Healthcare Staff Perspectives on the Reasons African Caribbean People may present later to Dementia Services

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Abstract

Background and aims: Existing research highlights the challenges faced by Ethnic Minority (EM) groups in accessing services for dementia. African-Caribbean (AFC) individuals are reported to be at increased risk of developing early-onset dementia, vascular dementia, and Alzheimer's disease. However, studies also suggest that AFC populations are less likely to access dementia services. This research aimed to explore this disparity by gathering National Health Service (NHS) staff perspectives on why AFC individuals may present at the later stages of dementia and what services are currently doing to 'reach out' to this community.

Method: A qualitative approach was employed. Three focus groups were conducted across three London boroughs with NHS staff working in memory services. Interview data was analysed using Reflexive Thematic Analysis.

Results: Participants highlighted the role of stigma in deterring AFC individuals from accessing services. Religion was seen as both a potential support and a barrier, with calls for more collaborative work with religious leaders. A further theme reflected how systemic racism can influence help-seeking behaviour and how services were often perceived as lacking cultural appropriateness. Finally, while participants acknowledged that AFC communities were beginning to access services, they emphasised the importance of services taking more proactive steps to 'reach out' to the AFC community. Questions were raised about whose responsibility it is to lead and participate in outreach and inclusivity initiatives.

Discussion: The research findings are discussed in relation to the existing literature and the research question. Clinical implications are considered within the context of Clinical Psychology and NHS provision.

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Chapter Overview

In this chapter, I discuss my interest in the topic, my positionality and epistemological perspective. I then discuss the terminology and outline the relevant literature, considering the historical, social, and cultural contexts surrounding dementia and Ethnic Minorities (EMs). I conclude by discussing current policies to support dementia prevention and the ethnic disparities in healthcare access across different ethnic groups in the United Kingdom, with a focus on the African-Caribbean community (AFC).

Personal position

Interest in research topic

I have long been interested in working with individuals experiencing memory difficulties. This has been shaped by my experiences working in both a dementia care home and a dementia inpatient unit. These roles have had a significant impact on my development as a practitioner and have solidified my desire to specialise in this area upon qualification. Additionally, I have always been drawn to qualitative research, particularly the results sections, as I deeply value individuals' perspectives and lived experiences. This appreciation for personal narratives informed my decision to adopt a qualitative design for this study. I decided to explore the topic of why AFC individuals may be seen in dementia services at a later stage of the condition because research suggests that they are at a higher risk of developing certain forms of dementia.

Positionality

Positionality refers to the researcher's context, beliefs, attitudes, and interests, or these could include aspects of their identity, such as the Social GGRRAAACCEEESSS (Burnham, 2012).

This is a researcher's makeup in essence and will contribute to how they interpret and shape the data (Bukamal, 2022). It is essential to acknowledge this, as we cannot maintain complete neutrality when conducting research (Skovlund et al., 2023).

When a researcher conducts research with a group to which they belong, they are referred to as an ‘insider researcher’; conversely, when the researcher is not part of the group, they are considered an ‘outsider’ researcher. There are advantages and limitations to both. The advantages of being an insider researcher are that you can build trust and rapport with participants more easily and have a deeper understanding of the topic. However, if the researcher has direct experience with the topic, they may interpret the results in a way that aligns with their experiences. For example, the researcher may view the data through a negative or positive lens if they have had bad or good experiences being part of that group themselves. The advantage of being an outsider researcher is that they can have more objectivity, though they can never achieve complete objectivity (Mohler & Rudman, 2022). However, it also means the researcher may have a limited understanding of the topic at hand.

In this research project, I position myself as both an insider and an outsider, moving away from the binary framing often found in the literature, where researchers are typically categorised as either insiders or outsiders (Milligan, 2016). This aligns with a social constructionist perspective that questions categories and instead focuses on how knowledge is shaped by context. Such a binary approach to positionality has been critiqued as limiting, and these concepts should be considered more fluid and context-dependent (Dwyer & Buckle, 2009). The reason I position myself as both an insider and an outsider is that I do not have lived experience of dementia, nor has anyone close to me been affected by it, which places me outside the direct experience of the condition. I am also of Middle Eastern heritage and, therefore, part of an EM, but I do not share the same ethnic background as AFC people. However, I am employed by the NHS and have worked within a dementia service, which I share in common with the participants, making me an insider in that context.

Epistemological stance

Social constructionism (SC) views reality as socially constructed rather than objectively determined. According to this perspective, people actively create a version of reality through their social interactions and the meanings they assign to things. In social constructionist thinking, reality is not fixed; it is continually shaped and revised through language, shared meanings, and evolving social conventions (Berger & Luckmann, 1966).

Social constructionists argue that reality is shaped by historical, cultural, political, and socioeconomic contexts, with new meanings developing through discourses and interactions among individuals (Phillips, 2023). SC suggests that knowledge, too, is created between people through language and is shaped by the norms in the societies in which we live (Burr & Dick, 2017).

The epistemological stance a researcher takes will impact their research question, the methods they choose to use to answer the research question, how they collect data, and how they interpret the data. For this research, I took a SC position, which means that the research question and the topic being discussed are seen as a collaborative process, where knowledge is constructed between participants and the researcher (Philips, 2023). SC encourages researchers to be transparent throughout the research process, acknowledging their positionality, as this will influence how the research unfolds, rather than shying away from their biases and assumptions. SC advises researchers to openly address these factors, as they can impact the research. SC also considers what people can do with the discourses they hold, in that they have control to choose certain discourses over others, which can support in breaking down strong narratives held that perpetuate injustice and inequalities (Harris, 2006).

I adopted a SC approach to explore staff perspectives, as I aim to understand the discourses surrounding the topic that have been constructed through language and within the context of healthcare services. In line with trying to understand how meaning is constructed, I also decided to use Reflective Thematic Analysis (RTA), which, like SC, takes into account the contextual influence on the discourses and truths that people can hold. Using RTA for analysis also meant that I had to engage in self-reflection to be aware of how my contexts would be influencing the research study throughout (see Appendix A)

Terminology

According to Foucault (1976), language is a form of power that evolves over time to reflect cultural norms and societal structures. The language used in this thesis is therefore a product of its time and context, and it is likely that some of the terms used here may shift in meaning or not be used over time. This aligns with the perspective of social constructionism, which holds that language both reflects and shapes social realities (Aliyeva, 2023). Language can be a tool for empowerment, but it can also reinforce systems of oppression.

The terminology used in discussions of ethnic inequalities has long been contested and attempts to find universally appropriate labels remain challenging (Aspinall, 2020). For example, terms such as ‘minoritised’ (Selvarajah et al., 2020) and ‘global majority’ have been proposed; yet neither fully resolves the complexities essential for capturing the depth of identity and lived experience, and this remains elusive. Additionally, ethnic labels may inadequately reflect the lived realities of people with mixed heritage, and do not fully reflect their experiences of inequity, whose experiences of discrimination can be distinct and nuanced (Christophe et al., 2022). One example of this is that the term BAME (Black, Asian, and Minority Ethnic) is no longer being used as it implies homogenising all non-white identities (Selvarajah et al., 2020) and can exclude certain groups, such as Irish travellers, who are also a minority and face discrimination and oppression (McGinley & Keane, 2022). For this reason, the language used throughout this thesis is contextually and temporally grounded (See Table 1).

Table 1

Terminology and Definitions

Dementia	The term 'dementia' refers to a collection of conditions that cause gradual changes in the brain's structure and function. These changes affect a person's thinking, behaviour, and capacity to handle daily activities. As a result, dementia has a significant psychological effect on both those living with the condition and their families. Since each person is unique, the impact of dementia varies from one individual to another (BPS, 2016)
EMs	The term 'Ethnic minority' was used in this thesis, reflecting the terminology used in the majority of studies described throughout. Though it appears the 'global majority' is being more commonly used in research as of recent times (Campbell-Stephens, 2021). In the United Kingdom, the term 'EM's' encompasses all ethnic groups excluding the White British population, primarily including people of Black, Asian, and Arab backgrounds.
Black	The term 'Black' is commonly used to describe people in research; however, it often overlooks the diversity within the Black community, including differences in history, culture, and identity. In this thesis, the term' black' is used only as reflected in the papers, if the papers themselves have not specified whom they are referring to.
African-Caribbean	I have used the term'African-Caribbean' to look at this specific ethnic group and no other ethnicities that can often get grouped together. This can be misleading, as it risks homogenising diverse groups, as well as their experiences and the statistics that represent them. The ethnic term 'African-Caribbean' was discussed by the field supervisor of the study, who identifies with a Caribbean background. We acknowledge that individuals within this community may identify in

	different ways, and while we cannot account for every personal preference, we aim to use terminology that is as accurate and respectful as possible within the context of this study.
People living with dementia	The term 'people living with dementia' (PLWD) is used instead of 'people with dementia', or 'dementia patients', as it emphasises that individuals are not defined by the condition but are living with it. It also avoids language that can be considered oppressive (Mfene & Pillay, 2023).
Cultural sensitivity	According to the American Psychological Association (APA, 2018), Cultural sensitivity means recognising and respecting the values, norms, and beliefs of groups that differ from one's own, whether cultural, ethnic, racial, or otherwise. It is also about being open to adapting one's behaviour in response to the difference. (Wong et al., 2024).
Cultural competency	The ability to engage effectively with people from a variety of cultural backgrounds, whether in personal or professional settings, involves recognising both the differences between cultures and the diversity that exists within them. It also requires self-awareness about one's own cultural identity and a readiness to adjust behaviours when necessary (APA, 2023).

Placing the research in context

Dementia

Dementia is a neurological disorder with over 100 known types (Martyr et al., 2024), including Alzheimer's disease, vascular dementia, and early-onset dementia. It is a progressive condition characterised by a decline in one or more areas of cognitive function that impacts daily living and social functioning (Livingstone et al., 2020). These cognitive domains include memory, learning, language, executive functioning, attention, perceptual-motor abilities, and social awareness (Gamble et al., 2022).

Symptoms of dementia vary depending on the type of dementia and the individual, and they often change as the condition progresses. Dementia is often described using a three-stage model: early, middle, and late stages, to help describe how the condition develops over time (National Health Service, 2023).

During the early stage, changes in cognition, such as memory and thinking, are usually minor. Individuals, or those close to them, may notice small difficulties with daily tasks, but they are typically still able to live independently (Alzheimer's Society, 2023). In the middle stage, these difficulties become more moderate. Individuals may struggle with activities, such as remembering to eat or attending appointments. In this stage, confusion can increase, and some people may also experience changes in mood or behaviour. During the late stage, memory and language abilities are significantly affected, and most individuals require support with daily living tasks. However, these stages are only a general guide; the progression can differ widely between individuals (Dementia UK, 2020).

Dementia globally

Globally, dementia is one of the leading causes of mortality (GBD, 2021). As populations continue to grow and life expectancy rises, the number of dementia cases is increasing (Stevenson-Hoare et al., 2023). An estimated 55 million people are currently living with dementia worldwide (Alzheimer's Society, 2024), and this figure is projected to rise to 132 million by 2050, with the largest increases expected in developing countries (Alzheimer's Disease International, 2020).

Dementia in the UK

According to the Office for Health Improvement and Disparities (2025), an estimated 735,842 people aged 65 and over in England were living with dementia in February 2025. It is estimated that the number of people living with dementia will increase to over 1.6 million by 2040 (Wittenberg et al., 2019). The cost of dementia to the UK is estimated to be £34.7 billion a year (Wittenberg et al., 2019). The reason for the rise in numbers is due to people living longer and better healthcare systems (Parveen et al., 2021).

Dementia is diagnosed using the Diagnostic and Statistical Manual of Mental Disorders-5 (American Psychiatric Association, 2013) or the ICD-11 (World Health Organisation, 2019), both of which require evidence that symptoms cannot be better explained by another medical or mental health condition.

The diagnosis typically involves identifying declines in areas such as memory, thinking, or language, alongside noticeable impacts on daily life. While both systems emphasise the importance of functional impairment, the ICD-11 also allows clinicians to specify the type of dementia and the stage of progression.

To obtain a diagnosis of dementia in the UK, the individual is usually seen by a general practitioner (GP) if someone close to them has noticed any symptoms. The GP will conduct an initial screening to rule out other causes of symptoms. If dementia is suspected, the individual is referred to a Memory Service for additional assessments, including cognitive testing, functional assessments, and brain imaging. A multidisciplinary team then reviews the results, and a diagnosis is shared with the person and their family, along with information about support options (National Health Service, 2023).

In some cases, dementia is identified when an individual seeks medical care for a different concern, and the doctor notices signs of the condition during investigations like brain imaging.

Support for PLWD and their families

In the UK, there is a wide range of support available for PLWD and for their families, beginning at diagnosis and continuing throughout the condition. NHS services provide needs assessments for individuals with dementia, as well as carers' assessments to identify the support that family members may need. Clinicians can recommend adaptations and strategies to help individuals live safely and independently at home for as long as possible. Care planning is an ongoing process and may include support at home, community services, or, when needed, planning for residential care (NICE, 2018). Additionally, there are numerous community-based groups for individuals living with dementia and their caregivers, offering memory cafés (Greenwood et al., 2017), singing groups, and gardening projects, which help reduce isolation and promote overall well-being (Toms et al., 2017). Financial support may also be available, including benefits and allowances to help manage the costs of care. Charities such as Alzheimer's Society and Age UK offer additional support by providing information, advice, and events for individuals affected by dementia (Age UK, 2025; Alzheimer's Society, 2023)

Why is this important?

In 2023, dementia was the leading cause of death in England and Wales, with 66,876 deaths registered, 11.6% of all deaths, and this pattern continued into 2024, according to the Official National Statistics (2024). Dementia cases on the rise will ultimately affect the UK government economically and the PLWD, their caregivers, families, socially and emotionally (Runacres & Herron, 2023).

The healthcare system in the UK is already under significant strain (Bolwell, 2025), and with the rising number of dementia cases, there will be an even greater need for staff and services to meet this growing demand. If the system cannot keep up, it could lead to serious consequences, including staff burnout (Wilkinson, 2015), longer waiting times, and impact the quality of care for those who need support (Torjesen, 2020). To tackle dementia effectively, growing the health and social care workforce will be essential, ensuring the right mix of skills. Alongside this, improving access to interventions and support services will be crucial in helping to prevent, diagnose, treat, and care for people living with dementia (Aranda et al., 2021).

Currently, unpaid carers, often family members, are saving the NHS around £11 billion each year by supporting people with dementia (Alzheimer's Society, 2020). However, as the number of diagnoses increases, so will the pressure on caregivers. If the health and social care system cannot keep pace, more of the responsibility will fall on families (Henderson et al., 2019), which could lead to increased stress and reduced quality of life for those who provide care.

Current National guidelines and policies

There are several national policies and strategies in place to support dementia prevention. The first National Dementia Strategy was published in February 2009 (Department of Health and Social Care, 2009). The five-year plan was to promote earlier diagnosis of dementia and enhance support for PLWD, their families, and carers. It aimed to improve understanding of the condition and reduce stigma. Although the plan acknowledges the higher prevalence of dementia among some EM groups, it does not discuss targeted outreach or tailored support for marginalised communities.

Truswell (2015) notes that even though there has been an acknowledgement in policies regarding how Black, Asian and minority ethnic communities are at higher risk of dementia, there has been little movement in adapting services to meet their needs

Ten years after the first Dementia strategy, Collins et al. (2019) conducted a scoping review examining dementia prevention policies and strategies at both national and local levels and assessing their implementation within primary healthcare services. They found that there is limited and inconsistent evidence regarding the implementation of dementia prevention policies within clinical settings.

Similarly, Mace et al. (2025) highlighted that although recommendations are often made, they are rarely developed into specific research methodologies or clinical practice guidelines that would support their practical implementation and wider dissemination. This has led to a substantial gap in evidence regarding the implementation and evaluation of these strategies, making it difficult to measure their effectiveness.

Ethnic disparities in healthcare access in the UK

Research has consistently shown that EM often experience systemic health inequalities, influenced by social determinants such as socioeconomic status, discrimination, and unequal access to healthcare, which contribute to poorer health outcomes and barriers to receiving appropriate care (Darko, 2021; Hossain et al., 2022; Patel & Hanif, 2022). For example, events such as the disproportionate impact of COVID-19 on Black and Asian communities highlight how structural racism and inequality are still embedded in many aspects of UK life (Greenaway et al., 2020; Sotubo, 2021). However, these findings must be understood in context. Measures of health outcomes are framed by researchers' definitions, the available data they have and societal norms (McCartney et al., 2019). From a social constructionist perspective, it can be argued that these disparities are not purely objective ‘facts’, but are constructed and maintained through social, institutional, and historical processes that shape how health, illness, and access are understood and experienced.

While the number of White British people with dementia is projected to double by 2051, interestingly, it has been posited that cases among people from EM groups are expected to increase sevenfold over the same period (Alzheimer’s Society, 2020). These projected increases reflect broader demographic changes, including rapid population growth (Jain et al., 2023) and rising life expectancy, which will lead to more people living with dementia across all groups (Nichols et al., 2022).

The disproportionate projected rise in EM populations requires further consideration and is likely due to a complex combination of factors. Global research suggests that people from EMs are at higher risk of developing dementia (Pham et al., 2018; Truswell et al., 2019; Tsamakis et al., 2021). Biologically, EM groups have higher rates of diabetes and cardiovascular disease (Daniel et al., 2023; Parlevliet et al., 2016) and hypertension (Abrahamowicz et al., 2023; Ogunniyi et al., 2021), all of which are associated with an increased prevalence of dementia (Mukadam et al., 2022).

In addition, social determinants of health can intersect with these biological vulnerabilities. Socioeconomic disadvantage, including lower levels of education (Rosselli et al., 2022), reduced access to healthcare (Chen & Zissimopoulos, 2018), and systemic inequities, may further exacerbate dementia risk in EM (Truswell, 2020). Importantly, the projected sevenfold increase in case numbers does not mean that EM individuals are seven times more likely to develop dementia than their White counterparts. Rather, the combination of population ageing, demographic growth, biological susceptibility, and social determinants collectively contributes to the expected increase (Pareveen et al., 2021).

Lastly, whilst these risks are reported in EM populations, a social constructionist lens emphasises that what counts as 'risk' is shaped by research definitions, measurement choices and social context, rather than being an objective characteristic of the group (Field-Springer, & Striley, 2014).

Barriers to access for EM

Research also suggests that people from EM are less likely to use NHS services (Giebel, 2015; Kenning, 2017) and usually present to services at the later stages of dementia (Duran-Kirac et al., 2022; Roche et al., 2018). Studies have found that people from EM may be reluctant to access current services for several reasons. Sayegh & Knight (2023) conducted a literature review looking at the barriers EM people may face when accessing services. These included: misinformation about the condition, lower levels of acculturation, stigma associated with the condition, health system barriers and cultural beliefs associated with dementia. Sagbakken et al. (2020) also found that people from EM may interpret dementia symptoms as a natural part of ageing or that PLWD have symptoms because they are 'mad', and some participants in these studies believe that it is 'god's will' for people to develop the condition.

In many collectivist cultures, memory loss and cognitive decline are often viewed as a normal part of ageing rather than signs of illness. Families may adapt to behavioural changes such as wandering or agitation instead of identifying them as symptoms of dementia. As a result, people may not access healthcare services early, leading to delays in the identification and diagnosis of dementia (Cipriani & Borin, 2015)

Barriers in service provision

Research on service provision suggests that people from EMs may have less available support than their White counterparts (Pinheiro et al., 2021). In addition, dementia care services may not provide culturally appropriate support to people from EM groups, meaning that their needs are often not met by services (Dodd et al., 2021; Nielsen et al., 2020).

A systematic review (Gaviola et al., 2024) found that language differences were a barrier to access, as the PLWD may not be able to communicate with care staff. This may make daily activities more challenging and potentially contribute to feelings of isolation or loneliness. The authors also found that not providing the traditional food of EM was another barrier to care provision.

For example, if care homes do not accommodate religious dietary requirements, such as halal or kosher foods, EM individuals may worry that their family members or loved ones will not be able to maintain their religious practices while receiving care. Also, a lack of culturally appropriate food in care homes can disrupt an individual's sense of familiarity and comfort. Because food practices are central to cultural identity and emotional well-being, this may adversely affect residents' mood (Chamberlain et al., 2024).

Additionally, staff's knowledge and skills in providing culturally specific care impacted the quality of life of the individuals receiving care (Gaviola et al., 2024). Similarly, Kenning (2017) found that services lacked bilingual staff, cultural awareness, and diversity in staff teams, and needed to effectively interact with different ethnic communities.

Furthermore, a significant challenge lies in the limited availability of screening and diagnostic tools that are culturally sensitive (Gove et al., 2021), although researchers are increasingly acknowledging the need for diverse norms and test materials that reflect ethnic variability (Czerwinski-Alley, 2024; Lunia et al., 2024; Mukaetova-Ladinska et al., 2022).

From a SC perspective, cognitive assessment tools are socially produced and shaped by the cultural and educational contexts in which they were developed, rather than serving as universally valid indicators. They embed assumptions about cognition, language, and education (Gove et al., 2021), making their validity contingent on cultural context. This presents challenges for the equitable assessment of dementia across diverse populations.

Though standard cognitive tests may reflect cultural bias (Nielsen, 2022), they provide valuable information that would be lost without assessment. Cognitive assessments can track changes in cognitive function over time (Tsoi et al., 2015), offering important information that can help PLWD and their families access support and services that might otherwise be unavailable (Molvik et al., 2025). While concerns about cultural bias are important, delaying cognitive assessment may contribute to delays in diagnosis and treatment. Interpreting test results within the individual's cultural context, alongside clinical judgement, may help ensure that cognitive assessments remain a valuable component of dementia care (Czerwinski-Alley et al., 2024).

Stigma as a barrier to access

Help-seeking patterns can be shaped by social meanings and cultural norms, with stigma playing a significant role in influencing how dementia symptoms are interpreted and whether support is sought (Farhana et al., 2023).

Stigma surrounding dementia is a consistent theme in research when looking at barriers to accessing services for EMs (Nielsen et al., 2020; Kenning, 2017). In some cultural contexts, dementia is believed to result from spirit possession or witchcraft (Aballa et al., 2025; Adebisi & Salawu, 2023; Musyimi et al., 2021), while others interpret it as a form of moral punishment or karmic retribution (Lwi et al., 2022). These interpretations demonstrate that understandings of dementia vary across cultures, shaped by socially constructed meanings that are maintained through discourses rather than determined by biomedical truths. The social construction of dementia can be traced across different cultures and historical periods, most often associated with negative connotations (Bosco, 2019). A diagnosis of dementia can also generate feelings of shame within families, contributing to non-disclosure of the condition and delayed help-seeking (Herrmann et al., 2017; Jeong et al., 2020; Lopez et al., 2020; Oliveria & Musyimi, 2025; Philip et al., 2024). Families may experience shame in response to behavioural changes in their loved ones, such as aggression or inappropriate behaviour (Avdikou et al., 2018), which can, in turn, make them reluctant to seek support promptly (Hanssen, 2024).

A scoping review found that shame and embarrassment are common reactions among both PLWD and their families across all cultures (Philip et al., 2024). Even when individuals understand that dementia arises from brain changes, stigma can persist; some PLWD described ongoing feelings of shame and insecurity, which acted as barriers to them accessing care (Brigiano et al., 2025; Pavković et al., 2025). These experiences are evident in the early stages of the condition, where individuals are aware of their cognitive and behavioural changes (Alexander, 2022). They may worry about how others perceive them, which can lead to concealment of the diagnosis, withdrawal from social situations, and increased isolation (Aldrige et al., 2019).

Similarly, Busted et al. (2020) reported similar experiences among people with early-onset dementia who felt ashamed of the changes happening, such as difficulties expressing themselves or forgetting things, especially in front of those close to them.

Lastly, participants living with dementia in Riley et al.'s (2014) study reported being treated differently after diagnosis and noticing their diminishing abilities, which contributed to feelings of shame, loss, and sadness. However, it is important to recognise that these feelings are most often reported in the earlier stages of dementia; as the condition progresses and cognitive decline becomes more noticeable, many individuals may have reduced awareness of their behaviour and circumstances and therefore may be less able to experience or articulate shame.

Dementia is often managed within mental health services, which can reinforce stereotypes that associate the condition with being 'mad'. The Health Stigma and Discrimination Framework (Stangl et al., 2019) provides a useful lens for understanding how stigma operates in these contexts, particularly by highlighting the role of social meanings and power dynamics in shaping health-related stigma. It was developed by public health researchers from various countries and is intended to be useful for a wide range of health conditions and communities, rather than focusing on a single specific group or profession (Stangl et al., 2019).

The framework identifies four formal components: first, the social and structural drivers and facilitators that create conditions for stigma; second, stigma-marking, which refers to applying the stigmatised label to individuals or groups based on a health condition or perceived difference; third, stigma manifestations, which include both how stigma is experienced (e.g. discrimination, fear, internalised shame) and how it is expressed in practices (e.g. social exclusion); and finally the resulting impacts on health, well-being, and access to care (Stockton et al., 2025). By capturing these different domains, the framework helps to explain not only individual experiences of stigma but also how social and structural factors shape those experiences.

For example, in EM communities, dementia can be perceived as a form of madness, leading families to conceal the condition to protect the individual's social reputation. Disclosure may be feared due to concerns that the individual and their family would lose respect or status within the community, and therefore not access services.

The framework also shows that stigma may not happen in isolation, as it can come alongside other forms of discrimination, such as racism (Edwards et al., 2025). This can be particularly useful for exploring how stigma operates within EM communities affected by dementia.

One limitation of the framework is that, because the framework is so broad, applying it to specific contexts, such as AFC accessing dementia care, requires careful attention to local cultural factors. Its relevance to this study, particularly in interpreting participant accounts of underutilisation of services, is explored further in the Discussion.

Early Diagnosis and Cultural Considerations

Early dementia diagnosis is associated with better outcomes for PLWD (Chauhan et al., 2020; Rasmussen & Langerman, 2019). Delayed diagnosis may mean missed early-stage interventions, such as support groups or medication, that may slow down the progress of the condition (Dubois et al., 2016). Research suggests that prevention and intervention strategies must be tailored to EM communities to promote earlier engagement with diagnostic services (Alzheimer's Society, 2023).

Several studies have highlighted the importance of engaging with EM communities through faith-based groups (Hossain & Khan, 2020; Kevern et al., 2022; Regan et al., 2012), as these populations often place a strong emphasis on religion and community.

Farooq (2022) emphasised how ethnicity, culture, and religion collectively influence how EM communities make sense of dementia and their experiences of accessing support. Information about dementia delivered by trusted individuals within these communities may encourage greater understanding and lead to earlier diagnoses. However, there is limited research on the practical implications of such approaches, what is required to sustain these initiatives over and how their impact on communities accessing services earlier could be systematically evaluated (Regan et al., 2012)

Also, there appears to be a misconception that PLWD from EM will more likely be looked after by their families (Kenning et al., 2017; Parveen & Oyebode, 2018). Such assumptions are shaped by discourses that reflect the expectations society and healthcare services attach to EM. If this narrative is taken as truth by healthcare services, it risks them assuming EM will not want support and therefore be offered less support (Parveen & Oyebode, 2018), which can lead to services failing to see the importance of reaching out to marginalised communities.

For example, Dodd et al (2022) found that significantly more people from white British backgrounds were recorded as being offered more than one form of dementia community support than BAME participants in their study.

In addition, Blix and Hamran (2017) conducted a study to explore HCP's understanding of the discourse that Sami people are reluctant to access services. Sami people are Indigenous people living in Norway and they found that HCPs attributed this reluctance both to the history of discrimination against the Sami people, and to aspects of Sami culture that influence help-seeking behaviour, such as the preference to care for family members at home when unwell, and the stigma surrounding conditions like dementia, which can make it harder to seek support. The authors highlight that when HCPs assume minority groups prefer to look after their own and do not want support from services, this can lead to neglect and reinforce health inequity.

Promoting Wellbeing and Quality of Life

Research has traditionally focused on the negative aspects of dementia, even though PLWD report continuing to lead positive and fulfilling lives (Wolverson et al., 2016).

Over time, there has been a shift from medical approaches, focusing on risk factors, cognitive decline, and stigma, to more positive psychology approaches (Pearson et al., 2021) that emphasise wellbeing and quality of life (Kim & Shin, 2023).

One model of care is the Person-centred approach, recommended by the Alzheimer's Association (2018), which places the needs, values, and interests of PLWD at the forefront of care (Kitwood, 1992). This approach prioritises interpersonal relationships and understanding the person rather than focusing solely on the dementia (Fazio et al., 2018).

Similarly, strengths-based models emphasise building on existing or new skills, supporting meaningful activity, and creating environments that promote connection, enjoyment, and emotional well-being (Hing, 2023; McGovern, 2015).

In the UK, ‘living well with dementia’ is a key policy objective. The concept originates from NHS England’s dementia care pathway, which outlines key stages including prevention, diagnosis, support, living well, and end-of-life care (Department of Health and Social Care, 2009). Consultation on the policy objective was held with PLWD and their carers, who highlighted that, although a dementia diagnosis is often devastating, appropriate support enables PLWD to maintain their quality of life, independence, social connections, and personal identity, supported by carers and services, throughout the condition (Quinn et al., 2020).

However, the meaning of ‘living well with dementia’ is complex and subjective for PLWD, influenced by their physical, social, and cultural environment, along with the wider impact of the condition on families (Clare et al., 2014). Several studies have been conducted asking PLWD, families, carers, as well as healthcare professionals (HCP), about their understanding of what ‘living well with dementia’ means to them.

Yaron et al. (2024) found that PLWD and their carers emphasised continuing activities they enjoy, maintaining social connections, and staying engaged with their communities, as much as possible. Kim and Shin (2023) interviewed PLWD, family members, and nurses. They identified key themes, including managing symptoms, maintaining their identity, continuing daily activities, experiencing personal growth, preserving dignity, sustaining social connections and community engagement.

Lastly, Clarke et al. (2020) conducted a scoping review using self-reports from PLWD and found six core aspects: staying active, maintaining relationships, feeling well, experiencing positive emotions, retaining a positive sense of self, and finding meaning in life despite the condition.

However, some researchers advise against focusing solely on the positive aspects of dementia, as this may invalidate the difficulties PLWD and their families face and may place pressure on them to ‘live better’ when they may be struggling (Quinn et al., 2020; Bartlett et al., 2017).

Parland et al. (2017) argue that perspectives on living well should be fluid, recognising both positive and negative experiences, with the focus on providing good care, promoting quality of life, and adapting to the condition.

The shift towards approaches, such as person-centred and strengths-based models, has important implications for how services are designed and delivered. Psychosocial interventions for dementia are increasing, with the goal of promoting well-being and social connections (Chirico et al., 2021). Research suggests that environments enabling PLWD to participate, maintain relationships, and feel included are key to living well (Chattat et al., 2025).

A holistic approach is often suggested by authors to support PLWD in maintaining engagement with their interests and social connections, alongside promoting autonomy, social participation (Craig et al., 2023), wellbeing, independence, coping skills, security, and positive relationships (Quinn et al., 2020).

Community initiatives, dementia-friendly programmes, and peer support services have also been highlighted as important resources that help PLWD and their families adjust to the diagnosis and sustain quality of life (Craig et al., 2024).

In addition, there has been a gradual increase in the involvement of PLWD in co-production (Swarbrick et al., 2019), dementia research (Groothuijse et al., 2024), and presenting at conferences (Frank et al., 2020), creating opportunities for PLWD to share their experiences and views on how services might be improved (Bethell et al., 2018). This demonstrates that many PLWD continue to offer valuable perspectives and expertise. However, PLWD at the later stages of the condition may not be able to contribute in the same ways, due to increasing communication, cognitive and behavioural challenges.

According to Morris et al. (2023), HCPs may play an important role in supporting PLWD to adjust to their diagnosis and enhance their quality of life through post-diagnostic support, culturally tailored services, and initiatives aimed at reducing stigma. Without timely diagnosis and access to care, treatment, and social activities, it may not be possible to truly ‘live well’ with dementia.

Healthcare professional perspectives

Research suggests there is a high turnover of staff who work in dementia settings, and this can be due to burnout (Duffy et al., 2019) and compassion fatigue (McPherson et al., 2016). There is often a lack of understanding and education among HCPs regarding dementia, which can contribute to stigma (Jenkins & Smythe, 2024). Increasing training and education for HCPs has been shown to improve the quality of care provided to individuals with dementia (Rasmussen et al., 2023; Zabihi et al., 2025).

From a SC view, attitudes and beliefs of staff towards dementia are shaped by the societal narratives, organisational culture and staff discourses. The impact of staff beliefs becomes even more significant when considering patients from EM backgrounds (Togioka & Young, 2024). Cultural assumptions and unconscious bias can all affect how symptoms are interpreted and how care is delivered (Gopal et al., 2021).

For example, some staff may misattribute dementia symptoms to language barriers or cultural behaviours, rather than recognising them as signs of cognitive decline (Sagbakken et al., 2018).

While the concept of cultural competence in healthcare has its origins in Leininger’s work (1978), the model developed by Papadopoulos, Tilki, and Taylor (1998) provides a framework for understanding how HCPs can deliver care that is sensitive to the cultural needs of diverse populations.

Initially designed for nurses, the model highlights key areas that enable professionals to engage effectively with people from diverse cultural backgrounds. It emphasises the importance of being aware of cultural differences, reflecting on one’s own assumptions and biases, and adapting care accordingly. It also emphasises the importance of possessing good interpersonal and communication skills, as well as the ability to apply this awareness in practice to deliver care that respects individual cultural contexts (Licen & Prosen, 2023). Its structured approach can help identify ways services meet the needs of EM.

While stage-based frameworks like this have been criticised for potentially oversimplifying a complex process (Botelho & Lima, 2020; Greene-Morton et al., 2019), given its ongoing prevalence as a framework used in research and its relevance to understanding how staff work with EM, the model is used to help interpret the findings in the current study. Later in the thesis the model is discussed more critically, and alternatives are considered (see discussion chapter).

