

**Cultural Perceptions of Psychosis and The Impact on Pathways to Care**

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## CULTURAL PERCEPTION OF PSYCHOSIS & THE IMPACT ON CARE PATHWAYS

### **Thesis Portfolio Abstract**

**Background:** Comparatively, people from Black African, Black Caribbean and other mixed Black ethnicities, and Asian ethnic backgrounds receive a diagnosis of psychosis at a much higher rate than people from White ethnic backgrounds globally. Specifically, people from Black African and Black Caribbean ethnicities with a diagnosis of psychosis are detained under the Mental Health Act, with subsequent higher contact frequency with the criminal justice system compared to people from White ethnic backgrounds. However, there is an under-representation of people from Black African and Caribbean ethnicities within community mental health services, suggesting a gap in service provision and/or engagement difficulties. Whilst research has explored the many barriers to accessing mental health services, little enquiry has been made into what continues service disengagement and psychosis treatment outcomes for people from Black African, Black Caribbean and Asian ethnic groups. Research thus far has narrowly focussed on the individual factors for [dis]engagement whilst neglecting how wider systemic, historical and cultural factors could impact pathways to care and engagement.

**Aims:** The current portfolio aims to explore the societal and cultural perception of psychosis from carer perspectives and how this impacts pathways to care, as well as examine the evidence base for effective therapeutic interventions for psychosis for Black African, Black Caribbean and other Black ethnic groups, and Asian ethnic groups. A further aim is to discern the mechanisms underlying disengagement from services and how the role of the family network may add to this understanding. Systemic theories are adopted to add a new conceptual framework for understanding and improving continued engagement in psychosis support services for people from Black African and Black Caribbean ethnic groups.

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**Methods:** A systematic review examined the outcomes of psychosocial interventions for psychosis for people from Black African, Black Caribbean and other mixed Black ethnicities and Asian ethnic groups. Narrative synthesis was used to review quantitative and qualitative articles, ascertaining treatment outcomes by intervention type and ethnicity. An empirical paper explored the perceptions of psychosis and service involvement from carers from Black African and Black Caribbean backgrounds. Semi-structured interviews ( $n=10$ ) were used and analysed through a thematic analysis approach.

**Results:** The systematic review found that CBT interventions had the high recovery outcomes compared to other psychological interventions (EIP, FI, Psychosocial). However, CBT interventions also had the highest attrition rates. Ethnic differences were found in that people from Black African and Black Caribbean ethnicities had long-term remission rates with the inclusion of a longer therapeutic alliance and integration with the community. People from Asian ethnic groups benefitted more from the inclusion of family. Low attrition rates were found in peer support and combined traditional and clinical interventions. The empirical paper added to these findings, sharing that connection and authenticity was pivotal to service support. The thematic analysis resulted in five crucial themes; (1) The impression of psychosis, (2) Barriers to Care, (3) Hidden cost of psychosis, (4) Generational cultural and societal interplay in mental health perceptions, and (5) Improving pathways to care. The EP argues for collaborative healthcare initiatives and addressing power hierarchies through equality and involvement of people from Black African and Black Caribbean ethnicities.

**Conclusion:** Both papers highlight the need for and benefit of developing authentic therapeutic relationships with professionals and service users. Using systemic theories to extend the current

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understanding of disengagement from services provides a more collaborative approach to improving engagement. Results and implications for service structure are discussed.

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## **Thesis Portfolio Introduction (Chapter 1)**

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This introductory chapter aims to provide a contextual understanding of the core concepts included within this portfolio. It aims to give the reader a summary of the literature on the prevalence of psychosis in different ethnic groups and how historical and sociological factors may have contributed to this, and possibly, contribute to sustained higher levels of psychosis in people from Black African, Black Caribbean and other Black ethnicities, and Asian ethnic groups compared to other ethnicities. In addition, the introduction will discuss factors that impact engagement and the identified gaps in the literature. Finally, this chapter concludes with the rationale for conducting a systematic review and empirical research project.

### **Inequalities**

The WHO Commission on Social Determinants of Health (2008) has determined a crucial link between social inequalities and poorer health outcomes, including the impact of housing, financial position, education, ethnicity, gender and race. The Commission on Social Determinants of Health (CSDH; 2008) concluded that these inequalities arise due to inequities in power, money and resources, which affect daily life. Consequently, this has a direct impact on the mental health of people who face inequalities, often revolving around current injustices that persist in current Society.

Research has suggested that people who have experienced socio-political injustices, such as systemic racism, stigma, discriminatory policies, historical trauma and denied access to care, are

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associated with poorer health outcomes (Nazroo, 2003; Panter-Brick et al., 2008). For instance, people from Black African and Black Caribbean ethnic backgrounds have been found to have a higher mortality rate from chronic diseases (Dwyer-Lindgren et al., 2022), poorer access to health services (Paradies et al., 2015), poorer socio-economic status (del Pino et al., 2019) and a higher fatality rate during COVID-19 (Mackey et al., 2021), in comparison to people from White ethnic backgrounds. Additionally, research has indicated that people from Black African and Black Caribbean backgrounds also have a higher rate of onset of psychological difficulties, associated stigma (Eylem et al., 2020; Myers, 2010), and lower recovery outcomes (Eack & Newhill, 2012). Paradoxically, people from Black African and Caribbean ethnic groups have been found to be under-represented in community care services in the UK (Henderson et al., 1998) as well as globally (Ngui et al., 2010).

These inequalities extend to mental health disparities, whereby research has indicated that people from Black African and Black Caribbean ethnic groups in the UK are between 3 and 7 times more likely than the White population to receive a diagnosis of psychosis (Fearon et al., 2006; Qassem et al., 2014), and 1.4 times more likely in South Asian populations. Between 2006 – 2010, the ‘Count Me In’ Census, which collects information on inpatient admissions, found that people from “Black” ethnicities were admitted or detained under the Mental Health Act at a consistently higher rate than people from White British ethnicities (CQC, 2010; Barnett et al., 2019; Bhui et al., 2003; Jongsma et al., 2020; Tortelli et al., 2015). People who were detained under the Mental Health Act in 2017/18 were four times more likely to be someone from a Black ethnicity in the UK than someone from a White British ethnic background (NHS Digital, 2018; Race Equality Foundation, 2017). Furthermore, due to the underrepresentation of minority ethnic groups in community mental health services, rates of psychosis are likely to be even higher than reported (Chow et al., 2003).

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The historical and societal injustices of minority groups have been evidenced to not only have psychological, social and health consequences but also epigenetic changes (i.e., changes to the genetic expression of DNA, which can be passed in the bloodline) (Kuzawa & Sweet., 2009). This has been hypothesised to lead to a predetermined vulnerability to experiencing stress due to a high level of historical trauma carried through generations within families (Luckett et al., 2011). It has also been a factor in the discussion of why more people from Black African and Black Caribbean ethnic groups appear to experience more distress (Meyer, 2003; Taylor, 2002) and thus are diagnosed with more severe mental illnesses such as psychosis.

Psychosis is a mental health condition characterised by hallucinations, delusions, thought disorder, withdrawal and social isolation (ICD-11). There has been evidence suggesting the biological link between psychosis and family members. For instance, in second-degree relatives, there was a 6% risk rate, a 9% risk rate for siblings and a 13% risk rate for children in first-degree relatives of effected individuals (Gottman, 1991). This genetic risk is not determined solely by ethnicity. However, there is research to suggest that there is a much higher likelihood of developing psychosis in siblings of second-generation (UK-born) African-Caribbean people (17%), compared to first-generation African-Caribbeans (9%), to just 2% in White British people (Sugarman & Crauford, 1994).

The societal landscape in which this occurs is essential to understand as rates of psychosis diagnosis differ depending on the country. For instance, Bhugra et al. (1996) found that in comparison to psychosis diagnostic rates in the UK, psychosis rates for people in Trinidad were low (.70 – 1.4). However, this is now a historical study conducted in a single country, and mixed evidence has subsequently been reported on different prevalence rates of psychosis across various

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countries of Africa. Rates of psychosis are also impacted by service provision, whereby the availability of clinicians to diagnose mental health difficulties is sparse due to a lack of financial expenditure, leading to significant gaps in the qualified workforce and mental health policy (Monteiro, 2015). For instance, most countries in Africa spent less than 1% of their health budgets on mental health provision (Daar et al., 2014), compared to the UK, where reported expenditure was 14% in 2022/23 (NHS England). There is consistent evidence of macro-level structures, such as financial and governmental plans, impacting micro-level difficulties that people experience, such as mental illness. For instance, research in low-middle-income countries (LMIC) consistently reports a higher incidence of mental health difficulties in the population, including psychosis diagnostic rates (Lilford et al., 2020). It's also reported that countries classed as LMIC also utilise traditional faith healers more frequently, which has been shown to increase the duration of untreated psychosis (DUP) from 30 weeks to 225 weeks (Lilford et al., 2020). The length of DUP has been shown to effect recovery outcomes, and this could be contributing to continued rates of psychosis in people from Black African and Black Caribbean ethnic groups (Drake et al., 2000).

The historical and societal treatment of grouping people infiltrates how one perceives health care. Research has found that perceived “cultural difference” was a significant factor in the perceived quality of outpatient care (Alizadeh & Chavan, 2020; Armstrong et al., 2022), including the perception of one's physician's professionalism, empathy and expertise. Therefore, how culturally “close” (i.e., shared characteristics, values and beliefs) one feels to their practitioner impacts how that care is received and one's satisfaction with that care. Alizadeh and Chavan (2020) found that “personal similarity” was a stronger predictor of patients' rating of healthcare quality than ethnic similarity, supported by further research on patients who identified as Black and South Asian ethnicity (Street et al., 2008). Street et al. (2008) also found that this mediated patient-centred communication. Patient-centred communication consists of trustworthiness and perceived

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similarity, which is arguably subjective and, therefore, difficult to measure. Another factor that impacted seeking care was a sense of “cultural responsibility” to care for loved ones and elders. Thus, seeking care is multi-faceted and deserves attention, with nuanced understanding in helping to promote service engagement and intervention. Cook (BPS, 2017) highly endorses such initiatives, albeit with the knowledge that this may require adaptations to the system, as opposed to a few select interventions.

This highlights the importance of addressing how wider societal structures are addressing current mental health difficulties in the context of people with different ethnicities and cultural backgrounds.

### **Ethnicity and Culture**

Firstly, the debate surrounds the definition of ethnicity and culture and how this impacts service engagement and perceived care, which will first be outlined for the purposes of this project. Eaton (2000) defines “ethnicity” as “a set of cultural patterns (values, beliefs, roles, affective and cognitive styles, and norms), heritage, or ancestry shared by a social group of common national or geographic origin”. Indicators of ethnicity are often found in “language, religion and cultural origin” (Eaton & Harrison, 2000). As seen from this definition, there is no biological marker for ethnicity. Historically, ethnicity has been used interchangeably with “Race”; however, there is now a greater understanding of “Ethnicity”, which captures more than observable attributes such as skin colour. “Culture” refers to the overarching set of social structures (not necessarily linked with the given Society), beliefs, behaviours, and cognitions (Faulker et al., 2006). Culture can also be used to refer to an individual’s or collective identity (Gupta & Ferguson, 2008), which is why this is important when considering how one identifies oneself in relation to where one lives or where they

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were born. One's cultural identity can change, and sometimes without choice, which can be termed as "acculturation". Acculturation is when someone moves from a different country, finding themselves in a different cultural framework, which may or may not align with the current Society. Acculturation then happens whereby someone adapts to the culture in which they reside. If one is not able to do this, societal structures can create inequalities based on rudimentary systems of social acceptance (Kidd & Teagle, 2012).

Within egocentric societies, psychosis, although diagnosable with specific criteria in the DSM-IV (APA, 2013), also exists on a continuum of experiences (Esterberg & Compton, 2009), with psychological and biological explanations. Within some socio-centric societies, particularly in rural low socio-economic areas in African and Asian communities, psychosis has been conceptualised as resulting from witchcraft, supernatural origins and religion (Abbo et al., 2008). Within some Asian cultures, supernatural origins form the basis of the onset of psychosis believed to be related to sins in a past life or a 'possession'. This results in a high level of shame, as being "possessed" is appraised negatively within the culture (Bhikha et al., 2015; Islam & Campbell, 2012). This results in fear in the family, placing a barrier in engaging with services (Patel et al., 2022). The National Institute for Health and Care Excellence (NICE, 2014) recommends Family Interventions (FI) as one of the first-line interventions for psychosis. Considering the impact of shame and the family within Black African, Caribbean, and Asian ethnic groups, there is a scarcity of literature examining the outcomes of these interventions for psychosis.

The impact of shame arising from various external socio-political and historical experiences can be defined as either symbolic or systemic violence. Bourdieu & Accardo (1999) originally coined the term "symbolic violence" as a phenomenon where people internalise a dominant narrative as acceptable that would otherwise be perceived as unacceptable or intolerable, for

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instance, subjugation of human rights and unfair treatment of people (i.e. in racism, gender, sexual orientation and class) which is viewed as a societal 'norm' in a given time frame. The unjust treatment can be internalised (where blame is placed upon oneself for suffering). Alongside Bourdieu's classification, Galtung (1975; 1993) specifies a related but separate violence that summarises the complex response to symbolic violence, whereby social institutions are ill-equipped to manage the repercussions of symbolic violence; this is termed "structural violence". Structural Violence can occur when a person experiences "structurally conditioned repression" in response to their emotions and responses resulting from the treatment of people within a given society. These both add to a sense of powerlessness, which is intensified for people who have also experienced injustice, and seeking support from the same systems evokes a paralysed position (Ascoli et al., 2012). Krishnan (2015) suggests this contributes to a sense of "othering", which would be heightened if one finds oneself within a culture that experiences different rules of "acceptable" and "non-acceptable" acts against human rights within contexts. This could be a factor in continued disengagement from services whilst rates of psychosis increase. This was heavily influenced by Colonialism, whereby a value-based system upon the term Race gave rise to racism and hierarchical injustices, such as slavery (Anyanwu & Ani, 2020), which may be termed "Structural violence" by Galtung (1975). The consequences of such have created ever-lasting ripple effects in the institutional systems used today to implement care, mainly where stigma presents itself in relation to people who identify as part of ethnically diverse groups (Faber et al., 2023).

A critical model that could explain the cycle of disengagement for people from Black African, Black Caribbean and other mixed-Black ethnic backgrounds is the systemic justification theory (Jost et al., 2004), which hypothesises that individuals have a fundamental need to be part of a society, living in pre-existing arrangements that may come at a cost to their own sense of well-being or way of living. The historical underpinnings of injustice may have led to a predetermined

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set of social rules that now continue to exist as the status quo, continuing rates of disengagement and high rates of psychosis. This also explains how, despite multiple methods of addressing this, no further intervention has been effective. Therefore, this portfolio attempts to use systemic theories to examine the underlying mechanisms and understand what is needed to bridge the gap to access services and engage in therapies.

This may start to provide one explanation for increased rates of mental health difficulties, specifically people from Black, African and Caribbean ethnic groups, whereby an increased amount of both systemic and structural violence has been historically and presently, experienced within the context of health inequalities, reinforcing barriers in accessing support, poorer health outcomes and a higher rate of psychological difficulty (Kim et al., 2023). This may be contributing to the continued rates of under-representation in community mental health services for psychosis and begs the question of what happens in the time where psychosis is managed in the community to being involuntarily admitted to an inpatient mental health hospital. With prolonged access to mental health services, the role of the family in supporting family members with psychosis increases (Greenwood et al., 2015). However, little research has determined how this is being maintained.

### **Shame and the family**

Given the role of the family and cultural expectations to care for family members, feelings of shame and burden can result among family members (Alvidrez et al., 2008). Gershen Kaufman (1989) describes how shame operates and continues to, for instance, “Society is a shame-based culture, but... shame remains hidden. Since there is [a] shame about Shame, it remains a taboo (Scheff, 2003).



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Shame has been heavily researched in different ethnic minority groups, given the cultural differences in viewing mental health difficulties. For instance, Gilbert et al. (2007; Mirza et al., 2019) focussed on how shame functions in mental health disclosures for Asian participants. For example, they found higher ‘external’ shame (the fear of others knowing) about their experiences and a preoccupation with confidentiality. Authors theorise that this could be linked to how “close-knit” the community is in South Asian cultures, as distant relatives will be privy to information about the family and personal histories, keeping all “shame” within the family. Therefore, an individual may present as socially “well” (protecting the family) yet be deeply affected by mental health difficulties. This comes with many problematic consequences; although the individual may exhibit observable mental health difficulties, it does not illustrate the true “wellness” of that person nor how satisfied that person is in their life. Alongside manifestations of structural violence (Galtung, 1975), the cultural manifestations of shame may keep mental illness support within the family, which continues the disengagement in service support (Greenwood et al., 2015).

Whilst shame operates within the contexts of Society, there is also a closely related theme of stigma. Stigma is often attributed to the way in which one is perceived by others, often negatively, on an attribute (i.e., one’s appearance, sound and expression) (Corrigan & Watson, 2002). Consequently, stigma can be internalised, which can result in mental health difficulties. A systematic review conducted by Misra and colleagues (2021) found that people from minority ethnic groups tended to have a high amount of stigma in relation to themselves and their mental illness, having a direct impact on their perception in their ability to cope and how this may reflect negatively on their families. The authors related this to a lack of awareness of mental health, consequently leading to a lack of engagement and, therefore, reduced contact with mental health services (Misra et al., 2021). Consequently, there are high levels of shame and perceived burden that one could bring onto the family in light of a mental illness (Triandis, 1995; Al-Adawi et al.,

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2002), impacting service engagement (Zang et al., 2020; Mirza et al., 2019). Therefore, it appears ever more paramount to include the family in recovery from psychosis. However, despite Family Interventions being one of the recommended first-line interventions (NICE), there is a scarcity of research on the outcome of these interventions for Black ethnic groups, in addition to understanding the role of the family in supporting psychosis and help-seeking from mental health services.

### **Attribution of Illness**

Alongside experiences of shame, the impact of family and culture and the way in which one understands one's illness have also been evidenced to impact help-seeking attitudes. A 2010 study found that recovery rates were not mediated by values or beliefs around psychosis. However, the quality-of-life rating was impacted if the individual held negative views and beliefs about psychosis and the future (Stainsby et al., 2010; Subandi & Good, 2018). These findings suggests that although recovery rates may increase, that does not necessarily correlate with a higher quality of life rating. Although this study did not assess cross-cultural or ethnic differences, it could be assumed that a different attribution of the antecedents of the illness or current cultural views may either inhibit or engage someone in a service that offers support. This may be particularly relevant for cultures where the belief system follows a non-westernised belief framework. Additionally, it may add to a feeling of not being heard, resulting in feeling disempowered, not wishing the engage in health care systems (Jongsma et al., 2021).

Within many non-western cultures, the development of psychosis is typically associated with spirituality or religion, shared amongst Indians (Shankar et al., 2006; Naik et al., 2012), Bedouin Arabs (Krenawi, 1999), Algerians (Isaa, 1990), and Haitians (Khoury et al., 2012), and Black communities (Edgerton, 1966; Ayinde et al., 2021). Moreover, research from those seeking

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traditional faith healers in Africa resulted in participants reporting better health outcomes even when the methods used were torture (Ayinde et al., 2021). Through a Western perspective, harmful practices experienced by participants, such as shackling and beating, as discussed in the Ayinde paper (Ayinde et al., 2021), would be considered unethical; however, it may be advantageous to assess the perceived underlying mechanisms of change in how participants associated these practices with improved health outcomes and increase engagement in services and therapies. In an attempt to achieve this, cultural adaptations have been utilised to improve engagement in therapies and services, yet there is limited evidence that cultural adaptations are any more efficacious than non-culturally adapted therapies (Degnan et al., 2018). Moreover, relapse rates post-intervention continues to be high for both Black and Asian ethnic groups (Griffiths et al., 2023). This calls into question whether those therapeutic adaptations are meeting the needs of people from Black ethnic groups with psychosis. This may suggest that engagement needs to be addressed on a wider level, incorporating the complex interplay between culture, historical injustices and power hierarchies within the system. This may help explain why there continues to be a lack of engagement in services, as well as a high drop-out rate when one enters psychotherapy from Black African and Caribbean or Asian ethnic backgrounds (Flaskerud, 1986; Maura & Weisman de Mamani, 2017; Nazroo et al., 2020).

Advances thus far have adapted psychological therapeutic approaches, yet little adaptation has been made to the services to create systemic change, an advancement supported by the Clinical Psychologist Ann Cook (BPS, 2017). Cook (2017) suggests a critical step needs to be included in addressing the systemic barriers, as opposed to adapting Western interventions that have made little difference (Degnan et al., 2018; Frieden., 2010; Morgen et al., 2017; Shim et al., 2014; Turner & Brown, 2010). This suggests further research is needed in order to explore the factors which would support mental well-being in people from Black ethnic groups.

## Gaps in Knowledge

Despite a wealth of literature exploring the barriers and facilitators to accessing services and the development of psychosis itself in people from Black, African and/or Caribbean ethnicities (Oluwoye et al., 2021; Jones et al., 2021; Bhui et al., 2021), there has been little progress in making any system or health service impact. In order to do this, there has to be an investigation into how the current societal and cultural landscape appears to maintain a cycle of disengagement of services, reinforced by the Systemic Justification theory proposed by Jost and colleagues (2000). Part of that landscape is the inquiry into the family-level mechanisms of support and how that features in the maintenance cycle of increased rates of psychosis, disengagement and non-engagement within current mental health services. The impact of stigma is complex, and Mantovani et al. (2017) suggest that a more tailored approach needs to be considered to adapt to the complexity that arises with the multicultural and systemic intersection of factors. A shift beyond the medical model of treating symptoms of psychosis for people from Black African, Black Caribbean and other Black ethnic groups may be needed to account for the wider systemic challenges that are interwoven throughout the experiences of people who have had systemic and structural violence in typically Western societies (Al-Faris et al., 2008).

The lack of a consistent understanding, as well as the lack of actionable outcomes to address the underrepresentation in community services and high prevalence rates of psychosis amongst UK Black minority ethnic groups, forms the rationale of this thesis portfolio. Firstly, a systematic review has been conducted to examine current literature regarding effective therapies for psychosis for people from minority ethnic groups. Then, an empirical project is undertaken to substantiate further the current wider systemic understanding of engagement/disengagement in services for

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people from Black African, Caribbean or other Black ethnic groups. The EP focuses on using qualitative methods to understand the family experience of caring for someone with psychosis, the influence of culture and ethnicity on perceptions of services and service engagement. The use of language is examined as pertinent in the way in which services are manufactured in Western societies, following a social constructionist perspective. As communities from minority ethnic groups are typically hard to engage, the real-life manifestations of attempting to conduct research are examined, discussed further in Chapter 6, “Recruitment and Interview Reflections”. This includes a critical reflection of the researcher, strategies of recruitment, and possible reasons for difficulties, such as geographical location, stigma, racism, language and structural discrimination. This chapter is necessary and part of the story of the premise of this thesis, that wider systemic influences continue to maintain a barrier in engaging people from Black, African and/or Caribbean ethnicities.

Within the preceding chapters of this thesis portfolio, definitions of psychosis are explained. Broadly, psychosis, schizophrenia, and psychotic-like symptoms are used interchangeably within the systematic review to encompass the linguistic differences between studies, cultures and nationalities. Within the empirical paper, definitions are used broadly and similarly to the systematic review to encompass all experiences relating to “unusual experiences, such as seeing or hearing things that are not there for an extended amount of time that causes distress”, based on diagnostic criteria set by the Diagnostic and Statistical Manual for Mental Disorders, Fifth Edition (DSM-5), or the International Classification of Diseases (ICD-10).

**Systematic Review (Chapter 2)****A Systematic Review Examining the Outcomes of Psychosocial Interventions for people from Black and Asian ethnic groups with Psychosis.**

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**Abstract**

A high incidence of psychosis continues to be reported in people from Black African, Black Caribbean ethnic groups as well as people from Asian ethnic groups, whilst recovery rates in these groups remain low. Compared to people from White British ethnic groups, there is less evidence concerning the efficacy of therapeutic interventions for psychosis among ethnic minority groups. This review aims to examine the outcomes of psycho-social interventions on recovery outcomes for Black and Asian ethnic groups with psychosis. Ten studies met the criteria for inclusion, and a narrative synthesis was used to examine the studies. A range of therapeutic modalities were found e.g., cognitive behavioural interventions (CBT), early intervention (EI), peer-support and traditional therapies. The review found that CBT accrued positive outcomes yet had limited evidence suggesting a sustained recovery outcome would be achieved. EI studies found positive effects in symptoms management, which was increased with the inclusion of the family. This was marginally more evident in Asian ethnic groups, however there were large attrition rates. There was also a theme evident in longer term therapies and combined traditional healing practices and clinical therapies that showed promise in sustained outcomes, with small attrition rates. This review suggests that additional research is needed to understand the long-term outcomes of NICE recommended interventions for psychosis, such as CBT, and the impact of including the family within interventions for psychosis for people from Black, African, Caribbean and Asian ethnic groups. This could enhance understanding in providing effective therapies and further understanding high attrition rates from support services.

*Keywords:* psycho-social interventions, Black and Asian ethnic groups, traditional therapies, relationship, structural barriers.

### **Introduction**

The term “Psychosis” is an umbrella term typically referring to a cluster of experiences that alter “perception, thoughts, mood and behaviour”, according to the National Institute for Health Care Excellence (NICE, 2014). Psychosis can be used instead of, or in combination with, the following diagnostic labels of Schizophrenia; “Schizophrenia-like disorders” and “Delusional disorders” and characterised by a combination of symptoms depicted by delusions and hallucinations (NICE, 2014). People from a Black African and Caribbean, as well as Asian ethnic backgrounds, are under-represented in community settings where psychosis support is offered (Saleem et al., 2013) in comparison to an over-representation in inpatient settings (Bhui, 2001). It is well-established that people from Black ethnic groups have a higher rate of diagnosis of psychosis than people from White ethnic backgrounds, which has been consistent for over 60 years (Halvorsrud et al., 2018; Tortelli et al., 2015). Whilst a more recent study found that the overall psychosis diagnostic incidence rate has increased by 26% between 2010 and 2012, diagnostic rates have decreased in people from Black Caribbean ethnic backgrounds; however, they continue to be substantially higher than other ethnic groups, such as White British ethnic groups (Oduola et al., 2021). People from South Asian ethnic groups are reported to have the second highest incidence of receiving a diagnosis of psychosis (Halvorsrud et al., 2020).

