Advisory Panel on Patient Engagement Meeting Summary

October 2015

Overview

The Advisory Panel on Patient Engagement held its fall meeting on October 26 and 27, 2015 in Washington, DC.

Reflections on the PCORI Annual Meeting

Darius Tandon, Co-chair of the panel, shared some reflections from the first PCORI Annual Meeting. He explained that the annual meeting gave a high-level overview of PCORI's work and generated informal conversations among participants on how PCORI has helped research teams galvanize their work.

Tandon encouraged the collection of evidence to be disseminated to those who need to be informed of PCORI's work. He would like a crisp soundbite to share that explains how PCORI and others can disseminate the research. Tandon and other panelists felt, however, that what the meeting lacked was granularity for topics such as the rubric, and how it can fit into researchers' work.

Refinement of Engagement Strategy/Pragmatic Clinical Studies and Targeted Studies

Jean Slutsky, Chief Engagement and Dissemination Officer, gave an overview of the Pragmatic Clinical Studies (PCS), a relatively new area of focus at PCORI. The first PCS funding announcement was February 2014.

Related Information

- About this Advisory Panel
- Meeting Details and Materials
- PCORI Engagement Program

The Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created to help people make informed healthcare decisions.

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Update from Joe Selby

Dr. Joe Selby, Executive Director, explained how PCORI's research is evolving toward a greater focus on more intensive engagement. The first studies funded by PCORI were the Broad funding announcements. Later, targeted funding announcements were introduced, and now PCORI is focusing on the Pragmatic Clinical Studies. Dr. Selby went on to highlight the importance of engagement in the PCS and Targeted studies to ensure that comparisons and outcomes are either determined by or vetted and supported by the patient and caregiver community.

Meaningful Engagement with Patient/Caregiver Organizations as Key Partners in PCS and Targeted Studies

The PCORI Engagement Officers shared some examples of promising engagement practices in PCS and Targeted studies that engaged patients, caregivers, and patient/caregiver organizations. The panel viewed the studies' governance structures and promising engagement practices in the research process.

The panel then discussed key questions to address to ensure meaningful engagement in research when the patient partner in a PCS or Targeted study is a patient/caregiver organization. Questions included:

- *What infrastructure is already available in patient/caregiver organizations for these approaches/activities to engage with PCORI and the research community?*
- *What approaches and activities would need to be adapted for patients/caregiver organizations? What is PCORI's role?*
- *Where are the gaps that could create barriers to patient/caregiver organizations participating in this phase of research? What can PCORI do to close these gaps?*

Stakeholder Surveys

Lauren Fayish presented results from the Engagement and Evaluation team's stakeholder surveys. The main objective of the stakeholder surveys was to inform methods to facilitate the use of CER and the engagement of patients and stakeholders in research.

The survey found that patient and caregiver views on engagement in research indicated that familiarity with research engagement is high. In particular, there is low interest and high engagement for translating results and sharing findings. The results also indicated that for patients and caregivers, key facilitators of research partnership were a belief that participation in research can result in meaningful findings, feeling respected by researchers, and having an interest in research.

Clinicians and researchers also saw value in partnership to improve research. In the survey of researcher interest in engagement, the respondents were knowledgeable about PCORI and familiar with CER. The majority of researchers were interested in partnering with patients and caregivers in their research. The results of these surveys indicate that there is interest among patients, clinicians, and researchers in partnering to improve engagement in research.

Patient-Focused Benefit-Risk: Drugs and Medical Devices

Bennet Levitan guided the panel through the work of the Medical Device Innovation Consortium (MDIC) and how it came into existence. Levitan is a panelist and senior director of epidemiology at Janssen R&D, as well as a member of the steering committee at the MDIC. Levitan explained patient choices for migraine medicine and maximum acceptable risk. What MDIC evaluations found is that patients accept a large amount of risky side effects for migraine medicine that works. The MDIC study provided data, not just anecdotes on patient preference. Levitan summarized his presentation by explaining that preference studies don't always cause clinicians to agree with patients, but they do help to understand where the other is coming from.

Training Update

Erica Sarnes, Training Manager, updated the panel on the Team Science Training Initiative. PCORI has convened a workgroup made up of Engagement and Science team members to develop an RFP. A clear finding of this workgroup is that the team is very interested in metrics and measuring the performance of PCORI research teams.

Sarnes explained that PCORI recognizes that it is has collected a lot of data and will start methodically studying research team activities and successes. While the initiative is still in the infancy stage, Sarnes shared how its ideas came together and how, moving forward, the panel can influence PCORI as well as the larger healthcare industry.

The panelists emphasized that trainings should not be one-size-fits-all. Sarnes explained that one of the goals of Team Science is to create trainings that are suitable for diverse groups of individuals. Panelists also expressed interest in seeing the training curriculum, particularly around helping patient partners feel confident enough to engage in scientific dialogue related to the design of studies. Panelists will be involved in the Team Science Training Initiative as a subgroup of the panel.

Toolkit Discussion

During the breakout groups and discussion around pragmatics in Engagement and Analysis, the panel heard that there is great interest but low know-how around how to implement engagement in research. To help with creating some practical tools for engagement in research, while also leveraging tools that already exist, the panel will form a toolkit subcommittee. This group will assist and guide the prioritization of tools that should be produced and their ability to meet the needs of all audiences that PCORI wants to reach.

The Patient Engagement team has created a draft charter and tasks that explain how the subcommittee will assist PCORI. The subcommittee will be formed in addition to the Team Science Training Initiative. The Engagement team will soon hold a webinar with the panel to continue the toolkit subcommittee conversation.

Pipeline to Proposal and Ambassador Program Updates

Courtney Clyatt, Senior Program Officer, updated the panel on Pipeline to Proposal (P2P) activities. The program is now extended throughout the country, with 1.8 million awarded throughout all cycles. The Patient Engagement team works closely with the PCORI Evaluation team to monitor and evaluate the program. The panelists suggested that PCORI send emails to successful applicants to encourage them to apply for the P2P program.

Suzanne Schrandt, Deputy Director of Patient Engagement, updated the panel on the Ambassador program, and there was discussion about a new monthly Ambassador newsletter. It was also shared that Aingyea Kellom, original lead of the Ambassador Program, has moved on to a new job.

Engagement Awards Update

Lia Hotchkiss, Engagement Awards Director, provided an Engagement Awards program update. Hotchkiss shared data on applications from and awards to patient organizations and listed some common reasons for declined applications. Hotchkiss highlighted a few projects from each funding cycle. She explained that the program has worked with unsuccessful applicants to help them submit stronger applications in the future. Many groups have gone on to resubmit, and a few have ultimately been successful. In 2016, the program plans to provide greater transparency into projects and teams, develop and implement strategy for reviewing and sharing work products, and hold a webinar. The next Engagement Award application reviews will be held in February and October 2016.

Wrap-Up and Reflections

In concluding the meeting, panelists discussed what they would like to see result from the meeting:

- Contribute to the conversation around dissemination that is happening at PCORI
- Gain clarity on how PCORI sees the role of the Ambassadors
- A mechanism to foster pipeline to PPRNs because there is an interest in patient community for patient registries
- An update on what can be learned about engagement from PPRN
- Leverage what already exists in training, toolkit, etc., instead of reinventing the wheel
- Matching patients to their providers
- Update on WE-ENACT data

The winter Advisory Panel on Patient Engagement meeting was cancelled due to snowstorms. The next panel meeting will be held April 11, 2016.