



External Meeting Summary

Clinical Effectiveness and Decision Science Virtual Advisory Panel Meeting

June 24-25, 2021

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Overview

On June 24-25, 2021, PCORI's Clinical Effectiveness and Decision Science (CEDS) Advisory Panel convened virtually via GoToWebinar.

Day 1 included an overview of the CEDS research area priorities and funding opportunities, a presentation of the proposed National Priorities for Health, and panel discussions. Day 2 included updates from PCORI staff on funding initiatives related to COVID-19 and the research priority area of intellectual and developmental disabilities, each followed by a panel discussion to identify topic areas within these initiatives that PCORI can address with future funding mechanisms. Day 2 closed with an update on the research priority area of maternal mortality and morbidity, followed by a Q&A session with the panel.

Day One: June 24, 2021

Welcome and Introduction

- Stanley Ip, MD, CEDS Interim Program Director, PCORI
- Kari Gali, DNP, APRN, PNP-BC, CEDS Advisory Panel Chair
- Julie Eller, BS, MPH Candidate, CEDS Advisory Panel Co-Chair

Stanley Ip welcomed the new panel chair, Kari Gali, and co-chair, Julie Eller, to the meeting. Gali and Eller introduced themselves, walked through the agenda for the day, and then facilitated full panel introductions.

Clinical Effectiveness and Decision Science Research Area Overview

- Holly Ramsawh, PhD, CEDS Senior Program Officer, PCORI

Ramsawh presented an overview of CEDS research to date. She shared PCORI's current CEDS portfolio, new research awards, and upcoming opportunities for broad and targeted research.

Strategic Planning: National Priorities for Health

- Nakela L. Cook, MD, MPH, Executive Director, PCORI

Cook presented an overview of PCORI's Strategic Planning Process and outlined the five proposed National Priorities for Health: 1) Achieve Health Equity, 2) Increase Evidence for Existing Interventions and Emerging Innovations in Health, 3) Advance the Science of Dissemination, Implementation, and Health Communication, 4) Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research, and 5) Accelerate Progress Toward an Integrated Learning Health System.

Following Cook's presentation, the panel members began a discussion on objectives to consider within each priority, their potential impacts for comparative clinical effectiveness research, and opportunities created by overlapping priorities. One panelist asked for clarification on where prevention fits into the priorities, and Cook explained that it is connected to most of them. Below is a summary of discussion topics by common themes:

Increase Evidence for Existing Interventions and Emerging Innovations in Health

Multiple panelists noted inclusion and equity issues with clinical trials and emphasized that PCORI should take a role in addressing them. One panel member noted the need for more evidence on the

efficacy of telehealth. Panelists noted overlap with two other priorities: 1) Health Equity and 2) Advance the Science of Dissemination, Implementation, and Health Communication.

Enhancing Infrastructure to Accelerate Patient-Centered Outcomes Research

Panelists suggested PCORI get more involved in training existing and future generations of researchers and providers on patient-centered outcomes research. Panelists also recommended that PCORI focus on increasing patient engagement in health care.

Advance the Science of Dissemination, Implementation, and Health Communication

One panelist recommended PCORI lead implementation of preventive measures related to hospital-acquired conditions. Multiple panelists noted the importance of trust and using a variety of dissemination techniques, given opportunities for bias in social media. Panelists also discussed the importance of making sure practitioners and patients have the digital literacy and access to tools necessary to engage in telehealth.

Achieve Health Equity

Panelists remarked that access to competent and comprehensive care is important, not merely access to care. One panelist suggested developing a pipeline program to encourage young people from historically marginalized populations to attend medical school, and another suggested more funding for community organizations.

Accelerate Progress Toward an Integrated Learning Health System

One panelist noted that a national policy allowing data sharing, standardization, and interoperability across multiple sectors is key to creating a learning health system and suggested advocacy from PCORI.

