Black Women - Perinatal and Infant Mental Health Care Services in Greater Manchester

Commissioned by Home-Start HOST on behalf of Greater Manchester Perinatal & Infant Mental Health Leads

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About the Evaluation Report

In March 2022, Home Start HOST, Greater Manchester (GM) on behalf of Perinatal and Infant Mental Health Leads commissioned the Caribbean & African Health Network (CAHN) to explore insights into Perinatal and Infant Mental Health (PIMH) service use by Black people in Greater Manchester. This exercise involved listening to Black women's lived experiences of mental health and the impact on their well-being through the perinatal period whilst at the same time engaging with PIMH teams in GM through surveys and consultations.

The report provides recommendations for improved perinatal and infant mental healthcare to support the development and optimisation of Black women and their infant's health and well-being during the first two years of birth. It also includes a call to action to the GM system given the urgency of the findings of this report.

About Home Start HOST, Greater Manchester

Who we are: Parents Supporting Parents

Home-Start HOST is a local charity of trained volunteers and dedicated, experienced staff. They help families with young children flourish during the years of early childhood. They offer compassionate, confidential and non-judgemental support which is offered by staff and trained volunteers who all have parenting experience. They work alongside parents, in their own homes, to help them cope with the stresses and strains of life and make sure they have the skills, confidence and strength they need to nurture their children.

HOST works in partnership with NHS clinical PIMH teams across Tameside & Glossop, Stockport, Bolton & Oldham to deliver our Parent-Infant Mental Health work (PIMH).

Their aim is to promote and support the importance of early relationships by educating and empowering families around parent-infant mental health and its benefits for future health, well-being & development.
They support early relationships for families with children aged 0-2 and those expecting a baby, and that service is available across Tameside & Glossop, Stockport, Bolton & Oldham.
You can visit their 'Get Support' page to find out how you can access PIMH support for yourself or someone else.

About The Caribbean & African Health Network (CAHN)

CAHN is a Black-Led national voluntary community-based organisation that was established in 2017 with the vision to eradicate health inequalities within a Generation for Black Caribbean & African People. We have six key health strands of work that are given priority attention.

Reproductive health throughout the prenatal and perinatal period is a strand of importance along with sexual health, and has been featured in our work since our consultations in 2016, (see diagram 1). Black women and their families acutely highlight the historical challenges and trauma that remain unresolved and create mental health turmoil for Black women, fathers and their children. We have supported hundreds of Black women and their families through aspects of this maternal journey and we are pleased to be working with partners to help improve the experiences of our communities.

As an organisation, we exist to provide practical and educational support to Black men and women so that they can live healthier lives. We have developed a platform that empowers people to self-care and self-manage due to the many challenges experienced that bring about inequities for Black people.

We want Black people to have the best possible health and well-being experiences. In order to do this succesfully, we work closely with our strategic partners across sectors to influence decision-making in research, policy and practice. Our collaborative and partnership work is key to CAHN and how we deliver and influence the services that our community tells us they need to improve their health and wellbeing. To find out more about CAHN and our work, visit us at **www.cahn.org.uk**

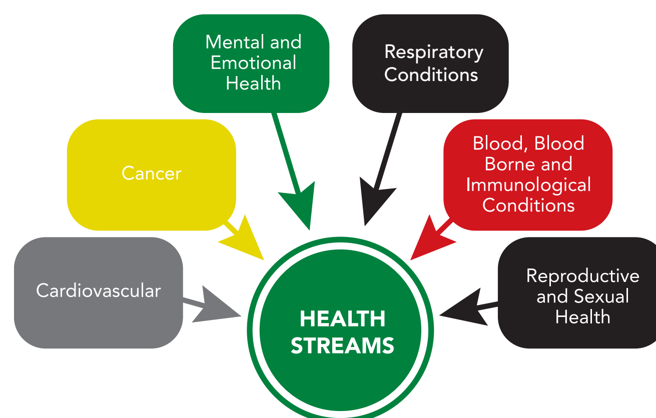


Diagram 1

Acknowledgements

We are grateful to all stakeholders that gave their time to support this important piece of work. I want to express a sincere thank you to all of the women who took part in the focus groups and interviews for which some very traumatic experiences were shared. I also want to thank Home Start HOST for recognising the work that needed to be explored in this area and for commissioning this study. Thanks are also extended to all of the Perinatal and Infant mental Health Teams for responding to the survey and consultations and for being so receptive to the feedback provided. We are hopeful that the findings and recommendations will be used to develop services that will support the mental health and well-being needs of Black women and their Infants in GM during their perinatal period. We want to thank Sarah Cook for her comments on this report and for recognising that hearing the lived experiences of Black mothers is vital to identifying practical solutions to improving maternal and infant mental health inequities across our services.

Glossary

CAHN- Caribbean & African Health Network

GM-Greater Manchester

NHS-National Health Service

PIMH Perinatal & Infant Mental Health

VCSE - Voluntary Community and Social Enterprise

Defining Concepts

Black African

The term refers to Black people that were born (native) in the African Diaspora.

Caribbean/African or Caribbean- African

The terms are used to refer to people of Black African ancestral descent & who migrated via the Caribbean islands. The terms Black and Caribbean African or Caribbean & African are used interchangeable.

Black

A person of African ancestry, who self identifies, or is categorised as Black, African, African or Caribbean or Caribbean/African. The word Black is capitalised when referring to people in this context. It conveys a shared sense of racial history, identity and community among people who categorise themselves as Black.

Mixed Heritage/Mixed Race

Refers to those who have a heritage that consists of Black Caribbean or Black African with another race.

1 Executive Report Summary

In the United Kingdom, Black women, followed by White and Black Caribbean and White and Black African women, are more likely to experience a mental illness such as anxiety disorder or depression (PHE, 2019). This Perinatal and Infant Mental Health study aimed to explore Black women's experience of mental health and use of maternity services throughout the perinatal period so that any barriers and solutions to engagement from this population group could be identified. The team at CAHN adopted a mixed approach to data collection that involved consulting with Black women and PIMH providers across Greater Manchester.

Methodology

The exploratory study was qualitative in design. An invitation flyer went out to communities across GM to participate in focus groups and interviews to share their experiences during the perinatal and infant periods. N= 30 women took part in one of four online focus groups over a period of 2 weeks. We gathered a representative number of participants from Caribbean and African Backgrounds and those who are migrant multi-lingual as well as those born in this country, N= 3 agreed to participate in a follow-on informal interview where they shared their lived experiences of mental health challenges during and after their pregnancies.

Translators were available during each session to interpret information where required. Counsellors were present following the focus group sessions for any participant that required support. Ethical processes that exhibit good practice were followed for this community-based study.

Eight PIMH teams across GM were emailed to gather open ended survey responses to questions, and five PIMH teams responded. Two consultation sessions took place with PIMH leads to discuss initial findings from the focus groups.

Main themes from the review and VCSE

The data from this sample of Black women revealed five descriptive key themes around the factors that can exacerbate mental illness during the perinatal period and leading to non-engagement with mental health services.

Overarching Themes & Subthemes

Theme 1.

Fear and Repercussions of Highlighting Concerns

1.1 Costs borne to Protect Self and Infants
1.2 Lack of Compassion and Safe Care
1.3 Racism and Poor Attitudes of Staff

Theme 2.

Identity & Expectations of Black Women

2.1 Cultural Expectations of Black Women.
2.2. Cultural Pressures and Mental Well-Being
2.3 Vulnerability, Loss of Pride and Confidence
2.4 Practices of Health Professionals according to Stereotypes

Theme 3.

Accessing help in Safe Spaces

3.1 Belonging, Acceptance and Ability to be Authentic Self
3.2 Health Information and Managing Overall Health
3.3 Peer support and Confidence to ask Questions and Share Information
3.4 Representation in Perinatal Services

Theme 4.

Religious and Cultural Barriers and Enablers

4.1 Religious Practices inherent in Black Communities
4.2 Mental Health and Maternal Literacy among Faith Leaders
4.3 Cultural Beliefs and Myths
4.4 Cultural Stigma

Theme 5.

Sharing Needs with Partners and Spouses

5.1 Challenges Sharing Feelings
5.2 Bonding with Baby
5.3 Increasing Parental Support and Involvement

Themes from the consultation survey with PIMH teams

Findings from a short survey with PIMH teams across GM highlight that more needs to be done to improve minority staff service representation at all levels of decision making. The survey found that the services are not culturally, religiously, linguistically and racially sensitive and therefore do not provide accessible services. These changes require a co-produced approach in order to engage Black women and their families in safe mental and infant health services.

Theme 1.

Limited visibility of racial, cultural and religious reflections in service materials

Theme 2.

Lack of education and training on race, culture and religious

Theme 3.

Low levels of involvement of minority staff and service user involvement working with and in PIMH teams

Theme 4.

Language barriers due to no translation of materials or adequate interpretation services

Conclusion

The views expressed from participants present insights into why perinatal and infant mental health care services are not utilised across Greater Manchester despite the need for mental health support. The findings align with what perinatal and infant mental health leads have told us about the lack of focused support for these women and their infants. It highlights that Black women and their infants are suffering from the lack of support that is needed to break the cycle of poor mental health for them, their families and their infants.

