An exploration of the factors influencing engagement and participation in mental health services and research in ethnic minority communities

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Portfolio Abstract

Background: Research demonstrates that ethnic minority communities have poorer health outcomes in comparison to their White counterparts. However, poor research participation among these groups, particularly in Patient and Public Involvement (PPI), may thwart efforts to close these inequalities. This thesis portfolio aimed to explore the factors that influence engagement with mental health services and research in ethnic minority communities.

Design: A systematic review of literature considering what factors impact engagement with mental health services among Black women in the UK and US was completed. A narrative synthesis of existing data was used to provide a summary of the factors that influence engagement among this group. A qualitative empirical research project used semi-structured interviews to explore what factors influence attitudes towards PPI in mental health research among South Asian and Black communities. This considered how race, experiences of mental health difficulties, and individuals' relationship with the healthcare system may influence attitudes towards PPI.

Results: Within the systematic review: Stigma, Cost, Practical constraints, Mistrust and distrust, Lack of mental health literacy, Stereotypes and culturally sanctioned behaviours, Alternative coping mechanisms, Failures of the care system, and Perceptions of mental health services, were identified as factors influencing engagement with mental health services. There were few key differences between the factors identified in the UK and US. In the empirical project, a thematic analysis identified five superordinate themes across 10 interviews: Drivers for participation, Power, Mistrust, Barriers to engagement and Facilitators of engagement.

Conclusions: Findings from this portfolio suggest that Black and South Asian communities face a number of barriers when looking to access mental health services, or take part in PPI. In particular, negative experiences within healthcare or other systems, may breed mistrust

and distrust, and in turn discourage engagement with services and PPI. Therefore, agencies must look to create a greater culture of trust in systems among these communities. This may encourage engagement, and provide the necessary data to resolve health inequalities.

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Chapter One

Introduction to Thesis Portfolio

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Before considering the importance of identifying the factors influencing engagement with mental health services and participation in research among ethnic minority communities, it is vital to understand the terminology commonly used in the literature when discussing ethnic minority groups.

Traditionally, the terms Black and Minority Ethnic (BME) groups and Black, Asian and Minority Ethnic (BAME) groups have been used to collectively refer to those of non-White origin (Bhopal, 2004). However, this umbrella term neglects the highly nuanced and diverse experiences across ethnic minorities. Instead, this attempts to group all non-White communities under a single collective identity, and fails to acknowledge that these groups often have different health and social care needs (Kapadia et al., 2022). Although these terms have fallen out of fashion in mainstream literature (Race Disparity Unit, 2018; American Psychological Association, 2022; Aspinall, 2021), within research, it still remains common practice to use 'BME' and 'BAME' (Bhopal, 2004). This highlights the need for researchers to move towards the use of terms that acknowledge the diverse experiences and resultant needs of ethnic minorities. This research will instead use the terms ethnic minority groups, communities or populations, or refer to specific minority groups, in order to model the necessary cultural shift in the discussion of race and ethnicity within research (Khunti et al., 2020).

Health inequalities cost the National Health Service (NHS) an estimated £4.8 billion extra a year. They cost society around £31 - £33 billion a year in lost productivity, and between £20 - £32 billion a year in lost tax revenue and higher benefit payments (Public Health England, 2021). The 2019 NHS Long-term Plan highlights health inequalities as one of the NHS's key priorities over the next 10 years (NHS, 2019). Along with pledges of taking 'stronger' action to address the discrepancies in health outcomes among different groups, this also promises to take greater action to prevent health inequalities (NHS, 2019). Black and South Asian communities in the United Kingdom (UK) face some of the most alarming health disparities in comparison to White British communities (Evandrou et al., 2016; Karlsen et al., 2010; Randhawa, 2007; Smith et al., 2000). The King's Fund (2021) reported that rates of infant and maternal mortality, cardiovascular disease, and diabetes are higher among Black and South Asian groups. Individuals from ethnic minority communities are also more likely to report poor general health in comparison to those of a White British background (Smith et al., 2009; King's Fund, 2021). In addition, those from Black and South Asian backgrounds are more likely to report life limiting long-term illnesses (Harding & Balarajan, 2000; Becares, 2013). Furthermore, it is important to note that the onset of the Covid-19 pandemic further widened the gap between groups, as those from ethnic minority communities showed higher overall mortality than the White population (King's Fund, 2021; Office for Health improvement and Disparities, 2022). Mental health outcomes among these communities also show similar disparities to physical health. Research shows that Black and South Asian people are more than twice as likely to experience psychosis than their White counterparts (Qassem et al., 2015). Members of the Black community are three to five times more likely to be diagnosed and admitted to hospital for schizophrenia in comparison to any other ethnic group (Bhugra & Bhui, 2001). In addition, data suggests that some mental health difficulties, like emotionally unstable personality disorder, are less likely to be diagnosed in Black patients in comparison to White patients (McGilloway et al., 2010). Rates of depression are significantly higher in Black and South Asian communities (Memon et al., 2016), and South Asian women have a relatively higher prevalence of mixed anxiety and depressive disorder in comparison to women from other ethnic groups (Rees et al., 2016).

These disparities raise questions of what may be driving these patterns. Ethnic minority communities face inadequate access to primary care (Dorwrick et al., 2009), and report higher levels of dissatisfaction with mainstream mental healthcare (Sandamas & Hogman, 2000). These communities are also more likely to prematurely disengage with treatment and mental health services (Wang, 2007). A review by Memon et al. (2016) into barriers to accessing mental health services among ethnic minority groups, identified inter-related environmental and personal barriers to engagement. Environmental barriers included the positive impact of social networks, negative perceptions of, and social stigma against mental health, and financial factors. Perceived personal barriers included the inability to recognise mental health symptoms or accept a diagnosis, cultural beliefs, such as being ‘strong’ (coping alone with mental health difficulties), a lack of awareness of mental health difficulties and their symptoms, and language constraints. The relationship between patient and healthcare provider was also cited as a barrier. Participants expressed that practitioner’s hesitance to consider how the ethnic minority experience, and racism may play a role in mental health difficulties, was a barrier. In particular, the distrust and mistrust of mental health services and professionals is often cited in literature when considering barriers to engagement with healthcare systems among ethnic minority communities (Kennedy et al., 2007; Wells & Gowda, 2020; LaVeist & Carroll, 2002; Jaiswal, 2019).

Within healthcare, trust is defined as a patient’s belief that their doctor is acting in their best interests (Ashcroft et al., 2006). Trust is essential to the patient-provider relationship, and without this, patients may not access healthcare services, or disclose all necessary medical information (Rowe & Calnan, 2006). The terms mistrust and distrust do not simply refer to a lack of trust, and though they are frequently used interchangeably in literature, they each represent distinct beliefs. Griffith et al. (2021) argues that the term distrust captures feelings of doubt or suspicion that someone is not competent, or does not have your best interests at heart. This may arise from what an individual knows, or has heard about a healthcare provider or organisation. Mistrust, however, relates to a general sense of unease or suspicion that may not always be directed at something or someone. These feelings may be rooted in prior betrayal, or a broken sense of trust stemming from historical and systemic injustices (Griffith et al., 2021). It is important to note that everyone could approach interactions with systems with a level of mistrust. However, for ethnic minority communities, this may be rooted in distinct historical experiences linked to group identity, personal experiences, oral histories, and vicarious experiences (Griffith et al., 2021).

Grier and Cobbs (1968) argue that for Black people, this ‘healthy cultural paranoia’ is an adaptive and valid approach to being Black and interacting with health systems, government, justice and educational systems, that have a long history of racism and systemic inequity. Medical mistrust can result in the under-utilisation of healthcare services (LaVeist et al., 2009), reduced engagement with care, and reduced adherence to care recommendations or instructions (Bickel et al., 2009). Within ethnic minorities, medical mistrust is a social determinant of health and healthcare disparities (The US Institute of Medicine, 2003). Evidence suggests this may develop in response to perceived discrimination both inside (Durant et al., 2011), and outside (Hammond, 2010), of the healthcare system. Furthermore, among these groups, the lack of engagement that results from medical mistrust can also lead to poor representation of these communities within healthcare decision making and policy (Bhopal et al., 2007).

In addition, literature suggests that cultural perceptions of mental health difficulties may also act as a barrier to accessing mental health treatment. For example, research conducted in India highlighted that people have distinct ways of labelling, categorising, and responding to experiences of distress (Weaver et al., 2023; Wahid et al., 2021). In particular, research completed by Roberts et al., (2020) in rural India, found that a key barrier to seeking care for mental health difficulties in this community was the lack of perceived need for the treatment of these symptoms among participants. Instead, depression-like symptoms were attributed to socio-economic circumstances, or stress associated with physical illness. Participants commonly reported physical, as opposed to emotional or psychological symptoms of mental health difficulties, due to perceptions that staff were only equipped to address these concerns. Prior work has hypothesised that this may stem from differences in the way mental health difficulties are conceptualised across cultures. In particular, contrasts between Western biomedical models of psychological distress, and social or spiritual explanations and understandings of mental health difficulties that may be adopted by other cultures (Karasz et al., 2013). This suggests that for those from other cultures, cultural perceptions of mental health difficulties may form an additional barrier to accessing mental healthcare.

It is also important to note that race cannot be considered in isolation when discussing health inequalities. This also intersects with other barriers such as gender, socioeconomic status, geographical location and culture, to further compound structural inequalities in healthcare (European Institute for Gender Equality, 2021). For example, there are gender differences in healthcare access and utilisation. Women are more likely than men to report unmet needs for medical care (Long et al., 2011), and delays in receiving medical care (Ng et al., 2010). These patterns may be the result of gender bias and discrimination within the healthcare system (Marcum, 2017; Chapman et al., 2013). Therefore, when discussing ethnic and racial inequalities in healthcare, additional characteristics such as gender cannot be neglected, as these factors also influence perceptions, and the use of healthcare services (European Institute for Gender Equality, 2021). An example of this can be found among the Black community. Here, the intersection between race and gender gives rise to different mental health inequalities and barriers to accessing care between sexes. Research found that the prevalence of common mental health difficulties among women varied across ethnicity, with Black women being more likely to experience a common mental health difficulty than their White counterparts (McManus et al., 2016; Department of Health and Social Care, 2018). These differences in prevalence across ethnic groups were not observed in men. A similar pattern has also been observed in the United States of America (US), where Black women show a higher prevalence of depression, in comparison to Black men (Ward et al., 2013). Furthermore, research suggests that for Black women, stereotypes such as the ‘strong Black woman’ present a barrier to accessing mental health care (Woods-Giscombe et al., 2016). However, for Black men, traditional ideas of masculinity and male ‘pride’ may prevent engagement with mental health services (Memon et al., 2016). Differences in the mental health needs, and barriers to engaging with mental health services among Black men and women, stand as a reminder of the complex and intersectional nature of health inequalities, especially within ethnic groups. These differences between men and women suggest that greater consideration must be given to the unique and individual experiences of Black men and Black women, when looking to engage with mental health services.

Evidence-based practice is fundamental to all healthcare systems. This is driven by the ethos that healthcare-based decisions should be based on the most relevant, timely, and valid research evidence (Titler, 2008). However, the quality of this evidence is only as good as the research from which it draws, and health research itself is guilty of perpetuating many of the inequalities in engagement and participation seen in the wider health system (Smart & Harrison, 2017). A report by the King's Fund (2021) into the health of people from ethnic minority groups in UK concluded that, 'Comprehensive, good-quality data is essential for enabling policymakers and health care professionals, to identify the specific needs of different ethnic groups, respond with tailored strategies for addressing inequalities, and track the impact of these strategies.' This suggests that research participation among ethnic minority communities is crucial to understanding and remedying health inequalities. However, research has reported a disproportionate lack of research participation among these communities (Redwood & Gill, 2013; Hussain-Gambles et al., 2006; Huang & Coker, 2010; Giuliano et al., 2000). This pattern may hinder progress to reducing health inequalities by thwarting researchers' attempts to better understand the needs of these communities. While previous research has investigated the lack of research participation among ethnic minorities (Hussain-Gambles et al., 2006; George et al., 2014; Shavers et al., 2001), this issue may be better addressed further upstream. Particularly, in the evidence development process, by involving ethnic minority communities in the conception and development of research.

A critical component of health research is lived experience and public involvement. Here, representatives act as advisors, drawing on their experiences as members of the public who use healthcare services, or their lived experience, to contribute to project development. Formally, this process is known as Patient and Public Involvement (PPI). This practice facilitates the inclusion of service users and members of the general public in research as consultants, advisors, collaborators or co-researchers (INVOLVE, 2012). Meaningful involvement in PPI activities has been associated with reducing systemic power imbalances, increasing levels of trust between participants and researchers, and improving recruitment, and outcomes in research studies (The Partners2 writing collective, 2020). This led to PPI, or user involvement, becoming a mandatory part of health research funding systems in the UK. As such, PPI has become a somewhat political asset to health researchers, and concerns have arisen that linking PPI activities to funding means that this practice has become tokenistic, as opposed to being truly equitable (Lewis, 2014).

Despite these concerns, PPI practices in research design may still offer a potential solution to difficulties in research recruitment among Black and South Asian communities, mental health service engagement, and, in the longer-term, the health disparities experienced by these groups. However, previous research has reported a systemic and consistent lack of PPI participation within ethnic minority communities across UK and US populations (Bret et al., 2010; Dawson et al., 2018; Ocloo et al., 2021; Ocloo & Matthews, 2016; Ocloo, 2018). Due to the lack of PPI participation in Black and South Asian groups, health research practices may remain unchanged, perpetuating cycles of exclusion. As a consequence of this, health research is unable to gather vital data from these communities to better understand unmet needs, shape services, and potentially increase engagement. Theoretically, as a result of this upstream exclusion, the health disparities these communities face, persist (Baah et al., 2019). A systematic review by Dawson et al. (2018), concluded that further research was necessary to identify specific factors that inhibit or facilitate ethnic minority involvement in health and social care research. This review also called for greater specificity when looking at patterns of involvement among different ethnic minority groups.

Despite the lack of representation of these communities in clinical research, little is known about the relevant factors that influence the participation of these groups in PPI. When combined with existing research, such insight can provide vital guidance for researchers on how to engage Black and South Asian populations in PPI. Long-term, this knowledge may facilitate the development of interventions and services that address the unique needs of these communities. This may increase engagement in these groups, and ultimately offer an approach to reducing structural health inequalities and marginalisation.

Summary of Thesis Portfolio

Given the gaps identified in existing literature, the aim of this portfolio is to explore the factors influencing engagement in mental health services, and participation in research, within ethnic minority communities. This will begin with a qualitative systematic review considering what factors impact engagement with mental health services among Black women in the UK and US. Following this, I will consider the conceptual links between the systematic review and empirical paper, reflecting on the overlapping barriers to engagement with mental health services and PPI. This will lead on to a qualitative study examining what factors influence attitudes towards PPI in mental health research among Black and South Asian communities. In an additional chapter, I will discuss the rationale for the epistemological position of the empirical research, considering how this impacted the completion of the project. This chapter also further details the process of completing PPI, and briefly reflects on the unique challenges this creates within a doctoral project. The portfolio will end with a critical examination of findings from both the systematic review and empirical paper. I will contextualise findings within existing research, consider the impact of this new contribution to the field, and the implications for practice within Clinical Psychology.

Chapter Two

Systematic Review

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Systematic review paper prepared for submission to ‘International Journal for Equity in Health’

Author guidelines can be found in Appendix A

What factors impact Black women's engagement with mental health services in the United Kingdom and The United States of America: A systematic review

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Background: Research has shown a lack of engagement with mental health services among Black women in the United Kingdom (UK), and United States of America (US). This trend persists in both locations, despite differences in the structure and funding arrangements of each healthcare system. While existing research has identified these patterns, the current research aimed to synthesise this data to present a coherent summary of factors impacting engagement across both settings.

Design: A systematic search of qualitative research across PsychINFO, Medline, CINHAL and Embase, identified a total of 9,372 records. Papers were screened at title and abstract and full-text level, according to eligibility criteria. Research quality was appraised using the Critical Appraisal Skills Programme (CASP). Relevant data considering the factors impacting Black women's engagement with mental health services were extracted.

Results: Twenty-two studies, 8 from UK and 14 from the US, met eligibility criteria. A narrative synthesis of data revealed that: Stigma, Cost, Practical constraints, Mistrust and distrust, Lack of mental health literacy, Stereotypes and culturally sanctioned behaviours, Alternative coping mechanisms, Failures of the care system, and Perceptions of mental health services, impacted Black women's engagement with mental health services. Cost was identified as a factor unique to the US.

Conclusions: Results suggest that Black women face barriers at systemic, community and individual levels when attempting to engage with mental health services in the UK and US. In particular, poor treatment outside of the health system bred distrust and mistrust, this led to a lack of engagement among Black women. Failures of the care system, such as cultural incompetence, also discouraged engagement among Black women. Systemic recommendations include the introduction of cultural competency training. This would equip professionals to work with the diverse populations encountered in the healthcare system. Healthcare professionals must also be aware of additional context when working with Black women, particularly how previous experiences within the healthcare system can impact present engagement, or lack thereof. Spaces such a supervision and reflective practice should be utilised to consider the reasons for potential disengagement among Black women.

Registration: This review was registered on PROSPERO (CRD4202231561) prior to completion.

Key words: Black women, mental health services, engagement, systematic review.

Introduction

Mental health difficulties have been identified as one of the major health concerns facing the United Kingdom (UK; The Mental Health Foundation, 2013). The World Health Organisation (WHO; 2016) estimates that one in four adults will experience an episode of mental ill health at least once in their lifetime. Global rates of mental health difficulties are on the rise, and have increased by 13% since 2017. Mental health difficulties now account for one out of every five years lived with disability (WHO, 2022). Annually, depression and anxiety cost the global economy $1 trillion (WHO, 2022).

While the burden of mental health difficulties on society is well documented, research suggests members of the Black community experience a number of mental health inequalities when compared to other ethnic groups. Black people are more likely to experience undiagnosed and untreated mental health difficulties (Cooper et al., 2013; Prady et al., 2016), be diagnosed with severe mental illness (Halvorsrud et al., 2019) and gain access to healthcare via crisis or compulsory pathways (Barnett et al., 2019; Bansal et al., 2014), in comparison to the majority ethnic group.

In the UK, Black women make up approximately 2% of the population (UK Government, 2022; UK Government, 2019). This group in particular face a number of mental health related inequalities. Despite higher rates of diagnosis of mental health difficulties, and greater need in this population (Mental Health Foundation, 2016), the majority of Black women do not receive the appropriate care they require, particularly in early intervention services (Bhui, 2001; Wagstaff et al., 2012). As a result, this group remains under-represented in primary care services, yet over-represented in inpatient and crisis facilities (Lubian et al., 2016). In addition, Black women are more likely to disengage from treatment such as therapy and counselling, limiting the effectiveness of these interventions, and resulting in poorer treatment outcomes (Wagstaff et al., 2012; Cooper et al., 2012).

Furthermore, this group often leave services that could help them sustain psychological wellbeing (Cooper et al., 2012).

These patterns of inequality among Black women in the UK, are also present in The United States (US), despite the distinct health systems in these two countries. In the US, Black women are less likely to seek care for mental health difficulties (González et al., 2010; Wang et al., 2005; Woodward, 2011) and are among the most under-treated groups for depression (Nelson et al., 2020). Furthermore, similar to the UK, when Black women do receive treatment, this is more likely to be insufficient, as healthcare providers often miss (Borowsky et al., 2000) or misdiagnose their symptoms (Gara et al., 2018; Olbert et al., 2018).

It is important to note that the discussion surrounding Black women's mental health is frequently undertaken in the context of the Black community as a whole. Wilson (2001) argues that the nuanced experiences of Black women can become subsumed by that of others in the Black community, or eclipsed by the experiences of ethnic minorities in general. However, when exclusively compared to other ethnic groups, Black women in particular experience poorer outcomes. For example, they are more likely to receive a severe mental health diagnosis such as schizophrenia than White women, despite presenting with similar symptoms (Gujawani et al., 2016). Evidence suggests this may be down to differences in the way mental health difficulties are interpreted and diagnosed in Black women. A study by Perez et al. (2022) found that among Black women, increased stress was associated with depressive symptoms that would not be detected by standard screening measures. A similar pattern has been found in emotionally unstable personality disorder (EUPD), with Black women presenting with greater difficulty controlling anger, and fewer suicidal behaviours in comparison to White women. Authors argue that this may increase the risk of misdiagnosis and mistreatment in this population (De Genna, 2013). In addition to differences between Black women and women of other ethnicities, research has also highlighted differences between Black men and Black women. Research suggests that Black women experience higher rates of depression in comparison to Black men in the US and UK (McManus et al., 2016; Ward et al., 2013). Furthermore, for Black women in particular, the intersection of gender and race give rise to experiences that are unique from that of White women, and Black men. Often referred to as 'double jeopardy', Black women may experience racism *and* sexism (Sesko & Biernat, 2010), both of which have negative impacts on mental health (Feigt et al., 2022; Thomas et al., 2008), and act as barriers to accessing mental health services due, in part, to fear of discrimination, experiencing negative interactions, and institutional distrust (European Institute for Gender Equality, 2021; Kapadia et al., 2022). Therefore, the unique experiences of Black women may create additional and distinct barriers when attempting to access mental health services, particularly in comparison to White women and Black men. This makes the sole consideration of this population all the more important.

The difficulties Black women face accessing the appropriate mental healthcare may lead to longer periods of untreated mental health difficulties. Research completed in the general population shows that longer durations of untreated common mental health difficulties like anxiety and depression, have been associated with higher rates of chronicity, higher comorbidity, and lower long-term quality of life (Green et al., 2012). For severe mental health difficulties such as psychosis, greater durations between onset and treatment, are associated with poorer responses to antipsychotic treatment (Perkins et al., 2005), and poorer quality of life at first contact with services (Marshall et al., 2005). Therefore, it can be hypothesised that some of the poorer health outcomes reported by Black women, could be directly linked to inadequate access, and delays in receiving care once early symptoms of mental ill-health emerge.

Examining this theory further, patterns of decreased engagement with, and disengagement from, mental health services have led Black women be branded as a 'hard to reach' group (De Maynard, 2009). Freimuth and Mettger (1990), and De Maynard (2009) argue that this term is pejorative, and stands only to further alienate and stigmatise this group, by suggesting they are to blame for not contacting services to meet their needs. In reality, Black women face a number of barriers to accessing and engaging with mental health services. Negative experiences, cultural mistrust, stigma, spiritual practices, social narratives, and stereotypes, have all been cited as factors that prevent Black women from accessing mental health services (Copeland et al., 2011; Mattis, 2002 ; Nadeem et al., 2007; Sabari et al., 2013; Whaley, 2001; Edge et al., 2010; Ward et al., 2013). While stereotyping, cultural assumptions, and cultural incompetence of healthcare professionals (Mclean et al., 2003; Dorwick et al., 2009), can lead Black women to disengage with treatment and mental health professionals when they access services.

While it could be argued that some of these barriers represent internal processes that influence Black women's choices to seek care, it is important to acknowledge that these barriers may arise due to interactions between Black women, society, and the healthcare system. For example, social narratives and stereotypes such as the 'strong Black woman', are argued to have arisen from the perpetual mistreatment and oppression of Black women, which necessitated strength and resilience for survival (West et al., 2016; Nelson et al., 2016). Furthermore, research highlights that the cultural mistrust, particularly medical mistrust among ethnic minority communities, may result from experiences of discrimination and poor treatment (Durant et al., 2011; Williamson et al., 2019). Therefore, while it may be tempting to place the burden of poor engagement squarely on the shoulders of Black women, interactions with the healthcare system and the social construction of their roles through social interactions, suggest that these patterns must also be considered through a systemic lens.

As discussed, Black women in both the UK and US face barriers to engaging with mental health services. These patterns remain similar across countries, despite differences between health care systems. In the US, a lack of financial coverage for health services through paid-for insurance among Black women living in disadvantaged areas, is often cited as the source of health inequalities in Black women (Young, 2020). However, it is important to note that as discussed, the UK displays similar mental health inequalities among Black women, despite a health system which is free at the point of delivery (Delamonthe, 2008). Therefore, this may indicate that Black women's mental health inequalities could be the result of socially constructed factors, as opposed to health service affordability. This means that the direct comparison of the factors impacting engagement with mental health services among Black women in these two contexts, could shed light on other key contributors to these inequalities.

Finally, to date, it appears there has been no attempt to synthesise existing data in this area to provide a clear account of the factors that limit Black women's engagement with mental health services. While definitions of 'engagement' vary within literature, the present research defines engagement as a complex combination of the following: attendance, sustained contact with mental health services or mental health professionals, accepting the need for help, adherence to agreed treatment plans, the development of a therapeutic alliance with professionals, and collaborative work towards shared goals (O'brien et al., 2009). This work will prove valuable to medical providers, policy makers and mental health professionals, by identifying potential barriers and in turn avenues for intervention.

Research Questions:

1. What factors impact Black women's engagement with mental health services in the UK and US from the perspective of Black women.
2. Are self-reported barriers to engagement with mental health services among Black women different in the UK and US?

Method

Design

A systematic review of published qualitative literature was completed in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). A protocol for the systematic review was registered on the International Prospective Register of Systematic Reviews (PROSPERO) database prior to commencing the review (reference: CRD4202231561). This detailed the inclusion and exclusion criteria, search and screening strategies, and methodological approach.

A review of qualitative data was selected as this research sought to consider the factors that impact Black women's engagement with mental health services, from the perspective of Black women. The experiences and accounts shared by Black women included in this review were considered through a social constructionist lens. This allowed the analysis and contextualisation of findings to account for the social interactions and influences that may impact engagement with mental health services in Black women.

Ethical Considerations

Due to research design there were no ethical issues identified relating to recruitment or data collection. The systematic review was limited to secondary data, therefore there were no data protection considerations.

Data Sources and Search Strategy

Available literature was reviewed by electronically searching four databases, CINHAL, Medline, PsycINFO (via EBSCO) and EMBASE (via OVID). These journals were selected due to their relevance, high research volumes and frequent use. Hand searches were also conducted, and the first 10 pages of Google scholar, as well as the reference lists of included studies were also reviewed for relevant additional research papers.

Boolean operators 'and' and 'or', wildcards, and truncation symbols '*', were used to combine search terms and maximise search results (Table 2.1), this was adapted to each database as appropriate. Medical Subject Headings (MeSH terms), or database equivalents, were used where available. The present research sought to identify the factors that impact engagement with mental health services among Black women. As outlined, existing research suggests women’s attitudes and beliefs may play a role in this. Both attitudes and beliefs are suspectable to change over time (Schwarz & Bohner, 2001; Sharot et al., 2023). Therefore, date restrictions from 1999 to current day were applied to searches. The year of 1999 was selected as this marked the introduction of the National Service Framework in the UK. This document outlined specific objectives in relation to mental health provision for working age adults in the UK, and ultimately led to the development of current day mental health services (Turner et al. 2015). In the US, the Surgeon General published the first ever report about the nation’s mental health, encouraging people to seek support (United States Public Health Service, 1999). Both of these events are likely to mark a key shift in attitudes and beliefs surrounding mental health.

Table 2.1:

Search Terms

Population		**Subgroup**		**Location**				**Qualitative methodology**
Women OR Woman OR Girl* OR Lady OR Ladies OR Female OR Trans	**A** **N** **D**	"Afro Caribbean" OR Afro-Caribbean OR African-American* OR “African American*” OR Caribbean OR Black OR Blacks OR “West Indian” OR Jamaic* OR Trinida*	**A** **N** **D**	UK OR “United Kingdom” OR Britain OR England OR Wales OR Scotland OR “Northern Ireland” OR USA OR “United States of America” OR	**A** **N** **D**	Provider OR "Mental health service*" OR "Psychological treatment" OR “psychiatric hospital” OR “increasing access to psychological therapies” OR IAPT OR Depress* OR Anxiety OR “mental illness” OR “mental disorder” OR “behavioral health units” OR	**A** **N** **D**	Experience* OR Perception OR Perceive* OR view* OR opinion* OR qualitative OR “grounded theory” OR (phenomenolog* not phenomenologist) OR narrative* OR Attitude*OR belief* OR understanding* OR Qualitative OR interview OR “focus group” OR “content analysis” OR “discourse analysis” OR

	OR BAME OR African-Caribbean OR “African Caribbean” OR “Women of colour” OR “Woman of colour” OR “ethnic minorit*”	Welsh OR Scottish OR American OR Irish OR “National Health Service” OR NHS	Counselling OR "cognitive behav* therapy" OR “Psychological therap*” OR “Primary care” OR Help-seeking OR “Help seeking” OR “community mental health Center” OR “community mental health Centre”	ethnography OR “grounded theory” OR “mixed methods” OR narrative OR “thematic analysis”

Screening and Selection of Studies

Final electronic searches were conducted on 19th June 2022, searches generated a total of 9,372 results. PsycINFO database yielded 2,199 results, CINHAL 1,989, Medline 2,769 and Embase 2,415 results. Hand searches via Google Scholar did not yield any additional results. After removing duplicates, a total of 5869 studies were retained. Records were screened by first author (N.F), according to inclusion and exclusion criteria outlined in table 2.2.

