



STEERING COMMITTEE MEETING NOTES

July 19, 2024, 12:00 – 1:30 pm EST

I. ATTENDANCE

Steering Committee

Carmel McGrath, Engaged Researcher; Kimberly Strain, Community Partner; Evan Villeneuve, Community Partner

Project Management Team

Marc Cohen, Principal Investigator; Erin McGaffigan, Co-Principal Investigator; Airia Papadopoulos, Qualitative Lead; Myrna Finn, Research Assistant; Missy Destrampe, Project Manager; Maya Singh, Research Assistant; and Sophia Webber, Facilitator/Engagement Lead

II. INTRODUCTIONS, MEETING GUIDELINES, AND HOUSEKEEPING

The group reviewed the [meeting guidelines](#). Sophia reminded the group that the remainder of Steering Committee meetings are scheduled.

Future Steering Committee meeting dates:

- Monday, 9/30 12-1:30 CST
- Monday, 1/27 12-1:30 CST
- Friday, 11/22 11-12:30 CST
- Friday, 3/28 11-12:30 CST

Sophia reviewed the project timeline and noted that we are currently completing our third activity: Focus Groups. Focus Group findings will inform the design of the PCOR-EM tool. Sophia also walked through the remainder of the timeline, emphasizing that the team will work from now until February of 2025 to design and test the tool. During this time, Sophia will also create a Pilot Partner Subcommittee, made up of individuals representing engaged research projects funded by PCORI. This Subcommittee will guide the design and implementation of the pilot process for the tool.

III. FOCUS GROUP OVERVIEW AND PRELIMINARY FINDINGS

Dr. Airia Papadopoulos, the Qualitative Lead for the project, presented slides outlining the purpose of Focus Groups, information about Focus Group Participants to date, and preliminary findings. Airia emphasized that Focus Group analysis is still underway, and findings will continue to be updated.

Focus Groups Overview

Airia reviewed the purpose of the Focus Groups:

- To explore “good” or “effective” engagement
- To receive guidance on how to prioritize and measure the elements
- To inform draft measurement tool

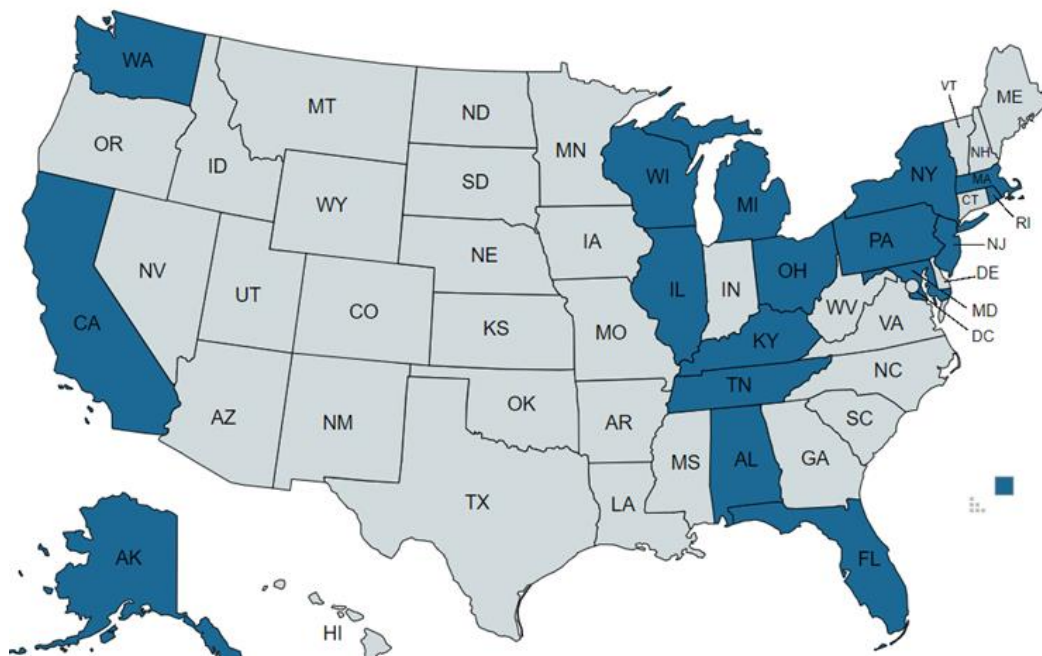


To date, we have hosted 6 Focus Groups, reaching 34 participants across 17 States. Airia provided insight into who participated in Focus Groups thus far.

