. Therefore, the language used throughout this chapter reflects this and the DSM 5 criteria is not applied.

Regardless of the diagnostic criteria being applied, the Mini Mental State Examination or MMSE (Folstein, Folstein & McHugh, 1975) has in the past been the principal instrument for observing symptoms related to dementia or NCD. It has been shown to have comparable diagnostic performance across geographic regions and recruitment settings. Due to a recent copyright charge being placed on the use of the MMSE (e.g. Powsner & Powsner, 2005), other cognitive assessments have been taking a more prominent place in clinical practice. These alternative cognitive assessments, namely the Mini Cog Test (Borson, Scanlan, Brush, Vitaliano & Dokmak, 2000), the Addenbrookes Cognitive Examination (Mioshi, Dawson, Mitchell, Arnold & Hodges, 2006) and the Montreal Congitive Assessment (Nasreddine et al, 2005), have also been shown to have comparable diagnostic performance (Tsoi, Chan, Hirai, Wong & Kwok, 2015). Paper and pencil cognitive assessments are a quick and easy tool for assessing cognition (Ashford et al, 2006). However, additional validation of cognitive assessments currently in use is required to better advance dementia diagnostics (Velayudhan et al, 2014).

More recently developed assessments can be automated and computerised rather than administered with paper and pen. A recent literature review has shown promising results for automated assessments being comparable to standardised paper and pen assessments at detecting early dementia (Aslam et al, 2018). This suggests that automated assessments could be advantageous when seeking a timely diagnosis. Although further evidence for their use is required as present use is not widespread. This study will further explore this area as it will be the first practical application of the Cognitive Computerised test battery for individuals with intellectual disabilities (or CCIID) for the purpose of informing the diagnosis of dementia. This computerised assessment was contained in the battery participants completed during this study, alongside paper and pen assessments. Moreover, the CCIID offers assessment of fluid abilities alongside the traditional tests of memory and overall cognition.

Prior to onset, and as dementia progresses, a variety of cognitive functions can decline at different time-points. Both fluid and crystallised abilities decline in the preclinical phase. Generally, fluid abilities such as processing speed, memory, visuospatial ability and attention are considered age sensitive; whereas crystallised abilities, such as verbal abilities, are less age sensitive and tend to remain stable throughout old age (Cattell, 1963; Crawford, Deary, Starr & Whalley, 2001; Horn & Cattell, 1967). Several epidemiological studies have highlighted an increased rate of decline of fluid abilities during the preclinical phase, and therefore these functions are associated with an increased risk of developing dementia (Fleisher, Sowell et al, 2007; Petersen, 2004; Roberts & Tersegno, 2010). This implies that a range of fluid abilities should be assessed during dementia diagnostics. Inductive reasoning, the specific ability to draw a 'most likely' conclusion based on the available evidence, has been shown to be an indicator of fluid ability since the 1920s (Spearman, 1927). More recent research has highlighted the importance of inductive reasoning in the execution of activities of daily living for older adults (e.g. Wolinsky et al, 2006). Furthermore, inductive reasoning has been shown to predict clinical symptoms of dementia in men (Olsson, Zettergren, Falk, Kern & Skoog, 2017). This proposes that assessing inductive reasoning prior to the observation of any clinical symptoms could offer the potential for early detection during the preclinical dementia phase. Thus, utilising the CCIID for the first time could offer an appropriate assessment of inductive reasoning.

As discussed in chapter 4, cognitive assessments such as the MMSE, account for a variety of functions affected by dementia and assess cognitive abilities such as orientation, registration, attention, calculation, recall and language. Alternative targeted cognitive tests assess specific functions that have been observed to decline as dementia progresses. Memory impairments, for example, are prominent and therefore memory is frequently assessed with tests such as the Hopkins Verbal Learning Test (Brandt, 1991). The use of multiple screening instruments to assess a range of cognitive abilities earlier than previously applied in clinical settings could be pivotal in improving time to diagnosis. However, clinicians are frequently under restrictions on the amount of time they can spend with each patient. Additionally, increased assessments can increase both patient and caregiver distress, amidst what could already be a distressing situation (e.g. Glasser & Miller, 1998). With all these considerations in mind the clinician is required to make a judgement based on an appropriate amount of assessments to deliver accurate diagnosis without taking too long or causing the patient or their family members any undue distress.

The study detailed in this chapter hence seeks to better understand which cognitive assesments are best placed to achieve this appropriately timed diagnosis. If diagnosis is appropriately timed, also termed efficient diagnosis, earlier treatment and care can be initiated. At the end stage of the disease it can be clinically difficult to discriminate between different pathologies and affect treatment strategies (Kalaria, 2016), therefore applying earlier treatment could be crucial for patient wellbeing. This study, therefore, aims to better understand which assessments of cognition can most accurately detect dementia, with the intention of informing an efficient and inclusive diagnosis. Based on previous research it was hypothesized that the proposed cognitive assessments would be well tolerated by individuals with and without dementia; and that controls would score more highly on the HVLT total score, MMSE, VF, CCIID subtests: Series, Odd One Out and Jigsaw, as well as the CCIID composite score, than ID dementia patients at both baseline and follow-up.

5.2 Methods

5.2.1 Participants

Participants were recruited from community groups and organisations with a focus on dementia or Alzheimer’s support for either the person with dementia, caregiver, or both. This included memory cafes, coffee mornings and church based groups. Advertisements for the study were also placed in local organisational newsletters to generate further interest in participation. Participants were included if they were community dwelling, aged 65 and over and able to consent for themselves. Participants with dementia were sought as well as age-matched controls. As participants were recruited from community settings dementia status was self-reported. Each participant was asked to self report having received this diagnosis from a GP or clinician. Recruitment methods often resulted in participants enrolling as a couple, with the caregiver of the person with dementia participating as the age-matched control. Twenty-five participants took part in this study, 15 of whom self-reported having a diagnosis of dementia compared with 10 age-matched controls. Participants had a mean age of 76.08 (SD: 9.5, range: 58 - 91) years and there was no significant difference in age between people with dementia and controls. All participants indicated receiving education to degree level or equivalent industry training, therefore education was not included in the analysis as it did not differ between participants. All participants were white in ethnicity and therefore ethinicity did not differ between groups. There were more males with dementia than females; similarly, there were more females acting as age-matched controls than males.

5.2.2 Procedure

Participants were invited to Loughborough University to participate in the study. All appointments took place in the morning, usually starting at 9.30am but the time could vary depending upon the travel arrangements of the participants. Maintaining the same assessment time for all participants meant that no variations in scores could be accounted for by time of day. Participants completed an informed consent form (Appendix 3) and general demographic and health questionnaire (Appendix 4), this included self-report of dementia status. Following these questionnaires, the cognitive assessments described in chapter 2 were completed. These cognitive assessments were conducted in the following order: MMSE, HVLT, VF, followed by the computerised section of the testing, with all of the subtests of the CCIID. The order in which the cognitive assessments were administered remained consistent for all participants.

Completion of the cognitive assessments lasted approximately 30 minutes, specifc times were not recorded in order to avoid any extra duress for the participant. Participants completed the assessments individually with one researcher, Jordan Elliott-King, present. If participants engaged in the study as a couple, two researchers would greet the participants but once inside the building the couple would separate into two adjacent rooms in order to complete testing individually. Participants were offered breaks throughout the testing session as well as a drink if needed. However, participants seldom took breaks due to the short time required for all assessments. Participants also reported enjoying the cognitive assessments, with several couples noting how fun it was to compete against each other for time spent engaging with the assessments. Although no tangible score or measure of who may have won was given, the couples still enjoyed the idea of doing the same activity at the same time.

5.2.3 Study Design

A cross – sectional study design was employed to compare individuals with dementia to age-matched controls. Using this type of study design allowed for assessment of the differences between cognitive scores of individuals with dementia compared to those without. This means that the sensitivity and specificity of each test can be examined at one point in time rather than requiring longitudinal analysis. This has benefits for both the researcher, as more data can be collected at the same time point and therefore the data collection phase of a study is more efficient, as well as the participant as less time is required from each participant to participate.

5.2.4 Statistical Analysis

A Mann Whitney U analysis evaluated the differences between individuals with dementia and aged-matched controls. Individuals with dementia were refered to as ‘cases’ in the subsequent analysis, this is simply for ease of labelling while using and analysing SPSS and statistical outputs during analysis. Spearman’s rank correlations and Chi square test of difference were then used to further investigate the associations between demographic variables and test scores. Following this, Receiver Operating Characteristic (ROC) analyses in SPSS 24.0 were then used to assess the accuracy, sensitivity and specificity of the MMSE, HVLT, VF and the CCIID, and the subtests of the CCIID, in detecting cases and controls. Stepwise backward Multiple Linear Regression (MLR) models were then completed for each cognitive assessment to indicate which participant variables, such as age, gender and diagnosis, influenced performance on each of the cognitive assessments.

5.3 Results

Descriptive statistics and Mann-Whitney U tests of difference for the participants with dementia, those without and the whole sample together are presented in Table 5.1. Pearson Chi square test was utilised to assess any gender differences and found a significant difference in gender between the two groups. This is resulting from more females acting as age-matched controls than males.

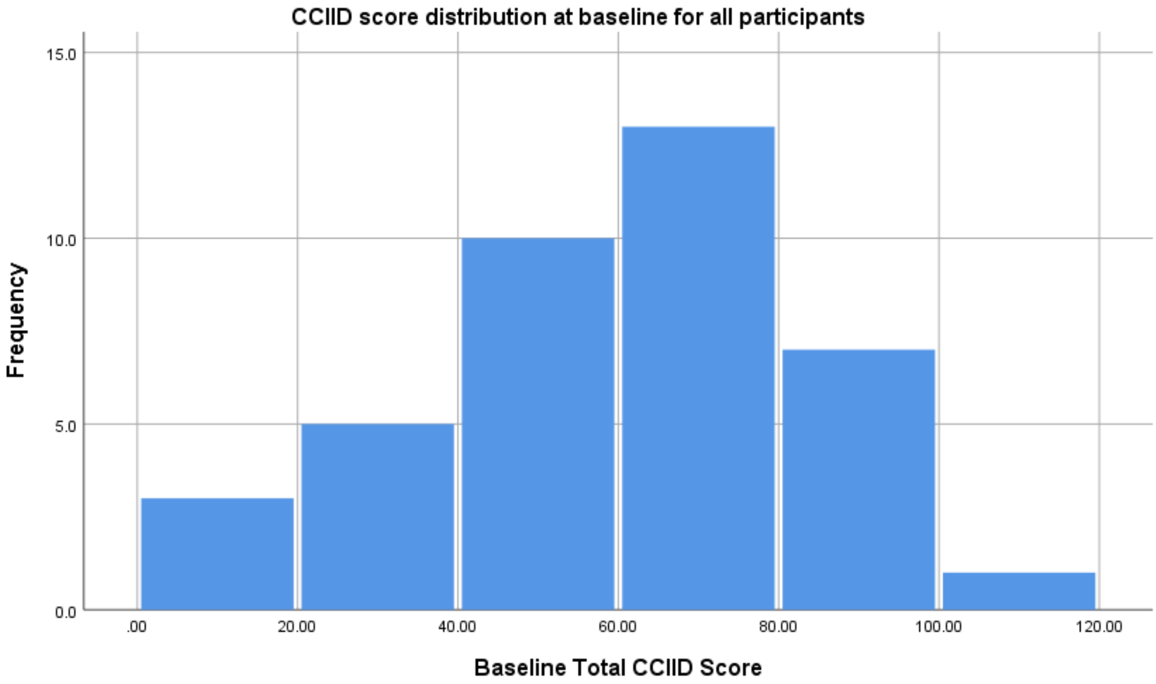
Table 5.1 - Descriptive Statistics:

	Dementia	Control	Total	Mann Whitney U (p value)
N	10	15	25	-
Gender (n)				
Male (%)	7 (70%)	3 (20%)	10 (40%)	**Pearson Chi square = 6.25 (p=0.012)***
Female (%)	3 (30%)	12 (80%)	15 (60%)	
Mean age in years (SD)	78.78 (8.91)	74.47 (9.79)	76.08 (9.5)	50.50 (p=0.318)
Mean MMSE (SD)	18.44 (6.84)	28.71 (1.44)	24.70 (6.67)	**5.00 (p<0.001)***
Mean HVLT (SD)	7.6 (6.62)	24.14 (6.59)	17.25 (10.54)	**7.00 (p<0.001)***
Mean Verbal Fluency (SD)	9.22 (8.27)	20.93 (5.37)	16.35 (8.72)	**16.00 (p=0.003)***
Mean Total CCIID (SD)	41.25 (22.15)	73.00 (19.38)	59.63 (25.67)	**8.5 (p=0.002)***
Mean Series (SD)	14.25 (10.73)	30.64 (8.81)	23.74 (12.53)	**10.00 (p=0.004)***
Mean Odd One Out (SD)	24.25 (9.69)	34.09 (8.26)	30.42 (10.18)	**13.50 (p=0.009)***
Mean Jigsaw (SD)	3.67 (2.34)	9.11 (4.78)	6.93 (4.76)	**6.5 (p=0.012)***

*** indicates a significant result (p≤0.05), ** indicates a significant result (p≤0.001**)**

Considering the novel application of the CCIID for individuals without ID. An examination of the distribution of the baseline scores was conducted. Figure 5.1 shows the histogram of the distribution. The test indicates normal distribution with only a slight negative skew apparent, but skewness (-0.351) and kurtosis (0.375) scores fall within normal range.

Figure 5.1 Distribution of CCIID Score at baseline



The hypothesis that participants with dementia would show significantly lower scores than those without dementia on the VF, MMSE, Total CCIID, and its subscales: the Series, Odd One Out, Jigsaw and HVLT scores was supported by the preliminary analysis shown in Table 5.1. All included cognitive assessments therefore warranted further analysis.

Table 5.2 shows correlational analyses that were undertaken to further investigate the associations between descriptive statistics and outcome variables. Significant Spearman's rank correlation confirmed the associations between whether the participant was a case or control and their score on the VF, HVLT, MMSE, Series, Odd One Out, Jigsaw and Total CCIID. All included cognitive assessments were significantly associated with each other. Verbal Fluency was the only cognitive assessment that was significantly associated with age, suggesting a potential age bias that was explored further in subsequent analysis. The HVLT was the only test that was shown to be sensitive to gender.

Table 5.2 - Spearman's rank correlation matrix

	Case	**Age**	**Gender**	**MMSE**	**HVLT**	**VF**	**Series**	**Odd One Out**	**Jigsaw**	**Total CCIID**
Case	**-**									
Age	rho=-0.212 p=0.32	**-**								
Gender	**rho=0.500** **p=0.011****	rho=0.031 p=0.885	**-**							
MMSE	**rho=0.788** **p≤0.001****	rho=-0.287 p=0.195	rho=0.334 p=0.119	**-**						
HVLT	**rho=0.770** **p≤0.001****	rho=0.311 p=0.148	**rho=0.397** **p=0.054***	**rho=0.787** **p≤0.001****	**-**					
VF	**rho=0.632** **p≤0.001****	**rho=-0.456** **p=0.033***	rho=0.357 p=0.094	**rho=0.759** **p≤0.001****	**rho=0.848** **p≤0.001****	**-**				
Series	**rho=-0.663** **p=0.002****	rho=-0.159 p=0.529	rho=-0.068 p=0.781	**rho=0.748** **p≤0.001****	**rho=0.821** **p≤0.001****	**rho=0.689** **p=0.002****	**-**			
Odd One Out	**rho=-0.595** **p=0.007****	rho=-0.320 p=0.196	rho=-0.088 p=0.721	**rho=0.533** **p=0.023***	**rho=0.764** **p≤0.001****	**rho=0.767** **p≤0.001****	**rho=0.788** **p≤0.001****	**-**		
Jigsaw	**rho=-0.651** **p=0.009****	rho=-0.148 p=0.613	rho=0.140 p=0.618	**rho=0.717** **p=0.003****	**rho=0.867** **p≤0.001****	**rho=0.740** **p=0.002****	**rho=0.917** **p≤0.001****	**rho=0.860** **p≤0.001****	**-**	
Total CCIID	**rho=-0.692** **p≤0.001****	rho=-0.177 p=0.484	rho=-0.058 p=0.812	**rho=0.671** **p=0.002****	**rho=0.827** **p≤0.001****	**rho=0.736** **p≤0.001****	**rho=0.952** **p≤0.001****	**rho=0.868** **p≤0.001****	**rho=0.964** **p≤0.001****	**-**

*** indicates a significant result (p≤0.05), ** indicates a significant result (p≤0.001**)**

Receiver Operating Characteristic (ROC) analysis was conducted to investigate the accuracy, sensitivity and specificity with the suggested optimal cut-off scores for the HVLT, VF, MMSE, Series, Odd One Out, Jigsaw and Total CCIID scores, as presented in Table 5.3. The ROC curves were produced by plotting the sensitivity against the specificity for each cognitive assessment in discriminating between those with dementia and those without. Cut-off scores that produce maximum sensitivity and specificity are highlighted in bold.

Table 5.3 - ROC Analysis for Cognitive Assessment

	Area	Std. Error	95% CI	P value	Cut-off	Sensitivity	Specificity
HVLT	0.95	0.046	0.86 – 1.00	p≤0.001**	9.5	80%	100%
					11.0	80%	93%
					14.5	**90%**	**93%**
					17.5	90%	86%
					24.0	100%	57%
VF	0.873	0.094	0.688 – 1.00	p=0.003**	9.5	67%	100%
					11.5	**78%**	**100%**
					13.5	78%	93%
					14.5	78%	86%
					15.5	78%	79%
MMSE	0.96	0.040	0.883-1.00	p≤0.001**	24.0	78%	100%
					26.5	**89%**	**93%**
					27.5	89%	72%
					28.5	100%	64%
Series	0.886	0.098	0.694 – 1.00	p=0.005**	17.5	75%	100%
					19.0	75%	91%
					20.5	**88%**	**91%**
					22.0	88%	82%
					25.0	88%	73%
					28.5	88%	64%
OOO	0.847	0.096	0.659 – 1.00	p=0.012*	27.5	63%	91%
					29.5	**75%**	**91%**
					31.5	75%	82%
					34.0	**88%**	**73%**
					36.5	88%	36%
Jigsaw	0.880	0.088	0.706 – 1.00	p=0.016*	2.5	33%	100%
					3.5	**67%**	**89%**
					5.0	67%	78%
					6.5	83%	67%
					7.5	100%	67%
Total CCIID	0.903	0.075	0.756 – 1.00	p=0.003*	**47.5**	**75%**	**100%**
					49.5	75%	91%
					55.0	75%	82%

* indicates a significant result (p≤0.05), ** indicates a significant result (p≤0.001**)

Following ROC analyses, multiple linear regression analyses were carried out, applying a stepwise backward method to establish which predictor variables explained the variance in each of the cognitive scores. The stepwise backward method involves starting with all the participant variables, which in this case was gender, age and diagnosis, and removing non-significant variables from the model.

Table 5.4 shows the results of the backward multiple linear regression seeking to explain the variation in HVLT total score. Sample size was deemed to be sufficient for this analysis as the HVLT had been verified in previous investigations of ID populations (e.g. Shaw et al, 2017). Multicollinearity, homoscedasticity, normality and linearity were also checked prior to completing the MLR and no assumptions were violated. Entering all the variables incurred a determination coefficient of 0.599 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression analyses which represented the best explanatory independent variables were significant ($F_{(1,21)} = 34.99$, $p \leq 0.00$) and explained 63% of the variance in HVLT scores (R Square). The final model only included diagnosis as a variable, as age and gender did not significantly contribute to the previous two models.

Table 5.4 –Multiple Linear Regression for HVLT scores

	Beta	95% CI	P value
Constant		-19.21 – 0.39	0.059
Diagnosis	0.79	10.80 – 22.52	≤0.001*

* indicates a significant result (p≤0.05)

Table 5.5 shows the results of the backward multiple linear regression seeking to explain the variation in VF total score. All assumptions were checked and none were violated. Entering all the variables incurred a determination coefficient of 0.447 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression analyses, which represented the best explanatory independent variables were significant ($F_{(1,20)} = 16.28$, $p=0.001$) and explained 45% of the variance in VF scores (R Square). The final model again only included diagnosis as a variable, as age and gender did not significantly contribute to the previous two models.

Table 5.5 –Multiple Linear Regression for VF scores

	Beta	95% CI	P value
Constant		-12.45 – 7.76	0.634
Diagnosis	0.67	5.64 – 17.72	0.001*

* indicates a significant result ($p \leq 0.05$)

Table 5.6 shows the results of the backward multiple linear regression seeking to explain the variation in MMSE total scores. All assumptions were checked and none were violated. Entering all the variables incurred a determination coefficient of 0.530 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression analyses, which represented the best explanatory independent variables were significant ($F_{(1,20)} = 28.81$, $p \leq 0.001$) and explained 59% of the variance in MMSE scores (R Square). The final model only included diagnosis as a variable, as age and gender again did not significantly contribute to the previous two models.

Table 5.6 –Multiple Linear Regression for MMSE scores

	Beta	95% CI	P value
Constant		1.63 – 14.96	0.017*
Diagnosis	0.77	6.27 – 14.23	≤0.001*

* indicates a significant result ($p \leq 0.05$)

Table 5.7 shows the results of the backward multiple linear regression seeking to explain the variation in Series score. No assumptions were violated. Entering all the variables incurred a determination coefficient of 0.625 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression analyses, which represented the best explanatory independent variables were significant ($F_{(2,15)} = 15.60$, $p \leq 0.001$) and explained 68% of the variance in Series scores (R Square). The variables included in the final model were diagnosis and gender, both of which contributed significantly but independently to the model. Age did not significantly contribute to the initial model.

Table 5.7 –Multiple Linear Regression for Series scores

	Beta	95% CI	P value
Constant		-6.65 – 23.38	0.253
Gender	-0.56	-23.11 – -4.96	0.005*
Diagnosis	0.94	14.57 – 32.71	≤0.001*

* indicates a significant result (p≤0.05)

Table 5.8 shows the results of the backward multiple linear regression seeking to explain the variation in Odd One Out score. No assumptions were violated. Entering all the variables incurred a determination coefficient of 0.432 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression analyses, which represented the best explanatory independent variables were significant ($F_{(2,15)} = 8.135$, p=0.004) and explained 52% of the variance in Odd One Out scores (R Square). The variables included in the final model were diagnosis and gender, both of which contributed significantly but independently to the model. Age did not significantly contribute to the initial model.

Table 5.8 –Multiple Linear Regression for Odd One Out scores

	Beta	95% CI	P value
Constant		7.48 – 37.14	0.006
Gender	-0.56	-20.45 – -2.52	0.015*
Diagnosis	0.81	7.59 – 25.52	≤0.001*

* indicates a significant result (p≤0.05)

Table 5.9 shows the results of the backward multiple linear regression seeking to explain the variation in Jigsaw score. No assumptions were violated. Entering all the variables incurred a determination coefficient of 0.323 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression analyses, which represented the best explanatory independent variables were significant ($F_{(1,12)} = 6.091$, p=0.030) and explained 34% of the variance in Jigsaw scores (R Square). Only diagnosis was included in the final model, as gender and age did not significantly contributed to the previous two models.

Table 5.9 –Multiple Linear Regression for Jigsaw scores

	Beta	95% CI	P value
Constant		-10.05 – 6.24	0.620
Diagnosis	0.58	0.65 – 10.40	0.030*

* indicates a significant result (p≤0.05)

Table 5.10 shows the results of the backward multiple linear regression seeking to explain the variation in Total CCIID score. No assumptions were violated. Entering all the variables incurred a determination coefficient of 0.590 (Adjusted R square). The statistical parameters associated with the final step of the multiple linear regression analyses, which represented the best explanatory independent variables were significant ($F_{(2,15)} = 14.154$, $p \leq 0.001$) and explained 65% of the variance in Jigsaw scores (R Square). Both diagnosis and gender significantly and independently contributed to the final model, whereas age was excluded.

Table 5.10 –Multiple Linear Regression for Total CCIID scores

	Beta	95% CI	P value
Constant		0.51 – 64.03	0.047*
Gender	-0.59	-49.42 – -11.02	0.004*
Diagnosis	0.92	28.12 – 66.52	≤0.001*

* indicates a significant result ($p \leq 0.05$)

5.4 Discussion

There is a pressing need to deliver an efficient diagnosis to those experiencing cognitive decline. Therefore, the assessments utilised to inform diagnosis need to be accurate and efficient. In line with the first overarching objective of this thesis, the primary objective of this study was to establish which cognitive assessments most accurately detected whether individuals without ID had dementia or not, with the aim to inform future diagnostic decisions. The findings from this study showed that participants with dementia scored significantly lower, on all included cognitive assessments, than their age-matched counterparts. Receiver Operating Characteristic analysis revealed that all included assessments significantly classified those who had dementia, with a high accuracy of above 0.847 for all assessments. Each assessment demonstrated moderate to good sensitivity and specificity, indicating potential for all assessments to be applied in clinical settings.

The most successful cut-off for the HVLT that yielded a sensitivity of 90% and a corresponding specificity of 93% was 14.5. A review of the use of the HVLT for the purpose of detecting MCI or mild dementia found that cut-off scores across the literature vary from 12.5 to 25.5 (Hogervorst, Xin, Rahardjo & Shifu, 2014). Therefore, the cut-off of 14.5 identified in this study falls within this range and thus supports previous findings. However, this cut-off is substantially lower than many studies have shown. This could be because this sample contains individuals who have already been diagnosed with dementia and potentially for a number of years. Thus, the categories being compared are more distinct than individuals with MCI and less severe cases of dementia that participated in reviewed studies and would be more likely found in practice.

Ability to complete the VF task, much like the HVLT, is heavily reliant on memory based functions (Rosen, 1980); such as semantic memory and executive functioning (Mayr, 2002). A number of studies have demonstrated that individuals diagnosed with dementia produce significantly fewer words on the VF test than cognitively normal individuals do (e.g. Henry, Crawford & Phillips, 2004; McDowd et al, 2011; Price et al, 2012). The Verbal Fluency demonstrated lower sensitivity than other tests applied within this study. The test was most accurate with a cut-off score of 11.5 (78% sensitivity and 100% specificity). Initial analysis of the VF scores in this sample showed significant correlations with age but later analysis using MLRs showed that age did not significantly explain variance in verbal fluency scores. This suggests a need to further investigate the impact of age on VF abilities. This is consistent with previous literature that has also shown age to affect VF scores, for individuals that are classed as being cognitively normal, having MCI and having dementia, as all groups decline in overall words recalled on the VF as they age. However, people with dementia have been shown to decline more substantially (Pakhomov, Eberly & Knopman, 2016).

Similarly, demographic factors, such as an individual’s age (e.g. Hedden et al, 2014), gender (e.g. Mielke, Vemuri & Rocca, 2014) and level of education (e.g. Chapko, McCormack, Black, Staff & Murray, 2017) have consistently been shown to influence an individuals’ cognitive abilities, regardless of their dementia status. In this study, a gender difference was found between the two groups. The HVLT specifically was correlated with gender, but gender did not significantly explain the variance in scores. This suggests that age specific cut-offs for the VF and gender specific cut-offs for the total CCIID and relevant subscales could be investigated further. However, diagnosis was shown to be independent from gender or age, and therefore the recommended cut-off scores could offer benefit to those working in clinical practice regardless.

Despite widespread use (Tsoi, Chan, Hirai, Wong & Kwok, 2015), the MMSE has been argued to be neither the most accurate nor the most efficient tool to detect cognitive decline. It has, however, provided a benchmark against which all newer tools can be measured (Mitchell, 2017). When originally validated, a cut-off of 24 was recommended on the MMSE by Folstein and colleagues for any individual who has received eight years of education or more (Folstein, Folstein & McHugh, 1975). A cut-off of 24 has continued to be applied across the literature as it has consistently been demonstrated to be most sensitive and specific to the diagnoses of dementia (e.g. Tsoi, Chan, Hirai, Wong & Kwok, 2015). This sample, however, reported having been educated to at least degree level. The analysis therefore showed that the highest accuracy with optimal sensitivity of 89% and specificity of 93% could be found using a higher cut-off of 26.5. This offers slightly contradictory findings to those in the literature, but is consistent with previous research that has shown MMSE to be sensitive to education (e.g. Hogervorst et al, 2002). It is important to also note that more recently the MMSE has become protected by copyright (Powsner & Powsner, 2005) and this restricts the clinical use. Alternative cognitive assessments that are more readily available can be better advised, such as the aforementioned Addenbrookes Cognitive Examination or the Mini-Cog test. Despite positive results for the MMSE within this sample, other assessments that are less sensitive to education effects and more freely available may be better advocated for informing dementia diagnostics.

This study presents the first application of the CCIID with individuals from the general population. Within this sample, both the whole test and the individual subtests demonstrated high accuracy. Scores highlight the potential for the CCIID to be applied to dementia diagnostics in the general population, offering a complimentary cognitive assessment to the traditional assessments of memory and learning. Findings from chapter 4 indicated that both the CCIID and the HVLT distinguish effectively between individuals with and without dementia in an ID population and could therefore offer great potential for clinical utility. The Series subtest specifically was most effective as a stand-alone assessment. Clinical use of the CCIID is supported for individual with and without a pre-existing ID, which could increase the opportunity for communication and understanding of dementia. Kohler and colleagues (2014) sought to investigate this using referral rates and found benefits in the provision of dementia specific medication and utilisation of medical based treatments following the implementation of an inclusive and interdisciplinary approach to diagnostics and subsequent care; suggesting that inclusive approaches to diagnostics could also increase treatment utility.

To continue to improve the cognitive assessments that inform dementia diagnoses and increase inclusivity in the diagnostic process, specific cut-offs for ID, as well as age specific cut-offs in particular for individuals without ID on the VF and HVLT can be researched further and used as guidance for clinical judgement. This, in turn, can lead to advancements in our understanding of dementia as a whole, not just in individual groups of people.

This study was conducted with individuals from community settings and therefore may not be representative of a clinical sample. As such this study is limited by the self-report of dementia status, which could be criticised for lacking a clinical gold standard. However, to ensure ethical standards and community based participation clinical confirmation was outside the remit of this study. Future research should seek to replicate these findings in a clinical sample. This could further inform diagnoses and progress our understanding of the assessments recommended in this study.

Overall, all cognitive assessments applied in this study have demonstrated good potential for clinical use. Selecting an appropriate test, however, depends on numerous factors that are often related to the specific context. This could include the setting in which cognitive assessments are being administered (e.g. primary or secondary care settings), the time available, the requirement to test general or specific cognitive functions and the availability of informants and trained staff (Larner, 2017). More research needs to be conducted to further investigate the need for age, gender and ethnicity specific cut-off scores, this is unfortunately, outside of the remit of this thesis.

The findings from this chapter demonstrate further potential for the cognitive assessments discussed and applied throughout chapters 2, 3 and 4 to inform an inclusive approach to dementia diagnostics. The next chapter investigates the second overarching research objective described in chapter 1. This chapter builds on research detailed thus far in the thesis by applying the same cognitive assessments, utilised in chapter 4 and this chapter, to assess the effects of physical activity for people with dementia. Applying the same cognitive assessments to the evaluation of physical activity effects as those used throughout the process of diagnosis provides consistent accuracy of cognitive assessment and could further our understanding of the progression of dementia, as well as the specific cognitive effects of physical activity for people with dementia.

Chapter 6

Acute cognitive effects of physical activity for people with dementia

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Chapter 6 – Acute cognitive effects of physical activity for people with dementia

6.1 Introduction

The onset and progression of dementia is characterised by cognitive decline. Treatments should aim to alleviate the effects of cognitive decline. Traditional treatment is sought through pharmacology. When successful, available treatments are only able to slow cognitive decline for a short period of time; no research has supported the use of current pharmacological therapies longer term (e.g. Sink, Holden & Yaffe, 2005). This is because there are currently no pharmacological treatments available that are disease modifying. Treatment strategies that have sought to act directly upon the disease, such as acetylcholinesterase inhibitor drugs, have so far been unsuccessful due to their poor solubility, lower bioavailability, and ineffective ability to cross the blood-brain barrier (Fonseca-Santos, Gremiao & Chorilli, 2015). Pharmacological treatments are therefore limited to therapies that alleviate the symptoms of dementia.

Antipsychotic agents are widely used to reduce the neuropsychiatric symptoms, and people with dementia represent a large portion of the antipsychotics prescribed in UK primary care (Marston, Nazareth, Petersen, Walters & Osborn, 2014). However, the evidence regarding antipsychotics for symptom management is controversial due to limited efficacy and the risk for serious adverse events (Azermai, 2015). Several studies have also reported an abundance of undesirable side-effects (e.g. Galimberti & Scarpini, 2010). Harding and Peel (2013), found sedation and worsening of cognitive function following the use of antipsychotics. Moreover, caregivers described their family members with dementia as ‘such a zombie’ and ‘wandering up and down in a dazed state’ (Harding and Peel, 2013), reiterating the unwanted side effects observed after antipsychotic use. It is therefore imperative to utilise treatments either in combination with - or independently of - pharmacology that could further prolong the maintenance of cognitive functioning for people with dementia.

Physical activity interventions have been shown to provide numerous benefits for people with dementia. Interventions often involve taking part in physical activity three to five times per week, for at least a two-week period, with some interventions continuing for up to 6 months

(Forbes, Forbes, Blake, Thiessen & Forbes, 2015). The most widely recognised benefits to physical health are those observed by increasing cardiovascular and cardiorespiratory fitness (e.g. Hernandez et al, 2015). Evidence has also been found for increases in balance, mobility, functional ability, performance of activities of daily living, flexibility, agility, muscle strength and reduced concern for falls (Bauman, Merom, Bull, Buchner & Fiatarone Singh, 2016; Taylor et al, 2017; Brett, Traynor & Stapley, 2016; Hernandez et al, 2015; Laver, Dyer, Whitehead, Clemson & Crotty, 2016).

Beyond the well-known physical effects of engaging with physical activity long term, research has shifted emphasis to the cognitive benefits resulting from engagement. A meta-analysis found that physical activity programmes lasting between 6 and 52 weeks had an overall positive effect on global cognitive function for people with dementia (Groot et al, 2016). This effect was shown regardless of the type of dementia diagnoses and whether the physical activity was high or low frequency. The benefits were most pertinent for combined physical activity programmes and aerobic based programmes. Programmes combining physical activity and cognitive stimulation have been found to benefit global cognitive functioning of older adults with dementia (Karssemeijer et al, 2017) and may be more beneficial than physical activity by itself (Hogervorst, Oliveira & Brayne, 2018). Specific benefits of physical activity have also been shown for attention, processing speed, executive functions, memory and conflict resoluation (e.g. Liu-Ambrose et al, 2010; Smith et al, 2010; Van Uffelen, Paw, Hopman-Rock & van Mechelen, 2008; Hsu et al, 2017). It is for these reasons that physical activity is frequently recommended as a treatment for dementia (e.g. Ahlskog, Geda, Graff-Radford & Petersen, 2011).

Reviews have most prominently shown positive effects for only aerobic physical activity programmes (e.g. Groot et al, 2016). However, several more recent studies have highlighted cognitive benefits of strength or resistance activities, a common form of non-aerobic physical activity. For example, Mavros and colleagues (2017) found high intensity progressive resistance training resulted in significant improvements in cognition, with strength gains mediating the cognitive benefits of resistance training (Mavros et al, 2017). Mavros and colleagues investigated resistence training over a period of six months, with particiapnts engaging with the strength based activity for 2 to 3 days per week during that time. Although this is substantial evidence in favour of utilising resistance activity, the effects were only assessed longer term. Strength promoting physical activity has also been advocated within physical activity guidelines and has been supported by Health Survey data for England and Scotland over and above generic physical activity recommendations (Stamatakis et al, 2017). Furthermore, resistance based physical activity has been shown to be feasible, require minimal investment in staff and equipment; and is tolerated well and enjoyed by older adults (Brill, Drimmer, Morgan & Grodon, 1995; Shakeel, Newhouse, Malik & Heckman, 2015; Gluchowski, Warbrick, Oldham & Harris, 2018). This indicates that resistance based physical activity may be feasible as a potential therapy for people with dementia.

Resistance based physical activity is advantageous as it can be performed using resistance bands from a seated position, increasing the feasibility and accessibility for individuals of all physical abilities. This is a particular benefit for individuals with dementia, as dementia can frequently co-occur with frailty (e.g. Kulmala, Nykänen, Mänty & Hartikainen, 2014). Frailty has been discussed as dynamic and a process rather than a fixed diagnosis. Increasing research has suggested frailty to be malleable and manageable with potential to prevent, halt or even reverse its progress (Holland, Garner & Gwyther, 2018). The argument for tailoring physical activity to individuals of all physical abilities, including those experiencing frailty, could potentially incur even further benefits.

Evidence substantiating the benefits of physical activity over a period of at least six weeks for people with dementia is pervasive. Research into the acute or immediate effects of physical activity for people with dementia, however, is sparse. Current literature does suggest that a single bout of physical activity can alter an individual’s cognitive performance (Chang, Labban, Gapin & Etnier, 2012; Scherder et al, 2014). Chang and colleagues (2012) offered both a narrative literature review and a meta-analysis, which included 79 studies. Although authors recognised that results across the literature were mixed they found small positive effects of physical activity, immediately after engagement, so specifically in that acute timeframe. The reviewed studies however, were conducted across the lifespan and therefore did not assess the specific acute effects for individuals with dementia.

