Experiences of Culturally Adapted Cognitive Tests in Memory Services

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Abstract

Introduction: There are multiple inequalities experienced by people from minoritised ethnic backgrounds when diagnosing dementia. One, is that the cognitive assessments are not culturally appropriate. The ACE-III has been culturally adapted for South Asian communities in the UK, specifically those who speak Urdu and Hindi. This study aims to explore service users', family and supporters' and staff members' experiences of the culturally adapted ACE-III.

Methods: Semi-structured interviews were undertaken with ten participants; three service users who had recently undergone the adapted assessment, three family members who supported during the assessment and four staff members who administered the assessment. The interviews were analysed using reflexive thematic analysis.

Results: Three themes were identified. *'What Culture Though? Language Matters'* explores how the adaptations within the culturally adapted ACE-III were valuable at times but were not always helpful or relevant. The theme *'Uncertainty Around the Purpose and Process'* focuses on the uncertainty experienced by the participants and how this impacted how it was administered and confusion when working with interpreters. Finally, *'It's a Start: Moving Towards Equitability'* considers how the cultural adaptations begin to address some of the inequalities in non-adapted assessments, and how to keep working towards this.

Discussion: This study highlights some of the challenges in culturally adapting a cognitive screen from the perspective of service users, their family and supporters and staff members. The cultural adaptations were valued in some respects, such as providing more familiar and relevant assessment content. However, some cultural adaptations were less helpful, and, for some, elements of the non-adapted assessment were preferable to the adapted version. The complexity and tension in personalising the assessments whilst still adhering to standard procedures in cognitive tests to maintain validity are discussed. The strengths of this study, such as this being one of the first in-depth studies to explore service user, family and supporter and staff members experiences, from a minoritised ethnic background, of culturally adapted cognitive screen as part of a memory assessment are discussed. This project has highlighted important areas for future research and provided novel insight into service user and family experiences of acculturation, the use of additional languages and personalising cognitive tests whilst maintaining the psychometric integrity of the test.

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Chapter One: Introduction

This chapter begins with an overview of the project and then focuses on the language used throughout the project. I then explore some of the literature on dementia and dementia diagnosis before considering psychometric testing and the development of cognitive tests. Factors affecting dementia diagnosis and inequalities experienced by people from minoritised ethnic backgrounds will then be discussed. This will lead onto cultural adaptations in dementia assessments and a culturally adapted cognitive screening test. Finally, the rationale for this research project and research aims and questions will be outlined.

1. Overview of the Project

This project explored service users, family and supporters and staff members' experiences of a culturally adapted cognitive screen as part of a memory assessment. Specifically, the Addenbrooke's Cognitive Examination (ACE-III) has been adapted for UK South Asian communities and has questions adapted from a cultural perspective as well as being in Urdu and Hindi; see '*Cultural Adaptation of the ACE-III*' below for more details of how the ACE-III has been culturally adapted. Before background the background literature is discussed, I will start by discussing some important considerations around language and cultural identity.

1.1 A Note on Language

The terminology used to describe people in this project has been considered whilst trying to be responsive to evolving language. The intention of this research is to add to the literature and consider ways to further improve care for people undergoing a memory assessment, in a sensitive and respectful way. I have tried to consider my own position and reflect on this throughout the research, whilst appreciating that this research is situated in a particular context (see below for more reflection on this). This intention has been central to this research, and it is hoped that this comes across to the reader. Before situating the current research, and the terminology and language used, some important factors will be considered such as culture, race and intersectionality.

1.2 Culture and Acculturation

In thinking about language, how we describe people and how people identify themselves, the concept of culture is important. Spencer-Oatey and Franklin (2012) highlight the complexity in defining culture. For the purposes of this research, the notion of culture will be summarised, drawing on key points from the literature, whilst crucially noting that culture is interpreted in many different ways. From the many definitions that have attempted to define culture, importance has been placed on values, morals, attitudes and beliefs that have been passed down through generations. A common feature amongst definitions is that behaviour is also influenced by culture (Spencer-Oatey & Franklin, 2012). From this, acculturation is a term that attempts to capture a shift in culture, the idea that culture can shift and changes depending on where someone is living. Examples of this drew upon migration and explored how people 'change' in accordance with the 'mainstream' culture they have moved to. As a result, migrant communities may develop 'bicultural' identities where they adopt aspects of the 'mainstream' culture they reside in as well as maintain aspects of culture from their countries of origin (Van de Vijver & Phalet, 2004). As mentioned, culture is something that is transient and is made sense of individually, so it would also make sense for culture to also be influenced by people who have migrated to different places. This is important to consider when exploring the culturally adapted memory assessment. This is particularly the case for communities such as people from South Asian backgrounds who have migrated to the UK, where considering culture and acculturation will impact what is relevant and meaningful in memory assessments.

1.3 Race as a Social Construct

When thinking about culturally adapted assessment tools, as well as considering the concepts of culture and acculturation, there are some aspects of 'race' which are important to understand. Race is a social and political construct with there being no scientific evidence for biological differences between 'racial' groups (e.g., Bryant, et al., 2022; Lopez., 1995; Smedley & Smedley, 2005; Witzig, 1996). Crucially though, the concept of 'race' and how it is used has a real impact on people's lives. It is important to recognise the role psychology has played in contributing to the development of 'race' in its use as a 'biological' determinant (see *'Understanding the Development of Neuropsychological Assessment'* below for a more comprehensive overview and the impact of this). The distinction between race and ethnicity and impact of using such terms in relation to power and inequality is complex (Song, 2009). This research has used the term ethnicity, which refers to cultural expression and captures someone's heritage, history, traditions, language and geographical location (Desmet et al., 2017). As this project is exploring the impact of cultural adaptations in cognitive tests, ethnicity as a term captures more around cultural expression and experience and also recognises this is also an individually and socially constructed concept.

1.4 Introducing Intersectionality

In thinking about culture and ethnicity, it is helpful to introduce 'identity' and the concept of 'intersectionality'. People can choose how they identify themselves, and different parts of their identity will be more important or more visible than other parts. The term intersectionality was first coined by Kimberlé Crenshaw to describe how different parts of people's identity intersect and result in very different experiences (Crenshaw, 1989). A key example Crenshaw has spoken about is how discrimination experienced by a black woman was dismissed as the experience was not shared by black men (i.e., not 'racial' discrimination) or white women (i.e., not sexist), failing to capture how two forms of discrimination impact black women (Crenshaw, 1989). Intersectionality will be considered throughout this research, for example, thinking about education, culture and language skills there are many different ways these aspects of identity intersect and impact the experience of the culturally adapted memory assessment.

1.5 The Language Within this Research Project

This project focuses on the experiences of service users who received a culturally adapted cognitive assessment in memory services. Specifically, this project will focus on experiences of people from the South Asian community. South Asia refers to eight countries: Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka. Where appropriate, the language used to describe participants will be as specific as possible, whilst acknowledging that the group being described is not a homogenous group of people. For this study, Mohammed, a collaborator (see *'Community Engagement'* in the *'Methodology'* chapter for more details) has provided support and valuable discussions about language use as well as cultural norms, stigma and taboos within the South Asian communities in Bradford.

It is noted that in the literature review that research has used different terms to describe the participants in the studies. When discussing this research, and where appropriate, the term 'minoritised ethnic' groups and communities will be used to describe participants. This is to recognise the context of the research and terms used within this context (i.e., in the UK, minoritised ethnic is a term used to describe people who aren't White British, and this also includes White minority ethnic groups such as Polish people). This term also recognises that people are minoritised by social processes of power (The Law Society, 2025). Furthermore, minoritised ethnic is preferred over 'ethnic minority' as the former recognises that everyone has an ethnicity and moves away from the shortening of ethnic minority to 'ethnic'. As mentioned, when describing people in this research project, I aim to be as specific as possible and acknowledge that using broad terms such as 'minoritised ethnic' should be used in a considered way. Where this term has been used, it is to reflect the current research studies and is aiming to highlight some of the social processes and power that people are minoritised by. For example, this is explored in relation to receiving a timely diagnosis of dementia and some of the inequalities experienced by minoritised ethnic communities in the UK. As above, language will rightly continue to evolve, and I have considered how to position the research and attempted to be thoughtful in the language used. As mentioned, people can choose how they identify, and this was also explored further in the interviews with participants.

1.6 The Term 'Service User'

Before thinking about what the above means for research in more detail, a further term used in this thesis - 'service user' – needs consideration. This term has been included given the research is about exploring the experiences of people who access Memory Assessment Services (MAS). Whilst there has been a recent shift to adopting the term 'people living with dementia' sometimes shortened to 'plwd', this abbreviation can be problematic as it arguably loses a person-centred focus. It should be noted that the participants in this study may not identify with this label for a number of reasons, a main one being they do not yet know at the time of the assessment whether they are a 'person living with dementia'. The term 'service user' has been selected as it is used within the service that the participants were accessing. Indeed, this term is not without its problems too (such as also losing a person-centred focus), and it is worth acknowledging that existing structures do not allow for people to be identified in other ways (Shannon, 2019). The term 'service user' is widely used in services and given the range of participants in this project, this term enables a distinction to be made between the groups (i.e. service users, family and supporters and staff members).

1.7 The Context of the Current Research

From this, the language used in this study is reflective of the current context in the UK and written from my perspective. I identify with a 'mixed' heritage (mostly) White and (partly) Arab. That being said, I do benefit from 'white privilege' or 'structural advantage' (i.e., benefitting in society from having light skin); I have tried to acknowledge this when thinking about the purpose of this research and how the project has been developed and interpreted. I am also a cis-gendered woman (i.e. I identify with the gender I was assigned at birth) studying to be a clinical psychologist from a working-class background in the north of England. Again, these feel like important aspects of my identity when thinking about how the project has been developed and interpreted and will be considered further in the *'Reflexivity'* section in the '*Methodology'* chapter. Indeed, trying to simply categorise identity in an efficient, relevant and meaningful way has required a lot of reflection and (un)learning and this also appears to be a theme of this research. This section has considered the language and terminology used in this research project. The next section focuses on dementia and the literature on how this is diagnosed.

2. What is Dementia?

It is estimated that around 982,000 people in the UK are living with dementia (Carnell Farrar, 2024). Dementia is a neurodegenerative condition that is chronic and progressive and affects brain functioning including memory and other cognitive functions such as language, thinking and reasoning (Arblaster, 2021). Dementia can also affect a person's mood, emotions and behaviour. The World Health Organisation (WHO, 2025) defines the cognitive decline characteristic of dementia as beyond that usually expected in biological ageing. Dementia has a huge impact on the person, family and support network, and society. Not only is there an understandable emotional impact of a diagnosis, but support is often needed from a health, care, social, financial and legal perspectives (WHO, 2025).

The process of diagnosing dementia can vary, but in the UK typically starts with an initial assessment of cognition and physical health with a GP or healthcare professional, followed by a longer assessment at a memory clinic and, if necessary, a brain scan (Alzheimer's Society, 2023). There is disparity in diagnosis rates, with people from a White ethnic background received an earlier (or 'timely', see below) diagnosis and people from minoritised ethnic backgrounds being more likely to be diagnosed in a crisis (Tsamakis et al., 2021). Worryingly, the Centre for Policy on Ageing and The Runnymede Trust (2010) predicted that by 2051, dementia in minoritised ethnic communities will increase nearly seven-fold, in comparison to just over a two-fold for the whole UK population. Given this, it is vital to understand more about risk factors and the complexities in developing and diagnosing dementia, and why people from minoritised ethnic backgrounds are more likely to develop dementia (Livingston et al., 2024) but experience additional diagnostic challenges.

It is also important to highlight that health inequalities are the result of social factors and social injustices such as racism and racial discrimination and austerity, impacting on both mental and physical health (Centre for Aging Better, 2021) and they will play a role in understanding the impact of different risk factors. It is essential to recognise the role of social injustices including racism in health inequalities, rather than viewing these as individual factors which cannot be changed and therefore perpetuate these inequalities (Byrd & Rivera-Mindt, 2022; Hardeman & Karbeah, 2020; Williams et al., 2019). The context of this research is in the UK, and it is necessary to consider these health inequalities and how they may impact communities. Furthermore, it is helpful to consider how people from minoritised ethnic backgrounds in the UK may access and experience memory services (including memory assessments which may not be culturally appropriate) and this will be considered in more detail below.

2.1 How is Dementia Diagnosed?

Dementia is assessed by taking a history of the person, including cognitive, behavioural and psychological symptoms. A physical examination is undertaken before cognitive testing takes place to rule out any physical health causes of cognitive difficulties (NICE, 2018). The diagnosis of dementia is a challenging process, particularly for many service users who experience the assessment process as lengthy, distressing and uncertain (Manthorpe et al., 2013). The British Psychological Society (BPS; 2016) highlights how psychological assessments can provide important information about the severity and progression of dementia. This can be important if people with dementia are to receive effective care and support. Importantly, research has also highlighted inequalities in people from minoritised ethnic backgrounds receiving a diagnosis of dementia (Arblaster, 2021; Pham et al., 2018). There are several different factors that contribute to these inequalities, such as inequalities in accessing services, understanding of dementia in minoritised ethnic communities and systemic factors such as a lack of cultural understanding and assessments within services. These will be explored in more detail below.

2.2 Dementia Assessments

There are many cognitive screening tools used in the process of diagnosing dementia; for example, commonly used assessments include the Mini-Mental State Examination, the Montreal Cognitive Assessment and the Addenbrooke's Cognitive Examination. These tools give an insight into cognitive difficulties someone may be experiencing. This research project focuses on the Addenbrooke's Cognitive Examination (ACE-III) cognitive screening tool used in the diagnosis of dementia (Bruno & Vignaga, 2019). The project focuses on the ACE-III as it is a widely used cognitive screen in the UK and has been adapted to use with different communities (see below for more details). The ACE- III is administered initially to establish if the individual is experiencing cognitive impairment and gives an overview of more specific areas of cognitive impairment. Within the ACE-III there are 5 cognitive domains that are assessed: attention, memory, fluency, language and visuospatial. The ACE-III involves asking individual questions as well as asking the service user to complete a set of tasks and questions which are marked out of 100. For example, reading tasks, remembering information, drawing and recognising images. Further tests such as a detailed neuropsychological assessment and structural imaging may be offered if a dementia diagnosis is unclear from the initial assessments (NICE, 2018).

2.2.1 Understanding the Development of Cognitive Testing.

When thinking about cognitive testing, it is important to consider the historical context and the development of psychometric testing more broadly. Psychology has a complex racialised history, including the use of psychometric testing as a way to 'prove' racial differences and 'white supremacy' such as through IQ testing and the bell curve, which is the distribution of IQ scores throughout the population (Mirza, 2000; Newby & Newby, 1995) and the use of racist stimuli in materials (Byrd et al., 2021; Guthrie, 2004; Richards, 2012). As well as the racialised development of psychometric testing, compliance to these standardised manuals that contain racist stimuli when administering psychometric tests are another example of structural racism (see the Boston Naming Test example below). These tests have largely been developed for and normed with White participants (Brickman et al., 2006; Gasquoine, 2009; Heaton et al., 2009). Furthermore, simply just accounting for demographic differences such as ethnicity is problematic when tests contain racist content and by adhering to these protocols, the discipline continues to disadvantage, and possibly cause harm, to those from minoritised ethnic communities. To highlight this, Byrd et al. (2021) give a striking example of the inclusion of the noose in the Boston Naming Test (BNT). They explain that the racialised weaponisation of the noose in the United States has resulted in the noose becoming a racial hate symbol, and the inclusion of this item in the BNT is deeply offensive and an example of the structural racism in psychology. The impact of the structural racism in psychology is huge and understandably can result in those from minoritised ethnic backgrounds distrusting the health care system. In relation to this current project, it is important to understand the development of psychometric testing, which includes cognitive tests and screening tools, and the impact on minoritised ethnic communities undergoing these assessments, and this will be explored further in the '*Additional Difficulties to Obtaining a Dementia Diagnosis for People from Minoritised Ethnic Backgrounds'* section below.

2.2.2 Service User Experiences of Cognitive Tests.

As well as attending to historical and ongoing bias in the development of psychometric testing, it is also important to attend to the experiences of those undergoing testing. The research on service user experiences of psychometric and cognitive tests captures a variety of experiences. Some studies have focused on service user experiences of assessments for a range of neurodegenerative conditions (such as Multiple Sclerosis, Parkinson Disease and Motor Neurone Disease), for example Blake (2004) and Sweetman (2018) discussed below. Predominantly, these studies have used quantitative methods such as questionnaires to assess patient satisfaction with the whole assessment process, from attending the appointment to receiving the feedback, which was a largely positive experience, i.e., they were largely satisfied with the assessment process (see Bennett-Levy et al., 1994; Hailey et al., 2016; Rosado et al., 2017; Westervelt et al., 2007). Some studies have explored service users' experiences of more in depth neuropsychological tests using qualitative methods, such as interviews. For example, Blake (2004) carried out interviews with service users with cognitive impairment, although this focused on a battery of neuropsychological testing for a variety of conditions including, stroke, head injury, epilepsy and autoimmune disease, rather than specifically focused on dementia. Also, the service users were all aged under 65 years old, excluding the older adult population. There was no reporting on the ethnicity of the participants; therefore, the inclusion of those from a minoritised ethnic background is unknown. This research explored the whole assessment process, and aspects of the neuropsychological assessment, concluding that participants' emotional responses to the test included anxiety, fear and uncertainty (Blake, 2004). Since then, Sweetman (2018) has also investigated service users' experiences of neuropsychological assessments. Participants all had a diagnosis of a neurodegenerative condition and were undergoing neuropsychological testing as part of monitoring their condition. All of the participants were from a White European background. The main findings from this research highlighted that service users generally experienced the assessment process as a positive experience on the whole. Collectively, these studies suggest that the assessment process in neuropsychological testing in the UK is generally positive. Some studies suggest participants feel anxious and uncertain about the assessment process, but the rapport with the staff member administrating the test was generally positive (e.g., Blake 2004; Sweetman, 2018). Other studies report a positive, or 'satisfied' experience (Bennett-Levy et al., 1994; Hailey et al., 2016; Rosado et al., 2017; Westervelt et al., 2007).

Some research has found that service users and their families experienced distress and uncertainty during neuropsychological assessment for dementia (Gruters et al., 2021; Keady & Gilliard, 2002; Robinson 2016; Samsi et al., 2014). For example, in Gruters et al. (2021), people reported feeling uncertain about the whole process of a memory assessment, accompanied by specific concerns about the neuropsychological assessment including what to expect and whether they were doing well. Within this research, there is some exploration of the experience of the cognitive test, however, this is grouped into the assessment process and there is relatively limited in-depth exploration of the cognitive test specifically and how the different aspects of the cognitive test were experienced (Watt & Crowe, 2018).

These studies either did not report the participant's ethnicity (Gruters et al., 2021; Keady & Gilliard, 2002) or largely recruited participants who were White British (Robinson 2016). This is important given the lack of diversity in the research and the inequalities experienced by those from minoritised ethnic backgrounds. There is limited research exploring service users, family and supporter experience of psychometric tests from a minoritised ethnic background. Dudley et al. (2014) explored Māori service users' experiences of neuropsychological tests and found these were limited in including their cultural identities, referring to this as 'cultural invisibility', and offered little choice in the managements of assessment process and procedures. This research specifically related to those who had experienced a traumatic brain injury, so again not to those with a diagnosis of dementia.

In relation to cognitive tests specifically in memory assessments more recent research has investigated service user experience of cognitive tests. Smith et al. (2023) conducted research across memory and assessment services across the UK. Within this, some services had made cultural adaptations to cognitive tests, and service users from minoritised ethnic backgrounds experienced the culturally adapted assessments as more comfortable and relaxed. The research did demonstrate that some aspects of the cognitive test remained unhelpful (such as tasks related to reading and writing when the service user did not read). The research was developed as a survey and case studies, some of which focused on culturally adapted cognitive tests. This research was developed into a report to highlight best practices and innovative services features, rather than in-depth research into people's experiences. Bharath et al. (2023) completed interviews with 15 people who had undergone a cognitive test who did not receive a diagnosis of dementia, in India. It was noted in the research how this impacted the participants experience of the cognitive test, with some service users feeling they had 'passed' the test and influenced their experience of the test and that they had found it simple and appropriate. Within the Bharath et al. (2023) study, the participants had undergone a culturally adapted Addenbrookes Cognitive Assessment cognitive subscale. The participants did not report feeling particularly anxious about the test, and some reported valuing engagement with a staff member during the test.

In summary, there is relatively little research exploring the experiences of service users, and family and supporters' experiences of cognitive tests in memory assessments, with very little from those from a minoritised ethnic background. Whilst there has been some research which includes service users and family and supporters' experiences of culturally adapted memory tests (e.g. Bharath et al., 2023; Smith et al., 2023) this remains an area of research which requires further in-depth exploration.

2.2.3 Staff Member Experiences of Cognitive Tests.

In addition to exploring service user and family and supporter experiences of neuropsychological assessments and cognitive tests, some research studies have focused on staff member experiences of administering cognitive tests. Understanding staff members' experiences of administering cognitive tests is important, as this will impact how the test is administered, as well as how service user and family and supporters experience this. Stigen et al. (2019) investigated Occupational Therapists' experiences of administering screening tests for cognitive impairment. The research noted how staff members often feel they are 'missing something' about a service user's cognitive functioning when using standardised tests alone. Despite this, the staff members would continue to use the tests, even though they were not quite good enough, they offered some insight into the service users' cognitive difficulties and functioning and spoke to the value of observations being used alongside the assessment. Within this research, Stigen et al. (2019) also demonstrated challenges experienced by staff members when selecting which screening test would be most appropriate for the service user. This leads onto thinking about how familiar staff members are with standardised tests and how this influences the administration of the test. Adhering to the standardised procedures within psychometric assessment is more likely when using a less familiar test (Wolfe-Christensen & Callahan, 2008). Furthermore, Hirst et al. (2017) found that for neuropsychologists, there were particular administrator characteristics that influenced how standardised procedures were followed. This included the type of service and client group, training history and the amount of time the neuropsychologist had been in practice. They found that neuropsychologists in children's and older adult services were less likely to follow standardised procedures, as well as neuropsychologists that had been practicing longer.

In relation to this project, it is important to understand what influences staff members' administration of standardised cognitive tests and how this is impacted when administering culturally adapted cognitive tests and working with those from minoritised ethnic backgrounds. The lack of culturally appropriate cognitive tests is explored in more detail in the '*Systemic factors: A Lack of Culturally Appropriate Assessments'* section below. There has also been some research investigating staff members' experiences of working with service users from a minoritised ethnic background. Dingwall et al. (2014) conducted some research with staff exploring their experiences of conducting cognitive assessments with service users from an Aboriginal background in Australia. They found that barriers to assessment included a lack of engagement with Aboriginal communities, language barriers and lack of knowledge and training. Furthermore, Smith and Surr (2024) highlight staff's experiences of administering a standardised cognitive tests that are not culturally sensitive as challenging, feeling the non-adapted assessments did not give service users a fair chance at getting an accurate representation of their memory, which often left the staff member feeling uncomfortable and trying to adapt the assessment to make it culturally relevant.

