



“Women Want Answers”

Experiences of women of color who are at risk for preterm birth

Researchable Questions

Between 2015 to 2017, UCSF researchers with the California Preterm Birth Initiative (PTBi-CA) conducted 14 focus groups with 54 women from San Francisco, Oakland and Fresno who identified as African-American, Hispanic/Latina or mixed-race. These women shared their experiences and priorities for research to reduce preterm birth and improve outcomes. Here are the researchable questions they proposed, listed under the broad priority topic headings. We call for researchers, healthcare providers and communities to work together to answer these questions - and to share and implement best evidence-based practices – for the health of mothers, babies and families everywhere.

Priority Research Topics* and Researchable Questions (86) – San Francisco Women

1. Medications, Procedures and Tests During Pregnancy

- How do medicines needed by pregnant women affect the fetus? Which medicine works best to prevent prematurity for women with high blood pressure?
- How do needed dental procedures during pregnancy affect the baby?
- Are lots of ultrasounds safe for the baby? Is 3-D ultrasound safe for the baby? Are x-rays safe? Does ultrasound deafen the baby?
- Do magnesium sulfate, potassium and progesterone cause hallucinations?
- Does a woman’s race or ethnicity make a difference in medication selection and affect preterm birth?
- How can doctors be encouraged to recommend natural remedies instead of drugs?
- Is marijuana safe during pregnancy? Is it safe? Is it beneficial for the baby?

2. Care Provision During Pregnancy and Birth

- How can healthcare encounters with pregnant women be conducted more respectfully when trainees are involved?
- Can Group B streptococcus (Group B Strep; GBS) be detected and tested earlier before 30 weeks?
- Does monitoring of learners and mentors improve their ‘bedside manner’? What is the most effective way to train learners and mentors to have better communication skills and improve their “bedside manner”?
- How can a woman check herself to see how dilated she is?
- How can health providers have better access to a woman’s health and pregnancy history?



- How can there be better ways to know which babies might have problems later?
- How come some babies are born with water bag intact?
- How do you stop pushing during contractions?
- I did everything right, why did I have a preterm baby? Why do babies come very early (24 weeks)? Why should I be worried about preterm birth?
- Is it possible to teach students and learners without further stressing high-risk or new moms?
- Is it safe to keep the baby in the womb after water has broken? For how long can a baby stay in before infection sets in?
- Is a whirlpool bath intervention more effective than fentanyl for labor pain?
- Should high-risk women with history of preterm birth have different care during pregnancy? What should be done differently?
- What are the best ways to establish trust between pregnant women and care givers? What are effective strategies to build trust with patients?
- What can be done to streamline all of the monitoring during pregnancy? What is the impact of the frequency of visits on patient stress and anxiety? What part of monitoring can women opt out of when it feels like too much?
- What is the evidence for safety of medicines during pregnancy? What is the impact of fentanyl and other medications during pregnancy and breastfeeding?
- What is the impact of stress on preterm birth and birth?
- What is the need for a “clean room” (isolation) during bed rest to prevent preterm birth?
- Why can some women deliver without contractions?
- Why do babies come late?
- Why do babies present with breech presentation?
- Why do we have Braxton-Hicks? How can we tell the difference between Braxton-Hicks and true contractions?
- Why is pregnancy care different depending on where you get care? What is the most effective care for pregnancy and high-risk pregnancy? How different is the care at different locations and why?
- Why is there bleeding during pregnancy? Does it mean miscarriage?
- Should there be a special birth plan for high-risk or preterm birth?

3. Stress and the Benefits of Social Support

- Do false tests cause harmful levels of stress?
- How does a mother’s stress affect the baby? Does stress cause a preterm delivery?
- What are the best strategies for emotional support and preparation for parents at risk for preterm parenthood?
- What are the major stressors during pregnancy and the impact these have on preterm birth?



- What are the most effective interventions to improve the overall care and sleep of parents of preterm babies? What educational supports do parents of preterm babies need to improve overall care and sleep?
- What are the ways and methods to support and inspire patients? In what way or to do what (and what not to do)?
- What is the impact of allowing all family members to stay during labor?
- What supports are most helpful for moms with children at home (with no support)? What could make hospital visits and in-hospital stays easier for families?
- What supports do women need in pregnancy decision-making?
- Which social supports improve patient satisfaction in birth experiences? Which social supports impact clinical birth outcomes? Would having childcare? Or access to food?
- What are the best and feasible models to provide childcare for other children and other supports for single moms when they go into labor?
- How can parents be more and better involved in a baby's NICU care?
- What is the best way for hospitals to provide accommodations and emotional support for parents when a baby needs neonatal intensive care unit (NICU) care so parents and babies aren't separated?

