MEETING SUMMARY

Advisory Panel on Patient Engagement

October 22-23, 2020

About This Advisory Panel | Meeting Details and Materials

Overview

On October 22-23, 2020, PCORI's Advisory Panel on Patient Engagement (PEAP) convened virtually via GoToWebinar. Kristin Carman, Director of Public and Patient Engagement, along with Gwen Darien, Chair of the PEAP, led the meeting. Day 1 started with a presentation and discussion on PCORI's strategic planning and update on their national priorities. This was followed by a discussion about the 2020 PCORI Virtual Annual Meeting. Next, PCORI staff described their two newly mandated research priorities: maternal morbidity and mortality and intellectual and/or developmental disabilities. The second half of Day 1 included a presentation on the Principles for the Consideration of the Full Range of Outcomes Data and a discussion on how to bring new organizations into PCORI's Eugene Washington Engagement Awards program. The day concluded by discussing the novel approaches that PEAP members have used to sustain engagement during the pandemic. Day 2 started with a welcome and director's update by Kristin Carman, followed by a discussion on practical strategies for consideration around trust and trustworthiness of organizations. The second half of Day 2 focused on discussions about PCORI's diversity equity and inclusion (DE&I) guiding Engagement principles and concluded with a short discussion on building a research agenda for studying DE&I in Engagement.

DAY 1

Strategic Planning: Identifying National Priorities

Jean Slutsky, Chief Engagement and Dissemination Officer, opened the discussion around strategic planning for PCORI's national priorities for research over the next 10 years. She shared that the PCORI Board of Governors has reframed their priorities from "national priorities for research" to "national priorities of health" to successfully achieve better health outcomes.

The existing national priorities the Board of Governors adopted in 2012 include:

- Addressing Disparities
- Assessment of Prevention, Diagnosis, and Treatment Options
- Communication and Dissemination Research
- Improving Healthcare Systems
- Accelerating PCOR and Methodological Research

Discussion

The following feedback provided by PEAP members is grouped around common themes.

- *Implementation science:* Panelists discussed the extent to which patient-centered outcomes research can inform the implementation science domain. The Board of Governors acknowledges that PCORI has a robust dissemination component, but not traditional implementation science.
- *Communicating uncertainty in clinical outcomes:* A priority area suggested by one panelist involves how to communicate uncertainty in clinical outcomes to patients and clinicians.
- *Eliminating health disparities:* This priority area is more important than ever, especially with the coronavirus pandemic, the current racial justice movement, and the disparities evident in PCORI's newly mandated research areas. PCORI must recognize that health disparities exist in order to improve the patient experience, improve health outcomes, and reduce cost.

PCORI's Mandated Research Priorities

Emma Kopleff, Program Officer, Public and Patient Engagement, provided an update on PCORI's two newly mandated research priorities:

- Maternal morbidity and mortality
- Intellectual and/or developmental disabilities

PCORI has up to $30 million set aside for each of these topics. Key considerations moving forward include facilitating engagement and refining a research agenda.

2020 PCORI Virtual Annual Meeting: Post-Meeting Report

Tasha Parker, Director of Communications, and Amy Damsker-Wright, Associate Director of Operations for Communications, provided a post-meeting report on the 2020 PCORI Virtual Annual Meeting, held on September 16-17, 2020. Parker explained that the switch to a virtual setting made the meeting more accessible, which likely caused the attendance to increase by 150 percent. Many of the topics were relevant to the current coronavirus pandemic, including a session on telehealth.

Discussion

The following feedback provided by PEAP members is grouped around common themes.

- *Outreach after the meeting:* There was a suggestion that the annual meeting recordings could be used as a teaching tool in clinical or professional education for medical students to learn about the process of research.
- *Accessibility of technology:* A panelist encouraged PCORI to acknowledge the disparities in technology among patients and other stakeholders.

