

**PIPC White Paper on “Road Map for Prioritizing Research”**

**Executive Summary**

**November, 2013**

The issue of how to set priorities for comparative research and health technology assessment has long been recognized as an important one.<sup>1</sup> The statute creating the Patient-Centered Outcomes Research Institute (PCORI) also recognized this, describing specific factors and procedural considerations for defining national priorities for research.<sup>2</sup> The question of how best to define research priorities, and whether to do so by proactively identifying specific topics or issuing broader solicitations for investigator-initiated prioritization, has been an area of ongoing debate.<sup>3</sup>

Accordingly, the Partnership to Improve Patient Care (PIPC) has long advocated for PCORI to identify a clear process for defining specific research priorities,<sup>4</sup> and applauded PCORI’s recent announcements to (a) establish advisory panels to help set research priorities and (b) make more of its research funding decisions based on specific priority topics. This white paper is intended to identify key elements and serve as a high-level “road map” for PCORI’s consideration in setting specific priorities for research.

In order to change the culture of research and meet its mandate to conduct patient-centered comparative clinical effectiveness research, PCORI must develop a targeted, national research agenda through an open and transparent process. To help PCORI achieve this goal, PIPC is developing a priority-setting “road map” that:

- Calls on PCORI to establish a targeted research agenda based on a broad and structured solicitation of topics from patients and providers;

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<sup>1</sup> Donaldson MS, Sox HC, eds. *Setting Priorities for Health Technology Assessment: A Model Process*. Washington, DC: National Academy Press; (1992).

Gibson JL, Martin DK, Singer, PA. Priority setting for new technologies in medicine: A transdisciplinary study. *BMC Health Services Research* 2:14 (2002).

<sup>2</sup> Patient Protection and Affordable Care Act of 2010, §6301. Available at <[http://dpc.senate.gov/dpcissue-sen\\_health\\_care\\_bill.cfm](http://dpc.senate.gov/dpcissue-sen_health_care_bill.cfm)>

<sup>3</sup> Sox, Hal, MD. The Patient-Centered Outcomes Research Institute Should Focus On High-Impact Problems That Can Be Solved Quickly, *Health Affairs*, October 2012; Vol. 31, No. 10:2176-2182

<sup>4</sup> Priority-Setting for Comparative Effectiveness Research: A Review of Key Elements: Partnership to Improve Patient Care. Available at <[http://www.pipcpatients.org/pipc-admin/pdf/dbfe1e\\_White%20Paper.pdf](http://www.pipcpatients.org/pipc-admin/pdf/dbfe1e_White%20Paper.pdf)>

- Directs PCORI staff to evaluate and distill the suggested research topics to ensure research topics meet PCORI's mandate of patient-centeredness and the statutory criteria for research;
- Develops a rationale and topic brief for research topics to provide both the PCORI board and the public with a clear and transparent understanding of PCORI's research agenda;
- Utilizes the relevant clinical expertise (both within and beyond PCORI's advisory panels) to help rank the topic list;
- Ensures the opportunity for public comment on the draft priority list and research agenda;
- Provides for input and approval by Board of Governors; and
- Promotes transparency of the priority-setting process in its entirety.

PCORI was implemented to answer specific research questions that will have the greatest impact on informing patient and provider health care decisions and improving health outcomes. To do so, PCORI "must drive the burgeoning discipline of comparative effectiveness research forward, starting with a research project agenda that conveys a sense of urgency and strategic direction."<sup>5</sup> With a national list of specific research priorities developed from the expertise of patients and providers, PCORI will be able to conduct patient-centered comparative clinical effectiveness research that is of priority to patients and providers.

PIPC intends to continue its support for PCORI in establishing a defined, patient-centered research agenda. As PCORI shifts toward a more targeted research agenda, the best practices outlined herein are intended to be a road map to help PCORI identify more specific research topics. PIPC is committed to supporting a long-term program for patient-centered outcomes research that focuses on the needs and priorities of patients and providers. In addition to presenting PCORI with this "road map," PIPC will continue to support PCORI's efforts through our series of roundtables designed to solicit input directly from patients and providers on issues related to CER, including research prioritization and dissemination. PIPC looks forward to continuing its work with PCORI as they implement an effective priority-setting process that best supports the needs of patients and their providers.

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<sup>5</sup> Sox, Hal, MD. The Patient-Centered Outcomes Research Institute Should Focus On High-Impact Problems That Can Be Solved Quickly, *Health Affairs*, October 2012; Vol. 31, No. 10:2176-2182.