



External Meeting Summary

Advisory Panel on Healthcare Delivery & Disparities Research

May 11, 2022

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Overview

The Advisory Panel on Healthcare Delivery & Disparities Research (HDDR) Spring 2022 Meeting offered members the opportunity to learn about current and ongoing PCORI activities, including PCORI's progress on strategic planning, as well as share their own experiences in the field. The meeting agenda included the following:

- Welcome, Introductions, and Setting the Stage
- Update on Strategic Planning: PCORI's Strategic Plan
- Update on the Health Equity Initiative
- PCORI's Targeted Funding Announcement on Healthy Aging – Overview & Feedback
- Addressing Health Disparities Faced by Sexual and Gender Minorities: Developing a Special Area of Emphasis
- HDDR Program Updates
- Wrap-Up and Next Steps

Welcome, Introductions, and Setting the Stage

- Nakela L. Cook, MD, MPH, Executive Director, PCORI
- Steven Clauser, PhD, MPA, Program Director, HDDR, PCORI
- Alicia Arbaje, MD, MPH, PhD, Johns Hopkins University, HDDR Advisory Panel Co-Chair
- Jane Kogan, PhD, University of Pittsburgh Medical Center, HDDR Advisory Panel Co-Chair

Nakela Cook welcomed participants and contextualized the Advisory Panel's focus relative to PCORI's broader events and goals. She acknowledged this as one of PCORI's most diverse panels, and noted that beyond HDDR-specific expertise, panelists also have experience in two new congressionally mandated focus areas: maternal morbidity and mortality, and intellectual and developmental disabilities (IDD). Once Steven Clauser introduced the Advisory Panel co-chairs, the co-chairs welcomed other Advisory Panel members and explained the Panel's purpose: to provide feedback on PCORI's Research Agenda. Advisory Panel members then introduced themselves, noting the different perspectives they bring to the discussion.

Update on Strategic Planning: PCORI's Strategic Plan

- Steven Clauser, PhD, MPA, Program Director, HDDR, PCORI

Steven Clauser provided an update on PCORI's strategic planning process, which has involved soliciting meaningful input from a wide range of stakeholders. Appreciative of this input, PCORI is pursuing more opportunities to solicit feedback on PCORI's Research Agenda and implementation planning processes. In October of 2021, PCORI's Board of Governors marked a significant strategic planning milestone by adopting the "[National Priorities for Health](#)" and setting corresponding goals—with substantial stakeholder input. Another milestone was reached in March 2022 with the adoption of a [Research](#)

[Agenda](#) for funding comparative clinical effectiveness research (CER). Panel members' input informed creation of this Agenda by emphasizing (1) the importance of PCORI's translation and communication of evidence to the public, (2) the need for alignment between PCORI and other actors in the field, and (3) the emphasis on research that is relevant to stakeholders and oriented around their needs and experiences. The Strategic Plan now in development will be considered for approval by the Board of Governors at the June 2022 meeting.

After outlining the substantive components of the Strategic Plan, Clauser led a discussion to solicit Advisory Panel members' input on considerations for implementing components of the plan (i.e., implementation planning). Notably, PCORI leadership is particularly interested in identifying ways that PCORI can become more responsive to changes in the healthcare environment when needed (as had been the case during the COVID-19 pandemic). Panelist feedback generated during this session, used to guide PCORI's implementation of changes in future meetings, included the following points:

What are meaningful ways to engage stakeholder communities represented to this panel to solicit their ideas and inform topic development?

- Utilizing smart phone and social media platforms to reach younger people
- For older members, adding some webinar and online convening opportunities, but planning them carefully to make sure a diverse sample shows up
- Identifying stakeholders and champions for communities to reach them and sharing how information will be used to address mistrust
- Training those giving surveys to avoid bias with preparation before engagement happens.
 - Analyzing the language being used in disseminated materials
- Utilizing surveys is an excellent strategy because those surveyed can complete it on their own time, but it is important to make sure the surveys are true to their ask and not disingenuous.

What does a responsive, transparent Research Project Agenda development process look like from your perspective?

The panel did not address this question directly during this meeting; however, it may serve as a future point of discussion.

