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Synopsis

Accessibility and acceptability of perinatal mental health services for women from ethnic minority groups: a synopsis of the PAAM study

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Abstract

Background: Ethnic minority women face worse maternity outcomes and increased risk of perinatal mental health issues, yet research on the accessibility and acceptability of perinatal mental health services for these groups is limited.
Objectives: (1) To explore access to and utilisation of mental health services during the perinatal period among ethnic minority women; (2) to explore care pathways to community and inpatient perinatal mental health services; (3) to explore the attitudes, experiences and service improvement suggestions of ethnic minority women with perinatal mental health problems, as well as those of their partners, family members and healthcare professionals and (4) to produce recommendations for improving clinical practice.
Methods: Mixed-methods study was conducted during 2018–23, encompassing four studies aligned with specific aims: (1) a population-based study of 615,092 women who gave birth in National Health Services hospitals in England, using data from the National Commissioning Data Repository; (2) a retrospective evaluation of patients accessing community perinatal mental health services in Birmingham and London (n = 228) and inpatient services in Birmingham, London and Nottingham (n = 198) using an adapted World Health Organization care pathways questionnaire; (3) a qualitative study with four cohorts across England: service users (n = 37), non-users or those who disengaged (n = 23), partners/family (n = 15) and healthcare professionals (n = 24); (4) findings informed recommendations for practice improvements, coproduced with individuals with lived experience of perinatal mental illness and of being in a minoritised ethnic group. Data were analysed using quantitative and qualitative approaches.
Results: Access issues to mental health services were evident for Black African, Asian and White other women compared to White British women. Variability in patient journeys to community perinatal mental health services seem to stem from service-level factors rather than patient needs. Asian patients had more emergency admissions to Mother and Baby Units, while Black patients were less likely to experience multiple services before Mother and Baby Unit admission. Barriers to access included limited service awareness, fear of child removal, stigma, remote clinical appointments and unresponsive services. Despite these challenges, many women found services helpful. Family members noted gaps in family-focused care. Recommendations for improvement include raising awareness, monitoring access for different ethnic groups and addressing concerns about child removal, with a focus on consistent care, family involvement and cultural sensitivity.
Conclusion: These findings shed light on health inequalities in perinatal mental health care for ethnic minority women. The results can be utilised to address existing barriers and improve outcomes for mothers, infants and families.
Limitations: Diversity within merged ethnic groups; limited sample of non-English-speaking women; reliance on self-reported measures; use of pre-COVID-19 data; under-representation of Black women who did not engage

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with services, and over-representation of Black and Asian patients in Birmingham and London samples in the study exploring patient pathways to Mother and Baby Units (compared to maternity population).

Future work: Implementation of good practices in perinatal mental health care, targeted interventions to address the fear of child removal, innovative strategies to recruit Black and non-English-speaking women and exploring the experiences of 'White other' women.

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This report presents key findings from the National Institute for Health and Care Research (NIHR)-funded study 'Accessibility and Acceptability of Perinatal Mental Health Services for Women from Ethnic Minority Groups' (PAAM). It offers actionable recommendations to improve care for ethnic minority individuals, focusing on better access and more positive experiences with mental health services. Driven by persistent evidence of inequities, this research supports global efforts to improve perinatal mental health (PMH) and aligns with the UN Sustainable Development Goals, which prioritise the well-being of mothers, infants, children and families. Over the past decade, perinatal mental health services (PMHS) in the UK have significantly expanded, offering more specialised support in both community and inpatient settings. While many examples of good practice and generally positive patient experiences exist, certain inequalities remain. This study highlights critical barriers and provides practical insights to help clinicians, policy-makers and service providers address these challenges effectively.

The word "woman" is used throughout the report because all participants in the reported studies identified as women. However, the research team is keen to acknowledge that perinatal mental health issues are also experienced by people who go through pregnancy, birth, and the postnatal period who do not identify as women (trans* people, including non-binary people). Additionally, little is known about the experiences and prevalence of perinatal mental health problems in trans* groups, and even less about trans* individuals who also belong to minoritised ethnic groups. Future research should explore the experiences of perinatal mental illness among people facing these multiple, intersecting marginalisations.

The report starts with targeted recommendations for decision-makers, grounded in the study's findings, with implications for both clinical practice and future research. Following this, the report outlines the rationale for the research, details the methods used, presents the results, discusses the implications and concludes with a summary of key insights. Together, these elements form a vital resource for driving meaningful change in PMH care.

Implications for decision-makers

The findings from the PAAM study contribute to the growing body of evidence on diversity and inclusion in PMH care. They highlight significant and concerning disparities in access to both community and inpatient mental health services, among women from different ethnic backgrounds during pregnancy and in the first postpartum year. There is an urgent need for targeted interventions to address these disparities, ensuring that mental health services are accessible, equitable and culturally responsive for all women.

The study findings informed the development of recommendations aimed at improving clinical and research practices. These recommendations have the potential to be applied across England and to inform the development of services internationally, thereby shaping both national and global policy.

Recommendations for improving clinical practice

These recommendations highlight critical areas that require attention to ensure that services are culturally sensitive and in tune with the populations they serve, therefore improving the life chances of mothers and children from all backgrounds. Two priorities were identified: (1) improving access to PMHS for women from ethnic minority groups and (2) enhancing the overall experiences of PMHS.

To enhance access to specialist PMHS, the following actions have been suggested for service providers:

1. All healthcare settings to provide information that specialist PMHS exist, what PMHS can offer and specifically what that support might look like.
2. Services should regularly check rates of access for different ethnic groups to monitor potential problems with access (taking into consideration ethnic structure of local maternity population).
3. Services should work with local communities to increase awareness of the diverse ways perinatal

mental illness can show up in someone's life, and to advertise what services offer, in different formats and languages.
4. All services working with mothers with perinatal mental illness should address the fear of their baby being removed rather than avoid it. Explain that different types of support are offered, and share that the goal of services is to support the mother and baby bond.
5. All healthcare professionals (HCPs) interacting with women in the perinatal period should routinely and repeatedly ask about well-being and mental health.
6. All services should consider ethnic diversity among their staff and share information that perinatal professionals come from different ethnic backgrounds. This can be relevant information for women and families considering accessing help.
7. All services should invest efforts to remove practical barriers, such as lack of time and resources. These barriers are important for some women, and services should make efforts to remove them, such as help with transport, child care and so forth.

To improve local service delivery within PMHS, as well as patient experiences of PMHS, the following actions have been recommended:

1. Responsiveness, respect and kindness from staff, and care being provided by the same person throughout, help to build and maintain trust.
2. Value peer support workers from ethnic minorities: people with a lived experience of perinatal mental illness are an important part of PMH teams and help positive engagement.
3. Once women have had contact with services, make sure it is explained to them and their families how to contact services, and set clear expectations.
4. Communicate effectively with other services and be aware of concerns women may have around confidentiality with interpreters.
5. Be clear, consistent and honest: cancellations, not hearing back from services and referrals not being passed on can leave women feeling abandoned.
6. Offer a choice of in-person, home or virtual appointments.
7. Involve families and members of support networks, while being careful not to pressure them into managing risks at home that they are not comfortable with.
8. Check with families and members of support networks, and offer them support where possible.
9. Show interest and avoid assumptions when asking about culture and childrearing practices.
10. Unconscious assumptions related to ethnicity can occur among staff. Create time and space for staff to reflect on potential biases.
11. Always consider asking about culture and ethnicity, as for some women having the space to share is important.
12. Reflect and use women's language for their experiences. Ask questions and seek to understand what women mean so that a shared understanding can be built.

Recommendations for future research

Based on findings from this research, future studies should focus on understanding the reasons behind limited implementation of best practices, identifying and overcoming access barriers, employing innovative and inclusive recruitment strategies and ensuring a comprehensive understanding of the experiences of various demographic groups for the advancement of healthcare services and policies.

Investigating reasons for limited implementation of best practices

Although some methods and approaches in mental health care are already considered best practices, such as increasing awareness of services and ensuring culturally sensitive care, their limited use highlights a critical gap that needs further investigation. Future research should focus on understanding the factors behind the limited adoption of best practices, such as insufficient awareness, resource constraints, resistance to change and so forth. Employing implementation science methods can help address these factors and produce robust and effective implementation strategies, thus enhancing the integration and impact of best clinical practices.

