

ISPOR



Building Meaningful, Effective, and Sustainable Partnerships in Patient-Centered Outcomes Research

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Patient-Centered Outcomes Research Institute

Leading Funder of CER in U.S.



| PCORI®

- Leading funder of patient-centered comparative clinical effectiveness research (CER)
- Independent, nonprofit, research institute
- Funds research designed to help people make better informed healthcare decisions



PCORI's Holistic Approach



Meaningful engagement, reflective of PCORI community, to...

...influence research to be patient-centered, relevant, and useful

...make research and evidence understandable and accessible to the public

...establish trust of and legitimacy for research findings

...foster successful uptake and use of research results

Patient-Centeredness vs. Patient Engagement



Patient-Centeredness

- Addresses outcomes (both benefits and harms) that are important to patients
- The interventions proposed for comparison are currently available to patients
- Study design is low burden to participants



Patient and Stakeholder Engagement

- Patients and stakeholders are partners in research, not only “subjects” or “participants”
- Leverages the expertise of patients, clinicians and other stakeholders for the purpose of improving study design and conduct
- Includes a range of engagement approaches: input, consultation, collaboration, shared leadership
- Can occur by building upon existing relationships, or developing new ones

“Research Done Differently”

PCORI research has shown that engagement makes a meaningful differences in studies:



User-Orientation & Acceptability:

studies in which patients and clinicians will be willing to participate based on burden, usability, and alignment with preferences, values, and needs



Feasibility:

interventions, enrollment, and data collection that are more doable in real-world settings



Study Quality:

study rigor, comprehensiveness, and quality of materials and products



Relevance:

results applicable and important for decision-making



Engagement Scope & Quality:

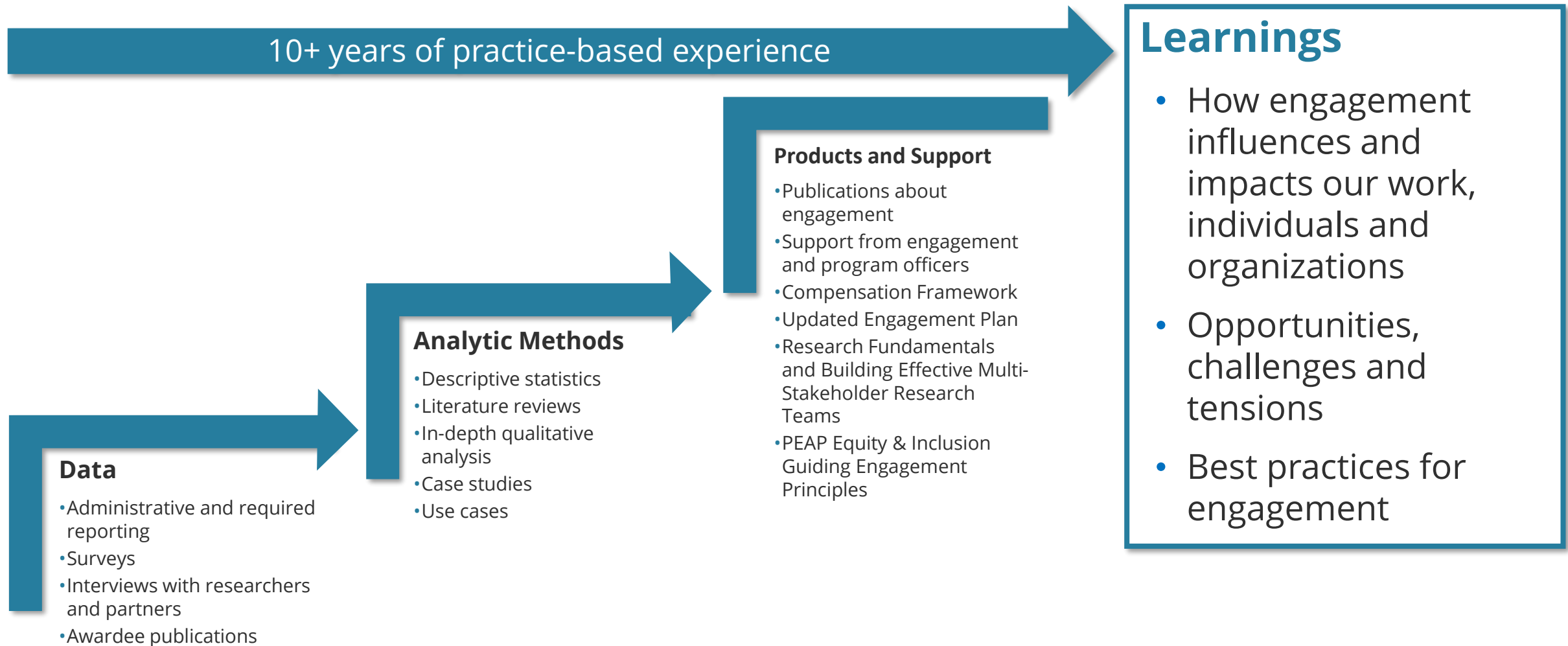
engagement processes are effective, and stakeholders are well equipped

