Community-Led Research Priority Setting for Highly Vulnerable Communities: Adaptation of the Research Prioritization by Affected Communities Protocol

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Abstract
While community engagement can occur at all levels of research development, implementation, and dissemination, there is a great need for participation from those with lived experience in the development of research priorities to be used by stakeholders in research, funding, and policy. The Research Prioritization by Affected Communities (RPAC) protocol has successfully developed community-driven priorities for those at risk for preterm birth, but the 2-day focus group methodology may not be suitable for all vulnerable communities. For the purposes of a larger study supporting pregnant and parenting individuals with opioid use disorder (OUD) in research prioritization, we adapted the RPAC protocol to meet the needs of this highly stigmatized community. This adaptation made it possible for those who may not have been able to attend two separate sessions to successfully engage in this participatory process and produce a completed set of priorities by the end of 1 day. The objective of this article is to validate the adapted protocol for prioritizing research and service delivery needs with vulnerable and stigmatized communities.

Keywords
research priority setting, research justice, patient and public involvement, pregnancy, opioid use disorder, substance use, health disparities, lived experience

Introduction
Engaging in community-centered participatory work is highly necessary for improving care quality and systems. While community engagement can occur at all levels of research development, implementation, and dissemination, there is a great need for participation from those with lived experience in the development of research priorities to be used by stakeholders in research, funding, and policy (Mullins et al., 2012; Pratt, 2019). Particularly with marginalized communities, lived experience provides a lens on health care problems that illustrate aspects that will not be seen by those outside of the experience (Pratt, 2019). Finding ways to bring community members into conversations around research priorities and development strategies represents an effective starting point for the more in-depth community engagement necessary to move forward with health disparity reduction.

Community-driven research priority setting has been used in many contexts with success (Manafo et al., 2018). The Research Prioritization by Affected Communities (RPAC) protocol was developed to specifically engage under-represented, often marginalized individuals and has successfully developed community-driven priorities for those at high social-demographic risk for preterm birth in the U.S. (Franck et al., 2018; Franck et al., 2020). The RPAC protocol is distinct in that it calls for literature review to occur after initially listening to community members about their experiences and eliciting their questions regarding a particular health topic. Discussions with affected groups should be separate from stakeholders, including frontline clinicians, to minimize
This protocol has demonstrated an innovative way to engage communities in priority setting for research using a two-stage, 2-day focus group methodology originally adapted from the James Lind Alliance’s framework (Reay et al., 2014). This framework utilizes community-engaged methods to elicit questions from participants at the first focus group session, followed by a 4- to 6-week recess before the second group session to allow for the research team to organize and categorize the questions into thematic headings and remove questions with evidence-based answers. The second focus group seeks to engage participants in ranking and prioritizing their questions. While this modality has been successful for communities of color (Franck et al., 2020) maintaining participant contact and retention between focus groups may not be feasible for all vulnerable populations due to structural and/or individual factors, such as transient living situations, child-care, or transportation (Bonevski et al., 2014).

People with opioid use disorder (OUD) are often identified in literature as a highly vulnerable population. The experience of treatment and recovery for those with OUD is highly stigmatized and often includes interactions with multiple systems of care, including primary care, detox and treatment services, and legal services (Secco et al., 2014). The experience of pregnancy and parenting can be particularly transformative for people with OUD, given that the ability to, and right to, parent is based on a successful recovery (Goodman et al., 2020). Often the experience of recovery is interlaced with episodes of relapse, and the requirements of recovery (meetings, court hearings, work requirements) can be time-intensive, making ongoing participation in community-engaged research difficult. For the purposes of a larger study supporting pregnant and parenting individuals with opioid use disorder (OUD) in research prioritization, we adapted the RPAC protocol to meet the needs of this highly stigmatized and often unstably housed community. The purpose of this paper was to describe an adapted protocol that condenses the RPAC protocol into a single day session to enhance engagement and provide flexibility for vulnerable communities.

**Methods**

This study engaged pregnant and parenting individuals with opioid use disorder in Washington State, USA to develop priorities for research and policy to be shared with key stakeholders at the state level. In addition to including those with direct experience with OUD, we also conducted separate focus groups for health care providers who directly supported those pregnant and parenting with OUD, including case managers and nurses. IRB approval was obtained through the University of Washington and all participants provided verbal consent prior to participating in the study.