Several recommendations have been made and reflect the findings from this study. Four thematic areas were identified, and the detail of each recommendation is provided below.

Recommendations for PIMH Service Providers and the GM Wide System

1. Resource Development

To create from a scoping exercise an online platform of perinatal and infant mental health services and resources available for service providers, users and carers. This resource should be made available in accessible formats.

Co-produced resources developed in collaboration with VCSE (including faith) organisations and health-care system partners.

2. Training, Education and Development

To equip both service providers and users with the racial, cultural and health literacy required to benefit users and to help providers deliver services that are culturally appropriate and sensitive the needs of Black women and their families.

3. Service Design and Recruitment

To utilise existing evidence-based recommendations from appropriate reports (at local and national levels) to shape services with a representative workforce.

4. Data Collection and Recording

To work with communities and system partners to support the gathering of data with ethnicity captured that that can be coded accurately and used to tailor and target services.

The Call to Action

Black women experience high and disproportionate levels of mental ill health but are half as likely to seek care as white women.

The Perinatal and Infant, mental health outcomes of Black women and their infants represent only one aspect of a much bigger problem of injustice and unfairness resulting in some of the mental health challenges experienced by Black people today.

To break the intergenerational cycle of poor mental health and well-being of Black people we require a call that:

- Brings system leaders together across GM to respond to the findings from this report
- Provides a GM wide evidence based framework that holds the GM system to account for sustainable action and investment in line with the recommendations
- Ensures that Mental health and wellbeing needs of the Black woman and her infants are built into every 5 year plan for the Health and Care System.

We call on all Black, and Black Mixed raced women and all those who care about breaking the intergenerational cycle of poor mental health to support the call to action and the recommendations in this report.

2 Background and Rationale

The prevalent and disproportionate poor mental health outcomes of the Black woman is not new with significant numbers experiencing physical and psychiatric complications and challenges during the pre-pregnancy phase and through the perinatal period.

Poorly managed perinatal mental health problems can have lasting effects on maternal self-esteem and confidence, partner/family and social relationships. Perinatal mental health challenges can adversely affect the psychosocial development of the child therefore, bringing intergenerational trauma for them and their infants over the life course. Infant mental health is interconnected with and affected by maternal mental health and the mood disorders can affect attachment, bonding and the ability of the infant to thrive.

The World Health Organisation (2013) defines mental health as a state of well-being in which every individual realises their potential and can cope with the everyday stresses of life, they can work productively and fruitfully and can contribute to their community or communities. However, for many, this statement will mean different things to different people, and the 'normal' and every stresses that many Black women face will be vary from the experiences of other groups of people affecting themselves, their families and those around them. For example, the constant worry about what will happen to their boys when they leave home due to the disproportionate suspicion and harsh treatment towards them by for example law enforcement officers and education providers in schools and colleges.

Pregnancy and the postpartum period carry an expectation of happiness. Still, it can also be a time of emotional turmoil, fear and worry that significantly impacts the lifestyle and relationships of the woman. Overall, birthing people are 10-20% more likely to endure mental health problems during this period, and this creates significant effects upon the mother, the unborn child and their families. However, Black women are 13% more likely to have postnatal depression and 23% of Black women who died in the postnatal period suffered from mental health disorders (Knight, 2020). Knight (2022) highlights that, mental ill-health and heart disease collectively account for 30% of maternal deaths during and up to six weeks after pregnancy.
Despite the disproportionate mental health experiences, Black women are least likely to engage with mental health services.

Worry and fear are likely to hinder attachment and is associated with a high percentage of mothers and fathers who describe the historical and current daily struggles as triggers to their mental health problems. Black women carry a burden of trauma-induced stressors from the daily life of racism and discrimination that manifests itself in health inequalities across the life-course (Edge, 2010). A mother or birthing person's mental health before and during pregnancy and the postpartum period is essential for a child's development and increased risk of adverse mental health effects for children later in life.

Untreated perinatal mental health problems, including postpartum depression and anxiety, present a significant public health concern and can have long-term impacts on the physical and mental health outcomes of mothers, babies, partners, and families.

Physical, Biological and Socio-economic factors

Black women are more likely to have underlying health conditions such as heart-related disease, diabetes, fibroids, and pre-existing mental health problems. They are also more likely to be overweight and all of the above health issues can complicate pregnancy (PHE, 2019). These conditions can be attributed multifactorial array of influences, such as poorer socio-economic and environmental living conditions, migration, deprivation, culture, social isolation and racism and discrimination (Wallace, 2016, PHE, 2019, Anderson, 2017). This can be further exacerbated for recent migrants who may have little English, be single parents or have lower educational levels (Moore, 2019, Womersley, 2021). Black women are 43% more likely to have a miscarriage (Lancet, 2021) and 121% more likely to lose their babies after childbirth (Knight, 2019). Black women are also at high risk of delivering a preterm and low birth weight baby (Patel, 2004, Puthussery, 2016, ONS, 2017), which can result in the baby being cared for in Intensive neonatal care or requiring transitional care and support. This separation is more likely to result in attachment/bonding delays, less likelihood of breastfeeding, and an increased risk of child behavioural, emotional and cognitive challenges (Russell, 2014).

In the context of all of this, the health and well-being of Black women can deteriorate rapidly and present further challenges and omissions of care when services lack an understanding of the racially, culturally, and religiously appropriate and specific holistic health needs of Black women.
Through the voices of Black women, this exploratory study sought to listen to Black women's lived experiences of mental health and the impact on their well-being through the perinatal period whilst at the same time engaging with PIMH teams in GM through surveys and consultations. . The report makes recommendations that identify the most effective ways of engaging Black women and their families in perinatal and infant mental health services and states the call to action from the system in response to the recommendations.

3 Research Design

3.1 Aim

To review what existing PIMH teams offer Black women and their families across Greater Manchester and to identify through the voices of Black women their experiences and barriers to perinatal mental health support and the most effective solutions that will benefit them and their infants through the perinatal period.

3.2 Objectives

- To consult with PIMH Team leads to identify what their services offer to engage and include Black women in mental health and infant services

- To explore the experiences of Black women through the perinatal period and to focus on the impact on their mental health

- To hold four diverse focus groups with Black women to explore what the system needs to do to break down the barriers to accessing mental health

- To recommend ways to engage Black women in mental health services and achieve improved health outcomes.

- To write an evaluation report

3.3 Materials and Methodology

3.3.1 Study Team

The study team comprised of a lead researcher, a clinician, and one public health liaison officer. The clinician was a midwife and had undergone counselling training; the other held a master's in public health and had the experience of conducting qualitative research and analysis. We had counselling support available for women and our in house team of interpreters were available for those with language and translation needs.

3.4 Participants

3.4.1 Focus group and Interview Participants.

In total, we had N=38 Caribbean and African mothers with children aged three months to four years old. The mothers participated in one of the four one-hour 30-minute focus groups (including informal follow-on interviews). All participants were aged between 21 and 43 years of age. The focus groups and informal interviews (N=3) were conducted between March and May 2022. Participants included women that had their babies pre-pandemic and also during the pandemic.

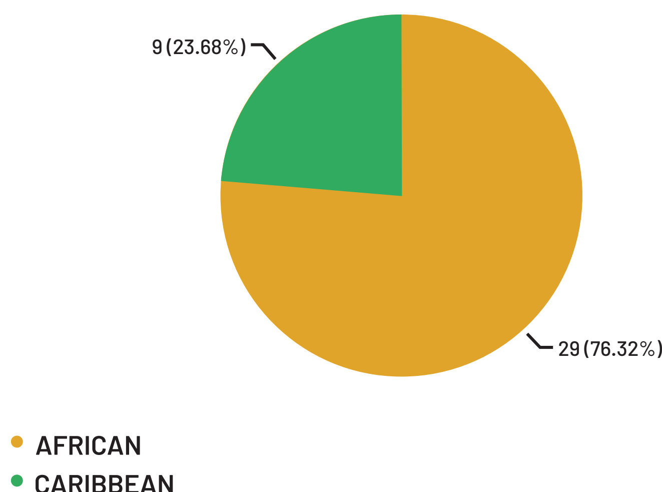
All participants were able to take part using English although for many it was not their first language.

Participants who completed the focus groups and had used perinatal and infant mental health services were asked whether they would like to participate in a follow-up interview via telephone or online (Microsoft Teams audio only). Participants contacted the research lead, who followed up 3 participants. A separate consent form and participant information sheet was provided, which participants were asked to return prior to the recorded interview.