To improve dementia service provision for EM patients, it is vital that HCPs understand what is needed from the communities to feel safe to use services. There also needs to be adequate training for staff on how to work with people from different backgrounds and to be culturally sensitive (Shatnawi et al, 2023). It is also important to recognise the diversity of beliefs around ageing and illness within EM, and to engage with families in culturally respectful ways to provide the best quality of care (Zubair & Norris, 2015).

The African-Caribbean Community

Migration from the Caribbean, particularly between the 1940s and 1960s, was driven largely by post-war labour shortages and government recruitment campaigns. While many migrants initially intended to return home after a few years, a significant number settled permanently, putting down deep roots in British society (Truswell, 2020).

This community's history in the UK is long and complex, shaped by the legacy of the British Empire and post-war migration (Shankley & Byrne, 2020). One of the most notable waves was the arrival of the Windrush generation in 1948, encouraged by the UK government to help rebuild the nation (Eldridge et al., 2023; Truswell, 2020).

Despite being invited to settle in the UK, AFC people faced widespread discrimination across housing, employment, and education, contributing to systemic inequalities and social exclusion (Wallace et al., 2022). The Windrush scandal further

exposed how structural racism remains deeply embedded in British institutions (Janes et al., 2024). The Windrush scandal involved the UK government wrongly detaining, denying rights to, or deporting Caribbean-born people who had legally lived in Britain for decades. This happened because the government failed to keep proper records and demanded proof of citizenship that many did not have (Slaven, 2021). Other forms of structural racism were that AFC men have been given higher diagnoses of Schizophrenia since the 1960s (Tortelli et al., 2015), with Kirkbride et al. (2012) reporting 5 times more than their white British counterparts. In addition, they are more likely to be detained in mental health facilities (Degnan et al., 2023). This could be explained by cultural stereotypes against black men, including clinicians' bias and institutional racism (Pinto et al., 2008).

The AFC community is now one of the oldest Black populations in the UK, and a significant portion of this community is now entering older age, the life stage when dementia becomes more prevalent (Truswell, 2020). Therefore, the ageing of this community has important health implications, especially in relation to dementia risk.

Risk Factors for Dementia in AFC People

People from AFC communities are at higher risk than White British people in the UK of developing dementia (Mukadam et al., 2022; Roche et al., 2021), specifically early-onset Alzheimer's disease and vascular dementia (Tsamakis et al., 2021; Tuerk & Sauer, 2015). Many of the factors discussed earlier for higher rates of dementia in EM populations apply and will now be considered more specifically in relation to the AFC community.

The Lancet Commission report (Livingston et al., 2024) identifies 14 modifiable risk factors that contribute to the development of dementia. These include air pollution, less education, hearing loss, uncorrected vision loss, traumatic brain injury, physical inactivity, hypertension, diabetes, smoking, excessive alcohol consumption, social isolation, high LDL cholesterol, depression, and obesity. The report emphasises that addressing these factors through healthcare interventions and lifestyle changes could prevent or delay the development of dementia, highlighting the importance of both biomedical and social approaches to dementia risk (Desai et al., 2023).

Biomedical explanations often link the higher dementia rates in AFC communities to increased rates of hypertension, high cholesterol, diabetes, cardiovascular disease, and stroke, conditions that are well-established risk factors for vascular dementia (Commodore-Mensah et al., 2018; Robinson et al., 2018). These patterns may reflect a combination of factors, including genetic predispositions and lifestyle influences.

Genetic risk factors, such as the APOE ε4 allele, are also considered; however, evidence suggests that African-descent populations have a lower risk associated with this allele compared to other groups (Rajabli et al., 2018).

Social and lifestyle factors may influence both the development of biomedical risk factors and the likelihood of developing dementia directly (Walsh et al., 2025). Many of the modifiable risk factors identified by the Lancet Commission (2024), such as obesity, physical inactivity, smoking, and lower education levels, also intersect with social and lifestyle factors relevant to AFC populations.

Some evidence suggests that AFC people in the UK have higher rates of being overweight or obese (Maynard et al., 2023; Ng Fat et al., 2023) and lower levels of physical activity than White British populations (Ige-Elegbede et al., 2019). However, national data (NHS Digital, 2022) indicate lower or similar smoking and alcohol use among many EM groups.

Although social isolation and poor diet are recognised modifiable risk factors for dementia, there is limited research examining these factors (Ojo et al., 2023) specifically in AFC populations in the UK. This gap makes it difficult to determine whether disparities in these behaviours contribute meaningfully to increased dementia risk in this community.

Broader social determinants, such as socioeconomic disadvantage, low education, chronic stress, discrimination, poor housing, and limited access to healthcare, may contribute to the risk of dementia (Adelman et al., 2011; Walsh et al., 2025).

For example, hypertension, diabetes, and cardiovascular disease, known biological risk factors for dementia, can be influenced by chronic exposure to stress and other social disadvantages (Mukadam et al., 2022). However, it remains uncertain to what extent differences across ethnic groups are driven by biological, social, or environmental factors (Chen & Zissimopoulos, 2018).

Access to Services for AFC Communities

Though demographic estimates indicate that the number of people in the AFC population living with dementia will rise more than the White population over the next 30 years in the UK (Truswell, 2019), AFC communities are less likely to use NHS services, with reasons similar to those of EM mentioned. These include cultural stigma, professional stereotyping of how to be culturally appropriate, mistrust of services from a history of abuse, fear of discrimination from services, fear of being forced to use western medications, culturally inappropriate services and racism (Lasrado et al., 2021; Roche et al., 2021). AFC communities may view dementia as a mental health problem and therefore do not want the stigma attached to that. Some AFC communities may also view the condition as caused by a demonic possession (Mantovani et al., 2016). There may also be a limited understanding of the condition.

For example, Berwald et al. (2016) ran focus groups with participants who were Black African and Caribbean from community groups to explore perceptions on dementia and found that the AFC communities viewed dementia as a white person's illness. The reasons that the AFC community may not access services can contribute to the avoidance and acknowledgement of early signs and symptoms, and help-seeking outside the family.

Not only can earlier access to services support PLWD from AFC backgrounds, but it can also decrease the risk of accessing services when in crisis, which places additional strain on the PLWD, caregivers (Woods et al., 2018). and the NHS (Banerjee et al., 2022).

Conclusion

There has been little research exploring PWLD from AFC communities' experiences of accessing dementia support in the UK. The upcoming chapter will elaborate on the research outlined in the introduction by presenting a systematic literature review, aimed at identifying gaps within the existing literature.

Chapter 2: Systematic Literature Review

Chapter Overview

This chapter will present and discuss the Systematic Literature Review (SLR). It will include details about the database searches, the inclusion and exclusion criteria, the summary of the synthesised papers that were included and the critical appraisal of the papers included for review. The systematic review utilises Khan et al. (2003) five steps: framing the question, identifying relevant publications, assessing study quality, summarising the evidence and interpreting the findings. The SLR will be that of a qualitative systematic review, exploring the experiences of events (Munn et al., 2018).

Rationale for SLR

A SLR was initially intended to focus solely on the experiences of AFC individuals accessing dementia support in the UK. However,citly due to a limited number of studies in this area, the scope was expanded to include the experiences of EM groups more broadly.

Studies from Europe (Czapka & Sagbakken, 2020; Ketchum et al., 2022; Nielsen et al., 2021), Australia (Haralambous et al., 2014), and the USA (Casado et al., 2018; Richardson et al., 2019) have explored this area, but their relevance to the UK is limited due to differences in healthcare systems, particularly the privatised models in Australia and the United States of America. Consequently, this review focused exclusively on UK-based studies to examine experiences within the NHS, a perspective that, to the best of my knowledge, has not yet been systematically explored

Due to a further shortage of studies focusing solely on the experiences of PLWD, the review also included the perspectives of caregivers. Although previous SLRs have explored EM experiences in accessing dementia support, this review includes more recent publications that were not covered in earlier reviews, thereby contributing updated insights to the field.

Aims

This literature review explores the current understanding of the following question:

'What are the experiences of EM's accessing support for dementia in the UK?'

To ensure that this question has not been previously reviewed, a search was conducted on PROSPERO and Elicit in August 2024 and again in January 2025. No systematic reviews were found; however, when searched for on Google Scholar, some systematic reviews on the topic were found. The justification for continuing to explore the question was that the previous systematic reviews had not included recent papers. Additionally, the previous SLRs had either not been UK-based or employed a different methodology to analyse the findings. The SLR was not registered on Prospero.

Systematic Literature Review Method

The method for the SLR involved the following steps: Searches were conducted on four databases, and the results were exported from the databases to an Excel sheet to track the concepts used (Appendix B). Then, the results from each database were exported to the Covidence software. All duplicates were removed, and titles and abstracts were screened. The remaining full-text articles were assessed against the inclusion and exclusion criteria and removed if they did not meet them. The remaining papers were then extracted.

A SPIDER search tool *(*Sample, Phenomenon of Interest, Design, Evaluation, and Research type*)* developed by Cooke et al. (2012) provides a methodological approach to identifying mixed-methods and qualitative research studies. It was utilised to help develop the SLR search terms and clarify the criteria for inclusion and exclusion (Table 2). As the SLR question pertains to people's experiences, it was felt that a qualitative framework was suitable for answering the question.

Table 2

SPIDER Tool

Sample	Phenomena of interest	Design	Evaluation	Research type
People from EM's (all ages)	Experience of accessing dementia support	Published peer-reviewed literature and grey literature	Experiences, challenges, perspectives	Qualitative. (Mixed methods, if experiences were explored)

Search strategy

The SLR looked at the following databases: Scopus, CINAHL, PubMed, PsycINFO, MEDLINE. These databases were selected to include research from other psychology and social care professions. PsycINFO was excluded from the search due to the lack of relevant papers found through their database, and MEDLINE was excluded due to the high number of irrelevant papers, as they primarily focused on the medical aspects of dementia rather than the experiences of people involved. To ensure no papers were missed, searches were also run through Google Scholar.

Search terms

The search terms were established using the University of Hertfordshire Library search planning form (see Appendix B), which identified main concepts and key terms related to the systematic literature research question, as outlined in the existing literature. Terms were searched within the ‘keywords’, ‘abstract’ and ‘article title’. Some terms were truncated (*) to allow for word variations (e.g., Ethnic* = ethnicity, ethnicities, etc.). Additionally, past systematic reviews and papers on the topic were reviewed to examine concepts related to the same terms as dementia/ accessing support, and experiences.

Inclusion/exclusion criteria

The inclusion and exclusion criteria were created based on the SLR question (Table 3). I only included papers reporting qualitative and mixed-methods research, as this was the methodology most appropriate to our research question, which inquired about people's experiences.

I did not limit the date of publication, as I felt all papers were relevant, given the small number that fit the criteria. However, Studies were based solely in the UK, as systematic reviews had previously utilised studies from abroad, mainly the USA, which has privatised healthcare.

Grey literature is an important resource and consulting it can help reduce publication bias (Paez, 2017). Relying solely on peer-reviewed studies risks overlooking vital research, such as doctoral theses, which often contain valuable findings that contribute meaningfully to a topic. Additionally, this research adopts a social constructionist perspective, emphasising that discourses and perspectives from diverse sources should be included to fully understand the subject matter. Grey literature is important as it provides accessibility to knowledge and resources, free of charge. From a decolonising perspective, it also broadens my lens and viewpoint that includes accessibility and offers a different perspective on knowledge, rather than the academic, peer-reviewed, colonised systems.

The disadvantage of using grey literature is that these pieces of work would not have undergone the same amount of critical review as a peer-reviewed process. However, peer-reviewed pieces of work are also subject to bias. Autobiographies were not included.

Google Scholar was searched using the terms ‘ethnic minority, dementia and experiences’. One paper came up, which was a thesis. Databases for grey literature were searched: Kings Library Hub Discover, CORE, ETHOS, The Health Foundation, Kinds Fund, National Academies Press and Nuffield Trust; however, no papers were found for synthesis.

I originally had wanted to include only the subjective experiences of PLWD for a richer understanding of their accounts; however, due to the limited number of studies on this, I decided to include the perspectives of caregivers of PLWD. Also, due to the limited number of papers, I included studies that include the perspectives of the public, or staff, when the participants of the study also included perspectives of PLWD, and or the caregivers.

My final search was conducted on January 3, 2025. An online systematic review platform called Covidence was used to identify all papers. The platform supports screening, removing duplicate papers, and data extraction. The database searches resulted in a total of 10,996 papers. After removing 8,680 duplicates, 2,316 titles and abstracts were screened against the predetermined inclusion and exclusion criteria. Of these, 495 full-text articles were assessed for eligibility. A total of 487 papers were excluded at the full-text stage, mainly because they did not focus on the experiences of PLWD or EMs in accessing dementia care, or because they were not UK-based.

Seven papers met the eligibility criteria , and an additional study was identified via Google search (Mawaka, 2018), resulting in eight included studies. On 29 June 2025, a Scopus alert identified a relevant study by Bawja et al. (2025) that met the inclusion criteria; however, because it was published only two weeks before the thesis submission deadline, it was not included in the review.

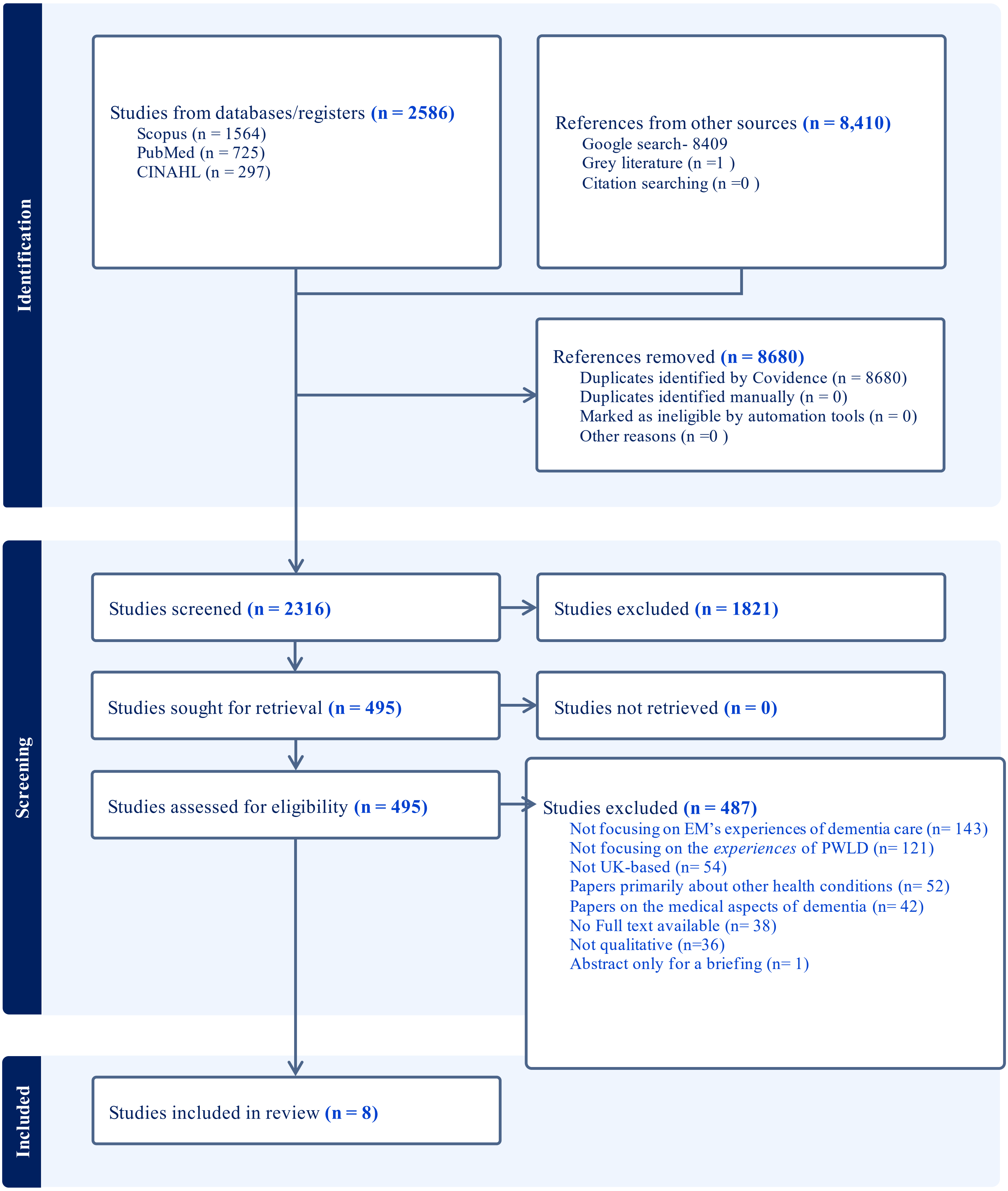
This review was conducted in accordance with the PRISMA 2020 guidelines (Appendix C) and the selection process is visually presented in the PRISMA flow diagram in Figure 1 (Page et al., 2021).

Table 3

Inclusion and exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
Included in a peer-reviewed journal or grey literature	Autobiographies, opinion papers, non-research-based account
Full text must be available	Full text not available
Consists of data focusing on EMs and accessing dementia support	Not referring to EMs accessing dementia support
Concerning EMs in the context of dementia	Any other condition other than dementia
Experiences of people living with dementia/ their families/and caregivers	Perspectives of stakeholders, the public and healthcare staff are excluded.
Written or translated into English	Written or translated in any language other than English
UK-based studies	Studies based in countries outside the UK
Qualitative or mixed methods only	Quantitative studies

PRISMA flow chart for the study selection procedure **(Page et al., 2020)**



Overview of the papers

The review identified 8 suitable papers focusing on EM's' experiences of accessing dementia services (Table 4). The use of two independent reviewers at the abstract review stage was used to minimise study selection bias. Any discrepancies were discussed, and decisions were collaborative. There was only one discrepancy during this process, which was resolved quickly as the reviewer had not noticed the study was not UK-based and therefore did not meet the criteria. A comprehensive summary of the papers can be found in Appendix M.

The studies captured the experiences of different groups of people in understanding the multifaceted topic of dementia care. One paper focused primarily on the experiences of PLWD (Mawaka, 2018), three focused on family caregivers' experiences (Herat-Gunaratne et al., 2020; Kevern et al., 2022; Victor et al., 2024). One study explored the perspectives of the community and family caregivers (Hossain & Khan. 2020). Three studies included PLWD, their families and their caregivers (Baghirathan et al., 2020; Carter et al., 2024; James et al., 2023).

Table 4

Summary of final SLR papers

Author and date	**Title**	**Aims**	**Methodology**	**Sample**	**Key Findings**	**Strengths and limitations**
Baghirathan, C., Hui, C., Shears & Currie (2020)	A grounded theory analysis of the experiences of caregivers for people living with dementia from three Black, Asian and Minority ethic (BAME) communities: Balancing the need for support against fears of being diminished	To develop a grounded theory guided by the following two questions: What are the experiences of people from three different BAME communities in Bristol who provide care for individuals living with dementia, specifically in relation to dementia care? Why do they think people may be hesitant to use dementia care services?	***Study design*** Qualitative ***Data collection*** Eight Focus groups attended ***Data analysis*** Grounded Theory	***Sampling technique*** Snowballing ***Participants*** 103 participants	The grounded theory, '*fear of diminishment'*, was present across all BAME communities. Participants expressed both a desire and a need for support, but were hesitant to accept it if it came at the expense of their sense of self.	**Strengths:** • Every participant was from a BAME background. • Used EBE advice, • Included under-researched Chinese population. • Consider the policy context to highlight systemic issues. **Limitations:** • Researcher's embedded social perspective in grounded theory • Timescale limited participation to local BAME communities;.

Carter, Roche, Whitfield, Budgett, Morgan-Trimmer, Zabihi, Birks, Walter, Wilberforce, Jiang, Ahmed, Dowdrige, Marchal l and Cooper (2024)	Equality of opportunity for timely dementia diagnosis (EQUATED): a qualitative study of how people from minoritised ethnic groups experience the early symptoms of dementia and seek help	To investigate the factors that may influence the timing of diagnoses in an ethnically diverse urban area in the UK	***Study design*** Qualitative ***Data collection*** Semi-structured interviews ***Data analysis*** Reflexive Thematic Analysis	***Sampling technique*** Purposive ***Participants*** 61 Participants	The authors identified three themes: Cultural identity and practices, Becoming like a tourist, and Naming and conceptualising dementia.	**Strengths:** • Recruited a range of stakeholders. • First qualitative study exploring help-seeking for dementia in ethnically minoritised communities, including perspectives of people with undiagnosed dementia and interpreters. **Limitations:** • Participants may have had enhanced awareness of dementia services and symptoms.

James, M., Sommerlad, B.-C., Livingston, (2023)	Equity in care and support provision for people affected by dementia: experiences of people from UK South Asian and White British backgrounds	To examine the care and support received and desired by South Asian and White British individuals affected by dementia in the United Kingdom, and to assess whether access to these services is equitable.	***Study design*** Qualitative ***Data collection*** Semi-structured interviews from 8 memory clinics across the UK (NHS trusts) ***Data analysis*** Reflexive TA	***Sampling technique*** Purposive ***Participants*** 62 Participants	The themes identified fell under two main areas: what people want from homecare workers, including carer characteristics and good quality care; and factors that help or hinder people from receiving care and support, such as families, relationships, attitudes towards care, financial means affecting choice, ease of access to services, and the availability and accessibility of culturally sensitive services	**Strengths:** • Included perspectives of clinicians and people living with dementia, often excluded from research. • Used purposive sampling to capture diverse backgrounds. • Recruited a South Asian researcher to support engagement with that community. **Limitations:** • Limited recruitment outside London; may not reflect groups who do not seek support. • Findings may be influenced by COVID-19, reflecting limited service use.

Herat-Gunaratne, C.,Mukadam, R., Leverton, H., Samus, B. (2020)	“In the Bengali Vocabulary, There Is No Such Word as Care Home”: Caring Experiences of UK Bangladeshi and Indian Family Caregivers of People Living With Dementia at Home	To explore the experiences of South Asian caregivers of people with dementia in the United Kingdom, considering economic situations, diverse migration histories, and cultural backgrounds in relation to their use of health and social care services.	***Study design*** Qualitative (critical realist position) **Data collection** Interviews **Data analysis** Inductive TA	***Sampling technique*** Purposive ***Participants*** 10 Participants	The authors identified four themes: an expectation and duty to provide care; how this expectation and duty can act as a barrier to accessing formal care, including reluctance from family carers, care recipients, and service organisations. culturally (in) sensitive, care; and the crucial role of support from informal care networks.	**Strengths:** • One of the few studies exploring caregivers’ experiences accessing dementia services post-diagnosis. **Limitations:** • Caregivers were recruited through the NHS only. • Excluded caregivers who did not speak fluent English. • Unable to recruit Pakistani participants; only Bangladeshi and Indian caregivers were included. • Interviewers and interviewees had different nationalities, which may have affected rapport and trust.

Victor, Van Den, Heuvel, Pentecost, Quinn, Charlwood and Clare (2024)	Perspectives of Ethnic Minority Caregivers of People with Dementia Interviewed as Part of the IDEAL Programme	To explore the Perceptions of ethnic minority caregivers of people with dementia	***Study design*** Qualitative, using an exploratory descriptive approach ***Data collection*** Semi-structured interviews ***Data analysis*** Inductive TA	***Sampling Technique*** Volunteer sampling ***Participants*** 18 Participants	The authors identified three key themes: the motivation to provide care; the mixed impact of caregiving; and the cultural context of caregiving.	**Strengths** • Extends existing research on caregiving in minority ethnic groups by identifying both positive aspects of caregiving and showing how positive and negative experiences are interlinked and dynamic. **Limitations** • Complex insider/outsider dynamic. • COVID-19 disruptions • Participants were likely more dementia-aware due to existing service engagement and willingness to volunteer. • Only English-speaking caregivers were recruited • Sample was predominantly daughters-in-law

Kevern, Lawrence, Nazir, and Isaroucha (2022)	Religious Influences on the Experience of Family Caregivers of People with Dementia in a British Pakistani Muslim Community	To explore the role of religious beliefs, practices and community networks on dementia care. Also, to identify how the Muslim religion impacts the understanding of access to care and the response to dementia in this community	***Study design*** Qualatative ***Data collection*** Semi-structured Interviews ***Data analysis*** Thematic analysis	***Sampling technique*** Purposive and then snowballing. ***Participants*** *7 Participants*	Authors identified the categories as: Carers' Religious Belief and Practice Muslim community response to dementia Barriers to accessing services	.**Strengths** • One of the few UK-based studies exploring the role of faith in dementia care, adding valuable insight to an under-researched area. **Limitations** • Small sample size • Remote interviews • Single-interview format • Language restriction • Age representation

Hossain & Khan (2020)	Barriers to access and ways to improve dementia services for a minority ethnic group in England	Examined the barriers to health care service use in the Bangladeshi community living in the United Kingdom.	***Study design*** Qualatative ***Data collection*** Focus group and semi-structured interviews. ***Data analysis*** Thematic analysis	***Sampling technique*** Purposive and snowball sampling Techniques ***Participants*** 27 participants	The authors identified two themes: Barriers to seeking and accepting help and Key opportunities for improvement	**Strengths** • First study to explore perspectives of Bangladeshi adults *with and without* experience of dementia. • Inclusive approach: Captured insights from individuals across different levels of dementia awareness and experience. **Limitations** • Sample not fully representative • Limited dementia knowledge Limited applicability

Mawaka (2018)	Exploring the lived experience of the individual of Black ethnicity living with dementia: A phenomenological l study	This study explored the lived experiences of individuals of Black ethnicity living with dementia, across four London boroughs. It sought to understand how these individuals perceive themselves while living with dementia, how they cope with the day-to-day realities of the condition, and how they construct meaning around their experiences from their own perspectives.	***Study design*** Qual ***Data collection*** Semi-structured interviews (3x each participant) ***Data analysis*** Thematic analysis	***Sampling technique*** Purposive ***Participants*** 6 Participants	The author identified three overarching themes emerged: Life before Dementia, Journey to Diagnosis, and Living with Dementia.	**Strengths** • The only qualitative study exploring the experiences of people living with dementia in four specific London boroughs with little prior research. • Rich, in-depth data: Researcher rapport: The researcher’s ability to build trust with participants strengthened data quality. • Ethical rigour **Limitations** • Small, geographically narrow sample • Limited applicability though authors highlight this was not the intention of the study

Table 5

Quality check for the SLR papers

Author	Worthy Topic	Rich Rigour	Sincerity	Credibility	Resonance	Significant Contribution	Ethical Consideration	Meaningful Coherence
Baghirathan, Cheston, Hui, Chacon, Shears, and Currie (2020)	Yes	Yes	Somewhat	Yes	Yes	Yes	Yes	Yes
Carter, Roche, Whitfield, Budgett, Morgan-Trimmer, Zabihi, Birks, Walter, Wilberforce, Jiang, Ahmed, Dowdrige, Marshall and Cooper (2024)	Yes	Yes	No	Yes	Yes	Yes	Somewhat	Yes
James, Mukadam, Sommerlad, Barrera-Caballero, and Livingston, (2023)	Yes	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Yes
Herat-Gunaratne, Cooper, Mukadam, Rapaport, Leverton, Higgs, Samus, and Burton (2020)	Yes	Yes	Somewhat	Somewhat	Yes	Yes	Yes	Yes
Victor, Van Den Heuvel, Pentecost, Quinn, Charlwood and Clare (2024)	Yes	Somewhat	Yes	Yes	Yes	Yes	Somewhat	Yes
Kevern, Lawrence, Nazir, and Isaroucha (2022)	Yes	Somewhat	Somewhat	Somewhat	Yes	Yes	Yes	Yes
Hossain and Khan (2020)	Yes	Yes	No	Yes	Yes	Yes	Somewhat	Yes
Mawaka (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Quality Assurance

Tracy's (2010) ‘big tent’ criteria were used to assess the quality of the papers for synthesis (Table 5). In comparison with other quality assessment tools, it was felt that Tracy’s (2010) offered a comprehensive approach to evaluate qualitative studies relevant across methods and approaches (Yadav, 2022). Tracy’s (2010) approach also aligned with a social constructionist epistemology, which is aligned with the thesis approach. Each paper was assessed against its worthiness, sincerity, significance, ethical stance, resonance, credibility and meaningful coherence. While applying Tracy’s (2010) Big Tent criteria, studies were assessed using a 'Yes', 'No', or 'Somewhat' rating to reflect the degree to which each criterion was met. The 'somewhat' category was used where elements of a criterion were present, but either not fully met or lacking sufficient detail.

Summary of quality assessment.

Across the eight studies assessed using Tracy’s (2010) “Big Tent” criteria, the overall quality can be described as good, as all studies met the criteria for worthiness, resonance, significant contribution, and meaningful coherence, although there was variation across the criteria of rich rigour, sincerity, credibility and ethical stance.

All studies clearly met the criteria for worthiness, offering timely, relevant and important insights into the dementia-related experiences of EM communities. In terms of rich rigour, most studies provided detailed accounts of their sampling, data collection and analytic procedures. However, some studies, such as those by Kevern et al. (2022) and Victor et al. (2024), lacked transparency regarding decisions about data saturation.

Sincerity was more mixed: while several studies demonstrated transparency and self-reflexivity (James et al., 2023; Mawaka, 2018; Victor et al., 2024), others offered little (Baghirathan et al., 2020; Heret-Gunartne et al., 2020; Kevern et al., 2022) to no reflexive account of the researcher's positionality or influence (Carter et al., 2024; Hossain & Khan, 2020). Credibility was also variable. Many studies demonstrated trustworthiness through thick descriptions, triangulation, or member reflections (Baghirathan et al., 2020; Carter et al., 2024; Hossain & Khan, 2020; Mawaka, 2018; Victor et al., 2024), whereas others provided limited evidence of multivocality or participant validation (James et al., 2023; Heret-Gunartne et al., 2020; Kevern et al., 2022).

Despite these inconsistencies, all studies demonstrated resonance, presenting findings in ways that are emotionally engaging and accessible. All also made significant contributions, deepening the understanding of dementia care experiences in EM groups and offering relevant recommendations for practice and policy.

Ethical considerations were addressed in some studies (Baghirathan et al., 2020; Heret-Gunartne et al., 2020; Kevern et al., 2022; Mawaka, 2018) more thoroughly than others (Carter et al., 2024; Hossain & Khan, 2020; James et al., 2023; Victor et al., 2024), though all studies obtained ethical approval. Finally, all studies demonstrated meaningful coherence, successfully aligning their aims, methods, and interpretations.

Overall, the body of evidence is of good quality, with strengths in worthiness, contribution, resonance, and coherence, and with variation mainly in sincerity, credibility, and reflexive transparency. These limitations should be held in mind by the reader when engaging with the findings. Further detail for each criteria is provided in the following section.

Worthiness

Tracy (2010) states that qualitative studies need to be interesting, relevant, timely, and evocative. All studies met the criteria for worthiness. Previous studies reflected how people from EM's did not want support from services, but these papers showed a different narrative, highlighting a discrepancy between accepting and rejecting support. In addition, all studies have been published from 2018-2024, meaning that they are timely, and since the pandemic in 2019, shedding light on the inequalities faced by marginalised people in health care, all studies captured the experiences of those communities accessing healthcare for dementia. All studies highlighted the need for better service provisions in supporting people from different ethnic backgrounds in dementia healthcare.

Rich Rigour

Tracey refers to the theme of rich rigour when the authors have a detailed description of their methods, methodology, and whether the study has face validity. All studies in the review had face validity and used appropriate samples in line with the aims of their study. One study used grounded theory for their analysis (Baghirathan et al., 2020), and all the other authors chose Thematic Analysis (TA). Two studies used Reflexive Thematic Analysis (Carter et al., 2024; James et al., 2023), and three used Inductive Thematic Analysis (Herat-Gunaratne et al., 2020; Hossain & Khan, 2020; Victor et al., 2024). Two stated TA only (Kevern et al., 2022; Mawaka, 2018).

Three studies used both focus groups and semi-structured interviews to obtain data (Baghirathan et al., 2020; Hossain & Khan, 2017; Mawaka, 2018). All the other studies used semi-structured interviews online. The sampling techniques employed by the authors were purposive (Carter et al., 2024; James et al., 2023; Herat-Gunaratne et al., 2020; and Mawaka, 2018). Victor et al (2024) used a volunteering sampling technique, Baghirathan et al (2020) used snowballing, and the remainder used both snowballing and purposive sampling (Hossain & Khan, 2020 and Kervern et al., 2022).

Most studies had rich rigour in their research, giving comprehensive detail regarding samples, data collection and analysis processes (Baghirathan et al., 2020; Carter et al., 2024; Herat-Gunai et al., 2020; Hossain & Khan, 2017; James et al., 2023; and Mawaka, 2018).

However, not all studies met the criteria for rich rigour. Braun and Clarke (2019) reflect that it is important to use self-reflexivity to be transparent about when deciding when to stop data collection. They report that stating data saturation was ‘met or not met’ is not sufficient detail (Braun & Clarke, 2022). Kevern et al. (2022) and Victor et al. (2024) failed to be transparent in explaining how they came to stop data collection. Kevern et al. (2022) stated that data saturation was not obtained as the purpose of the study was to identify themes for further research, but no further detail was given. Victor et al. (2024) stated they had reached data saturation but did not go into detail about what this meant.

Kevern et al. (2022) was the only study to employ a qualitative scoping methodology that combines both research methods and a review to gain a deeper understanding of the topic. This increased the rigour of the research, as it employed multiple methods for collecting first and secondary data. collection. Only Mawaka (2018) stated their ontological and epistemological stance.

Sincerity

Sincerity relates to the author's transparency about the research, their positionality, honesty about the author's goals and sharing their self-reflexive processes. Some studies were considered to meet the criteria as they demonstrated self-reflexivity and discussed how their contexts influenced the study (James et al., 2023; Mawaka, 2018; Victor et al., 2024).

Kevern et al. (2022) addressed the positionality of the researchers involved but did not explain how this might influence the study. Other authors were transparent in their research processes (James et al., 2023; Kevern et al., 2022; Mawaka, 2018; Victor et al., 2024).

