

## PROMISE

Principles of Engagement: Developing Methods to Increase  
Representation of Black Mothers in Maternal and Neonatal Healthcare Research

### Focus Group Participant Information Sheet Version 1.0: 04 Sept 2024

#### About the PROMISE study

The PROMISE study aims to develop guidance for research delivery teams to use when talking to Black mothers about opportunities to take part in maternity and neonatal healthcare research.

This is important because Black mothers, and their newborns, face worse health outcomes than their white counterparts. Black mothers are also less likely to take part in research. As such it is important that we engage Black mothers in relevant research so that we can develop healthcare treatments that best suit their individual needs.

To develop these guidelines our study team are working on three key tasks:

- 1) We are searching for and reviewing the relevant literature in this area, to read and pick out the important things to consider when talking to Black women about maternity and neonatal healthcare research.
- 2) We then want to talk about what we have found from this review process with (a) research delivery teams and (b) Black women and their birthing partners. This will help us to understand if our literature review has covered the main issues that we need to think about, or if we need to consider other important things.
- 3) Once we have a list of important things to consider we will get a panel of experts together to go over this list and agree on what the final guidelines should like.

#### How you can help

You are invited to take part in an online focus group. A focus group is where a small group of people, with similar interests, join to share their thoughts and experiences.

Our study team have already completed task 1 (the literature review). We now want to talk to research delivery teams and Black women and their birthing partners about what we have found. In particular, we want to show you what we have found and ask you if you think anything is missing, or if you don't agree with the findings from your experience. We also want to know if you think the findings are relevant in all situations/circumstances or only apply to some people, on some occasions.

The focus group will take online place using Microsoft Teams or Zoom, if you have any concerns about how to use Teams, we are happy to help you. If you prefer to speak to us on the telephone, we can arrange to do that.

## Who can take part?

### Inclusion

#### Research Delivery Teams:

- Currently, or have (in the past 3 years) actively worked in maternity and neonatal healthcare research *AND*
- Currently, or have been (in the past 3 years) in a clinical research delivery role *AND*
- Able to provide informed consent

#### Representatives for Black Women:

- Aged 18years or older
- Able to provide informed consent *AND*
- Identify as being a Black woman (including dual heritage) who has been pregnant during or after 2010 *OR*
- Identify as being a father/birthing partner of a Black woman of childbearing age *OR*
- Leader, or support worker/volunteer of a Black community group (including faith groups)

### Exclusion

#### Research Delivery Teams:

- Students who are not fully qualified
- Members of the research delivery team who are not working in a nursing or midwifery role

#### Representatives for Black Women:

- Lack of capacity to provide informed consent and understand the participant information sheet

## Do I have to take part?

No. It is up to you to decide if you want to take part in this research. If you agree to participate, we will send you the link to take part. However, you would still be free to withdraw from the study at any time, without giving a reason and without any negative consequences, by letting the researcher, Dr Georgia Clancy ([georgia.clancy@nottingham.ac.uk](mailto:georgia.clancy@nottingham.ac.uk)) know.

## What would happen if I chose to take part?

If you are happy to take part after reading this information sheet, please contact the study researcher if you have any questions and to let them know you would be interested in taking part: Dr Georgia Clancy: [georgia.clancy@nottingham.ac.uk](mailto:georgia.clancy@nottingham.ac.uk).

You will be taking part in an online focus group. The researcher will arrange the time with you and other members of the group to find a time and date that suits the most people. We will send you details on how to log into the online group.

The focus groups will be conducted using Microsoft Teams. We shall record the discussions. These recordings will be transcribed automatically by Teams into written text. Any reference to names, or other identifying information will be removed from the text. The audio/visual recordings will be permanently destroyed after this process. As such, all information shared will remain anonymous outside of the focus group members and the study team. You will not be asked to share any information that is discussed.

We expect the focus group to take 60-90 minutes. We will not exceed 90 minutes, but we will finish early if all the topics have been discussed. We expect to have no more than 10 participants in one focus group. You will only be asked to take part in one focus group.

You can say as much or as little as you wish to. Prior to the focus group we may give you some information to help facilitate the discussions. We do not expect this to take longer than 20 minutes to read.

Please [contact us](#) and let us know if you would like to take part and when would best suit you.

### **What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?**

There are no anticipated disadvantages of taking part in this study as the meeting focuses solely on your own experiences and perceptions of what may help others. All members of the focus group are required maintain confidentiality of the discussions.

### **What are the possible benefits of taking part in this study?**

There may be no direct benefit to you from taking part in this research, but your contribution will help understand more about how we can best talk to Black women about maternity and neonatal healthcare research opportunities. We hope that this will eventually improve the healthcare solutions that are offered to Black women during pregnancy.

### **Expenses and payments**

There will be no costs associated with taking part in the study. We will provide an [online shopping voucher \(£30\)](#) as a thank you for taking part.

### **Will my taking part be kept confidential?**

We will not report your name or anything that would make you identifiable in any outputs from the study. Your data will be stored safely in a password-protected folder at the University of Nottingham and will only be accessible by the research team. Contact details will not be stored in the same file as your survey responses. The University of Nottingham and its data storage procedures are fully compliant with General Data Protection Regulation.

## **What are my choices about how my information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

## **What will happen when the study ends?**

The anonymised data will be stored securely at the University of Nottingham and then destroyed after 7 years.

## **What will happen to the results of the study?**

The results of the study will be published in a final report. A peer-reviewed article may also be prepared for publication in an academic journal. You will be sent a summary of the study findings unless you request for us not to do so (please email us if you do not wish to be contacted about this).

## **What will happen if I don't want to carry on being part of the study?**

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you do agree to participate, you may withdraw from the study at any time. There will not be any consequence of this. You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw. If you withdraw from the study, we will need to keep and use the data collected up to your withdrawal.

## **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the University of Nottingham's Faculty of Medicine and Health Science Committee. Reference number: FMHS 284-0924.

## **Who is organising and funding the study?**

The National Institute for Health and Care Research (NIHR) are funding this study, which will be carried out by the Nottingham Clinical Trial Unit at the University of Nottingham and the Oxford Institute for Applied Health Research (OxInAHR), at Oxford Brookes University..

## **Who should I contact if I wish to make a complaint?**

If you have a concern about any aspect of this project, please speak to the researcher, Dr Georgia Clancy ([georgia.clancy@nottingham.ac.uk](mailto:georgia.clancy@nottingham.ac.uk)) or the study leads Dr Sophie Hall ([sophie.hall@nottingham.ac.uk](mailto:sophie.hall@nottingham.ac.uk)) and Professor Catherine Henshall ([chenshall@brookes.ac.uk](mailto:chenshall@brookes.ac.uk)), who will do their best to answer your query. The research team should acknowledge your concern and give you an indication of how they intend to deal with it.

If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals,

Nottingham, NG7 2UH or via E-mail: [FMHS-ResearchEthics@nottingham.ac.uk](mailto:FMHS-ResearchEthics@nottingham.ac.uk). Please quote ref no: FMHS 284-0924

### **What if I want more information about the study?**

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact Dr Georgia Clancy: [georgia.clancy@nottingham.ac.uk](mailto:georgia.clancy@nottingham.ac.uk) or the study team: [ms-promise-study@nottingham.ac.uk](mailto:ms-promise-study@nottingham.ac.uk).

**Thank you for taking the time to read this Participant Information Sheet.**