MEETING SUMMARY

Studying PCORI's Patient-Centered Approach

A Workgroup of PCORI's Advisory Panel on Patient Engagement (PEAP)

November 4, 2021

OVERVIEW

The PEAP Studying PCORI's **P**atient-**C**entered **A**pproach (PCA) Workgroup meeting on November 4, 2021, focused on plans for a scoping review on engagement literature that PCORI is conducting with a team from RTI International. This scoping review is being conducted to (1) help PCORI and our stakeholders understand the depth and breadth of information about engagement currently captured in PCORI's Engagement in Health Research Literature Explorer, (2) describe gaps in the engagement literature to identify opportunities for PCORI to advance the science of engagement, and (3) improve the usefulness and use of the Literature Explorer.

PCORI staff sought the PEAP PCA Workgroup's input on the proposed approach and methods for this project, with an emphasis on understanding workgroup members' information needs and priorities to ensure the scoping review will address what patients and stakeholders need to know about engagement in health research.

ATTENDEES

PEAP PCA Workgroup Members	PCORI Staff	RTI International Staff
• Beth Careyva • Karen Fortuna • Crispin Goytia-Vasquez • Neely Williams	• Lauren Fayish • Rachel Hemphill • Michelle Johnston-Fleece	• Karen Crotty

DISCUSSION SUMMARY

Lauren Fayish (Program Officer, Evaluation and Analysis, PCORI) and Karen Crotty (Program Director and Senior Research Scientist, RTI International) presented information about the project and facilitated a discussion about the proposed approach and methods and workgroup members' information needs and priorities for topics to include in the scoping review. Below, we summarize themes from PEAP PCA Workgroup members' input.

PEAP PCA Workgroup input regarding information needs for the scoping review:

- **Strategies for patient engagement:** PEAP PCA Workgroup members suggested identifying articles that describe how patients are engaged in health research, including the processes, activities, and best practices for patient engagement. Categorization should help describe patient-centered approaches for engagement in different types of research and health conditions and highlight information to facilitate the involvement of patients as partners in health research. This information can be used to show patients and researchers how patients can be involved in a research project.
- **Best practices for engagement:** Workgroup members recommended identifying articles that describe specific methods used to achieve successful engagement—for example, effective strategies for training stakeholders and researchers to participate in research, ways to successfully engage partners in different types of research (e.g., different health conditions and different study designs) and at different times in the research process, strategies for facilitating strong engagement in virtual settings, and methods for sustaining partnerships.
- **Outcomes of engagement:** Workgroup members recommended identifying information about the effects and outcomes of engagement, including the influence partners have on the design and conduct of research.
- **Ensuring equity:** Workgroup members emphasized the need for information about equitable engagement, including how equity is considered and maintained and what equity means for stakeholders, particularly individuals from disadvantaged populations.
- **Strategies for measuring engagement:** Workgroup members recommended identifying the tools and resources multi-stakeholder research teams use to assess the degree of engagement in research projects as well as the effects of that engagement. Members noted it would also be helpful to identify strategies for incorporating feedback from partners to improve ongoing engagement.

PEAP PCA Workgroup input regarding PCORI's Engagement in Health Research Literature Explorer:

- Workgroup members discussed the value of including the following proposed topics as filters within PCORI's Engagement in Health Research Literature Explorer: descriptions of engagement, engagement contexts, impacts of engagement, and engagement best practices.

- Workgroup members suggested some specific elements to capture within these categories, including the types of engagement that work well for particular populations, how and when engagement was measured, how to sustain partnerships, and barriers to engagement.

Additional input from PEAP PCA Workgroup:

- Workgroup members also emphasized a need to share engagement standards and practices for engagement across the research community—for PCORI, PCORnet® the Patient-Centered Clinical Research Network, and beyond. While the scoping review can identify relevant information, tools like PCORI's Engagement Rubric can help operationalize approaches to engaging and measuring engagement, and standards can foster a common ground of understanding of engagement principles in the field.