The PCORI Approach to Patient-Centered Outcomes Research

Patient-Centered Outcomes Research Institute
Welcome to Patient-Centered Outcomes Research at PCORI

Interested in being a part of stakeholder-driven research? Use this downloadable reference guide to explore these questions:

- Why was PCORI created?  
  **Section 1:** The Origins of Patient-Centered Research

- How does PCORI do research differently?  
  **Section 2:** The PCORI Approach to Research

- How is PCORI changing the research culture?  
  **Section 3:** PCORI's Impact on Healthcare Research

Patient-centered outcomes research (or PCOR) at PCORI is stakeholder-driven. Stakeholders are patients, those who care for them, clinicians, advocates, payers, and others interested in outcomes that are meaningful to patients.

- People like you are refocusing research on the things that matter most to patients.
- Patients and other stakeholders are partnering with researchers at every stage of research.
- The results of that research are informing healthcare decisions for millions of Americans.
The Origins of Patient-Centered Research

The Traditional Goals of Research

From Knowledge to Decision Making

Patient-Centered Health Care
The Traditional Goals of Research

For many years, healthcare research has improved how we diagnose, prevent, and treat a wide range of health conditions. Traditional healthcare research has answered important questions about:

• what causes diseases and health conditions,
• how health conditions affect the body over time, and
• how diseases and health conditions can be cured or managed.

The knowledge from traditional healthcare research can be useful for patients and those who care for them. But there hasn’t always been a way to involve patients, families, and healthcare professionals directly in the research process so that the findings reflect what matters most to them.

What does healthcare research focus on?

• Screening and diagnosing health conditions
• Preventing health conditions
• Safety and effectiveness of treatments
• Complications caused by health conditions
• How to deliver health care
• Equity and access to health care
From Knowledge to Decision Making

Traditional research teams may have different questions than patients, families, doctors, and other healthcare professionals.

- Traditional healthcare research may focus on more scientific questions to understand the specific effects of treatments, for example.

- Patients and those who care for them need information that will help them make day-to-day decisions or choose among healthcare options. Sometimes, this information is different than what researchers are studying.
From Knowledge to Decision Making

What do patients and caregivers want to know?

Patients and their caregivers need to know what options are available to prevent, manage, or treat a health condition given their values and preferences.

- In some cases, what matters most to them is improving their quality of life so that they can continue to work or enjoy their favorite activities.
- They may want to know that the treatment is one they can manage in terms of time and cost.
- They may also want to avoid more serious complications that could end their lives early.
From Knowledge to Decision Making

What do clinicians want to know?

Clinicians—doctors, nurses, and other health professionals who take care of patients—need options for patients and their families for prevention, management, and treatment.

• They want information on the potential effectiveness and the possible side effects of these options.
• They want to know how a treatment might work differently for various patients, so that the advice they give is patient-specific.
From Knowledge to Decision Making

What do payers and healthcare system administrators want to know?

Employers and payers who manage health benefits and pay for health care want to improve the quality and effectiveness of care for everyone who needs it.

Hospitals and health systems may want to know how different prevention, management, or treatment options might change the way care is provided.
Patient-Centered Health Care

Healthcare delivery is evolving to become more patient-centered. In patient-centered health care:

- Patients play an active role in their health care by partnering with clinicians to improve or manage their health.
- Patients and caregivers help clinics, hospitals, and healthcare systems design care to meet patient and family needs.
- Clinicians and patients work together to make treatment choices. They weigh the options based on the benefits and harms of each as well as patient and family values and preferences.

How does this affect healthcare research?

- Useful and trustworthy information that helps patients, families, clinicians, and others make decisions is key to patient-centered care.
- PCORI was authorized by Congress in 2010 to increase the quantity, quality, and timeliness of research evidence that can provide that information. In December 2019, Congress reauthorized PCORI for 10 more years.
- Like patient-centered care, patient-centered research needs an active partnership with the people who will be using the findings to make decisions.
The PCORI Approach to Research

PCORI’s Mission & Vision

The Role of Healthcare Stakeholders

The Research PCORI Supports
PCORI’s Mission & Vision

In the research PCORI funds, stakeholders partner with research teams to study outcomes that matter most to them.

PCORI’s mission is to 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. PCORI envisions that as a result of its work, patients and the public have information they can use to make decisions that reflect their desired health outcomes.

Learn more about PCORI’s research.
https://www.pcori.org/research-results/about-our-research

Learn about stakeholder engagement at PCORI.

How are stakeholders part of PCORI’s mission and vision?

Stakeholders play an important role in every aspect of PCORI research, from study design to sharing the findings with those who can use them to make decisions or change healthcare practices.

Stakeholders are at the heart of PCORI’s activities:

- helping groups understand more about patient-centered outcomes research,
- giving input on which conditions to study,
- recommending which proposals to fund,
- providing feedback about the engagement process, and
- creating materials to share research findings.
The Role of Healthcare Stakeholders

In PCORI-funded research, patients and other healthcare stakeholders are partners—as opposed to research subjects—who leverage their lived experience and expertise to influence research to be more patient-centered, relevant, and useful. Their early and continued involvement throughout a study can lead to greater use and uptake of research results by patients and stakeholders within the healthcare community.

Who can contribute as research partners?

