



## MEETING SUMMARY

# Advisory Panel on Patient Engagement

January 30-31, 2020

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## OVERVIEW

On January 30-31, the PCORI Advisory Panel on Patient Engagement (PEAP) convened in Washington, DC. Kristin Carman, Director of Public and Patient engagement, along with Thomas Scheid, chair and Gwen Darien, co-chair, led a two-day agenda. On the first day of the meeting, program areas, including the Eugene Washington PCORI Engagement Awards, Communications, and Public & Patient Engagement, shared updates. We also received feedback from the panelists about PCORI's topic generation process now that the organization has been reauthorized and they provided insights into our work in developing a taxonomy for Patient-Driven Research Communities (PDRCs). The day concluded with a call to action for panelists to be involved in special projects and workgroups related to engagement in research. On the second day of the meeting, Brendaly Rodríguez, Manager, Community and Stakeholder Engagement, University of Miami's Clinical and Translational Science Institute (CTSI) shared an overview of the CTSI's work and her work with training community health workers (CHWs) to be involved in patient-centered outcomes research (PCOR). The meeting ended with activity that focused on an assessment of PCORI's Engagement Principles.

## DAY 1

### WELCOME AND INTRODUCTIONS

Scheid 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, Chief Engagement and Dissemination Officer thanked the PEAP and Friends of PCORI for their efforts with reauthorization. She then introduced Josie Briggs, PCORI's Interim Executive Director and Acting Chief Science Officer and announced the imminent arrival of PCORI's new Executive Director, Dr. Nakela Cook, who will be joining PCORI on April 15, 2020.

### REAUTHORIZATION UPDATE

Slutsky reviewed the features of PCORI's new authorizing law, which extends PCORI's funding for an additional ten years. It also identifies intellectual and developmental disabilities and maternal mortality as new national research priorities for PCORI, among many other features. You can find all changes to PCORI's statute [here](#).

### IDEAS ON TOPIC GENERATION FOLLOWING REAUTHORIZATION

Jonathan Moore, Associate Director, Public and Patient Engagement, Greg Martin, Deputy Chief Engagement and Dissemination Officer, and Kelly Dunham, Senior Manager, Strategic Initiatives, Office of the Chief Science Officer, elicited feedback from the PEAP on how PCORI can evolve to better engage stakeholders in the topic generation process following reauthorization. PCORI is now in a unique position to reexamine how it generates topics for research. With a focus on making the process more inclusive, PCORI has started thinking about new methods for bringing more voices into the process that are not currently involved.

### **ENGAGEMENT: WHAT WE'VE LEARNED**

Carman described PCORI's efforts to develop a body of evidence about engagement that will help us better support PCORI applicants, awardees, and staff, and answer questions about the influence and impact of engagement on research. She indicated that, in addition to our practice-based experience in consulting PCORI-funded studies, PCORI has conducted and commissioned studies about the engagement that is occurring in PCORI projects.

Laura Forsythe, Director, Evaluation and Analysis, outlined findings from a recent study that looks at how engagement influences and impacts a range of domains including study conceptualization and execution, the design and practice of engagement, and researchers' understanding of the needs of real-world patients, clinicians, and organizations. Forsythe noted engagement influences all aspects of comparative effectiveness research (CER) design and conduct and highlighted the ways in which engagement influences research focus, design, recruitment and retention. Carman discussed some of the common challenges of engagement including having the appropriate infrastructure and resources in place, preparing partners and study teams for engagement, and balancing multiple viewpoints.

