



## External Meeting Summary

# Advisory Panel on Healthcare Delivery and Disparities Research

May 6, 2021

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## Overview

On May 6, 2021, PCORI's Advisory Panel on Healthcare Delivery and Disparities Research (HDDR) convened virtually via GoToWebinar. The meeting started with several program updates from the PCORI team, including a discussion about PCORI's research agenda on Maternal Morbidity and Mortality, as well as Intellectual and Developmental Disabilities (IDD). Next, there was a presentation and discussion regarding PCORI's COVID activities, with emphasis on COVID-related enhancements and an upcoming COVID-19 PCORI Funding Announcement (PFA). Following the briefing on PCORI's telehealth portfolio, panelists discussed benefits and limitations of telehealth across patient groups. The panel then provided feedback on PCORI's latest health research priorities, and discussed best practices for advancing PCORI's health equity portfolio, as well as its Centers for Health Equity Initiative.

## Key Meeting Details

### Welcome, Introductions, and Setting the Stage

- Steve Clauser, PhD, MPA, Director of HDDR, PCORI
- Jane Kogan, PhD, HDDR Advisory Panel Co-Chair
- Alicia Arbaje, PhD, MD, MPH, HDDR Advisory Panel Co-Chair

Steve Clauser welcomed the HDDR members to the meeting and walked through the agenda for the day. Jane Kogan and Alicia Arbaje introduced themselves as co-chairs of the HDDR. Lastly, Jane Kogan and Alicia Arbaje facilitated introductions of all other present HDDR members.

### HDDR Program Updates and Discussion

- Steve Clauser, Director of HDDR, PCORI
- Carly Parry, PhD, MSW, MA, Senior Advisor, Care Coordination and Transitions Research Initiatives, PCORI
- Elisabeth Houtsmuller, PhD, Associate Director, HDDR, PCORI
- Amanda Barbeau, MPH, Senior Program Associate, CEDS, PCORI
- Jane Kogan, HDDR Advisory Panel Co-Chair
- Alicia Arbaje, HDDR Advisory Panel Co-Chair

Steve Clauser reviewed three new research awards. Carly Parry reviewed updates from the learning health systems initiatives, including the details of multiple AHRQ/PCORI partnerships. Elisabeth Houtsmuller presented on Maternal Morbidity and Mortality efforts as part of a cross-departmental workgroup that will focus on this topic for the next decade. Amanda Barbeau presented on PCORI's cross-departmental Intellectual and Developmental Disabilities initiatives. She provided additional detail on an upcoming IDD-targeted PCORI Funding Announcement (PFA).

Multiple panelists suggested additional areas of research and intervention to address health inequities among Black and Brown women. Panelists agreed that providers and pregnant women's families could benefit from additional education, such as providing information on complication warning signs. Other panelists emphasized that providers across medical disciplines needed to learn these warning signs. Further, they maintained that providers need additional bias training to properly evaluate pain in Black women. They encouraged collaboration with Black communities. A panelist stressed the importance of cross-disciplinary research, as those with IDD also often have other mental or physical health needs. They encouraged PCORI to prioritize funding applicants that had multiple disciplines working together.

### PCORI COVID Activities

- Bill Lawrence, MD, MS, Senior Clinical Advisor, Office of the CEDO, PCORI
- Alicia Arbaje, HDDR Advisory Panel Co-Chair

Bill Lawrence first discussed COVID Connect, a cross-departmental team within PCORI focused on responding to the COVID-19 pandemic. He highlighted that HDDR has supported 116 enhancements awards on existing contracts; these enhancements allowed researchers to investigate COVID-19-related areas of concern. He also announced the COVID-19 targeted PFA, and reviewed the work done on the HERO registry through the PCORnet infrastructure.

