Assessment of Cognition in People with Intellectual Disabilities Using a Novel Set of Neuropsychological Tests

Zakiya Reid-Wisdom

A thesis submitted in partial fulfilment of the requirements of the University of East London for the degree of Professional Doctorate in Clinical Psychology

January 2025

ABSTRACT

Researchers in the UK have been making considerable efforts to develop cognitive test-sets for the detection of dementia in people with an Intellectual Disability (ID). However, existing test-sets have significant limitations. The current study aimed to evaluate the acceptability and feasibility of a novel cognitive test-set that aims to provide a diagnostic measure of dementia for people with an ID.

The tool was piloted with seven participants with an ID recruited from clinical and non-clinical settings. Feasibility was assessed through participant test scores, while acceptability was assessed using participant feedback and researcher observations. Results revealed that many of the tests included in the test-set generated a good range of scores, without floor or ceiling effects, including those that assess executive and olfactory functioning. Qualitative findings suggest that the test-set is generally well-received. Recommended revisions are discussed to support the validity and reliability of the tool. The current findings suggest the tool has potential (with refinements) for being useful for the comprehensive and accessible assessment of cognition and suspected neurodegeneration in people with ID, across a wide range of abilities.

ACKNOWLEDGEMENTS

Firstly, I would like to extend my gratitude to all of the participants who took part in this study. Your efforts were invaluable in making this research possible. I would also like to extend my sincere thanks to the recruitment sites involved in supporting this research.

A thank you to Dr Matthew Jones Chesters for your support throughout this process. Your ability to provide containing conversations, encouragement, and guidance has been invaluable to me.

A special thank you to Dr Ella Perry & Dr Kiri Clarke for going above and beyond in supporting me throughout this process. Your efforts did not go unnoticed, and I am incredibly grateful for your unwavering support.

To my village—my family and friends—thank you for your patience, love, and grace throughout this season. Your words of encouragement and countless pep talks have been a source of strength that kept me going even when times were tough. A thank you to my Mum, Dad, Omari, Kianna, Gabriella, Dr Reay Stoddart Isaac and Yinka for standing by me through it all, offering unconditional support and comfort and always being a phone call away. Also, a thank you to Dr Ishshah Marinker and Dr Pinar Marasli for all of your support throughout this thesis journey!

To my partner, Dwayne, thank you for being my rock. I am forever grateful for the love, prayers, and your constant reminders to keep pushing forward during the difficult moments. You truly kept me grounded.

Most importantly, thank you to God for providing me with the strength to persevere. Thank you for never giving up on me and guiding me through this journey.

Lastly, a dedication to my, late grandfather and Uncle Nicky. I carry your memory with me always. Thank you for the joy and laughter you brought into my life. It

definitely helped me through some of the most stressful times during my studies. I hope I have made you both proud. Rest in everlasting peace.

Do not be anxious about anything, but in everything by prayer and supplication with thanksgiving let your requests be made known to God. And the peace of God, which surpasses all understanding, will guard your hearts and your minds in Christ Jesus – Philippians 4:6-7.

TABLE OF CONTENTS

LISTS OF TABLES

1. INTRODUCTION

1.1. Intellectual Disability

1.1.2. Terminology and Definitions

The term intellectual disability (ID) is used internationally to describe what has been commonly known as 'Learning Disability' in the United Kingdom (UK) and 'mental retardation' in the United States of America (USA) (Cluley, 2018). Frequent usage of the term ID is partly attributable to the view that it is less offensive and stigmatising to persons with disability than terms that have been historically used such as 'mental retardation' (Schalock, 2011). The term 'intellectual disability' will thus be used throughout this thesis. It is worth highlighting that some self-advocates in the UK prefer the term 'learning difficulty', as they believe the term communicates the idea that learning needs are changeable over time, whereas the term 'learning disability' suggests an inability to learn (Perez, 2015). However, the term is also used to describe difficulties such as dyslexia and dyspraxia, and thus use of such terms may run the risk of adding confusion. To date, many definitions of ID exist in the literature. In the UK context it describes people who have "a significantly reduced ability to understand new or complex information to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood" (Department of Health [DoH], 2001, p.14). This definition will be used throughout this thesis.

Although it is beyond the scope of this research to deconstruct the concept of ID, it is important to acknowledge that it is a social construct "shaped by the interactions of people and their environments, human and legal rights operating within those environments, and the roles people with ID and their families play within society" (Schalock et al., 2019, p. 227).

1.1.3. Diagnostic Classification

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5; American Psychiatric Association, 2013) and the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10; World Health Organization, 2013) are widely used classification systems that offer diagnostic criteria for ID (Carr, 2016).

Due to its acceptability in the UK and the context of this research, the ICD-10 diagnostic criteria for ID are presented. The ICD-10 states that for a diagnosis, an individual should display a "reduced level of intellectual functioning which results in the reduced ability to adapt to the demands of their social environment" (World Health Organization [WHO], 1992, p. 227).

A significant impairment in intellectual functioning is typically defined as a full-scale IQ standard score of approximately two (or more) standard deviations below the mean as measured with an appropriately normed, standardised test of intelligence (Schalock et al., 2021). Significant impairments in adaptive behaviour are usually defined as a standard score of approximately 2 (or more) standard deviations below the mean, measured with an appropriate and standardised measure (Schalock et al., 2021).

The ICD-10 also identifies four discrete levels of ID: mild, moderate, severe, and profound. Mild ID is defined as individuals with an IQ score between 50-69, whilst those with a moderate ID are described as having an IQ score between 34 and 49 (WHO, 1992). Severe ID refers to individuals with an IQ score between 20 to 34, while profound ID refers to those with an IQ score below 20.

1.1.4. Aetiologies and Subtypes

The aetiology and manifestation of ID are highly heterogonous (Galasso et al., 2010) and may be caused by genetic and non-genetic factors. Whilst a detailed description of all of the different aetiologies and clinical presentation is beyond the scope of this research, I will briefly describe some of the main causes in this section, as they will inform the study design.

1.1.4.1. *Down syndrome*: whilst there are many genetic causes of ID, Down syndrome (DS) is considered the most common genetic cause of ID, known to date (Patterson, 2009). Down syndrome occurs when a person is born with an extra copy of the chromosome 21 (Patterson, 2009).There are three types of DS. The first, most common, type known as Trisomy 21, refers to a form whereby every cell in the human body has three separate copies of chromosome 21 (Wajuihian, 2016). The second type, termed Translocation DS, occurs when an extra part or a whole copy of the chromosome 21 attaches itself to another chromosome (Wajuihian, 2016). Finally, the third type, Mosaic DS, occurs when some cells contain an extra copy of the chromosome 21, whilst others contain the usual two (Wajuihian, 2016).

Whilst all individuals with DS are born with some degree of ID, the severity level can vary, spanning from mild-to-severe and profound (Akhtar & Bokhari, 2023). Nevertheless, most people with DS have mild-to-moderate levels of ID (Akhtar & Bokhari, 2023). Besides ID, DS is commonly associated with phenotypes, most of which are variable in their expressiveness and penetrance (Letourneau & Antonarakis, 2012). People with DS may display several physical characteristics including facial features such as brachycephaly, palpebral eye fissures with epicanthic folds, small ears, a flat nasal bridge, and a small oral cavity (Evans-Martin, 2009; Jackson et al., 1976). Other physical characteristics such as hypotonia, short stature, lax ligaments and broad and short hands are also commonly associated with the condition (Evans-Martin, 2009; Jackson et al., 1976; Wajuihian, 2016). Down syndrome is also commonly associated with several physical health conditions such as, congenital heart defects ((Morris et al., 2014; Paladini et al., 2000), hypothyroidism (Pueschel & Pezzullo, 1985), seizures (Roizen & Patterson, 2003) and sensory impairments (Roizen & Patterson, 2003). Epidemiological research also suggests that Dementia of the Alzheimer's Type (DAT) is exceptionally common among this population (Sekijima et al., 1998). This will be discussed in greater detail below.

Research concerned with identifying the cognitive phenotype of those with DS has revealed several cognitive strengths and weaknesses. For instance, there is a wealth of research suggesting people with DS to have weaknesses in several executive

functions (from childhood through to adulthood). Examples of the functions affected include set-shifting (Lanfranchi et al., 2010; Rowe et al., 2006), planning and organisation (Rowe et al., 2006). Research also suggests that individuals with DS display poor verbal working memory, relative to their overall level of cognitive functioning and visual spatial working memory abilities (Jarrold et al., 2002; Lanfranchi et al., 2004). Such weaknesses have been attributed to 'atypical' development of the pre-frontal cortex (Rowe et al., 2006). With regards to language abilities, it has been reported that people with DS show deficits in both receptive and expressive language, with the latter being more affected (Jafri & Harman, 2020; Martin et al., 2009). More specifically, phonological processing and language syntax (comprehension and expression) has been consistently reported to be predominantly challenging (Martin et al., 2009). Interestingly, pragmatic language has been identified as an area of strength among this population (Martin et al., 2009).

Further, there are consistent reports of a high rate of externalising behaviours among those with DS (e.g., hyperactivity, impulsivity and aggression), particularly during childhood (Dykens & Kasari, 1997; Patel et al., 2018; Pueschel et al., 1991). According to research, these externalising behaviours tend to decline with age, with internalising behaviours (e.g., depression and anxiety) becoming more prominent during adolescence and adulthood (Dykens et al., 2002; Foley et al., 2015; Patel et al., 2018). Moreover, attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) have been reported to impact a significant number of individuals with DS (Ekstein et al., 2011; Oxelgren et al., 2017; Richards et al., 2015).

1.1.4.2. *Other genetic conditions*: other examples of genetic causes of ID include Fragile X (FraX), William Syndrome (WS) and Prada-Willi Syndrome (PWS). Interestingly, FraX is considered the most common inherited form of ID, world-wide (Gallagher & Hallahan, 2012). Fragile X is an X-linked dominant disorder which occurs as a result of an unstable trinucleotide repeat expansion of Cytosine Guanine Guanine (CGG) in the 50-promoter end (Xq27.3) of the Fragile X Mental Retardation 1 gene (FMR1) (Gallagher & Hallahan, 2012).

Similar to DS, the phenotypes associated with FraX include cognitive strengths and weaknesses, and distinctive physical and behavioural characteristics, most of which vary considerably among affected individuals (Gross et al., 2011; McLennan et al., 2011). Physical features typically associated with FraX include, facial dysmorphism, connective tissue anomalies and macroorchidism (Gallagher & Hallahan, 2012). Similar to DS, ASD (Hatton et al., 2006) and ADHD (Sullivan et al., 2006) are common among this population. Fragile X is typically characterised by moderate-to-severe ID, among males (Hessl et al., 2009). However, most females have an IQ ranging from 70-90 (Hagerman et al., 1992).

In a comprehensive review of the literature, Huddleston et al. (2014) concluded that people with FraX show relative cognitive strengths in acquired knowledge, long-term auditory memory, and the processing of simultaneous information. However, relative weaknesses in cognitive functions such as auditory, and visual short-term memory and executive function (EF, e.g., attention and set-shifting) were also revealed. According to an extensive review by Hoffmann (2022) individuals with FraX have stronger receptive language skills relative to expressive language. Though, in both receptive and expressive language, vocabulary is often an area of strength, compared to syntax (Hoffmann, 2022). For instance, Finestack et al. (2013) found expressive vocabulary to be much stronger in those with FraX, compared to those with DS. In contrast to DS, pragmatic language is typically an area of relative weakness among this population (Hoffmann, 2022).

William Syndrome is a rare genetic disorder that emerges as a result of a microdeletion of 26-28 genes on chromosome 7 (Royston et al., 2019). It is associated with distinctive physical features such as facial dysmorphism, cardio-vascular disease and connective tissue abnormalities (Royston et al., 2019). Sensory and musculoskeletal impairments are also common among this population (Mervis & Klein-Tasman, 2000). The behavioural and cognitive phenotypes associated with the condition, are widely documented in the literature; however, as with DS and FraX, these vary between individuals. With regards to intellectual functioning, most people with WS have mild-to-moderate ID with specific weaknesses in visual-spatial skills (e.g., visuo-spatial learning and construction abilities), sensory motor processing, executive functioning (e.g., with behavioural

inhibition and planning ability) and attention (Royston et al., 2019). In contrast to those with DS, many individuals with WS show relative strengths in verbal short-term memory. Moreover, receptive language development is more delayed than expressive or written language. (Royston et al., 2019).

Prada-Willi Syndrome is a relatively common genetic disorder (prevalence 1/15 000-1/30 000) with a recognisable pattern of dysmorphic, neurologic, cognitive, endocrine and behavioural features (Cassidy et al., 2012). It occurs as a result of the absence of expression paternal genes from chromosome 15 (Cassidy et al., 2012). Key features of the condition include ID, hypotonia, hypogonadism, and hyperphagia which can result in morbid obesity. The behavioural phenotype typically includes emotional outbursts and compulsive traits (Cassidy et al., 2012). Research also suggests a distinct pattern of cognitive strengths and weaknesses in individuals with a diagnosis of PWS: relative strengths in visual skills (Dykens, 2002) and long term memory (Conners et al., 2000), and weaknesses in mathematical skills and short-term memory (Bertella et al., 2005). Interestingly, research by Chevalère et al. (2015) suggests that PWS may be associated with a global impairment of executive functioning.

1.1.4.3. *Non-genetic causes*: besides genetics, there are many other causes of ID. Examples include uncontrolled maternal illness during the pre-natal period (e.g., renal disease or epilepsy; Leonard et al., 2006), labour complications (e.g., preterm delivery due to premature rupture of membranes) and pre-natal exposure to infectious agents (e.g., rubella or cytomegalovirus) (Diav-Citrin, 2011; Winnepenninckx et al., 2003). Pre-natal exposure to toxic substances such as alcohol is also widely documented as an aetiological factor (Diav-Citrin, 2011). There are also a number of causes of ID that occur during early childhood such as meningitis (Bedford et al., 2001), traumatic brain injury (Winnepenninckx et al., 2003) and severe, prolonged undernutrition (Ivanovic et al., 2004).

It is important to note, that whilst many causes of ID have been identified and documented in the literature, the causes remain unknown in more than a third of affected individuals (Bhaumik & Alexander, 2020).

1.1.5. Prevalence

A systematic review completed by McKenzie et al. (2016) concluded that the global prevalence of ID may be lower than 1%. Interestingly, research has consistently shown higher prevalence rates of ID among those living in low-income countries (Durkin, 2002; Nair et al., 2022). In the UK, it has been estimated that there are approximately 1.5 million people living with an ID. Of this figure, 1.1 million are over 18-years-old, equating to 2.16 % of the adult population (Mencap, n.d.).

Epidemiological research into the incidence of ID is less common than studies of prevalence. According to Fryers (2008) measuring the incidence of ID as a whole is almost meaningless because of the variety of aetiologies and their distribution in time from pre-conception through foetal development and childhood. It is therefore unsurprising that there is a paucity of studies in the literature reporting the incidence of ID as a whole.

1.2. Dementia

1.2.1. Terminology and Definitions

To date, there is no universal definition of the term dementia. However, most definitions appear to be exclusively operational and primarily focuses on neuropathology and cognitive impairment (Albert & Mildworf, 1989). For example, Adams and Victor (1985) define it as a clinical syndrome of "failing memory and impairment in other intellectual functions due to chronic progressive degenerative disease of the brain" (p. 367). Similarly, the WHO has defined dementia as "a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement" (WHO, 1992, p. 45). In this thesis, the term 'dementia' will be used in a broader sense of neurodegenerative conditions. Terminologies for the specific disease sub-types (e.g., DAT) will be utilised when necessary.

Although this view that dementia can be conceptualised as a neuropathological condition is widely adopted in today's modern medicine, it is important to note that such conceptualisation has been criticised for failing to consider the "social forces that affect the definition, production, and progression of dementia" (Lyman, 1989, p. 600). As noted by Kitwood (1997), neurological causes cannot be the sole explanation for the deleterious effects of dementia, as cultural and social factors also contribute to the impact and progression of the disease (Kitwood, 1997).

1.2.2. Diagnostic Classification

Diagnostic criteria have been developed and included in the commonly used classification systems ICD-10 and DSM-5 to facilitate diagnosis of dementia and the various disease sub-types. Again, due to its wide usage and acceptance in the UK, the diagnostic criteria included in the ICD-10 are provided here (WHO, 1992). For a general diagnosis of dementia to be made, the ICD-10 requires the following:

- Indications of a decline in memory. Although impairment of memory is most evident in learning and memory, previously learned and familiar material may also be forgotten, particularly in the latter stages.
- A decline in other areas of cognition such as thinking, comprehension, calculation, language, and judgement.
- The deterioration in memory and other cognitive abilities impacts an individual's ability to carry out various activities of daily living.
- Indications of a loss of clear consciousness
- Impairments of cognitive function are usually accompanied, and sometimes preceded, by a decline in emotional control, social behaviour, or motivation.
- Symptoms and impairments should be present for at least 6 months.

1.2.3. Aetiologies and Subtypes

There are said to be over 100 forms of dementia (Alzheimer's Disease International, n.d.), which are distinguishable by their aetiology, clinical profile, management, and outcome (Alladi et al., 2011). Identifying the different sub-types of dementia is important as it can support individuals, families, and care providers to receive the

right support. For the purpose of brevity, the main disease sub-types will be described.

1.2.3.1. *Alzheimer's disease*: Alzheimer's disease (AD) is widely recognized as the most common cause of dementia (otherwise termed Dementia of the Alzheimer's Type), making up 60-80% of all cases (WHO, 2023). It is a neurodegenerative disease and is characterised by the insidious onset and progressive impairment of various behavioural and cognitive functions, especially new learning and memory (Karantzoulis & Galvin, 2011).

Neuropathologically, AD is characterised by the atypical accumulation of amyloid-b protein (i.e., amyloid plaques), produced through the proteolytic processing of the transmembrane protein, amyloid precursor protein (APP), by the enzymes β- and γ-secretases (Chen et al., 2017). It is also characterised by hyperphosphorylated tau protein (otherwise termed neurofibrillary tangles) along with cerebral atrophy (Karantzoulis & Galvin, 2011).

It is widely reported in the literature that the most prominent and one of the earliest features of the typical DAT syndrome is the impairment of episodic memory (Bäckman et al., 2001; Braak et al., 2006). This is thought to occur as a result of the early pathological involvement of the medial temporal lobe in the progression of AD (Gallagher & Koh, 2011). As the disease advances, a progressive disturbance of semantic memory is also observed, and verbal fluency becomes impaired (Kipps & Hodges, 2005). Moreover, remote memory for well-known faces and events is compromised and, more distant memories are relatively well preserved compared with more recent memories (Kipps & Hodges, 2005). In the middle stages of the AD, it is typical for visuo-perceptual difficulties to emerge as well as ideomotor apraxia which makes everyday tasks such as getting dressed and eating challenging. (Kipps & Hodges, 2005). As the disease progresses language skills begin to decline including speech production, reading, writing and calculation. Whereas, personality, and social behaviours are preserved well into the progression of the condition (Kipps & Hodges, 2005).

In recent years, researchers have shown considerable interest in the relationship between olfactory function and AD. Findings of several longitudinal research studies indicate olfactory dysfunction (namely impaired odour identification) to be associated with an increased risk of mild cognitive impairment (MCI) in individuals without dementia or cognitive impairment (Roberts et al., 2016; Wilson et al., 2007, 2009), and an increased risk of MCI converting to dementia (Devanand et al., 2020; Wheeler & Murphy, 2021; Zhao et al., 2020). Research also suggests that such deficit worsens with the progression of the disease (Velayudhan et al., 2013). Such findings have led researchers to propose that olfactory impairment could potentially serve as a non-invasive clinical marker for the early detection and monitoring of AD, supplementing traditional diagnostic methods, involving resource intensive cognitive assessments and neuroimaging (Roberts et al., 2016).

The exact mechanism linking olfactory dysfunction and AD is not well understood. Nevertheless, some of the brain regions that are among the earliest and most extensively affected in AD are known to play crucial roles in olfactory processing (Nijjar & Murphy, 2002).

As mentioned, the underlying cause of AD remains unknown; however, several risk factors have been documented in the literature. The greatest known risk factor for AD is advancing age, especially for those above the age of 65 (Niu et al., 2017). The disease is often divided into two sub-types, early-onset AD (EOAD) and late-onset AD (LOAD). Early-onset AD typically ranges from 30-years-to-60 or 65- years and is reported to account for approximately 5-6% AD cases in the general population (Tanzi, 2012). Late-onset AD, on the other hand, refers to AD that occurs after the age of 70 (Tanzi, 2012). This form of AD is considered the most common form of AD, making up 95% of AD cases (Bali et al., 2012).

Following advanced age, heritability is considered the second greatest risk factor for AD (Tanzi, 2012). It is estimated that genetic factors play a role in at least 80% of cases (Gatz et al., 2006). Other risk factors for AD include traumatic brain injury (Sivanandam & Thakur, 2012), history of depression (Shalat et al., 1987), and vascular-related risks (e.g. hypertension, diabetes mellitus, and heart disease) (Van Der Flier, 2005).

1.2.3.2. *Other cortical dementias*: Posterior cortical atrophy (PCA) is a rare progressive neurodegenerative disease that largely affects the occipital, parietal and occipitotemporal regions (Crutch et al., 2012). Initial symptoms of the disease therefore predominantly relate to cortical visual impairment, with particular deficits in visual spatial and visual perceptual processing (Crutch, et al., 2012). Other characteristic features include constructional difficulties, transcortical sensory aphasia (e.g., alexia, agraphia and anomia), Gerstman's syndrome, Balint's syndrome and decreased verbal learning (Benson et al., 1988). In comparison to AD, episodic memory, language abilities and insight is relatively preserved in the early stages of the disease (Benson et al., 1988; Charles & Hillis, 2005; North et al., 2021). Moreover, age of onset often occurs much earlier (i.e., <65) (Schott et al., 2016). Alzheimer's disease is the most common neuropathology associated with PCA and thus it is often referred to as the visual variant of AD.

Frontal-temporal dementia (otherwise termed, frontal-temporal lobar degeneration) is a term used to describe a group of clinically and pathologically heterogenous disorders characterised by the focal, progressive atrophy of the frontal and/or temporal lobes (Warren et al., 2013). It is considered a leading cause of early-onset dementia, following AD (Ratnavalli et al., 2002) and a highly heritable condition (Rohrer et al., 2009). There are three main clinical syndromes of FTD - behavioural variant frontal-temporal dementia (bvFTD), non-fluent primary progressive aphasia (nfPPA) and semantic primary progressive aphasia (svPPA).

Behavioural variant frontal-temporal dementia is the most common clinical syndrome of FTD (Ratnavalli et al., 2002). It is characterised by marked changes in social behaviour and personality (Neary et al., 1998).This is indicated by several behavioural characteristics such as inertia, behavioural disinhibition and distractibility, emotional blunting, and poor insight (Neary et al., 1998). Cognitive deficits also occur, particularly in the domains of attention, abstraction, planning, and problem solving, reflective of 'frontal dysexecutive syndrome'. In contrast, memory, language abilities, perception and spatial functions are relatively well preserved until late in the disease (Neary et al., 1998). Neuroanatomically, bvFTD has been

associated with symmetrical ventromedial frontal, insular, orbital frontal, and left anterior cingulate atrophy (Rohrer, 2011).

Non-fluent primary progressive aphasia is described in the literature as a disorder of expressive language, related to asymmetrical atrophy, mainly involving the left frontal temporal lobes (Neary et al., 1998). It is characterised by difficulties speech production, word retrieval, reading and writing, phonological and grammatical errors and preserved language comprehension (Neary et al., 1998). Though the disorder occurs in the absence of impairment in other areas of cognitive functioning, behavioural changes may appear at a later stage in the course of the disease (Neary et al., 1998). Semantic primary progressive aphasia, on the other hand, is characterised by difficulties in word naming and comprehension and recognising the visual precepts but with spared word production (Neary et al., 1998). This syndrome is typically characterised by bilateral atrophy and is most marked in the anterior temporal neocortex, with inferior and middle temporal gyri being predominantly affected (Neary et al., 1998).

The underlying pathology of FTD involves the atypical accumulation of proteins in the brain. Three main types of protein are associated with FTD: Tau protein TDP-43 protein and FUS protein (Bahia et al., 2013). It is important to note that there is also clinical overlap between FTD and other clinical disorders such as amyotrophic lateral sclerosis (ALS), progressive supranuclear palsy syndrome (PSP) and corticobasal syndrome (CBS) (Pan & Chen, 2013).

1.2.3.3. *Vascular dementia and other subtypes*: other dementia subtypes include vascular dementia (VaD), dementia with Lewy Bodies (DLB) and Parkinson disease dementia (PDD*).*

Vascular dementia is regarded the second most common cause of dementia following AD, making up approximately 20% of all cases of dementia (Rizzi et al., 2014). The progressive decline in cognitive abilities occurs as a result of various vascular events involving large and or small vessels and haemorrhagic or ischemic damage (Cato & Crosson, 2006). Although the clinical presentation and underlying pathology of VaD is highly heterogenous, it can be grouped into three clinical

conditions: multi-infarct dementia (MID), subcortical ischemic dementia (SIVD) and strategic infarction (Cato & Crosson, 2006). Multiple-infarct dementia emerges as a result of multiple ischaemic bilateral strokes (Meyer et al., 1988). Subcortical ischemic dementia, on the other hand, is pathologically driven by occlusion of the small vessels, that culminate into multiple lacuna infarctions and white matter ischemic in the subcortical structures (Roh & Lee, 2014). Strategic infarction dementia emerges as a result of ischemic lesion in a critical part of the brain involved in higher cortical functions (e.g., thalamus) (Kyung-won et al., 2003). Typically, VaD is characterised by an abrupt onset and stepwise deterioration (Qizilbash, 2003). Notably, this pattern can be seen with repeated lesions that affect cortical and cortico-subcortical brain structures, with large vessel multi-infarct dementia, and watershed infarcts (Qizilbash, 2003). Contrastingly, in people with SIVD, onset is relatively insidious, and the course of the condition is slower (Qizilbash, 2003). Typically, psychomotor slowing and executive dysfunction are the defining features of VaD (Levy & Chelune, 2007). Risk factors associated with VaD include atherosclerotic risk factors (e.g., history of hypertension, myocardial infarction, and diabetes) and increasing age (Skoog, 1994).

Dementia with Lewy bodies (DLB) may account for approximately 20% of dementia cases (Weiner, 1999). It is associated with marked impairments in attention, EF, and visual perceptual abilities (Gomperts, 2016). Other common features include pseudobulbar palsy, REM sleep disorder, repeated falls, visual hallucinations, spontaneous parkinsonism, and neuroleptic sensitivities (Gomperts, 2016). Memory impairment is not prominent in the early stages of the disease (McKeith et al., 2005). The defining neuropathological feature of DLB is the deposition of Lewy bodies, (alpha synuclein protein) in the substantia nigra and throughout the cortisol areas (McKeith, 2002). Amyloid plaques and loss of acetylcholine and dopaminergic producing neurones are also characteristic of the condition (McKeith, 2002). Neurodegeneration is notable in the anterior cingulate and frontal, insular, and temporal regions (McKeith & Burn, 2000). Risk factors associated with DLB include APOE4 alleles and family history of Parkinson's disease (Boot et al., 2013). Age of onset typically ranges from 50-to-83-years (McKeith et al., 1995).

Interestingly, DLB is closely related to the dementia sub-type, Parkinson's disease dementia (PDD). Both conditions share notable overlap in their clinical presentation (e.g., executive functioning deficits, visual hallucinations, REM sleep disorder and parkinsonism; Lippa et al., 2007) and underlying neuropathology (e.g., deposition of α-synuclein in Lewy bodies and loss of dopaminergic neurones) (Gomperts, 2016). The major clinical distinction between DLB and PDD, is the timing of when motor and cognitive impairments emerge (Gomperts, 2016). Earlier cognitive impairment relative to parkinsonism is indicative of DLB, whilst dementia onset after established idiopathic Parkinson diseases denotes PDD (Walker et al., 2019).

1.2.4. Prevalence

In a Global status report by the WHO, it was estimated there were approximately 55 million people living with dementia across the globe in 2020 (WHO, 2021). It was further estimated that globally, the prevalence of dementia among those over the age of 65 was 6.9%.

As mentioned, although dementia is not a characteristic of ageing, advanced age is regarded to be the greatest known risk factor dementia (Lobo et al., 2000). Prevalence estimates for dementia have been reported to be 2.1% for those aged between 65-to-69, 7.4% for those aged between 75-to-79 and 35.9% of those aged over 90 years (WHO, 2021).

Due to the ageing population, the number of dementia cases is predicted to rise nationally and globally (WHO, 2021). Researchers estimate that there are approximately 944, 000 people living in the UK with dementia and that this will rise to 1.6 million, by 2050 (Luengo-Fernandez & Landeiro, in preparation, as cited in Alzheimer's Research UK, n.d.). This expected rise in dementia cases poses significant economic challenges.

1.2.5. Impact of Dementia

It is well-documented that dementia can have deleterious effects on individuals, families, and society (Birtwell & Dubrow-Marshall, 2018). As noted, the diseases that cause dementia can make it difficult for individuals to carry out activities of daily

living and maintain their independence, reducing their quality of life. Such effects can cause an individual to experience a loss of identity, along with feelings of frustration (Birtwell & Dubrow-Marshall, 2018). The effects of being a family caregiver, albeit sometimes positive, are generally burdensome, with high rates of social isolation and psychological comorbidity, financial and physical health difficulties (Brodaty & Donkin, 2009).

At the societal level, dementia can have significant economic impact. The cost of providing care for individuals with dementia can be significant, and as the prevalence of the condition is expected to increase, an even greater burden on healthcare systems and economies worldwide, is expected. In 2021, the estimated cost of dementia in the UK was £25 billion, a figure that is expected to almost double by 2050 (Luengo-Fernandez & Landeiro, in preparation, as cited in Alzheimer's Research UK, n.d.), putting further strain on limited resources and access to care in a timely manner. The impact of dementia, along with the growing ageing population, make dementia a public health priority. In the absence of a cure, there is therefore an increasing focus on prevention, timely diagnosis and early intervention (Robinson et al., 2015).

1.3. Dementia in People with Intellectual Disability

Over the past few decades, life expectancy (LE) among people with an ID has significantly improved (Dolan et al., 2021). This has been extensively evidenced by empirical research carried out mostly in developed countries (Coppus, 2013). For example, in a UK based longitudinal study conducted by Emerson et al. (2014), it was found that the average LE among those with an ID increased from approximately 51-years-to -60-years, over three decades, between 1980-2012. With the increased LE among people with an ID, it has been acknowledged in the literature that, they are at an increased risk of developing conditions commonly associated with advancing age, such as dementia. With this increased risk, there has been growing interest among researchers to conduct further research in dementia in people with ID.

1.3.1. Aetiologies and Subtypes

1.3.1.1. *Alzheimer's disease in Down syndrome*: striking findings from neuropathological studies suggest that almost all individuals with DS develop AD neuropathology by the age of 40 (Wisniewski et al., 1985). Key features observed in the brain tissue of people with DS, include the presence of amyloid plaques and neurofibrillary tangles (Wisniewski et al., 1985). Research suggests that amyloid pathology begins to accumulate from the age of eight and progressively increases with advancing age (Leverenz & Raskind, 1998). The rate of accumulation is observed to accelerate between the ages of 35 and 45, with other types of pathology beginning to appear or worsen, such as the accumulation of neurofibrillary tangles and markers of neuroinflammation (Wisniewski et al., 1985).

While the findings of neuropathological studies indicate that developing DAT is an inevitable outcome of ageing with DS, prevalence and incidence studies show that some individuals with DS do not develop the clinical features of the disease (Holland et al., 1998; Lai & Williams, 1989; Visser et al., 1997).

Genetics may play a key role in the relationship between AD and DS. As previously mentioned, all of the features associated with DS occur as a result of an extra copy of chromosome 21. For this reason, people with DS, will also have an extra copy of the APP gene. It is hypothesised that the additional copy of APP gene may contribute to the development of AD in individuals with DS (AD-DS), through the overproduction of amyloid-β (Aβ; Wiseman et al., 2015).

As such, researchers have shown considerable interest in the clinical presentation of dementia, particularly DAT, among those with DS. There is substantial evidence suggesting that the prodromal period of AD among those with DS varies from that in the general population, in that it is characterised by the prominence of changes in social behaviour (e.g., apathy, lack of motivation and impulsivity) and personality as opposed to a decline in episodic memory (Deb et al., 2007; Holland et al., 1998; Lautarescu et al., 2017). Such changes have been linked to EF deficits with frontal atrophy, which may be suggestive of frontal lobe dysfunction (Ball et al., 2006, 2008;

Kittler et al., 2006; Wiseman et al., 2015). This neuropsychological presentation may mimic that of other kinds of dementia in people with an ID (e.g., FTD), highlighting the potential for diagnostic overshadowing and the importance of comprehensive assessment of a range of cognitive functions.

A number of hypothesises have been put forward to explain the similarity between the features of the prodromal stage of DAT among those with DS and the behavioural profile of FTD. A widely cited hypothesis by Holland et al. (1998) suggests that it may be attributable to the under-development, (and thus limited reserve capacity) of the frontal lobe region in people with DS. According to Holland et al. (1998), the progression of AD pathology in various areas of the brain as well as the pre-existing vulnerability of the frontal lobe may result in dementia first appearing through changes associated with frontal lobe dysfunction (e.g. personality changes).

Another distinct feature of AD among those with DS is the early appearance of neurological symptoms (e.g., gait disturbance and seizures) (Lautarescu et al., 2017). Similar to the general population, the decline through the later stages of dementia progressively affects greater areas of cognitive functioning and results in symptoms such as dyspraxia and parkinsonism (Wiseman et al., 2015). However, the rate of decline is more rapid compared to those in the general population (Prasher & Krishnan, 1993).

As mentioned earlier, olfactory identification deficits have been documented in individuals with AD. Given that there are similarities in the neuropathology of AD and DS, researchers have shown considerable interest in whether olfactory deficits are also evident in those with DS. The available evidence suggests that deficits in OF may also be present during the pre-clinical stage in DS population (Murphy & Jinich, 1996; Nijjar & Murphy, 2002). Additional findings suggest that people with DS also show declining OF with age, and a more severe impairment than age and IQ-matched people with non-DS ID (Nijjar & Murphy, 2002). Such findings suggest that olfactory dysfunction may serve as an early indicator of the dementing process in people with DS (Nijjar & Murphy, 2002).

1.3.1.2. *Other aetiologies*: whether individuals with non-DS ID are at an increased risk of developing dementia in comparison to the general population has been a subject of ongoing debate. Several studies suggest that people with non-DS ID may indeed face a higher risk of dementia compared to the general population (Cooper, 1997; Strydom et al., 2007). Contrastingly, some studies have indicated that the prevalence of dementia in this group may just be comparable to that in the general population (Zigman et al., 2004). As a result of the inconsistent findings, it is not yet possible to reach a conclusion about whether there is an increased risk of developing dementia among those with non-DS ID (Evans et al., 2013). Nonetheless, a number of hypothesises have been proposed to explain the potential elevated risk (Evans et al., 2013).

Further, head injury has been identified by researchers as being one potential risk factor for dementia in the general population (Li et al., 2017). While the level of risk that brain trauma poses for dementia in individuals with ID is yet to be determined, it has been established that traumatic brain injury during the perinatal period increases the likelihood of developing ID. In theory, such early-life trauma might also make individuals more susceptible to dementia in later life (Evans et al., 2013). Another hypothesis relates to diminished 'reserve' in brain functioning. When cognitive functioning is already impaired (i.e., in ID), a minor brain injury can have a significant impact, making it difficult for an individual to compensate (Cooper & Holland, 2007).

Although the presentation of dementia in other ID phenotypes is less researched, Strydom et al. (2010) suggests functional impairment to be an early sign of dementia among those with non-DS ID.

1.4. Neuropsychological Assessment

1.4.1. Definitions and Uses

Neuropsychological assessment is the normatively informed application of performance-based assessments of various cognitive skills (Harvey, 2012, p. 91). This can be completed using brief cognitive screening tests or by administering a battery of neuropsychological tests. (Kessels & Hendriks, 2023).

Neuropsychological assessment has a number of purposes. These include: assisting in the diagnosis and differential diagnosis of neurological or neuropsychiatric conditions, tracking the progression of disease, evaluating treatment effects and informing family and care staff on how best to manage and interact with the individual diagnosed (Kapur & Kemp, 2016). It can also inform on an individual's cognitive strengths and weaknesses to inform adjustment in the community (e.g., decision on returning to work) and help in planning of neuropsychological management and rehabilitation (Kapur & Kemp, 2016). In addition to its clinical uses, neuropsychological assessment has value in supporting research endeavours, by enabling the correlation of cognitive performance with structural and functional brain images (Harvey, 2012). This correlation offers valuable insights into the brain networks involved in particular functions (Harvey, 2012).

