Exploring traumatic brain injury survivors' experiences of completing a remote online cognitive assessment (The Amsterdam Cognition Scan)

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Abstract

Introduction: In light of the COVID-19 pandemic, digital healthcare has become a rapidly increasing area of research interest. Digital cognitive assessments, which can be completed remotely, without supervision, are being developed and used in both research and clinical contexts with multiple populations. However, very little is known about the way in which these digital assessments are perceived and experienced by survivors of traumatic brain injury (TBI), despite this being a population who commonly undergo cognitive assessment. This study aimed to address this gap by exploring how TBI survivors experience a digital cognitive assessment.

Method: Participants who self-reported sustaining a TBI at some point during their life were asked to complete an online digital cognitive test battery (ACS). An adjusted think-aloud protocol was used to encourage participants to share their ‘in the moment’ thought and reactions during the cognitive assessment, they then engaged in a brief retrospective semi-structured interview about their experiences. Data were analysed using reflexive thematic analysis.

Results: Analysis identified three core themes which focused on 1. Previous experiences which impact how the cognitive assessment is experienced; 2. In the moment experiences: emotions, thoughts and reactions during the cognitive assessment and interview; 3. The use of remote cognitive testing for TBI in the future. Within the core themes, nine subthemes were identified and a detailed narrative description of each theme is provided.

Discussion: Key findings are discussed within the context of the surrounding literature, including the perceived benefits and limitations of utilising digital cognitive assessments, and specifically remote digital assessments with TBI survivors; the in the moment emotional experiences of participants, such as anger, sadness and grief, and factors which were perceived to impact these; and the importance of balancing probable distress with the potential benefits of cognitive assessment. Subsequent recommendations for practice and research are also discussed.

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Introduction

Traumatic Brain Injury Context

The term traumatic brain injury (TBI) covers a broad range of different patterns of injuries and damage to the brain, but is defined by the National Institute for Health and Care Excellence (NICE) (2014, p. 2) as:

“*a traumatically induced structural injury and/or physiological disruption of brain function as a result of an external force that is indicated by new onset or worsening of at least one of the following clinical signs, immediately following the event:*

- *any period of loss of or a decreased level of consciousness*
- *any loss of memory for events immediately before or after the injury*
- *any alteration in mental state at the time of the injury (confusion, disorientation, slowed thinking, etc)*
- *neurological deficits (weakness, loss of balance, change in vision, praxis, paresis/plegia, sensory loss, aphasia, etc) that may or may not be transient*
- *intracranial lesion*.”

The total number of people admitted to hospital as a result of a head injury with symptoms of a brain injury increased by about 1% between 2005 and 2017 to approx. 155,919 in the 2016/17 financial year; equating to approximately one admission every 3 minutes (Headway, 2018). However, it is likely that these numbers reflect an underestimation of the true number of TBIs suffered within the UK each year. The United Kingdom Brain Injury Forum (UKABIF, 2018) discuss several barriers to accurately estimating prevalence rates of TBI. Most notably, published rates are usually based on data regarding the primary presenting problem at accident and emergency departments, therefore individuals who may have suffered a secondary head injury would not be counted. Moreover, it is suggested that data is often lost as a result of different NHS trusts using inconsistent classification systems for head and brain injuries, with data also being lost as individuals move through different NHS system due to a lack of co-ordinated care and consistent recording of information.

Survival rates of individuals who have experienced a Traumatic Brain Injury (TBI) have increased over the last several decades following improvements in detection and treatment, with the fatality rate for TBI currently estimated at 0.2% (NICE, 2014). This has resulted in an increase in the number of individuals living with the sequalae of their TBI (Headway, 2018).

TBIs are categorised into mild, moderate and severe injuries, however the parameters and definitions used to categorise injuries can vary between services and within the literature, as there is no universally accepted definition currently. One parameter commonly considered is loss of consciousness (LOC) following the initial injury, whereby extended periods of LOC are associated with more severe brain injuries (Headway, 2021). Another indicator used is the Glasgow Coma Scale score, which is a standard clinical assessment of level of consciousness ranging between 3-15, with lower scores indicating more severe injury and poorer clinical outcomes (BMJ Best Practice, 2021). Finally, the presence and length of post traumatic amnesia (PTA) is associated with the severity of brain injury. Although specific definitions for PTA can vary, PTA is generally regarded as a state of consciousness following a period of unconsciousness where the individual presents as confused, disorientated and experiences both retrograde and anterograde amnesia, this can also be coupled with acute agitation (Marshman et al., 2013). Table 1 gives an example of the characteristics which are generally used to define the different levels of TBI severity, however numbers used vary slightly between different sources.

A briefing paper on head injury released by NICE (2014) stated that approximately 95% of all individuals who presented at primary care services following a head injury had GCS scores greater than 12, suggesting mild injuries. Thus only 5% of head injuries result in moderate or severe brain injuries.

Table 1. Brain Injury Severity Classification

Injury severity	**LOC**	**GCS Score**	**PTA**
Mild	< 30 mins	13-15	< 1 hour
Moderate	30 mins – 6 hours	9-12	1 – 24 hours
Severe	6 – 48 hours	<9	>24 hours
Very Severe	> 48 hours	<9	>7 days

NB: data from Headway, (2021) and BMJ Best Practice (2021).

Common Sequalae of TBI

TBIs of all different kinds and severities are associated with a multitude of complex potential sequalae, including physical, cognitive, behavioural, and emotional changes, which can all have a significant impact on long term outcomes and quality of life (Stocchetti & Zanier, 2016).

It is frequently reported that moderate and severe brain injuries result in more pronounced cognitive changes than mild brain injuries, with the deficits to functioning being both more severe and enduring (Schretlen & Shapiro, 2003). One estimate suggests that approximately 65% of survivors of a moderate to severe TBI report long term difficulties with their cognitive function (Whiteneck et al., 2004). While both moderate and severe TBIs can result in global cognitive impairments, some of the specific areas of cognition which are most commonly reported to be impacted include: processing speed, short- and long-term memory, attention, executive function (e.g. working memory, planning, problem solving, inhibitory control, self-monitoring and cognitive flexibility), language processing, communication and visuospatial processing (Rabinowitz & Levin, 2014). These cognitive sequalae of TBI can cause significant disability when they impair people's ability to complete activities of daily living, ranging from complex work activities down to tasks such as washing or preparing food or drink. It has been suggested that the cognitive and neurobehavioral impacts of TBI are often the most significant for the individual, their family and their adjustment, and for long term functional outcomes, having the greatest association with long term disability (Brooks et al., 1986; Laborde, 2000; Ruet et al., 2019).

Mild TBIs have also been associated with cognitive sequalae such as changes in memory, attention, executive function and processing speed (Rabinowitz & Levin, 2014). However, these cognitive deficits have been reported in multiple meta-analyses to be short lived, with most people's cognitive functioning returning to baseline levels within no longer than three to six months of their injury (Carroll et al., 2004; Frencham et al., 2005). Yet, other researchers have criticised the meta-analytics methods used in these studies, suggesting that the pooling of data in this way prevents recognition of cases where long term cognitive deficits do persist, estimating that deficits persist in approximately 15% of mild TBIs (Bigler et al., 2013). This is supported by other research which has found persisting neurobehavioral and cognitive impairments in mild TBI survivors compared to healthy controls, even when controlling for other factors which may influence results on cognitive tests, such as depression symptoms or perceived performance (Konrad et al., 2010).

Indeed, a more recent paper by Maas et al. (2017) highlights the need for more research regarding the long term sequalae and outcomes of not just moderate and severe injury, but particularly injuries categorised as mild, as extensive evidence in this area is lacking. Increased research exploring the cognitive, physical, behavioural and emotional long-term impacts of TBI, and particularly mild TBIs, could provide the evidence required to increase commissioning and development of support services and treatment pathways for this population.

Neuropsychological Assessment in TBI

Given the research discussed above on the long-term impacts of TBI, it is clear why neuropsychological assessment is often considered a key part of primary care following TBI (Sherer et al., 2002). Indeed, NICE guidelines advocate for a follow up neuropsychological assessment by an appropriately trained professional following discharge from hospital for a moderate or severe head injury, but these are not routinely recommended for mild head injuries (NICE, 2019). These assessments aim to inform care, to highlight and increase awareness for individuals and their support networks regarding potential strengths and difficulties following TBI, and in turn inform potential compensatory strategies or adaptations in their life (Lezak et al., 2012). A thorough neuropsychological assessment aims to explore the nature and severity of a brain injury, including the cognitive, behavioural, emotional and social impacts, as well as the functional impacts of these (Roebuck-Spencer et al., 2017).

Neuropsychological assessments are conventionally conducted face-to-face, and involve various multidimensional aspects or sessions, of which standardised cognitive assessments form one part. Neuropsychological assessments involve clinical interviews, which should aim to gather detailed information regarding an individual's broad life context and current difficulties, allowing for planning and behavioural observation which contribute to result interpretation (Block et al., 2017). The standardised cognitive assessments used as part of the overall neuropsychological assessment are designed to assess different cognitive domains which could be impacted by a TBI, such as visual and verbal, short- and long-term memory, attention, executive function and processing speed. Findings should always be interpreted within the context of an individuals' educational, employment, socio-economic and medical history (Lezak et al., 2012).

Standardised neuropsychological assessments provide quantitative data regarding performance on tasks, which are usually compared to a sample of calculated population norms, which are designed to offer insight into cognitive abilities and highlight strengths and difficulties. This type of assessment can also generate valuable information from observation of the assessee by the assessor, such as the way in which tasks are approached, any compensatory strategies used, or other responses and interactions, which can offer further insight into cognitive, social, and emotional processes (Lezak et al., 2012). Neuropsychological assessment tests and subtests can be administered as fixed or full batteries, which is more commonly the case within TBI research, however, clinically these subtests can be used flexibly, based on clinical interviews and observation, to best fit the needs of an individual.

Cognitive Screens in TBI

There has bene noted confusion within the literature between the use of the terms neuropsychological assessment, cognitive testing and cognitive screening, with these phrases often being used interchangeably (Block et al., 2017). However, compared to neuropsychological assessment, described above, cognitive screens are usually much more brief, being able to be completed within a single session, and differ in their aims (Roebuck-Spencer et al., 2017).

Cognitive screens are commonly used during the more acute stages of TBI recovery, or when under time pressures. Some of these assessments can be done in a 'bed side' setting and can give some early indication of the presence of cognitive difficulties following a TBI (Hodges & Larner, 2017). These assessments aim to offer some indication of potential cognitive difficulties in areas such as executive function, verbal memory, attention, language and orientation. This information can be used to support the client and teams, as well as support to indicate when further in-depth neuropsychological assessment may be helpful for an individual (Roebuck-Spencer et al., 2017). Some examples of this type of assessment, presented from shortest to longest, are: the Mini Mental State Exam (MMSE), Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005), Addenbrookes Cognitive Exam – III (ACE-III) (Hsieh et al., 2013), Short Parallel Assessment of Neuropsychological Status (SPANS) (Burgess, 2014) and the Repeatable Battery for the Assessment Neuropsychological Status (RBANS) (Randolph et al., 1998).

There are limitations with the use of these screens in brain injury, as many were designed for screening in dementia (Freitas et al., 2012; Hodges & Larner, 2017), their design and psychometric properties may mean they are sensitive to severe cognitive impairment, yet are sometimes unable to detect subtle changes in cognition, but these subtle changes can still have a significant functional impact on individuals following TBI (McGhee et al., 2017). Moreover, the heterogeneity of cognitive changes in TBI has resulted in a significant challenge in identifying screening tools which are reliable and valid within this population (Teager et al., 2020). A recent systematic review, aiming to identify reliable and valid screening tools in TBI populations, which included 34 studies evaluating 22 different cognitive screens (but did not include the RBANS, ACE-III or SPANS), found that the MoCA and the MMSE were the most widely validated screens in TBI populations (McLaren et al., 2024). The review identified that the MoCA demonstrated sufficient structural validity, internal consistency, criterion validity (to distinguish between TBI and healthy controls) and convergent validity, however authors also note the limitations in study quality within the evidence base (McLaren et al., 2024).

Despite the acknowledged limitations, and lack of evidence for validity, many of these screens are used regularly in clinical settings, with many reporting that they have very good clinical utility (Hodges & Larner, 2017; Teager et al., 2020).

Computerised neuropsychological assessment and screening

Given the rich information which can be gathered alongside the quantitative data in both face-to-face cognitive screening and neuropsychological assessment, it is understandable that guidelines currently recommend these methods, to prevent crucial observational data being lost (Bilder & Reise, 2019). Moreover, face-to-face administration methods allow for structured support or redirection to be provided by the assessor, which may be important given the common sequalae of TBI can result in people being more distractible or impulsive (Bauer et al., 2012).

Over the last decade or so, with the rapid development of technology, many already widely used ‘pen and paper’ neuropsychological tools, screens and assessments have been developed into computerised versions which are commonly used within clinical contexts. For example the Montreal Cognitive Assessment (MoCA), discussed above, has an electronic version which can be administered via tablet. Similarly, Pearson developed Q-interactive, a tablet based system to administer the widely used Wechsler Adult Intelligence Scale (WAIS-IV) and the Wechsler Memory Scale (WMS-IV), as examples. While these assessments are computerised, and some aspects more automated, they still require face-to-face administration and interpretation by a suitably qualified clinician.

Benefits of face-to-face computerised assessments have previously been noted in the literature, such as more precise measurements, increased standardisation of presented materials and reduced costs associated with reduced clinical time, automatic scoring, reduced errors and increase speed of administration (Bauer et al., 2012; Spreij et al., 2020). Moreover, it has been suggested that digital administration can allow for collection of data which may otherwise be missed in traditional pen and paper testing, for example, live recording the drawing of visual stimuli that can be rewatched and analysed later, offering further insights into the process of test completion, contributing to the understanding of the test results and outcomes (Libon et al., 2021). There has also been discussion within the literature which has noted the historical underuse of technological advances within the field of neuropsychology, and encouraged for the continued development and implementation of technology within clinical practice (Parsons et al., 2018). Indeed, there has been an increased research interest in this area, and there is continuing exploration and development of multiple new computerised screens and assessments across a variety of clinical areas, such as in Alzheimer’s disease (e.g. Brooker et al, 2020; Hampshire et al., 2020) and TBI populations (Del Giovane et al., 2023).

While there are many noted potential advantages of using computerised assessments, there are also limitations which require consideration in clinical practice. Literature has suggested that computer literacy can impact test performance on computerised cognitive tests, disadvantaging those with less computer experience and raising questions regarding the validity of tests and whether they are indeed measuring targeted cognitive function, or computer literacy (Germine et al., 2019). Performance on a digital version of an assessment can vary from performance on the same pen and paper based assessment, and therefore in the development of new assessments new normative data are required for the use of these in practice (Canini et al., 2014), though this would be the case in the development of any new cognitive assessment, regardless of type.

Limitations of face-to-face assessments

The COVID-19 pandemic and subsequent social distancing restrictions highlighted limitations in the rigidity of conventional methods of neuropsychological assessment and screening, particularly the reliance on face-to-face administration of standardised assessments. However, even prior to COVID-19, access to neuropsychological assessment was a national issue, with waiting times varying significantly across the country, but very often exceeding nationally recommended limits in many places (Donovan et al., 2020; NHS Lanarkshire, 2022).

The issue of limited access also has an impact on neuropsychological research, as discussed previously, there is limited research exploring the long term sequalae of mild brain injuries, partly because this population are not routinely offered this type of assessments, due to limited resources and the time and cost demand this would entail if completed in a traditional face-to-face manner. If access were increased, more data may become available for collation and analysis, and thus contribute to this large gap in the literature (Maas et al., 2017).

The British Psychological Society (BPS) Division of Neuropsychology (DNP) issued interim guidelines during the pandemic, advocating for remote video assessments while acknowledging their limitations (BPS, 2020). The guidelines helped relieve pressure on services by enabling continued access to assessments while also highlighting challenges with remote testing, such as difficulties in standardising procedures and lack of valid norms. Many assessments were deemed unsuitable for remote use further limiting available tools for clinicians.

Research conducted in NHS Scotland during the pandemic found that clinicians working in a neuropsychology service agreed that in 96% of cases (total 212) they were able to complete adequate clinical interviews via video conferencing, and could formulate appropriately in 77% of cases, though clinicians noted key difficulties with having very limited availability of evidence based, validated, remote cognitive tests (Sumpter et al., 2022).

Remote digital cognitive assessments

The dilemmas discussed above therefore raise the question as to whether the use of remote neuropsychological assessments, which are specifically designed to be completed online in patient's own homes and thus do not require direct contact with a clinician or travel to a service, could be beneficial both clinically in the post COVID-19 healthcare climate, and more widely in neuropsychological research. Indeed, the current healthcare climate, alongside the NHS 10 year plan, which advocates largely for developments in digital health and social care, has sparked significant developments in this area over recent years, with researchers developing computerised cognitive screens which have been designed to be completed remotely (Roebuck-Spencer et al., 2017), though much of this research has focused on screening in Alzheimer's disease and older adult populations (e.g. Berron et al., 2024; Perin et al., 2020).

In some clinical areas remote digital assessments have been developed and historically used more widely, such as in the evaluation of post-concussive cognitive symptoms followings sports injury (Bauer et al., 2012). Several self-administered online screening assessments have also been designed and made available to the public online, such as The Brain Health Assessment (Troyer et al., 2014) and the Cognitive Function Test (Trusthram & de Jager, 2014). These assessments are advertised as being screening assessments for older adults who may be worried about their cognitive function or possible early dementia symptoms, and offer individuals 'reports on their brain health' and advice about whether they should seek further support from a medical professional based on their results (Brain Health Assessment; www.cogniciti.com). One study has reported that the Brain Health Assessment had similar diagnostic sensitivity to the MoCA in screening for mild cognitive impairment and dementia in a sample of over 50s (Paterson et al., 2021). This highlights how this form of self-administered screening assessment is already beginning to be utilised in other clinical areas.

More recently, the developers of the MoCA have developed a briefer self-administered version accessible to the general public by computer or tablet (XpressO), which includes subtests to assess memory, executive function and processing speed (https://mocacognition.com/digitaltools/XpressO). Again, this assessment has been developed in the context of screening for Alzheimer's disease in older adult research. An initial validation study which included 86 participants (mean age 70 years) and compared scores on the XpressO and the digital MoCA found a strong correlation between memory scores in the XpressO and the MoCA memory index, and between all XpressO subtest scores and total MoCA score (Klil-Drori et al., 2023). Authors concluded that the XpressO is a efficient cognitive prescreening tool, with good sensitivity and specificity compared to the MoCA, which can identify individuals with cognitive impairments which would warrant further investigation.

While there has been a rapid increase in research aiming to develop remote cognitive assessments in both research and clinical contexts (Germine et al., 2019; Marcopulos & Lojek, 2019), the options for using this type of assessment in brain injury services remain severely limited. This is likely due to the some of the proposed limitations of this method of assessment (e.g. less structured support from the clinician, limited control of the testing environment, less opportunity for wider observation, heterogeneity of cognitive deficits etc.) and conventional clinical favour of face-to-face administered assessments, meaning that up until the last few years, there has been limited resources directed into developing any assessments of this nature (Parsons et al., 2018).

One recent study did aim to explore the feasibility and sensitivity of a computerised battery of cognitive tests in survivors of traumatic brain injury (Del Giovane et al., 2023). The study had multiple phases whereby a series of individual online cognitive tasks were trialled in individuals referred to an NHS TBI clinic in London, leading to the development of a short battery of tasks which could be completed remotely via computer, tablet or smartphone, with minimal impact of device on outcome. They found that the online battery could discriminate processing speed, working memory, executive function and visual attention in TBI versus healthy participants when administered under supervision or remotely under no supervision (Del Giovane et al., 2023). The cognitive test battery used in this study was designed as a cognitive screen, to identify individuals who may benefit from further neuropsychological assessment, and the authors present several individual case studies in which the battery had been administered remotely and identified individuals who went on to have subsequent neuropsychological assessment, with the deficits identified in assessment being concurrent with those identified by the screening battery, further indicating possible clinical utility (Del Giovane et al., 2023). While this study offers some promising indication that remote cognitive testing could be feasible and clinically useful in TBI populations, it did not gather any data pertaining to service user experience of the computer test battery, and the study authors highlight the limited literature and lack of validated measures and tests, advocating for future research and development in the area.

Given this, and that clinicians have an ethical responsibility to constantly update their knowledge, it feels appropriate to explore avenues of research which may have previously been neglected, such as in the case of remote digital neuropsychological and cognitive assessments in TBI. This is particularly true if it is possible that, in the longer-term, development and implementation of remote assessments could increase access to clinical services, and support to fill the above described gaps within the TBI research literature.

If remote assessments were to start to be used in brain injury populations on a wide scale, then concurrent validity of these measures with currently favoured face-to-face measures would need to be established in larger scale studies which are beyond the scope of this project. However, in line with NHS and research emphasis on person centred care, it is vital that the experiences of those impacted are explored and considered in healthcare developments, such as those discussed here. Therefore it should be considered useful to establish how service users from this population experience completing online remote assessments, and whether the completion of these appears feasible and acceptable in this population, given the reduced structured support available and common presence of cognitive difficulties (Stocchetti & Zanier, 2016).

The Amsterdam Cognition Scan

The Amsterdam Cognition Scan (ACS) is an online remote cognitive screen which was developed in the Netherlands and was originally designed to be used in research settings to collect data regarding cognitive outcomes in cancer patients (Feenstra et al., 2018). This assessment is relatively unique in that it was developed to be self-administered by patients at home, or in any remote location where individuals have access to a computer and an internet connection. The subtests of the ACS were developed in digital versions which mirror widely used pen and paper cognitive tests (Feenstra et al., 2018). The 7 subtests of the ACS, their targeted cognitive domain and the traditional test these were adapted from are displayed in order of presentation in Table 2. The ACS is estimated to take approximately an hour to complete, which alongside the variety of tests included, places it in a unique position sitting somewhere between longer neuropsychological assessments (which often take several hours or days) and the shorter cognitive screens described above; though it fits most closely with the cognitive screen category. As the ACS was not developed as a tool for clinical screening, there is no data pertaining to sensitivity or specificity. However, in an initial validation study the test-retest reliability of the tests within the ACS were shown to be comparable to those of the face-to-face equivalents within the literature (Feenstra et al., 2018). Moreover, concurrent validity correlations of all tests except the box tapping test were in the medium to large range (Feenstra et al., 2018). While designed for research purposes in the field of oncology, developers of the ACS also propose that it would be appropriate for research studies of cognition in other clinical areas, due to the broad range of domains assessed.

While this study is not aiming to assess the validity, reliability or clinical utility of the ACS within a TBI population, nor is it suggesting that the ACS would be the assessment utilised in brain injury services in the future, it is suggesting that the ACS it is likely to be a useful and appropriate tool for exploring individuals' experiences of digital cognitive testing of this nature. This information may guide future developments in this area by exploring the views and experiences of service users completing digital assessments remotely, which may highlight potential advantages or difficulties of use within a TBI population and may also offer some preliminary information about the utility and acceptability of remote digital cognitive assessments following TBI.

Developers of the ACS agreed to give the researcher access to the assessment for the purposes of use in this research project.

Table 2. Tests of the ACS (adapted from Feenstra et al.(2018))

ACS Test	Cognitive Domain	Traditional Test
1. Connect the Dots I; Connect the Dots II	Visuomotor tracking, planning, cognitive flexibility, divided attention (executive function)	Trail making test A Trail making test B
2. (a) Wordlist learning	Verbal Learning	15 Word test (Dutch version of Rey Auditory Verbal Learning test)
3. Reaction Speed	Information processing speed and attention	Visual reaction time (substest FePsy)
4. Place the Beads	Planning, response inhibition, visuospatial memory	Tower of London Test (TOL-dx)
5. Box tapping	Visuospatial short term memory	Corsi block-tapping test
6. Fill the grid	Fine motor skills	Grooved Pegboard
2. (b) Wordlist delayed recall and recognition	Retention of information	15 Words Test
7. Digit sequences I; Digit Sequences II	I: Attention II: Working memory	WAIS III Digit Span (forward and backwards)

Literature Review: Service User’s Experiences of Neuropsychological and Cognitive Assessments

Aims of review

The following literature review aimed to scope the current literature which has explored service users experiences of face to face and digital neuropsychological assessment and cognitive testing, to assess the quality and breadth of this and to identify any gaps in the literature to inform research aims in the current study. The review also aimed to explore which methodological approaches have been utilised to investigate these experiences, and consider the strengths or limitations of these, to guide the development of a unique methodological approach which can contribute to any identified gaps.

Search Protocol

The preceding introduction and following literature review are supported by a literature search utilising the Ovid online platform of four online databases: APA PsychInfo (2002 to July 2024), Embase (1996 to July 2024), MEDLINE (1946 to July 2024) and the Cochrane Database of Systematic Reviews (2005 to July 2024). Search terms such as ‘brain injur*’ , ‘traumatic brain injur*’ , ‘TBI’ and ‘ABI’ were combined with OR, with terms such as ‘neuropsych* assessment’, ‘digital neuropsych* assessment’, ‘teleneuropsych*’, ‘online cognitive assessment’ , ‘computer* cognitive assessment’ , ‘online cognitive screen’ , ‘remote cognitive screen’, ‘digital cognitive screen’ , ‘digital cognitive assessment’ etc also being combined by an OR function. These two groups of results were combined using the AND function, and duplicates removed, resulting in 26 studies being identified for review from this search and screened for relevance and any exploration of service user experience or perspectives. The search was run initially in February 2022, and subsequently in August 2023 and again in September 2024 when preparing for submission, one further study was identified by the search in August 2023, and one in September 2024, totalling 28. The search was further supported by a search of Google Scholar, which included combinations of the same search terms used in the search protocol described above alongside terms ‘experiences’ and ‘perspectives’.

Based on the review aims, discussed above, literature was included if it aimed to gather data pertaining to, and report on, any aspect of service user experience of completing either a neuropsychological assessment, cognitive assessment or cognitive screening, which could be conducted either face to face, digitally or remotely, even if this was not the primary aim of the study. Studies utilising both quantitative and qualitative methods were included in the review. Studies who’s samples were made up solely of children (under 16) were excluded due to the current study’s focus on adult populations. Moreover, studies which only included or explored information gathered from third parties, such as family members or carers was not included in the review due to the focus on direct service user experiences. An overview of reviewed studies, including methods and key findings is presented below.

Quantitative approaches

One of the first studies which aimed to investigate individuals' experiences of neuropsychological assessment was conducted in Australia involving feedback from 129 outpatients with a variety of neurological diagnoses, including TBI (Bennett-Levy et al., 1994). The research team developed the Neuropsychological Assessment Questionnaire, which included mostly closed yes/no or Likert scale questions, with some space for any additional written feedback. In this study, approx. 50% of participants indicated that they experienced the assessment as positive, 91% indicated it was neutral or positive, with only 9% indicating that it was a negative experience. Ultimately, the authors concluded that a positive experience of neuropsychological assessment was determined by feedback and discussion following the assessment being considered useful (Bennett-Levy et al., 1994). However, it is also important to note that in some written responses participants referred to the test as 'too long', 'tiring' and that some had experiences of feeling like a 'failure'. The nature of the test questions limited the scope and depth of information gathered, and the insights into service user experience offered are therefore somewhat limited.

Donofrio et al., (1999) had 60 participants who were diagnosed with some form of 'brain dysfunction' complete a short questionnaire after receiving feedback regarding a recently undertaken neuropsychological assessment. The study aimed to investigate the patients' views on receiving feedback, with all participants reporting to have found this session helpful and just over 95% reporting that receiving a written summary of feedback was helpful.

Westervelt et al. (2007) investigated the perceptions of a sample of 129 patients, with a variety of neurological diagnoses including TBI, who underwent neuropsychological assessments in an academic medical centre in the USA. They also gathered the views of 80 of their significant others. Surveys which included 9 questions were sent to participants approximately four weeks following clinical feedback being provided about the assessment. Questions sought feedback on the experience of making appointments, the assessment environment, the clinician administering the assessment, feedback sessions and recommendations.

There are several other examples of studies which have used similar methods (surveys or questionnaires with closed scale questions) to investigate patients' experience of neuropsychological assessment; usually within the context of patient satisfaction and service evaluation projects (e.g. Foran et al., 2016; Mountjoy et al., 2017; Rosado et al., 2017). Most of the above-described studies highlighted similar themes within their results and conclusions, including the importance of useful feedback, general satisfaction with the assessment process, testing environment, and the importance of the relationship with the assessor/clinician. However, the use of closed questions within these studies may have limited service users' ability to give a true reflection of their experiences (Fricker & Schonlau, 2002), and prevented the research from being able to gather in depth data which may have given more insight into specific aspects of testing which impacted service users experiences.

Qualitative approaches

Several studies have adopted a qualitative design to explore the experience of completing face-to-face neuropsychological assessments, within a clinical context, in individuals from a variety of different populations. Blake (2004) explored the experiences of nine individuals with varying conditions such as stroke, TBI and neurodegenerative conditions, Conniff (2008) explored the experiences of children, Sweetman (2018) explored the experience of individuals with neurodegenerative conditions, Martin (2022) explored the perspectives of four individuals with an intellectual disability, Hobden et al. (2023) explored 26 individuals' experiences of completing cognitive assessment post stroke, and Krohne et al. (2011) investigated the experience of older adults completing cognitive screening.

While each of these studies discuss some findings related to the specific populations investigated, there was significant overlap in the themes identified, with common themes including:

- Anxiety being experienced due to confusion and uncertainty regarding the purpose of, and what to expect from, neuropsychological assessment or cognitive testing.
- Participants experiencing a wide mix of emotions throughout the assessment process, including fear, anxiety, confusion, frustration, sadness and hope.
- Factors relating to the clinician or administrator can influence how an assessment is experienced, such as whether they are perceived as friendly and compassionate.
- The importance of feedback, as this can often be perceived as unclear or unhelpful to service users.

Owen (2012) was the only study identified which explored the experiences of completing face-to-face neuropsychological assessment in people with TBIs; they conducted retrospective semi structured interviews with 8 clients with TBI who had completed a neuropsychological assessment within the past 6 months, data were analysed using interpretative phenomenological analysis (IPA). This study highlighted that neuropsychological assessments are not experienced as emotionally neutral or benign, with a wide variety of emotions such as anxiety, frustration, confusion, uncertainty, determination, enjoyment, and disappointment being expressed by clients. This finding was also in line with themes identified in the other studies mentioned above. Owen (2012) identified the relationship and factors related to the clinician administering the assessment as being closely related to how the assessment is experienced, again this was in line with findings from the studies which explored experiences in other populations. Moreover, participants discussed that fatigue caused by the assessment itself and negative environmental factors, such as a very small, visually distracting or excessively warm rooms contributed to negative experiences during the assessment process. Owen (2012) also reflected on the importance of feedback in how the neuropsychological assessment process is experienced, for example discussing that neuropsychological reports are generally written from a professional perspective, often with a focus on areas of difficulty, which can lead to participants perceiving this as failure and subsequently experiencing further distress.