In conclusion, this section has focused on staff member experiences of administering neuropsychological assessments and standardised cognitive tests. The current literature investigates staff member's understanding and experience in using different standardised tests and how this impacts adherence to standardised procedures. The current literature exploring staff member's experiences of administering cognitive assessments with service users from minoritised ethnic backgrounds is limited. As mentioned above in the *'Service User Experiences of Cognitive Tests'*, Smith et al. (2023) conducted research across memory and assessment services across the UK. They also interviewed staff members to capture their experiences of using the culturally adapted cognitive test and found that staff members generally felt the cultural adaptations were helpful and provided a more accurate picture of someone's cognitive functions. It is important to understand staff member's experience of administering culturally adapted cognitive tests and their knowledge and understanding impact the administration, and adherence to standardised procedures, as noted in the current literature (Hirst et al., 2017; Stigen et al., 2019) and how this is influenced by cultural adaptations which is explored in more detail in the '*Additional Difficulties to Obtaining a Dementia Diagnosis for People from Minoritised Ethnic Backgrounds'* section below.

2.3 Factors Affecting a Diagnosis of Dementia

Timely diagnosis refers to an individual being diagnosed with a condition at the right time for them. This involves balancing professional judgement and is not simply the time of a diagnosis (Dhedhi, et al., 2014). The term 'timely diagnosis' is a preferred term over 'early diagnosis' as the former reflects a more person-centred approach (Watson et al., 2018). In addition, the Alzheimer's Society (2021) highlight that a timely diagnosis is grounded in human rights law, meaning that people have a human right to a timely diagnosis.

There are a number of benefits to receiving a timely diagnosis. A timely diagnosis can enable opportunities to reduce distress and enhance wellbeing and quality of life. Dubois et al., (2015) highlight how one aspect to timely diagnosis of Alzheimer's disease can lead to early interventions and planning which can reduce distress and enhance wellbeing. This also includes access to more treatment opportunities that are only effective in the mild to moderate stages, including drug treatments and psychosocial interventions such as cognitive rehabilitation. A timely diagnosis can also provide some clarity around what is happening to the individual and help them and those around them come to terms with the diagnosis (Woods et al., 2019). Individuals can take time to adjust to the diagnosis, share with friends and family and implement future measures. Reduced costs are also associated with earlier treatments including drug treatments (Dubois et al., 2015). That being said, some people may not feel earlier diagnosis and treatment options as described above is the right option for them and timely diagnosis would take into account individual preferences.

It is important to note that narratives around timely diagnosis and perceptions around outcomes for people with dementia have changed over the years. Ahmad et al. (2010), for example, noted how some GPs did not feel timely diagnosis was beneficial because they believed there were limited positive outcomes once a diagnosis of dementia had been made. More recently, there has been a shift on timely diagnosis and interventions, with the importance of timely diagnosis being recognised by health professionals (Prince et al., 2013).

Timely diagnosis may be difficult to achieve in practice for a number of reasons. For example, differences in perspectives on the person's cognition between service users and families may complicate or delay access to a diagnosis. The BPS (2016) have highlighted the complexity of determining a diagnosis, given the emotional complexity of coming to terms with symptoms of dementia such as memory loss and loss of functioning, for both the individual and family and supporters. This may mean that people delay seeking support as they struggle to come to terms with some early symptoms of dementia. In addition, people may also believe that some cognitive problems are a part of normal aging. Despite the shift in professional narratives around dementia and a timely diagnosis, there are barriers to achieving a timely diagnosis. Stigma, lack of training and lack of specialised services are some factors which influence timely diagnosis (Dubois et al., 2015). Another key factor affecting timely diagnosis is awareness of dementia amongst health professionals and the wider public. Despite some of the challenges noted above in receiving a timely diagnosis, there has been an increase in referrals and diagnosis in dementia in the UK from 2005-2015 (Donegan et al., 2017). Although using words such as dementia are becoming more frequent and comfortable (Robinson, et al., 2015), there still remains barriers to people accessing services and receiving timely diagnosis in terms of acknowledgement and recognition of dementia. This will be considered in relation to people from minoritised ethnic backgrounds further below.

2.4 Additional Difficulties to Obtaining a Dementia Diagnosis for People from Minoritised Ethnic Backgrounds

Whilst many people can experience barriers to receiving a timely dementia diagnosis, people from minoritised ethnic communities often experience additional barriers and challenges. This will be discussed in more detail below. It should be noted that some of the barriers to accessing services are also experienced by White British people, such as stigma and lack of awareness. However, research has highlighted how these barriers are experienced differently by different communities and may be more pronounced or perpetuated.

Research highlights multiple inequalities in people from minoritised ethnic backgrounds receiving a diagnosis of dementia (Arblaster, 2021). For example, some research has also noted how people from minoritised ethnic backgrounds are less likely to receive a diagnosis of dementia in the UK (e.g. Adelman, 2010; Pham et al., 2018). Furthermore, White British people are more likely to access services earlier, where people from minoritised ethnic backgrounds often access services at a much later stage, often in crisis (Mukadam, et al., 2011). Previous literature has also highlighted that people from minoritised ethnic backgrounds are under-utilising services (e.g. Daker-White et al., 2002) however, this has the potential to shift the focus away from service-level inequalities which are explored further below.

2.4.1 Inequalities in Dementia Diagnosis and Accessing Services.

Whilst there are some difficulties with understanding what dementia is within minoritised ethnic communities in particular, there are also challenges within services and systems which it is also important to highlight. As well as awareness and understanding of dementia, awareness and understanding of services that are available, and anxiety and challenges navigating care systems, can also act as barriers (Alexander et al., 2022). Furthermore, people from minoritised ethnic backgrounds may also fear the implications of accessing services, including moving into long-term care, responses from the community, and perceived stigma (Blinka et al., 2023; Mukadam et al., 2015) and this also related to cultural and religious beliefs (Philip et al., 2024). This can be exacerbated by fears of racism and mistrust within medical systems (Kenning et al., 2017) due to systemic racism and oppression. Social stressors such as unemployment, poor health and racism can all act as barriers to seeking help, and it is important to recognise the impact of the factors (Arblaster, 2021). It is important to set the context in which the culturally adapted memory assessment central to this research project exists. The culturally adapted memory assessment is one way to try and embed culturally sensitive practice within memory services, however, some of these barriers experienced by minoritised ethnic groups occur before they have even accessed the services and so by not highlighting this, many people from minoritised ethnic backgrounds will continue to experience these inequalities in receiving a timely diagnosis of dementia.

2.4.2 Understanding of Dementia in Minoritised Ethnic Communities.

Awareness and understanding of dementia have shifted over recent years in professionals and the wider public. Cultural beliefs and values shapes understanding and awareness of some conditions, such as dementia. Kenning et al. (2017) suggest that preconceived ideas about the treatments available for dementia serve as a barrier to accessing support and can impact the perceived need to access medical support. Parveen et al. (2018a) suggest that better awareness and emphasis on timely diagnosis, presented in a culturally adapted way, led to a shift in South Asian families' understanding dementia. For example, those caring for someone living with dementia felt they had more empathy and confidence in supporting them.

Baghirathan et al., (2020) note how in some cultures, the word dementia is not commonly used or easily translatable. This is important as awareness is a vital factor in seeking a diagnosis and support. Another important aspect of understanding dementia is the symptoms of dementia. In the UK, South Asian people may delay seeking help for dementia due to stigma associated with it (Kenning et al., 2017; Mukadam et al., 2015). This includes perceptions of dementia being 'madness', a punishment from God, possession by 'jinns' or witchcraft (Meri Yaadain, 2020). This may lead to family members trying to hide it and finding it challenging to ask for help, due to the associated stigma. This can be further perpetuated by community responses such as fear, guilt, embarrassment and shame (Kenning et al., 2017). In contrast, **s**ymptoms of dementia such as memory loss and increased caring responsibilities are often perceived as a normal part of ageing within minoritised ethnic communities (Johl et al., 2016).

It is worth noting that this is not to position 'problems' within communities, but to highlight some of the ways in which services and systems can support people. This involves both awareness raising of dementia within communities, but also services becoming more culturally aware and sensitive. For example, The Alzheimer's Society report (Arblaster, 2021) recommends that connecting with cultural community interest groups and dedicated community link workers could support the process of supporting raising awareness for underserved communities. Again, this important to think about in relation to minoritised ethnic communities accessing services and how in order for the culturally adapted memory assessment to be accessed, these issues also need to be considered.

2.4.3 Systemic Factors: A Lack of Cultural Understanding.

There are also cultural barriers to accessing services caused by the lack of suitability of existing services for minoritised ethnic groups. A lack of specialist knowledge, language barriers and cultural awareness can deter people from minoritised ethnic backgrounds accessing services (Kenning et al., 2017; Parveen et al., 2017). As noted above, services and neuropsychological assessments have largely been developed for and normed with White participants (Brickman et al., 2006; Gasquoine, 2009; Heaton et al., 2009). Furthermore, health care systems often do not account for the social context, including social injustices and the role of racism, disadvantaging those from minoritised ethnic communities (Williams et al., 2019). Manthorpe et al., (2013) highlight how people experience the diagnosis process as lacking person-centredness, distressing and confusing and additional challenges such as a lack of cultural understanding can exacerbate this. Indeed, a lack of person-centredness in the assessment of dementia can overlook important life experiences which shape people's perceptions of dementia (Lawrence et al., 2011). Assumptions based on stereotypes and generalisations of particular communities can be avoided using a person-centred approach (The All Party Parliamentary Group, 2013). Parveen et al. (2018a) showed how information and interventions that have been adapted for people from a South Asian background (which included delivering in South Asian languages and culturally specific examples) had a positive impact, highlighting the need to adapt information. This is important to consider in relation to culturally adapted assessments and how cultural understanding will impact the assessment.

2.4.4 Systemic Factors: A Lack of Culturally Appropriate Assessments.

Further to the '*Understanding the Development of Cognitive Testing'* section above, Tuerk and Sauer (2015) also highlight how cognitive tests were originally designed for European and English-speaking participants. This is problematic for many people in the UK whom this now excludes. For example, Adelman et al. (2011) found African-Caribbean participants scored less well on cognitive screening tests for dementia compared to White participants. In contrast, when a culturally adapted cognitive screening test was used, African-Caribbean participants scored significantly better, demonstrating the potential value of culturally sensitive cognitive screening tests. Adelman et al. (2011) adapted the Mini-Mental State Examination (MMSE) with a group of community members who offered more suitable substitutes for the questions, and this was discussed with an academic group to ensure the questions remained conceptually relevant. The African-Caribbean participants scored significantly better on the culturally adapted cognitive screening test, showing the importance of culturally sensitive assessment tools. Similarly, Khan and Tadros (2014) suggest cognitive assessments underestimate cognitive abilities in people from minoritised ethnic backgrounds. It is important to have accurate cognitive tests considering dementia can be misdiagnosed or diagnosed much later in minoritised ethnic communities (Lin et al., 2021). Research has suggested that culture impacts a participant's perception and response on cognitive tests (Ganguli & Hendrie, 2005). In support of this, Jutlla (2021) highlights how getting a dementia diagnosis is challenging for South Asian in the UK people due to a lack of assessments that are culturally appropriate. Collectively, these studies begin to highlight the limited ability of existing cognitive tests to accurately capture cognitive functioning in participants from minoritised ethnic backgrounds.

Testing can be impacted in many ways and for many reasons for people from minoritised group. Scores on cognitive tests are impacted by many different factors such as country of education, preferred language (Harris et al., 2003), gender and social class (Warsi et al., 2016). Intersectionality is important when exploring inequalities and cultural adaptations. Multiple social identities and forces interact, such as gender and ethnicity, and can compound inequalities and disadvantages (Crenshaw, 2017). For example, when considering how culture, education, language and social class intersect, participants who have never learned to write and have very limited literacy skills could lack the fine motor skills required for non-literacy-based tasks such as drawing and copying (Warsi et al., 2016). Older migrants from India and Pakistan who came from rural areas and worked in farming may have had limited education and lower socioeconomic status, may to experience literacy-based tasks in cognitive tests as irrelevant or even be unable to complete them. In comparison, an older migrant from India or Pakistan with higher levels of education and socioeconomic status may be more able to complete literacy-based tasks in their first language or English. In both of these examples, the participant may have similar ethnicities, but how this aspect of their identity intersects with education, language skills and social class results in different experiences of cognitive tests.

This demonstrates the complexity in adapting a cognitive test. Also, completing a cognitive test in any additional language can result in additional challenges for the participant. For example, recalling words in English when it is a second language is a more challenging task and can impact the test scores (Khan & Tadros, 2014). Interpretation of test results is also important to consider from a cultural perspective. It is essential to interpret test results with an appreciation for the relevance and extent in which cultural factors impact those test scores (Echemendia & Harris, 2004). Within this, the concept of acculturation is also important to consider as people’s cultural identity shifts. There are different aspects of acculturation, one of which is acculturation orientations, which refers to the interaction between adopting the mainstream culture and maintaining heritage culture (Arends-Tóth & Van de Vijver, 2006). As such, there are many different domains in which acculturation occurs, such as language, skills and behaviours (Arends-Tóth & Van de Vijver, 2006). This is helpful to consider in relation to this project, and how service users from minoritised ethnic backgrounds who have migrated to another country will experience acculturation and how this impacts what is appropriate in a cognitive test as part of a memory assessment. The process of cultural adaptations will be explored below.

3. Culturally Adapted Cognitive Tests

3.1 General Adaptations of Cognitive Tests

Translation does not account for cultural bias (Parker & Philp, 2004) and there have been a number of cognitive tests that have been culturally adapted. For example, the Montreal Cognitive Assessment (MoCA) has been culturally (i.e. adapted to make sense in different cultures to maintain content validity) and linguistically (i.e. translated into another language) adapted (Cova et al., 2012). The MoCA has been translated into over 36 languages, however, only a small number have been validated (O'Driscoll & Shaikh, 2017). Whilst the adaptations varied in quality and validation, the researchers concluded the cultural and linguistic adaptations enabled participants to undergo an assessment that was appropriate and sensitive to culture. An example of cultural adaptation is the integrated palliative care outcome scale for dementia, which has been adapted into German (Hodiamont et al., 2021). The cultural adaptation of this measure involved consulting professionals, families and people living with dementia and incorporated their views in the development of the measure. Whilst people with lived experience have been involved in the adaptation of some tools, much of the research on adapted cognitive tests does not capture the experience of the people using or undergoing this test and this will be explored further below. There are two important aspects to culturally adapting a cognitive test: language and the content.

3.2 Cultural Adaptation of the ACE-III

As discussed above, there are a number of cognitive a tests that have been culturally adapted. It should be noted that there are different versions of the ACE; the ACE was originally developed in 1990's (Hodges & Larner, 2017) and revised in 2006 (known as the ACE-R) before the currently used ACE-III was developed. The ACE-III has been translated into many languages (Hodges & Larner, 2017) and there have also been a number of cultural adaptations (Mirza et al., 2017). Mirza et al. (2017) note how the process of translating and adapting varies in terms of the quality and standard procedures around the translation and adaptations. The processes used in the translations and adaptations varied from direct translation to another language, back translation (i.e. translating into another language and the translating back into English to check the translation), coproducing with potential users of the ACE-III which usually involved seeking feedback on the adaptations, expert recommendations from professionals (such as psychologists), revisions of the adaptations which involved continuous feedback, and involvement of the original authors of the ACE-III and a pilot study.

As mentioned above, South Asia refers to eight countries; Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka. In the UK, over 1.9 million people identified with an Indian heritage, and over 1.6 million with a Pakistani heritage (Census, 2021). In terms of languages, in the UK Punjabi and Urdu are the most spoken languages amongst South Asian communities (Census, 2021). There are many dialects within Indian and Pakistani languages and there are similarities and differences between different dialects. The ACE-III has been translated and culturally adapted for different countries within South Asia, for example, for the Gujarati population in India (Sharma et al., 2018) and several languages across India (e.g. Mekala et al., 2020). The cultural adaptations noted above were developed to be used in the 'dominant' cultures within the country they were adapted (for example, the Gujarati version is used with the Gujarati population in India). There are very few cultural adaptations of the ACE-III that have been developed for minoritised ethnic communities in the UK cultural context. 'Culture free' cognitive tests with no literacy aspects, such as the Clock Drawing Task (Parker & Philp, 2004) have been suggested, however, they offer limited insight into different cognitive domains that are assessed as part of the ACE-III. When considering cultural adaptations, this project is focusing on South Asian communities in the UK. As mentioned above, cultural context impacts the performance on cognitive tests (Ganguli & Hendrie, 2005; Parker & Philp, 2004). From this, it is important to think about South Asian communities in the within the UK when adapting the ACE-III as their experiences of culture and acculturation (i.e. living in the UK) will impact what is relevant and familiar in the cognitive screening test.

The ACE-III has been culturally adapted and translated into Urdu for UK South Asian communities (Mirza, 2016). Another adaptation for South Asian communities in the UK was carried out at Bradford District Care NHS Foundation Trust (Warsi et al., 2016). This service is situated in the National Health Service (NHS) in the UK, which is a public funded healthcare system. The ACE-III has been culturally adapted into Urdu and Hindi, and Bradford MAS currently use these measures. The rational for Urdu was that this is one of the mostly widely spoken languages amongst South Asian communities in the UK. Hindi is grammatically identical to Urdu and so could also be adapted in the same way (Warsi et al., 2016). Although it should be noted that this adaptation has not been validated. This process involved four steps:

1. Facilitating a focus group with UK South Asian participants and mental health professions who spoke Urdu and Hindi in Bradford, Dudley and Walsall and Black Country NHS trusts. The feedback from the focus group was implemented by the researchers and then shared with a clinical neuropsychologist to ensure the changes had the conceptual equivalence to the UK ACE-III.

2. The assessment was then forward translated from English into Urdu and Hindi.
3. The same assessment was backwards translated from Urdu and Hindi into English.
4. The assessment was then reviewed by an expert panel which involved the research team and health professionals familiar with the UK ACE-III and dementia diagnosis process.

The cultural translation aimed to improve validity by amending the structure and content to map onto the way items would be understood by people from South Asian heritage, capturing both language and cultural references (see appendix A). For example, one of the questions in the ACE-III requires participants to remember an address. In the UK ACE-III, the address is ‘Harry Barnes, 73 Orchard Close, Kingsbridge, Devon’. The structure of the address was changed to one more familiar in India and Pakistan (‘Amar Chaudhary, 52 Station Road, New Colony, Hyderabad’). Also, historic events that happened in India and Pakistan were used (e.g. ‘The year of the partition of India and Pakistan’ and ‘The name of the current prime minister of India/Pakistan’) as well as different images (such as replacing the drum with a dhol, a double headed drum). However, there are still challenges with administering the culturally adapted assessments. Professional skills, language barriers and use of interpreters, diversity within cultures can be barriers to administering and interpreting the culturally adapted ACE-III (Warsi et al., 2016). As noted above, this culturally adapted ACE-III has not been validated and is only available in Urdu and Hindi. Given the variety in languages and dialects spoken in South Asian communities, this culturally adapted ACE-III is limited in its use with different people with a South Asian heritage.

3.3 Existing Research on Experiences of Culturally Adapted Cognitive Screening Tests

There is limited research on culturally adapted cognitive screening tests and the existing research outlined above focuses on either the process of adapting the test, validity of the adapted test (e.g., Mirza et al., 2018) and guidance on how to adapt the test (Waheed et al., 2020). In relation to service user and family and supporter experiences of culturally adapted cognitive tests, Smith et al. (2023) suggest that cultural adaptations in cognitive tests are received well by service users, family and supporters and staff members, feeling the cultural adaptations are relevant and helpful. Furthermore, Bharath et al. (2023) reported a relatively positive experience from service users. In relation to staff members and experiences of culturally adapted cognitive tests, research has suggested that cultural adaption provide a more accurate picture of a service users’ cognitions and felt to be more appropriate by the staff members administering the test (Smith et al. 2023). Exploring perceptions of culturally adapted cognitive screening tests is important to understand barriers and facilitators to reaching and engaging with people from minoritised ethnic backgrounds with assessments and in maximising their accuracy. The ultimate aim of doing so is to support people from minoritised ethnic backgrounds to receive more equitable and timely dementia diagnoses and to improve their access to post-diagnostic support services early on.

4. Rationale for Study

To summarise, the ACE-III is a cognitive screening test used in the diagnosis of dementia (Bruno & Vignaga, 2019). The ACE- III has been culturally adapted and translated into different languages in an attempt to improve the accessibility and diagnosis of dementia in South Asian communities. Bradford District Care NHS Foundation Trust have culturally adapted the ACE-III into Urdu and Hindi and currently use these measures as part of their diagnostic process for people of South Asian heritage. As noted above, there is limited research exploring service user and family and supporter and staff member experiences of adapted cognitive screening tests. Much of the research on service user and family and supporter experiences of in-depth neuropsychological assessments and has been with White participants and explores service user experiences via quantitative methods (e.g., questionnaires) which limits the amount of detailed information that is gathered, as well as possible excluding potential participants who are not able to read or write. There is also relatively limited research focusing on memory assessments and dementia, with neurodegenerative conditions being captured in the research.

In relation to service user and family and supporter experiences of culturally adapted cognitive screening tests, whilst there has been some valuable research carried out in the UK (Smith et al., 2023), this research was not an in-depth exploration of the culturally adapted cognitive screening test and instead gave an overview of the experiences of service users, family and supporters rather than focusing specifically on the different aspects of the test. Other research that has been done within the ‘dominant’ cultures within the country they were adapted (e.g. Bharath et al., 2023), and so aspects of acculturation and culturally appropriate cognitive screening tests will be experienced differently in communities who have migrated to different countries. The research investigating staff member perspectives is limited also and overall, experiences of culturally adapted cognitive screening tests remains an area of research which requires further in-depth exploration.

Improving the accuracy and appropriateness of dementia assessments (and cognitive screening tests which form part of this assessment) for people from South Asian communities and exploring people’s experiences is important to understand barriers and facilitators to reaching and engaging with people from minoritised ethnic backgrounds with dementia assessments. As mentioned above, the aim is to support people with receiving a timely diagnosis and accessing appropriate services early on. This project will aim to explore service user, family and supporters, and staff members perceptions of the culturally adapted ACE-III.

4.1 Research Aims and Research Question

The aim of this project is to explore service user, family and supporter and staff members' experiences of a culturally adapted ACE-III within memory services. The research questions were as follows:

What are the experiences of South Asian service users undergoing a culturally adapted ACE-III in memory clinics?

What are the experiences of family and supporters of South Asian service users undergoing a culturally adapted ACE-III in memory clinics?

What are the experiences of staff members administering and interpreting a culturally adapted ACE-III in memory clinics?

5. Chapter Summary

This chapter has explored the literature on dementia, dementia assessment and cognitive tests and experiences of minoritised ethnic communities in relation to accessing services and receiving a dementia a diagnosis. The inequalities experienced by those from minoritised ethnic backgrounds in the UK includes the lack of culturally appropriate cognitive tests. The ACE-III has been culturally adapted for use with UK South Asian communities who speak Urdu and Hindi. This project aims to investigate service user, family and supporter and staff members' experiences of culturally adapted ACE-III. The next chapter, 'Methodology' focuses on the research design and methods in the study.

Chapter Two: Methodology

This chapter will begin by detailing the research design and justification for this approach. I will then describe the data collection, drawing on the participants, interviews, and procedures and outline the stages of reflexive thematic analysis used in the analysis. Finally, I will include ethical considerations and a section on reflexivity.