Addressing identified barriers to improve access to service

Future research should seek to understand the specific barriers hindering certain populations' access to services. This involves conducting comprehensive studies or assessments to identify socioeconomic, cultural, geographic or systemic barriers that prevent individuals, especially marginalised communities, from accessing necessary services. By recognising these barriers, interventions or policy changes can be developed to mitigate or eliminate them, thereby enhancing equitable access to services for all individuals. Following the completion of the national expansion of PMHS in England, it would be worth repeating the analysis of accessibility and utilisation of services, as done in work package (WP) 1 in the PAAM study, to assess the impact of the expansion on equality of access for each ethnic group. With improved data collection in the future, it should be possible to conduct a more detailed analysis of the accessibility of specific aspects of PMH care by ethnicity (e.g. whether there is equitable access to psychological therapies).

Employing innovative recruitment strategies in research projects

To ensure the inclusion of under-represented groups such as Black women and non-English-speaking women in research, people who do not identify as women, and people at the intersections of these groups, innovative recruitment strategies need to be adopted. This could involve engaging community leaders and organisations that have strong ties with these communities. Tailored outreach methods, culturally sensitive approaches and language-appropriate materials should be utilised to encourage participation and engagement of under-represented groups. Additionally, establishing trust and rapport within these communities is vital for effective recruitment.

Exploring experiences of 'White other' women

This research has shown significant disparities in access to mental health services for Black African, Asian and White other women relative to White British women. While discussing under-represented groups, it is important to explore the experiences of White other women in the UK to ensure a comprehensive understanding of diverse perspectives and experiences within healthcare settings. Research should aim to understand their specific needs, challenges and experiences concerning accessing services or navigating healthcare systems. This exploration can contribute to a more holistic approach in healthcare provision and policy-making, ensuring inclusivity and addressing the needs of all groups within the population.

Introduction

Perinatal mental health disorders are prevalent, affecting up to 25% of women during pregnancy and the first year after giving birth. This is in line with the latest prevalence date[1,2] These disorders may involve either a first-time episode or a relapse of known severe mental illnesses, such as depression, postpartum psychosis, schizophrenia, schizoaffective disorder and bipolar affective disorder. Other disorders include anxiety disorders, such as obsessive–compulsive disorder and post-traumatic stress disorder, as well as eating disorders and substance misuse. These disorders can develop gradually or emerge suddenly, affecting the mother's health, the children's well-being, the family and society.

In the UK, Confidential Enquiries into Maternal Deaths have identified PMH disorders as one of the leading causes of maternal death.[3] Failing to address these disorders results in substantial health, societal and economic burdens. The estimated cost of PMH problems is £8.1B per 1-year cohort of births in the UK, with nearly three quarters of the costs attributed to adverse impacts on children.[4] Therefore, ensuring prompt and easily accessible mental health services is crucial for the well-being of these women and their families.[5]

In recent years, PMH has gained global attention, and organisations and governments worldwide strive to achieve the UN Sustainable Development Goals aimed at improving health outcomes for mothers, infants, children and families.[6] Since 2016, significant investments have been made in the UK to ensure that women with moderate to severe perinatal mental disorders can access evidence-based interventions in a timely manner.[7,8] Specialised community PMHS and inpatient psychiatric facilities, known as Mother and Baby Units (MBUs), have been established.

These services have been commissioned to assess, diagnose and treat people aged 18 and older experiencing moderate to severe PMH disorders during the antenatal and postnatal periods.[5] The patient's journey to these services begins with their first contact with health or social care. They are then referred to PMHS, and if accepted, the service arranges the first appointment. In recent years, some community PMHS in the UK have allowed self-referrals. While many service users (SUs) report positive experiences with community perinatal services[9] and inpatient MBUs,[10,11] significant issues related to access have also been reported. Individuals experiencing PMH problems often face multiple barriers when seeking help. These barriers can stem from various factors, including individual issues (e.g. stigma associated with both the services and mental illness, low awareness of available services), organisational challenges (e.g. fragmented services, long waiting times, unresponsiveness from services), sociocultural factors (e.g. language and cultural barriers) and structural complexities (e.g. unclear policies).[12,13]

Barriers to accessing treatment in the perinatal period are likely to be even greater for women from ethnic minority backgrounds. Reports indicate that these women face a higher risk of PMH problems.[14–16] However, their issues are more likely to go unnoticed, and they are less likely to receive appropriate treatment.[17,18] Furthermore, women from Black and Asian ethnic groups have an increased likelihood of experiencing adverse maternity outcomes, including a two to four times higher risk of maternal death.[4]

In addition to the barriers affecting all women and mothers in accessing mental health services, such as stigma, service fragmentation and fear of child removal, women from ethnic minority groups face additional challenges when seeking support. These challenges may include language barriers, limited confidence in navigating services, non-medical explanations for mental distress, HCPs' uncertainty regarding diverse understandings of mental distress, shortage of practitioners from similar ethnic backgrounds, social isolation and stigma and discrimination within healthcare settings.[19–21] Addressing diversity and inclusion remains one of the most challenging aspects of providing mental health care.[5] The evidence base for the utilisation of PMHS by women from ethnic minorities in the UK remains poor, making it difficult to effectively advocate for and implement services that best meet their needs.

Aims and objectives

The main aim of this study was to gain a better understanding of the accessibility and acceptability of PMHS for women from ethnic minority backgrounds in the UK. This understanding is crucial for improving the care provided to these women, increasing the likelihood of successful treatment and preventing long-term negative consequences. The study included four WPs.

The study objectives include:

1. to establish the rates of women from ethnic minorities who use mental health services during pregnancy and the first year after giving birth (perinatal period) (WP1)
2. to identify pathways to accessing community and inpatient PMHS in localities with large ethnic minority populations in the UK (WP2)
3. to explore the attitudes, expectations and experiences of women from ethnic minorities who experienced PMH problems, along with their partners, family members/carers and HCPs (WP3)
4. to produce suggestions for improving clinical practice based on the findings from the previous phases of the study (WP4)
5. to disseminate the findings to a range of stakeholders (WP4).

Figure 1 shows research pathway diagram, including all WPs, research questions and main methodological approaches.

Methods

The protocols can be accessed on the Open Science Framework (https://osf.io/s94bp/).

A mixed-methods design was used, allowing for the exploration of the complex and multilayered aspects of the accessibility and acceptability of mental health services for women from ethnic minority backgrounds. Three panels supported the research: the Lived Experience Advisory Panel (LEAP), the Steering Committee and the Expert Reference Group (ERG). Please see Stakeholder engagement.

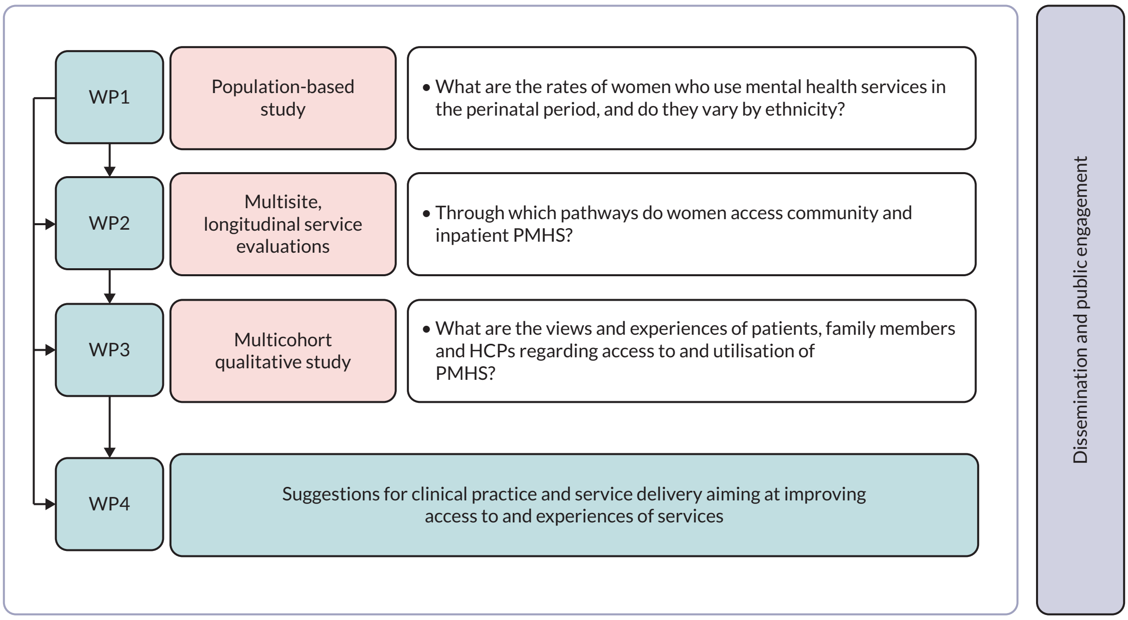

FIGURE 1 The PAAM project – research pathway diagram.