Multiple panelists commented that PCORI might want to encourage the use of retrospective data to evaluate COVID-19's impact. Unconventional data collection could yield additional information on a variety of topics, from vaccine uptake to the impact of staff burnout on safety-net hospitals. Panelists also agreed that processes put in place during pandemic, such as telehealth, needed further research. They indicated that the effects of long COVID, as well as COVID's effect on pre-existing conditions, should be studied further.

### Leveraging Telehealth for Chronic Disease Management among Vulnerable Populations with Complex Needs

- Carly Khan, PhD, MPH, Program Officer, HDDR, PCORI
- Jane Kogan, HDDR Advisory Panel Co-Chair

Carly Khan provided additional information on trends in telehealth since the pandemic began, along with additional information on PCORI's investments in telehealth. She emphasized an emerging need to identify the most effective, evidence-based ways to incorporate telehealth into patient care, and a need for additional research to investigate disparities in telehealth.

Panelists agreed that telehealth should be used as a complement to in-person care, not a replacement; PCORI should consider funding comparative effectiveness research (CER) that generates additional evidence on best practices for telehealth use. Panelists also acknowledged that telehealth platforms are often not user-friendly, especially for older users or those with IDD or hearing/visual impairment. Further, telehealth access may be more limited for patients living in rural communities or unsafe environments. Some panelists suggested potential improvements in telehealth experiences across a variety of cultural backgrounds. One panelist frequently works with patients who have limited English proficiency, and suggested recognizing their preferences with regard to interpreters. Another panelist added that telehealth visits may provide a better sense of the patient's living environment, but could introduce additional bias.

## Strategic Planning: Identifying National Priorities for Health

- Steve Clauser, Director of HDDR, PCORI
- Alicia Arbaje, HDDR Advisory Panel Co-Chair

Steve Clauser presented on the evolution of PCORI's national priorities for health. PCORI is working to generate evidence on these priorities and speed implementation of this evidence, aligning with stakeholder-driven priorities. Based on prior panel feedback and direction from the Board of Governors, Clauser announced that PCORI had identified five broad themes: health equity; emerging innovation; learning health system; communication, dissemination, implementation; and infrastructure and workforce.

Panelists observed that these themes are intertwined; any upcoming CER will likely address several of these topics simultaneously. Several individuals noted that PCORI needs to take a patient-centered approach; patient-reported outcomes impact policy makers just as much as medical outcomes. Further, decision support resources, as well as non-clinician healthcare workers, will continue to contribute significantly to the patient experience. PCORI may also want to consider innovative methods for information exchange, such as secure cards containing patient medical records.

## Advancing Health Equity in Comparative Effectiveness Research Framework

- Vivian Towe, PhD, MSc, MA, Program Officer, HDDR, PCORI
- Jane Kogan, HDDR Advisory Panel Co-Chair
- Alicia Arbaje, HDDR Advisory Panel Co-Chair

Vivian Towe presented on PCORI's current research portfolio to advance health equity. She focused on internal efforts to optimize PCORI's research portfolio to advance health equity, as well as providing background information on the PCORI Centers for Health Equity initiative. She shared that the PCORI Centers for Health Equity initiative will likely begin with two separate PFAs with five- to seven-year duration: one for health equity research centers and one for a coordinating center to support and coordinate the centers' activities.

Several panelists shared strategies to improve equity within the PCORI portfolio. One panelist suggested helping engaged communities further develop their methods and technical experience. Other panelists stressed integrating qualitative data into CER. They also suggested incorporating environmental and social determinants of health into methodology. The panel recommended that PCORI collaborate with local/community foundations, health profession groups, and government agencies.

When asked how to incorporate health equity into all facets of the Centers for Health Equity initiative, multiple panelists suggested funding pilot projects. Pilots can help engage new partners, and can be augmented by implementation science and qualitative methods utilized by larger initiative-funded CER projects. Panelists also stressed that, if PCORI wants to attract a wider variety of research partners, community stakeholders have to be at the center of all initiative work. Additional research on strategies for engaging under-resourced settings in research could also be valuable.