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Need for greater patient and clinician involvement in comparative clinical effectiveness research

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More involvement by patients, clinicians and others in the health care community in developing comparative clinical effectiveness research studies will make such studies far more useful in clinical decision-making, according to the Patient-Centered Outcomes Research Institute, in an article published in the April 18 issue of *JAMA*, a theme issue on comparative effectiveness research.

Anne C. Beal, M.D., M.P.H., of the Patient-Centered Outcomes Research Institute (PCORI), Washington, D.C., presented the article at a *JAMA* media briefing at the National Press Club.

The Patient Protection and Affordable Care Act of 2010 created PCORI to fund and promote comparative clinical effectiveness research (CER) that will "assist patients, clinicians, purchasers, and policymakers in making informed health decisions by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis," according to information in the article.

The institute developed a definition of patient-centered outcomes research that emphasizes the voice of the patient in assessing health care options. "The PCORI mission statement commits to producing and promoting high-integrity research that is 'guided by patients, caregivers, and the broader healthcare community.' The institute's first funding announcement solicited projects focused on methods for engaging patients and other stakeholders in all aspects of the research process," Dr. Beal and colleagues write. There have been more than 800 responses to this announcement, with merit review currently being conducted. The process has been modified in 2 ways: 1) stakeholders, including patients, caregivers, and clinicians, were invited via the PCORI website to sign up if they were interested in participating in the merit reviews; 2) proposed scoring criteria included an additional criterion - extent of patient engagement.

The founding legislation required PCORI to develop national priorities for research and a research agenda, and to post both for a 45- to 60-day public comment period before major funding for research could begin. The development process extended from July to December 2011, and included examination of other recent prioritization efforts and input received through discussions with stakeholder groups, including patients and their caregivers, clinicians, hospitals and health care systems, payers, the life sciences industry, and the research community. The process produced 5 national priorities, which are: 1) assessment of options for prevention, diagnosis, and treatment; 2) improving health care systems; 3) dissemination and communications research; 4) addressing disparities; and 5) accelerating patient-centered outcomes research and methodology. "The national priorities encompass many research areas cited by earlier priority-setting groups, but add a patient-centered perspective," the authors note.

According to the authors, transparency is a key principle for PCORI, and the public comment period included collection of input through an online survey, discussion with individuals through focus groups conducted throughout the United States, and a national dialogue event and webcast midway through the comment period. Analysis of this input and resulting revisions to the priorities and agenda are under way and the initial funding announcements are expected in May 2012. "Applicants will be instructed to explain how their proposed research aligns with the statutory criteria and to describe how patients and other stakeholders will be engaged in and benefit from the research. The initial portfolio of funded research is expected to cover a range of conditions and interventions, to be exemplary of stakeholder-engaged research, and to be highly aligned with the criteria."

"The proposition that greater involvement of patients, clinicians, and others in the research process could help reorient the clinical research enterprise, reduce clinical uncertainty, and speed adoption of meaningful findings holds great promise, but remains to be tested. PCORI will test this hypothesis. The underlying imperative is to improve patients' care experience, decision making, and health outcomes. Patients as well as the physicians and other health care professionals who care for and about them are invited and encouraged to join in this effort," the authors conclude.

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