4. Newborn Health and Problems Related to Prematurity

- Why do babies receive morphine, medications and fluids and what are the risks? Why is it desirable to not allow babies to move? Why does the NICU team not want babies to move around?
- What are the best ways to predict or treat lung disease, including tuberculosis and asthma in premature babies?
- What is the impact of strabismus (eyes turned toward each other) in preemies? Why does this occur?
- What is the main impact of walking and/or exercise on birth and preterm birth?
- Why do some babies born early get pneumonia and some do not?
- What is the impact of babies not meeting their milestones? How can we tell if they will catch up? Is there an impact of prematurity on babies/children meeting their milestones?
- Is circumcision necessary? If a baby is preterm, when should it be done?
- What causes Sudden Infant Death Syndrome (SIDS)?

4. Care After Birth

- How can the health system provide better care after birth?
- Could train-the-trainer experienced women moms be used more effectively for breast feeding support?



- How do decisions about discharge get made between families, insurance companies, providers, parents? What are the best practices (difference hospital stay)?

4. Communication and Cultural Sensitivity

- How can we increase cultural competence of health system staff and their respect for patients?
- How do we improve clinicians listening to women? How do we improve the listening of health care providers to what women say about their bodies and symptoms?
- What are the most effective interventions to ensure health care providers explain why tests need to be done and what the results mean?
- What are the most effective ways to improve patient-provider communication, particularly when patients perceive insensitive and rude comments from health care workers? How can women report insensitive and rude health care worker communication? How seriously are complaints heard?
- Why does Hospital X have an Asian floor, Chinese module and Spanish module, but nothing for people like me? Why are there differences in care? Why isn't there an African American floor?

5. Workplace and Insurance Issues

- If you have a “lower grade of insurance” are doctors not getting paid enough? Are there differences in compensation based on insurance for pregnancy care?
- Is care different based on insurance status or race? Does the type of insurance you have determine the type of care that you get? Or the quality of care?
- Is the number of ultrasounds and postnatal days provided based on insurance? Why are some services covered, but not others?
- What workplace supports are effective to prevent preterm birth? How does stressful physical work affect pregnancy?
- How can we make brand name formulary drugs (BF co-pay) more affordable? Why are BF copays and costs different based on insurance type?

6. Health Care Providers (and Researchers)

- Why aren't all women asked about their birth plan?
- How can the health care team better follow and read the birth plan? Why isn't review of birth plans part of the providers' script? How do birth plans help?
- How can we make sure all women's birth plans are honored? How can we make sure each woman has an advocate?



- What is the role of Child Protective Services (CPS) and reporting of women during pregnancy care? How do health care providers decide to involve CPS during pregnancy care when abuse and neglect are not clearly present? How do they pick and choose family?
- Why are nurses disrespectful and/or do not believe patients? How do negative attitudes among nurses develop? Can they be improved?
- Why do the health team's preferences take precedence over the laboring woman's? What are the power dynamics and hierarchy of needs during birthing women's labor experiences?
- How can researchers build trust with potential research participants?

Education and Empowerment of Birthing Women**

- How can partnership around birth be encouraged that honors women's knowledge but also teaches and informs? What are the benefits of this kind of partnership?
- What are the benefits of having all women (irrespective of risk) get more information about preterm birth? Why don't all pregnant women get more information about preterm birth?

Infant Nutrition, Feeding and Medications**

- Does stress contribute to a decrease in breast milk?
- What are contributions of prematurity to breastfeeding problems? Latch issues?
- What are the best "home remedies" for babies and preemies? What are the best at-home formula preparations?
- What is the best mix of breast milk and formula? How can we support moms and families with breastfeeding?
- Why does breast milk dry up? Is pumping and feeding as good as breastfeeding? Should babies be put to breast more than pumping? Study breast milk production.
- Why don't babies latch and/or breastfeed?
- What's the best diet for a breastfeeding mom so the breast milk has the most nutrition?

*Listed in order of topic priority, determined by weighted mean rank scores across sites; same priority number indicated a tie in ranking; Individual questions under each topic heading are listed in no particular order

**Unranked Topics