



PCOR-EM 2025 PILOT SURVEY DATA COLLECTION RESULTS & ANALYSIS REPORT

PROJECT OVERVIEW

The Measurement Matters: Refining and Validating a Patient-Centered Outcomes Research Engagement Measure project (SOE-2022C2-28570) is a two-year award, initiated 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 developed through a multi-phase process that included extensive patient and community partner engagement, a literature scan, two rounds of consensus methods, focus groups, and cognitive testing interviews. The result was the creation of a 30-item pilot measure representing seven domains essential to engagement, which was later refined to a 19-item version through psychometric analyses. As part of this work, the project team and our partners chose supplemental survey items (e.g., survey respondent demographics and outcome measures, including a modified version of the Research Engagement Survey Tool (REST),ⁱ to provide a comprehensive understanding of the people completing the PCOR-EM and their engagement outcomes. See Appendix A for the PCOR-EM.

In April 2025, the research team initiated survey pilot data collection in collaboration with PCORnet® Clinical Research Networks (CRNs), the PCORI Ambassador Program, and other engaged research partners. The pilot was designed to obtain a diverse and analytically useful sample of respondents with direct experience in patient or community engagement in research, with particular representation from studies relevant to older adults. This report summarizes data from the PCOR-EM pilot, including aggregate respondent demographic characteristics, responses to the PCOR-EM items, and responses to the engagement outcomes measures, which all served as the foundation for subsequent psychometric evaluation, including assessment of item performance, scale structure, and preliminary validity.

DATA COLLECTION METHODS

The research team conducted data collection between April and July 2025 using a cross-sectional, web-based survey administered through REDCap. REDCap provided a secure data environment and included built-in validation rules to support data quality, reduce missing data, and ensure consistent survey administration. A comprehensive Data Collection report can be found [here](#).

Sampling Strategy and Recruitment Approach. The research team designed a sampling strategy to yield a diverse, analytically useful sample of individuals with direct experience in patient or community engagement in research, with intentional variation across demographics and levels of engagement experience. Recruitment began with PCORnet® Clinical Research Networks (CRNs) and expanded to include PCORI Ambassadors, the PCORI Engagement Advisory Panel, NIH- and NIA-funded initiatives, Aging Special Interest Groups, universities, and other engaged research

networks. Outreach was conducted through targeted emails, listservs, webinars, conference follow-up, and partner-driven dissemination.

Data Collection and Quality Assurance. Participants completed an electronic eligibility screener and provided informed, written consent prior to survey participation. The survey was administered through REDCap and included the pilot 30-item Patient-Centered Outcomes Research Engagement Measure (PCOR-EM), which asked respondents to reflect on engagement practices within their current or most recent engaged research project using structured Likert-scale response options. The pilot 30-item measure was subsequently refined to a 19-item version through psychometric analyses. The survey also included supplemental sections assessing project characteristics, respondent roles and engagement experience, project and partnership outcomes, selected items from the Research Engagement Survey (REST) Condensed Scale, and demographic/background characteristics.

Participants who completed the survey and passed data quality and eligibility review received a \$35 incentive. To maintain separation between identifying information and survey responses, participants completed a separate form to indicate their preferred gift card and provide contact information. The research team stored these identifying data separately and did not link them to survey responses. The team implemented multiple data quality procedures, including validation rules, attention checks, manual review, unique survey links, and cross-checks to prevent fraudulent or duplicate responses. Recruitment and data collection were monitored in real time, with iterative adjustments to improve sample composition and ensure inclusion of participants with a range of engagement experience.

SURVEY REACH

The research team contacted an estimated 1,300 individuals through targeted outreach efforts. Of these, 879 individuals completed the eligibility screener. Among those screened, 403 individuals met eligibility criteria and received a survey invitation. A total of 316 eligible participants initiated the survey, and 301 participants completed a valid survey, representing a 74.7% completion rate among eligible invited participants.

The research team defined valid completed surveys as those in which participants met eligibility criteria and provided sufficient information to confirm participation. All 301 completed surveys met these criteria and were included in the initial analytic sample. The research team applied predefined eligibility and data-quality criteria to identify high-quality responses for primary analyses. Surveys





were classified as low quality when respondents completed the PCOR-EM and supplemental questions in under five minutes and failed an embedded attention check. The team reviewed duplicate or potentially fraudulent responses separately as part of its eligibility and verification procedures. Of the 301 valid completed surveys, 266 met the criteria for high-quality responses and were retained as the final analytic sample.