### **EUGENE WASHINGTON PCORI ENGAGEMENT AWARD PROGRAM UPDATE**

Alicia Thomas, Associate Director, Eugene Washington PCORI Engagement Awards, provided an overview of the program and previewed the upcoming project funding announcements (PFAs). The Eugene Washington PCORI Engagement Awards support projects that build a community of patients and other stakeholders equipped to participate as partners in CER and serve as channels to disseminate PCORI-funded study results. The first PFA previewed was the reworked Capacity Building Engagement Award, which seeks to build capacity/skills for PCOR and CER as well as evaluate the implementation and effectiveness within different settings and stakeholder groups. Also previewed was the Stakeholder Convening Awards, which seek to fund projects designed by organizations and communities to hold multi-stakeholder convenings, meetings, and conferences. These convenings seek to support collaboration and bring diverse stakeholders together around a central focus or theme that unifies stakeholders (e.g., geography, health condition, population) to explore issues related to PCOR/CER or communicate PCORI-funded research results to end-user audiences. An intent of the PFA is to increase the involvement of communities underrepresented in PCOR/CER, and in so doing consider the real-world circumstances or historical factors that may hinder involvement.

## INPUT ON DEVELOPING A TAXONOMY FOR PDRCs

Michelle Johnston-Fleece, Senior Program Officer, Public and Patient Engagement, Claudia Grossmann, Senior Program Officer, Research Infrastructure, and Prashila Dullabh, Senior Fellow, Health Sciences, NORC at the University of Chicago, provided an update on the activities of the PDRC Learning Network. They solicited input on an overview of their process for developing a taxonomy for characterizing PDRCs, the role of PDRCs in the broader research landscape, and implications for PCORI.

## COMMUNICATIONS UPDATE & DISCUSSION: TOOL REPOSITORY, WEB REDESIGN, & ANNUAL MEETING

Ivey Wohlfeld, Program Manager, Eugene Washington PCORI Engagement Awards, and Alana Cole, Program Associate, Public and Patient Engagement, presented on a new PCORI website feature, the Engagement Tool and Resource Repository. It is a searchable tool that contains Engagement Tools that have been identified by PCORI staff from research portfolios and Engagement Award deliverables. Resources are tagged with codes for resource focus, phase of research, health condition, patient and public stakeholders, and population of interest. Marla Bolotsky, Associate Director of Digital Media Engagement, Communications, presented on recent updates to PCORI's website and sought ideas from the panel on how to continue improving the website so that it can be more useful. Amy Damsker, Associate Director of Operations, Communications, sought guidance on different conference presentation formats for the Annual Meeting, specifically on how to best engage the community of people who can't be at the Annual Meeting in person.

## SPECIAL PROJECTS & WORKGROUPS: OPPORTUNITIES FOR INVOLVEMENT

Krista Woodward, Program Officer, Public and Patient Engagement, provided an update on the recent work of the Ambassador Program workgroup and solicited new members. Denese Neu, Engagement Officer, Public and Patient Engagement, solicited members for the Clinician Engagement Workgroup, a new opportunity for involvement focused on developing mechanisms to reduce burden on clinicians to participate in PCOR/CER studies. Christine Broderick, Engagement Officer, Public and Patient Engagement, solicited members for the Knowledge Translation and Uptake Workgroup, a new opportunity for involvement focused on translating knowledge about the influence and impacts of engagement in PCORI-funded research into messages and formats that resonate with different audiences. Michelle Johnston-Fleece, Senior Program Officer, Public and Patient Engagement, and Rachel Hemphill, Program Officer, Evaluation and Analysis, solicited members for the Workgroup Studying PCORI's Patient-Centered Approach, a new opportunity for involvement focused on providing advice on PCORI's evaluation agenda, specific projects that aim to build evidence about promising practices for patient-centered research, and projects that assess the effectiveness of PCORI's approach.

## DAY 2

## SPOTLIGHT: PEAPS IN ACTION

As a part of a continuing PEAPs in Action segment, Brendaly Rodríguez, Manager, Community and Stakeholder Engagement, University of Miami's CTSI, presented an overview of the CTSI's work and detailed the role of CHWs in PCOR. Throughout the presentation, she detailed the CTSI's current initiatives to strengthen community partnerships and elaborated on a Eugene Washington PCORI Engagement Award that she served on which developed a training on PCOR which can be used toward CHW state certification. In a closed session, Advisory Panelists Matt Hudson and Gwen Darien led an exercise that examined PCORI's Engagement Principles.

## CLOSING

Carman, Scheid, and Darien 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 June 4-5, 2020.