



## Transforming Patient-Centered Research: Building Partnerships and Promising Models

October 26-28, 2012 | Washington, D.C.

### 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

This workshop is one step toward fulfilling our commitment to receive guidance from patients and stakeholders throughout our work. Our goal for this weekend is to identify promising models of patient engagement in research, help various communities start working together to identify research topics that will improve patient care and outcomes, and get your feedback on how PCORI should work with the healthcare community in its future initiatives.

We will accomplish these goals through five breakout sessions that address key focus areas, described in greater detail in the following pages:

- 1. Identifying and Selecting Research Questions** – *How should PCORI identify and select specific research questions for funding that are patient-centered?*
- 2. Reviewing Research Proposals for Funding** – *How can PCORI effectively engage and use the real-world experience of patients to help evaluate research proposals we receive?*
- 3. Matching Patients and Stakeholders with Researchers** – *How can PCORI connect patients and stakeholders with researchers for collaborative work that ensures studies reflect patient perspectives?*
- 4. Disseminating Research to the Community** – *How do we ensure that patients and those who care for them can access and use PCORI's research to make more-informed decisions?*
- 5. Evaluating PCORI's Patient and Stakeholder Engagement Programs** – *How can PCORI measure the effectiveness of its programs to involve patients and stakeholders throughout its work?*

### Get Involved

You can continue to play a valuable role in PCORI's work through the following methods:

- Respond to Opportunities for Formal Public Comment
- Suggest a Research Question for PCORI to Consider
- Become a Reviewer of PCORI Funding Applications
- Contact us at [info@pcori.org](mailto:info@pcori.org)
- Receive PCORI Alerts and Updates at [pcori.org/subscribe](http://pcori.org/subscribe)

Find out more at [pcori.org](http://pcori.org)



## **Transforming Patient-Centered Research: Building Partnerships and Promising Models**

### **Breakout Session: Identifying and Selecting Research Questions**

The workshop agenda is built around breakout sessions addressing six key topics for participants to provide their feedback and recommendations. Each topic represents an important part of the patient-centered research process or PCORI's development as a national patient-driven research organization. The input received will be used by PCORI staff to develop policy and programmatic recommendations for the PCORI Board of Governors to consider for approval.

#### **Identifying and Selecting Research Questions**

PCORI is working to develop a transparent and deliberative process that produces patient-centered questions and encourages participation from patients and other stakeholders who are not involved frequently in the research process, including underserved populations. Incorporating web and social media tools is a priority for the developing process to allow for broader participation. Research questions PCORI will address: assessment of prevention, diagnosis and treatment options; improving healthcare systems; communication and dissemination research; addressing disparities; and accelerating patient-centered outcomes, methodological research and infrastructure. In each area, PCORI seeks patient involvement to identify and select the most important questions.

#### **Questions to think about:**

1. What are the best ways for PCORI to identify and select specific research questions for funding patient-centered research questions?
2. What are the most effective communication channels for engaging patients and clinicians, and related stakeholders so that there is a strong patient-led perspective in identifying and selecting research questions?
3. Which organizations or networks might be best matched to the different areas of research PCORI will address?

#### **For more information:**

PCORI, "Suggest a Patient-Centered Research Question," [www.pcori.org/get-involved/suggest-a-patient-centered-research-question-survey/](http://www.pcori.org/get-involved/suggest-a-patient-centered-research-question-survey/)

PCORI Blog, "Which Health and HealthCare Questions Can PCORI Study to Help You? Tell Us," [www.pcori.org/blog/which-health-and-healthcare-questions-can-pcori-study-to-help-you-tell-us/](http://www.pcori.org/blog/which-health-and-healthcare-questions-can-pcori-study-to-help-you-tell-us/)



## **Transforming Patient-Centered Research: Building Partnerships and Promising Models**

### **Breakout Session: Reviewing Research Proposals for Funding**

The workshop agenda is built around breakout sessions addressing five key topics for participants to provide their feedback and recommendations. Each topic represents an important part of the patient-centered research process or PCORI's development as a national patient-driven research organization. The input received will be used by PCORI staff to develop policy and programmatic recommendations for the PCORI Board of Governors to consider for approval.

#### **Reviewing Research Proposals for Funding**

PCORI invites patients and stakeholders to serve as reviewers for all submitted research proposals. Stakeholder reviewers play an important role in helping PCORI determine which research applications receive funding. The Institute conducts a merit review of applications through a two-phase process. For the initial round of our funding applications, Cycle I, stakeholder reviewers will be involved in the second phase only, after scientific reviewers establish that a proposal meets rigorous technical standards. This review will apply to applications that ranked highest in Phase I, focusing on the potential impact of the research for patients and other decision makers and on the quality of the plan in each proposal for engaging patients and other stakeholders in the research. This review will be conducted in a face-to-face meeting and will include in-person discussions that involve both scientific and stakeholder reviewers. These panels will assign criteria and overall scores for each application. These will be the final scores used in making funding decisions.

With the recent opening of Cycle II, PCORI is considering whether to involve stakeholders in both Phase I and Phase II, either for Cycle II or future cycles. Scientific reviewers are involved in both Phase I and Phase II. We are interested in refining our strategy for recruiting, training and utilizing patient and stakeholder reviewers to ensure that anyone who is interested in being a reviewer has an opportunity to do so, regardless of prior research or medical experience.

#### **Questions to think about**

1. What are the obstacles to patient reviewer participation and how can we address them?
2. How can we ensure being a patient or stakeholder reviewer is a positive experience?
3. What specific revisions should PCORI consider making to its application form and process?
4. What criteria do you feel are most important in evaluating Stakeholder Reviewer applications?
5. Should PCORI develop a broad pool of trained Stakeholder Reviewers from which to draw for future cycles? Or should PCORI review applications selectively in a cycle-by-cycle fashion?

