<u>**CoRIPS RESEARCH AWARDS OCTOBER 2020**</u>

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CoRIPS Research Grant 197 (Covid)
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Title of Project
Why are Black, Asian and minority ethnic women under-represented in pregnancy imaging studies? A multi-method study to explore attitudes, experiences and research priorities

Lay summary of the project
Recent reports looking at pregnancy, have revealed that in the United Kingdom the rate of women and babies dying during pregnancy are much higher in those from Black and Asian backgrounds when compared with White women. The COVID-19 pandemic has further highlighted health inequalities for people who are from racial minorities, and the UK government has pledged to tackle the issues that affect marginalised pregnant women. The reasons women from minority backgrounds have poor health/pregnancy outcomes are complex and research into the causes within the UK is limited. Ultrasound and MRI imaging (MRI being another way of safely imaging babies in the womb using magnets) are commonly used during pregnancy to diagnose health conditions with the baby and mum.

Unfortunately, many pregnancy-related studies do not have enough women from ethnically diverse backgrounds in them, which increases the risk of inaccurate results. This may mean that the results are not as valid for some women. The lack of diversity could be related to how women are recruited, the women's understanding of the research, or its accessibility. Whatever the reason, this has resulted in women from racial minority backgrounds being under-researched

For this project, we will use our women's health networks and virtual social media platforms to reach out to and speak to women from a wide range of community groups that represent Black, Asian and other minority ethnic (BAME) pregnant women. We will use a combination of surveys, one on one interviews and small focus groups to exchange ideas. The aim is to understand women's perspectives of the facilitators and barriers to participating in pregnancy-related research that involves US or MRI scans with voices from a broad range of racial, cultural, social and economic backgrounds. With these women, we will then create a top 10 list of the most important areas they want researching

Primary research question
What prevents women from Black, Asian and minority ethnic background from participating in pregnancy research that involves imaging, and what are their related imaging research priorities?

Secondary research questions
What are the perceptions of pregnancy research of BAME women who are also multiply disadvantaged (e.g. low socioeconomic status, immigrants, asylum seekers and refugees, young mothers)?

What are the most important research priorities for BAME (and multiple disadvantaged women and partners) for antenatal imaging research topics?

Outcomes

1. Development of a framework by which to understand the social, cultural and economic experiences of BAME women accessing antenatal imaging research
2. Generation of top 10 research priorities for BAME women in antenatal imaging research

Review of the literature and identification of current gaps in knowledge

People self-identifying as from Black, Asian and minority or mixed ethnicity backgrounds (BAME) have historically been underrepresented in clinical research[1–3]. Although scientific knowledge and medical care has advanced in recent years, ethnic minorities have benefitted less from these advances than Caucasians[4,5].

This lack of diversity is a moral scientific and medical issue that is woven into societal biases and its importance is now becoming increasingly recognised and highlighted stark health inequalities during the COVID-19 pandemic.[6–8] The study population (and in case control studies, the control or comparison group) must reflect the groups affected by the condition being investigated in order to derive meaningful results[9]. In clinical trials, it has been well described that differences may exist in how different ethnicities respond to medications[10,11]. If this is not considered when designing research studies, differences may not be identified. For example, 75% of Pacific Islanders are unable to convert clopidogrel (an antiplatelet drug) into its active form and are at higher risk of adverse outcomes following angioplasty[12]. If the study population had not included diverse participants, this may not have been identified. This is relevant to clinical imaging due to rapidly developing use of imaging in a range of efficacy drug trials but also in the development of artificial intelligence technology. Obermeyer et al.[13] showed that a popular commercial algorithm, used to stratify patients in to low and high risk categories of cardiovascular disease, was less likely to refer Black patients for further assessment, despite being as ill as the White patients. This inbuilt flaw was largely caused by researchers unable to recognise the bias of the training data, data in which the study population was skewed towards White participants. In this case, Black patients were less likely to receive the treatment needed to address complex health needs and this resulted in a higher risk of worse healthcare outcomes.[14]

Clark et al assessed barriers to participation in research from BAME patient groups through a literature review and using input from stakeholders.[15] Key themes describing five barriers to research participation were identified: 1) mistrust/lack of understanding of the value of research, fear/ stigma of participating and the communication style of investigators/staff 2) lack of comfort with the clinical trial process/mistrust of the process fear of family members' opinions and information 3) lack of information about clinical trials 4) time and resource constraints: time, transportation and compensation 5) lack of clinical trial awareness: understanding the value and information about the existence and importance of trials. Dawson et al's review of PPI in health and social care studies also highlighted the lack of BAME involvement, which is crucial to the design and execution of research studies.[16]