The benefits observed from a single session of aerobic activity, specifically, has been observed across various cognitive functions, including attention, information processing, memory and executive functions (Audiffren, Tomporowski & Zagrodnik, 2008; Coles & Tomporowski, 2008; Hillman et al, 2009). It has been further suggested that the influence of physical activity on higher order cognition is affected by ceiling effects. Therefore, for individuals that already have high cognitive functioning acute effects may be less pronounced, this may account for only small effects identified across the lifespan with healthy individuals identified by Chang and colleagues (2012). Pariticpants with dementia however, may have low performance on executive function tasks as a result of the dementia and thus could expect the greatest benefits from a single session of physical acitivity (Ludyga, Gerber, Brand, Holsboer-Trachsler & Puhse, 2016; Drollette et al, 2014; Sibley & Beilock, 2007). For that reason, it can be expected that people with dementia are likely to experience acute cognitive effects from physical activity, especially on executive tasks.

Although the positive effects of physical activity are well documented, evidence for the underlying biological mechanisms remains limited. Acute physical activity has been suggested to induce numerous molecular and cellular processes that support brain plasticity and general brain health (Knaepen, Goekint, Heyman & Meeusen, 2010). For instance, physical activity has been shown to enhance neurogenesis (e.g. van Praag, 2008; Lazarov, Mattson, Peterson, Pimplikar & van Praag, 2010) specifically in the hippocampus (e.g. Kerr & Swain, 2011), increase neurotrophin concentrations (Adlard, Perreau & Catman, 2005; Knaepen, Goekint, Heyman & Meeusen, 2010, Szuhany, Bugatti & Otto, 2015), increase blood flow throughout the vascular system (also termed vascularisation) (e.g Swain et al, 2003; Stimpson, Davison & Javadi, 2018) and finally, reduce the effects of neuroinflammation (e.g. Belarbi & Rosi, 2013).

Research has further indicated that physical activity can lead to longer term benefits on brain health. For example, meta-analysis has shown links between physical activity levels and white matter structure (Sexton et al, 2016), the prevention of prefrontal volume reduction (Tamura et al, 2015), as well as age-related hippocampal deterioration (Firth et al, 2018). Despite consensus from both animal and human studies that physical activity benefits brain function, further research is needed to establish the exact neurobiological mechanisms that mediate the benefits of physical activity on cognition, behaviour and neurodegenerative diseases (Voss, Vivar, Kramer & van Praag, 2013). Conclusions that can be drawn from research on the underlying biological mechanisms are limited, as the studies above are with healthy adults, rather than older adults or more interestingly in this context individuals with dementia. Although, our understanding of the underlying biological mechanisms is lacking, it is apparent through research conducted by cognitive psychologists with people with dementia that physical activity can offer cognitive benefits following 2 or more weeks of engagement (e.g. Groot et al, 2016). The mechanisms that underpin that can be pointed to those that are apparent for healthy adults but biological research is in it's initial understanding of this area. Having said that, based on this varying assemblage of mechanisms that indicate improvement through engagement in physical activity, researchers have suggested that physical activity is able to positively affect people with dementia through overall brain health rather than impacting dementia specific pathological mechanisms (Groot et al, 2016).

If there is potential for physical activity to improve brain health of people with dementia this could mitigate the effects of characteristic cognitive decline. Cognition should therefore be measured following a short bout of physical activity to better understand the potential for physical activity to act as a therapy for dementia. As discussed in chapter 5, the Mini-Mental State Examination (MMSE), Hopkins Verbal Learning Test (HVLT), Verbal Fluency (VF), the total Computerised cognitive test for individuals with intellectual disabilities (CCIID) and the subtests of the CCIID are sensitive to varying levels of cognition, showing accuracy in detecting those who had dementia and those who did not.

Previous studies have applied various cognitive assessments to measure the effects of physical activity programmes. The MMSE, for instance, has been used to compare cognitive scores of people with dementia before and after both aerobic (e.g. Arcoverde et al, 2014) and combined physical activities (e.g. Bossers et al, 2015). Toots and colleagues applied both the MMSE and the VF to their research into high intensity strength and balance training for people with dementia, but did not find significant differences between groups using these tests (Toots et al, 2017). Interestingly, this study included participants that were both male (n=45) and female (n=141) who have a variety of dementia subtypes. Although authors reported no differences between subgroups contained within the study, they did report inconsistencies in adherence to the activity. The strength training was intended to be high intensity, but authors noted that some participants may not have reached the minimal effective dose. However, cognitive assessments were applied effectively and were feasible for use with individuals who have dementia within the physical activity context.

Earlier research by Steinberg, Leoutsakos, Podewils and Lyketsos (2009) also used the HVLT to assess the effects of combined physical activity programmes within a much smaller group of 27 community dwelling individuals with Alzheimer's disease. Due to the small sample size in this study, limited conclusions can be drawn on the physical activity effects on cognition but the HVLT was found to be an acceptable measure within this context.

The CCIID, on the other hand, is yet to be utilised within this context. However, considering the initial assessment of the CCIID, alongside other selected cognitive assessments and the potential for accurately detecting diagnoses of demenia for previously healthy individuals, as well as those with a pre-existing intellectual disability (Elliott-King et al, 2016; Chapter 5), there is potential that the CCIID could also be sensitive to acute cognitive changes resulting from physical activity engagement. In line with the second overarching objective of this thesis, the aims of this study are twofold. Firstly, to establish the acute cognitive effects of a short bout of physical activity for people with dementia and aged-matched controls; and secondly, establish whether physical activity shows cognitive benefits over and above a psycho-social control activity on assessments shown to assess executive functioning, such as the VF, as well as the CCIID as various aspects of fluid intelligence that are assessed have been found to be realted to executive functioning (van Aken, Kessels, Wingbermuhle, van der Veld & Egger, 2016); alongside other assessments previously shown to be sensitive to effects of physical activity in dementia. It can be hypothesised that cognitive assessments would detect differences in cognitive scores between those with and without dementia before and after engagement with interventions. Furthermore, physical activity would show increases in cognitive scores for both groups; whereas before and after engagement with psychosocial control activity will show no difference in cognitive scores.

6.2 Methods

6.2.1 Participants and Procedure

Participants were recruited from Alzheimer’s or Dementia activity groups local to Loughborough University. In total, 25 individuals took part in the study, 10 who self-reported that they had been diagnosed with dementia and 15 were aged-matched controls. Participants were all educated at secondary school level or higher, identified as British or white British and were of a medium to high socioeconomic status. Participants were invited to three sessions at Loughborough University, with 6 weeks between each session. Participants came to each session as a pair, i.e. carers accompanied people with dementia and both took part. Sessions started at 9.30am on a weekday morning. Upon arriving all participants completed a cognitive assessment. They were then offered a drink and had a chat with the researchers. The participants would then complete 30 minutes of a social activity or 30 minutes of resistance band physical activity. The activities were order-balanced, so each couple would complete either a social activity and then the physical activity, or vice versa. Immediately following both of the activities all participants would complete a second cognitive assessment. The third and final session contained one cognitive assessment as a 6-week follow-up to the previous activity, but no activities were undertaken during this session.

The cognitive assessments applied during the study were completed in the same order each time but with different versions of the instruments utilised where possible. The included instruments were those described in chapter 2 and utilised in chapters 4 and 5; the MMSE, HVLT, VF and CCIID. Table 6.1 shows a visual representation of when each cognitive assessment was administered in relation to the interventions.

Table 6.1 Study design and timing of cognitive assessments

Visit 1		Visit 2		Visit 3
Ppts assigned to an activity				
Baseline cognitive assessment		Cognitive assessment (which reflects the pre-activity score as well as the 6-week follow-up for activity 1)		Final cognitive assessment to reflect 6-week follow-up for activity 2
	6-week interval		6-week interval	
Activity 1 (either Resistance Bands or Binge depending upon allocation)		Activity 2 (The opposite activity to activity 1 either Resistance Band or Bingo)		
Acute cognitive effects assessed immediately following activity engagement		Acute cognitive effects assessed immediately following activity engagement		

n.b. All cognitive assessments were completed in the same order:
1) MMSE, 2) HVLT, 3) VF and 4) CCIID Series, CCIID Odd One Out, CCIID Jigsaw.

6.2.2 Intervention

The activities took 30 minutes each. Two researchers and two participants were present for all activity sessions. In the context of each intervention participants and researchers conversed regularly, this interaction was controlled for throughout each intervention by the researchers ensuring participants were conversed with regularly. This meant that no one intervention offered any social benefits over and above the other. Researchers ensured that social interaction was encouraged, this ensured all participants were equally engaged with conversation throughout both activities. The psychosocial control activity involved a group of four people playing a game of bingo while seated at a table. One researcher called the numbers and the other three individuals participated in the game of bingo. Each player was given two bingo cards and the games lasted around 30 minutes each time.

The resistance band physical activity condition contained four activities. Each activity required participants to be seated, with each end of the resistance band to be held firmly in each hand, with the middle of the band tucked underneath the middle of both of the participant’s feet. Researchers checked the band had been placed correctly to guarantee safety when beginning the activity, if the band was not correctly centred under the feet. participants were asked to adjust this appropriately before receiving any further instruction. The first task asked participants to rotate their core while holding the band tightly to their side. This activates their core or trunk muscles (Willardson, 2018), which includes both the abdominal and paraspinal muscles, which have been shown to play a crucial role in maintaining balance and functional mobility in older adults (e.g. Kahle & Tevald, 2014).

Additionally, findings from Rogers and Jarrott (2008) indicated that upper body muscle strength is both associated with dementia and a key contributor to functional disability. The second and third activities therefore activated the muscles in the arms and shoulders as a way of building strength in the upper body. Arm muscle strength is also crucial for many activities of daily life, such as eating and drinking. Specifically, the second activity asked the participants to put their arms straight down by their side, then slowly extending them out to the side. The third asked the participants to maintain the band in the same position under their feet, but switch the hands in which they were holding the bands; this created a cross in the band in front of the participants’ knees. Participants were then asked to pull the band up towards their chest, while sticking their elbows out in a movement akin to rowing a boat. Leg strength could also be crucial for activities of daily living, playing a role in important activities such as walking, getting up and down from a chair, climbing stairs. Increases in leg strength have been significantly associated with increases in walking endurance in older adults (Ades, Ballor, Ashikaga, Utton & Nair, 1996).

Therefore, the final activity participants were asked to perform with the resistance bands activated the leg muscles. Specifically, the participants were required to ‘uncross the band’ or switch the hands in which they were holding the band and remove one foot from the band, so that the band looped round only one of the participants' feet this time. The participants were then asked to pull their knee up toward their chest while keeping the band held tightly and their arms still, this was followed by stretching their legs out towards the floor and away from their chairs. This was repeated for both legs. Each part of the physical activity was completed a minimum of 4 or 5 times, as researchers and participants were talking continuously however, number of repetitions were not strictly counted, just as long as participants felt the physical response from engaging with the resistance band this was deemed sufficient repetitions. All four components of the activity were then repeated at least one more time. This in total took around 30 minutes to complete.

6.2.3 Statistical Analysis

Analyses were conducted in SPSS version 24.0. To test the hypothesis that cognitive assessments would detect differences in cognitive scores between those with and without dementia before and after engagement with interventions, Descriptive Statistics, Mann Whitney U and Chi-square analysis were first conducted. Secondly, means and standard deviations of each of the cognitive scores were then examined across all three time-points, before, after and at 6-week follow-up. Finally, Boxplots were then created to further examine mean differences following each intervention. To investigate the second hypothesis that there would be a difference between groups across timepoints and between interventions too, a mixed effect measures 3x2x2 ANOVA was applied. This examined the interaction between two within subject factors “time” and “intervention” and the between subjects “group” factor.

6.3 Results

Table 6.2 shows baseline demographic information for all participants. The groups did not differ significantly in age or gender distribution. All cognitive assessments and instrumental activities of daily living showed significant differences between participants with dementia and controls. This supports the initial hypothesis that cognitive assessments would detect differences between those with and wihout dementia before interventions.

Table 6.2 – Baseline participant information

Characteristic	People with Dementia	Controls	Total Sample	Mann Whitney U or X_2 statistic, P value
N	10	15	25	-
Age mean ± SD	78.78 (8.91)	74.47 (9.79)	76.08 (9.514)	U= 50.50, p=0.310
Gender male n (%): female n(%)	7 (70%): 3 (30%)	3 (20%): 12 (80%)	10 (40%): 15 (60%)	$X_{2(1)}$= 6.25, p=0.012*
MMSE mean ± SD	18.44 (6.84)	28.71 (1.44)	24.70 (6.67)	U=5.00, p≤0.001**
VF mean ± SD	9.22 (8.27)	20.93 (5.37)	16.35 (8.72)	U=16.00, p=0.003**
HVLT mean ± SD	7.6 (6.62)	24.14 (6.59)	17.25 (10.54)	U=7.00, p≤0.001**
Series mean ± SD	14.25 (10.73)	30.64 (8.81)	23.74 (12.53)	U=10.00, p=0.005**
Odd One Out mean ± SD	24.25 (9.69)	34.91 (8.26)	30.42 (10.18)	U=13.50, p=0.012**
Jigsaw mean ± SD	3.67 (2.34)	9.11 (4.78)	6.93 (4.76)	U=6.50, p=0.015*
Total CCIID mean ± SD	41.25 (22.15)	73.00 (19.38)	59.63 (25.67)	U=8.50, p=0.003**

* indicates a significant result (p≤0.05), ** indicates a significant result (p≤0.01**)

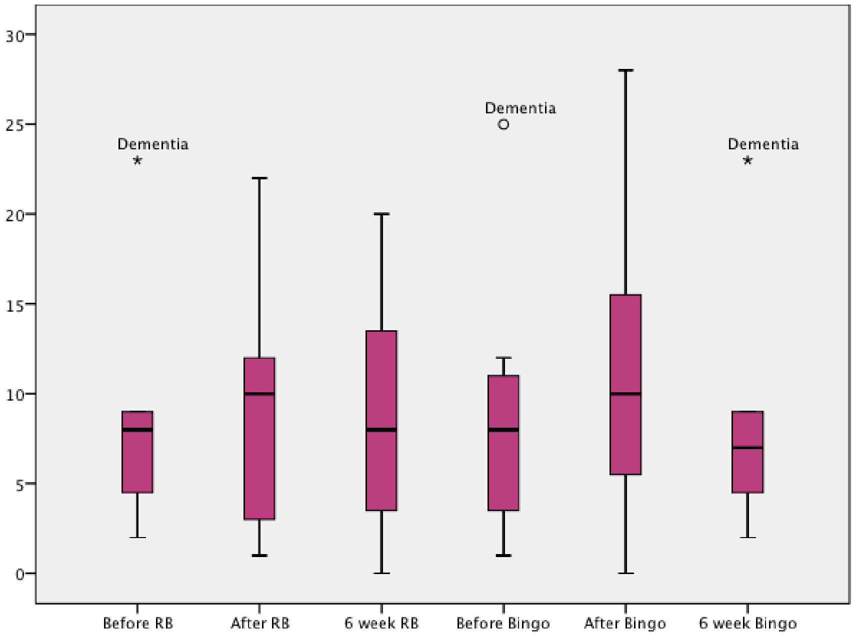
Cognitive scores were then examined across all three time-points of each intervention. Table 6.3 shows these means and standard deviations. For participants with dementia immediately after the resistance band physical activity, improvements can be observed on the MMSE, VF, HVLT, Series, Jigsaw and Total CCIID. Only the MMSE, Series and Total CCIID still showed improvements at 6-week follow-up. Immediately following the psychosocial intervention, participants with dementia only showed improvements on the HVLT, which were not sustained after 6-weeks. For age-matched controls acute effects of resistance band activity were observed on the VF, Series, Odd One Out and Total CCIID. None of these scores continued to improve at 6-week follow-up. Improvements in the Series and Total CCIID cognitive scores were observed for people without dementia immediately following the psychosocial intervention.

Table 6.3 - Means and Standard Deviations of Cognitive Scores across time-points

Assessment	Time-point	Physical Activity Intervention mean (SD)		Psychosocial Intervention mean (SD)	
		Dementia (n=10)	Controls (n=15)	Dementia (n=10)	Controls (n=15)
MMSE	Before	18.14 (7.73)	28.82 (1.54)	19.29 (7.16)	27.91 (2.17)
	Immediately after	18.86 (6.01)	28.45 (1.51)	19.71 (7.91)	27.72 (2.24)
	6 weeks after	19.57 (6.70)	28.82 (1.17)	19.71 (8.04)	28.18 (2.32)
VF	Before	9.71 (9.38)	20.09 (5.34)	9.86 (8.91)	22.18 (7.81)
	Immediately after	10.00 (7.42)	22.27 (2.83)	7.71 (4.54)	21.82 (4.14)
	6 weeks after	8.57 (6.55)	22.55 (8.12)	10.71 (9.25)	21.09 (6.77)
HVLT	Before	8.57 (7.04)	24.36 (5.35)	9.00 (8.08)	22.55 (5.43)
	Immediately after	9.00 (7.37)	22.91 (4.93)	11.43 (9.38)	22.09 (4.83)
	6 weeks after	8.86 (7.54)	23.82 (6.51)	8.43 (7.07)	24.09 (5.34)
Series	Before	16.67 (11.25)	30.38 (5.97)	18.17 (9.11)	27.50 (7.56)
	Immediately after	19.33 (9.93)	33.00 (4.31)	14.17 (9.70)	29.88 (9.20)
	6 weeks after	20.50 (11.31)	27.25 (7.56)	17.50 (12.63)	32.00 (6.30)
OOO	Before	26.83 (8.40)	32.63 (8.03)	30.00 (7.40)	33.25 (8.84)
	Immediately after	26.67 (9.20)	33.25 (4.13)	29.83 (7.08)	32.75 (8.22)
	6 weeks after	27.33 (7.94)	33.88 (5.33)	23.83 (11.51)	32.75 (8.26)
Jigsaw	Before	1.50 (0.71)	8.14 (3.39)	2.00 (1.41)	7.28 (3.90)
	Immediately after	2.00 (1.41)	7.14 (4.10)	1.50 (2.12)	7.29 (4.27)
	6 weeks after	2.00 (1.41)	8.86 (2.67)	2.00 (1.41)	7.43 (4.35)
Total CCIID	Before	47.17 (21.36)	70.88 (14.24)	53.17 (16.92)	67.63 (17.29)
	Immediately after	48.17 (20.88)	72.50 (10.14)	45.83 (15.94)	69.75 (16.93)
	6 weeks after	53.50 (18.51)	69.38 (14.36)	44.17 (26.77)	75.50 (11.80)

Boxplots were then utilised to visually examine any changes in means resulting from each intervention. Figure 6.1 shows the HVLT scores of people with dementia before, after and 6-weeks after each intervention. An increase on the HVLT immediately following the resistance band physical activity can be observed and a slight increase on the psychosocial intervention too. These improvements, however, were not maintained at 6-week follow-up.

Figure 6.1 HVLT Scores for participants with dementia



On the other hand, age-matched controls experienced a decline in HVLT scores immediately following the resistance bands and stayed the same following the psychosocial intervention, as shown in figure 6.2. Participants suggested through comments to the research that they were experiencing tiredness effects. This could have influenced participant’s cognitive scores for age-matched controls over and above intervention effects.

Figure 6.2 HVLT Scores for age-matched controls

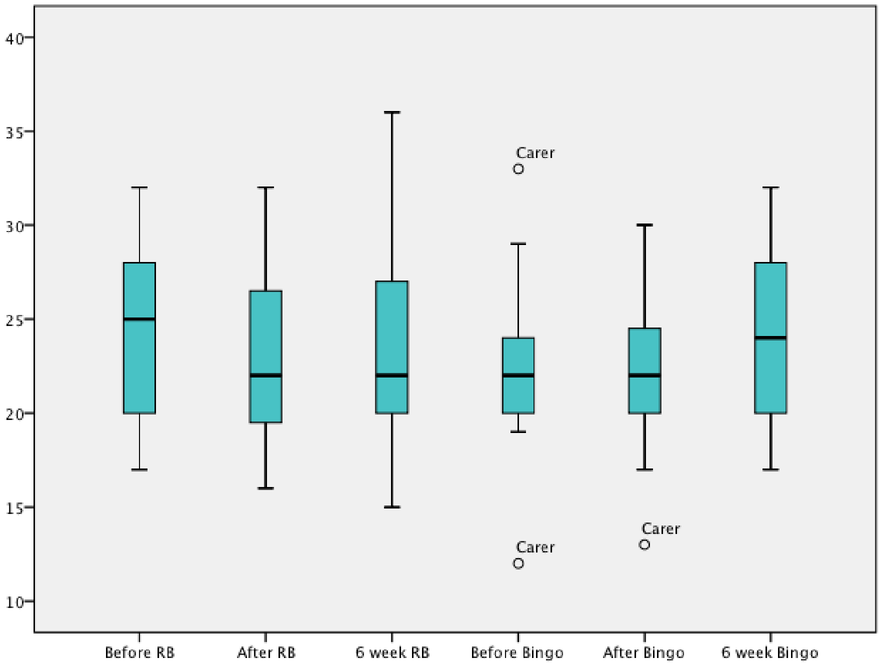


Figure 6.3 shows the CCIID Series subtest scores for participants with dementia before, after and 6-weeks after both physical and psychosocial interventions. Here the Series scores can be observed to increase following the physical intervention, whereas a decrease can be observed declining immediately following the psychosocial control activity.

Figure 6.3 Series scores for participants with dementia

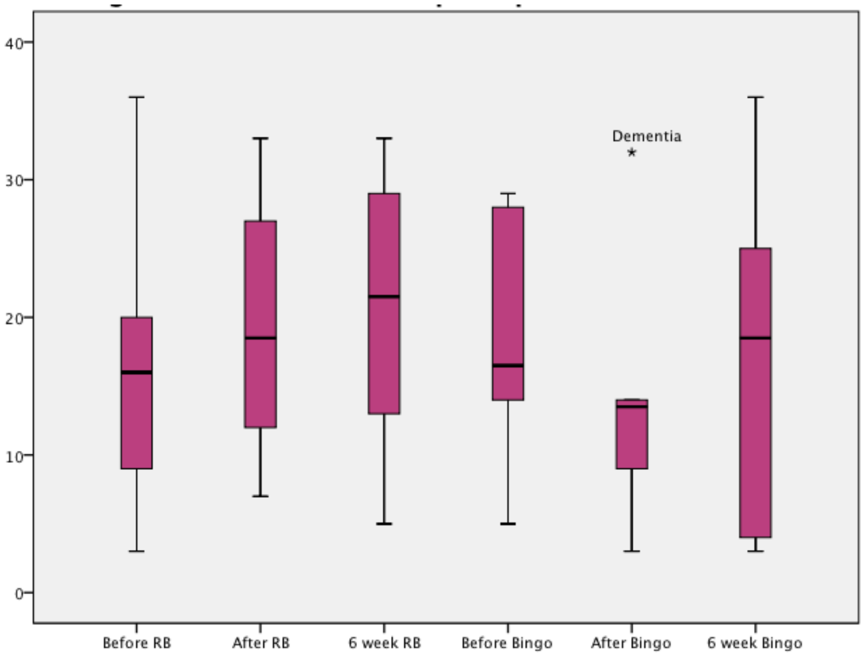
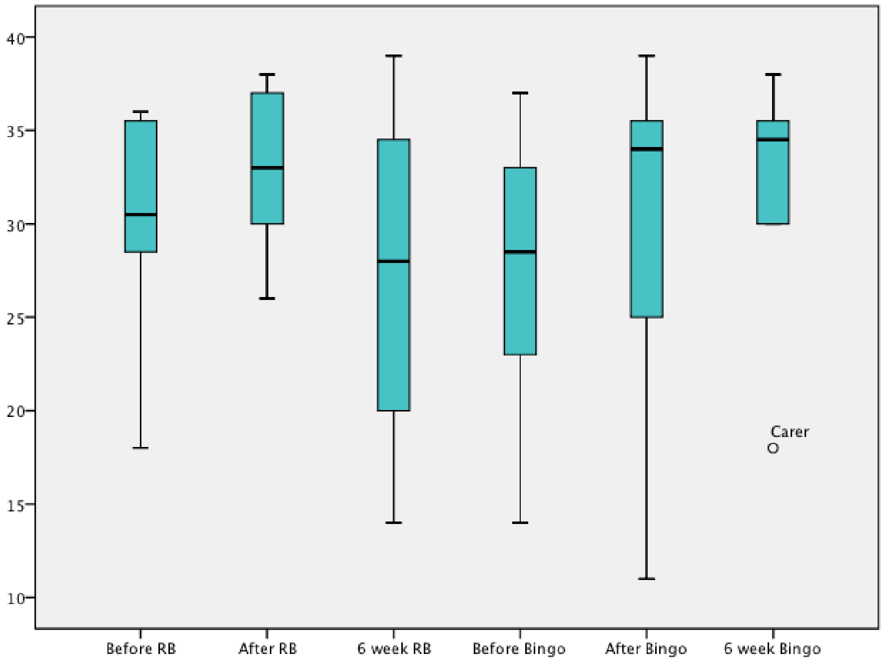


Figure 6.4 shows the Series scores for participants without dementia before, after and 6-weeks after both interventions. It can be observed that both interventions result in a slight increase in Series scores.

Figure 6.4 Series scores for age-matched controls



Following inspection of the means, a mixed-measures 3 x 2 x 2 ANOVA was used to investigate the second hypothesis. Specifically, whether there was a significant difference between “time”, “intervention” and “groups”. This is to begin to tease out where any differences in cognitive function can be observed. Whether differences are potentially across timepoints, so i.e. do the differences lie before and after the activity, or 6 weeks later. Whether there are differences between the interventions, physical activity or psychosocial activity. Or lastly, if the differences lie between the two groups, those with dementia and those without. As shown in table 6.4, the MMSE, VF, HVLT, Series and Total CCIID all showed significant group differences. This shows that people with dementia scored significantly worse than those without dementia across the whole study.

The HVLT showed a significant time by group effect; meaning that the HVLT detected differences between the groups before, immediately after and 6-weeks after the interventions. This does not support either hypothesis but does present interesting findings as it shows that the groups differed in their responses across timepoints. This would require much more research in order to unpack, but offers initial findings that suggest the HVLT has detected that those with dementia score differently than those without dementia at different timepoints.

Partial support for the second hypothesis was offered by trends towards significance in overall interaction effect of time, intervention and group for the Series and Total CCIID. If this study was to be replicated in a larger sample with sufficient power these trends suggest that the Series and total CCIID could detect significant interaction effects.

Table 6.4 - Mixed measures three-way ANOVA effects

Cognitive Assessments	**Group**	**Intervention**	**Time**	**Intervention * Group**	**Time * Group**	**Intervention * Time**	**Intervention * Time * Group**
MMSE	**$F_{(1,16)}$=18.05, p≤ 0.001*, n^2 = 0.53**	$F_{(1,16)}$=0.002, p=0.964, n^2 = 0.00	$F_{(2,32)}$=1.811, p=0.180, n^2 = 0.10	$F_{(1,16)}$= 2.485, p=0.135, n^2 = 0.13	$F_{(2,32)}$= 1.343, p=0.275, n^2 = 0.08	$F_{(2,32)}$= 0.100, p=0.905, n^2 = 0.01	$F_{(2,32)}$= 0.269, p=0.766, n^2 = 0.02
VF	**$F_{(1,16)}$=17.176, p≤ 0.001*, n^2 = 0.52**	$F_{(1,16)}$=0.004, p=0.950, n^2 = 0.00	$F_{(2,32)}$=0.061, p=0.941, n^2 = 0.00.	$F_{(1,16)}$= 0.004, p=0.950, n^2 = 0.00	$F_{(2,32)}$= 0.516, p=0.602, n^2 = 0.03	$F_{(2,32)}$= 1.205, p=0.313, n^2 = 0.07	$F_{(2,32)}$= 1.866, p=0.171, n^2 = 0.10
HVLT	**$F_{(1,16)}$=23.69, p≤ 0.001*, n^2 = 0.60**	$F_{(1,16)}$=0.001, p=0.980, n^2 = 0.00	$F_{(2,32)}$= 0.094, p=0.911, n^2 = 0.01	$F_{(1,16)}$= 3.59, p=0.076, n^2 =0.18	**$F_{(2,32)}$= 3.913, p=0.030*, n^2 = 0.20**	$F_{(2,32)}$= 0.605. p=0.552, n^2 =0.04	$F_{(2,32)}$= 1.121, p=0.338, n^2 =0.07
Series	**$F_{(1,12)}$=7.893, p=0.016*, n^2 = 0.40**	$F_{(1,12)}$=2.237, p=0.161, n^2 = 0.16	$F_{(2,24)}$=0.994, p=0.385, n^2 = 0.08	$F_{(1,12)}$= 1.047, p=0.326, n^2 = 0.08	$F_{(2,24)}$= 3.121, p=0.062, n^2 = 0.21	$F_{(2,24)}$= 2.170, p=0.136, n^2 = 0.15	*$F_{(2,24)}$= 3.024, p=0.067, n^2 = 0.20*
Odd One Out	$F_{(1,12)}$=2.256, p=0.159, n^2 = 0.16	$F_{(1,12)}$=0.145, p=0.710, n^2 = 0.01	$F_{(2,24)}$=1.200, p=0.319, n^2 = 0.09	$F_{(1,12)}$= 0.634, p=0.441, n^2 = 0.05	$F_{(2,24)}$= 1.989, p=0.159, n^2 = 0.14	$F_{(2,24)}$= 1.406, p=0.265, n^2 = 0.11	$F_{(2,24)}$= 0.695, p=0.509, n^2 = 0.06
Jigsaw	$F_{(1,7)}$=4.727, p=0.066, n^2 = 0.40	$F_{(1,7)}$=0.451, p=0.523, n^2 = 0.06	$F_{(2,14)}$=0.700, p=0.513, n^2 = 0.09	$F_{(1,7)}$= 0.451, p=0.523, n^2 = 0.06	$F_{(2,14)}$= 0.247, p=0.784, n^2 = 0.03	$F_{(2,14)}$= 0.162, p=0.852, n^2 = 0.02	$F_{(2,14)}$= 0.585, p=0.570, n^2 = 0.08
Total CCIID	**$F_{(1,12)}$=6.87, p=0.022*, n^2 = 0.36**	$F_{(1,12)}$=0.480, p=0.502, n^2 = 0.04	$F_{(2,24)}$=0.525, p=0.598, n^2 = 0.04	$F_{(1,12)}$= 0.524, p=0.483, n^2 = 0.04	$F_{(2,24)}$=1.615 , p=0.220, n^2 = 0.12	$F_{(2,24)}$= 0.333, p=0.720, n^2 = 0.03	*$F_{(2,24)}$= 3.119, p=0.062, n^2 = 0.21*

*** indicates a significant result (p≤0.05), ** indicates a significant result (p≤0.01**),** *italics indicates a trend towards significance*

6.4 Discussion

The present study did not provide sufficient evidence to conclude there are significant effects of physical activity on the cognitive functioning of individuals with dementia, but it did indicate trend significant cognitive benefits of physical activity over and above a psychosocial control activity. Increases in cognitive scores were visible on the MMSE, VF, HVLT, Series and Jigsaw subtests and total CCIID immediately after engaging in a short bout of resistance band physical activity. Acute effects following the psychosocial control activity were only observable on the HVLT for people with dementia. Both interventions offered social interaction, therefore these results suggest that greater benefits are available to people with dementia through engagement in physical activity with others, rather than just engaging in a psychosocial activity. Interestingly, the effects differed slightly for those without dementia, who showed cognitive improvements on the VF, Series, Jigsaw and Total CCIID following the physical activity, but following the psychosocial control activity only on the Series and Total CCIID. These findings are consistent with previous work that indicated that a single bout of physical activity can have acute cognitive benefits (Chang, Labban, Gapin & Etnier, 2012).

Results also suggest a greater benefit of physical activity for people with dementia than age-matched controls. Specifically, previous studies have found that the influence of physical activity engagement on higher order cognitive functions is affected by ceiling effects. This means that participants with lower baseline performance on executive function tasks, which in this case are the participants with dementia, can expect the greatest benefits from a single session of physical activity (Drollette et al, 2014; Sibley & Beilock, 2007). This was supported by these data.

The three-way mixed ANOVA analysis, although completed with a small sample size suggesting a potential lack of power, showed a time by group effect on the HVLT. This indicates that differences were observed between people with dementia and those without over each of the three time-points. Furthermore, the Series and Total CCIID showed a trend towards significance on the overall effect of time, group and intervention. This suggests that inductive reasoning could be an executive function that is affected by physical activity engagement. Inductive reasoning has been specifically highlighted as important in the execution of activities of daily living tasks (e.g. Wolinsky et al, 2006). Therefore, through physical activity engagement people with dementia could increase their inductive reasoning abilities, which could in turn help to maintain their abilities to engage with activities of daily living for longer. This prolongation of independence and activities of daily living could have widespread implications for people with dementia and their families. Literature has advocated home based dementia care as the best option for dementia care moving forward (Samus et al, 2018). With around 60% of people with dementia remaining in the care of familial caregivers at home (Clarkson et al, 2017), it is important to encourage the maintenance of activities of daily living and physical activity as part of dementia care.

The cognitive and physical benefits available to people with dementia through long term engagement with physical activity have been well evidenced throughout the literature (e.g. Groot et al, 2016; Hernandez et al, 2015). This study highlights the potential for acute benefits from engaging with physical activity and thus further supports the potential for people with dementia to use physical activity as a therapy for dementia in the absence of effective pharmacological treatments (e.g. Sink, Holden & Yaffe, 2005). Results from this study, however, should be interpreted with caution as this study was limited by its small sample size. Having said that, the cognitive assessments that were applied in this study, successfully detected subtle cognitive changes resulting from intervention engagement. Findings from chapter 4 and 5 suggest that the cognitive assessments, specifically the CCIID and the Series subtest, have good potential for clinical use in detecting and diagnosing dementia. This current study indicates further potential for the CCIID and Series to be used to assess of intervention effects.

Considering the well documented cognitive benefits available to people with dementia observed in substantive earlier research and supported by this present study, resistance band physical activity can be recommended as a potential therapy for people with dementia. The physical activity offered as a part of this study only took a short amount of time, was accessible for all abilities and could be performed at varying intensities. This was reflected in the positive response given by participants during data collection. Adherence to longer term physical activity has been highlighted throughout the literature as problematic (e.g. van der Wardt et al, 2017). The focal point of future research should therefore be to identify ways in which people with dementia can increase and maintain their engagement in physical activity. Increases in physical activity could slow cognitive decline, maintain activities of daily living and prolong the requirement for residential care. The following chapters, therefore, explore the question of engagement with physical activity. This subsequent chapters form the second part of the thesis, guided by critical realism. Chapter 7 begins part 2 by exploring adherence to physical activity in previous research. Subsequent chapters then investigate the inclusion of people with dementia in physical activity through their and professionals perspectives toward physical activity.

PART 2

Chapters 7 - 10

Chapter 7

Systematic Literature Review exploring adherence to physical activity for people with dementia

Chapter 7 – Systematic Literature Review exploring adherence to physical activity for people with dementia

7.1 Introduction

Physical activity offers substantial health benefits across the lifespan, including primary prevention, secondary prevention and as a treatment for many common diseases (e.g. MacAuley, Bauman & Fremont, 2016). Cognitive benefits of physical activity for healthy populations have been highlighted throughout the literature, such as improvements in overall cognition (Angevaren, Aufdemkampe, Verhaar, Aleman, & Vanhees, 2008; Barnes, Whitmer & Yaffe, 2007; Candela, Zucchetti, Magistro, & Rabaglietti, 2015), memory, attention, executive functioning and speed of cognitive processing (Kramer, Erickson, & Colcombe, 2006; Colcombe & Kramer, 2003; Candela et al., 2015). It is debatable whether the cognitive benefits observed in healthy populations are achievable for people with dementia. Earlier reviews looking at this with people with dementia found mixed results (e.g. Forbes et al, 2008; Heyn, Abreu & Ottenbacher, 2004). These mixed results are potentially due the methodological shortfalls of earlier trials with those who have dementia, as more recent investigations have demonstrated conflicting results. This indicates that there could be cognitive benefits available for those with dementia. However, as discussed in chapter 6, this still requires further investigation.

Additionally, a meta-analysis of randomised controlled trials (RCTs) examining physical activity over a longer period - on average around 15 weeks of engagement - found that physical activity positively influenced cognitive functioning for people with dementia (Groot et al, 2016). Literature reviews have identified further benefits of physical activity for people with dementia such as, improvements in performance of activities of daily living (Forbes, Thiessen, Blake, Forbes & Forbes, 2013), mobility and physical functioning (Pitkälä, Savikko, Poysti, Strandberg & Laakkonen, 2013) and levels of depression (de Souto Barreto, Demougeot, Pillard, Lapeyre-Mestre & Rolland, 2015). Therefore, the importance of engaging with physical activity for people with dementia is apparent.

