Exploration of a stroke population's experiences of a digital cognitive assessment: a think-aloud and interview study

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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'As humans, we can identify galaxies light years away and we can study particles smaller than an atom, but we still haven't unlocked the mystery of the 3 lbs of matter that sits between our ears'.

Barack Obama on the BRAIN Initiative

Abstract

Introduction: With technology advancing, digital cognitive assessments, including unsupervised cognitive assessments, are evolving and being used more frequently in both research and clinical settings. Yet little is known about the experience and perceptions of digital cognitive assessments from the direct perspective of service users who have experienced a stroke. This study aimed to address this gap by investigating how service users, who have had a stroke, experience a digital cognitive screen.

Method: The study invited people who have had a stroke to complete a digital fixed battery cognitive assessment called the Amsterdam Cognition Scan (ACS). They were asked to 'think aloud' or 'talk aloud' about their experiences whilst completing the cognitive assessment, as well as answering a few questions before and after the assessment about their experiences. This data were analysed using reflexive thematic analysis to develop themes and subthemes.

Results: The analysis uncovered 3 central themes focused around 1. past experiences: the service user's previous experiences and how these influence their experience and perception of the cognitive assessment; 2. direct and immediate experiences: responses and feelings evoked by the cognitive assessment and 3. potential future experiences: the utility of digital cognitive assessments with the stroke population going forwards.

Discussion: A narrative overview of the key findings is discussed, including the perceived benefits and limitations of digital cognitive assessments; the future of digital cognitive assessments; directly evoked feelings from cognitive assessments such as fear, anger, and sadness; the paradox of knowing cognitive difficulties, and the importance of experts by experience involvement within research. Practitioner recommendations for administering digital cognitive assessments to the stroke population are also discussed.

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Introduction

Chapter one

This chapter outlines the study's context and offers a detailed review of the current literature. It summarises background information about strokes, types and categories, their prevalence and timeframes following a stroke. It then discusses how strokes can impact cognition, as well as factors which can influence cognition, such as mood. It then considers interventions, including cognitive screening or testing following a stroke and available options. The chapter also summarises the current research exploring service user perspectives of cognitive tests and screens. It then reviews the advancements in digital cognitive testing and the advantages and disadvantages of these types of tests. The chapter ends with a summary and the research questions that were addressed.

Strokes and their prevalence

A *stroke* is a cerebrovascular event that occurs when the blood supply to part of the brain is cut off, and damage to the brain occurs (Stroke Association, 2022). In the United Kingdom (UK), a person has a stroke every 5 minutes; consequently, there are 1.3 million people living post-stroke in the UK (Stroke Association, 2020). Reoccurrence is common (Sacco, 1995), and the absolute number of strokes is rising due to, in part, higher life expectancies and population growth in most countries (Feigin et al., 2019). Subsequently, strokes are the leading cause of disability (Herpich & Rincon, 2020; Smajlović, 2015) and are the second most common cause of death worldwide (Bonita et al., 2004; Herpich & Rincon, 2020).

Our knowledge around strokes, their prevention and treatment are growing. Encouragingly, stroke-related deaths have fallen by 49% in the past 15 years, and stroke prevalence is significantly decreasing; this is partly due to better prevention and earlier and more advanced treatment options in high-income countries (Public Health England, 2018; Grefkes & Fink, 2020; Herpich & Rincon, 2020). However, this decline has only been shown in high-income countries (Feigin et al., 2014), and sadly stroke incidence in low-income countries has more than doubled due to poor

access to the equipment needed, lack of rehabilitation and preventative resources and limited understanding of risk factors associated with a stroke (Johnson et al., 2016). In fact, on average, strokes also occur 15 years earlier in low and middle-income countries, meaning that people are arguably affected during the most active part of their life when they are still working, driving, raising families etc. This can have detrimental impacts not only on the individuals but also on the economy (Johnson et al., 2016). Despite this, there remains relatively little attention on strokes generally and the disparity between high-income and low-income countries. There also continues to be a lack of research exploring the direct perspectives of people who have experienced a stroke.

For context, this study took place in the UK, a high-income country, and included people predominately from white British backgrounds. Thus, participants' cognitive assessment experiences are within a context where cognitive assessment and rehabilitation are recommended (NICE guidelines, 2013) and commonly offered following a stroke.

Types of strokes

There are two main types of strokes. An ischemic stroke, or cerebral infarct, is the most common type, with up to 80% of strokes being this subtype in Western countries (Andersen et al., 2009; Perna & Temple, 2015; Sudlow & Warlow, 1997). This subtype is caused by a blockage which cuts off blood flow to the brain and is the most heavily researched type of stroke (Kitago & Ratan, 2017). The other subtype is a haemorrhagic stroke, which is caused by bleeding in or around the brain (Stroke Association, 2022). Several studies have shown that haemorrhagic strokes are, unfortunately, associated with higher mortality rates (Andersen et al., 2009; Di Carlo et al., 2003; Kiyohara et al., 2003; Perna & Temple, 2015; Tsiskaridze et al., 2004), even when adjusting for age, gender, initial stroke severity, and relevant cardiovascular risk factors (Andersen et al., 2009). Some studies have also found an association between haemorrhagic strokes and a higher incidence of long-term disability (Chiu et al., 2010). On the other hand, some studies suggest that the percentage of haemorrhagic strokes is underestimated due to the previous lack of routine computed tomographic (CT) scans, meaning that staff relied on clinical examination alone, which can be inaccurate (Shiber et al., 2010).

Although these types of strokes are pathologically different, there is evidence to suggest that there are limited differences between them in terms of functional outcomes, impact on the individual, and recovery (Franke et al., 1992; Jørgensen et al., 1995; Perna & Temple, 2015). Indeed, much of the research available focuses on both subtypes of stroke collectively. In line with this, there are factors which are associated with worse functional outcomes for both subtypes of stroke, such as older age (Kelly et al., 2003; Weimar et al., 2002), being female (Fukuda et al., 2009), prior history of stroke (Weimar et al., 2002) and lesion location (Macciocchi et al., 1998). Stroke recovery, the management and impact of a stroke are also multifaceted for both types of strokes (Kitago & Ratan, 2017; Sacco, 1995) and subsequently need a multidisciplinary approach which will start and extend beyond hospital admission (Herpich & Rincon, 2020; Jeon et al., 2017).

Stages of time post-stroke

Another way of categorising strokes is the time since the stroke happened. The Stroke Roundtable Consortium proposed different stages of time post-stroke, summarised in Grefkes and Fink's (2020) paper. The first 24 hours is considered the hyperacute phase, the first seven days as the acute phase, the first three months as the early sub-acute phase, the months 4–6 as the late sub-acute phase, and six months onwards as the chronic phase.

It is reported that several recovery-related processes happened within different timeframes following a stroke. For example, it has been suggested that the most significant improvements in physical recovery occur within the first few weeks following a stroke, with less spontaneous physical recovery happening after the chronic phase (Grefkes & Fink, 2020). However, much research exploring 'recovery' has focused on physical recovery and less so on cognitive and psychological recovery, paralleling the emphasis on physical health more globally (Kolappa et al., 2013; Prince et al., 2007). In contrast, improvement in neuropsychological functioning can be observed for at least two years after brain injury (De Luca et al., 2018; Hochstenbach et al., 2003). Supporting this, Cramer (2008) found that some stroke-induced cognitive deficits, such as language, improved in the chronic phase. Similarly, De Luca et al. (2018) found that stroke service users showed global cognitive improvement following cognitive

computerised training 3-4 months following a stroke (early to late sub-acute phases); it must be noted that this study had a small sample (n=35), and the control group also showed improvement, suggesting that cognitive improvements may happen naturally, without cognitive computerised training.

Grefkes and Fink (2020) highlight the issues with rigidly using this system of categorisation; in that someone at ten days post-stroke is likely to present differently to the same person 80 days post-stroke, yet both would be considered in the early sub-acute phase. Considering this, the following study documented the phase of the stroke and the number of months since the stroke took place.

Impact of a stroke on an individual

Research exploring the impact of a stroke on individuals will use the term 'stroke' to refer to all types of strokes and all severities. However, the impact and severity of a stroke vary and depend on countless factors, including the type of stroke, where the stroke has happened in the brain, the size of the affected area, and comorbidities (Stroke Association, 2022; NHS website, 2022). This makes it difficult to measure a stroke's direct impact and to generalise the difficulties following a stroke (Kurtzke, 1994; McDonald et al., 2019). Subsequently, recovery can look different and have a different meaning to everyone. Whatever recovery looks like for a person, cognitive challenges are common sequelae across all stroke presentations (Al-Qazzaz et al., 2014; Allan et al., 2011; Chan et al., 2014; Douiri et al., 2013).

Cognition

Cognition is a term used to describe the processes and functions the brain uses to process information, such as memory, communication, spatial awareness, and executive function (NHS website, 2022). Post-stroke cognitive impairment can be defined as a 'new cognitive deficit that develops in the first three months following stroke and persists for a minimum of six months, which is not explained by any other condition or disease' (McDonald et al., 2019, p775) . Post-stroke cognition depends on the area of the brain the stroke has occurred. Still, it is estimated that 70% of people have cognitive difficulties at some point post-stroke (van Zandvoort et al., 2005), with cognitive impairment remaining highly prevalent

years after the stroke has occurred (Patel et al., 2003). Cognitive changes strongly correlate to a person's quality of life (Cumming et al., 2013) and rehabilitation recovery (Mysiw et al., 1989). Thus, assessment, monitoring and support within these areas are paramount following a stroke.

Although research focuses on physical functional recovery following a stroke, little research explores general cognitive functioning (Hochstenbach et al., 2003). Research has also found that cognitive deficits, unless in line with dementia, are often overlooked for the stroke population (Jacova et al., 2012). This may partly be because there is no distinctive profile of cognitive deficit in stroke, making it challenging to identify. This could be due to a plethora of variables, including strokes happening in different locations in the brain, with different severities, with people who may have varying health prior to the stroke etc. Hence, many cognitive areas can be affected following a stroke, such as difficulties with memory, attention, language, visuospatial, motor and executive functions and cognitive flexibility (Hochstenbach et al., 2003). Difficulties with information processing and executive dysfunction are also prevalent following a stroke (Cumming et al., 2013). All these areas must be considered when choosing what cognitive assessments may be appropriate for the stroke population.

Other challenges following a stroke that can affect cognition

A stroke can lead to widespread and long-term challenges. Public Health England (2018) estimates that around 65% of stroke survivors leave hospital with some sort of disability, with some people experiencing a global loss of function (Kurtzke, 1994). Some challenges affecting a person's cognition and, in turn, their ability to complete a cognitive assessment include communication, movement, and vision.

Communication: it is estimated that around a third of people will have changes in their communication post-stroke (Public Health England, 2018), which includes speaking, understanding language, as well as reading and writing. This is often given the name aphasia. Research suggests that aphasia is a strong predictor for long-term mortality and dependence for stroke patients (Tsouli et al., 2009), as

well as depression (Worrall et al., 2016). This can make it difficult for people to understand cognitive assessments and to give responses.

Movement: it is estimated that around 75% of stroke survivors have arm or leg weakness (Public Health England, 2018), and it is common for people to have difficulties with balance and coordination. Depending on where in the brain the stroke has occurred and which side of the brain it has taken place will depend on which side weakness or paralysis. This can make it difficult for people to engage with physical elements of cognitive assessments, such as pointing, moving blocks, or moving a computer mouse.

Vision: it is estimated that 60% of people will have visual problems post-stroke (Public Health England, 2018). This is because a stroke can damage areas of the brain responsible for processing and interpreting visual information (NHS Website, 2022). It is common for people to lose a field of vision (Fisk & Mennemeier, 2006). A stroke can also affect eye muscle control, leading to double vision. This can make it challenging for people to see cognitive assessments.

Mood

Following the changes and challenges outlined above, a stroke can significantly impact a person's day-to-day life, e.g., working, driving and intimate relationships (Daniel et al., 2009). This, in turn, can have a detrimental impact on a person's mood. Hackett et al. (2005) systematic review found that over a third of people who had a stroke experienced depression. Similarly, Lenzi et al. (2008) estimated that around 30-35% of people who have had a stroke will be diagnosed with post-stroke depression (PSD). In fact, the stroke population are more at risk of depression than physically ill patients with similar levels of disability, far into their stroke journey, regardless of other risk factors (Lenzi et al., 2008). Mood changes can affect not only the person's quality of life but also their progress within wider treatment; for example, research shows that people who experience PSD following a stroke show less improvement in their overall rehabilitation (Chemerinski & Robinson, 2000; Lenzi et al., 2008; Pohjasvaara et al., 2001).

Impact of mood and feelings on cognition

Mood has also been shown to impact cognition and, potentially, people's experiences of cognitive assessments. Evans (2003) argued that mood is essential to consider, as it can significantly impact neuropsychological testing performance and thus must be accounted for when interpreting test results. In line with this, Paradiso et al. (2001) found that depressed mood had an adverse effect on cognitive testing performance for people with temporal lobe epilepsy; this included language, visuoperceptual ability, memory, and executive function. Like Schubert et al. (1992), they found that depression was under-recognised and undertreated as a result. Furthermore, mood has also been shown to affect motivation (Lane et al., 2001; Venkatesh & Speier, 1999), which has been shown to affect cognitive performance (Fervaha et al., 2014).

In contrast, Andrew et al. (2000) found that mood did not influence neuropsychological performance; however, this study used a population of people who had cardiac surgery rather than a stroke population. Yang et al. (2013) also found no correlation between apathy or depression and scores on MoCA screening performance within two weeks of stroke onset. However, it is arguable whether the MoCA is exhaustive or sensitive enough to capture changes due to mood.

Despite stroke guidelines recommending cognitive and mood assessments, Lees et al. (2012) found that across 8826 studies, only 6% included either a cognitive or mood measure, suggesting that cognition and mood are both neglected within stroke research.

Intervention for cognition

There are a limited number of good-quality randomised control trials exploring cognitive rehabilitation (Cappa et al., 2005; Sigmundsdottir et al., 2016). Within this limited research, effective cognitive rehabilitation approaches have been found for some areas of functioning, such as visual neglect and language aphasia (Cappa et al., 2005; Cicerone et al., 2005; Cumming et al., 2013). However, treatments for improving other areas of cognition remain elusive, with mixed evidence for their effectiveness (Chalfont et al., 2020; Gillen et al., 2015). Instead, evidence suggests that identifying cognitive impairments and finding compensatory

techniques to counteract the difficulties experienced is more valuable (Dirette, 2002; Tomaszewski Farias et al., 2018).

Early detection of cognitive impairment post-stroke can be invaluable to service users and their families for understanding the diagnosis and their experiences (e.g. a change in behaviour), predicting functional outcomes and adapting rehabilitation (Chan et al., 2014). Cognitive impairment is a good predictor for the length of hospital stay (Galski et al., 1993) and the number of community resources used (Tatemichi et al., 1994), making the detection of cognitive impairment helpful for planning within healthcare services. Consequently, the current guidelines, including the National Institute for Health and Care Excellence (NICE, 2013) guidelines, recommend a cognitive assessment within days of a stroke (Campbell et al., 2022; Lindsay et al., 2014). However, there is a lack of cognitive assessments available that can accurately assess post-stroke cognition whilst accounting for the other impacts of a stroke, such as communication, movement, and vision (Wall et al., 2018; Wittich et al., 2010). Furthermore, there is limited availability of trained professionals e.g., neuropsychologists, to administer these assessments.

Cognitive assessments: neuropsychological assessment batteries versus cognitive screening

Neuropsychological assessments

The terms neuropsychological assessments, cognitive screening and cognitive testing are used interchangeably in the literature, and no formal criteria explicitly distinguish neuropsychological assessments from cognitive screening and testing (Block et al., 2017; Watt & Crowe, 2018). This has led to confusion within the literature (Block et al., 2017), with many studies labelling tests that are typically considered cognitive screens as neuropsychological tests (Martinelli et al., 2014) and vice versa.

However, Watts et al. (2014) highlight that a statement by the American Psychological Association Practice Organization proposes that neuropsychological assessments and cognitive screening vary in their goals, user requirements, indications for use, levels of complexity, and anticipated outcomes. In line with this, Block et al. (2017) clarify the distinctions between cognitive screening and

neuropsychological assessment. They suggest that neuropsychological assessment involves facilitating clinical interviews to obtain information on, e.g., demographics and medical histories to determine which tests are used and that behavioural observations are also considered in interpreting the results. Additionally, all neuropsychological assessments should always be interpreted within the context of educational, employment and medical history, family and socio-economic background and presenting difficulties (Lezak et al., 2012).

Roebuck-Spencer et al. (2017) suggest similar differentiations and add that neuropsychological assessments are usually multidimensional and can be used to determine the severity of a person's cognitive difficulties and to plan treatment and rehabilitation. Both authors also highlight the prevalent use of neuropsychological assessments for diagnostic and prognostic purposes.

Neuropsychological assessments subtests can be administered as a fixed battery of tests, an approach often used in research to ensure reliability, or subtests can be administered and used flexibly, an approach typically used in clinical settings to ensure that tests are adapted to the person's needs.

Cognitive screening

Cognitive screening tools are usually briefer and can identify individuals who may need additional evaluation or indicate whether a full neuropsychological assessment is necessary (Block et al., 2017; Roebuck-Spencer et al., 2017); they should not be used in replacement of neuropsychological assessments (Roebuck-Spencer et al., 2017). In theory, cognitive screens ensure that service users only undergo the most appropriate assessments fitted to their needs.

As well as being used clinically, cognitive screens and assessments are heavily used within stroke research. Within research, tests need to be standardised to help reduce confounding variables and allow group-level comparisons. Research using standardised cognitive tests can help with the understanding of brain functioning following a stroke, predict the impact of differences within the brain on a person's function, evaluate the outcome of different treatments (e.g. psychological, medical, social etc.), determine the best methods of treatment, guide practitioner guidelines (Glozman, 2020) and allow for the development of more comprehensive

neuropsychological assessments (Patry & Mateer, 2006). In fact, populations of individuals with strokes and tumours constitute the most frequently used subjects in neuropsychological research and establishing brain-behaviour relationships (Anderson et al., 1990).

Brief cognitive screens for the stroke population

In a focused review of 8826 stroke studies, Lees et al. (2012) also found that the most common cognitive assessment used within stroke research was the Mini-Mental State Examination (MMSE). The MMSE was designed to screen for dementia and delirium, and its validity has never been evaluated for the acute stroke population (Nys et al., 2005). However, Nys et al. (2005) found the MMSE to be inaccurate in detecting cognitive impairment; in fact, the accuracy of the MMSE was no better than chance, and no cut-off value could be identified. Similarly, Morris et al. (2012) found both the MMSE and the Addenbrooke's Cognitive Examination-Revised (ACE-R), which was also developed for dementia, to be inadequate at detecting cognitive impairment in a stroke population, and no cut-offs could be identified on either screen.

Evidence suggests that the Montreal Cognitive Assessment (MoCA) may be a more appropriate cognitive screen within stroke settings than the MMSE (Blackburn et al., 2013; Pendlebury et al., 2010). Dong et al. (2012) found that the MoCA accurately predicted significant impairment 3-6 months after a stroke. Similarly, Salvadori et al. (2013) found a MoCA completed 5-9 days post-stroke was a good predictor of cognitive impairment for 6-9 months after a stroke. Burton and Tyson (2015) systemically reviewed the psychometric properties and feasibility of the MoCA; they found that the screen accurately showed impairments at all levels of severity. However, other studies have shown that using the typical cut-off point on the MoCA of 26 indicating cognitive impairment (originally designed to measure cognitive deterioration in dementia), is not appropriate within a stroke setting (Chiti & Pantoni, 2014; Godefroy et al., 2011; Salvadori et al., 2013) and therefore a consensus on cut off needs to be reached before using the MoCA within stroke settings. Chan et al. (2014) also found that a strong performance on the MoCA did not reflect intact cognition and suggested that a full neuropsychological assessment is vital for the reliable detection of cognitive impairment following a stroke. Chan et

al. (2014) also highlight that the MoCA does not assess cognitive domains often impaired after a stroke, such as information processing speed. These screening assessments are also usually completed early in recovery, where there is minimal evidence around stabilisation speed (Campbell et al., 2022).

