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Exploring Help Seeking Experiences of People from Black and Ethnic Minority Backgrounds with Psychosis.

By

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Thesis for the degree of Doctor of Clinical Psychology

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Abstract

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Experiences of psychosis are typically associated with auditory and/or visual hallucinations, emotional disturbances, delusions, disorganised thinking and speech. People from Black and ethnic minority backgrounds are more likely to have a high prevalence of psychosis when compared to their White counterparts. Research has also illustrated that there are clear racial and ethnic disparities related to accessing support for psychosis. There is a need to explore the experiences of people of a Global Majority when seeking help for psychosis and understand the barriers and facilitators that underly this process.

The first chapter of this thesis is a systematic review conducted to systematically identify and analyse qualitative research on the barriers and facilitators to accessing psychological therapies for people from an ethnic minority background, with an experience of psychosis. Nine qualitative studies were included in the review and a thematic synthesis revealed four themes: 'stigma and shame,' 'accessing support from non-clinical sources', 'negative experiences of therapists and wider services' and 'perceived benefits of psychological therapies and accessibility issues'. The findings from the review highlight the importance of understanding the barrier and facilitators to accessing psychological therapies to improve experiences within services and reduce the disparities of the uptake of psychological therapies for people from a Global Majority, with psychosis.

The second chapter focuses on the empirical study which explored the experiences of help seeking for people from Black African and Caribbean backgrounds. Fourteen participants were interviewed and four main themes were identified from the thematic analysis. The findings illustrate that the pathways taken by Black people to seek help and support for long term psychosis are multifaceted. Findings suggested that people from Black backgrounds sought support from different sources in order to manage their long-term psychosis (e.g., from family and friends, religious and spiritual practices, community organisations). The study highlights important clinical implications for services to improve.

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forauthors.html Author Guidelines for Journal of Black Psychology (Chapter 2)

https://journals.sagepub.com/author-instructions/JBP

Research Thesis: Declaration of Authorship

Print name: Christabella Van Laarhoven

Title of thesis: Exploring Help Seeking Experiences of People from Black and Ethnic Minority Backgrounds with Psychosis.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University.
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: .... Date: 17/05/2023

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Most importantly, thank you God for providing me with wisdom and strength. You have kept me at peace when everything around me was shaky. Through You, I can do all things.

Definitions and Abbreviations

CaFI	Culturally adapted Family Intervention
CBT	Cognitive Behavioural Therapy
CASP	Critical Appraisal Skills Programme
ERGO	Ethics and Research Governance Online
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NVIVO	Software program used for qualitative data analysis.
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	International prospective register of systematic reviews

Chapter 1 What are the barriers and facilitators to accessing psychological therapies for psychosis for people from ethnic minority backgrounds/of the Global Majority: A systematic review.

1.1 Abstract

Background: Research has shown that there are clear racial and ethnic disparities related to accessing psychological therapies for people of a Global Majority. This systematic review aims to understand the perceived barriers and facilitators people from ethnic minority backgrounds/of the Global Majority experience when accessing psychological therapies for psychosis.

Methods: A systematic and comprehensive literature search of electronic databases (PsychArticles, PsycINFO, CINAHL and MEDLINE) was conducted. A thematic synthesis was used to identify analytic and descriptive themes from qualitative research published on the topic.

Results: Nine articles were included in the review. Thematic analysis revealed four analytical themes related to the barriers and facilitators of accessing psychological therapies for psychosis. The themes included: ‘stigma and shame,’ ‘accessing support from non-clinical sources,’ ‘negative experiences of therapists and wider services’ and ‘perceived benefits of psychological therapies and accessibility issues’.

Conclusions: This review identified a range of barriers and facilitators to accessing psychological therapies for people of a Global Majority. It is recommended that services 3focus on reducing stigma, move towards collaboration with local communities and develop an understanding of cultural differences. It is hoped that the findings of this review will reduce the disparities within the uptake of psychological therapies for people from a Global Majority, with psychosis. Further research is needed to understand family/carer’s views and experiences on the barriers to psychological therapies and how they can also be supported.

Key words: barriers, facilitators, psychosis, ethnic minorities, psychological interventions, systematic review

Practitioner Points

- Training and reflective practice should be provided for clinicians to increase cultural competency.
- The impact of stigma of psychosis in ethnic minority communities should be considered to promote anti-stigma interventions.

1.2 Introduction

Psychosis refers to experiences associated with auditory and/or visual hallucinations (hearing or seeing things that are not present), delusions (false fixed beliefs), cognitive impairments and emotional disturbances such as anxiety and paranoia (Kuipers, et al., 2014). The conceptualisation of psychosis is typically considered from a medical model perspective, focusing on neurobiological difficulties located within the individual (Millar,2023). However, research has shown that there are a range of socio-cultural aspects that may explain experiences of psychosis (e.g., Adriaanse et al.,2015; Halvorsrud et al., 2019). Though the current literature utilises terms such as ‘mental illness,’ ‘patient’ or ‘psychotic disorders’, it should be acknowledged how such language can contribute to the construction of the medical model narrative that affects the people represented within this review (Huda, 2021). Given the historical/social context and stigmatisation of psychosis, the authors prefer to use the term ‘people with experiences of psychosis’ to capture the cultural variation of psychotic experiences (Millar, 2023). Whilst some of the studies within this systematic review describe participants as being part of an ‘ethnic minority’ group, this term assumes comparisons within majority White populations (e.g., Black/Asian people in the United Kingdom). Other studies in the review describe participants that are considered to be a majority in their country e.g., China, Nicaragua, and Pakistan. Consequently, the term Global Majority will be used in this thesis to describe all participants as it highlights the importance of recognising populations on a worldwide scale, rather than centring the narrative around Western/Eurocentric perspectives.

The experience of psychosis has been associated with an increased mortality and research has continuously shown that people from ethnic minority backgrounds are more likely to face higher rates of psychosis in comparison to people from white backgrounds (e.g., JongsmaKarlsen et al., 2021). People from an African and Caribbean background in particular face negative experiences to accessing care and may have poorer clinical outcomes (Degnan et al., 2023). People from ethnic minority backgrounds (also referred to as people of a Global Majority, Campbell-Stephens,2021) are also more likely to go through coercive pathways into mental health services for psychosis treatment relative to their white counterparts (Anderson et al., 2014).

It seems fair to propose that help seeking behaviour theories such as the Theory of Planned Behaviour (Azjen,1991) could provide an understanding of various factors that may influence how and whether people from a Global Majority access psychological therapies. The Theory of Planned Behaviour (Ajzen,1991) posits that individual behaviour is driven by behavioural intentions, which are influenced by three factors: attitudes toward the behaviour, subjective norms, and perceived behavioural control.

In the context of accessing psychological therapies for psychosis, the theory can provide an explanation for how the attitudes (e.g., beliefs about the effectiveness of therapy), subjective norms (e.g., cultural conceptualisation of mental health), and perceived behavioural control (e.g., perceived difficulty of accessing services) of people from a Global Majority can influence their intentions to seek psychological support.

There are clear racial and ethnic disparities related to the access to mental health services for psychosis. Findings from a cross sectional study revealed that people of a Global Majority who were experiencing psychosis were more likely to be prescribed pharmacological treatment and less likely to be offered evidence based psychological interventions such as cognitive behavioural therapy (CBT) and family therapy (Das-Munshi et al., 2018). This is despite recommendations by the National Institute of Clinical Excellence (NICE) guidelines that the management and treatment of psychosis should consist of CBT for psychosis with or without family intervention (NICE,2014).

A recent cohort study by Morris et al (2020) revealed that Black African and Black Caribbean people with psychosis were less likely to have received CBT whilst an inpatient and were also less likely to receive the recommended requirement of at least 16 sessions (in accordance with NICE guidelines) (NICE,2014). In addition, in comparison to white/white British patients, significantly fewer Black and other minority ethnic group patients with a schizophrenia diagnosis were able to access psychological therapy (Mercer et al., 2019).

Though the reasons regarding this stark inequality were not explored within these studies, previous research has identified potential underlying barriers to people of an ethnic minority to access mental health services such as stigma, language and communication issues, and cultural insensitivity (Memon, et al.,2016). The majority of these studies have employed quantitative methods (e.g., Oduola, Morgan & Craig, 2019; Schlief et al., 2023; Watson et al.,2022)and therefore the lived experiences and perceptions of people who encounter these inequalities are unclear. Although there are a few reviews focusing on barriers and facilitators to accessing psychological therapies and treatments (e.g., Adams & Young, 2020) they do not focus specifically on psychosis and include participants from ethnic minority backgrounds.

Regardless of the global nature of psychosis, research in this area has focused on Western/White populations and countries (e.g., Fernando, 2010; Stevović et al., 2022). This emphasis has resulted in a significant gap in the literature regarding the experiences of people from the Global Majority (those from ethnic minority backgrounds in Western contexts but are part of the majority population in the world).

Previous systematic reviews on accessing psychological therapies have provided evidence for a lack of access to recommended therapies for individuals experiencing psychosis (e.g., Ince et al., 2016), but these findings have primarily been based on studies conducted in the UK. This limited scope fails to capture the broader, global experiences of people from the Global Majority.

A recent systematic review by Burgess-Bar et al. (2023) highlighted that access to recommended therapies is limited and the implementation of psychological therapies for psychotic disorders is inadequate on an international scale. Their findings indicated that rates of receipt of recommended psychological therapies for psychosis were low across nine international countries. However, the review predominantly included studies from European countries and did not cover regions in Asia, Africa, or South America. This Eurocentric perspective highlights the necessity of a more inclusive, global understanding of the implementation and access to evidence-based therapies.

The current systematic review focuses on exploring the barriers and facilitators to accessing psychological therapies for psychosis for people of Global Majority. To the author’s knowledge there have been no previous reviews exploring this important topic area. The aim of the review is to systematically identify and analyse evidence using a systematic approach, and to answer this research question: ‘what are the barriers and facilitators to accessing psychological therapies for psychosis for people of a Global Majority. Findings were synthesised using a thematic synthesis approach to improve and contribute to the understanding of the barriers and facilitators influencing access to psychological therapies for people of a Global Majority.

1.3 Methods

1.3.1 Search Procedure/Strategy

This review was conducted in accordance with the preferred reporting guidelines for systematic reviews and meta-analyses (PRISMA; Page et al., 2021) and the guidelines for conducting a narrative synthesis within a systematic review (Popay et al., 2006). The review protocol and strategy were registered on PROSPERO on the 23rd of November 2023. (PROSEPRO ID: CRD42023485867). A systematic and comprehensive literature search of four electronic databases (PsycINFO, Medline, CINAHL & PsychArticles) was undertaken in November 2023. In order to identify grey literature and minimise the risk of publication bias, the ProQuest database was also searched. The search strategy involved using both free text and subject headings. Free text keywords and subject headings were chosen to capture the main concepts of the review question. There were no restrictions on publication dates. Table 1 illustrates the search terms used across the databases.

Table 1 *Search terms used to identify papers for databases.*

	Free text	Subject headings
Terms for barriers and facilitators	Barrier* OR Obstacle* OR Challeng* OR Enabl* OR Disengag* OR Engag* OR Obstruct* OR Entry OR Access* OR participation OR Inequalit* OR Healthcare Disparities OR Hurdl*	"Boundaries (Psychological)" OR ,"Treatment Barriers") OR ("Health Care Access
Terms for psychological therapies	psycholog* intervention OR psycholog* therap* OR family intervention OR cognitive behavioural therap* OR dialectical behaviour therap*OR acceptance and commitment therap* OR Relaxation Therapy Or counselling	-
Terms for psychosis	psychosis OR Schizo* OR Psychotic Disorders OR Severe Mental Illness) OR AB (psychosis OR Schizo* OR Psychotic Disorders OR Severe Mental Illness OR enduring mental health OR first episode psychosis	Psychosis OR "First Episode (Disorders)") OR Schizophrenia OR "Serious Mental Illness"
Terms for ethnic minority	Minoriti#ed ethnic group*" OR "Minority Ethnic*" OR "Ethnic minorit*" OR "Black and Minority Ethnic" OR BME OR "Black, Asian and Minority Ethnic" OR "BAME" OR Global majorit* OR "racial* minority*" or "people of colo#r	DE "Racial and Ethnic Groups" OR DE "Minority Groups

1.3.2 Eligibility Criteria

Studies were deemed to be eligible for the current review if they met the inclusion criteria (see Table 2). Articles that employed quantitative methods and results, involved participants under the age of 18, with no experience of psychosis, and from a non-ethnic minority background were excluded. In addition, the review also excluded studies that were in languages other than English and did not focus on accessing psychological therapies.

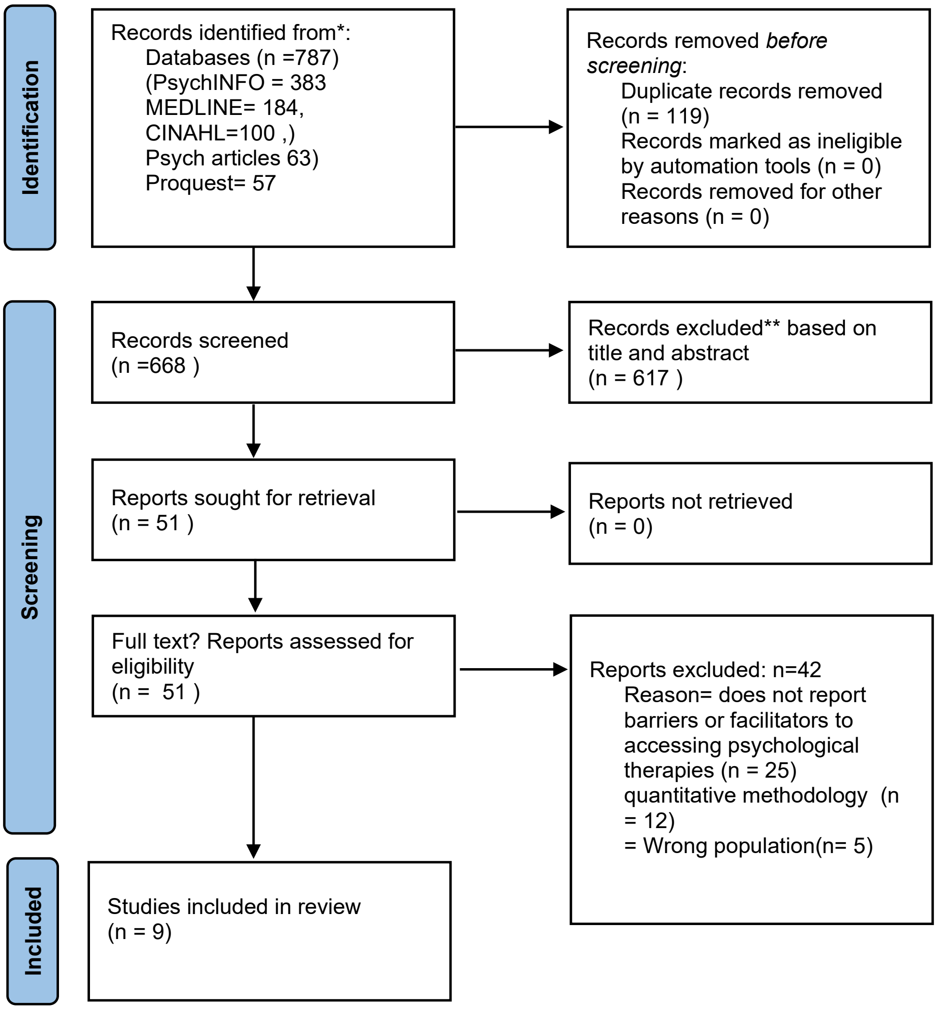
Table 2 *Inclusion and Exclusion Criteria*

Variable	Inclusion criteria	Exclusion criteria
Publication type	Qualitative research/studies, including focus groups and interviews. Mixed method research papers (only qualitative feedback extracted) Peer-reviewed publications in English No restrictions on publication dates. Grey literature	Studies that do not have qualitative results. Quantitative only studies. Studies in languages other than English. Conference abstracts Animal studies, letters, comments, editorials, books, opinion articles. Reviews, including non-systematic reviews.
Population	Adult population (aged 18 or over) with direct experience of psychosis (e.g., schizophrenia, schizotypy, schizoaffective and other psychotic disorders)	Participants not from an ethnic minority background and are under the age of 18. Participants without direct experiences of psychosis (e.g., carers, family, professionals) Participants with no diagnosis of psychotic disorder.
Intervention	Studies to include psychological therapies (e.g., CBT, family therapies, counselling) in reference to psychosis	Studies not relating to psychological therapies, or barriers and facilitators to accessing therapies
Outcomes of interest	Studies and/or intervention trials that have reported individual experiences in relation to accessing psychological therapies in a qualitative response	Studies that do not report individual experiences to accessing psychological therapies for psychosis a qualitative response

1.3.3 Study Selection and Data Extraction

Reference management software (Rayyan) was used to record the included and excluded studies (see Figure 1). The first stage of study selection involved the screening of titles and abstracts of articles. This was completed independently by the main researcher. Afterwards, a second reviewer independently screened ten percent of the titles and abstracts of the articles (n=66) with 93.8% agreement (Cohen’s kappa of 0.82), which is deemed to be a strong level of agreement (McHugh,2012). Disagreements regarding the inclusion of articles were discussed and resolved with the second reviewer. The second stage involved obtaining the full text of 51 articles, which were independently screened by the main researcher. Nine articles that met the eligibility criteria were identified to be included in the review. The last stage involved the extraction of qualitative data from the final nine papers, in order to gain rich insight into the barriers and facilitators of accessing psychological therapies for people of a Global Majority. The extracted data included the author, year of publication, study title, country of origin, research design, setting, participant characteristics and methods of analysis.

Figure 1 PRISMA diagram.



1.3.4 Quality Assessment

The Critical Appraisal Skills Programme (CASP, 2018) qualitative checklist tool for quality appraisal was used to assess the quality of the studies. The CASP tool has been recommended by Cochrane reviews and is commonly used in qualitative research. The tool consists of ten questions that evaluate the methodological aspects of each study and considers their strengths and limitations (Long et al.,2020). In order to reduce potential bias, the quality of the included studies were independently reviewed by the main researcher (CVL) and a research assistant. Any discrepancies in the CASP scores were discussed between the reviewers and resolved. Nine studies were appraised and received a minimum score of 8/10 (see Table 3). Any score above 7/10 was deemed to be acceptable.

1.3.5 Data Analysis

To synthesise the findings of the included studies, the extracted qualitative data from the nine studies were analysed using thematic analysis (Thomas & Harden, 2008). This analytic approach was chosen to provide a rich, in depth understanding of the experience and perspectives of people from racially minoritised backgrounds who, accessed psychological therapies for psychosis (Tong et al., 2012) by integrating the qualitative findings and identifying significant themes among the studies (Thomas & Harden,2008).

Based on the recommendations made by Thomas and Harden (2008), all qualitative results within the results section of the nine articles were used for coding and analysis. The process involved three stages: free line by line coding of texts, identification of descriptive themes and identification of analytic themes. The main researcher used NVIVO 14 to independently complete line by line coding for each of the included studies. The initial 'free' codes were then grouped together into related concepts and organised into descriptive themes. A total of 14 descriptive themes were developed and generated into analytical themes. The main researcher discussed this stage with the research team (TM and PP) in order to find agreement on the final analytical themes and to ensure descriptive themes appropriately captured the data. For this review, the researcher adopted a critical realist position. Critical realism postulates that knowledge is subjective and socially constructed, therefore in-depth experiences of people can be understood through the interpretative lens of the researcher (Maxwell,2012). The use of thematic synthesis is based on a critical realist approach, considering multiple viewpoints (e.g., people of Global Majority experiences of accessing therapy) and producing output that relates to a shared reality to inform policy and practice (Barnett-Page & Thomas, 2009).

