

Brief Insight Report: Focus group session on the views of an ethnically diverse groups of mothers with experience of pregnancy and preterm birth, in relation to inequalities in maternity research and outcomes.

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Background

The National Institute for Health Research (NIHR) currently funds 20 Biomedical Research Centres (BRC) across England. These are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics, and medical technologies. The Imperial BRC is a collaboration between Imperial College London and Imperial College Healthcare NHS Trust. It has twelve research themes, of which Pregnancy and Prematurity is one.

To assist with a project being undertaken by this theme, the PPIE lead for the BRC's Pregnancy and Prematurity theme facilitated an online discussion session to gain the perspectives of women with experience of term and preterm birth on inequalities in maternal and birth outcomes.

Public Involvement is defined by the NIHR as "research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'**, or **'for'** them.

'Public' includes patients, potential patients, carers and people who use health and social care services as well as people from specific communities and from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they are current patients or not.

Approach and purpose

Public involvement is considered a crucial component of the development of this research.

The aim of the session was to understand the views on inequalities in maternal and birth outcomes for mothers from minority ethnic backgrounds and to explore barriers and facilitators to participating in preterm birth prevention studies like the VMET2 study. The focus group session was hosted to complement a research project undertaken by a Bsc student, Neeraja Suresh, in reproductive and developmental health supervised by Dr Lynne Sykes, Dr Annemarie Lodder and Dr Sihao Zhao.

As part of this session, we particularly wanted to understand the following from individuals from minority ethnic backgrounds with lived experience of birth and preterm birth:

- a) The reasons they attribute to the higher risk of premature delivery for women from minority backgrounds.
- b) What barriers/challenges there are for participating in preterm birth prevention studies.
- c) How we could overcome some of these barriers.

Call overview and agenda

An in person focus group discussion was hosted on the 6th of March 2024 from 12:00 to 13.30 at the Somali Youth Development Resource Centre (SYDRC) in London and was attended by nine women (of which 8 mothers) including one interpreter.

The agenda of this session was as follows:

- Welcome and Introductions: An introduction was provided to the background of the project and attendees were given the opportunity to ask questions (see Appendix 2)
- Facilitate group discussion about the following key questions. The full topic guide can be found in Appendix 3. All attendees joined the same conversation hosted by a public involvement facilitator (Annemarie Lodder) and the researcher, Neeraja Suresh. Deeqa Diriye, an employee from SYDRC joined to provide translation when necessary.

- a) Why do you think women of minority ethnic backgrounds are a greater risk of premature delivery?
- b) Why do think women from minority ethnic backgrounds are less likely to take part in research?
- c) What do you think we can do to make our research more inclusive?

Payment

Participants were given a £25 Amazon voucher for their time.



Attendee recruitment

The focus group was organised in collaboration with Abdiwahab Ali and Deeqa Diriya who work at SYDRC. Every Wednesday morning they offer activities for local women such as yoga, coffee mornings, guest speakers, and English lessons. Abdi and Deeqa explained to the women in the week prior to the focus group we would come and join a morning session to talk about pregnancy and ethnicity.

Key Insights Summary

Attendees of the discussion session on 6th of March 2024 provided responses to the following questions posed and their insights have been themed under the questions below.

Why do you think women of minority ethnic backgrounds are at greater risk of premature delivery?

Stress during pregnancy

- General challenges for this community: less job opportunities, financial challenges, lack of opportunities to gain skills and importantly a lack of support -> all contribute to stress that becomes enhanced during pregnancy
- Stress of adapting to living in a foreign country without support (see below)
- Many women became pregnant very soon after moving to the UK -> did not have sufficient time to become accustomed to living in the UK and so left feeling unsupported and very stressed during pregnancy.
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- o One woman described living in a flat where the lift did not work so she had to carry heavy groceries up and down stairs during pregnancy -> felt that this impacted her physical wellbeing and stress levels during pregnancy

No control over their own healthcare decisions

- Due to **language barriers** feeling that they are not able to advocate for themselves -> feel like they have no control over their own healthcare decisions
- Not a clear enough explanation from HCPs

delay in seeking health care:

- No available interpreter: Even after requesting interpreter, are not given one -> this is because HCPs believe as the woman speaks English to an extent, does not need an interpreter even though she herself believes she needs one. Results in women feeling dismissed again.
- Limited consultation time; Not enough time to communicate across effectively to a mother whose first language is not English
- Not sufficiently signposted to support services during the limited consultation time
- Prefer second opinion from someone known within their own community
- Language barrier is a reason for preferring a doctor they know within their own community or a relative/friend
- Feel more comfortable and easier to communicate with a Somali doctor
- Results in them not seeing a GP or HCP sooner as they rely on their known contacts more
- Technology barrier -> online booking for GP appointments and self-referral for support services is challenging resulting in a delay in seeking help for a problem

Lack of support

- Lack support from family/friends/relatives when moving to the UK as they often move without the rest of their close family and lose this support network
- Most of the women believed they lacked support from their partner during pregnancy -> for example, one woman felt she had to do most of the housework during pregnancy, impacting physical and emotional wellbeing of the mothers
- Unaware how to access external support e.g. from healthcare services or community services

Cultural factors

- stigma around mental health within the Somali community results in opening up about stresses being more difficult which can result in lack of support
- Different language and cultural practices can be difficult to adapt to
- Somalian cultural practices of staying at their mother's home for 40 days and supported over this period with relatives visiting and food provided for the mother which they did not get to do in the UK

Food and nutrition during pregnancy

- In Somalia would have lots of support during pregnancy focusing on nutrition which they did not get in the UK
- Cultural practices which include 'feasts' and types of foods that are encouraged during pregnancy with guidance from community -> many women felt that they did not have this in the UK and this may have impacted their risk of prematurity or other obstetric complications
- Not knowing what they should eat during pregnancy. Information given does not include food they are used to cook.

