



External Meeting Summary

Advisory Panel on Patient Engagement

May 16, 2022

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

Overview

The Advisory Panel on Patient Engagement (PEAP) Spring 2022 Meeting focused on opportunities for panelists to hear updates on PCORI's strategic planning activities, share and discuss timely PCORI stakeholder engagement activities, and discuss how panel members' experiences in the field may inform these efforts and what and how PCORI learns from them. The meeting agenda included the following:

- PCORI's Strategic Plan
- PCORI's Engagement Rubric
- Healthcare Costs and Value
- PCORI Updates
- PEAPs in Action (a PEAP member's perspective on, and lessons learned, from participating in PCORI-funded research)
- Upcoming Work and Next Steps

Update on Strategic Planning: PCORI's Strategic Plan

- Laura Lyman Rodriguez, Deputy Executive Director for Strategy and Planning, PCORI

Laura Lyman Rodriguez reviewed PCORI's strategic planning process and the cornerstones of its strategic plan: the [National Priorities for Health](#) and the [Research Agenda](#). Rodriguez emphasized the importance of these priorities in guiding PCORI's planned activities for the next decade. She also noted the importance of stakeholder input already received, which informed development of the Research Agenda. PCORI is finalizing the full strategic plan document for review by the Board of Governors. Rodriguez also discussed accessibility and communication strategies for disseminating the strategic plan once it is final. She then posed the following questions to panelists:

What are meaningful ways to engage with stakeholder communities represented on this panel to solicit ideas and inform topic development (e.g., convenings, surveys, webinars)?

- Utilizing the value of partnerships: leveraging those that already exist and intentionally creating partnerships with those not yet engaged with PCORI
- Leveraging ability to improve accessibility (e.g., using plain language or sign language interpreters)

How would a responsive, transparent Research Project Agenda development process be reflected from your perspective?

- Creating a mechanism through which stakeholders can provide feedback on the Research Project Agenda would be helpful to PEAP members.



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How could PCORI demonstrate relevance to stakeholder communities represented on this panel?

- Attending annual meetings of organizations and professional associations working directly with historically excluded communities
- Developing meaningful relationships to ensure PCORI's priorities align with those of the communities they serve
- PCORI should explore work being done to collect data on family caregivers and highlight the gaps and challenges around collecting data on caregivers.

Are there innovative ways you see organizations tracking community needs and concerns?

- Using asset-based framing, a model that defines communities by their assets and aspirations before noting the challenges and deficits, in addition to highlighting needs and concerns
- Integrating community assets and aims into the Strategic Plan implementation plan, as the Strategic Plan should aim to support existing mechanisms for community health needs and assets assessments rather than creating new ones

Update of the PCORI Engagement Rubric: Preliminary Findings for Discussion

- Kristin Carman, Director, Public and Patient Engagement, PCORI
- Michelle Johnston-Fleece, Senior Program Officer, Public and Patient Engagement, PCORI
- Tania Dutta, Senior Researcher, American Institutes for Research (AIR)
- Melissa Henry, Senior Technical Assistance Consultant, AIR
- Jennifer O'Rourke Lavoie, Patient Partner
- Lee Thompson, Principal Technical Assistance Lead, AIR

PCORI has contracted with the AIR to update its Engagement Rubric, originally developed in 2014. Lee Thompson from AIR shared preliminary themes from an environmental scan they conducted in which stakeholders external to PCORI provided guidance on barriers and facilitators to engaging stakeholders in research. This informed their draft vision for updating PCORI's Engagement Rubric, which they presented to the PEAP. Jennifer O'Rourke Lavoie, a patient partner on this project, led the PEAP in a Jamboard activity to discuss the following questions:

What do researchers and stakeholders need in order to work together on teams and on projects?

- Key components of successful collaboration between researchers, patients, and other stakeholders include:
 - Equality, transparency, accessibility, good intentions, investment (financial and otherwise), cultural competency, true engagement, and bidirectional communication



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What is most relevant to include in the updated Rubric?

- PEAP members recommended that the updated Rubric include ways of addressing the barriers found in the environmental scan, such as:
 - Concrete examples of how challenges have been addressed in the past
 - Resources to teach researchers how to prepare *before* community engagement
 - Guidance on building stakeholder relationships that “go beyond” the research question
 - Strategies to address engagement in a hybrid world (e.g., leveraging virtual interactions, using multimodal communication strategies)
 - Linking to/expanding PCORI equity and inclusion principles in the Rubric
 - Guidance for funders supporting engagement (e.g., flexibility)
 - Guidance on how to intentionally select outcomes and objectives of research
- The importance of impact: ensuring outcomes and measures are relevant to the community being engaged and disseminating relevant information appropriately

What should the updated Rubric do and for whom?

The panelists did not directly address the “for whom” section of this question during this meeting; however, it may serve as a future point of discussion.

