Research Done Differently®:

Cutting-Edge Tools for Patient-Centered Trials

Society for Clinical Trials,
47th Annual Meeting
May 18, 2026

PCORI.org

pcori®
PATIENT-CENTERED OUTCOMES
RESEARCH INSTITUTE

No relevant disclosures

Agenda

- Speaker Introductions
- Overview of PCORI and Available Funding Opportunities, Nora McGhee
- Foundational Expectations for Partnerships in Research, Mabel Crescioni
- PCORI's Methods Portfolio and Standards, Jason Gerson
- PCORnet®: A National Resource for Patient-Centered Health Research, Claudia Grossmann
- Q&A

Introductions

Nora McGhee
Associate Director, Comparative Clinical Effectiveness Research
Speaker & Moderator

Mabel Crescioni
Senior Engagement Officer,
Public and Patient Engagement
Speaker

Jason Gerson
Senior Advisor for Methods, Research Infrastructure & Innovation
Speaker

Claudia Grossmann
Associate Director, Research Infrastructure & Innovation
Speaker

PCORI: Overview and Available Funding Opportunities

Nora McGhee

Get To Know PCORI®

PCORI

- Nonprofit that funds patient-centered comparative clinical effectiveness research (CER)
- Widely acknowledged as a leader in driving U.S. clinical research to become more patient-centered
- Provides funding for CER, engagement in research, dissemination and implementation and research infrastructure projects

Our Mission

Our Mission

Help people make better-informed healthcare decisions, and improve healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community

Multiple Funding Opportunities

Types of PCORI-Funded Projects

CER Awards

- Fund studies comparing two or more treatments, services or health practices
- Methodology studies

Engagement Awards

- Fund projects to bring more patients, caregivers, clinicians and communities into the health research process

Dissemination and Implementation Awards

- Fund projects to deliver the evidence to those who can use it

A Balanced Approach To Address Patient-Centered CER Evidence Gaps: Broad and Focused Funding

Broad Funding

Solicits CER proposals on any topic generated by CER community

Focused Funding

Solicits CER proposals aligned to the Research Project Agenda Topic Themes

2026 Research Project Agenda Topic Themes

- Addressing **Cancer**
- Harnessing **Digital Health Technologies**
- Improving Outcomes for People With **Intellectual and Developmental Disabilities**
- Preventing **Maternal Morbidity and Mortality**
- Improving **Mental and Behavioral Health**
- Improving **Metabolic and Endocrine Health**
- Managing **Pain**
- Advancing CER To **Promote Health and Prevent Disease**
- Addressing **Rare Diseases**
- Addressing **Sensory Health**
- Addressing **Substance Use**

Research Funding Opportunities

Phased Large Awards for Comparative Effectiveness Research	Broad Pragmatic Studies	Topic-Focused	Science of Engagement	Methods
Large, meritorious and innovative studies with some risks	Studies aligned with at least one of PCORI's three funding categories, including PCORnet® studies	Stakeholder-driven topics, issues and questions of national significance	Development and validation of measures; development and testing of engagement techniques	Improve use of AI and ML, improve study design, support data research networks, ethical and human subject protections in CER
Up to $22M (for feasibility and full-scale study phases)	**1. Up to $5M** **2. $5 to 12M** **3. Up to $12M**	**Variable**	**1. Up to $1M** **2. Up to $1.5M**	**Up to $750K**

2026 Funding Cycle LOI Deadlines

Cycle 1: Jan. 6 | **Cycle 2:** Apr. 28 | **Cycle 3:** Sept. 8

*All funds and timeline noted above are subject to change

Dissemination and Implementation of PCORI-Funded Research Findings

Engagement Dissemination *(open competition)*	**Dissemination Projects** *(limited competition)*	**Implementation Planning** *(limited competition)*	**Implementation Projects** *(limited competition)*	**Implementation Projects** *(open competition)*
Support projects that help organizations and communities actively deliver PCORI-funded research findings	Support projects that facilitate active communication of PCORI-funded research findings	Support the planning of projects that facilitate the uptake of evidence from PCORI-funded studies into practice	Support projects that facilitate the uptake of evidence from PCORI-funded studies into practice	Support projects that facilitate the uptake of evidence from PCORI-funded studies into practice
Up to $300K	**Up to $300K**	**Up to $200K**	**Up to $2.5M**	**Up to $2.5M**
Open Dates: Jan. 21 and TBD	Open Dates: Dec. 2	Open Dates: Dec. 2	Open Dates: Dec. 2	Open Dates: TBD

*All funds and timeline noted above are subject to change

Engagement Funding Opportunities

Capacity Building	Convening Support
Support projects that help communities increase their ability to participate across all phases of CER	Convene communities of interest to explore critical issues related to CER and/or communicate PCORI-funded research findings to targeted communities
$300K	**$125K**
Up to 2 Years	Up to 1 Year

2026 Funding Cycle LOI Deadlines

Spring: Mar. 30 | **Autumn:** TBD

*Funding opportunities, funds and timeline noted above are subject to change

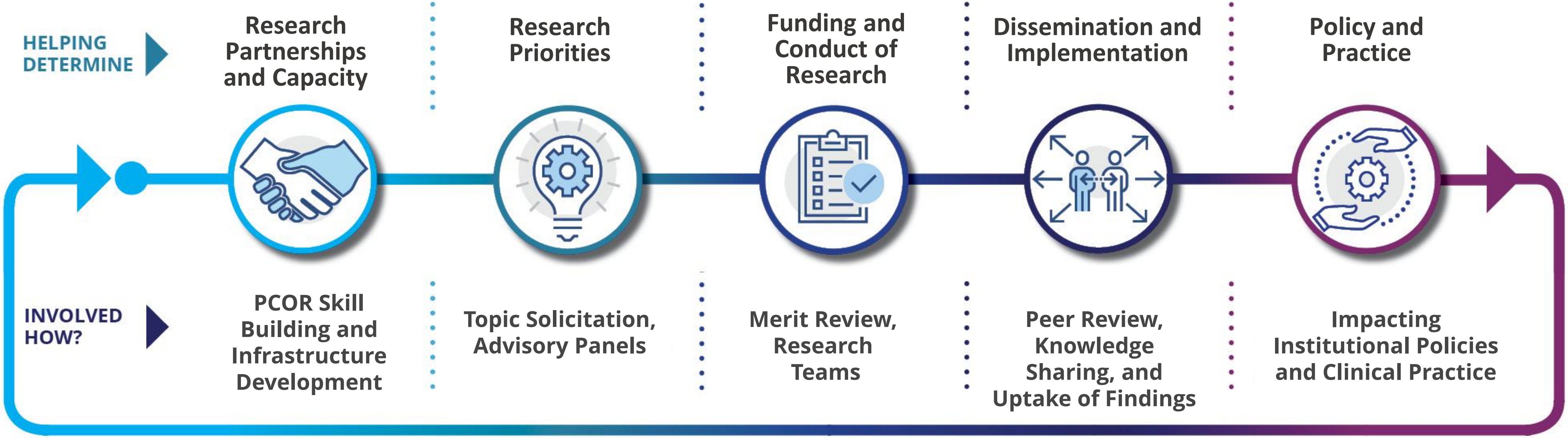
Connect with PCORI's Funding Opportunities

- www.pcori.org/funding-opportunities

Foundational Expectations for Partnerships in Research

Mabel Crescioni

Background: Engagement as a Path to Useful, Patient-Centered and High-Quality Research



HELPING DETERMINE

- Research Partnerships and Capacity
- Research Priorities
- Funding and Conduct of Research
- Dissemination and Implementation
- Policy and Practice

INVOLVED HOW?

