MEETING SUMMARY

Studying PCORI's Patient-Centered Approach

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

March 19, 2020

OVERVIEW

The PEAP Studying PCORI's **P**atient-**C**entered **A**pproach (PCA) Workgroup meeting on March 19, 2020, focused on a PCORI staff-led project being conducted in collaboration with colleagues from RAND Corporation to conduct a landscape review and gap analysis of measures of patient and stakeholder engagement in health research. PCORI staff sought the PEAP PCA Workgroup's input on the project plan, including priorities for which aspects of engagement are important to measure.

ATTENDEES

PEAP PCA Workgroup Members	PCORI Staff	RAND Staff
• Crispin Goytia-Vasquez • James Harrison • Brendaly Rodriguez • Beverly Rogers • Sandy Sufian • Daniel van Leeuwen • Neely Williams	• Christine Broderick • Lauren Fayish • Laura Forsythe • Rachel Hemphill • Michelle Johnston-Fleece	• Tom Concannon • Alice Kim • Sameer Siddiqi

DISCUSSION SUMMARY

Lauren Fayish (Program Officer, Evaluation and Analysis, PCORI) and RAND staff presented information about the project and facilitated a discussion about key aspects of engagement to measure, the project's focus and research questions, and key stakeholder communities to hear from. Below, we summarize input from PEAP PCA Workgroup members' discussion of guiding questions.

Question 1: What aspects of patient and stakeholder engagement in research should be measured and evaluated?

- Depth of researcher-patient relationship
- Application of Community-Based Participatory Research principles

- Application of professional ethics and principles by researchers
- Who, what, where, why, how:
    - Who are we engaging: patients, clinicians, researchers, or organizations; individual engagements or relationships and partnerships
    - What parts of the process have engagement: governance, design, recruitment, operations, analysis, dissemination
    - Where: academic, national, rural, community
    - Why is engagement important: access to information, decision-making, inclusion and participation, accountability, local capacity, access to resources
    - How does engagement impact research processes: recruitment, retention, change of study questions, partner roles on research project
- Paid and unpaid involvement
- Leading and participating roles
- Stakeholders' perception of engagement (e.g., Was it meaningful? Were engaged stakeholders satisfied?)
- Does engagement meet the key foundational aspects or best practices of engagement (e.g. trust, mutual respect, open dialogue)?
- Does engagement adhere to the PCORI Engagement Rubric recommendations?
- Address and consider transitions between projects – maintaining connections when there is not active engagement
- Diversity of engaged participants
- Engagement metric tools: what kind of tool is needed so engagement can be reflected in a scientific and meaningful way?
- Consistency and sustainability of implementation of findings

Question 2: Are these the right research questions to guide PCORI's work on this project? Are any questions unclear or missing?

Research Question 1: What topics or domains of engagement should be measured?
Research Question 2: What characteristics of measures are important, and why?
Research Question 3: What are the existing measures of engagement and their characteristics
Research Question 4: How can existing measures be used or refined through PCORI work?
Research Question 5: What new or revised measures are needed?

- A literature review: start with the fundamental processes of a literature review with domains for each aspect of the wider landscape and gap analysis. There are several methods books for literature reviews that we could draw on.
- Do healthcare professionals have what they need to ensure a patient is engaged? Do patients have enough information to ensure they are engaged? Is everyone informed or educated enough to make the decisions for themselves whatever the

tools are, whether it is a patient portal, telehealth, etc.? Do we know enough to actually measure engagement?

Question 3: Which stakeholder communities, in addition to patients, are especially critical to hear from and why?

- Caregivers
- Community action groups
- Principal investigators and researchers
- Funders and policymakers are very important. If we want to embed patient and stakeholder engagement in all research, not just PCORI-funded research, it is particularly important to have these groups at the table because they can help set priorities.

Additional PEAP PCA Workgroup Input

- Patient-reported outcomes and patient-reported experience literature may be interesting to look at since patients are already engaged in those areas for clinical outcomes. Methodology from these fields may be helpful for the current project.