1.3.6 Reflexivity

The concept of reflexivity has been argued to be an important part of qualitative research, and researchers need to be able to reflect on their own positionality and situatedness with the research they conduct and the impact this may have on the collection of data and interpretation. (Palaganas et al., 2017). Personal characteristics such as gender, race and culture can shape how the researcher makes meaning of findings due their specific world view, however, self-reflexivity can enhance the rigor of the research by acknowledging and monitoring potential biases (Dodgson,2019).

The researchers involved in this review are trained clinicians or are in the process of completing their doctoral qualification in the field of clinical psychology. They have had experience working with a range of service users experiencing psychosis and/or conducted research with participants with psychosis. The main researcher (CVL) is from a Black African background and has clinical and research experience working with individuals who experience psychosis. The researcher was aware and mindful of how their own experiences may influence on their interpretations of the data. For example, the researcher understood that they may interpret the data and explore meaning through a more empathetic lens, due to their own personal experiences of racism, their values and judgements regarding stigma and cultural conceptualisations of mental health. The subject area is also sensitive in nature and the researcher was aware of how their emotions may impact on what data they noticed initially or connected with. Therefore, the researcher kept a reflective log and utilised supervision during the data analysis process, to reflect on their own personal positioning in relation to the findings and how they made sense of the data. The researcher continued to revisit their biases and discussed their reflections with the supervisory team, in order to maintain reflexivity. The independent reviewer involved within this study did not have an expertise in this topic area to reduce potential bias.

Table 3 *Qualitative CASP Checklist*

Study	**1.Was there a clear statement of the aims of the research?**	**2. Is qualitative methodology appropriate?**	**3.Was the research design appropriate to address the aims of the research?**	**4. Was the recruitment strategy appropriate to the aims of the research?**	**5. Was the data collected in a way that addressed the research issue?**	**6. Has the relationship between researcher and participants been. adequately considered?**	**7 Have ethical issues been. taken into consideration?**	**8. Was the data analysis sufficiently rigorous?**	**9. Is there a clear statement of findings?**	**10. How valuable is the research?**	**Ratings**
Li et al. 2017	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	9/10
Naeem et al.2016	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	9/10
Islam et al, 2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/10
Phiri et al. 2019	Yes	Yes	yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	9/10
Rathod et al. 2010	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Carpenter-Song et al. 2010	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	9/10
Jensen et al.2021	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	9/10
Lyons et al.2022	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	9/10
Rathod et al. 2023	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10

1.4 Results

1.4.1 Study and Participant Characteristics

Nine articles were retained after the selection process (see Figure 1). All studies were journal articles, published between 2010 and 2023, employing qualitative methods, including focus groups (Islam et al.,2015; Lyons et al.,2022), semi-structed interviews (Jensen et al.,2021; Naeem et al.,2016; Phiri et al.,2019; Rathod et al.,2023), ethnographic approaches (Lin et al.,2017), and participant observation (Carpenter-Song et al., 2010). One study reported a combination of qualitative methods (semi structured interviews and focus groups, Rathod et al.,2010). The nine studies also reported a variety of data analysis methods including thematic analysis (Islam et al.,2015; Phiri et al.,2019; Rathod et al., 2023), systematic content and question analysis (Lin et al.,2013; Naeem et al.,2016; Rathod et al., 2010), framework analysis (Jensen et al.,2021), qualitative analysis (Carpenter-Song et al.,2010) and content analysis (Lyons et al.,2022).

Across the studies, a total of 190 participants were represented. Ages ranged from 18-79 years and both men and women were involved. Participants within the studies were from a range of ethnically minoritised backgrounds including African, Caribbean and South Asian. Studies were conducted with participants living in China (Lin et al.,2013), Pakistan (Naeem et al., 2016; Rathod et al.,2023=), the United Kingdom (Islam et al.,2015;Jensen et al., 2021;Phiri et al.,2019;Rathod et al.,2010), the United States (Carpenter-Song et al., 2010)and Nicaragua (Lyons et al.,2022). The studies reported findings from participants with direct experience of psychosis and were identified to have diagnoses such as schizophrenia, schizoaffective and delusional disorders. Detailed study and participant characteristics are shown in Table 4.

Table 4 *Study and Participant Characteristics.*

Author, Year	**Country of origin**	**Setting**	**Research design**	**Participant Characteristics**	**Analysis**	**Key findings: Main Themes**
Carpenter-Song et al. 2010	United States		Participant observation and conversation	N=25 Age= 26-69 Male= 13 Female= 12 Diagnosis: schizophrenia, schizoaffettive disorder Ethnicity: Latino, Euro-American and African American	Qualitative analysis	Key Themes: salience of biomedical perspectives Perspectives on mental health services
Islam et al. 2015	United Kingdom	EI service	Focus groups	Clinical sample: N=22 Male=N=11 Female N=11 Mean age = 22 years Ethnicity: British Pakistani, British Bengali, British African, British Caribbean.	Thematic analysis	Key themes: Help seeking Culture and beliefs Social stigma and shame Experience of EI service Improving BME access and experience of services
Jensen et al.2021[1]	United Kingdom		Semi-structured interviews	Service users (N=22) Male = 16 Female=6 Age not reported. Diagnosis: Paranoid schizophrenia, schizophrenia, schizoaffective, non-affective psychosis delusional disorder Ethnicity = Black British, White British and Black Caribbean, White Irish and Black Caribbean, Black Caribbean and South Asian.	Framework analysis	Key themes: Perceived benefits; Barriers and limitations to CaFI; and Delivery of therapy

Li et al. 2017	China	Outpatient clinic	Qualitative design. Ethnographic approach	Patients: N= 15 Male = 8, Female= 7 Mean age = 22 years Ethnicity= Chinese Diagnosis: schizophrenia/schizoaffective disorder or delusional disorder	Systematic content and question analysis	Key themes: Culture and related issues Stigma Issues related to system and resources. Understanding of illness, and beliefs about its causes and its management Assessment, engagement & adjustments in therapy
Lyons et al. 2022[1]	Nicaragua		Focus group	N=28 Male=11 Female=17 Age= 18-79 years. Diagnosis: Psychosis. Ethnicity: Nicaraguan. Race not reported	Content analysis	Key themes: the centrality of magical-religious forces, factors that precipitate the onset of psychosis, current management practices, barriers to the management of psychosis.
Naeem et al. 2016	Pakistan	Outpatient clinic of a psychiatry department	semi-structured interviews	Patients: N= 33 Male= 18 Female=15 Mean age = 32 years Ethnicity= Pakistani, south Asian Diagnoses: schizophrenia, schizoaffective disorder	Systematic content and question analysis	Key themes: Culture and religion Therapy issues Views about schizophrenia, its causes and its management Causes of illness Awareness of illness and pathways to care Management of illness

Phiri et al. 2019[1]	United Kingdom	Two study centres	Semi-structured interviews	Patients with a diagnosis of schizophrenia, schizo-affective, delusional disorders, or psychosis (n = 15) Gender and age not reported. Ethnicity= Black Caribbean, Black British, Black African, and Pakistani or Bangladeshi	Thematic analysis	Key themes: therapist awareness on culturally derived behaviours, beliefs and attitudes that can influence client response and participation in therapy
Rathod et al. 2010[1]	United Kingdom		Face-to-face semi-structured individual or focus groups	Patients with schizophrenia (n = 15) Age= Not reported Male= 9 Female=6 Ethnicity= African Caribbean, South Asian	systematic content and question analysis	Key themes: Health belief and attributions to psychosis Being arrested by the police Help seeking behaviours and pathways. Shame stigma Opinions regarding treatment and CBT. Barriers to accessing CBT. Validation Racism and it effects Role of religion.
Rathod et al. 2023	Pakistan	Mental health rehabilitation centre	Semi-structured qualitative interview	Individuals with a diagnosis of schizophrenia/schizoaffective disorder or psychosis, (n = 15). Age= 24-64 Female (n=4) Male (n= 11) Ethnicity: Pakistani	Thematic analysis	Key Themes: Philosophical orientation. Theoretical consideration. Technical adjustment. Practical considerations

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[1] Key demographics (e.g., gender and age) were not reported in these studies.

1.4.2 Quality Assessment Result

All of the papers scored 90% or more on the CASP quality appraisal checklist (see Table 2). A score above 70% was deemed to be of good quality. All of the studies clearly stated the aims and used appropriate qualitative methodology and research design. Four of the nine studies (Carpenter-Song et al.,2010; Islam et al.,2015; Jensen et al.,2021; Lyons et al.,2022) did not clearly report the reflexivity of the researcher. This was concerning as the studies involved interviewing participants from racially minoritised backgrounds, thus the consideration of the relationship between participants and the researcher(s) was important. It was unclear whether two studies considered ethical issues (Li et al., 2017; Naeem et al.,2016). Due to the high quality of the papers, no articles were removed.

1.4.3 Themes

Following the procedures of thematic synthesis (Thomas & Harden 2008), descriptive themes and four analytical themes were identified. The analytical themes were related to the barriers and facilitators of accessing psychological therapies for psychosis: ‘stigma and shame’, ‘accessing support from non-clinical sources’, ‘negative experiences of therapists and wider services’ and ‘perceived benefits of psychological therapies’. Additional quotations related to each theme can be accessed in the Appendix A.

Stigma and Shame

Stigma and shame were highlighted and reported by service users to be a barrier to accessing psychological therapies for psychosis and was a prominent theme in all of the studies. Stigma mainly appeared to be externally derived from their wider community or from the participants own family. For instance, a participant reported that negative labels placed upon them by others in their wider community can deter people from accessing psychological support:

*'The stigma to get labelled as mad refrain them from visiting the doctor. When you visit the psychiatrist or live in any rehabilitation centre it labels you as mad and society does not accept you as a normal person again, although a person is stable on medicine' (*Rathod et al.,2023).

Six studies (Carpenter-Song et al.,2010; Islam et al., 2015; Li et al.,2017; Lyons, et al., 2022; Naeem et al.,2016; Rathod et al., 2010 & Rathod et al., 2023) identified wider community stigma and highlighted the fears of participants revealing their diagnosis to others within in the community, due to potentially being judged negatively and treated differently. Li et al.(2017) discussed how patients and their families would often be worried about other people discovering their diagnosis and that they are seeking help and support for their mental health. As a result, it was reported that *'this hinders the initial help seeking as well as the follow-up visits for therapy.'* (Li et al., 2017). In addition, this external stigma influenced the participants likelihood of accessing treatment but also led to some avoiding services for support: *'Patients, carers and MHPs (Mental Health Practitioners) highlighted that mental illness was associated with being perceived as 'mad' by members of their wider community, which resulted in some avoiding mainstream services and presenting only when there was a crisis.'*(Rathod et al.,2023).

People also reported familial stigma that highlighted the judgement of receiving support for their mental health and also the negative consequences such as bringing shame to the family. Two studies (Rathod et al., 2010; Rathod et al., 2023) discussed this type of stigma experienced by participants. For example, it was reported that '*in the South Asian Muslim group, maintaining "family honour" by hiding anything that would be perceived as "disgrace to the community or family" is paramount to patients*' (Rathod et al., 2010).

Findings revealed that negative attitudes towards mental health difficulties and a failure to understand its impact on the individual's wellbeing, also played a role in whether individuals from a Global Majority would access psychological support. A South Asian participant stated *'[They don't understand] the actual problems that people get and how horrible it can be . . . They don't know how to identify it as well '*(Islam et al.,2015).

Furthermore, cultural explanations of mental health concerns appeared to exacerbate the stigma and shame experienced by participants, for example one stated that 'This *disease (schizophrenia) is caused by stress, problems in the society and family problems. I was forbidden to meet other people for three days because of their superstitious belief'* (Li et al., 2017). The findings from a majority of the studies (Islam et al.,2015; Li et al.,2017;Lyons et al.,2022; Naeem et al., 2016; Rathod et al., 2010 & Rathod et al., 2023) suggested that mental health conditions are often understood in the context of spiritual and religious beliefs and that external forces (e.g.,demons and supernatural entities) are an underlying cause, for example, Nicaraguan participants reported that psychotic symptoms were *a 'sign of witchcraft or Black magic'* (Lyons et al., 2022).

1.4.4 Accessing support from non-clinical sources

The second theme consists of service users' experiences of accessing psychological support for psychosis from voluntary community organisations, religion/spirituality, and use of cultural practices. These' non-clinical 'sources appeared to be a facilitator for individuals with psychosis from a Global Majority accessing psychological support as may be their first step to gaining support.

Six studies reported that accessibility to religious and faith leaders appeared to be beneficial for participants and was perceived to be a source of emotional support (Islam et al.,2015; Li et al.,2017; Lyons et al.,2022; Naeem et al.,2016; Rathod et al.,2010; Rathod et al., 2023) The importance of religion and spirituality was discussed across the majority of the reviewed studies (Islam et al.,2015; Li et al.,2017;Lyons et al.,2022; Naeem et al., 2016; Rathod et al., 2010 & Rathod et al., 2023). For some participants, being involved in spiritual practices such as prayer was an early step to receiving support during a crisis before accessing psychological support from mental health services. A participant highlighted this and stated:' *I first pray to God, he is the doctor par excellence; and when I am stressed because of school and work I go to the church to seek for hope, my family and the church leaders'* (Lyons et al.,2022).

It was reported that accessing support from religious leaders provided emotional peace *'This included visiting multiple faith and spiritual healers. For most, this practice proved to be beneficial and positive in bringing solace'* (Islam et al.,2015). Religious support was deemed to be very beneficial for participants. Some participants combined psychological therapy with faith and spiritual elements using collaboration between mental health professionals and religious leaders to better understand religious perspectives on mental health (Rathod et al., 2023).

Two studies included descriptions related to the use of cultural practices by individuals and their families. Their findings clearly suggested that service users sometimes preferred to access traditional non-scientific support for their mental health and avoided using mainstream services (Rathod et al., 2010,). It has been suggested that seeking traditional cultural avenues (e.g., homeopathy, traditional healing treatments) is a barrier to accessing psychological therapy due to delay caused for mental health treatment (Rathod et al.,2023). However, in Rathod et al., (2023) study, it was also reported that traditional healers would use psychotherapeutic methods of prayers to manage individuals' mental health concerns. Therefore, it is possible that cultural practices may be regarded as a source of emotional support for individuals from ethnic minority backgrounds.

Other informal structures of support also appeared to be a facilitator to enabling participants to engage and access psychological therapies. It was highlighted by the majority of the studies that familial support and decisions were vital in the process of accessing support (Carpenter-Song et al.,2010; Islam et al.,2015; Li et al.,2017; Lyons et al.,2022; Naeem et al., 2016; Rathod et al., 2010). One study (Naeem et al.,2016) discussed how the involvement of Pakistani families in the care of the patient would bring strengths to the therapy as they wanted to gain knowledge and join in with the therapy.

Practical support (e.g., providing finances or travel) from family and friends also played a crucial role in the facilitation of accessing psychological therapies and support. This type of support was important for individuals to be able to attend necessary appointments through the assistance of their support network (Islam et al., 2015; Lyons et al.,2022).

Additionally, engaging with voluntary community organisations gave individuals opportunities to access psychological therapies from spaces that were not considered to be mainstream. Experiences from such organisations were received positively by participants especially during periods of crisis, this was reflected by a Nicaraguan participant who stated that: ‘t*he therapies I have gotten at Cuenta Conmigo (third sector organisation) or have helped a lot’* (Lyons et al., 2022).

In contrast, three studies (Carpenter-Song et al.,2010; Lyons et al.,2022; Naeem et al.,2016;) included examples of participants experiencing a lack of support from their family and support systems. The inability to receive familial support was reported to be a barrier to seeking and accessing psychological therapies for some participants as it hindered their ability to be brought back for therapy (Lyons et al.,2022).

1.4.5 Negative experiences of therapists and wider service

Based on the findings of the studies, one of the main barriers to accessing psychological therapies, was the negative experiences of clinicians and wider services. Within the studies, participants were critical of the professionals’ cultural competency and the service provision such as lack of continuity and frequent staff changeover (Carpenter-Song et al., 2010; Islam et al.,2015). Participants reported that high staff turnover made it difficult for them to build trusting therapeutic relationships with staff and reported that repeating information to different professionals was traumatic*: ‘For me it was a negative thing because I wasn’t confident enough to disclose to someone who is new so I had to withdraw a bit’ (Black British-African service user)* (Islam et al.,2015) The importance of being able to relate to therapists was highlighted in two studies. It appeared that many participants had a preference to be treated and seen by professionals that understood what they were going through and were from a similar cultural and racial background as themselves (Phiri et al.,2019; Rathod et al.,2023).

Moreover, participants' criticisms of professionals included feeling 'controlled' by them and focusing too much on medication compliance (Carpenter-Song et al,. 2010; Lyons et al.,2022) This hindered some participants motivation to seek further support and left them critical of mental health services. In Carpenter-Song et al. (2010) study, one participant spoke about being concordant with medication as a means of staying out of hospital and protecting themselves '*against a corrupt mental health system'.*

The lack of understanding towards participants' culture was deemed to be problematic and also served as a barrier. Three studies illustrated the issue of participants being unable to connect with professionals due to this lack of cultural understanding and recognised that therapists need take into consideration the cultural and spiritual needs of people from ethnic minority backgrounds (Carpenter-Song et al.,2010 Islam et al.,2015; & Rathod et al., 2010). One of the reviewed studies also discussed how participants raised concerns about professionals avoiding important discussions surrounding racism, and how this negatively impacted on their engagement with therapy (Rathod et al.,2010)

Additionally other negative experiences that could be deemed to be a barrier included therapists lack of self-disclosure to the participants. A study by Phiri et al. (2019) Illustrates this and suggested that participants would test therapists in order to determine whether they could trust and engage with the therapist. Mistrust in services and therapists was described in two of the study's findings (Phiri et al.,2019; Rathod et al., 2010) and people from a Global Majority experienced frequent dissatisfaction with services which contributed to a lack of confidence when encountering mental health services. This issue reflected an overall obstacle to seeking, accessing and engaging with psychological therapies.

Alternatively, some studies did highlight some positive experiences. Receiving validation from therapists was appreciated by participants as this gave them the sense that they were being treated as people rather than ‘mental patients’ (Rathod et al., 2010). One of the studies (Jensen et al.,2021) discussed how services users valued being provided with choice, flexibility and a clear structure facilitated their ability to access psychological therapy.

1.4.6 Perceived benefits of psychological therapies and accessibility issues.

Being able to perceive benefits of psychological therapies was discussed as a facilitator for people wanting to access services and psychological support. Across a few studies, participants reported the benefits of a range of psychological therapies such as Cognitive Behavioural Therapy, Family Intervention and other talking therapies (Rathod et al., 2023; Jensen et al., 2021). One study also illustrated participants’ awareness and knowledge of psychological techniques that were deemed to be useful to them, for example distraction techniques (Lyons et al., 2022). Having this awareness of the benefits meant that some participants showed a preference for psychological interventions and wanted to talk to someone about their feelings.

Though there were many stated benefits for psychological therapies, some participants did not view their difficulties as a sign that something was wrong, therefore did not try access psychological treatment (Li et al., 2017). There was also a lack of awareness regarding the options and services available for support and therefore this served as a barrier for some participants (Islam et al., 2015; Rathod et al., 2023). Others were able to access psychological therapies such as counselling or relaxation therapy but were unable to see the benefits immediately (Islam et al.,2015).

Although some people were aware of the benefits of psychological interventions, there were certain barriers in place that made it difficult for individuals to access the support. One study highlighted personal issues such as lack of motivation and difficulty managing the symptoms of psychosis as a barrier to accessing psychological therapies. (Jensen et al., 2021). Other social and cultural aspects were also discussed, for instance it was apparent that participants and their family member avoided spending time in talking therapies due to language and communication difficulties with professionals (e.g., Li et al., 2017). In addition, low socio- economic status and finances were discussed to be an underlying reason as to why some people from a Chinese background were unable to access therapy. In addition, not being offered psychological therapy such as CBT and having limited access to these interventions was a huge hinderance to allowing people to receive the support they needed, especially to those who expressed a wish to receive it (Li et al.,2017; Naeem et al., 2016). Lastly, practical issues such as distance and being unable to travel to services was also a factor in contributing to the barriers faced by participants from a gGobal Majority (Li et al., 2017; Naeem et al., 2016).