Carter et al. (2024) and Hossain & Khan (2017) failed to share any self-reflexivity or transparency in their research. Others Baghirathan et al. (2020) & Herat-Gunai et al. (2020) attempted to include elements of what would constitute the criteria for sincerity; however, not enough to meet the criteria. For example, Baghirathan et al. (2020) were transparent about the research processes and spoke of recruiting a researcher from a BAME background to carry out the interviews and focus groups, as they already had a good relationship with the community; however, the authors of the paper failed to share their positionality and context. Hertat-Gunai et al. (2020) were transparent in their research process; however, they did not share their self-reflective processes with the reader.

Credibility

Tracy (2010) refers to credibility as how trustworthy the research findings are. Some authors included members' reflections, triangulation and multivocality (Baghirathan et al., 2020; Carter et al., 2024; Victor et al., 2024). All studies had a thick description of possible meanings from the findings. Mawaka (2018) documented the procedures undertaken at all stages of the study to address any concerns about credibility. Hossain & Khan (2020) also showed credibility; however, there was no mention of members' reflection. Some studies indicated some level of credibility of their research findings by having thick descriptions of the findings and triangulation; however, there was no Multivocality (Herat-Gunai et al., 2020; James et al., 2023; Kevern et al., 2022).

Resonance

Tracy proposes that resonance is the author's ability to promote empathy or a feeling of identification, even if the readers have no experience with the topic. It was felt that all papers might evoke an emotional connection within the readers as the topics and findings were novel and presented well.

Significance contribution

Tracy proposes that for a paper to have significance, researchers need to understand the current knowledge, practice and politics relevant to the topic. Authors need to ask themselves if their research improves practice, or whether it extends knowledge, empowers readers and those in the study, or generates thought for ongoing research. My review of the papers is that they all made a significant contribution.

All studies added to a deeper understanding of previous research and provided a deeper insight into the experience of EM accessing dementia support. All studies also provided strategies and practical recommendations for supporting EM accessing services, giving comprehensive recommendations for commissioners and practitioners. Carter et al. (2024) and Herat-Gunai et al. (2020) also added to the little research regarding post-diagnosis support for people from EM.

Some papers argue that dementia policy needs to change to reflect that community-based services and religious leaders should be given more attention to be able to provide support to EM groups, as EM groups feel more familiar with and less vulnerable utilising these services (Baghirathan et al., 2020; Carter et al., 2024; Kevern et al., 2022; Mawaka, 2018). James et al. (2023), however, argued that it is important to consider religion, cultural practices and language for all people of different ethnicities who are affected by dementia. In addition, there needs to be more staff training, which was reflected in all the papers. Not only training to be more culturally appropriate, but also for clinicians to think about how to convey a dementia diagnosis and provide information in a way that is accessible (Carter et al., 2024). Victor et al. (2024) added a different narrative to the previous research where papers focused on the negative aspects of caregivers, especially carer burden; however, the authors reported both positive and negative benefits to caring for a loved one with dementia.

Ethical stance

Some studies discussed ethics (Baghirathan et al.,2020; Herat-Gunai et al., 2020; Kevern et al., 2022; Mawaka, 2018). Others stated ethical approval but did not discuss ethics in sufficient detail or discuss any ethical concerns they may have had (Carter et al., 2024; Hossain & Khan, 2020; James et al., 2023; Victor et al., 2024).

Meaningful coherence

Tracey suggests that for papers to be meaningfully coherent, they must achieve what their aim sets out, utilise appropriate methods that align with best achieving the aims of the study and connect the findings with theories and paradigms. All studies had meaningful coherence.

All studies met the aims of the study that they had started to achieve, and their interpretations of their findings have contributed to the evidence base.

Synthesis of the findings

To synthesise the data from the eight papers and address the SLR question, we employed a thematic synthesis (Thomas & Harden, 2008). This approach was used as it combines findings from multiple papers in a structured way, allowing for cross-referencing across papers to check the relevance to the SLR question. During the initial line-by-line coding stage, I coded any parts of the findings and discussion that were relevant to answering the research question, such as experiences of the barriers to accessing services, facilitators of access, or help-seeking experiences for EM groups in the UK.

'What are the experiences of EM's accessing support for dementia in the UK?'

Thomas and Harden's (2008) synthesis includes three steps. Firstly, I coded the findings of each paper line by line. Secondly, I generated themes from these codes. Lastly, I developed analytical and interpretive themes by analysing the semantic meaning of the authors' results sections. Three main themes with subthemes were identified following the thematic synthesis (Table 6). For a more detailed view of the coding, please see Appendix F.

Table 6

Themes and subthemes of SLR

Theme	**Subtheme**
Cultural inappropriateness in care	*Proposed Solutions*
Relationships to help - Internal conflict	
Community membership impacting access to services	*Tradition, Faith, and Cultural Identity* *More awareness amongst our communities*

Theme 1: Cultural inappropriateness in care

The first theme reflects how participants from EM's felt that service provisions in the UK were not meeting their needs.

All studies reflected on how participants felt that the dementia services in the UK were not culturally appropriate (Baghirathan et al., 2020; Carter et al., 2024; Herat-Gunai et al., 2020; Hossain &Khan, 2020; James et al., 2023; Kevern et al., 2022; Mawaka, 2018; Victsor et al., 2024), and participants felt that the staff working for services to care for PLWD had little knowledge or understanding of the client's cultural and religious background. Participants felt this was a barrier to receiving good. This included understanding dietary requirements, hygiene practices, and prayer times (Hossain & Khan, 2020; Kevern et al., 2022).

"We couldn't find anywhere in the locality that would meet our cultural, linguistic, religious, and dietary needs" (Kevern et al., 2022)

But this did not mean that if services were culturally appropriate, people would not be opposed to using them:

"It would be ideal if they had a caring service that could provide the language and religious background knowledge. We don't have this kind of service in ..." (Hossain & Khan, 2020)

Some participants (Baghirathan et al., 2020; Herat-Gunai et al., 2020; Hossain & Khan, 2020; Victor et al., 2024) expressed a preference to care for their family members at home rather than place them in services lacking culturally appropriate support, fearing their loved ones would feel alienated:

"They said, 'Put her in a home'. I said, 'How can I put her in a home where she doesn't speak the language, there's her food, and the TV channels she is familiar with? It would just push her back. [...] She would just lie there and cry" (Baghirathan et al., 2020).

In Hossain and Khan (2020), a participant reported feeling the need to remain vigilant with external caregivers due to a lack of trust that their loved one would be properly cleaned. Part of the Muslim faith involves Qaḍāʾ al-Ḥāğa’, a set of personal hygiene practices related to toilet use, one of which involves using water to be cleaned. Ultimately, the family member had to perform the cleaning themselves, as the caregivers would only use wipes rather than water.

“. . . because they used to use only wipers (...) They didn't use water. . . If you want to work with other people, you need to know their culture. That's why I have been doing this for mom (Hossain & Khan, 2020)

In several papers, participants reported negative experiences when accessing support services, including being denied services and receiving poor-quality care (Baghirathan et al, 2020; Carter et al., 2024; Hossain & Khan, 2020; James et al., 2023; Mawaka, 2018).

One author (Baghirathan et al., 2020) described how people had gone back to their home countries to obtain a diagnosis due to feeling the GP was not taking them seriously. A participant in another study said that they had to get mental health services involved as the GP was not taking things further (Mawaka, 2018)

“He didn’t then take it further (...) it was only after I called the Mental Health Team that she got monitored (. . .) said it was dementia. So, it’s like the GP doesn’t know, isn’t aware that it even exists…He is the link to all these services, yet we got no referrals to anywhere from the GP.” (Mawaka, 2018)

Poor quality of care appeared to stem from systemic issues of limited resources. However, the implication of this was that the burden was left on the families, without support and could at times feel unfairly scrutinised:

"They asked me, everyday how many pads I used for my husband? (...) they said I used too many pads. I went mad after listening to that. What would I do with [the] pads if I [didn't] need them? (...) hospital upsets me many times this way. Their behaviour I don't like, they are not treating us well" (Hossain & Khan, 2020)

Herat-Gunai et al. (2020) reported that participants felt scrutinised for spending time at their loved ones' homes, as this often led to a reduction in carer support hours. Services, facing their own pressures, appeared to interpret the presence of family members as a signal that families could help, without fully considering the emotional and physical toll this placed on caregivers. One participant shared that the service described themselves as being "under the cosh," reflecting the broader staffing challenges and strain within the system:

"They got in touch with me, and they said we've observed that you are in the house with them in the evening. . . Unfortunately, we cannot send someone in the evening. Can you manage that yourself?..." (Herat-Gunai et al., 2020)

Subtheme: Proposed Solutions

All papers highlighted the importance of adapting services for EM (Baghirathan et al., 2020; Carter et al., 2024; Herat-Gunai et al., 2020; Hossain & Khan, 2020; James et al., 2023; Kevern et al., 2022; Mawaka, 2018; Victor et al., 2024). Some participants described what they believed was necessary for services to be culturally appropriate, emphasising the importance of inclusivity and shared characteristics between staff and service users (Hossain & Khan, 2020; Herat-Gunai et al., 2020; James et al., 2023; Victor et al., 2024), such as ethnicity, culture, or religion

"It sounds really simple, but I do think that having more images of people of colour will make people think, Oh, alright then, I can use that service. Oh, they will talk to me." (Victor et al., 2024)

"*Her mother tongue is Bengali, and she doesn't understand Spanish or English. . . So that person has to know that language.* (Herat-Gunai et al., 2020)

However, wanting caregivers who spoke the same language was not specific to EM, as James et al. (2023) reflected that white Irish and British participants also wanted caregivers who spoke English well, as this would cause a communication issue and barrier to receiving good care:

"I think from my husband's point of view, it would be an Irish lady... that could talk to him about Ireland or have some of the old interests." (James et al., 2023)

EM needs are not homogeneous, and not everyone felt they needed to have staff from the same backgrounds, or who spoke the same language (Herat-Gunai et al., 2020; James et al., 2023; Victor et al., 2024). Participants pointed out that as long as provided good care and were culturally aware of the client's needs, they were satisfied:

"If it's a Black, White, Asian person, it really doesn't matter, as long as they do the caring properly". (James et al., 2023)

Participants vocalised needing more dementia groups for PLWD specific to their religious or cultural background (Carter et al., 2024; James et al. 2023; Kevern et al. 2022; Herat-Gunai et al., 2020; Mawaka, 2018). In the Baghirathan et al (2020) paper, the author reported how mosques, black-led churches and gurdwaras were described by their participants as a "lifeline". In the Mawaka (2018) paper, participants expressed that services were meeting their needs due to running a group specifically for Black PLWD. However, this was not the case for everyone, as reflected by a participant:

"There's no group that I could go to and they're all Muslim, and who would probably understand . . . that you could offload or build that support network where you could. . . sharing that same experience, so it reduces the isolation. (Kevern et al., 2022)

Caregivers in Herat-Gunai et al. (2020) also spoke to how having a psychosocial programme for the families themselves would have helped deal with their own emotions related to the condition:

"I really needed something like that because I have suffered so much with guilt, you know, and if I'd had something like that to help me to cope (...) I would have coped better, and I would have had a better relationship with my mum. (Herat-Gunai et al., 2020)

Theme 2- Relationships to help – Internal Conflict

The second theme captures how participants from EM backgrounds perceived risks associated with using dementia services, which contributed to reluctance in seeking support, despite recognising their need for it. There appeared to be a constant dilemma of wanting and needing help, but there was a hesitancy due to fear of judgment from their communities, not trusting services, and worried that services would make their loved ones worse. This meant a decision to seek help had complexities and may be a reason why services see EM at the later stages of dementia or when they are in crisis.

Four papers (Baghirathan et al., 2020; Carter et al., 2024; Mawaka, 2018; Victor et al., 2024) reflected on how disclosing a dementia diagnosis was associated with shame, both personally and for their families. This was often linked to cultural misunderstandings about the condition, where dementia was not well recognised or was viewed as a source of blame or personal failure. As a result, PLWD and their families risked becoming isolated from their communities:

"Friends (are) not getting in touch anymore because of stigma (of dementia)" (Victor et al. 2024)

Fear of stigma from the communities meant that people from EM did not see the point of disclosing their or their loved ones' dementia diagnoses:

*"If you don't really recognise or understand dementia conceptually and there is a stigma in it, then why would you seek help?" (*Carter et al. 2024)

Participants in Baghirathan et al. (2020), Carter et al. (2024), and Mawaka (2018) spoke of the word 'Dementia' not being something that existed in their cultures, or that the translation of the word carried negative connotations. For example, in the South Asian culture, the word 'pagal' may be used, meaning that the PLWD is mad, due to doing bad things, or it has been caused by evil spirits. In Mandarin, the word 'chi-dai' may be used, which translates to idiotic and dull-witted. A participant in Mawaka (2018) explained that it was unnecessary to explain to relatives about a dementia diagnosis back home in Uganda:

"There was no need to tell everyone. . . it was not helpful for them ... they may not understand or know what dementia is, there is no word back home for dementia. . ." (Mawaka, 2018)

The papers highlighted that in the participants' native countries, there was little knowledge about dementia, and symptoms associated with the condition were negatively judged, perpetuating stigma around the illness. This made it difficult for participants to want to access support, even when participants were in the UK, where dementia may be more understood.

In addition, community participants expressed the view that caring for a person living with dementia was something one should simply 'get on with', reflecting a strong sense of familial duty (Kevern, 2022). There was little emphasis on the well-being of the caregiver, as the responsibility was often assumed to be a non-negotiable part of family life. This cultural expectation made it more difficult for families to access external support, as seeking help could be associated with shame or perceived as a failure within the community.

"They expect you to care and provide that care, because that's your duty. Not interested in how you're coping" (Kevern's, 2022)

A lack of trust in services also contributed to the internal conflict participants experienced when deciding whether to seek help. Several papers (Hossain & Khan, 2020; Herat-Gunai et al., 2020; James et al., 2023; Mawaka, 2018; Victor et al., 2024) highlighted participants expressing discomfort with allowing unfamiliar professionals into their homes to support their loved ones:

“If [social services] were to provide somebody, I’d be a little hesitant. I’d probably have to be there to keep an eye on them.” (James et al., 2023)

One family went through legal proceedings because they were made to feel powerless when social services came to their house, which led the family members to feel guilty for reaching out to the services:

“They said we might have to section her(...) they came in all guns blazing and I felt like, oh what I have done, what have I opened her up to? (Mawaka, 2018)

However, some participants felt comforted if it was from known services such as the NHS:

“If it’s from the local authority or NHS or wherever, those people are vetted, so we’re confident they’re not going to do naughty things with us”. (James et al., 2023)

Another conflict was the fear that utilising services would make the PLWD deteriorate as they would not be cared for properly (Herat-Gunai et al., 2020; Hossain & Khan, 2020; Victor et al., 2024). One participant reported that their dad was not looked after well, and for this reason, they would not send their mum to a care home, who also has dementia.

“. . . when my dad was in hospital, they did not change my dad's nappies (...) he had blisters on his bottom. Can you imagine [the] agony I was going through for my dad? It was 8 months [of] a nightmare for me (...) they didn't [even] give him a blanket. That kind of

experience has taught me, I would never give my mom to give to anybody like that, I wouldn't trust them" (Hossain & Khan, 2020)

Participants in Baghirathan et al. (2020), Hossain & Khan, (2020), and Mawaka, (2018) spoke of how using services was a last resort, which is reflected in research that EMs are seen in the later stages of dementia:

". . . culturally it is not something we do, we don't bring these services in, we are very private, but I had to because I didn't know what to do, I didn't know how to deal with it" (Mawaka, 2018).

"It is in our culture. We care for each other until the very end. When people do go into care homes, into hospital, it is at the very last". (Baghirathan et al., 2020)

Some participants sought help when there was an incident related to their physical health, such as a fall, stroke or seizures.

"It was after the mini-stroke, I was really sick, and I could not remember my daughter, that was very worrying". (Mawaka, 2018)

Theme 3: Community membership impacting access to services

The final theme explores how participants' communities can provide comfort and support throughout the dementia journey. However, community membership may also influence whether individuals access formal services. The subtheme 'Tradition, Faith, and Cultural Identity' reflects how these factors shaped participants' decision-making regarding help-seeking and perceptions of care. A second subtheme, 'More Awareness Amongst Our Communities', captures participants' views that a greater understanding of dementia is needed within EM communities. It was widely felt that community leaders should play an active role in raising awareness, addressing stigma, and encouraging the use of available support services.

Tradition, Faith, and Cultural Identity

All papers note that there is an expectation amongst many non-Western cultures that children will look after their parents when they become unwell or older. This duty of care can bring meaning to some people's lives as it feels like reciprocity for the care their parents gave them:

"I'm glad I'm doing it for my mum, we have a nice time together, we get on well. At least I know that she's being looked after well". (Victor et al., 2024)

"My parents did the best they could for me when I was younger, it's now time for me to support them". (James et al., 2023)

However, for some individuals, caring for a relative proved to be very challenging, and contemplating the use of support services elicited feelings of guilt that ultimately discouraged them from seeking help:

"There is an expectation now [to care](...) we could have been seen as quite selfish, or sort of absorbed the Western way of life". (Herat-Gunai et al., 2020)

*" . . . as a daughter-in-law, as a Muslim, as a Pakistani (...) my job is to just get on with it, and try and do the best that I can to support her, rather than try to find a solution out of the house". (*Kevern et al., 2022)

Others mentioned the challenges PLWD faced in accepting support from service providers, which in turn made things more difficult for their family members:

"She basically refused their assistance (...) quite proudly boasted that my son makes my food better, I don't need your help. So, whilst we appreciate the compliment, it also creates another job, doesn't it?". (Herat-Gunai et al., 2020)

Cultural traditions around caring for older or unwell family members were deeply rooted, but they often placed a significant strain on caregivers and left them feeling isolated. Some participants also spoke about the cost of looking after their relatives:

"I have lost the partner. What can I do about that? She essentially made me pick, and I said there's the door, you know. These are my parents. So that's how it ended". (Herat-Gunai et al., 2020)

"I've always wanted to be educated, go into career progression or go and travel and explore, because I'm quite active more than other family members, but that has had to just come to a halt". (Victor et al., 2024)

These participants often had to sacrifice their future, jobs, and relationships to care for their family members. However, some participants spoke of how they enjoyed their caregiving role:

"Oh, I get to spend an awful lot of time with her, which is really nice, we do silly things together". (Victor et al. 2024)

Four studies found that religion, as well as traditions and culture, could impact whether PLWD and their families accessed services (Carter et al., 2024; Hossain & Khan, 2020; Kevern et al., 2022; Mawaka, 2018). Across these studies, participants emphasised that their religious beliefs encouraged caring for older family members, particularly as they aged or became unwell. However, they also expressed concern that formal services often lacked an understanding of the significance of religion in their lives, which contributed to scepticism and reluctance to engage with available support.

"I think, as Muslims, it's very clear (...) that we look after our elders, and we should provide care and support and look for our elders, and know the Quran says". **(**Kevern et al., 2022)

Mawaka (2018) found a correlation between participants' likelihood of accessing support services and the strength of their religious faith. Their understanding of dementia was shaped by their religious beliefs, leading many to seek help from religious services before considering medical or social support.

More awareness amongst our communities

Awareness of dementia within EM communities can significantly influence decisions around accessing services. When knowledge about the condition is limited, early signs of dementia may go unrecognised, leading to delayed diagnosis. As a result, families often do not seek support until much later, often only when the PLWD reaches a crisis point:

"I think the Muslim community needs a bit of more education on this all because it is quite new subject for them (Kevern et al., 2022)

"There is still a taboo with mental health in Bangladeshi families, and the word dementia brings discomfort". (Carter et al., 2024)

"*We have heard of mental health but we have never heard of dementia*". (Hossain & Khan, 2020)

Baghirathan et al. (2020) identified the need for community work to raise awareness and upskill the groups led by EM, enabling them to sustain their projects and the people running them; however, the authors highlighted that these projects are not funded.

Participants identified a need for more dementia groups that were run by people by their own communities (Baghirathan et al., 2020; Kevern et al., 2022; Victor et al., 2024). In addition, they reflected that they felt dementia would be more accepted if dementia awareness came from their own religious leaders. Some participants reflected on how their experiences of this happening felt like a weight off their shoulders:

"The Imams I've spoken with, said that if it gets to the point where you are struggling (...) then that's permissible [seeking outside help] . . . and he used the word dementia directly,

which was ground-breaking, I think for a mufti [Islamic scholar] to do this and in the khutbah [sermon] said that you are permitted [to seek outside help], according to Islam". (Kevern et al., 2022)

This shift may mean that more people feel comfortable seeking help early for dementia if they feel their religion permits it. However, some participants felt their leaders did not engage in the topic, and some were disappointed by this:

"My caring for mum didn't weaken my Islam, but my faith in Muslims, certain people who are meant to be important gatekeepers, disappoints me, to be honest with you, because I feel they could do more, but they don't". (Kevern et al., 2022)

Conclusion of SLR

Previous research has often focused on the narrative that people from EM communities 'look after their own', which has been used to explain why these groups are less likely to access formal dementia services. When this assumption becomes the dominant narrative in wider society and among service providers, it risks marginalising EM individuals by healthcare systems. Services may presume that families will provide care without formal support, resulting in overlooked needs and reduced outreach to EM communities.

While participants across all eight studies reviewed in this SLR expressed a strong sense of cultural or religious obligation to care for their loved ones, this cannot be generalised to all EM individuals. A common theme across the papers was that the lack of engagement with services was often due to the cultural inappropriateness of those services, rather than solely the cultural expectations placed on caregivers. Several participants noted that if services were more culturally and religiously sensitive, more individuals from EM communities might be willing to utilise them

The SLR also revealed a range of experiences related to caregiving. While some participants described caring for a PLWD as stressful, challenging, and isolating, others found it to be a rewarding and meaningful role. For many, the emotional response was mixed, reflecting the complex nature of caregiving. Notably, the studies did not always clarify the level of external support participants were receiving, which may have influenced how they perceived their caregiving experience.

Awareness of dementia in communities may impact accessing services if communities are unaware of symptoms or feel a stigma attached to the condition. This means that people do not tend to seek early help and, therefore, do not receive an earlier diagnosis. Participants in multiple studies felt that religious and community leaders should be more vocal on the topic, as they are looked up to and listened to. The leaders can also share a narrative that seeking help is acceptable, which could have a major positive impact on family members caring for their loved ones with little or no support from others.

In conclusion, participants across the studies consistently reported that dementia services are often only accessed as a last resort. This reluctance was attributed to services being perceived as culturally inappropriate, alongside strong cultural or religious beliefs about family caregiving responsibilities.

Many participants described an internal conflict around seeking external help, driven by concerns that the cultural and religious needs of the PLWD would not be seen as important or incorporated into their care and services. Additionally, there was a clear call for greater involvement from community and religious leaders in raising awareness about dementia and promoting the acceptability of accessing services.

Evaluation of the Systematic Review

One limitation of this SLR is that a large proportion of the studies focused on South Asian families. Four out of the eight studies looked specifically at their experiences, while the others included a mix of South Asian, Black, and Chinese participants. This means the findings are based heavily on South Asian perspectives, which makes it harder to generalise the results to all EM groups. More research is needed to understand the views and experiences of other underrepresented communities when it comes to dementia care and accessing services.

Another limitation of the SLR is that all the studies group EMs together, and this risks homogenising the experiences of diverse communities. For example, the term ‘South Asian’ can apply to people from India, Bangladesh, Bhutan, the Maldives, Nepal, Pakistan, and Sri Lanka. All these countries differ significantly in culture, religion, traditions, and social norms. Grouping all South Asian people together means that their nuanced differences will be overlooked. This also affects the present review, as synthesising findings from such broad ethnicities inevitably reproduces this homogenisation. As a result, the unique challenges faced by specific communities may not be fully captured, limiting the applicability of recommendations for culturally tailored services and interventions.

In addition, failing to distinguish between first- and second-generation EMs creates another challenge in examining how people experience and engage with dementia services. For instance, first-generation migrants may face language barriers or mistrust of services, whereas second- or third-generation individuals may not experience these challenges in the same way (Calvo & Hawkins, 2015).

Similarly, differences in health beliefs and help-seeking behaviours vary widely, both between and within ethnic groups. Therefore, when studies group EM together, we may miss important patterns that help us understand the experiences of EM accessing dementia services in the UK.

Furthermore, 38 papers could not be accessed at the time of screening, which represents a relatively high number. In hindsight, best practice might have included contacting the university library to request these texts or reaching out to the authors directly, particularly where access did not require payment. While this limitation may have influenced the comprehensiveness and robustness of the review, it provides a useful learning point for future systematic reviews, highlighting the importance of exploring all possible avenues to access potentially relevant literature.

This thesis adopts a social constructionist approach, which holds that people's identities, beliefs, and ways of relating are shaped by historical, cultural, and social contexts. It is important to acknowledge that the themes and sub-themes presented here represent my interpretation of the data, influenced by the contexts and perspectives I bring to the analysis. Therefore, the same dataset could be interpreted differently by others.

A strength of the SLR was that it was the first to include these recent papers and use the Thomas and Harden (2008) synthesis to analyse the findings. All recommendations from the papers are listed in Table 7.

Table 7

Recommendations from papers

Authors	Recommendations
Baghirathan et al. (2020)	• More BAME-led VCSOS services/ religious institutions and supporting them by funding, training (including dementia training), and support.
Carter et al. (2024)	• Promote dementia-friendly communities, with a focus on supporting individuals even before a formal diagnosis. • Increase the representation of minority ethnic staff in dementia services and ensure interpreters receive dementia-specific training to enhance cultural competence. • Clinicians should adopt culturally sensitive approaches when discussing cognitive impairment with patients from diverse backgrounds. • When evaluating a person's daily functioning, clinicians should consider including religious practices alongside standard household tasks. • Clinicians should be aware of how cultural beliefs and roles can influence how symptoms are understood, including the tendency to normalise cognitive decline.
James et al. (2023)	• Ensure that all individuals are informed about the care and services they are entitled to, rather than assuming that EM

	families will provide all care for the person living with dementia (PLWD). - It is essential to address the financial barriers to accessing tailored services and to challenge misconceptions held by clinicians.
Herat-Gunai et al. (2020)	- Recommend implementing psychosocial interventions to support caregivers. - Emphasise the importance of helping individuals access culturally appropriate services. - Develop targeted campaigns to raise awareness of dementia and available support. - Introduce policies that set minimum training standards for paid carers and professionals involved in assessing care needs.
Hossain & Khan, (2020)	- None
Victor et al. (2024)	- Ensure that cultural and ethnic relevance is embedded throughout the entire dementia care journey, from diagnosis to long-term support. - Design services to be inclusive and reflective of the growing diversity among people living with dementia and their caregivers.

Kevern et al. (2022)	• Foster more informed engagement with the Muslim community by recognising and respecting their beliefs, values, and practices, addressing faith-based concerns, and offering culturally sensitive support. • Provide training for both caregivers and service providers to improve understanding and quality of care. • Conduct research to explore the religious lives of caregivers supporting people living with dementia.
Mawaka, (2018)	• Investigate the differences in lived experiences of dementia among specific ethnic groups, such as Black African and AFC individuals living in the UK. • Explore how understandings and perceptions of dementia vary across generations within Black UK communities, and how these differences shape the experience of dementia among younger generations. • Enhance family support, raise awareness of dementia, and carefully consider the use of language in the commissioning and design of dementia services.

The Rationale for the Current Research Project

The AFC community is at higher risk of developing Alzheimer's disease, Vascular dementia, and early-onset dementia than the white population (Tsamakis et al., 2021; Tuerk & Sauer, 2015).

Dementia prevalence studies in the Caribbean have been conducted in countries where AFC people are the ethnic majority or significant minority, including Jamaica (Ashby-Mitchell et al., 2020), Barbados (Acosta et al., 2021), the Dominican Republic, Puerto Rico, and Cuba (Liu et al., 2025; Llibre-Guerra et al., 2021). These studies indicate that the prevalence of dementia is rising rapidly, estimated at 10–12% among older adults in the Caribbean (Li et al., 2023), alongside challenges such as under-resourced healthcare systems and economic instability (Ibanez et al., 2021).

Higher prevalence in these majority-AFC contexts is primarily associated with structural and biomedical factors, including lower education levels, poorer healthcare, population ageing, cardiovascular risk factors, physical inactivity, and family history of dementia (Ashby-Mitchell et al., 2020; Davis et al., 2018; Acosta et al., 2021).

In contrast, studies in countries where AFC people are an EM, such as the United Kingdom (Berwald et al., 2016; Truswell, 2020; Roche et al., 2021) and the United States (Adkins-Jackson et al., 2022; Chejor et al., 2021), indicate that dementia risk is additionally shaped by social inequalities specific to minority contexts, such as discrimination, delayed diagnosis, and reduced access to culturally appropriate care. While social stressors such as discrimination may increase dementia risk through stress-related pathways (Palms et al., 2025), they do not fully explain prevalence patterns (Zahodne et al., 2021).

Biomedical risk factors such as cardiovascular disease, physical inactivity, and diet are observed in both majority-AFC and minority-AFC countries. Therefore, whether AFC groups are studied as a majority or a minority has important implications for interpreting the social determinants of dementia risk, and prevalence differences must be understood in context rather than assumed to result from the same social factors across all countries (Ribeiro et al., 2023).

Research suggests that people from Black communities tend to present to services in the later stages of the condition or at crisis points (Roche et al., 2018; Tuerk & Sauer, 2015; Webster et al., 2023). Meaning that they do not access early treatments and interventions. Earlier interventions are associated with better outcomes for PLWD (Berwald et al., 2016; Mukadam et al., 2015).

There has been research looking at how NHS services are 'reaching out' to communities (Islam et al., 2021; NIHR, 2021). However, many studies are done trying to understand why a certain group of people are not presenting in NHS services and branding them as 'hard to reach', which can be blaming, marginalising and perpetuating oppression (Sim et al., 2021; Routen et al., 2022 & Schwarz et al., 2023).

Several gaps in the literature emerged through the SLR. Although the papers included participants who were PLWD, caregivers, family members, and clinicians, there were only small samples of perspectives from PLWD and healthcare staff. It may be because PLWD from EM are likely to access services later in the condition; therefore, ethically, it may not be appropriate to recruit those people for studies.

My research aims to understand HCPs perspectives on why AFC individuals may present later in the condition to memory services and how and if services accommodate and reach out to this community. I hope to contribute to the literature by considering the implications of this and how we can adapt our knowledge, resources, and services to support individuals/families from AFC communities.

Aims and Research Question

Research Question: What are healthcare professionals' perspectives on the reasons AFC individuals may present to dementia services at later stages of the condition?

Aims:

- To explore healthcare professionals' perspectives on why AFC individuals may access services at a later stage of their condition.
- To explore if and how NHS memory services accommodate and reach out to this community

Chapter 3: Methodology

Chapter Overview

In this chapter, I will begin by describing my rationale for undertaking qualitative research and my choice of Reflexive Thematic Analysis (RTA) to analyse the data. I will also present details of my participants, recruitment, ethical considerations, involvement from the consultants and finally, data collection and analysis.

Design

Qualitative Research

Qualitative research was chosen as it enables the collection of rich, contextual data through the exploration of participants' beliefs, attitudes, and lived experiences (Moser & Korstjens, 2017; Tenny et al., 2025). This approach provides insight into how individuals make sense of their realities and navigate the world accordingly (Morse, 1996). Qualitative data also brings attention to the broader social and cultural contexts that shape how and why phenomena occur (Lim, 2024). However, qualitative research has been critiqued for the potential subjectivity in data interpretation (Noble & Smith, 2015). To address this, RTA was used to maintain transparency about the researcher's positionality and its influence on the analytic process.

Quantitative research aims to find causality between phenomena (Barroga et al., 2023). A quantitative research paradigm would not be the correct fit for this research paradigm, as it would not be able to answer the research question that is looking to explore participants' perspectives.

Focus groups were chosen as it was important to hear group discussions, shared understandings, and differences. During the focus groups, prompts that were designed and discussed with the consultants were used to allow for flexibility in exploring the participants' perspectives on the topic.

Choosing Reflexive Thematic Analysis

Reflexive Thematic analysis (RTA) was used to analyse the data for several reasons. RTA facilitates a richer exploration of individuals' experiences and understanding of a topic. Unlike approaches that seek objective truths, RTA constructs a story from the data, grounded in participants' perspectives (Braun & Clarke, 2022). It acknowledges and embraces researcher subjectivity, viewing it as a valuable resource rather than a limitation (Gough & Madill, 2012). RTA focuses on identifying and interpreting recurring key themes or patterns from group discussions to understand phenomena, which is why it was chosen, as this was suitable for the research design and question.

Limitations of Reflexive Thematic Analysis

While RTA offers many strengths as an analytical approach, it is not without its limitations. One such limitation is the potential impact on validity and reliability, as there is no strictly defined process for selecting themes, although guidelines have been outlined (Braun & Clarke, 2006, 2022). This lack of a clear process can lead to variations in the themes and interpretations identified by different researchers examining the same data, which may result in inconsistency amongst the results. However, RTA acknowledges this variability, which is why it is essential to discuss the positionality of researchers when conducting research using this approach.

In RTA, it is acceptable to have one person code (Byrne, 2021); however, throughout the study, steps were taken in collaboration with the supervisory team to review the themes and engage in reflexive discussions about the analysis. This process was essential to ensure that the analysis remained transparent and increased the rigour of the results. Regular reflection on the researchers' positionality and potential biases helped refine the interpretation of the data and ensured the credibility of the findings (Braun & Clarke, 2022).

Ethical considerations

The study was granted ethical approval from the Health, Science, Engineering and Technology Ethics Committee at UH. Ethical approval was received on the 26th of March 2025 after three amendments (Appendix E) with the protocol number 0320 2025 Mar HSET. The three amendments that were required were due to: a mistake on the form, a change to where the data would be stored, and one NHS trust required a demographic questionnaire, respectively. Final approval from the NHS Health Research Authority board was granted on the 26th of March 2025 (Appendix F).

