STEERING COMMITTEE MEETING NOTES

May 20, 2024, 1:00 – 2:30 pm EST

I. ATTENDANCE

<u>Steering Committee</u>

Carmel McGrath, Engaged Researcher; Kimberly Strain, Community Partner; Kate Wilber, Engaged Researcher

<u>Project Management Team</u>

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

II. INTRODUCTIONS, MEETING GUIDELINES, AND HOUSEKEEPNG

The group introduced themselves and shared the lens they bring to the Committee. The group also reviewed the [meeting guidelines](#). Sophia requested that members take breaks when needed. Sophia will check in with the group at the halfway mark to determine if a formal break is needed.

Sophia reminded the group that the remainder of Steering Committee meetings are scheduled. All members received calendar invites. Sophia asked that members reach out to her if they find that they will not be able to attend a significant number of meetings or if they have preferences for how they are engaged around meetings they cannot attend live.

Future Steering Committee meeting dates:

- 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

Sophia also reviewed the project timeline and reminded the group that we are currently finishing up our second activity: Consensus Methods. So far, we have administered and analyzed results from Survey 1. Based on these results, we developed and administered Survey 2, which remains open for responses. We are also preparing for our third activity: Focus Groups. Our Focus Group protocol and materials will reflect Consensus Methods findings and input from our partners, including this Steering Committee.

III. CONSENSUS METHODS SURVEY 1 FINDINGS AND DISCUSSION

Dr. Airia Papadopoulos, the Qualitative Lead for the project, presented slides outlining our findings from Survey 1. Many of these slides, alongside additional presentation from Airia and Quantitative Lead, Dr. Tam Nguyen, may be found in our [May Office Hours Recording](#). Airia highlighted that the focus of the Steering Committee meeting is to open discussion around the findings and hear directly from Steering Committee Members to inform interpretation of Survey 2 results and design of Focus Groups.

Definition of Engagement

As part of Survey 1, we presented panelists with the following 2014 PCORI definition of engagement:

"The meaningful involvement and partnership of patients and stakeholders throughout the research process, from planning and conducting research to disseminating research results"

Based on Survey 1 findings, 55% of panelists felt this definition captures most or all the important concepts, 43% felt this definition captures some of the important elements, but some are missing, and 2% felt this definition does not capture most of the important elements. Panelists also provided open ended responses about what concepts or terms they disagreed with or felt were missing. For example, many panelists did not like the use of "stakeholder" or "patient." Also, some panelists noted they would like the definition to include more phases of research and reference engagement impact. As a result, the Project Team developed the following definition of engagement:

"The active partnership of researchers and individuals with diverse lived experiences to ensure research is applicable and relevant to communities, from identifying research priorities, to designing and implementing research, and interpreting, sharing, and acting on findings."

Members noted that the new definition clearly infused the feedback provided by panelists and Members provided additional feedback to consider, including:

- Consider simplifying the definition to make it more accessible to partners of all literacy levels
  - A member provided the following example for simplification: The active partnership between researchers and individuals with diverse lived experiences. This includes identifying research priorities, designing and implementing research, and interpreting, sharing, and acting on findings. The aim of this partnership is to ensure that research is relevant to the communities impacted.
- Reivew and take inspiration from the following UK definition of engagement:
  - NIHR defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.
  - More information may be found here.
- Consider changing "diverse lived experiences" to "diverse perspectives" to account for partners that may not be living with a specific condition, but still bring important expertise such as caregivers.

Quantitative Analysis of Survey Items

Airia provided an overview of how items in the survey were rated by panelists and then analyzed by the team. Panelists were asked to consider a series of items commonly linked with "good" or "effective" engagement and rate them as either 1 (not very important), 2 (a little important), 3 (somewhat important), or 4 (very important/critical).

To measure the amount of agreement amongst panelists, the team used Content Validity Index (CVI). CVI uses a scale from zero to 1 to demonstrate the amount of consensus among panelists as to whether an item is important to "good" or "effective" engagement. Items that receive a score of 0.78 or higher (the highest being 1), are items with high consensus among panelists that they are somewhat or very important to good engagement. A low CVI score indicates that panelists agreed that the item was not very important or only a little important.

For instance, there was 100% consensus among panelists that "value place on lived experience or patient experience" is important to good engagement. This item received a CVI score of 1.

There was less consensus about whether having the "ability to find, understand, and use information and services" was important to good engagement. That item received a CVI score of 0.49.

Discussion of Findings: People Factors Commonly Linked with Good Engagement

Members reviewed the survey results for items considered People Factors. Members noted that many of these items intersect with Approach and Environmental Factors, so it made sense that some of these items rated less important in the People section, but more important elsewhere.

