Advisory Panel on Patient Engagement
September 20-21, 2013, Meeting Summary

Overview

On September 20-21, 2013, the Patient-Centered Outcomes Research Institute (PCORI) convened the Patient Engagement Advisory Panel to discuss PCORI's key evolving patient engagement initiatives, including the Ambassador Program, Pipeline to Proposal Awards, and PCORI's plans for developing an action plan for dissemination and implementation of research findings, as well as its effort to identify promising practices of meaningful engagement in the conduct of research.

The Advisory Panel and PCORI staff discussed how the strategic advancement of these initiatives could support achievement of PCORI's organizational goals—to increase the availability of information, speed implementation of research findings, and influence research practices.

Background

The Advisory Panel on Patient Engagement[1] includes patients, patient organizations, caregivers, clinicians, researchers, industry, and policy makers. The panel works closely with PCORI staff to ensure that PCORI activities reflect the highest standards of patient engagement and a culture of patient-centeredness. The panel advises PCORI on several subjects, including processes to identify research topics and priorities that are important to patients; all aspects of stakeholder review of applications for PCORI funding; the conduct of patient-centered research; methods to evaluate the impact of patient engagement research; communications, outreach, and dissemination of research findings; and other questions and areas of interest that may arise relevant to PCORI's mission and work.

This was the second convening of the panel. Members of the public were invited to listen to the discussion by joining a teleconference in "listen only" mode; questions and comments were accepted through advisorypanel@pcori.org. The meeting agenda and presentation slides are available on PCORI's website.

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[1] Available at pcori.org/get-involved/pcori-advisory-panels/advisory-panel-on-patient-engagement/.

Introduction

The meeting began with a series of updates from PCORI leaders about the institute's activities since the last panel meeting. Sue Sheridan, Director of Patient Engagement, and Anne C. Beal, PCORI Deputy Executive Director and Chief Officer for Engagement, set the stage for each day's discussion. Suzanne Schrandt, Deputy Director of Patient Engagement, Orlando Gonzales, Chief of Staff for Engagement, and Aingyea Kellom, Program Associate, provided updates and helped facilitate discussions with the panel on plans surrounding the PCORI Ambassador Program and Pipeline to Proposal Awards, as well as the Dissemination and Implementation Framework and Promising Practices in Meaningful Engagement in Research. Panel members were encouraged to propose other topics for discussion. Below, we summarize key discussions that took place over the course of the two-day meeting. Recommendations made by Advisory Panelists are for PCORI staff consideration and are not binding and do not necessarily reflect the opinion of PCORI.

PCORI Ambassador Program

The PCORI Ambassador Program is a volunteer initiative that will unite individuals and organizations around the promise of patient-centered outcomes research (PCOR). The initiative will equip, train, and mobilize patients, caregivers, organizations, and other stakeholders to share PCORI's vision, mission, and PCOR principles with their respective communities, participate as full partners in research, and facilitate the sharing and uptake of information generated from PCORI-funded projects.

At the outset of the PCORI Ambassador Program, Ambassador positions will be open to organizations, patients, caregivers, clinicians, researchers, and other healthcare professionals who (1) have participated in a PCORI workshop, roundtable, working group, or other designated PCORI event; (2) are members of PCORI advisory panels; (3) have served as PCORI merit reviewers and reviewer mentors; (4) are currently serving as a patient/stakeholder partners or researchers in funded PCORI projects; or (5) have hosted a PCORI presentation, panel, breakout session, or initiative. In six months, after the program has been established and evaluated, others will be given the opportunity to become PCORI Ambassadors. Our goal is to have at least one Ambassador in every state. Ambassadors will be asked to complete the PCOR Science training and Ambassador Web Intake, agreeing to comply with PCORI's principles, roles, and expectations.

Some key activities of PCORI Ambassadors include informing others about PCORI by sharing information, announcements, and other materials; participating in the Ambassador social network; enrolling in the PCOR Science training to cultivate skills for future participation as a patient/patient partner in research; collecting potential comparative effectiveness research (CER) questions; recruiting applicants for funding opportunities; and sharing results of PCORI projects with their networks.

Sheridan and Kellom called for the panel's feedback on PCORI's Ambassador Program activities to date. Below are the key recommendations of panel members.

