

FROM THE ANNUAL MEETING

Ensuring Engagement in Patient-centered Research

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Patient centeredness in care and research continues to be important to SGIM members and to the general internal medicine (GIM) community. An ability to create partnerships among providers, patients, families, and communities is key to the successful participation in research by both study investigators and patients.

The Patient-Centered Outcomes Research Institute (PCORI) provides support for this type of research and characterizes patient-centered outcomes research (PCOR) as helping “people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options.”

Stakeholder engagement is a critical factor in this process. Defined as a “bi-directional relationship between the stakeholder and researcher that results in informed decision making about the selection, conduct and use of research,”¹ stakeholder engagement requires identifying and employing strategies for success.

In our second and final year of a PCORI Eugene Washington Engagement Award, the 2016 SGIM Annual Meeting in Hollywood, FL, included special programming dedicated to PCOR. These presentations continued our two-year series of workshops on this topic and incorporated results from our patient and physician assessments on knowledge and attitudes about patient engagement in PCOR.

Patient Engagement

Workshop participants learned about the PCORI Pipeline to Proposal program, a funding mechanism that al-

lows patients, researchers, and stakeholders (including clinicians) to develop partnerships in preparation for a full research proposal. The mission of the program is to build a national community of patients, stakeholders, and researchers who have the expertise and passion to participate in PCOR and to create partnerships within that community that lead to high-quality research proposals. The funded programs are divided into three tiers: 1) organizing partnerships to engage key stakeholders, 2) developing questions for research funding, and 3) proposal preparation. (For more information on this process go to <http://www.pcori.org/funding-opportunities/programmatic-funding/pipeline-proposal-awards/pipeline-proposal-awards>.)

One example of a Pipeline to Proposal program was a two-year-old PCORI-funded project called Family Wisdom, which was described by Family Voices representative Clarissa Hoover. This program allows Family Voices to work with community-based partners to cultivate relationships within their local communities. A group-based outreach strategy was described that has successfully built relationships and focused on capacity building among the partners.

Workshop participants also learned about the My PaTH Storybook Project, a new initiative to help patients and researchers engage in the PaTH Clinical Data Research Network. The main goal of this project, aimed at bridging the gap in helping patients frame effective research questions, is to improve patient feedback on prospective research topics. The session concluded with the ob-

servation that patient-centered outcomes research is central to learning organizations. Traditional surveys of patient satisfaction fail to capture the depth, breadth, and nuance of what patients are seeking in the care that is provided to them. Patient engagement can help physicians mold their organizations and services to the needs of their patients, support open and honest conversations with patients, and improve the process of patient participation.

Patient Centeredness

Patient centeredness represents attitude, paradigm, and power shifts that can ultimately transform the health care system. The cornerstone of this transformation is patient and stakeholder engagement. In this session, Dr. Sciamanna spoke about patient engagement as a component of building positive patient outcomes, including engaging patients in redesigning care to make behavior change easier. His PCORI-funded large pragmatic trial will test the impact of “Band Together,” an intervention that incorporates strength, aerobic, and balance training to reduce recurrent osteoporotic fractures among seniors. This program has incorporated patient perspectives, needs, and expectations for success and grown from the feedback suggested by participants.

Dr. Odom-Walker, deputy chief science officer at PCORI, spoke about why engagement matters in patient-centered outcomes research. She noted that researchers might be less aware of outcomes that are important to patients and that stakeholder engagement helps overcome this by making research more pa-

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tient centered, relevant, and useful. This in turn helps establish trust in communities and build connections with community members, clinicians, policy makers, and other stakeholders. PCORI offers tools and resources for this in the form of an engagement rubric that helps participants gather and disseminate data focused on the science of engagement. Dr. Odom-Walker encouraged participants to apply for PCORI funding and to share their engagement successes in the process.

Patient-partner Ms. Hoover noted, "Patient-engaged research means sharing control of research goals, research design, research implementation and dissemination. We do this in order to produce results that patients find relevant and cognitively accessible in the implementation phase. It is very important to keep in mind that when a person goes to medical school, it really changes their perspective regarding the body. Having patients involved at every stage allows researchers to present results in a context that is accessible to patients."

