



LIVED EXPERIENCE
AT THE TABLE:
The PCORI Model in Practice

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CAHPS RESEARCH MEETING

SEPT 18, 2025

PATIENT-CENTERED RESEARCH

is important but it is not the same as engaging patients IN research!



Involving Patients in Research

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI)

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Funding Opportunities Research & Related Projects Engagement in Research Implementation of Evidence Health Topics News & Events About

PCORI funds patient-centered comparative clinical effectiveness research (CER)

FUNDING
Search for funding opportunities →

RESEARCH
Learn about research and related projects PCORI funds →

ENGAGEMENT IN RESEARCH
Include patients and others as partners in research →

Mission: help people make 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.**

SOURCE: [PCORI WEBSITE](https://www.pcori.org/)

Poll question:

What is the highest level of involvement that you have had with patient partners on your projects or studies?

- None
- Input (e.g. interviews, surveys and focus groups)
- Consultation (e.g. advisory board)
- Collaboration (e.g. co-investigator)
- Leadership (e.g. PI/co-PI)

Source: [PCORI website](#)

TESTIMONIAL

PCORI-FUNDED RESEARCHER



“My attitude was pretty typical, which was, ‘Let me find some patients and families that I can put on my grant ... and we’ll have them meet periodically ...”

“It was immediately apparent that [the partners] had things to add that we weren’t thinking about at all. It went from this notion of let’s have an advisory board ... to really understand that if this was going to work, they had to be central to the whole thing. ”

PCORI FRAMEWORK

- Expectations
- Resources
- Accountability

FOUNDATIONAL EXPECTATIONS FOR PARTNERSHIPS IN RESEARCH



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

SOURCE: [PCORI](#) WEBSITE

Lived experience at the table

From subject to stakeholder



How PCORI
changed my role
in research

LEVELS OF ENGAGEMENT

Patients may be involved in different ways, as participants, consultants, collaborators and principal investigators

For PCORI, consultant-level is the minimum and higher levels are encouraged



STAKEHOLDERS

focus on patient and families, but recognition of broad-base of partners who may contribute to the study design, conduct and dissemination



CAHPS

What matters most to patients about their experience of care?

Focus groups, cognitive testing interviews to gather feedback

Structured surveys to assess experience

Patient as data source



PCORI

What research questions and outcomes matter most to patients?

Partnership in shaping research proposals

Co-design, co-production

Patient as research partner and investigator

PCORI Engagement: What it looks like in my work

- VALVE training (2020 - 2022) to prepare patients as research advisors (PCORI Eugene Washington Award)
- Currently serving on 3 research teams (2 PCORI-funded)
- Contributing author on 10 published peer reviewed journal articles
- Elevate outcomes that reflect quality of life, trust, recovery—not just clinical endpoints

TESTIMONIAL

MGH PATIENT PARTNER



“I was not quite sure what I was getting into when I joined this group. It is fair to say the discussions ... gathering consumers and health care professionals together... had the kind of ‘thinking out of the box’ quality that is probably the key to advances in patient care.”

CHALLENGES AND CONSIDERATIONS



Identifying community and patient partners (job descriptions, roles and responsibilities)

Training and ongoing support to encourage involvement (hospital/org/IRB, grant-specific)

Administrative (aligning schedules, payments, timelines)

Maintaining connection and support (proposal writing, resubmissions – lag time, unfunded)

RESOURCES

PCORI's website has many tools, training and templates to support researchers who are interested in authentic patient involvement in research projects.

2020 SUMMIT ON MEASURE DEVELOPMENT

Report distills insights from 52 participants who came together to identify ways to involve patients in outcome and performance measure development (PCORI-funded)

PCORI ENGAGEMENT RESOURCES

Framework for engagement with templates and training for researchers and patient partners

Patient Engagement in OMERACT

International initiative focused on outcomes measurement for msk/ rheumatology research; developed PEIRS-22 item measure

EMERGING EVIDENCE

Growing literature studying the type and impact of patient involvement in research studies.

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2014 Domecq et al Systematic review

Includes 142 studies and found pt engagement assoc with increased enrollment and helped secure funding, design protocol and selection of outcomes.

●

2019 Forsythe et al Health Affairs

Summary of findings from 126 PCORI-funded studies examining approaches to engagement and impact on study and outcomes

How to move toward meaningful engagement?

1. How can CAHPS work meaningfully identify important outcomes that are rarely measured but important to patients (e.g. cumulative effects, multiple health issues)?
2. *"If research doesn't ask the right questions, it won't find the right answers."* How does this quote apply to the CAHPS survey work?
3. What are opportunities for patients as collaborators and co-investigators on CAHPS work? What are the concerns?

Involving patients in research

THANK YOU

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