



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Advisory Panel on Patient Engagement April 19-20, 2013, Meeting Summary

Overview

On April 19-20, 2013, PCORI convened the Advisory Panel on Patient Engagement in Alexandria, Virginia, for a two-day training and working session to help PCORI identify and prioritize research questions for potential funding. The panel included 21 members representing caregivers, patient-caregiver advocates, clinicians, researchers, organizational providers, and representatives from payers, industry, and purchasers.

Background

The [Advisory Panel on Patient Engagement](#)¹ was opened by PCORI Director of Patient Engagement Sue Sheridan, who began with an introduction to PCORI's legislative mandate and a review of the panel's charge, developed during a October 2012 workshop:

- Advise on processes to identify research topics and priorities that are important to patients
- Advise on all aspects of stakeholder review of applications for PCORI funding
- Provide general recommendations to PCORI and externally on the conduct of patient-centered research
- Advise on methods to evaluate the impact of patient engagement in research
- Assist and advise PCORI on communications, outreach, and dissemination of research findings
- Provide advice on other questions and areas of interest that may arise that are relevant to PCORI's mission and work.

Related Information

- [About PCORI's Advisory Panels](#)
- [Advisory Panel on Patient Engagement](#)
- [Orientation to PCORI's Research Prioritization](#)

The Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created to help people make informed healthcare decisions.

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Discussion

Over the course of the two-day meeting, panel members discussed the research topics presented in the briefs, with respect to the PCORI topic criteria.

Key discussion points included:

Need to communicate to the patient/caregiver community the reason why patient engagement in research is important. Panelists encouraged PCORI to recognize that many individuals may not readily grasp the personal and practical significance of patient engagement in research. In order to effectively engage patients and the general public in research, panelists felt PCORI must first clearly articulate the problem and solution in a way that is salient. Panelists agreed that PCORI should clearly state the “why” for engaging patients in PCORI’s work and move the current thinking from a “partnership in care” to a “partnership in research.”

Panelists also suggested a **need to reframe the invitation to patients:** “When you invite people to share what they think about, what matters to them, and what they think should be done—people come.”

Need to overcome barriers to patient-researcher partnerships. Panelists discussed barriers to patient-researcher partnerships, including an imbalance of power; time sensitivity for publishing research findings; a lack of incentives for patients and consumers; an unclear definition of what effective patient engagement entails; and a lack of real-life examples of how engagement can be done well.

Need to train research community and patients. Panel members identified a need to prepare the environment for meaningful patient engagement by first preparing the research. The group suggested PCORI break into the research silo by first conducting outreach to research leadership (PIs and deans) as partners. Panelists also emphasized the importance of making a consistent training structure available to organizations, even those without PCORI funding, who want to involve patients and families in their research.

Opportunities to learn from existing models of community and patient engagement. Panelists suggested that existing models of community engagement could and should serve as models for PCORI.

Need to define indicators and metrics of “success” in patient engagement. PCORI staff expressed an interest in evaluating the impact of an engaged research model to better identify research and support best practices. Panelists and PCORI staff agreed that PCORI will be better able to evaluate successes if the expectations around actions for what engagement is and thresholds for how engagement is measured are set and shared.

Dissemination activities occur at multiple levels and entail different strategies for different audiences.

Anne Beal, PCORI Deputy Executive Director and Chief Officer for Engagement, introduced a discussion on dissemination and communication and described PCORI's three-pronged approach to dissemination:

- Require researchers to develop dissemination plan
- Fund research in the Communications and Dissemination Program
- Develop PCORI dissemination plan and infrastructure in collaboration with AHRQ

Panel members noted this early involvement also helps to mobilize communities in driving the work and allows for measurement of the generalizability of the results. Panelists emphasized the importance of disseminating to individuals, patients/advocates, and communities in parallel time to researchers and recommended PCORI encourage researchers to bring patients/advocates they have partnered with to present their findings at research meetings.

Action

The panel discussed issues that remain to be addressed at future meetings and teleconferences, including collecting and sharing models of engagement, distributing materials and tool kits to use in communities, and determining the best mechanism for continued communication between panel members.

Next Steps

For the next meeting, panelists suggested more integration of the pre-work materials into the discussions and additional resources for preparation (e.g., a list of suggested resources related to best practices in engagement research for review prior to the meeting). Panel members also recommended more detailed agendas and greater use of the small group breakout sessions.

—Meeting summary prepared by Sue Sheridan, Suzanne Schrandt, and Kristen Konopka. Posted June 11, 2013 and available on [PCORI's website](#).¹

¹ Available at pcori.org/get-involved/pcori-advisory-panels/advisory-panel-on-patient-engagement