Challenges of Ethical Approval

During the study, significant challenges were encountered in obtaining ethical approval to begin the research. As the study involved three different NHS sites across two separate trusts, variations in protocols extended the approval process. One trust required three separate amendments, which collectively took six months to be approved by both the university ethics committee and the NHS Research Ethics Committee. In total, it took one year from the beginning of the ethics process to obtain full approval from both trusts to conduct the focus groups.

Recruitment

A purposive sampling strategy was used to recruit participants with relevant knowledge or experience (Palinkas et al., 2015). Staff were recruited from three NHS memory services in London, which had diverse populations, two of which had the highest number of AFC communities in London. All services involved in this project offered assessment, neurocognitive assessments, treatment, and post-diagnostic support, which includes signposting and referrals to relevant support services.

To preserve confidentiality and anonymity, the services are not named due to the small sample size and risk of identification. They are referred to as London boroughs A, B, and C.

According to the Department of Health and Social Care (2019), Birmingham has the highest proportion of AFC residents at 8%, followed by London Borough C (5.3%) and London Borough B (5.2%). London Borough A has one of the most ethnically diverse populations in the UK. A report by the National Audit of Dementia (2023) stated that 3% of residents in London Borough A were from a Black background. However, it did not distinguish between subgroups within this population, making it difficult to determine the number of AFC residents specifically.

It is important to recognise that ethnic groups are often grouped together despite their inherent heterogeneity. This is evident in government systems that collect demographic information. For instance, within the broader 'Black' community, Somalians and AFC individuals are often categorised together, yet their histories, cultures, and religious practices differ significantly, highlighting the diversity within these groups.

Managers shared the research poster (Appendix G) and participation sheets (Appendix H) with staff at the services to gauge interest and availability. Once enough participants had expressed interest, the focus groups were scheduled in coordination with managers.

Recruitment Challenges

Recruiting participants for all three focus groups required careful coordination due to NHS staff’s demanding schedules, including clinical responsibilities, meetings, and other commitments. Bringing together professionals from different disciplines at a shared time was challenging, with one focus group lasting only 45 minutes because participants had back-to-back meetings. Despite these constraints, the iterative nature of the research process allowed for the collection of meaningful and valuable insights. While follow-up questions were sometimes limited by time, the sessions nonetheless generated meaningful discussions that reflect the realities of the NHS context, where stretched services and limited staff availability also impact efforts to engage minoritised ethnic communities (Charlesworth et al., 2024).

Participants

Inclusion/ Exclusion Criteria

The inclusion criteria stated that all participants recruited must be over 18 years of age and employed by the NHS. They had to work in a memory service in the borough's chosen and work in a clinical job role (e.g., support worker, nurse, or physiotherapist). The exclusion criteria were individuals who did not meet the inclusion criteria and those who would find the study upsetting and did not wish to participate.

The purpose of the inclusion criteria was so specific because the research question focused on the perspectives of staff in memory services. Therefore, if a person did not work in the services where the focus groups were taking place, they would not be eligible for the study.

Sample Size

As this study used focus groups rather than individual interviews, the sample size was guided by methodological recommendations specific to group-based qualitative designs (Doria et al., 2018; Krueger & Casey, 2015; Krueger, 1998; Nyumba et al., 2018) and when using thematic analysis (Braun & Clarke, 2022).

Focus group literature indicates that 4–12 participants per group is appropriate for generating rich interaction and diverse perspectives (Doria et al., 2018; Krueger & Casey, 2015; Nyumba et al., 2018). Some researchers suggest that having as few as four participants can be sufficient when the individuals involved possess specialised knowledge or experience relevant to the discussion (Kruger, 1998; Kruger & Casey, 2015). Fewer than four participants can limit discussion, while more than 12 participants can be difficult to manage, potentially resulting in some voices being lost and others becoming dominant (Nyumba et al., 2018; Kruger & Casey, 2015).

Also, Braun and Clarke (2012) recommend 12–16 participants for qualitative studies, specifically those using thematic analysis, to ensure a sufficient number for rich and engaged discussion, as emphasised by Braun and Clarke (2022).

Furthermore, studies indicate that between three and six groups are typically sufficient to capture the themes necessary to address the research question and aims (Guest, Namey, & McKenna, 2017; Cortini et al., 2019).

Therefore, following these recommendations, the aim was to recruit 12–16 participants across three focus groups. This was considered suitable for a population with specialised knowledge and experience in working in memory services in the UK, which was the focus of the research question. Practical considerations, such as the time frame for the thesis, were also taken into account.

Ultimately, the study comprised three focus groups across three NHS services, each with four participants. This size was viewed to support both the depth of discussion and analytic richness, while remaining feasible within the scope of the thesis.

The aim was to recruit staff members who were from different professions. The reason for the variety of professionals in the focus group was to gain an understanding from different positions in the service. For example, staff who work indirectly with the client or only have one point of contact may have less opportunity to gain insight into reasons why the PLWD or their family had not accessed services till that point, compared to staff who work more directly with clients.

Data collection

Demographics questionnaire

Those who agreed to participate in the study after reading the participation sheet were given a demographics questionnaire (Appendix I) alongside the consent form (Appendix J).

The demographic questionnaire, which was a non-validated questionnaire, was used to obtain demographics in line with the NHS's commitment to promoting better equality, diversity, and inclusion in research. Demographics regarding gender and ethnicity were asked, but it was made clear to participants that this information was optional for them to provide. However, after discussion with the supervisory team, it was decided that grouping the demographic data was the best approach due to the small sample size, to preserve participant anonymity

The focus groups involved social workers, nurses, occupational therapists, assistant psychologists, counselling psychologists, clinical psychologists and administrators. There were two participants who identified as male and 10 who identified as female. The participants were asked to write their ethnicities, if they wished to do so. The reason we did not want to offer categories as mentioned previously was because we recognise that this can be problematic when a person's ethnicity is not listed and is usually listed as 'other'. This way allowed participants to be free in identifying their own ethnicities. Ethnicities included: Asian, Black British, Black British African, Indian, Black African, White British, White Irish, Middle Eastern, British Pakistani, White Welsh, Middle Eastern Jewish, and British Indian.

Focus groups

Face-to-face focus groups were conducted with NHS staff across three memory services in London, each lasting between 45 and 90 minutes. The sessions were audio recorded and transcribed using Microsoft Word.

Focus groups were chosen for several reasons. Firstly, they allow for follow-up questions to develop naturally from the group's discussion, rather than adhering to a rigid agenda as in structured interviews. This flexibility helps capture valuable insights that researchers might not have anticipated (Barbour, 2018). Additionally, one-to-one interviews can be time consuming, especially when coordinating NHS staff schedules to be part of the research. This method facilitates gathering insights from multiple staff members in a single session, helping to limit interruptions to their demanding workloads.

Lastly, focus groups bring together participants who are knowledgeable about the topic under discussion (Lauri, 2019). Since this study examines access to NHS services, it was appropriate to seek the perspectives of those who provide these services.

Issues of power in the focus groups

However, we had also thought about the limitations of having staff from different professions in the group, as some people may feel intimidated to talk in front of their seniors, as power dynamics within groups are inevitable (Fiske et al., 2016). Some participants might have preferred one-to-one interviews, as group dynamics can be challenging, especially if participants are not accustomed to discussing sensitive topics together.

Social constructionism emphasises that our realities are shaped through social interactions (Burr & Dick, 2017). Conducting focus groups with staff members means that existing power dynamics within the group are likely to influence the discussion. It is important to consider these dynamics when reflecting on social desirability bias, as some participants may feel pressured to respond in socially acceptable ways, particularly if certain individuals dominate the discussion or hold more power within the group, which may lead others to conform or remain silent (Gundumogula, 2020; Sim & Waterfield, 2019).

However, focus groups facilitate the collection of rich data, allowing the researcher to ask prompts and follow-up questions that encourage participants. It also offers an effective way to understand attitudes and perspectives (Luke & Goodrich, 2019). This method can also enable participants to build on each other's contributions. To address these potential issues, I remained attentive to these dynamics throughout the discussions and actively worked to minimise their influence, fostering open and honest dialogue. Having a reflexive consideration of my role strengthened the research design and ethical approach, which was discussed with supervisors throughout.

As a trainee clinical psychologist and principal investigator, I approached the focus groups with a clear intention to position myself not as an ‘expert’ but as a co-learner alongside participants, valuing their expertise and experiences. At the start of each session, I explicitly explained that the purpose was to understand participants’ perspectives without judgment of their work or services. This helped establish a respectful and collaborative relationship between myself and the participants.

Informed consent

Participants were provided with a participant information sheet prior to the study and given the opportunity to ask questions in advance. On the day of the focus group, their understanding of the information sheet and consent form was checked, and they were invited to ask any further questions before providing written consent. This process aimed to ensure that participants fully understood what the study involved, what was being asked of them, and understood their right to withdraw. In line with HRA protocol, participants were informed that they could change their minds about taking part at any time; however, data collected up to the point of withdrawal would be retained. Participants were also informed that direct quotes from the focus groups might be used in publications, but that these would be anonymised using pseudonyms. Permission to audio record the sessions was also requested on the participation sheet. Those who agreed to participate then completed the consent form (Appendix J).

Confidentiality

Information regarding confidentiality was provided in the participant information sheet and verbally again before the focus group started. I asked permission to audio record the discussion from all participants before the interviews started, and participants were told that their consent forms and demographic questionnaire forms could not be linked back to their names, email addresses, audio recordings or transcripts. Pseudonyms were used for the participants, and all identifiable information was removed. As the primary researcher, I was the only person who transcribed the audio recordings and had access to the data. All data, including consent forms, audio recordings and transcripts, were saved securely onto the University of Hertfordshire OneDrive, in line with the Data Protection Act 2018, UH data management policy and General Data Protection Regulations (GDPR). All the data will be deleted upon completion of the study in September 2025. The data will not be used beyond this study.

Responding to potential distress

It was not anticipated that the research would result in the risk of harm to the participants; however, signposting to appropriate support and services was provided on the participation sheet if they did feel distressed (Appendix H). No participants felt they needed this and were reminded to reach out if they had changed their minds. Participants were encouraged to only share what they were comfortable sharing during the session, and they were advised that they did not have to respond to all the questions asked if they did not wish to. Participants also understood that they had the right to withdraw from a session at any time, that they would not be asked to explain their decision unless they wished to share, and that a debrief would be available if needed. This provided an opportunity for participants to discuss any aspects of the discussion they may have found difficult. After the focus groups, participants were informed that they could remain if they wished to have a debrief or ask any questions about the study. However, no participants chose to do so.

Consultants

SC encourages different ways of evaluating how knowledge is produced and broadens the possibilities of different insights on a topic by integrating multiple perspectives (Camargo-Borges & Rasera, 2013). Therefore, it was important to include people who directly work in the field and/or share similar backgrounds to the project to provide a more authentic understanding of the topic (Cornish et al., 2023).

Three charities providing dementia services for AFC communities within the third sector were contacted. One did not respond, while another was transparent in expressing that they believed the AFC community generally preferred not to be involved in research. This is understandable given the long-standing history of unethical practices, oppression, and racism experienced by Black communities in research contexts, which has contributed to the mistrust of institutions. This includes harmful practices carried out by psychologists in past studies, as well as the broader history of exclusion and marginalisation by educational institutions. These realities prompted me to reflect on my own position as a trainee clinical psychologist, a student at a university and what I might represent to AFC individuals when seeking their support for my research, particularly given that these aspects of my identity are historically linked to systems that have oppressed their communities.

In (Roche et al., 2021), the authors reflected that researchers investigating ethnicity in relation to dementia should consider that participants are often more comfortable and willing to engage with a researcher who shares similar backgrounds. Dr Roche has written many papers regarding EM's accessing dementia support (Roche et al., 2018; Roche, 2023; Roche et al., 2023). I had originally emailed him and his co-authors to enquire about a leaflet they had created in their study (Roche et al., 2018), and Dr Roche offered to discuss the study further, so we met online. This conversation was fruitful in understanding the nuances of EM accessing dementia services, but also the nuances around research within the AFC community, the politics and institutional racism.

One charity, called the African-Caribbean Care Group in Manchester, kindly offered their time to discuss their thoughts on the project. They helped refine the interview schedule and spoke about their experiences and thoughts on AFC communities accessing support services. I asked if any of their service users who were PLWD would like to be involved; however, at the time, no one expressed interest in participating.

Interview schedule

The interview schedule (Appendix K) was developed by considering the research question and study aims, reviewing relevant literature (Berwald et al., 2016; Truswell et al., 2019), and consulting with the supervisory team and consultants.

All questions explored the topic of EMs' access to dementia care services. The questions were used as a guide and as prompts, as conducting a focus group involves an unstructured dialogue that is flexible among group members (Fusch et al., 2022). Follow-up questions were included in response to participants' answers to expand on their responses. The questions were presented to the supervisory team and consultants, who provided feedback on the questions.

Using pilot studies is helpful to improve the interview guide (Majid et al., 2017). A pilot was conducted, utilising 5 trainee Clinical Psychologists who gave up their free time to run through the interview schedule. This was to gauge whether the questions made sense and flowed from one to another. As a result, the grammar of several questions was revised to improve clarity.

The process of analysis

The focus groups were recorded via Microsoft Teams to ensure encryption. I listened to the recordings and transcribed them with minor edits, such as omitting filler words like 'um,' while preserving the original meaning. I also added basic punctuation to sentences to make them easily readable. All transcripts were anonymised, using pseudonyms for each participant.

I used Microsoft Excel to help organise codes and themes derived from the data (Appendix L). Braun and Clarke's (2022) six-step framework was followed for conducting the reflexive thematic analysis.

In addition, I held a reflexive position to explore my own assumptions, personal views and other factors that influenced my thinking on this process, as I cannot be neutral in qualitative research (Skovlund et al.,2023). Questions I would be asking myself were: What are the assumptions that are driving my interpretations? Why have I interpreted in this way? How does that relate to social constructionism? What is my understanding of the world through my discourses? How do I interpret the data through my context as an EM, but also as an NHS employee, and a trainee Clinical Psychologist?

The reflexive diary demonstrates how my position influenced how I conducted interviews, how I interpreted the analysis, and how it influenced my decision-making. I give specific examples of this (Appendix A).

Stages of Reflexive thematic analysis (Braun & Clarke, 2022)

Phase 1: Familiarising yourself with the dataset

I familiarised myself with the data by transcribing the audio recordings from the focus groups and reading them multiple times, becoming fully immersed as I became familiarised with the data. After transcribing each focus group, I added entries to my reflexive journal. (Appendix A), recording my initial thoughts on moments that sparked interest or curiosity. The reflexive journal allowed me to review how my context, beliefs and assumptions influenced the analysis.

Phase 2: Coding

I started to code the data, capturing important features across the entire data set and organising data linked to each code. I used semantic coding to capture the data as directly conveyed by participants, and latent coding to explore the deeper meanings or assumptions embedded within the data (Braun & Clarke, 2006). There were initially 372 codes, and to manage this, I reviewed them multiple times, deleting duplicates and merging similar ones I regularly discussed my coding decisions with my supervisors and Trainee Clinical

Psychology colleagues to reflect on my choices and examine how my assumptions could affect how I created codes and the language I used for them. This included thinking about my insider/ outsider researcher position and whether I was aligning more with NHS staff or advocating for EM. This helps readers understand how I arrived at these interpretations, demonstrating how I both shaped and was shaped by the study**.** Having supervisors and peers to discuss these with helped me see where my blind spots were.

Phase 3: Generating initial themes

I generated initial themes by gathering all data that were significant to participants, identifying prominent patterns across the dataset, and ensuring relevance to the research questions. I adopted an inductive, data-driven approach, deriving themes directly from the data without imposing a pre-existing coding framework or personal assumptions (Byrne, 2021). Through this process, I generated themes and subthemes

Phase 4: Developing and reviewing themes

Member checking was not used in this study, as it is not considered a necessary marker of quality within the reflexive thematic analysis approach (Braun & Clarke, 2022). Situated within a social constructionist paradigm, this research does not aim to validate participants' accounts or to discover an objective truth, but rather to interpret meaning through a reflexive lens. The themes and subthemes were, however, revisited and reviewed by the primary and secondary supervisors and myself. Consultants were also offered to review themes; however, due to time commitments and one consultant having left the job during the process, this was not possible. Multiple people reviewing the themes can help build the trustworthiness of the data. Braun and Clarke (2012) suggest asking yourself, 'If this is a theme, what is the quality of theme?' as a reflective tool to help organise the data. Themes that did not contribute meaningfully to the study were excluded.

Phase 5: Refining, defining naming themes

Themes were refined, defined and named to tell the overall story from the data. This meant thinking about the story of each theme and subtheme to ensure they reflected the data (Braun & Clarke, 2022).

Phase 6: Writing up the report

The results were written up, extracts were chosen to reflect the themes and story being shown. Braun and Clarke (2006) warn against simply rewording excerpts without providing a broader analytical storyline. The write-up was reviewed by the supervisors. I present the write-up of the analysis in Chapter 4.

Chapter 4: Findings

Chapter Overview

In this chapter, I will present the three main themes and eight sub-themes that were generated in the analysis (see Figure 2). The themes are as follows: (i) Faith, Fear, and Dementia: Cultural Forces Shaping Access to Care; (ii) The System's Limits: Exclusion and Inequity in Dementia Support; and (iii) Reaching in and Reaching Out: Navigating Engagement from Both Sides.

These themes capture the complex factors that shape HCP perspectives on why AFC communities may access dementia services at later stages, as well as how HCP navigate engagement and support.

Themes 1 and 2 describe participants' perceptions of barriers to access: Theme 1 focuses on cultural and societal factors, such as stigma and religion, while theme 2 describes systemic barriers that participants felt may constrain equitable care. Theme 3 illustrates participants' responses to these challenges, showing how efforts to engage communities and adapt services are shaped by the obstacles identified in the first two themes. Overall, the findings suggest how participants perceive the interconnected factors that may contribute to AFC accessing services at a later stage of the condition.

The themes were generated by examining patterns across the dataset and considering their relevance to the research question and study aim (Braun & Clarke, 2022).

Through the analysis, I aimed to answer:

Research Question: What are healthcare professionals' perspectives on the reasons AFC individuals may present to dementia services at later stages of the condition?

- Aim: To explore healthcare professionals' perspectives on why AFC individuals may access services at a later stage of their condition
- Aim: To explore if and how NHS memory services accommodate and reach out to this community.

Themes and Subthemes

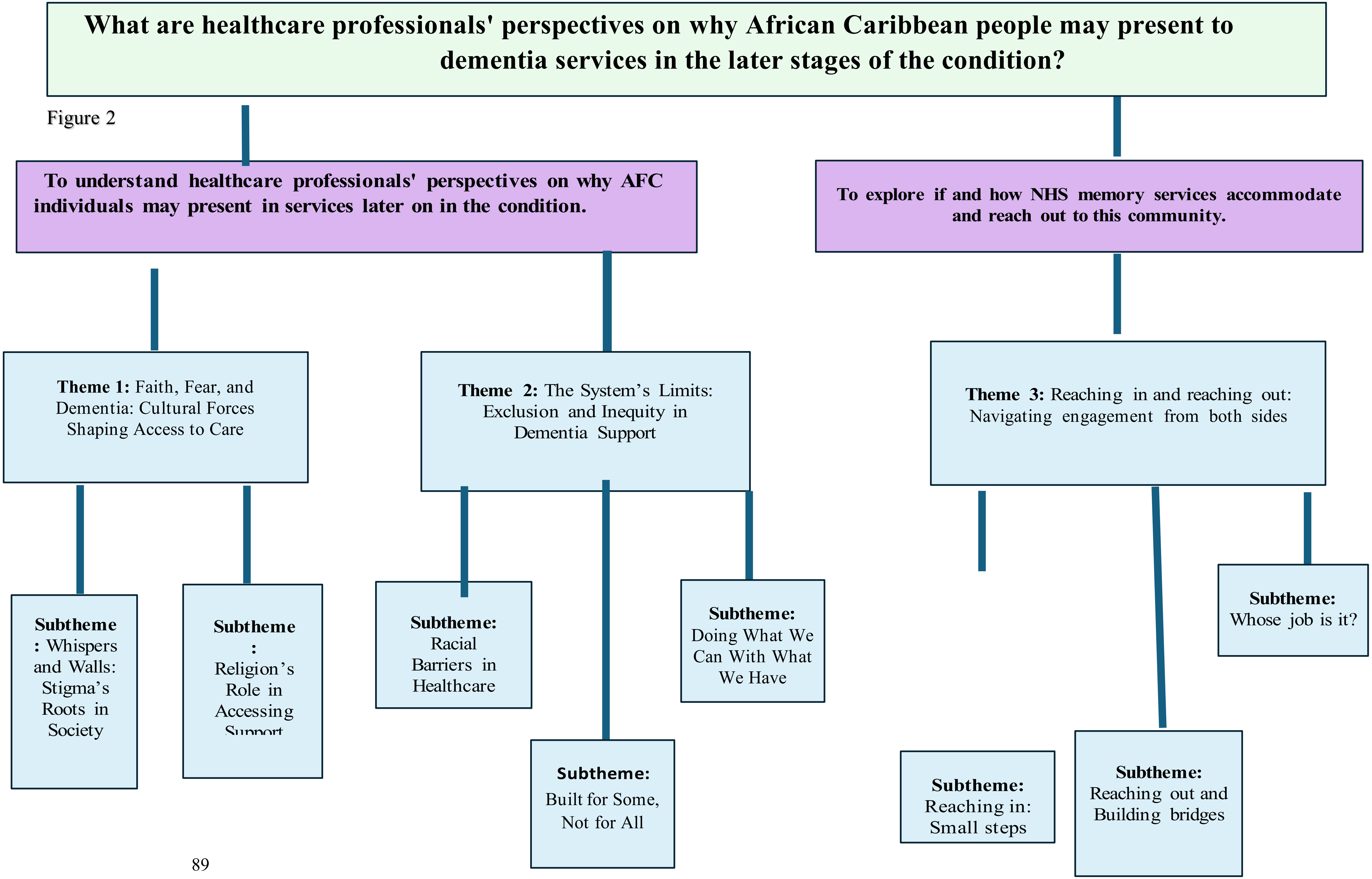
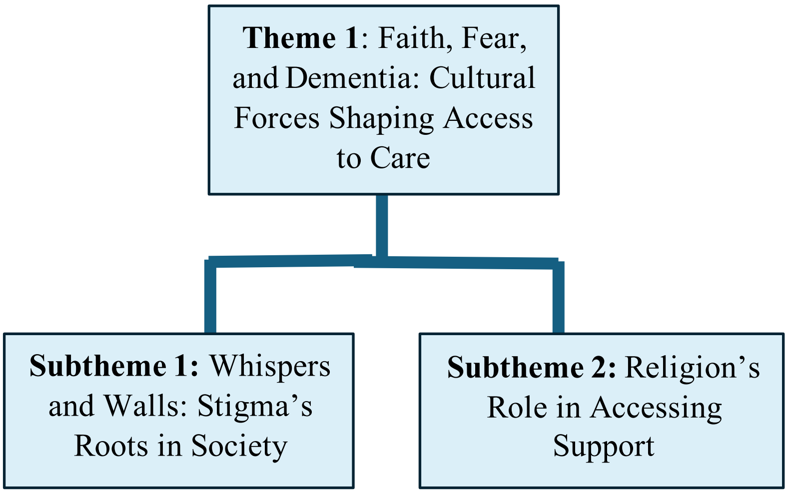


Figure 2

Theme 1: Faith, Fear, and Dementia: Cultural Forces Shaping Access to Care



This theme captures HCPs perspectives on how wider societal and cultural forces can shape AFC individuals accessing dementia services. Participants described how they thought stigma and religious beliefs may hold communities back from understanding the condition and wanting to get support. These influences were evident in societal narratives surrounding mental health, ageing, and the NHS, which appeared to be deeply embedded within communities.

Participants reflected on how they felt that these factors can influence whether individuals engage with dementia services.

Subtheme 1: Whispers and Walls: Stigma's Roots in Society

Participants spoke about how they felt stigma surrounding dementia may shape the ways AFC individuals access support. Stigma, while often seen as an individual-level issue, was described here as socially constructed and culturally embedded, shaped by shame, denial, and fear. Some participants felt the stigma was linked to shame within families and cultural discomfort around mental health. Sofie spoke about how her experiences were that AFC individuals tend not to involve family:

"I think it's may be coming from shame (...) although there was family in the picture, there was a refusal to bring us in touch with them (...) When I see Indian patients, they always come with family. . . (Sofie)

Others echoed this sense of avoidance. Tanya observed how families may recognise something is wrong but actively resist formal diagnosis:

"African-Caribbeans don't want the labels, so when it starts, I bet family members or themselves will notice, they are shy of those labels. It's not within the cultural practice to easily just accept (...) they want to hush hush on us so they won't come until it's going to moderate or severe stages" (Tanya)

Participants described how symptoms might be downplayed or normalised within community discourse. Jade summarised:

"There's stigma, cultural beliefs, you know, 'it's just a part of getting old, it's nothing'". (Jade)

This cultural minimisation may often extend to the first point of contact with services due to the fear of perceived stigma. Stevie shared:

"Couple of people come and say, 'I've not told anyone because I'm worried, they will think I'm crazy, I'm mad, so I've not told my GP this'" (Stevie)

Participants suggested that reluctance to share concerns, even with GPs, might contribute to why AFC individuals present later to dementia services. For some, stigma was linked directly to language and a potential fear of pathologisation. Nina recalled a conversation with an AFC service user who resisted diagnostic labels:

". . .and he's like, 'don't even call me crazy or you want to say I'm senile because those words that are just kind of, like, fluttered around in the community of like someone with

dementia is just being someone who's just not there anymore'. I think he was very unhappy with the labelling system" (Nina).

Sofie spoke about how, in her experience, AFC people come across as independent, and how seeking support for dementia may feel like it strips away that independence:

"I describe them as being very independent and very protective of their independence, that's a risk going to get diagnosis with dementia that will take it all from them (...) not coming across as strong as they were before (...) which is what we've experienced and that's the barrier (...) there is a lot of trying to mask around the difficulties as well" (Sofie)

Other participants shared similar experiences, highlighting how language rooted in madness or decline could increase denial:

"Often, we get patients come and say, 'I'm not going mad or, oh, I'm just getting old, it's normal'. And whether that's just people's fear of things developing or that its not the same level of education or just, you know, being conditioned to think that certain mental health problems are not caused by something like a disease of the brain like actual changes" (Stevie)

"There's a lot of negative language, isn't there? It's about 'losing marbles' or 'being mad'". (Sara)

Participants pointed out that stigma extended beyond individual beliefs to wider cultural representations. Nina noted how the internet and media can reinforce fear and avoidance of accessing support due to portraying a certain image of dementia. Nina explained how online images and narratives of dementia can be particularly damaging:

"It also doesn't help when you go on the Internet. If you just type dementia, you see the pictures of people they label with dementia. If you're an anxious person looking at that, you're automatically going to be like, Nope, don't even want a diagnosis of that" (Nina)

In addition, Sara described how personal experiences with dementia, particularly negative or distressing ones, could further strengthen stigma and denial:

"I think for some people, it's about perhaps knowing somebody else who's got dementia and (. . .) assuming that they're going to be like that (...) you do get that quite a lot. 'I'm nothing like them. How? Why are you saying I'm like my mum was, who I looked after, because she was mad?' There's a lot of that" (Sara)

These reflections suggest that stigma is not only about cultural silence or fear of mental illness but can also be about distancing from the diagnosis. Individuals may deny or delay accepting dementia due to fear of becoming like someone they cared for, or because of the way the condition is represented in the public domain. Participants consistently emphasised that stigma was not just about the condition itself, but about how services were perceived. Monica shared that she felt AFC communities may interpret institutional labels negatively:

"I think there's a lot of stigmas attached to 'TRUST NAME' (...) A lot of clients read the label at the front of the door like 'Psychological mental health of adults', and they're like. 'But I'm not mad. I'm forgetful. I just need meds for my forgetfulness (...) African-Caribbean people are more likely to be diagnosed with schizophrenia as well (...) So, if you are to be seen in 'TRUST NAME', they're immediately thinking of, I don't know, a cousin or a friend that they know has been sectioned and the history has not been great . . ." (Monica)

Stevie echoed the emotional reality of walking into services, potentially already shaped by fear:

"I can't blame people for coming in and saying, well, 'I'm not mad' because that's the label associated with our trust. We're a mental health trust. So, you know, it's scary for people" (Stevie)

Even when efforts have been made to increase cultural sensitivity, participants acknowledged that the legacy of these earlier harms may continue to shape perceptions. They described their experiences of hearing stories of negative experiences, such as being sectioned or misdiagnosed, often circulated within families or communities, potentially creating a powerful narrative of mistrust, that can persist even if it no longer reflects current practice. The participants suggested that the experience of AFC communities with the NHS, particularly mental health services, in the past may serve as cautionary tales, potentially reinforcing a hesitancy to fully trust or engage with services until necessary.

Subtheme 2: Religion's Role in Accessing Support

Participants reported that they believed religion to be an influential factor in how AFC individuals may understand and respond to dementia. While they felt religious spaces can offer emotional support and reduce isolation, they also felt religion shaped beliefs that either encourage or discourage engagement with healthcare services. Participants suggested that religion may play an important role in the lives of many within the AFC community, as Sofie shared:

"The African-Caribbean, they normally tend to associate with A church. It's something that it's very strong in their community life, and they get a lot of help from the church" (Sofie)

In some cases, pastors appeared to play a central role in ongoing care and post-diagnostic support, stepping in where formal services may have limited capacity. Tanya reflected:

"The pastor came. He was so good. Everything to do with, like, post diagnostic things, he says 'I'm going to do this. I'm going to do that' (...) for him to leave his work. Very busy job" (Tanya)

However, some felt that religion could give people mixed messages about accessing support. For instance, Jade spoke about the pressure some congregations place on spiritual solutions rather than medical intervention

". . .not so specific to dementia, but I have witnessed some churches whereby it could be any condition, it could be cancer, it could be autism, it could be anything (...) I don't know if they're unrealistic or if they generally believe this, but the congregation puts so much trust in this pastor, and they believe what he's saying. But he will say, 'I will pray this out of them'" (Jade)

Participants suggested that reliance on spiritual explanations might lead to delayed diagnoses, confusion, or rejection of medical support: Stevie also noted this pattern:

"We sometimes have clients who will say, 'I go to church and I pray away and it will go away, and I feel better every day'. And you know, we know that's not necessarily how it kind of works (...) we see that quite a lot here (...) we know that's not necessarily how it kind of works" (Stevie)

In some cases, this conflict between spiritual belief and medical reality was experienced as leading to a breakdown in trust. Nina reflected on how this tension could push people away from services altogether:

"Imagine, somebody who's hesitant to come to a dementia service if the pastor says 'I will cure you', and we are saying we're sorry but there's no cure. it's just gonna kind of maintain it. Yeah, they're more likely to be like 'yeah, I'm not gonna listen to you guys, You're not even offering me a cure. But here (church) I'm receiving that'. So again, that misinformation." (Nina)

There were also instances where participants felt religion was tied to denial. Jade described one case where a woman rejected her diagnosis and disengaged from support entirely:

"No, I'm a Christian God-fearing woman. These things can't happen to me (...) I'm going to tell everyone not to come back to your service' (...) She didn't want to accept it, and she didn't come back" (Jade)

It was suggested by Jade that their patient's denial, rooted in religious beliefs, and her desire to 'warn' her community about the service could contribute to narratives affecting dementia engagement. Despite these challenges, participants consistently saw value in engaging with religious leaders and faith-based spaces to reduce stigma and build trust. Nina explained:

". . . pastors of churches they're more influential (...) Because if a pastor's telling you, 'it's totally OK if you're experiencing this' versus like stigmatising it" (Nina)

Some services were already making efforts to collaborate with churches, though this work was described as sometimes limited by NHS resources. Monica described a strained attempt at co-production:

"The community leader, he's a pastor and said, 'Well, if you guys are not ready to work with us…'. I mean, he tends to take on most of the work as well. . . So, we try to co-produce, but sometimes it's not really co-production, I don't know what to call it." (Monica)

Others described small but meaningful steps, joining prayer groups, visiting church communities, and exploring opportunities for relationship-building:

". . . lot of things going on within churches, prayer groups, social groups that ('team manager name) has said she will let nearly all of us go to and interact and talk to the people

because it's like, they are not aware of us or we don't know about them. Let me come and tell you what we do" (Tanya)

"There's been attendance at church groups and things (Sara)

Sofie felt that the groups did not have to be named 'dementia' groups, but groups at the place of worship, so that AFC individuals could feel a sense of safety and help destigmatise memory difficulties:

"If we could have groups, not necessarily dementia groups, but just elderly groups within the church, it might be more inviting for African-Caribbean people because it's a familiar place to take the shame" (Sofie)

Dylan reflected that their service could be doing more outreach:

"There's literally a church across the road. We should be engaging with that" (Dylan)

There was also recognition that religious centres could offer practical post-diagnosis support, especially when language or cultural barriers made NHS services feel inaccessible:

"We can also signpost people there after being diagnosed. So, if there's a language barrier or anything of this sort, they have their own counsellors and therapists there" (Jade)

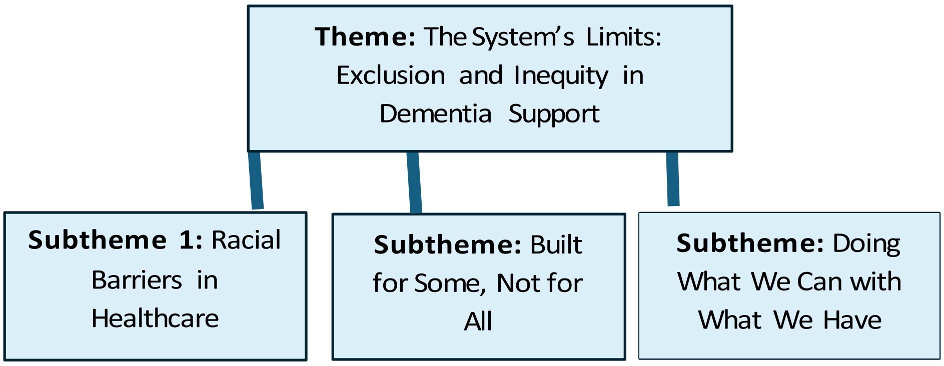
Still, the level of openness from churches was experienced as varying significantly. Some were described as "positive," while others were described as more closed or sceptical of medical framing:

"It depends on what churches you go to. Some churches might not receive it very well, but then there's the positive churches" (Jade)

"They are sometimes negative, sometimes really positive" (Sara)

Participants felt that messages from religious leaders also differed depending on who they were with; some were seen to promote open conversations about dementia, while others were viewed as reinforcing stigma. Participants felt that religious and community leaders often hold significant influence in shaping how communities respond to dementia and accessing services. They highlighted the need to engage these leaders to help reduce stigma and raise awareness of dementia, enabling earlier access to support.

