Pathways to Care, Ethnicity and Psychotic Disorders: Examining Policy Impacts and Community-Based Interventions

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Thesis Portfolio Abstract

Background: Outcomes for psychosis improve if people access early support and treatment. There are several sociodemographic, pathways to care (PtC) and clinical factors that are associated with delays in treatment. This thesis examines community-level interventions aimed at improving these delays within community and primary care settings for people from minority ethnic groups. Furthermore, it explores the impact of ethnicity, age, sex, relationship status, educational level, employment status, occupation, referral source and primary diagnosis on wait time for early intervention for psychosis (EIP) services.

Methods: A systematic review of community-level interventions aimed at improving PtC to psychosis treatment for minority ethnic communities was executed. An empirical study that explored wait time across sociodemographic, PtC and clinical factors was completed. Data from non-identifiable clinical records were analysed using descriptive statistics and regression models.

Results: Five studies met the inclusion criteria and reported on two interventions. Both interventions were conducted in the United States. Some increases in views of professional help-seeking were observed. Barriers and facilitators of the interventions were also identified. A total of 1806 patients were included in the empirical study. Results showed 73% of patients were not seen by the community EIP team within two weeks. Longer wait time for EIP services was associated with increases in age and contact via community EIP services and shorter wait time was associated with A&E or ‘other’ referrals. White non-British and South Asian groups had shorter wait times due to them being more represented in inpatient admission.

Conclusions: The empirical paper highlights ongoing disparities for minority ethnic groups, and the systematic review highlighted that community-level interventions could be valuable for improving help-seeking in minority ethnic groups (caution is needed due to limited evidence). Further research is required to develop and implement interventions for minority groups to reduce disparities in psychosis care and treatment.

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Chapter One

Introduction

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Chapter One

Introduction

This chapter provides an overview of the key concepts included throughout the thesis portfolio including psychosis and associated risk factors, the prodromal stage of psychosis, treatment delays, models of help-seeking, pathways to care (PtC) and ethnicity. The chapter concludes with the aims of the thesis portfolio and a brief overview of the subsequent chapters.

Psychosis and Associated Risk Factors

According to research, psychosis affects approximately 1% of the UK population (National Institute for Health and Care Excellence; NICE., 2014; McManus et al., 2016). The total yearly cost for psychosis including healthcare use, costs to carers and families, economic inactivity and mortality is estimated at £11.8 billion in England (NHS England, 2023). Research suggests that a higher incidence of psychosis is associated with migration (Cantor-Graae et al., 2013), being from a minority ethnic background (Termorshuizen & Selten, 2023), being male (Ochoa et al., 2012) and being aged between 15 and 29 years (Simon et al., 2017). Furthermore, the development of psychotic disorders has been associated with many socio-environmental factors including parental age (McGrath et al., 2014), maternal stress (Khashan et al., 2008), urbanicity (Vassos et al., 2012), substance misuse (Semple et al., 2005), sexual abuse (Thompson et al., 2014), physical abuse, family alcohol or drug use (Ranu et al., 2022), being bullied (Mayo et al., 2017) and stressful life events (Kraan et al., 2015). Additionally, psychotic disorders have also been associated with genetics, diseases, infections and exposure to Toxoplasma gondii (a parasite) (NICE., 2021).

Prodromal Stage of Psychosis

Research has suggested the presence of a prodromal period that begins before the onset of a first-episode psychosis (FEP) (Yung & McGorry, 1996). It is not uncommon for people to experience symptoms associated with psychosis (van Os & Linscott, 2012), with reviews noting experiences of hallucinations of a pooled estimate of 9.6% (Maijer et al., 2018) and delusions ranging between 3%–91% (Heilskov et al., 2020) in non-clinical samples. However, research has identified some notable differences between clinical and non-clinical populations, such as the appraisal and response to experiences (Johns et al., 2014) and factors that might mean that some people in the general population are more at risk of developing FEP (Fusar-Poli et al., 2019). These include childhood trauma, parental communication issues, substance misuse, adult life events and exposure to viruses (e.g. Borna disease virus) (Fusar-Poli et al., 2019).

People who are identified as being at risk of developing psychosis during the prodromal period are often referred to as being At Risk-Mental State (ARMS) (Schultze-Lutter et al., 2011). People with ARMS may experience less specific symptoms, such as anxiety, low mood (Fuser-Poli et al., 2013) or psychotic symptoms (e.g. hallucinations) that are less severe and frequent (Addington et al., 2023). Approximately 8-17% of people identified as ARMS go on to develop FEP (Davies & Whale, 2022). Interventions for ARMS include cognitive behavioural therapy (CBT) and family therapy (NICE, 2014). Intervening at this stage has also been associated with reduced delays to treatment (Gebhardt et al., 2020) and engagement in treatment (Davies et al., 2018). Studies reporting on CBT treatment during ARMS have shown improvements in the transition rate to FEP (Devoe et al., 2019a; Gebhardt et al., 2020; Mei et al., 2021), reduction of attenuated psychotic symptoms (Zheng et al., 2022) and social functioning (Devoe et al., 2019b).

Delays to Treatment

NICE guidance outlines that if someone is suspected to be experiencing a FEP then they need to be assessed by an early intervention for psychosis (EIP) team with minimum delay, and stipulate that this should be within two weeks (NICE., 2014). Following this, if it is identified that the person is experiencing FEP then it is outlined that they should be offered an anti-psychotic medication alongside Cognitive Behavioural Therapy (CBT) and family intervention (NICE., 2014). However, some demographic groups such as Black Caribbean people (Schoer et al., 2019), adolescents (<19 years of age) (Fond et al., 2018) and people from rural communities (Kvig et al., 2017) often experience delays to treatment.

There is an abundance of research reporting that delays to treatment predict worse outcomes for life expectancy (Hjorthøj et al., 2017), recovery from symptoms (Penttilä et al., 2014) and functional outcomes (Pelayo-Terán et al., 2018). Moreover, research suggests that outcomes in the first two years can be indicative of recovery 15 years later (Harrison et al., 2001). Consequently, identifying individuals with psychosis more efficiently has become a priority to improve outcomes for people with psychosis (Singh, 2010). This resulted in the development of EIP services in 1999 (Neale & Kinnair, 2017) that aimed to support people in the most critical (two-three year) period of developing symptoms with quicker access to treatment (Crumlish et al., 2009). EIP services have shown promising outcomes. For instance, a meta-analysis comparing 10 randomised clinical trials across EIP services and treatment as usual found that EIP services showed an improvement in treatment discontinuation, symptom severity, relapse, remission, recovery, global functioning, quality of life and less hospital admissions (Correll et al., 2018). Despite the success of EIP services, UK mental health services experienced funding cuts in (circa) 2012, and many teams were integrated into community teams (McGorry, 2015). However, in 2014 “Achieving Better Access to Mental Health Services by 2020” was published and outlined that mental and physical health services should be considered equal and should both offer timely access to high-quality care and treatment (Department of Health & NHS England., 2014). Following this, in 2016 an Access and Waiting Time Standard was introduced for EIP services. The Access and Waiting Time Standard specified that at least half of all referrals received by EIP services are offered NICE-approved interventions within two weeks of referral (NHS England, 2016). The two-week guidance aligned with physical health targets where rapid action is needed (e.g. suspected cancer) (NHS England, 2014). Baseline measurements from an NHS service revealed that before the introduction of the Access and Waiting Time Standard, only 21% of referrals were receiving treatment within two weeks (Singh et al., 2018). Since the introduction of the Access and Waiting Time Standard, there has been a limited number of studies that have reported on its success, but outcomes do appear positive, nonetheless. One study found that after six months, EIP service users were waiting below the outlined target, but they did not find that EIP improved wait times any more than when people received care in unspecialised mental health services for FEP (Kreutzberg & Jacobs, 2020). Another study used data from initial introduction to up to approximately one year and highlighted that 88% of referrals were seen within two weeks (Adamson et al., 2018). There does not appear to be research that identifies who is seen and who is not seen within the two-week timeframe since the introduction of the Access and Waiting Time Standard. This is surprising given that research has exposed disparities among certain populations (e.g. Schoer et al., 2019).

Pathways to Care

Delays to treatment can be a result of individual help-seeking and the response of services (Norman et al., 2004). To reduce delays to treatment, it is important to consider help-seeking and PtC for psychosis. PtC are defined as:

"the sequence of contacts with individuals and organisations prompted by the distressed person's efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response to these efforts") (Rogler & Cortes, 1993).

The concept of PtC is valuable in help-seeking research as it enables the measurement/understanding of help-seeking on an individual (and caregiver) level, whilst also capturing responses from services (Singh & Grange, 2006). PtC are measured by the number of contacts with services, the type of contacts and by measuring the duration that the pathway lasted (from onset to accessing treatment) (Singh & Grange, 2006). PtC information is useful because it can help us understand where to intervene (i.e. at the service level or individuals/caregiver level) (Lloyd-Evans et al., 2011).

Duration of untreated psychosis (DUP) is another widely used measurement in psychosis literature (e.g. Oduola et al., 2021; Srihari et al., 2022). DUP refers to the time between the onset of symptoms and treatment for psychosis (Norman & Malla, 2001). The measurement of DUP can vary across studies, but often involves the use of DUP measurement tools and/or clinical interviews (Register-Brown & Hong, 2014). Research that has made use of the DUP measurement has helped to highlight the importance of early detection and treatment of psychosis symptoms and the importance of addressing barriers to care (Penttilä et al., 2014).

Ethnicity and Psychosis

Bhopal (2006) defines ethnicity as a mix of cultural factors such as language, religion, diet, and ancestry that make up a particular social group that individuals identify with (or are identifiable by). Ethnicity is different from race, which refers to physical features that reflect a person's ancestry, but these terms are often inappropriately used, with the incorrect assumption that they are interchangeable (Bhopal., 2006). Both race and ethnicity are social constructs that have the potential to change over time, particularly ethnicity (Braveman & Dominguez, 2021). Racial and Ethnic terms are used differently according to country. For example, The United States tend to rely on racial characteristics (Braveman & Dominguez, 2021). This thesis will have a key focus on ethnicity and will attempt to be clear when referring to research by others. If research uses race and ethnicity interchangeably then this will be amended when reported.

Research documents a higher rate of psychosis in individuals who have immigrated (or have a family history of migration) and are from ethnic minority groups (Bourque et al., 2011; Cantor-Graae & Selten, 2005; Dealberto et al., 2011; Morgan et al., 2006; Termorshuizen & Selten, 2023). People from African and Caribbean backgrounds are particularly at risk of psychosis (Hollander et al., 2016; Kirkbride et al., 2017; Oduola et al., 2021). Schofield et al. (2019) used focus groups to understand the increased risk of psychosis with service users from African and Caribbean backgrounds. The authors found common themes of unfair treatment from services, a consistent lack of support from within communities, external stigmas from outside these communities surrounding ethnicity, and further stigma from within their communities about mental health difficulties. Furthermore, increased risk has been linked to the economic and social disadvantages, such as unequal access to healthcare, education, and employment opportunities that these ethnicities are confronted with (Bhugra et al., 2004; Jongsma et al., 2021).

There is a high occurrence of people from minority ethnic groups accessing care through compulsory admission (Anderson et al., 2014; Barnett et al., 2019; Oduola et al., 2019; Schofield et al., 2019). Mental health services are less accessible to minority ethnic groups due to social determinants (e.g. poor access to resources, discrimination, social policies), structural racism, racial disparities (e.g. economic injustices) and neighbourhood-level factors (e.g. urbanicity, residential stability) (Anglin et al., 2021). Furthermore, services may not be sensitive to cultural beliefs and needs (Gopalkrishnan, 2018; Maraj et al., 2023), which is a further access barrier that can result in people deciding to disengage from services (Gopalkrishnan, 2018; Maraj et al., 2023).

As a result of the inequalities in mental health care experienced by minority ethnic communities, the Reforming Mental Health Act White paper in 2021 outlined proposals for improving patient experience (Department of Health and Social Care, 2021a). This has resulted in plans to enhance patient choices, their right to challenge, the development of the Patient Carer Race Equality Framework, and the use of culturally appropriate advocacy (Department of Health and Social Care., 2021b). Furthermore, this has resulted in amendments regarding advocacy, raising the threshold for detention and more frequent review of detention, the redefining of “mental disorder”, allowing nomination of a person (rather than nearest relative), removal of prisons/police cells as a place of safety and more efficient pathways from the Criminal Justice System to hospitals (Garratt, 2024).

Alongside improving policies and secondary mental health services, research has highlighted the importance of non-secondary care support for people from minority ethnic groups (Oluwoye & Weeks, 2023; Rashid et al., 2012). Community-based interventions draw on resources within the community and take place in the community in the hope of improving well-being (McLeroy et al., 2003). For example, an intervention could include supporting religious leaders such as Imams who often support people with mental health difficulties in the community (Meran et al., 2019).

Portfolio Overview

This thesis aims to advance our understanding of PtC for psychosis by (a) examining the impact of the introduction of the Access and Waiting Time Standard (NHS England, 2016) on access and delay to EIP and assesses the associations between sociodemographic, pathway to care characteristics and access to EIP, and (b) assessing the effectiveness of community-level interventions in improving access to primary care for psychosis among people from ethnic minority backgrounds. It is hoped that this will help us to establish and improve disparities in wait time and help develop an understanding where we can improve interventions and reduce inequalities in mental health.

The second chapter presents a systematic review of the impact of community-level interventions on minority ethnic groups and access to primary care services. Specifically, the review describes the impact of interventions on help-seeking and PtC and examines the wider factors that enable or impede the interventions' ability to improve access to support through primary/community care. A bridging chapter follows the systematic review, providing an overview of the key findings and conceptual links between the systematic review and empirical paper, and then introduces the justifications for completing the empirical research. Chapter 4 describes a quantitative empirical study that investigates wait time for EIP and assesses the associations between sociodemographic, clinical factors and pathway to care characteristics and access to EIP using a sample of participants who accessed EIP the same year as the introduction of the Access and Waiting Time Standard (NHS England, 2016). Finally, chapter 5 provides an overview of the findings across the systematic review and the empirical paper, notes the overall strengths and limitations of the portfolio, and outlines the implications for clinicians, policy, and research.

Chapter Two

Systematic Review

The Impact of Community-Level Interventions on Improving Access to Primary Care for People from Minority Ethnic Groups Experiencing Psychotic Disorders

Prepared for submission to ‘Early Intervention in Psychiatry’[1]

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[1] See Appendix A for author guidelines. Figures and tables are provided within the main body of the text.

The Impact of Community-Level Interventions on Improving Access to Primary Care for People from Minority Ethnic Groups Experiencing Psychotic Disorders

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Abstract

Aim: Higher incidence of psychosis has been reported in people from minority ethnic backgrounds, and ethnic disparities exist in accessing care for psychosis. Research has shown that people with psychosis from ethnic minority groups are less likely to seek support from healthcare professionals (e.g. GP), but more likely to seek support from non-healthcare professionals (e.g. faith leaders). This systematic review assessed the impact of community-level interventions for people from minority ethnic groups with or at risk of psychosis, caregivers, or the general public to improve access to community support or primary care.

Methods: The EMBASE, PsychINFO, Medline Ultimate, CINAHL Ultimate and Scopus databases were searched on 16/12/23. Included studies were published in English, conducted in high-income countries, reported on psychosis and minority ethnic groups with a mean age of 18-65, and included interventions aimed at improving access to primary care or community support. Outcomes of interest were changes in help-seeking behaviours, pathways to care characteristics and barriers and facilitators of intervention implementation.

Results: Five studies met the inclusion criteria. All studies were conducted in the United States. Interventions varied. There were conflicting results regarding the recommendation of professional and non-professional help-seeking. One study measured duration of untreated psychosis and found no significant effect. Barriers and facilitators were identified across interventions.