A random sample of 10% of papers at title and abstract stage (*N*=587), were screened (blind) by an independent reviewer who was not part of the research team. Agreement between the first author (N.F), and this reviewer, was high, 99%. However, seven conflicts were detected, these were resolved by discussion with the reviewer after consulting and referencing the eligibility criteria. After full-text screening, a further random sample of 20% of papers were screened by other members of the research team (B.T and C.H), agreement between reviewers was 100%.

Table 2.2:

Inclusion and Exclusion criteria applied during screening.

Component	Inclusion Criteria	Exclusion Criteria
Population	Research involving Black women (including 1st, 2nd and 3rd generation immigrants) currently residing in the US or UK who are 18 years old or above. Women who currently engage or historically have never engaged with mental health services. Research including Black men and women (where research involves both male and female participants, only research that contains codable data e.g., quotes from women will be included)	Research conducted outside of the US and the UK Research with no codable data from Black women. Research that focuses on veteran populations Research looking at mental health service engagement exclusively in men. Research featuring adolescents Research looking at seeking support from university based psychological services or non-healthcare sources of support.
Study Design	Primary qualitative research. Data may have been collected via interviews, focus groups, ethnography or any other qualitative methods.	Dissertation research and books Research using quantitative methodology Pilot research or study protocols Secondary research e.g., Systematic reviews or Literature reviews. Qualitative data that has been converted into quantitative data e.g., via counting the frequency of particular words.
Outcome	Women seeking support or considering seeking support for mental health difficulties.	Research looking at mental health engagement in other facilities e.g., university counselling services. Research looking at access to, or engagement with, the general health care system

	as opposed to the mental health care system. Women seeking support or considering seeking support following a crime e.g., rape or domestic violence. Research considering health service engagement in the context of physical health conditions e.g., HIV or obesity

Data Extraction and Synthesis

Key data was extracted from eligible papers using a data extraction form. Information such as: author, location, research aims, recruitment criteria, sample characteristics, sampling and data collection methods, data analysis, main findings and additional notes was extracted. It is important to note that where research included both male and female participants, or participants of other ethnicities, only relevant quotes from Black women were extracted.

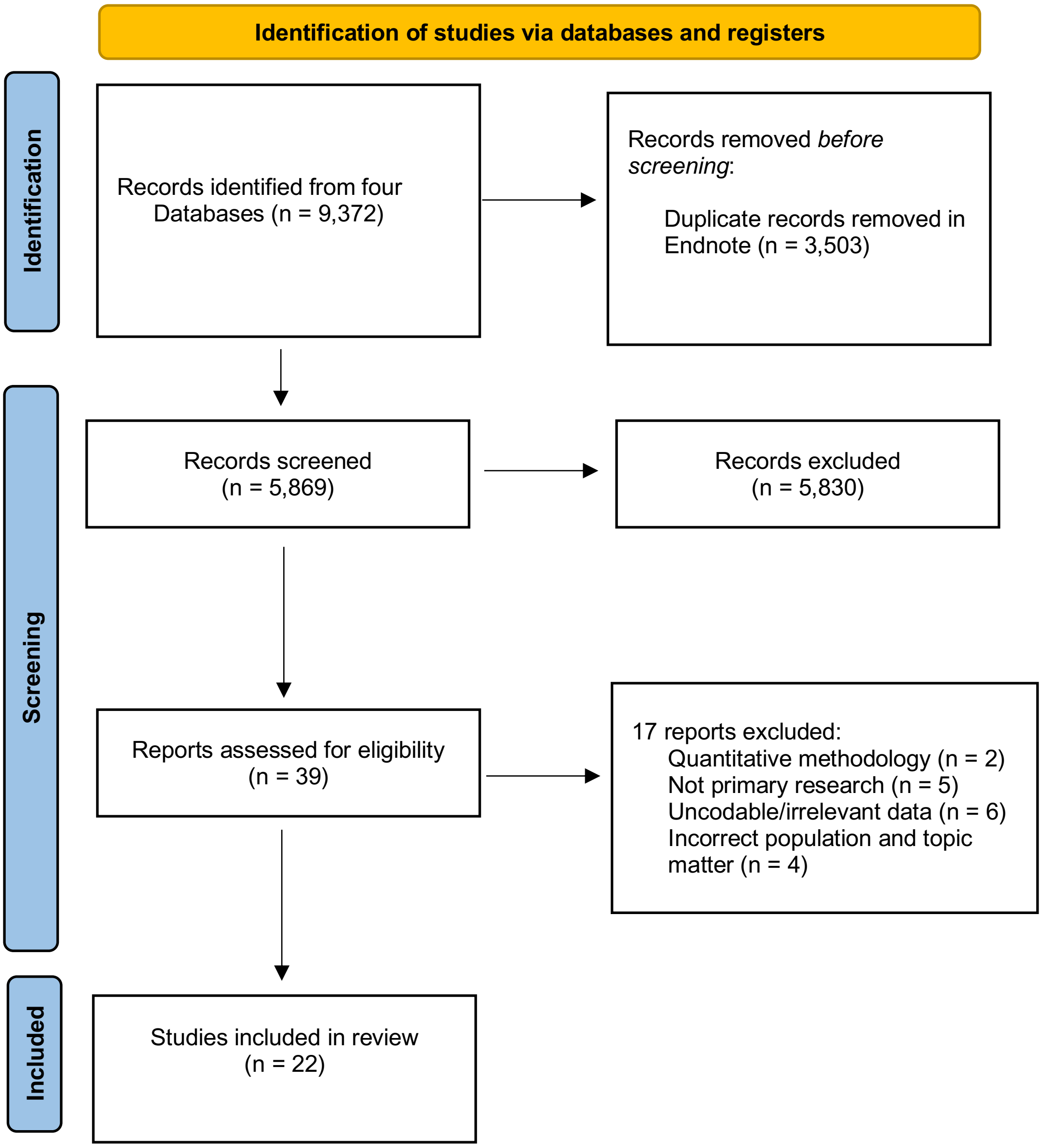
Due to heterogeneity among studies, a narrative synthesis (Popay et al., 2006) was used to provide a coherent summary of results.

Quality Assessment

Twenty-two studies were appraised by first author (N.F) using the Critical Appraisal Skills Programme (CASP) checklist (CASP, 2018; Appendix B). This measure provides prompts to consider when assessing the methodological quality of qualitative research. Specifically, the checklist has 10 questions that span research aims, qualitative methodology, research design, recruitment and data collection methods, reflexivity of researchers, ethical issues, data analysis and the presentation of findings, and their contribution to existing literature (CASP, 2018).

In line with recommendations, the CASP was used to guide information synthesis (Long et al., 2020; Noyes et al., 2018). Members of the research team (B.T and C.H) also appraised ~25% of papers (*N* = 6). Findings were discussed, and disagreements in interpretation were resolved through discussion.

Figure 2.1: *PRISMA Flow Diagram showing the Screening and Selection Process*



Results

The PRISMA flowchart (Figure 2.1) demonstrates the process used to narrow 9,372 prospective citations, to 39 studies based on title and abstract screening, and 22 studies following full-text screening. Of the 22 research studies featured in this review, eight of these studies were completed in the UK, and 14 studies were completed in the US. Hand-searches of reference lists of the final 22 studies did not generate any additional results.

Study characteristics

Research aims, inclusion criteria, sample characteristics, data collection, sampling and recruitment methods, qualitative analysis, and quality rating score are presented in table 2.3. Main findings and additional notes related to findings are presented in Appendix C.

Sampling methods varied across research, while 12 studies used purposive sampling, seven used convenience sampling, one used snowball sampling, one used a mixture of volunteer and snowball sampling, and another random digit sampling. Sample sizes ranged from 7 – 64 (M = 28.6).

Focus groups, and semi-structured individual interview methods were used across all studies included in the review, 11 studies used individual semi-structured interviews, 10 studies used focus groups, and one study used a mixture of these methods.

Finally, analysis methods also varied across research, 16 studies used Thematic analysis or variations e.g., reflexive or inductive thematic analysis, two studies used Interpretative Phenomenological Analysis (IPA), and Framework, dimensional, Grounded theory, and content analysis, were used by one study each.

Quality Appraisal

Research quality across studies was generally satisfactory according to prompts provided on the CASP. Overall scores awarded for quality can be found in table 2.3, (see Appendix D for a breakdown of the quality scores). One issue commonly noted across studies was a lack of reflexivity, and only eight studies had adequately considered the position of the researcher in relation to participants, and reflected on how this may have impacted research outcomes. Thirteen studies did not consider this, and another had only partially indicated consideration of this. In addition, six studies (Connell et al., 2019; Alang, 2019; Bailey & Tribe 2021; Sisley et al., 2011; Graham et al., 2021; Edge & Rogers, 2005) failed to provide inclusion criteria for recruitment, and therefore only partially met quality criteria around research recruitment strategy.

Table 2.3:
Study Characteristics

Author(s), Year and Country	**Aims**	**Inclusion Criteria**	**Sample Characteristics**	**Sampling and data collection methods**	**Data Analysis**	**Quality rating score**
Bailey et al. (2021) UK	To explore help-seeking views and strategies utilised for depression among older Black Caribbean people in the UK.	Not specified.	*N* = 8 Black Caribbean older adults aged between 65 – 79 years old (M = 71.37).	Individual semi-structured interviews Snowball sampling	Interpretative Phenomenological Analysis (IPA)	6
Babatunde & Moreno-Leguizamon (2012) UK	1. To identify cultural elements related to postnatal depression through women's narratives. 2. To help health professionals understand and identify postnatal depression in immigrant women and	1. Women in the postnatal period with babies ≤ 1. 2. Immigrant women who identified themselves as being of African descent between the ages of 16 and 45 years 3. Women who spoke and understood English. 4. Women whose babies were in good health.	*N* = 17 Immigrant women from Nigeria, Ghana, Kenya, Somalia and Sierra Leone, aged between 16 – 45 years old.	2 focus groups (*N* = 8 and 9). Purposive sampling	Thematic Analysis	10

	the cultural ambiguities surrounding this.	5. Women who lived in the South East				
Edge (2011) UK	To examine stakeholder perspectives on what might account for low levels of consultation for perinatal depression among a group of women who are, theoretically, vulnerable.	1. Self-identification as 'Black Caribbean' 2. 18 years old or over. No restrictions were placed on how long-ago women delivered their babies.	*N* = 42 Black Caribbean women aged between 18 – 43 years old. Women were split into 'church attendees' or 'community women'	5 Focus groups Purposive sampling	Framework Analysis	8
Edge (2008) UK	To explore the factors that may account for low levels of consultation for perinatal depression among Black Caribbean women and their absence from perinatal research in the UK.	1. Women of Black Caribbean origin (at least one parent of Caribbean origin), 2. Aged 18 years or older 3. Capable of self-completing the Edinburgh Post-natal Depression Scale (EPDS) (cut-off ≤12) and providing written informed consent.	*N* = 12 Black Caribbean women aged between 18 – 43 years old. Women were split into 4 categories: 1. Depressed during pregnancy. 2. Depressed after pregnancy. 3. Depressed during and after pregnancy. 4. Never depressed.	Semi-structed individual interviews Purposive sampling	Thematic Analysis	9
Sisley et al. (2011) UK	To explore individual explanatory models of experiences of distress, coping and help-seeking choices to improve the cultural relevance of services.	Not specified.	*N* = 7 Black African and Caribbean women who were in their 30's – 50's.	Semi-structed individual interviews Purposive sampling	Interpretative Phenomenological Analysis (IPA)	8

Edge & Rogers (2005) UK	To explore Black Caribbean women's ideas about perinatal depression and the ways in which these are linked to coping with personal adversity	Not specified	*N* = 12 Black Caribbean women in the perinatal period.	Semi-structured individual interviews Purposive sampling	Thematic analysis	7
Edge (2006) UK	To gain insight into the factors which may account for the apparent lack of perinatal depression among Black Caribbean women	1. Women of Black Caribbean origin 2. Aged 18 years or older 3. Capable of self-completing the Edinburgh Post-natal Depression Scale (EPDS; Cox, 1987) (cut-off ≤12) and providing written informed consent.	*N* = 12 Black Caribbean women. Women were aged between 20 – 42 years old.	Semi-structed individual interviews Purposive sampling	Thematic Analysis	7
Graham et al. (2021) UK	To explore how UK African Caribbean women make sense of, and negotiate the SBW stereotype in relation to their emotional wellbeing.	Not specified.	*N* = 18 African Caribbean Women aged between 19 – 57 years old (M = 42 years old).	5 Focus Groups Snowball sampling and volunteer sampling	Reflexive Thematic Analysis	9

Ward et al. (2009) US	To examine African American women's beliefs about mental illness, coping behaviours, barriers to treatment seeking, and variations in beliefs, coping, and barriers associated with aging.	1. African American women. 2. Women aged 25 years and over were eligible for the study.	*N* = 15 The sample was split by age as authors hypothesised that coping behaviours, and barriers might vary by age, age groups were as follows: 1. 'Young': 25 to 45 years (*n* = 5) 2. 'Middle-aged': 46 to 65 years (*n* = 5) 3. 'Older': 66 to 85 years (*n* = 5).	Individual semi-structured interviews Purposive sampling	Dimensional Analysis	10
Nelson et al. (2020) US	To consider how Black women conceptualise help- seeking for depression and how the help-seeking process is informed by the SBW role.	1. Participants had to identify as a Black woman 2. At least 18 years old.	*N* = 30 African American women aged between 18 – 66 years old. (M = 33.43 years old).	Individual semi-structured interviews Convenience sampling	Thematic Analysis	10
Leis et al. (2011) US	To explore perceptions of mental health services as a barrier to service use among low-income, urban, perinatal African-American clients of home visiting programs.	1. Women of African American Origin. 2. Pregnant or had a child 12 months or younger.	*N* = 64, this included staff (*n* = 26) and clients (*n* = 38). 'Clients' were of African American origin M = 24 years old.	5 semi-structured Focus Groups Purposive sampling	Inductive Thematic Analysis	8

Waite (2008) US	To identify and understand the factors that shape African American Women's views of treatment for depression.	1. Self-identified as a woman of African American Origin. 2. Between 18 - 64 years of age 3. Diagnosed with depression by a licensed mental health professional within the past year. 4. Were willing to discuss their perceptions of treatment for depression within a focus group setting. 5. Were able to speak and read English. 6. Were clients at the nurse managed health care centre.	*N* = 36 African American women between the ages of 35 – 45 years old.	5 semi-structured focus groups (6 – 8 participants in each). Purposive sampling	Content Analysis	8
Pederson et al. (2022a) US	To understand the perspectives of mental health, and the role of stigma among Black immigrant women given that limited studies focused on this population.	1. Black woman 2. Membership in two Black immigrant organizations 3. Ages 18–65 years old. 4. U.S. residency 5. Identify as female 6. English- language fluency.	*N* = 22 Black immigrant women ranging between 18 – 65 years old.	5 semi-structured focus groups. Convenience sampling	Thematic Analysis	10
Pederson et al. (2022b) US	To assess the perspectives of pregnant and postpartum African immigrant women on mental illness.	1. Identify as an African immigrant. 2. Pregnant or postpartum within the past 12 months. 3. English speaking. 4. 18 years of age or older.	*N* = 14 African immigrant women ranging between 18 – 65 years old.	1 semi-structured focus group. Convenience sampling	Thematic Analysis	10

Hall et al. (2021) US	To assess how the Strong Black women (SBW) ideal affects Black women's mental health utilisation.	1. Black woman 2. Endorsement of the SBW ideal assessed through the use of the SBW subscale of the Stereotypic Role of Black Woman Scale (Thomas et al., 2004). Scores >30 were considered to be endorsing the SBW ideal. 3. Positive or Negative attitudes towards mental health service utilisation using the Attitudes Toward Seeking Professional Psychological Help-Short Form (ATSPPH-SF: Fischer et al., 1995).	*N* = 62 Black African, Caribbean and African American women between the age of 18 – 72 years old.	8 Semi-structured focus groups (6 – 8 participants in each). Convenience sampling from 143 people who met inclusion criteria.	Thematic Analysis	9
Poleshuck et al. (2013) US	To understand women's health experiences of depressive symptoms and perspectives on the low uptake of psychotherapy.	1. Identify as a Black woman 2. Aged 18 or older 3. Demonstrated the ability to communicate in English. 4. Screened positive for symptoms of depression (scored ≥ 3 on the PHQ-2; Lowe et al., 2005).	*N* = 23 African American and Black women aged between 18 – 49 years old (M = 32.87 years old).	Individual semi-structured interviews. Purposive sampling.	Thematic Content Analysis	10

Abrams et al. (2009) US	To investigate barriers to formal help seeking for PPD symptoms among Low-income ethnic minority mothers.	Inclusion criteria for Low-income ethnic minority mothers included: 1. An infant under 12 months of age. 2. Maternal age of 18 or over. 3. Current recipient of the Women, Infant, and Children federal nutrition program, this meant that household income was at or below 185% of the federal poverty level. 4. English or Spanish language. 5. Self-report of past-year PPD symptoms.	*N* = 37, this included a mixture of: Low-income ethnic minority mothers with PPD symptoms (*n* =14). Ethnicities included Latina and African American/Black. Ages ranged between 21 – 35 years old (M = 28 years old.) ▪ Low- income ethnic minority mothers as community key informants (*n* = 11). ▪ Service providers who work with low-income new mothers in various professional capacities (i.e., nurse midwives, social workers, counsellors; *n* = 12).	A mixture of focus groups (*n* = 5) and individual interviews (*n* = 10) Convenience sampling	Grounded Theory Analysis
Alang (2019) US	1. To characterize unmet need by identifying characteristics of Blacks that are associated with reporting different reasons for	Not specified.	*N* = 30 African American and Latino Black men (*n* = 13) and women (*n* = 17) with mental health need. This included a mixture of community members and service	Semi-structured Focus Groups (*n* = 4) Purposive sampling	Thematic Analysis

	perceived unmet need for mental health care. 2. To examine the degree to which reasons for unmet need are a result of racism. 3. To construct anti-racism approaches to reducing unmet need.		providers. Ages ranged from 22 – 68 years old.			6
Alvidrez et al. (2008) US	To explore Black consumers experiences of stigmatisation and identify strategies for dealing with stigma.	1. Identity's as Black/African American. 2. Over the age of 18. 3. Has experience with county mental health services (including assessment and/or treatment).	*N* = 34 Black male (*n* = 20) and female (*n* = 14) mental health consumers between the ages of 25 – 60 years old (M = 44 years old).	Individual semi-structured interviews. Convenience sampling.	Thematic Analysis	9
Connell et al. (2019) US	To identify barriers to healthcare seeking from differing perspectives, including users and potential users of health care information and services, as well as health care providers.	Not specified.	*N* = 64 African American males (*n* = 24) and females (*n* = 40). Participants were made up of lay community members, volunteer community health advisors and health care providers.	Semi-structured focus groups (*n* = 9). Purposive sampling	Thematic Analysis	8
Conner et al. (2010)	To examine the experience of being	1. Identify as African American.	*N* = 37 African American male (*n* =6) and female (*n*	Individual Semi-structured interviews	Thematic Analysis	

US	depressed among African-American elders and their perceptions of barriers when contemplating seeking mental health services.	2. Men and women aged 60 years and older. 3. English speaking. 4. Reported at least mild-to-moderate symptoms of depression (a score of 5 ≤ on the Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001).	= 31) elders aged between 60 – 81 years old.	Random digit sampling.		9
Campbell et al. (2014) US	To identify culturally shaped beliefs that may be held by Black communities and to understand their impact on participants’ thoughts about depression and treatment, as well as their attitudes about help seeking.	1. Identified as Black or African American. 2. Were 18 years of age or older. 3. Responded yes to at least one of the screening questions.	*N* = 17 Black and African American men (*n* = 4) and women (*n* = 13) between the ages of 21 – 57 years old.	Individual Semi-structured interviews Convenience sampling	Thematic Analysis	9

Narrative synthesis of findings

Nine key factors impacting engagement with mental health services from the perspectives of Black women, were identified. In order of frequency, Stigma, Alternative coping mechanisms, Lack of mental health literacy, Stereotypes and culturally sanctioned behaviours, Failures of the care system, Mistrust and distrust, Practical constraints, Cost, and Perceptions of mental health services, were all identified as factors that impact engagement with mental health services in Black women.

It is important to note that while each of the factors identified are distinct from one another, these factors are also linked, and can be clustered together based on the 'type' of factor. Three broad types of factors included, Systemic factors, Individual factors and Community factors. Systemic factors included, failures of the care system, perceptions of mental health services, mistrust and distrust. Individual factors included practical constraints, alternative coping mechanisms and cost. Community factors included stigma, lack of mental health literacy, and stereotypes and culturally sanctioned behaviours. A diagrammatic representation of the potential links between factors are depicted in figure 2.2.

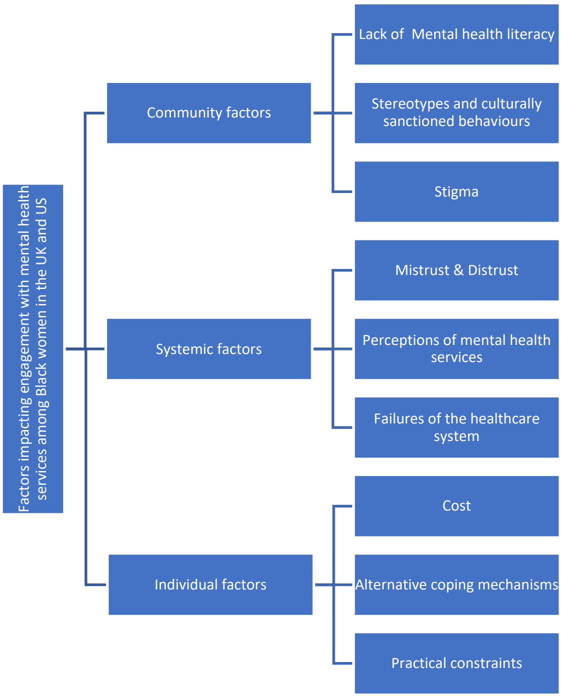


Figure 2.2: *Diagrammatic representation of the links between factors*

Stigma

Both internal and external stigma were identified as a barrier to engagement with mental health services among Black women in 15 research studies. Participants from both UK and US based research described how fears of judgement from others (external stigma) can lead to self-denial of mental health difficulties, and decrease the likelihood of seeking help (Bailey & Tribe, 2021). Participants shared personal experiences of seeing loved ones experience mental health difficulties, the ensuing shame, and how the topic remained a taboo in their family, this led to beliefs that it is not appropriate to discuss mental health with family members (Alvidrez et al., 2008).

One participant described the judgement from family members when she shared she needed help for depression:

‘When I told my family I needed help for depression they said 'you can do better than that. This isn't you. Get strong.' So I don't even mention it to them.’ (Waite, 2008, p. 17)

Participants also reflected on how family members can catastrophise, trivialise and dismiss mental health difficulties, these experiences made it less likely that women would seek support for their difficulties (Graham et al., 2021).

One woman shared her aunt’s response when sharing her experience of mental health difficulties:

‘like I remember saying to my aunty once ‘I’m so depressed’ and she’s like ‘You’re not depressed, that means you want to kill yourself’ (.) but I think you know (.) it is...it is...- there’s levels to depression I think and I was definitely on the scale.’ (Graham et al., 2021, p. 149).

Alternative coping mechanisms

Black women shared a number of alternative coping mechanisms in both UK and US studies. Seven studies conducted in the UK and eight in the US discussed the impact of alternative coping mechanisms on engagement. While women acknowledged that these exercises may not totally alleviate the need for engagement with mental health services, these mechanisms acted as a plaster and offered temporary relief. Women expressed their beliefs in alternative interventions such as increased social support, as opposed to engagement with formal mental health care (Edge, 2008; Edge, 2011). Women also shared their use of spirituality and religion to cope with and navigate the mental health challenges they encountered.

One woman shared her use of prayer as a coping mechanism:
'I had gone through something that I thought that I would never be able to handle. And my coping mechanism was prayer' (Ward et al., 2009, p. 1596).

While women acknowledged that these outlets provided a means of coping with current difficulties, at times, these could also present a direct barrier to engagement.

One participant described how her Christian faith prevented her from sharing her difficulties with others around her, and seeking help:

'... let us bind and get rid of that spirit (laughs) ... you know no Christian has any right with being depressed so you make such a big thing about it ...' (Bailey & Tribe, 2021, p. 116)

Women also shared more potentially unhelpful means of coping, these included the use of alcohol and self-harm, as well as isolating themselves from others, and bottling up their emotions (Abrams et al., 2009; Poleshuck et al., 2013; Alvidrez et al., 2009; Campbell et al., 2014).

Lack of mental health literacy

A lack of mental health literacy among Black women was identified as a barrier to engagement with mental health services in six UK studies, and seven US studies. In particular, a lack of knowledge of mental health difficulties and the symptoms associated with these, led to a lack of awareness, and in turn decreased the likelihood that women would seek the support they needed (Bailey & Tribe, 2021; Babatunde & Moreno-Leguizamon, 2012; Edge, 2011; Edge, 2008).

One participant shared her doubts around what postnatal depression looked like:

‘I don’t know what postnatal depression is, how you’re supposed to feel, look or whatever. I don’t know.’ (Edge, 2008, p. 384)

Another participant shared how people may not be aware they are experiencing mental health difficulties, and in turn that they could benefit from support:

‘... I think a lot of people don’t realise that they need help ... some of them think oh pull yourself together ... especially if you’re a person who talks to yourself ... they don’t know maybe I’ve been down for the last 2 months and probably need to go and get help.’ (Bailey & Tribe, 2021, p. 115).

Stereotypes and culturally sanctioned behaviours

Stereotypes such as the ‘Strong Black woman’ (SBW) were cited as factors impacting engagement in Black women in six UK studies, and seven US studies. Furthermore, culturally sanctioned behaviours such as greater self-reliance, hyper-independence, and simply ‘dealing with it’, all proved barriers for seeking mental health support.

One participant discussed how her endorsement of the SBW stereotype led her to believe that accessing therapy would transgress her beliefs:

‘Our parents taught us that being ‘strong,’ not allowing yourself to be overcome [by] racism and sexism are symbols of pride that represent our culture. Going to therapy would be an insult to our race’ (Hall et al., 2021, p.38).

While women were able to acknowledge the disadvantages of this identity, women also reported a source of pride at ‘doing it all’:

“Strong Black Women have emotional and financial burdens. You’re not thinking of the emotional burden and the financial burden, but it’s there! And so SBW don’t ask for help. We’re too strong for that! We’re stubborn, but then we burn out” (Nelson et al., 2020, p. 275 – 276).

Failures of the care system

Women in five UK studies and seven US studies gave accounts of how systems had previously failed them, and the effect this had on engagement with mental health systems. Women described how at times they had been met with cultural incompetence from medical professionals.

One woman shared an instance in which her therapist had made an assumption about her childhood experiences based on stereotypes:

‘Instead of just asking me, she said ‘it must have been hard growing up without your dad’ but I grew up with my dad always being there. I did not return for my next appointment.’ (Alang, 2019, p. 351)

Another woman told researchers about the discrimination her brother experienced when seeking physical health care:

‘In the emergency room, my brother heard the nurses saying that my other brother was not having psychosis from schizophrenia but that he was high on drugs. They wanted him to do a drug test first’ (Alang, 2019, p. 351)

Other failures of the healthcare system included the failure of medical professionals to detect difficulties (Edge, 2006), as well as offering medication over talking therapy (Waite, 2008). Interestingly, in one study, high staff turnovers among therapists was cited as a barrier to engagement. One woman shared how her experiences of opening up to her therapists only to have them leave their role shortly after, prevented her from seeking further treatment:

‘That’s what made me stop ... You gotta get close to your therapist, you know [be]cause you’re letting them know some really deep stuff you know that you really can’t tell a lot of people ... I’ve got abandonment issues too. ... you feel like a guinea pig, test monkey or whatever you know? They got what they wanted off you. ... passed around so like I said abandonment issues [be]cause you kinda get close to your therapist [be]cause like I said, you can’t help it because you know they’re there’ (Poleshuck et al., 2013, p. 53).