Theme 2: The System's Limits: Exclusion and Inequity in Dementia Support



Participants felt that systemic influences, such as racial barriers and culturally inappropriate services, could impact AFC individuals' access to healthcare. Systemic racism was perceived as embedded in the practices and norms of the healthcare system, including culturally insensitive assessments, misdiagnosis, and staff biases towards AFC individuals. Most participants acknowledged that existing neuro-testing was culturally inappropriate for EM groups and reported making adjustments and adaptations where possible, within the structural constraints of the NHS.

Subtheme 1: Racial Barriers in Healthcare

This subtheme captures HCPs views on systemic racism, both institutional and personal, and how they felt it acts as a significant barrier for AFC individuals to access dementia services. Participants reported the ongoing impact of historical injustices, organisational practices, and everyday discriminatory attitudes that may undermine trust and contribute to delayed presentation in healthcare. Stevie emphasised how she felt organisational racism can manifest in everyday healthcare interactions, suggesting AFC patients as often being dismissed by the system:

"There's an incidence where we find that a lot of African-Caribbean people are more reluctant to approach their healthcare providers because a lot of time people are quite just dismissed. I think a lot of our community, of our people of colour, is just completely shooed away (...) it's organisational racism" (Stevie)

This account situates late presentation within what the participant described as a broader pattern of exclusionary practices embedded in healthcare settings, suggesting that, in their view, mistrust may be generated through repeated experiences of marginalisation rather than in isolation.

Monica extended this critique by speaking to colonialism, emphasising the ongoing consequences of historically rooted inequities:

"There's a lot of cause and effect. The system hasn't been great for black communities, so they haven't used it properly, and now it's generations and decades of delay. . .it's partly to do with the community, but there's also a reason why (...) We're going to have to go all the way back to colonialism. This is realistically not our country, so this system isn't set up for us in the way it should be." (Monica)

Monica's framing invites reflection on what she perceives as the role of historical power relations in shaping current inequities, which, in her view, may contribute to AFC individuals being cautious about engaging with a system they perceive as not serving them. Others, like Maya, acknowledged the ethical responsibility of HCPs to recognise discrimination within the system:

". . .I do understand that there is institutional racism, more discriminatory practices, and that's a huge barrier there (...) that means we all have an ethical moral duty to do something about it. . ." (Maya)

Jade echoed how she felt systemic racism may shape attitudes toward help-seeking, noting that fears of discrimination may lead AFC individuals to manage symptoms privately rather than seeking care:

“Maybe they face discrimination or racism or maybe playing down their symptoms. So it's like what's the point of coming’?... They just manage it.” (Jade)

This insight suggests how structural racism can impact health behaviours, reinforcing that delayed presentation can protect individuals against anticipated discrimination rather than neglect of the symptoms. Dylan connected these barriers to the concept of minority stress when asked why AFC individuals may be at higher risk of certain types of dementia:

". . . People just deteriorate inexplicably, like a failure to thrive from the beginning, and you just wonder about minority stress. People aren’t held in mind, and what's the impact of that?" (Dylan)

Participants suggested that HCPs’ own biases can contribute to delayed diagnosis. Stevie shared that she felt HCPs themselves can hold biases towards people from EMs that may be impacting diagnosis, and acknowledged the presence of racism:

"Historically, many healthcare professionals, particularly older GPs or older white males, might hold certain beliefs against people of colour... that’s why you have untreated conditions like high blood pressure, which increase dementia risk and other health problems...There are a lot of those attitudes in the NHS that maybe we pretend don’t exist, but quite a lot of personal racism." (Stevie)

This aligned with Kian's story of a student who reportedly went to the media in opposition to discussions on equality and diversity:

“A trainee Psychologist went to a newspaper complaining about the discussions that were taking place regarding equality and diversity within training” (Kian)

This shows that not everyone may feel inclusive practices are important, and there might be pushback from certain individuals who hold certain views in the NHS.

Kian and Monica both commented on what they perceived as the unintended consequences of EDI discourse within professional spaces:

"It’s created a backlash. People who felt they had to be silent now feel validated to voice their displeasure. Things people say now about race and criticisms of changes, things that wouldn’t have been said seven or eight years ago." (Kian)

“I think we're talking about it too much now (Monica)

Kian and Monica's accounts suggest, from their perspective, that efforts toward inclusion may unsettle norms, potentially prompting defensive responses and revealing the emotional and political tensions they observed as embedded in institutional change.

Dylan spoke of his experiences of working with different services and how negative narratives of “angry black women” could impact the care they were receiving, and how he felt HCPs could position people from AFC backgrounds:

“It's really hard to get other services to connect with the need of a service-user from an AFC background (...) they don't trust that they can put a care package in place, or they've needed our support . . .I think it's a lot of “Angry Black woman” stuff.” That's definitely there.’ This person's hard to engage. We need your help to kind of have a bit more of a united front against them’ (...) a real sense of threat for the AFC people associated with (...) who really have to potentially be self-reliant to cope with what society throws at them relentlessly (Dylan)

Sara also acknowledged what she perceived as the presence of unconscious bias in assessment:

"The assessment is about taking collateral information, and I wonder how much we bring our own unconscious biases and impose them on people. I think that's something we all need to be aware of (...) suppose it's trying to be mindful about what kind of narratives or discussions we do have in team meetings. Because we all do cultural stereotype…conscious or unconscious." (Maya)

Participants indicated, from their perspective, that racial and ethnic inequalities may continue to influence how AFC individuals engage with dementia services. They suggested that addressing these intersecting challenges could be important for developing equitable and culturally sensitive services that better respond to the needs of the AFC community.

Subtheme 2- Built for Some, Not for All

Participants reflected on how they felt dementia services and diagnostic tools utilised in services are often not designed with EM populations in mind. Across all three boroughs, there was a consensus amongst participants' beliefs that the diagnostic process was inequitable, as they reflected that neuropsychological assessments were initially developed by and for Western populations. Participants suggested there was a lack of training and guidance when using the tests with ethnic populations and felt that services were culturally inappropriate.

Tanya described how her experience was that AFC individuals often struggle to relate to the materials presented during testing:

"A lot of times when you do have people from EM's, even black Caribbean for example, they don't relate to a lot of the material that were presenting to" (Tanya)

Kian went further, critiquing the underlying assumptions behind what is being tested:

“The skill sets that are being explored are valued within Western communities (...) they don't exist in the same way as they do in other communities. So, we're still asking people questions that may not be particularly relevant. That's the problem, right? “(Kian)

These accounts suggest an implicit critique of cultural dominance within clinical practice, highlighting that what counts as ‘knowledge’ or ‘memory’ in assessment settings may reflect white, Western norms.

Other participants described how clients themselves often pointed out the cultural difference:

“They would mention it anyway (. . .) I've noticed a lot during the test that the clients would say, I'm not familiar with these things and then you just make a note. . . ‘It's not part of my culture. I don't use it’(...). Then you would find them to be quite vocal about their history then you will take that into account” (Monica)

Nina echoed this, describing clients’ confusion and frustration:

“I feel a lot of them when they come, they just feel like ‘what is the point of this task? How am I supposed to give you an answer if I've never done something like this before or if I've never seen something like this before?’(...) With the memory list that we use, again, I think some of the words just don't resonate or are relatable to them. (Nina)

Participants highlighted how they felt that services have done little to respond to these concerns, even when feedback has been given. Sara shared her frustration with the lack of progress:

“We have feedback on ‘how is this relevant to me’? Have we really made a change? We're acknowledging that they're not culturally relevant, yet we've not done the research or anything to actually make it more culturally relevant…” (Sara)

Sara's frustration was also seen by Kian regarding what was being adjusted to accommodate EM’s :

“So the question is, what's being done about this? The answer is nothing” (Kian)

Dylan offered a slightly different perspective, suggesting that while cultural background matters, a person’s experience of education may have a more direct impact on how they engage with the assessment task:

“I guess my feeling is that if you're from an African-Caribbean background, you're probably very familiar with a very English style testing experience. But what might be more important is asking someone about their experience of being in education” (Dylan)

Sofie also suggested that the structure of assessments may be why people from AFC are more likely to fail, based on the assumption that AFC individuals will have lower educational levels:

“The African-Caribbeans or generally other minorities (...) when it comes to the diagnosis process they're more likely to fail and easier to diagnose. We consider those things when we assess, but all those assessments are built (...) not for people with poor educational backgrounds” (Sofie)

Stevie also spoke about how assessing people in a culturally insensitive way may fail to offer an accurate picture of their cognitive abilities, leading to either under- or over-diagnosis, not based on clinical reality, but shaped by culturally biased tools and assumptions:

“When people do come to our service, are we even doing them justice? Are we underdiagnosing? Are we over-diagnosing because, you know, if the measures aren't validated, they may fall lower? Or are we just assuming because they fall lower that they have dementia, you know, what are we not taking it into account?” (Stevie)

The participants' accounts appeared to reflect a tension at the heart of many services: while awareness of cultural inappropriateness may be growing, meaningful change remains stalled, perhaps due to lack of funding, resources or uncertainty about what culturally relevant care would look like.

Some participants highlighted the lack of formal training on cultural sensitivity in assessment practices. Stevie commented:

"No (...) there's no formal training that when you get the job in terms of how to do the measures for people with different education (...) no one pays attention to e-learning, let's be honest (...) and the people who need to learn the most are just going to dismiss it and go okay 100% done". (Stevie)

Both Monica and Nina described learning informally through their diverse team, rather than through structured guidance:

"No…just learn from each other. That's it." (Monica)

"Because we are such a diverse group working together, we kind of rub off on each other, right? Like things I never would have thought about suddenly is like, oh, never really thought of that, I'm gonna keep that in my head for next time" (Nina)

While these examples suggest valuable peer learning, participants suggested there was a lack of system-wide responsibility for preparing staff to work in culturally sensitive ways. They felt that the burden of culturally competent care was left to individuals in the team.

Together, these reflections suggest systemic exclusion in the design of the tests and in practice. The participants reported that when tools are not designed with diverse populations in mind, equity in diagnosis and care becomes compromised from the outset.

Subtheme 3: Doing What We Can with What We Have

While participants spoke about adapting assessments to make them more culturally appropriate, many expressed that these efforts were limited, making it difficult for them to offer truly inclusive care. Despite these challenges, participants conveyed a strong commitment to improving practice and recognised the importance of culturally responsive services.

Jade shared that being part of a diverse team made it easier to have open conversations with patients, helping build trust by showing cultural understanding:

"The one thing that I tend to explain to patients from EM's is that luckily for our borough, we're very diverse and we're all kind of understanding of the different cultural differences (...) So I think they're a bit more trusting and willing to continue when you explain it that way." (Jade)

Others shared how they had open discussions with families as a practice aimed at being transparent and how the scoring of tests were adapted to create equity, even when the tools themselves fell short:

"We tell them what we have done, then and there. We will say we have marked you out of X instead of X, and families are there, they know what is happening and that way we are adjusting." (Tanya)

Jade also spoke to this:

"We just might adjust it (...) we can sort of play around with it to fit the person." (Jade)

For Nina, this transparency was about managing expectations as well as recognising the limitations of the system:

"Patients from EM's say this is an unfair comparison. But we try to be as transparent as we can with (...) we also have our limitations. We're trying our best to make the most of it." (Nina)

Kian similarly spoke to the compromises made in everyday clinical practice, emphasising that honesty with patients was essential:

"Opening up the fact that the scores may not be entirely valid (...) because otherwise there are no real tools." (Kian)

At the same time, participants were realistic about the broader constraints they were working within. Funding, staffing, and time pressures was seen as limiting what was possible, even for teams committed to doing better:

"I appreciate that there's issues with budgets and funding and resources." (Kian)
"I think some of it stems in a little bit of funding and whatnot and resources towards that." (Nina)

Maya reflected how easily the pressure of clinical demands could pull her away from more relational or culturally attuned conversations, despite recognising their value:

"The way that our assessments are structured, there is scope for meaningful conversations, and I sometimes feel maybe I could go a bit task-oriented." (Maya)

Even in teams considered 'diverse', there appeared to be a frustration amongst the participants that diversity often felt incidental rather than intentionally built into training or systems. Faye shared how stark the lack of cultural focus had been during her training:

"It was frustrating, when I was on training, I was really struck by how it was so homogenised (...) but hopefully that is changing all round." (Faye)

Still, participants felt that being in a diverse team itself served as a kind of ongoing education, especially for white colleagues, who reflected on how much they had learned just by being in proximity to peers with different backgrounds:

"Speaking as a white person, I've definitely been able to take into account a lot more about people's races, their culture, their background, just by virtue of being in a team like this (...) I think we are in a better position than if we were just made up of white British people." (Stevie)

However, Nina highlighted the emotional and educational labour that minoritised staff often undertook in raising awareness of cultural and ethnic differences, questioning whether her white colleagues would have been as culturally attuned without those influences:

"I'd like to believe our white colleagues are also as aware of these cultural differences had we not been there to educate them about it." (Nina)

Throughout these accounts, participants navigated the tension between working within a system that they felt often fell short and still trying to offer care that was equitable, transparent, and thoughtful. Their reflections were not framed as solutions, but as pragmatic negotiations and care made possible by collective awareness, informal learning, and deep commitment to doing what they can, with what they have.

Participants spoke to the value of working within diverse teams, not only in terms of internal learning and peer conversations, but also in how clients from EM backgrounds might feel more at ease when they see someone who looks like them:

"Makes a huge, huge difference (...) it's like, 'oh, you're one of our own,' and they confide in something which they weren't comfortable sharing with another colleague (...) might also just relate to African-Caribbean individuals as well." (Nina)

"I think I'm really proud of this team because we have every culture, and I guess when a patient comes, not always, but they see their own kind. I think it feels good because they're like, 'she's like me and I'm comfortable'." (Tanya)

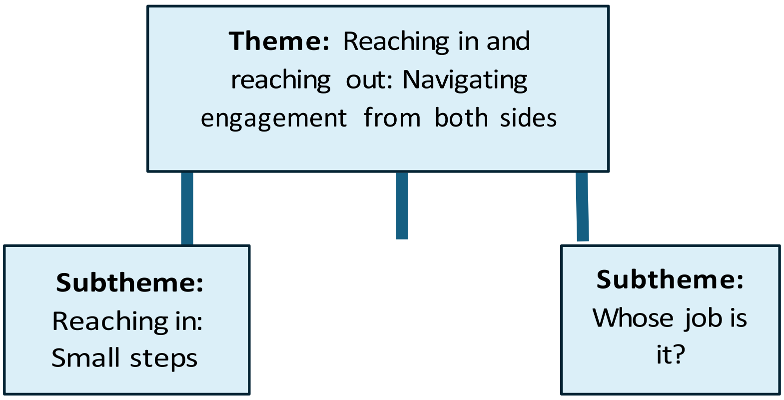
This account highlights clinicians' perception of the importance of representational belonging, with some suggesting that visibility alone can foster trust. Yet Tanya's phrase 'not always' subtly acknowledges that shared identity is not a guarantee of comfort or connection, just a potential doorway. Maya also related to this:

"I guess when I see people from my own community, where I can make a bit of a difference (...) I think people warm up often, not to generalise, because not everyone is like that (...) I think that just helps engagement, people can relate..." (Maya)

Maya's hesitation, like Tanya's, not to generalise, is important. It signals an awareness that identity is relational, and that people may or may not resonate with the cultural or ethnic background of their clinician.

These reflections highlight participants' perceptions of ongoing efforts to provide culturally responsive care within the constraints of the system. While challenges were reported to remain, the commitment to transparency, adaptation, and learning within diverse teams highlights a pragmatic and compassionate approach. Ultimately, this subtheme reveals that clinicians recognise the importance of doing what is possible with available resources while continuously striving for more inclusive and equitable care.

Theme 3: Reaching in and Reaching Out: Navigating engagement from both sides



Subtheme:
Reaching out:
and Building
bridges

The theme ‘Reaching in and reaching out’ reflects participants’ perceptions of the two-way process between AFC communities and dementia services. Participants reported that they perceive individuals from these communities are beginning to slowly engage with services. At the same time, HCPs described their own efforts, as they perceive them, to initiate contact and build relationships within these communities. The following sub-themes present engagement from both directions: how participants perceive AFC individuals navigate access to services, and how participants perceive their attempts to connect with communities in ways that are meaningful, yet often under-resourced or unsupported.

Subtheme 1: Reaching in: Small steps

Participants observed that some AFC individuals may approach the service with caution, which could contribute to patterns of inconsistent engagement. Nonetheless, they reported engagement is occurring, and small steps are being taken. Participants suggested that individuals may present to services for reasons unrelated to dementia, they may misunderstand the purpose of the service, or express frustration upon receiving a diagnosis they did not anticipate. Yet, participants suggested that their appearance at the service marks a meaningful act of ‘reaching in’:

“*Since I've been here, I've seen AFC people approach us. They would come with their own biases, you know, ‘I'm not mad’ but at least they're here…that's the first step. They do continue with our services even when they are in denial about the diagnosis (...) that’s kinda of reaching out to us. So, let's just continue that work” (Monica)*

Other participants echoed this idea of gradual engagement. Dylan, for example, reported that AFC individuals are attending their Cognitive Stimulation Therapy (CST):

"We do CST, it's wonderful, and actually 20% of that group is Caribbean, so that's a good representation, which I'm proud of (Dylan).

However, many noted that, in their experience, AFC individuals often arrive via crisis pathways rather than self-referral. They suggested that AFC individuals may not 'reach in' for support unless another healthcare provider has noticed symptoms and referred:

"They say 'I don't know why I've been referred' and sometimes it's because they've got to that crisis point, and the GP or the hospitals picked it up. It's not always that the person's kind of own action that's lead them there (Stevie)

In some cases, participants reflected that individuals may attend the service without a full understanding of what the service provides. Tanya described a woman who came for a cure for dementia:

"She said, 'No, no, no, no. There is a cure.' I left her to explain" (Tanya)

Tanya seemed to navigate the tension between medical truth and the patient's faith, opting to respect her belief rather than challenge it directly. Her account illustrates how HCPs may often feel they must balance professional integrity with cultural sensitivity, particularly when beliefs about illness differ.

Nina also shared that she had heard how alternative health beliefs, such as herbal remedies, shape some clients' understanding of interventions:

"…the healthy remedies (...) they're like, oh, we tried this tea, and it's actually helped. .... a friend in Russia gave him some medicine, which boosted his memory .... you don't know what medication it is, but he thinks it's having an impact..... It could be a placebo (Nina)

Tanya also noted that she felt some clients come seeking different support rather than for memory assessment itself:

"I'm not saying 100% that would be judgmental, but benefits, somebody to probably help them be there when the families are going to work, respite and stuff, advice .... (Tanya)

Expectations of what services offer was also reported to create misunderstandings. Some participants felt that once a diagnosis was given, the lack of ongoing support created frustration or disengagement:

"*We're just a diagnostic service, we are not involved in what happens after (. . .). But then I think they feel like 'oh, you're just trying to get rid of us. You're just trying to get us off your case list, I'm another statistic to you'". (Nina)*

Others shared how they felt younger AFC individuals might disengage quickly after initial contact:

"Some of the younger ones that have come have turned around and said I don't want this anymore (...) They've been discharged from the service because we have to take on what they want. One person said that 'it's too cold to come in', another said 'I've got things to do. I've got to travel here and there'". (Jade)

Though these reasons may appear superficial, they were understood by staff as avoidance strategies. From a social constructionist perspective, this reflects the way dementia is culturally constructed as an 'older person's disease'. For younger individuals, a dementia diagnosis may feel that much more shameful or identity-threatening, potentially leading to denial or psychological distancing. What presents as disengagement may possibly be an emotional coping mechanism in response to the confrontation between clinical labelling and culturally constructed understandings of self, health, and ageing.

Participants suggested that when some AFC individuals accessed services, a sense of mistrust, possibly stemming from negative past experiences, might contribute to scepticism toward the service and staff.

"I remember one gentleman, he had bad experiences of the NHS, he's like 'are you sure you're gonna do what you say you're gonna do because people don't actually do that'(...) I think a lot of services might have promised certain things not followed up on it" (Nina)

Sara and Nina both suggested that a dementia diagnosis may threaten the personal and social identities of AFC individuals, which can be seen as central to self-worth, and they felt this was apparent when discussing driving matters and during assessments in their services:

"It's that loss of independence of 'oh, if you give me a dementia diagnosis, I'm no longer able to care for my family. Respect in the Community will go down because they think I'm not able to drive'" (Sara)

"African-Caribbean individuals whom I've done assessments with, you can see this kind of trend, if they're struggling on a task, you will get a flurry of reasons as to why they're struggling. It can't just be acceptance of, 'oh, maybe my memory is declining, I didn't have a good night's sleep last night'(...) You can see a lot of the masking or trying to justify why performance wasn't like optimum…" (Nina)

Although issues of identity, threat, and stigma are commonly associated with dementia diagnoses across different communities, participants perceived these dynamics to be more pronounced within the AFC population. They suggested factors such as mistrust, denial, and identity-related concerns may shape whether individuals engage with services and how meaningfully they do so. Participants reflected on these barriers, but also saw value in every instance of contact, however tentative. Their reflections highlight a perceived need for relational and culturally sensitive engagement that extends beyond diagnosis and recognises the broader social meanings of dementia for the AFC community.

Subtheme 1: Reaching out and Building bridges

Participants acknowledged that some services were beginning to engage more meaningfully with EM communities. Specific initiatives for 'reaching out' were reported to be in place in two services in efforts to build trust and visibility with EMs. However, one thing that stood out was that across the focus groups, few participants were aware that research suggests that AFC individuals are at higher risk of developing certain dementias. Could this lack of awareness contribute to why services are not reaching out to this community more actively?

"No, I was really surprised to hear you say ...I'd heard dementia, but not Alzheimer's specifically. So that, yeah, it makes me feel quite embarrassed. I've been out of date" (Dylan)

Yes. Actually, no. I mean, yes. But at the same time, I know that everyone can get it, but I didn't realise it was a higher risk in the black community or the African-Caribbean community (Jade)

"No, it's news to me, so at least I know that now" (Faye)

However, Monica felt that there was a focus on racial differences when it came to research in dementia, which may be why the research suggests they are at higher risk:

"Could it be a bias in research as well, researchers focusing a lot on people of colour?" (Monica)

Participants described the initiatives as positive, however, they consistently emphasised that they felt these efforts were limited in scope. Though a starting point in the hope that the community would access support earlier, before they and their families reach a crisis point:

"*The NHS is incredibly reactive, not proactive. So instead of focusing on reaching out to communities, we let people get to the point where they're very unwell (...) we'll see someone who's quite far into their illness(...) we're getting a lot of people of colour who are coming in and just not having any support (...) then it's all scrambling to react to something instead of trying to work to prevent it getting to that point" (Stevie)*

Monica highlighted her view that this delay not only increases costs for the NHS but could also create unnecessary distress for patients and families:

"not only the fact that it then costs the NHS more money, but the amount of stress for the person themselves and the family around them to have to scramble around when someone's incredibly unwell" (Monica)

These accounts reflect participants' frustration with the system's focus on intervention only after deterioration, which participants felt may indicate limited confidence in the service's capacity to provide preventative care.

Some participants described their initiatives to engage with faith-based groups and local community settings as part of their outreach efforts. However, participants expressed that this progression was at the beginning phase rather than a comprehensive or sustained approach:

"that's why we started the initiative to reduce the stigma attached to 'TRUST NAME' a little bit(.....) it's about outreach into the communities to get them to come to us as a service and get diagnosed with dementia earlier on (Monica)

"There has been quite an attempt to kind of get people into service more and let them know the doors open" (Stevie)

This prompted Maya to reflect critically on the limitations of what was being done in their service:

"In terms of thinking about collaborating with African-Caribbean communities. How much of that do we do?" (Maya)

"The way I see it is just we don't just don't have enough engagement with the AFC population. How do you get them to come to you? (..) I think that we don't have enough exposure. "(Sofie)

Sofie's emphasis on the service needing greater 'exposure' to the AFC community illustrates a common but problematic framing that the responsibility lies primarily on AFC individuals to engage with services.

Participants reflected on the broader cultural dynamics within NHS structures. Dylan highlighted how he felt assumptions about culture can get embedded and left unchallenged, potentially shaping how services approach or avoid outreach altogether:

"Theres a real discourse around (...) was in a team meeting (...) Someone said, 'oh, well, you, you know, there is a cultural thing around African-Caribbeans not wanting people to know your business'. I think that was a belief that was shared in a team meeting and that's an assumption, isn't it? We don't know that to be true but I think we take that assumption and use it". (Dylan)

For some, these issues prompted deeper reflection on the systems they work within. Maya described becoming aware of her own blind spots, while others questioned the extent to which outreach is genuinely prioritised by services at a structural level:

"*I think that our memory service structure, sometimes the way we operate may not always necessarily be aligned to what our thinking is, but todays made me think about where my gaps were and where my blind spots are" (Maya)*

Several participants also voiced concern that while the NHS may publicise its inclusion work externally, but the internal commitment does not always match the public narrative. Kian expressed that there was a lack of deeper dialogue within services and had doubts about the capacity of services to fully address the challenges at hand:

"The NHS is very good at being able to publicise what it's doing when it's doing it across the trust, demographic and society, whenever it chooses to do something. But when you work within it and when you see what it looks like inside (. . .) if you just inspect what's actually

going on in the wider context of what should be achieved and what we should be doing, it's really, really minor (. . .) but also more importantly to me, what that suggests is it's not really important" (Kian)

This reflects participants' frustration that they felt some outreach efforts felt performative and were perceived as a drop in the ocean, given the scale of change they felt was needed. However, participants all reported the importance of 'reaching out', and building trust by creating dialogue that goes beyond diagnosis to explore what good dementia care looks like for the AFC community was seen as fundamental:

"a lot more outreach to just, kind of get that trust back, build it back more than anything" (Nina)

Maya reflected that without deeper structural commitment, progress may remain limited:

". . .There's much more to be done". Maya

While such initiatives were seen as encouraging, participants felt that these were initial gestures rather than substantive, systemic outreach, highlighting a pressing need for more comprehensive and culturally sensitive approaches to support earlier access and long-term engagement with dementia services.

Subtheme 3: Whose job is it?

Outreach efforts were described by participants as under-resourced and largely reliant on individual initiative, particularly from professionals from EM's. They reflected that these efforts are not formally embedded within job roles or institutional strategies. Therefore, participants questioned how seriously such engagement is taken at a systemic level. The emotional and professional toll of this informal labour was described as leading to feelings of burnout, opening into the last sub-theme, 'whose job is it':

"When it comes to equality diversity (...) which is the at the forefront of an NHS image and publicity, it's not factored into our work (...) its all on top of it (...) so all of this stuff , it's lovely, its important it's great but the only reason anything gets done is because people choose to do it, they have to volunteer" (Kian)

This emotional and professional duty led to partcipants' feelings of burnout, frustration, and resignation, particularly among staff who felt unsupported or isolated in these efforts:

"You're doing it, get stressed out and then just pack it in because, like, what's the point on top of the rest of it?" (Stevie)

Participants also raised questions about responsibility and clarity around their roles in this work:

"I guess there's a scope in there around us doing more, but who's tasked with doing what?" (Maya)

"It's a good initiative, but there's a lack of clarity within the group of outreach, who does what?" (Monica)

Monica also highlighted that people who become part of the initiatives to reach out to EM are usually from EM backgrounds:

"Another criticism is I think only a few white people are involved in the initiative, but everybody else is an ethnic minority. So, I'm like are we the only ones that care about this? then that's another question" (Monica)

Kian raised concerns about the limitations of asking staff to fix a system they did not create, and which they often lack the power to change.

"I think... we're not the people to ask that question to (. . .) The problem lies within here and within the culture or the chairs and the healthcare system, but the nuance behind why people don't access the services isn't within here, isn't within us." (Kian)

Others reflected on the discomfort white staff might feel stepping into outreach or EDI work and the difficulty this introduces. Stevie highlighted both her sense of the need for white professionals to be involved and the perceived risk of taking over:

"I'm fully aware that I have the benefit of the fact that I am a Caucasian person. I would worry that if I were to join the initiatives (...) can give the look of like OK, so now I'm a white person coming in. I'm talking over people (...) It is trying to find a balance because white people need educating. Unfortunately, the people who need educating are not going to go" (Stevie)

Finally, Kian raised an important reflection on the representativeness of research processes such as this research project, pointing to a self-selecting group of participants who may already be familiar with the issues, rather than including staff who perhaps are less familiar or even opposed to the ideas of EDI practices.

". . . Who are the sort of people who are going to attend this sort of focus group, given on what it is that you're research is about. It's only individuals who are going to be even more kind of open to the possibility that there are huge problems" (Kian)

These reflections appeared to show how participants felt outreach and equity work may remain mainly in the hands of minoritised staff, rather than being supported through formal structures or shared accountability with the services and teams. The lack of clarity over who holds responsibility represents a wider discussion about how inclusivity initiatives are framed in services, as being an 'add-on', and the role would not be factored into the already limited time staff have to offer. This left participants feeling that the work was not integral to their clinical work. This may produce an unsustainable dynamic in which those already most impacted by systemic inequality are left carrying the burden of fixing it.

In line with a social constructionist perspective, these narratives invite us to critically examine how societal discourses shape dementia care and how services reach out to the AFC community to support with earlier access to support. Without structural commitment, efforts toward equity risk remain symbolic. Moving forward, it may be helpful for outreach to be reframed not as an add-on but as a fundamental part of dementia care.

Chapter 5: Discussion

This chapter opens with a summary of the key findings situated within the context of existing literature. I also explore the implications of the study for clinical practice. The chapter also includes a critical appraisal of the study, followed by a discussion of the study's strengths and limitations. I then consider how the findings might be disseminated and make recommendations for practice and future research. The chapter ends with a conclusion of the study.

Summary of the findings

Participants highlighted the powerful role of stigma, which they perceived as a significant barrier to why AFC communities may not access dementia services. Participants suggested that religion could both support and delay help-seeking, and they described systemic racism and culturally inappropriate assessment practices as further limiting equitable care. They also reported incorporating adjustments into their work for EM communities and reflected on ongoing efforts to reach out to these groups but felt that such initiatives were often small-scale and inconsistently supported, with responsibility for them disproportionately falling to EM staff.

Faith, Fear, and Dementia: Cultural Forces Shaping Access to Care

Similar to the results of the SLR, participants all referred to stigma as a factor that may contribute to why AFC individuals do not turn to services for support when they begin experiencing memory difficulties. Participants acknowledged that both white and EM groups experience stigma associated with dementia (Lynch, 2020; Nguyen & Li, 2020). However, they felt that the context may differ for EM communities, where stigma is often shaped by cultural beliefs and fears of bringing shame to the family (Lopez et al., 2020). Participants suggested that this stigma can also contribute to mistrust of services, particularly when families feel their values and experiences are not understood or respected. In addition to this, participants noted that EM groups may face further barriers such as racism and a lack of culturally sensitive care (Philip et al., 2024; Wong et al., 2024).

The Health Stigma and Discrimination Framework (Stangl et al., 2019) is a useful theoretical framework that explains how stigma related to health conditions such as dementia is driven by social and structural factors. It also manifests through experiences like discrimination or internalised shame. Stigma, or perceived stigma, negatively affects health outcomes by limiting access to care and support (Bolster-Foucault et al., 2021). The model also highlights how stigma can overlap with other forms of social exclusion, like racism or gender bias (Stangl et al., 2019). The framework provides an understanding of how fear and shame can contribute to internalised stigma, leading individuals to feel they are no longer the person they once were and prompting them to hide their dementia from others (Fleming et al., 2020), which was spoken to by the participants. This may explain why AFC communities may underutilise dementia services, a pattern identified in previous research regarding EM (Berwald et al., 2016; Roche et al., 2021; Victor, 2024). However, despite this awareness, little appears to change (Truswell, 2020). Perhaps because, as the framework suggests, meaningful progress requires systemic change at macro levels, such as healthcare policy, service design, community outreach, and institutional practices rather than solely targeting individual behaviour or attitudes (Stangl et al., 2019). Therefore, broader systemic interventions are necessary to tackle the underlying causes of stigma and work toward its reducing it.

Participants also suggested that there is stigma associated with the NHS. This could be due to the historical and ongoing stereotyping of black communities. This aligns with research showing that Black African men are more likely to be sectioned in psychiatric units (Barnett et al., 2019; Freitas et al., 2022). Therefore, AFC individuals may avoid services due to concerns of being unfairly treated, misunderstood, misdiagnosed or detained. In addition, dementia services fall under mental health services, which can exacerbate shame in those who associate mental ill health with negative connotations, making them more reluctant to seek support.

Implementing changes to our services and the media that reduce the stigma surrounding dementia is important. This could include more positive and accurate portrayals in the media, ensuring that the language used is not oppressive (Gerritsen et al., 2018; Low & Purwaningrum, 2020). It is essential to raise awareness that memory difficulties do not always prevent a person from doing what they used to. This fits with the theoretical framework, the social model of disability (Oliver, 1983), where the focus shifts from the individual's 'impairment' to the societal structures and attitudes that can act as barriers and contribute towards stereotypes of dementia. These attitudes can reinforce both individual and public stigma (Siette et al., 2023), highlighting the importance of changing the narratives around dementia to encourage earlier help-seeking. Earlier diagnosis can improve quality of life, allow for better management of symptoms and potentially delay decline (Frederiksen et al., 2024; Ramussen & Langerman, 2019). Bosco et al. (2019) also suggest that improving our understanding of how dementia is socially constructed could enhance public health strategies for treatment. Equally, Farhana et al. (2023) highlighted that understanding the social construction of dementia can lead to better person-centred care, improve services, and the well-being of PLWD and their caregivers.