**Setting and Population**

We recruited community members, case managers, and nurses as part of our priority setting study around OUD in pregnancy. Agencies were invited to partner with our research team if they provided support for those pregnant and/or parenting with OUD, including community health organizations and nursing organizations. These community partners worked with community members and systems across Western Washington, including five counties representing both urban and rural settings. Recruitment was driven by our community partners, whose work and relationships with community members provided access to this otherwise “hard-to-reach” population. Snowball sampling was also employed as a strategy for successful recruitment (Sadler et al., 2010; Valerio et al., 2016). To be eligible to participate as a community member, individuals had to be 18 years of age or older, identify as pregnant or parenting, have a history of opioid use/abuse and OUD, and be able to communicate effectively in English. We held three focus groups with individuals with OUD, two focus groups with case managers, and one focus group with nurses. Of these focus groups, two community focus groups used the original 2-day RPAC protocol (two separate focus groups four to six weeks apart), and one community and two case manager groups used the adapted 1-day protocol. The nurse focus group used a different approach as it was conducted at a professional conference and therefore was not included in this comparison.

The demographics of participants in the focus groups using the original RPAC protocol and the adapted protocol are presented in Tables 1 and 2. Overall, participants in the community groups were predominantly white, with some college education, and in recovery from heroin or oxycodone (Table 1). Case worker participants were mainly white, had less than five years of professional experience in case management but worked frequently (daily) with OUD community members (Table 2). Of the two community groups that used the original RPAC methodology, one was held with participants currently staying in a residential treatment facility with their newborns and the other, in a rural setting, was associated with a community-based recovery support service. The third community group and both case worker groups were situated within community-based recovery support services and opted to use the 1-day adapted protocol.

**Approach**

Our adaptation of the RPAC protocol takes into consideration the need for this community to have the opportunity to participate while understanding the competing priorities and highly vulnerable nature of those who are in recovery from opioid use. Under the guidance of community partners, we condensed the RPAC protocol into one 5-hour session. The adapted protocol, in supplementation to the original RPAC protocol (Franck et al., 2018) is provided in Table 3. Materials
needed to implement the focus group protocol are provided in Table 4.

For the purposes of our study, each participant focus group was conducted the same way in regard to the content of each focus group session; the first session engaging participants in question generation and the second using ranking and prioritizing exercises to set group priorities. Of note, the first focus group participants requested to expand the scope of the study to include not only research questions but also questions related to expanding or improving service provision and changing policy to improve care. This expanded scope was continued throughout the breadth of the project with the other participant groups. The groups each developed an average of 56 questions (30–112) within the first session.

The ranking and prioritizing steps were similar between participant groups, while the overall priorities differed slightly. Groups had different techniques for coming up with the final priorities. Some groups organized questions under participant-created headings, leaving four to five main priorities with sub-priorities; other groups kept questions as independent priorities and ranked them without categories. Comparison of themes across participant groups was conducted at the end of the study, but due to differences in how groups set up their final themes and questions, we did not attempt to combine results across studies. Figure 1 documents the process by which participants generated questions, ranked and prioritized questions using sticky dots, and developed the final priorities.

All participants received a total of $150 (US) in gift cards for their participation (regardless of using the adapted or original RPAC protocol method), and partnering agencies received $1,000 honorarium for their support. Hot food was provided for a meal (lunch typically), with coffee and breakfast items available during the first session. Onsite childcare and transportation were also provided.

**Analysis**

The structure of our study allowed for comparison of the two approaches, which was accomplished through a reflective process conducted by the research team and a comparison of results across the different settings. During each focus group session, a research team member took field notes and noted observations about the structure and process that supported or hindered the participatory process. In addition, the participants were prompted at the end of the last session to share what they appreciated about the process or if there were any aspects to change or remove. Data analysis for assessment of the adapted protocol included research group reflection of the field notes and transcripts including the responses to prompted questions on satisfaction with process, all of which contributed to our metric of success for this adapted approach.
Results

Participant Feedback on the Priority Setting Process

Overall, participants of all focus groups were satisfied with the structure of the sessions and appreciated the community engaged process evident in the RPAC protocol. Specific to the community of people affected by opioid use disorder, participants shared that “[the process] is nice because you’re giving us addicts a voice, because usually people don’t listen to us. So, that’s awesome” (community member). There were overwhelmingly positive responses from both community members and case managers in regard to the process of question formation.

Table 3. Adapted Process for Focus Group Implementation.

| Preparation |
|-------------|
| 1 Engage and partner with community agencies to set the appropriate protocol and procedures to use for their particular service population. Offer community partners the original RPAC protocol with two group sessions across 2 days or the adapted protocol with an extended 1-day session. Invite community partners to co-facilitate sessions, can opt not to participate. (community agencies opted out given the highly sensitive nature of OUD conversations and the relationships with their clients who were participating). |
| 2 Agency supports recruitment of individuals for the priority setting activity, confirmation of space and time, and agency participation if desired. The time requirement includes scheduling a 2-hour period for the first group session, followed by a 1-hour lunch/meal break, concludes with a second 2-hour period for the final group session. Space requirements include having a separate room available for either the research team to go during the lunch break or for participants to go for lunch. |

Focus group session #1

1 Facilitate the first focus group session using the original RPAC protocol facilitation guide, amended as appropriate by agency partners. The first session entails developing questions based on lived experiences of having OUD (community), or through providing care for those with OUD (case managers). For this study, participants wanted to include how to improve service provision and policy as well as research questions. The facilitation guide was adapted to broaden the purpose of the project to research, service provision, and policy. Specifically, the guide was adapted to include the request for participants to think about their experiences and any questions or concerns related to research (what is known), service provision (what is provided), and policy (what guides the care that is provided), in the scope of opioid use disorder during pregnancy or parenting. |

During this session, at least three research team members are needed:
One facilitates the discussion
One writes questions on flip chart paper
One writes questions within an online document.

