What Should PCORI Study?
A Call for Topics from Patients and Stakeholders

December 4, 2012 | Washington, DC

Welcome to the PCORI Family

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, non-profit organization authorized by Congress. Our mission is to help people make informed health care decisions, and improve health care delivery and outcomes, by producing and promoting high integrity, evidence-based information.

Our Values

We believe in *research done differently*. Our 21-member Board of Governors represents the entire healthcare community, and our work is grounded in the idea that patients and those we care for them should be involved in every stage of the research process. PCORI will fund research that includes the patient's voice in establishing the questions to be studied, designing and conducting the research, and disseminating the results.

About the Workshop

The objectives for this workshop are to strengthen the community of healthcare stakeholders, inform you of PCORI's mission and research prioritization process, identify best practices in stakeholder engagement and receive recommendations on topics we should address in our future funding announcements and initiatives.

We will accomplish these objectives through breakout sessions that address four of our five national priorities for research:

1. **Assessment of Prevention, Diagnosis, and Treatment Options —** Comparing the effectiveness and safety of alternative prevention, diagnosis, and treatment options to see which ones work best for different people with a particular health problem.
2. **Improving Healthcare Systems —** Comparing health system-level approaches to improving access, supporting patient self-care, innovative use of health information technology, coordinating care for complex conditions, and deploying workforce effectively.
3. **Communication and Dissemination Research —** Comparing approaches to providing comparative effectiveness research information, empowering people to ask for and use the information, and supporting shared decision-making between patients and their providers.
4. **Addressing Disparities —** Improving the nation's capacity to conduct patient-centered outcomes research, by building data infrastructure, improving analytic methods, and training researchers, patients and other stakeholders to participate in this research.

What Should PCORI Study?

Assessment of Diagnosis, Prevention and Treatment

The workshop agenda consists of facilitated breakout sessions that highlight four of PCORI's five national priorities for research. Each priority drives PCORI's research funding announcements for broad and targeted study topics. As a PCORI stakeholder, we are interested in your feedback and recommendations to generate study topics and new initiatives to provide you with evidence-based information to make better-informed health-care decisions.

Background

PCORI's authorizing legislation guides our efforts for comparing the effectiveness and safety of alternative prevention, diagnosis, and treatment options in health conditions. Approximately, 40% of PCORI's funding is allocated to this priority. The utilization of comparative clinical effectiveness research can lead to well-informed decision-making for patients, caregivers, and health care professionals. As a PCORI stakeholder, your partnership in this effort is crucial. PCORI's success in this area can produce alternative clinical options and give patients a voice in the health care outcomes that they want to achieve.

Pre-Workshop Survey Responses

How comparative clinical effectiveness research is currently being used by you…

- To assess compliance nationally
- To enroll patients in real world effectiveness studies
- To inform program development and implementation
- To ascertain the most efficient and effective mechanism for improving the delivery of public health

Questions to consider:

1. How is comparative clinical effectiveness research (CER) used in your organization or by its members?
2. How has CER reduced wasteful or ineffective diagnosis, prevention and treatments options in your organization?
3. What are some examples of promising practices from your field on patient-centered research?

For more information

"National Priorities for Research and Research Agenda", Adopted by PCORI Board of Governors, May 21, 2012: http://www.pcori.org/assets/PCORI-National-Priorities-and-Research-Agenda-2012-05-21-FINAL.pdf

What Should PCORI Study?

Improving Health Systems

The workshop agenda consists of facilitated breakout sessions that highlight four of PCORI's five national priorities for research. Each priority drives PCORI's research funding announcements for broad and targeted study topics. As a PCORI stakeholder, we are interested in your feedback and recommendations to generate study topics and new initiatives to provide you with evidence-based information to make better-informed health-care decisions.