- PCOR Skill Building and Infrastructure Development
- Topic Solicitation, Advisory Panels
- Merit Review, Research Teams
- Peer Review, Knowledge Sharing, and Uptake of Findings
- Impacting Institutional Policies and Clinical Practice

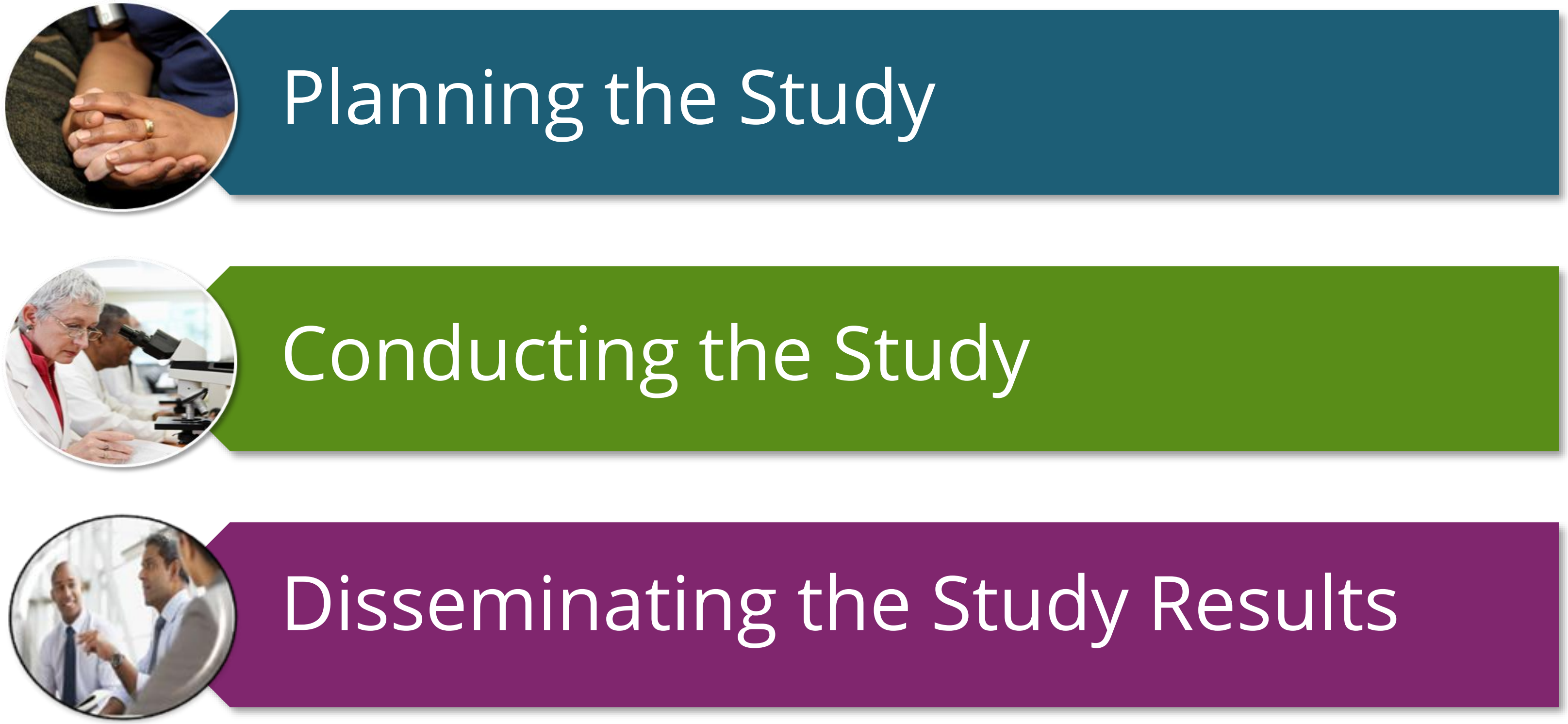
PCORI's findings about engagement in Patient-Centered CER

- Engagement improves study **feasibility**, **acceptability** and **quality** as well as the **relevance** of study findings
- Researchers have a better understanding of patients’ lives and of clinical processes and are committed to continuing engagement
- Patients and other partners benefit from developing skills, contributing in a positive way and improving their own health
- With meaningful inclusion in decision making throughout the study, researchers and partners build trusting relationships that can benefit communities, community organizations and academic institutions

See the Foundational Expectations for Partnerships (PDF) for citations: https://www.pcori.org/sites/default/files/PCORI-Engagement-in-Research-Foundational-Expectations-for-Partnerships.pdf

What is meaningful engagement?

The **meaningful involvement** of patients, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process—from planning the study, to conducting the study, and disseminating study results.



Planning the Study

Conducting the Study

Disseminating the Study Results

Continuum of Engagement Practices

Levels of Partners’ Decision-Making Authority for Study Design and Implementation

Input

EXAMPLE

Focus Groups, Town Halls, Crowdsourcing

Consultation

EXAMPLE

Advisory Committee

Collaboration

EXAMPLE

Patient Co-Investigator or Multi-Disciplinary Executive Team

Shared Leadership

EXAMPLE

Patient Co-Principal Investigator, Patient-Led Tasks

Adapted from: Hanley et al. (2004). Involving the public in NHS, public health and social care research.
Carman et al. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs, 32*(2), 223–231. Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association, 35*, 216–24

Six Foundational Expectations for Partnerships

Representative Involvement

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

Online Guidance

PDF

FAQs

Foundational Expectations for Partnerships in Research

Representative Involvement

Projects should include partners, organizations, researchers and other team members who reflect the range of patients and communities affected by the research topic.

Early & Ongoing Engagement

Projects should ensure that partners contribute early and throughout the study, including planning the study, conducting the study and disseminating study results.

Dedicated Funds for Engagement & Partner Compensation

Projects should dedicate funds to support engaging with partners and compensate partners for their time, expertise, and perspectives in a timely manner and in ways that reflect their preferences and roles.

Foundational Expectations Cont.

Build Capacity to Work as a Team

Projects should identify skills, strengths, and barriers to engagement and provide all team members with the information, training, and support they need to work as a team.

Meaningful Inclusion of Partners in Decision Making

Projects should use engagement structures and processes that include partners in decision making throughout all phases of the project, with consideration for the project’s goals, scope, and scale.

Ongoing Review & Assessment of Engagement

Projects should gather input and feedback throughout the project to identify what is working well and what could be improved, and then adjust engagement approaches as needed.

