Community Engagement Studio Toolkit:

For Researchers and Community Experts Interested in Maternal Mental Health and/or Opioid Use/Recovery

The Maternal Mental Health Research Collaborative

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MM:RC Maternal Mental Health Research Collaborative

Acknowledgments

This toolkit builds on the Community Engagement Studio (CES) model and Toolkit developed by the Meharry-Vanderbilt Community Engaged Research Core (CERC)[1]. The Maternal Mental Health Research Collaborative (MMHRC) tailored the CES model for Researchers and Community Experts interested in maternal mental health and/or opioid use/recovery to provide focused guidance for engaging these populations. Our goal is to build on and add to the work done by the Meharry-Vanderbilt group, acknowledging their original contribution while adding the nuances appropriate to our target population. Some paragraphs within each numbered section have been removed or condensed, while original language may appear in other sections.

The MMHRC is a peer-led, patient-centered initiative with research partners at the Heller School for Social Policy and Management at Brandeis University and Temple University's College of Public Health. MMHRC seeks to engage mothers with experience with maternal mental illnesses in research. The MMHRC is driven by a collective vision of developing a peer led, patient-centered think-tank and research hub where mothers, healthcare providers, researchers and other stakeholders co-create research questions and strategies to address them. These goals are guided by a shared desire to quickly improve health by focusing on patient identified priorities. Partnership and collaboration with stakeholders are key tools employed by the MMHRC team.

PCORI is an independent, non-profit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions. PCORI is committed to continually seeking input from a broad range of stakeholders to guide its work. The statements presented in this toolkit are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

MMHRC is grateful to our community collaborators at the Institute for Health & Recovery, and the Massachusetts Department of Public Health, and the many Community Experts who helped us refine and tailor the CES model and toolkit for maternal mental health and/or opioid use/recovery research.

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[1] Israel et al. 2019

Table of Contents

1) Overview of a Community Engagement Studio

Community involvement can increase the quality and relevance of research.[2] Journals and funders increasingly require investigators to provide evidence of stakeholder involvement in framing and conducting research, and disseminating research findings. Researchers in maternal mental health and/or substance use fields can particularly benefit from engaging with community members, whose perspectives may be invaluable to a person-centered approach to developing and testing interventions or treatment, and the uptake of evidence-based practices. Benefit may be conveyed to community participants, who feel valued and empowered by sharing their experiences and expertise on behalf of "a greater good" – informing research and practice approaches that may improve the lives of others.

How community stakeholders can impact research:
- Prioritize research topics
- Increase relevance to patients and communities
- Strengthen recruitment and retention efforts
- Help frame protocols and procedures
- Participate in data collection and analysis
- Assist with data interpretation
- Increase dissemination and uptake of research results

It may be challenging for researchers to engage community members, patients, caregivers, community health providers, advocates and policy makers as partners in research endeavors, rather than as subjects. Many researchers are not prepared to identify, recruit, convene and engage community stakeholders or prepare them for participation in research in an advisory capacity or as part of a research team. At the same time, community members may not feel comfortable participating, may be distrusting of researchers, or may have concerns that there could be possible legal or

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[2] Mitchener et al. 2012; Green 2003; Johnston et al. 2015

social services consequences to their involvement, due to stigma and the sensitive nature of maternal mental health and substance use.

The Community Engagement Studio (CES) provides researchers and stakeholders an interactive, efficient, and effective way to engage and provide meaningful input into all phases of research. The CES model provides a framework for engaging community members in a way that is culturally sensitive and in keeping with their priorities, values and needs. CESs provide community members opportunity to inform next steps in practice innovation.

> **Researchers in maternal mental health and/or substance use fields can particularly benefit from engaging with community members.**

In a CES, the **Researcher** gives a presentation about their project and poses specific questions to a group of **Community Experts**[3] (e.g., stakeholders including individuals with personal experience, practitioners, advocates and policy makers). The Researcher uses language that is appropriate and sensitive to the Community Experts' experience, background and role, and addresses questions of interest to the Community Experts. The discussion that follows is guided by a **Facilitator** to elicit authentic and constructive input and feedback on the development and implementation of a study, or the dissemination of research findings.

In prior research, CESs have addressed issues of participant compensation, the culturally appropriateness of recruitment materials, participant retention strategies, simplifying the consent process and identifying entry points for community-based recruitment, design, ethical considerations and translation of research findings into practice.[4] In our experience, the MMHRC pilot CESs focused on: 1) developing a survey on the experiences of stigma among pregnant women who use opioids and 2) developing questions for upcoming research on how the COVID-19 pandemic changed support for women in recovery.

The CES is an **interactive, consultative model**; it is not a standing advisory board, a tool for recruiting research participants, or a data collection or research method such as a focus group. **The Community Experts who participate in the CES are not**

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[3] Israel et al. 2019
[4] Israel et al. 2019

research subjects; rather, they are advisors and/or consultants who receive a stipend for helping with this effort.

The Difference Between a Community Engagement Studio and a Focus Group[5]

Characteristic	Community Engagement Studio	Focus Group
Purpose	Inform development, implementation or dissemination of research.	Qualitative data collection.
Approach	Multi-directional discussion	Uni-directional
Participants	Consultants. Identified as experts based on their personal and/or professional experience.	Research subjects. Screened, informed consent obtained.
Facilitator	Neutral – could be community member. Not affiliated with a research project. Uses techniques to balance power; understands power dynamic with mothers with experiences with mental health issues and/or opioid use, and is sensitive to their (possible) histories of trauma and other concerns. Uses guide for conversation: can diverge if relevant.	Research team member. Uses pre-approved script; cannot diverge.
Preparation	Coaching for Researcher on balancing expectations, managing potential power dynamics, and communicating in plain language. Orientation for Community Experts regarding research, roles and expectations, and the value of lived experience. Background materials for Facilitator regarding research questions, participants' experiences, and Researcher's goals for the session. IRB requirements may depend on institutional review.	IRB approval. Consenting of research subjects.
Compensation	Consulting stipend	Participant incentive
Use of Input	Participant comments and recommendations summarized. CES Team may help Researchers interpret and apply recommendations. Community Experts may be asked about their ability and willingness to participate in various stages of the research study discussed.	Participant comments transcribed. Transcription qualitatively analyzed. Findings reported in scientific journals and presentations.
Follow Up	Researchers are encouraged to continue to consult Community Experts interested in remaining involved.	None.

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[5] Israel et al. 2019

Partnering with Mothers and Others as Community Experts

Community Experts may be parenting or pregnant women with past or current experience of mental health conditions and/or substance use, family members, practitioners, policy makers or advocates. Mothers often feel judged, and mothers with experiences of mental health conditions or substance use may feel even more vulnerable. They may have experienced the negative attitudes and actions of others, who make assumptions about them, perhaps informed by stereotypes, and behave accordingly. Mothers may have past experiences contributing to trauma, either themselves or as the witness of bad things happening to others.

Consequently, addressing issues of participants' comfort and safety are paramount in any engagement scenario. The most important rule of thumb is dependability – that is, doing what you say you will do, showing up, and following up. Community Experts should be provided with information and choices regarding their participation and the extent to which they may choose to draw from their lived experiences to inform the discussion. Participants, who may have histories of victimization or violence, may be made uncomfortable or find themselves responding in negative ways to characteristics of the situation or to information shared by others. Literature regarding this topic shows that participants who have experienced trauma positively regard the experience of sharing their stories for research even if it may be triggering.[6] However, it is important to be alert to this possibility and take care to guide the discussion in a sensitive and respectful manner.

Confidentiality and Consent

The CES as described in this document was not deemed to be research by our Institutional Review Board. Therefore, signed informed consent was not a part of our CES process. It is advisable to check with your organization or university's Institutional

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[6] Abu-Rus et al., 2019

Review Board for their review and determination, and follow their procedures, as recommended.

Similar to a research study, however, Community Experts receive complete information and training on the CES process ahead of and again at the beginning of the planned session, and can opt-out of participation at any time along the way. As in any group situation (which may remind participants of group therapy, for example), it is advisable to remind participants that disclosure of any information is voluntary and to ask participants to respect the contributions of others. While the goal of the CES is to contribute to research, participants may find it beneficial to share their experiences and explore common concerns, as these may well shape the research agendas.

However, Facilitators or Researchers should refrain from asking Community Experts detailed or direct questions about their mental health or substance use status, beyond confirming their experience, as appropriate, for participation in the CES. It is important for participants to be mindful of this before engaging in the CES, and to be thoughtful and respectful during all encounters.

