

# STEERING COMMITTEE MEETING NOTES

January 29, 2024, 1:00 – 2:30 pm EST

# I. ATTENDANCE

# **Steering Committee**

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

## Project Management Team

Marc Cohen, Principal Investigator; Erin McGaffigan, Co-Principal Investigator; Tam Nguyen, Quantitative Lead; Myrna Finn, Research Assistant; and Sophia Webber, Facilitator/Engagement Lead

#### II. INTRODUCTIONS AND MEETING GUIDELINES

The group introduced themselves and shared where they are joining from. The Steering Committee currently includes members joining from the United Kingdom, Canada, and across the United States. The group also reviewed the <u>meeting guidelines</u> and added "taking breaks when needed" to the list.

#### III. STEERING COMMITTEE HOUSEKEEPING

#### Measurement Matters Google Drive

Sophia walked the group through the <u>Measurement Matters Google Drive</u>, which functions as a resource library for the project where Partners can access project newsletters, recruitment flyers, as well as a specific corner dedicated to the Steering Committee (SC). This corner includes:

- SC Meeting <u>Slide Decks</u>
- SC Meeting <u>Agendas</u>
- SC Meeting Recordings

- SC Meeting <u>Notes</u>
- SC Resources (such as SC Charter)

Sophia also highlighted the <u>Project Webpage</u> where information about the project is publicly shared, including the bios and pictures of our partners. Steering Committee partners that have not yet shared their bios and/or pictures but would like to may do so through this link: <u>Partner Bios Survey</u>

#### Steering Committee Scheduling

The Steering Committee aims to schedule the remainder of meetings in advance to improve predictability for members. SC members live in a variety of time zones, making scheduling challenging. To accommodate all members, Sophia suggested hosting meetings on an alternating schedule of later Monday meetings and slightly earlier Friday meetings. The group acknowledged the difficulty of making schedules work for everyone and thanked Sophia for her effort to be accommodating. Sophia will send along meeting invitations for the following meeting dates and members will respond if a significant number of meetings will not work for them or if they have additional suggestions.



## Potential meeting dates:

- Monday, 5/20 12-1:30 CST
- Friday, 7/19 11-12:30 CST
- Monday, 9/30 12-1:30 CST

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

#### IV. SETTING THE STAGE: MEASUREMENT MATTERS CONCEPTUAL PROCESS

The group discussed the overall project timeline and process, including how the Measurement Matters goals and activities build off the team's broader experiences with engagement and Erin's 2011 dissertation.

### Project background

While getting her PhD in Public Policy at University of Massachusetts, Boston, Erin conducted research on how long-term care programs for people with disabilities and older adults engaged service users in the design of their programs. Informed by a literature scan, web-based survey, and confidential interviews, Erin developed the PAE (people, approach, environment) Attention Framework. The PAE Attention Framework helps us understand engagement by identifying the people, approach, and environmental factors that impact engagement process and outcomes.

Established in 2014, Collective Insight, led by Erin, uses the PAE Attention Framework to guide engagement initiatives within research, program, and policy design. These experiences added to our understanding of the PAE Attention Framework and prompted thinking around how we might measure engagement using the PAE factors.

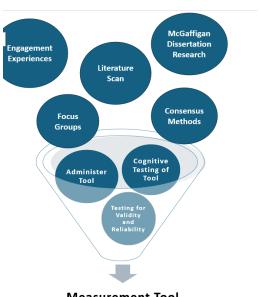
The Measurement Matters project is built off these experiences and offers us the opportunity to 'pressure test' the PAE Attention Framework as a means of measuring engagement.

#### Project activities

In the first year of the project, we are implementing a Literature Scan, Consensus Methods, and Focus Groups, We will use this data to draft our measurement tool and improve it through Cognitive Testing, a process that allows us to learn from participants as they try to use the tool so that we can improve it.

In the second year of the project, we will pilot the improved tool among a pool of researchers conducting engagement. Dr. Tam Nguyen will lead the analysis of the results of this pilot to test the validity and reliability of the tool.