NICE (NICE, Clinical Guideline CG178, 2014) recommends a multi-stage approach to treating psychosis. An individual with a first-episode psychosis (FEP), is recommended a combination of “pharmacological, psychological, social, occupational and educational interventions” (NICE, 2014). The World Health Organisation, (WHO, 2023) also recommends short-term interventions including CBTp, in conjunction with medication. Alongside or alternatively, Family Intervention (FI) is also recommended, which follows the UK National



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guidance on interventions for psychosis (NICE, 2014). The CBTp model is informed by research into the psychological mechanisms underlying psychotic experiences and tailored to accommodate the difficulties of people with psychosis. Whilst FI is advised for when systemic barriers are identified in the pathway to recovery.

In order to explore intervention efficacy across studies, defining recovery from psychosis is essential, as this is considered the primary purpose of therapeutic interventions. However, many studies comment on the lack of a coherent definition used for “recovery”, which results in too-broad conclusions regarding the efficacy of interventions depending on how recovery is defined and measured within the research study. Broadly, there are two critical aspects of recovery from psychosis in literature. In a patient-centred model, *recovery* can be defined as “...a way of living a satisfying... life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life” (Anthony, 1993). However, research intervention studies typically adopt a clinical standardised rating scale that measures the presence or absence of psychotic symptoms and functioning as the prime definition of whether a person has “recovered” from psychosis or not and rarely includes acknowledgement of the quality or purpose of one’s life as primary outcomes. A study by Lam et al. (2011) found that the definition of personal recovery expanded beyond the constructs of a psychotic symptom measure, rather, it was the ability to reintegrate and function within value-based activities, such as employment and social engagements (Lam et al., 2011; Pitt et al., 2007). Particular attention is placed on the “value-based”, which is idiosyncratic and, thus, may highlight why there is such ambiguity over the word “Recovery”.

Research into the efficacy of interventions for people from Black African and Caribbean ethnic and Asian ethnic minority groups is sparse in comparison to research conducted with White ethnic groups. Cognitive Behavioural Therapy for Psychosis (CBTp) (Rathod et al., 2005) and

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Family Interventions (FI) (Bucci et al., 2016) appear to receive some improvements in symptom management and recovery from psychosis post-intervention. However, most research suggests that there are high attrition rates and a lack of long-term symptom management in comparison to people from White British ethnic groups (Turkington et al., 2002). There is a scarcity of research exploring NICE-recommended interventions with people from Black African and Caribbean ethnic groups, and Asian ethnic groups. Bucci et al. (2016) discuss that people from Black, African, Caribbean and Asian ethnic groups face personal and systemic barriers to engaging in therapy, such as low mental health awareness, lack of cultural competency from services, stigma of mental health and the majority of accepted support coming from within the family (Greenwood et al., 2015). Even in the presence of culturally-adapted interventions, there are less than promising results. For instance, Degnan et al. (2018) found that culturally-adapted therapies were efficacious in treatment outcomes yet not significantly different from non-adapted interventions. A range of methodological discrepancies may have impacted these results, such as incomplete data, varying definitions of recovery and a lack of clarity on how the intervention was adapted. Therefore, it is possible that culturally-adapted therapies could be efficacious, however, given the lack of research and methodological rigour, it is difficult to determine this with certainty. As ethnic minority populations have poorer recovery outcomes in the UK, it may be helpful to examine alternative culturally appropriate methods of treating psychosis globally to explore if these approaches could be implemented in the UK.

There has been a lack of research attuning to the needs of populations with different cultural backgrounds. The terms “culture” and “ethnicity”, although related, are different concepts. Ethnicity refers to a shared set of cultural characteristics for an individual (such as language and ancestry) (Eaton, 2000), whereas “Culture” refers to a wider collection of notions of social structures, beliefs, behaviours and cognitions (Faulker et al., 2006). Both terms are important to use,

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as referring to a group of people who share a set of cultural characteristics (i.e., ethnicity) may not share the same cultural background. In determining the needs and beliefs of different ethnic groups, cultural appraisals associated with mental illness need also be addressed. For instance, people from Lao (Sydara et al., 2005), India (Parveen et al., 2020), Africa (Wassie et al., 2015) and Latin American ethnic groups (Pedersen & Baruffati, 1985) have been found to utilise alternative therapies and traditional medicine to address mental distress. In contrast, people from Western cultural backgrounds may utilise psychological and medical models of intervention for mental health (Nichter, 2010).

People who use traditional healing practices in African surmounts to a large majority (80%). Of that majority, 40%-60% of people utilising the traditional methods were to manage or treat mental illness (Mothibe & Sibanda, 2019). The WHO (2021) define *traditional medicine* as, "...the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, used in the maintenance of health and in the prevention, diagnosis, improvement or treatment of physical and mental illness.". Research studies have begun to explore the outcomes of combining Western and more traditional therapeutic modalities in the hope of providing better recovery outcomes for psychosis (Musyimi et al., 2018). However, little is known about the profiles and outcomes of this traditional approach to treatment. Abbo (2011) found that people from the Busoga region of Eastern Uganda gained a more significant clinical outcome when combining both Western and traditional methods (Abbo, 2011). Although Abbo (2011) was limited to Uganda, their findings suggest the importance of one's cultural appraisal for mental health and incorporating those within ethical treatment protocols where possible. This is supported by further research, showing post-intervention recovery benefits when including religious or spiritual belief systems in clinical interventions (Jensen et al., 2021; Habib et al., 2014; Messari & Hallam, 2003), however there are mixed findings overall. For instance, Nortje et al., 2016 saw no difference in symptom

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recovery using traditional healing methods, whilst Fekadu et al. (2019) found positive findings, but comments on the benefit seen when utilising social support in addition to the traditional practices. This may suggest that social support underlies the success of recovery.

Similarly, Asian ethnic groups in Hong Kong were found to benefit from the inclusion of the community, evidenced by recovery outcomes (Asian Network of Early Psychosis, 2012). Within the UK, social recovery models have been endorsed within Early Intervention services for Psychosis, although it is not yet widespread (O'Connell et al., 2022). However, there has been little research assessing the impact of this with people from Black African, Black Caribbean, and Asian ethnic groups. Additionally, there is no such review of different interventions for different ethnic populations to determine whether ethnic differences are a factor to address in therapies.

There appear to be several studies, including systematic reviews, exploring the outcomes of psychosocial interventions for psychosis in general. However, there is a paucity of this in people from Black African and Caribbean, and Asian ethnic groups with psychosis. Additionally, although there is a growing evidence base for culturally-adapted psychological/psychosocial interventions for psychosis, however, limited conclusions have been made due to methodological discrepancies (Degnan et al., 2018).

To address the current gaps in the literature, this systematic review of studies on psychosocial interventions, including traditional medicine in the treatment approach to supporting recovery from psychosis for Black African, Caribbean and Asian ethnic groups, the following questions will be addressed. For the purposes of the paper, the recovery outcome was measured by symptom reduction and manageability of psychosis post-intervention, evidenced through clinical scales (such as the PANSS) and self-report scales.

**Research questions**

1. What are the clinical and self-reported outcomes of a range of interventions tested in RCT's with individuals who have psychosis or Schizophrenia from Black, African, Caribbean and Asian ethnic backgrounds?
2. What are the approaches used in these interventions that promote positive post-intervention outcomes for people from Black African, Caribbean and other Black ethnic groups, and Asian ethnic groups?

**Methods****Aim**

This systematic review aimed to explore outcomes of psycho-social (non-pharmacological) interventions for Black and Asian ethnic groups, to identify the most effective interventions for psychosis. A narrative synthesis methodology was used to analyse the findings, following PRISMA guidelines (Moher et al., 2009) and registered on PROSPERO (CRD42022365649). As this was a secondary data analysis of pre-published work, ethical approval was not required.

**Study Selection**

The review included all frameworks of non-pharmacological interventions using randomised controlled study designs. The term “psychosocial” intervention has been used to capture multiple types of intervention, that include traditional healing practices, social recovery models, psychological models and the combination of both social and psychological interventions.

**Inclusion and Exclusion Criteria**

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### Inclusion criteria:

- Participants who had been diagnosed with Schizophrenia, or Schizophrenic-like disorders, such as schizoaffective disorder that included the experience of psychosis, or a psychotic episode.
- Studies that included at least one group from an Asian or Black African, Caribbean or other Black ethnicity, with their minority status within their population identified by the authors of the paper, without restriction on geographical location.
- Reported research outcomes from non-pharmacological interventions (psychological, social, group interventions and traditional healing practices) for psychosis.
- Randomised controlled trials
- At least one validated outcome measure on post-intervention psychotic symptoms

### Exclusion criteria:

- Studies not involving target populations.
- Reviews, case reports, and qualitative studies.
- Pharmacological interventions
- Non-randomised controlled trials

### Search Strategy

A systematic search through electronic databases were performed examining the intervention type and resulting outcome on psychosis for both people from Black ethnic groups and Asian ethnic groups. This was conducted on March 9, 2022, across multiple databases from 1970 to 2022, with an updated search performed on 26<sup>th</sup> of January 2024. Search terms were as follows:

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(“Afro-Caribbean” or “Black” or “African” or “Caribbean”) OR (“South Asian” or “Asian”) AND (“Therapy” or “Treatment” or “psychological Intervention”) OR (“Religious healer” or “Indigenous healer” or “Indigenous practice” or traditional healer”) AND (“Psychosis” or “Schizophrenia” or “Psychotic disorder”) AND (“Recovery” or “Rehabilitation” or “Healing” or “Outcome”). The updated search did not identify any additional studies that met eligibility for review inclusion.

### **Screening**

Three rounds of screening assessed the relevance and specificity of each paper (See Figure 1). Initial title screening excluded unrelated papers (i.e., unrelated subject areas, or pharmacological studies). Also excluded were conference abstracts, book chapters, dissertations, reports and papers not in English. The second round of screening included independently and systematically reading abstracts for relevance to the research questions and study design eligible for study inclusion. To minimize bias, a random selection of 25% of abstracts was checked by an independent researcher, with discrepancies resolved by a third reviewer. Full-text reviews were conducted based on the inclusion criteria. Out of 7,009 references, 5,598 duplicates were removed. Title screening resulted in 290 papers, and after full-text screening, 10 articles met the inclusion criteria (See Figure 1.).

### **Data Extraction**

Data extraction was independently performed by the main researcher and verified by a second reviewer for inter-rater reliability. Extracted data detailed the following (found in Table 1):

- Study characteristics (authors, publication year, country)
- Participant characteristics (sample size, ethnicity, diagnosis)
- Intervention details (type, duration, frequency).

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- Outcome measures (clinical outcomes, functional outcomes, quality of life, self-report measures).

### **Definition of recovery**

The definition of recovery ranged across studies, with some studies omitting a definition entirely. Definitions include recovery reported as a clinical outcome measure, most often using the PANSS Positive and Negative Symptom Scale (PANSS). Recovery using the PANSS was measured comparing pre- and post-scores, with other clinical measures (listed below). Definitions also included a qualitative measure of recovery, which included participant written and oral feedback, as well as long-term follow up. Due to the range of definitions included in this review, a specific question regarding the integrity of recovery measure was included in the risk of bias tool (found in Appendix B). This was further informed by Lam et al (2011) who discusses the importance of using a self-reported measure to determine participant level of satisfaction on recovery, as well as clinical outcome measures.

### **Quality Appraisal**

Articles were assessed using an adapted amalgamation of the ROBINS-I and RoB-2 tools, as to capture mixed methods, non-randomized, and randomized trials (see Appendix B). Each study was rated on the risk of bias in the reporting of the following categories; demographics, ethnicity, diagnosis, confounding variables, appropriate analysis (given confounding variables), recruitment, control group, baseline, outcome measure (to conclude participant perspective) and participant bias. Studies were rated on risk of bias across 12 items (with a maximum score of 15), with scores converted to percentages. High quality was defined as 80% or above, moderate as 20-80%, and low quality as below 20%. Discrepancies were resolved through discussion or a third reviewer.



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Evidence of validating measures in cross-cultural and ethnically diverse groups were not included within the tool, however, was independently conducted by the researcher conducting further exploratory searches of the literature. Of note, the CPRS and Insight scale were not validated against ethnic diverse groups.

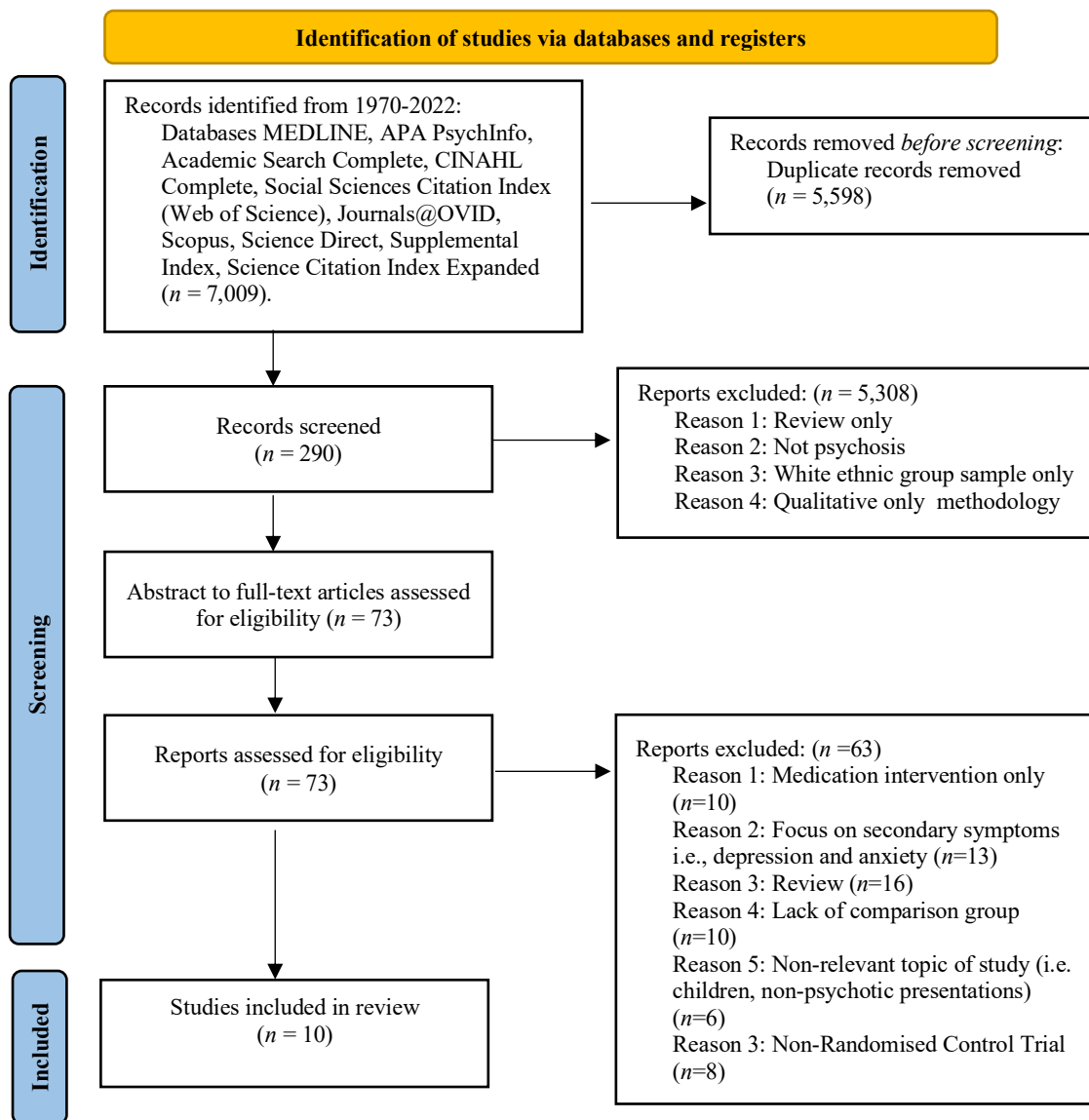
### **Narrative Synthesis**

Studies were not pooled for two reasons: (a) large heterogeneity in study characteristics including location, sample and intervention type; and (b) because a pooled estimate would be difficult to examine given the significance of the contextual understanding to the interventions reviewed. For this reason, a narrative synthesis was employed (Popay et al. 2006). The first stage of the synthesis was by means of developing a preliminary synthesis, which grouped intervention type, outcome, with descriptive summaries highlighting key findings and methodological quality (Table 1). The second stage involved exploring relationships and patterns amongst the data. This was done by systematically identifying the underlying mechanism of change in the intervention, commonalities between studies, and differences (Appendix D).

A final stage was assessing the robustness of the synthesis, which involved the research team cross-examining the studies included and patterns observed within the data, evidenced through inter-rater scores. This was also clinically measured by the ROBINS-I and RoB-2 tool which identified risk of bias. Key themes are discussed, while Table 1. Provides an overview of study characteristics, interventions, and outcomes (Table 1). The quality assessment scoring is presented in Appendix B. This was deemed an appropriate analysis for the research questions due to the complexity of the current picture of research.

**Figure 1.**

*PRISMA Flow Diagram of study selection.*



**Results**

**Study characteristics**

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### *Study design*

Study designs were all pre and post intervention outcome studies, conducted within a randomised controlled trial. Table 1. outlines the participants demographics and characteristics of the 10 RCT studies included in this review (for a detailed breakdown of study characteristics including limitations, see Appendix D).

### *Interventions*

Interventions examined were Cognitive Therapy ( $n=1$ ), group CBTp ( $n=1$ ), combined traditional healing and clinical approaches ( $n=1$ ), Culturally Informed Treatment for Schizophrenia (CIT-S) ( $n=1$ ), peer support ( $n=1$ ), Culturally-adapted Cognitive Behavioural Therapy (CaCBT) ( $n=1$ ), Family Intervention ( $n=1$ ), Illness Management and Recovery (IMR) ( $n=1$ ), psycho-education ( $n=1$ ), Cognitive Remediation (CR) ( $n=1$ ).

### *Diagnoses*

Diagnoses included for review fell under the umbrella term of “Psychosis”, which includes diagnoses such as chronic schizophrenia, non-organic psychosis, psychotic disorder, schizophrenia and schizoaffective disorder. Within clinical samples within hospital or community settings, a diagnosis was already established through participants’ interaction with a psychiatric hospital, in assessment in line with the diagnostic criteria set out in the Diagnostic Statistical Manual of Mental Disorders (Fifth Edition; DSM-V) or the International Classification of Disorders (ICD-10). However, within some studies (Malla et al., 2020; Rathod et al., 2013; Tan & King, 2013) it was unclear how the diagnosis was determined.

### *Definition of recovery*

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The definition of recovery ranged across studies, with some studies omitting a definition entirely. Definitions include recovery reported as an outcome measure, most often using the PANSS Positive and Negative Symptom Scale (PANSS), with other's listed in *Outcome Measures* below. Definitions also included a more qualitative measure of recovery, which included participant written and oral feedback, as well as long term follow up. Due to the range of definitions included in this review, a specific question regarding the integrity of recovery measure was included in the risk of bias tool (found in Appendix B). This was further informed by guidance from Lam et al (2011) who discusses the importance of using a self-reported measure to determine participant level of satisfaction on recovery, as well as clinical outcome measures.

### ***Outcome measures***

A range of outcome measures was used, including the Positive and Negative Symptom Scale (PANSS), Global Assessment Scale (GAS), The Brief Psychiatric Rating Scale (BPRS), Scale for the Assessment of Negative Symptoms (SANS), the Scale for the Assessment of Positive Symptoms (SAPS), the Social and Occupational Functioning Assessment Scale (SOFAS), Quality of Life Scale (QOL), the Family Burden Scale, Stigma Towards Schizophrenia scale, Satisfaction Scale, Psychotic Symptom Rating Scale (PSYRATS), Becks Anxiety Inventory (BAI), Becks Depression Inventory (BDI), Global Assessment of Functioning (GAF), World Health Organisation Quality of Life Scale-Brief (WHOQOL), Comprehensive Psychopathological Rating Scale (CPRS) and MATRICS Consensus Cognitive Battery (MCCB, a measure specifically for cognition relating to Schizophrenia).

### ***Setting***

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Studies included in this review had a range of settings including psychiatric hospitals, in-patient settings, out-patient settings and community-based settings. The implications of each are taken into account within the quality assessment tool (See Appendix B). Countries in which studies were conducted included areas of Asia, Africa and England.

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**Table 1.**

*A table demonstrating the characteristics of the studies included for this review.*

Study Characteristics										
Author	Title	Sample (n, ethnicity, mean age; M years)	Country of origin	Intervention	Control	Study Design	How was diagnosis determined?	How was recovery defined?	Outcome	Attrition rate
Gillard et al. (2022)	Peer support for discharge from inpatient mental health care versus care as usual in England (ENRICH): a parallel, two-group, individually randomised controlled trial	n = 590, 59% White, 15% Black, 11 %Asian, 8% Mixed ethnicity. M; 40 years.	England	Peer support	TAU - follow up from MH professional within 7 days of discharge.	A parallel, two-group, individually randomised controlled trial (RCT).	Pre-existing official diagnosis recorded against their data	Re-admission rate	In the peer support group, 136 (47%) of 287 patients were readmitted at least once within 12 months of discharge. 146 (50%) of 291 were readmitted in the care as usual group.	2%
Grant et al. (2012)	Randomized Trial to Evaluate the Efficacy of Cognitive Therapy for Low-Functioning Patients With Schizophrenia	n = 60, 65% African Caribbean, M; 38.4 years.	Philadelphia, Pennsylvania, America.	Cognitive Therapy (CT)	Treatment as usual (TAU) (minimum of antipsychotic pharmacotherapy however many patients may have had supportive counselling/day centre involvement)	RCT, single-blind design.	Diagnosis of schizophrenia or schizoaffective disorder was determined on a consensus best-estimate basis by research personnel (with PhD and MD degrees) using a structured interview.	“Clinically significant change in their functional outcome”	Patients treated with CT showed a clinically significant mean improvement in global functioning from baseline to 18 months that was greater than the improvement seen with standard treatment.	32.1%
Gureje et al. (2020)	The effect of collaborative care between traditional/faiih healers and primary health care workers to improve psychosis outcome in Nigeria and Ghana (COSIMPO) – a cluster randomized controlled trial	n = 307, Ghanaian, M; 33 years.	Nigeria and Ghana	Both clinical and traditional healer in joint care (consisting of all treatment methods, psychosocial, medical and spiritual)	Enhanced care as usual - traditional methods such as using herbs, rituals, prayer, fasting, and divination.	RCT (Cluster) Single-blind.	Assessed using the structured clinical interview for DSM-IV.	Not defined, but measured via reduction in symptoms (PANSS)	From baseline to post intervention score (6 months) on the PANSS, results went from 107.3 (SD 17.5) to 53.4 (19.9). The control group went from 108.9 to 67.6. Both positive and negative symptoms improved.	13%
Lin et al. (2013)	A randomized controlled trial of an adapted Illness Management and Recovery program for people with schizophrenia awaiting discharge from a psychiatric hospital.	n = 97, Taiwanese, M; 35 years.	Taiwan	Illness management and recovery (IMR)	TAU (management, occupational health, psychopharmacology)	RCT	A chart diagnosis of schizophrenia or schizoaffective disorder based on <i>DSM-IV</i> criteria - not specified who by.	Illness management, and what recovery means to that individual. Measures were taken to assess the progress of such goals.	Improvements in knowledge, attitudes towards medication, insight. No difference found on the brief psychiatric rating scale. For each interaction effect, participants in the IMR group improved more than those in TAU.	0 (inpatient setting)
Malla et al. (2020)	Comparison of clinical outcomes following 2 years of treatment of first-episode psychosis in urban early intervention services in Canada and India	n = 333, Montreal (165), Chennai (168), M; 25 years.	Canada	Family support in EIS	Baseline measures (2 year follow-up)	RCT	A diagnosis received in accordance with DSM-IV, however not specified how, when or who by.	Not defined.	Improvement in negative symptoms, no differences in positive symptoms. Family support was higher in Chennai than in Montreal at month 3. Improvement was greater in Montreal for positive symptoms and in Chennai for negative symptoms.	20%
Ngoc et al. (2016)	Effects of the family schizophrenia psychoeducation program for individuals with recent onset schizophrenia in Vietnam	n = 59, Vietnamese (in Australia), M; 25 years.	Vietnam	Psycho-education	Medication	RCT	ICD-10 diagnosis of schizophrenia.	Not defined, however outcomes included patient and family reports for (1) stigma towards schizophrenia, and the patients' (2) quality of life, (3) medication	There were significant treatment effects (moderate to large R = 0.08) on: quality of life, stigma, medication compliance, and satisfaction.	19%
Rathod et al. (2013)	Cognitive behaviour therapy for psychosis can be adapted for minority ethnic groups: A randomised controlled trial	n = 33, Black British 27%, Black African 15%, South Asian 21%, M; 34 years.	UK	Culturally-adapted Cognitive Behavioural Therapy (CaCBTp)	TAU	RCT	Diagnosis made in accordance with DSM-IV. Does not state by whom or when.	Not defined, however recovery was measured by CPRS and Insight Scale, which suggests a symptomatic and insight definition of recovery.	CaCBTp group resulted in higher scores post intervention on recovery than control group.	18%

