



STEERING COMMITTEE MEETING NOTES

January 29, 2024, 1:00 – 2:30 pm EST

I. ATTENDANCE

Steering Committee

Carrie Leach, Engaged Researcher; Carmel McGrath, Engaged Researcher; Angela Ruddock, Community Partner; and Evan Villeneuve, Community Partner

Project Management Team

Marc Cohen, Principal Investigator; Missy Destrampe, Project Manager; Alexa Fleet, Research Assistant; Dani Foster, Literature Scan Lead; Erin McGaffigan, Co-Principal Investigator; Tam Nguyen, Quantitative Lead; Airia Papadopoulos, Qualitative Lead; Maya Singh, Research Assistant; and Sophia Webber, Facilitator/Engagement Lead

II. INTRODUCTIONS AND MEETING GUIDELINES

Meeting attendees introduced themselves and shared brief background information. The group currently includes members with backgrounds as community or patient partners as well as researchers. Project team and Steering Committee members are joining from the United Kingdom and across the United States.

The group also reviewed the [meeting guidelines](#). These guidelines are “living” and will evolve over time based upon suggestions from the group and lessons learned over the course of the project.

III. ABOUT THE FUNDER: PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

The team leads, Marc, Tam, and Erin introduced the project and provided the following context:

- The Measurement Matters project is funded by the Patient Centered Outcomes Research Institute (PCORI). Our project is one of seven projects funded by PCORI’s Science of Engagement award.
- PCORI is a U.S.-Based funding organization. PCORI prioritizes patient-centered outcomes and requires those they fund to engage patients and other people with lived experience in the design, implementation, and dissemination of projects.
- The Measurement Matters project management team has worked with PCORI since 2020 on three capacity building projects: the Sages’ Symposium and the Aging PCOR Learning Collaborative 1.0 and 2.0 (Advanced Engagement)
 - The Sages’ Symposium was a virtual conference hosted in 2020 to expand researcher’s readiness to engage older adults as research partners.
 - The Aging PCOR Learning Collaborative began in 2021 and is ongoing. This project aims to build engagement capacity through training and education products.
 - Carrie also brings PCORI experience to the group and through her PCORI-funded capacity building project which is developing curricula for older adults who want to be research partners. This project is also developing a toolkit to assist older adults to connect with others through technology.



IV. WHAT DO WE MEAN BY ENGAGEMENT?

Sophia provided an “operational definition” of “engagement.” When we say engagement, we mean that “people who have lived experience in the research topic are engaged in the design, implementation, and dissemination of that research.”

Sophia noted that many different terms may be used to discuss this work, such as “public and participatory involvement” and “community-based participatory research.” By using the term “engagement,” we hope to capture the shared values of all these terms.

V. ABOUT THE MEASUREMENT MATTERS PROJECT

Most people do not agree on the elements that make up good engagement. Additionally, we lack an understanding of how “good” engagement impacts research outcomes. The Measurement Matters project seeks to study the “science of engagement.” We want to develop and validate a tool to measure engagement. For now, we are calling this tool the **Patient Centered Outcome Research Engagement Measure (PCOR-EM)**.

Project Timeline

Marc and Tam reviewed the project’s two-year timeline. Year 1, which began in December 2023, focuses on developing domains (or topics) for this tool. This phase of the project includes the following four activities:

- Literature Scan (month 1-3)
- Consensus Methods (month 4-6)
- Focus Groups (months 6-8)
- Cognitive Testing (months 9-12)

In year 2, we will pilot this tool. Tam provided insights into some of the methods we will use to pilot the tool. Tam will provide a training on our methods for team members, Steering Committee Members, and Technical Advisors.

