Validation of the Quality of Patient-Centered Outcomes Research Instrument

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Abstract

Objective

To validate the Quality of Patient-Centered Outcomes Research Instrument (QPCOR).

Methods

Baseline, 3-month, and 6-month follow-up data from a national prospective cohort study of 330 U.S. patients and community partners. The 10-item QPCOR was validated across several metrics: descriptive statistics, item response characteristics, internal consistency, test-retest reliability, and convergent validity.

Results

The QPCOR items (1) measured related aspects of researcher partnership efforts (correlations ranged from 0.485 to 0.712), (2) differentiated between levels of perceived researcher effort (all discrimination values > 2.550), (3) demonstrated internal consistency (Cronbach's alpha = 0.94) and test-retest reliability (intraclass correlation coefficient values ranged from 0.418 to 0.555), and (4) exhibited convergent validity with other validated scales, including the Brief Research Engagement Survey Tool (r = 0.75, $p < 0.001$), the Subjective Numeracy Scale (r = 0.48, $p < 0.001$), and the Trust in Medical Researchers Scale (r = 0.48, $p < 0.001$).

Policy Implications

Validated engagement quality instruments provide a practical starting point for evaluating engagement without imposing strict compliance metrics. Existing evaluations are predominantly qualitative and descriptive, limiting cross-study comparability and complicating efforts to assess engagement. Emerging efforts, such as the National Academy of Medicine's work on community engagement measurement and the development of validated instruments such as the QPCOR, highlight a growing consensus that engagement should be evaluated not only in terms of participation or structure, but also by influence, accountability, and relational quality.

Conclusions

The QPCOR provides a reliable, psychometrically validated instrument for measuring the quality of patient-centered outcomes research partnerships. This instrument advances the science of engagement through its inclusion as a standardized measure for patient-centered outcomes research.

Plain English Summary

Patient-Centered Outcomes Research (PCOR) is a process that outlines shared leadership, consultation, and ongoing collaboration. PCOR has transformed from patient partners taking more advisory-based roles to a more fundamental role in scientific research, with this report focusing on the development and validation of a tool called the *Quality of Patient-Centered Outcomes Research Instrument (QPCOR).* The introduction of the QPCOR and its validation process outlines a quantitative need for validated instruments that increases the evaluation of engagement beyond terms of structure or participation. The items on the QPCOR examined influence, accountability, and relational quality and was found to be validated, implying that tools like the QPCOR can advance the science of engagement and measure the quality of patient-centered outcomes research partnerships, advancing the science of engagement in PCOR.

*****The Gripp2 Short Form Checklist has been included as an additional file to this manuscript.

Introduction

Incorporating engagement approaches into patient-centered outcomes research in scientific studies yields more relevant research questions, increases uptake of findings, and leads to better clinical outcomes than research without engagement approaches.[1–5] According to the Patient-Centered Outcomes Research Institute (PCORI)'s continuum of engagement, patient-centered research is characterized as a process involving consultation (e.g., advisory boards), collaboration (e.g., community engagement studios), and shared leadership (e.g., community-based participatory research).[6–8] Yet, methods employed in patient-centered outcomes research often leave patient partners feeling disenfranchised, leading to premature disengagement, and limited influence and patient voice incorporated into research.[9]

Patient-centered outcomes research initially had patient partners in advisory roles, overseeing projects while having less direct impact on research direction, leadership, and scientific process.[9] Patient engagement is now recognized as a core scientific method rather than a "supplemental activity" in rigorous scientific inquiry.[1–5] National and international organizations such as the PCORI, the National Institutes of Health, the Centers for Disease Control & Prevention (CDC), the World Health Organization, and the National Academies of Sciences, Engineering, and Medicine have cross-cutting initiatives on patient engagement in research.[1–5]

Validated engagement instruments provide a practical starting point for evaluation of engagement activities without imposing strict compliance metrics. Existing evaluations are predominantly qualitative and descriptive,[1–5] limiting cross-study comparability and complicating efforts to assess engagement. Emerging efforts, such as the National Academy of Medicine's work on community engagement measurement and the development of validated instruments such as the Brief Research Engagement Survey Tool,[5] highlight growing consensus that engagement should be evaluated not only in terms of participation or structure, but also by influence, accountability, and relational quality. This report details the development and psychometric validation of the *Quality of Patient-Centered Outcomes Research Instrument (QPCOR).*

Methods

Instrument Development

The QPCOR was developed through a seven-step process, Measure, Express, Assess, Review, Evaluate, Update, and Evaluate Framework (MEASURE; Fig. 1), with each step contributing to the development and validation of the instrument's psychometric properties.