DATA ANALYSIS APPROACH

During the pilot, the research team analyzed high-quality responses to the initial 30-item PCOR-EM to assess the measure's reliability, validity, and overall performance. The team held ten participatory analysis meetings, each lasting one to two hours and open to all partners. Meetings typically included the Quantitative Lead, Principal Investigators, Engagement Lead, Project Assistant, and one to three partners representing patient and community partner or engaged researcher and facilitator perspectives. The Quantitative Lead shared updates, and the group discussed analysis decisions, challenges, and findings.

Before beginning the item response theory (IRT) analysis, the team examined whether the data met the assumptions required for this approach. Missing data were low, at less than 2% per item. Factor analysis identified one dominant factor, supporting treatment of the PCOR-EM as an essentially unidimensional measure of engagement quality across its seven domains. Partners also reviewed and validated the qualitative analysis of open-ended responses. Additional information appears in the [Qualitative Analysis report](#).

The team compared two IRT models and selected the Graded Response Model because it fit the data better. Using this model, the team examined item overlap, model fit, item difficulty, discrimination, measurement precision, and coverage across the seven engagement domains. Five items were removed because they overlapped excessively with other items, and six were removed because they demonstrated poor model fit. Partners reviewed each potential removal and considered the item's clarity, statistical performance, qualitative feedback, and contribution to domain coverage. The 11 removed items were retained for future evaluation. This process produced the final 19-item PCOR-EM and is described further under Refining the Measure.

To assess convergent validity, the team compared PCOR-EM scores with scores on the adapted Condensed Research Engagement Survey Tool, an established measure of engagement outcomes. The results provided preliminary evidence that the PCOR-EM measures the intended concept. The team also explored relationships between PCOR-EM scores, respondent characteristics, and supplemental project outcomes. These findings are presented in the Survey Findings section.

SURVEY DATA FINDINGS

Respondent Characteristics

The analytic sample included 266 respondents who met criteria for high-quality survey responses. The sample was concentrated among adults ages 25–44 (47.5%), with an additional 40.4% ages

45–64. Most respondents identified as women (76.6%), and the sample was highly educated, with 80.5% reporting a graduate degree or higher. Racial and ethnic composition was predominantly White/Caucasian (71.4%), with additional representation from Black or African American (11.3%), Asian (10.2%), and Hispanic/Latino (7.5%) participants. Respondents were distributed across geographic settings, with 50.4% from urban areas and 39.4% from suburban areas, and a smaller proportion from rural communities (8.3%). Table 1 summarizes respondent demographic characteristics for the high-quality analytic sample.

Table 1. Respondent Characteristics

Category	Response	n	%
Age	65 years and over	22	8.3%
	45 to 64 years	107	40.4%
	25 to 44 years	126	47.5%
	18 to 24 years	6	2.3%
	Prefer not to answer	4	1.5%
Gender	Woman	200	76.6%
	Man	50	19.2%
	Not listed	6	2.3%
	Prefer not to answer	5	1.9%
Education	Graduate degree or beyond	214	80.5%
	Bachelor's degree	39	14.7%
	High school / technical / some college	12	4.5%
	Prefer not to answer	1	0.4%
Race/Ethnicity	White/Caucasian	190	71.4%
	Black or African American	30	11.3%
	Asian	27	10.2%
	Hispanic/Latino	20	7.5%
	American Indian or Alaska Native	8	3.0%
	Native Hawaiian or Pacific Islander	1	0.4%
Geographic Area (residence)	Urban	133	50.4%
	Suburban	104	39.4%
	Rural	22	8.3%
	Other	2	0.8%

Respondent Roles and Engagement Experience

The analytic sample included respondents with substantial experience in engaged research. More than half had over five years of engagement experience (52.1%). Most reported being very involved

in developing engagement strategies (61.3%) and executing engagement activities (63.5%). Respondents represented a range of roles, most commonly researchers (69.9%), followed by project managers or coordinators (44.0%) and meeting facilitators (43.2%), with over one-third identifying as patient or community partners (36.8%), indicating representation across both research and partner perspectives. Only 36% reported having a single role (e.g., researcher or meeting facilitator), while 64% reported two or more roles, including 19% with three roles and 20% with four or more roles.