1.5 Discussion

Previous research has consistently shown that people from a Global Majority are less likely to receive psychological interventions in comparison to their White counterparts (Schlief et al., 2023). These ethnic differences are problematic and can impact outcomes for people experiencing psychosis. This systematic review aimed to establish an understanding of the barriers and facilitators for people of a Global Majority accessing psychological therapies for psychosis, as the evidence within this area is limited.

Using thematic synthesis, nine qualitative papers were analysed and four analytic themes were developed to answer the review question. These were: Stigma and Shame, Accessing Non-Clinical Sources, Negative Experiences of Therapist and the Wider Services, and Perceived Benefits and Accessibility. Using evidence from qualitative findings, this review has made a valuable contribution to the evidence base, as the rich and detailed experiences of people from ethnic minority backgrounds were explored, which cannot be fully understood from quantitative studies (e.g., Dixon-Woods, et al., 2006).

The Theory of Planned Behaviour (Azjen,1991) offers a framework for understanding some of the barriers and facilitators to accessing psychological therapies for psychosis among people from the Global Majority. For instance, the review identified participants' attitudes and experiences towards accessing psychological therapies, that in turn, influenced whether they would seek support. These findings align with the Theory of Planned Behaviour which posits that individuals' intentions to seek help (e.g., access psychological therapies) can be driven and influenced by their attitudes towards the intended behaviour (e.g., seeking psychological support for their psychosis from services). However, it should be noted that whilst the Theory of Planned Behaviour is a useful framework for understanding behaviours related to accessing psychological therapies, it is a theory developed through an American/Western European lens. It has also been criticised for not taking into consideration cultural differences and nuances that may influence behaviour (Sniehotta, Presseau & Araújo-Soares, 2014).

The findings of the review have highlighted a number of barriers and facilitators experienced by people from a Global Majority when accessing psychological interventions. It has been suggested that societal and familial stigma plays a significant role in whether people access psychological support. This is concurrent with previous literature that suggests that stigma towards mental health difficulties is an important factor in determining whether people are more likely to access support for psychosis (Islam et al., 2015; Memon et al., 2016). Fear of judgment from family members and the impact of revealing of their diagnosis may also influence whether service users are willing to receive support from therapists (Rathod et al.,2010).

Another key theme identified was the use of non-clinical sources by people from a Global Majority. The findings from this theme supports the literature that people are more likely to seek and access support from non-mainstream services and religious healers and leaders (e.g., Islam et al., 2015; Zafar et al.,2008). This was deemed to be an initial step and facilitator to accessing psychological support for many of the participants and highlighted the importance of religious and spiritual needs. Receiving support from family members and having a strong support network were also deemed to be vital facilitators in enabling people to seek and access psychological interventions. This could be via providing practical support such as finances or deciding and making suggestions on steps to seeking support (Rathod et al., 2023). The role of the family also served as a potential barrier for people, as a lack of familial support was highlighted to influence service users’ ability to attend therapy and to engage fully with it (Naeem et al., 2016). Difficult relationships with support networks were a fundamental reason for people disengaging with managing their mental health (Lyons et al., 2022) and as a result less likely to access psychological support. Strong family and social support networks may therefore play an important role in the management of psychosis for people from Global Majority and should not be undermined by services and clinicians.

Furthermore, people's negative experiences of professionals and mental health services are a significant barrier for an individual seeking to access psychological support. The findings highlighted that people from ethnic minority backgrounds often mistrust services due to multiple factors such as previous dissatisfaction, lack of confidence in services and cultural/religious needs not being met (Phiri et al.,2019 & Rathod et al., 2010). Such negative experiences are problematic for people from a Global Majority and illustrated that there is a difference in how people from ethnic minority backgrounds are treated by mental health services and also professionals. It is imperative that these experiences are acknowledged in order to improve the cultural competencies of professionals to support people from a Global Majority background but also to ensure that services are equitable and culturally sensitive.

The review findings also suggested that perceiving psychological interventions in a positive light is a facilitator for people accessing psychological support. Previous experience of engaging in mental health services can mean that individuals were provided with clarity and understanding about treatment options and as a result, their opinions regarding psychotherapy and psychological treatment enabled them access support (Rathod et al., 2023). One of the reviewed studies interviewed patients from Pakistan and explored their experiences and views of cultural CBT for psychosis. It was identified that half the patients with an awareness of talking therapies, were optimistic about it and expressed a wish to access it (Naeem et al.,2016). These findings suggest that providing an awareness of talking therapies can be beneficial and should be promoted to people and their local communities.

Language and communication issues should not be a barrier to informing people about the available options regarding psychological treatment, and services should continue to consider the use of trained interpreters and translating resources appropriately.

Overall, these findings suggests that there are significant barriers at both the individual level and wider systemic level that affect the uptake of psychological interventions by people from an ethnic minority background. However, there are also facilitators that enable people to access support, and these should be acknowledged and promoted when working with individuals from a Global Majority.

1.5.1 Strengths and Limitations

One of the strengths of this review is the use of thematic synthesis to analyse the findings of the reviewed studies. Following the framework outlined by Thomas and Harden (2008), allowed for the synthesis of rich detailed qualitative studies to understand the barriers and facilitators experienced by people from ethnic minority backgrounds, when accessing psychological therapies for psychosis. The process of the thematic synthesis was carried out in a rigorous and transparent way. The use of a second reviewer during the systematic review process helped to minimise potential bias and improve inter-rater reliability. Secondly, the majority of studies were deemed to be of excellent quality, employed similar research designs and were conducted across different countries. The reviewed studies also included a variety of participants from a range of ethnic minority backgrounds, gender and ages thus enhancing the ecological validity of the findings. The novelty of this review is a strong strength and an important contribution to the evidence base.

It should be noted however that the review only included studies written in English therefore there is a potential for some studies to have been missed due to this limitation.

Additionally, the review only explored service users' direct experiences and excluded the views of carers and professionals. Due to this exclusion, it is possible that other barriers and facilitators that are important may not have been identified.

Due to the small number of reviewed studies, robust and firm conclusions drawn from the review should be done with caution. Lastly, although the included studies were of good quality, some studies lacked quality in a specific area (e.g., researcher reflexivity and ethical issues). It would be of interest for future research to consider these issues in order to enhance the quality of studies.

1.5.2 Clinical implications and Future research

The findings of this review can provide useful contributions to current mental health services and clinical practice. It is of importance for clinical services and health professionals to acknowledge the barriers people from a Global Majority face, when trying to access psychological therapies for psychosis. There should also be a recognition of what can facilitate people to seek support and access psychological support as this is in line with the NICE guidelines for the management of psychotic disorders (NICE,2014).

The barriers illustrated in this review suggests that there are underlying reasons for the lack of access to psychological therapies by people from an ethnic minority background, such as stigma and negative experiences from services and professionals. Stigma has been shown to undermine help seeking behaviours and detrimentally impact on recovery and clinical outcomes amongst people from ethnic minority communities (Knifton, 2012; Wood, et al., 2022). Services and professionals should take into consideration the impact of stigma of psychosis in ethnic minority communities and promote anti-stigma interventions, education and awareness around mental health for individuals, their family, and their community (Codjoe et al., 2021).

Furthermore, the importance of addressing and understanding people's culture and spiritual/religious needs should not be understated. Training and reflective practice spaces should be provided for health professionals to discover and reflect on what learning needs to be done and to increase cultural competency. It is also important to take into account the broader socio-political context of the individuals being supported, encouraging colleagues to be reflective and aware of their own biases and blind spots that may impact an individuals' engagement with therapy and services.

Collaboration with religious leaders and local communities is necessary in order to bridge the gap between mental health services and ethnic minority communities. Findings of this review recognised that individuals from such communities often access psychological support from faith or traditional healers first before reaching out to mental health services. Thus, liaising and providing consultation to religious leaders and local communities is paramount. Services should also consider being involved in community outreach projects and reaching people at the grassroot level. Raising awareness and providing knowledge regarding where to access psychological therapies and what that may look like for people from and ethnic minority background, could be beneficial in reducing the barriers highlighted in this review. Islam et al. (2015) highlighted the importance of collaborative working with community organisations in order to build trust amongst people from ethnic minority communities and promote psychological services.

Future reviews may consider including the views of family/carers and professionals to build on current findings. Extensive research has shown the importance of carers in the role of supporting individuals with psychosis (e.g., Cairns et al.,2015; Sin et al., 2021), thus it would be of benefit to highlight this in future reviews. Qualitative studies should also take into account the importance of researcher reflexivity and being transparent regarding ethical issues that may arise when working with people from ethnic minority backgrounds.

1.5.3 Conclusion

This review synthesised qualitative studies to highlight the barriers and facilitators to accessing psychological therapies for people from a Global Majority with experiences of psychosis. Findings illustrated that stigma; negative experiences of clinicians/mental health services and lack of familial support can significantly hinder the process of help seeking and accessing evidence-based psychological therapies. The review also highlighted the importance of religion and spirituality, engaging in community organisations and knowledge surrounding talking therapies, as facilitators to accessing psychological therapies.

Understanding these barriers and facilitators to accessing psychological therapies cannot be ignored and is vital in order to reduce stigma, improve experiences within services, encourage collaboration with local communities and support understanding of cultural differences. This is likely to reduce the disparities of the uptake of psychological therapies for people from a Global Majority, with psychosis and improve access to psychological therapies.

The review contributes novel insights to the literature by highlighting the need for an international perspective to explore the experiences of people from the Global Majority in accessing psychological therapies for psychosis. Further research is needed to enhance the review by including the views and experiences of family/carers and professionals.

1.5.4 Acknowledgments

The author would like to thank Chakky Ng for her support in reviewing and appraising the included articles in the review.

1.5.5 Conflict of interest statement

There are no conflict of interests in relation to this piece of research. This research forms part of the submission to the University of Southampton for the Doctorate in Clinical Psychology Thesis.

Chapter 2 Exploring the experiences of help and support seeking for people of Black African and Caribbean heritage experiencing long term psychosis.

2.1 Abstract

There is a high prevalence of psychosis within the Black community and certain factors can impact the experiences of help seeking which consequently delays appropriate treatment. This study aimed to explore Black African and Caribbean people's experiences and views of help seeking and support for long term psychosis. Qualitative methodology using semi-structured interviews was employed. Reflexive thematic analysis was utilised to analyse the interview transcripts.. Fourteen people from Black backgrounds with long term (3+ years) experiences of psychosis were interviewed. Participants were recruited either from NHS services or the community in the UK.

Four main themes were identified from the analysis: (i) Family and support networks (ii) seeking help form mainstream services, (iii) non-traditional pathways to seeking help (iv) barriers to help seeking. The study's findings illustrate that the pathways taken by Black people to seek help and support for long term psychosis are multifaceted. The authors highlight important clinical implications for services to improve and encourage people of Black backgrounds to seek and access mental health services.

Keywords: Black African, Black Caribbean, psychosis, help- seeking, thematic analysis

2.2 Introduction

Psychosis is an umbrella term used to describe conditions characterised by positive symptoms such as auditory and visual hallucinations and negative symptoms (e.g., social withdrawal) (American Psychiatric Association, 2013). Black African and Caribbean people living in the UK have a high prevalence of psychosis and this is substantially higher when compared to their White counterparts (Bard et al., 2021). Although it has been reported that there are cultural differences between Black Caribbean and Black African people (e.g., different experiences of migration) both have high rates of psychosis in clinical studies, compared with the White population (Qassem et al.,2015).

Previous research has highlighted that Black African and Caribbean men are more likely to be diagnosed with schizophrenia than Euro-American men and they usually present with more psychotic symptoms than Black women (Arnold et al., 2004). In addition, a study conducted by Lawlor et al. (2010) explored ethnic differences in compulsory detentions for women experiencing a mental health crisis. Results showed that 42.3% of Black Caribbean, 48.8% of Black African and 44.8% of Black women of other heritage were compulsorily admitted under the Mental Health Act in comparison to 13.2% of White British women. It should be noted that these findings should be interpreted with caution as data was collected from clinicians rather than the women in the sample. Nonetheless, Black women with psychosis also face similar negative experiences to Black men with psychosis. It is therefore important to explore the needs of both Black African and Caribbean men and women with psychosis.

There are several different factors that may account for the high prevalence of psychosis within the Black community, these include social factors (e.g., unemployment and housing issues), selective migration, institutional racism and misdiagnosis (Pinto et al., 2008).

Due to some of these factors (e.g., institutional racism), people from Black ethnic groups may follow more adverse and coercive pathways to care (Nazroo et al., 2020). For instance, a meta-analysis on pathways to mental health care identified that compared to White groups, Black ethnic groups had greater numbers of compulsory admissions, and involvement with the police and criminal justice service, instead of contact with primary care services (Halvorsrud et al., 2018). Black people also reported more negative experiences in mental health services including higher rates of coercive care and readmissions to hospital, compared to other ethnic groups (Barnett et al., 2019; Morgan et al., 2017).

There are many barriers Black African and Caribbean people encounter when accessing support for their mental health. For example, Memon's (2016) qualitative study revealed that cultural identity, negative perceptions of mental health and stigma were key barriers to accessing mental health services for Black and ethnic minority people. Other issues such as discrimination and insensitivity within healthcare services were also reported as barriers to accessing services for support (e.g., Knight et al., 2023).

A few studies focus on the experiences of Black people with a first episode of psychosis, in relation to accessing early intervention services, pathways to care and help seeking (e.g., Islam et al., 2015). However, there is a significant lack of studies exploring the experiences of people with long term psychosis and how they may seek support or manage their symptoms. Such studies are vital to gain further insight into how people with long term experiences of psychosis can be supported longer term, especially as medical approaches are often prioritised in practice over other psychological interventions (Spandler & Calton, 2009). A recent study exploring access to treatments for schizophrenia corroborated this, reporting that Black service users were more likely to be prescribed antipsychotics and less likely to receive psychological interventions such as cognitive behavioural therapy, in comparison to people from White backgrounds (Das-Munshi et al., 2018).

2.2.1 Health Belief Model

Theories of help seeking behaviours can provide an understanding of various factors that may influence individuals' decision and intention to seek help. The Health Belief Model proposed by Rosenstock (1966) describes several constructs that predict whether people will engage in help seeking behaviours for their health condition. This includes their perceived susceptibility to experiencing a health condition, their belief about the severity of the health condition (perceived severity), their ability to weigh up the benefits and barriers of receiving help and be confident in their ability to access this support. This model can provide an explanation as to why some people from Black backgrounds may delay seeking help for psychosis if they are unable to meet these constructs, for example, not being able to perceive the benefits of accessing mental health services due to previous negative experiences (Knight et al., 2023).

2.2.2 Current Study

Overall, within the current literature there is extensive research focusing on help and support seeking in the prodromal stages of psychosis (e.g., Tanskanen et al., 2011). Qualitative research has identified a range of help seeking pathways for people with first episode psychosis. For example, caregivers/family, religion and spiritual institutions have been found to be important aspects of the initial path to help-seeking for people from ethnic minority backgrounds (Anderson et al., 2013; Islam et al., 2015; Rathod et al., 2010). However, there is a gap in the literature, as to the best of the author's knowledge there are no qualitative research studies exploring the views of people from Black African and Caribbean backgrounds experiencing long term psychosis on how they seek help and support within the UK healthcare services and community settings.

The current study had one main research question: what are the experiences of help seeking and pathways for Black African and Caribbean people with long-term psychosis? The objective of this study was to use the qualitative method of reflexive thematic analysis (Braun & Clarke,2022) to explore participants experiences and views.

2.3 Method

2.3.1 Design

The study adopted a qualitative approach using reflexive thematic analysis (Braun & Clarke, 2022). Semi structured interviews were used to explore the experiences and perspectives of Black African and Caribbean participants. The study is reported in line with the Consolidated Standards for Reporting Qualitative research (COREQ) guidelines (Tong et al., 2007).

2.3.2 Participants

Using an opportunity sampling technique, 14 participants were recruited from NHS (National Health Service) mental health services (e.g., rehabilitation services, assertive outreach, community mental health teams) and the community. Appropriate service teams were provided information about the study and NHS participants were identified by a key worker from their service. Research flyers were distributed across social media platforms to recruit people from the community. For the purpose of the study, long term psychosis referred to people who were not in EIP services and had experienced psychosis for a duration of at least 3 years. The inclusion criteria of the study were therefore as follows: (1) people who identify as Black African, Black Caribbean and Black British (2) a self-reported experience of psychosis for over 3 years or diagnosis of schizophrenia and/or schizoaffective disorder.

All participants were from either a Black African or Black Caribbean background with a long term experience and/or diagnosis of psychosis, ranging between the ages of 21- 57 years old. The majority of participants were recruited from the community in the UK (see Table 5 for participant characteristics).

Table 5 *Participant Characteristics.*

Demographics	Frequency (N)	Percentage (%)	M
Age			32.43
21-29	8	57.14	
30-39	3	21.43	
40-49	0	-	
50-59	3	21.43	
Gender			
Male	8	57.14	
Female	5	35.71	
Non-Binary	1	7.14	
Ethnicity			
Black African	9	64.29	
Black Caribbean	4	28.57	
Black African& Caribbean	1	7.14	
Recruitment Pathway			
NHS	4	28.57	
Community	10	71.43	
Reported Diagnosis			
Psychosis	13	92.86	
Psychosis and Borderline Personality Disorder	1	7.14	

2.3.3 Procedures

For NHS participants, firstly, key workers approached people they were working with within their service that fit the inclusion criteria and provided them with an information sheet describing the purpose of the study and a consent form (see Appendices C and D). Once completed, the key worker sent this back to the main researcher via email. Participants were also given a demographic form which was used to determine whether they met the inclusion criteria (see Appendix E). Participants were recruited from the community via research posters advertised on social media (see Appendix F). Those who were interested in the study, scanned the QR Code or used the link on the poster. This directed them to the Qualtrics website containing the study information sheet, demographic sheet and consent form. Participants who did not meet the inclusion criteria, were informed that they had not been selected for the study and thanked for completing the screening questionnaire. Participants who met the inclusion criteria were contacted by the main researcher to arrange a suitable time and date for the interview.

All interviews were conducted by the main researcher via video call software (Microsoft Teams). In order to confirm eligibility for the study, participants were asked to turn on their camera at the start of the interview and this lasted for a few minutes. They could then turn of their camera for the duration of the interview if that was their preference. NHS participants were given the option to be interviewed remotely or in person at the appropriate clinic room in their NHS service. Local participants from the community were also given a choice to be interviewed face to face at a community venue.

An interview topic guide (see Appendix G) was followed to allow the participants to provide rich detailed information about their experiences of seeking help and support for their long-term psychosis. The interviews lasted from 20 to 60 minutes approximately. All interviews were audio and video recorded and participants were informed of this prior to the interview. After the interviews, the transcripts were transcribed verbatim and anonymised using a participant ID number. Participants received a 25-pound voucher to compensate for their time.

2.3.4 Ethical Considerations

The study was granted ethical approval by the University of Southampton Ethics committee (ERGO:81699, the NHS Trust Research Governance (see Appendix H) and Health Research Authority, Research Ethics Committee (IRAS:325637). For NHS participants, only participants who were deemed to have capacity by their key worker were able to participate in the study. Participants in community settings were assumed to have capacity to consent unless proved otherwise. It was acknowledged that some of the interview topics may be upsetting but overall, there were minimal potential risks to the participants. A risk management plan was developed to manage potential risks during the interview (e.g., sharing information with the participant's Key Worker) and contact details of helplines were provided on the debrief sheet given at the end of the interview (see Appendix I).

To maintain confidentiality, data from the research was stored on a password encrypted OneDrive on the key investigator's laptop and only members of the research team were able to access the data.

