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Pursuing research justice through community academic partnership to address racial disparities in preterm birth

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Abstract

Background. The California Preterm Birth Initiative is a community-engaged research effort focused on addressing racial disparities in birth outcomes.

Objectives. To highlight three community-academic partnership strategies and identify partners' lessons learned and recommendations.

Methods. We conducted interviews (n=38), four focus groups (n=23), a document review (n=174), and meeting/event observations (n=36). We performed content analysis and structural and emerging coding of the data, which involved extracting and sorting information into themes.

Lessons Learned. Five themes emerged across the strategies as essential for successful partnerships addressing racial disparities: (1) incorporate a racial equity approach; (2) value community knowledge; (3) ensure accountability to community priorities; (4) build relationships and trust; and (5) address structural barriers to community-academic partnerships.

Conclusion. Community-academic partnerships addressing racial health disparities should confront internal and structural power dynamics early on and support affected communities to lead the efforts, including committing to funding and capacity-building activities to ensure research justice.

KEYWORDS:

Community-Institutional Relations, Premature Birth, Birth Outcomes, Health Status Disparities, Racism, Evaluation, Birth Justice, Community-Academic Partnerships

Background

Preterm birth (PTB) was the second leading cause of U.S. infant deaths in 2018.¹ In California, the PTB rate is highest among Black infants (11.9%), 55% higher than among White infants (7.5%).² Persistent racial disparities in PTB rates reflect the impact of systemic racism on social and environmental risk factors experienced by racially-marginalized groups.^{3, 4} Systemic racism is also perpetuated across the research enterprise by academic institutions. Examples include White researchers receiving a disproportionate share of funding to study health issues predominantly affecting communities of color and funding agencies prioritizing biomedical and mechanistic investigations, rather than community and population-level investigations of disease prevention and intervention proposed more frequently by Black researchers.⁵⁻⁷

However, alternative research paradigms exist – ones that pursue research justice by addressing underlying power inequalities between academic researchers and communities, including acknowledging the equal importance of multiple knowledge systems. ^{8, 9, 10} While approaches to ameliorate racial disparities in PTB have evolved, historically, few have incorporated community-academic partnerships (CAP) or fully incorporated community partner perspectives. ¹¹⁻¹⁵ Further, barriers to research participation by marginalized communities have been described, however few studies explicitly focus on CAP addressing racism. ¹⁶ The University of California, San Francisco's (UCSF) California Preterm Birth Initiative (PTBi-CA) is a place-based research effort in Fresno, Oakland, and San Francisco, California striving to close racial and ethnic gaps in PTB through authentic CAP.

Objectives

The purpose of this paper is to highlight examples of CAP strategies implemented by PTBi-CA, and lessons learned and recommendations from CAP members.

Methods

This examination was part of a larger evaluation by external evaluators to assess perceptions of the PTBi-CA activities and serve as a quality improvement opportunity to support collaboration and communication within the initiative. Evaluators engaged CAP members to solicit feedback and input throughout, including on annual evaluation plans and interpretation of findings, and revised language and framing for accuracy as needed. The UCSF Institutional Review Board determined that as a quality improvement activity, the project did not require institutional approval.¹⁷

Data sources

Mixed-methods data were collected between April 2017 and February 2020 to support a broad understanding of PTBi-CA CAP activities and processes.

Interviews and focus groups: Evaluators conducted 38 interviews and four focus groups with 23 total focus group participants. We purposively sampled participants from different CAP roles to capture varied perspectives, including leaders, key staff, and academic and community-based partners. Trained facilitators used semi-structured data collection guides focused on partnership, successes, challenges, and recommendations. Prior to data collection, facilitators discussed the evaluation purpose and explained the confidentiality and voluntary nature of participation. Interviews and focus groups lasted approximately one-hour each. Participants

received a \$20 gift certificate. Evaluators audio-recorded and transcribed interviews and focus groups.

Document review: Evaluators reviewed 174 PTBi-CA documents, including a sample of CAP meeting materials, the PTBi-CA website and other public communications, internal emails, and a sample of CAP-focused work plans, reports, and presentations. A document data extraction form captured content and terminology on evaluation themes of interest, such as community engagement, issues of race and racism, and other PTBi-CA priorities.