DEMOGRAPHICS	Researchers	Facilitators	Patient / Partners
Participants (N=34)	n=12	n=12	n=10
Median Age	54	44	66
Race / Ethnicity <i>(Some participants selected more than one)</i>	American Indian or Alaska Native (1) Black or African American (1) White (11)	American Indian or Alaska Native (1) Asian (2) White (10)	Asian (1) Black or African American (3) Hispanic or Latino/Latina/Latinx (2) White (5)
Gender Identity	Female (8) Male (4)	Female (9) Genderqueer (1) Male (2)	Female (9) Male (1)

*One Researcher self-identified as queer. One Facilitator self-identified as “Autistic/ Multiply Disabled.” Another Facilitator reported lived experience with disability.

Airia noted that some participants selected more than one race or ethnicity. She also reviewed the geographic locations of participants, shown in the graphic below.





Preliminary Focus Group Findings: Review and Discussion

The Measurement Matters team is qualitatively coding transcripts from each of the six focus groups. Two team members are coding transcripts in partnership to support focus group learning and another team member is coding separately. As they move through the data, the team members are comparing findings, including similarities and differences in coding. Coding is still underway, but Airia reviewed preliminary findings emerging from our work so far. We provide a summary of this discussion below.

The team discovered that Focus Groups themes fell into four broad categories: people factors, approach factors, environmental factors, and outcomes. The top themes identified within these broader categories thus far are listed below:

What is Qualitative Coding?

Why did we use it for Measurement Matters?

Qualitative coding is a way identify themes in a piece of written text, such as a transcript of an interview or focus group. We can use qualitative coding to understand what focus group participants shared in each focus group and then across all focus groups. We can even count the number of times a topic came up to understand its level of importance to focus group participants.

In our project, team members reviewed transcripts from six focus groups to identify broad themes that emerged. The team then reviewed text within those broad themes to identify more specific topics within each theme.

One example of a broad theme would be the “approach” used to engage individuals in research. Within this theme, our research team then found different characteristics of approach as well as lessons learned from these approaches.

Top Approach Factors (300+ references)	
Time and Resources	Accessibility
Decision-Making	Facilitation Practices
Incentives	Recruitment and Outreach
Clear Communication	
Top People Factors (120+ references)	
Diverse Representation	Lived (Life) Experience
Top Environmental Factors (30+ references)	
Power Sharing and Collaboration	Environmental Buy In and Readiness
Top Outcomes (150+ references)	
Trust and Relationship Building	Feeling Valued
Active Participation	Successful Engagement

The Steering Committee discussed these and additional findings, described below:



- The Steering Committee discussed participants' comments on effective engagement
 - The coding team noticed that while participants may provide one answer to the question "what does successful engagement look like?" Participants tend to provide additional insights into effective engagement throughout the entire discussion.
- The Steering Committee was interested in knowing if the findings from the Focus Groups aligned with the findings from Consensus Methods.
 - Generally, the data does align, but we need to code further to know for certain.
 - We asked questions in Focus Groups beyond what we learned from Consensus Methods surveys. For instance, we are learning more about what makes certain elements of engagement easy or difficult to do well.
- Members highlighted managing bias in assumptions that may be present among Focus Group participants.
 - There was some concern that Focus Group participants may be biased in their responses. For instance, some Steering Committee members wondered if researchers would talk about their research being more 'engaged' than it really is, and community partners may present being more satisfied with the experience than they actually are.
 - The group discussed how focus groups can help minimize these 'biases.' For example, when we code transcripts, we are not looking only for participants' direct answers to questions, but also what people say throughout the entire focus group that may point to other viewpoints, challenges, and new learning that may not be so obvious. This approach allows us to get more colorful and in depth answers to our questions and protects against the tendency of people to answer how they might think we want them to answer.
- The Steering Committee discussed implications of findings on a wide range of research settings.
 - Steering Committee members discussed whether the limited representation in research settings (e.g., lab research) will influence our findings and our ability to apply our findings broadly.
 - The team recognized that there are many research settings within the United States, like laboratory or "bench science," that have less mandates or champions for engaged research, and because of this, less people doing this type of research. Even so, our own team can point to a few individuals in these types of settings that see the benefits and are eager to apply these concepts, when they have a chance.
 - Based on the data we have reviewed so far, our team believes our research will have broad applicability. Even so, the research team recognizes the minimal time and resources dedicated to this project. The research team hopes to identify additional funding to test the tool in various settings.
- Members noted the implications of Focus Group participants' experience of Focus Group findings.
 - Steering Committee members discussed whether Focus Groups findings are influenced by the Focus Group participants' type of experience and extent of experience.