1. Research Design

The aim of this project was to explore service user, family and supporter and staff experiences of culturally adapted ACE-III within memory services. Semi-structured interviews were carried out both face-to-face and remotely (including over the phone and video calls on MS Teams). Interpreters and translated materials (see below for more details) were a part of the interviews where English was not the first or main language for participants. This study used a qualitative methodology and analysis of interview transcripts. Braun and Clarke (2013) define qualitative research as using words as data. This enabled the subjective experience of the participants to be explored. Furthermore, given the limited research in exploring people's experiences of culturally adapted cognitive test as part of a memory assessment, qualitative methods allow for rich, exploratory data to be collected. For example, the interview topic guide was designed to enable a flexible, conversational approach which was led by the participants' responses and evolved as the interviews progressed (see section on *'Reflexive Thematic Analysis'* below). Quantitative methods, such as questionnaires with predetermined questions, would not have been able to adapt to the participant responses in this way. Furthermore, it is likely that questionnaires would have missed opportunities for further exploration and clarification. In thinking specifically about the service users who participated in the project, a few of the participants did not read or write and required support from a family member, therefore, questionnaires would have left them unable to participate.

1.1 Ontology and Epistemology

Qualitative research is underpinned by different theoretical perspectives. A non-positivist research paradigm assumes that there are multiple versions of reality and knowledge (Braun and Clarke, 2013). This approach assumes people to construct their own reality which both influences and is influenced by their context. Braun and Clarke (2013) further argue that this is important when capturing experiences of people from marginalised groups, such as the participants in this study, which have often been overlooked in Western society and existing research.

Ontology refers to the beliefs about what reality is and epistemology is the ideas and beliefs about knowledge (Braun and Clarke, 2013). Ontology exists on a spectrum from a realist position (i.e., there is an external reality that we exist independent of individual ideas and beliefs) to a relativist position (i.e., reality is subjective and dependent on individual perspective). Like ontology, epistemology also sits on a spectrum with a number of different positions. This includes positivism where the data collected directly corresponds to the reality of the participant, uninfluenced by the researcher. Pragmatism which sits in the middle of the spectrum acknowledges that phenomena exists but that this is affected by the researcher's interpretation and the tools used. Constructivism assumes there is no objective truth and that each participant and their perspective is influenced by their own values and perspectives. Indeed, constructivism epistemology also acknowledges that the researcher interprets the data through their own perspective and values. Klakegg (2016) highlights the importance, therefore, in recognising the researcher's ontological and epistemological positioning. In order to conduct quality research, Klakegg (2016) argues that the researcher cannot separate their own perceptions and beliefs about the world from the ways in which they conduct and interpret their research, and so acknowledging this is important.

1.1.1 My Positioning as Researcher for the Current Study.

My positioning as a researcher is towards a relativism ontology and a pragmatic epistemological stance. The data collected in the study is a reflection of the participants construct of reality, which is influenced by their own values and perceptions. Indeed, when thinking about experiences of ethnicity and culture, this project takes the position that these are socially constructed phenomena and will therefore be experienced and made sense of on an individual basis. In line with a pragmatism epistemological stance, however, this research holds the position that the culturally adapted ACE-III is the same objective thing that each participant has experienced, but that is experienced differently by each person. This positioning also recognises that data has been interpreted through my own set of perceptions and values. As such, I also acknowledge that participants will be influenced by their context (Braun & Clarke, 2013). I feel this stance aligns to the research question and aims of the project. See '*Data Analysis'* section for more details on how this positioning has influenced the analysis.

2. Data Collection

2.1 Semi-Structured Interviews

I carried out semi-structured interviews with service users, family and supporters and staff members. This project used purposeful sampling which included service users and family and supporters from a South Asian background. Staff members used the culturally adapted ACE-III as part of their clinical work. Purposeful sampling was used to ensure participants with relevant experiences were included in the study, as well as ensuring a range of in-depth experiences within this sample. Intersectionality was considered during recruitment, for example, when recruiting service users, family and supporters, ethnicity as well as language and education (e.g. whether someone could read or write) was considered to make sure a range of experiences were captured. There was a total of 10 participants with 9 interviews (one interview was carried out jointly with a service user and a family member) completed for the project. See below for details of the participants and recruitment. This project aimed to recruit up to 8 service users and family and supporters and 5 staff members, totalling a maximum of 13 participants. This number of participants was agreed with my supervisors and was felt to be in line with an appropriate sample size for a DClin thesis to gain a range of experiences.

Interviews were recorded on Microsoft teams or an encrypted Dictaphone (or a similar platform permitted through the University of Leeds Information Governance pathway) and all files stored securely (password protected) on storage permitted through the University of Leeds Information Governance policy (e.g., OneDrive) and were transcribed into password protected files. Reflections from the interview were recorded in fieldnote books and subsequently typed up into digital notes. All hard copies of data (e.g., signed consent forms, process notes) were digitalised immediately following the interview and all hard copies confidentially destroyed. See details below for further details of how the interviews were carried out with service users and family and supporters and staff members.

2.2 Interview topics

The interviews focused on exploring participants' experiences of the culturally adapted ACE-III. This has been detailed below for service users and family and supporters and staff. The term 'memory assessment' has also been used throughout this chapter as this was also the language used by the service to describe the culturally adapted ACE-III appointment.

2.2.1 Service user, Family and Supporters.

The interview focused on the culturally adapted ACE-III, specifically how they found the assessment, what went well, what did not go well, what could be improved, how well the assessment captured their cultural experiences and memory problems (see appendix B). These questions were developed alongside Mohammed (collaborator at Meri Yaadain) and aimed to give some broad topics to cover with the view that interviews would adopt a conversational approach which would be led by the participants. As mentioned, this evolved over the course of the interviews to capture in depth experiences of the participants and respond to the data that had been collected. During this process, I aimed to be clear about the purpose of the project, attempting to communicate clearly and consistently, see also *'Reflexivity'* section for more details on how the interviews evolved. See procedure below for more details on how the interview were carried out in the study. During the interviews, a copy of the culturally adapted ACE-III and the UK standard ACE-III were brought for reference.

2.2.2 Staff members.

The topic guides for staff member interviews were also developed in line with the service user and family and supporter interview topic guides (see appendix C). In addition to the above, the demographic information differed slightly to keep in line with the necessary information required for the study and included their job role and ethnicity for example. The questions also aimed to capture their experiences of administering the culturally adapted ACE-III.

2.2.3 Undertaking of Service User, Family and Supporter Interviews.

Interviews were carried out with 3 service users and 3 family members, see below for demographic details. For 3 interviews, an interpreter was also present (see below for more information about the interpreter process). Interviews were recorded, transcribed verbatim by me and analysed. During the interviews, participants were asked for demographic details, including age, ethnicity, diagnosis details (see appendix D). As such, this personal data was only obtained and processed for specific purposes and only the minimum amount of data needed to meet the requirements of the study were collected (see *'Results'* chapter for more details).

Interviews lasted between 30-60 minutes and service users and family and supporters had the option to either complete the interview separately or together. Interviews were completed within 6 months of the culturally adapted ACE-III. The interviews were carried out between 1-4 weeks of the culturally adapted ACE-III. This was originally planned to be within 1 week of the culturally adapted ACE-III and the rationale for this being to ensure service users and family and supporters were able to recall the culturally adapted ACE-III in as much detail as possible. However, once recruitment began, it became evident that this time frame was too short to recruit service users and family and supporters and a barrier to recruitment. This was for a number of reasons, mainly that there was not enough availability within one week for myself and participants to arrange the interview. It was also the case that having a memory assessment was understandably a challenging time for service users and family and supporters and aiming to contact and arrange an interview within one week was not enough time for them to engage with the recruitment process (e.g., participants wanted more time to consider participation). To attend to these barriers, the time frame for recruitment was changed to within 6 months as it was felt this would give enough time to recruit participants. To maintain the integrity of the data collected, the inclusion criteria of participants must be able to 'recall their experiences of the memory assessment and accessing the service well enough to discuss these' continued to be adhered to.

Another change to the recruitment process was the inclusion of more languages. Originally, Urdu, Hindi and English were included in the inclusion criteria. The rationale for this was these were the languages of the culturally adapted ACE-III and so it was assumed that these languages would capture the potential participants for the project. However, once recruitment began and conversations held with staff, it became apparent that the culturally adapted ACE was being used with people who spoke a variety of languages (such as Punjabi, Gujarati and Bengali) from a variety of different cultural backgrounds (see *'Results'* chapter for more details). From this, the inclusion of more languages was made to capture the language use of different people who were undergoing the culturally adapted ACE-III. The inclusion criteria changed to reflect participants from 'South Asian communities' and speaking 'English, Urdu, Hindi and/or other similar languages' as opposed to being specific to Urdu or Hindi speakers.

2.2.4 Inclusion and Exclusion Criteria: Service users.

The inclusion criteria for services users were people from a South Asian background who have accessed Bradford MAS for a culturally adapted ACE-III. For participation in the interviews, the following criteria had to be met:

- Able to recall their experiences of the memory assessment and accessing the service well enough to discuss these
- Able to communicate well enough (e.g., in English, Urdu, Hindi and/or other similar languages) to be able to participate in an interview (interpreters can also be provided where appropriate)
- Aged over 60 years old (no upper age limit)

Participants were excluded if:

- If the person with dementia/cognitive impairment/memory problems was considered by a clinician responsible for their care too unwell to be approached to participate
- If the person with dementia/cognitive impairment/memory problems did not have capacity to consent for themselves and the researcher was unable to identify a suitable person to advise on their wishes
- Potential participants were also be excluded if, for any reason not mentioned above, staff feel it is inappropriate to try and recruit them to the study (for example, due to personal circumstances)
- Aged below 60 years old

2.2.5 Inclusion and Exclusion Criteria: Family and Supporters.

For participation in the interviews, family and supporters had to meet the following criteria:

- Have attended memory services with a service user who was receiving a culturally adapted ACE-III
- Have not recently been bereaved (within the last 3 months)
- Have capacity to give informed consent
- Able to communicate well enough (e.g., in English, Urdu, Hindi and/or other similar languages) be able to participate in an interview (interpreters can also be provided where appropriate)
- Be aged over 18 years old

2.2.6 Undertaking of Staff members.

Interviews were carried out with 4 staff members across the Bradford MAS. Interviews were recorded, transcribed verbatim by me and analysed. During the interviews, participants were asked for demographic details, such as their job role, ethnicity and languages spoken. As with service users and family and supporters, this personal data was only obtained and processed for specific purposes and only the minimum amount of data needed to meet the requirements of the study were collected. Purposeful sampling was adopted by attempting to recruit a variety of staff members (see *'Results'* chapter for more details).

For staff members, interviews took place either at a Bradford District Care NHS Foundation Trust site or remotely (e.g., online or telephone). Interviews lasted between 45-60 minutes, and all interviews were completed individually with staff members, although there was an option to complete a focus group. The main reason staff completed the interviews individually was due to availability and the challenges of being able to arrange a time for a focus group that could facilitate everyone attending.

2.2.7 Inclusion and Exclusion Criteria: Staff members.

For NHS staff, the following criteria had to be met:

- Working or have recently worked in memory services and have experience (administration and/or interpretation) of the culturally adapted ACE-III

Staff members were less likely to be invited to take part in interviews if they were:

- Allocated to the service as a student
- Working in the service on a temporary basis, for example as agency staff or on a voluntary basis

2.3 Demographic Information

Demographic information for the participants is set out in narrative form below, and for service users, family and supporters, table 1 details the demographic details for each participant. Staff members' demographic details have not been included in a table as it was felt this would risk compromising the anonymity of the participant. Also, the level of detail presented is limited to avoid the risk of compromising the anonymity of the participants. I have grouped the participants into service users, family and supporters, and staff, as the demographic details I obtained differed between groups, for reasons I set out below. For all of the service users and family and supporters, the assessment was ongoing at the time of the interview.

Table 1

Overview of the demographic details for *service users, family and supporters*

Participant*	**Age**	**Gender**	**Ethnicity**	**Country Born**	**Moved to the UK (Age)**	**First/Main Language**	**Religion**	**Education**
SU1	60s	Female	Pakistani/ British Pakistani/ Dual nationality	Pakistan	Teenager	Punjabi	Muslim	Primary School
SU2	70s	Male	Jatt	Pakistan	Teenager	Mirpuri	Muslim	None
SU3	70s	Male	Pakistani	Pakistan	60s	Punjabi	Muslim	College

Participant* (Relationship to SU)	**Age**	**Gender**	**Ethnicity**	**SU- Country Born**	**SU- Moved to UK (Age)**	**SU- First/Main Language**	**SU- Religion**	**SU- Education**
FM1 (Son)	40s	Male	British Bengali	Bangladesh	Not known	Bengali	Muslim	Primary School
FM2 (Son)	50s	Male	Indian	Kenya	20s	Gujarati	Hindu	Self-taught
FM3 (Daughter-in-law)	30s	Female	British Pakistani	Pakistan	Teenager	Mirpuri	Muslim	None

*Service users are SU, family and supporters are FM

Table 2 provides an overview of where and how the interviews were conducted with service users, family and supporters and staff members. Pseudonyms were considered; however, this was not discussed with the participants. Also, consideration was given to developing pen portraits, however, it was a concern that given the small number of participants, this may compromise anonymity.

Table 2

Overview of the interview with service users, family and supporters and staff members

Type of Participant(s)	Participant(s)*	Where Interview was Completed	Interpreter
Service user	SU1	Participant's home	Yes
Service user & Family member	SU2 & FM3 (completed jointly)	Participant's home	Yes
Service user	SU3	Participant's home	Yes
Family member	FM1	Remotely- Over the phone	No
Family member	FM2	Remotely- Over the phone	No
Staff member	S1	MS Teams	No
Staff member	S2	MS Teams	No
Staff member	S3	MS Teams	No
Staff member	S4	MS Teams	No

*Service users are SU, family and supporters are FM, and staff members are S.

2.3.1 Service Users.

For the three service users, age was asked to determine that the service user met the inclusion criteria (i.e., over 60) and to also get a sense of the age of participants that were having the assessments and their experiences. The participants were also asked their ethnicity and in line with the acculturation questions (Fontes, 2008), participants were asked where they were born and when they came to the UK, their main/first language, religion and education. This was to try and gain an understanding of the context of the participants' experiences and how this may have impacted the culturally adapted assessment.

The service users were aged between 67-77 years old. One service user was female and two were male. The service users described their ethnicity in a variety of different ways. This ranged from Pakistani, British Pakistani/ dual nationality and Jatt/British Pakistani. All of the service users were born in Pakistan and came over to live in the UK between the ages of 14-60 years old. The main/first languages for the service users were Punjabi and Mirpuri. All of the service users were Muslim, and their education levels ranged from 'none' to primary school and college.

2.3.2 Family and Supporters.

The three family and supporters were asked to describe their relationship to the service user who had the culturally adapted ACE-III, their age, gender and ethnicity. They were also asked acculturation questions (Fontes, 2008) in relation to the service user. This included where the service user was born and, if relevant, when they came to the UK, their main/first language, religion and education.

The family and supporters were aged between 34-55 years old and two were male and one was female. Two were the sons of the service user and one was the daughter-in-law. The family members described the ethnicities of the service users they were supporting as British Pakistani, British Bangladesh and British Indian. In relation to the service users who attended the culturally adapted ACE-III, they were born in Kenya, Bangladesh and Pakistan and came to the UK aged between 14-21 years old. Their main/first language of the service user was Bengali, Gujarati and Mirpuri. The religions practiced by the service users the family members were supporting were Hindi and Muslim and their education levels varied from 'none' to school and self-taught.

2.3.3 Staff.

The four staff members were asked for details of their job role and length of time in the role, ethnicity and languages spoken. Two of the staff members were Occupational Therapists and two of the staff members were Associate Mental Health Practitioners. The staff had been in their roles for between one and two and a half years. The staff members described their ethnicities as British Indian, British Pakistani, Black British Caribbean and White British. Additional languages to English that the participant spoke included Gujarati, Urdu and Punjabi.

2.4 Community Engagement

During this study, I connected with Meri Yaadain (Community Interest Company; CIC) to further my knowledge and understanding of dementia in South Asian communities. The founder and director, Mohammed, has been involved in the project as a collaborator. Mohammed's involvement in the project was formally recognised through a contractual agreement for which he was paid for his time. Mohammed also has a PhD in exploring transitions in care of South Asian family members looking after relatives with advanced dementia and so was able to provide advice and guidance on the project from a researcher perspective as well as a member of the South Asian community in Bradford. Mohammed's involvement has included discussions about cultural norms, stigma and taboos within the South Asian communities in Bradford, as well as helping to develop the participant information sheets, consent forms and interview guides and sharing their thoughts and reflections on the project, see below for more examples of Mohammed's involvement. This felt particularly important given myself and my supervisors do not identify as South Asian and so ensuring the research project was developed and carried out in a sensitive and respectful way was important. Mohammed's involvement in the project has been noted throughout, with specific examples of how he contributed.

3. Procedure

Originally, the project aims were to recruit up to 8 service users, family and supporters. The recruitment of staff was initially considered as additional to this, however, after a slow start with recruitment and whilst waiting for ethical approval for changes to the recruitment process, I decided to complete some interviews with staff. After this I began to complete more interviews with service users, family and supporters. I regularly reviewed the data I had collected in supervision and after the 9 interviews had been completed, common themes were beginning to develop, and it was felt that there was enough data and range of experiences for a DClin research project and recruitment was stopped. Indeed, Braun and Clarke (2019) suggest that data saturation may not always be a helpful concept when completing reflexive thematic analysis, as this term suggests that there is 'no new' information or data collection is complete, which is does not align with the epistemological position of this study, which also acknowledges the influences of the researcher. Therefore, the decision to stop collecting data was made based on reflection and the data collected in the study.

3.1 Service Users, Family and Supporters

Service users and family and supporters who were eligible for the study were identified by NHS staff at Bradford MAS. The potential participants were either contacted prior to their memory assessment (e.g. when the staff member arranged the appointment with them) and asked for consent for me to contact them, or there was the option for the participant to wait until their (or their family member/friend) memory appointment and discuss the research with an NHS staff member there. Those interested in hearing more about the study could either complete a 'consent to contact' form (see appendix E) or give verbal consent to be contacted by me, to an NHS staff member who could then complete a consent to contact form on their behalf. There was also an option for a short participant information sheet (see appendix F) to be shared with the participants at this time, giving a brief overview of the study. The contact details of the potential participants were sent to me securely via NHS email, and I contacted them to arrange an interview that could either take place remotely (e.g., over video call or telephone) or in person (e.g., at their home or community centre).

To support potential participants who did not speak English fluently, a number of research documents were translated into Urdu and Hindi. This included the participant information sheets, consent forms and further resources document (see appendix G). This was originally because the adapted ACE-III has been translated into these two languages. However, as the study progressed, it became clear that the adapted ACE-III was also being used with people from other South Asian communities, including Bengali, Punjabi and Gujarati. For these participants, the information was either also appropriate in English (i.e., they also understood English) or information was verbally translated by an interpreter as required. This was also the case if the participant struggled to read.

Before the interview took place, participants were asked if they had read the participant information sheet (see appendix H) and whether they had any further questions. As mentioned above, if the participant was unable to read or read the language the documents had been translated into, this was read out verbally with an interpreter prior to the interview commencing. The consent form (see appendix I) was gone through and either signed by the participant or verbal consent recorded prior to the interview commencing. This was dependent on where the interview took place (e.g. face-to-face or online) and whether the participant could/was able to read and sign. If the service user was unable to provide informed consent, a personal consultee was sought, and they completed a declaration form (see appendix J) advising on their wishes to participate (see ethical considerations for more details on this process). After the interview, participants were thanked, and as appropriate, they were provided with the further resources document for participants to access. Participants were advised that they could withdraw their data up to one week after completing the interview, however, no participants did this. All participants consented to being contacted with the outcome of the research following the completion of the project. All interviews were completed independently of the memory service (i.e., I did not disclose who had completed an interview) to ensure participants felt confident in sharing their experiences and this being kept anonymous.

The interviews with service users, including a joint interview with a service user and family member, all took place face-to-face at the participant's home with an interpreter (see below for interpreter procedures). The remaining two interviews with family members took place over the phone. Where an interview took place jointly with the two participants, I would ask each question to the service user and family member individually. I was sure to ask the interpreter to translate what had been said between me and family member, so they were aware of what was being discussed. The culturally adapted ACE-III was used as a prompt for all of the interviews with the service users and shown in the interview. The UK ACE-III was also helpful to show for comparison with the service users, for example to explain how some of the questions had been culturally adapted. For the two family members where the interview took place over the phone, it was not possible to share the ACE-III's but the participants remembered the assessment in detail and were able to share their thoughts; I would prompt some questions giving examples from the culturally adapted ACE-III as needed.

3.1.1 Interpreter process.

The decision to include an interpreter was made as the staff member sent over the 'consent to contact' form. Staff members would detail on the consent to contact form that an interpreter was required. All the family members and staff members in the project spoke English and completed their interview in English without an interpreter. For all of the service users, family and supporters, they completed the consent to contact form in the memory assessment and so the staff member was aware if they required an interpreter as they would have one in their appointment. This was included in the email to me advising they required an interpreter and detailing the language required. For one of the participants, an interpreter was also a part of the phone call with them to arrange the interview. For the other service users, they spoke some English or had a family member arrange the interview. Where needed, an interpreter was arranged for the interview and prior to the interview taking place, I gave an overview of the project and what would be involved. The interpreter was advised they would be audio recorded and could also have copies of the information (e.g. participant information sheet and consent form) as requested. The interpreter was asked to interpret what I had said and translate what the participant said back. I spoke to the service user and directed the questions towards them while the interpreter translated what was being said. See *'Reflexivity'* below for more reflections and impact of the interpreting process.

3.2 Staff Members

Staff members who were eligible for the study were identified by colleagues supporting the research in the service and were contacted via email. A total of four participants expressed an interest in participating in the study. They were sent the staff participant information sheet (see appendix K), and the staff consent form (see appendix L) prior to the interview taking place. Before the interview, the staff member was asked if they had read the information and if they had any further questions. All interviews with staff were completed over MS Teams and the consent forms were completed with the staff member giving verbal consent which was audio recorded. As detailed above for the service users and family and supporters, the staff member participants were advised that they could withdraw their data up to one week after completing the interview. Again, no staff member chose to do this. The staff members were advised that all interviews were completed independently of the memory service (i.e., I did not disclose who had completed an interview) to ensure participants felt confident in sharing their experiences and this being kept anonymous. The whole staff team at Bradford MAS will have the opportunity to hear about the outcome of the research project also.

4. Ethics

This project was approved by the sponsor (University of Leeds) and received ethical clearance from the HRA and Health and Care Research Wales (HCRW) NHS ethics committee (research ethics committee 24/WA/0309), see appendix M for a copy of the approval letter. Below details the main areas of ethical consideration, including informed consent, risks and burdens, confidentiality and working with interpreters.

4.1 Informed Consent and Recruitment

4.1.1 Service Users, Family and Supporters.

To avoid approaching service users immediately following an assessment at the memory service (where it may not have been appropriate to do so due to potential confusion and distress), consent for me to contact the service user and family and supporters was obtained by the staff member at Bradford MAS who had completed the memory assessment with them. This was done either prior to or after the appointment. Consent was either obtained verbally by a clinician within the Bradford MAS, or a consent to contact form was completed and provided, also via a clinician. The consent procedures were carefully planned to take the needs of service users into account. These procedures were developed in line with the Mental Capacity Act (2005) and its accompanying code of practice, and with guidance from the expertise and work of supervisors who have considerable experience in conducting research with people living with dementia.

