



MEETING SUMMARY

Studying PCORI's Patient-Centered Approach

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

January 27, 2021

OVERVIEW

The PEAP Studying PCORI's **P**atient-**C**entered **A**pproach (PCA) Workgroup meeting on January 27, 2021, focused on discussing how PCORI tracks the uptake and use of evidence from PCORI-funded research into real-world settings. PCORI staff sought the PEAP PCA Workgroup's feedback on PCORI's current efforts to track uptake, as well as their ideas for additional ways to advance this work (e.g., how can we know if patients are using PCORI research results? What other avenues of research uptake and use are we missing?).

ATTENDEES

PEAP PCA Workgroup Members	PCORI Staff
• Beth Careya • Sarah Donelson • Maureen Fagan • Crispin Goytia-Vasquez • James Harrison • Neely Williams	• Heather Edwards • Laura Forsythe • Rachel Hemphill • Michelle Johnston-Fleece • Emily Russel • Nick Wilson

DISCUSSION SUMMARY

Emily Russel (Senior Program Associate, Evaluation and Analysis, PCORI) presented information about the project and facilitated a discussion about tracking uptake of PCORI-funded research. Below, we summarize themes from PEAP PCA Workgroup members' input.

- **Getting the right medium:** PEAP PCA Workgroup members emphasized the importance of getting the right medium or outlet of information for patients and caregivers. This might include things like health blogs, traditional media (e.g., newspapers, magazines, radio), Wikipedia, and social media groups/discussion boards. It also involves understanding who the trusted sources of information are and the role that these sources play in disseminating information. Workgroup members suggested that one way for PCORI staff to explore where patients and caregivers get information about specific health topics or healthcare options is to try using search engines to search for relevant terms and see what the top search

results are. Patients don't necessarily go to WebMD—they do a web search and see what comes up. PCORI staff could use this technique to understand where patients and caregivers might go for information about specific topics and then explore possibilities for tracking or connecting with those information sources.

- **Language:** Both plain-language summaries in English and translated summaries of research results in languages other than English are important and can help us understand how widely results are being shared and if they're being shared in ways that meet patients' needs.
- **Making connections with continuing education providers and electronic health record systems:** PCORI may want to connect with groups like the Accreditation Council for Graduate Medical Education and EPIC (or other electronic health record systems) to understand how PCORI research evidence is shared, or can be shared, through these outlets.
- **Pathway from dissemination to uptake:** PEAP PCA Workgroup members commented on the pathways of successful uptake, which often start with targeted dissemination. Having community members involved in disseminating results to their networks is critical. PCORI should consider strengthening our requirements for dissemination activities in our funded projects and ensure that project budgets adequately cover dissemination activities.