Principles for the Consideration of the Full Range of Outcomes Data

Andrew Hu, Director of Public Policy and Government Relations, provided an overview of the principles that PCORI released for a 60-day public comment period on September 14. He emphasized PCORI's goal is two-fold: (a) provide principles for how PCORI interprets its congressional mandate and (b) discuss how PCORI can use these principles to guide future applicants.

Hu began his presentation with an overview of PCORI's reauthorizing language related to outcomes data. He provided an overview of three pillars for PCORI's cost data implementation plan.

- Pillar 1 involves developing guidance for future PCORI applicants and how they can use this guidance in their research proposals.
- Pillar 2 involves the methodology standards to be updated in December or January after the public comment period closes.
- Pillar 3 unpacks how the data will be used, with discussions of health cost and quality at every stage of implementation. PCORI will leverage its role as a convener to include stakeholder input.

Next, Hu discussed four proposed principles for the full range of outcomes data. These principles are a high-level framework to describe PCORI's interpretation of the new mandate to collect cost burden and economic impact data.

- Principle #1: PCORI-funded research may consider the full range of outcomes important to patients and caregivers, including burdens and economic impacts.
- Principle #2: PCORI-funded research may consider the full range of outcomes relevant to other stakeholders, when these outcomes have a near-term or longer-term impact on patients.
- Principle #3: The collection of data on burdens and economic impacts of treatment options must be appropriate and relevant to the clinical aims of the study.
- Principle #4: Beyond the collection of burden and economic impact data, PCORI may support the conduct of certain types of economic analyses as part of a funded research study, to enhance the relevance and value of this information to healthcare decision makers.

Lastly, Hu reported broad support for the consideration of costs and economic impact data in PCORI research, and categorized the themes from the input received on the principles to date, including the importance of:

- Ensuring a patient-centered and holistic approach to the consideration of costs
- Considering the cost burdens and impacts from a societal and community level
- Capturing implementation or program costs
- Applying patient-centered cost/impact data to value-based payment models

Discussion

The below feedback provided by PEAP members is grouped around common themes.

- *Nonfinancial and nonmedical impacts to the patient*: Many panelists emphasized the importance of looking at cost holistically. They suggested that researchers look at factors beyond treatment cost, such as loss of the patient's income, health inequities, and access to care. These factors play a crucial role in determining a patient's treatment plan.
- *Eliminating health disparities*: The coronavirus pandemic has had a tremendous impact on minority communities beyond loss of life. Outcomes data on costs and economic impacts of illness will help PCORI quantify the impact of health disparities. One panelist explained that examining costs is particularly relevant for vulnerable populations in long-term care facilities, especially staff, families, and residents from minority groups disproportionately affected by COVID-19.

Engagement Awards Update: Bringing New Organizations to the Table

Karen Martin, Program Director for the Eugene Washington PCORI Engagement Awards, queried panelists on how the Eugene Washington PCORI Engagement Awards program can encourage applications from a larger array of organizations, particularly smaller organizations. The program, started in 2014, supports organizations to build a community of patients and other stakeholders equipped to participate as partners in patient-centered outcomes research, as well as serve as channels to disseminate PCORI-funded study results. The funding opportunities available through an Engagement Award program include:

- The Capacity Building Engagement Award
- The Dissemination Initiative Engagement Award
- The Stakeholder Convening Support Engagement Award

Discussion

The below feedback provided by PEAP members is grouped around common themes.

- *Challenges for smaller organizations*: Many panelists explained that smaller organizations often do not have the resources, infrastructure, or staff that a larger company has, including standard operating procedures for writing grants or grant writing support. Bandwidth issues are also a large problem due to the COVID-19 and racism pandemics. PCORI must keep that in mind and make sure it is easy and straightforward to engage smaller organizations in research.
- *Rethinking the Engagement Award application process:* Panelists suggested that PCORI look at the language it uses in the application process and reframe it to help involve smaller organizations. Rather than a text-heavy written application, PCORI could move to smaller applications that could be submitted both through writing and video. Offering a different platform and innovative strategies could be helpful, as well.
- *Awareness of PCORI*: Especially in smaller patient-led organizations, panelists noted there may a lack of awareness about PCORI and its award opportunities. PCORI should become more active on Facebook and Instagram because many patient-led organizations are active on social media.