Updates to the Engagement Section for PCORI Funding Announcements

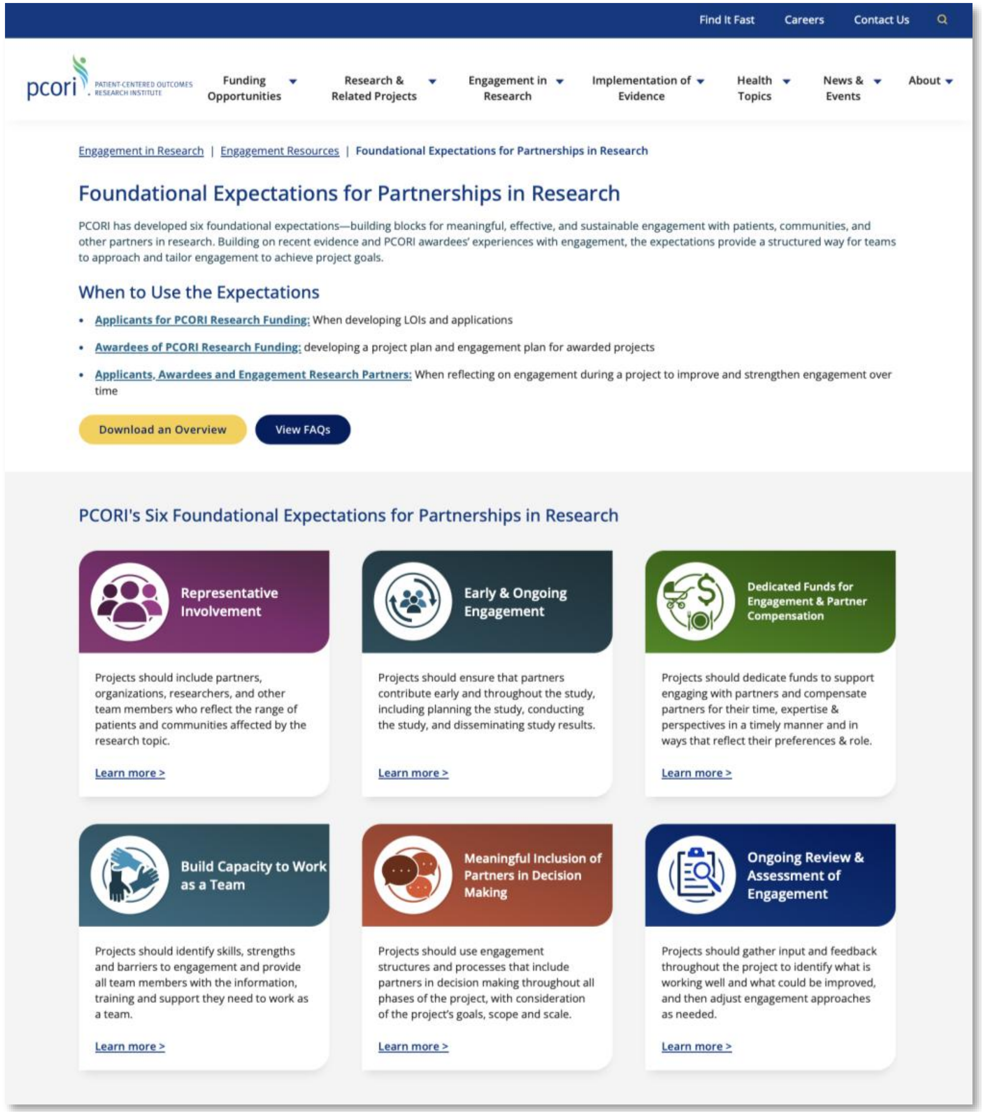
- Applicants are being asked to include an **overview of their engagement approach** that demonstrates that they have addressed the **six Foundational Expectations including:**
  - **Multiple engagement approaches that occur along a continuum of engagement**—from input to shared leadership. Approaches that ONLY solicit input would not be considered meaningful engagement and would be considered non-responsive.
  - **An assessment of engagement activities** is a required component of the engagement overview, which should also address plans to learn about what is working well and what could be improved, to allow for adjustments to engagement approaches as needed.
  - **A budget for engagement** and ensure that the budget narrative clearly identifies the funds to be allocated for engagement activities, personnel and partner compensation.

Implementing the Foundational Expectations

What You Can Find Online

- Comprehensive guide for each expectation
- Helpful questions to get you started
- Practical actions for implementation
- Examples from PCORI-funded projects
- Links to additional engagement resources

www.pcori.org/Foundational-Expectations



Engagement in Research | Engagement Resources | Foundational Expectations for Partnerships in Research

Foundational Expectations for Partnerships in Research

PCORI has developed six foundational expectations—building blocks for meaningful, effective, and sustainable engagement with patients, communities, and other partners in research. Building on recent evidence and PCORI awardees' experiences with engagement, the expectations provide a structured way for teams to approach and tailor engagement to achieve project goals.

When to Use the Expectations

- Applicants for PCORI Research Funding: When developing LOIs and applications
- Awardees of PCORI Research Funding: developing a project plan and engagement plan for awarded projects
- Applicants, Awardees and Engagement Research Partners: When reflecting on engagement during a project to improve and strengthen engagement over time

PCORI's Six Foundational Expectations for Partnerships in Research

Representative Involvement

Projects should include partners, organizations, researchers, and other team members who reflect the range of patients and communities affected by the research topic.

Early & Ongoing Engagement

Projects should ensure that partners contribute early and throughout the study, including planning the study, conducting the study, and disseminating study results.

Dedicated Funds for Engagement & Partner Compensation

Projects should dedicate funds to support engaging with partners and compensate partners for their time, expertise & perspectives in a timely manner and in ways that reflect their preferences & role.

Build Capacity to Work as a Team

Projects should identify skills, strengths and barriers to engagement and provide all team members with the information, training and support they need to work as a team.

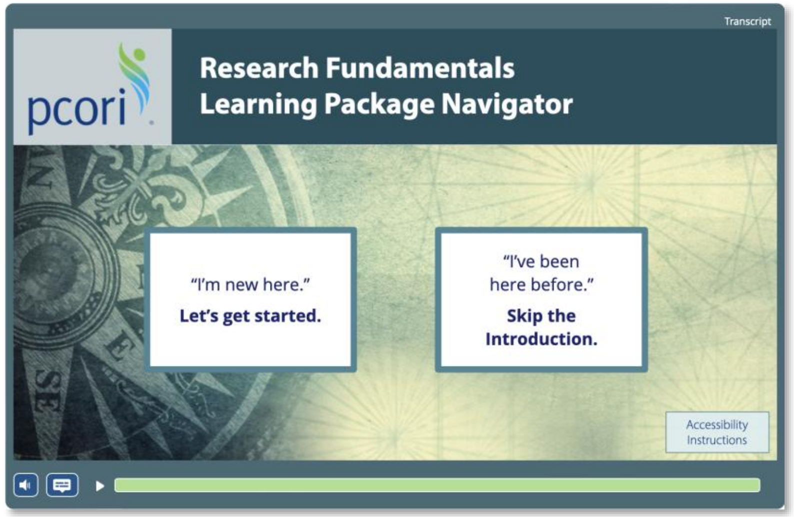
Meaningful Inclusion of Partners in Decision Making

Projects should use engagement structures and processes that include partners in decision making throughout all phases of the project, with consideration of the project's goals, scope and scale.

Ongoing Review & Assessment of Engagement

Projects should gather input and feedback throughout the project to identify what is working well and what could be improved, and then adjust engagement approaches as needed.

PCORI’s Tools and Resources to Support Engagement in Research

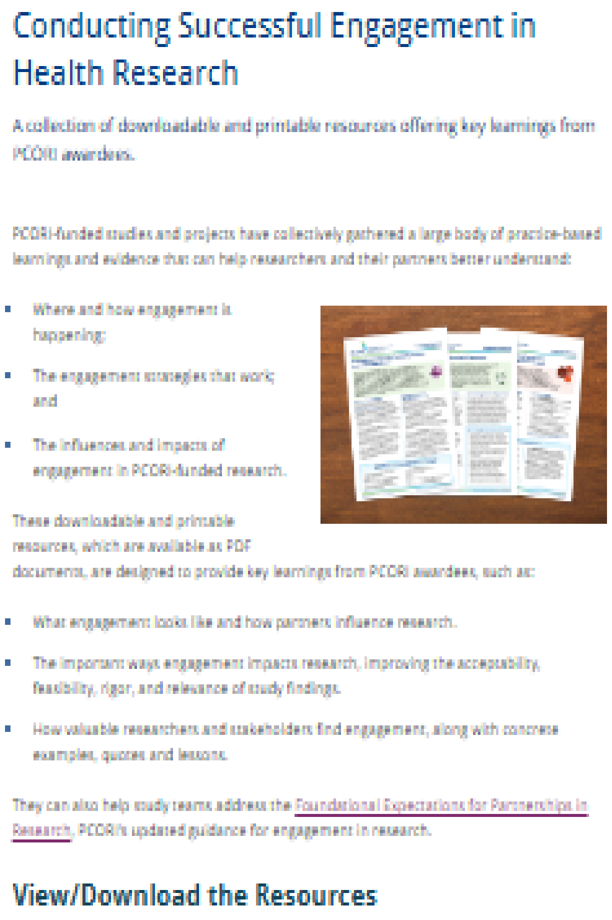


Research Fundamentals Learning Package Navigator

“I’m new here.”
Let’s get started.

