



PIPC's 6th Annual Forum

CER in the Real World: The Value of Patient-Centered Outcomes Research

December 3, 2015

INTRODUCTION

Today, at the Reserve Officers Association in Washington, D.C., the Partnership to Improve Patient Care (PIPC) hosted a forum for experts to discuss patient-centered research and the role of the Patient-Centered Outcomes Research Institute (PCORI) in the health care system. The discussion was divided into two panels, with the first focusing on PCORI's legislative history in relation to patient-centeredness and the second concentrating on the role of dissemination in engaging patients. The panels consisted of representatives from patient advocacy groups, former Senate staffers, and an official from PCORI, with PIPC Chairman Tony Coelho acting as moderator.

PANELISTS

- **The Honorable Tony Coelho**, Chairman, PIPC (Moderator)
- **Ms. Sarah Kuehl Egge**, Senior Manager, Washington Counsel Ernst and Young (Democrat, formerly with Senate Budget Committee)
- **Mr. Mark Hayes**, Principal, Hayes Health Policy Strategies (Republican, formerly with Senate Finance Committee)
- **Ms. Jean Slutsky**, Chief Engagement and Dissemination Officer, PCORI
- **Ms. Linda House**, President and CEO, Cancer Support Community
- **Mr. Andrew Sperling**, Director of Federal Affairs, National Alliance on Mental Illness

OPENING REMARKS

PIPC Chairman Tony Coelho provided opening remarks for the event, noting a "renewed interest" in comparative effectiveness research (CER) and the work of PCORI. He explained that researchers need to keep in mind the methods of how information could be disseminated to patients and empower their voices. In this light, Coelho discussed research that was "different than traditional CER," in both the topics of study and how research conclusions are communicated to clinicians and the public. He concluded that the movement towards patient-centeredness has been transformative and now needs to move towards "patient-directed research."

PANEL 1: PCORI'S ORIGINS AND IMPACT ON PATIENT-CENTEREDNESS IN RESEARCH

Mark Hayes and Sarah Kuehl Egge, who both served as Senate staff when PCORI was negotiated in Congress as a part of the Affordable Care Act (ACA) discussed what they envisioned for the research institute at that time and how closely PCORI has followed congressional intent. Highlights of the conversation include:

- **PCORI's Bipartisan Origin** – Both Hayes and Egge emphasized the early “bipartisan support” for an independent institute such as PCORI to complete patient-centered research and “inform clinical, patient, and payer decisionmaking.” Hayes added that from the beginning, PCORI was “not about cost-effectiveness.” Hayes and Egge asserted that a contentious issue was how to establish funding for PCORI, which could have been challenging due to possible “political interference” with the annual appropriations process. Therefore, a sustainable funding stream from insurance plans was constructed for the PCORI Trust Fund. Hayes harkened back to the bipartisan Medicare Modernization Act (MMA) and the creation of the Effective Health Care Program by Section 1013 as the early beginnings of discussions about “patient-centered” research.
- **Including Patients in the Process** – Coelho noted that in the early implementation of PCORI “patients were not really part of the process at first,” with both panelists agreeing with that observation. Egge added that PCORI’s increasing focus on bringing patients into the research process is “what we [Congress] imagined all along.” Hayes concurred, saying that the “intent is clear in the [PCORI’s] name itself.”

Both panelists also lauded PCORI’s role in moving patients to the center of the research process. Hayes noted its importance in defining what “patient-centeredness” truly means in a research setting, but added that there is work to be done as the health system still “measures a lot of things that don’t matter to the patient.” However, according to the panelists, the overall change in research has been very positive as research now looks at patient outcomes upon discharge from the hospital setting. Coelho agreed with this characterization saying that PCORI and patient-centeredness have created a “whole new approach” to health care that many have not understood or appreciated when legislated.

- **Importance of Stakeholder Input** – An audience member asked about patient input into research when there is no consensus among patient groups about the best way to approach a disease. Egge responded that PCORI was designed as a “consensus-based organization,” which can present challenges when there is a divide in the patient and stakeholder community. Hayes added that there “must be relevance for both clinical types and the patients,” with past research directed almost entirely by researchers rather than patients.

PANEL 2: PCORI RESEARCH AND DISSEMINATION

Two representatives of patient advocacy groups, Linda House of the Cancer Support Community and Andrew Sperling of the National Alliance on Mental Illness, discussed PCORI research priorities and its ability to disseminate findings to patients with PCORI Chief Engagement Officer Jean Slutsky. Highlights of the discussion include:

- **PCORI's Efforts in Dissemination of Research** – Sperling touted that PCORI has a significant contingent of staff dedicated to patient engagement, stating, “no NIH [National Institutes of Health] institute has anything like this.” He added that research “has to get down to the level of the individual clinician,” and that the future of patient-centered research will be tied to dissemination. For her part, Slutsky explained that results from studies will be coming online within 9 months and that PCORI is investigating “how to best communicate certainty about findings.” House amplified the need to identify value to the patient and outcomes that matter to patients to drive improve health decisions. House also emphasized the need to advance “patient-directed” care with patient-centered outcomes research.
- **Recognizing Disparities in Research** – An audience member asked about setting research priorities for minorities, particularly in terms of dissemination. Slutsky responded that the PCORI Board had made addressing disparities a priority, including in dissemination. She noted that the barriers in dissemination included not only different languages, but also unfamiliarity with numbers, i.e. numeracy. Slutsky finally noted that to address the problem, PCORI was working on using pictures and reverse translation to accurately convey research findings.
- **Resources to Empower Patients to Engage in Research, Policy and Advocacy** – A question from the audience focused on PCORI’s role in promoting patient advocacy, with Slutsky answering that the institute does not provide resources for advocacy, but does offer support. She was quick to point out PCORI’s Pipeline to Proposals initiative as a way to promote patients to participate in patient-centered research. Sperling agreed with PCORI’s approach, saying that the best way for patients to participate in research was to “engage with PCORI.” While recognizing PCORI’s progress toward patient-centeredness, House noted that community organizations are ideally situated to conduct patient-centered outcomes research, and would like to partner with PCORI, but are challenged by the cumbersome application process. House urged for PCORI to establish more community-based research opportunities outside of academia.

CLOSING REMARKS

Chairman Coelho closed the meeting by noting that culture change is not easy, something he experienced firsthand in passing the Americans with Disabilities Act, which just had its 25th anniversary. PIPC advocated strongly for PCORI’s creation because its members recognized the need for a stronger patient voice in research so that our needs are supported by the healthcare system. He emphasized that no patient is average and, therefore, quality and value should be based on achieving the outcomes that matter to patients. He ended by praising PCORI’s work and calling on stakeholders and policymakers to advocate for and advance patient-centered policies in health care.