Internal Thematic Meeting Summary

Advisory Panel on Healthcare Delivery and Disparities Research Winter 2021 Meeting

December 9, 2021

About this Advisory Panel | Meeting Details and Materials

Table of Contents

Overview

The Advisory Panel on Healthcare Delivery and Disparities Research (HDDR) Winter 2021 meeting began with a welcome of the HDDR members and attendees and an overview of the day's agenda. Next, PCORI provided an overview of the HDDR research program, reviewed updates to the HDDR research portfolio, and shared a sampling of new research awards. Following a lunch break, PCORI presented on improving hypertension management and control, including effective interventions to reduce high blood pressure. The panelists discussed their reactions to the disparities that exist surrounding hypertension and strategies to improve hypertension management. Next, PCORI provided an overview of the social needs evidence map and the panelists offered their feedback. Following a short break, PCORI staff shared details of a community-based approach as part of a health equity initiative; HDDR members provided feedback on areas where a health equity focus is most important. Finally, PCORI provided an update on their strategic plan and proposed research agenda and asked HDDR members for their feedback. At the end of their discussion, PCORI staff thanked the HDDR members for their enthusiasm and engagement and the meeting adjourned.

Welcome, Introductions, and Setting the Stage

- Carly Khan, PhD, MPH, RN, Associate Director, HDDR, PCORI
- Alicia Arbaje, PhD, MD, MPH Associate Professor of Medicine and Director of Transitional Care Research, Johns Hopkins University, HDDR Advisory Panel Co-Chair
- Jane Kogan, PhD, Associate Chief Research and Translation Officer, UPMC Center for High-Value Health Care, HDDR Advisory Panel Co-Chair

Carly Khan began the session by welcoming the panel and attendees then reviewed housekeeping items advising that the session recording and materials will be available on the PCORI website following the meeting. She introduced the panel leadership followed by the panel members. Khan then turned the meeting over to panelists chairs Alicia Arbaje and Jane Kogan for roll call.

Arbaje and Kogan welcomed panelists and attendees then proceeded with a roll call inviting panelists to share their HDDR perspective. Each panelist introduced themselves and noted a diverse set of research and healthcare industry perspectives. Following the introductions, Kogan reviewed the presentation agenda.

HDDR Program Updates and Discussion

- Carly Khan, PhD, MPH, RN, Associate Director, HDDR, PCORI
    - Maternal Morbidity and Mortality Discussion
    - Intellectual and Developmental Disabilities Discussion
- Discussion Facilitator: Jane Kogan, PhD, Co-Chair

Khan thanked PCORI for their hard work in putting the session together and how the feedback provided during the last session in May has informed the current research projects. She introduced the HDDR staff indicating several promotions and new team members.

Khan advised panelists and attendees of the 277 Comparative Effectiveness Research (CER) studies in healthcare delivery and disparities research awarded by PCORI as of December 2021 amounting to more than one billion dollars. The most recent research awards were awarded during July, September, and December include four Improving Healthcare Systems Broad awards, 11 Addressing Disparities Broad awards, three Phased Large Awards for Comparative Effectiveness Research (PLACER), four Suicide Prevention (brief interventions for youth) awards, and two Pragmatic Clinical Studies awards.

Khan then provided a high-level overview of the twenty-four newly awarded research programs, highlighting the creation of a palliative care learning network. She offered highlights from the 2021 Annual PCORI meeting before turning the call over to Jane Kogan for the panel discussion.

Discussion

Kogan welcomed panelists to engage in dialog and noted how impressive the new program portfolio addresses disparities. Additionally, the group discussed research to address COVID-19 and the resulting care disparities, quicker dissemination of research program results, and learning networks to enhance co-learning opportunities.

- One panel member commented on the new programs' relevance to the national conversation around healthcare inequality due to COVID- 19 and the need for a timely response to those needs. There was a general census that programs and initiatives are in flux during the public health emergency and funding for programs remain flexible to emerging needs.
- A few panel members raised interest in enhanced steps to increase shared learning such as open access, dissemination of preliminary results, and any early access vehicles for the interested stakeholders. PCORI advised that all suggestions would be taken under advisement and noted that many forms of open access are currently being utilized.

Improving Hypertension Management and Control

- Hillary Bracken, PhD, MHS, MA, Program Officer, HDDR, PCORI
- Els Houtsmuller, PhD, Associate Director, HDDR, PCORI
- Discussion Facilitator: Alicia Arbaje, PhD, MD, MPH, Co-Chair

Dr. Hillary Bracken, Program Officer, HDDR, PCORI provided an overview on hypertension management and control from a health equity perspective, followed by an open discussion to solicit thoughts on priority research areas, outcomes, and questions. Bracken indicated that they were pharmacological and non-pharmacological interventions to reduce blood pressure, cardiovascular events, and mortality. She noted that disparities exist in specific populations in rates of blood pressure control, exacerbated by the COVID-19 pandemic. The systemic and environmental factors that influence hypertension control include clinical uncertainty, explicit bias among health care workers, transportation, housing security, food, exposure to racism, and stress. The barriers to eliminating disparities hypertension occur at the individual, provider, community and provider level.