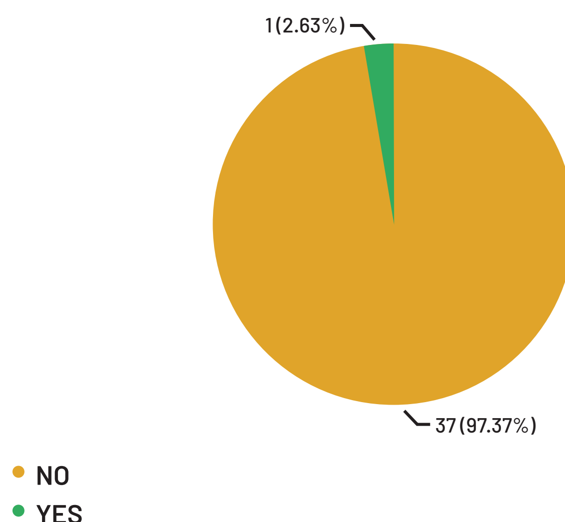
The purpose of the informal interviews were to gain further insight to experiences shared during the focus groups which lasted up to one hour. It explored all key focus group topics, including how they accessed support and any barriers and solutions they felt would help support Black women through the perinatal period.

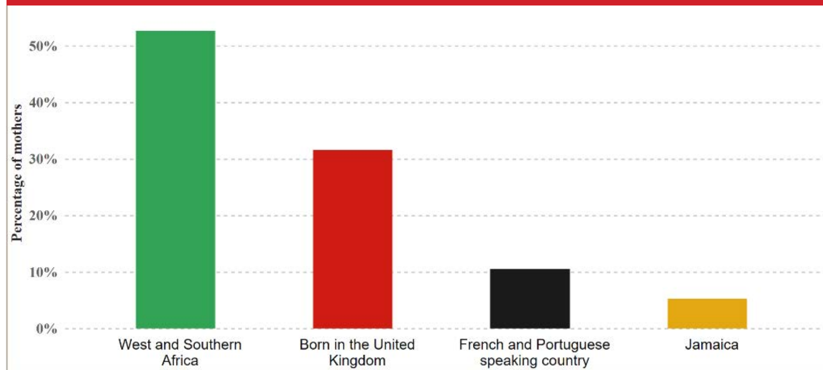
Participants were offered £25.00 for their participation in the focus groups and interview. These sessions were transcribed using Otter-ai and the focus groups. thematically analysed.

Participants Ethnicity

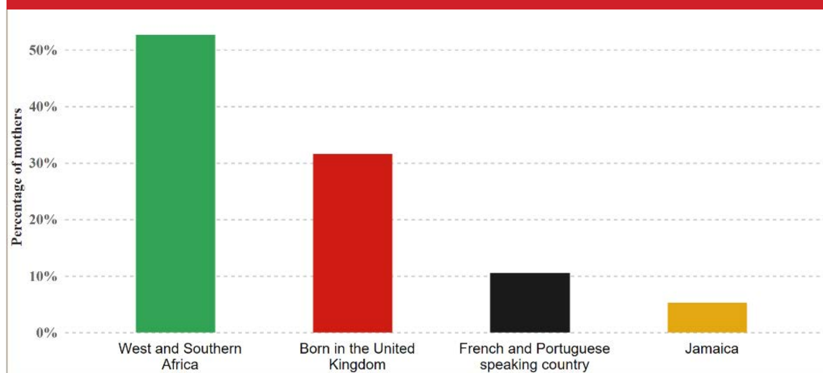


Participants Disability





Participants' Place of Birth



Participants Religious affiliation

Mapping of the current Perinatal Mental Health Services in GM

3.4.2 Survey sample

We invited the N=8 PIMH team to respond to surveys and had N=5 respondents. The open ended survey was conducted between March and April.

The scoping activity aimed to identify what and how services were provided and to use this intelligence to better engage Back women with their infants during the perinatal period. The survey was conducted between March and April.

An important element of the study was gathering information from perinatal, and infant mental health leads across GM to explore the degree of cultural, religious, and racial inclusion within and across services.

Following two introductory meetings with PIMH leads and the manager for HOST to discuss the study, eight emails were circulated to perinatal and infant mental health leads to answer questions about their GM services. For questions, please see appendix 1. Out of 8 emails sent, 5 responses were received from across the GM teams.

3.5 Ethics

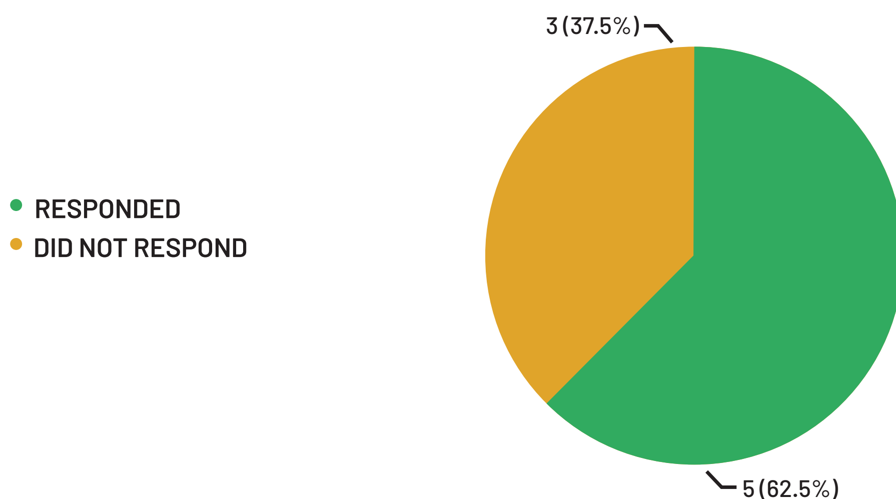
A researcher and clinician completed the study in the community setting. Ethical processes were followed to ensure the whole engagement process adhered to strict ethical guidelines that would keep participants in every aspect of this study's information safe and confidential. Consent was sought in writing from the focus group and interview participants before the commencement of the engagement sessions. Consent was rechecked at the start of each session, where participants would identify in the chat their consent. The participants were provided with a participant information sheet before taking part, and here the lead researcher explained how the data would be used, stored and destroyed. Inclusion in the study was by choice from the perinatal and infant mental health team leads, who were informed about the study via email. Each team lead had the option to respond to email survey questions. All responses were coded for confidentiality and anonymity.

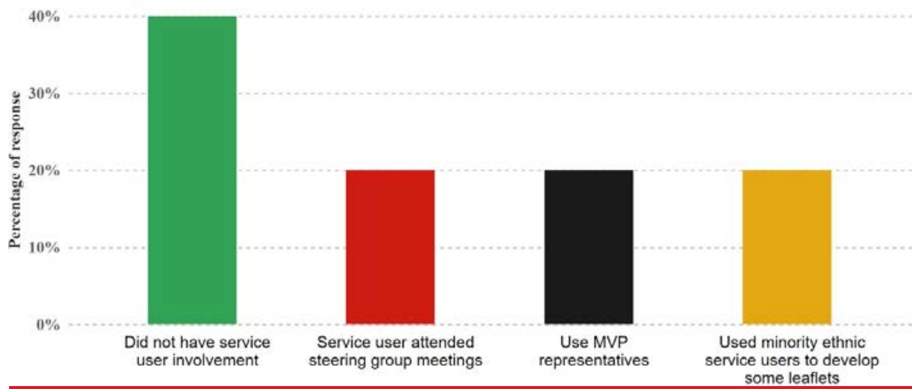
4 Results

4.1 Findings and analysis of data from PIMH Teams

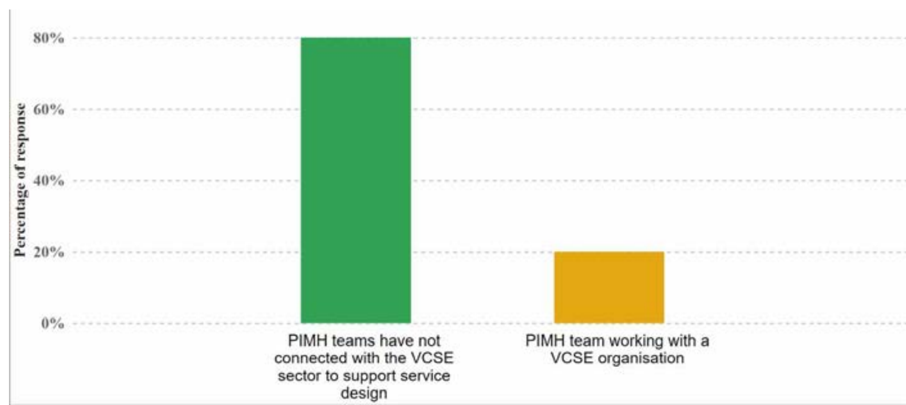
Perinatal and Infant mental health team mapping

This exercise involved identifying the current perinatal mental health services in GM. This exploration involved working with leads from the service to gather information through open ended survey questions via email.

