Better Research Through Engagement

The Patient-Centered Outcomes Research Institute (PCORI) is an independent nonprofit organization created by Congress to fund research that will help patients and those who care for them make informed healthcare decisions. We do this by supporting studies comparing which healthcare options work best for different people, based on outcomes most important to patients—an approach known as patient-centered outcomes research, or PCOR.

HOW WE PROMOTE ENGAGEMENT

We engage patients, caregivers, insurers, clinicians, and others across the healthcare community throughout the research process. They help us identify and prioritize research topics and questions to study. They review funding applications. We require they be part of our awardees’ study teams. And we see them as a key partners in the process of sharing the study results with those who need them.

WHY ENGAGEMENT MATTERS

Engagement helps ensure that the research we fund provides information that patients, their caregivers, and the broader healthcare community needs to inform the decisions they face daily. It brings insight and experience often missing in traditional research. This makes it more likely that researchers will study the right questions and that results will be patient-centered, trustworthy, relevant, and taken up in practice.

HOW ENGAGEMENT HELPS US DO OUR WORK

We include patients and the broader healthcare community in all our activities. Patients, caregivers, and their advocates represent 38 percent of overall membership of our seven advisory panels (including 68 percent of the Advisory Panel on Patient Engagement).

“Patients are our true north.”
—Harlan Krumholz, MD
PCORI Board of Governors
More than 250 patients have helped to review funding applications, a process that determines which research projects to fund. One patient and one other healthcare stakeholder join two scientists on each panel that evaluates applications for funding. The stakeholders provide important viewpoints on patient-centeredness, patient engagement, impact of the condition being studied, and potential to improve health and healthcare.

As the earliest research projects that we have funded come to completion, we will include patients and other stakeholders in the assessment of project findings. We are putting together a pool of volunteers to review project reports and results. So far, more than half of the volunteers are patients, caregivers, or patient advocates.

**HOW STAKEHOLDERS WORK WITH RESEARCHERS**

PCORI projects typically engage patients and other healthcare stakeholders as members of the research team or advisory groups, and sometimes as co-investigators. Stakeholders sharing personal perspectives and experiences provide feedback on study materials and processes, and participate in recruitment and other aspects of study conduct and dissemination of results. Our Engagement Rubric for Applicants, available on PCORI's website, guides researchers by presenting options for incorporating input from patients and other stakeholders throughout the research process.

Researchers report that stakeholders are strongly influencing each part of the research process. They say engagement often leads to more patient-centered research questions, clinical approaches, outcomes measured, and data collection, and to enhanced recruitment, enrollment, and retention practices and rates.

**INFLUENCING OTHERS**

One of our goals is to encourage all health research to become more patient centered, and we see more examples of this shift every day. Health systems are formulating policies promoting patient engagement in research. Other health organizations, government agencies, and industry are more often formally engaging patients in their work. More 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 beginning to include patients in the review of submitted manuscripts.

**FUNDING TO STRENGTHEN ENGAGEMENT AND PCOR**

We provide funding to support projects that promote engagement of patients and other healthcare stakeholders not traditionally involved in the research process in building a broader PCOR community.

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

**Pipeline to Proposal Awards** enable individuals and groups that are not typically involved in clinical research to develop the means to produce community-led PCOR funding proposals that they can submit to PCORI or other research funders.