2.3.5 Patient and Public Involvement (PPI)

A patient public involvement representative reviewed the acceptability of the research study documents and interview topic guide questions. Recommended changes (e.g., what information to put on the advertisement poster) were discussed with the research team and addressed. The PPI representative suggested changes to the language used in the poster and also the participant information sheet. Changes included using the term 'people with experiences of psychosis’ rather than people diagnosed with psychosis, and simplifying the information presented to make it more accessible.

2.3.6 Data Analysis

Reflexive thematic analysis was utilized to identify themes, concepts and meanings. According to Braun and Clarke (2006,2019) it should be seen as a method in its own right and not as a process of qualitative research. Unlike grounded theory and interpretive phenomenological analysis (IPA), thematic analysis is a relatively easy method to use and is accessible to a wide audience. It can also be useful for informing policy development and enable the researcher to investigate sensitive topics without altering the phenomena under investigation (Braun & Clarke, 2006).

The interview transcripts were analysed using an inductive thematic analysis procedure by the main researcher. The first phase involved familiarisation with the data by listening to the recording of the interviews. Initial ideas and codes were documented using a qualitative data analysis software (NVivo 14, Lumivero,2023). Inductive codes were defined in a coding manual and initial sub themes were generated and reviewed in relation to the codes. This was to ensure that the codes selected were meaningful and representative of the data. Codes that were not meaningful were discarded. The final phase of the data analysis included grouping relevant sub themes and defining and naming the main themes. This process was discussed with the research team.

2.3.7 Researcher’s reflexivity and epistemological position

The concept of reflexivity refers to the process of the relationship between the researcher and the research participants and how this process may influence the analysis of the data (Palaganas et al., 2017). Personal reflexivity takes into consideration how the researchers own personal, cultural background, values and beliefs may influence how they interact with the research from the gathering of information to the analytical process (Berger, 2015). The researcher is from a Black African background (Ghanaian) and was born in the Netherlands. The researcher is a trainee clinical psychologist and has had previous experience working with people from diverse backgrounds with psychosis.

Epistemologically, the researcher analysed and interpreted the data from a critical realist perspective which postulates that research is not entirely objective, as the social world is layered, and constructed via subjective perspectives and experiences we may give meaning to (Fletcher,2017). The researcher acknowledges that they may bring their own perspectives and experiences as a Black woman into the research process and is mindful of this, especially as they share a similar racial background as the participants. During the analysis process, the researcher reflected on their background and personal experiences of witnessing how mental health is perceived in their own community and family. This played a role in how they interpreted the data and developed the study's themes as they were more attuned to certain nuances in discussions with the participants that may be a blind spot or missed by an 'outsider researcher'. The researcher also recognised that they resonated with the participants responses and other times would feel strong emotions especially when analysing data related to familial support and cultural conceptualisations of mental health difficulties. In order to explore these feelings , the researcher used a reflexive journal, to reflect and document their views, feelings and experiences whilst gathering and analysing the data. (See appendix J for an excerpt of the reflective log). The researcher also received 1:1 support from an external Black clinical psychologist to discuss their interpretations and ensure that their personal experiences and biases were not being reflected strongly in their analysis and development of themes, but rather bringing forward the participants lived experiences.

2.4 Results

The 14 interviews were analysed using a reflexive thematic analysis approach. Four main themes and 13 subthemes were identified in the analysis to illustrate and understand the experiences of help and support seeking in Black African and Black Caribbean people with long term psychosis (See Figure 1). The four themes were: (i) Family and support networks (ii) seeking help from mainstream services, (iii) non-traditional pathways to seeking help and (iv) barriers to help seeking.

2.4.1 Theme 1: Family and support networks

The importance of family and social support networks was a strong theme that was identified across the participants. Family and friends played a significant role in how individuals from a Black background receive help and support for their long-term psychosis. In contrast, a lack of this support can affect participants help and support seeking behaviours.

Support seeking from family and friends.

The majority of participants described how they would reach out to their friends and family when they had difficult thoughts and mental health experiences. It was acknowledged that some participants felt comfortable enough to talk to their family and friends about what they were going through and would receive encouraging words from them. One participant illustrated this:

'Yeah, you know, I guess. I just share, what I am going through with friends and family. Some of them know what I am going through and so I get a lot of words of encouragement from them and they also help me and comfort me' (P1)

Another participant explained how they were able to disclose their problems and difficulties with their family and how their encouraging words were helpful to them:

‘So, whenever I'm going actually going through it, I let them know my conditions, I let them know my situations. They helped me, at least the word of advice’ (P2)

A few participants also reported that their main source of support when seeking help derives specifically from their parents and acknowledged that even though their parents were in the later stages of life, they could still seek help and support from them:

‘*Parents are good, my parents support me here. You know, they're getting old* now’ (P7).

‘…but my mom is there for me and my dad. They both pensioners, my dad just turned 85 yesterday and my mum, 75’ (P11).

The role of family did not only apply to providing emotional support but also managing practical issues for participants. For example, it was reported by one participant that her parents also supported with daily living tasks:

‘My mom does my washing and my dad does my shopping…because where my mobility is bad and I've got trapped nerve there so I can't lift or carry anything’ (P11).

Additionally, a few participants spoke about receiving prayers and cultural support from family and friends.

‘Everyone was praying for me and willing to help me’ (P1).

Participants also illustrated how family would play a role in initiating help and support for them when they were unable to do so for themselves. They also described how their families and friends may be involved in the treatment process.

'So anyway, I had a psychotic umm relapse episode and my sister was at home and she rang the ambulance for me' (P4).

Interestingly, the importance of friendships was highlighted by some participants when describing their experiences of help-seeking. They described the importance of being able to rely on their friends for support and to receive a 'lending ear'. Participant 8 reported how having a friend who is also a therapist was beneficial for him when needing help.

'When it comes to support, I have a friend, he's a therapist, and so he helps me a lot. And it makes things easier and better because aside from that…it wouldn't have been easy' (P8).

Participant 3 built on this idea and also described the role of friendship when trying to seek help and support: '*I have a friend who knows me very well. He's the one that usually assist me…. So, he's been there for me and I am also there for him. So, I think it's helping me*'.

Lack of support from family and friends.

Alternatively, when describing their experiences of help and support seeking, some participants spoke about the lack of involvement of family. Reaching out to them was not an option they would consider in their process of seeking help. One participant highlighted this:

'But there's no way I would tell my family or anyone in my family. I would not even go to them like this because my head would not allow me to do that.' (P12)

Another participant highlighted that even though their parent was present in their life and able to provide support through listening to the individual's difficulties, this had its limits. *'Who do I talk to? I've got all these like things going on and she was my support, but I didn't have her. like my mom, could only…Yes, she was there to, like see what was happening, but she could only listen to me talk so much* '(P4)

Participant 4 described a loss of community, cohesion and belonging, this meant that they were unable to reach out to people for support when they needed it.

'*In terms of seeking support It just means that I find that there's unfortunately even within the diaspora within the community, like sometimes there's, like, not always a cohesion. There's not always like a," you know, we're all Black.' (P4)*.

2.4.2 Theme 2: Seeking help from mainstream services.

Although some participants would initially go to their family for support, this theme highlighted that participants would seek support from mainstream services especially during difficult times.

The role of medication.

An important element of seeking help from mainstream services for Black people with long term psychosis was the role of medication. Some participants described how seeking help consisted of obtaining antipsychotic medication from doctors in order to manage the symptoms of their psychosis:

*'Now, my psychosis is sort of under control now. I don't know if it's the medication I'm taking or whatever, but it's kind of under control now' (P*5).

On the other hand, negative experiences of receiving medication were also reported by some participants. They explained that they would access mainstream services for support only to be offered medication, even though their main reason for seeking support was to be able to express and talk about their feelings. Participant 11 reported how they sought support from a service and were provided with medication that led to negative side effects:

'The medication they gave me and that. I couldn't even talk because I was dribbling, I've dribbled that much.' (P11)

She further added that she declined the option to take more medication as she wanted to talk about her feelings:

'Even at this stage, is this somewhere (NHS team) that I can go and talk to somebody about my feelings? Cause the doctor asked me if I wanted any more medication and I thought, no.' (P11).

Crisis support and help seeking from NHS services.

Five participants highlighted positive experiences from seeking help and support from NHS services, this was due to several factors such as feeling supported by staff, receiving recommendations from psychologists and feeling like they were able to access the services at any point:

'The [redacted] team is in NHS. OK, it's not a bad service. Basically, it's a life saver basically. So yeah, I don't have any problems about getting the support because that's helped keep me safe' (P6).

In addition, being able to access the free service provided by the NHS was a reason for seeking support:

'I don't worry about the costs because I don't, I don't pay for the mental health support I get, so if it wasn't for the NHS thing, I would find it more difficult to be able to access support and it's something that I'm quite grateful for' (P10).

Interestingly, two participants reported no experience of seeking help and support for their long-term psychosis from NHS services, instead speaking to support networks and relying only on private doctors to prescribe their medication:

'I talk to my private doctors, use medication and speak to family and friends' (P1).

Participants described how, during a period of crisis, they would be more likely to seek help and support from professionals and NHS services because of their ability to monitor and keep the individuals safe:

*'…but because of the [redacted] team, you're very closely monitored. They are able to intervene basically and help, but yeah, quite difficult to cope in that sort of situation' (*P6).

One participant described admitting themselves into an inpatient ward as an informal patient when they were seeking help during a crisis:

'So, I'd like to, uh, be entered at the hospital…. I go there myself because I want to prevent any regrettable you know, things from happening and I know how dangerous I get during an active crisis period' (P10).

In contrast, one participant reported that when seeking help during a period of crisis, reaching out to the crisis team had been unhelpful and unsupportive. They highlighted that they preferred reaching out to family instead:

'If I'm in a crisis, I'm not gonna phone someone and tell them on the phone. It's gonna make me feel worse. I'm just told someone will call me, so it's even worse because they're not going to do nothing to help me……. if mum was here, then I would phone her instead.' (P12)

2.4.3 Theme 3: Non-traditional pathways and self-help to seeking help.

This theme reflected descriptions of 'non-traditional' pathways to seeking support. When participants were asked about their experiences of help and support seeking, they also identified pathways that consisted of relying on their own support, religious and spiritual support, and other alternative sources of support. Some participants sought a range of non-traditional sources of support for their long-term psychosis.

Self -reliance and personal motivations.

Most participants spoke about the role of self-reliance when describing experiences of help seeking. It appears that people from a Black background with long term psychosis may sometimes draw on their own support when managing the symptoms of psychosis and other difficulties in their life. Leaning on personal resilience and preferring to 'suffer in silence' was a response that was noticed during interviews with some participants, for example:

'As for ongoing support and the day-to-day stuff, I feel like I'm very much on my own' (P4)

'And it's quite unfortunate because, erm, I kind of had to not get any support.
It was almost suffering in silence.'(P13)

Self-reliance as a source of support was notably seen to arise when participants perceived that they had a lack of social support or had awareness of their own relapse warning signs and acquired skills to manage their symptoms:

'And I was really sick, and my friend wasn't around So I think I went through the crisis alone.' (P3)

Other participants described their motivations for seeking help and support. Openness to seeking help was linked to experiencing multiple psychotic episodes and also to personal caring experiences:

'I think because from a young age like I've seen my mom be so ill and I've always been like, I don't wanna end up like that. So, when it comes to seeking help, I don't really have a problem with it'. (P5)

Alternatively, one participant highlighted that due to relying on themself for support, they would often draw on unhelpful coping and maladaptive strategies:

'I will use my natural ways of coping with mentality issue or depression or whatever I'm passing through. Yeah, at times I use pills, sleeping pills. Yeah, and then at times I try to take a shot of alcohol' (P8)

Seeking alternative sources of support.

This subtheme relates to how participants would seek support from private services that provided psychological therapy. Participants described how they valued being able to access this for many reasons such as being provided with choice and flexibility which may not always be an option in mainstream services such as the NHS:

'I get to choose who I want to. That's, I think the most important thing. Usually if you go to NHS talking therapies, going to your GP, say I like some talking therapies instead of antidepressant, you wouldn't exactly get that choice of who to pick' (P4)

Seeking support from private psychological services was received positively by participants and the quality of private therapy was also highlighted by one participant:

'I did seek my own therapy, which was EMDR therapy.
And that really helps a lot... had to turn to private practice and I'd get better quality therapy' (P13)

Using online information for support was also recognised to be a useful for some participants *'I read things online, I went through some sites although yeah, because I want to know my situation.' (P8)*

In contrast, though private therapy had its benefits, one participant spoke about being unable to continue to seek support from private therapy due to financial constraints:

'It's like a therapy service online, but because of finances and stuff, I didn't continue with it, but it was quite good'(P5)

Moreover, four participants described positive experiences when seeking help and support from community group organisations, these included crisis cafés, day centres and support group networks such as Hearing Voices Groups. One participant spoke about being involved in volunteering and connecting with people who had similar experiences managing their psychosis:

'I do you know go to crisis café. Not every time. Yeah, because, uh, this there is one very close by I would attend, you know, just to get encouraged and talk about what I am going through different kind of mental health challenges and also to talk about my story and, you know my history' (P10). Participant 10 also described how community organisations groups provided a 'sense of family' and gave them reassurance.

Seeking support from religious sources.

Drawing on religious beliefs and faith appeared to be an important path to receiving help and support. Some participants reported using prayers (e.g., dua - an Islamic prayer) and religious interventions when managing their symptoms, particularly during difficult times:

I pray for myself when things are going wrong in me That's how I am, because I am Muslim you know…. I make dua, dua helps' (P7)

Another participant also described seeking support from the church during hard times:

'Yeah, I also had some you know, financial issues during the times of my treatment and so I got support from my church members, you know like an association from the church was able to support me' (P9)

2.4.4 Theme 4: Barriers to help seeking.

This final theme reflects the barriers experienced by people from a Black background when seeking help and support for their entrenched psychosis. It captures the frustrations and disappointment felt by participants whilst also exploring ways to improve mental health services.

Racial and discriminatory experiences when seeking help.

One salient aspect of help and support seeking described by the participants was the reported experiences of racism and discrimination. All participants reported that a key factor hindering the process of reaching out to services or mental health professionals was that they had encountered unacceptable treatment related to racism and discrimination. Some participants spoke about how they felt they were being treated differently in comparison to their White counterparts:

‘So, they prefer not to give people like us support you know, they can just be discriminating, you know. So that's just some difficulty actually. When I was actually looking for help. What I actually meant by the discrimination is, you know, that some people actually prefer the white over Black people’ (P2).

Participant 1 described how witnessing a discriminatory incident taking place in a clinic that discouraged him from seeking further support:

‘Something happened in a community clinic, and I was not the victim but I felt victimised with what happened. These are some of the things that have discouraged me from seeking help.’

He further described: ‘*It was a Black person in the clinic harassed by a receptionist, a white lady and using words of insults. This made feel really bad and I have never been in such position before’.*

In addition, participants mentioned how they experienced microaggressions and typecasting from staff when seeking support:

'it's very hard to convey what you want within the [redacted] psychosis service…. Umm, a lot of the people are Caucasian and it's kind of hard because sometimes they expect you to be strong… that me as a Black person I'm just a bit different from the rest. I'm just structured different than the rest, therefore I should be able to get through this, you know, get through that adversity or to get through that or get through this mental health crisis because I'm Black.' (P13)

Some participants described feeling discouraged to seek help due to negative labels placed on Black people and felt that they were unable to express and report experiences of racism due to systemic and structural powers:

*'But you know the thing is, why I am not interested in getting help sometimes is because when I was growing up. They said Black people were mental (*P12)

'When you express this, umm, you often receive backlash from people who are Caucasian because of this guilt that they have and they don't really recognize that they do benefit from systems of power that that has to do with, you know, colonialism' (P13)

Participant 13 also identified that discrimination was not only experienced in services but also within their own community which made it challenging for them to receive support from religious and cultural community:

'because of all that discrimination I faced and I couldn't access that mosque within my town to practice… that really affected my mental health.'

Stigma, judgment and cultural perceptions.

Participants reported the significant role stigma, judgment and cultural perceptions of psychosis and mental illness played in their help-seeking experiences, particularly serving as a barrier to reaching out for support for their long-term psychosis. Participants made comments related to the shame they felt and had internalised the stigma that was prominent within their community. Participant 4 illustrated this and explained how seeking help for psychosis was perceived within the Black community:

‘Particularly in the Black community like I've had friends who, including the friend, I'm no longer friends with that I mentioned who, when I talk about getting help or myself or for other people needing help for mental health broadly as well as psychosis, it's almost like it's shamed, you're shamed for seeking therapy or it's seen as a white people's problem’ (P4)

Participant 4 further highlighted that due to shame of speaking about her psychosis she would rather avoid seeking help and support by hiding her symptoms:

‘And so, it makes you feel ashamed. It makes you feel scared. It stops you from wanting to talk about your feelings’ (P4)

Other participants also described how they feared negative judgments and comments made about mental illness from others when seeking help for psychosis: *‘You don't want to be branded as crazy because a whole lot of people, you know, once they hear that you’re seeking mental health support, you know, they say ' ohh must be going crazy*’ (P10)

Due to these concerns about stigma and judgment, there was fear of being judged by staff from their own cultural background:

‘*But I mean, that might not always be the case, b, because some people also afraid of talking to people from their own ethnical because they feel they have the same perception of mental health’* (P10)

Negative experiences of services.

During the interviews, participants discussed a number of factors that led to them having negative experiences of receiving support from services. Some spoke about how the long waiting times for receiving support such as therapy were a significant barrier to seeking help from services:

‘I wouldn't want to rely on the NHS again to get therapy because I know there's such a long wait time and by the time you get some, you don't know what's gonna happen when you have that kind of illness.’ (P13)

One participant described how navigating the process of seeking and accessing support from NHS services was difficult*: ‘I was actually thinking of going to the NHS service, like seeking help from them. It wasn't actually easy for me to access them, you know? It wasn't that easy to access, you know, unlike me just walking up to my own psychologist or therapist’ (P2)*

The cultural competency of professionals was questioned by the participants and they felt that the health professionals they encountered did not know how to support their needs. One participant even highlighted how she felt that her experiences were not believed by clinicians:

‘So, it's like even within the care, I'm not being believed for my experiences because of my heritage and my position, yeah… but it's like when I'm talking through my story, I can see, feel, and hear a sense of disbelief in my circumstances’ (P4)

Participants also described how clinicians lack of cultural knowledge and understanding:

‘I guess you could say with my psychiatrist, one thing that I experienced the culture clash, I don't I feel like he doesn't really understand kind of like the what the African household be like…. You know, I feel like I have to go out my way and be like yes, because of this…’(P13)

Language and communication differences were also emphasised to be a barrier when seeking help: *‘But that's the only thing. Sometimes I feel myself I can’t talk how I want. Now this will hold me back from looking for help’ (P12)*

Some participants spoke about how their inability to communicate their needs and being misunderstood by health professionals made it difficult to connect with them:

‘Like it's like getting help from, you know, or in general, maybe from other, from the white doctor or, you know from so it's kind of you know difficult or explaining what you need ‘(P9)

Some participants expressed further negative opinions about accessing support from mental health teams and believed that seeking support from services was a waste of time:

‘And especially from the surgery, I'm going to speak to one of the mental health nurses for five minutes and that's why I said it was wasted time (P11)’

Knowledge and awareness.

Knowledge and awareness in relation to psychosis influenced whether people were likely to seek help and support. Participants described how their family lacked knowledge about their psychosis and its management, this meant that they were only able to provide limited support:

*‘I mean, my family, they provide support, you know, but there isn't really much they can do, you know, because of the limited knowledge and isn't much they can do in terms of support’ (P*10)

Some participants explained that due to lack of knowledge about their diagnosis, they also felt lost and unaware of where to seek appropriate support or who to turn to.

‘But for me before I got to the peer team, there was still like a few months where I was just like what do I do? Who do I talk to?’ (P4).

