

# Advisory Panel on Patient Engagement (PEAP) Meeting Summary

## Overview

The Advisory Panel on Patient Engagement convened for a Spring meeting in Washington, DC on April 19<sup>th</sup> and 20<sup>th</sup>, 2018. The meeting began with a warm welcome from co-chairs Jane Perlmutter and David White. The first public session of the day was presented by Kristin Carman, Director of Public and Patient Engagement. She provided an overview of the Public and Patient Engagement Department priorities and key upcoming activities and projects. Then Marina Broitman, Senior Program Officer, explained the Peer Review process at PCORI.

Laura Forsythe, Director of Evaluation and Analysis, presented a new PEAP working committee, Literature Review of Engagement in PCORI-Funded CER, and welcomed panelist participation.

After lunch, a special guest joined the group, Maureen Maurer, Principal Researcher at American Institutes of Research. She presented a project contracted by PCORI that will expand upon the existing PCORI efforts to understand the influence of engagement on funded projects' processes and outcomes by interviewing awardees and partners directly.

The first day concluded with brief introductions by each of the panel working committees: Engagement Rubric 2.0, Ambassadors Program, and Merit Review Mentor Program. Panelists were invited to stay for working committee breakout sessions for the Rubric 2.0 and Ambassadors.

The second day resumed discussions with a welcome from Dr. Joe Selby, PCORI's Executive Director. He then presented awards to the eight panelists who transitioned off the panel: Jane Perlmutter (chair), Anjum Khurshid, Bennett Levitan, Jimmy Lin, Mark Mishra, Philip Posner, Ronnie Todaro, and Libby Hoy. These panelists served PCORI for 2-3 years and provided important insights throughout their tenure.

## 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.

1828 L St., NW, Suite 900  
Washington, DC 20036  
Phone: (202) 827-7700  
Fax: (202) 355-9558  
Email: [info@pcori.org](mailto:info@pcori.org)  
Follow us on Twitter: @PCORI

The two working committees that met the previous day reported back to the group with a summary of their discussions. Then panelist Tom Scheid presented a series of meetings held in his home state of Ohio with the support of PCORI. Lia Hotchkiss, Eugene Washington Engagement Award Program Director, explained new ways that the program is funding dissemination initiatives. The closing session was led by Elisabeth Truong, a senior adviser with the Centers for Medicare/Medicaid. Ms. Truong detailed the collaborative work between CMS and PCORI. The second day concluded with comments from Jane Perlmutter and Dave White.

## Public and Patient Engagement: Key Initiative

**Dr. Kristin Carman, Director of Public and Patient Engagement**, provided an overview of her team's work and upcoming activities. Public and Patient Engagement at PCORI supports activities such as the Science of Engagement, Engagement Officer integration into PCORI's work, and Stakeholder engagement.

The work around Science of Engagement is focused on building upon our current understanding of the effects of engagement in health research and providing guidance to the field. The literature review and portfolio analysis is key to this work, which was later detailed in an afternoon session. Cultivating receptor sites will contribute to this activity.

Engagement Officer integration will help Project Officers guide and support their engagement activities in PCORI-funded research. Panelist Libby Hoy asked if the Engagement Officers will speak with patients and families in research studies. Carman explained that the updated workflow analysis allows the Engagement Officer to be more proactive in identifying challenges. The team plans to create more tools and evidence to help all research partners think about maximizing their contribution to make an impact on research processes and outcomes. Panelist Anjum Khurshid asked how health equity is integrated into the strategy. Carman noted that health equity will be a major focal point of the Team Science Training initiative.

Activities in the stakeholder engagement arm of the Public and Patient Engagement Department are ramping up this year. Roundtables, forums, and convenings help strengthen stakeholder relations, promote dissemination and implementation, and translate findings for diverse audiences. A few upcoming events will contribute to this work including a telehealth workshop, a second payer roundtable, and a consumer roundtable.

