



MEETING SUMMARY

Advisory Panel on Patient Engagement

June 4-5, 2020

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OVERVIEW

On June 4-5, 2020, PCORI's Advisory Panel on Patient Engagement (PEAP) convened virtually via GoToWebinar. Kristin Carman, MD, PhD, Director of Public and Patient Engagement, along with Thomas Scheid, MA, Chair, and Gwen Darien, Co-chair, led a two-day agenda. On the first day of the meeting, PCORI's new Executive Director, Nakela Cook, MD, MPH, introduced herself to the advisory panel. Her address was followed by staff updates on PCORI's COVID-19 response and presentations from panelists Crispin Goytia, Maureen Fagan, DNP, MHA, and Umair Shah, MD, MPH, on their personal and professional experiences related to the COVID-19 pandemic. On the second day of the meeting, PCORI staff shared updates regarding PCORI's reauthorization and elicited feedback on its National Priorities for Research and Research Agenda. Next, panelist Katherine Capperella, VP, Global Patient Engagement Leader, Janssen Pharmaceuticals, presented on patient engagement in clinical trials in the drug industry. Following this, panelist Sandy Sufian, MA, MPH, PhD, Co-lead, Cystic Fibrosis Reproductive and Sexual Health Collaborative and Associate Professor, Disability Studies, University of Illinois at Chicago, shared lessons learned regarding virtual engagement from her experience working with the Cystic Fibrosis community. The second day concluded with appreciation and recognition of the PEAP panelists ending their terms.

DAY 1

INTRODUCTION

Carman, Scheid, and Darien welcomed attendees and panelists, thanking them for their adaptability in a virtual environment. Carman also recognized that the current climate can be stressful for many, between the COVID-19 pandemic, the social unrest against institutional racism, and the additional challenges these circumstances have introduced. An overview of the two-day meeting agenda was given, which included presentations. Scheid and Darien also welcomed panelists and meeting attendees. Carman then introduced Cook.

NAKELA COOK, MD, MPH, EXECUTIVE DIRECTOR, PCORI

Cook began by thanking advisory panelists for their service and noting that she is looking forward to greater opportunities to get to know the panelists. She provided a brief overview of her background and how it has shaped her career and fostered an interest in addressing health inequities. She noted that despite advances in health care, significant health disparities still exist, as exemplified by COVID-19 outcomes. Cook sees COVID-19 as a national learning opportunity to comprehend health disparities and a space where PCORI can make a long-term impact in health care.

Priorities for her first year at PCORI include learning more about the organization, continuing the organization's COVID-19 response, and focusing on advancing PCORI's National Priorities.

The session concluded with Cook answering questions from panelists about her involvement in patient-centered research and how PCORI can further incorporate the addressing disparities priority in its current research efforts and agenda. She looks forward to the PEAP's guidance on advancing engagement with communities.

OUR WORLD, OUR WORK

COVID-19: PCORI Immediate Commitments

Jean Slutsky, PA, MSPH, Chief Engagement and Dissemination Officer, provided updates on the PCORI-funded Healthcare Worker Exposure Response and Outcomes (HERO) Registry and Trial conducted by Duke University. This project consists of two parts: a registry for healthcare workers who are at risk of contracting COVID-19 and a hydroxychloroquine (HCQ) clinical trial. The goal of the HERO registry is to register 100,000 healthcare workers to monitor health outcomes, serve as a COVID-19 trial entry point, and create a defined community which can be used to better understand the impact of the COVID-19 pandemic on this population. The HERO HCQ trial is designed to test the efficacy of HCQ in preventing clinical infection of COVID-19 in healthcare workers. Joanna Siegel, SM, ScD, Director, Engagement, Dissemination and Implementation, then provided programmatic updates on PCORI's targeted funding announcements specific to COVID-19, adaptations and enhancements for existing PCORI-funded projects affected by COVID-19, and PCORI's webinar series which shared evidence-based practices and new solutions. Karen Martin, MIA, Director, Eugene Washington PCORI Engagement Awards, described enhancements for existing PCORI-funded Engagement Awards, as well as new Engagement Awards specific to COVID-19.

COVID-19: Frontline Perspectives

Goytia, PCORnet®, The National Patient-Centered Clinical Research Network Patient Partner, INSIGHT-NYC Clinical Research Network, and Program Manager of the Community Core of the Mt. Sinai CTSA, presented on the reality of the COVID-19 pandemic in New York City and her experience as she and her family contracted the virus. She has leveraged her experience and is partnering with local organizations and government to create a survey in 11 different languages for those diagnosed with COVID-19, to better understand the impact of the virus on New York City residents.

Fagan, Chief Nursing Executive, University of Miami Health System, spoke to the response to COVID-19 by a large health system. She detailed preparations for hospital staff in the early phases of the pandemic, which included learning about how to "flatten the curve," changing hospital protocols and hospital layouts to meet current needs, and messaging around how to take proper precautions while on the front lines. Fagan also reflected on how the pandemic can lead to moments of creativity and perseverance from staff and communities.

