



MEETING SUMMARY

Advisory Panel on Patient Engagement

September 17, 2019

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

OVERVIEW

On September 17, 2019, the PCORI Advisory Panel on Patient Engagement (PEAP) convened in Washington, DC, prior to the PCORI Annual Meeting. Kristin Carman, PhD, MA, director of public and patient engagement, along with newly appointed chair, Thomas Scheid, MA, and co-chair, Gwen Darien, led the meeting. In sum, the agenda covered the introduction of six new members to the advisory panel and a presentation on the newly formed Patient/Participant Driven Research Community (PDRC) Learning Network.

WELCOME OF NEW MEMBERS

Scheid welcomed all the panelists and thanked them for their ongoing commitment and participation. He introduced the six new panelists: Beth Careyva, MD, of Lehigh Valley Hospital, Inc. (Representing: Researchers); Tracy Carney of University of Pittsburgh Medical Center (Representing: Patients, Caregivers, and Patient Advocates); Crispin Goytia-Vasquez of the Icahn School of Medicine at Mount Sinai (Representing: Patients, Caregivers, and Patient Advocates); Simon Mathews, MD, of Johns Hopkins Medicine (Representing: Clinicians); Danny van Leeuwen, MPH, RN, CPHQ, of Health Hats (Representing: Patients, Caregivers, and Patient Advocates); and Neely Williams, EdD, of Community Partners' Network, Inc. (Representing: Patients, Caregivers, and Patient Advocates). Each new panelist shared extensively about their experience in patient engagement and interest in the PEAP.

PATIENT/PARTICIPANT DRIVEN RESEARCH COMMUNITY LEARNING NETWORK

Claudia Grossmann, PhD, senior program officer, research infrastructure, and Michelle Johnston-Fleece, MPH, senior program officer, public and patient engagement, presented on a new initiative called the Patient/Participant Driven Research Community (PDRC) Learning Network.

The PDRC Learning Network is focused on furthering the capacity and sustainability of patient and participant driven organizations to help them grow to play a greater role in guiding clinical and healthcare delivery research. The Learning Network is seeded by the Patient-Powered Research Networks, PDRCs originally funded by PCORI as part of PCORnet®.

The goals of the Learning Network are to exchange best practices, provide opportunity for learning from external organizations, disseminate generalizable learnings, and help shape a national discussion on the role of PDRCs in clinical and healthcare delivery research. Ultimately the goal is to have the learnings and products developed by the network be an open resource for all PDRCs.

CLOSING

Carman, Scheid, and Darien concluded the meeting with a brief review of the day and announcements. These items included an update on two new Engagement Award project funding announcements (the Community Convening Around Patient-Centered Research PFA and the Accelerating the Adoption of Tools and Resources PFA), and an announcement of the newly appointed PCORI Board of Governors chairperson, Christine Goertz, and vice chairperson, Sharon Levine. Panelists were thanked for their thoughtful and meaningful contributions before adjournment.

Slides from this meeting can be found on the event page. The next PEAP meeting will take place on Thursday, January 30, 2020.