# Measurement Matters

## Cognitive Testing Findings Report

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## Project Background

Funders, policymakers, researchers, and community advocates are increasingly recognizing the importance of involving older adults and individuals with chronic conditions in research design, implementation, and dissemination. While many engagement frameworks exist to support this involvement, researchers often struggle to put them into practice, leading to frustration for both research teams and the communities they aim to engage. To address this challenge, the Measurement Matters project, funded by a Patient-Centered Outcomes Research Institute (PCORI) Research Award (SOE-2022C2-28570), is developing and testing a comprehensive tool to measure engagement activities and their impact on research outcomes. In 2024, the research team collaborated with Technical Advisors and a Steering Committee to conduct a literature scan and implement consensus-building strategies, focus groups, and cognitive testing to guide tool development. In 2025, the team will pilot the engagement measurement tool with researchers and/or members of a research team that lead engagement activities in the National Patient-Centered Clinical Research Network (PCORnet), a nationwide consortium committed to patient-centered research. This report summarizes the cognitive testing methods used for this project and outlines the findings that informed the tool's refinement.

## Cognitive Testing Overview

The research team conducted cognitive testing on the PCOR-EM to assess the clarity, comprehension, and perceived effectiveness of its items. Participants included individuals with a wide range of engagement experiences, such as engaged researchers and patient and community partners. Many participants have experience leading in the engagement space, including researching and publishing on engagement best practices, advocating on behalf of other community partners, and taking on co-investigator roles as community partners in research.

The primary goals of cognitive testing were to confirm that participants understood the PCOR-EM items as intended and that the tool accurately reflected their range of engagement experiences. More specifically, cognitive testing aimed to:

- Evaluate how respondents **interpret** the proposed engagement measures.
- Assess the **clarity and usability** of the survey instructions.
- Identify potential **barriers** to completion.
- Ensure that the engagement measures are **relevant, understandable, and actionable.**

### Cognitive Testing Methods: Part One

The cognitive testing process unfolded in two phases. In Part 1, the research team along with Technical Advisors and Steering Committee members completed a web-based survey. Participants identified whether researchers, patient/community partners, or both would be best suited to answer each item. The main objective was to narrow the list of engagement measures and identify those most relevant to researchers or those leading engagement activities - the target users of the initial PCOR-EM. The team created the survey in SurveyMonkey, listing 89 items developed from prior focus group data (see Focus Group Report for details). These items were organized into seven thematic categories:

- Organizational and environmental readiness
- Time and resources
- Logistics and meeting techniques
- Clear and transparent communication

- Valuing diversity
- Trust and relationship building
- Collaboration, co-learning, and power sharing

The team distributed flyers to Technical Advisors and Steering Committee members to encourage participation. Ten individuals completed the survey. Based on their input, the team reduced the number of items from 89 to 41.

| Theme | Number of Items Applicable to Researchers or Engagement Leads |
|---|---|
| Organizational and environmental readiness | 12 |
| Time and resources | 9 |
| Logistics and meeting techniques | 6 |
| Clear and transparent communication | 6 |
| Valuing diversity | 3 |
| Trust and relationship building | 2 |
| Collaboration, co-learning, power sharing | 3 |

Participants also suggested splitting two existing items into separate measures, resulting in a total of 44 items for Part 2 of the cognitive testing.

## Cognitive Testing Methods: Part 2

In Part 2, the research team aimed to finalize the items for inclusion in the PCOR-EM survey and to ensure the measures are clear as written, the concept is measurable, and the survey instructions are sufficient. Participants—including researchers, facilitators, and patient/community partners—completed a subset of engagement measures using a web-based survey while participating in a 60-minute "think-aloud" interview using Zoom video conference technology.

A research team member conducted each one-on-one interview. First, the participant responded to the engagement measures, verbalizing their thought process while interpreting and answering each item. The participant offered feedback on question clarity and feasibility. During the interviews the research team member silently observed and took live notes and flagged moments when participants:

- Asked for clarification or suggested alternative wording
- Expressed uncertainty about how to respond
- Paused or hesitated before answering

The interviewer then revisited those flagged instances to further explore the participant's reasoning. This process generated valuable insights into how respondents cognitively processed each item.

## Part 2 Participant Selection and Outreach

The research team prioritized recruiting participants who have experience designing and/or implementing an engaged research project. This included Principal Investigators, researchers, or members of the research team responsible for conducting engagement. To ensure diverse perspectives, the team disseminated outreach materials through Steering Committee networks, Technical Advisors, PCORI Ambassadors, and existing partners. Guided by advisor input, the team created plain-language outreach materials, including:

- A study overview for partners
- A recruitment flyer explaining study goals, eligibility criteria, participation details, and compensation

- An interest form for self-nomination

Twenty-one individuals completed the interest form, all of whom met eligibility criteria and were invited to participate. Nineteen individuals completed cognitive testing. Each was assigned to one of three research team members for their interview. Participant characteristics are noted in Table 1 and Participant Roles are noted in Table 2.