The QPCOR was co-developed with patient partners. The purpose of the QPCOR is to hold research teams accountable for patient and community engagement throughout the entirety of patient-centered outcomes research. QPCOR is designed for anyone to complete, as it does not require a postgraduate degree or a high school diploma to read, understand, and confidently answer the survey questions. The instrument was accessible, as indicated by a Flesch-Kincaid Grade Readability Level of 4.7 and a Flesch Reading Ease Score of 73.1, suggesting that the tool is written at a 7th -grade level. QPCOR comprises 10 items that cover patient-identified vital areas of interest related to the quality of the community engagement process. QPCOR instructions read "*Consider your Patient-Centered Outcomes Research partnerships to date in one specific project and respond to each of the following questions on a scale from 0 = 'No effort was made by researchers' to 10 = 'Every effort was made by researchers'*."

The patient-led research team and research partners identified several candidate frameworks (e.g., Handbook of Citizen Engagement[10] and the World Health Organization's Community Engagement Framework for Quality, People-Centered and Resilient Health Services).[11] We then applied a Delphi method to establish group consensus on which approach to guide our instrument development process.[12,13] This process evaluated the frameworks identified from the literature review. The panelists responded to three Delphi rounds via email that presented candidate frameworks.[13] After each round, all responses were aggregated and shared with the group until a 100% consensus was achieved.[13] The Delphi panel chose the CDC's Principles of Community Engagement as the most appropriate theoretical foundation.[14]

Based on the principles of Community Engagement,[15] the patient-led research team and research partners generated several versions of the instrument items. Elements of community engagement we evaluated and discussed included: (a) purpose, goal, and population, (b) respect community diversity and culture, (c) inclusion/activate community assets, (d) co-learning/develop capacity, (e) become knowledgeable about the community, (f) self- determination, (g) shared-decision making/partner with the community,

(h) perceived support/interact and establish relationships with the community, (i) flexibility of engagement, and (j) sustainability/commitment to long term collaboration.

The next step to psychometric development focused on synthesizing the content and developing the scale. We also referred to an analysis of existing patient and community engagement measurement challenges for individuals with mental health conditions (e.g., usefulness during the community engagement process and complexity, as determined by terms, word count, sentence structure, and sentence length).[6]

Expert Reviews of the QPCOR Instrument

The next step involved expert reviews that were conducted through cognitive interviews. Cognitive interviews help reduce bias and improve comprehension and content validity.[16] We conducted two phases of cognitive interviews using independent samples. Cognitive interviews are an evidence-based method for investigating whether an item achieves its intended purpose.[17] During these interviews, participants were given ten minutes to review a set of proposed items before being debriefed on their thoughts about the instrument items. The primary objective was to understand how individuals interpret items and to assess whether the items aligned with the principles of community engagement.[6,15]

QPCOR Pre-Post Pilot Study

The sixth step involved a pilot study to assess the instrument's usability and efficacy. We piloted the items with 16 patients who were engaged in PCOR research projects to assess their acceptability, ease of use, and relevance. During this phase, the instrument was emailed to each participant in the sample. Participants were instructed to complete the online instrument. Through the pilot study, we found that the instrument was feasible to implement with a larger sample size. No changes were made. This instrument is feasible and acceptable, as evidenced by the outcomes of the pilot studies.[3,6] Finally, the last step involved evaluating the instrument's psychometric properties in real-world settings. The next phase of instrument validation is presented below.

Study Design, Setting, and Sample

This analysis used data from a national prospective cohort study of U.S. patients aged 18 years or older. The study team recruited 330 participants to complete a baseline, three-month, and six-month follow-up. Recruitment methods included emails to current PCORI investigators, recruitment flyers using universal design principles,[1–5] and LinkedIn posts tagging all recruitment committee members. As a fraud prevention measure, all prospective participants underwent a 15-minute virtual verification session with research personnel to authenticate their identity, project affiliation, and collaborating investigator. The team used web-based searches to corroborate these details before finalizing participant enrollment.