Schaefer et al. (2022) argue that brief screening assessments can help indicate the need for consultation with a neuropsychologist for further comprehensive examinations. Still, they are only sensitive to severe cognitive impairment and are relatively insensitive to milder forms of impairment. Similarly, Jokinen et al. (2015) advise that short screening tests of global cognitive function are not accurate and generally have yielded low prevalence rates, whilst more detailed neuropsychological assessments are more sensitive and subsequently have higher prevalence rates. Pasotti et al. (2020) raise that existing full neuropsychological tests are too expensive in time and effort and that cognitive screens are derived from instruments addressing different pathologies such as dementia. This is leading to the development of 'in-between' assessments, which are neither a e.g., 6-hour battery nor a 10-minute cognitive screen. For example, Pasotti et al. (2020) have developed a brief neuropsychological battery called the Mental Performance in Acute Stroke screening tool which was shown to have adequate construct validity for patients with acute stroke.

Similarly, the Short Parallel Assessments of Neuropsychological Status (SPANS) was developed to provide a more accurate assessment or screen of cognitive performance and recovery trajectory in the first year of post-acquired brain injury (Burgess, 2014). It includes a greater number of briefer subtests compared to other screens, such as the MMSE, but still covers a range of areas such as orientation, attention/concentration, language, memory/learning, visuomotor performance, efficiency, and cognitive flexibility, which can be done in approximately 30minutes, which is a considerably shorter amount of time than a full neuropsychological battery of tests. These more thorough cognitive screening assessments might be an innovative solution to achieving a balance between helpful and accurate testing, time constraints, and over-taxing of people at the early stages of recovery.

How do service users experience these cognitive assessments?

Although there is a wealth of research that reviews the effectiveness of these paper-based cognitive screening tools within stroke populations (Quinn et al., 2018), there is limited published research exploring service users' direct experiences of cognitive screens or neuropsychological assessments (Krohne et al., 2011; Owen, 2012). With NHS services and research organisations promoting person-centred care, more attention needs to be given to *experts by experience* within the clinical and research fields.

Watt and Crowe (2018) completed a systematic review focused on the beneficial effects of neuropsychological assessments; however, out of eighty-one studies reviewed, only six were considered to address service users' perceptions. Of these six, one focused on parental perceptions of their child's neurodevelopmental assessment (Arffa & Knapp, 2008), one focused purely on the feedback process (Donofrio et al., 1999), and three focused on clinician perceptions of neuropsychological services (Mahoney III et al., 2017; Temple et al., 2006; Tremont et al., 2002). Thus, only one study, by Bennett-Levy et al. (1994a), asked service users directly about their experiences and perceptions of cognitive tests. They suggested that there is an assumption that experiencing a neuropsychological assessment is comparable to having a neutral medical procedure, yet service users often remember them as a 'big life event'. Their study sent out questionnaires to clients, 36% of whom had a traumatic brain injury and 15% had a stroke; all participants completed a neuropsychological assessment within six months of completing the questionnaire. They found that 56% of participants reported that the experience of completing a neuropsychological assessment process was positive; 35% rated the experience as neutral, and only 9% rated the experience as unfavourable. However, participants reported the neuropsychological test itself as 'too long' and tiring. Participants also said that the test elicited feelings of being a 'repeated failure' and a quarter of participants reported that they got a headache during the assessment session. It is also noteworthy that the data were limited to the constraints of the questionnaire's questions and format. For example, participants reported that the neuropsychological assessment had been an important life event as it had implications for their self-concept and future; however, the data did not

capture whether their self-concept and future had been positively or negatively affected. Thus, it is uncertain whether a questionnaire platform captures the qualitative nuances and depth needed within this poorly understood area.

Owen (2012) instead used interviews focused on neuropsychological assessment experiences with clients who have experienced a traumatic brain injury. In this study, some participants felt valued as equal partners during the assessment process and reported that familiarity with the assessor helped them feel relaxed. On the other hand, some participants highlighted the power imbalances between the assessor and themselves and indicated that the assessment feedback used inaccessible technical language. It is also noteworthy that participants had mixed views about the purpose of the assessment; the only common view was that the assessments 'found out the problem'. Participants also reported that an unfamiliar assessor led to uncertainty and anxiety. Generally, participants reported feelings of anxiety, confusion, anger, fatigue, and frustration during the assessment process, as well as relief after completing the assessment.

Although it is encouraging that this study addresses an unknown area of patient experience, it asked participants to recall their experiences up to two years after the assessment process. It, therefore, relied on participants' retrospective memory, an area not screened/accounted for on the inclusion criteria, despite memory being a common deficit following a head injury (Vakil, 2005). Participants also had a mean age of 41 years old, and thus it is not representative of older populations, such as those from stroke populations.

All the studies above used populations of people under the age of 65 years old. Strokes in younger adults are less common. However, some publications report an increased incidence of first-time stroke in young adults (Kissela et al., 2012; Smajlović, 2015), with an estimated 38% of first-time strokes being adults between 40 and 69 years old (Public Health England, 2018). Kugler et al. (2003) also found that although age influenced mortality rates following a stroke, age didn't affect recovery speed, indicating that age, in its purest sense, may be less relevant in cognitive recovery. Similarly, Krarup et al. (2008) found that people's level of activity levels and how people lived before a stroke was more predictive of recovery than age. There is a dearth of research exploring the experiences of both younger

and older populations experiences and perceptions of cognitive assessments; thus, both are important to explore. That being said, extra challenges with an older population may need to be considered when interpreting the results.

Older population's experiences of cognitive assessments

Demographic data suggests that by 2050, one in three people that have a stroke will be over 85 years old (Howard & Goff, 2012). Currently, three-quarters of all strokes occur in persons over 65 years old (Yousufuddin & Young, 2019); thus, it is crucial to consider the perspectives of older populations on cognitive assessments. Krohne et al. (2011) addressed this by using qualitative interviews to gain the perspective of hospitalised older adults on cognitive screens; please note that only three out of the eighteen people interviewed were hospitalized due to having a stroke. Nevertheless, the study found that the purpose and significance of the cognitive screening were not known to service users until after the screen was complete. The service users also expressed that the cognitive screens were strenuous due to the pressure to 'perform'. Service users varied in how they felt following the screen, depending on how they assessed their performance; this ranged from feelings of shame to a sense of pride. It is also noteworthy that some service users found voicing their experiences of the cognitive screen an emotional challenge. Whether these experiences of, e.g., shame, are widely known and considered when administering cognitive assessments for either clinical or research purposes is questionable. Considering this, more practitioner recommendations must be developed to support service users and participants undergoing cognitive assessments.

It must be noted that Krohne et al. highlight that these assessments were mostly done at the bedside or in common areas, thus not in a conducive environment. Additionally, participants were interviewed up to three days after being assessed, which may have impacted what they could remember about their experience. In line with this, most participants did not consider the cognitive screen a 'memorable event'; some only recalled what they considered 'vague memories'. Nevertheless, this study gives a brief insight into older people's experiences of cognitive screening.

Although most stroke service users will be older adults (Horgan et al., 2011), their experiences will differ from the 'typical' older population. For example, older people in a stroke population may be aware of sudden changes in their cognition. Therefore, they may be able to compare their cognition before and after the stroke. Additionally, cognitive functioning in the stroke population is usually expected to improve (Desmond et al., 1996) compared to an older population being screened for, e.g., dementia, where cognition is expected to decline (Blondell et al., 2014).

Hobden et al (2023) highlighted that very little is known about stroke survivors' experiences of the cognitive assessment process. They interviewed stroke survivors (mean age of 73 years old) and caregivers, several months after completing a paper and pen cognitive assessment called the Oxford Cognitive Scan (OCS). Participants expressed varied emotional responses, with the assessment commonly evoking feelings of anxiety. Participants also expressed feelings of failure and shame when they perceived themselves to have done poorly on the assessment. Some participants also perceived the assessment 'threateningly as a test or exam', which made some participants feel 'not good enough'. They also found that some participants linked their performance of cognitive assessments to their self-worth and identity.

Although this study addressed the stroke population experiences of a cognitive assessments, like Owen et al (2012), it interviewed participants several months after the OCS had taken place and thus relied on retrospective memory of the entire cognitive assessment process. The authors also recognise that they could not verify the information provided.

Digital cognitive assessments and approaches

Neuropsychological assessments have long been used within neuropsychology, with more modern approaches and cognitive assessment tools developing in the 1960s (Eling, 2019). These neuropsychological assessments were first developed as paper and pen assessments, some of which are the same ones still commonly used today (Casaletto & Heaton, 2017). More recently, digital neuropsychological assessments and cognitive screens have evolved alongside advancements in technology and the use of computers. These assessments were

initially run via computer software, rather than online, such as the FePsy Neuropsychological Test Battery (Witt et al., 2013) and the MicroCog Assessment of Cognitive Functioning (Elwood, 2001). Then, online cognitive assessments were developed as the Internet became widely available, ranging from computer-administered versions of established clinician-administered paper and pen tests to fully web-integrated cognitive assessments (Bauer et al., 2012). Most recently, research has helped develop new unsupervised online cognitive assessments.

In line with the NHS 10-year plan (A Plan for Digital Health and Social Care, 2022), the use of digitalised cognitive screening and cognitive screening is increasing in both healthcare and research settings at a rapid rate (Roebuck-Spencer et al., 2017). Additionally, changes following the COVID-19 pandemic, such as limited face-to-face appointments, have highlighted how inflexible pencil and paper assessments can be for clinical and research purposes (Libon et al., 2021). This pandemic has furthermore encouraged the use of digital assessments, consultation, and treatment, which has been branded telecommunication (Larner, 2011; Roebuck-Spencer et al., 2017). Telecommunication has also led to the development of cognitive assessments that can be administered, scored, and interpreted all remotely online without the direct input of a clinician (Libon et al., 2021; Rabin et al., 2014). Consequently, online cognitive assessments are becoming more accessible and, in turn, are being used within both research and clinical practice (Casaletto & Heaton, 2017; Germine et al., 2019; Marcopulos & Łojek, 2019).

Cullum et al. (2006) found that administering cognitive screens, such as the MMSE, to elderly patients using telecommunication methods was reliable and valid. However, their sample (N=33) and the samples used in their literature review were small. Following this, Munro Cullum et al. (2014) completed a more extensive study (N=202) exploring cognitive screens delivered by telecommunication for older adults. Participants were able to receive technical support from staff but otherwise completed the screens independently. The study found that participants adapted well to the telecommunication version of tests such as the MMSE, Letter Fluency Test, Category Fluency Test, Digit Span Forwards and Backwards and the Clock Drawing Test. They found that the mean test scores for all tests were highly similar, suggesting that telecommunication methods are valid and reliable measures. If

shown to be consistently valid and reliable, these developments in online cognitive tests could potentially create more equal opportunities for service users, such as making cognitive screens and assessments more accessible for people who e.g., are unable to travel or cannot afford the cost of travel.

Telecommunication has been particularly utilised across stroke services, particularly with consultation appointments within stroke services, due to the urgency of general assessment preceding decisions on thrombolytic treatment (Hess & Audebert, 2013; Larner, 2011). Campbell et al. (2022) explored the suitability of using computerised cognitive assessments in the first-week post-stroke for both clinical and research purposes. They found that the optimal day for testing using computerised assessments was day four onwards, suggesting that testing can be effective and valuable early in recovery.

Advantages and disadvantages of digital assessments

Parsey and Schmitter-Edgecombe (2013) review the advantages and disadvantages of using computer-based neurological tests. They discuss the challenges of neuropsychological tests, such as the potential technological issues during the assessment, lack of control over distractions (if completed remotely), and data protection issues. Important observational data, such as how a person approaches the task, can also be lost if the assessment is completed remotely unsupervised (Bilder & Reise, 2019). Additionally, there is evidence that computer experience can help improve performance on digital tests (Germine et al., 2019; Tun & Lachman, 2010), which puts those who are less computer literate at a disadvantage; this questions whether the results of digital tests would be reflecting the level of cognition or level of computer skills. Making cognitive assessments exclusively online could also widen the existing digital inequalities (Beaunoyer et al., 2020). Furthermore, people have been found to perform differently on digital assessments than on paper-based assessments and thus, new normative data are needed if we are to use these tests within the standard practice (Canini et al., 2014b).

Moreover, completing an online or digital cognitive assessment may be more challenging for people who have experienced a stroke. As age is a factor in the likelihood of having a stroke (Roy-O'Reilly & McCullough, 2018), service users

using stroke services are typically older (as previously discussed). Evidence shows that there is still a critical gap in technology use between younger and older populations (Hill et al., 2015; Vaportzis, Clausen, et al., 2017). Thus, using an online forum may be less familiar to older stroke populations and may put older populations, who may not be as experienced in using digital platforms and computers, at a disadvantage. Similarly, evidence suggests that people who have experienced an acquired brain injury, such as a stroke, can experience 'sensory overload' when using technological and digital devices, particularly in demanding situations, such as a cognitive assessment (Scheydt et al., 2017).

However, Parsey and Schmitter-Edgecombe (2013), along with others (Libon et al., 2021), suggest an overall positive outlook on digital cognitive assessments and conclude that the potential of technology use in neuropsychological assessment has not yet been recognised. They highlight the benefits of digital assessments, such as improved reliability and increased ease and standardisation of administration, response, scoring, interpretation and data storage (Fillit et al., 2008), all of which are more accurate and less prone to errors (Bauer et al., 2012; Cernich et al., 2007). Online digital cognitive assessments can also be more time and cost-efficient (Spreij et al., 2020).

Additionally, online digital cognitive assessments could provide flexibility in location as participants/clients could complete them in their chosen environment. It could also be hypothesized that as online assessments can be completed independently without such close observation and in a familiar environment, they may also be perceived as less pervasive and anxiety-provoking than the face-to-face equivalents. Supporting this, Bennett-Levy et al. (1994b) found that a cold facial expression, a toneless voice and curt responses can cause an increase in anxiety during a cognitive assessment, which compromises the test performance. This would raise questions about whether service users perceive online assessments as less shaming and anxiety-provoking than face-to-face assessments.

In line with this hypothesis, Spreij et al. (2020) administered a digital cognitive assessment to a total of 120 service users who had experienced either a stroke (n=59) or traumatic brain injury (n=61). They used semi-structured interviews immediately following the assessment to gain their perspectives and found that 91%

of participants expressed finding the tests 'pleasant' or 'very pleasant'. They also found that technology familiarity didn't affect performance. Although these results are encouraging, it is significant to note that the mean age of the stroke service users was 53 years and thus is not representative of the typical stroke population; age is essential to consider due to the digital divide that exists between younger and older generations using digital devices (Serafino, 2019). The test was also completed on a digital tablet, which may be more intuitive than other digital platforms, such as a laptop. The interview questions also focused on practical elements or feasibility of the assessment, such as 'How accurate was the appearance of your drawing on the tablet screen'. Additionally, no questions asked how the participant felt whilst completing the tests; thus, the study only explored a limited part of the service user experience. While the interview was conducted immediately after the assessment (making it more likely that service users could remember their experiences), many 'live' thoughts, feelings, and experiences may have been difficult to remember until the end of the assessment and thus lost or forgotten.

Future scope of digital cognitive assessments

Looking into the future, another benefit to advances in telecommunication and technology is that 'big data' analytics are also becoming more affordable and accessible. Psychology services often do not have the capacity, provisions, or opportunity to collect the volume of data necessary for 'big data' analysis using pencil-paper tests and the human administration of results (Adjerid & Kelley, 2018). Ultimately, having assessments administered and data stored online could allow for collating a broader range of normative data for neuropsychological assessments. Furthermore, artificial intelligence and machine learning have created algorithms that can predict human behaviour (Lee et al., 2018; Michie et al., 2017). These algorithms could, in theory, allow clinicians to input data about an individual, such as ethnic background, cultural influences, age, socioeconomic status etc. and receive normative data for that specific individual. These technological evolutions may provide modern and sophisticated solutions to neuropsychological assessments, mitigating some of the impacts of individual differences within a population. This will not only help results be a more accurate representation of a person but may also help reduce discrimination due to differences.

The Amsterdam Cognition Scan

One example of an online cognitive assessment recently developed for online remote use is the Amsterdam Cognition Scan (ACS). The ACS is a validated neuropsychological screening test battery designed explicitly for unsupervised online assessment for adults (18-89 years). It was developed for research rather than clinical practice. It provides a solution for many common issues in cognitive testing within research; for example, there is no need for costly trained test administrators with the potential for inter-administrator differences or differences in scoring between administrators (increasing standardisation), and it could be more time efficient, and cheaper overall (Feenstra et al., 2018).

The ACS was developed based on widely used neuropsychological tests. The online versions of the cognitive tests are developed as a mirror image of the traditional paper and pencil tests. As the ACS was not developed as a screening instrument, sensitivity and specificity have not been investigated. However, the ACS has been shown to be reliable and valid in healthy controls and non-CNS cancer patients (Feenstra et al., 2018; Feenstra et al. 2019).

Although the battery was initially designed for oncology research settings, it measures a broad range of cognitive domains, including attention, verbal memory, information processing, and executive functioning, similar to the cognitive tests advised following a stroke (Cumming et al., 2013). Feenstra et al. (2018) endorsed that the ACS would be equally suitable for cognitive studies in other settings due to its wide range of cognitive abilities. They found large concurrent validity between the ACS and traditional test scores. They also found that 90% of participants preferred online assessments over traditional assessments in hospitals. However, their study

The ACS could potentially provide a valuable and remote alternative to typical pencil-pen screens used in research settings, as it can be done remotely and safely in service users' homes unsupervised. There is currently no research that directly explores service user perceptions of the ACS and no research exploring how a stroke population experience this assessment. Indeed, there is very little research exploring the experiences of online or digital cognitive assessments generally, particularly from a stroke population's perspective.

It is important to note that the ACS was not developed for the stroke population; thus, this study does not aim to provide any normative data for a stroke population.

Summary

In conclusion, little research directly explores service users' perspectives and experiences of cognitive screens and assessments. More specifically, we could find no research to date that explores the direct experiences of digital cognitive screens from the perspective of stroke service users. Gaining the perspectives of stroke service users will help guide practitioner recommendations and, in turn, guide improvements to service user experiences with neuropsychological screens and assessments.

Research question and aims

The introduction is supported by a literature search using two online databases, Web of Science and APA PsycINFO (2002 to July 2023) and Google Scholar. A brief literature search was repeated in May 2023 on the write-up, using the search terms 'stroke population experiences', 'digital cognitive screens', 'stroke populations perspectives of cognitive screens', 'stroke populations perspectives of cognitive assessments' and 'brain injury populations perspectives of cognitive screens'. This review was repeated again on submission of the viva and evidence was added accordingly.

As this is a relatively unexplored area of the stroke populations experience, an exploratory approach was taken in this study to allow emerging themes to develop more freely. Although previous research had touched on service user experiences of cognitive assessments, previous research had used different methods e.g., retrospective interviews or had not studied this area in detail. This study intended to explore perspectives in depth and directly 'in the moment'. To the researcher's knowledge, there was no other research exploring this area in this amount of depth and using this methodology; thus, the research team felt it was

important to keep the study flexible and open-ended in nature. As this was an exploratory study, a hypothesis is not appropriate.

This study aimed to provide insight into how the stroke population experience 1. cognitive screens 2. Online digital cognitive screens 3. Online unsupervised digital cognitive screens. Some of the broad research questions that this investigation explored include:

- Service users' views: What were the service users' experiences of the digital cognitive screen process? E.g., experiences before, during and after the cognitive screen.
- The evoked emotions and thoughts: What feelings and thoughts are prompted during the cognitive screen process?
- What do the stroke population want clinicians to know when administering cognitive assessments?

Chapter 2: Method

This chapter outlines the methodology used and the rationale for the approach. It includes steps taken to obtain ethical clearance and revisions made based on feedback from the ethics committee and expert by experience group. It also outlines the inclusion and exclusion criteria for participants, the measures used, and the interview structure. It further discusses the study procedures, the pilot study and consequent revisions made to the study.

Research design

Following discussions between the research team and within the transfer viva process, three methodologies were considered to obtain data that could address the research questions: 1) asking participants to complete the online cognitive assessment and then using one (longer) semi-structured interview focused on their experiences, e.g. Owen, 2012, 2) video recording the participant completing the online cognitive assessment and then both the researcher and participant watching the video recording and asking the participant about their experiences, i.e. retrospective think-aloud (Maaike van den Hakk et al, 2003), 3) using a concurrent think-aloud interview (Maaike van den Hakk et al, 2003) during the cognitive assessment.

