



External Meeting Summary

Advisory Panel on Patient Engagement

November 5, 2021

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

Overview

The Advisory Panel on Patient Engagement (PEAP) Fall 2021 Meeting focused on opportunities to share and discuss timely PCORI stakeholder engagement activities, as well as how panel members' experiences in the field may inform these efforts, and what and how PCORI learns from them. This meeting was also the first for new members who joined the panel in late September.

The agenda included the following:

- Strategies for Increasing Awareness of PCORI within Communities
- PCORI's Strategic Planning Process
- PCORI's Science of Engagement Funding Initiative
- PEAPs in Action (A PEAP member's perspective on, and lessons learned, from participating in PCORI-funded research)
- PCORI's Patient-Driven Research Community Learning Network Activities
- Modeling Community-Driven Research Approaches to Achieve Health Equity
- Upcoming Work and Next Steps

Panel Discussion: Increasing the Awareness of PCORI within Communities

- Neely Williams, Chair, Advisory Panel on Patient Engagement
- Karen Fortuna, Co-chair, Advisory Panel on Patient Engagement

This discussion was held in response to enthusiasm from advisory panel members about dedicating resources to building awareness of PCORI in local communities. To meet this interest, panel chairs facilitated a discussion that asked panel members to identify concrete actions that PCORI could take to increase its awareness and build capacity for patient-centered outcomes research in their communities. Key themes from this discussion are described below:

- *Dissemination channels:* Several panel members spoke to experiences in their own communities—communities that were unaware of what PCORI funds and its mission. The panel indicated that this could be overcome by encouraging people who are familiar with PCORI, or trusted messengers, to spread the word. For example, students, faculty, and patient partners at HBCUs, and Tribal and Hispanic-serving colleges, who are involved in PCORI/CER can serve as trusted messengers in their own communities by sharing their experience on a PCORI-funded project, etc. Many panel members also indicated that they have seen success in the use of non-academic outreach strategies to expand PCORI's reach, such as Facebook and radio interviews.

- *Tailored messaging:* Several panel members indicated that use of content that can be easily tailored and shared with their communities, such as videos, has been helpful in reaching wider audiences. They recommend that these videos include trusted messengers and concrete, real-world examples of PCORI's impact. Several panel members also noted the need for content that is tailored to their community. They also shared that funding opportunities for specific regions, fields, disciplines and/or populations would also be helpful for connecting PCORI to those specific communities.

PCORI Strategic Planning Update

- Andrew Hu, Director, Public Policy

As required by its legislative mandate, PCORI has been undergoing a strategic planning process, following its reauthorization in 2019. Panel members have previously provided input on the high-level priorities that supported the development of PCORI's recently adopted [National Priorities for Health](#). Hu's presentation served to update panel members on how PCORI has incorporated stakeholder feedback into this process, and to preview additional opportunities for their input. A few panel members reacted to the presentation with a recognition that the priorities align well with many of the themes discussed throughout the meeting agenda.

Science of Engagement (SoE) Funding Initiative

- Julie Kennedy-Lesch, Senior Engagement Officer, Public & Patient Engagement
- Rachel Hemphill, Program Officer, Evaluation & Analysis

Building on prior input from previous conversations with the panel about priority areas for studying engagement, Kennedy-Lesch and Hemphill provided an update on PCORI's recently released [Request for Information \(RFI\)](#) on the Science of Engagement. The RFI will inform the development of a new PCORI funding initiative that seeks to expand the evidence base on effective engagement of diverse patients and stakeholders throughout the research process.

Kennedy-Lesch defined the science of engagement and reviewed the potential topic areas for study and facilitated a discussion among panel members about their communities' evidence needs, as well as their suggestions for how PCORI can promote inclusivity, accessibility, and partnership among stakeholder organizations through this effort.

Panelists' responses highlighted the challenges surrounding the limited capacity that patient and community partners have, which is a barrier to engaging in this type of work. Several panelists offered specific strategies for addressing this challenge, such as:

- Targeted outreach about the RFI, and future funding announcements, to non-academic institutions
- Use of more inclusive and accessible language in the RFI, as well as acceptance of less strict requirements for required responses from patient partners

- Dedicated PCORI resources to provide technical assistance and guidance on program fit to smaller organizations

PEAPs in Action: Researching Health Together

- Tracy Carney, Senior Recovery Specialist, Community Care Behavioral Health

Carney presented on her experience as a patient partner on three PCORI-funded studies. She discussed trauma-informed research principles that she suggests can help researchers better integrate patients into the research process at all levels. These principles were woven into an overview of one of the PCORI-funded comparative effectiveness research study. The study led to the development of a state-wide Behavioral Health Home Plus program that continues to improve patient experience and health outcomes across Pennsylvania. PEAP members agreed that sharing stories about the impact of research in communities will help people understand the practical effects and importance of PCOR research.

Patient-Driven Research Community Learning Network: Overview of Activities

- Elizabeth L. Cope, Senior Director, AcademyHealth
- Claudia Grossmann, Senior Program Officer, Research Infrastructure
- Michelle Johnston-Fleece, Senior Program Officer, Public & Patient Engagement

Cope presented on activities undertaken by the Patient Driven Research Community Learning Network (PDRC LN), a PCORI-funded initiative led by NORC at the University of Chicago and AcademyHealth. The PDRC LN has produced issue briefs, case studies, slide decks, dissemination toolkits, and templates which are publicly available in the [PCORI Engagement Tool & Resource Repository](#). A [blog](#) on the findings has been published in Health Affairs.

Achieve Health Equity: Modeling Community-Driven Research Approaches

- Kelly Dunham, Senior Manager, Strategic Initiatives, Office of the Chief Science Officer
- Lisa Stewart, Senior Engagement Officer, Public & Patient Engagement

Dunham and Stewart presented feedback from a round of discussions with stakeholders on a developing concept for a funding initiative that would support community-driven research. The session sought ideas from the panel on operational models and staff asked the panel to share examples of novel partnerships where community organizations have acted in a co-leadership position with researchers. PEAP discussion centered around the importance of acknowledging and overcoming the power dynamics that occur in research, and ways to structure funding that ensures a greater balance of power. PEAP members suggested a variety of ideas and strategies to do so, including:

- Supporting efforts to address health literacy in communities
- Leveraging trusted messengers, such as local centers for health equity, to help community partners engage in the research process
- Investing in community priorities for building capacity to engage in research
- Investing in activities that facilitate partnerships and trust building among academic and community organizations

Upcoming Work and Next Steps

- Rachel Hemphill, Program Officer, Evaluation & Analysis
- Lisa Stewart, Senior Engagement Officer, Public & Patient Engagement

At the start of this session, Hemphill introduced an opportunity to join the Patient-Centered Approach (PCA) Workgroup, which advises on PCORI's evaluation agenda. Hemphill noted that the next workgroup meeting is planned for January 2022. PEAP members will have the opportunity to join that meeting before committing to further participation in the workgroup.

Lisa Stewart then shared important dates for upcoming meetings:

- Annual Meeting (November 17-19)
- Upcoming Board Meeting (December 1-2)

Lisa Stewart, Greg Martin, and Neely Williams thanked the PEAP members for their time and participation and closed out the meeting.