Conclusions: Community-level interventions have some success in promoting help-seeking for psychosis in ethnic minority populations. However, research in this area was limited. Future research could include studies across different countries, ethnicities, genders and socioeconomic status to ensure generalisable results.

Keywords: ethnic minority groups, psychosis, interventions, pathways to care, help seeking behaviour

Introduction

Psychosis can result in debilitating mental and social difficulties that include distressing symptoms, poor self-esteem, increased risk of suicide, impaired social skills, relationship difficulties, and discrimination due to stigmatisation (Rössler et al., 2005). Individuals experiencing psychotic symptoms need to access support and treatment as early as possible to prevent prolonged distress (Norman et al., 2004), severe symptoms (Kitchener & Jorm, 2006) and poorer recovery (Penttilä et al., 2014; Singh, 2010).

Research has reported a higher rate of psychosis in individuals who have immigrated, have a family history of migration (Bourque et al., 2011; Cantor-Graae & Selten, 2005; Dealberto et al., 2011; Termorshuizen & Selten, 2023) and are from minority ethnic groups (Oduola et al., 2021). Anglin (2023) highlighted that people from Black and Latinx populations are more likely than White populations to report psychotic experiences and proposed that this is largely due to racism and discrimination. Research has found ethnic and racial disparities in the care and treatment of psychosis. For example, people from Black populations are more likely to be misdiagnosed by clinicians (Olbert et al., 2018) and be prescribed long-acting antipsychotic medications (Das-Munshi et al., 2018) compared with White populations. Additionally, research reports variations in the duration of untreated psychosis (DUP) by ethnicity, with longer DUP for people from a Black-Caribbean background (Schoer et al., 2019) and shorter DUP for people from Black African and Asian backgrounds (Dominguez et al., 2013; Ghali et al., 2013). However, other studies have not observed differences in DUP by ethnicity (Oduola et al., 2021). Oluwoye et al. (2018) discovered that Hispanic participants were more likely to receive ‘medication management’, and Black (non-Hispanic) participants were less likely than White (non-Hispanic) participants to receive individual therapy and family psychoeducation.

There is a prominent stigma associated with psychosis, regardless of ethnicity, and a misconception that people living with psychosis are unpredictable and dangerous (Gronholm et al., 2017). One systematic review suggested that people from minority ethnic populations experience accentuated stigma regarding mental illness, as they view themselves as belonging to multiple stigmatised groups (Leamy et al., 2011). Another review demonstrated cultural stigma across Asian American, Black American and Latinx groups (Misra et al., 2021). The Asian American group concealed mental illness due to fears of being a burden, bringing dishonour to their family and mental illness being a poor reflection on families (Misra et al., 2021). Black American groups experienced stigmatising responses from others, reported that it was the private business of families and parents felt blamed for their family member's mental illness. Finally, the Latinx group concealed mental illness due to concerns about the extension of the stigma to family members and family members experienced blame for not doing enough to protect their family member from developing a mental illness (Misra et al., 2021). Additionally, in some cultures mental health difficulties could be viewed as grounds for a divorce (Pallaveshi et al., 2017).

Evidence suggests that help-seeking via primary care is associated with a reduced chance of inpatient admission and emergency healthcare services (Anderson et al., 2013). However, several studies have identified that people from numerous ethnic groups including Black ethnic groups (Anderson et al., 2014; Halvorsrud et al., 2018), Black British, Black Caribbean and White Other ethnic groups (not Black African groups) (Ghali et al., 2013) are less likely to seek support from primary care. Amri (2012) identifies that historical oppression, discrimination and racism faced by individuals from black populations (which also extends to minority groups such as Latinx, and Southeast Asian groups) has resulted in cultural mistrust which extends into healthcare services. This may be further exacerbated by language barriers (Inhorn & Serour, 2011; Isaacs et al., 2010), concerns about the ability to communicate symptoms, lack of awareness of services, fear of separation from family members (Pallaveshi et al., 2017) and cultural and religious beliefs (Amri, 2012; Inhorn & Serour, 2011).

Furthermore, in some societies (e.g. people of African, Caribbean or Asian heritage) psychosis symptoms are attributed to supernatural or spiritual causes (McCabe & Priebe, 2004). Therefore, people from minority ethnic groups may seek support from non-medical sources e.g. alternative healers or faith leaders (Oluwoye & Weeks, 2023; Rashid et al., 2012; Whitley et al., 2006). One study found that Imams spend two-thirds of their time each week providing support to people with mental health difficulties, including psychosis (Meran, 2019). There is evidence that religious support has positive outcomes on recovery (Nolan et al., 2012) and that faith leaders signpost people to mental health services (Meran, 2019). However, help-seeking via faith leaders may result in longer DUP (Bhui et al., 2014). Faith leaders may also not have the knowledge of mental health difficulties needed to provide support independently (Fitzgerald & Vaidyanathan, 2023). Therefore, collaborative working has been recommended so that clinicians can support recognition and understanding from a biopsychosocial perspective, and faith leaders can support clinicians in understanding the religious means that support recovery (Meran, 2019; Rashid et al., 2012).

The importance of interventions that reduce stigma (Amri, 2012; Ferrari et al., 2015), improve general knowledge of psychosis (Amri, 2012) and promote better recognition of signs/symptoms (Ferrari et al., 2015) has been recognised. Indeed, there are interventions/campaigns that aim to improve access to early treatment for psychosis. For example, early intervention for psychosis (EIP) services that target access to secondary care services (Marshall & Rathbone, 2011). EIP services have shown good outcomes, such as improved access, fewer hospital admissions, and improved social functioning (Bird et al., 2010). However, given the key role of healthcare professionals in primary care and the wider community play in care pathways for psychosis, it is essential that campaigns and interventions aimed at improving access to care not only focus on secondary care but primary care, too. However, such campaigns targeting ethnic minority populations aimed at improving access to primary care services or community support for psychosis are limited. Further, for reasons discussed earlier regarding negative experiences in access to and treatment of psychotic disorders in specialist mental health services, people from minority ethnic backgrounds may be reluctant to engage with such services. This concern was illustrated in a systematic review which identified interventions that included ethnic matching, pre-treatment programmes, post-discharge support, ‘managed care’ and an educational leaflet distributed in a GP practice (Sass et al., 2009). These interventions aimed to improve pathways to care (PtC) and increase service use for minority ethnic and racial groups across mental health presentations and services (i.e. across primary and secondary services) (Sass et al., 2009). Ethnic matching, pre-treatment services, and educational leaflets showed a positive trend for enhancing and influencing pathways to care. Additionally, ‘managed care’ appeared to minimise differences between ethnic groups. However, the authors found only six papers: three of which took place at one site. The authors concluded a surprising lack of evaluated research in this area. They were also surprised that there was a lack of research from the UK (one paper). Another recent review explored interventions to improve access to mental health care across mental health presentations, including psychotic disorders, mood disorders, and anxiety disorders for minority racial and ethnic groups (Lee-Tauler et al., 2018). They found that interventions that included integrative and collaborative working with primary care were effective at reducing disparities in the initiation of care in minority racial and ethnic groups.

In contrast with previous reviews (Lee-Tauler et al., 2018; Sass et al., 2009), the current review will focus specifically on psychosis. It will acknowledge interventions targeting early intervention help based in the community, but it will move beyond this by capturing help-seeking patterns in the community (e.g. via faith-based organisations, peer support groups, local council initiatives, non-profit or charitable organisations) and primary care services (e.g. via GP or primary care nurses). To our knowledge, no existing systematic reviews have examined community-level interventions that specifically aim to improve help-seeking for psychosis outside of secondary mental health services for minority ethnic groups. This is unexpected, due to the well-documented negative PtC (e.g. Inhorn & Serour, 2011) and research recommending interventions to resolve them (e.g. Oluwoye & Weeks, 2023).

This systematic review aimed to answer the following research question: What is the impact of community-level interventions aimed at people from minority ethnic groups with or at risk of psychosis, caregivers, or the general public to improve help-seeking or access to community support or primary care. We addressed the following study objectives:

(a) To describe community-level interventions for improving help-seeking or access to support for psychosis in primary care and the community,

(b) To examine the impact of the interventions on help-seeking and pathways to care in the community/primary care,

(c) To identify factors (barriers and facilitators) to implementing community-level interventions for improving help-seeking in primary care or the community for psychosis.

Materials and Methods

The systematic review protocol was designed according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)(Moher et al., 2009). It was registered with the International Prospective Register of Systematic Reviews (PROSPERO, https://www.crd.york.ac.uk/prospero/, registration number CRD42023398682).

The EMBASE, PsychINFO, Medline Ultimate, CINAHL Ultimate and Scopus databases were searched on 16th December 2023. Additional hand searches were completed using the reference lists of the papers that met the inclusion criteria. Table 1 outlines search terms using the PICO framework (Schardt et al., 2007). The search and MeSH/index terms (psychosis, minority groups, psychoeducation, help seeking behaviour, primary healthcare) were modified for each database. Search terms were developed with an expert librarian and the search strategy was informed by previous systematic reviews in the field (e.g. Lee-Tauler et al., 2018).

Table 1

Search Terms

Study Characteristics	Description	Search Terms
Population	Psychosis	psychosis OR schizophreni* OR psychot* AND

Table 1 Continued

Search Terms

	Minority Ethnic Group	ethnic* OR minorit* OR underserved OR cultur* OR immigrant OR race OR racial OR migrant* OR refugee* OR asylum OR asian OR latin* OR aborigin* OR islander* OR chinese OR indian OR african OR caribbean OR vietnamese OR mexican OR traveller OR gypsy OR polish OR native OR malay OR bame OR “black african” OR “black american” OR hispanic
		AND
Intervention	Intervention Type	literacy education OR campaign OR symposium OR intervention OR narrative OR workshop* OR communication OR "first aid” OR outreach OR psychoeducation OR knowledge OR awareness OR information OR program* OR training OR advert OR "focus group*" OR poster OR film OR leaflet OR radio OR ((worship N3 (place* OR house)) OR faith OR religio* OR ((stigma N3 (change OR resilience)) OR family OR relative* OR course* OR church-based OR faith-based OR pastor OR clergy OR “pastoral counselling” OR minister)
		AND

Table 1 Continued

Search Terms

Outcome	Improvement in Pathway to Care	“pathway* to primary care” or “pathway* to care” OR help-seeking OR ((attitudes N3 (support OR treatment)) OR ((seeking N3 (support OR treatment)) OR engage* OR willingness AND
	Help-seeking or access to support in the Community or Primary Care	“community support” OR care OR clinic OR clinics OR "health* service" OR GP OR physician* OR networks OR charit* OR “voluntary organisation” OR (primary N3 health) OR “professional support”

Note. AND and OR are Boolean operators used that were used during the search process

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were structured using the PICO Framework (Schardt et al., 2007) (see Table 2).

Table 2

Inclusion and Exclusion Criteria

Study Characteristics	Inclusion	Exclusion
Population	Adults with a mean age of 18 – 65 years from a minority ethnic background living in high-income countries (as defined by the World Bank)	Studies that include participants living in low- or middle-income countries (as defined by the World Bank). Due to the infrastructural and socio-economic differences in mental health care and treatment, it is difficult to compare studies from low- or middle-income countries with studies from high-income countries.
Intervention	Community-based interventions are defined as any intervention that is implemented within the community that promotes well-being, they may also draw on the community's internal resources (McLeroy et al., 2003) (e.g. collaboration with religious leaders). The community-based intervention should impact access to primary care or community support for people from minority ethnic groups with or at risk of psychosis, caregivers, or the general public	Interventions aimed at promoting access and support within secondary or specialist mental health services (e.g. Early Intervention Psychosis Teams, Co-ordinated Speciality Care). Interventions that are focused on other mental health difficulties. Interventions that are not community-level interventions

Table 2 Continued

Inclusion and Exclusion Criteria

Study Characteristics	Inclusion	Exclusion
Comparison	Waitlist control, non-exposed comparison, or pre-post intervention groups	None
Outcome	Information about help-seeking and pathways to care characteristics that are reported from any outcome measure or themes that are identified from qualitative data. Barriers and facilitators of the interventions that are either measured explicitly as an outcome or reported on in the discussion section	Studies that do not report separate outcomes for psychosis or minority ethnic groups
Study Design	All study designs including Qualitative, Quantitative and Mixed-methods designs	All grey literature: books, briefs, reports, brochures, presentations, conference papers, webpages
Other	Studies published in English	

Screening

In total, 2681 abstracts and 81 full-texts from database searches were screened by NW. Twenty percent of abstracts were screened for eligibility and independently checked by a second reviewer (n=536), with one discrepancy, suggesting almost perfect agreement (k = 0.99). A further three articles were discussed in consensus meetings with SO.

Quality Appraisal

The methodological quality of the included studies was assessed using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The MMAT is a firmly established inventory that can be used across quantitative, qualitative, and mixed methodologies. The first two questions are generic measures of quality, followed by five more specific questions tailored to the study method implemented by the researchers. Scores were calculated using guidance from Gronholm et al. (2017), which involved summing the criteria that was met, and then converting them to percentages, with higher percentages indicating better quality methodology. NW rated all the papers, and (n=2) of the papers were independently rated by CH, with 85.7% agreement. Discrepancies were resolved with SO.

Data Extraction and Narrative Synthesis

The following data was extracted from included (n=5) studies: study characteristics (design, study objectives, country), sample characteristics (*n*, mean age, gender, ethnicity, education level, previous experience of mental health difficulties) and intervention information (intervention description, duration, and intervention impact). Outcome data also included barriers and facilitators of the interventions' implementation (taken from study discussion sections), recommendations on help-seeking (for self and others) and DUP. We were unable to complete meta-analysis, due to the heterogeneity of the study designs. A narrative synthesis was undertaken in line with guidelines by Popay et al. (2006). This included descriptive summary paragraphs (that included the study design, participants, intervention description, key results) for each of the included studies, which allowed familiarity and initial identification of patterns. During data extraction the data were tabulated, and gender and age data was transformed to construct a common rubric. Qualitative themes were not transformed during extraction. Studies were then grouped according to which intervention they reported on, then if there were multiple studies for a single intervention these were grouped based on any common comparators, outcomes or content, which enabled direct comparison of effectiveness and the identification of themes in the data.

