Author’s response to reviews

Title: Research priorities of women at risk for preterm birth: Findings and a call to action

Authors:

Linda Franck (linda.franck@ucsf.edu)
Monica McLemore (Monica.mclemore@ucsf.edu)
Shanell Williams (shanell.williams@ucsf.edu)
Kathryn Millar (Katie.millar@ucsf.edu)
Anastasia Gordon (agordon@ymcasf.org)
Schnyeida Williams (Schnyeida.Williams@ucsf.edu)
Nakia Woods (nakia@baji.org)
Lisa Edwards (mslisaedwards@gmail.com)
Tania Pacheco (tacheco@csufresno.edu)
Artie Padilla (artie@everyneighborhood.org)
Fanta Nelson (anelson@fresnocountyca.gov)
Larry Rand (Larry.rand@ucsf.edu)

Version: 1 Date: 10 Nov 2019

Author’s response to reviews:

PRCH-D-19-01189 Research priorities of women at risk for preterm birth: Findings and a call to action

Response to Reviewers

We thank the reviewers for their positive comments about the study and are grateful for their constructive feedback. We have addressed all of the comments as detailed below and have highlighted the changes in the revised manuscript in red text.
Editor Comments:
This is a very well written manuscript drawing attention to an important, timely issue. However, there are some significant issues that require clarification.

1. I agree with the feedback provided by Reviewer 2, including the need to more clearly articulate how discussions unfolded between group facilitators and participants with respect to the body of research that already exists on a particular topic. It isn’t clear how facilitators or the authors attempted to guide participants in separating a true lack of research from lack of application of research in practice or to what degree facilitators pressed participants to drill down from broad to more specific questions (e.g., “is there an impact of prematurity on meeting developmental milestones?”—we know there is an impact, but perhaps there is less research on specific milestones?).

Under Methods, we added a Study Design sentence to more clearly describe the study design and aims. We have also added additional text to the Methods to clarify the role of the facilitators. The purpose of the RPAC method is not to guide participants in any way, but rather to uncover their unanswered questions that may be further developed into research. In session 1, facilitators refrained from specific discussion of the available evidence for the questions posed by the participants and focused instead on eliciting unanswered questions from the participants. In session 2, facilitators provided answers to any factual questions posed in session 1, and noted if any questions had been removed from the question list because of definitive research addressing those questions. In the Results section, we noted that only a few questions were removed and provided examples. In the Limitations section, we have added clarification that the questions generated by the participants should be considered as potential research questions and, like any initial idea for research, they need to be considerably refined after a thorough review of the literature and consultation with experts on potential research designs. There were very few questions posed by the participants that had definitive evidence such that no further research is needed.

2. The second issue with this paper is the length, which is likely driven by inclusion of multiple quotes/questions and comparisons between regions within the body of the results without clear subheadings. I suggest just including the most salient quotes/questions in text organized by sub-theme, as Reviewer 2 suggests, and referring reader to Table 2 for complete listing of questions/topics, also organized by subtheme.

We have substantially reorganized the Results section to be more succinct and reduce the number of quotes. We refer readers to the Appendices for the full list of questions by topic and region.

3. I also agree with Reviewer 2 about need for more commentary in discussion about what may be driving differences/similarities in prioritization areas between the different communities sampled.

Additional commentary has been added to the first paragraph of the Discussion section.

4. Also agree that the qualitative analysis process needs to be made more transparent (who analyzed? What was coding process/framework?)
Additional description of the qualitative analysis has been added to the Data Analysis section.

Specific comments:
5. Please include more information on how participants were invited to participate.

CBO partner staff posted fliers about the project in their locations and personally invited clients to participate. This has been added to Setting and Sample section.

6. Under setting/sample, page 6, please specify research questions pertaining to what—specify exact question participants were tasked with addressing.

We have added a Study Design section to clarify the study aim and design, and removed the unclear/redundant text from Setting and Sample and Procedures sections.

7. Please specify timeframe/year(s) in which all groups were conducted.

The focus groups were conducted between April 2015 to June 2017. This has been added to first paragraph of Results.

8. Please specify whether all women who attended first focus group also attended follow-up. How was this tracked?

Three of the participants were unable to attend the second sessions. Participation was tracked by audio/photo consent and payment receipt logs.

9. It is unclear why 4 overarching themes were chosen (why not 5? Or 10?). Authors state that these encompass the most urgent priorities, but it is unclear what is considered most urgent or how the topics/which topics in Table 1 were grouped into these themes.

More detail on the thematic analysis process has been added to the Data Analysis section. We used a standard qualitative thematic analysis approach and agreed the overarching themes by research team consensus.

10. Some of the questions/topics broached by participants (whether ultimately included in table or text) require further explanation. For example, it is unclear what is meant by “why are different measures used for weight and temperature?” or “is there monitoring of other types of ways to monitor new babies at home?”

We report the unedited questions of the participants. As noted in the new text in the Limitations section, as with all first stated research ideas, these potential research questions require additional literature review for the state of the science and further refinement before they would be considered ready for study.