Full written/verbal consent was sought from all participants who took part in the interviews. Verbal consent was audio recorded (see details confidentiality section below for how audio recordings were stored securely). After an initial approach introducing the study by a staff member, I then discussed the study with interested participants (i.e. service users and family and supporters) and, for those who were happy to take part, arranged an interview date. As mentioned, an interpreter was present as required and this requirement was identified when contacting participants to arrange the interview. Prior to the interviews taking place, a discussion took place, based on the participant information sheet, appropriate to each person's understanding and their communication abilities. As required, the information sheet was discussed either face to face (e.g. at the service user's home or the clinic) or online (e.g. MS Teams or the phone). Information was presented as clearly and simply as possible in order to maximise understanding. If participants could not understand English or preferred to carry out the interview in another language all information provided was also translated by interpreters. A consent form was completed with all participants- see below for details around capacity.

The research was discussed with participants as clearly and simply as possible to aid understanding of the project. There was the option for this to take place in the presence of someone who knew the service user, if this would aid their understanding. I have professional experience of working with people living with dementia which helped me to tailor communication of the project to the communication abilities of each person. Interpreters and adapted information were developed for participants and their family and supporter and used as needed.

For service users, I used the above discussion about the PIS to assess whether or not the person had capacity to make a decision about taking part in the study. This judgment was made on the basis of whether or not the service user was able to understand, retain and use the information they are provided to make a decision about taking part. Capacity was assessed by me, and I have received training and have experience of conducting capacity assessments. As needed, advice was also taken from family and supporters and staff on communication strategies for each person. Capacity was always presumed to be present until it was otherwise suggested. Family and supporters were required to be able to give informed consent to participate in the project.

Following this process, if the person was deemed to have capacity to consent, they were asked if they would like to take part in the study. They were offered time to consider and discuss the study with others before deciding whether or not to take part. If the person decided to take part, they were asked to sign the consent form or give verbal consent which was audio recorded. For example, if the interview was taking place remotely or a participant struggled to sign the consent form, audio consent was recorded.

If the person was not deemed to have capacity but showed no signs of unwillingness to take part, the advice of a personal consultee was sought. As it was likely that most people who lacked capacity would be accompanied to the memory service, it was deemed possible to identify a personal consultee as required. The personal consultee was provided with an information sheet explaining their role and had the opportunity to discuss and ask questions about the project. They were then asked to advise on the likely wishes of the person who lacked capacity about taking part in the project. The advice of the consultee would always be adhered to, as would any advance statements that had been made by the service user about taking part in research. If the consultee advised that the person would be willing to take part in the research, they would be asked to sign a consultee declaration form to confirm this. If an appropriate Personal Consultee could not be identified, then the service user would be unable to take part in the research. Consent was always obtained prior to the interview taking place and as the interviews were 45-60 minutes it was unlikely that capacity would fluctuate during this period of time, assessment of capacity was, therefore, a one-off rather than repeated process. For this project, a personal consultee was required for one of the interviews.

4.1.2 Staff Members.

A participant information sheet was also provided to staff and either full written consent or verbal consent which was audio recorded was sought from any staff members who were invited to participate in the interviews. Staff members were required to give informed consent to participate in the study. Staff members were made aware they did not have to take part in the study, and this would not affect their role.

4.2 Risks and Burdens

Risks and burdens included the discussion of negative aspects of care, concerns about confidentiality, and the discussion of potentially upsetting issues with participants. There was also the potential for participants to misunderstand the research or its purpose due to cognitive difficulties and different languages. All information provided to potential participants had been developed with this in mind and translated as appropriate (see PIS). All documents were translated by a company approved by the University of Leeds (Accuro Transcriptions Soultions Limited) into Urdu and Hindi.

I had clear plans in place for safeguarding if I was concerned about a participant. For example, if any negative examples of care had been discussed which could have been deemed to be serious or untoward these were discussed with the research supervisors as necessary. If any incidents of risk were identified, this was reported to the appropriate service (e.g. safeguarding, crisis services). If required, University and NHS procedures for reporting such incidents would be followed. If a participant did become upset or distressed, I was prepared to provide appropriate support and check in with whether or not the participant wished to continue with the study. I also had details of relevant support agencies for participants who wanted these, and these were provided to service users and family and supporters who wished to have more information about other resources and sources of support. If I was concerned about the well-being of a participant, with their permission I could contact a relevant professional (e.g., a senior member of staff or GP) or family and supporter to ensure that the participant is offered support. Confidentiality would only be broken if there was a risk to the participant or others. In practice, these procedures were not necessary.

4.3 Confidentiality

To protect participants' anonymity, all data collected was stored securely and reported anonymously. Identifiable data was stored separately from anonymised research data. Personal data was only obtained and processed for the specific purposes and only the minimum amount of data needed to meet the requirements of the study has been collected. A small amount of identifiable data (e.g. name, address and telephone number) was held, so arrangements could be made for interviews and to send out copies of the research findings. Staff members recruited in the study provided their work contact details. This identifiable data has been stored on a separate, password protected file from the rest of the research data. The only link between this identifiable data and the research data was an ID number which was unique to each individual. All hard copies of data (e.g., signed consent forms, process notes) were digitalised immediately following the interview and all hard copies destroyed, as needed.

All files were stored securely (password protected) on storage permitted through the University of Leeds Information Governance policy (e.g. OneDrive). As necessary, all paper copies have been destroyed as soon as they have been saved electronically. All personal information and raw audio recordings will be deleted as soon as the study is complete, all other data has been stored securely at the University of Leeds for 3 years in an access-controlled storage file for the DClin programme research staff, after this time all data will be deleted.

4.3.1 Interpreters.

As mentioned, the interpreters were hired through a company approved by the University of Leeds (Accuro Transcriptions Solutions Limited). This meant they were bound by the same confidentiality requirements, such as what was said in the interview was confidential. Although this did not happen, interviews would not have taken place if the interpreter was known by the service user and family and supporter to protect confidentiality.

5. Data Analysis

Reflexive Thematic Analysis was selected as it encourages the researcher to maintain a reflexive approach to data interpretation and the influence the researcher has on the process of data collection and analysis (Braun & Clarke, 2020). This has been considered further below in the *'Reflexivity'* section particularly drawing on the aspects of my social identity and the influence of this on the research project. Indeed, the aims of this project were to explore different groups of participants (i.e., service users, family and supporters and staff members) experiences of the culturally adapted ACE, with a view to actively generating common themes and patterns of meaning and generalising these experiences around this assessment. Reflexive thematic analysis enables meaning making across the samples, which was appropriate for this study (Braun & Clarke, 2021).

Alternative approaches were considered, such as Interpretive Phenomenological Analysis (IPA) however, the assumptions that underly IPA and participant's being a 'homogenous' group, (Braun and Clarke, 2021; Cuthbertson et al., 2020) do not necessarily fit with the aims of the research project, as the participants in this study include service users, family and supporters and staff members. Also, IPA focuses on meaning making through individual responses, whereas reflexive thematic analysis draws on the data across interviews to generate patterns of meaning. Reflexive thematic analysis was therefore more appropriate for this study there was heterogeneous groups of participants where common themes could be generated, whilst also taking into account the researchers' position and influence on this.

5.1 Reflexive Thematic Analysis

For the data analysis, I followed Braun and Clarke (2006) six steps of analysis. As Braun and Clarke (2020) more recently documented, the stages of reflexive thematic analysis are not necessarily to be done in order, but a more 'back and forth' process. For purposes of clarity, I have number the stages and described them in detail below. I also read other literature that uses reflexive thematic analysis and a worked example (Byrne, 2022).

Step one involves familiarisation with the data. I transcribed all of the data by listening to the interviews and typing up the content verbatim into a transcript. Once the data had been transcribed, I immersed myself in the data by listening to the interview recordings alongside the transcripts to make sure I had captured the data accurately. I then listened to the interview recordings again and noted down any initial thoughts and reflections that came up. At this stage, I noticed some of my reactions to what was being said in the interviews. For example, I was struck by how much I was searching for 'positives' in relation to the culturally adapted ACE-III, wanting participants to find this helpful, and actually the way I conducted the interviews reflected this. An example came up when I was interviewing a service user, and I kept wondering what parts of the adaptations were helpful, until she shared something that suggested she had found *something* useful. At the time, I remember being aware that it was tricky to navigate this interview but was not sure why. It could be that I was wanting to capture something positive about the assessment but also I noticed that I was finding it hard to cover the topics in the interview guide. I noticed that halfway through I had not asked the service user about their experience of the culturally adapted ACE-III. The interview was carried out with an interpreter and a lot of the conversation centred around the participants memory difficulties. I was really aware that this person was struggling with their memory, but also, I wanted them to feel heard and build rapport with them. I also thought about my identity and the power imbalance in this situation. Drawing on intersectionality and thinking not only about ethnicity, but also my educational experiences, I found it challenging to interrupt the service user as I did not want to perpetuate the power imbalance. Indeed, by being able to exercise some choice in how much space I took up in the interview demonstrates the power I held in this situation. This is also explored in more detail in the *'Reflexivity'* section below. This is particularly important to me, but also I felt it was important to the research project. At one point the interpreter said, "*I don't know if we're going in the right direction, I'm just obviously doing the [translation]..."* and noticed how I was aware of the time and the aims of the project, and then gently tried to move the conversation to focus more on the culturally adapted ACE-III.

Step two involved forming initial codes from the data. This next stage involved going through each individual transcript and using Microsoft Word; I used the comment function to capture my thoughts and reflections (see appendix N for extract of analysis). This was the initial coding that took place. I did this in both an inductive (i.e. a data-driven approach to coding) and a deductive (i.e. meaningful coding in line with the research questions) approach to coding (Braun & Clarke, 2012). For example, I coded a lot of data around interpreters and the impact of some inequalities experienced by the participants, and I was holding in mind some questions around how the culturally adapted ACE-III was impacting the participants in a helpful or less helpful way. Furthermore, I also coded data in a semantic (i.e. surface level meaning) as well as a latent (i.e. interpreting the meaning behind the data) way (Braun & Clarke, 2019a). With this, I identified hundreds of different codes, many of which were similar in concept. I then extracted the data from the transcripts and created a table with the codes and initial reflections and the quotes (see appendix O).

Step three is generating initial themes. Themes are patterns within the data set and are developed from the codes (Braun and Clarke, 2021). I then began to collate the different codes together and at this point, I looked back at some of the initial thoughts and reflections I had when first listening to the interviews. Initially, I found that I struggled to move away from the semantic coding and spent some time discussing this in supervision and with Mohammed (collaborator for the project). I was able to interpret some of the meanings behind the data and started to make meaningful patterns and connections between the codes. For example, when thinking about interpreters, I started to link the data by what was challenging and missing when interpreters were a part of the culturally adapted ACE-III. Again, I considered my identity and experiences, mainly that I have never required an interpreter to be able to communicate with a health professional, and how this meant I interpreted the data through this experience. For example, I assumed that professional interpreters would be a standard part of the assessment and had not considered the impact of policies, family members interpreting, as well as the interpreters' skills (such as ability to read) and different dialects. After reflecting on this in supervision and with Mohammed as described above, I started to interpret the data in a more reflexive way. A detailed example is given below in the *'Reflexivity'* section. Linking this back to the research question helped to keep the analysis focused and relate the experiences of interpreters back to the culturally adapted ACE-III.

Step four includes reviewing and developing themes. I reviewed the themes in supervision and with Mohammed and developed some sub-themes to capture the diversity in the data. Initially I had lots of themes and sub-themes and struggled with trying to capture everything that participants had said in the interviews. I had wondered about how my role as a clinician impacted this part of the process and again, thinking about how my training and education impacted how I interpreted the data. An example of this is when thinking about hearing and advocating for the clients I work with and when examples of inequality came up, such as parts of the assessment that were unhelpful, I felt pulled to capturing every detail. This is considered in more detail below in the *'Reflexivity'* section.

Step five includes refining, defining and naming the themes. I then began to name the themes and spent some time writing a description of what the themes were capturing. Following in from the example about was when I had started to think about interpreters but then found that there were actually different aspects to this, such as difficulties in translating and the impact of interpreters. The overarching themes helped me to think about the broader themes and so the aspects of the 'interpreter' codes formed the *'Getting Lost in Translation'* sub-theme.

The final stage, stage six, involved writing up the themes and using the quotes to illustrate the narratives within the themes. Again, this was shared with my supervisors and Mohammed (collaborator) to review and refine. I found it helpful to include more quotes and refine over time, focusing back on the theme description and research questions. The *'Results'* chapter of this report demonstrates the write up of the themes.

5.2 Reflexivity

Researcher reflexivity refers to the process of the researcher reflecting on their own experiences, social identities, values and biases, as well as professional experiences (Wilkinson, 1988) and how this influences the research process which is key to reflexive thematic analysis (Braun & Clarke, 2023). The researcher impacts the research process from the start, from selecting the research project to the questions asked, how they are asked and the interpretation of the data. I have, therefore, spent time considering and recording ways in which I have impacted the research throughout this project.

I began by thinking about my ethnicity, something that has been challenging to 'define'. I feel like this is particularly important to think about given the research project focuses on experiences of people from a South Asian community of a culturally adapted assessment. As mentioned in the *'Introduction'* chapter, I have a 'mixed' heritage, and whilst I am mostly White, I am also partly Arab. Indeed, the lack of language and choice in how ethnicity is described is part of the challenge here. To recap, the term ethnicity refers to cultural expression and captures someone's heritage, history, traditions, language and geographical location (Desmet et al., 2017). In thinking about my ethnicity, I have been holding a question in mind; *what is it that I am trying to describe?* Interestingly this also came up in the interviews (see '*Results'* chapter and *'Discussion'* chapter).

It is important for me to acknowledge that I do have light skin which perhaps enables me to benefit from 'White privilege' or 'structural advantage' because of this. McIntosh (1990) described this as the absence of discrimination based on skin colour. But as described, ethnicity captures other aspects of someone's identity. And so, this leads me to think about how I experience my 'mixed' heritage. For example, particularly throughout my childhood, I experienced my Grandad practicing Ramadan, I have been to Arab weddings and went to a madrassah in a mosque for Arabic lessons. I also have memories of been unable to visit Yemen with my Grandad, the reason being that it was too dangerous. Furthermore, narratives around Muslim cultures and immigration to the UK continue to 'other' communities. This leaves me wondering what this means for my family who identify with this. Although this project focuses on South Asian communities in the UK, there are some parts of the project that will have some relevance to experiences within my family, such as immigration to the UK and religious practices. I will share examples below of how my experiences connected with the participants in the interviews.

Importantly, the sharing of my heritage is one that I often have choice and power over. I have been brought up in the UK and I speak English (and only English despite the Arabic lessons!). I have been socialised in a society that privileges 'Whiteness' and I have actively benefitted from that as well. From this I will have made assumptions and have been unaware of things. That being said, it is my responsibility to learn and unlearn this. I have tried to attend to some of this. I hope that when I am sharing my reflections, this comes across in a respectful and curious way, my learning on cultural humility will continue.

I also think it important to acknowledge that my supervisors for this project are all White. To begin, I had many different ideas for the research project, but dementia and memory assessments were the main areas of interest for me. It was at this point I selected my supervisors. As I developed the project and came across the culturally adapted ACE-III, I was drawn to exploring this and so the project started to become more focused. As such, I felt it would be important to connect with some organisations to learn more about dementia and memory assessments within South Asian communities in the UK. This was when I met with Mohammed at Meri Yaadain CIC, who has shared invaluable experiences and feedback on the project. He has been able to draw on academic and lived experience to support, guide and critically challenge my learning and observations.

Before reflecting further on how my experiences and identities have impacted the research project, I will continue to think about other aspects of my identity. I am a cis-gendered woman training to be a clinical psychologist in the NHS. I therefore will have a degree at a doctorate level, and this brings in some questions around class. I come from a working-class background and wonder how this has changed since training to be a clinical psychologist. Further to this, I think my professional identity has greatly impacted this research project and this will be considered further below, with an example.

I pay particular attention to the aspects of my identity, and I noticed that there are other parts of my social identity that I have not described but will undoubtably impact the way I experience the world. I will focus on some specific examples to demonstrate some of the ways I have reflected on the way I have impacted this study. In doing so I become aware of intersectionality and how this may shape the worldviews and experiences of the participants in my study as well as my relationship with them - i.e., a power imbalance between the researcher and research participants.

5.2.1 Examples.

When completing the interviews, I noticed that I found myself thinking about how my Grandad might experience this, particularly as the service users I interviewed were a similar age. They may also have had similar experiences of immigrating to the UK, some at a young age. I noticed that I felt angry and disappointed at some of the experiences of inequalities shared in the interviews. That is not to say that most people would not have also felt this way, but I think for me, there was something about also knowing that a family member had similar experiences that connected with me. Also, I have not experienced this myself, and so there was a discomfort in knowing that I represented a part of the system (i.e., being an NHS employee) and benefitted from a more privileged service because of my ethnicity. This could be referred to a ‘White fragility’ which Ford et al. (2022) described as the difficult feelings experienced by White people associated with racism. In this instance, there was some understanding due to my experiences, but also some uncomfortableness which could be described as guilt or shame, due to the ‘White fragility’. As a result, I did spend some time noticing participants’ experiences of inequalities and tried to give voice to them, both in the interviews and analysis.

Another example that came up in the interviews was when thinking about some of the assumptions and unchallenged decisions that take place in services. As mentioned, I am training to be a clinical psychologist, and I am employed by the NHS. I am a part of this system and so will be influenced by some of the practices. What is important to note in this example, is that I have never needed an interpreter in any other context than my professional work. I have been able to understand and communicate with others in the language I speak, especially in professional appointments (for example when seeing healthcare professions). This example was taken from an interview with a service user and family member. The family member was explaining that they were asked not to interpret for their relative, the service user, during the assessment. They were unsure as to why, and I gave this explanation:

> *"So sometimes, if we ask family members to interpret, something that's happened is they might give like examples, or try to help. With really good intentions, but then what happens is the memory assessment is then like not valid. Because we've not asked it in the same way, if that makes sense?"*

This example highlights how I had absorbed a policy without questioning this and likely perpetuated an unhelpful narrative around family interpreting. Importantly, a policy that did not impact me was taken at face value and remained unquestioned. I think that there are many other reasons as to why an interpreter is preferred in the assessment, and more of these had been considered int the *'Results'* chapter. But what I had not done in this example, is think about what that might be like for a family member and service user to hear. In this example I was trying to be sensitive to the family member, but actually, could that have been interpreted as family members being untrustworthy? For people that have memory problems, a familiar person to communicate with is sometimes more helpful and comfortable. Instead, I placed the 'problem' within the family member when actually there are lots of reasons why an external interpreter may be required. Could the explanation I gave have been more inclusive of some of these reasons or should I have been giving an explanation at all? Could that have been an opportunity to explore more about their experiences of that? After spending some time reflecting on this, I felt it would be helpful to consider why we are doing what we are doing, particularly when it comes to policies. And some of the conclusions (See the *'Discussion'* chapter) from this study are encouraging of others to do the same.

One final example of how the field of psychology has influenced this project can also be drawn upon. I noticed that within the interviews, I wanting to find something helpful about the assessment to report. It was when I was analysing the data and relistening to the audio recordings of the interviews that I realised I kept asking questions until I found something 'helpful' or 'good' about the assessment, and then I would move on. I think acknowledging this and having some awareness as to how this is likely to impact this project and in particular the analysis, is important to hold in mind.

6. Chapter Summary

This chapter has detailed the research design and approach (i.e. a relativism ontology and a pragmatic epistemological stance). The data collection was outlined, with semi-structured interviews were carried out both face-to-face and remotely. The details of the participants and procedures, including ethical considerations were explained. Finally, the analysis (i.e., reflexive thematic analysis) and reflexivity sections were included. The next chapter, *'Results',* will explore the results from the data analysis.

Chapter Three: Results

This chapter will focus on the results from the data analysis. Firstly, a brief overview of the results and a thematic map (see Figure 1) is detailed with all of the themes, and sub-themes and relationships between them. Then the themes and sub-themes are detailed with supporting quotes from the participants within the project to enable the participants' voices to be at the heart of this project.

1.Results of Analysis

The aim of this research project was to explore people's experiences of the culturally adapted ACE-III. Within the service, staff often refer to this as the 'South Asian ACE-III' and so this has been used within the interviews. I did consider giving the participants pseudonyms (i.e., a fictitious name) alongside the description which group they represented (e.g. service user), however, this was not something I had asked participants about in the interviews, specifically participants would not have been aware I would give them a pseudonym and would have had no involvement in selecting a name that they felt was appropriate. As such, I felt it was more appropriate to refer to the participants in relation to the 'grouping' with a number (e.g., SU1). To recap, Service users are SU, family and supporters are FM, and staff members are S.

The major themes are: *'What Culture Though? Language Matters'* which explores how the adaptations within the culturally adapted ACE-III are not always helpful or relevant, with the language used within and to administer the culturally adapted ACE-III also being important. Within this theme, the sub-themes *'Either/Or'* which focuses on how the dichotomous approach to having either the culturally adapted ACE-III or the UK ACE-III is entirely not helpful and *'What's Gets Missed'* which explores the consequence of this approach. The theme *'Uncertainty Around the Purpose and Process'* focuses on the uncertainty experienced by the participants in understanding different aspects of the culturally adapted ACE-III including working with interpreters. The sub-themes within this are *'Finding our own way'* which details staff members experiences of administering the culturally adapted and the uncertainty in how this is done ACE-III and *'Getting Lost in Translation'* which explores the role of interpreters and language in the culturally adapted ACE-III and the uncertainty confusion when working with interpreters. Finally, *'It's a Start: Moving Towards Equitability'* considers how the cultural adaptations begin to address some of the inequalities in non-adapted assessments, and how to keep working towards this. This theme has the sub-themes *'Adapting in the Moment'* which focuses on how staff members make adjustments to the culturally adapted ACE-III in order for it to make sense to the service users and *'A Good Start, Where Next?'* details what participants felt needed to be done to keep moving towards equitability, including personalising the assessment to individual needs. See Figure 1 for a thematic map of themes.

Figure 1. Thematic Map

2. Major Theme 1: What Culture Though? Language Matters

This theme explores how although some the adaptations made within the culturally adapted ACE-III were valued, some adaptations were not always helpful (and sometimes unhelpful) due to the service users' needs in terms of the cultural adaptations. This highlights the importance of what culture the adaptations are based on and that the language used in the assessment matters, both in terms of how culture is conceptualised and the language the assessment is administered in. As mentioned, culture has many definitions that have been interpreted differently in the literature. Within the interviews with all participants, questions were asked around what culture the adaptations within the assessment were based on, and was captured in this quote, which inspired the name of this theme:

> *"Interpreter: 'What culture though?' [name] is asking"* (SU1)

There were some challenges too when trying to get a sense of the person's cognitive difficulties and this is explored in the *'Either/Or Approach'* sub-theme, where the premise that a service user can only have the culturally adapted ACE-III or the UK ACE-III is described. This sub-theme also highlights the importance of language, and how the language the culturally adapted ACE-III was administered in, impacted the whole assessment. The sub-theme, *'What Gets Missed'* focuses on the impact of the adaptations not being helpful, such as not getting a full or accurate reflection of someone's cognitive abilities as well as what gets missed in the cultural adaptation.

2.1 Sub-Theme: Either/Or

The participants spoke about how they had to choose either the UK ACE-III or the culturally adapted ACE-III, and how this created some confusion and challenges. This either/or approach is necessary to make sure that the service user is being assessed with a standardised assessment which is valid, so that there is confidence in conclusions drawn from this assessment. However, this either/or approach does not capture some of the nuances in culture and acculturation and how there are pros and cons to doing either ACE-III.