The study team included a Governance Board (established in 2023) comprising four patient and community partners, and a Recruitment Committee (established in 2024) consisting of patient-centered researchers from British Columbia, Canada, and eight U.S. states (Alaska, California, Illinois, Minnesota, New Hampshire, New York, Pennsylvania, and Virginia). This study was approved by the Institutional Review Board at [BLINDED FOR REVIEW] and when applicable, the study team followed the Strengthening the Reporting of Observational Studies in Epidemiology guidelines.[2]

Quality of Patient-Centered Outcomes Research

The QPCOR Instrument comprised 10 items that measured researchers' effort in patient-centered partnerships (Appendix A). The ten items were: (1) I had a clear understanding of the purpose of the study, (2) I felt listened to, (3) I feel prepared to be an equal partner in the research study, (4) Researchers were knowledgeable about people like me or were willing to learn about people like me, (5) I believe that I had choices in how I could be a part of the research study, (6) I felt accepted by all members of the research study team, (7) Researchers used language that was consistent with my values and culture, (8) Both community members and researchers are thinking of ways we can continue to work together in the future, (9) I felt comfortable engaging with the members

of the research study team, and (10) I felt my views were incorporated into the research study (Appendix 1). Details regarding the development of the QPCOR are described in detail elsewhere.[3]

Additional Measures

Sociodemographic Factors. Sociodemographic characteristics included age (< 30, 30–39, 40–49, 50+), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic Other), gender identity (female, male, non-binary/transgender), educational attainment (high school/occupational training, some college/associate's degree, college degree or higher), marital status (married, single, divorced/separated), household size (1–2, 3–4, 5+), U.S. census region (Northeast, South, Midwest, West), and disability status (yes/no). The non-Hispanic Other racial/ethnic group included participants who identified as Asian, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, or Multiracial. The U.S. census region was derived from the respondent's self-reported U.S. state.

Research Engagement. We assessed research engagement using the Brief Research Engagement Survey Tool (REST).[5] Participants were asked to rate how often the partners leading the research do each of the following: (1) The focus is on problems important to the community, (2) All partners assist in establishing roles and related responsibilities for the partnership, (3) Community-engaged activities are continued until the goals (as agreed upon by all partners) are achieved, (4) The partnership adds value to the work of all partners, (5) The team builds on strengths and resources within the community or patient population, (6) All partners' ideas are treated with openness and respect, (7) All partners agree on the timeline for making shared decisions about the project, (8) The partnership's processes support trust among all partners, and (9) Mutual respect exists among all partners. Each item was scored using a 5-point Likert scale from *(1) never* to *(5) always*. We averaged these scores to create a composite score (Cronbach's alpha = 0.86), with higher values indicating greater research engagement.[5]

Subjective Numeracy. Subjective numeracy was examined using the Subjective Numeracy Scale.[20] Participants were asked the following eight questions: (1) How good are you at working with fractions? (2) How good are you at working with percentages? (3) How good are you at calculating a 15% tip? (4) How good are you at figuring out how much a shirt will cost if it is 25% off? (5) When reading the newspaper, how helpful do you find tables and graphs that are parts of a story? (6) When people tell you the chance of something happening, do you prefer that they use words ('it rarely happens') or numbers ('there's a 1% chance')? (7) When you hear a weather forecast, do you prefer predictions using percentages (e.g., 'there will be a 20% chance of rain today') or predictions using only words (e.g., 'there is a small chance of rain today')? (8) How often do you find numerical information to be useful? Items 1 through 4 were scored on a 6-point Likert scale ranging from *(1) not at all good* to *(6) extremely good*. Item 5 was scored on a 6-point Likert scale ranging from *(1) not helpful at all* to *(6) extremely helpful.* Items 6 and 7 were scored on a 6-point Likert scale ranging from *(1) always prefers words* to *(6) always prefers numbers* (item 7 was reverse-coded). Item 8 was scored on a 6-point Likert scale ranging from *(1) never* to *(6) very often*. Scores were averaged to create a continuous variable, with higher scores indicating greater subjective numeracy (Cronbach's alpha = 0.85).