Apparent contradictions in previous research could be due to the individuals' willingness to initially engage with physical activity, but also could be a result of a plethora of barriers to continuing to adhere to physical activity engagement. During the normal ageing process, even without the presence of pathology, most physiological systems experience structural and functional deterioration (Marom-Klibansky & Drory, 2002). This can lead to a preponderance of barriers to inhibit older adults from taking part in physical activity. Individuals with dementia often have low functional and cognitive capacity, it is therefore conceivable that the barriers, motivators and facilitators of physical activity are more so for older adults with dementia compared with those without (van Alphen, Hortobagyi & van Heuvelen, 2016). Despite recommendations and increasing evidence substantiating the benefits of physical activity, levels of physical inactivity are still high with only few older adults achieving the minimum recommended amount of physical activity (e.g. Elsawy & Higgins, 2010). Researchers have hence labelled physical inactivity as a pandemic requiring global action (Kohl et al, 2012).

There are numerous barriers to physical activity for people with dementia (Kelly et al, 2016), that can occur at many levels, such as individual, environmental or organisational (Benjamin, Edwards, Ploeg & Legault, 2014). Recent systematic reviews have highlighted as many as 59 barriers to physical activity for older adults (Baert et al., 2011). The barriers that have been most consistently highlighted are: a lack of time (this could be due to family, household or occupational responsibilities); transportation difficulties, lack of facilities or resources; financial costs; entrenched attitudes and behaviours; restrictions that stem from the physical environment; low socioeconomic status; and a lack of knowledge about health (Kelly et al, 2016). Additionally, specific demographic factors, such as age and family history, were shown throughout a multi-ethnic cohort study to significantly determine an individual's willingness to engage with positive health behaviours (Seifan et al, 2017).

Further barriers that have been noted include overall health, specific symptoms related to depression and pain; the general environment; neighbourhood crime rate; a lack of physician advice; knowledge; childhood experiences with physical activity; and marital hardships (Schutzer & Graves, 2004; Schoeny, Fogg, Buchholz, Miller & Wilbur, 2017). In addition to the barriers pertinent to all older adults, people with dementia due to their increased care needs, have the further barrier of mobilizing the caregivers or support staff (Bonner & O'Brien Cousins, 1996). It is also possible that the support that caregivers provide for people with dementia modifies the structure of variables that predict whether or not a person with dementia remains physically active (Stubbs et al, 2014). Therefore, the influential role of the caregiver should be considered when encouraging physical activity. As a result of this preponderance of barriers, people with dementia often find it difficult to participate in physical activity.

Many people with mild to moderate dementia are often very motivated and willing to take up physical activity. Phinney and colleagues, for example, reported that for several participants in their study, being physically active is the most important driving force in their lives and they consistently do as much as they possibly could (Phinney, Chaudhury & O'Connor, 2007). Therefore, reducing barriers can be a very effective way to increase physical activity. In this circumstance where willingness to take up physical activity is present, the availability, accessibility and convenience of recreational facilities become important in ensuring physical activity participation (Wendel-Vos, Droomers, Kremers, Brug & Van Lenthe, 2007). Once people with dementia and their carers have demonstrated willingness to participate in physical activity, the subsequent challenge involves adhering to that physical activity. Adherence is essential for both a meaningful outcome (Rao, Chou, Bursley, Smulofsky & Jezequel, 2014), and to improve health status for people with dementia (van der Wardt et al, 2017). Benefits cannot be achieved without adherence, which has so far proven difficult (van der Wardt et al, 2017). Researchers suggest encouraging greater adherence to interventions to increase the likelihood that participants will engage in an adequate amount of physical activity for health benefits to occur (Heesch, Masse, Dunn, Frankowski & Mullen, 2003).

Earlier studies with older adults have indicated that the largest attrition occurs within 6 months of exercise initiation, with half of all participants dropping out before even realizing any health benefits (Dishman, 1994; Resnick, 2000). Similar to uptake of physical activity, there are a number of factors that can affect adherence. Autonomy is one such example that has been highlighted across the lifespan as an important factor in facilitating adherence to physical activity (Kinnafick, Thogerssen-Ntoumani & Duda, 2014). Decline in autonomy experienced by people with dementia (Hoek et al, 2018) can, therefore, result in difficulties maintaining physical activity without support. Support is often necessary to help people with dementia to be physically active.

Randomised controlled trials (RCT) represent physical activity interventions conducted for the purpose of research, whereby people with dementia are offered the support in order to achieve physical activity. Under these circumstances adherence rates are often reported. This chapter continues to investigate the third overarching objective of this thesis and seeks to better understand how barriers can inhibit people with dementia from adhering to physical activity. The aims of this chapter are, therefore, to establish how much people with dementia are currently adhering to physical activity interventions and discuss the potential factors highlighted in the literature that could affect these adherence rates.

7.2 Methods

A literature review was conducted to establish adherence to physical activity interventions by people with dementia under RCT conditions. The following inclusion criteria were applied: 1) the study followed a randomised control trial design or RCT, 2) the research was published within the last 10 years (from January 2008 up until and including December 2018), 3) the RCT delivered an intervention of solely physical activity, 4) the intervention was designed for and delivered to people with dementia, 5) the study reported the adherence participants demonstrated to the intervention and lastly, 6) the intervention lasted for at least 3 weeks. The literature search was conducted in three databases; PubMed, Science Direct, and Google Scholar. These databases were selected due to the depth and breadth that they offer in literature searching as well as their relevance to the reviewed topic. The search string included various terms for (1) the participants of interest (e.g. Alzheimer’s disease, dementia, dementia of Alzheimer’s type) as well as (2) the output of interest (e.g. Randomised controlled trial, RCT, physical activity programme, physical activity RCT, exercise, exercise intervention). Advanced settings of search engines were used to limit the searched studies to those published between 2008 and 2018; and those included studies were then hand-searched to identify any further relevant studies. Publications were included regardless of the original language, however, as searches were completed using English databases, limited non-Enlgish publications were identified.

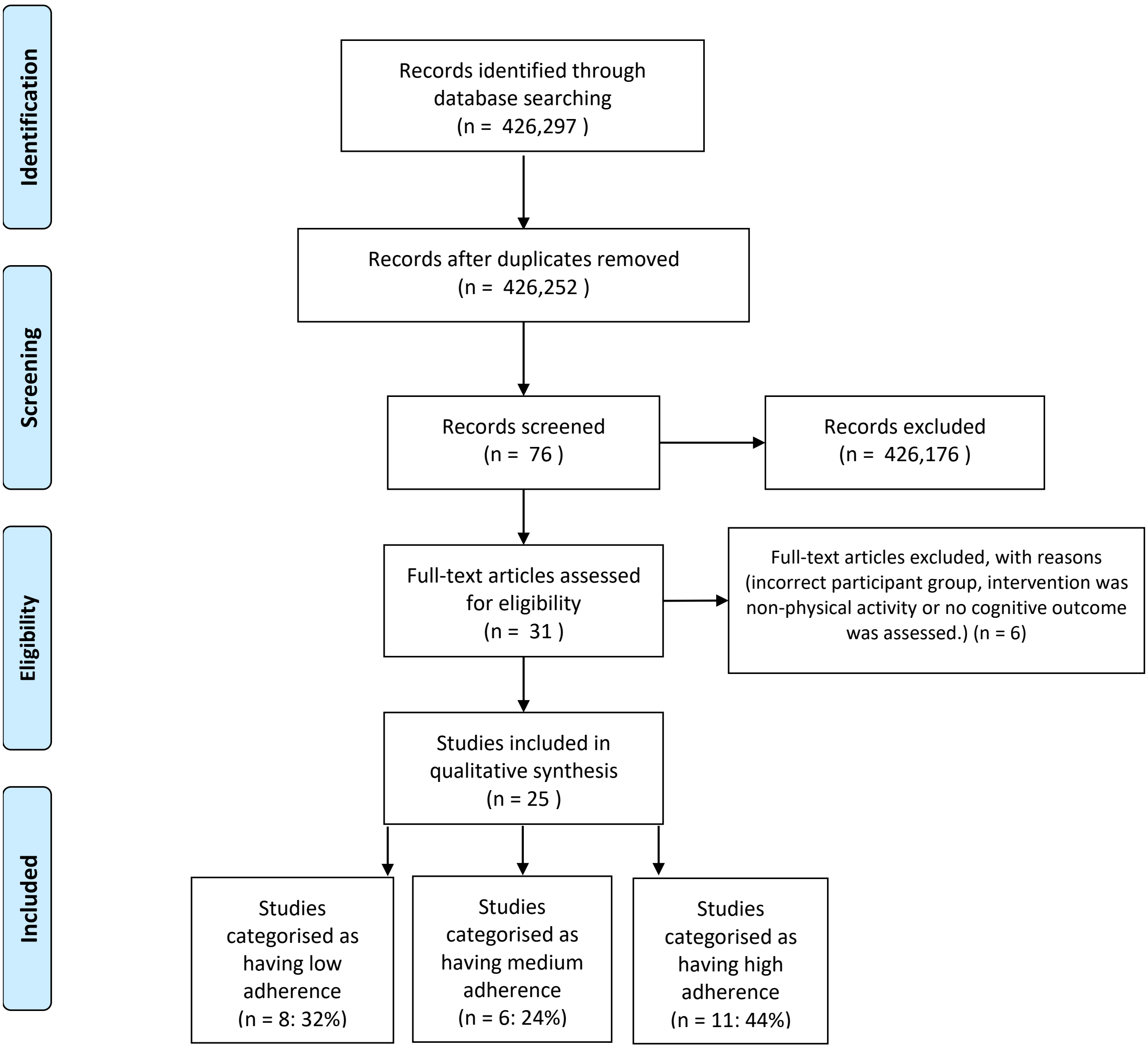
Once studies were identified full texts were read to determine their relevance and whether necessary information was available in the publication, i.e. the adherence or drop-out rates of the participants in the RCT. For each of the studies, a percentage of adherence was either extracted from the full text or calculated based on the figures available within the text. This percentage described the number of participants that completed the intervention of those that were enrolled. Therefore, dropouts and individuals that did not adhere to the minimum amount of physical activity required by the study were not counted as having completed the study. At this stage, these percentages were then used to categorise each study and collate the studies into a table. Studies were categorized as being either high, medium or low adherence. Studies with an adherence rate of 90% or higher were categorized as having high adherence. Studies with a medium adherence had between 80 and 89% adherence rates; and low adherence studies had 79% or below adherence rates. The applied categories facilitated analysis of the included studies. Such analysis involved comparing the studies within the table and noting down key ways in which studies differed as well as key characteristics that studies shared. This comparison is then followed by an in-depth discussion of key characteristics and factors that impact adherence to physical activity for people with dementia.

7.3 Results

7.3.1 Literature search results

The literature searches conducted in all three databases yielded a total of 426,297 studies. After screening titles and abstracts, 76 studies remained. A further 45 studies were excluded as duplicates. These were assessed in full text, and a further 6 studies were excluded at this point for not meeting the inclusion criteria. Twenty-five studies remained. An overview of the whole search and the results is shown in figure 7.1. The studies were then categorised into low adherence (n=8), medium adherence (n=6) and high adherence (n=11).

Figure 7.1 Modified PRISMA flow diagram of search strategy and results



7.3.2 Included studies

The included studies varied in a number of factors such as: the amount of activity participation required, the type of activities being facilitated, the groups sizes in which these activities were conducted, the degree to which these activities were supervised or guided and how participation was recorded. The variations in these factors could potentially be influencing adherence to the physical activity throughout the RCT.

Studies took different approaches to the delivery of physical activity. Some studies sought to vary the physical activity, through either the use of different types of physical activity, or by offering progression and increases in challenge as the trial developed; while other studies kept the physical activity consistent throughout the trial. In the low adherence studies, 43% of the studies (3 out of 7) offered varied physical activity, for the medium adherence studies this increased to 50% of the studies (3 of 6); this increased again to 64% for the high adherence studies (7 of 11). This suggests that offering variety to participants with dementia could increase adherence to physical activity.

The length of time participants were asked to be physically active varied between studies, the median time participants were asked to be physically active in the low adherence study group was 24 weeks (range: 12 weeks to 60 weeks); in the medium adherence studies the median was 13.5 weeks (range: 6 weeks to 1 year); in the high adherence studies, 12 weeks was the median length of RCT (range: 4 weeks to 1 year). This suggests that adherence is more successful for shorter RCTs. The amount of time participants spent each week being physically active also varied between studies. This did not, however, substantially differ between low, medium and high adherence studies. In the low adherence studies this ranged from twice a week to everyday with a median of 3 times per week. In the medium adherence studies this ranged from twice a week to five times per week, with a median of 2.5 times per week. In the high adherence studies this ranged from once a week to everyday, with a median of 3 times per week.

The length of each physical activity sessions, on the other hand, did vary slightly between the studies classified as low, medium and high adherence. In the low adherence studies participants were asked to be physically active for a median of 36 minutes (range: 15 minutes to 60 minutes). In the medium adherence studies the median was much higher at 60 minutes, with a range of 30 minutes to 90 minutes. Finally, in the high adherence studies the median session length was 35 minutes, ranging from 30 minutes to 90 minutes.

Studies classified as having low adherence are presented in table 7.1 (Steinberg, Leoutsakos, Podewils & Lyketsos, 2009; Cancela, Ayan, Varela & Seijo, 2016; Low et al, 2016; Toots et al, 2016, 2017; de Souto Barreto et al, 2017; Yu et al, 2015; Henskens, Nauta, van Eekeren & Scherder, 2018). Out of the low adherence studies, physical activity was completed 1) alone or in pairs (Cancela. Ayan, Varela & Seijo, 2016), 2) with just a supervisor or caregiver

(Steinberg, Leoutsakos, Podewils & Lyketsos, 2009; de Souto Barreto et al, 2017), 3) with a group of supervisors (Toots et al, 2016; 2017), or 4) in groups of participants with supervision (Low et al, 2016; Yu et al, 2015; Henskens, Nauta, van Eekeren & Scherder, 2018).

Table 7.1 - Studies with Low adherence to physical activity RCTs for people with dementia

Study	Participants	Type of Physical activity	Frequency, Length and Supervision of RCT	Cognitive Outcome	Adherence Rate	Outcome of study and Notes
Steinberg, Leoutsakos, Podewils & Lyketsos, 2009 – United States	27 community dwelling participants with dementia	Physical activity focusing on aerobic, strength, balance and flexibility	Participants acquired points for performing activities in the aerobic, strength and balance categories (1 point for partially performing a task; 2 for completing). The goal was to acquire 6 aerobic points and 4 each of strength and balance per week. For 12 weeks. Caregivers of participants filled out weekly diaries	1 hr cognitive test battery (Rebok et al., 1990) which included the MMSE (Folstein, Folstein & McHugh, 1975), the Boston Naming Test (BNT - Kaplan, Goodglass & Weintraub, 1983) and the Hopkins Verbal Learning Test (HVLT - Brandt, 1991)	59% of the diaries were received. From the diaries received, participants in the physical activity group achieved 79%, 74% and 72% of their goals for the aerobic, strength and balance categories respectively	No significant differences between groups were noted on any of the cognitive outcome measures
Cancela, Ayan, Varela & Seijo, 2016 – Spain	189 homecare residents with dementia	Daily aerobic physical activity (Cycling)	15 mins daily for 15 months. Physical activity was completed alone or in pairs	MMSE (Folstein, Folstein & McHugh, 1975); Fuld Object Memory Evaluation (Fuld et al, 1980)	88% attendance rate for those that completed the physical activity arm of the trial.	Aerobic physical activity showed significant impact on improving

	(n=73 in physical activity group)				114 participants in total completed the trial of the 189 that started suggesting a 60% adherence rate across the whole trial	cognitive functioning. Lack of supervision or lone activity could perhaps explain low adherence but outcome was still beneficial for those who adhered.
Low, Carroll, Merom, Baker, Kochan, Moran & Brodaty, 2016 - Australia	18 nursing home residents with dementia	Dance intervention group compared to music control group	45 min sessions, 3 times per week for 16 weeks. Guided by experienced dance teachers	Severe Impairment Battery (SIB - Panisset, Roudier, Saxton & Boiler, 1994)	67% attendance was observed in the dance group, lower than expected; attendance was 89% in music control group	Researchers decided to serve tea before dance classes to increase attendance. Ceiling effects on the SIB meant cognitive outcomes were unclear
Toots et al, 2016, 2017 - Sweden	186 nursing home residents with dementia	High intensity functional exercise programme or seated attention control activity	45 min sessions, 5 times over 2 weeks for 4 months. 3 physiotherapists and 1 occupational therapist or assistant	MMSE (Folstein, Folstein & McHugh, 1975); Alzheimer's Disease Assessment Scale-Cognitive Subscale (ADAS-Cog: Rosen, Mohs & Davis, 1984); Verbal Fluency (McCarthy, 1972)	73% adherence rates.	Physical activity had no superior effects on global cognition or executive function in people with dementia compared to an attention control activity

						A lot of supervision and support offered by this RCT
De Souto Barreto, Cesari, Denormandie, Armaingaud, Vellas & Rolland, 2017 – France	91 nursing home residents with dementia	Physical activity included balance, coordination, strength and aerobic components; were compared to a social control activity	60 min sessions, 2 times per week for 24 weeks. Guided by instructors who had experience working with people with dementia in care settings. Group sizes not described	MMSE (Folstein, Folstein & McHugh, 1975)	97 participants completed baseline assessments, 6 dropouts were reported thus 93% of the cohort completed the trial. Authors reported a median adherence of 74% in the PA group and 83% in the social control group	Physical activity group declined more than social control on the MMSE, however this change was only slight
Yu, Thomas, Nelson, Bronas, Dysken & Wyman, 2015 – United States	28 participants with mild to moderate Alzheimer's disease	Aerobic physical activity (Cycling)	15 to 45 min sessions, 3 times per week for 6 months. Groups of 2 to 3 participants were supervised by an exercise interventionist	Alzheimer's Disease Assessment Scale-Cognitive Subscale (ADAS-Cog: Rosen, Mohs & Davis, 1984)	Participants attended 83% of their prescribed sessions. N=28 started the trial, n=26 completed 3 month follow-up and n=22 completed 6	Cognitive scores remained unchanged after 6 months, could be positive considering cognition should have worsened.

					month follow-up. Representing 79% adherence	
Henskens, Nauta, van Eekeren & Scherder, 2018 – The Netherlands	87 nursing home residents with dementia	4 groups: 1) Activities of daily living training 2) Strength and Aerobic training 3) Combined ADL, strength and aerobic training 4) Social control but care as usual	30-45min sessions, 3 times per week for 6 months. Qualified movement teacher guided training, care home staff supported in the other groups	MMSE (Folstein, Folstein & McHugh, 1975); Severe Impairment Battery – short form (Saxton et al, 2005); Category Fluency from Groninger Intelligence Test (Snijders & Verhage, 1983); The Wechsler Digit Span Task backwards (Wechsler, 1987); the go-no-go test and conflicting instructions test of the Frontal Assessment Battery (Dubois et al, 2000)	55% of PA sessions were attended. N=22 were lost to follow-up leaving 87 participants total. Therefore, overall RCT adherence rates were 79%	Benefits of activities of daily living training (light physical activity) were observed in executive functions

Additionally, studies classified as having low adherence showed minimal effects on cognition. Two of the eight studies only showed slight improvements in executive functioning (Henskens, Nauta, van Eekeren & Scherder, 2018) and overall cognition (Cancela, Ayan, Varela & Seijo, 2016). Three studies found no difference in cognitive function between the physical activity and control groups (Toots et al, 2016, 2017; Yu et al, 2015; Steinberg, Leoutsakos, Podewils & Lyketsos, 2009), one study was not clear about the cognitive outcome due to ceiling effects of the chosen cognitive assessment (Low et al, 2016); and the final study found the physical activity group to decline more than the social activity being used as a control (de Souto Barreto et al, 2017). The lack of cognitive benefits observed in these studies could be associated with the lack of adherence shown throughout these RCTs.

Studies classified as having medium adherence are shown in table 8.2 (Yerokhin et al, 2012; Kemoun et al, 2010; Telenius, Engedal & Bergland, 2015; Lamb et al, 2018; Ohman et al, 2016; Eggermont, Swaab, Hol & Scherder, 2009b). The medium adherence category did not have any studies that asked their participants to complete their physical activity alone. Physical activity was completed either supervised in a group (Yerokhin et al, 2012, Telenius, Engedal & Bergland, 2015; Lamb et al, 2018; Ohman et al, 2016), or supervised individually (Eggermont, Swaab, Hol & Scherder, 2009b). The group sizes varied between studies from 3 participants (Telenius, Engedal & Bergland, 2015) to 10 participants (Ohman et al, 2016). Interestingly, Ohman and colleagues (2016), compared group based physical activity to home based physical activity. Home based activity was performed one on one with an instructor, whereas the group activity was performed with one instructor for 10 participants. In this instance, better adherence and outcomes were observed for the home based physical activity group. This indicates that the one on one supervision and personalisation of the physical activity had a positive impact on adherence.

Studies with medium adherence found varying outcomes on cognitive assessments. Three studies, 50% of the medium adherence category, found no cognitive benefit of physical activity participation (Eggermont, Swaab, Hol & Scherder, 2009b; Telenius, Engedal & Bergland, 2015; Lamb et al, 2018). The remaining three however, found improvements in executive functioning alone (Ohman et al, 2016) or; overall cognitive functioning (Yerokhin et al, 2012; Kemoun et al, 2010).

Table 7.2 - Studies with Medium adherence to physical activity RCTs for people with dementia						
Study	**Participants**	**Type of Physical activity**	**Frequency, Length and Supervision of RCT**	**Cognitive Outcome**	**Adherence Rate**	**Outcome of study and Notes**
Yerokhin, Anderson-Hanley, Hogan, Dunnam, Huber, Osborne & Shulan, 2012 – United States	13 participants with early dementia and 9 healthy controls	Low intensity strength physical activity	45 min sessions, 3 to 5 times per week for 10 weeks. Guided by adult day care staff while watching a video recording of an instructor leading older adults through the physical activity	Stroop Test (Golden, 1978), Colour Trails 1 and 2 (D'Elia, Satz, Uchiyama & White, 1996); Digit Span Forwards and Backwards (Strauss, Sherman & Spreen, 2006); Fuld Object Memory Evaluation (Fuld et al, 1980)	81% overall adherence	Results point to increased cognitive efficiency following 10 weeks of strength based physical activity
Kemoun, Thibaud, Roumagne, Carette, Albinet, Toussaint, Paccalin & Dugué, 2010 - France	31 participants with dementia	Progressive physical activity focusing on walking, equilibrium and stamina	1 hr sessions, 3 times per week for 15 weeks. Potentially organized by the nursing home staff, however supervision levels are not made explicitly clear	French version of the Rapid Evaluation of Cognitive Function (ERFC - Gil et al, 1986)	Of the 38 patients initially enrolled only 31 completed the protocol. This suggests an 81% adherence rate	Findings show that physical activity programme can slow cognitive decline for people with dementia

Telenius, Engedal & Bergland, 2015 - Norway	170 nursing home residents with dementia	High intensity functional physical activity programme focusing on balance, vs control of leisure activities	2 times per week for 12 weeks. Small groups of 3 participants with 1 physiotherapist	MMSE (Folstein, Folstein & McHugh, 1975)	Out of a possible 216 participants 84.2% agreed to participate (n=182). 12 participants dropped out after agreeing to participate (6.6%) a further 16 participants did not complete the 12 week follow-up. Overall 85% adherence rate	No significant changes in cognition were observed but improvements in balance and strength and reductions in apathy and agitation were reported
Lamb, Mistry, Alleyne, Atherton, Brown, Copsey, Dosanjh, Finnegan, Fordham, Griffiths & Hennings, 2018 –	494 people with dementia: (n=329 intervention group and n=165 usual care)	Moderate to high intensity aerobic and strength physical activity compared with care as usual	60 to 90 min sessions, 2 times per week for 4 months. Participants also completed home activities for an additional hour each week. Participants completed the physical activity in groups of 6 to 8, supervised by	Alzheimer's Disease Assessment Scale-Cognitive Subscale (ADAS-Cog: Rosen, Mohs & Davis, 1984)	83% of participants from the care as usual group completed the trial. In the physical activity group of the 329 participants that started the trial, 281 completed the activity and follow-up assessments,	Physical activity did not slow cognitive impairment in people with mild to moderate dementia. Improvements were seen in physical fitness though

United Kingdom			physiotherapists and activity assistants		suggesting an 85% adherence rate	
Öhman, Savikko, Strandberg, Kautiainen, Raivio, Laakkonen, Tilvis & Pitkälä, 2016 - Finland	210 participants with Alzheimer's disease or their spousal caregiver. (n=70 per group)	3 groups: 1) Home physical activity 2) Group based physical activity 3) Care as usual control All activities consisted of aerobic, endurance, balance, and strength and dual tasking. The home activities were tailored to individuals' needs	1 hr sessions, twice a week for 1 year. Home activity was supervised by a physiotherapist. Group sessions were conducted in groups of 10 with 2 physiotherapists supervising	Clock Drawing Test (CDT – Sunderland et al, 1989); Verbal Fluency (VF- McCarthy, 1972); Clinical Dementia Rating (CDR – Hughes, Berg, Danziger, Coben & Martin, 1982); Mini Mental State Examination (MMSE – Folstein, Folstein & McHugh, 1975)	65 participants in the home activity condition (93%) attended at least half of the sessions. 55 participants in the group activity condition (79%) attended at least half of the sessions. Mean of 86% adherence rate between the two groups, suggesting high adherence	Regular, long-term, personalised physical activity <u>at home</u> improved executive function of people with dementia, but the effects were mild and were not observed in other cognitive functions. This study had lower expectations on adherence (attending at least half of the sessions) therefore adherence rate may look more favourable than stricter trials. Interestingly, higher adherence was seen from the home activity group,

						where benefits were also observed for executive functioning
Eggermont, Swaab, Hol & Scherder, 2009 (b) – The Netherlands	97 nursing home residents with moderate dementia	Walking	30 min sessions, 5 times per week for 6 weeks. Supervised individually for walking by psychology students	MMSE (Folstein, Folstein & McHugh, 1975), Face recognition and Picture recognition from Rivermead Behavioural Memory Test (Wilson, Cockburn & Baddeley, 1986), 8 words list learning test assessing immediate, delayed and recognition memory, Digit Span (both forward and backward), Category and Letter Fluency	Of a potential 103 participants, 6 did not complete the study protocol. From the remaining 97 participants 7 did not want to continue the experimental condition. This suggests and overall adherence rate of 87%	No benefits on cognitive functioning were observed, this could be a result of the low intensity activity being undertaken. Did not report reasons for participants not completing the study

The remaining studies were classified as having high adherence and are presented in Table 7.3 (Yaguez, Shaw, Morris & Matthews, 2010; Eggermont et al, 2009a; Bossers et al, 2015; Venturelli, Scarsini & Schena, 2011; Cheng et al, 2014; Hoffman et al, 2016; de Andrade et al, 2013; Kwak, Um, Son & Kim, 2008; Lee & Kim, 2008; Holthoff et al, 2015; Vreugdenhil, Cannell, Davies & Razay, 2012).

Five studies with high adherence asked their participants to complete their physical activity with the one on one supervision of either their caregiver (Venturelli, Scarsini & Schena, 2011; Holthoff et al, 2015; Vreugdenhil, Cannell, Davies & Razay, 2012) or a professional, such as a physiotherapist, occupational therapist or researcher staff member (Bossers et al, 2015; Lee & Kim, 2008). Three studies asked their participants to perform physical activity within a group (Yaguez, Shaw, Morris & Matthews, 2010; Cheng et al, 2014; Hoffman et al, 2016; Kwak, Um, Son & Kim, 2008), but group sizes remained small, with the largest group size noted as five participants. The remaining studies did not explicitly state the group sizes utilised throughout the trial (Eggermont et al, 2009a; de Andrade et al, 2013).

Furthermore, 8 studies with high adherence reported overall improvements in cognitive functioning (Yaguez, Shaw, Morris & Matthews, 2010; Bossers et al, 2015; Hoffman et al, 2016; de Andrade et al, 2013; Kwak, Um, Son & Kim, 2008; Lee & Kim, 2008; Holthoff et al, 2015; Vreugdenhil, Cannell, Davies & Razay, 2012). A further 2 studies reported that cognitive functioning was maintained in comparison to a decline in functioning in the control groups (Cheng et al, 2014; Venturelli, Scarsini & Schena, 2011). The remaining study reported no significant difference in cognitive scores (Eggermont et al, 2009a). This suggests that more consistent adherence to physical activity enhances the potential for people with dementia to experience cognitive benefits as an increase in adherence from the low to medium group, and then again, from the medium to high studies has been reflected in researchers reporting increases in favourable cognitive outcomes.

Table 7.3 - Studies with High adherence to physical activity RCTs for people with dementia						
Study	**Participants**	**Type of Physical activity**	**Frequency, Length and Supervision of RCT**	**Cognitive Outcome**	**Adherence Rate**	**Outcome of study and Notes**
Yaguez, Shaw, Morris & Matthews, 2010 – United Kingdom	27 participants with Alzheimer's disease	2 groups: 1) Physical activity group completing movement training. 2) Control group receiving standard care	2 hr sessions with a half an hour break. Once a week for 6 weeks. Convened as a group but level of supervision was not specified	The Cambridge Neuropsychological Test Automated Battery (CANTAB) Expedio version (Robbins et al, 1994)	15 participants were originally allocated to each group but 3 dropped out of the control group. Over 90% adherence rates were observed across groups	Significant improvements in sustained attention, visual memory and a trend in working memory were found in the Physical activity group after 6 weeks
Eggermont et al, 2009 (a) – The Netherlands	66 nursing home residents with dementia	Hand motor activity	30 min sessions, 5 times per week for 6 weeks. Supervised by recreational therapists or psychology masters students	MMSE (Folstein, Folstein & McHugh, 1975), Face recognition and Picture recognition from Rivermead Behavioural Memory Test (Wilson, Cockburn & Baddeley, 1986), 8 words list learning test assessing immediate, delayed and recognition memory,	4 participants from the activity group withdrew participation on the first day, 2 further participants withdrew for health reasons unrelated to the activities; suggesting a	No significant differences in cognitive functioning were observed

				Digit Span (both forward and backward), Category and Letter Fluency	91% overall adherence	
Bossers, van der Woude, Boersma, Hortobagyi, Scherder & van Heuvelen, 2015 – The Netherlands	109 participants with dementia	3 groups: 1) Combined aerobic and strength physical activity group 2) Aerobic only physical activity 3) Social group	30 min sessions, 4 times per week for 9 weeks. (36 sessions in total). 1 on 1 supervision from a human movement scientist research assistant	MMSE (Folstein, Folstein & McHugh, 1975); Visual Memory was measured using visual memory span forward test from the Wechsler Memory Scale Revised (WMS-R), face recognition test and picture recognition test from the Rivermead Behavioural Memory Test (Wilson, Cockburn & Baddeley, 1986); Verbal Memory was measured using 8 word recall test and digit span forward test - from the WMS-R; Executive function was measured using the visual memory span backward test and digit	101 participants completed the 9 week follow-up suggesting overall a 92% adherence rate	A combination of aerobic and strength training is more effective than aerobic-only training in slowing cognitive and motor decline in participants with dementia High level of supervision and short session length, could be why adherence is so high here

				span backward test (WMS-R), the Stroop test (Golden, 1978), verbal fluency test (McCarthy, 1972), picture completion test (Groningen Intelligence Test), and trail making test-A (Tombaugh, 2004)		
Venturelli, Scarsini & Schena, 2011 - Italy	21 participants with Alzheimer's disease	Walking at moderate intensity	30 min sessions, 4 times per week for 24 weeks. Caregivers completed the walking programme alongside the participants and sought to encourage participants and give positive reinforce throughout	MMSE (Folstein, Folstein & McHugh, 1975)	93.4% had a presence at the 96 scheduled training sessions. 3 people dropped out from study, 2 from the control group and 1 from the walking intervention	Control group declined in MMSE scores while the walking group remained the same
Cheng, Chow, Song, Edwin, Chan, Lee & Lam, 2014 – Hong Kong	110 nursing home residents with mild dementia (MMSE of	Tai Chi (physical activity) compared to Mahjong (cognitive activity) and handicraft activity	3 times per week for 12 weeks. Supervised by student helpers, 1 helper to every 3 members of the	MMSE (Folstein, Folstein & McHugh, 1975), Immediate/delayed recall, Categorical fluency, and Digit span	117 were enrolled onto the trail, 110 participants completed 3 month	Those who were in the Mahjong and Tai Chi physical activity groups all maintained their cognitive abilities

	between 10 and 24)	(social/psychosocial control activity)	group in each condition		assessment suggesting 94% adherence rate	while the control group deteriorated. This was most notable on the MMSE, delayed recall and forward digit span
Hoffmann, Sobol, Frederiksen, Beyer, Vogel, Vestergaard, Brændgaard, Gottrup, Lolk, Wermuth & Jacobsen, 2016 - Denmark	200 participants with mild Alzheimer's disease	Strength physical activity, focusing primarily on the lower extremities; which builds up over the intervention. One of the sessions per week was devoted to aerobic physical activity at a moderate to high intensity	60 min sessions, 3 times per week for 16 weeks. 2 to 5 participants completed the physical activity together supervised by an experienced physiotherapist	Symbol digits modalities Test (SDMT – Smith, 1982); Alzheimer's Disease Assessment Scale-Cognitive Subscale (ADAS-Cog: Rosen, Mohs & Davis, 1984); 10 learning word list assessing immediate and delayed recall; Stroop Colour & Word Test (Golden, 1978); Verbal Fluency (McCarthy, 1972); Mini Mental State Examination (MMSE - Folstein, Folstein & McHugh, 1975)	10 participants dropped out suggesting a 95% adherence rate. 81 of 107 participants in the intervention group (76%) attended more than 80% of the physical activity sessions. This further suggests high adherence in this study	Physical activity provided possible benefits of preserved cognition in a subgroup of patients exercising with high attendance and intensity. Small group sizes with experienced supervision, as well as varied physical activity could account for the high adherence
de Andrade, Gobbi,	30 participants	Physical activity combining aerobic,	1 hr sessions, 3 times per week for	MMSE (Folstein, Folstein & McHugh,	70% attendance at sessions	Intervention group participants showed

Coelho, Christofoletti, Costa, Stella, 2013 – Brazil	with Alzheimer's disease (n=14 in physical activity group)	muscle strengthening, flexibility and balance components	16 weeks. Supervision not specified.	1975); Montreal Cognitive Assessment (Nasreddine et al, 2005); Clock Drawing Test (Sunderland et al, 1989); Frontal Assessment Battery (Dubois et al, 2000); Symbol Search Subtest from Wechsler Adult Intelligence Scale (Wechsler, 1974)	required by the trial and 0 dropouts were reported, suggesting 100% adherence rates	a significant increase in frontal cognitive function
Kwak, Um, Son & Kim, 2008 – republic of Korea	30 older women with dementia (n=15 physical activity group and n=15 controls)	Physical activity gradually increased in intensity from 30 to 60 % of expected maximal oxygen consumption. Most participants were encouraged to do other forms of routine activity throughout the day, such as stretching, upper extremity exercise, lower extremity exercise, and walking	30 to 40 min sessions, once a week as a group for 12 months. Supervision not specified	Mini-Mental State Examination (MMSE – Folstein, Folstein & McHugh, 1975)	Authors do not report any dropouts over the 12-month period. The small sample size of 30 older women remains the same throughout the trial. 100% adherence rate	Findings showed that regular physical activity can enhance cognitive functioning in people with dementia As there is only one mandated session per week perhaps this encouraged consistent adherence

Lee & Kim, 2008 – Republic of Korea	23 nursing home residents with dementia reported to have sleep disturbance or agitation	Indoor gardening (light physical activity involving selecting beans; setting roots and/or planting beans; emptying containers; watering; touching; cleaning and arranging containers; wiping floors; harvesting; cutting and washing)	1 hr sessions, 2 times per day for 4 weeks. Participants were assisted by research assistants and nursing assistants to grow their plants	HDS-R Revised Hasegawa Dementia Scale; (HDS-R: Imai & Hasegawa, 1994)	100% adherence Rates as all 23 participants completed the entire trial	The primary outcome of this study were sleep an agitation outcomes as the intervention was targeted toward people with dementia experiencing these symptoms, but the cognitive outcomes showed beneficial effects
Holthoff, Marschner, Scharf, Steding, Meyer, Koch, Donix, 2015 – Germany	30 people with Alzheimer's disease	Home based strength and balance physical activity	3 times per week for 12 weeks. No supervision for the physical activity. Month clinical visits and counselling as per care as usual, caregiver was told to be encouraging but did not stay in the room for the activity	MMSE (Folstein, Folsteing & McHugh, 1975); CERAD (Morris et al, 1989) measuring executive functioning and language ability; FAS-test (Tombaugh, Kozak & Rees, 1999)	32 individuals declined participation as they wouldn't adhere. But of those who started, all completed the study for 12 weeks. 100% adherence rates for those who started	Findings suggest cognitive benefits of physical activity Although adherence was high, lack of participants that agreed to enroll onto the study suggests a lack of willingness to take up physical activity

Vreugdenhil, Cannell, Davies & Razay, 2012 - Australia	40 community dwelling older adults with Alzheimer's disease	Walking and Home based progressively challenging physical activity that focused on upper and lower body strength as well as balance	Daily for 4 months. Prior to intervention the carer and the person with dementia were trained in the programme and provided with a manual. Caregivers supervised activity. Participants received a phone call to check on their wellbeing at 2 weeks and 2 months	MMSE (Folstein, Folstein & McHugh, 1975)	64 participants were invited to participate. However, 17 declined participation stating reasons such as: not interested, health issues, or too busy. 7 did not respond to the invitation. Meaning 63% of the invited participants completed the trial, but of the 40 who started the trial 100% adherence rates were reported	Findings suggests that participation in a community-based physical activity can improve cognitive function for people with dementia Participation figures suggest lack of willingness to participate

7.4 Adherence Support Strategies

In order to encourage people with dementia to continue to be physically active after the initial uptake of physical activity, in an RCT, for example, participants' lifestyle behaviours need to adjust to facilitate more activity. The disparity in adherence rates observed across the included studies highlights that this is not always achieved. Table 7.4 details the specific recommendations for encouraging participant adherence based on the reviewed studies. There were key differences observed across the reviewed studies in the variety of physical activity offered by the RCT. This corresponds with the importance placed on autonomy in maintaining adherence to physical activity previous research investigating physical activity across the lifespan (e.g. Kinnafick, Thogerssen-Ntoumani & Duda, 2014). This review therefore supports the use of variety in order to offer participants autonomy in their physical activity behaviours. The length of RCT also differed between the reviewed categories, with shorter RCTs demonstrating higher adherence hence it can be recommended that RCTs are not longer than 13.5 weeks. Other key factors considered in this review included the number of sessions each week, the length of those sessions, group sizes that participate in those session and the level of supervision provided. These factors however, did not differ substantially between the reviewed categories and therefore no clear recommendations can be made at this time, suggesting the need for further investigation.

