Advisory Panel on Patient Engagement Meeting Summary

February 2014

Overview

On January 13–14, 2014, the PCORI Advisory Panel on Patient Engagement convened in Washington, DC, to review and counsel PCORI on its efforts to model full and meaningful patient and stakeholder engagement in its programs.

The Advisory Panel on Patient Engagement is made up of 21 representatives of patients, caregivers, patient advocates, clinicians, researchers, industry, and policymakers. The panel was joined by PCORI leadership, staff, and Board member Gail Hunt. The meeting was open to the public via teleconference, and slides and meeting materials were posted to the website in advance of the sessions.

At the meeting, the panel discussed and advised PCORI on programs including the inaugural Pipeline to Proposal Tier I Awards, the Eugene Washington PCORI Engagement Awards Program, the Ambassadors Program, PCORnet, and Patient-Powered Research Networks (PPRN). The panel also deliberated on projects in development, including the Patient and Family Engagement Rubric, a position statement on parity in compensation to patients engaged in PCORI-supported research, and patient-engagement criteria for the PPRNs.

The panel decided to create two subcommittees to advise PCORI on evaluation of its programs and development of a position statement on compensation.

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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Introduction

The Advisory Panel on Patient Engagement reviewed specific areas for improving the patient-centeredness of PCORI programs and initiatives. They included the inaugural Pipeline to Proposal Tier I Awards,[1] the Eugene Washington PCORI Engagement Awards Program,[2] the Ambassadors Program,[3] PCORnet,[4] and Patient-Powered Research Networks[5] (PPRN).

Framework for Meaningful Patient Engagement

At its previous meeting, the advisory panel had focused on the PCORI Patient and Family Engagement Rubric, which PCORI staff had developed to guide applicants, merit reviewers, awardees, and PCORI program staff on meaningful engagement practices, without stifling innovation or being prescriptive. The rubric was created by PCORI staff by identifying promising practices of engagement within our first three funding cycles. The panel tested the prototype and provided recommendations that improved usability.

In January, at its third face-to-face meeting, the panel discussed the most recent iteration of the rubric[6] and the staff's plan for its implementation. The panel stressed implementation of the rubric, for example, emphasizing that this rubric does not present a one-size-fits-all approach. Rather, the engagement practices identified may not be applicable to every project, and the degree of engagement may vary without decreasing the significance of the partnership. As one panelist pointed out, while it may be important to include patients in every stage of the research project, it is critical that they play a role in deciding to what degree they wish to be included in each step.

Sample PCORI Evaluation Questions

- Does "research done differently" make a difference? Is it worth it?
- What are the effects of "the PCORI way" on the quality of research and usefulness of the information that results? Is it worth it?
- If the PCORI way works, what's the best way to implement it?
- What are the most effective ways to engage people?

Evaluating PCORI's Work

Dr. Michele Orza, PCORI's Senior Advisor to the Executive Director, and Dr. Laura Forsythe, Senior Program Officer Research Integration and Evaluation Program, presented PCORI's draft evaluation

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[1] Available at pcori.org/funding-opportunities/pipeline-to-proposal-awards/

[2] Available at pcori.org/funding-opportunities/eugene-washington-pcori-engagement-awards/

[3] Available at pcori.org/blog/pcori-ambassadors-building-an-empowered-research-community-2/

[4] Available at pcori.org/funding-opportunities/pcornet-national-patient-centered-clinical-research-network/

[5] Available at pcori.org/funding-opportunities/funding-announcements/patient-powered-research-networks-pprn-improving-infrastructure-for-conducting-patient-centered-outcomes-research-pcor/

[6] Available at pcori.org/assets/2014/02/PCORI-Patient-and-Family-Engagement-Rubric.pdf

framework, which outlines the major questions we aim to answer about PCORI's work and how we plan to go about answering them. The initial list of fundamental questions was developed by the PCORI Evaluation Group, a collaborative group of PCORI staff, PCORI Board members, PCORI Methodology Committee members, and external evaluation experts, including Kimberly Bailey of the Advisory Panel on Patient Engagement. The panel provided feedback on the draft evaluation questions, as well as how to prioritize the questions, and how best to capture this information.