Given the broad, integrated nature of the adopted National Priorities for Health and Research Agenda, how could PCORI demonstrate relevance to stakeholder communities represented by this panel?

- Improving engagement by spreading the word about PCORI to more diverse audiences is key.
- Focusing on populations that are harder to reach but impacted by this work (ex. low income, disabled individuals not receiving home or community-based services)

Based on this panel's expertise in healthcare delivery and equity of care, what are this panel's suggestions to stay up to date on emerging issues in this space?

- Exploring ways that PCORI open its "aperture" to get more organizations involved who may not have the resources or knowledge currently, such as through mentoring

Update on the Health Equity Initiative:

- Kelly Dunham, MPP, Senior Manager, HDDR, PCORI
- Vivian Towe, PhD, MSc, MA, Program Officer, HDDR, PCORI
- Andrea Brandau, MPP, Program Officer, HDDR, PCORI

Kelly Dunham provided an update on the Health Equity Initiative and the ways it is informed by PCORI's strategic plan. She outlined the Initiative's focus including a new topic focus of improving maternal outcomes for at-risk populations, the stakeholders engaged to date, and the enthusiastic responses PCORI has received to this approach. This input shaped PCORI's choices for structuring the award and led to PCORI considering a two-pronged funding approach to advance this Initiative: a research mechanism for specific topics supported by existing partnerships (focus for today), and emerging partnership awards (under development).

For its enhanced research mechanism to advance equitable CER, PCORI has proposed the topic of *Improving Maternal Outcomes for At-Risk Populations: Multicomponent Models of Care to Reduce Maternal Morbidity and Mortality*. Panelist feedback included the following:

Which outcomes are most important to consider for these research questions?

- Extent to which days at home can be helpful
- Measures of care coordination
- Integration with systems that patients already use: *How do we coordinate with the current health plan to avoid overburdening patients with many new interventions? Think about the "whole" person*
- Extent to which participation increases or decreases participant stress
- Effectiveness of training models (for creating access, providing better care) and consideration of complexities
- Consideration of non-clinical outcomes: *How do patients' experiences impact whether they stay with versus change healthcare systems?*

Are there any contextual factors, considerations, or potential challenges that we should be mindful of when considering CER in this space?

- The interconnections of virtual care, equity, and outcomes
- The impact of medical professionals' bias

Are there other important issues regarding addressing health equity that you would like to bring up?

The panel did not answer this question directly during this meeting; however, it may serve as a future point of discussion.

Are there any considerations or mechanisms that would enhance scalability and learning?

- It's important to consider if communities have the time needed to build capacity for addressing health equity.
- PCORI might consider more contextual factors when designing measures or interventions, such as, for example, whether a pregnant woman has broad social support (i.e., from an extended or nontraditional family network versus one caregiver) as that can make a difference in someone being more resilient.
- It would be helpful to consider means of rapid dissemination to encourage PCORI and other stakeholders to engage now and to increase needed awareness.

PCORI's Targeted Funding Announcement on Healthy Aging – Overview & Feedback

- Neeraj Arora, PhD, Associate Director, HDDR, PCORI
- Tabassum Majid, PhD, MAgS, Program Officer, HDDR, PCORI

Neeraj Arora shared an update on PCORI's funding announcement on [Healthy Aging: Optimizing Physical and Mental Functioning Across the Aging Continuum](#), released in September 2021. As background on the announcement, it was noted that the number of older adults in the United States is growing significantly and is diversifying. Most of these individuals have two or more chronic conditions, and many want to age in their homes. Recognizing that the current healthcare system is not well-equipped to address the complex needs of this population, PCORI awarded \$50 million for CER studies focused on healthy aging for community-dwelling older adults and their caregivers. Arora outlined PCORI's framework for the Healthy Aging Funding Announcement, focused on interventions optimizing physical and mental functioning across the aging (and the parallel caregiving) continuum(s) by:

- maintaining function and independence
- managing chronic conditions
- providing support for significant functional impairment
- reducing caregiver stress and improving their quality of life

After a presentation on key elements (e.g., research questions, stakeholder consultation, target population, study considerations) of the past funding announcement, the Advisory Panel split into breakout groups to inform potential reissuance of the Healthy Aging Targeted PCORI Funding Award (TPFA). The breakout groups provided the following feedback:

If we were to reissue the Healthy Aging targeted PFA, what revisions, refinements, or areas of focus would you recommend?