“I’ve been here before.”
Skip the Introduction.

Building Effective Multi-stakeholder Research Teams


Conducting Successful Engagement in Health Research

A collection of downloadable and printable resources offering key learnings from PCORI awardees.

PCORI-funded studies and projects have collectively gathered a large body of practice-based learnings and evidence that can help researchers and their partners better understand:

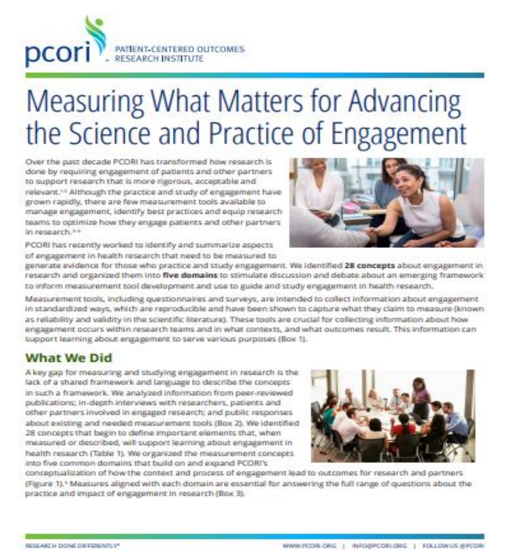
- Where and how engagement is happening;
- The engagement strategies that work; and
- The influences and impacts of engagement in PCORI-funded research.

These downloadable and printable resources, which are available as PDF documents, are designed to provide key learnings from PCORI awardees, such as:

- What engagement looks like and how partners influence research.
- The important ways engagement impacts research, improving the acceptability, feasibility, rigor, and relevance of study findings.
- How valuable researchers and stakeholders find engagement, along with concrete examples, quotes and lessons.

They can also help study teams address the Foundational Expectations for Partnerships in Research, PCORI’s updated guidance for engagement in research.

View/Download the Resources


PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

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).

RESEARCH DONE DIFFERENTLY® | WWW.PCORI.ORG | INFO@PCORI.ORG | FOLLOW US @PCORI

Questions about Engagement?

Email us at engagement_questions@pcori.org

Find more at: pcori.org/engagement-resources

PCORI’s Methods Portfolio and Standards

Jason Gerson

Methods PFA Overview

Objective:

- Fund studies that advance understanding and appropriate use of methods for patient-centered CER

Improved Methods for Patient-Centered CER

Improved Patient-Centered CER Studies

Improved Clinical Evidence

Research Supported by the Methods PFA

Methods Program
Portfolio Snapshot: Size, Scope, Impact

- Funds and duration: $750K in direct costs/36 months
- Funding announcement published 3 funding cycles/year

- **Current Program Priorities,*** ***Improving Methods for Conducting Patient-Centered Comparative Clinical Effectiveness Research***:
    - Methods To Support the Use of Patient-Centered Measurement in Patient-Centered CER
    - Methods To Support the Use of Real-World Data (RWD) in Multi-Site Patient-Centered CER
    - Methods To Improve the Use of Artificial Intelligence (AI) and Machine Learning (ML) in Patient-Centered CER
    - Methods To Improve Study Design in Patient-Centered CER

Improving Methods PFA: Recent Updates

- New topics have been added to the “Methods To Support the Use of Real-World Data (RWD) in Multi-Site CER” priority, including methods to generate, validate and apply synthetic data based on RWD to support CER, and methods to improve outcome measurement using RWD, including data from digital health technologies.
- New topics have been added to the “Methods To Improve the Use of AI/Machine Learning (ML) in CER” priority, including applications of AI/ML to augment or transform research methodologies or processes.
- “Methods Related to Ethical and Human Subjects Protections Issues in CER” has been retired as a stand-alone programmatic priority and integrated across the other priorities. PCORI maintains a strong programmatic interest in this research area.
- New priority on Patient-Centered Measurement added (see next slide)

Improving Methods PFA: New Priority on Patient-Centered Measurement (PCM)

PCORI is interested in funding projects that seek to advance the methods and application of PCM. High-quality CER relies on the use of valid, reliable, and relevant measurement of outcomes. This priority supports research on improved methods for the development, evaluation, analysis, and interpretation of such measures for use in CER. Topics of interest include:

- Methods to evaluate and improve the psychometric properties of PCMs
- Methods to analyze and interpret data from PCMs, including handling non-standard distributions or statistical assumptions
- Methods to harmonize, link, compare, or synthesize data from multiple measurement instruments used across diverse settings and time points
- Methods for improving the measurement and analysis of contextual factors confounders, mediators, and effect modifiers relevant to patient-centered outcomes
- Develop, validate, or apply standardized methodological approaches for measuring patient-centered burdens and economic outcomes (PCBEOs; e.g., employment continuity, family and caregiver burdens, financial hardship) across various conditions/settings (e.g., tracking across different health systems)

Why are Methodology Standards Necessary for Patient-Centered CER?

- Departures from basic good research practices are partially responsible for the mismatch between the quality and relevance of the information that research provides and the information patients need to make informed clinical decisions
- There are substantial inconsistencies in how methods are applied in practice (Helfand, et al., 2011; Lohr, 2007; Schneeweiss, et al., 2012)
- And it’s the law:
    - Patient Protection and Affordable Care Act, Subtitle D, Paragraph (6)(C) “Methodological standards shall provide specific criteria for internal validity, generalizability, feasibility and timeliness of research and for health outcomes measures, risk adjustment, and other relevant aspects of research and assessment with respect to the design of research.”

Methodology Standards: Summary

67 individual standards in 16 categories

5 categories that are relevant to most PCOR studies (i.e., the cross-cutting standards)

- Formulating research questions
- Patient centeredness
- Data integrity and rigorous analyses
- Preventing and handling missing data
- Heterogeneity of treatment effects

2 categories that provide guidance on developing specific types of data and using these data

- Data registries
- Data networks as research-facilitating structures

9 categories that apply to studies with varying designs and purposes

- Causal inference methods
- Adaptive and Bayesian trial designs
- Studies of medical tests
- Systematic reviews
- Research designs using clusters
- Studies of complex interventions
- Qualitative methods
- Mixed methods research
- Individual participant-level data meta-analysis
- Usual Care as a Comparator

Update to PCORI Methodology Standards: Public Comment Period: April 20 – June 18, 2026

- The Methodology Standards are currently undergoing a comprehensive update.
- PCORI is seeking input from the public – comment period is **OPEN NOW** until June 18th. Please go here to review proposed Standards and make comments:

https://www.pcori.org/about/provide-input/public-comment-draft-update-pcori-methodology-standards-2026

PCODR Is Focused Exclusively on Patient-Centered CER Data

Discover, Access and Analyze Comparative Clinical Effectiveness Research Data

https://myumi.ch/ICPSR_PCODR

- PCORI funded PCODR to improve the capacity to conduct patient-centered comparative clinical effectiveness research (CER) to:
  - *Facilitate reproduction of analyses to increase the integrity of PCORI-funded CER*
  - *Build on study findings or integrate data from multiple studies to generate new evidence*