Table 7.4 Recommendations for encouraging physical activity adherence

	Number of studies that offered a variety of PA	**Median Length of RCT**	**Range of length of RCT**
Studies reviewed:			
Low Adherence	43% (3 out of 7 studies)	24 weeks	12 – 60 weeks
Medium Adherence	50% (3 out of 6 studies)	13.5 weeks	6 weeks – 1 year
High Adherence	64% (7 out of 11 studies)	12 weeks	4 weeks – 1 year
Recommendations based on reviewed studies	More variety of physical activity available to participants	Keeping the length of the RCT shorter, ideally shorter than 13.5 weeks.	

n.b. other factors that require further investigation include number of sessions each week, length of sessions, group size and level of supervision provided.

Findings from this review support previous research that has also highlighted difficulty in maintaining adherence to physical activity. Subsequently, researchers have further suggested a need for behaviour change techniques to increase adherence to physical activity programmes (e.g. Nyman, Adamczewska & Howlett, 2018). This could also increase the inclusivity provided by physical activity interventions. However, evidence to date suggests that no one single form of adherence intervention will work with all individuals. This is unsurprising given the complex and multifactorial nature of adherence and the myriad of barriers that exist that people with dementia and supporting professionals need to overcome to inclusively provide and benefit from physical activity (Kelly et al, 2016). Therefore, a wide range of adherence support strategies are being included in physical activity interventions for people with dementia.

The evidence for the effectiveness of these interventions is so far limited (van der Wardt et al, 2017). The strategies discussed in the RCTs included in this review, such as telephone calls, small group sessions, one to one sessions and peer support, suggest that more contact with professionals, who encourage or facilitate the physical activity, could induce better adherence. Studies that requested participants to complete physical activity individually, often at home, frequently meant participants struggling to engage with the activity consistently unless supervised by a professional on a one on one basis.

Much like barriers to physical activity, support strategies can occur at many levels. A study by Resnick (2000) advised seven steps to aid initiation and adherence to regular physical activity. The seven steps include: education; physical activity pre-screening; setting goals; seeing this activity; role models; verbal encouragement; and verbal reinforcement/rewards (Resnick, 2000). When these seven steps were implemented, Resnick found that far more participants were engaging with physical activity regularly. Nyman, Adamczewska & Howlett (2018) recently reviewed behaviour change techniques that intended to improve physical activity behaviours of people with dementia and found that only goal setting behaviours showed promise for sustaining adherence to physical activity. Many techniques or strategies that are often successful in healthy populations, such as social support, communication and using a credible source, were shown to be ineffective for people with dementia (Nyman, Adamczweska & Howlett, 2018). This further emphasises the myriad of difficulties presented when seeking to increase physical activity for people with dementia. Symptoms characteristic of dementia, like decline in memory, orientation and autonomy, limit the potential for interventions and behaviour change techniques to benefit individuals with dementia. However, goal setting remained as a strategy to be used for adherence.

Research into the potential for support strategies to enhance physical activity programmes for people with dementia is relatively novel, and therefore current evidence is limited. Having said that, the emergence of this line of enquiry in the literature further emphasises the problem of inconsistent adherence and the subsequent effect on cognition. Moreover, the need to address this problem is pressing if people with dementia are to achieve any health benefits from engaging with physical activity (van der Wardt et al, 2017); most importantly, the potential for cognitive benefits that could mitigate the symptoms of dementia (Groot et al, 2016).

7.5 Discussion

Previous research indicates that most older adults do not participate in enough physical activity; and physical activity levels decline further with age (Hallal et al, 2012; McKee et al, 2015). This systematic literature review aimed to establish how much people with dementia adhered to physical activity in randomised controlled trials (or RCTs) and discussed the potential factors that could affect these adherence rates. Inconsistent levels of adherence were found across the literature. Of the 25 included studies, 8 were classified as having low adherence, 6 studies had medium adherence and the remaining 11 had high adherence. Findings from this review are in accordance with previous reviews that have also pointed to inconsistent adherence to physical activity for people with dementia (van der Wardt et al, 2017). This review adds to our previous understanding by establishing the exact levels of adherence reported across physical activity trials for people with dementia and examining the contexts of each study that could have contributed to the differences observed.

It is apparent from the varying levels of adherence across the included studies that multiple factors can affect the potential success of a physical activity intervention. Most notably, cognitive benefits were more consistently reported as the physical activity adherence increased. This suggests that adherence to physical activity could increase the chances of individuals with dementia experiencing cognitive benefits. Additionally, adherence was associated with greater variety of physical activity, this could be in the type of physical activity conducted or the level of progression offered through the intervention. Higher adherence was also found in shorter RCTs with the median RCT length for the high adherence studies being 12 weeks, compared to 24 weeks for the low adherence studies. How frequently participants were asked to complete physical activity each week did not seem to impact adherence, but the length of the sessions did slightly alter between groups, with longer session times achieving less favourable outcomes.

People with dementia require a large amount of support in order to become physically active. It has been well documented that providing care for an individual experiencing a gradual but progressive decline, such as in the case of dementia, can be stressful and detrimental to the caregivers’ health (e.g. Savla et al, 2019); this has been termed differently between studies with resulting subtle variances in meaning, but all concepts used to capture these negative impacts on health (burden, strain, stress) point to difficulty that the caregiver experiences within the caregiving role. This lack of autonomy has been repeatedly found to inhibit physical activity participation (Stubbs et al, 2014; van Alphen, Hortobagyi & van Heuvelen, 2016). Increasing physical activity for people with dementia can, therefore, increase time pressure and burden or strain for the caregiver. Studies that require caregivers to take on additional responsibilities in order to support participants to be physically active, such as filling out diaries or guiding participants through the activity, could negatively impact adherence rates. This was most notable for Steinberg and colleagues (2009), who achieved a 59% adherence rate, the lowest of all reviewed studies. Interestingly, one on one support from either a caregiver or professional was found regularly in the higher adhered to studies. Some research has also pointed to concerns that caregivers may have about physical activity and their beliefs about the potential outcome of physical activity (van Alphen, Hortobagyi & van Heuvelen, 2016). This suggests that caregivers play an important role in adherence to physical activity and therefore should be considered and potentially consulted alongside the individuals with dementia when planning a physical activity intervention.

People with dementia often experience difficulties with verbal language production, resulting in them appearing unreachable (Ellis & Astell, 2017). It is however, possible to facilitate social interaction for people dementia despite inherent difficulties with communication. Physical activity is an example of an activity that can encourage social interaction, which has been suggested to be one of the key benefits of physical activity for people with dementia (Yvonne, Khoo, Schaik & McKenna, 2014). Many studies showing high adherence throughout this review were organised to have one-on-one supervision or be conducted in small groups. These group sizes offer increased opportunity for people with dementia to interact socially without getting overwhelmed. The included studies did not explicitly state why these group sizes were selected. However, it can be suggested that people with dementia being encouraged to interact socially during physical activity could be influencing their adherence to the provided intervention. It also promotes better control over health and safety concerns, such as falls.

The RCTs reviewed provided a supported and encouraging environment with materials or demonstrations that allowed for easy engagement with physical activity. An RCT, therefore, often represents the best-case scenario for facilitating physical activity. Under these supported conditions adherence rates were still not consistent. The studies with the lowest adherence involved home based activities with families and the people who have dementia still living in the community, rather than a residential or nursing home that replicates the environment of two thirds of people with dementia. The studies with the highest adherence facilitated physical activity within a small group of peers with supporting professionals available. This indicates an essential role for professionals being available to support and facilitate physical activity for people with dementia and their caregivers. This, however, is not always financially feasible and professionals often have to consider the cost benefit analysis in order to facilitate the appropriate number of instructors to support the number of participants attending without this becoming too costly.

Unfortunately, this review was limited as not all RCTs clearly report the adherence rates of their participants, as well as the surrounding information that can help to explain physical activity behaviours of people with dementia during the intervention. In order to best understand the adherence rates in the present study, the adherence criteria applied to each individual study was collated. This however, limited the comparison of individual studies adherence. Therefore, future reviews should seek to develop their own adherence criteria in which to assess RCTs against. This way a clearer comparision of the differences in adherence can be made. Although the methods of each study has been discussed a quality appraisal tool was not applied in this initial exploratory review of the literature, therefore the next stage of developing our understanding of adherence to physical activity is to apply a quality appraisal tool to appreciate the varying levels of evidence quality available throughout the literature. Despite limited information available on the adherence of people with dementia to physical activity interventions and a lack of standardised adherence criteria, the literature overall has indicated the problematic nature of adherence (e.g. van der Wardt et al, 2017). The studies included in this review all provided support for their participants to complete the activity, which in turn increased the chance that participants were able to engage with the provided activities. The varying levels of support offered had a resultant impact on adherence to the RCT.

Adherence support strategies have been discussed in order to maximise participation in physical activity for people with dementia. This further highlights that adherence can be problematic for people with dementia. By bettering our understanding of when barriers can be experienced, support strategies can be targeted to facilitate physical activity for people with dementia. Increasing physical activity levels could have immediate implications for the health of the individuals participating in physical activity, as well as wider implications for the cognitive and physical health of people with dementia (e.g. Groot et al, 2016; Pitkälä, Savikko, Poysti, Strandberg & Laakkonen, 2013).

Overall, this review has emphasised that people with dementia can adhere to physical activity, well with the appropriate support and facilitation by professionals. Where this support is less available or not planned into physical activity delivery, people with dementia show inconsistent adherence. This could be a result of an increase in barriers to physical activity for people with dementia and their caregivers. Facilitating physical activity was most successful with the support of professionals, either one to one, or in small groups. The subsequent chapters of this thesis, therefore, seek to better understand these barriers for people with dementia through the perspectives of people with dementia themselves, detailed in chapter 8; followed by the experiences of professionals who are positioned to help to reduce these barriers, discussed in chapter 9.

Chapter 8

Perspectives towards physical activity: walking interviews with people who have dementia

Chapter 8 – Perspectives toward physical activity: walking interviews with people who have dementia

8.1 Introduction

Up until the 1990s the perspectives of people with dementia were largely ignored within dementia research (e.g. Downs, 1997). Consequently, the experiences of people with dementia is a considerably under-researched area, with people with dementia traditionally excluded from research altogether (e.g. Nygard, 2006). This was a result of two misguided perceptions. Firstly, that people with dementia were difficult to access, which Lloyd and colleagues (2006) suggest is due to the well documented language difficulties associated with dementia (e.g. Klimova & Kuca, 2016). Secondly, that the verbal accounts of people with dementia could not be relied upon due to impairments in decision-making capacities (Smebye Kirkevold & Engedal, 2012). Prior to 2005 no legislation had specifically addressed the concept of capacity, or an individual’s ability to make decisions. In 2005 however, the mental capacity act stipulated a change in perspectives that has had subsequent implications for dementia research. The principles contained within the act most pertinent to research were firstly, that capacity should always be assumed. This is regardless of any clinical diagnosis; therefore, it is illegal to exclude individuals with dementia based on diagnosis alone. Secondly, a person’s ability to make their own decisions must be optimised before concluding that capacity is absent (Department of Health, 2005). Therefore, attempts to optimise representation of those with dementia in research is of heightened importance since the release of the act.

Moore and Hollett (2003) argued that these perceptions fail to take into account the abilities and diversity of people with dementia. Reviews have since demonstrated that people with dementia are well able to express their needs and should be included in research to provide valuable insights into their experiences (e.g. von Kutzleben, Schmid, Halek, Holle & Bartholomeyczik, 2012). Cowdell (2008) has also suggested that people with dementia are not only able to participate, but it is possible to do so even into the later stages of the illness.

Despite this increase in the inclusion of people with dementia in research, the debate as to the feasibility, ethical and methodological issues surrounding their inclusion persists (e.g. Pesonen, Remes & Isola, 2011). Many studies have utilised traditional seated interviews to better understand the perspectives of people with dementia, on topics such as living with dementia (e.g. Gillies, 2000), becoming cared for (e.g. Borley & Hardy, 2017), developing dementia friendly communities (e.g. Smith, Gee, Sharrock & Croucher, 2016); and the use of assistive technologies in dementia care (Newton, Dickinson, Gibson, Brittain & Robinson, 2016). These studies, alongside many others, demonstrate that it is feasible for people with dementia to participate in research.

Potential ethical and methodological issues have also been addressed. Ethical dilemas surrounding the topic of consent stem from many people with dementia lacking the capacity to give informed consent, and assessing whether capacity is present or not is particularly challenging (Warner, McCarney, Griffin, Hill & Fisher, 2008). Smebye, Kirkevold and Engedal (2012), however, suggest that capacity is not an absolute, fluctuates from question to question, and people with dementia can therefore be competent in some domains but less so in others. Research has shown people with mild dementia to have the capacity to participate in medical decision making as defined by legal standards (Moye, Karel, Azar & Gurrera, 2004). Many researchers have suggested altering consent procedures in order to accommodate differences in competencies between participants (e.g. Murphy et al, 2015). Further strategies have been discussed across the literature to tackle any issues that may arise while working with people who have dementia, for a review see Murphy and colleagues (2015).

Hellström and colleagues (2007) have stated that the problem does not lie in whether to include people with dementia in research, but in fact, how is best to include people with dementia. As discussed, conventional seated interviews are a feasible method. However, different methods of interviewing are yet to be fully explored. Mobile methods or walking interviews, offer a novel method of collecting data about movement whilst on the move (Büscher, Urry & Witchger, 2010; Ross et al, 2009). Walking interviews have been used for diverse purposes in previous research. For example, walking interviews have shown to be a viable and dynamic method of data collection for dog walking activity with healthy participants, generating rich, in-depth data (Cameron, Smith, Tumilty & Treharne, 2014; Campbell, Smith, Tumilty, Cameron & Treharne, 2016). Interestingly, this method was chosen as the topic of discussion pertained to the activity being conducted during the interview, walking with a dog. This generated rich and in-depth data that discussed aspects of dog walking as they happened.

To the author’s knowledge, Kullberg and Odzakovic (2017) are the only researchers, to date, to explore mobile methods of interviewing with people who have dementia. In this instance, the purpose of the interviews were to better understand the relationship people with dementia have with the environment, specifically the neighbourhood in which they live (Kullberg & Odzakovic, 2017). Kusenbach (2003) noted that collecting data on the move allows observation of interactions between participants and their environment while interviewing.

This method was therefore beneficial for Kullberg and Odzakovic (2017), as researchers were able to observe the interaction between their participants and the local neighbourhood in which they lived. Environmental cues were also continuously provided for researchers and people with dementia to draw upon and keep conversation flowing. In this instance, walking interviews enhanced the potential for people with dementia to present their perspectives. It has been proposed that by using walking interviews greater insight into movement related activities is possible (Carpiano, 2009; Trell & Van Hoven, 2010), compared to conventional seated interviews that do not allow for movement while interviewing.

Furthermore, researchers versed in this method noted that the distractions and natural interruptions caused by environmental stimuli during a walking interview result in a more comfortable and “free flowing” conversation, with the walk promoting productive distractions (Ross et al, 2009; Lee & Ingold, 2006). Previous studies have further highlighted the dynamic, multi-sensory nature of walking interviews that can enhance the richness of data collected (Garcia et al, 2012; Sheller & Urry, 2006; Law & Urry, 2004).

The research process has been critiqued for giving rise to uneven power relations between the researcher and the researched; as the researcher was more traditionally thought of as the source of authority (Karnieli-Miller, Strier & Pessach, 2009). These power relations in research have been particularly problematic for people with dementia. Mobile methods have been praised for their potentital to allow people with dementia to have control over the research situation, and to be more active compared to traditional sit-down interviews (Kullberg & Odzakovic, 2017). This shift in power relations has been found to be beneficial during both data collection and the analytic process. For instance, Cameron and colleagues (2014) found the mobile methods used in their study facilitated equality of power between interviewer and interviewee, this could be because the pair met at an agreed location and the participant led the walk, adjusting the emphasis of the interaction to fully engage both pariticpant and interviewer in the topic being discussed (Cameron, Smith, Tumilty & Treharne, 2014).

Mobile methods are not without logistical challenges, such as the physical health of the participant, the weather, the time of day, the safety of the outdoor area, risk for falls, equipment used and the level of analysis that can and should be engaged with (e.g. Carpiano, 2009; Garcia et al, 2012; Kushenbach, 2003; Evans & Jones, 2011; Hein et al, 2008; Miaux et al, 2010). However, these ethical tensions are a part of the everyday practice of doing research (Guillemin & Gillam, 2004) and researchers should always consider their ethics in practice regardless. Kullberg and Odzakovic (2017) demonstrated that walking interviews can be successfully carried out with people with dementia, but are yet to be utilized to understand the perspectives of people with dementia toward physical activity.

Numerous barriers to physical activity for people with dementia have been consistently highlighted in the literature (e.g. van Alphen, Hortobagyi & van Heuvelen, 2016). Findingd from a systematic literature review presented in chapter 7, however, found inconsistencies in adherence to physical activity for people with dementia. This suggests that barriers are most impactful in inhibiting longer term adherence. Despite the plethora of potential barriers to physical activity, recent research has shown people with dementia attribute positive meaning to and value physical activity (Lindelöf, Lundin-Olsson, Skelton, Lundman & Rosendahl, 2017). Alongside the well documented benefits of participation (e.g. Groot et al, 2016), discussed in more detail in chapters 1 and 6, it is imperitive that people with dementia have equal access to physical activity; and physical activity is made inclusive. As physical activity is a topic that involves bodily movement through space, walking interviews could be a beneficial method for interviewing people with dementia about physical activity. Conventional seated interviews were also conducted to discuss differences in data from the differing interview techniques as well as to offer participants a choice in their participation. This study, therefore, explores physical activity from the perspective of people with dementia while conducting light physical activity in the form of walking interviews and conventional seated interviews.

8.2 Methods

8.2.1 Pilot Study

Prior to commencing this study, a brief pilot study was conducted in order to gather an initial understanding of physical activity for people with dementia. Key questions were asked about whether they already participated in physical activity, what type of physical activity and whether they are willing to take up new and different physical activities. This pilot study also had the specific intention of developing a well-informed interview schedule to utilise in subsequent interviews with people with demenita.

Following ethical approval from Loughborough University, 38 participants were recruited from dementia events and groups throughout Leicestershire. Participants were both people with dementia and their family caregivers. Participants were shown a demonstration of seated resistance band physical activities within a group, the size of which varied from 2 to 10 participants. Following a demonstration, participants were asked to complete the feedback form (Appendix ?) in order to provide initial information regarding physical activity behaviours.

Of the 38 participants, 14 (37%) self-reported having dementia; 18 participants (47%) were female and 20 (53%) were male. The mean age of the sample was 73.63 (±10.51) years old, ranging from 50 years old to 91 years old. The most popular physical activities were walking and gardening, with a large percentage of the sample being active either 2 to 3 times per week or more than 4 times per week. This indicates that a large portion of this sample could already be meeting physical activity guidelines that suggest doing 150 minutes of moderate intensity physical activity per week in smaller bouts spread across several days (Chief Medical Officers, 2011). 30 participants (88%) also indicated that they would like to take up the demonstrated physical activity; 11 of which had dementia, while the remaining 19 participants did not. The 30 participants that indicated willingness to take up the new activity reported being both active and inactive. This suggests that activity was appealing to those that are already regularly being physically active as well as those who were not.

Participants were given the option to report their reasons for their response to the activity demonstration. Several participants cited reasons for wanting to engage with physical activity around the concept of enjoyment or because of the benefits to their health, both mental and physical. Others cited reasons such as sociable, active, new or different and easy. Those that did not want to take up the demonstrated activity offered explanations surrounding an inability to do the activity, previous injuries and general lack of interest. These initial pilot study findings suggest that people's willingness to engage with physical activity is influenced in many ways by their own health and enjoyment, with activities such as walking and gardening being of preference. These findings were then utilised in the development of the interview schedule utilised in the subsequent study.

8.2.2 Participants

In the main study of this chapter, participants were people with dementia recruited from community groups in the Leicestershire and Rutland area of the United Kingdom. Participants who took part in the physical activity study detailed in chapter 6 were the first to be invited to participate in this study. Previous participants responded enthusiastically to invitations which meant recruitment was not widened to inviting new participants as initially planned. Therefore, the participants in this study all took part in chapter 6 first. Participants were invited to Loughborough University to take part in a semi-structured interview regarding their experiences with physical activity. A semi-structured interview schedule was used to stimulate discussion about physical activity. Each interview, regardless of interview type, commenced with the same question in order to begin the participant in thinking about their engagement with physical activity across their lives:

> 'Interviewer: Can you tell me about a sport or physical activity that you played when you were young?'

Later questions then asked the participant to talk about their current physical activity:

> 'Interviewer: How have your physical activities changed since then?'
>
> 'Interviewer: What physical activity do you enjoy nowadays?'

The interviewee took an inquisitive approach that encouraged participants to discuss in detail their physical activity across the lifespan, in order to better understand their perspectives towards physical activity. For full interview schedule see Appendix 11.

Discussions were audio recorded and transcribed verbatim. Participants were also asked about their experiences in the earlier physical activity study that they had taken part in, as well as their experiences with physical activity across their lives. 9 participants in total completed interviews. Participants chose an interview type, either seated (n=4) or walking interviews (n=5), based on numerous factors, most notably, their preference and the weather on the day of interview. The ethical approval for this study was obtained via the Loughborough University ethical committe. Ethical considerations were made for the safety of participants while walking, which led to the caregivers being invited to join the interview process, regardless of the type of interview that the participant was allocated to.

Table 8.1 shows the characteristics of the participants in this study. The total interview time amounted to 129.55 minutes of data. The average interview length was 24.79 minutes for seated interviews and 26.66 minutes for walking interviews. Although, this analysis is based on a small number of participants and the ideal goal of a qualitative inquiry would be to reach data saturation (e.g. Fusch & Ness, 2015), considerations for the novelty of the methods at hand were made and researchers deemed 9 participants to be sufficient for this initial investigation. Potential for replicating this study is discussed later in the chapter, especially considering the further discussion that can be had about the suitability of the method for different individuals, such as those with different diagnoses of dementia, different levels of physical and functional ability, and other key wellbeing factors that may impact their engagement with an active method of interviewing.

Table 8.1: Characteristics of interview participants

	Participant with dementia	**Care Partners**	**Method of Interview**	**Interview Duration (in minutes)**	**Word count of interview transcript**
1	Sally	Ben	Seated	15:04	1919
2	David	Margaret	Seated	34.54	5482
3	Peter	Carol	Walking	31.05	4830
4	John*	*Not present*	Walking	10.49	1385
5	Tom**	Penny	Walking and seated	38.43	4061

*John chose to walk on his own, although his dementia appears more severe he is confident physically and was comfortable walking without his caregiver.

** Tom started his interview alone, Penny joined the interview towards the end and Tom chose to take a seat at this point.

8.2.3 Analysis

Inviting the caregiver to participate in the interview alongside those with dementia meant that the interviews often became a co-constructed discussion of the participants' lives together. The data was therefore treated as a shared account. Interviews with people with dementia and their care partners have been successfully conducted when discussing shared activities (e.g. Vikstrom, Josephsson, Stigsdotter-Neely & Nygard, 2008). It is in this sense that applying a thematic analysis seemed most appropriate. As Braun and Clarke (2019) reflect in their most recent writings on thematic analysis, themes are patterns of shared meaning that are underpinned by a core concept. In this instance, the core concept is physical activity as a couple and the shared meanings are derived through both participants engaging with the interview process and the researchers actively generating themes that tell a story of physical activity for these couples.

The subsequent analysis was conducted in two parts. The first part of the analysis applied a thematic analysis guided by the six steps laid out initially by Braun and Clarke (2006) and later discussed by Braun, Clarke, Hayfield and Terry (2019). This involved an initial familiarisation of the dataset. Codes were then generated inductively, meaning there was not a coding framework applied to these data. Coding required a continual bending back on oneself, questioning and querying the interpretations being made (Braun & Clarke, 2019). In this way, the application of a thematic analysis is synonymous with the critical realist approach which treats knowledge as fallible and should be subjected to inherent critique throughout the process (O'Mahoney & Vincent, 2014). Codes were then grouped and themes actively generated. Themes were then reviewed, defined and named. Data excerpts were selected to best describe the themes being discussed throughout the results section based on how clearly they portrayed the shared meaning being discussed. Lastly, the analysis was written up, offering an in-depth discussion of people with dementias' experience with physical activity.

During the initial familiarisation and coding of the data the influence of the methodology applied to the interviews was apparent to the researchers. In consideration of this novel walking approach for people with dementia, it was therefore decided to conduct a second analysis to offer a discussion of the methodology applied during these data. The interview scripts were therefore re-coded to comment on the methodology of the interviews and how this influenced the discussion of physical activity throughout the data. These codes were then grouped into two columns, the first was for seated interviews and the second for walking interviews. These codes, alongside researcher diary notes, were then used to inform a discussion of the methodologies seen in these data. This was then written up as a detailed description of the differences between the two interview types observed during data collection, from the transcripts of these data and later observed during the analytical process. This discussion intends to add a further layer of understanding as to whether discussing physical activity while being physically active is feasible and ultimately beneficial for people with dementia.

8.3 Results

Four key themes were identified in these data. The first, *Physical activity across the lifespan*, described the participants' experiences with physical activity from birth to the present day. The journey participants described indicated varying levels of physical activity at different times, both embedded into the participants' lives or added on as a intentional activity. The second theme is titled *Competition* and detailed the participants' interactions with competition throughout their lives and how this has impacted their approach to physical activity both in their younger years and in present day. In the third theme, *Injury and decline*, participants discussed their more recent physical capabilities. The story of injury management and age-related decline detailed in the third theme foregrounds the fourth and final theme, titled *Accumulated and Escalating barriers*, that showed the breadth of challenges participants have encountered when seeking physical activity opportunities.

8.3.1 Physical activity across the lifespan

Throughout these data each participant described their engagement in physical activity in varying phases across the lifespan. Physical activity, although given importance in most participants' accounts, was present at different times in participants' lives, in different forms, and frequently of less importance to other endeavours such as family life and career aspirations. Although physical activity engagement seemed to be consistent for these participants across their lifespan, the ways in which this was achieved, and the attitudes towards the activities could not be more varied. All participants introduced their experiences with physical activity by describing the sports they played during their youth, particularly during their school years. With most participants, this engagement was extensive and in multiple sports too, as David described here:

> I used to play Rugby, I used to play tennis, certainly table tennis. I don't suppose you count snooker. What else did I do? Hockey. I took up hockey. (David: I02)

On multiple occasions thoughout these data participants associated their childhood sporting experiences with school attendance. David, for instance, emphasised his participation in sport at school by calling his school a 'Rugby playing school' (David: I02). Peter, however, used the phrase 'when I was at school' (Peter: I03) to pinpoint the timing of his experience on 'a cycling holiday' (Peter: I03). An experience Peter reported as 'excellent exercise' (Peter: I03), which demonstrates his enthusiasm for consistent physical activity during his youth. This enthusiasm was apparent for other participants too, when Sally was asked whether she played sport at school, her response was 'Anywhere' (Sally: I01). This further implies the constant and important nature of physical activity during these participants' younger years. Moreover, Peter in this subsequent quote expresses the importance of, not only physical activity participation, but also physical activity achievement during youth.

> It used to be a very important part of my life to make sure I was, I think basically if you're one meter sixty-five or less and you're a kid, the ability to run quite fast is important (Peter: I03).

The phrasing Peter uses 'and you're a kid' (Peter: I03) infers a more widespread importance of physical activity for all children at school. Overall, despite physical activity being recurrently associated with school attendance in these participants' discussions, the two were not mutually exclusive. Physical activity during youth, in fact, seemed to have great importance for all participants regardless of setting. Research has reflected the importance of sport for children. For example, a Foucauldian analysis of children's experiences of organised sport found children associated physical activity with competition, fun and fair play (Walters, Payne, Schluter & Thomson, 2015). This idea of fun and competition was echoed by the accounts of participants in this study during their youth, and will be further explored in subsequent themes.

Following accounts of their youth, participants moved onto discussing their engagement with sports during the next phase of their lives. For Sally this meant at ‘University I played it’ (Sally: I01), but for David when asked if he played at University his response was: ‘No I had to go in, well I had to do national service.’ (David: I02). Although David did not specify which armed forces he entered, it prevented him from attending University. For those participants that did attend University physical activity, alongside other leisure pursuits, continued to be of high importance.

> I played, when I was a student I did actually play both squash and then I played at an advanced level of squash. I found it very useful for training in its own right and I did play hockey, you know, for the University, but only at the second eleven level. And I, my main sport was chess but that’s round the board activities and not, there was always a big debate as to whether chess was an athletic sport or not. The Russians always said it’s athletic (Peter: I03).

Peter is ironically discussing chess as a sport due to its competitive element, despite the lack of physical engagement. Through the phrase ‘my main sport’ (Peter: I03), Peter shows the multitude of engagement in physical activity that persisted for him throughout his University education. Ben discussed similar prioritisation of physical activity during this University phase.

> …When I was at University sport was a major part of my life but not since. Not in the last 60 years…(Ben: I01).

In this quote, Ben also introduced the next phase of the participants’ lives. This portion of adulthood consisted of physical activity based around a chosen career. David, who had mentioned not going to University in order to join the army, described how ‘Oh we had to do all sorts of physical activity’ (David: I02). Much like in childhood where the discussion of physical activity and school was interchangeable, participants discussed physical activity alongside their careers in adulthood. Carol for instance, described how ‘we used to be able to go on long cycle rides when Peter was working’ (Carol: I03).

In addition to career discussions, participants spoke about their engagement with physical activity through family life. Research suggests parenthood is associated with a less healthy diet and exercise patterns (e.g. Reczek, Thomeer, Lodge, Umberson & Underhill, 2014). Being physically active with the family, however, participants implied to be more incidental than any previous engagement. Ben, for example, discussed Sally as '…the active one. Just bringing up five kids…' (Ben: I01). Margaret further emphasised this:

> I don't think we did a lot of like team things when we had small children. We used to take them out on a Sunday rather than put them on a treadmill, we used to take them out round the park and that (Margaret: I02).

Margaret also discussed how this physical activity positioned in family life as different from any activity she had been involved with previously. She used the term 'we' to discuss her and her care partners joint engagement. Where University and school might have involved 'team' (Margaret: I02) sports and running on a 'treadmill' (Margaret: I02), family based physical activity consisted of 'pram pushing' (Ben: I01), which 'would have been about your exercise' (Ben: I01). Additionally, Carol introduced the social and fun element of physical activity when incorporated into family or home life.

> We all played at, we had a silly table at home and we used to play silly table which is great fun (Carol: I03).

Using the term 'We' (Carol: I03) Carol evokes a sense of togetherness through physical activity, alongside 'great fun' (Carol: I03). Many of the participants discussed this concept of social connection and fun through physical activity. Penny, for example, discussed her experiences with their Badminton club 'always go(ing) for a drink on the last night before Christmas…' (Penny: I05). Although going for a drink is not a physical activity in itself it is because of the physical activity, Badminton, that this group of people knew each other and were able to socialise together; allowing Tom and Penny to have this consistent social experience throughout their adulthood.

The social, family and career based physical activity during adulthood meant that for participants 'time was at a premium' (Margaret: I02); for Margaret this was 'because I then went to college and I was working and David was working' (Margaret: I02). However, when participant's retired from their chosen careers, the discussion of physical activity once again changed. Literature has highlighted that retirement is a major life transition which may influence health behaviours and time use, with increases observable in total and domain specific sedentary time (e.g Leskinen et al, 2018). This is potentially a result of increase in available time to be sedentary without work commitments. Participants discussed physical activity during this phase of their lives as having a higher prominence in day to day activities for the first time since University or childhood. Margaret introduced her and David's retirement by saying 'When we retired we took up cycling and walking with the caravan' (Margaret: I02). David followed on by saying:

> We had the caravan and the motorhome and we spent about three, four months a time abroad at least once or twice a year (David: I02).

During these long periods of time in their caravan, Margaret and David were engaging in new physical activities that they had chosen and 'took up' (Margaret: I02) during their retirement. This suggests a new phase of adulthood that allowed participants the time to engage with a variety of physical activities that they were previously less able to do due to career and familial commitments.

Following early retirement, however, for these couples came a diagnosis of dementia. This, as observed throughout these data with most events across the lifespan, had an impact on the participants' physical activity behaviours. Although physical activity has continued, participants described adjustments they have made to account for symptoms and difficulties associated with the dementia, as well as other mobility issues that came with older adulthood. Penny discussed how she and Tom have continued to swim, but that more recently she has made adjustments to their routine in order to maintain this physical activity:

> …a lot of help getting sorted before and after, but we go in a family changing room now so there's more space and I can help him get changed. Because he was going in the locker [room] on his own and he was ages just sitting there (Penny: I05).

Penny discussed getting ready before and after swimming as problematic, as opposed to the physical activity itself. This suggests that the difficulties Tom is experiencing do not inhibit his ability to swim, but do hinder his ability to perform activities of daily living, such as getting changed. This is encouraging for Penny as this means Tom can continue to be physically active with appropriate support. Penny applies the phrase ‘a lot of help’ (Penny: I05) to further describe Tom’s care needs before and after swimming.

Ben and Sally did not report such issues with physical activity engagement, and in fact discussed an increase in Sally’s physical activity as a result of her receiving a diagnosis of dementia. Due to Sally’s diagnosis she was recruited to participate in a study that educated the couple on physical activity and mandated Sally’s engagement in a physical activity that she had not engaged with previously. Ben described Sally’s activity as an ‘intensive blood flow to the mind’ (Ben: I01). Although Ben admitted that he was unsure of the ‘word for the sort of exercise that was involved’ (Ben: I01), the result of Sally’s involvement was ‘Certainly more structured exercise’ (Ben: I01) whereby the people in which Sally chose to be physically active with ‘have become friends’ (Ben: I01). Ben continuously related Sally’s engagement back to the study as the beginning of their recent experiences with structured physical activity. David discussed a similar structured physical activity routine that he was first shown when in the hospital. David described completing these physical activities daily, indicating a consistent commitment to physical activity through retirement and dementia diagnosis.

> Because in the hospital, they told me one time about foot exercises. So I do heel and toe, heel and toe. You know sort of no great effort and running your feet and I go into the study where there’s a bit more room and there is a long sofa so if I lose my balance then I can sit down and I do various exercises there. So I suppose all in all I do it in the morning [for] about half an hour (David: I02).

David further discussed how these activities have ‘changed somewhat according to my muscles and problems at the time’ (David: I02). Similar to Penny’s experiences, these quotes highlight more recent physical activity requiring participants to adapt to continue to be physically active. Encouragingly, participants discussed continuing their physical activity regardless, this may be due to the enjoyment and numerous benefits they observe from participating in regular physical activity. Peter supported this suggestion, asserting that he…

> would be very keen to do any exercise that I can do. I’ll be happy to do and I’d like to improve the amount of exercise that I do do (Peter: I03).

This enthusiasm for an increase in physical activity since being diagnosed with dementia was echoed by participants. As described by Penny and David, however, this was not without an increase in difficulties. The theme *Injury and decline* discussed in section 8.3.3, details how participants perceived physical and mental decline to impact their physical activity, despite their observable eagerness to continue and even increase their physical activity. This eagerness could be because participants associated competition and fun with physical activity across the lifespan. The next theme, therefore, explores the role of competition for people with dementia.

8.3.2 Competition

Participants described varying levels of competition as important to, their engagement with physical activity across the lifespan. Competition, in the form of sports, has been shown to provide unique benefits above and beyond participation in general physical activity, such as companionship, motivation to work harder, the joy of a challenge, among others (Dionigi, Baker & Horton, 2011). Competition has, therefore, been widely used as a behaviour change technique for physical activity interventions (e.g. Peng, Crouse & Lin, 2013). David discussed his experiences in the navy playing different social games and how this became incredibly competitive, despite being a ‘simple game’ (David: I02):

> …depends on how you play it. When I was in the navy they used to play a lot of cluedo, which was called uckers in the navy and it was a fetish but it was played on sort of cut-throat principals and you know it’s surprising how you can make a simple game like cluedo cut-throat (David: I02).

