



## MEETING SUMMARY

# Advisory Panel on Patient Engagement

June 27-28, 2019

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## OVERVIEW

On June 27-28, 2019, the PCORI Advisory Panel on Patient Engagement (PEAP) convened in Washington, DC. Kristin Carman, MA, PhD, director of public and patient engagement, along with David White, chair and Thomas Scheid, MA, co-chair, led a two-day agenda. On the first day of the meeting, we heard updates from program areas including the Eugene Washington PCORI Engagement Awards, Communications, Peer Review, and Healthcare Delivery and Disparities Research. The day concluded with a hands-on session led by Maureen Maurer, MPH, principal researcher at American Institutes of Research, who shared preliminary results from a PCORI-commissioned study that assesses the influence and impact of engagement on PCORI-funded research. On the second day of the meeting, Janet Woodcock, MD, the director of the Center for Drug Evaluation and Research at the Food and Drug Administration (FDA) and a PCORI Board member, discussed the FDA's Patient-Focused Drug Development initiatives.

## DAY 1

### WELCOME AND INTRODUCTIONS

White welcomed panelists and thanked them for their ongoing commitment and participation. He provided a brief review of the two-day meeting agenda which included a range of presentations and working sessions. Advisory panelists then provided an update on their personal and professional work that connects with the mission of the PEAP. Following, Carman and Jean Slutsky, PA, MSPH, chief engagement and dissemination officer, thanked the PEAP for their efforts to continually engage with PCORI to advance our work.

### SPOTLIGHT: PEAPS IN ACTION

As a part of a continuing PEAPs in Action segment, Gwen Darien, executive vice president for engagement and patient advocacy at the National Patient Advocate Foundation (NPAF) and Patient Advocate Foundation (PAF), presented an overview of NPAF's and PAF's work. She detailed NPAF's current initiatives including The Roadmap to Consumer Clarity in Health Care Decision Making.

### ENGAGEMENT PROGRAM UPDATES

Lia Hotchkiss, MPH, director of engagement awards, kicked off a series of PCORI-led updates on current initiatives in multiple programmatic areas. Highlighted was the recent Pipeline to Proposal (P2P) program's evaluation which looked at whether the program achieved its goals to strengthen researcher and stakeholder relationships (particularly in underrepresented communities), build partnership capacity for future patient-centered outcomes research (PCOR) funding, and establish an infrastructure for patients, caregivers, and other healthcare stakeholders to increase knowledge about PCOR and engagement in research, dissemination, and implementation. The outcomes and opportunities for program enhancement were shared.

Key takeaways from the evaluation included the need for early partnership development, greater avenues for underrepresented stakeholder communities to get involved, and the potential for learning networks to support awardee and partnership needs.

### **PCORI 2019 ANNUAL MEETING**

Bill Silberg, director of communications, provided a brief nod to the upcoming PCORI Annual Meeting, *Making a Difference: Using Patient-Centered Research Results in the Real World*. He noted that the opening keynote will be given by Scott Berns, MD, MPH, and Leslie Gordon, MD, PhD, from Progeria Research Foundation. Plenary sessions will cover topics ranging from practical approaches to personalized medicine to how engagement is making research more useful. Registration is now open for attendees and the meeting will be held at the Marriott Wardman Park September 18–20, 2019 in Washington, DC.

### **PEER REVIEW**

Hal Sox, MD, director of peer review and scientific publications, discussed PCORI's peer-review origins, processes, and ongoing improvements to ensure the review process for PCORI-funded studies is accessible and inclusive. Sox detailed the steps for conducting peer review in medical journals to set the stage for how PCORI's peer-review process is both alike and different from traditional medical journals. PCORI's legislative mandate was also discussed as it drives the processes that the peer-review team has put into effect. All research results from PCORI-funded studies require that there is a final report that is accessible and useful to both scientific and nonscientific audiences.

### **LEARNING HEALTH SYSTEM NETWORKS**

Carly Parry, PhD, MSW, MA, senior advisor, care coordination and transitions research, presented on the Agency for Healthcare Research and Quality (AHRQ) Learning Health System (LHS) K12 Mentored Career Development Program. She detailed the genesis of the LHS project and partnership with AHRQ which stemmed from a technical expert panel that met in 2016 to develop a framework and competencies for LHS researchers. The framework and competencies will be used in training clinical and research scientists to conduct PCOR and to generate and apply evidence to improve quality of care and patient outcomes within learning health systems. There are eleven Centers of Excellence currently funded under this initiative, which form the Learning Collaborative. The Learning Collaborative serves as a forum to promote cross-institutional, scholar-mentor interactions, collaboration, dissemination of project findings, and development of a shared curriculum for patient-engaged research. This initiative is currently underway.

### **RESEARCH ON ENGAGEMENT: PRELIMINARY FINDINGS**

Rounding out the first day, Maurer presented findings from PCORI's current investigation into the influence and impact of engagement on PCORI-funded studies. The PEAP deliberated on questions posed by Maurer that will assist the study team in further analysis. The session concluded with key considerations for the work going forward and appreciation for the PEAP's input.

## DAY 2

### APPRECIATION AND FAREWELL

Slutsky expressed her appreciation for the PEAP and how the panel's work greatly contributes to advancing PCORI's mission. Five PEAP members whose terms will be ending in August were given special recognition for their contribution. Retiring members include Emily Creek, Megan Lewis, Ting Pun, Jack Westfall, and White, the current chair.

### FDA PATIENT ENGAGEMENT INITIATIVES

Advisory panelists heard from Woodcock, who discussed the FDA's Patient-Focused Drug Development initiatives, providing an overview of its growth and development as well as the ongoing opportunities for patient input through public workshops and externally led patient-focused drug development workshops. She discussed the new FDA grant program (Standard Core Clinical Outcome Assessments and Endpoints Grant Program) that aims to make the incorporation of patient perspectives more sustainable.

### CLOSING

Carman, White, and Scheid concluded the meeting with a brief review of the two days and items for future consideration. They also thanked the panelists for their thoughtful and meaningful contributions.

Slides from this meeting can be found on the event page. The next PEAP meeting will take place on Tuesday, September 17, 2019.