California Preterm Birth Initiative (PTBi-CA)

Preterm birth (PTB) is a birth which is more than 3 weeks before the baby’s estimated due date. More than one-third of infant deaths in California are related to preterm birth, and infants born prematurely have elevated risks of multiple health complications.

The reality of preterm birth in California, and throughout the United States, is one of health inequity, with Black women and birthing people having 47% more preterm births than all other racial/ethnic groups in California (1). These racial disparities reflect the impact of structural racism in our society, which can be traced back to a long history of racist policies and practices around housing, policing, segregation, employment, and education.

The California Preterm Birth Initiative (PTBi-CA) is a research effort that strives to reduce preterm birth rates by closing racial and ethnic disparities and is committed to authentic community partnership as one of its central tenets.

What are Community-Academic Partnerships?

Community-Academic Partnerships (CAP) offer unique opportunities to create meaningful and equitable partnerships between researchers and community members directly impacted by the targeted health issue to achieve health equity (2).

Authentic CAPs in research efforts are more likely to reflect the priorities, values, and experiences of the involved communities, foster strong communication, cooperation, and trust between community stakeholders and external researchers, and generate feasible and useful innovations (3).

CAPs addressing racial disparities and promoting birth justice should address internal and external power dynamics early on, support affected communities to lead the efforts, and include funding and capacity building activities to ensure research justice (4).

This Brief outlines lessons learned from an evaluation of three PTBi-CA strategies to increase community involvement in research and includes experiences and recommendations from partners who participated in these efforts.
PTBi-CA initiated three strategies to increase community involvement in research

Three CAP strategies were included in the evaluation and are outlined in the table below.

<table>
<thead>
<tr>
<th>Community Advisory Board</th>
<th>Benioff Community Innovation Project</th>
<th>Parent-Clinician Advisory Boards</th>
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</thead>
<tbody>
<tr>
<td><strong>Who?</strong></td>
<td><strong>Why?</strong></td>
<td><strong>What?</strong></td>
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<tr>
<td>19 women including those with PTB experiences, frontline community health and social service providers, and representatives of community-based organizations</td>
<td>Involve community members in research priority-setting</td>
<td>Serve as consultants on PTBi-CA research projects</td>
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<tr>
<td>Four community-based organizations, local department of public health, 10 women with PTB experience selected by community-based organizations, 13 graduate students</td>
<td>Develop capacity of academic and community members for research partnerships to examine inequities in PTB</td>
<td>Bring awareness and trust among impacted communities</td>
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<tr>
<td>15 parents of premature infants, 25 Neonatal Intensive Care Unit (NICU) clinicians, providers, and researchers</td>
<td>Build capacity of community-based scientists to conduct community-based participatory research</td>
<td>Review proposals submitted for PTBi-CA funding</td>
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<td>Build trust respect between parents and clinicians in the NICUs</td>
<td>Examine community perspectives on the impact of housing insecurity on PTB in San Francisco</td>
<td>Serve as consultants to clinicians and researchers to decrease racial institutional barriers that deny equitable access to respectful health care</td>
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<td>Create infrastructure for community-based research in the NICUs</td>
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Evaluation Methods

Lessons learned from the PTBi-CA CAP were part of a larger evaluation by external evaluators at the University of California. San Francisco's Philip R. Lee Institute for Health Policy Studies. Information in this brief was collected April 2017 to February 2020 via in-depth interviews (38), four focus groups (23 total), meeting and event observations (36), and a review of materials (174). Results were shared annually with CAP participants to gather feedback and for interpretation.
Key Themes, Actions, and Recommendations

Five themes emerged across the CAP groups during the evaluation, which included recommendations for successful CAPs addressing racial disparities in outcomes. We also list below PTBi-CA actions in response during the time of evaluation.

Incorporate a Racial Equity Approach

CAP participants shared the need for PTBi-CA to reflect on their approach to addressing racial and ethnic disparities in PTB rates, particularly when the majority of the PTBi-CA leadership and academic partners were White and the majority of community partners represented people of color.

PTBi-CA Actions:
- Host internal cultural humility workshops and on-going racial equity trainings
- Shift language and focus from “health equity” to “addressing anti-Black racism”
- Hire people of color into leadership positions

Recommendations:
- Assess CAP anti-racist competencies and practices
- Ensure resources, power, and opportunities reflect the aims to address racial disparities

Value Community Knowledge

Differences between academic and community partners in culture, skills, and interests can create power imbalances and tension.

PTBi-CA Actions:
- Provide training for community members on research methods, and for academic partners on explaining relevance and expected impact of the research to lay audiences

Recommendations:
- Increase compensation for community-based partners
- Make space for community wisdom within academic structures
- Promote more two-way dialogue between researchers and community representatives

Ensure Accountability to Community Priorities

Academic and clinical partners need to be held accountable for prioritizing community needs, as well as for open communication about decision-making.

PTBi-CA Actions:
- Increase listening and response to community needs in a timely fashion

Recommendations:
- Create transparent and equitable decision-making processes
- Dedicate resources towards community partnership activities

We’re also focusing on spending some time thinking about racial equity and cultural humility, and how that work is integral to doing this right, and we haven’t done that work as a group.

We need decision-making power as well. There is a lot that goes on behind the scenes, and we don’t have any say about the direction they go in. They listen to our ideas, but they don’t move them forward.

There is still high value when it comes to credentials rather than a value on the lived experiences of people.
Building Relationships and Trust

Trust is essential for the sustainability and quality of CAP efforts. Many community-based participants shared a desire for academic and clinical partners to spend more time engaging with community members and leaders in order to build relationships with the research communities.

**PTBi-CA Actions:**
- Increase awareness of preterm birth and PTBi-CA efforts within affected communities

**Recommendations:**
- Prioritize community outreach in community spaces
- Partner with community in planning events
- Collaborate with community leaders and fund trusted community-based organizations

Addressing Structural Barriers to CAP

Both community and academic-based partners described some university-level barriers to the CAP.

**PTBi-CA Actions:**
- Host events in community spaces catered by community-based businesses
- Remove degree requirements from job listings that don’t need them

**Recommendations:**
- Work to help make academic spaces more welcoming to represented communities
- Uplift the expertise of community members with preterm birth experience to the same respected standard of expertise given to academic partners

Conclusion

The PTBi-CA engaged in an evaluation to reflect on and continue to improve their efforts. Experiences shared by academic and community-based partners revealed areas for growth, including the need for greater community voice in the initiative, an initial lack of affected communities represented in the leadership, structural barriers to community partnership at the academic institution-level, as well as the need to work on anti-racist competencies and practices. Findings also show the ongoing learning and evolution of the CAP in response. CAPs can be used to address structural inequities within U.S. society and traditional hierarchies of university research to improve health outcomes of focus (5). CAPs addressing racial disparities and promoting birth justice need to address power dynamics early on, and support affected communities to lead the research through funding and capacity building that help ensure research justice.

References


We would like to acknowledge the PTBi-CA Community Advisory Board for their guidance on this project.