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The study included four WPs as described below.

WP1 was a population-based study conducted in collaboration with NHS Digital. All women aged 18 + who gave birth in 2017 in England, UK, were included (*n* = 615,092). The study explored access rates to secondary mental health services and patterns of engagement with these services for women from ethnic minority groups in the perinatal period in England by: (1) exploring access rates to community mental health services, rates of inpatient psychiatric hospital admissions and rates of involuntary inpatient psychiatric hospital admissions; (2) exploring whether a higher density of ethnic minority populations is linked to lower access rates and (3) exploring the number of contacts with community mental health services, the number of cancellations and the number of non-attendances.[22] Reproduced with permission from Jovanović *et al.*,[22] this is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/.

Two data sets from the National Commissioning Data Repository, the Acute Inpatient Dataset and Mental Health Services Dataset, were linked. Data sets covering the full perinatal period (e.g. pregnancy up to 40 weeks and first 12 postnatal months) for each woman were included. In the calculation of all access rates, both the numerator and denominator missing ethnicities were assumed to be missing at random, and as such, they were inflated based on adding the number of missing ethnicities in proportion to known ethnicities. Rates were standardised by age and deprivation. The study used pseudonymised data, and therefore, ethical approval was not required.

WP2 included two longitudinal retrospective service evaluations. The first service evaluation was conducted in community PMHS in Birmingham and London during a 6-month period (1 July and 31 December 2019). Data from electronic records of 228 individuals were analysed for this purpose. The second service evaluation was conducted in inpatient MBUs in Birmingham, London and Nottingham during a 12-month period (1 January 2019–31 December 2019). Data from electronic records of 198 individuals were analysed. The selection of these sites was based on achieving a balance between areas with varying levels of ethnic diversity. Birmingham and London were chosen because they have more ethnically diverse populations, while Nottingham was selected as a site with a less diverse population. The list of patients was obtained from technical services in participating trusts. Eligible patients were newly referred to services at least once during the study period. Referrals that did not meet the commissioned threshold for moderate to severe mental illness were declined by services, and these referrals were not included in this study. Only accepted referrals were analysed. Declined referrals were often redirected for support within primary care and third-sector organisations. Study researchers accessed patient electronic records to extract data on patients' sociodemographics, clinical characteristics, the involvement of children's social services and pathways to community (PMHS) and inpatient MBU. The type of pathway was defined as 'simple' – contact with one clinician/service before contacting PMHS/MBU or 'complex' – contacts with two or more clinicians/services before PMHS/MBU. Data were collected using the adapted WHO Encounter form[23,24] and analysed using uni- and multivariable analyses.

WP3 was a multicohort qualitative study that complemented quantitative analyses from WP1 and WP2. The accessibility and acceptability of PMHS was explored through qualitative, in-depth, semistructured interviews. The study was conducted during 2020–1, a period of the COVID-19 pandemic, which posed significant limitations to recruitment and face-to-face contacts with participants. The study included four cohorts: (1) women who accessed PMHS (*n* = 37); (2) women who did not access PMHS (*n* = 23); (3) partners/carers/family members of participating women (*n* = 15) and (4) HCPs working with women in perinatal period, such as midwives, health visitors, obstetricians, social workers, specialist perinatal nurses, general practitioners and so on (*n* = 24). Eligibility criteria are listed in *Table 1*.

Participants who were referred to PMHS and/or who engaged with services (Cohort 1) were recruited through East London NHS Foundation Trust (ELFT), North East London NHS Foundation Trust, Devon Partnership NHS Trust and Birmingham and Solihull Mental Health NHS Foundation Trust.

Participants who did not engage with PMHS (Cohort 2) were recruited through social media and community organisations, and they came from different parts of England.

Non-probabilistic, purposive sampling was used to maximise variation within the key sample criteria of ethnicity, migration experience (e.g. first-/second-generation migrants in the UK) and ability to speak English (e.g. English-speaking individuals and non-English-speaking individuals requiring interpreters).[25] Grouping women by

TABLE 1 Participants' eligibility criteria for the qualitative study (WP3)

Cohort	Informed consent	Age	Ethnicity	Other
1. Women who accessed PMHS	Yes	≥ 16	South Asian (i.e. Indian/Bangladeshi/Pakistani) and/or Black (i.e. Black African/Black Caribbean/Black other)	• Have experiences of PMH problems (pregnancy and first postnatal year) of moderate to severe intensity in the last 2 years • Be actively involved in the care of their baby • Have accessed and engaged with PMHS
2. Women who did not access PMHS	Yes	≥ 16	South Asian (i.e. Indian/Bangladeshi/Pakistani) and/or Black (i.e. Black African/Black Caribbean/Black other)	• Have experiences of PMH problems (pregnancy and first postnatal year) of moderate to severe intensity in the last 2 years • Be actively involved in the care of their baby • Never referred to PMHS or declined their referral to PMHS or did not attend offered appointments with PMHS
3. Family members/carers	Yes	≥ 16	Any	• Related to, or supporting, a Black or South Asian woman who had experienced PMH problems
4. HCPs	Yes	≥ 18	Any	• Have minimum 6 months' experience of working with women who experience mental health problems in the perinatal period

Note
The symbol ≥ means greater than or equal to. 'Access' is defined as having attended at least one appointment with PMHS.

high-order ethnic groups using the British census categories was done for ease of comparison across studies.[26,27] Efforts to include people who did not speak English fluently were made also because they are often left out of research studies on ethnic minority populations.[25]

Interviews with participants in Cohorts 1–3 (see *Table 1*) were conducted over the phone or using video calls. Although the interviews were initially planned as face-to-face, remote interviewing was chosen due to COVID-19 restrictions. Interviews with HCPs (Cohort 4) were held either online or face-to-face, depending on the participant's preference and COVID-19 regulations at the time. Prior to the interview, the researcher provided participants with an information sheet, were given informed consent and completed a demographic information form. Participants in Cohorts 1–3 were reimbursed for their time with a £30 shopping voucher.

Interviews were audio-recorded and transcribed verbatim by an external transcription agency. Data were analysed using framework analysis.[28] The analysis was conducted by an ethnically diverse multidisciplinary team of clinicians, researchers and people with lived experience of perinatal mental illness. Initially, a framework was created by combining predefined topics from the interview guide and emerging themes from the data. This framework was consistently applied to the transcripts and adjusted as new codes emerged. The data were then summarised in a matrix, where each participant was assigned a row and each subtheme a column. This charting process facilitated the next stage, which involved reviewing the charted material and developing new emergent themes through mapping and interpretation. Regular discussions with the wider analysis team were held to review the themes. Throughout the analysis, reflective and reflexive practices were employed to identify any biases, learnings or other factors that might have influenced data interpretation.

The qualitative study with women who did not engage with services included four non-English-speaking participants, who were interviewed with the assistance of professional interpreters to ensure accurate communication and respect for their perspectives. In qualitative research, thematic saturation – the point at which no new themes emerge – typically occurs after about 12 interviews in homogenous groups. However, due to the diversity of participants, we took a conservative approach and set an a priori target of 20–30 participants to ensure data richness. During data coding, researchers closely monitored the emergence of new themes, with the option to increase the sample size if additional perspectives were needed. These interviews were conducted remotely, which introduced both opportunities and challenges. The rapport between

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interviewer and participant may have been affected by limited ability to observe non-verbal cues, and some women may have struggled to find private spaces at home to openly discuss difficult topics. As a result, participants may have shared more cautiously, potentially affecting the depth of disclosure. However, a key advantage was that online interviews offered flexibility, enabling participation from women who might otherwise have been unable or unwilling to attend in-person sessions.

For non-English-speaking participants, consent to participate in research was obtained with the assistance of professional interpreters to ensure clear communication and understanding of the study. An interpreter was present during the consent process to verbally explain the study details, including the purpose, procedures and potential risks, while also answering any questions the participants had. This ensured that the participants fully understood the study and their involvement. Additionally, the consent process was documented, with the interpreter confirming the participant's understanding and agreement.

WP4 focused on producing the recommendations for improving clinical practice and dissemination strategy. This was completed in close collaboration with LEAP and the ERG. The ERG was established to prepare draft guidelines based on the PAAM study results. The group included a variety of stakeholders, including NHS clinicians, service commissioners, third-sector groups, experts with lived experience of PMH, carers and family members. Draft guidelines with implementation recommendations were presented at a public webinar in January 2023. With feedback from the webinar, the ERG finalised the guidelines. Please see Implications for decision-makers and Stakeholder engagement for more information.