Participant 13 explained his lack of understanding of psychosis stopped him from seeking support: *'I didn't feel like I wanted to get any support and because I didn't understand my psychosis, I didn't understand what psychosis was'.*

Alternatively, a few participants highlighted how having an awareness of their own relapse warning signs, reaching acceptance of their diagnosis and developing their understanding of their psychosis motivated them to want to seek help and support:

'So, I've got almost like a not a tool kit that's a bit of a formal phrase, but I've got like an inner sense of when I need to take foot off the pedal or, you know, take a day off, or consult my friends, or talk to my family'(P4).

A need to improve services.

Due to the barriers to help and support seeking, participants highlighted a need to improve services. There appeared to be an agreement across participants that services need to ensure that they are equitable and culturally sensitive to people from Black backgrounds. Participants suggested that for people with long-term psychosis to feel encouraged to seek help and support, services should be free from discrimination and be aware of how they communicate with patients: '*Yeah, I guess they need to, be enlightened properly about the side effect or the disadvantages of abusive words and how they treat the patients' (P8)*

Participant 13 explained that in order for services to be free from discrimination, it is important for health professionals and other staff to understand the underlying issues that drive racism and discrimination: *'But you really have to get to the stem...the root of the issue and one would be understanding institutionalized racism'.*

Participants also identified concerns related to professional's cultural competency and suggested that there is a need for training to educate staff about the cultural, religious and spiritual needs of people from Black backgrounds. Participants reported that they wanted professionals to take into consideration their race and culture when they are seeking support from mental health services:

‘Consider the background of people of colour, basically important to understand the trials that people of colour have been through, basically where they're coming from is really important’ (P6)

Additionally, it was recognised that for services to meet the needs of Black service users, there is a need for a diverse workforce that is culturally representative and relatable to the people that seek help and support. For instance: *‘I think you just you got to get more doctors that are like you. That's what you got to do.’’ (P12)*

One participant suggested that services provide ‘BAME (Black Asian and Minority Ethnic) peer groups:

‘For people that have psychosis and stuff like that, I think that would be good to go to. Just to hear people's experiences and how they grew up. Because growing up in a Black household is really different to how a white person will grow up or how an Asian person would grow up or how you know it just in general. So, I think having a group for BAME people would be really good. ‘(P5)

Supporting and encouraging service users was suggested as another way for services to improve. For example, participants recommended that clinicians and professionals focus on empowering service users with knowledge, raising awareness of where they can seek support and what that may look like : ‘*I think if they can just make, create awareness for people so that people will be aware of where you can actually go to seek help, that would be, that would be good.’(P2)*

Lastly, some participants spoke about their frustrations regarding not feeling valued or heard. They reported that listening to service users was a fundamentally important task for clinicians:

‘Not listening to what I'm saying, you cannot do that, you're in the wrong line of job. And if you haven't got the patience to listen to what the patient is saying? No, no, no, no, no.’ (P11).

2.5 Discussion

This study explored how people from Black African and Black Caribbean backgrounds seek help and support for their long-term psychosis.). To the best of the author’s knowledge, this study is the first to explore the views and experiences of Black people specifically with an experience of psychosis for three or more years. Four main themes emerged from the data that highlighted the help and support seeking pathways undertaken by people from a Black background. Findings suggested that people from a Black background were multifaceted in their approach to help and support seeking to manage their long-term psychosis. It is important to recognise that help and support pathways may look different for people from Black African and Caribbean cultures, in comparison to people from White backgrounds. This is due to various systemic factors that impact how Black people with psychosis seek and receive mental health care. For example, following more adverse and coercive pathways to care, and experiences of institutional racism and discrimination (Nazroo et al., 2020). These factors often lead to a mistrust of mainstream services, and as a result people from Black backgrounds may seek support from alternative/non-traditional support systems reported by the participants in this study (e.g., religious and spiritual practices).

The first theme described how participants sought help and support from friends and family. Many of the participants explained how seeking help from friends was beneficial and enabled them to receive advice and encouragement. The findings suggested that the role of the family and other support networks is a significant factor in the process of seeking help for people who have entrenched psychosis. More specifically, parents played a pivotal role in initiating and being alongside individuals during their process of seeking support. This finding is similar to previous research that revealed how parents are often involved in initiating the help seeking process (e.g., Anderson et al.,2013). A lack of support from family and friends was also recognised to influence help seeking behaviours, and some participants highlighted that receiving support from their support network was not enough to help them manage their symptoms. It was also identified that reaching out to family or community for support was not an option for some people. Due to this, individuals had to draw on other sources of support that may not have been first choice for them. This finding is consistent with literature that suggests how a lack of social support can be considered to be an external constraint that leads individuals to avoid seeking help (Ma et al.,2023). Research has shown that having a strong support network can aid in reducing delays in receiving appropriate treatment for psychosis (Sogutlu et al., 2021). Thus, it can be argued that the role of the family and support network is a crucial factor in the help and support seeking pathways for Black African and Caribbean people with long term psychosis.

Moreover, some of the findings of the study may also be linked with psychological theories/ models of help-seeking behaviours. For example, the health belief model (Rosenstock, 1966) posits that individuals are more likely to seek help if they perceive a health threat (perceived susceptibility), are able to perceive the benefits and barriers to receiving support for the problem and are confident in their ability to access support. This explanation of help seeking is in line with the study's results, which illustrated that when individuals were aware of their symptoms/relapse warning signs and were able to recognise the sources of support available to them, they were more willing to seek help.

However, it is important to recognise that this theory was originally formulated for preventative health behaviours in the United Stated (Rosenstock,1966) thus providing a westernised explanation of help-seeking behaviour. This is a limitation of the model as it is reductionist and does not take into account values, beliefs, socio-cultural and environmental factors that can influence health and help seeking behaviours (Abraído-Lanza, Armbrister, Flórez & Aguirre, 2006; Carpenter,2010). Participants in this study reported facing cultural/systemic factors such as racism and discrimination, that may make it more difficult for them to meet these constructs in order to engage in help seeking behaviours.

The results of the study also revealed that mainstream services (e.g., NHS mental health services, GPs) were utilised when individuals needed support. Studies have shown that people with psychotic symptoms often consider seeking help from medical professionals as a first contact for support, however it should be noted that these studies were conducted with people in the early stages of psychosis (e.g., Fridgen et al., 2013). It was identified from the interviews that when individuals accessed mainstream services they would be provided with antipsychotic medication. Some participants explained that part of their help seeking process consisted of obtaining medication as this was considered helpful to manage their symptoms.

On the other hand, participants identified that they would be provided with medication but not offered alternative options such as talking therapy. These findings are concurrent with numerous studies that have illustrated how people from Black backgrounds are more likely to be prescribed medication than psychological treatments for psychosis, compared to white service users (e.g., Das-Munshi et al.,2018; Spandler & Calton, 2009). Many participants also had negative attitudes towards adhering to antipsychotic medication due to the negative side effects they experienced. This is consistent with a recent study that explored first episode psychosis patients' experiences and help seeking, revealing that Black participants were fearful and expressed negative attitudes toward prescribed antipsychotic medication, including fears of the side effects. (Knight et al., 2023).

There was a willingness to seek help and support from mainstream services when participants were experiencing a crisis or going through a difficult time. One participant described that during a crisis they wanted to be admitted to a psychiatric inpatient unit. This is an interesting finding, especially as the literature has shown that Black people are more likely to enter services via coercive pathways which can lead to involuntary admission, leading to mistrust of services (Barnett et al., 2019). It seems that regardless of this, services can be seen as a safety net. Some participants expressed that when they experienced a crisis, they would be more likely to seek help and support from mental health services due to the resources they have available. This finding is similar to previous research that suggested that crisis points were an important variable to consider in help seeking and that the majority of service users accessed mental health services only after a crisis occurred (Singh et al., 2013).

Non-traditional pathways to seeking help and support was a strong theme identified across participants. This highlighted the range of sources participants sought help from to manage their psychotic symptoms. Self-reliance referred to participants drawing on their own resilience and strengths to support themselves. This was particularly apparent in participants who had no other sources of support such as family or friends. Personal motivations such as previous experiences of being a carer for a relative with psychosis were also a driving factor for some to seek help. Other sources of support included seeking support from private therapy due to having more choice and flexibility in choosing their therapist. Community organisation groups were also sought for support and participants reported positive experiences as they felt that their experiences were normalised when attending these groups and were able to make connections.

These findings are similar to Tanskanen et al. (2011) study, as they revealed that service users also made positive comments regarding community organisations, which led to further support from other services. Drawing on religious and spiritual sources such as praying or attending church was common for some participants in their help seeking process. Previous research has highlighted the important role of religion in influencing help seeking behaviours for service users and their families (Islam et al., 2015). Help seeking from religious faith/spiritual healers and other religious practices was often seen as an initial step for some individuals with psychosis (Rathod et al.,2023).

A number of factors were identified as barriers to help seeking for people from Black backgrounds. Concerningly, participants described experiences of racism and discrimination when they sought help and support for their psychosis. This was mainly reported to be experienced within mental health services, where participants felt that they were being treated differently in comparison to White service users, experienced microaggressions and witnessed others being discriminated against. This finding is not surprising as previous research have suggested that people from Black and ethnic minority backgrounds with psychosis, do experience discrimination and racism within hospitals (e.g., Knight et al., 2023). It is clear from the results that experiences of racism and discrimination can hinder the process of help and support seeking for people with long term psychosis. This is supported by evidence that suggests that racial discrimination can inhibit help-seeking behaviours due to instilling a lack of trust and confidence in services, thus delaying appropriate treatment and care (e.g., Spencer & Chen,2004; Woodward 2011).

Stigma, judgments, and cultural perceptions of mental health were recognised to be another barrier to help seeking for psychosis. Participants described experiences of stigma which included negative judgments made about mental health and being labelled ‘crazy’ by others within the community. This type of societal stigma resulted in participants avoiding seeking help and being more likely to conceal their symptoms. Stigma as barrier to help seeking for psychosis has been identified across the literature (e.g., Anderson et al., 2013; Tanskanen et al., 2011). This finding is consistent with previous research that social stigma and shame hold negative repercussions for individuals and their families, delaying help seeking in Black and minority ethnic service users (Islam et al., 2015).

A lack of knowledge and awareness of psychosis and a failure to recognise what appropriate help is available also served as a barrier to help seeking for participants. The findings of this study suggested that having insufficient knowledge about psychosis and its management can delay help seeking and limit support from families. Lack of knowledge has been identified as a common barrier to help seeking for individuals with psychosis and this is reflected in previous literature (e.g., Anderson et al., 2013; Vyas et al., 2021).

Reported negative experiences of services was also a barrier affecting individual's willingness to seek further help. This study identified specific factors why participants struggled to utilise mental health services. These related to service provision (e.g., lack of staff continuity, long waiting times) and lack of personalised care. The results indicated that clinicians' lack of understanding and cultural competency influenced individual perspectives on whether their needs would be supported appropriately. This is consistent with previous research that staff are not receiving enough cultural training (Islam et al., 2015).

All participants highlighted ways services could improve in order to encourage other Black individuals with entrenched psychosis to seek and access support from mental health services. The need for staff to be relatable was recommended. Other suggestions included acknowledging and validating service user's experiences. Islam et al. (2015) study mentioned similar suggestions for improvement. Similarly, education and training to enhance cultural competency amongst professionals and reduce cultural mistrust has been recommended in other studies (e.g., Anderson et al., 2013; Knight et al., 2023).

Overall, there is evidence that the themes found in this current study are consistent with the findings shown in literature for the prodromal stage of psychosis (e.g., Knight et al.,2023; Islam et al.,201). However, this research further contributes to the literature by exploring these themes in the context of entrenched psychosis in a Black population.

2.5.1 Strengths and Limitations

The current study provides a novel insight into the experiences of Black African and Black Caribbean people with long term psychosis. Though there are previous studies that have explored help seeking experiences of Black people with psychosis (e.g., Islam et al., 2015), this is often conducted in the context of a first episode of psychosis or the prodromal stages. This study sheds light on a specific area that appears to be limited and under-researched within current literature and may provide useful implications for clinical practice and services. Employing the use of thematic analysis is a key strength of the study, as it allowed for rich, detailed and insightful perspectives into the experiences of Black people with entrenched psychosis, which is not possible with quantitative methodology.

Another strength was the researchers background which helped to facilitate open conversations. Participants reported feeling comfortable to openly share their experiences, due to the researcher also being Black.

Discussing the themes and sub-themes within supervision allowed for the analysis of data to be conducted in a rigorous and robust manner and to acknowledge possible bias. The credibility and rigour of the study was also enhanced as the researcher was able to discuss reflexivity and was attentive to their own potential biases and beliefs when interpreting the data, by utilising a reflective log. The use of PPI to review the study design and study documents (including the interview topic guide) provided another layer of credibility to the study.

There were a few limitations within the study. Firstly, although participants were recruited across different settings (both NHS and the wider community), all participants were from the UK. Therefore, caution is needed when drawing conclusions from the study's findings and applying them to Black people from other geographical locations. Generalisability of the findings may be limited as other countries outside of the UK adopt a different healthcare system. Furthermore, it should be noted that Black people are not a homogeneous group, therefore cultural experiences will differ between people from different African and Caribbean backgrounds that were not interviewed within this study. Some of the participants had also been involved in clinical research previously which could mean that they may be more inclined to provide specific responses to align with the researcher's expectations (e.g., McCambridge et al., 2014).

Lastly, there were methodological issues that arose during the interview process such as people not wanting to turn their camera on for the duration of the interview, this may have affected openness between the researcher and participant. However, it is acknowledged that people who have had experiences of psychosis may be more likely to be paranoid or apprehensive when speaking to strangers. None of the interviews were conducted face to face (although the option was given to participants). This may have made a difference in responses given during the interviews, as conducting face to face interviews could have enhanced the rapport between some participants and the researcher. As a result of this, richer and more detailed responses may have been yielded. Previous research has illustrated that face to face interviews often lead to a higher level of rapport and trust which encourages participants to share in-depth information with the researcher (Irvine, Drew & Sainsbury,2013).

2.5.2 Clinical implications and Future Research

It is hoped that the findings of this study will have significant positive implications for Black African and Caribbean people with long term psychosis on an individual level and systemic level. Results provided further insight into the experiences of help seeking for people who are experiencing long term psychosis as the literature is limited within this area. Participants identified two separate areas of key clinical and cultural implications that need to be addressed in order to improve help seeking experiences for Black people with psychosis: (1) pathways into services and outreach (2) implications within the services themselves.

Pathways into Services and Outreach

The study identified that there is a lack of knowledge and awareness of psychosis management within some Black families. It may be useful for services to provide culturally sensitive psychoeducation for individuals and their families. Psychoeducation groups and workshops can provide information on the nature of psychosis, its symptoms, warning signs to be aware of, relapse prevention and management strategies. These groups can also focus on addressing cultural misconceptions and stigma surrounding psychosis, but this will need to be done with sensitivity.

Moreover, implementing peer support groups within the community may be a beneficial way to help engage people from Black African and Caribbean communities. This can also provide a layer of support for people experiencing psychosis and their families, where they can share their unique experiences together, especially during difficult times. Supporting service users to share testimonials and success stories can help normalise experiences of psychosis and encourage others to seek help.

Services can also support people from Black backgrounds to access appropriate mental health services by developing resources such as leaflets, brochures or webinars explaining what services can provide and how individuals and their families can be supported, in an accessible format (e.g., information provided would be translated in the appropriate language, and webinars could be presented by a mental health professional from a similar ethnic background).

Findings highlighted how stigma can prevent Black individuals from seeking help and in turn, delaying the process of accessing appropriate support. Therefore, reducing stigma within Black communities is paramount and more should be done to destigmatise experiences of long-term psychosis. Promoting collaborative work within local communities may a first step to addressing this. Outreach work can include making links with relevant community organisations, community leaders and outreach groups in order to raise awareness of psychosis, and the available services and support that people can access. This cooperation may involve attending festivals (e.g., Notting Hill Carnival), community radio stations and engaging with Black community groups on social media platforms (e.g., see Beck & Naz,2019).

Participants in the study suggested that having the option to choose a psychologist or therapist from a similar ethnic background could enhance trust and engagement with services. It is therefore important for services to prioritise recruiting a diverse staff group that reflects the communities they serve, which can improve relatability and trust but also their experiences within services.

Clinical Implications within Services

The themes identified in the data, brought to light supportive structures that may need to be put into place in mental health services in order to engage people from these groups. Recommendations and suggestions highlighted by the participants provided useful ideas on how services can be improved in the future.

Results highlighted the importance of clinicians developing an understanding of different cultures and being more sensitive to people's cultural experiences of support systems external to the NHS. It is therefore a necessity for services and clinicians to provide and attend appropriate and regular training on cultural humility and competency, to develop further skills in working with Black communities.

It is imperative for mental health services and clinicians to commit to anti-racist practices by continuously engaging in training, research and adhering to Trust policies that promote equality and inclusivity. This commitment can be reinforced by services utilising anti-racist resources such as books, podcasts and webinars. These resources can be retrieved from the Psychological Professions Network website.

Lastly, understanding and incorporating cultural contexts into psychological formulations can enable clinicians to explore cultural experiences, perspectives, and values, and as a result lead to more personalised intervention plans. Understanding specific cultural beliefs and practices that influence help-seeking behaviours is essential for developing interventions that are culturally sensitive and effective. Using therapy resources that are culturally sensitive may also be beneficial in establishing rapport and trust with people from Black communities. For example, Adinkra Cards are an African centred engagement tool. These symbols represent cultural concepts and proverbs used by people from the Akan tribe in Ghana. These cards can be used during a session with clients from a Ghanaian or Akan/Ashanti background to build rapport (McInnis,2020). Additionally, CBT techniques such as behavioural activation can also be adapted to incorporate the client’s cultural values and beliefs, in order to make the therapy more relatable and effective.As the current study only explored people’s direct experiences of long-term psychosis, it would be of interest for future research to focus on exploring Black families and carers experiences/perspectives on help seeking for individuals with entrenched experiences of psychosis. Future research could also explore how services can implement some of the suggested recommendations to improve clinical practice and how these may impact on clinical outcomes for people from Black backgrounds, with long term psychosis.

2.5.3 Conclusion

This study explored the experiences of help seeking and support for Black people with long term psychosis. Research is limited in investigating this specific topic area, and this study will contribute to the evidence base. The study’s findings illustrate that the pathways taken by Black people to seek help is multifaceted. Important clinical implications for services are highlighted to improve and encourage people from Black background to seek support. This is important for the overall trajectory and wellbeing for people with long term psychosis. Future research should focus on exploring on how services can adapt and implement the suggested improvements within their services and also explore the perspectives of Black families and carers on help seeking for relatives with long term psychosis.