Foundational Expectations for Partnerships in Research



A Journey to Build the Evidence Base and
Develop New Guidance

Developing a Body of Evidence for Engagement in Research



Collaborative Process to Develop New Guidance For Engagement in Research



Strategic input and guidance from PCORI's Advisory Panel on Patient Engagement (PEAP)

Conducted Formative Activities

- PCORI evidence review
- External guidance review
- Focus groups with PCORI awardees and partners
- Interviews with experts in engagement and diversity, equity and inclusion

Generated & Synthesized Practices

- Started with a list of 64 practices that reflect meaningful engagement
- Combined and organized practices into eight draft expectations

Held Convening

- 46 diverse attendees
- A collective vision and content for new guidance
- A summary report

Finalized New Guidance

- Listening sessions with PCORI staff
- Session at the PCORI's 2023 Annual Meeting
- PCORI Leadership review

Foundational Expectations for Partnerships in Research



Diversity &
Representation



Early & Ongoing
Engagement



Dedicated Funds for
Engagement &
Partner Compensation



Build Capacity to
Work as a Team



Meaningful Inclusion of
Partners in
Decision-Making



Ongoing Review &
Assessment of
Engagement

1. Updated Definition of Meaningful Engagement and Partner
2. Six Foundational Expectations
3. Information to Support Implementation of the Foundational Expectations



The screenshot shows the PCORI website with the title "Engagement in Research: PCORI's Foundational Expectations for Partnerships". It includes a navigation menu, a breadcrumb trail, and a list of six foundational expectations: Diversity & Representation, Early & Ongoing Engagement, Dedicated Funds for Engagement & Partner Compensation, Build Capacity to Work as a Team, Meaningful Inclusion of Partners in Decision Making, and Ongoing Review & Assessment of Engagement. A diagram on the right shows these expectations in a flowchart format.

pcori PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

[Engagement in Research: PCORI's Foundational Expectations for Partnerships](#) / [Engagement Resources](#)

Engagement in Research: PCORI's Foundational Expectations for Partnerships

PCORI has developed six foundational expectations—building blocks for meaningful, effective, and sustainable engagement with patients, communities, and other partners in research. Explore ways to tailor them by each expectation or by examples in practice.

Address these expectations when:

- Applying for PCORI funding
- Developing a project plan and engagement plan for awarded projects
- Reflecting on engagement during a project to improve and strengthen engagement over time

[Overview of the Foundational Expectations - Download Now](#)


Diversity & Representation


Early & Ongoing Engagement


Dedicated Funds for Engagement & Partner Compensation


Build Capacity to Work as a Team


Meaningful Inclusion of Partners in Decision Making


Ongoing Review & Assessment of Engagement

[Explore each expectation >](#) [View the expectations in action >](#)

