

## Research priorities by parents of premies and clinicians who care for them (POP!)

Research priorities of parents of premature babies and Neonatal Intensive Care (NICU) clinicians  
*Oakland, CA*

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Beginning in January 2018, the Parent Clinician Advisory Boards (PCABs) of the California Preterm Birth Initiative (PTBi-CA) in San Francisco, Oakland, and Fresno convened to create priorities for postnatal researchers. The PCABs are made up of researchers, parents of premature infants, and front-line Neonatal Intensive Care Unit (NICU) clinicians from several disciplines (medicine, nursing, respiratory therapy, social work). Priority setting happened over 2-3 meetings at each site and consensus on the top priority topics was achieved at the 2018 all-site meeting. The Oakland-specific priority research topics, priority research questions, and full list of researchable questions, sorted by topic, are shown below.

We call for researchers, healthcare providers, and health systems to work together to answer these questions - and to share and implement best evidence-based practices – for the health of parents, babies and families everywhere.

### Top 8 Topics

1. Implementing novel strategies to prevent preterm birth. Why has the rate of preterm birth not decreased in the groups with the highest preterm birth rates? Is it because of the microbiome? Genetics? Racism? Systemic stressors?
2. Hospital/NICU practices and policies for family integrated care and psychosocial/emotional support in the NICU
3. Implementation science and best practices with early parent involvement and education in the discharge process
4. Best practices for communication between families and clinicians
5. Developmental care for the preterm infant
6. Family care after discharge
7. NICU environment
8. Family transition from birth hospital to NICU

### Top 10 Questions

1. How can we enhance bonding and reduce feelings of separation between mom and baby/How do we support the role of the parent and let parents be parents in the NICU? How do we ask parents this?/What types of support (e.g., emotional, resources, etc.) do parents want in the NICU

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2. Why has the rate of preterm birth not decreased in the groups with the highest preterm birth rates? Is it because of the microbiome? Genetics? Racism? Systemic stressors?
3. Model for parents support groups during NICU stay and after discharge? Involve graduate parents to facilitate groups? What is the research? And how to make this important to stakeholders?
4. How can we make the discharge process better?
5. How to improve continuity of information?
6. How do we improve continuity of care?
7. Why are African-American women's preterm birth rates comparable to those in Africa?
8. What training can be done to help clinicians have better communication skills in talking with parents (e.g., speak plainly)?
9. How can NICU staff learn and increase their cultural competency levels to improve quality of care delivery?
10. How do we best support parents after they leave the NICU?

## Researchable questions by topic – Oakland parents of preterm babies and NICU clinicians

### Clinical care processes and outcomes

- What can be done to provide care to preterm baby in a “covered” way (so they aren’t out in the open)?\*
- Are there any early interventions for preterm birth risk (e.g., controlling blood pressure)?
- Is there a blood test that could predict risk of preterm birth?
- How can clinicians effectively provide information about disease processes and interventions?

### Hospital/NICU practices and policies for family-centered care

- How to best integrate/communicate resources from in-patient to out-patient?\*
- What are the best visitation policies to support parents and babies (extended family)?
- How do visitation practices/processes affect families in crisis situations?
- How effective is a Navigator (i.e., dedicated family support person) in helping families?
- What are hospital’s responsibilities regarding disclosure around end-of-life care and medical errors?
- How can we make the NICU more welcoming for parents?
- How do we improve continuity of care?
- What are the most crucial resources/needs/services to support care at the bedside?
  - Childcare?
- How do you provide an environment to facilitate bonding?
- What types of support (e.g., emotional, resources, etc.) do parents want in the NICU?

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- How can we accommodate families who want to stay at their baby's side?
- How to scale post-discharge parent support groups model to other NICUs and settings?\*
- What support do siblings need during NICU stay?
- How does an infant's hospitalization impact his/her siblings?
- What are unique needs of 1<sup>st</sup> time moms and how do we address them?
- What can hospitals do to support parents with coping with overwhelming emotions?
- Once you're in the NICU, who is going to be there for your transition?\*
- Will there be an on-site person (individual with preterm birth experience) to comfort the mother in the new transition?
- How can clinicians learn about trauma-informed care?
  - Should we standardize this in their training?
- If we provided a more positive care environment, can we reduce preterm birth rates?
- Is there support available for other family members in the NICU?
- How do we improve our services to meet parents' preferences and expectations in the process of transition between the referral hospital and NICU?
- How can NICU staff learn and increase their cultural competency levels to improve quality of care delivery?