PCODR features:

- Professionally curated, de-identified datasets
- Secure data environment
  - Data are only accessible for analysis; data are not downloadable
  - Users have access to a robust set of statistical analysis software packages

PCODR Deposited Studies

- **Asthma** (Israel, PESRAMHIP)
- **Lower Back Pain** (Delitto, TARGET TRIAL)
- **Stroke** (Duncan, COMPASS)
- **Migraine** (Schwedt, MOTS TRIAL)
- **Aspirin Dosing*** (Hernandez, ADAPTABLE)
- **CVD** (Moser)
- **COVID-19: Infection Control in Nursing Homes** (Kraschnewski, PROJECT ECHO)
- **Crohn's Disease** (Lewis, DINE-CD)
- **Telepsychiatry** (Fortney, SPIRIT)
- **Appendicitis** (Flum, CODA)
- **COVID-19 & Hydroxychloroquine*** (Hernandez, HERO-HCQ TRIAL)
- **Community Engaged Research** (Goodman)
- **Fall Injuries** (Sciamanna, WISE STUDY)
- **COVID-19** (Pletcher)
- **COVID-19: Frontline Worker's Mental Health** (Siedel-Meredith)
- **Pediatric Crohn's Disease*** (Kappelman, COMBINE TRIAL)
- **COVID-19: Remote Monitoring** (Delgado, COVID WATCH)
- **Smoking Cessation** (Evins)
- **Chronic Pain** (Krebs, VOICE STUDY)
- **COVID-19: Healthcare Worker Wellness*** (Hernandez, HERO REGISTRY)
- **Advance Care Planning** (Totten)
- **COVID-19 & Telehealth*** (Kaushal)
- **Multiple Sclerosis** (Corboy, DMTs)
- **Pediatric Trauma Care** (Marcin)
- **Chronic Pain** (McCormack, INSPIRE)
- **Advance Care Planning** (Grudzen & Goldfeld, EMPallA)
- **Lower Back Pain** (Barret, STAMP)
- **COVID-19 and Housing** (Henwood)
- **Metastatic Cancer** (Basch, PRO-TECT)
- **COVID-19 Prevention** (Bartels)
- **TBI** (Hoffman, BRITE STUDY)

***uses PCORnet**

PCORnet®: A National Resource for Patient-Centered Health Research

Claudia Grossmann

PCORnet®

- National-scale resource to conduct patient-centered CER
- Research ecosystem also well suited to conduct:
  - Real-world evidence studies
  - Pragmatic clinical trials
  - Population health research
  - Health systems research
  - Studies on how best to engage patients in research

PCORnet®: A Vetted National Resource

50

States

PCORnet is linked to patients in every state in the U.S.

78

PCORnet® Network Partners

8 PCORnet® Clinical Research Networks across the U.S.

47

Million People

PCORnet represents data from everyday healthcare encounters with >47 million people annually across the U.S.

1,074

Publications

Supported by PCORnet resources

62

PCORnet® Studies

Funded by

PCORI
34 (57%)

Federal
18 (27%)

Industry
10 (17%)

$704

Million

PCORnet® Studies funding by source

PCORI
$325M
(46%)

Federal
$328M
(47%)

Industry $51M (7%)

Over the last 10 years, PCORnet® Studies have already answered critical patient-centered questions on heart disease, metabolic conditions, obesity, and more, demonstrating the power of PCORnet® to improve patient care through efficient, high-quality research.

Research that leverages this network is tapping into a proven engine for discovery.

Data as of March 2026

PCORnet®: Access to Clinical Data and Research Expertise on a National Scale

8

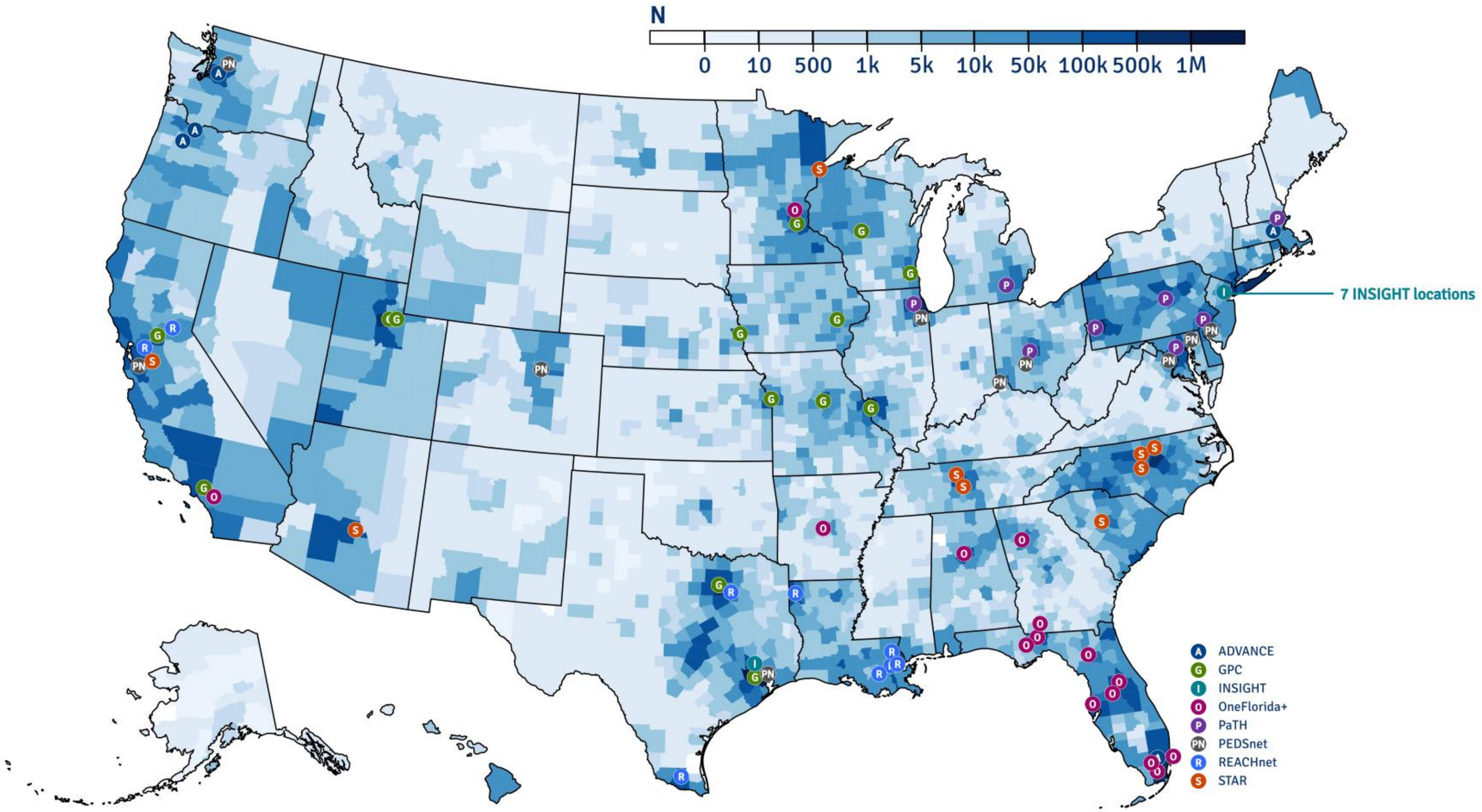
Clinical Research Networks

13K+

Clinical Care Sites

47M+

Patients With an Encounter



The PCORnet® Common Data Model

For data to be useful, it has to be standardized across systems. Frequent data curation and a single language enabled by the PCORnet® Common Data Model delivers fast insights.