This is also true when making the decision about which ACE-III to use. For example, the below quotes show how staff found it difficult to determine which version of the ACE-III would be most appropriate for this service user. Although the service user spoke Urdu, there was still some confusion around what might be helpful. The two options that staff were able to offer appeared to miss what this service user needed and how the decision-making process took an either/or approach:

"So I recently had a patient who is Pakistani, and he said he doesn't speak Urdu as fluently, but his English isn't as good, so I was bit confused, but he said he doesn't understand... He don't want to do [the] Urdu ACE....We carried on in Urdu because he said he doesn't understand English either, which was weird because he was speaking English the most part." (S4)

Participants also spoke about how they might find different parts of the UK ACE-III *and* the culturally adapted ACE-III helpful. Again, this links to the idea of what culture the adaptations are based on; for many participants there were elements of both assessments that were helpful. These preferences for the different assessments speak to the idea of acculturation, the idea that culture can shift and changes depending on where someone is living, making cultural identity both transient and made sense of individually. For example, participants would share that they have lived in the UK for varying amounts of time and how different aspects of the culturally adapted ACE-III made more sense to them. The result of this is that whilst parts of the culturally adapted ACE-III were helpful, it was not necessarily the case that all elements of the adapted version were best suited to the person's needs, and elements of the UK ACE-III could actually be more helpful than the culturally adapted version. For example, one service user (SU2) could speak but was unable to read Urdu but could recognise English letters in the UK ACE-III, as he had written his name and address for decades as he lived in the UK but was not asked this in the assessment he had. This again demonstrates how language is important where verbal tasks in the assessment were more appropriate in Urdu, while the written test was more appropriate in English. The family member (FM3) also commented on this:

"A little bit, I can read English but not writing... Name and address that's all maybe." (SU2)

"But you know with the letters, you can try because like he [SU] knows how to write his name [in English]" (FM3)

The either/or approach was also a similar issue when thinking about the question where participants are asked to remember an address. For this participant, it was felt that the UK address would have been more helpful, as the service users are more likely to have come across UK addresses. From this, acculturation is important to consider when making cultural adaptations. Again, this ties in with the idea of 'what culture' and the language are important and that by having an either/or approach to the assessment, service users were disadvantaged as the context of the question was not as relevant to them:

"So like they have changed the address to the Pakistani address. Which didn't help out here because he has never been in Pakistan...Because he's lived here, he was used to, with the address done in here..." (FM3)

Furthermore, there was also some confusion when thinking about how these adaptations were intended to make sense for people of Indian heritage who speak Hindi. However, this particular adaptation would make sense for people from Pakistan, and how 'what culture' and language are key when making these adaptations for service users from different places, such as India. Participants shared that there was some confusion when thinking about the question where participants are asked to remember an address:

"But then by confusing it by having places that are in like Hyderabad... 'New Colony, Hyderabad', and she kept saying 'Ahmedabad' which is the capital of Gujarat rather than Hyderabad. So we were chuckling within ourselves. But it was, and I think it's the association she was making as well." (FM2)

2.2 Sub-Theme: What Gets Missed

As a result of the 'either/or' approach not meeting people's needs, participants identified that the culturally adapted assessment could lead to aspects of their cognition not being fully assessed. For example, participants spoke about what gets missed such as not being able to ask certain questions and some parts of the assessment being confusing and how this could lead to a limited understanding of someone's cognitions and memory problems. Specific examples included how some of the questions may still be unfamiliar despite the cultural adaptations and how factors such as education and acculturation impacted this. This was largely related to service users not being able to understand the question, such as, if they could not read or write in that specific language. It may also be that the service user did not understand the context of the question. The implication of this is that the questions that were irrelevant were removed from the assessment (i.e. not asked) which undermined the psychometric validity of the assessment, leaving domains of cognitive functioning unassessed:

"Then they might be like... I don't know they might just not understand how to answer... So I think it would then make it not accurate of what we actually understand because they just don't understand the context, of the question." (S3)

"We'd either have to [not ask the] question or they'd they'd not be able to answer it and lose points that way, which is quite unfair, it'd be quite unfair, wouldn't it?" (S2)

“We're doing an ACE, but we're not getting the full picture of a person.” (S1)

Additionally, the translation to Urdu and Hindi within the culturally adapted ACE-III, were intended to make sense for people of Indian heritage. These adaptations again raise questions around what culture are the cultural adaptations based on, and which language, as there are many different languages spoken in India, with different dialects. When these different languages are not accounted for in the culturally adapted ACE-III, the questions become confusing. It is not always possible to translate parts of the culturally adapted ACE-III into other languages and what gets missed as a result is the assessment being clear and again, the psychometric validity of the assessment comes into question, as it is unclear whether the changes in language are in line with the conceptual equivalence to the UK ACE-III. These examples highlight some of the nuances that meant cultural adaptations became confusing when trying to translate from one language to another:

“I mean even things like there are things in there that were in Hindi, which is like the national language of India and then it's kind of almost interpreting in Gujarati to Hindi kind of thing in in their head. So it probably confused her a little bit more...” (FM2)

“I think the, there is some words... I don't know if it was the Gujarati, I can't quite remember what they were saying, there isn't really a word for that...I think it was... Yeah, ‘famous encouragement, ideal, century’. She was saying there isn't, there isn’t a word for some of those...She was struggling to find the right word to use.” (S3)

Similarly, some participants also shared some of the language barriers when the culturally adapted ACE-III was administered in different languages. The culturally adapted ACE-III was also being administered with service users from different South Asian countries, such as Bangladesh. Whilst the adaptations were not designed for Bengali service users specifically, here participants highlighted some of the challenges with this and what gets missed. It also brings into question if service users from other South Asian counties also benefit from this culturally adapted ACE-III, given the large geographical area of South Asia and the differences in cultures. This highlights the complexity in culturally adapting an assessment and who this might be helpful for:

“... a lot of the time we didn't understand... You think how to explain it to ourselves. So we have to improvise” (FM1)

“... repeat the words after me, although they may not understand for example, the Bengali patients may not understand the Hindi and Urdu version like what they're saying, they can't repeat what I'm saying after they can't repeat after me, if that makes sense.” (S4)

> *“I think some of it's interpret[ed]..How do I put this? It's it felt like some of it was geared more towards the Pakistani community. So like some of the kind of wording in that was...And I and I can probably understand that because of the community in Bradford being more from that, you know the Pakistani community, but that can cause confusion as well, I think...”* (FM2)

3. Major Theme 2: Uncertainty Around the Purpose and Process

Uncertainty around the purpose and process is a theme exploring how those supporting or administering the assessment experience uncertainty in relation to what they are doing, and why. This includes a sub-theme *‘Find Our Own Way’* exploring staff member’s experiences of administering the culturally adapted ACE-III and uncertainty relating to administering the assessment. The sub-theme *‘Getting Lost in Translation’* is also captured within this theme, focusing on staff member and family and supporters. Here the role of interpreters in the culturally adapted ACE-III is focused on and draws on experiences of uncertainty in relation to interpreters, such as who interprets and how to work with interpreters when administering the culturally adapted ACE-III.

3.1 Sub-Theme: Finding Our Own Way

Staff have shared their experiences of when they were introduced to the culturally adapted ACE-III and the training they have had around this, which usually involved shadowing other staff members. Within this, there were themes of uncertainty relating to how staff members understood the culturally adapted ACE-III. Due to the limited training and guidance related to the culturally adapted ACE-III, this meant staff members were often finding their own way that worked for them:

> *“I haven't really been given a guide really of how to do it or conduct it. Which probably would be downfall in some ways because like you said, it is a bit more trial and error and it's probably not very consistent across the board.”* (S3)

Importantly, staff largely referred to this culturally adapted ACE-III as the South Asian ACE-III and were not aware of the development of this test and it being aimed at British Pakistani and British Indian service users who speak Urdu and Hindi. As a result, the culturally adapted ACE-III was often used with a wider variety of participants than it was intended for, which as noted above in the sub-theme *‘What gets Missed’* creates some confusion and bring into question the psychometric integrity of using additional languages:

> *"But the different languages we do use, you know like Gujarati, Bangladesh, Farsi, Arabic... So I think it's adapting based in the culture that we're in, that everyone speaks different languages and Bradford is a multicultural city so everyone speaks not just one language you know, do you know what I mean?"* (S1)

Another aspect of uncertainty around the process of the assessment was staff members not knowing what they were asking in the assessment due to both the language differences and the unfamiliar content of the questions, within the culturally adapted ACE-III. This led to staff members 'finding their own way' and looking up answers themselves, but also left some unsure how to score different parts of the assessment, particularly the reading and writing components:

> *"Also, the questions you know, "when did the partition of India and Pakistan happen?" You know, I've googled that so I know whether or not they've got it right or wrong and not look like... Is it right? You know, you know, name Indian, you know or Pakistani Prime Minister. I know both the names of I know the Indian one and I know the... Pakistani one again, I know myself whether they've got it right or wrong."* (S2)

> *"I mean, as an assessor's point of view, I can't read or understand what they're writing... So, how do we assess and mark that, if that makes sense?"* (S4)

> *"I try and mark as to go along if I can and I try and chat with the interpreter at the end that it's all right, because otherwise I have had it where I've been a bit like, oh, I don't know if that's right actually, you know, the words I've been like oh, I should have asked them. So then I have to ask like someone who speaks Urdu in my team."* (S3)

> *"...would the assessor be able to read and understand what they've wrote and mark them based on that? That's another issue, I think, because I can't read it, Urdu or Hindi. So how do I do grammatically assess them?"* (S4)

3.2 Sub-Theme: Getting Lost in Translation

This sub-theme explores how understanding the language the assessment is in, is a fundamental part of being able to complete the assessment in a meaningful way. Interpreting is a complex, but essential part of the culturally adapted ACE-III. Whilst these challenges are part of working with an interpreter more generally, it is important to consider how this impacts people's experiences of the culturally adapted ACE-III. Particularly when considering the importance of the assessment needing to be carried out in a standard way. This sub-theme focuses on staff member and family and supporters' experiences. Service users did not comment on their experiences of interpreting as uncertain. It is important to note that all the interviews with service users did involve an interpreter so this may have impacted how able or comfortable they were to comment on some of the challenges. It could also be that the service users in this project did not find the interpreting process uncertain and this will be considered in line with the current literature in the *'Discussion'* chapter. Challenges in communication, particularly when working with interpreters can result in things getting lost in translation. This often left those involved in the assessment uncertain about what was happening. For example, staff members spoke about how much they might miss in relation to interacting with service users:

> *"I guess I really like to pick up, and I do it in English, I can pick up if, like the person's going off or doesn't understand the question or I can pick up a lot more. Whereas with the South Asian version, I'm having to ask at the end of the visit a bit like 'oh, was there any word finding difficulties? Did they not understand the question? Are they're processing it?' There's a lot more I can pick up and infer from... Whereas actually there, [with an interpreter] I don't really get much of a feeling, to be honest..."* (S3)

> *"I don't get much feeling after, you know if they're confused or or if they've done well with it, or if they've not done well, like until I mark it. Whereas in the other ones [in English] I can kind of tell that all you know, they've got quite a cognitive impairment or the short-term memories really affected even from what they talk around you know?"* (S3)

> *"Yeah, yeah. So how how, yeah, how they speak to you, the tone of voice and the body language. Whereas they're not communicating that all back to me, it's communicated differently, but with the interpreter too, I don't know if that makes sense."* (S4)

Here a staff members and family share their experience of an interpreter that was unable to interpret a large part of the assessment. Although this is not a unique feature of the culturally adapted ACE-III and occurs whenever an interpreter is involved, it is important to note how these inequalities impact the assessment and the experience of this. Staff members felt this was unprofessional and found this process difficult. Family members stepped in to support and this then creates some potential problems with if the family member is able to interpret:

"And I think luckily, because there's a family member there, if there are any words that have been unable to be interpreted, they will always step in and say, "oh, this is what this is, what it is" or they'll say it to the person correctly. So then I do get the information anyway, but if they weren't there, it would make it really difficult." (S2)

"...if it we weren't there, you're either... The lady at the assessment, she would have probably only only managed to have done about 25% of the stuff." (FM1)

"And her daughter-in-law was sat there just, like rolling her eyes and she says to her husband, 'She's not really good, is she?' I just think that's embarrassing. And I think that it don't look, it doesn't look very professional. You know, I'm hiring an interpreter to support me and then not even knowing how to interpret words, I find that really embarrassing." (S2)

Furthermore, there was also some thoughts around who interprets in the culturally adapted ACE-III, specifically whether there is a role for family and supporters to interpret. Staff members usually had an interpreter present when the culturally adapted assessment was not conducted in English. Here, the participants spoke about some of the uncertainty around interpreting, particularly when family members interpreted. This was specifically around if family members had the skills and language ability to interpret in a good enough way, but also whether family members might unintentionally help (or not) as part of the assessment. This created some concerns as to whether the culturally adapted ACE-III was then valid due to what might have been lost in translation:

"So if you don't know if you don't speak their language, and then if they're saying things for each other without your knowledge, then you're like this invalidates the kind of thing you know." (S1)

"...but it's often misinterpreted by the family member, so it's always best to get interpreter. Yeah." (S4)

"So they want their own interpreter with them. Because actually the person who is doing the assessment, if he doesn't know the other languages. So I think it, it, it brings them in doubt whether the family member interpreting, are they interpreting with the patient or what the applicant is saying? So that's why they want their own people with them." (FM3)

"And a lot of families say, 'oh, I'll do it' [interpret] but I think family can help, or might say it a bit wrong or, or might not help if they want the person to get a diagnosis, they might say it wrong..." (S3)

4. Major Theme 3: It is a Start: Moving Towards Equitability

This theme explores some areas where the culturally adapted ACE-III enables a more equitable service for the service users and their families. Within this, there are suggestions for ways to continue working towards equitability, and an acknowledgement that this is an ongoing process. The sub-themes that are explored in more detail are *'Adapting in the Moment'* and '*A Good Start, Where Next?'*. The *'Adapting in the Moment'* sub-theme explores how further adaptations are made in the moment to make the assessment more relevant or appropriate. The '*A Good Start, Where Next?'* sub-theme considers how to keep moving towards equitability and what needs to be done next, such as personalising the assessments to reflect individual differences and cultural experiences.

Participants shared their thoughts on how the cultural adaptations felt more relevant and gave opportunity to assess their memory and cognitions in a way that would otherwise be missed. Participants shared their thoughts on what felt more relevant:

> *"Yeah, well, it does help, isn't it? Because the lady that did the assessment, she she felt she felt that, you know, she needs to be seen by the doctor as well. So I think it does get them thinking. Yeah."* (FM1)

> *"Interpreter: 'So it wouldn't have mattered if it wasn't an address in Pakistan, but it did help because it made it easier for me. But it wouldn't have mattered if it wasn't'.... She says 'if it was in English, [it] may be something that I'd not remembered'... Ok, so "because it was a Pakistani name, I remembered.'"* (SU1)

> *"...the tools, the drum and the other thing, that was helpful for him because he was familiar with them."* (FM3)

> *"Interpreter: 'Because back in village, yeah, I used to... do drums...*
> *Service user: 'And weddings and things you know, used to do music'...*
> *Interpreter: 'So these, these the instruments...yeah are very, [I] come across [them] while I was... back in Pakistan yeah, so very familiar is all these'"* (SU2)

> *"Interpreter: ...but he could only recall the city, Hyderabad... he could remember that this city was in Pakistan."* (SU3)

In line with the above, participants being more likely to be able to answer the questions, impacts the whole assessment. Specifically, these quotes capture more staff member's perspectives, although there is a comment from a family member. When asking service users and family members, they felt it was difficult for them to comment on as they did not have the outcomes of the assessment, and they did not have anything to compare it to. It could be that staff felt more able to comment on this as they have experience of completing a variety of assessments and have more understanding of the assessment and the purpose of them. The staff members in this project felt the culturally adapted ACE-III gave a fuller, more accurate picture of someone's difficulties as a result, moving towards a more equitable assessment:

"I think that it's really it really helps individuals... You know, it'd be more appropriate for them and culturally, culturally you know appropriate, really. And I think you'll probably get more of an accurate representation of their actual cognition." (S3)

"...then you're not going to get a full picture of then you kind of misdiagnosing that kind of symptoms still, you know." (S1)

"...So I think that the fact that you know items are used that they would've grown up around or in their environment, that that works really well and they they're guaranteed to be able to recognise them and name them, and obviously not lose points that way." (S2)

4.1 Sub-Theme: Adapting in the Moment

The participants shared how adaptations made in the moment made the assessment feel more appropriate. As described in the *'What Culture Though? Language Matters'* theme, some parts of the culturally adapted ACE-III felt less helpful or relevant. This sub-theme explores how some further adaptations were made in the administration of the culturally adapted ACE-III, and how the either/or (either the UK ACE-III or the culturally adapted ACE-III) becomes both/and (both aspects of the UK ACE-III and the culturally adapted ACE-III). This moves towards a more equitable experience, adapting the assessment process to the individual, whilst still maintaining the standard format of the assessment, as appropriate. For example, a staff member used aspects of the culturally adapted ACE-III in the mini ACE (a shorter version of the ACE-III):

"So then if they, when we do the first part, if you know they're struggling, then I'll just jump onto the mini ACE that's what I do.... [When completing the mini-ACE] "But then what I do is the English one, I adapt the name. Instead of saying, instead of saying "Harry Barnes" I'll change it to "Amar Chaudhary" on the thing. And then I'll say them instead of "Harry Barnes, 73 Orchard Close" I use "Amar Chaudhary". Well, I forgot the address now because. Yeah, but that's how we'll do it." (S1)

This was also in relation to the languages spoken within the culturally adapted ACE-III. Sometimes, multiple languages were spoken in the culturally adapted ACE-III, allowing for some of the individual differences in order for that person to complete the assessment. This included the service user speaking in their first language, as well as English, and for answers to be in both languages:

"Yeah, and and absolutely, because although sometimes mum was answering straight in English..." (FM2)

"Interviewer: So they would ask some questions in Urdu, some in English?" "Yeah, both languages." (SU2)

"Interpreter: Mostly he communicated with the assessor directly [in English]. It's only when interpreter was needed he, he communicated in Urdu." (SU3)

For a certain part of the assessment where the service user is asked to repeat a few words, if the language the service user spoke was not Urdu or Hindi, the staff member administering the culturally adapted ACE-III would ask the interpreter to say the words in another language, rather than Urdu or Hindi (or English). This meant that by making a further adaptation in the moment, this part of the assessment made sense, and the service user was able to understand it:

"You know when it says 'repeat the words'?...So 'soo- pra-sid-dh' and 'encouragement' I think that's a really hard one for some of them, you know, like when we get interpreters [to] say, the "constitute" you know that "cost..." I can't say the word myself man, the Urdu one, you know. I think they struggled to say, you know, but then we said to say [it] in, how would we say in the language [they understand] and then they say it." (S1)

"...Like that one way you have to give all the words- fluency, they give them sometimes in English and in Urdu." (S3)

4.2 Sub-Theme: A Good Start, Where Next?

Staff members shared that asking people about which version of the ACE-III they would like or what adaptations they need could be a helpful way to continue moving towards equitability. Indeed, there are examples where staff members are asking the service users and their family and supporters which version they would like and basing this off a number of different factors such as language, amount of time living in the UK and the questions, demonstrating that the adaptations made are a good start, but there needs to be ongoing thought as to how this can keep improving:

> *"But I think I have you know people say, 'Oh no, I've lived here like most of my life, I'm confident with British politics.'... Or sometimes people say, 'Oh no, I think she she does, you know, has is more culturally maybe Pakistani' so.."* (S3)

> *"...do you want me to conduct it in English or in, like, the British kind of version' if they've lived here a long time or or 'do you want me to do the South Asian version?'"* (S3)

Participants also spoke about the languages that the culturally adapted ACE-III has been adapted into (i.e. Urdu and Hindi) and how adaptations in more languages would be helpful for more people. Again, this is acknowledging that by having questions around reading and writing that were in Urdu and Hindi, different areas of cognition can be assessed and give a clearer and more reflective account of their cognitions:

> *"For Punjabi and Gujarati to be added on to it... So that would obviously include you know words and sayings that are more appropriate to their culture, you know, then be able to read the writing because they recognise it because it's in their language."*
> (S2)

> *"Oh and obviously the reading the letters in a language where we've asked them to ask the client to read the following words if it's in their own language, they've read the ACE, then it's got to be in their language..."* (S1)

The staff members who participated in the study also spoke about some guidance to support them in the administration and scoring of the culturally adapted ACE-III. It was felt this would help with some of the uncertainty experienced by the staff members, as noted in the theme *'Uncertainty Around the Purpose and Process'* above. It was also considered how this might impact the service users as well, by showing an interest and having some knowledge about their cultural experiences**:**

> *"Yeah, administering it [guide] would be good. Yeah, I think that would be helpful. Yeah because otherwise you're just asking people who have done it before then... Maybe trained on it as specifically on that that [South Asian] version."* (S3)

> *"...You know, I'm coming into somebody's house and I'm I'm interested. I'm not just here as a health professional and I'm doing my job and I'm, I'm leaving. I'm showing an all around*

> *interest. That's the way I sort of look at it and and it definitely does [help with] rapport building."* (S2)

There were also some suggestions for bespoke assessments which may be relevant to the service users, and so this will also be culturally relevant. However, this would lose standardisation elements, and would rely on the service user having people within their support network that can provide this information:

> *"Find different methods for the assessing different sub sections if that makes sense, like the memory and fluency of the try doing something they'd probably be familiar with."* (S4)

> *"...for example, where we lived before, could my could my mum, does my mum remember the post code for that place? The answer should be yes, because it, you know, she lived in that house for 30, 30 odd years, right? So you'd think she can still remember that postcode? I'm guessing right, I mean I can still remember it... Are there any specific kind of questions that could be asked? Where the assessor knows the answers already. And you ask it of the person being assessed to see if they can answer them, so it makes it unique to them as well."* (FM2)

It was also recognised that the cultural adaptations were specific to British Pakistani and British Indian service users who spoke Urdu and Hindi. As noted in the *'What Culture Though? Language Matters'* theme, not capturing the different cultural experiences leads to confusion and an incomplete cognitive test, as some part of the assessment cannot be asked. Here, participants suggest that there be assessments that have been culturally adapted to more specific cultures so the culturally adapted ACE-III is relevant and enables different aspects of cognition to be assessed:

> *"You know, Pakistan, the way they are might be a bit different to to the way Bangladeshi cultures are. So you know in in, in, you can't just be broad and say the Indian which we were all part of one continent once but India, Bangladesh and Pakistan then they are differences there."* (FM1)

> *"Oh and obviously the reading the letters in a language... Where we've asked them to ask the client to read the following words if it's in their own language... so they might be able to read their own language perfectly fine, but because obviously it is in Urdu, we haven't got nothing on there."* (S1)

Finally, the significance of this being an assessment for people with memory and cognitive difficulties may have been overlooked, reflecting a good start but where next may include reconsidering the appropriateness of the questions and consulting with those with lived experience (see 'Discussion' chapter). The adaptations were designed to reflect the UK ACE-

III and this process also involved consulting with people from with a South Asian heritage, both professionals and the general public. In this study, there was some concern that the material was insensitive. An example that some participants gave was around one of the questions, a culturally adapted phrase; '*how can a monkey know the taste of ginger?'* which essentially means how can someone know something if they lack the knowledge or experience. Although the adaptations seemed to be culturally relevant, the fact that this featured in a memory assessment mattered as people were anxious about their cognitive difficulties and having a phrase that questioned cognitive abilities was insensitive for some people:

> *"And I think he [family member] sort of mentioned that, yeah, it is... It is like a how can a monkey know the taste of ginger? I think it's pretty much calling someone stupid."* (S2)

> *"I think that's maybe a little bit seen as offensive, especially because it's a cognitive assessment. They might be already thinking they actually, I don't think it means to be, but so they were saying and they say it's a bit patronising."* (S3)

5. Chapter Summary

This chapter has focused on the results from the data analysis, with quotes from participants included in each theme and sub-theme. To recap, the major themes are *'What Culture Though? Language Matters'* which explores how the adaptations within the culturally adapted ACE-III are not always helpful or relevant, with the language used within and to administer the culturally adapted ACE-III also being important. Within this theme, the sub-themes *'Either/Or'* which focuses on how the dichotomous approach to having either the culturally adapted ACE-III or the UK ACE-III is entirely not helpful and *'What's Gets Missed'* which explores the consequence of this approach. The theme *'Uncertainty Around the Purpose and Process'* focuses on the uncertainty experienced by the participants in understanding different aspects of the culturally adapted ACE-III including working with interpreters. The sub-themes within this are *'Finding our own way'* which details staff members experiences of administering the culturally adapted and the uncertainty in how this is done ACE-III and *'Getting Lost in Translation'* which explores the role of interpreters and language in the culturally adapted ACE-III and the uncertainty confusion when working with interpreters. Finally, *'It's a Start: Moving Towards Equitability'* considers how the cultural adaptations begin to address some of the inequalities in non-adapted assessments, and how to keep working towards this. This theme has the sub-themes *'Adapting in the Moment'* which focuses on how staff members make adjustments to the culturally adapted ACE-III in order for it to make sense to the service users and *'A Good Start, Where Next?'* details what participants felt needed to be done to keep moving towards equitability, including personalising the assessment to individual needs. See Figure 1 for a thematic map of themes. The next chapter, *'Discussion'* will focus on exploring each theme in relation to the current literature, with the strengths, limitations and implications for clinical practice and future research also considered.