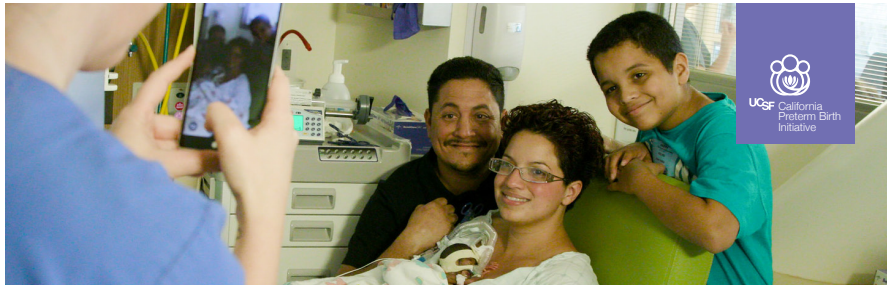
### **Developmental**

- How can we enhance bonding and reduce feelings of separation between mom and baby?
- How can we support neonatal milestones (e.g., wearing home clothes)?
- What are ways that we can keep premature babies on the same developmental path to a normal baby?
- How can clinicians support normalization in the NICU?

### **Psychosocial/emotional care**

- Can treatment of PTSD help parents of babies in the NICU?
- How common are symptoms of trauma in parents of preterm babies in the NICU and after discharge?
- What are parents looking for from clinicians to improve experience in NICU?
- How do clinicians assess what's helpful to individual families?\*
- How can you help a parent feel like a parent when they have no control?
- What things help parents cope with bereavement? (i.e., clinicians attending services, staying in touch)?
- How do we make space to let parents be parents in the NICU?
  - How do we ask parents this?
- How can we humanize experience of parent, baby, and clinician?

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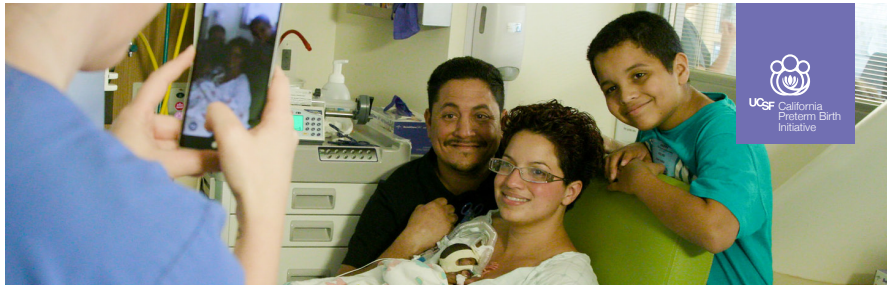
- In the first 24 hours, how do we provide compassionate care to parents and babies?
- How do clinicians create a relationship with parents?
- How can clinicians help parents engage from the 1<sup>st</sup> moment with so much going on?\*
- How can we not judge parents to fit in a “typical mode”?
- How comfortable is the nurse and parent relationship?\*
- How does one’s nursing practice impact a family’s hospitalization?

## Technology

### Information/communication

- How can we help parents access info about their child’s care?
- What would parents ask their clinicians if they felt able to?
- What are barriers of communication between clinicians and parents?
- How to improve continuity of information?\*
- How do clinicians keep parents updated throughout their hospitalization?
- How much information do clinicians give parents when they have preterm babies?
- What is the best info to give parents when they have preterm babies?
- What is current communication between delivery and referral hospital?\*
- How can providers learn quickly how much info parents know and want at XXX time?
- What can be done to improve communication with parents at birth?\*
- What training can be done to help doctors have better communication skills in talking with parents? (e.g., speak plainly)
- How do you prepare clinicians to give parents distressing news or uncertainty?
- Who is/are the best person(s) to give parents distressing info (e.g., roles, training, model, and support)?\*
- What can be done to support maternal mental health?
- What does “discharge” mean to families at the beginning of hospitalization?
  - Does it change?
- How do clinicians propose treatments in difficult situations?
- How do we help parents understand information in moments of crisis?
- How can we get a better understanding of an unclear diagnosis – i.e. “rule-out” bowel perforation vs. NEC?
- Are there better ways to communicate an uncertain/unknown diagnosis?
  - How can we be mindful of this information giving?
- Is it helpful to involve other family members to hold information in crisis moments?
- How can clinicians improve the delivery of negative information regarding the child’s health?
- How can the doctor convey his/her daily diagnoses/status where the parent understands?