- The team noted that it has been difficult to track “experience” since engagement practices are not standardized and people define their lenses (e.g., wearing more than one hat) and experiences (e.g., leading, facilitating, or participating in) differently. This reality impacts our ability to track responses as they relate to true experience.
- The differences in experience may impact the elements we learn about in the data since people can only speak to their experiences. For instance, if a partner isn’t aware that incentives were available, then they may not describe incentives as important.
- We are seeing differences in the type of answers provided by Focus Group participants and the lens they bring to engagement. For instance, patient partners tended to discuss issues of trust and relationship building often, whereas researchers focused more on time and resources.
- The Steering Committee discussed topics referenced more than others within Focus Groups.
 - Overall, Focus Group participants discussed Approach and People factors far more than Environment factors. In Focus Group discussions, we noticed that people tend to focus on approach factors, which may be because they are tangible.
 - Lower references to Environment doesn’t necessarily mean Environment factors are not important. Instead, these factors may be less understood than the approach people use and the personal characteristics that make engagement more successful.

IV. DESIGNING THE DRAFT TOOL

Marc, Erin, and Tam reviewed the knowledge and steps being used to inform the tool design, including previous research conducted as well this project’s Literature Scan, Consensus Methods, and Focus Groups.

Tool’s Purpose

The purpose of this tool is to measure an engagement process and to score that engagement on a scale from low to high. The tool may also enhance our understanding of whether certain outcomes are associated with high or low engagement. The tool should be feasible for people with knowledge of their engagement process to complete.

Measurement Categories

The group discussed some potential categories (sometimes referred to as domains) that may be addressed through the tool. These are:

- Communication
- Diversity
- Power Sharing
- Resources
- Logistics
- Trust
- Environmental Readiness



Finding Ways to Measure these Categories

Dr. Tam Nguyen, our Quantitative Lead, described the importance of trying to determine what is ‘most important’ and ‘least important’ to do in engagement as well as what is ‘easy to do’ and “difficult” to do in engagement. For instance, rather than simply list “communication” as an element of engagement, the tool will ask questions that sit on a range of less ideal and more ideal communication.

This is not an easy task. This also will not be a perfect task. We just need some idea of these answers so we can test these ideas when we pilot the tool. Seeking these answers will help us develop a tool that includes an engagement scale. The goal is for the scale to help us score answers and then compare those answers to their outcomes.

Tam also emphasized that the ideal tool should not be overly burdensome and should have about 20 questions or less. For the sake of testing, our goal is to build a larger pool of about 35 questions (called ‘items’), which we will refine through our testing process.

Measurement Tool Discussion

The Steering Committee provided a range of points as a part of this measurement tool discussion, which are provided below:

- Communication, trust, and power sharing are tightly linked together
 - A member noted that relationships, connection, and community are essential to engagement and often more motivating than other factors.
 - Airia noted that data from both Consensus Methods surveys and Focus Groups underscore this point.
 - Participants often mentioned that elements build upon one another and may be difficult to separate.
- Respect is a critical element of effective engagement
 - One member noted that as a patient partner, respect is very important to them.
 - Airia noted that respect and trust emerged often in Focus Groups, particularly among patient partners.
 - During one Focus Group, a patient partner noted that when trust is built, partners are more likely to forgive other mistakes or gaps in the engagement process.
 - Participants also offered insights into how trust and respect are built within engagement processes.
- We need to capture high and low levels of each concept, such as trust, in the tool
 - We want to build a tool that can distinguish a project’s capacity level for engagement. For instance, rather than simply measure *if* communication happened in an engagement project, we would measure how effective the communication was.
 - The project team will work with the Steering Committee to brainstorm questions that demonstrate a range of capacity. For instance, what questions capture “high” or effective trust building? What questions will demonstrate “low” or poor trust building?



