

Research Priorities of Women at Risk for Preterm Birth: Findings and a Call to Action

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For which topic were research priorities identified?

preterm birth

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Traditional hierarchical approaches to research give privilege to small groups with decision-making power, without direct input from those with lived experience of illness who bear the burden of disease. A Research Justice framework values the expertise of patients and communities as well as their power in creating knowledge and in decisions about what research is conducted. Preterm birth has persisted at epidemic levels in the United States for decades and disproportionately affects women of color, especially Black women. Women of color have not been included in setting the agenda regarding preterm birth research.

What was the objective?

to elicit and prioritize potential research questions and topics directly from women of color living in three communities that experience disproportionately high rates of preterm birth

What was the outcome?

a list of 4 research topics

How long did the research prioritization take?

April 2015 - June 2015

Which methods were used to identify research priorities?

focus group

How were the priorities for research identified exactly?

Step 1: 7 focus groups: each group held 2 sessions, participants described their health care experiences and generated potentially researchable questions based on uncertainties or unanswered questions about their health and/or healthcare during current or recent pregnancies, questions were noted on flipcharts and thematically organized under research topics, women reviewed cumulative list of the unanswered questions they generated, multiple rounds of individual and group voting and discussion to achieve consensus, a total of 375 researchable questions were generated representing 22 distinct research topic areas, second session closed with women sharing their views about participation in this process and their reflections on what having answers to their priority questions might mean to the future healthcare and health outcomes of their communities

Which stakeholders took part?

Pregnant or parenting women. 54 participants.

How were stakeholders recruited?

Seven community-based organizations (CBOs) partner agencies serving pregnant of color at high medical and/ or social risk for preterm birth in Fresno, Oakland, and San Francisco were invited to participate as partners in the research.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.