



“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 (171) - Fresno Women

1. Stress and the Benefits of Social Support

- Why aren't we given tools to reduce stress?
- Why aren't we asked about stress in ourselves?
- Why isn't there more funding for education for education to prevent stress; why isn't it more widely publicized?
- Why can't there be more coordination/alignment of stress prevention resources?
- What can be done to improve assessment of stress? With providers or self-assessment?
- Why aren't there more widely available education materials or videos, etc., to help women recognize their own stress?
- Why is the Black Infant Health program the only pregnancy support service in Fresno?
- What supports can be put in place when you have a bad outcome with one of your children?

2. Mental Health Support

- What mental supports should parents seek after preterm birth or birth trauma?
- What support groups are available to people who have had preterm birth?
- What additional supports are available to new parents when advocating for their children?
- What mental health supports are available to moms with babies who have deficits as a result of prematurity and what more should society do?

3. Newborn Health and Problems Related to Prematurity

- Is it harmful to babies to be separated from mom (family) even if they are sick?
- What educational pamphlets or video are available for people with preterm babies about infant development?
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- Why are there so many tubes and needles hooked onto our babies in the neonatal intensive care unit (NICU)?
- Why do we have to wait so long before seeing our babies in the NICU?
- Why do some premature babies have complications and other premature babies do not?
- Why do some premature babies suffer from a cough?
- Why is it that babies born prematurely often suffer from respiratory problems?
- Why was progesterone given with first child, but not second?
- Are premature infants at higher risk for frequent earaches and respiratory infections later in childhood?
- Are tongue ties a side effect of preterm birth?
- Why don't they prepare us or tell us what to expect when we walk into the NICU?
- What can be done to remove barriers to NICU visitation?
- Is there risk to family bonding in the NICU?
- Why did my baby get morphine?
- Why was I told my baby couldn't get medicine for respiratory syncytial virus (RSV)? Why did she then get medicines for pneumonia much later?
- How does a babies age affect whether they can receive medications?
- What are the most accurate ways to weigh babies?
- Why are different measures used (weigh/temperature)?
- Why do we weigh babies?
- What causes Sudden Infant Death Syndrome (SIDS)?
- Why does stillbirth happen?
- What caused my baby to die? What did I do?
- How can a preemie get Group B strep when mom is negative and didn't have a vaginal birth?
- What is the role of parents in the NICU?

4. Medications, Procedures and Tests During Pregnancy

- Is there a standard of lab testing that doctors could do to find out conditions, or is it just dependent upon the doctor?
- Why are some women prescribed progesterone by suppository vs shot?
- Why can't you have appointments/tests closer to your home?
- What testing should be done to find blood conditions during pregnancy?
- Is there a standard of lab testing that doctors could do to find out conditions, or is it just dependent upon the doctor?
- Why does it take so long for doctors to decide to do further diagnostic testing after multiple miscarriages?
- Do vaginal procedures cause complications?
- Do procedures in first trimester have increased risk?
- Why doesn't magnesium sulfate and steroids stop labor?
- What is the impact of multiple medication treatments on development (such as progesterone, aspirin)?
- Which medicines have both a negative and positive impact on pregnancy?



- Why do we keep on bleeding after being subjected to certain examinations?
- Why are we told that we need our pregnancies induced?
- How is it that certain medical treatments affect women and men differently?
- What are the possible side effects if we take the medications that we are prescribed?
- Why did I still feel pain despite having been administered an epidural?
- Why is it that when I was given medication to stop by premature labor, it did just the opposite and brought upon my labor faster?
- Is there a connection between autism and certain medications?
- Why doesn't anyone talk to us about the long term consequences of certain medications?
- Should people who are pregnant be taking medications?
- Why was I given different medications that didn't effectively treat my condition?
- Are natural treatments and remedies (alternative medicine) effective at preventing preterm birth?
- Why do staff give you medicines that you don't want?
- Is the curl position best for epidural insertion (and if so, why)?