Whether using a battery approach or a subset of tests for a specific assessment, or utilising both approaches, there are a number of issues one must consider (Vanderploeg, 2014). Firstly, the chosen assessment measures should cover all cognitive domains that are relevant to the client's specific referral questions and suspected neurological, medical, or psychiatric conditions (Vanderploeg, 2014). Relying solely on general screening measures might overlook the diverse and intricate brain-related behavioural patterns that present.

Second, it is essential to utilize tests with robust normative data (i.e., standardized) that are applicable to the individual being assessed. This ensures that the client's performance can be accurately compared to appropriate comparison groups. It is also important to use tests/assessments that are appropriately challenging (Vanderploeg, 2014). Tests that are too easy (i.e. ceiling effects) or too hard (i.e. floor effects), reduce possible variability in performance, thereby compromising reliability (Vanderploeg, 2014).

It is also important to use test measures that are valid and reliable. Validity refers to the extent to scores from a measure represent the construct they are intended to (Sherman et al., 2011). Various models of validity have been proposed and documented in the literature. However, the most frequently used, is the tripartite

model whereby validity is divided into three components: construct validity, content-validity and criterion validity (Sherman et al., 2011). Construct validity refers to the degree to which an individual's test scores are correlated with the theoretical concept the test is designed to measure (Sherman et al., 2011). Content-validity describes the extent to which the test content reflects the subject of interest and supports a test's use for its intended purposes. (Sherman et al., 2011). Finally, criterion-validity refers to the degree of correlation between an individual's test scores and another variable thought to measure the same construct of interest (i.e. criterion) Fenn et al. (2020). Criterion validity is composed of concurrent validity and predictive validity (Fenn et al., 2020). Concurrent validity refers to the degree to which a new test correlates with another measure taken at the same time (Fenn et al., 2020). Predictive validity however refers to how well the score can predict a criterion measure (Fenn et al., 2020)

Reliability refers to the degree to which scores from a test are stable and consistent. If a construct is not reliably measured, the obtained scores will deviate from accurately reflecting the true value of the psychological variable being measured (Sherman et al., 2011). Reliability is generally evaluated in four ways: test retest, inter-rater, alternative forms, and internal consistency (Sherman et al., 2011). Test-retest refers to consistency of test scores over time, whereas inter-rater reliability refers to the consistency of test scores among independent assessors (Sherman et al., 2011). Alternate forms describes the consistency of scores across different forms of the test (Sherman et al., 2011). Finally, internal consistency refers to how well each item in a test measures the relevant construct of interest (Fenn et al., 2020).

1.4.2. Neurocognitive Domains and their Assessment in Dementia

A formal neuropsychological assessment in the context of dementia assessment typically evaluates the following cognitive domains: *language, praxis, perception, attention, executive function, and memory*. In this section, I describe each of these domains, and how they are usually assessed in the general population.

1.4.2.1. *Language*: neuropsychological assessment of language typically evaluates four principal areas: spontaneous speech, repetition, speech comprehension, and

confrontation naming (naming of objects and pictures; Hodges, 2018). Analysis of spontaneous speech enables identification for difficulties with articulation, fluency, syntax (grammar), paraphasic errors and prosody (Hodges, 2018). This can be assessed using standardized tests such as the Boston Diagnostic Aphasia Examination (BDAE) cookie theft picture (Goodglass & Kaplan, 1983). In this test, examinees are asked to describe everything they see in a pictorial scene. There are several tests of confrontational naming including the extensively used Boston Naming Test (BNT Kaplan et al., 1983). In this test, individuals are shown line drawings of common objects and requested to name them. A commonly used formal test of language comprehension is the Token Test (TT) (De Renzi & Vignolo, 1962).This test requires individuals to respond with gestures to the assessor's verbal commands (e.g., touch a circle) (Spreen & Risser, 1998). Repetition tests tap into an individual's ability to repeat the exact wording of what was just heard. These involve a series of words and sentences of varying complexity (Dening & Thomas, 2013). Sentence repetition is widely assessed using phrase, 'No ifs, ands or buts' (Kipps & Hodges, 2005).

1.4.2.2. *Praxis*: praxis can be defined as the ability to plan and perform skilled movements in a non-paralytic limb based on the previously learned complex representations (Negin et al., 2018, p. 2). Apraxia is the term used to describe the inability to carry out a motor movement that is not linked with sensory-motor deficits. (Kipps & Hodges, 2005). A comprehensive assessment of apraxia typically entails asking individuals to imitate a series of meaningful (e.g., wave) and non-meaningful actions, and pantomime the use of everyday objects (e.g., combing hair) (Kipps & Hodges, 2005). Examinees are asked to perform a number of oro-buccal movements (e.g., blow out a candle). Finally, individuals are typically asked to engage in sequencing a series of praxic movements.

1.4.2.3. *Perception*: visuospatial perception refers to a cognitive process which involves the extraction and interpretation of spatial information from visual stimuli (Mandal et al., 2012). It includes a number of skills such as spatial memory, mental imagery, rotation, distance and depth perception and navigation (Pinker, 1984). Although deficits in constructional ability are suggestive of apraxia, they are believed to reflect visuospatial, rather than motor deficits (Kipps & Hodges, 2005). Several

cognitive tests are used in clinical practice to assess visuo-spatial abilities. Examples of these include the Block Design Test (Wechsler, 1997) test and the Benton Line Orientation Test (Benton et al., 1975). The Block Design Test requires individuals to reconstruct a two-dimensional pattern using multi-coloured cube faces. The Benton Line Orientation test on the other hand, requires individuals to identify, among alternatives, the lines that are the same orientation as a presented stimulus. Drawing tests such as the Rey Osterrieth Figure Copy (ROCF; Rey & Osterrieth, 1941) and clock drawing tests are also commonly used to measure visuo-spatial functioning (Budson & Solomon, 2015). The ROCF test, requires individuals to reproduce complex line drawings, by copying and also from memory (Philips, 2012). There are multiple versions of the clock drawing test (CDT) in which examinees are typically asked to draw a clock face and then to draw the hands at a fixed time-point (e.g., ten past eleven) (Budson & Solomon, 2015).

1.4.2.4. *Attention*: the term attention broadly refers to a range of "cognitive processes that relate to actively processing information from the environment focusing on certain aspects and filtering out others" (British Psychological Society, 2015, p. 9). There have been many attempts to characterize the various components of attention. However, for clinical purposes, Hodges (2018) suggest that attentional abilities can be broken down into the following components: arousal, sustained attention, divided attention, and selective attention. Arousal refers to a general state of responsivity to the environment and wakefulness. Selective attention, on the other hand, describes the ability to focus upon one stimulus while supressing awareness of other stimuli (Hodges, 2018). In contrast, divided attention describes a person's capacity to attend to more than one stimulus at a time (Hodges, 2018). Finally, sustained attention (otherwise termed vigilance) describes the ability to maintain attention over prolonged periods of time (Hodges, 2018). According to Hodges (2018) disorientation to time or place, distractibility, impersistence and confusion reflect impairments to attention.

There are a number of tests clinicians use to assess attention. For example, standardized tests of orientation to time and place such as the orientation sub-test (Molloy & Standish, 1997). This sub-test asks 10 items on that assess orientation to time and place such as "what is todays date?" or "where are you now?" Attention can

also be assessed using other tests such as serial 7s (i.e., counting back from 100 in 7s), and the digit span forwards and backwards test (i.e., individuals asked to repeat back sequences of numbers of increasing length, in the same or reversed order) (Hodges, 2018). Sentence repetition tests are also used to assess attention (Meyers et al., 2000).

1.4.2.5. *Executive functions*: executive functions can be defined as super-ordinate cognitive processes that govern the orchestration of mental capacities, movements and actions into complex goal directed behaviours (Nadu, 2005). These cognitive processes include, inhibitory control, mental flexibility, self-monitoring (i.e., learning from errors), abstract thinking, working memory, planning, and sequencing and task initiation (Nadu, 2005). Inhibitory control describes one's ability to control their attention, behaviour, thoughts, and/or emotions to override a strong internal urge or external temptations, and instead choosing a more appropriate action. (Diamond, 2013). This aspect of executive functioning is typically assessed using tests such as Go/No-go tests. The examiner asks examinees to tap once in response to a single tap, and to inhibit a response for two taps. The test can be made more challenging by altering the initial rule after a number of trials (e.g., ''tap once when I tap twice, and not at all when I tap once'') (Kipps & Hodges, 2005).

Mental flexibility (otherwise termed set-shifting) refers to the ability to alternate between mental sets or tasks and changing strategies within the same task (Diamond, 2013). Trail making tests are commonly used to assess this specific function. These tests typically comprise of two parts, with the first requiring individuals to draw a line to connect numbers consecutively from 1 to 25 (Hodges, 2018). In part B, individuals are asked to connect numbers and letters in an alternative progressive sequence (e.g., 1 to A, A to 2, 2 to B etc.) (Hodges, 2018).Verbal fluency tasks are typically used to measure the ability to initiate a task (Hodges, 2018). In standard versions of the tasks, participants are given one minute to produce as many unique words as possible within a semantic category (category fluency) or starting with a given letter (letter fluency) (Hodges, 2018).

Abstract reasoning is an integral part of executive functioning and necessitates the examination and manipulation of information pertaining to events, objects, and

concepts that exist beyond the immediate surroundings (Solomon et al., 2011). This cognitive process is believed to encompass two key components: the capacity to recognize underlying category attributes to better understand them), and the capability to construct concepts (i.e., generate cognitive schemas to organize information) based on these distinctions (Solomon et al., 2011). A common approach to testing this cognitive function is by asking individuals are asked in what ways two words (objects or concepts) are similar (Hodges, 2018).

Working memory can be defined as a "system of temporary storage and manipulation of verbal and visual information" (Baddeley, 1992, p. 556). Verbal working memory can be assessed using tests such as Digit Span Backwards tasks (described above) (Nadu, 2005). Visuo-spatial working memory can be assessed using Spatial Span tests such as the Corsi Block Test (CBT) (Berch et al., 1998). In this test, individuals are presented with a set of nine blocks on a board. The examiner starts by tapping a sequence of two blocks which the examinee must reproduce from memory. The sequence length increases with each trial, using up to all nine blocks (Brunetti et al., 2014).

Finally, planning describes "a higher-level cognitive function that includes executive functioning processes involved in the formulation, evaluation and selection of actions acquired to attain a goal" (Cristofori et al., 2019, p. 2). The Tower of London test developed by Shallice et al. (1997) is a commonly used as a test of planning abilities. In the TOL, examinees are required to move coloured disks individually from an original state to match a goal state. The examiner instructs the examinee to mentally plan the sequence of moves before they begin the task (Phillips et al., 2001).

1.4.2.6. *Learning and memory*: according to Kipps and Hodges (2005), a helpful framework for evaluating memory impairment divides memory into several components: episodic memory, semantic memory and working memory (previously described). Episodic memory refers to the recall of a personally experienced events (Ennaceur, 2010). It can be divided into anterograde episodic memory (acquisition of newly encountered information) and retrograde episodic memory (recall of previously learnt information) (Kipps and Hodges, 2005). Examples of verbal and non-verbal

tests of anterograde memory include the Rey Auditory Verbal Learning Test (RAVLT; Rey, 1964) and the Rey-Osterrieth Figure Test (previously described).

The RAVLT involves five consecutive presentations of a 15-word list (List A). After the list is read aloud to the examinee, the participant is required to immediately recall as many words as they can remember (Moradi et., 2017). After the fifth trial, a new word list is presented (List B) to the examinee, after which they are asked to immediately recall the words. Following this trial, the examinee is asked to recall words from List A again. After 30 minutes, the examinee is then asked to recall the words as many words as they can from List A (Moradi et., 2017). In case the person recalls only 13 words or fewer during the delayed recall trial, a recognition trial takes place (Woodard, 2006). In this trial, the 15 words from List are mixed with List B words and 20 additional distractor words that were not part of either List A or List b (Woodard, 2006). The person being tested is required to say whether each word presented was from List A or not (Woodard, 2006).

In contrast to episodic memory, semantic memory refers to the ability for recollecting facts and general knowledge about the world (Squire & Zola, 1998). Deficits in semantic memory are typically assessed using verbal tests, such as confrontational naming and verbal fluency (previously described) (Hodges, 2018).

1.4.2.7 *Pre-morbid ability*: pre-morbid ability refers to the estimation of an individuals' intellectual functioning prior to known or suspected onset of brain disease or cognitive decline (Schoenberg et al., 2011). This estimate is the baseline against which an individual's current cognitive functioning is compared to ascertain the existence of cognitive decline. It also allows one to establish the degree, and rate if cognitive deterioration (Baade & Schoenberg, 2004). In most cases, an examiner must rely upon indirect methods of deficit assessment from which individual comparison standards can be estimated (Lezak et al., 2012). This estimate can be generated various sources of information. Commonly used indirect approaches include the demographic regression equations and irregular word reading tasks (Baade & Schoenberg, 2004).

Tests that measure an individual's ability to read aloud irregularly spelled words is another used method to estimate pre-morbid functioning. Use of such tests as a measure of premorbid functioning is based on the view that an individual's ability to pronounce irregularly spelled words is resistant to cognitive decline (Overman et al., 2021). An example of such a test is the Wechsler Test of Adult Reading (WTAR; Wechsler, 2001). Although these tests are widely used, it is important to acknowledge they are not without limitations. For example, such approach cannot be used for those who have dyslexia, visual acuity problems, or articulation problems (Watt & O'Carroll, 1999).

1.5. Neuropsychological testing in people with Intellectual Disabilities

As mentioned, neuropsychological assessment serves a number of important purposes in the field of dementia, including clinical diagnosis. However, when applied to individuals with an ID, this form of assessment can be challenging for a number of reasons. For instance, due to the great heterogeneity in cognitive performance across a number of domains in individuals with ID (and differing levels of communication and sensory abilities), neuropsychological tools used to screen for dementia in the general adult population are not appropriate (Rösner et al., 2021). This is because tools as such assume a typical pre-morbid level of functioning (Paiva et al., 2020). Consequently, administering such tools in people with ID may make it difficult to distinguish pre-existing cognitive impairments from those relating to neurodegeneration (Deb & Braganza, 1999).

Another challenge that comes with neuropsychological testing in the ID population pertains to estimating pre-morbid intelligence. As noted earlier in the thesis, neuropsychological assessment requires the comparison of obtained scores against some level of pre-morbid functioning. Such comparison enables an assessor to determine a cognitive decline which is essential to the diagnosis of dementia (Overman et al., 2021). However, common methods used to ascertain pre-morbid functioning, such as word reading, are not appropriate for those with ID, as they require verbal and reading abilities. As there is considerable variability in the degree

of ID, the development and use of large normative datasets for tests of specific cognitive domains is questionable (Oliver & Kalsy, 2005).

The clear implication of such issues is that the longitudinal assessment of intra-individual changes in cognitive performance relative to a baseline level becomes essential in neuropsychological assessment, to determine whether a decline due to dementia is evident or not (Oliver & Kalsy, 2005). However, this method of testing can be very costly, in terms of time and resources (Oliver & Kalsy, 2005). One may therefore argue that there is a need to identify something more sufficient for services, and it may be beneficial to develop normative datasets for specific ID groups (e.g., DS).

A further challenge presented when using neuropsychological testing with people with ID is that probable sensory, motor, communication, and attention issues may interfere with test performance, thus compromising the validity and reliability of results (Lezak et al., 2012). Additionally, behavioural and emotional difficulties could cause frustration and fatigue, which may jeopardise the validity and reliability of test results (Hom et al., 2021). Therefore, it is imperative that neuropsychological tests that are developed for use with those with ID, are sensitive to, and considerate of these, various issues.

1.6. Summary

With consideration to the challenges noted, it is apparent that there is an evident need for the development of a norm-based cognitive test for dementia that is appropriate for the ID population. To address this, researchers and clinicians in the UK have made and continue to make considerable efforts to develop a test such as this. The next section presents a literature search concerned with identifying tests developed in the UK for the detection for dementia in the ID population.

1.7. Systematic Scoping Review

A number of literature reviews exist in the literature on available research on the various tools used in the assessment of dementia in the ID population across the globe. Such reviews report on available research concerning informant-based and direct cognitive test measures, and those not necessarily designed for dementia assessment or individuals with ID. However, the main objective of the current scoping review was to explore the available research on direct cognitive tests and batteries developed in the UK for people with ID, specifically designed for the detection of dementia. As documented in the literature, culture can influence test performance, especially when a test or test-set includes culturally specific elements such as pictures, figures, words or phrases (Nielsen, 2022). This holds true for tests developed in western contexts such as the United States (US), which may include content that is not culturally or linguistically aligned with UK norms.

The following orienting questions were used to guide the scope:

- What direct cognitive assessment tools have been developed in the UK to assess for dementia in people with ID?
- How useful/appropriate are these tests (e.g., psychometric performance, cognitive functions addressed etc)?

1.7.1. Search Strategy

A search was carried out across five databases (January 2024) for the review. These included: APA PsychInfo, Academic Search Complete, CINAHL, Scopus and Science Direct.

A combination of the following search terms was used: ‘Cognitive test, ‘neuropsychological test’, ‘dementia, ‘Alzheimer’s, ‘intellectual disability, ‘mental retardation’, ‘learning disability, ‘Down-syndrome’. Where permitted, Boolean operators ‘AND’ as well as ‘OR’ were used to combine search terms. Additional literature was sourced from the reference lists of identified literature and review papers.

Studies were eligible for inclusion if they described the use or development of a cognitive test for the detection of dementia in people with ID. Studies were also

included if they aimed to evaluate the effectiveness of a direct cognitive test developed for this purpose. The tests included in these studies were required to be developed in the UK. It is important to note that the search was not limited to a specific timeframe. Moreover, papers not published in English peer reviewed journal were excluded.

1.7.2. Search Results

The database search identified a total of 1117 papers (see Fig.1.). An additional 29 papers were also identified from manual reference searching. Following the removal of duplicates, a total of 1083 papers were screened by the author. Upon full text review of 22 papers, 10 papers were excluded based on the eligibility criteria. A common reason for being excluded was that the tests developed or evaluated were not designed for use in a UK context. Papers not readily available to the researcher at the time of study were also excluded. A total of 12 studies were included in the review.

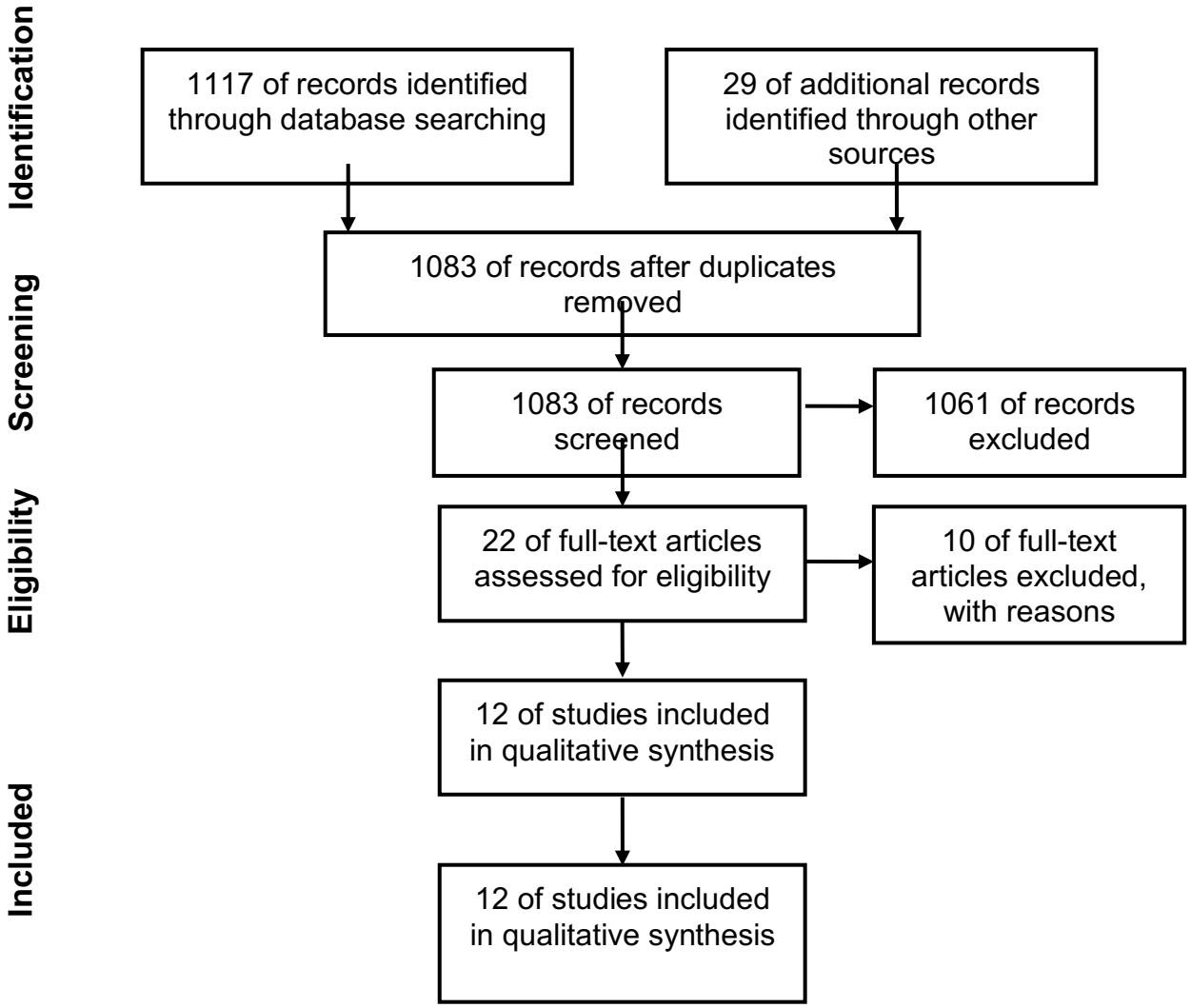


Figure 1. PRISMA (Moher et al., 2009) Flow Diagram of Article Selection Process.

1.8. Literature Review

1.8.1. Cognitive Batteries for People with Intellectual Disability

1.8.1.1. *The Cambridge Cognitive Examination for Use in Down Syndrome*: the Cambridge Cognitive Examination modified for use in a group with Down Syndrome

(CAMCOG-DS) developed by Hon et al. (1999) was adapted from the Cambridge Cognitive Examination (CAMCOG; (Huppert et al., 1995). The CAMCOG-DS comprises various tests for the following domains: Orientation; Language (expression and comprehension); Memory (new learning, remote, and recent); Attention; Praxis; Abstract thinking, Perception (visual and tactile recognition) and Calculation. The tool was adapted to reduce the floor effect for individuals with DS. In this tool, some of the questions from the original CAMCOG are omitted. For other questions, examinees can obtain a half-score, as the interviewer can provide prompts, if needed. Interestingly, many of these tests rely on verbal abilities and general knowledge, which is influenced by cultural context.

Hon et al. (1999) assessed the suitability of this tool for older adults with DS at the age of risk for dementia. The test was administered to 74 adults with DS aged 30 and over, across the whole range of abilities (i.e., mild through to severe and profound). The results revealed that, with the exception of the Attention, Calculation and Abstract Thinking subtests, the majority of the participants scored above floor on most of the other subscales (e.g. Memory, Language, Praxis and Perception). Though many of the participants performed above, it is important to note that participants who were at floor for all of most of the tests were primarily individuals with pre-existing severe or profound ID, significant sensory impairments, or advanced dementia.

Such results suggest that this test is not appropriate for everyone this population and may only be useful for those with mild to moderate ID. Notably, CAMCOG-DS scores were found to be strongly related to age, with the older participants (i.e., 45 years) performing worse than the younger participants (30-to-44 years). With the exception of the Attention/Calculation subscale, significant differences were found on the subscales between younger and older participants. Such results suggest that some of the sub-tests included in the CAMCOG-DS may be useful in examining cognitive change overtime in those with mild-to-moderate ID.

1.8.1.2. *Neuropsychological Assessment of Dementia in Intellectual Disabilities*: The Neuropsychological Assessment of Dementia in Intellectual Disabilities (NAID) developed by Crayton et al. (1998) comprises seven subscales that assess language

(expressive and receptive), praxis, working memory and verbal short-term memory. The NAID subscale scores produce two domain scores, early (memory) and Late (aphasia, agnosia, and apraxia) (Oliver et al. 2022), reflecting the sequence of decline shown by Oliver et al. (1998). Interestingly, many of the tests included in the NAID rely heavily on language and visual perception skills.

The reliability and concurrent validity of the NAID was assessed in the recent research by Oliver et al. (2022). Split-half reliability ranged from 0.74-0.94, while internal consistency ranged from 0.82-0.94, both suggesting high levels of reliability. Concurrent validity (as indicated by Kendall's tau b) of the early and late domains and total score of the NAID and the Action on request subscale and the Brief Praxis test ranged from 0.6-.077, suggesting acceptable to good levels of reliability. The results also indicated that NAID scores at subscale and domain level declined with age. Such results are supportive of criterion validity. It is important to note that the research sample only included those with DS and therefore it is not possible to comment on the tool's suitability across the wider ID population.

1.8.1.3. *The Prudhoe Cognitive Function Test*: The Prudhoe Cognitive Function Test (PCFT, Kay et al., 2003) is a brief test (relative to other tools) comprising 94 items. The items are distributed into five domains: Orientation, Recall, Language (expression and comprehension), Praxis and Calculation. Most of these items included in the test were adapted from the Mini Mental State Examination (MMSE; Folstein, 1997), clinical approaches commonly used to evaluate expressive language and comprehension and other dementia rating scales. Items included in the tool can be administered to people with non-verbal abilities, if necessary (Tyrer et al., 2010). Administration of the test is reported to take between 25-to-45 minutes. Two shortened versions of the PCFT (i.e., form A and form B) have also been developed (Tyrer et al., 2010). These shortened versions comprise 21 items, with administration time lasting approximately 15-20 minutes. Thus, beneficial for those who may have attentional difficulties.

Kay et al. (2003) assessed the concurrent validity of the PCFT by comparing its total score with a widely used informant instrument, the Adaptive Behaviour Scale-Part 1 (ABS; Nihira et al., 1974). A correlation coefficient of 0.87 was reported between the

two tools, thus suggestive of very good concurrent validity. Comparisons have also been made between the PCFT (long form) and the Kaufman Brief Intelligence test (K-BIT; Kaufman & Kaufman, 1990); a standardised and widely utilized test to assess cognitive functioning in people with ID (Tyrer et al., 2010). Strong correlations between the non-verbal and verbal parts of the K-BIT and the Long PCFT were also reported (correlation coefficients of 0.85 and 0.78, respectively), further evidencing concurrent validity of the tool (Tyrer et al., 2010). It is noteworthy that all of the participants assessed in this study had a diagnosis of DS and therefore the generalisability of the results to other ID aetiologies are limited.

High correlations were also found between the short versions of the PFCT and the log version of the tool. Such results suggest that the shortened forms can be used inter-changeably and therefore allowing intra-individual measurement and further reducing the chances of practice effects (Tyrer et al., 2010). However, it is important to note that the ID aetiology of those assessed in this research was not reported on, therefore it is not possible to comment on the tool's suitability across the ID aetiologies. Current research has also demonstrated the PCFT (long-form) to be a highly reliable tool.

Margallo-Lana et al. (2003) reported the intra-class correlation coefficients (ICCs) for raters using the tool in their research (n=3) were 0.99, 0.99 and 0.98, thus indicating excellent inter-rater reliability. Moreover, the ICC for test-retest reliability was 0.99, indicating excellent temporal stability. Again, all participants in this study had a diagnosis of DS, thus limiting the generalisability of the findings.

Despite its notable strengths, the PCFT also has a number of limitations. Although Kay et al. (2003) revealed the PCFT to correlate strongly with the ABS, their results also showed that participants with higher levels of disability (i.e., profound) scored at the floor (or close too) on the PCFT and its cognitive domains. The authors reported that the mean PCFT scores of participants with speech impairments was significantly lower than in those without. Interestingly, an association between visual deficits and impaired performance was reported for both scales. These findings suggest that the PCFT may be limited in detecting cognitive decline among those with pre-existing severe or profound learning disabilities and/or visual and speech impairments.

1.8.1.4. *The London Down Syndrome Consortium Adult Cognitive Assessment:* Startin et al. (2016) developed the London Down Syndrome Consortium Adult Cognitive Assessment (LonDownS), to support future research on identifying risk and protective factors for the development of dementia in people DS. They developed the tool by compiling several established novel assessments (comprising both tabletop and computer tasks) requiring minimal verbal responses. The various cognitive tests included in the tool assess general abilities, memory (visuospatial short-term, delayed incidental memory, delayed object memory and verbal memory), EF(set-shifting, working memory and planning, rule learning and switching, inhibitory control and attention) and motor functioning abilities in adults with DS. Administration of the test is reported to take approximately 3 hours.

Startin et al. (2016) report on data from baseline cognitive assessments completed with two cohorts of people (mild, moderate, and severe) using the LonDownS. A total of 181 adults with DS aged 36 years and over, both with and without a clinical diagnosis of dementia), were in cohort 1; and 121 people with DS aged between 16-to-35 were in cohort 2. It was reported that for those aged 36 and above and without dementia, completion rates were deemed acceptable, with approximately 80% for computer-based tests and 90% for all non-computer subtests. Moreover, fewer than 10 of participants scored at the floor and less than 20% of participants scored at the maximum level. Interestingly, the completion rates for those aged 36 and over, with dementia, were lower (65%). Moreover, less than 25% of participants among this group scored at the floor, and fewer than 15 at the celling.

High completion rates were reported for those aged between 16-to-35 across the subtests included in the battery. Though lower completion rates were observed for some of the computer-based tasks, due to technical issues. Few participants among this group scored at the floor (<5%). Ceiling effects were observed for some of the tests included in the battery (e.g., CAMCOG object naming task). Additionally, outcome data collected for this group revealed that most of the subtest scores were highly correlated, excluding the computer-generated arena which is a computer-based task assessing visual spatial short-term memory.

Though the findings of Startin et al's. (2016) study suggest that the LonDownS carries evident strengths (e.g., low floor and ceiling effects), it is important to recognise its limitations. For instance, Startin et al. (2016) also found that completion rates were higher for table-top tasks compared to computer-based tasks among those diagnosed with dementia. Such results suggest that computer-based tasks may not be appropriate for an older adults at risk for dementia (Startin et al., 2016). While it is a notable strength that the authors acknowledge the importance of assessing EF, it should be noted that all executive functioning tests in the battery are computer-based, and this may not be accessible for all individuals for various reasons (e.g., sight impairments and motor skills). One may also question whether the assessment administration time is arduous and lengthy for those with an ID. It is unsurprising that the authors note observed attention levels negatively affected performance in their research.

1.8.2. Cognitive Tests of Specific Functions for People with Intellectual Disability

1.8.2.1 *The Cambridge Executive Functioning Assessment*: *The Cambridge Executive Functioning Assessment (CEFA; Ball et al., 2008)* is a comprehensive battery of executive functioning and memory tests that was developed for the detection of dementia in people with ID. The test comprises six EF tests postulated to assess a wide range of executive functioning processes (i.e. initiation, efficient organization of retrieval and recall, response inhibition, working memory, set-shifting, and abstract thinking). The battery also includes six memory tests which are thought to assess a wide range of memory processes (i.e. prospective memory, retrieval with a cue, working memory, verbal short-term memory, immediate retrieval, delayed recognition, delayed recall).

Ball et al. (2008) utilised the tool in their research aimed at examining the relationship between executive dysfunction and the clinical characteristics of AD in individuals with DS. The tool was completed by 103 individuals with DS (mild-to-moderate ID), both with-and-without a diagnosis of DAT as determined by informant reports on the CAMDEX-DS informant interview (Ball et al., 2006). The relationship between DAT diagnosis and performance on each neuropsychological test, whilst controlling for any differences in age and severity of LD, was then examined. The

data revealed that those without DAT performed consistently better on all measures compared to those with DAT (demonstrating concurrent validity).

However, some of the tests of executive functioning, i.e. *Verbal Fluency* (assessing initiation, set-shifting, working memory and organization of retrieval and recall), *Cats and Dogs* (assessing response inhibition and working memory), and *Weigl Sorting* (assessing set-shifting and abstract thinking; Grant & Berg, 1948) were less sensitive than others e.g. *Scrambled Boxes* (assessing working memory), and *Tower of London* (assessing planning and working memory) tests and also the delayed recognition and recall tests. The severity of intellectual disability significantly affected scores on all tasks except spatial reversal (assessing set-shifting). It was further found that the scrambled boxes test, along with the prospective memory and delayed recall tasks, were less sensitive to the effect of intellectual disability severity than memory for sentences and immediate memory.

For the *Tower of London* and delayed recall tasks, the severity of intellectual disability had a significant impact, but only in the non-DAT group, due to floor effects with the presence of DAT. For the *Weigl Sorting*, those with moderate ID scored at the floor level whether they had DAT or not, indicating it is an insensitive measure. Further, age contributed significantly to the scores for the *Tower of London*, prospective memory, and delayed recognition tasks; and there was a trend across all the tasks for increasing age to be associated with poorer performance. It is important to acknowledge that exclusion of people with severe ID and other ID aetiologies from this research, thus limiting the generalisability of the results to the wider ID population.

The validity of the CEFA has also been examined by Willner et al. (2010) who administered the CEFA and the children's version of the Behavioural Assessment of the Dysexecutive Syndrome; BADS-C; Emslie et al., 2003) to 40 adults with mild-to-moderate ID, without dementia. Descriptive statistics in this study revealed that a large number of participants obtained a score of zero on three of the subtests included in the BADS-C, whilst a relatively high percentage of participants scored at the maximum level on the *Weigl Sorting* (32.5%) and *Cats and Dogs* (25%) tasks. A high proportion of participants were observed to obtain maximum scores for many of

the subtests included in the CEFA-Memory battery. These include the Delayed Recognition (70%), Prospective Memory (32.5%) and Immediate Memory (45%) subtests.

Analyses also showed that both sets of executive functioning tests were poorly correlated with receptive language ability (measured by the BVPS). The absence of a strong correlation between these measures is suggestive of their suitability for individuals with ID (Bevins and Hurse, 2016). The authors also carried out principal component analyses of the CEFA which revealed two factors that differed by the degree of involvement of working memory and sensory processing type (e.g. visuospatial and verbal). Although, this research suggests that CEFA is suitable for people with ID, it is important to note that people with, severe ID or dementia were excluded from the study.

More recent research by Bevins and Hurse (2016) evaluated three subtests included in the CEFA battery (*the Weigl*, *Cats and Dogs* and the *Verbal Fluency* task). In this study, people with ID were required to complete at least one of the CEFA tasks in the CEFA, the *Object Memory* task from the NAID, and the British Picture Vocabulary Scales (BPVS-II; Dunn et al., 1997) which is a measure of verbal comprehension in children. Carers were required to complete the *Dementia Questionnaire for Learning Disabilities* (DLD; Evenhuis et al., 2007), which is used to assess social and cognitive functioning in the ID population (Eurlings et al., 2006). Descriptive statistics revealed a good spread of scores including *Verbal Fluency*. Though a ceiling effect was observed for the *Cats and Dogs* subtest, the test was found to be positively correlated with the object memory task, and negatively with cognitive abilities based on the reports of carers.

Interestingly, no correlation was observed between the *Cats and Dogs* subtest and the BPVS. The absence of a correlation suggests that the measure be useful for populations with varied verbal abilities, such as the ID population. It was also reported that the verbal fluency subtest did not correlate with any of the other measures. The authors concluded that such findings may suggest that this test either assesses a novel area of functioning or that it may be a redundant measure. Nevertheless, they suggest that as the test appears to be acceptable for use (e.g.

not distressing, time efficient), its use should be continued until further research is carried out.

1.8.2.2. The Behavioural Assessment of Dysexecutive Functioning-Intellectual Disabilities-Adaptation: The Behavioural Assessment of Dysexecutive Functioning-Intellectual Disabilities-Adaptation (BADS-ID) was developed by Webb et al. (2020) to assess executive functioning in adults with ID. It is an adapted version of the Behavioural Assessment of Dysexecutive Syndrome battery (BADS; Wilson et al., 1996). The BADS-ID comprises six subtests that aim to assess various aspects of EF including, set-shifting, problem solving, planning, organisation, self-monitoring, and prospective memory. The tool was adapted based on the strengths and the weaknesses of the BADS for use with individuals with ID after consultation with clinical and neuropsychologists. Examples of modifications include the simplification of instructions, omission of difficult tasks and use of visual prompts for some tasks and reducing complexity of tasks.