Similarly to the results of the SLR, participants suggested that religion can both hinder and help PLWD. Participants discussed how religion and partnerships with faith-based groups could help open conversations about dementia, reduce stigma, and encourage individuals to seek support for memory difficulties sooner, which is in line with previous research (Hussain et al., 2024). However, there was consensus among participants that this approach may not be as straightforward, as some religious centres may discourage using services if they believe illnesses can be 'prayed away', sending mixed messages to the community. Participants perceived this relationship as complex and two-way. They suggested that while religion can provide meaning, community, and coping strategies for PLWD, it may also delay help-seeking if religious explanations or stigma override medical understandings. As one participant mentioned, sometimes it is the NHS that needs to improve collaboration with religious communities. They suggested that this lack of partnership can deter effective collaboration and may not be the best way to build a trusting relationship. From a social constructionist perspective, this speaks to how institutional narratives and professional practices can shape, and also at times limit the space for collaboration, reinforcing barriers rather than dismantling them. Hossain and Khan (2020) similarly called for more meaningful engagement with religiously tailored interventions, which may better align with community values and belief systems. Epps et al. (2020) also highlight the importance of working with faith-based groups, as their study explored how African American churches support people affected by dementia by providing them with the right resources to access care. Epping et al. (2021) also found working with African American churches integral to African Americans' understanding of the condition and highlighted that working collaboratively acts as a guide for creating culturally relevant, faith-based interventions. While these studies focus on African American communities rather than the AFC community, the shared African ancestry and the prominence of Christianity in both groups (Hope et al., 2020) suggest that the insights may still be relevant as religion is not simply a personal belief system but a socially embedded structure that shapes how dementia is understood and responded to within communities. This suggests that NHS services may need to develop more culturally and spiritually sensitive approaches to engagement.

If NHS services overlook the influence of religious worldviews, they may risk reinforcing existing health inequalities through assumptions of cultural neutrality. It is important to rethink how services engage with religious communities, not as passive messengers of information but as active partners in meaning-making regarding dementia. This shift may help to move towards equitable access, moving beyond surface-level cultural competence and developing sustained and relational informed approaches to collaboration.

The System's Limits: Inequity in Dementia Support

Participants reported that they felt ongoing systemic racism, along with inequalities in service provision for people from EMs, perpetuates health disparities (Banaji et al., 2021; Chisolm et al., 2023; Needham et al., 2023; Yip et al., 2024). Participants also suggested that these factors may explain why AFC individuals often access dementia services later during the condition. They also illustrated how problematic narratives about AFC individuals can influence the care provided to this group. For example, the use of the term 'angry black women' is a well-known stereotype that is damaging to black women and shapes how Black women are perceived and treated within healthcare settings (Green & Talpade, 2023; Motro et al, 2022). Jones and Norwood (2017) describe how the term may be used by individuals in confrontational situations to shift focus away from themselves as the aggressor and place blame on the other. This mirrors situations in healthcare, where providers must follow protocols that may not always suit the individual.

When patients resist or challenge these protocols, the HCPs may respond more firmly (effectively becoming the aggressor) and use this term to deflect responsibility for their actions, instead blaming the individual for not adhering to the expectations of the healthcare worker or setting. These narratives are maintained through the language used in public and institutional discourse, as well as through everyday practices and policies, which can reflect underlying dynamics of power and bias. Another layer of racial barriers lies in the unconscious biases held by HCPs (Lee & Hastie, 2024; Marcelin et al., 2019; Singh, 2021). Meidert et al. (2023) report that unconscious biases are a significant contributor to health disparities. Similarly, FitzGerald and Hurst (2017) found that HCPs show the same levels of implicit bias as the general population and that these biases can influence HCPs in diagnosis, treatment decisions, and the level of care provided (Fotsch, 2021). It is important for healthcare staff to receive ongoing training on unconscious bias, as participants described that they felt existing training in this area was inadequate. Additionally, HCPs should be encouraged to discuss these issues with supervisors, as acknowledging and addressing unconscious biases may support HCPs in reflecting on their practice with individuals from underrepresented backgrounds, with the aim of reducing health disparities.

While many of the barriers described by participants were linked to ethnicity or cultural differences, it is important to recognise that all patients, regardless of ethnicity or culture, may encounter systemic barriers within the NHS, such as long waiting times, limited specialist services, and understaffed teams (Salisbury et al., 2023). These universal challenges could be compounded for AFC communities when intersecting with stigma, mistrust, or culturally inappropriate care, creating additional delays in help-seeking and access.

For example, navigating long waiting lists may be more daunting for individuals who are also concerned about being misunderstood or experiencing discrimination, increasing the likelihood of delayed engagement with services.

While participants focused on stigma, racism, and the need for more inclusive practices, considering broader service-level barriers shows that improving access requires tackling both the wider problems within the NHS and ethnic- specific challenges.

Primary care often serves as the first point of contact for people experiencing memory difficulties (Jerjes, 2024). GPs play a crucial role in assessing cognitive decline (Jones et al., 2024), and they also have regular contact with elderly individuals. However, dementia can be underdiagnosed due to the GP's dementia knowledge (Imre et al., 2019; Giezendanner et al., 2019), which can include a limited understanding of the dementia modifiable risk factors (Jones et al., 2024).

In addition to this, research suggests that GPs may be less likely to diagnose dementia in black communities (Brown et al., 2025), potentially due to differences in symptom presentation, communication challenges, or unconscious biases (Brown et al., 2021). When combined with systemic constraints, such as high GP caseloads and limited specialist appointments, this can further delay access to assessment and support. In this way, universal and ethnicity-specific barriers can compound each other, making access to and engagement with services more difficult.

Another potential approach to reducing health disparities is the need for adjustments in neurocognitive testing. While previous research has found that PLWD and their caregivers often identify services as culturally inappropriate (Gaviola et al., 2024; Gove et al., 2023; Pachana & Gallagher-Thompson, 2018), concerns typically centre on HCPs lack of understanding around religious practices, beliefs, and cultural norms (Carter et al., 2024; Herat-Gunaratne et al., 2020; Hossain & Khan, 2020).

In contrast, this study offers a different perspective of HCPs who reflected on cultural inappropriateness specifically within the context of neurocognitive assessments. Participants raised concerns that culturally insensitive testing practices may play a role in both over- and under-diagnosis (Wong et al., 2024).

Participants described using MDT discussions to account for cultural differences when interpreting scores and making adjustments. However, some participants believed that education level, rather than cultural differences alone, was a critical factor to consider when interpreting cognitive assessments.

For instance, individuals with fewer years of formal education or those from socioeconomically deprived backgrounds may be more likely to receive a diagnosis of dementia (Gamble et al., 2022). Therefore, it is important for HCPs to think about the intersectionality of a person’s background that may affect assessment outcomes (Fujii, 2022; Wong et al., 2024).

Participants across groups expressed confidence in their ability to provide culturally competent care during assessments.

The cultural competence model developed by Papadopoulos, Tilki, and Taylor (1998) conceptualises competence as a developmental process involving four stages: cultural awareness, knowledge, sensitivity, and the ability to apply these in practice. Viewed through this lens, participants' contributions suggested engagement with elements of each stage.

However, this model presents the complex and ongoing process of developing cultural competence as a linear progression, one that 'achieves' cultural competency. It may be more appropriate to view these elements as aspects that require continuous reflection and integration, rather than sequential steps. Other critiques of the model are that if the steps were applied rigidly, they could unintentionally present cultural traits as fixed and therefore may lead to stereotyping. It can also create the impression that a person can 'master' cultural understanding, potentially limiting further self-reflection (Dadzie, 2025; Konidaris & Petrakis, 2025).

Cultural humility, conceptualised as an approach within healthcare (Tervalon & Murray-Garcia, 1998), moves beyond obtaining knowledge about other cultures and instead emphasises ongoing self-reflection. It promotes a mindset that is curious, respectful, and open to learning from everyone, whilst acknowledging that we can never fully 'know' every culture (Lekas et al., 2020; Foronda et al., 2016).

Cultural humility is posited as something to be practised rather than 'achieved' (Foronda et al., 2016), which involves examining our own beliefs, biases, and assumptions about different cultures. However, although cultural humility offers a reflective, lifelong approach, some researchers argue that its lack of clear structure makes it difficult to measure or consistently apply in practice (Bauer et al., 2025).

Combining the knowledge-based approach of cultural competence with the reflective, relational stance of cultural humility offers a balanced approach to engaging inclusively across cultures (Stubbe, 2020).

In the early stages of this research, the term ‘cultural competence ' was used because that language remains dominant in professional training, academic literature, and policy. For example, the British Psychological Society (2025) hosted a webinar called “Becoming a More Culturally Competent Practitioner 2” in October 2025 as part of its DECP EDI programme.

Additionally, the NICE guidelines (2022) define cultural competence, but they do not define cultural humility (NICE, 2022). As the project developed, I became more aware of the limitations of a competence-based model, especially its implication that cultural understanding can be ‘completed’. This led me to engage more critically with cultural humility, which is increasingly used because it emphasises ongoing learning, reflexivity, and awareness of power dynamics, which is what the participants speak to.

While participants generally felt competent in making adaptations and discussing cultural differences within the team, many acknowledged limits to their capacity. They described doing what they could ‘within their limits’ but stressed the need for broader systemic change. This echoes Nguyen et al. (2024), who argue for clear guidelines for the adaptation and translation of neuropsychological tests to ensure cultural validity and diagnostic accuracy.

While individual HCPs may be committed to culturally responsive care, having culturally appropriate services requires structural support, clear frameworks, ongoing training, and organisational cultures that prioritise learning and critical reflection, to ensure efforts are sustainable (Clegg, 2016).

Reaching in and Reaching out: Navigating engagement from both sides

Participants provided examples of how they felt AFC individuals were beginning to access services, such as attending intervention groups like Cognitive Stimulation Therapy, or for assessment. Though participants suggested that they may end up at their service through other pathways and may not always engage with the service for long, these were seen as positive movements. According to the participants, AFC communities may disengage for reasons such as stigma or feeling the service is culturally inappropriate.

Participants also observed that younger AFC individuals would attend the service, but when informed of their memory difficulties, participants felt that they were often in denial and subsequently disengaged from the service. Participants expressed their view that AFC communities have experienced discrimination within services and that they felt racism remains structurally embedded within institutions, including the NHS.

Since the death of George Floyd in 2020, there has been a movement in awareness around issues of race and power (Fisher & Rouse, 2022; Primbs et al., 2024). However, some participants felt that the movement around EDI was "going backwards". Others described that EDI would get spoken about 'too much'.

The participants reflected on how they felt that the focus on EDI is interpreted and experienced in different ways by people, some of whom are resistant and feel defensive towards it within the wider society. This suggests how ideas about race and fairness are constantly being shaped and reshaped through how we talk about them, within services and the wider society.

Equity in care requires a shared commitment across all levels and roles. Yet participants perceived a lack of allyship from white colleagues. This raises questions about the role of white fragility (Diangelo, 2012; Liebow & Glazer, 2019), where discomfort or fear of 'getting it wrong' when discussing race may lead to avoidance or silence (Strauss et al., 2023). This may have been reflected in the focus group (please see Appendix A), prompting reflection on the phenomenon of 'white silence' (Durrheim, 2024).

Within clinical settings, this silence may lead HCPs to avoid culturally sensitive conversations with patients from EM backgrounds, particularly if they fear saying the wrong thing or causing offence. As a result, important aspects of a person's identity may be overlooked, limiting opportunities to discuss parts of people's identities that may be important to them and the care they receive.

It is essential for everyone working in the NHS to be committed to achieving health equity for all people. The responsibility for outreach should not fall solely on EM staff, which is common (Chislom et al., 2023; Trejo, 2020) and can lead to burnout (Campbell, 2021).

In the SLR findings, Baghirathan et al. (2020) reported that participants described BAME-led groups as a 'lifeline'. However, these groups were unfunded and at risk of closure, reflecting how EDI initiatives supporting EM's in dementia care are not prioritised or recognised as vital preventative work. Similarly, participants in the current study felt that EDI initiatives were undervalued, often viewed as an 'add-on' rather than integrated into their work schedules, adding to their already busy workloads. This is in line with other research, which uses the term 'minority tax' to speak to how people from marginalised backgrounds get extra work placed on them in situations such as healthcare services or academia (Betancourt et al., 2024; Faucett et al., 2022).

This concept emerges from the way institutions often place unspoken expectations on EM to lead change in EDI initiatives. It highlights how power operates within systems, and how certain roles or responsibilities are valued or taken for granted in ways that can reinforce inequality and often in ways that go unquestioned.

In addition, when individuals are overstretched and unable to work in alignment with their values, such as being unable to fully engage in EDI initiatives, they may experience moral injury. Moral injury refers to the psychological distress that can occur when individuals are involved in or fail to prevent actions that violate a person's moral or ethical beliefs (Williamson et al., 2021). These symptoms have been strongly associated with greater psychological distress, lower levels of self-reported wellbeing and increased clinician burnout (Rabin et al., 2023).

Participants also questioned whether they were the ones who needed to be discussing the issues raised in the focus groups, as they felt the people who held more power to change things needed to be part of these conversations. These perspectives reflect broader societal tensions about how inclusion is shaped by both clinical practices and individual behaviours, and that tackling systemic inequities requires collective responsibility across the NHS.

Lastly, few participants were aware of research highlighting that AFC communities are at increased risk for Alzheimer's disease and early onset and vascular dementia (Adelman et al., 2011; Truswell, 2018; Tsamakis et al., 2021). These insights suggest there may be a need for greater awareness around the topic, as it may contribute to missed opportunities for outreach. One participant suggested that specialist services such as the diabetes service, or routine check-up services such as the NHS health check, which are offered to people 40-74 years old every 5 years (Tanner et al., 2022), could act as initial points of contact to communicate dementia risks. This integrated approach may facilitate earlier engagement with memory services, which is known to improve outcomes (Gomes et al., 2019; Smith & Surr, 2024).

Implications of the study

Implications for clinical practice

This research is relevant to clinical psychology, as clinical psychologists are trained to work with people in context, including how culture, history, and identity shape experiences of distress and illness. A psychological perspective helps us understand how people make sense of memory problems and what factors might delay help-seeking. The findings also encourage reflection on how services and HCPs might unknowingly create barriers.

Clinical psychologists often hold roles that include facilitating supervision and reflective practice for teams, which provides a space to think about more inclusive ways of working and challenging biases the team may hold about EM. Also, Clinical Psychologists do not only work with individuals and staff but often support families, helping them reframe how dementia is understood from stigmatised views to more hopeful and ability-focused narratives. Overall, this study supports the profession's aim to reduce health inequalities and promote access to care that is culturally responsive, respectful, and adapted to the needs of EM.

Importance for NHS, Commissioners and Stakeholders

This research provides an understanding for commissioners and stakeholders regarding the potential challenges that AFC communities may face, from the perspective of HCPs when trying to access dementia services. This can inform the development of care that is better tailored, culturally appropriate, and easier to access. When PLWD access services later and at crisis points, it results in higher costs for the NHS. Therefore, investing in preventative work is important, as it can improve outcomes for PLWD and their families while simultaneously reducing NHS costs.

In addition, the findings suggest that EDI work may be disproportionately carried out by EM staff, which can be unsustainable. It is important that EDI initiatives, such as outreach, are prioritised by management and supported at all levels of the organisation

Lastly, service managers, commissioners, and stakeholders have a duty, under the NHS Public Sector Equality Duty (2010), to reduce health inequalities, ensure services are culturally appropriate, and address the higher risk of dementia among AFC communities. This includes increasing awareness and psychoeducation around dementia, as well as providing staff with appropriate training. Fulfilling this legal and ethical responsibility requires adequate investment and funding.

Importance for AFC communities

Based on participants' reflections, this research highlights key barriers that may prevent AFC individuals from accessing dementia services, including cultural inappropriateness, stigma, racial discrimination, and religious factors. Addressing these issues could improve the experiences of AFC individuals and their families, who might otherwise feel excluded from the healthcare system, and encourage earlier engagement with services

Beyond its practical implications, the research itself highlights that the experiences and well-being of AFC communities are worthy of inquiry. It models a commitment to asking critical questions about equity and cultural relevance in dementia care. By undertaking and disseminating this research, we communicate to both service providers and the AFC community that their histories, identities, and needs matter and deserve attention in health service design and delivery.

Quality appraisal

I was drawn to use Tracy's (2010) 'big tent' criteria previously applied in the SLR to assess the quality of my research using the same standards. Tracy's framework provides a comprehensive approach to evaluating qualitative research and also aligns with the social constructionist epistemology. Please see Table 8 for the quality appraisal.

Table 8

Critical Appraisal of the Study

Critical Appraisal of the study using Tracy's "Big Tent" Criteria (Tracey, 2010)	
Criteria	**Evaluation**
Worthy Topic- Is the study interesting, relevant, timely and evocative	• There are no studies specifically looking at NHS staff perspectives on why the AFC community may be presenting later to memory services • It is relevant as research suggests the AFC community may be at higher risk of developing certain dementias. It is significant for Clinical Psychologists and memory service teams who typically carry out neuro assessments to have this knowledge to be able to adapt and adjust tests and services to be culturally appropriate. • It also sheds light that services may not put in effort to reach out to communities if they assume they are not in the area or that they do not want help, which can perpetuate inequalities. • It highlights to NHS services, stakeholders, and commissioners the importance of culturally appropriate services and the importance of incorporating EDI initiatives within them, which can often be under-resourced and underfunded.

Rich Rigor- a detailed description of their methods, methodology, and whether the study has face validity.	• I felt I have written a detailed methodology, which includes an appropriate chosen analysis (RTA) • Themes were discussed with both the supervisors, and they provided feedback on analysis and self-reflections • I also provided a comprehensive literature review, which gave a clear description of the theoretical lens which was considered throughout the thesis • To improve rigour, perhaps an additional focus group would have been useful in an area that had a low population of AFC people to understand the nuances of different services putting importance on 'reaching out.
Sincerity- Author's transparency about the research, their positionality, honesty about the author's goals and sharing their self-reflexive processes	• I provided my positionality from the beginning, including my own biases which allows the reader to understand my interpretation within this context. These were presented in my self-reflections; however, I felt I could have been more explicit about how these biases influenced me and, therefore, how I had interpreted and influenced the analysis. • I used first person throughout so that my voice and positionality was centred throughout.
Credibility- How trustworthy the research findings are	• Credibility was enhanced through thick description using rich participant quotes

	• There was triangulation across three distinct focus groups, and the inclusion of diverse staff perspectives; however, perhaps adding the voices of AFC, people and commissioners could have improved credibility. • While formal member checking was not conducted due to time limitations, reflexivity and transparency were maintained throughout analysis to ensure trustworthy interpretation.
Resonance- The author's ability to promote empathy or a feeling of identification, even if the readers have no experience with the topic	• I felt that I have tried to make this thesis interesting and convey to the audience its importance when thinking about health inequalities.
Significant contribution- To understand the current knowledge, practice and politics relevant to the topic.	• The thesis was significant as it is one of a few studies that look at the staff perspectives when thinking about the AFC community. • It spoke to how this can improve clinical practice and how Clinical Psychologists can support with some of the recommendations • Further research looking at whether outreach initiatives support earlier access in AFC would be essential for services and funding.
Ethical	• Ethical considerations (see chapter 3) were thoroughly thought about with the supervisors and will continue to be thought about during dissemination.

	• Consideration was given to how the quotes and demographics of the participants maintain anonymity. • The services were also kept confidential.
Meaningful Coherence- Achieve what their aim sets out, utilise appropriate methods that align with best achieving the aims of the study and connect the findings with theories and paradigms	• The Health Stigma and Discrimination Framework, and the cultural competency model applied to attempt to understand the complexity of the topic • This study has effectively connected literature, research questions, methodology, and findings to ensure meaningful coherence. The research has addressed its aims, and its findings and recommendations are applicable to current practice.

Strengths

This research strengthens the existing evidence base, which suggests that AFC individuals may access memory services later due to factors such as services being culturally inappropriate, stigma, and religious beliefs. Although previous research has explored the perspectives of PLWD from EM and AFC individuals, and their families, there has been limited focus on the views of HCPs. This study makes a significant contribution by looking at HCPs perspectives and by highlighting shared understandings between AFC communities and NHS staff, whether staff were aware of barriers to accessing services and how they perceived their role in addressing or perpetuating inequalities. The study's findings shift the focus toward what services can do to address these challenges in practice and who needs to take responsibility.

My methodology allowed for in-depth conversations, allowing for detailed and rich insights (Braun & Clarke, 2006). This gave me a clear picture of how inclusive and accessible dementia services really are in practice. It also highlighted significant gaps in knowledge and support within services as participants did not feel equipped to address the issues, as they felt it was outside their control, something important for service managers, stakeholders, and commissioners to consider. In addition, using RTA enhanced the transparency of the study by providing readers with a clear understanding of the research process. Embedding reflexivity throughout further strengthened the study's credibility.

Another strength of this study is that the interview schedule was developed collaboratively with experts by experience, clinical supervisors, and piloted with Trainee Clinical Psychologists. During the focus groups, some questions closely matched the study's research aims. For example, the question, "What is something you are proud of that your service does to be culturally sensitive for EM's?" directly relates to the aim of exploring how

NHS memory services accommodate and reach out to these communities. The purpose of these questions was not to lead participants' answers, but to reflect the topics they were already discussing.

This research provides commissioners and stakeholders with a clearer understanding of the challenges faced by staff on the ground and reinforces their responsibility to ensure that EDI initiatives are prioritised and adequately resourced within services. It also presents practical recommendations for improving service provision to better support AFC communities and enhance the inclusivity of dementia care moving forward.

Limitations

The research focused on three memory assessment services in boroughs chosen because they have different proportions of AFC populations. This was to capture a range of perspectives, but it means the findings may not apply to other boroughs or services across the country. Also, since participants volunteered themselves, there is a risk of bias that those who took part might be more interested or involved in the topic than others.

Within the focus groups, there was a mix of staff roles, and hierarchy may have influenced participation, with some junior staff potentially feeling less able to contribute openly. Social desirability bias is also something to consider, as participants may have responded in ways they perceived as favourable. Additionally, the ethnic backgrounds of participants may have influenced group dynamics, as most participants were from EM backgrounds and may have had more to say.

A further limitation is that the findings reflect only the perceptions of participants regarding why AFC communities may not engage with dementia services. While these perceptions are valuable as they work in NHS memory services, they do not fully capture the lived experiences of AFC individuals and their families.

Participant interpretations could be influenced by unconscious biases, cultural assumptions, or stereotypes, even unintentionally. As a result, some of the barriers described, such as stigma, religion, or systemic racism, may represent participants' assumptions rather than the community's actual experiences, which could further reinforce barriers to accessing services. Future research should include the perspectives of AFC individuals and their caregivers, as well as clinician perspectives, to gain a more comprehensive understanding of the factors influencing service engagement.

Overall, these limitations suggest caution when interpreting the findings. The study provides an in-depth exploration of staff perspectives within specific services but does not claim to represent all memory services across the UK.

Dissemination of the study

This piece of work has been submitted to the 19th UK Dementia Conference in the hope of presenting the findings in the format of a 30-minute presentation. As the audience will primarily consist of professionals and service providers within the field of dementia care, research, and policy, this would provide an opportunity to discuss the study with those engaged in the field.

I intend to submit this research for publication in a relevant academic journal. In addition, I will share the findings and recommendations with all the participating services, and provide copies of the research to support ongoing improvement.

Recommendations

Training for New Staff on Neurocognitive Testing Inequities

New staff to be trained on the inequities that can arise when using neurocognitive tests, especially with EM's, people with different educational backgrounds, and neurodiverse individuals. MDT discussions must consider these factors to ensure fairer and more accurate assessments.

Adjusting Neurocognitive Tests for Diversity

Where possible, it would be helpful to adapt and adjust neurocognitive tests to ensure they provide more meaningful results rather than relying on ‘one-size-fits-all’ measures.

Cultural Awareness in Assessments and Support

When assessing and supporting people with memory difficulties, it is important to consider cultural factors beyond simply asking about them. Every person is different, even within the same cultural group, so open discussions with PLWD and their families are important to understand their specific needs. However, cultural awareness also requires ongoing learning about the history and experiences of AFC communities, engaging with community and religious leaders. Importantly, services should strive to bring care to the community, rather than expecting individuals to come to a clinic. Cultivating cultural humility, curiosity, and active engagement is vital to providing truly inclusive and respectful dementia care.

Do not Assume Communities Are Not Present

Avoid assuming specific communities are not in your area, as this can lead to services not making the effort to reach out. For example, this can be done by looking at the Consensus 2021 (Office for National Statistics, 2022) to understand the demographics of an area. Of course, these are not accurate, as some people do not fill this out; however, it may give a picture of who is in the area compared to whom you are seeing in your services.

Collaboration with Community Leaders

Work more closely with local religious and community leaders for outreach. Building these relationships can potentially help people decide whether they access support earlier if leaders are open to discussing dementia and how accessing support can be beneficial. Especially since EM(EM) communities may look up to these figures as trusted role models,

Incorporating EDI into Staff Timetables

Managers and team leaders to allocate dedicated time for staff to engage with EDI initiatives. This may reduce the risk of staff burnout from taking on extra work and moral injury.

Research

Future research could benefit from examining quantitative data on AFC individuals' use of memory services, including looking at referral numbers, the proportion of service users from AFC backgrounds, dropout rates, or the stage of dementia at which individuals accessed services, as these could provide valuable insights to improve care and service delivery. A mixed methods approach could incorporate these data, providing a more comprehensive understanding of service use patterns alongside perspectives and experiences of the AFC community.

Final Reflections

Although this research journey has had its challenges, it has been a privilege to hear staff perspectives, from which I have learned a great deal. Before training, I wanted a career as a Clinical Psychologist working in memory services, and as I near the end of this process, my passion for dementia care has only grown stronger.

More importantly, this work has deepened my understanding of the systemic inequalities faced by AFC communities and why dementia services may be accessed only as a last resort by this group and EM's more broadly. As someone personally committed to EDI, I recognise my role as a psychologist not only in advocating for culturally sensitive care but also in challenging the structures that perpetuate these inequalities.

This research has highlighted that addressing health inequalities is an essential part of ethical clinical practice and service delivery, not an optional extra. Moving forward, I am determined to embed these values into my clinical work, ensuring that ongoing research and cultural awareness continue to shape and improve dementia care within the NHS.

Conclusion

This thesis included a systematic review of the existing literature on the experiences of EM's accessing dementia services in the UK. The results revealed that caregivers of PLWD may not utilise services unless it is a last resort, due to services not being culturally appropriate, or that caregivers may hold strong beliefs to look after their family members due to cultural or religious duties.

The current research explored the perspectives of NHS staff on why AFC individuals may present later to memory services and examined how current services are attempting to engage with this community. The study was grounded in a social constructionist framework and employed reflective thematic analysis to interpret staff narratives across three focus groups. It contributes to existing literature by shifting the focus from caregivers who are often the central subjects in previous research to professionals, providing a different angle on barriers to timely access for the AFC community.

After analysing data from three focus groups, the findings echoed themes identified in previous research, including perceptions of dementia services as culturally inappropriate and the importance of collaborative work with community and religious leaders to reduce stigma and promote earlier access to care.

Staff participants also highlighted systemic limitations within the NHS. They shared that they felt that making true, meaningful change was something beyond their control and expressed uncertainty about whose responsibility it was to 'reach out' to communities and drive the EDI initiatives. Notably, this ambiguity often resulted in outreach efforts being taken up as extra work by staff from EM backgrounds, leading to concerns about unequal workload distribution and emotional burden.

Participants described that 'reaching out initiatives', including working with faith-based groups, yet acknowledged that these efforts were typically small in scale. The findings indicate that, although individual staff demonstrated a strong commitment to driving change, meaningful and lasting progress remains unlikely without structural support and clearly defined roles.

The clinical implications of this research emphasise the need to make cultural awareness and responsiveness a normal part of everyday practice. Some key suggestions include providing training for staff on inequalities in dementia care, making sure culture and religion are considered during team assessments, and recognising community outreach as part of people's actual job roles. If these structural changes are made, services could become more approachable for AFC communities, helping people to seek support earlier.

Using a social constructionist lens allowed for a deeper understanding of how staff narratives were shaped by their personal experiences and broader cultural, institutional, and historical contexts. This approach also brought into focus how power dynamics within the healthcare system and wider societal discourses around race and care influence both assumptions about the AFC community and the unequal distribution of responsibility for equity work.

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Appendices

Appendix A: Reflexive diary

Decision making- Recruitment

During supervision discussions, we decided that the focus group locations should reflect areas with the highest populations of AFC people, alongside one focus group in a more diverse but not specifically AFC-populated area. This decision was partly influenced by a study by Blix and Hamran (2017), which questioned whether their finding would have differed had they engaged with areas containing different ***populations*** of Sámi people. This raised an interesting point for me, but on reflection, I now recognise a key gap in my approach.

I consciously chose not to include a less diverse area in the study, based on an assumption that such communities would have little to contribute, that if there were few or no AFC individuals present, staff might simply say they do not engage with or know much about these communities. However, I've come to realise that this assumption mirrored those made by some participants, who also believed there was no need to reach out if the community "was not there." In a similar way, I didn't reach out to less diverse areas to understand their perspectives.

As an EMresearcher, I also assumed that staff in non-diverse areas would be predominantly white and perhaps feel the focus group topic wasn't 'relevant' to them, and perhaps some internalised stigma contributed here. These assumptions, grounded in my own positionality and experiences, influenced the decision to exclude certain locations, potentially limiting the breadth of perspectives captured in the study.

Interviews

"Could it be a bias in research as well, researchers focusing a lot on people of colour?" (Monica)

Monica's comment made me feel somewhat awkward in the moment. I was sitting with participants from Black ethnicities, and I, being a non-Black researcher, was conducting a study focused on the AFC community. Her question stayed with me. If this were true, was I also contributing to a problematic trend in research, where non-Black researchers study communities they are not a part of? Was I perpetuating unhelpful narratives, even though unintentional? I also wondered how the other participants felt in that moment. Did they notice my discomfort? Did they question my presence in the research space? Was I being perceived as "one of those researchers" Monica referred to? Could it also have been that participants themselves felt more anxious regarding this knowledge for themselves or their families if they were from the same background? However, the participation sheet clearly states what the rationale for the study is (AFC at higher risk wanting to know staff perspectives). But, they may have attended the focus group out of curiosity, and as we do not ask why people decided to take part, we cannot make assumptions about their participation.

My positionality as a non-Black researcher, though from an EM background myself, clearly shaped my emotional response in that moment. It also made me reflect more on how I engaged with the participants and interpreted the data.
Earlier on, before recruitment, I had spoken with Dr. Moïse Roche about his paper (Roche et al., 2021), where they examined the ethnic backgrounds of researchers studying Black, African, and Caribbean communities. They found that most of this research is conducted by individuals who are not members of these communities. The paper stressed the importance of not generalising findings solely to AFC groups, as similar issues may be experienced across various EM groups.
This really resonated with me. It aligned with findings from both my systematic literature review and my own study, where many of the themes were echoed across ethnic backgrounds. I asked Dr. Roche what he thought about me conducting this research. He reassured me because I am from an EM background, and my rationale was grounded in evidence (i.e., that AFC communities are at higher risk), he felt the research had value. He also reminded me, however, that representation matters not just in terms of participants, but in who tells the story. This conversation stayed with me as I continued analysing the data.

Decision making- Analysis

"How do you get them to come to you?"(Sofie)

I acknowledge that my lens as a researcher is not neutral. Reflecting on Sofie's comment, I now realise that I may have interpreted it incorrectly. At the time, I perceived her question as placing the responsibility on the AFC community to 'reach in', rather than considering it as a genuine inquiry about how services could reach out more effectively. On further reflection, it's possible that her intention was the latter.

However, given Sofie's visible identity as someone not from a racial minority, and my own positionality as someone who is from a racial minority background, I may have been particularly sensitive, perhaps even hypervigilant, in interpreting her words. This heightened sensitivity likely shaped how I initially coded and understood the data.

I also noticed that in my early stages of coding, I was more drawn to what I perceived as 'negative' comments or examples, perhaps driven by a subconscious desire to highlight where institutions were falling short in their outreach to EM. I perhaps felt a strong pull to show that 'we are not doing enough'. But when I later revisited the data with more openness, I realised I had initially overlooked quotes that reflected more positive or proactive efforts, examples where participants had gone above and beyond to engage with diverse communities.

This moment of self-awareness highlighted to me how my positionality directly influenced what I noticed in the data, what I prioritised, and ultimately, what I chose to include or exclude. It reminded me that interpretation is not neutral; it is filtered through our experiences, identities, and assumptions. Realising this made me more aware of how important it is to be transparent about how I make decisions during analysis, and how much influence I have in shaping how participants' voices are shared.

Reflection of group dynamics

"Who are the sort of people who are going to attend this sort of focus group, given on what it is that you're research is about. It's only individuals who are going to be even more kind of open to the possibility that there are huge problems" (Kian)

I found Kian's point interesting. It made me reflect on the dynamics of participation across the focus groups. In two of the groups, there was an individual who did not contribute at all, and I was curious about what might have been influencing both their silence.

In the first group, the quiet participant was not a member of the clinical team. Being in a room with psychologists may have made them feel anxious or uncertain about the value of their contributions. Interestingly, a fellow group member made an effort to involve them in the conversation, but this had little impact. I wondered after if I also should have made more effort to bring them in; however, it being my first focus group, I was hesitant as I did not want to make someone feel I had put them on the spot.

