



PIPC

Partnership to
Improve Patient Care

PIPC remarks for PCORI Meeting Tuesday, November 23, 2010

My name is Katie Orrico, the Washington Director for the American Association of Neurological Surgeons, and as a Steering Committee member of the Partnership to Improve Patient Care (PIPC) I am pleased to speak today on behalf of the PIPC, a coalition of more than 40 patient, provider, and other organizations who have joined together in support of patient centered CER. PIPC was a strong supporter of the Affordable Care Act's provisions on comparative clinical effectiveness research. Our members are enthusiastic about the opportunity now before the Patient-Centered Outcomes Research Institute (PCORI) to advance a research agenda that is centered on the needs of patients and their care providers.

I am speaking today in place of PIPC's Chairman, Congressman Tony Coelho, and my remarks borrow heavily from the article he authored in the October issue of Health Affairs. As Mr. Coelho stated in this article, we are excited about the opportunity before us because, "Correctly implemented, the comparative effectiveness research provisions in the Affordable Care Act can go a long way toward addressing the inadequacies of health care delivery and answering the research questions that matter most to patients and providers.

PIPC applauds your leadership and supports your vision for a CER research program that is sustained, significant, objective and patient-centered. As you move forward to achieve the goal of patient-centered outcomes research, we ask that you consider the following important elements:

1) Transparency and Opportunities for Input

PIPC is very appreciative of today's opportunity to attend this initial meeting of the PCORI Board of Governors and provide comments for your consideration. As described in the health reform law, providing a high degree of openness and transparency in the work of PCORI is important to ensuring the program addresses the research needs of patients and providers. PIPC strongly supports provisions ensuring openness and transparency and providing opportunities for comment on issues such as draft research priorities and reports. It is important to engage the broader community in all aspects of PCORI's decision-making, not just share decisions after they are made.

Although the statute is explicit about some of the requirements for openness and transparency, it leaves it up to the Board to define and implement many of the details. PIPC last week released a white paper describing a "Procedural Framework for the Conduct of Comparative Effectiveness Research" that identifies many of the important process issues that must be addressed. We hope this document proves valuable to you as you begin your work.

2) Stakeholder Engagement

One of the major reasons PIPC strongly supports the health reform law's CER provisions is that they provide meaningful stakeholder engagement throughout the process. As noted by Tony Coelho in his

Health Affairs article, bias in health care can come from any stakeholder, be it insurance companies, manufacturers, public payers, or providers. The Affordable Care Act “recognizes this and brings all stakeholders together in support of a common bias in favor of the patient.”

Allowing for adequate, equal, and broad stakeholder representation throughout PCORI’s research priority setting process, on the Institute’s advisory and ad hoc panels, and in the development of guidelines and protocols for dissemination of research results will help encourage patient and provider confidence in PCORI, and could foster more rapid adoption and use of research results.

Recognizing Individual Patient Differences

A concern about CER that was frequently raised throughout the health care reform debate, was that CER would obscure important differences between individual patients and patient subgroups. When CER is designed and applied in ways that are based on population averages, this can and does occur. PIPC is pleased that the health reform law recognizes and addresses this by calling for a recognition of differences in patient needs and preferences in the design of studies and communication of results. In addition, the law recognizes the growing importance of genomic science in helping explain differences in patient response to treatment. Including genetic and molecular subtypes in research populations will help advance our ability to tailor care to the needs of the individual.

PIPC stands ready to serve as a partner and resource for the PCORI Board of Governors as you work to establish this important new program in the coming months. To that end PIPC recently released an inventory of government funded comparative effectiveness research, via the website www.cerinventory.org. We hope the information contained in the inventory can help inform PCORI’s work moving forward.

PIPC appreciates the opportunity to comment today, and recognizes the commitment by the PCORI board to define strong procedures for operations and governance so that patient centered CER can truly be realized.

The Partnership to Improve Patient Care (PIPC) is a diverse group of healthcare organization representing patients, physicians and other health care providers, researchers and innovators, and other groups that have come together to promote comparative effectiveness research that supports patient access and informed health care decision-making and fosters continued medical progress. Visit us online at improvepatientcare.org