Chapter 4: Discussion

This chapter will discuss the findings placing the themes within the context of the current literature. From this, clinical implications will be considered in relation to culturally adapted cognitive tests. Finally, the strengths and limitations of the research project will be discussed before a final conclusion.

1. Revisiting the Research Aims and Questions

To recap, the ACE-III contains 5 cognitive domains that are assessed: attention, memory, fluency, language and visuospatial ability. The ACE-III involves asking individual questions as well as asking the service user to complete a set of tasks including reading tasks, remembering information, drawing and recognising images. The culturally adapted ACE-III (also known by staff members as the South Asian ACE-III), was developed for South Asian people who speak Urdu and Hindi living in the UK, as described in the *'Introduction'* chapter. To summarise, the cultural translation aimed to improve validity by amending the structure and content to map onto the way items would be understood by people from South Asian heritage, capturing both language and cultural references (see appendix A). For example, one of the questions in the ACE-III requires participants to remember an address. In the UK ACE-III, the address is 'Harry Barnes, 73 Orchard Close, Kingsbridge, Devon'. The structure of the address was changed to one more familiar in India and Pakistan ('Amar Chaudhary, 52 Station Road, New Colony, Hyderabad'). Also, historic events that happened in India and Pakistan were used (e.g. 'The year of the partition of India and Pakistan' and 'The name of the current prime minister of India/Pakistan') as well as different images (such as replacing the drum with a dhol, a double headed drum).

This research project aimed to explore service user, family and supporter's and staff members experiences of a culturally adapted ACE-III within memory services. Data was collected through nine interviews with ten participants and analysed using reflexive thematic analysis with a view to addressing the following research questions:

What are the experiences of South Asian service users undergoing a culturally adapted ACE-III in memory clinics?

What are the experiences of family and supporters of South Asian service users undergoing a culturally adapted ACE-III in memory clinics?

What are the experiences of staff members administering and interpreting a culturally adapted ACE-III in memory clinics?

2. Summary of Findings

I will discuss the findings in relation to each theme, drawing on the wider literature. *'What Culture Though? Language Matters'* which explores how the adaptations within the culturally adapted ACE-III are not always helpful or relevant, with the language used within and to administer the culturally adapted ACE-III also being important. The *'Either/Or Approach'* sub-theme explores the challenges where a service user can only have the culturally adapted ACE-III or the UK ACE-III. The sub-theme, *'What Gets Missed'* focuses on the impact of the adaptations not being helpful, such as not getting a full or accurate reflection of someone's cognitive abilities as well as what gets missed in the cultural adaptation. This theme is considered in relation to wider literature on acculturation and this project adds to the literature by demonstrating how the culturally adapted ACE-III does not accommodate for acculturation in some parts of the assessment, resulting in an incomplete cognitive test. This theme is also situated in the wider literature around the use of additional languages in cognitive tests, and the impact of this, such as challenges with translating some words into additional languages and whether this impacts the reliability and validity of the test. Finally, this theme is discussed in relation to existing literature on service user and family and supporter experiences of cognitive tests, and how this project contributes to the literature by adding the novel insight into how service users and family and supporters experienced cultural adaptations as part of a cognitive test.

Next, the theme *'Uncertainty Around the Purpose and Process'* is discussed, focusing on the uncertainty experienced by the participants in understanding different aspects of the culturally adapted ACE-III including working with interpreters. The sub-theme *'Finding our own way'* details staff members experiences of administering the culturally adapted. These findings are discussed in relation to staff member experiences of administering cognitive tests, and how uncertainty and challenges in administering standardised assessments are highlighted in current literature. Training and guidance are also important supporting with these challenges. Again, this project adds novel insight into staff member experiences of administering culturally adapted cognitive tests. The sub-theme *'Getting Lost in Translation'* explores the role of interpreters in the culturally adapted ACE-III and the uncertainty and confusion when working with interpreters. This is discussed in relation to existing literature on challenges in working with interpreters, and how this is an integral part of the administration of the culturally adapted ACE-III.

Finally, *'It's a Start: Moving Towards Equitability'* considers how the cultural adaptations begin to address some of the inequalities in non-adapted assessments, and how to keep working towards equitability. This theme is discussed in relation to service user and family and supporter experiences of the cultural adaptations that were helpful, drawing on the wider literature. This theme has the sub-themes *'Adapting in the Moment'* which focuses on how staff members make adjustments to the culturally adapted ACE-III in order for it to make sense to the service users is discussed, focusing on staff member experiences of culturally adapted cognitive tests, and the usefulness off this. Finally, the sub-theme *'A Good Start, Where Next?'* details what participants felt needed to be done to keep moving towards equitability, including personalising the assessment to individual needs. These themes add to the current literature highlighting the tension between making cognitive tests relevant and culturally appropriate whilst maintaining the psychometric integrity of the cognitive test.

2.1 What Culture Though? Language Matters

As detailed in the '*Either/Or*' sub-theme, staff members often used their judgement and experience when administering the culturally adapted ACE-III. For example, when making decisions about when to administer the culturally adapted ACE-III or the UK ACE-III, some staff members would determine this themselves based on the language the service user spoke. However, making this decision was often a complex one, and the inflexibility of having to administer either the culturally adapted ACE-III or the UK ACE-III, when neither was necessarily best suited to the person in its entirety, meant that some parts of the culturally adapted ACE-III were either not helpful or unhelpful. These findings speak to several key topics from the literature that will be discussed in more detail below: *'Acculturation'* which described 'shifts' in cultural identity; *'Additional Languages'* which explores the use of additional languages in the cognitive test and '*Service User and Family and Supporter Experiences'* which draws on literature around service user and family and supporter experiences of cognitive tests and cultural adaptations more broadly (e.g. in psychological therapy).

2.1.1 Acculturation.

In this study, service users shared that parts of the standard UK ACE-III would actually have been more helpful to them than the culturally adapted version of that component of the test. For example, recognising the letters and address due to living in the UK most of their lives. As such, there will be many individual differences in which cultural adaptations are helpful, which made choosing whether or not to offer the culturally adapted ACE-III, and whether the culturally adapted ACE-III best met the service users' needs was complex. Theories around acculturation are helpful in understanding the impact of culture in neuropsychological testing. As mentioned in the *'Introduction'* chapter, acculturation refers to shifts in culture depending on where someone is living. As a result, migrant communities may develop 'bicultural' identities where they adopt aspects of the 'mainstream' culture they reside in as well as maintain aspects of culture from their countries of origin (Arends-Tóth & Van de Vijver, 2006; Van de Vijver & Phalet, 2004). As such, there are many different domains in which acculturation occurs, such as language, skills and behaviours (Arends-Tóth & Van de Vijver, 2006). In relation to the neuropsychological tests, Tan et al., (2021) completed a systematic review concluding that there is complexity in determining the effect of acculturation on neuropsychological testing. This was also reflected in the findings in this project, where participants gave unique examples of how their experiences of living in the UK had impacted what was helpful for them as part of a cognitive screen. For example, when a family member shared that the UK address was more helpful as the service user was more familiar with UK address format as they had spent more time in the UK. This was also highlighted in the current literature suggesting acculturation is a multidimensional construct which impacts languages and general knowledge (e.g., Horn & Blankson, 2005).

Participants suggested that some service users continue to be disadvantaged. For example, not understanding the content in the culturally adapted ACE-III leaves participants having an incomplete cognitive assessment. This was the case for service users who spoke languages other than those the adapted assessment was intended for, such as Gujarati. This was also the case for those who were not able to read Urdu or Hindi, for example in Question 16 where the service user is asked to read some words in Urdu and Hindi. What was also interesting was that one participant who could not read Urdu was not able to recognise the Urdu letters in Question 21 which assess visuospatial abilities but could recognise the English letters. This shows there is variability in what is helpful for one person, may not be for another. It is important for the staff member administering the assessment to have a good understanding of the service users' experiences, including culture and acculturation experiences.

It is also helpful to consider how education intersects and impacted the service users' experience of the assessment. Being able to read and write is thought to impact the neural networks within the brain and skills such as problem solving (Ardila et al., 2010). Neuropsychological and cognitive testing can be problematic in accurately capturing someone's memory problems if they don't read or write (Ardila et al., 2010; Goudsmit, et al., 2018) with some research concluding that many tests are unsuitable for the use with those how do not read or write (Kosmidis 2018; Maher & Calia, 2021) with this also potentially lead to misdiagnosis (Parker & Philip, 2004). This is important to consider for older migrants who may have limited educational experiences and understanding of the main language in the country they live (Franzen at al., 2020). This highlights the importance of careful consideration of both reading and writing ability in a particular language when culturally adapted assessments are being designed and offered. This was not considered in this project, when staff members would typically offer the culturally adapted ACE-III in relation to spoken languages. The importance of intersectionality, particularly education, is highlighted when culturally adapted cognitive tests are administered as what is relevant and meaningful for a service user is influenced by different aspects of their identity and by their experiences. Cultural experiences *and* education intersect, resulting in different experiences dependent on both factors. For example, as noted in the *'Introduction'* chapter, if the culturally adapted ACE-III contains information in Urdu, but the service user does not read, then this part of the assessment becomes meaningless to the service user. The intersectional aspects of the service users' identity (such as education) beyond ethnicity may mean cognitive test are limited. This project and the wider literature suggest that it is important to consider both reading and writing skills when completing cognitive tests. As mentioned in the *'Introduction'* chapter, intersectionality is key when assessing cognitions and how different parts of people's identity intersect and result in very different experiences (Crenshaw, 1989). The findings in this study highlight how an either/or approach to cognitive testing has led to challenges in fully assessing someone's cognitive functioning. The idea of personalising neuropsychological testing is important to consider as such and will be explored below in the *'Personalisation'* section.

These findings, corroborated by existing literature, are particularly important because collectively they highlight a key impact of the inability to fully participate in aspects of a cognitive test due to its design. This results in incomplete and inaccurate assessments as highlighted by Lin et al. (2021) who discuss that it is important to have accurate cognitive tests considering dementia can be misdiagnosed or diagnosed much later in minoritised ethnic communities. Accurate and timely diagnosis and improving access to this for minoritised ethnic groups is, as mentioned in the *'Introduction'* chapter, particularly important as it can enable opportunities to reduce distress and enhance wellbeing and quality of life (Dubois et al., 2015). This includes the ability it has to provide access to more treatment opportunities that are only effective in the mild to moderate stages, including drug treatments and psychosocial interventions such as cognitive rehabilitation.

To summarise, acculturation is complex and impacts individuals on a unique basis, which is also confounded by factors such as education. Acculturation is important to consider in neuropsychological testing (Fernández & Evans, 2022; Tan et al., 2021) and this project has highlighted some of the challenges experienced by service users, family and supporters and staff members when acculturation is not considered, from selecting the most appropriate cognitive test, to being able to fully assess someone's cognitions. Next, language, and the impact of additional languages will be considered in more detail.

2.1.2 Additional Languages.

Participants also spoke about the importance of language and how completing the culturally adapted ACE-III in additional languages (i.e., not Urdu or Hindi) created some confusion and challenges with translating particular parts of the assessment such as certain words which were not easily translatable. To recap, culturally adapting an assessment involves adapting the content to make sense in a different culture (for example, using culture specific examples and content such as the phrases used in Question 13 in the culturally adapted ACE-III, see Appendix A) whilst maintaining content validity. Linguistically adapting the assessment involves translating the content into another language. Both parts of these adaptations require careful consideration to ensure accuracy and integrity of the test

(Waheed et al., 2020). Importantly, the findings from this study showed that when translating certain aspects of the test into an additional language, this did not work well for participants. For example, a family member and a staff member shared that when translating some words into Gujarati, there were sometimes no specific words for in Gujarati, so they were either unable to translate the word or had to think of an alternative word or way to describe the concept in a way that was culturally acceptable. This is further corroborated by Parker and Philip (2004) who suggest that translation alone does not account for cultural bias. Words, phrases and phenomena are bound by the culture in which they were developed, that simply translating words might not only be difficult, but impossible (Guerra, 2012). As discussed in the *'Introduction'* chapter, research has shown the problems with cognitive assessments underestimating cognitive abilities in minoritised ethnic communities (Adelman et al., 2011; Khan & Tadros, 2014), highlighting the importance of culturally appropriate cognitive tests. Furthermore, education will also play an important role in what a service user will be able to complete in a cognitive test, for example reading and writing tasks may not be relevant depending on the service users' educational experiences and is important to consider alongside language. When considering adaptations for service users from South Asian communities, it is also important to note, as highlighted both by participants in this study, that, unlike English, there are several different dialects spoken which needs further consideration when adapting assessments into South Asian languages, with different levels of understanding (i.e., similarities and differences) between different dialects (Nazir, 2020). This research project offers novel insight into how cultural adaptations and the use of a culturally adapted cognitive test with a group of service users whom the cultural adaptations were used for created some challenges. This raises some questions around whether culturally adapted assessments that have been adapted for a particular culture and into a particular language, are appropriate to administer in additional languages.

An important finding related to language that has been demonstrated in this project is that the use of the culturally adapted ACE-III in additional languages it was not intended for, such as Gujarati and Bengali, results in some additional confusion and challenges in being able to accurately interpret parts of the assessment. This was specifically the case with translating some of the words, but there was also some reflection in the data that the content of some of the questions were specific to British Pakistani and British Indian service uses (such as the memory question where service users are asked to remember an address) and how this created some confusion or was not culturally relevant. Specifically, a family member shared that the address, which included the city *'Hyderabad',* the service user kept getting this confused with *'Ahmedabad'* which was the capital of Gujarat. This linked with wider literature, such as Wong et al. (2025) who show how lack of exposure to the content and cultural assumptions within the test negatively impacted the scores and experience of the test. Research has well established that cultural background impacts cognition (Ardila, 2007; Fernández & Evans, 2022; Tan et al., 2021). Despite the cultural adaptations in the ACE-III, this project has highlighted the need for the adaptations to be specific and relevant to the individual’s culture.

However, another important finding was that even if service users did speak Urdu, for example, there were still parts of this assessment that were not helpful or relevant, even though these service users were the ‘target’ audience. In contrast, for the participants in the study that spoke Bengali, who were not the ‘target’ audience, there were still parts of this assessment that were considered helpful. For example, the participant with a Bengali heritage shared that they felt the culturally adapted ACE-III was a good assessment and got a sense of the cognitive difficulties for that person’s family member. This highlights that even though the assessment was culturally adapted for Urdu and Hindi speakers from Pakistan and India, there was still some relevance with other South Asian communities. That being said, the participants did not have the UK ACE-III, so it is not to say that there would not have been helpful elements to this assessment as well. As noted, participants did find some parts of the UK ACE-III helpful as well. This project has highlighted how there is much complexity in thinking about cultural adaptations and what is helpful for some, may be less helpful for others. From this, it may be more helpful to consider whether culturally adapted assessments would be helpful on an individual basis. It is important to consider how administering culturally adapted assessments in additional languages impacts the integrity of the psychometric assessment. This is beyond the scope of this project and will be considered in the ‘*Clinical Implications’* and *‘Future Research’* sections below. Whilst there is limited research in this area, it is promising to understand more about how service users, family and supporters and staff members experience the impact of the cultural adaptations, and this research adds novel insight into the complexity in cultural adaptations in cognitive tests. This has implications for the accuracy of dementia diagnoses and enabling service users to access support in a more equitable way.

2.1.3 Service User and Family and Supporter Experiences.

As mentioned in the *‘Introduction’* chapter, there is very little research exploring the experience of cultural adaptions in memory assessments. Within this project, service users, family and supporters shared that they found some of the cultural adaptations in the ACE-III helpful as they were more relevant to them, and this will be explored further in the ‘*It’s a Start: Moving Towards Equitability’* section below. In this project, there were also some suggestions that parts of the assessment were not helpful or relevant and this corroborated with other research. Smith et al. (2023) conducted research across memory and assessment services across the UK. Within this, some services had made cultural adaptations to cognitive tests, and found similar findings to this study- i.e., mixed findings around the cultural adaptations being helpful, but there are some aspects that are not helpful or relevant. Specific examples in this project have been highlighted in the *‘Acculturation’* and

'Additional Languages' sections above, including how the adaptation in the address to reflect and address in Pakistan was not helpful for some service users.

Whilst there was some uncertainty experienced by the staff members in relation to administering the assessment and family members in relation to clear communication with interpreters (see '*Uncertainty Around the Purpose and Process'* section below), the data in this project did not reflect previous literature in relation to the assessment being distressing. Some participants did report confusion in relation to the questions and translation of the culturally adapted ACE-III into additional languages (as detailed in the *'Acculturation'* and *'Additional Language'* sections above). Previous research has suggested that service users and their family and supporters experience the neuropsychological assessment for dementia as uncertain and distressing (Keady & Gilliard, 2002; Gruters et al., 2021; Robinson 2016; Samsi et al., 2014). This project corroborates the current literature on service users from a minoritised ethnic background experience of cognitive tests. For example, Smith et al. (2023) suggest that service users from minoritised ethnic backgrounds experience culturally adapted assessments are more comfortable and relaxed. Furthermore, Bharath et al. (2023) found that service users were not particularly anxious about a culturally adapted Addenbrookes Cognitive Assessment cognitive subscale in India. However, it is important to note in that research is that all the service users had undergone the cognitive test and had not been diagnosed with dementia. Bharath et al. (2023) reported that the service users felt they had 'passed' the test and influenced their experience of the test and that they had found it simple and appropriate. Within this project, all of the service users were awaiting an outcome of their cognitive assessment, which is a significant difference in what the service users were experiencing in the Bharath et al. (2023) study. Further research with those from a minoritised ethnic background suggest that service users found unadopted neuropsychological assessments were limited in including their cultural identities in the assessment (Dudley et al. 2014). This was also highlighted in this study, with participants reflecting on some of the challenges and confusion when the culturally adapted ACE-III was used with service users from minoritised ethnic backgrounds whom culturally adapted ACE-III was not intended for (e.g., Gujarati or Bengali service users).

Whilst experiences of culturally adapted cognitive assessments specifically have received limited research attention, experiences of culturally adapted psychological therapy have received more attention and provide some insights into service users experiences. An example of a study on cultural adaptations in therapy is discussed below and considered in relation to this project. What is important to note is that within psychological therapy, there is room for more of the flexibility in relation to cultural adaptations, for example, by finding different ways to explain different concepts or ask questions in different ways. Whereas the standardised nature of cognitive tests means there is less room for flexibility, where questions and instructions need to be given in a specific way. This was also highlighted in the data when thinking about the need for the information and administration of the culturally adapted ACE-III to be accurate in order for a potential diagnosis to be accurate. This leads onto the consideration that cultural adaptations are an ongoing process and the flexibility within cognitive tests to enable this and further thought will be given to this below in the '*It's a Start: Moving Towards Equitability'* section.

In this project, family members highlighted that the cultural adaptations were not always relevant. As mentioned above, when a family member shared that the question around the remembering the address that had been culturally adapted, was not relevant and caused more confusion. The service user was of Indian heritage and was confused between the city *'Hyderabad',* the service user kept getting this confused with *'Ahmedabad'* which was the capital of Gujarat. This was similar to previous research which has highlighted cultural adaptations only going so far. Jensen et al. (2021) also highlight some limitations with adapted approaches, for example, family members may sometimes feel frustrated with cultural adaptations, feeling that some of the adaptations were not always appropriate for certain groups within broad definitions of ethnicity (such as African-Caribbean). This sense of cultural adaptations, at present, only going so far was supported by the data for this project. As mentioned in the *'Acculturation'* and *'Additional Language'* sections above, neuropsychological and cognitive testing can be problematic in accurately capturing someone's memory problems if they don't read or write (Ardila et al., 2010; Goudsmit, et al., 2018). Furthermore, some research suggest that many tests are unsuitable for the use with those how do not read or write (Kosmidis 2018; Maher & Calia, 2021) with this also potentially lead to misdiagnosis (Parker & Philip, 2004). This is important to consider in relation to service user experiences where parts of the culturally adapted ACE-III were irrelevant and linked to educational experiences (e.g. participant who were unable to read or write). Again it is essential to consider the role of education when developing culturally adapted cognitive tests, and in order for the cultural adaptations to be meaningful, educational experiences also need to be accounted for.

In summary, the findings in the study in relation to service user and family and support experience of cultural adaptations in cognitive tests provide novel insight into some of the challenges and complexity in making cultural adaptations for people with a South Asian heritage in the UK. Whilst there were some positive experiences reflected in the data and wider literature around the cultural adaptations being helpful and relevant within the cognitive tests, explored in more detail below, these cultural adaptations do not provide an adequate or full solution to the challenges of accurately assessing cognition in South Asian communities in the UK.

2.2 Uncertainty Around the Purpose and Process

This theme explored some of the uncertainty around the purpose and the process of the culturally adapted ACE-III. As mentioned, staff members often use their judgement and experience when administering the culturally adapted ACE-III. This was highlighted when making decisions about when to administer the culturally adapted ACE-III. So, for some staff members, if the service user did not understand English, then the staff member would use the culturally adapted ACE-III if they spoke a language within South Asia, such as Punjabi, Gujarati, or Bengali. Some staff members went beyond this, for example, by administering the culturally adapted ACE-III with participants who spoke Arabic or Farsi, moving out of the South Asian communities. For other staff members though, if the service user spoke or understood English, then they would administer the UK ACE-III regardless of their cultural background. Ideas around acculturation could help make sense of these decisions, but as we have seen, even if someone does not speak English, the UK ACE-III may still have helpful aspects to it as the service user lives in the UK and is familiar with many different aspects of the culture. This leads onto considerations around the extent to which giving choice and personalising cognitive assessments is possible and will be discussed in more details below.