Background

PCORI is interested in funding projects that will bring innovative change to health systems. Health systems include health plans; physician groups; hospitals; academic medical centers; integrated delivery systems; community-based and safety net clinics; federal, state, and municipal providers and payers; and other entities organized to deliver, arrange, or coordinate healthcare services. PCORI aims to provide information of value to patients, their caregivers, and clinicians, as well as to healthcare leaders and decision makers on which types of systems and which system strategies lead to better patient outcomes.

Pre-Workshop Survey Responses

- Best practices in chronic care coordination between primary care and community organizations for cardiovascular disease, diabetes, and obesity.
- Any project on utilization of electronic health records for care coordination or meaningful use.
- Strategies to support implementation and sustainability of effective and meaningful care solutions.
- How do we use the community to guide our decisions about those programs and processes that will affect population health?

Questions to consider:

1. How can PCORI measure success of integrated health systems?
2. How are some of the unanticipated consequences of "eHealth" initiatives?

For more information

"National Priorities for Research and Research Agenda", Adopted by PCORI Board of Governors, May 21, 2012: http://www.pcori.org/assets/PCORI-National-Priorities-and-Research-Agenda-2012-05-21-FINAL.pdf

What Should PCORI Study?

Addressing Disparities

The workshop agenda consists of facilitated breakout sessions that highlight four of PCORI's five national priorities for research. Each priority drives PCORI's research funding announcements for broad and targeted study topics. As a PCORI stakeholder, we are interested in your feedback and recommendations to generate study topics and new initiatives to provide you with evidence-based information to make better-informed health-care decisions

Background

Disparities in health care have an impact on who receives care, where care is received, and the quality of the care received. Race, gender, socioeconomic status and other factors contribute to health care decisions. Innovative interventions that identify and aim to reduce disparities, can lead to health equity. PCORI is interested in addressing disparities at their various levels for improving health outcomes.

Pre-Workshop Survey Responses

- Addressing disparities of care based on race and limited English proficiency and disability.
- Patient Satisfaction Development of strategies for patients with multiple comorbidities Medication management
- How do we best achieve improved population health outcomes
- Ways in which the family caregiver can be better supported by technology and improved engagement by the healthcare system

Questions to consider:

1. What models have been successful in eliminating disparities in health care?
2. What are the best systems-level interventions for improving overall performance and promoting healthcare equity?
3. What are some of the obstacles in receiving quality health care?

For more information

"National Priorities for Research and Research Agenda", Adopted by PCORI Board of Governors, May 21, 2012: http://www.pcori.org/assets/PCORI-National-Priorities-and-Research-Agenda-2012-05-21-FINAL.pdf

What Should PCORI Study?

Communication and Dissemination Research

The workshop agenda consists of facilitated breakout sessions that highlight four of PCORI's five national priorities for research. Each priority drives PCORI's research funding announcements for broad and targeted study topics. As a PCORI stakeholder, we are interested in your feedback and recommendations to generate study topics and new initiatives to provide you with evidence-based information to make better-informed health-care decisions

Breakout Session Priority:
Communication and dissemination of comparative clinical effectiveness research (CER) findings is an important component of PCORI's research portfolio. We aim to fund research to raise awareness amongst patients, caregivers and other health care professionals of CER and Patient-Centered Outcomes Research findings and help better-inform their health care decision making. We are interested in stakeholder recommendations on how to close the gap between the time best practices are identified in research and commonly accepted as practice among patients, caregivers, and providers.

Pre-Workshop Survey Responses

- How do patients best receive information?
- How do you best present information?
- How do you best communicate risk?
- How do we use the community to guide our decisions about those programs and processes that will affect population health

Questions to consider:

1. What are some of the promising practices from your organization of dissemination of clinical research (e.g. communicating research results to a diverse base, clinical decision aids)?
2. How may patient engagement be leveraged to distribute CER information?

For more information

"National Priorities for Research and Research Agenda", Adopted by PCORI Board of Governors, May 21, 2012: http://www.pcori.org/assets/PCORI-National-Priorities-and-Research-Agenda-2012-05-21-FINAL.pdf