

Research Done Differently®

THE PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI) TAKES AN UNUSUAL APPROACH TO RESEARCH, ONE THAT



Focuses on research topics, questions and **outcomes most important to patients** and those who care for them.



Works closely with a **range of healthcare stakeholders**—including patients, caregivers, scientists, clinicians, health systems, and insurers—to guide our research funding.



Requires that **patients be engaged** in the research we fund, not as subjects but as partners who help determine what to study and how.

THIS NEW APPROACH IS CALLED **PATIENT-CENTERED OUTCOMES RESEARCH, OR PCOR.**

By engaging the end users of study results throughout the research process, we are more likely to focus on asking the right questions, study the outcomes that matter most to patients, and produce the useful and relevant results that are more likely to be used in practice.

Changing the Culture of Research

Since we began funding research in 2012, our approach to research has fueled a rapid increase in patient-centered research and collaborations among patients, family caregivers, clinicians, researchers, health system leaders, and other healthcare stakeholders. In the process, we're spurring a change in the culture of research from being researcher-driven to stakeholder-driven.

We believe that PCORI's leadership in patient and stakeholder engagement is one of the key reasons this trend is accelerating throughout the research and health policy arenas. In just the past few years:

- Institutions such as Geisinger Health System have been revamping their research processes to include patients and enhance engagement.
- The US Food and Drug Administration announced its first patient engagement advisory committee in 2015.
- The National Institutes of Health has welcomed robust involvement of patients in the Precision Medicine Initiative.

"It's difficult to imagine research without engaging patients and caregivers and other stakeholders anymore. That's a cultural shift that PCORI's responsible for."

—Victor Montori, MD
Professor of Medicine
Mayo Clinic

"As part of the reexamination of our strategic plan, we formed a working group to explore patient engagement in research and to answer the question of how we could best take advantage of the opportunities that working with PCORI offered us."

—Marc S. Williams, MD
Director
Genomic Medicine Institute,
Geisinger Health System

"[PCORI has] made it very clear that we are partners in this. It isn't that they're the researchers and we're just the parents. [It's] that we're equals in this."

—Andrea Jensen,
Patient Caregiver

As of December 2018, PCORI has awarded

\$2.4 BILLION TO FUND MORE THAN 600

CER studies and related projects to enhance the methods and infrastructure to support PCOR.

PCORI funds **patient-centered comparative clinical effectiveness research, or CER**. This is research that aims to determine which healthcare options work best for which patients given their needs and preferences. The goal is to help patients and those who care for them to make better informed health and healthcare decisions.

By **patient-centered**, we mean that the studies we fund focus on outcomes that matter most to patients. We are also leading efforts to engage patients, family caregivers, clinicians, and other healthcare stakeholders as active partners in research, helping research teams decide what to study and how to study it.

"My interactions with PCORI have completely changed my approach to research. In fact, they inspired me to establish a center for patient-centered comparative clinical effectiveness research."

—Debra Fiser, MD
Professor and Former Dean
College of Medicine, University of Arkansas for Medical Sciences

"This PCORI-funded project has truly taught me about the benefits of conducting research in partnership with patients, caregivers, and advocates. I will never again be able to conceptualize or implement a research project without the input of these important stakeholders."

—Supriya Mohile, MD, MS
Professor of Medicine
University of Rochester



Our research funding includes **\$1.54 billion** to support patient-centered studies comparing two or more healthcare options, and another **\$124 million** for research to improve the science and methods of CER.

We've Invested \$325 million to develop PCORnet®, the National Patient-Centered Clinical Research Network, a **resource for conducting faster, more-efficient health research** by harnessing data representing 100 million patients and partnerships among hundreds of patients, clinicians, and healthcare organizations.

In addition to our research funding, we've provided another \$58 million to support projects and activities to stimulate partnerships, grow communities engaged in PCOR, and nurture ideas for PCOR into study proposals.