Mistrust and Distrust

Both mistrust and distrust of systems and structures remained a consistent barrier to engagement with mental health services in Black women. This factor was cited in nine US based research papers, and in three research studies completed in the UK. In the UK, women discussed how previous experiences of care, particularly related to physical health e.g., childbirth and chronic physical health conditions, could deter them from seeking mental health support due to a loss of confidence in the system (Bailey & Tribe, 2021; Edge, 2011; Edge, 2008). Women also shared how previous experiences of treatment for mental health difficulties also discouraged them from seeking help if a future need were to arise (Waite, 2008), women's own experiences of working in the healthcare system also stood to prevent them from seeking help for mental health difficulties (Nelson et al., 2020).

Women also discussed mistrust in professional judgement due to claims that professionals had been wrong in the past (Conner et al., 2010). Distrust was also based on beliefs that medical professionals did not know enough about their personal circumstances or histories, to provide an accurate diagnosis (Waite, 2008).

Finally, women also discussed the implications of poor treatment in other parts of the system e.g., workplaces, schools and society, and how this negatively impacted future engagement with mental health services.

One woman shared:

'They treat us bad in school, at work and on the streets. If I'm not dying I'm not going to the hospital. They'll treat us bad there too. You want them to give you medications for mental health? That stuff can mess with you real good…' (Alang, 2019, p. 349).

Perceptions of mental health services

Women's perceptions of mental health services, and what accessing support would entail, also impacted engagement. This was cited in three UK based research studies, and eight US research studies. Here, participants described fears of not being understood and judged by medical professionals. It was unclear whether these concerns were independent of the professional's race.

One participant expressed drawing on her religious beliefs and the support of loved ones to cope as she fears professionals will not understand her:

'I have been through depression. I never sought any professional help. I mostly just lay it on God and ask Him to help me and then I will talk to like someone that I'm very close to. But to seek professional help? I don't feel—because even though they might have that degree, they still won't understand it in my shoes. Because they don't live it—like they might know about it and read about it, but until they actually are in that situation, they won't really understand it completely.' (Nelson et al., 2020, p. 272).

While another participant described her preference for seeking support from family members as opposed to medical professionals:

'I go to my grandmother and my sisters, I don't worry about no psychiatrist or no social worker cause I feel as though that my sisters and my grandmother relate more to what I'm going through than an outsider.' (Leis et al., 2011, p. 316)

Participants also expressed doubts about the efficacy of treatment, particularly therapy (Poleshuck et al., 2013).

Practical constraints

Practical constraints such as childcare, a lack of time, and uncertainty as to how to access mental health services were cited across five US research studies, and one UK study.

In addition to difficulties securing childcare (Edge, 2008), Black women also shared how their experiences of wearing multiple hats created additional pressure. Women reported that in light of the other things they were tasked with, going to therapy seemed redundant when they could barely complete tasks necessary to survive (Waite, 2008; Hall et al., 2021; Connell et al., 2019).

One woman described engagement with psychological therapy as a 'luxury':

'I agree with others but want to add that it's difficult being a Black woman in today's world, carrying the weight of the world on your shoulders, putting up with all the B.S. out in the world while providing and protecting your family and giving the gentleness to those you love. I just keep my business in my house. We don't have the luxury to sit on the therapy chair.' (Alang, 2019, p. 351).

Cost

While cost can also be considered a practical barrier to engagement with mental health services, it was important to identify this specific financial element given the differences in the way the US and UK healthcare systems are financed. Cost was not cited as a factor that influences engagement with mental health services in UK based research. However, this was identified as a barrier in five US based research studies. In particular, cost was seen to dictate access, and whether Black women would receive the appropriate care (Ward et al., 2009; Abrams et al., 2009).

One participant described her fears around what treatments may be prescribed if she accessed support for mental health difficulties, and the financial ramifications of this:

'…even for a lot of working people, their insurance covers "x" number of visits and if you have to go beyond that, you pay out of pocket. A lot of people simply don't have that ability to pay' (Ward et al., 2009, p. 1597)

Factors in the US and the UK

The distribution of factors across UK and US based research can be found in table 2.4. All factors were identified in both UK and US based research with the exception of cost, which was only identified by Black women in the US. All identified factors were present in a greater number of US based research, in comparison to UK based research. However, a greater number of US based research was included in this review, therefore, the increased presence of each factor may be the result of the inequality in research from the UK and US.

In addition, while barriers to engagement remained similar across studies in both of these locations, there were still nuances that must be noted.

In UK based research, perceptions of mental health services appeared to often be tied to perceptions of long waiting lists and a lack of, or limited resources. Women reflected on how these features of the healthcare system in the UK, deterred them from accessing support.

One lady shared her frustration with the wait associated with accessing mental healthcare services:

'... you know with all the cut backs, now my concern is the long waiting ... all the bureaucracy and the long waiting ...' (Bailey & Tribe, 2021, p. 117).

This perception of long waiting times and limited resources in healthcare, was also reported in Edge (2006), and was in contrast to the perceptions of services held by Black women in the US. Instead, Black women's reports in the US reflected beliefs that interventions or support from mental health services would not be helpful (Leis et al., 2011; Poleshuck et al., 2013). However, women across both US and UK samples shared fears that mental health professionals would coerce them into a specific form of treatment, particularly medication, and that this would start a spiral of increasing dosage, medications, and mental health diagnoses.

One woman shared her fears in relation to the experiences of other women around her:

'It's more my auntie that I don't want to end up like. Because she had depression, went on the antidepressants and now she's got like five different types of tablets she has to take in a day and they say that she's got schizophrenia' (Edge & Rogers, 2005, p. 21)

As discussed, cost was only identified as a barrier to accessing care for women in the US. This was discussed in a number of ways, and interestingly, women shared how considerations of costs didn’t end at just accessing services, this worry also extended to treatment options. Women’s experiences also suggested they had competing demands for financial resources and that healthcare did not always win.

A woman shared her fears of accessing mental healthcare and how this may conflict with other financial priorities:

‘Yes I have insurance and a $25 co-pay with each visit. But it is still $25. What if they give me pills? What if I have to go to therapy every week? I just thank God that I don't need to go. My first priority is a making sure we pay our rent, then food. My family cannot be another Black family depending on welfare’ (Alang, 2019, p. 350).

Another woman shared how going to therapy may look through a financial lens:

‘…talking to someone else and you’re having to pay for that, is not seen as a smart purchase in our community” (Abrams et al., 2009, p. 545).

As presented, a mixture of distrust and mistrust was identified across US and UK research. It is important to note that both mistrust and distrust appeared in UK and US research.

Mistrust in US and UK samples was primarily based on prior poor experiences within the healthcare system or mental health services.

A woman in the US shared how her previous experiences had impacted the likelihood of future engagement:

‘I've been hospitalized before against my will. That experience is something I will never forget nor will I easily trust psychiatrists I am very cautious who I talk to and about what.’ (Waite, 2008, p. 17)

A woman in the UK expressed her disappointment with previous care:

‘That is probably why a lot of Black women don’t bother going to the system ... the majority have had nightmares. So you’re thinking, “What’s the point in going back?” It [negative experience during pregnancy and labour] just doesn’t give you any confidence to think they’ll be sympathetic.’ (Edge, 2011, p. 258).

This highlights the importance of previous experiences in the healthcare system, and how this can influence future engagement or lack thereof.

Table 2.4:

The distribution of factors across UK and US based research

Author(s), Year and Country	**Factor influencing engagement with services**								
	Stigma	**Cost**	**Practical constraints**	**Distrust and Mistrust**	**Stereotypes and culturally sanctioned behaviours**	**Perceptions of mental health services**	**Alternative coping mechanisms**	**Lack of mental health literacy**	**Failures of the system**
Bailey & Tribe (2021) UK	X			X	X	X	X	X	
Babatunde & Moreno-Leguizamon (2012) UK	X						X	X	X
Edge (2011) UK				X			X		X
Edge (2008) UK	X		X		X		X	X	X
Sisley et al. (2011) UK					X		X		X
Edge & Rogers (2005) UK	X				X	X	X	X	
Edge (2006) UK				X	X	X		X	X
Graham et al. (2021) UK	X				X		X	X	

Ward et al. (2009) US		X					X	X	X
Nelson et al. (2020) US	X			X		X	X	X	
Leis et al. (2011) US						X			
Waite (2008) US	X		X	X			X		
Pederson et al. (2022a) US	X					X	X	X	X
Pederson et al. (2022b) US	X								
Hall et al. (2021) US	X		X	X	X				
Poleshuck et al. (2013) US	X			X		X	X		X
Abrams et al. (2009) US	X	X	X	X	X	X	X	X	X
Alang (2019) US		X	X	X					

Alvidrez et al. (2008) US	X				X	X	X	X	X
Connell et al. (2019) US		X	X	X					
Conner et al., (2010) US	X	X		X	X	X		X	X
Campbell et al. (2014) US	X			X	X	X	X	X	X

Discussion

The present review aimed to identify what factors impact engagement with mental health services among Black women in the UK and the US. Given the differences in healthcare systems between these two countries, this review also looked to determine whether there are different barriers to engagement with mental health services in the UK and US.

Results revealed that Stigma, Cost, Practical constraints, Distrust and mistrust, Lack of mental health literacy, Stereotypes and culturally sanctioned behaviours, Alternative coping mechanisms, Failures of the care system and Perceptions of mental health services, were all factors that impacted Black women's engagement with mental health services across both countries. Cost was only identified as a barrier by Black women in the US. These factors can be divided into three main groups, systemic factors, individual factors and community factors.

When pieced together, these factors paint a complex picture of the obstacles Black women face when looking to engage, or engaging with mental health services.

Stigma has consistently been identified as a barrier to engagement with mental health services among all ethnicities (Thornicroft, 2008; Thornicroft et al., 2016; Henderson et al., 2013; Henderson et al., 2009). However, this disproportionately impacts those from minority communities (Clement et al., 2015). Black women described how both internalised-stigma, and fears of external stigma, prevented them from seeking support, even when they were aware this may help with their current difficulties. Black women also discussed how stereotypes like the SBW and culturally sanctioned behaviours like 'dealing with it' impacted their engagement with mental health services. The SBW stereotype incorporates a combination of independence, caretaking, strength, resilience and invulnerability (Geyton et al., 2020; Abrams et al., 2019; Beauboeuf-Lafontant, 2007; Romero, 2000). This stereotype is rooted in the enslavement of Africans. Characterising Black women as innately strong justified their mistreatment, however, the embodiment of such characteristics was also necessary for individual and communal survival (West et al., 2016). For those that endorse this standard, this can form a barrier to help-seeking, leading to fears of judgement and shame. Participants spoke of how these expectations of strength and resilience prevented them from to seeking support. However, even among those that reject this stereotype, its pervasion in popular culture and media (Anyiwo et al., 2018), may create expectations of Black women within society, leading Black women to fear external stigma when seeking help for mental health difficulties.

Furthermore, this increased stigma around the experience of mental health difficulties in ethnic minority communities, may lead to a lack of mental health literacy. As the taboo nature of mental health difficulties extinguishes conversation around mental health and wellbeing. Women shared their uncertainty around how particular mental health difficulties presented, this meant they were unable to recognise these experiences in themselves, and in turn, were less likely to seek support from services. However, it is important to note that within existing literature, the relationship between stigma and mental health literacy is unclear, and potentially complex (Jung et al., 2017).

Another potential explanation for a lack of mental health literacy among the Black women featured in this sample, could be that mental health difficulties present differently among Black women. Therefore, when in crisis or psychological distress, because these experiences do not marry with the traditional symptoms they may be aware of, Black women do not seek help. Research has shown differences in the way both depression and EUPD present in Black women (Perez et al., 2022; De Genna, 2013). In this case, it could be argued that this apparent lack of mental health literacy among Black women is actually the result of systemic racism within the healthcare system. As this system has failed to acknowledge the nuances in mental health presentations and symptoms across ethnicities. Instead, this system has centred the experiences of the White population, allowing this to become the template by which all other experiences are judged. This may have marginalised the experiences of minorities like Black women, and given rise to an apparent lack of mental health literacy. In turn, this now acts as a barrier to this group engaging with mental health services. Medical hegemony, and the centring of Whiteness and the White experience as the norm in healthcare is not uncommon. For example, research has highlighted the underrepresentation of diseases depicted on medium and dark skin tones in popular medical textbooks (Louie & Rima, 2018). This phenomenon encourages othering, where care for non-dominant people becomes the exception, rather than regular practice (Smedley et al., 2003). In reality, the lack of mental health literacy identified in Black women may be a complex interaction of both cultural incompetence within the healthcare system, and stigma within the Black community (Memon et al., 2016). Therefore, attempts to overcome this barrier must address both cultural stigma within the Black community, and cultural incompetence within the healthcare system,

This lack of mental health literacy may also explain the use of alternative coping mechanisms expressed by Black women. Black women shared instances of attempts to self-medicate through alcohol. On the other hand, religious practices like prayer, and attending church proved to be a source of strength and comfort for Black women. Research suggests that this may present a more culturally sanctioned alternative to accessing mental health services given the stereotypes around strong Black women (Woods-Giscombe et al., 2020).

Experiences and the awareness of failures of the health care system were also shared by women as a barrier to engagement with mental health services. Stories of misdiagnoses, failures to detect mental health difficulties, as well as a lack of cultural competence, discrimination, and racism were shared by Black women. Understandably, this deterred help-seeking. Research suggests that experiences of discrimination both inside and outside of the healthcare system can influence medical mistrust (Durant et al., 2011; Hammond, 2010). Therefore, these experiences may stoke existing mistrust, or create mistrust in Black women, resulting in another barrier to accessing mental healthcare.

A mixture of distrust and mistrust was cited across both UK and US research as a barrier to engagement with mental health services. Reports from women suggested that poor experiences outside of the health system fed mistrust, and in turn prevented engagement with mental health services. Both the UK and US have long histories of colonial rule, slavery, and ensuing systemic racism. This may have led to a climate of mistrust and distrust of systems, structures, and government (Jaiswal, 2013). In addition, historical examples such as the abuse of Black people in the Tuskegee Syphilis study (The US Public Health Service, 1932) in the US. As well as examples like the death of David Bennett whilst admitted to an inpatient facility (Norfolk, Suffolk and Cambridgeshire Strategic Health Authority, 2003), in the UK, may have continued to breed distrust in Black people. Furthermore, current day experiences of racism and discrimination that Black women face in their own lives, may cement beliefs about the untrustworthy nature of societal systems and structures. This was evident in reports from women in both UK and US samples, and the presence of this barrier in both countries highlights its centrality.

Perceptions of mental health services were also cited as a barrier by Black women across UK and US research. Women's perceptions of mental health services included concerns around being misunderstood, as well feeling that 'talking' about things would not work. This may be due to a perceived lack of cultural competence within the healthcare system, as women may believe that their healthcare providers are not equipped with the knowledge or skills to manage and understand their experiences. In the UK, perceptions of limited resources and long wait times were expressed. These differences may have arisen from the different financing models of health systems in the US and UK. In the UK, residents are frequently bombarded with articles, news segments and political debates about the NHS, often concluding that this system is overstretched and under-resourced (Walker & Raisborough, 2021). This does not mean to say that Black women in the US are not concerned about healthcare provision, however, the lack of resources may not be as salient in this setting. Finally, participants' concerns about being pressured into a particular form of treatment, particularly medication, appeared across US and UK research. These beliefs may stem from the existing power imbalances that feed into how care is delivered within the healthcare system. Research by Memon et al. (2016) identified power and authority between service user and healthcare providers as a barrier to accessing mental healthcare among ethnic minority communities. For Black women, the unique intersection of gender and race may amplify the existing effects of power within the mental healthcare system through additional discrimination such as sexism. Research in the US found an association between state-level structural sexism, a greater inability to access healthcare, and more barriers to affording care among women, but not men (Rapp et al., 2022).

Healthcare costs were not identified as a factor that impacted engagement with mental health services for Black women in the UK. While the identification of costs in the US and not the UK was expected due to differences in financing between health systems. Costs, may be particularly relevant for Black women, as Cocchiara et al. (2006) argues that Black women’s earnings are important contributors to household incomes, and potentially often the sole source of such income. Women frequently spoke about exclusively carrying the burdens within the home, including the financial burden.

Clinical Implications and recommendations

As discussed, Black women face the same patterns of poor care and disengagement within both UK and US health systems. The present review has also highlighted that there are similar systemic, individual and community factors that prevent Black women from engaging with mental health services across both settings. This evidence suggests that while factors within the healthcare system influence Black women’s engagement with mental health services, factors beyond the health system are also implicated in patterns of poor engagement among Black women.

Systemic factors, such as failures of the system, especially cultural incompetence and discrimination, were reported as a barrier to engagement by Black women in the US and UK. Not only did these experiences stand to deter women from engaging with mental health services, these experiences may also increase mistrust and distrust among Black women, creating further barriers to engagement. Changes such as training to increase cultural competence among staff, may decrease instances of discrimination, and in turn, potentially distrust and mistrust among Black women. Research has found that cultural competence training can improve health care provider knowledge and skillset for treating patients from diverse backgrounds (Like, 2011; Truong et al., 2014; Renzaho et al., 2013).

However, this potentially offers a superficial solution to what appears to be a deep-rooted and widespread distrust and mistrust of systems and structures among people of colour. Therefore, solutions must also be sought beyond the healthcare system. In particular, mistrust rooted in historical mistreatment continues to be reinforced by very current racial abuse and miscarriages of justice. As reported by women, mistreatment within schools, workplaces and wider society impacted their willingness to engage with mental health services. Therefore, Black women must be able to trust their governments, justice systems, and research programmes, if they are to trust their doctors, nurses and psychologists. Change in those systems may begin to breakdown historical mistrust to foster the vulnerability and faith necessary for Black women to engage with mental health services.

This being said, health professionals must be aware of the unique mix of barriers Black women face when looking to engage, or when engaging with mental health services. This contextual information is crucial when making sense of Black women's experiences through psychological practices such as 'formulation'. Research has found that participants valued when therapists asked about their culture and background, as they felt this helped the therapist to understand their experiences (Faheem, 2023). Clinicians should also use supervision and reflective practice spaces to discuss the potential presence of their own biases, and consider how this may feed into client engagement.

Limitations and directions for future research

To our knowledge, this appears to the first systematic review synthesising qualitative research to consider what factors impact engagement with mental health services from the perspective of Black women across the UK and US. While this work has provided valuable insight, it also has a number of limitations.

This review sought to examine engagement with mental health services, however clinical offering within mental health services can be extensive and varied. Many of the papers featured in this review consider Black women's engagement with, or views towards therapy. While psychological therapies are a large part of treatment within mental health services, engagement with other forms of treatment e.g., medication, may have been overlooked, and it is possible that Black women have different views on these forms of treatment.

In addition, some of the factors identified in this research may have been pre-determined by the authors questions during data collection. In some cases, research focused exclusively on these factors, so it is unsurprising these same factors arose during data analysis. In these cases it could be argued that the factors are less those described by the women themselves, but more those explored by the researchers. Therefore, future research should utilise more open discussion to allow the identification of additional barriers that may not have been explored by researchers.

It is also important to note that five of the eight UK based research papers included in this review focused on Black women in the perinatal period. While this research still met the inclusion criteria outlined for this systematic review, the lack of research capturing Black women's engagement with mental health services outside of the perinatal period may hint at the neglect of this group among the wider research community here in the UK, as well as an overall lack of value placed on this knowledge. This gap in the literature means that it is imperative that future research looks to better understand engagement with mental health services, or lack thereof, among Black women in the UK outside of the perinatal period.

While several factors have been identified in both the UK and US, it is likely that each barrier may be more or less important in UK and US contexts, given the different health and social priorities in both countries. Therefore, having identified the barriers that exist in both of these countries, future work must consider which factors form the largest or most significant barriers for Black women in the UK or US. This stands to inform health policy and allow mental healthcare providers to tailor their agenda's accordingly, in order to facilitate engagement among Black women.

Furthermore, this preliminary work has tenuously discussed the link between factors, future research may wish to further explore the connections and likely complex interplay between the factors identified in this research. Finally, this work has also focused for the most part on the barriers that Black women face when attempting to engage with mental health services, when reversed, these barriers stand to act as facilitators, therefore, future research could build on this work by considering additional facilitators to engagement among Black women.

Conclusions

In summary, this review has identified a number of factors that impact Black women's engagement with mental health services in the UK and US. These included: Stigma, Cost, Practical constraints, Distrust and mistrust, Lack of mental health literacy, Stereotypes and culturally sanctioned behaviours, Alternative coping mechanisms, Failures of the care system and Perceptions of mental health services. Cost was only identified as a barrier in the US, and not the UK. These factors appear to exist at systemic, community and individual level, and interact with one another to prevent Black women in the UK and US from engaging with mental health services. In particular, failures within the healthcare system prevented engagement among Black women, while poor treatment outside of the healthcare system appeared to stoke mistrust and distrust, and in turn discourage engagement. Clinical recommendations include the introduction of cultural competency training. Health professionals should use supervision and reflective practice spaces to consider their own underlying biases, and the contextual factors that may be prompting disengagement in Black women. Further research may wish to consider the relative importance of each barrier in the UK and US individually, this knowledge can be used to inform policy and service agendas.

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Chapter Three

Bridging Chapter

Word count (excluding references): 1,099

As presented in Chapter two, the systematic review synthesised existing research to provide a comprehensive summary of the factors that impact engagement with mental health services among Black women in the UK and US. These complex and inter-related factors included: Stigma, Cost, Practical barriers, Distrust and mistrust, Lack of mental health literacy, Stereotypes and culturally sanctioned behaviours, Alternative coping mechanisms, Failures of the care system, and Perceptions of mental health services.

Research suggests that Black women are one of the most vulnerable groups due to the intersectionality of ethnicity and gender, driven by entrenched power imbalances. Worryingly, mental health needs among this group appear to be rising (Department for Health and Social Care, 2018; Bignall et al., 2019), creating mounting pressure for mental health services to cater to, and meet the unique needs of this population.

Factors identified within the systematic review provide a window into the relationship between ethnic minority communities and the healthcare system. Though this insight may be limited, as work focused exclusively on Black women, this research exposes the systemic inequalities at work within healthcare. These systemic inequalities and barriers can be observed across all aspects of healthcare, including health research (National Academies of Sciences, Engineering, and Medicine, 2022). Health research conducted with service user participants is essential to providing the best evidence for clinical practice and decision-making. Outcomes from research can lead to the implementation of effective new treatments, improve the efficiency of services, and improve experiences and outcomes for users of health services (Nass et al., 2009). However, health research itself is responsible for perpetrating the same inequalities in access for ethnic minority groups, as seen in the healthcare system (Duran & Norris, 2014). This creates a limited evidence base for the development of interventions and healthcare services, as healthcare research fails to capture the distinct needs of ethnic minority communities, due to their under-representation in research (Redwood & Gill, 2013). In turn, healthcare services remain unrepresentative of, and inaccessible to, ethnic minority communities, perpetuating cycles of exclusion, and fuelling established health inequalities. Given this, the barriers that Black women experience when attempting to engage with mental health services presented in chapter two, may represent the downstream effects of systemic inequalities within healthcare research, in which ethnic minority communities are shut out of healthcare research.

These inequalities may be better addressed further upstream, within healthcare research. One strategy proposed for reducing these systemic inequalities is through Patient and Public Involvement (PPI) in research. PPI is an approach to involving patient or service user representatives as advisors or co-researchers in research studies. PPI representatives provide the ‘patient voice’ to research, and can advise on acceptable methods of research design, participant materials, and recruitment sources and strategies. PPI as part of the research development and management process has been associated with improved recruitment in health research (Crocker et al., 2018), and developing more person-centred approaches in health interventions (Modigh et al., 2021), particularly in mental health research. Using PPI to include ethnic minority communities in the conception and development of mental health research, may increase research participation among these communities. This may create a more diverse evidence base that captures the needs of ethnic minority communities, which can be used to inform the development of mental health services and interventions. Adapting services and interventions in this way may minimise the barriers that these communities face when seeking mental healthcare, this could increase engagement, and in turn, resolve persistent mental health inequalities. However, while a valuable tool for researchers, PPI itself is also associated with poor diversity, and is dominated by the ‘usual suspects’ – those who are retired, White, and of a professional background (Locock et al., 2017).

One explanation for this may be because PPI within mental health research frequently recruits participants who are engaging with mental health services (Department of Health, 2017). This means research activities may reflect, or be impacted by, the wider dynamics of inequality and exclusion seen in mental health services. It has been speculated that mental health services continue to perpetuate cycles of mistreatment, stereotyping, discrimination, institutional racism, and cultural incompetence (Miller et al., 2021; McKenzie & Bhui, 2007). Therefore, it is possible that as highlighted in chapter two, negative experiences within the healthcare system, and perceptions of the mental healthcare system, either when receiving treatment or attempting to access treatment, may colour attitudes towards PPI in mental health research. This may be because PPI, typically initiated by health researchers and clinicians, becomes associated with the wider healthcare system. Furthermore, these negative experiences and perceptions may fuel existing distrust and mistrust towards clinical or academic researchers, further tainting attitudes towards PPI among ethnic minorities, and decreasing the likelihood of engagement.

Collectively, Black and South Asian communities make up 13.3% of the UK population (The UK government, 2022), these communities are the two largest minority groups in the UK, and stand to increase in size in future. Black and South Asian communities face some of the most troubling health disparities. For example, rates of cardiovascular disease, diabetes and infant and maternal mortality are all higher in these populations than White counterparts (King’s Fund, 2021). Sadly, these patterns are also mirrored in mental health outcomes. These communities are more likely to have undiagnosed and untreated mental health difficulties in comparison to White counterparts (Prady et al., 2016), and are more than twice as likely to experience psychosis in comparison to White British communities (Qassem et al., 2015). Rates of mixed anxiety and depression are also higher among South Asian women in comparison to all other ethnic groups (Rees et al., 2016). Again, as with Black women, these patterns of inequality within Black and South Asian communities creates an urgent need for mental health services to meet the needs of these groups. Therefore, understanding the factors that influence attitudes towards PPI in these communities, could increase research participation within these groups. This may facilitate the development of an evidence base that speaks to the needs of these populations, drawing them into mental health services, and resolving the current gaps in mental health outcomes.

Having narrowed the lens to focus on the downstream effects of these systemic inequalities among one of the most vulnerable groups, Black women. The next chapter seeks to widen perspective to consider how ‘upstream’ practices like PPI may be a potential solution to disparities in healthcare access and utilisation among Black and South Asian communities. Therefore, chapter four will present a qualitative research study exploring the factors that influence attitudes towards patient and public involvement in mental health research, among Black and South Asian communities with self-reported mental health difficulties.

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Chapter Four

Empirical Paper

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Empirical paper prepared for submission to ‘Health Expectations’ Journal.

Author guidelines can be found in Appendix E

What factors influence attitudes towards patient and public involvement in mental health research among Black and South Asian communities with self-reported mental health difficulties: A Qualitative study

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Introduction: Patient and Public Involvement (PPI) is a central part of the research process in which members of the public and patients shape research through their contributions. Research shows that this practice increases the impact and integrity of research. However, a lack of diversity among those who participate in PPI has attracted criticism. In particular, the lack of PPI participation among ethnic minorities raises concern, as minorities such as Black and South Asian communities experience some of the worst health inequalities in comparison to White British counterparts. PPI may offer a potential solution to these health inequalities by facilitating cultural competence within mental health services and interventions, however, a lack of PPI participation among these groups may hinder progress.

Methods: Ten semi-structured individual interviews were completed with South Asian and Black participants with self-reported mental health difficulties. Thematic analysis was used to identify themes. PPI representatives provided input throughout the research process.

Results: Five overarching themes: Drivers for participation, Power, Mistrust, Barriers to engagement and Facilitators of engagement were identified. Barriers to potential engagement included language, negative experiences within the healthcare system and a lack of access to opportunities. Findings suggest that negative experiences within the healthcare system and research, may decrease the likelihood of PPI engagement among South Asian and Black communities. In addition, perceived cultural incompetence was linked to increased scepticism among participants. Drivers for participation included previous experiences, a desire for change, helping others and sharing knowledge.

Conclusion: The present research suggests that negative experiences within the healthcare system and research, impact engagement in PPI within Black and South Asian communities with self-reported mental health difficulties. Researchers seeking to recruit individuals from these communities to PPI opportunities must create conditions to empower participants, and

demonstrate the value of their contributions through financial compensation and formal recognition in research outputs. Researchers must also create psychological safety, encourage trust through transparency and accountability, and ensure participants have a clear role within projects.

