

## Advisory Panel on Patient Engagement Meeting Summary

April 2016

### Overview

The Advisory Panel on Patient Engagement met on April 11, 2016 to offer feedback and advice on how PCORI evaluates engagement. The panel looked specifically at PCORI's third goal, which is to influence clinical and healthcare research funded by others to be more patient-centered.

At the start of the meeting, the panel was introduced to new PCORI staff, including the new Chief Science Officer, Evelyn Whitlock. New Engagement team staff were also present, including Chinenye Anyanwu, Engagement Officer, and Sunbo Igbo-Osagie, Program Associate.

### Related Information

- [About This Advisory Panel](#)
- [Meeting Details and Materials](#)

The Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created to help people make informed healthcare decisions.

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## **Q&A with Joe Selby**

Dr. Joe Selby, PCORI's Executive Director, underscored the importance of showing that engagement in research makes a difference. He emphasized that the work of the panel will help to further strengthen the accumulating evidence of the impact of patient engagement in research, such as how patient engagement has increased participation of patients in clinical trials. Following his introduction, Dr. Selby answered some questions from panelists. A question was asked regarding whether CER will become cost effectiveness research instead of comparative effectiveness research. Dr. Selby explained that PCORI has succeeded in showing that cost and comparative effectiveness are different by providing the clinical inputs to a cost effectiveness evaluation. The question, "What is the value of PCOR?" is often asked of PCORI, which Dr. Selby considers something that PCORI should evaluate while considering patients' values.

Panelists asked if PCORI is seeing more participation and better inclusion of diverse and underrepresented populations among investigator teams and across groups being studied in funded research. Dr. Selby explained that PCORI has been evaluating how those hard-to-reach populations are included. The evaluation team collects demographics of the Project Investigators, and they will consider how to collect the demographics of the broader research teams.

## **Patient Engagement in Action**

Members of the panel shared how their respective actions and activities have influenced the drug development community as well as other sectors in the healthcare ecosystem to be more patient-centered.

Marc Boutin provided an overview of the efforts of patient engagement in research over the past couple of decades, which has helped move toward a patient-centered approach in drug development. He applauded the work of the PEAP in helping to move along patient-centeredness and predicted that, within five to ten years, the whole health ecosystem will look dramatically different.

Kim McCleary described the work of FasterCures and how they work to expand thought leadership, enhance practice, and improve policy. Specifically, she summarized findings from the "Operational Tools to Support Expanded Patient Engagement." In a survey that resulted from the meeting, the promotion of existing resources was found to greatly contribute to patient-centeredness while presenting a low challenge to execution.

Anjum Khurshid discussed the new Interoperability Experience Task Force that was created by the Office of the National Coordinator for Information Technology. The task force was created in response to the observation that the healthcare industry is still siloed despite the adoption of electronic medical records. The goal of the task force is to improve the experience of patients and providers through technical policy and other barriers. Khurshid's panel includes patients on the task force, including PCORI panelists Jane Perlmutter and Phil Posner. He stressed the importance of their inclusion in this work by sharing their experiences.

## **Farewell Luncheon**

At a farewell lunch ceremony, seven panelists were honored whose terms have ended. These panelists include Kristin Carman, Perry Cohen, Bruce Hanson, Amy Kratchman, Kim McCleary, Julie Moretz, and Sally Okun. Joe Selby and Sue Sheridan thanked all the outgoing panelists for their service and dedication to PCORI's mission of patient engagement. Panel Chair Charlotte Collins will be staying on as a panelist while a new co-chair is groomed to serve alongside Darius Tandon.

## **Telling the PCORI Engagement Story**

In the afternoon session, PCORI Engagement staff provided a high-level overview of the various engagement programs including:

- Ambassador Program
- Pipeline to Proposal
- Advisory Panel on Patient Engagement (PEAP)
- Engagement Rubric
- Engagement Officers
- Compensation Framework
- Current Patient/Caregiver Partners in PCORI Portfolio

The PEAP then broke into three small group discussions with each group being assigned to one of the evaluation models below:

- Model for Evaluating the Impact of PCORI: What is the Effect of PCORI's Approach to Developing a PCOR Community?
- Model for Evaluating Engagement in Research: What is the Effect of Engagement in Research?
- Model for Evaluating the Overall Impact of PCORI: How Does PCORI's Work Influence Others?

The PEAP was asked to address the questions below:

- How do the engagement programs/activities map to the models for evaluation?
- What potential evaluation questions and metrics could we add to the evaluation models to more effectively demonstrate the value of the engagement programs?

Some of the panelists suggested new evaluation measures to more effectively tell PCORI's engagement story including:

- Measuring PCORI's influence on the broader healthcare ecosystem (not only the research community) to become more patient-centered
- Measuring research relevance with patients
- Comparing outcomes in PCORI studies to outcomes in studies funded by other research funders



- Measuring the number of patients in the “PCOR community” in a more inclusive manner to include patients engaged in PCORnet
- Measuring diversity in the various activities at PCORI

Working with PCORI’s Evaluation and Analysis Team, the Engagement Team will help synthesize the recommendations from the PEAP regarding proposed new evaluation questions and measures. These recommendations will be considered for inclusion in future iterations of the Evaluation Framework.

The results of this meeting are intended to inform the board, the evaluation and analysis team, the public, and the upcoming portfolio mining process. The next Advisory Panel on Patient Engagement meeting is scheduled for October 21, 2016. The panel will welcome seven new panelists at that meeting.