Participants were primarily affiliated with academic or research institutions (84.6%), though many also reported connections to nonprofit community organizations (60.5%), government agencies (28.2%), and private-sector or community-based providers (25.2%), reflecting cross-sector hosting of engagement activities. Many participants also reported their own lived experience relevant to populations commonly engaged in research, including self-reported representation from racial and ethnic minority groups (29.3%), individuals with mental health conditions (26.3%), and low-income populations (24.1%). Detailed distributions of respondent roles and engagement experience are presented in Table 2.

Table 2. Respondent Roles and Engagement Experience

Category	Response	n	%
Role in Engaged Research*	Researcher (e.g., PI, staff)	186	69.9%
	Project Manager / Coordinator	117	44.0%
	Meeting Facilitator	115	43.2%
	Patient / Community Partner	98	36.8%
	Engagement Specialist	74	27.8%
	Other	13	4.9%
	More than 1 role	169	64%
Involvement in Development of Engagement Strategies	Very involved	163	61.3%
	Involved	61	22.9%
	Not very involved	27	10.2%
	Not at all involved	15	5.6%
Involvement in Executing Engagement Component	Very involved	169	63.5%
	Involved	71	26.7%
	Not very involved	19	7.1%
	Not at all involved	5	1.9%
Years of Engagement Experience	5+ years	137	52.1%
	1–4 years	101	38.4%
	First project	25	9.5%
Organizational Affiliation*	Academic or research institutions	225	84.6%
	Non-profit community organization	161	60.5%

Category	Response	n	%
	Government agency	75	28.2%
	Private, for-profit provider or community agency	67	25.2%
	Other	13	4.9%
Personal Lived Experience*	Racial/ethnic minorities	78	29.3%
	Persons with mental health conditions	70	26.3%
	Low-income populations	64	24.1%
	Persons with serious chronic conditions	60	22.6%
	Persons with disabilities	57	21.4%
	Older adults	54	20.3%
	Not applicable	44	16.5%
	LGBT+ individuals	39	14.7%
	Immigrants/Refugees/Migrant Workers	33	12.4%
	Other	25	9.4%
	Persons who have experienced homelessness	13	4.9%
	Prefer not to answer	12	4.5%

* For items marked with an asterisk, respondents could select more than one response option.

Project Characteristics

Respondents reported on a diverse set of engaged research projects, the majority of which were currently active (69.2%), with fewer in development (8.3%) or completed (22.2%). Study designs varied, with over one-third categorized as “other” (35.3%), followed by observational studies (23.7%) and randomized controlled trials (17.7%), reflecting a mix of traditional and applied research methods.

Projects varied in scale. The most frequently reported project size category included 300 or more research participants (28.2%), followed by projects with fewer than 50 participants (21.1%) and 50–100 participants (19.2%). Respondents most frequently reported that their projects focused on older adults (52.3%), racial or ethnic minority populations (51.1%), individuals with serious chronic conditions (39.8%), and low-income populations (31.6%). Table 3 shows detailed distributions of project characteristics.

Table 3. Project Characteristics

Category	Response	n	%
Project Stage	Active	184	69.2%
	Ended	59	22.2%
	Development	22	8.3%

Category	Response	n	%
	Missing	1	0.4%
Study Type	Other	94	35.3%
	Observational	63	23.7%
	RCT	47	17.7%
	CER	36	13.5%
	Pragmatic	23	8.6%
	Missing	3	1.1%
Sample Size	300+	75	28.2%
	201–300	20	7.5%
	101–200	36	13.5%
	50–100	51	19.2%
	<50	56	21.1%
	N/A	27	10.2%
	Missing	1	0.4%
Populations of Focus*	Older adults	139	52.3%
	Racial/ethnic minorities	136	51.1%
	Persons with serious chronic conditions	106	39.8%
	Low-income populations	84	31.6%
	Persons with disabilities	78	29.3%
	Other	71	26.7%
	Persons with mental health conditions	51	19.2%
	Immigrants	39	14.7%
	LGBT+ individuals	30	11.3%
	Refugees	24	9.0%
	Persons experiencing homelessness	14	5.3%
	Migrant Workers	12	4.5%

* For items marked with an asterisk, respondents could select more than one response option.