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Tan & King (2013)	The effects of cognitive remediation on functional outcomes among people with schizophrenia: A randomised controlled study	n = 70, Chinese, Malay and Indian (no further breakdown available), M; 33 years.	Singapore	Randomised to receive a 60-hour programme of cognitive remediation (CR)	Physical exercise (Vocational training)	RCT	Not specified	Improved neurocognitive function and overall functional outcome (longer employment hours or greater improvement in community ability) than the control group.	Participants who received CR had significantly greater improvement in all neurocognitive domains. CR group achieved greater attainment of vocational or independent living skills and better functional outcomes at post-intervention and at the end of the 1-year follow-up.	29%
Weisman de Mamani et al. (2014)	A randomized clinical trial to test the efficacy of a family-focused, culturally informed therapy for schizophrenia.	n = 69, 20% White, 15.9% Black, 5.7% other, 8% Hispanic/Latino, M; 42 years.	"Spanish speaking". No country of origin noted.	CIT-S (Culturally Informed Treatment for Schizophrenia)	3-session psychoeducation (PSY-ED)	RCT	Structured clinical interview in accordance with DSM-IV.	Reduced symptom severity	Patient ethnicity and patient-therapist ethnic match (vs. mismatch) did not relate to treatment efficacy or satisfaction with the intervention. CIT-S condition had significantly less severe psychiatric symptoms at treatment termination than did patients assigned to the PSY-ED condition. No ethnic differences found.	33.30%
Wong et al. (2019)	Group cognitive behavioural therapy for Chinese patients with psychotic disorder: A feasibility controlled study	n = 48, Chinese, M; 30 years.	Hong Kong	Group CBTp	Psycho-education	RCT	Psychiatric assessment.	A reduction in clinical symptoms.	Patients received group CBTp (n = 25) showed significantly greater improvement in their delusion compared with those receiving PsyEdI (n = 23). Nearly 61% of patients in the group CBTp showed at least 50% reduction on their score of delusion in the PSYRATS.	21%

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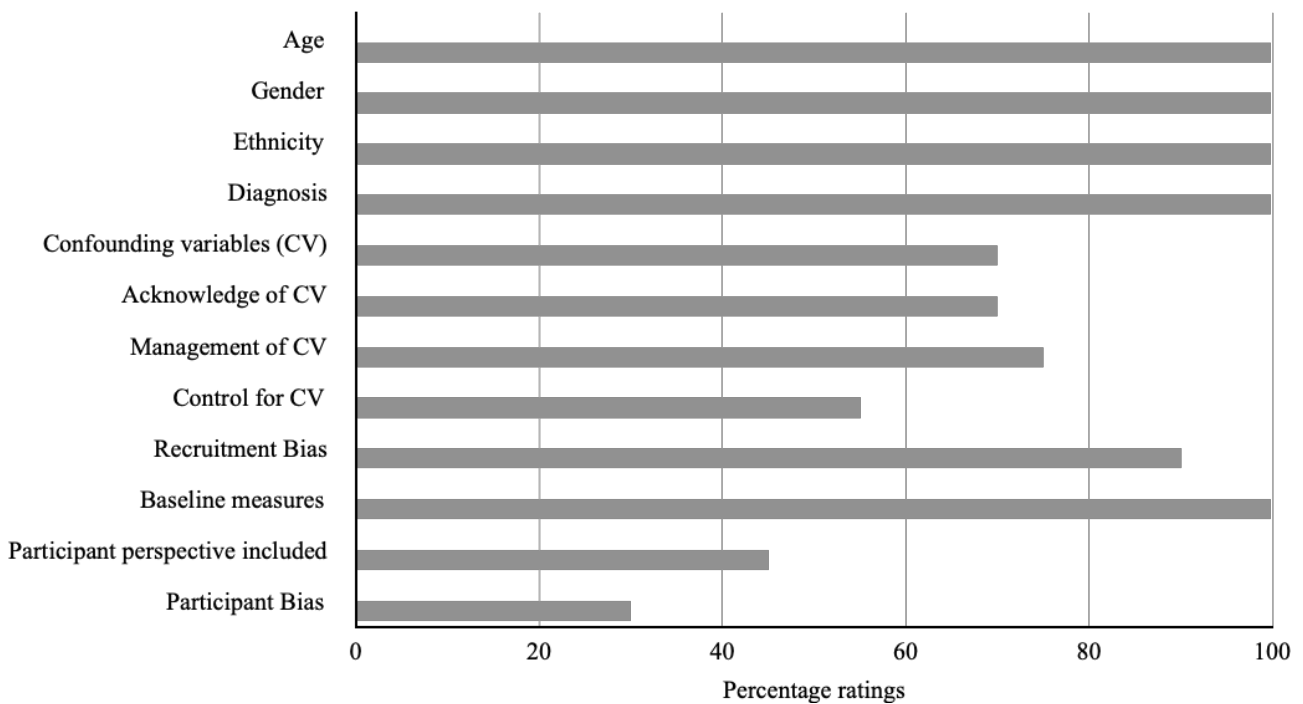
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### *Quality Assessment Summary*

As a result of the quality assessment tools (adapted ROBINS-I and RoB-2), studies were given a percentage indicating a low, medium or high-quality score. Three studies were assessed to be of high quality (Gillard et al., 2022 [100%]; Weisman de Mamani et al., 2014 [100%]; Tan & King, 2013 [93%]). Moderate quality was found in the remaining studies (Lin et al., 2013 [64%]; Wong et al., 2019 [64%]; Grant et al., 2012 [71%]; Rathod et al., 2013 [71%]; Gureje et al., 2020; Malla et al., 2020; Ngoc et al., 2016 [78%]). See Appendix C for further details. Studies were assessed by the primary researcher and an independent rater, resulting in 80% agreement in quality scores. Discussions between the primary researcher and the independent rater resolved any disagreement in quality assessment ratings.

Overall, papers were less likely to report on the management of confounding variables, recruitment bias, the inclusion of participant perspective, and participant bias (blinded or not) (See Figure 2). All papers provided a clear description of the study rationale. Samples were taken from original data collection and secondary sources (for instance, studies that focused on pre- and post-outcome measures routinely collected by services). Therefore, papers were likely to be reliable yet, not necessarily in studies using traditional healing practices, given the lack of a protocol used for the intervention. All papers reported adequate primary data and methodology, allowing for possible replication of their research.

All papers reported ethical consent without conflicts of interest. In summary, the quality of the papers included in this review was generally moderate, with improvements possible in managing confounding variables (“CV”), participant selection bias, blind trials, and inclusion of participant perspective.

**Figure 2.**

*A graph to demonstrate overall study ratings in accordance with each quality assessment question.*

### ***Intervention outcome***

The search resulted in reviewing a wide range of interventions, accompanied by a range of outcome measures to assess recovery. Recovery outcomes are reported below, which capture multiple definitions and outcomes. The “outcome” consisted of an assessment of psychological, social and behavioural functioning. The “outcome” also included a measure of re-admission rates as a method to determine long term positive outcomes of interventions. Outcomes based on ethnicity have been taken as reported by authors. Intervention outcomes are listed below. All studies providing an intervention over treatment as usual (TAU) showed positive improvements in symptom management and showed a reduction in problematic positive and negative symptoms,

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however the attrition rate and length of time of continued symptom management differed, as will be outlined below.

### *Cognitive-based interventions*

Four RCT's explored the effect of a cognitive-based intervention (Grant et al., 2012; Tan & King, 2013; Rathod et al., 2013; Wong et al., 2013). Grant et al. (2012) found that CT (without cultural adaptations) reduced the occurrence and distress of positive symptoms of psychosis (hallucinations and delusions) but less so for negative symptoms (withdrawal, low mood and catatonia) in participants from Black ethnic groups. This was sustained for 18 months; however, the dropout rate was 32.1%, reflected in the moderate quality rating of 71%. Cognitive remediation (Tan & King, 2013) was also found to promote significant recovery outcomes, shown in neuro-cognitive domains. Although there were increased employment rates in the intervention group, there was a 29% dropout rate, and the effects of the intervention started to decline a year later, however due to the study's rigorous methodology, and management of confounding variables, it achieved a high quality rating of 93%.

Rathod et al. (2013) found that a culturally-adapted CBT for psychosis (CaCBTp) provided short-term recovery as measured on the PEQ for participants from Black ethnic backgrounds. Short-term clinical measures evidenced a positive reduction in symptoms; however, this was not found in clinical measures in the study (i.e., CPRS and Insight Scale). Additionally, there was an 18% attrition rate. This limits the applicability of the study as it is unclear whether the intervention's true effect or whether the appropriate outcome measure was used (reflected in the quality assessment score of 71%). To the researcher's knowledge, the CPRS and Insight scales have yet to be validated in ethnically diverse groups, which may reflect the lack of concordance between scales.

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Additionally, CBTp and CaCBTp were not compared, limiting conclusions made on CaCBTp outcomes compared to treatment as usual. Despite this, participant satisfaction predicted clinical recovery outcomes in CaCBTp. This outcome is subject to interpretation. A hypothesis could be that the scales used did not capture the participant's self-reported recovery or could result from demand characteristics (Nichols & Maner, 2008).

Wong et al. (2019) explored the impact of group CBT finding a 50% reduction in scores relating to delusions on the PSYRATS in nearly 61% of the sample. However, a participant perspective was not obtained; rather, clinical measures were used, which from previous research has yet to be evidenced as the most reliable method of assessing recovery in the form of quality of life (Lam et al., 2011). Additionally, 9 participants (18.7%) dropped out, and a follow-up outcome measure was not completed. This would have been advantageous in assessing the intervention's lasting effects, and therefore impacted Wong et al. (2019) quality score (64%).

Cognitive behavioural interventions were limited for Asian ethnic group samples within the sample of reviewed studies (Wong et al., 2019). There appeared to be positive outcomes reducing positive symptoms of psychosis. The remaining studies with samples from Black ethnic groups were more plentiful, however were limited by either dropout rates (Grant et al., 2012; Tan & King, 2013; Rathod et al., 2013) or a lack of longer-term recovery outcomes (Grant et al., 2012).

### ***Traditional Faith Healers***

This review resulted in one RCT meeting eligibility requirements for inclusion which assessed the effect of combining traditional faith healers and clinicians to provide a holistic treatment (Gureje et al., 2020). Within this study, traditional and Western methods were combined, which included traditional herbs and spiritual readings, alongside psychoeducation guided by a

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clinician. The PANSS showed a reduction in positive and negative symptoms in individuals living in Ghana (Gureje et al., 2020). Although Gureje et al. (2020) found significant improvements from baseline to 6-month follow-up in the control group (traditional methods, as outlined in Table 1.), the combination of traditional and clinical intervention still resulted in a significant difference between intervention and control. The control group consisted of culturally appropriate “enhanced care as usual”, which consisted of monitoring and the use of herbs, rituals, prayer, fasting, and divination, which resulted in sustained recovery six months post-intervention.

There were no studies regarding the use of TFH in Asian communities.

### ***Early Intervention***

One Early Intervention (EI) study met the eligibility criteria for this review. The early intervention followed the framework proposed by NHS England in that it is characterised by a social recovery model, working with all aspects of health (physical, medical, psychological) for three years (NHS England, 2023). Malla et al., (2020) found a global reduction in positive and negative symptoms of psychosis and achieved moderate quality rating (78%). Compared to the cognitive-based interventions, a greater reduction in adverse symptomatology was found. Symptom reduction was significantly greater when family support was integrated into the intervention, sustaining a reduction in symptoms over three months, positively predicting remission at 24 months. Regarding ethnic variations by intervention and outcome, participants in Chennai had a longer duration of negative symptom remission ( $M = 16.1$  months) than participants in Canada ( $M = 9.8$ ).

Regarding functional outcomes, EI programmes promote an ecologically valid intervention given social skills experience and training, which supports the participants post-intervention.

### ***Family intervention studies***

Studies that assessed the outcomes of using Family Intervention (FI) ( $n = 2$ ) in Black and Vietnamese ethnic groups resulted in reductions in symptoms. Weisman de Mamani et al. (2014) scored 100% on the quality tool, proposing its robust methodological quality. A medium effect size was found in reducing symptoms of psychosis despite an attrition rate of 33.3%. Twenty-five families remained in the experimental condition (CIT-S) and 21 in the control (psychoeducation). Both Black African and Black Caribbean as well as White ethnic groups benefitted equally from the intervention (both positive and negative symptoms reduced on outcome measures used in the study).

For Vietnamese individuals, Ngoc et al. (2016) found a significant moderate to large treatment effect on the experimental condition ( $R=0.08$ ) on measured elements of quality of life, stigma, medication compliance, and satisfaction. The study achieved 78% in the quality rating tool, where improvement could be made in ensuring participant bias was reduced. Although this may have been difficult given the explicit consent to engage in family interventions. Additionally, an attrition rate of 19% impacted the intervention's cumulative long-term effects and reasons for drop out were not explored.

### ***Other social recovery models***

Two RCT studies were included pertaining to other social recovery models. Gillard et al. (2022) compared groups receiving manual-based, one-to-one peer support, focused on building individual strengths and engaging with activities in the community, beginning during the index admission and continuing for four months after discharge, plus care as usual (follow up seven days

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after discharge with a general practitioner). Whereas, Lin et al. (2013) explored supporting people in achieving their personal recovery goals through the Illness Recovery Model (IRM) in the context of social recovery (using peer relationships for support) in two major hospitals in Taiwan.

Gillard et al. (2022), scoring a high-quality score (100%), found that patients of Black ethnicity in the peer support group were significantly less likely to be readmitted than patients of any other ethnicity. Despite this, no differences were found in psychotic symptoms from baseline to post-intervention. This suggests that peer support programs may contribute more to preventing relapse and improving overall functioning, rather than directly reducing symptoms. The IRM study (Lin et al., 2013) scored a moderate quality rating (64%), resulting in improved insight, yet no marked differences in improving symptoms. This could indicate that while social recovery models can enhance personal insight and social functioning, they may not be as effective at directly targeting psychotic symptoms. The study's moderate quality rating and lack of control over confounding factors suggest that more research is needed to validate these findings, particularly in Black and Asian populations.

### **Summary**

This systematic review was conducted to assess the outcome of interventions (i.e., psychological, group and traditional interventions) for Black and Asian ethnic groups with psychosis. Overall, CBT interventions resulted in a reduction of positive symptoms (Grant et al., 2012; Wong et al., 2013) for both Asian and Black ethnic groups, yet were not sustained within yearly follow-ups and had high attrition rates. The culturally adapted CBT intervention only showed short term recovery (Rathod et al., 2013). Although general symptoms improved with EI, there was a more significant effect on the reduction of negative symptoms (Malla et al., 2020). However, this was limited by only one EI study meeting inclusion criteria for the review. Further

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research has found that no significant differences have been found 1 – 2 years post-intervention, which suggests a limited effect of EI interventions for Asian ethnicities (Rangaswamy et al., 2012). Symptoms were further improved with the inclusion of family in EI intervention (Malla et al., 2020).

Group interventions were limited in that only one study was included within a sample of Asian ethnic groups (Wong et al., 2019), although a reduction of symptoms was found. Further research is needed to explore group interventions with people from Black ethnic groups.

FI studies broadly improved symptoms; however, there were significant attrition rates without long-term follow-up. The intervention combining clinical and traditional healing practices (Gureje et al., 2020) also had significant reductions in symptoms, and it was noted that participants had a belief system aligned with spiritual/religious beliefs regarding the psychosis, which was not controlled for and may have had an impact on results. Tan & King (2013) found reductions in symptoms; however, longer-term effects wavered in Asian ethnic groups. Peer support and the combined clinical and traditional interventions had the lowest attrition rates (Gillard et al., 2022; Gureje et al., 2020). Results suggest that longer-term interventions that mention the relationship consequently had conditions whereby contact time was higher, which resulted in higher recovery outcomes, specifically for Black ethnic groups. Relationship building and duration of time were overarching themes of the synthesis. Overall, differences were found in that people from Black ethnic groups showed better recovery outcomes when including elements of community and social support, whilst people from Asian ethnic groups benefitted from the inclusion of the family.

## Discussion



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The review largely concluded that, despite methodological inconsistencies (i.e., lack of controls, inaccurate or inappropriate outcome measures, nondescript treatment groups, and attrition rates), patterns emerged which could indicate useful strategies for delivering effective ethnically-sensitive psychological interventions. For instance, longer treatment interventions (6 months-one year) resulted in longer-term recovery outcomes evident in one-year follow-ups (Grant et al., 2012; Gureje et al., 2020), which has also been found in other studies (Sorketti et al., 2013; Bradley et al., 2006; Pang et al., 2016; Rangaswamy et al., 2012). This was further sustained if one were in a treatment group that combined relational components (i.e., via a group, peer support) and extended therapeutic relationship building (in the form of longer-term treatments), shown through the lowest attrition rates in comparison to CBT and EI interventions. Interventions that did not sustain such remission periods were short-term interventions, which focus solely on the individual (Rathod et al., 2013; Lin et al., 2013).

The World Health Organisation (WHO, 2023) recommends a short-term interventions including CBTp, alongside medication. FI is also recommended (NICE, 2014). Currently, research suggests that although CBTp provides a small to moderate effect size in effective treatment for people with psychosis, the long-term treatment effect is not sustained past 47 weeks (10.5 months) (Mehl et al., 2015). This review suggests this could be improved from a longer duration on long-term symptom management. This is particularly evident for people from Black, African and Caribbean ethnic groups, whereby the inclusion of the community resulted in higher recovery outcomes and lower attrition rates. In contrast, people from Asian ethnic groups benefitted from more family interventions.

Specifically, the review found that CBTp interventions resulted in a reduction of positive symptoms for both Asian and Black ethnic groups (Grant et al., 2012; Wong et al., 2013). However,

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outcomes were not sustained past a year for both samples. In comparison to the EI study by Malla et al. (2020), participants appeared to have further reductions in negative symptoms. This could represent intervention type in that CBTp targets belief systems, and therefore, delusions and hallucinatory experiences are often reduced, whereas EI programmes are predicated on a social recovery model, which facilitates social integration to target the negative symptoms of social withdrawal (Fulford & Holt, 2023). This is consistent across the literature within ethnically diverse groups (Garety et al., 2008). However, another factor that could impact outcome is the duration of symptoms, as this has consistently shown to be shorter when compared to other ethnic groups, such as White ethnic groups (Mehl et al., 2015). A 10-year follow-up study found that specifically participants who were from Black, African or Caribbean ethnic groups reported worse social functioning outcomes in comparison to White ethnic groups, which impacted employment and social integration post-intervention (Morgan et al., 2017; Rotenburg, 2019). As noted by Lin et al., (2013), whilst social recovery models can enhance personal insight and social functioning, they may not be as effective at directly targeting psychotic symptoms, and therefore may support in post-therapeutic recovery from psychosis.

Comparatively, participants from Asian ethnic groups appeared to have greater recovery outcomes with the integration of family, despite high dropout rates. Research supports that, regardless of ethnicity, the dropout rate for FI tends to be higher than that of other interventions, such as CBT (Pilling et al., 2002). Research is scarce on families attending therapy for psychosis from Asian ethnic groups, which suggests that difficulties with engagement are not only reflected in service use but also in research. For Black African, Black Caribbean and other Black ethnic groups, where the research is more plentiful, the dropout rate in FI is also a common finding (23.6% in Edge et al., 2018). Some research has suggested that this is largely contributed to by a sense of shame, which is particularly pronounced in the context of Asian communities experiencing

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psychosis and schizophrenia (Patel et al., 2023; Vyasa et al., 2021). Qualitative research has determined that there is an internalised stigma within the family, where members wish to protect the family's pride in "looking good" to others (Vyas et al., 2021), which consistently acts as a barrier to engaging, as well as maintaining attendance to an intervention, particularly with the family present (Wyanden et al., 2005). This may shed light on how FI interventions are particularly effective in reducing psychotic symptoms, however, continue to see the highest drop-out rate when compared to other interventions.

Research has suggested that addressing the stigmatised group can lessen the shame felt (Knifton, 2012). One way in which this could be achieved is by showing acceptability of cultural difference, by including traditional healing methods, shown by Gureje et al. (2020). An intervention that combined cultural sensitivity with evidence-based treatments, such as culturally adapted CBT or the integration of traditional healing methods with clinical interventions, which showed positive outcomes as a result of the intervention. Addressing shame culture, including the family, may therefore, increase recovery outcomes for Asian ethnic groups. However, this may still incur attrition rates, as help-seeking attitudes are also impacted by the cultural perception of mental illness (Akutsu & Chu, 2006). Knifton (2012) suggests that a full representation of ethnic diversity needs to be included in the development and implementation of interventions, and to not assume that Western medicalised concepts of illness apply to all. This may explain how those who continued treatment saw higher recovery rates (as the intervention was successful) and may also explain high attrition rates (due to shame).

Attrition rates are known to be higher in non-white ethnic groups (Farris et al., 2020; Kreyenbuhl et al., 2009; Maura & Weisman de Mamani, 2017; Ouellet-Plamondon et al., 2015; Smedley et al., 2003), which highlights the importance of exploring the explanatory factors of why

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this could be. Many interventions showed high dropout rates (18%–33%) and limited long-term follow-up, which suggests that more work is needed to make interventions more engaging and sustainable for Black and Asian populations.

This review hypothesises that an underlying mechanism of change could be found in the establishment of a therapeutic relationship which maintained a longer engagement, coincidentally established in interventions with a longer duration. Overall, longer interventions saw a reduction in symptoms of psychosis that lasted longer than the reduction of symptoms resulting from short-term interventions (Grant et al., 2012; Gillard et al., 2022; Gureje et al., 2020). Asen & Schuff (2006) found that due to the nature of psychosis (a break in reality and disconnection with others), an authentic relationship and the inclusion of others are essential for developing connection, which could explain the positive outcomes resulting from a wide range of interventions (psychosocial, TFH and FI and EI), but only those interventions that were longer-term. In comparison to participants from White ethnic groups, the therapist-client relationship has not been reported as a significant factor in the engagement and recovery from psychosis (Wood et al., 2018). Within the IMR intervention by Lin et al. (2013), all participants ( $n=8$ ) qualitatively reported that “sharing their experiences” was a valuable element of the program, feeling that participants were not “alone” (van Langen et al., 2016). Although this study was limited by potential participant selection bias, it may hint at the underlying mechanisms of reaching a more sustained recovery within psychosis. This is supported by van Langen et al. (2016), who found through qualitative measures that symptoms remained manageable 19 months after completion with a similar IMR intervention.

In summary, people with psychosis from Black and Asian ethnic groups appeared to benefit from interventions that including cultural sensitivity, social support, and family involvement. While cognitive-based approaches show promise for positive symptoms, the long-term therapeutic outcome remains uncertain. Further research and the development of more inclusive, culturally

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relevant models are essential for improving outcomes for these groups, with further exploration needed in assessing the impact of a sustained and long-term relationship between client and therapist/facilitator.

### **Implications for Practice**

This review has two primary findings which have implications for psychological practice: The duration of the intervention course and the role of family and community in treatment plans. EI pathways endorse this currently, spanning treatment across three years (NICE, 2014). However, recommendations regarding cultural inclusion or adaptations are less clear, and the findings from this review appears to suggest that longer treatment length might be a consideration for certain ethnic groups. Recommended first-line intervention for first-episode psychosis is CBTp, which may need careful thought with regards to those who are from Black African, Caribbean and Asian ethnic groups, where the integration of the family or community in CBTp approaches may be more beneficial in recovery outcomes.

Research has found that barriers to accessing support are multifaceted, including internal and external perceived shame and stigma, racism and structural barriers that include a lack of social support or lower socio-economic status as well as different belief systems (Memon et al., 2016). Cultural attributions of illnesses may impact one's willingness and awareness to seek support. For instance, some research has found that people from Black ethnic groups can attribute the illness to religious or spiritual causes (Codjoe et al., 2013), whereas Asian communities can attribute illness to supernatural causes (Castilho et al., 2019). Qualitative research suggests that one of the main barriers for diverse ethnic groups is a difference in perceived belief systems (Islam et al., 2015; Sorketti et al., 2013). Interestingly, Weisman de Mamani et al. (2014) found that there was no

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difference in the efficacy of culturally-adapted therapies between Black and White ethnic groups, which is supported by a large systematic review (Degnan et al., 2018). This suggests that illness beliefs may impact help-seeking but not necessarily therapy outcomes. It may also suggest that despite adaptations, factors outside of the therapeutic role need to be addressed. The consideration of wider systemic factors that may be implicating help-seeking attitudes and willingness to engage/continue therapies offered by services needs to be addressed (Knifton, 2012). These wider systemic factors include implementing culturally inclusive person-centred interventions, which may involve incorporating spiritual or religious beliefs whilst considering the inclusion of family or community (e.g., within social recovery models, groups, and religious communities in the church or other institutions). These considerations may indirectly address shame and internalised stigma that families from Asian and Black ethnic backgrounds experience, which features as one of the barriers to engaging and sustaining engagement in treatment (Vyas et al., 2021).

To conclude, although some studies lacked self-report measure and consistent definition of recovery, it appears that incorporating illness belief and developing an effective therapeutic relationship may contribute to improved and more sustained recovery outcomes, particularly for Black and mixed Black ethnic groups, whilst Asian ethnic groups may benefit more from the integration of family in interventions, reducing mental illness stigma. Additionally, there is a severe lack of studies pertaining to CBT and the outcome for people from Black African, Black Caribbean and Asian ethnic backgrounds. Further research is needed to determine the long-term benefits of CBT in Black and Asian ethnic populations.

### ***Limitations and Further Research***

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This review has shed light on some unseen but ever-present aspects of treatment for Black and Asian ethnic groups, such as the impact of illness belief (i.e., spiritual or medical), the relationship established with therapist and the inclusion of family/community within intervention type. However, many studies had limitations. For instance, some studies did not include a self-report measure, which is essential due to research supporting that clinical outcome measures do not always capture the quality of life of the individual (Lam et al., 2011; Pitt et al., 2007).

A further limitation was that a wide range of interventions and ethnic groups were included in the current review. Although this was the aim of the review, a consequence was that this gave rise to varied heterogeneity, limiting direct comparison between outcomes of interventions, whereby a meta-analysis of specific interventions would have been advantageous. Arguably, however, this review was essential in providing a more nuanced thematic approach to understanding the underlying mechanisms of change, essential for improving therapeutic outcomes. Further research should consider the impact of the therapeutic relationship (between therapist and/or peers) and longer-term interventions for Black African, Black Caribbean and other mixed Black ethnic groups and the inclusion of family in interventions for Asian ethnic groups.