Appendix A Illustrative Quotes

Theme	Studies	Example Quotes
Stigma and Shame	All studies	I am not getting better soon. Yes, there is improvement but it is very slow. My family says are you mad. if you are seeing a psychologist (Patient 23). (Naeem et al)
Accessing non-clinical source of support	All studies	*'Well, I think this is where it's important that the health care professionals and the psychiatrists or consultants and the nurses, work with the Imams and try and understand Islamic perspective on mental health. '. (Islam et al)*
Negative experiences	All studies	*'They assigned me to a man . . . I have no intentions of talking to him about anything. I told you before: when you get comfortable with someone, they change that person to another team or they leave. I don't feel like starting all over again and I sure as hell ain't talking to a man. I can't be building trust with someone new and then they get changed and then it's someone else new.* (Carpenter-Song et al)
Perceived benefits and accessibility issues	All studies	*Service users reported experiencing personal and interpersonal benefits, such as increase in confidence in social settings and learning adaptive coping mechanisms, 'when I get anxious, I do the breathing exercises' (Jensen et al*)

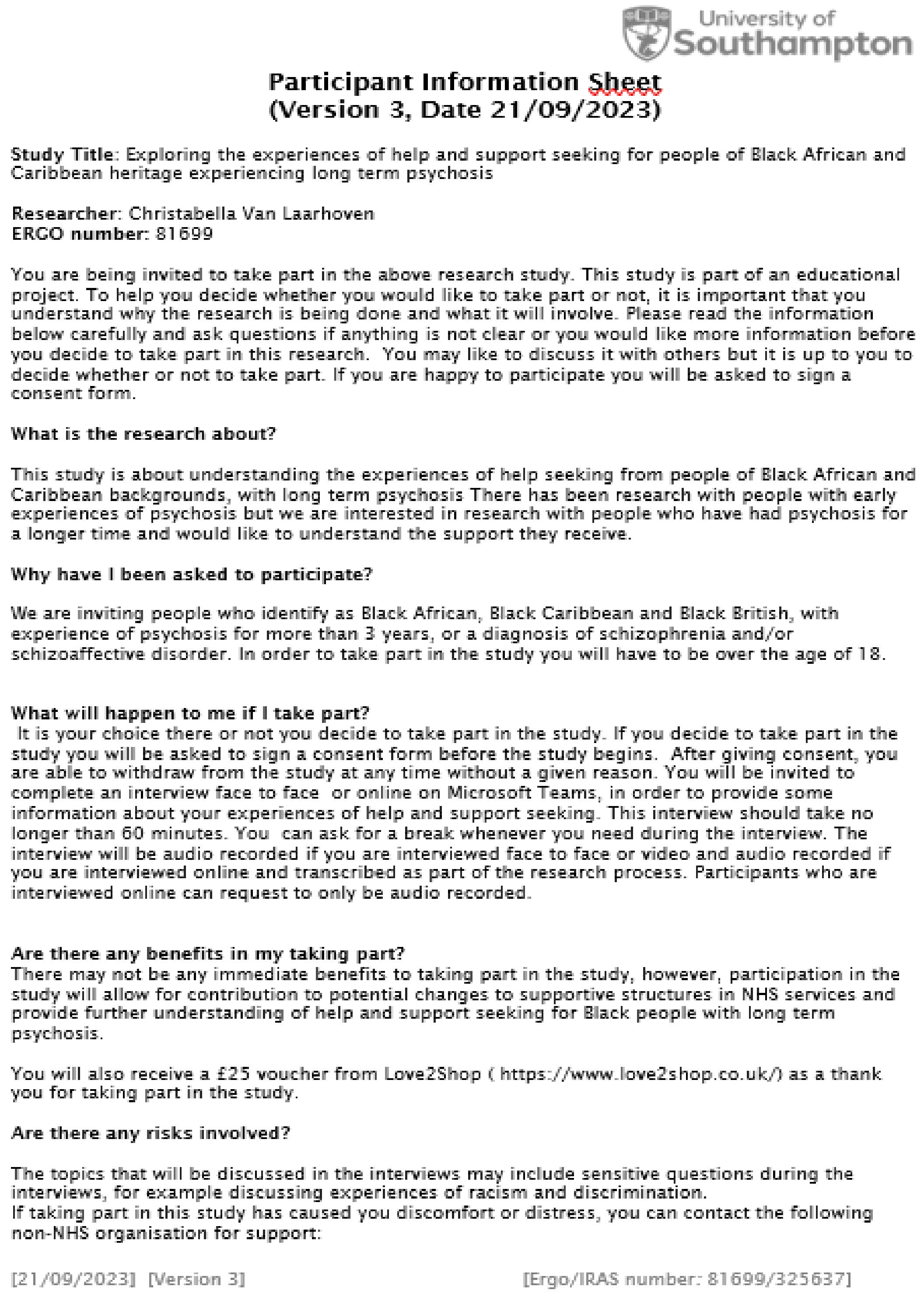
Appendix B Coding Manual

Themes	**Sub-themes**	**Codes**	**Example Quotes**
Family and social support networks	Support seeking from family and friends. Lack of support from support network	Involvement of family in therapy Practical support from family Family initiating help and support Receiving emotional support from family Not seeking support from family Support from family is not enough.	*'So, it's a family therapy and I have most of my loved ones involved. In the treatment process, to help me to improve our understanding and support within the family system, yeah. (P14)* *I don't always turn to family. Depends, because sometimes I don't feel like they understand, but I do talk to them quite a lot (P5)*
Seeking help from mainstream services	The role of medication Crisis support and help seeking from NHS services.	Positive experience seeking support from NHS service. Being offered medication but service user wants to talk about feelings. When in crisis seeking support from NHS services Contacting crisis team is not helpful.	*'So now I'm with a rehab and recovery team and they're quite helpful as well.'(P5*) *'It's when I took the medication I was out and I remember I couldn't remember how to get home or to use my phone. (P11)'*
Non-traditional pathways to seeking help	Self -reliance and personal motivations	Relying on oneself for support	*'Basically, I think that after my second psychotic episode, in conclusion, I was more*

	Seeking alternative sources of support Seeking support from religious sources	Open to seeking help due to personal caring experiences. Seeking help and support from community group organisations Going to private therapy due to choose and flexibility options. Drawing on religious beliefs and faith Seeking support from the church	*willing to access support through therapy (P13)* *'I feel OK seeking help for it now and talking about psychosis now. I think that's because I went to a hearing voices group in [redacted] since end of 2021. So, I've been going for nearly three years and that's been helpful speaking to people that have the similar experience of psychosis'(P5).* *'I think that despite all the things that I've been through, things that have helped me along the way has been religion' (P13)*
Barriers to help seeking	Racial and discriminatory experiences when seeking help. Negative experiences of services and barriers to help seeking. Knowledge and awareness Stigma, judgment and cultural perceptions A need to improve services.	Experiences of discrimination Structural typecasting Long waiting time for therapy in the NHS Difficulty connecting with clinicians. Unawareness of what to do to seek support. Lack of knowledge and understanding of psychosis from the community Judgement and shame from the community Cultural perceptions of	*…sometimes, it does play a part in how I seek support. Obviously, it's better to receive help from people who understand your mixed-race background Basically Black background and that has been a helping hand but yeah it is important to me. It brings a bit, of an understanding to understand the journey I've had in life, basically. And the trials and tribulations that we phrase basically as being a person of colour (P6)* *'You don't really know what you need but the point in time because it's it took me quite a while to kind of accept that I was crazy you know' (P10)*

		mental health from others can be a barrier. Services to be free from discrimination. Clinicians to acknowledge and validate service users experiences.	*'So, I guess one way they could improve is having, I guess, well it really starts with listening to people (P13)*

Appendix C Participant Information Sheet



University of Southampton

Participant Information Sheet
(Version 3, Date 21/09/2023)

Study Title: Exploring the experiences of help and support seeking for people of Black African and Caribbean heritage experiencing long term psychosis

Researcher: Christabella Van Laarhoven
ERGO number: 81699

You are being invited to take part in the above research study. This study is part of an educational project. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This study is about understanding the experiences of help seeking from people of Black African and Caribbean backgrounds, with long term psychosis There has been research with people with early experiences of psychosis but we are interested in research with people who have had psychosis for a longer time and would like to understand the support they receive.

Why have I been asked to participate?

We are inviting people who identify as Black African, Black Caribbean and Black British, with experience of psychosis for more than 3 years, or a diagnosis of schizophrenia and/or schizoaffective disorder. In order to take part in the study you will have to be over the age of 18.

What will happen to me if I take part?
It is your choice there or not you decide to take part in the study. If you decide to take part in the study you will be asked to sign a consent form before the study begins. After giving consent, you are able to withdraw from the study at any time without a given reason. You will be invited to complete an interview face to face or online on Microsoft Teams, in order to provide some information about your experiences of help and support seeking. This interview should take no longer than 60 minutes. You can ask for a break whenever you need during the interview. The interview will be audio recorded if you are interviewed face to face or video and audio recorded if you are interviewed online and transcribed as part of the research process. Participants who are interviewed online can request to only be audio recorded.

Are there any benefits in my taking part?
There may not be any immediate benefits to taking part in the study, however, participation in the study will allow for contribution to potential changes to supportive structures in NHS services and provide further understanding of help and support seeking for Black people with long term psychosis.

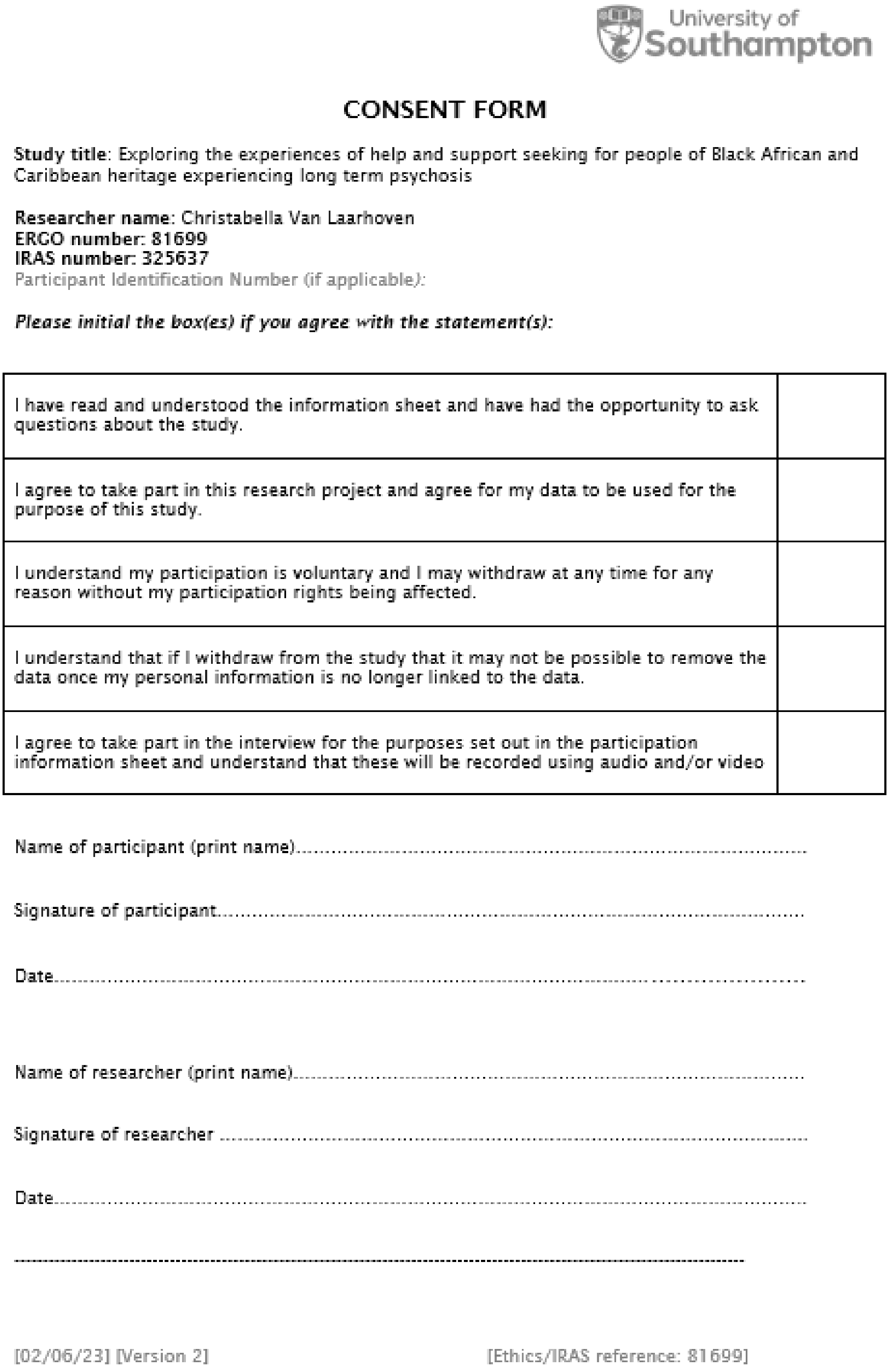
You will also receive a £25 voucher from Love2Shop (https://www.love2shop.co.uk/) as a thank you for taking part in the study.

Are there any risks involved?

The topics that will be discussed in the interviews may include sensitive questions during the interviews, for example discussing experiences of racism and discrimination.
If taking part in this study has caused you discomfort or distress, you can contact the following non-NHS organisation for support:

[21/09/2023] [Version 3] [Ergo/IRAS number: 81699/325637]

Appendix D Consent Form



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CONSENT FORM

Study title: Exploring the experiences of help and support seeking for people of Black African and Caribbean heritage experiencing long term psychosis

Researcher name: Christabella Van Laarhoven
ERGO number: 81699
IRAS number: 325637
Participant Identification Number (if applicable):

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw at any time for any reason without my participation rights being affected.	
I understand that if I withdraw from the study that it may not be possible to remove the data once my personal information is no longer linked to the data.	
I agree to take part in the interview for the purposes set out in the participation information sheet and understand that these will be recorded using audio and/or video	

Name of participant (print name)……………………………………………………………………………

Signature of participant……………………………………………………………………………

Date……………………………………………………………………………

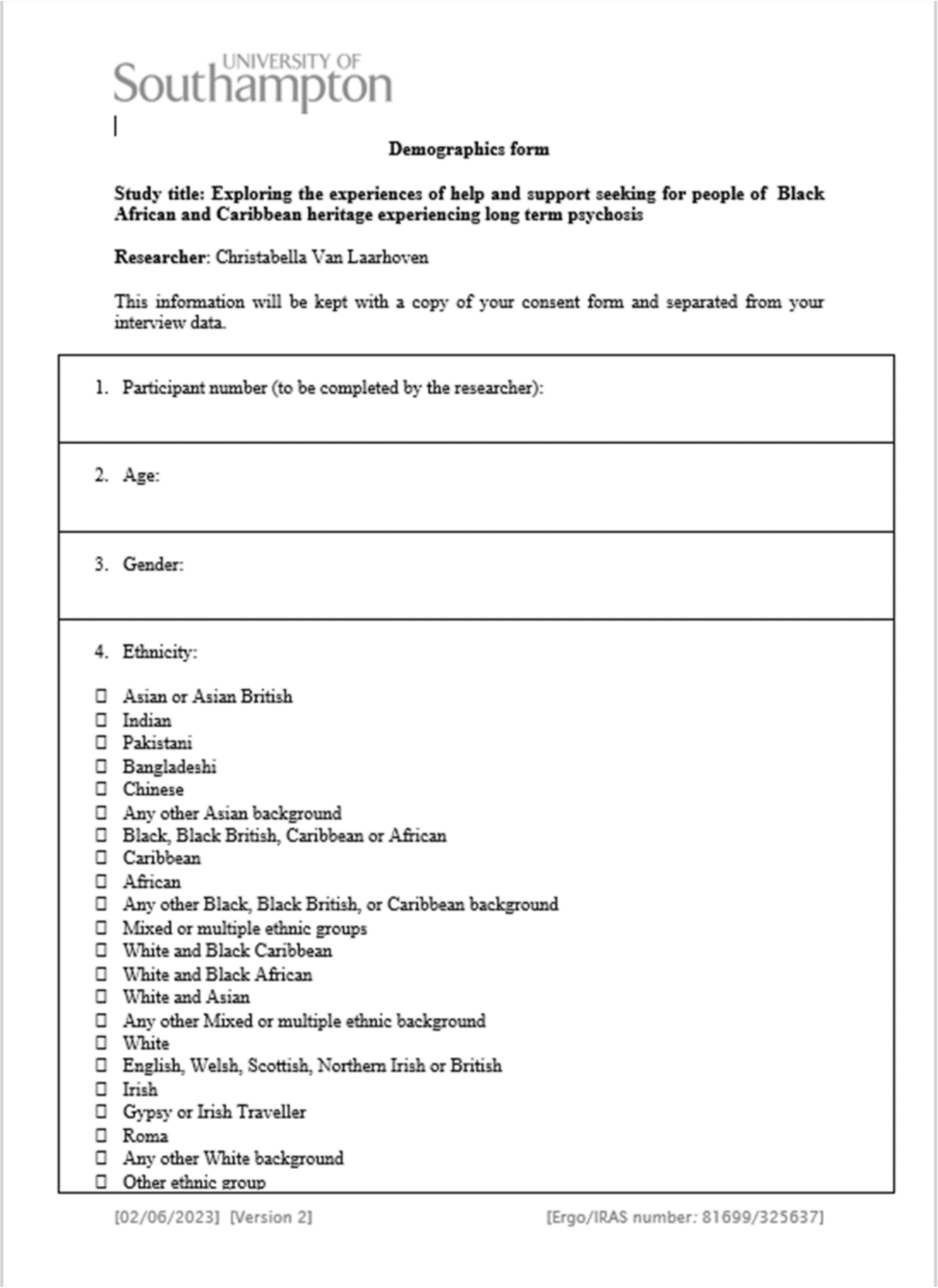
Name of researcher (print name)……………………………………………………………………………

Signature of researcher ……………………………………………………………………………

Date……………………………………………………………………………

[02/06/23] [Version 2] [Ethics/IRAS reference: 81699]

Appendix E Demographic Sheet



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Demographics form

Study title: Exploring the experiences of help and support seeking for people of Black African and Caribbean heritage experiencing long term psychosis

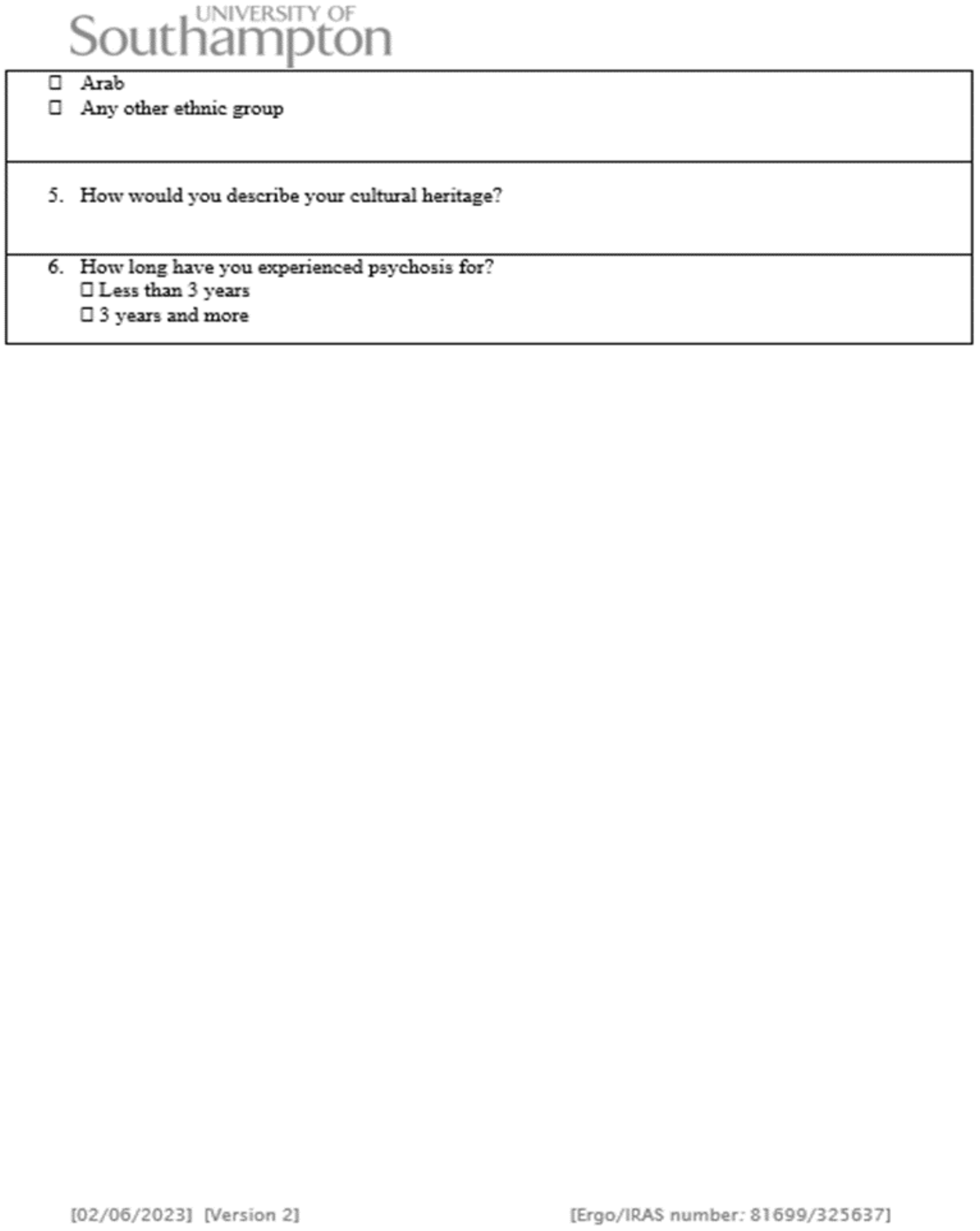
Researcher: Christabella Van Laarhoven

This information will be kept with a copy of your consent form and separated from your interview data.