Note for conducting a virtual CES: If the CES will take place online using a virtual meeting platform, it is possible that some Community Experts, especially those who have experienced trauma, may feel uncomfortable with using a video function that "exposes" or "intrudes" into their home environment. In initial conversations with the Community Experts, the CES team should explain that participants can opt-out of the video function at any point during the CES.

> **Many women with mental health and substance use challenges may have had prior experiences with professionals or others who made negative assumptions about their capacity to parent their children safely.**

Helping Participants Feel Comfortable and Safe

Pregnant and parenting women with mental health and/or substance use issues may be, and may feel, particularly vulnerable to the judgments of others. Unfortunately, many women with mental health and substance use challenges may have had prior experiences with professionals or others who made negative assumptions about their capacity to parent their children safely; admittedly, some of the concerns of others, in some circumstances, may have been justified. Mandatory reporting of the risk or suspicion of harm to self or others refers to the obligation or requirement for

professionals who may have contact with vulnerable people (e.g., children, elders, disabled individuals) to report suspected or observed abuse. Health services researchers who are licensed clinicians or service providers may be required by law or their code of ethics to take action if the likelihood of harm to self or others becomes apparent. Laws vary from state to state; people who are required to report abuse may include teachers, social workers, physicians, or probation officers, for example. If you, as the Facilitator or Researcher, are in this position (e.g., a licensed mental health professional) and have any concerns about this issue, please check with your institutional review board or state licensing board for clarification of your responsibilities.

If you decide that mandatory reporting is your obligation in a CES-type of scenario, it is important for you to acknowledge your responsibility at the beginning of the session and proceed with transparency. It has never happened, in our several decades of research with this patient population, that we, as researchers, have been obligated to file a report of abuse or neglect. However, it is your responsibility to clarify your role and responsibilities, and to be transparent about these issues in setting up and conducting a CES with any patient population.

Benefits of the Community Engagement (CES) Model

The CES model provides Researchers and Community Experts an interactive, efficient, effective way to provide meaningful input into all phases of research. If conducted during the earliest stages of project development, a CES can be an effective tool to develop a strong partnership with community partners[7].

The CES provides community members the opportunity to learn not only about research and how it can benefit themselves, their families, or their community, but also to contribute to its development and execution in a way that increases Researchers' understanding of and sensitivity to the community and, ultimately, the value and meaning of their work. For Researchers who are not familiar with community engagement, it can open the door to a more participatory approach in their work.

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[7] Israel et al. 2019

How a CES benefits the community:

- Community voice is heard
- Engagement in how and what type of research is conducted
- Ownership of opinions and valued input
- Ability to impact the research process

Feedback from Researchers and Community Experts who have participated in past CES's indicates that the experience increases the Researcher's understanding of, and sensitivity to the community, and creates an awareness of community priorities, values and needs.[8] Participating in a CES often prompts Researchers to reflect on the significance and impact of their work.

Community Experts have indicated that the experience increases their understanding of the research endeavor, including the motivation of the Researchers and how and why research is conducted.[9] For example, the Researchers from the both of MMHRC CES sessions reported that the Community Experts' feedback increased their understanding of and sensitivity to the community and informed the feasibility and appropriateness of their projects. Community Experts from the two CES's agreed – the vast majority of the Community Experts who completed the CES evaluation reported that they contributed to the research projects by increasing the Researchers' understanding and sensitivity to the community.

> **Researchers from the both of MMHRC CES sessions reported that the Community Experts' feedback increased their understanding of and sensitivity to the community and informed the feasibility and appropriateness of their projects.**

[8] Israel et al. 2019

[9] Joosten YA, Israel TL, Williams NA, Boone LR, Schlundt DG, Mouton CP, Dittus RS, Bernard GR, Wilkins CH. Community Engagement Studios: A Structured Approach to Obtaining Meaningful Input from Stakeholders to Inform Research. Acad Med. 2015;90(12):1646-50 PMCID: PMC4654264. doi:10.1097/ACM.0000000000000794. PMID: 26107879.

2) The Community Engagement Studio Team

The CES is implemented by a team that includes a Community Navigator, Science Navigator, and a Manager. The team members must be knowledgeable about the research process and have experience engaging and maintaining relationships with diverse communities.

Community Navigator

The Community Navigator is a boundary spanner with familiarity with the target community, experience with academic-community partnerships, and understanding of principles of community engagement. They have experience working in diverse communities and have demonstrated a capacity to build rapport and trusting relationships with key community leaders.[10]

The Community Navigator's responsibilities include:

- Participating in the planning meeting with the CES team.

- Helping to identify, orient, and support Community Experts who participate in the CES.

- Coaching the Researchers on communicating with Community Experts with personal or professional experience with maternal mental health and/or opioid use.

- Identifying and building professional relationships with community organizations and community advocates who have an interest in building academic-community research partnerships.

- Developing and maintaining mechanisms to communicate with community partners, increase interaction between community partners and academic Researchers, and track the development of academic-community research partnerships.

- Supporting community education and outreach activities.

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[10] Israel et al. 2019

Hiring a Community Navigator from the community puts into practice fundamental principles of community engagement such as mutual benefit, respect and community capacity building. A respected community member is likely to have access to networks unfamiliar to someone who works in an academic setting.[11] Community Navigators may have developed skills as social workers, mental health counselors, community organizers, advocates, or community health workers, for example.

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[11] Israel et al. 2019

Science Navigator

The Science Navigator of the team provides guidance on identifying and recruiting Researchers to participate in the CES and coaches the Researchers on communicating effectively with non-Researchers and engaging Community Experts as consultants, rather than research subjects. The CES Team Science Navigator must have experience in patient-centered outcomes research, community-engagement, comparative effectiveness and community-based participatory research.[12]

The Science Navigator's responsibilities include:

- Participating in the planning meeting with the CES Team.

- Helping to identify, orient, and support Researchers who participate in the CES.

- Coaching the Researchers on communicating effectively with non-Researchers.

- Coaching the Researchers on engaging Community Experts as consultants.

- Developing a recommendation report from the Community Experts feedback to share with the Researcher.

- Encouraging Researchers to consult Community Experts who would like to remain involved as the research project develops.

Manager

The Manager will assist with the planning and implementation of the CES. They will work closely with the Community Navigator and Science Navigator to reach out to selected Researchers and Community Experts, securing the time and location for the CES, and preparing necessary materials. The Community Navigator, Facilitator, or Science Navigator could take on this role if needed.

The Manager's responsibilities include:

- Participating in the planning meeting with the CES team.

- Managing logistics such as securing a location and time for the CES that is convenient for the Community Experts.

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[12] Israel et al. 2019

- Making sure the appropriate documentation is completed for each CES, including capturing the Community Expert feedback from each session and the completion of evaluation surveys, and forms needed to process payments (e.g., external consultant form and the IRS W9).

3) The Facilitator

The Facilitator's task is to create a comfortable, safe environment that allows for open and frank discussion and to guide the conversation among Researchers and Community Experts. A skilled Facilitator does not interject their opinions or biases into the conversation.[13] The Facilitator should have experience working with mothers with experience of mental health and/or substance use and possess the ability to balance the differences in power

> **The Facilitator should have experience working with mothers with experience of mental health and/or substance use.**

that can naturally occur when Researchers and lay community members come together. Ideally, the Facilitator has relevant training or experience that prepares them to work with groups of individuals representing diverse social-economic backgrounds, with varied learning and communication styles.[14]

While individuals can receive formal certification as a Facilitator, it is not necessary. Individuals who are most successful in CES facilitation have been trained in the principles of community organizing or group facilitation, and incorporate a participatory approach into their style of facilitation. Ideally, the CES Facilitator appreciates that stakeholders' perspectives are shaped by their experiences in an environment where faith, class, race and culture play an important part in who we are and how we see the world.

The Facilitator's responsibilities include[15]:

- Explaining discussion ground rules (e.g., be concise, don't interrupt, stay on track, and maintain confidentiality).

- Listening carefully to the presentation and comments, as a way to keep the discussion on track.

- Using the predefined questions as the discussion framework.

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[13] Israel et al. 2019
[14] Israel et al. 2019
[15] Israel et al. 2019

- Watching the clock (1 to 1/2 -2 hours maximum) to politely move things along if someone is monopolizing the conversation, and to ensure that the two to three specific research questions/topics are addressed.

- Recognizing that more needs to be said, and in some cases, using probes and follow up questions when needed.

- Requesting examples when comments are unclear.

- Being comfortable with silence as people consider their answers.

- Guiding the discussion, only interjecting their own opinion and personal observations with intention and purpose.