Recommendations from these studies commonly include the clinician spending time preparing the client, explaining the rationale for, and implications of assessment, answering any questions, and building rapport prior to the administration of any tests. They also highlight the importance of providing clear, concise feedback which does not use jargon and is meaningful for the individual (Blake, 2004; Hobden, 2023; Martin, 2022; Owen, 2012).

Computerised and remote cognitive assessments

Two studies were identified which used qualitative methods to explore the experience of completing face-to-face administered computerised assessments. Robillard et al. (2018) explored the experience of 19 older adults, who had been involved in a larger study exploring the use of computerised cognitive screening for diagnosing Alzheimer’s disease (Cognigram), using semi structured interviews and thematic analysis. They identified themes around computerised testing becoming more accepted, however a balance between technology and human interaction was also deemed important, and mixed views between participants on the testing process highlighted the importance of user-testing in the development of these assessments. The authors in this study highlighted the potential benefits of the development of assessments which could be used in the home, to reduce anxiety and to increase the amount of data able to be gathered over time in both research and clinically.

Macleod et al. (2020) used interviews and thematic analysis to explore the experiences of 5 individuals who had a concussion of completing a computerised assessment (The Cognition Battery of the National Institute of Health Toolbox for Assessment of

Neurological and Behavioural Function) as part of a larger study evaluating this assessment. All four participants who had also completed pen-and-paper neuropsychological assessment since their concussion reported a preference for the computerised assessment citing the efficiency of computer testing, and this fitting more within the context of their lives. Other themes which arose were that using computerised testing ‘made sense’ and appeared to have benefits, such as automatic scoring and increased response time accuracy, but that there may be challenges in using computers for testing after concussion, as this may lead to symptom exacerbation, such as headaches and fatigue.

Kochan et al. (2022) used a quantitative approach to gather information regarding older adults’ experience of completing a remote computerised cognitive assessment as part of a study which primarily aimed to evaluate the reliability and validity of the computerised assessment. 52 participants completed a brief battery of computerised cognitive tests from the Cogstate Brief Battery and Cambridge Brain Sciences, unsupervised at home, followed by a ‘user-experience questionnaire’. The questionnaire included 5-point Likert scale questions (strongly agree to strongly disagree), and asked participants to rate things such as each individual tasks’ difficulty level and how much they enjoyed each task. Participants were also asked to rate their overall experience of performance anxiety, ability to concentrate and any difficulties with using a computer to complete the tasks. Authors conclude that most participants generally enjoyed the tasks, though only 55% of participants rated ‘agree’ or ‘strongly agree’ on seven or more of the nine tasks completed and nearly half of participants reported experiencing performance anxiety. While this study gives some insight into the fact that remote digital cognitive testing is, as with face-to-face testing, not experienced as emotionally neutral, it is highly limited in its depth of exploration.

Day (2023) utilised a qualitative approached with an adapted think-aloud protocol to explore how 11 older adults, from a stroke population, experienced completing the Amsterdam Cognition Scan. This study’s findings were in line with previous literature relating to the experiences of face-to-face cognitive assessment in this population, with participants experiencing a range of emotions, including fear, anger and sadness. Themes in this study also highlighted the importance of past experiences and how these influenced an individual’s ‘in the moment’ experiences and perceptions of the digital cognitive assessment.

Summary

The literature search conducted revealed that literature exploring experiences of service users when completing traditional pen and paper based neuropsychological and cognitive assessments is limited, with much of the existing research in this area focusing on the experiences or perspectives of third parties, such as family members, carers or other professionals (Owen, 2012; Watt & Crowe, 2018). The literature exploring experiences of completing digital remote assessments, broadly across healthy and clinical populations, and specifically in TBI survivors, appears almost non-existent. The majority of studies identified in the search which did aim to explore direct service user experiences utilised quantitative approaches, such as questionnaires with closed questions, usually in the context of service evaluation projects, which while offering some useful broad insights into experience, were significantly limited in their depth of exploration. Studies which utilised qualitative methods offered a more detailed exploration of experiences, however these nearly unanimously utilised retrospective interview methods, which limited their ability to speak to ‘in the moment’ experiences of completing cognitive assessments.

I was not able to identify any studies which investigated the experience of completing a digital cognitive assessment which is designed to be completed remotely and independently in individuals with TBI, nor was I able to identify any study which aimed to explore ‘in the moment’ experiences of TBI survivors completing any form of cognitive assessment. Considering this, the literature discussed in the introduction, and the research which highlighted the importance of considering user experience in the development of these assessments, this is a useful area to explore to inform future developments in the cognitive assessment of brain injury, both clinically and in research.

Study aims and research question

While some research has begun to explore TBI survivors’ experiences of completing neuropsychological and cognitive assessments, these studies have utilised alternative methods, such as retrospective interviews, sometimes months after the fact, or quantitative methods which have not allowed for detailed exploration. Alternatively, this study looks to provide an in depth exploration of TBI survivors’ ‘in the moment’ experiences of completing a digital cognitive assessment. Due to the very limited literature pertaining the experiences of TBI survivors in this research area, this study will utilise a flexible, exploratory approach to gathering data and developing knowledge, therefore a hypothesis is not appropriate.

This study aimed to provide insight into how TBI survivors experience 1. Cognitive assessments 2. digital online cognitive assessments 3. digital remote unsupervised cognitive assessments. Due to the exploratory nature of the study, research questions are purposefully broad and include:

- What are the TBI survivors’ views on the digital cognitive assessment? E.g. experiences before, during and after? If they have completed face-to-face testing in the past, what were their experiences of that and how does it compare to remote digital assessment?

- What emotions and thoughts are experienced by TBI survivors ‘in the moment’ when completing an (online remote digital) cognitive assessment? What about the assessment process evokes these reactions?
- What do TBI survivors perceive the benefits or limitations of online digital cognitive assessment to be? E.g. What might be important for clinicians and/or researchers to consider if utilising these in the future?

Method

Design

Research design considerations

Several methodologies were discussed with supervisors during the study design process. The first of these was the use of semi-structured interviews, a widely used method in qualitative research (Fylan, 2005), which would be completed retrospectively following participants completing the ACS. This would allow participants the space to reflect on their experience and for the researcher to gather qualitative data which would represent the participants' experiences of reality.

Some strengths of semi-structured interviews were considered to be that it would allow the researcher the opportunity to tailor questions to explore participants' experiences in line with the study aims, while still allowing participants the flexibility to share their ideas and thoughts freely. However, given the common cognitive consequences of TBIs, including attention and memory difficulties (Rabinowitz & Levin, 2014), it is possible that some individuals with TBIs may find it difficult to engage in retrospective interviews, due to the heavy reliance on memory. This is particularly true following a cognitive assessment, as in the context of this study, when individuals will be at higher risk of already being cognitively fatigued (Jonasson et al., 2018). Difficulty recalling and processing information about the retrospective experiences could then lead to lower quality data being collected regarding the experiences themselves. Difficulty engaging with the interview may also feel threatening to the participant, and could impact rapport between the participant and interviewer, which may in turn influence the participants' and interviewers' responses within the interview.

An alternative methodology to retrospective semi-structured interviews which was considered was a think aloud method (Van Someren et al., 1994). Think aloud methodology has previously been utilised in psychological research which aimed to explore cognitive processes during problem solving tasks (Charters, 2003), and in research which has aimed to explore the way in which questionnaires are processed, thus evaluating their use in particular populations (e.g. Johnstone et al., 2006). This method involves participants being presented with a task and being asked to 'think aloud' throughout completing the task, verbalising their thoughts as they come into their mind (Charters, 2003). In traditional think aloud methods (e.g. Van Someren et al., 1994) the qualitative data gathered is analysed using a priori codes, in a 'top down' analysis.

More recently think aloud methodologies have been adapted to be used to explore individuals experiences of completing particular tasks. For example, think aloud methods have been used to explore the cognitive, emotional and physical experiences of individuals while completing different intensities of exercise (Marien, 2017) and while playing videogames (Tan et al., 2014). Other researchers have also suggested that think aloud methods can be adapted based on the epistemological position of the research and the specific goals of the research (Koro-Ljungberg et al., 2013), for example by analysing the data collected in using a ‘bottom up’ analysis, such as thematic analysis.

Traditional think aloud methods do not advocate for the use of ‘probes’ during the task being undertaken, apart from neutral probes such as “keep talking” if required (Charters, 2003). This is because probes are thought to distract participants from their cognitive processes in the moment. However, in adapted think aloud research which has focused more on exploring experiences, probes have been included in the protocol, in order to gather more detailed information about participants’ experiences or thoughts in the moment (e.g. Marien, 2017).

While the use of an adapted think aloud method would reduce the reliance on memory processes and allow more access to ‘in the moment’ thoughts or ideas compared to the retrospective interview method; the increased cognitive load of processing the ACS tasks while verbalising their thoughts may be particularly difficult for participants with TBIs. It has previously been noted that individuals with cognitive difficulties can find think aloud methods with no prompts difficult to complete, due to the extra cognitive load of verbalising thoughts while processing a cognitively demanding task (Johnstone et al., 2006), which lead to limited data collection. Indeed, Ahmadi et al. (2022) utilised an adapted think aloud methodology when exploring the experiences of TBI survivors using social media and found that the inclusion of regular prompts and more directive questions was helpful with this population. Therefore, based on guidance from Johnstone et al. (2006), prompts during and between tasks, if required, were used in this study to support participants to verbalise their experiences.

Expert by experience involvement in the study design

During the design process feedback was sought from five experts by experience from a social media support group for brain injury who volunteered to offer their thoughts on the project. These individuals engaged in telephone conversations with the researcher, offering their views on the design and the pros and cons of the think aloud versus retrospective interview methods. Given the wide range of cognitive difficulties experienced by people following TBI, the individuals consulted felt that participants may find one of these methods preferable based on their own difficulties or strengths, which is also supported by the literature above. Ultimately, four out of the five experts felt that it would be best to employ both the adapted think aloud and semi-structured interview methods, allowing participants some flexibility in the use of these to best suit them.

Research Design

To meet the study aims and considering the literature discussed above, discussion with the research supervisory team and the feedback from the experts by experience, this study utilised a cross sectional qualitative design, including a combination of adapted think aloud and semi-structured interview methodologies. Participants were asked to complete the ACS, during which data was collected via the adapted think aloud methodology, utilising flexible prompts between tasks, or in response to observed visual cues. Following completion of the ACS, participants were asked to take part in a short semi structured interview to further explore their experiences and retrospective reflections.

Ethical Approval

Ethical approval for this study was granted by the NHS HRA and Health and Care Research Wales (HCRW) on 12/12/2023; IRAS number 308165 and REC reference 23/NW/0338.

The committee advised clarifying that participants would require access to a computer device (or willingness to attend in person to use one) and that this would not be provided in cases where the study was to be completed remotely; the participant information sheet was revised accordingly. The committee asked for more detail regarding the ACS and what completing this would involve for participants, a document describing the requirements of each task was provided.

Ethical approval was then granted by the NHS Research and Development (R&D) department of a local NHS trust. Ethical approval was requested from another local NHS trust R&D department, however unforeseen delays in this process resulted in this being incomplete at the point recruitment was completed. Inclusion and exclusion criteria utilised in this study ensured all participants could clearly demonstrate consent.

Sample and recruitment

Due to the qualitative nature of the study, formal sample size calculations were not viable. Rather, sample size was estimated based on being large enough to meet the study aims and to reach saturation of themes, while also resulting in a manageable amount of data to be analysed within the project time frame. Research of a similar nature often uses sample sizes of less than 10 participants (e.g. Owen, 2012). However, due to the varying nature of the analysis used in these studies (IPA) and the analysis utilised in this study (reflexive thematic analysis), this study was deemed to require a marginally larger sample size (Willig, 2008). Ultimately this study aimed to recruit a sample size of between 10 and 15 participants, which is within guidance from a review which suggested that theme saturation will likely be reached between 7 and 19 interviews, depending on the amount and depth of the data collected (Hennink & Kaiser, 2022).

Inclusion criteria:

- ≥18 years of age
- Have sustained a Traumatic Brain Injury (self reported)
- Fluent in English language
- UK resident
- Willing and able to provide informed consent
- No physical disability which would prevent ability to engage in remote online assessment
- Access to a device appropriate for completing the ACS if taking part from home (laptop, PC computer, tablet with separate keyboard and mouse)

Exclusion Criteria:

- Unable to complete consent procedures and/or study outcomes due to legal incompetence or insufficient mastery of English, as determined by their treating professional (if recruited through NHS service) or the researcher (if recruited through study advertisement).
- Receptive or expressive aphasia (as the ACS is not adapted for severe language difficulties)
- They do not provide informed consent.
- Under 18 years old
- Visual impairment which would impact ability to complete ACS tasks
- No access to device appropriate for completing the ACS (if participating remotely)

The research team acknowledge that the exclusion criteria constrain the sample greatly compared to the general population of TBI survivors, which highlights one limitation of using the ACS with this group. However, this is also true for many cognitive screens which are currently used to assess TBI survivors, and therefore represents a wider issue.

Participant recruitment

Several streams of recruitment processes were used within this study to ensure the recruitment of a sufficient number of participants for meaningful results.

1. Headway

Headway is a national charity organisation who support individuals who have an acquired brain injury. The researcher attended a local headway support group based in Wakefield, with the consent of the group organisers. The researcher discussed details of the study and shared recruitment materials (e.g. posters and participant information documents). Individuals who were interested and met inclusion criteria were asked to contact the researcher outside of the group if they wanted further information or to ask questions, following this written consent was obtained and an appointment for data collection set.

A recruitment advert giving a brief overview of the study and inclusion criteria was submitted to Headway (UK brain injury support charity) following discussion with their research lead about the current study. Unfortunately, this was not published on the Headway website prior to recruitment ceasing. Headway cited a backlog of requests for study participants as the reason for this.

2. Social media (Brain Injury Support Groups)

A recruitment advert giving a brief overview of the study and inclusion criteria was submitted to Brain Injury Support group pages on social media platform Facebook with the consent of the page administrators. The study was shared in three UK based groups, ranging from 350 to 17,000 participants in each group. Those interested in participating were asked to contact the researcher directly, following which an appointment was made for an initial contact (either via telephone or videocall) to explain the study and for the researcher to check participant eligibility. Participant who expressed interest in the study but did not meet inclusion criteria had this communicated to them sensitively by the researcher, they were thanked for expressing their interest. Participants who met inclusion criteria and agreed to take part completed the written or electronic consent form and a subsequent appointment was set for data collection.

3. NHS Services

The study was advertised within an outpatient neurological rehabilitation team in Barnsley. Eligible patients were planned to be identified by a member of the clinical team (e.g. clinical psychologist, physiotherapist, occupational therapist etc) and asked whether they would like to hear more about the study from a researcher. This initial contact was to be in clinic during a follow-up visit, or via phone call or letter sent by the clinical team for those patients who were not attending clinic regularly. Unfortunately, no eligible service users who were interested in the study were identified by the clinical team during the recruitment period.

Participants who agreed to take part in the study through any of the above recruitment streams could choose to take part via several methods. Face-to-face options included taking part in an NHS clinic room, in a private room at the university of Leeds, or in a private room at Headway Wakefield. Participants also had the option to take part remotely via videocall. These options were discussed with all potential participants during recruitment procedures, and described in the participant information document. Overall, nine participants completed the study remotely and one took part in person.

Measures

The Amsterdam Cognition Scan (ACS)

The ACS is an online digital battery of neuropsychological tests which can be completed remotely, without supervision, using a computer or other digital device with a keyboard and mouse. It was originally developed for use in oncology research at the Netherlands Cancer Institute, University of Amsterdam. A British English version of the ACS platform has been developed in collaboration with the University of Leeds, with norm scores from the general UK population available. Creators and owners of the ACS have granted permission for its use in this study.

The ACS includes seven validated subtests which are based on already well established traditional ‘pen and paper’ neuropsychological tests. The tests included in the ACS are designed to assess a range of cognitive functions, including processing speed, attention, working memory and learning, and executive functioning. The test takes approximately 60 minutes to complete, and each subtest includes an instruction video alongside demonstration and practice examples. The ACS was designed for individuals with minimal computer literacy and there is no requirement to download any specific software, only a standard browser and internet access is required to access the ACS.

While the ACS was originally designed to be used within oncology, the cognitive domains it assesses are also commonly impacted by TBI (Rabinowitz & Levin, 2014). While the ACS does not cover every domain which could be impacted by TBI, this is also the case with other cognitive screening tools which are commonly used, such as the MoCA and ACE-III, which were also developed for use in other populations, such as dementia. The ACS was therefore deemed appropriate for this study, to use as a tool to gather information on TBI survivors' experiences of a remote digital cognitive assessment, rather than to validate the assessment itself within this population.

Interview schedule

The semi-structured interview schedule (Appendix B3) was developed using guidance from Charters (2003) paper on the think aloud method and Paterson and Scott-Findlay's (2002) discussion paper on using qualitative interview methods with survivors of TBIs. The research team discussed the development of the interview schedule on several occasions, refining this each time. It was developed with aim to elicit thoughts and reflections related to TBI survivors direct experiences of completing the digital cognitive assessment (e.g. 'how did you find completing the assessment?') as well as perceptions of the ACS itself (e.g. 'what did you think about the instructions?'). The schedule also included questions which aimed to gather information relating to context, to support the researcher to make meaning of the results. This included asking about average computer use, and screening for gender and socioeconomic background, as these factors have been demonstrated to have the potential to influence the results of cognitive assessments (Hyde, 2016, Noble et al., 2007), and are associated with variations in technology use (Goswami & Dutta, 2015). Questions pertaining to whether they had previously completed any cognitive assessment, and their perceptions and experiences of these were also included. The interview schedule was developed to be used flexibly, to support data collection related to the research question, while also allowing space for participants to share their reflections spontaneously.

Procedure

During the initial contact, participants were informed that the interview would be expected to last approximately 90 minutes, but meeting slots would be booked for two hours to allow for breaks or extra time if participants required this. Once a participant had returned a completed consent form, the researcher sent the participant a link to an online Microsoft teams meeting for the agreed time. For the participant who completed the study face-to-face, the study was explained at the support group, and a time was organised to meet at the

Headway centre to take part, the consent form was completed before the commencement of the face-to-face testing session.

At the beginning of the online meetings, the researcher re-introduced themselves and the outline of the project. The aims of the session, as being to explore their experiences of completing a remote digital cognitive assessment, were also reiterated. For participants taking part remotely, the researcher asked what kind of device the participant was using, to ensure it was appropriate for completing the ACS. It was explained that the session would be recorded, so that the interview could be transcribed and later analysed, and that following this the videos would be destroyed. The researcher abided by ethical guidelines, explaining the procedure for recording, confidentiality, the use of the data collected and participants right to withdraw at any point during the interview without this affecting their care elsewhere.

Once verbally confirming consent to continue, the recording was started, the researcher informed the participant of this and asked the participant to re-confirm their consent verbally for the video. The researcher then asked the background and pre-interview questions (see Appendix B3). The researcher then explained the think-aloud protocol before sending a link for participants to begin the ACS in the chat function of Microsoft teams. The participants then started the ACS and think-aloud interview. The researcher provided prompts where required such as ‘what are you thinking now?’, and made notes of observations to support sense making and analysis of the interview data. On completion of the ACS and think-aloud portion of the interview, the researcher offered participants to take a short break before commencing the retrospective portion of the interview. The researcher then asked the retrospective semi-structured interview questions and participants were given opportunity to ask any of their own questions. The participants were thanked for their time and the recording was ended.

Interviews were transcribed smooth verbatim by the researcher. During transcription, non-verbal observations were included such as tone of voice, and physical actions e.g. ‘wide eyes’ or ‘hands over face’ which were used to complement the data and not analysed separately. While it is acknowledged that these are subjective to the researcher and will influence interpretation, this is the nature of qualitative reflexive analysis, and it has been suggested that these can add valuable insights and support understanding of the data (Henderson, 2018).

Analysis and Epistemological Position

Researchers credentials

I, Mrs Rachel Evans, BSc Msc, was the lead researcher for this project, which was completed as part of my Doctorate in Clinical Psychology (DClinPsy) Thesis. I was a Trainee Clinical Psychologist during the design, data collection and analysis phases of the project. At the time of final write up and submission, I am working full time in an outpatient neuropsychology service. At the time of write up, I have experience of using both qualitative and quantitative research methods from previous research projects and service audits completed during the DClinPsy and my MSc course. As lead researcher, I designed the study, obtained ethical approvals, conducted the interviews, transcribed the data, led the analysis, and led the write up.

I was supported by my supervisors, who made up the research team, Dr Charlotte Baker, Consultant Clinical Neuropsychologist and Senior Teaching Fellow in Neuropsychology, University of Leeds and Dr Florien Boele, Associate Professor of Medical Psychology, University of Leeds.

Epistemological position

In designing the current study, I reflected on my own ontological and epistemological position and remained mindful of this, and the study aims (to capture TBI survivors' experiences of completing a remote digital cognitive assessment), when considering the most appropriate methodology to adopt. I would place my own ontological beliefs between those of realism and idealism, falling slightly more towards idealism, in that I believe there are aspects of reality which are universally true, and which exist independently of ourselves and our minds, however, I believe that this reality is experienced and accessed through the lens of individuals' values, ideas and experiences. My epistemological position falls between pragmatism and interpretivism, whereby participants would experience an objective reality or phenomenon through the lens of their own values and ideas, and the researcher will interpret the data gathered through their own ideas and values and that this allows for a useful reflection of reality to be understood. Pragmatism's emphasis on the importance of utility and accessibility of acquired data and knowledge also resonates with my own beliefs. The current study therefore utilised a qualitative approach, to capture and make meaning of the nuanced detail of participants' experiences.

Given my position, I am also mindful that my past experiences will have constructed my own lens, through which I process and interpret information, and that will be the lens through which I analyse, interpret, and make sense of the data. Given this, I believe it is important to reflect on some of the experiences which have contributed to the shaping of my lens. I first encountered neuropsychological tests on a work placement year in a paediatric neuropsychology service during my undergraduate psychology degree. I observed and learned how to administer these assessments carried out with children suffering from a variety of neurological conditions, including TBIs. At the time, it struck me that many younger children appeared to enjoy these assessments, and view them like games, while older children and parents or carers often appeared to express worry, anxiety and sadness.

Later in my career, I administered neuropsychological tests and cognitive screens in a variety of settings, including on an inpatient neurological rehabilitation ward and as part of an outpatient team based on the same ward. I witnessed the distress that these assessments could evoke, particularly for individuals who were becoming aware of changes or difficulties with their cognition in that moment. However, I also observed the relief some people, and families or carers, expressed at understanding why they were struggling to cope with activities of daily living, and the hope experienced when cognitive rehabilitation strategies, which were based on feedback from cognitive assessment, were implemented and worked for them. I was working within this service during the beginning of the COVID-19 pandemic, and experienced the frustration of families and service users who could not access cognitive screening or assessment, which they had been referred for, due to social distancing restrictions. During this, I gained first hand experience of the significant limitations of trying to use face-to-face cognitive tests remotely and of the significant lack of literature pertaining to remote digital cognitive assessments. I believe that ultimately, these experiences fuelled my drive to complete this research. I aimed to have an open and neutral approach to interpreting the data while also acknowledging that I used my experiences to help make sense of the results.

Reflexive thematic analysis

The current study aimed to investigate TBI survivors' experiences of completing cognitive assessment, specifically in a digital and remote format. Research questions (which are described in more detail in chapter 1) are broad and exploratory in nature, with examples including:

- What are the TBI survivors' views on the digital cognitive assessment?

- What emotions and thoughts are experienced by TBI survivors ‘in the moment’ when completing an (online remote digital) cognitive assessment? What about the assessment process evokes these reactions?
- What do TBI survivors perceive the benefits or limitations of online digital cognitive assessment to be?

When determining the most appropriate data analysis method, several methods were considered, including interpretative phenomenological analysis (IPA), as this had been utilised in some others studies exploring the experience of neuropsychological assessment which were identified in the literature review (e.g. Owen, 2012). However, given the broad exploratory nature of the research questions, it was believed that reflexive thematic analysis (TA), as described by Braun and Clark (2006; 2019), would allow a valid systematic, yet flexible approach, which would also allow a depth of analysis that could offer valuable insight into the questions posed. Moreover, TA allows for identification of explicit and nuanced or implicit meaning within the data collected, which is further strengthened by its emphasis on researcher reflexiveness. This was considered particularly beneficial in the current study which aimed to explore complex and nuanced experiences such as ‘in the moment’ thoughts and emotional responses.

Therefore, in line with my epistemological position and the study aims, Reflexive Thematic Analysis (TA), as described by Braun and Clark (2006; 2019), was implemented to analyse the data. Braun and Clark (2019; 2021) advocate for a flexible and creative approach to qualitative data analysis, encouraging researchers to immerse themselves in the data, and embrace their reflexivity and subjectivity, noting that these are fundamental in making meaning of the data and generating knowledge. Braun and Clarke (2019) offer guidance around the practical steps to be taken when conducting TA, but also state that *‘epistemological and ontological assumptions inescapably inform analysis’* (Braun and Clark, 2021) and recommend that researchers reflect and explicitly report on their own theoretical assumptions which have guided their analysis, as I have done in the section above.

Themes were developed through an inductive process, as they were derived from the data in a ‘bottom up’ manner. Microsoft Word was used for coding the data, the researcher installed a macro which allowed codes, comments, and quotes to be extracted and transferred into Microsoft Excel for further analysis, and refinement and organisation of codes into themes and subthemes. The researcher read the transcripts numerous times to familiarise and immerse themselves in the data, this was also supported by the transcription process where the researcher re-watched the videos of the original interviews. The researcher highlighted sections of the transcripts pertaining to the research aims and added codes and comments relevant to each highlighted section. After the analysis of six transcripts the researcher met with the research team to discuss emerging themes and subthemes, codes were also discussed and refined at this point. After the coding of all transcripts and the development of the final table of themes, the researcher read each original transcript again to ensure that all information was captured within the codes. Anonymised quotes were extracted from the transcripts and included within the results to add depth to the description of the (sub)themes.

Analysis was carried out according to the steps recommended by Braun and Clarke (2006; 2019), and in line with their suggestion that analysis should be a fluid and iterative process, the researcher moved back and forth between steps throughout the analysis process to establish final conclusions for write up. A brief overview of the steps is provided below:

1. Familiarisation and immersion in the data: Immersive engagement with the data, including transcribing, reading and rereading the data. Keeping notes of initial thoughts and observations.

2. Generating codes: identifying specific important sections of the data which relate to the research question(s) and marking these with relevant descriptive or interpretative codes. Each transcript was coded several times, codes and relevant data extracts were then collated in Microsoft Excel. Data coding in this study was completed by the lead researcher.

3. Generating initial themes: reviewing codes and collating these into broader themes which represent something important about the data, and its meaning, as it links to the research question. This involved collating initial codes into broad themes, and reviewing the data to establish whether the themes appeared viable and representative of the data.

4. Theme development and review: Continually checking emerging themes against codes and across full transcripts to establish whether they capture the key elements and result in a credible narrative which addresses the research question. At this point themes which appeared to be closely intersecting were combined, while others were split to best represent the emerging meaning being made from the data.

5. Refining, naming and describing themes: defining themes by providing a clear narrative of each theme, and assigning these a representative name. Themes and subthemes were also organised, using post it notes, into a visual thematic ‘map’ (Appendix C4), to establish how these best fit and interrelate together in the overall results narrative. This map was discussed with the research team and an educated

layperson to ensure the narrative was clear and made sense to an individual who was not directly involved in the research.

6. Reporting: writing up a clear report, which provides a clear account of the analytic process, a coherent written narrative of themes and subthemes, addresses the research question, includes data extracts to demonstrate themes, and places the knowledge gained from the analysis in the context of the relevant existing literature.

Dissemination

Recommendations based on the current study are provided after the discussion and are applicable to a broad audience, including clinicians, academics and any other interested party. Summary emails will be sent to participants who consented to this, and to the local clinicians and R&D departments involved in recruitment. Any feedback from these sources will be considered in the process of writing up for potential future publication. Results will also be disseminated to the developers of the ACS, to provide feedback on how survivors of TBI experienced the assessment. An electronic version of the final thesis transcript will be made available online via the White Rose eThese repository, which can be accessed by the public for free.

Results

Participants overview

During the analysis phase the researcher met with supervisors on several occasions to discuss analysis progress and to reflect on and refine emerging themes and subthemes. Theme saturation was reached after coding of ten participant transcripts, nine of whom were recruited through online brain injury support groups, and one who was recruited through a local Headway peer support group. All participants self-reported having sustained a TBI at some point in their life, with the time between reported injury and interview being between 1 and 27 years. Injury severity was not recorded due to an inability to verify records, though through participants' descriptions of their injuries and subsequent recoveries, all ten participants' TBIs would likely be considered at least moderate or severe, for example all participants reported prolonged periods of loss of consciousness and extended hospital admissions, including neurological rehabilitation. Participants all identified as white British and ranged in age from 27 to 59 years, seven identified as male and three as female. There was large variation in laptop or computer use between participants, ranging from less than one hour a week to over 60 hours a week. Confidence in computer use also varied across participants, with most participants reporting at least being confident in using a computer or laptop for day-to-day needs, such as online shopping, using Microsoft office and sending emails etc. One participant reported that they would likely require some support with these day-to-day tasks on a computer, however, would be confident to do these things on another device such as a smart phone. See Table 3 for a summary of participant demographics.

All participants were able to complete all subtests of the ACS independently within 75 minutes. On two occasions a participant repeated instructions for clarification, which the researcher acknowledged as correct e.g. '*this time the numbers need to be backwards, right?*', no direct support with tasks was offered.

Table 3. Summary of participant demographics

Participant	Sex	Age	Time Since Injury (years)	Avg. computer use per week (hours)	Recruitment pathway	Participation method
1	M	45-50	13	3-5	Online	Remote
2	M	55-60	16	20	Online	Remote
3	F	55-60	1	7	Online	Remote
4	M	25-30	3	>60	Online	Remote
5	M	50-55	1	1	Online	Remote
6	F	45-50	27	10-15	Online	Remote
7	F	45-50	4	15-20	Online	Remote
8	M	30-35	3	<1	Second Chance	Face-to-face
9	M	40-45	7	10	Online	Remote
10	M	50-55	18	1-5	Online	Remote

Thematic Analysis results

As discussed in the method section above, the researcher utilised their reflexivity, and previous experience of administering cognitive assessments clinically, to support their analysis and to help make sense of themes and subthemes as these emerged from the data. The researcher's previous experiences allowed them to be sensitive and compassionate during the interview process, while also allowing the researcher to be more deeply immersed and to connect with the data during analysis.

