PCOR-EM 2025 PILOT SURVEY
QUALITATIVE FINDINGS REPORT

PROJECT OVERVIEW

The Measurement Matters project (SOE-2022C2-28570) is a two-year award granted in 2023 to the LeadingAge LTSS Center at UMass Boston and Collective Insight, LLC to develop and pilot the Patient-Centered Outcomes Research Engagement Measure (PCOR-EM). Funded by the Patient-Centered Outcomes Research Institute (PCORI), the PCOR-EM was designed through a multi-phase process that included a literature scan, consensus methods, focus groups, and cognitive testing interviews. In 2025, the study team piloted the PCOR-EM to assess if it is a valid and reliable instrument capable of measuring engagement quality. Pilot participants completed the PCOR-EM in REDCap, which included 30 core items and a supplemental section on project and respondent characteristics. Respondents were also prompted to provide optional open-ended feedback "that will be helpful for us to know based on the survey section you just completed." This prompt was presented to respondents at the end of each of the three PCOR-EM sections. A total of 301 respondents completed the PCOR-EM from April to July. After a quality review, 266 PCOR-EM respondents were retained for analysis. Twenty-five of the 266 respondents (9%) provided responses to the optional feedback question. The study team analyzed the open-ended responses received, and this report presents the findings from this qualitative analysis.

DATA COLLECTION METHODS

The study team extracted the open-ended data from the PCOR-EM and folded them into one comprehensive Word document. This Word document was uploaded into NVivo qualitative analysis software to conduct the analysis. Two members of the study team independently coded all open-ended responses line-by-line to capture patterns, themes, and meaning. Following this independent coding, two separate study team members independently compared the two node structures, reviewed discrepant codes, and reconciled conceptual differences. Overall, inter-coder agreement was high, with approximately 75–80% of coded segments aligning thematically. The study team found that the majority of discrepancies identified reflected differences in coding hierarchy rather than data interpretation. The study team's reconciled analysis highlighted nine topics that fell into two major categories: PCOR-EM design and PCOR-EM content. These findings are described below. The full list of qualitative responses, organize by the nine topic areas, are provided in the Appendix.

DATA COLLECTION RESULTS: PCOR-EM DESIGN

Overall Impressions

Eight of the 25 respondents (32%) expressed positive impressions of the PCOR-EM, describing the questions as clear, authentic, and reflective of real-world engagement experiences. Phrases like *"The questions are authentic and engaging"* and *"This feels like something we actually experience in projects"* may demonstrate that the PCOR-EM resonates with both researchers and partners.

Item Clarity

Eighteen of the 25 respondents (72%) noted unclear or confusing item wording and/or suggested revisions to language to improve clarity. **Table 1** summarizes respondents' feedback, with specific items noted when this information was provided.

Table 1 Item Clarity and Language Feedback

Item #	Respondent Comment	# of Respondents (n=25)
Q3	"Engagement happening because of a funder mandate was hard to answer - not reflective of real practice." "This question assumes all engagement is voluntary; that's not always true."	2 (8%)
Q5	"I would recommend avoiding the word 'incentive.' 'Compensation' is more appropriate." "Use 'compensation' instead of 'incentive'; it implies fairness rather than reward." "The term 'incentive' feels transactional, not aligned with engagement principles."	3 (12%)
Q11	"I don't know what you mean by 'new individuals.' New as compared to what, prior projects?" "'New individuals' relative to when? I don't understand this question so I left it blank." "'There are some new individuals included as patient/community partners…' This statement is confusing. New to what? The project? Engaged research?" "The phrase 'new individuals' could mean new staff or new community members, it's unclear."	4 (16%)
Q13	"It is not clear what you mean by 'accommodation needs.'" "What do you mean by 'accommodation needs'?" "Does this refer to accessibility supports, like translation or captioning?" "'Accommodation' could mean schedule flexibility or disability access, please clarify." "Not sure if 'accommodation' includes technology access; wording could be clearer."	5 (20%)
Use of term Diversity	"What kind of diversity do you mean - demographics, experience, or role on the team?" "The word 'diversity' is vague, could refer to population, background, or perspective." "Do you mean diversity of lived experience or of identity?" "Needs clarification whether diversity is about who's at the table or how they're engaged."	7 (28%)

	"Unclear if 'diverse' means racial/ethnic or professional diversity." "Diversity can mean so many things, specify what's intended." "Add examples to clarify what 'diverse perspectives' means."	
General	"Some of the items don't read as complete sentences." "The survey questions were clear, but it would help to include examples or definitions for terms like 'underrepresented communities.'" "Some statements could use plain language to make sure everyone interprets them the same way."	3 (12%)

Survey Design and Response Options

Twelve of the 25 respondents (48%) commented on survey design or response options. Nine respondents requested additional response options, especially a neutral midpoint, "Not Applicable," or "Unsure." Several also raised usability issues: they wanted a "save and return" feature (5/25), a visible progress bar (4/25), and improved mobile compatibility (3/25). One respondent reported that the "reset" button appeared above the "definitely no" choice on mobile screens, causing accidental deletions.