2.2.1 Staff Member Experiences.

Within this project, staff members shared their experiences of feeling uncertain about the administration of the culturally adapted ACE-III, specifically in relation to how to ask the questions, what it is they are asking and the answers to the questions. Furthermore, it was felt that there needed to be more guidance and training (which will be explored in more detail in the *'Training and Guidance'* below) which would be helpful in understanding more about the culturally adapted ACE-III. This has also been highlighted in previous research where staff members noted a lack of knowledge and training in relation to administering cognitive assessments with minoritised ethnic communities (Dingwall et al., 2014). A unique finding in this project was that staff members were not always sure how to score the culturally adapted ACE-III and were uncertain how the service user was doing in the assessment. The standardised procedures in administering and scoring neuropsychological tests are important to enable the scores to be compared to normative data and interpretations can be made about how someone may be struggling, including making a diagnosis (Zucchella et al., 2018). Therefore, a lack of scoring guidance raises questions around the reliability and validity of the scores generated from the culturally adapted ACE-III. However, staff members also experienced the culturally adapted ACE-III as a helpful tool to assessing someone's cognitive function, and this will be explored further in the *'It's a Start: Moving Towards Equitability'* section below.

2.2.2 Training and Guidance.

Staff members shared that they had no formal training or guidance on how to administer and interpret the culturally adapted ACE-III. This sometimes left them wondering if what they were doing was consistent or 'right'. However, research has shown that even with training, the everyday administration of neuropsychological tests does deviate from the standard test procedures (Howieson, 2019). That is not to say that some guidance around the culturally adapted ACE-III would not be helpful. Staff members in this project felt that more understanding of the assessment, how it was adapted and how to score it would be helpful. A clear approach to administering and scoring cognitive tests will enable a more consistent approach which service users and family and supporters will also understand. The importance of training and guidance will also be discussed in the *'Future Research'* section below.

2.2.3 Interpreters.

This project highlighted some of the challenges experienced by staff members when working with interpreters as part of the culturally adapted ACE-III. These challenges left staff members feeling uncertain about how the culturally adapted ACE-III was being administered. For example, the staff members in this study shared that they often feel like they get limited information about the non-verbal communication and how a service user may be managing in the assessment (for example, repeating things) which left them feeling uncertain about the assessment process. Other research corroborates this finding by also suggesting that staff members find it harder to make sense of non-verbal communication when working with interpreters (Gerchow et al., 2021) and feel less in control during cognitive tests (Haralambous et al., 2018). There was also some consideration as to how the verbal information was filtered, and staff members in this project reported that they were not always aware of what was happening in the assessment. Jiang et al. (2014) suggest that interpreters have a complex social role where decisions are made by the interpreter that are filtered through different processes throughout the conversation. Staff shared some uncertainty around working with interpreters, which is supported by existing literature. The importance of working with interpreters in a consistent way was highlighted by Torkpoor (2024) who suggested that the competence of the interpreter as well as the ability of the professional administering the cognitive test impacted the assessment, with a lack of competence leading to the misjudgement of a service users' cognitive functions. As detailed, staff members feel uncertain about aspects of working with interpreters and as the culturally adapted ACE-III is in Urdu and Hindi, the use of interpreters is an integral part of the assessment, and it important to consider how this impacts the assessment.

The role of staff interpreting also came up in the interviews. It was acknowledged that bilingual staff members could offer some 'enhanced' service by being more consistent and having an awareness of the culturally adapted ACE-III. However, depending on the staff member's language skills, there may be some challenges in whether they are able to interpret. Staff members in this project shared that as they were born and raised in the UK, they were less familiar with some dialects or understanding. This was also highlighted in other research (e.g. Moreno et al., 2007) suggesting staff may benefit from additional support when also interpreting as part of their role. It is important to consider that interpreting is more than translating and how staff are supported in doing this. This project has contributed to the current literature by indicating some of the challenges when working with interpreters when administering culturally adapted cognitive tests.

2.3 It's a Start: Moving Towards Equitability

In line with the need to capture more languages and cultures, there was some thought in this project around how far to take this, and who will continue to get missed. These are important points that were raised, leading into consideration of whether bespoke elements could be introduced to the assessment. The rationale being that if an assessment had elements adapted in an individualised way, it would also capture culture and acculturation. So, for example, when culturally adapting the assessment, the question which requires service users to remember an address could have different options for addresses in different cultures. This is discussed in the *'Personalisation*' section below. Before this, service user and family and supporter (see *'Service User and Family and Supporter Experiences'* section below) experiences and staff member experiences (see *'Staff Member Experiences*' section) in relation to the benefits of the culturally adapted ACE-III are discussed below.

2.3.1 Service User and Family and Supporter Experiences.

In this project, service users shared that some of the cultural adaptations were helpful and relevant and staff members felt this gave a more accurate representation of the service user's cognitive difficulties. Whilst this project did not specifically explore the accuracy of the culturally adapted ACE-III, previous research has shown that cultural adaptations had a positive impact on cognitive test scores (Adelman et al., 2011) demonstrating the importance of culturally sensitive cognitive tests when diagnosing dementia. The positive impact of cultural adaptations is also noted in other areas, such as psychological therapy. Generally, research suggest that cultural adaptations in psychological therapy are considered effective by those undergoing therapy and lead to positive outcomes. Chowdhary et al. (2014) completed a systematic review of cultural adaptations in psychological therapy, suggesting that these cultural adaptations are effective. Perry et al., (2019) conducted a study exploring both quantitative outcomes and qualitative experiences of culturally adapted therapy. For Turkish participants living in the UK, they found that cultural adaptations to the therapy led to positive outcomes. In terms of qualitative experiences, participants shared that the adaptations were more relevant and culturally sensitive therapeutic interventions. This suggests that cultural adaptations are helpful across a range of different assessments and interventions.

As mentioned in the *'Introduction'* chapter, culturally appropriate adaptations can have a positive impact on people from minoritised ethnic backgrounds (Parveen et al., 2018a) and cultural and linguistic adaptations enable participants to undergo assessments that are more culturally sensitive (Cova et al., 2012). It appears from this data that there are some positive aspects to these adaptations that are enabling clinicians to get a fuller picture of service user's cognitions. The participants in this study shared how having to recall information, such as the address, and naming different images that had been culturally adapted, was easier than this would have been using the standard assessment approaches. In particular, one of the items (a dhol, which is a double headed drum used in South Asia) being more relevant as they had experience of using these items. This particular question is assessing language skills and for all of the service users who participated in this project, they spoke their first language predominantly. This suggests that the cultural adaptations were important when assessment memory and language domains. Language degeneration is highlighted in research which shows that a person's second language is more vulnerable to neurodegeneration (Ellajosyula et al., 2020). As such, this suggests that language has an important influence in cognitive tests and should be considered when selecting and administering cognitive tests.

2.3.2. Staff Member Experiences.

This study found that staff members made further adaptations to the culturally adapted ACE-III so it would make sense or be more appropriate for service users. For example, one staff member shared that they would include the culturally adapted questions for a mini ACE (a shorter version of the full ACE-III) when service users struggled with a full assessment due to their difficulties. This finding adds new insight how staff members are administering culturally adapted cognitive tests. Similar findings were found by Smith and Surr (2024) when exploring how staff members manage non-adapted cognitive tests with service users from minoritised ethnic backgrounds, staff members shared that they would make adaptations to the cognitive tests in an attempt to make the assessment culturally relevant.

Within this project, participants shared how understanding and knowledge about different cultures made the experience of the culturally adapted ACE-III better. From a staff member perspective, they felt more confident about administering the assessment and felt this also had a positive impact on rapport with the service user and their family and supporters. From a service user and family and supporter perspective, they reported that they felt relaxed and made the experience more positive. This corroborates the wider literature on rapport building in neuropsychological assessments (Barnett et al., 2018; Quang et al., 2025). This finding highlights the importance of rapport in neuropsychological testing and how staff understanding the cultural adaptations and service users' cultural experiences is particularly important for rapport building in the culturally adapted ACE-III.

Whilst the process of culturally adapting the ACE-III has led to some positive experiences documented by the participants in this study, there was some reflections on how some of the cultural adaptations may have been insensitive. Although this was not specifically reported by the service users in this project, the staff members shared how some service users and family and supporters who they had used the culturally adapted ACE-III with had shared some feedback on a particular adaptation (i.e., Question 13.ii). As documented in the current literature, the consultation with focus groups with members of a particular community is considered best practice when making cultural adaptations (Mirza et al., 2017; Waheed et al., 2020). However, as the data in this current study reflects, there may still be challenges to these cultural adaptations being appropriate and relevant. Despite consulting with members of the general public from a South Asian background*,* some participants felt aspects of the adapted test were not culturally appropriate. For example, the phrase 'a stitch in time saves nine', which SUs are required to remember and repeat, was adapted with agreement to 'how can a monkey know the taste of ginger?'. However, this was felt by some study participants to be an insensitive phrase as it implies a lack of knowledge or experience. As this cognitive test forms part of a memory assessment, this phrase was felt to be insensitive as it means how can someone know something if they lack the knowledge or experience, and service users may already be concerned about their memory and cognitive functioning. People attending the assessment are likely to be anxious about their cognitive difficulties and having a phrase that questioned cognitive abilities was insensitive for some people. This is considered in the *'Future Research'* section below where consulting with people who have lived experience is helpful to in designing research to minimise such problems occurring. This has also been highlighted in other research in relation to culturally inappropriate content, where Wong et al. (2025) show how culturally offensive content negatively impacts performance and experiences of neuropsychological assessment. As this project demonstrates, it is important to consider cultural adaptations alongside the purpose of the cognitive test.

2.3.3. Personalisation.

Neuropsychological assessments are generic in nature as they are standardised in a way so scores can be compared and give an overview of the cognitive difficulties someone may be experiencing (Zucchella et al., 2018). Interestingly, within this project, participants suggested that there be a need for some balance with how the tests are consistently administered whilst allowing for some flexibility. An example of this is when service users were able to respond to questions in both their first language and English, as reported by the participants in this study. Personalising neuropsychological assessment has been suggested by previous research such as Foran et al. (2016) who suggest that the application of standardised assessments be flexible and individualised. Within this project, staff members shared that they might ask the service user or family and supporters which assessment they would prefer; the UK ACE-III or the culturally adapted ACE-III. Here the assessment process has been personalised to account for the service user's preferences and what they feel would be most appropriate. This was corroborated by other research, such as Foran et al. (2016) who suggested that professionals administering the assessments be clear in why they are administering that particular test, giving a clear rationale for doing it. This may be useful to consider when thinking about using a culturally adapted assessment and could also include involving the service user and their family in the decision-making process.

The suggestions made, and actions taken, to introduce more personalisation into the cognitive assessment process in this study need careful consideration because they are not necessarily compatible with maintaining the psychometric integrity of the assessment. Within the data, participants also shared that they felt it would be helpful to have culturally adapted assessments in different languages and to reflect different cultures. It may be helpful to think about what aspects of the culturally adapted ACE-III may be useful, and which parts may not be relevant. What this project and previous literature has shown is that this should be done on an individual basis. As suggested above, having a good understanding of the service users' culture and experiences is important in neuropsychological testing.

3. Clinical Implications

This project has highlighted some of the complexities in cultural adaptations. The findings of this project will be fed back to the Bradford District Care NHS Foundation Trust so staff can consider ways this project could influence practice. From this, recommendations around some things to consider when administering a culturally adapted cognitive test are discussed. The clinical implications for this research can be applied in any service where culturally adapted cognitive assessments are being used. It should be noted that the sample size in this project was small and the recommendations that can be drawn from this are therefore limited in in scope. This is discussed in more detail in the *'Limitations'* section below but this is important to note when determining the clinical implications of this study. Furthermore, the culturally adapted ACE-III focused on in this study has not been validated and is only available in Urdu and Hindi. Although this study has highlighted the use of the culturally adapted ACE-III with participants who the cultural adaptations were not intended for (i.e. Urdu and Hindi people from a South Asian community living in the UK). As such, this culturally adapted ACE-III is limited, particularly given the variety of languages and dialects spoken in South Asian communities. There are also validated versions of the ACE-III in different South Asian languages which could be used with different people. It is important to consider the use of the culturally adapted ACE-III and other versions which can be used with people from a South Asian background. This will be discussed in more detail in the *'Limitations'* section below.

As noted above, having a sound rationale for using (or not using) a culturally adapted cognitive test is important for both the clinician's administering the cognitive test and service users undergoing it. This could involve having a conversation with service users and their family and supporters prior to an assessment about which cognitive test might be helpful, and the pros and cons of this. In relation to the culturally adapted ACE-III, for those who speak Urdu and Hindi whom the cultural adaptations were designed for, there were some parts of the assessment that were helpful, such as remembering information that was culturally adapted, like the address, and naming different images. However, for these same participants, there were some adaptations which felt less helpful, and some parts of the UK ACE-III could have been more appropriate, such as the visuospatial questions involving letters. Indeed, the culturally adapted ACE-III was felt to be helpful for service users from other South Asian communities, such as Bengali service users who had undergone this assessment. There were some parts of the assessment that were difficult to translate and caused some confusion, however, and this raises the question of whether the UK ACE-III would have been more helpful. As the participants had only undergone one assessment (in this sample it was the culturally adapted ACE-III) it is difficult to say whether the culturally adapted ACE-III or the UK ACE-III was more helpful. Indeed, the aims of this project was to explore experiences of the culturally adapted ACE-III, and the overall conclusion from this project is that there are some important factors to consider when making decisions and administering culturally adapted cognitive tests. The considerations include the impact of acculturation and additional languages. From this, it would be helpful to consider training and guidance in relation to the culturally adapted cognitive tests and personalising the assessment.

In relation to training and guidance, it would be helpful for more formal training or workshops on the culturally adapted ACE-III to be facilitated. This is also true of any culturally adapted cognitive test where there may be some uncertainty experienced by the staff member's administering the assessment. More knowledge and understanding of the purpose and process involved in the culturally adapted cognitive tests will enable a clear and consistent approach which service users and family and supporters will understand. Making decisions in collaboration with the person undergoing the assessment and consider which may be the most helpful, and why. It may be that there are pros and cons to each assessment, and here it is useful to consider the rationale for using one over the other. As mentioned, this is likely to be a decision made on a case-by-case basis, and staff members having more understanding around the assessment will be important to helping guide these decisions. Indeed, no standardised cognitive test is able to account for all individual differences and be standardised. Therefore, it is helpful to consider what adaptations can be made to reduce the amount of error within the cognitive tests, giving the most accurate representation of the person's cognitive functioning as possible.

Alongside more training and guidance when administering culturally adapted cognitive tests, having some formal guidance on how to score and interpret the results is essential to the use of the culturally adapted ACE-III. There is also the important point around how to assess the writing components of the assessments if this is being completed in another language. This would be useful to consider in for future research and this point will be explored in this section below.

In terms of personalising the assessment, this leads on from staff members having a good understanding of the assessment (which can be supported through training and guidance) as well as having a good understanding of the service users' culture and experiences. As the data in this current study, and previous literature has shown, having a culturally appropriate cognitive test leads to a more accurate representation of the person's cognitive functioning. Flexibility in personalising the assessment to be more appropriate for the service user, within the limits of a standardised cognitive test is important to consider. For example, as highlighted in the data, service users being able to respond in their first language and English is one way the assessment can be flexible to suit the needs of the service user. However, it is worth noting that careful consideration needs to be given to the impact that personalising has on the psychometric properties of the cognitive test. What is important to note is that by not adapting the cognitive test, service users from minoritised ethnic groups continue to be disadvantaged (Arblaster, 2021) and are less likely to receive an accurate diagnosis (Adelman, 2010; Pham et al., 2018).

4. Strengths and Limitations

4.1 Strengths

This project is one of the first in-depth studies to explore service users, family and supporters and staff members experience of a culturally adapted ACE-III. In particular, there is fairly limited research that captures service user's experiences, particularly when thinking about memory problems and dementia. This research captures a breadth of experiences and has enabled some important issues to be raised. This research project was also responsive to the needs of service users, family and supporters by changing the recruitment process to be more inclusive and sensitive to the participant's circumstances. This aided the recruitment process and enabled participants to be included and share their valuable experiences.

Within this project, I have tried to acknowledge my own experiences and how this will have impacted the research project. There have been times where I have tried to attend to limited knowledge and understanding, such as linking in with Mohammed at Meri Yaadain. I have also tried to remain curious, and the clinical implications are ones that also adopt curiosity rather than a knowing and 'expert' position with definitive guidelines. This is partly because, as I have attempted to acknowledge in the *'Reflexivity'* section, I will only be able share my thoughts and reflections and have limited experiences in this, both personally and professionally. Furthermore, I am not sure that definitive guidelines would actually be helpful. As the research has highlighted, there are many nuances in how the culturally adapted ACE-III is useful and can be used. It is encouraging that the culturally adapted ACE-III can be a tool that supports service users and family and supporters to access the service and have a more beneficial experience of the memory assessment.

4.2 Limitations

It is important to note that within this research, some of the challenges of working with interpreters were highlighted. This was largely reflected by family and supporters and staff members, who were able to communicate directly with me. For all of the interviews with service users, an interpreter was also involved. This raises some questions around what got missed or overlooked in the interviews. That's not to say that the interpreters within this project haven't been valuable, in fact the interviews with service users wouldn't have been able to take place otherwise. But this is to highlight some of the complexities in being able to work with interpreters. My clinical training has enabled me to learn about working with interpreters, although this is something I have little experience in. Whilst this project has tried to acknowledge some of the limits of my experiences, there will no doubt be 'blind spots'. This was further highlighted when explaining about the rationale for interpreters, blindly following a policy, to the family member as described in the *'Methods'* chapter. This will have been done in the project in other ways that have not been highlighted, and I think it is important to name that.

As mentioned above, Mohammed from Meri Yaadain was involved in the project as a collaborator. On reflection, it would also have been helpful to consider involving people with lived experience, for example of dementia, in the development of the project. Parveen et al. (2018b) note how involving experts by experience provides invaluable input in research and was particularly important for recruitment of minoritised groups. Whilst I tried to take care in designing the projects and materials and holding potential participants in mind, involving people with lived experience would have strengthened this project and ensured that the voice of people living with dementia from minoritised ethnic communities was throughout this project.

Another limitation of this projected is the small sample size. Whilst this project has tried to centre the participants voices, there will no doubt be many more experiences which have not been reflected, and so the clinical implications of this project are restricted by this. Whilst there were common themes throughout the data, a breadth of experiences has been shared, including both the positive and negative aspects. It should also be noted that the clinical implications are focused on how to keep attending to the nuances within cultural adaptations, and so regardless of the sample size, there is a lot of important points raised in this project. Also, the service users were interview between 1-4 weeks. Whilst this study initially aimed to complete interviews within 1 week of the culturally adapted ACE-III, there were practical challenges to this, such as availability. I ensured the integrity of the data by making sure the service users were able to recall their experiences for the interviews, however, future research could try to minimise this further by recruiting service users as quickly as possible.

As mentioned above in the *'Clinical Implications'* section, this study focused on the culturally adapted ACE-III which has been developed for people who speak Urdu and Hindi, from a South Asian background in the UK. As such, this culturally adapted ACE-III is limited, particularly given the variety of languages and dialects spoken in South Asian communities. There are also validated versions of the ACE-III in different South Asian languages which could be used with different people. From this, the study is limited in the clinical implications and generalisability of the findings.

5. Future Research

Future research could continue to build on exploring the impact of the culturally adapted ACE-III. It might be useful to evaluate the effectiveness of the culturally adapted ACE-III and possibly consider validating the measure to be used more widely, as this may benefit other communities outside of Bradford. Future research could also build on this project, and address some of the limitations, for example by involving those with lived experience of dementia in the development of future projects. This would be particularly helpful when developing the questions, as we have seen how not consulting with those with lived experience has led to some content which is felt to be insensitive been in the culturally adapted ACE-III (see example above of the use of 'how can a monkey know the taste of ginger?' phrase in the section *'It's a Start: Moving Towards Equitability').*

As detailed above, this project highlighted how the culturally adapted ACE-III is used with service users from a variety of cultural backgrounds. This often mean that the culturally adapted ACE-III was administered in additional languages from Urdu and Hindi, such as Gujarati and Bengali. As the data in this study demonstrated, this creates additional challenges, however, participants did note that there were still some useful parts to the culturally adapted ACE-III even though the adaptations were not specifically designed for them. Future research could investigate the impact of completing a culturally adapted cognitive test in additional languages, with a view to this guiding clinician's use of the measure in additional languages.

Future research could also explore the impact of acculturation and how this is experienced and the impact on culturally adapted cognitive tests. From this, future research could also explore the how cognitive tests could be personalised and the tension between accounting for some individual difference and maintaining the psychometric integrity of the test. It may be a case of having additional options for more specific cultures to create some more bespoke elements of the assessment, but as with the inclusion of additional languages, the impact of this would need to be explored.

6. Conclusion

Overall, this project has contributed to the wider literature by providing novel insights in a number of different ways. Service user and family experiences of a culturally adapted cognitive screening test has been highlighted, with some of the benefits, such as more familiar content, drawbacks, such as confusion or irrelevant material due to other factors such as education and acculturation. This is a novel insight into the experience of culturally adapted cognitive screening test for minoritised ethnic communities in the UK. This project also added to the literature by highlighting some of the complexities in using culturally adapted cognitive tests with communities that the cultural adaptations were not intended for, including the use of additional languages. There were both helpful and unhelpful aspects to the culturally adapted ACE-III and this raises important questions around *how* culturally adapted cognitive tests are administered. From this, the importance of selecting which test to administer should be done on an individual basis and in collaboration with the service user, family and supporters to understand which test may be most appropriate. This project demonstrated the importance of specific guidance in relation to scoring the culturally adapted ACE-III. Finally, ideas of personalising cognitive tests to account for some of the complexity in individual differences in cultural adaptations were raised. With fairly limited research, personalising cognitive tests would be helpful to consider further, including the impact this has on the reliability and validity of the cognitive test.

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Appendices

Appendix A: Cultural Adaptation of the ACE-III

Question		Adaptation
	Introductory Statement	An introductory statement was added to the ACE-III to put subjects at ease and encourage them to respond to the best of their abilities
1	Orientation to Time	Guidance was added for administrators on asking about the season
2	Orientation to Place	Guidance was added for administrators on asking about the ‘county’. Question on ‘clinic/hospital’ was changed to ‘place/address’.
3	Repeating 3 Words	Items changed to: Shirt, Mango, Key [*kurta, aam, chaabi*]
4	Subtracting Serial 7s	Guidance provided for administrators on alternative way of asking the question. Question was broken down into two parts for clarity.
5	Recalling 3 Words	None
6	Words with ‘P’	None
7	Naming Animals	None
8	Name & Address	Name and Address changed to: Amar Chaudhary, 52 Station Road, New Colony, Hyderabad
9	Semantic Memory	Questions changed to: When did the partition of Pakistan and India happen? Tell me the name of the current Indian or Pakistani prime minister. Tell me the name of the Indian or Pakistani female prime minister who was killed. Tell me the name of the American president. Guidance provided to administrator to say “fifty-two” in English.
10	3-Stage Command	Clearer distinction made on the form between the practice trial and the 3-stage command. Clear instruction provided to place the pencil and paper in front of the subject before each command. Question format changed to put subject at ease.
11	Writing Sentences	Guidance provided for the administrator to encourage the subject to attempt a response if possible. Scoring changed so that 1 point awarded for proper sentence construction rather than correct grammar and spelling.

