



“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 (119) - Oakland Women

1. Healthcare Providers

- Why does the labor process with the staff feels disconnected?
- Why do doctors judge patients?
- Why do doctors talk down to patients?
- Do you have the option to change doctors and nurses?
- What can we do to help our providers to help us?
- Why are nurses doing doctors job?
- Where are the doctors?
- Why don't doctors come check in more often?
- Why can't prenatal provider be on call for my delivery? Why wasn't it explained? The relationship is important.
- Why don't doctors take mothers questions more seriously and explain more?
- How are we supposed to trust doctors and tell you concerns I have?
- How can health care providers be more culturally sensitive?
- How can staff provide better communication?
- What's the guidelines for nurses?
- How can nurses be less robotic, sterile?
- What are the factors that determine how staff interact with patients?
- What are the boundaries of care? How can we set boundaries?
- How can we make guidelines more transparent?
- How real is confidentiality (between doctors and others)?

1. Mother's Health Before and During Pregnancy

- How does a mother's medical issues, such as spontaneous pneumothorax affect pregnancy and baby?



- Why would I have a spontaneous pneumothorax? I had no known risk factors.
- What is the correlation between gestational diabetes and preterm birth?
- How long before you heal after birth?
- Why do you still feel pregnant post birth, for example: wobble, knee pain, and fatigue?
- Does pregnancy cause heartburn?
- Are there health risks associated with pregnancy?
- So what if a doctor can't explain your illness or your condition to you, what are they supposed to do?
- What cause gestational diabetes?
- How do you know your risk of diabetes?
- What is pre-diabetes? What is borderline diabetes? Is there a better test for it?
- What is extreme morning sickness? How long does it last? Does age matter?
- Why is age a risk factor for problems?
- Does age affect test results?

2. Newborn Health and Problems Related to Prematurity

- Does having a small baby mean the child is unhealthy?
- When babies smile at young newborn age is it gas or something else? Such as “antho” kicking in spirits, ancestors thoughts?
- What extra care do preemies need?

2. Stress and the Benefits of Social Support

- How does stress impact pregnancy?
- What are the holistic ways I can reduce stress during pregnancy, including work and family stress?

3. Medications, Procedures and Tests During Pregnancy

- Is the non-stress test (NST) necessary? What is the purpose of NST?
- How do doctors know what to prescribe for you?
- Are you supposed to take pills and vitamins during pregnancy?
- How accurate is genetic testing? When should it be done?
- Do prenatal vitamins help? What happens if you can't follow the recommendations?

4. Decision Making During Pregnancy

- How do decisions about epidurals get made?
- Why can't you pick your provider around the date? I don't want unknown person!!
- Why are women categorized as high-risk?
- Are women categorized as high-risk because of advanced maternal age?
- Why are prenatal visits at those intervals?
- Are you supported to be asked about option for midwife or doctor?



- Why wasn't "my high-risk" explained? The relationship is important.
- Is it normal the doctors tell you that you have to have a cesarean section?
- Who decides if you need a cesarean section and how do they decide?
- Can you have a vaginal birth after a cesarean section?
- When is the line drawn for active labor and dilation?
- Can you have a mediator and a birth plan?
- What is the role of women in decision-making?
- How is high-risk decided? How are women told about it?

5. Education and Empowerment of Birthing Women

- Is it normal for pregnant women to forget a lot? Is it normal when you forget?
- How do you know how dilated you are?
- How can women learn about pregnancy risk factors before pregnancy?
- How do conditions or physical traits pass down through generations?

5. Maternal Nutrition

- Why can't you eat when you get to the hospital but it's okay to eat before?
- How can we better support pregnant women who are vegetarian or have cultural food traditions?
- Is diet enough to control diabetes?
- Why do we get conflicting advice about diet?

6. Infant Nutrition, Feeding and Medications

- Why can't some women breastfeed?
- Why is it hard for some babies to latch?
- Why do some women make more milk and others don't?
- Do babies have preferences for their mother's milk or not?
- Why do we get different times for keeping breast milk out or stored?
- Can you use breast milk for other things?
- Do babies need iron and vitamins after they go home?
- Can they make iron and vitamins for babies that don't make them throw up or stop eating?
- If you do both breastfeed and bottles do babies know difference?
- If I breastfeed and pump will my baby be confused from the nipple and the bottle or do you have to choose?
- How to make more breast milk than you need?

7. Care After Birth

- Why don't community services respect you just had a baby?
- How restful does the period have to be?



8. Hospital and Health System Practices

- Why do hospitals send you home at a certain centimeter dilation?
- If you want to do whole labor at hospital why do they send you home?
- Why do you have to give birth on your back?
- If you are contracting and you are only 5 centimeters dilated? Why can't you stay at the hospital if you feel more relaxed at the hospital?
- Should you be concerned when they take the baby at night and should I go with the baby?
- Why can't accommodations be made to keep moms and babies together after cesarean section?
- What more can be done to allow moms to have skin-to-skin and breastfeeding after anesthesia?
- Why do moms have to wait to see baby in neonatal intensive care unit (NICU)?
- Why does there need to be separation between moms and babies after cesarean section?
- How can we have better ways to identify active labor?
- What happens when labor doesn't progress?

8. Care Provision During Pregnancy and Birth

- Are epidurals necessary? Or for money?
- Do epidurals cause back problems?
- What controls weigh gain during pregnancy?
- Shouldn't you not feel anything with an epidural?
- Why don't we have alternative options for support during delivery, such as a doula or midwife?
- What is the purpose of the 24-hour rule for giving antibiotics or delivery?
- Why did people wait so long after water break?
- When is the timeframe for risk of infection?

9. Innovations in Care Models

- Is there a different way to provide care?
- Could there be a different outcome?

10. Communication and Cultural Sensitivity

- What is the best way to resolve differences when doctor has one opinion and you have another?
- Why don't doctors explain what they are doing and when you will see them?
- How can we keep everyone in the loop?
- How much is advice biased based on person giving advice?
- Can patients provide how they really feel without retaliation?
- How much advice is based on race?
- Do health workers who are culturally similar related to patients differently than those who aren't?



11. Workplace and Insurance Issues

- Does work related stress make my baby come early?

12. Preconception, Contraception and Sexuality

- Can you prepare your body for pregnancy?
- Why do a very few women get pregnant while on birth control?
- Is there complications if you get pregnant on contraception?
- At what age are doctors allowed to tie your tubes?
- What the connection between tilted uterus and sterilization (versus getting your tubes tied)?
- Why don't providers tell you after effects of getting your tubes tied?

13. Support for Fathers During and After Pregnancy

- How can hospitals support fathers and make them feel more involved?
- What can the hospital do to make the father feel comfortable and relaxed to make the mom more relaxed and so the father won't have to leave the mother?

14. The Impact of Men on Pregnancy Outcomes

- Do men affect a woman's risk during pregnancy, such as their blood type or DNA?
- Can baby be at risk for HIV if fathers mother had HIV (and father does not)?
- Can the father's mood and attitude affect the woman's state of pregnancy?

*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