Webb et al. (2020) evaluated the psychometric properties of the BADS-ID and compared it with the CEFA. The BADS- ID was found to have good inter-rater reliability, but poor internal consistency, which was comparable to the CEFA. Results also showed that most participants were able to attempt all the tests in the battery. Moreover, the proportion of participants who obtained a minimum score for each test ranged from 0%-9.8%. The proportion of participants who scored the highest possible score ranged from 0%-12.7%, excluding one sub-test (*Supermarket Map 2*), where it increased to 40.2%. The floors and ceilings of the BADS-ID tests are favourable compared to those of the CEFA, with the CEFA floors ranging from 0%-22% and ceilings ranging from 5%–50.9%, as reported by Willner et al. (2010).

The BADS-ID was compared with the CEFA to assess concurrent validity. The total BADS-ID score was found to be positively correlated with the CEFA total score. Moreover, significant correlations were revealed between most of the subtests included in the two batteries, suggesting that the BADS-ID assesses similar skill areas to those assessed by the CEFA. The total BADS-ID score as well as four subtests (rule shift, key search, supermarket map 1 and 2) was negatively correlated with age. Such findings suggest the BADS-ID may be sensitive to age-related

changes to executive functioning. Interestingly, there were no correlations the CEFA subtests and age.

As noted by the authors, content validity of the tool is likely preserved, as it maintains connections to the original test, and all tests were underpinned by research into executive functioning. Content validity is also achieved by the similarity between the BADS-ID and CEFA in relation to the skills assessed. However, it is important to note that the BADS-ID does not include a test which assess initial and verbal set-shifting which is assessed by the CEFA *Verbal Fluency* test. With reference to this limitation, the authors suggest that the CEFA *Verbal Fluency* test could be included in the BADS-ID.

Overall, quantitative and qualitative feedback indicated that the adapted tests were experienced positively. A high percentage (81-100 %) of participants rated each of the individual sub-tests as being “easy” and not too long (ranging from 69-88%). Also, a high percentage of participants rated the test instructions for each of the tests as being very clear (ranging from 69% to 100%). Participants also reported that they made use of their knowledge of real-life situations when completing the subtests thus evidencing face validity.

Finally, principal component analyses suggests that the BADS-ID has a two-component structure, which reflect the core executive functioning features: planning, and inhibition/shifting. It appears that the BADS-ID is a comparable or arguably a better measure of executive functioning in the ID population. Therefore, cognitive test batteries developed for detecting dementia in people with ID may benefit from including these set of EF tests.

1.9. Summary and Discussion

The current literature review shows that researchers in the UK have made considerable efforts to develop cognitive tests for the detection of dementia in people with ID. However, all of these cognitive test sets/batteries carry significant limitations. Upon inspection of the literature, it appears that the available cognitive test sets,

developed in the UK, are of limited clinical utility with people with pre-existing severe or profound difficulties (e.g. CAMCOG-DS and NAID). Suggesting that informant measures continue to be the most appropriate for this population.

As noted earlier, it is imperative that neuropsychological tests that are developed for use with those with ID, are sensitive to and considerate of the sensory, motor, communication, and attentional needs among this group (Lezak et al., 2012). However, it appears that most of the existing test-sets do not consider these factors.

The comprehensive assessment of all areas of cognitive functioning relevant to dementia is crucial as its early detection, accurate diagnosis of the various disease sub-types, monitoring the progression of disease, evaluating treatment effects, treatment planning and supporting research. However, none of the existing test-sets appropriately assess all areas of cognitive functioning, particularly EF.

In light of current research suggesting that EF is affected in the prodromal phase of AD, in those with DS (Ball et al., 2006, 2008), it is crucial that cognitive test-sets specifically assess this function. It appears from the literature that there exists only one test-set (i.e. LonDownS) that adequately assesses EF in people with ID (Startin et al., 2016). However, most of these tests are computer-based tasks, thus carrying significant limitations (e.g. technical issues and resource intensive) and reducing its accessibility to service users.

Although current cognitive test-sets fail to appropriately assess EF, the literature reviews shows that researchers have made considerable efforts to develop specific tests for this purpose. Some of the tests included in these tools show promising clinical utility, while others have evident limitations (e.g. marked floor effects). Researchers concerned with developing new cognitive test-sets for the detection of dementia in people with ID may benefit from incorporating the tests found to be to be useful, while also continuing to develop other EF tests.

Interestingly, none of the identified cognitive test sets include olfactory tests, despite recent research suggesting their potential for being an accessible approach to identifying DAT in people with DS. Integrating such tests into a cognitive test-set will

contribute to research on whether non-aversive olfactory assessment may provide reliable insight into whether a person with ID is experiencing a cognitive decline.

1.10. The Current Study

1.10.1. Current Study Rationale

Altogether, the available evidence indicates a need for a comprehensive and accessible test battery which considers both the type of ID and possible dementia pathology, to measure functioning, support differential diagnosis and allow earlier detection for suitable support. The current study therefore aims to evaluate the acceptability and feasibility of a set of tests that together provide a diagnostic measure of dementia for people with ID. This tool aims to assess all cognitive domains to facilitate differential diagnosis and be acceptable and feasible to people with ID. It also aims to be administrable with low cost to services in the National Health Service. The specificities of the progression of dementia in individuals with ID as well as the elevated risk of developing dementia in people with DS, emphasises the need for the accurate assessment and diagnosis of dementia for those with ID. Early detection of dementia is crucial to ensure the provision of appropriate healthcare and to enhance quality of life for individuals with an ID, their families, and carers (Zellinger, 2013). It also supports effective future planning, the development of timely interventions, and personalised support. Failure to reliably identify dementia in individuals with ID places the population at a disadvantage and hampers their ability to live well whilst coping with dementia.

The current study was part of a set of three studies, undertaken as the thesis element of clinical psychology training. Together with the supervisor, the researchers reviewed the existing literature in the area and formulated a first draft of the test set formats and items. Each study involved preliminary quantitative data collection, to address the *feasibility* of the test set, and were focussed on deriving qualitative data (observation and feedback) to address test set *acceptability*. Each of the researchers separately undertook their own participant recruitment, involving both NHS and third sector organisations working with people with an ID, aged between 18 and 55 years; and analysed the data independently. One researcher collected data from people

with DS (age 30-to-55), recruited in the NHS and third sector organisations. The results of this study suggested that test-set to be broadly acceptable and feasible for the DS population, although many items included in several of the subtests require revision. Tests of EF were found to be particularly challenging for this group. The other researcher collected data from people with mild to moderate ID (age 30-to-55, without DS) from the NHS and non-NHS organizations. This study also found the test-set to be both acceptable and feasible for this population, though refinements are needed to ensure accessibility for a range of severity levels and for people with low verbal abilities.

For the current study, data was collected from people with mild ID (age 18-to-55, without DS) from the NHS and a non-NHS organization. The overarching aim of these three studies is to combine data from the first test piloting and inform the development of a second draft of the test battery, which will be further tested, and validity and reliability assessed.

Fenn et al. (2020) identifies 15 key steps in constructing, piloting and validating a test. The literature review above reflects steps one and two (i.e. test construction decision and investigation into the concept) and steps three, four and five (test-format decision, item writing and item review by expert) are described in (Pearce, 2024) and an upcoming publication by another researcher involved in the project. The current project addresses steps 6 and 7 which involve data collection using the first draft of the tool and item analysis. This process will provide the necessary insights for developing the second draft of the test.

Research Questions

The current study will address the following research questions:

- Does each test in the assessment set generate a useful range of scores, without floor or ceiling effects, where appropriate?
- How do people with ID experience the novel cognitive test battery and its subtests?

2. METHODS

2.1. Epistemology

Ontology refers to a branch of philosophy concerned with existence and the fundamental nature of reality or being (Sol & Heng, 2022, p.82). It addresses the question of "whether or not there is a social reality that exists independently from human conceptions and interpretations" (Ormston et al., 2014, p.4). Epistemology, on the other hand, is the branch of philosophy that pertains to the nature of knowledge (Mallett et al., 2014). In simpler terms, it is the assumptions we make about the kind of knowledge (Richards, 2003) or how itis possible to find out about the world (Snape & Spencer, 2003). As emphasised by Cohen et al. (2007), the specific epistemological assumptions position we hold about the nature of knowledge (i.e. epistemological position) will influence how one goes about uncovering knowledge of social behaviour (i.e. one's methodological approach to research).

There is a wide range of epistemological positions, each aligned with specific ontological beliefs. The current study adopts a critical realist epistemological and ontological position.

Critical realism (CR) is a relatively new philosophical perspective that offers a methodological alternative to positivism and interpretivism (Lawani, 2020), and allows for the integration of realist ontology and epistemological relativism (Baboulene & Willig, 2023). Ontologically, critical realism assumes the existence of a real social world that can be objectively observed (Mukumbang, 2023). However, such observations are shaped by personal, social, historical, and cultural contexts (Mukumbang, 2023). Epistemologically, critical realism refutes the notion that there is such thing as final truth (Mukumbang, 2023). It is thus imperative that researchers are value-aware when carrying out research (Mukumbang, 2023). Method integration aligns with the idea that there is a

single reality and assumes that employing a variation of methods will generate a "family of answers that would foster the understanding of the complexities of reality" (Mukumbang, 2023, p.97).For critical realists, "the ultimate goal of research is not to identify generalisable laws (positive realism) or to identify the lived experience or beliefs of social actors (interpretivism); it is to develop deeper levels of explanation and understanding" (McEvoy & Richards 2006, p. 69).

The cognitive domains (e.g. EF) discussed in this research are assumed to exist in the brain anatomy. However, it is important that they are understood as being constructs shaped by specific social, cultural and political contexts. Adopting a critical realist approach permits the use of both qualitative and quantitative approaches to address the research questions and enhance our understanding of cognition in people with ID. Aligned with a critical realist approach, the researcher maintains the position that the findings of this study represent "interpretations of possibilities rather than certainties" (Willig, 2012, p.14).

2.2. Design

A cross-sectional research design in a mixed methods approach was used to assess the acceptability and feasibility of the test battery. Participant scores on the test battery produced quantitative data. Participant feedback on their experiences of the test was gathered using semi-structured interviews and generated qualitative data. The researcher's qualitative observations of participant behaviour (i.e. their verbal and non-verbal indications of interest and difficulty) throughout the testing sessions were also video recorded. An exploratory approach was adopted to data analysis to support further refinement of the test battery.

2.3. Participants

2.3.1. Participant Recruitment

Participant recruitment was carried out across two NHS Adult learning disability services and a local charity for adults with ID. Psychologists in each of the NHS services, and the community coordinator in the local charity, were responsible for identifying potential participants and discussing the research with them and their carers/guardians (where appropriate) using the recruitment materials (they were all trained about the inclusion/exclusion criteria of the study). These materials included the research poster (see Appendices A and B), participant and carer invitations letters (see Appendices C, D, E and F). With their written consent, contact details for potential participants were passed on to the researcher if they expressed an interest in participating. The researcher then made contact with potential participants and their carers/guardians (where appropriate), to discuss the research further. For those who expressed an interest in the research but were not contactable via telephone or email, the researcher arranged a time (via a member of staff embedded in the recruitment sites) to discuss the research with prospective participants in-person. A YouTube link was also sent (or shown) to participants and carers/guardians, if they wished, explaining the research. This allowed participants to provide informed consent before proceeding to the testing stage.

2.3.2. Inclusion and Exclusion Criteria

Inclusion Criteria:

- Aged between 18 and 55 years
- Diagnosis of an Intellectual Disability
- English as a primary language

Exclusion Criteria

- Suspected or diagnosed dementia
- Current experiences of severe and/or enduring mental illness (e.g., a current psychotic episode)
- Active neurological illness
- History of acquired brain injury

2.3.3. Sample Characteristics

As the current project is a feasibility study, a smaller sample size is preferred and a priori sample size calculation is not required (Bowen et al., 2009). The current study therefore aimed to recruit a sample of 5-to-8 participants with an ID diagnosis as it is typical for pilot studies using qualitative data to consist of a smaller sample.

A total of seven people participated in the research project. Participant ages ranged between 25 and 55 years (M=38.77, SD=11.26). Two males and five females participated. None of the participants reported any sight or hearing impairments. A summary of participant demographics is provided in Table 1.

Table 1

Participant Demographics

ID Number	Sex	Age	Ethnicity	Handedness	Years* of Education
P101	F	35	White British	Right	14
P102	F	25	Black African	Right	14
P103	F	29	Mixed White & Asian	Left	21
P104	M	31	White British	Right	18
P105	M	40	White British	Right	13
P106	F	55	White British	Right	18
P107	F	55	White British	Right	NK

Note. * Years of Education includes years of continuing education (e.g. attending college for life skills).

2.4. Ethical Considerations

2.4.1. Ethical Approval

2.4.1.1. *Recruitment in the charity organisation*: Ethical approval for the study to be carried out in third sector organisations was approved from the University of East London ethics committee (see Appendices G and H). An amendment request was made and approved to update the easy-read materials previously used in

the aforementioned research projects to improve accessibility of recruitment materials (see appendix I).

2.4.1.2*. Recruitment in the NHS:* The research obtained ethical approval from the Health Research Authority via the NHS Research Ethics Committee (NHS-REC; Appendix J), and the Ethics and Integrity Sub-Committee at the University of East London (EISC; see Appendix K). Local ethical approval was also obtained through the Research and Development Department of the participating NHS Trusts. A substantial amendment request was made to the ethics committee, to extend participation to people who have an ID of any aetiology and were aged between 18-55 years, which was subsequently approved (see Appendices L). The request also included adding the NHS Trust associated with the two participating services as a recruitment site and including the researcher as part of the research team. A non-substantial NHS amendment request was subsequently made to extend the data collection phase of the research and also update the easy read materials previously used in the aforementioned research projects to be consistent with the accessible easy read written communication style of the services involved (See Appendix M).

2.4.2. Informed Consent

It is well documented in the literature that people with ID may be at a heightened risk of coercion when deciding whether to participate in research (McDonald et al., 2009). This increased risk may stem from factors such as communication challenges, a tendency to acquiesce, inexperience with decision-making and social isolation (McDonald et al., 2009). To minimise the risk of coercion, participants were encouraged to consult a trusted family member or an advocate prior to agreeing to participate. All consenting participants were invited to bring a relative/carer or a friend with them to the meeting, if they wished. Where appropriate, consent was obtained from both participants (see Appendix N) and carers (see Appendix O); however, the latter was not a requirement for all. Easy read versions of the recruitment materials - the invitation sheet (see Appendices P and Q) and participant consent forms (see Appendix R) - were used when appropriate, to aid understanding of the research.

2.4.3. Confidentiality and Anonymity

Participants were each assigned a numerical code (e.g. P101, P102) to ensure anonymity of their data. Both quantitative and qualitative data were stored securely on the researchers UEL IT account, using the participant's assigned numerical code instead of their names. A separate password protected Microsoft Excel spreadsheet, linking participant names data to their numerical code, was stored separately on a secure cloud. Data on this spreadsheet was kept for three weeks after it was collected from each participant. This allowed the identification of participants in the event that requested to be withdrawn from the research within the timeframe indicated. After three weeks, this information was securely deleted. The research data was accessible only to researcher and the research supervisor.

All testing sessions were recorded using a video camera camcorder (.mp4 format), thus ensuring accurate scoring and interpretations of test accessibility when subsequently reviewed. All video recordings were uploaded on to the researcher's university secure cloud and erased after they were reviewed, and the semi-structured interview were transcribed.

Participant scores were inputted into an Excel and SPSS spreadsheet to be analysed. After the inputting of this data, the paper record forms were destroyed. Completed paper consent forms were stored in a locked file folder drawer stored at UEL, under the care of the principal investigator.

2.4.4. Protection of Participants

Undergoing neuropsychological testing may evoke stress in people, especially in those from stigmatised communities (Malik & Norman, 2023). Taking this into consideration, participants were carefully observed for any verbal and non-verbal signs of discomfort or distress during the testing phase. They were also informed at the start of the testing session that they could terminate the test at any time Careful consideration was given to ensure the testing environment was comfortable and safe for participants. All rooms were large to promote

accessibility, well-ventilated and adequately lit. They were also soundproofed to maintain confidentiality and checked for any hazards and obstructions.

Prior to taking part in the research and at the start of the testing session, participants were told that the test instrument did not have any diagnostic value. They were also reassured that it was not essential for them to complete all parts of the research in one sitting.

It was hoped that such information, would also prevent or lessen possible anxiety. The researcher also gave participant's positive feedback throughout the testing phases to manage possible anxiety and build rapport. To prevent possible fatigue and support engagement in the test, participants were offered regular breaks, snacks and water.

After participating in the research project, participants were fully debriefed verbally and provided a debrief letter (see Appendices S). Participants were invited to ask questions and discuss any issues the research may have raised.

2.5. Materials

The following materials were used:

- Research poster
- Invitation letter
- Consent forms (standard and easy read versions)
- Standard and easy read debrief form (see appendix T)
- Semi-structured interview schedule (see Appendix U)
- Pen
- Table and Chair
- Video camera
- Novel cognitive assessment battery (see description below)

2.5.1. Cognitive Test Battery

The cognitive test battery was designed by the project research supervisor. The battery comprised cognitive tests adapted from existing batteries and entirely novel tests. The tests that were adapted from existing batteries are known to adequately assess the relevant cognitive functions. However, changes were made to them to ensure they were appropriate for people with ID's. All of the subtests included in the battery, the cognitive functions they assess, what they entail, and relevant adaptations made to them are outlined in table 2. Information on where adapted tests originated from are also provided.

Table 2

Overview of Battery subtests, Cognitive Functions Assessed, Test Description, Original Sources and Modifications

Subtest Name	Cognitive Function	Test Description	Adapted From (example)	Changes Made
Smell Description	Sensory, olfactory	Participants are individually presented with five smell jars, each containing a cotton pad with a different odorant. Participants are then required to tell the examiner what they think each jar smells like.	The University of Pennsylvania Smell Identification Test (UPSIT) (Doty et al., 1995)	Scents of familiar substances are used.
Motor Function Part A Motor Function Part B	Motor, upper limb	Participants are asked to perform a series of simple motor tasks.	Edinburgh Motor Assessment Scales (EMAS, Bak et al., 2015)	Eight of the easiest items pulled out from original test set. Accessible instructions developed.
Orientation & Information	Attention - receptive	Participants are asked a number of questions which assesses orientation to time, place and person.	The MMSE 'Orientation' task', (Folstein, 1997)	Items adapted to be culturally unbound, suited to the context and simplified.
Sentence Repetition	Attention - receptive	Participants are read aloud 12 sentences one at a time. After each sentence is aloud participants are asked to immediately repeat the sentence exactly how it was said.	(Spreen & Strauss, 1998)	Sentences have been made simple and contain common single-syllable words.

Eight Detection	Attention - expressive	An audio recording is played to the examinee of a series of numbers being read aloud. Participants are required to tap the table when they hear the number 8.	Kaplan Baycrest Neurocognitive Assessment Auditory Signal Detection Test (KBNA, Leach et al., 2000)	Adapted test is of a shorter format and used a restricted range of numbers.
Circle Search	Attention - expressive	Participants are presented with a page of shapes (i.e. stars, circles, triangles, squares and smiley faces). They are given 90 seconds to cross out as many circles as they can.	KBNA (Leach et al., 2000)	The thickness of the shapes' outlines was increased to improve visibility. A familiar shape (i.e. circle) was used for the target. Fewer distractor shapes are used.
Verbal Reasoning	Executive - receptive	Participants are read aloud part of a sentence and asked to complete the sentence with a word that makes the sentence true.	WRIT style 'verbal analogies task (Glutting et al., 2000)	Easier items using accessible language.
Visual Reasoning	Executive - receptive	Participants are presented with a series of patterns. For each pattern they are asked to identify from a list which picture logically fits with the pattern.	Raven's style 'Matrix Reasoning' task (Raven, 1995)	Colour of item figures appropriate for people with colour blindness. Simpler items included.
Word Generation	Executive - expressive	In trial one participants are asked to recall as many animals as they can think of in one minute. In trial two participants are required to recall as many foods as possible in one minute.	Original format 'category fluency' tasks (Lezak et al., 2012)	Instructions made simpler and prompts are used to support performance.
Cat-Dog Inhibition	Executive - expressive	Participants are presented with pictures of cats and dogs. They are then asked to say 'cat' when shown a picture of a 'cat and 'dog' when shown	CEFA (Ball et al., 2008) 'Cats and Dogs' task	Format of test is shortened. More realistic pictures uniform colours are used.

		a picture of a' dog'. They are subsequently asked to say 'cat' when shown a picture of a dog, and 'dog' when shown a picture of a 'cat'		
Motor Programming	Executive - expressive	Participants to perform several complex motor movements: *Bimanual alteration*: participant required to perform over ten cycles of fist-clench to palm-open in bimanual alterations. *Luria Sequencing*: participant to perform over ten fist-chop-slap cycles. *Knock-Knock opposition*: Participants to perform contradictory behaviour under verbal control (i.e. if I knock once you knock twice and if I knock twice, you knock once.). *Knock Inhibition*: Participants asked to tap table twice when the examiner once and to inhibit a motor response when they hear the examiner tap twice.	(Golden & Freshwater, 2001)	Instructions made simpler and examiner required to model tasks in practice trials.
Verbal Comprehension Part A	Verbal - comprehension	Participants are asked to perform a series of simple motor tasks.	Boston Diagnostic Aphasia Examination (BDAE, Goodglass & Kaplan, 1972)	Test instructions made easier, fewer items included in the subtest, and prompts provided.
Verbal Comprehension Part B	Verbal - comprehension	A watch, pen, coin and bunch of keys are placed on a table in front of the participants. Participants required to follow several instructions using the various objects (e.g. 'point to the keys').	BDAE (Goodglass & Kaplan, 1972)	Test instructions made easier, less items included in the subtest, and prompts provided.

Verbal Expression	Verbal - expression	Quality of expressive speech is assessed by participant's responses to questions in the orientation to situation task and smell detection subtest.	BDAE (Goodglass & Kaplan, 1972)	Speech output is assessed by responses in previous subtests.
Picture Naming	Verbal - expression	Participants are presented several pictures and required to name what each picture shows.	BDAE (Goodglass & Kaplan, 1972)	A novel set of colour photographs of familiar things (e.g. body parts, animals etc.) are used.
Angle Judgement	Visual - perception	This test is presented in a flip-book style (10 items) whereby an array of five lines appears on the top page and two lines appear at the bottom. Participants are required to identify the two lines presented on the bottom page that match the angles of the two lines shown on the top page.	Judgment of Line Orientation (JLO, Benton, 1978)	Reference key simplified (i.e. 5 points) and fewer target lines.
Matchsticks Copy	Visual - construction	Participants are shown a design comprising of matchsticks and asked to copy with the model present.	Novel Task	Participants are no longer required to copy a model by drawing.
Praxis	Visual - action	Participants asked to carry out various actions (e.g., 'show me how you would brush your teeth?').	(Heilman & Rothi, 1993)	Tasks limited to pantomiming both tool use (i.e. transitive movement) and emblems which are arbitrarily coded non-verbal communications such as waving goodbye. Instructions made more accessible.
Word List Learning and Immediate Recall	Learning - verbal	Participants are read aloud the same list of words multiple times (four trials). After each trial	Rey Auditory Verbal Learning Test and formats adapted to be more	Frequently used, concrete single-syllable words are used. The test

		participants are asked to immediately recall the list of words in any order.	simpler (RAVLT, Lezak et al., 2012)	also includes fewer trials and trials include fewer words.
Word List Delayed Recall	Memory - verbal	After an interval, participants are asked to recall the list of words they were presented with earlier.	RAVLT (Lezak et al., 2012)	See above.
Word List Recognition	Memory - verbal	Directly after delayed recall trial, participants are read aloud a list of words from the word list presented earlier as well as new words. Participants are asked to say which words were on the list presented earlier by saying yes or no to each word read aloud.	RAVLT (Lezak et al., 2012)	See above.
Matchsticks Immediate and Delayed Recall	Learning and Memory - visual	Immediate Recall Trial: After the copy trial, the matchstick design is removed, and examinee is asked to create the design again from memory. Delayed Recall Trial: After an approximately 20-minute interval, participants are asked to make the design again from memory.	Rey Complex Figure test (Rey, 1964)	Participants are no longer required to copy a model by drawing.
Picture Recognition	Memory - visual	Participants are presented with two similar pictorial stimuli, one of which were presented in the picture naming test. Participants are asked which one they were presented with earlier.	(Wilson & Antablin, 1980)	See changes noted in picture naming task. Paired two option forced-choice responses, to items previously seen. Motor responses also allowed.

2.6. Procedure

Prior to obtaining consent, the researcher individually met face-to-face with all participants and their parents/carers and guardians (where suitable) and read through the relevant information sheet and consent form with them. This offered the opportunity for any questions relating to the research to be asked. Participants who had capacity and agreed to take part were asked to sign a standard or easy read version of the consent form and were told that they could withdraw from the research at any time point. Participants were also informed that withdrawal from the research would not affect the care they received from the organisation at which they were recruited from. Where applicable, parents, carers or guardians provided signed an assent form.

Using guidelines from the Mental Capacity Act 2005 Code of Practice (DoH, 2005), a participant's capacity to consent was assessed. This included a participant's capacity to understand, weigh up, retain and communicate a decision. If a participant was thought to not have capacity, the testing session was terminated, and they received a £10 shopping gift voucher.

After obtaining informed consent, the video recording was started. Before the testing session began, the examiner asked the participant several questions regarding their demographics. Administration of the test battery was then commenced. Administration of the test took place in large a private room at the site at which the participant was recruited. Where applicable, parents, guardians or carers were also present in the room during the testing session and were asked to sit behind the examinee to avoid distractibility.

After completion of the test, participants took part in a brief interview (semi-structured) to provide feedback on their experience of the test battery. After the interview, the examiner thanked participants for their participation in the research project and read through the debrief form. Both participants and parents, carers or guardians (where appropriate) were offered another opportunity for any questions. They were then given a £10 gift voucher as a thank you.

2.7. Data Analysis

2.7.1. Feasibility

Participant test scores were coded and sorted in Microsoft Excel and analysed using IBM Statistics for Windows (version 29). Descriptive statistics were computed to evaluate participant performance for each subtest in the battery to identify the range of scores obtained and possible ceiling and/or floor effects. **NB**: These analyses are for information on the tests, rather than of the participants.

An item-level analysis was subsequently conducted to evaluate participant performance on, and the appropriate scaling of, the individual items included in each of the test battery subtests (Urbina, 2014).Traditional methods for calculating item difficulty, like the P-value in Classical Test Theory (CTT), typically apply to test items that allow binary scoring (i.e. items are either scored as correct or incorrect) (Crocker & Algina, 1986). Though such approach is commonly used to evaluate participant performance, it does not consider test items that give partial credit. Since several of the subtests in the test battery include items that give partial credit, and a range of scores (e.g., 0, 1 or 2) an alternative approach to calculating item difficulty was employed. The *item difficulty index* was calculated as the proportion of the maximum possible score that was obtained by participants.

2.7.2. Acceptability

Participant responses (verbal and non-verbal) to interview questions were recorded and transcribed verbatim. The transcripts were reviewed and utterances regarding the test, subtest or test items were transferred onto a Microsoft Excel sheet, alongside their anonymous numerical code identifier. Principles of manifest content analysis were used to analyse participant responses (Hsieh & Shannon, 2005). A coding schedule was developed and used to code responses, to yes/no questions and ascertain which subtest participants were referring too (See Appendix V). The schedule was developed using both inductive (by reviewing recordings and deductive methods (based on knowledge of the assessment tool components). Frequency of these occurrences was subsequently recorded. Responses to open-ended questions (e.g. what could we change about these tests to make them

better?) were recorded. Such responses were collated for tool refinement and therefore did not undergo further analysis.

Whilst reviewing the video recording of each participant, the researcher coded additional comments and non-verbal behaviours during the test administration, which indicated engagement, disinterest, or difficulty. See Appendix W for the coding schedule. The researcher's coding schedule was informed by the Mental State Examination guidelines, and guide developed by Boardman et al., (2014) on communicating with people with ID.

3. RESULTS

3.1. Test Performances Overall

Descriptive statistics were computed to evaluate participant performance on each subtest included in the test battery, these are provided in tables 3, 4 and 5 below. Missing data are indicated by the smaller sample size. One person did not wish to attempt the *Cat-Dog Inhibition Incongruent trial* subtest as they said it would be "too hard." Given the small sample size in this study, tests for skewness, kurtosis and other measures of normality were not conducted.

3.1.1 Ceiling Scores

Ceiling effects occur when a majority of participants attain the maximum possible score on a test, with a group mean close to the test maximum, and/or a range restricted to near the maximum score. Ceiling effects indicate that test is "too easy" for the sample and may not be discriminating between levels of ability on the function assessed.

Results showed that six people scored at the ceiling on *Eight Detection*, indicating a ceiling effect. Four people reached the ceiling on *Verbal Comprehension A, Motor Function A* and *Cat-Dog Congruent subtests,* which is also suggestive of a ceiling effect.

While no ceiling effect was observed the range of scores was narrow and close to the maximum on *Verbal expression, Picture Naming, Motor Function B, Praxis, Circle Search and Word List Recognition.* The range of scores was also narrow and close to the maximum for *Orientation Subtotal A*, *Orientation Subtotal B*, and *Matchsticks Copy*.

3.1.2 Floor Scores

Floor effects occur when most participants attain the minimum possible score (or a score of zero on a test), with a group mean close to the test minimum, and/or a range restricted to near the zero or minimum score. Floor effects indicate that test overall is too difficult for the sample.

To inspection, there was no floor effect for any of the subtests, though one participant obtained the minimum score for *Matchsticks Immediate,* and *Matchsticks Delayed Recall*. One person also obtained a minimum score for the *Word List Delayed Recall.* For *Sentence Repetition*, participants overall scored at the lower end (Median = 5, *IQR* = 4) of the range.

3.2. Item-Level Analyses

Item-level statistics were computed to evaluate participant performance on each item included in each subtest, these are provided in tables 6, 7, 8 and 9 below.

The item *total score* is the total score is the combined scores of all participants. An item *difficulty index* was computed for each item, representing how easy or difficult an item is. Difficulty indices were calculated by dividing the total score by the maximum possible score for each item. A score of zero indicates an item for which no participant gave a correct response; while a score of 1 indicates an item for which all participants gave a correct response. The item difficulty index therefore ranges between 0.0 and 1.0. The higher the difficulty score, the easier the item.

3.2.1. Item Difficulty

In the research literature in this area, the ideal item difficulty score should fall between 0.4 and 0.6 (Raykov & Marcoulides, 2011). Items with difficulty scores outside of this range may considered too easy (above 0.6) or too difficult (below 0.4). These criteria are reflected in the tables below, whereby items with a difficulty index between 0.4 and 0.6 are highlighted in yellow (i.e. moderate difficulty), those above this threshold in green and those below red. Of course, in any given test there ought

to be items that are easy and hard for the typical sample, to capture responses at the lower and upper ends of functioning.

Table 3

Descriptive Statistics for the Tests of Verbal, Visual, Motor, and Olfactory Functions

Subtest	Number Attempt	Max Score	Range (min-max)	Mean	*(SD)*	Median *(IQR)*	Number at Floor	Number at Ceiling
Smell Description	7	5	1-4	2.71	1.11	3 *(2)*	0	0
Verbal Expression	7	20	17-20	18.57	0.98	19 *(1)*	0	1
Picture Naming	7	16	14-16	14.71	0.76	15 (1)	0	1
Verbal Comprehension A	7	5	2-5	4.14	1.21	5 *(2)*	0	4
Verbal Comprehension B	7	23	14-17	14.71	1.11	14 *(1)*	0	0
Verbal Comprehension Total	7	28	16-22	18.86	2.04	19 *(3)*	0	0
Motor Function A	7	5	2-5	4.14	1.22	5 *(2)*	0	4
Motor Function B	7	12	9-12	10.29	1.60	9 *(3)*	0	3
Motor Function Total	7	17	11-17	14.43	2.15	14 *(4)*	0	0
Praxis	7	30	25-29	28.00	1.41	28 *(1)*	0	0
Matchsticks Copy	7	24	14-24	20.00	4.12	20 *(7)*	0	3
Angle Judgment	7	20	7-20	14.43	5.32	14 *(11)*	0	1

Table 4

Descriptive Statistics for the Tests of Attention and Executive Function

Subtest	Number Completed	Maximum Score	Range (min-max)	Mean	*SD*	Median *(IQR)*	Number at Floor	Number at Ceiling
Orientation A	7	12	6-12	10.29	2.22	11 *(3)*	0	3
Orientation B	7	4	3-4	3.43	0.54	3 *(1)*	0	3
Orientation total	7	16	10-16	13.71	1.98	14 *(2)*	0	1
Sentence repetition	7	12	2-9	4.86	2.48	5 *(4)*	0	0
Eight detections	7	14	4-14	12.57	3.78	14 *(0)*	0	6
Circle search	7	26	24-26	25.29	0.76	25 *(1)*	0	3
Verbal reasoning	7	12	6-11	9.00	1.83	9 (3)	0	0
Visual reasoning	7	10	2-7	5.29	1.80	6 *(3)*	0	0
Word generation	7	N/A	22-44	32.86	8.01	32 *(15)*	0	N/A
Motor programming	7	12	2-11	6.71	2.93	7 *(04)*	0	0
Cat-dog naming score	7	32	14-32	29.14	6.69	32 *(01)*	0	4
Cat-dog naming time	7	N/A	18-36	26.29	6.50	25 *(12)*	N/A	N/A
Cat-dog inhibition score	6	32	18-32	26.50	5.75	28 *(11)*	0	1
Cat-dog inhibition time	6	N/A	25-56	38.50	11.04	37 *(18)*	N/A	N/A

Table 5

Descriptive Statistics for Tests of Learning and Memory

Subtest	Number Attempted	Maximum Score	Range (min-max)	Mean	*(SD)*	Median *(IQR)*	Number at Floor	Number at Ceiling
Word List immediate recall	7	36	9-30	20.00	6.93	21 *(11)*	0	0
Word List delayed recall	7	9	0-9	5.00	3.27	5 *(6)*	1	1
Word List recognition	7	18	13-18	16.43	1.90	17 *(3)*	0	3
Word List learning	7	9	1-4	2.86	1.35	3 *(3)*	0	0
Matchsticks immediate Recall	7	24	0-23	23.00	16.00	18 *(10)*	1	0
Matchsticks delayed Recall	7	24	0-23	13.29	8.45	17 *(3)*	1	0
Picture recognition	7	16	10-15	13.29	1.80	14 *(3)*	0	0

Item analyses suggested that all items included in the *Verbal Expression*, *Matchstick Copy*, *Praxis, Eight Detection* and *Motor function B* subtests were overall easy for participants to answer.

The *Verbal Comprehension A* subtest comprises five items. Except for item four, all items included in the subtest had an item difficulty index above 0.60. For item 4, participants were asked to follow the instruction, *"before you touch your ear, tap your shoulder".* This item was revealed to be of moderate difficulty. The *Verbal Comprehension B* subtest comprises three sections: *Pointing* (items 1-7), *Instructions* (items 8-12) and *Meanings* (items 13-18). Items 1 through 4 were shown to be easy for participants to answer, and item 5 moderately difficult. Items 6 ("*point to the cap"*) and 7 (*"point to the nib"*) proved very difficult, with no participant answering item 6 correctly. Items 11 (*"before you touch the coin turn over the keys"*) of the *Instructions* subsection was of moderate difficulty, whilst all other items proved to be easy for participants. All items in the *Meanings* section were answered correctly by all participants.

The *Smell Description* subtest comprises five items. Item 3 (coconut fragranced jar) proved too difficult for participants to describe. Answers given included "chewing gum", "bath stuff", "cinnamon", "Vaseline" and "Don't know". Only item 4 (*"before you touch your ear, tap your shoulder")* was revealed to be of moderate difficulty in the *Motor Function A* subtest was revealed to be of moderate difficulty. All other items had an item difficulty index above 0.60. All items in the *Angle Judgement* subtest, excluding item 5, had an item difficulty index above 0.6. Item 5 was revealed to be of moderate difficulty.

For the *Picture Naming* subtest, most items had an item difficulty index above 0.6. Only items 8 (foot) and 9 (moon) were of moderate difficulty. Most of the items included in the *Picture Recognition* task proved easy for participants. Only two items, item 5 (knee) and item 8 (snake) out of the total eighteen were of moderate difficulty. There was only one item in *Orientation subtest A* that was calculated to be of moderate difficulty (item 4). This item required participants to name their town or city when recalling their home address. All other items in the subtest were revealed to be easy for participants.

The Sentence Repetition subtest comprises twelve items. Analyses revealed that all items after item 6 in the *Sentence Repetition* subtest had an item difficulty index of less than 0.30, with no participant answering item 7, 9 or 12 correctly. Item 4 also proved difficult for participants. There was only one item of moderate difficulty (item 6), all other items (items one, 2,3,4 and 5) were easy for participants.

Four out of the twelve items included in the *Visual Reasoning* subtest proved too difficult for participants (items 5, 6, 8 and 10). Items 1, 3, 4 and 7 were found to be easy, whilst items 2 and 9 were of moderate difficulty.