PCORI must provide training and resources to PCORI Ambassadors to ensure the program's success. Panelists noted that training is important to ensure that Ambassadors are able to accurately relay PCOR messages to others. PCORI should provide a toolkit of resources for Ambassadors, such as a slide deck that Ambassadors can use to tailor outreach efforts to the needs of their audiences. PCORI should also train Ambassadors on innovative strategies that they can use to disseminate PCORI research results.

When researchers and patients partner to conduct research, it is important to train both parties. Both patients and researchers need support to understand each other's vocabulary and perspectives. Non-researchers in particular could benefit from a better understanding of the basics of methodology, engagement standards, and PCOR principles

PCORI should consider reaching potential Ambassadors through topic-specific or disease-specific patient communities. Panelists noted that many patients will approach PCORI through their connection to a specific topic area and that it makes sense to leverage those connections.

The Ambassador Program must be accessible to all interested stakeholders. Panelists raised concerns about the length of the list of activities for Ambassadors, noting that some may find the list of activities to be overwhelming or discouraging, even if they are not requirements. PCORI staff noted that the program will be set up so that Ambassadors can have varying levels of involvement. The only requirement will be that Ambassadors complete the PCOR Science training.

PCORI should clearly define the benefits of becoming an Ambassador and the value proposition for stakeholders to join the program. Several panelists were unsure of the benefit for researchers to join this program or the incentives that would drive them to participate. One panelist pointed out that because researchers are competing with one another for the same funding opportunities, they may not be inclined to share resources or inform others about available funding

Panelists suggested that PCORI could promote the program to researchers as a way to be informed about PCORI and have access to training and materials that will be useful in tailoring their responses to PCORI funding announcements.

PCORI must define expectations for organizations that will take part in the Ambassador Program. Panelists cautioned that most organizations would require a board resolution to become part of this type of program, often requiring several months of effort. Organizations will need a clearly defined role before they are able to be part of the program. One possibility is a different application process for organizations. The application could include a menu of different ways that the organization could be involved in the Ambassador Program.

Evaluation of the Ambassador Program is critical. Panelists stressed that PCORI should track the activity of the Ambassadors to understand whom they are reaching and where they are reaching them. To understand the program's impact, it is important to have feedback from both Ambassadors and the

people whom they are reaching. PCORI staff agreed and noted that they plan to have an "activity tracker" that Ambassadors can use to report their accomplishments to PCORI.

In the coming months, PCORI will:

- Invite the members of the Patient Engagement Advisory Panel to become the inaugural PCORI Ambassadors;
- Continue to enhance the draft Ambassador website until it is ready for publication;
- Launch the PCORI Ambassador program;
- Offer PCOR Science training in early 2014; and
- Determine how Ambassadors can facilitate relationships among organizations and connect PCORI programs.

Pipeline to Proposal Awards

The Pipeline to Proposal Awards provide resources to individuals, consumer/patient organizations, clinicians, researchers, and emerging partnerships, enabling them eventually to develop successful applications for PCORI funding announcements (PFAs). The program has three tiers, each of which provides different levels of funding:

- **Tier I awards**—up to $15,000 for up to nine months—available to individuals, consumer/patient organizations, clinicians, researchers, or a combination of stakeholders to support community building around an area of research interest to improve outcomes for patients, create structure and communication strategies, and develop an understanding of PCORI and "research done differently."

- **Tier II awards**—up to $25,000 for up to one year—available to emerging research/non-research partnerships to support data network and registry development, development of infrastructure, and the generation and refinement of a research question through community events.

- **Tier III awards**—up to $50,000 for up to one year—available to advanced research/non-research partnerships, including those that submitted PCORI proposals and were not funded. The awards are intended to support PCORI research proposal (re)submission focusing on the development of an engagement plan and research partnership skill development.

Currently, the Pipeline to Proposal Awards program is in its pilot phase. A pilot, intermediate funder for Tier I awardees has been announced, and the Tier I pipeline request for proposals (RFP) opened October 15, 2013. PCORI looked to the advisory panel to get a better sense of what characteristics the Tier I applicants and awardees should have, how the program can extend its reach so that people who have not already applied for funding will be aware of the RFP announcement, and how PCORI can ensure that

the application process is user-friendly. Below is a summary of panelists' feedback concerning PCORI's planned actions in this area.