Finally, Shah, Executive Director, Harris County Public Health, presented on how Harris County, the third most populous county in the United States, has been managing COVID-19. Shah elaborated on the need for more attention to the public health system in order to prevent future pandemics and strain on the healthcare system. He has worked to raise public awareness of this "invisibility crisis," helping people to recognize the significance of public health and its "behind

the scenes" role. Shah led Harris County through the first global alert of COVID-19 in January and worked to develop the county's guidelines for reopening, which were issued at the end of May.

ADVISORY PANEL DISCUSSION ON COVID-19

Darien recapped the main takeaways from the previous session. Scheid noted that during this pandemic it is important to continue addressing existing crises, such as mental health and substance use, and emphasized the importance of addressing disparities in access to technology across the country. PEAP members echoed Scheid's point and added the need to recognize what is happening in smaller communities, specifically those impacted by health disparities and those lacking resources. The session concluded with a discussion around to how to best engage stakeholders at the community level, while taking into consideration the current mistrust that exists between researchers and community members as a result of historical abuse of power toward marginalized communities and a research culture rooted almost exclusively in academic settings.

DAY 2

WELCOME

Carman began day two by welcoming participants and detailing the schedule for the day. The welcome continued with a roll call of advisory panelists and an introduction of PCORI's new Director of Communications, Tasha Parker.

PCORI REAUTHORIZATION ACTIVITIES-UPDATE ON NATIONAL PRIORITIES AND RESEARCH AGENDA

Michele Orza, ScD, Chief of Staff, and Greg Martin, Deputy Chief Engagement and Dissemination Officer, presented updates on efforts around the organization's National Priorities. They shared further updates regarding PCORI's reauthorization including new priority areas and a new ability to consider cost outcomes data. New priorities include maternal mortality (and morbidity) and intellectual and developmental disabilities (IDD). PCORI is currently working to engage stakeholders in the field of maternal mortality and IDD to gain a better understanding of current research in the field and stakeholder needs. PCORI's reauthorizing legislation now permits PCORI to collect information regarding the burden and economic impact of treatments.

Currently, PCORI is in the process of planning and seeking input from advisors, key stakeholders, and the public, therefore the majority of this session was spent soliciting input from panelists as to how relevant the outlined priorities are and how they could be changed to better fit current needs. Panelists suggested including a focus on public health and noted that all areas of research and engagement should continue to focus on addressing disparities. Additionally, panelists discussed the need for meaningful community-level engagement, especially in historically disadvantaged communities.

PEAPS IN ACTION – CURRENT ADVANCES IN PATIENT-FOCUSED DRUG DEVELOPMENT”

Capperella shared insights from her work in the pharmaceutical industry implementing patient-focused drug development. Historically, the pharmaceutical industry has not incorporated the patient voice throughout the drug development process, but the patient voice has been progressively more incorporated in the drug development process due to increased Food and Drug Administration involvement and collaboration across the industry. Incorporating the patient voice into drug development is key to ensuring the drugs are successful and appropriate for those who will benefit from their approval. Patient input has been influential in altering clinical trial procedures and drug characteristics to be more appropriate for patients' specific needs.

VIRTUAL ENGAGEMENT: LESSONS FROM A CYSTIC FIBROSIS COMMUNITY

Sufian shared lessons learned through her experience virtually engaging cystic fibrosis (CF) patients. This population relies extensively on virtual engagement and has been doing so for decades, as maintaining social distance is essential to mitigating the spread of infections within this population. She has learned that virtual engagement can be as stimulating as in-person interactions and can even help facilitate a closer community as it eliminates common barriers for those with CF, such as travel and keeping distance. In her work discussing women's health with CF patients, she utilizes various engagement platforms and has found that meeting organization combined with tools such as polling, meeting recording, and breakouts are important to making the most of a virtual environment.

APPRECIATION AND FAREWELLS

Carman and Lisa Stewart, MA, Senior Engagement Officer, shared their appreciation for PEAP members whose terms are ending. Panelists Sonya Ballentine, Capperella, Brendaly Rodriguez, MA, CPH, Beverly Rogers, Norah Schwartz, MPA, PhD, Freddie White-Johnson, MPPA, and Scheid were honored and given the opportunity to share their sentiments about their experience with the PEAP.

WRAP UP/WHAT'S AHEAD?

PCORI staff members updated PEAP members on the progress and next steps of current work groups. Michelle Johnston-Fleece, MPH, Senior Program Officer, Public and Patient Engagement, informed panelists that PCORI is developing a learning package on research fundamentals that will be available to the public in July. She also shared updates for the Studying PCORI's Patient Centered Approach work group. Krista Woodward, MPH, MSW, Program Officer, Public and Patient Engagement, shared updates regarding the Ambassador Workshop. Christine Broderick, Engagement Officer, Public and Patient Engagement, updated panelists on PCORI's work on knowledge translation and uptake. Finally, Denese Neu, PhD, Engagement Officer, Public and Patient Engagement, discussed the Diversity, Equity & Inclusion workgroup's progress and reiterated the importance of this workgroup. Carman, Scheid, and Darien concluded the meeting with a brief review of the two days and items for future consideration. They also thanked the panelists for their thoughtful and meaningful contributions.

Slides from this meeting can be found on the event page. The next PEAP meeting will take place October 22-23, 2020.