Out of the ten items included in the *Verbal Reasoning* subtest, two items (5 and 10) proved too difficult for participants. Item 5 required participants to complete the sentence, '*a robin is a bird; a rabbit is a…*', and item ten, '*moon is to earth as the earth is to…*'. Only item 6 ('*I see with my eyes; I hear with my…*') was of moderate difficulty; all other items easy.

The *Motor Programming* subtest consists of four items. Item 1 (two hands opening) of this subtest was found to be more difficult than items 2 (hand sequencing) and 3 (knock-tap opposition). As expected, item 4 (i.e. knock-tap inhibition) was the most difficult for participants.

Six out of the total nine items (i.e. individual words for participants to remember) included in the *Word List Immediate Recall* subtest were found to be of moderate difficulty. Though participants were found to experience notable difficulty with recalling items 3 (ball) and 4 (tree). Comparable results were revealed for the *Word List Delayed Recall* subtest, though only one item was shown to be difficult to remember (item 6; road). All the items included in the *Word List Recognition* subtest, had an item difficult index above 0.6, except for item 4, which was revealed to be of moderate difficulty.

The *Matchstick Immediate Recall* task comprises twelve items (i.e. matchsticks for participants to arrange). The item difficulty index for all items ranged from 0.4-0.8.

For *Matchstick Delayed Recall* items 9, 10 and 12 proved difficult to remember, though no participants scored at the floor.

3.2.2. Within Item Scaling

If tests are scaled, and graded appropriately, it is anticipated that the earlier/lower items to be easier (with greater total scores and lower difficulty indices), items of moderate difficulty in the middle of the subtest, and harder items at the end. One aim of doing this is to provide subtests with *discontinue rules*; that is, guidance on when to stop test administration as it becomes too difficult for the examinee. This prevents the examinee from having to attempt items in tests that will be too difficult for them and avoid unnecessary stress and a negative experience of the test. It also provides for a more efficient tests strategy for the examiner who does not have to administer items that will not add to the interpretation of the examinee's function.

This is reflected in the tables below where items highlighted in green, indicate more accessible items, the middle items to be yellow, and the items at the latter end are highlighted in red. The arrangement of items in subtests was undertaken with estimated *a priori* expectation of difficulty, which are now subject to evaluation here. It is important to note that some subtests are not designed to be scalable (e.g. *Orientation*, and *Angle Judgement*).

As noted above, in any given test there ought to be items that are easy and hard for the typical sample, to capture responses at the lower and upper ends of functioning. It is also worth including easy items at the start of the test, to provide the examinee with an introduction to the test procedures, and some experience of success on the test before moving on to more discriminating items. This may also form the basis for Wechsler style 'start' and 'discontinue' rules, which permit the examiner to begin a test at the level appropriate for the examinee, and to stop a test at the point at which the items are too difficult.

Item 3 (i.e. coconut fragrance) of the *Smell Description* subtest was revealed to be more difficult than all other items in the subtest (i.e. items 1, 2, 4 and 5), and therefore ought to be presented later in the subtest. Items 4 (i.e. lemon fragrance)

and 5 (chocolate fragrance) were revealed to be easier than items 1 (mint fragrance) and 2 (coffee fragrance) could be moved around; however, with so few items, and no need of a discontinue rule, it is not necessary to rearrange these items in order.

Item 4 (i.e. *"before you touch your ear, tap your shoulder")* was revealed to be the least accessible item in the *Verbal Comprehension A* subtest, and therefore ought to be swapped with item 5 (i.e. *"Now look at the ceiling, then the wall, and then the floor")*, which is currently the last item in the subtest.

Item 11 (*"Before you touch the coin turn over the keys")* of the 'Verbal Comprehension B' subtest was more difficult than item 12 ("*You pick up the watch and then give me the pen"*), and all other items in this section. Item 11 could be moved to be the final item of this subtest.

Items 5 ("*a robin is a bird; a rabbit is a…*") and 10 ('*moon is to earth as the earth is to…)* were the most difficult items in the *Verbal Reasoning* subtest, suggesting these items need to be moved to later in the subtest; accordingly, items 7, 8, 9, 11 and 12 should be presented earlier on in the test.

The item difficulty scores of items 5 and 6 in the *Visual Reasoning* subtest suggests that they could be moved to the latter end of the test. Moreover, items 2 and 9 should be moved to the middle section of the subtest and item 8 nearer the start of the subtest.

Item difficulty scores of items 1 (two hands opening) and 2 (hand sequencing) in the *Motor Programming* subtest, suggest they need to be swapped with each other.

Table 6

Item level Scores and Difficulty Indices for the Tests of Verbal and Olfactory Functions

Item #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Smell Description																		
Total	3	4	1	5	5													
Difficulty	0.43	0.57	0.14	0.71	0.71													
Verbal Expression																		
Total	14	14	14	11	14	13	11	11	14	14								
Difficulty	1.00	1.00	1.00	0.79	1.00	0.93	0.79	0.79	1.00	1.00								
Verbal Comprehension A																		
Total	7	6	6	4	6													
Difficulty	1.00	0.86	0.86	0.57	0.86													
Picture Naming																		
Total	7	7	7	7	7	7	7	4	3	7	7	7	7	6	6	7		
Difficulty	1.00	1.00	1.00	1.00	1.00	1.00	1.00	0.57	0.43	1.00	1.00	1.00	1.00	0.86	0.86	1.00		
Verbal Comprehension B																		
Total	7	7	7	6	4	0	1	7	5	7	3	7	7	7	7	7	7	7

Difficulty	1.00	1.00	1.00	0.86	0.57	0.00	0.14	1.00	0.71	1.00	0.43	1.00	1.00	1.00	1.00	1.00	1.00	1.00

Note. Total = The combined scores of all participants. Difficulty = The proportion of the maximum possible score obtained by participants. Yellow = item difficulty index between 0.4 and 0.6; Green = $>$ 0.6; Red = $<$ 0.4

Table 7

Item level Scores and Difficulty Indices for the Tests of Visual and Motor functions

Item #	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Motor Function A																		
Total	7	6	6	4	6													
Difficulty	1.00	0.86	0.86	0.57	0.86													
Motor Function B																		
Total	18*	19	17	18														
Difficulty	1.00	0.90	0.81	0.86														
Matchsticks Copy																		
Total	14	11	13	12	13	11	14	11	11	10	11	9						
Difficulty	1.00	0.79	0.92	0.86	0.93	0.79	1/00	0.79	0.79	0.71	0.79	0.64						
Praxis																		
Total	14	14	14	11	12	13	14	6	14	14	14	14	14	14	14			
Difficulty	1.00	1.00	1.00	0.71	0.86	0.86	1.00	0.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00			
Angle Judgment																		
Total	11	9	11	11	8	9	10	10	12	10								
Difficulty	0.79	0.64	0.79	0.79	0.57	0.64	0.71	0.71	0.86	0.71								

Note. * Indicates data that does not include all participants due to some not attempting the item. Total = The combined scores of all participants. Difficulty = The proportion of the maximum possible score obtained by participants. Yellow = item difficulty index between 0.4 and 0.6; Green = $>$ 0.6; Red = $<$ 0.4

Table 8 *Item level Scores and Difficulty Indices for the Tests of Attention and Executive Function*

Item	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Orientation Subtotal A																		
Total	7	6	6	4	6	6	6	6	7	5	7	6						
Difficulty	1.00	0.86	0.86	0.57	0.86	0.86	0.86	0.86	1.00	0.71	1.00	0.86						
Orientation Subtotal B																		
Total	13	11																
Difficulty	0.93	0.79																
Sentence Repetition																		
Total	7	7	4	2	5	4	0	2	0	1	2	0						
Difficulty	1.00	1.00	0.57	0.29	0.71	0.57	0.00	0.29	0.00	0.14	0.29	0.00						
Eight Detection																		
Total	7	7	7	7	6	6	6	7	7	7	7	7	7					
Difficulty	1.00	1.00	1.00	1.00	0.86	0.86	0.86	1.00	1.00	1.00	1.00	1.00	1.00					
Verbal Reasoning																		
Total	7	5	7	7	2	4	6	7	5	1	7	5						
Difficulty	1.00	0.71	1.00	1.00	0.29	0.57	0.86	1.00	0.71	0.14	1.00	0.71						
Visual Reasoning																		
Total	7	5	7	7	2	4	6	7	5	1								
Difficulty	0.71	0.57	0.86	0.86	0.14	0.29	0.86	0.29	0.57	0.14								
Motor Programming																		
Total	10	12*	17	8														
Difficulty	0.48	0.67	0.81	0.38														

Note. * Indicates data that does not include all participants due to some not attempting the item. Total = The combined scores of all participants. Difficulty = The proportion of the maximum possible score obtained by participants. Yellow = item difficulty index between 0.4 and 0.6; Green = $>$ 0.6; Red = $<$ 0.4

Table 9 *Item level Scores and Difficulty Indices for the Tests of Learning and Memory*

Item	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Word List Immediate Recall																		
Total	20	13	8	11	17	12	22	13	24									
Difficulty	0.71	0.46	0.29	0.39	0.61	0.43	0.79	0.46	0.86									
Word List Delayed Recall																		
Total	4	5	3	4	4	1	6	4	4									
Difficulty	0.57	0.71	0.43	0.57	0.57	0.14	0.86	0.57	0.57									
Word List Recognition																		
Total	5	7	7	4	7	6	7	6	7	7	5	6	7	7	7	6	7	7
Difficulty	0.71	1.00	1.00	0.57	1.00	0.86	1.00	0.86	1.00	1.00	0.71	0.86	1.00	1.00	1.00	0.86	1.00	1.00
Matchstick Immediate Recall																		
Total	12	10	12	11	11	9	12	12	8	7	7	6						
Difficulty	0.86	0.71	0.86	0.79	0.79	0.64	0.86	0.57	0.50	0.50	0.50	0.43						
Matchstick Delayed Recall																		
Total	11	9	10	9	10	8	9	7	5	5	6	4						
Difficulty	0.79	0.64	0.71	0.64	0.71	0.57	0.64	0.50	0.36	0.36	0.43	0.29						
Picture Recognition																		
Total	6	7	6	7	4	7	7	4	5	5	6	5	6	5	7	6		
Difficulty	0.86	1.00	0.86	1.00	0.57	1.00	1.00	0.57	0.71	0.71	0.86	0.71	0.86	0.71	1.00	0.86		

Note. Total = The combined scores of all participants. Difficulty = The proportion of the maximum possible score obtained by participants. Yellow = item difficulty index between 0.4 and 0.6; Green = $>$ 0.6; Red = $<$ 0.4

3.3. Participant Feedback

After undertaking the tests, participants were asked specific questions about their experience of the tests overall, and of any particular subtests. A summary of their response is set out below.

Q1. Did you find any of the tests interesting?

Six participants responded "yes" to this question, whilst one participant answered, "a little bit". Subtests referred to as interesting included the *Matchsticks Memory* subtests (n=1) and the *Picture Naming* subtest (n=1). Three participants noted that they found "all" of the tests interesting, whilst one participant did not specify what aspect of the test, they found interesting.

Q2. Do you find any of the tests boring?

Five participants responded "no" to this question, with one person noting that they *"enjoyed"* all of the tests. Two participants reported that they found the overall test-set boring. One of these participants further stated that the test-set was too long and cited the *Picture Naming* subtest as being boring.

Q3. Did you find any of the tests too easy?

Five participants fed back that they did not experience any of the test as too easy, whilst one participant was unsure. One participant indicated that they found the *Matchsticks* and *Circle Search* subtests too easy.

Q4. Did you find any of the tests too hard?

Three participants reported that they did not experience any of the tests as too hard, whilst four noted that they did. Three participants indicated experiencing difficulty with recalling the words in the *Word List Memory* subtests. One participant noted that they experience difficulty with matching the lines in the *Angle Judgment* subtest. Another participant expressed that they found the *Cat-Dog inhibition* subtest too hard and attributed the difficulty to the task of being asked to perform against what they knew to be correct. No participant commented on how any of the tests could be improved.

3.4. Researcher Observations

As noted earlier, people with ID may be likely to acquiesce or be suggestible to what another person says, especially when engaging with individuals in positions of power (Clare & Gudjonsson, 1993). Such factors along with communications challenges (common in people with ID) may compromise the reliability and depth of the feedback provided by participants regarding the test battery. It was therefore important for the researcher to record qualitative observations of non-verbal and verbal indications of interest and difficulty throughout the testing sessions.

Overall, the test took 50-to-90 minutes to administer, depending on whether participant wished to take one or more breaks, and length of break time. It should be noted that for the final test-set, testing time will be much shorter, as the final test set will include only those tests that proved feasible and acceptable to participants, and efficient for the clinicians, from among the candidate subtests investigated in this study. Most participants attempted all the subtests included in the test, though as noted, one participant did not wish to try the *Cat-Dog Inhibition* test. One participant was not able to attempt item 2 included in the *Motor Programming* subtest and item 1 included in the *Motor Function B* subtest due to arthritis. Two participants also were observed to become noticeably fatigued halfway through in the assessment (i.e. notably during the *Visual Reasoning* subtest and in some of the subsequent subtests). One participant showed this by the way in which they sat in their seat (e.g. palm in chin, shoulders slouched). They were also observed to frequently sigh in response to items being presented. The other participant was observed to frequently yawn and sit in a slouched position.

All participants showed signs of positive engagement with the *Orientation* subtests. This was evidenced by participants good speech output, use of body language (e.g. engaged posture and good eye contact with the examiner). Most participants were also observed to smile throughout these subtests.

All participants appeared engaged with the *Smell Description* subtest. This was evident by verbal indications of enjoyment (e.g. “I like strong smells!”), good speech output and use of eye contact with the examiner as well as frequent smiling when

presented with a small jar. Two participants were observed to show non-verbal indications of confusion (i.e. frowns) when presented with the 'Coconut' fragranced smell jar.

All participants showed good level of engagement throughout the *Verbal Comprehension A* and *Motor Function A* subtests. This was evidenced by all participants showing an open stance towards the examiner and also an engaged posture. One participant was also observed to laugh throughout.

Participants also appeared to be engaged with the *Motor Function B* subtest. This was indicated by body language (engaged posture, open stance towards the examiner and smiles).

All participants showed some level of engagement with the items included in the *Motor Programming* subtest. This was evident by participants use of body language (e.g. engaged posture and open stance towards the examiner) and also verbal indications of enjoyment, such as "I am going fast". One participant appeared to particularly enjoy the *knock tap opposition* item, stating, "that is quite good, it's got a bit of a rhythm".

All participants showed good levels of engagement with *Praxis* subtest (as evidenced by smiles, body posture, eye contact with examiner and smiles). No signs of distress or difficulty were observed. Similar observations were also made in the *Circle Search* and *Word Generation* subtests.

Participants appeared to be mostly engaged with the *Angle Judgement* subtest (e.g. engaged posture and good speech output). One participant was observed to be confused by the instructions, as evidenced by hesitance with starting the task and also a confused facial expression. Therefore, the instructions for this subtest had to be simplified from "tell me which one of the numbers up here do these lines match" to "Which lines do these this match up here?"

All participants showed good levels of engagement with the *Word List Immediate Recall* subtest. This was evidence by participants' open posture, good speech

output, eye contact examiner. There were some indications of struggle with recalling the various items. For instance, one participant verbally communicated their difficulty, saying “Gosh, that’s a lot. Oh no, my head is gone… Nah see, my brains gone, I got short memory”. Another was hesitant to begin recalling the words list in the first trial. Participants showed good levels of engagement with the *Word List Delayed Memory* and *Word List Recognition* subtests, as evidenced by body language (e.g. engaged posture and open stance towards examiner).

Most participants were engaged with the *Visual Reasoning* subtest. This was indicated by engaged posture in relation to test materials (i.e. pictures) and objective signs of happiness (e.g. smiling).

Most participants were observed to smile when presented with the test materials in the *Cats and Dogs Naming* subtest were introduced (i.e. pictures of cats and dogs). They also showed good levels of engagement when completing the test, as evidenced by their open body posture. Three participants were observed to display signs of struggle with the *Cats and Dogs Inhibition* subtest. As noted, one participant expressed that they did not wish to take part in the test, saying, “Na, na my brain is getting confused. I know what you’re tryna say, I find it quite hard sometimes.” Another participant showed hesitation in starting the task and commented on its difficulty, stating, “it’s difficult for me to say Dog when it is a Cat”. The third participant proceeded to sit with their shoulder’s slumped whilst completing the test.

All participants showed good levels of engagement across all of the *Matchsticks’* subtests. This was mainly evidenced by non-verbal indications of engagement (e.g. open stance towards examiner and also engaged posture when engaging with test materials).

Participants appeared engaged (e.g. good speech output, open stance towards examiner and materials) throughout the *Picture Naming* and *Picture Recognition* subtests. These observations were also made for most participants in the ‘Eight Detection’ subtest.

All participants appeared engaged (e.g. engaged body language) with the *Sentence Repetition* subtest, despite providing incorrect answers to most items.

All participants showed good levels of engagement with the *Verbal Comprehension B* subtest, as indicated by their use of body language (e.g. engaged posture, and good use of eye contact and an open stance towards the examiner). Three out of the seven participants were also observed to be objectively happy (e.g. smiling), whilst the tone of one participant was observed to be jovial in nature.

All participants showed positive levels of engagement with the *Verbal Reasoning* subtest as evidenced by body language (e.g. smiles, good speech output and engaged posturing). One participant struggled with understanding the instructions, as indicated by hesitancy to answer the first item. However, they were able participate in the subtest when the instruction was simplified to 'What word fits at the end of this sentence?'.

4. DISCUSSION

4.1. Research objectives and questions

The current study aimed to evaluate the acceptability and feasibility of a set of tests that together provide an assessment of cognitive function for people with ID including subtests that are useful in contributing to the detection of dementia. This tool aims to assess all cognitive domains to facilitate differential diagnosis and be acceptable and feasible to people with ID. It also aims to be administrable with low cost to services in the NHS. To address the current studies aims the research questions were as follows:

- ***Feasibility***: Does each test in the assessment set generate a useful range of scores, without floor or ceiling effects, where appropriate?
- ***Acceptability***: How do people with ID experience the novel cognitive test battery and its subtests?

As noted, the current study forms part of a series of studies evaluating the utility of the test-battery, including studies exclusively with people with DS and those at lower levels of ability. The overarching aims of these studies are to inform the development of a second draft of the test battery.

4.2. Summary and Interpretation of Findings

The acceptability and feasibility of each subtest will be discussed in this section, along with suggestions for further development of the tool.

4.2.1. Acceptability and Feasibility of Verbal and Olfactory tests

Most participants performed highly on the verbal expression and verbal comprehension subtests. However, such outcome is to be expected in an unimpaired sample with ‘good’ verbal abilities (Lezak et al., 2012). Nevertheless, the

Verbal Comprehension A subtest may benefit from the addition of more challenging items, to capture a wide range of abilities. For the *Verbal Comprehension B* subtest each of the three sections: Pointing, Instructions and Meanings may also benefit from the addition of more challenging items (i.e. mid and higher-level difficulty), to capture a wide range of abilities. For example, item 6 *("point to the cap")* and item 7 *("point to the nib")* proved challenging for participants, so items at around this difficulty level may be sensitive to 'better' levels of verbal functioning. Participant engagement with both of these tests suggest that subtests are acceptable for use for people with mild ID. To shorten the administration time of the tool, the removal of one of the subtests is recommended, as they both assess comprehension abilities.

The *Smell Description* subtest was also found to generate a good range of responses and well-accepted among participants. Such test may therefore be a feasible and acceptable tool for testing olfactory functioning in people with ID. Care must be taken not to require very specific or accurate smell descriptions.

Most participants scored highly on the *Picture Naming* subtest suggesting that it may benefit from the addition of more challenging items, to capture a useful range of functioning abilities preferably, familiar but less frequently named. For example, animals such as 'skunk' or 'deer' included in BDAE (Clare & Gudjonsson, 1993) might be appropriate replacements. Such finding may explain why one participant experienced the test as boring. Overall, the test was well-received by participants, as indicated by feedback and the researcher's observations.

4.2.2. Acceptability and Feasibility of Visual and Motor Functioning Tests

Participants scored highly on the *Motor Function* subtests. Such findings are to be expected given participants in the study had unimpaired motor functioning abilities. As above, more challenging items are necessary in both of these tests to capture a wide range of functioning/abilities. It is important to note that the observed difficulty with items that required participants to carry out multiple motor movements (e.g. *"before you touch your ear, tap your shoulder")* was not due to participants inability to carry out the instructed motor movements, but rather due to struggles with comprehending the instruction, as evidenced by participants only following part of

the instruction. It thus needs to be clearly stated in the examiner's manual that participants can obtain a full mark even if they only follow part of the instructions. This will ensure an examinee's score accurately reflects their motor functioning abilities. To shorten the administration time of the tool, the removal of one of the subtests is recommended, as they both assess motor function abilities. As noted, one participant was unable to attempt item one of the items in the motor function subtests, due to rheumatoid arthritis. Careful consideration might need to be taken when administering these tests to those with physical health conditions affecting motor functioning. This may be particularly relevant to the DS population, where there is high prevalence of musculoskeletal issues (Foley et al., 2014). Overall, the tests appear to be well-accepted by people with mild ID.

It is worth noting that the range of participant scores were narrow and near to the maximum for the praxis subtest. It might therefore be useful to introduce more challenging items, to capture a wide range of functioning/abilities. As noted earlier, the tasks included were limited to pantomiming tool use and coded non-verbal communications. To make the subtest more challenging, it may be useful to include several serial act tasks for participants to complete (Heilman & Rothi, 1993). For instance, "show me how you would take a matchstick from a box and light a candle?". Overall, the test was found to be well-received by participants suggesting it may be acceptable for individuals with mild ID.

Participants performed well on the 'matchsticks' subtest, including placing the matchsticks in the correct position. It is important to acknowledge that this test requires participants to draw upon fine motor skills to manipulate the matchsticks and place them in their correct position and orientation. Greater difficulty might have been observed among those with WS and other ID aetiologies, whereby fine motor skills difficulties are common (Berencsi et al., 2016). As indicated by participant feedback and the researcher's observations this test appears to be engaging for participants.

The *Angle Judgment* subtest was found to generate a good range of scores and appears a feasible tool for visual-spatial abilities; it has the advantage of not drawing upon motor functions. The test was found also found to be well-accepted among

participants, though instructions might need to be further simplified to ensure wider accessibility.

4.2.3. Acceptability and Feasibility of Attention and Executive Functioning tests

Most participants to performed highly on the 'Orientation' subtests, as expected in people without suspected cognitive decline. These tests may however be more challenging for those with pre-existing severe or profound learning disabilities or language impairment (Hon et al., 1999). The tests were also found to be engaging for participants, indicating its acceptability for people with mild ID.

Although no ceiling or floor effect was observed for *Sentence Repetition*, descriptive statistics and item analyses suggest that most participants struggled with repeating the lengthier sentences. As the sample demonstrated good verbal expression abilities, difficulties might be attributable to limitations with short term memory (which are prevalent among those with ID of different aetiologies including down syndrome, Vicari et al., 2013). So, this subtest is measuring a different function, as hoped. As the test proved too challenging for participants, it might be suggested that this test is replaced with the widely used digit span forward subset, which assesses the same aspect of cognitive functioning (Hodges, 2018). It is important to note that although participants appeared to struggle with this task, the test was well-tolerated.

A ceiling effect was revealed for the *Eight Detection* subtest suggesting it may be useful to increase the test difficulty. This may be achieved by lengthening the test or increasing the inter stimulus interval. Based on the researcher's observations, it appears that this test was well received by participants, suggesting it is acceptable for use for individuals with ID.

Both the verbal and visual reasoning tests generated a useful range of scores. However, it suggests that the *Verbal Reasoning* subtest may benefit from the addition of more mid-level and high-level difficulty items, to capture a wide range of abilities. The *Visual Reasoning* subtest on the other hand, may benefit from the addition of more mid-level difficulty items. The instructions for the verbal reasoning test may need to be further simplified to ensure accessibility. Overall, both tests were

revealed to be acceptable for people with mild ID, as indicated by the researcher's observations.

The *Motor Programming* subtest generated a full range of scores suggesting that it captures a wide range of cognitive abilities providing it is administered only to examinees with good motor functions, as are measured in the previous are measured in the previous tasks. This test also appears to be well-tolerated by people with mild ID.

The *Cat-Dog Inhibition* subtest was found to generate a useful range of scores, with only one person scoring at the ceiling. Such findings are similar to and thus strengthen the findings of Willner et al. (2010) where only 25% of participants scored at the ceiling for this test. The findings strengthen the current findings in the literature suggesting that the test may be useful for the exploration of executive functioning symptoms and thus dementia (Bevins and Hurse, 2016). Although, the test was found to generate a range of scores, participants appeared to experience significant difficulty with test, as indicated by feedback and the researcher's observations. Given the knock-tap inhibition test was generally well received, and assesses the same aspect of EF, it may not be necessary to retain the *Cats and Dogs* subtest in the test-set. This will also support the shortening of the administration time.

The *Word Generation* subtest was also found to generate a useful range of scores, as found in the previous research of Bevins and Hurse (2016) and be well accepted by participants.

Participants performed highly on the *Circle Search* subtest, as evidenced by the narrow range of participants scores, near to the maximum, suggesting the test may be too easy for people with ID. This was further evidenced by participant feedback. Difficulty of the task may be increased by adding more distractor stimuli to the test to capture a wider range of cognitive abilities. Interestingly, tests of similar format have been found to be effective in discriminating those with dementia from those without, among the ID population (Krinsky-McHale et al., 2008). Overall, the test appeared to be engaging for participants, suggesting it might be acceptable for people with ID.

4.2.4 Acceptability and Feasibility of Learning and Memory tests

The *Word List* subtests generated full useful range of scores, suggesting that it captures a wide range of cognitive abilities and thus a feasible tool for assessing explicit memory. Though the test generated a useful range of scores, qualitative findings suggest that participants found the test difficult, as indicated by participant feedback and the researcher's observations. Participants performed generally well on the *Word List Recognition* subtest which suggests it may offer a means to assess learning/memory at lower levels of ability. The *Picture Recognition* subtest also generated a useful range of scores. The test was also well-accepted by participants suggesting that this test might be acceptable for use in the ID population. To support acceptability of the tool and also shorten the administration time, it might be advisable to remove the delayed recall subtest.

Participants performed well on *Matchsticks'* subtests, with a good variability in scores was observed for the 'delayed recall', thus capturing a wide range of abilities. As with the 'picture recognition' subtest, participants engaged well with this test.

4.2.5. Additional Findings: Within Item Scaling

Additional analyses were carried out to evaluate the appropriate scaling of items in several of the subtests. The current findings suggests that the *a priori* scaling (decided in advance) was overall appropriate, and only a few items among the subtests would be best re-ordered in a revised version. These include items in the *Smell Description*, *Verbal Comprehension* and *Motor Programming* subtests. However, for these short subtests, there will not be discontinue rules, so scaling is not imperative. Also, it may not be necessary for the *Picture Naming* subtest items to be scaled, as all of the items in this subtest are administered, in order to be included among the item pairs for the *Picture Recognition* subtest. For the verbal and visual reasoning subtests, additional items at the mid-and-higher difficulty levels ought to be included (see above), and these new and existing items can be re-scaled using data from the next test set iteration.

4.3. Clinical Implications

The results suggest that the test battery was acceptable to participants and generate a good range of scores, including those that assess executive and olfactory functioning. The tool has potential (with refinements) for being useful for the comprehensive and accessible assessment of cognition and suspected neurodegeneration in people with ID, across a wide range of abilities.

Although not formally recorded, the participants in the current study had mild levels of ID. Despite this, test performance was variable. Such variability in performance further demonstrates the heterogeneity of cognitive functioning among the ID population that is widely acknowledged in the literature. It is vital that neuropsychological assessment tools designed for use in the ID population are applicable to a wide range of cognitive functioning/abilities.

The qualitative findings of this study suggest that the tests included in the battery are generally well-received by all participants; and it appears to be sensitive to and considerate of the sensory, motor, communication, and attentional needs, of participants with mild ID. It may be suggested that the tests included in the subtest could be beneficial in clinical practice.

The current findings show that it is possible to create a feasible and acceptable (with necessary refinements) tool with readily and low-cost materials. Given then the current economic climate and the impact on NHS services (Emmerson et al., 2000), the availability of such a battery is becoming increasingly important.

4.4. Strengths and Limitations

Most cognitive assessment batteries carry significant limitations as they do not comprehensively assess all areas of cognitive functioning (including EF). This is particularly true for the NAID (Crayton et al.,1998) and the CAMCOG-DS (Ball et al., 2008). However, research has shown that changes in EF to be the earliest indicators dementia in people with ID (Ball et al., 2006, 2008), leading to calls for tests of EF to be included in cognitive assessment batteries (Rowe et al., 2006). It is therefore a

notable strength that the test battery in the current study includes a set of potentially feasible and acceptable EF tests that are co-normed with other tests included the battery.

There is a growing body of literature exploring olfactory dysfunction in dementia. Current evidence suggests that olfactory dysfunction may serve as an important biomarker of DAT (Nijjar & Murphy, 2002; Roberts et al., 2016; Wilson et al., 2007), both in individuals with ID and in the general population. To our knowledge, this is the first test battery that assesses for olfactory functioning. Moreover, the test uses widely available and low-cost common household materials thus low resource. Future researchers may consider exploring whether this low resource approach to assessing olfactory functioning may be as discriminative as validated tools such as the UPSIT (Doty et al., 1995).

A major strength of the study is that participants were recruited from both clinical and non-clinical settings thus enhancing the representativeness of the findings and applicability to the wider mild ID population.

Another strength of the study is the use of both qualitative and quantitative methodologies. Adopting such approach offered a comprehensive understanding of the acceptability and feasibility of the cognitive test battery. The studies use of semi-structured interviews is also a notable strength. This approach has enabled participant's voices to be heard and be instrumental in the development phase of the test battery. This is particularly important, as people with ID are often marginalised and not included in research studies of this kind.

Though the study has several strengths, it also carries several limitations. Although semi-structured interviews were employed, it is important to acknowledge that the feedback provided was limited. This may be due to a number of reasons such as possible communication barriers. However, it is also important to acknowledge that the questions included in the interview schedule were very brief.

As mentioned, the feedback provided by participants may have been subject to social-desirability effects, despite efforts made to foster a safe space for participants

to be honest and open about their experiences. In this research, the researcher had multiple roles that participants were aware of. This included administering the test, development of the test, and also collecting feedback. It could be postulated that multiple roles of the researcher may have widened the power imbalance between them and participants. As a result, participant's may have been more likely to provide positive feedback about the test-set.

As emphasised throughout the thesis, people with ID may be likely to acquiesce or be suggestible to what another person says, especially when engaging with individuals in positions of power (Clare & Gudjonsson, 1993). Although the study made efforts to minimise potential bias by recording observations of participant's verbal and non-verbal indications of engagement with the test, such data is also subject to observer bias. To reduce the potential impact of the researcher's multiple roles, future pilot studies may benefit by separating the roles of test-administrators and those responsible for collecting qualitative feedback.

It is also noteworthy that limited clinical information was collected about the research participants, such as their ID aetiology, and mental and physical health comorbidities. As noted in the thesis, behavioural and cognitive phenotype various across ID aetiology, and mental health and physical health co-morbidities may interact with performance and engagement with cognitive testing. Without knowledge of various clinical characteristics, it is difficult to comment on the representativeness of the data, which affects generalisability of the data. Collecting such information will also provide greater context for and a more nuanced interpretation of the current findings. For example, in the absence of information about underlying physical health issues (e.g., nasal polyps), it is difficult to determine whether test performance is indicative of potential cognitive decline or pre-existing olfactory dysfunction. Future researchers may wish to consider using formal mental health screening tools, reviewing medical records of consenting participants and routinely and asking participants about their current physical health status (e.g. nasal issues).

The research sample predominately consisted of White-British females, with mild ID. Consequently, the current findings are limited in terms of its generalisability to males and those of other ethnicities (and ID severity levels). It is also important to note that

small sample size was intended to facilitate the collection of both quantitative and qualitative data from participants.

4.5. Recommendations for Future Research

As noted, Fenn et al. (2020) identifies 15 key steps in the development and validation of a psychological test. Steps 1-to-5 are outlined in chapter 1.0. Step 6 involves data collection using the first draft of the tool, step 7 focuses on item analysis of the test and step 8 addresses the implementation of the recommended changes to support the development of a second draft. The current study, along with the aforementioned studies, reflect steps 6-to-8. Following the development of the second draft, it should undergo further piloting (step 9), and its validity and reliability assessed (step 10). The tool should then be subjected to exploratory factor analysis (step 11). Findings of the factor analysis should inform on a third draft (step 12), followed by a confirmatory factor analysis (step 13). This will enable the creation of the final test (step 14). Once the test has been proven to be psychometrically robust, with high reliability and validity, a manual can be made summarising the test making procedure as well as providing instructions for test administration (step 15).

Validity may be assessed by means of comparing the tool to an existing measure (i.e. concurrent validity) such as the CAMCOG-DS (Ball et al., 2008). One problem here is that the existing tests have their own limitations which the current battery is intended to overcome. It will also be important for the tools predictive value to be evaluated. This may be achieved by the longitudinal administration of the test to people with ID, both with and without suspected dementia. The tests' ability to effectively differentiate those that are later diagnosed with dementia as compared with those without (based on baseline scores) can thus be explored. Reliability of the tool may be assessed by evaluating the test-reset reliability to determine its temporal stability, as well as evaluating its internal consistency, ensuring items intended to measure the same construct are highly correlated with each other.

It is important to note that the research was originally planned to be conducted solely within NHS services. However, recruitment proved challenging in this context,

contributing to significant delays in completing the project. It appeared that many of the service user's accessing these services did not meet the inclusion criteria, primarily due their experiences of severe and enduring mental health difficulties. As a result, recruitment was extended to third-sector organisations. Future researchers may therefore benefit from completing subsequent pilot and validation studies in third sector organisations and possibly extending recruitment to educational establishments, such as community colleges.

As mentioned, those from racially minoritised backgrounds were under-represented in the current sample, which reflects a wider issue in health and social care research (Redwood & Gill, 2013). The reasons for reduced participation in clinical research are widely documented in the literature. These include researchers' poor engagement with communities from racially minoritised backgrounds, mistrust of research (stemming from a history of harm done by clinical researchers) and inaccessible recruitment materials. To support the recruitment of people from racially minoritised backgrounds in future piloting and validation studies, researchers should ensure all recruitment materials are accessible for carers, as well as participants. They should also prioritise building relationships with prospective participants of minoritised groups. One way in which this may be achieved is by increasing researcher presence in community organisations and being readily available to answer any questions about the research. It may also be achieved by building relationships with trusted advocates in the relevant organisation, to effectively engage with diverse groups.

As noted, males were under-represented in the current sample. Future researchers may therefore benefit from using more tailored recruitment strategies. For instance, partnering with specific organisations that work with these under-represented groups.

To support the comprehensiveness and depth of participant feedback regarding the acceptability of the test set, researchers should consider adding more questions to the interview schedule about the test-set materials (e.g. subtest pictures, matchsticks and also instructions) in subsequent piloting studies.

It is important to acknowledge that participants included in this study were in the upper range of functioning. To reduce potential effects for participants who are less able, it is recommended that subtests include very easy items at the start, and training and practice trials. These considerations may facilitate engagement and allow assessment at the lower range of functioning.

Another approach to addressing variability in ability levels is adaptive testing, where items (and their difficulty level) are adjusted based on the examinee's responses (Weiss & Betz., 1973). For example, if an examinee is unable to complete an item (i.e. receives a score of zero) then subsequent items that are of increasing difficulty are not administered. Instead, a separate set of easier items of the same difficulty are presented, which are sensitive to the lower range of abilities. The Wechsler Adult Intelligence Scale (Wechsler, 1997) adopts this approach in several subtests whereby examiners are instructed to administer three or four very easy items, if the first two standard items are not answered correctly. Such approach may be used for some of the subtests in the second draft of the test-set. For instance, if an examinee cannot do the practice items of Circle Search, they can be administered an alternative version with larger items and fewer distractors.

4.6. Personal Reflections

As the current research adopts a critical realist epistemological position, researcher reflexivity forms an important part of the work (Flanagan, 1981).

There were a number of professional and personal experiences that led to my interest in the research topic. During my time on the professional doctorate course, I completed a placement in an Adult Learning Disability service. In this placement, I worked in the dementia pathway, whereby neuropsychological assessments are administered to adults with an ID. It was during this time that I became aware of the challenges of administering such assessments (e.g. inaccessibility of test materials) and how this can delay service-users from receiving timely and appropriate support.

My interest was further sparked by my personal experiences of dementia in my family, and seeing first-hand how late-diagnosis can impact both the individual and

caregivers. Also, as a person from a racially minoritised background, I am acutely aware that neuropsychological assessment is based on Westernised norms and values and may be biased in people with diverse cultural experiences and values (Ardila, 2005). Such awareness also contributed to my motivations for developing inclusive and culturally sensitive assessment tools.