## Peer Review: Innovations and Opportunities

**Dr. Marina Broitman, Senior Program Officer**, presented updates on the unique methods behind PCORI Peer Review process. She and her team conduct the peer review process of primary research to assess scientific integrity. Broitman walked through the process of peer review from receipt of the draft final research report (DFRR) to the final research report. As of April 4, 2018, there were 240 patient reviewers in the pool. The reviewers are invited based on their experience and expertise.

Broitman detailed the impacts of patient review on the final research report.

Panel Chair, Jane Perlmutter, asked for clarification of the difference between peer review and abstract review. Broitman explained that abstract review is the next step after peer review with the Translation Center and is called, "The Public Reporting Process". Perlmutter also noted that there is increasing evidence on the importance of including patients in summaries of results. She asked if PCORI requires that summaries go back to the patients who participated in the study. Jean Slutsky, Chief Engagement and Dissemination officer, explained that final research reports are required to be shared with research participants. Panelist, Bennet Levitan, recommended that the team draw on the analogy of clinical study enrollment to keep peer reviewers engaged and reduce dropout.

## Literature Review of Engagement in PCORI-funded CER

**Dr. Laura Forsythe, Director of Evaluation and Analysis**, discussed the planned targeted literature review project. She pointed to the wide interest in the impact of engagement and highlighted four relevant systematic studies. The findings across the articles point to the feasibility of engaging in research, that it is implemented in the earliest phases, and that there are signals that engagement helps studies to be more relevant. However, there is limited evidence about the impact of engagement which PCORI feels it can fill. Perlmutter noted a set of components that is important to the work: appreciation, trust, and support for research. Panelist, Megan Lewis, suggested to make a compelling argument for researchers by saying what was effective and what changed as a result of engagement.

Forsythe asked for feedback from the panel on a series of questions. She asked what to mark or time stamp to inform future comparative literature reviews. Panelist, Jack Westfall, said that engagement is related to T4 Research on the research continuum, which involves taking translational research out into the community. Forsythe also asked if there are new questions that the team should consider answering. Panelist, Phil Posner, recommended exploring the entire field, not just literature. Panelist, Mark Mishra, said that it might be worthwhile to conduct the literature review as a first step and then do a comparison between PCORI and outside literature.

## Research Portfolio Science of Engagement Project

Special guest **Maureen Maurer, Principal Researcher** from **American Institutes of Research** joined the panel to discuss a new project to mine the PCORI portfolio. This project is part of the IDIQ and the purpose is to explore how engagement influences the course of PCORI-funded studies and understand how successful engagement has been achieved. Two tasks will go towards completing this project: Task one is currently underway, which includes conducting interviews with the Project Investigators (PIs) and research partners (N=60 projects), in order to gather and summarize information on the perceived impacts of engagement. Task two is the next step, which will include in-depth interviews to focus more intensely understand the context and variables associated with successful and unsuccessful engagement. Maurer requested panelist input on drafting interview protocols for the PI and partner interviews for Task 1.

## PEAP Working Committee Breakout Sessions

### Ambassador Working Committee

The committee members met to discuss mechanisms and platforms to effectively communicate with the Ambassadors' communities. Other topics for discussion were how to prepare Ambassadors to host convenings and conversations, and what a training could look like. Committee members recommended resources that PCORI can provide Ambassadors, such as a PCORI 101 training, elevator pitch template, fact sheets, and slide decks.

The committee recommended that the Ambassador Program create a tool to provide a list of things an Ambassador can do. They also recommended that PCORI share a contact list of all Ambassadors to facilitate collaboration. The committee will work together in the coming months to create these initiatives.

### Engagement Rubric 2.0 Working Committee

The committee met with the goal of creating a set of recommendations on "pre-engagement" for PCORI-focused researchers and partners. They recommended to refer to pre-engagement as "early engagement" within the lifetime of a research project. To understand pre-engagement, portfolio analysis and data mining from PCORI-funded projects will be key. The committee recommended to incorporate a visual model into the portfolio. The committee agreed to reconvene to focus on dissemination and on including partnerships to help disseminate results.