Closing Remarks/Adjourn

- Kari Gali, DNP, APRN, PNP-BC, CEDS Advisory Panel Chair
- Julie Eller, BS, MPH Candidate, CEDS Advisory Panel Co-Chair
- Nakela L. Cook, MD, MPH, Executive Director, PCORI

Gali, Eller, and Cook thanked the panel for their participation in the discussion and adjourned the meeting.

Day Two: June 25, 2021

Welcome, Recap, and Overview of Day 2 Agenda

- Kari Gali, DNP, APRN, PNP-BC, CEDS Advisory Panel Chair
- Julie Eller, BS, MPH Candidate, CEDS Advisory Panel Co-Chair

Gali and Eller welcomed the PCORI staff, CEDS panel members, and public to the second day of the CEDS Advisory Panel Summer Meeting.

Update on COVID Funding Initiatives and Panel Discussion

- Jason Gerson, PhD, CEDS Senior Program Officer, PCORI

Gerson presented updates on PCORI's activities in response to the COVID-19 pandemic, including COVID Connect, COVID-related research programs, and COVID-related PCORnet efforts and engagement

efforts. The CEDS Chair and Co-chair then guided the panel in discussion on where PCORI can focus its efforts to address the pandemic.

During the discussion, one panelist noted that the speed of the COVID-19 vaccine rollout may have contributed to hesitancy. Panelists also discussed nontraditional ways to disseminate research to better reach patients and the general public. Panelists noted the importance of educating affected communities on relevant research in an accessible manner. One panelist suggested PCORI focus funding on mental and behavioral health in response to the uptick of these issues given the pandemic. Panelists debated the pros and cons of the rise in telehealth usage due to COVID-19. One panelist noted continued health and health coverage issues among COVID-19 patients. Another panelist remarked that difficulties with clinical follow-up may result in gaps in COVID-19 patient histories, which could be problematic for researchers.

Update on Intellectual and Developmental Disabilities Priority for Research and Panel Discussion

- Holly Ramsawh, PhD, CEDS Senior Program Officer, PCORI

Ramsawh provided a background on PCORI's national priority on Intellectual and Developmental Disabilities (IDD) and presented on the different PCORI funding opportunities for this priority area. Panelists participated in a discussion and answered poll questions via Mentimeter on IDD topics.

During the discussion, one panelist indicated that PCORI should focus on training the next generation of physicians to treat patients with IDD. Via Mentimeter, panelists indicated that comparison of parent/caregiver-mediated interventions for IDD should be a top funding priority for PCORI. One panelist questioned the percentage of IDD patients who are subsequently classified as having IDD from exposure to environmental insults/trauma, and PCORI staff noted that it defines IDD broadly and allows investigators to specify how they are defining IDD in their applications.

Update on Maternal Mortality and Morbidity Priority for Research and Panel Discussion

- Kim Bailey, MS, CEDS, Interim Associate Director, PCORI

Bailey presented a short background of maternal mortality in the United States, provided an update on the work that PCORI is doing around this national priority, and answered questions posed by the panel.

Multiple panelists shared they would like PCORI to fund research on mothers with comorbid conditions and chronic disease. Two panelists suggested prioritizing the IDD community and the impact of COVID-19. Multiple panelists also underscored the importance of engaging communities to identify effective interventions. Panelists discussed the need for research funding outside of healthcare entities and suggested a "flipped" model of giving directly to community-based organizations. A panelist noted overlap with the dissemination and implementation national priority. Another panelist pointed out a research opportunity for PCORI on why women do not access evidence-based care in a timely manner. Multiple panelists emphasized the importance of focusing on equity in implementation.

Closing Remarks/Adjourn

- Kari Gali, DNP, APRN, PNP-BC, CEDS Advisory Panel Chair

Gali thanked the panel members and presenters for two days of fruitful discussion, shared that the public may contact PCORI at info@pcori.org with comments or questions, and adjourned the meeting.