Additionally, not all outcome measures used in each study were appropriate for the population. For instance, Rathod et al. (2013) used an insight scale and a general psychopathology outcome measure (CPRS), which would encapsulate general psychopathology and understanding of illness but not necessarily recovery, which could result in an inaccurate representation of recovery. Future research may wish to narrow the focus of enquiry and conduct a meta-analysis. This would be clinically beneficial in determining the cumulative outcomes of studies using a particular outcome measure to determine the quantitative outcomes based on interventions (for instance, the PANSS).

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Finally, selected search terms for assessing paper inclusion within the review were non-specific to account for interventions encompassing traditional healing practices, which may have inadvertently excluded local terms used in other parts of the world. Additionally, the inclusion criteria only specified that a sample of Asian or Black ethnicity to be included, however this includes a broad range of groups, sample sizes and ethnicities, and therefore further research would benefit from a more streamlined approach in exploring specific ethnic groups, with specific interventions. Finally, included studies did not report specific attrition rates according to ethnicity, which limited conclusions on long term outcomes.



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### **Bridging Chapter (Chapter 3)**

The systematic review was conducted to examine the outcomes of psychosocial and traditional interventions for psychosis for individuals who identify as from Black African, Black Caribbean, and other mixed Black or Asian ethnic groups. This was achieved by examining intervention outcome by recovery outcome, in the form of clinical and self-report measures. The review largely concluded that despite methodological discrepancies (i.e., lack of controls, inaccurate or inappropriate outcome measures, vague recovery definitions, high attrition rates), reoccurring themes were found which could provide guidance in delivering effective and sensitive psychological interventions for people from Black, African and Caribbean and Asian ethnic groups. For instance, longer treatment interventions (6 months - one year) resulted in longer-term recovery outcomes evident in one-year follow-ups (Grant et al., 2012, Gureje et al., 2020). This was further sustained if one were in a treatment group that brought together a relational component, either via group, peer support, traditional methods and/or extended therapeutic relationship building, evidenced by low drop out rates in comparison to other interventions (Gillard et al., 2022). Although there was more of a positive clinical outcome recorded for CBT interventions, longer term interventions examined through EI or traditional methods provided longer term positive therapeutic benefit evidenced through outcomes measure scores on psychosis symptomatology. Interventions that did not sustain such remission periods were short-term interventions, which focus solely on the individual (Rathod et al., 2013; Lin et al., 2013). It is no coincidence therefore that higher rates of psychosis are evident in individuals who may benefit from more sustained and trusted relationships between the service provider and service user when what is offered in Western cultures is usually a short-term intervention.



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The relationship, whether that be through therapist connection or familial integration within interventions appears to be a pivotal finding, deserving further attention. Previous literature has confirmed that the integration of the family improves recovery outcomes, although the integration comes with a cost of psychological burden to family members (Addington et al., 2005). There has been research to confirm that there is an association between family member involvement in therapy and higher outcome scores on interpersonal factors, although no differences were found between White and Black participants on Quality of Life (QoL) scores (Oluwoye et al., 2020). A study within the SR conducted as part of this thesis portfolio commented on the lack of implementation of family interventions for psychosis despite evidence suggesting a quicker remission may be achieved and higher outcomes scores (Bucci et al., 2016). There appears to be a clinical-to-practice gap in the implementation of family-focused interventions for ethnic minority people living with psychosis.

Similarly, the therapeutic relationship has been a long-standing topic in the psychological field for decades, mentioned by psychologists such as Rollo May (1958; May & Yalom, 1989), Irvin Yalom (1990), and Bowlby (1977, in Hooper et al., 2012) as the key to effective therapy. However, there is no consensus on how much time is needed to establish an effective therapeutic relationship, partly due to complex interplay of trauma and intergenerational history (Ren, 2012), therapist approach and manner (Jin et al., 2008) and the service user's prior experience of health services (Tindall et al., 2018). Therefore, if a specific time frame cannot be established, one is inclined to assess the importance of the mechanisms of a relationship, and how it manifests in different cultures. Within the social context of intergenerational trauma, those who have experienced trauma (such as immigration, war, racism, or discrimination) continue to experience mental health difficulties at a much higher rate compared to people from other ethnic backgrounds (Fearon et al., 2006). A theory that explains the continual rates of psychosis, barriers and

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disengagement in engaging in services is the systemic justification theory (Jost et al., 2000). This explains that a cycle continues to operate in a context that where change would disrupt the system. This provides a systemic understanding that without the social context being addressed, the cycle of disengagement continues, despite changes (i.e., culturally-adapted therapies). This also suggests that a deeper systemic change is needed to shift the current cycle of disengagement. Research suggests that the link between developing psychosis and being of a first-generation Black, African, Caribbean ethnic group is of the highest compared to other generational relations (Sugarman & Crauford, 1994). Although first generation individuals were not highlighted as the sole participatory groups within the review, the intergenerational passing of trauma has been evidenced to create epigenetic changes, and therefore those traumatic reactions will be present within the family (Kuzawa & Sweet, 2009). The legacy of trauma highlights why a compassionate, deliberate and careful approach to developing an effective therapeutic relationship could be essential to promoting recovery for people with psychosis in Black, African or other Black ethnic groups. Considering the presentation of psychosis, as illustrated in the Diagnostic Statistical Manual for Disorders, Fifth Edition (DSM-IV), which includes delusional and relational difficulties, trusting others can be profoundly difficult, highlighting an additional need for developing trusted connections with others to improve recovery outcomes.

Research has solely focussed on the individual factors that may operate in acting as a barrier to engaging in support, however, to the researcher's knowledge, research has made limited strides in exploring the role of the family, perceptions of illness, and services within the current Western context. This empirical project aims to bring a systemic lens to explore the wider barriers for people from Black, African, Caribbean or other Black ethnic groups in accessing or engaging in services who have psychosis. The empirical paper sought to achieve this by conducting interviews with carer's for family members experiencing psychosis from Black African, Black Caribbean and other

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mixed Black ethnic groups. The paper aims to understand the impact of culture and the family to inform and improve service engagement.

**Empirical Paper (Chapter 4)****A Qualitative Study Exploring the Cultural Perception of Psychosis and its Impact on  
Pathways to Care for Black ethnic groups in the UK.**

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### **Abstract**

Increased prevalence rates of psychosis in people from Black African and Caribbean ethnic groups compared to white ethnic groups have been widely reported in previous research. Although studies have explored the barriers to accessing psychological support for psychosis from Black ethnic groups, literature appears to have neglected exploring the wider contextual system surrounding individuals that could be maintaining a lack of engagement (including the impact of family, history and the perception of services). This paper explores the experience of family carers of people who have psychosis in self-identified Black ethnic groups in the UK, to add to the understanding of continued increased rates of psychosis and barriers to engagement in this population. Thematic analysis was utilised to explore the perspectives of ten participants recruited for the study. Five themes were found to be crucial in the experiences of carers; (1) The impression of psychosis, (2) Barriers to care, (3) Hidden cost of psychosis, (4) Generational cultural and societal interplay in mental health perceptions, and (5) Improving pathways to care. These themes showcased the difficulties in engaging with services throughout the entire care pathway, from initial engagement, the role of law enforcement during crises, the impact on family and resulting power imbalances in engaging in mental health services.

### **Keywords:**

Psychosis, social constructionism, culture, language, power, connection, shame, thematic analysis.

## Introduction

Psychosis is a mental illness which has been diagnosed frequently in people from Black African and Black Caribbean ethnic groups more than any other ethnic group in the UK (Morgan et al., 2017). Psychosis can be defined by using the Diagnostic Statistical Manual for Mental Disorders (DSM-5, American Psychiatric Association, 2013) as a person experiencing two or more of the following symptoms that has continued for 1-month; (1) delusions, (2) hallucinations, (3) disorganised speech (e.g., incoherence), (4) disorganized or catatonic behaviour and/or (5) negative symptoms (i.e., flat affect, reduction in speech, or avolition). Psychosis could also be defined as an altered state of consciousness, that can manifest as “any one of several altered states of consciousness... that [can] prevent integration of sensory...information into reality models accepted by the broad consensus of society, and that lead to maladaptive behaviour.” (Nelson, 1994; McCarthy-Jones, et al., 2013).

People from Black, African or Caribbean ethnic groups are also an ethnic group that receive one of the highest rates of detention under the mental health act (CQC, 2010; Barnett et al., 2019; Tortelli et al., 2015; Jongsma et al., 2020; Bhui et al., 2003; NHS Digital, 2018; Race Equality Foundation, 2017), and contact with the justice system (Degnan et al., 2022). The field of research examining these health inequalities examines various contributory factors that could account for this disparity, including the role of systemic racism (Banaji et al., 2021), ethnic differences in psychosis presentation (Sharpley et al., 2001), a diagnostic bias (higher incidence of diagnosing psychosis based of discriminatory characteristics, such as ethnicity) (Hickling et al., 1999), limited social support systems (including family/community structures) (Mascayano et al., 2021) and the

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stigma of having a mental health condition, as well as the stigma around seeking support outside the family (Crocker et al., 1998).

Research has found that whilst family support promotes recovery from psychosis, recovery can also be hampered by the accepted family narrative of the cause of the psychosis, (Faber et al., 2023; Stompe et al., 2006). For example, York et al. (2016) found that people from Black, African or Caribbean backgrounds did not consider their psychosis treatable with the use of mental health services if they had a supernatural explanation for their illness. Due to the demand on the family for support, the family can also experience a high level of burden (Boydell et al., 2014). Family burden can be defined as the resulting feeling of having limited choice over how their lives can change when caring for a family member, and these feelings can include sadness, overwhelm and hopelessness (Jimena et al., 2024). Therefore, impacting carer wellbeing, and the individual being cared for. This can result in caring for family members with psychosis for longer within the family home, which can lead to an escalation in symptoms. This has been shown to manifest in a higher rate of compulsory admissions due to carer “burnout”, particularly in the participant groups belonging to Black Caribbean ethnicities (Boydell et al., 2014). Whilst a substantial amount of literature has contributed to the knowledge base of carer burnout, limited attention has been made to the dynamics and generational tensions within the family and how this may aid or inhibit service engagement (Moss et al., 2006). This provides a rationale for the need to examine pathways to care, and what contributes to dis- and non-engagement within services from the perspectives of family carers.

Contextually, mental health stigma is prevalent in many different societies and cultures, but particularly prevalent in people from Black, African or Caribbean cultures, often driven by cultural, religious, or historical factors. Mental illness stigma is often typified by negative treatment based on prejudices or judgements based on negative stereotypes of the illness, for instance in psychosis, this

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is often associated with criminal and unpredictable attributions (Turkmen et al., 2018). The impact of stigma and its relationship to impacting help-seeking behaviours for health conditions has been established (Cheang & Davis., 2014; Bos et al., 2013; Ward et al., 2013; Dinos et al., 2004). Once a society has a prejudice or stigma, it can result in a “social identity that is devalued” (Crocker et al., 1998), resulting in “internalised stigma” (Franz et al., 2010; Ward & Besson, 2013). This internalised and societal stigma can discourage individuals from seeking help for psychotic symptoms due to fear of discrimination or ostracisation from their family and wider communities (Cheang & Davis., 2014; Bos et al., 2013; Ward et al., 2013; Dinos et al., 2004), leading to a delay or avoidance of seeking support (Franz et al., 2010; Ward & Besson, 2013). Of interest to this piece of work, stigmas remain present within families, and are often passed down intergenerationally through oral narratives (Minuchin, 2018). Whilst the impact of stigma has been found to predict help-seeking attitudes and behaviours (Jacobs & Pentaris, 2021), the extent to which this interacts with societally held beliefs, family narratives and personal beliefs is less clear. This importance of this clarity would inform service engagement and treatment orientation.

One of the drivers of stigma in families is perceived and received systemic racism and discrimination within healthcare systems, which can significantly impact access to and quality of care for people from Black ethnic groups. Systemic racism is a concept that describes institutional discrimination based on ethnicity or race (Banaji et al., 2021). This is perpetuated by using frameworks that are Westernised, and not attuned to the needs of specific populations. Research has found that incorporating religious or spiritual components to an intervention result in greater engagement and reduced attrition rates in people from Black ethnic groups, with increased openness to coping with their mental health through religious meaning and support (Ward et al., 2013). However, there is limited evidence that clinicians use this in practice, with the acknowledgment that



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clinicians feel ill-equipped in their knowledge base regarding spirituality and religion (Islam et al., 2015).

Barriers, such as stigma and systemic racism, continue to contribute to the disparities in accessing and engagement with psychosis services for Black ethnic groups. Jost and colleagues (2000) refer to this as “system justification theory” (Jost et al., 2000; 1999). Ann Cook (BPS, 2017) suggests that rather than culturally adapting treatment, a broader societal shift is needed to encourage inclusivity to enable access to services. This is important not only for the individual experiencing these difficulties but also for the NHS system and the five-year forward initiative to increase engagement in mental health services (NHS, 2016). Culturally-adapted therapy interventions in mental health services may only have a limited impact as wider systemic barriers continue to impact on help-seeking, engagement and outcomes (Degnan et al., 2018). The family continues to remain as a central point of either engagement or disengagement within services, to explore their views on psychosis, and appropriate care approaches. Therefore, the following research questions were created;

### **Research Questions**

1. What are the experiences and views of family carers about accessing psychosis support services for people from Black ethnic backgrounds?
2. What are carer’s perceptions of psychosis in people from Black ethnic groups and carers living in the UK?
3. What roles do culture and beliefs play in accessing help for psychosis from mental health services from the perspectives of carers?

## **Methodology**

### **Design**

This study utilised a qualitative design, using semi-structured interviews to explore carers' perceptions of psychosis and care needs from family and/or professional backgrounds. The rationale is that those who care for an individual who is of Black African, Caribbean or other Black ethnicity and has psychosis will also have a unique insight into service engagement. Following a social constructionist approach, a thematic analysis (TA) method was employed to ascertain differences and similarities in overarching and sub-themes within interviews.

### **Recruitment**

To address the research questions, participants were approached who had lived experience of caring for a person with psychosis in a professional or personal capacity (i.e., friends and family). Therefore, purposive snowballing sampling methods were adopted (Palinkas et al., 2015). Using purposive sampling supports the study's aim of generating a deeper understanding of the experiences of individuals and families of Black African or Caribbean ethnic groups with experience of psychosis. The researcher engaged in attending face-to-face events, promoting the research, as well as contacting national and regional charities, organisations, independent community groups, support groups, carers groups, faith and healing groups and the University of East Anglia study groups (such as the UEA African and Caribbean Society). In addition, regional charities, such as The Hearing Voice Network, agreed to promote the advertisement in their newsletter.

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The focus on attending events was intentional, as using advertisements and contacting organisations via email or online was unsuccessful. However, this is not uncommon in attempting to reach marginalised communities and immersing oneself in the community has been found more effective (Leisssa et al., 2021). The most successful recruitment method was using social media, and this yielded 7 participants. The remaining 3 were recruited through organisations. Reflections on recruitment are outlined in Chapter Six.

### **Participants**

Participants were those who self-identified as being from a Black, African, Caribbean or mixed-multi ethnicity including Black, African, Caribbean ethnicity who had caring responsibilities for a family member or non-related individual who is also from a Black, African or Caribbean background. The inclusion criteria below outlines the sample sought for this study:

### **Inclusion criteria**

- Identify as from Black African, Black Caribbean or Black mixed-multi ethnicity.
- Unpaid Carers, family carers or paid professionals that provide community support to someone who experiences psychosis and who is either Black African, Black Caribbean or Black mixed-multi ethnicity.
- UK resident, over 18 years old

### **Exclusion criteria**

- Unwilling or unable to provide consent to take part in study activities.
- NHS-employed professionals and carers

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- NHS employees were excluded from the study due to maintaining an unbiased account of experience with Black ethnic groups with psychosis.

### **Public Participant User Involvement (PPI)**

A public participant user involvement (PPI) consultant contributed to the formation and quality control of the interview topic guide, advertisements and language for the interviews. The consultant met the participant inclusion criteria for the study, as being a carer from a Black African, Caribbean or other Black ethnicity. They were able to provide meaningful contributions from the population the study hoped to recruit for.

### **Procedure**

### **Ethics**

This study was approved by the University of East Anglia FMH Ethics Committee (Reference: ETH2324-0240) to conduct in-depth interviews. Given the nature of the interview content involving family member's experiences, the well-being of participants was paramount. This was maintained by explicitly stating and reminding participants that they could take regular breaks at any point and could withdraw at any time during the interview. They were advised that they could withdraw up to two weeks post-interview. A two-week time frame was given as it would not be possible to identify the participant after this time due to anonymisation of data for analysis.

### **Interviews**

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Interviews were conducted virtually by the researcher, following a semi-structured interview schedule (See Appendix G). For interviews, written consent and acknowledgement of the information sheet were obtained from the participants before interviewing (see Appendix H for a template).

The interview recordings were uploaded to the University of East Anglia server, whereby information remained encrypted. Interviews were conducted through Microsoft Teams (MS Teams), via the University links through an encrypted server. The transcription tool on MS Teams was used to transcribe the interviews. The researcher independently downloaded the transcript, anonymised the data, and coded accordingly.

### *Position of Researcher*

The researcher adopted a semantic and latent approach to the analysis (Braun & Clark, 2006), considering the content of the data, but also what the content may suggest about underlying assumptions made and the context surrounding participants' statements.

The researcher approached the data from a social constructionist perspective (Burr, 2003). Information was gathered through in-depth interviews about the "social world" (Miller & Glassner, 1997). Through this process, it can be understood how meaning is made around particular social practices within a particular cultural lens. This is in line with the ethos adopted by Gadamer's (1975) hermeneutics, which posits that each individual will experience the world in a unique way that is personally meaningful through the context of their historical, societal and cultural roots (See Chapter Five for more detail). This invited viewing culture and ethnicity as a way of seeing, rather than a way of being, which helped to reduce 'othering' by the researcher (Brubaker et al., 2004). Therefore, the participant's accounts were taken as an interpretation of their historical journey, situated within an interview context. The interest of this paper is in how aspects of the mental health

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system, psychosis and people from Black ethnic groups' experiences sit within broader discourses around culture, society and language.

### **Data Analysis**

TA was used to analyse the data to ascertain similarities and differences between transcripts (and thereby, individual narratives) (Braun & Clark, 2006). Braun & Clark (2006) highlight that there is passivity in some researchers adopting thematic analysis and that this should be rectified by the researcher taking an active role in acknowledging that they bring a perspective to the analysis (Willig, 2013). For this reason, a self-reflective practice of writing a journal as well as frequent supervisory sessions were held to examine the researcher's position and examine any unconscious biases present to bring them into conscious awareness (Clarke & Braun, 2013).

The researcher was guided by the methodology of Braun and Clark (2006), and the theoretical underpinnings of hermeneutics (Gadamer, 1975) and social constructionism (Nightingale & Cromby, 1999). Transcripts were downloaded and anonymised by the researcher. The transcripts were familiarised by the researcher by performing multiple readings of the transcripts, as outlined by Braun & Clark's (2006) second stage of analysis. The data were 'free coded' by the researcher and tentative hypotheses and comments were noted. Key quotations were taken from the transcripts that appeared prominent to the research questions. Generated themes were then visually displayed in thematic maps (See Appendix J), which aided the researcher observe patterns of similarity and difference. The analysis was then cross-examined by supervisors on the research team, who confirmed that the themes generated made contextual and linguistic sense, in line with the research questions.

### **Quality assurance**

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The researcher utilised Yardley's (2007; 2015) guidance on ensuring the rigour of qualitative research is upheld. Guidance was referred to throughout the analysis. Key components of the guidance were sensitivity to context, commitment and rigour, coherence and transparency and impact and importance were met using a reflective log kept by the lead researcher in addition to reflective discussions with an advisor in affiliation with the University of East Anglia (See Appendix I for guidance).

### Results

#### Participants

A total of 10 participants were recruited for the study ( $n = 8$  female,  $n = 2$  male). Nine participants held family carer roles and were aged between 23 – 45. One participant held a dual role, being both a professional carer role, but also had a family member with psychosis. All participants identified as being from a Black African, Caribbean or other Black ethnic background. Interviews lasted between 45 minutes and two hours over Microsoft Teams held over the encrypted UEA server to ensure confidentiality.

#### *Demographic data*

**Table 1.**

*A table to represent the demographic data of participants.*

Participant number	Self-reported gender	Association to Psychosis (family relation)	Ethnicity
1	Female	Carer (Sister)	Black British African
2	Female	Professional Carer	White mixed Caribbean

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3	Female	Carer (Mother)	Black British Indian African
4	Female	Carer (Daughter)	Black Caribbean
5	Female	Carer (Daughter)	White Mixed African
6	Female	Carer (Mother)	Black British Jamaican
7	Male	Carer (Son)	Black British African
8	Female	Carer (Mother)	Black British
9	Female	Carer (Daughter)	White mixed Jamaican
10	Male	Carer (Son)	Black British African

Five intersecting and overlapping themes emerged as playing a crucial part in the experiences of being a carer for a family member who has psychosis from Black ethnic groups in the UK. These five themes (see Table 2) were as follows: (1) The impression of psychosis, (2) Barriers to Care, (3) Hidden cost of psychosis, (4) Generational cultural and societal interplay in mental health perceptions, and (5) Improving pathways to care. In providing a synthesis of participant stories and experiences, data is presented within these themes based on the TA approach (Braun & Clark, 2006; 2013).

**Table 2.**

*A table demonstrating themes and sub-themes.*

Overarching Themes	Subordinate themes
The Impression of Psychosis	- Lived experience versus medical definition. - Media Portrayals of Psychosis



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Barriers to Care	<ul style="list-style-type: none"> <li>- Us and Them (Feeling disbelieved, Impact of Race, Society)</li> <li>- Gaps in Support from Institutions and services</li> <li>- Care only in a Crisis (Police involvement, Support, Superficiality)</li> </ul>
Hidden Cost of Psychosis	<ul style="list-style-type: none"> <li>- The Personal Cost of Psychosis (Adjustments to life, Access and quality of support for carer, Family dynamics and advocacy)</li> <li>- Family management and Understanding of the illness.</li> </ul>
Generational Cultural and Societal Interplay in Mental Health Perceptions	<ul style="list-style-type: none"> <li>- Generational Trauma</li> <li>- Attitudes to illness in society</li> </ul>
Improving Pathways to Care	<ul style="list-style-type: none"> <li>- Support (Carer recognition)</li> <li>- Understanding (Creating a non-blaming culture, cultural competency)</li> </ul>

### **The impression of Psychosis**

The impression of psychosis theme was multifaceted and impacted by a historical and generational pattern of portrayals of people from Black African, Caribbean or other Black ethnic

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groups with psychosis in the media. Additionally, a story emerged around the unhelpful nature of using medical language within family homes, and rather a sense of using more humanistic language (more descriptive) was adopted by all participants. There was also a sense of continued internalised stigma within the family. There were two sub-themes in this theme: 'Lived Experience vs Medical Definition' and 'Fear (Media)'.

### *Lived Experience versus the Medical Definition*

The interview invited a discussion around the use of the word "psychosis", which family members shared that the medical use of the word was not indicative of their daily life or experiences. For instance, participant 2 shared, "I don't use that word ["Psychosis"]".

This intersected with the historical underpinnings of associations with having a mental illness, which revealed the stigma present within the participants in the study, for instance, participant 3 states,

"They called it the looney bin back in the day. And she [Mum] said they put her in a looney bin once. And she was like, there's nothing wrong with me whatsoever. She said make sure you don't get put into one of those places. "

This stigma had generational influence on how the older generation of people may view services. For instance, participant 5 states, "Older people [in]... The Black community can be very suspicious of institutions, public services professionals.". These quotes represent the participants collective voice in the apprehension of receiving a diagnosis of psychosis, as well as engaging in health services. Simultaneously, there was a synonymous voice regarding the preferred use of more humanistic language, that was more descriptive and compassionate towards their family member.

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For instance, participant 3 shared, “Well, he’s just put in a different reality, like he’s fine, but he’s not fine... he’s intelligent. He’s got a good heart.”. Likewise, participant 5 states “He can be quite self-aware when he feels well, but if he’s not feeling well, he can be very ignorant, and he will swear at anyone.”.

The diagnostic framework used within medical fields intersected with the media portrayal of people that have psychosis, to the reality of being a carer of someone who is struggling with their reality are interlinked concepts, which has created a barrier in accessing services.

### *Media Portrayals of Psychosis*

The fear that “Psychosis” elicited was partly based on media portrayal of the illness, and the resulting criminal associations with the diagnosis. This resulted in a fearful emotional reaction for participants. For example, participant 2 shares,

“I guess you do have them natural thoughts around schizophrenia that people are generally quite unwell can be dangerous. All the things that you see in the media about what that means... It was frightening to me, very frightening because all you can think of when you hear voices, even now, whenever any crime happens.” (Participant 6).

A confliction of understanding was seen in one participant whereby the media portrayals of psychosis did not match the view of her son, for instance “And in the media and stuff is just not really, in my mind got anything to do with my son. I don’t see it.” (Participant 3). This highlights the dissonance of the lived experience versus the media-driven portrayal of a psychotic presentation.

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### *Barriers to care*

The pathways to care theme reflected the challenges of navigating the mental health care system, including shared experiences of maintaining consistent support, the immediacy of the use of medication and the involvement of the police in mental health crises which all appeared to point to systemic issues in the provision of care. In addition, there was a lack of support and information for families, as well as the variability in care based on race, which further emphasised the systemic barriers to effective mental health treatment and support. There were three sub-themes in this theme; “Care only in a crisis”, “Us and Them” and “Support”.

### **Care only in a Crisis**

The first subordinate theme of the pathways into care were categorised under “Care only in a crisis”. For the carer, accessing support and advocacy did not feel like a choice, and was further barricaded when access to support was fraught with the use of the police. For instance, participant 1 shares,

“He was a total wreck and, the more of a wreck he is, the more they’re gonna’ feel they need to use coercion with his care... The charges got dropped because clearly this person is not in their right mind. But why did ‘you’ put him through that?”.

Participant 4 shared that the first contact is typically the police for her father, “If mental health services have been called for my dad, then usually they would use the police”.