David described a ‘cut-throat’ (David: I02) approach to social activities suggesting he enjoys a very competitive approach to activities. Peter also described a similar competitive approach when discussing playing crib with Carol:

> Carol and I used to play crib but when I found she always beat me we stopped (Peter: I03).

Peter in this quote demonstrated an unwillingness to lose, David showed the same approach when he discussed how ‘I don’t like losing certainly. Never did’ (David: I02). The words David chose to use in this quote ‘Never did’, and the scenario Peter described that involves him no longer participating if he does not win both suggest that being competitive is an inherent part of these participants’ identities. The competitive experiences Peter and David discussed in these quotes however, were in social settings, but this approach to competition was apparent in participants’ physical activity accounts too. In the subsequent quote, for instance, David discussed how he is no longer at the ‘standard’ (David: I02) that he has been previously; and without someone to compete against he suggests that he would no longer enjoy that physical activity anymore:

> … I think I could probably play table tennis but I wouldn’t have a hope in being anything like the standard I was so in other words I could play ping pong against some other person who also plays ping pong but really you get bored with that so it wouldn’t work out (David: I02).

Participants, like David does here, discussed competition against another player. Peter also discussed competition being against the clock rather than another individual or team:

> It’s amazing how keen and enthusiastic the neighbours are to talk to you when you’re doing a timed walk. It really is astonishing. (Peter: I03)

In this quote, Peter jokingly puts across his frustration when trying to win a small competition with his care partner. This suggests his desire to win, even though the competition is only a small motivator himself and his care partner have chosen to add into their physical activity routine. For both David and Peter, regardless of the type of competition being undertaken, competition is a large aspect of physical activity engagement for them. For other participants, however, it was part of their identity to not be competitive about physical activity. For example, Ben described his and Sally’s family as a ‘Strictly non-sporting family’ (Ben: I01). This suggests that Ben and Sally were less interested in engaging in the competitive element of physical activity. In this subsequent quote however, following Sally’s participation in a research study she sparked an interest in engaging in physical activity:

> …the research that so obviously had a beneficial effect and Sally enjoyed it and that and so on. So when the research exercise finished, we said well come on let's keep this process going and that's ended up with the class (Ben: I01).

Although Sally does not enjoy traditional competitive sport, her introduction to structured physical activity offered through a recent research opportunity had been a hugely positive experience for her and instigated an increase in physical activity engagement. This suggests that physical activity can be beneficial for participants, but those who were competitive during their youth and early adulthood remain so across their lifespan and through dementia diagnosis. This can affect their enjoyment and participation if they perceive themselves as less able to compete at the same level as before the diagnosis. The next theme explores the reasons participants may feel less able to compete or engage with physical activity in their older adulthood.

8.3.3 Injury and Decline

A recurrent theme throughout these data is the inevitability of decline or injury in physical capabilities. Participants did not often associate this decline with their dementia, but more commonly attributed this decline to ageing in general. The process participants are describing could be termed as frailty; a process that results from a decline in stress response systems and age-related biological changes (Walston, 2017). Although research has suggested frailty to be malleable and potentially even reversible, given the appropriate intervention (e.g. Holland, Garner & Gwyther, 2018), David asserted that…

> The thing is of course when you get to my age you're on a one way street and there's no going back. (David: I02)

When David discussed this feeling of 'no going back', he expressed frustration towards his current physical difficulties. This perception of helplessness is apparent throughout various studies detailing older adults' experiences with frailty (e.g. Puts, Shekary, Widdershoven, Heldens & Deeg, 2009; Faes et al, 2010). David also asserted that he would not engage, 'not until I get new legs' (David: I02), because in his opinion 'you can't make them as good as new' (David: I02). Peter reflected this feeling of decline or feeling 'decrepit' (David: I02) by stating: ‘I’ve done it all my life but it’s more, it is more difficult now’ (Peter: I03). The use of the phrase ‘all of my life’ suggests that the difficulties with physical activity are only in the present day and have not been problematic prior to the most recent years of Peter’s life. This further implies an importance of physical activity preceding the decline in physical abilities. Margaret offered a timeline for when she and David began to reduce their engagement in physical activity:

> No, no since we gave up the caravan, first of all we were cycling, we used to cycle at home a lot. But then since we gave up the caravan so just the last two years really. David has not been wanting to walk and of course I had a replacement knee so that limited [our activity] (Margaret: I02).

Margaret presented a relatively short timeframe, just two years, in which her and David’s engagement in physical activities had reduced. She also points to a knee injury or related problem as the potential cause or confounding factor for this reduction in physical activity. Other participants had also been experiencing physical decline in more recent years, but not in general physical capabilities as they relate to physical activity. Rather, changes were seen in tiredness, mobility and balance during day to day life. David described how ageing drastically impacted tiredness levels:

> Well I mean I don’t do it much then but ummm as you get older you don’t benefit from a short rest so much as you do from a much longer rest and you know it takes you longer to recover your energy (David: I02).

The tiredness David discussed could impact on the amount of physical activity he is able to participate in, but could also influence his activities of daily living. Penny explained how Tom experiences difficulties with his mobility, which impacts directly on his activities of daily life. Penny discussed how Tom finds his current physical health difficult to manage:

> He struggles when he gets out of bed, we’re in the bungalow you know but he’s sort of hanging on all the way down the hall to the bathroom (Penny: I05).

The difficulties Penny described in this quote involve Tom’s mobility and balance upon first waking up in the morning. Balance problems are a common challenge for individuals with dementia resulting in an increased risk for falls, with studies showing fall risk to be around double that of cognitively healthy individuals (e.g. Allai & Verghese, 2017; Tinetti, Douchette, Claus & Marottoli, 1995). Moreover, systematic review and meta-analysis found a consistent inverse association between frailty and quality of life among community dwelling older people (Kojima, Iliffe, Jivraj & Walters, 2016). The 'struggle' (Penny: I05) Penny described here could therefore be Tom's quality of life being impacted by his physical difficulties. David also described balance difficulties explaining how 'I go not exactly dizzy but I lose balance' (David: I02). To counteract his balance difficulties David utilises mobility aids. He discussed how 'the stick is very necessary.' (David: I02). Tom also discussed using a walking stick to aid with his balance, suggesting that using mobility aids, such as walking sticks, provide the support participants require in order to continue to conduct their activities of daily living and get about. Peter also discussed how his muscular response to physical activity now 'hurts' (Peter: I03). He further described this sensation:

> I expect with any exercise that the muscles will have a response but ummm the lifting my arms for above my head for a period of time, they do ache quite a lot.' (Peter: I03).

Although a number of the physical ailments participants discussed were potentially a part of general ageing, balance issues could be attributable to dementia specifically. Other injuries could also be resulting from earlier life sporting engagement. Each participant described or pointed to a substantial injury. However, the context in which these injuries were discussed often framed a resultant physical activity difficulty in present day. For example, Peter used the phrase 'but I think that's probably down to the neck hurting' (Peter: I03) to attribute blame for a current physical activity difficulty. Ben also framed his discussion of Sally's injury in a similar way:

> broke her arm in France…eighteen months ago and as a result of that her mobility in her left arm, it was quite a bad fracture and they cured it not by plating it but by keeping it immobile and letting the thing grow and the result was of course that the mobility in the muscles [was reduced] (Ben: I01).

With both injuries like the one Ben describes, and age-related decline, participants discussed the physical challenges associated with their physical difficulties. Participants, however, offered further insight into the additional difficulties that can follow physical decline or injury. For example, Peter described his experiences with a balance therapist following a neck injury, Carol suggested that Peter's confidence was also influenced by the neck injury and not just the physical balance issues:

> Carol: You did lose a lot of confidence didn't you once your neck got bad.
> Peter: Yes.

This suggestion of a psychosocial impact of physical challenges has been discussed throughout literature pertaining to frailty and positive psychology as well. Researchers have suggested a distinct intertwining between the concept of psychological resilience and physical frailty (Holland, Garner & Gwyther, 2018). This research is currently limited in the available evidence, but as participants have indicated here, this could be an important association in understanding physical activity in older adulthood. In the quote below, David demonstrated a resistance to engaging in physical activities that he might find difficulties with. This suggests a potential fear or cautiousness toward physical activity due to mobility and balance problems. David used the term 'don't want' (David: I02) which implies, not that David is physically incapable of engaging with the activity being discussed, but is in fact unwilling. This suggests a substantial influence of the psychosocial aspects of engagement with physical activities.

> I don't want to stand up and put myself in a position where I'm going to keel over (David: I02).

Peter further explained how psychosocial factors influence his physical activity behaviours. Peter discussed a neck injury and muscle aching and pain as his key physical challenges when engaging with physical activity. He described how he is unsure of how much he can physically manage without causing further damage, using the terms 'limitation', 'irritating' and 'a pain' (Peter: I03) Peter highlights his frustration with his injury difficulties and current cautiousness around certain physical activities:

> It is a limitation and what is from a medical viewpoint irritating is I don't know if it's a pain I can ignore which is what I'd do if I was circuit training or whether it's

> something that I need to say well that’s it because I’m causing damage to the muscle or bone I should not be doing that (Peter: I03).

In this instance, Peter suggests an uncertainty around his own injury and decline. He is unsure of whether it is medically advisable to continue to do vigorous physical activity when experiencing aches and pains related to his previous injuries. Similarly, Tom discussed not wanting to over-exert himself either: ‘No, no, no. I don’t like overdoing things’ (Tom: I05). Although Tom does not offer an explanation as David did, his assertion shows that the varying difficulties participants experience with injury and decline can mean that engaging in physical activity across the lifespan, regardless of dementia, can be challenging. Therefore, adjustments to physical activity are necessary in order to continue being active and participants described the ways in which they have continued to be active despite their health status.

Participants discussed both adjustments they have made to their physical activity behaviours, as well as direct interventions from professionals such as physiotherapists, that have impacted their current engagement with activity. Sally’s arm injury discussed earlier, for instance, was followed by ‘physiotherapist… for a session once a week. Initially focusing on simply getting the movement back in the arm’ (Ben: I01), ‘but as a consequence of that we’ve got a hand bicycling machine’ (Ben: I01). This, Ben went on to explain, has led to daily structured physical activity for Sally to complete with her paid caregiver who supports Ben with caregiving. The impact of an injury, discussed by participants, although damaging and painful after recovery frequently resulted in an increase in physical activity. This was observed across the lifespan for David who ‘took up hockey when I was crippled from rugby’ (David: I02) in his earlier adulthood, but in other more recent instances this has resulted in physiotherapist engagement:

> I collected some injuries sort of periodically that I had to go to physiotherapy. I mean I once went to the spinal injuries clinic. (David: I02).

Alongside specific interventions following injury difficulties, participants also discussed how they have adapted their day to day lives to account for changes in physical capabilities. Penny, for example, discussed how using mobility aids has enabled Tom to remain physically active. In this instance, Tom and Penny were on a family holiday which requires walking.

This type of incidental physical activity can be troublesome for Tom, as Penny explained earlier in these data. Using a wheelchair for reassurance Tom was enabled to continue with more physical activity than he would have otherwise done so:

> [B]ut on the last day we got hold of this wheelchair but Tom walked down with this wheelchair, holding it, and he could of got in but he didn’t he walked all the way down to the seafront, just twenty yards away from the seafront and we went in all of us and had a drink and then he started off pushing this wheelchair back and then my daughter and son-in-law said as soon as you feel like you’ve had enough, get in and we’ll push you back but he made it, very slow, we had to keep stopping, all the way back up this hill. It was like a Z-bend. Yeah, he made it all the way back (Penny: I05).

The experience Penny discussed in the preceding quote involved Penny considering Tom’s physical capabilities prior to engaging with the physical activity. Much like these considerations David discussed adapting his physical activity routine following a minor stroke.

> So I had this sort of minor stroke that sort of effected my knees. So everyday I’ll start off by just sitting on a low stool in the kitchen and just standing up, sitting down, standing up sitting down (David: I02)

In this instance, the physical activity routine David describes was instigated as a result of the adverse health event. The adaptations participants make, however, may not be as large as beginning a new physical activity routine. John, on the other hand, makes sure that when he goes walking he walks in ‘places where I can get round easily, without getting stuck’ (John: I04). Peter, also adapted his walking behaviour following advice from the balance therapist. This involved walking on the field near his home deliberately where the ground is uneven:

> it’s got big clumps of grass on it and I mean big clumps of grass and my physiotherapist for balance suggested I should walk on uneven surfaces as opposed to this that is a very even surface indeed (Peter: I03).

Peter compares the surface walked on during the interview with the uneven grass. Peter also further remarked that ‘the balance therapist has actually helped’ (Peter: I03). Whether during incidental physical activity or through a direct intervention from a professional, physical activity adaptations were discussed positively and were followed by increases in physical activity engagement. Overall participants highlighted the ongoing issue of decline within their day to day lives, affecting both their physical activity behaviours, but also their activities of daily living such as getting up in the morning, changing for swimming, for example. All participants, however, presented physical activity solutions that they applied in order to continue being active.

8.3.4 Accumulated and Escalating Barriers

Participants discussed a multiplicity of barriers to physical activity participation. Many of these have been previously cited in the literature (e.g. Innes, Page & Cutler, 2016; van Alphen, Hortobagyi & van Heuvelen, 2016). Although these barriers were varied and different from couple to couple, these data highlight the plethora of difficulties people with dementia and their caregivers have in completing physical activity. The multiplicity of roles each individual plays, caregiver or person with dementia and husband or wife, impacted the interactions between spouses. Discussions of physical activity in these data were between spouses and therefore inferred how interactions could impact physical activity behaviour as a couple. Margaret and David, for example, consistently showed tension in their relational dynamics. Margaret expressed disappointment in David not participating in the activities she enjoyed, such as tai chi:

> There’s no point in asking him anymore because he’s made up his mind and that’s it (Margaret: I02).

Here Margaret states that David is unwilling to change his mind once he has made a decision, implying a stubbornness that is accompanied by tension throughout the interaction. Margaret further suggested that she thinks David and herself should be doing more walking and then again reiterated her previous point in the subsequent quote:

> No, no I think we should be walking I really do. But David’s I don’t know quite how to put it, he’s convinced that he can’t so he doesn’t try (Margaret: I02).

Margaret's repetition of this point suggests a frustration towards David for not participating in physical activities with her more. This tension persisted throughout the interview and frustrations were reflected in David's comments too. In the following quote, he comments on how Margaret is interacting with the interviewer. Although this quote does not pertain to the couple's physical activity behaviours, it highlights how much relational tension exists between Margaret and David:

> Well she always does she'll then monopolise the conversation and I will say 'well bugger it' (David: I02).

David and Margaret, despite their interactions engaged with reasonably high levels of physical activity. They did report engaging with physical activity independently, rather than as a couple. In contrast, Tom and Penny demonstrated a need for each other's support in order to complete physical activity. For instance when walking with the interviewer Tom requested to sit down until Penny re-joined him and the interviewer, as he did not want to continue without her.

> Alright we'll sit down on one of these chairs and watch it, looking that way because she's going to come that way (Tom: I05).

This suggests that relational dynamics can impact physical activity behaviours in numerous ways. Penny also discussed the support she offers Tom in order to facilitate continuous physical activity for him, as shown previously (under injury and decline).

> a lot of help getting sorted before and after but we go in a family changing room now so there's more space and I can help him get changed. Because he was going in the locker [room] on his own and it was ages just sitting there (Penny: I05).

The relational dynamics between Tom and Penny indicate an adjustment needed for the carer, cared for roles which in turn facilitates joint physical activity. In addition to relational dynamics, participants discussed logistical challenges that impact the opportunity for physical activity. Ben, for instance, discussed how his daughter (Melissa) orchestrated the setting up of an affordable physical activity class at the local gym due to previous lack of affordable provisions locally.

> Melissa [daughter], in effect, organised the fusion people at the leisure centre and the borough council to contribute some modest funding so it only costs £3 a week (Ben: I01).

Alongside the affordability of physical activity is the barrier of travel to the opportunities that are available. Peter discussed how traveling to and from the nearest town can be time consuming and, therefore, problematic for older adults living in villages.

> and some of them come to the gym and others say they'd like to come to the gym but there is a problem, probably shouldn't mention it, in *Local town*, because the nearest, the main gym centres and about fifteen miles away from *Village* and urrr it's quite hard to get there. It's a good three quarters of an hour drive (Peter: I03).

The timescale Peter denotes in this instance suggests a difficulty with spending too much time on physical activity endeavours. David reflected the lack of time available for physical activity as a barrier to his engagement and similar hobbies 'one of which of course is finding the time to do it' (David: I02). The diverse of barriers discussed by participants suggests that physical activity, although part of participants' lives, is not achieved without difficulty. The barriers discussed, however, are not consistent between participants. Relational dynamics for example, resulted in increased difficulty engaging with physical activity for one couple, but for another facilitated physical activity. This theme thus suggests that the challenges individuals with dementia and their caregivers face as a couple are varied and personal. Considering this variability, it is important that support is provided for people with dementia and their care partners to navigate the barriers restricting their participation in physical activity. Professionals in various settings can frequently fill this void and increase physical activity for people who have dementia. Professionals such as leisure centre staff members, community coaches, charity volunteers and employees, care home staff to name a few. The diverse barriers, particularly those relating to mobility and physical health, were observable during walking interviews, suggesting a potential impact of methodology during the interview process. The next section of this chapter examines the impact interview type had on the data collected.

8.4 Does moving impact conversation about movement?

Five participants took part in three walking interviews, the remaining participants took part in seated interviews. This allowed comparison between the interview type, and discussion of how this impacted data related to the topic of physical activity. The first point to note from observations was that participants who chose to be interviewed while seated showed signs of being uninterested and distracted throughout the process. Sally, for example, gave short one-word answers and sometimes just noises as the interview progressed ‘Hmmm’ (Sally: I01). As Sally was more and more disengaged from the interview process as the interview went on, this suggests that she was perhaps bored or tired in the traditional interview setting, and therefore less willing to talk about physical activity. Sally also fell asleep at one point in the interview. While Ben was talking, he suddenly asked ‘are you with us?’ (Ben: I01), directed at Sally.

> Then as soon as Sally, well you came to *Leicester* didn’t you after that to do, dear dear what do you call that teachers qualification that you got at *Leicester*? Teaching diploma… helloooo, are you with us? (Ben: I01).

Sally did not respond when Ben asked if she was ‘with us?’, this led to Ben eventually becoming frustrated with repeatedly trying to wake Sally and he began to answer the questions on behalf of Sally instead. He then asked: ‘Do you want me to carry on with the dialogue?’ (Ben: I01). This shows that he was not sure if he should continue with the interview about Sally, but that he was giving up trying to keep Sally awake now. This only happened in the seated interview scenario. Research has shown people with dementia have increased tendency to fall asleep during the daytime, as well as increased wakefulness during the night, commonly known as sundowning (e.g. Bonanni et al, 2005; Sterniczuk, Dyck, LaFerla & Antle, 2010). Therefore, asking participants to remain in a seated position for an extended period of time is likely to result in drowsiness. This suggests that walking interviews may be a more favourable strategy when trying to talk to the person with dementia, as walking and talking will keep them awake and engaged in the interview process.

Furthermore, in the second seated interview, David often spoke about his life experiences that were less related to his physical activity behaviours. Margaret showed frustration towards David for going off topic and this, in turn, resulted in relational tension within the seated interview setting. In this subsequent dialogue David and Margaret are speaking to each other:

> Margaret: They don’t want to know all that.
> David: Oh well nevermind he went in the army (Margaret and David: I02)

The distractedness of David and the daytime sleepiness shown by Sally, in the two seated interview scenarios suggested that seated interviews were not able to maximise the time with participants as they were less appropriate for facilitating conversation about physical activity. This could result from the sedentary nature of a seated interview being unstimulating for people with dementia.

People with dementia, and certainly those with more severe symptoms, might benefit even more from walking interviews due to the environmental cues that are available to them in a walking interview scenario. The environmental cues available in a seated interview scenario do not stimulate physical activity conversation in the way that being out for a walk can. It was noted in these data that the interviewer could ask questions about the physical activity being conducted to stimulate further talk about physical activity. For instance, ‘and this pace is okay for you?’ (Interviewer: I04) or ‘do you want to keep walking?’ (Interviewer: I03). In the second example Peter responded: ‘Oh yes for about half an hour, we’ll be fine’ (Peter: I03). This indicated to the interviewer that Peter was able to walk for long periods of time and also that he was happy to do so. This further provided evidence for the information Peter was discussing and was able to re-new conversations about physical activity.

John, although in a walking interview setting, was not as talkative as other participants, but through walking the interviewer was able to observe how comfortable John was with light physical activity, and ask questions about what John was doing while walking and then help to facilitate richer conversation. When the interview was drawing to a close John and the interviewer headed back towards the building. This involved walking up a short flight of stairs together. Here the interviewer asked about John’s current physical capabilities, as the stairs as the environmental stimuli gave the opportunity to explore a further layer of information about John and his physical activity. This can be seen in the subsequent dialogue:

> Interviewer: So you’re still pretty good on the stairs.
> John: Yes I manage.
> Interviewer: Do you have stairs in your house or do you live in a bungalow?
> John: No, we don’t have stairs. Well, we do for little things.
> Interviewer: Right, we’re going to go up now so do you think you’ll be okay with this big staircase or would you prefer we used the lift?
> John: No I’m quite even with both (Interviewer and John, I04).

This, again, happened in interview five whereby Tom used a mobility aid which allowed the interviewer to understand more about Tom’s physical capabilities and subsequently engagement in physical activity. This dialogue with Tom showed the role of the walking stick in stimulating the conversation. The interviewer asked whether Tom ‘always walk(s) with the walking stick? (Interview: I05) and this prompted the conversation about physical movement and provided a productive distraction for Tom to begin to feel comfortable with the walking interview scenario.

> Tom: Oh there it is there, yea. That’s it yea. This is my stick. Don’t you know.
> Interviewer: Brilliant. So do you always walk with the walking stick?
> Tom: Usually yeah (Interviewer and Tom: I05).

Overall, differences in the interview data were noticeable between the two types of interviews. Walking interviews facilitated engaged conversation. Environmental ques reassured participants of the topic of conversation and stimulated wider discussion of physical activity between participants and interviewer. Seated interviews were less successful and participants in the two circumstances discussed here, were disengaged and drowsy within the sedentary seated interview. This restricted topic conversation and placed limitations on the data that could be collected.

In conclusion, walking interviews were not only feasible for people with dementia, but data suggests that they were in-fact advisable as they showed noticeable increases in stimulated conversation and participant engagement. Although initial analysis (see Table 9.1) suggests no absolute difference in number of words or duration of conversations elicited, the form of the interview, such as level of engagements, how tired or distracted the participants is, was apparent in interview content.

8.5 Conclusions

The four key themes derived from the perspectives of people with dementia presented throughout this chapter: *physical activity across the lifespan*, *competition*, *injury and decline* and *accumulated and escalated barriers*; demonstrated the diversity of experiences people with dementia associate with physical activity. The two themes "physical activity across the lifespan" and "competition" showed how participation in physical activity can either increase or decrease, depending on the individuals. In both these themes, participants demonstrated differing responses to the same topic, showing that competition and phase of the participants' life can increase or decrease physical activity participation for people with dementia. The subsequent themes "injury and decline" and "accumulated and escalated barriers" offered further insight into the barriers most common for individuals with dementia. Future physical activity interventions and promotion should, therefore, target the common barriers people with dementia experience that have been highlighted in these data and previous research (e.g. Innes, Page & Cutler, 2016; van Alphen, Hortobagyi & van Heuvelen, 2016).

The relatively novel methodology applied in this study has further suggested that walking interviews are an appropriate method for interviewing people with dementia. Kullberg and Odzakovic (2017) demonstrated this when exploring how people with dementia interact with their neighbourhood. The present study found that it is also feasible to discuss the topic of physical activity through mobile methods with people with dementia. This, in several circumstances, gave the opportunity to use environmental stimuli to facilitate conversation regarding physical activity. Participants also spoke freely and comfortably whilst walking, as found in previous studies with people without dementia (e.g. Ross et al, 2009; Lee & Ingold, 2006). Walking interviews encouraged topics relevant to conversation and environmental stimuli allowed for relevant distractions that supported wider discussion of the topic.

Care partners have a large and complex role in the facilitation of physical activity for people with dementia (e.g. Tretteteig, Vatne & Rokstad, 2017) and taking into account the ethical concerns that can arise from walking with people with dementia, this study chose to include care partners if participants were happy to do so. This also supports the inclusive approach taken throughout this thesis. By including both people with dementia and their care partner interactions between participants, as well as between participants and the interviewer, gave the opportunity for more in-depth conversation and rich data. This layer of added information gave further insight into how the care partner and person with dementia interact around the topic of physical activity. This allowed researchers to explore the relational dynamics impacting physical activity behaviours, as well as overall barriers to and facilitators of physical activity.

This study was limited by the small number of participants that completed walking interviews. Due to the novelty of this approach, a small sample size was selected to assess the effectiveness of the method. Following these interviews that have demonstrated the feasibility and benefits of conducting walking interviews with people who have dementia, future studies should seek to further explore this topic with a wider range of participants who have dementia.

In consideration of the wide range of barriers people with dementia discussed encountering personally, future studies should better establish the strategies that can increase physical activity participation for all people with dementia. These strategies should aim to increase physical activity participation for all people with dementia regardless of participant factors. Local authorities have a responsibility to promote physical activity amongst older adults, but knowing how to stimulate regular activity at the population level is challenging (McPhee, French, Jackson, Nazroo, Pendleton & Degens, 2016). Professionals who work with people who have dementia seek to bridge the gap between barriers and physical activity engagement with people with dementia. The next chapter therefore, explores the professionals' perspectives toward physical activity for people with dementia.

Chapter 9

Physical activity for people with dementia: Professionals' perspectives

Chapter 9 – Physical activity for people with dementia: Professionals' perspectives

9.1 Introduction

Substantial health benefits for engaging in physical activity have been evidenced across the lifespan (Northey, Cherbuin, Pumpa, Smee & Rattray, 2017; Groot, et al, 2016). Current discourses based on 'successful ageing', however, position older people as responsible for engaging in physical activity and other related health behaviours to produce good health (Stephens, 2017). This discussion of healthy or successful ageing has been critiqued for oppressing older people, as not all older adults are able to age successfully (Breheny & Stephens, 2017); and many remain inactive throughout older adulthood (Dumith, Hallal, Reis & Kohl, 2011).

Some older adults believe that physical activity is unnecessary or even potentially harmful (Franco et al, 2015); others recognise the benefits, but report a range of barriers that inhibit their participation (Van Alphen, Hortobágyi, & van Heuvelen, 2016,). Barriers, in this context, are factors that can influence an individual's willingness or capacity to participate in physical activity. Schutzer and Graves (2004), for example, discussed five key barriers for older adults to engagement in physical activity. These barriers were i) health, ii) environment, iii) a lack of physician advice, iv) knowledge and v) childhood exercise experiences (Schutzer & Graves, 2004). These broad barriers are summative, whereas more recent reviews of the literature have identified as many as 59 barriers for older adults, and a further 35 barriers that are specific for people with dementia (Baert, Gorus, Mets, Geerts & Bautmans, 2011; van Alphen, Hortobágyi, & van Heuvelen, 2016).

The specific barriers described by the literature can be classified into three distinct groups, that encompass the most common types of barriers people with dementia experience. These include Intrapersonal, Interpersonal or Community, by classifying the barriers in this way the sheer quantity of barriers is apparent and the various levels in which these barriers can occur. Examples of intrapersonal barriers include pre-existing health status, fear around physical health, pain, fall risk or potential for injury (e.g. Malthouse & Fox, 2014; Suttanon, Hill, Said, Byrne & Dodd, 2012) and emotional barriers related to feelings around physical activity (e.g. Cedervall Torres & Åberg, 2015). The next level of barriers identified in the literature are interpersonal factors. These barriers include concerns regarding safety or a lack of understanding by other people (e.g. Yu & Kolanowski, 2009; Malthouse & Fox, 2014) and factors related to the caregiver (e.g. Suttanon et al, 2012). Lastly, barriers have been discussed at a community level. For instance, the cost of physical activity, time of physical activity classes, neighbourhood safety and access to facilities (e.g Yu et al, 2011; Meyer, Castro-Schilo & Aguilar-Gaxiola, 2014).

Bonner and O'Brien Cousins (1996) described the single greatest barrier to physical activity for people with dementia as mobilizing the caregiver or support staff. Consistent with the critique of ageing discourse that places responsibility for producing good health on the individual (e.g. Stephens, 2017), highlighting caregivers as a barrier to physical activity in this way endeavours to shift that responsibility for good health from the individual who has dementia to the caregiver. Van der Roest and colleagues in 2009, interviewed people with dementia and their carers regarding their caring needs and found that people with dementia needed or received assistance from professional or informal caregivers regarding food, household activities, money, support with memory problem and coping with memory loss. A large number of the needs of people with dementia, however, remain unmet (Van der Roest et al, 2009).

High reliance on caregiver support in completing activities of daily living results in people with dementia often being unable to participate in physical activity without the support of a caregiver. Therefore, the caregiver and supporting individuals become crucial in adherence of physical activity. Yet, there is a prominent concern for the high rates of caregiver burden and psychological morbidity, as well as social isolation, physical ill health and financial hardship for caregivers of people with dementia (Brodaty & Donkin, 2009). Caregiver burden is not just specific for caregivers of those with dementia, but can occur across conditions (e.g. for ID). Cuthbert and colleagues (2017), when addressing caregiver burden for family caregivers of individuals with cancer looked at the role of physical activity for the caregiver as a means of reducing caregiver burden and improving health and wellbeing. Caregivers in this circumstance discussed a downward spiral and used this metaphor to represent the experience of being in the caregiving role. On the other hand, caregivers applied a metaphor of an upward spiral to represent the experience of participating in the physical activity themselves. This highlights the value caregivers place on physical activity when participating themselves, and indicates potential for physical activity to positively influence both the cared for and caregiver. Although caregivers providing end of life care are at the highest risk of caregiver burden, all types of caregivers are susceptible to and often do experience negative impacts from their caregiving role (Williams, Wang & Kitchen, 2016). Therefore, we can postulate the potential for physical activity to have similar positive effects for caregivers of those for individuals with dementia; as demonstrated with caregivers of those with cancer.

It is against this backdrop that professionals who work with people who have dementia, but are not full-time caregivers, have a substantive voice when seeking to provide solutions to the barriers people with dementia encounter toward physical activity participation. Recommendations of professionals and paid carers based on practical experience are highly valuable when informing the care of people with dementia (Beattie, Daker-White, Gillard & Means, 2005). It is, therefore, crucial to consider the perspectives of professionals who work to encourage and facilitate physical activity for people with dementia. Their role is important for a number of reasons. Firstly, due to the resources available to professionals and the time they are able to spend with people with dementia, professionals are frequently positioned to empower caregivers and motivate people with dementia to participate socially and engage with physical activities (Donkers et al, 2017). Secondly, the current literature that emphasises the personal responsibility of the caregiver or individual with dementia to achieve ideals of successful ageing (Breheny & Stephens, 2017) highlights a pressing need for a shift to a multidisciplinary discourse that facilitates physical activity without individual burden.

Furthermore, focusing on personal responsibility typically disregards the social and environmental circumstances within which physical activity occurs; that can substantially influence the level of physical activity engagement, but is often out of the control of the caregiver (King & King, 2010). A lack of description of barriers at multiple levels has been identified as a flaw in existing literature (Benjamin, Edwards, Ploeg & Legault, 2014). Therefore, this present study seeks to move beyond the largely decontextualized documenting of barriers that is available thus far.

The potential types of physical activity available to people with dementia are enormously varied. Current evidence is not sufficient to determine a dose-response rate between the type, duration or frequency of physical activity and the degree of resultant cognitive benefits (Forbes, Thiessen, Blake, Forbes & Forbes, 2013). Therefore, the more holistic and life-course oriented approach of ‘active ageing’ has been widely advocated (e.g. Foster & Walker, 2014). This approach encourages older adults to participate in different types of physical activities with the intention of reducing frailty and dependency, maintaining independent physical and cognitive function, mental health and well-being (Bauman et al, 2016).

Synonymous with the increase in the focus on active ageing is the concern regarding the amount of time older adults spend being sedentary, or inactive. Harvey, Chastin and Skelton (2015) reviewed 22 studies investigating sedentary time for older adults and found a consistent increase in sedentary time with increasing age; with or without comorbidity sedentary time averages around 9 or more hours a day. Individuals who increased their time spent being physically active will further benefit from this time by reducing their sedentary time (Siddique et al, 2017). This highlights a distinct need to not only increase physical activity, but also decrease inactive time in order to obtain holistic active ageing. Hence, there is potential for various activities to be beneficial for people with dementia to both increase activity levels and decrease inactivity levels.

Buman and colleagues (2011) recommended replacing sedentary or inactive time with low to light physical activity rather than focusing on increasing moderate to vigorous physical activity. Encouraging this increase in light physical activity may function as the first step toward people with dementia engaging in moderate intensity activity as World Health Organisation guidelines suggest (Barber, Forster & Birch, 2015). Decreasing inactivity can be gradually encouraged through embedding light physical activity into the daily activities of people with dementia. This embedded or incidental approach often involves a different focus to the activity other than the physical activity outcomes. Dog walking is a prime example of incidental physical activity. Peel and colleagues (2010) discussed how older adults with type 2 diabetes who are advised to take up physical activity often found any adopted physical activities to attenuate over time. Dog walking, however, facilitated incidental walking and consistent physical activity over time; and improved social interactions.

Conversely, add-on physical activity allows people with dementia to achieve a higher level of physical activity intensity; which could increase potential physical and cognitive benefits. For example, moderate aerobic physical activity is associated with benefits in functional ability, cardiorespiratory fitness, improved memory performance and reduction in hippocampal atrophy (Morris et al, 2017). Strength, balance, endurance or mobility training can reduce risk of falls (Burton et al, 2015) and lessen probable decline in activities of daily living (Littbrand, Stenvall & Rosendahl, 2011) enabling people with dementia to maintain independence for longer. Multiple benefits can be achieved through both embedded physical activity and add-on physical activity sessions. The role of the professional often influences the type of physical activity they are able to facilitate. Therefore, subsequent interviews with professionals present the possibility for both embedded and add-on physical activity to be encouraged and provided for people with dementia. Through subsequent discussions with professionals this chapter addresses the third overarching objective of this thesis and explores the context in which physical activity provision is situated and the role professionals have in navigating barriers for people with dementia and their caregivers.

9.2 Methods

The emphasis in this chapter is on professionals' reflections of the barriers they have encountered, how they have navigated these barriers, and the specific strategies they have applied when doing so. The intention here is to provide a more detailed and contextually nuanced understanding of the barriers that exist for people with dementia from the perspective of those who work professionally to navigate these barriers on a regular basis. This, hopefully, offers an extra layer of depth than that of the existing literature and a deeper understanding of the complexity of the professional engagement with physical activity for people with dementia. Consistent with the philosophical underpinnings outlined in the methodology chapter of this thesis, critical realism provides the lens in which this research was conducted.

Research currently highlights the effects of physical activity and the potential benefits to health and wellbeing for both the caregiver and the individual with dementia (e.g. Heyn, Abreu & Ottenbacher, 2004). It has also explored the barriers to physical activity that people with dementia and their caregivers have (e.g. Kelly et al, 2016). Despite the existence of these lines of inquiry there is little research that draws a clear causal link between the effects of physical activity and the accessibility of physical activity that people with dementia currently have. Critical realism offers a way to investigate the potential links between these paralleled questions. The process applied is both inductive and deductive, as it is interchangeably informed by the data collected and previous literature. This involved first inductively establishing trends or themes in interview data, then re-describing these themes in the context of theoretical concepts and current understandings of the topic.

Finally, the analysis focused on the mechanisms and conditions in which causal influences can take shape. This gives the subsequent data the context needed to understand how and when professionals are able to facilitate physical activity for people with dementia and the strategies that are used to do so. This final stage moves from 'the manifest phenomena of social life, as conceptualized in the experience of the social agents concerned, to the essential relations that necessitate them' (Bhaskar, 1979). Therefore, as a reasoning process the analysis moves from concrete to abstract and back again (Fletcher, 2017) and by doing so is able to provide a nuanced explanation of the casual social relationships that facilitate physical activity for individuals with dementia.

A semi- structured interview schedule was used during this study with the purpose of learning more about the professionals' experiences with barriers to physical activity facilitation, how they sought to navigate those barriers and consequently the outcomes they observed as a result. The questions posed to professionals required them to reflect holistically on their experiences of working with individuals with dementia. Each interview began with the same question in order stimulate initial discussion around the topic as well as inviting participants to provide contextual information around their own experiences with physical activity for people with dementia:

> 'Interviewer: Can you tell me about your experiences with physical activity for people with dementia?'

Further questions invited participants to discuss key barriers they had encountered within their role, as well as any strategies they used to navigate these barriers. The full interview schedule is detailed in Appendix 10 but some key example questions include:

> 'Interviewer: What are some of the key barriers you have faced in your work around this topic?'
>
> 'Interviewer: What would you recommend to other providers of physical activity?'