In preparation for the CES, the Facilitator should receive and review the Facilitator CES Guide that includes a detailed overview of the CES process, a copy of the Researcher's presentation, and general background on the Community Experts. (See Appendix A.) If possible, it may be helpful for the Facilitator to attend the Researcher preparation meeting, to meet and get to know the Researcher.

A note for conducting a virtual CES: If the CES will occur online using a virtual meeting platform, it may be more difficult for the Facilitator to monitor the group's responses and requests. We suggest having an additional CES Team member assist the Facilitator by tracking the chat functions and checking participants' video images to ensure that those who want to speak are given the opportunity to do so.

4) The Researcher

Researchers focused on maternal mental health and/or opioid use/recovery are great candidates to apply to participate in the CES. In the application, Researchers describe their research and plans for community engagement including a summary of the problem or questions their project will address, target population, stage of research, and questions they want to propose to Community Experts along with feedback needed. (For more details on the application and recruitment email see Appendix B.) The CES team chooses the research project that appropriately matches and could benefit most from input from available Community Experts.

Once selected, the Science Navigator will email the Researcher the CES Researcher Guide that details the purpose and structure of the CES. (See Appendix C.) The Manager will then email the Researcher to request a short description of the research topic to provide the Community Experts in advance and to schedule a one-hour Researcher prep meeting for about two weeks prior to the CES.

In the one-hour meeting, the CES team will further explain how the CES works and what to expect, review the Researcher's presentation and planned questions, and provide guidance on communicating with the arranged Community Expert group. The CES team can recommend changes to the presentation as needed to improve clarity and ensure the language is appropriate and sensitive to the Community Experts' experiences.

Here are key concepts to convey when coaching Researchers[16]:

- The presentation should serve to elicit feedback from a group of knowledgeable consultants on how best to move forward with a research project.

- The Community Experts, while not trained in research, are the experts in the room.

- After making the presentation, the Researcher's role is primarily to listen, asking and answering questions for clarification.

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[16] Israel et al. 2019

- Researchers often use a language that non-Researchers may find difficult to understand. Jargon, technical terms and acronyms should be explained clearly or avoided altogether.

The Researcher's Presentation

The presentation must be brief – up to 15 minutes. It is important that the Researcher devote adequate time to prepare, as it can be difficult to explain research-related concepts in brief, plain language. It is not appropriate to use a presentation that was previously prepared for an academic audience, unless it was adapted/modified for a lay audience. Keep text to a minimum and avoid complex tables, formulas and diagrams.[17]

In preparing the presentation, the Researcher must remember Community Experts need to know:[18]

- What the Researcher is trying to find out, and why the Researcher thinks it is important.

- The Researcher's motivation or personal connection to the topic.

- How the planned research might impact people who would serve as research participants.

- What phase the research project is in and what kind of advice the Researcher needs.

- How the Community Experts' feedback will contribute to the research project.

The Researcher should prepare two to three specific questions and/or topics for the group to discuss.[19] The Facilitator will move the group discussion along to ensure that these items are all discussed.

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[17] Israel et al. 2019
[18] Israel et al. 2019
[19] Israel et al. 2019

5) The Community Experts

Community members, be they mothers, caregivers, peer specialists, advocates or providers are the key to the success of the CES. Ideally, they represent diverse backgrounds and are connected to the community in various ways.[20] Community members bring different experiences to the table and can provide insights from multiple perspectives. For example, a care manager or peer specialist who works with mothers in metal health/substance use treatment may have a very different, but equally valuable, perspective from a mother currently in recovery with a similar condition.

Generally, Community Experts should be a member of the population or community of interest and have[21]:

- Good verbal communication skills.

- Good listening skills.

- Desire to learn about research.

- Willingness to share his or her experiences.

The process of identifying people to serve as Community Experts will initially focus on having a diverse group of stakeholders, including those with personal and/or professional experience with maternal mental health and opioid use/recovery, with an end goal of creating a core group or pool of experts familiar with and committed to the CES process. Researchers studying maternal mental health and/or opioid use/recovery can benefit from engaging several different perspectives including: mothers who are in recovery as well as their family members, direct service providers, program planners and community organizers, and recovery coaches. It is important however, to consider how the makeup of the Community Expert panel may affect women participants who are in treatment and recovery and may have

> **Researchers studying maternal mental health and/or opioid use/recovery can benefit from engaging several different perspectives.**

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[20] Israel et al. 2019
[21] Israel et al. 2019

experienced trauma. You may, for example, inadvertently invite a mother as a participant and her current or prior therapist or counselor, if they are from the same community. It is probably wise to check for any "conflicts of interest" prior to conducting the CES session.

A note on working with mothers with mental health and/or opioid use experience: Certain research areas and topics discussed in a CES may be sensitive or triggering for mothers. By participating in a CES, mothers are choosing to engage with that content matter. It is therefore important that the Researcher and CES team treat the mothers (and all CES stakeholders) with the utmost respect and sensitivity. Additionally, the CES is not research, per se, and the CES team should not ask or collect information beyond what is needed to ensure an appropriate, diverse group of participants.

Recruitment Process

There are numerous strategies that can be used in the recruitment process but it is important to look beyond the "usual suspects"- those individuals who are commonly called upon to serve on Boards, Coalitions and positions where they are asked to represent an entire community.[22] Ideally a panel of eight to ten Community Experts should be present for an in-person CES and three to ten for a virtual CES. Sometimes life gets in the way and people have to drop out. For this reason, it is ideal to recruit a few extra people to ensure adequate participation.[23]

The MMHRC used two different recruiting approaches. For one of the CES's, we partnered with a long-standing community agency, which serves and employs women with experience with maternal mental health issues and opioid use, to help recruit a group of recovery coaches within their organization. For the second CES, we partnered with a state agency to recruit perinatal peer mentors within several statewide grant programs. These processes enabled us to reach a diverse group of Community Experts across the state who are not "usual suspects" and who have both personal and professional experience with maternal mental health issues and opioid use/recovery. In

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[22] Israel et al. 2019
[23] Israel et al. 2019

addition, through these approaches MMHRC built professional relationships with community organizations and community advocates who have an interest in building academic-community research partnerships. (See Appendix D for materials for recruiting Community Experts.)

Compensation

The experience and knowledge that Community Experts bring to the research process are tremendous assets; they should be appropriately compensated for their time.[24] MMHRC provided a stipend lump sum to an agency that allowed Community Experts who were staff members to participate during regular work hours, and gift cards to the Community Experts who participated outside of work hours. (See Appendix G for more details on the CES costs, including compensation.)
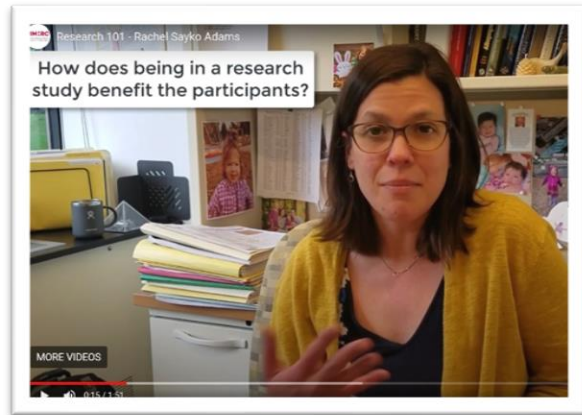
Community Expert Prep

Preparing Community Experts for the CES and buttressing their sense of agency is an important step in the CES process. Community Experts should come into the CES confident that they know what will occur during the studio, their questions and feedback will be heard and respected by all of the participants. Even though they might not have a research background, they will be able to contribute to the research process.

Prior to the CES, the CES team should email or mail the Community Experts: 1) the Community Expert CES Guide (Appendix E) that provides a general description of CES and the role of the Community Experts, and a glossary of research terms; and 2) an online survey that captures Community Experts' general background information (Appendix F). The experts can complete these materials at their convenience. It is important that these materials adequately prepare the Community Experts without being overly cumbersome or time consuming, which can be a barrier to participation. Community Experts are encouraged to contact the CES team with any comments and/or questions.

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[24] Israel et al. 2019

We prepared a series of videos of Researchers addressing questions provided by mothers regarding research – Research 101 for Mothers. These are available on the MMHRC website: https://research4moms.com/research-101/. Mothers provided video clips for Researchers regarding research participation, also available on the MMHRC website: https://research4moms.com/mothers-101-video-series/. Encouraging participants to view these videos in advance of the CES will help them prepare.