Involving experts by experience in the study design

All three designs were initially discussed with two charity stroke support groups. Both service user groups expressed that the think-aloud design would work best with the stroke population. They gave reasons such as difficulties with retaining their thoughts until the end of the assessment and feeling anxious about watching their video recordings. The service user group's voices were the primary influence on the final choice of the methodology.

The research team also discussed the advantages and disadvantages of potential designs, using evidence in the literature review to help guide the discussion. For example, the research team agreed that just using an interview at the end of the assessment may increase the likelihood of information being forgotten.

The team also discussed the practicalities of having a participant complete an hour-long assessment to then watch the assessment for another hour, making comments, which may lead to fatigue. The team also considered that the think-aloud method would increase cognitive demand and, in turn, impact participants' performance on the assessment, particularly the subtests requiring language. However, ultimately, the study was not interested in the test results; therefore, the think-aloud method was deemed appropriate to explore participants' assessment experiences.

Think-aloud methodology

A think-aloud approach involves a person verbalising their thoughts whilst completing a task (Güss, 2018) and thus does not rely on long-term memory. Johnstone et al. (2006) provide an overview of the advantages and disadvantages of using think-aloud data. The paper presents evidence to suggest that people are less likely to entwine their interpretations on a subject if they are verbalising their thoughts concurrently with cognitive processes (van Someren et al., 1994). This is an advantage, as the data is less biased to challenges such as compromised memory and social desirability.

In contrast, Branch (2000) found that although the think-aloud method collected data on behavioural, cognitive, and affective processes, many participants found verbalising their experiences while problem-solving challenging. Considering there can be an increased cognitive load in simple and more complex tasks following a stroke (Puh et al., 2007), this may be challenging for the stroke population. Johnstone et al. (2006) provide a brief overview of the think-aloud method. However, unlike typical think-aloud studies, where the researcher does not probe for questions or give direction to remain unbiased (Charters, 2003), Johnstone et al. suggest a two-step process. In this method, data are first collected in real-time, asking participants to think aloud. During this stage, researchers use infrequent and neutral probes, such as 'keep talking', during problem solving activities. The second step is to ask 'follow up' questions; these questions can supplement any unclear data from the think aloud techniques. This two-step process may be more appropriate for a stroke population.

Similarly, Aujla et al. (2020) make similar suggestions for future research based on their findings using a think-aloud method. They asked participants to think aloud whilst completing a questionnaire and found that participants were often silent towards the end. They suggest that the traditional think-aloud method is problematic for older stroke survivors, as fatigue and forgetfulness often affect people. They argue that the participants' silence limits the validity and potential usefulness of research and thus recommend using more frequent prompts to 'keep talking'. They also suggest modifying prompts during the interview, guided by the researcher's 'intuition, experience and flexibility' (Beatty & Willis, 2007). Furthermore, it has been found that some cultures can find it unusual or uncomfortable to say their thoughts out loud spontaneously (Kim, 2002) and thus may need more encouragement or reminders.

Adapting and applying think-aloud methodology to this study

This research used the think-aloud method to collect data centred on a structured task (the ACS). It aimed to gather secondary information about the participants in a more flexible and open-ended way, as described by Charters (2003), to understand participants' experiences rather than to explain their experiences (Fontana & Frey, 2000).

One of the concerns of rigidly following think-aloud principles is the cognitive load on participants. Thus, the researcher followed guidance from Johnstone et al. (2006) and Aujla et al. (2018) and was flexible in this approach to ensure that the research was adapted to the needs of stroke service users. Charters (2003) also recommends breaking a task into shorter units as it helps prevent an overload within working memory. Thus, participants were offered short one-minute breaks between subtests if needed; the ACS also has short breaks with videos built into the programme. Gibson (1997) suggested having a pre-task orientation to help reduce 'cold start effect'; thus, the participants were given a 1-minute practice task before starting the study. Charters (2003) also recommends having a post-task interview for triangulation purposes; the researchers asked questions post-interview and observed participants in person to help support data collected in the think-aloud interview.

The think-aloud method usually requires the researcher to provide no prompts during the task (Someren et al., 1994). However, following the literature review, the researcher used more prompts to 'keep talking' and was flexible with prompts where appropriate, following the guidance from Aujla et al. (2018) to adapt the study to stroke service user needs. The researcher kept in mind that even with recording participants' live thoughts, not every cognitive process was verbalised, and there may be elements of participants' experiences that were not captured using this design. It must also be kept in mind that the mere presence of an observer may have increased the likelihood of demand characteristics whilst completing a task. The research team also considered that the think-aloud methodology can be very time consuming and thus allowed time for the study procedure and the time-consuming analysis.

The unsupervised nature of the ACS also allowed the researcher in this study to take an observer role, which was important as researcher observations complemented the analysis.

Ethical clearance

Ethical approval was granted from the Surrey Health Research Authority and the NHS Research Ethics Committee; IRAS number 309321 and REC reference 22/LO/0477. The committee advised adding an inclusion criterion around having access to an IT device or willingness to attend to use one; this was added. They recommended clarity around all participants receiving a £20 voucher for participation on the participation sheet and protocol; this was revised. They also advised revisions to the participation sheet, such as an explanation of the word 'cognition'; this was also modified. They asked for screenshots of the cognitive assessment to be sent; this was completed. They also advised that the experts by experience group should review the participation information sheet for readability; this was facilitated and revised based on feedback. A summary sheet was also created based on expert-by-experience groups' feedback.

Ethical approval was then granted from the local NHS Research and Development departments of two NHS trusts. Exclusion and inclusion criteria

ensured that all participants volunteering to participate in the research could demonstrate their consent.

Setting and sampling

Due to the descriptive and qualitative nature of the study, formal sample size calculations were not appropriate. This study used predominantly think-aloud methods, with some cognitive interviewing (as suggested for a stroke population). There are currently no concrete guidelines for the number of participants to be included in a think-aloud study (Aujla et al., 2018). The suggested sample size varies; from Willis and Artino (2013), who suggest that 10-30 participants are sufficient for a cognitive interview to generate rich enough data to Nielsen et al. (2002), who indicate that a sample size for a think-aloud study can be as small as five participants. The research team focused on obtaining a sample size large enough to reach saturation of themes. The research team anticipated reaching saturation from 10-15 participants, supported by a systemic review by Hennink and Kaiser (2022) which suggests that between 7 and 19 interviews will reach saturation.

The following inclusion and exclusion criteria were developed for the study:

Inclusion criteria

- Have experienced a stroke and are aware of their diagnosis.
- 18 years old or older.
- Willing and able to provide informed consent.
- Have movement in the dominant hand due to the ACS requiring movement of the mouse with one hand.

Exclusion criteria

- Comorbid neurological conditions: to ensure that the sample is homogenous.
- Receptive or expressive aphasia, as the Amsterdam Cognition Screen is not adapted to severe language difficulties.
- Children; those 17 years old or younger.

- Insufficient mastery of English.

- A visual impairment that would compromise their ability to complete tasks.

- They do not provide informed consent.

- Significant physical impairment in the dominant hand due to the ACS requiring movement of the mouse using their hand.

- Must have the use of a laptop and computer mouse if completing the cognitive assessment at home.

For participants residing on the inpatient ward, the participants treating team on the stroke ward, e.g., their treating Clinical Psychologist and other members of the multidisciplinary team were considered participants care team. For participants in the community attending stroke support group, their charity lead was the Stroke Association Support Coordinator. The participants' care team or charity lead determined whether potential participants fitted the inclusion and exclusion criteria; this helped ensure the protection of participants, e.g., only recruiting those aware of their diagnosis and able to consent. It was the Clinical Psychologist on the stroke ward or the Stroke Association Support Coordinator that initially approached participants, giving them information about the study and who gained consent for the researcher to contact. It was also the treating team and the stroke charity lead who documented the study in clinical notes, and who were contacted if/when the researcher had any ethical concerns during the study process.

The research team recognised that the exclusion criteria created a limited sample compared to the typical stroke population; this shows the limitations of using the ACS with a stroke population. However, many cognitive screens and assessments are also limited in this way, and thus this represents a wider problem within the field.

Gender and socioeconomic backgrounds were also screened due to evidence that these factors can influence the results for cognitive screens (Feingold, 1993; Herlitz et al., 2015; von Stumm & Plomin, 2015), and these social positions are often linked to differences in the use of technology (Goswami & Dutta, 2016). These demographics were used to help make meaning of the results.

The research team agreed that if the researcher believed that the participant did not fit the inclusion/exclusion criteria whilst taking consent or acquiring demographic details, e.g., the cognitive screen would not be possible due to language difficulties, the researcher would handle this sensitively by gently explaining the requirements of the assessment. The researcher would apologise for this not being addressed earlier and thank the participant for their time. The participant would still be given a £20 voucher for their time. However, this did not occur during the study.

Measures

The Amsterdam Cognition Scan (ACS) was initially developed at the Netherlands Cancer Institute, University of Amsterdam and VU University Amsterdam; permission was granted to use ACS within the study. The ACS is based on seven well-established traditional neuropsychological tests chosen to detect dysfunction throughout the spectrum of cognition, including attention, information processing speed, learning and memory, executive functioning, and psychomotor speed.

It can be completed without supervision and takes about one hour to complete. It includes validated unsupervised tests with instructions, practice examples and feedback if incorrect. The assessment requires no downloads and can be done from home. The ACS is designed to be used by people who have little computer experience. Although the research team did not collect scores or personal information from the ACS, it is important to note that the ACS collects no personal information and has certified data security; thus, participant scores were kept secure.

Although the ACS was initially developed for an oncology population, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, suggests that assessments in stroke settings should include tests of complex attention; executive function; learning and memory; language; perceptual-motor; and social cognition. The ACS covers these domains, apart from language and social cognition. Similarly, other cognitive screens and assessments commonly used with a stroke population such as the MMSE, ACE III and MoCA were also designed for other populations,

such as dementia populations and also miss stroke relevant domains such as social cognition. Thus, these limitations did not preclude the use of the ACS and it was considered applicable for use within the context of the study, i.e., to primarily gain service users experiences of a cognitive screen (rather than to explicitly test the reliability or validity of the ACS with the stroke population).

Part of the exclusion criteria was that participants have sufficient mastery of English, as determined by their clinical team.

Interview structure

The semi-structured interview protocol was constructed using principles from Aujla et al. (2020) and Charters (2003) papers. Multiple discussions by the research team facilitated the development of the interview schedule. The interview schedule was designed to elicit the perceptions and experiences of stroke service users of cognitive assessments; for example, 'what it was like completing the assessment today?', and 'how did you feel after completing the assessment?'.

A representative from a local Stroke group was consulted over the study documents, such as the interview schedule, participation sheet and consent forms. Positive feedback was received on the clarity and detail of the documents. They recognised that the participation information sheet needed a lot of detail and suggested having an additional 'summary sheet' that participants could refer to. Thus, an extra summary sheet with key information and a larger font print was also created to give to participants.

Participant identification

The study was first advertised within Leeds NHS stroke services. Eligible service users were identified by a member of the treatment team (e.g., treating consultant, clinical nurse specialist) and were asked whether they would like to hear more about the study from a researcher. This initial contact was on the ward, where the clinical team provided the participant information sheet. Potential participants were given a maximum of three months to decide whether they wished to take part; this allowed for sufficient time for participants to weigh up their decision in line with the time constraints of the clinical doctorate. Service users in inpatient settings

were given a minimum of 24 hours between being informed about the study and taking part to ensure they had enough time to make a decision. When potential participants were given the information sheet to read, they were asked if it was acceptable for the researcher to contact them to hear their decision about whether they wished to participate. Alternatively, the potential participants were given the researcher's contact details so the service user could contact the researcher if they wished to participate once discharged.

The study expanded recruitment to another NHS trust and the Stroke Association. With the Stroke Association, eligible service users were identified by a leading charity member and asked whether they would like to hear more about the study from a researcher. This initial contact could have been in person or via a phone call or letter sent by the charity team for people who were not in regular face-to-face contact with the charity.

NHS trusts and the Stroke Association were given a consent to contact form if they wished to complete this before the researcher made contact. Alternatively, consent to contact could be given verbally and documented in clinical notes. With the service user's verbal consent, a researcher met with the participant in person or over the phone and then provided the participant with an information sheet in person or via email, explaining the study in detail. As indicated, a relationship between the researcher and participants was not established before the study commenced. The participants knew what the research would involve and the reasons for doing the research, i.e., to understand their experiences of the digital cognitive screen and to develop practitioner recommendations. As the themes were derived from the data, no previous findings, personal goals or themes were discussed with participants.

The participant could choose whether to participate in an NHS, university, or charity group environment (in a private room) or in their own homes on a video call; this was discussed in the recruitment stage over the telephone or by letter. However, all participants ultimately completed the study in person.

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┌─────────────────────────────────┐
│ Clinical team or charity group  │
│ screen for people who meet the  │
│ study criteria                  │
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                │
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│ Those who fit the criteria are  │
│ given information about the     │
│ study by the clinical team or   │
│ charity group                   │
└─────────────────────────────────┘
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│ Participant expressed interest  │          │ Did not meet inclusion or│
│ in the study and gave consent   │─────────▶│ exclusion criteria (n=0) │
│ for the researcher to contact   │          │ Declined to participate  │
│ them; contacted by the chief    │          │ (n = 1)                  │
│ investigator (n = 12)           │          └──────────────────────────┘
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│ Completed study (n=11)          │
│ Did not complete study (n=0)    │
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│ Analysis (n=11)                 │
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│ Eligible participants (n=11)    │
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Figure 1. Flowchart to illustrate the recruitment strategy

Procedure

The researcher first introduced themselves and the project, explaining the aims of the think-aloud interview; this was in person either at a charity stroke group, on a stroke inpatient ward, or over the phone. The researcher explained that the assessment and think-aloud interview should take around 90 minutes, and they can take breaks between tasks if needed. It was explained that the interview would be video recorded so that the audio could be transcribed, and the video reviewed to help complement the data from the audio recording.

If agreeable, the researcher and participant went to a pre-booked private room either on the stroke ward, university premises or the charity stroke group premises (assistance was given if needed); no one else was present during the study. The researcher then checked or asked the participant to check that the laptop screen brightness and volume were set to their comfort and that they could clearly see and hear the cognitive screen. The researcher adhered to ethical standards: explaining the video recording, confidentiality, and their right to opt-out without affecting care. The researcher completed the demographic information sheet with the participant. The researcher then started a video recording using Microsoft Teams and stated the number of the interview.

Once recording, the researcher let the participant know that the recording had started. If a physical consent form had been signed, the researcher reconfirmed whether the participant was happy to continue and consent. If no physical consent form were taken (i.e., it was a video call interview), then the researcher would have gone through the patient consent form with the participant, asking them to state that they give consent to participate at the end of the form; however, all participants attended in person, and thus this was not done. The researcher then asked the pre-interview questions (see Appendix B). The researcher then read through the verbal instructions adapted from Aujla et al. (2020) paper and asked participants to do a one-minute practice task to ensure they understood what they were asked to do. The participant then started the assessment and think-aloud interview. During the interview, the researcher provided some prompts, such as 'keep talking', and asked questions between tasks if needed. The researcher also wrote observation notes to help complement and make sense of the audio when transcribing. After the interview, the researcher asked the 'end of interview' questions, and the participant had an opportunity to ask their own questions. The participants were then given £20 vouchers for participating in the research. The researcher then stopped the video recording.

The think-aloud interviews were transcribed smooth verbatim. When transcribing, the researcher included non-verbal observations such as tone of voice while acknowledging that their interpretation would affect how it is written up, as Fontana and Frey (2000) recommended. In this study, the researcher was also writing down visual observations that seemed significant; this was to complement the data and was not analysed separately.

Pilot study

The researcher was granted ACS tokens to complete a run-through of the ACS to pilot the assessment. Following the pilot test, the following modifications were made:

1. Following a discussion, the research team decided to ask participants to save their feedback until the end of the introduction video to allow participants to focus entirely on the video instructions. If participants

started talking during the explanation video, this was noted for analysis, and they were reminded to save their feedback until the end of the video.

2. If a participant could not complete a task, the researcher documented what they did and, if an easy and quick solution, e.g. knowing where something was on the keyboard, assisted the participant in moving on to the next task or the assessment would end.

3. As the tasks were quite challenging, the team decided that using a neutral statement such as 'scores won't be counted, but all information and feedback will be helpful' for encouragement would be beneficial.

4. Considering how specific the mouse movement must be, the research team added 'must have use of dominant hand' into the participant criteria.

In reporting, the research team followed the consolidated criteria for reporting qualitative research (COREQ) to ensure the accuracy of this qualitative study.

Chapter 3: Analysis and epistemological positioning

Chapter 3 outlines the analysis chosen for the study. It starts by discussing the researcher's epistemological position and experiences, which is particularly important when considering the qualitative and subjective nature of the analysis chosen. It discusses the aims of reflexive thematic analysis and the analysis process undertaken in this study. It ends with plans for dissemination of the study findings.

Researcher's credentials

Ms Rebecca Louise Day, BSc MBPsS (myself), was the chief investigator for this research as part of my Doctorate in Clinical Psychology Thesis. I identify as female and was a Trainee Clinical Psychologist at the time of thesis submission. At the time of write-up, I had experience using qualitative methodology for research published in a peer-reviewed journal, experience collecting data for a large research trial, and knowledge of using both qualitative and quantitative analysis methods for service audits. As chief investigator, I conducted the interviews, led the analysis, and led the write-up.

Researcher's epistemological position

This study aimed to capture the stroke population's experiences of a digital cognitive assessment. The study used a qualitative approach to help capture the detail and nuances of the participant's experience. Using qualitative methods, the researcher, myself, was particularly mindful of being aware of my epistemological position and how this may influence the data.

When starting the doctorate, I considered myself a critical realist in that I believed that, although there are elements of reality that will exist, regardless of our individual experiences (positivism), much of how we, as humans, make sense of the world is influenced by social construction (relativist). However, throughout training, I have become more aware of how my past experiences and language have constructed a lens for how I process and interpret all modes of information. Thus, I believe that my experiences will influence how I make sense of the data and codes

and that I can use my experiences as a lens to interpret the data. I consequently believe myself still within the spectrum of critical realist but leaning more towards a constructionist standpoint. With that in mind, I wanted to acknowledge some of my experiences that have shaped 'my lens'. For example, my first neuropsychological assessment experience was undergoing one at university as part of a dyslexia assessment and subsequent diagnosis at 19 years old. I remember wanting a better understanding of my experiences and found that a diagnosis gave some meaning to what I had experienced in educational systems. It also allowed me to access appropriate support; thus, I perceived the process to be positive overall. However, I also remember the assessments evoking fear and thoughts of 'feeling stupid', and how much I worried about the subtests I struggled with. Later in my work life, I learnt to administer neuropsychological assessments and cognitive screens; I anecdotally found similar themes that arose within service users. I believe these experiences are part of what has driven me to complete this research. I wanted to take an open and neutral stance when interpreting the data and yet not shy away from using my experiences to help understand the results.

Analytic process: reflexive thematic analysis

Reflexive Thematic Analysis (TA) was chosen to analyse the data. With Reflexive TA, Braun and Clarke (2019) encourage the researcher to embrace reflexivity, subjectivity and creativity as assets in knowledge production. This allows for flexibility in interpreting the data and for researchers to make meaning of large amounts of in-depth data. Braun and Clarke (2019) recognise that thematic analysis approaches have expanded. They acknowledge that research is a deliberate process shaped by epistemology and ontology, in line with my positioning.

Themes were inductive (derived from the data). The researcher used NVivo to manage the data, a qualitative data analysis computer software package by Lumiver. The researcher read the transcripts several times to familiarise themselves with the content and highlighted sections related to the research objectives. For several transcripts, the researcher also met with the research team to discuss their findings and refine codes, the key points and (sub)themes. The researcher examined the raw transcripts again to confirm that all data were reflected in the coding. Quotes from

the data were also reported to illustrate the results (Crowe et al., 2015) and to capture the essence of a theme (Crowe et al., 2015), with the aim of quotes being purposeful, vivid and powerful (Eldh et al., 2020; Finlay, 2021). To ensure anonymity, all identifying information was removed from the quotes.

Themes were generated using the revised steps suggested by (Braun & Clarke, 2019), summarised below:

1. Familiarising self with the dataset: transcribing data, reading and rereading the data and noting initial observations and ideas, both in relation to individual data items and the entire dataset.