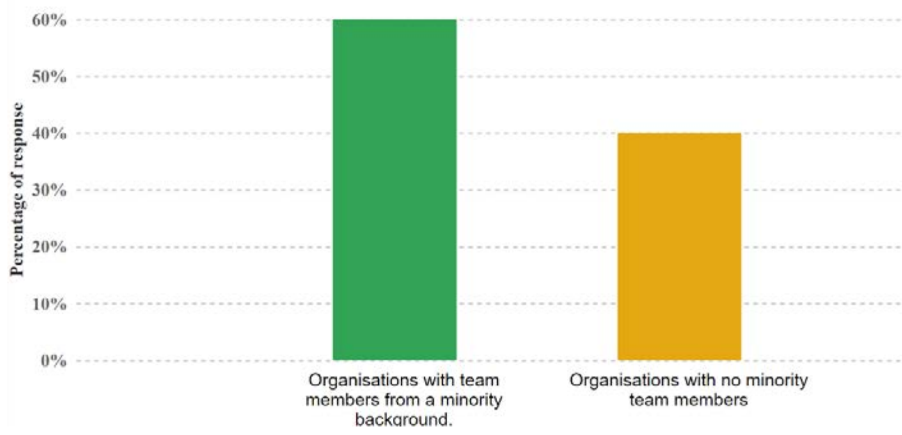




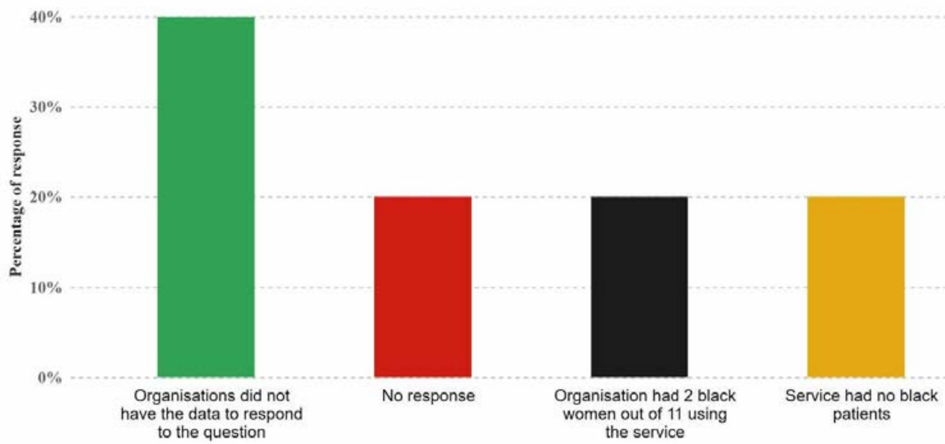
1) How much involvement do you have with minority service user voice in your service, do they get involved in reviewing information about services?



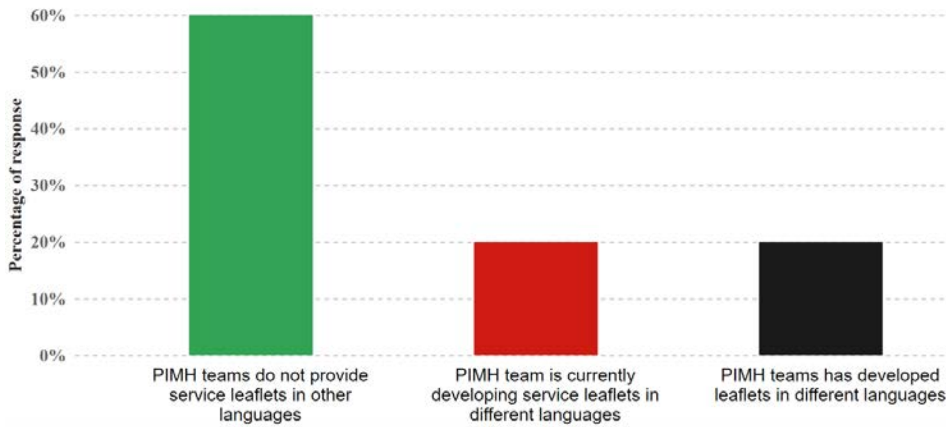
2) Do you have any input from the VCSE sector for those with protected characteristics in your service design?



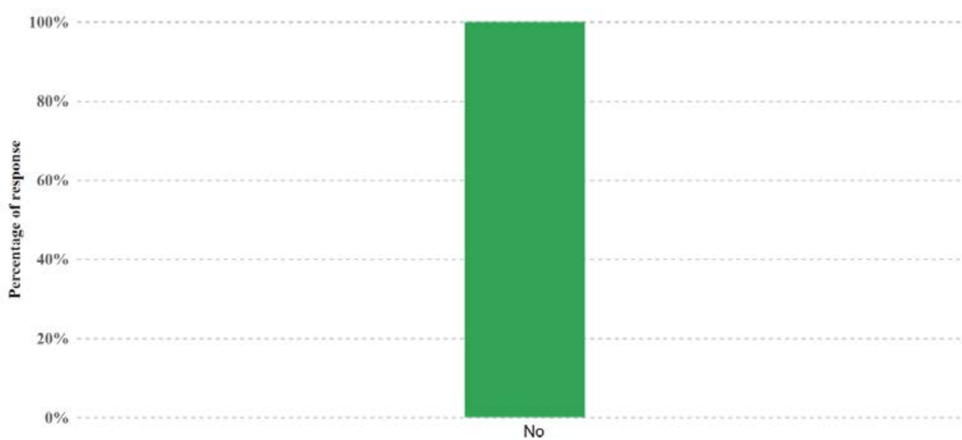
3) How diverse is your workforce?



4) How engaged are Black women within your service?

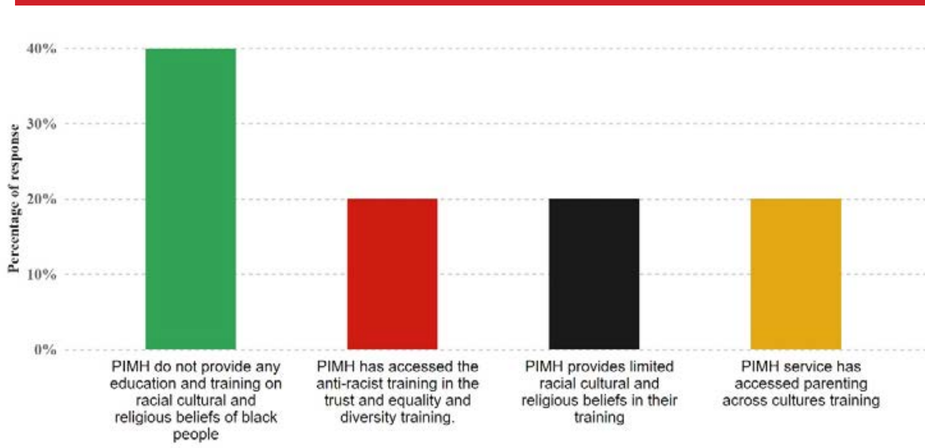


5) Do you have information available in different languages?

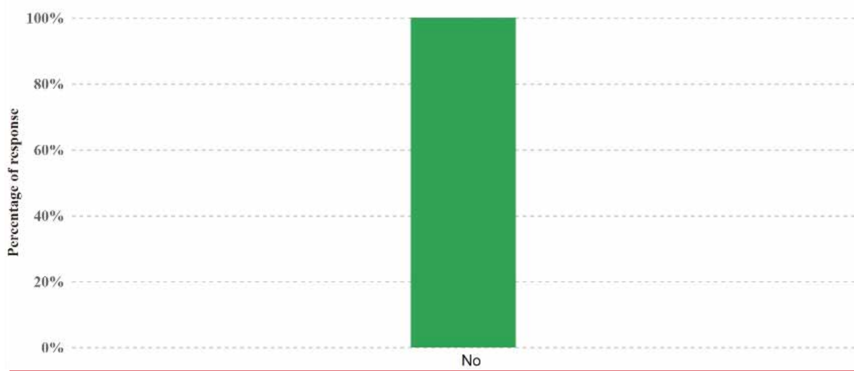


6) Do you have any materials that relate to the cultural and religious issues of ethnic minorities

7) What Education and Training is provided on race, culture and religious beliefs and practices of Black People?



8) Any complaints from Black women and what has been learnt?



Findings from the short survey and consultations with PIMH teams across GM highlight four themes

1. Limited visibility of racial, cultural and religious reflections in service promotional materials
2. Lack of education and training on race, culture and religious beliefs and practices
3. Low levels of involvement of minority staff and service user involvement working with and in PIMH teams
4. Language barriers due to no translation of materials or adequate interpretation services

Overarching findings highlight that more needs to be done to improve staff service representative and inclusion of Black people in teams and services. There needs to be further culturally, linguistically and racially appropriate provision of services.

Two presentation meetings took place over a period of 4 months to report on the initial findings from the focus groups and a discussion took place which recognised that there could be several activities to try to address the lack of inclusive services provided across GM. These suggestions have been included in the recommendations. PIMH were keen to look at ways in which they could work with VCSE community leaders and Faith leaders across GM.

4.2 Themes and Analysis of data from across the Focus Groups and Interviews

The data from this sample of Black Caribbean and African women highlight the challenges on their mental health during preconception, and throughout the perinatal period. The findings illustrate how this is compounded by the demands of caring for a new baby exacerbated by the challenges of racism, discrimination, cultural beliefs and practices and also their faith. Most of the women's experiences took place during their engagement with maternity services including in acute, primary and community settings. For questions guiding the focus groups and interview sessions see appendix 1.

Five descriptive themes were reported on.

