The PCORI Approach to Patient and Stakeholder Engagement

Anne Beal, MD MPH
Deputy Executive Director
Patient-Centered Outcomes Research Institute (PCORI)

Mark Twain House
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About PCORI

An independent non-profit research organization authorized by Congress as part of the 2010 Patient Protections and Affordable Care Act (ACA).

Committed to continuously seeking input from patients and a broad range of stakeholders to guide its work.
Our Mission and Vision

Mission
The Patient-Centered Outcomes Research Institute (PCORI) helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community.

Vision
Patients and the public have the information they need to make decisions that reflect their desired health outcomes.
PCORI Funding

- 2012: $150,000,000
- 2013: $350,000,000
- 2014: $500,000,000
- 2015: $500,000,000
- 2019: $500,000,000
PCORI’s Core Duties

- Establish national research priorities
- Establish and carry out a research agenda
- Develop and update methodological standards
- Disseminate research findings
National Priorities for Research and Research Agenda

Assessment of Prevention, Diagnosis, and Treatment Options
• Comparisons of alternative clinical options to support personalized decision-making and self-care
• Identifying patient differences in response to therapy
• Studies of patient preferences for various outcomes

Improving Healthcare Systems
• Improving support of patient self-management
• Focusing on coordination of care for complex conditions and improving access to care
• Comparing alternative strategies for workforce deployment

Communication & Dissemination Research
• Understanding and enhancing shared decision-making
• Alternative strategies for dissemination of evidence
• Exploring opportunities to improve patient health literacy

Addressing Disparities
• Understanding differences in effectiveness across groups
• Understanding differences in preferences across groups
• Reducing disparities through use of findings from PCOR

Accelerating PCOR and Methodological Research
• Improving study designs and analytic methods of PCOR
• Building and improving clinical data networks
• Methods for training researchers, patients to participate in PCOR
• Establishing methodology for the study of rare diseases
Advise Us as to What PCORI Should Study:
- What questions are most important? (research prioritization)
- What outcomes should be studied? (topic generation)

Tell Us How We Are Doing
- How can we improve on what we are doing and how we are doing it?

Review Proposals and Partner in Research
- Review research proposals for impact and patient-centeredness
- Participate in conducting research

Help Us Share the Findings
- How do we best communicate important research findings?

Patient and Stakeholder Engagement in Patient-Centered Outcomes Research

Patients and Stakeholders
Engagement Workshops

The Power of Partnership in Research: Improving Healthcare Outcomes in Rural Settings

Help build a patient-centered research community in the central states.

- Dates: March 9-10, 2013
- Location: Wichita, Kansas

http://www.pcori.org/events
Advisory Panels

- We include clinicians, researchers, patients, and other experts with appropriate experience and knowledge to help PCORI achieve its goals.

- We assure meaningful patient engagement in:
  - Research activities
  - Identifying research priorities and topics
  - Conducting randomized clinical trials
  - Performing special research studies

- First Training Held on April 19th and 20th in Washington, DC
Suggest a Research Question

We want to know what health care question you may be facing.

Your input can help us refine our research agenda.

Suggest a Patient-Centered Research Question

Every day, patients and people who care for them must make health care decisions. They may have to choose between two or more options for preventing, diagnosing or treating a health condition. Or, they might need to decide between doing, or not doing something. For these situations, the Patient-Centered Outcomes Research Institute (PCORI) was created. PCORI funds research to help patients make the best decisions about their health care.

We at PCORI want to know what health care question or decision you may be facing. We want to hear from you. Your input can help us refine our research agenda.

Whether you are a patient with a health condition, a caregiver for someone who is sick, or a consumer who wants to improve care for your patients, or a researcher, we invite you to submit questions about options faced by patients, we also are interested in learning about care delivery, address disparities in health care, or improve the communication of health care information, please see PCORI’s National Priorities for Research.

Suggesting a research question is the first step in a five-part process to secure funding. We will carefully consider each question and, along with public input, decide which ones we will study as part of our portfolio of patient-centered research.

This will be an ongoing feature on the PCORI website. So, please feel welcome to come back and suggest additional research questions in the future.

Is your question about a certain disease, behavior or health condition?

If yes, please name the disease, behavior or health condition. If no, leave blank and continue.
Become a Reviewer of Funding Applications

PCORI invites professional and lay audiences to be reviewers of research applications.

Help us support research that will be both scientifically rigorous and truly patient-centered.

Learn more and apply online: www.pcori.org/get-involved/reviewers/
What roles should patients and stakeholders play in research teams?

The engagement of patients and stakeholders should include:

- Participation in formulation of research questions
- Defining essential characteristics of study participants, comparators, and outcomes
- Monitoring of study conduct and progress
- Dissemination of research results
Establishing a PCORI Blueprint and Framework for Dissemination & Implementation

PCORI’s Blueprint for Dissemination and Implementation is being established:

△ To guide the organization in disseminating the research findings of funded research conducted in the national program areas; and

△ To enhance implementation by actively facilitating how PCORI’s research findings can be used by health care decision-makers.

△ To evaluate how the effect of the dissemination of such findings reduces practice variation and disparities in health care.
Touch Points for Effective Dissemination

- Speeding the implementation of and use of PCOR
- Becoming a trusted resource for information
- Engaging stakeholders from across the healthcare community to include PCORI research in training, practice, and standards

[pre-award]
Topic Generation:
Likelihood of Implementation in Practice
Proposals:
Researchers Proactively Plan to Disseminate

[post-award]
Patients and Stakeholders Engaged in the Research Study
Staff Actively Evaluates Progress
Share Early Results

[completed]
Researchers Carry Out Dissemination Plans
Patients and Stakeholders Engaged in the Process
Recent Addition to the PCORI Team

- Director, Center for Healthcare Equity at Northwestern University
- Associate Professor at the Feinberg School of Medicine

Romana Hasnain-Wynia, PhD
Scientific Lead, Program on Health Disparities
Connect with PCORI

Keep Informed about PCORI Funding Announcements and Opportunities to Get Involved

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