Altogether, this process allows us to crystalize our concepts of engagement so that we can create a meaningful and useful measurement tool.



**Measurement Tool** 



#### **Overall Process Discussion**

The Steering Committee highlighted important complexities to consider as we move towards building the tool, including:

- Potential intersections between People, Approach, and Environmental factors
  - A member highlighted the potential relationship between factors and noted that the tool may need to account for this.
- The range of experience and knowledge among community partners
  - One member shared their experience as a community/patient partner. They explained that community partners often lack the traditional knowledge and qualifications required in the research world, which can be intimidating and limit a partner's ability to contribute to their full potential. Over time, this can improve as a partner learns to navigate the research space. The measurement tool may need to account for these differences in experience, confidence, and knowledge of various patient partners.
  - The group also discussed how a partner's confidence and preparedness may result from key approach factors, such as training and information sharing. The tool could measure these factors.
  - This issue will also impact who we select as our target audience for the tool. If engagement is not done well, a community partner will likely not know the answers to many of the questions in the tool. In fact, taking the tool in collaboration with a partner may in and of itself be an indicator of good engagement.
- Potential response bias in the tool
  - One member shared their experience with researcher bias in rating engagement experiences. They shared that often a researcher may think that their engagement process was amazing because it 'checked all the boxes,' but this perception can be in serious conflict with the actual experiences of the patient partners they engaged.
  - The group also noted that environmental factors, such as a historical lack of inclusion or people factors such as a lack of experience, may also lead community partners to rate an engagement experience highly merely because it happened, even if the process itself was not very effective.
  - The group brainstormed ways to account for this bias in the tool, such as designing
    questions that focus on the key factors of meaningful engagement rather than the
    perception of engagement.
    - For instance, rather than ask the researcher if their process was well done, we might ask if they shared educational materials with partners ahead of time.

## V. LITERATURE SCAN AND CONSENSUS METHODS OVERVIEW AND DISCUSSION

#### Literature Scan Introduction

A Literature Scan is a method for systematically, but swiftly, reviewing and synthesizing new literature when a full literature review is not possible. Our Literature Scan sought to identify and analyze literature



about engagement published after November 2022 as well as all literature shared with us by our Technical Advisors and Steering Committee Members. This process led to over 80 sources to review and synthesize.

### **Literature Scan Findings**

Our Project Team continues to conduct an in-depth analysis of the sources identified and will produce a final report and several 'snapshots' exploring key topics in more detail. In the meantime, the Project Team developed a <u>preliminary report</u> based on an initial review of these sources. This review also produced our preliminary list of key factors that influence engagement.

#### Consensus Methods Introduction

In our second activity, Consensus Methods, roughly 30 survey participants, called Expert Panelists, will take a series of surveys. These Expert Panelists will include a range of people based in the U.S. with engagement experience, including researchers, community/patient partners, and other experts, such as engagement facilitators. Three or four rounds of surveys will be administered to the Expert Panelists to illuminate the key factors of engagement that should be measured to understand engagement impact. After each round, the survey will be revised to include only the key factors that Panelists most agreed upon. The new survey is sent back to Panelists to gain further agreement and clarity. Through this process, we strive to produce a refined list of key factors, which we will seek to refine further through Focus Groups. On Member described this process as a means of "distilling to the essence."

Our Project Team collaborated with our Technical Advisors (TAs) to inform our Consensus Methods materials, including our survey, consent forms, and outreach materials. TAs provided the following insights as a part of that process:

#### Survey Content

- TAs identified factors that impact engagement that were not clearly captured in the Literature Scan. These suggestions were incorporated into our list of key factors for the Consensus Methods Survey
- TAs suggested strategies for how we might describe the key factors in the survey to improve clarity

#### Accessibility

- TAs reviewed our consent forms and survey instructions to ensure simplicity and transparency
- TAs suggested accommodations for Panelists, such as providing the option to take the survey by phone with a Project Team member