Trust in Medical Researchers. Trust in medical researchers was measured using the 12-item Trust in Medical Researchers Scale.[9,18] Participants used a 5-point Likert scale ranging from *(1) strongly disagree* to *(5) strongly agree* to rate the following items: (1) To get people to take part in a study, medical researchers usually do not explain all of the dangers about participation, (2) Participants should be concerned about being deceived or misled by medical researchers, (3) Usually, researchers who make mistakes try to cover them up, (4) Medical researchers act differently toward minority subjects than toward White subjects, (5) Medical researchers unfairly select minorities for their most dangerous research studies, (6) Some medical research projects are secretly designed to expose minority groups to diseases such as AIDS, (7) Medical researchers are generally honest in telling participants about different treatment options available for their conditions, (8) Usually, medical researchers tell participants everything about possible dangers, (9) All in all, medical researchers would not conduct experiments on people without their knowledge, (10) Most medical researchers would not lie to people to try to convince them to participate in a research study, (11) In general, medical researchers care more about doing their research than about the participants' medical needs, and (12) Researchers are more interested in helping their careers than in learning about health and disease. Items 1–6, 11, and 12 were reverse-coded. The scores from the 12 items were summed, and 12 was subtracted from the total (48), yielding a composite score where higher values indicated higher trust in medical researchers (Cronbach's alpha = 0.86).

Statistical Analysis

We computed baseline characteristics using frequencies and percentages for categorical measures and means and standard deviations (SD) for continuous variables. Descriptive statistics for each QPCOR item included count, mean, SD, median, minimum, maximum, skew, kurtosis, and standard error. We also plotted the distribution of each item. For item response characteristics, we calculated pairwise correlations among the ten QPCOR items and employed a graded response model to estimate the discrimination and difficulty parameters for each item.[16] We performed internal consistency and test-retest reliability analysis to evaluate reliability. The assessment of internal consistency included computing the overall Cronbach's alpha and the Cronbach's alpha if each item was deleted. For test-retest reliability, we fit a linear mixed-effects model among participants who completed baseline and 3-month follow-up surveys to compute the intraclass correlation coefficient (ICC) for each item using the two-way mixed effects, consistency, and single rater approach according to McGraw and Wong.[19] For validity, we conducted a confirmatory factor analysis to estimate the factor loadings for each item. Lastly, we assessed convergent validity by computing correlations with the Brief REST,[5] the Subjective Numeracy Scale,[20] and the Trust in Medical Researchers Scale.[9,18] All statistical analyses were performed using R version 4.5.1 (R Core Team, R Foundation for Statistical Computing) with statistical significance set at $p < 0.05$.

Results

Baseline Sample Characteristics

We screened 343 people, of whom 330 (96%) were eligible and enrolled (completed informed consent). All 330 enrolled participants completed all three surveys.

Baseline characteristics for 330 participants are shown in Table 1. Seventy-two percent were at least 30 years old, 37% were non-Hispanic White, 56% were male, and 48% had a college degree or higher. Fifty-six percent were married, 63% had a household size of 3 or more, and 39% resided in the South. Seventy-nine percent were not disabled.

Table 1
Baseline characteristics of 330 participants from the QPCOR Study

Characteristic	N = 330
Age, No. (%)	
<30	91 (27.6)
30–39	137 (41.5)
40–49	71 (21.5)
50+	31 (9.4)
Race/ethnicity, No. (%)	
non-Hispanic White	123 (37.3)
non-Hispanic Black	105 (31.8)
Hispanic	36 (10.9)
non-Hispanic Other	66 (20.0)
Gender identity, No. (%)	
Male	185 (56.1)
Female	125 (37.9)
non-Binary/Transgender	20 (6.1)
Educational attainment, No. (%)	
High school/Occupational training	23 (7.0)
Some college/associate's degree	109 (33.0)
College degree or higher	159 (48.2)
Missing	39 (11.8)
Marital status, No. (%)	
Married	186 (56.4)
Single	102 (30.9)
Divorced/Separated	42 (12.7)
Household size, No. (%)	
1–2	123 (37.3)
3–4	149 (45.2)
5+	58 (17.6)
Census region, No. (%)	
Northeast	73 (22.1)
South	130 (39.4)
Midwest	30 (9.1)
West	83 (25.2)
Missing	14 (4.2)
Disability status, No. (%)	

Characteristic	N = 330
No	260 (78.8)
Yes	67 (20.3)
Missing	3 (0.9)
Research engagement, Mean (SD)	4.3 (0.5)
Missing, No. (%)	5 (1.5)
Subjective numeracy, Mean (SD)	4.6 (0.9)
Trust in medical researchers, Mean (SD)	28.2 (8.1)

Validation Results for the Quality of Patient-Centered Outcomes Research Instrument

