



Advisory Panel on Patient Engagement Meeting Summary

October 2016

Overview

During the Fall Advisory Panel on Patient Engagement meeting, eight new panelists were welcomed who had been approved by the PCORI Board over the summer. The meeting began with a speed mentoring session for the new panelists. Each of the new panelists met with representatives from the Engagement team to get to know each other and learn about Engagement at PCORI. New panelists include John Chernesky, Emily Creek, Libby Hoy, Megan Lewis, Suzanne Madison, Ting Pun, Jack Westfall, and Dave White.

Later in the morning, the full panel joined the new panelists. New Engagement staff were introduced from the Dissemination and Implementation team, including new Program Officer Chris Gayer, and Program Associates Arielle Gorstein. New Engagement Merit Review Program Associate Whitney McInvale recently joined the team. Additionally, two National Urban Fellows have joined, Tania Guaman and Jacqueline Gannon. Sue Sheridan bid the panel a heartfelt farewell, as she will return to her roots of patient safety and quality care.

Evaluation Update

Laura Forsythe gave an update on Evaluation at PCORI. The Evaluation and Analysis Team incorporated PEAP feedback elicited at the previous advisory panel meeting regarding the PCORI Evaluation Framework. For example, the evaluation framework graphics were revised to more clearly illustrate the expected impacts of engagement in research. This was directly related to the panelists' suggestion to simplify the graphic. Also, the Evaluation Team incorporated the panelists recommendation regarding

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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PCORI's tracking of its influence on others to be more patient-centered and expanded the tracking to include aspects of the healthcare sector beyond research. Laura also provided an update on learnings from awardees and partners regarding engagement in research. Findings demonstrate that engagement has affected PCORI study questions, research processes, design, and outcomes selected. Further, partners report their engagement has other effects on their lives, such as developing new relationships and better managing one's personal health. Findings also provide examples of the PCORI principles in action in PCORI funded studies.

Dissemination Opportunities at PCORI

The Advisory Panel on Patient Engagement (PEAP) was joined by the Advisory Panel on Communication and Dissemination Research (CDR) for an afternoon session. The two panels heard presentations from Lia Hotchkiss, Director of the Eugene Washington Engagement Awards Program, Chris Gayer, Program Officer with the Dissemination and Implementation Program, and William Lawrence, Senior Program Officer with the Communication and Dissemination Research team. Chris Gayer explained how PCORI's authorizing legislation recognized the gap between optimized healthcare delivery and implementation in everyday practice as well as the length of time it takes for new evidence from clinical research to influence healthcare. Chris overviewed some Dissemination and Implementation D&I Activities at PCORI such as capacity building, which the Engagement Awards and CDR programs fall under. Under the initial dissemination falls the Limited Competition D&I Awards.

After learning about each program, both PEAP and CDR panelists discussed ways to approach collaboration. The chairs agreed that they would like to meet to discuss the agenda of both programs, as there is synergy between the panels. Panelists suggested that during meetings we try to move away from jargon and acronyms as much as possible, in order to promote equal communication.

Rethinking Pipeline to Proposals

Courtney Clyatt led a discussion to garner feedback from the panel on the Pipeline to Proposals (P2P) program, an initiative aimed at building a national PCOR community of patients, stakeholders and researchers. She asked the following questions:

- Are the overarching goals of the P2P still relevant?
- Are the P2P near term goals of developing PCOR capacity (as defined in our evaluation framework) still a priority for PCORI?
- What more do we need to know to determine the ideal structure of Pipelines going forward (i.e.: Are all three tiers valuable/necessary)?
- Is our current evaluation framework providing PCORI with the relevant information to determine "success" based on the P2P goals?
- What are the options for the structure of P2P going forward?

The panel suggested that Tier I and II should be combined, as the awardees do not need so much time for community building. They recommended that support groups may be a way to engage people quickly so that the awardees can then move on to Tier III.

PEAPs in Action

Towards the end of the meeting, several panelists presented their individual work related to patient engagement. The presentations from panelists included the following:

- Regina Greer-Smith - Pastors4PCOR, a PCORI-funded Eugene Washington Engagement Award
- Anjum Khurshid – A patient-centered story-telling app for complex needs children
- John Chernesky – Rick Hansen Institute- Spinal cord injury
- Lorraine Johnson - Lyme Disease.org activities
- Megan Lewis - RTI International's consolidated model of patient engagement
- Jack Westfall - High Plains Research Network

Slides from this meeting can be found on the event page. The next panel meeting will be held in Spring, 2017, date to be determined.