Ready for Research	Available, But Still Evolving
Demographics Diagnoses Procedures	Immunizations Tumor Registry Biosamples
Vital Signs Labs Clinical Observations	Social Determinants of Health Patient-Generated Data Genomic Results
Medication Orders & Administrations	Patient-Reported Outcomes Natural Language Processing Derived Concepts
Data from PCORnet® Clinical Research Networks available in the PCORnet® CDM and ready for use in research	Data available at some PCORnet® Clinical Research Networks, may or may not be in the PCORnet® CDM and require additional work for use in research

The PCORnet® Front Door

A “knock” on the PCORnet® Front Door can support:

STUDY DESIGN

Preliminary data for proposals, effect sizes, and potential study power

DATA NETWORK REQUEST

- Get data insights from PCORnet® Clinical Research Networks
- Obtain aggregated results for informing research project development

[Learn More About the Front Door]

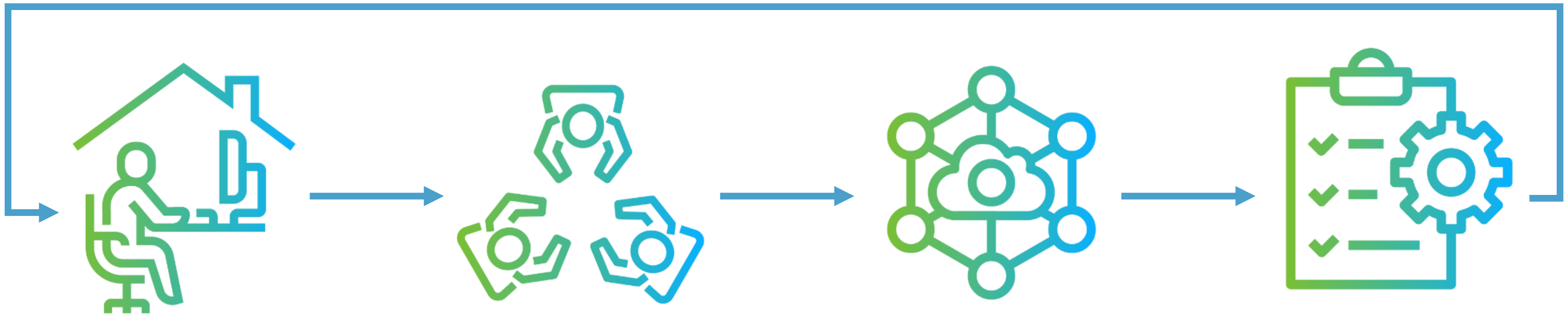
CONNECTIONS TO NETWORK COLLABORATORS

- Partners to co-design research
- People with specific expertise

PCORnet® STUDY SUPPORT

Deeper partnership with PCORnet provides access to best practice sharing, patient engagement, and transparent quality improvement initiatives

A Secure Infrastructure Makes Real-World Data Accessible



Step 1
The Requestor submits a question through the PCORnet® Front Door

Step 2
The Coordinating Center reviews the question and consults with the Requestor about next steps

Step 3
The Coordinating Center converts the request into a query and sends it to Network Partners via a secure portal in the Cloud

Step 4
Network Partners provide a response, which is sent back through the Coordinating Center to the Requestor

Requestor queries are sent to the data — and answers, not data, are sent back to requestors.

Read the PCORnet® Privacy Statement

High Burden of Constipation Among Autistic Youth

- Leveraged Data Network Request process through PCORnet® Front Door to support feasibility analysis to inform study design.
- Initial query led to brief report in the Americal Journal of Gastroenterology published in February 2026.
  - Results show that approximately 1 in 5 autistic children have constipation and experience high unplanned healthcare utilization.
- Investigators recently awarded PCORI funding for a pragmatic trial using PCORnet®

Data Query Snapshot

- 2015-2024: 578,807 autistic children out of 20+ million youth patients 6-17 years old
- Constipation
  - 22% of autistic youth
  - 9% of nonautistic youth
- Included healthcare utilization characterized by more frequent abdominal pain, emergency department visits, and hospitalizations for abdominal pain/constipation

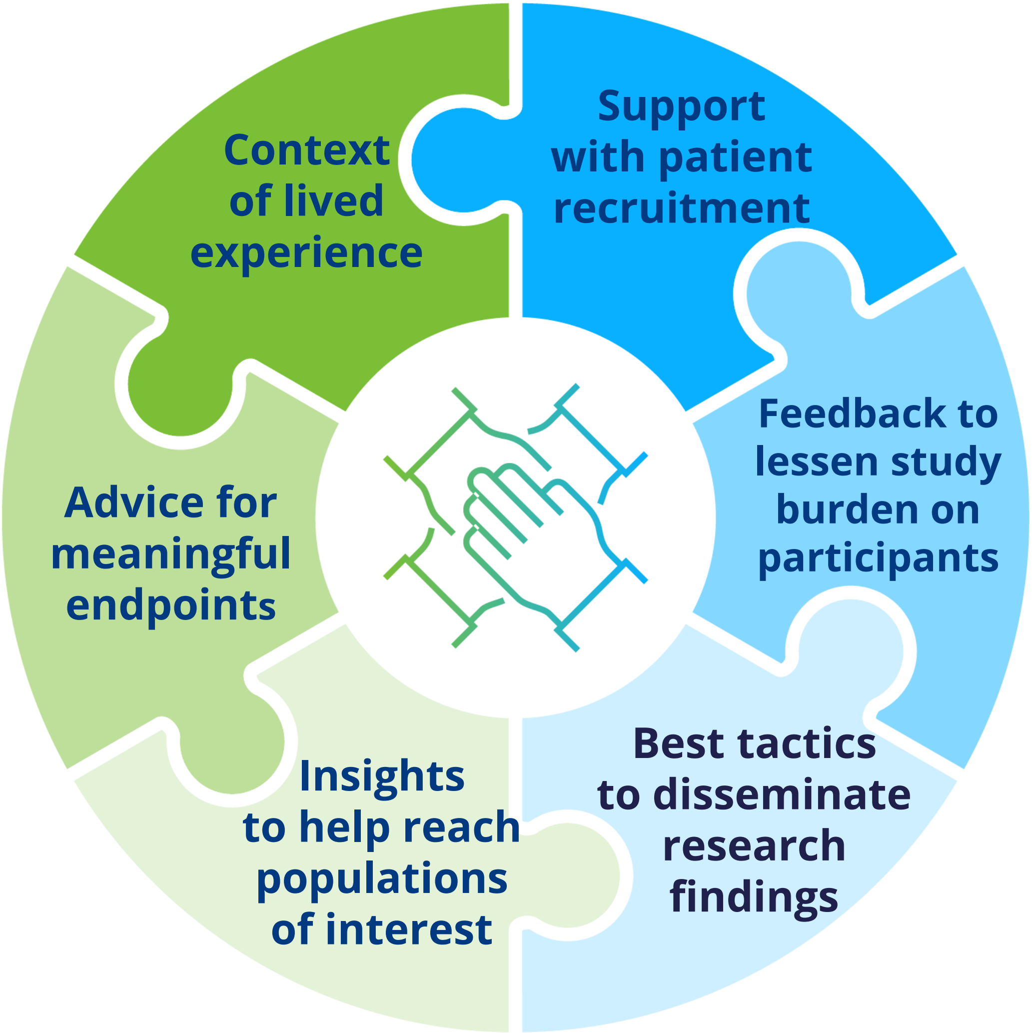
Chumpitazi, Bruno P. MD, MPH, FACG1,2; Zelinski, Allison MS3; Marchesani, Nicole MSHI3; Brantner, Carly L. PhD2,4; Tomaiuolo, Maurizio PhD3; Kappelman, Michael D. MD, MPH, FACG5; . High Burden of Constipation Among Autistic Youth: A Nationwide Query Powered by PCORnet. The American Journal of Gastroenterology ():10.14309/ajg.0000000000003967, February 18, 2026. | DOI: 10.14309/ajg.0000000000003967

Engaged Communities Drive Better Research

What do we mean by “communities”?