As shown in Table 2, mean scores for all ten items ranged from 8.515 to 8.764, indicating that respondents perceived researchers as making substantial efforts across all partnership dimensions measured. This finding is confirmed in Table 3 as all items exhibited a right-skewed distribution with a high concentration of responses at the upper end of each item. Table 3 shows the interrelationships among all ten QPCOR items. All correlations were positive and moderate-to-strong, ranging from 0.485 to 0.712. The strongest correlations were between Item 10 and Item 8 (r = 0.712) and between Item 8 and Item 9 (r = 0.696). The weakest correlations were observed between Item 3 and Item 6 (r = 0.485) and between Item 1 and Items 4, 6, and 7 (r = 0.518–0.519). These consistent positive correlations suggest that the QPCOR items measure related aspects of researcher partnership efforts.

Table 2
Descriptive statistics and results from the analyses of internal consistency and test-retest reliability for the Quality of Patient-Centered Outcomes Research Partnerships Instrument.

Item 1	N	Mean	SD	Median	Min	Max	Skew	Kurtosis	SE	Cronbach's alpha if item deleted	Intraclass correlation coefficient	Loading
	330	**8.697**	**1.477**	**9**	**2**	**10**	**-1.108**	**1.020**	**0.081**	**0.934**	**0.555**	**0.834**
Item 2	330	8.727	1.543	9	2	10	-1.138	0.806	0.085	0.932	0.418	0.848
Item 3	330	8.621	1.535	9	2	10	-1.125	1.238	0.085	0.932	0.507	0.785
Item 4	330	8.694	1.504	9	4	10	-1.087	0.434	0.083	0.932	0.474	0.824
Item 5	330	8.603	1.714	9	0	10	-1.564	2.973	0.094	0.932	0.489	0.822
Item 6	330	8.694	1.622	9	2	10	-1.246	1.107	0.089	0.934	0.471	0.845
Item 7	330	8.718	1.587	9	3	10	-1.257	0.961	0.087	0.931	0.498	0.762
Item 8	330	8.697	1.571	9	2	10	-1.211	1.111	0.086	0.930	0.477	0.802
Item 9	330	8.764	1.529	9	4	10	-1.176	0.660	0.084	0.929	0.452	0.848
Item 10	330	8.515	1.66	9	3	10	-0.997	0.367	0.091	0.929	0.553	0.863

Notes: SD = Standard Deviation; SE = Standard Error

Table 3
Inter-item correlation matrix for the Quality of Patient-Centered Outcomes Research Partnerships Instrument.

Item 1	Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	Item 7	Item 8	Item 9	Item 10
	1.000									
Item 2	0.578	1.000								
Item 3	0.638	0.622	1.000							
Item 4	0.519	0.671	0.583	1.000						
Item 5	0.536	0.579	0.654	0.570	1.000					
Item 6	0.519	0.536	0.485	0.553	0.589	1.000				
Item 7	0.518	0.588	0.611	0.588	0.568	0.651	1.000			
Item 8	0.575	0.582	0.630	0.610	0.584	0.586	0.641	1.000		
Item 9	0.598	0.623	0.613	0.604	0.640	0.600	0.667	0.696	1.000	
Item 10	0.561	0.636	0.592	0.613	0.647	0.595	0.681	0.712	0.690	1.000

All items exhibited high discrimination (all values > 2.550), indicating that these items differentiate between levels of perceived researcher effort (Supplemental Table 1). Items 8–10 showed the highest discrimination (range: 3.614 to 3.968), while Items 1, 4, and 6 showed the lowest discrimination (range: 2.552 to 2.857). All lower and middle thresholds were negative, indicating that respondents tended to endorse higher response options. The absence of upper thresholds for 9 of 10 items reflects ceiling effects, with most respondents selecting values of 8 or higher.

Internal consistency analysis demonstrated that the QPCOR had excellent internal reliability (Cronbach's alpha = 0.94). The average inter-item correlation was 0.60, confirming that the ten items are related but not redundant. Item 8 (alpha if deleted = 0.930), Item 9 (alpha if deleted = 0.929), and Item 10 (alpha if deleted = 0.929) contributed the most to QPCOR's internal reliability, as their removal produced the largest decreases in alpha (Table 2). This pattern aligns with their high discrimination values in the graded response model. Conversely, Items 1 (alpha if deleted = 0.934) and 6 (alpha if deleted = 0.934) contributed the least to the scale's overall internal reliability, consistent with their lower discrimination parameters.