12	Repeating 4 Words	Transliterations of Urdu and Hindi words provided in English translation.
13	Repeating phrase 1	Guidance provided for interpreter and administrator to check phrase repeated properly.
14	Repeating phrase 2	Guidance provided for interpreter and administrator to check phrase repeated properly.
15	Object Naming	Image of pig changed to a cow. Image of drum changed to a *dhol* (double-faced drum) Indian flag changed to Union Jack Guidance provided on possible responses for ‘cow’ and ‘sickle’.
16	Object Identification	None
17	Reading Irregularly Spelled words	Guidance provided to ensure Romanized transliterations are covered while showing subjects the words. The words ‘bilkul’ and ‘khwab’ were switched in the Urdu ACE-III so that ‘khwab’ is at the top of the list of words to read. This was done as ‘khwab’ is easier to identify and could encourage subjects to attempt the question.
18	Drawing Infinity Signs	Guidance included to encourage subjects to attempt the question.
19	Drawing Wire Cube	Guidance included to encourage subjects to attempt the question.
20	Drawing Clock Face	Guidance included to encourage subjects to attempt the question. Question broken into separate parts for clarity.
21	Counting Dots	Guidance provided to emphasize not pointing to dots with fingers to count.
22	Speckled Letters	English letters used in the question and Urdu/Hindi letters provided as appendices.
23	Address Recall	None
24	Address Recall	Guidance provided in Urdu/Hindi versions on how to ask about not recalled items.

Appendix B: Topic Guide (Service Users and Family and Supporters)

Interview topic guide- Service user and family/supporters

Demographic information- see separate document

Tell me about the memory assessment in the centre:
What do you remember about it?
What do you think worked well?
What didn't work well?
How well do you think it managed to get a picture of your memory problems?

I think the assessment that you had, had been adapted to make it more suitable for your culture:
How well do you think it did that?
Did it make a difference to you?
What parts of the adapted assessment worked well/not so well (visual prompts with the adapted ACE-III, e.g. different questions asked or different structure of questions)?
What do you think was the impact of the interpreters (if applicable)?

What could be improved?
What would you say to someone who was going to be having this memory assessment?
What advice would you give to the person carrying out the assessment?

Option for additional feedback or comments at the end of the interview.

Visual aids will be used during the interview (e.g. a copy of the adapted ACE-III assessment).

Appendix C: Topic Guide (Staff Members)

Interview topic guide- Staff members

Demographic information

Job role:

Number of years using adapted ACE-III:

Language used in adapted ACE-III:

Ethnicity:

Background information

How are service users usually referred/identified for the culturally adapted ACE-III?

Who is usually present at the assessment?

I've questions about the memory assessment in the centre:
What do you think works well?
What doesn't work well?
How well do you think the assessment manages to get a picture of the client's memory problems?
What do you think was the impact of the interpreters (if applicable)?
How well do you think the adaptations work?
Does it make a difference to accuracy or other aspects of the assessment?
What could be improved and why?

Other comments on the overall impact of the culturally adapted ACE-III?

Option for additional feedback or comments at the end of the interview.

Appendix D: Demographic Questions (Service Users and Family and Supporters)

Demographic Questions

Age:

Gender:

Diagnosis (e.g., Dementia (and type), mild cognitive impairment, no cognitive impairment, other, ongoing assessment)**:**

Background information

How/when were they referred for assessment?

When was the assessment?

Who was present at the assessment?

Type of memory assessment?

What language was the assessment conducted in (Urdu, Hindi or English)?

Ethnicity:

Culture:

Where were you born?

What is the first language you learned and what language do you mostly speak at home?

What is your religion and how observant are you in practicing that religion?

How do you identify yourself culturally?

Questions informed by: Fontes, L. A. (2008). Interviewing clients across cultures: A practitioner's guide. New York, NY: Guilford Press.

Appendix E: Consent to Contact Form (Service Users and Family and Supporters)

There was also a translated version in Hindi and Urdu

Experiences of Culturally Adapted Cognitive Tests in Memory Services

Consent to Contact Form

Please read the following statements:

1. I confirm that I am happy for my personal details to be stored by the researcher (at the University of Leeds).
2. I am happy for my personal details to be used to allow the researcher to contact me about the research project.
3. I understand my personal details will not be shared with anyone else except relevant members of the research team.
4. We will only retain personal details for those who agree to full participation in the research. Once the interview is completed, personal details will be deleted.

I am the person attending the Memory Assessment appointment ☐

I am responding on behalf of my friend or relative and should be the initial point of contact for further information about the study ☐

My name ______________________________

Patient name (where completed by friend/relative) _____________________

Address ____

____

Postcode _____________________________

Email _____________________________

Phone number ____

My preferred method of contact is

Email ☐ Telephone ☐

Signature ________________________________ Date _____________

OR if completed on behalf of a service users of family member/supporter

Completed by ____________________________

Organisation and Role ___________________________

Email ___________________________

Phone number ____

I confirm the above named person gave verbal consent to be contacted by the research team

Signature ________________________________ Date _____________

When completed: 1 for researcher site file, participants can request a copy of the consent to contact form

Appendix F: Short Participant Information Sheet (Service Users and Family and Supporters)

There was also a translated version in Hindi and Urdu

Culturally Adapted Memory Assessments: Service user and family/supporter experiences

Short Participant Information Sheet

What is this study about?

The aim of this study is to explore experiences of memory assessments that have been adapted for South Asian communities

What does taking part involve?

An interview with a researcher (Hannah Own) to share your experiences

The interview will last around 45-60 minutes and will be audio recorded

You can choose to speak to the researcher alone or with another person (e.g. family member, supporter and/or translator)

The interviews will be in person, in a private space online or over the phone

Do I have to take part?

Taking part is up to you. If you decide not to take part, it won't affect your care or your family/friend's care.

If you change your mind you can:

- Stop the interview at any time.
- Ask us to take your interview out of the project up to 1 week afterwards.

What are the benefits and risks of taking part?

There may be no benefits to you taking part

You could help to find ways of providing improved culturally adapted assessments for people with memory problems.

You might find talking about your experiences upsetting. If this happens, we will support you and you can take a break or stop the interview.

What will be done with the information?

We might use quotes from your interview in reports or presentations, but we will never use your name. Anything you tell us is confidential, unless you tell us you or someone else is at risk of harm.

Who do I contact if I have any questions or want to take part?

Please contact Hannah Own. Hannah will be very happy to tell you more or to answer any questions you may have about this research. You can also complete a ‘Consent to Contact’ form with a staff member and Hannah will contact you to discuss the research.

Call: 0113 343 6358

Email: umho@leeds.ac.uk

Appendix G: Further Resources (Service Users and Family and Supporters)

There was also a translated version in Hindi and Urdu

Further resources

Meri Yaadain

Organisation based in Bradford supporting people and families from Black and Asian minority ethnic (BAME) backgrounds where someone is living with dementia or caring for a relative living dementia.

Address: The Girlington Centre, Girlington Road, Bradford, West Yorkshire BD8 9NN

Website: http://www.meriyaadain.co.uk/

Phone: 07966 166 665

Email: info@meriyaadain.co.uk

Alzheimer's Society

Provides information and support for people living with dementia and their families/supporters in the UK. There is also translated information available.

Website: https://www.alzheimers.org.uk/

Phone: 0333 150 3456

Dementia UK

Information about dementia

Website: https://www.dementiauk.org

Phone: 0800 888 6678

Carers UK

A website for carers and supporters

Website: https://www.carersuk.org

Email: advice@carersuk.org

Appendix H: Participant Information Sheet (Service Users and Family and Supporters)

There was also a translated version in Hindi and Urdu

Culturally Adapted Memory Assessments

Participant Information Sheet

What is this study about?

The aim of this study is to explore experiences of memory assessments that have been adapted for South Asian communities

You have been invited to take part in this study because you or your family member/friend has had a culturally adapted memory assessment in the last 6 months

Why is this study happening?

This memory assessment that you/your family member/friend completed has been adapted to make sense and be more meaningful to the South Asian communities

It is important to study how helpful these culturally adapted memory assessments are and how to continue improving them

What does taking part involve?

An interview with a researcher (Hannah Own) to share your experiences
To help with the study, the researcher will ask you some questions, including demographic details (such as age, gender and ethnicity)

The interview will last around 45-60 minutes and will be audio recorded

You can choose to speak to the researcher alone or with another person (e.g. family member, supporter and/or translator)

You can request a translator for the interview

You can take part in the study even if your family member/friend chooses not to, provided this does not cause distress

The interviews will be in person, in a private space (e.g. at home, a community centre), the NHS Trust the study is taking place or online or over the phone

You will be reimbursed for any travel to a venue to do the interview

Do I have to take part?

Taking part is up to you. If you decide not to take part, it won't affect your care or your family/friend's care.

If you change your mind you can:

- Stop the interview at any time.
- Ask us to take your interview out of the project up to 1 week afterwards.

What are the benefits and risks of taking part?

There may be no benefits to you taking part

You could help to find ways of providing improved culturally adapted assessments for people with memory problems.

You might find talking about your experiences upsetting or tiring. If this happens, we will support you and you can take a break or stop the interview

What will be done with the information?

This study will be written up as a Doctoral Thesis at the University of Leeds

The information collected for this study may be used for further research
We might use quotes from your interview in reports or presentations, but we will never use your name. Anything you tell us is confidential, unless you tell us you or someone else is at risk of harm.

All files will be stored securely (password protected) on storage permitted through the University of Leeds Information Governance policy (e.g. OneDrive). All paper copies will be destroyed as soon as they have been saved electronically. All personal information and raw audio recordings will be deleted as soon as the study is complete, all other data will be stored securely at the University of Leeds for 3 years in an access-controlled storage file for the DClin programme research staff, after this time all data will be deleted

You can also receive a copy of the findings of the study (via email or the post) once this has been completed

Who has approved this study?

The project has been approved by the University of Leeds and HRA and Health and Care Research Wale (HCRW) NHS ethics committee.

Research ethics committee (24/WA/0309)

The University of Leeds is the research sponsor

Your NHS community service has agreed to taking part

Who do I contact if I have any questions or want to take part?

Please contact Hannah Own. Hannah will be very happy to tell you more or to answer any questions you may have about this research.

Call: 0113 343 6358

Email: umho@leeds.ac.uk

Complaints or concerns?

If you would like to speak to someone else about the study, or have any complains, please contact:

Professor Gary Latchford, joint programme director of clinical psychology training programme at University of Leeds

Email: g.latchford@leeds.ac.uk

Or

The Sponsor Representative at the University of Leeds

Email: governance-ethics@leeds.ac.uk.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name, address and contact details to discuss the research and arrange the interviews. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

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

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason. You can ask us to take your interview out of the project up to 1 week afterwards.

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

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by contacting the researcher (Hannah Own, details above)
- https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf
- By contacting the data protection officer at the University of Leeds on dpo@leeds.ac.uk.

Appendix I: Consent Form (Service Users and Family and Supporters)

There was also a translated version in Hindi and Urdu

Culturally Adapted Memory Assessments: Service user and family/supporter experiences

Consent Form

Please read the following statements and initial the boxes to show you agree:

1. I confirm I have read and understand the participant information sheet dated 24.10.24 (version 2) and have had a chance to ask any questions I may have. ☐
2. I am happy to participate in the research project. ☐
3. I understand I can change my mind about taking part in the research without this affecting the care I or my family/friend receive. ☐
4. I understand that taking part is my choice and I can stop the interview at any time, without giving a reason. ☐
5. I agree to my interview being audio recorded. ☐
6. I understand the interview recording will be stored securely and will not be shared with anyone else except relevant members of the research team. ☐
7. I agree to my data being transcribed and reported anonymously in study reports, presentations and publications. ☐
8. I understand I can contact the researcher and withdraw my data up to 1 week after the interview, without giving a reason. ☐
9. I understand information collected for this study may be used for further research, and the named person will remain anonymous. ☐

10. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Leeds, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.
I give permission for these individuals to access my records. ☐

Participant

Signature ....

Name (block capitals) .... Date ....

Researcher

I have explained the study to the above named person and they have indicated their willingness to participate ☐

OR if completed remotely

I confirm the above named person gave verbal consent to participate in the research ☐

Name (block capitals): ....

Signature: ....

Date: ....

When completed: 1 for researcher site file, participants can request a copy of the consent form

Appendix J: Declaration Form (Service Users and Family and Supporters)

There was also a translated version in Hindi and Urdu

Culturally Adapted Memory Assessments: Service user and family/supporter experiences

Personal Consultee Declaration Form

Completed in relation to the wishes of: ______________________________

Please read the following statements and initial the boxes to show you agree:

1. I confirm I have been consulted about the named person’s potential participation in this study. I have had the opportunity to ask questions about the study and understand what is involved. ☐
2. I understand that taking part is the named person’s choice and they are free to change their mind without this affecting their care. ☐
3. I understand that if the named person changes their mind any data collected will be used unless we ask for it to be deleted within 1 week of the interview. ☐
4. I understand information collected for this study may be used for further research, and the named person will remain anonymous. ☐
5. I agree for my details and those of the named person and a copy of this form to be stored by the University of Leeds for the purpose of this study. ☐
6. I understand the named person will take part in an interview that will be audio recorded and transcribed. ☐
7. I understand the named person can ask the interviewer to stop the interview at any time without giving a reason. ☐
8. I understand direct quotes from the interview may be used in study reports and presentations and that the named person will not be identified. ☐

☐

9. I believe the named person would wish to take part in this study.

Personal Consultee

Signature ....

Name (block capitals) .... Date ....

Relationship to named person...

OR

Researcher

I confirm the personal consultee has completed this form in relation to named person and has agreed with the above statements ☐

Name (block capitals): ....

Signature: ....

Date: ....

When completed: 1 for researcher site file, participants can request a copy of the declaration form

Appendix K: Participant Information Sheet (Staff Members)

Culturally Adapted Memory Assessments

Staff Information Sheet

What is this study about?

The aim of this study is to explore staff member’s experiences of culturally adapted memory assessments.

This includes conducting interviews with staff at the Memory and Assessment Services in the Bradford District Care NHS Foundations Trust (BDCFT) who:

- Use or have recently used the culturally adapted (South Asian) ACE-III, either administering or interpreting this cognitive test

Why is this study happening?

The culturally adapted (South Asian) ACE-III has been adapted to be more meaningful to the South Asian communities

There is little research exploring cultural adaptations to memory assessments, and it is important to study how helpful these culturally adapted memory assessments are and how to continue improving them

What does taking part involve?

An interview with a researcher (Hannah Own) to share your experiences of administering or interpreting the culturally adapted (South Asian) ACE-III. To help with the study, the researcher will ask you some questions, including demographic details (such as age, gender and ethnicity)

The interview will last around 45-60 minutes and be audio recorded

You will be asked to speak to the researcher alone or as part of a focus group with other staff members

The interviews will be in person, the NHS Trust the study is taking place, in a private space (e.g. a community centre), online or over the phone.

Your employer has agreed to you taking part in the interview during your normal working hours

Do I have to take part?

Taking part is up to you. If you decide not to take part, it won't affect your job/role.

If you change your mind you can:

- Stop the interview at any time.
- Ask us to take your interview out of the project up to 1 week afterwards.

What are the benefits and risks of taking part?

There may be no benefits to you taking part
You could help to find ways of providing improved culturally adapted assessments for people with memory problems.

You might find talking about your experiences challenging. If this happens we will support you and you can take a break or stop the interview.

What will be done with the information?

This study will be written up as a Doctoral Thesis at the University of Leeds

The information collected for this study may be used for further research
We might use quotes from your interview in reports or presentations, but we will never use your name. Anything you tell us is confidential, unless you tell us you or someone else is at risk of harm.

All files will be stored securely (password protected) on storage permitted through the University of Leeds Information Governance policy (e.g. OneDrive). All paper copies will be destroyed as soon as they have been saved electronically. All personal information and raw audio recordings will be deleted as soon as the study is complete, all other data will be stored securely at the University of Leeds for 3 years in an access-controlled storage file for the DClin programme research staff, after this time all data will be deleted

You can also receive a copy of the findings of the study (via email or the post) once this has been completed

Who has approved this study?

The project has been approved by the University of Leeds and HRA and Health and Care Research Wale (HCRW) NHS ethics committee.

Research ethics committee (24/WA/0309)

The University of Leeds is the research sponsor

Your NHS community service has agreed to taking part

Who do I contact if I have any questions or want to take part?

Please contact Hannah Own. Hannah will be very happy to tell you more or to answer any questions you may have about this research.

Call: 0113 343 6358

Email: umho@leeds.ac.uk

Complaints or concerns?

If you would like to speak to someone else about the study, or have any complains, please contact:

Professor Gary Latchford, joint programme director of clinical psychology training programme at University of Leeds

Email: g.latchford@leeds.ac.uk

Or

The Sponsor Representative at the University of Leeds

Email: governance-ethics@leeds.ac.uk.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name, address and contact details to discuss the research and arrange the interviews. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

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

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason. You can ask us to take your interview out of the project up to 1 week afterwards.

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

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by contacting the researcher (Hannah Own, details above)
- https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf
- By contacting the data protection officer at the University of Leeds on dpo@leeds.ac.uk.

Appendix L: Consent Form (Staff Members)

Culturally Adapted Memory Assessments: Staff member experiences

Consent Form

Please read the following statements and initial the boxes to show you agree:

10. I confirm I have read and understand the participant information sheet dated 24.10.24 (version 2) and have had a chance to ask any questions I may have. ☐

11. I am happy to participate in the research project, either in a 1:1 interview or as part of a focus group interview with other staff members. ☐

12. I understand I can change my mind about taking part in the research without this affecting my role. ☐

13. I understand this is my choice and I can stop the interview at any time, without giving a reason. ☐

14. I agree to my interview being audio recorded. ☐

15. I understand the interview recording will be stored securely and will not be shared with anyone else except relevant members of the research team. ☐

16. I agree to my data being transcribed and reported anonymously in the study reports, presentations and publications. ☐

17. I understand I can contact the researcher and withdraw my data up to 1 week after the interview, without giving a reason. ☐

11. I understand information collected for this study may be used for further research, and the named person will remain anonymous. ☐

10. I understand that relevant sections of my data collected during the study may be looked at by individuals from the University of Leeds, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to access my records. ☐

Participant

Signature ……………………………………………………………….

Name (block capitals) ………………………………………………. Date ………………………….

Researcher

I have explained the study to the above named person and they have indicated their willingness to participate ☐

OR if completed remotely

I confirm the above named person gave verbal consent to participate in the research ☐

Name (block capitals): ……………………………….

Signature: ………………………………………………….

Date: ………………………………………………………..

When completed: 1 for researcher site file, participants can request a copy of the consent form

Appendix M: Ethics Approval Letter

Study title: Experiences of Culturally Adapted Cognitive Tests in Memory Services

IRAS project ID: 322709

Protocol number: N/A

REC reference: 24/WA/0309

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.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

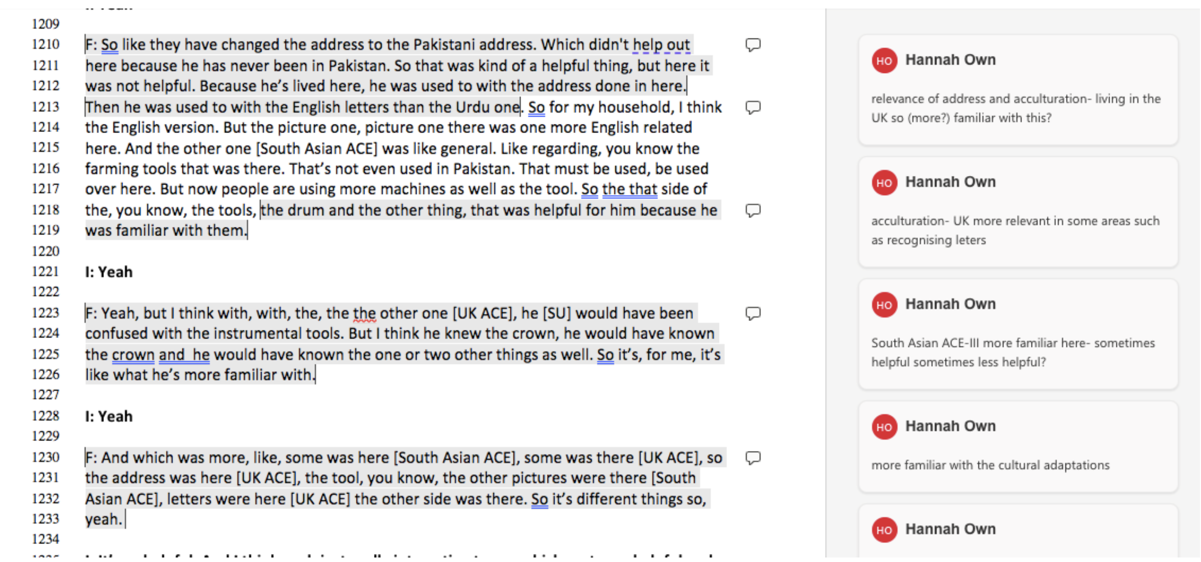
Your IRAS project ID is **322709**. Please quote this on all correspondence.

Yours sincerely,

Anne Gell Approvals Specialist

Email: HCRW.approvals@wales.nhs.uk

Appendix N: Extract of Analysis



F: So like they have changed the address to the Pakistani address. Which didn't help out here because he has never been in Pakistan. So that was kind of a helpful thing, but here it was not helpful. Because he's lived here, he was used to with the address done in here. Then he was used to with the English letters than the Urdu one. So for my household, I think the English version. But the picture one, picture one there was one more English related here. And the other one [South Asian ACE] was like general. Like regarding, you know the farming tools that was there. That's not even used in Pakistan. That must be used, be used over here. But now people are using more machines as well as the tool. So the that side of the, you know, the tools, the drum and the other thing, that was helpful for him because he was familiar with them.

I: Yeah

F: Yeah, but I think with, with, the, the the other one [UK ACE], he [SU] would have been confused with the instrumental tools. But I think he knew the crown, he would have known the crown and he would have known the one or two other things as well. So it's, for me, it's like what he's more familiar with.

I: Yeah

F: And which was more, like, some was here [South Asian ACE], some was there [UK ACE], so the address was here [UK ACE], the tool, you know, the other pictures were there [South Asian ACE], letters were here [UK ACE] the other side was there. So it's different things so, yeah.

HO **Hannah Own**

relevance of address and acculturation- living in the UK so (more?) familiar with this?

HO **Hannah Own**

acculturation- UK more relevant in some areas such as recognising leters

HO **Hannah Own**

South Asian ACE-III more familiar here- sometimes helpful sometimes less helpful?

HO **Hannah Own**

more familiar with the cultural adaptations

HO **Hannah Own**

Appendix O: Example of Table with Codes

Initial codes/reflections	Quote	Line number
Able to say more easily/ more familiar	...I mean the new colony and the Hyderabad that was obviously different. But the name I guess is a bit more familiar. They might be able to say it a little bit more easily.	860
more accuracy for memory with items being more familiar	I think it probably tests their cognition more accurately short-term and long-term memory more accurately.	868
more comfortable/less anxious as understand more/more familiar	And they maybe feel more comfortable. They may be less anxious because they feel they understand generally more because if you don't find anything that's been said, it's already anxious, anxious, isn't it anxiety provoking, doing an ACE for anyone?	869
not understanding the items, can create more anxiety for person	So I think probably the added layer of not understanding what like, even what things are, like pictures are you would be like, think ‘Oh my gosh, I don't know anything’. So you might think it worse than you actually are.	879
More accuracy and more relevant	I suppose you just get better and more accurate representation,	882