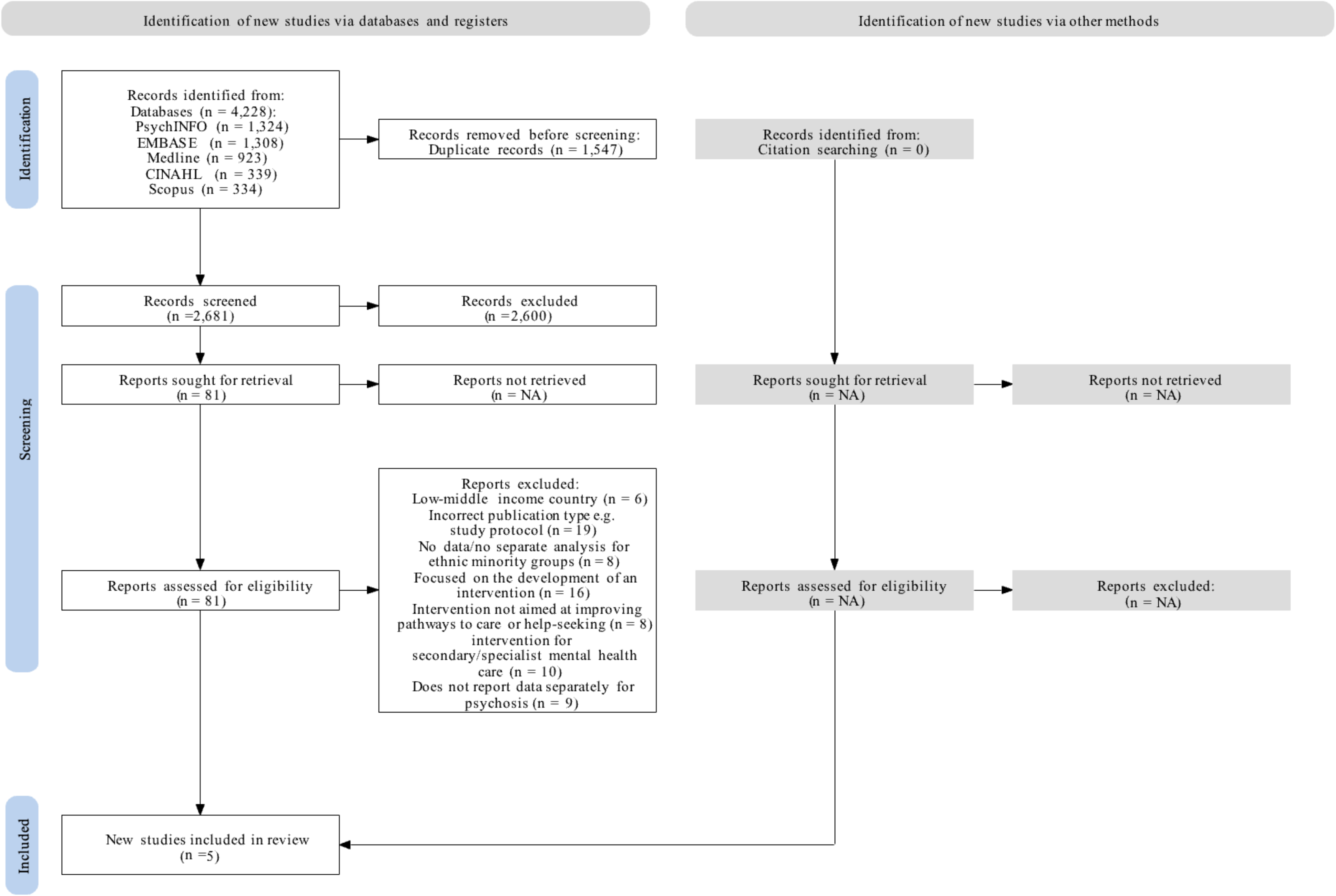
Finally, a thematic framework was used to allocate themes and triangulate the data across studies.

Results

Database searches returned 4228 papers (2681 without duplicates). The PRISMA flowchart of the full selection process is shown in Figure 1 (Haddaway et al., 2022). Following title and abstract screening, 81 full-text articles were screened for eligibility. Five papers met the inclusion criteria. No further papers were identified by hand-searching the reference lists of the included papers. Four of the five papers reported on the same intervention (La CLAve Campaign)(Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022) and the remainder reported on the Bringing Psychiatry into the Mosque intervention (Mushtaq et al., 2020). There was a combined sample size of 332.

Figure 1

PRISMA diagram



Study and Participants Characteristics

All studies were conducted in the United States. There was one quantitative study (Mushtaq et al., 2020), one qualitative study (Hernandez et al., 2016) and the remaining studies utilised a mixed-design (Calderon et al., 2022; López et al., 2009, 2022). Study sample sizes ranged from 31 (Mushtaq et al., 2020) to 123 (López et al., 2022). Two studies used community residents (Calderon et al., 2022; Mushtaq et al., 2020), two studies used a combination of community residents and caregivers (Hernandez et al., 2016; López et al., 2009) and the final study involved people with first-episode psychosis (FEP) and their caregivers (López et al., 2022). The mean age of participants ranged from 25 years (López et al., 2022) to 49 years (Hernandez et al., 2016). The percentage of male participants ranged from 9.5% (López et al., 2009) to 72% (López et al., 2022). Four studies reported the average number of years that participants were in education (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022), which varied from eight (López et al., 2009) to 11.2 years (López et al., 2022). All studies recruited participants from minority ethnic groups (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022; Mushtaq et al., 2020). Four studies used participants from a single minority ethnic group: Latinx participants (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022). Most participants (94%) in the study by Mushtaq and colleagues were from a minority racial background, and 7% were from a White background (Mushtaq et al., 2020). See Table 3 for a detailed overview of the study characteristics.

Table 3

Study Characteristics

Intervention	Study	Study Design	Study Objectives	Country	Participants	*N*	Mean age (years)	% Male	Ethnicity or Racial category
La CLAve Campaign	Calderon et al. (2022)	Mixed Methods	This study evaluated whether the message of the La CLAve DUP reduction program delivered during the campaign increased the psychosis literacy of a U.S. Latinx community	United States	Community residents	81	38.8	13.6	Latinx
	Hernandez et al. (2016)	Qualitative	Participants were exposed to a 15-minute film titled La CLAve designed to encourage conversation and help Latinx, particularly caregivers, identify the symptoms of a serious mental illness so that they can seek treatment early	United States	Community residents and caregivers	40	49.0	12	Latinx
	López et al. (2009)	Mixed Methods	The program uses popular cultural icons derived from music, art, and videos, as well as a mnemonic device—La CLAve (The Clue)—to increase (a) knowledge of psychosis, (b) efficacy beliefs that one can identify psychosis in others, (c) attributions to mental illness, and (d) professional help-seeking	United States	60% community residents and 40% caregivers of people with schizophrenia	57	42.0	9.5	Latinx

Table 3 Continued

Study Characteristics

Intervention	Study	Study Design	Study Objectives	Country	Participants	*N*	Mean age (years)	% Male	Ethnicity or Racial category
La CLAve Campaign	López et al. (2022)	Mixed Methods	To evaluate a communications campaign (La CLAve) to reduce the duration of untreated psychosis (DUP) in a U.S. Latinx community	United States	People with first episode psychosis and their caregivers	123	25	72	Latinx
Bringing Psychiatry into the Mosque	Mushtaq et al. (2020)	Quantitative	The objective of this study was to analyse views about psychiatric illness and treatment before and after a mental health symposium at a community mosque led by faith leaders and mental health professionals	United States	Community residents	31	37	32.3	7% White 17% Black 47% South Asian 30% Middle Eastern

Intervention Information

La CLAve Intervention

The La CLAve campaign ran from 2015-2017 and focused on reducing the duration of untreated psychosis (DUP) for the Latinx population (López et al., 2022). Several studies were undertaken that evaluated the effectiveness of different intervention components that were included in the campaign (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009). These studies were completed independently and used different samples. López et al. (2022) reported the outcomes of the full campaign.

All four studies utilised a mnemonic device to support the memory of psychosis symptoms (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022). Three of the studies included a narrative film and discussions (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2022). Two studies included video clips (Calderon et al., 2022; López et al., 2009). López et al. (2009), utilised PowerPoint slides with audio clips and artwork, and the full campaign paper by López et al. (2022) described additional inclusion of liaison with organisations/community leaders, brochures, a booth at public events and the use of multiple media formats (radio, TV, print, advertisements, social media).

The studies that were part of the La CLAve campaign used a variety of formats that differed in duration. The shortest was a four-minute video (Calderon et al., 2022) and the longest intervention was a 35-minute PowerPoint presentation (López et al., 2009). The full campaign lasted 24-months (López et al., 2022).

Researchers made cultural adaptations to help meet the specific needs of the population, such as providing interventions in a choice of languages (Spanish or English) (Calderon et al., 2022; López et al., 2009). In the Hernandez et al. (2016) study, it was not clear which language was used. However, the main campaign paper also reported using campaign coordinators with Spanish language skills and lived experience as a Latinx member of the community (Lopez et al., 2022).

Three studies reported on the impact of a fictional account of what it is like to experience the symptoms of psychosis (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009). Two studies used these accounts to help evaluate the ‘intervention’; Calderon et al. (2022) and López et al. (2009) combined the fictional account with a questionnaire that measured psychosis literacy. However, in Hernandez et al. (2016) the fictional account was included as part of the intervention (15-minute film) that was used to prompt discussion.

Bringing Psychiatry into the Mosque

This intervention used fictional written vignettes and experts by experience with personal experience of psychosis (Mushtaq et al., 2020). It included a group discussion element, information that participants could take away with them about local mental health services and internet resources (Mushtaq et al., 2020). Additionally, the study included facilitators and speakers who shared the same cultural background (Mushtaq et al., 2020). The intervention lasted for half a day.

La CLAve Campaign and Bringing Psychiatry into the Mosque

The La CLAve campaign and Bringing Psychiatry into the Mosque symposium shared several similarities. Firstly, they both included conversational elements. Secondly, they made use of fictional/non-fictional accounts of what it is like to experience the symptoms of psychosis. However, there were also some contrasting points between the two interventions. Bringing Psychiatry into the Mosque Intervention included internet resources, whilst the La CLAve campaign used a narrative film, PowerPoint, video and audio clips, artwork, liaison with organisations/community leaders, brochures, a booth at public events and media. Both interventions included facilitators/speakers who shared the same cultural background as the intervention’s target audience.

Intervention Outcomes

Quality Appraisal

The outcomes from the MMAT quality assessment can be found in Table 4. Ratings varied between 71.4% (Calderon et al., 2022) and 100% (Hernandez et al., 2016). Only the qualitative study scored 100% (Hernandez et al., 2016). The majority of studies included clear research questions and the data collected was appropriate for the question (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022). The main issue regarding the quantitative study was due to the representativeness of the sample (Mushtaq et al., 2020). The studies that employed a mixed-methods approach scored less, due to an absence of rationales for using the mixed-methods methodology and a lack of adherence to individual qualitative and quantitative methods (Calderon et al., 2022; López et al., 2009).

Help-seeking Outcomes

Help-seeking Recommendations.

All studies reported on help-seeking recommendations. See Table 5. Two studies (Calderon et al., 2022; López et al., 2009) reported on professional help-seeking recommendations. They used non-standardised self-report questionnaires to collect participants' views on recommending professional help. One found a significant change after the intervention (Lopez et al., 2009), whilst the other study did not find a significant change in professional help-seeking recommendations (Calderon et al., 2022). Notably, Lopez et al. (2009) showed in their analysis that differences between caregivers and community residents were not significant for professional help-seeking, so this is not likely to explain the difference in findings between studies.

The Bringing Psychiatry into the Mosque symposium used non-standardised self-report surveys pre- and post-intervention to examine whether participants reported a change in where they would seek support for themselves (Mushtaq et al., 2020). They found an increase in the percentage of participants stating that they would seek support from formal routes (medical doctors or therapists) and non-formal routes (Imam, family or friends), but this increase was not statistically significant (Mushtaq et al., 2020). During the quality appraisal, it was identified that there were potential issues with the representativeness of the sample for this study, due to the high education level of participants. Mushtaq et al. (2020) found that higher education level was positively associated at the pre-intervention stage with the willingness to speak with a medical doctor and other sources of professional support. Consequently, high education level may explain why the intervention did not show a significant change.

In the final two La CLAve campaign studies, qualitative data from Hernandez et al. (2016) identified a theme of seeking treatment early and López et al. (2022) provided two case qualitative examples from a survey that showed the campaign had resulted in help-seeking. However, caution should be exercised with these outcomes due to the small number of case examples included.

Duration of Untreated Psychosis. López et al. (2022) examined the impact of the La CLAve campaign on DUP. Data was collected by interviewing people with FEP and their caregivers using a combination of The Positive and Negative Symptom Scale and a series of questions to establish the type of treatment and start date. DUP was measured in two ways: (a) onset to start of any treatment and (b) onset to prescription of antipsychotic medication. There was a reduction in the number of weeks for both DUP outcomes for the La CLAve campaign, but neither outcome reached statistical significance.

Table 4

Quality Appraisal

Study type		Calderon et al. 2022	Hernandez et al. 2016	López et al. 2009	López et al. 2022	Mushtaq et al. 2020
Screening Questions	Are there clear research questions?	+	+	+	+	+
	Do the collected data allow to address the research questions?	+	+	+	+	+
Quantitative nonrandomized	Are the participants representative of the target population?	n/a	n/a	n/a	n/a	-
	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	n/a	n/a	n/a	n/a	+
	Are there complete outcome data?	n/a	n/a	n/a	n/a	+
	Are the confounders accounted for in the design and analysis?	n/a	n/a	n/a	n/a	+
	During the study period, is the intervention administered (or exposure occurred) as intended?	n/a	n/a	n/a	n/a	+
Qualitative	Is the qualitative approach appropriate to answer the research question?	n/a	+	n/a	n/a	n/a
	Are the qualitative data collection methods adequate to address the research question?	n/a	+	n/a	n/a	n/a
	Are the findings adequately derived from the data?	n/a	+	n/a	n/a	n/a
	Is the interpretation of results sufficiently substantiated by data?	n/a	+	n/a	n/a	n/a
	Is there coherence between qualitative data sources, collection, analysis and interpretation?	n/a	+	n/a	n/a	n/a

Table 4 Continued

Quality Appraisal

Study type		Calderon et al. 2022	Hernandez et al. 2016	López et al. 2009	López et al. 2022	Mushtaq et al. 2020
Mixed methods	Is there an adequate rationale for using a mixed methods design to address the research question?	?	n/a	?	+	n/a
	Are the different components of the study effectively integrated to answer the research question?	+	n/a	+	+	n/a
	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	+	n/a	+	+	n/a
	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	+	n/a	+	+	n/a
	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	-	n/a	+	?	n/a
Total percentage %		71.4	100	85.7	85.7	87.7

+ yes, - no, ? can’t tell

Table 5

Intervention information and help-seeking outcomes

Intervention	Study	Intervention description	Duration	Help-seeking recommendations	DUP	Outcome measures
La CLAve Campaign	Calderon et al. (2022)	Video, use of a mnemonic device (La CLAve) for symptoms of psychosis, a narrative film, group conversations	Four-minute video (in addition to teaching, narrative film, and conversations)	Professional help seeking recommendation (pre 64.2%, post 72.8%), *p*=.25 Non-professional help-seeking recommendation (pre 49.4%, post 25.9%), *p*=.001. This was not an intended outcome and may not be a positive finding	Not reported	Non-standardised self-report questionnaire with rating scales and open-ended questions
	Hernandez et al. (2016)	15-minute narrative film and group discussion. Included mnemonic device (La CLAve) for symptoms of psychosis	15 minutes (in addition to discussion time)	Seeking early treatment - “I learned that if I see the symptoms in the family, the sooner one seeks treatment the better…”	Not reported	Non-standardised measure with open questions that was delivered to focus groups
	López et al. (2009)	42 PowerPoint slides that included five audio clips, three video clips and four paintings/drawings, use of mnemonic device (La CLAve)	35 minutes	Suggestion of professional solutions (pre 58%, post 80%), *p*<.008 Suggestion of personal solutions (pre 73%, post 44%), *p*=.001. This was not an intended outcome and may not be a positive finding	Not reported	Non-standardised self-report questionnaire with open questions, rating scales and closed questions

Table 5 Continued

Intervention information and help-seeking outcomes

Intervention	Study	Intervention description	Duration	Help-seeking Recommendations	DUP	Outcome measures
La CLAve Campaign	López et al. (2022)	Liaised with organisations and community leaders, distributed brochures, Set up a booth at public events, conversations, narrative film. Workshops, radio, TV, print, advertising, social media, use of mnemonic device (La CLAve)	24-month campaign (including 60–90-minute workshops and a 15-minute narrative film)	The article outlines two case examples in which La Clave led to treatment: Exposure to La CLAve prompts both father and police officers to facilitate care, Wife learns of La CLAve at a swap meet (a community event where people can sell, trade or buy items they no longer use)	At baseline DUP to any treatment for Spanish speaking persons was approximately 300 weeks, during the campaign this reduced to approximately 100 weeks and post campaign this was approximately 250 weeks post-campaign. There was not a significant main effect for campaign period for DUP any treatment *p* = .13 At baseline DUP to prescribed antipsychotic medication for Spanish speaking persons was approximately 400 weeks, this reduced to 200 weeks during the campaign and was approximately 300 weeks post-campaign. There was not a significant main effect for campaign period for medication *p* = .43. There was also no interaction for DUP any treatment and DUP medication *p* = .63	Help-seeking case examples were collected from a household survey interview DUP was measured by conducting interviews using The Positive and Negative Symptom Scale and by using a series of questions aimed at identifying the type of treatment and start date.