PCORI is planning to target communities that normally would not have opportunities for funding. To accomplish this goal, panelists agreed that PCORI should set up different application tracks for junior researchers and grassroots groups. Panelists also suggested that PCORI set aside a certain amount of funding for each population that it hopes to target.

Strategic support for applicants is necessary to encourage strong proposal submissions. Panelists suggested creating a colorful, easy-to-read "Are you ready?" checklist and a list of frequently asked questions. Most panelists agreed that an example of a successful model, along with actionable criteria, would be most helpful to applicants. One panelist was concerned that excessive training could be a deterrent for some Tier I applicants. Others noted that testimonials from previous Tier I awardees could make the training seem less burdensome to applicants.

PCORI should expand and elaborate its application and evaluation criteria. One panelist suggested that PCORI ask applicants to write a narrative about something they have achieved either personally or professionally that took significant effort. PCORI staff agreed that the exercise would help them find awardees who had greater potential to achieve their proposed goals. Also, panelists encouraged PCORI to ask applicants how they view success because an applicant with clear measures of success will be more likely to get future funding.

Another panelist recommended that PCORI develop criteria for filling gaps in communities (e.g., geographically isolated populations) that are often overlooked by traditional resources.

PCORI should set standards that encourage collaboration and mentoring among awardee groups. A couple of panelists suggested that the Tier III awardees be required to reach down to help someone in Tier I. This mentorship structure could work especially well for junior researchers.

There are various ways to measure the program's success, especially because it is in its infancy. Panelists agreed that the program would be a success even if only one- third of the pipeline projects were completed. It would also be a success if PCORI received a high volume of applications on both ends of the pipeline; this would tell PCORI that it has activated groups that will eventually be ready to submit PFAs. Members stressed that success can also be demonstrated by groups' presence in the community, talking about CER and thinking about what research questions are important to investigate.

PCORI staff and panelists agreed that, for the Pipeline to Proposals Program to come to fruition, monitoring and evaluation of awardees' and applicants' successes and failures will be key.

In the coming months, PCORI will:

- Consider creating a mentorship program for Tier I applicants and applicants who were not selected. Ambassadors might serve as mentors;

- Release another round of applications for Intermediate Funders and continue to get the panel's feedback on various aspects of the Pipeline Program, including the role of the Intermediate Funders;
- Continue to consider avenues for reaching out to potential Tier I awardees;
- Consider developing a matching service for Tier II and Tier III awardees that will help operationalize the community's framing questions;
- Continue to revise the application process for Pipeline applicants to make it as user-friendly as possible; and
- Continue to host webinars to raise awareness of promising patient-engagement practices.

Developing PCORI's Action Plan for Dissemination and Implementation

PCORI's authorizing legislation calls for a focus on dissemination. It requires PCORI to make the findings of awardee research available no later than 90 days after completion, and the research findings must be made available to clinicians, patients, and the general public. Furthermore, the legislation states that the institute shall ensure that the research findings are conveyed in a manner that is **comprehensible and useful to both patients and providers** in making health care decisions. PCORI is working on an Action Plan for Dissemination and Implementation that is intended to close the gap between knowledge, practice, and optimal healthcare delivery using awardees' findings and existing research. The Action Plan will aim to:

- Guide awardees in disseminating their research findings;
- Speed implementation by actively facilitating how PCORI's research findings can be used by healthcare decision makers; and
- Evaluate how the dissemination of awardee findings reduces practice variations and disparities in health care.

PCORI has already led a number of efforts to inform the development of its dissemination action plan. One was an InCrowd survey of patients and providers. Survey results showed that the internet—not peer-reviewed literature— is the primary source of health information for both patients and clinicians. However, when patients were asked what source of information they most trust, they reported that it was their doctors. This discrepancy demonstrated that there is no one-size-fits-all approach to dissemination.

A roundtable on dissemination and implementation, convened on July 29, 2013, provided the following feedback regarding important topics related to dissemination:

Consortia. Involve key groups—patients, providers, consumers, media, journal publishers, opinion leaders, community and public health workers, government agencies, and health-data consortiums—to manage effective dissemination of research findings to speed their implementation.

Framework. Build on a variety of already existing frameworks and agree on a generalizable model which supports PCORI's mission.

Readiness. Include a preliminary plan for assessing readiness for the people and organizations affected by new knowledge.

Tailor Messages. Consider tailoring messages to different audiences through trusted channels. Include a focus on underserved populations.