2. Coding: generating labels and codes that capture and evoke important data features relevant to the research question. This involved coding the entire dataset multiple times and collating the codes and relevant data extracts. Data coding was completed by Rebecca Day, Trainee Clinical Psychologist (one data coder).

3. Generating initial themes: examining codes and collating data to develop broader patterns of meaning and potential themes. It involved collating data relevant to each theme and reviewing the viability of each potential theme.

4. Developing and reviewing themes: checking themes against the coded data and the entire dataset to determine whether a convincing story is told that addresses the research question. Themes were further developed to be more succinct; this involved splitting, combining and discarding themes.

5. Refining, defining and naming themes: developing a detailed analysis for each theme, determining the story for each theme and generating clear names for each theme. The research team also generated a thematic 'map' of the analysis to help think about how the themes weave together.

6. Writing up: weaving together the narrative and data extracts and contextualising the analysis in relation to existing literature.

Braun and Clarke (2019) suggest that analysis is typically a recursive process; in line with this, the research team moved back and forth between these steps to establish conclusions for the write-up.

Dissemination

The researcher has generated recommendations for a broad set of audiences. In disseminating findings, the researcher will meet with organisations such as local charity stroke groups to feedback a summary of the results and send summary emails to participants who agreed to this on the consent form. Any feedback from these groups will be considered when writing up for potential future publication. The results have also been verbally disseminated to representatives of the Amsterdam Cognition Scan to provide feedback on how a stroke population experienced the assessment, as well as any practical challenges that occurred during the assessment with the stroke population.

We hope to increase the impact of this research by ensuring we not only publish in academic journals but also disseminate a summary of our findings through our charity contacts.

Chapter 4: Results

This chapter summarises the study's outcomes and details the participants' demographics. It discusses the results from reflexive thematic analysis. It includes a table and figure showing the themes and subthemes generated by the analysis and a 'themes map' to show how the themes and subthemes link together. The chapter then discusses each theme and subtheme in more detail and includes direct quotations from the data to support the story.

Results overview and demographics

During the later stages of recruitment and the start of the analysis of results, the research team met on a weekly basis to discuss codes and developing themes. During these meetings, the research team discussed whether new codes and themes were occurring, in order to determine when saturation had been reached. The research team agreed that saturation was met at eleven participants: six from Stroke Association groups in the community and five from NHS-based inpatient services. Considering the inclusion and exclusion criteria, all participants represented the target group, in line with TA principles. Participants ranged from 46 to 80 years old; seven out of eleven (64%) participants were over 60 years old. Two participants identified as female, and nine participants identified as male. Nine participants were from a white British background, one was Indian, one was Chinese, and one was Nigerian. Time from stroke to time of interview varied from 3 months to 127 months; at the time of the interview, two participants were within the early acute phase, three participants within the late acute phase and six participants were within the chronic phase. The number of hours on digital devices varied from 3.5 to 70 hours a week; the average was 30 hours per week.

Generally, there appeared to be a link between the number of hours using digital devices and participants' age, with younger participants using digital devices for more hours a week. However, this did not correlate with verbally reported confidence in using a laptop and mouse. All participants indicated that the main devices they used were their phones and iPad, with only a few stating that they commonly used a desktop.

See Table 1 below for a summary of the participants' demographics. For the purposes of confidentiality, participants' names have been changed to pseudo names.

Participant number and pseudo name	Gender	Age	No. of months between stroke and interview and phase	Ethnic Background	Any other neurological conditions	No. hrs. a week on digital devices	The setting of the participant (at the time of the interview)
001 **Mike**	M	61-65	7 months Chronic Phase	White British	NA	30 hrs	Inpatient
002 **Yagna**	M	46-50	5 months Late-acute phase	Indian	Previous lacuna infarct	70 hrs	Inpatient
003 **Wai**	M	51-55	3 months Early-acute phase	Chinese	NA	56 hrs	Inpatient
004 **Richard**	M	66-70	6 months Late-acute phase	White British	Ependymoma – treated in 1989	14 hrs	Community
005 **James**	M	71-75	20 months Chronic	White British	NA	14 hrs	Community
006 **Whitney**	F	76-80	4 months Late-acute phase	White British	NA	3.5 hrs	Community

007 **Ben**	M	66-70	9 months Chronic phase	White British	Brain tumour – treated	3.5 hrs	Community
008 **Paul**	M	71-75	52 months Chronic phase	White British	NA	14 hrs	Community
009 **Jenny**	F	51-55	127 months Chronic phase	White British	NA	42 hrs	Community
010 **Jason**	M	71-75	3 months Early acute phase	White British	NA	14 hrs	Inpatient
11 **Patrick**	M	51-55	8 months Chronic phase	Nigerian	NA	70 hrs +	Inpatient

Table 1 Demographics of Participants

Only four participants were able to complete the entire assessment within 90 minutes. Five participants could not complete the assessment, and two did not complete the assessment in 90 minutes (and were both about halfway through the assessment). This did not seem to link to whether participants resided in an inpatient setting, the community, or the time since the stroke.

Some participants recognised that they could not proceed with the assessment and stopped. Whereas some participants felt that there was a problem with the assessment and consequently stopped; on these occasions, the researcher felt there were difficulties with either understanding or retaining the instructions of subtests or problem-solving following an error.

Results of the analysis

The researcher used their reflexivity, e.g., their unique perspective of both receiving a cognitive assessment as a service user and delivering cognitive assessments as a clinician, to help make sense of the themes and the results. The researcher believed that their experiences and direct awareness to help them be sensitive and empathic throughout the data collection process, and more in tune with the data during the data analysis process.

The analysis uncovered three central themes focused around 1. past experiences: the service user's previous experiences and how these influence their experience and perception of the cognitive assessment; 2. direct and immediate experiences: responses and feelings evoked by the cognitive assessment and 3. potential future experiences: the utility of digital cognitive assessments with the stroke population going forwards. There were ten subthemes; please see Table 2 for a summary of these themes.

Theme	Subthemes
1. Past experiences: the service user's previous experiences and how these influence their experience and perception of the cognitive assessment	1.1 The impact of the stroke 1.2 'Damaged' identities and connecting with others with similar identities 1.3 Individual differences and adaptations 1.4 Making meaning and processing what happened
2. Direct and immediate experiences: responses and feelings evoked by the cognitive assessment	2.1 Experiences and feelings evoked by the cognitive assessment 2.2 Confidence and self-determination
3. Potential future experiences: the utility of digital cognitive assessments with the stroke population going forwards	3.1 Perceived issues with digital cognitive assessments with a stroke population 3.2 Perceived benefits of digital cognitive assessments with a stroke population 3.3 Digital assessments vs paper and pen assessments with a clinician 3.4 The value of experts by experience in research focused on digital cognitive assessments

Table 2. Demographic Themes and Subthemes

The author also used a thematic map (Figure 2) to determine how the themes and subthemes were linked. The author also created Figure 3 from this thematic map to help illustrate the themes visually.
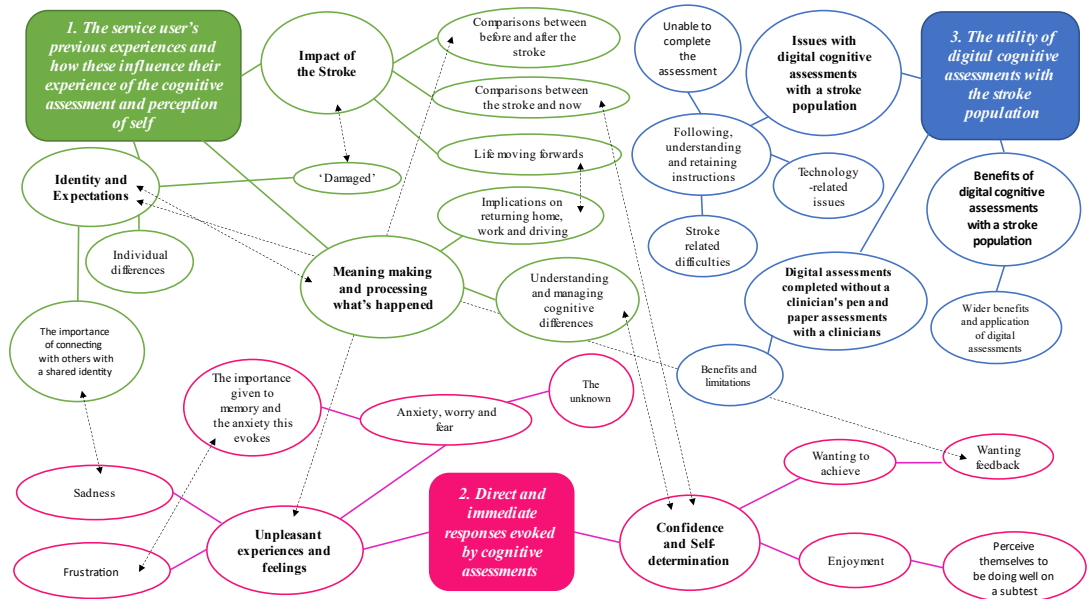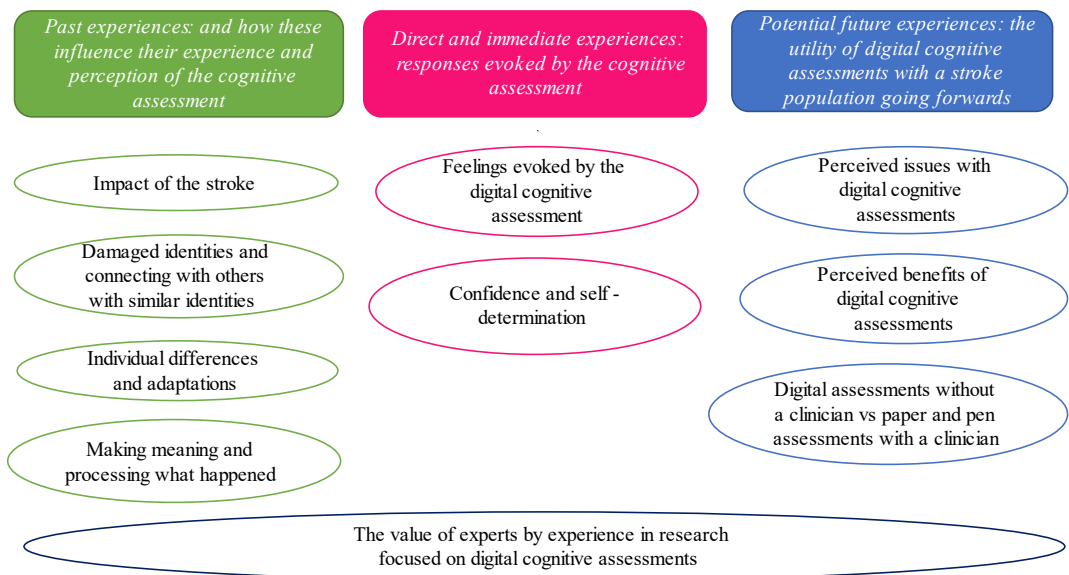
Figure 2. Thematic Map

Figure 3. Visual representation of themes and subthemes

Theme 1: Past experiences: and how these influence their experience and perception of the cognitive assessment

Despite the interview schedule being focused on their experiences of cognitive assessments, all participants referred to a range of experiences from the

past and present interchangeably throughout the interview process. Indeed, participants' wider previous experiences seemed to influence their experience and perceptions of the digital cognitive assessment itself; thus, it was paramount to consider their previous experiences as part of the research question.

1.1 The impact of the stroke

Before, during and after the cognitive assessment, most participants spoke about a change in their cognition following the stroke, '*big big change*' (Mike, inpatient), and some commented about this change being sudden. Most participants indicated that their cognition had declined following the stroke. Those who were community-based referred to the everyday struggles they found challenging at home. In contrast, those who were residing in inpatient settings did not have as much experience of this direct comparison and, other than one participant, who broadly spoke about being unsure about how much had changed:

> *I don't want to use the word 'normal', but before now, my cognitive functioning would be at a certain level. Well, after the stroke, I don't know how much is altered… is changed* (Patrick, inpatient).

A few participants also highlighted that cognitive and mental health difficulties were not something that they anticipated, with strokes often being more strongly associated with physical health changes. These changes following the stroke appeared to evoke feelings of shock, anger, and hopelessness:

> *I thought, you know, when I've thought about having a stroke, it's people in wheelchairs and physical problems. I never expected it being mental problems… It's unbelievable, really is unbelievable… I'm thinking, that's it, I've had a stroke, this could be the end of my life, as I know it*
> (Mike, inpatient).

During and after the assessment, many participants also reflected on comparisons between their abilities when they first experienced the stroke and now (time of the interview), and many reflected on improvements since the initial stroke, '*how far I've come on*' (James, community). This comparison occurred whether the participants were in the sub-acute or chronic phase. Those in the community also made the comparison of their abilities between being an inpatient in the hospital and now (time of the interview):

that was easier than some of the ones I've had when they've been testing me in hospital, you know and I maybe I wasn't as ... quite as with it then, I don't know (Whitney, community).

Participants also referred to these improvements happening gradually and emphasised the labour that had been put into making these changes:

you've gotta work at it. It just doesn't happen on its own. It really is hard work. Sometimes you think, can't be bothered doing that and then you think I'm going to have to do it (James, community).

The cognitive assessment seemed to prompt many participants to think about their life moving forwards, with some expressing that they wished to develop their cognition further and others suggesting more acceptance of the changes to cognition that the assessment highlighted. Both participants in inpatient and community settings expressed a need to keep going and not give up and stressed the importance of focusing on what they can do for their wellbeing:

I don't like saying actually...actually... stating what I can't do, cause that's not very helpful generally, in my wellbeing, mustn't spend all my day thinking about things I can't... I want to move on (Richard, community).

Participants residing in inpatient settings spoke about their anticipated futures when returning to the community. For example, the assessment appeared to prompt Jason to think about what support he may need with his cognition in the future:

I'll need more and more help with that, I think in future… I will need a lot more help and rehabilitation, that kind of thing… Yeah. So, think I realised that it's something I will need help with.

Whereas Patrick anticipated that the changes would not be permanent and that there would be improvements in his cognition over time:

But I have only scored bad, it is nothing permanent… I will be flying, yeah. We will get there, just time and patience.

1.2 'Damaged' identities and connecting with others with similar identities

The cognitive assessment process appeared to provoke broader philosophical ideas, such as what it is to be human and what makes us who we are:

I know there was serious trauma to my brain... I know it is. I had my bleeding ... the bleeding was on my brain, which our brains are part of being human... the powerhouse of being human for me (Patrick, inpatient).

Similarly, Richard (community) described the cognitive assessment as helpful as it gave him an understanding of his identity and his behaviour:

I: How is [the cognitive assessment] helpful?

R: I need to know who I am... Yeah…. Part of your very identity… it goes on to, you know, how I behave with people.

Although only Patrick and Richard made direct reference to the outcomes of the assessment being linked to identity, there was an undercurrent theme of participants losing their identities because of the stroke. For example, participants repeatedly referred to themselves and their brains as 'damaged':

My memory got slightly destroyed by the stroke. Damaged. That's the way I see it, it's hard to be clear about this, but I think the stroke must have damaged my cognition... form of, you know, memory of things that used to be familiar and straightforward, some of that has been lost (Jason, inpatient).

However, there was also a sense from some participants that although the stroke may have damaged the brain, there is hope that the brain will find ways to repair and recover, '*yeah, I heard actually, if part of your brain is damaged, that the brain will find new pathways* (James, community) and that '*other areas [of the brain] can compensate for whatever damage has been done'* (Patrick, inpatient), giving a sense of potential growth. This, in turn, gave the sense that identity is organic and can change as the damage is healed.

A few participants alluded to feeling on their own since the stroke, and others not understanding them following the stroke:

I'm just thinking that if I can help somebody else, make it easier for somebody else to actually… cause it's, you're on your own… Particularly in my case where, you know, you've lost the things that you enjoy doing, sort of thing, you know (James, community).

Understanding how... What's happened when people have strokes... cause a lot of people don't understand (Ben, community).

Linked to this, some participants spoke about being damaged and the benefits of being able to talk to others who have shared elements of identity:

R: I'll use the word 'damaged'… from the stroke... And, life has slowed down, and I need to move on and… don't let that bother me. OK, I live it. It's how I am, don't worry

I: And do you feel that doing tests like this, is that part of that, or?

R: there's no reason why not… And it's great talking with other people who've had strokes… Yeah, surprisingly (Richard, community).

1.3 Individual differences and adaptations

One individual difference was the participants' outlook on their stroke, which appeared to impact how they perceived their performance. For example, a couple of participants spoke about being 'fortunate' and 'lucky' for what they *do* have, which seemed to create a more positive experience of the assessment.

Overall, I think, hey, you're lucky you're still walking around, you're still talking. You know, I was lucky, if that's all I've come out with after three strokes (Whitney, community).

Throughout the assessment process, participants in both inpatient and community settings spoke about realising that everyone is different and is affected by their stroke differently. Patrick (inpatient) said:

Since I came to [hospital], I realised that a stroke has different branches… I've been in hospital here; I've come to see different stroke patients with different symptoms'...

Similarly, Ben (community) said that the main thing they would want clinicians to know is that everyone is different:

Not everybody's the same, not everyone's the same... you get some people sat here that are far worse than me, or you could get those who... are far better than I am.

Participants suggested adapting sessions to individual differences, such as knowing background information about a person. For example, Mike (inpatient) suggested that discussing a person's stroke experiences would help them adapt the assessment to individuals:

> *It would be a good idea to have a chat about you... maybe a stroke as a whole. There might be some approaches you can change differently… so you can change it slightly.*

Similarly, Wai (inpatient) raised an important point about adapting cognitive assessments to different ethnic and cultural backgrounds:

> *If you were to like, you know, cause you asked me about my ethnic background before [for demographic questionnaire]. What about... you know... you need like you know... different languages and that like you know across the board, yeah, and you probably like, can't....it will depend on if person is literate or not, to be able to do this task.*

As well as adapting sessions, Paul (community) raised questions about how clinicians would interpret a cognitive assessment without knowing someone's individual differences, identity, and premorbid ability before the stroke*:*

> *It's difficult because logically you would have a cognitive assessment before you have your stroke, so you've got baseline to work on. You don't have a baseline, and I don't know how this will slot in… Logically, you'd work on the assumption they have had a stroke and they have got difficulty working things out in his head, etcetera, but again, you don't know what I was like before.*

He also highlighted the idea of repeating assessments, which is common practice for neuropsychological assessments.

1.4 Understanding the cognitive assessment and making meaning of what hasn' happened

Participants in the community considered the cognitive assessment an important and valuable part of the rehabilitation process after a stroke. Ben implied that cognitive assessments are beneficial to people who have had a stroke, and those in their social network, for further understanding and processing of what's happened:

I think anyone who has survived a stroke, I think it is really important that they do have a cognitive test, because a lot of people think you've had a stroke, but in the background, they don't understand how it's happened, what happens after it's happened, and I think the cognitive part of it is that… there's a lot in that part, what can be picked out by clinicians, like yourself, and who can then get people to understand... what what's really the underlying thing of it.

Similarly, participants in inpatient settings anticipated that cognitive assessments would give them insight and an enhanced understanding of their cognition. Patrick also indicated that cognitive assessments can also help with learning ways to manage changes following the stroke:

It will be good to have a good understanding of where I am cognitively, because an understanding of where I am will help me... would help me manage, whatever the impact. Yeah, I'll find a way to improve my cognitive function.

Participants were prompted to reflect on what they felt was the purpose of cognitive assessments. Many participants speculated that the assessments were used to assess whether people are safe to return home and spoke about the influence cognitive assessments can have on returning to work and driving:

'*To make sure that you're safe to go into … the home environment I suppose…I think you're vulnerable and you get that… a bit of a panic situation with, you know, I'm not gonna be able to do this… I thought, I aren't going to be able to go home… it's far more at stake, cause I want to go home, you know. I am a home bird'* (James, community)

I wanted to know that… where I was lacking and what I did do well and what I didn't do well yeah, with that it helped me with, which helped me know with returning back to work as well, cause it's work-related, where you know, what is affected you (Yagna, inpatient).

Losing my licence was the biggest, biggest drawback. But then again, I can get on the coach. I can get in a taxi, I can get on a train… So, I do feel quite lucky, but my brain isn't as good as it should be (Whitney, community).

