Advisory Panel on Patient Engagement Meeting Summary

October 2014

Overview

The Advisory Panel on Patient Engagement met on October 1 and 2 to review and advise on PCORI Engagement programs, address new issues emerging in engagement, and to learn about new funding strategies in the scientific program areas.

Two new members were welcomed to the panel, Amy Kratchman, from The Children's Hospital of Philadelphia (CHOP) and Kim McCleary from FasterCures. The panel discussed the progress of the Ambassador Program, focusing on how to increase the participation of patient organizations; the Pipeline to Proposals Program and its national expansion; the Engagement Officer role and measures of success and patient engagement in PCORnet.

The panel learned about the WE-ENACT tool, and how their recommendations for evaluation measures were incorporated into the tool, and the Compensation Subcommittee presented a refined draft of the *PCORI Statement on Compensation Fairness for Patients, Caregivers, and Patient/Caregiver Organizations Engaged in PCOR.*

The Advisory Panel meeting concluded with a discussion on patient privacy, patient participation on Data and Safety Monitoring Boards (DSMB), and a request to the panel to submit topics for the next meeting. A specific focus will be on topics related to how engagement is making a difference.

Related Information

- About This Advisory Panel
- Meeting Details and Materials

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

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Rubric/Engagement Officers

The first session was led by Sue Sheridan, the Director of Patient Engagement. Sue explained the ways in which the rubric is being refined and updated. She explained that the Patient and Family Engagement Rubric has evolved into the Engagement Rubric that now includes examples of other stakeholder engagement. The goal is to publish and disseminate the rubric for public use, so that it may be used not only by researchers, but by patients and other stakeholders involved in research. The revised rubric is embedded in the latest PCORI Funding Announcement and is used in merit review to determine successful proposals. The panel encouraged PCORI to communicate with applicants who were not funded to tell them how they can improve the engagement component of their application by using the rubric. The panel also recommended that PCORI no longer post examples of Engagement Plans on the PCORI website, so as to strengthen the creativity of applications.

PCORI's Engagement Officers Kimberly Bailey, Jaye Bea Smalley, and the Addressing Disparities Program Officer, Ayodola Anise, then gave an update on their projects. Kim gave an overview of some day-to-day activities of an Engagement Officer (EO) that include bridging Science and Engagement in PCORI, ensuring meaningful engagement in the research that PCORI funds through monitoring and support, and sharing lessons learned within PCORI and with the public. Jaye Bea shared an update on patient engagement in PCORnet and her role as an EO to assure robust patient engagement in the development of a patient-centered data research network. Ayodola introduced the panel to PCORI's Evidence to Action Networks, which are learning networks with more engagement of end users. Ayodola also discussed how patient and stakeholder engagement is being carried out in the asthma projects funded by the Addressing Disparities program.

WE-ENACT Tool

Evaluation was discussed with Laura Forsythe and Kristen Konopka leading the session. PCORI developed a tool entitled the WE-ENACT (Ways of Engaging - ENgagement ACtivity Tool). PCORI researchers and their patient and stakeholder partners will fill out the tool once a year to help PCORI describe engagement in PCORI research projects and to measure its impact. The panel learned that the Subcommittee on Evaluation's recommendations for evaluation activities from the April in-person panel meeting were incorporated in the creation of the WE-ENACT tool. These proposals included suggested language, tools to track the impact of how PCORI funds "research done differently," and the collection of feedback of external stakeholder communities on their attitudes about PCORI and its work.

Introduction to Pragmatic Studies

The panel learned about the Pragmatic Studies program in a session led by Dr. Stanley Ip and Dr. David Hickam, from the Comparative Effectiveness Research program at PCORI. They explained that Pragmatic Clinical Effectiveness Research studies answer practical, real-world comparative effectiveness research questions that are important to patients and decision makers. The panel asked which measures, such as the Engagement Rubric, will be used to follow the progress of the Pragmatic Studies. They learned that the Engagement Officers will be supporting and managing the engagement in each study. The panel agreed that there is a real need for funding this type of study. They concurred that this program likely will have an important impact.