Sustaining Engagement during the Pandemic: Sharing Novel Approaches

Gwen Darien, PEAP Chair, moderated this session, which queried panelists on what they have learned works and does not work to sustain engagement during the coronavirus pandemic. PCORI staff also shared some preliminary lessons they have learned through analysis of the current portfolio.

Discussion

The following feedback provided by PEAP members is grouped around common themes.

- *Elevating social media presence:* One panelist hired a social media manager to help its organization build a community. They targeted messages toward specific communities and engaged with patients and patients’ families by featuring their stories on Instagram and Facebook. Different stakeholders use different platforms, so they modified messaging and framing on each platform to best engage particular stakeholders.

- *Mental health during COVID-19*: In the discussion, one panelist stressed the importance of recognizing that their stakeholders are juggling many priorities during the pandemic, including Zoom fatigue, obligation fatigue, and “being at home” fatigue.
- *Positives from adapting to virtual environment*: PCORI noted that some of its awardees can now host 2,000 people virtually, instead of 18 people in person. Many panelists suggested leveraging the switch to a virtual format to increase inclusivity and they recommended requiring captions for all virtual meetings.

DAY 2

Trust and Trustworthiness of Organizations

Julie Kennedy Lesch, Senior Engagement Officer, Public and Patient Engagement, and Lauren Fayish, Program Officer, Evaluation and Analysis, led a discussion on how to build trust in an organization, both internally and externally. Findings from PCORI on how to be a trustworthy organization include:

- Trust must be cultivated and earned through actions.
- Perceptions of trust and trustworthiness may differ between collaborators.
- Trust is necessary but not entirely sufficient for effective partnerships.
- Trust is ongoing and dynamic, and it must be built and rebuilt and also understood and viewed in the context of past abuses.

Discussion

The below feedback provided by PEAP members is grouped around common themes.

According to the panelists, trustworthy organizations are:

- *Compliant with industry standards of evidence and practice:* Panelists emphasized the importance of an institution being compliant with practice standards and driven by evidence shared with stakeholders.
- *Caring and empathetic:* Panelists indicated that researchers should demonstrate true empathy when communicating with community members and complete prework to ensure their approach is sensitive and trauma informed.
- *Authentic:* Panelists suggested that organizations build honest representations of themselves and their research and build partnerships with the communities they serve.
- *Reciprocal and generous:* Panelists indicated that organizations should do the hard work to meet individuals and communities where they are.
- *Ready to examine own biases:* Panelists encouraged organizations to be aware of their own culture and understand how that affects their research methods, subjects, and products.

Next, the panelists shared that PCORI has shown it is a trustworthy organization by:

- Encouraging diversity in invited speakers and panel members
- Focusing on the community by amplifying community voices and communicating research findings

Finally, panelists discussed how PCORI can become an even more trustworthy organization. Recommendations for improvement include:

- *Hire more people from diverse backgrounds*. Panelists suggested advertising open positions in historically excluded communities and hard-to-reach populations in ways that bridge the rural/urban divide, such as local newspapers or radio stations.
- *Address barriers to participation in research*. Panelists suggested holding more discussions that are free from financial barriers, using closed captioning and translation services, and expanding Engagement Award funding.
- *Highlight current engagement efforts and expertise internally and externally*
- *Increase transparency in shared decision making, roles and responsibilities, and expectations and outcomes in research*
- *Create and mandate a code of ethics for researchers and stakeholders across all PCORI-funded research projects*. This would ensure researchers are adhering to engagement principles and best practices.
- *Create guidance and materials for pre-project work for researchers*
- *Enforce recommendations around engagement.* Panelists suggested that building assessment and evaluation processes into grant criteria would hold research teams accountable.