1. Participant number (to be completed by the researcher):
2. Age:
3. Gender:
4. Ethnicity:

☐ Asian or Asian British
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background
☐ Black, Black British, Caribbean or African
☐ Caribbean
☐ African
☐ Any other Black, Black British, or Caribbean background
☐ Mixed or multiple ethnic groups
☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed or multiple ethnic background
☐ White
☐ English, Welsh, Scottish, Northern Irish or British
☐ Irish
☐ Gypsy or Irish Traveller
☐ Roma
☐ Any other White background
☐ Other ethnic group

[02/06/2023] [Version 2] [Ergo/IRAS number: 81699/325637]



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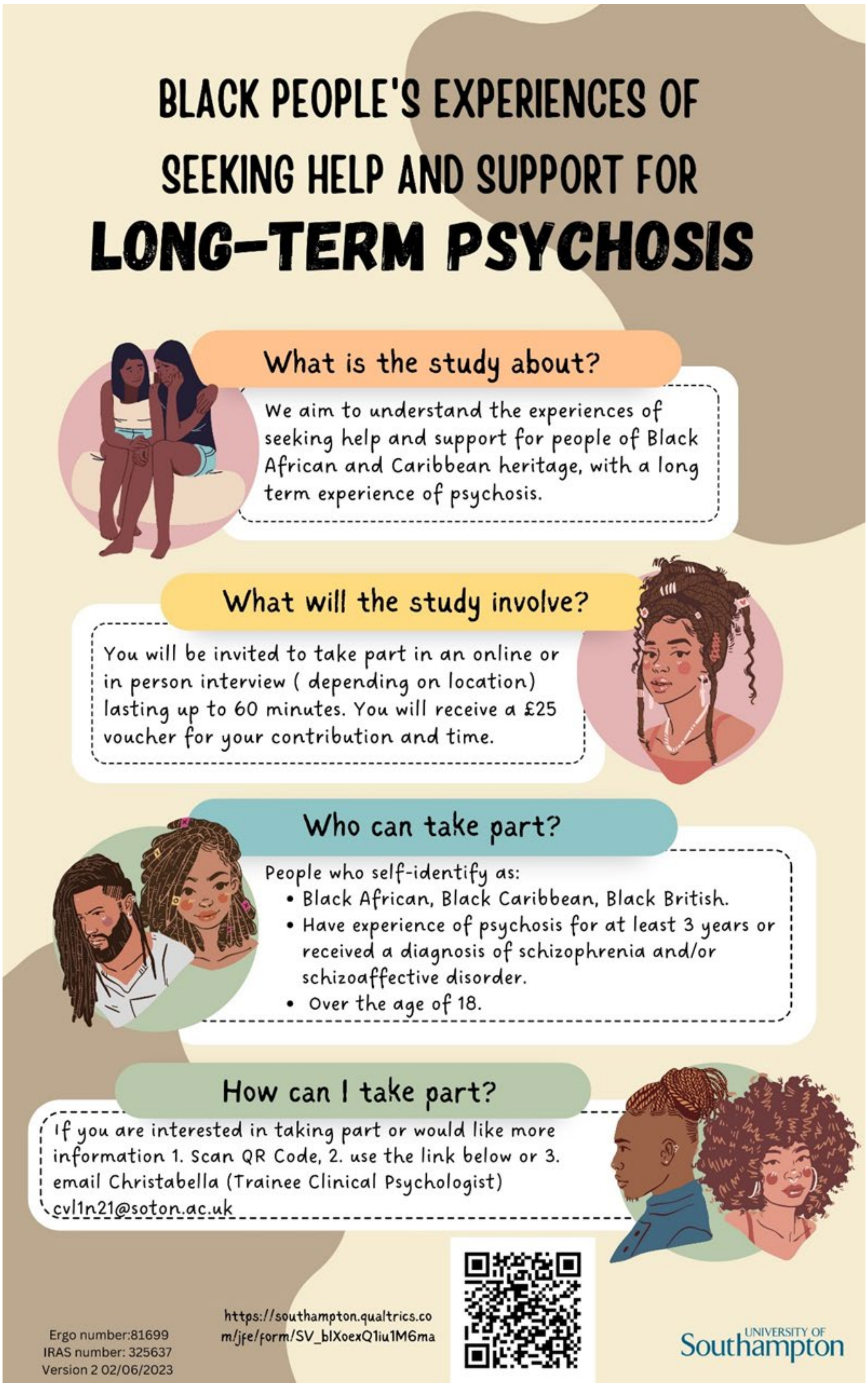
☐ Arab
☐ Any other ethnic group

5. How would you describe your cultural heritage?

6. How long have you experienced psychosis for?
   ☐ Less than 3 years
   ☐ 3 years and more

[02/06/2023] [Version 2] [Ergo/IRAS number: 81699/325637]

Appendix F Research Advertisement



BLACK PEOPLE'S EXPERIENCES OF SEEKING HELP AND SUPPORT FOR LONG-TERM PSYCHOSIS

What is the study about?

We aim to understand the experiences of seeking help and support for people of Black African and Caribbean heritage, with a long term experience of psychosis.

What will the study involve?

You will be invited to take part in an online or in person interview (depending on location) lasting up to 60 minutes. You will receive a £25 voucher for your contribution and time.

Who can take part?

People who self-identify as:

- Black African, Black Caribbean, Black British.
- Have experience of psychosis for at least 3 years or received a diagnosis of schizophrenia and/or schizoaffective disorder.
- Over the age of 18.

How can I take part?

If you are interested in taking part or would like more information 1. Scan QR Code, 2. use the link below or 3. email Christabella (Trainee Clinical Psychologist) cvl1n21@soton.ac.uk

https://southampton.qualtrics.com/jfe/form/SV_bIXoexQ1iu1M6ma

Ergo number:81699
IRAS number: 325637
Version 2 02/06/2023

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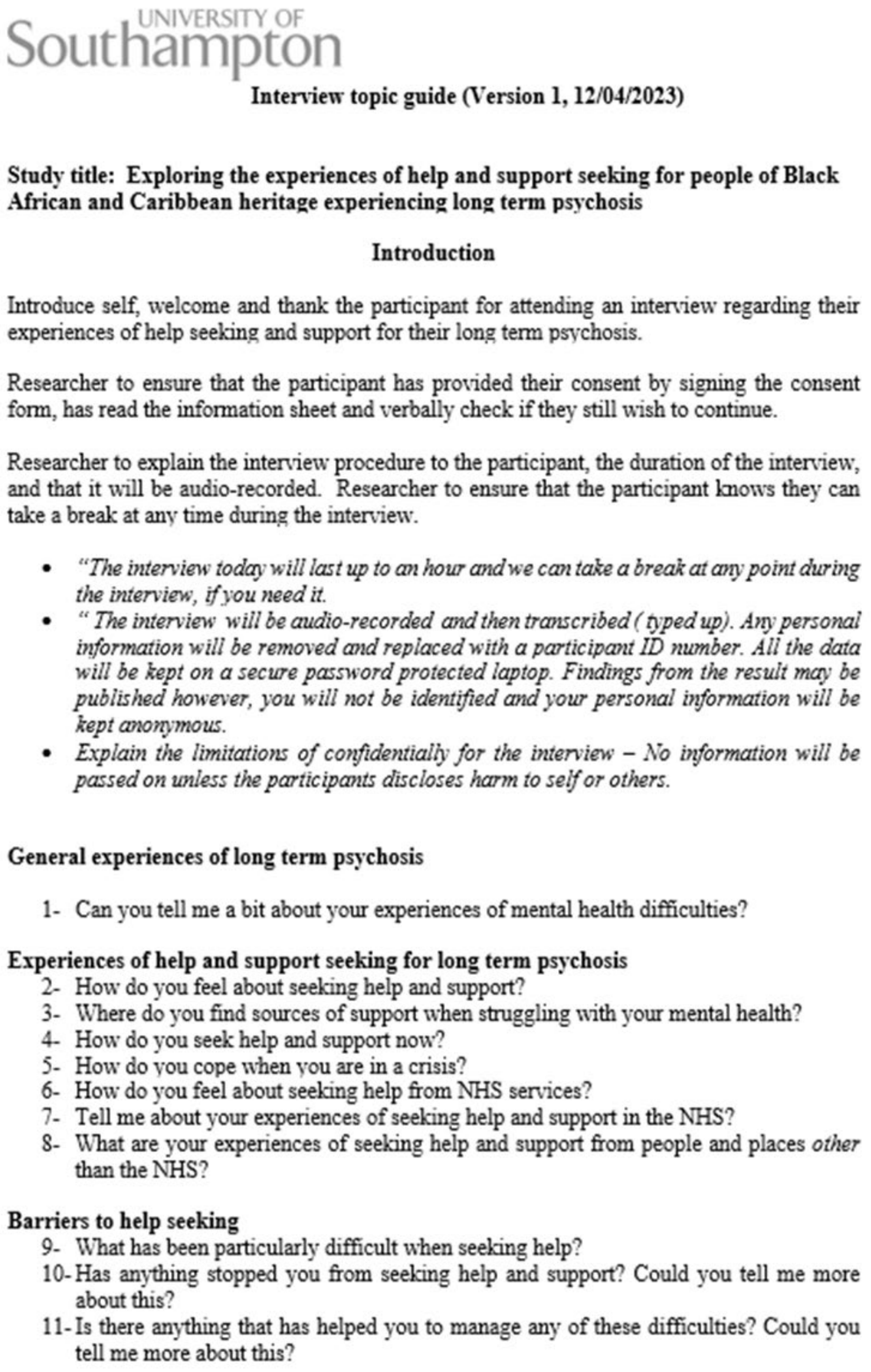
Appendix G Interview Topic Guide



Interview topic guide (Version 1, 12/04/2023)

Study title: Exploring the experiences of help and support seeking for people of Black African and Caribbean heritage experiencing long term psychosis

Introduction

Introduce self, welcome and thank the participant for attending an interview regarding their experiences of help seeking and support for their long term psychosis.

Researcher to ensure that the participant has provided their consent by signing the consent form, has read the information sheet and verbally check if they still wish to continue.

Researcher to explain the interview procedure to the participant, the duration of the interview, and that it will be audio-recorded. Researcher to ensure that the participant knows they can take a break at any time during the interview.

- *"The interview today will last up to an hour and we can take a break at any point during the interview, if you need it.*
- *" The interview will be audio-recorded and then transcribed (typed up). Any personal information will be removed and replaced with a participant ID number. All the data will be kept on a secure password protected laptop. Findings from the result may be published however, you will not be identified and your personal information will be kept anonymous.*
- *Explain the limitations of confidentially for the interview – No information will be passed on unless the participants discloses harm to self or others.*

General experiences of long term psychosis

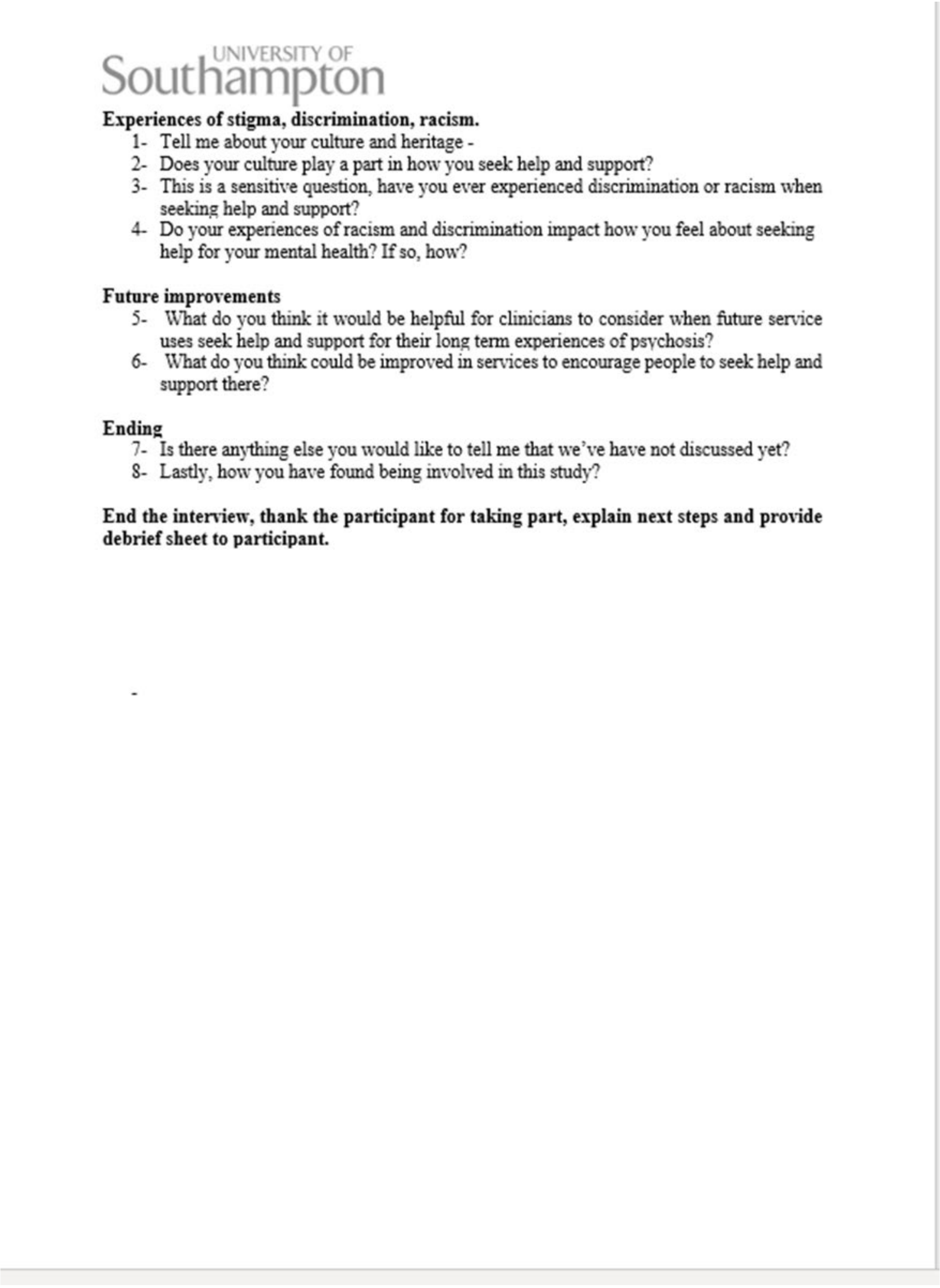
1- Can you tell me a bit about your experiences of mental health difficulties?

Experiences of help and support seeking for long term psychosis

2- How do you feel about seeking help and support?
3- Where do you find sources of support when struggling with your mental health?
4- How do you seek help and support now?
5- How do you cope when you are in a crisis?
6- How do you feel about seeking help from NHS services?
7- Tell me about your experiences of seeking help and support in the NHS?
8- What are your experiences of seeking help and support from people and places *other* than the NHS?

Barriers to help seeking

9- What has been particularly difficult when seeking help?
10- Has anything stopped you from seeking help and support? Could you tell me more about this?
11- Is there anything that has helped you to manage any of these difficulties? Could you tell me more about this?



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Southampton

Experiences of stigma, discrimination, racism.

1- Tell me about your culture and heritage -
2- Does your culture play a part in how you seek help and support?
3- This is a sensitive question, have you ever experienced discrimination or racism when seeking help and support?
4- Do your experiences of racism and discrimination impact how you feel about seeking help for your mental health? If so, how?

Future improvements

5- What do you think it would be helpful for clinicians to consider when future service uses seek help and support for their long term experiences of psychosis?
6- What do you think could be improved in services to encourage people to seek help and support there?

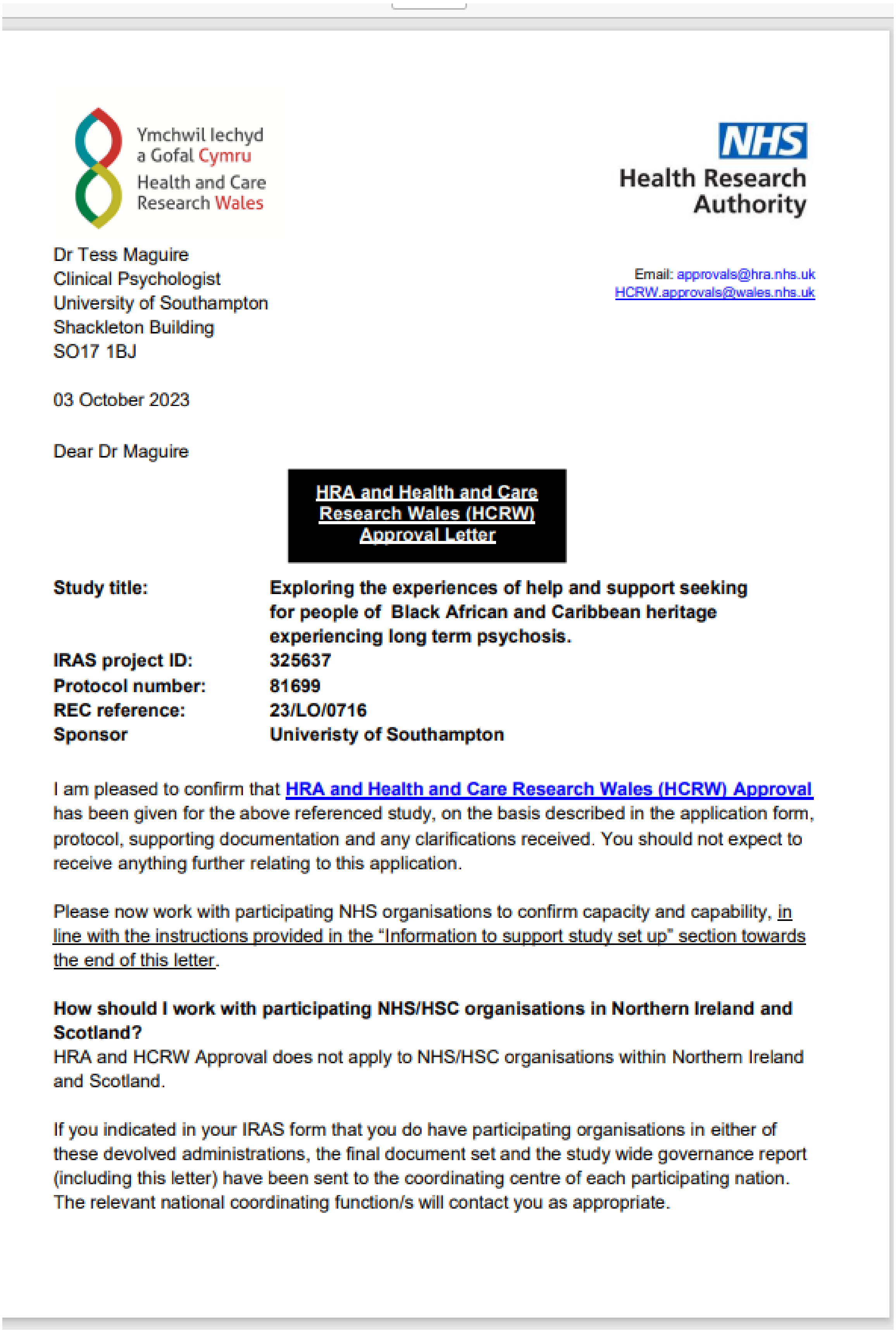
Ending

7- Is there anything else you would like to tell me that we've have not discussed yet?
8- Lastly, how you have found being involved in this study?