- **Patients** who have a health condition
- **Family caregivers** who know what is involved in caring for someone with that condition
- **Clinicians** who care for people with that condition
- **People who represent hospitals or health systems** that organize care
- **Employers and payers** who manage health benefits and pay for health care
- **Policymakers** who want to improve rules for how to provide care
- **Researchers** with special expertise in designing studies needed for the condition
- **Members of groups that advocate** for people with the condition
- **People who represent training institutions**, such as universities that train doctors and nurses

Learn about PCORI’s stakeholders.
https://www.pcori.org/about-us/our-programs/engagement/pcoris-stakeholders
The Research PCORI Supports

What kind of research does PCORI fund?

To help patients, family caregivers, clinicians, and others make decisions, PCORI funds comparative clinical effectiveness research, or CER. CER studies compare outcomes, including risks and benefits, of two or more approaches to healthcare.

**PCORI promotes a special kind of CER called Patient-Centered Outcomes Research, or PCOR.** PCOR is CER that focuses on comparing the outcomes that matter most to patients, family caregivers, clinicians, or other healthcare stakeholders.

PCORI also supports research that improves the way in which PCOR is conducted.

Learn more about PCORI's research priorities.  
https://www.pcori.org/research-results/about-our-research/research-we-support/national-priorities-and-research-agenda
The Research PCORI Supports

What are PCORI’s research priorities?

PCORI sought input from healthcare stakeholders and the general public to determine seven national priority areas to guide its funding. They are:

- Assessment of Prevention, Diagnosis, and Treatment Options
- Improving Healthcare Systems
- Addressing Disparities
- Communication and Dissemination Research
- Accelerating Patient-Centered Outcomes Research and Methodological Research
- Maternal Mortality
- Intellectual and Developmental Disabilities

Within these priorities, PCORI is especially interested in studying conditions that:

- affect large numbers of people across a range of populations,
- place a heavy burden on individuals, families, specific populations and society, and
- are considered rare and difficult to study.
The Research PCORI Supports

What populations does PCORI research focus on?

PCORI pays attention to research that addresses the health of all populations. But PCORI makes it a priority to include populations that are often underrepresented in traditional research:

- racial and ethnic minorities,
- older adults,
- people with low incomes,
- residents of rural areas,
- women,
- children,
- individuals with special healthcare needs, including individuals with disabilities, multiple chronic diseases, rare diseases, and individuals whose genetic makeup affects their medical outcomes,
- patients with low health literacy or numeracy and limited English proficiency,
- lesbian, gay, bisexual, transgender (LGBT) persons, and
- veterans and members of the armed forces and their families.
PCORI’s Impact on Healthcare Research

Stakeholder-Driven Research in Action

Creating a New Culture of Healthcare Research

Learning from Experience
Stakeholder-Driven Research in Action

How do stakeholders work with researchers?

Stakeholder partners in PCORI-funded studies work with researchers in every stage of the research study.

- They serve as advisors to the researchers, providing perspective and direction on every decision, from what questions to ask to what data to collect and how to collect it.
- They advise researchers on how to understand and share the findings.
- They do specific tasks such as creating materials, recruiting study participants, or presenting the findings to others.

Having stakeholders play active roles helps shape the research to be useful and trustworthy.
Stakeholder-Driven Research in Action

Why, and how, do study teams incorporate stakeholders?

While there are different team structures across PCORI-funded studies, they all share a goal in producing research findings that can actually make a difference in treatment choices and outcomes, or improve the way care is delivered. To accomplish this, team members are committed to inviting as many stakeholders to the table as possible. Different stakeholders have different uses for the information from a research study that should be considered, and they all add an important perspective that can improve the usefulness of the study.

Many stakeholder-driven teams form before they apply for funds from PCORI, and some may add members when a study gets funded. Often, these teams are made from long-term relationships between researchers, patients, family caregivers, clinicians and other professionals.
Creating a New Culture of Healthcare Research

As a result of PCORI's efforts, the traditional approaches to research are evolving. Several academic medical institutions now have centers devoted to PCOR. Stakeholder engagement in research is being taught in scientific training programs and young scientists are being mentored to involve stakeholders as a standard part of the research process.

What are some other examples of changes in healthcare research?

More stakeholders are interested in working with researchers to answer the questions that matter the most to them.

- Patients and other stakeholders coauthor articles and present to medical societies, professional organizations, and healthcare systems.
- Patients and caregivers are creating research networks that share data for studies.
- Stakeholders are working with PCORI to make PCOR more credible and reliable.

Learn more about how PCORI is changing the culture of research. https://www.pcori.org/engagement/influencing-culture-research
Learning from Experience

Each study funded by PCORI is an opportunity to learn more about how to engage stakeholders and conduct PCOR. PCORI evaluates funded projects to learn more about stakeholder engagement in research.

Learn more about patient engagement in research.
https://www.pcori.org/engagement/research-fundamentals/Engaging-stakeholder-driven-research

Learn about the influence and impact of stakeholder engagement on PCORI-funded research.

How PCORI shares knowledge about stakeholder-driven research.

PCORI has a number of reports, publications, and presentations that share knowledge about PCOR and how to conduct it using stakeholder-driven teams. Many are available on the PCORI website.

PCORI hosts an annual meeting where stakeholder-driven research is discussed and findings are shared. Patients and other stakeholders play a critical role in these meetings.
Thank you for viewing
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