



## Meeting Summary

# Advisory Panel on Patient Engagement

February 11-12, 2021

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

## Overview

On February 11-12, 2021, PCORI's Advisory Panel on Patient Engagement (PEAP) convened virtually via GoToWebinar. Day 1 started with the PEAP members discussing their communities' reactions to the current climate of change, hope, scarcity, and mistrust, including the innovative ways communities have addressed the mistrust around the COVID-19 vaccine. Next, PCORI staff presented updates on their strategic planning process and plans for updating PCORI's Engagement Rubric. The second half of day 1 included a discussion on engagement around diversity, equity, and inclusion (DE&I) for upcoming PCORI evaluation and research projects. The day concluded by reviewing the recommended DE&I guiding engagement principles that were submitted to PCORI for consideration following the meeting.

Day 2 started with a review of outstanding comments from Day 1, additional details on the Advisory Panel application process, and a presentation by PEAP Co-chair Neely Williams, MDiv, EdD, on her work with the National Institutes of Health (NIH) Tennessee Community Engagement Alliance (CEAL) Project. Next, there were two lightning rounds of presentations that covered the preferred qualifications of patient engagement leads on large trials and strategies to apply the recommended DE&I principles. PEAP member James Harrison presented on learning health systems with PCORI staff member, Carly Parry. Lastly, PCORI transitioned into an open discussion with the PEAP about what is needed from PCORI to effectively work with communities.

## Day 1

### Welcome

- Kristin Carman, MA, PhD, Director, Public and Patient Engagement, PCORI
- Gwen Darien, Chair, Advisory Panel on Patient Engagement
- Neely Williams, MDiv, EdD, Co-chair, Advisory Panel on Patient Engagement
- Meghan Berman, Program Associate II, PCORI

Carman welcomed the PEAP members and the public to the meeting and walked through the agenda for the day. Darien and Williams introduced themselves as chair and co-chair of the PEAP. Lastly, Berman discussed logistics and held roll call for the PEAP members.

## Advisory Panel Perspectives: Community Reactions in a Climate of Change, Hope, Scarcity, and Mistrust

- Moderators: Kristin Carman, MA, PhD, and Gwen Darien

Carman and Darien asked the PEAP members to discuss their communities' lived experiences with scarcity and mistrust, including how they define hope and how they can close the gaps in health equity. PEAP members offered comments on the following themes: COVID-19 vaccine uptake; health equity; connections between hope, scarcity, and mistrust; and examples of community engagement to address mistrust.

## PCORI Updates

- Kristin Carman, MA, PhD, Director, Public and Patient Engagement, PCORI
- Bill Lawrence, MD, MS, Senior Clinical Advisor, Communications, Dissemination, and Implementation, PCORI
- Meghan Berman, MPH, Program Associate II, PCORI
- Joanna Siegel, SM, ScD, Director of Dissemination and Implementation, PCORI

Lawrence provided an overview of the funding opportunities that support PCORI's national priorities. He also highlighted PCORI's work on COVID-19, including the PCORI-funded HERO Registry that captures data on concerns of healthcare workers. Berman reminded the PEAP members that the advisory panel application is currently open for new members. Siegel answered questions from the PEAP members on returning research results to study participants in an accessible way.

## Engagement Rubric Updates

- Kristin Carman, MA, PhD, Director, Public and Patient Engagement, PCORI
- Michelle Johnston-Fleece, MPH, Senior Program Officer, Public and Patient Engagement, PCORI

Carman and Johnston-Fleece provided an overview of PCORI's approach to engagement and the planning to update PCORI's Engagement Rubric. They provided background on why the existing rubric needs an update, opportunities for PEAP engagement in the update process, and next steps for PCORI's internal strategic planning activities.

## How to Understand Diversity, Equity, and Inclusion (DE&I) in Engagement: Input for Upcoming Projects

- Esther Nolton, PhD, Med, Program Officer, Evaluation and Analysis, PCORI
- Lisa Stewart, MA, Engagement Officer, Public and Patient Engagement, PCORI

Nolton and Stewart recapped the discussion on DE&I from the October PEAP meeting and reviewed PCORI's upcoming research projects. They polled PEAP members about their comfort levels sharing their demographic information on questionnaires. The PEAP members engaged in discussion on what additional questions PCORI should ask applicants to increase DE&I in engagement for research and how PCORI can ensure the organization's trustworthiness.

PEAP members offered several recommendations, including that respondents may not know the answer to some demographic questions (e.g., sexual orientation), that research teams should involve individuals in research projects who have been historically excluded, and that PCORI and researchers can achieve change more effectively through collaboration with trusted sources in the community.