Racism / discrimination experienced by HCPs

- Discriminated by their appearance (for example, wearing a hijab) and they feel this impacts the way HCPs communicate with them and may stereotype them
- Feel **dismissed** by HCPs
- Increases scepticism and mistrust in staff and even research -> makes them prefer a second opinion
- Unaware of how to complain about mistreatment so left with no closure for their negative experiences

What barriers/challenges do you think women of minority ethnic backgrounds experience to participating in research? (most reasons above apply to this question too)

- Not understanding the purpose of the research
- “How will this benefit me or my community?”
- Language barrier – if not able to understand written English on a leaflet, are more likely to dismiss it
- End result of the research: Many have completed several questionnaires / surveys in the past but do not see the changes this research results in which makes them less willing to participate
- What will happen with my data? Concerns and mistrust about the use of their data.
- Vaginal swab collection: Hesitant to give samples if it is not necessary as part of their care
- Some women shared they have experienced circumcision or female genital mutilation (FGM) so feel uncomfortable with vaginal swabs

Solutions/ideas:

How can we recruit more Somali mothers into the VMET2 study?

- Talking to the mothers face-to-face and building rapport would encourage participation most compared to giving leaflets
- A Somali recruiter would encourage participation within their community as they would feel more comfortable and this reduces language barrier
- Respect and acknowledge the faith and religious/cultural beliefs of the mother when discussing research
- Approaching local communities and educating mothers on premature births and the associated health consequences and why research is important
- They are aware there is support available but lack awareness on how to access these and use these -> particularly psychological support
- If healthcare services linked more with communities this would increase use of these available services and raise awareness for these communities

Further experiences of the mothers:

- One woman mentioned she was told she needed an iatrogenic preterm delivery but this was not clearly explained to her why
- May agree to healthcare decisions recommended by doctors even if the patient themselves don't understand it
- Some mothers were mistreated by staff and would have wanted to complain but were not aware of how to do this at the time -> feel unable to advocate for themselves -> creates a feeling of mistrust or apprehension when using healthcare services.

How we will use the insights

The insights gained from this public involvement session have highlighted the following:

- The importance of the personal relationships/ rapport in recruitment of women
- The importance of explaining what the research is for and how it can benefit the community.
- The need for feedback about the research
- The need to educate/ share the learning with health care professionals/ researchers wishing to recruit more representative participants for their research.

Appendix 1: Demographic of public attendees

Table 1: Demographic characteristics provided during event registration for discussion group (N=9)

Characteristics	n (%)
Age groups (in years)	
18-24	2
25-34	3
35-44	2
45-54	2
55-64	0
65 – 74	0
75+	0
Prefer not to say	0
Gender	
Female	9(100%)
Male	0
Prefer not to say	0
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	0
Irish	0
Gypsy or Irish Traveller	0
Other White background	0
Mixed/Multiple Ethnicity	
White and Black African	0
White and Black Caribbean	0
White and Asian	0
Other Mixed/Multiple background	0
Asian/Asian British	
Indian	0
Pakistani	0
Bangladeshi	
Chinese	0

Other Asian background	0
Black/African/Caribbean/Black British	
African	9
Caribbean	0
Other Black/African/Caribbean background	0
Other	
Arab	0
Any other ethnic group	0
Prefer not to say	0

Appendix 2: Questions/comments asked by attendees during the session.

Questions answered during focus group:

- What is this for?
- What will you do with our feedback?
- Why are we doing this research? What is the importance of it and the purpose of this research?
- How will taking part in this research benefit me and my community? Is my contribution to this research likely to result in a real impact to current standard of care?

Appendix 3: Focus group guide

Welcome & Introductions

Confidentiality

Icebreaker: say one thing you liked/ disliked about your pregnancy (remind everyone to have 2 min)

Questions

- 1. Are you aware that there are differences in outcomes for mothers and babies from minority ethnic backgrounds?**
 - Where did you learn about this?
 - How did you notice?
- 2. Do you have any personal experience or stories that you have come across related to pregnancy within minority ethnic communities?**
- 3. What do you think the reasons are for these inequalities?**
 - How do you believe societal and cultural factors may influence the prenatal health of women from minority ethnic communities?
 - In your opinion, how does access to healthcare contribute to the likelihood of premature births among women from minority ethnic backgrounds?

- Are there specific barriers or challenges that women from these communities might face in accessing prenatal care?
- What about the role of socioeconomic factors (income) for women from different backgrounds?

Taking part in research

- 1. Why do think women from minority ethnic backgrounds are less likely to take part in maternity research?**
- 2. Have you ever been asked to take part in research? What made you say yes/ no?**
 - Language barriers?
 - Transport/ access?
 - Trust?
 - Understanding importance of research?
- 3. What do you think we can do to make our research more inclusive?**
- 4. How would you like to hear about research? Posters? Flyers? Social media? Community Centre?**