Supporting Diversity, Equity, and Inclusion (DE&I) in Research Partnerships: PEAP/DE&I Guiding Engagement Principles

Debra Joy Perez, Consultant, facilitated a discussion about the PEAP's four Diversity, Equity, and Inclusion Guiding Engagement Principles. She began by acknowledging that all teaching, learning, research, advising, and advocacy occurs on Indigenous land. She also reminded the PEAP that the coronavirus pandemic has pushed racial anxieties even further than before, as the disease is disproportionately affecting BIPOC (Black, Indigenous, People of Color) populations in America.

The four draft Diversity, Equity, and Inclusion Guiding Engagement Principles include:

- *Inclusion:* Inclusion of diverse groups in research partnerships goes beyond numerical representation. This requires deliberate actions, humility, and use of anti-racist practices.
- *Equitable partnerships*: Partnerships between researchers and nonscientists must provide mutual benefit. They should be anchored in a commitment to collaborative decision making, fairness, and transparency through shared agreements that are open to renewal and change.
- *Trust and trustworthiness:* Trusting relationships between researchers and research partners depend on ongoing demonstrations of trustworthiness.
- *Accountability:* Accountability relies upon practices, processes, and people who can hold research teams to standards that embody DE&I and, importantly, draw people back to their common humanity.

Discussion

The below feedback provided by PEAP members is grouped around common themes.

- *Inclusion:* Informed language is important to fostering inclusivity. Examples exclude: "people from diverse backgrounds and perspectives" or "historically excluded" rather than "minority." Inclusion requires an explicit invitation from an individual or organization who has actively reached out.

- *Equitable partnerships:* An organization must recognize the expertise of the community and individual research panelists to overcome traditional hierarchical power dynamics and empower historically excluded communities. Equitable partnerships lead to mutual benefits, including the co-creation and ownership of research products.
- *Trust:* Organizations must acknowledge that trust has been broken and understand the historical and social context of people and communities. Panelists suggested PCORI build guidance on this, as communities should be involved at all levels of the research process.
- *Accountability:* Researchers' teams need an accountability contract to ensure all parties agree on roles and expectations. DE&I work should not be the sole responsibility of a DE&I officer—all stakeholders should be engaged. Barriers to financial compensation, such as qualification for disability income and equitable compensation for all panelists, need to be overcome.

Building a Research Agenda for Studying DE&I in Engagement

Esther Nolton, Program Officer, Evaluation and Analysis, and Lisa Stewart, Senior Engagement Officer, Public and Patient Engagement, led a discussion on building a research agenda for studying DE&I. They queried the panelists on how PCORI can make progress, both in the organization and outside the organization.

Discussion

The below feedback provided by PEAP members is grouped around common themes.

- *Acknowledge historical trauma*: Use trauma-informed language and take the time to learn the historical context of a population.
- *Listen to the community*: Community members need to be central in all stages of research, and questions should be open-ended to avoid making assumptions about panelist responses.
- *Create frameworks to legitimize DE&I work and codify guidelines and best practices:* Pull from the existing work in the community-based participatory research field.

Meeting Wrap-Up

Lisa Stewart, Senior Engagement Officer, Public and Patient Engagement, made an announcement on upcoming PCORI meetings and deadlines:

- Ambassador Workshop – November 18, 2020
- Advisory Panel Application Deadline – March 31, 2021 at 5 pm ET
- Winter PEAP Meeting (Virtual) – February 11-12, 2021
- PCORI 2021 Annual Meeting – November 17-19, 2021

Darien, Carman, and Neely Williams, Co-chair of the Advisory Panel on Patient Engagement, closed out the meeting by thanking everyone for their work. Carman highlighted accomplishments from the two days, including input from the panelists on PCORI's strategic priorities, its new authority to collect cost data, suggestions to bring new organizations to the table, and ways to increase engagement within the community.