Through analysis, three core themes were identified which focused on 1. Previous experiences which impact how the cognitive assessment is experienced; 2. In the moment experiences: emotions, thoughts and reactions during the cognitive assessment and interview; 3. The use of remote cognitive testing for TBI in the future. Within these core themes, nine subthemes were identified. A summary of themes and subthemes is presented in Table 4, below.

Table 4. Summary of themes and subthemes.

Theme	**Subthemes**
1. Previous experiences which impact how the cognitive assessment is experienced by participants.	1.1 Story sharing, sense making and feeling understood 1.2 Previous experiences of care post TBI including cognitive testing 1.3 Adjustment to the cognitive impacts of TBI 1.4 Adjustment to the impact of TBI on identity
2. In the moment experiences: Emotions, thoughts and reactions during the cognitive assessment and interview.	2.1 Emotions experienced during testing 2.2 Factors influencing emotional responses during testing: acceptance, perspective and context.
3. The use of remote cognitive assessment for TBI in the future.	3.1 Potential benefits of remote digital cognitive testing in TBI 3.2 Potential limitations of remote digital cognitive testing in TBI 3.3 Importance of considering individual differences and holistic assessment

Theme 1. Previous experiences which likely impact how the cognitive assessment is experienced by participants.

Although the research question aimed primarily to explore ‘in the moment’ experiences of participants when completing the ACS and previous experiences of cognitive testing, with the interview schedule reflecting this in its focus, many participants discussed an array of experiences relating to their TBI and personal life journeys throughout the interview. These past and current experiences clearly held important meaning to participants, which is also in line with the researchers previous clinical experience of administering cognitive assessments, where service users would also share previous experiences, and these were considered highly relevant in making sense of their experiences of completing cognitive testing in the context of the current research, thus it is imperative that these experiences are considered here. Initially, when completing analysis and developing themes, it was debated whether these narratives warranted explicit inclusion within the results, given that they could be considered not directly linked to the study research questions. However, while reflecting on previous clinical experience of working with survivors of TBI, it was felt that individuals' narratives are often incredibly meaningful for them, and that hearing these allows for rapport building and the development of a shared understanding of their perspectives of themselves and the world more broadly. These perspectives offer essential context in which to interpret the data pertaining more directly to the research questions, such as the 'in the moment' experiences, and therefore are also essential and contribute to answering the research questions in this study.

1.1 Story sharing, sense making and feeling understood

The interview schedule asked participants to share a brief overview of their injury, if they were happy to do so, to confirm inclusion criteria that they had sustained a TBI. However, the vast majority of participants spoke at length and in detail about the circumstances of their injury and subsequent recovery processes either during the interview or during discussion pre interview when considering participation in the study. As discussed above, it was felt important to include aspects of these narratives to offer broader context to the following themes and subthemes. Moreover, listening to these narratives, and being compassionately curious during these conversations allowed the researcher to build rapport with participants, likely further impacting their experiences during the cognitive assessment. Participants offered vulnerable and personal accounts of their experiences, and in line with the researchers own clinical values, it felt unjustified to exclude these from the results.

It was evident that the events of their injuries had been incredibly traumatic for many participants, with several discussing experiencing flash backs and nightmares, and that sharing their experiences of sustaining and recovering from their injuries and having this be heard was important for them. All participants shared their individual narratives, which varied hugely in content, but across participants four were involved in road traffic accidents (RTAs), two were involved in serious assaults and other injuries were sustained through a variety of other incidents. Specific identifiable details of participants' stories will not be shared here to retain their anonymity.

Some participants discussed broader philosophical ideas such as 'fate' and reflected on decisions made at time of their injury, e.g. one participant discussed making a last minute change of decision to wear a motorcycle helmet, and reflected on the potential consequences of their accident had they not made this decision.

Other participants discussed trying to make sense of the circumstances surrounding their injuries but struggling with this due to memory loss:

> *"…wish we'd taken photos, because now every medical programme that comes on all right, is that what I looked like? They go no you were worse. I'm like, well, OK. All right. And then once I actually got somebody up with a brain injury, take a picture taken in hospital. He went. That's what you look like. I went oh, Jesus wow… I don't wanna see a picture of me like that."* (P5)

> *"No, I don't even remember the event at all. That's just the weirdest thing… Because literally… I mean, I have had no recollection whatsoever. The only reason I know what happened is because people who were there told us what happened."* (P10)

Several participants also spoke about the impact of their injury on family, with one specifically reflecting on the trauma this caused them, discussing feeling guilt and relying on family to support them to make sense of what happened to them:

> *"they've [family] got to live with that person. When that person comes out of that coma and it's no different, but he's like, what happened? Dunno can't remember….They [family] remember. They [family] remember every minute of it."* (P5)

Overall, this subtheme reflects participants desire to share their story, and the way in which they have made sense of what has happened to them, and to have this be heard and understood by the researcher. These conversations allowed the researcher to build rapport with participants, and to have a broader understanding of the participants' experiences, providing a lens through which the rest of the data pertaining to current experiences and experiences of cognitive testing could be understood.

1.2 Previous experiences of care post TBI including cognitive testing

Many participants discussed their experiences of hospital and subsequent care that they received following their TBI and in their recovery journey. When developing subthemes, particularly pertaining to previous experiences, it was the researchers clinical experience that previous experiences of care may influence how individuals experience any interactions or assessments associated with clinical care, including cognitive assessment. Therefore, it was felt important to explicitly explore and include these experiences when participants discussed these, again to offer important context to understanding their current thoughts and experiences. Previous experiences of care and support, and thoughts around this may have contributed to some participants desire to take part in the current research, this will be discussed further in the discussion. Experiences of care were mixed between participants, though many discussed feeling as though they were left to attempt to manage and adjust to the significant impacts of their TBIs with little support. Many discussed feeling as though they were discharged prematurely, or that the complexity of their needs or the impact of their injury was not understood and managed accordingly, particularly on discharge from acute or inpatient hospital care.

> *"... I literally would not have got any support because there was nothing there was, you know, I was sort of discharged out the door and off you go. So after two weeks in hospital, I was on my own. So, yeah … Googling as I did a lot rehab plan … Googling rehab plan for traumatic brain injury…"* (P3)
>
> *"I mean, yeah, it was great up until I left hospital and like fizzled out. And then I had a year wait as well. Like, I was with my mum's for a year before they recognised that I need extra care. So it was kind of like a huge gap before they recognised it."* (P4)
>
> *"Like my experience with the NHS ... is like the second you're out of the coma. If you can talk and you could eat and you can somewhat clean yourself, it's straight out of the hospital like it was a very quick like come out of my coma then like the second I was able to like just slowly walk I got left then I had a psychologist, a clinical psychologist. She was only with me for like 3 weeks when I got out of hospital and the same with my OT."* (P4)
>
> *"…I think there's a lot more that needs to be done with people… explaining to people with brain injury… What it's going to be like and what's going to happen. And what you're going to go through and whether its right and whether it's normal? I think a lot more can be done that way…"* (P5)
>
> *"And I was in for two weeks. I think it was after the first week I turned around and made a point about the fact that my nose kept running. But well, you know, that'll happen with as I know, but it's actually crystallising. Don't think it's just normal mucus stuff, you know. And then they did a test, and it was with cerebral fluid coming out… And then after a couple weeks, I was released. I went home…It was pretty bad. I mean, I've just thought it would take us a couple of weeks and that I'd be fine.*
>
> *And I was just sleeping on my mum's couch…but I was just forgetting everything and I was getting confused and I would wake up and I didn't know where it was." (P10)*

One participant spoke at some length about the difficulties they had experienced with lack of service provision and a deep sense of feeling invalidated and unheard by services when attempting to access support for cognitive and mental health changes associated with their TBI and associated trauma. This participant was tearful throughout this discussion and expressed feelings of anger towards the care system. Other participants also expressed frustration and anger when discussing their perceived lack of support and resources available:

> *"Oh my God. I was like, my God, surely there must be something in this day and age?! I can do an Ultramarathon training plan [online], for God's sakes, why can't I do a brain rehab training plan?! Yeah, there isn't anything …. (P3)*

Some participants discussed positive experiences of neurological rehabilitation services, and finding these helpful in their adjustment to their TBI, expressing gratitude towards these for supporting them to adapt to the impacts of their injuries, particularly understanding what their difficulties were.

> *"I've done these sort of tests. I'm pretty sure at [rehabilitation unit], during my rehabilitation. Obviously I did some to work out where my flaws were…which did help me alot. It's short term that's knackered. I can remember things from years back and I'm piecing together things 'cause I'd forgotten so much of my life…"* (P1)
>
> *"…I think for me because I've been discharged now only recently [from a community neuropsychological rehabilitation service], but I was discharged out now I feel a lot more confident and comfortable doing things for myself."* (P9)

Nine of the ten participants interviewed discussed that they had previously engaged in some form of cognitive testing, all of which had been conducted in a face-to-face setting. Some participants reported that this was in inpatient settings and some discussed travelling to outpatient appointments for this testing. Recollection of previous experiences of testing appeared to vary between participants, as did their emotional experiences of these. Some participants discussed finding cognitive testing difficult and this evoking emotions such as anxiety, frustration and anger:

> *"…You know, so that that was the words were hard, hard and then she gave me this map. And I've got a thing about maps. I love maps. Always have done since I was a kid. I think from my dad used to drive everywhere. I'd always I'd read a map looking for a football ground. OK… and this map of this safari park and it's like you've got to go and see them. You've got, you've got to go and see the lion and the tigers and then the bears and then the penguins… shop there like cafe there and you've got to work your way out… I was getting a right hump with it. I could have literally volleyed that test all about the dining room with the of the hospital…"* (P5)

Another participant used sarcasm while discussing their feelings towards tests they had done in the past which felt similar to subtest of the ACS:

> *I: Have you done one like that before on paper?*
>
> *P9: On paper. Yeah. And I hated it.*
>
> …
>
> *I: Have you done any tasks a bit like this, you know when you did your stuff [testing] before?*

> *P9: Not this task, I don't think. I've done a similar one with blocks and creating the different shapes for the blocks which is absolutely…*
>
> *I: The red and the red and the red and white blocks?*
>
> *P9: Yeah, yeah, yeah. That one. Yeah…It's good fun….I don't actually mean that.*
>
> *I: You don't mean that?*
>
> *P9: No. [laughs]*

Other participants discussed aspects of previous testing they had done to feel somewhat patronising, or simplistic, and that this appeared to have felt unhelpful at the time.

> *"She placed three things of mine around a room and I had to remember where they were, but I was like, well, that's quite simple. How? How bonkers would you have to be to not remember that my keys were over there because I know I need my keys…"* (P3)
>
> *"I can't think of the word, but it's like we're not as daft as we ******* look sometimes. I mean, some of them are a bit. They make you feel like am I really that deformed or ******* stupid sort of thing."* (P1)

A couple of participants reflected on previous testing in a tone which suggested they had some positive experiences, and one directly expressed that they had enjoyed previous cognitive testing and that this had been stimulating in a positive way, despite being aware testing was also likely to highlight potential difficulties or impacts of their injury.

> *"… I enjoyed them when I was in hospital as well because it just felt like I was doing something. But also testing whether I could still do something and I didn't know at that point whether I could, so yeah."* (P7)

1.3 Adjustment to the cognitive impacts of TBI

Many participants discussed the cognitive impacts of their TBI, and these varied between participants. This subtheme was developed and included in the results because an understanding of participants' perspectives and reflections on their own cognitive changes and how they have adjusted to these was felt by the researcher, based on previous clinical experience, to be an important aspect of the context in which their direct experiences of cognitive testing could be understood. Interestingly, there did not appear to be a link between time since injury and the way in which participants discussed their adjustment, though it may be important to note that all participants were at least one year post injury, and thus none were in the acute phase of recovery.

All participants discussed some changes to their cognitive function as a result of their injuries. All identified memory as a specific function which had been impacted by their TBI, with other functions such as processing speed, executive function and attention being identified by some participants. Some participants also discussed physical impacts, with most participants expressing that they are fully aware of the cognitive and physical changes associated with their injuries that they are accepting of these.

> *"…my particular issue is remembering words and names and things like that but I don't for some reason I don't appear to have any issues with the numbers, so that is just the way it is I guess…. I struggle with words, just just kind of remembering words and picking the right words from what I want to say and stuff."* (P2)

> *"But yes, my memory's a bit dodgy now. And like I walk when I walk, it's a bit dodgy. I don't don't particularly walk the greatest" … " Yeah, but I guess you know catch 22, I had free brain surgery and they save my life. So I'm not really complaining if that makes sense. You know, like I'm just chilling is, is what it is."* (P4)

> *"… So I've got facial palsy and I've also got double vision. Which was torsional, but I've had the torsion fixed, but it's still double.. left side affected weakness…couldn't walk, couldn't do anything, really. Couldn't walk, couldn't eat. I've learnt to do all of that now. I still at this stage still have mobility issues and I still have issues with coordination. And some….I can't think what the word is…Like cognitively. I'm generally fine, everything's a lot slower and I have issues with… [executive function]"* (P7)

Some participants gave examples of their awareness of their cognitive difficulties and how this impacts them in everyday situations, such as in social situations with friends or at work. Some participants also reflected that they are conscious of their cognitive difficulties and how this might be perceived by others.

> *"… you know, like sometimes I'm talking to people and I just forget what I'm thread of the conversation or particularly if I'm tired or if I'm distracted by something. And then I'm like, oh, what was I talking about, you know, and or I lose thread for a for what feels like to me a long time. And then I pick the conversation up again… But because I've noticed it then it makes me more aware of it. So then you know, then you forget stuff."* (P3)

> *"I've been to HR meetings since my injury, I've had some HR meetings I literally can't remember. I came out the room and I have no idea what we just talked about. In fact, one I came out and I thought it's been sacked at the end of the month and that wasn't the conversation with that at all apparently…"* (P3)

> *"I can't do it still just remembering my pin number's difficult enough and if I have to ring the bank and they give 4 digit account, just even remembering that I struggle with sometimes."* (P7)

Despite most participants discussing that they are aware and accepting of the impacts of their injury, some also discussed or implied that this process happened over time, and pointed out some changes in perspective which allowed them to become more accepting of their difficulties.

> *"But when they can't do some tasks and I think it's changing a mindset, isn't it? So you're not, you're not stupid. It's just you've got a disability and makes things a lot harder for you. So yeah. And I think, I think I've said it when people seen there in doing group tasks just going I'm just an idiot. I'm stupid. You know I can't do these things…It's like, no, you're not. You've got a brain injury."* (P9)
>
> *"…now I've learned to just accept it. It doesn't really frustrate me as much. If I can't do something. I just admit it now and I just can't do it, just got to accept it and get on with it. But if you're new brain injury, that would annoy you because you think I should be able to do that…and then you find out you can't. You get yourself mad because you think, I should be able to do this..."* (P8)

One participant discussed the very early stages of their recovery, when they first noticed that they were experiencing cognitive difficulties, and how this had been unexpected and frightening:

> *"My memory was horrendous. I would start, I would start cooking food and even a bird flying past the window would be enough to distract us and I would actually just walk away from cooking food and that set the kitchen on fire about three times in the week. So I thought oh **** maybe I should just go and spend a bit of time with some family."* (P10)

The same participant had linked their emotional reactions at this time to their early expectations of their recovery. They reflected on their expectations of their recovery changing drastically over time, and the emotional challenge of accepting that the impacts are likely to be lifelong.

> *"It was pretty bad. I mean, I've just thought it would take us a couple of weeks and that I'd be fine….and I mean that was 18 years ago now… the effects are still hitting us hard at the moment…"* (P10)
>
> *"At that state where I'd kind of made the realisation of all these things that were problems and then trying to work out how to deal with those problems. Because if you know the first couple of years like, that's fine just being a bit daft. So that actually that's not going away, you know…"* (P10)

There was a clear sense of grief and loss at times when some participants discussed the cognitive impacts of their TBI and their adjustment to these over time. Though this was not always explicitly discussed by participants, this was felt in their implicit use of language and expression during discussions about change or loss of function with the researcher, particularly when comparing previous ability to current functioning.

> *"Yeah, this is something I wouldn't have struggled with pre-brain injury. When I was younger, I mean, I probably would struggle a bit being nearly 50, but I know I wouldn't of…words would have been my forte… You know English and words were the things I was good at…and I had a very had a very good memory."* (P6)
>
> *"Oh, I was struggling at the end there, those numbers… I used to be able to remember loads of telephone numbers. [sighs]"* (P6)
>
> *"It's short, it's shorts term that's knackered. I can remember things from years back and I'm piecing together things 'cause I'd forgotten so much of my life…"* (P1)
>
> *"Yeah, memory's really not my strong point anymore…"* (P4)

Most participants discussed perceptions that the cognitive impacts of their TBI changed over time, usually referring to improvements in function between the more acute stages of their injury recovery and now.

> *"If you if we'd have done this test in August…It would have been a lot longer…and a lot more…Oh, I don't get that. I don't know that…I don't… you know, 'cause that was only a few months after the actual accident itself."* (P5)
>
> *"I'm OK now, but I know if I'd done this a couple of years ago…they would have just blown my mind to just drag my focus to it." "I'm much better now than I was…"* (P7)
>
> *"…I would say a little bit easier, but it was probably about a year and a half ago, a year and a half to two years since the last time I did a test. So it's been a long, long time….and so I think I I've made a lot of improvements."* (P9)

Some participant also discussed continually trying to encourage positive changes in their function with their own actions, such as practising with games which involve using cognitive functions.

> *"I know that my memory's got a lot better. 'cause I do a lot of I play a lot of memory games and stuff like that, so I've got lots of things on my phone to try and and I'm always trying to push myself on that."* (P10)
>
> *"Hard but… I try and play tetris and that everyday on me phone to try and help us with my brain, so it did help a little bit that, yeh"* (P8)
>
> *"I mean, from doing it [digital puzzle game] at [rehabilitation centre], I since redid it. I've I redownloaded it. [shows Ipad on camera]. I thought I wonder if I could do*

> *any better than last time 'cause…I'm not too bad on it now, although I've got further on it and it gets more and more difficult sort of thing..."* (P1)

Many participants discussed learning and using cognitive strategies to support their cognition and reduce the impacts of their TBI day to day. Participants discussed using multiple different methods, usually referring to memory strategies, such as writing lists, using their phones, and were also observed using chunking and stories during testing. Most participants who discussed these reported that they were effective in helping them to cope with the impact of their injury day to day.

> *"I've kind of got into the habit of recording all the tasks down into my phone, so I've got a a special notes pad notes section in my phone where I write my tasks that I'll need to do, and then I've got them set up at like a check box, so I'll check them off as I go…and that definitely works pretty well…If I don't use it, it's like I. It's like not using walking stick with someone with one leg…"* (P9)

> *"I think the fact that I find it easier is because I have the skills to be able to do it. I think when I think back to after my accident and when I was in rehab…they got me to use the computer there to try and see if I could still type…and I just, I know I just. I wasn't with it… I wasn't…I didn't have the skills… it took me very long while to get to the state I'm at now. Yeah, I can function in the real world."* (P7)

As well as strategies to be used independently, some participants discussed an increased reliance on others, particularly family and close relationships, to support their cognitive function. There was a sense that relationships were impacted by the consequences of participants' TBI, and that this was not just an adjustment for the participant but for those around them too. There was a sense that participants harboured feelings of gratitude towards those who they rely upon, but also feelings of guilt.

> *"Put it on this they they, my family's journey was far worse than mine…I'm the one who nearly died, but they had to watch that. And if you…if somebody says to you right heres tickets to go and watch somebody in a coma. Oh, a loved one in a coma, you know, there you go. It's not going to be nice."…" You know, my wife has become my brains and ears.*

> *And she'll explain things 'cause.. she'll look at me and go like you haven't got a clue what this means do you? And I'm going…no, I don't really. What was it like, actually about? Right. If that… then she will break it down."* (P5)

> *"I met somebody [a year after injury] and we were together, living together up until last year, so she helped me through my recovery and was also a major part of my mechanisms of how to deal with day-to-day stuff, we split up last year and and I'm having to relearn how to do everything by myself again...and all the things that I*

> *thought I'd actually got on top of and was capable of managing… It's it's kind of hit home again hard now, yeah."* (P10)
>
> *"But I did set this up myself today. So I've done things previously and not been able to to…my husband has to do it, he has to help me… but I've set the laptop up myself."* (P7)

A possible difficulty of a reliance on others was highlighted by one participant when they reflected on their family's early expectations of their recovery, and lack of understanding of the long term cognitive and emotional impacts of TBI, suggesting that family would expect more than the participant was able to do at the time, and this being frustrating and emotionally difficult for the participant.

> *"They didn't know how to support me…I found family were like that, to be honest. Family would be…like, alright, it's been…It's been a while now…You know you... You're better now, aren't you?... If this had put me in a wheelchair, would you tell me to get up and walk?"* (P10)

Another participant made reference to having their cognitive abilities compared to others during their recovery, and specifically a comment made by a professional and how this had been unhelpful for them in their adjustment and expectation of themself. They had been referred to as 'high functioning' and there was a sense that this increased feelings of pressure on themself, and increased distressing emotions when they struggled to complete tasks due to the impacts of their TBI.

> *"I know there were some people that I was in rehab with, who cognitively wouldn't have been able to have followed any instructions or done any of it, and that might be just a case of they wouldn't go through this cognitive test anyway, but. But I guess…I was always told I was high functioning...which really wasn't necessarily helpful, but hey…"* (P7)

Overall, it was clear that an understanding of participants' experiences of adjusting to the cognitive impacts of their TBI would be crucial in understanding and reflecting on their experiences of digital cognitive testing in the current study.

1.4 Adjustment to the impact of TBI on identity

Alongside the variety of cognitive and physical impacts of TBI, many participants also implicitly and explicitly reflected on the impacts that their injury has had on their sense of self and identity. Again, while this subtheme may not explicitly link directly to the research questions in the current study, the information presented here offers valuable insight into participants' views of themselves, offering context, which was felt by the researcher, to be essential in making meaning of their direct emotional experiences during cognitive testing, as well as their broader perspectives on digital cognitive testing, thus, it is included here. Several participants reflected on ways in which they perceive that their personality or lifestyle has changed, and this often came with a sense of grief or loss.

> *"That's the thing. I was always the life and soul of the party, you know, I mean, when I was running pubs, if those fights and stuff like that, I could diffuse the situation using my words. You know, I could always make it make it funny and silly and stuff like that…*[Now I can't]*"* (P10)
>
> *"It's it's strange 'cause in my head… I still think like I did before. I still… I've had to kind of learn that I can't just do things that I did before because it I won't succeed or fall over or… Yeah, I don't…. Life is very much slower now… Yeah, I know my confidence level for anything is is like rock bottom now, so..."* (P7)

Some participants discussed the impact that their injury has had on their ability to engage in activities which they had previously found meaningful, again sharing a sense of sadness and loss when reflecting on these.

> *"At the same time, I was doing lots of Zumba, so I actually became a Zumba teacher for children. So I used to teach Zumba to kids, which I loved…So obviously the Zumba business I had to close and I can't even, I don't know if you've ever done Zumba, but I can't do a Grapevine. I can't do anything. I don't have the coordination to be able to see it…"* (P7)

While there was a strong sense of grief and sadness when participants discussed the impacts of their injury on their identity, there were also moments of hope where some participants discussed ways in which they had found new meaning in activities, this was often related to supporting others with disabilities and brain injuries.

> *"It's the [name of organisation]. Now it's a it's a place that you can go stay…they have chalets and they have rooms on the inside, the buildings and stuff like that. But they do things like archery, zip lines as well. It's all…It's all disabled friendly, so it's all designed for people with disabilities and stuff, so people have got head injuries no matter what their ability levels they go there. And I've been there…I've been there as a therapist and as a relaxation [guide], because as I'll do like yoga, nidra and things like that. So I've been there for the last five years."* (P10)

One participant discussed their involvement in running local support groups for those with brain injuries and in research projects with veterans with PTSD when initially discussing the study during the recruitment phase, making further reference to this during the interview.

> *"I ran my local [organisation] group and I was involved in a suicide study at northern [inaudible] and I'm interested in research in all different areas."* (P1)

Another participant reflected on building skill in videogaming, sharing that they found enjoyment in this and spent long periods playing due to not being able to work stating:

> *"I'm a master video gamer now."* (P4)

Some participants discussed their experiences of their TBI resulting in altered perspectives on life, which supported their overall adjustment and wellbeing, for example, expressing gratitude to still be alive, and considering themselves 'lucky' when considering alternative possible consequences of the incidents which led to their injuries.

> *"Life is very much slower now…but I do still have a life, and that's the important bit."* (P7)

> *"I've met many people who have got all different brains injuries in the past and I'm yet to meet someone who's had my sort of injury but come through as lucky as I am so."* (P1)

Several participants reflected on the importance of peer support in their adjustment journeys, this was often related to third sector organisations, or online support groups, indeed one participant was recruited from a peer support group which they attend regularly, and the remainder were recruited from an online support group, where each interacted with the page regularly.

> *"I think that's why going into hospital and being with other people similar to yourself is is beneficial in that way."* (P9)

Some participants reflected on their career or work prior to and post TBI. There was a mixture of experiences relating to this within the participant sample. Some participants had returned to work at the time of interview, which appeared to be important to their senses of self and identity, although participants also reflected on some of the challenges of this.

> *"I didn't have any issue with doing it online, but I'm used to doing stuff online. I work, I work in IT [full time] so that's … I don't know if that makes me a good a good judge of that."* (P2)

> *"I've worked in offices many years ago, but I have been a riding instructor for 20 odd years."* (P3)

> *"But I also then got a part time IT job as well because I realised I was getting older and wouldn't be able to maintain the same level of physicality that I was doing. So I had an IT job as well…but my IT job was for a police force and and they've been amazing. So I do now work. I used to do three days a week. I do now do two days a week….either end of the week so that I could… but it does impact me to the point that I can't do anything else on the days that I work, I have tried splitting up the days as well, but that doesn't really work very well. That just takes me out for the whole four days rather than two days so…."* (P7)

Another participant discussed previously attempting to, but being unable to return to work due to the impacts of their TBI, and reflected on some of the challenges they faced. There was a sense that multiple attempts and perceived failures to return to work had been experienced as traumatic for this participant, these were discussed mostly during discussions at the recruitment phase, though were also reflected on during interview.

> *"Yeah, it's it's when people say to somebody we're bringing when you're having a break. Sure. Let me know or give me a ring. And you're like, well, no, that's not a break to me that I need to be in silence. That was one of the problems when I was at work, there was nowhere for me to go and sit and be silent. I used to go and lock myself on a cubicle in toilets on another floor that I didn't work on … because I just …you know, I remember putting forward is there not a room we could use just for people who want to sit in silence on their break and my rather chatty manager looked at me in horror. And that's one of, you know, one of the reasons why workplaces don't necessarily work for me because when I'm having a break, I need. I have like a shutdown."* (P6)

There was some discussion at times on the way in which participants identified themselves, or the labels they used to describe their own identity in relation to their TBI. The current study had used the phrase TBI survivors, based on feedback from a number of experts by experience, though it was interesting that participants used a variety of other phrases, mostly in discussions during the recruitment phase, highlighting the way individuals likely relate differently to their injury and experiences. Common phrases used included 'person with a brain injury' and brain injury 'sufferers' and 'survivors'. During the interview, one participant reacted quite strongly to the use of the phrase sufferers, which they were reflecting had been used in the past, and referred to themself as a 'nutter'.

> *"Brain injury sufferers? I don't like the word makes it sound epic. Yeah. Brain injuries? Yeah, brain injury nutters would to be about right. [Laughs]"* (P3)

Theme 2. In the moment experiences: emotions, thoughts and reactions during the cognitive assessment and interview.

2.1 Emotions experienced during testing.

Participants had many different emotional experiences while taking part in the current study, with these appearing to fluctuate throughout the assessment and interview. Some of these emotional experiences were explicitly discussed and identified by participants, while others were inferred, using clinical judgement, through the researcher's observations of participants implicit behaviours while completing testing and during interview.

One of the most commonly occurring emotions during testing was frustration, and even at times what felt like anger. It was clear that all participants experienced a sense of frustration at some point during the assessment, with many directly identifying this in the post testing interview.

> *"The frustration only comes in little bits when you think oh God that's not right…"* (P5)
>
> *"Especially in the recall tests when it's is… I did find myself getting quite frustrated."* (P9)
>
> *"That one was starting to annoy us, I didn't think it was going to end."* (P8)
>
> *"…The memory, the memory one was frustrating…"* (P10)

Frustration was also evident in the observed responses and self-talk of many participants during testing, and this appeared to particularly prominent during tasks which were perceived as more difficult.

> "*What? Pissing me off* [under breath to self]" (P1)
>
> "*this is so annoying*" (P4)
>
> *"Bollocks, I've forgotten it. [sighs] … Oh. God… That one is wrong."* (P5)

There was a strong sense that participants experienced frustration when they perceived that they were struggling with a particular task, though which task varied between participants. However, all participants specifically identified the list learning task as being particularly challenging, with most also citing the box tapping and digit span tasks, which was in line with the observed reactions of many participants during this task.

> *"So that one needs to be a second … do that…so why is it the second move, which I'm kind of finding the hardest? I think I've done it actually… oh Nah, that's got to be there. Crap….*[places hand on head and shakes head]*"* (P9)
>
> P8: *"That goes there, so that goes there, wait no [laughs]…That's if we put that there just put that there….That there put that there….Uhhhhh [laughs]…I don't know how to do this now….I've f***** it…Put that there…. Hang on, how do you restart this now?"*
>
> *I: Can't restart this one*
>
> *P8: "Urgh, How do I get off the bottom though? Errm **** sake [shakes head]"*
>
> *"Did I put wine in?... Now I've over complicated myself...I don't know what I've put in. I don't know what I've remembered. [hand on head]"* (P10)

Feelings of frustration also appeared to be increased when some participants attempted to use cognitive strategies when completing the tasks, but struggled to implement these or found them to be ineffective, thus still perceiving themselves to struggle with the task.