## Recommendations for PEAP DE&I Guiding Engagement Principles

- Matthew Hudson, MPH, PhD, Member, Advisory Panel on Patient Engagement
- Debra Joy Perez, Consultant

Hudson and Perez provided an overview of the Use Statement that accompanies the recommended DE&I Guiding Engagement Principles that include principles on inclusion, equitable partnerships, trust/trustworthiness, and accountability. They asked the PEAP members to consider what resonated with them in the Use Statement and what is missing from the included critical self-assessment questions and the tactics list.

## Day 2

### Housekeeping & Remarks

- Kristin Carman, MA, PhD, Director, Public and Patient Engagement, PCORI
- Lisa Stewart, MA, Senior Engagement Officer, Public and Patient Engagement, PCORI
- Meghan Berman, MPH, Program Associate, Public and Patient Engagement, PCORI

PCORI welcomed all participants to the second day. Berman provided additional information on the process for the advisory panel applications and addressed questions. She indicated that PCORI will review each application thoroughly and holistically to develop a well-rounded panel.

## PEAPs in Action: Fashioning Effective Connections for Working with Underserved Populations

- Neely Williams, MDiv, EdD
  - Co-chair, PCORI's PEAP
  - Director of Statewide Community Engagement for Tennessee for the NIH CEAL Against COVID-19 Disparities; and
  - Steering Committee Member, Executive Management Team Member and Engagement Workgroup Co-Chair, PCORnet®, the National Patient-Centered Clinical Research Network

Williams presented on her work the Engagement Workgroup of PCORnet® and with the COVID-19 Community Engagement Research program with NIH CEAL. CEAL teams are currently working in counties with COVID-19 hotspots in Alabama, Arizona, California, Florida, Georgia, Louisiana, Michigan, Mississippi, North Carolina, Tennessee, and Texas. CEAL leverages existing well-trusted community partnerships with historically Black colleges and universities, faith-based organizations, and historical social service organizations, such as 100 Black Men, the Urban League, and the National Association for the Advancement of Colored People.

## Lightning Round 1: Staffing Engagement

- Julie Kennedy-Lesch, MPA, Senior Engagement Officer, Public and Patient Engagement, PCORI

Kennedy-Lesch facilitated a discussion of potential requirements in PCORI's current and future funding announcements about engagement leaders on study teams. She explained that PCORI intends to fund

high-cost, large-impact trials that allow for 18 months as a feasibility phase during which study teams will have an opportunity to fully develop and operationalize engagement plans. The PEAP members suggested that PCORI: identify individuals with lived experience and advocacy organizations who represent those individuals and focus on soft versus hard skills and engage experts in the science of community engagement. A few PEAP members also acknowledged that engagement experts may contribute to further silo-ing of engagement in the research process (e.g., “the engagement leader is seen as the prime steward of the community, [while] researchers are perceived to be disengaged or marginalized in [such] relationships.”)

## Lightning Round 2: Applying DE&I Principles

- Debra Joy Perez, Consultant
- Matthew Hudson, MPH, PhD, Member, Advisory Panel on Patient Engagement

Returning to the discussion from day 1, Perez and Hudson invited PEAP members to reflect again on the DE&I principles and Use Statement and share how they can contribute to research efforts. PEAP members noted that they wanted more education around alternative language for stigmatizing terms, like “vulnerable” and “marginalized,” and being more direct when discussing the population of interest. They emphasized that individuals living with disability are important to include in the conversation about populations that have been historically excluded and stressed the importance of intersectionality. PCORI mentioned that it will be releasing the Building Effective Multi-Stakeholder Teams package soon, that will include tools and resources to guide users on addressing bias and managing difficult conversations.

## PCORI Support for Learning Health Systems: Envisioning Next Steps and New Directions

- Carly Parry, PhD, MSW, MA, Senior Advisor, Healthcare Delivery & Disparities Research Program, PCORI
- James Harrison, Assistant Professor, University of California San Francisco (UCSF)

Parry presented on the K12 Mentored Career Development Program. This program is jointly funded by the Agency for Healthcare Research and Quality and PCORI for five years (2018-2023). It is designed to train the next generation of patient-centered outcomes research (PCOR) professionals to lead research within institutional training programs. Harrison, a PEAP member representing researchers, described his involvement in the program, including two of its initiatives: 1) the Hospital Medicine Reengineering Network (HOMERuN), and 2) UCSF’s COVID-19 Patient and Community Advisory Board.

Harrison and Parry presented questions around how to advance the model of learning health systems. The PEAP members recommended that PCORI focus on the differences in capacity of learning health systems, support and sustain engagement, pay community members to honor their work, use lay language, and connect with patients to meet their needs.

## Open Panel Discussion

PCORI invited the PEAP to continue the discussions around DE&I and engagement that began on day 1. They led a discussion on how PCORI can generate information that is meaningful to communities and

show value and authenticity in their work. PEAP members agreed that holding PCORI accountable is an important part of the DE&I discussion.

In closing, PCORI reminded all participants that the deadline for advisory panels is Wednesday, March 31. The link to the application and more information can be found [here](#).