Throughout the duration of this project, I have been aware of how the research topic runs the risk of reinforcing discourses that frame individuals as 'impaired' or 'deficient', as based on their performance on cognitive tests. Such views can cause one to view cognition as fixed and static in nature. However, adopting a critical realist position, I acknowledge that the various cognitive domains discussed throughout this thesis can be understood as being social constructs. This awareness encouraged me to approach the data collected with a critical lens rather than interpreting it at face-value.

4.7. Critical Evaluation: Yardley's Criteria

Yardley (2000) offers four broad principles for assessing the quality of research that draws upon qualitative methodology (Smith, 2003). These include: 1) *sensitivity to context,* 2) *commitment and rigour,* 3) *transparency and coherence* and 4) *impact and importance.* The follow sections will evaluate the current research against these criteria. Since the impact and importance of the study have already been discussed elsewhere in thesis, this evaluation will focus on the first three criteria.

4.7.1. Sensitivity of Context

Yardley (2000) contends that a high-quality qualitative research study should demonstrate sensitivity to the context in which the study is situated. This involves the researcher's awareness of the research topic and method, as well as consideration of the socio-cultural context in which the study is situated and its influence on the outcome (Smith, 2003). The researcher's sensitivity to context is demonstrated by their extensive review of the research topic, as detailed in chapter 1.0. Moreover, their clinical experience in an adult learning disability service offered an increased

awareness of the issues surrounding cognitive assessment in people with ID. The social cultural context in which participant's provided feedback and completed the cognitive assessment was reflected upon and considered during the data collection phase and the analysis and interpretation of the research findings (e.g. acknowledgment of the evident power imbalance between the researcher and participant. To mitigate the potential influence, efforts were made to create a warm, safe and non-judgmental space encouraging comprehensive feedback.

4.7.2. Commitment and Rigour

Commitment can be demonstrated by the researcher's level of engagement with the topic. This may be evidenced by a thorough approach to data collection, showing expertise in the methodological approach used and carrying out comprehensive data analysis. (Smith, 2003). The researcher demonstrated their commitment by making great efforts to increase their knowledge and skill set in principles drawn upon for manifest content analysis. This was achieved through research supervision and the review of relevant academic papers.

Rigour describes a studies thoroughness in terms of appropriateness of the research sample and the completeness of the analysis taken (Smith, 2003). In this study, rigor was achieved by obtaining a sample size suitable for an acceptability and feasibility study. Moreover, the use of observational data to complement the data collected through the semi-structured interviews.

Reflexivity was facilitated throughout the research process by discussions during research supervision.

4.7.3. Transparency and Coherence

Transparency and coherence describes how clearly the various stages of the research process are outlined in the write up of the study (Smith, 2003). Coherence also refers to the extent to which a piece of research is aligned with the underlying philosophical assumptions of the approach (Smith, 2003). These principles are demonstrated in the current study through the detailed description of the methodological and analytical approaches used provided in chapters 2.0 and 3.0 as

well as the supplementary information provided in the appendix (e.g. research materials, coding schedules). Transparency is further evidenced by the inclusion of data extracts in the results section which serve as evidence for the researcher's interpretations. The researcher has also consistently adhered to the principles of critical realism throughout the research process.

4.8. Conclusion

The specificities of the progression of dementia in individuals with ID as well as the elevated risk of developing dementia in people with DS, emphasises the need for the accurate assessment and diagnosis of dementia for those with ID. Researchers in the UK have thus made considerable efforts to develop cognitive test batteries for the detection of dementia in people with ID. However, all of these cognitive test sets/batteries carry significant limitations. Most do not comprehensively and appropriately assess all areas of cognitive functioning, including EF, despite this area of functioning being compromised in the prodromal phase of AD, in those with DS. Moreover, none include olfactory tests, despite recent research suggesting their potential for being for being an accessible approach to identifying DAT in people with DS.

The current study therefore aimed to evaluate the acceptability and feasibility of a set of tests that together provide a diagnostic measure of dementia for people with ID. The results of the study revealed that many of the tests included in the test-set generated a good range of scores, without floor or ceiling effects, including those that assess executive and olfactory functioning. Moreover, the qualitative findings suggest that the test-set is generally well-received by all participants. Such findings demonstrate the tools acceptability and potential to be feasible, while highlighting the importance of the recommended revisions. Future research should be now concerned with making the recommended refinements to enhance the validity and reliability of the tool. Such a tool is crucial to the early detection of dementia in the ID population.

REFERENCES

Adams, R. D., & Victor, M. (1985). *Principles of Neurology*. McGraw Hill.

Akhtar, F., & Bokhari, S. R. A. (2023). *Down Syndrome*. StatPearls. http://www.ncbi.nlm.nih.gov/books/NBK526016/

Albert, M. L., & Mildworf, B. (1989). The concept of dementia. *Journal of Neurolinguistics*, *4*(3–4), 301–308. https://doi.org/10.1016/0911-6044(89)90022-5

Alladi, S., Mekala, S., Chadalawada, S. K., Jala, S., Mridula, R., & Kaul, S. (2011). Subtypes of Dementia: A study from a memory clinic in India. *Dementia and Geriatric Cognitive Disorders*, *32*(1), 32–38. https://doi.org/10.1159/000329862

Alzheimer's Disease International. (n.d.). *ADI - types of dementia*. Retrieved 30 September 2023, from https://www.alzint.org/about/dementia-facts-figures/types-of-dementia/

Alzheimer's Research UK. (n.d.). *The economic impact of dementia*. Dementia Statistics Hub. Retrieved 9 October 2023, from https://dementiastatistics.org/statistics/the-economic-impact-of-dementia/

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Baade, L., & Schoenberg, M. R., (2004). A proposed method to estimate premorbid intelligence utilizing group achievement measures from school records. *Archives of Clinical Neuropsychology*, *19*(2), 227–243. https://doi.org/10.1016/S0887-6177(03)00092-1

Baboulene, K., & Willig, C. (2023). Benefits of a dual focus methodology utilising IPA and FDA in understanding meaning-making around the experience of psychosis. *QMiP Bulletin*, *1*(35), 36–46. https://doi.org/10.53841/bpsqmip.2023.1.35.36

Bäckman, L., Small, B. J., & Fratiglioni, L. (2001). Stability of the preclinical episodic memory deficit in Alzheimer's disease. *Brain*, *124*(1), 96–102. https://doi.org/10.1093/brain/124.1.96

Baddeley, A. (1992). Working memory. *Science*, *255*(5044), 556–559. https://doi.org/10.1126/science.1736359

Bahia, V. S., Takada, L. T., & Deramecourt, V. (2013). Neuropathology of frontotemporal lobar degeneration: A review. *Dementia & Neuropsychologia*, *7*(1), 19–26. https://doi.org/10.1590/S1980-57642013DN70100004

Bak, T., Bennett, G., Symonds, A., Parra, M., Elamin, M., Connick, P., & Pal, S. (2015). Motor symptoms in healthy ageing and dementia: Frequency, patterns and the relation between motor and cognitive functions. *European Journal of Neurology*, *22*, 94–94.

Bali, J., Gheinani, A. H., Zurbriggen, S., & Rajendran, L. (2012). Role of genes linked to sporadic Alzheimer's disease risk in the production of β-amyloid peptides. *Proceedings of the National Academy of Sciences*, *109*(38), 15307–15311. https://doi.org/10.1073/pnas.1201632109

Ball, S. L., Holland, A. J., Hon, J., Huppert, F. A., Treppner, P., & Watson, P. C. (2006). Personality and behaviour changes mark the early stages of Alzheimer's disease in adults with Down's syndrome: Findings from a prospective population-based study. *International Journal of Geriatric Psychiatry*, *21*(7), 661–673. https://doi.org/10.1002/gps.1545

Ball, S. L., Holland, A. J., Treppner, P., Watson, P. C., & Huppert, F. A. (2008). Executive dysfunction and its association with personality and behaviour changes in the development of alzheimer's disease in adults with Down syndrome and mild to moderate learning disabilities. *British Journal of Clinical Psychology*, *47*(1), 1–29. https://doi.org/10.1348/014466507X230967

Bedford, H., De Louvois, J., Halket, S., Peckham, C., Hurley, R., & Harvey, D. (2001). Meningitis in infancy in England and Wales: Follow up at age 5 years. *BMJ*, *323*(7312), 533–533. https://doi.org/10.1136/bmj.323.7312.533

Benson, D. F., Davis, R. J., & Snyder, B. D. (1988). Posterior cortical atrophy. *Archives of Neurology*, *45*(7), 789–793. https://doi.org/10.1001/archneur.1988.00520310107024

Benton, A., Hannay, H. J., & Varney, N. R. (1975). Visual perception of line direction in patients with unilateral brain disease. *Neurology*, *25*(10), 907–907. https://doi.org/10.1212/WNL.25.10.907

Benton, A. L. (1978). Visuospatial judgment: A clinical test. *Archives of Neurology*, *35*(6), 364. https://doi.org/10.1001/archneur.1978.00500300038006

Berch, D. B., Krikorian, R., & Huha, E. M. (1998). The Corsi Block-Tapping task: Methodological and theoretical considerations. *Brain and Cognition*, *38*(3), 317–338. https://doi.org/10.1006/brcg.1998.1039

Berencsi, A., Gombos, F., & Kovács, I. (2016). Capacity to improve fine motor skills in Williams syndrome. *Journal of Intellectual Disability Research*, *60*(10), 956–968. https://doi.org/10.1111/jir.12317

Bevins, S., & Hurse, E. (2016). The assessment of executive functioning in people with intellectual disabilities: An exploratory analysis. *British Journal of Learning Disabilities*, *44*(2), 87–94. https://doi.org/10.1111/bld.12112

Bhaumik, S., & Alexander, R. (Eds.). (2020). *Oxford textbook of the psychiatry of intellectual disability*. Oxford University Press. https://doi.org/10.1093/med/9780198794585.001.0001

Birtwell, K., & Dubrow-Marshall, L. (2018). Psychological support for people with dementia: A preliminary study. *Counselling and Psychotherapy Research*, *18*(1), 79–88. https://doi.org/10.1002/capr.12154

Boardman, L., Bernal, J., & Hollins, S. (2014). Communicating with people with intellectual disabilities: A guide for general psychiatrists. *Advances in Psychiatric Treatment*, *20*(1), 27–36. https://doi.org/10.1192/apt.bp.110.008664

Boot, B. P., Orr, C. F., Ahlskog, J. E., Ferman, T. J., Roberts, R., Pankratz, V. S., Dickson, D. W., Parisi, J., Aakre, J. A., Geda, Y. E., Knopman, D. S., Petersen, R. C., & Boeve, B. F. (2013). Risk factors for dementia with Lewy bodies: A case-control study. *Neurology*, *81*(9), 833–840.

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., Bakken, S., Kaplan, C. P., Squiers, L., Fabrizio, C., & Fernandez, M. (2009). How we design feasibility studies. *American Journal of Preventive Medicine*, *36*(5), 452–457. https://doi.org/10.1016/j.amepre.2009.02.002

Braak, H., Alafuzoff, I., Arzberger, T., Kretzschmar, H., & Del Tredici, K. (2006). Staging of alzheimer disease-associated neurofibrillary pathology using paraffin sections and immunocytochemistry. *Acta Neuropathologica*, *112*(4), 389–404. https://doi.org/10.1007/s00401-006-0127-z

British Psychological Society. (2015). *Guidance on neuropsychological testing with individuals who have intellectual disabilities.*

https://www.bps.org.uk/guideline/guidance-neuropsychological-testing-individuals-who-have-intellectual-disabilities

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217–228.

Brunetti, R., Del Gatto, C., & Delogu, F. (2014). eCorsi: Implementation and testing of the Corsi block-tapping task for digital tablets. *Frontiers in Psychology*, *5,* 939. https://doi.org/10.3389/fpsyg.2014.00939

Budson, A. E., & Solomon, P. R. (2015). *Memory loss, Alzheimer's disease, and dementia: A practical guide for clinicians* (2nd ed.). Elsevier.

Carr, A. (Ed.). (2016). *The handbook of intellectual disability and clinical psychology practice* (2nd ed.). Routledge/Taylor & Francis Group.

Cato, M. A., & Crosson, B. A. (2006). Stable and slowly progressive dementias. In D. K. Attix & K. A. Welsh-Bohmer (Eds.), *Geriatric neuropsychology: Assessment and intervention* (pp. 89–102). Guilford Publications.

Charles, R. F., & Hillis, A. E. (2005). Posterior cortical atrophy: Clinical presentation and cognitive deficits compared to Alzheimer's disease. *Behavioural Neurology*, *16*(1), 15–23. https://doi.org/10.1155/2005/762569

Chen, G., Xu, T., Yan, Y., Zhou, Y., Jiang, Y., Melcher, K., & Xu, H. E. (2017). Amyloid beta: Structure, biology and structure-based therapeutic development. *Acta Pharmacologica Sinica*, *38*(9), 1205–1235. https://doi.org/10.1038/aps.2017.28

Clare, I. C. H., & Gudjonsson, G. H. (1993). Interrogative suggestibility, confabulation, and acquiescence in people with mild learning disabilities (mental handicap): Implications for reliability during police interrogations.

British Journal of Clinical Psychology, *32*(3), 295–301. https://doi.org/10.1111/j.2044-8260.1993.tb01059.x

Cluley, V. (2018). From “Learning disability to intellectual disability”-perceptions of the increasing use of the term “intellectual disability” in learning disability policy, research and practice. *British Journal of Learning Disabilities*, *46*(1), 24–32. https://doi.org/10.1111/bld.12209

Cooper, S. A. (1997). High prevalence of dementia among people with learning disabilities not attributable to Down’s syndrome. *Psychological Medicine*, *27*(3), 609–616. https://doi.org/10.1017/S0033291796004655

Cooper, S.A., & Holland, A. (2007). Dementia and mental ill-health in older people with intellectual disabilities. In N. Bouras & G. Holt (Eds.), *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities* (2nd ed., pp. 154-172). Cambridge University Press. *https://doi.org/10.1017/CBO9780511543616*

Coppus, A. M. W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews*, *18*(1), 6–16. https://doi.org/10.1002/ddrr.1123

Crayton, L., Oliver, C., Holland, A., Bradbury, J., & Hall, S. (1998). The neuropsychological assessment of age-related cognitive deficits in adults with Down’s syndrome. *Journal of Applied Research in Intellectual Disabilities*, *11*(3), 255–272. https://doi.org/10.1111/j.1468-3148.1998.tb00066.x

Cristofori, I., Cohen-Zimerman, S., & Grafman, J.H. (2019). Executive functions. In M. D'Esposito & J.H. Grafman (Eds.), *The frontal lobes* (pp.197-219*).* Academic Press. https://doi.org/10.1016/B978-0-12-804281-6.00011-2

Crocker, L., & Algina, J. (1986). *Introduction to classical and modern test theory*. Wandsworth Publishing Co Inc.

Crutch, S. J., Lehmann, M., Schott, J. M., Rabinovici, G. D., Rossor, M. N., & Fox, N. C. (2012). Posterior cortical atrophy. *The Lancet Neurology*, *11*(2), 170–178. https://doi.org/10.1016/S1474-4422(11)70289-7

De Renzi, E., & Vignolo, L. A. (1962). The Token Test: A sensitive test to detect receptive disturbances in aphasics. *Brain*, *85*(4), 665–678. https://doi.org/10.1093/brain/85.4.665

Deb, S., & Braganza, J. (1999). Comparison of rating scales for the diagnosis of dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research*, *43*(5), 400–407. https://doi.org/10.1046/j.1365-2788.1999.043005400.x

Deb, S., Hare, M., & Prior, L. (2007). Symptoms of dementia among adults with Down's syndrome: A qualitative study. *Journal of Intellectual Disability Research*, *51*(9), 726–739. https://doi.org/10.1111/j.1365-2788.2007.00956.x

Department of Health. (2005). *Mental Capacity Act.* London: HMSO.

Devanand, D. P., Lee, S., Luchsinger, J. A., Andrews, H., Goldberg, T., Huey, E. D., Schupf, N., Manly, J., Stern, Y., Kreisl, W. C., & Mayeux, R. (2020). Intact global cognitive and olfactory ability predicts lack of transition to dementia. *Alzheimer's & Dementia*, *16*(2), 326–334. https://doi.org/10.1016/j.jalz.2019.08.200

Diamond, A. (2013). Executive functions. *Annual Review of Psychology*, *64*(1), 135–168. https://doi.org/10.1146/annurev-psych-113011-143750

Diav-Citrin, O. (2011). Prenatal exposures associated with neurodevelopmental delay and disabilities. *Developmental Disabilities Research Reviews*, *17*(2), 71–84. https://doi.org/10.1002/ddrr.1102

Dening, T., & Thomas, A. (2013). *Oxford textbook of old age psychiatry* (3rd ed.). Oxford University Press.

Department of Health. (2001). Valuing people: A new strategy for learning disability for the 21st century. HMSO.

Dolan, E., Lane, J., & Hillis, G. (2019). Changing trends in life expectancy in intellectual disability over time. *Irish Medical Journal 112*(9), 1006. https://pubmed.ncbi.nlm.nih.gov/31651135/

Doty, R. L., McKeown, D. A., Lee, W. W., & Shaman, P. (1995). A study of the test-retest reliability of ten olfactory tests. *Chemical Senses*, *20*(6), 645–656. https://doi.org/10.1093/chemse/20.6.645

Dunn, L. M., Dunn, L., Whetton, C., & Burley, J. (1997). *The British Picture Vocabulary Scale II*. National Foundation for Educational Research.

Durkin, M. (2002). The epidemiology of developmental disabilities in low-income countries. *Mental Retardation and Developmental Disabilities Research Reviews*, *8*(3), 206–211. https://doi.org/10.1002/mrdd.10039

Dykens, E. M., & Kasari, C. (1997). Maladaptive behaviour in children With Prader-Willi syndrome, Down syndrome, and nonspecific mental retardation. *American Journal on Mental Retardation*, *102*(3), 228. https://doi.org/10.1352/0895-8017(1997)102<0228: MBICWP>2.0.CO;2

Dykens, E. M., Shah, B., Sagun, J., Beck, T., & King, B. H. (2002). Maladaptive behaviour in children and adolescents with Down's syndrome. *Journal of*

Intellectual Disability Research, *46*(6), 484–492. https://doi.org/10.1046/j.1365-2788.2002.00431.x

Ekstein, S., Glick, B., Weill, M., Kay, B., & Berger, I. (2011). Down syndrome and Attention-Deficit/Hyperactivity Disorder (ADHD). *Journal of Child Neurology*, *26*(10), 1290–1295. https://doi.org/10.1177/0883073811405201

Emerson, E., Glover, G., Hatton, C., & Wolstenholme, J. (2014). Trends in age-standardised mortality rates and life expectancy of people with learning disabilities in Sheffield over a 33-year period. *Tizard Learning Disability Review*, *19*(2), 90–95. https://doi.org/10.1108/TLDR-01-2014-0003

Emmerson, C., Frayne, C., & Goodman, A. (2000). *Pressures in UK healthcare: Challenges for the NHS.* Institute for Fiscal Studies. https://ifs.org.uk/publications/pressures-uk-healthcare-challenges-nhs

Emslie, H., Burden, V., Nimmo-Smith, I., Wilson, B. A., & Wilson, C. (2003). *Behavioural assessment of the dysexecutive syndrome for children*. Thames Valley Test Company.

Ennaceur, A. (2010). One-trial object recognition in rats and mice: Methodological and theoretical issues. *Behavioural Brain Research*, *215*(2), 244-254. https://doi.org/10.1016/j.bbr.2009.12.036

Eurlings, H. A. L., Evenhuis, H. A., & Kengen, M. F. F. (2006). *Dementia questionnaire for people with learning disabilities*. Pearson.

Evans, E., Bhardwaj, A., Brodaty, H., Sachdev, P., Draper, B., & Trollor, J. N. (2013). Dementia in people with intellectual disability: Insights and challenges in epidemiological research with an at-risk population. *International Review of*

Psychiatry, 25(6), 755-763. https://www.tandfonline.com/doi/abs/10.3109/09540261.2013.866938

Evans-Martin, F. F. (2009). *Down syndrome*. Chelsea House.

Evenhuis, H. M., Kengen, M. M. F., & Eurlings, H. A. L. (2007). *Dementia Questionnaire for People with Learning Disabilities: UK Adaptation of the Dutch Instrument Dementia Questionnaire for People with Intellectual Disabilities (DMR)*. Harcourt Assessment.

Fenn, J., Tan, C.-S., & George, S. (2020). Development, validation and translation of psychological tests. *BJPsych Advances*, *26*(5), 306–315. https://doi.org/10.1192/bja.2020.33

Flanagan, O. J. (1981). Psychology, progress, and the problem of reflexivity: A study in the epistemological foundations of psychology. *Journal of the History of the Behavioral Sciences*, *17*(3), 375–386. https://doi.org/10.1002/1520-6696(198107)17:3<375::AID-JHBS2300170308>3.0.CO;2-U

Foley, C., MacDermott, E., & Killeen, O. (2014). Musculoskeletal anomalies in a national cohort of children and adolescents with trisomy 21. *Pediatric Rheumatology*, *12*(Suppl 1), 160. https://doi.org/10.1186/1546-0096-12-S1-P160

Foley, K.-R., Bourke, J., Einfeld, S. L., Tonge, B. J., Jacoby, P., & Leonard, H. (2015). Patterns of depressive symptoms and social relating behaviours differ over time from other behavioral domains for young people with Down syndrome. *Medicine*, *94*(19), e710. https://doi.org/10.1097/MD.0000000000000710

Folstein, M. F. (1997). Differential diagnosis of dementia. *Psychiatric Clinics of North America*, *20*(1), 45–57. https://doi.org/10.1016/S0193-953X(05)70392-0

Fryers, T. (2008). Epidemiological issues in mental retardation. *Journal of Intellectual Disability Research*, *31*(4), 365–384. https://doi.org/10.1111/j.1365-2788.1987.tb01382.x

Galasso, C., Lo-Castro, A., El-Malhany, N., & Curatolo, P. (2010). 'Idiopathic' mental retardation and new chromosomal abnormalities. *Italian Journal of Pediatrics*, *36*(1), 17. https://doi.org/10.1186/1824-7288-36-17

Gallagher, A., & Hallahan, B. (2012). Fragile X-associated disorders: A clinical overview. *Journal of Neurology*, *259*(3), 401–413. https://doi.org/10.1007/s00415-011-6161-3

Gallagher, M., & Koh, M. T. (2011). Episodic memory on the path to Alzheimer's disease. *Current Opinion in Neurobiology*, *21*(6), 929–934. https://doi.org/10.1016/j.conb.2011.10.021

Gatz, M., Reynolds, C. A., Fratiglioni, L., Johansson, B., Mortimer, J. A., Berg, S., Fiske, A., & Pedersen, N. L. (2006). Role of genes and environments for explaining Alzheimer disease. *Archives of General Psychiatry*, *63*(2), 168. https://doi.org/10.1001/archpsyc.63.2.168

Glutting, J., Adams, W., & Sheslow, D. (2000). *Wide Range Intelligence Test (WRIT)*. Psychological Assessment Resources,Inc.

Golden, C. J., & Freshwater, S. M. (2001). Luria-Nebraska Neuropsychological Battery. In W. I. Dorfman & M. Hersen (Eds.), *Understanding Psychological Assessment* (pp. 59–75). Springer. https://doi.org/10.1007/978-1-4615-1185-4_4

Gomperts, S. N. (2016). Lewy body dementias: Dementia with Lewy bodies and Parkinson disease dementia. *CONTINUUM: Lifelong Learning in Neurology*, *22*(2, Dementia), 435–463. https://doi.org/10.1212/CON.0000000000000309

Goodglass, H., & Kaplan, E. (1972). *The assessment of aphasia and related disorders*. Lea & Febiger.

Goodglass, H., & Kaplan, E. (1983). *The Bostton Diagnostic Aphasia Examination.* Lea & Fibiger.

Grant, D. A., & Berg, E. (1948). A behavioral analysis of degree of reinforcement and ease of shifting to new responses in a Weigl-type card-sorting problem. *Journal of Experimental Psychology*, *38*(4), 404–411. https://doi.org/10.1037/h0059831

Gross, C., Yao, X., Pong, D. L., Jeromin, A., & Bassell, G. J. (2011). Fragile X mental retardation protein regulates protein expression and mRNA translation of the potassium channel Kv4.2. *The Journal of Neuroscience*, *31*(15), 5693–5698. https://doi.org/10.1523/JNEUROSCI.6661-10.2011

Guk-Hee Suh. (2013). Adoption of two standard deviation notions of mental retardation for the diagnosis of dementia. *East Asian Archives of Psychiatry*, *23*(3), 78–79. https://pubmed.ncbi.nlm.nih.gov/24088399/

Hagerman, R. J., Jackson, C., Amiri, K., O'Connor, R., Sobesky, W., & Silverman, A. C. (1992). Girls with Fragile X syndrome: Physical and neurocognitive status and outcome. *Pediatrics*, *89*(3), 395–400. https://doi.org/10.1542/peds.89.3.395

Harvey, P. D. (2012). Clinical applications of neuropsychological assessment. *Dialogues in Clinical Neuroscience*, *14*(1), 91–99. https://doi.org/10.31887/DCNS.2012.14.1/pharvey

Hatton, D. D., Sideris, J., Skinner, M., Mankowski, J., Bailey, D. B., Roberts, J., & Mirrett, P. (2006). Autistic behavior in children with fragile X syndrome:

Prevalence, stability, and the impact of FMRP. *American Journal of Medical Genetics Part A*, *140A*(17), 1804–1813. https://doi.org/10.1002/ajmg.a.31286

Heilman, K. M., & Rothi, L. J. G. (1993). Apraxia. In K. M. Heilman & E. Valenstein (Eds.), *Clinical neuropsychology* (3rd ed., pp. 141–163). Oxford University Press.

Hessl, D., Nguyen, D. V., Green, C., Chavez, A., Tassone, F., Hagerman, R. J., Senturk, D., Schneider, A., Lightbody, A., Reiss, A. L., & Hall, S. (2009). A solution to limitations of cognitive testing in children with intellectual disabilities: The case of fragile X syndrome. *Journal of Neurodevelopmental Disorders*, *1*(1), 33–45. https://doi.org/10.1007/s11689-008-9001-8

Hodges, J. R. (2018). *Cognitive assessment for clinicians* (Third edition). Oxford University Press.

Hoffmann, A. (2022). Communication in fragile X syndrome: Patterns and implications for assessment and intervention. *Frontiers in Psychology*, *13*, 929379. https://doi.org/10.3389/fpsyg.2022.929379

Holland, A. J., Hon, J., Huppert, F. A., Stevens, F., & Watson, P. (1998). Population-based study of the prevalence and presentation of dementia in adults with Down's syndrome. *British Journal of Psychiatry*, *172*(6), 493–498. https://doi.org/10.1192/bjp.172.6.493

Hom, C. L., Walsh, D., Fernandez, G., Tournay, A., Touchette, P., & Lott, I. T. (2021). Cognitive assessment using the Rapid Assessment for Developmental Disabilities, Second Edition (RADD-2). *Journal of Intellectual Disability Research*, *65*(9), 831–848. https://doi.org/10.1111/jir.12863

Hon, J., Huppert, F. A., Holland, A. J., & Watson, P. (1999). Neuropsychological assessment of older adults with Down's Syndrome: An epidemiological study

using the Cambridge Cognitive Examination (CAMCOG). *British Journal of Clinical Psychology*, *38*(2), 155–165. https://doi.org/10.1348/014466599162719

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Huddleston, L. B., Visootsak, J., & Sherman, S. L. (2014). Cognitive aspects of Fragile X syndrome. *WIREs Cognitive Science*, *5*(4), 501–508. https://doi.org/10.1002/wcs.1296

Huppert, F. A., Brayne, C., Gill, C., Paykel, E. S., & Beardsall, L. (1995). CAMCOG—a concise neuropsychological test to assist dementia diagnosis: Socio-demographic determinants in an elderly population sample. *British Journal of Clinical Psychology*, *34*(4), 529–541. https://doi.org/10.1111/j.2044-8260.1995.tb01487.x

Ivanovic, D. M., Leiva, B. P., Pérez, H. T., Olivares, M. G., Díaz, N. S., Urrutia, M. S. C., Almagià, A. F., Toro, T. D., Miller, P. T., Bosch, E. O., & Larraín, C. G. (2004). Head size and intelligence, learning, nutritional status and brain development. *Neuropsychologia*, *42*(8), 1118–1131. https://doi.org/10.1016/j.neuropsychologia.2003.11.022

Jackson, J. F., Iii, E. R. N., & Thomas, J. G. (1976). Clinical diagnosis of Down's syndrome. *Clinical Genetics*, *9*(5), 483–487. https://doi.org/10.1111/j.1399-0004.1976.tb01601.x

Jafri, S. K., & Harman, K. E. (2020). Neurocognitive abilities in individuals with down syndrome-a narrative review. *The Turkish Journal of Pediatrics*, *62*(6), 897. https://doi.org/10.24953/turkjped.2020.06.001

Jarrold, C., Baddeley, A. D., & Phillips, C. E. (2002). Verbal short-term memory in Down syndrome: A problem of memory, audition, or speech? *Journal of Speech, Language, and Hearing Research*, *45*(3), 531–544. https://doi.org/10.1044/1092-4388(2002/042)

Kaplan, E., Goodglass, H., & Weintraub, S. (1983). *The Boston Naming Test.* Lea & Fibiger.

Kapur, N., & Kemp, S. (2016). Neuropsychological assessment: Principles, pearls and perils. *The Neuropsychologist*, *2*, 7–15. https://doi.org/10.53841/bpsneur.2016.1.2.7

Karantzoulis, S., & Galvin, J. E. (2011). Distinguishing Alzheimer's disease from other major forms of dementia. *Expert Review of Neurotherapeutics*, *11*(11), 1579–1591. https://doi.org/10.1586/ern.11.155

Kaufman, A. S., & Kaufman, N. L. (1990). *Kaufman Brief Intelligence Test manual (K-BIT) circle pines*. American Guidance Service.

Kay, D. W. K., Tyrer, S. P., Margallo-Lana, M. L., Moore, P. B., Fletcher, R., Berney, T. P., & Vithayathil, E. (2003). Preliminary evaluation of a scale to assess cognitive function in adults with Down's syndrome: The Prudhoe Cognitive Function Test. *Journal of Intellectual Disability Research*, *47*(3), 155–168. https://doi.org/10.1046/j.1365-2788.2003.00451.x

Kessels, R. P. C., & Hendriks, M. P. H. (2023). Neuropsychological assessment. In H. S. Friedman & C. H. Markey (Eds.), *Encyclopedia of Mental Health* (3rd ed., pp. 622–628). Academic Press. https://doi.org/10.1016/B978-0-323-91497-0.00017-5

Kipps, C. M., & Hodges, J. (2005). Cognitive assessment for clinicians. *Journal of Neurology, Neurosurgery & Psychiatry*, *76*(suppl_1), i22–i30. https://doi.org/10.1136/jnnp.2004.059758

Kittler, P., Krinsky-McHale, S. J., & Devenny, D. A. (2006). Verbal intrusions precede memory decline in adults with Down syndrome. *Journal of Intellectual Disability Research*, *50*(1), 1–10. https://doi.org/10.1111/j.1365-2788.2005.00715.x

Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Open University Press.

Krinsky-McHale, S. J., Devenny, D. A., Kittler, P., & Silverman, W. (2008). Selective attention deficits associated with mild cognitive impairment and early-stage Alzheimer's disease in adults with Down syndrome. *American Journal on Mental Retardation*, *113*(5), 369–386. https://doi.org/10.1352/2008.113:369-386

Kyung-won, P., Byoung-Lip, H., Jae-Kwan, C., Sang-Ho, K., Do-Young, K., & Jae-Woo, K. (2003). Strategic infarct dementia: Clinical features, neuroimaging and neuropsychological findings. *Journal of the Korean Neurological Association*, 239–247.

Lai, F., & Williams, R. S. (1989). A prospective study of Alzheimer disease in Down syndrome. *Archives of Neurology*, *46*(8), 849–853. https://doi.org/10.1001/archneur.1989.00520440031017

Lanfranchi, S., Cornoldi, C., & Vianello, R. (2004). Verbal and visuospatial working memory deficits in children with Down syndrome. *American Journal on Mental Retardation*, *109*(6), 456. https://doi.org/10.1352/0895-8017(2004)109<456:VAVWMD>2.0.CO;2

Lanfranchi, S., Jerman, O., Dal Pont, E., Alberti, A., & Vianello, R. (2010). Executive function in adolescents with Down syndrome. *Journal of Intellectual Disability Research*, *54*(4), 308–319. https://doi.org/10.1111/j.1365-2788.2010.01262.x

Lautarescu, B. A., Holland, A. J., & Zaman, S. H. (2017). The early presentation of dementia in people with Down syndrome: A systematic review of longitudinal studies. *Neuropsychology Review*, *27*(1), 31–45. https://doi.org/10.1007/s11065-017-9341-9

Lawani, A. (2020). Critical realism: What you should know and how to apply it. *Qualitative Research Journal*, *21*(3). https://doi.org/10.1108/qrj-08-2020-0101

Leach, L., Kaplan, E., Rewilak, D., Richards, B., & Proulx, G. B. (2000). *Kaplan Baycrest Neurocognitive Assessment (KBNA)* [Database record] APA PsycTests. https://doi.org/10.1037/t15108-000

Leonard, H., De Klerk, N., Bourke, J., & Bower, C. (2006). Maternal health in pregnancy and intellectual disability in the offspring: A population-based study. *Annals of Epidemiology*, *16*(6), 448–454. https://doi.org/10.1016/j.annepidem.2005.05.002

Letourneau, A., & Antonarakis, S. E. (2012). Genomic determinants in the phenotypic variability of Down syndrome. *Progress in Brain Research, 197,* 15–28. https://doi.org/10.1016/B978-0-444-54299-1.00002-9

Leverenz, J. B., & Raskind, M. A. (1998). Early amyloid deposition in the medial temporal lobe of young Down syndrome patients: A regional quantitative analysis. *Experimental Neurology*, *150*(2), 296–304. https://doi.org/10.1006/exnr.1997.6777

Levy, J. A., & Chelune, G. J. (2007). Cognitive-Behavioral profiles of neurodegenerative dementias: Beyond Alzheimer's disease. *Journal of*

Geriatric Psychiatry and Neurology, *20*(4), 227–238. https://doi.org/10.1177/0891988707308806

Lezak, M. D., Howieson, D. B., Bigler, E. D., & Tranel, D. (2012). *Neuropsychological assessment* (Fifth ed.). Oxford University Press.

Li, Y., Li, Y., Li, X., Zhang, S., Zhao, J., Zhu, X., & Tian, G. (2017). Head injury as a risk factor for dementia and Alzheimer's disease: A systematic review and meta-analysis of 32 observational studies. *PLOS ONE*, *12*(1), e0169650. https://doi.org/10.1371/journal.pone.0169650

Lippa, C. F., Duda, J. E., Grossman, M., Hurtig, H. I., Aarsland, D., Boeve, B. F., Brooks, D. J., Dickson, D. W., Dubois, B., Emre, M., Fahn, S., Farmer, J. M., Galasko, D., Galvin, J. E., Goetz, C. G., Growdon, J. H., Gwinn-Hardy, K. A., Hardy, J., Heutink, P., …DLB/PDD Working Group. (2007). DLB and PDD boundary issues: Diagnosis, treatment, molecular pathology, and biomarkers. *Neurology*, *68*(11), 812–819. https://doi.org/10.1212/01.wnl.0000256715.13907.d3

Lobo, A., Launer, L., Fratiglioni, L., Andersen, K., Di Carlo, A., Breteler, M., Copeland, J., Dartigues, Jagger, C., Martinez-Lage, J., Soininen, H., & Hofman, A. (2000). Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts. Neurologic Diseases in the Elderly Research Group. *Neurology*, *55*(11), 4–9.

