MEASUREMENT MATTERS

DATA COLLECTION 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 to capture meaningful engagement of patients and community partners in research. Pilot data collection began in April 2025 in collaboration with PCORnet® Clinical Research Networks (CRNs), the PCORI Ambassador Program, and other engaged research partners. The pilot seeks valid, representative responses from individuals with direct experience in patient or community engagement, particularly in research relevant to older adults. To support expanded psychometric testing after the tool grew from 15–20 to 30 items, the final recruitment goal was increased to 300 participants, up from the original 175–225. This report provides data collection methods to meet that goal along with challenges, solutions, and limitations.

DATA COLLECTION METHODS

Outreach and Recruitment

Our PCOR-EM outreach and recruitment process intended to reach diverse participants, including participants diverse in age, gender, race/ethnicity, education level, and engagement experience. To support outreach, the research team created the following recruitment materials:

- Pilot Partner Outreach Flyer
- Pilot Survey Flyer for potential participants
- Frequently Asked Questions
- Sample outreach language for partners

Outreach Partners

In September 2024, the research team hosted a webinar where the partnership opportunity was first presented to PCORnet® clinical research networks (CRNs). The webinar detailed the study's purpose, outreach activities, incentives, and timeline. CRNs expressed interest in being a Pilot Outreach Partner through Frontdoor. The research team also engaged a Pilot Partner Subcommittee, consisting of 8 individuals from 6 PCORnet® sites, to inform our outreach methods. The research team then collaborated with PCORnet® Frontdoor and the Pilot Partner

Subcommittee to identify up to six Clinical Research Networks (CRNs) to serve as Pilot Outreach Partners. The research team conducted 6 informational meetings to familiarize Pilot Outreach Partners with the study and solicit their support. CRNs serving as Pilot Outreach Partners were offered a $1,500 incentive for recruitment support. Due to administrative challenges for CRNs, outlined in our Pilot Site Implementation Report, some CRNs did not accept the incentive.

Pilot Outreach Partners distributed email messages containing the Pilot Survey Flyer and survey link to individuals within their PCORnet® networks. Efforts targeted a broad range of participants across the "patient-engagement" continuum through partnerships with 3 CRNs: STAR, Greater Plains Collaborative (GPC), and REACHnet. To reach our recruitment goal, we expanded partnerships with PCORI Ambassadors, the PCORI Engagement Advisory Panel, NIH/NIA-funded initiatives, Aging Special Interest Groups, universities, and PCORI-funded projects. Outreach methods included targeted emails, listserv announcements, webinars, and conference engagement. See **Appendix A** for a comprehensive PCOR-EM Recruitment History report.

Screening, Consent, and Survey Administration

The pilot began with an electronic screener page outlining eligibility criteria, which required participants to be English-speaking and able to report on engagement in an engaged research project. Those who met the criteria were directed to an informed consent page that described the study's purpose, potential risks and benefits, and investigator details. Only individuals who confirmed their consent were able to proceed to the survey.

The survey itself was administered through REDCap, a secure, web-based platform with real-time validation rules to ensure data quality. Its structure included the screener and informed consent, followed by the 30-item PCOR-EM survey, a 43-item supplemental survey, and an incentive form. To ensure accessibility, the research team offered accommodations such as a paper survey, screen reader compatibility, and recorded responses; however, no participants requested or used these accommodations during the pilot.

DATA COLLECTION CHALLENGES AND SOLUTIONS

The research team encountered several challenges during data collection that affected recruitment, participant representation, and data integrity. The team implemented targeted solutions to address each issue.