Project Goals

This team is coming with some assumptions and values. Erin reviewed these with the group:

We aspire to create a tool that:

- Uses plain language
- Can easily be used
- Centers equity and addresses disparities
- Can be used across disciplines, settings, populations
- Can be used across multiple engagement approaches

We aspire to develop this tool through a process that:

- Includes those most impacted
- Defines ‘expertise’ broadly
- Involves ‘experts’ early and often
- Is accessible and inclusive
- Supports constructive dialogue and conflict
- Incentivizes financial and non-financial participation



Steering Committee Feedback

The group raised important questions to consider in the tool development, including:

- How will we capture the broad range of experiences with engagement?
 - Members noted that standardizing the tool may be challenging due to varying degrees of knowledge about engaged research amongst the public
 - This may mean that assessing community partners' preparation and understanding of engaged research is a critical part of this tool
- How will we implement the tool?
 - Members noted that supporting researchers to evaluate their engagement processes is difficult. Even in environments like the U.K., where engagement is mandated, conducting evaluations remains a challenge.
 - The [UK Standards for Public Involvement](#) is a tool for assessing effective engagement, used for these evaluations.
 - This challenge underscores the need to develop an easy-to-use tool
- How will we capture the quality of engagement beyond quantitative metrics?
 - Members noted that institutions, like funders, often prefer metrics and numbers. This preference can overshadow equally important measures of engagement, such as stories about impact.
 - We will use our qualitative methods during the first 12 months of the project to capture stories and then try to figure out how to measure elements described in stories.

VI. PURPOSE OF THE STEERING COMMITTEE

Sophia reminded the group about the purpose and role of the Steering Committee, as discussed in one-on-one orientations. Steering Committee members will engage in bi-monthly 90-minute meetings with the Project Management Team to share their expertise and backgrounds in engaged research and enforce project values. We hope to bring up to 8 individuals onto the Steering Committee and are still in the process of building the group. Steering Committee members may choose to receive \$1200 USD stipend as compensation for their time and expertise. Sophia noted that additional information about the Steering Committee purpose, expectations, logistics, and compensation in the [Charter](#), stored in the [Measurement Matters Resource Center](#), a google drive folder. The Charter is a living document that will be updated based on Steering Committee feedback and lessons learned throughout the project.

VII. DISCUSSION ON ENGAGEMENT

The Steering Committee discussed why engagement matters in their work and shared more on their personal backgrounds. Themes from the discussion are below:

- Improving engaged research
 - Members highlighted the need to improve the quality of engaged research. Even as it becomes more common to conduct engagement, few researchers have the knowledge or skillset to “do” engaged research.



- Surface level engagement
 - Members noted that although engagement is becoming more common and is even required by some funders, it is often done in a “shallow” or “check box” way. Members noted the following issues that contribute to “shallow” engagement:
 - Community partners (public contributors) are often consulted as an afterthought when decisions have already been made.
 - Community partners are consulted about the problem that impacts them, but engagement ends there. Researchers fail to establish authentic partnerships that drive research across the design and implementation.
 - Researchers fail to disseminate research back into the community, which leads to lack of trust and a hesitation to engage.
- Engagement improves outcomes
 - The group highlighted their experiences with engagement improving research. Members noted that funders and researchers alike are beginning to recognize engagement as a crucial element to designing meaningful health interventions.
- Pursuing meaningful engagement
 - Members noted that while many researchers are committed to engagement, they face difficult questions, including:
 - What does meaningful engagement entail?
 - How do we avoid tokenizing people?

VIII. NEXT STEPS

- Sophia/Collective Insight team to send the follow up materials to the Steering Committee including:
 - An [evaluation survey](#)
 - A link to the [Zoom meeting recording](#)
 - A link to the [Measurement Matters Resource Center](#), which includes materials such as the [Charter](#), meeting notes, and [slide deck](#)
 - A [When2Meetpoll](#) request for Steering Committee members to submit their availability for bi-monthly meetings
- Steering Committee members will send Sophia:
 - [When2Meet poll](#) response
 - Response to evaluation survey
 - A brief bio and headshot
- Dani and Airia will [video record an update](#) on the Literature Scan and Consensus Methods phases of the project to be shared with the Steering Committee



- An optional discussion session will be hosted for Steering Committee members who wish to discuss these activities in a live meeting