- Include a mentorship component
- Ensure that engagement is held to the same rigor as research
- Provide guidance on finding existing engagement resources from trustworthy organizations
- Clarify the difference between skills needed for general engagement and specifically engaging diverse groups

Healthcare Cost and Value: Addressing the Full Range of Outcomes

- Greg Martin, Acting Chief Engagement and Dissemination Officer, PCORI
- Kristen Giombi, Research Economist, RTI International
- Olga Khavjou, Research Economist, RTI International

PCORI recently developed a project studying healthcare cost and value with the aim of supporting understandings of “patient-centered value” across stakeholder groups, in patient-centered research, and in policy development. After reviewing the objectives of the project, Greg Martin discussed the project’s progress on conducting a landscape review of the meaning of patient-centered value in health and health care, and hosting convenings with patient and stakeholder representatives via key informant interviews, small focus groups, and large group discussions. The findings from these activities will be described in a report that will be delivered to the PCORI Board. This was followed by a moderated discussion with the PEAP, during which key insights emerged.



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Do the direction, activities, and goals resonate with you?

The panelists did not directly address this question during this meeting; however, it may serve as a future point of discussion.

Will the activities meet the informational needs of your stakeholder community?

The panelists did not directly address this question during this meeting; however, it may serve as a future point of discussion.

What additional considerations should be kept in mind as we proceed?

- Healthcare value is defined in many different ways. It is important to develop a common lexicon when discussing value of outcomes, value of care, cost benefit, etc.
- Not *accessing* health care is different than not *valuing* health care. Contextual factors and cultural norms can influence decisions to seek care, and it is important to understand why people act the way they do in terms of seeking and valuing care.
- Elevating value means looking at the person as whole; this includes mental health care, preventative health care, medication management, and provider interference before conditions become irreversible. Patients feel valued when they experience trust, thoroughness, and concern; making patients feel valued also necessitates understanding caregivers' limitations.

PCORI Updates

- Kate Boyd, Senior Program Officer, Eugene Washington PCORI Engagement Awards
- Courtney Clyatt, Senior Program Officer, Eugene Washington PCORI Engagement Awards
- Michelle Johnston-Fleece, Senior Program Officer, Public and Patient Engagement
- Karen Martin, Program Director, Eugene Washington PCORI Engagement Awards

Michelle Johnston-Fleece and Karen Martin provided updates on two new PCORI Engagement Awards: [The Science of Engagement Initiative](#) and the [Building Capacity for Small Organizations to Engage in PCOR/CER Award](#). Recipients of both new awards will be engaged in respective learning communities.

During the open comment period, the PEAP suggested hosting an applicant workshop for the Engagement Awards program, featuring successful awardees to discuss their challenges and experiences applying for funding. Panelists also suggested (1) partnering with community organizations who may be able to help smaller organizations draft proposals, and (2) building a mentorship component into these awards to help guide new awardees.



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PEAPs in Action

- Beth Careyva, Lehigh Valley Health Network

Beth Careyva described her experience as a clinician, healthcare executive, and health services researcher engaging with PCORI—noting her lessons learned and future opportunities for others. She described the challenge of balancing the engagement of patients without overburdening them during a project on cancer screening. Careyva also described working with community stakeholders on data collection, research question development, study design, and results review/analysis. Based on Careyva's experience with patient advisory teams, she offered the following best practices for similar work: use structured agendas, clear definitions, frequent communication, and skilled facilitators; and provide materials for stakeholders to respond to rather than ask them to create materials from scratch. She also recommends engaging patients from the onset of work; expanding participants' roles to ensure purposeful, meaningful engagement; proactively addressing issues of retention; and sustaining engagement between meetings. Panelists then engaged in a brief discussion:

What within this resonated with your experience?

- Panelists agreed with the idea of involving skilled facilitators in this work.

What have you done differently that you found to be effective?

- Panelists suggested starting observation and qualitative work before designing an aid or intervention (e.g., surveys, interviews).

What other engagement strategies are you considering within hybrid communication (i.e., virtual and in person)?

The panelists did not directly address this question during this meeting; however, it may serve as a future point of discussion.

Upcoming Work and Next Steps

- Meghan Berman, Program Associate II, Public & Patient Engagement, PCORI

Meghan Berman shared updates on the work of the Patient-Centered Approach Workgroup, a voluntary subset of PEAP members who advise on PCORI's evaluation agenda and staff-led projects that assess the effectiveness of PCORI's approach or build evidence about promising practices for patient-centered research. After noting their advisory role on several PCORI projects, she explained that the Workgroup's meeting agendas and summaries will be featured on a designated PCORI website page.

Berman then reminded PEAP members of important dates for upcoming meetings:

- PEAP Meeting (October 25)
- Upcoming Board Meetings (June 13 & 14, July 26, September 19 & 20, December 13)



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- PCORI Annual Meeting (October 26-27)

Brendaly Rodríguez, Senior Engagement Officer at PCORI and former PEAP member (2017-2020), noted the strength of PEAP member relationships and described her journey with PCORI over the years. Kristin Carman and Karen Fortuna, PEAP Co-chair, then thanked Lisa Stewart, former Senior Engagement Officer at PCORI, for her tenure with the PEAP, and the PEAP members for their time and participation, and then closed out the meeting.