Lyman, K. A. (1989). Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist*, *29*(5), 597–605. https://doi.org/10.1093/geront/29.5.597

Malik, H. B., & Norman, J. B. (2023). Best practices and methodological strategies for addressing generalizability in neuropsychological assessment. *Journal of*

Pediatric Neuropsychology, *9*(2), 47–63. https://doi.org/10.1007/s40817-023-00145-5

Mallet, C., Rynne, S., & Tinning, R., (2014). *Philosophy of Knowledge.* In L. Nelson, R. Groom & P. Potrac (Eds.), *Research methods in sports coaching* (pp. 9-17). *Routledge. https://doi.org/10.4324/9780203797549*

Mandal, P., Joshi, J., & Saharan, S. (2012). Visuospatial perception: An emerging biomarker for Alzheimer's disease. *Journal of Alzheimer's Disease : JAD*, *31*, S117-35. https://doi.org/10.3233/JAD-2012-120901

Margallo-Lana, M. L., Moore, P. B., Tyrer, S. P., Dawson, H., Jenkins, K., & Kay, D. W. K. (2003). The Prudhoe Cognitive Function Test, a scale to assess cognitive function in adults with Down's syndrome: Inter-rater and test–retest reliability. *Journal of Intellectual Disability Research*, *47*(6), 488–492. https://doi.org/10.1046/j.1365-2788.2003.00450.x

Martin, G. E., Klusek, J., Estigarribia, B., & Roberts, J. E. (2009). Language characteristics of individuals with Down syndrome. *Topics in Language Disorders*, *29*(2), 112–132. https://doi.org/10.1097/TLD.0b013e3181a71fe1

McDonald, K. E., Kidney, C. A., Nelms, S. L., Parker, M. R., Kimmel, A., & Keys, C. B. (2009). Including adults with intellectual disabilities in research: Scientists' perceptions of risks and protections. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(4), 244–252. https://doi.org/10.1111/j.1741-1130.2009.00225.x

McEvoy, P., & Richards, D. (2006). A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of research in nursing*, *11*(1), 66-78. https://doi.org/10.1177/17449871060601

McKeith, I. G. (2002). Dementia with Lewy bodies. *British Journal of Psychiatry*, *180*(2), 144–147. https://doi.org/10.1192/bjp.180.2.144

McKeith, I. G., & Burn, D. (2000). Spectrum of Parkinson's disease, Parkinson's demetia, and Lewy body dementia. *Neurologic Clinics*, *18*(4), 865–883. https://doi.org/10.1016/S0733-8619(05)70230-9

McKeith, I. G., Dickson, D. W., Lowe, J., Emre, M., O'Brien, J. T., Feldman, H., Cummings, J., Duda, J. E., Lippa, C., Perry, E. K., Aarsland, D., Arai, H., Ballard, C. G., Boeve, B., Burn, D. J., Costa, D., Del Ser, T., Dubois, B., Galasko, D., … Consortium on DLB. (2005). Diagnosis and management of dementia with Lewy bodies: Third report of the DLB consortium. *Neurology*, *65*(12), 1863–1872. https://doi.org/10.1212/01.wnl.0000187889.17253.b1

McKeith, I. G., Galasko, D., Wilcock, G. K., & Byrne, E. J. (1995). Lewy body dementia – diagnosis and treatment. *British Journal of Psychiatry*, *167*(6), 709–717. https://doi.org/10.1192/bjp.167.6.709

McKenzie, K., Milton, M., Smith, G., & Ouellette-Kuntz, H. (2016). Systematic review of the prevalence and incidence of intellectual disabilities: Current trends and issues. *Current Developmental Disorders Reports*, *3*(2), 104–115. https://doi.org/10.1007/s40474-016-0085-7

McLennan, Y., Polussa, J., Tassone, F., & Hagerman, R. (2011). Fragile X syndrome. *Current Genomics*, *12*(3), 216–224. https://doi.org/10.2174/138920211795677886

mencap. (n.d.). *How common is learning disability?* Mencap. Retrieved 30 September 2023, from https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability

Mervis, C. B., & Klein-Tasman, B. P. (2000). Williams syndrome: Cognition, personality, and adaptive behavior. *Mental Retardation and Developmental Disabilities Research Reviews*, *6*(2), 148–158. https://doi.org/10.1002/1098-2779(2000)6:2<148::AID-MRDD10>3.0.CO;2-T

Meyer, J. S., McClintic, K. L., Rogers, R. L., Sims, P., & Mortel, K. F. (1988). Aetiological considerations and risk factors for multi-infarct dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, *51*(12), 1489–1497. https://doi.org/10.1136/jnnp.51.12.1489

Meyers, J. E., Volkert, K., & Diep, A. (2000). Sentence Repetition Test: Updated norms and çlinical utility. *Applied Neuropsychology*, *7*(3), 154–159. https://doi.org/10.1207/S15324826AN0703_6

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *BMJ*, *339*(jul21 1), b2535–b2535. https://doi.org/10.1136/bmj.b2535

Molloy, D. W., & Standish, T. I. M. (1997). A guide to the standardized Mini-Mental State Examination. *International Psychogeriatrics*, *9*(S1), 87–94. https://doi.org/10.1017/S1041610297004754

Morris, J. K., Garne, E., Wellesley, D., Addor, M.-C., Arriola, L., Barisic, I., Beres, J., Bianchi, F., Budd, J., Dias, C. M., Gatt, M., Klungsoyr, K., Khoshnood, B., Latos-Bielenska, A., Mullaney, C., Nelen, V., Neville, A. J., O'Mahony, M., Queisser-Luft, A., … Dolk, H. (2014). Major congenital anomalies in babies born with Down syndrome: A EUROCAT population-based registry study. *American Journal of Medical Genetics Part A*, *164*(12), 2979–2986. https://doi.org/10.1002/ajmg.a.36780

Mukumbang, F. C. (2023). Retroductive theorizing: A contribution of critical realism to mixed methods research. *Journal of Mixed Methods Research*, *17*(1), 93–114. https://doi.org/10.1177/15586898211049847

Murphy, C., & Jinich, S. (1996). Olfactory dysfunction in Down's syndrome. *Neurobiology of Aging*, *17*(4), 631–637. https://doi.org/10.1016/0197-4580(96)00008-5

Nadu, T. (2005). Clinical assessment and diagnosis of dementia. *Annals of Indian Academy of Neurology*, *8*, 149–161.

Nair, R., Chen, M., Dutt, A. S., Hagopian, L., Singh, A., & Du, M. (2022). Significant regional inequalities in the prevalence of intellectual disability and trends from 1990 to 2019: A systematic analysis of GBD 2019. *Epidemiology and Psychiatric Sciences*, *31*, e91. https://doi.org/10.1017/S2045796022000701

Neary, D., Snowden, J. S., Gustafson, L., Passant, U., Stuss, D., Black, S., Freedman, M., Kertesz, A., Robert, P. H., Albert, M., Boone, K., Miller, B. L., Cummings, J., & Benson, D. F. (1998). Frontotemporal lobar degeneration: A consensus on clinical diagnostic criteria. *Neurology*, *51*(6), 1546–1554. https://doi.org/10.1212/WNL.51.6.1546

Negin, F., Rodriguez, P., Koperski, M., Kerboua, A., Gonzàlez, J., Bourgeois, J., Chapoulie, E., Robert, P., & Bremond, F. (2018). PRAXIS: Towards automatic cognitive assessment using gesture recognition. *Expert Systems with Applications*, *106*, 21-35.

Nihira, K., Foster, R., Shellhaas, M., & Leland, H. (1974). *Adaptive behavior scale manual*. American Association on Mental Deficiency.

Nielsen, T. R. (2022). Cognitive assessment in culturally, linguistically, and educationally diverse older populations in Europe. *American Journal of*

*Alzheimer's Disease & Other Dementia*s, 37: 15333175221117006. DOI: 10.1177/15333175221117006

Nijjar, R. K., & Murphy, C. (2002). Olfactory impairment increases as a function of age in persons with Down syndrome. *Neurobiology of Aging*, *23*(1), 65–73. https://doi.org/10.1016/S0197-4580(01)00263-9

Niu, H., Álvarez-Álvarez, I., Guillén-Grima, F., & Aguinaga-Ontoso, I. (2017). Prevalence and incidence of Alzheimer's disease in Europe: A meta-analysis. *Neurología (English Edition)*, *32*(8), 523–532. https://doi.org/10.1016/j.nrleng.2016.02.009

North, C., Desai, R., Saunders, R., Suárez-González, A., Bamiou, D., Costafreda, S. G., De Haan, G., Halls, G., Heutink, J., O'Nions, E., Utoomprurkporn, N., John, A., & Stott, J. (2021). Neuropsychological deficits in posterior cortical atrophy and typical Alzheimer's disease: A meta-analytic review. *Cortex*, *143*, 223–236. https://doi.org/10.1016/j.cortex.2021.07.011

Oliver, C., Adams, D., Holland, A. J., Brown, S. S. G., Ball, S., Dodd, K., & Carr, J. (2022). Acquired mild cognitive impairment in adults with Down syndrome: Age-related prevalence derived from single point assessment data normed by degree of intellectual disability. *International Journal of Geriatric Psychiatry*, *37*(2), gps.5674. https://doi.org/10.1002/gps.5674

Oliver, C., Crayton, L., Holland, A., Hall, S., & Bradbury, J. (1998). A four year prospective study of age-related cognitive change in adults with Down's syndrome. *Psychological Medicine*, *28*(6), 1365–1377. https://doi.org/10.1017/S0033291798007417

Oliver, C., & Kalsy, S. (2005). The assessment of dementia in people with intellectual disability: Context, strategy and methods. In J. Hogg & A. Langa (Eds.),

Assessing adults with intellectual disabilities: A service providers' guide (pp. 98–107). John Wiley & Sons, Ltd. https://doi.org/10.1002/9780470773697.ch7

Ormston, L., Spencer, L., Barnard, M., & Snape, D. (2014). The foundations of qualitative research. In J. Ritchie (Ed.), *Qualitative research practice: A guide for social science students and researchers* (2. ed). Sage.

Overman, M. J., Leeworthy, S., & Welsh, T. J. (2021). Estimating premorbid intelligence in people living with dementia: A systematic review. *International Psychogeriatrics*, *33*(11), 1145–1159. https://doi.org/10.1017/S1041610221000302

Oxelgren, U. W., Myrelid, Å., Annerén, G., Ekstam, B., Göransson, C., Holmbom, A., Isaksson, A., Åberg, M., Gustafsson, J., & Fernell, E. (2017). Prevalence of autism and attention-deficit–hyperactivity disorder in Down syndrome: A population-based study. *Developmental Medicine & Child Neurology*, *59*(3), 276–283. https://doi.org/10.1111/dmcn.13217

Paiva, A. F., Nolan, A., Thumser, C., & Santos, F. H. (2020). Screening of cognitive changes in adults with intellectual disabilities: A systematic review. *Brain Sciences*, *10*(11), 848. https://doi.org/10.3390/brainsci10110848

Paladini, D., Tartaglione, A., Agangi, A., Teodoro, A., Forleo, F., Borghese, A., & Martinelli, P. (2000). The association between congenital heart disease and Down syndrome in prenatal life: Congenital disease and Down syndrome. *Ultrasound in Obstetrics and Gynecology*, *15*(2), 104–108. https://doi.org/10.1046/j.1469-0705.2000.00027.x

Pan, X., & Chen, X. (2013). Clinic, neuropathology and molecular genetics of frontotemporal dementia: A mini-review. *Translational Neurodegeneration*, *2*(1), 8. https://doi.org/10.1186/2047-9158-2-8

Patel, L., Wolter-Warmerdam, K., Leifer, N., & Hickey, F. (2018). Behavioral characteristics of individuals with Down syndrome. *Journal of Mental Health Research in Intellectual Disabilities*, *11*(3), 221–246. https://doi.org/10.1080/19315864.2018.1481473

Patterson, D. (2009). Molecular genetic analysis of Down syndrome. *Human Genetics*, *126*(1), 195–214. https://doi.org/10.1007/s00439-009-0696-8

Pearce, D. (2024). *Assessment of Cognition in People with Intellectual Disabilities Using a Novel Set of Neuropsychological Tests* [Doctoral dissertation, University of East London*]*. UEL Repository. https://doi.org/10.15123/UEL.8XY14

Perez, W. (2015). *A citizen with learning difficulties.* Citizen Network. https://citizen-network.org/library/a-citizen-with-learning-difficulties.html

Philips, K.A., (2012). Body dysmorphic disorder. In T. Cash (Ed.), *Encyclopaedia of body image and human appearance* (pp. 74-81). https://doi.org/10.1016/B978-0-12-384925-0.00013-4

Phillips, L. H., Wynn, V. E., McPherson, S., & Gilhooly, K. J. (2001). Mental planning and the Tower of London task. *The Quarterly Journal of Experimental Psychology Section A*, *54*(2), 579-597. https://doi.org/10.1080/713755

Pinker, S. (1984). Visual cognition: An introduction. *Cognition*, *18*(1–3), 1–63. https://doi.org/10.1016/0010-0277(84)90021-0

Prasher, V. P., & Krishnan, V. H. R. (1993). Age of onset and duration of dementia in people with down syndrome: Integration of 98 reported cases in the literature. *International Journal of Geriatric Psychiatry*, *8*(11), 915–922. https://doi.org/10.1002/gps.930081105

Pueschel, S. M., Louis, S., & McKnight, P. (1991). Seizure Disorders in Down syndrome. *Archives of Neurology*, *48*(3), 318–320. https://doi.org/10.1001/archneur.1991.00530150088024

Pueschel, S. M., & Pezzullo, J. C. (1985). Thyroid dysfunction in Down syndrome. *American Journal of Diseases of Children*, *139*(6), 636–639. https://doi.org/10.1001/archpedi.1985.02140080106045

Qizilbash, N., (2003). Evidence-based dementia practice. Blackwell Science

Ratnavalli, E., Brayne, C., Dawson, K., & Hodges, J. R. (2002). The prevalence of frontotemporal dementia. *Neurology*, *58*(11), 1615–1621. https://doi.org/10.1212/WNL.58.11.1615

Raven, J. C. (1995). *Coloured Progressive Matrices Sets A, Ab, B. Manual Sections 1 & 2.* Oxford Psychologists Press.

Raykov, T., & Marcoulides, G.A. (2011). Introduction to psychometric theory. Routledge/Taylor & Francis Group.

Redwood, S., & Gill, P. S. (2013). Under-representation of minority ethnic groups in research—Call for action. *British Journal of General Practice*, *63*(612), 342–343. https://doi.org/10.3399/bjgp13X668456

Rey, A. (1964). *L'examen clinique enpsychologie.* Presses Universitaires de France.

Rey, A., & Osterrieth, P. A. (1941). *Rey-Osterrieth Complex Figure Copying Test* [Database Record]. APA PsychTests. https://doi.org/10.1037/t07717-000

Richards, C., Jones, C., Groves, L., Moss, J., & Oliver, C. (2015). Prevalence of autism spectrum disorder phenomenology in genetic disorders: A systematic review and meta-analysis. *The Lancet Psychiatry*, *2*(10), 909–916. https://doi.org/10.1016/S2215-0366(15)00376-4

Richards, K. (2003). *Qualitative Inquiry in TESOL*. Palgrave Macmillan. https://doi.org/10.1057/9780230505056

Rizzi, L., Rosset, I., & Roriz-Cruz, M. (2014). Global epidemiology of dementia: Alzheimer's and vascular types. *BioMed Research International*, *2014*, 1–8. https://doi.org/10.1155/2014/908915

Roberts, R. O., Christianson, T. J. H., Kremers, W. K., Mielke, M. M., Machulda, M. M., Vassilaki, M., Alhurani, R. E., Geda, Y. E., Knopman, D. S., & Petersen, R. C. (2016). Association between olfactory dysfunction and amnestic mild cognitive impairment and Alzheimer disease dementia. *JAMA Neurology*, *73*(1), 93. https://doi.org/10.1001/jamaneurol.2015.2952

Robinson, L., Tang, E., & Taylor, J.-P. (2015). Dementia: Timely diagnosis and early intervention. *BMJ*, *350*. https://doi.org/10.1136/bmj.h3029

Roh, J. H., & Lee, J.-H. (2014). Recent updates on subcortical ischemic vascular dementia. *Journal of Stroke*, *16*(1), 18. https://doi.org/10.5853/jos.2014.16.1.18

Rohrer, J. D. (2011). Behavioural variant frontotemporal dementia—defining genetic and pathological subtypes. *Journal of Molecular Neuroscience*, *45*(3), 583–588. https://doi.org/10.1007/s12031-011-9542-2

Rohrer, J. D., Guerreiro, R., Vandrovcova, J., Uphill, J., Reiman, D., Beck, J., Isaacs, A. M., Authier, A., Ferrari, R., Fox, N. C., Mackenzie, I. R. A., Warren, J. D., De Silva, R., Holton, J., Revesz, T., Hardy, J., Mead, S., & Rossor, M. N. (2009). The heritability and genetics of frontotemporal lobar degeneration. *Neurology*, *73*(18), 1451–1456. https://doi.org/10.1212/WNL.0b013e3181bf997a

Roizen, N. J., & Patterson, D. (2003). Down's syndrome. *The Lancet*, *361*(9365), 1281–1289. https://doi.org/10.1016/S0140-6736(03)12987-X

Rösner, P., Berger, J., Tarasova, D., Birkner, J., Kaiser, H., Diefenbacher, A., & Sappok, T. (2021). Assessment of dementia in a clinical sample of persons with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *34*(6), 1618–1629. https://doi.org/10.1111/jar.12913

Rowe, J., Lavender, A., & Turk, V. (2006). Cognitive executive function in Down's syndrome. *British Journal of Clinical Psychology*, *45*(1), 5–17. https://doi.org/10.1348/014466505X29594

Royston, R., Waite, J., & Howlin, P. (2019). Williams syndrome: Recent advances in our understanding of cognitive, social and psychological functioning. *Current Opinion in Psychiatry*, *32*(2), 60–66. https://doi.org/10.1097/YCO.0000000000000477

Schalock, R. L. (2011). The evolving understanding of the construct of intellectual disability. *Journal of Intellectual & Developmental Disability*, *36*(4), 227–237. https://doi.org/10.3109/13668250.2011.624087

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2019). The contemporary view of intellectual and developmental disabilities: Implications for psychologists. *Psicothema*, *31*(3*)*, 223–228. https://doi.org/10.7334/psicothema2019.119

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). An Overview of *Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports* (12th ed.). *American Journal on Intellectual and Developmental Disabilities*, *126*(6), 439–442. https://doi.org/10.1352/1944-7558-126.6.439

Schoenberg, M. R., Lange, R. T., Marsh, P., & Saklofske, D. H. (2011). Premorbid Intelligence. In J. S. Kreutzer, J. DeLuca, & B. Caplan (Eds.), *Encyclopedia of Clinical Neuropsychology* (pp. 2004–2010). Springer. https://doi.org/10.1007/978-0-387-79948-3_2140

Schott, J. M., Crutch, S. J., Carrasquillo, M. M., Uphill, J., Shakespeare, T. J., Ryan, N. S., Yong, K. X., Lehmann, M., Ertekin-Taner, N., Graff-Radford, N. R., Boeve, B. F., Murray, M. E., Khan, Q. U. A., Petersen, R. C., Dickson, D. W., Knopman, D. S., Rabinovici, G. D., Miller, B. L., González, A. S., … Mead, S. (2016). Genetic risk factors for the posterior cortical atrophy variant of Alzheimer's disease. *Alzheimer's & Dementia*, *12*(8), 862–871. https://doi.org/10.1016/j.jalz.2016.01.010

Sekijima, Y., Ikeda, S., Tokuda, T., Satoh, S., Hidaka, H., Hidaka, E., Ishikawa, M., & Yanagisawa, N. (1998). Prevalence of dementia of Alzheimer type and apolipoprotein E phenotypes in aged patients with Down's syndrome. *European Neurology*, *39*(4), 234–237. https://doi.org/10.1159/000007940

Shalat, S. L., Seltzer, B., Pidcock, C., & Baker, E. L. (1987). Risk factors for Alzheimer's disease: A case-control study. *Neurology*, *37*(10), 1630–1630. https://doi.org/10.1212/WNL.37.10.1630

Shallice, T., Broadbent, D. E., & Weiskrantz, L. (1997). Specific impairments of planning. *Philosophical Transactions of the Royal Society of London. B, Biological Sciences*, *298*(1089), 199–209. https://doi.org/10.1098/rstb.1982.0082

Sherman, E. M. S., Brooks, B. L., Iverson, G. L., Slick, D. J., & Strauss, E. (2011). Reliability and Validity in Neuropsychology. In M. R. Schoenberg & J. G. Scott (Eds.), *The Little Black Book of Neuropsychology* (pp. 873–892). Springer. https://doi.org/10.1007/978-0-387-76978-3_30

Sivanandam, T. M., & Thakur, M. K. (2012). Traumatic brain injury: A risk factor for Alzheimer's disease. *Neuroscience & Biobehavioral Reviews*, *36*(5), 1376–1381. https://doi.org/10.1016/j.neubiorev.2012.02.013

Skoog, I. (1994). Risk Factors for vascular dementia: A review. *Dementia and Geriatric Cognitive Disorders*, *5*(3–4), 137–144. https://doi.org/10.1159/000106711

Smith, J. (2003). *Qualitative psychology: A practical guide to research methods*. Sage Publications, Inc.

Snape, D., & Spencer, L. (2003). The foundations of Qualitative Research. In J. Ritchie (Ed.), *Qualitative research practice: A guide for social science students and researchers* (pp. 1-23). SAGE Publications Ltd.

Sol, K., & Heng, K. (2022). Understanding epistemology and its key approaches in research. *Cambodian Journal of Educational Research*, *2*(2), 80–99. https://doi.org/10.62037/cjer.2022.02.02.05

Solomon, M., Buaminger, N., & Rogers, S. J. (2011). Abstract reasoning and friendship in high functioning preadolescents with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *41*(1), 32–43. https://doi.org/10.1007/s10803-010-1017-8

Spreen, O., & Risser, A. H. (1998). Assessment of aphasia. In M.T. Sarno (Ed.), Acquired aphasia (3rd ed., pp. 71–156). Academic Press. https://doi.org/10.1016/B978-012619322-0/50007-5

Spreen, O., & Strauss, E. (1998). *A compendium of neuropsychological tests: Administration, norms, and commentary* (2nd ed.). Oxford University Press.

Squire, L. R., & Zola, S. M. (1998). Episodic memory, semantic memory, and amnesia. *Hippocampus*, *8*(3), 205–211. https://doi.org/10.1002/(SICI)1098-1063(1998)8:3<205::AID-HIPO3>3.0.CO;2-I

Startin, C. M., Hamburg, S., Hithersay, R., Davies, A., Rodger, E., Aggarwal, N., Al-Janabi, T., & Strydom, A. (2016). The LonDownS adult cognitive assessment

to study cognitive abilities and decline in Down syndrome. *Wellcome Open Research*, *1*. https://doi.org/10.12688/wellcomeopenres.9961.1

Strydom, A., Livingston, G., King, M., & Hassiotis, A. (2007). Prevalence of dementia in intellectual disability using different diagnostic criteria. *The British Journal of Psychiatry*, *191*(2), 150–157. https://doi.org/10.1192/bjp.bp.106.028845

Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., Jokinen, N., Courtenay, K., Bass, N., Sinnema, M., & Maaskant, M. (2010). Dementia in older adults with intellectual disabilities—epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities, 7*(2), 96-110. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1741-1130.2010.00253.x

Sullivan, K., Hatton, D., Hammer, J., Sideris, J., Hooper, S., Ornstein, P., & Bailey, D. (2006). ADHD symptoms in children with FXS. *American Journal of Medical Genetics Part A*, *140A*(21), 2275–2288. https://doi.org/10.1002/ajmg.a.31388

Tanzi, R. E. (2012). The Genetics of Alzheimer Disease. *Cold Spring Harbor Perspectives in Medicine*, *2*(10), a006296. https://doi.org/10.1101/cshperspect.a006296

Tyrer, S. P., Wigham, A., Cicchetti, D., Margallo-Lana, M., Moore, P. B., & Reid, B. E. (2010). Comparison of short and long versions of the Prudhoe Cognitive Function Test and the K-BIT in participants with intellectual impairment. *Journal of Autism and Developmental Disorders*, *40*(8), 1000–1005. https://doi.org/10.1007/s10803-010-0949-3

Urbina, S. (2014). *Essentials of Psychological Testing*. Wiley. https://doi.org/10.1002/9781394259458

Van Der Flier, W. M. (2005). Epidemiology and risk factors of dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, *76*(Suppl. 5), v2–v7. https://doi.org/10.1136/jnnp.2005.082867

Vanderploeg, R. D. (2014). *Clinician's guide to neuropsychological assessment* (2nd ed). Psychology Press.

Velayudhan, L., Pritchard, M., Powell, J. F., Proitsi, P., & Lovestone, S. (2013). Smell identification function as a severity and progression marker in Alzheimer's disease. *International Psychogeriatrics*, *25*(7), 1157–1166. https://doi.org/10.1017/S1041610213000446

Vicari, S., Pontillo, M., & Armando, M. (2013). Neurodevelopmental and psychiatric issues in Down's syndrome: Assessment and intervention. *Psychiatric Genetics*, *23*(3), 95–107. https://doi.org/10.1097/YPG.0b013e32835fe426

Visser, F., Aldenkamp, A., van Huffelen, A., Kuilman, M., Overweg, J., & van Wijk, k. (1997). Prospective study of the prevalence of Alzheimer-type dementia in institutionalized individuals with Down syndrome. *American Journal of Mental Retardation*.

Wajuihian, S. O. (2016). Down syndrome: An overview. *African Vision and Eye Health*, *75*(1), 1-6. https://doi.org/10.4102/aveh.v75i1.346

Walker, L., Stefanis, L., & Attems, J. (2019). Clinical and neuropathological differences between Parkinson's disease, Parkinson's disease dementia and dementia with Lewy bodies – current issues and future directions. *Journal of Neurochemistry*, *150*(5), 467–474. https://doi.org/10.1111/jnc.14698

Warren, J. D., Rohrer, J. D., & Rossor, M. N. (2013). Frontotemporal dementia. *BMJ*, 347. https://doi.org/10.1136/bmj.f4827

Watt, K. J., & O'Carroll, R. E. (1999). Evaluating methods for estimating premorbid intellectual ability in closed head injury. *Journal of Neurology, Neurosurgery & Psychiatry*, *66*(4), 474–479. https://doi.org/10.1136/jnnp.66.4.474

Webb, Z., Dodd, K., Livesey, A., Sunak, S., Marshall, C., Harrison, L., & Liddiard, H. (2020). Developing and evaluating the validity of the behavioural assessment of dysexecutive functioning – intellectual disabilities adaptation (BADS-ID). *Advances in Mental Health and Intellectual Disabilities*, *14*(6), 229–245. https://doi.org/10.1108/AMHID-12-2019-0043

Wechsler, D. (1997). *Wechsler Adult Intelligence Scale—Third Edition* [Database Record]. APA PsychTests. https://doi.org/10.1037/t49755-000

Weiner, M. F. (1999). Dementia associated with Lewy bodies: Dilemmas and directions. *Archives of Neurology*, *56*(12), 1441. https://doi.org/10.1001/archneur.56.12.1441

Weiss, D. J., & Betz, N. E. (1973). Ability Measurement: Conventional or Adaptive?

Wheeler, P. L., & Murphy, C. (2021). Olfactory measures as predictors of conversion to mild cognitive impairment and Alzheimer's disease. *Brain Sciences*, *11*(11), 1391. https://doi.org/10.3390/brainsci11111391

Willig, C. (2012). Perspectives on the epistemological bases for qualitative research. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol 1: Foundations, planning, measures, and psychometrics.* (pp. 5–21). American Psychological Association. https://doi.org/10.1037/13619-002

Willner, P., Bailey, R., Parry, R., & Dymond, S. (2010). Evaluation of executive functioning in people with intellectual disabilities. *Journal of Intellectual*

Disability Research, *54*(4), 366–379. https://doi.org/10.1111/j.1365-2788.2010.01249.x

Wilson, R. H., & Antablin, J. K. (1980). A picture identification task as an estimate of the word-recognition performance of nonverbal adults. *Journal of Speech and Hearing Disorders*, *45*(2), 223–238. https://doi.org/10.1044/jshd.4502.223

Wilson, R. S., Arnold, S. E., Schneider, J. A., Boyle, P. A., Buchman, A. S., & Bennett, D. A. (2009). Olfactory impairment in presymptomatic Alzheimer's disease. *Annals of the New York Academy of Sciences*, *1170*(1), 730–735. https://doi.org/10.1111/j.1749-6632.2009.04013.x

Wilson, R. S., Schneider, J. A., Arnold, S. E., Tang, Y., Boyle, P. A., & Bennett, D. A. (2007). Olfactory identification and incidence of mild cognitive impairment in older age. *Archives of General Psychiatry*, *64*(7), 802. https://doi.org/10.1001/archpsyc.64.7.802

Winnepenninckx, B., Rooms, L., & Kooy, R. F. (2003). Mental retardation: A review of the genetic causes. *The British Journal of Development Disabilities*, *49*(96), 29–44. https://doi.org/10.1179/096979503799104138

Wiseman, F. K., Al-Janabi, T., Hardy, J., Karmiloff-Smith, A., Nizetic, D., Tybulewicz, V. L., Fisher, E.M.C., & Strydom, A. (2015). A genetic cause of Alzheimer disease: Mechanistic insights from Down syndrome. *Nature Reviews Neuroscience, 16*(9), 564-574. https://doi.org/10.1038/nrn3983

Wisniewski, K. E., Wisniewski, H. M., & Wen, G. Y. (1985). Occurrence of neuropathological changes and dementia of Alzheimer's disease in Down's syndrome. *Annals of Neurology*, *17*(3), 278–282. https://doi.org/10.1002/ana.410170310

Woodard, J.L. (2006). Memory performance indexes for the Rey Auditory Verbal Learning Test. In A.m. Poreh (Ed.), *The quantified process approach to neuropsychological assessment* (pp.53-82). Psychology Press. https://doi.org/10.4324/9780203720899

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. World Health Organization.

World Health Organization. (2021). *Global status report on the public health response to dementia*. https://www.alzheimer-europe.org/sites/default/files/2021-11/Global%20status%20report%20on%20the%20public%20health%20response%20to%20dementia.pdf

World Health Organization. (2023). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Zeilinger, E. L., Stiehl, K. A., & Weber, G. (2013). A systematic review on assessment instruments for dementia in persons with intellectual disabilities. *Research in Developmental Disabilities*, *34*(11), 3962-3977. DOI: 10.1016/j.ridd.2013.08.013

Zhao, A., Li, Y., Yan, Y., Qiu, Y., Li, B., Xu, W., Wang, Y., Liu, J., & Deng, Y. (2020). Increased prediction value of biomarker combinations for the conversion of mild cognitive impairment to Alzheimer's dementia. *Translational Neurodegeneration*, *9*(1), 30. https://doi.org/10.1186/s40035-020-00210-5

Zigman, W. B., Schupf, N., Devenny, D. A., Miezejeski, C., Ryan, R., Urv, T. K., Schubert, R., & Silverman, W. (2004). Incidence and prevalence of dementia in elderly adults with mental retardation without Down syndrome. *American Journal on Mental Retardation*, *109*(2), 126–141. https://doi.org/10.1352/0895-8017(2004)109<126:IAPODI>2.0.CO;2

APPENDICES

Appendix A: NHS Research Poster

Are you a person with a learning disability?
Are you between 18 and 55 years of age?
Could you help me with some research?

Hello! My name is Zakiya. I am a student in the School of Psychology at the University of East London, and I am studying for a Doctorate in Clinical Psychology. As part of my studies, I am doing the research described in this poster. To do my research, I need people with a learning disability who are aged between 18 and 55 years old, who do not have a diagnosis of dementia, and who come to the [redacted] Service, to take part in my study.

University of East London

What would I have to do?

If you take part in my study, you would participate in some tasks called 'cognitive tests'. Don't worry, this is not like a school test! I will ask you to do some short tasks, like answering questions, drawing things, or copying what I do back to me. I would then ask for your feedback on the test. If you participate, your data will be anonymous, which means nobody but me will know who you are when the data is published in my research paper.

Why are you doing this research?

There are currently no tests for dementia that have been created for people with a learning disability that accurately look at all the different things that the brain can do accurately. I would like to make a test for people with a learning disability that feels engaging and takes into account what people think about it, so I can make the tests better.

What will I get for taking part?

If you choose to take part, you will help to improve the tests for other people with a learning disability in the future. You will also get a £10 Amazon gift voucher to say thank you for your time.

How can I take part?

If you would like to take part, please speak to your health care professional at your Learning Disability Service, or ask you parent/carer/guardian to let them know you are interested. They will put you in touch with me. Thank you for reading! 😊

Appendix B: Charity Research Poster

Are you a person with a learning disability?
Are you between 18 and 55 years of age?
Could you help me with some research?

University of East London

Hello! My name is Zakiya. I am a student in the School of Psychology at the University of East London, and I am studying for a Doctorate in Clinical Psychology. As part of my studies, I am doing the research described in this poster. To do my research, I need people with a learning disability who are aged between 18 and 55 years old, to take part in this study

What would I have to do?

If you take part in my study, you would participate in some tasks called 'cognitive tests'. Don't worry, this is not like a school test! I will ask you to do some short tasks, like answering questions, drawing things, or copying what I do back to me. I would then ask for your feedback on the test. If you participate, your data will be anonymous, which means nobody but me will know who you are when the data is published in my research paper.

Why are you doing this research?

There are currently no tests for dementia that have been created for people with a learning disability that accurately look at all the different things that the brain can do accurately. I would like to make a test for people with a learning disability that feels engaging and takes into account what people think about it, so I can make the tests better.

What will I get for taking part?

If you choose to take part, you will help to improve the tests for other people with a learning disability in the future. You will also get a £10 Amazon gift voucher to say thank you for your time.

How can I take part?

If you would like to take part, please speak tell the staff here, who can let us know. Or ask your parent, carer or guardian to telephone [redacted] or email u2075228@uel.ac.uk on your behalf, and we will get in touch. Thank you for reading! 😊

Appendix C: NHS Participant Invitation Letter

Participant ID:

University of East London
School of Psychology

Assessment of Cognition in People with Intellectual Disabilities:

Participant Invitation Sheet

You are being invited to participate in a research study. Before you agree to take part, it is important that you understand what your participation would involve. Please read the following information carefully before deciding.

Who am I?
My name is Zakiya, I am a student in the School of Psychology at the University of East London and am studying for a Doctorate in Clinical Psychology. As part of my studies, I am conducting the research you are being invited to participate in.

What is the research?
I am conducting research into making an assessment tool which can see if somebody with a learning disability may also be experiencing dementia. Dementia is when someone experiences a loss of memory, language, problem-solving and other thinking abilities that may make daily life more difficult. There are many different types, the most common kind of dementia is called Alzheimer's. I would like to investigate whether dementia looks different in people who have a learning disability, so that we can identify it sooner and help people who experience it have better support and quality of life.

My research has been approved by an independent NHS Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?
You have been invited to participate in my research as I am looking to involve people who have Down Syndrome (Trisomy 21) or any other learning disability, and are aged between 18 and 55, to help me explore my research topic.

You will not be judged or personally analysed in any way, and you will be treated with respect at all times.

You do not have to say 'yes' to taking part, and there will be no consequences if you decide not to take part. You are free to choose what feels most comfortable to you.

What will your participation involve?
You will be asked to attend a 'testing session' with me. I will ask you to complete a series of short tasks including questionnaires and other short exercises exploring various skills and abilities including language, thinking and puzzle-solving. Some of these will involve me asking you questions, and others are pen-and-paper tasks, and some may involve you following instructions. Tasks with verbal answers will be video recorded so that your answers can be accurately scored and analysed. This will be safely stored on a password-protected computer and destroyed once the research has finished.

This will take around 1 hour. We will take a break in the middle where you can have some snacks and drinks that I will provide for you, and you can also take short breaks in between the different tasks if you wish. If you need, we could have two shorter sessions on two different days. I will also ask you to tell me what you thought of the tests, including what you think worked well and how you think I could make any of them better. This will take around half an hour, and can be done on the same day as the tests or a different day.

This will take place in a private room at XX or XX NHS Learning Disability Service at a time we decide in advance, that fits for us both.

What are the potential risks and disadvantages of taking part?
Though we do not anticipate any negative affects of participation, some may arise. Testing may make you feel tired, which could lead to headaches. Taking part in some of the tests could also feel stressful. We will remind you throughout to take breaks if you need, and provide refreshments while you take part in the testing session. We will also provide you with services and organisations you can contact at the bottom of this sheet, and in a debrief letter.

What are the potential benefits of taking part?
As a thank you for your time, you will be given a £10 Amazon voucher. There may not be any specific benefits to yourself in participating, but by taking part you can help to create tests for dementia which are better suited to other people with a learning disability in the future.

How will we use information about you?
We will need to use information from you for this research project. This will include:

- Your name
- Your mobile number or email address (to get in touch with you)

- The responses you give to the tests we try out together.

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.
We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

The video recordings that we take of you completing the verbal tests will not be fully transcribed, and will only be used to write down the answers you give on the tests. We will use this video to record your answers within one week of you completing the tests. After one week, the video recording will be safely destroyed.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

After the study has been completed, your data will continue to be stored in a secure location, only accessible by the research team, for 10 years, as recommended by the UK Research and Innovation (UKRI) guidelines. After this, all data will be destroyed.

If you wish, I can provide you with a copy of the results of this study once it is finished.