Table 5 Continued

Intervention information and help-seeking outcomes

Intervention	Study	Intervention description	Duration	Help-seeking Recommendations	DUP	Outcome measures
Bringing Psychiatry into the Mosque	Mushtaq et al. (2020)	Personal stories from two practicing Muslims. A psychiatrist discussed psychiatry and Islam. A panel (psychiatrist, social worker, imam, mosque youth coordinator) discussed experiences working with people with mental health difficulties and their role. A speaker with a background in Islamic sciences. Two group sessions, one aimed at discussion around a hypothetical case and a second around family dynamics. Folder with symptoms, Muslim mental health providers, crisis hotline and internet resources	Half day	For mental health problems I would talk to: Medical doctor (pre 52%, post 70%), *p* = .10 Therapist (pre 86%, post 100%), *p* = .08 Imam (pre 67%, post 83%), *p* = .10 Family (pre 88%, post 92%), *p* = .56 Friends (pre 88%, post 92%), *p* = .56	Not reported	Non-standardised self-report pre- and post-intervention surveys that included rating scales and closed questions

Barriers and Facilitators

Table 6. provides a full breakdown of the barriers and facilitators identified for each intervention, as reported in the studies.

Suitability of Content. The studies linked to the La CLAve campaign identified that whilst there were positive increases in help-seeking via professional routes, participants said that they would be less likely to recommend non-professional help-seeking in two studies (Calderon et al., 2022; López et al., 2009), and neither study aimed to reduce this. Whilst orientating people to mental health difficulties using a social context may promote familiarity, compassion and understanding, this could also result in mental health difficulties being overlooked (López et al., 2009). Incorporating narratives may facilitate identification with characters (Hernandez et al., 2016). However, researchers questioned whether fictional accounts of psychosis may not be generalisable to real life (López et al., 2009). The initial intervention may not be effective enough on its own to make changes to perceptions and may need further follow-up with educators to facilitate further discussions and answer questions (Hernandez et al., 2016). In contrast, the Bringing Psychiatry to the Mosque symposium included personal narratives from people with lived experience, as well as information from culturally-appropriate speakers (e.g. Muslim mental health providers) (Mushtaq et al., 2020).

Socioeconomic. Research from the La CLAve campaign highlighted the expense of multi-faceted campaigns (Calderon et al., 2022), and it did not make use of digital advertisements, which may have been more cost effective (López et al., 2022). Furthermore, whilst the intervention may have been effective, a potential barrier to the whole campaign is that mental health support is limited, and even if participants did seek support, it is possible that care may not be available to them (López et al., 2009).

Cultural. One of the La CLAve campaign studies identified that using Microsoft PowerPoint is an effective format, as it can be easily adapted to meet the needs of different regional Latinx groups. However, they also suggested that campaigns may be too focused on the mental health field’s understanding of psychosis, instead of acknowledging and understanding cultural constructions across different communities (López et al., 2009).

Audience. The study that reported on Bringing Psychiatry to the Mosque used a variety of methods to advertise the symposium (e.g. flyers) in the hope of reaching a wide audience, but it is also possible that they captured the attention of people with a specific interest (Mushtaq et al., 2020). Similarly, studies from the La CLAve intervention identified that attendees may have had a familiarity or interest in mental health issues, which may have motivated them to attend (Calderon et al., 2022).

Delivery Format. Studies from the La CLAve campaign detailed that the campaign did not utilise the internet or smartphone applications. Instead, they used traditional channels (e.g. radio) (López et al., 2022). There was also a reflection that training other professionals (e.g. community health workers) might enhance the effectiveness of the campaign (López et al., 2022). Additionally, some of the workshops were limited because they could only be run by mental health professionals (López et al., 2009). However, using a narrative film appeared to be an engaging format that facilitated dialogue with others (Calderon et al., 2022), which included social networks outside of the workshops (Hernandez et al., 2016). Furthermore, learning appeared to be effective using the Mnemonic device and modelling, based on fictional accounts (Hernandez et al., 2016). Parts of the campaign were modified to enable remote delivery during the Coronavirus pandemic (López et al., 2022). The Bringing Psychiatry to the Mosque symposium involved the collaboration of religious organisations/leaders and mental health professionals (Mushtaq et al., 2020).

Table 6

Intervention Barriers and Facilitators

Barriers	Facilitators
Suitability of Content La CLAve campaign • Despite there being no message of reducing social support, there was a reduction of social support (Calderon et al., 2022; López et al., 2009) • Familiar social context may result in people overlooking mental health problems (López et al., 2009) • Hypothetical case content may not be generalisable to real life (López et al., 2009) • Altering perceptions is challenging and may require additional interventions. May need additional dialogue facilitated by health educators to explore questions (Hernandez et al., 2016)	**Suitability of Content** La CLAve campaign • Social context of mental health difficulties may help construct unfamiliar experiences into familiar ones resulting in understanding and compassion (López et al., 2009) • The use of narratives helps identification with characters (Hernandez et al., 2016) Bringing Psychiatry to the Mosque • Inclusion of personal narratives/lived experiences, included various Muslim professionals (Mushtaq et al., 2020)
Socioeconomic La CLAve campaign • Multi-faceted campaigns are expensive (Calderon et al., 2022) • Digital ads could have been used as a cost-effective method (López et al., 2022) • The intervention could be effective, but mental health services are limited and may make the provision of care less likely (López et al., 2009)	**Socioeconomic** None reported
Cultural La CLAve campaign • Campaigns may be too focused on mental health fields construction of psychosis, rather than cultural constructions that are observed in the community (López et al., 2009)	**Cultural** La CLAve campaign • Use of Microsoft PowerPoint can be culturally adapted to regional preferences of Latino communities (López et al., 2009)

Table 6 Continued

Intervention Barriers and Facilitators

Barriers	Facilitators
Audience La CLAve campaign • Attendees may have been predisposed/have familiarity/interest in mental health issues which prompted them to attend (Calderon et al., 2022) Bringing Psychiatry to the Mosque • Possible self-selection and specific interest in symposium attendees (Mushtaq et al., 2020)	**Audience** Bringing Psychiatry to the Mosque • The event was advertised in flyers, social media, and announcements after routine religious services to reach a wide audience (Mushtaq et al., 2020)
Delivery format La CLAve campaign • The campaign was missing systematic use of the internet and smartphone applications (López et al., 2022) • Training others (e.g. outreach workers) could enhance message permeation (López et al., 2022) • Requires a mental health professional to deliver the workshop limits how many can be run (López et al., 2009)	**Delivery format** La CLAve campaign • The film was engaging and stimulated dialogue. It also added to other formats of the La CLAve message (Calderon et al., 2022) • Engagement with the film facilitated discussions with participants social networks (Hernandez et al., 2016) • Learning was achieved through modelling and the mnemonic device (Hernandez et al., 2016) • The campaign included traditional media channels (e.g. radio) (López et al., 2022) • Parts of the campaign were adapted to be delivered remotely during the Coronavirus pandemic (López et al., 2022) Bringing Psychiatry to the Mosque • Collaboration of religious leaders and mental health professionals (Mushtaq et al., 2020)

Note. Barriers and facilitators for interventions were extracted from the study discussions

Discussion

Main Findings

In this systematic review and narrative synthesis, we examined the impact of community-level interventions aimed at people from minority ethnic groups with or at risk of psychosis, caregivers, or the general public to improve help-seeking or access to community support or primary care. We found five papers: four papers reported on one community-level intervention and one paper reported on another community-level intervention. Collectively, the included studies showed a trend in favour of the interventions for increasing professional help-seeking recommendations. There was also an increase in people suggesting that they would seek help from an Imam, friends and family help-seeking in one study (Mushtaq et al., 2020), although these observed differences did not reach the traditional statistical significance level. In contrast, two of the La CLAve studies (Calderon et al., 2022; López et al., 2009) found a decrease in seeking help from non-professional/personal sources. The studies highlighted that this was not an objective of the intervention and acknowledged the importance of non-professional help-seeking alongside professional help-seeking for reducing DUP (Calderon et al., 2022; López et al., 2009). Several barriers and facilitators to interventions were identified, which included the suitability of content, socioeconomic factors, cultural factors, target audience and delivery format.

Interpretation of Findings

Across both interventions identified within this review, psychoeducation via several mediums such as film, vignettes, experts by experience, discussion, mnemonic devices, PowerPoints, audio clips, artwork, liaison, brochures, and media (radio, TV, print, social media) were delivered. There was also evidence that interventions included cultural adaptations, such as artwork, and involved experts by experience from a similar cultural background. These were important, as they help participants’ sense of being understood (Amri, 2012; Inhorn & Serour, 2011), and allowed space for reflection on the interaction between cultural beliefs and mental health difficulties. This resulted in less discrimination, which is often a reason for hiding symptoms (Ferrari et al., 2015). Additionally, many of the studies considered language. This was likely to promote more engagement due to the removal of language barriers (Inhorn & Serour, 2011; Isaacs et al., 2010).

There were increases in professional help-seeking across studies and interventions. Additionally, some participants were more aware of the importance of early help-seeking, which is key to improving outcomes (Kitchener & Jorm, 2006; Norman et al., 2004; Penttilä et al., 2014; Singh, 2010). These results are promising and may indicate that participants had improved levels of trust (Lawrence et al., 2021) and perceptions of support (Whitley et al., 2006) around ideas of seeking support for psychosis.

Interestingly, one intervention (Mushtaq et al., 2020) included collaboration between mental health professionals and religious leaders. Research suggests the potential benefits of these collaborations (Meran, 2019; Rashid et al., 2012). Some participants seemed more likely to seek support for themselves from professional and non-professional sources, but these changes were not statistically significant. This could be because the participants were highly educated (Mushtaq et al. (2020) found that education level was associated with higher scores pre-intervention).

One study reported on DUP (López et al., 2022) and did not find that delays to antipsychotic medication or any kind of treatment improved for people from a Latinx population post-campaign. However, there may have been increased primary care use, thus making inpatient admission and emergency service use less likely (Anderson et al., 2013). Therefore, whilst delays did not show improvement, PtC may have altered, but this information is unavailable.

There were several barriers and facilitators identified. One identified barrier was that cultural explanations of psychosis may be overlooked, which may result in people feeling that their religion or culture is not understood, which has been identified as a barrier in the literature (Amri, 2012; Inhorn & Serour, 2011) and could potentially lead to disengagement. A further barrier identified was unintentional outcomes of the La CLAve intervention, namely, a significant reduction in recommendations for non-professional help-seeking. This is particularly concerning because research suggests that the inclusion of non-professional help-seeking aids PtC (Allan et al., 2021), and leads to results of positive outcomes when combined with professional help-seeking (Nolan et al., 2012).

Limitations

It is possible that the current review may not have identified studies related to the topic, due to their availability within the databases that were searched. Previous reviews in this area have looked more widely at interventions across mental health difficulties (Lee-Tauler et al., 2018; Sass et al., 2009), whilst our search terms focused specifically on psychosis. Widening the search terms (e.g. ‘mental health difficulties’ or ‘serious mental health difficulties’) may have resulted in the retrieval of studies with interventions that included psychosis alongside other mental health difficulties, and these could have been included in the review if psychosis data was independently reported. The search also included a list of minority ethnic groups. This list may not have been exhaustive, and we may not have captured some ethnic groups in our search. Differences in how ethnicity is recorded and understood across countries make this even more likely. However, other search development options were limited regarding ethnicity, and this was considered to be the most suitable method.

Due to our focus on non-secondary mental health care, we likely excluded interventions by secondary mental health services that could be influencing help-seeking and access to community support or primary care. This review did not consider grey literature, so it is possible that potentially relevant documents may have been missed. Additionally, there was heterogeneity in the sample, so it was not possible to complete a meta-analysis and calculate effect sizes. Furthermore, the MMAT does not include cut-offs, thus making it difficult to identify how high ratings need to be for a study to be considered good quality.

Participants in one of the studies included highly educated participants (Mushtaq et al., 2020) and other studies appeared to include a disproportionate number of participants that were female participants (Hernandez et al., 2016; López et al., 2009) or male participants (López et al., 2022). The ethnicities included in the group were also limited to

Latinx, Black Americans, South Asian Americans, Middle Eastern Americans and White Americans. Only one study included a follow-up (López et al., 2009), so we do not know if the outcomes were long-lasting for the remaining studies. Finally, all the La CLAve studies included the same group of authors, which may have increased the potential for bias and limited perspectives. Therefore, due to the sampling methods, the participants, same group of authors and the lack of follow-up, it is not clear if results are generalisable, accurate and long-lasting.

Implications for Research

The results should be approached with caution due to the small number of studies identified for the review, and the use of the same authors across studies in the La CLAve Campaign. We found a limited number of studies reporting on interventions for promoting help-seeking for psychosis among minority ethnic groups, despite recommendations in many papers to develop them. Due to the cost of campaigns, it will be important to continue research to identify which methods are the most effective for improving help-seeking. Research would benefit from investigating how best to engage people from minority ethnic groups who are less likely to engage in interventions (e.g. it might help to incorporate mental health teaching into religious services). There was limited information available about the content of the interventions that were offered, which makes it difficult for future researchers to replicate and develop these interventions further. This needs to be improved on to ensure that these interventions are effective, can be adapted and will also aid implementation efforts.

The quality of the included studies may have been improved by providing clear research questions, robust sampling strategies and representative samples. Mixed-methods approaches could have been improved by providing a rationale for the use of mixed-methods approaches, ensuring triangulation of the results and that key quality parameters were adhered to for both qualitative and quantitative methods.

Recommendation for Clinicians

Government and community-based organisations have a key role in improving access to primary care and community-level support by ensuring that there are policies in place, alongside funding and access to resources. Healthcare professionals who work in primary care services (e.g. GPs) can promote knowledge, help-seeking, identify at risk individuals and improve experiences of healthcare for patients. Primary care professionals may also be well placed to work in collaboration with community organisations, social care, education, and faith-based organisations. Non-profit organisations, such as faith-based groups, mental health charities and community centres or hubs can promote awareness, offer support and identify at risk individuals. Additionally, these organisations are knowledgeable of the local area, as well as community needs, and may help to advocate for policy change, especially for underserved communities. Furthermore, schools, colleges and universities have a role in promoting awareness, reducing stigma, and identifying students who may need mental health support. Finally, local media (e.g. newspapers, radio, news broadcasting, social media pages) may have a role in the perception of mental health difficulties in the community and have a role in stigma reduction and help-seeking behaviour.

Many of the interventions included dialogue and conversational approaches, which allowed a safe space for discussion, exploration of ideas and normalisation. There may be benefits to providing these spaces or peer-led support groups within the community. This may also help reach people who have not had prior experience with psychosis and assist with better identification in the early phase.

The use of fictional accounts to support learning appears successful, but it may be more advantageous to include people with personal experiences of psychosis. Additionally, mental health professionals must collaborate with non-professionals to develop campaigns to ensure that healthcare services can meet the needs of the community, as outlined in the campaign. It is also imperative that campaigns acknowledge and respect the understanding of psychosis that may already exist within an ethnic group.

Future research is needed to develop and evaluate interventions that encourage use of primary care services and community resources. Of the included studies, both interventions mentioned working with community leaders, but they did not report on the outcomes of collaborating with faith leaders or community leaders. These relationships are likely to be a valuable source of knowledge that is mutually beneficial and may also result in increased trust from the community.

There is also a need for co-development of policies with people from minority ethnic groups that focus on making services feel inclusive, culturally safe, and accessible. To inform these policies, we need more robust sampling methods in future studies that span across minority communities and socio-demographic factors.