Strategies for improving hypertension management include:

- Improving awareness;
- Improving treatment; and
- Improving control.

Bracken stressed that no single intervention is uniquely effective and a sustained, coordinated effort with a multi-level approach is necessary to manage hypertension.

Discussion

Bracken asked the clinicians their feedback on how to incorporate comparative effectiveness research in this space, other important issues to consider, and suggestions for stakeholders PCORI should be in contact with. Below is a summary of the panel members' discussion by theme.

Trust in health care systems

- Most clinicians indicated that addressing trust in the health care system is critically important to manage hypertension control. One clinician noted that they hope to see more evidence at the intersection of trauma, discrimination, and marginalization as it relates to the measures and outcomes to address cardiovascular disease.
- Another clinician recommended the health care system engage individuals in the community to increase awareness of the potential ramifications for high blood pressure and options for managing it. Non-medical leaders, including leaders in places of worship, beauty shops, and other community-based places, are potentially more trusted than institutions on hypertension management.

Racial bias in medicine

- A few clinicians noted how hypertension relates to the racial bias of many health care providers. One clinician remarked on his personal experience as an African American male who has a history of high blood pressure in his family. Even though he did not have

high blood pressure himself, he was required to report his family history on job applications and was therefore prevented from getting jobs with physical requirements. He also noted that a doctor prescribed him blood pressure medication solely due to his family history, but the side effects were severe. Addressing the stigma and racial bias surrounding high blood pressure may help improve patient's willingness to treat their hypertension.
- Another clinician indicated the importance of transparency around implicit biases of researchers. They recommended the health care system reframe high blood pressure as a "factor" of one's health, instead of a marker of whether one is healthy or unhealthy.
- Lastly, one clinician discussed how biases from health care providers may impact the patient's diagnosis. They believe that there is a gap in literature and research proposals on biased care from personal characteristics of the caregiver and the patient.

Importance of a combination of treatments

- One clinician suggested looking at health systems that use blood pressure control as a financial incentive to see if patient's outcomes improve. They also stated that treatments such as the indicators of salt at restaurants may help with treating hypertension and obesity.

Emphasis on looking at the entire population

- Two clinicians emphasized looking at the entire population, including populations that are generally overlooked in research. One clinician noted that pregnant women are often excluded in clinical trials due to pregnancy being a "temporary medical condition" that only occurs for nine months. However, it is critically important to include research on pregnant women because they often have high blood pressure during pregnancy.
- Another clinician stated that blood pressure has been used as a gatekeeping strategy to make it more difficult to receive hormones for the transgender population. The health care system must be careful to approach the risk factors to hypertension in a sensitive manner and make sure to include gender and sexual minority populations, or else they could do more harm than good.

White coat syndrome and masked hypertension

- Three clinicians emphasized the importance of Instances of white coat hypertension and masked hypertension. For example, one clinician recalled a story of a patient facing discrimination in the waiting room of a doctor's office, resulting in high blood pressure. Another clinician stated that their blood pressure is always 15-20 points higher at the doctor's office due to anxiety. A third clinician remarked on the widespread issue of the gap between knowledge and clinical practice and adoption for white coat system. In order to improve outcomes for hypertension, it is critically important to consider patient's prior experiences with the health care system.

Social Needs Interventions: New Interactive Evidence Map

- Michelle Althuis, Associate Director, Engagement, Research Synthesis and New Technology, PCORI
- Rachael Parsons, Program Associate, Engagement, Research Synthesis and New Technology, PCORI
- Discussion Facilitator: Jane Kogan, PhD, Co-Chair

Michelle Althuis, Associate Director, Engagement, Research Synthesis and New Technology, PCORI provided an overview of the scope, history and description of the social needs interventions evidence map. The evidence map is an interactive repository of eligible primary studies assessing social needs
interventions that evaluate health outcomes.

The map displays eligible studies according to:

- Population, intervention, outcomes;
- Study quality; and
- Directionality of findings.

Althius described how social needs interventions address social conditions that are associated with poor health and identified or prioritized by the patients' perspective. The study of social needs interventions can help improve health outcomes for vulnerable populations and reduce disparities, potentially without increasing health care costs.

Rachael Parsons, Program Associate, Engagement, Research Synthesis and New Technology, PCORI walked through a live presentation of the evidence map. She indicated that each dot reps a study and each study is sorted according to social need addressed. Users are able to filter the studies according to the following data:

- Social need addressed;
- Study population recruited;
- Study design;
- Study quality (high, medium, or low);
- Intervention setting.

Overall, the evidence map seeks to accelerate research on social needs interventions and health equity, improve future evidence synthesis products, and inform future funding opportunities around PCORI's national priorities.