DATA COLLECTION RESULTS: PCOR-EM TOPICS

Engagement Funding

Twenty of the 25 respondents (80%) noted funding challenges in their comments, emphasizing that engagement is often underfunded (20/25), delayed (10/25), or deprioritized within project budgets (8/25) compared with other research activities. Respondents consistently stressed that meaningful engagement requires adequate and timely financial resources. Respondents linked insufficient funding to inequitable participation (7/25), burnout among community partners (5/25), and a lack of sustainability once projects end (4/25). One respondent explained that the existing funding climate makes it harder to justify including underrepresented communities, given the additional resources often required to support equitable participation.

Engagement Training

Fifteen of the 25 respondents (60%) discussed training and capacity-building needs, emphasizing that while researchers often receive engagement training, community or patient partners rarely have equal access to such opportunities. Several respondents recommended training that addresses specific topics, including trauma-informed practices (6/25), inclusive communication (8/25), and power-sharing (7/25), noting that these areas are necessary for fostering equitable engagement. Some respondents (5/25) described successful efforts where community partners co-designed or co-facilitated training.

Diversity and Inclusion

Many respondents valued that the PCOR-EM addresses diversity and inclusion, but some questioned how the term "diversity" should be interpreted. Ten of the 25 respondents (40%) raised questions about whether the measure's items around diversity referred to demographic, experiential, or contextual diversity and how this applied to their specific projects. Respondents noted differences in project contexts (7/25): some worked with a single population, while others engaged across multiple demographic or

cultural groups. A few highlighted the need for more explicit recognition of intersectionality (5/25) and linguistic access, such as bilingual or multilingual engagement (4/25).

Accommodations and Accessibility

Nine of the 25 respondents (36%) sought greater clarity around accommodations and accessibility. While related to wording, these comments reflected deeper questions about what types of supports qualify as accommodations. They questioned whether the term referred to disability supports, technology access, or other forms of assistance (5/20). Respondents suggested adding concrete examples like translation services, screen readers, hybrid meeting formats (6/25) and ensuring that accessibility is addressed proactively rather than reactively (3/25).

Tokenism and Authenticity

Six of the 25 respondents (24%) described experiences of tokenism or unequal power dynamics in engagement, where participation felt symbolic or limited in influence rather than collaborative and decision-oriented. Some respondents described experiences where partners were included for compliance rather than shared decision-making (5/25). Others recounted being excluded or having advisory groups dissolved after expressing dissent (3/25).

Contextual Factors

Five of the 25 respondents (20%) noted that contextual factors such as institutional policies, funder expectations, and national norms, shape the feasibility and consistency of engagement practices across projects. Respondents compared PCORI projects to those funded by other agencies such as NIH (4/25), noting differences in culture, expectations, and available resources (3/25). Some described how national context (e.g., United States vs. international) (2/5) and institutional policies (3/25) affect the feasibility and consistency of engagement.

CONCLUSION

As the Measurement Matters project progresses, the study team will incorporate the insights from this qualitative analysis into the next phase of PCOR-EM refinement. Feedback from pilot participants will inform item revisions, improve wording clarity, and strengthen the tool's applicability across diverse research settings. These qualitative results will also complement ongoing quantitative analyses, which are testing the reliability, validity, and factor structure of the PCOR-EM using the full pilot dataset. Together, these efforts will ensure that the final measure reflects the lived experiences of both researchers and community partners and is psychometrically sound for use in broader applications.

APPENDIX: ALL RESPONDENT RESPONSES BY THEME

1. Funding & Resources

Primary Issues Identified: Insufficient, delayed, or inequitable funding for engagement activities.

Funding Delays and Equity

"There's always enough money for methods but not for outreach and engagement."
"Funding for partners always comes last."
"We can't expect participation without timely compensation."
"Community partners are asked to commit time without pay."
"Funding arrives after the project has already started, making it hard to engage meaningfully."
"Delayed payments discourage continued involvement."
"Engagement budgets need to be more predictable and accessible."

Budget Priorities and Fairness

"Funds go to research first; engagement gets what's left."
"Engagement is treated as optional when budgets are tight."
"Budgets rarely include resources for interpreters or accessibility."
"Payment to community members is always the hardest to process."
"Grants don't account for the real time community members spend on these projects."
"Partners should be paid like consultants, not volunteers."

2. Item Clarity & Language

Primary Issues Identified: Confusing or incomplete phrasing ("new individuals," "accommodation needs"); need for examples/definitions.

