



Ensuring under-served groups are represented in maternal health research



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'To provide safe and effective care through research to pregnant women and their babies, it is critical that we engage, partner with, and listen to mothers from varied backgrounds.'

Participants

Chair: Professor Shakila Thangaratnam, Professor of Maternal and Perinatal Health, NIHR Senior Investigator, Lead for Maternal and Reproductive Health, Co-Director of WHO Collaborating Centre for Global Women's Health, Institute of Metabolism and Systems Research, University of Birmingham

Co-Chair: Dr Lucy Oakey, Research Manager for Maternal Health Research, Institute of Metabolism and Systems Research, University of Birmingham

Dawn Carr, Associate Researcher, Health Exercise and Activity Therapy (HEAT) and Patient and Public Involvement Representative, The Hildas

Professor Wiebke Arlt, William Withering Chair of Medicine, Director of the Institute of Metabolism and Systems Research, University of Birmingham

Yesmin Shahid, Patient and Public Involvement Representative, Katie's Team

Hannah Ackom-Mensah, Underserved Populations Community Development Worker, Black Country Healthcare NHS Foundation Trust

Ms Inderjeet Kaur, Director of Midwifery Services, Fernandez Hospitals

Mrs Amy Maclean, West Birmingham Development Lead, Maternity and Children Ladywood & Perry Barr Integrated Care Partnership

Sylvia Owusu-Nepaul, Lead midwife for Equity, Birmingham & Solihull United Maternity & Newborn Partnership, Hosted by Birmingham Women's & Children's

Professor Phil Newsome, Deputy Director of the NIHR Birmingham Biomedical Research Centre, Director of Research and Knowledge Transfer, College of Medical and Dental Sciences, University of Birmingham

On 23 March 2022, the National Institute for Health and Care Research (NIHR) Birmingham Biomedical Research Centre (BRC) convened a roundtable on how to ensure under-served groups are represented in maternal health research, with a focus on women from ethnic minority backgrounds. The roundtable brought together leaders within the BRC with researchers, community development workers, midwifery leaders, equity experts all with a shared interest in improving women's health in Birmingham. The session was chaired by Shakila Thangaratnam in her role as Professor of Maternal and Perinatal Health at the University of Birmingham.

Disparities in maternal health outcomes

Inequalities in maternal health outcomes for women from minority ethnic groups are both glaring and concerning. A recent report highlighted that out of every 100,000 women giving birth, 34 Black women, 15 Asian women and 8 white women died. There are other disparities too including higher rates of stillbirth and neonatal death. Outcomes such as diabetes and hypertension are also more common in non-white mothers, however despite these disparities, research in this area is lacking.

Pregnant women are often excluded from research and of the studies conducted in pregnant women, few women from

minority ethnic groups are involved. The disparities mentioned above prove this needs to change. A conversation around the barriers to research participation for women from ethnic minority backgrounds highlighted a key area that needs to be developed, 'trust'.

A legacy of suspicion and mistrust

One member of the roundtable brought to everyone's attention James Marion Sims who is known as the 'Father of Gynaecology' and is credited with the invention of the Speculum, a commonly used piece of apparatus in Women's Health care. Sims developed this piece of equipment by subjecting Black women to repeated examinations and experiments all in aid of gynaecological research, with the justification that Black women feel no pain.

This was a poignant addition to the conversation and explained why a number of areas of 'Women's Health Research' may be feared or avoided by women from ethnic minority groups. The legacy of mistrust in the medical profession from these groups feeds into the research studies and the concept of experimentation is rejected.

Poor experiences during pregnancy, childbirth and beyond highlight that these issues are still apparent. One member of the roundtable volunteered a story of when she was in hospital;

“When I was in hospital with my third child, I was in a lot of pain. The nurse wouldn’t help me and told me I should know better as this was my third baby. She helped a white lady instead.” The inference being, and seconded during the discussion, that there is systemic bias within the health care services which is leaving women from ethnic minority backgrounds feeling underserved and not listened to.

Women, their families and the wider community

It was widely acknowledged that more needs to be done to engage with women from ethnic minorities in order for them to feel comfortable being involved in

research studies. Access to services that are fair and equal is vital to reach these underserved groups. “We need to support women from minority ethnic groups in taking responsibility for their health throughout pregnancy and beyond. Despite all the challenges, they should have access to the right knowledge.” There were discussions around barriers to understanding maternal care and research opportunities such as lack of digital literacy or not speaking English.

Another focus was that of the family. Often in different cultures, women’s families play a large role in decisions and engagement with maternal care and the concept of research needs to be accepted by the wider family. “Families can be pivotal in decision making. In some communities, women are unlikely to make decisions without involving wider

family members, such as their mother-in-law.” Of course, the role of family and community can vary hugely from one minority ethnic group to another. “Women from different groups are often thrown in together. But some issues are only relevant to certain groups such as the mother-in-law decision-making example.” Therefore, it was stipulated that valuing women for the individuals they are is at the heart of creating an inclusive and equal approach to maternal health research.

Each individual mum experiences her own challenges and stress – from racism through to being more likely to be living below the poverty line. “A mum’s background may mean she doesn’t have the advantages other mums have. We need to be aware of individual circumstances when approaching women about research.”



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Looking to the future



A key theme from the event was understanding that now is the time to develop different ways to empower and inspire women from ethnic minority backgrounds to be involved in research relevant to them. Answering points from the sections above has allowed a plan of action to be formulated that should work towards realising the aim of increasing participation of women from ethnic minority backgrounds in maternal health research.

Training of maternal healthcare staff

It was mentioned during discussions that “Inequality needs to be addressed at a clinical level before we can engage women from ethnic minority backgrounds in research.” This highlights the need for training of maternal healthcare staff on how best to communicate with women from different backgrounds to ensure that all women have a positive, lasting impression of maternal healthcare services.

Infographics and translated pieces

The barrier of exclusion through lack of digital literacy and not speaking English can also be addressed through training of staff too, to enable all women to feel included and encourage participation from hard to reach groups. This could be addressed through infographics, with little text, or documents translated into additional languages to increase awareness.

Community events for the whole family

Where each member of the family can interact and ask questions of the researchers, as opposed to a leaflet being taken home from hospital with no additional follow-up/support. “It’s about going where the women are – mums’ groups, church groups.” Holding events in the community and putting a face to the name/institution will again increase engagement and open communication between researchers and the women they are trying to help.

Training of research staff

This training also feeds into researchers. Appreciating cultural differences will enable researchers to be more approachable to women from ethnic minorities and could work towards breaking down the barrier of mistrust.

Engaging with young people from ethnic minority groups

Lastly, engaging with young people from minority ethnic groups will help us take positive steps to overcome barriers and build trust. Education early on and encouraging dialogue with young people will hopefully feed into families and ensure future generations have more confidence and trust in healthcare services.

“It’s about good care and sorting out the basics. Valuing women, identifying who’s at risk from health conditions, having empathy – these are the things that will make the difference.”



Endnotes

1. MBRRACE-UK Saving Lives Improving Mothers’ Care Report 2021 available at <https://www.npeu.ox.ac.uk/mbrance-uk/reports>
2. Captured in 2011 Census. Data is available at <https://www.ons.gov.uk/>