Challenge	Solution
Low yield from initial PCORnet® recruitment	Expanded eligibility to all engaged research projects; broadened outreach channels
Underrepresentation of low-engagement-experience participants	Targeted outreach to balance representation across the continuum

Fraudulent/bot responses due to public link	Added open-ended screener question; manual review; issued unique one-time links. For more details, see **APPENDIX B**: *Addressing Fraudulent Survey Responses in the PCOR-EM Pilot*
Risk to incentive integrity	Embedded incentive claim in REDCap after verification; cross-checked eligibility
Administrative burden	Implemented real-time fraud detection and verification workflow

DATA COLLECTION RESULTS

The PCOR-EM pilot was initiated in April 2025 and completed in July 2025, with 301 surveys collected. Although the pilot ran longer than originally planned, it stayed within the overall project timeline. The research team continually tracked progress, identified issues as they emerged, and implemented solutions to protect data quality and ensure recruitment goals were met. The most serious challenge came from fraudulent and low-quality responses when the survey link was shared outside intended networks. To address this, the team paused data collection, removed public access to the survey, and began issuing unique, one-time links only to verified individuals. A second challenge was that initial outreach through PCORnet® did not yield enough participants, leading the team to broaden recruitment to include PCORI Ambassadors, the PCORI Engagement Advisory Panel, NIH- and NIA-funded initiatives, Aging Special Interest Groups, and other engaged research partners. Finally, monitoring revealed gaps in representation, particularly among researchers with limited engagement experience. In response, the team conducted targeted outreach to balance participation across the engagement continuum.

Recruitment and Survey Completion Progress

The table below summarizes final progress for the PCOR-EM pilot survey. These figures reflect the number of individuals screened, found eligible, and ultimately completed the survey.

Metric	Value
Screeners Completed	879
Surveys Distributed	403
Surveys Started	316
Valid Completed Surveys	301
High-quality Surveys	266

The bullets below outline how the research team defined and counted each step.

- **Screeners Completed (879):** This number represents all individuals who accessed the initial eligibility screener.
- **Surveys Distributed (403):** Only those who met the eligibility criteria on the screener were considered qualified and received a survey link. This explains why fewer surveys were distributed than the total number of screeners.
- **Surveys Started (316):** This reflects the number of eligible individuals who began answering survey questions after passing through the consent process.
- **Valid Completed Surveys (301):** A survey was considered valid if the participant met eligibility requirements, completed the PCOR-EM survey in full, and provided sufficient information to confirm participation.
- **High-Quality Surveys (266):** High-quality responses were identified using a set of predetermined criteria, including reasonable completion time, non-duplicated entries, and passing embedded attention checks. While these checks provide a useful filter, they cannot guarantee the absence of low-quality responses. It is important to acknowledge that this definition of "high quality" is operational and based on black-and-white thresholds; we cannot know with certainty the true quality of every individual response.

DATA COLLECTION LIMITATIONS

While the pilot reached its recruitment goal, several limitations in data collection exist. Early in the process, fraudulent and automated responses came in before stronger screening measures were implemented. At the same time, strict quality controls, while necessary to protect data integrity, may have excluded some legitimate participants, e.g., those using shared devices or community internet connections. The online-only design also limited participation for individuals without reliable digital access, despite offering accommodations. Recruitment remained uneven, with certain groups, such as researchers with limited engagement experience and those from underrepresented populations. Additional screening steps extended the pilot period, though the pilot still concluded within the overall project timeline. Finally, what we define as "high-quality" responses is based on set thresholds like completion time and attention checks, which help flag concerns but cannot fully capture the true quality of every survey. These limitations are common in online survey research, particularly when incentives are offered, and highlight the importance of careful screening and transparency in reporting.

APPENDIX A: PCOR-EM RECRUITMENT HISTORY

Alexa is drafting

MEASUREMENT MATTERS ISSUE BRIEF

Addressing Fraudulent Survey Responses in the PCOR-EM Pilot

PROJECT BACKGROUND

The *Measurement Matters* project (SOE-2022C2-28570) is a two year award granted to the LeadingAge LTSS Center @UMass Boston and Collective Insight, LLC in 2023 to develop and pilot a 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-phased process inclusive of consensus methods, focus groups, and cognitive testing interviews to assess meaningful patient and other community partner engagement in research. The research team partnered with PCORnet® Clinical Research Networks (CRNs) to reach individuals with direct experience in patient or community engagement to pilot the PCOR-EM. The research team then expanded outreach to other partners to increase the pilot response rate, including PCORI Ambassadors, the PCORI Engagement Advisory Panel, NIH/NIA-funded initiatives, Aging Special Interest Groups, universities, and PCORI-funded projects. Individuals who tested the PCOR-EM were offered a $35 gift card incentive for completing the survey.