Whilst participants were democratic in their reflections of services and hesitant to using the “race card”, others felt very strongly about the injustices they observed within the current health care system, participant 6 reflects this “You don’t want to look at the race card straight away, but

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then when you see it keep happening then then you do and then when you see other people get treated in a certain way.”.

Synonymous with using the police in crises, participants shared that support was only offered when mental health challenges had reached a crisis point. For instance, “And then after she got [placed under] section, that’s when support was in place.” (Participant 4), shared with participant 6’s experience, “It’s only because he attempted and he was thinking of suicide in December, and he actually went on a bridge [that he received care].”. This suggests that family members experienced care only when someone reaches a crisis point, emphasising that care only occurs at crisis points.

### *Us and Them*

There was a sense of othering in the participants’ experiences, feeling outside of the system, and finding it difficult to access, and from this a subordinate theme was created of “Us and Them”. For instance, participant 6 reflected on the difference in treatment for parents from Black ethnic backgrounds specifically, “It is and then sometime when you speak to other Black parents then you find that it’s a system across the board.”.

This is highlighted further by participant 4, “I can see the difference between how society will treat my dad when he’s by himself, or if he’s with me right and English-speaking person, who’s much lighter in complexion in comparison to how they would treat like my mum for example”.

There was a strong sense of advocacy from the carers, and although participant criteria were either family member or voluntary carer for employment, all participants were family members, and the intersection between race and support was intertwined with advocating for their family member,

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which evoked passion and frustration. For instance, “Why aren’t they listening to us?” (Participant 6).

### *Gaps in Support from Institutions and services*

Beyond the use of police force as the first contact with services, support was inconsistent, and, at times felt superficial, “He’s supposedly got a care coordinator, although I don’t know who this person is, and it’s changed about four times. I’ve lost track now and I’m just like, you know what? You don’t have a care coordinator.” (Participant 1).

The superficiality of the treatment or support received was also met with discontentment, for instance participant 8 shares, “The first thing they put you on is medication straight away. I don’t agree with that.”. Whilst the support could be there, there was a discontentment with the lack of longevity within service providers. For instance, “Sometimes a psychologist might be passing through CAMHS (Children and Adolescent Mental Health Service) and then he would get on well with that person.... Within six months, they are gone.” (Participant 6). On the other hand, some carers had found support for their cared for had received was beneficial, for instance, “He [cared for] doesn’t take medication for his mental health. He’s had to go to CBT before and he found it helpful.” (Participant 5).

Once support was established, it was received well by the carer, and the carer’s perspective on how the cared for experienced support, e.g., “...I talk more to the professionals...And I think that’s what helps me the most” (Participant 5), and that some had not “had any racism or anything personally from my experience.” (Participant 4). Participant 4 also shared how she felt a sense of understanding in having a support from people who shared her ethnicity, “She [support worker] was from Trinidad, and I think having that shared ethnicity... was nice in some way when she did come

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to my house and ...we did talk about it a little bit.” (Participant 4). Additionally, carers found support in more community initiatives, such as Participant 2 who goes to “a voices group once a month”.

This may reveal how the support provided is often of quality care, but the trajectory in gaining access reinforces and perpetuates an already fractured system with the historical and generational injustices experienced by people from Black ethnic backgrounds with mental health difficulties.

### **The Hidden Cost of Psychosis**

This theme of the hidden impact of the illness was multifaceted and followed a narrative of struggling with managing the illness at home and the impact of that on relationships, employment and a sense of closeness changing depending on the level of disclosure of experiences to carer from their family member. Therefore, two subordinate themes were crucial for capturing the experience of this, the (a) Personal Cost of Psychosis (Adjustments to life, Access and quality of support for carer, Family dynamics and advocacy) and (b) Family management and understanding of the illness.

### ***The Personal Cost of Psychosis***

This subordinate theme captured the practical as well as emotional elements of the “cost” of psychosis, including social issues, “I had to reduce my hours at work to manage my daughter’s care” from participant 8 and “Trying to get housing, it was a struggle, and... my dad’s always kind of lived with me until I supported him to get housing from the Council.” (Participant 5). A sense of advocacy from family members was evident, which unintentionally created a shift in family

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dynamics which evoked a sense of burden, illustrated by participant 1, whose brother had psychosis, “[it] isn’t purely just a sibling relationship, then it also changes the power dynamics in the relationship too because I ended up like taking more responsibility for things”. With this came a sense of feeling uninformed and less included in their family member’s experience of psychosis. For instance, participant 1 shared,

“He doesn’t really talk about intrusions too much to me. I think he... keeps things to himself and I don’t know why ... he might see it as this is the thing that can get me back into hospital if I start talking about that.”.

Participant 3 shared a similar experience of feeling a sense of protection, not wanting to burden others. For instance, “I didn’t find out until a year later. He kept it a secret for me. He’s very independent and he just didn’t wanna’ worry me. He also felt like it was his business.”

Many of the participants felt a sense of powerlessness and a lack of understanding in how to manage the psychosis, e.g., “There’s nothing [to help understanding], they don’t send you on a course” (Participant 8).

None of the participants reported an increase of sharing experiences with their family member.

### **Family Understanding and Management of the Illness**

Alongside changing dynamics and personal cost of the illness, families were conflicted in how to manage the illness, convoluted by their understanding of the illness. Many participants



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followed an avoidance of the illness which was shown through participants language of wanting to “Push it under the rug”, some wanted to “pray it away”, and others wanted to “insist he’s not psychotic”. Consequently, family dynamics shifted and followed a trajectory of wanting to protect others from the illness that do not “need” to be involved. For instance, participant 10 shared “My mom used to go and visit him [relative with psychosis], but it wasn’t discussed.”. This led to others disagreeing, feeling passionately about how the “care” should be done, leading to further tension in the family. For instance, “[They] Just don’t address the issue, ignore it, pretend like everything is not happening... “Let me do everything for you”. I’m gonna’ completely enable you. “ (Participant 1).

Underneath the family management strategies came a confliction of understanding where the psychosis had “come from”. For instance, participant 5 reflected a spiritual element to understanding, “And in this country these days, they would ask sometimes, like if my dad’s not feeling well or when my sister wasn’t feeling well, we were like “they’re having a spiritual attack”.

Similar language was used in multiple participant interviews, using a spiritual explanation for the experience they were observing within their family. For instance, participant 6 shared, “But the hearing voices... he’s tortured or tormented” and “...those voices can sometimes be referred to as... *demonic*.”. Other participants shared a more psychological understanding of the onset of psychosis. For instance, “She always thinks that mental illness is caused by *worrying* too much, which I can’t always say is true.” (Participant 4). None of the participants reported a biological, medical or sociological explanation for psychosis.

### **Generational Cultural and Societal Interplay in Mental Health Perceptions**

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Culture was found to be pivotal in the experiences of participants. It was interwoven throughout the transcripts, impacting how one views the mental health system. The perception of the mental health system was impacted by two sub-themes, (a) Generational trauma and (b) Attitudes to Illness in Society.

### *Generational Trauma*

Within the theme of culture, a conglomeration of factors were at play from present experience to the impact of generational trauma, with some participants sharing parts of their story that extended back to Slavery. For instance, “So slavery is probably like 8 generations for him [friend], but it’s only about four or five for me. So, it depends how close you are [to slavery].” (Participant 5). Similarly, in sharing historical narratives, participant 4 reflected on politics, “Enoch Powell was who was very openly racist. He wasn’t the Prime Minister, but he was a leading politician, and he had an open campaigned against a mass immigration.”.

Held within the trauma of history, the participants shared a suspicion of power and hierarchical structures, “Elder people because they can’t be very suspicious of the Black community can be very suspicious of institutions, public services professionals.” (Participant 5).

Despite the length of time since Slavery and politically racist powers, the historical injustice remains within the narrative of people’s experiences and shows how interwoven and very present it continues to be in the re-telling of one’s story. This suggests the importance of acknowledging the historical context.

### *Attitudes to illness in society*

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Within the theme of Culture, came an attitude towards mental illness that older generations within the family adopted, which often held the values of shame, and consequently hiding people who did not fit a particular social structure. That value-based system was sometimes in conflict within the individualist culture that Britain has adopted. For instance, “No, it’s a concept here because if you go to most Black countries, they still have the concept passed down... it’s [psychosis] an embarrassment... So, there you will find people ...hidden away.” (Participant 6). Likewise, participant 10 shares how if his father was to be treated in Ghana, he would have been left to “walk the streets”.

This shame, causing people to be “hidden away”, was contributed by a sense of “taboo” and “if they’ve had negative experiences with services before and then, that’s a big stigma in the Black community that if you’ve got mental health issues, then you’re weak” (Participant 5). Participant 7 felt that this was perpetuated by the current societal framework of the UK, “In the UK, is that sense of individual in a very individualistic way.”. This reveals how raising the psychological distress was perceived as shameful, and perpetuated by an individualistic society that the UK has.

### **Improving Pathways to Care**

As part of the semi-structured interview process, an invitation for participants to share what they wished would be different about their experience, or what they feel should be changed within their current understanding of the system were explored.

This theme consisted of two subordinate themes of (a) Developing Understanding and (b) Support. Within these subordinate themes, a recognition of hardship for the carer, involving carers in co-production and development and a re-wiring of the current blame culture into a culture of

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learning. These were participant's ideas for change and what they would wish were different to their stories of accessing support and managing the illness within their families.

### *Developing Understanding*

This theme demonstrated a thread of hope for creating a non-blaming culture that participants felt was essential to the improvement of the care of people from Black ethnic backgrounds with psychosis. For instance, participant 2 shared "It's about not blaming, ...not punishing people for making mistakes. I think people can get easily caught up on things like ...that". Participant 2 goes on to say that "it is trial and error... Let people make mistakes if they have the right intention".

Similarly, "I don't think all police are bad ... they're burnt out...but also some of them are just really not nice people and they don't like Black people... you can't just say that like, "this is a bad person then not in their right mind" (Participant 1).

The subordinate theme of support was in response to participants feeling a lack of recognition as their hardship also being difficult, but often feeling neglected, which is demonstrated by participant 4. For instance, "The thing is, I just want my family to hear my experience as a carer.", and participant 6, "I know money and all that, but there should be more emphasis on the carer also, and because the impact on the entire thing is so severe...".

## **Discussion**

Five core themes were found as a result of the thematic analysis, these were (1) The impression of psychosis, (2) Barriers to Care, (3) Hidden cost of psychosis, (4) Generational

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Cultural and Societal Interplay in Mental Health Perceptions, and (5) Improving pathways to care.

These overarching themes were crucial in the experiences of families managing and understanding psychosis.

Many quotes highlighted the stigma and misunderstanding surrounding mental health conditions such as psychosis. Terms like “looney bin” and the reluctance and minimal use of the words such as “psychosis” or “schizophrenia” reflect the participants’ fears about mental illness. The mention of “hearing voices” being associated with danger or being “tormented” may hint at the negative stereotypes of receiving a diagnosis of psychosis from Black ethnic groups. Prior research has found that there was a higher level of stigma within families from Black ethnic backgrounds, compared to families from other ethnic backgrounds (Wong et al., 2009; Lawrence et al., 2021). Stigma has consistently found to be impacting in the perceptions of care, as well as help-seeking attitudes (Jones et al., 2009). Likewise with participants within the current study associating mental illness with weakness, and it being seen as “shameful”, research has found similar connotations within Chinese ethnic groups, not wanting to “lose face” within close communities and society (Chen et al., 2016). This suggests how pivotal developing an understanding of the strong stigma associated with psychosis, not only within the individual, but the family system around them is in developing a more attuned health care system.

The findings of this research also suggest that a diagnostic paradigm and language used within the medical model was not helpful for families. Research agrees in that the perception of psychosis from a cultural perspective is needed to best support those who are diagnosed more frequently than people from White ethnic backgrounds (Saravanan, et al., 2008). However, little research has paid attention to the cultural-societal interplay, and the communication of diagnoses such as psychosis, and this seems important when adjusting services to meet the needs of those the most effected.

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Several quotes address how cultural and racial backgrounds influence perceptions of mental health. The suspicion of institutions from people from Black, African and/or Caribbean ethnic backgrounds, the taboo nature of discussing mental health issues, and the belief in spiritual attacks as explanations for mental health symptoms illustrate how cultural beliefs and experiences with systemic racism impact the way mental health is perceived. The mention of historical figures such as Enoch Powell and the impact of slavery highlights the deep-rooted intergenerational racial tensions that can influence mental health perceptions (Love, 2016). There appears to be very little research in this area, however these perceptions may illustrate how historical injustices continue to play a role in how able, or at ease, one feels able to engage in institutions (such as health services) (Hope & Spencer, 2017). The context of history may also play a part in the sense of “Us and Them”, inviting an othering experience, a feeling of difference, and therefore a maintenance in the system of feeling misunderstood, which is supported by systemic theories of continuous feedback within a system (Jost et al., 1994).

This is highlighted in participants experiences of police being the first contact when in crisis with psychosis, which has been seen to emphasise a distrust of the system, exacerbating disengagement from services, supported by research (Anderson et al., 2014). Police officer involvement has been the centre of media attention and has had increased attention in political campaigns (Aymer, 2016; Grills, Aird, & Rowe, 2016). However, despite acknowledgement of the institutional racism, the ripple and reactivation of trauma experiences within people from Black African, Caribbean or other Black ethnic groups remains present and continues to persist as a barrier to engaging in support (Bhui et al., 2018; Love, 2016).

Literature has found a high level of racism perception in people from Black, African and/or Caribbean ethnic groups accessing mental health services, which has been found to increase psychological distress which requires intervention (Pieterse et al., 2012; McLean et al., 2003).

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Snowden (2001) hypothesises that help-seeking behaviours from people in Black African ethnic groups may reflect the influence of the stigma felt in society. Martinez de Andino, & Weisman de Mamani (2022) find similar results in an undergraduate sample, which suggests that increasing enculturation (“pride and engagement in the culture of origin”) may help to improve the current underutilization of mental health services for psychosis in people from Black African, Black Caribbean and other Black ethnic groups.

Alongside the carer reflection on their family member’s experiences, the wider impact of mental health conditions on family dynamics and the role of caregivers in navigating both the illness and health system were prominent themes. Quotes discussing the change in roles within families, the burden on caregivers to manage care and support housing, and the desire for more emphasis on the caregiver’s experience highlight the complex interplay between mental health conditions and family relationships. The secrecy and desire to protect family members from worry also reflects the challenges in communication and support within families, which has been well-documented in the literature (Sin, et al., 2005). A meta-analysis of qualitative studies found that there was a severe emotional impact on family members, contributed by the impact of stigma, and how it functions in the context of help-seeking behaviour (Oluwoye et al., 2020). Specifically, caregivers were found to have increased anxiety and depression, with more frequent visits to general practitioners (GP’s) (Tennakoon et al., 2000). These findings highlight the need to address how carer’s access support, and how effective that support is. Research supports the use of co-production in mental health care and research, to minimise the hierarchical structure of institutions, and maximise personal empowerment (King & Gillard, 2019). However, there are some queries regarding how this is operationalised within a system that already represents oppressive historical narratives (Faulkner & Thompson, 2023; Soklaridis et al., 2024), supported by the findings presented in this EP, specifically regarding the difficulty in accessing the service first and foremost. Therapeutic communication has been found to be integral to reducing inequalities (Williams &

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Healy, 2001), including how professionals may communicate a diagnosis or formulation of difficulties for clients. Canales et al. (1997) proposes a ‘narrative interaction’, which is the formation of a therapeutic communication in the sharing of personal stories. Due to the present perceived manifestations of historical injustices, a personalised care approach appears to support the need for reconnection and establishment of safety needed for ethnic groups that have felt marginalised and unheard.

Personal experiences of mental health care, including positive interactions within culturally similar support workers and the benefits of Cognitive Behavioural Therapy (CBT), provide insight into the support mechanisms that individuals find helpful. However, the use of police in mental health needs urgent change, as it continues to maintain a non- and dis-engagement from services and professionals. The Crisis Intervention Team conducted a study evaluating the impact of stigma on mental health for police officers, finding a significant interaction, with a positive change in police officer attitudes after completing a 40-hour training programme (Nick et al., 2022). Not only does this show that the impact of stigma affects everyone, it also appears that the programme itself was effective in targeting mental health stigma within police forces.

The themes of stigma, cultural and racial influences, systemic challenges, family dynamics, and personal coping strategies highlight the complexity for families navigating mental health care and support. It appears that if services are going to adapt their promotion or access, a deeper, systemic level change needs to occur that promotes the dissolution of racism and stigma (Cook, 2017). For instance, including members of Black ethnic groups to be consulted in the formation of services, “bringing people together” and dissolving power hierarchies. The acknowledgement that the system is perceived as oppressive and “racist”, and education on psychosis for police officers were initiatives put forward by the participants, that has found benefit from further research. This suggests that raising the awareness of stigma within formal support services, from police to health



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practitioners, could help support people from Black, African and Caribbean backgrounds with psychosis when accessing health services.

### **Implications for clinical practice**

Key themes revealed that adopting sensitivity in addressing mental health in the first point of contact, whilst allowing failure to occur is essential. Within this sample, participants perceived care providers and services to inadvertently continue to carry the racial injustice that have been before, a viewpoint which has been supported by other qualitative studies. The clinical implications of this mean that services must address a large inequality gap in the promotion of services, and not necessarily the adaptation of therapies, which is something that literature has focussed on so far.

Mental health services need to understand and engage with Black, African and Caribbean ethnic groups' experiences, and work collaboratively to build trust, which appears to be largely addressed by reducing hierarchical structures (i.e., by introducing community members into boards, co-production and being mindful of representation within services). Initiatives to reduce mental health stigma within these communities could also play a significant role in encouraging individuals to seek help when needed.

### **Limitations**

There has been some research into the use of social media and recruiting hard-to-reach groups, with notable success (Dusek et al., 2015). Although this limits the sample pool to individuals who are actively on social media (and follow mental health charities and initiatives), leaving those who may not be as adept in those areas, it did allow for people to take part from different geographical regions in the UK, socio-economic backgrounds, and lifestyles. This was advantageous given the time limit of the research. It would be beneficial for further research to

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establish trust in local communities, to gather the stories of those who engage in community establishments (i.e., church) as opposed to social media. Additionally, the sample was female dominated, which may reflect the carer demographic, however further research would benefit from exploring other gendered perspectives on service engagement and family support. Reflections on difficulties of recruitment are documented in Chapter Six, where non-engagement is explored in relation to a distrust of medical establishments (Corbie-Smith et al., 1999), amongst other factors.

To conclude, this EP follows a story of injustice still present within the Black historical and social context surrounding hierarchical institutions, such as mental health services. The utility of the medical model, prescribing the diagnostic framework to mental illness was obsolete in helping caregivers describe the behaviour of their family member, thereby emphasising the impact of language in communication of difficulties. The family structure is likely to be disrupted with differing caring responsibilities, advocating a sense of advocacy, which enforced a sense of othering, illustrated in the theme of “Us and Them”. Service engagement was primarily through police contact, which appeared to act as a barrier in engaging with services. Lastly, the underpinning theories of hermeneutics and social constructionism provided a unique method for conceptualising the gap between engagement and non-engagement. Further research would benefit from larger samples, across genders, as well as direct research with those who have had a diagnosis of psychosis.

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### **Additional Methodology Chapter (Chapter 5)**

This chapter is to provide a framework for the positioning of the researcher in the approach to the research conducted as part of this thesis portfolio.

#### **Epistemological position**

The “truth” is moulded by every individual, based on experiences and feedback from others, all of which constitute some truth but not reality. Therefore, all that is known is one’s version of the truth/reality (Eatough & Smith, 2017). This is known as a social constructionist position (Cromby & Nightingale, 1999).

Heidegger (2005) proposes that a human being is a “Dasein”, meaning ‘being there’ (but is typically understood as ‘Being-in-the-world’) (Spinelli, 1989), and is the stance taken for this thesis. Using the thematic analysis methodology, which focuses on the individual’s lived experience as an idiosyncratic narration of their life, one adopts a social constructionist approach to reveal the truest account of their experience. This is particularly pertinent to researching psychosis, a development of various factors influenced by the socio-cultural environment. In understanding how this particular experience interacts with a Western intervention or care pathway, this project aimed to understand people and the language used as socially and historically contingent and contextually bounded.

Schleiermacher (1998) proposed a twofold interpretative perspective made up of the grammatical and the psychological. This dual-stance enables understanding, working well in the

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parameters of this project, exploring the lived experience of people from Black African, Caribbean ethnic groups experiencing psychosis whilst noting the impact of language on making sense of experience. This position informed the analysis of the transcripts of interviews conducted, to not only examine what is said (content) but also how it is said (language and meaning).

Ontologically, there is debate about whether social constructionism lands in relativism or realism. Relativism is the concept of instances in the world being unique to one individual, and that is how it exists, within the individual, whereas realism posits that instances, experiences and objects are objectionable truths that exist regardless of the subjective lens we may use (Keller & Keller, 2019). Cromby & Nightingale (1999) highlight that constructionism is a stance that lends itself to a relativist position. For this project, one lends itself to the latter argument that reality exists outside our language; however, to understand one's reality, we utilise the language to infer meaning. Therefore, the analysis may not necessarily address an objective reality, but a subjective one that is truer to the lives of the sample for this project. This project takes a stance proposed by Stanley et al. (2001) in that psychosis, and the symptoms associated, are culturally-bound, and made sense of in the context of societal norms, as opposed to taking a diagnostic objectionable criteria outlined in ICD-10 and DSM-5. In this way, the relativist position will be taken to account for these nuances in participants' experiences, as opposed to identifying objectionable truths which may not align with the individual experiences.

### **Determining capacity**

Prior to interviewing, the researcher assessed the well-being of participants so they could ethically and meaningfully participate. This was done by discussing how they were feeling about the interview. Capacity to take part was then assessed by understanding if the participants could weigh up their wish to be involved versus the emotional toll it could have, and a way to manage the



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emotional content if need be (which was then discussed further with the researcher). Before the beginning of the interview, details of the study were explained to the participants. Within the interview, the participant was required to show an understanding of the details of the study by sharing their understanding of the research project to the researcher. Next, the researcher asked if participants had any questions to further substantiate understanding and discuss any concerns. It was important that the participant understood what their role entailed and their right to withdraw (HRA, 2017), which was documented on a consent form with the participant's signature and an initial signed next to each statement outlining the purpose of the research (See Appendix H). The researcher then discussed ways in which the participant could show the researcher signs of distress, such as waving a hand, turning the video off or using the private chat function to allow different forms of communication other than verbal language.

### **Researcher safety**

To maintain the researcher's safety, a buddy system was implemented with the primary supervisor of the project, which made the supervisor available during the interview times for assistance. All interviews were conducted virtually using Microsoft Teams, in a non-clinical setting, within a confidential environment. The researcher made use of a reflective diary, as well as supervision, to explore her experiences and related personal responses to the interview and emerging data.

### **Public Participant Involvement (PPI)**

The PPI consultant was instrumental in constructing and reviewing materials used for the study. The consultant identified herself as Black Caribbean ethnicity, which provided an insight into the content of the interview questions and the adverts used to recruit for the study. This allowed the

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researcher to consult on any unconscious biases in developing materials (i.e., advertising, interview question development, use of appropriate language and asking appropriate questions). For instance, the wording of “those who identify as Black ethnicity” was changed due to some concern over how “those” may be interpreted. This was then changed to “people from Black ethnic groups” and “people from Black, African and Caribbean groups”, which was agreed to be more culturally and linguistically sensitive. The PPI consultant also asked thoughtful questions about the researcher’s wish to pursue this area, given the ethnic orientation of the researcher being different from the sample. This allowed the researcher to become more curious about the role of ethnicity in the interviews, and her role as a White British female academic. A good example of this was in interview 1 whereby a reflective discussion was held around the origins of ethnicity, and the meaning of it being constructed out of society and power dynamics. In understanding this, the researcher was more able to bring reflexivity, reflecting in and out of the moment, to disentangle any underlying biases, further built upon in supervision.

### **Interview Content**

The interview topic guide was adapted from Twining et al. (2019) and informed by a social constructionist epistemological position whereby a detailed account from the individual is needed. However, the wider mechanisms of society and culture (micro and macro levels) are needed to form part of the wider understanding (Bur et al., 2015).

Initially, participants were asked to reflect on the definition of psychosis with the interviewer, as participants may have constructed personal definitions or meanings of what psychosis meant to them. In line with the epistemological position of social constructionism, it was important to use the participant's language to ascertain the truest version of their truth. However, none of the participants opted to adopt an alternative word for psychosis.

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Participants were then asked to share their story of caring for someone who experiences psychosis, their perceptions of services and service engagement, and their beliefs and cultural standpoint regarding mental illness. Participants were informed that they could withdraw from the interview at any time. They were also informed that they had a maximum of two weeks to withdraw after the interview has been conducted due to data collection and analysis procedures. Due to participant anonymisation, it would only be possible to withdraw their individual scripts once interviews have been conducted.

### **Choice of analysis method**

The project considered various analysis methods to appropriately answer the research questions. As this project meets a gap in the literature in exploring the systemic connection to engagement, grounded theory (Walter & Myrick, 2006) could have been used to integrate previous literature and new insights from the EP. However, due to a lack of research concerning the systemic understanding of the continued non- and dis-engagement in services from people from Black, Caribbean or Black African ethnic groups with psychosis, this would not yet be an appropriate approach.

Narrative Inquiry (NI) (Bell, 2002) was also considered as it may have been beneficial to elucidate a story from the participants experiences, however thematic analysis (Braun & Clark, 2006) was opted for due to the advantage of discerning similarities and differences as well as constructing a story. Using the social-constructionist framework then met the need of understanding the systemic interplay between history and the present day through the perceptions of black carers on psychosis and care. This allowed a systematic analysis of codes and interview transcripts that contains nuances easily observable to the researcher. In contrast, NI may have elicited some bias

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from the researcher, depending on the epistemological position of the researcher. Although bias is unavoidable, it can be contained if the researcher seeks out supervision and records thoughts and wonderings about the interview transcripts. Therefore, it was decided that thematic analysis and a reflective journal will be used to analyse the transcripts.