Observations: Evaluators attended and observed 36 PTBi-CA-hosted meetings/events, including a sample of internal CAP workgroup, and subcommittee meetings, and research symposia. Evaluators utilized an observation tool to capture discussions and illustrative quotes on evaluation themes, and other meaningful impressions of participant engagement.

Analysis

Qualitative data analysis involved both structural and emerging coding, creating an initial list of codes based on data collection guides, and refining the list during data collection and the coding process. A subset of transcripts was double-coded for inter-coder consistency with an inter-rater reliability kappa level of 0.80. Transcriptions were coded using Dedoose online software version 8. During the coding process, evaluators discussed code application, definitions, commonalities and discrepancies, and the need to merge, delete, or add new codes. Data extracted from documents and observation notes were thematically analyzed using Microsoft Excel, with quotes and text integrated with related themes reflecting all data sources. Evaluators examined how often themes occurred in the data overall and whether themes emerged

in specific CAP groups. We also examined topics across time within documents to assess changes and emerging themes.

All PTBi-CA Community Advisory Board members were invited to participate in the development of this manuscript and to provide feedback on the interpretation of results. Two members are co-authors and four are acknowledged for contributions in early manuscript discussions.

Partnerships

PTBi-CA initiated three primary CAPs: the Community Advisory Board, the San Francisco Benioff Community Innovation Project, and Parent-Clinician Advisory Boards (Table 1). The primary purpose of the Community Advisory Board is to help review pilot intramural research programs for PTBi-CA funding.^{20, 21} Fifteen women who participated in a research prioritization activity facilitated by PTBi-CA at community-based organizations (CBOs) were invited as members; additional members were selected through an application process.²² Members committed to serving two years with potential opportunities to extend their term.

PTBi-CA spearheaded the Benioff Community Innovation Project by contracting with the San Francisco Department of Public Health and San Francisco State University's Health Equity Institute, which sub-contracted with four CBOs. CBOs selected 10 women with PTB experience to assess the relationship between inadequate housing and PTB.²³ Participants received research training and helped conduct focus groups. The project was also a learning opportunity for university students who conducted the assessment with the community partners.

PTBi-CA established Parent-Clinician Advisory Boards within three neonatal intensive care units, including researchers, parents of premature infants, and front-line clinicians.²⁴ PTBi-

CA conducted a research prioritization activity at each site and incorporated the top priorities in PTBi-CA's research funding request.²⁵ Parent-Clinician Advisory Boards received training in reviewing research funding proposals. Select members reviewed PTBi-CA research funding proposals, while others served as co-researchers in PTBi-CA-funded projects.

Lessons Learned

Five themes emerged across the groups as essential for successful partnerships addressing racial health disparities (Table 2 and below). We describe each, including illustrative quotes, participant recommendations, and PTBi-CA actions responding to lessons learned.

Theme 1: Incorporate a racial equity approach to address disparities in PTB rates. PTBi-CA's initial leadership team included solely White researchers, while most community partners represented people of color. A community partner explained their concern with this dynamic:

I think in White-led institutions, and most institutions in this country are White-led, there's always going to be stuff that is perpetuating White privilege – White advantage – and we need to disrupt it and think about it and talk about it and continue to unravel it.

Many interview participants recommended PTBi-CA prioritize people of color, specifically Black women, in recruitment for leadership positions. One PTBi-CA leader commented on their efforts in this direction, and recommended next steps, which also relate to the next theme – *value community knowledge*:

We've been very focused on hiring solely women of color. And so, I think we have to do more of that, and we also have to work to – if there aren't the senior people that we need – identify the junior people that we can support and move through the infrastructure more quickly than you might generally... to elevate those voices of people who are both researchers and have the lived experience [of PTB].

Many key staff and leadership shared a sentiment about the need for internal reflection:

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.

A review of PTBi-CA's communications also illustrated an evolution in the racial equity approach and language used. A key staff member commented on the importance of these communications:

The work we do is about racism and reproductive justice, but we aren't highlighting that. I can see why. It's not easy and it requires thinking about this and fighting against it. It requires real mobilization of many different resources and sectors, and thoughtfulness in the message and how it is framed.