The complex problems people with dementia experience in various aspects of their lives require an integrated approach to dementia care that can only be provided by a multidisciplinary team (Schols & Kardol, 2017); requiring a diverse range of professions. Interviewees were sought that reflected the diversity of a multidisciplinary dementia team.

Professions could therefore include service providers, physical activity instructors, employees of funding organisations, general activity providers, charity employees working with people with dementia, among other professions who also work with people with dementia. By reflecting the diversity of professions that provide dementia support or care in a variety of different settings, this study is able to discuss the diversity of the opportunity for physical activity for people with dementia, how and where that physical activity is currently being provided.

Once audio data files had been listened to at least once, data were transcribed verbatim. A thematic analysis (Braun & Clarke, 2006) was then applied to transcriptions of the discussions had with professionals. Each transcript was analysed individually by, first, being read through thoroughly at least twice. Then the transcript was coded, codes sought to summarise that section of writing in an inductive manner and without the use of predetermined coding framework. Codes were then listed and similarities highlighted. This meant shorter lists could be formulated containing potentially related themes. These lists of related codes were then checked and rechecked for congruency and once groups were established, potential themes were formulated. These were then compared across transcripts before themes were confirmed and named.

Data consisted of 13 interviews with professionals who are involved in the provision of physical activity for people with dementia. Background information that participants were willing to provide is detailed in Table 9.1. This study intended to recruit participants that represented varying levels of professional involvement in physical activity for people with dementia, in order to generate a more in-depth understanding of the entire picture of physical activity provision for people with dementia. Therefore, participants were included in the study if they had worked, at any point during their career, within the context of facilitating physical activity for people with dementia. This could include individuals who do not regularly work directly with people who have dementia. This could also include individuals who do not consider their job role as specifically facilitating or providing physical activity, such as care workers or charity volunteers, however through their work with people with dementia do encourage physical activity and therefore also have an understanding of the context being addressed in this study. Participants were excluded if they had never worked with people with dementia and they had never worked in the provision of physical activity. Included participants had a variety of job roles, which reflected varying types of involvement within this context. Job roles varied from sports and activity lead, focusing on the provision of physical activity specifically, to researcher who focuses on the assessesment and observation of this context; to head of house who plays a role in fudning allocation for future physical activity delivery for people with dementia.

Table 9.1 – Professionals' background information

Pseudonym	Role	Type of organisation	Type of Physical activity	Further information
John	Sports and Activity Lead	Charity	Embedding physical activity into daily activities	6 years working with health charities with interest in dementia and physical activity.
Michael	Project lead for work with a health charity collaboration	Charity	Activities in the community	
Rebecca	Head of House	Funding Body	Varied add on physical activity programmes	
Jasmin	Head of impact	Business	Add on physical activity sessions using props, with a focus on enjoyment	
Colin	Physical activity coordinator	Public Sector	Add on physical activity sessions	
Doris	Fitness Instructor	Business	Add on physical activity sessions	24 years working with care homes, including people with dementia and then 8 years ago moved to instructing physical activity
Daniel	Head of community development	Business	Add on physical activity sessions using props, with a focus on enjoyment	
Pete	Instructor	Public sector	Add on physical activity sessions, usually chair based exercises	
Adam	Researcher	University	Add on physical activity sessions	
Gavin	Researcher	University	Add on physical activity sessions	
Emma	Carer, Co-founder and CEO of social enterprise	Social Enterprise	Embedded into social and group activities	9 years working with people with dementia facilitating activities and leisure
Chloe	Project officer	Charity	Add on physical activity sessions	
Angela	Researcher	University	Add on physical activity sessions	

9.3 Results

Throughout the data professionals discussed their understandings of barriers, their strategies for navigating these barriers and the specific ways their professional role influences physical activity for people with dementia. Some professionals discussed how they felt barriers to physical activity developed for people with dementia. There is a big impact on an individual's identity, when a diagnosis of dementia is given, this can often lead to feelings of loss, anger, fear and frustration (Bunn et al, 2012). Through this impact on an individuals' identity Michael discussed the potential for barriers to form. He suggests that even if an active lifestyle was previously maintained, barriers can still develop following a diagnosis: 'a certain amount of reflection in terms of what they think their diagnosis means for them and barriers can develop whereby people think they can't access services that they used to or the leisure activities that they used to' (Michael: I02).

Participants in a study described by Read and colleagues, when diagnosed with dementia the core problem, conceptualised as losing control, was observed in role function and independence (Read, Toye & Wynaden, 2016). Michael's account is synonymous with this concept of loss of control, the use of the word 'can't' suggests that they no longer have control over their independence and services that were previously very familiar seem inaccessible. Michael particularly specifies people that have previously been active to perhaps highlight the absence of barriers prior to the diagnosis of dementia. Rebecca further noted that professionals working with people who have dementia often aspire to offer the support required 'so that they [people with dementia] can continue playing the sport that they've always loved' (Rebecca: I03). In order to help people with dementia to be physically active professionals appear to have amassed a knowledge of the barriers people with dementia experience around physical activity and therefore are able to freely discuss how they, as professionals, navigate these barriers to encourage physical activity.

The three themes derived from these data were 1) E*nvironment*; 2) *Social connection*; and 3) *Structure*. Each theme is better understood through the contributing sub-themes. The subthemes for 'Environment' are i) *Type of environment*, ii) *The surrounding environment*, and iii) *Accessibility and sensory aspects of the environment*. The subthemes for 'Social connection' are i) *Social isolation and dementia*, ii) *Strategies to encourage social* *interaction*, iii) *Social motivation*. Lastly, ‘Structure’ consists of i) *Funding*, ii) *Evaluation*, and iii) *Collaborations*. The subthemes discussed seek to give more depth to the explanation of the the development of the themes presented.

9.3.1 Environment

Being active in the longer term successfully enables people with dementia to ‘continu[e] to be a part of their community’ (Michael: I02). Physical activity environments should be ‘where people can do what they’ve done previously’ (John: I01). Emma suggests, ‘for people with dementia to do more physical activity it’s about creating the right support environment’ (Emma: I11). There are several facets of the environment that professionals discussed as influential in facilitating physical activity. The environment could be most crucial when considering the facilitation of embedded physical activity. These environmental factors discussed by professionals are summarised in three subthemes: 1) *Type of environment*; 2) *The surrounding environment*; and 3) *Accessibility and sensory aspects of the environment*.

9.3.1.1 Type of environment

The traditional sports environment, such as a gym or leisure centre facility is continuously developing and often reflects modern fitness trends. This is further reinforced by the global fitness industry (Andreasson & Johansson, 2014). Consequently, the current environments in which physical activity is readily available are often unfamiliar for people with dementia as they are continuously changing and frequently do not reflect the environments that people of this age would traditionally associate with physical activity. Professionals discussed this type of environment to be unsuitable for people with dementia.

Colin discussed that many people with dementia have ‘never been into a gym’ and ‘the idea of a gym puts the fear of god into them’ (Colin: I05). Professionals perceived a traditional sports environment as ‘pretty daunting’ (Colin: I05) and ‘too intimidating’ (Emma: I11) for people with dementia. This could be due to intrusive background noise that has been shown to be distressing for people with dementia (e.g. Brown et al, 2016). Noisy environments can also result in communication difficulties, discomfort and frustration which can prompt withdrawal or avoidance of social situations (Heinrich, Gagne, Viljanen, Levy, Ben-David &

Schneider, 2016). In attempts to 'shut out' noisy environments, people with dementia experience disorientation (Day, Carreon & Stump, 2000). Therefore, the noise levels of a traditional sports environment could be problematic for people with dementia.

Professionals described delivering physical activity in alternative, potentially more appropriate settings. Colin discussed instructors in his team 'going in and delivering exercise within sheltered accommodation' (Colin: I05); whereas Doris instructs 'fun and fitness' sessions in both residential homes and 'in community centres' (Doris: I06). Daniel shared his organisations attempts to 'put exercise in every sort of local community. We're in churches, the libraries, community centres, the scout huts, we're in the lobbies of housing association communal lounges' (Daniel: I07). The settings mentioned by professionals really support physical activity being embedded within the environments that are most familiar for people with dementia. These environments could be more suitable than the traditional sports environment and have been discussed positively by these professionals.

By physical activity being readily available and a part of everyday life this could seek to normalise physical activity for people with dementia. The more normalised physical activity is, the more easily people with dementia can benefit from physical activity. Daniel, for instance, discussed how professionals 'saturate a community of options for exercise, which means people don't have to travel so far and even better than that, people leading exercise are members of the community' (Daniel: I07).

This extract highlights the potential benefit of more people in the community being able to get involved in physical activity, both as participants and facilitators. Increased community engagement has been shown to yield substantial benefits for people with dementia, and can markedly encourage increases in embedded physical activity. Following add-on physical activity provision several professionals discussed trying to increase activity beyond the add-on class they already provide for people with dementia. Previous research has shown home based physical activity to be feasible and beneficial for people with dementia (e.g. Steinberg, Leoutsakos, Podewils & Lyketsos, 2009). However, in studies demonstrating good adherence to physical activity programmes, still only 58% of participants completed the programme (e.g. Suttanon et al, 2013). The consistently low adherence to physical activity programmes highlights potential difficulties for people with dementia may have participating in physical activity within the home environment. Gavin, for example gave out an activity DVD and exercise band. Unfortunately, he discussed, people were not completing the activity as advised. He discussed this in a tone of bewilderment as participants were engaged and enjoying physical activity within the group setting:

> ‘These people are inactive in the first place they’ll come to the sessions and they are enjoying the sessions when they’re there…still not doing anything outside of the session’ (Gavin: I10).

Gavin points to individuals’ inactivity levels prior to their participation in his class, suggesting that this could be a factor. Colin, on the other hand, discussed that there could be further difficulties with physical activity at home. Colin admitted that ‘in my own house if I’ve got a bike there it’s got clothes hanging on it’ (Colin: I05). Previous studies have also highlighted this idea of exercise equipment in the home being ‘used as a clothes rack’ (Peel et al, 2010). So when visiting care homes and sheltered accommodations where it is ‘their home essentially’ (Colin: I05) professionals discussed seeking a community room or space within that environment ‘where we can take people away from it and get them in that room and get them exercising’ (Colin: I05). Overall, professionals highlight several types of environments that could facilitate physical activity, but seemingly the most beneficial are, more often than not, community based venues that people with dementia are comfortable with. It is not just the type of environment that determines whether people with dementia are willing to engage with physical activity, professionals also discussed the surrounding environment as influential.

9.3.1.2 The surrounding environment

Professionals discussed the aspects of the surrounding environment that can affect the willingness of people with dementia to engage with activity within that environment. Daniel first discussed how people with dementia ‘don’t want to travel more than five minutes, they want it on their doorstep’ (Daniel: I07). Embedding physical activity within the community directly impacts whether people with dementia would need to travel for physical activity or not. Research has shown that neighbourhood plays an active role in the lives of people with dementia, setting limits, and constraints but also offering opportunities to support (Ward et al, 2017). If the neighbourhood is considered unsafe this could form a barrier to physical activity as people with dementia are less likely to venture out of the house (e.g. CDC, 1999; Bracy et al, 2014). Professionals discussed solutions to concerns that their participants had with neighbourhood safety and travel. Chloe, for instance, had a person with dementia attending her dance class who 'comes on her own, so I went to fetch her from the station' (Chloe: I12). Chloe was able to navigate the barrier of travel in this circumstance by providing transport for her participant. Other professionals discussed further shared transport solutions that could potentially alleviate any transportation barriers, particularly if the physical activity is being facilitated in a harder to reach location.

Colin gave an example of the surrounding environment being situated in an unfamiliar neighbourhood that his team found problematic to navigate. He described 'a very unusual street setup all the streets are quite hilly and bumpy…it's all cobbled and everything so it's very difficult to for people to even walk from one place to another'. He further discussed that 'we always used to struggle with that, so again working with a volunteer group there they were able to really target the areas and where we would be best to go' (Colin: I05). Colin sought assistance from a local volunteer group and was therefore able to facilitate physical activity in the ideal location for that community. Professional involvement here navigated the environmental barriers to help people with dementia to acesss add-on physical activity. Professionals subsequently discussed specific aspects of the chosen environment that could be impactful once the physical activity is taking place.

9.3.1.3 Accessibility and Sensory aspects of the environment

During design, research suggests that the environment should be tailored to the diversity of human abilities and conditions (Heylinghen, Van der Linden & Van Steenwinkel, 2017). Professionals discussed the requirement for the environment to be accessible to encourage activity for people with dementia. Physical environment strategies that support this include changes to the global environment and to architectural features, use of moveable environmental aids and tailored individual approaches (Woodbridge et al, 2016). Specifically, the importance of designing environments in such a way that supports successful orientation for people with dementia has been emphasised, as people with dementia often experience marked difficulties in their orientation abilities (O'Malley, Innes, Muir & Weiner, 2017). Aiding with orientation, can support individuals in their activities of daily living.

John summarised: 'to make something dementia accessible, it means that it should be accessible for all people…it is about clarity of signage, friendly faces, there are some dementia specific things but a lot of it is about being a good supporting environment' (John: I01).This is synonymous with the ethos of 'dementia friendly communities' a charity led initiative that encourages community wide acknowledgement of the difficulties of dementia and seeks to provide further support for individuals when navigating community environments. Research has shown the culture of looking out for each other contributes to the social support provided by a community. In particular, this allows people with dementia to remain connected to community members and, although often fragile, this type of support offers somewhat of a safety net for people living with dementia (Wiersma & Denton, 2016).

John discussed the importance of clear signage. Similarly, the maintenance of independent toileting has been an important aspect of design guidelines, essential aspects include making facilities easy to locate and identify through signage (Bichard, Hanson & Greed, 2005). Emma highlights this as key for people with dementia participating in physical activity as they want to be able to identify the toilet immediately if necessary.

> In an environment toilets that were really really accessible and really really obvious because that's the number one concern everybody with dementia has… they may not voice it to you initially but they're wanting to know where the toilet is, that it's easily recognisable so if they need to do to the toilet they can get there quickly or that there is somebody there that can help, who recognises the signals (Emma: I11).

Due to symptomatic difficulties people with dementia have in planning and remembering toilet breaks, situations such as trips to the toilet, as Emma described here, can be worrisome for the individual. If reassurance is provided by the environment people with dementia are far more likely to enjoy engaging with the activity. Thus, having an accessible environment can increase engagement and enjoyment.

Additionally, professionals discussed promoting physical activity through sensory aspects of the environment. This could involve incorporating sensory areas ‘so being outside, being in touch with nature’ (John: I01) as well as the use of sensory props. Some examples of props discussed by professionals were ‘Giant Scrunchies…Indian based fabrics’ (Chloe: I12) and ‘pom-poms’ (Daniel, I07). Professionals highlighted several benefits of using sensory props, They can provide ‘a lot of tactile experience’ (Chloe, I12) that can ‘encourage people to take part’ (Daniel, I07). Providing ‘something that they can hold onto and feel connected to everybody else in the room’ (Chloe, I12) was discussed as impactful, especially for individuals that were less willing to engage initially. Heyn (2003) indicated that a multisensory physical activity approach could be beneficial for individuals with dementia. After engaging with multisensory stimulation people with dementia have shown improvements in behaviour (Maseda et al, 2014), talked more spontaneously, related better to others, did more from their own initiative and were less bored and inactive (Baker et al, 2001). Overall evidence supports the positive impact of sensory stimulation as a nonpharmacological behavioural treatment for dementia, however research into the longer-term effects have shown mixed results (Lorusso & Bosch, 2017). Thus, sensory props discussed by professionals could incur further positive benefits during physical activity.

Both research and professional discussions point to the immediate physical environment as an influential factor in the engagement of people with dementia in physical activity. Recommendations for the environment that have arisen from these interview data included considerations for the type of environment, transport to and from the environment, accessibility and safety of the environment, and the sensory elements provided by the environment. Data also suggest the social connectivity afforded by the provision of physical activity to be important to the experience of physical activity for people with dementia. The following theme examines the social aspects that professionals discussed as influential for their participants.

9.3.2 Social Connection

Social influences on the navigation of physical activity barriers were discussed extensively and highlighted as highly influential on an individuals’ experience of physical activity. This theme examines the social connectivity available through physical activity, which can be encapsulated in three subthemes: 1) *Social isolation and dementia*; 2) *Strategies to encourage social interaction* and 3) *Social motivation*.

9.3.2.1 Social Isolation and dementia

Many older adults experience an increased risk of social isolation as their social networks decline, with fewer traditional opportunities available to add new social relationships (Abbott, Bettger, Hampton & Kohler, 2013). This can be exaggerated for people with dementia as they often experience substantial impairments in semantic memory and knowledge of words, concepts and symbols (Tulving, 1972); which frequently results in communication difficulties. For example, people with dementia display discourse impairing features such as disruptive topic shifts and empty phrases that reflect declines in their memory (Dijkstra, Bourgeois, Allen & Burgio, 2004). For many caregivers, communication problems are an important part of their partner's decline in functioning at home; apparent in almost all activities of daily living, but most evident in conversation involving personal life (Small, Geldart & Gutman, 2000).

This decline in social functioning is characteristic of dementia. Research instruments have been developed to assess social functioning in the hopes of offering interventions, where needed, to reduce the risk of further social isolation for people with dementia (Sommerlad et al, 2017). Difficulty with communication has been significantly associated with smaller social network size, fewer positive social exchanges, less frequent participation in social activities and higher levels of loneliness; this suggests that those with communication difficulties are at increased risk for social isolation and loneliness and decreased social participation (Palmer, Newsom & Rook, 2016). Emma suggested that 'Everybody underestimates' (Emma: I11) these social difficulties as these social skills are 'just second nature, [but] for somebody with dementia they have to think and worry at each of those steps' (Emma: I11). Professionals described these social difficulties for people with dementia as 'daunting' (Colin: I05), and discussed how they can often act as a barrier to physical activity. Professionals, therefore, discussed employing strategies to navigate this barrier.

Family relationships are important throughout the life course and especially so for people with dementia (la Fontaine & Oyebode, 2014). However, with the onset of dementia normative familial relationships are often ‘fractured and reconfigured’ in order to adapt to the developing difficulties of dementia (Peel, 2017). Alongside this renegotiation of relationships caregivers are at risk for caregiver burden. Caregiver burden is the physical, psychological, emotional, social and financial problems that are experienced due to the caring role (George & Gwyther, 1986). This is repeatedly seen when the demands of care outweigh the available resources of the caregiver or when the emotional or physical health of the caregiver is compromised (Given et al, 1992). Caregiver burden affects the health of both the caregiver and the person with dementia (Kim, Chang, Rose & Kim, 2012).

Orgeta, Miranda-Castillo (2014), reviewed four randomised control trials of home based physical activity of low to moderate intensity explicitly for the caregivers of people with dementia. The review showed a reduction in subjective caregiver burden for carers of people with dementia through the uptake of physical activity. This highlights the potential benefits of physical activity for caregivers and suggests potential for embedding physical activity into the lives of both the caregiver and the person with dementia in order for both individuals to benefit. However, further exploration into how physical activity can be enjoyed as a familial dynamic, without further increasing caregiver burden, is warranted before recommendations can be made. Adam discussed his participants’ family relationships. He particularly focused on those that were entangled in the care dynamic, which in this instance includes a mother and her daughter; and a husband and his wife:

> There’s been people within those relationships suffering with dementia to the extent of they don’t recognise who the other person is but they’re able to do, by competing in the kind of physical activity against each other they’re still able to kind of express an emotion to each other through you know laughter, a bit of joy, a bit of happiness. You know the odd hug happens when they do something well again as well, although you’re not creating that feeling of being recognised and aware again of who the person, you know, who their relative is, by being able to create a bit of joy and happiness between the two, you know the relatives have said back to us what that has meant to them (Adam: I09)

This extract highlights a joy and happiness created through family members participating in physical activity alongside their relative with dementia. Adam acknowledged that it is not feasible to create the feeling of being recognised again, but through physical activity there are opportunities for relatives to express emotion to each other and to receive ‘the odd hug’. Adam’s insights suggest a further emotional benefit to embedding physical activity into the lives of people with dementia, as even further unforeseen benefits could be available to families.

Not all professionals perceived family involvement as positive. Chloe for example, explained that in an add-on physical activity session, where the activity is non-restrictive and focused on people enjoying movements to music regardless of the instructor’s movements. However, when a familial caregiver accompanies a person with dementia to the add-on class the caregiver frequently finds it difficult to step out of their caregiving role and allow the person with dementia to operate without instruction. Therefore, Chloe often observed caregivers correcting the movements of people with dementia.

> It can be difficult with carers sometimes, it’s fine if they’re joining in and everybody’s having a nice time together but sometimes the carers are still in that kind of carer mode and are trying to almost force them to do the movement correctly. (Chloe: I12)

Although Chloe has found difficulty with caregiver involvement in add-on dance based classes, this may not be the case in more instruction or rule based forms of physical activity. Pete for instance, instructs large groups in chair based physical activity. In this context, caregiver involvement and extra instruction for people with dementia was discussed as helpful, as the group size could be large so Pete discussed not being able to give individual attention to mitigate any confusion around the physical activity movements.

> If the carer wants to take part they can take part and if they needed the extra help then we would advise saying actually we can’t just give that one to one attention because the group is so big we can’t give that individual attention. (Pete: I08).

Although professionals expressed mixed opinions, overall, family involvement was discussed as being positive. Professionals highlighted benefits of family members at least observing physical activity. Through observation family members can be reassured that the physical activity is appropriate for their relative and this can encourage familial support.

> Only by coming to the sessions people are starting to realize that for themselves, even the older adults some of them get lifts, transport provided by their family members, sons, daughters that sort of thing and when they stay at the session they realize that “oh yes this is suitable for my dad, my grandma” (Gavin: I10).

This extract implies that family members before observing the physical activity considered physical activity to be unsuitable for their relative. However, family involvement to this extent was encouraging. Laver, Dyer, Whitehead, Clemson & Crotty (2016), highlighted the need for primary carers to encourage people with dementia to be physically active, as well as be trained and supported in doing so. Therefore, family involvement could potentially encourage future physical activity for the person with dementia.

Further to family relationships social connections with peers during add-on physical activity opportunities were also highlighted as important by professionals. For people with dementia, the ability to undertake leisure activities is more likely to be inhibited by a range of barriers that contribute to social exclusion if not addressed. If overcome, however, leisure activities can be framed as a form of resistance to the social difficulties experienced by individuals with dementia and the potentially isolating impact that comes along with that (Innes, Page & Cutler, 2016). Professionals discussed aiding their participants to feel socially connected while attending their physical activity class. Gavin described this as needing to ‘invest time in this population and get to know people and build up that sense of rapport’ (Gavin: I10). Pete further emphasised how as an instructor he wouldn’t want any of his participants to struggle with social isolation, particularly when at his physical activity sessions.

> I don't want anyone coming to a class, sit in their chairs, waiting and not chatting to anybody. So it’s to break down the barriers. And they’ll feel more comfortable about asking or looking at others to see if they’re doing it right (Pete: I08).

Pete suggested that through chatting participants feel more comfortable during physical activity. Professionals discussed and further emphasised how instructors’ role in physical activity provision is foremost to help participants to feel comfortable engaging in physical activity. Additionally, Colin discussed making participants feel comfortable interchangeably with the requirement of ‘making sure everyone…you do the session for is happy’ (Colin: I05). Potential benefits of an approach to physical activity facilitation that focuses on participants being happy and comfortable in the setting were highlighted throughout these data. Most notably, professionals discussed increases in engagement with physical activity when participants are happier and more comfortable.

Angela suggested that this approach to physical activity delivery that emphasises the comfort and happiness of participants is unfamiliar to many instructors. Nevertheless, Angela discussed how instructors should be trying to ‘encourage interaction between the residents’ (Angela: I13). The benefits of this focus are yet to be fully explored due to its unfamiliarity. However, professionals anecdotally commented on ‘the rapport in the room chang[ing]’ (Chloe: I12) as the participants became more comfortable within the physical activity context. Pete also underlined the effect social adaptations have to the engagement levels of the physical activity sessions he has experienced: ‘It brings them out their shells so it’s not a class where they’re just sitting and going through the motions they will take part and they will engage’ (Pete: I08).

The metaphor Pete evokes here of physical activity bringing participants “out of their shells”, is effective in highlighting how Pete feels people with dementia experience physical activity sessions socially. This emphasises potential benefits of social interactions facilitated by instructors in an add-on physical activity setting and shows a reduction in social isolation. Furthermore, Pete discussed a positive influence on the engagement levels of participants in the physical activity sessions.

9.3.2.2 Strategies to encourage Social Interaction

What is missing from the story so far, however, is the operationalisation of the social focus to physical activity provision. The strategies professionals harness to encourage social interaction in the context of physical activity; and increase engagement in physical activity are examined in this subtheme.

Angela discussed observed differences between types of physical activity setting. She noted ‘that care settings are so different from sheltered housings, it’s not only - it’s a level of frailty, disability but also the level of the prevalence of people with dementia’ (Angela, I13). This suggested difference in functional, as well as cognitive, ability between settings has implications for the delivery of physical activity, and therefore the interpersonal strategies or adaptations facilitators need to make often differ too.

Firstly, professionals discussed methods they use to help people with dementia to feel more comfortable talking within the group setting. Emma, for example, explained how staff on her holiday intervention ‘deliberately think about things that we know people with dementia enjoy, that they’re passionate about’ which results in people with dementia better able to contribute to the conversation, ‘it gives that person the self-confidence to chat about it’ and ‘then they realise they have got the social skills’ (Emma: I11). The idea of self-confidence that Emma introduced here suggests that people with dementia still have the capability to engage socially, but require guidance and support from those around them to do so.

The appearance of the instructor was also discussed by several professionals as influential during physical activity. Following on from the idea of making participants feel comfortable, Colin discussed how having an instructor with a “relatable appearance” can be helpful. He noted that a typical fitness instructor appearance can be intimidating for those that are older and or less active. Therefore, he discussed his experiences with employing instructors with a slightly different appearance and how well this was received. Through this description, Colin infers that people with dementia respond more positively to physical activity if the instructor is not slim or muscular, but perhaps an individual with an endomorph body shape. This, he supposes, could be due to intimidation, as people less physically able may perceive someone with a slim or muscular body shape to be more physically able than themselves and therefore be less comfortable following their instruction. An instructor with an endomorph body type may be less capable of rigorous physical activity and therefore participants are visually reassured that the physical activity will be achievable.

> [I]t’s not that we try and stay away from that, it’s just that we have found that that can be quite intimidating. So some of our more popular instructors have been overweight which is, again you kind of have this vision that they look a particular way all dressed in lycra, but they are generally the more popular instructors because they are more relatable. So if somebody’s coming to the class for the first time they don’t want to feel uncomfortable (Colin: I05)

This extract highlights the importance of the appearance of an instructor. Adam also discussed the importance of the instructors' appearance. He noted that in his experience instructors have needed to maintain a consistent appearance to achieve successful physical activity delivery. He discussed an example of when an instructor within his organisation found this particularly important for their participants.

> Our instructor will always wear her hair in the same way because we found in the first few weeks that people actually were remembering her by her hairstyle so she would always keep it in the same way rather than changing it … because people didn't recognise her. So that was one subtle little thing that we found that we had to do to kind of help subtly, it was only a small difference but it helped us kind of be a couple of stages ahead at the start of the session (Adam: I09).

Throughout this quotation, Adam implies a sense of normality for participants to not recognise the instructor. However, "actually we're remembering her" suggests a sense of revelation for the participants, intimating an importance for this consistency of appearance for people with dementia to recognise their instructor. Both the consistency of appearance, and amount participants feel comfortable with the instructors' appearance can influence the social connections made between participants and instructors. The amount participants feel comfortable with their instructor's appearance can influence the initial social connection, whereas the consistency of appearance influences the social connection that can be built up through recognising the instructor at every physical activity session. The appearance of the instructor was only discussed for add-on physical activity sessions, as these inherently involve an instructor delivering physical activity to a potentially unfamiliar group of participants. It is possible to find ways around participants being unfamiliar with instructors, as Adam discussed. The alternate embedding approach may be easier to consistently maintain, as there is less likely to be that barrier of unfamiliarity at the beginning of the activity; as the physical activity facilitator could be a carer, friend or family member, rather than an instructor from an outside organisation.

Following on from instructor appearances, professionals discussed social strategies an instructor might use to include all group members. Strategies included the instructor not being stood in the middle of the room, but instead moving around the room to have personal interactions with each participant. For Doris, this involves non-verbal communication during physical activity that can be used to help participants to feel more comfortable:

> By us calling, speaking to them by their name and getting down on to their level so that instead of being stood up in the middle of the room you know you actually go over to the person sat in the chair, kneel down so that you're you know on the same eye level as them and make eye contact with them and perhaps you know gently touch them on the hand, you know and perhaps put your hand on their arm so it's the sort of non-verbal communication as well as the verbal (Doris: I06).

Sabat and Collins (1999) conducted an in-depth case study with an individual with Alzheimer's disease and revealed a variety of intact social and cognitive abilities, that were otherwise undetectable through cognitive assessments. But most significantly Sabat established intact manifestations of selfhood. More recent research has further supported that although people with moderate to severe dementia experience memory loss and cognitive deficits, this does not necessarily lead to a loss of "self" (Batra, Sullivan, Williams & Geldmacher, 2016). Therefore, research has contended that interventions for people with dementia should seek to enhance personhood for the individual (e.g. Johnston & Narayanasamy, 2016). The strategies professionals, such as Doris, discussed do seek this sense of personhood for the person with dementia.

Further strategies discussed by professionals noted the specific importance of ensuring participants stand or sit in a circular shape. The benefits discussed included encouraging social interaction between group members, taking the focus away from the instructor and making it possible for participants to more easily see each other and the instructor complete the physical activity movements. The social setup Pete discussed in his physical activity groups allow the participants' focus to be away from the instructor and on fellow participants. He added that this was to encourage interaction between participants. Harris (2013) highlighted both social interaction and potentially resultant friendships as an integral part of the human experience. The importance of social relationships has also been shown to effect quality of life of people with dementia (e.g. Moyle et al, 2011). Therefore, could be substantially beneficial for people with dementia.

> Make sure both sides of them are in vision, so they're not always looking at me, they can look at the people next to them and you know it's also trying to get the other group to interact. So before any elderly class we normally have ten minutes chatting and at the end of it we'll have ten minutes chatting (Pete: I08).

Alongside strategies used to facilitate social interactions throughout the physical activity session, Pete also added that he habitually allocated time around the session purposefully to allow participants to socialise. Most professionals discussed similar methods that further facilitate social interaction outside of instruction of physical activity. For example, nearly all professionals described providing tea and coffee for the group before and/or after participation in physical activity: 'they have the physical activity session and then they have tea and coffee as well at the end, so they have the half an hour to have a chat' (Gavin: I10). Professionals discussed the benefit of refreshments to the social interactions throughout the physical activity experience and highlighted that this time is specifically allocated 'so they can chat' (Chloe: I12).

The strategies that professionals discussed in these data highlight a focus on increasing the social interactions of people with dementia. These strategies were often to make the participants feel more comfortable in the physical activity context. When professionals are successful in facilitating social interactions, participants may enjoy this aspect so much that this becomes their motivation for participating.

9.3.2.3 Social motivation

Professionals discussed the potential for the social benefits available through physical activity to become participants' primary motivation for continued engagement. Jasmin discussed that even though some participants are still motivated to attend by the physical benefits, most are attending for the benefit of seeing friends and having fun.

> [T]he motivation to come is because of fun or because your friends are there, you know afterwards you sit and have a cup of tea which you really like doing or because you like some of the music. You know most people come, there are obviously people that come because they want to get, you know "my legs hurting and I want to

> strengthen my leg", so I'm not saying that, but the way we position it in general is much more kind of about coming and having a good time (Jasmin, I04).

Jasmin is suggesting that professionals promote their add-on physical activity sessions as a fun and social occasion rather than a physical requirement. Gavin further discussed the promotion of physical activity, highlighting the importance of this enjoyment as 'word of mouth' (Gavin: I10) is how participation increased. Many professionals also discussed the use of music, a 'really powerful' (Emma: I11) technique in increasing the social draw of the activity. As Pete described: 'Music helps especially if you use Rock and Roll or sixties… I always get them to bring their own music in if they want' (Pete: I08).

McDermott, Orrell and Mette Ridder (2014), found that individual preference of music is preserved throughout the process of dementia. Therefore, personal music choice is sustained and could be beneficial during physical activity. Although professionals discussed playing a variety of different music, era specific music was most frequently chosen. Doris emphasised specific choices in music and how this can lead to remembering song lyrics. This, in turn, can be in increasing social engagement.

> Music kind of unlocks a different part of the brain so if they're not able to remember what they did five minutes ago they seem to be able to remember the words to the song and be able to sing along without a problem (Doris: I06).

This extract highlighted participants being able to sing along to familiar songs during physical activity. This use of familiar music, many professionals agreed, to be 'incredible' (Emma: I11); and discussed music as 'another way to kind of lift the mood' (Gavin: I10). Jasmin, in greater detail, discussed the benefits for participants' mood and consequently their engagement too.

> So kind of using the music as a reminiscence tool but also we do kind of mix in newer music because residents don't always want to hear the same thing so kind of keeping it a bit fresh and varied. So the props and music and then just trying to create a really positive atmosphere, that kind of party atmosphere where you are there to have some fun, we have the instructor encourage them to act a bit silly and make up moves and that kind of positive vibes of smile and laughter hopefully then, even for them living

> with dementia that’s kind of infectious in terms of the emotions and getting them to feel that positive energy (Jasmin: I04)

Jasmin highlighted the variety offered through music and how this can create a fun, party atmosphere for participants to enjoy during physical activity. Mathews, Clair and Kosloski (2001), compared physical activity participation with rhythmic music playing to physical activity without music playing; they observed substantial increases in participation throughout the rhythmic music condition. This could be, as professionals suggested in these data, due to the enthusiasm participants feel with music playing. The fun, party atmosphere Jasmin described could lean toward the focus of physical activity sessions being on the social aspects, and potentially not on the physical benefits at all; which I will explore in more depth later in the theme.

Although professionals discussed the benefits of music, literature has highlighted music to only be effective for those who are generally interested in participating in the first instance (van der Wardt et al, 2017). Therefore, professionals often seek to adapt the physical activity itself, rather than using a supplementary strategy to increase participation. Competition is a key method professionals discussed to increase social motivation for people with dementia. Dionigi, Baker and Horton (2011) have previously explored the use of competition, with older adults competing in a variety of sports at the Masters level, a competition bracket specifically for those aged fifty and over. They found the use of competition to offer unique benefits for older adult above and beyond those gained through general physical activity. This included having a challenge, being motivated to work harder and companionship. Professionals in these data discussed introducing competition into their physical activity provision for people with dementia. This meant physical activity sessions were then to be fashioned as ‘sport that involves light physical activity’ (Angela: I13). Professionals frequently highlighted the social benefits associated with the introduction of competition. For instance, Adam discussed the social atmosphere created through competition during physical activity. He further noted that competition became a selling point for the physical activity; meaning individuals were encouraged to participate by the social aspect of the available competition: ‘a big selling point for us is the healthy kind of competition element. We’ve found that that’s helped to engage you know peers together, it creates a bit of a camaraderie kind of situation’ (Adam: I09).

Adam discussed the use of competition as helpful in engaging peers ‘together’. This choice of language invokes a sense of social togetherness achieved in the physical activity session that has not otherwise been discussed. Camaraderie, meaning mutual trust and friendship, is a military word often highlighted as a cultural resource for resilience for those in the military (Koenig, Maguen, Monroy, Mayott & Seal, 2014). The use of this word infers a friendship made between people participating in the physical activity that is strengthened further by the increased time spent competing in physical activities together. Daniel further discussed this idea of engagement through competition. Daniel’s perception of competition may be contradictory to the traditional sense described by Adam, that usually involves the activity concluding with a winner and a loser. Daniel in fact used the word competition to describe physical activity that contained a goal, or ‘purpose’. This, although not consistent with the wider notion of competition, offers participants a chance to compete against perhaps the time it takes them to complete the activity, or the amount of goals they achieve. Daniel described this less pronounced competition as beneficial for participants, suggesting that it completely transforms peoples’ motivation for participating and gives purpose to the physical movements.

> Because the moment you give a motivation to a movement or you give purpose to an exercise more so than the fact ‘we’re doing exercise’ it just people want to take part so much more, a tiny bit of competition does wonders (Daniel: I07).

This extract highlights the positive effect of competition. Daniel maintained that competition, in any sense, had a positive effect regardless. Professionals did not discuss any disadvantages to using competition, but did use the phrase ‘healthy competition’ (Adam: I09) to show that perhaps there are levels of competition that can be applied. This should potentially be considered in the add-on physical activity context as a potential tool to increase the social motivation for physical activity engagement.

Professionals presented the use of competition, both in the traditional sense and in lesser forms, as substantially beneficial. These benefits were most viewed as influencing participants’ motivation and encouraging peer to peer engagement, alongside increased engagement, in physical activity. Competition is another possible interpersonal strategy that could be most suitably applied to add-on physical activity for people with dementia. People with dementia could then strive to embed physical activity competition into their weekly routines to benefit from prolonged participation in more moderate to vigorous intensity physical activity.