### **Underlying guiding principles**

Throughout the empirical paper, Gadamerian principles (1975) were used to guide the methodology, emphasising how the Gadamerian principles (1975) can guide and shape the conceptualisation of mental illness. The philosophical underpinnings of hermeneutics (e.g., Gadamer's principles) are concerned with the mutual understanding of phenomena, as opposed to an objective meaning of phenomena (Smith, 1993). As the interviews progressed, the researcher became aware of how one moved from a position of a technical interviewer to a human that wanted to "be with" the participants. This became more evident to the researcher whilst journaling their experience and reflectively discussing the experience through supervision. Gadamerian principles (1975) were essential to fully utilising the material presented by the participants, as it specifically emphasised the context surrounding that individual, such as culture, history and generational family patterns. This also helped the researcher determine that although psychosis is presented as a clinical term, the interpretation of psychosis appeared more subjective, and the use of the word was not frequently used within family scripts. Rather, it appeared that "unusual behaviour" was used to describe behaviour, and this more accurate to their experiences. Moreover, contextual understandings of the history of oppression and systemic racism shed light on the possible unseen barriers to accessing services. In line with Ann Cook (Cook, 2017), Lysaker and Roe (2013) that although there is indisputable utility in evidence-based interventions for psychosis, a rigid and narrow focus on interventions could limit the ability to consider that psychological suffering is embedded in the history and culture of the individual which often overlooked within interventions.

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A way forward for interventions could consider that framing client–practitioner interactions in the socio-historical context of mental health to establish awareness and connection. This also enables a conversation regarding power, naming differences between people, aiding a more authentic connection.

This provides further evidence that systemic dynamics continue to impact people from Black, African and/or Caribbean ethnic groups when entering a service. This project argues that the relationship and acknowledgement of the context appear to provide the best recovery outcomes and may explain the nuances and gaps within the current literature regarding culturally-adapted therapies that accrue mixed, but limited, evidence for Black African, Caribbean or other, mixed Black ethnic groups yielding positive outcomes.

### **Analysis**

Thematic analysis was used to analyse the data to ascertain similarities and differences between transcripts (and thereby, persons) (Braun & Clark, 2006). However, Braun and Clark (2006) highlight that there is a passivity about some researchers adopting thematic analysis and that this should be rectified by the researcher taking an active role in acknowledging that they bring a perspective to the analysis. For this reason, terminology such as “themes emerging” will not be used, but rather acknowledging that a theme has been “generated” as the researcher has applied their own epistemology and background to the presenting data.

As detailed in their original paper, Braun and Clark (2006) set out six stages of analysing thematically. Firstly, the researcher familiarised oneself with the interview transcripts to embed oneself in the experience, which meant repeated reading of the transcripts. Next, preliminary ideas around topics were made through a reflective journal.

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The second stage of the analysis consisted of generating initial codes that helped to understand parts of the transcripts that illuminated the participant's experience concerning the research questions. The third stage included generating broader-level themes that encompassed the codes. There were stronger themes than others, such as the meaning of "psychosis". At this stage, the researcher started to think about relationships between themes and interconnectedness. Sub-themes started to develop to organise the themes hierarchically according to the level of importance, for instance, the theme of the sub-themes of "Fear" and "Us and Them".

The fourth stage was to review the themes by constructing a "thematic map" (see Appendix J). Firstly ("level one"), themes were reviewed to assess the quality of the codes and if they appeared coherent under the theme name. If they did not fit under the theme coherently, a series of actions were to be made. For instance, the theme itself may be incorrect, and a new theme is considered, the codes contributing to the theme may be incorrect or incoherent in some way, or data extracts belong to another theme. In this instance, a new theme, a reworked theme, re-organising the themes or discarding the theme entirely would be considered. For instance, the theme of "Care only in a crisis" was initially named "Police involvement" which was purely descriptive, and did not capture the nuance of the feeling inherent within the experience, therefore "Care only in a crisis" was adopted to capture not only police but service involvement.

Secondly, ("level two") consisted of reviewing the data as a whole. Reviewing the thematic map (Appendix J), the researcher analysed whether the themes reflect the story, by re-reading the transcripts, codes and themes. The research team then discussed the naming of the themes ensuring it accurately reflected the content of the codes within that theme.

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The fifth stage included naming and defining themes. Braun and Clark (2006) use the terminology “defining the essence of the theme”. While constructing this, the researcher’s position and awareness of a social constructionism approach was noted to attempt to remain impartial when analysing (Smith et al., 2012). The final stage was to produce a report that will capture the essence of the transcripts. This is the empirical paper.

Finally, the data will be uploaded onto the University of East Anglia digital repository as per university policy for post-graduate and doctoral-level students once submitted to the University. Data stored in the digital repository will be anonymised. Per the university policy, research is stored for at least 10 years.

### **Self-Reflexivity**

Utilising the social constructionist theory, which posits that one will use one's own subjectivity and experience of the world as a lens through which one sees the research and interprets the data. Being a White female researching Black ethnic groups, the researcher is naïve about the discrimination and structural violence experienced (Agyeman, 2008). To this end, the researcher acknowledges their position that experience makes up the contents of this world, and therefore truth, and with that comes blind spots, which the researcher documented in a self-reflective diary (Mizock & Harkins, 2012). The researcher also utilised supervision for reflection.

## **Recruitment and Interview reflections (Chapter 6)**

**Word count: 2,221**

This chapter aims to bring together the reflections of the researcher on the challenges faced when recruiting for the empirical project. This chapter also addresses the dynamics present within the interviews.

### **Advertisements**

During the design and making of the advertisements, guidance was taken Jenson et al.'s (2021) research which outlined key initiatives specifically to encourage people from Black, African and/or Caribbean ethnic backgrounds to take part in research. Jenson et al. (2021) outlined that people from Black, African and/or Caribbean ethnic groups should feel fairly represented and have a sense of connection when deciding to take part in the research. Therefore, it was well-intentioned to create a pictorial representation of people from Black African, Black Caribbean and other Black ethnic groups and review this with the PPI consultant (see Appendix L). Despite this however, recruitment was slow. Research concerning the barriers to engagement has been well-documented. The most effective recruitment strategy outlined that the researcher must immerse themselves into the community, to create direct contact with community members. Research from various subject fields support this. For instance, Bamidele et al. (2018) found that in Black African, Caribbean and other mixed Black ethnic groups with prostate cancer, direct and meaningful engagement was the



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most successful recruitment strategy (i.e., going to community establishments, meeting face to face and spending time with people).

Given this finding and other evidence supporting similar conclusions (Bhui & Bhugra, 2002), the researcher took on a more immersive role in recruitment, which proved more advantageous, however, did not improve recruitment uptake. Bhui & Bhugra (2002) found that a multi-agency collaboration of individuals including traditional healers, specialist services, religious venues and contact with psychiatrists strengthened engagement, although this was not possible for this research given the timeframe.

It's important to consider that this is not purely an ethnic difference. This may reflect the history and the culture of one's home country, family origins, cultural identity and mental health difficulties. This evidence is inconsistent for White ethnic groups, for several hypothesised reasons. The history of oppression, racism and stigma provides an immediate distrust and encouragement to stay in reliable communities where one feels identified. Despite movements in the 21<sup>st</sup> Century promoting equality and diversity, it would be naive to propose that this would eradicate the intergenerational trauma and oppression that has faced a particular community for centuries before.

Additionally, with advancements in equality and diversity, events such as the unjust murder of George Floyd by a police officer, encourage the separation between ethnicities and reinforce a story of hierarchical difference between ethnicities (White et al., 2023). Trauma has been found to extend multi-generationally across times and people (Sangalang & Vang, 2017), impacting how one interacts with services associated with such traumas or inequalities (Menzies, 2010). This may explain how an advert with an inaccurate representation would fail to engage a population from a

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Black ethnic group, and why direct, truthful engagement with the community would yield the most effective engagement, thereby recruitment.

### **Personal Reflections from the Researcher**

*[“I” will be used throughout this section to reflect the researcher’s true reflections]*

*Reflection journal entry, dated 19th December 2022,*

“No participants have come forward; it feels disheartening and anxiety provoking. I’m wondering about my racial identity and the perception of this when I engage in groups solely for people from Black ethnic backgrounds (such as the ZICAN event and AMHE). It seems the culture is within a micro-culture within the UK, and I wonder if my ethnicity feeds into the wider cultural messages around academia and studying a population associated with stigma. My intention, albeit good, may be perceived as widening the divide between “them and us”, whilst I intended to bridge this gap, I can only bridge this gap once individuals feel comfortable enough to engage with me. This explains the dynamics I see in the literature, for instance, the underrepresentation of Black and minority ethnic groups in community services and overrepresentation in inpatient services. This finding alone, that I am struggling to recruit anyone, may show how alive the historical context may be for some individuals.”

Recruiting for this study was slow and difficult, reflected by not only the time pressures of writing a thesis but also in trying to reach a stigmatised group. During the delay in recruitment, I reflected on whether I had done everything correctly and within my power. This spurred me to connect with people from the Black community. My perspective changed, notably when I attended a ZIMCAN event. The supporting speaker disclosed personal experiences of being discriminated

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against, the cultural messages that particularly Black men grow up with (to be strong and provide for your family), and racist experiences which was shocking to hear. He spoke about fighting harder for job promotions and the tokenistic nature of promoting someone who was Black just for equality and diversity purposes in the speaker's eyes. He then spoke of a pressure to perform and outperform colleagues to get an inch of the recognition perhaps a person of White ethnicity would receive. The cultural messages that I learned through the immersion in events and the community not only touched me, but provided additional hypotheses around barriers to engagement and how needing help could be seen as a weakness, which is not uncommon for many communities, including people from Asian ethnic backgrounds (Atkinson & Gim, 1989).

In light of this reflection, I attended a drop-in mental health group in Cambridgeshire, where ethnic diversity was higher than the general population in Cambridgeshire. Staff were perplexed as to why they had a lack of Black African, Black Caribbean and other mixed Black ethnicities, however upon reviewing their advertisements, I saw that this only represented White ethnic people. Although my presence was an act to promote the study, it became a consultative practice in reviewing the organisation's advertisements to promote ethnic inclusivity. This was incredibly rewarding but also highlighted how promoting diversity and equality may be due to a lack of awareness. Therefore, future initiatives or directions may benefit in providing psychoeducation to local mental health groups to ensure inclusivity and diversity.

The recruitment strategy deserved further thought. Whilst a need to obtain a representative sample is urgent for the purposes of research, this neglects the intention to create meaningful connections, which ultimately is what is supported in research. Therefore, it would have been advantageous to build up a meaningful connection with a few chosen organisations to create connection, as opposed to reaching out to many. Ultimately, using social media proved the most

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successful recruitment strategy, with multiple and repeated advertisements routinely posted on a dedicated account made for the research. In light of authenticity and connection, I also provided a personal synopsis of who I was, which proved advantageous.

### **The interview**

The interaction between interviewer and interviewee is noted as being essential to the quality of conducting research. De Andrade (2000) describes his own reflections in interviewing Cape Verdeans' experiences, whilst being Cape Verdean himself. Surprisingly, his racial identity hindered the research process as opposed to it being an opener to a deeper connection with his participants. He terms this the "position of the insider". Similarly, I wondered on what my position represented to participants, which may have raised certain unconscious or conscious biases. As one participant identified in her interview, that was visibly White, but with a Caribbean ethnic background spoke of how she would unintentionally represent historical oppression in a way that is visible to others of different ethnic orientations, but completely invisible to oneself in a White ethnic body. This was substantiated whereby this participant directly enquired to my ethnicity, "I guess ...way, way back, you're [talking to researcher] from Africa. So ...what does that make you, African now as well?" (Participant 1).

There is a sense of comfort exuding from the participant as she felt comfortable enough to raise this, whilst suggesting that language plays a vital role in how one identifies oneself, and how that may be contributed by geographical, cultural and societal viewpoints. It occurred to me the power that language had to either create closeness or distance. This unintentionally created a "you and us" dynamic and part of me wondered about the use of social construction as a theory, as using this theory allowed a theoretical distance to be created, which gave me some comfort. The theory allowed me to that racism exists in the structures of societal and historical oppression. However, I

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had to bring in my awareness to the potential naivety that this brings. Racism continues to exist and exists in many people's lives, and bringing historical underpinnings it not always appropriate. For me to do that would have been to equip me with a semblance of understanding, but I would never understand. Once I reflected and became aware of this paradigm, my interviews became more authentic and valid. This reflection aided the research process.

During the interviews, I found myself moving from different positions. For instance, the position of my White privilege, to a position of an empathetic human being who felt connected to a participant, particularly when a participant became tearful when discussing the passing of her mother which impacted caring for her brother, who had psychosis. As I moved from different positions, from researcher, to academic, to human, I noticed a multi-layered, connected relationship to develop. I noticed that we appeared more connected when we shared experiences and found similarities in us both, of which Kerstetter (2012) refers to as the "space between". For instance, we also had similarities in our genders and our experiences of caring for someone with psychosis. This was typified by an amalgamation of multiple identities from the researcher, including one's cultural background and relationships, which could influence how participants are positioned within that space. One might lean into fitting into a category coined by Banks (1998) as an "external-outsider" (being neither indigenous nor part of her community). However, I might be inclined to argue that this was mediated by our similarities in our gender, age and passion for caring for psychosis (Narayan, 1993). Further research comments on the stance of the researcher being flexible and dynamic, encouraging a "dialectical relationship" which aids the interviewee feeling comfortable to share their experiences (Serrant-Green, 2002; Dwyer & Buckle, 2009; Serrant-Green, 2002). As I became comfortable within myself, noticing these different positions, and noticing when to be in which position, "the space between" became more familiar, which proved more evident as interviews went on, and a more varied breadth of information was explored.

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The intersection between positions allowed flexibility and awareness of one's position, including when considering the impact of ethnicity. Donnelly et al. (2005) explains that as a White person, I do not "see" my ethnicity, because I've never had to. It's not been highlighted to me that my ethnic orientation or appearance would be a barrier or evoke any sort of reaction from others - which is a privilege.

McIntosh (1989) suggests that White privilege is much like an "invisible weightless knapsack [full] of special provisions, passports..., clothes, and blank checks" (p. 10). People that are of White ethnicity have a plethora of unearned assets that can perpetuate the strength of status and narrative of White people. This is evidenced in the availability of essential or desired convenience items in stores, for instance, make-up that is designed for White skin colour. White people see people who look similarly to them on adverts. When one interacts with institutions or services, it is not within the mindset that asking for support would reflect negatively on the community, and authority, such as the government. Donnelly et al. (2005) suggest that society only notices colour when patterns emerge that concern people who are not White. It appears that White is seen as "neutral" or "Normal" and it's used as a baseline, or comparative standard to assess "normality". This comparison is also seen within research, whereby one looks for a comparison against a White control group, evidenced in the systematic review written as part of this portfolio. This discourse surrounding minority and majority groups, may have been influenced by early narratives and legacies of European colonisation and imperialism. By introducing a hierarchy that aimed to keep the power, European powers justify their discrimination over other people in the name of progress and civilisation, which typically places non-European people as "inferior" to maintain this structure (Mishra & Hodge, 1991).

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The awareness and understanding of White privilege, whether unearned or earned, and disadvantage is rarely related to one sense of being but is an intersection of many different factors. Although this is unchangeable, it's important to remain aware of the intersectionality, not only in research but clinically in therapeutic practice. It's important to consider what one represents, that could adversely impact the relationship, as well as what could strengthen those attributes that continue to keep client and therapist/researcher and participant connected. Again, as portrayed throughout the portfolio, the relationship and connection appear paramount to promoting change. This informed the researchers awareness of unconscious biases, and assumptions which indicated how services may have also adopted practices and or language that promotes disconnection. Highlighted in both the EP and the SR, relationships have an impact upon service engagement, and therefore the reflections presented within this chapter is hoped to support evidence that a more embedded and authentic connection is need in order to establish meaningful connections, and therefore engagement in services.

**Discussion and Critical Evaluation (Chapter 7)****Word count: 7,021 (excluding references)**

This chapter incorporates previous chapters to discuss their findings concerning previous literature and applications to clinical practice. This chapter will also critically evaluate the chapters as a whole, examining the methods used to arrive at the conclusions made for this project. It begins by summarising the key findings from the empirical paper (EP), systematic review (SR) and additional chapters. Wider theoretical and clinical implications are discussed, leading to recommendations for further research and suggestions for improving engagement in services for people from Black African, Black Caribbean and other Black mixed ethnic groups who experience psychosis. The chapter finishes with an overall conclusion to the portfolio.

**Summary**

The SR and EP collectively highlight the difficulties in engaging and accessing services for psychosis for people from diverse ethnic groups. The SR highlighted that whilst CBT showed positive symptoms reduction, long term outcomes were not sustained past 2 years. EI outcomes showed promise in reducing symptoms, and even more so with the integration of family support. However, this was limited by only one EI study included in the review which focussed on Asian ethnic groups. Therefore, further research is needed overall, with a particular emphasis focussing on samples from Black African, Black Caribbean and other Black ethnic groups. A hypothesis regarding the underlying mechanism of change in individuals with psychosis from Asian and Black ethnic groups were that ensuring a therapeutic relationship be established for an intervention to be effective (either through social, community, peer or therapist connections). This was because more sustained recovery outcomes resulted from longer term interventions (such as EI, traditional



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interventions and family support), with lower attrition rates, compared to short-term interventions (CBT) for people from Black ethnic groups. However, the review found a limited pool of eligible studies which continues to show the lack of engagement still present in participating research.

The EP provided a qualitative understanding of this finding from the perspectives of family members, suggesting that wider historical and contextual influences may exist in barriers to service engagement. For instance, participants from Black African, Black Caribbean and other Black ethnic groups commented on the immediacy (or lack of) family support, which was reinforced by current mental health structures. This was underpinned by the current and generational stigma that appeared maintained by the current system that has made limited progress in promoting inclusivity, compassionate police involvement, or achieved adaptations to easing access to services by promoting a shared understanding of illnesses. The papers found that stigma is held within families, as well as perceived within the wider systems resulting in a bi-directional pattern of disengagement from services that provides evidence for the systemic justification theory (Jost et al., 2000). This essentially suggests that systemic factors reinforce a given behaviour due to multi-faceted factors, that can persist even in the face of many attempts to change the system, and why a system-based change is needed in order to improve outcomes and experiences of care. This discussion aims to make sense of both the EP and the SR, with suggestions for informing clinical practice.

### **Systematic review**

The SR sought to examine the outcomes of psychosocial interventions for Black African, Black Caribbean and other Black ethnic groups, and Asian ethnic groups diagnosed with psychosis. Methodologically, the definition of recovery was ambiguous with vague descriptions that did not

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often match a definition of recovery, that included a self-report measure or quality life measure, as suggested by authors in recovery literature (Pitt et al., 2007). Research has found that “recovery” is much more than a clinical reduction in problematic symptoms; it is how an individual perceives their level of social and adaptive functioning post intervention (Lam et al., 2011). A range of interventions were assessed within the review, including Cognitive Behavioural Therapy (CBT), Culturally adapted CBT (CaCBT), traditional methods, peer-support interventions, family interventions (FI), group interventions and early intervention in psychosis programmes (EI). Ten RCT studies were included for the review, of which highlighted positive outcomes from CBT interventions, yet was limited in long-term follow ups. Social recovery models, including EI and peer support showed promise, however the varied nature of such suggested that a possible effect of sustained and long term client-therapist relationship may have impacted intervention outcome (Gillard et al., 2022; Grant et al., 2012; Gureje et al., 2020). There were high attrition rates, yet also positive recovery outcomes found in samples who participated in family or community interventions (Weisman de Mamani et al., 2014). There was also a small difference noted by ethnicity, in that participants from Asian backgrounds benefitted from family involvement (seen in higher recovery outcomes), whereas Black African, Caribbean or other Black or mixed-Black ethnic groups benefitted from sustained relationship building in the context of recovery and therapies. High attrition rates were found throughout the studies, however low attrition rates were found in the interventions that included peer support and a combined traditional and clinical intervention approach (Gillard et al., 2022; Gureje et al., 2020), compared to other interventions included in the review. The SR argued that amongst the interventions with the highest recovery rates and lowest attrition rates, an effective therapeutic relationship and integrating the client’s belief system appeared to support recovery from psychosis. However, this conclusion is limited by lack of long term follow up’s on CBTp interventions, which limits the comparability of assessing

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recovery outcomes. This is consistent with some of the results from the EP that examined the impact of culture and beliefs on service engagement for psychosis.

### **Empirical paper**

The EP sought to explore the experiences of pathways to care and perception of psychosis for family carers of people from Black African, Caribbean or mixed Black ethnic groups who have psychosis. The paper found five themes that appeared crucial in the re-telling of participant experiences: (1) The impression of psychosis, (2) Barriers to Care, (3) the Hidden cost of psychosis, (4) Generational cultural and societal interplay of mental health perceptions, and (5) Improving pathways to care.

The theme of “The Impression of Psychosis” initially induced a stigmatised reaction, linking this to the media portrayals of psychosis and violence, particularly for people from Black African, Caribbean or mixed Black ethnic groups. This idea of psychosis was then ill-matched to the caregivers’ perceptions of their family members, who often adopted caring and humanistic language. This informed reflections on the barrier in the use of medical language and how this may unintentionally create a further barrier to engaging in services, which has been evidenced in the literature, further stigmatising individuals (York et al., 2015). The use of labels creates a sense of certainty yet appears to also create distance between individuals, resulting in shame and stigma. The medical model relies on certainty and is aptly utilised in physical health; however, it fails to address the nuances of the human experience, which is not always aided by a prescriptive suggestion/therapy. Research within systemic therapy advocates for safe uncertainty (Mason, 1993), as certainty can limit and diminish the opportunity for understanding. Therefore, a direction to

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explore is the use of safe uncertainty, coincidentally dissolving power dynamics within interventions and approaches used within mental health services that would also target the implicit discrimination some people feel when encountering services from Black, African and/or Caribbean ethnic groups (Boston, 2000). One of the first steps in dissolving the power hierarchies is through recruiting PPI consultants, and why this project was advertising this integration from the start.

The second theme, “Barriers to care”, illustrated a story of delayed support, often accessed through the police or criminal justice systems. This was interlaced with participants perceiving a strained system attempting change but unable to relinquish hierarchical and structural racism. Once support was accessed, participants shared overall positive experiences, gaining access to medication and therapy. However, this was also mixed as some participants felt this was superficial in managing their difficulties (i.e., using medication, inconsistent staff within services), resulting in dissatisfaction. Some also shared that their cared-for family member experiencing psychosis was often met with medication, as opposed to exploring the benefits of therapy. Where there was an offer of therapy, it came with waiting lists or only in response to a crisis situation, which made participants feel less important and less heard. None of the participants shared that they continued using medication, which highlighted the disdain and disengagement from seeking further support.

The third theme found was the “Hidden Cost of Psychosis”, which illustrated adaptations carers had to make to support their family member. This extended to social arrangements, limiting employment, and the physical and mental energy it took to support their loved ones. Consequently, this resulted in a shift in the family dynamics, interlaced with the generational script of how to support, parent and look after those who need support. This generational script was often littered with words such as “brush it under the rug”, “secret” and “hidden”. This generational script appeared to follow a shame-based method of coping, often resulting in delaying help-seeking,

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further increasing the burden on families, which has been supported in the literature (Shefer et al., 2013).

The fourth theme, “Generational cultural and societal interplay of mental health perceptions”, highlighted the ever-present injustices, such as slavery, in the stories of the participants’ experiences in gaining access to support and the perceptions of psychosis. The ripples of the societal, moral and ethical violations are reactivated every time one faces discrimination, which was found within all participant’s stories. Beliefs regarding psychosis were partly informed by generational beliefs, which extended back to the cultural standpoint taken by a participant’s home country. For instance, mentions of people being “tormented” or having a “spiritual attack” were indicative of the unknown of the illness's origin, with spiritual or religious undertones or suspicions. None of the participants recalled a biological or scientific method of explanation; rather, it followed a psychological (by “worrying too much”) or spiritual belief system. There was also mention of how different cultural frameworks convey how care is given and received, which is particularly different in a Western culture and a non-Western culture. Within Black African, Caribbean and other Black ethnic groups, care appeared to be immediate, whereas in White communities, care is established through official structures that do not have immediate connections to the person experiencing psychosis. Inadvertently, this may create the stigma that a “problem” only resides within the individual, thereby perpetuating the increase of psychosis amongst people from Black, African and/or Caribbean ethnic groups (Boston, 2000). This may also explain how the same rates of psychosis are not observed in Africa. It may also suggest that receiving professional support attracts a stigma within British society. Although there are narratives in African regions surrounding mental illness equating to not being “strong” (Memon et al., 2016), receiving support within the family may not be seen as so stigmatising, thereby lesser prevalence rates in Africa. The use of Western biomedical models of health (i.e., separating physical and mental health) tends to

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ignore other, alternative models of health, such as Medicine Wheels (a native American framework for encapsulating physical, mental, emotional and spiritual health), which negates many other ways that people could frame their experiences, leading to non-engagement (Patel, 1995). Littlewood (1990) describes this as current psychiatric models lacking the “dialectical interplay of human biology and society” and reinforces a need for a more complex understanding of improving engagement within services.

The fifth and final theme of “Improving pathways to care” highlighted that despite perceived barriers to engaging, police contact, and a reactivation of hierarchical historical injustices perceived in mental health systems, participants shared suggestions for what would improve their experiences. This included including service-user groups in service production to dissolve power hierarchies in the current system that may be exacerbating barriers to accessing care. Additionally, acknowledging poor experiences in mental health services faced by people from Black African, Caribbean and other mixed Black ethnic groups is a must, and reducing or changing police interaction styles with people who have psychosis is essential. Due to the first theme of the “Impression of psychosis”, with connotations of violence, police need to take an active role in understanding mental health as a need as opposed to a threat. Treating people as if they are threats increases challenging behaviour, reinforcing the current stigmatised narrative and causing disengagement from services. This is evidenced within statistics that there is a widespread under-representation of people from Black, African and/or Caribbean ethnic groups in early intervention services and GP consultations for mental health (Edge et al., 2010). There appears to be a bi-directional process whereby institutional barriers continue to exist, whilst individuals from Black, African and Caribbean ethnic groups hold generational shame and stigma that also reinforces non and disengagement in services, which reinforces the systemic justification theory (Jost et al., 2000).

