

*Developing a New Vision  
for Community Based  
Participatory Research on  
Pregnancy Related Care*

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Disclosures

- None



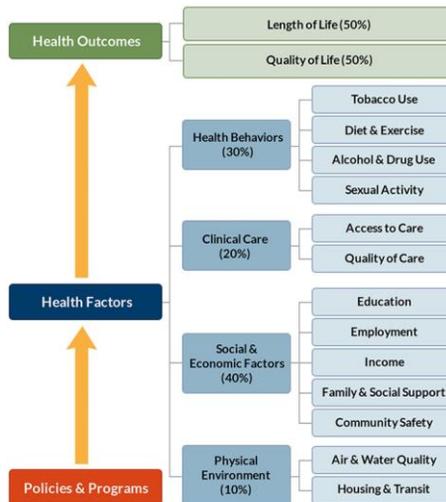
# Nurses Are Transforming Health

## *The Future of Nursing: Campaign for Action:*

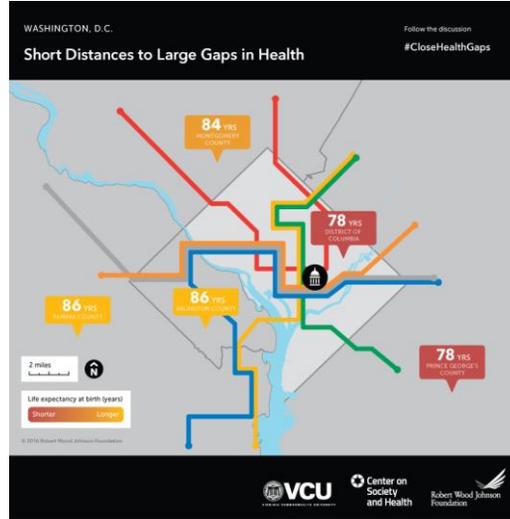
Everyone in America can live a healthier life, supported by a system in which nurses are essential partners in providing care and promoting health.



# Many Factors Affect Health

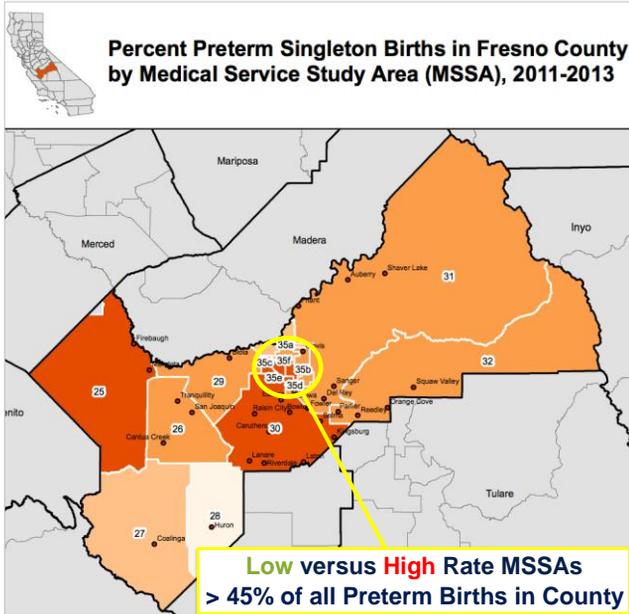


# Where You Live Affects Your Health



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## Terminology

- **Community Involved** – Defined as the highest level of contact, where patients and members of the public are actively involved in shaping research projects and research strategies, including as co-researchers
- **Community Engaged** – The meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results.

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## Terminology

- **Community Advised (Community Advisory Boards)**
- **Community Infused**

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## UCSF Preterm Birth Initiative

- East Africa and California
- 5 year initiative to turn the curve on preterm birth
- Focus on toxic, chronic stress throughout pregnancy and women of color
- Cells to society, precision public health approach

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## **STRATEGIES FOR NEW DIRECTIONS:**

## **RESEARCH PRIORITIZATION**

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## Background and Significance

- Several studies have documented the health care related inequities and poor birth outcomes of women of color.
- Involving women who are at risk for preterm birth, in a research prioritization process creates new opportunities for their engagement as full partners in all aspects of research.
- Meaningful information about women's experiences, perceptions and values during their healthcare visits can be elucidated that inform clinical practice.



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## Methods

- Identification and prioritization of research questions that are important to them using an adapted UK James Lind Alliance Patient and Public Involvement (PPI) methodology.
- 2 audio-recorded focus groups, 6-weeks apart.
- In the first session participants generated a list of potentially researchable questions that reflected uncertainties in knowledge based on their experiences and values.
- San Francisco: 14 women
- Oakland: 10 women
- Fresno: 14 women

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## Session #1



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## Methods

- The ranking and prioritization occurred in the second session.
- During these groups, women discussed in detail their health care experiences and described their perceptions and feeling about a wide range of topics.
- Thematic analysis was used to code the transcripts and develop themes related to healthcare as experienced by the women during pre- and postnatal care.