Theme 2: Direct and immediate experiences: responses evoked by the digital cognitive assessment

Direct experiences and feelings evoked by the digital cognitive assessment: anxiety, frustration and sadness

As well as bringing their previous experiences to the cognitive assessment process, participants also expressed their immediate responses and feelings. Although participants reported finding cognitive assessments helpful for understanding and managing their stroke, they also experienced the assessments as putting a spotlight on their cognitive difficulties:

> *I'm struggling with numbers and such and… Yeah, you know… and it, if it's not working right. This... just might be a stroke... But if it's not working very well, it just really marks the struggle that I am having at the minute* (Mike, inpatient).

This left some participants feeling exposed and was a contributor to unpleasant feelings, such as fear, frustration, and sadness experienced by participants:

> *I: how are you feeling at the moment?*
>
> *R: crap (laughs) it's important… Um… it exposes my poor memory from the stroke… frustrating* (Richard, community).

Most participants expressed worry and panic either before, during and/or after the assessment:

> *I think it's… I'll be honest here; I think it is quite intimidating… You know, after a stroke, they're gonna throw all sorts at you, tests… everything* (Mike, inpatient).

This anxiety was often evoked by not knowing what to do next on the digital assessment without the assistance of a clinician, which affected how some of the participants engaged with the assessment. Jenny (community) stopped the assessment due to not knowing what to do next and the unpleasant feelings being evoked:

'I forgot where I am. Oh I don't know what to do... I don't know where to do with it, so... I've lost it now… I'm a bit anxious with it… I'm fed up… I'm disappointed, but I feel like I can't pick it up now. I've lost it'.

Many participants also related some worry and fear to the unknown. Before starting the digital cognitive screen, Paul (community) described his knowledge of cognitive assessments as an '*empty void*' and later went on to say that this was causing '*turmoil*':

I: what's going through your mind at the moment before...?

R: turmoil

I: OK, in what way?

R: I don't know what's happening.

Similarly, Jason (inpatient) highlighted the fear of the unknown and unfamiliar too:

There was a sort of fear that it's all a very unfamiliar world… the whole language in which this is this is conducted, like cognitive and cognition. It's unfamiliar. I think most people say the same, that it's, you know, it is an unfamiliar world sort of analysing your cognitive skills or performance.

Another specific fear that participants shared was about the cognitive assessments uncovering dementia*:*

I think they are doing an Alzheimer's test on me here… I've completely failed it (Mike, inpatient)

It's always in the back of my mind, you know, I'm right... my worry is that I'm gonna end up with dementia (Ben, community).

Most participants shared a specific worry about their memory, which appeared to be particularly evoked during the verbal memory subtest. Some participants expressed ambivalence in their expectations in remembering information. For example, although Ben (community) validated that '*things like forgetting and things like that, it's to be expected*', he also expressed worry concerning his memory during the verbal memory subtest:

My wife will ask me something or tell me something, and an hour later I'll ask the same thing, and she says, I just told you. And that... That that worries me does that, that part… that worries me.... really does.

Similarly, although Paul (community) explained that he didn't need to use his memory as much due to his current lifestyle, *'probably because I don't need to... use my memory as much, I'm not exercising my memory',* he also expressed unpleasant feelings during the memory subtest:

I: how are you feeling?

R: defeated because it's only short-term memory.

Most participants indicated that they felt distressed or panicked when they could not remember all the words after five repeated attempts to remember the word list. Furthermore, even when speaking to participants at the end of the assessments about their collective experiences, most participants focused on their unpleasant experience of the repeated memory subtest, and Richard highlighted this cognitive bias:

Well, it's different to escape the test, the screen test with the words, because that sort of... In my memory, as I walk out, that will be the big memory of the session. Yeah, yeah, it can't be helped, can it?

Similarly, some participants appeared to have cognitive bias focused on the speed at which they could complete a task, *'just feel a bit slow… felt as if I should have done it quicker'* (James, community). This also evoked unpleasant feelings in participants:

I: What makes you laugh?

R: when she says as fast as possible… I'm pathetic

I: Oh, in what way?

R: So slow. Like I can't you know… I can't. I can't. I don't do fast
(Richard, community).

Participants also suggested that clinicians must acknowledge and understand that assessments are worrying and unfamiliar to most people:

'a lot of people are gonna find this kind of thing a bit worrying because it's just unfamiliar way of being presented with information and having to deal with it even and even the sort of basic things like numerical and alphabetical order because you haven't been subjected to any kind of testing for that... as adults for a long time' (Jason, inpatient).

Participants suggested that providing an informal and relaxing atmosphere, e.g., offering people a drink, could help anxiety. Participants also indicated that clinicians providing patience in a non-judgmental environment could be helpful:

All been really nice and patient… I've always felt really, you know, confident about people doing that sort of thing with me, knowing that you're not judged, either. Not... like I think to myself, sometimes, you're thick. But I know that the people that are doing that, aren't doing that
(Whitney, outpatient).

Participants also highlighted the importance of giving informative feedback and validation:

Well, where it says memory assessment, when they come back, when you've done the test, the only thing they say is you're average, or you're doing fine, or below average. There's nothing constructive about it. Cause I've asked about this, I've got a friend who went for it, and he was very dismissive of their attitude towards people who want to know how to correct or how to improve their status   (Paul, community).

Most participants verbally expressed frustration and annoyance, and nearly all participants appeared to show signs of frustration within the observation notes at some point during the digital cognitive screen. This frustration and anger seemed particularly evoked when unable to complete a task correctly. Frustration was also often evoked during the verbal memory subtest:

R: But I can't right now. Think of any of the words and those that I have just typed in okay

I: Are there any feelings that come up with that?

R: Yeah, annoyance and yeah… Yeah… Annoyance with myself for not… cause I'm better than that (Whitney, community)

Interestingly, this anger was typically directed towards themselves rather than the assessment, particularly for female participants:

I: OK. Any other thoughts coming up?

R: Loads, angry with myself, because I would have been able to do it one time… disappointed with myself (Jenny, community).

Similarly, most participants used self-critical descriptions such as 'stupid', 'useless', 'thick' and 'pathetic'. This appeared to be during times when participants were unable to complete a task due to cognitive difficulties, which led to a perception that they had failed:

A lot trickier, so I couldn't... I couldn't actually work it out, so I was feeling, you know, what a failure, cause I couldn't quite work it out…
(Mike, inpatient).

Another common feeling that was evoked during the cognitive assessment process was sadness. Many participants also expressed feeling 'hopeless', 'disappointed' or low in mood, elicited directly from being unable to do a subtest:

R: I laugh because I can't remember.

I: OK. And how does that make you feel?

R: Shit. OK. Yeah. Sorry, I can only answer in blunt terms in the confines of this (Richard, community).

Participants also expressed sadness related to the loss following the stroke:

Well, it's really scary. You know, I have openly admitted to my wife that I don't think there's anything left for me in the world. Because it's gone, everything's gone (Mike, inpatient).

Patrick (inpatient) also spoke about how he felt low in mood but expressed more hope for the future:

Sometimes it gets a little bit dark… but now, things are… there's more lights though. I can see the light at the end of the tunnel.

2.2 Confidence and self-determination

On the other hand, a few participants expressed feeling confident going into cognitive assessments, and many said that although the digital cognitive assessment was initially daunting, they felt better once they had started. Participants enjoyed specific subtests, particularly the 'place the beads' subtest (Tower of London test). Participants also seemed to enjoy subtests they perceived themselves to be doing well on. For example, Whitney (community) reflected that:

> I've always felt really, you know, confident about people doing that sort of thing with me... When I first started on some of them... I thought, oh it's too hard this, but once I got going, it got a bit easier... so I was quite pleased with myself.

Participants' confidence level oR enjoyment appeared to influence how much participants applied themselves to the assessment, with most participants reporting that they were going into the assessment wanting to achieve:

> Whether I'm gonna do... you know... will it be a complete failure or will it be a success... hope it will be as well. Yeah, it'll be a success. I'll give it 100%... Would be nice for me to know how... I am... (Ben, community).

Patrick (inpatient) indicated that, despite the study assessment not being scored or a valid assessment, he wanted to apply himself as there were still implications for what the results mean to him/his identity:

> I know there was no pass of fail to it, but... The test... every test comes with an anxiety, you know, however, it's a test, and you have to push to... learn... cause if you don't do well, surely that's something cognitively, because not passing a cognitive assessment means that there is something wrong with you, cognitively, so you have to try and pass a cognitive assessment just to try to prove that cognitively, you are okay.

Indeed, despite being aware that the study would make the scores invalid, and they consequently would not be receiving scores, many participants expressed wanting to know whether they had completed a subtest correctly and what the outcome of the assessment was:

> I'd like to know, get a feeling of if I'm making any progress with if I did a... roughly how well I did in this exam (Jason, inpatient).

A few participants expressed frustration that there's no feedback from your test. Paul (community) suggested '*they need feedback. You will you take all these results and dump them in a supercomputer and where the programs are, but they don't come back'*.

It is important to note that a few participants initially spoke positively about completing the cognitive assessment, expressing intrigue and excitement, but later expressed fear, frustration, and sadness during the assessment, as outlined in the previous section.

Theme 3: Potential future experiences: the perceived utility of digital cognitive assessments with the stroke population

3.1 Perceived issues with digital cognitive assessments with a stroke population

Most participants had difficulty reading, understanding and following parts of the cognitive assessment instructions. Similarly, Richard (community) explained that he could often struggle to understand the details of what he had been asked to do if an unfamiliar task:

> *I'm not surprised that I don't immediately understand the details of what I have been asked to do. It's a bit like, I'm good with routines, anything that's not routine becomes tricky.*

This led to participants not understanding what they were being asked to do:

> *I didn't quite understand that question… I didn't quite... I thought I'd followed the instructions* (Mike, inpatient).

Another common theme was participants struggling to concentrate and attend to the instructions and tasks, which some participants linked directly to changes following their stroke:

> *I wasn't concentrating, don't know if I was right or not... it's just gone? And I don't know if this is right or wrong cause see I wasn't concentrating… I don't tend to have… have the same concentration levels as I used to have* (James, community).

However, a few participants indicated that it was difficult to concentrate due to finding the assessment boring or monotonous, particularly subtests which had repeated elements:

Any tests are quite boring, aren't they? Quite monotonous? ...And I think my attention span is quite good, but even I could switch off sometimes of these tests... so repetitive, so like you start switching off" (Wai, inpatient).

Additionally, some participants, although initially able to attend to and understand the instructions, were unable to retain these instructions, which led to delays in completing subtests or participants stopping the assessment altogether. Some participants verbalised that being unable to understand, retain and follow the assessment caused frustration and anxiety. Many participants visibly looked more frustrated when they did not know what to do. However, most participants looked for guidance from the researcher when unsure what to do or externalised these difficulties to problems with the assessment.

Some participants were unfamiliar with the laptop hardware, which made completing some subtests more challenging. For example, being unsure where keys were on the keyboard:

Oh, that thing that I thought were a comma, isn't a comma... see, this is me not being very techy... I just, cannot find it (Ben, community).

The majority of participants also commented about the computer mouse's usability, which led to delays in the assessment. Many participants also completed the assessment whilst sitting in a wheelchair, which made reaching and using the mouse yet more challenging.

3.2 Perceived benefits of digital cognitive assessments with a stroke population

Most participants said that they found the digital assessments more engaging than the paper and pen assessments and said they would prefer a digital cognitive assessment to a paper and pen assessment. Participants appeared to recognise the potential wider benefits of digital cognitive assessments, which could be done independently, such as saving time and money for services. Paul (community) also recognised that they could be used in NHS environments where there is an increase in demand for care but limited resources:

[NHS staff are] worked off their feet because they are trying to make
unhealthy people healthy etc., they don't have time to do it… if you can send
some web addresses across so I can do tests like this on my own… you could
send [the results] back by e-mail for a reduction in costs'.

Supporting this suggestion, other participants highlighted the lack of care and resources they received following a stroke, highlighting the challenges of covid:

The initial care was fantastic. The follow-up was garbage. It's not just me
that said that, a lot of people said that, and I know covid has been there
but… (James, community).

3.3 Digital tests completed unsupervised compared to pen and paper facilitated by a clinician

Participants were asked about their reflections on comparing the online digital cognitive assessment with their previous experience of a paper and pen cognitive assessment. Participants gave their views on the benefits and limitations of each platform; please note that participants spoke about their experiences of a paper and pen assessment, facilitated by a clinician. However, digital assessments are now often facilitated by clinicians as well, but participants did not have experience of this, and thus, this is not commented on.

Most participants suggested they preferred a digital assessment to a paper and pen assessment. They gave reasons such as being more familiar with working on digital platforms on a screen and finding it more interactive than paper and pen:

I'm used to that kind of working on the computer or laptop or an iPad, hmm,
makes it bit easier for me… it's good that you have it on the computer
because something on papers like, you know… it's not interactive
(Wai, inpatient).

Mike (inpatient) also indicated that the digital assessment unsupervised made it less intimidating:

Cause it was one person sat talking to me throwing me these problems, and I
found that quite hard. I find this less intimidating.

Some of the participants also recognised that the digital assessment had the potential to be more accurate or '*cleaner*' than a clinician.

Jenny (community) said that the paper and pen tests she had completed previously made her feel like she was back at school and being treated like a child, whereas the digital test was something that she would expect more as an adult:

> *R: felt like I was being treated like a baby, like was doing something at school*
>
> *I: and can you say that anymore about that?*
>
> *R: not really. Just like I felt like I was doing child's things that kids would do*
>
> *I: Yeah, okay, and what was doing this test like compared to doing the pen and paper one in hospital?*
>
> *R: this is a bit more difficult. It's more like something that I would expect an adult to do… I didn't feel like I was being treated like a child with this one at all.*

On the other hand, some participants found the technology elements of the digital cognitive assessment more challenging; this was particularly true for female participants. Whitney (community) reported finding the technology hardware elements more challenging, which she felt slowed her down:

> *Not as easy because I'm having... cause I'm not very good with the mouse control and I think that's the difference... with the pen and paper, I was quicker. That was it… I think I was better, um, with paper and pen really… I felt more confident.*

Some participants also found the computer screen challenging due to visual difficulties and fatigue. Richard (community) commented directly on the benefits of having a clinician to help facilitate the assessment, as the clinician can show patience, unlike a digital device.

3.4 The value of having experts by experience involved in research focused on digital cognitive assessments

It is noteworthy that Paul (community) commented on being surprised that the researcher had '*time to talk to retirees* (laughs)'. However, participants were able to give detailed and helpful accounts of their experiences and reported enjoying their involvement with the study as a whole. Participants seemed keen to be involved in the research as they were eager to help others that are going through a similar situation, *I think if I can make it easy for somebody else, that's why I'm doing this'* (James, community).

Chapter 5: Discussion

This chapter provides a summary of outcomes, findings, and implications. Discussion points are then explored based on themes generated in the analysis. Discussion points include the accessibility of cognitive assessments for the stroke population, the perceived benefits of digital cognitive assessments and perceived and observed challenges of digital cognitive assessments. Difficulties in attention and retention during digital cognitive assessments and a think-aloud platform are also discussed. The chapter then discusses the future of digital cognitive assessments, including assessment with and without a clinician and within research and clinical settings. The chapter then discusses the participants' direct experiences and feelings cognitive assessments can evoke, including fear, anger and sadness. Linking with this, it also discusses the paradox of highlighting someone's cognitive difficulties, i.e., it can evoke difficult feelings and yet may start a supportive adjustment journey for service users and families. The chapter ends with discussing experts by experience roles in future research, as well as the strengths and limitations of the study.

Summary of outcomes

Very little is known about how the stroke population experience digital cognitive assessments. In fact, a general absence of research has focused directly on how people experience cognitive assessments and digital unsupervised cognitive assessments. This study aimed to provide insight into how the stroke population experience 1. cognitive screens 2. Online digital cognitive screens 3. Online unsupervised digital cognitive screens.

The findings from this study offer a unique insight into a stroke population's experience of a digital cognitive screen and raises ideas about how services can further support individuals undergoing cognitive screens and assessments.

Please note that ten out of eleven participants had previously undergone a paper and pen cognitive assessment; however, it was unclear which assessments these were, e.g., full neuropsychological assessments or brief cognitive screens. As participants referred to neuropsychological assessments and cognitive screens

interchangeably, the author has also referred to these assessments collectively as cognitive assessments when making meaning of these results (unless otherwise stated by a participant). Although some experiences of neuropsychological assessments and cognitive screens can be widely applied, this limitation must be considered throughout all reflections, implications, and recommendations.

The accessibility of digital cognitive assessments for the stroke population

A key matter that participants said that they would want clinicians to know is that everyone is different. In line with this, all participants had different needs throughout the cognitive screen and had differing outcomes. Only four participants were able to complete the entire assessment within 90 minutes. Two did not complete the assessment in 90 minutes with the think-aloud elements of the study (and were both about halfway through the assessment at the end of 90 minutes). Five participants could not complete the assessment due to stroke-related difficulties or difficulties understanding and retaining instructions. This did not seem to correlate with whether participants were residing in an inpatient setting, the community, or the time since their stroke.

The researcher gave basic assistance such as confirming where the 'enter' button was on the keyboard and providing supportive statements, like 'well done', to help retain rapport and motivation with participants. However, the researcher did not give any assistance or guidance otherwise, often asking participants what they would do if the researcher was not there. It is unclear whether the five participants, unable to complete the ACS, would have been able to complete it with the assistance of a clinician. One of these participants stopped at 'reaction speed' (traditional equivalent is the visual reaction time) due to the participant thinking that there was something wrong with the digital assessment. In this case, the researcher believed there were difficulties understanding and retaining subtest instructions. The other four participants ended the assessment on the first subtest, ' Connect the dots I & II' (the traditional equivalent is the trail-making test A & B). On these occasions, the researcher believed there were difficulties with both retaining all the instructions and cognitive difficulties (e.g., the task being too complex and perseveration). In all

cases, the researcher felt the participants would have benefited from assistance from a clinician throughout the assessment, which would have helped with incompletion issues.

This message of 'everyone is different' links back to differences between neuropsychological assessments and cognitive screens discussed in Chapter 1. For neuropsychological assessments, clinicians typically tailor and adapt different tests to the individual's case to account for individual needs; these results support the need for this approach. However, neuropsychological assessments in research settings typically use a set battery of tests (like the ACS). Thus, any clinical application of the ACS may be more comparable to screening tests like MMSE and MoCA. In line with these findings, Lees et al. (2017) raised that cognitive screening assessments can be complicated for a stroke population; due to stroke-related difficulties and common pre-existing difficulties with this population.

Consequently, they found that even brief tools such as the MMSE, MoCA and ACE-III are associated with substantial incompletion. Their cross-sectional study found that 63% of participants needed direct assistance to complete the screening test and that partial completion of tests was common (ACE-III: 14/51, MMSE: 22/51; MoCA: 20/51 fully complete). However, there is currently no guidance on interpreting test results when cognitive impairments affect test completion (Pendlebury et al., 2015). This poses challenges for using cognitive screens with service users who have had a stroke in research and clinical settings.

One solution would be to continue with clinician-led assessments at the current time, which can help adapt tests to the individual. This may be easier for clinicians administering full neuropsychological assessments who have extended information from the clinical interview etc., about a service user and extended time with a service user (often seeing people over several hours and sessions). A further solution would be for cognitive screens to be designed purposely for a stroke population. For example, the Oxford Cognitive Screen (OCS) (Demeyere et al., 2015) targets stroke survivors. It is appropriate for people who experience aphasia and visual neglect, common following a stroke, to be more inclusive. More recently, Benaim et al. (2022) also developed the Cognitive Assessment Scale for Stroke Patients (CASP), which is a short screening battery that has been shown to have

good psychometric properties for screening cognitive impairment in a stroke population during the subacute post-stroke phase. It also has been adapted to suit people with aphasia and hemispatial neglect. These paper and pen screening tools could be considered if screening for cognitive changes following a stroke.

The perceived benefits of digital assessments with a stroke population

In line with Feenstra et al. (2018) findings, most participants said that they liked the digital assessment and they preferred the digital cognitive assessment to paper and pen screens and assessments they had done previously. They gave reasons such as being more familiar with a digital platform and finding it more interactive and less intimidating than someone administering the assessment. Participants also acknowledged the clear benefits of the future of digital advancements and cognitive assessments. For example, some participants recognised that digital assessments could be 'cleaner' and more accurate than paper and pen tests. Luciana (2003) and Parsey and Schmitter-Edgecombe (2013) also conclude that computerised neuropsychological batteries can record aspects of performance that are difficult for paper and pen psychometrics to achieve, like accurate reaction speed (Robbins et al., 1994).