Interim analysis and preparation (during 1-hour break)

1 Organize all questions on the online document into themes/headers. Multiple research team members can work on same document simultaneously to rapidly categorize questions into basic headings. Free online platforms, such as GoogleDocs, are available to facilitate this process. Duplicate questions are assessed and combined if necessary. The final document includes all questions grouped under headings, with a “miscellaneous” heading when necessary. |

5 Print questions in preparation for session #2. The questions and preliminary theme headings are printed on index cards or half-sheets of paper (see List of Materials—Table 2). Questions are taped under their headings to the walls or other surfaces in the focus group room in preparation for session #2. |

Focus group session #2

8 Facilitate the second focus group session using the original RPAC protocol facilitation guide, amended as appropriate by agency partners. First, review each question to verify that the research team adequately captured what the participants intended during session #1. Any questions that need rewording are amended in real-time. Participants then use their 15 dots to choose 15 questions that are most meaningful and important to them, using one dot per question. All questions without dots are then removed from the wall. Participants then review the preliminary theme headings, revise as needed, and rank them in order of priority as a group. Participants then use their five dots to further rank the remaining questions, but can place as many dots on one question as desired. Facilitator then determines the top 10–15 questions using number of dots as a guide, finding the “cut-off” number and removing all questions with less than the cut-off number. Lastly, discussion among the group to determine the final ranking of the remaining questions, grouping questions into new themes/headers if needed, and rewording final questions if appropriate.

Wrap up

9 Transcribe audio recordings from the focus groups. |
10 Review transcripts for any missing questions, confirm wording of original questions, and generate complete list of questions. |
11 Disseminate results to the community agency in the form of a poster or infographic handout of focus group sessions within 1 month of the focus group.
and subsequent prioritization, mainly in being heard and having experience valued—“It was an honor to have a chance to make a difference based on our experiences” (community member). The value of being heard in the process and recognized for the hard work being done on the front lines in regard to the opioid epidemic was also appreciated—“I don’t think that the state actually knows what we have to deal with day in day out [regarding systems of care]. It was good to talk about it” (case manager). Both community members and case managers expressed value in sharing their experiences, with reported feelings of inclusivity, validation, and support throughout the group process. In one group, community members exchanged contact information in hopes to rebuild a supportive social network as they work through both recovery and parenting.

Participant Feedback on the Protocol Structure

When queried about the structure of the two sessions (1 day or 2 days), there were varied responses. The two focus groups that used the original RPAC protocol were happy with the split nature of the sessions, mainly due to the intensity of each session—“It would have been too much for one [day] I think” (community member). Having two, 2-hour sessions was also beneficial in regard to those who had either flexible schedules or were in a residential treatment facility. Local context for each of these focus groups and the supporting community organizations dictated the 2-day model, which worked well due to one site being a residential treatment facility and the other having extensive community support such as drivers and in-house childcare.

The other focus groups (one community group and two case manager groups) were conducted using the 1-day extended protocol. For these groups, the participants shared positive feedback about condensing the focus group sessions into 1 day—“[One day] was the way to go, I wouldn’t have been able to come twice” (case manager). Others shared that they appreciated the condensed model due to time constraints—“I don’t think I could have come back for another day” (community member). Having the option of conducting the priority setting process within 1 day was preferred, despite the long day—“It was long but worthwhile” (case manager).

Observations From the Research Team

For both the original and adapted RPAC protocols, participants were noted to engage deeply in both sessions and fully participate in all activities. The adapted protocol was able to hold participant’s engagement throughout the full 5 hours; however, participants were noted to be tired by the end. Food and drink throughout the entire process was an effective strategy for keeping participants focused. Attrition was significantly decreased using the 1-day protocol, with only one participant unable to return to complete the second day of the original RPAC protocol.

An a priori concern regarding the adapted protocol was that participants would not have had sufficient time to separate from the questions in the first session in order to engage in thoughtful prioritization. While participants occasionally continued sharing experiences into the second session, we noted no
difference in groups with the transition into the priority setting exercises, and the final priorities were equally as thoughtful and developed between the two protocols. In fact, we observed that participants were able to engage in the questions more deeply as they were fresh in their minds and could provide corrections on wording and phrasing more readily than with the 2-day groups.

