

## “Women Want Answers”

### Research priorities of women of color at risk for preterm birth

Community Report - San Francisco, Oakland, Fresno

#### Background

Almost 1 in 10 infants in the United States (US) are born too early (before 37 completed weeks of pregnancy).<sup>1</sup> The US preterm birth rate is much higher than in other high income countries and rates are higher for women of color compared to rates for white women. In California, African-American women suffer the highest rate of preterm birth, while Hispanic women suffer the greatest number of preterm births. The causes, prevention and treatment of preterm birth remain poorly understood. From April 2015 – July 2017, UCSF researchers with the California Preterm Birth Initiative (PTBi-CA) conducted 14 focus groups with 54 women who identify as African American or Latina from San Francisco, Oakland, and Fresno. These women shared their pregnancy and birth experiences. Together they identified 376 unanswered research questions and agreed the top priorities for preterm birth research.

#### Women’s Priority Focus Areas for Prematurity Research

The following four major themes summarize the women’s research questions:

##### Maternal health and care before, during and after pregnancy

Questions about maternal health conditions before and during pregnancy; effectiveness of contraception and birth spacing; causes and risk factors for pregnancy complications; utility, safety, and effects of procedures and tests during pregnancy; safety and utilization of medications during pregnancy and labor, miscarriage and stillbirth; process of care, including labor and delivery unit practices; decision making, and the roles of healthcare providers in providing care before, during and after pregnancy and birth

##### Newborn health and care of the preterm baby

Questions about: Care practices in the newborn intensive care unit (NICU) settings; infant health and developmental effects of preterm birth; effects of separation from parents and supports for parents; feeding practices and interventions to support NICU parents to be involved in their baby’s care.

##### Understanding stress and interventions to prevent or reduce stress

Questions about: what are the major stressors (life, work, family, societal) during pregnancy and how stress affects maternal and newborn health; research on interventions for pregnant women to reduce their own stress as well as effective healthcare and social supports to reduce stress and protect mental health; especially for groups that might need additional support, eg. single parents who have other children at home.

##### Interpersonal and structural health inequities

Questions about why institutions and providers give different levels of care to people based on race or ability to pay; profit motives of doctors and pharmaceutical companies; what can be done to train providers to be culturally sensitive and give respectful care

## Women's Top Priorities Topics for Future Research

Fresno, Oakland, San Francisco (combined)

1. Medications, procedures and tests during pregnancy
2. Stress and the benefits of social support care provision during pregnancy and birth
3. Mother's health before and during pregnancy
4. Care provision during pregnancy and birth
5. Care after birth
6. Newborn health and problems related to prematurity
7. Health care providers
8. Education and empowerment of birthing women
9. Communication and cultural sensitivity
10. Hospital and health system practices
11. Workplace and insurance issues
12. Decision making during pregnancy
13. Preconception, contraception and sexuality
14. Mental health support
15. Infant nutrition, feeding and medications
16. Maternal nutrition
17. Support for fathers during and after pregnancy
18. The impact of men on pregnancy outcomes
19. Innovations in care models
20. Role of family and friends in caring for families
21. Pharmaceutical company involvement in birth

### How to Use These Priorities

**PTBi-CA** uses the research priority topics and questions generated by these focus groups to inform the research priorities of the initiative. PTBi-CA research and collective impact activities are focused on decreasing racial disparities in preterm birth.

We call on **healthcare and social service providers** to use the best available evidence to improve services related to the priority topics and questions, to educate patients/clients on what is known about these and to practice respectful care and shared decision-making in all patient/client interactions.

We call on **research funders and researchers** to join us in tackling the unanswered questions about pregnancy birth and newborn health that matter most to women at high risk for preterm birth – and to partner with women, families and communities most affected by the preterm birth epidemic when doing this research. Join us!

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