Members also validated the importance of people being "authentic and genuine in their communication." A member noted that being authentic and genuine can indicate other important People Factors. For instance, someone with this factor may be likely to adapt even if they do not originally know engagement best practices.

Members also voiced interest in learning more about where community partners and engaged researchers significantly differed in responses.

Discussion of Findings: Approach Factors Commonly Linked with Good Engagement

Members provided insights into why the item "Impact is Evident" may have been rated lower (CVI .771):

- The meaning of "impact" can be confusing and vague, or it may imply more concrete changes than people are used to seeing directly from engagement
    - A member recommended the group review the NHIR Public Involvement Impact definition for inspiration in better defining the term
    - A member highlighted experience using the term "closing the loop" rather than "impact." This may be more familiar to community partners.
        - More information about the term can be found here
- Members discussed how many community partners may not get the opportunity to see the impact of their engagement due to poor communication or long project timelines so seeing impact may not feel crucial to engagement from their perspectives

Members voiced interest in discussing the item further in Focus Groups.

Discussion of Findings: Environmental Factors Commonly Linked to Good Engagement

Members highlighted items they were interested in discussing further in Focus Groups, including:

- Engagement knowledge/training consistently available
  - A member highlighted that this item does not specify if training is available to community partners or engaged researchers. Members highlighted the following reasons why this difference is important:
    - Training for partners can be important to ensure they are empowered and comfortable. It can also be an incentive for some partners interested in becoming researchers. Training can also be used to "turn partners into researchers" rather than respect their role and expertise
    - Training for researchers in engagement best practices is often lacking, which leads to a lack of 'know how.'
  - A member highlighted how training in engagement is often connected to how roles are communicated and agreed upon. Getting clarity on the roles, responsibilities, and expectations of partners will impact how training is used in the engagement process.
- Organizational readiness for change
  - Members noted a lack of clarity around indicators of this readiness
  - Members highlighted the connectedness between this item and other items rated lower such as external pushes for change and mandates for engagement. Members encouraged further discussion on what each of these items mean to better understand their importance.
    - For instance, does external push for change indicate push from community organizations and/or community members themselves?

A Member also shared the following resource on "engagement capable environments" to inform Focus Group discussion questions: https://healthcareexcellence.ca/en/resources/engagement-capable-environments/

Qualitative Analysis of Survey Findings

Alongside rating items linked to good or effective engagement, Survey 1 also provided several open-ended questions for panelists to remark upon items missing, items they found unclear or unnecessary, and other comments. The project team organized and analyzed this data using a qualitative coding software called Nvivo. The group reviewed and discussed key findings from this analysis.

Discussion of Findings: Potential Missing or Unnecessary Elements Discussion

Panelists rated "shared beliefs/values" as less important in the survey but noted that additional nuance is necessary as they felt shared beliefs/values around collaboration and partnership are critical to good engagement, but otherwise engagement processes should capture a diversity in beliefs and values. Members provided the following insights around this point:

- The survey results indicate other shared beliefs among panelists, such as the importance of engaging people regardless of health or cognitive status
- Differences in beliefs and values will also impact how people conceptualize expertise and roles within engagement. For instance, in some cultures it is not typical to question or see oneself as equal to health professionals.
- Power-sharing as a concept should be explored further in this context

Discussion of Findings: Qualitative Themes

The Project Team identified seven themes that emerged from Survey 1 open-ended responses. These themes directly informed the development of Survey 2. Members provided the following feedback about the themes:

- Consider how trauma-informed engagement fits across these themes
  - While this term did not emerge in the Survey 1 data, a member highlighted its importance since patients often become engaged due to negative experiences
  - The group discussed how trauma-informed engagement connects across several of the themes, including accessible engagement spaces and communication practices
  - A member provided the following resources for more information about trauma-informed engagement:
    - Valuing All Voices: refining a trauma-informed, intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00217-2
    - The Importance of Trauma-informed Engagement: https://www.youtube.com/watch?v=oCyiAu30lR8
- Consider expanding the theme of "Exercising principles of Collaboration, Co-Learning, and Power-Sharing in group activities" beyond group activities to all practices, such as communication between meetings

Members also discussed how these themes will impact how engagement will be measured, including who will complete the tool. Erin clarified that our goal is to first determine what is important to measure before determining how is should be measured. Members validated this approach and appreciated that the team will not bring a bias about who should use the tool into the development process.

IV. 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 incorporate Steering Committee feedback into Focus Group design and report back to the Steering Committee regarding how their input is used

- The Project Team will share Survey 2 results with the Steering Committee, including information such as where responses differed based on panelist lens