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## Lactation

- Who can provide additional emotional support? (lactation)

## Discharge practices and policies

- What's the best timing for discharge education?
  - a. How much at a time?
  - b. How to tell when parents are ready?
- How can clinicians implement best practices in discharge education?
- How can we make the discharge process better?
- How can we incorporate our discharge process earlier in the hospitalization?
  - a. Expectations? Timelines?
- Can a communication log be created to keep abreast of discharge needs?
- How can we be more effective and efficient in supporting parents at discharge?\*- a. Sensitivity – how should we be more cognizant of that?\*
- How effective is a dedicated discharge nurse?
- How do clinicians best prepare parents to go home?

## Post-discharge care

- How do we best support parents after they leave the NICU?
- How to prevent complications and sudden death after discharge?
- What long-term help is available for the child and parents after leaving the NICU?
- Is a post-discharge meeting important to have?
  - a. If so, when?
- How do we answer parent's questions post-discharge?\*
- Unanswered questions – what to ask?

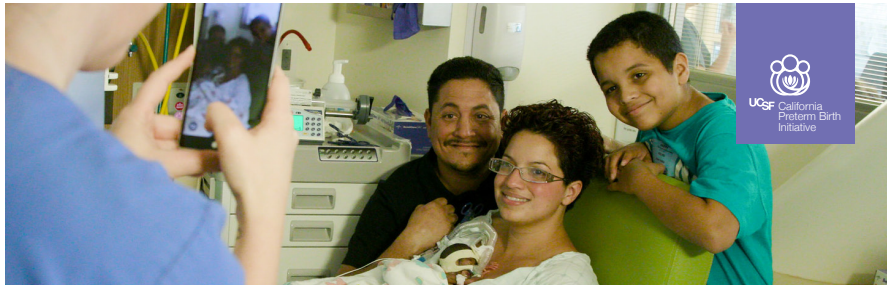
## Preterm birth risk factors and outcomes

- What predictors can be used to develop prognosis for new preterm babies?
- What are risk factors for micro-preemies?
- How does age and weight relate to outcomes?
- Why are having pregnancies back-to-back a risk for some and not others?
  - a. What are lifestyle factors, such as diets, daily life conditions, environments like?
- How does my (mom's) mental health after NICU discharge affect my baby's development?

## Potpourri

- What strategies should we use to prevent bowel perforation?
- How can we prevent NEC?

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- Does maternal indomethacin increase risk of bowel perforation?
- Regarding NEC, is there another form of nutrition to provide outside of breastmilk? (until baby is  $\geq 30$  to be introduced to breastmilk?)
  - a. How much breastmilk helps?
  - b. How beneficial is it?
  - c. Pros and cons to giving breastmilk when intestinal line not fully developed?
  - d. Risk of giving breastmilk so early when intestines too immature?
  - e. When babies recover, everything bounce back?
- Model for parents support groups after discharge?
  - a. Involve graduate parents to facilitate groups?
  - b. What is the research?
  - c. And how to make this important to stakeholders?
- Can we access technology (MyChart) in the Unit?
- How current is the research on risk factors for preterm birth?
  - a. What are the risk factors?
- Why has the rate of preterm birth increased in African-American race?
  - a. Is it because of the microbiome? Genetics? Racism? Systemic stressors?
- How do African-American women's preterm birth rate compare to those in Africa?
- Why are African-American-birth rates so high?
- What does the research show for African American preterm birth rates?
- When did preterm birth rates for African American women become the highest rate?
- Among African-American women, what is the main problem, scientifically speaking?
  - a. What is going on with her body, like an incompetent cervix, that is affecting preterm birth?
- What is the long-term relationship for parents and clinicians for NFRC?
- What are the long-term goals of parents and clinicians in the NFRC after the 2 years?

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