What if you want to withdraw?
You are free to withdraw from the research study at any time without explanation, disadvantage, or consequence. If you tell me that you would like to stop the video recording, any of the tests, or the discussions we are having at any point, we will stop these immediately. You will be offered the chance to have a talk about how you are feeling with me (this is called a debrief) and I will give you some resources of other people to speak to also. Any data collected about you, on paper, computer, or video, will be immediately and safely destroyed.

Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within **3 weeks** of the data being collected. After 3 weeks, your name and other identifiable information will be deleted and your data will only be referred to by a numerical code, meaning we will no longer be able to identify which is your data.

If during your participation in the study you lose the ability to consent, we will immediately stop testing and offer you and your carer/guardian a debrief. We will then immediately and

safely destroy your data, and you will no longer be included in the study. You will still receive a £10 Amazon voucher for your time.

Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to u2075228@uel.ac.uk or
- by ringing us on [redacted] copyright reasons

If you have any questions or concerns about how the research has been conducted, please contact:

- The research supervisor:
  Dr Matthew Jones Chesters
  School of Psychology, University of East London, Water Lane, London E15 4LZ
  Email: m.h.jones-chesters@uel.ac.uk
  Phone: 020 8223 4603

or

- Chair of the School of Psychology Research Ethics Sub-committee:
  Dr Trishna Patel
  School of Psychology, University of East London, Water Lane, London E15 4LZ.
  Email: t.patel@uel.ac.uk

Appendix D: Charity Participant Invitation Letter

University of East London
School of Psychology

Assessment of Cognition in People with Intellectual Disabilities:

Participant Invitation Sheet

You are being invited to participate in a research study. Before you agree to take part, it is important that you understand what your participation would involve. Please read the following information carefully before deciding.

Who am I?
My name is Zakiya, I am a student in the School of Psychology at the University of East London and am studying for a Doctorate in Clinical Psychology. As part of my studies, I am conducting the research you are being invited to participate in.

What is the research?
I am conducting research into making an assessment tool which can see if somebody with a learning disability may also be experiencing dementia. Dementia is when someone experiences a loss of memory, language, problem-solving and other thinking abilities that may make daily life more difficult. There are many different types, the most common kind of dementia is called Alzheimer's. I would like to investigate whether dementia looks different in people who have a learning disability, so that we can identify it sooner and help people who experience it have better support and quality of life.

Our research has been approved by the University of East London Ethics Committee. This means that our research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?
You have been invited to participate in my research as I am looking to involve people who have Down Syndrome (Trisomy 21) or any other learning disability, and are aged between 18 and 55, to help me explore my research topic.

You will not be judged or personally analysed in any way, and you will be treated with respect at all times.

You do not have to say 'yes' to taking part, and there will be no consequences if you decide not to take part. You are free to choose what feels most comfortable to you.

What will your participation involve?
You will be asked to attend a 'testing session' with me. I will ask you to complete a series of short tasks including questionnaires and other short exercises exploring various skills and abilities including language, thinking and puzzle-solving. Some of these will involve me asking you questions, and others are pen-and-paper tasks, and some may involve you following instructions. Tasks with verbal answers will be video recorded so that your answers can be accurately scored and analysed. This will be safely stored on a password-protected computer and destroyed once the research has finished.

This will take around 1 hour. We will take a break in the middle where you can have some snacks and drinks that I will provide for you, and you can also take short breaks in between the different tasks if you wish. If you need, we could have two shorter sessions on two different days. I will also ask you to tell me what you thought of the tests, including what you think worked well and how you think I could make any of them better. This will take around half an hour, and can be done on the same day as the tests or a different day.

This will take place in a private room of your choice at a time we agree upon and plan in advance.

What are the potential risks and disadvantages of taking part?
Though we do not anticipate any negative effects of participation, some may arise. Testing may make you feel tired, which could lead to headaches. Taking part in some of the tests could also feel stressful. We will remind you throughout to take breaks if you need, and provide refreshments while you take part in the testing session. We will also provide you with services and organisations you can contact at the bottom of this sheet, and in a debrief letter.

What are the potential benefits of taking part?
As a thank you for your time, you will be given a £10 Amazon voucher. There may not be any specific benefits to yourself in participating, but by taking part you can help to create tests for dementia which are better suited to other people with a learning disability in the future.

How will we use information about you?
We will need to use information from you for this research project. This will include:

- Your name
- Your mobile number or email address (to get in touch with you)
- The responses you give to the tests we try out together.

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

The video recordings that we take of you completing the verbal tests will not be fully transcribed and will only be used to write down the answers you give on the tests. We will use this video to record your answers within one week of you completing the tests. After one week, the video recording will be safely destroyed.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

After the study has been completed, your data will continue to be stored in a secure location, only accessible by the research team, for 10 years, as recommended by the UK Research and Innovation (UKRI) guidelines. After this, all data will be destroyed.

If you wish, I can provide you with a copy of the results of this study once it is finished.

What if you want to withdraw?
You are free to withdraw from the research study at any time without explanation, disadvantage, or consequence. If you tell me that you would like to stop the video recording, any of the tests, or the discussions we are having at any point, we will stop these immediately. You will be offered the chance to have a talk about how you are feeling with me (this is called a debrief) and I will give you some resources of other people to speak to also. Any data collected about you, on paper, computer, or video, will be immediately and safely destroyed.

Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within **3 weeks** of the data being collected. After 3 weeks, your name and other identifiable information will be deleted and your data will only be referred to by a numerical code, meaning we will no longer be able to identify which is your data.

If during your participation in the study you lose the ability to consent, we will immediately stop testing and offer you and your carer/guardian a debrief. We will then immediately and safely destroy your data, and you will no longer be included in the study. You will still receive a £10 Amazon voucher for your time.

Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to u2075228@uel.ac.uk or
- by ringing us on [redacted] copyright reasons

If you have any questions or concerns about how the research has been conducted, please contact:

- The research supervisor:

  Dr Matthew Jones Chesters
  School of Psychology, University of East London, Water Lane, London E15 4LZ
  Email: m.h.jones-chesters@uel.ac.uk
  Phone: 020 8223 4603

or

- Chair of the School of Psychology Research Ethics Sub-committee:

  Dr Trishna Patel
  School of Psychology, University of East London, Water Lane, London E15 4LZ.
  Email: t.patel@uel.ac.uk

Appendix E: NHS Carer Invitation Letter

Participant ID:

University of East London
School of Psychology

Assessment of Cognition in People with Intellectual Disabilities:

Carer Invitation Letter

Your child, relative or friend is being invited to participate in a research study. We have asked you to accompany them as their guardian and advocate. Before they agree to take part, it is important that you understand what their participation would involve. Please read the following information carefully before deciding.

Who am I?
My name is Zakiya, I am a student in the School of Psychology at the University of East London and am studying for a Doctorate in Clinical Psychology. As part of my studies, I am conducting the research your child, relative or friend is being invited to participate in.

What is the research?
I am conducting research into making an assessment tool which can see if somebody with a learning disability may also be experiencing dementia. Dementia is when someone experiences a loss of memory, language, problem-solving and other thinking abilities that may make daily life more difficult. There are many different types, the most common kind of dementia is called Alzheimer's. I would like to investigate whether dementia looks different in people who have a learning disability, so that we can identify it sooner and help people who experience it have better support and quality of life.

My research has been approved by an independent NHS Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why has my child/ relative/ friend been asked to participate?
Your child/ relative/ friend has been invited to participate in my research as someone who has Down Syndrome or other learning disability, and is aged between 18 and 55 years.

Your child/relative/friend will not be judged or personally analysed in any way and will be treated with respect at all times. They do not have to say 'yes' to taking part, and there will be no consequences if they decide not to take part. They are free to choose what feels most comfortable to them.

What will their participation involve?
They will be asked to attend a 'testing session' with me. I will ask them to complete a series of short tasks including questionnaires and other short exercises exploring various skills and abilities including language, thinking and puzzle-solving. Some of these will involve me asking them questions, and others are pen-and-paper tasks, and some may involve them following instructions. Tasks with verbal answers will be video recorded so that their answers can be accurately scored and analysed. This will be safely stored on a password-protected computer and destroyed once the research has finished.

This will take around 1 hour. We will take a break in the middle where you and your child, relative or friend can have some snacks and drinks that I will provide for you, and your child, relative or friend can also take short breaks in between the different tasks if you wish. If your child/relative/friend needs, we could have two shorter sessions on two different days. I will also ask your child/ relative/friend to tell me what they thought of the tests, including what they think worked well and how they think I could make any of them better. This will take around half an hour, and can be done on the same day as the tests or a different day.

This will take place in a private room at XX or XX NHS Learning Disability Service at a time we decide in advance, that fits for us all.

What are the potential risks and disadvantages of taking part?
Though we do not anticipate any negative affects of participation, some may arise. Testing may make your child/relative/friend feel tired, which could lead to headaches. Taking part in some of the tests could also feel stressful. We will remind your child/ relative/ friend throughout to take breaks if they need, and provide refreshments while they take part in the testing session. We will also provide you both with services and organisations you can contact at the bottom of this sheet, and in a debrief letter.

What are the potential benefits of taking part?
As a thank you for your child/relative/friend's time, they will be given a £10 Amazon voucher. There may not be any specific benefits to them in participating, but by taking part they can help to create tests for dementia which are better suited to other people with a learning disability in the future.

What will happen to the information that my child/ relative/ friend provides?
We will need to use information from your child/ relative/ friend for this research project. This information will include:

- Their name
- Their mobile number or email address (to get in touch with them)
- The responses they give to the tests we try out together.

We will also ask for information from you, which will include:

- Your name
- Your mobile number or email address (in case it is preferable to get in touch with you)

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your child/relative/friend's data will have a code number instead.

We will keep all information about your child/relative/friend safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your child/ relative/ friend took part in the study.

The video recordings that we take of your child/relative/friend completing the verbal tests will not be fully transcribed, and will only be used to write down the answers they give on the tests. We will use this video to record their answers within one week of them completing the tests. After one week, the video recording will be safely destroyed.

What are your choices about how your information is used?
Your child/ relative/ friend can stop being part of the study at any time, without giving a reason, but we will keep information about your child/ relative/ friend that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

After the study has been completed, your data continue to be stored in a secure location, only accessible by the research team, for 10 years, as recommended by the UK Research and Innovation (UKRI) guidelines. After this, all data will be destroyed.

If you wish, I can provide you with a copy of the results of this study once it is finished.

What if my child/ relative/ friend wants to withdraw?
Your child/ relative/ friend is free to withdraw from the research study at any time without explanation, disadvantage, or consequence. If they tell me that they would like to stop the video recording, any of the tests, or the discussions we are having at any point, we will stop these immediately.

They will be offered the chance to have a talk about how they are feeling with me (this is called a debrief) and I will give you both some resources of other people to speak to also. Any data collected about either of you, on paper, computer, or video, will be immediately and safely destroyed, and they will no longer be a participant in the study. They will still receive a £10 Amazon voucher for their time.

Separately, your child/relative/friend may also request to withdraw their data even after they have participated, provided that this request is made within **3 weeks** of the data being collected. After 3 weeks, names and other identifiable information will be deleted and their data will only be referred to by a numerical code, meaning we will no longer be able to identify which is their data.

If during your participation in the study your child/relative/friend loses the ability to consent, we will immediately stop testing and offer you both a debrief. We will then immediately and safely destroy their data, and they will no longer be included in the study. They will still receive a £10 Amazon voucher for their time.

Where can you find out more about how your information is used?
You can find out more about how we use your information

- At www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to u2075228@uel.ac.uk, or
- by ringing us on [redacted] copyright reasons

If you have any questions or concerns about how the research has been conducted, please contact:

- The research supervisor:
  Dr Matthew Jones Chesters,
  School of Psychology, University of East London, Water Lane, London E15 4LZ
  Email: m.h.jones-chesters@uel.ac.uk
  Phone: 020 8223 4603

or

- Chair of the School of Psychology Research Ethics Sub-committee:
  Dr Trishna Patel
  School of Psychology, University of East London, Water Lane, London E15 4LZ.
  Email: t.patel@uel.ac.uk

Appendix F: Charity Carer Invitation Letter

University of East London
School of Psychology

Assessment of Cognition in People with Intellectual Disabilities:

Carer Invitation Letter

Your child, relative or friend is being invited to participate in a research study. We have asked you to accompany them as their guardian and advocate. Before they agree to take part, it is important that you understand what their participation would involve. Please read the following information carefully before deciding.

Who am I?
My name is Zakiya, I am a student in the School of Psychology at the University of East London and am studying for a Doctorate in Clinical Psychology. As part of my studies, I am conducting the research your child, relative or friend is being invited to participate in.

What is the research?
I am conducting research into making an assessment tool which can see if somebody with a learning disability may also be experiencing dementia. Dementia is when someone experiences a loss of memory, language, problem-solving and other thinking abilities that may make daily life more difficult. There are many different types, the most common kind of dementia is called Alzheimer's. I would like to investigate whether dementia looks different in people who have a learning disability, so that we can identify it sooner and help people who experience it have better support and quality of life.

Our research has been approved by the University of East London Ethics Committee. This means that our research follows the standard of research ethics set by the British Psychological Society.

Why has my child/ relative/ friend been asked to participate?
Your child/ relative/ friend has been invited to participate in my research as someone who has Down Syndrome or other learning disability, and is aged between 18 and 55 years.

Your child/relative/friend will not be judged or personally analysed in any way and will be treated with respect at all times.

They do not have to say 'yes' to taking part, and there will be no consequences if they decide not to take part. They are free to choose what feels most comfortable to them.
What will their participation involve?

They will be asked to attend a 'testing session' with me. I will ask them to complete a series of short tasks including questionnaires and other short exercises exploring various skills and abilities including language, thinking and puzzle-solving. Some of these will involve me asking them questions, and others are pen-and-paper tasks, and some may involve them following instructions. Tasks with verbal answers will be video recorded so that their answers can be accurately scored and analysed. This will be safely stored on a password-protected computer and destroyed once the research has finished.

This will take around 1 hour. We will take a break in the middle where you and your child, relative or friend can have some snacks and drinks that I will provide for you, and your child, relative or friend can also take short breaks in between the different tasks if you wish. If your child/relative/friend needs, we could have two shorter sessions on two different days. I will also ask your child/ relative/friend to tell me what they thought of the tests, including what they think worked well and how they think I could make any of them better. This will take around half an hour, and can be done on the same day as the tests or a different day.

This will take place in a private room at a place of your choice at a tune we decide at a time in advance, that fits for us all.

What are the potential risks and disadvantages of taking part?
Though we do not anticipate any negative affects of participation, some may arise. Testing may make your child/relative/friend feel tired, which could lead to headaches. Taking part in some of the tests could also feel stressful. We will remind your child/ relative/ friend throughout to take breaks if they need, and provide refreshments while they take part in the testing session. We will also provide you both with services and organisations you can contact at the bottom of this sheet, and in a debrief letter.

What are the potential benefits of taking part?
As a thank you for your child/relative/friend's time, they will be given a £10 Amazon voucher. There may not be any specific benefits to them in participating, but by taking part they can help to create tests for dementia which are better suited to other people with a learning disability in the future.

What will happen to the information that my child/ relative/ friend provides?
We will need to use information from your child/ relative/ friend for this research project. This information will include:

- Their name
- Their mobile number or email address (to get in touch with them)
- The responses they give to the tests we try out together.

We will also ask for information from you, which will include:

- Your name

- Your mobile number or email address (in case it is preferable to get in touch with you)

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your child/relative/friend's data will have a code number instead.

We will keep all information about your child/relative/friend safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your child/ relative/ friend took part in the study.

The video recordings that we take of your child/relative/friend completing the verbal tests will not be fully transcribed, and will only be used to write down the answers they give on the tests. We will use this video to record their answers within one week of them completing the tests. After one week, the video recording will be safely destroyed.

What are your choices about how your information is used?
Your child/ relative/ friend can stop being part of the study at any time, without giving a reason, but we will keep information about your child/ relative/ friend that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

After the study has been completed, your data continue to be stored in a secure location, only accessible by the research team, for 10 years, as recommended by the UK Research and Innovation (UKRI) guidelines. After this, all data will be destroyed.

If you wish, I can provide you with a copy of the results of this study once it is finished.

What if my child/ relative/ friend wants to withdraw?
Your child/ relative/ friend is free to withdraw from the research study at any time without explanation, disadvantage, or consequence. If they tell me that they would like to stop the video recording, any of the tests, or the discussions we are having at any point, we will stop these immediately.

They will be offered the chance to have a talk about how they are feeling with me (this is called a debrief) and I will give you both some resources of other people to speak to also. Any data collected about either of you, on paper, computer, or video, will be immediately and safely destroyed, and they will no longer be a participant in the study. They will still receive a £10 Amazon voucher for their time.

Separately, your child/relative/friend may also request to withdraw their data even after they have participated, provided that this request is made within **3 weeks** of the data being collected. After 3 weeks, names and other identifiable information will be deleted and their data will only be referred to by a numerical code, meaning we will no longer be able to identify which is their data.

If during your participation in the study your child/relative/friend loses the ability to consent, we will immediately stop testing and offer you both a debrief. We will then immediately and safely destroy their data, and they will no longer be included in the study. They will still receive a £10 Amazon voucher for their time.

Where can you find out more about how your information is used?
You can find out more about how we use your information

- At www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to u2075228@uel.ac.uk, or
- by ringing us on [redacted] copyright reasons

If you have any questions or concerns about how the research has been conducted, please contact:

- The research supervisor:
  Dr Matthew Jones Chesters,
  School of Psychology, University of East London, Water Lane, London E15 4LZ
  Email: m.h.jones-chesters@uel.ac.uk
  Phone: 020 8223 4603

or

- Chair of the School of Psychology Research Ethics Sub-committee:
  Dr Trishna Patel
  School of Psychology, University of East London, Water Lane, London E15 4LZ.
  Email: t.patel@uel.ac.uk

Appendix G: UEL Ethics Application

University of East London

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS (Updated October 2021)

FOR BSc RESEARCH;
MSc/MA RESEARCH;
PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Section 1 – Guidance on Completing the Application Form (please read carefully)	
1.1	Before completing this application, please familiarise yourself with: ▪ British Psychological Society's Code of Ethics and Conduct ▪ UEL's Code of Practice for Research Ethics ▪ UEL's Research Data Management Policy ▪ UEL's Data Backup Policy
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must **NOT** commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).
1.5	Research in the NHS: ▪ If your research involves patients or service users of the NHS, their relatives or carers, as well as those in receipt of services provided under contract to the NHS, you will need to apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance. ▪ Useful websites: https://www.myresearchproject.org.uk/Signin.aspx

	https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/ ▪ If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required. ▪ HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example. ▪ The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
1.6	If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: https://fadv.onlinedisclosures.co.uk/Authentication/Login You may also find the following website to be a useful resource: https://www.gov.uk/government/organisations/disclosure-and-barring-service
1.7	Checklist, the following attachments should be included if appropriate: ▪ Study advertisement ▪ Participant Information Sheet (PIS) ▪ Participant Consent Form ▪ Participant Debrief Sheet ▪ Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5) ▪ Permission from an external organisation (see section 7) ▪ Original and/or pre-existing questionnaire(s) and test(s) you intend to use ▪ Interview guide for qualitative studies ▪ Visual material(s) you intend showing participants

Section 2 – Your Details		
2.1	**Your name:**	**Elicia McGregor & Zakiya Reid Wisdom**
2.2	**Your supervisor's name:**	**Dr Matthew Jones-Chesters**
2.3	**Name(s) of additional UEL supervisors:**	2nd supervisor
		3rd supervisor (if applicable)
2.4	**Title of your programme:**	**Doctorate in Clinical Psychology**
2.5	**UEL assignment submission date:**	**01/05/2024**
		Re-sit date (if applicable)

Section 3 – Project Details		
Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.		
3.1	**Study title:** Please note - If your study requires registration, the title inserted here must be the same as that on PhD Manager	Assessment of cognition in people with intellectual disabilities using a novel set of neuropsychological tests
3.2	**Summary of study background and aims (using lay language):**	People with an intellectual disability (learning disability) are living longer, partly due to better healthcare; but as people get older, they are more likely to develop dementia (problems in mental abilities, thinking and action). There are many different types of dementia, each affecting some mental abilities more than others. Dementia may present differently in people with intellectual disability, as they already have differences in mental abilities, compared to typically developed people. It is important to check for problems that might reflect the onset of dementia, so that proper help, care, and support can be given to the person and their family. The tests we now have available to check for dementia in people with intellectual disabilities have problems. Most do not check all areas of thinking and behaviour, and especially miss out the 'executive' functions (planning, organising, and control of thinking and action). Most require the person taking the test to have good language abilities. In this research, we are trying out new tests of mental abilities, that are specially designed for people with intellectual disabilities. The tests are quick but thorough, and look at a wide range of mental abilities, with the aim of finding where problems in thinking and action are emerging. In this study, we will try out the new tests with people who have Down syndrome and intellectual disabilities due to other causes. We will collect scores on the new tests, to make sure that they can find problems; and we will ask people with intellectual disabilities how they find the tests, and how they might be improved. This study aims to create a novel scalable diagnostic

		measure of dementia for people with intellectual disabilities, which is feasible, acceptable, and accessible. It will be made with accessible, low-cost materials for ease of use within the NHS.
3.3	**Research question(s):**	Is the test set we have designed for use with people with intellectual difficulties feasible? That is, do the tests involved give useful scores (not at floor or ceiling, and reflecting the range of typical functioning) in people with intellectual disabilities? Is this test set appropriate and acceptable for people with intellectual disabilities of other aetiologies? That is, is it engaging and involve materials that are appropriate for use with this population?
3.4	**Research design:**	Cross-sectional correlational design for analysis of feasibility; collecting preliminary quantitative data and qualitative feedback to address acceptability and inform future development of the test.
3.5	**Participants:** Include all relevant information including inclusion and exclusion criteria	Participants will be males and females with Down syndrome or other intellectual disabilities. Participants will be recruited through local day centres, clubs, societies, and charities which support people with Down syndrome or other intellectual disabilities. As this research is a feasibility design, it will not require an a-priori sample size calculation based on statistical power. Therefore, in total between all three researchers, we aim to recruit between 15-24 participants. This is suitable for a feasibility design, as a small number of participants will be sufficient to establish the feasibility, acceptability and accessibility of the novel battery, and this research is not attempting to establish normative data.
3.6	**Recruitment strategy:** Provide as much detail as possible and include a backup plan if relevant	Potential participants will be identified through local charities and day centres that specifically support individuals with intellectual disabilities. Potential participants aged 18-55 who are accessing the clubs/group/service, and their guardians, will either be approached by a staff member known to them at the service, or will be self-selected through registering their interest in the study through study posters that will be places around the charities/services. Only those wishing to hear more about the study (and who give permission to sharing

		their contact details) will be contacted by the researcher.	
3.7	**Measures, materials or equipment:** Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	The cognitive test set is a novel set created by the researchers, with some tests adapted from existing tests for people with intellectual disabilities, and some novel test formats. Some of these tests will be entirely novel (e.g.: olfactory recognition) reflecting an emerging literature which suggests that olfactory tests may be an effective and accessible way of accessing sensory dysfunction in dementia. Other tests will be formats of existing means of assessing cognitive function, tailored for the people with intellectual disabilities. A full outline of each test, in what order they will be done, and what the participants will be asked to do in the test verbatim, is provided in the appendices below.	
3.8	**Data collection:** Provide information on how data will be collected from the point of consent to debrief	Participant meetings will take approximately 1-1.5 hours, and occur in the charity or day centre in which the participant was recruited. Meetings will be video-recorded to ensure accurate scoring and interpretations of test accessibility. Upon expressing interest in the study, participants and guardians will first be sent a video including the researcher explaining the process and purpose of the study. They will then be invited to read the information sheet and ask questions, before signing the consent form if they agree to participate. An easy-read information sheet and assent form will also be provided. The researcher will speak with participants beforehand to ascertain their age, current mental state, and primary language. Refreshments will be provided. On the day of meeting, the procedure will include introductions, completing the test battery (with unlimited break options), and then acquiring feedback on the test set and potential improvements from participants and guardians. Afterward, participants will be given a debrief letter, easy-read debrief letter, and a £10 Love2Shop or Amazon voucher as thanks. The video explanation, information sheets, consent and debrief forms are all attached to this application.	
3.9	**Will you be engaging in deception?**	**YES** ☐	**NO** ☒

	If yes, what will participants be told about the nature of the research, and how/when will you inform them about its real nature?	If you selected yes, please provide more information here	
3.10	**Will participants be reimbursed?**	**YES** ☒	**NO** ☐
	If yes, please detail why it is necessary.	To pay the participants for their time and cover travel expenses.	
	How much will you offer? Please note - This must be in the form of vouchers, not cash.	£10 Love2Shop or Amazon voucher.	
3.11	**Data analysis:**	Quantitative and qualitative data will be analysed at the University of East London, on a university computer using the UEL IT systems, through SPSS and NVivo respectively, by the researchers.	

Section 4 – Confidentiality, Security and Data Retention			
It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations. If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.			
4.1	**Will the participants be anonymised at source?**	**YES** ☐	**NO** ☒
	If yes, please provide details of how the data will be anonymised.		
4.2	**Are participants' responses anonymised or are an anonymised sample?**	**YES** ☒	**NO** ☐
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed during transcription, pseudonyms used, etc.).	All data will be anonymised by assigning a numerical code instead of participant names. For up to 3 weeks after participation, a separate document will be kept which links names to their numerical code, in case participants decide to withdraw from the study during this period. After 3 weeks, names will be deleted from our records. Data will be stored and backed up to the UEL OneDrive, a secure and encrypted service. Once uploaded here, all records of data in paper or video camera format will be destroyed.	
4.3	**How will you ensure participant details will be kept confidential?**	Completed consent forms will be stored in a locked file folder drawer within UEL, under the care of the supervisor, before being destroyed. Pseudo-	

		anonymised data will be kept in a spreadsheet (.csv) within a folder separate to the identifiable data spreadsheet(.csv). We will back data up to the UEL H: drive, managed by logging in to a UEL managed computer. Identifiable data will be destroyed after 3 weeks of collection, retained only in the case that participants wish to withdraw in this time. Links to the folder will be password-protected. The only people with access to this folder will be the researcher and the supervisors.
4.4	**How will data be securely stored and backed up during the research?** Please include details of how you will manage access, sharing and security	Participant responses will be video-recorded and stored as .mp4 files, to ensure accurate scoring and interpretations of test accessibility. This will be immediately uploaded to OneDrive for Business after collection through a UEL computer, using a USB cable link. The video will then be deleted from the device. Paper data will be immediately entered into a .sav SPSS file, kept within OneDrive for Business. All information provided and recorded will be kept strictly confidential. Data will be uploaded to the UEL OneDrive, which is a secure, encrypted online service. After uploading, all paper information will be safely destroyed, alongside data on the video camera. A spreadsheet (.csv) file containing locations of all data available will accompany this as metadata. This spreadsheet will be encrypted (password-protected). Only the researcher and supervisor will have access to this password. Locations for a sample of the completed questionnaire, blank consent forms, participant information sheets and scoring guides will also be included in this spreadsheet.
4.5	**Who will have access to the data and in what form?** (e.g., raw data, anonymised data)	Only the researchers and principal investigator will have access to data during the study.
4.6	**Which data are of long-term value and will be retained?** (e.g., anonymised interview transcripts, anonymised databases)	No personal/pseudo-anonymised data of long-term value will be collected, as this is a pilot study. Data kept will be on tool administration and anonymised data for prospective norms. These will be kept in the UEL OneDrive during analysis and write-up, and in the UEL data repository after analysis. Data will be preserved in UEL's data repository (https://repository.uel.ac.uk).

4.7	**What is the long-term retention plan for this data?**	After the study has been completed, data will continue to be stored in this secure location, only accessible by the research team, for 10 years, as recommended by the UK Research and Innovation (UKRI) guidelines. After this, all data will be destroyed. This data will not contain sensitive information and so will be suitable for sharing via the repository	
4.8	**Will anonymised data be made available for use in future research by other researchers?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐
4.9	**Will personal contact details be retained to contact participants in the future for other research studies?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐

Section 5 – Risk Assessment			
If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.			
5.1	**Are there any potential physical or psychological risks to participants related to taking part?** (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	**YES** ☒	**NO** ☐
	If yes, what are these, and how will they be minimised?	There is a risk of taking part in any in-person research during this endemic phase of the COVID19 pandemic. To minimise risk of infection for the participant, current guidelines will be followed i.e., masks will be worn, the room will be large enough for social distancing and hands and surfaces will be regularly washed/sanitized. The researchers will be completing lateral flow tests twice a week and will isolate for 10 days if the test is positive. The	

		researchers will adhere to the NHS and school's policies and processes for risk assessments.		
5.2	**Are there any potential physical or psychological risks to you as a researcher?**	**YES** ☒	**NO** ☐	
	If yes, what are these, and how will they be minimised?	There is a small risk of completing the research during this endemic phase of the pandemic. To minimise risk of infection for the researcher, guidelines will be followed i.e., masks will be worn, the room will be large enough for social distancing and hands and surfaces will be regularly washed/sanitized. The researchers have received both doses of the vaccine and will be completing lateral flow tests twice a week.		
5.3	**If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that you have attached a GRA form as an appendix:**	**YES** ☒		
5.4	**If necessary, have appropriate support services been identified in material provided to participants?**	**YES** ☐	**NO** ☐	**N/A** ☒
5.5	**Does the research take place outside the UEL campus?**	**YES** ☒	**NO** ☐	
	If yes, where?	In a private room in the participant's local day centre/charity/ supported living.		
5.6	**Does the research take place outside the UK?**	**YES** ☐	**NO** ☒	
	If yes, where?	Please state the country and other relevant details		
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard).	**YES** ☐		

	Please confirm a Country-Specific Risk Assessment form has been attached as an appendix. Please note - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics survey), regardless of the location of the researcher or the participants.		
5.7	**Additional guidance:** ▪ For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance. ▪ For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Director of Impact and Innovation, Professor Ian Tucker (who may escalate it up to the Vice Chancellor). ▪ For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must also be carried out. To minimise risk, it is recommended that such students only conduct data collection online. If the project is deemed low risk, then it is not necessary for the risk assessment to be signed by the Director of Impact and Innovation. However, if not deemed low risk, it must be signed by the Director of Impact and Innovation (or potentially the Vice Chancellor). ▪ Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.		

Section 6 – Disclosure and Barring Service (DBS) Clearance			
6.1	**Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?** If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project	**YES** ☒	**NO** ☐
	* You are required to have DBS or equivalent clearance if your participant group involves:		

	(1) Children and young people who are 16 years of age or under, or (2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak with your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible.		
6.2	**Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?**	**YES** ☒	**NO** ☐
6.3	**Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?**	**YES** ☒	**NO** ☐
6.4	**If you have current DBS clearance, please provide your DBS certificate number:**	Elicia McGregor: 001793921860; Zakiya Reid-Wisdom	
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	Please provide details of the type of clearance, including any identification information such as a certificate number	
6.5	**Additional guidance:** ▪ If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian). ▪ For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.		

Section 7 – Other Permissions			
7.1	**Does the research involve other organisations (e.g., a school, charity, workplace, local authority, care home, etc.)?**	**YES** ☒	**NO** ☐
	If yes, please provide their details.	Charities and local day centres will be approached once ethical approval has been granted for the research to take place.	
	If yes, written permission is needed from such organisations (i.e., if they are helping you with	**YES** ☐	

	recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation). Please confirm that you have attached written permission as an appendix.	
7.2	**Additional guidance:** ▪ Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as 'my' or 'I' with 'our organisation' or with the title of the organisation. This organisational consent form must be signed before the research can commence. ▪ If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s.	

Section 8 – Declarations		
8.1	**Declaration by student. I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor:**	**YES** ☒
8.2	**Student's name:** (Typed name acts as a signature)	Elicia McGregor & Zakiya Reid-Wisdom
8.3	**Student's number:**	Elicia U1945505; Zakiya u2075228
8.4	**Date:**	26/07/2023
Supervisor's declaration of support is given upon their electronic submission of the application		

Student checklist for appendices – ***for student use only***

Documents attached to ethics application	**YES**	**N/A**
Study advertisement	☒	☐
Participant Information Sheet (PIS)	☒	☐
Consent Form	☒	☐
Participant Debrief Sheet	☒	☐
Risk Assessment Form	☒	☐

Country-Specific Risk Assessment Form	☐	☒
Permission(s) from an external organisation(s)	☒	☐
Pre-existing questionnaires that will be administered	☐	☒
Researcher developed questionnaires/questions that will be administered	☒	☐
Pre-existing tests that will be administered	☐	☒
Researcher developed tests that will be administered	☒	☐
Interview guide for qualitative studies	☐	☒
Any other visual material(s) that will be administered	☐	☒
All suggested text in RED has been removed from the appendices	☒	☐
All guidance boxes have been removed from the appendices	☒	☐

Appendix H: UEL Ethics Approval Letter

University of East London

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in **blue** | **Student:** Please complete/read sections in **orange**

Details

Reviewer:	Please type your full name **Fevronia Christodoulidi**
Supervisor:	Please type supervisor's full name **Matthew Jones Chesters**
Student:	Please type student's full name **Elicia McGregor and Zakiya Reid-Wisdom**
Course:	Please type course name **Prof Doc Clinical in Psychology**
Title of proposed study:	Assessment of cognition in people with intellectual disabilities using a novel set of neuropsychological tests

Checklist
(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☐	☐
Detailed account of participants, including inclusion and exclusion criteria	☐	☐	☐
Concerns regarding participants/target sample	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☐	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☐

If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☐	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☐	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☐	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☐	☐
If required, General Risk Assessment form attached	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☐
If required, a DBS or equivalent certificate number/information provided	☐	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☐	☐	☐
All relevant information included in the participant information sheet (PIS)	☐	☐	☐
Information in the PIS is study specific	☐	☐	☐
Language used in the PIS is appropriate for the target audience	☐	☐	☐
All issues specific to the study are covered in the consent form	☐	☐	☐
Language used in the consent form is appropriate for the target audience	☐	☐	☐
All necessary information included in the participant debrief sheet	☐	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☐	☐	☐
Study advertisement included	☐	☐	☐
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	☐	☐	☐

Decision options	
APPROVED	Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice), to the date it is submitted for assessment.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made **before** the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	In this circumstance, a revised ethics application **must** be submitted and approved **before** any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious

	concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision:	**APPROVED**

Minor amendments

Please clearly detail the amendments the student is required to make

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher

Has an adequate risk assessment been offered in the application form?	**YES** ☒	**NO** ☐
	If no, please request resubmission with an **adequate risk assessment.**	
If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐

MEDIUM	Approve but include appropriate recommendations in the below box.	☐
LOW	Approve and if necessary, include any recommendations in the below box.	☒
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer's signature

Reviewer: (Typed name to act as signature)	**Dr Fevronia Christodoulidi**
Date:	**01/08/2023**

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data

Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a date

Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required

Appendix I: UEL Amendment Request for Easy Read Materials

University of East London

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request	
1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents	
A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details	
Name of applicant:	Zakiya Reid-Wisdom
Programme of study:	Professional Doctorate Clinical Psychology
Title of research:	Assessment of cognition in people with intellectual disabilities using a novel set of neuropsychological tests
Name of supervisor:	M Jones Chesters

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
PIS easy-read amended	PIS easy-read format and text have been updated to reflect best practice.
Easy-read participant consent form amended	Easy-read consent form format and text has been updated to reflect best practice.
Easy-read debrief sheet amended	Easy-read debrief sheet format and text have been updated to reflect best practice.
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student's signature

Student: (Typed name to act as signature)	**Zakiya Reid-Wisdom**
Date:	**05/07/2024**

Reviewer's decision

Amendment(s) approved:	YES ☒	NO ☐
Comments:	Page 26, Debrief Form, Question 'Can I have a copy', the response is incomplete.	

Reviewer: (Typed name to act as signature)	Trishna Patel
Date:	15/07/2024

Appendix J: NHS Ethics Approval

Dr Matthew Jones-Chesters
Senior Lecturer
The University of East London
UEL School of Psychology
Water Lane
London
E15 4LZ

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

10 August 2022

Dear Dr Jones-Chesters

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Assessment of cognition in people with intellectual disabilities using a novel set of neuropsychological tests**
IRAS project ID:	**295654**
REC reference:	**22/WA/0238**
Sponsor	**University of East London**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Appendix K: UEL EISC Ethics Approval Letter

University of East London
Pioneering Futures Since 1898

7th January 2025

Dear Zakiya,

Project Title:	**Assessment of cognition in people with intellectual disabilities using a novel set of neuropsychological tests**
Researcher(s):	**Ms Zakiya Reid-Wisdom**
Principal Investigator:	**Dr Matthew Jones-Chesters**

I am writing to confirm that the application for the aforementioned NHS research study reference: **22/WA/0238**, IRAS project ID: **295654,** Amendment number: **295654/310723** has received ethical approval from the Ethics and Integrity Sub-Committee (EISC) and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **21st August 2027**. If you require EISC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why EISC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

With the Committee's best wishes for the success of this project.