Introduction

Patient and Public Involvement (PPI) in research is defined as research carried out ‘by’ or ‘with’ members of the public, as opposed to ‘for’, ‘about’ or ‘to’ them (INVOLVE, 2012). PPI is the umbrella term used to refer to public ‘engagement’, ‘participation’ and ‘involvement’ in research, and though these terms are frequently used interchangeably, each denotes distinct categories of research activity (INVOLVE, 2012).

Research ‘participation’ refers to individuals taking part in research, whilst ‘engagement’ is the process by which information and knowledge about research is disseminated. During both participation and engagement, members of the public may have limited power and decision-making authority in steering research development, completion or implementation (INVOLVE, 2012; Carman et al., 2013). In contrast, public ‘involvement’ facilitates active, equitable involvement in research organisations and projects. Service users and members of the public work alongside academic or clinical researchers, encouraging shared power and responsibility (INVOLVE, 2012).

Research often lacks consistency when reporting details of how PPI was conducted within a study, frequently omitting details of the activities undertaken as part of PPI, and the impact this had on the research (Dawson et al., 2018). As there is no single agreed definition, this research defines PPI as an active partnership between researchers and members of the general public (INVOLVE, 2012). This work specifically considers involvement and the ensuing activities which support the development and or conduct of a research study.

PPI has become a central element of the research process nationally and internationally (Gasson et al., 2015). The growing emphasis on PPI within research can be attributed to calls for greater inclusion and representation of the public and patient voice (Boivin et al., 2018), as well as growing recognition of the benefits of this practice on research outcomes, and subsequently healthcare (Boivin et al., 2018). PPI improves the relevance (Mockford et al., 2012), integrity (Wicks et al., 2018), impact, and appropriateness of health research (Brett et al., 2014). Theoretically, this increases the likelihood that outcomes or evidence from research is more likely to be accepted by patients, and implemented in clinical practice. Furthermore, in the UK, PPI addresses demands for greater public input in the leadership of the healthcare system and health research commissioning, as well as political agendas for greater system efficiency (Entwistle et al., 1998). As evidence suggests, PPI is an integral and valuable practice within research. However, the rising popularity of PPI may also hinge on somewhat political motives, as research funding organisations like the National Institute for Health and Care Research (NIHR) make PPI a mandatory part of research when applying for grants (NIHR, 2020). Despite the benefits, PPI has drawn criticism in practice, as key issues such as uncertainty around how to forge genuine, equitable partnerships, and the failure of PPI to address power imbalances, have raised concern (Martin, 2008; Denegri et al., 2015). This criticism, along with PPI’s status as a somewhat political asset, have led some to brand the practice ‘tokenistic’’ (Ocloo & Matthews, 2016; Martin, 2008). Tokenistic forms of PPI may impact both research outputs and those who participate, leading to feelings of frustration. Conversely, when conducted meaningfully, PPI facilitates a partnership between lay members and researchers. This empowers representatives to contribute to research, as they understand their ability to make a difference (Jackson et al., 2020).

Of particular concern, are claims of discrimination and exclusion surrounding PPI. PPI opportunities remain limited to a select few, and discrimination, social exclusion and inequality remain key barriers to PPI engagement among traditionally marginalised groups, including those who are disabled, experience mental health difficulties and members of the LGBTQIA+ community (Ocloo & Matthews, 2016). This lack of diversity has also led to claims that the practice is not representative of the diversity within the British public. In particular, research has highlighted the lack of ethnic minority engagement in PPI, with PPI members disproportionately comprised of White, well-educated and retired representatives (Howe et al., 2006).

The failure to include ethnic minority communities within PPI, as well as the lack of engagement among these groups, is of particular concern given the health disparities these groups face. In comparison to a White population, disability free life-expectancy is estimated to be lower among several ethnic minority groups (Byrne et al., 2020). In particular, Black and South Asian communities experience some of the poorest health outcomes in comparison to White British communities. Black people experience a greater prevalence of hypertension, stroke and diabetes, while South Asian groups experience higher rates of heart disease (Byrne et al., 2020). These inequalities in health outcomes between ethnic groups also extend to mental health outcomes. Detention rates under the Mental Health Act are four times higher in the Black population in comparison to White counterparts (National Health Service Digital, 2020). Black and South Asian men show a higher prevalence of psychosis in comparison to other ethnicities (Bebbington et al., 2016). Furthermore, data also shows higher rates of hospital admissions for psychotic illness among the Black community (Byrne et al., 2020). In light of the health inequalities experienced by Black and South Asian communities, the present research focused exclusively on these groups.

Explanations for the health inequalities within these populations propose a complex interplay of overlapping factors. Intersectionality of gender, ethnicity, geography and socio-economic status, as well as structural racism and discrimination may give rise to health inequalities. In particular, access to, and experiences of, health services among these communities continue to fuel inequalities. While access to primary care is considered equitable among ethnic groups, this is less consistent across other health services, furthermore, ethnic minority groups also report poorer experiences of using health services than White counterparts (King’s Fund, 2021). Outside of the healthcare system, ethnic minority communities are also disproportionately affected by socio-economic deprivation – a key determinant of health (Robertson et al., 2021). Research shows that the proportion of people from ethnic minority groups living in the most deprived areas in the United Kingdom

(UK) is higher for nearly every ethnic group in comparison to White British people (King's Fund, 2021).

Literature on PPI participation among ethnic minority communities is limited. However, a systematic review by Dawson et al. (2018) examined ethnic minority involvement in health and social care research across 45 studies. Research found that involvement was limited to certain ethnic minority groups, and particular phases of research. In addition, 41 of these studies focused on physical health, and only 11 studies considered the barriers and facilitators to involvement. Commonly reported barriers included time constraints, as well as a lack of previous research involvement. The review did not identify research that provided insight into personal, social or cultural factors specific to ethnic minority communities that influenced PPI participation. Furthermore, only two studies were completed in the UK, with the remainder completed in the United States of America (US). Given the distinct ethnic make-up of both countries, along with the unique health and social care landscape of the US, factors influencing PPI among ethnic minority groups here in the UK may markedly differ. Authors concluded by calling for future research to identify specific factors that inhibit or facilitate ethnic minority involvement in health and social care research, and greater specificity when looking at patterns of involvement among different ethnic minorities.

Though research into the barriers and facilitators of PPI engagement within ethnic minority groups is limited, research into barriers to research participation among these groups may shed light on potential factors at play. A review by Jutlla et al. (2017) identified mistrust of governmental services and health professionals as a barrier to research participation among ethnic minority populations. This barrier is commonly reported across research in this area (Hussain-Gambles et al., 2004; Sullivan et al., 2007; Gill & Redwood, 2013; Bruton et al., 2020; Hatchett et al., 2000; Scharff et al., 2010), and hints at the potential systemic factors that may also impact engagement in PPI among Black and South Asian populations. However, little direct work has been undertaken to understand the origin of this mistrust, and how this specifically impacts PPI engagement among ethnic minority communities.

One theory suggests that negative experiences of ethnic minority communities as service users within the healthcare system, as well as interactions outside of the health system with other government authorities, could colour attitudes towards PPI. In turn, this discourages engagement in PPI among these communities. Black and South Asian communities are frequently subject to mistreatment by health professionals and government authorities. Stereotyping, discrimination, racism and cultural incompetence has been detected in the delivery of care across the health service (Bryne at al., 2020). Outside of the healthcare system, ethnic minority communities also experience structural racism and discrimination within housing (Elliot, 2021), employment (Hussein, 2022), and the criminal justice system (Monteith et al., 2022). This could suggest that having been mistreated by these systems, particularly within healthcare, to ethnic minority communities, engaging in PPI would require interacting with the same structures and systems responsible for perpetuating cycles of exclusion, mistreatment, and discrimination. This may explain the lack of engagement across these communities.

Finally, existing research into ethnic minority engagement in PPI has focused on those who have previously participated in this activity. While this has its own merits, it may also bias the pool of potential participants by excluding those who have not been involved to date. Concepts such as perceptions or attitudes also provide a precursor to behaviour. Allport (1935) defines attitudes as a state of mental or neural readiness organised through experience, this exerts an influence on an individual’s response to an object or situation. By considering attitudes towards PPI among South Asian and Black communities who may not have taken part in PPI previously, research can identify what drives engagement or lack thereof.

In summary, meaningful PPI is central to research, improving both the research process and, in turn, research outputs. However, though often encouraged, PPI remains limited in who and whom takes part. Engagement in PPI is particularly limited within ethnic minority communities. This raises a number of issues as ethnic minority populations, particularly Black and South Asian groups, face some of the poorest health outcomes in comparison to White British populations. Increasing ethnic minority engagement in PPI may address issues further downstream, such as the lack of ethnic minority engagement in health services, which contributes to poorer health. This may allow researchers to shed light on the drivers of these health inequalities.

Research Aims

The present research aimed to:

1. Identify which factors influence attitudes towards PPI in mental health research among Black and South Asian communities.
2. Identify barriers and facilitators to PPI engagement among Black and South Asian communities.

Methods

Epistemology and Design

This qualitative research study used semi-structured interviews to identify factors that impact attitudes towards PPI in Black and South Asian communities. Research was conducted from a social constructionist epistemology. This position proposes that the social and psychological worlds are constructed through social processes and interactions (Berger & Luckmann, 1966). Here, the focus is on ‘meaning making’ and the role of individual cognitive and social factors in this process (Gergen, 2015). Within this epistemological framework, this research considered the sociocultural and structural factors that give rise to participants’ attitudes towards PPI.

Patient and Public Involvement

This research hoped to model the values central to PPI, creating a partnership between members of the public and researchers. Two representatives were recruited via local charities working with under-served health populations. PPI representatives provided feedback on all research materials, including the interview schedule, they also identified potential recruitment sources. One representative (A.S), was also involved in data analysis. Representatives were reimbursed for their time.

Participants

Eligibility criteria for participation was as follows: (a) people of African, Caribbean, South Asian or Mixed Heritage, (b) had experienced self-identified mental health difficulties, (c) were 18 years old or above and (d) willing and able to voluntarily provide informed consent to participate in the research interview.

Participants were recruited across the UK through social media (Twitter and Facebook), posters (Appendix F) displayed in various community settings in the East of England, and ethnic minority community-based organisations. Potential participants expressed interest via email to the researcher. Following this, eligible participants were sent a participant information sheet (Appendix G), and invited to ask any questions about participation. A date was agreed for interview. At the start of this session participants were given further opportunity to discuss participation, and informed consent was gained via the research consent form (Appendix H).

A total of 12 responses to research advertisements were received, two of these did not meet study eligibility criteria, therefore, 10 participants (three men and seven women) were recruited. All participants received a £10 Amazon voucher for their participation. Participant ethnic backgrounds included: Black African, South Asian, Mixed Black African/Irish, Mixed Tamil/European and Black Caribbean. No participants withdrew from the study or withdrew their data. In line with the data protection guidelines (British Psychological Society, 2018), participants' confidentiality was maintained by anonymising recorded interviews, transcripts and verbatim extracts.

Data Collection

Ten semi-structured interviews were completed via Microsoft Teams. The duration of interviews ranged from 48 - 90 minutes, with an average length of 70 minutes. All interviews were conducted remotely by the first author (N.F), and were video recorded using Microsoft Teams. An interview schedule (Appendix I), was used to guide interviews. Questions explored participants' motivations for taking part in the research project, their views on PPI, their experiences of mental health difficulties, and their experiences of receiving care from the NHS (for either mental or physical health difficulties). Questions included 'Can you tell me what led you to take part in this interview?', 'What do you know about Patient and Public Involvement (PPI) in research and what do you think of this?' and 'Could you tell me about an experience of receiving care from the NHS?'. The interview schedule remained flexible, this allowed discussions to be responsive and actively shaped by the participants' reflections.

A blend between codebook and reflexive thematic analysis was conducted from a social constructionist perspective. The concept of ‘data saturation’ in which no new information, codes or themes are drawn from the data (Lincoln & Guba, 1985), is often discussed in thematic analysis. Dey (1999) later suggested ‘theoretical sufficiency’ as an alternative to saturation, however, Braun and Clarke (2021) argue that both of these concepts may not be relevant for all forms of thematic analysis. Instead, this concept must be considered in the context of the study’s epistemological position and practical constraints. The authors also propose that ‘information power’ (Malterud et al., 2016) can be used to guide sample size. Here, larger samples produce the adequate amount of information to allow for qualitatively meaningful conclusions to be drawn from the data. This idea, along with the practical constraints associated with doctoral research e.g., issues of time and resource, and the challenges recruiting participants from ethnic minority communities, led to a sample size of 10 being deemed both sufficient for meaningful conclusions to be drawn, and feasible within the constraints of a doctoral project.

Data Analysis

Interviews were transcribed verbatim, and transcripts were analysed using a blend of codebook and reflexive thematic analysis completed by the first author (N.F). Codebook Thematic analysis (Braun & Clarke, 2021) uses a coding framework that is developed prior to or after some familiarisation with the dataset. This coding framework is then applied to the entire dataset. In contrast, reflexive Thematic Analysis (Braun & Clarke, 2022) proposes that themes are produced as a result of researchers’ analytic engagement with data, these patterns of meaning are anchored by a shared meaning or concept. Blending these two approaches provided structure and accountability for the analysis, allowing others in the research team insight and input into the analysis process. However, unlike in traditional codebook thematic analysis, the codebook was not fixed, instead, this was a starting point, and codes were adapted throughout analysis. The analysis was completed using NVivo qualitative data analytical software (version 20.7.1). In line with Braun and Clarke’s (2006) guidelines, all data was first read and re-read to allow familiarisation with the dataset. During this process interesting elements and initial ideas about the data were noted, but not yet coded. Data was then re-read and initial codes were generated. This process was theory driven, and features of the data related to the research question were identified.

The first transcript was coded individually by all members of the research team (N.F., B.T., C.H and A.S). Data was first coded at semantic level, focusing on surface meanings in data by assigning labels that described what was said (Appendix J). A group discussion was then held to discuss 'interesting' features of this transcript (Braun & Clarke, 2006). Following this, a further two transcripts were coded in the same manner, labelling interesting elements of the data at a semantic level. This was followed by another group discussion between all members of the research team during which the first author (N.F), fed-back initial codes generated from further coding. As detailed by Braun and Clarke (2006), the analysis of data moved from description to interpretation. Therefore, while data was first coded at a semantic level, this later moved to latent coding. This process was conducted by reading and re-reading transcripts, reading relevant literature, and continual dialogue between members of the research team. Following this, codes were tentatively collated into potential themes to form a draft coding framework (Appendix K) including theme and code definitions. This was applied to a further two transcripts, and adapted as necessary to capture any new ideas or features of the data in line with the research question. Following this, the coding framework was reviewed by authors C.H and B.T, and then applied to the remaining interview transcripts. It is important to note that this framework remained open to adaptation in light of new concepts in the remainder of data. This involved redefining code definitions and led to the production of a 'final' coding framework (Appendix L). This iterative approach resulted in five key themes and 19 sub-themes being identified across all interviews.

Reflexivity and Rigor

In qualitative research it is recognised that the researcher's perspective plays an instrumental role in data interpretation and analysis (McCracken, 1988). Therefore, it is important to acknowledge the views and experiences that researchers bring to the research process. The first author (N.F) is a Black British woman of African descent. The impact of this, along with other personal, social and cultural factors were closely considered in supervision. In line with the social constructionist position, this included discussions around the multiple identities, and in turn realities, that some participants held as members of ethnic minorities, clinicians and researchers. These discussions were valuable in contextualising and interpreting results. In addition, in line with reflexive thematic analysis, group discussions during the analysis process were used to facilitate reflexivity and collaboration, as opposed to consensus among members of the research team.

In addition, a reflective diary was maintained throughout data collection and analysis by the first author (N.F) (Appendix J). This reflective account included internal and external dialogue to consider how the first author's (N.F) beliefs, characteristics and experiences impacted the data (Tobin et al., 2004). These practices are commonly used to ensure rigor in research (Yardley, 2000; 2017).

Ethical Considerations

This research received ethical approval from The University of East Anglia Faculty of Medicine and Health Sciences Ethics Panel (Appendix M). Participants were treated with dignity and respect at all times (British Psychological Society, 2021). All participants were provided with the Participant Information Sheet and had a minimum of 24 hours to read this. Informed consent was gained prior to participation using the remote procedures outlined in McCarthy et al. (2021), and procedures to manage the disclosure of risk or expressions of distress by participants during or after the interview were developed. Data was kept confidential and anonymised at the earliest opportunity, and pseudonyms have been used when presenting results to maintain participant confidentiality.

Results

A total of five key themes: Drivers for participation, Power, Mistrust, Barriers to engagement and Facilitators of engagement, along with 19 sub-themes, were identified. Subthemes within Drivers for participation included: hope, sharing my knowledge, previous experiences and helping others. Subthemes within Power included: social power, addressing the power imbalance and structural violence, while subthemes within Mistrust included: mistrust of institutions and systems and mistrust of research. The theme Barriers to engagement included subthemes: perceptions of research requirements, language, identity, practical constraints, access and negative experiences. Finally, subthemes within Facilitators of engagement included: psychological safety, research characteristics, empowerment and role. A diagrammatic representation of themes and sub-themes can be found in Appendix N.

Drivers of Participation

Participants cited a number of reasons for their participation in the current research project. These included hopes for change and improvement, increasing awareness of a perceived issue, inclusivity, accessibility and representation.

> '…I think that's what drew me to your research, it's how can we change that? What are the ways we can make sure that it's different, it's inclusive for other people...'
> *Kashm*

Participants also expressed an explicit desire to help others through their participation, this including advocating for others and a desire for equity.

> '…we all have personal experiences that if I could share and it would help someone, you know, it's worth it.'
> *Alice*

Participants' previous experiences were also motivation for their participation.

> '…I've been through that where the help just has not been there, and the help that has been available just isn't suitable for me. There are, like, lots of barriers so any opportunity I see where I can help improve that for other people I want to be one of the first people to take part in it…'
>
> *Grace*

Finally, participants expressed desires to share their knowledge and provide their perspective as a factor in their decision to participate in the present project. Reasons for sharing this knowledge included bridging the gaps in current knowledge and understanding, as well as offering insight and improving research or practice.

> 'Like, I guess giving back or giving a voice, and that's kind of it I suppose. And just knowing that there have been times where I wished things had been different, and maybe services can learn from that, I guess.'
>
> *Amanda*

Power

This theme captured how power affects Black and South Asian communities' engagement with systems. This included engagement with practices like PPI, as well as the healthcare system.

Participants reflected on how the various elements of their identity e.g., gender, level of education, experiences of mental health difficulties and race, impacted their level of power and privilege within society, and in turn, their engagement with systems and structures. Participants' reflections suggest that individual levels of social power (French et al., 1959), may impact their ability and willingness to engage with practices such PPI.

> ‘I am educated and I do have power compared to my mum for example, my mum has more power compared to my grandma for example. And if I was to sit in a room full of [PAUSE] you know, certain demographics, which I perceive as holding quite a lot of power, erm, it would take a lot for me to even express myself. It's almost like I have to be vulnerable. I have to. I have to risk my internal safety or mental safety is sort of.’
>
> *Kashm*

Current and historical abuses of power were also discussed by participants. These patterns of abuse were identified in the healthcare system, as well as within research. Understandably, these events created uncertainty about research.

> ‘The most famous one I think over the last couple of years was the Tuskegee syphilis study, things like that. So I think yes, research can be so harmful, and I think there’s a lot of power that can be abused by researchers…’
>
> *Sophia*

Participants also offered potential strategies for addressing perceived power imbalances in the participant - researcher relationship. Having professionals create space to hear from members of the public, as well as showing compassion, were identified as potential remedies for power imbalances.

> ‘…authentic compassion creates psychological safety and psychological safety, then breaks down the barriers that you know that people feel that people feel that they are on an even footing where they're not gonna be judged and then it enables them to perceive it as a more equal footing rather than a power imbalance…’
>
> *Ayesha*

Barriers to engagement

This theme considered the barriers to engagement with PPI. Participants shared a number of internal and external barriers to engagement with PPI. These included perceptions about the requirements of research, participant fears about whether they have the necessary competency to participate, and specific research characteristics e.g., the topic of research.

> '…I mean, there's a difference between having opinions and experience, which is why, you know, in terms of like the information sheet, I read it and thought, well, am I?- Can I bring enough to the research…'
>
> *Laura*

Language also formed a barrier to engagement, this included the language research is conducted in, how research opportunities and roles are presented, and the use of jargon.

> 'The panel for example, the way the research is done, materials that are done, you know, if I think about my mum and she was asked to take part in a research that's in English and she can barely speak a word of English, how is she going to make that choice for herself?.'
>
> *Kashm*

Experiences of discrimination based on participants' race, health status, socioeconomic status and level of education, impacted participants willingness and ability to engage with systems, including health research. This was due to feelings of disempowerment, resulting in a lack of confidence, or courage, to come forward and volunteer for research.

> '…I think people from ethnic backgrounds due to the discrimination that they've faced, but also due to their cultural upbringing and childhoods and generational

> trauma and migration and all of that…. Potentially whether they're in denial about their mental ill health or not is a different matter, but generally… do probably suffer more potentially underreported, but suffer more from mental ill health anyway, and so potentially might have less courage.'
>
> *Ayesha*

This participant also went on to reflect on the impact of experiences of mental health difficulties and how this can impact levels of 'courage' and in turn PPI engagement.

> 'Your innate courage is also a luxury….when you're in the throes of significant mental ill health, you might face the least amount of courage and people may be scared of making a fool of themselves'
>
> *Ayesha*

External barriers and practical constraints such as time, lack of transportation, and financial compensation were also identified.

> 'Yes, it would be just another thing to do on the to-do list, but for an already overwhelmed person they wouldn't do- And it's not just about the person, like. You want to give research the credibility as well, so if they agree to it and they're not in the right headspace you're going to get the wrong information from them. And then, you know, it jeopardises the research itself too.'
>
> *Alice*

> 'The Sun newspaper and others will pay you for your story. I think something similar needs to happen in research.'
>
> *Benjamin*

Inequality in access to research opportunities was also identified as a barrier to engagement among ethnic minorities. In some cases this was the result of intentional exclusion.

> ‘…So in IAPT for example, they used to say if they require interpreters, don't call them for a service user involvement or focus group.’
>
> *Kashm*

Negative experiences such as invalidation, being misunderstood, minimising, being dismissed or neglected by individuals in systems and organisations like research and healthcare, also acted as a barrier to future engagement.

> ‘…What exactly was the criteria? And then they were really vague again, and that just made me feel really dismissed so that’s one thing I’ve learned about why people might not want to participate in research….It made me, what’s the word - apprehensive about participating in research capturing that topic, because then it made me assume that I wouldn’t be eligible for the rest of them and, like, why waste my time emailing when someone’s just going to be, like, “Sorry, no,” you know.’
>
> *Sophia*

Participants also considered how negative experiences in the healthcare system may impact future engagement.

> ‘I also wonder about, like, those panels for example, or interviews, whether they are capturing everyone’s voice…. like maybe people who’ve had really negative experiences just want to have nothing to do with research or clinicians or, yes, anything to do with the health service.’
>
> *Amanda*

Participants appeared to attribute these negative experiences within the healthcare system to cultural incompetence among staff.

> ‘it's not my own personal experience, my parent going to the doctor - you know with what was presenting as an issue, was just sort of fobbed off with medication and I don't… I think that's as a result of people not understanding the backgrounds of people and the cultures of people…you know, some of the things that he was experiencing would be actually quite normal in Africa’
>
> *Laura*

> ‘…one of my therapists in the past did a role play with me where she was going to say something about me that could be interpreted negatively…the example she gave was someone comes up to you and tells you that they don’t like your hair, and she was saying that and I just thought, this White woman is saying that to me. Like, there are so many layers here that are just not being considered. That’s not just a generic experiment, it’s not just a generic situation…that has so many implications for me particularly as a Black woman. And it wasn’t until our next session that she was, like, “I just want to let you know that I’m aware of, like, what that means for Black women in particular.” But I was, like, “You’re aware *now*, because if you were aware before you wouldn’t have said it.’
>
> *Sophia*

Mistrust

This theme captured the scepticism and doubt that individuals may hold towards established systems and practices such as research and mental health services. This theme also considered the uncertainty that people may hold towards those who they associate with, or they believe represent these systems and practices.

Two broad categories of mistrust were identified, this included mistrust of research and mistrust of institutions and systems. Participants expressed doubts about research safety, researcher intentions, and biases within research.

> '…Everyone has initial biases and that's also the case for researchers who go about their research. And even with people who try to be quite impartial, I think that it's often unfortunately the case that people can usually only be so impartial as human beings.'
>
> *Robert*

Participants also expressed scepticism towards research due to concerns about a perceived lack of diversity in samples and participant populations.

> 'Like I say, if you're not using a spread of like someone from every corner of the planet, then you present, you know your results and the percentage results, and you have a sweeping statement saying that 'there's a percentage of people'… if you're going to make such statements, you need to be able to take a representative quantity from all these different backgrounds and I don't think that happens'
>
> *Laura*

A mistrust of societal structures and systems was also identified, this included mistrust of healthcare professionals.

> 'There's this arrogance that medical professionals can develop, a bit of a God syndrome or an infallibility complex. And me coming from a more open-minded point of view relative to science- I think my colour might have been an issue, I don't know…'
>
> *Benjamin*

In particular, participants expressed scepticism towards perceived culturally insensitive diagnoses.

> ‘…From a cultural perspective, you know, you read that well, you know that…certain mental health issues are predominant in African cultures, which I think is a misunderstanding of the culture itself… not misunderstanding, but not enough research into the culture itself, or… they may be hesitant in diagnosing people. Essentially they don't-… I don't think they see the person, especially from an African community… they don't look at them the same way as they would have Western person…they've just gone ‘oh, this is you!’, when if they actually knew anything about the culture… they would be like ‘ohh and this makes sense- it makes sense some of the things that you're saying’
>
> *Laura*

Facilitators of engagement

This theme captured how systems can create an environment where people can engage e.g., in PPI within mental health research.

Participants discussed the need for psychological safety that facilitates the trust and vulnerability necessary for engagement.

> ‘Let’s say somebody experienced racism in the health service and they brought it to a panel, are they going to be safe to talk about that openly in a panel or in an interview? I hope they would but I know my family would definitely be, like, “Don’t bother anything,” kind of. Yes, there’s no point going down that path…’
>
> *Amanda*

The need for transparency and accountability among researchers, in order to foster trust, was also raised.

> ‘…so to enhance PPI patient involvement, do what builds greater trust. Transparency and accountability build trust…’
>
> *Benjamin*

Research characteristics were also relevant when considering how to facilitate engagement among Black and South Asian communities. Features such as the researcher, research purpose, topic, methodology and use, were considered by participants when considering engaging with PPI.

> ‘I think that it would be who I’m doing the research with, whether I’m interested in the topic of research, what the plans for the research are once it’s done or what it’s going to be used for.’
>
> *Robert*

Empowerment and the belief that feedback would be valued and have the power to change and shape systems also appeared to facilitate potential engagement.

> ‘I felt like my participation was- I mean I could basically see it, my contribution or my participation or the group’s participation…I feel like we had kind of a real effect on the results, on the work of this project.’
>
> *Khan*

Finally, participants reflected on the impact of clearly defined roles when engaging in PPI.

> ‘I would want them to say, “We are bringing you in as kind of like an expert in this area. This is what we’d like you to take charge of, but while you’re doing that we’d also like you to contribute input into this area.” And the person in charge of the other area is also going to be doing the same thing for you. Unless there were clear definitions, I wouldn’t want to do it.’
>
> *Grace*

Discussion

This research sought to explore the factors that impact attitudes towards PPI among Black and South Asian communities. Following the analysis of participants' reports, five key themes were identified, these included: Drivers for participation, Power, Mistrust, Barriers to engagement and Facilitators of engagement, along with 19 sub-themes.

Barriers to engagement among ethnic minority communities included language, perceptions of research requirements, a lack of access to opportunities, practical constraints, negative experiences, and elements of these communities' identities. These barriers are consistent with existing findings. In particular, the language used to advertise and discuss research opportunities, as well as the language research is conducted in, have been reported as a barrier to research participation among ethnic minority communities in existing literature (Mir et al., 2003; Papadopoulos, 2006; Llyod et al., 2008; Atkin et al., 2009).

Participants also identified a number of practical barriers to potential engagement in PPI. These included a lack of financial compensation and time. This mirrors existing findings on barriers to research participation among ethnic minorities (Waheed et al., 2015; Gill et al., 2013). Though these challenges are not unique to ethnic minority communities, they must be addressed to facilitate successful PPI engagement among these communities.