Interventions that involved culturally-adapted materials seemed to be effective at engaging minority ethnic groups (Calderon et al., 2022; López et al., 2009, 2022; Mushtaq et al., 2020), although it was not possible to make any comparisons with studies that did not include this. It also seems inevitable that providing individuals with information in their first language will assist engagement, especially if someone is not fluent in the language of the country they are living in.

Conclusions

To summarise, this review suggests that there is potentially an impact of community-level interventions on help-seeking for psychosis and identified some of the barriers and facilitators of these interventions. More research into the long-term outcomes of these interventions on primary care and community support is warranted. Future research also needs to include studies across different countries, ethnicities, genders and socioeconomic status to ensure that results are generalisable.

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Chapter Three

Bridging Chapter

Word Count: 1247

Chapter Three

Bridging Chapter

This chapter aims to provide an overview of the key findings from the systematic review and outline the rationale for the empirical paper.

Systematic Review Findings

The systematic review retrieved literature on community-level interventions aimed at people from minority ethnic groups with or at risk of psychosis, caregivers, and the general public that were focused on improving help-seeking or access to community support or primary care. A small number of papers were identified, with only five papers meeting the inclusion criteria. Furthermore, four of the papers were linked to the same intervention, so overall the searches revealed two interventions: Bringing Psychiatry to the Mosque symposium (Mushtaq et al., 2020) and the La CLAve campaign (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022). The Bringing Psychiatry to the Mosque symposium was a quantitative study (Mushtaq et al., 2020) and the La CLAve campaign included one qualitative (Hernandez et al., 2016) and three mixed methods studies (Calderon et al., 2022; López et al., 2009, 2022). Both interventions were conducted in the United States (US). There were no United Kingdom (UK) papers retrieved from searches. Participants were from a Latinx background, or they had a Muslim faith (participants were also from a racial minority). The results may not be generalisable outside of these ethnic groups, racial groups or outside of the US. Therefore, further research across ethnic groups and countries would be beneficial.

During the period of its 24-month duration, the approach of La CLAve campaign utilised mnemonic devices, narrative films, group discussions and a PowerPoint presentation, and was led with a strong-armed campaign backing, which included a variety of media advertisement, workshops, as well as liaising with organisations and community leaders (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022). The overall aim of the campaign was to reduce Duration of Untreated Psychosis (DUP) for people from

Latinx backgrounds (López et al., 2022). The Bringing Psychiatry to the Mosque symposium included personal stories from practising Muslims, a panel of professionals, speakers with a background in Islamic sciences, group time and discussion, and culturally-relevant resource folders (Mushtaq et al., 2020). The overall aim of the symposium was to measure participants' views of psychiatric illness (including psychosis), help-seeking and treatment (Mushtaq et al., 2020).

We found that the included studies reported limited information regarding Pathway to Care (PtC) factors, such as referral source or PtC contacts. However, information was available and extracted for help-seeking recommendations for both interventions. Additionally, one paper from the La CLAve campaign included an analysis of DUP (López et al., 2022). Interventions appeared to improve views on professional help-seeking for self and others, but some of the studies did not reach statistical significance (Mushtaq et al., 2020; Calderon et al., 2022). Despite some changes in the length of DUP, there was also no significant improvement found for DUP.

Barriers and facilitators to carrying out the interventions included: the suitability of content, socioeconomic factors, cultural appropriateness, reaching the target audience and delivery format. Campaigns included a fictional or non-fictional account of what it is like to live with psychosis, which appeared to facilitate engagement. Both research teams identified that mental health interventions may be attractive for certain groups of people (e.g. people with familiarity or interest), and therefore, there may be groups of people who would benefit who are not attending, and who may benefit most. Both interventions used delivery formats that were likely to engage the target audience. The La CLAve campaign (Calderon et al., 2022; Hernandez et al., 2016; López et al., 2009, 2022) involved a huge number of formats, whilst the Bringing Psychiatry to the Mosque symposium (Mushtaq et al., 2020) included collaboration with trusted figures in the community.

There were several limitations of the systematic review. Firstly, our searches only identified two different interventions. This was possibly due to availability in databases, the focus of search terms on psychosis only, exclusion of secondary mental health service data or the exclusion of grey literature. This lack of retrieved interventions was surprising, due to the disparities in care and treatment for psychosis across some minority ethnic groups (Calderon et al., 2022; Hernandez et al., 2016), and considering the high amount of literature recommending community-level interventions (Chien & Compton, 2008; Lee-Tauler et al., 2018; Oluwoye & Weeks, 2023; Rashid et al., 2012). Secondly, the Bringing Psychiatry to the Mosque paper used a small sample of participants who were highly educated, and this may have resulted in the intervention appearing less impactful. Therefore, it was difficult to make inferences about the effectiveness of interventions, but our results suggested that they are likely impactful in promoting professional help-seeking for minority ethnic populations.

Outline and Rationale for the Empirical Paper

The systematic review examined the first aim of the portfolio which was to assess the effectiveness of community-level interventions in improving access to primary care/community support for psychosis among people from ethnic minority backgrounds. This first aim was focused on interventions at a primary care level, whilst the second aim of the thesis portfolio focused on access at the secondary care level. More specifically, the second aim was to examine the associations between sociodemographic, pathway to care characteristics and access to EIP in a sample who accessed support the same year as the introduction of the Access and Waiting Time Standards.

Previous research has suggested that DUP may be impacted by many sociodemographic factors including unemployment (e.g. Singh & Grange, 2006), age of onset (e.g. Souaiby et al., 2019) and ethnicity (e.g. Schoer et al., 2019). DUP may be dictated by the PtC that people take. For example, accessing support from the GP has been associated with a longer DUP (Bechard-Evans et al., 2007), whilst accessing support from emergency services is associated with a shorter DUP (Ghali et al., 2013). Furthermore, people from different racial groups may seek support differently. For example, White British groups may be more likely to seek support from their GP (Ghali et al., 2013), whereas people from Black African, Black Caribbean, Bangladeshi, Indian and Pakistani ethnic groups may be more likely to seek support from faith-based organisations (Singh et al., 2015). Therefore, due to the PtC associated with sociodemographic factors, this likely results in differences in DUP.

Early intervention services were introduced in the UK to improve timely care for people experiencing psychosis (Singh et al., 2015). The National Health Service (NHS) has more recently defined ‘timely’ by introducing an Access and Waiting Time Standard which states that half of people referred must receive support as outlined by the National Institute of Clinical Excellence (NICE) within two weeks of referral (NHS England, 2016). We are interested in whether particular populations are more likely to be seen within the outlined two weeks and whether there are characteristics that result in particular PtC.

Therefore, the objective of the empirical paper presented in chapter 4 is to examine whether sociodemographic, PtC or clinical factors result in variation in waiting times for EIP and whether particular characteristics result in people accessing support through the community or inpatient services. The empirical paper makes use of a large sample of ethnically diverse people who have experienced psychosis. It is hoped that the outcomes of the empirical paper will help us to identify the impact of the Access and Waiting Time Standard, and whether there are populations that face disparities. This will help us to inform target audiences for interventions, and policies leading to less disparity across psychosis care.

Chapter Four

Empirical Paper

Which sociodemographic, clinical and pathways to care factors influence wait time for early intervention for psychosis? A cross-sectional electronic health records analysis

Prepared for submission to 'Early Intervention in Psychiatry'[1]

Word Count: 7622 (including tables and references)

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[1] See Appendix A for author guidelines. Figures and tables are provided within the main body of the text.

Which sociodemographic, clinical and pathways to care factors influence wait time for early intervention for psychosis? A cross-sectional electronic health records analysis

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Abstract word count: 232

Text body word count: 4723

Abstract

Aim: Delays in accessing treatment for psychosis result in poorer outcomes. In the UK, the Access and Waiting Time Standard was introduced, which outlined that people referred for first-episode psychosis should receive treatment from an early intervention for psychosis (EIP) service within two weeks. We examined sociodemographic, Pathways to Care (PtC) and clinical factors associated with wait time to EIP services.

Method: We collected data from de-identified electronic health records from South London and Maudsley NHS Trust, starting from 2016 when the Access and Waiting Time Standard was introduced. Data were analysed using descriptive statistics for categorical and continuous outcomes and multivariable linear regression models.

Results: A total of 1806 patients with psychosis were identified. Analyses showed 73% of the sample waited over two weeks. Longer wait time was strongly associated with age increases and accessing the community EIP service. Shorter wait time was associated with A&E and 'other' referrals. White non-British and South Asian groups had shorter wait times for EIP services due to inpatient EIP service use.

Conclusions: We found that the majority of patients referred to community EIP were not seen within the two weeks outlined by the Access and Waiting Time Standard. Analyses showed strong associations between sociodemographic factors, PtC and clinical factors and wait time. Interventions and initiatives are required to reduce disparities in mental health care and to support EIP services to meet clinical guidance.

***Keywords**: psychosis, early intervention psychosis, treatment delays, pathways to care*

Introduction

The early detection of psychosis has become a significant priority in mental health care (Lloyd-Evans et al., 2011). Delays in accessing appropriate care and treatment for psychosis have been associated with poor quality of life (Penttilä et al., 2014), higher risk of violent symptoms (Farooq et al., 2009), poorer recovery/remission of symptoms and increased relapse rate (Perkins et al., 2005). Therefore, to improve outcomes, treatment delays should be avoided (Norman et al., 2005).

Delays to Treatment

Delays can occur at both an individual level and a service level. Research has identified several factors at an individual level that may prevent people from seeking support from services, such as poor public knowledge of mental health difficulties preventing recognition and help-seeking (Jung et al., 2017; Martin et al., 2018), lack of insight into symptoms (Penttilä et al., 2014), concerns about stigma associated with psychosis (Martin et al., 2018) and concerns of hospitalisation (Jansen et al., 2018). Furthermore, studies have demonstrated the importance of family members who recognise symptoms (Connor et al., 2016) and promote help-seeking (Allan et al., 2021), whilst delays have been associated with social isolation (Oduola et al., 2021).

At a service level, mental health services in the United Kingdom (UK) experience underfunding and low staffing levels (NHS England, 2016b; British Medical Association; BMA, 2021). Despite this, Early Intervention for Psychosis (EIP) services tend to act extremely quickly (Royal College of Psychiatrists; RCP, 2022). Some research has suggested that services may contribute to a longer duration of untreated psychosis, due to failure to engage people with psychosis (Birchwood et al., 2013). However, it can be difficult to engage patients with psychosis and keep them engaged in treatment (Doyle et al., 2014). Services have also been criticised for not being culturally sensitive (Gopalkrishnan, 2018; Maraj et al., 2023), with language barriers (Inhorn & Serour, 2011; Isaacs et al., 2010) and poor understanding of cultural and religious beliefs (Amri, 2012; Inhorn & Serour, 2011) that act as barriers to service use (Amri, 2012; Inhorn & Serour, 2011; Isaacs et al., 2010;

Lawrence et al., 2021), and thus impact on timely support and pathways into care (Maraj et al., 2023). For example, research shows that minority ethnic groups are more represented in inpatient services (Halvorsud et al., 2018).

Improving Wait Time to Early Intervention in Psychosis Services

Due to the negative consequences associated with treatment delay, mental health services have prioritised improving access to treatment (Addington et al., 2015). Specifically, there has been a focus on earlier detection of psychosis, reduction of waiting times and improved accessibility for underserved communities (Marshall & Rathbone, 2011). This resulted in the introduction of EIP services in the UK, which aimed to provide timely care for psychosis, but until now ‘timely’ was not defined (Singh et al., 2018). In 2016, the Access and Waiting Time Standard was implemented in the National Health Service (NHS) and the age of acceptance for an EIP service was extended from 14–35 years to 14–65 years (NHS England, 2016a). This standardised code of practice outlined that at least half of the people referred to EIP services must be offered National Institute of Clinical Excellence (NICE) approved support within two weeks of referral (NHS England, 2016a). The two-week target includes weekends and bank holidays within the calculation (NHS England, 2024). The clock starts once a central triage point or EIP service receives the referral. The EIP service then assesses whether the person has a first-episode psychosis (FEP). If FEP is confirmed, the clock is stopped following acceptance onto an EIP caseload that can deliver NICE-recommended care, and once a care coordinator has been allocated and engaged with the person (NHS England, 2023). The NICE guidance outlines the following treatments: anti-psychotic medication, CBT and family intervention (NICE, 2014). If someone is admitted to inpatient services the two-week target still applies, and the person should be referred to the EIP service as soon as it is suspected that they may have FEP (NHS England., 2023). If appointments are cancelled or people do not attend this does not stop the clock (NHS England, 2016a).

The National Clinical Audit of Psychosis (NCAP) was established in 2017 (RCP, 2024). It is funded by NHS England, NHS Improvement and the Welsh Government. It aims to improve the quality of care provided to people with psychosis. The NCAP audit utilises clinical standards to evaluate the quality and performance of psychosis services offered across the United Kingdom (RCP, 2024). From 2018, this included reviewing whether services are meeting the Access and Waiting Time Standard (RCP, 2019). The findings of the NCAP audit, alongside areas for improvement and best-practice examples, are available annually on the Royal College of Psychiatrists website (RCP, 2024).

Some studies have examined factors associated with wait time to EIP, but most have used data that pre-dates the introduction of the Access and Waiting Time Standard in 2016 (Kirkbride et al., 2017; Oduola et al., 2024). Additionally, studies that have evaluated the implementation of policy have largely focused on estimating the proportion of people seen within two weeks (Adamson et al., 2018; Kreutzberg, 2018; Singh et al., 2018). To date, there have been limited studies comprehensively examining wait time for EIP according to sociodemographic, pathways to care (PtC) and clinical factors since the implementation of the Access and Waiting Time Standard. Therefore, in this study, we addressed the following research questions: (1) What are the characteristics of patients accessing EIP services (inpatient vs. community)? (2) Which sociodemographic, PtC and clinical factors are associated with waiting times for EIP services? (3) Are there ethnic variations in waiting times for EIP services?

Materials and Methods

Design

A cross-sectional design was employed. South London and Maudsley (SLaM) NHS Trust serve 1.3 million people in South London (Croydon, Lewisham, Lambeth, and Southwark) (Office for National Statistics; ONS, 2011a). SLaM services for FEP include a community EIP service across each catchment area and an inpatient EIP ward based at Lambeth Hospital available for all boroughs, specifically for people experiencing FEP (Fusar-Poli et al., 2020). SLaM was the first NHS trust to implement EIP services and serves a diverse population of people, which has resulted in SLaM being a key research site for EIP and ethnic disparities (Fusar-Poli et al., 2020). In 2007, the Clinical Records Interactive Search (CRIS) system was developed which de-identifies SLaM clinical records for research purposes (Perera et al., 2016). Each record goes through a stringent process of anonymity (see Perera et al., 2016 for an in-depth overview) to ensure that information is not identifiable by blocking significant parts of a record (e.g. names or the second half of a postcode). CRIS has been used for several epidemiological studies that have provided valuable insight into psychosis (de Freitas et al., 2022; Heslin et al., 2018; Oduola et al., 2021). CRIS studies have also been used to understand delays for EIP services (e.g. Oduola et al., 2024).

Data is available from the CRIS system using Structured Query Language (SQL) and Natural Language Processing (NLP) to extract data from structured and unstructured fields of a database or by using the ‘Front End’ system (a web-based searchable interface of the electronic records at SLaM) to retrieve data manually from each record (Perera et al., 2016).

Participants

Data were drawn from the CRIS system using SQL and NLP applications (Perera et al., 2016) based on study inclusion and exclusion criteria. We used the Front-End system to search for any missing data not identified from the SQL. The dataset consisted of 1806 patients referred to SLaM for FEP between 1st May 2016 and 30th April 2019. We focused on this period as the Access and Waiting Time Standard was introduced in April 2016 and 2019 was before the Coronavirus pandemic.