#### Diversity & Inclusion

- TAs identified language barriers to non-US experts due to the differing uses of engagement terminology, such as "involve." As a result, The Expert Panelists will include only U.S. based engagement experts
- TAs informed the design of panelist demographics questions, including the addition of language explaining why we are requesting certain information



# Consensus Methods Recruitment

The Project Team is collaborating with our partners to recruit eligible Panelists. Thus far, we have recruited 31 potential panelists, about 50% of which identify as community/ patient partners and 50% identify as engaged researchers and other experts. The group discussed our recruitment to understand what lenses may be missing and how we may reach them:

- Members discussed the need to capture diverse lenses in our recruitment
  - Members noted that the community engagement field tends to be majority women and majority white and recommended seeking greater diversity in gender, race, and ethnicity
  - Members noted that older adults, people with gaps in literacy, and people who lack digital access frequently fall through the cracks in recruitment processes
  - o Members suggested prioritizing diversity in age and research experience
    - Members noted that diversity here will help us capture the range of researcher experiences. For instance, researchers' experience with engagement often varies based on their tenure/experience and funding. A recent PhD will likely have a different experience with conducting an engaged research project than a high-level researcher with access to high levels of grant funding.
  - Members also noted that funders of engaged research and policymakers involved in public engagement policy may have a unique perspective and should be included as "other" engagement experts
- The group also offered strategies for improving our outreach and recruitment
  - Members noted that recruitment materials should avoid academic jargon
  - Members encouraged the Project Team to include gray literature/literature that exists
    outside of academic spaces in the Literature Scan as these sources may include partners
    who serve underrepresented communities. For this reason they may also be a helpful
    place to tap for outreach and recruitment as well.
  - Members suggested using multiple modes to effectively reach underserved communities, such as by phone and through physical mailers. The group emphasized finding ways to meet people where they are

The Project Team also requested that Steering Committee Members share <u>Consensus Methods flyer</u> with eligible panelists in their networks.

#### VI. FOCUS GROUPS OVERVIEW AND DISCUSSION

## Focus Group Introduction

In June, our third activity, Focus Groups will build off Consensus Methods to further refine our list of key factors influencing engagement and dive deeper into how we might measure these factors. We seek to end our Focus Group process with the information necessary to produce a measurement tool.

The Focus Groups will be virtual meetings, facilitated by the Project Team. Focus Group participants will include a range of engagement experts based in the U.S., including engaged researchers, community/patient partners, and other experts, such as engagement facilitators.

#### Focus Group Discussion



The Steering Committee discussed what we must learn from Focus Groups to produce a draft of the measurement tool.

- A member suggested learning about the impact of engagement and whether good engagement makes a difference for people in communities as well as how it may do so
- A member underscored the need to measure if an engagement initiative matters to the partners and whether they feel heard

The group also discussed how we can design our Focus Groups to ensure they are safe and accommodating for all participants. Steering Committee members provided the following insights:

- Members suggested that community partners that work with underserved populations may be more comfortable or worry less about their psychological safety if the Focus Groups are hosted by their organization
- Members also noted that community partners may feel anxiety about speaking up around
  engaged researchers or others that are thought to have more authority due to their access to
  financial resources or decision-making power. When conducted well, Focus Groups can produce
  a sense of 'radical democracy' and embrace diverse perspectives. It is important the Focus
  Groups empower community partners to speak about their experiences freely
- A member emphasized the importance of sharing information back with participants and underscored the power of people getting to see their own words or the words of their peers reflected to them. They also emphasized that this can create a sense of ownership and empowerment.

# VII. NEXT STEPS

- Steering Committee Members will fill out the meeting evaluation survey
- Sophia will develop and share meeting notes and recordings
- Sophia will schedule all remaining Steering Committee meetings
- Sophai to update meeting guidelines to include "take breaks when needed"
- Steering Committee Members will share the <u>Consensus Methods Flyer</u> with U.S. based engagement experts in their networks
- The Project Team will incorporate Steering Committee feedback into upcoming activities and report back to the Steering Committee regarding how their input is used