Present findings also revealed that experiences of discrimination and mental health difficulties may impact PPI engagement among Black and South Asian communities. Participants' reports suggest that experiences of mental health difficulties and discrimination, may erode the 'courage' necessary to partake in PPI opportunities. These findings suggest that those from Black and South Asian communities may be disproportionately disadvantaged in their ability to participate in PPI in comparison to White counterparts, due to the additional barriers they may experience e.g., discrimination. For ethnic minorities, the cumulative effects of experiences such as mental health difficulties *and* discrimination may result in lower 'courage' necessary to engage with PPI opportunities. While previous research has reported that patient representatives are less commonly from ethnic minority communities (Beresford, 2013; Stuart, 2008; Boote et al., 2013), these findings may provide a potential explanation for this pattern. Furthermore, participants' reports suggest that a lack of access to PPI opportunities, and in some cases, the deliberate exclusion of individuals, were also barriers to engaging with PPI opportunities. Again, these findings may further explain the lack of engagement with PPI among South Asian and Black communities, as well as the lack of patient representatives from ethnic minority communities.

Within the current research, participants reflected on how negative experiences in the healthcare system and research may decrease the likelihood of engagement with PPI. Participants appeared to attribute negative experiences in the healthcare system, in part, to cultural incompetence among staff. This included beliefs about being dismissed with medication, as well as a perceived lack of awareness of the unique cultural considerations that may pertain to ethnic minority communities. While participants did not consider how these experiences may impact levels of mistrust towards these systems, reports of perceived cultural incompetence were linked to scepticism around diagnoses. Previous research has highlighted the importance of trust in the patient-provider relationship, and the negative impacts of its absence on patient engagement (Rowe & Calnan, 2006). Scepticism around the diagnostic labels assigned to ethnic minority communities, may explain the lack of engagement with mental health services seen in these communities (Cook et al., 2017; Memon et al., 2016; Bhui et al., 2003; Mclean et al., 2003). The effects of cultural incompetence in the healthcare system highlight the importance of cultural competence within research, in order to avoid causing harm or offence to participants (Papadopoulos, 2006).

In addition to mistrust around diagnoses from medical professionals, participants also expressed doubts about the healthcare system, research, and researchers. However, participants did not reflect on how this mistrust may impact their engagement with PPI. Despite this, the role of mistrust in ethnic minorities' engagement with systems and institutions has consistently been reported in literature (Jaiswal, 2019; Whaley, 2001; Gill et al., 2013; Hussain-Gamble et al., 2004; Sullivan et al., 2007). Furthermore, participants did reflect on how perceived levels of social power may impact their engagement with PPI. In particular, they considered how characteristics such as level of education and race may be tied to social positioning, and in turn, engagement and contribution to PPI. Social power has been linked to engagement with mental health treatment among ethnic minorities (Falgas-Bague & Fong, 2020), and results from the present research suggest that this may also impact engagement in PPI among Black and South Asian communities.

Drivers of participation included hopes for change, participants' desire to share their knowledge, a desire to help others, and previous experiences. The role of altruism and the desire to help others has previously been identified as motivation for research participation in ethnic minorities (Rooney et al., 2011). Previous experiences, particularly negative experiences, also provided motivation for participation, and were closely tied to desires for change, in order to ensure others did not have the same negative experiences. This aligns with existing evidence that suggests those from minority communities are more likely to receive inadequate care (Dorwick et al., 2009).

Clinical implications and recommendations

Results suggest that among Black and South Asian communities, factors such as the PPI role, psychological safety, empowerment and research characteristics all impact attitudes towards PPI. Research shows that a lack of clarity around participants' role in research, and what is expected of them, may hinder engagement (Beresford, 2019). Therefore, when attempting to engage any community in PPI, researchers must ensure expectations, and activities associated with the role are made clear. This has led to suggestions of using role descriptions and briefs when recruiting for PPI roles (Crocker et al., 2019; Kelson, 2005). This may be particularly valuable when recruiting ethnic minorities to PPI roles, as evidence has shown that uncertainty about research as a concept, and what this entails, forms a barrier to engagement among this group (Sheik et al., 2009; Gill et al., 2012; Rooney et al., 2011).

Results suggest that the presence of psychological safety is a key facilitator in engagement among Black and South Asian communities. As discussed, mistrust towards research and the healthcare system was expressed by participants. For ethnic minorities historical abuses of power within research such as the Tuskegee Syphilis study (The US Public Health Service, 1932), and the abuse of Black women in the development of modern-day gynaecological practices (Axelson, 1985), continue to stoke mistrust towards research. Researchers must seek to build trust with participants through transparency and accountability, in order to foster the psychological safety necessary for PPI engagement. Existing research suggests that open and straightforward communication, and assuring confidentiality can help to build the trust necessary for participation (Bexley et al., 2014; Rooney et al., 2011).

Furthermore, results suggest that potential empowerment within the PPI role, increased the likelihood of engagement with this practice among Black and South Asian communities. Ocloo and Matthews (2016) argue that elements of current PPI practices can give rise to power differentials between researchers, professionals, and those taking part. Therefore, it could be argued that when utilised incorrectly, researchers may unknowingly be re-creating power-imbalances that individuals from these communities have faced when engaging with other systems e.g., the healthcare system. Given this, when looking to engage ethnic minority communities in PPI, it is essential to create conditions that facilitate empowerment among PPI contributors. This includes showing representatives that their contributions are valued, and have the power to change and shape practice. In addition to creating space to listen to contributions, researchers must show compassion, and demonstrate that they value the role of those taking part in PPI. Practically, this involves financially compensating volunteers for their contributions, and formally recognising contributions in any published output. These actions may serve to redistribute and balance the power in the relationship between researchers and PPI representatives.

Finally, the effects of perceived cultural incompetence reported by participants highlights the need for early PPI in mental health research and service development. This stands to make mental healthcare services and interventions more culturally attuned to the needs of ethnic minority service users. This may increase engagement among these communities, and in turn, close the gap in health outcomes between ethnicities.

Limitations and future research

Although the study was not promoted in the NHS, a number of participants who came forward to be interviewed were in professional or training roles within the NHS, or had previously conducted research themselves. These participants were able to reflect on the impact of these additional identities on the views expressed during interview. However, it is likely that these experiences also gave these participants a greater level of insight and knowledge about research, and practices such as PPI, compared to other members of the public. While this does not invalidate the experiences and perspectives of these participants, the results must be considered in this context. Furthermore, this research focused solely on Black and South Asian communities. While, there is likely to be a number of similarities across ethnic minorities, results must be extrapolated to other populations with caution, and future research may wish to replicate research among other ethnic minority groups.

Research sought to consider the factors that influence attitudes towards PPI among South Asian and Black communities. While research suggests that attitudes provide a precursor to behaviour (Glasman & Albarracín, 2006). The present research did not determine whether the attitudes expressed during interview went on to impact participants' engagement in PPI.

In addition, participants' engagement in research suggests that while individuals' may have encountered some of the barriers identified within this project, ultimately, they were able to overcome these obstacles to participate. However, it is important to note that this may not be the case for others within these communities. Therefore, an inherent limitation of this research is that the perspectives of people who do not engage with research in any capacity, were not captured. However, findings contribute to growing literature investigating the lack of engagement in PPI among ethnic minority communities.

Future research may wish to employ quantitative methodology to explore the link between identified barriers to participation in PPI. In particular, given the impact of negative experiences, cultural incompetence, and mistrust, research could look to establish a statistical relationship between these experiences or beliefs, and the likelihood of PPI engagement within minority communities.

Conclusions

The present research aimed to consider the factors that influence attitudes towards PPI in Black and South Asian communities with self-reported mental health difficulties. Barriers to potential engagement included language, negative experiences within the healthcare system, and a lack of access to opportunities. Findings suggest that negative experiences within the health care system and research, decreased the likelihood of PPI engagement among South Asian and Black communities. In addition, perceived cultural incompetence was linked to mistrust among participants. Drivers for participation included: previous experiences, a desire for change, helping others, and sharing knowledge. Researchers seeking to recruit individuals from these communities to PPI opportunities must create conditions to empower participants, including demonstrating compassion, a value for their contributions through financial compensation, and formal recognition in research outputs. Researchers must also create psychological safety and encourage trust through transparency and accountability. Finally, researchers should ensure participants have a clear role within projects. Though current research provides a starting point, future research should seek to build on current findings using quantitative methodology.

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Chapter Five

Additional Methods

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This chapter aims to consider the impact of the researcher's epistemological position on the research process, and reflects on the PPI process conducted in completion of the empirical paper presented in chapter four. This includes a brief overview of the social constructionist perspective, its relevance to the current research, and the impact of this on the research methodology. To conclude, reflections on the experience of conducting PPI within the context of doctoral research are shared.

Social constructionism

Social constructionism is a philosophical position that asserts knowledge is social in origin, as a result, an individual's reality is constructed within their specific social context (Gablin, 2014; Andrews, 2012). Berger and Luckmann (1966) were instrumental in bringing this perspective into mainstream scientific thought. They proposed that society is created through 'habitualisation', a process of repeated patterns of human interactions. Over time, these patterns become embedded in society, therefore, while individuals create their reality, they also accept this reality as it is, as others have previously created it. This assumption raises questions of power, and why some realities are prioritised or 'believed' over and above others (Dreher, 2016). Within a social constructionist perspective, researchers focus more on how phenomena are viewed, as opposed to the actual phenomena themselves (Harper, 2011).

Relevance to current research

The current research sought to determine what factors influenced attitudes towards PPI among Black and South Asian communities. Attitudes are considered a central concept in social psychology (Schwarz & Bohner, 2001). Allport (1935) defined an attitude as a mental and neural state of readiness organised through experience. Other definitions emphasise the stable nature of attitudes, for example, Krech and Crutchfield (1948) argue that an attitude can be defined as an enduring organisation of motivational, emotional, perceptual and cognitive processes, with respect to social aspects of an individual's world. Others have highlighted the link between individual attitudes and behaviour (Fuson, 1942; Campbell, 1950), arguing that in simple terms, attitudes determine the probability that a person will display a particular behaviour in a specific situation. This emphasis on the role of experience in the construction and composition of attitudes, suggests that from a social constructionist perspective, attitudes can be seen as versions of the world constructed by people in the course of their interactions with others (Bidjari, 2011). Therefore, this understanding of attitudes, as well as the nature of the research question, meant that the social constructionist perspective provided an appropriate lens through which to understand and interpret data.

The focus on Black and South Asian communities within present research was also particularly compatible with the social constructionist perspective. It has long been argued that ethnicity and race are social constructs (Ford & Harawa, 2011), in particular, many researchers argue that race is a social construct based on the phenotypic genetic expression, as opposed to objective biological differences (Sheldon & Parker, 1992; Senior & Bhopal, 1994; LaViest, 1994; Freeman, 1998; Jones, 2001). Despite this assertion, those from ethnic minorities have markedly different healthcare experiences and outcomes to their White counterparts. When considered from a social constructionist perspective, socially constructed racial categories may be used to uphold systems of racial oppression, in turn, it is the exposure to these systems that produces these racialised health inequalities (Bailey et al., 2017; Goosby et al., 2018; Green & Darity, 2010; Sewell, 2016). Jadotte (2020) further argues that power plays a central role in sustaining and contributing to the proliferation of health inequalities. According to the proposed theoretical model, patient’s agency is socially constructed as they move through the healthcare system, interactions are shaped by perceptions of patient’s skin colour and their disease. The author argues that those with darker skin are afforded less agency. In turn, this negatively impacts patient’s ability to obtain what they need from the health care system, which feeds health inequalities.

Given the role of social constructionism in race, ethnicity, attitudes, and health inequalities. This perspective provided an appropriate position to explore the experiences of Black and South Asian communities that may give rise to their attitudes towards PPI.

Impact on methodology

The social constructionist position adopted informed various aspects of the research methodology. According to Gergen (2004), social constructionist research must value: reflection, the 'subject' voice, collaborative participation, multiple standpoints and representational creativity. The current research aimed to embrace these values through the use of qualitative methodology, PPI, sharing power where possible, and gaining multiple perspectives throughout data analysis.

The social constructionist position adopted for this project informed the decision to conduct qualitative research, particularly the use of interviews, in order to amplify the participant voice and share their worldview. In addition, the emphasis on the role of language in the generation of knowledge within social constructionism, meant that individual interviews allowed participants the opportunity to legitimise their unique reality (Slater, 2017). Finally, the use of semi-structured interviews allowed the researcher to collect data according to research aims, whilst also being led by the participant. The social constructionist perspective would suggest that participants' attitudes towards PPI may not be fixed, but instead would emerge over the course of the interview. Using semi-structured interviews provided the opportunity for further probing and discovery (Fylan, 2005).

The use of PPI representatives to shape and guide the project, particularly during analysis, provided multiple perspectives, promoted shared power, and allowed the collaborative and communal construction of knowledge (Gergen, 2004; Losantos et al., 2016).

Patient and Public Involvement

As discussed in previous chapters of this work, PPI refers to the involvement of members of the public and patients in the research process (INVOLVE, 2012). PPI is often divided into three main categories, ‘engagement’, ‘participation’ and ‘involvement’. Each category gives rise to different research activities, and thus different levels of power for the person involved in the research process (Ocloo & Matthew, 2016). Ideally, involvement activities within research and service development should give rise to co-production. As defined by the Coalition for personalised care, co-production involves people who use health and care services, carers, and communities, in equal partnership within research. These groups are engaged at the earliest stages of design, development, and evaluation (2020). This practice is underpinned by five key principles: the sharing of power, including all perspectives and skills, respecting and valuing the knowledge of all those working together on the research project, reciprocity, and building and maintaining relationships (NIHR, 2021).

PPI in the current research

Ethnic minority communities are currently under-represented within PPI activities (Howe, 2006). The current research aimed to understand why this pattern persists, and what can be done to address this. In order to better understand these barriers and contribute to the much-needed shift in representation within PPI, this research also conducted PPI, recruiting representatives to steer and contribute to the research process. Table 5.1 provides a summary of the involvement activities completed by representatives throughout this project and their resultant impact.

Table 5.1:
PPI activities and the resultant impact on research

Stage of research	Involvement activity	Impact
Designing recruitment materials	▪ PPI representatives met to discuss recruitment materials. ▪ Recruitment posters created with representatives.	This led to changes in the wording on the recruitment poster, examples of changes included using the term 'any' experience of mental health difficulties to indicate that participants were eligible regardless of the severity of their difficulties.
Designing the interview topic guide	▪ Co-creation of the interview guide, including considering what questions to ask and how these should be worded.	This resulted in the inclusion of an explanation and example of what 'research' is at the beginning of the interview guide. This also led to greater consideration of how to distance the researcher from the healthcare system to encourage the disclosure of both positive and negative experiences.
Recruitment	▪ Discussions about how to present the participation opportunity and explain research. ▪ Help with identifying suitable avenues for recruitment e.g., links with the wider community and religious organisations.	This led to an expansion of recruitment locations e.g., approaching churches and other religious organisations, as well as hairdressers, barbers and ethnic food stores.
Data Analysis	▪ The analysis of transcripts, and development of an initial coding framework.	Discussing transcripts and initial codes and themes provided multiple viewpoints throughout the analysis, this also promoted reflexivity and rigor, improving research quality.

Dissemination	▪ Contribution to the design of dissemination materials.	This will emphasise the value of participant contributions, and the impact this work will have.

The PPI process

PPI opportunities were advertised in various community spaces including, community and health centres, The Citizen’s Advice Bureau, mental health charity ‘Mind’, and local ethnic minority support organisations. Two representatives were recruited at the start of the project via local charities working with under-served health populations, representatives were a male of South Asian ethnicity, and a female of Black Caribbean ethnicity. Unfortunately, one representative was unable to see the project to completion, attempts to recruit a replacement were unsuccessful. An initial meeting was called to discuss the project aims and intended outputs. This meeting provided an opportunity to introduce members of the research team and discuss the existing evidence base and rationale for the project.

In a later meeting, recruitment materials for the project were developed together. An initial poster had been developed as part of the submission of the thesis proposal, this was used as a starting point for discussion. During the meeting changes to the wording of the eligibility criteria were made. This made language more accessible, encouraging participation regardless of the severity of mental health difficulties. The image on the poster was also selected to reflect the target population.

PPI representatives also contributed to the development of the interview guide. An early draft was used as a starting point to guide discussion. This was developed on an iterative basis, in which each version was trialled in a mock interview and adapted based on feedback. Changes based on PPI feedback included providing a brief introduction to research, and examples of the research process before commencing the interview. Discussions about participants’ willingness to disclose more negative experiences of care within the NHS, also led to considerations of how to distance the primary researcher from the healthcare system. This resulted in explicit instructions for participants, encouraging the disclosure of both positive and negative experiences throughout the interview.

The need to distance the primary researcher from institutions and systems in order to facilitate the disclosure of potentially negative experiences within the healthcare system was closely considered in meetings. The primary researcher is a clinician within the NHS, a researcher and member of the public, PPI representatives highlighted the importance of not denying or hiding any of these identities as participants would likely be aware of them. Instead, they suggested that during data collection, the primary researcher highlight the imperfections within systems through comments such as, ‘I know the NHS isn’t perfect’, ‘sometimes researchers get it wrong’ and ‘I’m really interested in hearing about any experiences you’ve had in the NHS, positive or negative’, where appropriate. Highlighting that the primary researcher was aware of the imperfections within the healthcare system and research, was used to create an alliance with participants, and create the necessary psychological safety for disclosure. Furthermore, acknowledgement of the flaws within these systems may have encouraged participants to see the primary researcher as a peer, and in turn speak more freely. The primary researcher’s identity as a Black woman may have also helped to create distance from these systems, as participants may have felt she could relate to experiences of racism and poor treatment.

During recruitment, the primary researcher and PPI representatives considered how to present the opportunity for research participation. This included thinking about what to say to potential participants, as well thinking about the potential questions members of the public may have. Representatives also provided a rich knowledge of potential recruitment sources, and were eager to peruse less traditional routes to engage those who may be less likely to hear about research participation opportunities. It was decided that religious and community organisations, as well as non-traditional outlets like haircare shops, hairdressers, barbers and ethnic food stores, would be utilised for recruitment. When recruitment was slower than expected, representatives were able to troubleshoot with the primary researcher to consider reasons for this and potential solutions.

When interviews had been transcribed, one PPI representative, A.S., joined the initial coding meetings, and shared her ideas about the transcripts and segments of the interview that stood out to her. When an initial coding framework was developed, she also provided feedback on whether themes reflected the data. This discussion among the research team promoted reflexivity and rigor, improving the overall quality of the research. Finally, as part of the dissemination of findings, a resource summarising the key findings of this project will be co-created with A.S, to ensure this is accessible to participants.

Simultaneously researching and conducting PPI provided a unique perspective, as whilst looking into the barriers to PPI engagement among ethnic minorities, I also experienced these first-hand when attempting to recruit and involve members of this community in the research process. The remainder of this chapter will reflect on my own experiences of conducting PPI with those from ethnic minority communities, particularly within the context of doctoral research.

Reflections on the PPI process

Barriers

I encountered a number of barriers whilst conducting PPI as part of this project. Recruitment of PPI representatives was challenging for a number of reasons. Opportunities for involvement were often confused for opportunities for participation. Once this had been corrected, people cited a lack of time, and an inability to commit to the responsibilities attached to the role, as reasons why they were unable to accept the opportunity. In particular, commitment for the duration of the project was a barrier, and people shared fears around not being able to see the project to completion due to competing demands on their time. There was also a lack of awareness around PPI, and the value that this could add to a project. At times, it seemed that people felt pressure to bring something that went beyond being a member of the public, or a patient with lived experience. It was difficult to convey that those were the integral criteria for the role, and so people often expressed fears of not being ‘qualified’ enough. Fears expressed around not being ‘qualified’ for the role, may suggest that only those who are empowered and secure in their own knowledge and voice volunteer to be part of PPI activities.

Facilitators

Remote participation via Teams made PPI meetings more accessible to attendees, and they felt that the role could fit around existing commitments. Both representatives cited this as a factor that impacted their decision to accept the role. In addition, compensating representatives for their time also facilitated engagement, again, both representatives agreed that this helped them to prioritise meetings in the midst of other commitments, and feel like valued members of the research team.

The contribution of PPI representatives throughout my project was invaluable. However, contributions, suggestions, and feedback, also had to be weighed according to the criteria of a doctoral thesis. Throughout the process of conducting PPI, I looked to promote shared ownership of knowledge and research to foster shared power. As part of this, the contribution of PPI representatives will be acknowledged through authorship on published outputs from the empirical project. However, other elements of this were more difficult, and in reality, as this work was a requirement for gaining my doctoral qualification, I had to exert a level of ownership over its timelines and outputs to fulfil this criteria. This had knock on effects for involvement activities within the project. PPI representatives were unable to shape the scope of this project, as the aims and overall agenda were to an extent pre-determined in line with the completion of a doctoral thesis. For example, PPI representatives suggested that it may be interesting to also interview researchers to understand their perceptions of the barriers and facilitators to engaging ethnic minority communities in PPI. In particular, they wanted to consider collecting data via focus groups with those from Black and South Asian communities, and researchers, to bridge the gap between both of these groups. This was a great idea, and would have made for an interesting project. However, the target population had already been selected, and completing data collection in the allotted time would likely have proven difficult.

These restrictions in conducting PPI conflicted with what I had come to learn about PPI throughout my doctoral training, and my learning for the completion of this project. These restrictions also clashed with my own personal values and beliefs about how research should be conducted, especially within ethnic minority communities where researcher power has historically been abused. However, every effort was made to adhere to the principles of co-production where possible. When opportunities arose where representatives could have a greater input, or steer the conversation, particularly in the development of recruitment resources, the interview guide, and data analysis, their suggestions were actioned. Given the restrictions associated with conducting PPI within doctoral research, more thought may need to be given to how to embed the unique principles of co-production in research that requires greater researcher ownership.

The constraints of doctoral research, and the resultant impact on key principles of co-production such as power and co-ownership, also speak to the larger debates around what true co-production within research is, and what it is not. True co-production involves equal partnerships between researchers, members of the public, and service users, facilitated through shared power and decision making. When utilised correctly, these partnerships can have a profound impact on the way services are designed, delivered, and evaluated, making services more effective, more efficient, and more sustainable. Given this, this title should not be bandied about, or attached to research activity lightly.

Researchers may face a number of challenges when attempting to co-produce with service users and members of the public. In particular, patients and members of the public often become involved in a project after applications for funding have been approved, or in my case, after a project has been approved by an academic institution. By this point, the scope and aims of the project are often already set, this limits the capacity for shared power and decision making, and as a result, potentially steers a project away from true co-production. For those who eventually join the project as PPI representatives, this may lead to feelings of frustration and disempowerment. Among ethnic minority communities, these feelings could be particularly detrimental, as these interactions may replicate feelings of disempowerment these communities have experienced during interactions with other systems. Instead, from a social constructionist perspective, true co-production when applied correctly, may actually offer an opportunity to re-balance, and re-distribute power, through new social interactions with these same systems.

Given the enormous value of co-production, I feel it was a real shame that I was unable to complete this to its fullest extent during my own research. However, conducting PPI during this project has provided me with an experience of involving members of the public in research, allowing me to witness first-hand how this can improve research, benefitting researchers, patients, and members of the public. While I was not able to complete true co-production within this project, I was able to learn more about the values and principles that underpin this practice. I look forward to using these values to shape my own clinical practice and future research, as I embark on my career as a qualified clinical psychologist.

Chapter Six

Discussion and Critical Evaluation

Word count (excluding references): 6,057

This thesis portfolio aimed to explore the factors influencing engagement and participation in mental health services and research within ethnic minority communities. In line with this, a systematic review and qualitative research project were completed.

Results across both projects identified a number of complex internal and external barriers to engagement with healthcare services and research. In particular, negative experiences inside and outside of the health system, cultural incompetence, and distrust and mistrust, impacted engagement with mental health services among Black women, and PPI among South Asian and Black communities.

The present chapter will present results from both pieces of research and contextualise findings within the wider evidence base. It will also discuss the theoretical, practical, and clinical implications of this work, as well as critically appraise the thesis portfolio in its entirety. Finally, personal reflections of the experience of conducting this research will be shared.

Health disparities are one of the biggest concerns within the UK healthcare system (Marmot, 2010; Beaglehole, 2006; Garthwaite et al., 2016). In particular, ethnic differences in health outcomes can be observed across both physical and mental health (The King's Fund, 2021; Copper et al., 2013; Prady et al., 2016a; Prady et al., 2016b; Moore et al., 2019; Barnett et al., 2019; Bansal et al., 2014). Evidence suggests that Black women are one of the most vulnerable groups within this minority, and mental health needs among this group appear to be rising (DHSC, 2018; Bignall et al., 2019). Furthermore, Black and South Asian communities in particular, face a number of health inequalities. These communities experience higher rates of infant and maternal mortality, cardiovascular disease, and diabetes, compared to White British populations (King's Fund, 2021). High quality data on the needs of these communities is critical to resolving these inequalities (King's Fund, 2021). However, a lack of both research and PPI participation among ethnic minorities may be leading to a paucity in data, thwarting efforts to solve this problem. Increased engagement in PPI among ethnic minorities may break cycles of exclusion within health research, increasing research participation among these communities. This may shed light on the needs of these communities, and how services can be better adapted to serve these groups. In turn, this may improve engagement with services, reducing health disparities.

In light of these inequalities, and the role of PPI as a potential catalyst for understanding and rectifying these patterns, the present thesis portfolio sought to identify barriers to engagement with mental health services, and health research PPI, among ethnic minority communities.

Overview of Findings

Systematic Review

A systematic review investigating what factors impact engagement with mental health services among Black women in the UK and US was completed. Twenty-two research studies were identified. Stigma, Cost, Practical constraints, Distrust and mistrust, Lack of mental health literacy, Stereotypes and culturally sanctioned behaviours, Alternative coping mechanisms, Failures of the healthcare system, and Perceptions of mental health services, were all factors that impacted engagement with mental health services among Black women. Despite differences in healthcare structure and funding in both locations, except for cost, the same barriers were identified across both settings. Findings suggest that a complex interaction of individual, systemic, and community level factors impact engagement with mental health services among Black women in the UK and US. A lack of mental health literacy identified in Black women may be the result of a mixture of cultural incompetence in the mental healthcare system and stigma within the Black community, this may also impact the use of alternative coping mechanisms. In particular, Black women’s awareness of the failures of the care system, as well as poor treatment inside and outside of the healthcare system, may stoke or create distrust and mistrust among this group which discourages engagement.

Empirical Study

The empirical research study utilised qualitative methodology to consider attitudes towards PPI in mental health research among Black and South Asian communities. Ten individual semi-structured interviews of participants with self-identified mental health difficulties were completed. Thematic analysis of the data identified five themes and 19 sub-themes. Themes included: Drivers for participation, Power, Barriers to engagement, Mistrust, and Facilitators of engagement. While some themes and their relation to participants' engagement or lack thereof with PPI were clear, other themes detailed the nuance of the participants' experiences, and in turn their ability, or willingness to engage with PPI. Overall, attitudes towards PPI among South Asian and Black communities are influenced by the complex interaction of factors. In particular, negative experiences within research and the health system discouraged engagement in PPI.

Thesis Portfolio

Overall, results suggest that among Black women negative experiences outside and inside of the healthcare system fuel distrust and mistrust. This decreases the likelihood of engagement with mental health services. Among Black and South Asian communities, participants' reports suggest that negative experiences within the healthcare system and research, discouraged engagement with PPI. Participants attributed these negative experiences within the health system to cultural incompetence among staff. These perceptions of cultural incompetence appeared to lead to increased scepticism towards health system engagement e.g., the acceptance of diagnoses, but not towards PPI.

In its entirety, this work considers the multi-layered experiences of South Asian and Black communities, and how these may impact engagement with PPI and mental health services. Results from the systematic review considered how the intersections of gender and race, give rise to a number of barriers to accessing mental healthcare. The empirical work identified how factors such as race, and negative experiences within the healthcare system may impact Black and South Asian communities' relationship with the health system. As well as their courage, power, and in turn perceived agency, and thus, their willingness or ability to participate in PPI. Both pieces of work paint a highly complex and nuanced picture, one that doesn't appear to have been captured within existing research. Together, results from the systematic review and empirical project suggest it is not simply about identifying these barriers, but considering how these barriers interact to give rise to the present patterns of participation and engagement among South Asian and Black communities.

Theoretical Implications

Results from the systematic review detailed patterns of inequality in access to mental health services among Black women in the UK and US. Although existing research had identified a number of barriers to engagement with mental health services among Black women. The systematic review evolved current knowledge by synthesising existing findings to consider how the healthcare system, and experiences within other systems and institutions, impact Black women's engagement with mental health services.