> *"…it's a little bit frustrating as well 'cause you think you got your strategy right? Try to kind of follow it …[then] it just disappears out of your head."* (P9)
>
> *"Do you know it's really it's really hard. 'cause. You start at the start, you kinda repeat them, repeat them, repeat them, repeat them, repeat them. You're thinking I spent so long trying to repeat them three. I can't Remember the next 4. And then your head's gone, and it's just like, literally … None of them stay in. [sigh]"* (P5)
>
> "*I kind of can't…devise a strategy that works… which is I guess the idea of the testing itself, but…ugh* [sighs]" (P7)

Participants' experiences of frustration tended to be directed towards themselves, rather than the test, and this linking to the desire to be able to 'do better' and an awareness of their cognitive difficulties, that although many reported being accepting of, having these explicitly highlighted reignited feelings of frustration and anger.

> *"Come on, come on, come on [to self] [hits forehead with hand]…. Ahh you muppet [to self]"* (P10)
>
> *"Its hard to explain…I guess maybe annoyed at myself that I couldn't have done better."* (P2)
>
> P9: *Especially in the the recall tests when it's is. I did find myself getting quite frustrated… I'm a pretty laid back person anyway, so I don't tend to get angry with myself, but frustration is definitely something I did experience, yeah.*
>
> I: *does that feel like frustration like with yourself or frustration sort of with the test or both?*
>
> P9: *With myself…Definitely with myself, but then again, I've kind of been living with this injury for quite a few years now, so I'm kinda use to those frustrations.*

Throughout the cognitive testing and interview some participants also expressed a feeling of sadness, which appeared linked to a sense of loss of abilities they may have previously had. Several participants explicitly discussed how completing the digital cognitive tests highlighted ways in which their brain injury has impacted their cognition and placed a spotlight on their difficulties which led to uncomfortable emotions.

> *I: How does it feel now?*
>
> *P6: It's it's not nice. It's. Yeah, it really illuminates…you know the difficulties you have at times.*

> *"Its nearly 28 years, you know? So you know I can see a difference [in cognitive function]. And yeah, there's some things going on. I'm not too bad with that. And as I say, yeah, just some of it was like, alright and then others it was a bit upsetting." (P6)*

> *"Yeah, I mean, but I felt retarded a few of the times, but I use that word a lot. Like, yeah, I use that word a lot. I don't mean how everyone thinks. I mean it. I just use it. But no, I felt it there at some point… like its just like unable. Like just why can't I remember?"…"I know I have memory loss, but it only comes up like twice in a day. Like when you start doing activities that require severe brainpower, you then start to realise how haven't quite got it there, if that makes sense. It's just humbling. Yeah, its just very humbling. That's the only way I can really describe it is. It's humbling."…" because it makes you realise, like actually you're not as able as you think you are. Because here's the data and you've just proven it."* (P4)

> *"This [ACS] makes you think of what you can't do anymore."* (P3)

At other times, a sense of sadness was felt through participants implicit reactions during testing, while difficulties were clearly being highlighted.

> *I: How did it feel that time round?*

> *P8: Hard, because I can't remember that many words. You try to start and remember them, and then because you're focused on trying to remember the first ones, the next set and the last set its just like a blur [sighs]*

> *" [sighs and places hands over face] this is ridiculous… I can't remember anything…No….They're all gone. I can't think of any Rachel."* (P5)

> *"I don't know what I've put in. I don't know what I've put in. I don't know. I don't know. I've written in what I've remembered. [hands over face]"* (P10)

There were moments in testing for some participants where there was a sense of feelings of disheartenment or defeat, particularly when they were really struggling, or at times when participants decided to 'give up' on a task.

> *"Yeah, knowing that there's eight numbers coming, it's almost like makes me think I'm just not going to remember it. I'm just like there's no point because I'm not going to remember 9 numbers or 8 numbers, you know, so… I could remember 6 numbers, but then I wasn't sure if I got those muddled up and then they were still empty empty boxes at the end. I was like 3…3, you know. So I didn't even try and remember what… what it was. I just I just knew I couldn't remember it so."* (P3)

> *"I'd get to a point where I'm thinking, but I can't do this anymore. Like the numbers it, but I know, by about five I'm kind of done with remembering. I can't remember anymore. So I give up trying."* (P7)

> [participant stuck on a single trial for several minutes] *"I was just trying to work out how how to do it…so now I've gotta move the black one underneath the Grey one. I just don't know how to move it [sighs]."* (P9)
>
> *"The hardest one was the words that was just…that felt like swimming in treacle. Just getting absolutely nowhere…"* (P5)

Although the test clearly evoked some uncomfortable emotions in participants by highlighting some of their difficulties, some participants also reflected on their awareness that this would be the case and acknowledged the importance of this related to the purpose of cognitive testing, to allow people to understand their cognitive changes, strengths and weaknesses.

> *"Yeh but that's part of it isn't it [being challenging]… if it was a 10 minute test then you wouldn't get what you need out of it."* (P8)
>
> *"I guess some of it, I felt quite overwhelmed slightly with some of the memory test types things… but I guess that's part of the testing, is to kind of push people a bit and get them out of the comfort zone maybe."* (P2)
>
> *"So you know that to me, that is a sign of how good it is. And I'll admit…the tests aren't easy, but. But you don't want them easy, cause easy, doesn't give you any yourself readings about, you know, about a brain injury. You wanna…yeah."* (P5)

Interestingly, only one participant explicitly discussed having feelings of anxiety or worry as a direct experience of digital cognitive testing and shared that this had been prior to taking part and appeared to be linked to uncertainty about what to expect from testing, and an apprehension that the tasks may be difficult or that they may not be able to complete some or all of the cognitive test.

> *P7: Yeah, I didn't get frightened by it a bit by the look and feel of it, which was what I was kind of quite worried about.*
>
> *I: When you just said, you said that you'd been frightened that it might be…scary or it might feel frightening. I don't know if can you tell me a bit more about that?*
>
> *P7: Yeah. Before today, yeah, just before today, but…I no not frightening as such, but a bit worried. I know previously and I've done them because they I wasn't very confident in what I could and couldn't do… but I did find it really fine.*

While many participants did not explicitly discuss feelings of worry or anxiety, most did appear to show observational signs at times. Almost all participants exhibited nervous laughter, particularly at times when they were struggling, or perceived that they were going to struggle with a task.

> [reading instructions for delayed word list] *"Bastards [laughs]"* (P9)

> [list learning instructions play] *"Oh god [laughs]"* (P8)
>
> *"I think I failed that. [laughs]"* (P10)
>
> *"I'm so crap at this one [laughs]"* (P3)

Several participants also used self-deprecating humour, or sarcasm, and this also appeared to be linked to moments of anxiety, frustration and other more uncomfortable emotions.

> *"Yeah, just rubbing that in there. 'cause obviously…obviously people with head injuries have struggled sleeping, so you know. [laughing] … So yeah, just telling us how everybody's having a lovely night's sleep there. That's what we need.* [laughing]" (P3)
>
> *"Can you see smoke coming out of my ears?* [laughs]" (P1)
>
> *"It's it's…yeah, I just like, go everywhere [attention]. I'm a nightmare. [laughs]"* (P4)

Some participants described feeling 'overwhelmed' while completing the ACS. However, this appeared to be reflective of being cognitively overwhelmed by a task, rather than feeling overwhelmed by emotion, although this also appeared to be an emotionally unpleasant experience.

> P6: *And and then as some of them went on and there was more words or more numbers, it was just like. Ahhh [pulled wide eyed face and gestures with hands]…Yeah.*
>
> I: *A bit overwhelming maybe?*
>
> P6: *Yeah, yeah, yeah, definitely*
>
> -
>
> *I: What are you thinking, how was that?*
>
> *P9: Yeah, there's a lot going on there….Yeah….I kind of I felt initially I had a bit of a a strategy going. It's just it kind of overwhelmed, overwhelmed me. That's probably the best thing to way to describe it. Too many things, flashing different locations and quite hard to follow it if that makes sense. Yeah. I just... Yeah, it's just I... I just felt overwhelmed. Basically. Yeah.*
>
> *"I think the only thing was probably that intro video by the end of it I was like Christ what the hell was she saying before? And I was… because I was trying to think of…right…. I forgot what she'd actually said. I wasn't listening to the end of it. Because I was focusing trying to think, OK, and I forgot what she's just said and then I didn't hear what she was saying. And I was like, Christ was that important? [laughs] Yeah, it was… It was a lot of information. I mean, I guess you've got, I know*

> *you've got to have it and you've got to get people these information, but yeah, it was kind of like woah…too much." (P10)*
>
> *"I guess I guess some of it, I felt quite overwhelmed slightly with some of the memory test types things." (P2)*

One participant did appear to discuss feeling overwhelmed by frustration, and this being linked to the test highlighting their cognitive difficulties following their TBI. This participant discussed feeling aggravated and what appeared to be mental turmoil, and this leading to thoughts of wanting to stop testing, but also being motivated by a desire to finish and to take part in the research.

> I : *What does it feel like for you when the task is quite hard, like when you're finding it hard?*
>
> P5: *Do you know what it's…. It's as if aggravating 'cause it, it's a hard test. You know, as I said, I wouldn't have struggled before the accident, but it's like, oh, oh God [raised voice], you just you kind of you think, right, I'm off….I'll stop...then oh, no, no, go. No, no. It feels very… You know, uncontrolled, like you've just kind of been [makes wide eyes and motion shakes hands around head].*

Another emotion expressed by some participants was surprise, or shock, which was usually related to expectations of the test, either based on previous experiences of testing, or based on practice subtests during the digital test. There was also a sense that at times of shock this was related to a task where participants had felt a sense of confidence, and this changing to feeling daunting or suddenly becoming more difficult.

> *"The initial doing the numbers in order was a shock. The practice test is only kind of half a dozen numbers. Then when the actual test comes on, it's about 20 numbers. So took me by surprise early…"* (P2)
>
> *"I was kind of surprised that that was all kind of in order rather than randomly in box."* (P2)
>
> "[completing trial task connect the dots] *this one is fun…* [full trial appears on screen with many more numbers] *Oh shit* [wide eyes]…" (P4)
>
> *"So with some of those boxes where you had to go and follow the line and then the test was like 4 boxes and then there was like a gazillion on the screen. It was a little bit like ooooooh you know… crap you know.* [laughing]" (P3)

Along with the emotions discussed already, which would generally be considered unpleasant, there were also moments within testing and interview where some participants expressed or exhibited more positive emotions, such as happiness, enjoyment and feelings of self-confidence. These emotions appeared to be experienced at times when participants were perceiving themselves to be doing well on a subtest, increasing their feelings of confidence in themselves. Some participants were observed to be smiling at the times, as well as observed to stop critical self-talk which had been present for many participants when experiencing frustration (discussed above). Some participants also explicitly discussed that they experienced enjoyment while completing the digital cognitive test, or perceived the test to be ‘fun’.

> *“… Now I'm.. I'm thinking. I think I've got them all there actually…Think I got them all* [smiles]*” … “Jogged memory is way better, I'll get all of these now…Beautiful, yes.* [smiles]” (P10)
>
> *“Quite happy that I did it right with the numbers cause I've got as I said, I'm OK with numbers, it's just words. I struggle with a bit.”* (P2)
>
> *“…this is good, this is fun” … “some of them are quite fun, some of them aren't” … “that was good, good fun, I wouldn't… Yeh I would do it again…”* (P4)
>
> *“I enjoyed doing it, I really did enjoy doing it”* (P8)
>
> *“it was enjoyable… I do feel absolutely shattered now…”* (P5)
>
> *“Yeah, I actually enjoyed them…I did enjoy them in hospital as well because it just felt like I was doing something”* (P7)

2.2 Factors influencing emotional responses during testing: acceptance, perspective and context.

While it was clear that some emotional responses were linked directly to the experiences of testing, such as highlighting cognitive difficulties or perceived strengths etc. it was also evident that the emotional responses evoked during testing were influenced by multiple other interplaying factors, many of which were directly reflected on by participants.

The first of these was conceptualised as acceptance of the impacts of brain injury, which included participants' awareness of their cognitive strengths and difficulties, and their level of comfort with these, which participants also often linked to the time since their injury. Observationally though, across participants, variation in this did not appear to correlate with time since injury. Many participants explicitly discussed how they believed that this had an impact on emotional experiences of testing, with several reflecting on how they felt this might have been different under different circumstances, suggesting that less time since injury, or reduced levels of awareness and acceptance would have led to much more intense emotional experiences.

> *P8: I think if you were new in a brain injury, that would annoy you. But because now I've learned to just accept it. It doesn't really frustrate me as much. If I can't do something. I just admit it now and I just can't do it, just got to accept it and get on*

> *with it…but if you're new brain injury, that would annoy you… because you think I should be able to do that…and then you find out you can't. You get yourself mad. Because you think, I should be able to do this, but...yeh*
>
> *I: Yeah. How do you think it would have felt if it had been 2/3 years ago doing this?*
>
> *P8: Ohh that would have made me walk out the door now, yeh.*
>
> *"… every time I laughed, I went..Oh, yeah, the things that I know that I find difficult. But if you're still unsure about what you find difficult and you're doing this as a way to discover that. You wouldn't be laughing."* (P7)
>
> *"Like I fully accepted my injury, so like I'm cool with it. But like there are some… because I live in a care home and they're like… there are some people here that if they… if they did the test, it would upset them for the next two or three days because it makes you realise, like actually you're not as able as you think you are.* (P4)

Further, participants' perspectives on their difficulties, and their ability to be compassionate to themselves appeared to be a factor which influenced their perceived ability to cope with uncomfortable emotions. However, participants who shared reflections of this nature did not observationally appear to experience emotions such as anger, frustration, and sadness any less intensely during testing.

> *"But it's, you know…I think if you've got a brain, if you've got a brain injury, there's not, you know, don't be…don't be too hard on yourself for not getting it."* (P5)
>
> *"I think it's it's changing a mindset, isn't it? So you're not, you're not stupid. It's just you've got a disability and makes things a lot harder for you. So yeah. And I think, I think I've said it when people have been there in doing group tasks just going… 'I'm just an idiot. I'm stupid. You know I can't do these things.' It's like, no, you're not. You've got a brain injury." (P9)*

Another factor which was reflected on by many participants was the context in which cognitive testing was taking place, and the impact that they believed this would have on the emotional experience of testing. In the current study, it was made clear to participants that there would be no recording of scores, and that their 'performance' on the measure was not part of the research questions. Several participants reflected on how testing in this situation meant there were minimal, if any, perceived 'consequences' and that this likely influenced their emotional experiences of completing cognitive testing, specifically reducing feelings of pressure, stress and anxiety which might have been present in a clinical context.

> *"I'm sure if if people were under the like realisation that this could be a judgement of how they score on or whatever. Like say whether whether or not it gets them further appointments for some other sort of clinic or whether it's even for benefits and stuff like that. I think that's a lot of pressure."* (P10)

> *"So you know how much of the cognitive stuff and and there's no… obviously it says in the beginning of this, there's no pressure. It's just there's no scores kept. So I'm, you know, laughing as I'm doing it. But actually if it…if there was an impact to the results, whether it's…I don't know getting your driving licence back, which I don't have mine yet, but you know. Whether it might be driving, getting your driving licence back, or whether it's, I don't know, a work… going into work, whatever it might be. But if there's like a direct impact, then that would also have an effect on how you feel about it."* (P3)

> *"Doesn't have any consequences if you if you mess up like there's nothing at all…I mean you. Yeah, they are testing you but… I've done similar things to this like in neuro rehab, I'm trying to get back to work. There's quite a lot. I feel. I'm like … I've got a bit of pressure on. I wanna perform to the best I can. I mean, I I still do now, but I don't have the extra pressure of if I do badly then…work might not take me back."* (P9)

While the research context was considered to be an important factor influencing emotional experiences of cognitive testing by most participants, some reflected that due to personal perspectives on testing and what this means to them, that context did not have a big, if any, impact on their emotional experiences while completing the test.

> *I: Do you think it would have felt different if this had been like part of your clinical care or part of something that was kind of you were going to get your scores and it was going to mean something?*
>
> *P10: For me, no, because if I'm doing a test, I'll always. I'll always challenge myself and I'll always…I know no you're going to do this… You're going to kick the **** here. So I have to try and score the highest I possibly can because I'm a pain in the butt. But I think…I don't think the fact that it wasn't being scored made a difference for me, but at the same time….I'm sure if people were under the like realisation that this could be a judgement of how they score on or whatever. Like say whether or not it gets them further appointments for some other sort of clinic or whether it's even for benefits and stuff like that. I think that's a lot of pressure.*

> *I: Today, and it was just having a go, it wasn't recording any scores, you know, it was just to see how you find it. How do you think it might have felt if you were doing this kind of assessment as part of your care? You know, when you kind of have scores and they were going to mean something. Do you think that would have felt different or?*

> *P7: I don't think it would have done, I think. Yeah, no. Yeah. The uncertainty of whether you've answered it right or wrong or whether you've taken too long or that's still there now whether it and it was before it, that doesn't change…doing it online*

Individual personality factors were also reflected on by some participants, which appeared to influence individuals emotional experiences, for example, one participant referred to themselves as ‘perfectionist’, and another as generally ‘self-critical’ and this appeared linked to increased observations of frustration when these participants had difficulty with tasks.

> *“…just making sure that I try and doing everything that it says and not ******* up sort of thing 'cause I don't… I like perfect me. I'm a bit of a perfectionist. I want things to be spot on.”* (P1)

> *“I'm quite self critical in that in that I realised the issues I have and I'm not particularly comfortable with them.”* (P2)

Several participants discussed the impact of the presence of the researcher on their emotional responses to testing. Participants tended to reflect thoughts that the presence of the researcher had reduced feelings of anxiety and stress, through knowledge of being able to ask questions, or seek support if they were to become stuck, appearing to find this reassuring. Some participants explicitly reflected that these emotions would have been increased had the researcher not been present.

> *“…I mean, even knowing that you were there and still being able to have a little bit of communication was quite relaxing. Whereas if you'd sent that on an e-mail. ‘Can you follow the link and can you do this?’ I could have sat there and then I could have got*
>
> *myself a little bit flustered.”* (P10)

> *“for me, I didn’t mind it, but then I knew you were there, so there’s that…”* (P6)

> *“Erm… I think having you here .. yeh.. it didn’t stress me out as much….because obviously like… I don’t know.. I just feel like … yeh I was calmer”* (P8)

There was also a sense at times that the presence of the researcher and the research context, alongside participants’ beliefs, prior experiences, thoughts about what the interviewer might be thinking, motivations for taking part and own social narratives etc, may have caused participants to moderate the expression of some of their thoughts and instinctive emotional responses, with one participant highlighting this openly.

> *P5: You know, if I'm if I'm done this test with just me, nobody watching me, the amount of swear words that would have been coming out of me, not getting it, getting the right words and…*

> *I: If that's what comes up for you, honestly let them out, because that's that's what we you know, that's what we need to know is how is how you react to it, you know.*
>
> *P5: But you'll be like Oh, my God. He's got the language of a gutter. [laughs]*

Theme 3. The use of remote digital cognitive testing for TBI in the future

3.1 Potential benefits of remote digital cognitive testing in TBI

All participants were able to complete the digital cognitive assessment, with many making comments that the instructions were clear, and that they were able to process and follow these without significant difficulty, despite finding some of the tasks themselves challenging.

> *"The way that the instructional videos were there, just explaining it. Yeah, not a problem. Clear as anything. perfectly understood. Everything that needed to be done. Clear enough, just enough length and not overpowering, but not condescending like some of them are."* (P10)
>
> *"I mean the instructions were very clear and the lady had a very nice voice."* (P2)
>
> *"But I find the instructions easy enough that in that respect you know. Again, as I said, I felt it was user friendly. Yeah. Yeah. I thought all that was done concisely and clearly. You know, it wasn't overwhelming or too verbose, you know, but not too sparse either. You know. It was just enough, you know, for me anyway, yeah."* (P6)
>
> *"Yeah. I mean, I've I thought, like I say, I thought it was quite user friendly. I didn't find it difficult to get into. It wasn't difficult to follow, you know…"* (P3)

Some participants made comparisons between their experiences of completing face-to-face pen and paper cognitive testing and digital cognitive testing, and suggested that the use of a screen and mouse made testing visually clearer and 'easier' to engage with, usually referring to tasks which would traditionally involve drawing e.g. connect the dots.

> *"No, I actually like found in the…Using the mouse made it easier for me to participate. And even today, I'd still struggle with that so.I was left hand dominant but now trying to be right hand dominant and not very good at either. But yeah, so…The fact that I didn't have to use my hands was brilliant, and for anyone who's affected by stroke or any such brain injuries where there's a particular side. If the dominant side is taken away. Yeah, that's really good and useful."* (P7)
>
> *I: Have you done one like that before on paper? [connect the dots task]*
>
> *P9: On paper. Yeah. And I hated it.I find it a lot easier to do on the computer.*
>
> *I: What do you think about it being on the computers making it easier?*

> *P9: I think what the lines I drew are… it's a lot easier to follow, so I think before I did it, I'd go to each number and then I'd I'd look for the next number and then I'll chase my pen following around to that next number. And I think that's something I'd get lost or wouldn't like….Hand eye coordination just probably wasn't quite there.*
>
> *So yeah, and then and then just got really busy and messy and yeah.*

When reflecting on the potential benefits of digital cognitive testing in a TBI population, many participants shared that completing testing in their own home, rather than an unknown or clinical environment, resulted reduced feelings of anxiety and stress, and increased feelings of comfort and relaxation.

> *"It's well, yeah. I mean, it's obviously it's it's always nicer to be at home and stuff like that, isn't it?"* (P10)
>
> *"I would say it's it's a lot more comfortable doing it in your own environment I would have thought. Especially someone like me who's got complex PTSD…so and I'm always on guard. Yeah, I mean I'm sure the majority do have a similar thing."* (P1)
>
> *"Yeah, well, it's great [being at home] 'cause. Yeah. I mean, you wouldn't get me out of the house to do this test if you tried to. Like, if you said I'll meet you at the library or I'll meet you at the hospital. I would have declined, like, so. That's good. Like people… I'm all for that… People need to have to do stuff at home. Yeah. Yeah, that's it. No, but I'm…I'm a lot more relaxed doing it..definitely a lot more relaxed."* (P4)

This was often also linked to the requirement to travel to take part in face-to-face testing, with several participants discussing the requirement to use public transport or plan travel, often over long distances, stressful and anxiety provoking.

> *"That's that's really positive. The fact that, I mean one of one of them I had to go to [hospital], so in London. So that was a a big massive trek and trauma and the anxiety before I even got there. So it yeah, it reduces all of that stress, anxiety and worry and therefore there would be from a cognitive fatigue to actually have to go somewhere and do it this is. Much, much easier."* (P7)
>
> *"I know when I first had me head injury… I used to get very panicky about getting, nervous about driving all the time, and if I was having a bad day, I knew I couldn't drive…but getting on a bus was torture was absolute hell. I mean, at one point I became completely agoraphobic."* (P10)

Some participants also reflected on the cognitive burden of planning travel, using public transport and using maps to find, often new or unknown locations. They discussed how in previous experiences of face-to-face testing this had left them feeling cognitively fatigued even before engaging in any testing, and that a benefit of remote digital cognitive testing would be a reduced cognitive burden prior to and after testing, which may even improve performance.

> *"Doing this as opposed to the other way, it's quite nice being at home and being able to do it at home. 'cause you don't have the same amount of fatigue like you would if you had to like travel like use public transport to get to a hospital to do the test. 'Cause it it's been charged when I've had to go do these type of tests and I'd really like I'd. I'd mess up my travel times or get on the wrong train and it's just and by by the time I get there my my fatigue's through the roof and then sit down and do your your tests and things like that. Then it's just…impossible…Yeah. And it's really hard, but doing it at home without having to travel or anything like that and you're a bit more comfortable, it's a lot. It is a lot better in my opinion."* (P9)

Several participants acknowledged the lack of resource in many NHS services, and reflected on the importance of increasing access to care, including cognitive testing, and suggested that they agreed that remote testing could be a positive step to increasing access to more service users, particularly in TBI populations.

> *"Like especially 'cause, it's so hard nowadays to see anyone like like all the charities like [organisation]. I've been on that waiting list for, like, nearly three months. It's everything so long so people can access these resort resources. It would speed up a lot of things for a lot of people."* (P4)

> *"I literally would not have got any support because there was nothing there was, you know, I was sort of discharged out the door and off you go. So after two days in hospital, I was on my own. So, yeah, I think he having even online contact and tests with somebody is certainly better than having no idea and Googling, as I did a lot, rehab plan, Googling rehab plan for traumatic brain injury."* (P3)

> *"You know this type of thing could maybe mean more people could [access support], but then obviously staff are still needed, you know."* (P6)

Finally, some participants explicitly stated that given the choice, they would prefer to complete remote digital testing over traditional face-to-face cognitive testing.

> *"I think for me…It was quite good because…I was sitting in front of the person and she was able to answer questions, answer my questions. When she was allowed to. [discussing experience of face-to-face cognitive testing] But…I still say I'd prefer to do it in this environment at home."* (P9)

> *"I found this better. [remote testing] … And I found it a lot easier than you know, being stuck in an office with a Busy corridor next to it and you can hear stuff and you can hear bits of conversations and hear certain words you like. Your ears pop up and they want to go out and enjoy it, but, yeh I prefer this way"* (P5)

> *"I think for things like this, I think, you know, online isn't suitable for everything, but something like that for me personally is better. And I'd say quite a few others."* (P6)

3.2 Potential limitations of remote digital cognitive testing in TBI

While all participants were able to complete the cognitive assessment, there was evidence of participants' cognitive difficulties, particularly memory and attention, potentially impacting their ability to retain information during the assessment. For example, several participants commented that they had forgotten elements of instruction videos by the end of them, or that they were struggling with their attention.

> *"The video at the beginning….Although it's obviously it's got to give you all the information….felt very long.I know it has to give you information, but I mean…when you're trying to process by the end of the video, I was like, I've completely forgot what she said before."* (P10)
>
> *"Wow, that was a lot of information in one go. I'll be honest, that was quite um difficult to pay attention to, so I might have missed a bit. Yeah, it was a lot. Yeah. I might have missed a bit, but I've got the general gist, but it was a bit of a struggle to keep attention on that one, but so just for a bit of feedback."* (P3)
>
> *[completing reverse digit span, appearing to forget instructions for task] "Is this reverse or normal order?"* (P4)
>
> *"Interestingly, I don't know if it's interesting, but I went to do that, but I'd actually forgotten what the first one was." (P7)*

Nine of the ten participants completed the assessment remotely from their own homes. A clear limitation of remote testing was highlighted in that, despite instruction videos making clear statements about reducing and removing distraction, the majority of participants responded to multiple distractions during cognitive testing and interview. For example, four participants were distracted by pets, three of which moved away from the computer to intervene with them in some way during testing.

> *"Sorry, Rachel. My cat is trying to join the conversation. Meowing away at me…[picks up cat]"* (P5)
>
> *"…I've got a lot of other extract distractions… like I've got a kid bouncing basketball next door. Got the dog being annoying, running around barking at the kid playing basketball… As that you probably heard when my dog was outside barking that…that was probably the most distracting bit."* (P9)

Other distractions included other people in the household interacting with participants, or distractions directly on the computer resulting in participants attention being divided while completing tasks, such as messaging or music applications.

> *"Yeah, I know. The other thing that's a little bit distracting. I've got a couple alerts that keep coming up on my...My computer like is connected to WhatsApp, so I'm getting WhatsApp messages. They're not coming up on the screen, but they're dinging…They're clicking to save message."* (P9)
>
> *"Yeah, I can't even remember doing that. I might have been faffing around with Spotify."* (P4)

When reflecting on potential limitations of unsupervised remote digital testing, several participants raised concerns about the possibility of 'cheating', malingering or purposely altered performance, particularly when considering the possibility of using remote digital cognitive tests in a clinical context, where there may be perceived implications for further access or care or benefits.

> *"I think if I got a link I would have been OK. I'd have, you know, probably laughed about it. Might have been inclined to cheat a little bit and write down the numbers, but…Yeah, or the words. So I could remember them so and then justified it as coping strategies. You know, that's my coping strategy. [laughing]"* (P3)
>
> *"I don't know whether or not it's for. This is the right way to say it. I don't know if somebody who was trying to say that they were a bit worse than they are could maybe click buttons or something like that, whereas if you're face-to-face you'd be able to read that you'd be able to see that. Yeah, I suppose that'll be the only thing that somebody could make themselves come across worse than they were. If they wanted to."* (P10)
>
> *"I guess for some people it might be tempting…Just to kind of write things down as rather than…I don't know how you police that or whether whether you even want to or."* (P2)
>
> *P7: If I was left to do it on my own…Would I?... I wouldn't ask for assistance, but is that …that then brings in the real people. Then you'd hoped that they would do it because it's about what they can do….How they're cognitively functioning, not people.*
>
> *I: Do you mean? It would like, open some opportunities for people to kind of write things down or use other things?*
>
> *P7: Yes people might think about wanting to do better or maybe worse, depending on their whatever their circumstances are*

Some participants discussed how the use of a screen and mouse would not be suitable for all TBI survivors, for example given the wide variety of cognitive difficulties and the common occurrence of physical disability, or visual impairments, and reflected on how in the digital assessment they completed (ACS) there is not currently any adjustments for this.

> *"The thing with obviously with TBI is that some people have got physical Issues. So yeah, [would be unable to] moving the mouse and stuff like that. But I mean, if somebody's had a stroke and stuff like that and could take them a bit of time…Then yeah, then, then that's that's, you know. Yeah. But I mean, there are obviously some people at varying degrees [of symptoms/physical disability], as you know yourself."* (P10)

> *"I've had quite a lot of interaction with other people, with brain injuries over the years as well with regards to headway and things like that. So I completely understand there's a full scale of…of people's how people are with regards, you know, some people have got limited motor skills and some things and but…And I'm just telling you what you're probably already know so." (P2)*

> *"I know there were some people that I was in rehab with, who cognitively wouldn't have been able to have followed any instructions or done any of it, and that might be just a case of they wouldn't go through this cognitive test anyway, but…yeh"* (P7)

Indeed some participants reflected on their own physical disabilities as a result of their injury, and how they had some impact on their ability to engage in the remote cognitive test.

> *"I mentioned I got issues from my eyesight, so I was having to scan around the screen quite a lot, but it was all generally right in the middle of the screen, so that wasn't a problem for me…I have to take …it takes a bit more energy as well. With regards being aware of what's on screen and where on screen it is."* (P2)

> *"I found the flicking around the yes no button difficult because it goes from right above the words, then below the word. After yeah, I found that difficult that I had to keep moving my mouse button. You know for me it's very much about my vision and there's lots of physical impacts to doing the test before we even get to whether my brain works and how it works."* (P7)

Despite many participants discussing a variety of potential benefits of remote cognitive testing, many also said that they would prefer face-to-face testing if given the choice, often citing face-to-face testing appearing more personable, and less clinical or cold. It did appear that it tended to be older participants within the sample who had a preference for face-to-face testing.