- Priority populations include the LGBTQ population and homebound individuals – as well as those with IDD, experiencing accelerated aging, facing domestic violence or elder abuse, and living with substance use disorder or HIV. They also include patients transitioning between settings or who may lack social support as well as those who may be stigmatized, experiencing homelessness, multi-morbid, or of different language and cultural communities.
- Panelists also suggest studying factors affecting caregivers' health and ability to provide support.
- Panelists recommended looking at community centers, community space, transitional housing, and homeless shelters.
- They also noted that structural racism and discrimination change as people age, and that it is important to design studies and interventions to be sustainable after the study ends.

Addressing Health Disparities Faced by Sexual and Gender Minorities: Developing a Special Area of Emphasis

- Brendan Weintraub, MPH, CHES®, Program Associate, HDDR, PCORI
- Soknorntha Prum, MPH, Senior Program Associate, HDDR, PCORI

After presenting a general overview of Sexual and Gender Minorities (SGM) in the United States, Brendan Weintraub described PCORI's SGM Research and Engagement Portfolios and noted that PCORI has awarded \$96.2 million to fund 43 CER studies, engagement projects, and a patient-powered research network (PPRN) related to this topic. He outlined common themes across the portfolio (e.g., healthcare needs of transgender individuals, models of appropriate mental health treatments) and outlined a potential role for PCORI in furthering SGM research. Advisory Panel members then split into

two breakout groups to provide feedback on opportunities for CER focused on SGM health, addressing the following questions:

In addition to the three areas identified, what are other salient opportunities for meaningful CER?

- Include intersex status and other forms of variation in sex development (underdeveloped areas relative to sexual orientation and gender identity data collection). Identifying those populations is necessary to understand where the disparities are.
- Use CER to compare data collection approaches (i.e., standardized capture of gender, race, and ethnicity data) and identify those that are unbiased, accurate, and intersectional.

What other stakeholder partners (e.g., patients, clinicians, regulators) are important to engage?

- If there is intention to strongly encourage or even require priority stakeholder groups (e.g., Black or Indigenous individuals and people of color who are also SGM), it is important to design those studies with an emphasis on intersectionality from the beginning.
- It is important to consider the influential effects of contextual factors (e.g., the political climate) and roles of other key stakeholders (e.g., health systems, community health centers, payers, policymakers, faith-based leaders) who should be engaged in this work.

What is the best way to get the word out among researchers and others working in this population?

- Connect to advocacy organizations and collaborate on addressing discrimination

HDDR Program Updates

- Steven Clauser, PhD, MPA, Program Director, HDDR, PCORI

Steven Clauser welcomed new HDDR staff, noting that the HDDR Team now has 32 members, and then provided updates on five new research awards that PCORI is funding. He also shared that in 2017, HDDR created the Palliative Care Research Network, which involved nine multi-site CER studies. In winter 2022, the study principal investigators (PIs) met with representatives from the Centers for Medicare and Medicaid Innovation Studies to discuss preliminary lessons from their trials, including strategies for assessing the impact of COVID-19 on each study and ways to impact Medicare policymaking related to palliative care. PCORI will regularly communicate with these study teams and is convening PIs again in Spring 2022.

Clauser then introduced the [Learning Health Systems Training Program](#), which embeds PCORI professionals (e.g., scientists, clinicians) in learning health systems. Based on feedback from the first year, anticipated improvements during the second phase of work (LHS 2.0) include increased program scholar diversity, expansion of partnerships to include minority-serving institutions, and greater opportunities for executing embedded research and direct engagement with system stakeholders.

Finally, Clauser reminded members that the 2022 PCORI Annual Meeting will be held in-person and virtually on October 26-27, 2022. Members are encouraged to participate.

Wrap-Up and Next Steps

- Steven Clauser, PhD, MPA, Program Director, HDDR, PCORI
- Jane Kogan, HDDR Advisory Panel Co-Chair

Members reacted to the meeting via responses to several poll questions. Before co-chairs' closing remarks, Steven Clauser thanked co-chairs and panelists whose three-year terms end in August 2022.