The dissemination strategy was developed to ensure meaningful sharing of study outputs with key stakeholders, including mental health service commissioners, clinicians, women with PMH experience and their families, as well as academics. The LEAP played an active role in dissemination to ensure findings are accessible and meaningful to SUs, carers and the public. The strategy included multiple routes of dissemination and public engagement, such as presentations at local, national and international events; social media engagement and scientific publications.

The team recognised language and culture as potential barriers to accessing the research project and collaborated with the LEAP to ensure that study and promotional materials, as well as interactions with participants, were culturally sensitive and accessible. Trust-building efforts with local communities, religious groups and third-sector organisations helped to engage under-represented groups ethically and effectively.

Stakeholder engagement: role of advisory panels in supporting the research

The study involved several layers of patient and public involvement, and community and stakeholder engagement. As mentioned, three panels supported the research: the LEAP, the Steering Committee and the ERG. These panels provided invaluable input, helping the research team address unconscious bias, promote continuous reflection and reflexivity and ensure targeted, meaningful public engagement and dissemination.

The LEAP was established specifically for this project, comprising seven members all identifying as from South Asian and Black backgrounds: six with lived experience of perinatal mental illness and one carer. The role of this panel was to ensure perspectives of women who already had experience of PMHS and/or perinatal mental illness. Chaired by one of its members, the panel met twice a year throughout the project. All members were reimbursed for their contributions in accordance with NIHR guidelines. The LEAP involvement included the following:

- Members initially reviewed study documents, including information sheets, consent forms and demographic sheets.
- The panel played a key role in formulating interview questions in qualitative studies, advising on the number of questions, interview length and the language used. Several questions were modified based on LEAP discussions, addressing issues such as confidentiality, potential harm and participant distress.
- LEAP members supported recruitment by sharing study information within their networks, including WhatsApp (1 Meta Way, Menlo Park, California, USA) and social media groups, and recommending specific organisations that support Black and South Asian women. They also suggested extending the inclusion criteria, increasing the time since a woman experienced perinatal mental illness from 2 to 5 years, based on their own experiences.
- A subgroup of three to four LEAP members formed an analysis group, meeting regularly during the analysis phase of WP3. They were trained in the principle of the framework analysis.[29] Their involvement was a key component of step 5 'Interpretation' in the framework analysis, helping to identify researcher bias and ensure constant reflection and reflexivity during the analysis process. They identified key quotes

that best illustrated ideas and highlighted the most important themes based on their own experiences. LEAP members provided valuable insights into both the facilitators and barriers to accessing services for ethnic minority women, ensuring that the final recommendations were relevant and meaningful.
- The panel provided useful suggestions for the dissemination strategy, ensuring that the findings reach all relevant stakeholders.

The Steering Committee, which included women with lived experience of perinatal mental illness from ethnic minority backgrounds, family members, academic researchers and mental HCPs, provided oversight, meeting at key project milestones (at least once a year). The committee brought together a range of perspectives and expertise essential for providing oversight on study direction, alignment with objectives, methodological rigor and ethical considerations.

Lastly, an ERG was formed towards the end of the project to draft recommendations for clinical practice with ethnic minority women experiencing perinatal mental illness, based on the study results. The ERG included members of the research team with relevant expertise or lived experience, along with representatives from partner organisations, healthcare providers, commissioners, clinicians, policy-makers and other academics in the field. The ERG held two video meetings. The first meeting focused on discussing the study findings and identifying key points to include in the recommendations. Based on this input, the research team drafted the recommendations and e-mailed them to ERG members, who provided further feedback either by e-mail or through individual video calls with the research team. The second meeting took place during a public webinar in January 2023, where the recommendations were further discussed in both large and small group settings. The public was invited to provide comments and ask questions to the ERG. Following the webinar, the recommendations were finalised and e-mailed to the ERG for the final round of feedback.

Results summary

Differences in access and utilisation of mental health services in the perinatal period for women from ethnic minorities: a population-based study (work package 1)

The study findings revealed significant disparities in access to both community mental health services and psychiatric inpatient care among women from various ethnic groups during the perinatal period.[22] Out of 615,092 women who gave birth in England in 2017; 22,073 (3.5%) initiated contact with mental health services during the perinatal period. Among them, 713 (3.2%) were admitted to inpatient care, with 282 (39.5%) being involuntary admissions. Ethnicity data were available for 98% of the sample. A comparative analysis of access to services across ethnic groups reveals significant disparities for Black African, Asian and White other women relative to White British women. More specifically, significantly lower access to community mental health services was found among women from Black African [rate 25.2, 95% confidence interval (CI) 21.9 to 28.7], Indian (17.3, 95% CI 14.8 to 20.1), Pakistani (19.4, 95% CI 17.3 to 21.7), Bangladeshi (22.2, 95% CI 18.1 to 26.9), Irish (38.6, 95% CI 31.1 to 47.3) and other White backgrounds (21.6, 95% CI 20.6 to 22.8). The reported rates are per 1000 births, standardised for age and deprivation and significantly different ($p < 0.05$) from the White British group (42.4, 95% CI 41.8 to 43.1).

Regarding admission to inpatient psychiatric units, Indian women (0.40, 95% CI 0.17 to 0.82) had statistically significantly lower admission rates than White British women (1.14, 95% CI 1.03 to 1.25), after standardising for age and deprivation.

The findings on involuntary psychiatric admissions also indicate ethnic disparities. While one-third of White British women were admitted involuntary (29.3%), the percentages were significantly higher for White other women (over 55%), Asian women (all subgroups: over 60%), Black African women (over 60%) and other groups (over 50%). While the total number of women admitted involuntarily was relatively small, making it difficult to standardise by age or deprivation, the differences between ethnic groups were still quite large.

Regarding service utilisation, several ethnic minority groups demonstrated higher attendance at community contacts compared to their White British counterparts (rate 8.6, 95% CI 8.6 to 8.7). These include Irish (13.1, 95% 12.3 to 13.8), White other (9.3, 95% 9.2 to 9.5), Indian (10.1, 95% 9.6 to 10.7), Pakistani (11, 95% 10.6 to 11.4), Bangladeshi (16.8, 95% 16 to 17.5), Black African (rate 12.7, 95% CI 12.2 to 13.2) and Black Caribbean (12.7, 95% CI 12.2 to 13.2). Similarly, several ethnic minority groups demonstrated fewer missed or cancelled appointments (per 100 contacts) compared to the White British group (rate 16.6, 95% 16.4 to 16.8). These include White other women (14.8, 95% CI 14.1 to 15.6), Pakistani (12.7, 95% CI 11.3 to 14.1) and Black African (13.7, 95% 11.6 to 15.7). The reported rates are standardised by age and deprivation and statistically significant different ($p < 0.05$) from the White British group. These patterns of engagement suggest that the primary issue is the access to services rather than the utilisation of services.[22]

In summary, disparities in access to community PMHS exist across ethnic groups. To address these inequities, efforts should focus on improving access to community mental health services for Black African, Asian and White other women, which may help reduce the rates of involuntary hospital admissions for these groups.

Pathways to community perinatal mental health services: a two-site, longitudinal retrospective service evaluation (work package 2)

After gaining insights into the access issues from the population-based study in WP1, efforts were made to describe the pathways women took to access specialist community PMHS and explore their variations across services and ethnic groups. A report outlining key findings from this study has been published.[29] A two-site, longitudinal retrospective service evaluation was conducted in Birmingham and London during a 6-month period, from 1 July to 31 December 2019. Both services serve inner-city, ethnically diverse communities. The number of live births in 2019 was almost double in the area covered by the Birmingham service (n = 8003), compared to London (n = 4331). Electronic records of 228 women were accessed, 131 (58%) from Birmingham and 97 (42%) from London.

The results indicate that the median time from the onset of perinatal mental illness to contact with community PMHS was 20 weeks. The majority of patients accessed these services through primary care (69%), and the majority followed a simple pathway (63%), defined as having contact with only one service before engaging with PMHS. The simple pathway was used as a proxy for accessible services. In Birmingham, compared to London, more referrals came from secondary care, a higher proportion of women were experiencing a deterioration in mental health and more women followed a complex pathway. In Birmingham, the most common complex pathway (29%) involved multiple contacts with midwives, likely due to the higher number of pregnant women in this subsample. In contrast, the most common complex pathway (36%) in London was characterised by a crisis pathway, involving presentations to emergency and crisis teams. Although there were differences between ethnic groups in terms of pathway type and the duration of the patient journey, no significant differences were found once the models controlled for confounders, such as clinical presentation, general characteristics and location. The location of the service was the strongest predictor of both the type of pathway and the duration of the patient journey.