Some participants also recognised potential benefits of completing a digital cognitive assessment unsupervised, such as less demand on resources in busy healthcare systems and collecting normative data pre and post-stroke. Indeed, digital use has become integral to healthcare practice, largely due to the cost and time benefits (Luciana, 2003). Similarly, Feenstra et al. (2017) also highlight the benefit of digital assessments' ease of facilitating normative data collection across different client groups.

One participant in this study, whose first language was not English, raised the issue of translating cognitive assessments into different languages. Some digital cognitive assessment batteries, such as the CANTAB, are being promoted as non-verbal and 'culturally blind' (Sharma, 2013), as they can be translated and administered in different languages and thus claim to be appropriate for cross-

cultural research. However, language proficiency is still needed to understand initial instructions. Additionally, computers, at the current time, are arguably less able to adapt assessments to individual cultures and capture the nuances that must be considered when administering and interpreting assessments with people from different ethnic backgrounds. Mitigating challenges of inaccessibility of cognitive assessments for people from different ethnic backgrounds, as well as the social injustices evident in this area, are complex and have harrowing issues requiring thought and action on a vast scale. Further research on how our ethnic backgrounds and discrimination affect our experience of cognitive screens and neuropsychological assessments is long overdue.

The perceived and observed challenges of digital assessments with a stroke population

The benefits of digital cognitive assessments will only apply if the assessments are feasible and achievable for the appropriate client populations (Lees et al., 2017). Although most participants indicated that they preferred the digital assessment over pen and paper assessments, which is in line with other research which suggests that older adults are eager to use technology (Vaportzis, Giatsi Clausen, et al., 2017), most participants encountered difficulties with technology at some point during the study. The two women who participated in the study were the only two participants who preferred the pen-and-paper assessment to the digital assessment. This may be reflective of the digital divide that exists in older adults (Friemel, 2016), particularly with women (Antonio & Tuffley, 2014), due to factors such as negative attitudes towards technology (Wu et al., 2015) and ageism (McDonough, 2016). Some participants suggested that, although they used their smartphones and iPad regularly, they rarely used a computer, which is common in older adults (Canini et al., 2014a; Vaportzis, Giatsi Clausen, et al., 2017). This may have affected the results, considering cognitive performance on digital assessments has been shown to positively correlate with frequent computer activity (Tun & Lachman, 2010) and to be adversely impacted by low confidence in using a computer (Fazeli et al., 2013). Thus, when using digital cognitive assessments, computer usage frequency would need to be considered and accounted for, particularly with older people who may not

be as familiar or less confident with computers. Research has also found that the digital divide in the older population influences a person's perceived usefulness too (Neves & Mead, 2021). Thus, more action is needed to narrow this gap, not only to ensure that older people have less barriers and disadvantages linked to digital assessments, but also for improving wellbeing in this digital age. Clinicians could consider giving people a choice of a paper and pen or digital cognitive assessment to ensure they are using the platform people are most comfortable with. Services could also promote the use of technology and digital devises for all ages, ensuring that older people are not excluded.

During this current study, the researcher also used written notes detailing observations to help understand any issues, such as problems with technology or why participants had difficulties completing the subtest, which could not be known from cognitive screens completed unsupervised. Although many digital neuropsychological assessments in clinical practice still require clinicians to facilitate, digital assessments may permit clinicians to be less involved in the assessment process. This may lead to observations and nuances surrounding the interpretation of results to be missed. These challenges would be amplified with assessments that require no clinician to be present. Supporting this, Bauer et al. (2012) highlight similar challenges of unsupervised assessments, such as lack of monitoring to ensure validity (compliance, effort, motivation), lack of support should a person need help with a subtest or technology problem, and loss of observational and qualitative data available. Indeed, qualitative behavioural observations before, during and after test sessions have long been respected as fundamental for interpreting data from cognitive scans and neuropsychological assessments (Anderson, 1994; Hubley & Mangaoang, 2016). Thus, even when using digital cognitive assessments, the current guidelines, at least for neuropsychological assessments, suggest that clinicians must use multiple sources of relevant and reliable information, including behavioural observations (American Psychological Association, 2020).

Challenges with attention and retention during digital cognitive assessments and the think-aloud platform

A shared challenge for digital cognitive assessments and paper and pen assessments is difficulties with attention and retention. Many participants found it difficult to attend to, understand and retain instructions at different points during the digital cognitive assessment. This led to delays in completing subtests and stopping the assessment for some participants. The researcher hypothesised that these difficulties were mainly due to changes following the stroke. For example, participants would commonly follow the primary instruction but not retain any additional instructions. A few participants also indicated that they had forgotten all the instructions. Thus, simple and clear instructions are paramount, especially for assessments aimed at stroke populations. Test developers may also want to consider having the option to repeat the instructions (like in many face-to-face assessments) or have prompts during the task.

The researcher was mindful not to speak or create a distraction during the subtest's instructions. However, attention may have been adversely impacted by the additional working memory demands of the think-aloud platform. Attention may have also been adversely affected by anxiety.

However, some participants indicated that they found it difficult to attend to and engage with the assessment instructions fully because they found some elements of the assessment, such as the repeated verbal memory task, boring, repetitive, and not interactive. Although the cognitive screen in this study was not used as a valid screening assessment, this feedback does raise the importance of measuring performance validity. This study's cognitive assessment did not include performance validity tests; DeRight and Jorgensen (2015) highlight that research protocols involving neuropsychological tests rarely include assessments of performance validity. The British Psychological Society (Division of Neuropsychology Working Party, 2021) provide guidance when considering assessments of performance validity, which services and future research could consider.

Although many participants indicated that they found the digital cognitive screen more interactive than paper and pen assessments, this feedback also prompts

discussion about making digital cognitive assessment more interactive. One growing area of research is focused on 'gamification', a term used for adding game elements to, e.g. cognitive assessments (Wiley et al., 2021). Making cognitive assessments more rewarding through 'play' may be one way of addressing tests feeling boring and monotonous for service users. Additionally, studies have found that digital cognitive games were perceived as less stressful and more interesting and enjoyable compared to a standard cognitive task (Friehs et al., 2020; Lumsden et al., 2016), and thus they may help address issues of anxiety and distress as well, as discussed previously. Mantell et al. (2023) highlight that older adults' preferences and needs are rarely heard within research; they facilitated focus groups exploring older adults' experiences of a game-based cognitive assessment. Outcomes raised some difficulties that may come with gamification, such as getting gameplay at the correct level for each individual and ensuring that any childish factors are avoided; these were also issues that one participant in the current study raised about paper and pen assessments. Additionally, the client group for Mantell et al.'s (2023) study were service users within a prison who had not experienced a stroke. Thus, a wealth of further research focused on the gamification of cognitive assessment for a stroke population needs to occur before any conclusions about their effectiveness can be made.

The future of digital cognitive assessments with the stroke population

Digital cognitive assessments, with a clinician, in research settings

Cognitive assessments have long been used in research settings, but the administration cost is comparatively high. As discussed in Chapter 1, the development of ACS came from the need to reduce, e.g., the demand and price of administering cognitive screens and cognitive assessments within oncology research and allowing participants to complete assessments in their homes. Although the current results would suggest that the ACS is not an appropriate cognitive screen to use within the research for a stroke population to use unsupervised in its current form (as only 4 participants could complete the assessment), future research could

explore whether the ACS could be suitable for a stroke population for research purposes, with the help of a clinician.

Digital cognitive assessments, with a clinician, in clinical settings

NHS England and the Department of Health and Social Care are investing £150 million into a digital transformation, which they consider a top priority (A Plan for Digital Health and Social Care, 2022). These policies ultimately aim to improve the quality of care but also simplify procedure processes and reduce costs. These developments will be across disciplines, including stroke services, cognitive assessment, and rehabilitation. Consistent with these progressions, standard cognitive screens and neuropsychological assessments are becoming digitalised and being administered in telepractice and face-to-face. For example, developers such as 'Pearson', offer advice for telepractice and the Wechsler Adult Intelligence Scale–Fourth UK Edition (WAIS–IV UK) (Telepractice and the WAIS-IV, n.d.), such as considering factors such as screen size, gesturing using the mouse and audio checks (Eichstadt, 2013). They also compare telepractice versus face-to-face administration and digital versus traditional paper and pen format.

These digital neuropsychological assessments still require substantial and often demanding assistance and facilitation from clinicians. However, Sharma (2013) highlighted that having support from a clinician on online digital cognitive assessments can also supply helpful information collected through observation and help enhance the assessment process.

Some digital cognitive screens are also being developed specifically for the stroke population. For example, Willer et al. (2016) have developed a brief digital screening assessment for stroke patients called the Cognitive Assessment at Bedside for iPad (CABPad). The CABPad could also overcome physical accessibility issues encountered with the ACS, such as difficulties getting service users to a computer monitor and screen, issues with getting participants in wheelchairs to an accessible table and problems using a computer mouse.

Similarly, Parsey and Schmitter-Edgecombe's (2013) review identified the Cogstate (Cogstate, 2023) and the Revised Cambridge Cognition Examination (R-CAMCOG, 2009) (Strokengine, 2009) as computer-based neuropsychological

screening batteries that are reliable in the detection of cognitive deficits in the stroke population (Cumming et al., 2012; Winkel-Witlox et al., 2008).

Likewise, the Short Parallel Assessments of Neuropsychological Status – Extended (SPANS-X) has also been developed as a more detailed cognitive screening battery; this is designed for the assessment of acquired brain injury and other neurological conditions and can be completed remotely via video call (Burgess, 2022). The SPANS-X also has extended norms up to 90 years old, making it appropriate for an older stroke population. These digital cognitive assessments could be considered in stroke services stepping into the NHS digitalisation transition. When administering these assessments, clinicians could consider the perceived benefits and challenges of digital cognitive assessments highlighted previously, such as that screen time may evoke fatigue; instructions may need to be repeated by the clinician (where appropriate), and clinicians may want to offer technical support to those that use digital devices infrequently.

Most research thus far has focused on the psychometric properties of digitalised versions of paper and pen neuropsychological tasks (Parsey & Schmitter-Edgecombe, 2013; Smith et al., 2013). However, service user experiences of these digitalised tests have not yet been considered. Thus, future research could focus on service user experiences of assessments such as the CABPad and the SPANS-X. This information may then be used to help further develop these assessments or new digital assessments from the ground up.

The BPS has published international guidelines on computer-based and internet-delivered testing (2005) for professional practice. They offer recommendations for the test developers, test publishers and test users. These recommendations could be disseminated to help equip stroke services for these digital changes and guide what digital cognitive screens and assessments may be feasible for clinical use with a stroke population moving forwards.

Digital cognitive assessments, unsupervised, in research settings

Digital cognitive assessments completed unsupervised, such as the ACS, are primarily used in research settings. Backx et al. (2020) argue that online digital cognitive assessments completed without a clinician could 'improve the accessibility

and flexibility of research and clinical assessment, widen participation, and promote research recruitment while simultaneously reducing costs'. Similarly, Feenstra et al. (2017) also promote that digital neuropsychological test batteries could allow for large-scale cognitive data collection in clinical studies. They offer guidelines for unmonitored digital neuropsychological tests, such as acquiring reliability and validity norm scores for a given population.

Although the ACS served as an excellent basis for acquiring the experiences of the stroke population within qualitative research, it was primarily developed for research purposes with an oncology population. Thus, other assessments may be more reliable and valid for a stroke population if considering other digital cognitive assessments that can be completed unsupervised. For example, the digital cognitive screen is the Cambridge Neuropsychological Testing Automated Battery (CANTAB) (Cambridge Cognition, 2023). The CANTAB can be done over an Ipad or using web-based testing and can be done unsupervised (Backx et al., 2020). Campbell et al. (2022) found that the CANTAB was feasible with a stroke population, with the CANTAB having similar completion rates to the MoCA. Their age range varied from 51-96 years old, and the average age was 74.5 years old, suggesting that this would also apply to an older population.

Digital cognitive assessments, unsupervised, in clinical settings

The utility of digital cognitive assessments, without the need for a clinician, is also being recognised in clinical settings too; with the acknowledgement that they would minimise costs and practice barriers (Feenstra et al., 2017; Scott & Mayo, 2018), reduce examiner effects and give greater accessibility in remote locations, reduce the need for an interpreter. Bissig et al. (2020) also promote the potential benefits of online unsupervised digital screens, such as low cost, high accuracy, relative freedom from language barriers, less time investment for clinicians, and potential for remote use, either via telemedicine or with assistance from non-clinicians. However, they could find no examples of self-administered cognitive screening tests that were appropriate for a dementia population. In response, they developed the SATURN, which aimed to provide cognitive screening within clinical settings. They found that SATURN strongly correlated with previously validated

MoCA. Although this used participants with dementia as a population, the MoCA is a commonly used tool for the stroke population as well (as discussed in chapter 1).

Similarly, the eSAGE, commercially known as BrainTestR, is a self-administered digital cognitive assessment and measures cognitive domains appropriate for a stroke population (Scharre et al., 2017). eSAGE shows a strong association with the validated pen and paper SAGE and a neuropsychological battery.

However, Tsoy et al. (2021) completed a systematic review of self-administered brief digitalised cognitive assessments for the detection of cognitive disorders. From 10 self-administered digitalised cognitive assessments, only two measures evaluated feasibility and usability in the intended clinical setting; these were the Computer Assessment of Mild Cognitive Impairment (CAMCI)(Saxton et al., 2009) and the CogState (Hammers et al., 2011; Lim et al., 2013). Again, these assessments were for a dementia population. Thus, further research is needed to explore whether online digital unsupervised cognitive assessments are feasible with a stroke population in a clinical setting.

Participants' direct experiences of cognitive assessments

The main research question focused on the stroke population's experiences of a digital cognitive assessment. Participants offered direct insights into their thoughts, feelings, and responses *during* a digital cognitive assessment and provided information about how they found testing sessions previously. This is also noteworthy as mood and feelings have been shown to affect performance on cognitive assessments and thus must be considered as part of the assessment process.

When exploring a stroke population's experiences of a digital cognitive test, it became apparent that the cognitive assessment process prompted participants to think about their wider experiences of their stroke. Research shows that previous cognitive dissonance and self-perception affect current experiences (Albarracin, 2021). Likewise, past schemas can also affect how we understand and store information (Marshall, 1995); thus, it is arguably impossible for participants to fully

separate their past and current experiences to isolate their experiences of the assessment. Therefore, participants' experiences and feelings are spoken about broadly.

Fear and anxiety

Most participants expressed fear and anxiety during the digital cognitive screen or when discussing their previous experiences during the testing session. Many also reported that the main thing they would want clinicians to know when administering these assessments is that they can be immensely worrying for service users. This is similar to findings from Hobden et al's (2023) and Owen (2012), indicating that cognitive assessments can be anxiety provoking for the stroke population whether in paper and pen or digital format.

Linked to this, participants indicated that they were mindful of the implications of cognitive assessments on future planning, such as returning home, returning to work, and returning to driving. Research would also support that cognitive assessments can be predictive of independence and returning home (Hajek et al., 1997; Sveen et al., 1996), returning to work (Hofgren et al., 2007; Ramsing et al., 1991), and returning to driving (Marshall et al., 2007; Tan et al., 2011). Thus, it is understandable that service users find these assessments anxiety-provoking as they may uncover positive or negative predictions about their future.

This is important when considering the adverse effects that state anxiety can have on cognition, as it is consistently associated with adverse effects on verbal memory, attention, inhibition, and working memory (Angelidis et al., 2019; Dorenkamp & Vik, 2018; Harris & Cumming, 2003; Ikeda et al., 1996; Williams et al., 1996). Similarly, Martens et al. (2018) found that state anxiety predicted performance across various cognitive domains, such as attention/working memory, executive functioning, memory, and language for people with Parkinson's Disease. To explain this phenomenon, Eysenck and Calvo (1992) proposed the Processing Efficiency Theory, which suggests that the effects of anxiety on cognitive functioning are mediated by anxiety, creating a reduction in the storage and processing capacity of the working memory system. Although it has long been known that neuropsychological assessments and cognitive screens can evoke anxiety

in people, a systematic review of the literature by Dorenkamp and Vik (2018) found that most studies examined healthy adult populations, very few studies used clinical samples, and no studies focused on older adults from clinical populations. Thus, this current study provides evidence that older adults from clinical populations also experience anxiety during testing sessions and supports that services must consider anxiety levels in their interpretation of the results for this population.

To screen for anxiety, services commonly screen for changes in mood. Many mood screens focus on a person's anxiety over a period of time, such as the Hospital Anxiety and Depression Scale (Johnston et al., 2000), which asks users to rate their responses based on the past week, which may capture *state* or *trait* anxiety. Clinicians could also consider using measures that focus on *state* anxiety, such as the Visual Analog Scale (VAS), which is freely available and is valid in both pencil and paper and computerised form (Abend et al., 2014; Rossi & Pourtois, 2012). This may help obtain a more accurate picture of state anxiety, which appears to be more strongly linked with effects on cognitive performance.

Additionally, services could consider what could help reduce state anxiety to obtain a more accurate reflection of cognitive functioning and, more importantly, help a service user's wellbeing during the assessment process. For example, Bennett-Levy et al. (1994b) highlight that the assessment is likely to impact their self-confidence significantly and thus suggest that clinicians should be compassionate towards anxious clients. Like one participant in this current study, they also suggest offering service users hot and cold beverages, which may help create a more informal/less anxiety-provoking atmosphere. The London Dementia Clinical Network (2021) indicate that assessments should be adapted, e.g., timing and length/number of sessions, to help with engagement. Although aimed at students, Huberty (2009) suggested similar recommendations and recommends validating that test anxiety is real and normal with clients and does not reflect laziness, lack of motivation, or lack of capability. They also suggest allowing breaks, acknowledging effort, and providing relaxation training. Gruters et al. (2021) also recommend paying attention to contextual details within the testing environment, e.g., having the test materials to hand so testing administration can be done with ease. Ko et al. (2020) found that access to a view from a window can increase positive emotions

and improve working memory and concentration, which could be simple contextual details to consider where possible.

Moreover, all participants reported specific worry about their memory, which was evoked during *memory* subtests. Like Bennett-Levy et al. (1994b), some participants also expressed particular stress and anxiety around being timed during some subtests. This is arguably unsurprising when considering Western culture's weight on memory, specificity and efficiency (Gutchess & Indeck, 2009; Leger & Gutchess, 2021; Millar et al., 2013). The NICE guidelines (2013) recommend assessing memory and providing interventions such as increasing awareness of memory deficit and using errorless learning techniques. However, the guidelines do not include guidance on supporting a person's wellbeing whilst exposing potential memory deficits. Considering the study's results, it is arguable that more consideration may be needed for emotional support following assessments or subtests focusing on memory.

Many participants related some of their worries to 'the unknown' or uncertainty. Likewise, Gruters et al. (2021) also found that the cognitive assessment process evoked feelings of uncertainty. They also found that neuropsychological testing for dementia evoked negative experiences, emotions, and psychological distress during the testing due to revealing their cognitive difficulties. The authors provide recommendations which include clinicians being aware of the high levels of uncertainty and taking steps to reduce this, such as using clear communication adapted to the needs of the service user. They also recommend clearly explaining the procedure of neuropsychological assessment to service users. Although describing the process of cognitive screens or assessments to service users may seem evident, Bennett-Levy et al. (1994b) questionnaire found that between 40-60% of service users reported that they were not adequately prepared for the neuropsychological assessment, e.g., they hadn't been told the length of the assessment or its purpose.

Similarly, they found that 60% of service users were told nothing about what to expect before they came to the assessment, and 34% said that the information given before the assessment was 'not at all' helpful. In line with this, participants in the current study indicated that being given more information prior to the assessments would have reduced their anxiety levels. Consequently, Bennett-Levy et

al. (1994b) suggest providing an example handout summarising what a neuropsychological assessment is and what it will involve; services could consider adapting this handout for service users to help ease uncertainty. They also recommend that clinicians contact and prepare the service user directly to ensure the correct information has been given.