1. Fear and Repercussions of Highlighting Concerns
2. Assumptions and Expectations of Black Women
3. Accessing Help in Safe Spaces
4. Religious and Cultural Barriers
5. Communicating with Partners and Spouses'

Theme 1 Fear and Repercussions of Highlighting Concerns

The theme reported here highlight the fear that Black women perceive they are subject to if they disclose their mental health concerns with professionals. Black women use experiences of other Black women including those known to them and reports in the media to make decisions about what they are prepared to share.

1.1 Costs Borne to Protect Self and Infants

Women shared feelings about the health system itself and that it was not conducive to sharing their experiences openly and honestly. Many women spoke of fear of having their children taken away even when they were feeling desperate for some support. The worry of being labelled with terms such as mentally ill and having their baby taken away from them via social services was a great concern and inhibited disclosure of mental ill health.

"Despite how I was feeling, I was worried that if I spoke out honestly that I would be judged as not capable. I did not want to be labelled so I kept quiet and now and I believe that it has affected my baby now, I cried throughout my pregnancy and felt so low".

"There is no-way that I could begin to speak to my midwife about the struggles I was having with my older children that was making me feel mentally unwell and unable to cope so much that I felt like giving up. I did not know where to turn for help".

Women spoke about their 6-week postnatal check and only nine of the women from across the focus group were asked by their GP asked about their emotional or mental health issues. Of those that were asked some stated that even though they were feeling emotionally unwell they did not feel able to disclose any worries they had about their emotional and mental well-being.

"I didn't speak to the doctors about my anxiety, because I was worried about what might happen to my kids, if something happened to me.

1.2 Lack of Compassion and Safe Care

Women across the focus groups and interviews experienced some sort of unprofessionalism in maternity services on the part of the health workers which in turn affected their confidence in the service they received and their trust in them. In some areas, health care professionals also proved to be incompetent.
Some women complained about neglect and how they felt they were being mistreated by health providers.

One of the women talked about how a health care provider tried to overdose her because they felt she was making noise and was causing problems in the hospital but due to her knowledge in the medical sector, she used her discretion and did not take the tablets.

She went on to say;

"And that didn't help my confidence in the service, then I didn't feel confident at all that day, when I asked questions, she didn't know. I could see her going through Google to check."

There were four women in the group that had experienced bereavement through still birth and they shared that there was a lack of support for them during that time.

"I could really have done with someone providing more support when I was grieving for my baby, it was a really tough time, I had pressure from my in-laws as though it was of my doing and I had nowhere to turn, I was left to deal with it alone."

Another woman said,

"This was a turning point for me, I was really looking forward to the birth of my baby and when I was told that he had died just before 24 weeks and that there was nothing they could do they didn't even offer support. I believe had I been a woman with a partner and maybe a White woman things would have been different".

1.3 Racism and Poor attitudes of Staff

Many women stated that, race and racism played a huge role in how they were treated during their pregnancy. The assumption that Black women are "strong" and can withstand high level of pain resulted in the low priority given to them in such cases. Hence, the extra effort that would be put into seeking additional and appropriate care for white women was not given to them.

"But I still think if I was white, I would have been offered so much more."

Women spoke of the fear of how all [education, criminal justice, employment, housing] systems treat them and how they [professionals] de-prioritised their care and treatment. They stated that so much of the responses they received from professionals were based upon stereotypes and judgements made in part by the colour of their skin.

"I did go to seek support and it wasn't long before they were ushering me out of the door with medication, I wasn't offered any support"

Women questioned where the stereotypes about Black women had come from, they could not understand why they were treated with lack of care and compassion and left to cope on their own or with inappropriate services.

"This is why I just don't bothered going to see these people [health professionals], in one way I have to wait ages to be seen and when I am seen I do not get the time of day to talk about issues properly anyway"

Theme 2: Identity & Expectations of Black Women

There are many examples in maternity care in the UK and US where Black women experience substandard care due to stereotypes and assumptions of 'the strong Black woman.' This would often leave Black women without the sensitivity, care and appropriate treatment. Women in this study shared stories from their youth here in UK or abroad of their mothers and grandmothers who stressed that there were expectations of them to be resilient and strong and that this had been passed on through the generations. This expectation of Black women has continued and resulted in practices from both White and Black professionals to the point that it has caused harms to them in the receipt of care.

2.1 Cultural Expectations of Black women

For Black women, the mental health challenges they experience through the life course are often exacerbated by their intersectional identities. There are colonial attitudes that depict Black women as being "strong and resilient" and requiring little or no support.

Women who I interviewed from the Caribbean spoke about how this expectation did not only come from Black [In particular women] people in the community but also from Black health professional midwives. She went onto say:

"I just felt sad, I was so low after I deliver my premature baby and I tried to speak to the Black midwife about it and she told me I need to remember what I would have been taught when growing up and that was to be strong"

There are so many pressures to be strong, and women said this made them less likely to seek support. Although they did not recognise symptoms of mental ill health, they expressed their feelings as creating more anxiety and low mood. This led them to become more and more isolated from their babies, and they felt that this had a negative impact on their children growing up.

One woman said her 2-year kept on trying to wake her up from sleeping so much,

"I just could not move, it really wasn't good for my babies. To top this up babies dad was never home as he travelled to Nigeria a lot"

2.2 Cultural Pressures and Mental Well-Being

Women in the focus group discussion stated how much culture played a significant role in their perinatal and infant health care. Most women had cultural traditions that were passed down from generations. Women, regardless of where they came from across the African continent, expressed the need to reproduce children as gifts to their husband's parents. They said that this was not reflected in care and support from health professionals especially when they had been trying to get pregnant for a long time.

"Can you believe that I came to this country seven years ago from Nigeria where I got married and there was an immediate expectation that we would have children. The pressure was so much and everyone asked me what was wrong with me. My in-laws looked at me with pity to the extent that my husband with all the shame said we must travel abroad. We carried on trying and 5 years after I left I finally gave birth. I was so depressed for years even my husband didn't support me. There was no compassion or sensitivity towards me from the midwife and I was discharged having no knowledge about any mental health support".

Some women stated that, there was also limited support from the community because death is something that is not spoken about in some African communities and in addition Black people are unlikely to say that they are pregnant due to the witchcraft and superstitious practices that take place.

"I had 3 miscarriages before I had my son, I was convinced there was something going on", however, I could not say anything to people close to me in my community.

2.3 Vulnerability, Loss of Pride and Confidence

The expectation that Black women should just 'get on with it' regardless was expressed as affecting their self-esteem and confidence during their pregnancy and postnatally that they lost the ability to communicate well with others.

"I felt so vulnerable, it was a period where I felt that anyone could have told me anything and I would believe what they told me to do, I just listened to people, when I look back now I know it was because I was unwell. I did see my GP and he gave me medication but I couldn't take it for long because I was worried about what my mum would say if she saw the tablets"

"I felt so useless, I had no confidence in my ability to look after myself or my baby, it is a horrible feeling especially when I had no one to talk too to help normalise my situation, I just needed someone to say it was (or i) will be ok"

2.4 Practices of Health Professionals according to Stereotypes

Women shared beliefs and experiences that presented situations where thy had been told that they are far too big to be tearful and emotional after she finally gave birth to her baby girl after 9 years of trying to conceive.

"There was simply no care, sensitivity or compassion towards me, like I was just another number, I felt like nothing to be celebrated".

One African women that had a baby 2 years ago spoke about the pain she endured during her labour and was left to suffer, she said that" she still feels mentally scared years later.

Some women also spoke about the fact that they did not feel involved in their own care and were not carried along in the decision making. The health care professionals were not transparent, they would have prescriptions stopped and medication added without giving adequate information as to why it happened.

"I feel like I am not involved in my own care. All I wanted was for the midwives to talk to me and get to know me better".