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### **What does this mean?**

A theory proposed by Jost and colleagues (2000), namely “Systemic Justification Theory”, outlines that the manifestation of phenomena is maintained by the context in which it’s in, which may help explain how the disengagement and lack of engagement in services for Black African, Caribbean or mixed Black ethnic groups is continued in western society (Chow et al., 2003). For instance, one of the key mechanisms appears to be a lack of contextual understanding, and recognition mitigating the engagement or disengagement into services. This may explain the overrepresentation of Black African and/or Caribbean ethnic groups with psychosis in inpatient hospitals and under-representation in community settings (Public Health England, 2016). The systemic justification theory posits that this is a continual feedback cycle, where the system continues to do the same action, hoping for different outcomes. The system neglects the contextual factors concerning people from Black, African and Caribbean ethnic groups when entering and engaging in mental health support from services. In line with the post-cultural feminist movement (Love, 2016) where race was a factor continuously addressed, but due to the failure in addressing race alongside the contextual issues of gender, class, and history, change stagnates which creates the potential to further marginalise people from Black African or Caribbean or other Black ethnic backgrounds (Jefferies et al., 2018).

This appears particularly important for those who are from Black African, Caribbean or other mixed Black ethnic groups due to the narratives present within Black ethnic families that are outlined within in the EP. Participants outlined that the person’s struggles are surrounded by injustice, misunderstanding, brutality, and misaligned belief systems. Support was immediate to the individual within their system in non-British culture, whereas, in British culture, it was a process of engaging with higher levels of the system, not within immediate reach to access support. It may be

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that taking the mental illness out of the person's life context is a Western method of attempting to provide care for an individual to promote recovery. However, this process or method is not one adopted in other cultures, specifically in African cultures. If one's history, tradition and generational scripts are neglected in the understanding of the psychosis (or any mental illness), it may limit the individual's ability to make sense of their own experience. The belief system has been highly important in the outcome of recovery, evidenced by the present SR, often related to an individual's attribution of illness (Leamy et al., 2011).

Additionally, Black African, Caribbean and other mixed Black ethnic groups report that there is stigma related to race, in addition to the stigma associated with having a mental illness. This stigma is also cultivated through one's internal perception of themselves and their belonging, through what is termed "Internalised stigma" (Franz et al., 2010), and relates to their own, as well as their family member's attribution of illness. Gureje et al. (2020) note that participants had more of a bias towards having spiritual explanations for their illnesses (Gureje et al., 2020), supported by research (Rathod et al., 2005; Sorketti et al., 2013), which may have impacted intervention outcome, and its success. This is supported by Rathod et al. (2005), who found that CBT interventions were most effective when the belief system was incorporated. This is supported by literature examining the role of causal beliefs in psychosis recovery outcomes and the efficacy found within Cognitive Behavioural interventions where the focus on belief is a goal for therapy. For instance, Bard et al. (2021) found that how people from Black African, Caribbean or mixed Black ethnic groups perceived their experience of psychosis positively influenced their scores on the positive and negative symptoms checklist, which suggests that belief could influence the outward presentation of psychosis. This suggests that incorporating one's belief system into treatment may be beneficial. A recent systematic meta-analysis concluded that culturally-adapted interventions had no more efficacy than non-culturally adapted interventions for psychosis in



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people from many different ethnic backgrounds (Degnan et al., 2018). However, the ethnicity criteria lacked specificity (e.g., categorising ethnicity by “Chinese” or “not Chinese”), which provides limited conclusions to be made on the impact of ethnicity. Secondly, a culturally-adapted (western) therapy may differ from an intervention that utilises the client’s belief system. For instance, using a CBT model and incorporating religious or supernatural beliefs regarding illness may only target a small proportion of the client’s need for being understood due to the Westernised framework or model. Peer support models and combined traditional and clinical interventions for psychosis achieved the lowest attrition rates within the SR, which may provide evidence for this hypothesis (Gillard et al, 2022; Gureje et al., 2020). Leamy and colleagues (2011) found that, in comparison to White ethnic groups, it was more common for people from Black African and Black Caribbean ethnic groups to associate their recovery with their relationship to spirituality and religion. Not only this, but carer appraisals of the illness have been found to be highly correlated with the patient’s, specifically from people in Black African and Black Caribbean ethnic groups (Upthegrove et al., 2013). This suggests the importance of understanding the illness within the context of the family and the additional difficulty there may be in adopting a different appraisal for the illness (Westernised and scientific). It also suggests that authentic relationship building and building connections is vital for sustained post-intervention outcomes (Gillard et al., 2022; Gureje et al., 2020). Arguably, a more complex understanding is needed to highlight the interplay between human biology and society (Littlewood, 1990), and this includes inviting different frameworks for understanding mental health to promote inclusivity and, ultimately, recovery.

The SR synthesised evidence that revealed a pattern of longer interventions involving peers, groups and/or family members, which yielded the most positive outcomes in symptom management and regaining functionality. Although, caution must be drawn from this conclusion due to a lack of CBT interventions included in the review. A hypothesis might suggest that regardless of the

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intervention offered, establishing trust through connection was the most important factor in improving access to services and outcomes from interventions. The power of a connection has been shown to improve recovery outcomes. For example, Pang et al. (2006), found that married individuals appeared to have better recovery rates than people who were single, which suggests the power of a connection in the journey of recovery. This is also apparent in other difficulties, such as Addiction, and hence the success of Alcoholics Anonymous (AA) and groups alike (Pettersen et al., 2019). This connection may be harder to find in a society which is typically individualistic in its approach to wellbeing and support giving and seeking. This is particularly relevant for those with a diagnosis of psychosis, evidenced in a 2018 meta-analysis which found that loneliness was moderately associated ( $r .32$ ) with psychosis (Michalska da Rocha et al., 2018). Associations between environment and mental health have also been demonstrated within neighbourhood assessments, which have indicated an increased risk of psychotic disorders if there was a presence of social isolation or social fragmentation (Ku et al., 2021; Richardson et al., 2018), further compounded by socio-economic status (Lilford et al., 2020). Lim et al. (2018) suggest that the link between increased rates of psychosis and environment may be more complex than purely the isolation an individual feels. For instance, co-morbid mental health difficulties, perceived discrimination, stigma and poor social support also play a crucial factor in the sense of safety in engaging services, which is supported by this project.

To promote a sense of safety within society, one firstly explores the framework with which society's are orientated. An individualistic society can lend itself to the ideology that a "problem" resides within the individual, and therefore that individual's responsibility to manage, which for people from Black African or Caribbean/mixed Black ethnic backgrounds may translate to delaying help-seeking for fear of being labelled as responsible due to historical and institutional racism and injustices (Misra et al., 2021). Within a collectivist cultural framework, support is facilitated by

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bringing people together, and managing support with the community. An individualistic culture may feel blaming, which could delay help-seeking, giving rise to shame and stigma. It may also account for higher attrition rates within research (Weisman de Mamani et al., 2014). This argument provides evidence of more integrative, trust-building relationships in order to promote recovery.

Both the EP and SR place significance on the impact of relationship building and illness appraisal. The SR found trends in studies that yielded the highest recovery outcomes with an emphasis on relationship building (be that through peer, group or family). Edge and Grey (2018) also support this conclusion, suggesting that incorporating “shared learning” in family-based interventions, including acknowledging power dynamics, was favoured amongst those consulted in adapting FI interventions. This approach would also highlight what appraisal system is being used, and how best to use this to support the family (Upthegrove et al., 2013). Lysaker and Buck (2006) advocate for a reconceptualisation of support. They outline that recovery-focused psychotherapy could be advocated as a non-hierarchical dialogue in which practitioners help clients create their narratives, with the inclusion of community and professionals who take time to appreciate the nuances of the family and the impact of psychosis on the family. The impact on the family was found to be a huge factor within the EP. Themes concerning the reason for the onset of illness and how the family managed the illness featured in either delaying or accessing support. Other research has found that the impact of the family moderates help-seeking, contributing to delayed help-seeking (and consequently a worsening in symptoms) (Wong et al., 2020).

### **Strengths and Limitations**

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The SR followed a narrative synthesis of findings following an exclusion and inclusion criteria of studies. The research question was to ascertain the recovery outcomes of Black African, Black Caribbean or other mixed Black and Asian ethnic groups engaging in a psychosocial intervention for psychosis. Using a narrative synthesis approach allowed for an organic process in which findings were compared and contrasted based on the researcher's reading of the studies. This allowed certain nuances to be brought to the fore, such as the impact of the relationship and the participants' self-reported symptoms. In essence, this allowed the researcher to conclude the importance of relationships, connections and belief systems, a conclusion unlikely to be drawn if one were conducting a meta-analysis, for example. However, with any qualitative synthesis comes researcher bias. The researcher's position is grounded in social constructionism, which may lend itself more to understanding the nuances of experiences as opposed to the intervention; thus, making a conclusion based on experience may be more likely. However, one would argue that the researcher's position in assessing the quality scores of the studies presented within the SR mitigated this. Additionally, this approach was deemed necessary given how the participant's experience determined the outcome of their symptom management/recovery, and it is rather novel compared to previous literature.

Although quantitative methods are deemed as more objectionable and scientifically rigorous, that approach has not yet seen changes in the engagement or outcome of psychosis interventions for people from Black African, Black Caribbean or other Black mixed ethnic groups. Although a narrative and qualitative approach may bring unconscious biases and subjective criteria, a wider view of the interplay between historical, psychological, societal and cultural factors was able to be formed, in which quantitative methods have not been able to yet determine. Likewise with the qualitative EP, bringing inevitable subjectivity, it is arguably necessary to move forward within a quantitatively dominated field that has yet to improve access to services nor improved

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outcomes for Black African, Black Caribbean or other mixed Black ethnic groups who have psychosis.

Another factor worth considering is the impact of symptom severity on recovery outcomes, a variable rarely mentioned within the studies included in the SR. This would have been important given that research has found that people with a higher symptom severity have been associated with higher attrition rates, specifically for Black African and Black Caribbean ethnic groups (Maura & Weisman de Mamani, 2017; Maura et al., 2022). Maura & Weisman de Mamani (2017) discuss the possible reasons for this. Firstly, there is a lack of trust within services, the lack of family involvement, and the lack of connection/relationship with the service provider that may impact attrition rates. It appears that developing this sense of connection or a relationship could target many of the barriers faced in engaging with services for Black African, Black Caribbean or mixed Black ethnic groups who have psychosis. Whilst psychosis interventions have now focussed on a social recovery model, supported by clinical research (Hodgekins et al., 2015), the systemic framework should also be applied to how services engage individuals.

A similar study was conducted by Shefer and colleagues (Shefer et al., 2013), who found qualitative evidence of stigma and shame regarding the illness and protection of some spiritual or traditional methods of perceiving the illness, but it has neglected to extend this understanding into the wider context. Within the current EP, the extent to which generational events continue to impact the current understanding of mental illness and help-seeking behaviour is unpicked to an extent that provides an understanding that in order for services to adapt to meet the needs of Black African, Caribbean service users, and their families, a consideration of repairing old wounds needs to be addressed. Furthermore, this paper does not specify the participant's link to psychosis, and arguably, the current EP boasts a validity in speaking to family members directly involved.

### **Clarity of definition**

Within the SR, there were limitations. For instance, the vague or purely diagnostic definitions of recovery (e.g., using outcome measures), the vague or broad definitions of diagnosis, and ethnicity. This was problematic for the review, which aimed to examine the specifics of these variables. As outlined in the SR, the definition of recovery was designed to capture recovery and how functioning had returned or improved as an intervention outcome. In many studies, the psychosocial functioning of individuals was reported, however, via a clinical measure, which was either not validated in groups of different ethnicities or did not match self-reported measures of symptom recovery. This may represent how complex this research field is, which deserves a more in-depth understanding of the mechanisms of barriers and facilitators to accessing services. This also may highlight how, despite a wealth of literature, limited changes have been seen in the clinical population. On the other hand, it may illustrate a complex multi-layered knowledge base that is difficult to conceptualise within one study. The current SR aims to resolve some of these difficulties by enquiring into the more dynamic processes that cannot be measured (such as building connection, satisfaction of the intervention and belief regarding psychosis onset), hoping to provide understanding in the continued under-representation of people from Black, African and Caribbean ethnic groups (Ngui et al., 2010).

### **Recruitment**

The above discussion may shed light on the difficulty that was encountered within the EP with recruiting. Initially, three participants were recruited over ten months, and then a further 7

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participants over an additional six months. The researcher utilised physical and virtual advertisements through forums, social media, external agencies, organisations affiliated with the University of East Anglia, and national schizophrenia and psychosis societies. After this was unsuccessful, the researcher conducted further preliminary research on recruiting Black African, Caribbean or other Black mixed ethnic groups. It was found that researchers immersing themselves in the culture and attending face-to-face events would be more successful in recruiting for academic purposes. This was then actioned by the researcher (See Chapter 6). Despite various methods to immerse in the community, recruitment was still slow. Difficulty in recruiting is not uncommon within empirical studies looking to recruit people from Black African, Caribbean or other mixed Black ethnic groups. It may hint at some of the systemic barriers (unseen and seen) in engaging in any hierarchical position (i.e., the researcher representing privilege, Whiteness and gender), as highlighted within this discussion. Initially, three participants were recruited from two mental health organisations and one from social media. Upon the correction period for the thesis portfolio, a further 7 participants were recruited solely from social media, with a dedicated campaign which included paid-for advertisements to a targeted audience based on a social media algorithm. The successes of using the internet for recruitment allowed a wider audience to be contacted; however, it may have also created a disconnect between researcher and participant. This was managed by a short introductory space to discuss the study before moving into the interview. Given the importance of connection and relationship building within this project and engaging Black African, Caribbean or other mixed Black ethnic groups, it may have been more beneficial to establish fewer but more meaningful connections with a chosen few organisations, as opposed to reaching out to multiple organisations that were unable to support the project.

Through reflective practice, the researcher wondered if there was an interface between what the researcher's ethnicity represented to people from Black African, Black Caribbean or other

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mixed Black ethnic groups. The researcher wondered if, by visual representation, contributed to the systemic justification of the barrier to engaging in services (Jost et al., 2000). The interface between clinician and patient has been researched, specifically in regard to ethnicity. Hypotheses have been made regarding the lack of effect on matching ethnicity with the client within the review (Weisman de Mamani et al., 2014). Research has found that within Asian cultures, there may be utility in having a bilingual clinician (and not necessarily ethnic matching), which promotes longer stays out of hospital and greater contact with community health services, with lower contact with crisis teams (Ziguras et al., 2003). Therefore, it may not be the ethnic representation of an individual or the researcher; it may be how understood that person feels through appropriate language. One would be inclined to suggest that a longer duration of time and dedication be made to immersing oneself within the community from which one wishes to recruit, to develop trust, a sense of security and rapport, and to utilise appropriate language.

### **Public Participant Involvement (PPI)**

To minimise unconscious bias, a public participant consultant was approached to aid the researcher in adapting the language on the interview protocol, participant information sheet and debriefing document. This was guided by the Health and Care Professionals Council (HCPC) standards of practice for psychologists and the BPS Code of Ethics and Conduct, which outlines that practising psychologists should ‘understand the need to act in the best interests of service users at all times’ (HCPC, 2016) and should always show ethical awareness of the engagement we have with others (BPS, 2021). This was seen as a relative strength of the project, as a consistent thread of reflexivity was utilised throughout to guarantee a minimisation of bias. However, this could have been improved with additional consultants, although, as mentioned earlier, this was also difficult to recruit.



### **Clinical Implications**

Many clinical implications arose from the conclusions made from this project. The Systematic Review and Empirical Paper suggest the importance of developing relationships and connections in promoting recovery for Black African, Caribbean or other mixed Black ethnic groups who have psychosis, a group that is recognised to experience complex and structural inequalities of healthcare relating to their diagnosis of psychosis. It is pertinent that changes are made to meet the needs of every diverse group in society. It appears that where previous research had been lacking was addressing the gap between symptom onset and accessing services. From this project, the researcher concludes that it is the need to engage people from Black African, Caribbean or other mixed Black ethnic groups in developing consultations on psychosis services, and to develop trust that needs to happen first and foremost. The participants in the study suggest that service-users' involvement needs to be taken more seriously and implemented routinely in developing services and interventions to help identify some of these social and structural barriers to engagement. Research has found that the most effective way to tackle stigma is to educate, create awareness and contact the individuals who have been stigmatised (Rusch et al., 2005). This creates value within the community through supporting empowerment and understanding. The system justification theory (Jost & Burgess, 2000) posits that phenomena exist within the system because it maintains it. By inserting meaningful change and dissolving power dynamics (i.e., services versus people), an alliance could be formed that integrates belief systems and encourages links with the community. This would nudge the system in maintaining a change, that feels valuable, deconstructing the cycle of stigma, perceived racism and a lack of engaging in services.

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The EP also highlighted that participants were passionate about reforming the police's response to those who are experiencing distress. Participants shared that creating awareness of how a punishment-based, and paternalistic response may impact someone later in life, and activate past racist or discriminatory generational experiences. There needs to be cultural sensitivity education for police officers, who often have first-hand contact with people who are experiencing distressing symptoms from psychosis, to manage and approach with kindness. This is important given the historical and current divide between authority and people from Black ethnic groups. To support engagement in psychosis services, the historic and cultural chasms between policing, healthcare, and Black African, Black Caribbean, and other mixed Black ethnic groups need to be reduced (Bowleg et al., 2022).

Reflecting on recruitment difficulties, it also appears important for researchers and clinicians to immerse themselves in communities. This is important to create connections and safe points of contact with the aim of establishing trust and collectively standing against systemic racism and structural inequalities (Lawrence et al., 2021). Given the importance placed on belief systems from the systematic review, it may also be important to showcase that all explanations for illness are represented within mental health support services, to encourage inclusion and ease of access to engaging with services. Research into early intervention into psychosis for Black African, Caribbean or other mixed Black ethnic groups suggests that the integration of spiritual leaders may lead to treatment delays (Islam et al., 2015). However, there is also research to suggest that the outcomes of interventions that integrate spiritual leaders within medical models achieve positive recovery outcomes for psychosis for Black African, Caribbean or other mixed Black ethnic groups, which is also cost-effective (Gureje et al., 2020). Incorporating belief systems could foster joined-up care that advocates for more cohesive interventions and recognition of Black ethnic groups'

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needs. This would create respect and dismantle the current perceived system based on Western White majority systems.

The systematic review highlighted a discrepancy between the definition of recovery and the lived experience of self-reporting the quality of life after an intervention. The most used outcome measures within clinical practice are clinical, which provides the foundations of NHS targets and key performance indicators (KPIs). Considering the importance placed on the quality-of-life ratings, it may be beneficial to supplement clinical outcome measures with quality-of-life/self-report measures to ascertain individuals' perception of the intervention's success, not merely symptom management rating. This is important because research has found that clinical outcomes do not accurately reflect individuals' perceptions of their recovery (Lam et al., 2011).

Creating change to the system could create organisational challenges. The NHS has promoted short-term interventions for psychosis, such as CBTp which should be delivered for 16 sessions (NICE guideline 1.3.7, 2014). This has a consistent evidence base of a small to medium effect size of the effectiveness of therapy (Hazel et al., 2016), yet what is reported as the most important factor for participants is the impact of the therapeutic relationship (Messari & Hallam, 2003). Additionally, the small to medium effect size suggests that this will not help everyone who presents with psychosis. Again, adapting therapies is ideal for people who are already engaged in a service; however, this is not the case for Black African, Caribbean or other Black mixed ethnic groups. An initiative to challenge the established systems, by integrating care teams and spiritual healers could create organisational as well as personal resistance to change, and indeed a fear of failure and reasonability as a result (Menziés, 1960). Change threatens an already established system, which may partly explain some of the failings so far. Thus far, the approach is to “add” to what has already existed, instead of using new ideas to understand what needs to be done to create

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meaningful change, which can mean a dismantlement of the system. Integrating the community and religious/spiritual leaders within systems or creating new systems encompassing these values could offset an initial higher expenditure with longer-term remission rates and reduce reoccurring admissions to inpatient hospitals. By encouraging a model of joined-up care, inpatient admission and detentions under the Mental Health Act may reduce, limiting further distress whilst creating closeness, reducing the systemic divide. This could also be an exciting opportunity to develop more trusted and connected relationships with other spiritual professionals and alternative methods to support people of Black ethnic groups with psychosis.

Considering the aforementioned clinical implications, it would be advantageous to measure the outcomes of these new initiatives. For instance, a service audit may be helpful to capture the outcomes of integrating care systems by measuring clinical and self-report post-intervention reports (e.g., Quality of Life questionnaire, Positive and Negative Symptom Scale (PANSS) and Goal-Based Outcome measures), satisfaction reports, the frequency of diverse ethnic groups accessing the services and on attrition rates.

### **Future Directions**

The systematic review revealed inconsistencies in defining ethnicity and recovery within studies. This proved problematic when determining the validity of reported recovery rates and satisfaction with such therapies. Therefore, it would be beneficial that the meaning of mental health recovery for Black African, Black Caribbean and other Black ethnic groups would be important to develop, as recovery is context-specific. Psychosis research and clinical practice involving ethnic minority groups should routinely include patient-reported outcome measures, and these should be analysed and compared by ethnic group to establish if there are differences. In addition, it may be

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beneficial to conduct a study using clinical outcome measures alongside self-report, goals-based or quality-of-life measures to assess the internal consistency of reporting outcomes from interventions for psychosis. It would also give an insight into what the participants vocalised as an important factor in establishing or moving towards recovery from psychosis. Clinically, this would also be advantageous to use as a benchmark for creating further meaningful change in a client's life. Additionally, CBT was found to have positive outcomes in the management of psychotic symptoms, however lacked evidence to suggest sustained long-term outcomes. Simultaneously, EI and FI interventions appeared to provide positive symptom management yet with high attrition rates. Further research would be advantageous to determine the underlying reasons why and isolating the power of a relationship in moving towards recovery from psychosis in Black African and Black Caribbean, and Asian populations. An idea to pursue may consist of conducting focus groups or group therapy initiatives to understand the underlying mechanisms of change and observe the impact of the therapeutic relationship. This may come with some challenges, such as isolating the relationship's impact versus the effects of the group dynamics. One could isolate this by conducting a between-groups design, where one group is allocated a consistent therapist who incorporates the belief system and spends time developing rapport, connection, and trust. The control group is assigned group therapy, in which the impact of the connection between peers and the therapist can be determined.

The empirical paper's largest limitation may have been the sample representation, which included predominantly female-identified carers ( $n=7$ ) versus male-identified carers ( $n=3$ ). However, according to Carers UK, women are more likely to provide unpaid care compared to men, and therefore a 70/30 split may be more representative of this particular group. However, it may be advantageous to cross-reference the findings of this empirical paper to an NHS-recruited sample to understand the differences between those who have difficulty engaging in services versus those who

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are already engaged. Further research would benefit from expanding the sampling population (gender and age). Future research would have to incorporate methods of recruitment to allow additional participation to be achieved. For instance, immersing oneself in the community for a longer period and consistently creating communication with spiritual leaders and churches. In terms of therapeutic engagement, it appears it may be beneficial to conduct therapy within safe places, perhaps in a non-clinical setting such as faith centres, which remain confidential and physically safe where interventions and contact could be carried out. This may help bridge the gap between the perception of services and the internalised stigma that one may feel, which stops them from accessing services. Some ideas of non-clinical settings could include places of worship and community churches.

### **Conclusion**

The project overall revealed the benefit of using systemic frameworks to conceptualise distress; it may be beneficial to apply this in other areas of mental health to improve access to services, such as reducing the hierarchical dialogue between patient and therapist, as recommended by Lysaker and Buck (2006). A theme amongst the research found the benefit of building relationships. However, consideration must be taken as the review found limited eligible studies, and further research is needed specifically to explore the outcomes of people who are Black African and Black Caribbean, and Asian ethnic groups who have psychosis. It appears important to re-structure systems to incorporate the importance of building trust between professionals and religious leaders to engage cultures whereby which is a fundamental feature of wellbeing.

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**Appendices**

<b>Appendix</b>	<b>Description</b>
A	Journal submission guidelines for Systematic Review (Clinical Psychology Review)
B	Quality Assessment Scoring guide for Systematic Review
C	Quality scoring of papers included for review
D	Outcomes and Limitations of Studies included for review
E	Journal submission guidelines for Empirical Paper (Journal of Cross-Cultural Psychology)
F	Interview schedule and Protocol
G	Informed consent document
H	Quality Assurance Guideline Steps Taken Sensitivity to Context
I	Visual representation of thematic generation
J	Hypothesised systemic feedback loop
K	Social Media Advertisements

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**Appendix A: Journal submission guidelines for Clinical Psychology Review (for Systematic Review)**

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reproducibility and data reuse, this journal also encourages you to share your software, code, models, algorithms, protocols, methods and other useful materials related to the project.