Anger

As well as anxiety, many participants expressed anger during the assessment, which many directed at themselves, using words such as 'pathetic' and 'stupid' to describe themselves. Bennett-Levy et al. (1994b) also found that some people became frustrated and highlighted that these feelings are 'almost endemic' to the cognitive assessment process, as the assessments are prolonged and yield repeated failure. Additionally, other studies have found that changes following a stroke, such as reliance on others, aphasia and dysarthria, can also leave people feeling 'stupid' (Dickson et al., 2008; Maclean et al., 2000; Taubner et al., 2020). Therefore, another consideration is whether people need longer-term compassionate support following the testing session/s or assessment process.

In line with this, Collins et al. (2018) offered six weekly Compassion Focused Therapy (CFT) group sessions to people who had experienced a dementia diagnosis following cognitive testing. They found the group effective at improving quality of life and reducing symptoms of anxiety and depression in people with dementia and their partners. Although this study was with a dementia population, a similar intervention could be helpful with a stroke population.

Indeed, Leaviss and Uttley's (2015) systematic review found CFT effective with a range of populations, particularly with people with high self-criticism; however, this review did not include a stroke population. Addressing this gap, Ashworth et al. (2015) looked at the effects of individual and group CFT sessions on people with acquired brain injury. The authors found significant reductions in measures of self-criticism, anxiety, and depression and an increase in the ability to reassure the self, although only a quarter of the participants in this study were from a stroke population. Thus, further research is needed to explore whether CFT could benefit a stroke population following any anger evoked during a cognitive

assessment. Furthermore, in the current climate of healthcare services, it may not always be possible to offer 1:1 or group therapeutic input following screening or testing. Thus, another area of potential research would be exploring the effectiveness of CFT self-help programmes with a stroke population, which have been shown to improve wellbeing and reduce psychological distress in other populations (Sommers-Spijkerman et al., 2018).

Sadness

When completing the cognitive screen, all participants spoke about the stroke's impact on their lives. Many participants indicated that they had previously associated a stroke with physical changes rather than cognitive and psychological changes. Supporting this, Quinn et al. (2018) highlight that the neuropsychological aspects of a stroke have received little attention. Many participants spoke about the impact of the stroke on their mood, with some expressing hopelessness and experiences in line with a diagnosis of depression. The UK National Clinical Guidelines for a stroke (Conditions, 2008) stipulated that 'every patient entering rehabilitation should be screened for depression using a validated simple screening test'. Supporting this, Tang et al. (2020) found that priorities following a stroke included access to psychological services and screening for mood. However, depression is vastly under-recognised and undertreated within the stroke population (Medeiros et al., 2020; Turner-Stokes & Hassan, 2002).

Furthermore, depression is generally under-recognised and untreated with older adults, with misconceptions that low mood inevitably comes with older age (Vieira et al., 2014). Thus, stroke rehabilitation services could ensure that mood screening materials and training are provided, as this has been shown to improve rates of mood screening (Morris et al., 2012). This could promote services to refer service users for detailed assessment and treatment of depression if appropriate, as stipulated by NICE guidelines (2003).

Relating to low mood, some participants also alluded to perceiving themselves as 'damaged' whilst completing the cognitive assessment. Some raised broader explorative ideas around the brain being part of our identity and what makes us human, and in turn, raises questions around what happens to our identities if our

brain becomes 'damaged'? Loss of identity is a commonly reported experience following a stroke (Anderson & Whitfield, 2013; Clarke & Black, 2005), and social identity has been shown to predict wellbeing following a stroke (Haslam et al., 2008). Ellis-Hill and Horn (2000) explored changes in identity following a stroke. They found that individuals described a more negative sense of self, e.g., describing themselves as less interesting, less capable, and less independent. Consequently, they also found that people had reduced social activity following a stroke. Anderson and Whitfield (2013) found that it was difficult for people to construct a valued social identity following a stroke without the support of other people. Ch'Ng et al. (2008) and Hole et al. (2014) also found that social support was crucial in post-stroke adjustment. Likewise, participants in this current study made note of the importance of connecting with others with similar identities. Thus, services could consider facilitating or signposting service users to stroke support groups, such as the Stroke Association led groups. Morris and Morris (2012) found that participation in a stroke group was beneficial for offering advice, making connections and increased awareness. Speaking with others may also be beneficial to sharing and making meaning of their experiences going through a cognitive screening or assessment process, which would otherwise be uncommon in the general population.

The paradox

On the one hand, participants expressed anxiety, anger, and sadness during the assessment, which was often evoked by the cognitive screen exposing their cognitive challenges following the stroke. However, on the other hand, participants also reported that exposing these challenges was also beneficial for themselves and their support network in that the results provided an understanding and insight, as well as guided strategies to manage changes following a stroke, which is in line with previous research (Donders, 2020). This was true for reflections about the digital cognitive screen completed as part of the study and when reflecting on past experiences of cognitive screens and assessments. Gruters et al. (2021) also highlight this paradox when gaining perspectives of service users receiving a dementia diagnosis, which they named 'the early diagnostic paradox'. Indeed, much of the research within this area is focused on cognitive assessments used for

dementia diagnosis, which suggests that service users and their families can often feel relief once an explanation for symptoms and experiences is known (Carpenter et al., 2008).

Karnieli-Miller et al. (2012) found that diagnostic disclosure following a cognitive assessment was a critical moment in which family members started making important decisions about the future. Likewise, the NICE guidelines (2013) recommend screening people after a stroke for cognitive deficits and conducting detailed assessments where a cognitive deficit is identified *before* designing a treatment programme. Thus, future planning for families and professional teams can often be on hold until cognitive assessments are complete. This may influence when service users and families can start to process and adjust to what has happened. Woods et al. (2019) found that the outcomes of cognitive assessments help with the process of acceptance and adjustment for people with dementia, but the outcomes are unknown for a stroke population. Further research could focus on whether cognitive screens and assessment help start the process of acceptance and adjustment for people who have experienced a stroke.

Many of the benefits of cognitive screens and assessments that participants emphasised, such as a better understanding, meaning making and learning ways to manage changes following the stroke, were rooted in the outcomes and feedback part of cognitive assessments. Despite the researcher explaining that the assessment results were not valid and, thus, participants would not receive the results during the recruitment process, many participants requested feedback or raised frustration that there was no feedback. This suggests that feedback is a critical part of the cognitive assessment process, supported by Gass and Brown (1992), who suggest that 'neuropsychological test feedback is of central importance in helping patients and their families cope with the consequences of brain injury'. Donofrio et al. (1999) explored service users' evaluation and perceptions of neuropsychological testing feedback. Their paper highlighted that despite the APA Ethics Code mandating the provision of test feedback in most cases, research indicates that only two-thirds of service users receive test results. Furthermore, they highlight that only 25% received written feedback, which is important considering testing is usually requested when there are difficulties with cognition, such as memory. Griffin and Christie (2008)

found that the written reports given to service users in their review were considered unhelpful or difficult to understand. In contrast, a review by Gruters et al. (2022) found that neuropsychological feedback was provided for a broad spectrum of diagnoses and was usually given in person. They found that overall satisfaction with neuropsychological tests increased when useful feedback was provided. They also found that communication aids, such as written feedback, helped improve the retention of feedback given.

Similarly, other research suggests that verbal feedback is usually given and helps facilitate a better understanding and better management of symptoms (Mountjoy et al., 2017). King et al. (2022) discuss the lack of research exploring the quality of the neuropsychological assessment process; their extensive review found no set of applicable audit standards for neuropsychological testing. They suggest daily clinical practice may drift from the gold standard without routine monitoring and audit. In response, they have developed a self-audit tool for neuropsychology assessment practice. They propose 39 quality standards, e.g., a face-to-face or video call feedback session is offered and a report detailing test outcomes and interpretation written, that can be used to assess practice which services can tailor to suit their service user needs. Services facilitating cognitive assessments could consider using this audit tool to monitor practice.

Experts by experience; their role in future research

This study included experts by experience in the development of the design methodology. Kwok et al. (2022) have written about the experiences and processes of including stroke service users as collaborative partners in the research team. They found that although the stroke population can bring unique challenges, such as differences in cognition and mobility, they provided invaluable contributions at each stage of the research process, such as the interview schedule and assisting with the thematic analysis. Frisch et al. (2020) suggest that research competencies training should be provided to research teams and experts by experience when involving patients in research. Their scoping review indicated that the research teams receive training on participation, communication and conflict management, and that experts by experience receive training on research knowledge and skills, cultural

competence, and participation. Future research exploring the experiences of stroke population could consider being yet more inclusive by including experts by experience in the analysis of data and providing appropriate training.

The study also focused on the experiences of the stroke population, i.e. the users of cognitive assessments. Göttgens and Oertelt-Prigione (2021) explore the application of human-centred design and discuss the innovations and effectiveness of having 'end users' as part of the design team. Future research could include service users/experts by experience/end users as design partners for developing current and future cognitive assessments.

Strengths and limitations of the study

Participants varied in age, gender, years of education, and time since their stroke; this makes the sample less homogenous. Furthermore, the implications and generalisability of the findings need to be considered in the context of the number of participants in the study, as well as the participant demographics. Similarly, only people deemed able to consent by the care team or charity lead were invited to participate in the research. Although this was considered unavoidable due to ethical reasons, the voice of those participants who could not consent was absent.

These demographic factors did not seem to have any clear influences on participants' experiences of the cognitive assessment. There were some differences between participants residing in inpatient settings and those in the community. For example, there was more speculation about future cognitive functioning for those in inpatient settings, whereas those in the community described more stability and acceptance. However, there were no other notable differences when uncovering the themes.

When considering the demographics, it is important to acknowledge that the study was voluntary. This was, of course, necessary for ethical reasons, but nevertheless, the self-selection bias is vital to consider, as it is possible that people who are more cognitively impaired were less inclined to take part and thus are not captured within the research. It is also important to note that only 2 participants were female, which may parallel the digital divide between older people, particularly with

women. It is also important to note that most participants from inpatient settings were from racially minoritised backgrounds. Yet, all participants from community settings were from white British backgrounds. This may reflect the racial disparities in health outcomes and access to support following a stroke (Cruz-Flores et al., 2011; Ottenbacher et al., 2008). The study also acknowledges that the exclusion criteria included the need to speak English proficiently, which would have been a further barrier to those from racially minoritised backgrounds. This represents a more significant problem within neuropsychology (Elbulok-Charcape et al., 2014; Manly, 2008; Rivera Mindt et al., 2010).

Participants ranged from 41-80 years old. It is commendable that 64% of the participants were above 60 years old, as older people's experiences are often not heard within health research, despite suffering the greatest burden of ill health (Mantell et al., 2023; Witham & McMurdo, 2007). However, the average age of a stroke is around 74 years in the UK (Akyea et al., 2021), and thus more than half of the participants were under the average age for a stroke. Witham and McMurdo (2007) raise that older people are systematically excluded from research due to having age limits or comorbidities in the exclusion criteria. Although considered necessary, this study included exclusion criteria such as no comorbid neurological conditions, such as dementia, which will have excluded more older people from taking part. The research team aimed to recruit as many people as possible over the age of 60 years old as possible, to help ensure the sample was more representative of the stroke population. However, many older people who met the criteria did not wish to participate. The current study also followed other recommendations from Witham and McMurdo (2007) to encourage inclusion; for example, it did not have an age limit, it used face-to-face recruitment, it paid participants for their time, and it involved older people who have had a stroke in the design of the study protocol. Future research with older people or the elderly population could also consider providing transportation to and from the study and allowing longer recruitment time.

Although the inclusion and exclusion criteria were abided by, the study had no criteria for other demographics, such as gender. This meant that a higher percentage of men took part in the study, possibly further reflecting the digital gap between gender discussed previously.

One more unique aspect of this study was using a think-aloud methodology for experiences of digital cognitive assessments. Using this methodology meant that the study could ascertain immediate and direct responses and gave participants flexibility in what they expressed. This would not have been possible using other modes, such as retrospective structured interviews. Davison et al. (1997) reviewed studies using a think-aloud methodology and found similar benefits; however, their focus was on studies involving stimulus scenarios rather than cognitive assessments.

Once the cognitive assessment had started, the study had an unstructured response format, encouraging participants to say whatever came into their minds. However, unlike strict think-aloud protocol, participants were given more neutral prompts, such as 'Keep talking', 'What's coming up in your mind now?' or 'Can you tell me about that' throughout, which may have influenced participants' responses. This followed guidance from Johnstone et al. (2006) and allowed participants with cognitive impairments following a stroke to make important contributions to the data. Still, it must be noted that the typical think-aloud framework was not followed. Additionally, it was common for participants to make short comments during the assessment, using the think-aloud format; these comments were valuable but lent themselves less to reflexive thematic analysis and write-up in the results section.

The interview schedule also included questions before and after the ACS. Although the interviewer took steps to ensure that questions remained unbiased, participants may have been influenced by a *researcher bias* and *demand characteristics*. For example, if they felt the researcher was a clinician themselves, they may not have wanted to give any direct negative feedback. Efforts to avoid this were made by clearly explaining, at the start of each interview, that there were no right or wrong answers and that the researcher was separate to their clinical treating teams.

Furthermore, the research noted that participants often had difficulties completing cognitively demanding tasks and thinking out loud about their experiences simultaneously. Participants usually gave more detail about their general thoughts and feelings before and after each subtest. They then provided a narrative for their problem-solving thought processes during a subtest. Still, this

study demonstrates that think-aloud methodology can yield interesting and meaningful results.

The ACS allowed the researcher to take an observer role in the study and was fit for gaining service users' qualitative experiences. However, it was not developed for a stroke population. This means it is not appropriate to make any conclusions about its use with the stroke population or comment on the feasibility of using it with the stroke population.

The study did not screen for mood. This followed discussions with the research team around how to raise the risk if a participant rated themselves highly on mood screening tools and thus felt that they had communicated this to someone, but in fact, these results were inaccessible to the care team. The researcher did ask about how participants were feeling, and in cases where they were concerned about a participant's mood, they informed the clinical team to ensure the participant had the correct support following the study.

Davison et al. (1997) suggest that think-aloud methods can also help understand and get feedback on a particular product. Consequently, general and specific feedback has been discussed with a representative of the ACS, who was pleased that most participants liked the digital assessment and agreed with the benefits and limitations of digital assessments. Feedback was given about the limitations of using the ACS with the stroke population. In order to be used with a stroke population, developers might want to consider having a clinician to help facilitate the assessment, having extra prompts of the instructions or written guided prompts if there is an error; this was discussed with the ACS representative.

Although Feenstra et al (2018) endorsed that the ACS is a reliable, valid, and highly usable tool for the online assessment of various cognitive abilities, the current study results would question whether the ACS is appropriate for a stroke population, for those with brain related disease, or those with highly impaired cognitive functioning. This study did not have a big enough sample to investigate the reliability and validity of the ACS with this population. However, this study could help drive future research exploring the feasibility of using the ACS with the stroke population. Future research may also want to explore the importance of examinee engagement to the reliability and validity of cognitive test scores.

The ACS representative prompted the research team that the ACS was not developed for the purposes of cognitive assessment for a stroke population but were keen to hear about its use with a clinical population.

Due to participants speaking freely about their current and past experiences, it was challenging to distinguish and separate findings, e.g., experiences which are only applicable to the ACS or online cognitive screens and experiences applicable for wider cognitive assessments, such as face to face and digital neuropsychological assessments. Thus, the researcher has included study findings, broad recommendations based on the findings and the evidence which supports this recommendation below, in order to ensure the reader can make their own conclusions regarding how to apply each recommendation.

Chapter 6: Recommendations

This chapter amalgamates information from all the chapters to generate recommendations based on the results and supporting literature and summarises this in Table 3 below.

Study Findings	Recommendations	The evidence base that supports recommendations
Recommendations guided by participants' experiences		
Participants want clinicians to know that everyone is different. **Only four participants could complete the full ACS assessment in 90 minutes without assistance.**	1. Clinicians or researchers to assist or lead with cognitive assessments at the current time, who can help adapt screens and tests to the individual and reduce incompletion rates. Encourage clinicians to explain or repeat instructions on digital cognitive assessments where appropriate. Research-led cognitive assessments could consider introducing automatic prompts into the software to help if people are 'stuck'. 2. Continue with the development of cognitive assessments and screens designed for a stroke population	1 Lees et al. (2017) 2 E.g. Oxford Cognitive Screen (OCS) (Demeyere et al., 2015) Cognitive Assessment Scale for Stroke Patients (CASP) Benaim et al. (2022)
Participants want clinicians to know that cognitive	1. Clinicians and researchers are encouraged to administer mood screens as part of cognitive screening	1 Visual Analog Scale (VAS) (Abend et al.,

assessments can be very worrying.	and neuropsychological assessment.	2014; Rossi & Pourtois, 2012).
Anxiety can be triggered by the unknown and uncertainty	2. Clinicians and researchers do what they can to reduce anxiety, e.g., being sensitive towards anxious users, offering hot or cold beverages, adapting the length of sessions, allowing breaks, validating that test anxiety is real and expected, and acknowledging effort. Clinicians and researchers could also consider contextual factors such as having material to hand and a view from a window.	NICE guidelines (2003) 2 Bennett-Levy et al. (1994b), Huberty (2009), Gruters et al. (2021), Ko et al. (2020) 3 Gruters et al. (2021) Bennett-Levy et al. (1994b)
	3. Clinicians to be aware of high levels of uncertainty and communicate clearly and directly about the procedure of the cognitive assessment. Clinicians could also provide a handout summarising what cognitive assessment process.	
The paradox: Digital cognitive assessments can expose cognitive difficulties and, in turn, evoke fear,	1. Longer-term compassionate support could be considered for people whose cognitive changes have negatively impacted their mood.	1 Collins et al. (2018) Ashworth et al. (2015)

anger, sadness, and a change in identity. **Digital cognitive assessments can expose cognitive difficulties, which can help improve understanding and insight and potentially start an adjustment and acceptance process.**	2. Clinicians and researchers could consider signposting people to social support groups so that people can connect with others who have similar identities. 3. Future research is needed to explore the impact of cognitive assessments and their outcomes on adjustment and acceptance of experiences.	Sommers-Spijkerman et al. (2018) 2 Ch'Ng et al. (2008) Hole et al. (2014) Morris and Morris (2012) 3 Gruters et al. (2021) Woods et al. (2019)
Most participants reported that they preferred the digital cognitive assessment to paper and pen assessments due to perceptions that they could be more accurate, less demanding on staff, and could provide normative data.	1. Clinicians promote and offer digital assessment for all ages and don't presume preference dependent on age. 2. However, clinicians should also be mindful of the digital divide between younger and older people. Clinicians could offer digital cognitive assessments or paper and pen equivalent. 3. Services and research teams to consider digital cognitive assessments that are accessible in a wheelchair, e.g., can be completed on an iPad, facilitated on an	1.Vaportzis, Giatsi Clausen, et al. (2017), Feenstra et al. (2018) 2. Friemel (2016) 3. Cognitive Assessment at Bedside for iPad (CABPad) (Willer et al., 2016) Cogstate (Cogstate, 2023) (Hammers et al., 2011; Lim et al., 2013). Computer Assessment of Mild Cognitive

	ergonomic desk, or facilitated remotely. 4. Follow current advice on digital cognitive assessments and telepractice	Impairment (CAM CI) (Saxton et al., 2009) Revised Cambridge Cognition Examination (R-CAMCOG, 2009) (Strokengine, 2009) Short Parallel Assessments of Neuropsychological Status – Extended (SPANS-X) (Burgess, 2022). 4 Eichstadt (2013), BPS international guidelines on computer-based and internet-delivered testing (2005) for professional practice
Most participants found it challenging to attend to and retain elements of	1. Include performance and validity tests both for clinical use and for research use.	1 Division of Neuropsychology Working Party (2021),

the digital cognitive assessment	2. Further research into gamification used with cognitive assessments and for the stroke population needed; may help with attention and reducing stress	DeRight and Jorgensen (2015) 2. (Friehs et al., 2020; Lumsden et al., 2016) Mantell et al. (2023)
Participants felt that cognitive assessment feedback was critical	1. Clinicians and researchers should always consider giving feedback on the results of cognitive assessments where possible, even if using a cognitive screen. This feedback should be adapted to the person's language and easily understood. 2. Clinicians could consider using a self-audit tool to guide good neuropsychology assessment practice in clinical settings.	1 Mountjoy et al. (2017), Gruters et al. (2022), Griffin and Christie (2008) 2 King et al. (2022)
Recommendations guided by the research process		
Observations were important for complementing the verbal transcripts.	Observations are still needed to make sense of the data for neuropsychological assessments and cognitive screens.	1 American Psychological Association (2020), Russell M Bauer et al. (2012)

Think-aloud methods elicited how participants found the cognitive assessment 'in the moment'.	1. Cognitive assessment developers could consider using adapted think aloud methodology to explore service user experiences further and could use 'end users' being part of the design team.	1.Göttgens and Oertelt-Prigione (2021)
Experts by experience enjoyed their involvement in the study and gave good feedback on the design and development of the study.	1. Experts by experience should be included in the design and development of new research and considered collaborative partners in research teams. 2. Research teams could consider providing training to their team on topics like communication and conflict management and training to experts by experience on topics like research knowledge and cultural competence. 3. Experts by experience are 'end users' of cognitive assessments and thus could be part of the design team to develop current and future digital cognitive assessments.	1 Kwok et al. (2022) 2 Frisch et al. (2020) 3 Göttgens and Oertelt-Prigione (2021)

Table 3. Summary of recommendations guided by participant's experiences and the research process

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Appendix

Appendix A: ethical approval and documents

A1 Ethical approval and documentation

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
**Health Research
Authority**

Ms Rebecca Day
Clinical Psychologist in Training
NHS
University of Leeds
Woodhouse Ln
Leeds
LS2 9JT

Email: approvals@hra.nhs.uk

23 August 2022

Dear Ms Day

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	**What is it like to Experience an Online Cognitive Screen for People who have had a Stroke?**
IRAS project ID:	**309321**
Protocol number:	**na**
REC reference:	**22/LO/0477**
Sponsor	**University of Leeds**

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.