Q11 – "New Individuals"

"I don't know what you mean by 'new individuals.' New to what?"
"New individuals could mean a lot of things — new to the project, to engagement, or to the field."
"'There are some new individuals included…' feels vague and confusing."
"This question doesn't apply to our project because our group hasn't changed."

Q13 – "Accommodation Needs"

"It is not clear what you mean by 'accommodation needs.'"
"Do you mean accessibility accommodations or adjustments to scheduling?"
"Would you include translators or hybrid meetings under 'accommodations'?"
"Add examples so people know what counts — interpreters, screen readers, etc."

Terminology & Wording

"Avoid using the word 'incentive' — compensation is more appropriate."
"The survey questions were clear but would be helpful to define 'underrepresented communities.'"
"Some items are not written as full sentences."
"Clarify what 'diversity' means — race, lived experience, or role?"
"Rephrase double-barreled questions into simpler statements."

3. Training & Capacity Building

Primary Issues Identified: Unequal access to engagement training; need for inclusive, trauma-informed content and partner involvement.

Training Access and Equity

"Researchers get training on engagement, but partners don't."
"There should be training for community members too, not just academics."
"Training should happen for everyone involved in the project."

Training Content and Approach
"Include topics like trauma-informed practice and inclusive communication."   "We need training about equity and power dynamics."   "Offer examples of what good engagement looks like."   "Use real case studies instead of general guidelines."
Partner-Led or Co-Designed Training
"Community partners should co-facilitate the training."   "Our best training came from peers — those with lived experience."   "It helps when community voices lead the conversation."

4. Response Options & Survey Design
Primary Issues Identified: Limited response choices and usability concerns (neutral/N.A. options, mobile layout).
Response Options
"There should be a neutral or 'sometimes' option."   "Not everything is a yes or no."   "Add a 'Not Applicable' option for when something doesn't fit our project."   "We need an 'Unsure' choice too."
Survey Functionality & Usability
"It would be nice to save progress and return later."   "A progress bar would help show how far along you are."   "Make the mobile version easier to use."   "On my phone, the reset button was above 'definitely no' — I deleted answers by accident."   "Some pages were long; breaking them up might help."

5. Diversity & Representation
Primary Issues Identified: Ambiguity about what "diversity" means (demographic, experiential, contextual).
Meaning of Diversity
"What kind of diversity? Demographics, experience, or ideas?"   "Our project only works with one group, so this didn't apply."   "We don't have racial diversity but we do have role diversity."   "Add examples of what diversity could mean."
Intersectionality
"Engagement looks different when people have overlapping identities."   "It's not just about race — age and disability matter too."   "Need a question that recognizes multiple dimensions of identity."
Linguistic Access
"Language access should count as diversity."   "We work with bilingual communities — this wasn't captured."   "Include examples of bilingual or multilingual participation."

6. Accommodations & Accessibility
Primary Issues Identified: Unclear meaning of "accommodations"; requests for concrete examples (translation, hybrid formats).
Definition of Accommodations
"I wasn't sure if accommodations meant disability supports, technology, or something else."   "Add examples so people know what counts."   "List things like interpreters, captions, or hybrid meetings."

Examples and Proactive Framing
"Accessibility should be built in from the start."   "Plan for accessibility, not just react to it."   "Screen readers and translation services are examples that should be mentioned."   "Hybrid meetings help when travel is a barrier."
7. Tokenism & Power Dynamics
Primary Issues Identified: Experiences of symbolic or compliance-driven engagement rather than shared decision-making.
Experiences of Tokenism
"Sometimes engagement feels like checking a box."   "We're invited to meetings but not part of decisions."   "Partners are added for compliance, not collaboration."
Exclusion or Dismissal
"Advisory groups are dissolved when they disagree with researchers."   "Input is collected but not acted on."   "There's no accountability — feedback disappears."
Lack of Shared Power
"Decision-making is still in the hands of researchers."   "There should be ways to measure how much influence partners really have."
8. Contextual Factors
Primary Issues Identified: Institutional, funder, or national context affects feasibility of engagement.
Funder & Institutional Differences
"PCORI expects engagement to be built in; NIH doesn't always."   "University rules make it hard to pay partners."   "Policies about compensation differ across institutions."
National & Cultural Context
"International projects require different engagement strategies."   "Engagement means something different outside the U.S."   "Cultural expectations shape how much people participate."
9. Strengths & Positive Impressions
Primary Issues Identified: Overall positive views of the measure's authenticity and relevance.
Positive Feedback on Tool Design
"The survey questions were clear and relevant."   "This felt authentic to how we engage."   "It captures what engagement really looks like."   "I appreciate that engagement quality is being measured."   "The tool could help justify engagement work to funders."   "Finally, something that reflects real-world engagement."