6) Planning and Logistics

In scheduling an in-person CES, it is important to choose a location and time that is as convenient and accessible for the Community Experts as possible. The Community Expert recruitment process will likely dictate your scheduling approach. For example, when recruiting within one partner organization it is best to have the organization set the date, time, and location that is most convenient for the group. When reaching out to several organizations, it may be most efficient to set the date, time, and location prior to recruitment activities. In the latter case, the CES team should be cognizant that Community Experts may not have flexibility during the weekdays due to work and other conflicts, and transportation or the lack of childcare may be a barrier to participation. CES are often held in the evenings and/or on the weekends and in locations accessible by public transportation and/or where there is adequate free parking available.

Food appropriate to the time of the meetings should be provided (i.e., breakfast, lunch, dinner or snacks). The meeting room should be equipped with a computer and a projector for the PowerPoint presentation and large enough to comfortably seat everyone.[25] If that technology isn't available, handouts can be prepared to summarize the research questions. In the spirit of inclusivity, presentation materials should be accessible (e.g., large font if on slides, appropriate reading level, etc.) Arrangements should be made ahead of time for any accommodations required to facilitate participation.

A note for conducting a virtual CES: If the CES will occur online using a virtual meeting platform, the CES team should ask about available resources, expertise and comfort with technology, and offer technical support to participants unfamiliar with the virtual meeting platform.
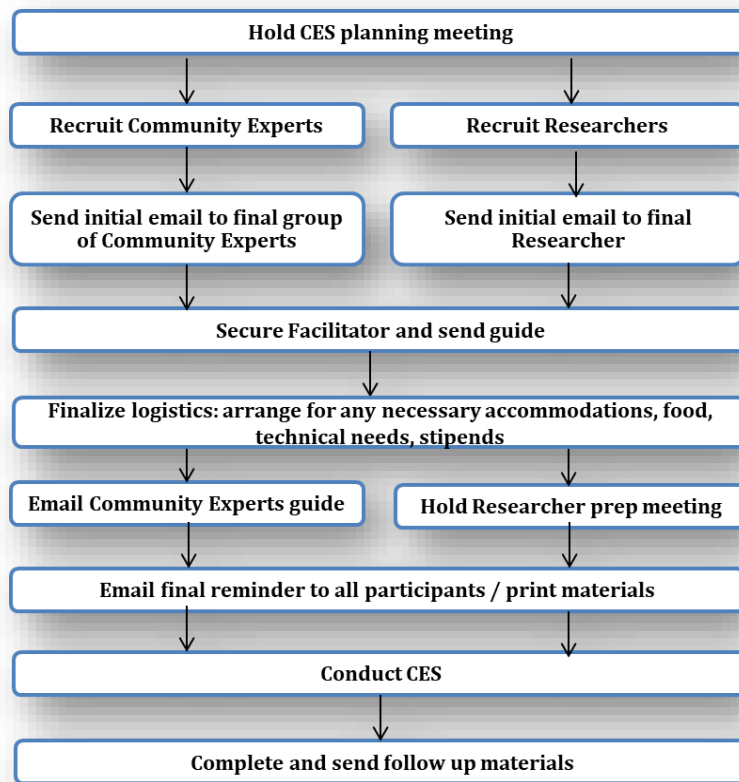
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[25] Israel et al. 2019

Step-by-step: Planning

Below are the outlined steps and a flow chart for preparing and hosting the overall CES.[26]

1) CES team planning meeting: Discuss goals, potential pools of Community Experts and Researchers, recruitment strategies, and outline team responsibilities.

2) Recruit community members for the expert panel.

3) Recruit Researchers to participate.

4) Email Community Experts to begin to establish a relationship, thank them for their participation, inform them of next steps, inquire about any accessibility issues, and send Initial Background Survey.

5) Email Researcher to confirm and thank them for their participation, send CES Researcher Guide, and schedule the prep meeting with the CES team.

6) Secure a Facilitator for the CES and provide the Facilitator CES Guide.

7) Arrange for food and drink on location. Check out other aspects of the location, such as convenience of restrooms, accessibility, etc.

8) Order and/or arrange Community Experts' and other appropriate stipends.

9) Email Community Experts the Community Expert Guide and research topic description.

10) Hold meeting with the Researcher/research team to review the presentation. Make recommendations for improvement if needed. Request the final version prior to the CES.

11) Confirm time and location with Community Experts, the Researcher, and Facilitator. Request any outstanding items.

12) Print and get together appropriate forms and materials [see below]. Adapt materials, as necessary, to overcome accessibility issues (e.g., large font for those with vision impairments).

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[26] Israel et al. 2019

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│ accommodations, food, technical needs, stipends  │
└─────────────────────────────────────────────────┘
         │                            │
         ▼                            ▼
┌────────────────────┐      ┌────────────────────┐
│ Email Community    │      │ Hold Researcher    │
│ Experts guide      │      │ prep meeting       │
└────────────────────┘      └────────────────────┘
         │                            │
         ▼                            ▼
┌─────────────────────────────────────────────────┐
│  Email final reminder to all participants /      │
│              print materials                     │
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│                  Conduct CES                     │
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│        Complete and send follow up materials     │
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What to bring to an in-person CES?

There are several items that the CES team should bring to an in-person CES:[27]

- Forms for sign-in sheet, Community Expert roster with contact info, and Consultant Stipend (as appropriate).

- All evaluation and comment forms (Community Expert, Researcher, and Facilitator)

- Flip charts, markers, name tags, pens.

- Researcher's presentation on USB.

- Laptop computer and projector, if needed.

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[27] Israel et al. 2019

- Copies of Researcher materials if needed such as study brochures, consent forms and recruitment flyers. Materials should be assessed for accessibility (e.g., reading level, research jargon, etc.).

To accommodate all learning styles and ensure transparency and trust between the CES team and Community Experts, we advise displaying flip charts around the room and using them to take notes during the CES.[28] Using flip charts allows for all participants to stay engaged in the studio as active participants and ensures the note-taker is writing down exactly what is being said. This method also allows experts to refer back to a point made earlier in the Studio and increased transparency/trust between the Community Experts and the CES team.

A note for conducting a virtual CES: Any forms or surveys for participants to complete prior to or following the CES, need to be created as online surveys that can be completed via smartphones because participants may not have access to printers or computers.

In the introduction, Community Experts were informed that the Science Navigator would take notes and share key points at the end of the CES. The Science Navigator did not share their screen or display the notes during the CES. Instead, we prioritized having the participants view each other's faces.

The CES Team should ask permission to record the meeting. This recording should only be used as a reference for notes and should never be shared without permission from participants.

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[28] Israel et al. 2019

Step-by-step: The CES[29]

1) Facilitator and Community Navigator greet all participants warmly when they arrive.

2) The Community Navigator passes around a sign-in sheet and assists the Community Experts with any questions.

3) When the group is seated, the Community Navigator welcomes everyone and asks them to introduce themselves.

4) Community Navigator, Science Navigator and Facilitator introduce themselves and describe their personal/professional background to build trust with the group.

5) Community Navigator sets the context by giving a brief overview of the purpose of the meeting and gives instructions on the forms provided to each participant (comment sheet, evaluation, and paperwork needed to process payment, if applicable).

6) Facilitator explains ground rules: be respectful of others' opinions and experiences, keep confidential any personal information that might be discussed in the meeting, stay on topic and give everyone a chance to participate.

7) Researcher introduces themselves and gives a brief presentation (no more than 15 minutes) describing their research project and the specific questions for the experts' consideration.

8) Community Navigator repeats the specific questions for the experts' consideration and opens up the group discussion.

9) Facilitator keeps the conversation on track, making sure everyone's voice is heard and the two to three research topics are addressed.

10) Science Navigator takes notes throughout the discussion.

11) The Science Navigator provides a high-level overview of key points made during the discussion.

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[29] Israel et al. 2019

12) Community Navigator thanks everyone for their participation and explains next steps.

13) The Community Navigator asks the Researcher, Community Experts, and Facilitator to complete an evaluation survey. See the Community Expert, Researcher, and Facilitator surveys in Appendix H. Community Experts hand in their Research Comment Form.

A note for conducting a virtual CES: Following the CES, the Manager emails the Community Experts the online Research Comment Survey and the online CES Evaluation. The Researcher and Facilitator also receive their respective online evaluation surveys by email. The Manager will email the participants online gift cards once the appropriate surveys are completed as applicable.

Costs

CES costs include CES Team time, compensation for the Community Experts, Facilitator fees, food, and supplies. Including CES costs in grant proposals is a good idea as institutional support is not guaranteed. (See Appendix G for time/effort estimates.)