Reported Engagement Practices (PCOR-EM Results)

Respondents completed the PCOR-EM based on their current or most recent engaged research project. Table 4 summarizes responses across the seven PCOR-EM domains, highlighting patterns in reported engagement practices related to organizational readiness, resources, communication, inclusion, relationship-building, and shared decision-making. All items were rated on a four-point scale ranging from “Definitely No” to “Definitely Yes.” The majority of respondents reported “Definitely Yes” to the following PCOR-EM items: research team is motivated to do engagement in the project (74.8%); money is allocated to engagement activities (58.0%); there is a written plan for

engaging patient/community partners in research (64.3%); time is dedicated during meetings to allow for open discussion (69.4%); individuals facilitating meetings are skilled in reflective listening and collaborative facilitation strategies (56.0%); research improvements resulting from engagement are shared with patient/community partners (57.0%); there is diversity among patient/community partners (51.1%); and research team has spent time talking to patient/community partners to inform research methods (59.9%). Table 4 shows participant responses across PCOR-EM domains and items.

Table 4. Participant Responses to the Final 19 PCOR-EM Items

Domain	Item	Definitely Yes	Mostly Yes	Mostly No	Definitely No
Organizational Readiness	Research team is motivated to do engagement in the project	74.8%	23.7%	1.5%	0.0%
	Research team has reviewed materials on best practices of engagement	47.4%	39.8%	11.4%	1.5%
	There is money allocated to engagement activities	58.0%	28.4%	9.5%	4.2%
Time & Resources	There is a written plan for engaging patient/community partners in research	64.3%	23.7%	9.8%	2.3%
	Researchers have access to training or mentoring on topics to enhance the engagement process	40.4%	41.1%	15.1%	3.4%
Logistics & Meeting Techniques	Patients/community partners have more than one way to access engagement meetings	38.4%	40.6%	15.4%	5.6%
	Meeting materials are shared at least 48 hours before meetings	34.2%	48.1%	13.5%	4.1%
	Time is dedicated during meetings to allow for open discussion	69.4%	24.5%	4.5%	1.5%
Clear and Transparent Communication	Patient/community partners and the research team communicate at least once per month during the project	49.6%	34.2%	11.7%	4.5%
	Individuals facilitating meetings are skilled in reflective listening and	56.0%	36.5%	5.6%	1.9%

	collaborative facilitation strategies				
	Patient/community partners' perspectives are thematically recorded through meeting notes	47.9%	33.5%	13.3%	5.3%
	Written summaries of meetings are shared with meeting attendees	42.8%	31.8%	18.6%	6.8%
	Research improvements resulting from engagement are shared with patient/community partners	57.0%	33.6%	7.2%	2.3%
Valuing Diversity	There is a written plan to engage underrepresented communities in the project	47.6%	33.6%	14.7%	4.2%
	There is diversity among patient/community partners	51.1%	36.5%	11.7%	0.8%
	The research team reflects one or more communities being studied	47.7%	33.1%	15.0%	4.1%
Trust & Relationship Building	Research team has spent time talking to patient/community partners to inform research methods	59.9%	31.8%	7.6%	0.8%
	Patient/community partners' perspectives are thematically recorded through meeting notes	47.9%	33.5%	13.3%	5.3%
	Research improvements resulting from engagement are shared with patient/community partners	57.0%	33.6%	7.2%	2.3%
	The research team reflects one or more communities being studied	47.7%	33.1%	15.0%	4.1%
Collaboration, Co-Learning & Power Sharing	Patient/community partners are engaged in the design of research questions	45.5%	31.1%	19.3%	4.2%

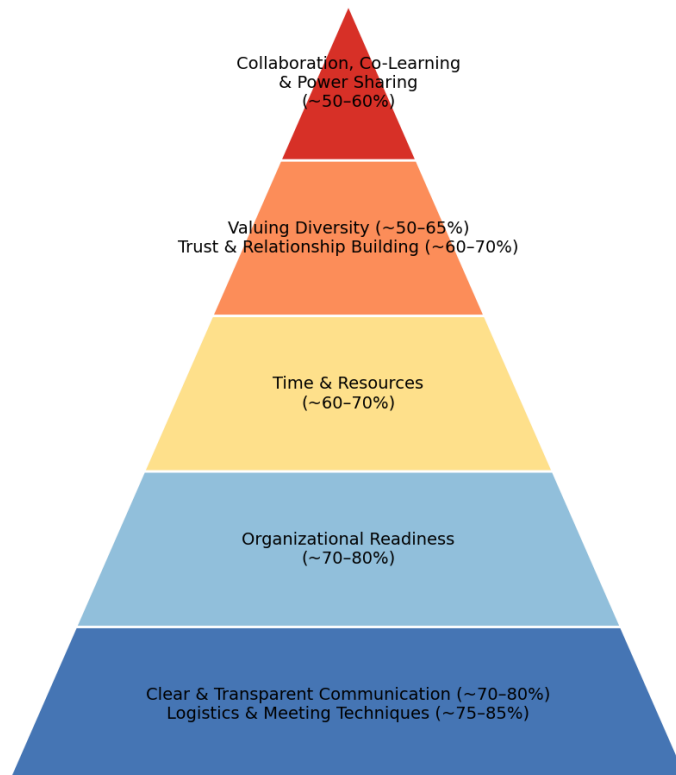
	Patient/community partners are active participants in the project's decision-making process	48.9%	34.9%	13.3%	3.0%
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Note. Sample sizes vary across items due to item-level missing responses.