A total of 318 participants completed baseline and 3-month follow-up encounters (Supplemental Table 2). Compared to baseline, the QPCOR items at the 3-month follow-up had lower means (range: 8.242–8.478 vs. 8.515–8.764), skewness closer to zero (range: -0.619 to -0.984 vs. -0.997 to -1.564), and kurtosis values closer to zero, collectively indicating distributions closer to normal with slightly more variability in responses. The ICC values ranged from 0.418 to 0.555, indicating moderate temporal stability across all items (Table 2). Items 1 (ICC = 0.555), 10 (ICC = 0.553), and 3 (ICC = 0.507) showed the highest test-retest reliability, while Items 2 (ICC = 0.418), 9 (ICC = 0.452), and 6 (ICC = 0.471) showed the lowest. Table 2 also shows the factor loadings from the confirmatory factor analysis. All loadings exceeded 0.75, with Items 10 (loading = 0.863), 9 (loading = 0.848), and 2 (loading = 0.848) having the highest loadings and Items 7 (loading = 0.762), 3 (loading = 0.785), and 8 (loading = 0.802) having the lowest loadings. The average variance extracted was 0.699, indicating good convergent validity and that the latent factor accounted for 69.9% of the variance in the observed items. The QPCOR's correlative validity was exhibited by its moderate-to-strong correlations with baseline measures of the Brief REST (r = 0.75, $p < 0.001$),[5] the Subjective Numeracy Scale (r = 0.48, $p < 0.001$),[20] and the Trust in Medical Researchers Scale (r = 0.48, $p < 0.001$).[9,18]

Discussion

Drawing on a national sample of U.S. patients and community partners, we validated the 10-item QPCOR Instrument. Key findings indicate that the QPCOR items: (1) measure related aspects of researcher partnership efforts, (2) differentiate between levels of perceived researcher effort, (3) demonstrate internal consistency and test-retest reliability, and (4) exhibit convergent validity with other validated scales, including the Brief REST,[5] the Subjective Numeracy Scale,[20] and the Trust in Medical Researchers Scale.[9,18] QPCOR demonstrates excellent reliability and convergent validity with the Brief REST measure. QPCOR is a feasible, practical tool

that people can use with confidence to assess how well patient–partner relationships are functioning—not just whether engagement activities occurred.

QPCOR demonstrates convergent validity with other engagement measures while maintaining conceptual distinctiveness, capturing the quality of research partnerships rather than the volume of engagement activities. The QPCOR exhibited statistically significant positive correlations with the Brief REST ($r = 0.75$, $p < 0.001$),[5] the Subjective Numeracy Scale ($r = 0.48$, $p < 0.001$),[20] and the Trust in Medical Researchers Scale ($r = 0.48$, $p < 0.001$).[9,18] This pattern is consistent with the QPCOR assessing the quality of partnership efforts and the Brief REST assessing the level of research engagement. In practice, QPCOR assesses the quality of patient and community partnerships, indicating whether engagement fosters trust and shared decision-making.

QPCOR demonstrates excellent reliability and strong validity based on accepted psychometric standards, performing as expected in relation to an established engagement measure in a field where no single gold standard exists. QPCOR's validation follows the standard benchmarks for similar proposed psychometric scales. QPCOR demonstrates both a high reliability (Cronbach's alpha = 0.94) and convergent validity with the Brief REST measure. While validity would ideally be evaluated against a "gold standard" test of stakeholder engagement, no such test exists; therefore, we compared QPCOR results with a previously validated measure. The Brief REST has demonstrated strong construct validity,[5] and the strong correlation between the QPCOR and the Brief REST provides evidence of convergent validity for the QPCOR. We recommend using REST and QPCOR together to capture both the level and quality of engagement. REST documents the level (quantity and quality) of engagement activities across the research lifecycle, while QPCOR assesses the quality of partnership and shared decision-making that underpins meaningful engagement.

Overall, the QPCOR instrument offers a feasible and scalable approach to measuring patient and community engagement, supporting routine adoption across projects and institutions. By providing a standardized measurement infrastructure, QPCOR enables consistent use in real-world research settings and facilitates cross-project and cross-institution comparisons valued by funders, journals, and research networks.