7) Follow Up

The CES follow up materials provide the Researcher important feedback from the Community Experts, allow the CES team to learn ways to continue to improve future CES, and facilitate further collaboration between the Researcher and the Community Experts.

For the Researcher

A summary report including the Science Navigator's notes and verbatim written comments from the Community Experts is shared with the Researcher within one week of the CES. We recommend highlighting specific recommendations as related to the topics that were discussed during the meeting.[30]

The Researcher will also receive a one-page Continuing Community Engagement Guide that suggests ways for the Researcher to maintain appropriate communication with the Community Experts who reported interest in serving as a consultant as the research project develops (See Appendix I).

For the Community Experts

Notify them of any changes, adjustments and improvements made as a result of their input. Items shared as follow-up may include updated outreach materials, policy and procedural changes or significant accomplishments of the study due to advice received during the CES. If possible, give the Community Experts periodic updates on the project as well as any findings published or disseminated by the Researcher.[31]

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[30] Israel et al. 2019
[31] Israel et al. 2019

8) References

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Please use the following citation for this toolkit:

Maternal Mental Health Research Collaborative. (2020). *Community Engagement Studio Toolkit: For Researchers and Community Experts Interested in Maternal Mental Health and/or Opioid Use/Recovery*. Brandeis University Institute for Behavioral Health. Retrieved from http://research4moms.com.

Note: Images obtained from Google images, Pixabay and Shutterstock. No copyright infringement intended.

9) Appendices

Appendix A: Facilitator CES Guide

Dear Facilitator,

On behalf of the [insert organization name], thank you for participating in the upcoming Community Engagement Studio (CES). The CES provides Researchers an interactive, efficient, and effective way to engage with Community Experts who can provide meaningful input into all phases of research. We look forward to working with you and will do our best to ensure that the CES is a positive and productive engagement experience for everyone.

Facilitator CES Guide

Overview of a Community Engagement Studio (CES)

The CES is a structured session for Community Experts (e.g., stakeholders, including individuals with experience with maternal mental health issues and/or opioid use, practitioners, advocates, and policy makers) and Researchers to come together and discuss research in a way that is culturally sensitive and honors Community Experts' priorities, values and needs.

In a CES, the **Researcher** gives a brief presentation about their project and poses specific questions to a group of **Community Experts**. The Researcher uses language that is appropriate and sensitive to the Community Experts' experience, background and role. The discussion that follows is guided by a **Facilitator (you),** along with the Community Navigator, to elicit authentic and constructive input and feedback on the development and implementation of a study or the dissemination of research findings.

The CES is an interactive, consultative model; it is <u>not</u> a standing advisory board, a tool for recruiting research participants, or a data collection or research method (such as a focus group). The Community Experts who participate in the CES are not research subjects; rather, they are advisors and/or consultants who receive a stipend for helping with this effort.

Partnering with Mothers and Others as Community Experts

Community Experts may be parenting or pregnant women with past or current experience of mental health conditions and/or substance use, family members, practitioners, policy makers or advocates. Mothers often feel judged, and mothers with experiences of mental health conditions or substance use may feel even more vulnerable. They may have experienced the negative attitudes and actions of others, who make assumptions about them, perhaps informed by stereotypes, and behave accordingly. Mothers may have past experiences contributing to trauma, either themselves or as the witness of bad things happening to others. Literature regarding this topic shows that participants who have experienced trauma positively regard the experience of sharing their stories for research even if it may be triggering[32].

However, it is important to be alert to this possibility and take care to guide the discussion in a sensitive and respectful manner. However, Facilitators or Researchers should refrain from asking Community Experts detailed or direct questions about their

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[32] Abu-Rus et al., 2019

mental health or substance use status, beyond confirming their experience, as appropriate, for participation in the CES. It is important for participants to be mindful of this before engaging in the CES, and to be thoughtful and respectful during all encounters.

Your role as the Facilitator
The Facilitator's task is to create a comfortable, safe environment that allows for open and frank discussion, and to guide the conversation between the Researcher and Community Experts. The CES Facilitator appreciates that stakeholders' perspectives are shaped by their experiences in an environment where faith, class, race, culture and relationships play an important part in who we are and how we see the world.

During the CES, the Facilitator's responsibilities include:

- Explaining discussion ground rules (e.g., be concise, don't interrupt, stay on track, and maintain confidentiality).

- Listening carefully to the presentation and comments, to keep the discussion on track.

- Using the predefined questions as the discussion framework.

- Watching the clock (1 1/2 -2 hours maximum) and politely moving things along if someone is monopolizing the conversation and to ensure that the two to three specific research questions/topics are addressed.

- In some cases, recognizing that more needs to be said and using probes and follow up questions when needed.

- Requesting examples when comments are unclear.

- Being comfortable with silence as people consider their answers.

- Guiding the discussion and only interjecting your own opinion and personal observations with intention and purpose.

[Include if conducting online CES:] If the CES will take place online using a virtual meeting platform, it may be more difficult for the Facilitator (you) to monitor the group discussion. The CES Manager will provide additional support during the CES by tracking the chat functions and participants' videos to ensure that those who want to speak are given the opportunity to do so.

Below is the step by step procedure for the CES.

1) <u>Facilitator</u> and Community Navigator greet all participants warmly when they arrive.

2) The Community Navigator passes around a sign-in sheet and assists the Community Experts with any questions.

3) When the group is seated, the Community Navigator welcomes everyone and asks them to introduce themselves.

4) Community Navigator, Science Navigator, and <u>Facilitator</u> introduce themselves and describe their personal/professional background to build trust with the group.

5) Community Navigator sets the context by giving a brief overview of the purpose of the meeting and gives instructions on the forms provided to each participant (comment sheet, evaluation, and paperwork needed to process payment if applicable).

6) Facilitator explains ground rules: be respectful of others' opinions and experiences, keep confidential any personal info that might be discussed in the meeting, stay on topic and give everyone a chance to participate.

7) Researcher introduced themselves and gives a brief presentation (no more than 15 minutes) describing their research project and the specific questions for the Experts' consideration.

8) Community Navigator repeats the specific questions for the experts' consideration and opens up the group discussion.

9) <u>Facilitator</u> keeps the conversation on track, making sure everyone's voice is heard and the two to three research topics are addressed.

10) Science Navigator takes notes throughout the discussion.

11) The Science Navigator provides a high-level overview of key points made during the discussion.

12) Community Navigator thanks everyone for their participation and explains next steps.

13) The Community Navigator asks the Researcher, Community Experts, and <u>Facilitator</u> to complete an evaluation survey. See the Community Expert, Researcher, and Facilitator surveys in Appendix H. Community Experts hand in their Research Comment Form.

About one week before the CES, we will send you a copy of the Researcher's presentation and general background on the Community Experts. Please let us know if you have any questions and we thank you for participating in our CES.

Appendix B: Tools for Recruiting Researchers

CES Researcher Recruitment Invitation Template (sent via email)

Subject: An important opportunity to obtain input on your research from Community Experts

The [insert organization name] invites Researchers studying issues related to maternal mental health and substance/opioid use/recovery to apply to participate in a **Community Engagement Studio (CES) on [insert date].** Journals and funders increasingly require investigators to provide evidence of stakeholder involvement in framing and conducting research. CESs provide Researchers an interactive, efficient, effective way to engage Community Experts (e.g., stakeholders including individuals with personal or professional experience with maternal mental health issues and/or opioid use, practitioners, advocates and policy makers) who can provide meaningful input into all phases of research.

In a CES, Researchers give a brief presentation about their project and pose specific questions to a group of Community Experts. The discussion that follows is guided by a Facilitator to elicit authentic and constructive input and feedback on the development and implementation of a study, or the dissemination of research findings.

The CES is an interactive, consultative model; it is not a standing advisory board, a tool for recruiting research participants, or a data collection or research method such as a focus group. The Community Experts who participate in the CES are not research subjects; rather, they are advisors and/or consultants who receive a stipend for their efforts.

What does participating in the CES entail?
1. Complete the CES application to provide a brief background of your research project and interest in participating in a CES. The application should take only a few minutes to complete.

2. If selected, you will:

1. Prepare a brief (up to15 minutes) presentation with questions to pose to the Community Experts.

b. Attend a one-hour planning meeting with the CES team to review your presentation and planned questions, and receive guidance on communicating with the proposed stakeholder group.

c. Participate in the 1.5 to 2 hour CES, which will include your presentation with group discussion led by a trained Facilitator in response to your questions. Participants will complete a brief evaluation form.

d. Following the CES, Researchers are asked to inform the CES team of any changes or adjustments made to their research as a result of the input from Community Experts.

e. You will have the opportunity to maintain communication with Community Experts interested in serving as consultants as your research develops. We will provide you with suggestions for the most appropriate way to build a lasting partnership with interested Community Experts.