In summary, this study highlights significant variability in patient journeys to community perinatal services and that this variation appears to stem from service-level factors rather than differences in patient needs or clinical presentations.

Pathways to Mother and Baby Units: a three-site, longitudinal retrospective service evaluation (work package 2)

Mother and Baby Units constitute specialised psychiatric facilities that deliver inpatient services for women facing complex mental health issues during pregnancy or in the postpartum period. This study explored patient pathways to MBUs in three UK localities, with focus on variations in pathways between services and among ethnic groups. This was a three-site, longitudinal retrospective service evaluation conducted in Birmingham, London and Nottingham during a 12-month period (1 January 2019–31 December 2019). A report outlining key findings from this study is under review at NIHR HSDR Journal in October 2023.[30] The study analysed electronic records from 198 patients, distributed proportionally across three sites: Birmingham (n = 70, 35.4%), London (n = 62, 31.3%) and Nottingham (n = 66, 33.3%). At the time of the study, all MBUs were nationally commissioned and received referrals from across England. Most patients were in the postpartum period, admitted to the MBU for the first time through an emergency admission, informally and via a complex pathway. The average length of stay was 6 weeks. Significant differences were observed across services in terms of admission type, length of stay, contact with emergency services, referrer type, main referral reasons and the duration of the patient journey to the MBU. Patients of Asian ethnic background had significantly more emergency admissions compared to those of Black and White ethnic backgrounds. When exploring the multiple factors influencing the simple/complex care pathway, ethnicity was the only factor with a significant association. After controlling for pathway-level and patient-level factors, the study found that Black patients were 6.24 times less likely to experience a complex care pathway compared to White patients. There was no significant difference in the rates of involuntary admission among the studied ethnic groups.

In summary, this study provides valuable insights into patient journeys to MBUs and highlights the role of ethnicity in care pathways, with Black patients being less likely to experience multiple services before MBU admission compared to White British patients. While this may suggest more direct access to specialist care, it could also reflect gaps in community-based interventions for Black patients. In contrast to previous studies, this research found no evidence of higher detention rates for Black patients compared to White patients, indicating that MBU admissions may differ from other psychiatric admissions.

Attitudes, experiences and suggestions for improvement from women of ethnic minorities who have used perinatal mental health services: a qualitative study with Cohort 1 (work package 3)

Subsequently, qualitative methodology was employed to explore the experiences of Black and South Asian women in accessing PMHS and the care they received from these services (Cohort 1).[25] Semistructured interviews were conducted with 37 women, of whom 46% were born in the UK. Four interviews were conducted with the assistance of an interpreter for women speaking Bengali (*n* = 2) and Urdu (*n* = 2). The majority of participants were recruited via mental health services from Birmingham and East London, with two participants recruited from mental health services in Devon (see *Methods* for more information). The interviews revealed a complex interplay of factors affecting how women seek and experience support. The following four themes emerged: (1) self-identity, social expectations and varying perspectives on distress discouraged help-seeking; (2) the absence of clear and structured service pathways created barriers to access; (3) curiosity, kindness and clinician flexibility fostered a sense of support for women; (4) shared cultural backgrounds could either enhance or hinder trust and rapport.[25]

In summary, the women described diverse experiences shaped by multiple factors influencing access and engagement with services. While some women found services supportive, others felt confused and uncertain about where to find help. Major barriers included stigma, mistrust, limited service visibility and gaps in the referral process. Despite these challenges, many women felt heard and valued, reporting that the care was high quality and inclusive of diverse mental health perspectives.

Attitudes, experiences and suggestions for improvement from women of ethnic minorities who did not use perinatal mental health services: a qualitative study with Cohort 2 (work package 3)

As a next step, the study explored experiences of women from Black and Asian ethnic backgrounds who face perinatal mental ill health and do not utilise care and treatment from PMHS (Cohort 2).[31] In this qualitative study, 23 women were interviewed. Of these, 16 were never referred to PMHS and 7 declined referral or did not attend appointments. Three themes related to perceived barriers to accessing PMHS were identified, each consisting of several subthemes. These included: (1) societal and cultural barriers, such as stigma, fear of being perceived as inadequate mothers, negative encounters with healthcare services when dealing with women from ethnic minority backgrounds, and lack of privacy in intergenerational homes to receive calls, post or visits from services; (2) barriers resulting from women's lack of awareness and negative perceptions of PMHS focused on fear of child removal, minimising symptoms in front of HCPs and choosing to rely exclusively on family support; and insufficient financial and time resources were also significant barriers to attending appointments; and (3) barriers resulting from organisational issues, such as lack of responsiveness from services, lack of continuity of care and remote working and mask wearing seen as barrier to engagement. While most of these barriers were associated with access, three barriers – fear of child removal, remote appointments and mask wearing during COVID-19 pandemic – had a pervasive effect throughout the entire perinatal care pathway. The study participants provided recommendations to address these barriers, such as increasing awareness of PMHS, advertising that services' goal is to keep the mother and baby together, proactive inquiring about mental health for all mothers, staff training, streamlining referrals from primary care and setting up support groups for mums from the same ethnic minority background.

In summary, women who did not access PMHS, despite struggling with their mental health, described a series of barriers that did not exist in isolation. Instead, they highlighted multiple, interconnected factors that prevented them from accessing these services. These findings offer qualitative insights into the health inequalities observed in PMH outcomes. They can be used to address existing barriers and promote better outcomes for mothers, infants and families.

Attitudes, experiences and suggestions for improvement from partners, carers and family members: a qualitative study with Cohort 3 (work package 3)

To complement previous findings, this research also included interviews with family members of Black and South Asian women included in the qualitative study (Cohort 3).[32] The aim was to explore their experiences of caring for a relative with perinatal mental illness, focusing on the personal impact on them. A total of 15 family members, including 12 husbands and/or partners, and 3 mothers and/or mothers-in-law, were interviewed. Three main themes were indentified from the interviews: (1) recognising and understanding their relative's perinatal mental illness was important to make sense of the situation; (2) high emotional cost of supporting a relative with perinatal mental illness; and (3) varied experiences and expectations of services, with opportunities for improvement. Many family members described how their relative's perinatal mental illness significantly affected their own physical and mental health and well-being, as well as their relationship with the affected relative. While many family members spoke highly of perinatal services, they also expressed the need for support in managing family relationships and practical assistance in navigating the various services required during this period (e.g. social services, benefits system, child care, health visiting).

In summary, family members and partners appreciated the support provided by services and offered several recommendations to ensure that a family-focused approach is adopted to better address the needs of family members, services should demonstrate greater awareness of their role, including the extended family. Proactive support should be offered to them, and family peer support groups and dedicated workers to specifically assist family members were suggested as valuable additions to the services currently provided.

Attitudes, experiences and suggestions for improvement from healthcare professionals: a qualitative study with Cohort 4 (work package 3)

The study also explored the perspectives and experiences of 24 HCPs (Cohort 4) working with individuals with perinatal mental illness.[33] The interviews focused on HCPs' views on the accessibility and acceptability of PMHS for Black and South Asian women, with the aim of addressing health inequalities. HCPs' unique insights offered valuable understanding and potential solutions. The sample included HCPs from various professions, such as mental health staff, obstetrics, midwifery, primary care and social care. Three main themes emerged from the data: (1) lack of awareness and understanding of perinatal mental illness and service structure among both HCPs and patients; (2) patients' relationships with family, friends and HCPs can either hinder or facilitate access to services; and (3) HCPs suggested raising awareness, flexibility, developing shared understandings and questioning assumptions to improve the accessibility and acceptability of services.[33] Reproduced with permission from Bains *et al.*,[33] this is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. The text below includes minor additions and formatting changes to the original text.

Healthcare professionals working with perinatal patients proposed key insights for addressing and remedying health inequalities observed among ethnic groups. Their recommendations included sharing information and treating each woman as an individual with unique cultural, ethnic and childrearing practices. Additionally, HCPs emphasised addressing unconscious bias through personal reflexive practices.

In summary, HCP offered important insights and recommendations regarding the accessibility and acceptability of PMH care for ethnic minority women. Further research is needed to explore why these recommendations are not consistently and broadly implemented, although they seem to be in line with good clinical practice.

Recommendations for improving clinical practice

The study findings were used to inform the development of recommendations aimed at improving clinical and research practices. These are listed under 'Implications for decision-makers'.