> *"Oh, I'm not gonna lie, I'll prefer face-to-face. I do prefer face-to-face. I mean, even when I was, like, on the other side, listening to people who had head injuries and*

> *stuff like that when covid hit, people were saying, oh, can we do it by zoom and stuff like that? And I was on because I studied hypnotherapy. So I was like, no, because I need to read a person. I need to see them and I need to see the colour changes, whether the breathing changes and can't we do that with the screen, especially when you got to wear glasses."* (P10)

> *"I would prefer the face-to-face one, definitely just personal perspective. Yeah, it's it's, you know, it's more…It's just more personal isnt it, I guess, yeah, yeah. I'm a bit even though I work in IT, I'm a bit old school, in fact I always prefer face-to-face interactions rather than, you know, teams or skype or what or things like that so."* (P2)

> *"So, yeah, I think I think probably face-to-face is probably a little bit more sympathetic or empathetic because you can see what's going on, you can see how that person's reacting, whereas this one is just like bang, bang, bang, bang, bang...you know, which would probably suit some people and not others."* (P3)

Most participants felt that completely remote testing, with no researcher or clinician present, could lead to increased emotional distress, which could be difficult for service users to cope with, particularly if they were to struggle with tasks on the cognitive assessment. While many participants felt that they would engage in this type of testing if asked by a clinician with a clear rationale, there was also a strong sense of reluctance to this.

> *"I think in all honesty the the face-to-face side being it more interpersonal, whether it's be via camera or just sitting across. It's important that you you feel comfortable and turn and say right are you ready to go ahead and stuff like that. And so because I think it was just a very plain clinical here's an e-mail, here is some information click the link do was you what you're told to do on the screen sort of thing. If somebody's unsure about it…Then that's just going to compound any like feelings that I've got as they're going. Whereas when you have this little bit of communication, you can feel relaxed and you get the chance to actually look is this, is this going to be like this or is that something like that? I think that's I think that's important." (P10)*

> *[if sent test to do completely remotely] "Yeah, I would probably try to avoid it to the last minute till I really had to do it." (P10)*

> *I don't know, I think if the doctor sent us it I'd still give it a go. But… they would have to make sure you knew its not a test, its just for the reasons your doing it. I think if a doctor sent me that and then ya started doing it then you just [struggled] … I don't know. Yeh you know I get frustrated very easily, and that would just… be too much" (P8)*

> *"Just to say that that's my computer system stuff. But you know, yes, it all worked really well for me. But actually what happens if it doesn't work? And if you then got to do it on your own and if you're not getting it, then what you do?" (P7)*

> *"I would probably need some explanation as to what is the reason for it and what what the benefits were because…You know 'cause, to kind of be sat at a computer for an hour without any kind of interaction. It's quite tricky to do. Even even the best of times." (P2)*

Many participants also reported that they would be happy to take part in remote cognitive testing as part of their clinical care, but that they would have a strong preference for there to be a clinician present remotely, reflecting the set up in the current research.

> *"I I wonder if it's if something like this will be better as you've done it today sort of supported, even if it's just there quietly in the background. Or to have that option for people to do because I I wonder if Just having that sort of individual attention might just give them you know a bit of support to get through it."* (P3)

> *"I think it's something a bit it's kind of reassuring knowing that if you 'cause, you're there some go wrong. I've got you to rely on. Like, if I couldn't open open the link for whatever reason or I couldn't access teams for whatever, I think that would probably add to the stress…So yeah, unfortunately I think. Yeah, ideally in the ideal world it would be perfect to have someone like yourself on the outside [present during testing]. Yeah, rather than you know [completely remote]."* (P9)

> *"I suppose it depends on the person you know what the circumstances are, you know, it could be encouraging I would have thought, but also I could see the potential for it to be upsetting as well. Yeah, yeah. No. It would…would probably be better with some support attached. I think, yeah….I don't think the human touch should be completely eliminated, no. Yeah, I don't. I don't think that would be beneficial."* (P6)

One participant reported scepticism about the ability of a remote assessment, particularly completed at one time point, to give an accurate reflection of a person's cognitive ability, and that this would reduce the likelihood of them engaging in this as part of their clinical care. There was a sense, for this participant, that lack of confidence in the assessment may also reduce their ability to engage with feedback of results, and the implications this may have for them.

> *I: If someone, you know who's involved in sort of your rehab or something had sent you this and said can you do this at home? And it had kind of... the results would mean something. How do you think that might have felt?*

> *P4: Yeah, not. No, not cool. 'cause this this only measures like 1/2 of it. This only measures your like amplitude through your hand like like you. It's impossible to gauge my memory or my reactions unless you spend like time with me physically. Like I'll forget your name 20 times or something like so. I know these tests are good. They only measure like half of you can't decorate someone's whole picture with a online test.*
>
> *…*
>
> *P4: I think like in order to do like one test, it should actually be 2 tests like 'cause. If we run this test tomorrow again there'll be a totally different set of results because that's how like how. That's how. Like what? My brain injury is specifically. So I think maybe like.*
>
> *I: but if you'd been sent this sort of part of when you're in rehab, how do you think you would have felt about that?*
>
> *P4 :Well, it depends what they're using it for like. For example, a lot of my like therapy and speech and language, all of that. When I when I went to claim the benefits they requested to know like. Like that. So like, let's say I was to do this now and then six months we did another one and the reason one was a lot better if that was to then affect me…like financially, so that when you start using it, it's like clinical. I don't know, I don't, I don't know how much merit this [remote digital testing] would hold like.*

3.3 The importance of considering individual differences and holistic assessment

In relation to the prospective use of remote cognitive testing in a TBI population in the future, almost all participants highlighted the variety of needs and individual differences that exist across this population. Most participants explicitly reflected on the importance of considering these needs as well as an individual’s preferences and wishes when establishing whether remote testing might be appropriate for any single individual.

> *I: When you're doing this kind of assessment, then because you've done some sort of in person and you've had a go at this one, then what do you think are like for you? What are the most important things about it?*
>
> *P7: Definitely the setting…But if you're being asked to complete paper based ones, you can actually have a space to complete them and everyone's perception of what that space should look like is different.*

> *"Yeah. I mean, as you probably know, everyone with a brain injury is slightly different"…" But again everybody's different, aren't they, some people might really struggle with that, some people less so." (P2)*

Several participants also highlighted how computer literacy could impact an individual's experience of, and potentially, ability to engage in remote cognitive testing, and that this should be taken into consideration by professionals.

> *"So again, a mixed bag. But yeah, I I quite liked doing it on the computer. But then again, that depends on the person and their experience with computers and things like that as well. And you know, I'm not too bad on a computer like…You know, you know, I suppose it would depend on the person's experience with computers and stuff."* (P6)

> *"I think so. Familiarity [with computers]. Yeah, I think. Some people might find it a bit more daunting because they're not computer savvy."* (P3)

> *"The only other thought. you need to have quite good mouse skills, don't you to do it. I can understand why you suggested using a proper mouse rather than a touch pad, definitely. …Equally people might have never really used a mouse. Even pre brain injury. You know, not everyone is kind of au fait technology, I guess."* (P2)

Several participants highlighted an importance of being aware of the stage of recovery that individuals may be at, relating this to their awareness of their individual difficulties and the potential impacts that remote testing may have on individuals who are less aware of the cognitive impacts of their injury.

> *"It's just the fact that both and I'm sure they are anyway, but the fact that everyone's brain injury's different, and the earlier they're doing this in their recovery, the less likely they are to know the areas that they have problems with…and just be just to be aware of that really" …"[discussing time taken to adjust to own injury]…outside, for others I guess it depends on. I guess it depends on the brain injury and how long ago it was. It'll be person specific won't it really."…"so it would very much be dependent on the person really and whoever's doing the… Working with them, knowing them well enough that they know they wouldn't be able to do it."* (P7)

> *"Like I fully accepted my injury, so like I'm cool with it. But like there are some because I live in a care home and they're like, there are some people here that if they if they did the test, it would upset them for the next two or three days because it makes you realise, like actually you're not as able as you think you are. Because here's the data and you've just proven it. Like, do you know what I mean? So it's I'm cool. I'm cool with it personally, but I know some people might feel that way."* (P4)

Finally, one participant highlighted specific concerns regarding any single test, but specifically remote digital tests, being used to inform clinical or care related decisions. This participant reflected on the importance of cognitive testing, and remote cognitive testing, being only part of a wider assessment, including discussion and face-to-face meeting, suggesting that this is the only way to establish and accurate picture of someone's strengths, difficulties, and needs.

> *"For example, a lot of my like therapy and speech and language, all of that. When I when I went to claim the benefits they requested to know like…Like that. So like, let's say I was to do this now and then six months we did another one and the reason one was a lot better if that was to then affect me…Like financially, so that when you start using it, it's like clinical. I don't know, I don't, I don't know how much merit this would hold like. I don't know what I'm trying to say…Like this is it's good to measure like measure your like ability, but I don't think the result should finalise anything like in your care like all your medical thing if that makes sense."* (P4)

Although this was not explicitly referred to by other participants, there was a sense when discussing previous experiences of assessment, that participants did value these more when they were perceived as broad and thorough, regularly mentioning the involvement of multiple specialism such as psychology, physiotherapy and occupational therapy.

Discussion

Summary of findings

Despite a rapidly emerging literature pertaining to the development of digital and remote digital cognitive assessments, less is known about service user experiences of engaging in these, with this being especially true in the case of TBI survivors. Indeed, as is highlighted in chapter one, there is a general paucity of research exploring service users' direct experiences of completing cognitive assessments.

The current study therefore aimed to provide insight into how TBI survivors experience: 1) cognitive assessments; 2) digital online cognitive assessments; 3) digital remote unsupervised cognitive assessments. The findings of this study offer new and unique insights into the way in which cognitive assessments, and specifically remote digital cognitive assessments, are experienced by survivors of TBI. Findings highlight considerations for future research and clinical services offering cognitive assessment and supporting individuals with TBIs.

As covered in the results section above, all but one participant discussed previous experiences of completing cognitive assessment in a traditional face-to-face manner. In some cases this appeared to be brief cognitive screening, in others this appeared to be more comprehensive neuropsychological assessment, though this was not always clear and participant recollection was sometimes limited. Participants discussed these experiences interchangeably and it was not possible to discern the experiences of one from the other. Therefore, in this discussion, experiences of previous cognitive screening, cognitive testing and neuropsychological assessment are considered together as experiences of cognitive assessment. This limitation is reflected on further within the strengths and limitations section.

Perceived benefits of remote digital assessment in TBI

Participants in the current study highlighted several benefits of remote digital cognitive assessments, including suggesting that the use of technology made these clearer and easier to engage with (particularly subtests which in traditional face-to-face testing would have involved drawing e.g. connect the dots in the ACS vs trail making from the DKEFS). Indeed, previous research has suggested that digital cognitive assessments have benefits such as more consistent and clear presentation of material (Bauer et al., 2012; Spreij etl al., 2020).

Over half of the participants in the current study expressed a preference for remote digital testing over the traditional face-to-face methods they had encountered previously.

Though less of an overwhelming majority, this is generally in line with Feenstra et al.'s (2018) previous finding where approximately 97% of 225 cancer patients who answered the relevant question selected a preference for completing online remote testing from home, compared to testing in a hospital. This difference may be explained by the higher prevalence of more significant cognitive difficulties in TBI survivors compared to cancer patients (with non CNS tumours) (Wefel et al., 2008).

Participants who cited a preference for face-to-face cognitive testing tended to associate this with feeling more personable and comfortable for them, these participants also tended to be older. This may be linked to the age-related digital divide, whereby older adults, particularly over the age of 60, are more likely to have reduced access and familiarity, lesser skills, and more negative attitudes towards digital technologies, compared to younger adults and adolescents (Heinz et al., 2013). Future developers of digital remote cognitive assessments could therefore consider adaptations which have been shown to improve accessibility and acceptability in older adults, such as large text, simplified visual interfaces and human interaction where possible (Mannheim et al., 2019). This is also supported by Robillard et al.'s (2018) findings, where older adults completing a face-to-face digital cognitive assessment emphasised the importance and value of human interaction during the testing process.

The current study found that many participants associated taking part in remote online cognitive testing from their own home with reduced anxiety and stress compared to their previous experiences of face-to-face cognitive assessment. Participants linked this to both a feeling of increased comfort and relaxation within their own environment, and removal of stress and anxiety associated with travelling to a clinic. The reduction of time, cost, burden and stress associated with the removed need for travel in remote digital cognitive assessments (Geddes et al., 2020) and in teletherapy more widely (Poletti et al., 2021) has been previously noted in the literature. This, along with the current findings, suggest that this reduced burden could be an important benefit of remote cognitive testing to consider in the future in both clinical and research contexts.

The specific finding that participants associated completing the cognitive assessment from their own home with reduced anxiety, due to the environment itself, compared to in a clinic environment, appears to be a novel one within the current literature. This may be due to the vast majority of research on remote cognitive testing focusing on establishing psychometric properties and validating new digital measures against traditional pen and paper tests, rather than participant experience. While state anxiety has been associated with performance on cognitive assessments (Derakshan et al., 2009), previous research into remote assessments has found that there was no association between performance and whether a digital assessment was completed in a clinic or in a service users' home (Backx et al., 2020). However, given that clinical and ethical guidelines advocate for minimising patient distress wherever reasonable and possible (e.g. Royal College of Psychiatrists, 2003), this finding suggests it may be beneficial for clinicians to explore and consider this, ideally with feedback from patients, when deciding whether remote cognitive assessment may be most appropriate for a particular service user.

Participants in the current study highlighted the cognitive impact of having to travel to face-to-face cognitive or neuropsychological assessments and how this added burden was removed in the remote cognitive assessment. Due to the sequalae of their injuries, many TBI survivors are not able to drive, and thus rely on others or public transport. Survivors of TBI's of varying severities are known to be much more susceptible to physical and cognitive fatigue than healthy individuals (Ali et al., 2022). It is plausible, as discussed by participants in the current study, that the route planning, use of maps, and anxiety associated with travel could lead to TBI survivors experiencing cognitive fatigue, prior to arrival at a clinic, or research appointment. It has also been shown that fatigue can have a detrimental impact on cognition and performance on cognitive assessments, even bringing into question the validity of scores on tests done when a service user is experiencing significant cognitive fatigue (Strober & DeLuca, 2013). Thus, it is possible that the use of remote cognitive assessments could give a more valid indication of an individual's abilities or deficits, particularly if an alternative measurement would require a service user or participant to travel extensively to complete face-to-face testing. Moreover, as discussed previously, there is an ethical and clinical obligation to reduce distress where possible and reasonable (e.g. Royal College of Psychiatrists, 2003), and current findings suggest that removing the need for travel may reduce distress linked to anxiety.

Participants in the current study acknowledged the possibility that the introduction and use of remote cognitive assessments in clinical settings could increase access to this type of assessment. As discussed in chapter one, there are currently very long waiting times for many NHS and third-sector neuropsychology services (Donovan et al., 2020), and digital remote cognitive assessments have been associated with reduced administration time, increased accuracy of measurement and reduced cost (Bauer et al., 2012; Spreij et al., 2020). It is therefore plausible to suggest that the introduction of supervised or unsupervised remote digital cognitive assessments could support the reduction of waiting times, which is an ongoing government NHS initiative (Department of Health and Social Care, 2023).

Increased access and utility are also applicable in the research context, as discussed in chapter one, there is a significant lack of research into the long term cognitive outcomes of mild to moderate TBIs (Maas et al., 2017). This is partly attributed to the time and monetary cost of conducting supervised neuropsychological assessment or cognitive testing on such a large scale, as this data is not routinely collected clinically and thus is not available for large scale meaningful collation (Maas et al, 2017). The current research findings suggest that the ACS or similar remote digital assessments could be appropriate for further exploration in TBI populations. For example, the Cambridge Neuropsychological Test Automated Battery (CANTAB) (Cambridge Cognition, 2023) is a digital cognitive assessment application which can be completed unsupervised remotely via computer, or via an Ipad with a facilitator. Lunter et al. (2019) found the Ipad version of the CANTAB to be effective at detecting cognitive deficits in individuals with mild traumatic brain injuries during the acute stages of their recovery. Future research could aim to investigate whether the unsupervised version of the CANTAB could be effective in identifying cognitive changes in post-acute stages of mild TBI. With further research into their validity and reliability in this population, these remote digital cognitive assessments could be utilised to collect large amounts of cognitive assessment data, in an efficient and cost-effective manner (Feenstra et al., 2018), contributing to the closing of this gap in the literature, and possibly giving new insights into the long-term cognitive outcomes of mild and moderate TBIs.

It is to be acknowledged that the potential benefits of remote digital cognitive assessment discussed here would only be applicable if the assessments used are achievable and feasible within the TBI population (Del Giovane etl al., 2023). All participants in the current study were able to complete the ACS with negligible assistance from the researcher, they also reflected that instructions were clear and easy to follow. This might suggest that the ACS or similar remote digital cognitive screens could be feasible and appropriate for use within a TBI population in the future. This is somewhat supported by previous research, which explored the feasibility of a digital cognitive testing battery in a sample of TBI survivors (n=61), found that 90% were able to complete the entire digital test battery (Spreij et al., 2020). Moreover, Del Giovane et al. (2023) investigated the feasibility of an online cognitive assessment battery in a cohort of TBI survivors in a London TBI clinic and found that it was both feasible and able to detect cognitive deficits associated with TBI. Overall, these results alongside the findings of the current study give promising indication that online digital remote cognitive assessments could be feasible for use with survivors of TBI.

Perceived challenges of remote digital assessment in TBI

Almost all participants highlighted a key message within their feedback that ‘everyone is different’, that all TBIs are different, and that remote digital testing may not be appropriate for all survivors of TBI. Participants cited issues such as significant cognitive difficulties which would prevent individuals from being able to understand or retain instructions and visual or physical impairment, which could make the use of a screen or mouse unsuitable. Indeed, as discussed previously, cognitive, physical and or visual disability are well documented common sequalae of, particularly moderate to severe TBIs (Hillier et al., 1997).The message that everyone is different, and every injury is different, can be linked to the difference between full neuropsychological assessment and standardised or routine cognitive screening. In neuropsychological assessment, a clinician should gather information from multiple sources, including the service user and potentially friends, family or carers, before tailoring a battery of neuropsychological tests, if these are deemed appropriate (Lezak et al., 2012). This would mean that consideration is given to what tests may be appropriate for an individual based on any physical and cognitive impacts of their TBI, as well as any adaptations which may be required. Cognitive screening tools or brief fixed cognitive assessments, including both pen and paper and digital or remote tools, do not usually allow for the same level of consideration (Block et al., 2017), and thus a process of pre-screening, e.g. when booking an appointment, may be helpful in determining whether a face-to-face or remote digital cognitive screen or assessment would be appropriate for any individual (Glover & Albers, 2007).

Participants also highlighted the importance of personal preference and choice in their care relating to remote or face-to-face cognitive assessments. This is in line with NHS constitution values which advocate for patient choice and patient centred care (Department of Health and Social Care, 2024). Moreover, being given choice in relation to assessment and treatment in healthcare has been shown to positively impact motivation and engagement more widely (Ryan & Deci, 2000) potentially leading to better outcomes (Medley & Powell, 2010). Therefore, if digital remote cognitive assessments are to be used by services in the future, it may be important for them to consider the feasibility of offering a choice to service users or participants.

While all participants were able to complete the ACS in the current study, there were times where some participants reported difficulties with attending to, or retaining information from instruction videos, but suggesting that they got the ‘gist’ of the video. It is possible that not having a full understanding of test instructions could impact the validity of any results (Lezak et al., 2012), particularly when using an unsupervised remote digital cognitive screen such as the ACS, where the clinician or researcher cannot see a participant’s responses in real time. In traditional face-to-face cognitive screening, the facilitator can observe responses, and thus gather information about whether the participant appears to have understood instructions adequately, thus make a clinical judgement about result validity. Similar concerns regarding validity of unsupervised cognitive testing are reported in the literature, for example Bauer et al. (2012) note a loss of behavioural observations relating to compliance, understanding, effort and motivation. Therefore, it may be that supervised digital cognitive assessments, or remote assessments using a screen sharing function, may be more appropriate in this population due to the high prevalence of attention and memory difficulties (Rabinowitz & Levin, 2014).

A further challenge of remote digital cognitive assessment identified in the current study was the reduced control over distractions, with most participants experiencing some distraction which caused them to move attention away from the assessment, or even to physically move away. One study which used eye tracking technology to measure distracted attention during a brief unsupervised digital cognitive assessment found that 7.4% of all test administrations involved distractions, moreover participants who were more distracted during the assessment scored significantly lower than those who were not (Madero et al., 2021). This study utilised a five-minute cognitive assessment, and authors acknowledge that increased length of assessment likely increases risk of distraction and thus the risk of lower scores, further reducing confidence in the validity of results. However, other research which has utilised experimental within subjects counterbalancing designs, along with longer digital cognitive assessments, have found that participants scored similarly across supervised and unsupervised conditions (Cromer et al., 2015; Backx et al., 2020), though these studies included no measures of distraction. If unsupervised digital cognitive assessments are to become clinically useful, then further research is required to establish effective methods of monitoring for distracted attention, and ascertaining the likely impacts of this on results.

Participants in this study highlighted concerns regarding the potential for purposely altered performance if unsupervised tests were to be used clinically, particularly if results were perceived to have a significant impact for service users. This does raise the issue of measuring and monitoring effort, motivation and performance validity generally, in remote digital cognitive assessments, particularly if unsupervised. The assessment used here (ACS) did not include any specific measures of performance validity, which is reportedly common throughout much of the experimental neuropsychological literature (DeRight et al., 2015). Research suggests that clinicians often hold beliefs that behavioural observations are important and effective for monitoring performance validity in cognitive assessments (Larrabee et al., 2012), which would lead to the suggestion that supervised remote cognitive assessments may be more valid in this respect. However, a recent critical review highlighted how research utilising experimental designs has indicated that clinician observation is an ineffective method of ascertaining performance validity (Lippa, 2018). Therefore, published clinical guidelines surrounding the use of measures of performance validity (e.g. BPS, 2021; Lippa, 2018) should be considered in future research, or by services looking to use this type of assessment clinically.

Given the findings of the current study and previously discussed literature which has demonstrated that completing neuropsychological or cognitive assessment, including remote digital cognitive assessment can result in distressing emotions such as frustration, anger, anxiety and sadness (e.g. Bennet-levy et al., 1994; Owen, 2012; Day, 2023; Kochan et al., 2022), it is not surprising that the literature has identified a lack of practical and emotional support as a limitation of unsupervised digital cognitive assessments (Bauer et al., 2012). This is particularly relevant in TBI populations, where difficulties with attention and emotional regulation, including emotional lability are common (Stocchetti & Zanier, 2016). In traditional face-to-face cognitive assessments, a clinician would be present to monitor distress or distraction, and respond to this accordingly. This was also identified as a limitation by participants in the current study, with most sharing that they would prefer to have a facilitator present to offer reassurance and support if this was required, with some even suggesting the assessment could cause significant emotional distress if the researcher was not present. These findings suggest in their current form, that these assessments may not be appropriate to be completed unsupervised with TBI survivors. If unsupervised digital cognitive assessments were to be used with any, but specifically TBI, populations in the future, then research would need to establish ways of monitoring and managing acute distress during the testing process.

Expanding on this, a key theme identified in the current study was the importance of participants' previous experiences, and a sense of the therapeutic importance of sharing their stories and 'feeling heard'. Unsupervised remote cognitive assessment, such as in the current form of the ACS, does not allow for this process. While it could be argued that pen and paper cognitive assessment and screens are structured and standardised, and while testing is taking place there may be minimal time allowance for broader sharing, in reality, prior to and post assessment administration, general good practice guidelines advocate for facilitators spending time building rapport (Gorske, 2017). Thus, there is more likelihood of participants or service users sharing and 'feeling heard'. This is even greater in full neuropsychological assessment, where service users would engage in clinical interviewing and much more detailed information gathering with a qualified clinician (Lezak et al., 2012), allowing ample opportunity to have their narrative heard and understood. Thus, future research may look to investigate the potential impact of the loss of this aspect of supervised digital cognitive assessment on participants, or service users.

Finally, these limitations which ultimately indicate that it may be beneficial to have a facilitator present, even in a remote setting, have implications for accessibility. As previously discussed, a potential benefit of digital remote unsupervised testing was the reduced requirement for clinician or facilitator presence (Feenstra et al., 2018), and thus the potential for considerable increased access with the same amount of clinician or researcher resource. If clinicians or facilitators will be required during administration, such as with face-to-face assessments, then this raises the question of how this demand on resource would be met, given that this is already a significant challenge for services. However, it is noted that facilitators may not need to be fully qualified clinicians, which could reduce cost burden, and given the other noted benefits of digital assessments, such as automated scoring, reduced administration time and increased measurement accuracy (Bauer et al., 2012), future research into the cost and time efficiency and feasibility of remote digital supervised versus face-to-face cognitive assessment and screening is warranted; helping guide services and researchers as to where resources may be best placed for maximum impact.

Direct emotional experiences evoked by cognitive testing in TBI survivors

Participants expressed a wide range of thoughts, reflections and emotional experiences, which varied in intensity, while completing the remote cognitive assessment in the current study. This finding is in line with previously discussed research which has suggested that taking part in neuropsychological assessment, and cognitive testing, is not an emotionally neutral experience. It has been previously demonstrated within the literature that strong emotional experiences, such as heightened anxiety or anger, can impact cognitive functions such as attention and executive functioning, and thus the outcome of a cognitive assessment (Blanchette & Richards, 2010; Lindert et al., 2021). Therefore, an increased understanding of the emotional experiences of service users while completing these assessments could support the interpretation of results in both clinical and research settings.

Despite the key research aim being to explore ‘in the moment’ experiences during cognitive assessment, all participants also shared reflections on their wider experiences of being a TBI survivor. Participants tended to move fluidly, sometimes without distinction, between reflections on experiences during the assessment and past events. It is also generally accepted that past experiences influence the way in which current events are interpreted and experienced, with this also being true in healthcare settings (Edvardsson et al., 2017). Due to the research context in which participants completed the digital cognitive assessment, participants’ experiences of taking part in the current research are also interwoven with specific experiences of cognitive testing, with no clear way to discern these. Thus, it would be futile to attempt to fully separate these experiences, or attempt to completely isolate experiences of the cognitive assessment, therefore these are discussed together.

Frustration and anger

All participants in the current study expressed feelings of frustration and anger, either implicitly or explicitly while completing the ACS. This frustration tended to be directed to the self, rather than the assessment. The observed intensity of these emotions varied between participants but generally emerged when participants found tasks difficult or perceived themselves to be struggling. Previous qualitative research has identified anger as being evoked during neuropsychological assessment in individuals with a variety of neurological disorders (Bennet-Levy et al. 1994; Blake, 2004) and traumatic brain injuries specifically (Owen, 2012). Moreover, Day (2023) found that older adults from a stroke population also experienced feelings of anger when completing the ACS, noting some participants referring to themselves as 'stupid' or 'pathetic' when they struggled with tasks. Indeed, Bennet-Levy et al. (1994) commented that experiences of frustration and anger are likely to be inherent to neuropsychological assessment and cognitive testing, due to the continual exposure to failure or highlighting of deficit, which is in line with the findings of the current study.

Some participants suggested that feelings of frustration were mediated by the presence of the researcher and speculated that completion of a completely unsupervised remote cognitive assessment would have likely resulted in more intense emotional experiences of anger. There is currently no literature available to indicate whether this is a valid speculation, however, research has identified that many TBI survivors struggle with emotional regulation and emotional lability as a result of their injury (Stocchetti & Zanier, 2016), and that many of those who experience this are reliant on others or carers to support their emotional regulation (Godfrey et al., 2003). Thus, it is plausible that the presence or absence of a facilitator may impact the emotional experience of completing the testing, particularly in TBI survivors.

Moreover, if emotional experiences (including self-directed anger and sadness) were to be more likely or more intense in the absence of a facilitator this may have implications for the use of this type of assessment in the TBI population. Previous research has shown heightened distressing emotions (such as anger towards the self or sadness) to be linked to increased risk of harm to self in individuals who engage in self-harm (Klonsky & Muehlenkamp, 2007). Moreover, TBI survivors are more likely to engage in self-harm (both with and without suicidal intent) than the general population (Wadhawan et al., 2019), and research has shown that TBI survivors who struggle with disinhibition, which is common post TBI (Stocchetti & Zanier, 2016), are approximately four times more likely to engage in self-harm, and 21 times more likely to make a suicide attempt than TBI survivors who do not experience disinhibition (Ladner et al., 2024). While more research would be required to explore whether the presence, or lack of, a facilitator would indeed impact emotional experiences of service users or participants, and whether this would be linked to any risk, this may be an important consideration if unsupervised cognitive assessment, where distress and risk levels would not be directly monitored, were to be considered in this population in the future.

However, knowing the likelihood that TBI survivors will experience heightened frustration or anger towards themselves during a cognitive assessment, whether supervised or not, raises the question of how best to support individuals to reduce the potential adverse impacts of this. Mindfulness based interventions may be appropriate for this context, given their focus on self-compassion, self-soothing and awareness of emotional states (Kabat-Zinn, 2003). Indeed, Azulay and Mott (2016) found that brain injury survivors, including moderate and severe TBI survivors, who took part in a 10-week mindfulness meditation group, showed clinically meaningful reductions in anger and improvements on measures of emotional regulation and moment to moment self-awareness. However, under the current NHS climate, it is acknowledged that most services may not have the resources available to offer an extensive intervention. It is worth noting that even a single session of guided mindful meditation has been shown to significantly reduce physiological signs of anger, even in participants who had never previously engaged in mindfulness (Fennell et al., 2016). Therefore, services could consider offering a single session such as this, or signposting to online videos or applications offering guided mindful meditation, potentially directly following cognitive assessment, to support service user or participant wellbeing. Future research should look to investigate the efficacy of self-directed interventions for anger in survivors of TBI, to further guide clinical practice in a climate of highly limited resources.

Sadness, loss, and grief

Many participants expressed a sense of sadness while taking part in the current study. This appeared to be linked to having their cognitive difficulties highlighted, resulting in reflections on what is perceived to have been lost. There was a strong sense of loss, and this related to both cognitive function and aspects of identity which had changed due to the impacts of their TBI.

Sadness, grief and loss are common experiences for survivors of TBI (Chamberlain, 2006), these are regularly cited in the literature and are considered normal experiences in the adjustment to any life-changing injury and reflect multiple psychological models of grief (Coetzer, 2003). Carroll and Coetzer (2011) found that all 29 participants in their study, who had sustained TBIs and had undergone community-based rehabilitation, identified significant changes to their sense of identity or ‘self-concept’ as a result of their injury. Participants also perceived their ‘old self’ more positively than their ‘new self’ post injury, and higher levels of perceived identity change were associated with increased depression and grief. Moreover, rates of depression are much higher in TBI survivors than in the general population, which are estimated at approximately 15% (Kessler et al., 2003), with estimates of frequency ranging from 20% to 50% of TBI survivors suffering with clinical depression, and these rates increasing further with injury severity (Jorge et al., 2004).