[Insert organization name] will recruit and prepare the Community Experts and the Facilitator for the CES, manage all logistics (including securing a location, scheduling, AV, meeting materials, refreshments and stipends for the Community Experts) and provide a brief report following the CES.

If you are interested in participating in a CES, please complete the initial application (see link below) by [insert date].

If you have any questions regarding the CES or the initial application, please contact [insert Science Navigator's name) at the [insert affiliated institution, university, or agency].

Application link: [insert application link]

CES Researcher Application Template (sent via Qualtrics)

Thank you for applying to participate in the [insert organization name]'s Community Engagement Studios. Please complete the below application.

1. Researcher/PI name

2. Researcher contact info (phone and email)

3. Researcher background/discipline

4. Name of project

5. Summary of the problem or questions the project will address

6. Target population

7. Stage of Research

8. Questions to propose to Community Experts and feedback needed

9. How do you plan for the Community Experts' feedback to impact your research?

10. If hosted in [insert state], able to attend in person or would you need to participate via video conference?

Appendix C: Researcher CES Guide

Dear Researcher,

On behalf of the [insert organization name], thank you for participating in our upcoming Community Engagement Studio (CES). The CES provides Researchers an interactive, efficient, and effective way to engage Community Experts who can provide meaningful input into all phases of research. We look forward to working with you and will do our best to ensure the CES is a positive and productive engagement experience for everyone.

Researcher Guide – Frequently Asked Questions (FAQs)[33]

Q: What is the purpose of the Community Engagement Studio (CES)?
A: The CES is a structured session for Community Experts and Researchers to come together and discuss research in a way that is culturally sensitive and honors Community Experts' priorities, values and needs. A CES may be used for different types of research, including both quantitative and qualitative studies.

Q: What is the difference between a CES and a focus group?
The CES is an interactive, consultative model; it is not a standing advisory board, a tool for recruiting research participants, or a data collection or research method such as a focus group. The Community Experts who participate in the CES are not research subjects; rather, they are advisors and/or consultants who receive a stipend for their efforts.

Q: Why should I participate in a CES?
A: Both funders and Researchers are seeking cost-effective and time efficient methods that engage groups of stakeholders to inform research questions, enhance research practices and improve the dissemination and use of findings. The CES creates a welcoming environment that works to empower community members to provide meaningful insight into all phases of research.

Q: What does participating in the CES entail?
A: The CES requires a small investment of your time. You should expect to spend on average about four hours of your time preparing for and participating in the CES. Researchers will:

- Prepare a brief (up to 15 minutes) presentation with questions to pose to the Community Experts.

- Attend a one-hour planning meeting with the CES team to review your presentation and planned questions, and receive guidance on communicating with the proposed stakeholder group.

- Participate in the 1.5 to 2 hour CES, which will include your presentation with group discussion led by a trained Facilitator in response to your questions. Participants will complete a brief evaluation form.

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[33] Israel et al. 2019

- Following the CES, Researchers are asked to inform the CES team of any changes or adjustments made to their research as a result of the input from Community Experts.

- You will have the opportunity to maintain communication with Community Experts interested in serving as consultants as your research develops. We will provide you with suggestions for the most appropriate way to build a lasting partnership with interested Community Experts.

Q: Can I recruit experts for my study?

A: You may not use the CES to recruit for your study. You may, however, share information regarding the study so that an expert can contact you or your research staff for more information outside of the CES.

Q: Why is there a Facilitator? Can't I just facilitate it myself?

A: The CES utilizes a trained Facilitator who has experience working with group processes and understands the principles of community engagement. The use of an independent Facilitator allows a Researcher to listen to feedback without having to worry about leading the process.

Q: Can I pick or recommend specific experts to participate?

A: The Community Navigator and the CES team are charged with the recruitment of Community Experts. Ideally experts should not have a prior relationship with the Researcher or the staff to ensure that feedback is open and honest.

Q: What do I need to know about mothers with mental health conditions and/or mothers who use opioids in order to participate? Are there things I am not allowed to say?

A: The Community Experts may be mothers or pregnant individuals with past or current experience with various mental health conditions and/or substance use. They may also have experienced trauma. Literature regarding this topic shows that participants who have experienced psychological trauma positively regard the experience of sharing their stories for research even if it may be triggering (Abu-Rus et al., 2019). However, participants should refrain from asking the Community Experts detailed or direct questions about their mental health or substance use status, beyond confirming their experience, as appropriate, for participation in the CES. It is important to be thoughtful and respectful during all encounters with the Experts.

Q: Do I need IRB approval to participate in a CES?

A: The CES is a process to inform the development, conduct or dissemination of research but is not considered research itself. The Community Experts who participate in the CES are not research subjects, rather, they are advisors and/or consultants.

Q: Can the information from the CES be used for research purposes or publication?
A: Yes and No. It is acceptable to describe the process and the input that you received, however the Community Experts are not research participants and therefore you cannot provide details of who participated or analyze the input by any demographics. You could quote them with their permission. If you have additional questions about this, ask the CES team.

An example of how the CES could be written about is below:

We received detailed input from a representative group of mothers with mental health conditions and/or mothers who use opioids using a structured process called the Community Engagement Studio (CES). The CES uses best practices for community engagement and an experienced team to overcome barriers to engaging groups of stakeholders and facilitate meaningful input from stakeholders. From the CES, we learned that consumers thought the registration process was too long and that the experience with the interdisciplinary team was very important in determining whether they would return to the clinic. We used the input from the CES to streamline our registration process and provide more opportunities for consumers to engage with our interdisciplinary team. Overall the input we received from participants was extremely helpful in understanding how our services are used and for identifying areas we could improve.

Researcher CES Guide – Presentation[34]

The presentation must be brief – up to 15 minutes at the most. It is important that the Researcher devote adequate time to prepare as it can be difficult to explain research-related concepts in plain language. It is not appropriate to use a presentation that was previously prepared for an academic audience. Keep text to a minimum and avoid complex tables, formulas and diagrams.

In preparing the presentation, the Researcher must remember Community Experts need to know:

- What the Researcher is trying to find out, and why the Researcher thinks it is important.

- The Researcher's motivation or personal connection to the topic.

- How the planned research might impact people who would serve as research participants.

- What phase the research project is in and what kind of advice the Researcher needs.

- How the Community Experts' feedback will contribute to the research project.

PowerPoint is a favored method of presentation among Researchers. This format can be effective in a CES, particularly if images or diagrams are used. However, PowerPoint slides, particularly those with a lot of text can also distract from the speaker so we recommend its use with caution. Handouts, prepared in advance, may be more appropriate to the situation or context. The presentation should be fairly short (no more than 5 to 10 slides) and should include:

1) Title of study, Researcher name, Researcher department/institution, date [note: during this slide the Researcher should describe their motivation or personal connection to the topic].

2) Brief description of the purpose of the study and why the study may be important to the community and potential impact on/benefit to the community.

3) Study design: who, what, when, where, how.

4) How will findings be used? (dissemination/utilization plan, translation for community use).

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[34] Israel et al. 2019

5) Describe current step/phase in the project and which component you need Community Experts to help inform/provide feedback.

6) Two to three questions to propose to Community Experts and hoped-for feedback.

Appendix D: Tools for Recruiting Community Experts

Below is a template of the one-page recruitment flyer that we emailed to partner organizations and posted on social media.

[Insert organizations name]'s Community Engagement Studio

> ### Join us online on [insert date] from [insert time]
> ### Connect with other recovery coaches and have your voice heard!

As a Community Expert, we need you now more than ever! You are one of the most important resources available to directly guide a research project and impact persons served.

What is a Community Expert? What makes me a Community Expert?

A Community Expert is an individual who has experience or possesses first-hand knowledge of a particular community or health issue. A Community Expert has a desire to learn about research, an ability to provide input and feedback, and a willingness to be an advocate for the community.

What is a virtual Community Engagement Studio (CES)?

The Community Engagement Studio (CES) is a structured online meeting for Community Experts and Researchers to come together and discuss research in a way that honors the priorities, values, and needs of the community.

Why should I participate?

Participating in a CES allows you to have a direct impact on research. Your participation and unique perspective help ensure that research will be relevant and meaningful to your community.

How a CES benefits the community:

- Community voice is heard. health issues.
- Ownership of opinions and valued input.
- Ability to impact solutions to public
- Ability to impact the research process.