The empirical paper sought to determine whether negative experiences with, and perceptions of, the health care system among ethnic minorities, impact attitudes towards PPI and the likelihood of engagement with this practice. Previous research has consistently reported the lack of engagement in PPI among ethnic minorities (Bret et al., 2010; Dawson et al., 2018; Ocloo et al., 2021; Ocloo & Matthews, 2016; Ocloo, 2018). In particular, a systematic review by Dawson et al. (2018) concluded that further research was necessary to identify specific factors that inhibit or facilitate ethnic minority involvement in health and social care research. This review also called for greater specificity when looking at patterns of involvement among different ethnic minorities. The current research built on existing knowledge by providing insight into what factors influence attitudes towards PPI, specifically in South Asian and Black communities.

While previous research into specific barriers to engagement in PPI among ethnic minorities was limited, existing research has considered barriers to research participation among these communities. This research suggests that factors such as a lack of confidence in individuals' ability to meaningfully contribute (Gill et al., 2013), distrust of governmental systems and healthcare professionals (Hussain-Gambles et al., 2004; Sullivan et al., 2007), practical constraints such as competing commitments, time and location of research, availability of childcare (Waheed et al., 2015), and language (Vickers et al., 2012), all act as barriers to research participation among ethnic minorities. Current findings identified the same barriers to engagement with PPI. Similarities in barriers across PPI and research participation could suggest that strategies used to bolster research participation, may also be applicable when looking to promote PPI. Furthermore, the present research also built on this work by identifying additional barriers such as elements of individual identity e.g., experiences of mental health difficulties, negative experiences in the healthcare system, and access to opportunities for participation in PPI. A systematic review by Ocloo et al. (2021) did not identify any theories of PPI relating to equality and diversity. Therefore, present findings could be used as a starting point to develop theories of involvement in this area.

In addition, participants' reports of mistreatment in the empirical project align with existing literature about the experiences of ethnic minorities within the healthcare system. For example, ethnic minority communities see their GP several more times than White people before being referred to the hospital in relation to cancer (National Cancer Experience Patient Survey, 2016). In addition, these communities are more likely to report dissatisfaction with their care (Smith et al., 2009; King's Fund, 2021; Rudat et al., 1994; Airey et al., 1999), and report poorer experiences in health services (King's Fund, 2021). However, current research has also been able to consider how these experiences may influence participation in research, specifically PPI.

In the empirical paper, participants also shared how wider life experiences of discrimination and racism can erode individual 'courage'. This aligns with existing research that reports the effects of racism include, higher levels of internalised shame (Johnson, 2020), lower self-esteem (Harris-Britt et al., 2007), and overall poorer mental health

(Paradies et al., 2015). However, again, the current research demonstrates how these experiences specifically impact engagement with PPI, as participants shared this meant they were less likely to take up opportunities to engage in this.

Furthermore, while results from the empirical study detailed barriers to participation in PPI among South Asian and Black communities, participants also shared facilitators to engagement. These included feelings of psychological safety, research characteristics (e.g., topic area and purpose), clear definitions around the role they would hold in the project, and feelings of empowerment (e.g., feeling valued within the role and project). This aligns with previous research that identified the importance of ‘planning’ to ensure there was a clear role, purpose, and remit for PPI, as well as a sense of shared ownership (Selman, 2021).

Clinical and Practical Implications

The systematic review identified barriers to engagement with mental health services such as failures of the healthcare system, particularly a lack of cultural competence. This highlights the need for a shift towards greater cultural competence within both UK and US mental healthcare systems. The NHS continue to offer mandatory inclusion and diversity training for staff. However, Kalra et al. (2009) argue that while this training is ubiquitous and has been in place for over 20 years, this has not proved effective, suggesting this often remains a ‘tick-box’ exercise. Therefore, the NHS may benefit from reforming current diversity and inclusion training. In particular, updating this to consider unconscious bias and micro-aggressions, both of which may contribute to racism, discrimination, and stereotyping identified within the NHS (Byrne et al., 2020), and perpetuate health inequalities (Marcelin et al., 2019). Staff treatment towards patients was implicated in Black women’s willingness to access mental healthcare, and Black and South Asian communities’ willingness to engage in PPI. Furthermore, cultural incompetence also appeared to encourage mistrust towards health professionals, and potential diagnoses among Black and South Asian communities. Given that medical mistrust has been implicated in healthcare engagement (Jaiswal, 2019), cultural incompetence among staff may further discourage engagement among these communities.

In addition, given the barriers to accessing mental health services for Black women, mental health practitioners should not only aim to make themselves aware of these barriers, but also use spaces such as supervision and reflective practice, to think critically about how these barriers may be presenting when working with Black women. Furthermore, evidence suggests cultural competence is necessary for therapeutic success (Miller et al., 2021; Castillo & Guo, 2011). Therefore, it is even more important that mental health practitioners do not shy away from raising issues of race and culture within the therapeutic relationship. Work by Faheem (2023) reported that clients appreciated therapists who asked about their background, beliefs, and culture, as they felt this helped them to better understand their circumstances. This also stands to create genuine partnerships between Black women and healthcare professionals as outlined in the NHS Long-term Plan (2019).

As previously discussed, PPI presents a potential research solution to persistent health inequalities. However, if this is the case, this practice must capture the opinions and experiences of those who these health inequalities disadvantage. As previously discussed, research has consistently pointed towards the lack of diversity within PPI. While expert research organisations like INVOLVE have released guidance around this (INVOLVE, 2021), little practical progress has been made. Instead, PPI remains full of the ‘usual suspects’ comprising of retired, White people, with professional backgrounds (Locock et al., 2017). However, this issue may be resolved in a similar fashion to how ethics committees and research funders approached the introduction and promotion of PPI. The increased focus on this practice within these organisations, and ties to funding, may have motivated researchers to adopt this when writing proposals and seeking grants. An increased push by these same bodies to diversify PPI, may once again motivate researchers to consider whether those taking part in PPI are representative of the group for which evidence is being generated. The development of guidance reflecting findings from this research, could also provide a practical contribution in this area.

Participants' reports from the empirical study also suggest that language plays a key role in potential participation. As the way an opportunity is presented may shape perceptions of whether the research is suitable, or of interest. In particular, participants shared that this project had been the first, or one of the first, they had seen to mention race when recruiting. They discussed how this cultivated a sense of inclusion, which led them to feel this research could be of interest to them. Researchers may want to consider being more explicit when recruiting participants. In particular, highlighting which ethnicities are being targeted, and if all ethnicities can participate, explicitly communicate this.

Finally, together, results from both pieces of work suggest that factors both inside and outside of the healthcare system have the potential to influence engagement with mental health services and attitudes towards PPI. In particular, results from the systematic review highlighted the influence of negative experiences outside of the healthcare system on Black women's engagement with mental health services. This would suggest that it is not simply a distrust or mistrust of healthcare professionals or the health service, but distrust and mistrust in wider systems such as research organisations, educational institutions, and the justice system, may also impact engagement. This suggests that the solutions to these issues must also be sought beyond the healthcare system. This is because as consistently discussed through the systematic review and empirical research, for Black communities in particular, healthcare is just one area where they experience inequalities. This community is frequently confronted with poor treatment across systems. This includes the healthcare system, the justice system, where ethnic minorities are more likely to be physically restrained whilst in police custody (Equality and Human Rights Commission, 2016), and the educational system, where rates of permeant exclusion are three times higher among Black Caribbean children than other groups (Equality and Human Rights Commission, 2016). Therefore, if poor treatment experienced in these arenas has the potential to influence engagement with mental health services and health research PPI, this must also be addressed in an effort to encourage engagement among these communities. A more equitable society in which ethnic minorities feel safe, valued and empowered, may facilitate the engagement that research, healthcare, and other systems seek from these groups.

Critical Appraisal of Research

Systematic review

The present portfolio sought to fill the gaps in the current understanding of the factors that impact engagement with both mental healthcare services, and healthcare research PPI, among Black and South Asian communities.

Within the systematic review, as presented, quantitative data had identified patterns of underutilisation of mental health services among Black women. Though existing qualitative research had highlighted the barriers that these women may experience when trying to access services. This work has expanded on this by synthesising data across 22 studies to produce a coherent summary of the barriers that prevent Black women from accessing mental healthcare. This work can be used by policy makers and governments to address these inequalities.

A further compliment of this work is the comparison of barriers in the UK and US. The selection of these two countries was prompted by the distinct healthcare systems in both locations. This comparison highlighted that problems in the patterns of access among Black women, extend beyond the UK, contextualising this issue on a global scale. Furthermore, this comparison provided early hints that the potential solution for these inequalities may need to be sought beyond the healthcare system, and incorporate other systems and agencies. Though all barriers identified in the UK and US were not the same, this information still allows policy makers to customise their approach to tackling this issue based on the factors identified in each location.

In addition, this portfolio looked to produce high quality research outputs, in line with this, where possible, PRISMA guidelines were followed (Page et al., 2021). To ensure transparency, and minimise the risk of bias, the systematic review protocol was registered on PROSPERO (CRD4202231561) prior to completion. The search strategy was also developed in an iterative process, and with the input of UEA librarians who have extensive experience in systematic searching. This produced a robust search strategy which was applied across four databases to maximise the identification of relevant research. Furthermore, a second reviewer was utilised throughout the screening process, 10% - 25% of papers identified at each stage were independently reviewed by a second reviewer. Evidence shows that using a second reviewer throughout the entire screening process can increase the number of relevant studies identified for synthesis (Stoll et al., 2019). Papers included in the final synthesis of data were assessed for methodological quality using the CASP checklist (CASP, 2018). A total of 10% of papers were also independently appraised by a secondary reviewer using the CASP. Agreement between the two raters was high, and conflicts were resolved by consensus. Although quality across studies was variable, research was discussed in the context of any methodological weaknesses. In addition, though a meta-synthesis was not completed, a narrative synthesis combined findings across research. As discussed, the results from this work have a number or practical uses.

While this work has a number of strengths, this review also presents some limitations. In particular, the exclusive comparison of the UK and US, while a good starting point, neglected the experiences of Black women elsewhere. This work could be improved by considering whether the same patterns are observed in contexts where Black women are not a numerical minority, as it could be argued that this would result in fewer instances of racism and discrimination within the healthcare system. However, research suggests that power is central to minority status, particularly reduced power (Lucken & Simon, 2005). Therefore, it is possible that results could remain the same in different societal structures. In the same vein, this work focused exclusively on Black women. While this was driven by evidence of the vulnerability and growing need in this group (DHSC, 2018), future research would do well to consider synthesising this data across ethnic minorities. Though this was considered for this portfolio, even if just completed for data within the UK, this was not feasible within the constraints of a doctoral project.

Furthermore, it could be argued that though the patterns of under-utilisation are similar across the UK and US, these settings have different racial and historical contexts. This means that the mechanisms that underpin these patterns may be different across these settings.

Empirical study

This work identified both barriers and facilitators to engagement in PPI among Black and South Asian communities, as well as other influences such as mistrust and power. The qualitative methodology was used to capture the complexity of participant experiences, as well as how this may have impacted their views towards PPI.

Yardley (2000) argues that sensitivity to context is central to high quality qualitative research, as this understanding of the socio-cultural setting provides a context for which data can be understood and interpreted. The first author's (N.F) position as a Black woman provided a sensitivity to the context, and facilitated an understanding of the socio-cultural background of participants. While the experiences of ethnic minority communities are highly nuanced, N.F was able to draw on her own experiences and knowledge when contextualising participants' experiences. The first author's ethnic identity also bred a mutual understanding of shared experiences such as racism. This was demonstrated through statements like 'you know what it's like' and 'I'm sure you get this' from participants. This may have allowed participants to disclose experiences in greater depth, or share instances they otherwise may not have done. For example, research found that Black women reported higher levels of life stressors when interviewed by a researcher of ethnic minority background (Samples et al., 2014). Sensitivity to context was further achieved through contributions from PPI representatives. As discussed, while it was not possible to achieve true co-production due to constraints on the scope and ownership of this project, the use of PPI is a particular strength. The co-production of research resources such as the recruitment poster, and interview schedule, allowed materials to be sensitive to the target group. As a researcher N.F has a thorough knowledge of research methodology and design, given this, it was easy to project this understanding onto the target population when designing resources. Contributions from PPI representatives ensured materials were accessible, and sensitive to the potential recruits. This was particularly important given the lack of participation in research among ethnic minority communities. Furthermore, the contribution of PPI representatives to the analysis process, also allowed for investigator triangulation. Denzin (1978) argues that this process provides different perspectives which can confirm findings, and add breadth the phenomenon of interest, this process also increases the validity of findings (Carter, 1969).

It is important to note that while N.F's position as a Black woman provided experiences that helped her understand the context of participants' experiences. It was important that these experiences were not used to interpret participant reports, and instead were merely a tool for greater understanding of the data, and themes that were generated. Reflexivity was central to facilitating this, Berger (2015) proposes that to better understand the role of the self in the creation of knowledge, researchers must carefully self-monitor the impact of their biases, beliefs, and personal experiences on their research. Within this work, this process of reflexivity was maintained through the use of a reflective diary. This was completed throughout data collection and analysis, and allowed N.F to consider the impact of her own personal characteristics and beliefs, on the data collection and analysis process.

In addition, the completion of this work from a social constructionist perspective is also a strength. As discussed in chapter five, this allowed participants to construct their reality through sharing their experiences. This is particularly important given the evidence that the experiences of Black and South Asian communities across systems, is distinctly different from those of their White counterparts. Therefore, rather than clinging to an objective reality, understanding data from a social constructionist perspective allowed the existence of multiple realities across participants. In turn, this allowed the commonality in these experiences to be identified and organised into themes. Furthermore, conducting thematic analysis from this perspective allowed for the consideration of the socio-cultural contexts, and structural conditions that gave rise to participants' experiences (Braun & Clarke, 2006). In particular, how experiences inside and outside of the healthcare system have influenced participants' views towards PPI.

While this work has a number of strengths, there are also a number of limitations. Of particular note, is the absence of those with experiences of severe mental health difficulties within the sample. Severe mental illness (SMI) refers to mental health difficulties that lead to severe impairment in an individual's ability to engage in functional and occupational activities, examples include schizophrenia and bipolar disorder (National Mental Health Intelligence Network, 2018). Therefore, this group may face distinct barriers to engaging with PPI when compared to those with other mental health conditions. Furthermore, this population is particularly vulnerable to experiences of poor treatment within the NHS. For example, experiences of diagnostic overshadowing, a phenomenon in which patients physical health complaints are mistakenly attributed to their existing mental health difficulty (Molloy et al., 2021). Due to these unique experiences within the healthcare system, this population may have also had distinct views towards PPI, and in turn exhibit differences in their willingness to engage with this.

In addition, it must be noted that while this research has repeatedly highlighted the potential link between mistreatment and engagement in PPI. Despite this, this project manged to recruit 10 participants along with two PPI representatives. As such, it could be argued that these barriers such as mistreatment identified in this research, can be surmounted. The author does not wish to overstate the influence of barriers that may deter engagement, but merely consider why participants from South Asian and Black communities are *less* likely to engage. Participants varied across a number of attributes including, age, gender and ethnicity, in addition, a number of participants had professional backgrounds in healthcare or research. Therefore, although these participants conformed to the eligibility criteria, their level of understanding of research and associated concepts may not necessarily be representative of the general population. This may also, in part, explain why some participants were willing to take part in this project.

In particular, this portfolio has considered how repeated injustices experienced across systems by the Black and South Asian community, may have impacted attitudes towards PPI, and engagement with mental health services. While the evidence gathered supports this idea, results must still be interpreted with caution, and future research should look to build on, and replicate findings. In particular, quantitative research methods would complement this work, to determine whether statistically those who have experienced poor treatment in healthcare, are less likely to take part in PPI when offered the opportunity.

Finally, the consideration of how the mistreatment of minority communities may impact their engagement with PPI has featured at the forefront of this work. This is because as outlined, previous work has captured many of the other barriers and facilitators when considering ethnic minority participation in research. The consideration of previous experiences in the healthcare system and other agencies, represents a new barrier, that to this research team's knowledge, had not been considered in existing literature. Despite this, when considering results from this work, it is important to remember that negative experiences in the healthcare system are just one of the factors that influence attitudes towards PPI in Black and South Asian communities. This barrier must be viewed in the context of a collection of barriers experienced by these communities, in order to get the full picture.

Future Research

In part, the absence of ethnic minority communities in PPI within the UK, is a reflection of the failure of research and funding bodies to take concerted action towards greater diversity, not just in PPI, but within research overall. In the US, The National Institutes of Health require researchers to include those from ethnic minority communities in their research (Public Health Service Act, 1993). Similar action in the UK may provide the necessary motivation for researchers to ensure diversity in the voices that are captured in PPI. To facilitate this, future research should look to identify and evaluate initiatives and strategies to promote greater diversity within PPI. This may prove useful for engaging not only ethnic minorities, but other minorities such a members of the LGBTQIA+ community, who have also historically been excluded from practices such as PPI (Ocloo & Matthews, 2016).

Future research would also do well to build on the findings of the empirical project, by considering which barriers are present within other ethnic minority communities. Given the different experiences of each ethnic minority, attitudes towards PPI, and the factors that influence this, are likely to be different. In particular, the Gypsy, Roma and Traveller community face the poorest health outcomes across ethnic groups (King’s Fund, 2021), and evidence shows that services have historically failed to engage this group (McFadden et al., 2018). Once again, identifying the factors that impact attitudes towards PPI in this group, may highlight potential solutions, improve engagement, and reduce health inequalities in line with the 2019 NHS Long-term plan.

Finally, the synthesis of data specifically identifying the barriers to accessing mental health services among each ethnic minority group in the UK, would provide a good starting point for the development of the necessary initiatives. Again, this stands to help the NHS reach key objectives around health inequalities set out in the 2019 NHS Long-term plan.

Personal Reflections

The year 2020 was unprecedented for many reasons. Along with the onset of a global pandemic, this year gave rise to more conversations about race than I can remember. The murders of George Floyd, Breonna Taylor and Ahmaud Arbery sparked conversations about the experiences of Black people, not just in the US but also in the UK. I selected the present research project because diversity, inclusion and equality have always been, and continue to be, core values of mine. Coming to this project in 2021, post 2020 discourses around race and inequality, I was excited that themes captured in this project would allow me to pursue my personal passions.

Through the completion of this project I have been able to further develop my skills as both a researcher and clinician. Having never completed a project on this scale, with such high levels of responsibility, I approached the research process with a level of nervous excitement. Under the guidance of my supervisors, I learnt how to navigate the many challenges that can arise whilst completing research, such as slow recruitment, and balancing various interests among stake holders during PPI. While, I've leaned on the expertise of my supervisors and fellow researchers, as a budding researcher I have also felt empowered to make independent decisions in line with project aims and goals.

Personally, this project is not just important, it has real life ramifications. As a Black woman seeking to understand the barriers other Black women face when attempting to access mental health services, I didn't have the luxury of treating my results as just data. I saw the same experiences I read about in my own life, and the lives of the many Black women around me. At times, I ruminated on how health inequalities around maternal health, diabetes, and mental health may affect my loved ones. In particular, I worried about what the fact that as a Black woman I am four times more likely to die shortly after giving birth than a White woman (Knight et al., 2017), could mean for me in the future.

For me, even more shocking was the fact that we still knew so little about what may be driving these patterns, and as such, policy makers and those in positions of power could only do so much to address these biases. My identity as a Black woman also created at times, what felt like an overwhelming sense of responsibility to complete this project. This stemmed from the recognition that the ethnic minority experience, and the experiences of those that are so often 'othered' have not just been 'under-represented' within research, these experiences are systematically excluded because they're often not seen as important. All these factors at times had a negative impact on my own mental health, but also acted as a unique source of motivation when the research process stalled.

After repeatedly reading about the role of mistrust and distrust in government, healthcare, and educational systems, and identifying this as a barrier to engagement with mental health services and PPI in my own research. I found it frustrating that I was unable to offer an immediate solution to this issue. Despite this, throughout this process I was reminded of the role of research and scientific method as a vehicle for change. Having now completed this work, while I may not be able to offer a quick fix, my findings can add to what will hopefully be a growing evidence base that sheds light on how these health inequalities may be maintained, providing policy makers with sufficient information to make the necessary changes.

Professionally, hearing participants share their experiences of racism, discrimination and mistreatment at the hands of various systems, was challenging. At times, this tugged on the threads of my own experiences, and sparked internal conflicts. As I considered being part of a healthcare system that was simultaneously responsible for huge amounts of good, yet pockets of damage and abuse. Listening to these experiences also reminded me of the power healthcare professionals hold, and how overtime this position can be forgotten, leading to its abuse. This serves as a warning to continue to exercise the values of clinical psychology throughout my career, treating all clients with dignity and respect, and working with clients collaboratively, as equal partners (Harvey, 2001).

Completing PPI as part of my project also allowed me to put NHS core constitutional values such as ‘Everyone counts’ (DHSC, 2021), into practice within research. Amplifying the voices of those who may not traditionally have a say, gave a unique perspective at several points during the research process. This has produced what I hope are results that speak to the real-life experiences and views of participants. Though enriching, this process was also at times challenging, logistically, devising times when everyone could attend meetings was tricky. In addition, drafting and re-drafting key resources was also time consuming, especially when I was conscious of the many key deadlines along the research process. As with any group, there were also disagreements, and at times conflicting perspectives. These moments often helped me to see issues differently, and invited me to take off the ‘clinician’ or ‘researcher’ hat I may have been wearing. Finally, this process also taught me that ultimately PPI does not demand perfection. This process isn't linear, but actually it is often 'messy' (Taylor-Hughes, 2018). Instead, PPI requires researchers to be open to change, challenge, and critique, all of which stand only to make research better.

Conclusions

This portfolio has explored the factors impacting engagement with mental health services and research, among Black and South Asian communities. A systematic review of the factors impacting engagement with mental health services among Black women in the UK and US was completed. This revealed that factors such as: Stigma, Cost, Practical constraints, Mistrust and distrust, Lack of mental health literacy, Stereotypes and culturally sanctioned behaviours, Alternative coping mechanisms, Failures of the healthcare system, and Perceptions of mental health services prevent Black women from accessing mental health services. Findings suggest that a collection of systemic, individual, and community factors interact to give rise to a lack of engagement with mental health services in Black women. In particular, poor treatment inside and outside of the healthcare system contributed to mistrust and distrust of the healthcare system, and discouraged engagement.

Having identified the factors impacting engagement among this group at service level, the focus turned to potential barriers upstream. An empirical paper considered the factors that impact attitudes towards PPI in mental health research in Black and South Asian communities. Participants' reports highlighted barriers as well as facilitators to engagement, drivers of participation, as well as themes of power and mistrust. Results also highlighted the intricate interactions between race, negative experiences within healthcare system, and the resultant impact on PPI engagement. Findings across this portfolio highlight the need to consider the relationship between ethnic minority communities and various systems when seeking to understand the historic lack of engagement in these communities. Further research is necessary to synthesise evidence of barriers to engagement with mental health services and PPI across other ethnic minority communities. This knowledge could provide a potential solution to the under-representation of ethnic minority communities within PPI, and in turn, may shed light on how to resolve current health inequalities.

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Appendices

Appendix A

International Journal for Equity in Health author guidelines

Systematic review Criteria

Systematic reviews should be titled in the style "The effectiveness of audit and feedback: a systematic review". The background to the area should be stated, what is already known and why a systematic review is needed. Then search strategy should be described, including the databases searched, inclusion and exclusion criteria, the data extraction methods and the proposed methods of data aggregation and analysis. The results should be presented and their interpretation and implications discussed.

Systematic reviews should adhere to the PRISMA standards for reporting: http://www.prisma-statement.org/documents/PRISMA%202009%20checklist.doc.

Additional non-English language abstract

An additional non-English language abstract can be included within the article. The additional abstract should be placed after the official English language abstract in the submitted manuscript file and should not exceed 350 words. Please ensure you indicate the language of your abstract. In addition to English, we can support Arabic, Bulgarian, Bengali, Bosnian, Czech, Danish, German, Greek, Spanish, Estonian, Basque, Persian, Finnish, French, Hebrew, Hindi, Croatian, Hungarian, Indonesian, Italian, Japanese, Korean, Latin, Lithuanian, Latvian, Mongolian, Dutch, Norwegian, Panjabi/Punjabi, Polish, Portuguese, Romanian, Russian, Slovak, Slovenian, Serbian, Swedish, Thai, Turkish, Ukrainian, Vietnamese, and Chinese abstracts.

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

- present a title that includes, if appropriate, the study design
- list the full names, institutional addresses and email addresses for all authors

  - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below
  - Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript
- indicate the corresponding author

Abstract

The Abstract of the manuscript should not exceed 350 words and must be structured into separate sections:

- **Background:** the context and purpose of the review, including the review question.
- **Methods:** how the review was performed, including data sources, study eligibility criteria, participants and interventions; study appraisal and statistical tests used.
- **Results:** the main findings, including results of search and assessment of evidence base.
- **Conclusions:** brief summary and potential implications for policy/management and research.
- **Registration:** authors are asked to provide registration information about the systematic review, including a registration number, if available.

Keywords

Three to ten keywords representing the main content of the article.

Background

This section should be written in a way that is accessible to researchers without specialist knowledge in that area and must clearly explain why a systematic review on this topic was needed and what it aimed to contribute to the field. The section should end with the main question(s) of the review and a brief statement of what is being reported with reference to participants, interventions, outcomes and study design (PICO).

You may also wish to use this section to mention discussions that have been organized with stakeholders and the role of stakeholders in the formulation of the question should be described and explained.

Methods

This should include a clear description of all stages of the review process and the design of the review, the setting, the type of participants or materials involved, and the type of analysis, including:

- **Searches:** search terms and languages, comprehensiveness and effectiveness of the search, search strings and/or combinations of searches, databases, searches for grey literature i.e. contacts, searches on internet, use of specific search terms or strings, filtering or limitations and literature provided directly by stakeholders. Tables and lists of bibliographies, search terms and databases or other information can be provided as additional files.
- **Study inclusion and exclusion criteria:** provide explanation about the rationale followed to include/exclude articles, including specific study characteristics (PICO, length of follow-up, etc), specific report characteristics (year of publication, language, etc) and study selection procedures (screening).
- **Potential effect modifiers and reasons for heterogeneity:** potential effect modifiers and reasons for heterogeneity should be discussed here and should be identified by discussions with stakeholders and experts as early as possible.
- **Study quality assessment:** how you are planning to or have assessed the study quality. Describe the methods used for assessing risk of bias of individual studies, including specification of whether this was done at the study or outcome level, and how this information was used in any data synthesis. Discussions with experts and stakeholders at early stages should help identify the methodological standards for the topic of interest.
- **Data extraction strategy:** what sort of data do you expect to find or have finally extracted and how you computed effect sizes and their variability.
- **Data synthesis and presentation:** report the qualitative and quantitative methods you used to synthesize and present the data, as well as elements you anticipate or have identified such as effect modifiers, type of methodologies and their current appraisal, biases etc. Describe any additional analyses (sensitivity, sub-group analysis, meta-analysis) done and indicate which were pre-specified.

For an example of how a search strategy should be presented, see the Cochrane Reviewer's Handbook.

If existing, make reference to an accessible review protocol. Authors are additionally asked to provide registration information about the systematic review, including a registration number, if available.

Results and discussion

The results and discussion should be presented separately. The results and discussion sections may also be broken into subsections with short, informative headings. Results of each stage of the review should be clearly reported, including:

- **Review statistics:** i.e. the number of articles found in the search and included at each inclusion/exclusion level, along with any relevant information on the distribution of the studies found (e.g. geographical location and source of study). A flow diagram (conforming to relevant reporting guidelines e.g. PRISMA) reporting the inclusion/exclusion process should be presented.
- **Study quality assessment:** a summary of what the different studies found, the confidence in the results of the different studies, what biases were present in each of the studies, and quality of the different studies needs to be included.
- **Quantitative synthesis/Meta-analysis (when possible):** if effect sizes can be calculated for the included studies which measure similar outcomes then a quantitative assessment of these effect sizes should be carried out, including summary statistics of the mean effect, confidence in the mean, the range of effects and sources of heterogeneity in the effect. Please note, if there are a large number of confounding variables or outcome measures such that effect sizes which measure the same outcome cannot be calculated then a summary statistic should not be calculated.
- **Evidence of effectiveness:** a detailed evaluation of the information on the impact of the intervention that the papers give, what evidence of an effect is there and what is the strength of the evidence including the critical appraisal of the articles. In addition, there needs to be an unbiased assessment of what level of evidence the studies provide.