PTBi-CA's website showed its initial mission broadly described pursuing, "equally good birth outcomes regardless of racial or ethnic background or socioeconomic status." In response to community partner concerns about a lack of focus on Black communities, which experience the highest PTB rates, PTBi-CA removed the word "ethnicity" in a revised mission. A PTBi-CA leader described their research priority populations:

How do you rationalize and focus on both Black women and Latino women? And I think we have to get better about talking about risk and burden. So, we know that there's this apparent risk among Black women who have the much higher rate, but we also know, in the state of California, that the burden, in terms of numbers of preterm births, is vastly, overwhelmingly Latina women, so I think we have to hold both things in mind at the same time.

However, some community partners advocated for a commitment to addressing anti-Black racism and prioritizing Black communities, as those most negatively impacted by racial injustices. In one observed meeting, a community partner commented:

Black people get erased with terms like, "Black and Brown" and, "POC" [people of color]. It just seems like there's this unspoken rule or fear to truly advocate and center Black folks.

Theme 2. Value community knowledge addresses the differences between academic and community partners in culture, privilege, values, and skills, and the resulting power imbalances. Two quotes from community partners reflect this dynamic within PTBi-CA:

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

Sometimes I would come to meetings; I would give a brief background. I felt like a showpiece.

Additionally, community partner expectations of involvement varied across CAP groups and members. Community members involved in a CAP group for a longer period, such as within the Community Advisory Board, and representatives working within connected CBOs expressed a higher expectation for their level of involvement, while parent representatives from two CAP groups with less relevant professional or CAP experience shared mixed satisfaction with their involvement.

As reflected in review of documents, PTBi-CA worked to increase the capacity of academic researchers to incorporate community voices, including a requirement that all PTBi-CA funding applications describe the relevance and expected impact of the proposed research for community partners. Internal communications showed the PTBi-CA also promoted the Community Engagement Specialist position to a Director-level role on the leadership team. Both academic and community partners recommended supporting greater two-way dialogue across groups and roles.

Theme 3. Ensure accountability to community priorities reflects the desire to hold academic partners responsible to fulfill priorities elicited from the community, as well as decision-making transparency. For example, some community partners felt their recommendations for research funding proposals were overridden by PTBi-CA leadership and the external scientific committee, which was also reflected in funding decision documentation. A community partner shared their perspective:

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 what direction they go in. They listen to our ideas, but they don't move them forward.

In contrast, several academic partners spoke positively about PTBi-CA eliciting community priorities, especially compared to their experiences in other research initiatives. Only a few academic partners noted the need for accountability to these priorities, as described by one:

If we claim that we want to prioritize things that the community members are finding important, then how are we holding ourselves accountable for that?

Both academic and community-based evaluation participants noted that, over time, PTBi-CA improved its responsiveness to community needs. Participants further recommended that PTBi-CA require their funded research projects dedicate resources towards community

partnership activities and to create mechanisms for accountability, including at a minimum, reporting study findings back to the community that generated the data.

Theme 4. Build relationships and trust addresses the nature of the CAP relationships, and its importance in the quality and sustainability of the efforts. One community partner shared their insight about the dynamic:

I think there needs to be more opportunities to engage with families beyond just trying to study them. People will probably then be more inclined or want to participate in research if their only introduction to researchers wasn't from the standpoint of being researched.

A community-based participant explained what they felt is needed to build trust in a CAP:

Actually being in the community. Speaking to people who live where you're doing outreach. Speaking to community leaders who have been and know the community. Understanding, for lack of a better term, the rules of the community.

Community-based participants shared that increasing awareness of PTBi-CA among communities most affected by PTB would be an important step towards building relationships and trust. Recommendations also included conducting outreach within spaces and communication channels utilized most by community members, partnering with community in planning events, and collaborating with, and funding, trusted community leaders, organizations, and businesses for capacity-building, instead of creating new partnerships.

Theme 5. Address structural barriers to CAP emerged from both community and academic partners and encompassed academic institution-level barriers. One example was described by a PTBi-CA leader:

There have certainly been some problems at [university campus]. For example, security being straight-up racist with how they deal with [community members] coming into the building.