Details:

We are inviting 10-12 Community Experts to participate in our virtual CES focused on maternal mental health and opioid & substance use/recovery research on **[insert date] from [insert time]**.

We will connect with you beforehand to learn about your technology access and experience to facilitate participation. We will guide you through the online format – you do not need to have any prior experience with online meetings.

Community Experts will receive a $[insert stipend amount] as a stipend for their contribution.

Community Experts will spend about an hour at home to prepare for the CES and about two hours to participate in the actual CES session itself.

Interested in participating or have questions? **Contact [insert Community Navigator name and email]**

Appendix E: Community Expert CES Guide

Dear Community Expert,

On behalf of the [insert organization name], thank you for agreeing to serve as a Community Expert for the Community Engagement Studio (CES). The CES provides Researchers an interactive, efficient, and effective way to engage people who can provide meaningful input based on their own experiences into all phases of research. The CES provides you the opportunity to not only learn about research and how it can benefit you, your family and community, but also to contribute to its development and implementation. Our goal is to increase the Researchers' understanding of, and sensitivity to the community and what makes the findings most relevant.

We appreciate your participation as an expert because of your knowledge of maternal mental health and/or substance use/recovery. The CES is a forum for learning for both Researchers and Community Experts. We encourage you to offer honest feedback, constructive criticism, and serve as an advocate for your community.

We look forward to working with you and will do our best to ensure that the CES is a positive and interesting experience for everyone!

Community Expert CES Guide – Frequently Asked Questions[35]

Q: What is the purpose of the Community Engagement Studio (CES)?

A: The CES is a structured session for Community Experts and Researchers to come together and discuss research in a way that is culturally sensitive and honors Community Experts' priorities, values, and needs. A CES typically takes about two hours to allow for a brief presentation from a Researcher and an interactive discussion, with everyone participating.

Q: What is a Community Expert?

A: A Community Expert is an individual who has experience or possesses first-hand knowledge of a community or health issue. For our purposes, we are looking for individuals with personal or professional experience with maternal mental health and/or substance use/recovery. A Community Expert has a desire to learn about research, an ability to provide constructive input or feedback, and a willingness to be an advocate for their community.

Q: Why are Community Engagement Studios important?

A: CES help assure that research meets the needs of people who live in a community or are affected by a specific health issue. Community Experts are one of the most important resources available to directly guide a research project. Through the CES, the Community Expert:

- Provides the Researcher with a deeper understanding of and sensitivity to persons served and their unique circumstances.

- Helps assess the relevance, feasibility, and appropriateness of the research activities.

- Engages the community in developing research questions and considering the best ways to find answers.

- Enables community voices to be heard, and impact the research process as well as the eventual uptake of research findings.

Q: Is it ok if I don't know anything about research?

A: You do not need to know anything about research in order to be a Community Expert. We just ask that you be yourself and share your thoughts and opinions based on your experience. We are providing you a glossary of some research terms and

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[35] Israel et al. 2019

several short Research 101 videos [see more details below] as helpful resources that you can review before the CES.

Q: How do I prepare for a CES?
A:

- Please finish reviewing this guide.

- Please complete the brief online survey that asks for your general background information (we emailed you a link to the survey). The survey should only take a few minutes. The background information you provide will be kept confidential.

- If you would like to learn more about research prior to the CES, the Maternal Mental Health Research Collaborative (MMHRC) created a series of Research 101 videos as an additional reference. You can find these videos on the MMHRC website: https://research4moms.com/research-101/.

- [If conducting a virtual CES:] Please make sure you have [insert platform name] downloaded on your computer or phone and that you are able to login. If you have any questions or problems with [insert platform name], please email [insert manager contact information]. She will help you set everything up to make sure you are ready to go before the CES.

- There is no need for additional preparation. You are participating in this CES because of your experience, background, and knowledge. Remember, you are already an expert!

Q: What can I expect?
A:

- The CES will last no more than two hours. After introductions, the Researcher will give a brief overview of their project and then pose specific questions for you to consider to help inform and/or improve the research project. The Researchers value your advice, opinions, and experience and would like to incorporate your feedback into their projects.

- Following the short presentation, the rest of the CES will be a group discussion around the two to three questions the Researcher posed to the group. A Facilitator will help moderate the discussion to make sure everyone has a chance to be heard.

- The CES is a group experience. We ask all participants to respect each other and to keep confidential any comments made during the CES by either the other Community Experts or the presenting Researchers.

- At the close of the CES, you will be asked to complete a brief online comment form and CES evaluation survey that will allow you to give additional feedback that might be helpful to the Researcher and future CESs.

- If you indicate that you would like to continue as an expert, the CES team or the Researcher may contact you in the future to get additional feedback on and/or help with other parts of the research project. You can of course decline to participate at any time.

Q: Do I have to share any personal information?
A: The CES is not a research study and the Researcher will not ask personal questions about your life. The questions asked during the CES will be about your thoughts and opinions about the presented research. Should you desire to share personal information during the CES, we ask all participants to keep the information confidential.

Q: Will I get paid for my time?
A: Yes. We will provide Community Experts a [insert stipend amount] as a stipend for their contributions.

Glossary of Research Terms[36]

Clinical Research: Generally, it is research that involves human subjects.

Comparative Effectiveness Research (CER): A comparison of existing interventions to determine which works best and to accelerate the translation and dissemination of interventions found to have solid evidence.

Community Engaged Research (CEnR): A distinct approach to research involving the building of trusted and authentic partnerships between Researchers and the community. CEnR requires that a relationship be built between the Researchers and the community in which it serves based on respect, trust and mutual benefit, and addresses community needs, and health issues as defined by the community itself.

Community-based Participatory Research (CBPR): Research that is conducted as an equal partnership between traditionally trained "experts" and members of a community. In CBPR projects, the community participates fully in all aspects of the research process. Community is often self-defined, but general categories of community include geographic community, community of individuals with a common problem or issue, or a community of individuals with a common interest or goal.

Data Analysis: The process of displaying, describing, summarizing, and looking for relationships among data.

Data Collection: The process of collecting evidence to answer research questions. Common data collection methods include gathering information from available resources (ex: hospital treatment costs or patient service uptake), making observations, conducting individual or group interviews, and administering surveys.

Data Interpretation: Drawing conclusions and meaning from the findings and results.

Dissemination: A planned process for maximizing the impact of the research project by informing the stakeholders who could benefit from the research and those who could make real-world changes based on the research.

IRB or Internal Review Board: A committee of community members, scientists, and others that ensures that any research done on and about humans is ethical and that the rights of study participants and communities are protected.

Human Subjects Protection: Laws set by the U.S. Department of Health and Human Services (DHHS) to protect a person from risks in research studies that any federal agency or department has a part in. Also called 45 CFR 46, 45 Code of Federal

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[36] Israel et al. 2019

Regulations Part 46, and human participant protection regulations. Research institutions require that anyone engaged in research that involves humans must complete training in human subjects protection.

Patient-Centered Outcomes Research (PCOR): Helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options. This research aims to answer patient-centered questions as defined by individual patients.

PI or Principal Investigator: The Researcher in charge of a research project and the person responsible for the overall management and direction of the project.

Recruitment and Retention: How Researchers reach out to the population they are interested in studying and get members of that population to agree to participate and stay in a research project throughout its duration.

Research Design: The overall strategy the Researchers will use to answer their research questions. Some research designs describe the current landscape of an important issue (ex: the number of women in MA who have used opioids before and after pregnancy). Other research designs try to explain and make predictions about how introducing something new to an existing issue will make a change (ex: adding peer specialist services to existing opioid treatment programs). The research design will influence what, how, and when the research project will measure, collect, and analyze data.

Stakeholders: Individuals, organizations or communities that have a direct interest in the process and outcomes of a research project. Stakeholders may be patients, caregivers, advocates, research volunteers or community leaders. The target stakeholders for the CES are individuals with experience with a particular health issue. We refer to stakeholders as "experts" and each is compensated for participation.

[insert organization name]: [insert organization background]

Appendix F: Community Expert Initial Background Survey (sent via Qualtrics)

Now that you have read the Community Expert CES Guide, please complete this brief survey so we can learn more about you. The background information you provide will be kept confidential.

