

# **Reducing Maternal Mortality and Morbidity for People with Chronic Conditions**

## **Community Research Feedback Session FAQ**

### **ABOUT US**

We are a team comprised of researchers, physicians and community partners who want to see improved reproductive wellness and outcomes for Black and Native American women with chronic conditions. We are supported through an engagement award from the Patient Centered Outcomes Research Institute (EACB 26852).

We are working with The Community & Stakeholder Engagement (CaSE) program at NC TraCS which is a group that works with researchers to improve health by promoting the inclusion, engagement and recruitment of diverse communities and patients.

### **WHAT IS A COMMUNITY FEEDBACK SESSION (CFS)?**

A CFS is a 1.5 hour facilitated, virtual discussion during which researchers can obtain input on their work from patients/community members. For this project, participants will be people who identify as women who are Black and/or Native American and have one or more chronic conditions. They have a particular interest in advising on research related to reproductive health and outcomes. We estimate there will be 10 participants with lived experience in the session.

### **HOW CAN IT HELP MY RESEARCH?**

The insight and perspectives from people with lived experience can inform research questions, approaches, and patient centered measures and outcomes, leading to studies that are more relevant and less burdensome to potential participants.

Patients/community partners can help identify potential barriers and opportunities for recruitment and retention. They can provide input on the cultural and linguistic acceptability of recruitment materials and data collection tools.

We have held three sessions to date and researchers have received input on patient educational materials / website, perspectives on data in EHR notes, and how to engage and build community trust for sensitive topics including genetic screening.

We have found that this is particularly impactful for scientists who are in the process of designing studies / applying for a grant. The insights have already influenced study design and approach. Additionally, researchers can mention the session in their applications demonstrating early community engagement! We have worked with researchers at all stages of their career.

### **HOW IS A CFS DIFFERENT FROM A RESEARCH FOCUS GROUP?**

- A CFS is not considered research. It is not intended to collect data or produce generalizable evidence. People provide input on a researcher's study. They are not asked to dive deep into their personal experience related to the research.
- A research focus group is designed to collect data. Research focus groups must be approved by an Institutional Review Board. Focus group participants typically are required to complete an informed consent process.

### **WHAT HAPPENS DURING A CFS?**

- We will facilitate a welcome, introductions, and group discussion guidelines.
- Then the researcher gives a very short overview of their work and what they hope to learn about during the session (5 minutes). There will be time for Q&A.
- Next, we will post about 4 big questions posed to the group with multiple prompts.
- Discussion guided by a facilitator that elicits authentic and constructive feedback.

### **WHAT CAN YOU EXPECT FROM THE PROJECT TEAM?**

- A pre-event 1-hour meeting with our project team to prepare for the session.
- Advice on community-friendly materials (including slides) for your session.
- Co-development of the facilitator guide.
- A facilitator and note-takers for your session.
- A feedback report

### **WHAT IS EXPECTED OF YOUR PROJECT TEAM?**

- You and your team (if applicable) will meet with the project team for 1-hour to prepare for the event. This largely focuses on identifying questions
- Prepare community-friendly materials for your session, including a short 5-minute recording to be shared with participants in advance of the event.
- Be on camera (and your team if applicable) for the entire session.
- Complete the follow up evaluation survey.

### **HOW MUCH WILL IT COST?**

PCORI funding will support compensation for patient/community participants as well as for the UNC team's time. There is no cost to you.

### **QUESTIONS?**

Please contact Dr. Sarah Verbiest ([sarah\\_verbiest@med.unc.edu](mailto:sarah_verbiest@med.unc.edu) or 919.638.5183) or Dr. Narges Farahi ([narges\\_farahi@med.unc.edu](mailto:narges_farahi@med.unc.edu)).