The panel reiterated the importance of representing community and patient perspectives in the evaluation and development of measures for success. This representation will better inform the metrics we track, as well as present opportunities for more-immediate measures of impact in the community. The panel recommended that we collect different perspectives to map out PCORI's impact on different players at different stages of research. The panel also noted that not all evaluation components will be applicable across all projects and programs.

The panel endorsed a holistic approach to developing an overall evaluation strategy that aims to measure the impact of patient engagement in research, as opposed to simply assessing individual research practices. The panel recommended a focus on tracking the usability of information generated by PCORI projects: how PCORI findings inform patient decisions, clinical care, standard-of-care guidelines, insurance reimbursement schedules, etc. To provide more strategic guidance, the panel decided to create a subcommittee to work with staff and the PCORI Evaluation Group.[7]

Parity of Compensation in Research

In previous meetings, the panel discussed parity in compensating patient partners in research projects. PCORI recognizes how important it is that the time and contributions of patient partners be valued and that appreciation be demonstrated in fair financial compensation, as well as making only reasonable, thoughtful requests for time commitments. PCORI had tasked the panel with drafting a position statement providing guidance on the practice of equitable compensation of patient and stakeholder partners for their contributions to a research project.

The panel agreed at its January meeting that a PCORI position statement should not provide a blanket approach to participant compensation. The panel noted that purpose of compensating research partners is to remove barriers to participation on the team and reimburse the value of the partners' time and commitment. To be fair and reasonable, the actual implementation of this compensation would have to be considered case by case. For instance, some patient partners may not be able to accept federal financial compensation for their participation, some patient partners may require different levels of support based on their employment status, and the amounts budgeted for project teams will vary by project. The issue of risks associated with this opportunity was also raised by panelists, who noted that compensation should not be the primary incentive for becoming a research partner because, for example, it might attract people who are not genuinely interested the project.

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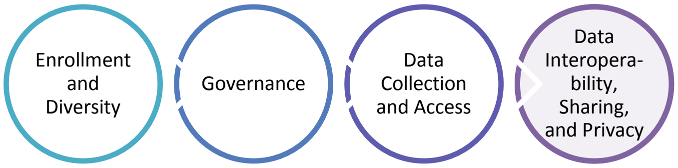
[7] Available at pcori.org/blog/evaluating-the-pcori-way-first-steps/

Patient Engagement in Data Network Development

The panel discussed patient-engagement criteria for PCORnet,[8] the national data network that PCORI is developing for conducting clinical outcomes research (see figure below). The panel provided feedback that staff incorporated into their presentations at the PCORnet kickoff meeting a week later.



The panel reiterated the importance of responsibly curating the data to ensure safety and transparency, for example promoting transparency by providing open access to organizations beyond the PCORnet awardees. The panelists noted the difficulty of integrating minority populations into research, which limits the available data. (During this and other discussions, the panel suggested that a group with representatives from various PCORI Advisory Panels address strategies to increase minority-population participation in research.)

Panelists recommended that PCORnet build standardized language and expectations, including standardized data elements, trainings, and milestones, as well as differentiating between patient-reported outcomes and patient-identified outcomes, which include not just the symptoms but also how they affect the patient's life.

Next Steps

- The Advisory Panel on Patient Engagement will form subcommittees in the upcoming months to advise PCORI on:
  - Evaluation of its programs
  - Development of a position statement on compensation of research partners
- The panel will work with other PCORI Advisory Panels to form a subcommittee to address strategies to increase minority-population participation in research.
- The panel will consider developing other subcommittees.
- The panel will continue to play a crucial role in refining the PCORI Patient and Family Engagement Rubric and advise PCORI on its use.
- The panel will continue to advise PCORI staff on the patient-centeredness elements of PCORnet.
- The panel will next convene in April 2014.

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[8] Available at pcori.org/funding-opportunities/pcornet-national-patient-centered-clinical-research-network/