



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

October 2017

Overview

The Advisory Panel on Patient Engagement welcomed seven new panelists to the group. The new cohort includes Sonya Ballentine, Katherine Capperella, Brendaly Rodriguez, Beverly Rogers, Thomas Scheid, Norah Schwartz, and Freddie White-Johnson.

The meeting began with a warm welcome from co-chairs Jane Perlmutter and David White. Kristin Carman, Director of Public and Patient Engagement, gave a preview of what to expect during the meeting and reviewed the agenda.

Jean Slutsky, Chief Engagement and Dissemination Officer, and Andrew Hu, Director of Public Policy and Government Relations, led a discussion about PCORI's recent efforts to engage with stakeholder partners. Later, two guests from PCORI's Science division, Evelyn Whitlock, Chief Science Officer, and Claudia Grossman, Program Officer, gave an overview of current activities within Science and PCORnet, respectively.

Bill Silberg, Communications Director and Chinenye Anyanwu, Engagement Officer, previewed the upcoming PCORI Annual Meeting. Then the Communications team showed a draft of a new section of the PCORI website showcasing examples of influence.

Following lunch, directors from different PCORI Engagement Programs updated the panel on recent activities. Programs included: Eugene Washington PCORI Engagement Awards, Dissemination and Implementation, and Education and Training. The last presenter in this series was Kristin Carman, who then led a discussion on the future direction of Engagement at PCORI.

The meeting closed with brief introductions by each of the panel working committees: Engagement Rubric 2.0, Ambassadors Program, and Merit Review Mentor Program. Panelists were invited to stay for working committee breakout sessions following the full meeting.

Advisory Panel on Patient Engagement Meeting Summary

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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PCORI Science at a Glance

Evelyn Whitlock, Chief Science Officer, presented the work of the PCORI Science department with an introduction to research and evidence synthesis, programmatic goals, and portfolio highlights. Whitlock showed examples of patient engagement in the portfolio and emphasized PCORI research aims to implement evidence toward patient care and outcomes.

Evidence synthesis is part of PCORI's authorizing legislation and is a core responsibility. PCORI must work toward building the evidence base and synthesizing results for the public. Evidence synthesis allows PCORI to achieve a more comprehensive view of results, enhance knowledge, and identify evidence gaps. It also provides knowledge beyond individual studies and aggregate results. It helps to identify areas of agreement and disagreement in results (quantitative and qualitative). This methodology also allows PCORI's Science team to understand saturation of research areas and direct research funds toward projects that address knowledge gaps.

Because research is a lever for improving health care, PCORI plans to study the research portfolio using evidence synthesis methodologies to better explore variation in data and arrive at knowledge about the best treatment options. Evidence synthesis exercises can help answer questions like: How can PCORI's research portfolio come together to suggest synergy and gaps in our funding investments?

Whitlock noted that evidence synthesis cannot be separated from other PCORI methods, such as strategic topic development. For example, PCORI needs to ensure that nominated research topics are discussed in the context of the existing portfolio and other funders. The PCORI portfolio allows for these methods to address imbalances in our funding (condition, population, etc.) and communicate it to the public.

Programmatic goals for evidence synthesis include:

- Addressing heterogeneity of treatment effects (HTE) and range of treatment responses to develop more personalized healthcare options
- More rapid deployment of actionable comparative effectiveness study findings
- Communicate current portfolio to share value before results are available for dissemination
- PCORI pursues meta-analysis, predictive analysis, systematic reviews, and other techniques to identify actionable findings and add to the robust evidence base. For example, evidence mapping and proof-of-concept modeling help determine what is useful and in what context our findings can be more valuable.

Whitlock then highlighted some portfolio studies. PCORI is working to update evidence for the following topics:

- Psychological and pharmaceutical treatment evidence for PTSD
- Urinary incontinence and preterm birth
- Arthritis
- Stroke prevention...and more



Currently, PCORI is using evidence synthesis for portfolio mapping and communication to allow users to interact with our funded research. Even in these early stages, PCORI is already publishing papers from evidence synthesis work. High-priority topics that have emerged from the portfolio and public opinion include:

- The national opioid crisis: PCORI works across departments to synthesize evidence surrounding health crises. There are efforts to work on the opioid crisis outside of pain management and holistically explore the care continuum.
- New investments in palliative care (\$100 million) to ensure that patients receive the care they want in end-of-life treatment. One of the primary goals is to explore patient preferences/goals and alignment of treatment options.

PCORI wants to better incorporate patient engagement in the evidence synthesis work stream. To do so, PCORI is attempting to introduce more core outcomes by patients/caregivers. PCORI can start to influence outcomes measurements moving forward to be more patient-centered.

