

**Patient Centered Outcomes Research: Where are We Now?
Stakeholder Perspectives on PCORI Implementation to Date
Executive Summary
October, 2013**

Three years into the creation of the Patient-Centered Outcomes Research Institute (PCORI) under the Affordable Care Act, the Partnership to Improve Patient Care (PIPC) embarked on a mission to evaluate PCORI's progress in meeting its statutory mandate to prioritize, conduct, and communicate comparative effectiveness research (CER) in ways that are patient-centered – or to quote PCORI, identify what it means to do “research done differently.”¹ Our analysis focuses on the following issues:

- **Patient Centeredness:** PCORI's patient-centered mission is a key criteria differentiating itself from existing federal agencies that conduct CER.
- **Patient Engagement:** Although PCORI has conducted a vast array of activities to engage patients and clinicians to date, in our analysis it was not always clear how the input PCORI is receiving is being factored into PCORI's research program.
- **Research Methods:** Our analysis found that the breadth of activities undertaken by the Methodology Committee could create challenges for focusing on the areas of work required by Congress - to develop methodological standards for research and a translation table.
- **Research Priorities:** In response to stakeholder concerns about the breadth of PCORI's National Priorities for Research, PCORI has added new processes for targeted funding announcements utilizing ad hoc workgroups and advisory panels, and has articulated its intent to shift funding over time toward targeted topics.
- **Advisory Panels:** To support the shift to targeted funding, PCORI selected five targeted topics that could be developed into targeted funding announcements using ad hoc workgroups. Additionally, in March 2013, the PCORI Board of Governors approved four advisory panels to assist with identification of specific topics for research.
- **Research Dissemination:** Stakeholders place a high priority on identifying new strategies to inform patient decision-making. However, it is not clear whether AHRQ will adopt the patient-centered dissemination strategies being developed by PCORI in its Dissemination and Implementation Action Plan.
- **Evaluation:** Going forward, it will be important for PCORI to define what success looks like and to develop criteria for self-evaluation.
- **PCORI Funding:** The bulk of PCORI funding has awarded comparative clinical effectiveness research, around \$370 million in combined broad and targeted funding announcements to date. PCORI has spent \$30 million on Pilot Projects. Over \$3 million has been allocated to other purposes, including data infrastructure and dissemination activities.

¹ Selby, Joe. “Investing in Research Done Differently.” Executive Director's Corner, Patient-Centered Outcomes Research Institute, June 5, 2012. <<http://www.pcori.org/executive-directors-corner/research-done-differently/>>

Our analysis resulted in the following recommendations:

1. Changing the culture of research will require PCORI to include stakeholders, particularly patients and providers, who are the primary end-users of comparative clinical effectiveness research in every step of the research process. Therefore, PCORI should embrace the expertise of specific patient and provider communities to identify research priorities, to be partners in research, and to develop dissemination strategies for research relevant to their needs. PCORI should also create incentives for researchers to pursue research topics that patients and providers identify as useful to their health care decision-making.
2. PCORI should establish meaningful, specific national research priorities, and “enter into contracts for the management of funding and conduct of research” per its authorizing statute, thus continuing to shift away from the investigator-initiated research model.
3. Advisory panels were authorized by Congress as “expert advisory panels” including “representatives of practicing and research clinicians, patients...” and others. Therefore, PCORI should create expert advisory panels that have a depth of expertise on the specific topic that will be developed into a targeted funding announcement to ensure that the resulting research is useful to patients and their providers.
4. PCORI’s Methodology Committee should focus its work on the activities mandated by its authorizing statute, to develop methodological standards for research and a translation table.
5. PCORI should continue its efforts to develop improved strategies for dissemination and communication of research findings, in consultation with patients, providers and other stakeholders. In addition, AHRQ should collaborate closely with PCORI to develop and adopt strategies for dissemination that meet the statute’s patient-centered mandate for disseminating PCORI research findings.
6. PCORI should adopt an evaluation model that looks critically at the impact of PCORI’s stakeholder engagement and other activities on its mission to be truly patient-centered. PCORI should also develop criteria for self-evaluation consistent with the measures for success defined by its statute for the five-year review of PCORI by the Comptroller General.