In the second group, the silent participant was a clinician with many years of experience. I attempted to bring them into the discussion towards the end as I had reflected on the first group and spoke with my peers about gentle ways to bring people into the discussion without shining a spotlight on them, but again, with little effect. I began to wonder whether their silence could be linked to their race as they were white, and I considered whether they may have felt unsure or at risk of saying something 'wrong' in a room where others, mostly from EM backgrounds, spoke passionately and confidently about the topic. Was their silence a form of discomfort, or perhaps a reflection of uncertainty about whether or how they should contribute?

This reflection also made me think more deeply about one of the themes in my analysis: *'Whose job is it?'* In both focus groups, where one participant remained silent, I noticed a pattern. In one group, the most vocal contributors were psychologists, and in the other, those who spoke the most were individuals from EM (apart from one white participant who appeared highly informed and positioned themselves as an ally). This made me question whether conversations about EDI are still being left to EM professionals and psychologists whose roles are more explicitly tied to promoting equity in healthcare. Notably, in the final focus group where everyone participated equally, all participants were from an EM background and all clinical members of staff. This made me reflect on the nuances of power in the focus group dynamics and how participation itself can be shaped by positionality, perceived safety, and the emotional labour often carried by EM in conversations around race and inequality. It's something I'll need to reflect on further as I continue to interpret the group dynamics and meaning making in the data.

Appendix B: Excel sheet for Systematic Literature Review Concepts

DATE	DATABASE NAME	SEARCH TERMS & FORMAT
824 9.24 24.1024 4.25	**Pubmed**	(Title/abstract) Dementia ORAlzheimer's OR "Alzheimer's Disease" AND {Title/abstract) "EM's" OR Miniorit* OREthnic* OR"Global majorit"' ORCultural* OR "Cultural* difference•" OR "Ethnic g,oups" OR BAME AND {Title/abstract) Experienc• ORBelief* ORview* OR attitude* ORPerspect* OR difference• AND (Title/abstract) "Accessing support" ORAccess* OR Support• OR Help* OR NHS
8.24 9.24 24.10.24 4.25	**SCOPUS**	(TITLE) dementia OR alzheimer's OR"Alzheimer's Disease") ANDMLE-ABS-KEY(african AND caribbean ORafro-caribbean OR afrIcan-<:aribbean ORblack AND caribbean) OR TITLE-ABS-KEY(experienc• OR belief• ORview· OR attitude· OR perspect• OR difference• OR cultural• OR ·cultural• difference.. OR BAME) ANDmLE-ABS-KEY("Accessingsupport" OR access• OR suppon' ORhelp* OR accessing AND healthcare OR HS))
8.24 9.24 24.10.24 *425*	**Google scholar**	dementia, ORethnic, ORMinorities. ORminority, ORcultural. ORdifferences, OR experiences. OR attitudes, OR perspectives, OR views, OR beliefs, OR NHS, OR Accessing, OR support, OR help, OR accessibility
8.24 9.24 24.10.24 4.25	**cinAHL**	TII demenna arcoenitiv,e□irment ormema,yloss ardemen patientarpeapleYoith dementia)ORTI [almemer's **disease or atzllecmers or atzheuner or atzhecmer's or dementia or relateddementia] OR AB (dementia or cogrrtt.•e** impairment or memory lass or dementia patient or people with demen JORAS I alzheimer's cisease or atzheimers or **alzheimer oratzheimer's or dementia or related dementia □ ANOTI (EM's or racial minorities or e-tlwc groups** ơ minority groups or borne or bme) OR TI (cu al differences or aoss cultural or cultural dl\'emly I ORTII global ma,orrty or **cultural competence or cultural awareness orcu tural competency or cultural sensrtNity >OR AB (ethnic manonbes or racial minoritiesorethnjcgroupsorminoritygroupsorbame orb.me) OR AB (cut al ditterences oraoss cultural or cultural** dive"'ty J ORAS I global majanty arruttural competence or cultural awareness or cul al competency or cultural sensruvity **)ANDTI (differences or comparison or contrast orsimilarmesordifferfrom)ORTI (belre sorperceptionsorviewsor attrtIIdes or perspectives orpercep on) OR *AB*(erences orcompanson orcontrast or 5imllarities ordiffer from} ORAS** (belie s or perceptions or view.; or **attrtudes or perspectNes or perceplIan J AND**TI (**access** ta care or**access** ta **healthcare** or **access to services or5trateg e-s or· tervention)ORTI(5upport or help or care or guidance or inteiventian) OR TI (nhsor 'na DMI health service·oruk or 'united kingdom') ORABI acces<s to care or access to healthcare Of acces<s to sernces or** strategies or intervenbOn) OR AB(support or help or care or gwdance or111tervent1an J ORAS(nhs or 'na-.al health seNice· or uk or 'urvted lorgdam·

Appendix B.1: Library search

- **SLR Question :**
- What are the experiences of African-Caribbean People accessing support for dementia?
- What are the experiences of EM’s accessing support for dementia?

Concept 1	**Concept 2**	**Concept 3**	**Concept 4**
Dementia	**Ethnicities**	**Experiences**	**Accessing support**

Concept 1	**Concept 2**	**Concept 3**	**Concept 4**
Dementia	“EM’s”	Experienc*	“Accessing support”
OR Alzheimer’s	OR Miniorit*	OR Belief*	Access*
OR Alzheimer's Disease	OR BAME	OR view*	Support*
	Ethnic*	OR attitude*	Help*
	“Global majorit*”	OR Perspect*	NHS
	“Cultural* difference*”	OR difference*	UK
	Cultural*		
	“Ethnic groups”		

⇦ AND ⇨ ⇦ AND ⇨

Dementia OR Alzheimer's OR “Alzheimer’s Disease”

African Caribbean people OR African Caribbean OR afro-Caribbean OR afro-caribbean people OR Black Caribbean OR black Caribbean people

Experienc* OR Belief* OR view* OR attitude* OR Perspect* OR difference* OR Cultural* OR “Cultural* difference*”

“Accessing support” OR Access* OR Support* OR Help*

NEW

Dementia OR Alzheimer's OR “Alzheimer’s Disease”

“Ethnic minority’s” OR Miniorit*
OR Ethnic* OR “Global majorit*” OR Cultural*

OR “Cultural* difference*” OR “Ethnic groups” OR BAME

Experienc* OR Belief* OR view* OR attitude* OR Perspect* OR difference*

“Accessing support” OR Access* OR Support* OR Help* OR NHS

OR “UK”

Appendix C- Prisma 2020 Checklist

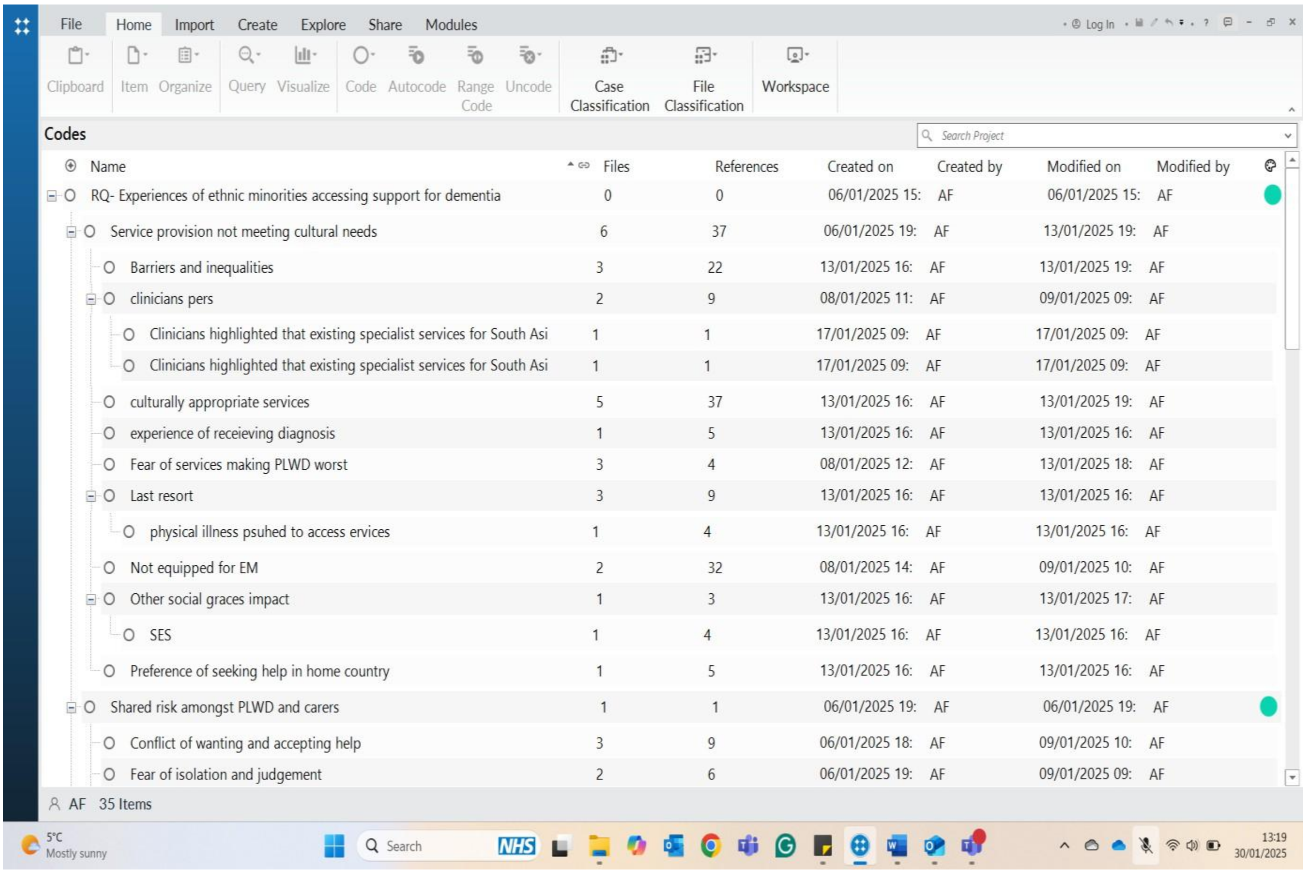
Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 26
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	The SLR is part of the overall thesis; no separate abstract was required
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 26-27
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 27
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 29
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 28+30
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 29
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 30+33
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 30
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 34-41
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 34-41
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	43-50
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 29
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 50
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 51
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 50

Section and Topic	Item #	Checklist item	Location where item is reported
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Page 35-42
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/a
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/a
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 32
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 33
Study characteristics	17	Cite each included study and present its characteristics.	34-41
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	44-50
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	35-42
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	44-50
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	50-63
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	n/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Page 65
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	n/a
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	51-63
	23b	Discuss any limitations of the evidence included in the review.	65
	23c	Discuss any limitations of the review processes used.	68
	23d	Discuss implications of the results for practice, policy, and future research.	67-69
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 28
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 28
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	n/a
Competing interests	26	Declare any competing interests of review authors.	n/a
Availability of	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included	Appendix

Section and Topic	Item #	Checklist item	Location where item is reported
data, code and other materials		studies; data used for all analyses; analytic code; any other materials used in the review.	B+C

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

Appendix D: Nvivo codes and themes



Name	Files	References	Created on	Created by	Modified on	Modified by	
RQ- Experiences of ethnic minorities accessing support for dementia	0	0	06/01/2025 15:	AF	06/01/2025 15:	AF	●
Service provision not meeting cultural needs	6	37	06/01/2025 19:	AF	13/01/2025 19:	AF	
Barriers and inequalities	3	22	13/01/2025 16:	AF	13/01/2025 19:	AF	
clinicians pers	2	9	08/01/2025 11:	AF	09/01/2025 09:	AF	
Clinicians highlighted that existing specialist services for South Asi	1	1	17/01/2025 09:	AF	17/01/2025 09:	AF	
Clinicians highlighted that existing specialist services for South Asi	1	1	17/01/2025 09:	AF	17/01/2025 09:	AF	
culturally appropriate services	5	37	13/01/2025 16:	AF	13/01/2025 19:	AF	
experience of receieving diagnosis	1	5	13/01/2025 16:	AF	13/01/2025 16:	AF	
Fear of services making PLWD worst	3	4	08/01/2025 12:	AF	13/01/2025 18:	AF	
Last resort	3	9	13/01/2025 16:	AF	13/01/2025 16:	AF	
physical illness psuhed to access ervices	1	4	13/01/2025 16:	AF	13/01/2025 16:	AF	
Not equipped for EM	2	32	08/01/2025 14:	AF	09/01/2025 10:	AF	
Other social graces impact	1	3	13/01/2025 16:	AF	13/01/2025 17:	AF	
SES	1	4	13/01/2025 16:	AF	13/01/2025 16:	AF	
Preference of seeking help in home country	1	5	13/01/2025 16:	AF	13/01/2025 16:	AF	
Shared risk amongst PLWD and carers	1	1	06/01/2025 19:	AF	06/01/2025 19:	AF	●
Conflict of wanting and accepting help	3	9	06/01/2025 18:	AF	09/01/2025 10:	AF	
Fear of isolation and judgement	2	6	06/01/2025 19:	AF	09/01/2025 09:	AF	

Appendix E: Ethical approval and Amendments

To: Ms Armita Farsinejad

Your application for an amendment of the existing protocol listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: “Are they hard to reach or are we not reaching out?” : Exploring healthcare staff perspectives of why African Caribbean people may be presenting later to dementia services.

Your UH protocol number is: **0320 2025 Mar HSET**

This reference must be quoted on all paperwork, including advertisements for participants.

If you wish to use the UH Ethics Committee logo disclaimer in your communications with participants, please find it in our UH Ethics Canvas site under ‘Units - Application Forms’: UH Ethics Approval (instructure.com.

This ethics approval expires on 30/09/2025

Amending your protocol

Individual protocols will normally be approved for the limited period of time noted above. Application for minor amendments (including time extensions) of a protocol, may be made for a maximum of 4 working weeks after the end date of that protocol.

It is expected that any amendments proposed via the online system will be minor. Should substantial modification be required, it would be necessary to make a fresh application for ethical approval.

Note that you must obtain approval from the relevant UH Ethics Committee with Delegated Authority **prior to implementing any changes**. Failure to do so constitutes a breach of ethics regulations (UPR RE01).

Any adverse circumstances that may arise because of your study/activity must be reported to ethicsadmin@herts.ac.uk as soon as possible.

Permissions
Any necessary permissions for the use of premises/location and accessing participants for your study/activity must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Ethics Administration Team

ethicsadmin@herts.ac.uk

Amendment Tool

For office use
QC: No

Section 1: Project information

Short project title":	are they hard to reach or are we not reaching out?			
IRAS project 10• (or REG reference if no IRAS project ID is available):	346999			
Sponsor amendment reference number•:	NSA01			
Sponsor amendment date• (enter as DD/MM/YY):	06 November 2024			
Briefly summarise in lay language the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study. If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained (note: this field will adapt to the amount of text entered)":	Two NHS sites where the focus groups will take place in part C on the form had the wrong address and NHS site. Address and NHS site updated to be able to commence study. There is an addition of South London and Maudsley NHS Foundation trust as a site and removed is Lewisham and Croydon University NHS trusts. The local leads of the trust have been changed from Armita Farsinejad to Kathleen Fellbaum for South London and Maudsley NHS and to Natascha Basedau for the Central North West London NHS trust on the IRAS form page 'research sites'.			
Project type (select):	**Specific study** Research tissue bank Research database			
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REG) prior to this amendment?:	**Yes**		No	
What type of UKECA-recognised Research Ethics Committee (REG) review is applicable? (select):	**NHS/HSC REC** Ministry of Defence (MoDREC)			
Is all or part of this amendment being resubmitted to the Research Ethics Committee (REG) as a **modified amendment** (i.e. a substantial amendment previously given an unfavourable opinion)?	Yes		**No**	
	England	Wales	Scotland	Northern Ireland
Where is the NHS/HSC Research Ethics Committee (REG) that reviewed the study based?:	**Yes**	No	No	No
Was the study a clinical trial of an investigational medicinal product (CTIMP) OR does the amendment make it one?:	Yes		**No**	
Was the study a clinical investigation or other study of a medical device OR does the amendment make it one?:	Yes		**No**	
Did the study involve the administration of radioactive substances, therefore requiring ARSAC review, OR does the amendment introduce this?:	Yes		**No**	
Did the study involve the use of research exposures to ionising radiation (not involving the administration of radioactive substances) OR does the amendment introduce this?:	Yes		**No**	
Did the study involve adults lacking capacity OR does the amendment introduce this?:	Yes		**No**	
Did the study involve access to confidential patient information outside the direct care team without consent OR does the amendment introduce this?:	Yes		**No**	
Did the study involve prisoners or young offenders who are in custody or supervised by the probation service OR does the amendment introduce this?:	Yes		**No**	
Did the study involve children OR does the amendment introduce this?:	Yes		**No**	
Did the study involve NHS/HSC organisations prior to this amendment?:	**Yes**		No	
Did the study involve non-NHS/HSC organisations OR does the amendment introduce them?:	Yes		**No**	
	England	Wales	Scotland	Northern Ireland
Lead nation for the study:	**Yes**	No	No	No
Which nations had participating NHS/HSC organisations prior to this amendment?	**Yes**	No	No	No
Which nations will have participating NHS/HSC organisations after this amendment?	**Yes**	No	No	No
Was this a "single site, self sponsored" study in England or Wales prior to this amendment?	Yes		**No**	

Section 2: Summary or change(s)

Please note: Each change being made as part of the amendment must be entered separately. For example, if an amendment to a clinical trial of an investigational medicinal product (CTIMP) involves an update lo the InvestigatMs Brochure (1B), affecting the Reference Safety Information (RSI) and so the information documents lo be given to participants, these should be entered into the Amendment Tool as three separate changes. A list of all possible changes is available on the "Glossary of Amendment Options" tab. To add another change, click the "Add another change" box.

Change 1				
Area of change (select)":	Administrative details for the project			
Specific change (select - only available when area of change is selected first)":	Other administrative change - Please specify in the free text below			
Further information (free text - note that this field will adapt to the amount of text entered):	Two NHS sites where the focus groups will take place In part C on the form had the wrong address and NHS site. Address and NHS site updated to be able to commence study. There is an addition of South London and Maudsley NHS Foundation trust as a site and removed is Lewisham and Croydon University NHS trusts. The local leads of the trust have been changed from Armita Farsinejad to Kathleen Fellbaum for South London and Maudsley NHS and to Natascha Basedau for the Central North West London NHS trust on the IRAS form page 'research sites'.			
Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHSIHSC organisations located that will be affected by this change?":	**Yes**	No	No	No
Will all participating NHSIHSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	
			Add another change	

Section 3: Declaration(s) and lock for submission

Declaration by the Sponsor or authorised delegate

I confirm that the Sponsor takes responsibility for the completed amendment tool
I confirm that I have been formally authorised by the Sponsor to complete the amendment tool on their behalf

Name [first name and surname}'"	Professor Wendy Wills
Email address:*	w.j.wills@herts.ac.uk

Lock for submission

Please note: This button will only become available when all mandatory (") fields have been completed. When the button is available, clicking it will generate a locked PDF copy of the completed amendment tool which must be included in the amendment submission. Please ensure that the amendment tool is completed correctly before locking it for submission.

Lock for submission

After locking the tool. proceed to submit the amendment online. The "Submission Guidance" tab provides further information about the next steps for the amendment.

Section 4: Review bodies for the amendment

Please note: This section is for **information only**. Details in this section will complete automatically based on the options selected in Sections 1 and 2.

	Review bodies																		
	UK wide:						England and Wales:				Scotland:				Northern Ireland:				
		[illegible]	[illegible]			[illegible]				[illegible]			[illegible]		[illegible]				Category:
Change 1:						y				(Y)									C
Overall reviews for the amendment:																			
Full review:						y				N									
Notification only:						N				y									
Overall amendment type:	Non-substantial																		

Amendment Tool

For office use

QC:No

Section 1: Project information

Short project title':	are they hard to reach or are we not reaching out?
IRAS project ID* (or REG reference if no IRAS project ID is available):	346999
Sponsor amendment reference number*:	NSA02
Sponsor amendment date• (enter as DDIMM/YY):	03 February 2025
Briefly summarise in lay language the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study. If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained {note: this field will adapt to the amount of text entered)':	Amendment - Added non-validated questionnaires to gather demographics in line with NHS's commitment to promoting better equality, diversity, and inclusion in research. Demographics regarding gender, ethnicity and duration of time worked in memory services will be asked but not mandatory. This has been added to the IRAS form (A27-2) and attached in the documents section and checklist section. In addition- the amendment to the hard copies being kept in a cabinet at the university has now been changed. All hard copies which include the demographics form (not mandatory) and consent form, will be provided at the focus group to fill out, and the information **will** be stored on the University One Drive after the focus group has finished and all paper **will** be shredded immediately. All data will be deleted after completion of the thesis. (added to A36,A37 and A40)

Project type (select):	**Specific study** Research tissue bank Research database			
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REG) prior to this amendment?:	Yes		**No**	
Is review by a UKECA-recognised Research Ethics Committee (REG) being sought for the first time because of this amendment?:	Yes		**No**	
Did the study involve NHSIHSC organisations prior to this amendment?:	**Yes**		No	
Did the study involve non-NHSIHSC organisations OR does the amendment introduce them?:	Yes		**No**	
	England	Wales	Scotland	Northern Ireland
Lead nation for the study:	**Yes**	No	No	No
Which nations had participating NHS/HSC organisations prior to this amendment?	**Yes**	No	No	No
Which nations will have participating NHS/HSC organisations after this amendment?	**Yes**	No	No	No
Was this a "single site, self sponsored" study in England or Wales prior to this amendment?	Yes		**No**	

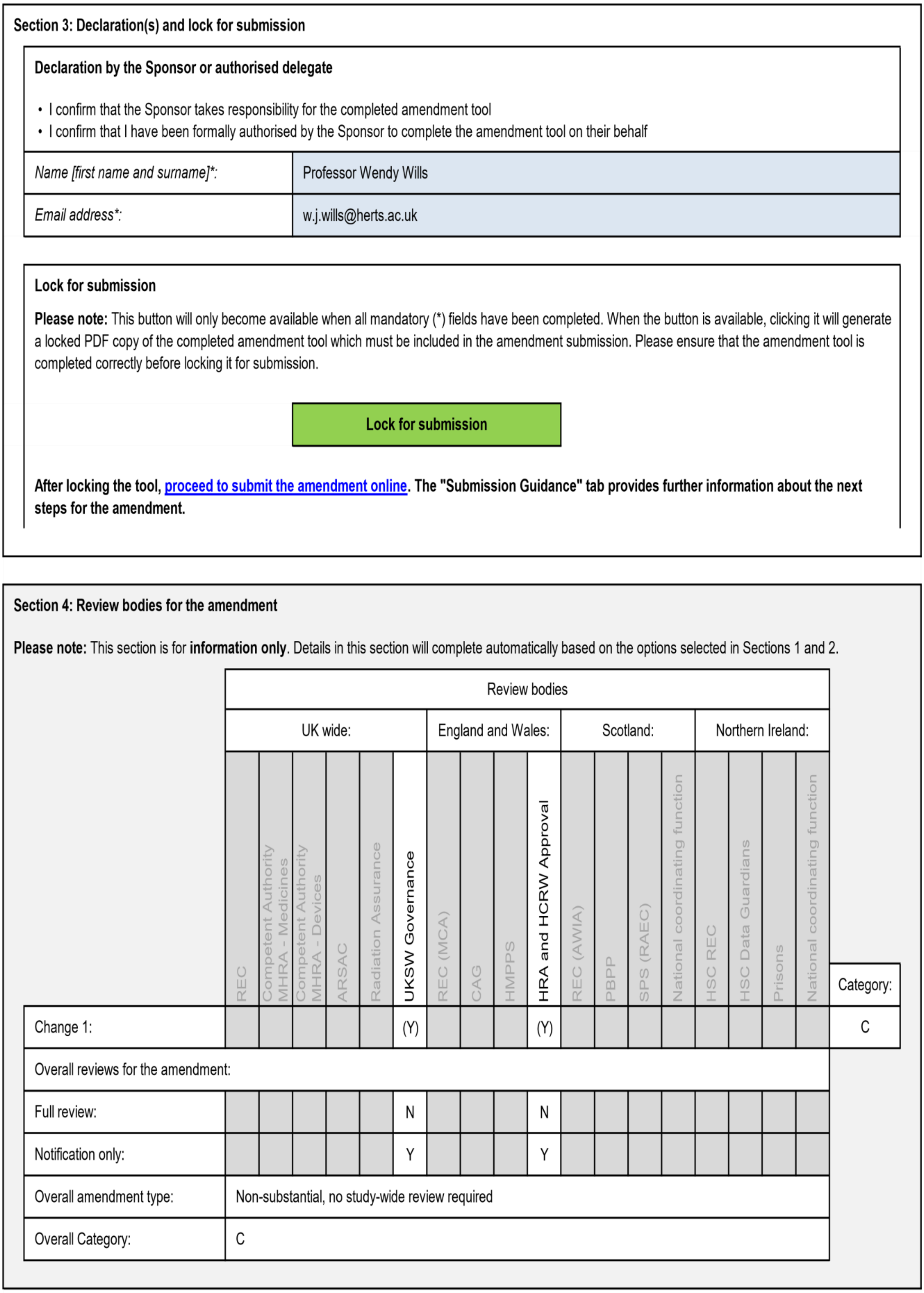
Section 2: Summary of change(s)

Please note: Each change being made as part of the amendment must be entered separately. For example, if an amendment to a clinical trial of an investigational medicinal product (CTIMP) involves an update to the Investigator's Brochure (18), affecting the Reference Safety Information (RSI) and so the information documents to be given to participants, these should be entered into the Amendment Tool as three separate changes. A list of all possible changes is available on the "Glossary of Amendment Options" tab. To add another change, click the "Add another change" box.

Change 1	
Area of change (select)':	Participant Procedures
Specific change (select - only available when area of change is selected first)':	Participant procedures - minor change that can be implemented within existing resource at participating organisations - Please specify in the free text below
Further information In particular, please describe why this change can be implemented within the existing resource in place at the participating organisations (free text - note that this field will adapt to the amount of text entered)'	Added a non-validated questionnaire asking for demographics (Gender, ethnicity and duration of job in a memory service). Also, a change that all hard copies will be uploaded to the University of Hertfordshire One Drive immediately after the focus group and all hard copies will be destroyed immediately after the upload. All reflected in the IRAS form- A27-2: A36; A37 and A40. Demographics form uploaded to checklist documents on IRAS

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHSIHSC organisations located that will be affected by this change?':	**Yes**	No	No	No
Will all participating NHSIHSC organisations be affected by this change, or only some? **(please note** that this answer may affect the categorisation for the change):	**All**		Some	

Add another change



Section 3: Declaration(s) and lock for submission

Declaration by the Sponsor or authorised delegate

- I confirm that the Sponsor takes responsibility for the completed amendment tool
- I confirm that I have been formally authorised by the Sponsor to complete the amendment tool on their behalf

Name [first name and surname]:*	Professor Wendy Wills
Email address:*	w.j.wills@herts.ac.uk

Lock for submission

Please note: This button will only become available when all mandatory (*) fields have been completed. When the button is available, clicking it will generate a locked PDF copy of the completed amendment tool which must be included in the amendment submission. Please ensure that the amendment tool is completed correctly before locking it for submission.

After locking the tool, proceed to submit the amendment online. The "Submission Guidance" tab provides further information about the next steps for the amendment.

Section 4: Review bodies for the amendment

Please note: This section is for **information only**. Details in this section will complete automatically based on the options selected in Sections 1 and 2.

	Review bodies																	
	UK wide:						England and Wales:				Scotland:				Northern Ireland:			
	REC	Competent Authority MHRA - Medicines	Competent Authority MHRA - Devices	ARSAC	Radiation Assurance	UKSW Governance	REC (MCA)	CAG	HMPPS	HRA and HCRW Approval	REC (AWIA)	PBPP	SPS (RAEC)	National coordinating function	HSC REC	HSC Data Guardians	Prisons	National coordinating function	Category:
Change 1:						(Y)				(Y)									C
Overall reviews for the amendment:																			
Full review:						N				N									
Notification only:						Y				Y									
Overall amendment type:	Non-substantial, no study-wide review required																		
Overall Category:	C																		

Section 1: Project information

Short project title':	are they hard to reach or are we not reaching out?
IRAS project 10• (or REC reference if no IRAS project ID is available):	346999
Sponsor amendment reference number•:	NSA03
Sponsor amendment date· (enter as DD/MM/YY):	12 March 2025
Briefly summarise in lay language the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study. If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained (note: this field will adapt to the amount of text enteredt:	There was a previous accepted amendment regarding where data would be stored (3.2.25) however this was not added to the proposal document. The proposal now states that data will be kept only on the university of hertfordshire one drive and will not be using paper copies of anything, kept in a cabinent at university.It has now been added and uploaded to IRAS. In addition, we specify that the audio will be recorded via microsoft teams and transcribed using the software (MS can transcribe during recording) and then tramscriptions will be used via nvivo the software. Lastly, we specify that pseudonyms will be linked to staff professions. All documents that have changed are attached and highlighted yellow.

Project type (select):	**Specific study** Research tissue bank Research database			
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REC) prior to this amendment?:	**Yes**		No	
What type of UKECA-recognised Research Ethics Committee (REC) review is applicable? (select):	**NHS/HSC REC** Ministry of Defence (MoDREC)			
Is all or part of this amendment being resubmitted to the Research Ethics Committee (REC) as a **modified amendment** (i.e. a substantial amendment previously given an unfavourable opinion)?	Yes		**No**	
	England	Wales	Scotland	Northern Ireland
Where is the NHS/HSC Research Ethics Committee (REC) that reviewed the study based?:	**Yes**	No	No	No
Was the study a clinical trial of an investigational medicinal product (CTIMP) OR does the amendment make it one?:	Yes		**No**	
Was the study a clinical investigation or other study of a medical device OR does the amendment make it one?:	Yes		**No**	
Did the study involve the administration of radioactive substances, therefore requiring ARSAC review, OR does the amendment introduce this?:	Yes		**No**	
Did the study involve the use of research exposures to ionising radiation (not involving the administration of radioactive substances) OR does the amendment introduce this?:	Yes		**No**	
Did the study involve adults lacking capacity OR does the amendment introduce this?:	Yes		**No**	
Did the study involve access to confidential patient information outside the direct care team without consent OR does the amendment introduce this?:	Yes		**No**	
Did the study involve prisoners or young offenders who are in custody or supervised by the probation service OR does the amendment introduce this?:	Yes		**No**	
Did the study involve children OR does the amendment introduce this?:	Yes		**No**	
Did the study involve NHS/HSC organisations prior to this amendment?:	**Yes**		No	
Did the study involve non-NHS/HSC organisations OR does the amendment introduce them?:	Yes		**No**	
	England	Wales	Scotland	Northern Ireland
Lead nation for the study:	**Yes**	No	No	No
Which nations had participating NHS/HSC organisations prior to this amendment?	**Yes**	No	No	No
Which nations will have participating NHS/HSC organisations after this amendment?	**Yes**	No	No	No
Was this a "single site, self sponsored" study in England or Wales prior to this amendment?	Yes		**No**	

Section 2: Summary of change(s)

Please note: Each change being made as part of the amendment must be entered separately. For example, if an amendment to a clinical trial of an investigational medicinal product (CTIMP) involves an update to the Investigator's Brochure (1B), affecting the Reference Safety Information (RSI) and so the information documents to be given to participants, these should be entered into the Amendment Tool as three separate changes. A list of all possible changes is available on the "Glossary of Amendment Options" tab. To add another change, click the "Add another change" box.

Change 1	
Area of change (select)":	Study Documents
Specific change (select - only available when area of change is selected first)":	Other minor change to study documents (e.g. information sheets, consent forms, questionnaires, letters) that can be implemented within existing resource in place at participating organisations - Please specify in the free text below
Further information In particular, please describe why this change can be implemented within the existing resource in place at the participating organisations (free text - note that this field will adapt to the amount of text enteredt	No additional resources arrangements needed

Applicability:	England	Wales	Scotland	Northern Ireland
Where are the participating NHS/HSC organisations located that will be affected by this change?•:	**Yes**	No	No	No
Will all participating NHS/HSC organisations be affected by this change, or only some? (**please note** that this answer may affect the categorisation for the change):	**All**		Some	

Add another change

Section 3: Declaration(sl and lock for submission

Declaration by the Sponsor or authorised delegate

I confirm that the Sponsor takes responsibility for the completed amendment tool
I confirm that I have been formally authorised by the Sponsor to complete the amendment tool on their behalf

Name {first name and surname]':	Professor Wendy Wills
Email address•:	w.j.wills@herts.ac.uk

Lock for submission

Please note: This button will only become available when all mandatory(*) fields have been completed. When the button is available, clicking it will generate a locked PDF copy of the completed amendment tool which must be included in the amendment submission. Please ensure that the amendment tool is completed correctly before locking it for submission.