Inclusion and Exclusion Criteria

Participants were included if they (a) lived in the London boroughs (Lambeth, Croyden, Lewisham and Southwark) served by SLaM, (b) presented to services between May 2016 and April 2019 (c) were under the age of 65 years (inclusive), (d) were referred for a suspected FEP as categorised by the International Classification of Diseases-10 (ICD-10) F20-29 (World Health Organisation; WHO, 2011). They were excluded if there (a) was evidence that psychotic symptoms were due to an organic cause or acute intoxication, or (b) they were aged over 65.

Ethics

CRIS was granted ethical approval by the Oxfordshire Research Ethics Committee (reference 23/SC/0257) as a secondary dataset for research, and we obtained a SLaM/CRIS Oversight Committee approval for this study (reference: 22-032). Under UK law, patient consent was not required for this study.

Procedure and Variables

Sociodemographic Characteristics

Sociodemographic data which included ethnicity, occupation, age, sex, relationship status, education level and employment status were extracted from CRIS.

Ethnicity.

Ethnicity is recorded as self-ascribed by patients in SLaM and based on the 18 categories stated by the UK 2011 census (ONS, 2011b), but these were collapsed ahead of analysis due to small numbers in some ethnic groups, and in line with previous research in this area (Oduola et al., 2021). We re-categorised ethnicity as follows: White British, White non-British (White Irish, Traveller, Other White), Mixed (all mixed ethnic groups), Other (Arab, Chinese, Other), Black African, Black Caribbean, Black Other, South Asian (Indian, Pakistani, Bangladeshi).

Occupation.

Occupation was categorised using the Extended Standard Occupational Classification 2020 Framework (ONS, 2020) and collapsed to account for groups that were redundant or had small numbers. They were categorised as: management/professional, admin, skilled trades, care/leisure, customer services, machine operatives, elementary occupations, student and economically inactive.

Sex, Relationship Status, Education Level and Employment Status.

The remaining variables were: age, sex as assigned at birth (male, female), relationship status (single, married/steady relationship, divorced/widowed), education level (no school qualifications, school qualifications, vocational/tertiary qualifications, university qualifications), employment status (unemployed, student, employed). Aside from the data for occupation, all sociodemographic data was coded using the Medical Research Council Socio-demographic Schedule (Mallet et al., 1997), which were used in previous CRIS studies (Oduola et al., 2021, 2024).

Sociodemographic Variables with Missing Data.

There were some variables with missing data. Namely ethnicity, relationship status, employment status, education level and occupation. Missing data was searched for in the CRIS free-text clinical records using the following search terms: ethnicity (white, black, Asian, mixed, language), relationship status (wife, husband, separated, partner, relationship, divorced), employment status and occupation (work, unemployed, job, part-time, self-employed, student) and education level (school, college, university, degree, qualification). The extracted free-text ethnicity data was independently checked with moderate agreement (K=0.41).

Pathway to Care and Clinical Factors

Wait time, referral source, mode of contact and primary diagnosis were extracted from the structure fields in CRIS, guided by the Personal and Psychiatric History Schedule (WHO,1996).

Pathway to Care Factors.

Wait time was calculated as the date of acceptance by an EIP service minus the date of referral to an EIP service and reported in number of days. Referral source was labelled as GP, health and social care, A&E, police/Criminal Justice Agency, self/family, voluntary service or other. Mode of contact was categorised on whether patients had accessed an EIP service through the EIP community or EIP inpatient service.

Clinical Factors.

Primary diagnosis was categorised according to ICD-10 diagnoses (WHO, 2011) using the labels: schizophrenia, acute, schizoaffective disorder, unspecified psychotic disorder, diagnosis not stated.

Statistical Analysis

The data were analysed using STATA 15.1 (StataCorp., 2017). Descriptive statistics were used to describe the sample, including frequencies and percentages for categorical data; and means, medians, standard deviation, range and interquartile range for continuous data.

To address research question 1, chi-square tests (and t-test as appropriate) were used to explore the difference between mode of contact and study variables.

For research question 2, we undertook two sets of analyses. First, Kruskal-Wallis tests were used to analyse the differences between wait time and study variables. Second, we fitted multivariable linear regression analysis using complete data to estimate the associations between wait time and the variables that were statistically significant in the Kruskal-Wallis. The multivariable analysis did not include ethnicity because this was addressed in a separate research question. Since the wait time variable was positively skewed, we performed log-transformation to allow parametric analyses. An arbitrary value of 1 was added to EIP wait time to avoid omitting patients with an inpatient admission. This approach has been adopted in previous studies (e.g. Kirkbride et al., 2017).

For research question 3, we fitted three further regression models to assess the magnitude of associations between ethnicity and wait time, while controlling for confounders, using the White British group as the reference group. First, we estimated the crude beta coefficients. Second, we adjusted for age and sex as a-priori confounders. In the third model we added variables that we associated with wait time in the Kruskal-Wallis test as potential confounders (i.e. referral source, diagnosis, and mode of contact). We performed sensitivity analyses that dichotomised wait time two weeks or longer and separate analyses that included patients with community contact only (see appendix B).

Results

Sample Characteristics

A total of 1806 participants were included in the analysis. Table 1 shows that the majority of patients were male, Black British, single, university-educated and students. The largest number of referrals were made by A&E, the most common diagnosis was unspecified psychotic disorder and the most common mode of contact was via community EIP. The median wait time for an EIP service was nine days (IQR=1-15). However, when wait time was dichotomised into ≤ 2weeks vs > 2 weeks, we observed that 73% of patients were not seen within two weeks of referral (see table 1a, appendix B).

Table 1

Sociodemographic, pathways to care and clinical factors

Characteristics	*N*	%	*M (SD), Mdn (R, IQR)*
Age in years			30 (10.17)
EIP wait time (days)			9 (0-1195, 1-15)
Sex			
Male	1078	59.7	
Female	728	40.3	
Ethnicity[1]			
White British	345	19.1	
White non-British	168	9.3	
Mixed	96	5.3	
South Asian	115	6.4	
Black African	312	17.3	
Black Caribbean	124	6.9	
Black British	448	24.8	
Other	166	9.2	
Relationship Status[2]			
Single	1441	79.8	
Married/Steady relationship	214	11.9	
Divorced/Widowed	94	5.2	
Education Level[3]			
No school Qualifications	81	4.5	
School Qualifications	237	13.1	
Vocational/tertiary Qualification	408	22.6	
University Qualification	820	45.4	
Employment Status[4]			
Unemployed	376	20.8	
Student	495	27.4	
Employed	928	51.4	

Table 1 Continued

Sociodemographic, pathways to care and clinical factors

Characteristics	*N*	%
Occupation[5]		
Management/Professional	233	12.9
Admin	104	5.8
Skilled Trades	87	4.8
Care/Leisure	170	9.4
Customer services	89	4.9
Machine Operatives	25	1.4
Elementary Occupations	115	6.4
Student	505	28.0
Economically Inactive	376	20.8
Referral Source[6]		
GP referral	375	20.8
Health and Social Care	243	13.5
A&E referral	609	33.7
Police/Criminal Justice Agency	175	9.7
Other	334	18.5
Self/Carer	38	2.1
Voluntary Sector	16	0.9
Primary Diagnosis		
Schizophrenia	208	11.5
Acute	176	9.8
Schizoaffective Disorder	49	2.7
Unspecified Psychotic Disorder	697	38.6
Diagnosis not Stated	676	37.4
Mode of Contact		
Community EIP	1559	86.3
Inpatient Ward	247	13.7

Missing data: 1=32 patients, 2=57patients, 3=260 patients, 4=7 patients, 5=102 patients, 6=16 patients.

Characteristics of Patients Accessing EIP Services (Inpatient vs. Community)

The largest proportion of patients' mode of contact was via the community (86.3%), in comparison to via inpatient admission (13.7%). We found strong evidence that mode of contact (i.e. community vs inpatient) differed by age, sex, ethnicity, relationship status, referral source and primary diagnosis (see Table 2). Chi-squared tests showed that patients seen in the community waited approximately twice as long as those seen by inpatient services (see table 2a, appendix B).

Table 2

Sociodemographic Characteristics by mode of contact

Characteristics	Community *N* = 1559 (%)	Inpatient *N* = 247 (%)	Statistic	*df*	*p*
Mean age (*SD*) years	29.49 (10.6)	26.76 (6.1)	$F = 29.17$	1	0.001
Sex					
Male	950 (60.9)	128 (51.8)	$X^2 = 7.36$	1	0.007
Female	609 (39.1)	119 (48.2)			
Ethnicity					
White British	301(19.7)	44 (18.0)	$X^2 =33.04$	7	0.001
White non-British	127 (8.3)	41 (16.7)			
Mixed	80 (5.2)	16 (6.5)			
South Asian	91 (6.0)	24 (9.8)			
Black African	279 (18.3)	33 (13.5)			
Black Caribbean	106 (6.9)	18 (7.4)			
Black British	389 (25.4)	59 (24.1)			
Other	156 (10.2)	10 (4.1)			
Relationship Status					
Single	1231 (81.2)	210 (90.5)	$X^2 = 13.16$	2	0.001
Married/Steady relationship	196 (12.9)	18 (7.8)			
Divorced/Widowed	90 (5.9)	≤10 (1.7)			
Education Level					
No school Qualifications	71 (5.4)	10 (4.4)	$X^2 = 1.18$	3	0.757
School Qualifications	204 (15.5)	33 (14.6)			
Vocational/Tertiary Qualification	352 (26.7)	56 (24.8)			
University Qualification	693 (52.5)	127 (56.2)			
Employment Status					
Unemployed	332 (21.4)	44 (17.8)	$X^2 = 1.72$	2	0.424
Student	426 (27.5)	69 (27.9)			
Employed	794 (51.2)	134 (54.3)			
Occupation					
Management/Professional	199 (13.5)	34 (14.5)	$X^2 = 11.80$	8	0.160
Admin	81 (5.5)	23 (9.8)			
Skilled Trades	81 (5.5)	≤10 (2.6)			
Care/Leisure	152 (10.3)	18 (7.7)			
Customer services	77 (5.2)	12 (5.1)			
Machine Operatives	21 (1.4)	≤10 (1.7)			
Elementary Occupations	99 (6.7)	16 (6.8)			
Student	432 (29.4)	73 (31.2)			
Economically Inactive	328 (22.3)	48 (20.5)			
Referral Source					
GP referral	350 (22.6)	25 (10.3)	$X^2 = 68.29$	6	0.001
Health and Social Care	223 (14.4)	20 (8.2)			
A&E referral	477 (30.8)	132 (54.3)			
Police/Criminal Justice Agency	142 (9.2)	33 (13.6)			
Other	307 (19.8)	27 (11.1)			
Self/Carer	34 (2.2)	≤10 (1.7)			
Voluntary Sector	14 (0.9)	≤10 (0.8)			

Table 2 continued

Sociodemographic Characteristics by mode of contact

Characteristics	Community *N* = 1559 (%)	Inpatient *N* = 247 (%)	Statistic	*df*	*p*
Primary Diagnosis					
Schizophrenia	184 (11.8)	24 (9.7)	$X^2 = 35.91$	4	0.001
Acute	157 (10.1)	19 (7.7)			
Schizoaffective Disorder	36 (2.3)	13 (5.3)			
Unspecified Psychotic Disorder	567 (36.4)	130 (52.6)			
Diagnosis not Stated	615 (49.5)	61 (24.7)			

Note. ≤10 is used where less than 10 patients were identified in line with guidance from Clinical Records Interactive Search team

Sociodemographic, Pathways to Care and Clinical Factors by Wait Time for EIP

Table 3 shows patients aged 35-65 waited longer with a median of 11 days compared to patients aged 14-35. Across all ethnic groups, people of White British and ‘other’ ethnicities waited longer than other ethnicities with a median of 10 and 11.5 days respectively. Patients referred by the voluntary sector, a GP or Health and Social Care waited longer than other referral routes with medians of 12.5 and 11 days. Patients with a diagnosis of schizophrenia and diagnosis not stated waited longer, with a median of 10 days. Finally, if patients accessed support through the community, they had a median wait time of 11 days.

Table 3

Sociodemographic, Pathways to Care and Clinical factors by wait time for EIP

Characteristics	Median wait time for EIP in days (IQR)	Kruskal-Wallis test	*df*	*p*
Age band				
14-35	8 (0-15)	21.948	1	0.001
36-65	11 (6-18)			
Sex				
Male	9 (1-16)	0.716	1	0.398
Female	8 (0-15)			

Table 3 Continued

Sociodemographic, Pathways to Care and Clinical factors by wait time for EIP

Characteristics	Median wait time for EIP in days (IQR)	Kruskal-Wallis test	*df*	*p*
Ethnicity	10 (1-21)	24.295	7	0.001
White British	7 (0-14)			
White non-British	9 (0-16.5)			
Mixed	8 (0-14)			
South Asian	8 (3-15)			
Black African	8 (0-15)			
Black Caribbean	8 (0-14)			
Black British	11.5 (4-20)			
Other				
Relationship Status				
Single	8 (0-16)	3.714	2	0.156
Married/Steady Relationship	10 (5-14)			
Divorced/Widowed	11 (3-17)			
Education Level				
No school Qualifications	11 (3-24)	3.287	3	0.349
School Qualifications	9 (0-14)			
Vocational/tertiary Qualification	8.5 (0-15)			
University Qualification	8 (0-15)			
Employment Status				
Unemployed	10 (1-17)	3.549	2	0.170
Student	8 (0-16)			
Employed	9 (1-15)			
Occupation				
Management/Professional	9 (1-14)	12.479	8	0.131
Admin	7 (0-14.5)			
Skilled Trades	8 (2-15)			
Care/Leisure	12 (3-20)			
Customer Services	9 (0-15)			
Machine Operatives	7 (0-14)			
Elementary Occupations	7 (0-14)			
Student	8 (0-16)			
Economically Inactive	10 (1.5-15)			
Referral Source				
GP referral	11 (3-24)	54.503	6	0.001
Health and Social Care	11 (2-23)			
A&E referral	7 (0-13)			
Police/Criminal Justice Agency	8 (0-14)			
Other	9 (2-14)			
Self/Carer	10 (2-17)			
Voluntary Sector	12.5 (3.5-24)			
Primary Diagnosis				
Schizophrenia	10 (1-22)	21.315	4	0.001
Acute	9.5 (2.5-14)			
Schizoaffective Disorder	4 (0-14)			
Unspecified Psychotic Disorder	8 (0-14)			
Diagnosis not Stated	10 (1-20)			

Table 3 Continued

Sociodemographic, Pathways to Care and Clinical factors by wait time for EIP

Characteristics	Median wait time for EIP in days (IQR)	Kruskal-Wallis test	*df*	*p*
Mode of Contact				
Community EIP	11 (5-19)	492.307	1	0.001
Inpatient Ward	0 (0-0)			

Multivariable Analysis.

Table 4 shows un-adjusted and adjusted multivariable regression analysis. In the un-adjusted regression model, we observed strong evidence that being older was associated with longer wait time. Referrals from A&E, police/criminal justice system and ‘other’ were associated with shorter wait time, compared to GP referral. People with a primary diagnosis of schizoaffective disorder and unspecified psychotic disorder had a shorter wait time than people with schizophrenia. Patients who entered services through community services were twice as likely to wait than people who entered services through the inpatient service. When we adjusted for all variables, the strength of association for age (β = 0.01, 95% CI [0.00, 0.01]), A&E (β = -0.22, 95% CI [-0.37, 0.10]), other (β = -0.21, 95% CI [-0.37, -0.04]), access via community services (β = 2.21, 95% CI [2.05, 2.37]) and wait time remained, whilst the association for schizoaffective disorder (β = -0.15, 95% CI [-0.50, 0.20]) and unspecified psychotic disorder (β = -0.03, 95% CI [-0.21, 0.14]) diminished. Sensitivity analysis (see table 2a, appendix B) where community EIP data was analysed independently from inpatient EIP data showed that the strength of association was the same for age and A&E and ‘other’ referral.