Professionals frequently discussed participants in their sessions only attending ‘for the social aspect of it, they’re not too bothered about what they do when they’re there’ (Colin: I05). Subsequently professionals have capitalised on this social appeal and used social aspects of the session to mask the physical activity being undertaken, contending that ‘the more fun it is the less they feel like it’s actual exercise’ (Colin: I05). Professionals gave examples of some activities that they had previously used to increase physical activity for principally inactive groups of older individuals. This often meant ‘doing something else where their minds are distracted and they’re doing physical activity’ (Emma: I11). Examples included: ‘small gardening projects’ (Colin: I05), ‘Botcha’ (Adam: I09), and ‘a day out somewhere which you structure in such a way that there’s a lot of walking’ (Emma: I11). Additionally, Doris strives to add variety to her physical activity sessions intending them to be ‘different each week’ (Doris: I06).

Professionals gave plenty of suggestions of ways to increase physical activity without physical activity being the primary focus of the activity. Colin chose the term ‘physical activity by stealth’ (Colin: I05) to describe this shift in focus. Shifting the focus of the activity enabled participants to enjoy a social activity where the discussions are intentionally not on physical activity; resulting in people ‘getting active whilst having fun’ (Colin: I05). For more inactive groups this approach is potentially far more successful than the focus of the activity remaining on the physical aspects. This approach is heavily supported by the embedding approach to physical activity. Embedding physical activity proposes that physical activity be a part of everyday activities of daily life. In this instance, it is more than likely that the therapeutic outcomes of physical activity become secondary to the task in question. Thus, by design physical activity happens naturally as a part of alternative activities.

The engagement people with dementia have with physical activity can be greatly influenced by the social aspects of the activity. Whether it is by minimising social isolation, increasing interaction through instructor facilitation, motivating participants to further engage or concealing the physical part of the activity altogether; social aspects have a substantial role to play in physical activity for people with dementia.

9.3.3 Structure

Three subthemes were identified as relevant to the structure of physical activity. These were 1) *Funding*, 2) *Evaluation* and 3) *Collaborations*. This theme examines the structure of physical activity through these three subthemes. It is important to note that the differing perspectives presented by professionals offer valuable insights into an exceedingly nuanced and complex sector of health and social care.

9.3.3.1 Funding

Dementia care represents a substantial financial burden for society (e.g. Hurd, Martorell, Delavande, Mullen & Langa, 2013), thus the financial implications of providing physical activity need to be considered. Professionals discussed the finances surrounding physical activity provision, with many noting an abundance of available activity opportunities, but the cost of those opportunities frequently became a barrier to participants' engagement.

> …there are actually a lot of physical activity opportunities in each of the areas but a lot of them you have to pay for and then you come to the barriers that I explained earlier again about people not wanting to pay for things (Gavin: I10)

In Gavin's view, participants having to pay for physical activity was a barrier to uptake and participation. Many professionals noted older adults being reluctant to spend money on physical activity opportunities. Breheny and Stephens (2010) showed how discursive accounts of ageing are grounded in the material circumstances of participants' lives; so access to material resources often constrains older people from spending money on positive ageing (Breheny & Stephens, 2010). Hence older adults might remain unwilling to pay for physical activity, despite being aware of the benefits. Emma further emphasised participants' reluctance to spend money on positive ageing and how this can influence their engagement with physical activity.

> We are speaking about a generation who don't like paying for anything for themselves, they're brought up in a time where you didn't spend money on yourself, yea. You spent it to do things for other people, you put your money away for a rainy

> day but they don’t do something, they don’t spend their money unless they’ll really see the benefit so it’s quite a catch twenty two because who pays to do all the exercise with people with dementia when you’ve got to [have] a far higher staffing ratio than you have for anything else (Emma: I11).

Many professionals mentioned the cost of instructors or staff facilitating activity, and the incurred venue costs; and emphasised these to be expensive. Emma noted that for physical activity aimed at people with dementia more staff or instructors are required to successfully deliver the activity. This of course, comes with a higher costing and can therefore hinder individuals’ willingness to attend. Daniel expanded on this and described how quickly costs can accumulate when providing an add-on physical activity session:

> The cost of running a session normally, hiring an instructor, hiring the venue what can I think it’s total sixty, seventy eighty pounds generally for an hour. So from a breakeven perspective for public health they’re thinking of getting so many people at three pounds a session so you need twenty people at least (Daniel: I07).

The mounting costs for hiring the instructor and the venue can put pressure on providers to have a large number of participants engaged with the session in order to financially ‘breakeven’ (Colin: I05). In Colin’s view, the perceptions participants have of the cost of physical activity is subjective. The majority of formal care services are financed out of pocket primarily by individuals and their families (Rice et al, 1993); with the overall cost of care increasing significantly with the severity of the dementia (Hux et al, 1998). Therefore, families of people with dementia may already be under financial burden with accumulating care costs. Colin suggested that individuals’ willingness to pay for physical activity is thus varied, as is to be expected considering the cost of overall dementia care, an depends on the value that is placed on physical activity.

> So as long as you can keep the cost as nominal as possible but cost is subjective, everybody sees a particular value in something…As long as they see value in it that’s usually not a barrier, that’s why some people will pay six quid a session but some people are willing to pay nothing, it just depends on what that person values in that physical activity. (Colin: I05)

The value of physical activity to individuals, Colin discussed as largely influencing whether cost becomes a barrier or not. Bowes, Dawson, Jepson and McCabe (2013) found cost and logistical difficulties to be a barrier to physical activity for people with dementia. It is possible, however, to mitigate the barrier of cost and even facilitate physical activity without this barrier. John discussed the expenses often incurred when providing physical activity but suggested that with available volunteers physical activity can be delivered without the barrier of cost.

> There are a lot of barriers, so it is tricky and the services …is expensive on a person level because they do there's a lot of support needed, but there is kind of positive initiatives where there's things like dementia walks where you have volunteers to support people and you just walk round a park essentially. (John: I01)

In this extract participants were walking around a local outdoor space within a supported group. This promotes an embedded approach to physical activity through light physical activity in a familiar setting as a part of everyday life. The only difference here is the support provided by the volunteer. The volunteer support replaces the alternative funded instructor or physical activity provider, so is far less costly; however, requires individuals to be enthusiastic about helping older adults with dementia to facilitate such groups without formal funding or structural support.

Research into the neuroprotective effects of physical activity support a dose-dependent neuroprotective relationship between physical activity and cognitive performance (e.g. Kirk-Sanchez & McGough, 2014). Therefore, for people with dementia to benefit cognitively from physical activity, it is necessary to maintain physical activity levels. The maintenance of physical activity, however, is not easily achieved. Systematic reviews and meta-analyses highlight that once interventions put in place to increase physical activity cease the majority of individuals relapse to being less active than during the intervention or entirely inactive (Dishman & Buckworth, 1996; Marcus et al, 2006; Muller-Riemenschneider et al, 2008). Professionals therefore discussed a need to sustain funding so that physical activity provision for people with dementia can be maintained. When professionals are able to provide this physical activity setting that is akin to a physical activity intervention, participants are able to continue to receive the neuroprotective effects of physical activity. Add-on physical activity opportunities thus need to be appropriately planned and financially stable in order to be sustainable.

Many professionals discussed the difficulty in sustaining funding longer term to provide consistent physical activity. Chloe, for instance, discussed how the demand for her physical activity classes is high but she is unable to deliver as much physical activity as has been requested due to the limited funding available to her organisation. This, she viewed as an issue with funding availability for the maintenance of physical activity programmes as well as future classes being setup.

> It’s normally funding which is the issue, but that’s why we’re in quite a nice position that we have funding to be able to go to places and say we will give you these classes. I know there is a lot of places that want them and people who we’ve worked with who want to continue afterwards and the issue is there’s no funding for it to carry on and for it to be sustainable (Chloe: I12).

Chloe highlighted professionals’ reliance on funding for the provision of physical activity. Funding can be from charitable organisations, the public sector and the private sector. Professionals in these data operate under differing financial circumstances, many represented charitable funded organisations, relying on volunteer time and donations; however, the majority represented organisations financed through the public sector. Jasmin, represents the minority of the professionals who operate under funding from the private sector. She called this an alternative business model and described the potentially different focus a business can have when it comes to funding physical activity. Jasmin described applying and benefiting from funding grants from charitable organisations to allow the business to expand and grow, but otherwise the physical activity being provided is set up to self-sustain as it is paid for under subscription by private clients, such as care home owners. This is important in ensuring the continued delivery of physical activity for people with dementia, as there is consistency and less reliance on successful application to charity or public sector funding opportunities.

> The kind of business supporting itself effectively. … we kind of look to bring in some extra money so that we can grow…every product should be profitable so we don’t want to kind of we don’t want the business to be run on grants. So but equally if there are grants available that support us to for example develop our test or do something

> else, then we'll happily take that to help us grow. So I would say it's kind of like it's not, we want to be able to exist without grants, but the grants would be a bonus (Jasmin: I04).

In this extract, Jasmin described grants as 'a bonus' (Jasmin: I04). Colin, who works within the public sector, also discussed the importance of sustaining physical activity. He is allocated government funding once a year to deliver physical activity within the community, under the aims specified by his commissioner. He, like Jasmin, perceived grants in a similar way as his entire physical activity provision is not reliant on grant funding as is often the case in the charity sector. He expressed a desire to remain delivering physical activity regardless of grants or extra funding. To Colin, this is achieved through setting up the physical activity correctly in the first instance. When setup is achieved successfully, managing the financial aspects of the physical activity is usually less problematic.

> I mean we can't be naïve enough to think it's always going to be there. That's the biggest thing… I always say to my team, if the money stopped tomorrow, funding, would we still be able to deliver something? So as long as that's yes then I'm happy because the worst thing would be you've done something great, funding cut and then you stop. So that's the biggest thing for me so balancing the money aspect of it is a big thing but it usually takes care of itself if the sessions are good, you know you target the right sort of locations, you've got the buy in from participants, they understand the benefits of exercise, public health are happy because what you're giving them is valuable, you're showing them the difference that you can make in a community (Colin: I05).

Although Colin expressed a desire to continue as a self-sustaining provider of physical activity regardless of any changes to funding, the underlying importance of funding to physical activity provision is emphasised. He further described the consequence of a cut in funding as 'the worst thing' (Colin: I05). The reliance on outside organisations to fund physical activity is a deeply embedded part of the structure of physical activity provision. Professionals seemed uncomfortable with this financial dependency, but discussed it to be an inherent part of providing physical activity for people with dementia. Funding can also incur even further benefits. Most notably, affording add-on physical activity sessions to be provided free of charge for numerous older adults and those with dementia that potentially without physical activity provision would remain inactive.

> … people don’t want to be paying too much for this, or at all, which is where the [physical activity programme] is quite good because they’re all free sessions because of the funding provided by leading funding organisation, which is why when we’re actually finding individuals when they’re actually coming to the sessions everyone actually loves it (Gavin: I10).

Funding processes were also discussed as important. Throughout the dataset professionals discussed the funding involved with their projects. Many had been funded by leading physical activity funders, predominantly one public organisation, which channels funds from the government through to organisations that deliver physical activity to inactive groups of individuals throughout the community. Rebecca, a representative of this leading funding organisation, discussed recent changes in the allocation of funding on a national scale.

> The biggest change for us is that 25% of our investment is going to go into tackling inactivity. So it will see us become one of the biggest funders of tackling inactivity and that kind of national level and what that really means is we are going to have 120 million pounds of dedicated funding for tackling inactivity…but also through specific funds that come from the government through the exchequer for very particular programmes of work (Rebecca: I03).

Rebecca discussed funding as originating from government budget allocation directly from the exchequer, as well as receiving national lottery funding to filter into physical activity programmes nationwide. The recent funding allocation through Rebecca’s organisation is in a transitional period as they have previously not been the leading funder of physical inactivity for older adults. With this change, other professionals questioned the allocation of funding due to the debate surrounding embedding physical activity or taking an add-on approach. Previously, the leading funder prescribed the primary outcome of projects to be increased participation in sport, rather than the social and wellbeing outcomes often favoured for people with dementia.

> …there is a question of who is best to lead. I think people don't necessarily enjoy sport or physical activity so for the sport sector and the physical activity sector to lead the really inactive guys the kind that are doing either nothing or 0 to 30 that might just not ever want to do any physical activity then it's probably not the sport sector who should be leading it, although that's how it's kind of playing out. (John: I01).

John proposes that perhaps sports funding bodies are less appropriate to lead for more inactive older adults, such as those with dementia. Through this question John is suggesting an argument for an embedded approach whereby, as discussed in the social connection theme, the social aspects of physical activity are given primary focus. This, he implies, could potentially be better achieved through organisations with a social focus leading on the allocation of funding.

Through the current funding structure, funders habitually specify what they are seeking from future projects. Recent funding available for inactive older adults seeks for organisations to co-design their programmes with the older adults. Co-designing services for people with dementia has been shown to be feasible and is often advocated in dementia studies (e.g. Hendricks, Truyen & Duval, 2013). However, topics that funders are interested in investigating are specified prior to the application process. Pete discussed funders specifying categories of programmes they have an interest in funding: 'Every funder has its category of the year, last year…wanted to target elderly. So all their money went to elderly groups or elderly populations initiatives that are going to help them with social isolation' (Pete: I08).

Pete noted that with many funders this is on a yearly basis, ensuring differing distribution of funding from one year to the next. Professionals are required to remain prepared for alterations in funding. Colin discussed how following several applications, he had to then ensure his organisation were in a position to deliver the exact outcomes specified by the grants.

> [W]e're putting in a number of different bids...Then it's making sure that if you put that plan in place how are you going to deliver exactly the outcomes that are required on that plan and the more funding you get obviously the more you've got to deliver on that as well… we're really lucky we have a very varied team that are able to deliver on tens of different activities depending on what is wanted (Colin: I05).

Colin discussed how more funding means more delivery, which in turn requires instructor availability and scope within the organisation. Funding applications require ‘doing so much work for the [Name of funder] bid’ (Daniel: I07). Following ‘expressions of interest’ (Rebecca: I03), paper applications are written and if successful, organisations are usually invited to present their project to a panel, who will ultimately determine whether funding is achieved.

Throughout the process of applying and managing a funding grant, organisations are given a specified timescale. Professionals often discussed timescales as they are required to be mindful of not running out of money. If this happened professionals would be unable to deliver physical activity. Therefore, professionals will ‘try and approach during the third-year commissioners and try and get them to start funding it’ (Chloe: I12). Alongside timescales, funders mandate evaluation of physical activity provision. Professionals are required to plan for and incorporate evaluation into physical activity programmes throughout and therefore planning for a new application for funding is required far in advance of needing the funding to be available.

9.3.3.2 Evaluation

All professionals discussed the mandate to evaluate physical activity programmes as a part of the structure of being awarded funding. Angela, for example, highlighted that the funding she is working under specifies a remit to fully evaluate the programme.

> This particular stream of funding for [Name of funder], there is a big evaluation pot under this stream of funding because part of the remit is to fully and properly evaluate. So [Name of funder] in when it’s given out this funding, allocated this funding and part of the aim of the funding is not only to deliver but to evaluate. (Angela: I13).

As a researcher, evaluating the programme is Angela’s role within the structure of physical activity provision. However, for other professionals within physical activity programmes evaluation is an unfamiliar procedure, therefore the large amounts of required data collection is often ‘very new for our instructors’ (Colin: I05). Evaluation of funded physical activity operates under a timescale, alongside the overall project timescale. Evaluations were scheduled at the beginning of the physical activity programme, often referred to as baseline. Professionals discussed differing timescales for follow-up evaluations but each maintained evaluation throughout the programme with the final evaluation always signifying the overall length of the physical activity programme. Unfortunately, professionals described how evaluation can often become a barrier to physical activity participation. Chloe discussed how her participants have experienced difficulties completing evaluation forms and are often put off by the ‘stack of paperwork’ (Chloe: I12).

> It’s quite difficult actually, some of the other barriers really is the paperwork. So obviously because we’re funded we have to give back all the monitoring forms and all the information but when you’re getting older people to come to a dance class and the first thing they see is a stack of paperwork. They either don’t want to fill it in or it’s quite difficult for them to fill it in because of their eyesight and I’ve found particularly carers can be quite, they don’t really want to fill in anymore paperwork because I suspect they get paperwork shoved at them everywhere they go and so they come to something creative and think they’re not going to get that then suddenly there’s a bunch of paperwork to fill in (Chloe: I12).

Chloe highlights here how the overload of evaluation requests on participants can create difficulties, resulting in some participants temporarily refusing to complete evaluation forms. Although less commonly utilised for evaluation purposes, observational methods offer a potential alternative to current methods described by Chloe. Dementia care mapping which Kuhn, Ortigara and Kasayka (2000) describe in full, for example, is grounded in the theoretical perspective of person centred care for those with dementia and aims to observe participants and by doing so track their quality of care. Although research into this methods validity and reliability are still developing, dementia care mapping shows the feasibility of alternative observational methods (Brooker, 2005). Adam described using this method within his evaluations, however, he has only tried this once so far.

> When we can’t do those methods of data collection it’s predominantly because of a cognitive impairment which means they are not able to complete our data collection tools to the kind of relevant standard. So what we’ve kind of introduced then is,

> we've only piloted it at one site at the minute and then are looking to continue it within our next few rounds is we've used dementia care mapping as an observational tool to see the impact it has had upon things such as a person's mood or their interaction with peers or stuff like that and that's predominantly with people with dementia who are taking part in the programme as well (Adam: I09).

The potential for observation methods, with dementia care mapping as a specific structured example is clear. However, professionals discussed these methods very tentatively as this is ultimately determined by funders rather than physical activity providers. Additional difficulties of evaluation were also discussed by professionals. These included specific difficulties when obtaining 'ethical approval for people who don't have capacity to consent' (Angela: I13), obtaining informed consent, inaccuracies stemming from 'questionnaires [that] are based on recall for the last seven days' (Gavin: I10); among other contentions.
Many professionals found personal difficulties with the process of evaluation. Daniel particularly, highlighted the constant mandate to evaluate the benefits of the physical activity itself as counter-productive, as evidence for the health benefits of physical activity has been available since the 1950s (Kohl et al, 2012), and further evidenced for people with dementia in recent years (e.g. Heyn, Abreu & Ottenbacher, 2004; Forbes, Thiessen, Blake, Forbes & Forbes, 2013). Daniel discussed how funders could possibly benefit more from an interest in whether or not the way that specific organisation have approached and facilitated the programme has been successful or not in increasing engagement, tackling inactivity and motivating participants to change their lifestyle behaviours to involve more engagement with physical activity in the future as well.

> [organisations] should be evidencing participation, behaviour change and motivation not PA itself…we shouldn't have to be arguing the benefit of it, the only thing I think we should be evidencing is that a model works that's the most important thing, it's actually about participation rate, motivation, behaviour change I think that's more important than…that we have the minor change in fall prevention because if people take part that's a given (Daniel: I07).

In this extract, Daniel raised a key concern regarding the long-term maintenance of physical activity for people with dementia. Meta-analysis has shown high attrition rates and poor adherence to physical activity interventions for people with dementia (Forbes, Thiessen, Blake, Forbes & Forbes, 2013), highlighting the prevalence of this concern in the literature as well. Amireault, Godin and Vezina-Im (2013) showed physical activity maintenance to be most predicted by beliefs about capabilities, motivation and goals. Professionals discussed intentions to change participants' behaviours to increase physical activity participation in the long term. However, the influence professionals can have on the psychosocial factors highlighted by Amireault and colleagues may be limited. As a result, professionals are currently unable to find a solution to the problem of long term activity adherence, as Gavin discussed:

> [T]hey'll come to the sessions and they are enjoying the sessions when they're there and they're enjoying the social aspect but they're still not doing anything outside of the session, which is why the maintenance Get Healthy Get Active sessions are so important because they go beyond the twelve weeks and keep people engaged and that's where we're really pushing advertising other sessions in the local area (Gavin: I10).

In this exert Gavin noted the need for maintenance sessions to go beyond the original timescale of the programme in order to sustain participants' engagement in physical activity. He further stated that physical activity providers should be pushing advertising of other sessions in the local area, this is with the intention of encouraging participants to begin to seek future and differing physical activity opportunities. Ideally, professionals discussed the possibility of available funding to maintain physical activity sessions in order for participants to be able to sustain physical activity.

Sustaining physical activity could be helpful in preventing future health related problems. Health related issues can be costly for society, a number of funders are therefore interested in reducing the economic cost of potentially preventable health problems. An example of a costly health issue for older adults that results in substantial economic burden on society, are falls. Pete highlighted that 'falls cost the NHS like two point three billion a year. So it's a massive amount' (Pete: I08). Heinrich and colleagues (2010) called for efforts to be directed to economic evaluations of falls prevention programmes aiming at reducing fall related fractures which contribute extensively to fall related costs. Professionals discussed their experiences with suggested economic evaluations. Colin further explained the potential implications for healthcare.

> [I]t could be completely changing someone's life and then when you look at it based on an NHS cost scale and that's saved the NHS X amount or approximately X amount based on that person's issues that they might have had going forward, there really is a small price to pay (Colin: I05).

Evaluations built into physical activity programmes therefore could have substantial implications for healthcare services if shown to be beneficial in reducing participants' risk of future health problems. Additionally, evaluations are able to improve and develop existing physical activity and service provision and target future interventions to better benefit older adults with dementia. Rebecca discussed her funding organisations approach to learning from, and continuously developing, programmes across the country through evaluations.

> We want to learn a lot more about how we best work with older people and support them to become more active, to benefit their health and wellbeing, and help them remain more independent; and to meet their own needs and wants, so whether that's about more time with their family or about staying independent or whether that is about raising money for a charity that perhaps means something important to them or volunteering. So it means lots of different things to lots of different people I guess (Rebecca: I03).

In this extract, Rebecca highlighted that although the focus of the evaluations may often be the economic and long term health benefits of physical activity provision, the outcomes enjoyed by participants, and to be learnt from, can be varied and advantageous to professionals too.

9.3.3.3 Collaborations

To achieve a successful funding award from a funding body, whether a charitable or public grant, there is often a collaboration between at least two organisations. Collaborations are encouraged for numerous reasons and are advantageous for physical activity programmes to be successful. Professionals discussed their experiences with a variety of collaboration types. Commonly discussed collaborations included those between a physical activity provider and a University, a physical activity provider and a care organisation; and between a physical activity programme and everyday organisations and community groups that people with dementia may be a part of.

Collaborations with Universities were brought about for the purpose of evaluation and were frequently stipulated by funding requirements. A collaboration such as these are beneficial as Universities can offer expertise on how to conduct and disseminate evaluations. Moreover, bias in evaluation is minimised, as data collection is conducted by an organisation that is not leading the physical activity, and therefore are more invested in conducting the evaluation correctly and are less concerned with the outcome of the evaluations.

Collaborations between physical activity programmes and care organisations are fostered when care organisations wish to promote increases in physical activity among their residents. Lastly, collaborations with smaller community based groups were discussed as purposeful. Often collaborations such as these exist for recruitment functions. Chloe discussed how important collaborations like these are to the success of many physical activity programmes: ‘most of it comes from whichever organisation we’re working with from their existing network, so it’s really important the relationship we have with the organisation’ (Chloe: I12).

Chloe uses the term “relationship” here to describe the collaboration; which signifies the regard professionals have for the collaborations they have. Professionals perceived partnership working in this way as valuable to their physical activity programmes and discussed the variety of collaborations they had experienced.

Professionals discussed their role in supporting existing organisations to accommodate people with dementia. John discussed how organisations were ‘looking to kind of support providers more than being a provider themselves. So support providers in making their services dementia accessible’ (John: I01). By doing so, people with dementia can complete activities of daily living more independently and for longer as well. Collaborations that facilitate the acclimatisation of existing organisations encourage people with dementia to continue to remain an active part of their community. Collaborations such as these therefore facilitate embedded physical activity for people with dementia, alongside the maintenance of independence.

Several professionals discussed the collaborations that foster far wider implications than those at the programme level. Most notably, professionals underlined the current large charity network collaborating in the co-production of physical activity messaging. This network of collaborations was described as a ‘rare’ and ‘massive collaboration opportunity’ (Michael: I02). The network aims to establish ‘how we can use our mutual insights to better campaign and influence people around physical activity’ (Rebecca: I03). Michael discussed how shared messaging through large scale collaboration networks such as this could reach a wider audience.

> If you, to have consistency it just means you might reap more audiences in that way as well. So we’re very conscious as well that people might well have more than one long term condition and that might be, well as long as you’re getting the same message across and you might get the message across twice for instance but you might, given that not everyone uses the same services from charities, so if they’re using one and we’ve got that consistent message in then we can be confident that that message is getting across better and then we don’t have to compete on messaging (Michael: I02).

Involved professionals discussed that the consistency and repetition of positive physical activity messages can only incur additional benefits, and increase the chances that inactive individuals will benefit from messaging. Moreover, professionals discussed how the collaborators involved already have consensus on the benefits of physical activity, so the work to be done is in packaging that message and disseminating it as appropriately and widely as possible, so that people at risk for adverse health conditions are ‘getting that message in a timely fashion so they can take control of it themselves’ (Michael: I02).

Schutzer and Graves (2004) discussed the key and pivotal role that health professionals specifically play in the initiation and maintenance of physical activity behaviour for older adults (e.g. Schutzer and Graves, 2004). Professionals also discussed working with general practitioners (GPs) or doctors to better facilitate and encourage physical activity. This was often achieved through referrals into physical activity programmes. Daniel’s experience with doctors’ referrals required him to work ‘incredibly hard to forge that relationship with local GPs’ (Daniel: I07). He later added that he had sought a consistent method for achieving referrals for physical activity with ‘GP referral assistance networks’ but ‘there is no one single x at the moment (Daniel: I07). This infers that GP involvement in physical activity is in its infancy, but has the potential to develop further to better influence physical activity behaviours of those living with dementia.

Pete also discussed doctor involvement in encouraging physical activity to individual patients. He noted that doctors' interests in physical activity can often influence their willingness to refer patients with dementia to physical activity programmes: 'You notice at GPs, GPs that are into physical fitness themselves will refer… people that aren't and they give themselves medication to a certain extent, they will just prescribe medication' (Pete: I08).

To counteract the personal interests of GPs described by Pete, John discussed clarifying the role of the healthcare professional within the structure of physical activity provision. He discussed highlighting to doctors how beneficial their input could be without adding to their workload.

> Clarify the healthcare professional's role and make them see what they could do without adding considerable amount to their workload. So half of it is to try and position the charity as part of the solution and trying to make it easy as possible to kind of trying to make it as easy as possible for healthcare professionals to promote physical activity (John: I01).

John discussed his organisations' role in helping doctors to promote physical activity, and being available to aid GPs in this process. Professionals discussed the possibilities to enhance their job roles and achieve professional development through collaborations. Angela described how instructors delivering the physical activity programmes whose experience originated in the sports sector are less likely to be accustomed to working with people with dementia. Therefore, through physical activity programme collaborations professionals have been able to develop their capabilities, and learn to adapt their delivery appropriately for people with dementia.

> There's a lot of professional development going on in terms of staff and there's not much work being done apparently in the field of sport, sport sector with people with

> dementia, so what we want to do is draw up some best practice guidance for delivering sports to people with dementia in care settings (Angela: I13).

The advantages of professional development are bidirectional within the collaboration structure. Professionals also discussed those who have expertise in working with people with dementia, but are not accustomed to delivering physical activity. Collaborations in instances such as these could develop their understanding of physical activity and how to encourage people with dementia to participate in activity. Literature asserts lack of knowledge about physical activity as a consistent barrier to physical activity for older adults (e.g. Mathews et al, 2010). In order to navigate this barrier, Adam's programme developed an education seminar for professionals from the care sector that were collaborating with the physical activity programme.

> Luckily within [Name of care organisation] they kind of were open to the fact of kind of being educated around the benefits of physical activity so we were able to go in and give some you know some pretty damning evidence around the effects so it can have not only physical health benefits but peoples' general quality of life as well and I think when they saw that then they were really happy to get on board with the programme and influence that (Adam: I09).

Adam discussed the importance of the care organisation being willing to receive training on physical activity. He discussed how this positively influenced staffs' enthusiasm to encourage physical activity for their participants. Jasmin further discussed the effects of professional development, referring specifically to the physical activity refresher courses facilitated by her organisation, as energising for professionals. Training courses offer the benefits afforded by 'coming together, sharing best practice, learning a few more things and getting kind of re-motivated' (Jasmin: I04).

Professionals highlighted a plethora of benefits achieved through collaborating with a variety of different partners. The potential for collaborations to expand and better inform the delivery of physical activity for people with dementia is yet to be explored. Vast improvements in physical activity provision for people with dementia could be enjoyed, whether that involves embedding physical activity through the continuation of services for people with dementia or through the add-on approach delivering physical activity classes to supplement everyday activities.

9.4 Conclusions

The professionals' perspectives presented throughout this chapter highlighted an underlying contradiction in approaches toward physical activity for people with dementia. The first approach establishes physical activity as an embedded part of everyday life. This approach advocates opting for more physically demanding activities over and above sedentary alternatives. This could mean, as an example, walking into town rather than taking the bus; or perhaps choosing to do some gardening over watching the television. The contradictory approach contends that more active lifestyle choices may not be sufficient or appropriate and therefore positions physical activity as an add-on activity. This approach allows physical activity to be targeted to specific ailments and physical difficulties. An example could be a falls prevention class for older adults experiencing frailty and thus risk of falls. It could be suggested from barriers established throughout this analysis that an add-on approach offers more opportunity for barriers to arise as the activity is not a fundamental part of participants' pre-existing activities.

Both methods of physical activity provision evidence health benefits for people with dementia, as both seek to increase the amount of time spent being physically active. The current emphasis on personal responsibility of the carer to facilitate physical activity, typically disregards the social and environmental circumstances within which the physical activity is situated (King & King, 2010). Correlates of physical activity for older adults have been found at all ecological levels, supporting multiple levels of influence over the physical activity behaviours of older adults and those with dementia (Thornton et al, 2017). Discussions with professionals and the resultant themes demonstrate these multiple layers of influence. If co-ordinated correctly, the physical and social environment, alongside the structure of the organisations involved with the physical activity, can lead to increased participation in physical activity. Conversely, these multiple layers of influence can further create and sustain pre-existing barriers to physical activity for people with dementia.

Literature investigating interventions for people with dementia frequently describe a ‘holistic view’ (e.g. Kolanowski & Whall, 2000). This theoretically aligns with an embedding approach to physical activity. A literature review of physical activity interventions for people with dementia noted that assessed interventions took this holistic view toward physical activity and found physical activity to be effective in improving cognition, mood, behaviour and physical condition. The services studied that took this more holistic view, often focused on enjoyment and wellbeing of their participants (Bowes, Dawson, Jepson & McCabe, 2013). This has been supported by data from these professionals, particularly throughout the social connectivity theme. The descriptions accompanying the holistic, embedding approach did, however, seem to combine embedding approaches with either weekly or bi-weekly add-on physical activity classes as well. The literature discussed in this chapter is hence supportive of both approaches, and is yet to untangle the nuances of the two approaches. Establishing the role of each approach could help us to better understand how each can benefit people with dementia. This could better facilitate appropriateness of physical activity for people with dementia, and consequently increase the likelihood of participants sustaining physical activity and benefiting from doing so.

The environmental, social and structural barriers were discussed by professionals from their experiences. Many highlighted the overarching issue of sustaining physical activity long term, and all discussed the implications each theme had on the issue of adhering to consistent physical activity. Many discussed embedding approaches and add-on classes interchangeably. This suggests a current overall focus on helping people with dementia to be active in whichever way is most feasible at the time. It can be concluded that professionals play a key role in the provision of physical activity for people with dementia. The barriers they reported navigated were varied and far-reaching. From the social interactions and strategies applied within the context of a specific environment and how this can be navigated to encourage physical activity. All of these barriers were placed within a structural context of physical activity for people with dementia.

Structure was reported to act as both a facilitator and a barrier to physical activity, and ultimately determined whether professionals could provide physical activity or not. Professionals pointed to a need to review the structural requirements within this context. The main contentions discussed by professions were that current evaluations are ineffective, labourious and frequently deterred individuals from participating in activity. Professionals highlighted the importance of funding and maintaining good standards of practice to ensure continuous delivery of physical activity. Lastly, professionals noted how, despite the shortfalls of the current structure of physical activity provision, it does successfully facilitate collaborative relationships that ultimately benefit the individual with dementia. Findings from this chapter, alongside perspectives of people with dementia in chapter 8 could inform local and national authorities of the wider methods that can be applied to stimulate population level physical activity, specifically for people with dementia, a population of older adults that are largely inactive (e.g. Moyle et al, 2018).

Chapter 10

Discussion

Chapter 10 – Discussion

This thesis aimed to investigate the use of cognitive assessments in informing dementia diagnosis and assessing physical activity effects; and explore the role of physical activity for people with dementia. A thread of inclusivity throughout the journey of dementia was investigated, from inclusive assessment to inclusive interventions consistent importance for consideration of inclusivity was apparent.

The overarching objectives of the thesis were…

i) To investigate cognitive functioning across a wide range of individuals in order to better establish inclusive, reliable and valid cognitive assessments that could also inform dementia diagnostics in vulnerable adults.

ii) To use the same cognitive assessments to evaluate the benefits of physical activity in vulnerable individuals with dementia to develop inclusive physical activity protocols that benefit a wide range of people.

iii) To assess the best ways people with dementia can better take up physical activity as a potential intervention to treat dementia using inclusive methods and practices.

Part one of the thesis consisting of chapter 3 through to 6, through positivistic investigation, explored the first and second objectives laid out here. A review of the literature in Chapter 3 identified a lack of consensus regarding the cognitive assessments that are administered to best inform dementia diagnosis for individuals with intellectual disabilities (ID). This has been highlighted as a prevailing issue for the wider population requiring dementia diagnostics, with previous research calling for additional validation of current cognitive assessments to better advance dementia diagnostics (e.g. Velayudhan et al, 2014). The Cognitive Computerised test battery for individuals with intellectual disabilities (CCIID), specifically the Series subtest, alongside the Hopkins Verbal Learning Test (HVLT) were found to distinguish effectively between individuals with dementia and controls in individuals with ID (Chapter 4) and in individuals from the general population (Chapter 5). Moreover, these assessments detected increases in cognitive scores following a short bout of resistance band physical activity (Chapter 6).

The second part of this thesis consisted of chapters 7, 8 and 9 and investigated, through critical realism, the third and final objective of latter chapters of this thesis sought to investigate how people with dementia access physical activity. Findings from a systematic literature review suggested that adherence, even in a randomised controlled trial where physical activity is easily accessible and supported, is inconsistent at best (Chapter 7). Longer term adherence to physical activity is problematic for people with dementia. The barriers people with dementia experience that inhibit physical activity have been listed in previous studies (e.g. Van Alphen, Hortobagyi and van Heuvelen, 2016). However, short interventions, variety and one to one or small group support had better adherence. Chapter 8 offered a more in-depth discussion of the perspectives of people with dementia toward physical activity. Professionals' then discussed their role in navigating these barriers and facilitating physical activity for people with dementia (Chapter 9). This final discussion chapter will discuss the findings of this thesis in the wider context of research in which it is situated, as well as the real-world implications for the discussed findings.

10.1 Inclusive dementia diagnostics

Flowing from previous understandings of person centredness, but accompanied by the consideration for the diversity of individuals who experience the journey of dementia, the overarching concept of inclusivity was applied to the dementia research laid out in this thesis. Inclusivity was defined as the inclusion of all individuals across the whole journey of dementia. Inclusivity was first investigated through the lens of positivism. These initial investigations sought to increase the inclusivity of the process of diagnosing dementia, by evaluating the potential for cognitive assessments to be accessible to a diverse range of individuals that could be requiring of a diagnosis of dementia. The application of inclusivity, in this thesis, therefore began with inclusive dementia diagnostics. Inclusive and interdisciplinary approaches to diagnostics have been shown to provide measurable benefits for people with dementia (Kohler et al, 2014). This thesis has shown that cognitive assessments can be inclusively applied across populations, which could in turn, increase communication between services and advance our understanding of dementia. Selecting an appropriate test, however, depends on numerous factors that are often related to the specific clinical situation. This could include the setting in which cognitive assessments are being administered (e.g. primary or secondary care settings), the time available to perform testing, the requirement to test general or specific cognitive functions and the availability of informants and trained staff (Larner, 2017).

The Series subtest of the CCIID and the HVLT were very efficient and easily administered in both studies, suggesting their potential for practical implications. Diagnosis in reality is not a one-off event, but rather a process (e.g. Hellstrom & Torres, 2013). A process, which is often influenced by varying constraining factors. The most pressing of which are the limited time and resources clinicians have access to (e.g. Boise, Camicioli, Morgn, Rose & Congleton, 1999; Ólafsdóttir, Foldevi & Marcusson, 2001). Clinicians receive pressure from most national and international health authorities, such as the World Health Organisation, that call for an early diagnosis (e.g. Waite, 2012). However, clinicians have reported a sceptical attitude towards the benefit of diagnosis in consideration of current shortcomings of drug treatments (Ólafsdóttir, Foldevi & Marcusson, 2001). This highlights the conflict within healthcare settings surrounding the process of diagnosis. The research in this thesis demonstrated that it is possible to apply cognitive assessments quickly and efficiently with minimal training with assessments such as the CCIID specifically the Series subtest, and the HVLT as they do not require extensive training or a particularly long appointment with the patient to administer effectively (Chapter 4 and 5).