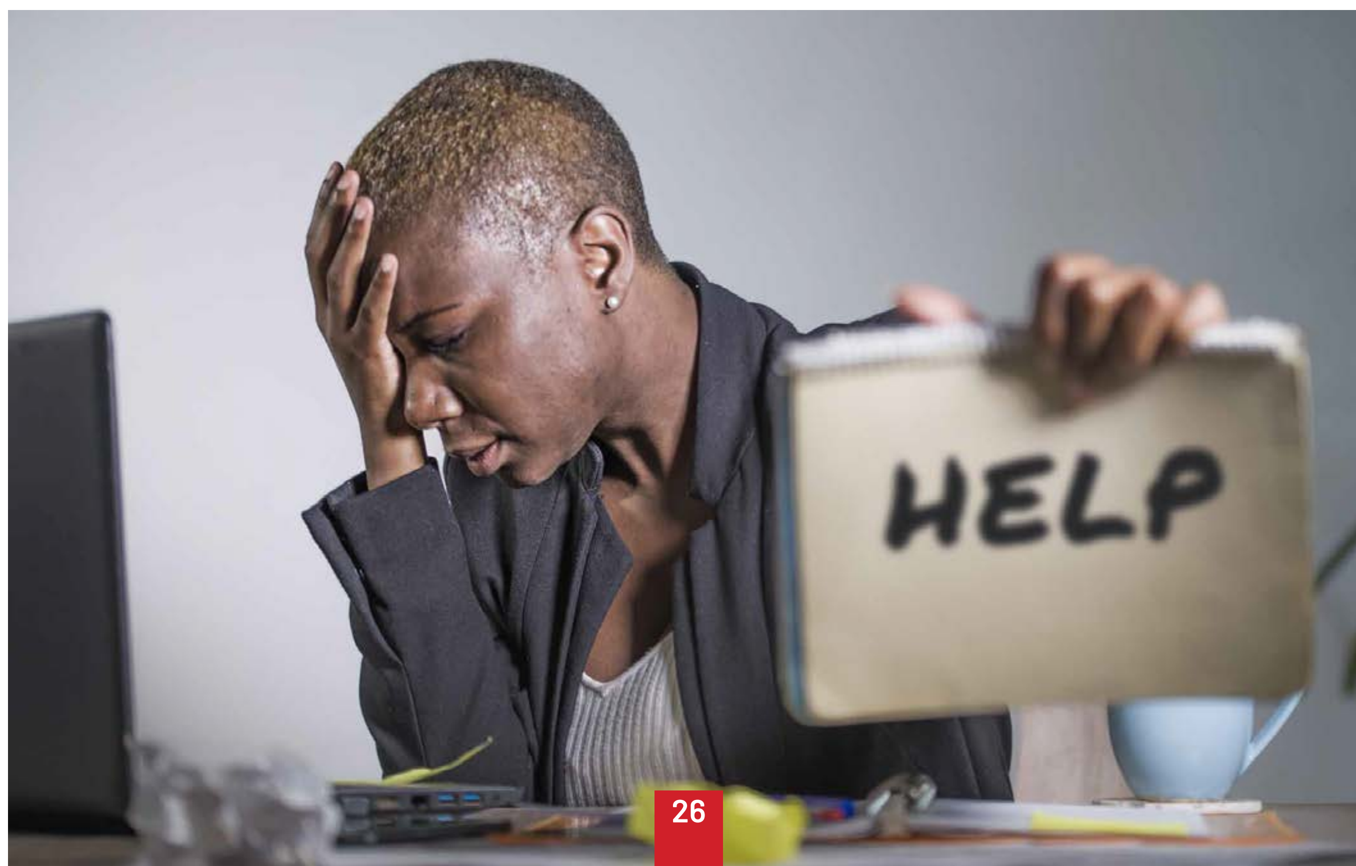
"In my case, when my supplement was stopped with no communication whatsoever; it really affected me."

Nearly all the women felt they were not being heard and listened to, they felt they were not taken seriously and that they were treated like their opinions did not matter. The lack of involvement was also a problem discussed.

"So, if I were listened to and heard, and my points of view taken into consideration, then my experience would have definitely been different".

Mothers stated that, there is often the assumption and stereotype that Black woman aren't interested in the detail about their health and that they do not care enough to be involved as decision makers

"I had a blood test done and when I called my GP for the results, I was told there was nothing to worry about without any details communicated so I said no, I need to know what my results said."



3 Accessing Help in Safe Spaces

This theme is about women who had accessed their health providers particularly GPs, when pregnant or when they had their babies. They stated that whilst their experiences were not negative in relation to how they were treated, they felt that they wanted to share more with their provider but were not confident that they would be understood and their experiences accepted in the way that would not judge them negatively.

3.1 Belonging, acceptance and ability to be authentic self

Women spoke about how they did not feel that they belonged in certain spaces such as antenatal classes and that the space was not designed to cater for them. They spoke about the model baby demonstrations that always used white babies. They echoed the classes were largely attended by women that did not look liker them and that included the midwives that were also leading the groups.

"It is difficult to build relationships with your midwife and GP when you see different people all of the time. There have been times when I have had a GP that really understands the situation I am in emotionally, and this does not always need to be a Black person".

One woman agreed with another participant about that person being Black and said:

"It isn't just about being Black, it is important that health professionals understand the position that many of us Black mothers are in whether it is because of racism or sexist behaviours that stereotype, expecting things to be the same for me as it is for White women who are not challenged with the same issues as me then it is not great for my mental health, it actually makes me feel worse."

Women spoke about how services, such as antenatal baby classes are not racially, culturally or religiously sensitive to their needs and how it makes them feel.

"It is important to have a space and people who understand you, it is so difficult and stressful when you are with professionals that you have to explain your cultural behaviours, food and all that too over and over again, especially if you are unwell".

3.2 Health Information and Managing Overall Health

Many of the women spoke about several other physical health issues that they were likely to contract, which included conditions such as high blood pressure, diabetes, fibroids and sickle cell and how this affected their mood and fear during pregnancy. They wanted more support around managing these issues, but they said it was often not spoken about.

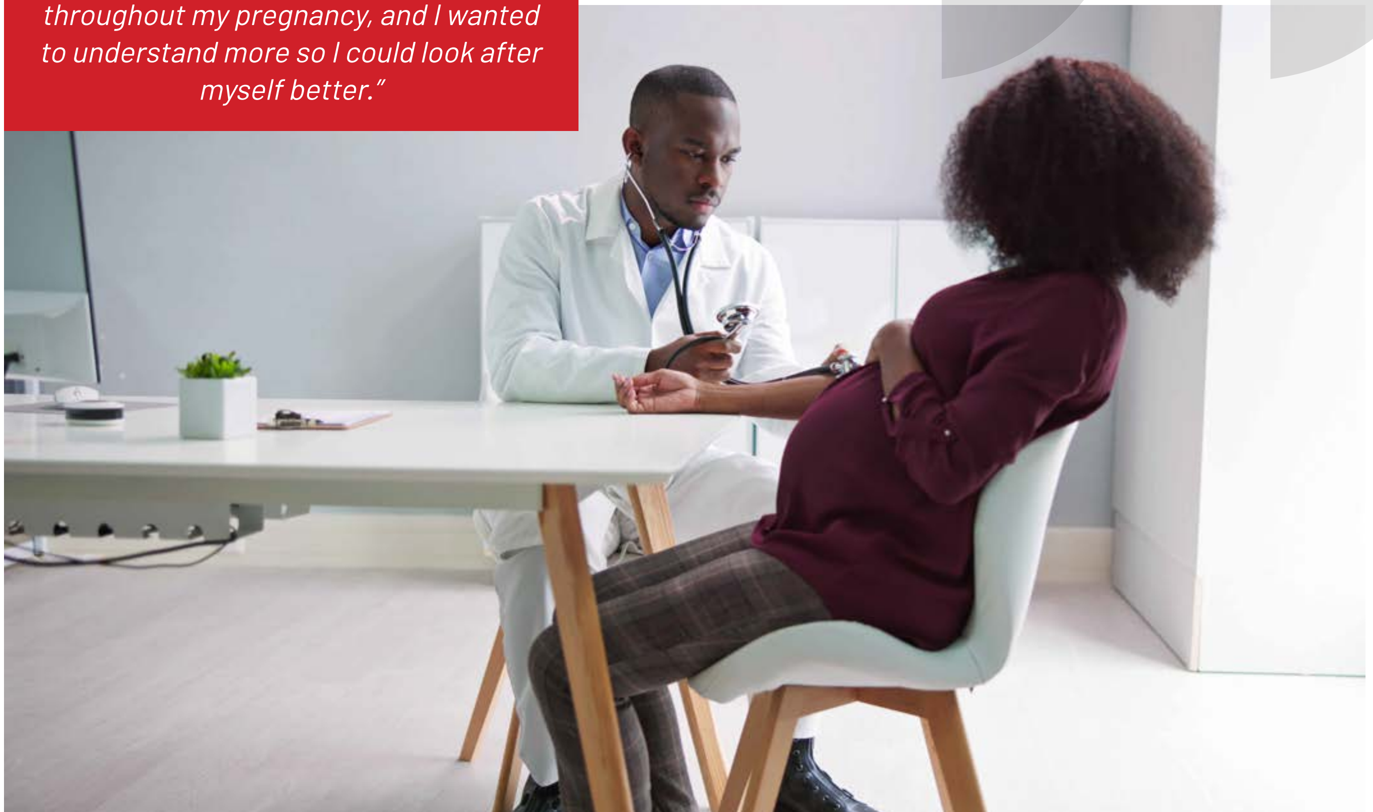
"I have sickle cell, and although the midwives speak to me about it in my pregnancy, I don't think I have enough information about how it could affect my baby."

One woman spoke about her fibroids and was concerned about how this would affect her pregnancy, others listed a whole number of conditions, but one raised about the likelihood of having a small baby, which she heard was typical in Black mums and how this could affect her baby's development.

"My mum had all small babies and she worried throughout all of her pregnancies; you can see how some of my siblings didn't develop as well, and this causes me the same mental health worries".

The women shared how knowing these risks and not been given the education to manage or prevent them being a risk during their pregnancies caused them to become more prone to perinatal depression, stressors and anxiety.

"I couldn't think of anything else, I was so stressed even though I prayed night and day for a safe delivery for myself and my baby. The risks because my blood pressure was always high was a concern throughout my pregnancy, and I wanted to understand more so I could look after myself better."



3.4 Peer Support and Confidence to ask Questions and Share Information

There was overall consensus across the groups that there needs to be a space where Black women would be able to gather and support each other. They spoke about tips they could share that could help others especially more experienced mums.