Discussion

With community partnership, we were able to successfully adapt the RPAC protocol to meet the needs for pregnant or parenting people who were working through addiction and recovery from opioid use in Washington State. The adaptation of the RPAC protocol was perceived by many in our study as being easier to coordinate and attend, as well as fit the available resources of the community partners and research team. We perceived benefits and drawbacks for each approach, lending toward the importance of tailoring the approach for the intended community and their needs and barriers. Having this adapted method as a valid and reliable option for community-based research priority setting allows for more flexibility to meet those needs while upholding the same level of rigor seen in the original RPAC protocol.

Some benefits of the adapted 1-day approach included only needing to schedule 1 day for attendance, which is easier for those who may not be able to schedule two different days, and the ability to provide immediate results and gratification for work done. Additionally, the 1-day approach lessened the burden on agency partners who may already have limited time and resources available. Drawbacks to the adapted 1-day approach included the need for additional staff support to accomplish data analysis in between sessions, with at least four staff needed for the adapted protocol as compared to two staff for the original RPAC methodology. The carryover of additional questions from the first session into the second session (participants thought of more questions during the break) limited time for ranking and prioritizing; however, this step was deemed important for maintaining rigor within the process. There was also the potential for missing questions as transcripts from the first session were not available prior to the second session. Participant fatigue by end of the full day was also a drawback, though didn’t appear to affect engagement in the process. One of the largest obstacles to using the adapted protocol is the interim

Figure 1. Images from adapted protocol (top row from left: question generation, review and revisions of questions, initial ranking, second phase of ranking; bottom row from left: final ranking exercise, final priorities).
analysis that needs to occur in between the first and second session, but the adapted protocol was successful if the requirements were met for personnel and resources.

In addition to the adapted logistics of the 1-day protocol, there were several other smaller adaptations to the RPAC protocol that were co-created by community partners and participants within this study. First, the expansion of the aims of the project from solely research priorities to an expanded view of research, service provision, and policy priorities occurred after community participants shared their need to improve care and change systems as part of the priority setting process. This change, while important in shifting the research aims of the study, also created space and motivation for participants to be fully engaged as a change agent rather than just supporting the role of the researcher. Additionally, participants chose to take the process one step further than what the original RPAC protocol described, and further shift, group, and categorize the final priorities into themes and sub-themes. Their ability to provide this further level of analysis may be due to a deeper engagement in the process given its relationship to their own care and wellbeing, rather than solely focused on research. Given the lack of data on these types of community-engaged processes, more research exploring this is needed.

This study also highlighted the importance of creating space for community involvement in priority setting, independent of stakeholders (Franck et al., 2018). Both participants and the participating agencies acknowledged the need for participants to be unhindered in sharing their perspectives, free of potential stigma or bias from those involved in the process. As noted by our community partners in our study, even having agency collaborators involved in facilitating the focus groups could have had effect of suppressing participants’ ability to share openly, and thus the focus groups were only led by external members of the research team. Future priority setting projects should consider these potential impacts on community members and structure their teams accordingly.

The adapted RPAC protocol needs to be considered in light of several limitations. While participant demographics were fairly homogenous with regard to race/ethnicity and education, they matched the relative prevalence of opioid use in the respective communities in Washington State. Also, by limiting to adults over the age of 18, we effectively missed any differences in acceptability with the adolescent population. Communities of pregnant and parenting individuals with OUD in other geographic areas and with different demographic identities likely differ from the community within our study, and thus application of this protocol should be tailored to the specific needs of each community. In addition, given we conducted the focus groups in English, we did not assess the suitability of this approach for communities for which English is not the native language. Further exploration of the suitability of both the original and adapted RPAC protocol for other marginalized communities is necessary to facilitate community engagement in research and health care systems improvement.

Conclusion
The adapted RPAC protocol as an extended 1-day session provided an alternative modality for research priority setting that may accommodate those communities that may not be easily engaged for two distinct sessions. Providing opportunity for even the most highly vulnerable populations to contribute to research priority setting, and community participatory research as a whole, brings a level of experience and expertise currently missing from health care systems development. If the purpose of community engaged research is to center the communities in which we serve, providing options for participation and engagement that are tailored to the needs of the community is essential for improving the health care system as a whole.

Author’s Note
Jane Kim and Morgan Busse were students at the time of the study.

Acknowledgments
The authors would like to acknowledge the support and guidance of Dr. Linda Franck and Dr. Monica McLemore towards this adaptation of the Research Prioritization by Affected Communities (RPAC) methodology, as well as the community agencies and participants who contributed their knowledge and expertise to this study.

Declaration of Conflicting Interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was funded by the Washington State Health Care Authority, Grant K3786.

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