Demographic Information
Gender:
Age:
City/Town where you work:
Race/Ethnicity: (check all that apply) □ African American □ Caucasian □ Hispanic/Latino □ Asian/Pacific Islander □ Native American □ Other (describe):
Experience
Please indicate the areas you identify and/or have personal or professional experience with (check all that apply). □ Motherhood and/or pregnancy □ Opioid use □ Cannabis use □ Alcohol use □ Nicotine use □ Cocaine use □ Other drug/substance use □ In recovery □ Perinatal mental health challenges □ Health advocate □ Policy maker □ Healthcare provider □ Peer Specialist/Recovery Coach □ Person served/consumer □ Behavioral health clinician or counselor □ Other (please describe):

Thank you for completing this survey as well as reviewing the Community Expert CES Guide. We look forward to working with you at the CES, hearing Researchers' ideas for upcoming studies, and learning from Community Experts' important feedback.

Appendix G: CES Time/Effort Estimates

Person/Item	Time/Effort	Total Estimated Hours
Community Navigator	1 hour CES team planning meeting 15 hours recruiting Community Experts 1 hour Researcher prep meeting 2 hour CES	19 hours
Manager	1 hour CES team planning meeting 3 hours on meeting logistics and prep	4 hours
Science Navigator	1 hour CES team planning meeting 3 hours recruiting Researcher 1 hour Researcher prep meeting 2 hour CES 1 hour CES notes	7 hours
Facilitator	.5 hour prep 2 hour CES	2.5 hours
Community Experts gift cards	1 hour prep 2 hour studio	3 hours

Appendix H: Participant CES Forms and Surveys[37]

Community Expert Research Comment Form

Researcher:_____ [Prepopulate]

Thank you for participating in today's Community Engagement Studio (CES). We'd appreciate your anonymous feedback on today's session.

Please be as detailed as possible. Your feedback is crucial to furthering the quality of the research discussed today. Feel free to use the back of the page for more writing space.

1. What did you think was good about the research ideas?

2. What challenges do you think a research project like this will have in the community?

3. What would you like to see the Researcher do differently or add to the project?

4. Do you have any additional thoughts about the ideas or the proposed project?

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[37] Israel et al. 2019

Community Expert Evaluation Survey

Thank you for participating in [insert organization name]'s Community Engagement Studio. Please complete the following survey to help improve the effectiveness of the Community Engagement Studio and the quality of the academic-community research partnerships that result. Your feedback will be kept anonymous, and your participation is appreciated.

Please tell us whether you agree or disagree with the following statements:

1) The scheduling/communications for this Community Engagement Studio session were handled in a timely and efficient manner.
□ Strongly agree □ Agree □ Disagree □ Strongly disagree

2) The allotted time for the Community Engagement Studio was sufficient.
□ Too much time □ Enough time □ Not enough time

3) The Community Engagement Studio Facilitator managed the allotted time sufficiently and addressed my questions and comments.
□ Strongly agree □ Agree □ Disagree □ Strongly disagree

4) I felt adequately prepared for the Community Engagement Studio.
□ Strongly agree □ Agree □ Disagree □ Strongly disagree

5) The Community Engagement Studio process was worth my time.
□ Strongly agree □ Agree □ Disagree □ Strongly disagree

6) The Researcher's presentation was easy to understand and gave me enough information to provide appropriate feedback.
□ Strongly agree □ Agree □ Disagree □ Strongly disagree

7) Would you participate in a Community Engagement Studio again?
□ Yes □ No

8) What do you feel was **your** contribution to the research project? Please check all that apply.

□ Increased the Researcher's understanding of the community

□ Increased the Researcher's sensitivity to the community

□ Gave feedback on the feasibility of the project

□ Gave feedback on the appropriateness of the project

□ Provided ideas on recruiting research participants

□ Provided ideas on research procedures, e.g., questions to ask and how to ask them

□ Provided ideas on how to inform the community about the project

□ Provided ideas on how to use results of project to benefit the community

□ Other (type here):

9) Please suggest at least one way the Community Engagement Studio could be improved in the future:

10) Can the Researcher(s) contact you sometime in the future for your feedback on other parts of the project as the research moves forward?

□ Yes □ No

If yes, please provide the best way to contact you: _____

Researcher CES Evaluation Survey

Thank you for participating in [insert organization name]'s Community Engagement Studio. Please complete the following survey to help improve the effectiveness of the Community Engagement Studio and the quality of the academic-community research partnerships that result. There are no known risks to completing this survey, and your participation is voluntary and greatly appreciated.

Please tell us whether or not you agree or disagree with the following statements.

1) The scheduling/communications for this Studio session were handled in a timely and efficient manner.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

2) The allotted time for the Studio was sufficient.
   □ Too much time □ Enough time □ Not enough time

3) The Facilitator effectively managed Community Expert feedback.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

4) The Community Experts provided me with valuable feedback.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

5) The Studio process was worth my time.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

6) The expert feedback was conveyed to me in an appropriate way.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

7) This Studio session will improve my research.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

8) I would recommend the Community Engagement Studio session to a colleague.
   □ Yes □ No

9) If relevant to your research, would you request a Community Engagement Studio in the future.
□ Yes □ No

10) Would you request input again on your current research from the individuals who participated in this Studio?
□ Yes □ No

11) What do you feel were the Studio experts' contribution to the research project? Please check all that apply.
□ Increased my understanding of the community
□ Increased my sensitivity to the community
□ Gave feedback on the feasibility of my project
□ Gave feedback on the appropriateness of my project
□ Provided ideas on recruiting research participants
□ Provided ideas on how to inform the community about the project
□ Provided ideas on how to use the results of my project to benefit the community
Other:_____

12) Has your perception about the role of patient or community stakeholders in research changed as a result of the Community Engagement Studio?
□ Yes
If yes, how has it changed:
□ No

13) What do you plan to change as a result of the feedback you received from the Studio? (check all that apply)
□ Research question
□ Research design
□ Level of community / patient engagement in research activities
□ Recruitment/retention strategies
□ Consent process
□ Data collection
□ Data interpretation
□ Dissemination
□ Change in number of questions (i.e. survey items)

☐ More patient-centered questions

☐ Less technical/medical jargon

☐ More culturally relevant questions

☐ Other

Please describe other:

☐ I do not intend to change anything

14) To what degree has the Community Expert input you received from the session impacted the community or patient-centered components of your project? This includes community or patient preferences, needs, wants and values.

☐ No impact

☐ Minor impact

☐ Moderate impact

☐ Major impact

Facilitator CES Evaluation Survey

Thank you for participating in [insert organization name]'s Community Engagement Studio. Please complete the following survey to help improve the effectiveness of the Community Engagement Studio and the quality of the academic-community research partnerships that result. Your participation is voluntary and greatly appreciated.

Please tell us whether or not you agree or disagree with the following statements.

1) The scheduling/communications for this Studio session were handled in a timely and efficient manner.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

2) The allotted time for the Studio was sufficient.
   □ Too much time □ Enough time □ Not enough time

3) The relevant experts were present at the Studio session.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

4) The Studio process was worth my time.
   □ Strongly agree □ Agree □ Disagree □ Strongly disagree

5) Would you recommend a Community Engagement Studio session to a colleague?
   □ Yes □ No

6) Would you facilitate a Community Engagement Studio in the future?
   □ Yes □ No

Appendix I: Continuing Community Engagement Tips for Researchers

Consultants, Not Research Subjects

Researchers have the opportunity to move beyond the one-sided approach of learning from Community Experts' experience as a knowledge development effort that informs your general understanding of an issue. Instead, we encourage you to continue to engage Community Experts as knowledgeable consultants who can provide you insightful, tangible advice on important components of your research project.

For example, Community Experts can contribute to research projects by:
- Prioritizing research topics
- Increasing the relevance to communities
- Strengthening recruitment and retention efforts
- Helping frame, review, or develop protocols and procedures
- Participating in data collection and analysis
- Assisting with data interpretation
- Increasing dissemination and uptake of research results

As consultants, Community Experts' voices should carry the same weight as other academic consultants and they should be appropriately compensated for their contributions and time.

Sensitivity and Respect

Certain research areas and topics may be sensitive or triggering for mothers with personal and/or professional experience with maternal mental health issues and/or opioid use/recovery. Therefore, it is important to remember that:
- In initial conversations with the Community Experts, you should state that you may discuss sensitive topics and that not only are the experts not required to share any personal experiences but they can also choose to not participate at any time.
- Researchers should treat the Community Experts with the utmost respect and sensitivity.
- It is inappropriate and unethical to collect unnecessary or excess information pertaining to an individual's background, mental health, or substance use.

Convenient and Accessible

- Schedule phone and/or virtual meetings during times that are most convenient to the Community Experts. This may be after work hours, on weekends or when childcare is available.
- If asking Community Experts to review materials or complete surveys, consider that they may not have access to printers or computers outside of work. Online surveys and communications should be smartphone compatible. Again, surveys should be regarding concrete advice on your project, not as a general data collection effort.