The recommendations are grounded in the study findings and are informed by input from all relevant stakeholders. For example, the importance of increasing awareness of PMHS (Recommendations to increase access #1 and #3) was voiced by many women with lived experience of perinatal mental illness, such as: 'I feel like I've heard the term, but I wouldn't be able to tell you anything about it . . . I wouldn't ever have thought that you could go [to MBU] with the baby. I thought you'd have to go on your own. And I wouldn't be able to see [the baby]' (Participant 11, Woman, Black Caribbean ethnicity). The recommendation to increase access #2 was linked to results from the service evaluation in WP 2, which indicated that the ethnic composition of patients under perinatal services may not fully represent the ethnic composition of the maternity or general population in the local area. Recommendation to increase access #4, to address the fear of child removal, was linked to repeatedly voiced experiences of raised anxiety around services being involved in removing children due to maternal mental illness: 'I did feel like I really wanted to talk to someone [. . .], but I was like, well, hang on a minute, if I thought if I start opening up, then she [midwife] might take my baby away, and that's the god's honest truth. Because she did ask me about it and I pushed it off and I just said that yeah, everything's fine' (Participant 14, Asian

Indian). Similarly, the recommendation to improve service delivery #1, related to providing continuity of care, was linked to experiences like this: 'My health visitors were changing all the time as well because of the constraints of the NHS. So that didn't help as well because if it was a new person, I didn't want wanna open up to them. [. . .] Only after seeing them for two or three sessions that, erm they, they kind of, I became comfortable with them' (Participant 8, Asian Pakistani).

Discussion and interpretation of study findings

The discussion focuses on the accessibility of perinatal community and inpatient mental health services, highlighting the role of ethnicity and identified barriers. It also explores the implications of these findings for both clinical practice and future research and discusses recommendations for improvement.

Mental health care for ethnic minority women in the perinatal period: challenges in access and positive utilisation once accessed

This research highlights that community mental health services in England, including but not limited to perinatal services, are less accessible to some ethnic minority women compared to White British women. This disparity is particularly pronounced among Black African, Asian and White other women. Importantly, the study found that once these women access community mental health services, they engage well, indicating that the primary issue lies in access rather than utilisation.

The lack of access to community-based interventions may explain why individuals from these ethnic groups experience higher rates of hospital admissions, as also noted in the study. It is plausible that some of these hospital admissions could have been avoided if better access to community-based interventions had been available. Addressing these barriers, particularly for Black African, Asian and White other women during the perinatal period, could improve outcomes and help reduce hospitalisations.[34,35] This is particularly critical for postnatal women, as hospital admissions may require separation from their babies, which can negatively impact both the mother and the baby.

Since the completion of this data linkage study in 2017–8, the expansion of PMHS across England has been completed. This may have improved access for ethnic minority women. It is reasonable to expect that repeated analyses of mental health service accessibility would now yield different results, making this an important area for future research.

Focusing on the accessibility of community perinatal mental health services for ethnic minority women

This research also sheds light on the accessibility of PMHS and the pathways women take to reach these services. Primary care emerged as the main entry point for most patients, with the majority of study participants initiating help-seeking for their mental health problems. These findings suggest that further capacity building within primary care, as well as consistently opening PMHS for self-referrals, could facilitate access to support for those who need it.

Importantly, linked to our main research questions, the study did not find substantial differences between ethnic groups in the variables studied, suggesting a degree of equality in access to PMHS. While this is a positive finding, further research with larger sample sizes and more specific ethnic groups (i.e. not using higher-order merged categories) is necessary to confirm these results and uncover any nuanced disparities.

However, several challenges in accessing PMHS were identified such as significant variation in the time between first experiencing symptoms and receiving help and the influence of service location on patient pathways. This finding requires further exploration to better tailor mental health services to patients' needs. Services can utilise methodology used in this research, including the adapted WHO care pathways questionnaire, to identify critical points where access issues and delays occur. These insights can be used as a foundation for developing targeted interventions and policies that could reduce delays and disparities in care, ultimately enhancing patient outcomes and satisfaction. This is in line with the already published recommendations made for health practice and policy.[36]

Accessibility and pathways to inpatient perinatal mental health services for ethnic minority women

The pathways to inpatient PMHS, also called Mother and Baby Units (MBUs), were characterised by postpartum entry, referrals through secondary care due to mental health decline, first-time admissions and voluntary admission. Significant differences were found between MBUs in terms of journey duration, referral process, admission type and length of stay. The study also highlighted that ethnicity plays a significant role in shaping patient experiences.

Importantly, the characteristics of MBU admissions were generally aligned with the guidance and standards established for these services.[5,36] However, the study also highlighted areas for improvement in MBU admissions. For instance, perinatal inpatient standards stipulate that admission to an MBU should occur within 24 hours of acceptance.[36] Yet, this study showed that only one quarter of all admissions met this timeline, and half of the admissions occurred within 1 week of acceptance. While the study did not investigate the reasons behind these delays, they may be linked to factors such as limited bed availability, staffing challenges, or culture within certain units.

Ethnicity emerged as a key factor in determining the care pathway. Specifically, Asian women had higher emergency admission rates than Black and White women, while Black women were less likely to access multiple services before admission. Unlike previous studies, this research found no evidence that Black patients are more frequently detained than White patients on MBUs, suggesting these admissions differ from other psychiatric hospitalisations. Previous reports have suggested that ethnic minority and migrant groups are at a greater risk of psychiatric detention than are majority groups.[37] Understanding the complex interplay between ethnicity, patient care pathways and treatment outcomes remains a significant challenge. This study contributes new evidence about the influence of ethnicity in the journey to MBUs, and future research should explore this aspect in greater depth.

Another key finding was that a quarter of patients arrived at the MBU through a general psychiatric ward, with most of these patients being in the post partum period, leading to separation from their babies. Although the perinatal inpatient standards allow for prior admission to an acute adult ward under exceptional circumstances, this separation has been a significant concern in previous reports. The study also revealed significant differences in patient experiences at MBUs across different locations. These variations could reflect differences in patient needs, such as the severity of their mental health condition, social support systems and individual care preferences. Additionally, the differences might be influenced by service protocols, bed availability and geographical factors, which can affect the logistics of patient admissions and stays. Further research is needed to explore how these variations may lead to inequities in access to mental health care.

Addressing perceived barriers to access and engagement

Stakeholders identified several barriers to accessing and engaging with PMH care, including limited awareness of available services, fear of child removal, stigma surrounding maternal mental illness, challenges with remote service delivery, negative treatment experiences among ethnic minorities, insufficient opportunities to disclose concerns, a lack of staff training to address unconscious bias, poor service organisation and negative perceptions of services.

However, before discussing these barriers, it is important to acknowledge that many patients in this study reported feeling heard by staff and well-supported by the services. Additionally, this research gathered perspectives from individuals who did not engage with services. Non-engagement or disengagement is a critical issue in mental health care, as it can lead to worse outcomes and the inefficient use of resources.[38] Therefore, it is crucial that any research on barriers to access and engagement includes the voices of those who are not accessing services.

These research findings align with previous reports suggesting that mental health and maternity services often lack culturally competent care.[39] For example, SUs frequently report difficulties accessing culturally sensitive support, while HCPs state limited opportunities and resources for developing cultural competency. Watson *et al.* highlighted the 'double stigma' faced by ethnic minority women with mental illness, noting how stereotyping and a lack of cultural sensitivity in services can discourage disclosure and help-seeking.[19] Culturally competent care, by definition, involves being attentive and responsive to beliefs and practices influenced by cultural heritage.[39] It is concerning that research continues to identify these barriers despite evidence-based guidelines aimed at overcoming them. For instance, the 2014 NICE guideline on antenatal and postnatal mental health recommends providing culturally sensitive information while addressing women's fear of stigma.[40] Similarly, the 2010 NICE guidance on pregnancy and complex social factors outlines measures to help recent migrants, asylum seekers, refugees and women with limited English access antenatal care, such as using diverse communication methods and training healthcare providers to address their specific needs.[41]

The fear of child removal is a longstanding barrier that continues to hinder access to services,[42,43] and in this research its impact was observed across all stages of the perinatal pathway. Addressing this significant barrier requires a multifaceted approach from various sources. Participants in this study emphasised the importance of promoting services by highlighting the role of services in supporting mothers and infants, facilitating the development of a healthy mother-infant bond and assisting them in establishing or strengthening their existing support networks. This aspect could be instrumental in alleviating the fear of child removal and fostering a sense of trust and assurance among potential SUs.