Qualitative activities conducted in year one informed the conceptual framework for the seven engagement domains. The framework shows how the domains work together, with foundational practices supporting more complex engagement practices related to inclusion, sustained partnership, and shared decision-making.

Responses varied across the domains and items retained in the final PCOR-EM. Higher proportions of respondents selected “Definitely Yes” for research team motivation to engage patient and community partners (74.8%) and allowing time for open discussion during meetings (69.4%). Lower proportions selected “Definitely Yes” for sharing meeting materials at least 48 hours in advance (34.2%) and providing more than one way for patient and community partners to access meetings (38.4%). These findings show variation in how consistently specific engagement practices were implemented across respondents’ projects.

PCOR-EM Engagement Domain Pyramid



Engagement practices are strongest at the base (blue) and become more variable toward the top (red).



Refining the Measure: From 30 Items to 19

The research team examined how well each of the 30 original items performed, including whether items overlapped excessively with one another and whether they fit the selected item response theory model. Five items were removed because they overlapped excessively with other items, and six were removed because they demonstrated poor model fit. The team discussed each potential removal with partners and considered the item's statistical performance, clarity, qualitative feedback, and contribution to coverage of the seven engagement domains.

Some removed items included wording that respondents found confusing, such as items addressing funder-mandated engagement and single-language communication. Other items were removed because they covered concepts similar to those measured by stronger-performing items. Partner input helped ensure that item reduction reflected both statistical findings and the concepts the measure needed to retain. The 11 removed items were saved for future evaluation.

The resulting 19-item PCOR-EM demonstrated good overall model fit and strong measurement precision at low to moderate levels of engagement quality. The measure was less precise at higher levels, indicating a need for additional items that capture more advanced engagement practices. Items retained in the final measure include “Were partners involved in identifying the research questions?” (Collaboration and Power Sharing), “Did the team provide materials in plain language?” (Communication), and “Were partners compensated in a timely manner?” (Time and Resources). These items ask respondents about specific engagement practices rather than general impressions.

Understanding PCOR-EM Scores

Each respondent's answers to the 19 PCOR-EM items are converted into a single overall score on a 0 to 10 scale. Scores near 0 reflect lower-quality engagement practices, while scores near 10 reflect higher-quality engagement practices. Among the 266 respondents in the pilot, scores ranged from approximately 0.4 to 8.8 and were centered near the middle of the scale, with few scores at either extreme. The PCOR-EM measured lower and moderate levels of engagement quality more precisely than higher levels. This means the measure was better able to distinguish among projects at the lower and middle portions of the engagement continuum. Additional item development is needed to improve measurement precision at higher levels of engagement quality.

Outcome Findings (Project-Developed Items)

In addition to the PCOR-EM, respondents answered five supplemental items about engagement-related outcomes for their current or most recent project. The project team developed, refined, and piloted these items with engagement partners during Year 1. The items assessed project-level outcomes not covered by the adapted Condensed REST tool. Response options varied by item and included either “Yes,” “No,” and “Not Sure or Not Applicable,” or a scale ranging from “Not at All” to “To a Great Extent.” The most frequently reported outcomes were recognition of patient and community partner contributions in project outputs (78.4%) and production of project outputs

such as publications, presentations, or reports (71.8%). Additional funding was reported least frequently (36.2%). Table 5 summarizes responses to the five supplemental items.