Leverage Partnerships. Disseminate in coordination (not in isolation) with other organizations through the engagement efforts.

New Media. Be innovative and go to new venues, such as social media and magazines and journals not usually used for this purpose.

This feedback helped shape an RFP for a contractor to develop an action plan for the dissemination and implementation of comparative effectiveness research (CER) findings, as well as the process for evaluating those efforts (released August 30, 2013).

Beal emphasized that the PCORI Patient Engagement team will pull best practices from existing dissemination and implementation models and will be careful not to duplicate the Agency for Healthcare Research and Quality (AHRQ) dissemination programs. She called for the panel's feedback on what types of awards PCORI can offer that would encourage successful dissemination and what other dissemination strategies PCORI could execute or support. Below is a summary of the feedback that the panel provided.

PCORI should encourage proposal writers to think in advance about dissemination and implementation. The panel advised that the RFP should specify that dissemination and implementation will be a shared responsibility of the contractor, the research group, and the community. One panelist called for dual tracks—a research track and a dissemination track—to be written into the RFP..

PCORI's goal of presenting information to help inform decisions should drive the dissemination strategy. Multiple panelists highlighted the importance of engaging physician, patient, consumer, and professional associations to harness their communication strategies to translate awardee findings to targeted consumers. Successful dissemination and implementation will require engaging with the groups that care most about research findings and learning how to establish the credibility of the information with these groups. Panelists warned that if information is disseminated too quickly or without the certification of the relevant medical groups, few societies will share it. One concern about the broader dissemination strategy was that promoting certain findings over others could potentially cause insurers to limit access to other treatments.

In response to the findings of the InCrowd survey, which highlighted the use of the internet for health information, panelists suggested that PCORI invest in search engine optimization (SEO), social media, and other technologies for dissemination. To utilize such tools effectively, it would be important to study how populations search for information.

As a portfolio manager, PCORI can put awardees' findings in the context of other research, thereby helping consumers to sort through the uncertain nature of study results. PCORI has the responsibility to look at conclusions to make sure they are helpful and useful. One panelist is working with the National Health Council to define usefulness. His team put together a straw man to see what usefulness will look like at the patient and provider level. This type of criteria is useful to PCORI because it can help researchers define the questions they ask and evaluate. It will also provide context for a dissemination strategy.

PCORI should consider how adults learn. Adults look for information that confirms that their actions are positive and beneficial. One panelist emphasized that PCORI should think about what motivates action on a larger scale—across payers, regulatory and accreditation agencies, and information technology vendors — to see how PCORI can use them to drive practice change.

In the coming months, PCORI will:

- Hold a meeting to discuss future dissemination programs and the types of awards or projects PCORI can administer;
- Continue to explore how it will define and evaluate what research findings are valid and/or useful. Once this is established, it can become a framework for how PCORI characterizes awardee study results;
- Distribute information to the panelists on any finalized dissemination and implementation processes; and
- Continue to develop methods for dissemination and implementation training.

Call for Topics

Outside of the structured discussion on the PCORI Ambassador Program, Pipeline to Proposal Awards, and a framework for dissemination and implementation strategies, PCORI staff invited panel members to raise and discuss topics of their choice. Below is a summary of those discussions.

PCORI should clearly communicate how patient-safety researchers can apply for funding. PCORI will consider providing examples of patient-safety research that is currently being funded so that patient-safety researchers understand where their research fits within PCORI's portfolios.

While it is important that PCORI provides guidelines for applicants, PCORI should be careful not to cultivate a check-box mentality. It will be important to consider the delicate balance between funding

research teams that are already successful (i.e., academic medical centers) and providing support for non-traditional groups that have not yet had many funding opportunities.

PCORI should consider funding research on how new technologies are driving system changes and how integration of care is a key variable in deciding whether a system is functioning well. PCORI awardees could look at subspecialty groups and analyze how those networks could be used as a conceptual framework for system development. Both structural and system variables are important.

PCORI should evaluate the National Health Council's usability criteria and continue to develop a framework for evaluating proposals. PCORI will also continue to collect dissemination and implementation best-practices.

It is important for PCORI to explore the concept of meaningful engagement in research. The panel discussed the importance of establishing processes to ensure meaningful engagement of patients and other stakeholders in research to inform researchers, patients, and otherstakeholders about possible models for collaboration.