



## MEETING SUMMARY

# Advisory Panel on Patient Engagement

## January 24 and 25, 2019

[About This Advisory Panel](#) | [Meeting Details and Materials](#)

### OVERVIEW

On January 24-25, 2019, the PCORI Advisory Panel on Patient Engagement (PEAP) convened in Washington, DC. On the first day of the meeting we heard updates from PCORI's Public and Patient Engagement (PPE) team, the Dissemination and Implementation team, the Eugene Washington PCORI Engagement Awards team, and the Communications team. We also met Kara Ayers, the newest patient representative on the PCORI Board of Governors. The day concluded with breakout sessions and a report-back to the larger group. On the second day of the meeting, Maureen Maurer, Principal Researcher, American Institutes of Research, provided an overview of the PCORI-commissioned project that is currently assessing engagement practices and the impacts of engagement on PCORI-funded studies. After she solicited feedback from the PEAP, the meeting concluded with a strategic planning session.

### DAY 1

#### WELCOME AND INTRODUCTIONS

David White, PEAP Chair, welcomed everyone and went over the agenda for the meeting. He thanked all attendees for their commitment and then turned it over to Thomas Scheid, PEAP Co-Chair. He reminded the group that the PEAP is a working group and the breakout sessions later in the day would get everyone acclimated to the subcommittees. Kristin Carman, Director, Public and Patient Engagement, thanked the PEAP for their efforts to move ideas, knowledge, and practice forward, and Jean Slutsky, Chief Engagement and Dissemination Officer, thanked everyone for coming and for their ongoing hard work.

#### WHAT'S AHEAD IN 2019

Kristin Carman began the presentation by reminding everyone that the four major work pillars of the PPE team are to strengthen stakeholder relationships, support and enhance engagement practice, build support for dissemination, and advance the science of engagement. These pillars were intertwined throughout the entire PEAP meeting.

To strengthen stakeholder relationships, the PPE team has been organizing consumer meetings and payer forums to bring organizations up to speed on key priority issues and to hear their perspectives. In 2019, the PPE team will continue to act as a convener and advance the work of engaging with key sectors. To support and enhance engagement practice, the Engagement Officers will continue to focus on refining the integration of their work with Science and standardizing the collection of project-level data on engagement through the Updated Engagement Plan milestone. Related to advancing the science of engagement, the PPE team will continue to examine engagement practices and impacts across the entire

portfolio and work cross-functionally in data synthesis. Lastly, the PPE team in 2019 will continue to build support for dissemination through the Ambassador Program.

Joanna Siegel, Director, Dissemination and Implementation, concluded the discussion by providing an example of an impact analysis that captures the impact of PCORI-funded studies on populations that are affected by the findings.

### **DISSEMINATION AND IMPLEMENTATION**

Joanna Siegel provided an overview of PCORI's process for encouraging the dissemination and implementation of research results. She shared that 154 public and professional abstracts of PCORI-funded completed studies have been posted to the PCORI website and reviewed the public reporting requirements that are mandated by PCORI's authorizing law. Abstracts are posted within 90 days of PCORI's acceptance of the draft final research report.

Next, Lia Hotchkiss, Director, Eugene Washington PCORI Engagement Award Program, went over the three available funding opportunities through the Engagement Award Program: Capacity Building, Conference Support, and, the newest one, Dissemination Initiative. The Dissemination Initiative award gives organizations and communities the opportunity to propose meaningful dissemination projects aimed at spreading awareness and increasing knowledge of new evidence generated from PCORI-funded research. She provided some examples of Engagement Awards that were awarded through the Dissemination Initiative. Joanna Siegel then spoke about PCORI's funding initiatives that promote the uptake of research findings through limited competition awards for PCORI-funded research and awards that support the implementation of effective shared decision making approaches. Another dissemination effort underway involves the editing of Wikipedia pages with relevant findings from PCORI-funded studies. Wikipedia is a major resource for clinicians and medical students, in addition to patients and consumers. The pages that PCORI staff edited on January 17, 2019 at PCORI's Wikipedia Edit-A-Thon have already been viewed thousands of times.

### **MEET AND GREET**

The PEAP had the opportunity to learn more about Kara Ayers, Patient Representative member, PCORI Board of Governors, as she discussed her long-standing work on behalf of disability rights. Kara Ayers is the co-founder of the Disabled Parenting Project and is an Assistant Professor in the Department of Pediatrics at the University of Cincinnati, where she is involved with the Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program at its Center for Excellence in Developmental Disabilities. Kara Ayers serves on the Selection Committee and Research Transformation Committee of the Board of Governors

### **COMMUNICATIONS UPDATE**

Bill Silberg, Director, Communications, Marla Bolotsky, Associate Director, Digital Media, Communications, Blake Whitney, Senior Editor, Communications, and Krista Woodward, Senior Program Associate, Public and Patient Engagement, provided an overview of the 2018 PCORI Annual Meeting, plus shared updates to the PCORI website. Survey results show that the 2018 Annual Meeting was well-received and that, overall, attendees felt the sessions presented impactful research results and useful information for making better-informed health care decisions. Following a discussion of the Annual

Meeting the web team shared the many ways in which PCORI tells the stories of our work including blogs, fact sheets, abstracts, and evidence updates. Additionally, the advisory panel was shown the Engagement in Health Literature Explorer, a tool that has already provided a lot of benefit to audiences, and the Ambassador Center, which is a new, centralized hub for ambassadors that allows for greater connectivity.

## **AMBASSADOR PROGRAM WORKSHOP: LESSONS LEARNED AND NEXT STEPS**

This session was folded into the breakout sessions, below.

### **BREAKOUT SESSIONS**

PEAP members participated in two different breakout sessions: Engagement Rubric and PCORI Research Results. Kristin Carman led a report-back of the Engagement Rubric session. Suggestions included making the Engagement Rubric more directive and actionable. The PCORI Research Results group focused on sharing and translating research results through the Ambassador Program. Feedback focused on providing ambassadors with more direct asks, creating an incentive structure for ambassadors that will create interest, and considering different models that would facilitate affinity group organizing.

### **DAY 2**

## **PCORI RESEARCH PORTFOLIO: DATA MINING TO INFORM THE PRACTICE OF ENGAGEMENT IN RESEARCH**

Maureen Maurer, Principal Researcher, American Institutes for Research, provided an overview of one current effort to build a more robust evidence base for the value of engagement in research. She is leading a team that is collecting data on engagement practices on PCORI-funded studies. Their research is guided by the question, if patient and stakeholder engagement changes the course of studies, how did that happen? Defining what is “successful” and “worthwhile” engagement is an important aspect of the study. Maureen Maurer facilitated a mind mapping activity to get to an understanding from the PEAP of how they interpret these terms. Next steps for this project are to complete data collection and analysis, draft the final report and manuscript, and determine a sampling approach to identify successful and unsuccessful cases.

## **2019 STRATEGIC PLANNING SESSION**

The last item on the agenda was a series of small group activities aimed at identifying topics of greatest interest to the PEAP for the purpose of planning their involvement on PCORI initiatives for the year. As outcomes, it was determined that PCORI staff would revisit establishing a PEAP subcommittee that advises on Evaluation & Analysis projects, a committee that focuses on the Engagement Rubric would continue, staff would explore establishing a work group that addresses issues related to Diversity and Inclusion, and the Ambassador subcommittee would continue.

### **CLOSING**

Kristin Carman, David White and Thomas Scheid concluded the meeting with a recap and thanked everyone for their contributions.

Slides from this meeting can be found on the [event page](#). The next PEAP meeting will take place June 27-28, 2019.