Speculation within the discussion section should be limited only to suggestions for further enquiry or analysis e.g. potential reasons for heterogeneity in outcome, including the possible effect modifiers and impact of variation in the study variables such as experimental design. A section on review limitations should normally be included, including limitations due to the search strategy and bias in articles found, as well as limitations due to underlying bias within studies found such as baseline bias and confounding variables. Gaps in the information provided by the studies should also be highlighted.

Conclusions

This should state clearly the main conclusions of the article and give a clear explanation of the implication for policy/management summarizing the state of the evidence base and the extent to which this informs decision making in relation to the review question and any measure of uncertainty surrounding the outcome. In addition, it should also provide a clear explanation on the implication for research summarizing the shortcomings of the current evidence base in terms of knowledge gaps and the need for primary research.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and materials
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee’s reference number if appropriate

Studies involving animals must include a statement on ethics approval and for experimental studies involving client-owned animals, authors must also include a statement on informed consent from the client or owner.

See our editorial policies for more information.

If your manuscript does not report on or involve the use of any animal or human data or tissue, please state “Not applicable” in this section.

Consent for publication

If your manuscript contains any individual person’s data in any form (including any individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our consent form if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

See our editorial policies for more information on consent for publication.

If your manuscript does not contain data from any individual person, please state “Not applicable” in this section.

Availability of data and materials

All manuscripts must include an ‘Availability of data and materials’ statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Authors are also encouraged to preserve search strings on searchRxiv https://searchrxiv.org/, an archive to support researchers to report, store and share their searches consistently and to enable them to review and re-use existing searches. searchRxiv enables researchers to obtain a digital object identifier (DOI) for their search, allowing it to be cited.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

- The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]
- The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
- All data generated or analysed during this study are included in this published article [and its supplementary information files].
- The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.
- Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.
- The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].
- Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available here.

BioMed Central strongly encourages the citation of any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs. For example:

Hao Z, AghaKouchak A, Nakhjiri N, Farahmand A. Global integrated drought monitoring and prediction system (GIDMaPS) data sets. figshare. 2014. http://dx.doi.org/10.6084/m9.figshare.853801

With the corresponding text in the Availability of data and materials statement:

The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].[Reference number]

If you wish to co-submit a data note describing your data to be published in *BMC Research Notes*, you can do so by visiting our submission portal. Data notes support open data and help authors to comply with funder policies on data sharing. Co-published data notes will be linked to the research article the data support (example).

Competing interests
All financial and non-financial competing interests must be declared in this section.

See our editorial policies for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.

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Acknowledgements
Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials.

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If you do not have anyone to acknowledge, please write "Not applicable" in this section.

Group authorship (for manuscripts involving a collaboration group): if you would like the names of the individual members of a collaboration Group to be searchable through their individual PubMed records, please ensure that the title of the collaboration Group is included on the title page and in the submission system and also include collaborating author names as the last paragraph of the “Acknowledgements” section. Please add authors in the format First Name, Middle initial(s) (optional), Last Name. You can add institution or country information for each author if you wish, but this should be consistent across all authors.

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Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

References

Examples of the Vancouver reference style are shown below.

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Web links and URLs: All web links and URLs, including links to the authors' own websites, should be given a reference number and included in the reference list rather than within the text of the manuscript. They should be provided in full, including both the title of the site and the URL, as well as the date the site was accessed, in the following format: The Mouse Tumor Biology Database. http://tumor.informatics.jax.org/mtbwi/index.do. Accessed 20 May 2013. If an author or group of authors can clearly be associated with a web link, such as for weblogs, then they should be included in the reference.

Appendix B

The CASP Quality Appraisal Tool

CASP Checklist: 10 questions to help you make sense of a Qualitative research
How to use this appraisal tool: Three broad issues need to be considered when appraising a

qualitative study:

Are the results of the study valid? (Section A) What are the results? (Section B) Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes Can't Tell No

Yes Can't Tell No

HINT: Consider • what was the goal of the research • why it was thought important • its relevance

HINT: Consider

• If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal

Comments:

2. Is a qualitative methodology appropriate?

HINT: Consider

• If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes Can't Tell No

HINT: Consider

• if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes, No, Can't tell?

HINT: Consider If the researcher has explained how the participants were selected If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes, No, Can't tell

- If the setting for the data collection was justified

- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)

- If the researcher has justified the methods chosen

- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)

- If methods were modified during the study. If so, has the researcher explained how and why • If the form of data is clear (e.g. tape recordings, video material, notes etc.) • If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes, No, Can't tell

HINT: Consider if the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes, No, Can’t Tell

HINT: Consider If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes, No, Can’t Tell

HINT: Consider If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process If sufficient data are presented to support the findings • To what extent contradictory data are taken into account Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes, No, Can’t Tell

HINT: Consider whether • If the findings are explicit If there is adequate discussion of the evidence both for and against the researcher’s arguments • If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider • If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research- based literature If they identify new areas where research is necessary If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Additional notes related to findings

Author(s), Year and Country	Main findings	Additional notes related to findings
Bailey et al. (2021) UK	3 main themes: 1. 'If you don't know, you don't seek help'; 2. ' ... I was depressed ... I knew I was depressed ... ' 3. 'You have to decide': Attitudes to help-seeking and mental health service use	- Participants' past personal experiences of coping with depression, including migratory histories, cultural and religious views, and personal relationships influenced their help- seeking views and preferred coping methods for depression. - Research discovered several issues that influenced people's views on depression and how previous experience, migratory histories, cultural and religious views and personal relationships played a role for the older adults in this study.
Babatunde & Moreno-Leguizamon (2012) UK	8 Themes: 1. Responses to pregnancy. 2. Emotional feelings before and after giving birth. 3. Social support or the lack of it. 4. Being alone with feelings. 5. Lack of information about health services. 6. Poverty 7. Signs of postnatal depression 8. Not coping.	- The women did not perceive the signs as related to illness but as something else in their daily lives, that is, the notion "that you have to get on with it." - The study also highlights the fact that the signs were not identified by health visitors, despite prolonged contact with the women.
Edge (2011) UK	2 main focuses: 1. Experiences of current services and barriers to care. 2. Alternative models of care	- Perceptions of practitioners' lack of compassion in delivering physical care and women's inability to develop confiding relationships with professionals during pregnancy and childbirth were significant barriers to consulting for depressive symptoms in particular, and health needs more generally. - Black Caribbean women suggested that new care pathways are required to address the full spectrum of perinatal mental health need and that there was much to be gained from receiving care and support in mixed ethnic groups.

Edge (2008) UK	2 Broad themes: 1. Social and structural barriers to help-seeking 2. Personal barriers to help-seeking	- Black Caribbean women experienced difficulty conceptualising perinatal depression and were hesitant about the nature and treatability of the condition. - Barriers to help seeking included: Personal and social imperatives to minimise distress, reluctance to discuss problems, and stoicism in the face of adversity. - Black Caribbean women were willing to counter personal barriers and fears of engaging with mental health services to seek help. However, health professionals appeared to be unable/unwilling to diagnose perinatal depression when this was done.
Sisley et al. (2011) UK	5 super-ordinate themes: 1. Explanations of distress 2. Experiences of distress 3. Managing distress 4. Social and cultural influences 5. Seeking help	- Overall, 23 sub-themes identified: Life experiences, Stressful life events , Performing roles, On my own, Frameworks of Understanding, Unwanted emotions, Perceptions of self, Relationship with the world , Fear of judgment, Responding to emotions, Me time, Talking with myself, Support from others, Sources of strength, Personal journey, Being strong, Getting on with it, Keep it to yourself , Generations, Approaching a GP, Accessing services , Perceptions of mental health and services Tailoring services. - Gender roles and a cultural legacy of being strong and hiding distress emerged as influential in participants' beliefs about managing personal difficulties. This was balanced with an acknowledgement that intergenerational differences highlighted an increasing acceptance amongst the community of talking about issues and seeking professional support. - Findings offered support for the idea that understandings and responses to personal distress are subject to broad-ranging and interwoven influences.
Edge & Rogers (2005) UK	4 Main themes: 1. Conceptualising the nature and causes of perinatal depression 2. Conceptualising psychological distress and its relationship to identity	- Women's narratives suggested that they rejected 'postnatal depression' as a central construct for understanding responses to psychological distress associated childbirth and early motherhood. - Rejection of depression as illness was associated with imperatives to normalise distress and a self-concept which stressed the importance of being 'Strong-Black-Women' for maintaining psychological well-being. This identity served to reinforce notions of resilience, empowerment, and coping strategies characterised by the need to problem-solve practically, assertively, and materially.

	3. Dealing with psycho-social distress 4. Ambivalence about help-seeking	
Edge (2006) UK	3 main themes: 1. Black Caribbean women's construction of perinatal depression 2. Attitudes to perinatal depression – perceptions of differences between Black and White women 3. Black Caribbean women's attitudes to help seeking	- Women's beliefs about mental illness underpinned by personal and socio-cultural attitudes to help seeking might act as barriers to accessing primary care mental health services. - Service provision, antenatal education and the attitudes of some health professionals may also prevent women from this ethnic group receiving care and treatment for perinatal depression. - The combination of structural, socio-cultural, and personal barriers might account for the apparent absence of Black Caribbean women from those receiving treatment for perinatal depression.
Graham et al. (2021) UK	5 Inter-connecting themes: 1. Strength: A way to cope with racism 2. "Mad, Crazy and Weak": Psychological distress stigma in Black African communities 3. Distress: My secret 4. Ultimate trust: Seeking support 5. Minimising distress: A way of coping	- The importance of "being strong" consistently underpinned the participants' narratives. - This requirement for strength often negatively impacted their ability to cope effectively with their distress, leading them to manage it in ways that did little to alleviate it and sometimes increased it.
Ward et al. (2009) US	3 Dimensions: 1. Beliefs about mental Illness 2. Coping Responses 3. Barriers	- Participants endorsed the use of prayer and counselling as coping strategies, but were ambivalent about the use of medications. - Treatment-seeking barriers included poor access to care, stigma, and lack of awareness of mental illness. - Few age differences were found in beliefs, coping behaviours, and barriers.

Nelson et al. (2020) US	3 Overall themes: 1. You should see somebody; I just would not 2. Do I really need to go and see somebody. 3. Self-care despite what others may say. 3 Themes related to the influences of the SBW: 1. Masking or ignoring pain. 2. Inability to ask for help 3. Lack of self-care.	- Although some Black women’s attitudes pertaining to help-seeking for depression were positive and grounded in need for self-care, others declined seeking help, despite expressing that others should do so, due to prior negative treatment experiences and distrust of mental health services. - For Black women who endorsed seeking treatment, seeking help may follow the utilisation of informal sources of support and inner psychological resources, or severity of symptoms. - All participants discussed how adherence to the SBW role negatively influenced some Black women’s views regarding the acceptability of help-seeking for depression
Leis et al. (2011) US	4 Complementary themes: 1. Perceptions of mental health care providers. 2. Concerns about confidentiality. 3. Beliefs about the effectiveness of psychotherapy. 4. Perceptions of psychotropic medication.	- Perceptions of mental health services were clearly an impediment to service use in this population of low-income, perinatal African-American women. - Overall, women expressed a negative view of mental health care providers as well as treatment options. Perceptions of providers as immediately wanting to prescribe medication, rushing to make a diagnosis without fully understanding the problem, and not keeping information shared confidential all served as barriers to mental health service use. - The majority of women perceived both psychotherapy and psychotropic medication unfavourably. Specifically, women suggested that psychotherapy was ineffective and that the side effects associated with psychotropic medication use outweighed their benefits, especially when trying to care for young children.
Waite (2008) US	4 Themes: 1. Readiness for treatment 2. Negative judgment 3. Mistrust of the healthcare system, providers and treatment. 4. The value of complementary and alternative therapy.	- Group members reinforced that nurses who want to improve treatment outcomes need to be cognizant of socio-cultural factors that influence styles of coping with depression and 'treatment' of depressive symptoms. - Results from this cohort of women also suggest that successful treatment for depression would benefit from: establishing a partnership based on trust and understanding of cultural customs, providing clients with increased information about the signs and symptoms of depression, improving provider-client

		discussions about depression as an 'illness' and collaborating with the client on identifying options for treatment.
Pederson et al. (2022a) US	5 ‘Core’ Themes: 1. The critical role of trusted sources and confidentiality. 2. Conceptualisation of mental illness and anticipated discrimination 3. Acculturative influence and migration as a source of emotional distress 4. Spirituality as a source of support and source of stigma 5. Management of mental illness and addressing stigma	- The conceptualisation of mental illness and the associated stigma may be rooted in cultural and religious belief systems among black immigrants. - Cultural beliefs and biopsychosocial models can coexist positively without interrupting the pathway toward optimised engagement in mental health care.
Pederson et al. (2022b) US	5 ‘Core’ themes: 1. Conceptualisation of mental health. 2. Community stigmatising attitudes. 3. Bio- psychosocial stressors. 4. Management of mental health. 5. Methods to reduce stigma.	- Stigma toward mental health was associated with the label of being ‘‘crazy’’ or being judged. - Medication was not viewed as acceptable, but there was openness to activities such as support from the community and psychotherapy. - There was acceptance of the biopsychosocial aspects of pregnancy (including hormonal changes); despite this acknowledgment, most respondents had stigmatising views of medications. - Some respondents endorsed beliefs that sadness or depression is a moral failure, a sin, or caused by evil spirits.
Hall et al. (2021) US	3 main themes: 1. Tension and Stigma 2. Privilege 3. Racial-Cultural Pride	- All participants endorsed an ongoing tension to maintain their emotional stability. These women talked about the importance of maintaining psychological well-being and acknowledged that they had knowingly engaged in behaviours that did not preserve their emotional health.

		- Focus group participants agreed that, unlike their parents and grandparents, they did not have jobs that were physically demanding. They acknowledged privilege and the manner in which their socioeconomic status served as a buffer and barrier to their beliefs about seeking professional psychological help - Being a model SBW was a consistent category within the racial–cultural pride theme. This type of pride is displayed through confidence in self, both as a woman and as a Black person.
Poleshuck et al. (2013) US	3 main themes: 1. Perceived Threat of the Therapeutic Relationship 2. Physical and Mental Health Symptoms; Significant Obstacles 3. Psychotherapy Might Provide Safety, Insight, and Ability to Change	- Participants' concerns about the patient–therapist relationship were identified as a primary barrier to engagement in psychotherapy. Lifelong experiences of prejudice, trauma, and abandonment likely exacerbate feelings of vulnerability, distrust, and caution about psychotherapy and psychotherapists. - Many of the women's health patients described physical and mental health symptoms as direct obstacles to engaging in psychotherapy. Symptoms of depression such as fatigue, lack of motivation, and poor self-care have been found to interfere with obtaining care in other studies as well. Similarly, patients with comorbid conditions reported that their symptoms, such as agoraphobia, arthritis, seizures, and interaction effects from multiple medications, interfered with treatment attendance. - Despite the significant theme of women feeling unsafe in therapy, each and every woman interviewed also felt therapy could be beneficial. This apparent contradiction likely reflects a common feeling of ambivalence toward psycho-therapy, with women recognising there are both potential risks and potential benefits.
Abrams et al. (2009) US	Results mapped the mothers' help-seeking trajectories, beginning with thinking about symptoms, moving to seeking advice, and then to rejecting formal care in favour of self-help practices.	- Individual, community, and provider-level barriers operating at various stages of the help-seeking process: thinking about symptoms, seeking advice, and rejecting formal care. - Although mothers overwhelmingly recommended "talking it out" for other mothers with PPD, an array of attitudinal and instrumental barriers led mothers to choose self-help practices in lieu of formal mental health care.
Alang (2019) US	Four inter-related themes characterised respondents' perceptions of racism as central to unmet need:	- Racism is implicated in why Black people report these reasons for not receiving treatment for mental health problems. Specifically, the fear of double discrimination may be exacerbated among Black people in middle class positions where they work, compete, and are evaluated side- by-side White people.

	1. Interconnected systems of oppression. 2. Double discrimination 3. Institutional mistrust 4. Racial micro-aggressions	- Simply focusing on minimisation of symptoms among Black people would miss the need to confront broader contextual reasons such as the fear of oppression in mental health settings, exposure to racial micro-aggressions, and mistrust in mental health systems that might cause avoidance of care.
Alvidrez et al. (2008) US	3 Overarching stigma-related themes were identified: 1. Exposure to stigmatizing beliefs about mental illness and mental health treatment. 2. Stigma as a barrier to seeking mental health treatment. 3. Stigma as an ongoing treatment experience.	- Stigma clearly influenced the way Black consumers experienced both mental health problems and mental health treatment. Consumers reported growing up in environments where they learned that mental illness was a topic to be avoided and that mental health issues were to be kept within the family. Growing up in a culture that valued strength in the face of adversity, consumers learned that succumbing to mental illness or requiring professional help to address it was a sign of weakness. - The consequences of stigma concerns for these consumers were significant. Most suffered for many years with untreated mental health problems because they avoided, delayed, or refused voluntary mental health treatment to avoid the external and internal stigma of being “crazy.” The concerns that kept consumers out of treatment were often justified once they did enter treatment. Consumers commonly experienced negative reactions from the people in their lives for seeking mental health treatment.
Connell et al. (2019) US	2 broad themes: 1. Structural barriers 2. Interpersonal barriers	- Barriers were broadly categorised as structural and interpersonal with all groups notable structural barriers including poverty, lack of health insurance, and rurality. - All groups identified common interpersonal barriers of gender socialisation of African American males, and prevention being a low priority.
Conner et al., (2010) US	3 main themes: 1. Beliefs about Depression Among Older African-Americans. 2. Barriers to Seeking Treatment for Older African-Americans.	- African-American older adults with depression in this study have experienced a lifetime of discrimination, racism, and prejudice, and they lived in communities where they learned to survive despite these oppressive circumstances. - These experiences impacted study participants’ attitudes about mental illness and seeking mental health treatment. African-American older adults endorsed cultural beliefs that valued keeping mental health status private and not talking to others about mental health concerns. - African-American older adults in this study believed that it is harder to be an African-American and have depression, and that they experienced greater stigma

	3. Cultural Coping Strategies for Depressed African-American Older Adults.	in the Black community than they believed existed in other communities, and that this stemmed at least partially from the lack of information about mental health in the Black community.
Campbell et al. (2014) US	3 Key themes: 1. Black people don't get depressed. 2. I don't trust the doctors and/or the treatment. 3. You don't need a doctor—it'll go way—just pray.	- The stories of these respondents reinforced the notion that culture, particularly beliefs about depression, help seeking, and service use, was a clear determinant of mental and behavioural health of Black Americans. - Respondents in this study talked about how Black Americans may prefer to keep problems in-house and feel that going to therapy amounts to airing one's dirty laundry. - Respondents also spoke at length about the various ways in which help and treatment are viewed in Black communities. - Many respondents believed that Black Americans in general were reluctant to engage in more medicalised forms of treatment. Respondents felt that many Black people were resistant to taking medication and sceptical of therapists, assuming that they would be white and not understand the unique experiences of Black Americans. - Respondents also discussed how Black Americans believed in using other forms of addressing depression rather than professional services. Respondents felt that Black Americans found prayer and support from friends and family preferable to formal treatment.

Appendix D

Summary of quality appraisal using the CASP

Author(s), Year and Country	Summary of Assessment of Methodological Quality using CASP checklist (CASP, 2018)									
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. Is the research valuable?
Bailey et al. (2021) UK	Yes	Yes	Yes	Yes/no	Yes	No	Can’t tell	Can’t tell	Yes	Yes
Babatunde & Moreno-Leguizamon (2012) UK	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Edge (2011) UK	No	Yes	Yes	Yes	Yes	No	Can’t Tell	Yes	Yes	Yes
Edge (2008) UK	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Sisley et al. (2011) UK	Yes	Yes	Yes	Yes/ no	Yes	Yes	Yes	Yes	Yes/No	Yes
Edge & Rogers (2005)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes/ No	Yes

UK										
Edge (2006) UK	Yes	Yes	Yes	Yes	Yes	No	Yes / No	Yes/No	Yes	Yes
Graham et al. (2021) UK	Yes	Yes	Yes	Yes/ no	Yes	Yes	Yes	Yes	Yes	Yes
Ward et al. (2009) US	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Nelson et al. (2020) USA	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Leis et al. (2011) US	Yes	Yes	Yes	Yes/ No	Yes	No	Yes	Yes	Yes	Yes
Waite (2008) US	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes
Pederson et al. (2022a) US	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Pederson et al. (2022b) US	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hall et al. (2021) US	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Poleshuck et al. (2013) US	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Abrams et al. (2009) US	Yes	Yes	Yes	Yes	Yes	Yes/ No	Yes	Yes	Yes	Yes
Alang (2019)	Yes	Yes	Yes	Yes/ No	Yes	No	No	Yes/ No	Yes	Yes

US										
Alvidrez et al. (2008) US	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Connell et al. (2019) US	Yes	Yes	Yes	Yes/ No	Yes	No	Yes	Yes	Yes	Yes
Conner et al. (2010) US	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Campbell et al. (2014) US	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

Appendix E

Health Expectations Author Guidelines

1. Submission and Peer Review Process

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        - funding statement
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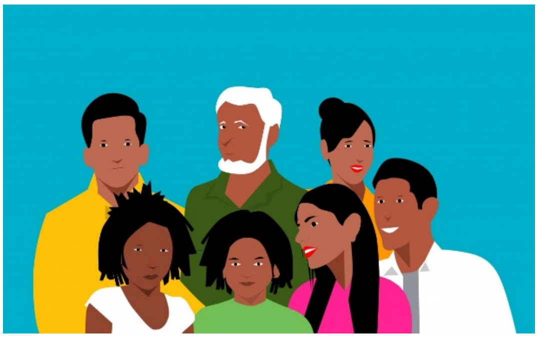
Appendix F

Research Recruitment poster

Attitudes towards mental health research in African, Caribbean and South Asian Communities



Are you of African, Caribbean or South Asian Heritage? ✓

Do you have any experience of mental health issues? ✓

Are you 18 years old or above? ✓

Would you like to take part in a research study looking into attitudes towards mental health research in African, Caribbean and South Asian Communities?

What does taking part involve?
If you choose to take part, **you will be invited to attend an interview with a researcher**. This will last up to 90 minutes and can be completed in person or remotely, via Microsoft TEAMS, or over the phone.

You will receive a £10 Amazon voucher for your time.

If you are interested or you want to find out more, please contact me using the email below or scan the QR code on the top left of the poster to get in touch.

Chief Investigator:	**Natalia Fagbemi**
Email:	n.fagbemi@uea.ac.uk

Appendix G

PARTICIPANT INFORMATION SHEET

Attitudes towards research design in African, Caribbean and South Asian Communities

My name is Natalia Fagbemi and I am a trainee Clinical Psychologist at the University of East Anglia (UEA). As part of my Professional Doctorate in Clinical Psychology, I am conducting a research study into the attitudes towards research design among African, Caribbean and South Asian communities.

I would like to invite you to take part in this study. However, before you decide if you want to take part, it's important that you understand why this research is being conducted and what it will involve for you. I'm happy to go through this information sheet with you and answer any questions you have. Please remember that **taking part is completely your choice.**

What is the aim of the study?

I am interested in interviewing people of African, Caribbean or South Asian heritage who have experienced mental health difficulties, about their attitudes towards research design. This is because these communities are currently under-represented in mental health research. To address this, it is important to identify the attitudes towards research in these communities and consider why they exist. This will help researchers make necessary changes to ensure research can be inclusive and representative of everyone's experiences going forward.

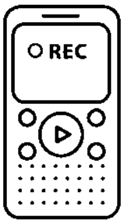
Do I have to take part?

No, you do not have to take part. It is entirely up to you to decide whether or not you want to take part. You can take your time to think about it. If you decide to take part, you will have the opportunity to find out more about the study and you'll be asked to sign a consent form, which just means that you agree to take part.

What will taking part involve?

If you choose to take part, **you will be invited to complete an interview**.
This interview will last for a maximum of 90 minutes, during this time I will ask about your attitudes towards research design as well as your previous experiences within the healthcare system. I want to hear the good and the bad, so I welcome your honesty! All questions are optional and you do not have to answer anything you do not want to. You can also stop

the interview at any time and you are free to specify if you would like anything you have said to be deleted or replaced. **You will receive a £10 Amazon voucher for your time**.

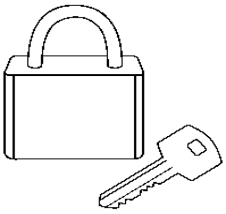


Confidentiality

All the information I collect about you throughout your involvement in the study will be kept strictly confidential within the research team. I will ask if you agree for me to record the interview using an encrypted recording device so that what we discussed can be transcribed (this means the interviews will be typed up word for word). If the interview is completed on Microsoft TEAMS, I will ask if I can video record this. Any identifiable information will be stored securely and separately from your consent form and audio-recorded interview.

Your data, including your recorded interview and typed-up interviews (transcripts), will be stored using an encrypted password-protected storage device. The transcripts will be anonymized (meaning no information that could identify you personally will be included) and the information analysed. I will use a pseudonym (a fake name) for each participant during data analysis and when presenting my findings from the study to maintain your confidentiality. Any word for word (verbatim) quotes of your interview included in the research study will also be anonymised. However, despite this, I cannot guarantee that these quotes or any other data in the final research report will not be recognised by other people.

Your interview data will only be accessed by the members of the research team and professionals from transcription services with your consent. If you agree, we will send the audio recording to a specialist transcription company (outside of the University), who will do this task while maintaining confidentiality. Academic and professional staff may also be able to access your anonymised data in order to evaluate the quality of this doctoral research study. However, they also have a duty to maintain confidentiality.



Any data related to your involvement in this research will be transferred to the University of East Anglia's Research Data Storage Facilities. Here, data will be stored securely, routinely controlled and regularly backed up to avoid data corruption, loss and theft. Your data will be stored for ten years following the final submission of the project, after this time this data will be destroyed.

Are there any exceptions for breaching confidentiality?

It’s important that we ensure the safety of both you and others. Should you disclose any information that raises concerns about your safety or that of other people, the appropriate third parties and services may be contacted without your formal consent. This would normally be discussed with the project supervisors first, unless immediate support was required due to an imminent risk to life or health.

What are the risks or downsides of taking part?

The interview will ask you to share both positive and negative experiences within the healthcare system. Sadly, this system can show racism, discrimination and prejudice, therefore the research interview may ask you to recall and share some of these experiences (if this is relevant to you). Understandably, this may be upsetting. If this happens the I will try to help you feel at ease and remind you that **all questions are optional**.

What are the good things about taking part?

The main advantage to this study is that the feedback you provide will help us to improve research practices in the future. In addition, everyone taking part in the study will receive a £10 Amazon voucher for taking part.

What will happen to the results of the study?

If you agree, a summary of the findings will be made available to all participants once the study is complete, this will be sent via email. The findings of this study will be included in my doctoral thesis, this will be held by the University of East Anglia. Quotes from the interviews may also be included in scientific papers and at conferences.

What will happen if I don't want to carry on with the study?

Taking part is always your choice and you can change your mind at any time. If you change your mind about allowing me to use your data after you have been interviewed, you will have **2 weeks to withdraw your data.** If someone taking part loses the ability to make decisions for themselves, they will be withdrawn from the study.

Where can I get support?

Please see the contact details for local organisations at the end of this Participant Information sheet. These organisations can offer further help and support even if you decide not to take part in this research.

Who has reviewed the study?

This study is funded and organised by the University of East Anglia and it has received full ethical approval by University of East Anglia Faculty of Medicine and Health Sciences Ethics Panel. This research is being undertaken as a part of a Professional Doctorate in Clinical Psychological.

Information and contact details

Should you have any questions, please do not hesitate to contact me (Natalia Fagbemi). If you would like to take part in this research, please contact me so that we can schedule an interview. Please see my details below:

Principal Investigator: Natalia Fagbemi
Email: n.fagbemi@uea.ac.uk
Address: Department of Clinical Psychology and Psychological Therapies,
Norwich Medical School, Norwich Research Park, University of East
Anglia, Norwich, Norfolk, NR4 7TJ.

Primary Supervisor: Dr Bonnie Teague
Email: b.teague@uea.ac.uk

Address: Department of Clinical Psychology and Psychological Therapies,
Norwich Medical School, Norwich Research Park, University of East
Anglia, Norwich, Norfolk, NR4 7TJ.

What if I have a complaint?

If you have any concern or complaints about anything related to the study, please don't hesitate to contact the Director of the Doctorate in Clinical Psychology, Professor Niall Broomfield, whose contact details are included below.