Pipeline to Proposals Program Update

Courtney Clyatt, Senior Program Associate, gave an update on the Pipeline to Proposals and Pipeline Evaluation, providing various examples of the partnerships developing in the Western Region Pipelines Pilot Project. She also shared that successful Pilot Awardees will transition to Tier II upon demonstration of achievement of milestones instead of having to go through a competitive process as originally planned. The national expansion of the program, including Pipeline Program Offices in all four regions as well as a national program office, was shared. The program is expected to be announced nationally by November 17, 2014.

Ambassador Program Update

The Advisory Panel members were provided with a general Ambassador Program update, including an introduction of new staff members, how the launch of the new website has enhanced the program web page, changes to the Ambassador Training, and demographics of current program participants.

Findings from the mid-point survey and future evaluation efforts, such as targeted interviews, were shared with the Ambassadors.

Staff from the FDA, Michael J. Fox Foundation, and COPD Foundation joined as guest panelists for the "Why build a networked community?" discussion. There was a discussion on how to keep volunteers engaged, the opportunities and challenges for a network, and fostering research partnerships.

The session concluded with a breakout section where the advisory panel members provided staff with suggestions on how to grow, add value, and build collaboration efforts in the Ambassador Program. Panel members expressed an interest in opening the program to the public, involving currently funded PCORI projects, enhancing the current tool kit, and additional activities and trainings.

Q&A Session with Dr. Joe Selby

On the second day of the meeting, Dr. Joe Selby, PCORI's Executive Director, attended for a question and answer session. He informed the panel that PCORI is now funding larger studies, which are focused on high-priority topics. The panel inquired into the areas and topics that will be funded. Dr. Selby pointed out the various priority topics included in the Large Pragmatic Studies funding announcement and explained that PCORI will provide ongoing support on rare disease studies and will continue to spread the word about PCORI in underserved and rural areas.

Compensation Framework

The Subcommittee on Compensation presented their draft Compensation Framework to the panel, which they had refined since the April meeting. Their goal in creating the framework is to help create equity within the research team and to broadly define compensation terminology and concepts. The subcommittee was cautious not to suggest a fixed “rate” for patient partners participating in research. However, the subcommittee recommended that a research team should have a dialogue about compensation with patient and other stakeholder partners early in the process to ensure partnership and equity. The panel supported the inclusion of an “opt-out” option for those who do not wish to be compensated; however, the panel suggested that a statement be included in the framework reflecting the value of patient and other stakeholder expertise. The Subcommittee on Compensation plans to move forward with editing a draft and incorporating the feedback from the panel.

Update on PCORnet

The Patient Engagement Advisory Panelist and PCORnet Patient Council member Lorraine Johnson gave the panel an update on the council's work on the privacy policy. Jaye Bea Smalley, Engagement Officer, updated the panel on the Greater Plains Collaborative CDRN site visit during their learning engagement kickoff.

Privacy/Data and Safety Monitoring Board/Institutional Review Board

The Advisory Panel had a brief discussion led by Suzanne Schrandt, Deputy Director of Patient Engagement, about several topics related to human subject protection in research. The conversation included topics such as data privacy, privacy and confidentiality of information of patient partners in research, the distinction between patient partners and patient subjects or participants in research, the role and function of Data Safety Monitoring Boards, and the concept of lay or patient involvement on such boards. The panel also discussed the need for training for patients and researchers involved in patient-centered, patient-engaged research. Members of the panel offered several ideas for online training modules and volunteered to be involved in future discussions about human subject protection related to PCOR. As this was a very brief and high-level introductory conversation about these varied issues, no specific action items or next steps were identified.

Next Steps

The meeting concluded with a request to the panel to submit topics for the next meeting. A specific focus will be on topics related to how engagement is making a difference. Topic suggestions can be sent to Rachel Melo at rmelo@pcori.org.