As participants in the current study highlighted, cognitive assessments, both supervised or unsupervised, and digital or pen-and-paper, have the potential to place a spotlight on an individual's cognitive difficulty, which likely represents a change in their ability and identity. It is therefore likely that participants or service users will experience heightened feelings of sadness at these times. It is also important to consider that this may be exacerbated in individuals who are not aware of the impacts of their injury on cognition. Qualitative research has explored the experiences of TBI survivors gaining awareness of their cognitive deficits post injury, and highlighted similar themes of intense sadness and loss, particularly at the point of initial awareness being gained (O'callaghan et al., 2006).

In line with the literature discussed above, current guidelines state that all services who offer cognitive assessment and rehabilitation to TBI survivors should use validated screens for mental health conditions, including depression (Mehta et al., 2024). This could also be implemented in remote unsupervised digital cognitive assessments, and indeed the ACS battery, when used in its standard research context, contains the Hospital Anxiety and Depression Scale (HADS), which is commonly used in neuropsychology services and has been demonstrated to have good validity when used with TBI survivors (Dahm, et al., 2013). This is important, not only for supporting service user and participant wellbeing, but because depression has been shown to influence scores on cognitive assessment in TBI survivors, particularly processing speed and cognitive flexibility (Terry et al., 2019), and thus this information is important for the valid interpretation of results.

Given the findings of the current study and other literature which indicated that TBI survivors are at increased risk of depression, and that cognitive assessment can evoke intensified feelings of sadness and grief, it would be appropriate that therapeutic support for this is offered following testing. Currently CBT is considered the most effective evidence-based treatment for depression following acquired brain injury, including TBI, with one-to-one online, telephone and face-to-face interventions showing good efficacy (Faltynek et al., 2024). However, a recent systematic review noted that it is difficult to fully assess the efficacy of psychological interventions, including CBT, for depression following TBI, highlighting a lack of high quality RCTs within the literature (Beedham, et al, 2020). Services should consider offering CBT based interventions for individuals who are identified through screening, though, given the well-known challenges with capacity within neuropsychology services, service users could otherwise be signposted to specific mental health services who can offer these interventions. Future research could aim to develop, and investigate the efficacy of, self-directed CBT, or other therapeutic model, based interventions for depression in TBI survivors.

Anxiety

Only one participant explicitly discussed feelings of anxiety in the current study, and this was linked to uncertainty about what to expect from, and whether they would be able to complete the remote cognitive assessment. However, most participants did show some observed signs of anxiety, such as nervous laughter. Nonetheless, this finding is interesting given that previous research which has explored the experiences of individuals with a variety of neurological conditions in completing neuropsychological and cognitive assessments have reported anxiety as a common response (Bennet-Levy et al., 1994; Blake, 2004; Gruters et al., 2021; Hobden et al., 2023). Indeed, Day (2023) also found that the vast majority of their 11 participants from a stroke population explicitly expressed anxiety and worry when completing the ACS.

Participants in the current study did explicitly reflect that taking part in the cognitive assessment in the research context influenced their emotional reactions, due to the lack of perceived personal consequences of their cognitive performance. Previous studies have primarily explored service users' experience of cognitive testing and neuropsychological assessment within the clinical context. Literature has demonstrated that perceived threat is associated with increased state anxiety (Lazarus, 1984). Given that in clinical contexts, results from cognitive or neuropsychological assessments can have greater perceived implications, such as informing diagnosis and thus prognosis, guiding future recommendations for access to care and support (Lezak et al., 2012), informing decisions regarding access to financial benefits as well as returning to work or driving etc, it is highly plausible that perceived threat is higher when completing cognitive assessment in this context. This offers an explanation for the discrepancy in apparent anxiety between the current study and previous literature.

Interestingly however, Day (2023) found participants from an older adult stroke population explicitly expressed anxiety when completing the ACS within a research context, despite participants being informed of the lack of score recording or clinical implications of taking part. They note that participants expressed worries about memory, and possible implications of results of cognitive testing. Approximately half of the participants in this study were in the acute phase of recovery from their stroke, and indeed took part on an inpatient stroke rehabilitation ward. As mentioned previously, it has been suggested that in the acute phases of brain injury, when individuals are initially becoming aware of cognitive difficulties, this can be linked with more intense psychological distress and anxiety (O'callaghan et al., 2006). Moreover, findings from the current study suggested that remote testing from home reduced anxiety in participants when completing cognitive assessment.

Therefore, it may be that taking part in the research in a physical clinical context (e.g. on a stroke ward) increased experiences of anxiety in these individuals, despite being informed of the lack of direct consequences. Future research could aim to investigate the impact of environment (e.g. home or ward) on anxiety during cognitive testing, in both clinical and research contexts, in a more controlled comparative manner.

While findings from the current study might suggest that anxiety is not a significant concern for researchers engaging in remote digital cognitive assessment or screening with TBI survivors, findings from the previous literature should be considered carefully. This is especially true given that increased state anxiety has been shown to negatively impact multiple cognitive functions, including attention, verbal and working memory and executive function (Blanchette & Richards, 2010; Dorenkamp & Vik, 2018; Dorenkamp et al., 2023; Lindert et al., 2021), potentially impacting the validity of cognitive assessments undertaken at these times. Therefore, services and researchers should remain aware of the potential for cognitive assessments, both digital and pen and paper, to evoke anxiety in survivors of TBI, and consider when intervention to manage or limit this may be appropriate. Many common measures of anxiety, such as the HADS used with the ACS, measure anxiety across a period of time, usually over one to two weeks, which can be indicative of state or trait anxiety (Johnston et al., 2000). Given that state anxiety has been most strongly associated with direct impacts on cognitive function (Ehgoetz-Martens et al., 2018), it may be helpful for services, or researchers, to administer a specific measure of this to support interpretation of cognitive assessment results, such as the Visual Analogue Scale (VAS), which is a very brief validated measure that can be used in both pen and paper or remote digital formats (Abend et al., 2014).

Previous literature has made several suggestions regarding the management of state anxiety during neuropsychological assessment and cognitive testing, including facilitators acting with compassion, working to make the environment feel less formal or clinical, for example by offering refreshments, and spending time building rapport prior to testing (Bennet-Levy et al., 1994). These principles are also likely to be helpful in remote digital testing with a facilitator and should be considered by services or researchers using these methods in the future. Other research has also highlighted the importance of context and environment in reducing state anxiety as much as possible, for example having well-lit rooms, windows with a view and natural light where possible, as these things have been demonstrated to support positive emotions and concentration (Ko et al., 2020). While in a face-to-face context, these things are usually under the control of a clinician, and thus can be monitored, it is important to consider these factors in remote digital cognitive assessment in the future. The current research suggests that taking part in cognitive testing from home may reduce state anxiety in some TBI survivors, however, including relevant recommendations about lighting, comfort, and refreshments, either in instructional videos in unsupervised testing, or by a facilitator in remote testing, is likely to be beneficial.

Happiness and confidence

Participants in the current study occasionally expressed more positive emotions, such as joy and self-confidence, appearing to be linked to perceptions of doing well on a task, highlighting a perceived cognitive strength. This is in line with previous research which also highlighted moments of enjoyment in stroke survivors who completed the ACS when they perceived themselves to be doing well on a subtest (Day, 2023). Owen (2012) also noted that there were mixed emotions, including moments of happiness or enjoyment, for TBI survivors during the process of neuropsychological assessment in a clinical setting.

It is important to note that the context in which participants took part in the cognitive assessment in this study, e.g. with no perceived consequences and no scores or feedback, likely impacted their emotional responses (as discussed previously). However, as discussed above, high levels of state anxiety and frustration may impact scores on cognitive assessments, and thus it may be important for clinicians and researchers to consider the importance of including a variety of tasks or subtests which may allow for more positive emotional experiences throughout testing. Clinicians or researchers should provide compassionate encouragement (Gruters et al., 2021), and at the test development stage, should carefully consider the possible emotional implications, as well as the neuropsychological validity of the variety and likely varying difficulty of subtests included.

Finding balance: potential for distress versus supporting adjustment

Findings from the current study clearly demonstrate that cognitive testing can evoke unpleasant emotions such as frustration, anger, sadness and grief, and that this is usually linked to testing highlighting difficulties and cognitive changes, or cognitive function which has been ‘lost’. Participants suggested that these emotions were present in the remote digital assessment completed in the study context, and in previous experiences of cognitive assessment. However, participants also reflected on how previous experiences of cognitive testing, or neuropsychological assessment, in clinical or rehabilitation settings had been important in their understanding, insight and adjustment to the impacts of their TBIs. This is in line with a literature review which indicated that neuropsychological assessment had strong value in the treatment of TBI survivors, and suggested that these assessments, and subsequent feedback and treatment recommendations were linked to better daily life outcomes (Donders, 2020). Gruters et al. (2021) discussed this dilemma in the context of diagnosing dementia, noting the acute distress caused by cognitive assessment raising awareness of cognitive difficulties, but also the relief and increased insight following diagnosis and feedback, which they referred to as ‘the diagnostic paradox’.

Further in line with this, participants in the current study reflected on the importance of feedback in their previous experiences of cognitive assessment, often discussing their individual feedback or referencing reports. Participants often discussed cognitive strategies they had learned to manage difficulties highlighted in previous cognitive testing, and reflected on the importance of these in their adjustment. Indeed, despite participants being clearly informed of the nature of testing in the current research meaning there would be no results shared, one participant requested feedback and expressed disappointment that this would not be provided. Bennet-Levy et al. (1994) also reported that service users who received feedback, particularly when perceived as helpful, were more satisfied and had more positive feedback about the process of neuropsychological assessment, despite still experiencing uncomfortable emotions during cognitive assessment. These findings highlight the clear importance of feedback in any cognitive assessment, screen or neuropsychological assessment.

One study found that when personalised face-to-face feedback was provided to TBI survivors after neuropsychological assessment, this resulted in increased effort in subsequent rehabilitation therapy, increased satisfaction, and better cognitive and daily outcomes long term (Pegg et al., 2005). Moreover, ethical and clinical guidelines advocate for the provision of meaningful feedback following any psychological or neuropsychological assessment (APA, 2017). Feedback should provide a clear overview of results, include both strengths and areas of difficulty, be delivered compassionately and be tailored to the needs of the individual (Postal & Armstrong, 2013). For example, for individuals with memory or processing speed deficits, which are common following TBI, it may be beneficial to provide information in small ‘chunks’ and to also provide a written summary of feedback (Postal & Armstrong, 2013). Indeed, in a recent literature review, Gruters et al. (2022) found that information retention is commonly reported as low following feedback from neuropsychological assessment, and that written reports were helpful in increasing retention and perceived as helpful by service users. Finally, it is important that feedback is delivered compassionately, but that it remains accurate, as moderating feedback or being overly optimistic can contribute to unrealistic expectations in service users and family members, leading to increased distress (Wilson, 2008).

In the context of cognitive screening, and remote digital cognitive assessments, currently there is limited specific clinical guidance and literature related to giving feedback, however the guidelines and literature above suggesting compassionate and meaningful feedback are likely still applicable. Remote digital cognitive screens which already exist, such as The Brain Health Assessment (Troyer et al., 2014) and the Cognitive Function Test (Trusthram & de Jager, 2014), often provide standardised written feedback on results, either immediately or in an email, these can include profile scores across cognitive domains and infographics highlighting relative strengths and weaknesses. Given the literature discussed above, services or researchers who intend to utilise remote digital cognitive screens with TBI survivors in the future should carefully consider what, and how, feedback will be provided. Future research could aim to explore TBI survivors' experiences of receiving feedback from remote digital cognitive assessments in clinical and research contexts, to further guide best practice.

Strengths and Limitations

Participants in the current study varied in gender, age and time since their injury, which reflects the incredibly varied demographic landscape of TBI survivors. The sample included more men than women, which is also reflective of the reported demographics of TBI survivors, with an estimated 60-70% of TBIs worldwide being sustained by men (Nguyen et al., 2016). Moreover, there were no apparent differences between participants' experience of the remote digital cognitive assessment based on these demographic factors. This study included a small sample of 10 participants, which is a common and appropriate sample size given the study aims and methodology (Braun & Clarke, 2021). However, while participants recruited through online channels gave good accounts of their injuries, and all self-identified as a TBI survivor, it was not possible to formally verify this information or gather detailed data on injury severity.

Older adults are one demographic group at greater risk of sustaining TBIs (Peters, 2016), yet the current study did not have any participants over the age of 65, meaning that the voices of this group are not present in the findings of the current study. This may reflect wider issues surrounding older adults limited involvement in research (Witham & McMurdo, 2007). Moreover, while the current study aimed to recruit through multiple streams, including face-to-face recruitment which has been suggested to encourage inclusion of older adults (Witham and McMurdo, 2007), most participants were recruited through online channels, further hindering older adult participation through the well documented digital divide amongst young, or working age, and older adults (Heinz et al., 2013). Future research should aim to explore the experiences of older adult TBI survivors' experiences of remote digital cognitive testing, to help guide practice in this population.

A clear limitation of the current study is that all participants were from a white British ethnic background, meaning it is impossible to make inferences about the possible experiences of individuals outside of this group. This is reflective of a wider issue with racially minoritised groups experiencing significant health inequality (Wheeler & Bryant, 2017), and being underrepresented in the scientific literature broadly (Konkel, 2015) and in the neuropsychological literature specifically (Elbulok-Charcape et al., 2014). While there were no exclusion criteria pertaining to ethnicity or racial identity, it is acknowledged there were inclusion criteria requiring the need to be a UK resident, and to be fluent in English, which likely served as an obstacle to individuals from racially minoritised backgrounds taking part. Future research should seek to explore the experiences of minoritised groups in completing cognitive assessments, both digitally and face-to-face.

Participation in this study was voluntary, and 90% of participants self-initiated contact with the researcher directly, in response to online advertisement. While there was variety in general computer use, this still suggests that most participants are comfortable using digital technology and had some motivation or interest in scientific research, which was also evident in their self-reports during interview. While voluntary participation is of course ethically necessary, it inevitably introduces bias, whereby individuals who are less comfortable with digital technology, who do not use social media, who are less interested or motivated to take part in research or are more severely cognitively impaired are not represented within the research, representing some potential recruitment bias.

It may be important to note that nine of the ten participants in the current study reported previous experience of some form of cognitive assessment, which as discussed above, likely influenced their experience of the ACS in the current study. This is not likely representative of many TBI survivors, particularly survivors of mild TBIs, as this population do not routinely undergo enhanced cognitive screening, or thorough neuropsychological assessment (Maas et al., 2017). While one participant had not undergone cognitive assessment previously, and their experiences did not appear to significantly differ from other participants, this study is limited in its ability to speak to the experiences of this group, and thus it would be useful for future research to explore the experiences of TBI survivors who have not previously undergone cognitive testing. This is especially true if future intended research use of remote digital cognitive assessments would specifically target survivors of mild TBIs, to contribute to previously discussed gaps in the literature.

Guidelines on good research practice clearly advocate for the inclusion of experts by experience in the development of any research project (Van Dijck & Steen, 2024), thus the inclusion of TBI survivors in the design of the methodology of the current study should be considered a strength. The adjusted ‘think aloud’ methodology itself can also be considered a strength, as it allowed for participants to share freely and in the moment responses to be captured, which would not have been possible using alternative methods such as solely retrospective interviews. These in the moment think-aloud responses, though often brief, offered invaluable insights into the moment-to-moment emotional experiences of participants when completing the online remote cognitive assessment. It is important to recognise that a strict think-aloud protocol was not followed, as the researcher would offer prompts or ask questions such as ‘what are you thinking now?’ and ‘what is running through your mind?’. However, this was in line with previous guidelines for adjusting the think aloud protocol to be inclusive and appropriate for individuals with cognitive deficits (Johnstone et al., 2006), such as those resulting from a TBI.

The methodology also included the use of open questions before and after participants completed the ACS, again this was based on expert by experience feedback. These open questions yielded insightful detailed information regarding participants’ past experiences and current thoughts and feelings, which appeared more difficult to share while undergoing the ACS, likely due to cognitive demand. While efforts were made to ensure neutrality and reduce bias, such as emphasising that the researcher is not associated with the development of the ACS itself, that results are not being recorded and that any feedback shared would have no impact on any clinical care, it is possible that participant responses were influenced by researcher bias and demand characteristics. Indeed, this was explicitly observed on some occasions, such as when a participant reflected that they were moderating their responses due to the presence of the researcher.

Clinical implications

Findings from the current study and exploration of the surrounding literature have highlighted a number of factors which may be important to consider in clinical and research contexts in the future. For example, the presence of a researcher/facilitator likely had a mediatory influence on participants’ experiences during the cognitive assessment, and therefore exploration of experiences without a facilitator present should be explored prior to clinical administration of this type of assessment. Participants here were not given feedback, yet this appeared important to many and within the literature is highlighted as a key aspect in the experience of cognitive assessments, therefore in clinical contexts meaningful feedback should be offered, and research should explore the ‘in the moment’ experiences of participants receiving feedback from remote digital cognitive assessments to guide best clinical practise.

Overall, the findings from the current study suggest that if completing digital cognitive assessment with service users, clinicians should ensure the presence of a compassionate facilitator, consider whether participants have completed cognitive testing previously, their age, their familiarity with technology, their perceptions and awareness of their own cognitive difficulties and changes and whether any assessment is likely to result in meaningful feedback, as all of these factors may influence how any assessment is experienced by service users. Clinicians should then use their own clinical judgement and skills in planning assessment and managing any distressing emotions, which are likely to arise. Future research should aim to further explore in more detail how these factors may influence experiences of cognitive assessment to guide future clinical recommendations.

Due to the sample size and methodological design, the current study did not investigate, and thus cannot speak directly to, the feasibility, reliability, or validity of the ACS with TBI survivors. However, despite the highlighted limitations, findings from the current study do indicate that the ACS, or other similar remote digital cognitive assessments, may be acceptable and appropriate for use with TBI survivors who experience cognitive impairment in the future, and that future research exploring its feasibility, reliability and validity utilising larger samples in this population is warranted and should be pursued.

Recommendations

This section provides a summary of recommendations, based on both the findings of this study, and the literature reviewed within it, which are presented in Table 5, below.

Table 5. Summary of recommendations guided by the findings of this study

Key findings	**Recommendations** (including other supporting literature)
All participants were able to complete the ACS within 75 minutes with negligible assistance **Some participants appeared to struggle to attend to all instructions or became distracted during the remote digital assessment, though this did not impact their ability to complete the assessment.**	Future research exploring the feasibility, reliability, validity and clinical utility of the ACS and other similar remote digital cognitive assessment in TBI survivors is warranted and should be pursued. (Backx et al., 2020; Del Giovane et al., 2023; Maas et al., 2017; Spreij et al., 2020) Continue with the development of both digital and remote cognitive assessments specifically designed for use with TBI survivors. For example developers of remote unsupervised digital cognitive assessments may consider providing instructions in smaller ‘chunks’, additional inbuilt prompts, or a function to have instructions repeated where appropriate. (Backx et al., 2020; Del Giovane et al., 2023; Spreij et al., 2020; Ponsford et al., 2014)
Majority of participants had a preference for remote digital cognitive assessment over face-to-face assessment. This was attributed to reduced anxiety associated with the environment, and reduced stress and fatigue, associated with travel.	Services and researchers should consider whether options for remote digital cognitive assessment are feasible and to offer this as an option to service users or participants if appropriate and possible, while continuing to follow current guidelines on digital and remote assessments. (BPS, 2005; Department of Health and Social Care, 2024; DNP, 2020; Geddes et al., 2020) Research could aim to further explore the impact of setting on emotional experiences of digital cognitive testing in a clinical context (where there may be perceived

Anxiety was likely reduced in the current study due to the research context and lack of direct ‘consequences’.	consequences) e.g. exploring whether remote digital cognitive assessment elicits reduced anxiety compared to that undertaking in a face-to-face clinical context. When completing cognitive assessment in a clinical context, including remote digital assessments, facilitators should be aware that these can evoke significant anxiety. Facilitators should spend some time building rapport and provide compassionate encouragement where appropriate. In the case of face-to-face assessments, facilitators could offer a beverage and should manage the environment to reduce anxiety as much as possible, such as utilising a room with natural light, minimal distractions and a view. (Bennet-Levy et al., 1994; Gorske, 2017; Gruters et al., 2021; Ko et al., 2020)
Participants emphasised that every TBI is different, that digital remote assessment would not be appropriate for everyone and that individuals will have different preferences.	Service users or participants should be pre-screened, as should be the case when using any cognitive screen or assessment, to establish whether a digital or remote cognitive assessment is likely to be appropriate, this could also involve establishing service user or participant preferences. (Block et al., 2017; Department of Health and Social Care, 2024; Glover & Albers, 2007; Lezak et al., 2012)
Cognitive assessments, including digital and remote assessments can evoke distressing emotions such as frustration, anger, sadness, grief and anxiety. **Participants generally had a preference for a facilitator to be present**	Researchers and clinicians should continue to be present and involved in the cognitive assessment or screening process currently, whether or not these involve digital or remote assessments. Facilitators should monitor for emotional distress and manage this compassionately. (Grutter et al., 2021) Validated mood screens, including measures of state anxiety should be included in digital cognitive assessments to support with the interpretation of results and identify

during remote digital testing, suggesting that this would support completion and emotional wellbeing during assessment.	individuals at risk of increased distress. (Abend et al., 2014; Mehta et al., 2024) Research could aim to explore innovative ways to monitor distress during unsupervised digital testing. Researchers or clinicians should consider signposting individuals who express heightened distress related to their cognitive changes or score above clinical thresholds on mood screens during cognitive assessment to appropriate mental health services. (O'callaghan et al., 2006; Gruters et al., 2021; Faltynek et al., 2024; NICE; 2022) Research should aim to investigate effective brief, or self-directed therapeutic interventions for anger, anxiety and depression in TBI survivors, which could be implemented directly by services providing cognitive assessment. (O'callaghan et al., 2006; Faltynek et al., 2024)
Participants raised concerns regarding performance validity in unsupervised digital cognitive assessments, particularly if used in a clinical context.	Performance validity measures should be included in face-to-face and digital remote cognitive assessments in both research and clinical contexts. (BPS, 2021; Lippa, 2018)
Participants highlighted the importance of feedback in the process of cognitive assessment. **Participants often associated feedback with the development of**	Researchers and clinicians should consider providing feedback following any cognitive assessment, where possible and appropriate, including following brief cognitive assessment or screening. Feedback should be clear and understandable to the person it is being delivered to. (Day, 2023; Gruters et al., 2022, Krohne et al., 2011; Owen, 2012) Services and researchers should consider signposting individuals involved in cognitive screening or brief

strategies to support the management of the cognitive impacts of their TBI.	cognitive assessment to resources relating to cognitive strategies following TBI (e.g. Headway resources). (NICE, 2022; Headway, 2024)
The demographics of the sample within this study are limited.	Future research should aim to explore the experiences and views of TBI survivors from a broader range of ethnic backgrounds, from an older adult population, and those with reduced digital confidence, when completing cognitive assessments. (Elbulok-Charcape et al., 2014) Future research should explore the experiences and acceptability of remote digital cognitive assessment in individuals who have sustained a mild TBI and those who have not previously undergone any cognitive assessment. (Maas et al., 2017)
The adapted think-aloud method was effective at eliciting 'in the moment' experiences of TBI survivors when completing a cognitive assessment.	Developers of digital cognitive assessments should consider utilising adapted think aloud method during the development of any future assessments to explore the experiences of individuals from populations whom these assessments are designed. (Baines et al., 2022) Future research could utilise this methodology to explore 'in the moment' experiences in other research areas with TBI survivors. (Ahmadi et al., 2022)

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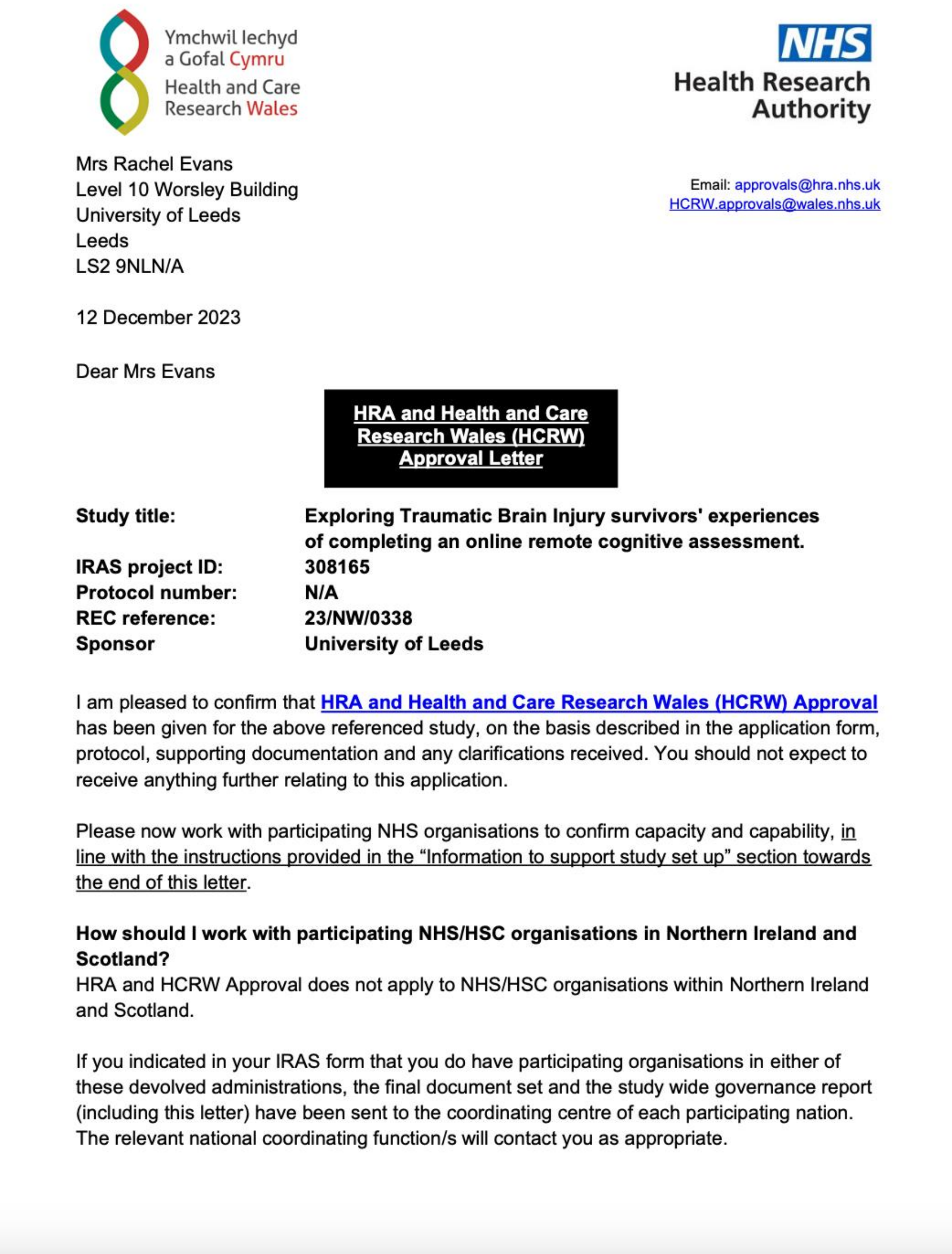
Appendix

Appendix A – Ethical Approval Documentation

A1 – HRA Ethical Approval Letter



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12 December 2023

Dear Mrs Evans

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

Study title:	**Exploring Traumatic Brain Injury survivors' experiences of completing an online remote cognitive assessment.**
IRAS project ID:	**308165**
Protocol number:	**N/A**
REC reference:	**23/NW/0338**
Sponsor	**University of Leeds**

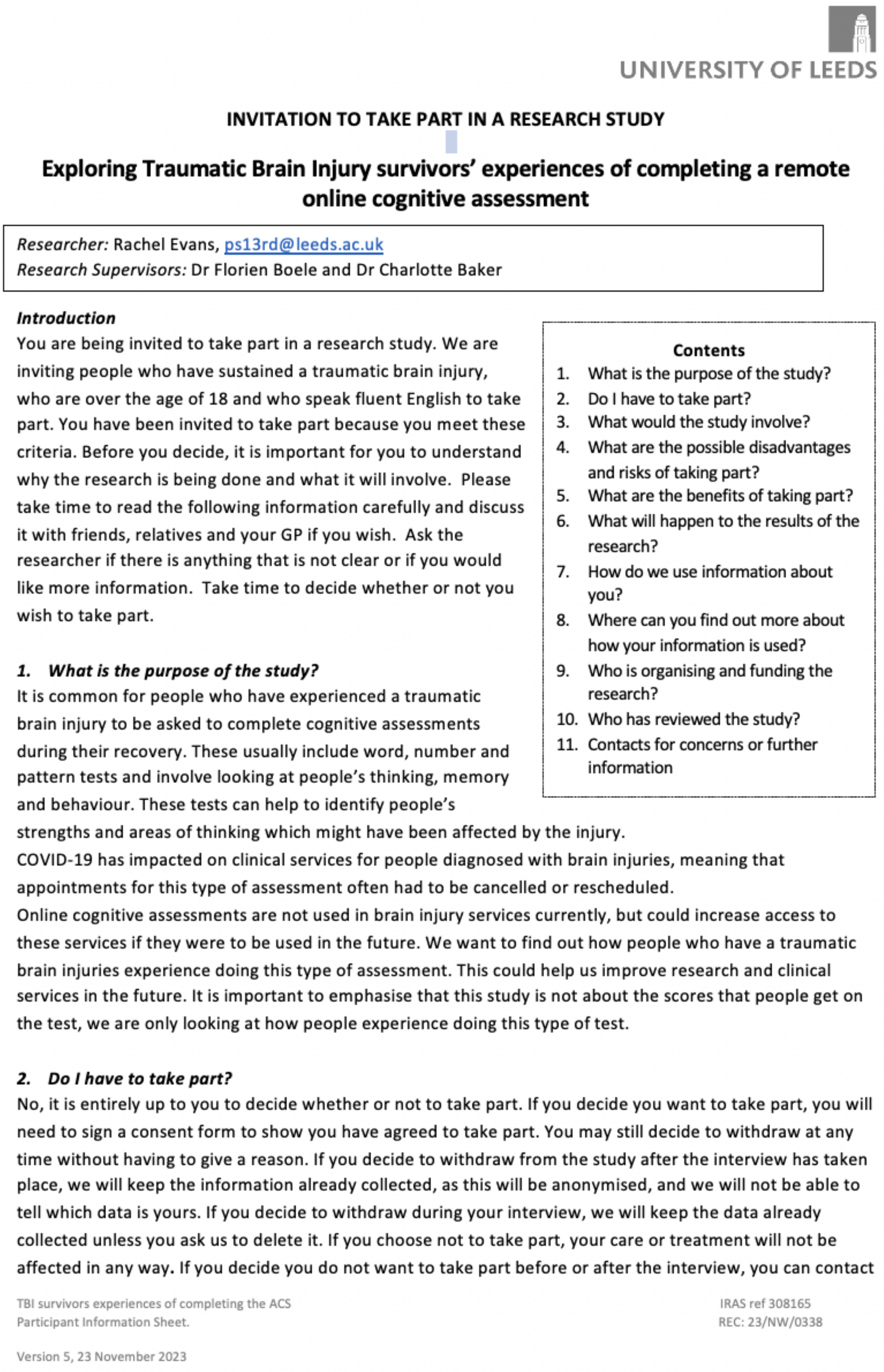
I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further 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



