

PIPC Comments to the PCORI Board of Governors
May 5, 2014

My name is Sara van Geertruyden, and I am the Executive Director of the Partnership to Improve Patient Care. Thank you for the opportunity to provide comments. I want to first thank Sue Sheridan for her great leadership in managing the PCORI Patient Engagement Advisory Panel, which I sit on. Our last meeting was our most productive thus far, with the development of subcommittees to address issues at the early stages of PCORI's development so that our input really helps to set the course of PCORI's work. I am also looking forward to working with Jean Slutsky and thank her for participating with us in future roundtables.

My comments today will be centered around a recent roundtable that PIPC held related to PCORI's development of an Evaluation Roundtable, including members of our Steering Committee and members of the PEAP, to discuss how PCORI can and should measure their success. I very much appreciated the participation of Kristin Konopka and Suzanne Schrandt at that meeting.

The summary and recommendations coming from that roundtable are available on the PIPC website. To summarize, the roundtable group identified that PCORI has a dual role, being both a mission-oriented non-profit – the mission being patient-centeredness in research - and a research funder. It was the view of the roundtable group that PCORI's mission should be a core component of its evaluation framework to support the brand that PCORI is trying to develop – that brand being “research done differently.” An important step in developing this brand is to better define through its evaluation metrics what makes PCORI truly different from other research organizations, such as patient engagement, the use of advisory panels to prioritize research and the application of patient-centered criteria that must be included in all PCORI-funded research. This will give PCORI's brand of “research done differently” credibility.

We agreed that PCORI must use both qualitative and quantitative metrics in its evaluation framework. If “research done differently” is the brand, it is the qualitative measures that will immediately distinguish PCORI from other research organizations. Although it is vital for PCORI to conduct rigorous research to ensure it has a high quality product that leads to an enduring high quality brand, it is the mission of patient engagement in research that makes PCORI immediately different. For example, quality measures would identify “standing ovations” for PCORI's work, such as the use and replication of PCORI's engagement practices

and patient-centered programs, patient involvement to determine usefulness of research, and stakeholder perspectives on engagement in research.

Our roundtable concluded that the aspect of the Evaluation Framework focused on PCORI's patient-centered mission should have a 3-year timeline, with many of the measures being used to immediately identify PCORI's commitment to its patient-centered mission.

Although PIPC is pleased that PCORI's draft evaluation framework recognizes the value of patient engagement and usefulness of information, we hope that the draft evaluation framework will capture whether there was adequate patient and stakeholder involvement in Topic Generation and Research Prioritization (TGRP) in the broad funding announcement process as compared to the targeted process utilizing advisory panels.

I was interested to hear Dr. Krumholtz comment about identifying the “headline” for the research at the early stages of developing the research question as a means to determining its usefulness in very practical terms. This is a view very consistent with our roundtable discussion. I would argue that the “headline” to which you refer is really driven by the patients and providers that will either use – or not use – the research findings at the point of care. Therefore, this point underscores even more the importance of engaging patients and providers in determining the *usefulness* of potential research questions early in the process of topic development and research design. Related to dissemination, it also concerns me that I often encounter patient and provider groups that are not aware of the research PCORI is already funding that targets populations they serve simply because they are not stakeholder partners in the individual project. Although this is a natural consequence of a broad funding announcement process, we hope that the Dissemination and Implementation Action Plan provides PCORI with guidance to address this issue. PIPC has consistently recommended that PCORI engage those groups that will be integral to dissemination of specific projects at the front end of the research so that there is an eagerness and demand for the research findings. Patient and provider engagement will ensure the research is disseminated in a manner that is useful and is therefore more likely to be actually be used. This all gets at closing the should/would gap discussed in the earlier conversation.

In closing, PIPC is pleased to see the transition to targeted funding announcements and meaningful engagement of advisory panels. Thank you for considering our recommendations and thank you for this opportunity to comment.