ISSUE BRIEF PURPOSE

While PCOR-EM outreach targeted specific, trusted networks, the **web-based nature of the survey** introduced vulnerabilities that allowed ineligible individuals (or possibly automated bots) to pilot the tool solely for the incentive. The research team recognized this issue within days of initiating the pilot process, and at that time, assessed root causes and solutions to mitigate the inclusion of fraudulent responses so not to undermine the validity of the PCOR-EM pilot findings and inappropriately disseminate gift card incentives. Given the growing challenge of fraudulent online survey responses, particularly when financial incentives are offered,[i] project advisors requested the research team document their PCOR-EM pilot experiences and lessons learned, which are highlighted in this issue brief.

EXPERIENCES AND LESSONS LEARNED

Problem Identification

The research team designed the PCOR-EM pilot survey for distribution only within networks conducting community-engaged research. Within the first days of the pilot, however, we discovered that the survey link had been shared broadly and accessed by individuals outside these networks who were not conducting or partnering in engaged research. We identified this issue through the following data characteristics:

- Duplicate names, emails, and/or IP addresses across survey responses
- Email patterns typical of fraudulent activity (e.g., name + numbers @gmail.com)

- Large batches of survey responses within minutes of each other
- Vague or implausible answers to “how did you hear about this study?”
- Numerous non-U.S. IP addresses
- Minimal completion time (less than 5 minutes)

Root Cause of the Issue

The research team held internal meetings to investigate the root cause of the fraudulent PCOR-EM survey responses and conducted brief literature and web reviews to compare our experience with others. We determined that the primary cause was linking the eligibility survey directly to the PCOR-EM survey. This design allowed anyone who passed the eligibility screener to immediately complete the full survey without additional review or verification by the research team.

SOLUTIONS IMPLEMENTED

The research team paused the survey immediately upon detection of fraudulent activity and implemented a multi-pronged verification protocol to address the large number of fraudulent responses. This multi-pronged verification protocol included 1) Controlled Survey Access, 2) Enhanced Eligibility Screening, and 3) Secure Incentive Distribution. Each of these protocol elements are described below.

Controlled Survey Access

The research team removed public access to the full survey to reduce opportunities for fraudulent entry. Instead, we created a separate screener link that allowed us to complete robust eligibility screening before granting access to the pilot survey. Once participants passed this review, we sent them a unique, one-time survey link directly to their verified email. This controlled process ensured that only eligible and authentic participants advanced to the survey stage.

Enhanced Eligibility Screening

The research team required all participants to complete a screener before they could enter the pilot survey. To strengthen verification, we added an open-ended question, “How did you hear about our study? Please be specific.” Our team manually reviewed each screener submission and applied multiple checks to determine authenticity. These checks included assessing the plausibility of the referral source, reviewing email address formats, conducting Google searches of participant names to confirm research affiliations, identifying duplicate contact information and IP addresses, and monitoring response timing and submission patterns. This process allowed us to confirm eligibility while filtering out fraudulent or suspicious entries.

Secure Incentive Distribution

The research team embedded the incentive claim link directly into the survey platform (REDCap) so participants could only access it after verification. We then cross-referenced the incentive distribution list against verified participants to ensure that only eligible individuals received the $35 gift card. This step safeguarded resources while rewarding authentic participation.

OUTCOMES & LESSONS LEARNED

The research team successfully identified and addressed fraudulent PCOR-EM survey responses promptly, and as a result, completed the pilot process within a 3 month timeframe and initiated the PCOR-EM pilot analysis. During this process, the research team found:

- Fraudulent responses practically ceased after implementing the new screening and access measures.
- These strategies, as described above, preserved the integrity of pilot data and ensured that incentives went to individuals who had experience with engaged research.
- There is a need for proactive fraud prevention planning in all online research involving incentives to timely detect, halt, and prevent further fraudulent entries while maintaining recruitment momentum.
- While linking eligibility screening tools directly to the pilot tool appears to save time and administrative burden, it can lead to additional staff time for manual review and numerous potentially fraudulent responses and misappropriation of incentives that cannot be recovered.

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