UNIVERSITY OF LEEDS

INVITATION TO TAKE PART IN A RESEARCH STUDY

Exploring Traumatic Brain Injury survivors' experiences of completing a remote online cognitive assessment

Researcher: Rachel Evans, ps13rd@leeds.ac.uk
Research Supervisors: Dr Florien Boele and Dr Charlotte Baker

Contents

Introduction

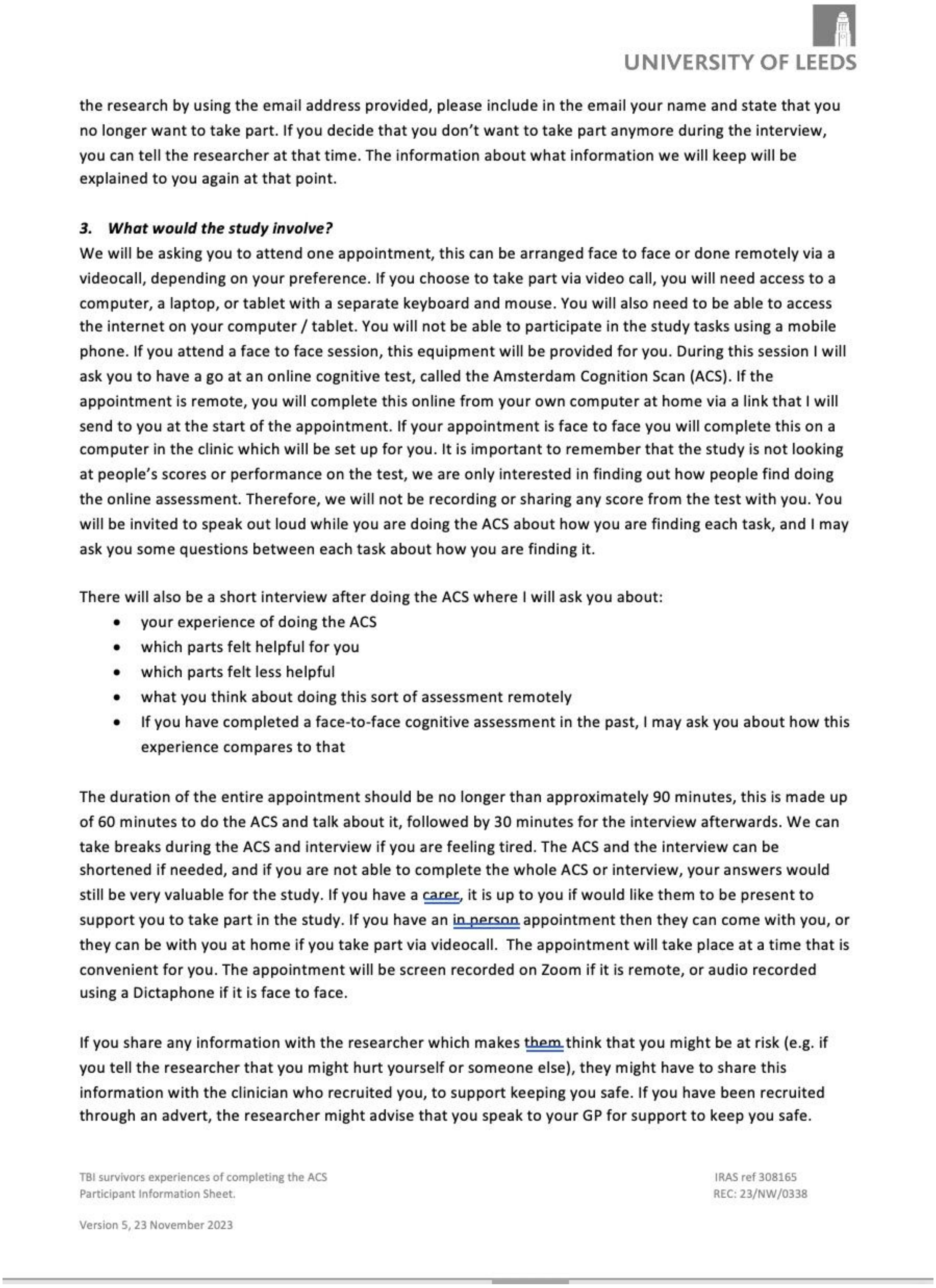
You are being invited to take part in a research study. We are inviting people who have sustained a traumatic brain injury, who are over the age of 18 and who speak fluent English to take part. You have been invited to take part because you meet these criteria. Before you decide, it is important for 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 the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

It is common for people who have experienced a traumatic brain injury to be asked to complete cognitive assessments during their recovery. These usually include word, number and pattern tests and involve looking at people's thinking, memory and behaviour. These tests can help to identify people's strengths and areas of thinking which might have been affected by the injury.
COVID-19 has impacted on clinical services for people diagnosed with brain injuries, meaning that appointments for this type of assessment often had to be cancelled or rescheduled.
Online cognitive assessments are not used in brain injury services currently, but could increase access to these services if they were to be used in the future. We want to find out how people who have a traumatic brain injuries experience doing this type of assessment. This could help us improve research and clinical services in the future. It is important to emphasise that this study is not about the scores that people get on the test, we are only looking at how people experience doing this type of test.

2. Do I have to take part?

No, it is entirely up to you to decide whether or not 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 has taken place, we will keep the information already collected, as this will be anonymised, and we will not be able to tell which data is yours. If you decide to withdraw during your interview, we will keep the data already collected unless you ask us to delete it. If you choose not to take part, your care or treatment will not be affected in any way. If you decide you do not want to take part before or after the interview, you can contact



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the research by using the email address provided, please include in the email your name and state that you no longer want to take part. If you decide that you don't want to take part anymore during the interview, you can tell the researcher at that time. The information about what information we will keep will be explained to you again at that point.

3. *What would the study involve?*

We will be asking you to attend one appointment, this can be arranged face to face or done remotely via a videocall, depending on your preference. If you choose to take part via video call, you will need access to a computer, a laptop, or tablet with a separate keyboard and mouse. You will also need to be able to access the internet on your computer / tablet. You will not be able to participate in the study tasks using a mobile phone. If you attend a face to face session, this equipment will be provided for you. During this session I will ask you to have a go at an online cognitive test, called the Amsterdam Cognition Scan (ACS). If the appointment is remote, you will complete this online from your own computer at home via a link that I will send to you at the start of the appointment. If your appointment is face to face you will complete this on a computer in the clinic which will be set up for you. It is important to remember that the study is not looking at people's scores or performance on the test, we are only interested in finding out how people find doing the online assessment. Therefore, we will not be recording or sharing any score from the test with you. You will be invited to speak out loud while you are doing the ACS about how you are finding each task, and I may ask you some questions between each task about how you are finding it.

There will also be a short interview after doing the ACS where I will ask you about:

- your experience of doing the ACS
- which parts felt helpful for you
- which parts felt less helpful
- what you think about doing this sort of assessment remotely
- If you have completed a face-to-face cognitive assessment in the past, I may ask you about how this experience compares to that

The duration of the entire appointment should be no longer than approximately 90 minutes, this is made up of 60 minutes to do the ACS and talk about it, followed by 30 minutes for the interview afterwards. We can take breaks during the ACS and interview if you are feeling tired. The ACS and the interview can be shortened if needed, and if you are not able to complete the whole ACS or interview, your answers would still be very valuable for the study. If you have a carer, it is up to you if would like them to be present to support you to take part in the study. If you have an in person appointment then they can come with you, or they can be with you at home if you take part via videocall. The appointment will take place at a time that is convenient for you. The appointment will be screen recorded on Zoom if it is remote, or audio recorded using a Dictaphone if it is face to face.

If you share any information with the researcher which makes them think that you might be at risk (e.g. if you tell the researcher that you might hurt yourself or someone else), they might have to share this information with the clinician who recruited you, to support keeping you safe. If you have been recruited through an advert, the researcher might advise that you speak to your GP for support to keep you safe.

TBI survivors experiences of completing the ACS
Participant Information Sheet.

IRAS ref 308165
REC: 23/NW/0338

Version 5, 23 November 2023

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

Completing cognitive assessments can feel difficult and can sometimes be upsetting. If you become upset the researcher will be supportive, you can speak about why it has upset you, we can take a break, you can choose to skip a section of the ACS, or we can stop the appointment completely if you wish. It is also important to remember that this study is not looking at how you perform or what scores you get, we are only interested in how you find doing the assessment. Therefore, it is helpful for the study to know if doing this assessment makes you feel upset or frustrated etc, even if this means you choose to stop the appointment.

The researcher can offer you information about different services which might be able to offer you support if you become upset. Some contact details for services are also given below.
Doing this type of task can sometimes lead to people feeling extra tired. People might also be at increased risk of getting a headache, this is particularly true for people who have a traumatic brain injury. I will explain these risks again before we start the session. If this happens, we can take a break, or we can stop the appointment completely if you wish.

Below is a list of some organisations you can contact if you would like some emotional support –

Samaritans – Free confidential emotional support (available 24/7)
Telephone - 116 123
Email – jo@samaritans.org

Headway (Emotional support for people with Brain injury) –
www.headway.org.uk
Telephone - 0808 800 2244

Mind Mental Health Charity
www.mind.org.uk
Telephone (9am – 6pm Monday to Friday) – 0300 123 3393

5. *What are the benefits of taking part?*

You will not personally benefit from the study, although, you may find it positive to talk about your experiences and have your thoughts heard. More widely, the information we get from this study may help to improve access to cognitive assessments in the future.

6. *What will happen to the results of the research?*

Your participation and the information we collect about you during the course of the research will be kept strictly confidential. The researcher will record the interview. After the interview, an external transcription will 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. After the recording has been typed up it will be deleted. 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.

7. How will we use information about you?

University of Leeds is the sponsor for this study. We will need to use information from you for this research project. Your data will be anonymised and have a code number instead of your name. We will keep all information about you safe and secure. We will keep anonymised information about you from this study for 3 years after the study has finished. Any personal information such as your name or contact details will be destroyed by the researcher as soon as the study is finished.

The data that will be collected about you will include your name, your age, your telephone number and email address (to be able to contact you).

Once we have finished the study, we will keep the anonymised 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.

If you would like us to send you an update with the result of the study after it is finished, then we will need to store your name and contact information until the end of the study. This will be stored securely and only be accessible to the lead researcher. This is optional, if you do not want this then we will not store this identifiable information about you.

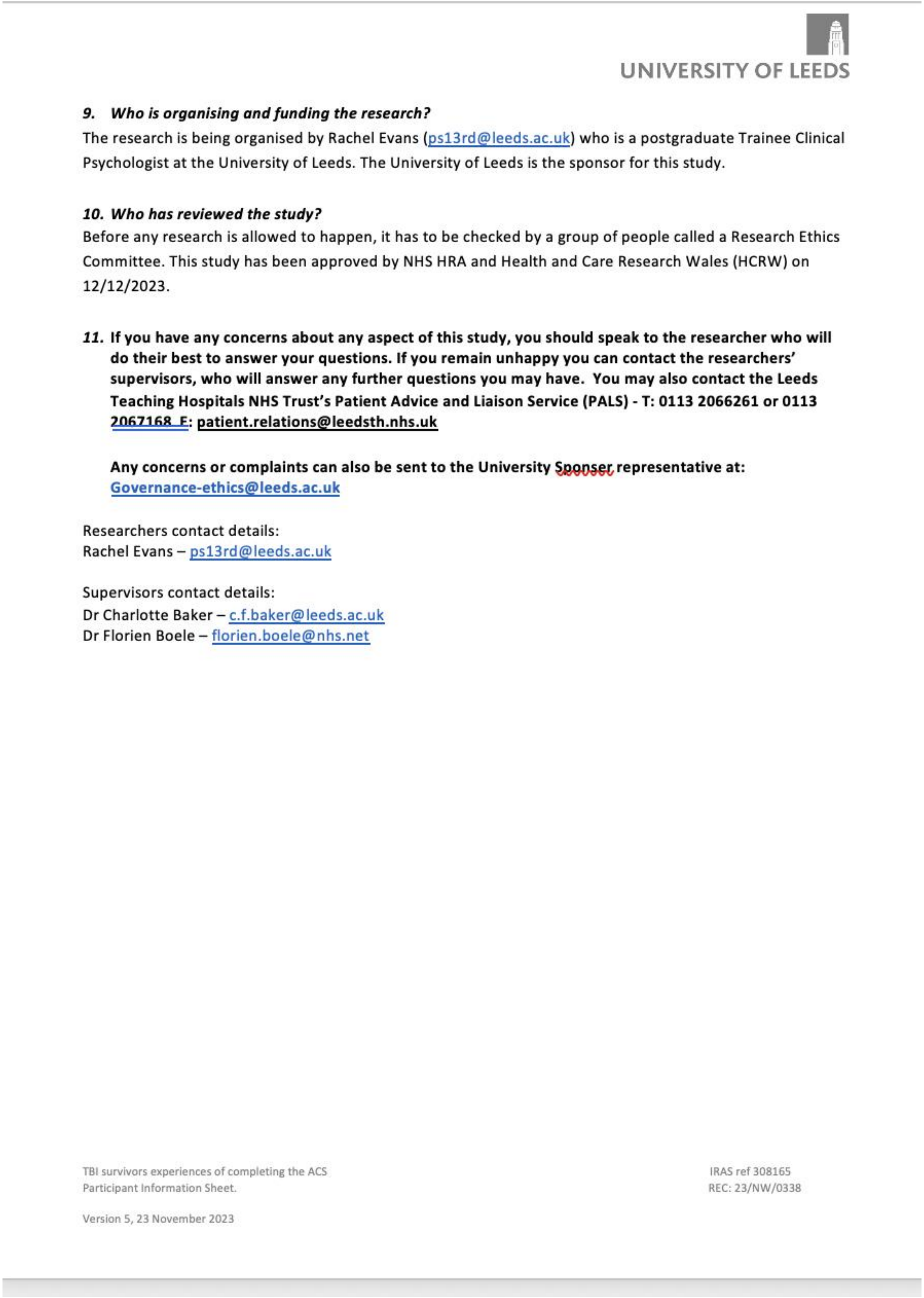
What are your choices about how your information is used if you have decided to take part?

- 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.

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 www.hra.nhs.uk/information-about-patients/
- at the University of Leeds privacy notice: https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf
- by asking the researcher
- by sending an email to the Data Protection Officer on dpo@leeds.ac.uk



9. Who is organising and funding the research?

The research is being organised by Rachel Evans (ps13rd@leeds.ac.uk) who is a postgraduate Trainee Clinical Psychologist at the University of Leeds. 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 has been approved by NHS HRA and Health and Care Research Wales (HCRW) on 12/12/2023.

11. **If you have any concerns about any aspect of this study, you should speak to the researcher who will do their best to answer your questions. If you remain unhappy you can contact the researchers' supervisors, who will answer any further questions you may have. You may also contact the Leeds Teaching Hospitals NHS Trust's Patient Advice and Liaison Service (PALS) - T: 0113 2066261 or 0113 2067168 E: patient.relations@leedsth.nhs.uk**

Any concerns or complaints can also be sent to the University Sponser representative at: Governance-ethics@leeds.ac.uk

Researchers contact details:
Rachel Evans – ps13rd@leeds.ac.uk

Supervisors contact details:
Dr Charlotte Baker – c.f.baker@leeds.ac.uk
Dr Florien Boele – florien.boele@nhs.net

A3 – Recruitment poster

Version 3 – 21 August 2023
IRAS ref 308165
REC: 23/NW/0338

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PARTICIPANTS WANTED

Hello! My name is Rachel and I am looking for people to take part in my thesis research project for my Clinical Psychology Doctoral degree.

Exploring the experiences of Traumatic Brain Injury survivors completing an online remote cognitive assessment

This study is looking to recruit participants who:

- **Have had a Traumatic Brain Injury**
- **Are a current UK resident**
- **Are 18 years of age or over**
- **Fluent in English language**

After a traumatic brain injury many people are asked to do neuropsychological assessments to support their recovery. These are tests of memory, thinking and behaviour which can involve number, word and pattern tests. These tests are usually done face to face, but COVID-19 made it hard to do these assessments in many services.

Online versions of these test are sometimes used in some other areas, like after a sports injury. These tests are not usually used in brain injury at the moment. Online tests that people can do at home could be useful for people's treatment and for research in the future. Online tests could allow more people to get access to these types of assessments and services.

An important first step is to find out how people with traumatic brain injuries find doing this type of remote online assessment, and what they think about them.

This study will involve participants having a go at an online cognitive assessment and being interviewed about how they find doing this. We are not looking at performance or scores, we are only interested in finding out how people experience doing the assessment. This information can be very useful to guide future research and the development of this type of test.

You can attend a face to face appointment or this study can be done remotely via a videocall, the total appointment time will be no longer than approx. 90 minutes.

If you are interested in finding out more about this study, participating in this study, or have any questions about the study, please contact the lead researcher using the contact details below:

Lead Researcher –

Rachel Evans (Post Graduate Trainee Clinical Psychologist) – ps13rd@leeds.ac.uk

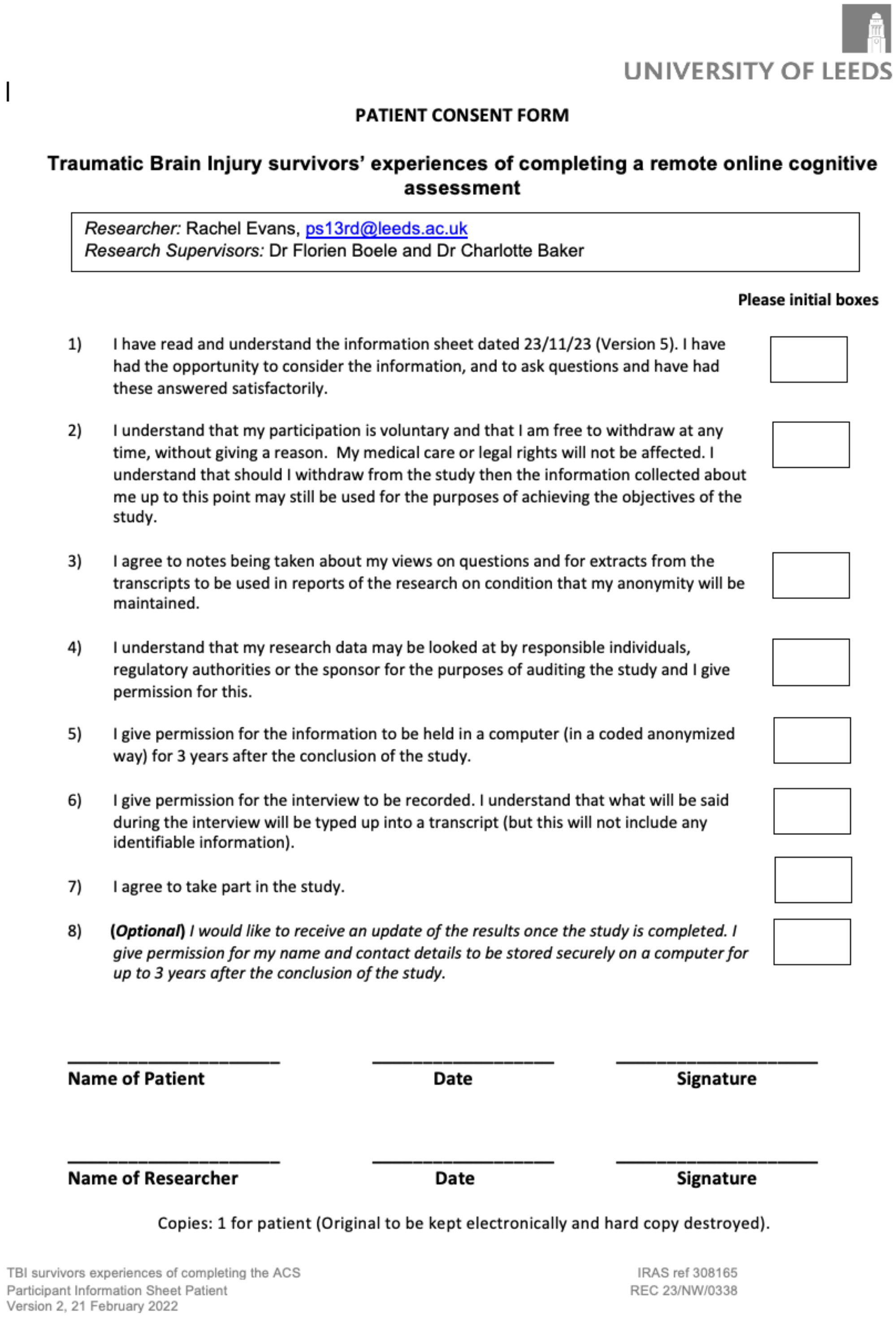
Research Supervisors –

Dr Florien Boele (Research Fellow at the University of Leeds) – f.boele@leeds.ac.uk

Dr Charlotte Baker – (Clinical Neuropsychologist, NHS) – c.f.baker@leeds.ac.uk

Ethical Approval – This study has been approved by NHS HRA and Health and Care Research Wales (HCRW) on 12/12/2023

A4 - Participant consent form



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PATIENT CONSENT FORM

Traumatic Brain Injury survivors' experiences of completing a remote online cognitive assessment

Researcher: Rachel Evans, ps13rd@leeds.ac.uk
Research Supervisors: Dr Florien Boele and Dr Charlotte Baker

Please initial boxes

1) I have read and understand the information sheet dated 23/11/23 (Version 5). I have had the opportunity to consider the information, and 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 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 the information to be held in a computer (in a coded anonymized way) for 3 years after the conclusion of the study. ☐

6) I give permission for the interview to be recorded. I understand that what will be said during the interview will be typed up into a transcript (but this will not include any identifiable information). ☐

7) I agree to take part in the study. ☐

8) ***(Optional)*** *I would like to receive an update of the results once the study is completed. I give permission for my name and contact details to be stored securely on a computer for up to 3 years after the conclusion of the study.* ☐

____________________	________________	___________________
Name of Patient	**Date**	**Signature**
____________________	________________	___________________
Name of Researcher	**Date**	**Signature**

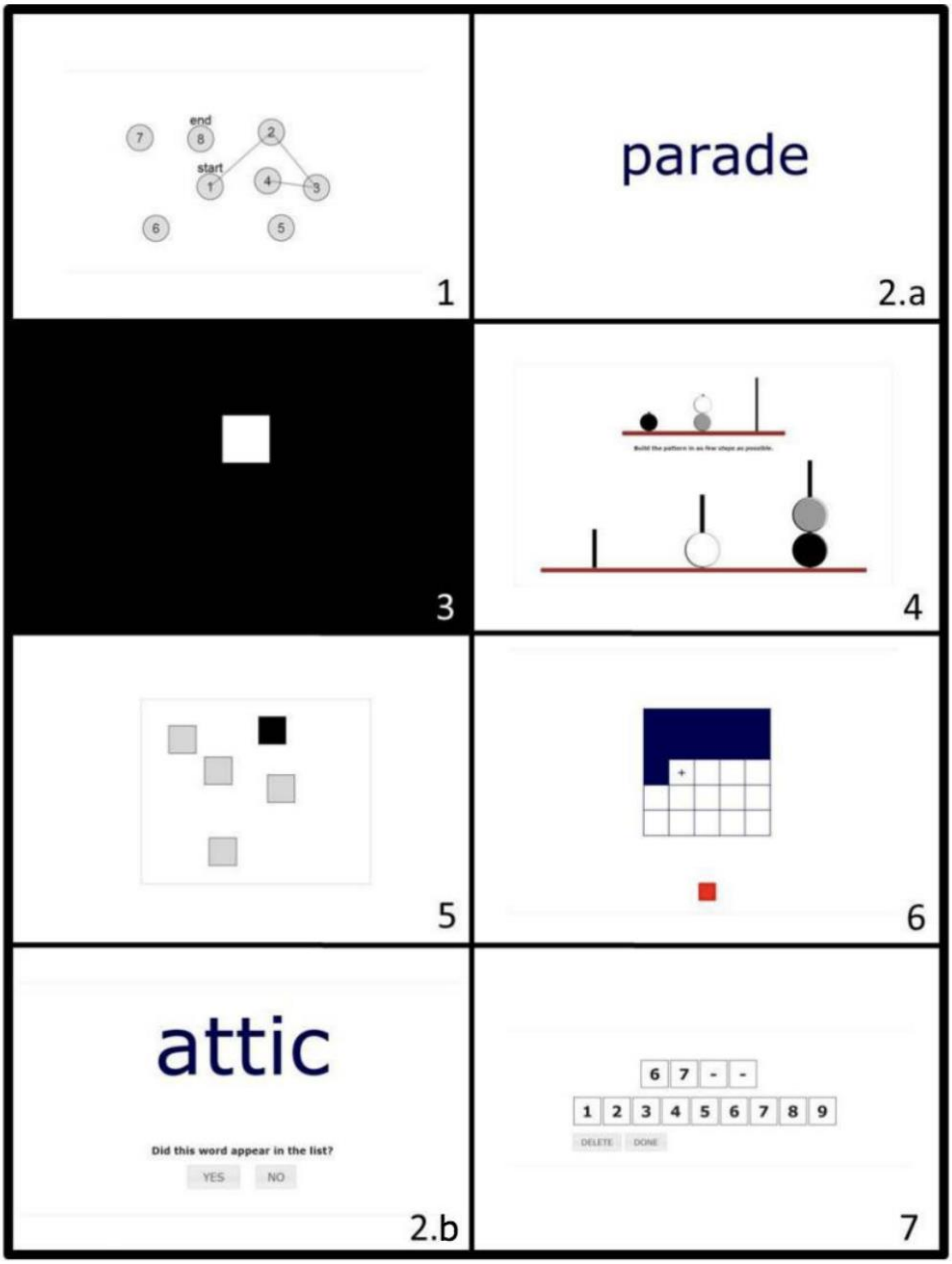
Copies: 1 for patient (Original to be kept electronically and hard copy destroyed).

TBI survivors experiences of completing the ACS
Participant Information Sheet Patient
Version 2, 21 February 2022

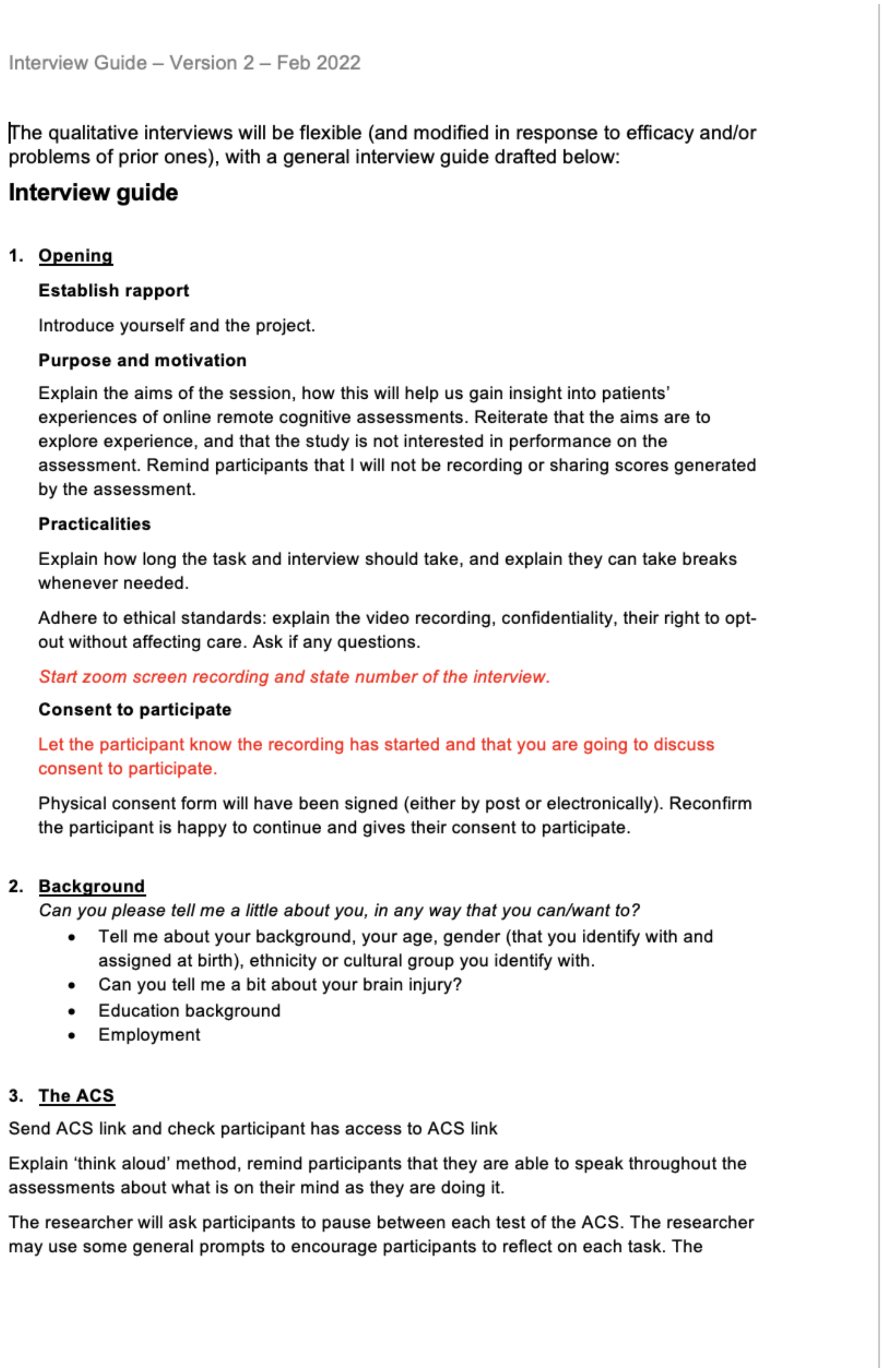
IRAS ref 308165
REC 23/NW/0338

Appendix B – Measures / Interview materials

B1 – visual representation of the cognitive tests from the ACS, in order of presentation



B3 – Interview guide



Interview Guide – Version 2 – Feb 2022

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:

Interview guide

1. Opening

Establish rapport

Introduce yourself and the project.