Updating the Definition of Meaningful Engagement

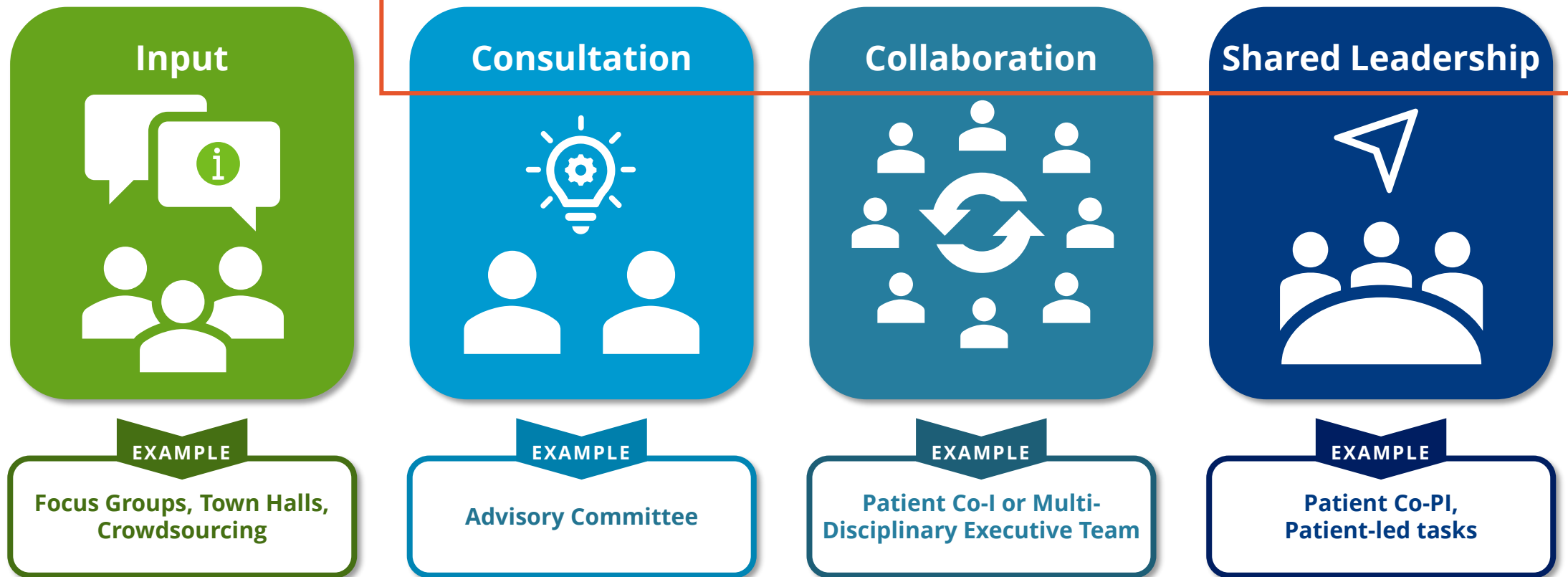
- An **active partnership** between researchers, patients, caregivers, clinicians and other partners throughout the entire research process — from planning the study to conducting the study and disseminating study results.
 - Engagement occurs along a continuum ranging from input to consultation to collaboration and shared leadership.



Patient-Centered Outcomes Research Institute

Continuum of Engagement Practices

Levels of Partners' Decision-Making Authority for Study Design & Implementation



Information to Support Implementation of the Foundational Expectations

Online information includes:

- **Overview** of the Foundational Expectations in PDF.
- **Definition of each expectation** and how the expectation helps the project.
- **Questions** to get started.
- **Actions** that project teams can take to put each expectation into practice.
- **Examples** of how PCORI-funded projects implemented the expectations.
- **Links** to other PCORI engagement resources.

[Engagement in Research: PCORI's Foundational Expectations for Partnerships](#) / [Engagement Resources](#)

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PCORI's Tools and Resources to Support Engagement in Research



Measuring What Matters for Advancing the Science and Practice of Engagement

Over the past decade PCORI has transformed how research is done by requiring engagement of patients and other partners to support research that is more rigorous, acceptable and relevant.^{1,2} Although the practice and study of engagement have grown rapidly, there are few measurement tools available to manage engagement, identify best practices and equip research teams to optimize how they engage patients and other partners in research.^{3,4}

PCORI has recently worked to identify and summarize aspects of engagement in health research that need to be measured to generate evidence for those who practice and study engagement. We identified **28 concepts** about engagement in research and organized them into **five domains** to stimulate discussion and debate about an emerging framework to inform measurement tool development and use to guide and study engagement in health research.

Measurement tools, including questionnaires and surveys, are intended to collect information about engagement in standardized ways, which are reproducible and have been shown to capture what they claim to measure (known as reliability and validity in the scientific literature). These tools are crucial for collecting information about how engagement occurs within research teams and in what contexts, and what outcomes result. This information can support learning about engagement to serve various purposes (Box 1).

What We Did

A key gap for measuring and studying engagement in research is the lack of a shared framework and language to describe the concepts in such a framework. We analyzed information from peer-reviewed publications; in-depth interviews with researchers, patients and other partners involved in engaged research; and public responses about existing and needed measurement tools (Box 2). We identified 28 concepts that begin to define important elements that, when measured or described, will support learning about engagement in health research (Table 1). We organized the measurement concepts into five common domains that build on and expand PCORI's conceptualization of how the context and process of engagement lead to outcomes for research and partners (Figure 1).⁵ Measures aligned with each domain are essential for answering the full range of questions about the practice and impact of engagement in research (Box 3).



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WELCOME | Building Effective Multi-stakeholder Research Teams



Research Fundamentals Learning Package Navigator

Transcript

"I'm new here."
Let's get started.

"I've been here before."
Skip the Introduction.

Accessibility Instructions



Find more at: pcori.org/engagement-resources

Stay Connected & Thank You

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