Annual Meeting Overview

Bill Silberg, Director of Communications, gave an overview of the upcoming PCORI Annual Meeting, which will take place October 31–November 2, 2018. The theme of the meeting is *delivering results and informing choices*. Goals for the meeting include reporting to the nation on selected results from PCORI's funded research and their usefulness, and learning how PCORI can do a better job of sharing results with communities. To date, there are 592 registrants for the meeting, which is comprised of 38 percent researchers and 36 percent patients. The Communications team is doing targeted outreach to boost attendance of payers, employers, and policy makers.

There are two registrant categories:

- PCORI awardees, prospective awardees/partners, and the broader stakeholder community
- GAO representatives. PCORI anticipates that the announcement of results at the Annual Meeting will breathe life into projects and results for GAO review.

PCORI decided that the Annual Meeting should be conducted not just for patients but rather with patients/stakeholders as speakers. For example, Freddie White-Johnson (PEAP member) will deliver the keynote speech and moderate a discussion about how PCORI can produce results that matter and share them with targeted audiences. Alan Alda, the actor who also works tirelessly as an advocate for science communication, is another plenary session speaker we are excited to have. Other speakers include Harlan Krumholz, board member, and Trent Haywood, who will be speaking about patient-centered healthcare improvement.

To incorporate buy-in from many groups, the Annual Meeting steering committee is comprised of patients and other stakeholders who help design the meeting and choose speakers and plenary panels/workshop panelists. There will be more stakeholder presenters and speakers at this Annual Meeting than ever before. Notably, 100+ Ambassadors and patients were awarded scholarships to attend the Annual Meeting. There are novel breakout session and workshop topics planned that include



data sharing, improving healthcare efficiency, D&I methods, opioid addiction prevention, and many more!

Chinenye Anyanwu, Engagement Officer, gave an overview of the patient, Ambassador, and trainee pre-conferences. The sessions are focused on engagement with patients, stakeholders, and graduate/medical students with an interest in PCOR. Goals for the sessions include building scientific capacity and helping to grow the respective communities. The sessions will provide an opportunity for patients and stakeholders to connect with junior researchers.

Preview of PCORI Influence Web Pages

Bill Silberg, Director of Communications, gave a quick glimpse at new PCORI “Influence” web pages. These pages showcase examples of influence that go beyond study results, demonstrating how PCORI is more broadly changing the culture of research. Examples of PCORI’s influence include how institutional policies and guidelines are changing to be more patient-centric. “Influence” examples show how engagement is changing the way research is done.

Currently, the website displays an initial collection of materials and case studies. Included are examples from the FDA Advisory Committee, the uptake of PCORI’s Engagement Rubric, and the Comparative Effectiveness Research Center. These examples have been vetted and investigated by PCORI Evaluation & Analysis staff.

Silberg requested panel volunteers to review the web page to evaluate its accessibility to patients and lay public. The Web team will send an email request to panelists to test aspects of the web page. Initial recommendations from the panelists included:

- Host a small focus group or webinar about website changes.
- Troubleshoot the page with patients who are blind or have compromised eyesight. *Note:* All PCORI web pages go through 508 compliance testing.

Engagement Program Updates

The panel was updated on recent activities of the four programs within the Engagement Department: the Eugene Washington PCORI Engagement Awards, Ambassadors, Education and Training, and Patient and Public Engagement.

Lia Hotchkiss, Director of the Engagement Awards Program, began the session with highlights from her program. Hotchkiss reported that the program received more Letters of Intent (LOIs) than ever before in the October 2017 application cycle. The program is building a national network of receptor sites for disseminating PCORI findings and evaluating how to use this platform to reach patient-led, patient-focused organizations not typically involved in research.

One lesson learned from three years of program operation is that it is vital to support organizations to encourage the dissemination of findings. Based on this understanding, the program revised its latest



funding announcement to de-emphasize categories of projects. Rather, the program is focusing on its goal of equipping organizations to have meaningful partners in dissemination and implementation of results. Other revisions include nurturing existing training content rather than creating new content, preparing applicants for the uptake and network development for sharing results, and revising the EAIN funding amount from 250k for two years to 50k for one year.

Hotchkiss highlighted two outstanding Engagement Awards: the INSPIRE research portal and Pastors 4 PCOR. There will be 23 Engagement Award posters presented at the PCORI Annual Meeting.

Two members of the Dissemination and Implementation program, **Jane Chang**, Program Officer, and **Arielle Gorstein**, Program Associate, provided updates on three pieces of the D&I program's ongoing work: meeting PCORI's public reporting mandate, PCORI's targeted dissemination activities, and the newest funding opportunity being offered by the D&I program. First, Chang reviewed the process PCORI has in place for releasing findings, the number of projects in each stage of that process, and the PCORI web pages that present these findings. Then she shared some information on PCORI's latest activities in targeted dissemination, highlighting the recent evidence update for prostate cancer. Finally, Gorstein provided background and details around the Implementation of Effective Shared Decision Making Approaches in Practice Settings PFA, which is the second funding opportunity to be released by PCORI's D&I team.