"It is important that we have somewhere we can go to share what we are going through whilst still have that professional input and support".

It was evident through the conversations that women wanted support and to be able to access that easily. They wanted to be able to link with professionals, ask questions have health checks and seek advice.

"Back home we have "community" I miss that here and feel so lonely and isolated, when I went to mum and baby classes I was the only Black and didn't feel I belonged. We need our own groups to help us"

"I personally feel that I need a safe space to emotionally be myself and not fear what may happen to me when I do so" I feel that having a support group will empower many of us and help us raising our families."

Women spoke about the high levels of nurturing and support they received when they were pregnant in the Caribbean or Africa and the difference they experience when pregnant in the UK.

"It is incredibly lonely here; you are alone when pregnant and alone when you have a baby, I miss my family' Having my baby during the pandemic made it even worse, so isolated".

One woman spoke about support for dads and said that we often forget what they are going through when we are pregnant and have babies. They suggested that there needs that support should be made for them, too and including parenting and bonding support skills because Black men can be very distant from children. Several women agreed and supported this and said

"We so need to involve our partners more, but they don't open up always appearing macho when they are also scarred."

Another mum spoke about the fear her husband had when she was in so much pain at home and shared how scared he was thinking that she was going to die.

"He felt helpless, he cried for me it is like this has scarred him as he does not bond well with the baby."

A few of the women spoke about how comforting it was to hear that other women also had challenges during their pregnancy and that it was not only them.

"I just want to hug you across the screen, I felt like how you describe your experience but I could not share it with anyone".

3.4 Representation in Perinatal Services

Although some women stated that being Black was not the most important thing in receiving good care, they still emphasised how much better they felt seeing people that looked like them. They spoke about how this gave them some confidence to speak up and be themselves. They spoke about how much they had to loose some of themselves when engaging with the people from outside of their own community.

"When I was in the waiting area to be seen for my appointment, I really wanted the Black midwife to attend to me because I wanted to share a few things that I didn't feel I could with the other midwives. I didn't get her and didn't feel able to raise the concerns I had"

"Me too, I don't feel I am fully able to open up to professionals they just will not understand my particular issues and what is causing me to worry so much".

Women spoke about how they had to act white to fit in or too say very little because they did not know how to express their feelings in a way that they thought would be understood by those caring for them

"I too just want to be myself, I often find that I act differently when with white people and that is just not me"

Theme 4: Religious and Cultural Barriers and Enablers

Several women experience barriers to accessing mental health services due to religious beliefs and cultural practices. Mental health is understood to be an 'evil' that is not of God so cannot be accepted as a label. Many faith leaders will pray to cast this out of those claiming mental or emotional instabilities. From a cultural perspective, mental health issues are only for those who have transgressed in one way or the other and is seen as a punishment.

4.1 Religious Practices Inherent in Black Communities

Some women voiced out the discomfort they felt when they approach their faith community with religious views on their mental health problems. They felt that they were indirectly being blamed for believing and disclosing that they had health problems. They also felt that their problems were made to seem insignificant and exaggerated.

> *"If I speak to some of my church members about my mental health, they will say I should pray about it, and it would go away"*

One woman spoke about how her pastor completely dismissed her from the church because he thought she was of as a bad spirit because she said that she had mental health problems.

> *"I couldn't believe it, I went to the church pastor to ask for him to pray for me as I wasn't coping well and thinking I was hearing and seeing weird and dangerous things, I didn't want to go the GP because I was scared they may try to medicate me. My pastor told me that it was all in my head".*

4.2 Mental Health and Maternal Literacy among Faith Leaders

In contrast, two women spoke about the support given by their pastors, who had been in training in mental health and understood and accepted the challenges that pregnancy can bring to women and their families. Women spoke about how important it was to have pastors educated about mental health

"My pastor prayed with me and directed me to a counselling service that I am using now and that has helped me so much. He also put me in touch with the women's group at the church".

A strong faith plays a key part in how women manage their mental and emotional well-being. Women spoke about how an environment that is not conducive to engagement and recognition of their faith contribute to many Black women not coming forward and suffering in silence. Pastors with training made a positive impact.

"If only I could go into a space where my religion and culture were recognised in my care, then this would be amazing, I think this would really help to engage and involve me in things much more as I would feel that this service was particular to me and my needs".

4.3 Cultural Beliefs and Myths

Many of the women had cultural beliefs and practices practised within their homes regardless of whether they were born in the UK or had settled in this country for a long time. These practices were passed on through the generations and guided their pregnancies and childbirth. Mental health problems were highly disregarded among them, and their antiquated beliefs and traditions were still held in high regard.

"I spoke to a couple of people from home so, and they would say Oh, as for us, we don't have depression".
"I have heard people say that depression is not for Black people".

When women spoke about mental health conditions, they shared how some mental health issues were seen as White women's illnesses. One woman who came here less than 12 months and had a young baby said

"Even though I didn't feel well happy, in fact, I was a bit flat for months, but I wouldn't label that as depression".

"As a Black person, you shouldn't pick some diseases which are for White people".

4.4 Cultural Stigma

The women found themselves in situations where it was hard for them to seek help because of the environment they were brought up in, how they perceived themselves and how they felt their community or society would view them. One of the challenges to accessing mental health services raised by the women was the fear of being stereotyped by people around them and therefore not always feel able to seek help.

The stigma and shame of being unable to cope is influenced and compounded by "cultural expectations". Despite this, the stigma of seeking services, and the need to wear the self management hat as their mothers and grandmothers did prevents people from asking for help .

"I think the lack of adequate milk production was because of how I was feeling; so much pressure from family."

There are traditional beliefs about breastfeeding in parts of Africa and teh caribbean and there is an understanding that breastfeeding helps to create a bond between you and your baby and at the same time it is so powerful that it helps to cast away evil spells that people may have around you".

Theme 5. Sharing Needs with Partners and Spouses

In this theme, we report on data related to access to perinatal mental health and Infant services for dads and spouses. Women told us that men, in particular were even further removed from the idea of mental ill health during pregnancy, childbirth and postnatally. Mental ill health was something that many were unfamiliar with in their home country apart from those that you saw displaying signs of physical, mental instability. Thinking that low mood or uncontrollable crying was associated with mental unwellness during pregnancy was unheard of, so it was a strange concept to many.

5.1 Challenges Sharing Feelings

Several women who had experienced mental illness during the perinatal period found it hard to share how they were feeling with their partners; to them it was a sign of weakness.
One woman said that her husband left for work at 7.00 in the morning to find her still sitting in bed at 6 pm. In addition, she spoke about how isolated she felt during the pandemic with her new baby.

She said

"He knew something was wrong, and when she tried to explain how she was feeling, he dismissed her and told her that she had to get up and get on with it".

In all of the focus groups and interviews, women expressed fear to the extent that they could not reveal they had an emotional or mental health challenge to their family and those close to them. This was not helped by the way they experienced mainstream care.

"I felt so isolated and alone asking myself whether this was normal; there was no one to confide in, no one around, especially during the pandemic".

5.2 Bonding with Baby

Some women found this very difficult and were themselves worried that their mental state would affect how they bonded with their babies over time. Despite this fear, some women felt angry that having a baby made them feel so emotionally low and just wanted their life back to how it was before pregnancy.

> *"It took me nine months to start to pick up my baby and cuddle her; times during the day, the baby would just be left in the cot, I never went out, I never saw anyone, and I feel bad about that".*

She went on to say:

> *"It was the same for her dad, he was the 'macho type; didn't want to appear to soft by cuddling her or me for that matter"*

> *"I worry that my baby isn't developing well because his dad does nothing with him, he doesn't feed him read to him or anything, I worry about their relationship, his dad just seems scared".*

Women that did not bond with their babies noticed that their babies were more withdrawn and clingier in the company of others.

> *"I just can't leave shefor a moment; he seems very unsettled and not sociable at all."*

5.3 Increasing Parental Support and Involvement

Woman and their spouses expressed the need for more support with attachment and bonding. They wanted to know how to develop closer relationships with their infants. They spoke about how traditionally physically close relationships between children and their parents were missing and that they wanted more for their children.

"I just remember that my dad never hugged me or told me he loved me; it didn't seem like a very 'macho' thing to do."

Parental education was spoken about in the groups, and women felt that this needed to be offered to Black women and men who often have different kinds of pressures when raising their children. These pressures were often cultural, religious or due to racism, lack of high quality work opportunities, good pay and conditions and women wanted guidance.

"I think we need some more support here because how we are parenting our children, who face so many barriers growing up in this country, causes up to wrap them up for fear of what they might experience."

One woman remembers talking to her health visitor about some challenges she was facing and not getting the support or advice she needed. She had no idea how to respond.

"Yes, I have been seeking this support because I want to create a healthy bond with my boys and not one that causes them to fear the sight of authority."