Purpose and motivation

Explain the aims of the session, how this will help us gain insight into patients' experiences of online remote cognitive assessments. Reiterate that the aims are to explore experience, and that the study is not interested in performance on the assessment. Remind participants that I will not be recording or sharing scores generated by the assessment.

Practicalities

Explain how long the task and interview should take, and explain they can take breaks whenever needed.

Adhere to ethical standards: explain the video recording, confidentiality, their right to opt-out without affecting care. Ask if any questions.

Start zoom screen recording and state 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.

Physical consent form will have been signed (either by post or electronically). Reconfirm the participant is happy to continue and gives their consent to participate.

2. Background

Can you please tell me a little about you, in any way that you can/want to?

- Tell me about your background, your age, gender (that you identify with and assigned at birth), ethnicity or cultural group you identify with.
- Can you tell me a bit about your brain injury?
- Education background
- Employment

3. The ACS

Send ACS link and check participant has access to ACS link

Explain 'think aloud' method, remind participants that they are able to speak throughout the assessments about what is on their mind as they are doing it.

The researcher will ask participants to pause between each test of the ACS. The researcher may use some general prompts to encourage participants to reflect on each task. The researcher will be watching the participant via the videocall while completing the ACS and may use any noticed reactions to structure prompts

- E.g. I noticed that your facial expressions changed a bit during that task, can you tell me what was going on for you then?

4. **Interview**

4a) Experiences of completing the ACS

- How did you find completing the assessment?
- Practical difficulties / problems with using the equipment or the layout of the test?
- How did you find the test platform / instructions (e.g. able to understand the instructions / were the tasks clear?)
- How did you find it to complete an assessment like this on a computer?
    - Was there anything about this which felt helpful?
    - Was there anything about this which felt difficult?
- How did it feel to do an assessment like this from your own home?
    - Was there anything about this which felt helpful?
    - Was there anything about this which felt difficult?
- Did you notice any emotions in yourself while you were completing the assessment?
    - At what point?
    - What did you feel?
    - What do you think made you feel that way?
- Did you notice any physical sensations in your body while you were doing the assessment?
    - At what point
    - What did you feel?
    - What do you think was causing that?
- Were there any thoughts running through your mind while you were doing the assessment / before / afterwards – explore these
- Have you ever completed an assessment a bit like this with someone face to face (yes/no)
    - If yes – how did completing this assessment online compare to that experience.
    - Were there any similarities or differences between these experiences?
    - How were the experiences different?
    - How were they similar?
    - Do you have a preference having tried both ways – why?
- What is most important to you when completing this type of assessment?
    - Prompts – setting, the assessor, results
- Anything you think is important for researchers developing this type of assessment for people with TBI should know? / think about?
- How would you feel if you had been asked to complete this as part of your clinical care – received feedback on it?

5. End of the interview

- Is there anything else that you think I need to know/ that you would like to tell me?
- Do you have any questions?
- How have you found this interview?

Turn off audio-recorder.
Explain following procedure. Provide contact information to contact us if anything is unclear or they need further information. Thank the participant for his/her time.

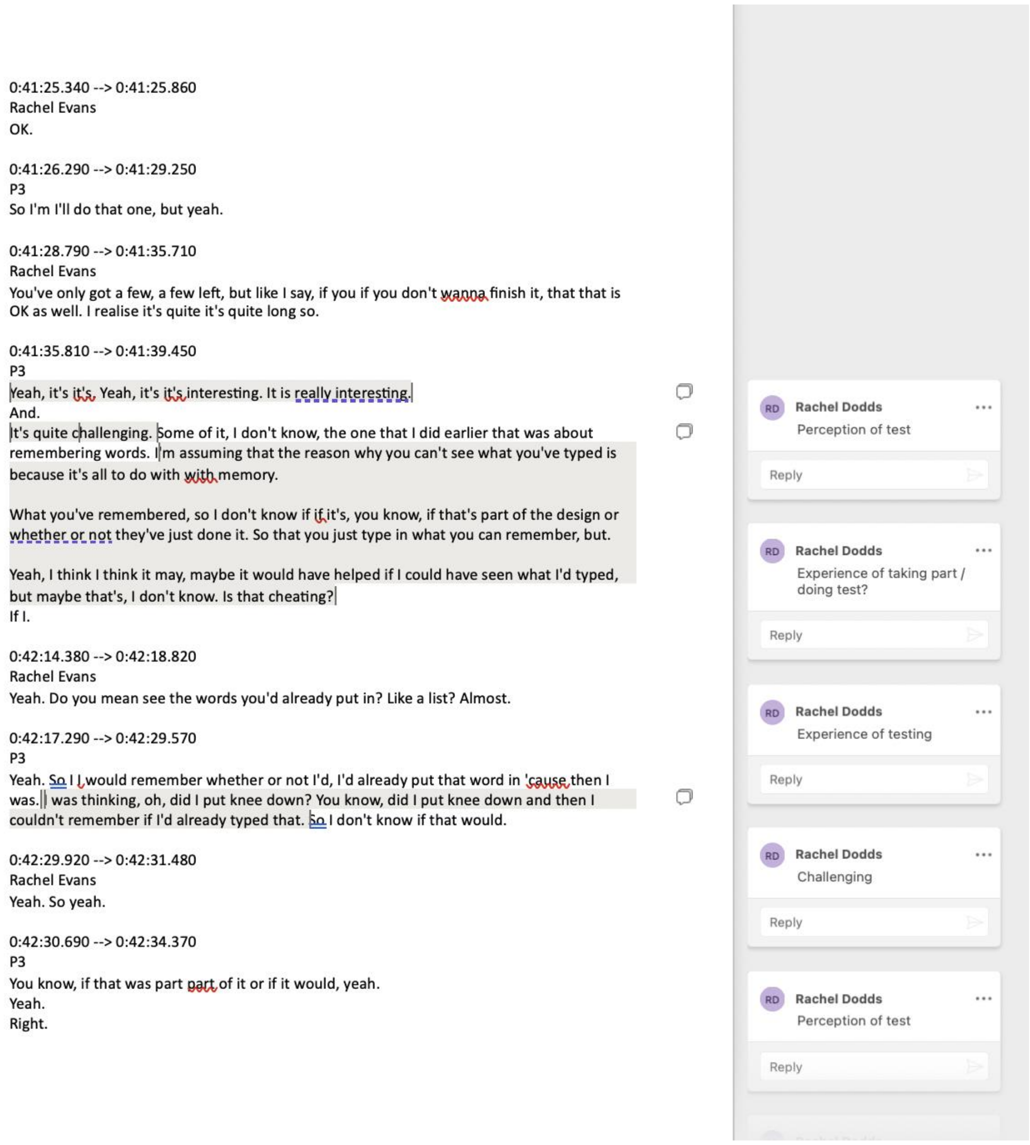
Note time end interview.

Standard follow-up questions

- What do you mean exactly?
- 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?
- Is there anything else that pops up?

Appendix C – Screenshots of analysis process

C1 – initial thoughts, annotations and codes added to transcripts



0:41:25.340 --> 0:41:25.860
Rachel Evans
OK.

0:41:26.290 --> 0:41:29.250
P3
So I'm I'll do that one, but yeah.

0:41:28.790 --> 0:41:35.710
Rachel Evans
You've only got a few, a few left, but like I say, if you if you don't wanna finish it, that that is OK as well. I realise it's quite it's quite long so.

0:41:35.810 --> 0:41:39.450
P3
Yeah, it's it's, Yeah, it's it's interesting. It is really interesting.
And.
It's quite challenging. Some of it, I don't know, the one that I did earlier that was about remembering words. I'm assuming that the reason why you can't see what you've typed is because it's all to do with with memory.

What you've remembered, so I don't know if if it's, you know, if that's part of the design or whether or not they've just done it. So that you just type in what you can remember, but.

Yeah, I think I think it may, maybe it would have helped if I could have seen what I'd typed, but maybe that's, I don't know. Is that cheating?
If I.

0:42:14.380 --> 0:42:18.820
Rachel Evans
Yeah. Do you mean see the words you'd already put in? Like a list? Almost.

0:42:17.290 --> 0:42:29.570
P3
Yeah. So I I would remember whether or not I'd, I'd already put that word in 'cause then I was. I was thinking, oh, did I put knee down? You know, did I put knee down and then I couldn't remember if I'd already typed that. So I don't know if that would.

0:42:29.920 --> 0:42:31.480
Rachel Evans
Yeah. So yeah.

0:42:30.690 --> 0:42:34.370
P3
You know, if that was part part of it or if it would, yeah.
Yeah.
Right.

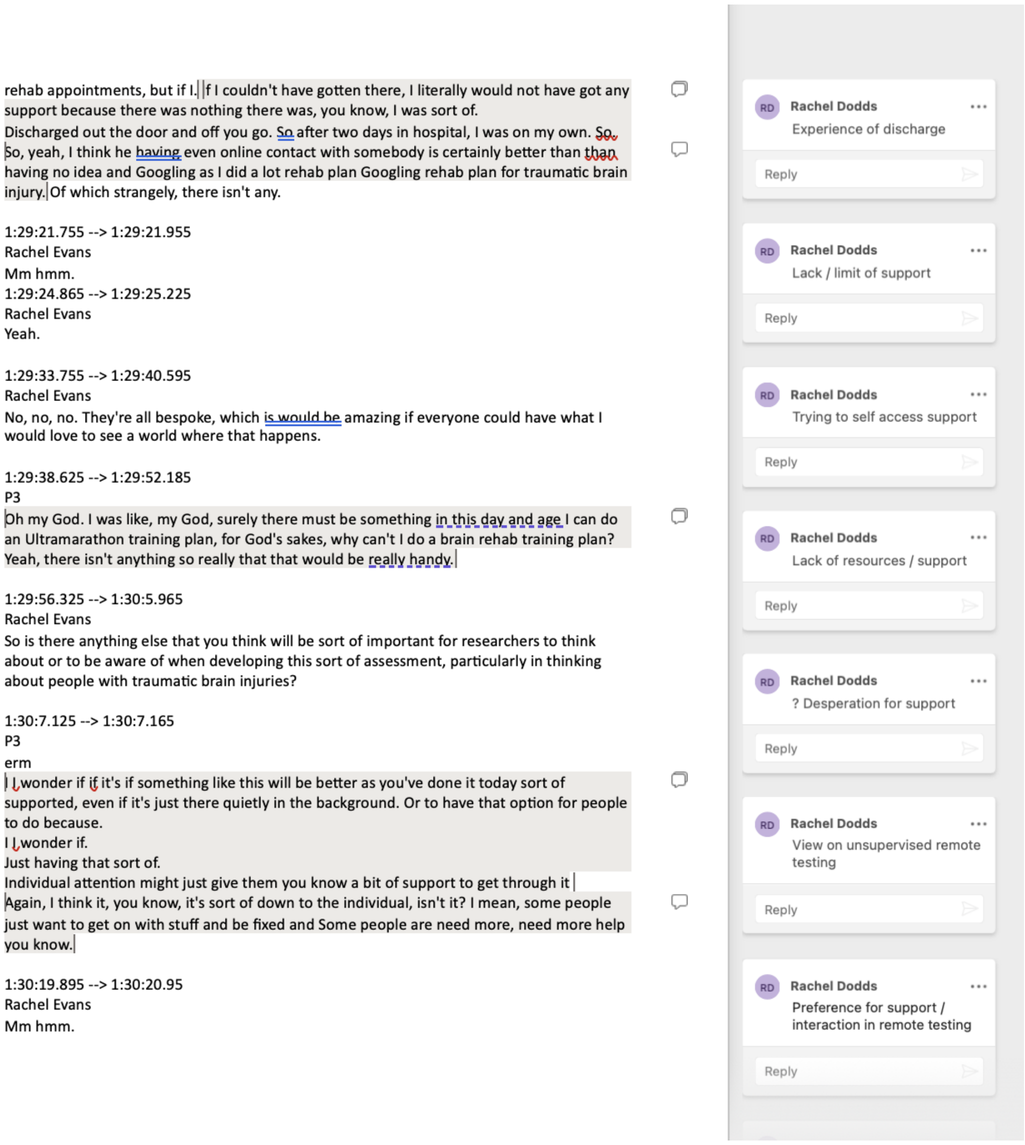
Rachel Dodds
Perception of test

Rachel Dodds
Experience of taking part / doing test?

Rachel Dodds
Experience of testing

Rachel Dodds
Challenging

Rachel Dodds
Perception of test



rehab appointments, but if I. If I couldn't have gotten there, I literally would not have got any support because there was nothing there was, you know, I was sort of.
Discharged out the door and off you go. So after two days in hospital, I was on my own. So.
So, yeah, I think he having even online contact with somebody is certainly better than than having no idea and Googling as I did a lot rehab plan Googling rehab plan for traumatic brain injury. Of which strangely, there isn't any.

1:29:21.755 --> 1:29:21.955
Rachel Evans
Mm hmm.
1:29:24.865 --> 1:29:25.225
Rachel Evans
Yeah.

1:29:33.755 --> 1:29:40.595
Rachel Evans
No, no, no. They're all bespoke, which is would be amazing if everyone could have what I would love to see a world where that happens.

1:29:38.625 --> 1:29:52.185
P3
Oh my God. I was like, my God, surely there must be something in this day and age I can do an Ultramarathon training plan, for God's sakes, why can't I do a brain rehab training plan? Yeah, there isn't anything so really that that would be really handy.

1:29:56.325 --> 1:30:5.965
Rachel Evans
So is there anything else that you think will be sort of important for researchers to think about or to be aware of when developing this sort of assessment, particularly in thinking about people with traumatic brain injuries?

1:30:7.125 --> 1:30:7.165
P3
erm
I I wonder if if it's if something like this will be better as you've done it today sort of supported, even if it's just there quietly in the background. Or to have that option for people to do because.
I I wonder if.
Just having that sort of.
Individual attention might just give them you know a bit of support to get through it
Again, I think it, you know, it's sort of down to the individual, isn't it? I mean, some people just want to get on with stuff and be fixed and Some people are need more, need more help you know.

1:30:19.895 --> 1:30:20.95
Rachel Evans
Mm hmm.

RD **Rachel Dodds**
Experience of discharge

RD **Rachel Dodds**
Lack / limit of support

RD **Rachel Dodds**
Trying to self access support

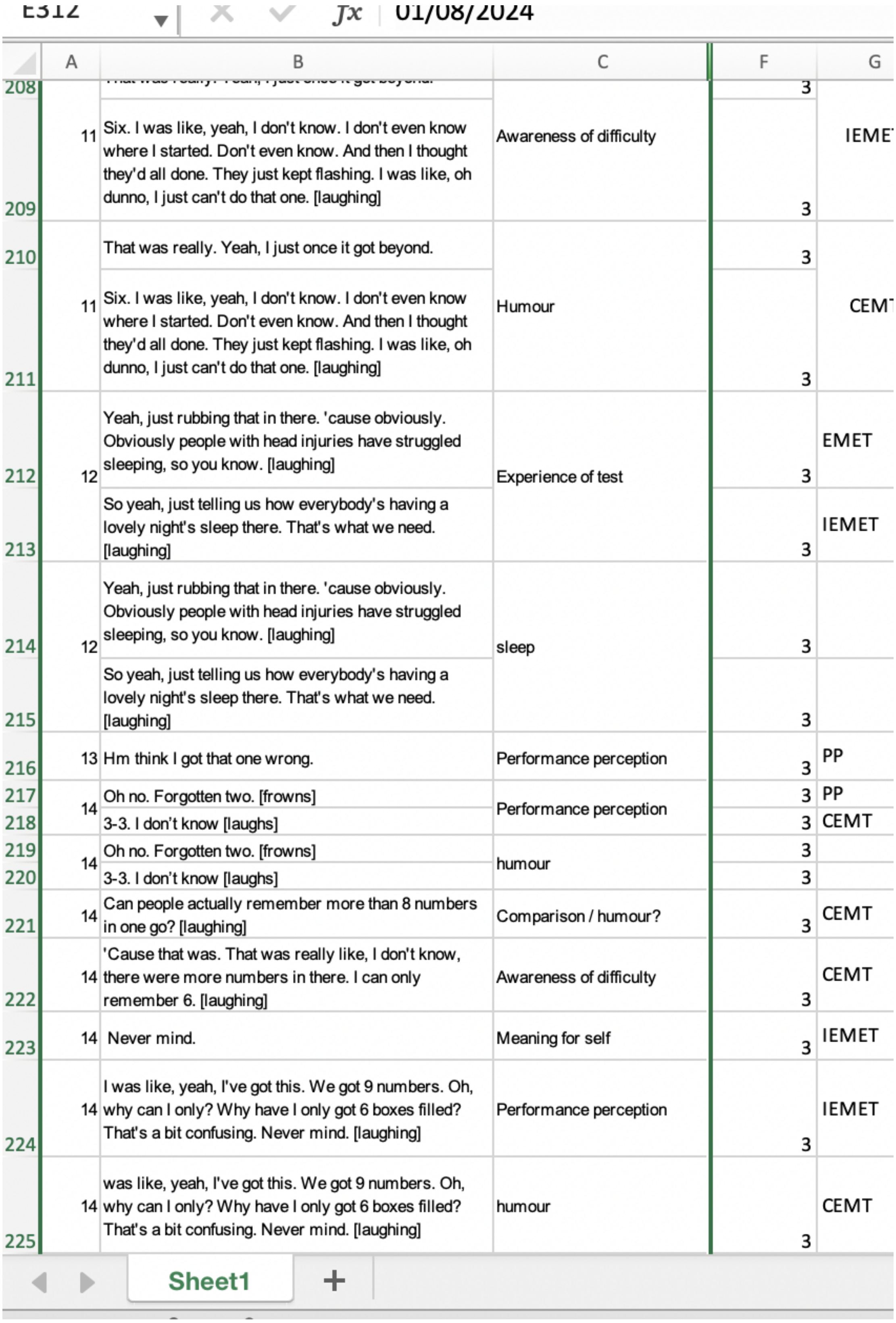
RD **Rachel Dodds**
Lack of resources / support

RD **Rachel Dodds**
? Desperation for support

RD **Rachel Dodds**
View on unsupervised remote testing

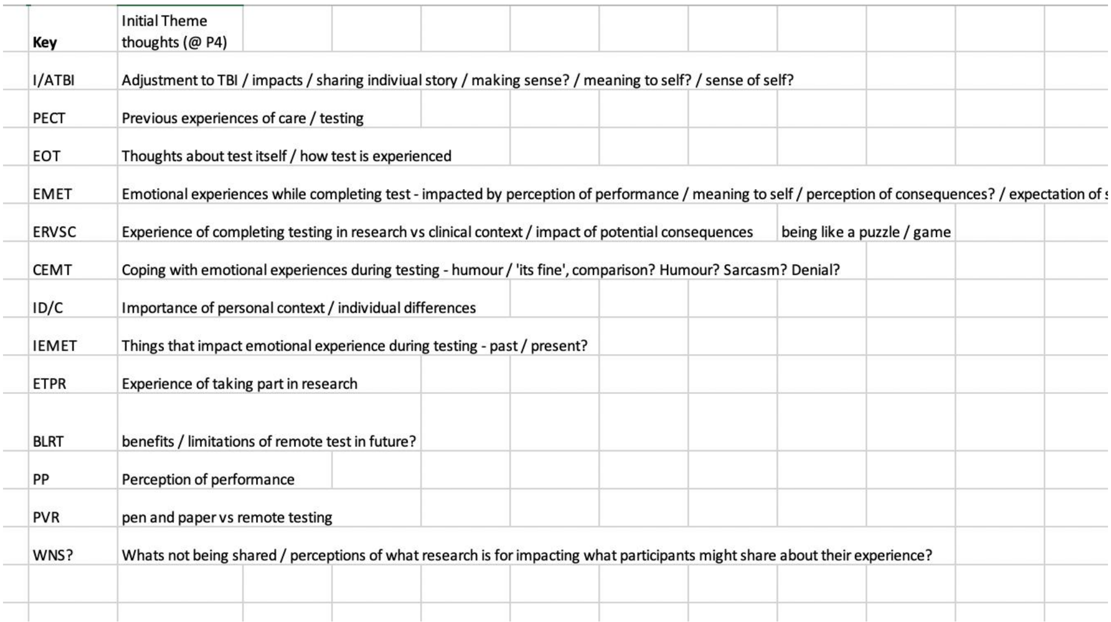
RD **Rachel Dodds**
Preference for support / interaction in remote testing

C2 – quotes and comments extracted and further codes added



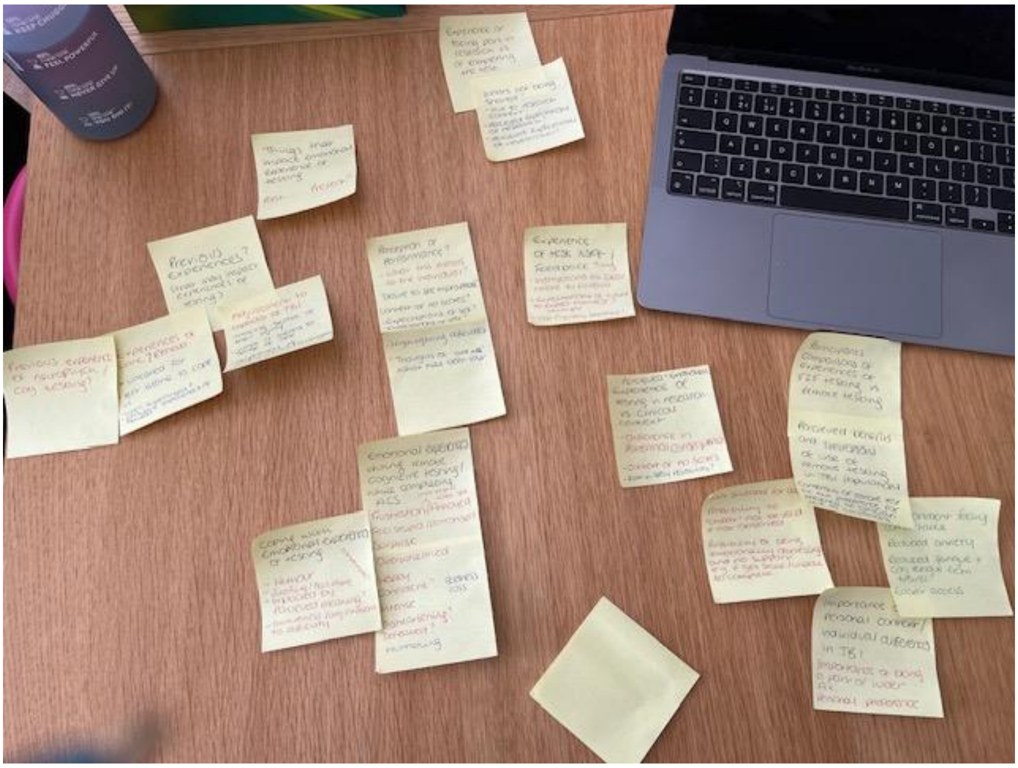
	A	B	C	F	G
208	11		Awareness of difficulty	3	IEME
209		Six. I was like, yeah, I don't know. I don't even know where I started. Don't even know. And then I thought they'd all done. They just kept flashing. I was like, oh dunno, I just can't do that one. [laughing]		3	
210	11	That was really. Yeah, I just once it got beyond.	Humour	3	CEM
211		Six. I was like, yeah, I don't know. I don't even know where I started. Don't even know. And then I thought they'd all done. They just kept flashing. I was like, oh dunno, I just can't do that one. [laughing]		3	
212	12	Yeah, just rubbing that in there. 'cause obviously. Obviously people with head injuries have struggled sleeping, so you know. [laughing]	Experience of test	3	EMET
213		So yeah, just telling us how everybody's having a lovely night's sleep there. That's what we need. [laughing]		3	IEMET
214	12	Yeah, just rubbing that in there. 'cause obviously. Obviously people with head injuries have struggled sleeping, so you know. [laughing]	sleep	3	
215		So yeah, just telling us how everybody's having a lovely night's sleep there. That's what we need. [laughing]		3	
216	13	Hm think I got that one wrong.	Performance perception	3	PP
217	14	Oh no. Forgotten two. [frowns]	Performance perception	3	PP
218		3-3. I don't know [laughs]		3	CEMT
219	14	Oh no. Forgotten two. [frowns]	humour	3	
220		3-3. I don't know [laughs]		3	
221	14	Can people actually remember more than 8 numbers in one go? [laughing]	Comparison / humour?	3	CEMT
222	14	'Cause that was. That was really like, I don't know, there were more numbers in there. I can only remember 6. [laughing]	Awareness of difficulty	3	CEMT
223	14	Never mind.	Meaning for self	3	IEMET
224	14	I was like, yeah, I've got this. We got 9 numbers. Oh, why can I only? Why have I only got 6 boxes filled? That's a bit confusing. Never mind. [laughing]	Performance perception	3	IEMET
225	14	was like, yeah, I've got this. We got 9 numbers. Oh, why can I only? Why have I only got 6 boxes filled? That's a bit confusing. Never mind. [laughing]	humour	3	CEMT

C3 – Initial themes emerging through discussion with research team after coding transcripts

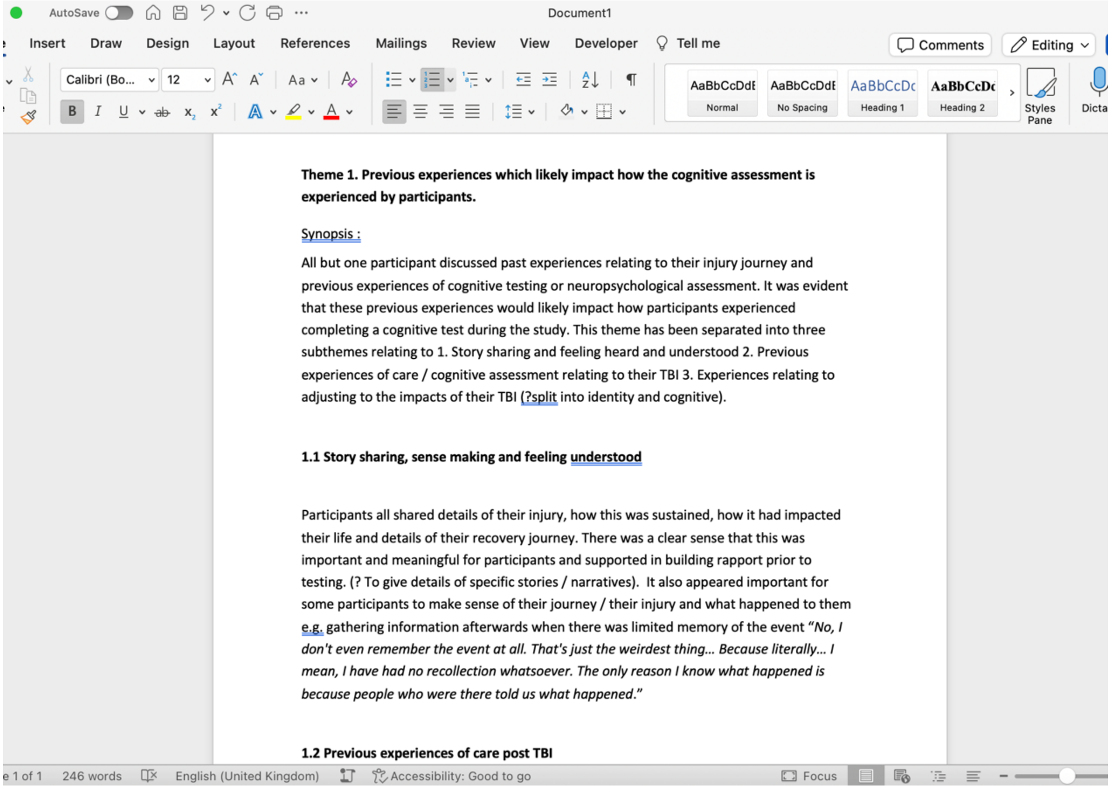


Key	Initial Theme thoughts (@ P4)	
I/ATBI	Adjustment to TBI / impacts / sharing indiviual story / making sense? / meaning to self? / sense of self?	
PECT	Previous experiences of care / testing	
EOT	Thoughts about test itself / how test is experienced	
EMET	Emotional experiences while completing test - impacted by perception of performance / meaning to self / perception of consequences? / expectation of	
ERVSC	Experience of completing testing in research vs clinical context / impact of potential consequences	being like a puzzle / game
CEMT	Coping with emotional experiences during testing - humour / 'its fine', comparison? Humour? Sarcasm? Denial?	
ID/C	Importance of personal context / individual differences	
IEMET	Things that impact emotional experience during testing - past / present?	
ETPR	Experience of taking part in research	
BLRT	benefits / limitations of remote test in future?	
PP	Perception of performance	
PVR	pen and paper vs remote testing	
WNS?	Whats not being shared / perceptions of what research is for impacting what participants might share about their experience?	

C4 – Refining, defining and organising themes and subthemes in discussion with research team



C5 – producing a synopsis for each theme and discussing these with the research team prior to final write up of results



Theme 1. Previous experiences which likely impact how the cognitive assessment is experienced by participants.

Synopsis :

All but one participant discussed past experiences relating to their injury journey and previous experiences of cognitive testing or neuropsychological assessment. It was evident that these previous experiences would likely impact how participants experienced completing a cognitive test during the study. This theme has been separated into three subthemes relating to 1. Story sharing and feeling heard and understood 2. Previous experiences of care / cognitive assessment relating to their TBI 3. Experiences relating to adjusting to the impacts of their TBI (?split into identity and cognitive).

1.1 Story sharing, sense making and feeling understood

Participants all shared details of their injury, how this was sustained, how it had impacted their life and details of their recovery journey. There was a clear sense that this was important and meaningful for participants and supported in building rapport prior to testing. (? To give details of specific stories / narratives). It also appeared important for some participants to make sense of their journey / their injury and what happened to them e.g. gathering information afterwards when there was limited memory of the event *"No, I don't even remember the event at all. That's just the weirdest thing… Because literally… I mean, I have had no recollection whatsoever. The only reason I know what happened is because people who were there told us what happened."*

1.2 Previous experiences of care post TBI