Table 4

Multivariable regression analysis associations between sociodemographic, Pathways to Care and Clinical factors and wait time

	β (95% CI): Unadjusted Models	β (95% CI): Adjusted Model
Age	0.02 (0.01, 0.02)***	0.01 (0.00, 0.01)**
Sex (Female)	-0.06 (-0.19, 0.71)	0.03 (-0.08, 0.14)
Referral Source		
GP	Reference	
Health and Social Care	-0.04 (-0.27, 0.18)	0.01 (-0.17, 0.19)
A&E	-0.57 (-0.74, -0.39)***	-0.22 (-0.37, -0.10)**
Police/Criminal Justice System	-0.44 (-0.68, -0.19)***	-0.13 (-0.34, 0.08)
Other	-0.23 (-0.43, -0.03)*	-0.21 (-0.37, -0.04)**
Self/Carer	-0.12 (-0.57, 0.33)	-0.03 (-0.40, 0.34)
Voluntary Sector	-0.10 (-0.79, 0.60)	-0.01 (-0.59, 0.56)
Mode of Contact (community)	2.28 (2.43, 2.13)***	2.21 (2.05, 2.37)***
Primary Diagnosis		
Schizophrenia	Reference	
Acute	-0.04 (-0.32, 0.23)	-0.01 (-0.23, 0.22)
Schizoaffective Disorder	-0.52 (-0.95, -0.10)*	-0.15 (-0.50, 0.20)
Unspecified Psychotic Disorder	-0.21 (-0.42, 0.00)*	-0.03 (-0.21, 0.14)
Diagnosis not Stated	0.10 (-0.17, 0.26)	0.09 (-0.17, 0.18)

Unadjusted Model: variables were entered into individual regression analyses

Adjusted Model: all variables were entered into one multivariable regression model

*$p \leq 0.05$; **$p \leq 0.01$; ***$p \leq 0.001$

Ethnicity and Wait Time for EIP Services

In the unadjusted analysis, we observed that patients who were White non-British (β = -0.40, 95% CI [-0.65, -0.15]), South Asian (β = -0.36, 95% CI [-0.65, -0.07]) and Black British (β = -0.21, 95% CI [-0.40,-0.02]) had shorter wait times than White British patients (Model 1, Table 5). When accounting for age and sex (Model 2, Table 5), strong evidence remained that White non-British patients and South Asian patients had shorter wait time for EIP services, but not the strength of association no longer held for the Black British patients. Finally, in Model 3, when we added referral source, diagnosis, and mode of contact, the strength of the association of ethnicity with wait time attenuated.

In Model 3, we observed the adjusted R^2 = 33.7% compared with R^2 = 2.4% in Model 2. Therefore, source of referral and mode of contact explained 33.7% of the variance in the associations between wait time and ethnicity. This was confirmed further by our sensitivity analysis (see table 3a, appendix B) which showed that when we removed inpatient data there was no association for difference in community EIP wait time for White non-British and South Asian groups across models.

Table 5

Unadjusted and adjusted models of associations between ethnicity and EIP wait time (N = 1759)

Ethnicity	β (95% CI): Model 1	β (95% CI): Model 2	β (95% CI): Model 3
White British	Reference		
White non-British	-0.40 (-0.65, -0.15)**	-0.38 (-0.63, -0.13)**	-0.12 (-0.33, 0.10)
Mixed	-0.15 (-0.46, 0.16)	-0.10 (-0.40, 0.21)	-0.02 (-0.30, 0.23)
South Asian	-0.36 (-0.65, -0.07)**	-0.34 (-0.63, -0.10)*	-0.14 (-0.38, 0.10)
Black African	-0.06 (-0.27, 0.15)	-0.05 (-0.25, 0.16)	-0.09 (-0.26, 0.10)
Black Caribbean	-0.21 (-0.49, 0.07)	-0.19 (-0.47, 0.10)	-0.15 (-0.38, 0.10)
Black British	-0.21 (-0.40, -0.02)*	-0.15 (-0.34, 0.04)	-0.15 (-0.30, 0.01)
Other	0.17 (-0.10, 0.42)	0.14 (-0.11, 0.40)	0.02 (-0.18, 0.23)

Model 1 – unadjusted

Model 2 – adjusted for age and sex

Model 3 – adjusted for age, sex, referral source, diagnosis and mode of contact

*$p \leq 0.05$; **$p \leq 0.01$; ***$p \leq 0.001$

Discussion

Main Findings

This study aimed to examine the characteristics of patients accessing EIP services via inpatient or the community, characteristics associated with waiting times for EIP and whether there were ethnic variations in waiting times for EIP. Our analysis identified that age, sex, ethnicity, relationship status, referral source and primary diagnosis were associated with how people accessed EIP (inpatient vs. community). We found that the majority of the sample were not seen by EIP services within two weeks of referral. Increases in age and accessing support via the community EIP team were strongly associated with longer wait times. Shorter wait times were associated with referrals from A&E and ‘other’ referrals. White non-British and South Asian groups had shorter wait times, due to them being more represented in inpatient services and possibly due to quicker referral sources (i.e. A&E referral).

Comparison of Findings with Previous Research

We found that single people were more likely to access support via the inpatient team over the community team, and people in relationships were seen more in the community team than inpatient services, which may add further to the literature that identifies the importance of support from others to promote help-seeking (Oduola et al., 2021).

Female patients were more represented in inpatient services, whilst male patients were more represented in community services. This contrasts with previous research (Polachek et al., 2017) that suggests male patients with psychotic disorders are more represented in inpatient services than female patients. This could be due to the ethnic diversity in our sample, as research suggests that female patients from some ethnic groups are less likely to seek support from mental health services (Kapadia et al., 2018).

We found that patients from White British, Black African, Black British and ‘Other’ groups were most represented in community EIP services. This could indicate that services provided accessible and culturally informed support for these ethnic groups. In contrast, Black Caribbean, South Asian, Mixed and White non-British groups were more represented in the inpatient EIP service. This is in line with other studies that have identified some minority ethnic groups are more at risk of adverse pathways to care (Halvorsrud et al., 2018) and suggests that some groups remain underserved (Marshall & Rathbone, 2011).

In contrast with previous research, (Adamson et al., 2018; Kreutzberg et al., 2018; Singh et al., 2018) the majority of patients in our sample were not seen within the two weeks outlined by the Access and Waiting Time Standard. This was especially true for patients who accessed support via the community EIP service. We used data over three years, whereas previous studies ranged from three–12 months (Adamson et al., 2018; Kreutzberg et al., 2018; Singh et al., 2018).

Referrals to mental health services have increased since 2016 (BMA, 2021), and referrals for EIP services have increased due to the extended age range (NHS England, 2016a). Furthermore, service pressures (e.g. staffing levels) continue in NHS services (BMA, 2021), making it increasingly difficult to meet the Access and Waiting Time Standard. Despite this, recent NCAP data from the 2021/2022 report (RCP, 2022) suggested that only 10 trusts in the UK saw less than 60% of referrals within two weeks of referral.

The NCAP data from the spotlight audit 2018/2019 (RCP, 2019) showed that 78% of patients were seen by SLaM within two weeks of initial referral. However, we found that 73% of patients were not seen within two weeks. It is important to note that we removed inpatient data in our sensitivity analysis, and the NCAP data described above refers to data between November 2018 and January 2019, contrary to our data that was collected between May 2016 and April 2019.

We found that as patient age increased, so did their wait time for EIP services. Before 2016, EIP services focused on the critical period of symptom onset (late teens and twenties) (Bromet & Fennig, 1999) and were only available to those under 35 years (NHS England, 2016a). Therefore, services might need to adapt to meet the needs of older patients (Adamson et al., 2018). Furthermore, older patients are reported to have higher rates of substance misuse (Thakrar et al., 2023) which can make it difficult for people to engage with services (Solmi et al., 2018).

Similarly to the inpatient EIP service, we observed that A&E was the most common referral source for the community EIP service. This suggests that many referrals that meet the criteria for community support are identified through ‘emergency’ routes. This could be due to factors that increase delayed help-seeking, such as poor recognition of symptoms (Penttilä et al., 2014), social isolation (Oduola et al., 2021), concerns associated with help-seeking (e.g. stigma) (Martin et al., 2018; Lawrence et al., 2021; Jansen et al., 2018) or accessibility issues (Gopalkrishnan, 2018; Maraj et al., 2023; NHS England, 2016b).

Halvorsrud et al. (2018) found increased admission for people from their South Asian group and more police and Criminal Justice System involvement in their ‘White Other’ group.

Our study highlighted ongoing disparities for White non-British and South Asian groups who had shorter wait times, due to their representation in the inpatient EIP service. Unfortunately, it was not possible to use census data to estimate a detailed breakdown of the composition of the ‘White Other’ group. However, according to census data from 2011 (ONS, 2011c) and 2021 (ONS, 2021) there were more people from an Indian ethnic group living across all South London boroughs, in comparison to Pakistani and Bangladeshi ethnic groups, but it was not possible to determine if these differences were substantial and remained the same across 2016 – 2019.

There are several possible explanations for disparities in these populations. Whilst family members can often aid help-seeking, in South Asian populations they can also delay and prevent timely help-seeking, due to poor recognition of symptoms or concerns about stigma, making compulsory admission more likely (Connor et al., 2016). South Asian ethnic groups also appear less likely to utilise first-line support, making them more vulnerable to crisis care (Koffman et al., 1997). UK literature focusing on White Other ethnic groups, such as people from Eastern European backgrounds has demonstrated that language barriers (e.g. difficulty describing symptoms in their non-native language), poorer social support, less understanding of NHS services, stigma and lower education levels could all impact help-seeking (Radez et al., 2024).

As previously mentioned, this may also suggest ongoing accessibility issues (Addington et al., 2015), despite efforts to improve access for underserved communities (Marshall & Rathbone, 2011). More specifically, services may not be meeting cultural needs (Gopalkrishnan, 2018; Maraj et al., 2023), which is essential for reducing barriers and disparities at a service level (Amri, 2012; Inhorn & Serour, 2011; Isaacs et al., 2010; Lawrence et al., 2021).

Methodological Considerations

This study is the only study that we are aware of that has looked in detail at sociodemographic, PtC and clinical variables and differences in wait time for EIP services using data onwards from the introduction of the Access and Waiting Time Standard.

However, it is also important to note again that SLaM is a well-resourced trust that serves an extremely diverse population. SLaM was the first NHS trust to set up EIP services, making it a key site of research about ethnic disparities, cultural adaptation, and community outreach for psychosis (Fusar-Poli et al., 2020). SLaM may be more familiar or have more provisions than other NHS trusts to work across cultural and language barriers. In contrast, NHS trusts elsewhere may serve populations where most patients are not faced with the same barriers. There may also be differences across NHS trusts according to factors such as social deprivation and accessibility (e.g. rural trusts may cover larger catchment areas with less transport available). Furthermore, due to a stronger research presence in SLaM (i.e. the addition of the CRIS) this may also result in more robust data collection and SLaM being selected to test and evaluate new and innovative assessment and treatment methods not available elsewhere. Consequently, the results found in this study may be less generalisable to other NHS trusts across the country.

CRIS allowed access to data for a large number of patients living in an ethnically diverse population. However, because the CRIS data set is clinical information routinely recorded by clinicians, we were unable to control how the data was collected and recorded. Likewise, we could not control for potential inaccuracies unlike data produced specifically for research. Additionally, there were limited numbers of patients from a Chinese ethnic background, so this ethnic background was included in the ‘Other’ ethnic group alongside patients with an Arab ethnic background. Similarly, the White non-British group included people from White Irish, Traveller and Other White ethnic backgrounds. This makes it difficult to generalise to individual ethnicities and identify any differences between the ethnic groups within one category. Whilst we adjusted our model for several sociodemographic PtC factors, it was possible that the data may have been confounded by other factors, such as living situation, socio-economic status, and previous service use for other mental health difficulties.

In the current study, we utilised data collected before the Coronavirus pandemic. Whilst the NCAP data (RCP, 2021) does not seem to suggest that there was a reduction in the number of referrals seen within the two weeks following the initial referral, there may have been fewer referrals or more inpatient presentations to services, rather than community presentations. Therefore, future research may benefit from looking in more detail at any changes during the coronavirus pandemic.

Implications of Findings

Overall wait time exceeded two weeks for community EIP so we could not conclude that patients were seen by community EIP within two weeks. Interventions could be utilised to reduce the number of A&E referrals and disparities for ethnic minority groups. They could target referrers and the general public (with a focus on underserved minority ethnic groups identified in this research) to increase mental health literacy, identification, information on accessibility and treatment. Alongside this, we need to ensure that there is improved access to primary care and community-level resources (e.g. religious and voluntary agencies). According to NCAP, most EIP services are meeting the Access and Wait time standards (RCP, 2022) but they would likely benefit from increased funding, improved staffing levels, as well as culturally informed policies, training and resources to meet the increasing demands. Further research may benefit from including ethnic groups that were under-represented in our sample and by including characteristics such as living situation, socio-economic status and previous service use to see if these act as confounding variables.

Conclusions

Previous studies have highlighted the negative impact of treatment delays for people with FEP. Therefore, standards have been introduced in the hope of increasing access and reducing waiting times. We found that most patients were not seen by community EIP services within the timeframe set by the NHS. Sociodemographic status, PtC and clinical factors were associated with wait time and whether patients access support from community or inpatient EIP services. This research also suggests that there are ongoing health inequalities with some minority ethnic groups more represented in inpatient services. Campaigns and interventions are needed to improve accessibility and community links. EIP services may need further support to meet timeframes and improve cultural sensitivity. Future research may benefit from addressing additional sociodemographic factors and ethnicities.

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Chapter Five

Discussion and Critical Evaluation

Word Count: 2105

Chapter Five

Discussion and Critical Evaluation

The final chapter summarises the findings from both the systematic review and the empirical paper. Alongside this, the final chapter serves to outline the overarching clinical, research and theoretical implications that span the breadth of the findings. Finally, the chapter concludes with a comprehensive critical evaluation of the thesis portfolio.

Summary of Findings

The systematic review examined community-level interventions aimed at people from minority ethnic groups with or at risk of psychosis, caregivers, or the general public, to improve help-seeking or access to community support or primary care within the framework of the systematic review and narrative synthesis. Five papers were identified that met the inclusion criteria of the review. The papers reported on two separate community-level interventions that varied in their approach. The first intervention was La CLAve project (2015-2017), which was executed with the aim of reducing the duration of untreated psychosis within Latinx communities (López et al., 2022). The second intervention was Bringing Psychiatry into the Mosque, which examined views of mental health difficulties (including psychosis), help-seeking and treatment before and after a mental health symposium held at a community Mosque (Mushtaq et al., 2020). Generally, the review recognised that the interventions impacted positively on help-seeking, particularly on recommendations for professional help-seeking. Several barriers and facilitators were identified. There was a theme shared by interventions for the suitability of content and delivery format and how this may have acted to facilitate the intervention. Additionally, another shared barrier was regarding the audience of the interventions, as they seemed to capture people with a potential interest and existing knowledge, rather than people who know less about psychosis and may benefit more from the interventions.