#### **For more information**

PCORI, "Become a Stakeholder Reviewer for PCORI Funding Applications," [www.pcori.org/get-involved/reviewers/become-stakeholder-reviewer/](http://www.pcori.org/get-involved/reviewers/become-stakeholder-reviewer/)



## **Transforming Patient-Centered Research: Building Partnerships and Promising Models**

### **Breakout Session: Matching Patients and Stakeholders With Researchers**

The workshop agenda is built around breakout sessions addressing five key topics for participants to provide their feedback and recommendations. Each topic represents an important part of the patient-centered research process or PCORI's development as a national patient-driven research organization. The input received will be used by PCORI staff to develop policy and programmatic recommendations for the PCORI Board of Governors to consider for approval.

#### **Matching Patients and Stakeholders with Researchers**

Collaboration between patients, caregivers and researchers is an important aspect of patient-centered research and a major commitment of PCORI. Our funding announcements include a requirement that researchers engage patients and stakeholders as meaningful partners in their research teams. Supporting this requirement, PCORI is exploring options for helping interested patients and stakeholders to become connected with researchers to pursue collaborative projects. PCORI seeks the feedback of patients and other stakeholders on engagement models to connect researchers with the patients and communities for whom their research is relevant. By engaging patients and stakeholders in the design of procedures to match patients and stakeholders with researchers, there is an opportunity to ensure that PCORI sustains a lead role in developing patient-centered research.

#### **Questions to think about**

1. How would the optimal match making process work for patients and stakeholders if this was a patient led process and how would it be made optimal for researchers?
2. What are the most successful models for matching patients and stakeholders with researchers in health care or in analogous fields where consumers and citizens collaborate with scientists or other experts?
3. Which communication channels and organizational procedures are most likely to prove effective for matching patients and stakeholders with researchers, e.g., social network tools for crowd sourcing (for example, Angie's List), collaboratives with advocacy groups, credentialing processes?

#### **For more information**

"Our Questions, Our Decisions: Standards for Patient-centered Outcomes Research", Preliminary Draft Methodology Report, PCORI, June 4, 1012 (see pages 25-26) [www.pcori.org/assets/Preliminary-Draft-Methodology-Report.pdf](http://www.pcori.org/assets/Preliminary-Draft-Methodology-Report.pdf)



## **Transforming Patient-Centered Research: Building Partnerships and Promising Models**

### **Breakout Session: Disseminating Research to the Community**

The workshop agenda is built around breakout sessions addressing five key topics for participants to provide their feedback and recommendations. Each topic represents an important part of the patient-centered research process or PCORI's development as a national patient-driven research organization. The input received will be used by PCORI staff to develop policy and programmatic recommendations for the PCORI Board of Governors to consider for approval.

#### **Disseminating Research to the Community**

The Affordable Care Act's language establishing PCORI specifically mentions disseminating PCORI's research findings to physicians, healthcare providers, patients, payers and policy makers. Successfully disseminating research means having an impact on practice and patient outcomes. The role of patient engagement is vital to that success. This success may depend on centering the communication on the different audiences and meeting their requirements for accepting evidence. Audience differences and other barriers to the translation of research may account for much of the resistance to changing practices in the face of evidence from research. It is clear that improving dissemination will be key to PCORI success, but many unknowns must be addressed. This is an important area for patient engagement, which could lead to new techniques for translating research into improved outcomes.

#### **Questions to think about**

1. How can patient engagement serve as an accelerator in disseminating research to change practices and improve outcomes?
2. What are the ways in which patients and related stakeholders can lead in translating results and influencing behaviors when disseminating PCORI research?
3. Which modes of disseminating research can patients and related stakeholders best help PCORI succeed in through patient engagement?

#### **For more information**

"Can You Hear Us Now?", Status Report to the Board of Governors by PCORI Dissemination Workgroup, January, 2010, [www.pcori.org/assets/Dissemination-Workgroup-Report-Updated.pdf](http://www.pcori.org/assets/Dissemination-Workgroup-Report-Updated.pdf)



## **Transforming Patient-Centered Research: Building Partnerships and Promising Models**

### **Breakout Session: Evaluating PCORI's Patient and Stakeholder Engagement Programs**

The workshop agenda is built around breakout sessions addressing five key topics for participants to provide their feedback and recommendations. Each topic represents an important part of the patient-centered research process or PCORI's development as a national patient-driven research organization. The input received will be used by PCORI staff to develop policy and programmatic recommendations for the PCORI Board of Governors to consider for approval.

#### **Evaluating PCORI's Patient and Stakeholder Engagement Programs**

Evaluating the quality of PCORI's patient and stakeholder engagement efforts is critical to the organization's success. We need patients and those who care for them to be effectively engaged and feel a genuine sense of ownership in PCORI's work. PCORI would like to expand mechanisms for receiving feedback on its patient and stakeholder engagement programs so they are responsive to those they are meant to serve. In addition to establishing those channels for feedback and evaluation, it is important that we define success in engagement and assess our efforts to date.

#### **Questions to think about**

1. How can PCORI best measure the effectiveness of patient and stakeholder engagement in research?
2. What novel methods can patients and patient advocates propose for evaluation of research engagement that would capitalize on the growing networks of patients engaged in research?

#### **For more information**

"National Priorities for Research and Research Agenda", Adopted by PCORI Board of Governors, May 21, 2012 (see pages 18-19): [www.pcori.org/assets/PCORI-National-Priorities-and-Research-Agenda-2012-05-21-FINAL.pdf](http://www.pcori.org/assets/PCORI-National-Priorities-and-Research-Agenda-2012-05-21-FINAL.pdf)