End the interview, thank the participant for taking part, explain next steps and provide debrief sheet to participant.

-

Appendix H Ethical Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Dr Tess Maguire
Clinical Psychologist
University of Southampton
Shackleton Building
SO17 1BJ

03 October 2023

Dear Dr Maguire

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

Study title:	**Exploring the experiences of help and support seeking for people of Black African and Caribbean heritage experiencing long term psychosis.**
IRAS project ID:	**325637**
Protocol number:	**81699**
REC reference:	**23/LO/0716**
Sponsor	**Univeristy of Southampton**

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

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

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

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

What are my notification responsibilities during the study?

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

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

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below. Your IRAS project ID is **325637**. Please quote this on all correspondence.

Yours sincerely,

Katherine Ashley-Barber
Approvals Specialist

Email: approvals@hra.nhs.uk
Copy to: Dr Linda Hammond (sponsor contact)

Appendix I Debriefing Form

Debriefing Form

Study Title: Exploring the experiences of help and support seeking for people of Black African and Caribbean heritage experiencing long term psychosis

Ethics/ERGO number: 81699
Ethics/IRAS number: 325637
Researcher(s): Christabella Van Laarhoven,
University email(s): cvl1n21@soton.ac.uk
Version and date: Version 3. 21/09/2023

Thank you for taking part in our research project. Your contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research is to understand the experiences of help and support seeking for people from a Black African and Caribbean background, experiencing long term psychosis. We hope that the findings will help us and mental health services to understand how to support people experiencing psychosis from these backgrounds. Your data will also help our understanding of different cultures and may help services become more sensitive to people's cultural experiences of support outside of the NHS.

Confidentiality

Results of this study will not include your name or any other identifying characteristics

Study results

If you would like to receive a copy of the summary of the research findings/dissertation when it is completed, please let us know by using the contact details provided on this form.

Further support

If taking part in this study has caused you discomfort or distress, you can contact the following non-NHS organisation for support:
The Black, African and Asian Therapy Network https://www.baatn.org.uk/
The Samaritans https://www.samaritans.org/
https://talkingelephantscounselling.com/counselling-for-ethnic-minorities

Further reading

If you would like to learn more about this area of research, you can refer to the following resources:

Bard, S., Degnan, A., Berry, K., & Edge, D. (2021). Exploring the relationships between illness beliefs and psychosis symptoms among Black African and Caribbean people with non-affective psychosis. Psychosis, 13(3), 265-275.

Further information

If you have any concerns or questions about this study, please contact **Christabella Van Laarhoven at** **cvl1n21@soton.ac.uk** who will do their best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing: **rgoinfo@soton.ac.uk,** or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your participation in this research.

Appendix J Excerpt of reflective log

Reflective Log

October 25 2023

Interview 1

For some reason I was not aware that there may be a communication barrier e.g broken English, difficult to understand at some points

Wondering about my style of interviewing, at times I felt like a therapist wanting to ask more questions/formulate

October 26 2023

Interview 3

This interview was hard. I found it upsetting to hear that this individual did not have many people to go to for support and often relies on themselves for support.

The participant did not speak much about culture, identified as black African but did not want to specify where from, maybe I prodded too much for that information ?

List of References

Abraído-Lanza, A. F., Armbrister, A. N., Flórez, K. R., & Aguirre, A. N. (2006). Toward a theory-driven model of acculturation in public health research. *American journal of public health, 96*(8), 1342-1346.

Adams, D., & Young, K. (2021). A systematic review of the perceived barriers and facilitators to accessing psychological treatment for mental health problems in individuals on the autism spectrum. *Review Journal of Autism and Developmental Disorders*, *8*(4), 436-453.

Adriaanse, M., Van Domburgh, L., Hoek, H. W., Susser, E., Doreleijers, T. A. H., & Veling, W. (2015). Prevalence, impact and cultural context of psychotic experiences among ethnic minority youth. *Psychological Medicine*, *45*(3), 637-646.

American Psychiatric Association. (2013*). DSM 5 diagnostic and statistical manual of mental disorders.*

Anderson, K. K., Flora, N., Archie, S., Morgan, C., & McKenzie, K. (2014). Race, ethnicity, and the duration of untreated psychosis: a systematic review. *Social psychiatry and psychiatric epidemiology*, *49*, 1161-1174.

Arnold, L. M., Keck Jr, P. E., Collins, J., Wilson, R., Fleck, D. E., Corey, K. B., ... & Strakowski, S. M. (2004). Ethnicity and first-rank symptoms in patients with psychosis. *Schizophrenia Research*, 67(2-3), 207-212.

Bard, S., Degnan, A., Berry, K., & Edge, D. (2021). Exploring the relationships between illness beliefs and psychosis symptoms among Black African and Caribbean people with non-affective psychosis. *Psychosis*, 13(3), 265-275.

Barnett, P., Mackay, E., Matthews, H., Gate, R., Greenwood, H., Ariyo, K., ... & Smith, S. (2019). Ethnic variations in compulsory detention under the Mental Health Act: a systematic review and meta-analysis of international data. *The Lancet Psychiatry*, 6(4), 305-317.

Beck, A., & Naz, S. (2019). The need for service change and community outreach work to support trans-cultural cognitive behaviour therapy with Black and Minority Ethnic communities. The Cognitive Behaviour Therapist, 12, e1.

Berger, R. (2015). Now I see it, now I don’t: Researcher’s position and reflexivity in qualitative research. *Qualitative research*, *15*(2), 219-234.

Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative psychology*, *9*(1), 3.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Bourque, F., van der Ven, E., & Malla, A. (2011). A meta-analysis of the risk for psychotic disorders among first-and second-generation immigrants. *Psychological medicine*, *41*(5), 897-910.

Burgess-Barr, S., Nicholas, E., Venus, B., Singh, N., Nethercott, A., Taylor, G., & Jacobsen, P. (2023). International rates of receipt of psychological therapy for psychosis and schizophrenia: systematic review and meta-analysis. International Journal of Mental Health Systems, 17(1), 8.

Cairns, V. A., Reid, G. S., & Murray, C. (2015). Family members' experience of seeking help for first-episode psychosis on behalf of a loved one: a meta-synthesis of qualitative research. *Early intervention in psychiatry*, *9*(3), 185-199.

Carpenter, C. J. (2010). A meta-analysis of the effectiveness of health belief model variables in predicting behavior. *Health communication, 25(8),* 661-669.

Carpenter-Song, E., Chu, E., Drake, R. E., Ritsema, M., Smith, B., & Alverson, H. (2010). Ethno-cultural variations in the experience and meaning of mental illness and treatment: implications for access and utilization. *Transcultural Psychiatry*, *47*(2), 224-251.

Codjoe, L., Barber, S., Ahuja, S., Thornicroft, G., Henderson, C., Lempp, H., & N'Danga-Koroma, J. (2021). Evidence for interventions to promote mental health and reduce stigma in Black faith communities: systematic review. *Social psychiatry and psychiatric epidemiology*, *56*, 895-911

Critical Appraisal Skills Programme (2018). CASP (Qualitative) Checklist. Retrieved 28th February 2024 from https://casp-uk.net/checklists/casp-qualitative-studies-checklist-fillable.pdf.

Das-Munshi, J., Bhugra, D., & Crawford, M. J. (2018). Ethnic minority inequalities in access to treatments for schizophrenia and schizoaffective disorders: findings from a nationally representative cross-sectional study. *BMC medicine*, *16*, 1-10.

Degnan, A., Berry, K., Crossley, N., & Edge, D. (2023). Social network characteristics of Black African and Caribbean people with psychosis in the UK. *Journal of psychiatric research*, *161*, 62-70.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of health services research & policy*, 10(1), 45-53.

Fernando, S. (2020). Race and culture in psychiatry. In *The Routledge International Handbook of Race, Culture and Mental Health* (pp. 92-102). Routledge.

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181-194.

Freitas, D. F., Walker, S., Nyikavaranda, P., Downs, J., Patel, R., Khondoker, M., ... & Hayes, R. D. (2022). Ethnic inequalities in involuntary admission under the Mental Health Act: an exploration of mediation effects of clinical care prior to the first admission. *The British Journal of Psychiatry*, 1-10.

Fridgen, G. J., Aston, J., Gschwandtner, U., Pflueger, M., Zimmermann, R., Studerus, E., ... & Riecher-Rössler, A. (2013). Help-seeking and pathways to care in the early stages of psychosis. *Social Psychiatry and Psychiatric Epidemiology*, *48*, 1033-1043.

Halvorsrud, K., Nazroo, J., Otis, M., Brown Hajdukova, E. & Bhui, K. (2019). Ethnic inequalities in the incidence of diagnosis of severe mental illness in England: a systematic review and new meta-analyses for non-affective and affective psychoses. Social Psychiatry and Psychiatric Epidemiology, 54(11), 1311–1323.

Huda, A. S. (2021). The medical model and its application in mental health. *International Review of Psychiatry*, *33*(5), 463-470.

Ince, P., Haddock, G., & Tai, S. (2016). A systematic review of the implementation of recommended psychological interventions for schizophrenia: rates, barriers, and improvement strategies. Psychology and Psychotherapy: Theory, Research and Practice, 89(3), 324-350.

Irvine, A., Drew, P., & Sainsbury, R. (2013). ‘Am I not answering your questions properly?’Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews. *Qualitative research*, *13*(1), 87-106.

Islam, Z., Rabiee, F., & Singh, S. P. (2015). Black and minority ethnic groups’ perception and experience of early intervention in psychosis services in the United Kingdom. *Journal of Cross-Cultural Psychology*, *46*(5), 737-753.

Jensen, E., Carr, R., Degnan, A., Berry, K., & Edge, D. (2021). Exploring service user and family perspectives of a Culturally adapted Family Intervention (CaFI) for African-Caribbean people with psychosis: A qualitative study. *British Journal of Clinical Psychology*, *60*(2), 270-289.

Jongsma, H. E., Karlsen, S., Kirkbride, J. B., & Jones, P. B. (2021). Understanding the excess psychosis risk in ethnic minorities: the impact of structure and identity. *Social psychiatry and psychiatric epidemiology*, *56*(11), 1913-1921.

Knifton, L. (2012). Understanding and addressing the stigma of mental illness with ethnic minority communities. *Health Sociology Review*, 21(3), 287-298.

Knight, S., Jarvis, G. E., Ryder, A. G., Lashley, M., & Rousseau, C. (2023). ‘It just feels like an invasion’: black first-episode psychosis patients’ experiences with coercive intervention and its influence on help-seeking behaviours. *Journal of Black Psychology*, *49*(2), 200-235.

Kuipers, E., Yesufu-Udechuku, A., Taylor, C., & Kendall, T. (2014). Management of psychosis and schizophrenia in adults: summary of updated NICE guidance. *bmj*, *348*.

Lawlor, C., Johnson, S., Cole, L., & Howard, L. M. (2010). Ethnic variations in pathways to acute care and compulsory detention for women experiencing a mental health crisis. *International Journal of Social Psychiatry*, 58(1), 3–15.

Li, W., Zhang, L., Luo, X., Liu, B., Liu, Z., Lin, F., ... & Naeem, F. (2017). A qualitative study to explore views of patients', carers' and mental health professionals' to inform cultural adaptation of CBT for psychosis (CBTp) in China. *BMC psychiatry*, *17*, 1-9.

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*, *1*(1), 31-42.

Lumivero (2023) *NVivo* (Version 14) Retrieved 6th January 2024 from: www.lumivero.com.

Lyons, M., Evison, P., Berrios, R., Castro, S., & Brooks, H. (2022). The lived experience of psychosis in Nicaragua: A qualitative examination of the views of service users. *Journal of Mental Health*, *31*(1), 50-57.

Ma, R., Wang, Y., Wang, X. Q., Yu, K., Zhang, C. C., & Zhou, Y. Q. (2023). Analysis of hindering and facilitating factors of help-seeking behavior in schizophrenia based on COM-B model: a descriptive qualitative study. *BMC psychiatry*, *23*(1), 770.

McCambridge, J., Kypri, K., & Elbourne, D. (2014). Research participation effects: a skeleton in the methodological cupboard. *Journal of clinical epidemiology*, *67*(8), 845-849.

McHugh, M. L. (2012). Interrater reliability: the kappa statistic. *Biochemia medica*, *22*(3), 276-282.

McInnis, E. M. (2020). An African Psychology Perspective on White Supremacy within UK Clinical Psychology. Journal of Critical Psychology, Counselling and Psychotherapy, 20(3), 5-15.

Memon, A., Taylor, K., Mohebati, L. M., Sundin, J., Cooper, M., Scanlon, T., & De Visser, R. (2016). Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England. *BMJ open*, *6*(11), e012337.

Millar, C. (2023). Psychosis: A ever-changing conceptualisation. *PSYPAG,24*, 32-37. DOI: 10.53841/bpspag.2023.1.124.32

Morris, R. M., Sellwood, W., Edge, D., Colling, C., Stewart, R., Cupitt, C., & Das-Munshi, J. (2020). Ethnicity and impact on the receipt of cognitive–behavioural therapy in people with psychosis or bipolar disorder: an English cohort study. *BMJ open*, *10*(12), e034913.

Naeem, F., Habib, N., Gul, M., Khalid, M., Saeed, S., Farooq, S., ... & Kingdon, D. (2016). A qualitative study to explore patients', carers' and health professionals' views to culturally adapt CBT for psychosis (CBTp) in Pakistan. *Behavioural and Cognitive Psychotherapy*, *44*(1), 43-55.

National Institute for Health and Care Excellence. Psychosis and schizophrenia: treatment and management. (Clinical guideline 178.) 2014. Retrieved 15th March 2024 from: http://guidance.nice.org.uk/CG178].

Nazroo, J. Y., Bhui, K. S., & Rhodes, J. (2020). Where next for understanding race/ethnic inequalities in severe mental illness? Structural, interpersonal and institutional racism. *Sociology of Health & Illness*, 42(2), 262-276.

Oduola, S., Morgan, C., & Craig, T. K. (2019). Are ethnic differences in pathways to care for psychosis in England reducing?: Analysis of two population-based studies of first-episode psychosis in South London. In *Early intervention in psychiatric disorders across cultures* (pp. 73-86). Oxford University Press.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... & Brennan, S. E. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ [Internet]. *British Medical Journal Publishing Group*.

Palaganas, E. C., Sanchez, M. C., Molintas, M. P., & Caricativo, R. D. (2017). Reflexivity in Qualitative Research: A Journey of Learning. The Qualitative Report, 22(2), 426-438

Phiri, P., Rathod, S., Gobbi, M., Carr, H., & Kingdon, D. (2019). Culture and therapist self-disclosure. *The Cognitive Behaviour Therapist*, *12*, e25.

Pinto, R., Ashworth, M., & Jones, R. (2008). Schizophrenia in black Caribbeans living in the UK: an exploration of underlying causes of the high incidence rate. *British Journal of General Practice*, 58(551), 429-434.

Popay J, Roberts, H., Snowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., Duffy, S. *Guidance on the conduct of narrative synthesis in systematic reviews*. Lancaster, UK: Institute of Health Research; 2006.

Qassem, T., Bebbington, P., Spiers, N., McManus, S., Jenkins, R., & Dein, S. (2015). Prevalence of psychosis in black ethnic minorities in Britain: analysis based on three national surveys. *Social Psychiatry and Psychiatric Epidemiology*, 50(7), 1057-1064.

Rathod, S., Javed, A., Iqbal, R., Al-Sudani, A., Vaswani-Bye, A., Haider, I., & Phiri, P. (2023). Results of a qualitative study of patient, carer and clinician views on the experience of caring for individuals with psychosis in Pakistan. *The Cognitive Behaviour Therapist*, *16*, e17.

Rathod, S., Kingdon, D., Phiri, P., & Gobbi, M. (2010). Developing culturally sensitive cognitive behaviour therapy for psychosis for ethnic minority patients by exploration and incorporation of service users' and health professionals' views and opinions. *Behavioural and cognitive psychotherapy*, *38*(5), 511-533.

Rosenstock, I. M. (1966). Why people use health services. *The Milbank Memorial Fund Quarterly,* 44(3), 94–127.

Schlief, M., Rich, N., Rains, L. S., Baldwin, H., Rojas-Garcia, A., Nyikavaranda, P., ... & Johnson, S. (2023). Ethnic differences in receipt of psychological interventions in Early Intervention in Psychosis services in England–a cross-sectional study. *Psychiatry research*, *330*, 115529.

Sin, J., Elkes, J., Batchelor, R., Henderson, C., Gillard, S., Woodham, L. A., ... & Cornelius, V. (2021). Mental health and caregiving experiences of family carers supporting people with psychosis. *Epidemiology and Psychiatric Sciences*, *30*, e3.

Singh, S. P., Islam, Z., Brown, L. J., Gajwani, R., Jasani, R., Rabiee, F., & Parsons, H. (2013). Study 1: determinants of ethnic variation in pathways to care during first-episode psychosis. In *Ethnicity, detention and early intervention: reducing inequalities and improving outcomes for black and minority ethnic patients: the ENRICH programme, a mixed-methods study*. NIHR Journals Library.

Sniehotta, F. F., Presseau, J., & Araújo-Soares, V. (2014). Time to retire the theory of planned behaviour. *Health psychology review*, 8(1), 1-7.

Sogutlu, L., Varlik, C., Guler, A., Bilge, Y., & Sifa Goktas, S. (2021). The effectiveness of family psychological training program applied to relatives of patients with schizophrenia. *Psychiatria Danubina*, *33*(broj 4), 551-559.

Spencer, M. S., & Chen, J. (2004). Effect of discrimination on mental health service utilization among Chinese Americans. *American Journal of Public Health*, *94*(5), 809-814.

Stevović, L. I., Repišti, S., Radojičić, T., Sartorius, N., Tomori, S., Kulenović, A. D., ... & Jovanović, N. (2022). Non-pharmacological interventions for schizophrenia—analysis of treatment guidelines and implementation in 12 Southeast European countries. *Schizophrenia*, *8*(1), 10.

Tanskanen, S., Morant, N., Hinton, M., Lloyd-Evans, B., Crosby, M., Killaspy, H., ... & Johnson, S. (2011). Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study. *BMC Psychiatry*, 11(1), 1-11.

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC medical research methodology*, *12*, 1-8.

Vyas, A., Wood, L., & McPherson, S. (2021). A qualitative exploration of stigma experiences of second-generation British South-Asian people using an early intervention in psychosis service. *Psychosis*, *13*(4), 302-314.

Watson, A., Mellotte, H., Hardy, A., Peters, E., Keen, N., & Kane, F. (2022). The digital divide: factors impacting on uptake of remote therapy in a South London psychological therapy service for people with psychosis. Journal of Mental Health, 31(6), 825-832.

Wood, L., Byrne, R., Enache, G., Lewis, S., Fernández Díaz, M., & Morrison, A. P. (2022). Understanding the stigma of psychosis in ethnic minority groups: A qualitative exploration. *Stigma and Health*, *7*(1), 54.

Zafar, S. N., Syed, R., Tehseen, S., Gowani, S. A., Waqar, S., Zubair, A., ... & Naqvi, H. (2008). Perceptions about the cause of schizophrenia and the subsequent help seeking behavior in a Pakistani population–results of a cross-sectional survey. *BMC psychiatry*, *8*, 1-8.