Lock for submission

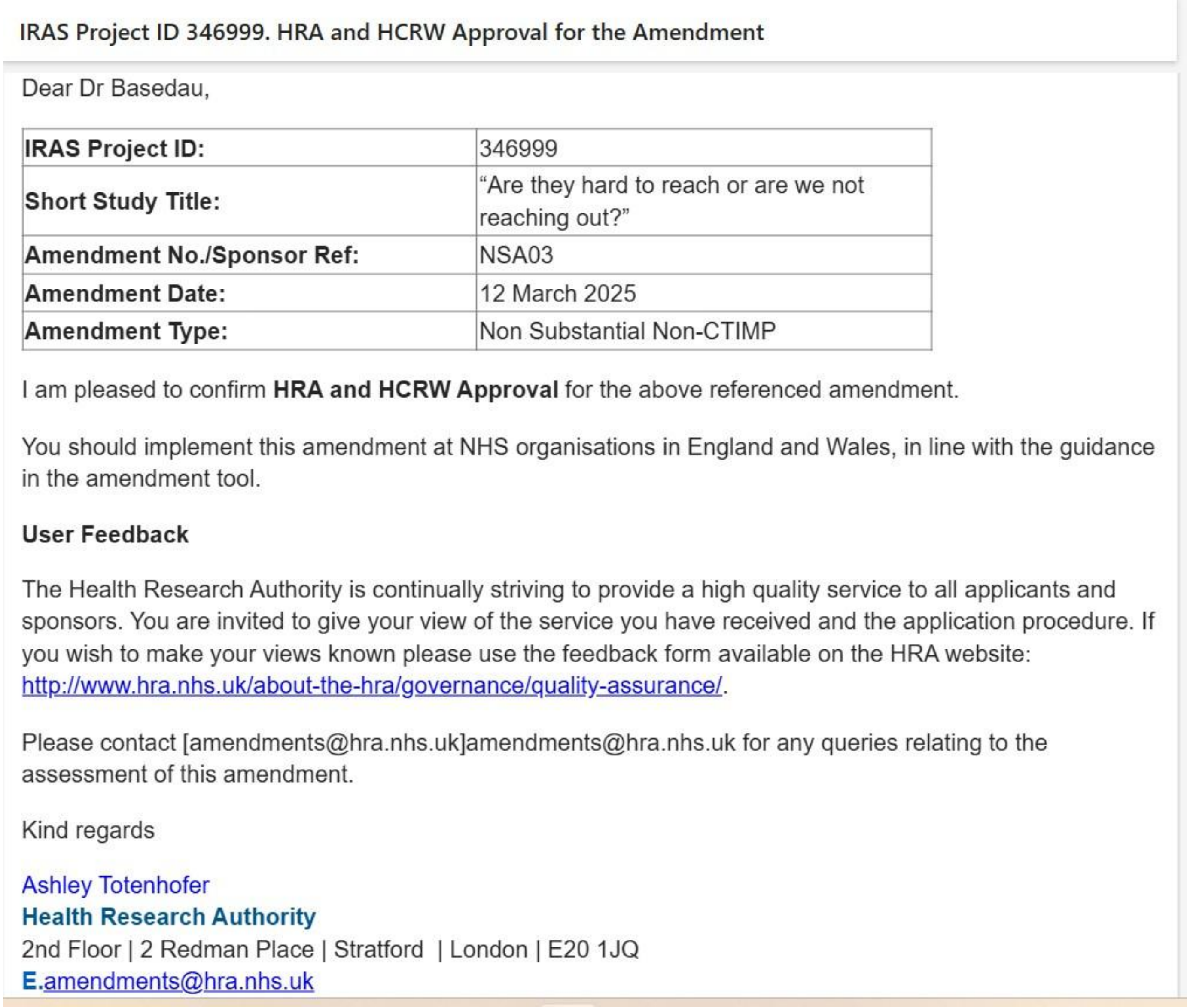
After locking the tool. proceed to submit the amendment online. The "Submission Guidance" tab provides further information about the next steps for the amendment.

Section 4: Review bodies for the amendment

Please note: This section is for **information only.** Details in this section will complete automatically based on the options selected in Sections 1 and 2.

	Review bodies																		
	UK wide:						England and Wales:				Scotland:				Northern Ireland:				
		[illegible]	[illegible]			[illegible]	[illegible]			[illegible]	[illegible]		[illegible]			[illegible]		[illegible]	Category:
Change 1:						(Y)				(Y)									C
Overall reviews for the amendment:																			
Full review:						N				N									
Notification only:						y				y									
Overall amendment type:	Non-substantial, no study-wide review required																		
Overall Category:	C																		

Appendix F: HRA approval



IRAS Project ID 346999. HRA and HCRW Approval for the Amendment

Dear Dr Basedau,

IRAS Project ID:	346999
Short Study Title:	"Are they hard to reach or are we not reaching out?"
Amendment No./Sponsor Ref:	NSA03
Amendment Date:	12 March 2025
Amendment Type:	Non Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please contact [amendments@hra.nhs.uk]amendments@hra.nhs.uk for any queries relating to the assessment of this amendment.

Kind regards

Ashley Totenhofer
Health Research Authority
2nd Floor | 2 Redman Place | Stratford | London | E20 1JQ
E.amendments@hra.nhs.uk

Appendix G: Research poster

TAKE PART IN OUR RESEARCH STUDY!

We Are Conducting Research To Understand Healthcare Professional's Perspectives On Why African Caribbean People May Be Presenting Later To Dementia Services.

We are recruiting NHS staff working in memory services

We will be holding face-to face focus groups that will last up to 1-1.5 hours

If you would like to take part, please let your manager know or contact a.farsinejad@herts.ac.uk- Trainee Clinical Psychologist
This doctoral research study has been approved by The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority.
Protocol number- 0320 2025 Mar HSET

University of Hertfordshire UH

Appendix H: Participation sheet

Title of study

Are they hard to reach or are we not reaching out? Exploring healthcare staff perspectives of why African Caribbean people may be presenting later to dementia services.

Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation).

The study sponsor and data controller is the University of Hertfordshire.

Thank you for reading this.

1 What is the purpose of this study?

My name is Armie Farsinejad, and I am a third-year trainee Clinical Psychologist at the University of Hertfordshire, conducting a student study. I am exploring healthcare staffs perspectives of why African Caribbean people may be presenting later in dementia services when they are at higher risk of developing Alzheimer's, vascular dementia, and early onset dementia. The method of analysis will be thematic analysis to understand common themes that will answer the research question.

There is currently limited research in the area of African Caribbean people using dementia services though the literature is growing. We need to be able to understand potential barriers to accommodate EM's and increase equity in healthcare for minoritised groups. The study will aim to recruit from memory community NHS services in Lewisham, Croydon and Harrow. The study findings will be shared with the teams to help inform whether services can do more to support this populations needs. No personal identifying data will be shared.

2 Do I have to take part?

It is completely up to you whether you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you must complete it.

3 Are there any age or other restrictions that may prevent me from participating?

You must be 18 or over to participate in this study.

4 How long will my part in the study take?

If you decide to take part in this study, you will be invited to attend a focus group which will take about 1-1.5 hours. The focus group will involve pre-determined questions with some prompts, these prompts will provide an opportunity for us to explore your responses with you further too. The focus group will be to ask participants about their experiences of working with people from an African Caribbean background in memory services and their experiences of services accommodating EM's. You will be asked open-ended questions to support with getting an understanding of your own personal lived experience on this topic.

5 What will happen to me if I take part?

The first thing to happen will be if you decide to take part, you will be given this information sheet to keep, and you will also be asked to sign a consent form. You will then be invited to take part in a focus group will last around 60-90 minutes and will be voice recorded. . If you change your mind about taking part in the study, you can withdraw at any point by contacting the researcher (see contact details below), however we will keep information about you that we already have to the point of you withdrawing. Direct quotes from the focus groups will be used in publications, however the quotes will be anonymised by using pseudonyms & profession only. Audio recordings will be transcribed via Microsoft teams, and transcriptions will then be uploaded to Nvivo for thematic analysis but without identifiable information.

6 What are the possible disadvantages, risks, or side effects of taking part?

The main cost to you will be the time needed to take part in the focus group. I do ask that you only share what you are comfortable to share during the session, and that you do not have to respond to all the questions asked if you do not wish to. If you do find the discussion difficult, you can withdraw yourself from the session while it is ongoing, you will not be asked why you have withdrawn and there will be debriefing. This will be an opportunity to discuss anything you may have found difficult about the discussions held, the content of the debrief discussions will not be recorded or included in the project findings.

Due to these measures, we feel the risk of any serious distress is low. If you experience serious distress and feel you require ongoing support, you will be signposted to the appropriate support or service.

Confidential text support service, you can access support by texting SHOUT to 85258 for mental health support 24/7

NHS Website with resources for support with mental health including helplines and apps:

https://www.england.nhs.uk/supporting-our-nhs-people/support-now/

For non NHS and NHS workers below:

Mental health Foundation provides resources on services that offer support:
https://www.mentalhealth.org.uk/explore-mental-health/get-help

7 What are the possible benefits of taking part?

We hope that you will find the research activities interesting and an opportunity to contribute and shape services to accommodate AFC in dementia services. We also hope you will take satisfaction from helping to co-develop knowledge of this important topic and influence future practice.

8 How will my taking part in this study be kept confidential?

If you chose to be interviewed for this study all information you provide will be kept confidential. Data will be collected and stored in line with the Data Protection Act 2018 and the General Data Protection Regulation (GDPR) 2016. The recording of your interview will be given a code (i.e., Interview A) and stored on a secure in a secure file on the University of Hertfordshire's One drive. A transcription service will be used to transcribe the interview which involves typing up the interview verbatim. No identifiable information will be shared with the transcription service; although it is possible you could make yourself identifiable during the focus group, the responses you provide will be pseudo-anonymised,

A signed confidentiality agreement from the service will be obtained before any recordings are provided. All names and personally identifiable information will be removed from the transcripts by the researcher. Personal information will be kept securely and separately from the transcripts. Demographic information questionnaires will also be stored securely and separately from your name and contact details. The researcher's supervising team will also be kept blind to the identity of participants when reviewing transcripts.

The audio recording and transcripts will be handled only by the student researcher who will transcribe the audio, in line with data protection principles and our approved research protocol. Audio recordings will be transcribed via MS Teams, and those transcriptions will then be uploaded to Nvivo for thematic analysis but without identifiable information. Copies of any consent forms and demographics will be uploaded to the University of Hertfordshire One drive, and all hard copies will be shredded immediately after. All electronic files are kept on password protected devices which are not accessible to any other university staff. Once the audio recordings have been transcribed, they will be deleted. The data will be kept for the length of the study and destroyed after this time which we intend to be completed by August 2025

9 Audio-visual material

The focus group interview will be recorded via Microsoft teams and therefore will be encrypted. Audio recordings from the focus group will be deleted once transcribed. The focus group interviews will also be transcribed onto a written password-protected Word document. At the end of the study, all anonymised transcripts will be destroyed. Any information that identifies you, or that gives any clues to your identity, will be removed. We are confident that these precautions will ensure that no-one will be able to trace your transcript back to you.

You will not be named or otherwise identified in any publication arising from this project. Excerpts of things you have said during the interview discussion may be published as they form an important part of the project findings. If there is anything you have said that includes identifiable information (for example, where you work, where you live, or your name) we will omit or change these details to protect your identity becoming known. I will exercise all possible care to ensure that you cannot be identified by writing up our findings.

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, job role and years worked in the service. People will use this information to do the research or to check your records to make sure that the research is being done properly. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

The student researcher will analyse all the data and use this as a basis for writing up their thesis on the topic. The data collected will be stored electronically, in a password-protected document until August 2025, after which time it will be destroyed under secure conditions. Participants will have rights to request their data, participants will not however be able to access, change or delete their research data themselves as this would compromise the security of the University shared drive and confidentiality of the other participant's data involved in this project. By signing the consent sheet, you are consenting to have your recordings used as part of the research

The results of the research will be presented in a thesis for the purpose of gaining a qualification in Clinical Psychology as this is a student study. The thesis will be held at the University of Hertfordshire Learning Resource Centre and will be accessible to all interested parties. A summary of the main research findings may be published in written work or articles that project myself or my supervisors write, as well as for the purposes of teaching and conferences. Information originating from the study will only be made public in an unattributable format.

10 What are your choices about how your information is used?

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

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/
- Our leaflet avaible from: www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to a.farsinejad@herts.ac.uk
- By ringing us on 01707286417
- By contacting the university of Hertfordshire Data Protection officer, Abigail Tomlinson, via email at dataprotection@herts.ac.uk.

11 Will the data be required for use in further studies?

The data will not be used in any further studies.

12 Who has reviewed this study?

The study has been reviewed and approved by the Health Research Authority (HRA) who are responsible for managing the NHS Research Ethics Committees in England.

The study has also been reviewed by the University of Hertfordshire Social Sciences, Arts and Humanities Ethics Committee with Delegated Authority. The UH protocol number is **0320 2025 Mar HSET**

13 Factors that might put others at risk

Please note that if, during the study, any medical conditions, or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

14 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by email: a.farsinejad@herts.ac.uk

Supervisor Dr Natascha (N.basedau@herts.ac.uk)/ Telephone contact: 01707 284000)

Doctorate in Clinical Psychology

Wight Building

College Lane Campus

Hatfield

AL10 9AB

You can also contact the Research Governance and information office for data protection related concerns via email: research-sponsorship@herts.ac.uk.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

Thank you very much for reading this information and giving consideration to taking part in this study.

AL10 9AB

Appendix I: Demographic questionnaire

Demographics

It would be helpful to know some information about you. However, this is not mandatory. This information will be uploaded onto the University of Hertfordshire Drive at the end of the focus group and this paper will be shredded immediately after. The demographics will NOT be linked to your pseudonym name (fake name) if you do not want it to be.

How do you describe your gender identity (please circle)

- Female
- Male
- Prefer not to disclose
- Self-identify as male/female
- Other (please specify in space)……………………………..

What is your ethnicity? (Please write in the space below what best describes your ethnicity)
……………………………………………………………………………

Are you okay for your demographics to be linked to your participant number? (please circle)

- Yes
- No
- Only my gender
- Only my ethnicity

Appendix J: Consent form

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS

(‘ETHICS COMMITTEE’)

FORM EC3

CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

hereby freely agree to take part in the study entitled:

Are they hard to reach or are we not reaching out? Exploring healthcare staff perspectives of why African Caribbean people may be presenting later to dementia services

This doctoral research study has been approved by The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority.
UH Protocol number: 0320 2025 Mar HSET

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason. However, we will keep information about you that we already have as stated in the participation information sheet. This information will be annoymised.

3 In giving my consent to participate in this study, I understand that a voice recording will take place and I have been informed of how the recording will be transmitted & displayed. I also give consent for the recordings to be used as part as this research project. I understand that direct quotes from the audio will be used in publication, though kept anonymised.

4 I have been given information about the risks of my suffering harm or adverse effects

5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

Signature of participant…………………………………..…Date…………………………

Signature of investigator Date… ………………………

Name of the investigator

Appendix K: Interview schedule

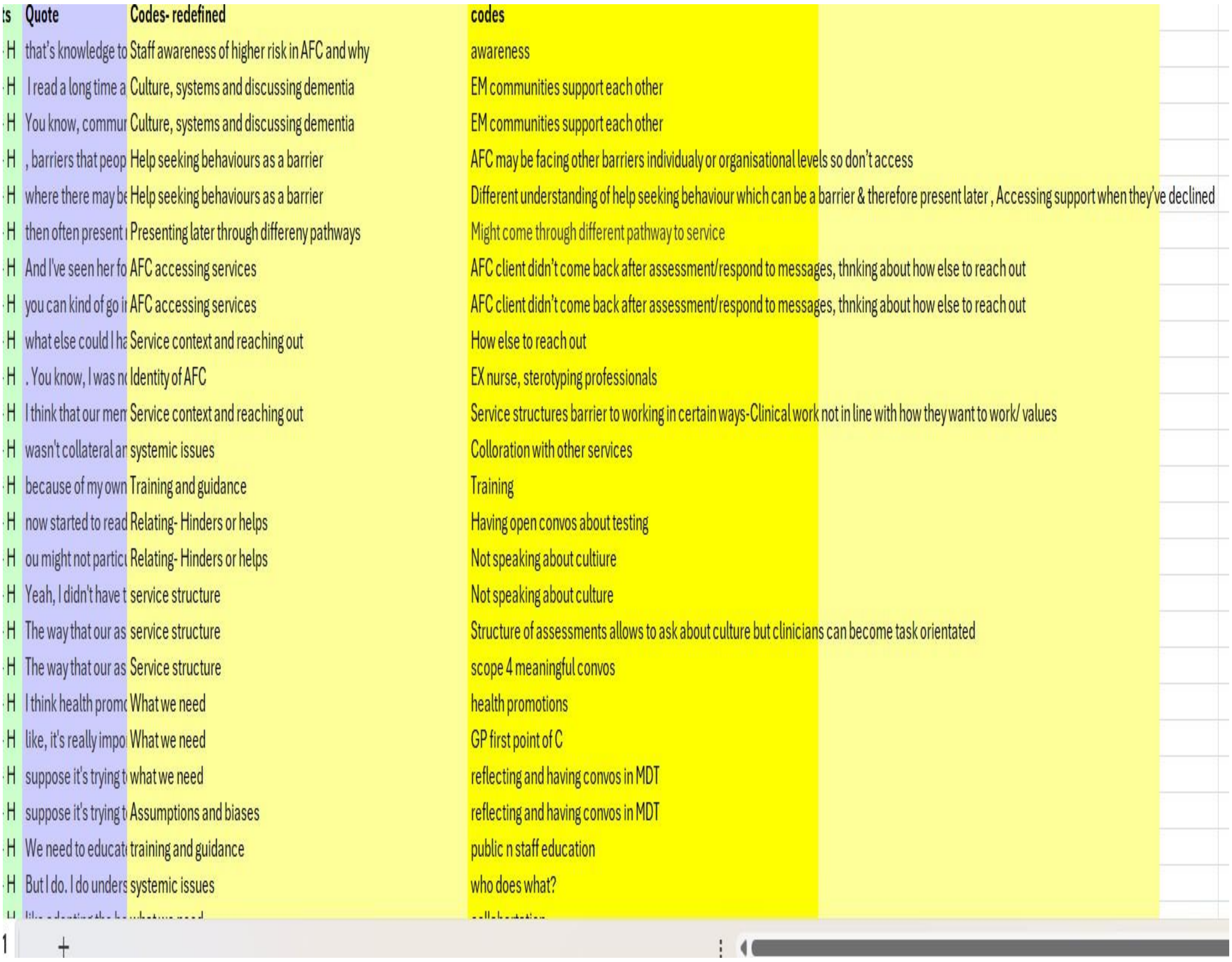
Are they hard to reach or are we not reaching out? Exploring healthcare staff perspectives of why African Caribbean people may be presenting later to dementia services

I am exploring healthcare staffs perspectives of why African Caribbean people may be presenting later in dementia services. There is currently limited research in the area of African Caribbean people using dementia services though the literature is growing. We need to be able to understand potential barriers to accommodate EM's and increase equity in healthcare for minoritised groups. We hope that you will find the research activities interesting and an opportunity to contribute and shape services to accommodate AFC in dementia services. We also hope you will take satisfaction from helping to co-develop knowledge of this important topic and influence future practice.

Introductions

- Do you have many people from the African Caribbean community accessing your service?- at what point do you tend to see this? Early on/later on?
- What do you think the AFC clients are looking for when they come to memory service?
- How do you think we could reach out to AFC communities? (Prompt- What do we know? What do they/we need)
- Any challenges of reaching out?
- Do you think AFC need cultural adaptations when using memory services? Can you think of any examples?
- Have there been any examples in your work where you have been culturally sensitive to people based on their ethnicities? Did this work well/ not well? Was there feedback from the clients/families/carers?
- What is something you are proud of that your service does to be culturally sensitive for people from different cultures? e.g. adaptations of assessments/ leaflets in diff languages
- What do you think services on a whole need to do better to reach out to AFC communities? Is there anything services could do differently? More of?
- Do you feel you get enough training and guidance on how to work with people from different communities and how to be culturally sensitive?
- Do you think it is important?

Appendix L: Microsoft Excel screenshot for codes



ts	Quote	Codes- redefined	codes
H	that's knowledge to	Staff awareness of higher risk in AFC and why	awareness
H	I read a long time a	Culture, systems and discussing dementia	EM communities support each other
H	You know, commur	Culture, systems and discussing dementia	EM communities support each other
H	, barriers that peop	Help seeking behaviours as a barrier	AFC may be facing other barriers individualy or organisational levels so don't access
H	where there may be	Help seeking behaviours as a barrier	Different understanding of help seeking behaviour which can be a barrier & therefore present later , Accessing support when they've declined
H	then often present	Presenting later through differeny pathways	Might come through different pathway to service
H	And I've seen her fo	AFC accessing services	AFC client didn't come back after assessment/respond to messages, thnking about how else to reach out
H	you can kind of go i	AFC accessing services	AFC client didn't come back after assessment/respond to messages, thnking about how else to reach out
H	what else could I ha	Service context and reaching out	How else to reach out
H	. You know, I was n	Identity of AFC	EX nurse, sterotyping professionals
H	I think that our mer	Service context and reaching out	Service structures barrier to working in certain ways-Clinical work not in line with how they want to work/ values
H	wasn't collateral ar	systemic issues	Colloration with other services
H	because of my own	Training and guidance	Training
H	now started to read	Relating- Hinders or helps	Having open convos about testing
H	ou might not partic	Relating- Hinders or helps	Not speaking about cultiure
H	Yeah, I didn't have t	service structure	Not speaking about culture
H	The way that our as	service structure	Structure of assessments allows to ask about culture but clinicians can become task orientated
H	The way that our as	Service structure	scope 4 meaningful convos
H	I think health prom	What we need	health promotions
H	like, it's really impo	What we need	GP first point of C
H	suppose it's trying t	what we need	reflecting and having convos in MDT
H	suppose it's trying t	Assumptions and biases	reflecting and having convos in MDT
H	We need to educat	training and guidance	public n staff education
H	But I do. I do unders	systemic issues	who does what?

Appendix M: Full *Summary of final SLR papers*

Author and date	**Title**	**Aims**	**Methodology**	**Sample**	**Key Findings**	**Strengths and limitations**
Baghirathan, C., Hui, C., Shears & Currie (2020)	A grounded theory analysis of the experiences of caregivers for people living with dementia from three Black, Asian and Minority ethic (BAME) communities: Balancing the need for support against fears of being diminished	To develop a grounded theory guided by the following two questions: What are the experiences of people from three different BAME communities in Bristol who provide care for individuals living with dementia, specifically in relation to dementia care? Why do they think people may be hesitant to use	***Study design*** Qualitative ***Data collection*** Eight Focus groups attended	***Sampling technique*** Snowballing ***Participants*** 103: PLWD (25 Caribbean, people of 31 Chinese heritage, and 47 South Asian origins) caregivers, and Volunteers or staff from BAME-led organisations that	The grounded theory, '*fear of diminishment'*, was present across all BAME communities. Participants expressed both a desire and a need for support, but were hesitant to accept it if it came at the expense of their sense of self. In response to this, they described turning to BAME-led Voluntary and Community Sector Organisations for	Every participant was from a BAME background. The authors utilised EBE advice, they provided the participants with a choice of focus or interview. They included the Chinese population, which is under-researched. The study included a policy context, speaking to the systemic issues.

		dementia care services?	***Data analysis*** Grounded Theory	provide services to older people.	ongoing support. However, the way these services operated varied, and these differences could influence how each community experienced or enacted the theory.	The strength of the author's use of grounded theory allows us to look at social processes. However, they recognise the limitations of using grounded theory and highlight that the researcher was embedded within a particular social frame. To account for this, they shared a draft of the research with the steering group and outside resources. Another limitation of their study the timescale of

						the study. This timescale meant that they were not able to hear from local people, other BAME communities, BAME communities outside of the Bristol area, isolated BAME people who do not attend organisations such as the BAME-led VCSO, which is where the researchers heavily relied on recruiting. It was good that they addressed the differences in communities and stating that BAME

						groups are not homogenous
Carter, Roche, Whitfield, Budgett, Morgan-Trimmer, Zabihi, Birks, Walter, Wilberforce, Jiang, Ahmed, Dowdrige, Marchal	Equality of opportunity for timely dementia diagnosis (EQUATED): a qualitative study of how people from minoritised ethnic groups experience the early symptoms of dementia and seek help	To investigate the factors that may influence the timing of diagnoses in an ethnically diverse urban area in the UK	***Study design*** Qualitative ***Data analysis*** Reflexive Thematic Analysis ***Data collection*** Semi-structured interviews	***Sampling technique*** Purposive ***Participants*** 61: 10 PLWD; 30 family members (18 caregivers OF PLWD); 16 HCP, 2 interpreters, 3 paid caregivers.)	The authors identified three themes. *Cultural identity and practices* shaped participants' responses: they described how gendered expectations, such as women traditionally managing household duties, meant that when families took over these roles for elders, signs of functional decline often went unnoticed or unaddressed. However,	The authors expressed that a strength of their study was that a range of stakeholders were recruited for the study. This is also the first qualitative study to explore how individuals from ethnically minoritised communities seek help for dementia symptoms, incorporating the perspectives of people with undiagnosed dementia and

l and Cooper (2024)					when older adults struggled to maintain religious practices, which remained expected of them, this more visibly prompted help-seeking The second theme, *Becoming like a tourist*, captured participants' descriptions of how everyday experiences began to feel unfamiliar as they developed dementia in a country they had moved to, sometimes prompting a desire to reconnect with their country of origin.	interpreters on the recognition of these symptoms. The limitations were that participants who were part of the study may have had enhanced awareness of dementia services and symptoms.

					Professionals and interpreters described challenges in faithfully translating meanings and balancing the voices of relatives and clients. The third theme, *Naming and conceptualising dementia*, highlighted how the term carried stigma, with cultural factors influencing its interpretation; participants also noted that early signs often included physical symptoms in addition to cognitive issues.	

James, M., Sommerlad, B.-C., Livingston, (2023)	Equity in care and support provision for people affected by dementia: experiences of people from UK South Asian and White British backgrounds	To examine the care and support received and desired by South Asian and White British individuals affected by dementia in the United Kingdom, and to assess whether access to these services is equitable.	***Study design*** Qualitative ***Data collection*** Semi-structured interviews from 8 memory clinics across the UK (NHS trusts) ***Data analysis*** Reflexive TA	***Sampling technique*** Purposive ***Participants*** 62: 13 PLWD, 24 family caregivers and 25 clinicians	People from the same background make differing choices about care, and equitable access is influenced by personal resources. Those from South Asian backgrounds may face a double disadvantage, having fewer culturally appropriate care options as well as fewer resources to seek care elsewhere. The themes identified fell under two main areas: what people want from homecare workers, including carer characteristics and	The strengths of this study were that they included perspectives of clinicians and people living with dementia, who are often excluded from research. They also used purposive sampling to gather views from people with different backgrounds. However, they spoke of not being able to recruit many people from outside of London. They spoke to their limitations, being that due to the sampling

					good quality care; and factors that help or hinder people from receiving care and support, such as families, relationships, attitudes towards care, financial means affecting choice, ease of access to services, and the availability and accessibility of culturally sensitive services	technique, it meant they may not have captured groups of people who do not seek support. None of the researchers collecting data was South Asian, which is why they recruited a South Asian researcher. As the study commenced during COVID-19, it may be that the findings reflect limited use of support and services.
Herat-Gunaratne, C.,	"In the Bengali Vocabulary, There Is No Such	To explore the experiences of South Asian caregivers of	***Study design***	***Sampling technique*** Purposive	Participants described intergenerational tensions arising from	A strength of the study is that it is one of the few studies to explore

Mukadam, R., Leverton, H., Samus, B. (2020)	Word as Care Home": Caring Experiences of UK Bangladeshi and Indian Family Caregivers of People Living With Dementia at Home	people with dementia in the United Kingdom, considering economic situations, diverse migration histories, and cultural backgrounds in relation to their use of health and social care services.	Qualitative (critical realist position) ***Data collection*** Interviews ***Data analysis*** Inductive TA	***Participant*** Ten family caregivers, each having at least monthly contact with a person living at home with dementia, were recruited from National Health Service (NHS) memory clinics in Bradford and North London UK, as well as through the researchers' professional networks.	differing views on familial care obligations. The expectation to manage care led to feelings of burden and guilt, and the personal cost, such as lost employment and strained relationships. The authors identified four themes: an expectation and duty to provide care; how this expectation and duty can act as a barrier to accessing formal care, including reluctance from family carers, care recipients, and service organisations; culturally (in)sensitive	caregivers' experiences accessing dementia services postdiagnosis. The authors reflected on the limitations, being that the caregivers were recruited from the NHS, which may mean that they identified more with Western norms compared to other studies that recruited from community sources. Also, that caregivers who did not speak fluent English were not included and

					care; and the crucial role of support from informal care networks	therefore did not capture their perspectives. They were unable to recruit any Pakistani participants and therefore only Bangladeshi and Indian. Lastly, Interviewers in the study had different nationalities from the interviewees, and therefore, rapport and trust might not have been gained.
Victor, Van Den	Perspectives of Minority Ethnic	To explore the perceptions of minority	***Study design***	***Sampling technique***	he authors identified three key themes: the	The authors stated limitations as the

Heuvel, Pentecost, Quinn, Charlwood and Clare (2024)	Caregivers of People with Dementia Interviewed as Part of the IDEAL Programme	ethnic caregivers of people with dementia	Qualitative, using an exploratory descriptive approach ***Data collection*** Semi-structured interviews ***Data analysis*** Inductive TA	Volunteer sampling ***Participants*** Eighteen caregivers of people with dementia were recruited. The participants came from two minority ethnic groups that represented the oldest postwar migrant communities in the UK: Black African/Caribbean and South Asian people.	motivation to provide care, including a desire to spend time with the care recipient and a sense of reciprocity; the mixed impact of caregiving, highlighting both its rewards and difficulties; and the cultural context of caregiving, shaped by supportive cultural norms and values, alongside stigma associated with dementia. Their findings emphasised the importance of spending time with the person being cared for,	differences in identified ethnicities between the research team and participants. They also identified the insider/outsider relationship as being complex. The project was disrupted by the COVID-19 pandemic, and social contact restrictions required a revision of the recruitment protocol. Face-to-face interviews were conducted via telephone instead. They felt this influenced their participants. They felt

					noted the absence of faith as a motivating factor for caregiving, and highlighted the difficulty of witnessing a parent’s health decline, showing how these motivations are interconnected and constantly evolving	their participants may have been more dementia aware as they engaged in services and volunteered for the research. They also stated that they only recruited people who spoke English (meaning they excluded caregivers who had just arrived in the UK, less integrated caregivers, and those who were much older). Also, they stated that their participants were predominantly daughters-in-law who

						have to take on the care -taking role and this may have contributed to the absence of a strong faith-based caring narrative.
Kevern, Lawrence, Nazir, and Isaroucha (2022)	Religious Influences on the Experience of Family Caregivers of People with Dementia in a British Pakistani Muslim Community	To explore the role of religious beliefs, practices and community networks on dementia care. Also, to identify how the Muslim religion impacts the understanding of access to care and the response to dementia in this community	***Study design*** Qual ***Data collection*** Semi-structured Interviews ***Data analysis*** Thematic analysis	***Sampling technique*** Purposive and then snowballing. ***Participants*** 7 caregivers of PLWD from the British Pakistani Muslim community	The findings indicated that the Muslim faith was an important source of support for individual carers and their families. However, support from the wider faith community and its leaders was generally lacking and sometimes acted as a barrier to accessing external care.	The author's findings suggest that the participants gained support and strength from their faith at an individual level when navigating dementia care. This is one of the few studies to explore faith in dementia care in the UK, which is a strength of the study.

					This was attributed to cultural pressures and limited awareness among religious leaders and the broader community. The study concluded that addressing inequalities in access to dementia services could be improved by service providers engaging with faith-related concerns and collaborating with religious leaders to better meet the needs of Muslims of British Pakistani origin.	The limitations of the study were that the sample size was small and that the interviews were online or via telephone, which limited the freedom for participants to explore feelings and thoughts when compared to face-to-face interviewing. Also, the authors reflect that the 'single interview' via phone/online meant they did not get a more thorough description of the social and familial context. Lastly, the

						authors excluded individuals who were not fluent in English, which likely omitted the voices of those who were older, more recent migrants to the UK, or less integrated outside the British Pakistani community, resulting in their perspectives being underrepresented. No participants were over the age of 60.
Hossain & Khan (2020)	Barriers to access and ways to improve dementia services for a	Examined the barriers to health care service use in the Bangladeshi community living in the United Kingdom.	***Study design*** Qual ***Data collection***	***Sampling technique*** Purposive and snowball sampling techniques	Participants faced barriers connected to their religious and cultural beliefs and practices, alongside	The authors reflect that the strength of their study was that it was the first to explore perspectives of both

	minority ethnic group in England		Focus group and semi-structured interviews. ***Data analysis*** Thematic analysis	***Participants*** 27: 21 Bangladeshi community and 6 Bangladeshi family caregivers	challenges related to the complexity of the UK healthcare system. Gender-based caregiving was often seen as conflicting with religious ideologies, while having access to healthcare services that respected religious requirements was viewed as crucial for effective service use. The authors identified two themes. Theme 1: barriers to seeking and accepting help and Key opportunities for improvement	Bangladeshi adults who have and do not have experience with dementia. The authors report limitations in the sample's representativeness as age and gender were not the same in the two phases to be matched. The authors also stated that participants in focus groups had limited knowledge regarding dementia, and therefore, the findings cannot be transferable across the population and family caregivers of people with

						dementia. Also, the study only included those aged 18 and above, meaning that results were not transferable to those under 18.
Mawaka (2018)	Exploring the lived experience of the individual of Black ethnicity living with dementia: A phenomenological study	This study explored the lived experiences of individuals of Black ethnicity living with dementia, across four North East London boroughs. It sought to understand how these individuals perceive themselves while living with dementia, how they cope with the day-to-day realities of	***Study design*** Qual ***Data collection*** Semi-structured interviews (3x each participant) ***Data analysis*** Thematic analysis	***Sampling technique*** Purposive ***Participants*** 6 PLWD	The role of God and religion was significant across different stages of life and shaped decisions about accessing health services. Three overarching themes emerged: Life before Dementia, Journey to Diagnosis, and Living with Dementia.	The author reported a limitation to be their small sample, as participants were from a specific part of London. Therefore, it does not represent all of the Black population living with dementia in the UK, However, it cautions this by stating it was not the purpose to

		the condition, and how they construct meaning around their experiences from their own perspectives				generalise findings. The strengths of the study were reported to be the 3 separate interviews capturing rich data from each participant. Also, the author's phenomenological methodology was stated as a strength and the researcher's capacity to be able to develop rapport with the participants. The author took a mental capacity assessment training to make sure they were confident that participants, the people living with

						dementia, had the capacity to consent during the research. In addition, this is the only qualitative study that looked at the experiences of PLWD in 4 specific London boroughs where little research has taken place regarding the topic.