In the report-out, the larger PEAP suggested that the rubric guidance should be used to guide other organizations. Kristin Carman would like to have a larger discussion about language and terminology to ensure consistency for end users.

### Chat with Dr. Joe Selby

**Dr. Joe Selby, PCORI Executive Director**, welcomed the panel to Day 2 of the meeting. He remarked on the work at Dell Medical School, where the Panelist, Anjum Khurshid, is the inaugural Director of Data Integration. Dr. Selby visited Dell Medical School recently and has hope that other medical schools can follow suit on how they train physicians and clinicians to be patient-centered in everything they do.

He thanked the panel for their commitment and recognized that PCORI still needs to prove that engagement makes a difference in research. One way that PCORI is addressing this is through the launch of a careful systematic effort to compare studies with the NIH. The collaboration will identify CER projects funded by the NIH between 2013-16 to investigate how engagement made a difference. Dr. Selby said that one of the things that PCORI will look at is subject, study designs, and outcomes. The comparisons may contribute to asking the right questions.

## PEAPs in Action: Ohio Regional Meetings

Panelist, **Tom Scheid**, and **Emma Kopleff, Public and Patient Engagement Program Officer**, led a discussion about two regional, multi-stakeholder collaborative meetings. These collaboratives included The Healthcare Collaborative of Greater Columbus and the Better Health Partnership in Cleveland. Both groups were ideal test sites for messaging new PCORI research findings, as they are highly motivated to identify opportunities for healthcare improvement within their local communities. They reacted with enthusiasm to the information presented and voiced high interest in becoming more involved in PCORI activities.

Ultimately, these meetings served as the beginning of a dialogue between PCORI and these regional collaboratives. Coming out of these meetings, the Healthcare Collaborative of Greater Columbus (HCGC) is applying for a dissemination initiative Engagement Award and is continuing to collaborate with PCORI staff. Furthermore, PCORI Ambassadors in Columbus have dedicated themselves to reconnecting to identify additional opportunities for collaboration. Tom Scheid encouraged other panelists to bring their ideas to PCORI on engaging their respective communities.

## Engaging Communities in Disseminating PCORI-funded Research Findings

To elaborate on the Ohio Regional Meetings, **Lia Hotchkiss**, Director of Eugene Washington **Engagement Award** and **Arielle Gorstein, Senior Program Associate of Dissemination and Implementation**, discussed how the Engagement Awards program is addressing PCORI dissemination needs. They detailed the new Engagement Award dissemination initiatives, awards for capacity building, and conference support.

Questions from the panelists focused on evaluation of the program and its effects on research capacity. Panelist Anjum Khurshid asked how the Engagement Awards are supporting community events and data collection of patient-reported outcomes. Ms. Hotchkiss remarked that the program is exploring the feasibility of community event support, although data collection nor support of infrastructure and registry development are supported through the program. The Engagement Awards team spent the majority of 2017 working with Insight Policy Research to create a taxonomy that categorizes their funded portfolio for future evaluation. Planned next steps include working with the Evaluation and Analysis team to create a survey tool.

## PEAPs in Action: CMS Patient and Family Engagement Affinity Group

Panelist, **Libby Hoy**, introduced special guest **Elisabeth Truong, Division Director of the Centers for Medicare and Medicaid (CMS)**. Ms. Hoy's organization, Patient and Family Centered Care Partners, works closely with CMS to augment knowledge about family and patient engagement to inform their processes. CMS uses Patient and Family Engagement profiles to engage patients in families in their



work. Panelists applauded the work that CMS is doing, which has involved themselves and their family members to make the Medicare system more navigable.

## **Closing**

Kristin Carman concluded the meeting with a recap of two days of discussions and thanked the panelists for their contributions.

Slides from this meeting can be found on the event page. The next panel meeting will be held in Fall of 2018.