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**Appendix B: Quality Assessment Scoring guide for Systematic Review**

Question	Point System	How to Score
<b>Q1 - Age</b>	Reporting Age Metrics (0-1)	1 = reported Age, 0 = No reporting of Age.
<b>Q2 - Gender</b>	Reporting Gender Metrics (0-1)	1 = reported Gender, 0 = No reporting of Gender.
<b>Q3 - Ethnicity</b>	Reporting Ethnicity Metrics (0-1)	1 = reported Ethnicity, 0 = No reporting of Ethnicity.
<b>Q4 - Diagnosis</b>	Reporting diagnostic criteria (0-1)	1 = reported Diagnosis, 0 = No reporting of Diagnosis.
<b>Q5 - Confounding Variables</b>	Reporting Confounding variables (0-1)	0 = no reporting or acknowledgement of confound Variables. if acknowledgement of confounding = 1
<b>Q6 - Confounding Variables 2</b>	Managing for confounding variables (0-1)	If participants could switch between intervention groups then associations between intervention and outcome may be biased by time-varying confounding. This occurs when prognostic factors influence switches between intended interventions. Or outcome could be influenced by other confounding variables such as medication use, external input, support etc. = 0. If participants did not switch up groups, or researchers managed by performing analyses = 1.
<b>Q7 - Analysis Methods</b>	Reporting Analysis Measures (0-1-2)	0 = if measures are inappropriate or failed to consider major confounding variables (major confounding variable is one that would have a difference on the overall outcome). 1 = analysis method appropriate, but failed to consider confounding variable, 2 - Analysis appropriate and considered and accounted for confounding variables i.e. medication implications, baseline and follow up etc. Even for qualitative studies, were there sufficient parameters taken to ensure lack of confounding variables as much as possible?
<b>Q8 - Recruitment Bias</b>	Recruitment (0-1-2)	0 = if participants were selected on the basis of their characteristics before the start of the intervention/study? 1 = sampled through advertisement/snowballing methods, 2 = randomised (NB: Qualitative studies will score a 0 in this category, it does not necessarily reflect a poor recruitment method, but merely the rigour of which it as done and what is appropriate for that study).
<b>Q9 - Control Group</b>	Control Group (0-1)	0 = No control group or insufficient detail on control group and therefore can not make a valid conclusion on the outcome of the study, 1 = Control group used and sufficiently stated.
<b>Q10 - Baseline measures</b>	Baseline (0-1)	0 = No baseline measure or post intervention taken, 1 = baseline measure and post-intervention taken
<b>Q11 - Outcome measure</b>	Outcome Measure (0-1-2)	0 = Intervention not measured in terms of psychosis recovery/outcome symptoms, 1 = Intervention measured via recovery outcome, but may be limited to account for all experiences (i.e. quality of life, or qualitative measure to determine participant view), 2 = psychosis measure as well as participant view.
<b>Q12 - Participant bias</b>	Participant Bias (0-1)	1 = Participant may have knowledge of intervention beforehand, potentially incurring order effects or placebo, 0 = participant has no knowledge of intervention (For Qualitative studies, this will score a 0.) <b>(Reversed scored)</b>

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## Appendix C: Quality scoring of papers included for review

Study no.	Author	Q1 Age	Q2 Gender	Q3 (Ethnicity)	Q4 (Diagnosis)	Q5 Confounding variables (do they acknowledge confounding variables?)	Q6 (manage confounding variable)	Q7 - Does analysis control from CV (0-2)	Q8 - recruitment bias (0-2)	Q9 - presence of control group 0-1	Q10 - baseline measures	Q11 - outcome measure to include participant perspective (0-2)	Q12 - ppt bias, did they know ? (Reversed)	Q total (out of 14)	% (1dp)
1	Gillard et al. (2022)	1	1	1	1	1	1	2	2	1	1	1	1	14	100
2	Grant et al. (2012)	1	1	1	1	0	1	2	0	1	1	1	0	10	71
3	Gureje et al. (2020)	1	1	1	1	1	1	2	0	1	1	1	0	11	78
4	Lin et al. (2013)	1	1	1	1	0	0	0	2	1	1	0	1	9	64
5	Malla et al. (2020)	1	1	1	1	1	0	2	1	0	1	1	1	11	78
6	Ngoc et al. (2016)	1	1	1	1	1	1	1	1	1	1	2	0	11	78
7	Rathod et al. (2013)	1	1	1	1	1	1	2	0	1	1	1	0	10	71
8	Tan & King (2013)	1	1	1	1	1	1	2	2	1	1	0	1	13	93
9	Weisman de Mamani et al. (2014)	1	1	1	1	1	1	2	1	1	1	2	1	14	100
10	Wong et al. (2019)	1	1	1	1	0	0	0	2	1	1	0	1	9	64
Combined score	<b>TOTAL</b>	10	10	10	10	7	7	15	11	9	10	9	6		
	<b>Total possible</b>	10	10	10	10	10	10	20	20	10	10	20	20		
	<b>% (1dp)</b>	100	100	100	100	70	70	75	55	90	100	45	30		

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## Appendix D: Outcomes and Limitations of studies included for review.

Author	Outcome	Author comments	Limitations/Comments	Quality score	Themes
Gillard et al. (2022)	In the peer support group, 136 (47%) of 287 patients were readmitted at least once within 12 months of discharge. 146 (50%) of 291 were readmitted in the care as usual group.	The model underpinning the intervention presumes that peer support begins with building trusting relationships on the basis of shared lived experience, and the assumption was that this would happen while the patient was still in the hospital. Unable to interview around 48% of patients face-to-face at the 4-month follow up.	First, many patients might not have had the opportunity to establish a good relationship with the peer worker (the relationship is featuring highly here too).	14	Assumptions made around establishing therapeutic relationship but no guarantee this happened.
Grant et al. (2012)	Patients treated with cognitive therapy showed a clinically significant mean improvement in global functioning from baseline to 18 months that was greater than the improvement seen with standard treatment.	Use of the newly developed Schizophrenia Outcomes Functioning Interview and Clinical Assessment Interview for Negative Symptoms is warranted in future clinical trials of CT.	Positive symptoms reduced. GAS includes symptoms in the ratings and, as such, is not a pure measure of functional outcome. Non-specific factors could have influenced the conditions, for instance the CT condition had more contact time than the control, which may have impacted group differences. Both clinician and patient were aware of conditions, so there is potential for order effects.	10	Relationship and "contact" time may have impacted findings
Gureje et al. (2020)	From baseline to post intervention score (6 months) on the PANSS, results went from 107.3 (SD 17.5) to 53.4 (19.9). The control group went from 108.9 to 67.6. Both positive and negative symptoms improved.		Bias - The providers were given incentives to make the visits to the TFH facilities and medications were provided free for the purpose of the trial. In Nigeria, as opposed to Ghana, patients would have had to pay for these medications. Additionally, there was a decrease in scores in the control group, which mean there was some mechanism creating change in the non experimental condition?	10	Bias and unexplained improvement in control group
Lin et al. (2013)	Improvements in knowledge, attitudes towards medication, insight - no difference found on the brief psychiatric rating scale. For each interaction	Small $n$ = limits statistical power.	Not specific psychosis measure? As substance misuse, low education level was included in the criteria which limits the study generalisability.	9	Improvements in knowledge, but not translated across all
Malla et al. (2020)	Improvement in negative symptoms no differences in positive symptoms. Family support was higher in Chennai than in Montreal at month 3. Improvement was greater in Montreal for positive symptoms ( $\eta^2 = 0.19$ ) and in Chennai for negative symptoms ( $\eta^2 = 0.08$ ).		All participants were on medication. Family support was measured via a service provider - is this reliable?	11	Differences in symptom presentation?
Ngoc et al. (2016)	There were significant treatment effects (moderate to large $R = 0.08$ ) on: (1) quality of life, (2) stigma, (3) medication compliance, and (4) consumer satisfaction.		Only focussed on recent onset schizophrenia, small $n$ size. contextual/location impacts on recovery rates	11	
Rathod et al. (2013)	CaCBTp group resulted in higher scores post intervention on recovery than control group.	Some long term benefits sustained, but lower scores on PEQ were not sustained long term, authors suggest that 16 sessions was not enough.	9% attrition rates in both groups. Did not directly compare CBT with CBTP. There were significant differences at baseline. Satisfaction from ppts received and correlated with the success of the intervention. Also didn't compare ethnic differences, which was the aim the study.	10	Satisfaction
Tan & King (2013)	Participants who received cognitive remediation had significantly greater improvement in all neurocognitive domains. Furthermore, the cognitive remediation group achieved greater attainment of vocational or independent living skills and better functional outcomes at post-intervention and at the end of the 1-year follow-up.	improvement was less marked during the follow-up phase, even though participants were continually reminded of the strategies. This might be due to either ceiling effects reached during the intensive computer-assisted phase, or it might be that any further gains would require a change in the intervention.	Attrition 29% (attendance was required daily - this is not very practical for people).	13	Living skills/functionality improvements. Perhaps an effect of being part of a community



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Weisman de Mamani et al. (2014)	Patient ethnicity and patient-therapist ethnic match (vs. mismatch) did not relate to treatment efficacy or satisfaction with the intervention.	Not always blinded to condition. Another study limitation is that cultural mechanisms of change were not directly assessed.	Twenty-three families dropped out! 25 were in the CIT-S condition and 21 were in PSY-ED who remained. CIT-S yielded a medium effect size in reducing symptomatology.	14	Large drop out rate? Lack of relationship? Cognitive effect?
Wong et al. (2019)	Patients received group CBTp (n = 25) showed significantly greater improvement in their delusion compared with those receiving PsyEdI (n = 23). Nearly 61% of patients in the group CBTp showed at least 50% reduction on their score	Mostly females - therapist had many years experience, and this may have had an influence on outcomes.	Group therapy in general has benefits (Unity, connection, togetherness etc.). No real control established in managing confounding and extraneous variables that could impact the results.	9	CBT- Positive symptoms decreased

**Appendix E: Journal submission guidelines for Journal of Cross-Cultural Psychology****(Empirical Paper)**

## Submission guidelines

## Manuscript Submission Guidelines:

*Journal of Cross-Cultural Psychology (JCCP)* publishes material in three categories: (1) regular, unsolicited manuscripts, (2) brief reports, and (3) special issues. We do not publish book reviews. Summary details of each category are as follows:

1. Regular, Unsolicited Manuscripts. This is *JCCP*'s main emphasis. See [Aims and Scope](#) for a detailed description of appropriate manuscripts.

Manuscripts should be submitted electronically to <http://mc.manuscriptcentral.com/jccp>.

Authors will be required to set up an online account on the SageTrack system powered by ScholarOne. Manuscripts will be sent out anonymously for editorial evaluation. Obtaining permission for any quoted or reprinted material that requires permission is the responsibility of the author. Submission of a manuscript implies commitment to publish in the journal.

Authors submitting manuscripts to the journal should not simultaneously submit them to another journal, nor should manuscripts have been published elsewhere in substantially similar form or with substantially similar content. Authors in doubt about what constitutes prior publication should consult the Editor.

Manuscript length should normally be 15 to 35 double-spaced, typewritten pages. Longer papers will be considered and published if they meet the above criteria. Manuscripts should be prepared according to the most recent edition of the American Psychological Association

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Publication Manual. Manuscripts are reviewed by the Editorial Advisory Board. Allow up to 3 months for a publication decision and up to 1 year for publication.

2. Brief Reports. Accepted Brief Reports should be no more than 10 double-spaced manuscript pages long, including title page, references and any tables.

3. Special Issues. An important part of *JCCP*'s publication policy is the periodic publication of special issues or special sections of regular issues. Current needs, emerging trends, and readership interest guide the publication of material in this category. Ideas or suggestions for special issues or special sections should be discussed with Walter J. Lonner ([Walter.Lonner@wwu.edu](mailto:Walter.Lonner@wwu.edu)), Founding and Special Issues Editor, or other members of the Editorial Advisory Board, especially current Editor, Deborah L. Best ([best@wfu.edu](mailto:best@wfu.edu)).

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## **Appendix F: Interview Schedule and Protocol**

### Joining the interview

Introductions - Hello, my name is Charlotte, and I am a trainee Clinical Psychologist. What's your name?

What's your understanding of my job role? Do you have any questions before we begin the interview?

I'd like to start off by thanking you for being a part of this process today. I do want to check with you that you have read the information that was sent to you via email. The consent and information sheet? Do you have any questions for me regarding those? Could you tell me what you understand about what it means to take part in the interview today?

**(if not reported above)** Finally, I want to remind you that you can withdraw at any point. If we start to talk about something you find uncomfortable or difficult, you can pause or stop the interview. If there's anything you'd like me to do if that happens, please let me know now. You're more than welcome to take regular breaks or pauses during the interview.

### Interview structure

*Psychosis*

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What made you want to take part in today's interview? (*Could you tell me more about that, empathise with emotion*)

*Understanding of psychosis, difficulties with terms, beliefs about psychosis and influences*

Some people have argued that the language used to describe psychosis is quite "medical", I

wondered what your thoughts were on the word "psychosis"?

Is there an alternative word or definition that would make more sense? (*I will use the*

*alternative word/definition throughout the interview*).

What is your understanding of psychosis? (*Has that changed over time?*)

*Service engagement, barriers and cultural influences*

There are a lot of people that don't access services when they experience psychosis or

unusual experiences, what are your thoughts around this?

How do you think culture or family backgrounds have an impact on this [service

engagement]?

Have you always thought like this? [have thoughts on this changed over time?] (*When did*

*you start to think differently?*)

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How do you see the local mental health services near to you? [how are support services for psychosis seen from Black communities] (*Follow up: Are they easy to access? What about services for psychosis?*)

How do you think your background has influenced the way psychosis is seen in your community or in your family, if at all?

How did you (or someone else) get support for their psychosis experience? [what are peoples experiences of support for psychosis] (follow up question; how effective was this for you?)

### *Impact of family on illness*

What did your family do or say when they knew of your (or close friends') psychosis?

This may be a difficult question, but has there ever been anyone in your family that has experienced psychosis? (*If so, what happened, where were they, where were you, do you know what their experience was like? what was that like for you?* )

### *Empowerment and reflections on experience*

Given all that you've told me and all that you've experienced, looking back, is there anything that you wish was different about how people addressed psychosis, or your

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individual experience? [Looking back at your experiences is there anything you'd like to share about how you would want things to be different?]

Is there anything you'd like to share about what you'd like others to know about your experience?

### **Closing down the interview**

- How have you found today?
- I have some organisations you could get in contact with if you'd like to talk about your experiences more, if you would like this. Sometimes when we talk about difficult subjects, it can emotionally affect us later on in the day or week, so I would just like you to be aware of those feelings and remember those organisations I spoke about earlier on.
- What are your plans after leaving this interview?



**Appendix G: Informed Consent Document****Informed Consent Version 3 - 10/05/22****CONSENT FORM**

**Title of Project: A qualitative study exploring the cultural perception of psychosis and its impact on pathways to care for Black African and Black Caribbean communities in East Anglia.**

Name of Researcher: Charlotte Taylor

Affiliate organisation: University of East Anglia, as part of the fulfilment of the Doctorate in Clinical Psychology.

Supervisor of the project: Dr Bonnie Teague

1. I confirm that I have read the information sheet (version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being effected.
3. I understand that I can stop or leave the interview/group at any time whilst its being conducted.

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4.I understand that the information collected about me will be used to support other research  
in the future and may be shared anonymously with other researchers.

5. I understand that my interview/group transcript will be audio-recorded and will be  
transcribed. I understand that my words will be anonymised and not linked back to me  
as an individual.

6.I agree to take part in the above study.

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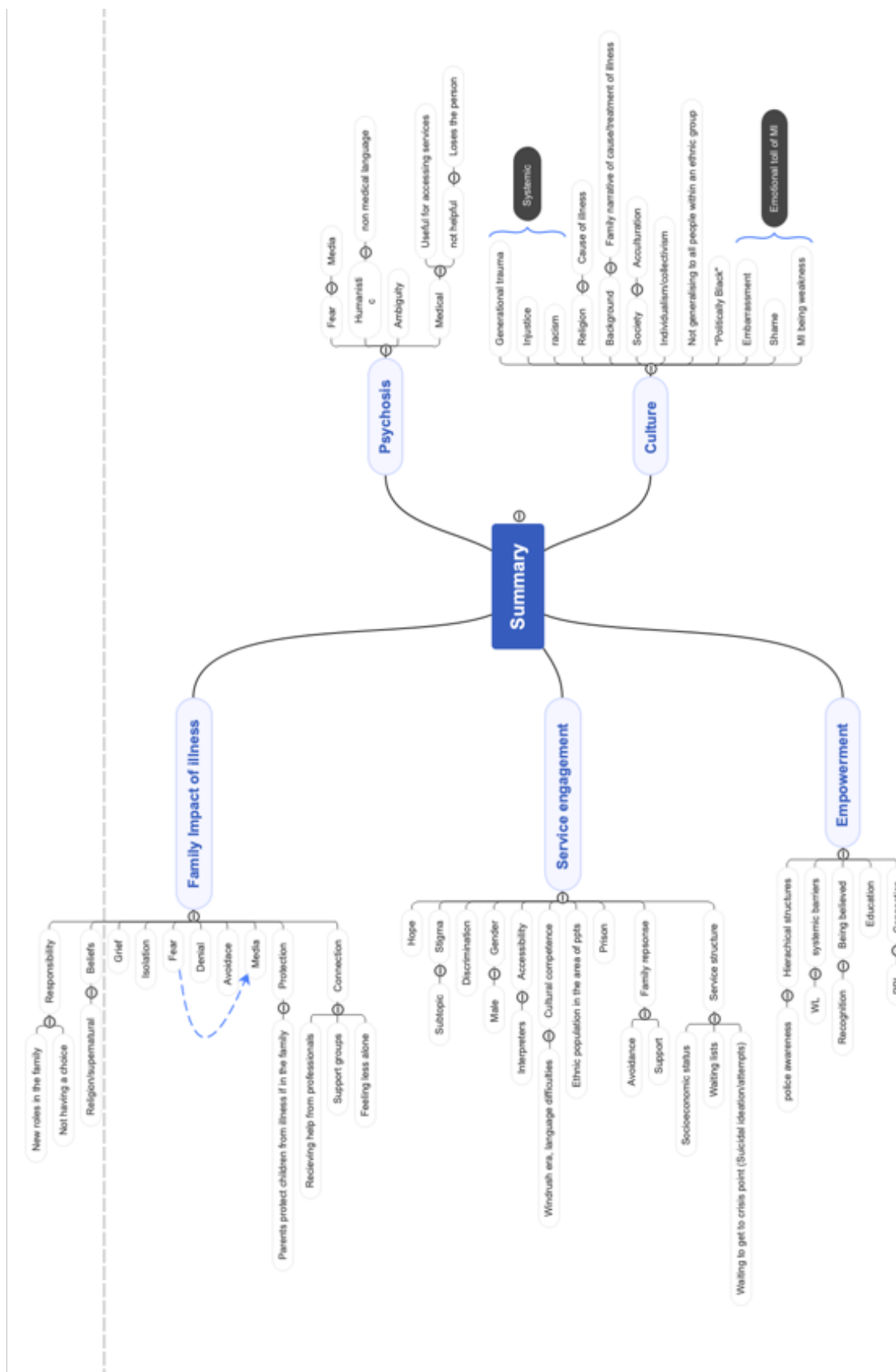
Name of Participant	Date	Signature
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**Appendix H: Quality Assurance Guideline Steps Taken Sensitivity to Context**

- In order for participants to feel as comfortable as possible, a range of options regarding the interview medium and was offered (in-person, video call or telephone call) and duration (offered the opportunity to break the interview into multiple sessions).
- 1:1 interviews allowed for privacy when discussing emotive topics (though the option to invite a friend/ family member/ carer was offered if this would enhance comfort).
- The use of empathy and respect was demonstrated for the participant in order for them to feel at ease, and empowered in what they would like to share.
- Rapport was built prior to commencing the interview to manage the power dynamic between the participant and the researcher.
- Pre-existing biases from researcher were managed by performing a systemic analysis of the interview transcripts, in conjunction with other members of the research team.
- To promote reflection and reflexivity, the researcher used a reflective journal in addition to reflective supervision. Reflections were considered in relation to the data and were often checked to ensure that they were grounded in the data.
- Participants will be offered an executive summary of the research upon completion.
- The findings of this research provide a new insight into the dynamic nature of engagement and disengagement based on systemic concepts within psychology, to help promote engagement in services.
- This research has given a voice to individuals who are often marginalised and unheard.

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Appendix I: Visual Representation of thematic generation summary



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**Theme generation**

Topic	Codes	Sub-themes	Theme
The utility of the psychosis diagnosis/Impression of psychosis	-Lived experience versus medical definition -Fear -Media portrayal of psychosis - Humanistic/person-centred language -medical jargon	-	- <b>The use of medical language to families</b> - what makes sense to the carer is different to what makes sense to medical communities – due to media, culture, understanding. - <b>Fear</b>
Pathways to care	Carer; -adjustment to new role within the family	- <b>Support</b> - <b>Feeling disbelieved</b> - <b>Impact of Race</b> - <b>Society</b>	- <b>Us and Them (Othering)</b>

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	<p>-Being advocate rather than family member</p> <p>-responsibility without choice</p> <p>-Feeling disbelieved</p> <p>-Support (when accessed is good, hard to access)</p> <p>-Accessibility</p> <p>Cared for;</p> <p>Care only in a crisis</p>	<p>- <b>Superficiality</b></p> <p>- <b>Police involvement</b></p>	<p>- <b>Care only in a crisis</b> (multi layered barriers to accessing helpful support, often through the use of police, which deters support. Evidence that care is good but hard to access)</p>
Family impact	<p>Making sense of psychosis – Belief systems (religion, witchcraft, “worrying too much”</p>	<p>- <b>Belief system</b></p> <p>- <b>Isolation</b></p> <p>- <b>“Why aren’t they listening to us?” pp6.</b></p>	<p>- <b>Hidden impact of illness on the family</b> (managing the new family member, grief</p>

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	<p>Support groups, not feeling alone (need of connection) Grief/adjustment to new family member Isolation</p>		<p>and adjustment to FM)</p> <ul style="list-style-type: none"> <li>- <b>The personal cost of psychosis</b> (care burden, including need for personal support, include support groups, need for connection).</li> <li>- <b>Identity</b> (not within solely the psychosis carer, but rather intersectionality of culture and ethnicity).</li> </ul>
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<p>Ideas for change/Reform</p>	<p>System barriers (crisis) Lack of gatekeeping information (PPI, share info, involve the carers in development of materials) Recognition as a carer Cultural competence Allowing mistakes to happen / Non blaming culture. Community support MH awareness and education</p>	<ul style="list-style-type: none"> <li>- Levelling the power imbalance (between us and them, co-creating, co-developing).</li> <li>- Recognition of hardship (carer)</li> <li>- Create a non-blaming culture (MH awareness mostly for police)</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Support</b> (pathway to care police versus community)</li> <li>- <b>Understanding</b> (include recognition as carer, cultural competence, allow mistakes, non-blaming culture, MH awareness)</li> </ul>
<p>Generational and societal interplay of</p>	<p>Generational transmission of</p>	<ul style="list-style-type: none"> <li>- Attitudes to illness</li> </ul>	<ul style="list-style-type: none"> <li>- Cultural understanding</li> </ul>



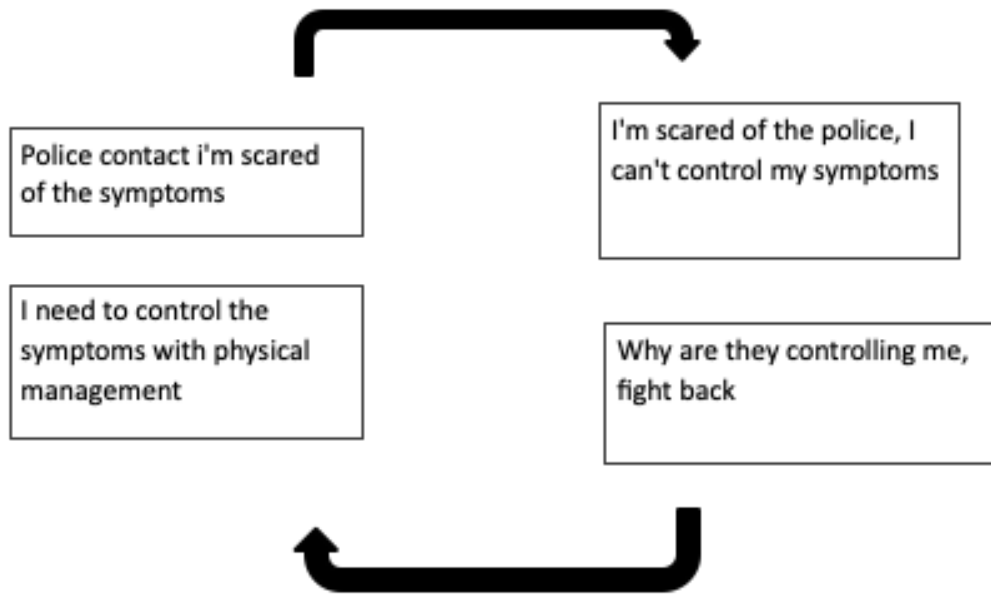
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<p>mental health perceptions</p>	<p>trauma (history of trauma in lots of families lives being replayed in accessing care) Families wanting to “push it under the rug”. Religious impact of illness Attitudes to illness shame Hidden Society – individualism versus collectivism Gender – Men looked at differently What does race mean? Politically versus identity.</p>	<p>(Culturally not accepted, seen as shameful). - Confusion around how to make sense of psychosis - Society - Race</p>	<p>of psychosis (Impact of generational experiences, impact of shame, how do we know when psychosis is spiritual versus medical?, society playing into help seeking – individualism versus collectivism). - The relevance of race (two pronged; race still being seen as other, versus why are we looking at race,</p>
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			it's become political?)
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**Appendix J: Researchers' hypotheses regarding the systemic feedback loop of the police in maintaining the disengagement from services for people of Black ethnic groups who experience psychosis.**



**Appendix K: Advertisement posters for the Empirical Paper, advertised over social media.**



By talking to you, we hope to increase our understanding of how society and cultural differences play a part in the experience of psychosis. Research has shown us that people from Black, African and/or Caribbean communities experience psychosis at a much higher rate than other ethnicities, but seeking care or support for psychosis has many barriers, including racism, stigma and shame. We want to know what you think, what could help and how society may play a role in this.

**To be eligible to take part in the study, you will need to be:**

## CULTURAL PERCEPTION OF PSYCHOSIS & THE IMPACT ON CARE PATHWAYS

- Over 18 years old
- Live in the UK
- Identify as Black, Caribbean or any other Black ethnicity.
- Currently or historically cared for someone who has psychosis from a Black, Caribbean or any other Black ethnic background.
- A carer in a professional and/or family capacity unpaid.

**Get in touch if you would like to be entered into a raffle where you could win £20!**

Get in touch via [c.taylor5@uea.ac.uk](mailto:c.taylor5@uea.ac.uk)