- **Patients and caregivers,** engaging as coequal collaborators with health professionals
- **Clinicians/Clinic Staff**
- **Insurers**
- **Policymakers**
- **Others**

> ***“Good studies consider all relevant evidence — and no evidence is more relevant than the community experience.”***
>
> ***— PCORnet® Steering Committee Member***



Context of lived experience

Support with patient recruitment

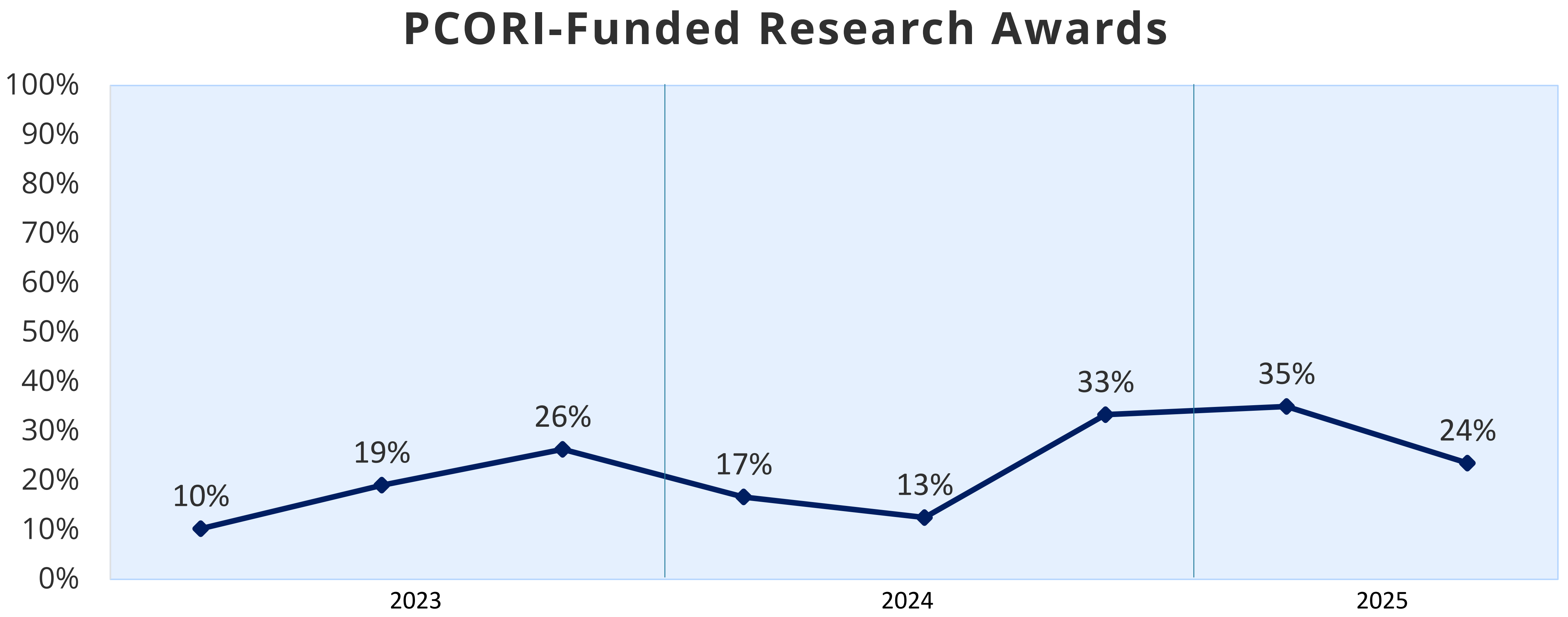
Feedback to lessen study burden on participants

Best tactics to disseminate research findings

Insights to help reach populations of interest

Advice for meaningful endpoints

Many PCORI-Funded Studies Are Using PCORnet®



*Awards are attributed to the year in which it was submitted

Unique Features of PCORnet® That Investigators Can Use To Optimize Patient-Centered Research

Prep-to-Research

Tools for Study Startup

Sites for Recruitment

PCORnet® Common Data Model

Engagement Tools

Dissemination Tools

Getting Started With PCORnet®

Other Resources

Other resources to explore:

PCORnet® Playbook

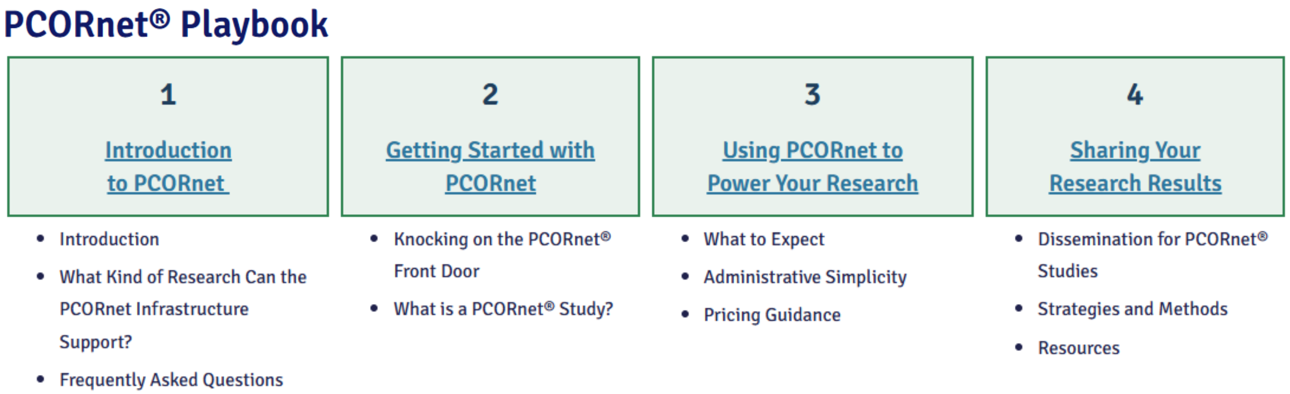
- Modules offering information on how to use PCORnet and what to expect when collaborating with the Network

PCORnet® Population Insights

- Data visualizations and reports offering cohort descriptions of populations available through PCORnet

PCORnet® Clinical Research Network Site Profiles

- Linked snapshots of PCORnet site capabilities



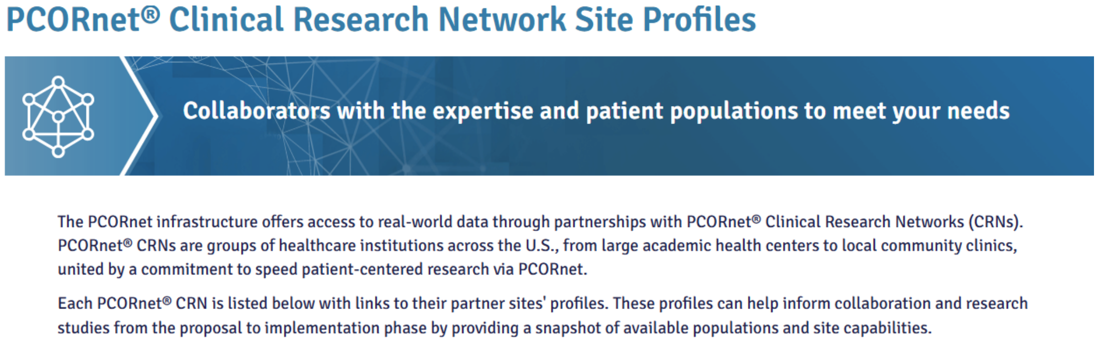
PCORnet® Playbook

1 Introduction to PCORnet	2 Getting Started with PCORnet	3 Using PCORnet to Power Your Research	4 Sharing Your Research Results
Introduction What Kind of Research Can the PCORnet Infrastructure Support? Frequently Asked Questions	Knocking on the PCORnet® Front Door What is a PCORnet® Study?	What to Expect Administrative Simplicity Pricing Guidance	Dissemination for PCORnet® Studies Strategies and Methods Resources

PCORnet® Population Insights

Each year, PCORnet connects researchers with health data from everyday healthcare encounters with nearly 47 million people nationwide through eight PCORnet® Clinical Research Networks (CRNs) and over 70 partner organizations participating in PCORnet.