Institutional barriers in financial administration and bureaucratic processes surfaced with delays in remuneration and inequitable compensation of community partners, and barriers in attempts to hire community members into staff positions due to qualifications weighing academic credentials above relevant life experience; also reflecting the theme of *value community knowledge*. These issues were described by one academic partner as follows:

It would be really great if we could hire these women who are passionate about what we're doing and how it affects their community. That's been a barrier – [university] regulations of job positions, and who you can hire – and we want them to be hired at a fair wage.

As noted in review of applicant solicitation materials, PTBi-CA worked with university human resources to eliminate delays and remove unnecessary degree requirements from job listings to expand and diversify the eligible applicant pool. Other structural barriers PTBi-CA

addressed included eliminating restrictions on events being held in community settings and contracting with community-based catering companies owned by people of color, instead of campus caterers.

Discussion

PTBi-CA engaged in this evaluation as an opportunity for ongoing reflection to improve their CAP efforts. This reflective process is necessary for progress in achieving the systemic changes needed to address racism impacting racial disparities in health. Our findings highlight the critical need for academic institutions to assess their anti-racist practices, including representation of affected communities, particularly in their leadership, as a means of ensuring that resources, power, and opportunities reflect the aim to address racial disparities. Language used in communicating priorities, including defined primary or excluded groups, mirrors the ongoing evolution of language and understanding of diverse communities within U.S. society. A study of a CAP evaluation published in 2022 similarly described the need for academic partners to embed an anti-racism focus in research structures and processes as a key lesson from their efforts. PTBi-CA continued to pursue ways of addressing racism as a root cause of racial/ethnic disparities in PTB rates, including explicitly committing to addressing anti-Black racism.

Community-based participants expressed the need for a greater voice in the initiative, reflecting their personal experience, and expertise in community-based work, which is a common issue in studies on CAP.²⁹ In response, PTBi-CA made capacity-building attempts with both academic and community partners towards meaningful research partnership. Our findings of varied expectations of community partner involvement within different PTBi-CA CAP groups

mirror other studies, including one that measured preferred and actual levels of participation in different community-based research projects.³⁰ Assessing expectations of both community and academic partner roles in different research phases and activities, beginning at project inception, would improve alignment of CAP role expectations.

Most academic partners expressed confidence in PTBi-CA's CAP processes in comparison to their previous research experiences. In contrast, community partners expressed the desire for increased decision-making power and the importance of transparency about priority-setting from leadership. These results reflect previous studies that recommend identifying and implementing practices early on that address power relations, acknowledging the interaction of historical and current community conditions with partnership processes and perceptions that form power dynamics, and fostering a process of reflection and bidirectional communication.³¹,

While we did not find many previous studies that examined CAP within the context of birth outcomes research, one study of pregnancy/birth outcomes among African American and Latinx participants evaluated their CAP and reported findings similar to those in our evaluation. Establishing trust, such as the need for open communication, especially about contentious, but important issues, was reflected in both studies. A case study of two community-based research projects reported that recognition and discussion of racial and social injustices early in their projects supported partners to build stronger and more trusting relationships. Our evaluation participants also recommended spending time in the community and working with and funding trusted CBOs, rather than creating new academic-based CAP strategies.

Our evaluation documented academic institution barriers, such as administrative processes delaying compensation and hurdles in hiring community members. Examinations of

previous CAP have reported on the lack of flexibility and support within institutional research hierarchies, impacting CAP dynamics regardless of members' intentions.³⁴ However, examples exist of CAPs leveraging academic institutional connections to better position community partners to influence decision-making towards their goals.³² A review of research partnerships described a feedback loop wherein successful CAPs transform the context of their efforts, including academic institutions and local project contexts, which in turn creates environments to better support achieving future outcomes.³⁵

Limitations

Our evaluation has two limitations. First, the data were collected at different timeframes within each CAP strategy, in part due to the differing implementation periods for each strategy. Despite these timing differences, we found that cross-cutting themes remained consistent across strategies and time frames. Second, although we purposively invited a varied and balanced sample of participants, our sample may still include bias due to voluntary participation and the time needed to participate. Despite these limitations, our evaluation results include relevant implications for others attempting CAP, particularly those focused on racial equity.

Conclusion

CAPs addressing racial disparities and promoting birth justice should confront internal and structural power dynamics early on and support affected communities to lead the efforts, including committing funding and capacity-building activities to ensure research justice.

