CONSIDERATIONS FOR PATIENT EXPERIENCE EVALUATION IN MATERNAL HEALTH PROGRAMS WITH MARGINALIZED PARTICIPANTS

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BACKGROUND

The Massachusetts Health Policy Commission (HPC) is an independent state agency charged with monitoring health care cost trends and making policy recommendations to improve the affordability of health care for all residents of the Commonwealth. The HPC makes investments to support care delivery transformation and innovation that align with the agency's mission to advance a more transparent, accountable, and equitable health care system.

The HPC administered a grant program called Cost-Effective Coordinated Care for Caregivers and Substance Exposed Newborns (C4SEN) from 2021-2023. This program was designed to provide comprehensive support to the birthing parent-infant dyad for those with a history of substance used disorder (SUD), particularly opioid use disorder (OUD). The HPC also administered a grant program called Birth Equity and Support through the Inclusion of Doula Expertise (BESIDE) from 2022-2024. This program was designed to provide racially and/or culturally concordant doula care to Black birthing people to address racial disparities in maternal health outcomes.

As a part of evaluation efforts for each of these programs, a separate evaluation of patient experience was implemented for each through the hiring of a third-party contractor to conduct surveys and interviews with participants in each program. The HPC issued a request for proposals for each program, selected a contractor through a standard state bidding process, and worked with the selected contractor to design the survey questions and interview guides. The HPC also oversaw the contractor's data analysis and the development of a final report for inclusion in the overall grant program evaluation report.

PATIENT EXPERIENCE EVALUATION ACTIVITIES

The contractor team for each program undertook the development of a project plan and protocol, IRB review, collaboration with hospital grant program sites for recruitment of enrolled participants, administration of surveys and interviews, and data analysis and synthesis of findings. These findings were then incorporated into comprehensive evaluation reports about each program.

Both programs had independent evaluation plans co-developed with their contractor teams which included patient experience evaluation questions, survey questions, and an interview guide based on the goals of the program and evaluation. The C4SEN patient experience evaluation focused on experiences of stigma or bias in the program as well as overall satisfaction with the amount and type of services provided by the program. The BESIDE patient experience evaluation focused on domains of comfort, trust, respect, and agency and how the support of a doula impacted patient experience in these domains. The C4SEN program had 37 survey respondents and 13 interviews conducted. The BESIDE program had 39 survey respondents and 21 interview participants.

RATIONALE

The HPC considers including participant voice in evaluation to be a key priority to ensure responsiveness to population needs in care delivery transformation and as a means of centering equity in program evaluation. As these programs served marginalized populations (Black individuals and those with a history of SUD) at a vulnerable life stage (pregnancy and postpartum), centering patient voice was an even higher priority than in other HPC programs. However, the HPC also recognized the need to create a patient experience evaluation process that felt comfortable and safe for participants and take steps to avoid any harm from participating in the evaluation.

KEY CONSIDERATIONS

GENERAL CONSIDERATIONS:

- **Contractor selection**
  - Staff diversity and experience working with marginalized populations were key considerations for selection of contractor
- **Strengths-based and positive interview questions**
  - Interviews included questions such as "Tell me about some moments of joy you have had in the first year since you gave birth," "Where do you see your future in the next year?" and "What brought you strength and/or joy during your pregnancy, labor and delivery, and/or postpartum?"
  - These questions were featured near the beginning and end of the interview guides to foster participant comfort and conclude interviews on a positive note
  - Responses allowed participants to focus on a broader range of their experiences and identities rather than solely focusing on their marginalization or need for program services
- **Participant safety**
  - Survey instructions included information such as individuals to be contacted at each program site in the event of serious concerns about safety and/or hotlines for maternal mental health
  - Participants were allowed to decline answering any questions they were uncomfortable with or end an interview at any time if needed

FOR PARTICIPANTS WITH A HISTORY OF SUD:

- **Sensitivity around question selection**
  - Questions were selected to avoid focus on participant substance use history, and care was taken to avoid asking questions that might have direct legal implications for participants
- **Transparency with participants and pre-planning for evaluators around state policy and mandated reporting**
  - State policy around child protective services and potential legal risks for discussion of substance use were considered in question selection
  - As some interviewers were considered mandated reporters, a process was developed for discussion of any concerns surfaced
    - This process was communicated to participants prior to taking the survey and participating in the interview
  - Consider obtaining a Certificate of Confidentiality[1,2] for your project to protect participant responses from inclusion in legal proceedings, should any occur

FOR PARTICIPANTS OF COLOR:

- **Racially concordant interviewers**
  - Some interview questions concerned experiences of discrimination and experience as a Black birthing person
  - Contractor staffed an interviewer who was also Black (racially concordant with participants) to increase comfort discussing these topics
  - Interviewer also participated in analysis and synthesis of findings, ensuring cultural knowledge and experience with interviewees was part of analysis
- **Language access and translation considerations**
  - A significant population of participants in the BESIDE program had a preferred language of Haitian Creole
  - Contractor was able to arrange for materials to be translated and a concordant interviewer
  - Adjustments to questions had to be made for appropriate linguistic and cultural translation
    - For example, Haitian Creole does not have a single word for "postpartum," so a phrase needed to be substituted, and questions about participant gender identity also needed to be adjusted

DISCUSSION

Centering participants with marginalized identities in program evaluation is critical for ensuring equitable and high-quality evaluations. However, working with marginalized populations comes with important considerations in designing evaluations to create a comfortable, trauma-informed environment for participants in the evaluation and avoid causing harm. These individuals may have personally experienced prior research or evaluation work that was harmful or did not fully accommodate their needs or be aware that their populations and communities have historically experienced this harm, heightening the need to incorporate these considerations into present day evaluation work to avoid further harm and attempt to rebuild trust.[3,4] Some of these considerations are general to any marginalized population and some will be specific to individual populations.[5,6] Consultation with evaluators with this specialized knowledge and advanced research experience can be helpful for evaluators in anticipating these considerations, designing evaluation activities with them in mind, and ensuring plans are in place to address or avoid potential risks and harms.

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