4. Mother's Health Before and During Pregnancy

- Why does false pregnancy happen?
- If I've had a preterm birth in the past, will I have a preterm birth in the future?
- What is HELLP syndrome? Why does it happen?
- What is polycystic ovaries syndrome (PCOS) and why do some women get this?
- Why do healthy people have miscarriages? Why do people have multiple miscarriages?

5. Hospital and Health System Practices

- Does being from another country with different health systems affect how you are treated here?
- Are there differences in pregnancy related care in one country versus another?
- Why do we have unpleasant experiences at the hospital?
- Why are we not seen promptly in an emergency room if we are having an emergency? Why do we have to wait so long?
- Why don't they examine us properly?
- Are there different treatments available for mothers that speak English?
- Why didn't Medi-Cal cover the cost of my dilation and curettage (D&C) procedure?
- Why don't hospitals communicate share better and trust/use each other's results?
- Why do hospitals have different levels of care and so me or my child need to be transferred?
- What are the guidelines for vaginal delivery after cesarean section and why are we told different things?
- Why aren't there more prenatal checks? (why is the prenatal schedule the way it is?)
- Why is there a "rush-rush" process at hospitals?
- Why don't hospitals consult you when you go home?
- How does our local hospital not have respiratory support?
- Why are there different types of support at different hospitals?
- Why does Hospital X have support that Hospital Y doesn't have?
- How many ultrasounds should you have during pregnancy?



- How can we help parents to hold and support their babies even when they are sick?
- Why is there stigma about certain facilities and hospitals?
- What can we do to support parents to visit in the NICU every day?
- Why don't the clinical team support or make recommendations the mental health needs of patients (e.g., clergy, mental health)?
- How can emergency room and ambulance staff be better prepared for preterm babies with the proper equipment and training?
- Does being from another country with different health systems affect how you are treated here?
- Are there differences in pregnancy related care in one country versus another?
- How can pharmacies and doctors' offices "run out" of medicines and vaccines that babies need now?

6. Care After Birth

- Is there monitoring or other types of ways to monitor new babies at home?
- Why do some women bleed so much after delivery and do so for multiple pregnancies?
- What kind of follow up and home support can be provided to help parents-make sure they were given right treatments or know signs of problems?
- Is there monitoring or other types of ways to monitor new babies at home?
- Why did it take so long for me to see my baby after birth?
- I still have pain after being administered my epidural over a year ago. Why is this?
- Why do we sometimes get fevers after giving birth?
- Why do we, as new moms, often fall into depression?
- So, the question is, if you had a cesarean one time, do you have to have a repeat cesarean if you want to have another baby?

7. Education and Empowerment of Birthing Women and their Families

- How do we know baby is developing properly?
- Why aren't there more experienced moms available to support new moms?
- How do women know when they need to go on pregnancy related disability?
- What can women do when they have concerns that are not listened to or they disagree with medical advice?
- How can parents and nurses better partner to take care of babies in the NICU?
- What can we do to support keeping babies and moms/families together even when they are sick?
- How can parents be given more specific information about procedures on infants and long term effects tailored to parents?
- Is there something that we can do as mothers to help our babies when they are in the NICU?
- How can educate women on potential complications and the decisions they may have to make without undue fear?



7. Support for Fathers

- What about the dads?
- What supports do men need during pregnancy and in the NICU?

7. Workplace and Insurance Issues

- Why are providers not able to provide some services regardless of insurance?
- Why aren't there standard pregnancy services the same for all types of insurance?
- Why don't insurance companies, hospitals and doctor's offices let you know you have a choice and options?
- How could pregnancy care coverage be better coordinated/communicated to meet the needs of patients and reduce bureaucracy?
- Why am I provided with insurance that no specialists will take (cardiologist)?
- Why are there different services covered with different insurance?
- What can be done to make it easier in the workplace during pregnancy?
- What can be done to make work accommodations for pregnant women while working?
- Are there differences in care based on type of insurance?
- How can we better streamline pregnancy care so people get they need, when they need it regardless of insurance?
- Why are there different pharmacies and medications covered by different insurance?
- Why are there so many problems with medical coverage and billing for new babies and parents getting incorrect or extra bills?
- Why don't insurance companies communicate more or better (e.g., send letters, call)?