Table 5. Participant Responses to Supplemental Project Outcomes Items

Outcome Area	Item	N	Yes	No	Not Sure; n/a	Not at all	To a small extent	To some extent	To a great extent
Changes to Research Methods	Research methods changed based on what was learned through the engagement process	264	68.6%	19.7%	11.7%	—	—	—	—
Project Outputs	Project resulted in outputs such as publications, presentations, or reports	266	71.8%	11.7%	16.5%	—	—	—	—
Recognition of Patient / Community Partner	Patient/community partner contributions were recognized in project outputs	264	78.4%	3.0%	18.6%	—	—	—	—
Funding and Sustainability	Project led to additional funding	265	36.2%	35.1%	28.7%	—	—	—	—
Use of Project Outputs	Project outputs were used by target populations or decision-makers	265	—	—	14.3%	20.4%	1.9%	34.7%	28.7%

Note. Sample sizes vary across items due to item-level missing responses.

Outcome Findings (Validated REST Tool)

Respondents also completed supplemental items to understand outcomes for their current or most recent project using adapted items from the Research Engagement Survey Tool (REST),ⁱⁱ originally developed by Melody S. Goodman and colleagues to assess engagement outcomes in research partnerships. The research team modified and selected items for inclusion in the PCOR-EM pilot survey. Responses were rated on a five-point scale ranging from Poor to Excellent. The REST measures are publicly available [here](#).

Across adapted REST outcome items, responses were most frequently rated as “Very Good” or “Excellent.” The highest proportions of “Excellent” ratings were observed for creating an inclusive engagement environment (66%), treating partners with respect (61%), valuing partner contributions (61%), and strengthening partnerships over time (60%). The highest proportions of “Very Good”

ratings were observed for maintaining open and transparent communication (41%), clearly defining roles and responsibilities (40%), supporting long-term engagement (40%), and adapting engagement to community needs (39%). Table 6 summarizes participant responses.

Table 6. REST Condensed Scale Item Response Distributions

Adapted REST Item*	N	Poor	Fair	Good	Very Good	Excellent
Focus on community priorities	263	0.4%	3.0%	12.9%	33.8%	47.1%
Consider cultural factors in research	264	2.7%	8.7%	18.9%	29.5%	34.1%
Clearly define roles and responsibilities	262	1.1%	8.0%	17.2%	40.5%	31.3%
Maintain engagement to meet project goals	262	2.7%	6.1%	14.9%	32.8%	37.8%
Partnership adds value to research	264	1.5%	6.1%	15.2%	34.1%	40.2%
Build on community strengths and resources	263	1.5%	6.1%	16.3%	32.3%	40.7%
Treat partners with respect	264	0.4%	2.7%	8.3%	25.8%	61.0%
Ensure all voices are heard	264	1.9%	7.6%	25.8%	29.2%	29.5%
Foster mutual respect among partners	263	1.5%	5.3%	15.6%	31.6%	43.7%
Value partner contributions	260	0.8%	3.5%	11.5%	20.8%	60.8%
Address issues important to community	265	0.4%	3.4%	7.5%	37.4%	48.3%
Establish shared decision-making processes	264	0.8%	6.1%	21.6%	34.8%	31.1%
Maintain open and transparent communication	265	1.1%	3.8%	16.2%	41.1%	34.3%
Build trust among partners	264	1.1%	1.9%	13.3%	36.4%	41.7%
Ensure equitable participation	264	1.9%	1.9%	12.9%	37.5%	43.6%
Support long-term engagement	265	1.1%	3.8%	11.3%	40.4%	39.2%
Create inclusive engagement environment	265	0.4%	0.8%	5.3%	25.7%	66.0%
Adapt engagement to community needs	264	0.0%	2.3%	23.9%	39.0%	29.5%
Promote shared understanding of goals	264	1.1%	3.4%	13.3%	31.1%	48.5%
Strengthen partnerships over time	265	0.4%	1.9%	6.8%	28.3%	60.0%

* Note: Item labels are abbreviated descriptions. Full item wording is available in Appendix A.

Relationship Between PCOR-EM Scores and Engagement Outcomes

The research team examined the relationship between PCOR-EM scores and scores on the adapted Condensed REST tool. The analysis found a moderately strong, positive, and statistically significant relationship between the two measures ($r = 0.53$, $p < 0.001$). Respondents with higher PCOR-EM scores also tended to report more favorable engagement outcomes on the REST, including trust, respect, shared decision-making, and mutual value. This finding provides preliminary evidence that the PCOR-EM measures the intended concept.