Networking in the PCOR Community

In order to facilitate communication within the field, PCORI created PCORNet, now in its third year, which includes 13 Clinical Data Research Networks, or CDRNs, and 20 Patient-Powered Research Networks, or PPRNs, across the United States. The goals for the CDRNs are to identify and engage a million or more patients across two or more health systems, build infrastructure that allows for sharing of electronic health records and other patient-related data, develop informatics tools

PCORI Sessions

General Session

"The Paradigm Shift: Patient-Centered and Patient-Engaged"

Faculty: Jennifer L. Kraschnewski, MD, MPH, Penn State College of Medicine; Christopher N. Sciamanna, MD, professor of medicine and public health, Penn State College of Medicine; Kara Odom Walker, MD, MPH, MSHS, deputy chief science officer in the Office of the Chief Science Officer, PCORI; and Clarissa G. Hoover, MPH, patient partner, Family Voices, Inc.

Workshops

"Building Patient Engagement from the Ground Up"

Faculty: Clarissa G. Hoover, MPH, Family Voices, Inc.; Kathleen McTigue, MD, MPH, University of Pittsburgh; James Richter, MD, MA, Massachusetts General Hospital Gastroenterology; Courtney Clyatt, MA, MPH, PCORI; Jennifer Thomas, youth development specialist, Institute for Educational Leadership, and patient partner, Family Voices, Inc.

"Addressing Disparities through Patient-Centered Outcomes Research: How to Successfully Overcome Barriers to Participation"

Faculty: Irene Alexandraki, MD, MPH, Florida State University College of Medicine; Olveen Carrasquillo, MD, MPH, University of Miami Miller School of Medicine; Carol Horowitz, MD, MPH, Icahn School of Medicine at Mt. Sinai; and Crispin Goytia, program manager, Icahn School of Medicine at Mt. Sinai

"How Can Physician Networks like PCORNet Help Clinicians Participate in Research"

Faculty: Joan M. Neuner, MD, MPH, Medical College of Wisconsin; Russell Rothman, MD, MPP, Vanderbilt University Center for Health Services Research; and Jennifer L. Kraschnewski, MD, MPH, Penn State Hershey Medical Center

to support research, engage key stakeholders throughout the process of research, and support comparative effectiveness research and pragmatic clinical trials. For example, some PCORNet sites have built robust data warehouses for better research, employing novel informatics tools (i.e. iPads, e-mail) in order to more affordably and efficiently recruit patients and collect data. As with all PCORI-funded work, this work is built on the

cornerstone of stakeholder engagement, including patients, families, communities, clinicians, and health system leaders. The CDRNs span entire health systems and create a broad-based data resource.

Community Engagement

The usual process for conducting research is to do the work, give presentations, publish results, get more

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grants, and hopefully generate new knowledge that will change something. Community partners, however, also want this process to be meaningful, enduring, and scalable, which may mean slowing down the process to look at the long-term effects of research in communities. This workshop focused on how to improve community engagement by working closely with community partners. Sometimes the benefit for community partners is unclear—they are used to people swooping in, doing a bunch of work, and not leaving a trace behind. Dr. Horowitz described a contact from New York who noted that although researchers demonstrated interest in working with his community, there had been no measurable improvements following decades of work. Patients in research studies want to know that there is some benefit for them in the process. How do researchers include community members throughout the process to ensure that the research question resonates within the community? Are they celebrating the successes of working together with

community partners? And are those partners informed of the outcome once the research is complete?

Community engagement should include “listening meetings” to ascertain the most important issues for the community. Patience is essential in order to ensure that no one be discouraged from the process of relationship building—a process that is not always free from conflict. When working with communities, it is important to have the support of local organizations that can help ensure the development of long-term relationships. Communication with key organizational stakeholders is key to withstanding changes over time. Lastly, members from the target population should be included on the project team because they may speak the dominant language for that group, have the trust of community members, or provide a cultural perspective on the research questions. Community health workers have long been successful in providing health education and care in many communities for these reasons, and this holds true for research.

The final months of SGIM’s PCORI award will focus on identifying tools for our members and their regions to support understanding of, and engagement in, patient-centered outcomes research. There is still time to complete the physician assessment. Go to https://www.surveymonkey.com/r/PCOR_Survey.¹ Our SGIM PCORI project team welcomes suggestions from our members on how this information can be presented in a meaningful way. Engaging stakeholders in general internal medicine research, as in clinical care, results in better outcomes for everyone.

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Reference

1. Concannon T, Meissner P, Grunbaum JA, et al. A new taxonomy for stakeholder engagement in patient-centered outcomes research. *J Gen Intern Med* 2012; 27(8): 985-91.

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