11. Page 20, line 39, although the group is “Black Mammas Matter Alliance,” is it proper for authors to later refer to this demographic as “Black Mamas” at end of sentence?
This is a direct quote from the report. Quotation marks have been added.

12. In discussion, authors note need for improvements to consensus-establishing methods in community setting. Have authors considered concept mapping?

It’s an interesting idea. We’re not sure how it would work toward achieving a consensus decision on research. It seems a bit algorithmic and perhaps something that includes more values-based discourse such as Deliberative Democracy approaches might be better suited. The different approaches could be explored in a subsequent paper.

13. Please revise following sentences for clarity: page 24, lines 7-17, 51-54; missing a word: page 24, line 49 and line 61, page 25 line 27.

The sentences have been revised.

14. First sentence of conclusions needs to be revised for clarity/succinctness.

The first two sentences have been revised.

15. Please also just use full name of BMMA throughout paper rather than acronym, as it is only used one other time in manuscript.

This has been corrected.


This text was inadvertently included from the journal sample manuscript and has been deleted.

17. Table 1—why would a topic be “unranked” as noted in footnote. Table 2 is not referenced in text.

Each group determined the number of ‘Top Priority Topics’ and some topics were not ranked by the these groups. This has been added to the footnote for Table 1. Reference to Table 2 has been added to the Results section.

Alex Friedman Peahl (Reviewer 2): This article is quite timely given the emphasis on disparities in maternity care seen in the media and amongst key policymakers on the state and national level. The idea of including women's voices in setting a research agenda through a research justice framework is a novel idea, and ensures questions are not designed in isolation of the community.

My enthusiasm for this article is damped by three key issues:
1. The background fails to adequately account for the needed partnership between patients, community leaders, providers, and researchers. No single stakeholder can address maternity outcomes on their own, and a greater emphasis on collaboration would be helpful for the framing.
We couldn’t agree more. In the opening paragraphs of the introduction, our main focus is on the importance of partnership between those who set research strategy/funding and the patients/communities who are the focus of that research. In the subsection Preterm Birth, we highlight the poor US maternal and infant health outcomes and discuss the partnership approach taken by the California Preterm Birth Initiative.

While we could opine further on the importance of partnership, and include providers or other stakeholders, we prefer to keep the background focused on the gap in partnership with respect to patients and community involvement in research priority setting and funding, which is the focus of the work.

2. The methods section does not sufficiently describe the focus group leaders’ role in developing research priorities and questions; while the video describes a method of sharing information preterm birth and pregnancy, the focus group leaders’ credentials for providing complex counseling on these topics is not clear. Additionally, how misconceptions were corrected is not addressed in the manuscript.

See response to Editor’s first comment above.

3. The results section does not employ a specified qualitative framework of analysis, and how the specific themes were selected remains unclear. Perhaps the use of the framework would help with organization of the participant responses and aid in making comparisons.

We used thematic analysis as our qualitative framework for analysis. See last sentence of analysis section and reference 32.

4. Background:
The background is well written and logically flows. My main concern is the dismissal of Community Based Participatory Research. CBPR is a well-established framework that is designed to engage key community stakeholders across all levels. While the framework may not have been employed properly across all settings, this does not mean the framework itself is broken. Based on the language describing the RPAC approach, partnership between community experts (i.e. patients/community leaders) and clinical experts (researchers and physicians) does not seem to be as valued; softening of the language or further description of how these stakeholder groups can work together would be helpful.

We do not intend in any way to dismiss CBPR but rather to point out the limitation that it, and other research methods, are typically funded by agencies with limited to no requirement for patient or public involvement in setting the research strategy or research agenda, or in research funding, as stated in the opening paragraph. We disagree that our description of RPAC devalues partnership between community experts and clinical experts. Our focus is on addressing the historic devaluing (absence) of patient and community expertise in identifying research priorities. In the Discussion, we focus on the application/integration of community research priorities in research strategy and funding decisions, and highlight the important role of clinicians and service providers in the second to last paragraph.
5. Preterm birth:
This section is a bit disorganized, and does not acknowledge medical interventions that have shown reduction in preterm birth including birth spacing, 17-hydroxyprogesterone, cervical length screening, and cerclage. While many preterm births are unexplained, we do have some interventions that can impact outcomes.

Thank you for the feedback. We have reorganized the section and added additional text and references.

6. Methods:
I appreciate the video shared within the methods section- this gives great insight into the approach. Further description of the thematic analysis and qualitative approaches would be helpful. Additional information on the focus group leaders' methods for providing education and clarification of misconceptions would be helpful.

The methods were previously published in detail in a paper accompanying the video (see reference #13). We have added additional text to Methods and Results to further describe the role of the facilitator.

7. Results:
Overall, without a background theoretical framework or clearer organization of key themes, I struggle to see the connections and differences between specific communities. More rigorous qualitative analysis using an accepted framework would be helpful for clarifying the data. Additionally, clarification between participant questions and resulting research questions is needed within the text. Separation into main these with subcategories and quotes would be a helpful data presentation.

We have clarified our analytic approach and reworked the presentation of the results to achieve better clarity and organization.