Email: n.broomfield@uea.ac.uk
Tel: 01603 591 217
Address: Department of Clinical Psychology and Psychological Therapies,
Norwich Medical School, Norwich Research Park, University of East
Anglia, Norwich, Norfolk, NR4 7TJ.

Thank you for reading. Please keep a copy of this information sheet for your records.

Further Support – Cambridgeshire & Peterborough

Sometimes we all need a little extra help. Below are contact details to some organisations which may offer some support

Cambridge and Peterborough NHS Foundation Trust

Lifeline: 365 days 7pm – 11pm:

0808 8082121

Urgent Care Cambridgeshire:

0330 1239131

All other queries:

111 (Option 2)

Cambridgeshire County Council

Access to food, employment and financial support (COVID-19)

0345 0455 202

Peterborough County Council

COVID-19 Emergency Phoneline for support, food, supplies

01733 234724

Citizen's Advice

For financial, housing and employment concerns

0808 278 7850 (Peterborough)

08082787808 (Cambridge)

COVID Health Support:
If you are worried that you or a loved one has COVID-19, please call the NHS on:
111 (non-emergency) or 999 if you feel extremely unwell.

Black and Ethnic Minority Community Support:

Cambridgeshire Race Equality & Diversity Service:
01223 703882

Peterborough Racial Equality Council:
07934 719 760

Domestic Abuse
Cambridge Woman's Aid
01223 361214 (Cambridge)
08454 103123 **(Peterborough)**

Call 999 if you feel in immediate danger.

Further Support - Norfolk & Suffolk

Sometimes we all need a little extra help. Below are contact details to some organisations which may offer some support

Norfolk & Suffolk NHS Foundation Trust

24/7 First Response Helpline for psychological support:

0808 196 3494

Mental health and Wellbeing Services (non-emergency):

0300 123 1503

Norfolk County Council

Access to food, employment and financial support (COVID-19):

0344 8008020

Suffolk County Council

COVID-19 Emergency Phoneline for support, food, supplies:

0800 876 6926

Citizen's Advice

For financial, housing and employment concerns:

03444 111 444

COVID Health Support:
If you are worried that you or a loved one has COVID-19, please call the NHS on:

111 (non-emergency) or 999 if you feel extremely unwell.

Black and Ethnic Minority Community Support:
The Bridge+ (Norfolk):

01603 617076

Ipswich & Suffolk Council For Racial Equality:

01473 408111

Domestic Abuse Hotline (Leeway):

0300 561 0077
or call 999 if you feel in immediate danger.

Appendix H

CONSENT FORM

Title of Study: Attitudes towards research design in African, Caribbean and South Asian Communities

Name of researcher (Chief Investigator): Natalia Fagbemi, Trainee Clinical Psychologist at The University of East Anglia

Please add initials in each box if you agree to each statement

1. I confirm that I have read and understand the participant information Sheet for the above study. I have had the opportunity to consider the information and ask questions. I have had these answered to my satisfaction. ☐
2. I understand that my participation in the study is entirely voluntary and that I am able to withdraw from the study before or during the interview. I understand that I can also withdraw up to two weeks after the interview and ask that my data be destroyed without giving any reason. ☐
3. I understand that my interview will be either audio-recorded using a digital recorder or video-recorded and audio-recorded using the recording function in Microsoft TEAMS (through the researcher's university account), and I consent to these recordings. ☐
4. I have been informed and I understand how my personal information and information related to my involvement in the study will be handled. I understand how this will be stored securely, who will have access to this and how this will be used. ☐
5. I understand that should I disclose any information that raises concerns about my safety or the safety of others, appropriate third parties and services may be contacted without my formal consent to ensure the safety of myself and others. ☐
6. I understand and agree that quotes from my interview may be included in research reports and publications, all data used will be treated anonymously and with confidentiality. ☐
7. I agree to take part in the above study ☐

Please turn over for some optional questions
Please note these will NOT affect your involvement in this research

OPTIONAL QUESTIONS: ***Please add initials in each box if you agree to each statement***

☐

1. I agree for my recorded interview to be shared with a transcription company for the purposes of typing up the contents of the interview. If you do not agree to this, a member of the research team will type up your interview instead. ☐

2. I agree to be contacted via email to receive a short summary of the findings of this research.

	XX/XX/2022	
Name of Participant	**Date**	**Signature**
	XX/XX/2022	
Name of person taking consent	**Date**	**Signature**

If you wish to be contacted by email to receive a short summary of the findings of this research, please provide your email below:

Email Address:	

Appendix I

Interview Schedule

What factors influence attitudes towards patient and public involvement in mental health research among African, Caribbean and South Asian communities with self-reported mental health difficulties?: A Qualitative study

START RECORDING AND TRANSCRIPTION

Introductions and Background Information

- *Introduce yourself, thank participant for attending. Researcher from UEA*
- *Explain purpose of interview, stress your interest in both positive and negative views/experiences. Ask, for* ***any questions for me?***
- *This interview is part of the research study I am running.*
- *Contextual information on what research is and the research process?? Give an example of common knowledge that came to light through research e.g. Eating too much sugar rots your teeth.*
- *Outline relevant issues around use of data, including confidentiality and right to withdraw.*
- *Check whether participant has agreed to be contacted about the results, if yes, collect email address for correspondence.*
- *Outline relevant issues around information sharing in the event of risk (i.e., when it may be necessary to break confidentiality)*

Recruitment to the study

1. Can you tell me what led you to take part in this interview?
   a. *probe for values e.g., wanting to give back, helping others etc*
2. Can you tell me what you remember about deciding whether or not to take part? What, if anything, were you unsure about?
   a. probe for the potential attitudes of others and whether this influenced their decision
3. Before taking part in this study, had you ever considered participating in any other research study?
   a. *If not, probe for why. If yes, probe further about their previous experiences of taking part in research.*

Research

4. What is your view of research?
   a. encourage both negative and positive views on research e.g., ‘it’s a bit of a waste of time’
5. What do you think has influenced these views?
   a. probe for ***previous experiences*** e.g., my mum died of cancer so I think it’s important to gain more knowledge or ***values*** **e**.g., I think it’s important to give back

6. What do you know about Patient and Public Involvement (PPI) in research and what do you think of this?
    a. *probe to determine participants grasp of PPI.*

- If participant is unsure, offer definition: *PPI is an active partnership between members of the public and researchers. This means that members of the public work alongside the research team and are actively involved in contributing to the research process as advisers and possibly as co-researchers. (INVOLVE, 2012). PPI is advocated for by the* National Institute for Health and Care Research. While the NIHR bases their research in NHS Trusts to host their research, it is still run separately from the NHS.

7. What do you think of Patient and Public Involvement?

8. Could you tell me about some of the factors that you think have influenced the likelihood of your engagement in practices like PPI? – if you did take part in PPI do you feel like you would be heard.
    a. *probe for feelings around empowerment and perceived self-efficacy following mental health experiences.*
    b. *probe for influences of experiences of accessing mental healthcare (if relevant)*
    c. *probe for potential impact of mental health difficulties.*
    d. *probe for potential impact of race, culture and ethnicity.*

Now, I'm going to ask some questions that you may be more sensitive, please remember you don't have to answer any questions you do not want to.

<u>The impact of Mental health and Ethnicity</u>

9. What is your experience of mental health difficulties?

    Determine if participant is happy to share more information about this, if yes, probe for:

    a. the nature of the difficulty

    b. i)whether the participant accessed mental health support for their difficulty

    ii) if yes, probe about their experience of accessing support, also determine whether at any point they were encouraged to take part in research or offered any PPI opportunities.

    c. How did they understand their difficulty

    d. what they feel this experience says about them (if anything)

Now I'm going to ask you some questions about your experiences of receiving care from the NHS, as a researcher, I'm really interested in anything you have to say either positive or negative.

10. Could you tell me about an experience of receiving care from the NHS?
    a. Probe for both negative and positive experiences.
    b. Probe for explanations of experiences, e.g. NHS is so underfunded or my doctor didn't listen to me because I'm Asian.

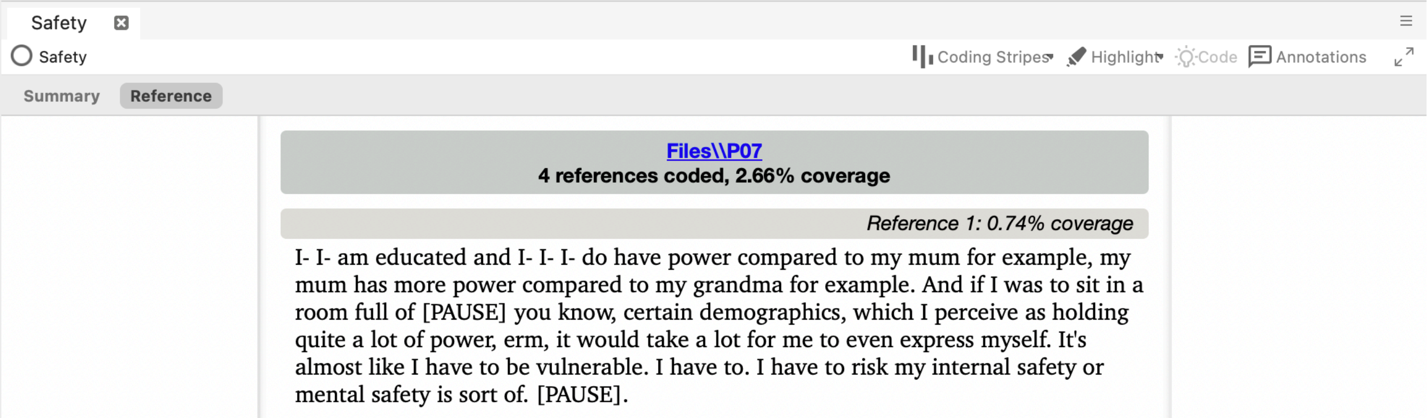
11. Now you've taken part in this research study, do you feel you will go on to take part in other research and why?

<u>Concluding Thoughts</u>

b. Is there anything else you would like to say?
c. Do you have any questions for me?

Appendix J

Example of Open Coding using NVivo (Release 1.7.1) for the Code 'Safety' and Researcher's Reflections from the Reflective Diary



Files\\P07

4 references coded, 2.66% coverage

Reference 1: 0.74% coverage

I- I- am educated and I- I- I- do have power compared to my mum for example, my mum has more power compared to my grandma for example. And if I was to sit in a room full of [PAUSE] you know, certain demographics, which I perceive as holding quite a lot of power, erm, it would take a lot for me to even express myself. It's almost like I have to be vulnerable. I have to. I have to risk my internal safety or mental safety is sort of. [PAUSE].

The image above is an excerpt from a transcript that was coded during analysis. Thus demonstrates the use of open coding during the initial stages of the analysis. As shown above the above excerpt was coded under 'safety', it was also coded under 'power'. Semantic coding aimed to code data according to participants explicit statement, conceptual coding was completed later to allow grouping and the development of themes.

An entry from the reflective diary kept by the researcher is reported below, this entry was related to the above interview:

5th October 2022 – Interview no.7

It was a really interesting interview, it got me thinking more about power, and how our personal characteristics can affect our levels of power. Characteristics like levels of education, gender and race all have an impact on our levels of power. I was also interested in this idea of psychological safety and how this plays into the practice of PPI. I hadn't really considered the role of this in PPI, and how much we're asking those who take part to at times compromise their sense of safety by speaking-up in a room full of people they don't know. If we're asking them to do this, are we creating environments that are psychologically safe to facilitate this?

Appendix K

Draft Coding framework

	Theme	**Definition**			
			Sub-Theme	**Definition**	**Example Quotes**
1.	**Drivers for Participation**	Reasons participants chose to take part in research.	**Hope**	Participants hopes for participating in this research: change, improvement, awareness, inclusivity, representation.	'I don't know, I just love helping people, you know, putting so much effort into [PAUSE], making, you know, mental health or research, urm, better for the future.' – **P07**
			The value of Participation	The unique role of PPI consultants: bridging the gaps in researchers', knowledge, cultural insight and understanding, improving research quality.	'In order to kind of be successful you need someone to fill in the gaps that you might not know about.' **-P02** 'people who are from the same background can perhaps be more likely to understand a lot of the perspectives that would be coming from the people who are actually answering the questions in the research.' **-P03**
			Previous experiences	Experiences of discrimination, mental health difficulties and conducting research and the sense of duty this may create to participate in this research.	'Yes. Like, I don't know if we'll get onto this later, but when you go through your own experiences, like when I mentioned how the services now aren't that appropriate, I've been through that where the help just has not been there, and the help that has been available just isn't suitable for me.' – **P02**
			Alignment with values	Helping others, equity, advocating for others.	'it aligns with my values of what I want to do, how much I want to help out people from- from- those communities, yeah' – **P07**
2.	**Power**		**Social graces**	How elements of individuals identity e.g., gender, race, education impact	'I- I- am educated and I- I- I- do have power compared to my mum for example, my mum has more power

		The role of power in the researcher-participant relationship.		the relationship between researchers and members of the public and participants willingness/ ability to engage in PPI.	compared to my grandma for example. And if I was to sit in a room full of [PAUSE] you know, certain demographics, which I perceive as holding quite a lot of power, erm, it would take a lot for me to even express myself. **-P07**
			Addressing the power imbalance	How potential power imbalances between researchers and members of the public can be addressed.	'Take a step back and even if it's a focus group, it has to be a room full of service users, with a couple of professionals, I think we need to take a step back in those, when- when that happen' **-P07**
			Structural violence	Historical and current abuses of power within/by institutions and systems e.g., within research.	'I don't blame anyone for not wanting to be part of, you know, a 'trial'. You know, it sounds a bit scary, 'research trial' cos it has, it-it's it's- associated with certain connotations from the past for people, you know.' **– P07**
3.	**Mistrust**	The scepticism and doubt that people may hold towards established systems and practices such as research and mental health services. This theme also captures the uncertainty that people may hold towards those who they associate with/ they believe represent these systems and practices.	**Mistrust of institutions and systems**	Participants mistrust of systems and structures e.g., government, healthcare systems, mental health services.	'It's almost like the- the training that happens in the NHS about inclusivity and competency, culturally competent. But it's check, check, check mmm, OK, we've done that, you know [Laughs] yeah.' **– P07**
			Mistrust of research	Doubts about elements of research e.g., research safety and researcher intentions.	'everyone has initial biases and that's also the case for researchers who go about their research. And even with people who try to be quite impartial, I think that it's often unfortunately the case that people can usually only be so impartial as human beings' **– P03**

4.	**Barriers**	Barriers to engagement with systems, institutions and practices e.g. PPI	**Perceptions of competence/ skills**	Doubts about individual competence or skills that are necessary to participate in research.	'And I always- I think for me, was like I- I- kind of doubted my own knowledge and expertise as well, I was like, mmm do I really wanna put myself out there and because it says 80 minutes, urm, you know, and I was like, mmmm what am I gonna do in those 80 minutes? What am I supposed to say [laughing] you know?' **- P07**
			Language	The language that research is conducted in, how research opportunities and roles are presented, advertised and discussed. Is language accessible for members of the public.	'We need to make it more inclusive and reach out to those participants like… like I said earlier in those hard-to-reach places and in terms of the language that we use' **- P10**
			Identity	Experiences of mental health difficulties discrimination and disability as well as individuals socioeconomic status, level of education and how these experiences impact participants willingness/ ability to engage in research.	'Your innate courage is also a luxury. Urm so and I expect that people who experience mental ill health they can sometimes turn out… once they've done their healing or, you know, are embracing healing, actually can turn out to be the most courageous people, but equally when you're in the throes of significant mental ill health, you might face the least amount of courage and people may be scared of making a fool of themselves' **- P10**

			Practical barriers	Lack of time, transport, financial means.	‘if they don't have the means to compensate people to- to- give them token for example, then it's it's-, it's not going anywhere you know.’ - **P07**
			Access	Inequality of opportunity and means to engage with these opportunities.	‘Do you have a seat at the table? You know, are you a member of that WhatsApp group where you… you know, it's an NHS BAME leaders group, Am I NHS leader? I have to be NHS leader to be invited to that WhatsApp group. You know where I can then see that there's an opportunity? Am I on LinkedIn where I can see… umm, those sort of opportunities?’ **- P10**
5.	**Facilitators of engagement**	What researchers have to do to create an environment where people can participate in PPI within MH research	**Psychological safety**	The need for psychological safety that facilitates the trust and vulnerability necessary for participation.	‘I’d say how much it would affect me. So, if it’s a sensitive topic, I don’t know, let’s say you have someone who was recently sexually abused and the research is on sexual abuse, I don’t think it would be the best thing for that person to engage in that kind of research because of triggers that could come up.’ -**P02**
			Research characteristics	Research purpose, topic, methodology e.g. interviews vs. focus groups, and use.	‘I think that it would be who I’m doing the research with, whether I’m interested in the topic of research, what the plans for the research are once it’s done or what it’s going to be used for’ -**P03**
			Empowerment	Participants feel valued and that their input has the power to change and shape research.	‘I’d say yes. If I feel like my input isn’t going to be that respected then I would just feel like I don’t want to go into an environment or a situation where my ideas are just going to be

					constantly shut down, I'm not going to be listened to. Like, I just don't want to go into that kind of environment or dynamic.' **-P02**
			Boundaries	Clearly defined role for PPI consultants.	'I would want them to say, "We are bringing you in as kind of like an expert in this area. This is what we'd like you to take charge of, but while you're doing that we'd also like you to contribute input into this area." And the person in charge of the other area is also going to be doing the same thing for you. Unless there were clear definitions I wouldn't want to do it.' **-P02**

Appendix L

Final Coding framework

	Theme	Definition			
			Code	Definition	Example Quotes
1.	**Drivers for Participation**	Reasons participants chose to take part in research.	**Hope**	Participants' hopes for participating in this research: change, improvement, increasing awareness, inclusivity, representation, accessibility and making things better.	'I don't know, I just love helping people, you know, putting so much effort into [PAUSE], making, you know, mental health or research, urm, better for the future.' – **P07**
			Sharing my knowledge	The role of participants in bridging the gaps in researchers' knowledge, by sharing their knowledge. Participants can offer cultural insight, further understanding, improve research quality.	'Like, I guess giving back or giving a voice, and that's kind of it I suppose. And just knowing that there have been times where I wished things had been different, and maybe services can learn from that, I guess.' **-P06**
			Previous experiences	Experiences of discrimination, mental health difficulties or conducting research and how this motivates people to participate in research.	'Yes. Like, I don't know if we'll get onto this later, but when you go through your own experiences, like when I mentioned how the services now aren't that appropriate, I've been through that where the help just has not been there, and the help that has been available just isn't suitable for me.' – **P02**
			Helping Others	Helping others, promoting equity, advocating for others.	'it aligns with my values of what I want to do, how much I want to help out people from- from- those communities, yeah' – **P07**
2.	**Power**	The impact of power on engagement with systems	**Social power**	How elements of individuals identity e.g. gender, race, education impact the relationship between researchers	'I- I- am educated and I- I- I- do have power compared to my mum for example, my mum has more power compared to my grandma for

		within Black and South Asian communities.		and members of the public and participants willingness/ ability to engage with systems e.g. PPI, research, NHS etc.	example. And if I was to sit in a room full of [PAUSE] you know, certain demographics, which I perceive as holding quite a lot of power, erm, it would take a lot for me to even express myself. **-P07**
			Addressing the power imbalance	How potential power imbalances between researchers and members of the public can be addressed.	'Take a step back and even if it's a focus group, it has to be a room full of service users, with a couple of professionals, I think we need to take a step back in those, when- when that happen' **-P07**
			Structural violence	Historical and current systemic abuses of power within/by institutions and systems e.g. within research.	'I don't blame anyone for not wanting to be part of, you know, a 'trial'. You know, it sounds a bit scary, 'research trial' cos it has, it-it's it's- associated with certain connotations from the past for people, you know.' **– P07**
3.	**Mistrust**	The scepticism and doubt that people may hold towards established systems and practices such as research and mental health services. This theme also captures the uncertainty that people may hold towards those who they associate with/ they believe represent these systems and practices.	**Mistrust of institutions and systems**	Participants mistrust and criticisms of systems and structures e.g. government, healthcare systems, mental health services, educational systems (e.g. universities, training courses)	'It's almost like the- the training that happens in the NHS about inclusivity and competency, culturally competent. But it's check, check, check mmm, OK, we've done that, you know [Laughs] yeah.' **– P07**
			Mistrust of research	Participants' doubts and criticisms about research e.g., research safety and researcher intentions.	'everyone has initial biases and that's also the case for researchers who go about their research. And even with people who try to be quite impartial, I think that it's often unfortunately the case that people can usually only be so impartial as human beings' **– P03**

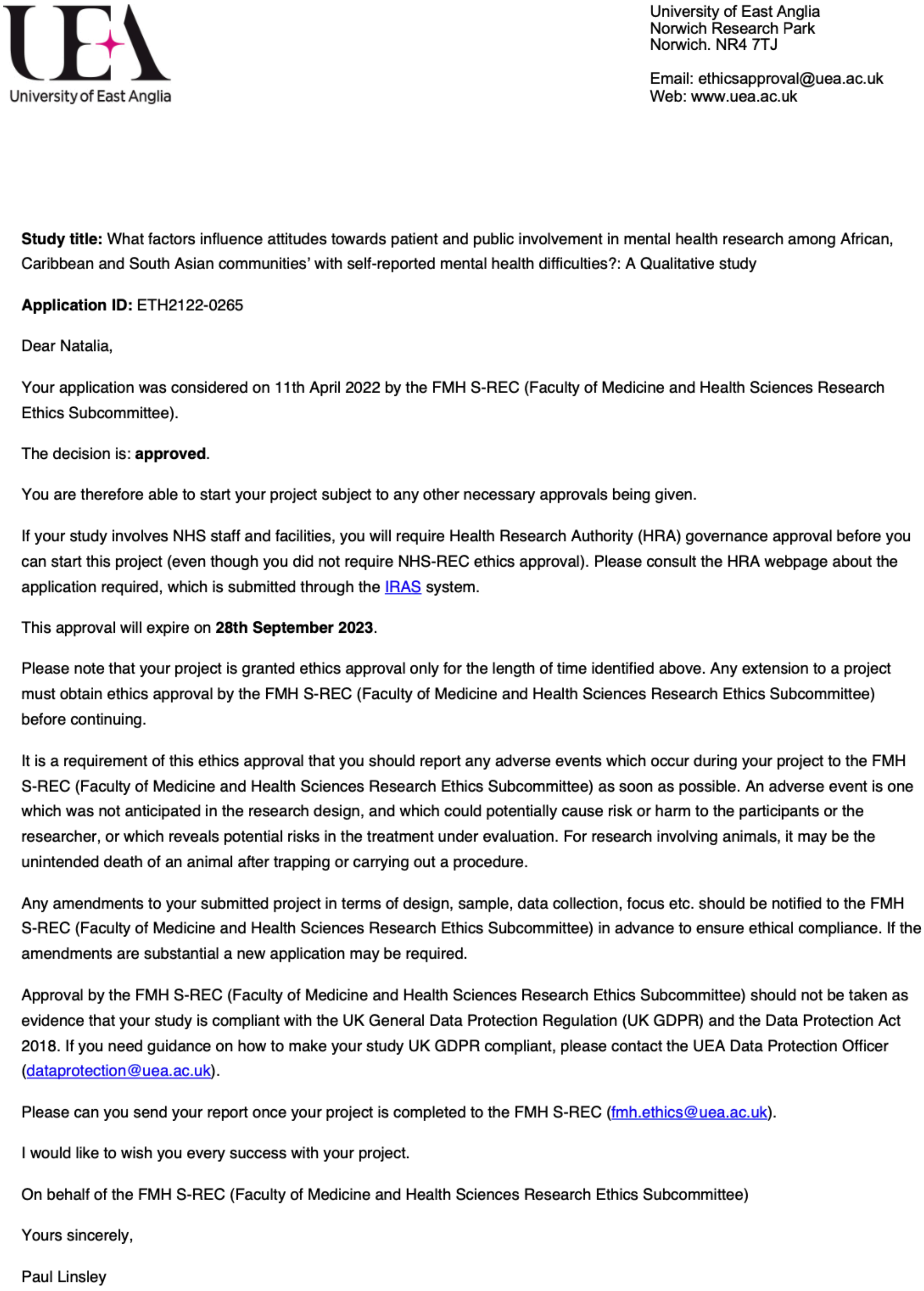
4.	**Barriers to engagement**	Barriers to engagement with systems, institutions and practices e.g. PPI	**Perceptions of research requirements**	Doubts about research requirements and whether individuals will have the competence or skills necessary to participate.	'And I always- I think for me, was like I- I- kind of doubted my own knowledge and expertise as well, I was like, mmm do I really wanna put myself out there and because it says 80 minutes, urm, you know, and I was like, mmmm what am I gonna do in those 80 minutes? What am I supposed to say [laughing] you know?' **- P07**
			Language	The language in institutions e.g. research and healthcare can create a barrier to engagement. This includes the language research is conducted in, how research opportunities and roles are presented/advertised and discussed.	'We need to make it more inclusive and reach out to those participants like… like I said earlier in those hard-to-reach places and in terms of the language that we use' **- P10**
			Identity	Experiences of mental health difficulties, discrimination, internalised stigma and disability as well as individuals socioeconomic status, level of education and how these experiences impact participants willingness/ ability to engage with systems such as research, the healthcare system and other organisations.	'Your innate courage is also a luxury. Urm so and I expect that people who experience mental ill health they can sometimes turn out… once they've done their healing or, you know, are embracing healing, actually can turn out to be the most courageous people, but equally when you're in the throes of significant mental ill health, you might face the least amount of courage and people may be scared of making a fool of themselves' **- P10**
			Practical constraints	Lack of time, transport, financial means.	'if they don't have the means to compensate people to- to- give them token for example, then it's it's-, it's not going anywhere you know.' - **P07**

			Access	Inequality of opportunity including mental health treatment, research opportunities, and means to engage with these opportunities.	'Do you have a seat at the table? You know, are you a member of that WhatsApp group where you… you know, it's an NHS BAME leaders group, Am I NHS leader? I have to be NHS leader to be invited to that WhatsApp group. You know where I can then see that there's an opportunity? Am I on LinkedIn where I can see… umm, those sort of opportunities?' **- P10**
			Negative experiences	Experiences of invalidation, being misunderstood, minimising, being dismissed or neglected by individuals in systems and organisations e.g. research.	'What exactly was the criteria? And then they were really vague again, and that just made me feel really dismissed so that's one thing I've learned about why people might not want to participate in research….It made me, what's the word - apprehensive about participating in research capturing that topic, because then it made me assume that I wouldn't be eligible for the rest of them and, like, why waste my time emailing when someone's just going to be, like, "Sorry, no," you know.' -**P08**
5.	**Facilitators of engagement**	How can systems create an environment where people can engage e.g. in PPI within mental health research	**Psychological safety**	The need for psychological safety that facilitates the trust and vulnerability necessary for engagement and how this can be created. Transparency, accountability, integrity.	Let's say somebody experienced racism in the health service and they brought it to a panel, are they going to be safe to talk about that openly in a panel or in an interview? I hope they would but I know my family would definitely be, like, "Don't bother anything," kind of. Yes, there's no point going down that path

					-P06
			Research characteristics	Research purpose, topic, methodology e.g. interviews vs. focus groups, and use.	'I think that it would be who I'm doing the research with, whether I'm interested in the topic of research, what the plans for the research are once it's done or what it's going to be used for' -**P03**
			Empowerment	Participants believe that their input/feedback has the power to change and shape systems e.g. research, healthcare etc.	'I'd say yes. If I feel like my input isn't going to be that respected then I would just feel like I don't want to go into an environment or a situation where my ideas are just going to be constantly shut down, I'm not going to be listened to. Like, I just don't want to go into that kind of environment or dynamic.' **-P02**
			Role	How clearly defined roles for PPI consultants can facilitate engagement and thinking critically about how we implement PPI in practice.	'I would want them to say, "We are bringing you in as kind of like an expert in this area. This is what we'd like you to take charge of, but while you're doing that we'd also like you to contribute input into this area." And the person in charge of the other area is also going to be doing the same thing for you. Unless there were clear definitions I wouldn't want to do it.' **-P02**

Appendix M

University of East Anglia FMH ethical approval



University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsapproval@uea.ac.uk
Web: www.uea.ac.uk

Study title: What factors influence attitudes towards patient and public involvement in mental health research among African, Caribbean and South Asian communities' with self-reported mental health difficulties?: A Qualitative study

Application ID: ETH2122-0265

Dear Natalia,

Your application was considered on 11th April 2022 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **28th September 2023**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Paul Linsley

Appendix N

Diagrammatic representation of the themes and sub-themes