A2 Participant information sheet and invitation form

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Participant Information Sheet

Stroke Population's Experiences of an Online Cognitive Screen

If you need help/have difficulty reading this information sheet, please contact your care team or Ms Rebecca Day, Psychologist in Clinical Training, {:umrld@leeds.ac.uk"}

Introduction

You are invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives, and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

1. What is the purpose of the study?

Cognition is a term used to describe thinking skills, such as remembering, judging, and problem-solving. After a stroke, many people undergo cognitive screens and assessments to detect whether there are any changes in cognition following the stroke. These cognitive assessments can involve exercises like remembering a sequence of numbers or words, solving visual puzzles, and completing a task as quickly as possible. These tests can help identify whether there have been changes in things like memory, attention, and processing speed. These tests can help people know what their strengths are and what they may want/need some support with. With technology advancing and with the COVID-19 pandemic, many of the tests are going online. However, very little is known about people's experiences of these assessments. We aim to investigate how service users, who have had a stroke, experience these online tests. It is hoped that this research will help guide recommendations for online assessments in the future and, in turn, help other people who have had a stroke.

> **Contents**
> 1. What is the purpose of the study?
> 2. Do I have to take part?
> 3. What would the study involve?
> 4. What are the possible disadvantages and risks of taking part?
> 5. What are the benefits of taking part?
> 6. What will happen to the results of the research?
> 7. How do we use information about you?
> 8. Where can you find out more about how your information is used?
> 9. Who is organising and funding the research?
> 10. Who has reviewed the study?
> 11. What if I have any complaints?
> 12. Contact for further information

2. Do I have to take part?

No, it is entirely up to you to decide whether to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part. You may still decide to withdraw at any time without having to give a reason. If you decide to withdraw from the study after

the interview took place, we will keep the information already collected. If you choose not to take part, your care or treatment will not be affected in any way.

3. What would the study involve?

We would like you to complete one online cognitive assessment, whilst sharing your thoughts and experience of doing the tasks within the assessment. We will not score your performance, but we are interested in how you find undergoing this assessment. During the assessment, we would like you to share any thoughts and experiences you have during each task. We will also ask you a few questions about your thoughts and feelings before, during and after the assessment to gather more information about your experience of the assessment.

After explaining the study verbally and gaining consent, the duration of the cognitive assessment and answering questions will be approximately 90 minutes and the interview will be video recorded. It will involve testing things like your memory, attention, and problem-solving skills. We can take a break during the assessment in between tasks if you are feeling tired and the researcher can assist you during the assessment if needed. It is very normal to find the assessment challenging and normal to not complete all tasks on the assessment. If you are not able to complete the whole assessment, your answers and shared experiences will still be very valuable for the study. The assessment will take place at a location you prefer, e.g. (a private room at Leeds Teaching Hospitals Trust or a private room at the University of Leeds or at your home via Zoom or MS Teams), at a time that is convenient for you. Please note that social distancing guidelines will be applied at the hospital location. If you decide to participate in a video call assessment, we will ask you for your verbal consent to agree to participate; this will be video recorded via Zoom or MS Teams.

4. What are the possible disadvantages and risks of taking part?

While some people enjoy puzzles and cognitive tasks, some people may find completing cognitive tasks difficult and tiring, which may possibly lead to upset. If this happens, we can take a break, you can always choose to skip questions, or we can stop the assessment if you wish. If you did find that you were upset at the end of the discussion, you can approach your care team to talk with you further.

5. What are the benefits of taking part?

You may enjoy some of the puzzles and tasks and will be given £20 worth of vouchers for your time and effort in attending the cognitive assessment session. More widely, the information we get from this study may help us to improve patient care in the future and you may help contribute to practitioners' recommendations for online assessments.

6. How will my research data be managed?

Your participation and the information we collect about you during the research will be kept strictly confidential. The researcher will video record your verbal feedback and experiences of the assessment. After the interview, we will use the recording to type out everything that was discussed and to observe/note down how people responded to questions. Once this has been done, the recording will be deleted. An external transcription service may be used to type up your interview; any transcription service used is fully vetted and confidentiality agreements are in place to ensure any information you share during the interview is kept confidential during the transcription process. No medical or personal details are shared with the transcription service. Some of the words you use may be included as quotes in reports and publications, but these will be pseudonymised. This means that to protect your privacy, your identifiable data will be replaced by a code. Your name and other information that can directly identify you will be removed. All electronic data will be stored on a secure, password-protected University of Leeds database server, accessible only to the research team.

Only members of the research team may be given access to data about you. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All these people have a duty to keep your information, as a research participant, strictly confidential. For the purposes of this study, you will be given a unique numbered code.

7. How will we use information about you?

The University of Leeds is the sponsor for this study. We will need to use information from you for this research project. This information will include your name and contact details (shared with the research team at the University of Leeds). 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. We will keep identifiable information about you from this study for 3 years after the study has finished.

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.

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.

Please note that if you give us any information that raises concerns about your own safety or the safety of others, we will have to share this information with your care team, your GP or authorities if needed, in order to keep you and others safe.

The results will be written up within a Clinical Psychology Doctorate thesis project. We will aim to publish the research in a peer-reviewed journal. If you wish to receive a summary of the study results via email or post, you can give consent to this on the consent form.

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

- at {HYPERLINK "https://www.hra.nhs.uk/information-about-patients/"}
- at the University of Leeds privacy notice: {HYPERLINK "https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf"}
- by asking one of the research team
- by sending an email to the Data Protection Officer at {HYPERLINK "about:blank"}, or

9. *Who is organising and funding the research?*
The research is being organised by Ms Rebecca Day, Psychologist in Clinical Training, who is a Clinical Psychology Doctorate student at the University of Leeds ({HYPERLINK "mailto:umrld@leeds.ac.uk"}). The University of Leeds is the sponsor for this study.

10. Who has reviewed the study?
Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. This study was approved by London Surrey Research Ethics Committee on 08/12/22.

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions; their contact details are below. If you remain unhappy, you can contact the Sponsor Representative at the University of Leeds: {HYPERLINK "mailto:governance-ethics@leeds.ac.uk" \t "_blank"}

If you would like to take part in this study, please contact LTHT care team or Rebecca Day directly using the contact details below. If you have any concerns or questions about this study at any time, please contact:

Ms Rebecca Day, Psychologist in Clinical Training, {HYPERLINK "mailto:umrld@leeds.ac.uk"}

Thank you for taking the time to read this information sheet

A3 Participant summary sheet

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Stroke Population's Experiences of an Online Cognitive Screen

- Little is known about how people find tests that assess thinking skills such as memory and processing speed.
- We would like to invite you to take part in our study which will explore how people who have had a stroke, experience an online test that assesses thinking skills, such as memory and processing speed.
- If you are interested, you will be invited to **complete an online test** and **asked to talk about your experiences** during the test. You will also be asked a few questions before and after the test about your experiences. This will take approximately **90 minutes.**
- **We are only interested in your experience of the test;** we will not be scoring the test.
- We will **video-record** this so that we can have a record of what you say about your experiences; this will be kept confidential.
- We can **meet you in person or online** to complete the test, whatever you prefer.
- A **family member or friend can assist you** with getting to the research session, helping you get set up online and filling out the forms etc.
- If you wish to take part, you **will be paid £20** for your time and effort attending the research session.
- We hope that outcomes will be used to **develop practitioner recommendations** for administering online assessments to people who have had a stroke. We also hope it will help **give people who have had a stroke 'a voice' within** research.

If you would like to take part in this study, please contact [change to the name of the care team or charity name as appropriate] or Rebecca Day directly using the contact details below. If you have any concerns or questions about this study at any time, please contact:

A4 Participant consent form

UNIVERSITY OF LEEDS

PATIENT ID:

PATIENT CONSENT FORM

What is it like to Experience an Online Cognitive Screen for People who have had a Stroke?

Study coordinator: Ms Rebecca Day, umrld@leeds.ac.uk
Research team: Dr Florien Boele, Dr Charlotte Baker

Please initial boxes

1) I have read and understood the information sheet (26/07/22, version 2). I have had the opportunity to consider the information, to ask questions and have had these answered satisfactorily.

2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason. My medical care or legal rights will not be affected. I understand that should I withdraw from the study, then the information collected about me up to this point may still be used for the purposes of achieving the objectives of the study.

3) I agree to notes being taken about my views on questions and for extracts from the transcripts to be used in reports of the research on the condition that my anonymity will be maintained.

4) I understand that my research data may be looked at by responsible individuals, regulatory authorities, or the sponsor for the purposes of auditing the study and I give permission for this.

5) I give permission for anonymised data to be held in a computer (in a coded anonymised way) for 3 years after the conclusion of the study.

6) I give permission for the interview to be video recorded via Zoom or MS Teams. I understand that what has been said during the interview will be typed up into a transcript (but this will not include any identifiable information). I understand that the video recording will be deleted once the data has been analysed.

7) I agree to take part in the study.

8) I would like to receive a summary of the overall study results (THIS IS OPTIONAL): If you tick this box, we will keep your email and postal address until the end of the study in order to post/email you a summary of the results.

X _____

Name of Patient   **Date**   **Signature**

_____ _____ _____
Name of Person Researcher   **Date**   **Signature**

Copies: 1 for the participant (Original to be scanned and stored on private university drive).

Appendix B: test materials

B1 Interview schedule and script

Interview Schedule

The qualitative interviews will be flexible (and modified in response to efficacy and/or problems of prior ones), with a general interview guide drafted below:

1. **Opening**
   Establish rapport
   Introduce yourself and the project.

   Purpose and motivation
   Explain the aims of the think-aloud interviews, how this will help us gain insight into stroke service users' experiences of online cognitive assessments and will help guide practitioner recommendations.

   Practicalities
   Explain how long the assessment with the think-aloud interview should take (90 mins) and explain that they can take breaks in between tasks if needed.
   Either check or ask the participant to check that the laptop screen brightness and the volume of the laptop are set to their comfort and that they can clearly see and hear the programme.
   Adhere to ethical standards: explain the audio-recording, confidentiality, and their right to opt-out without affecting care. Ask if any questions.
   Complete demographic information sheet with the participant.
   Start audio-recording and state the number of the interview.

   Consent to participate
   Let the participant know the recording has started and that you are going to discuss consent to participate.
   If a physical consent form has been signed reconfirm the participant is happy to continue and gives their consent to participate. If no physical consent form can be taken (i.e., video call interview) then run through the patient consent form with them, asking them to state that they consent to participate.
   Stop recording following consent and start again before commencing with the interview.

2. **Before they start the screen**
   I am going to ask just a few questions before you start the assessment...
   - What are your views on having a cognitive test? What is running through your mind at the moment?
   - How are you feeling about doing a cognitive test?
   - What, typically, do you think cognitive assessments are used for? What is their purpose?

3. **Read out verb instructions regarding the think aloud:**

1

'We are interested in your experience of completing this cognitive assessment.
To do this, I would like you to complete this cognitive screen while thinking out loud. So, I want you to tell me everything that you are thinking as you complete each task and I want you to tell me how you decide to answer or solve it. There is no right or wrong answer. It is okay if you find some of the questions and tasks easy or difficult to answer. Remember, we are only looking at your verbal feedback; scores will not be analysed. I would like you to talk constantly. Please do not plan what you are going to say, just say whatever comes into your head.

I may ask some additional questions to your answers, such as 'can you tell me more' or 'what do you mean by that'. If you remain quiet/silent for any long period of time, I will ask you to "please keep talking" or "can you say anything else" or "can you tell me more". Please try to speak as clearly as possible, as I shall be recording you as you speak.

When a video is on, please wait until the end of the video before sharing your thoughts; this is so you can hear all the instructions.

If you cannot do a task, it would be helpful to know how you try and problem-solve the task regardless. If you cannot complete a task, don't worry, this is also helpful information for our team; if this is the case, we can stop the assessment.

Let's practice for a minute using this task here:
[ask the participant to practice using a short 1-minute task to ensure they understand what they need to do]

Do you understand what I want you to do? [run through again if needed]

Please remember that I will not be able to explain any of the questions to you. This is because part of the research is around making sure that the assessment is clear for people who have had a stroke to answer. If you get really stuck on a task, this is useful information for our team; in this case, we can stop the assessment and discuss a few more questions.

Assist the participant to start the Amsterdam Cognitive Screen (ACS).

4. <u>Questions during the cognitive screen if needed:</u>
   - 'Keep talking' if the participant hasn't spoken in 10 seconds
   - What is going through your mind at the moment/whilst doing this task? If the participant needs to be reminded of the instructions

Give technical assistance if needed; document what technical assistance is given.

Participants can have short breaks in between subtests if needed. The ACS also has breaks built into the program.

5. **Once the cognitive assessment has been completed/the participant has completed as much as they can**

   Thank you for completing the cognitive assessment. Can I ask...
   - What is going through your mind now?
   - Have any feelings come up?
   - What did you like about the assessment?
   - What did you not like about the assessment?
   - If you had a magic wand and could change the assessment, what would you change?
   - Have you experienced a paper and pen cognitive screen or test like this before with a clinician? What was that like? How does this experience compare with your previous experience?
   - What would you want clinicians administering the assessment to know?

6. **End of the interview**
   - Is there anything else that you think we need to know?
   - Do you have any questions?
   - How have you found this think-aloud interview?

Turn off video-recorder.
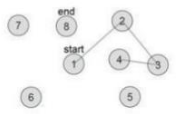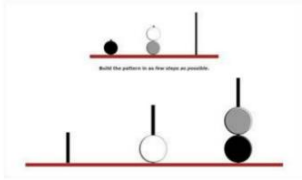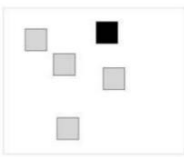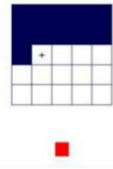
Provide contact information to contact us if anything is unclear or if they need further information. Thank the participant for their time.

Note end time.

Standard follow-up questions/statements for all interview questions:

- In what way?
- Could you explain that a bit more?
- What else can you tell me about that? There is no right or wrong, just tell me what you are thinking right now.
- Could you explain why (you feel like that)?
- Could you explain that further, in your own words?
- What do you mean exactly?
- Is there anything else that pops up?
- Scores won't be counted, but all information and feedback will be helpful

B2 Neuropsychological tests of the Amsterdam Cognition Scan, in chronological order.

Appendix C: screenshots of analysis

C1 Screenshot of annotations on NVIVO and initial 70 codes

C2 Screenshot of emerging thoughts and themes discussed with research team

Initial Thoughts:

Performance Anxiety and Uncertainty

Keen to know what the test is looking at:

e.g.

- -speed – mindful of this – feel they should be faster
- -accuracy – worried they have it wrong
- Often anticipating what they would have to do next – does this add to cognitive load?
- A few people commented that they would like to know the results – had not retained that I would not be giving them their scores – feedback important – and what to do with that feedback, e.g., strategies important too

Identity

- Thoughts that the stroke had changed them
- Worries of dementia and what that would mean
- Individual differences – someone raised issues of base rates – or estimates of pre-morbid functioning
- The brain is the 'powerhouse for humans' – its what makes us human – so if there are difficulties, it influences what it is to be human

Feelings

- Many felt - Frustration, Worry, 'crap', ... Pathetic - these were the people who felt they were not doing very well (objectively, on face value, didn't seem to correlate with who actually would be scoring highly or not – just their perception) = 'reminds me of what I can't do'
- Apologizing if wrong – culture?
- Vs some felt good – showing them how far they have come since the beginning of the stroke journey
- Fear of the unknown
- Memory tasks seemed to provoke particularly distressing feelings – didn't like that it repeating – feeling that they were failing it or not doing well and that was why it was repeating

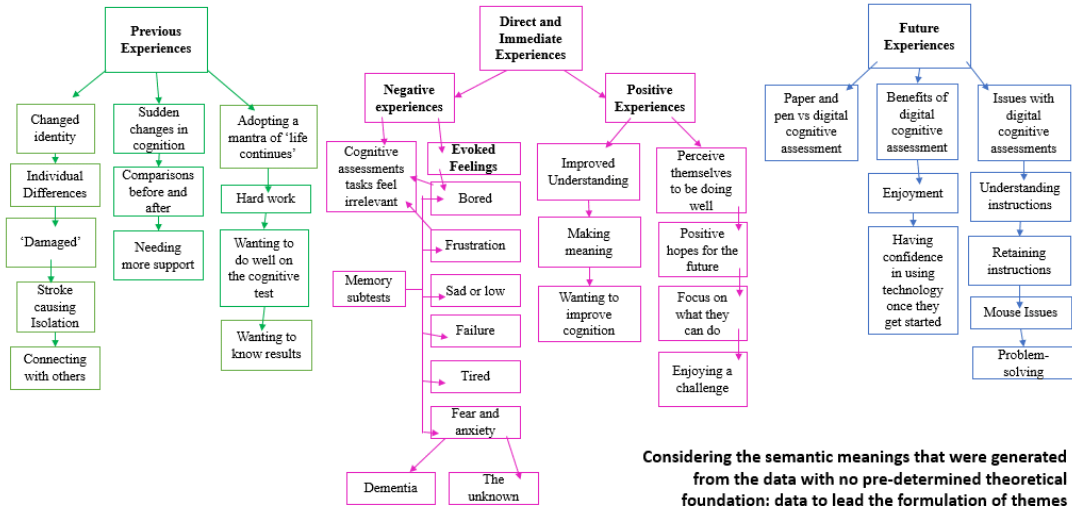## C3 Screenshots of themes emerging on NVIVO following discussion with research team:

C4 Screenshot of more developed themes on NIVIVO

C5 Reflexive Thematic Analysis Revised Coding Tree

Exploration of a stroke population's experiences of a digital cognitive assessment: Coding Tree

Previous Experiences
- Changed identity
  - Individual Differences
  - 'Damaged'
  - Stroke causing Isolation
  - Connecting with others
- Sudden changes in cognition
  - Comparisons before and after
  - Needing more support
- Adopting a mantra of 'life continues'
  - Hard work
  - Wanting to do well on the cognitive test
  - Wanting to know results

Direct and Immediate Experiences

Negative experiences
- Cognitive assessments tasks feel irrelevant
- Memory subtests

Evoked Feelings
- Bored
- Frustration
- Sad or low
- Failure
- Tired
- Fear and anxiety
  - Dementia
  - The unknown

Positive Experiences
- Improved Understanding
  - Making meaning
  - Wanting to improve cognition
- Perceive themselves to be doing well
  - Positive hopes for the future
  - Focus on what they can do
  - Enjoying a challenge

Future Experiences
- Paper and pen vs digital cognitive assessment
- Benefits of digital cognitive assessment
  - Enjoyment
  - Having confidence in using technology once they get started
- Issues with digital cognitive assessments
  - Understanding instructions
  - Retaining instructions
  - Mouse Issues
  - Problem-solving

Considering the semantic meanings that were generated from the data with no pre-determined theoretical foundation: data to lead the formulation of themes

C6 Writing a synopsis for each theme and discussing this with the research team before the final write-up