The research team also compared PCOR-EM scores with the project-developed outcome items presented in Table 5. These items addressed whether the project produced outputs, whether the

research methods changed based on engagement, the extent to which project outputs were used, and the number of engagement roles held by the respondent. None of these relationships were statistically significant. However, the results generally followed the expected direction, with somewhat higher PCOR-EM scores among respondents who reported more favorable project outcomes. Additional testing with a larger and more diverse sample is needed to further evaluate these relationships.

Limitations

Several limitations should be considered when interpreting these findings. The study relied on respondents' assessments of engagement practices in a current or recent research project. Responses may have differed based on the respondent's role, level of involvement, and knowledge of project activities. The research team did not collect project names to protect confidentiality. Therefore, the team could not determine the number of unique projects represented or whether multiple respondents reported on the same project.

The sample included participants from different engagement roles and research settings, but most respondents had advanced education and substantial engagement experience. Individuals from low-income communities and those with limited English proficiency were underrepresented. Recruitment also relied on distributed research networks and referrals, which may have resulted in greater participation among individuals already connected to engaged research. These factors may limit the applicability of the findings across other populations, roles, and settings.

The cross-sectional design did not allow the team to assess changes in engagement quality over time or determine whether engagement practices caused specific project outcomes. The sample also did not include sufficiently large comparison groups to test whether PCOR-EM items performed consistently across demographic groups, engagement roles, or population areas of focus. Future testing will require a larger and more evenly distributed sample.

Finally, the PCOR-EM measured lower and moderate levels of engagement quality more precisely than higher levels. Future work should develop and test additional items that better distinguish among projects with advanced engagement practices.



APPENDIX A: THE PATIENT-CENTERED OUTCOMES RESEARCH ENGAGEMENT MEASURE (PCOR-EM)

Instructions

Please complete the PCOR-EM based on your current or most recent engaged research project. Select one response for each statement. Estimated completion time: 4–6 minutes.

1. Engagement Infrastructure

Statement	Definitely No	Mostly No	Mostly Yes	Definitely Yes
Research team is motivated to do engagement in the project	☐	☐	☐	☐
Research team has reviewed materials on best practices of engagement	☐	☐	☐	☐
There is money allocated to engagement activities	☐	☐	☐	☐
There is a written plan for engaging patient/community partners in research	☐	☐	☐	☐
Researchers have access to training or mentoring on topics to enhance the engagement process	☐	☐	☐	☐

2. Inclusive Engagement

Statement	Definitely No	Mostly No	Mostly Yes	Definitely Yes
There is a written plan to engage underrepresented communities in the project	☐	☐	☐	☐
There is diversity among patient/community partners, such as their age, race, gender, opinion, lived experience, and expertise.	☐	☐	☐	☐
The research team reflects one or more communities being studied	☐	☐	☐	☐

3. Partnership and Communication

Statement	Definitely No	Mostly No	Mostly Yes	Definitely Yes
Patient/community partners are engaged in the design of research questions	☐	☐	☐	☐
Research timelines are influenced by engagement of patient/community partners	☐	☐	☐	☐

Patient/community partners and the research team communicate at least once per month during the project	☐	☐	☐	☐
Patients/community partners have more than one way to access engagement meetings	☐	☐	☐	☐
Individual and group conversations are available to patient/community partners	☐	☐	☐	☐
Time is dedicated during meetings to allow for open discussion with patient/community partners	☐	☐	☐	☐
Individuals facilitating meetings are skilled in both reflective listening and collaborative facilitation strategies	☐	☐	☐	☐

4. Feedback, Documentation, and Impact

Statement	Definitely No	Mostly No	Mostly Yes	Definitely Yes
Patient/community partners perspectives are thematically recorded through meeting notes	☐	☐	☐	☐
Written summaries of all patient/community partner meetings are shared with meeting attendees	☐	☐	☐	☐
Actions that result from meetings with patient/community partners are documented and shared with meeting attendees	☐	☐	☐	☐
Research improvements that result from patient/community partner engagement are shared with all patient/community partners	☐	☐	☐	☐

ⁱ Goodman MS, Ackermann N, Pierce KA, Bowen DJ, Thompson VS. Development and validation of a brief version of the Research Engagement Survey Tool. *Int J Environ Res Public Health*. 2021;18(19):10020. doi:10.3390/ijerph181910020.

ⁱⁱ Ibid.