Through collaborative strategies and anti-racism approaches, CAPs can be used to address the

impact of structural inequities within U.S. society, traditional academic research hierarchies, and improved health outcomes.

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Tables

Table 1. Description of California Preterm Birth Initiative's community-academic partnership groups, membership, purpose, and activities

Facilitator organization	Community Advisory Board - University funder	San Francisco Benioff Community Innovation Project - Local state university	Parent-Clinician Advisory Boards - Three NICUs
Shared resources	 Members paid \$250 hourly stipend for six hours per month PTBi-CA 1 full time equivalent 	 Members paid \$18 hourly stipend for five hours per week PTBi-CA 1 full time equivalent Local state university 1.5 full time equivalent 	 Parent members paid \$250 hourly stipend for six hours per month Clinician members' time paid by NICU site
Time period	- 2016 – ongoing	- 2017 – ended 2018	- 2018 – ended 2020
Members	- 19 women including those with PTB experience, frontline community health and social service providers, and representatives of community-based organizations	 Four community-based organizations Local department of public health 10 women who experienced PTB and selected by community-based organizations 13 graduate students 	 15 parents of premature infants 25 NICU clinicians, providers, and researchers
Purpose	 Involve community members in research priority-setting Develop capacity of academic and community members for research partnerships to examine inequities in PTB 	 Build capacity for community-based scientists to conduct research Examine community perspectives on the impact of housing insecurity on PTB in San Francisco 	 Create awareness and infrastructure for community-based research in the NICUs Involve NICU communities in research priority-setting

Activities	 Review proposals submitted for PTBi-CA funding Serve as consultants on PTBi-CA research projects Participate in PTBi-CA transdisciplinary research collaborative 	 Receive training in research methods Conduct a research project Disseminate results to policy makers and other stakeholders 	 Review proposals submitted for PTBi- CA funding Serve as co- researchers on PTBi- CA funded NICU research projects
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Abbreviations: PTBi-CA = California Preterm Birth Initiative; PTB = preterm birth; NICU = neonatal intensive care unit

Table 2. Description of California Preterm Birth Initiative's community-academic partnership evaluation themes, related community recommendations, and response

Theme	Community	PTBi-CA response
	recommendation	_
Incorporate a racial equity approach	Recruit and hire Black women into leadership positions Clarify priority populations with care to chosen language and communications Commit to addressing anti- Black racism and prioritizing Black communities	 Shifted from minority to majority staff of color Hired Black female community-based partner as Executive Director Continued in-depth, ongoing trainings on racial equity Created an organizational anti-Black racism agenda and conducted an evaluation
Value community knowledge	Support ongoing dialogue between researchers and community representatives Conduct capacity-building with community members to lead research efforts Conduct capacity-building with academic-based researchers to incorporate community voices	 Hosted 'speed dating' event to facilitate dialogue between academic and community partners Academic researchers share their studies at Community Advisory Board meetings Funded new cohort of Benioff Community Innovation Project community-based research trainees Hosted academic researcher training on community partnership
Ensure accountability to community priorities	Require PTBi-CA funded research projects dedicate resources towards community partnership activities Create mechanisms for accountability to community partners	 Required research funding applications to include relevance and expected community impact Required community-focused summaries for all publications
Build relationships and trust	Increase awareness of the PTBi-CA among communities most affected by PTB	 Launched community- designed public awareness campaign focused on Black communities Increased community-led and community-based

	Conduct community outreach within known community spaces and communication channels Partner with community in planning events Collaborate with and fund trusted leaders, organizations, and businesses in the community	PTBi-CA hosted research seminars - Supported inclusion of community-based businesses in university preferred vendors list - Supported expansion of university procurement with community-based partners
Address structural barriers to CAP	Address institutional barriers in financial administration and bureaucratic processes Share CAP lessons learned across the institution	 Worked with university human resources to improve payment systems and address barriers to eligible applicants without academic degrees Addressed institutional restrictions for contracting with community-based event locations and catering Promoted university supplement for community partnership in research funding Facilitated consultation by PTBi-CA community-based partners with other university departments

Abbreviations: PTBi-CA = California Preterm Birth Initiative; PTB = preterm birth; CAP = community-academic partnership