8. Role of Friends and Family in Caring for Families

- What can friends and families do to support families in the NICU?

9. Care Provision During Pregnancy and Birth

- Why aren't there more delivery options offered?
- Why are there regional options for birth positions?
- Why aren't doulas offered?
- Why is the quality of prenatal care different depending on who the provider is?
- What causes placental abruption?
- Why don't you perform a cesarean section?
- How long can you safely labor before a cesarean section?
- Why do they send you home when you are in pain?
- What level of bleeding is normal during pregnancy?
- Why are some babies born early and others born at full term?
- Why are vaginal exams done and what are the reasons for them?
- Why did they treat your dilation as a urinary infection instead of an imminent birth?



10. Impact of Men on Pregnancy Outcomes

- What effect does having your partner present with you at prenatal visits? Will they give you more information if your partner is there?

11. Healthcare Providers

- Why do I have more than one doctor?
- Why can't I have more continuity in my provider care? See the same person for my whole pregnancy when cared for by different hospitals?
- Why am I assigned a resident and not a doctor when transferred to another hospital?
- Why aren't the staff at doctors' offices diverse when California is a diverse state?
- Why don't the care providers explain more about what they are doing (e.g., procedures) and what do the results mean?
- Why don't providers trust patients who know their own body?
- How are travel nurses trained and why do they practice differently in different states?
- Why do people use rude language or are rude?
- How can care be more respectful and/or responsible?
- Why do medical providers hurt us so much when performing physical exams on us during pregnancy and when we come in for our ultrasounds?
- Why do obstetricians and gynecologists see us as a business? Cesarean sections are painful, but they make money from doing these operations on us.
- Why do doctors recommend that we opt for cesarean sections instead of vaginal deliveries?
- Why are doctors not more careful regarding the medications they are prescribing to us during pregnancy?
- Why don't doctors explain which medications are best for us?
- Why are they allowed to have long nails when they do vaginal exams?
- Why do they criticize us Mexican women if we don't want certain examinations done on us during our pregnancy? I refused to get an amniocentesis and received insults and criticism from my doctor.

12. Communication and Cultural Sensitivity

- Why can't they be more coordinated in good communication?
- Why did the doctors not tell me that my blood pressure was high during my pregnancy?
- Why didn't anyone explain what was happening to me?
- Why did they come in and replace my epidural without giving me an explanation?
- Why didn't my doctors listen to me?



13. Preconception, Contraception, and Sexuality

- How long should you wait in between pregnancies?
- Why did the doctor tell me that I wasn't able to engage in physical intimacy with my partner during my pregnancy?
- Does the recommended pregnancy interval differ/change for pregnancy conditions or birth outcomes?

14. Pharmaceutical Company Involvement in Birth

- Why are pharmaceutical companies more interested in profits and money over finding real solutions?

15. Decision Making During Pregnancy

- How is it decided when a baby can go home early and what is too early?
- Why aren't there more options for methods of birth (e.g., water birth)?
- How are decisions about progesterone treatment made for individual women?
- Why aren't women involved in decisions about their care and treatment?
- Why don't you keep people longer when they know their bodies when they've had a cesarean section?
- Why not keep people longer when they have pre-existing conditions or other medical condition?
- How do you determine when someone is ready to go home? What are the criteria? Who decides?

16. Infant Nutrition, Feeding and Medications

- What are the techniques to help mothers produce milk when the supply is low?
- Why does a pregnant woman need to stop breastfeeding her older child and why aren't other women told that?

*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