*Table 1: Participant Demographics*

| **Cognitive Testing Participant Demographics** | |
|---|---|
| **Number of Participants** | n = 19 |
| **Mean Age** | 53 (age range: 31 – 78)<br>**One participant did not provide age information* |
| **Race/Ethnicities** | American Indian or Alaska Native (1)<br>Asian (2)<br>Black or African American (3)<br>White (11) |
| **Gender Identities** | Female (15)<br>Male (2) |
| **U.S. States** | California (2), Massachusetts (1), Michigan (1), Nebraska (1), Pennsylvania (1), Tennessee (1), Texas (2), Utah (1), Virginia (1), Wisconsin (1)<br>*** Five participants were from outside of the U.S.* |

****Two participants did not fill out demographic information*

*Table 2: Participant Roles*

| Participant Role | Count (Percent) |
|---|---|
| **Researcher** | 12 (70.6%) |
| **Engagement Facilitator** | 13 (76.5%) |
| **Patient, Participant, or Community Partner** | 9 (52.9%) |

**Participants were invited to select as many roles as applied*
***Two participants did not fill out role information*

## Part 2 Accommodations and Incentives

To promote equitable participation, the research team offered various accommodations, including plain-language documents, large-print versions, and personalized support from a designated team member. Participants who were not otherwise compensated (e.g., from their own employer) received a $50 gift card to Amazon, Target, or Walmart. These strategies helped ensure the process remained inclusive, accessible, and respectful of participants' time.

# Cognitive Testing Interview Analysis and Reporting

The research team combined data from the web-based survey with notes taken during the live interviews to evaluate how easily participants completed the items, where they faced interpretation challenges, and which themes consistently emerged. They organized the data by item so that each question could be analyzed across all participants.

The team used two primary questions to guide their analysis and refine the survey:

1. Based on participant feedback, should this item remain in the first draft of the PCOR-EM survey as written, be revised, or be removed?
2. Can this item be clarified to make it simpler and more direct?

These questions helped the team prioritize which items to include and how to revise them for clarity. The findings were compiled into a plain-language slide deck and shared with the Steering Committee and Technical Advisors for review and discussion. Participants also received a summary report for their reference.

## Cognitive Testing Interview Findings

Cognitive testing played a pivotal role in shaping the first draft of the PCOR-EM survey. Participant feedback directly influenced the tool's structure, clarity, and relevance across a variety of research settings.

### *Participation in Cognitive Testing Interviews*

The team conducted 19 cognitive testing interviews, each lasting around 45 minutes. On average, participants completed the PCOR-EM in 16 minutes. Most participants navigated the survey with ease and responded using Yes/No answer options; some were unsure how to answer certain items and left them blank.

### *Participant Feedback and Key Themes*

Every PCOR-EM item received at least one comment. Some items generated as many as ten comments. Several key themes emerged:

- **Clarification of Terms**: More than half of the items contained words or concepts that needed further explanation. Ambiguities made it harder for participants to respond confidently. Commonly flagged terms included: *community partner, training, obstacles, motivated, tasks, multiple times, outreach, small group conversations,* and *frequency of meetings*.
- **Duplication and Redundancy**: Participants pointed out overlapping items that asked similar questions in slightly different ways and recommended we remove duplicative items.
- **Flow and Navigation**: Some participants found the item order confusing. They recommended grouping related questions to create a smoother and more intuitive flow.
- **Difficulty Responding**: Some questions required respondents to assess decisions made by the research team, such as engagement funding or diversity practices. Patient partners often lacked insight into these decisions and were unsure how to respond.

### *Challenges Identified by Patient Partners*

Patient partners often found it challenging to respond to questions that fell outside their direct experience or knowledge. They pointed to items such as:

- "The research team has allocated time and money for engagement in research."
- "Patient/community partners have diversity in age, race, gender, opinion, lived experience, and expertise."
- "The research team conducts outreach multiple times to engage underrepresented communities."
- "The team has engagement policies in place for research."

These examples suggest that the tool is primarily suited for researchers or research team members with experience in designing and/or implementing engaged research projects.

## PCOR-EM Revision and Finalization

The development and refinement of the PCOR-EM followed an extensive and deliberate item-reduction process grounded in both expert input and participant feedback. The initial version of the PCOR-EM contained 89 items, which emerged from a comprehensive Year 1 development phase that included a literature scan, consensus-building activities, and focus groups. During the first phase of cognitive testing, Steering Committee members, Technical Advisors (TAs), and research team members were asked to review the draft items and identify which ones researchers or those leading engagement would be able to answer with confidence. This step helped narrow the tool down to 44 items, serving as the foundation for more participant-centered testing.

Based on the cognitive testing findings, the PCOR-EM was reduced from 44 items to 29 items. The revised tool includes content that has been consolidated and refined, with many items now addressing more than one domain area. These revisions aim to improve usability, clarity, and alignment with real-world engagement experiences.

