



MEETING SUMMARY

Studying PCORI's Patient-Centered Approach

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

February 1, 2022

OVERVIEW

The PEAP Studying PCORI's **Patient-Centered Approach** (PCA) Workgroup meeting on February 1, 2022, focused on a PCORI staff-led project to examine the extent to which PCORI's funded research projects include study participants from diverse populations and groups that are representative of those with the highest burden of disease. PCORI staff sought the PEAP PCA Workgroup's input on the proposed approach and methods for this project and recommendations on how best to interpret and disseminate findings.

ATTENDEES

PEAP PCA Workgroup Members	PCORI Staff
• Russell Bennett • Crispin Goytia-Vasquez	• Kim DiGioia • Rachel Hemphill • Michelle Johnston-Fleece

DISCUSSION SUMMARY

Kim DiGioia (Program Officer, Evaluation and Analysis, PCORI) presented information about the project and facilitated a discussion about definitions of diversity, project methods, and strategies for interpreting and disseminating subsequent findings. Below, we summarize themes from PEAP PCA Workgroup members' input.

- **Capturing information about social determinants and other dimensions of diversity:** As part of the discussion about information PCORI should collect related to study participants, PEAP PCA Workgroup members suggested that it would be important to consider gender, socioeconomic status, beliefs, and social determinants of health, including food insecurity and health literacy. Members also cautioned that the salient dimensions of diversity will differ for every study.
- **The importance of engagement, trust, and transparency:** As a key step on the path toward enhancing diversity of study participant populations, the PEAP PCA Workgroup members emphasized that early engagement with study participant populations is critical. Community engagement is intertwined with cultural norms and issues around trust and

transparency, which must also be taken into consideration as we aim to include more diverse study participants in research.

- **Measuring social determinants of health:** PEAP PCA Workgroup members noted that there is not yet one specific resource that we can turn to for guidance on operationalizing and measuring social determinants of health in the context of a comparative effectiveness research study. There is still a lot of work to do in this space before we get to clear guidance for investigators on best practices.

- **Future PCORI-funded research portfolios to examine:** This staff-led project is starting with a close look at diversity of study participants in the following condition-specific areas of PCORI's funded research portfolios: cancer, cardiovascular disease, and diabetes. PEAP PCA Workgroup members recommended that staff consider examining diversity of study participants in PCORI's funded research on mental health and gastrointestinal issues in the future.

- **Sharing findings:** One possible audience for these findings might be the National Hispanic Medical Association, or similar interest groups.