Access to broad data through PCORnet helps researchers design and implement large-scale, innovative, patient-centered health research.



PCORnet® Clinical Research Network Site Profiles

Collaborators with the expertise and patient populations to meet your needs

The PCORnet infrastructure offers access to real-world data through partnerships with PCORnet® Clinical Research Networks (CRNs). PCORnet® CRNs are groups of healthcare institutions across the U.S., from large academic health centers to local community clinics, united by a commitment to speed patient-centered research via PCORnet.

Each PCORnet® CRN is listed below with links to their partner sites' profiles. These profiles can help inform collaboration and research studies from the proposal to implementation phase by providing a snapshot of available populations and site capabilities.

PCORnet® Population Insights, 2024

Total Number of unique patients: 46,797,628

Race

American Indian or Alaska Native	**284,495** (1%)
Asian	**1,947,263** (4%)
Black or African American	**7,364,299** (16%)
Native Hawaiian or Other Pacific Islander	**114,114** (<1%)
White	**28,668,290** (61%)
Multiple race	**565,603** (1%)

~7,853,564 (17%) unknown or missing

Age (years)

Mean	**40.3** (±22.7)
Children **0-9**	**6,854,362** (15%)
Children **10-19**	**5,774,710** (12%)
Adults **20-34**	**7,537,127** (16%)
Adults **35-54**	**10,676,750** (23%)
Adults **55-64**	**5,917,151** (13%)
Adults **65-74**	**5,756,235** (12%)
Adults **75+**	**4,281,293** (9%)

Sex

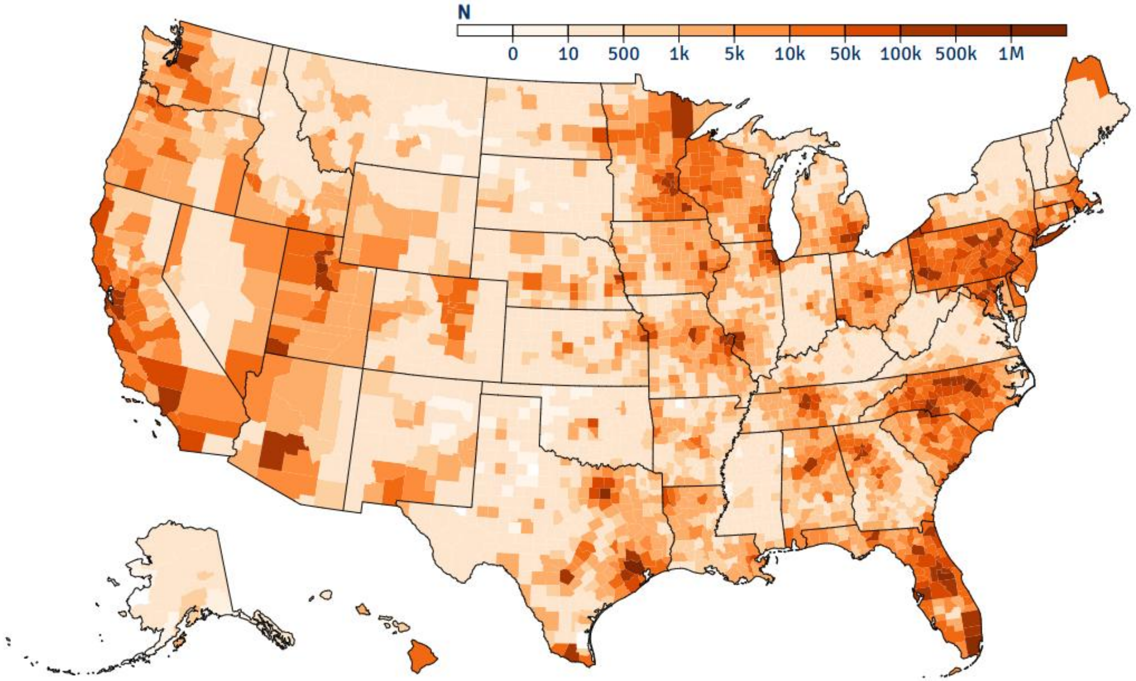
Female	**26,295,324** (56%)
Male	**20,481,961** (44%)

~20,343 (<1%) unknown or missing

Ethnicity

Hispanic	**7,368,948 (16%)**
Non-Hispanic	**32,632,438 (70%)**

6,796,242 (15%) unknown or missing



Face-to-Face Encounter Care Setting

Ambulatory Visit	**40,539,250** (87%)
Emergency Department	**9,213,321** (20%)
Telehealth	**6,360,676** (14%)
Inpatient Hospital Stay	**2,991,480** (6%)
Emergency to Inpatient	**1,034,540** (2%)
Observation Stay	**597,139** (1%)
Non-Acute Institutional Stay	**89,990** (<1%)

Rural-Urban Commuting Area (RUCA) Codes

Metropolitan areas	**34,977,779** (75%)
Micropolitan areas	**3,377,342** (7%)
Small towns	**1,444,600** (3%)
Rural areas	**73,681** (<1%)

~6,924,226 (15%) missing

Area Deprivation Index (ADI)

ADI Quartile 1 (Higher SES)	**15,013,616**
ADI Quartile 2	**7,855,799**
ADI Quartile 3	**9,003,787**
ADI Quartile 4 (Lower SES)	**7,642,290**

~ 7,282,136 (16%) missing

PCORnet® Population Insights

*Data are from patients with at least 1 face-to-face encounter and a recorded diagnosis in 2024.

Connect with PCORnet

pcornet® The National Patient-Centered Clinical Research Network

LEARN MORE ABOUT
the PCORnet® Front Door

SUBSCRIBE
to the PCORnet newsletter

FOLLOW
PCORnetwork on LinkedIn
@PCORnetwork on X

Time for Q&A!

Learn More About PCORI and PCORnet®

pcori.org

pcornet.org

Get Involved

Several Ways to Get Involved with PCORI

- Apply to serve on one of PCORI's four Advisory Panels
- Become a Merit Reviewer
- Become a PCORI Ambassador
- Become a Peer Reviewer
- Participate in PCORI Events
- Suggest a Patient-Centered Research Question

PCORI Advisory Panels

Apply or Nominate Someone Today:

- Clinical Trials
- Comparative Clinical Effectiveness Research
- Patient Engagement
- Rare Diseases

Stay Connected

Looking to Stay Current on All Things PCORI?

Sign up to receive our weekly email newsletter and alerts about:

- Funding opportunities
- Results from our funded research
- Webinars, meetings and events
- Our new strategic initiatives and more!

PCORI.org/Subscribe