Erica Sarnes, Senior Manager, Education and Training, gave an overview of training and education activities. The continuing medical education (CME) credits are currently underway for the D&I program. Soon, research fundamentals of PCOR and CER will be implemented. Team Science is an initiative that will enable teams of researchers, patients, and stakeholders to participate effectively in PCORI-funded research teams. Patients are involved as members of advisory groups and pilot testing. Sarnes offered areas for PEAP involvement such as serving in advisory groups, recommending tools to include in environmental scans, and piloting test materials.

Following the presentations, the program presenters heard questions and comments from the panelists. A topic of discussion was shared decision making (SDM). Panelists would like to see more aggressive dissemination and education to underserved, underrepresented groups as well as clinicians. Panelists also recommended developing overlay with PCORI awardees and thinking about how SDM overlays can be utilized. Panelists noted that SDM is not a discrete activity or event, but rather, a process.

Panelists asked for clarification on the target audience of the Team Science initiative: Is it for patients or researchers? The initiative is for researchers, patients, and stakeholders so they can support each other as team members. PCORI recognizes that all parties need to be trained for this exchange.

Engagement: Future Directions

Kristin Carman, Director of Public and Patient Engagement, updated the panel on the future directions of engagement at PCORI. Before launching into her update, she recapped the April 2017 Advisory Panel Meeting and lessons learned from that exchange. Since that meeting, Public and Patient Engagement has integrated separate stakeholder and patient engagement teams into one group. PCORI 2.0 initiation



and the advancement of the science of Engagement have been priorities for the past six months. Other strategic areas of importance are strengthening stakeholder relationships, translating and sharing findings with the field, and dissemination and uptake. In the effort to promote dissemination and uptake, consideration is also being given to how to create receptor sites for findings and how to prepare communities to receive them. Carman discussed the IDIQ vehicle through which vendors will conduct key tasks that will support the overall goals of Public and Patient Engagement.

Panelists shared their thoughts on the direction of engagement after the presentation. Panelists asked: How is PCORI engaging with faith-based communities? There are multiple areas where PCORI is funding faith-based organizations to develop research and ready themselves to participate. These include projects that are working with faith-based organizations to help disseminate the implementation of their ideas. As the Patient and Public Engagement program develops ways to prepare communities for PCOR research, faith-based communities will play a significant role.

Panelists also discussed financial compensation for community organizations partnering with larger research organizations. If an applicant does not include compensation of their community partners in their plan, the Engagement Awards team responds to these applicants to ask that they revisit the ways they are compensating the community organizations. The program provides the tools to push researchers in the right direction to include fair reimbursement plans in their projects.

PEAP Working Committee Presentations

There are three newly formed Advisory Panel on Patient Engagement Working Committees. These are focused on the Ambassadors Program, the Merit Review Mentor Program, and revising the current PCORI Engagement Rubric. The committees were created with the overall goal of planning for the future of patient and public engagement.

Ambassador Program Working Committee – Co-chair **Sara van Geertruyden**, former panelist and representative from Partnership to Improve Patient Care, along with co-chair **Chinenye Anyanwu**, Engagement Officer, introduced their working committee to the panel. The purpose of this committee is to mobilize Ambassador Program participants to share PCORI's vision. Its goal is to provide guidance and inform components with redesign. So far, the committee deployed a 2.0 survey to current Ambassadors to determine how to revise program goals, objectives, and training materials to determine the infrastructures to maintain and develop. A main priority is deciding the best modes of communication with the program. Currently, Yammer is the primary mode of communication, which needs to be updated.

Merit Review Mentors Working Committee – Co-chair **Jane Perlmutter**, panelist, and **Whitney McInvale**, Program Associate, introduced the Merit Review Mentors working committee. The committee is focused on enhancing the structure of the mentor program, which is a peer-to-peer structure to help navigate the merit review process. The committee will hold bi-weekly calls and will



work in collaboration with the Merit Review team. Informational sessions with mentors, in the form of focus groups or interviews, are being planned.

Rubric 2.0 Working Committee – Co-chairs **Megan Lewis**, panelist, and **Lisa Stewart**, Engagement Officer, introduced the Rubric 2.0 working committee. The existing Engagement Rubric is a guiding foundation for PCORI's work; however, the field has changed. A main question for this committee is how to represent those changes in the Rubric. The committee will provide staff with recommendations for meaningful engagement and effective models.

Activities for this committee include summarizing the document about the history of reviewing influences and critiques, developing a timeline, conducting a literature review, gaining input from stakeholders, and ultimately providing recommendations. The committee will submit final recommendations to PCORI staff that will include dissemination strategies.

The full panel was invited to participate in working committee breakout sessions after the meeting.

Closing

Kristin Carman concluded the meeting with a recap of the day's discussions and thanked the panelists for their contributions.

After the full meeting, many panelists stayed on and had robust discussions in the three working committee breakouts. The working committees look forward to sharing their progress at the next panel meeting.

Slides from this meeting can be found on the event page. The next panel meeting will be held April 19 and 20, 2018.