- The tool may benefit from including supplemental resources
 - A member suggested the team consider providing illustrative examples of certain concepts, such as trust, to help respondents
 - It may be possible to partner with projects working on tools, such as those that measure participants' perceptions of engagement
- We must determine what role measuring perceptions of engagement will play in our tool
 - Many Science of Engagement projects are developing tools to measure feelings and perceptions of engagement. It is important to consider that sometimes people walk away from engagement feeling good, but a deeper inspection of the process indicates a lack of important elements, such as power sharing
 - One participant noted that some of the concepts are more tangible than others. They noted that some of the domains, such as communication and power sharing, may be more about feeling.
 - A member reminded us of the Maya Angelou quote: "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."
 - The team will consider if "engagement behaviors" measured by the tool correspond with feelings about engagement
- We should consider multiple uses for the tool
 - The tool may be useful for measurement as well as capacity building
- The tool must balance competing priorities to be usable and applicable to a range of engagement projects
 - There is a need for balance between getting the information we need and avoiding a burdensome tool that creates survey fatigue
 - There is a need to balance specificity of questions so they are applicable across unique processes but still gather the information needed

A member noted that engaging the Steering Committee and our Technical Advisors is critical for balancing the project team members' nitty gritty review of the data and tool development with the bird's eye view that our partners process.

Science of Engagement Learning Network Discussions

Measurement Matters is funded by a PCORI Science of Engagement award. PCORI hosts a "Learning Network" to bring all the Science of Engagement awardees together to network and share lessons learned. Erin provided an overview of the most recent Learning Network meeting:

- Many projects are still in the early design stages and testing out strategies for engagement
- Many projects are focused on designing tools to assess perception of engagement

At the most recent meeting, Sophia presented as part of a panel discussion about "preparing team members for discussions about complex research topics." Sophia drew from previous Steering Committee meeting discussions about training in engagement to inform her presentation. She focused



on the need to prioritize co-learning for all those participating in a project and to ensure researchers receive training on engagement best practices.

V. COGNITIVE TESTING DESIGN AND OVERVIEW

Airia walked the group through our next qualitative activity, Cognitive Testing. Cognitive Testing is a method to identify and correct problems with survey questions. It entails asking a participant draft survey questions while collecting verbal information about the survey responses. The purpose is to evaluate the quality and clarity of a question and determine whether the question is generating information that we intend to gather. The facilitator may give “think-aloud” prompts, such as: “Please walk me through what is going on in your mind as you answer this question.” Or they may ask probing questions, such as: “I noticed you paused when answering. Why?” or “Please tell me what this question means, in your own words.”

Cognitive testing will begin in September after we design the tool. It will occur over Zoom with 10-15 individuals who lead or manage PCOR activities. Participants will receive \$50 gift cards.

The group discussed Cognitive Testing and highlighted the following points:

- Ensure questions capture the real experiences of everyone in a project
 - One member noted that in her experience with other surveys around engagement, she found that the questions asked do not accurately paint a picture of her experience. She has found that some surveys ask questions that she has only “positive” answers to even though her experience in the engagement process was not positive.
 - For instance, sometimes questions such as “did you have appropriate resources” or “were you supported” do not paint the whole picture
- Determine Cognitive Testing participant representation
 - The team must decide if participants will include both engaged researchers as well as engaged partners. This will be determined in part by ensuring those who use the tool have the information necessary to answer the questions.
 - For engaged projects that are less effective, it is likely that community partners may not have access to the information necessary to answer all questions in the tool. In strong engagement, those leading the project may very well be community partners.
 - The group noted that it is important to have diverse opinions during the testing of the tool to ensure our questions paint the whole picture.
- Review from Steering Committee members is essential
 - The group will explore the opportunity to conduct additional Cognitive Testing with Steering Committee members.

VI. NEXT STEPS

- Steering Committee members will fill out the meeting evaluation survey
- Sophia will develop and share meeting notes and recordings
- The Project Team will share Focus Group findings when coding is finished



- The Project Team will explore the possibility of additional Cognitive Testing with Steering Committee Members