In the second phase of cognitive testing, participants completed the 44-item version of the tool in real time while verbalizing their thought processes. This "think-aloud" protocol was combined with in-depth interviews to explore areas of confusion, ease of response, and suggestions for improvement. Based on this feedback, the research team made further refinements, ultimately reducing the instrument to 29 items. This final version prioritizes clarity, relevance, and user-friendliness while still capturing the core dimensions of meaningful engagement.

## Alignment with Engagement Domains

The research team reviewed the final 29-item version of the PCOR-EM to ensure that each item contributed to the measurement of key dimensions of engagement. Ultimately, the testing led to refinements that appear to make the tool more accessible, effective, and capable of capturing key aspects of engagement in research.

Each item maps onto one or more of the following **seven engagement domains**, which were derived from prior literature and partner consensus. Notably, several items now address more than one domain area, increasing the tool's efficiency while preserving its conceptual richness.

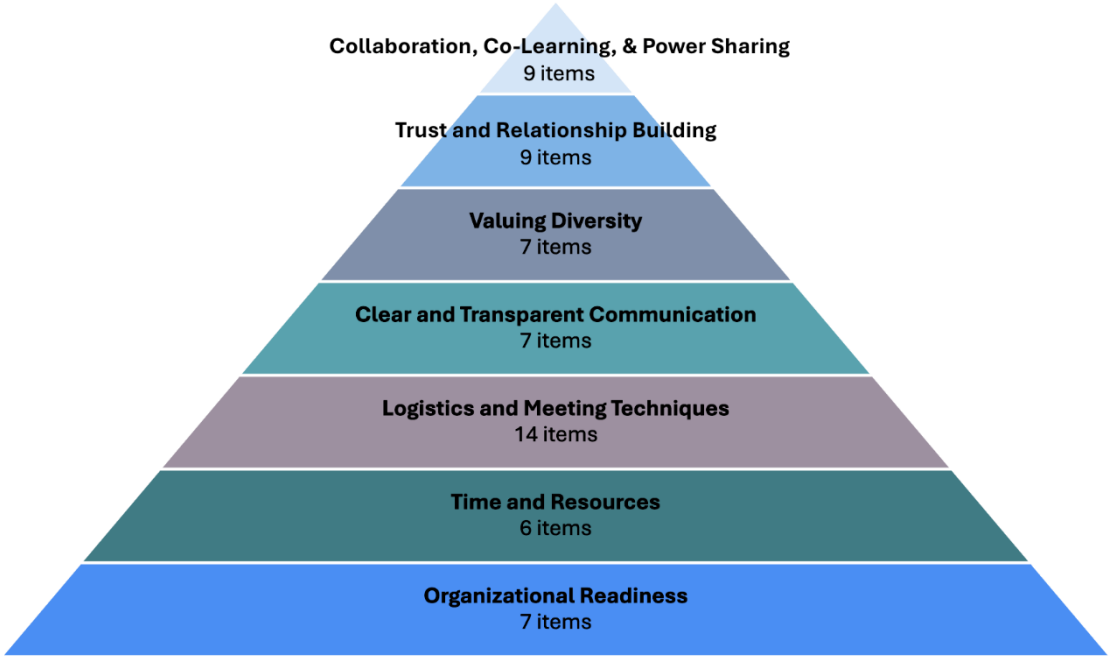


*Figure 1: PCOR-EM Item Engagement Domains*

This domain-based framework ensures that the tool reflects both interpersonal and structural dimensions of engagement, making it adaptable for various research contexts and stakeholders.

## Conclusion

The cognitive testing phase of the Measurement Matters project played a crucial role in refining the PCOR-EM tool to ensure its clarity, usability, and relevance for diverse research contexts. Through in-depth interviews and think-aloud protocols, participants provided valuable insights that led to significant improvements in question wording, survey structure, and overall accessibility. Key revisions, including the reduction of items from 44 to 29, were guided by participant feedback, ensuring that the tool remains comprehensive while minimizing redundancy and confusion. Findings from this process underscore the importance of iterative testing in the development of engagement measurement tools. Addressing challenges related to term clarity, survey flow, and participant perspectives has strengthened the PCOR-EM's ability to capture meaningful engagement practices. The final tool aligns with established engagement domains and offers a practical, user-friendly framework for evaluating research engagement efforts.

As the next part of the Measurement Matters project, the revised PCOR-EM will undergo piloting within PCORnet to assess its effectiveness in real-world research settings. In this phase, we're testing whether our survey tool (the PCOR-EM) reliably measures engagement in research across different groups of people. We'll use a diverse sample—based on age, race, ethnicity, and experience—to check if people from different backgrounds interpret and respond to the survey in similar ways. We'll also look at whether engagement scores are linked to outcomes like satisfaction, inclusion, recruitment success, and impact on policy or funding. To do this, we're using advanced statistical methods (like Item Response Theory and Rasch Modeling) to test if each survey question works well, is clearly understood, and gives consistent results. We'll also analyze whether all questions measure a single core concept (unidimensionality) and check that the tool works equally well across different groups (e.g., by race or ethnicity). These tests will help ensure our tool is fair, accurate, and meaningful across diverse populations.