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## Session #2



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## RESULTS

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# SAN FRANCISCO

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## Top 10 research priorities –women in **SAN FRANCISCO** at high risk for preterm birth

1. How does a mother's stress affect the baby?
2. What are the most effective ways to improve patient-provider communication, particularly when patients perceive insensitive and rude comments from health care workers?
3. What is the most effective care for pregnancy and high-risk pregnancy? If AA women are at higher risk, why isn't there specialized care to improve outcomes ?
4. What causes SIDS?
5. Does the type of insurance you have determine the type of care that you get? Or the quality of care? Is care different based on insurance status or race?
6. What workplace supports are effective to prevent preterm birth?
7. What is the evidence for safety of medicines during pregnancy?
8. How do birth plans help and how can the health care team better follow a woman's birth plan?
9. How do health care providers decide to involve CPS during pregnancy care when abuse and neglect are not clearly present?
10. Could experienced moms be used more effectively for breast feeding support?

MAJOR THEME: Healthcare Seeking  
Experiences of Women of Color at Medical  
and Social Risk for Preterm Birth

- Disrespect
- Stressful Interactions
- Consistent Social Support
- Perceived Confidence to Provide Care

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**OAKLAND**

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### Top 10 research priorities –women in OAKLAND Group 1 at high risk for preterm birth

1. How can women learn about pregnancy risk factors before pregnancy?
2. What are the factors that determine how staff interaction with patients?
3. How accurate is genetic testing?
4. How is high risk decided? How are women told about it?
5. Are there health risks associated with pregnancy?
6. Why don't providers tell you after effects of getting your tubes tied?
7. Is it normal the doctors tell you that you have to have a c-section?
8. Why do doctors talk down to patients?
9. How real is confidentiality? (between physicians and others?)
10. Can the father's mental attitude/affect effect the women's state of pregnancy?

Franck, McLemore, Cooper, Williams & Rand 2016 – preliminary unpublished findings



### Top 10 research priorities –women in OAKLAND group 2 at high risk for preterm birth

1. Why don't we have alternative options for support during delivery (i.e., doula, midwife)
2. What extra care do preemies need?
3. Why do some women make more milk and others don't?
4. So what if MD can't explain your illness or your condition to you? What are they supposed to do?
5. Why is age a risk factor for problems?
6. How can staff provide better communication
7. What are the holistic ways I can reduce stress during pregnancy with work and family stress?
8. Why do a very few women get pregnancy while on birth control?
9. Why would I have a spontaneous pneumothorax, when I have no known risk factors?
10. When babies smile at young newborn age, is it gas or something else? Are their "anthro kickin in" spirits? Ancestors' thoughts?





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**MAJOR THEME: Healthcare Seeking  
Experiences of Women of Color at Medical  
and Social Risk for Preterm Birth**

- Patient Provider Interactions
- Institutional Practices

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## Community Partners



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## FRESNO

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### Top 10 research priorities –women in FRESNO at high risk for preterm birth

1. What testing should be done to find blood conditions during pregnancy?
2. How can ER + ambulance staff be better prepared and preterm babies-equipment and training? Including progress, outcomes and understanding families.
3. What mental health supports should parents seek after PTB, birth trauma?
4. Is it harmful to babies to be separated from Mom (family) even if they are sick?
5. What can women do when they have concerns that are not listened to?
6. What kind of follow up and home support can be provided to help parents take care of their babies at home and make sure they were given the right treatments or know signs of problems?
7. What can women do when they disagree with the medical advice?
8. What support do men need during pregnancy and in the NICU?
9. Is there risk to extended family bonding in the NICU?
10. What causes placental abruption?
11. Why does it take so long for doctors to decide to do further diagnostic testing after multiple miscarriages?

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## MAJOR THEME: Complex Medical Conditions Shape Pregnancy Care

- Disjointed Services and Fractured Care Environments
- Disproportionate Amounts of Disability and Loss

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## Concrete Suggestions

- Participants made *concrete suggestions* about how the healthcare system can be improved, which include: attention to birth plans, better communication among and between multiple caregivers when women are classified as high risk, listening to patients during clinical encounters and less reliance on previous case files and child protective services involvement.

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## **STRATEGIES FOR NEW DIRECTIONS:**

## **COMMUNITY DRIVEN FUNDING**

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## COMMUNITY DRIVEN FUNDING

- <https://youtu.be/ewexfadhp24>

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- “And so we want everybody -- we’re putting a special emphasis on girls, young people of color, who so often are underrepresented in the STEM fields. We want to make sure they feel a confidence about so much of the technology and information, revolutions and science that is transforming their lives all around them. **And we want them to be creators of science, not just consumers of it.** So I think that’s very important.” - President Barack Obama, October 2016 Frontiers of Science Conference

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Questions?