Additionally, family members highlighted gaps in family-centred care and the absence of a systemic approach, echoing findings from previous studies.[44,45] Relationships with family, friends and HCPs were also identified as key factors that could either hinder or facilitate access to care. This research supports the need for services to be more aware of the role of family members, including extended family, and to offer wider support proactively. Importantly, PMHS have been commissioned to assess fathers, partners and co-parents, and to direct them to appropriate support.[8] With the full implementation of this intervention, it is expected that services will be seen as more supportive of partners and more effective in working systemically.

Another barrier is worth discussing. This research identified certain challenges specifically associated with COVID-19 restrictions, such as remote appointments and mask-wearing. It is crucial to acknowledge and address these issues, as remote appointments remain common even in the post-COVID era. For example, in the UK, approximately one-third of clinical appointments in primary care are still conducted remotely.[46] The question is to what extent this prevents individuals from ethnic minority groups from accessing support within primary care. This is particularly relevant during the perinatal period, as this research showed that the majority of initial contacts and referrals occur within primary care.

In conclusion, the study highlighted the multifaceted nature of perceived barriers in accessing PMHS, and provided crucial insights for developing targeted interventions to improve accessibility and support for women during this critical period.

Recommendations for improving clinical practice

As mentioned, recommendations for improving clinical practice were formulated to address two main areas: (1) enhancing access to services and (2) improving experiences within services. Many of these recommendations have broader implications for service delivery, influencing decision-makers and engaging other stakeholders. They focus on key aspects such as better communication, increased openness and heightened awareness. These recommendations have the potential to improve the overall quality of care in perinatal services, ensuring that patients and their families receive culturally sensitive and individualised support during this critical period. For example, raising awareness of PMH needs and the services available – both within the NHS and the third sector – could help women and families access support earlier. By doing so, they can be empowered to recognise symptoms and behavioural changes that may indicate PMH disorders, allowing for more proactive care. When considering recommendations for improvement and addressing the perceived barriers identified in this study, it is difficult to overlook the fact that these suggestions align with established best practices and interventions that have already demonstrated their benefits. The fact that these recommendations are not yet widely implemented highlights challenges in the implementation process.[47]

Strengths and limitations

This project had several strengths and limitations across its WPs.

The strengths of this research include the use of a population-level dataset in WP1, which enabled robust and generalisable findings on access to PMHS across England. The comprehensive data set, covering a full calendar year, ensured high completion rates for ethnicity data and allowed for the identification of key trends, such as the impact of age, deprivation and ethnic population density on service access. The care pathway studies in WP2 were the first of their kind in the UK and globally, providing unique insights into patient journeys, emergency admissions and referral patterns. The adapted WHO care pathway questionnaire can be used in future research on PMH care. The qualitative study in WP3 gathered valuable data from women, their family members and HCPs, offering a more holistic understanding of care experiences, barriers and areas for improvement. This study uniquely included non-English-speaking women, women who disengaged from services, as well as partners – groups often difficult to recruit and therefore overlooked in mental health research. Additionally, the involvement of a diverse range of HCPs added varied perspectives on the barriers to access faced by ethnic minority women.

However, there were several limitations in this research. In WP2, the study faced challenges with sample composition, as Black and Asian women were over-represented in the Birmingham and London samples, thus not fully reflecting the wider maternity population. Services need to make more efforts to address this issue and ensure that women from all ethnic groups are able to access any support needed. Furthermore, in WP3, another limitation is the under-representation of Black women (22%) recruited in the study with women who did not engage with services, compared to South Asian women (69%). This is in reference to the UK 2021 census data, which reported a population of 5.4 million South Asian individuals (9.6%) and 2.4 million Black individuals (4.2%). This aligns with the well-established marginalisation of Black women, even within research that focuses on marginalised groups.[48,49] The research team made significant efforts to address this issue and recruit more individuals from Black ethnic backgrounds. We partnered with community organisations and leaders to build trust and foster relationships, ensured cultural sensitivity in all communications and materials and worked closely with community organisations to raise awareness and encourage participation. Future research should consider innovative recruitment strategies that could overcome this issue. Another limitation in WP2 was that data was extracted from available electronic records and not validated with patient's own accounts of their pathways to care.

In WP3, various ethnicities were grouped together, potentially obscuring important differences within these subgroups, and the study lacked interviewers who shared racial identities with the participants, which could have impacted the depth of the data collected, especially around sensitive issues. The reliance on self-reported data and remote interviews during the COVID-19 pandemic also introduced limitations, as non-verbal cues could not be captured, and some participants may have been less comfortable or forthcoming in a remote setting. Additionally, the findings from WP1 and WP2 reflect the period before the COVID-19 pandemic, meaning they do not account for any changes in care pathways that may have occurred since then. The use of pre-pandemic data may limit the study's relevance in understanding current service provision and access, particularly in light of changes brought on by the pandemic. Additionally, potential biases introduced by the topic guide, particularly around sensitive issues like unconscious bias, may have led HCPs to present more socially desirable responses. Lastly, the sample size for HCPs was not large enough to explore differences in experiences and opinions between various types of professionals, and the inclusion of only two male participants may have under-represented male perspectives in a field dominated by female professionals.

Despite these limitations, the study provided a valuable contribution to understanding the accessibility and acceptability of PMHS for women from different ethnic backgrounds, offering several actionable insights and areas for future research to address the gaps identified.

Equality, diversity and inclusion

Since the study focuses on understanding the inequalities and inequities in PMH, equality, diversity and inclusion (EDI) are central to the project's ethos and research aims. This section will outline the project's commitment to EDI by covering: (1) language considerations, (2) opportunities within the research team and (3) participant recruitment. It will also discuss ways in which each of these areas could have been improved.

1. Language around gender and ethnicity was carefully considered, researched and terminology was deliberated: from the capitalisation of ethnic groups, to the terms used for people experiencing mental distress and being seen by services.[50] People have strong and differing opinions when it comes to the terminology for people who are supported by mental health services. Some prefer the term 'client', some prefer 'service user' and some prefer 'patient'. There is stigma attached, and connotations linked with each term. As a reflection of the complexity, and in an attempt to embody person-centeredness, the current study employs the term 'person' and 'individual' where possible. The terminology used throughout the report is often imperfect: it is limited by language and the terms available. The research team took steps within these limits to be respectful, accurate and reflective.
2. This research was conducted by a group of researchers with diverse experiences when it comes to perinatal mental illness, ethnic background, migration background, as well as discipline (psychiatry, psychology and mental health research). Opportunities to lead on publications were provided to the junior members of the team, including people from groups that are under-represented in mental health research, including South Asian women. An important limitation of the study team's composition is that none of the researchers leading on publications or in supervisory roles were Black.
3. The participant populations for the different studies were diverse and inclusive in terms of ethnicity, and migration status. All of the participants in our sample described themselves/identified as women. Throughout the paper we described the participants, other than the carers and practitioners, as women. However, it is important to note that people who have children and are at risk of PMH problems do not always identify as women. This is important in particular given the increased risk of mental health problems the trans and non-binary community.[51,52] Research exploring the experiences of non-binary individuals and trans individuals who have had children is needed, to explore the additional multiple layers of discrimination they experience.

The project's approach also had limitations. It could be argued that these studies' ambitious approach, in an attempt to be inclusive and thorough, fell into a trap that may have elided the experiences of Black women. The study did not recruit enough people to explore whether certain experiences were more common or more resonant for any of the subgroups included in the study. Crenshaw, who introduced the term intersectionality, described in 1991 how social movement organisation and advocacy around violence against women elided the vulnerabilities of women of colour, particularly those from immigrant and socially disadvantaged communities.[53,54] In a similar way the experience of particularly disadvantaged and at-risk groups have been elided in the context of severe mental illness. More work should, as outlined above, and in the published papers, examine specific groups' experiences so that there is no risk of certain marginalised voices being obscured.

Dissemination to participants and related patient and public communities

In addition to publishing the findings in peer-reviewed journals, the study results and recommendations were shared with a broad range of stakeholders and public audiences. The team sought to engage a diverse audience at local, national and international levels. This included the research participants, clients/patients/SUs and family members of NHS and third sector perinatal services (e.g. Action on Postpartum Psychosis, Maternity Voices Partnership), PMH clinicians and academics (local, national and international), antenatal and maternity clinicians (e.g. midwives and obstetricians involved in referring to PMHS), members of community groups (e.g. religious and community leaders), members of national advisory groups and professional networks (NHS England and NHS Improvement, Regional Perinatal Mental Health Clinical Networks), and mental health service commissioners and senior leaders within NHS organisations (i.e. those responsible for designing and commissioning local and national PMHS).