10.2 Role of physical activity for people with dementia

There is no cure for dementia or pharmaceutical treatments that can improve cognitive functioning for people with dementia (e.g. Tzeng et al, 2017). Physical activity could offer benefits in health and wellbeing outcomes (Junge, Ahler, Knudsen & Kristensen, 2018) and the argument for physical activity to be prescribed as a treatment is gaining momentum. This thesis found initial suggestion that a short bout of resistance band physical activity could benefit cognition across a number of cognitive functions, as discussed in Chapter 6. The positivistic lens through which this study was conducted offered valuable insights to the potential for cognitive assessments to assess the effects immediately following a short bout of physical activity. Further benefits of applying cognitive assessments during the process of diagnosis can be seen in later assessmentof the effectiveness of interventions and treatments. Most notably, cognitive functioning following physical activity can be measured, using cognitive scores from diagnosis as a baseline in which to compare to. This suggests that the

CCIID and HVLT could, not only inform dementia diagnostics but also, detect patient response to interventions post diagnosis.

These findings are consistent with previous work showing acute cognitive benefits of a short bout of physical activity (Chang, Labban, Gapin & Etnier, 2012). There has been debate over the longer-term impact of physical activity throughout earlier research discussions. However, more recent findings, which have been further confirmed through meta-analysis has demonstrated positive cognitive effects following consistent engagement with physical activity (Groot et al, 2016). This is adjacent to a variety of benefits that are available such as increases in fitness, physical function, balance and decrease in concern about falls, for instance (Lamb et al, 2018; Heyn, Abreu & Ottenbacher, 2004; Taylor et al, 2017).

Substantial research has shown that, despite well evidenced benefits of physical activity for people with dementia and the potential for physical activity to act as a treatment, physical activity is still not perceived as a necessary prescription and physical inactivity levels remain high in this population (Schutzer & Graves, 2004; Dumith, Hallal, Reis & Kohl, 2011). Part 2 of this thesis offered an investigation of physical activity throguht the lens of critical realism. Beginning with a literature review to develop a deeper understanding of the context in which people with dementia adhere to physical activity. Inconsistent levels of adherence to physical activity were commented on in previous research (van der Wardt et al, 2017) and further confirmed in the literature review detailed in chapter 7. This is despite people with dementia indicating a willingness to take up physical activity. The findings in this thesis therefore suggest that barriers to physical activity inhibit people with dementia from participating in physical activity longer term.

The widespread need for an increase in physical activity, however, spans far beyond the individual benefits available. Prolonged sedentary behaviour causes a considerable burden to the National Health Service (NHS) in the United Kingdom (Heron, O’Neill, McAneney, Kee & Tully, 2019), with further research indicating this is the case for adjacent healthcare services worldwide (e.g. Ding et al, 2017). This economic burden and increase in mortality risk through sedentary behaviour suggest a need for health promotion and an increase in physical activity population wide. There is, however, debate over who is best placed to implement this health promotion. Current healthy ageing discourse places responsibility on individuals for achieving good physical health and ignores their broader circumstances and the context in which physical activity is situated (Stephens, Breheny & Masvelt, 2015). When it comes to dementia care, care partners are often given this responsibility of maintaining health for the individual with dementia. Care partners thus have a large and complex role in the facilitation of physical activity for people with dementia (e.g. Tretteteig, Vatne & Rokstad, 2017), which, as discussed in chapter 8, can further inhibit physical activity participation; particularly if the dynamics of that care relationship is under strain. Professionals who work with people who have dementia on a daily basis, but are not familial caregivers, represent the potential solution for health promotion. Findings from discussions with professionals (Chapter 9) identified numerous strategies that can be applied to increase physical activity on an individual or group level. The issues identified were not with delivering physical activity itself or finding ways to motivate or encourage people with dementia, but with the overall structure of physical activity provision. The barriers for professionals were discussed in the inconsistencies in funding required to facilitate physical activity, the collaborations needed to acquire that funding and the subsequent evaluations that can delay delivery of physical activity and discourage people with dementia (Chapter 9).

Dementia care represents a substantial financial burden for society (e.g. Hurd, Martorell, Delavande, Mullen & Langa, 2013). The financial implications of providing physical activity for people with dementia are complex, as highlighted by professionals in chapter 10. This leads to a key issue in dementia care today: who is best placed to fund physical activity? Professionals discussed various organisations that are currently involved in funding physical activity, such as charities, government funding channels, and businesses that are self-sufficient but rely on the wealth of those that require physical activity or the private sector, such as care homes, opting to allocate resources toward physical activity. Researchers have argued that local authorities have a responsibility to promote physical activity amongst older adults. Knowing how to stimulate regular activity at the population level, however, is challenging (McPhee, French, Jackson, Nazroo, Pendleton & Degens, 2016). Findings from this thesis have pointed to the problematic nature of implementing physical activity for optimising public health. Further investigations should therefore explore the national landscape of physical activity for public health and investigate further where funding can be allocated from to more consistently support physical activity at the population level.

10.3 Current dementia research and the person with dementia

The research in this thesis aimed to be inclusive throughout, informed by person centred approach that places emphasis on people with dementia having a prominent role in their own welfare (Kitwood, 1997). The operationalisation of the concept of person centred care, however, is complicated. Mathorpe and colleagues (2013) found that few participants experienced the process of diagnosis as patient centred. Mathers and Paynton (2016) have expanded to suggest that person centred care is yet to be implemented ‘at scale’ in any meaningful way. There are therefore apparent tensions between person centred care in theory and the practical application of this approach.

This thesis found that person centred care is also at odds with health promotion, which, as discussed is crucial in increasing population wide physical activity. Professionals perspectives operationalised health promotion through two approaches: i) add on physical activity classes or ii) by embedding physical activity in to the daily lives of people with dementia. The embedded approach has become associated with the phrase “physical activity by stealth” for some professionals. This phrase, and the overall embedded approach to physical activity, highlights how professionals use strategies to increase physical activity without explicitly making the individuals aware that they are going to engage with physical activity. This strategy of stealth is at complete odds with the concept of person centred care.

Although there are tensions between person centred approaches and physical activity, person centred approaches have positively impacted dementia research. Most notably, the influx in novel research methods being used to better understand dementia have been observed in recent years. These methods have been previously applied in other research fields but their application in dementia research is a relatively new phenomenon (Keady, Hyden, Johnson & Swarbrick, 2017). In line with person centred approach, this thesis presented the first study to explore the perspectives of people with dementia toward physical activity while being physically active. Kullberg and Odzakovic (2017), have previously found these mobile methods to be feasible for people with dementia when discussing the surrounding environment. This thesis adds to this previous research and demonstrates that research can be inclusive in the methods used.

10.4 Limitations and Future directions

This thesis is not without limitations. Firstly, the individuals that participated in this research were white individuals, from the middle-class who were already willing and able to support themselves, as well as reach out to seek available resources. This is not representative of all individuals who have dementia and therefore is limited in the conclusions it can draw. Future research should therefore further investigate the topics discussed in this thesis in a sample that is more representative of the individuals affected by dementia. Through widened recruitment the effects of various demographic factors such as age, gender and ethnicity can be discussed in more detail. Specifically, how they impact cut-off scores needed for accurate dementia diagnostics, physical activity effects, and how physical activity is accessed by individuals with dementia from different backgrounds.

Secondly, investigations into the acute effects of physical activity were conducted in a sample from the general population, which did not include individuals with ID. This was, unfortunately, outside the scope of this thesis, with recruitment and operationalisation of physical activity for people with both ID and dementia not possible within the limited potential recruitment pool of participants available, as well as the time frame available for the research contained within this thesis. Future research should thus investigate the cognitive effects of a short bout of physical activity for individuals with ID and dementia.

The biggest overarching concern for the research detailed in this thesis are the small sample sizes that were able to participate in part 1 of the thesis. This meant that the conclusions that could be drawn about the effectiveness of cognitive assessments in informing dementia diagnostics for individuals with and without ID, and the cognitive effects of a short bout of physical activity are currently inconclusive. Although potential indications can be suggested, further research is required to replicate these investigations within larger samples, and more representive samples as discussed above, in order to confidently draw conclusions.

Although this thesis has limitations, it offers valuable insights that can contribute to dementia research. A field that is developing and increasing the potential to facilitate inclusive and person centred approaches, but as discussed has not yet been able to consistently achieve this.

This thesis has also stimulated future research inquiry that can continue to advance our understanding of dementia in a way that is informed by inclusivity and person centredness.

10.5 Conclusions

This thesis sits within a context of conflict and tensions between what is possible for the individual and what is necessary for optimising affordable public health. This thesis has shown that it is feasible to apply cognitive assessments inclusively in the process of dementia diagnosis regardless of pre-existing functioning, as well as be used to assess the effects of interventions. This thesis has also supported the cognitive benefits of physical activity for people with dementia. However, inconsistencies were found in studies investigating adherence to physical activity amongst people who have dementia. The perspectives of people with dementia and professionals toward physical activity were then discussed in consideration of their potential implications for treatment of dementia. Although inclusivity was sought throughout this thesis the concept, as informed by a person centred approach, this is much more problematic to operationalise that the theoretical concept implies. Therefore, future research should build on these findings through novel approaches to understanding dementia inclusively.

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Appendices

Appendix	Title	Page number in thesis
1	Information sheet for individuals with intellectual disabilities (symbols form)	
2	Caregiver assent form	
3	Informed consent for individuals with intellectual disabilities	
4		

	Demographic and Health Questionnaire for individuals with intellectual disabilities
5	Informed consent for individuals from the general population with and without dementia
6	Demographic and Health Questionnaire for individuals from the general population
7	Couch Potatoes for Cognition – physical cativity information booklet
8	Feedback forms used to assess uptake of physical activity and develop interview schedules
9	Semi-structured interview schedule for chapter 8
10	Semi-structured interview schedule for chapter 9

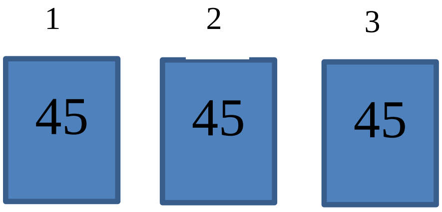
Appendix 1

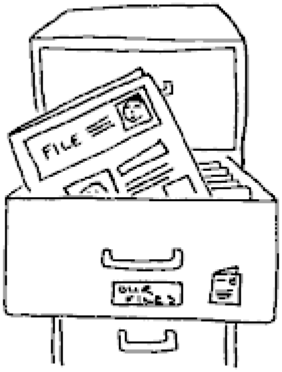
Leicestershire Partnership NHS Trust Loughborough University University of Leicester

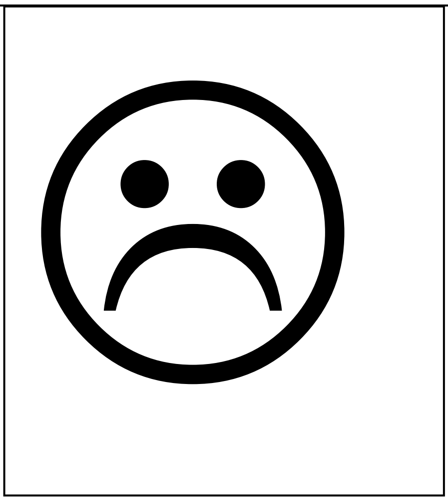
Dementia in Learning Disabilities Project

	Our names are Jordan Elliott-King and Sarah Shaw, we are students at Loughborough University and we are doing a project as part of our course.
	**What is this project trying to find out?** Sarah and Jordan want to see if there is a better way to find out if someone with a learning disability has dementia.
	**How will Sarah and Jordan see if there is a better way to find out if someone has dementia?** With my help, Sarah and Jordan can try out some tests that could be used to see if someone has dementia.
	**Why do Sarah and Jordan want me to take part in this project?** Finding out if someone has dementia is very important so we can make sure they get the

	best care. So Sarah and Jordan want to find out the easiest way to see if someone has dementia.
 • CANARY • SHOES • EAGLE • BLOUSE • NAILS • CROW • BLUEBIRD • SCREWDRIVER • TROUSERS • CHISEL • SKIRT • WRENCH	**What will I have to do?** I will be asked to remember as many of the words read out to me as possible. This is not a test so it does not matter how many I get right.
	I will then do some fun games on a touch screen computer.
	**What information do Sarah and Jordan need to know about me?** Sarah and Jordan will need to see my medical records. These are the notes the Doctor has. My carer will also be asked to answer some questions about my health.

	**Do I have to take part in the project?** No! Sarah and Jordan would really like me to take part but I do not have to. Taking part in the project will help other people at the clinic in the future and will help staff to see when people have dementia.
	**Where will the project be?** Sarah and Jordan will come and visit me at the clinic or at my house.
	**How long will the project take?** I will be asked to do 2 or 3 sessions. Each session will take about 45 minutes.
	**Are there any risks to participating?** No! A group of people called an ethics committee have made sure the project is safe for me to do.

	**What will happen to the things Sarah and Jordan find out?** Sarah and Jordan will keep my results private so no one can see them. My results will be put with everyone else's. The results will then be put in a big piece of writing called a report.
	**What if I am not happy with the project?** If I am not happy I can ask for the test to stop. I can talk to Sarah or Jordan about it and they will not get cross. If I want to I can talk to my carer or one of the doctors instead.
	**What will happen to the results of the project?** Sarah and Jordan will do a big piece of writing called a report about the project. The report will not have my name in it. I am only doing the test to help Sarah and Jordan see if the test works, so I do not need to worry about the results of my test.

	**If I have any more questions how can I talk to Sarah or Jordan?** **Phone** Sarah: 07913117680 Jordan: 07577438500 **Email** Sarah: s.shaw-10@student.lboro.ac.uk Jordan: J.Elliott-King@lboro.ac.uk
	**What if I am unhappy with the way Sarah and Jordan have treated me?** If I am unhappy with Sarah or Jordan I can talk to my carer. Either me or my carer can then contact Jacqueline Green on: Phone: 01509 222423 Email: J.A.Green@lboro.ac.uk Or Dr Avinash Hiremath on: Phone: 0116 2255274
	**Thank you for reading this sheet.** I will now be asked if I still want to take part. If I do, I will be given a form to take home and sign with my carer.

Appendix 2

Leicestershire Partnership NHS
NHS Trust
Loughborough University
University of Leicester

Dementia in Learning Disabilities populations: is there a better way to diagnose?

CONSULTEE CONSENT FORM

Study ID: __________

Investigators: Jordan Elliott-King (J.Elliott-King-11@student.lboro.ac.uk)
and Sarah Shaw (s.shaw-10@alumni.lboro.ac.uk)

Supervisor: Dr Eef Hogervorst (e.hogervorst@lboro.ac.uk)

Clinician: Dr Latha Velayudhan (lv24@Leicester.ac.uk)

To allow the participant to become a part of this study, and to authorise use of his/her personal information, you must sign and date this form.

Please initial each box

1.	I confirm that I, ………………………………. have been consulted about ………………………………..'s participation in this research project and have read and understand the information sheet dated ________ (version __) for the above study and have had the opportunity to ask questions.	☐
2.	In my opinion, s/he would have no problem participating in the above study.	☐
3.	I understand that I can request that s/he is withdrawn from the study at any time, without giving any reason, and without his/her medical care or legal rights being affected.	☐
4.	I agree to ………………………….'s GP being informed of his/her participation in the study, and of the findings of the study, if it is felt appropriate by the research team.	☐

5. I agree to information in his/her medical records being made available to the researchers. ☐

6. I authorise the investigators to disclose the results of his/her participation, but not his/her name. ☐

5. I agree that ……………………………. can take part in the above study. ☐

Name of Consultee	Date	Signature

If signed by consultee, description of relationship to the participant or other basis for legal authority:

____

Name of researcher	Date	

Appendix 3

Leicestershire Partnership NHS
NHS Trust

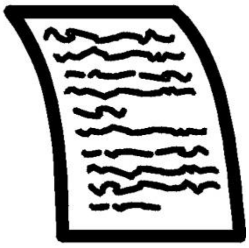
Loughborough University

University of Leicester

Dementia in Learning Disabilities project

Please sign the sheet if you want to take part in the project.

Please tick each box

1.		I have read the information sheet.	
		I have asked any questions I want.	
2.		I know I do not have to take part if I don't want to.	

3.		I am happy for Sarah and Jordan to see my medical records. These are the notes the Doctors have about me.	
4.		I am happy for my results to be put in a big report at the end.	
5.		I want to take part in the project.	

______________ ______________ ______________

Name of patient Date Signature

______________ ______________ ______________

Name of researcher Date Signature

Appendix 4

Dementia in Learning Disabilities populations: is there a better way to diagnose?

HEALTH QUESTIONNAIRE

Study ID: __________

Investigators: Jordan Elliott-King (J.Elliott-King-11@student.lboro.ac.uk)
and Sarah Shaw (s.shaw-10@alumni.lboro.ac.uk)

Supervisor: Dr Eef Hogervorst (e.hogervorst@lboro.ac.uk)

Clinician: Dr Latha Velayudhan (lv24@Leicester.ac.uk)
Dr Avinash Hiremath (Avinash.Hiremath@leicspart.nhs.uk)

Please fill out the questionnaire on behalf of the participant.

1. Demographics

(a) Town:………………….. County:……………………….

(b) Date of birth: Day…………….. Month………………. Year………………..

(c) Age……….years 1d. Gender (circle) male / female

(e) Education (circle) none/primary / secondary / university degree

(f) Profession (circle) Grade A (higher - manager, admin or professional)
B (intermediate - manager, admin or professional)
C1 (supervisory or clerical, junior manager, admin or professional)
C2 (skilled manual)
D (semi and unskilled manual)
E (state pensioner, no other earner, causal or lowest grade workers)

(g) Ethnicity……………….Father……………………..Mother………………………

(h) Is the participant living (circle) alone with children with relatives institution
other………………………………

(i) Has the participant received a diagnosis of dementia? Please circle Yes / No

2. Medical History

Weight measurement ………..kg Height measurement …………………mtrs

At present, does the participant have any health problem for which they are:

(a)	on medication, prescribed or otherwise (list)	Yes		No	
(b)	Attending your general practitioner (reason)	Yes		No	
(c)	on a hospital waiting list (reason)	Yes		No	

In the past two years, has the participant had any illness which require them to:

(d)	consult your GP (reason)	Yes		No	
(e)	attend a hospital outpatient department (reason)	Yes		No	
(f)	be admitted to hospital (reason)	Yes		No	

Has the participant ever had any of the following:

(g)	Hormone medication (corticosteroids, thyroid hormone etc.)	Yes		No	
(h)	Asthma or other lung disease	Yes		No	
(i)	Thrombosis or other blood (clotting) disorder	Yes		No	
(j)	Diabetes	Yes		No	
(k)	Digestive, gastrointestinal problems	Yes		No	
(l)	Heart Problems	Yes		No	
(m)	Convulsions/epilepsy	Yes		No	
(n)	Head injury/ Neurological problems	Yes		No	
(o)	Intolerance, hypersensitivity to, or dislike of foods containing soya	Yes		No	
(p)	Psychiatric problems (depression, psychosis)	Yes		No	
(q)	Dementia (e.g. Alzheimer's disease)				
(r)	Cancer or benign growths (polyps etc.)	Yes		No	
(s)	Vision/ ear / hearing problems	Yes		No	

(t)	Thyroid problems or other endocrine disorders (Cushing's, Addinson's disease etc.	Yes		No	
(u)	Kidney or liver problems	Yes		No	
(v)	Other (e.g. dyslexia)	Yes		No	
(w)	Allergies (state)	Yes		No	

3. Family History

Has any member of the family had any of the above diseases, please state **which disease** and **age** at onset:

Whom:

(a) Father…………………………………………………………………….

(b) Mother…………………………………………………………………

(c) Brother/sister…………………………………………………………………….

4. Health Related Behaviour

(a) Do they smoke? (circle) Yes No

(b) If yes, how many a day

Cigarettes	40 or more	20-39	10-19	1-9
Cigars or pipes only	5 or more or inhaled	Less than 5 or non-inhaled		

(c) Do they exercise regularly? (circle) Yes No

(d) How many days per week do they spend at least 20 minutes in moderate to strenuous exercise?

0 1 2 3 4 5 6 7 days per week

(e) Can they walk 4 miles briskly without fatigue (circle) Yes No

(f) Units of alcohol consumed per week……………………

(1= glass beer, 1= glass wine, 1= unit of spirit)

(g) Number of cups tea/coffee per week …………………

5. Additional questions for FEMALE participants

(a) Do they still have a monthly period? If ‘yes’ answer (b-e + k-l) If ‘no’ answer (g-l)	Yes		No	
(b) If yes, are their periods normal/regular? (c) When was their last period? ………………………………….. (d) How long is their cycle on average? ……………………………	Yes		No	
(e) Are they using a hormonal contraceptive (e.g. the pill, injection, implant) state which type (f) Is it oestrogen, combination or progestagen based? (circle)	Yes		No	
(g) Are they postmenopausal? (h) If yes, what year did their menses stop? …………………… (i) Are they ‘naturally’ or ‘surgically’ menopausal? ………………	Yes		No	
(j) Have they taken an HRT in the last 3 months? If yes, name………………………………………………..	Yes		No	
(k) Could they be pregnant or planning pregnancy?	Yes		No	
(l) Are they breast feeding	Yes		No	
(l) Do they have (had) any gynaecological problems (PMS, endometriosis, polyps, malignant growth/tumors of breast/ovary, problems conceiving) (circle)	Yes		No	

6. Memory problem (DQ) questions

Please tick yes or no.

	Yes	No
a) Does the participant have memory problems and is this different from how it was before? b) Did the participant’s memory problems occur suddenly? c) Did the participant’s memory problems come on gradually? d) Why do you think the memory problems started? (stress, sadness, sickness, other, don’t know)………………………………………………………..		

Appendix 5

The effect of a short intervention on cognition in elderly adults with dementia and their carers

Researchers involved in the project:
Jordan Elliott-King, Loughborough University, Loughborough, LE11 3TU
Email: J.Elliott-King@lboro.ac.uk

Professor Eef Hogervorst, Loughborough University, Loughborough, LE11 3TU
Email: E.Hogervorsrt@lboro.ac.uk
Tel: 01509 223 020

What is the purpose of the project?

Past research has shown that exercise can help to improve cognitive functions of people of all ages. Most research has focused mainly on the effects of aerobic exercises such as walking, or stretching exercises such as Tai Chi. These exercise studies usually last for 6-12 weeks. However, little research has focused on the effect of using resistance exercise for a short period and its effect on the brain straight away. This project aims to see if resistance exercise can immediately benefit cognitive functioning.

Who is doing this research and why?

This project is part of a research project that is supported by Loughborough University. Jordan Elliott-King is a PhD student and will be conducting the research. Professor Eef Hogervorst will be supervising the project.

Are there any exclusion criteria?

Participants will be excluded if they have been advised by a physician not to participate in exercise.

What will I be asked to do?

After reading this information sheet, you will be invited to ask any questions that you may have about the project. If you would like to take part, then we will arrange a time to meet with you to have the first visit. This will involve doing a few questionnaires and playing some cognitive games, completing an activity together, either physical activity using resistance bands in a seated position or playing bingo, then repeating the questionnaires and games that were completed at the beginning. If you enjoyed your visit we will then book a second visit, which will follow the same format as the first. But this time you will get to try the activity that you didn't do the first time. The final visit shall involve completing the questionnaires and having refreshments and a chat. Each visit will be roughly six weeks apart.

Once I take part, can I change my mind?

Yes. After you have read the information provided, and asked any questions that you may have, we will ask you for your informed consent to take part in the project. However, you may withdraw from the project at any stage and we will not ask you for your reasons of withdrawing. Please contact Jordan Elliott-King if you wish to withdraw from the project.

However, when it is written into a final report, you will be unable to withdraw your data from analysis. Your data will be kept anonymous at all stages. Data will be protected anonymously for six years for the cognitive assessment and 10 years for the questionnaire data, after these dates data will be destroyed.

Will I be required to attend any sessions and where will these be?

You will only need to take part in three sessions. These will be held at Loughborough, or if you would like to be visited at a community group then this can be arranged where appropriate.

How long will it take?

Each session takes a morning. Starting at around 9.30am would mean we would be finished just in time for lunch.

What personal information will be required from me?

We require minimal personal information from you, we only ask for information such as your age, gender, and relationship to the person with dementia if you are a carer. All personal information will be kept separately from the project data to ensure your anonymity. These will be kept in a secured area and only the researchers involved in the project will have access to this information via password protected computers.

Are there any risks in participating?

The risks involved in participating in this project are minimal and it should be lots of fun. However, if at any moment you feel uncomfortable, please feel free to talk to any researcher involved. If your difficulty is with an exercise please speak up as researchers can offer extra assistance to help to safely finish the exercise you are doing.

Will my taking part in this project be kept confidential?

Yes. Your results will be kept confidential so that no one would be able to tell that you participated in the project, or which participant you were. Your results will be kept separately from your consent forms in a locked file, and your results will be kept in a password-protected computer that only the researchers can use.

I have some more questions; whom should I contact?

After reading this, the researcher will talk to you about what you have just read and what has been said to you. If you have any more questions, you can ask them as we continue with the project, by emailing any of the researchers involved. Their email addresses are found at the beginning of this information sheet.

What will happen to the results of the project?

The results of the project will be written up in a report. However, the report will be about the results of the physical activity programmes and not the individual participants who did the physical activity. No personal information will be included in the report.

What if I am not happy with how the research was conducted?

If you are not happy with how the research was conducted, please contact Ms Jacqueline Green, the Secretary for the University's Ethics Approvals (Human Participants) Sub-Committee at:
Ms J Green
Research Office
Hazlerigg Building
Loughborough University
Epinal Way
Loughborough
LE11 3TU
Alternatively, you can contact her on 01509 222 423 or email her at J.A.Green@lboro.ac.uk

The university also has a policy relating to Research Misconduct and Whistle Blowing, which is available online at http://www.lboro.ac.uk/committees/ethics-approvals-humanparticipants/additionalinformation/codesofpractice/

Thank you for reading this sheet. You may keep this sheet to refer back to whenever you want. Please make sure that you have understood all the information that has been given to you and you have asked any questions that you may have.

The effect of a short intervention on cognition in elderly adults with dementia and their carers

INFORMED CONSENT FORM FOR CARERS

(to be completed after Participant Information Sheet has been read)

Taking Part **Please initial box**

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the Loughborough University Ethics Approvals (Human Participants) Sub-Committee. ☐

I have read and understood the information sheet and this consent form. ☐

I have had an opportunity to ask questions about my participation. ☐

I understand that I am under no obligation to take part in the study, have the right to withdraw from this study at any stage for any reason, and will not be required to explain my reasons for withdrawing. ☐

I agree to take part in this study. ☐

Use of Information

I understand that all the personal information I provide will be treated in strict confidence and will be kept anonymous and confidential to the researchers unless (under the statutory obligations of the agencies which the researchers are working with), it is judged that confidentiality will have to be breached for the safety of the participant or others or for audit by regulatory authorities. ☐

I agree for the data I provide to be securely archived at the end of the project. ☐

Name of participant [printed] Signature Date

Researcher [printed] Signature Date

The effect of a short intervention on mood, cognition and caregiver strain in elderly adults with dementia and their carers

INFORMED CONSENT FORM FOR PEOPLE WITH DEMENTIA
(to be completed after Participant Information Sheet has been read)

Taking Part **Please initial box**

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the Loughborough University Ethics Approvals (Human Participants) Sub-Committee. ☐

I have read and understood the information sheet and this consent form. ☐

I have had an opportunity to ask questions about my participation. ☐

I understand that I am under no obligation to take part in the study, have the right to withdraw from this study at any stage for any reason, and will not be required to explain my reasons for withdrawing. ☐

I agree to take part in this study. ☐

Use of Information

I understand that all the personal information I provide will be treated in strict confidence and will be kept anonymous and confidential to the researchers unless (under the statutory obligations of the agencies which the researchers are working with), it is judged that confidentiality will have to be breached for the safety of the participant or others or for audit by regulatory authorities. ☐

I agree for the data I provide to be securely archived at the end of the project. ☐

______________________________ ________________________ _________

Name of participant [printed] Signature Date

______________________________ ________________________ _________

Name of Carer [printed] Signature Date

______________________________ ________________________ _________

Researcher [printed] Signature Date

Thank you for your interest in taking part in our research. I hope that this will be a positive experience for you and welcome any feedback that you may have throughout this project. Your participation is entirely voluntary, and if you wish to know more about anything, or you feel as though you cannot do something, please let me know and I will do my best to help you. I want to make this fun for you, and any help you can give would be greatly appreciated.

If you have any questions about the information so far, the please email me and I will get back to you as soon as possible. My email address is J.Elliott-King@lboro.ac.uk

If you are happy to carry on then please give me a call and we can make sure everything is clear. Once we have done this, you can sign the consent form and fill out the questionnaires in this pack.

I really appreciate the time you are taking to participate in the study and do not hesitate to contact me with any queries or feedback along the way.

Appendix 6

Participant ID: ……………

1. Date of Birth: ……./……./19……

2. Gender (please circle): male / female

3. What is your occupation? (please tick):

Higher manager, admin or professional …
Intermediate manager, admin or professional …
Supervisory or clerical, junior manager, admin or professional …
Skilled manual …
Semi or unskilled manual …
Retired …

4. Do you or have you in the past suffered from any of the listed medical conditions? (please tick)

- Diabetes mellitus …
- Endocrine problems (prostate/testicular) or hypofunction of the thyroid …
- Coronary heart disease/arrhythmia/ myocardial infarct/stroke …
- Asthma or other lung disease …
- Thrombosis or other blood (clotting) disorder …
- Digestive, gastrointestinal problems …
- Dementia (e.g. Alzheimer's disease) …
- Cancer or benign growths (polyps etc.) …
- Vision / ear / hearing problems …
- Kidney or liver problems …
- Allergies (please state) ……………………………………………………………………….
- Other (please circle): lung or kidney disease, neurological (e.g. epilepsy, or mental health disorders e.g. depression for which you are receiving medical treatment) or (please state) …………………………………………………………………………………………………… ……………………………………………………………………………………………………

Are you still receiving medical treatment for these conditions now? (please circle) yes / no

5. Do you have a physically demanding job? (please circle): yes / no

Appendix 7

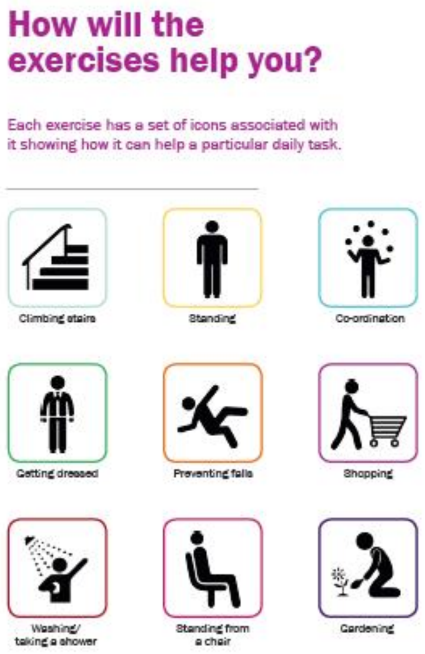
National Centre for Sport and Exercise Medicine East Midlands
W: www.ncsem-em.org.uk

School of Sport, Exercise and Health Sciences
Loughborough University
W: www.lboro.ac.uk/ssehs

V1/07/2016

Couch potatoes for cognition

Exercise for physical and cognitive wellbeing



How will the exercises help you?

Each exercise has a set of icons associated with it showing how it can help a particular daily task.

Tummy rotation

1. Sit on your chair with your legs comfortably bent and your feet flat on the floor. Wrap your resistance band underneath your feet and hold the ends of the band in each hand.
2. Pull the band with your right hand and turn your torso to the right at the same time so that you feel your stomach muscles working.
3. Slowly return to the middle until the resistance band is held evenly with each hand.
4. Repeat the process on the other side, pulling the band with your left hand and turning your torso to the left
5. Slowly return to the middle until the resistance band is held evenly with each hand and repeat on both sides.

1


2


3


4


5


Straight arm pull

1. Sit on your chair with your feet shoulder-width apart. Wrap your resistance band underneath your feet and hold the ends of the band in each hand.
2. Slowly begin to pull the band outwards on either side of your body, making sure you do not sit forward in your chair.
3. Raise your arms until they are at shoulder height, ensuring you do not 'lock out' your elbows.
4. Slowly begin to lower your arms.
5. Bring your arms back down to your side at hip height and repeat the exercise.

1


2


3


4


5


Cross and pull

1. Sit on your chair with your legs shoulder-width apart. Wrap your resistance band underneath your feet and hold the ends of the band in each hand.
2. Cross the band over in each hand.
3. Pull the band up to shoulder height with your elbows pointing out. You should be able to feel your back muscles under your armpit tighten as you perform the movement. Try to avoid leaning forward in your chair.
4. As you begin to straighten your arms, try to slow the movement down and avoid 'locking out' your elbows.
5. Repeat the exercise.

1


2


3


4


5


Leg press

1. Sit on your chair with your feet shoulder-width apart and your back straight. Bend one knee towards you and loop your resistance band around the bottom of your foot, holding one end of the band in each hand.
2. Push your leg out straight in front of you without 'locking out' your knee, squeeze your leg muscles as hard as you can throughout the movement.
3. Bend your knee again to repeat the movement and ensure you do an even number of movements on each leg.

Note the images also show a side view of how to perform the exercise.

1


2


3


4


5


Appendix 8

Activity Feedback Form

We are interested in gathering information about who takes up physical activity. The questions below will help us to see who likes to take up activity so if you are happy to, please take a moment to fill out the form below. All information will be kept anonymous and we appreciate you taking the time to fill this out.

1. What is your gender?
Male ☐
Female ☐

2. What is your Year of Birth? 19

3. Do you have any memory problems?
Yes ☐
No ☐

4. Have you been diagnosed with dementia?
Yes ☐
No ☐

5. If yes, Which type of dementia?
Alzheimer’s Disease ☐
Vascular Dementia ☐
Mixed ☐
Other ☐
If other, please specify:

6. Would you like continue to do the resistance band physical activity you saw in the study?
Yes ☐
No ☐
- Why?

7. Where would you like to do the resistance bands? (tick all that apply)
At Home ☐
In a group – at the GPs/ hospital setting ☐
In a group – at a community centre ☐
In a group – in a public space (e.g library) ☐
Would not like to do the activity ☐

8. What activities do you currently do? (tick all that apply)
Walking ☐
Organised Sport at a gym ☐
Seated Exercise without resistance band ☐
Seated Exercise with resistance band ☐
Gardening ☐
Other ☐

If other, please describe:

9. How often do you already do these activities?
Less than once a week ☐
Once a week ☐
2-3 times a week ☐
More than 4 times a week ☐
Almost every day ☐

10.If not why do you think you have difficulties doing exercise? (tick all that apply)

- Mobility Problems ☐
- Pain ☐
- Not sure how to do ☐
- Can’t do it without help ☐
- Too time consuming ☐

Other, please describe: ☐

11.How could this be overcome?

- An exercise program designed just for me ☐
- Someone to instruct me how to do it ☐
- Friends to exercise with ☐
- An exercise routine that can be completed while seated or that is adjusted for my physical needs ☐
- With the help of an app/ phone or computer ☐

Other ideas to help me exercise more: ☐

We are really grateful for all your time and hope you have enjoyed taking part in the research! Your help is incredibly valuable!

Appendix 9

Semi-structured interview script for Chapter 8 – Perspectives towards physical activity: walking interviews with people who have dementia:

1. Can you tell me about a sport or physical activity that you played when you were young?
2. Where did you play this sport?
3. Can you tell me a positive experience you have had with physical activity?
4. Are there any experiences you have had that you did not enjoy?
5. When you started work did you still ________*(fill in the activities they have already brought up)*?
6. How have your physical activities changed since then?
7. What physical activity do you enjoy nowadays?
8. Are there any physical activities that you would like to try?
9. Are there any physical activities that you wouldn't like to try now?
10. Is there anything else you'd like to tell me about your physical activity?

Appendix 10

Semi-structured interview script for Chapter 9 Physical activity for people with dementia: Professionals' perspectives

* Thank you for your time today. Explain recording and consent. *

Can you tell me about your experiences with physical activity for people with dementia?
What would you say is important when encouraging people with dementia to be physically active?
Can you tell me about a particularly positive experience when encouraging PA in this group?
Can you tell me about an experience that went less well?
What are some of the key barriers you have faced in your work around this topic?
What have you been able to do to overcome these?
What would you recommend to other providers of physical activity?
In your view, which groups of people with dementia are harder to reach?
What has your experience been with harder-to-reach groups?
Have you found anything works particularly well to increase outreach?
Is there anything you'd like to add, or anything that we've not covered that you think is important to the topic of physical activity for people with dementia?

* Thank you so much for your time, is there anyone you can recommend that might be good to talk to about this topic? *

Could also have participant specific questions derived from focus group as well, for example:
You noted that fun is a crucial part of your exercise programmes, how do you achieve this?
Have you ever had anyone who is not receptive to your methods?
You noted that larger scale physical activity projects are heavily reliant on the quality of local deliverers of exercise could you elaborate on this? How are you able to navigate this?