Yours sincerely,

[redacted]

Catherine Hitchens, Ethics, Integrity and Compliance Manager
For and on behalf of
Professor Winston Morgan
Chair, Ethics and Integrity Sub-Committee (EISC)
Email: researchethics@uel.ac.uk

Appendix L: NHS Substantial Ethics Amendment Request and Approval

Amendment Tool

v1.6 06 December 2021

For office use

QC: No

Section 1: Project information

Short project title*:	Assessment of cognition in people with intellectual disabilities
IRAS project ID* (or REC reference if no IRAS project ID is available):	295654
Sponsor amendment reference number*:	295654/310723
Sponsor amendment date* (enter as DD/MM/YY):	31 July 2023
Briefly summarise in lay language the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study. If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained (note: this field will adapt to the amount of text entered)*:	1. As the research programme is ongoing, another doctoral student (Ms Zakiya REID-WISDOM) will join the project team, undertaking data collection and analysis. Ms Reid-Wisdom is being supervised by the CI, Dr Matthew Jones Chesters. 2. At present, study participation is limited to people who have Down's syndrome. We would like to extend participation to people who have a learning difficulty for any reason. This will make recruitment easier at the involved clinical centres, and be more inclusive of the range of people affected by a learning disability. 3. . At present, we have restricted participation to adults aged from 30 years up to 55 years. We would like to extend the lower age for participation to age 18 years. This will make the study more inclusive of younger people and widen the range of application of the next draft of the test set. 4. We would like to add [redacted] as a research site for the study and have a clinician in the [redacted] who is prepared to join the study and recruit participants from the service client lists.

Project type (select):	**Specific study**			
	Research tissue bank			
	Research database			
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REC) prior to this amendment?:	**Yes**		No	
What type of UKECA-recognised Research Ethics Committee (REC) review is applicable? (select):	**NHS/HSC REC**			
	Ministry of Defence (MoDREC)			
Is all or part of this amendment being resubmitted to the Research Ethics Committee (REC) as a **modified amendment** (i.e. a substantial amendment previously given an unfavourable opinion)?	Yes		**No**	
Where is the NHS/HSC Research Ethics Committee (REC) that reviewed the study based?:	England	Wales	Scotland	Northern Ireland
	No	**Yes**	No	No
Was the study a clinical trial of an investigational medicinal product (CTIMP) OR does the amendment make it one?:	Yes		**No**	
Was the study a clinical investigation or other study of a medical device OR does the amendment make it one?:	Yes		**No**	
Did the study involve the administration of radioactive substances, therefore requiring ARSAC review, OR does the amendment introduce this?:	Yes		**No**	
Did the study involve the use of research exposures to ionising radiation (not involving the administration of radioactive substances) OR does the amendment introduce this?:	Yes		**No**	
Did the study involve adults lacking capacity OR does the amendment introduce this?:	**Yes**		No	
Did the study involve access to confidential patient information outside the direct care team without consent OR does the amendment introduce this?:	Yes		**No**	
Did the study involve prisoners or young offenders who are in custody or supervised by the probation service OR does the amendment introduce this?:	Yes		**No**	
Did the study involve children OR does the amendment introduce this?:	Yes		**No**	
Did the study involve NHS/HSC organisations prior to this amendment?:	**Yes**		No	

Did the study involve non-NHS/HSC organisations OR does the amendment introduce them?:	Yes		**No**	
	England	Wales	Scotland	Northern Ireland
Lead nation for the study:	**Yes**	No	No	No
Which nations had participating NHS/HSC organisations prior to this amendment?	**Yes**	No	No	No
Which nations will have participating NHS/HSC organisations after this amendment?	**Yes**	No	No	No
Was this a "single site, self sponsored" study in England or Wales prior to this amendment?	Yes		**No**	

Section 2: Summary of change(s)

Please note: Each change being made as part of the amendment must be entered separately. For example, if an amendment to a clinical trial of an investigational medicinal product (CTIMP) involves an update to the Investigator's Brochure (IB), affecting the Reference Safety Information (RSI) and so the information documents to be given to participants, these should be entered into the Amendment Tool as three separate changes. A list of all possible changes is available on the "Glossary of Amendment Options" tab. To add another change, click the "Add another change" box.

Change 1	
Area of change (select)*:	Researchers
Specific change (select - only available when area of change is selected first)*:	CI - New CI, or temporary arrangements to cover the absence of a CI
Further information (free text - note that this field will adapt to the amount of text entered):	As the project is ongoing, another clinical psychology doctoral student will join the project, undertaking data collection and analysis. Title Forename/Initials Surname: Ms Zakiya REID-WISDOM Address: [redacted] Post Code: [redacted] E-mail: u2075228@uel.ac.uk Telephone: [redacted] Name and level of course/ degree: Professional Doctorate in Clinical Psychology (DClinPsy) Name of educational establishment: University of East London

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	**Yes**	No	No	No
Will all participating NHS/HSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	
			Remove all changes below	

Change 2	
Area of change (select)*:	Participant Procedures
Specific change (select - only available when area of change is selected first)*:	Recruitment - Change in identification, approach, recruitment or consent of participants
Further information (free text - note that this field will adapt to the amount of text entered):	In addition to recruiting participants with a diagnosis of Down's Syndrome (DS), we would like to extend participation to people who have a learning difficulty (intellectual disability, ID/LD) of any kind/aetiology. This will make the study more inclusive of people with ID/LD who do not have DS. Our other inclusion and exclusion criteria, and processes for recruitment and consent will remain the same, including that the participants should have capacity to consent to taking part in the study.

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	**Yes**	No	No	No
Will all participating NHS/HSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	
			Remove all changes below	

Change 3	
Area of change (select)*:	Participant Procedures

Specific change (select - only available when area of change is selected first)*:	Recruitment - Change in identification, approach, recruitment or consent of participants
Further information (free text - note that this field will adapt to the amount of text entered):	At present, we have restricted participation to adults aged from 30 years up to 55 years. We would like to extend the lower age for participation to age 18 years. This will make the study more inclusive of younger people and widen the range of application of the next draft of the test set.

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	**Yes**	No	No	No
Will all participating NHS/HSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	
			Remove all changes below	

Change 4	
Area of change (select)*:	Participating Organisations
Specific change (select - only available when area of change is selected first)*:	Addition of sites undertaking the same activities as existing sites
Further information (free text - note that this field will adapt to the amount of text entered):	4. We would like to add [redacted] as a research site for the study and have a clinician in the [redacted] service [redacted] who is prepared to join the study and recruit participants from the service client lists. [redacted] have been informed.

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	**Yes**	No	No	No
Will all participating NHS/HSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	
			Add another change	

Section 3: Declaration(s) and lock for submission

Declaration by the Sponsor or authorised delegate

- I confirm that the Sponsor takes responsibility for the completed amendment tool
- I confirm that I have been formally authorised by the Sponsor to complete the amendment tool on their behalf

*Name [first name and surname]**:	Trishna Patel
*Email address**:	t.patel@uel.ac.uk

Lock for submission

Please note: This button will only become available when all mandatory (*) fields have been completed. When the button is available, clicking it will generate a locked PDF copy of the completed amendment tool which must be included in the amendment submission. Please ensure that the amendment tool is completed correctly before locking it for submission.

Lock for submission

After locking the tool, proceed to submit the amendment online. The "Submission Guidance" tab provides further information about the next steps for the amendment.

Section 4: Review bodies for the amendment

Please note: This section is for **information only**. Details in this section will complete automatically based on the options selected in Sections 1 and 2.

Review bodies															
UK wide:						England and Wales:				Scotland:				Northern Ireland:			
									ireau				function				function

	REC	Competent Authority MHRA - Medicines	Competent Authority MHRA - Devices	ARSAC	Radiation Assurance	UKSW Governance	REC (MCA)	CAG	HMPPS	HRA and HCRW App	REC (AWIA)	PBPP	SPS (RAEC)	National coordinating	HSC REC	HSC Data Guardians	Prisons	National coordinating	Category:
Change 1:	Y					Y				(Y)									C
Change 2:	Y					Y				Y									A
Change 3:	Y					Y				Y									A
Change 4:	N					(Y)				(Y)									New site
Overall reviews for the amendment:																			
Full review:	Y					Y				Y									
Notification only:	N					N				N									
Overall amendment type:	Substantial																		
Overall Category:	A																		

For national coordinating function office use:	
Update HARP:	This amendment may involve an update to contact details, project end date, or other project details. Ensure that HARP is updated with the current details. If this is the only change, no further study-wide review is required.

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 3
Cardiff

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

22 August 2023

Dr Matthew Jones-Chesters
Senior Lecturer
The University of East London
School of Psychology
Water Lane, London
E15 4LZ

Dear Dr Jones-Chesters

Study title:	**Assessment of cognition in people with intellectual disabilities using a novel set of neuropsychological tests**
REC reference:	**22/WA/0238**
Amendment number:	**295654/310723**
Amendment date:	**31 July 2023**
IRAS project ID:	**295654**

The above amendment was reviewed at the meeting of the Sub-Committee held on 21 August 2023 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment_Tool_v1_6 (IRAS Project 295654) v1.01 of 31July2023]	1.01	31 July 2023
Letters of invitation to participant [CARER INVITATION LETTER (04August2023)]	V1.04	04 August 2023
Other [PARTICIPANT DEBRIEF LETTER EASY-READ (04August2023)]	V1.04	04 August 2023
Other [PARTICIPANT INFORMATION LETTER EASY-READ (04August2023)]	V1.04	04 August 2023

Other [PARTICIPANT INVITATION LETTER (04August2023)]	V1.04	04 August 2023
Other [PARTICIPANT RECRUITMENT POSTER (04August2023)]	V1.04	04 August 2023
Other [Amendment Documents Versions (04August 2023)]		04 August 2023
Other [RE Amendment 22WA0238AM02]		04 August 2023
Participant consent form [CARER CONSENT FORM (04August2023)]	V1.04	04 August 2023
Participant consent form [PARTICIPANT CONSENT FORM (04Aug2023).]	V1.04	04 August 2023
Research protocol or project proposal [RESEARCH STUDY PROTOCOL (04August2022).]	V1.04	04 August 2023

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 295654:	**Please quote this number on all correspondence**

Yours sincerely

[redacted]

PP Miss Joanne Love
Dr Supriya Kapas
Chair

E-mail: Wales.REC3@wales.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Miss Danielle Pearce*
Ms Catherine Hitchens

Wales REC 3

Attendance at Sub-Committee of the REC meeting on 21 August 2023

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Supriya Kapas	Quality Assurance Pharmacist / Histopathology Quality Manager	Yes	Chaired Meeting
Mr Gwyn Morris	Retired - Deputy Director. Colindale Site, National Standards, Quality and Safety	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Joanne Love	Approvals Administrator (minuted meeting)

Appendix M: NHS Non-Substantial Amendment Request and Email Receipt

Amendment Tool

v1.6 06 December 2021

For office use

QC: No

Section 1: Project information

Short project title*:	Assessment of cognition in people with intellectual disabilities
IRAS project ID* (or REC reference if no IRAS project ID is available):	295654
Sponsor amendment reference number*:	295654-090224
Sponsor amendment date* (enter as DD/MM/YY):	09 February 2024
Briefly summarise in lay language the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study. If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained (note: this field will adapt to the amount of text entered)*:	1. As the research programme is ongoing, we are asking to extend the data collection period to 1st July 2024. 2. A data collection centre at [redacted] added in our last amendment. Our patient facing materials have been updated to include the new contact details and locations, and to be consistent with the accessible (easy-read) written communcation style of the new service.

Project type (select):	**Specific study**			
	Research tissue bank			
	Research database			
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REC) prior to this amendment?:	**Yes**		No	
What type of UKECA-recognised Research Ethics Committee (REC) review is applicable? (select):	**NHS/HSC REC**			
	Ministry of Defence (MoDREC)			
Is all or part of this amendment being resubmitted to the Research Ethics Committee (REC) as a **modified amendment** (i.e. a substantial amendment previously given an unfavourable opinion)?	Yes		**No**	
Where is the NHS/HSC Research Ethics Committee (REC) that reviewed the study based?:	England	Wales	Scotland	Northern Ireland
	No	**Yes**	No	No
Was the study a clinical trial of an investigational medicinal product (CTIMP) OR does the amendment make it one?:	Yes		**No**	
Was the study a clinical investigation or other study of a medical device OR does the amendment make it one?:	Yes		**No**	
Did the study involve the administration of radioactive substances, therefore requiring ARSAC review, OR does the amendment introduce this?:	Yes		**No**	
Did the study involve the use of research exposures to ionising radiation (not involving the administration of radioactive substances) OR does the amendment introduce this?:	Yes		**No**	
Did the study involve adults lacking capacity OR does the amendment introduce this?:	**Yes**		No	
Did the study involve access to confidential patient information outside the direct care team without consent OR does the amendment introduce this?:	Yes		**No**	
Did the study involve prisoners or young offenders who are in custody or supervised by the probation service OR does the amendment introduce this?:	Yes		**No**	
Did the study involve children OR does the amendment introduce this?:	Yes		**No**	
Did the study involve NHS/HSC organisations prior to this amendment?:	**Yes**		No	
Did the study involve non-NHS/HSC organisations OR does the amendment introduce them?:	Yes		**No**	
	England	Wales	Scotland	Northern Ireland
Lead nation for the study:	**Yes**	No	No	No
Which nations had participating NHS/HSC organisations prior to this amendment?	**Yes**	No	No	No
Which nations will have participating NHS/HSC organisations after this amendment?	**Yes**	No	No	No
Was this a "single site, self sponsored" study in England or Wales prior to this amendment?	Yes		**No**	

Section 2: Summary of change(s)

Please note: Each change being made as part of the amendment must be entered separately. For example, if an amendment to a clinical trial of an investigational medicinal product (CTIMP) involves an update to the Investigator's Brochure (IB), affecting the Reference Safety Information (RSI) and so the information documents to be given to participants, these should be entered into the Amendment Tool as three separate changes. A list of all possible changes is available on the "Glossary of Amendment Options" tab. To add another change, click the "Add another change" box.

Change 1				
Area of change (select)*:	Study Design			
Specific change (select - only available when area of change is selected first)*:	Extension to study duration that will not have any additional resource implications for participating organisations - Please specify in the free text below			
Further information In particular, please describe why this change can be implemented within the existing resource in place at the participating organisations (free text - note that this field will adapt to the amount of text entered)*	As the research programme is ongoing, we are asking to extend the data collection period to 1st July 2024.			
Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	**Yes**	No	No	No
Will all participating NHS/HSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	
			Remove all changes below	

Change 2				
Area of change (select)*:	Study Documents			
Specific change (select - only available when area of change is selected first)*:	Other minor change to study documents (e.g. information sheets, consent forms, questionnaires, letters) that can be implemented within existing resource in place at participating organisations - Please specify in the free text below			
Further information In particular, please describe why this change can be implemented within the existing resource in place at the participating organisations (free text - note that this field will adapt to the amount of text entered)*	A data collection centre at [redacted] added in our last amendment. Our patient-facing materials have been updated to include the new contact details and locations, and to be consistent with the accessible (easy-read) written communcation style of the new service.			
Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	**Yes**	No	No	No
Will all participating NHS/HSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	
			Remove all changes below	

Change 3				
Area of change (select)*:	Administrative details for the project			
Specific change (select - only available when area of change is selected first)*:	Contact details - CI or other project staff			
Further information (free text - note that this field will adapt to the amount of text entered):	Due to a change in staff teams, [redacted]			
Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?*:	**Yes**	No	No	No
Will all participating NHS/HSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	
			Add another change	

Section 3: Declaration(s) and lock for submission

Declaration by the Sponsor or authorised delegate

- I confirm that the Sponsor takes responsibility for the completed amendment tool
- I confirm that I have been formally authorised by the Sponsor to complete the amendment tool on their behalf

Name [first name and surname]:*	Trishna Patel
Email address:*	t.patel@uel.ac.uk

Lock for submission

Please note: This button will only become available when all mandatory (*) fields have been completed. When the button is available, clicking it will generate a locked PDF copy of the completed amendment tool which must be included in the amendment submission. Please ensure that the amendment tool is completed correctly before locking it for submission.

Lock for submission

After locking the tool, proceed to submit the amendment online. The "Submission Guidance" tab provides further information about the next steps for the amendment.

Section 4: Review bodies for the amendment

Please note: This section is for **information only**. Details in this section will complete automatically based on the options selected in Sections 1 and 2.

	Review bodies																	
	UK wide:						England and Wales:				Scotland:				Northern Ireland:			
	REC	Competent Authority MHRA - Medicines	Competent Authority MHRA - Devices	ARSAC	Radiation Assurance	UKSW Governance	REC (MCA)	CAG	HMPPS	HRA and HCRW Approval	REC (AWIA)	PBPP	SPS (RAEC)	National coordinating function	HSC REC	HSC Data Guardians	Prisons	National coordinating function	Category:
Change 1:	N					(Y)				(Y)									C
Change 2:	N					(Y)				(Y)									C
Change 3:	(Y)					Y				(Y)									C
Overall reviews for the amendment:																			
Full review:	N					Y				N									
Notification only:	Y					N				Y									
Overall amendment type:	Non-substantial																		
Overall Category:	C																		

For national coordinating function office use:	
Update HARP:	This amendment may involve an update to contact details, project end date, or other project details. Ensure that HARP is updated with the current details. If this is the only change, no further study-wide review is required.

From: no-reply-IRAS <no-reply-iras@hra.nhs.uk>
Sent: 16 February 2024 08:52
To: Matthew Jones Chesters <m.h.jones-chesters@uel.ac.uk>
Subject: IRAS 295654. Amendment

IRAS Project ID: 295654
Sponsor amendment reference: 295654-090224

Thank you for submitting a non-substantial amendment. Your amendment will be processed, and you will receive further communication in due course.

Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.

Please note that acknowledgement from NHS Research Ethics is not required for non-substantial amendments.

Appendix N: Participant Consent Form

University of East London
School of Psychology

Assessment of Cognition in People with Intellectual Disabilities:

Participant Consent Form

		Please Initial
1.	I confirm that I have read and understood the information sheet for this study, and I have been given a copy of this to keep.	
2.	I confirm that the nature and purposes of this study have been explained to me, and I have been able to ask questions that have been answered to my satisfaction.	
3.	I understand that my involvement in this study and data produced will remain strictly confidential. I understand that only the researcher conducting this study will have access to identifiable information. The researcher has explained what will happen to my data once the research study has been completed. I understand what will happen to my data once the research study has been completed.	
4.	I understand that my participation in this study is entirely voluntary and that I am free to withdraw from the study at any time without having to give a reason.	
5.	I understand that I am entitled to a break in the middle of testing, where snacks and drinks will be provided for me. I understand that I am also entitled to unlimited additional rest breaks upon request.	
6.	I understand that I will be video recorded during my participation, and this will be used for data analysis. I consent to being video recorded for participation in this research.	
7.	I understand that the recording device or tests can be stopped at any time without giving a reason. I understand that if I request to stop the recording devices or tests, that I will be offered a debrief and my data will be safely destroyed. I understand that this will not affect my receipt of a £10 Amazon gift voucher.	
8.	I understand that I can choose to withdraw my data from this study at any point **up to 3 weeks after participating.** I understand that after 3 weeks from my participation date, the researcher reserves the right to use my anonymous data in the analysis for this study.	
9.	**Given the above points, I hereby freely consent to participate in this study.**	

Participant's Name (BLOCK CAPITALS)	Date	Signature
Carer's Name (BLOCK CAPITALS)	Date	Signature

Researcher's Name (BLOCK CAPITALS)	Date	Signature

Appendix O: Carer Consent Form

ID:

University of East London
School of Psychology

Assessment of Cognition in People with Intellectual Disabilities:

Carer Consent Form

		Please Initial
1.	I confirm that I have read and understood the information sheet for this study (Carer Information Letter v1.04), and I have been given a copy of this to keep.	
2.	I confirm that the nature and purposes of this study have been explained to me, and I have been able to ask questions that have been answered to my satisfaction.	
3.	I understand that I have been asked to accompany my child / relative / friend during the study as their guardian and advocate, to ensure the study treats them fairly and with respect at all times.	
4.	I understand that my child / relative / friend's involvement in this study and data produced will remain strictly confidential. I understand that only the researcher conducting this study will have access to identifiable information. The researcher has explained what will happen to my child/ relative/ friend's data once the research study has been completed. I understand what will happen to my child/ relative/ friend's data once the research study has been completed.	
5.	I understand that my child / relative / friend's participation in this study is entirely voluntary and that they are free to withdraw from the study at any time without having to give a reason.	
6.	I understand that my child / relative / friend is entitled to a break in the middle of testing, where snacks and drinks will be provided. I understand that they are also entitled to unlimited additional rest breaks upon request.	
7.	I understand that my child / relative / friend will be video recorded during their participation, and this will be used for data analysis. I consent to my child/ relative/ friend being video recorded for participation in this research.	
8.	I understand that the recording device or tests can be stopped at any time without giving a reason. I understand that if my child / relative / friend requests to stop the recording devices or tests, that we will be offered a debrief and their data will be safely destroyed. I understand that this will not affect their receipt of a £10 Amazon voucher.	
9.	I understand that my child / relative / friend can choose to withdraw their data from this study at any point **up to 3 weeks after participating.** I understand that after 3 weeks from their participation date, the researcher reserves the right to use their anonymous data in the analysis for this study.	
10.	**Given the above points, I hereby freely consent to my accompaniment to my child / relative / friend's participation in this study.**	

Participant's Name (BLOCK CAPITALS) Date Signature

Carer’s Name (BLOCK CAPITALS)	Date	Signature
Researcher's Name (BLOCK CAPITALS)	Date	Signature

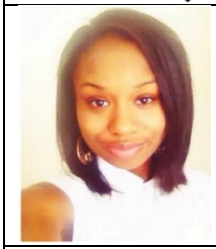
Appendix P: NHS Easy Read Invitation Letter

University of East London
School of Psychology

Assessment of Cognition in People with Intellectual Disabilities

Participant Information Letter (Easy-Read)

University of East London

	**What is this meeting about?**
	My name is Zakiya
	I am a clinical psychologist in training.
	I am doing some research.
	We want to learn more about dementia in people with learning disabilities.

We want to know what you think about the tests for dementia.

What is Dementia?

Dementia is an illness that causes memory difficulties.

A person with dementia may

- forget things

- feel different
- find everyday activities harder

- find things harder over time

We do not think you have dementia

	**Who can take part in the research?**
	People with a learning disability.
	Age 18 – 55 years old.
	People who do not have dementia.
	The research has been approved by the NHS Ethics Committee.
	This means that they think it is safe to take part in.

What will happen in the research meeting?

[redacted]

We will meet at XX or XXX

I will ask you to try out our new test for dementia.

There will be some

- questions
- puzzles
- drawing

I will video you doing the test.

if you are happy for me to.

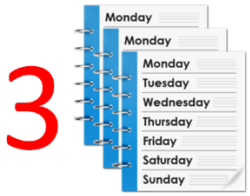
	I will ask what you think about the dementia test.
	I will write down your ideas.
	It will take 1 hour.
	You can stop or take a break at any time.
	There will be snacks.
	We will give you a £10 Amazon voucher as a thank you.

	**What will happen to my information?**
	Your personal information will be kept private.
	Your information be kept in a file that is protected with a password.
	We will put everyone's ideas in a big report.
	Your name will be kept private.
	We will share the report with researchers and learning disabilities teams.
	This will help teams to support people with dementia.

What if I change my mind?

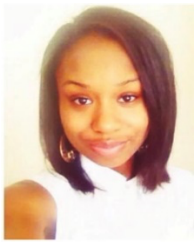
You can stop taking part at any time.

You can ask for your information
to be removed from the research.



If you want to remove your
information
you must let me know in 3 weeks.

If you have any questions



please call me on 020 8223 4603

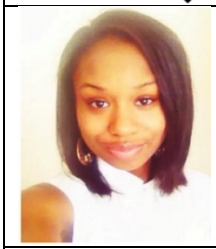
Or email me on:
u2075228@uel.ac.uk

Appendix Q: Charity Easy Read Invitation Letter

University of East London
School of Psychology

Assessment of Cognition in People with Intellectual Disabilities

Participant Information Letter (Easy-Read)

	**What is this meeting about?**
	My name is Zakiya
	I am a clinical psychologist in training.
	I am doing some research.

We want to learn more about dementia in people with learning disabilities.

We want to know what you think about the tests for dementia.

What is Dementia?

Dementia is an illness that causes memory difficulties.

A person with dementia may

- forget things

- feel different
- find everyday activities harder

- find things harder over time

We do not think you have dementia

Who can take part in the research?

People with a learning disability.

Age 18 – 55 years old.

People who do not have dementia.

University of East London

The research has been approved by the UEL Ethics Committee.

This means that they think it is safe to take part in.

What will happen in the research meeting?

[redacted]

We will meet at the XX

I will ask you to try out our new test for dementia.

There will be some

- questions
- puzzles
- drawing

I will video you doing the test.

if you are happy for me to.

I will ask what you think about the dementia test.

I will write down your ideas.

It will take 1 hour.

You can stop or take a break at any time.

There will be snacks.

We will give you a £10 Amazon voucher as a thank you.

What will happen to my information?

Your personal information will be kept private.

Your information be kept in a file that is protected with a password.

We will put everyone's ideas in a big report.

Your name will be kept private.

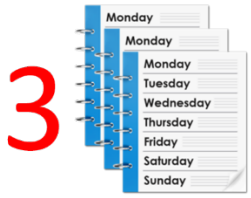
We will share the report with researchers and learning disabilities teams.

This will help teams to support people with dementia.

What if I change my mind?

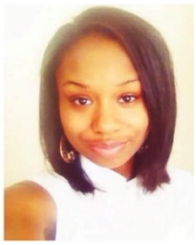
You can stop taking part at any time.

You can ask for your information to be removed from the research.



If you want to remove your information
you must let me know in 3 weeks.

If you have any questions



please call me [redacted]

Or Email me on: u2075228@uel.ac.uk

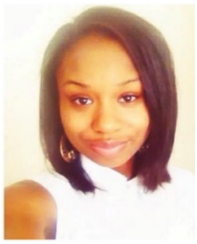
Appendix R: Easy Read Participant Consent Form

University of East London, School of Psychology

Assessment of Cognition in People with Intellectual Disabilities

Participant Consent Form (Easy-Read)

		Consent
	☐	This form has been explained to me
	☐	I am happy to take part in the research
	☐	I am happy to be video recorded
	☐	I understand my name will be kept private
		My name or signature Date

	Researcher name:	*Zakiya Reid-Wisdom*
	signature	
	Date	

Appendix S: Debrief Form

University of East London
School of Psychology
Assessment of Cognition in People with Intellectual Disabilities – Participant Debrief Form
V04.08.2023

Thank you so much for participating in my research study on creating a test set to look for dementia in those who have a learning disability. This letter offers information that you might find important now that you have now taken part.

What will happen to the information that you provide?
All the information you provide will be kept strictly confidential. That means that only the researchers in the team and their supervisor (Dr. Matthew Jones-Chesters) will be able to see it. Your data will be stored on the UEL OneDrive, which is a secure and encrypted online service. After uploading your information to the UEL OneDrive all paper information will be destroyed. Your data will be anonymised by using a numerical code instead of your name. For up to 3 weeks after you participate in the study, a separate document will be kept to link your name to your numerical code (this is in case you decide you want to withdraw your data from the study during this period), and after 3 weeks your name will be deleted from our records.

Your anonymised data will be seen by me, the other researcher on the team and my supervisor (Dr. Matthew Jones-Chesters). Data will be analysed in groups and will be incorporated into my thesis paper. This will be read by examiners and will be made available to the public, NHS Learning Disability services, and to you. If the study is published it will appear in an academic journal. No individual or identifiable information will be included in any report or publication.

After the study has been completed, your data continue to be stored in a secure location, only accessible by the research team, for 10 years, as recommended by the UK Research and Innovation (UKRI) guidelines. After this, all data will be destroyed.

If you wish, I can provide you a copy of the results of this study when it is finished.

What if you want to withdraw?
You are free to withdraw from the research study at any time during participation without telling me why, and there will be no consequences for doing so.

Additionally, you may also request to withdraw your data even after you have participated, provided that this request is made **within 3 weeks** of the data being collected. After 3 weeks, your name and other identifiable information will be deleted and your data will only be referred to by a numerical code, meaning we will no longer be able to identify which is your data.

What if you have been adversely affected by taking part?
We do not anticipate that you will be negatively affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful for information and support:

Down's Syndrome Association
The Down's Syndrome Association is dedicated to helping everybody with Down's Syndrome to feel included and empowered. They are a community of people which will provide support, advice, friendship and advocacy.
Tel: +44 (0)333 1212 300– Monday to Friday 10:00am – 4:00pm
Website: https://www.downs-syndrome.org.uk/

British Institute of Learning Difficulties (BILD)
BILD (British Institute of learning difficulties) informs you of the types of advocacy available for people with learning difficulties. They work in partnership with people with learning difficulties and families enabling them to get the right support to make informed choices about their own lives.
Tel: 0121 415 6960– Telephone line open Monday-Friday 9am-5pm
Website: http://www.bild.org.uk/about-bild
e-Mail: enquiries@bild.org.uk

Mencap
Mencap offers a range of personal and unique services for people with a learning disability, families and carers. Mencap's Empower Me service gives personalised advocacy support for people with a learning disability, helping to develop skills, confidence and knowledge needed to voice concerns and secure rights.
Tel: 0808 808 1111 Phoneline is open 9am to 3pm, Monday to Friday
Website: https://www.mencap.org.uk/our-services/personal-support-services/advocacy

You are also very welcome to contact me or my supervisor if you have questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please ask me:

- Zakiya Reid-Wisdom
  E-Mail: u2075228@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact:

- The research supervisor:
  Dr. Matthew Jones-Chesters,
  School of Psychology, University of East London, Water Lane, London E15 4LZ
  Email: m.h.jones-chesters@uel.ac.uk
  Phone: 020 8223 4603

or

- Chair of the School of Psychology Research Ethics Sub-committee:
  Dr Trishna Patel
  School of Psychology, University of East London, Water Lane, London E15 4LZ.
  Email: t.patel@uel.ac.uk

Or to find out more about how we use your information:

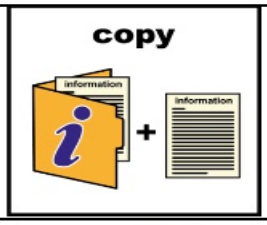
www.hra.nhs.uk/information-about-patients/

Appendix T: Easy Read Debrief Letter

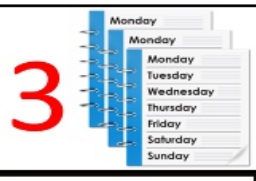
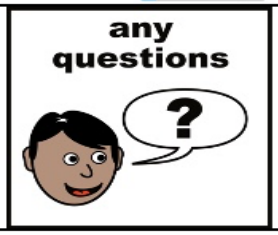
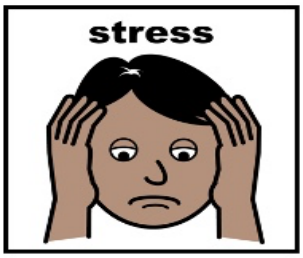
University of East London School of Psychology Assessment of Cognition in People with Intellectual Disabilities Participant Debrief (Easy-Read)	University of East London

thank you 	**Thank you** for taking part in our research study!
	**What were the tests for?** We think that the tests you did might be better for people with a learning disability than the tests we have already.
	**What will you do with my information?** Your personal information will be kept private
	Your information be kept in a password protected file

	We will put everyone's ideas in a big report

	Your name will be kept private
	We will share the report with researchers and learning disabilities teams.
	This will help teams to support people with dementia.
	**Can I have a copy?** If you want, we can give you a copy of the results of this study once it has ended.
	**What if I change my mind?**
	You can stop taking part at any time.

	You can ask for your information to be removed from the research

	If you want to remove your information, You must let me know in 3 weeks.
	**Do you have any questions?**
	We hope that you have not felt stressed doing these tests, but if you would like someone to talk to about it, you or your carer/ guardian can contact the person that you usually see at XX

	If have any questions please call me on: [redacted] or email me on: u2075228@uel.ac.uk

Appendix U: Semi-Structured Interview Schedule

SEMI-STRUCTURED INTERVIEW SCHEDULE

University of East London
School of Psychology
Assessment of Cognition in People with Intellectual Disabilities – Semi-Structured Interview Schedule
V07.08.2022

1. Did you find any of the tests interesting?
    a. Which ones in particular?
    b. Why?
2. Did you find any of the tests boring?
    a. Which ones in particular?
    b. Why?
3. Did you find any of the tests too easy?
    a. Which ones in particular?
    b. Why?
    c. What could we change about these tests to make them better?
4. Did you find any of the tests too hard?
    a. Which ones in particular?
    b. Why?
    c. What could we change about these tests to make them better?
5. Do you have anything else you would like to say about the tests you did today?

Appendix V: Example Coding Schedule for Semi-Structured Interview Feedback

Code	Example Verbal Responses	Example Non-Verbal Responses
Yes	"Yes", "Yeah"	Nodding of the head
A little bit	"a little bit" "kind of" "somewhat"	Hesitant hand gesture (e.g. slightly turned palm)
No	"No", "Nope", "None"	Shaking of the head
Overall test	"All", "Everything", "All of it"	N/A
Orientation	Responses alluding to questions about name, place, time or how they travelled to the session.	N/A
Smell Description	"Smells", "Jars", "Coffee", "Mint", "Lemon", "Coconut", "Chocolate"	Pointing to test materials
Motor Function A & Verbal Comprehension Part A	Verbal expressions of the instructions (e.g., "closing my eyes and opening them")	Gesturing of instructions (e.g., touching their nose, closing their eyes, and opening them)
Motor Function B	Verbal expressions of the instructions (e.g. "Holding my arms out")	Gesturing of the instructions (e.g., finger-to-nose, holding out their arm)
Motor Programming	Verbal expressions of the instructions (e.g., "knocking the table")	Gesturing of instructions (e.g., knocking on the table).
Praxis	Verbal expressions of the instructions (e.g., "brushing my teeth").	Gesturing the different instructions (e.g. brushing teeth).
Verbal Comprehension Part B	Verbal expressions of the instructions (e.g., "put the pen on the watch"), items included in the instructions	Pointing to test materials. Gesturing of instructions (e.g. "putting the pen on the watch").

	(e.g., “watch,” “pen”, “coin”).	
Word List Memory Subtests	“List of words”, “Memory one” “Remembering words”. Items included in the instructions (e.g. “Dish”, “Shoe”, “Frog”).	N/A
Circle Search	“Shapes”, “Circles”, “drawing”	Pointing to test materials. Drawing gesture.
Angle Judgment	“Lines”, “matching lines”, “angles”	Pointing to test materials
Visual Reasoning	“Patterns”, “Pictures”, “Puzzle”	Pointing to test materials
Cat-Dog Inhibition	“Cat”, “Dogs” “Pictures” (with clarifying questions)	Pointing to test materials
Matchsticks	“Matchsticks”, “Sticks”, “Picture: (with clarifying questions)	Pointing to test materials. Gesture of assembling matchsticks.
Eight Detection	“Numbers”, “8”, “Tapping on the table” (with clarifying questions).	Pointing to test materials. Gesturing of instructions (e.g. tapping on the table; with clarifying questions).
Picture Naming and Recognition	“Pictures” (with clarifying questions), Items included in the instructions (e.g. “fire”, “butterfly” “ostrich”)	
Sentence Repetition	Repetition of the instructions (e.g. “where is the shop”)	N/A
Word Generation	“Animals” “Foods” (with clarifying questions)	N/A

Appendix W: Example Coding for Verbal and Non-Verbal Communication

Verbal	Positive Examples	Negative Examples
• Speech • Volume • Tone • Rate • Clarity • Fluency	• Verbal indications of enjoyment e.g. “This is fun!” • Jovial tone, laughter • Good speech output	• Verbal indications of distress e.g. “I don’t like this” or “I don’t want to do more” • Sighing, ‘huffing’ • Hesitancy • Limited speech output (though noting this can be impacted by verbal ability) or refusal to talk
Non-Verbal	Positive Examples	Negative Examples
• Body language • Facial expression • Eye contact • Posture & gait • Gesture • Signing • Distance • Vocalisations / noises • Behaviour	• Facing towards examiner, open stance • Objectively happy, smiling • Good eye contact • Engaged posture • Vocalisations to indicate happiness, • Behaviour to indicate happiness, such as jumping up and down in excitement or clapping hands	• Facing away from examiner, folded arms, retreating • Objectively unhappy, tearful • Poor eye contact, avoidant (though this is common in autistic individuals) • Slumped shoulders • Vocalisations to indicate unhappiness, such as screaming • Non-verbal indications of confusion (e.g. frown) • Behaviour to indicate unhappiness, such as

		banging the table, pushing the test materials away, or hitting/ kicking, wringing hands, fidgeting, attempting to leave