The current investigation has several limitations. First, the data were drawn from a convenience sample recruited using snowball sampling, which limits generalizability. Second, the high mean scores across partnership dimensions suggest potential ceiling effects and social desirability bias, as respondents may have been inclined to provide favorable ratings due to existing collaborative relationships or normative expectations. Reliance on self-reported measures may further limit the detection of critical or negative perspectives. Limited variability observed across both the QPCOR and REST measures suggests that score compression likely reflects selection bias within a highly engaged sample rather than limitations of the measurement instruments. Future studies should include more diverse and less-engaged stakeholders to better differentiate engagement quality and strengthen external validity.

Conclusions

In summary, QPCOR is a validated and practical instrument for assessing the quality of patient and community research partnerships. Drawing on a national sample, the measure demonstrates strong reliability and evidence of construct and convergent validity, performing as expected in relation to established engagement measures. QPCOR focuses on the quality of partnership and shared decision-making within patient-centered outcomes research. QPCOR is intended to complement existing engagement measures rather than replace them. Instruments such as the REST capture engagement processes and activities across the research lifecycle, whereas QPCOR focuses on the perceived quality of research partnerships. Used together, these tools may provide study teams with a more complete picture of both the presence of engagement activities and the quality of partnership underlying those activities. Broader adoption of standardized engagement measures remains a major challenge in patient-centered outcomes research. Future studies should examine the combined use of instruments such as QPCOR and REST to better understand how engagement activities and partnership quality interact to influence research processes and outcomes. Establishing consistent measurement approaches will support cross-study comparison, benchmarking, and stronger accountability to patients and communities.

Declarations

This study was funded by the Patient-Centered Outcomes Research Institute (PCORI) (Contract No. SOE-2023C2-33411). PCORI had no role in the design and conduct of the study; collection, management, analysis, or interpretation of the data; preparation, review, or approval of the manuscript; or the decision to submit the manuscript for publication.

All participants in this cohort study provided their informed consent prior to participation.

The Ethics Committee of Dartmouth College's Geisel School of Medicine approved the methodology used for this study. The study was performed in adherence to Dartmouth College's ethical tenants and received IRB approval from Dartmouth College.

Clinical Trail Number: Not Applicable

Author Contribution

All authors contributed to the study design and manuscript preparation, and approved the final version.

Data Availability

The datasets generated and/or analyzed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

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Figures

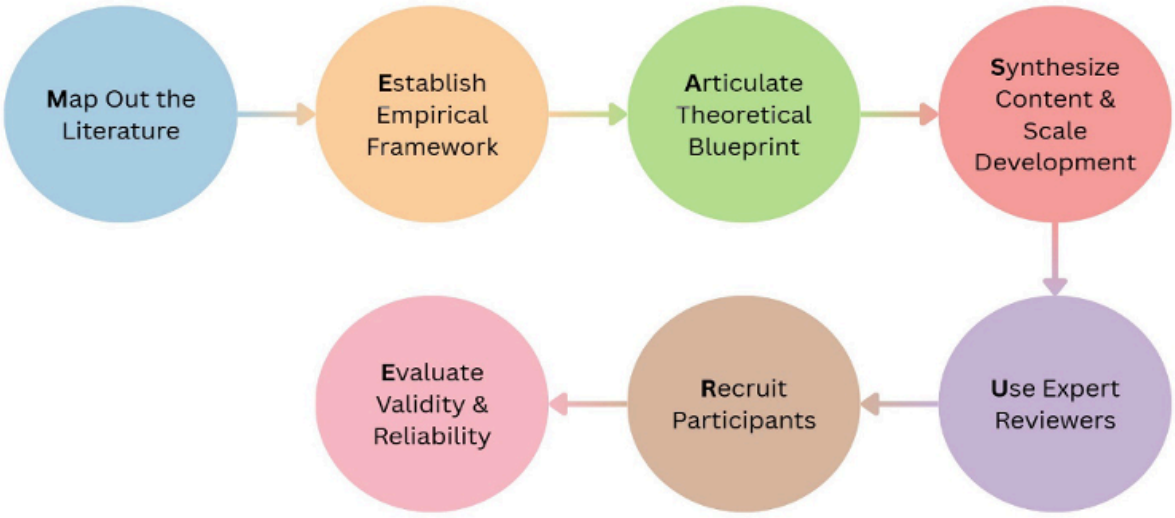

Figure 1

The Seven-Step MEASURE Framework Guiding Instrument Development and Validation

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- ValidationQPCORSupplmentaryMaterials.docx
- ValidationofQPCORAppendixA.docx