

Better Research through Engagement



The Patient-Centered Outcomes Research Institute (PCORI) funds research that will help patients and those who care for them make informed healthcare decisions. We support studies that compare which healthcare options work best for whom, based on outcomes most important to patients—an approach known as patient-centered outcomes research, or PCOR.

HOW ENGAGEMENT HELPS US DO OUR WORK

By **engagement in research**, we mean the involvement of patients, caregivers, clinicians, insurers, and others across the healthcare community in every aspect of the research process.

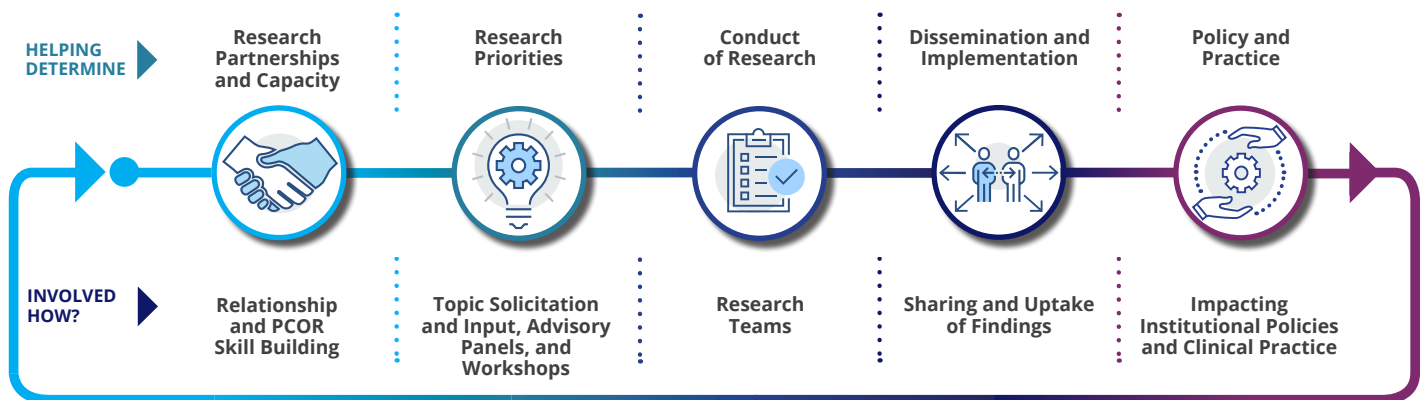
Topic Development: We involve stakeholder communities in identifying and selecting research topics.

Merit Review: We recruit and train patients and other stakeholders to review every application for PCORI funding, and we support merit reviewers in each cycle through our Merit Review Mentor Program.

Engagement in Research: PCORI staff provides technical support and resources to PCORI-funded research teams throughout a project's cycle and across PCORI's program areas.

Dissemination: We recruit and train patient and stakeholder peer reviewers of final research reports that come out of PCORI-funded projects, and work with stakeholder communities to disseminate findings.

PATIENTS AND OTHER STAKEHOLDERS ARE INVOLVED IN...



Between 2012-2019,

850

unique organizations have participated in PCORI's workshops, work groups, and roundtables

More than

300
patients and
370

other stakeholders have served as merit reviewers to decide which projects PCORI funds

263

patient peer reviews and

45

stakeholder peer reviews submitted for final research reports

WHY ENGAGEMENT MATTERS

We believe engagement influences research to be more patient centered, useful, and trustworthy, and will ultimately lead to greater use and uptake of research results by the patient and broader healthcare community. In fact, our stakeholders increasingly report that engagement has:

- **Improved study conduct**, including effective recruitment and meeting enrollment targets
- **Substantial and positive impacts on stakeholders, patients, and communities** such as improvements to personal health and healthcare and increased skills and professional opportunities
- **Improved the relevance** of research

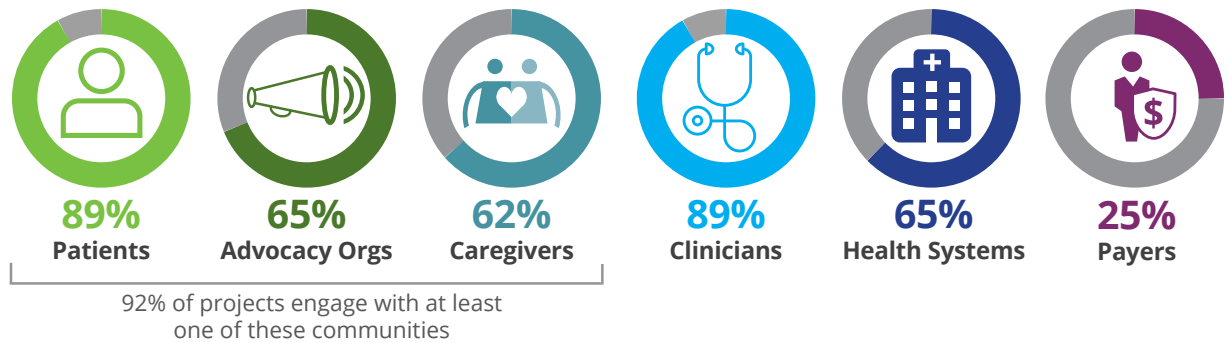
HOW WE STRENGTHEN THE PCOR COMMUNITY

PCORI works to nurture patient and stakeholder relationships that will grow the PCOR community. By holding local, regional, and national meetings, roundtable events, forums, and webinars, PCORI learns from stakeholders who discuss relevant research topics, and strategizes ways to disseminate research findings and implement them in clinical practice.

The **PCORI Ambassador Program** is a national network of volunteers who engage healthcare stakeholders at the community level to shift research culture by partnering with researchers, leading engagement initiatives, setting priorities, and spreading the word about the importance of stakeholder engagement in research.

The **Eugene Washington PCORI Engagement Awards** fund organizations to conduct projects to increase meaningful engagement of patients, caregivers, clinicians, and other healthcare stakeholders in CER and PCOR by expanding their knowledge and skills, and by creating opportunities to build connections and share research findings. The awards also support CER and PCOR conferences.

Top Stakeholder Communities Engaged in PCORI-Funded Research
By percentage of projects



PCORI projects also engage with subject matter experts (58%), community-based organizations (24%), training institutions (26%), policymakers (25%), industry (8%), and purchasers (6%). (N=499; data collected through September 2019).

HOW WE ADVANCE ENGAGEMENT & INFLUENCE OTHERS

One of our goals is to encourage all health research to become more patient centered. We evaluate and study the engagement activities across the research cycle. Using our research and practice-based knowledge, we actively develop approaches, resources, and knowledge to share more broadly. PCORI tracks its influence on the field and finds that, increasingly:

- Health systems are formulating **policies promoting patient engagement** in research.
- Other health organizations, government agencies, and industry are **formally engaging patients** in their work.
- Universities are offering seed money to **support research-patient partnerships** and **developing training programs** on patient-centered research.
- Journals that report on clinical research are including patients in the **review of submitted manuscripts**.

Engagement in Research
<https://www.pcori.org/engagement>

Engagement Tools and Resources
www.pcori.org/EngagementResources

Engagement in Health Research Literature Explorer
www.pcori.org/literature/engagement-literature