Possible solutions were: involvement of these groups in the actual design of the study, and engaging and partnering with community leaders and community based organisations to effectively disseminate information and emphasise the importance of research participation[15,17] as lack of education may also contribute[18]. Ensuring appropriate remuneration for patient's time is also essential and may mitigate some of the participant's concerns. Adaption of study follow-up to utilise technology instead of face-to-face approaches, including flexible hours and utilising social media may also help overcoming the

practical issues regarding participation (e.g. ill-health, geographical barriers, travel costs, childcare). Improving research awareness within the BAME community is also critical[15]. All stakeholders need to be able to communicate research effectively,[19] with appropriate communications/dissemination training provided for researchers.[20] Language barriers may also pose an issue,[17] and this should be considered when designing research studies to ensure that information is accessible to all.

However, despite guidance on inclusive research recruiting, health disparities continue to grow and much of the research on this topic is from a US perspective and in only certain groups. Yet in the UK, women from a Afro-Caribbean backgrounds are 5 times more at risk of maternal death and 2 times more likely to experience perinatal death, this in addition to be under represented in pregnancy research that should be addressing their needs and investigating the complex causes of these disparities[21–24]. Imaging (Ultrasound and MRI) is an integral part of maternity screening, diagnosis and care, and it is important that, as a caring profession, sonographic/radiographic services understands cultural and social and economic experiences of vulnerable groups, with research that are shaped by publicly guided priorities.

Methodology to be adopted (including methods)

A participatory worldview is interactive, collaborative and holistic. It favours rich qualitative data. Although often regarded as a research method, participatory research is also considered an epistemological stance that is rooted in the notions of democracy, social equity and justice and draws on critical theory (feminist, critical race, queer, disability, neo-Marxist, indigenous, and/or post-structural)[25]. Participatory research can also be considered the inevitable instrument of choice when taking a realist-constructivist stance which values knowledge generation produced from a lived experience as equal to that produced by academic researchers.[26]

  This inclusive method therefore results in communities and researchers sharing expert knowledge and experiential knowledge and co-learning with reciprocal knowledge transfer and shared decision making[27]. This will result in a co-created understanding of why BAME women's participation in pregnancy research is so often limited and shared conclusions relating to the top 10 research priorities in the area of obstetric imaging. With this in mind a community based participatory research methodology will be adopted to incorporate the voice of the communities of interest at all stages of the research cycle.

Method

Study Design
Peer Participatory Research Design, which draws on community partnerships and with content and thematic analysis approaches to explore lived experience.

Outline of Procedure
Our women health community advisory group (CAG) will be recruited via university's established Women's Health PPI groups and partner charity Best Beginnings networks who work with studies that address topics of inequality in maternity services. It will include service users (women of all ethnicities including expert and lay PPI members), partner organisations (charities, religious and community groups representing women).The CAG and the academic research team will form the research steering group (RSG) of the project, which includes a member of the SCoR ultrasound advisory group and the SCoR research group. The study begins with a preliminary survey and has two parallel arms: a qualitative exploration of experience and perceptions and a priority setting partnership qualitative study (as outlined by the NIHR James Lind Alliance priority setting partnership, JLA PSP,

process).[28] Both arms will be conducted in 4 distinct phases with each phase informing the next, see flowchart of procedure below:

Ethical considerations

There will be no intervention and no recruitment of patients from NHS trusts. This study will be suitable for university level ethics, for which we have applied. We have aimed to reduce the power dynamic by having trained peer interviewers/facilitators and to have inclusive CAG meeting where we can build authentic relationships. We recognise the burden of time and input for the participants and PPI group, so we have provided incentives and rewards in line with NIHR guidance of costs. The is an increased chance that the under-represented groups we seek to hear from may not have English as a second language, there for we have considered translators and translation of written material where possible. There is a small risk that some of the discussion will trigger feelings of upset, trauma or loss. Sensitive interviewing training will be provided for the interviewer/facilitator and every participant in the interviews and focus groups will be provided with a comprehensive list of support services that are accessible nationwide, should any further support be necessary during the study. Documentation and procedures will be produced with the support from the NIHR South London ARC Maternity and Perinatal Mental Health Research Team.

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