The project team created a brief summary report of the results and guidelines in plain English. This report included details of the main barriers and facilitators to accessing PMHS reported by study participants, quantitative data analyses of service access rates, and recommendations for service improvements. The goal was to demonstrate the impact of the research and highlight the value of participation, in an accessible manner.

Towards the end of the PAAM project, two dissemination events were held. The first was an ERG webinar, attended by a diverse range of stakeholders, including representatives from third-sector organisations, NHS professionals and individuals with lived experience of PMH. During the session, initial results from each of the WPs were presented, and attendees participated in activities to suggest and discuss recommendations for clinical practice.

Following this, and after finalisation of the recommendations, the team hosted an online dissemination event which over 250 people signed up to, and 188 people attended. The event, entitled 'Mental Health, Motherhood and Me' attracted a wide audience, including many parents from ethnic minority groups who had experienced perinatal mental illness. It was shared through a wide array of channels with support from ELFT. To attend people signed up for a free ticket on Eventbrite. People who wished to attend but did not wish to give personal information to Eventbrite were sent the link to the webinar. There was active engagement in the chat throughout the event and questions from the different people who attended from a wide variety of groups with an interest. Charity groups, policy-makers, local councillors and researchers in similar and adjacent fields, as well as clinicians were in attendance and engaged with our findings. This was open to all, free to attend and enabled the team to share the complete findings of the study and think with a wider group about how the recommendations could be implemented. The session was recorded and available to watch through a link online for the people who signed up to the event for 6 months after the event, until August 2023.

Conclusion

In conclusion, this research highlighted examples of good practice and generally positive patient experiences with specialist perinatal mental health service in the UK. However, significant inequalities persist, and the study uncovered various cultural, organisational and individual barriers that hinder access to these services for women of Black and South Asian ethnic backgrounds in the UK. Additionally, the findings illuminated how these barriers affect different stages of the perinatal care pathway.

These insights are valuable for policy-makers and service providers aiming to improve access for Black and South Asian women, who are less likely to receive support from services and were disproportionately impacted by the COVID-19 pandemic. Key recommendations for improving access include raising awareness of available services, regularly monitoring access across ethnic groups and addressing fears surrounding child removal. Services

This synopsis should be referenced as follows:
Jovanović N, Conneely M, Bicknell S, Janković J. Accessibility and acceptability of perinatal mental health services for women from ethnic minority groups: a synopsis of the PAAM study.
Health Soc Care Deliv Res 2025;**13**(36):1–22. https://doi.org/10.3310/TDAS1298

should also focus on engaging with local communities, removing practical barriers and fostering ethnic diversity among staff.

To enhance local service delivery, it is vital to build and maintain trust through responsive and continuous care, prioritise peer support from ethnic minority groups, improve communication, offer flexible appointment options and tackle unconscious bias. Involving families, providing support and ensuring cultural sensitivity in service provision are also critical to enhancing patient experiences.

By implementing these recommendations, services can become more accessible to all women in need of specialist treatment and care. For future research, it is recommended to develop interventions for addressing the identified barriers, adopt innovative recruitment strategies to include under-represented groups and investigate why certain recommended practices – despite being recognised as best practices – remain under-implemented.

Additional information

CRediT contribution statement

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Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

This research has been conducted in accordance with the World Medical Association Declaration of Helsinki. The study received approval from the Health Research Authority through the Research Ethics Committee on 12 February 2020 (REC reference: 19LO1830).

Information governance statement

East London NHS Foundation Trust (ELFT) is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under Data Protection legislation ELFT is the Data Processor; the Department for Health and Social Care (DHSC) is the Data Controller, and we process personal data in accordance with their instructions. You can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for DHSC's Data Protection Officer here: www.nihr.ac.uk/documents/nihr-privacy-policy/12242#how-we-protect-your-personal-data.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/TDAS1298

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This synopsis was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

Publications

Work package 1

Janković J, Parsons J, Jovanović N, Berrisford G, Copello A, Fazil Q, Priebe S. Differences in access and utilisation of mental health services in the perinatal period for women from ethnic minorities: a population-based study. *BMC Med* 2020;**18**:245. https://doi.org/10.1186/s12916-020-01711-w

Work package 2

Jovanović N, Lep Z, Janković J, Dirik A, Rees A, Conneely M. Pathways to specialist community perinatal mental health services: a two-site longitudinal retrospective service evaluation [published online ahead of print October 30 2024]. *Health Soc Care Deliv Res* 2024. https://doi.org/10.3310/YTRK6337

Jovanović N, Lep Ž, Berrisford G, Dirik A, Barber J, Kelani B, Protti O. Understanding patient pathways to Mother and Baby Units: a longitudinal retrospective service evaluation in the UK [published online ahead of print July 16 2025]. *Health Soc Care Deliv Res* 2025. https://doi.org/10.3310/GDVS2427

Work package 3

Conneely M, Packer KC, Bicknell S, Janković J, Sihre HK, McCabe R, *et al*. Exploring Black and South Asian women's experiences of help-seeking and engagement in perinatal mental health services in the UK. *Front Psychiatry* 2023;**14**:1119998. https://doi.org/10.3389/fpsyt.2023.1119998

Bains K, Bicknell S, Jovanović N, Conneely M, McCabe R, Copello A, *et al*. Healthcare professionals' views on the accessibility and acceptability of perinatal mental health services for South Asian and Black women: a qualitative study. *BMC Med* 2023;**21**:370. https://doi.org/10.1186/s12916-023-02978-5

Jovanović N, Packer KC, Conneely M, Bicknell S, Copello A, McCabe R, *et al*. Barriers to accessing perinatal mental health services and suggestions for improvement: qualitative study of women of Black and south Asian backgrounds. *BJPsych Bullet* 2024:1–8. https://doi.org/ 10.1192/bjb.2024.82

Bicknell S, Jovanović N, Janković J, Packer K, Conneely M, Bains K, *et al*. Family members' experiences of supporting black and South Asian women with perinatal mental illness: a qualitative study in the UK. *BMC Psychol* 2025;**13**:363. https://doi.org/10.1186/s40359-025-02656-6

Study registration

This study is registered as IRAS ID: 264632. Study protocols can be accessed on the Open Science Framework (https://osf.io/s94bp/).

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This synopsis provided an overview of the research award *Accessibility and acceptability of perinatal mental health services for women from Ethnic Minority groups (PAAM)*. For other articles from this thread and for more information about this research, please view the award page (www.fundingawards.nihr.ac.uk/award/17/105/14).

About this synopsis

The contractual start date for this research was in May 2019. This synopsis began editorial review in October 2023 and was accepted for publication in March 2025. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The Health and Social Care Delivery Research editors and publisher have tried to ensure the accuracy of the authors' synopsis and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this synopsis.

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Glossary

Expert Reference Group The Expert Reference Group consists of national and/or international members with long-standing experience and expertise in a specialty field. Entry is by invitation from the chair of the group. In this research study, the Expert Reference Group was set up to help develop the recommendations for improving clinical practice, as well as to identify meaningful dissemination routes for the recommendations.

Lived Experience Advisory Panel The Lived Experience Advisory Panel is a group of people with lived experience of perinatal mental ill-health and/or the use of perinatal mental health services and/or participation in mental health research. The Lived Experience Advisory Panel was assembled to advise on all aspects of this research project, including development of study materials, interpretation of study findings and dissemination of study findings. The research team has met with the Lived Experience Advisory Panel on a regular basis throughout the study. The Lived Experience Advisory Panel members were reimbursed for their time and efforts in line with the National Institute for Health and Care Research guidelines.

Mother and Baby Unit The Mother and Baby Unit is a specialist inpatient unit for women with mental health problems during pregnancy and after the birth of their child. Women in need of hospital admission during the perinatal period can be admitted together with their babies.

Perinatal mental health services Perinatal mental health services stands for specialist community services established to focus on assessing, diagnosing and treating women aged 18 and older who experience moderate to severe perinatal mental health disorders during the preconception, antenatal and postnatal period.

List of abbreviations

EDI	equality, diversity and inclusion
ELFT	East London NHS Foundation Trust
ERG	Expert Reference Group
HCP	healthcare professional
LEAP	Lived Experience Advisory Panel
MBU	Mother and Baby Unit
NIHR	National Institute for Health and Care Research
PAAM	Accessibility and Acceptability of Perinatal Mental Health Services for Women from Ethnic Minority Groups
PMH	perinatal mental health
PMHS	perinatal mental health services
SU	service user

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