Women also wanted some support that would help them to juggle all of the things they need to do like work, some women spoke about the many jobs they had and responsibilities on them and their partners to send money back home to Africa to support their families. They said that the work and family life demands was a problem

"It is difficult when you need to work early, finish late and the you only get a bit of time in between for your family, it would be helpful to get some support and guidance on how to do this well"

5 Discussion

This report provides a picture of the stark reality of the challenges for Black women through the perinatal period and the factors that influence their engagement with mental health services. In this report, findings from the women's perspectives were directed towards the cultural, religious and racial challenges of living in GM and using services. Overall, women experienced a lack of sensitivity, and religious and cultural understanding of their needs from professionals when they used services. Fear, stigma and lack of culturally sensitive treatment and care can act as barriers to accessing mental health care. Service providers should be aware of the dangers of this and what this means for the woman, infant and their family. The women saw service providers as catering for their own and did not believe services were developed with them in mind, including when providing baby loss services and parent and baby groups in community settings. Women spoke about the lack of attention given to prioritising their personalised needs and involving them in care, especially when at their most vulnerable.

Women shared stories about the lack of trust towards health professionals when protecting themselves and their infants despite requiring help and support at some of their lowest moments. They spoke about the expectations of women from their own communities and the associated stigma; this impacted their mental well-being and bonding with their infants. For several focus group participants, they said there was nowhere to turn. Case studies highlighted that the risk was too significant to confide in professionals about their needs for fear of being judged as incapable mothers to care for themselves and their infants. These views point to racist actions and stereotyping of Black women resulting in unfair practices leading to an increased risk of poor perinatal outcomes.

Engaging Black Women in Perinatal and Infant mental health services is vital to break the cycle of intergenerational mental ill health.

Participants' voices identified five key themes with undertones of concern behind each thematic area where they shared fears of being pregnant, being mistreated, risk of complications and the exacerbated anxiety and mental distress that ensued. We identified through our work with communities that socio-economic, migration, cultural, religious and historical racial and discriminatory factors create barriers to engagement.

The provision of specifically cultural, religious and racialised tailored services delivered within community-based spaces is limited across PIMH services in GM. Black women have told us that they were unaware of exisiting perinatal and infant mental health services and did not know where to go for help. They found that faith and or community leaders were often a source of help and support through the perinatal period but in some cases identified that faith leaders often had limited knowledge of mental health during maternity and post maternity care. They have highlighted that peer-to-peer support, antenatal and post natal education, parental education, support with traumatic experiences, welfare advice, health information and emotional support can help them adjust to life during the perinatal period and begin to break the intergenerational cycle of poor mental health for them and their families.

The development of Black-Led Mental Health and Physical Well-Being hubs with a focus on Perinatal Care and Support will really help us.

The findings highlight how race and racism and religious and cultural practices intersect on Black people negatively and influences perinatal and infant mental health. Hearing about the experiences of Black mothers is key to helping systems to learn and implement often easily obtainable solutions to improve maternal and infant mental health inequities.

PIMH leader's findings highlight how their services are not providing spaces where Black women experience a sense of safety, identity and belonging, which can be the key to unlocking some of the challenges experienced by Black women. This report has made recommendations emphasising the need for wrap-around support from mainstream pre-natal and perinatal and infant mental health teams. From the feedback consultation sessions with PIMH leads, there is a willingness to do things differently to engage Black women in services. The solutions to bring about change require a system-wide approach to providing a with resources that will enable Black women from all socio-economic backgrounds, educational abilities, and religious and cultural beliefs to experience safe accessible care.

Strengths and Limitations

The remit of this study was centred on Black Caribbean and African women from a heterogenous group in Greater Manchester. We gained cross-cultural and religious views from a diverse group that consisted of women born in the UK, women born in either the Caribbean or Africa, and women who gave birth during and pre the pandemic. It provides a cross sample of Black women of different ages and with varied linguistic abilities. It was clear that the study required Black women to speak out with other Black women where the stigma of mental ill health is high. Therefore, while the sample is small, the quality and in-depth views and experiences shared by the women that came forward provides some rich data. In addition, the PIMH team's responses to the survey and the added consultations give a good overall picture of GM PIMH services and where action needs to be taken to improve the care to Black women. More engagement across PIMH teams would have benefited this study.

6 Conclusion

It is tragic that Black women experience high and disproportionate levels of mental ill health but are half as likely to seek care as white women. Black women including those of mixed heritage are more likely than any other population group to experience common mental health problems such as anxiety and depression throughout the perinatal period. The mental health of women during this period can create an intergenerational cycle of mental health problems which can have lasting effects on both the mothers' relationships and the infants' development. Women are often the foundation and stabilising force within families. If their mental health is in turmoil, there is the likelihood that this will also have a negative impact on their physical wellbeing and their families. As a result, we will continue to witness high rates of maternal mortality and poor physical health resulting from a lack of care and support for their mental ill health.

The exploratory study across GM PIMH services surveyed found the provider services are inadequate to the point where they are not linguistically, culturally or religiously inclusive. In addition, they are not representative of the people they need to provide care for. The lack of sensitive and inclusive services to meet Black womens needs are disabling access and prohibiting possibilities to address and engage Black women, who are more likely than any other population group to be at risk of perinatal mental ill health.

New pathways to culturally religiously and racially sensitive care is needed to ensure that Black women, their partners and infants receive supportive care from pre-conception and through the perinatal period. This support is also required during baby loss and transitional care where rates of pre-term and low-weight babies are at their highest among Black babies. It is evident that, there needs to be a fundamental shift in societal, systemic, cultural and religious practices to bring about solutions to improve the life of the Black woman and her infants during this period.

7 Recommendations for PIMH Service Providers and the GM Wide System

1) Resource Development

a. A full scoping activity that will create a live directory of local initiatives across Greater Manchester that support the health and wellbeing needs of Black Women and their infants during the perinatal period.

b. An online platform of evidence-based interventions that positively support the mental health and well-being of Black women and their infants throughout the perinatal period.

c. The system should commission VCSE partners, including faith leaders, to work with PIMH teams to co-produce materials and help to shape services for Black communities and with those where there is a lack of service user engagement within mental health services.

2) Training, Education and Development

a. Train community ambassadors to support the mental health of women, and fathers ensuring that the information disseminated enables people to recognise when they need to access appropriate services.

b. To provide educational resources that will increase the mental health literacy of women, fathers, and their trusted communities/leaders including faith.

c. Develop a culturally, religiously and racially appropriate training programme to PIMH teams to support and respond to Black women's needs more accurately and with cultural humility.

3) Service Design and Recruitment

a. To undertake further work to shape transitional care for Black women and their infants given the higher prevalence of pre-term babies.

b. To work with existing services to enhance culturally and religiously appropriate support for bereaved parents suffering from loss through miscarriage, stillbirth etc

c. To develop and sustain complimentary Black-led community peer support hubs across GM for women, dads and their infants.

To improve the visibility of PIMH service and to provide some PIMH services in VCSE community hub spaces where access, timely assessments and treatments can be provided close to home.

Increase the availability of interpreter services in community hubs that work with health and welfare advocates to ensure correct and supportive relationships are established throughout the perinatal period.

To ensure that recommendations from other relevant reports such as The Patient and Carer Race Equality Framework (PCREF) are incorporated into strategies and plans for improvement.
PIMH providers encouraged to set targets for increasing Black health professionals at all staff levels in proportion to the population it services in GM.

4) Data Collection and Recording

To adopt a partnership and collaborative approach that works with Black communities and the system to gather robust disaggregated data so that appropriate and targeted actions can be tailored to specific communities.

To ensure that the ethnicity recording system across perinatal and infant mental health is robust and accurate and that training is provided to staff collecting and coding data.

Call to Action

To break the intergenerational cycle of poor mental health and well-being of Black people we require a call that:

1) Brings system leaders together across GM to respond to the findings from this report.

2) Provides a GM wide evidence-based framework that holds the GM system to account for sustainable action and investment for this community in line with the recommendations

3) Ensures that Mental health and wellbeing needs of the Black woman and her infants are built into every 5 year plan for the Health and Care System.

We call for all Black, and Black Mixed raced women and all those who care about breaking the intergenerational cycle of poor mental health in this underserved group to support the campaign to action and the recommendations in this report.

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Appendix 1

Questions to PIMH Teams

1. How much involvement do you have with minority service user voice in your service, do they get involved in reviewing information about services?
2. Do you have any input from the VCSE sector for those with protected characteristics in your service design?
3. How diverse is your workforce?
4. How engaged are Black women within your service?
5. Do you have information available in different languages?
6. Do you have any materials that relate to the cultural and religious issues of ethnic minorities?
7. What education and training are provided on racial, cultural and religious beliefs of Black people?
8. Have you received any complaints from Black women, and what has been learnt?

Appendix 2

Questions to Participants

Generic questions guiding the focus groups and interview sessions

1) Do Black people access support in GM after an experience during the perinatal period? If so why not?

2) Can you identify any barriers to perinatal and infant mental health support and what the system (including the role of primary care) needs to do to break down any of those barriers?

3) Is there a role for the VCSE (including faith) sector to work alongside mental health support services during the perinatal and perinatal infant mental health period?

4) What does a good mental health service look like for Black mothers and Infants during the perinatal period?

5) How racially, culturally and religiously responsive are perinatal and perinatal infant mental health services in GM?

HOME START
HOST

Black Women - Perinatal and Infant Mental Health Care Services in Greater Manchester

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