The empirical paper examined whether certain characteristics or factors lead to people accessing support through community or inpatient EIP services. Alongside this, it examined whether sociodemographic, pathways to care (PtC) or clinical factors lead to variations in waiting times for EIP services. We were particularly interested in this within the context of a sample between 2016 and 2019, to observe whether the Access and Waiting Time Standard (NHS England, 2016) was being met, and whether there were disparities for particular populations. Our results revealed a median wait time of nine days, however only 73% of the sample were actually seen in the community EIP team within the outlined two weeks. We found that the majority of the sample accessed support in the community and that inpatient EIP was accessed most by younger patients, female patients, White non-British, South Asian, single, referred by A&E or the Criminal Justice System and had a diagnosis of schizoaffective or unspecified psychosis disorder. We also found that increases in age were associated with longer wait times, whilst shorter wait times were associated with accessing support in the community and being referred by A&E or ‘Other’. We observed shorter wait times for people from non-White British and South Asian groups, which appeared to be due to accessing support via the inpatient EIP service.

Considered collectively, the empirical paper highlights the need for interventions to improve access to care, whilst the systematic review highlights an absence of interventions. The empirical paper demonstrated that White non-British and South Asian patients had shorter wait times due to inpatient admission. This suggests that people from these ethnic groups were entering from more adverse pathways and may have presented with more severe symptoms associated with delayed help-seeking (Farooq et al., 2009; Kitchener & Jorm, 2006). This identifies the need for more tailored interventions to improve help-seeking and pathways to care. Our systematic review identified that currently, these interventions were lacking, especially in the UK. However, our results demonstrated that the interventions resulted in promising trends toward improved views of professional help-seeking in minority ethnic groups. Therefore, these interventions appear worthwhile for improving help-seeking in minority ethnic groups in line with the recommendations for them in numerous studies (Amri, 2012; Ferrari et al., 2015; Fitzgerald & Vaidyanathan, 2023; Meran, 2019; Rashid et al., 2012).

Clinical Implications

This research highlighted a need for interventions to increase access to primary care and support in the community that focused on access to support for psychosis within minority ethnic groups. Government policies and funding of community resources are likely needed to enable communities to provide this necessary support. In the community, primary care clinicians, non-profit organisations (e.g. charities, faith-based, community centres), schools, colleges and universities and local media may have a significant impact towards shaping how psychosis and mental health services are perceived within local communities. In addition, they might be best placed to promote awareness, detect people in the prodromal stage of psychosis and support people to develop an understanding of what treatment for psychosis might involve.

The systematic review suggested that many people who engaged with interventions had familiarity or interest in mental health difficulties (Calderon et al., 2022; Mushtaq et al., 2020). Therefore, interventions aimed at improving psychosis need to ensure that they reach wider audiences who may not engage normally, as these are the people who may have less understanding of mental health difficulties or may be at risk of being stigmatised. This may be resolved with the integration of information about mental health services in the community and consultation with community leaders (Meran, 2019; Oluwoye & Weeks, 2023; Rashid et al., 2012). Interventions in the community could also consider delivering content over a longer time with follow-up time to reinforce content and give people space to reflect and ask questions at a later stage. Additionally, the systematic review demonstrated a reduction in people stating that they would seek support from non-professional sources (Calderon et al., 2022; López et al., 2009). Research has demonstrated that family and religious leaders (e.g. Imams) promote help-seeking and recovery (Meran, 2019; Nolan et al., 2012). Thus, future interventions could ensure that they acknowledge the benefit of non-professional help-seeking (e.g. family and religious leaders) to prevent professional help-seeking from seeming more desirable than accessing non-professional support.

In the systematic review, one paper highlighted the concerns of Westernised mental health ideas being focused on interventions (López et al., 2009). Therefore, future interventions could ensure that they acknowledge the existing cultural understanding of psychosis for the ethnic group that the intervention is targeted. In addition, to ensure cultural accessibility, interventions might include culturally adapted materials (e.g. information in their first language), experts by experience who can share their experiences and delivery approaches (e.g. conversational) that are tailored to individual cultures.

Furthermore, research (Gopalkrishnan, 2018; Maraj et al., 2023) and policies (Department of Health and Social Care, 2021a) have identified the importance of culturally sensitive services. Experts by experience are likely to add valuable contributions to policies and support the development of culturally relevant resources. Furthermore, staff may need support to understand and learn how to adapt their practice to ensure that they are meeting the needs of the people that they work with. Collaboration with trusted members of minority ethnic communities can promote understanding for professionals across community-based institutions (e.g. education, social care), primary care and mental health services and vice versa (Meran, 2019; Rashid et al., 2012).

Regarding secondary and specialist mental health care services, it is important to consider the amount of pressure these services may be under, especially if there are increased referrals (British Medical Association; BMA, 2021). Furthermore, if interventions result in improvements in mental health literacy and identification of psychosis by referrers and the general public, it is important to ensure that services can meet increases in referrals (López et al., 2009). Akin to this, the number of referrals expected to meet the outlined two weeks in the original guidance has already been increased (NHS England, 2023). Initially, it was outlined that 50% of referrals should be seen in two weeks (NHS England, 2016), and this has recently been updated to 60% of referrals (NHS England, 2023). To ensure that guidance is met, we need to equip services with suitable funding, staffing levels and resources to be able to meet the increased demands that are being placed on them (BMA, 2021).

Research Implications

Whilst there may be many interventions aimed at improving primary care and community support for minority ethnic groups that are not being empirically studied and reported, the systematic review revealed a lack of literature on community-level interventions aimed at improving access to primary care for minority ethnic communities. Therefore, it will be important for researchers to evaluate interventions to build an evidence base. Due to the costly nature (Calderon et al., 2022) and time invested in interventions, it will be beneficial for research to evaluate and examine which intervention methods work best for different ethnicities. Additionally, identifying the best delivery formats will ensure that interventions are cost-effective. Research that evaluates digital formats may be beneficial, whilst also evaluating older formats such as radio and newspapers to ensure that they are widely used by target audiences. It will be beneficial for people from ethnic communities to be involved in research design and the development of interventions to ensure that they are culturally relevant (Gopalkrishnan, 2018; Maraj et al., 2023). This might also help with engaging hard-to-reach audiences and draw on the differing communication styles across cultures. Studies in this area may benefit from using a longitudinal design or using follow-up measures to see if the participants went on to seek support for themselves or recommended help-seeking to others. Additionally, qualitative research with people who experience psychosis, referrers and staff teams in EIP may help to identify the ongoing barriers and facilitators faced by services and the people who use them.

Strengths and Limitations

Our research adds to the evidence base for psychosis and PtC. The systematic review informed the evidence base on interventions available for minority ethnic groups, and such interventions have been recommended by many studies (Amri, 2012; Ferrari et al., 2015; Fitzgerald & Vaidyanathan, 2023; Meran, 2019; Rashid et al., 2012). Furthermore, we were able to identify several barriers and facilitators that can be used to inform future interventions. The empirical study was the first study that we are aware of that has looked into the sociodemographic, PtC and clinical factors associated with wait time since the introduction of the Access and Waiting Time Standard (NHS England, 2016). Additionally, we utilised a large number of real patients who had attended EIP services and were from an ethnically diverse area in London.

Our findings should be considered alongside the following limitations: Our systematic review included a small number of papers and interventions. Future reviews may benefit from including additional databases, grey literature and could use wider search terms to enable the review to capture additional documents that may have been missed. Initial screening was completed by one person with a small proportion of papers screened by a second reviewer, and no papers were checked by a second reviewer at the full-text screening stage. The data recorded in the CRIS dataset is not recorded for research purposes, so it comes with the risk of some data inaccuracies, which may not be the case when data is recorded for research. The empirical study outcomes may not be generalisable outside of SLaM NHS trust. Future studies could use a similar methodology in other NHS trusts across the country (including rural locations) and compare results. Some minority ethnic groups were less well represented in the empirical study, and there were also a limited number of ethnic groups studied in the systematic review.

Final Summary

To summarise, this thesis included a systematic review and empirical paper that provided an overview and insight into interventions aimed at increasing help-seeking in minority ethnic groups at a primary care level, and an evaluation of characteristics associated with mode of contact and wait time with EIP services. Interventions appeared to have a positive impact on help-seeking, and barriers and facilitators were identified which may help with the intervention development moving forward. The empirical study revealed that services may face challenges in meeting the Access and Waiting Time Standard. There were also differences in mode of contact, age and diagnosis identified. Furthermore, age and referral source were impacted by wait time. Further research is needed to develop and evaluate interventions for help-seeking across different minority ethnic groups. These interventions would benefit from keeping the barriers and facilitators identified with a particular focus on the inclusion and collaboration with communities to develop interventions, as this is likely to increase learning for all, reduce stigma and build trust with communities. Additionally, interventions to improve mental health literacy and support public understanding of services and treatment may be beneficial for reducing A&E referrals. Both papers discussed in this thesis will be submitted to Early Intervention in Psychiatry for publication.

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Appendices

List of Appendices

Appendix A

Early Intervention in Psychiatry Author Guidelines

Author Guidelines

Sections

1. SUBMISSION

Thank you for your interest in *Early Intervention in Psychiatry*. Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

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Articles reporting original work that embodies scientific excellence in psychiatry and advances in clinical research (suggested word count for text 3000; abstract maximum 250);

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Brief Reports which present original research that makes a single point, or negative studies of important topics (suggested word count for text 1500; abstract maximum150);

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· Acknowledgments;

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Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

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Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from http://www.youtube.com/watch?v=Vja83KLQXZs

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Appendix B

Supplemental Results – Sensitivity Analysis

Supplementary Table 1a

Sociodemographic, Pathways to Care and Clinical factors by wait time (less than two weeks vs. more than two weeks)

Characteristic	>2weeks *N* (%)	≤2weeks *N* (%)	Statistic	*df*	*p*
Wait time	1323 (73.3)	483 (26.7)			
Mean age (SD)	28.8 (10)	29.4 (10.2)	$F = 1.26$	1	0.261
Sex					
Male	782 (59.1)	296 (61.3)	$X^2 = 0.70$	1	0.404
Female	541 (40.9)	187 (38.7)			
Ethnicity					
White British	238 (18.3)	107 (22.6)	$X^2 = 10.06$	7	0.185
White non-British	127 (9.8)	41 (8.7)			
Mixed	69 (5.3)	27 (5.7)			
South Asian	91 (7)	24 (5.1)			
Black African	231 (17.8)	81 (17.1)			
Black Caribbean	91 (7.0)	33 (7.0)			
Black British	341 (26.2)	107 (22.6)			
Other	113 (8.7)	53 (11.2)			
Relationship Status					
Single	1051 (82.2)	390 (82.8)	$X^2 = 2.44$	2	0.326
Married/Steady Relationship	163 (12.7)	51 (10.8)			
Divorced/Widowed	64 (5)	30 (6.4)			
Education Level					
No school Qualifications	54 (4.7)	27 (6.7)	$X^2 = 2.76$	3	0.430
School Qualifications	178 (15.6)	59 (14.6)			
Vocational/tertiary Qualification	298 (26.1)	110 (27.2)			
University Qualification	612 (53.6)	208 (51.5)			
Employment Status					
Unemployed	270 (20.5)	106 (21.9)	$X^2 = 0.55$	2	0.759
Student	362 (27.5)	133 (27.6)			
Employed	685 (52)	243 (50.4)			
Occupation					
Management/Professional	181 (14.5)	52 (11.5)	$X^2 = 9.21$	8	0.325
Admin	78 (6.2)	26 (5.8)			
Skilled Trades	65 (5.2)	22 (4.9)			
Care/Leisure	111 (8.9)	59 (13.1)			
Customer Services	65 (5.2)	24 (5.3)			
Machine Operatives	19 (1.5)	≤10 (1.3)			
Elementary Occupations	89 (7.1)	26 (5.8)			
Student	369 (29.5)	136 (30.1)			
Economically Inactive	275 (22)	101 (23.4)			

Supplementary Table 1a Continued

Sociodemographic, Pathways to Care and Clinical factors by wait time (less than two weeks vs. more than two weeks)

Characteristic	>2weeks *N* (%)	≤2weeks *N* (%)	Statistic	*df*	*p*
Referral Source					
GP referral	240 (18.3)	135 (28.1)	X^2 = 53.26	6	0.001
Health and Social Care	152 (11.6)	91 (18.9)			
A&E referral	496 (37.9)	113 (23.5)			
Police/Criminal Justice Agency	132 (10.08)	43 (8.9)			
Other	251 (19.17)	83 (17.3)			
Self/Carer	28 (2.14)	10 (2.1)			
Voluntary Sector	10 (0.76)	≤10 (1.25)			
Primary Diagnosis					
Schizophrenia	136 (10.3)	72 (14.9)	X^2 = 29.88	4	0.001
Acute	138 (10.4)	38 (7.9)			
Schizoaffective Disorder	37 (2.8)	12 (2.5)			
Unspecified Psychotic Disorder	551 (41.7)	146 (30.2)			
Diagnosis Not Stated	461 (34.9)	215 (44.5)			
Mode of Contact					
Community EIP	1076 (81.3)	483 (100)	X^2=104.46	1	0.001
Inpatient Ward	247 (18.7)	0 (0.00)			

Supplementary Table 2a

Multivariable regression analysis associations between sociodemographic, pathways to care and clinical factors with community early intervention for psychosis data only

	β (95% CI): Unadjusted Model	β (95% CI): Adjusted Model
Age	0.01 (0.00, 0.01)**	0.01 (0.00, 0.01)***
Sex (female)	0.06 (-0.06, 0.19)	0.04 (-0.09, 0.17)
Referral Source		
GP	Reference	
Health and Social Care	0.00 (-0.21, 0.21)	0.01 (-0.19, 0.22)
A&E	-0.27 (-0.43, -0.10)**	-0.25 (-0.42, 0.08)**
Police/Criminal Justice System	-0.17 (-0.40, 0.01)	-0.14 (-0.37, 0.10)
Other	-0.22 (-0.40, -0.03)*	-0.22 (-0.41, -0.04)***
Self/Carer	-0.03 (-0.45, -0.40)	-0.03 (-0.45, 0.40)
Voluntary Sector	0.07 (-0.59, 0.73)	0.01 (-0.66, 0.67)
Mode of Contact (community)	Omitted	
Primary Diagnosis		
Schizophrenia	Reference	
Acute	-0.65 (-0.32, 0.20)	-0.01 (-0.28, 0.25)
Schizoaffective	-0.25 (-.68, 0.18)	-0.21 (-0.64, 0.23)
Unspecified	-0.07 (-0.28, 0.13)	-0.05 (-0.25, 0.16)
Diagnosis Not Stated	-0.01 (-0.21, 0.20)	-0.00 (-0.20, 0.20)

*$p≤0.05$; **$p≤0.01$; ***$p≤0.001$

Supplementary Table 3a

Unadjusted and adjusted models of associations between ethnicity and EIP wait time with community early intervention for psychosis data only

Ethnicity	β (95% CI): Model 1	β (95% CI): Model 2	β (95% CI): Model 3
White British	Reference		
White non-British	-0.18 (-0.43, 0.08)	-0.17 (-0.42, 0.08)	-0.14 (-0.40, 0.01)
Mixed	-0.07 (-0.36, 0.23)	-0.05 (-0.34, 0.25)	-0.25 (-0.32, 0.27)
South Asian	-0.21 (-0.49, 0.07)	-0.20 (-0.48, 0.08)	-0.17 (-0.45, 0.11)
Black African	-0.13 (-0.33, 0.07)	-0.13 (-0.33, 0.07)	-0.10 (-0.30, 0.10)
Black Caribbean	-0.19 (-0.46, 0.08)	-0.19 (-0.45, 0.08)	-0.18 (-0.45, 0.10)
Black British	-0.23 (-0.41, -0.05)**	-0.20 (-0.38, -0.02)*	-0.17 (-0.35, 0.01)
Other	0.00 (-0.23, 0.24)	-0.00 (-0.23, 0.23)	0.02 (-0.22, 0.25)

Model 1 – unadjusted

Model 2 – adjusted for age and sex

Model 3 – adjusted for age, sex, referral source, diagnosis

*$p≤0.05$; **$p≤0.01$; ***$p≤0.001$