Discussion

Parsons and Althius opened the dialogue for clinicians to discuss their reactions to the evidence map.

- One clinician noted that they could use the map to help address hypertension, similar to the group today. PCORI agreed that they could use the map to help identify studies and still benefit from the human element of the workgroup discussions.
- Another clinician asked PCORI for their plans to inform stakeholders about the map and how to use it. PCORI noted the map is linked to a social need's intervention research network and they hope to write a published paper on the evidence map. Parsons and Althius indicated that they have had 1,000 visits to the landing page and 500 users of the map. PCORI is also considering hosting a roundtable in the spring to discuss how to further disseminate the map and whether to create a second version of the map.
- A PCORI representative stated that that trust could be a topic to consider for a future map, including the measures, interventions, and outcomes associated with trust, since it has been a theme of the meeting's discussion.
- Finally, one clinician recommended including PCORI's priority areas of maternal health and intellectual and developmental disabilities in the evidence map.

Achieve Health Equity: Modeling Community-Driven Research Approaches (Part 1)

- Kelly Dunham, MPP, Senior Manager, HDDR, PCORI
- Lisa Stewart, MA, Senior Engagement Officer, Public and Patient Engagement, PCORI
- Discussion Facilitator: Alicia Arbaje, PhD, MD, MPH, Co-Chair & Jane Kogan, PhD, Co-Chair

Kelly Dunham, Senior Manager, HDDR, PCORI, provided an update on a new initiative that their colleague, Vivian Towe, had presented on at the panel's meeting this past Spring. The initiative is focused on community-driven approaches to advance health equity and is a component of PCORI's approach to achieving health equity, one of PCORI's new national priorities.

The initiative aims to address the fundamental historical and societal forces and barriers to achieving health equity such as social determinants of health, that prevent all Americans from achieving the health and healthcare they desire. The initiative will be structured according to the needs and gaps identified by stakeholders and informed by best practices and will focus on interventions that affect the individual and organizational levels of influence such as telehealth, peer support programs, and team-based care.

Further, Dunham noted that downstream interventions may not be sufficient to achieving health equity and therefore, PCORI is aiming to address the root causes and structural factors that contribute to racial and economic inequities in health by focusing more on population-based, community-directed intervention strategies that mobilize, rather than marginalize, underserved communities. Dunham noted two recently published consensus reports from the National Academies of Science, Engineering, and Medicine that highlight the need for health research funders to focus on upstream drivers of health equity to better address structural inequities in underserved communities. The report provides recommendations for funders including support of community capacity building, training initiatives, and transdisciplinary research that integrates social care and healthcare and fosters intersectional collaboration.

PCORI aims to fund research collaboratives that would include cores to support research training, stakeholder engagement, and governance, as well as a coordinating center and external advisory group with the intent of creating a learning network across all funded research collaboratives. Dunham concluded her presentation by asking to hear the panel's thoughts on what health equity research means to them and if there are specific funding models or structures PCORI should consider. Below is a summary of the panel members' discussion by theme.

Discussion

Alignment with other organization's initiatives

- One member noted this initiative aligns with the work of NQF's Committee on Person-Centered Medication Safety.

Language used to discuss and/or define populations

- One member suggested when aiming to achieve health equity, using the term 'marginalized' rather than 'underserved' better defines the population(s) of interest for this initiative. Further, they suggested involving stakeholders and professionals who play an important role in achieving health equity, especially when addressing topics such as behavioral and mental health.
- Another member echoed the sentiments of the former member and noted the importance of recognizing our own implicit bias. The member cited an example where those with disabilities are often pared down to a single identity when in fact, people with disabilities within a community may be affected by an intervention or program in different ways.
- A third member also agreed with the panelists' comments and noted care should be taken when comparing or contrasting groups and further, considering whether that is even appropriate to do within or across certain populations.
- A PCORI staff noted the discussion around language made them think of two documents, the first is a style guide from the AANC and a second is a guidance document titled, Equity Inclusion Guiding Engagement Principles, that was developed by PCORI's Advisory Panel on Patient Engagement, which consists of a set of principles and practices that they would like researchers to hold themselves to.
- Another panel member shared there is a style guide for referencing older adults to avoid stigmatizing language. They noted the importance of considering the intersection between structural racism and ageism, noting that ageism is often forgotten when discussing health equity.

Engagement strategies

- A panel member noted consideration of app technologies as an engagement strategy for certain populations. In their experience, using apps has made a significant impact among sexual and gender minority communities. They noted use of this technology may not be feasible or relevant for all populations, but mentioned it is worth considering for some to better engage communities and to measure adherence to a program or intervention. The member also shared that the technology can be expensive, so funding of an app would need to be a key consideration as well.
- Another panel member suggested having communities propose research projects and then pairing them with research institutions to conduct research together. They noted this would benefit not only researchers who would be able to collect and use the data for their purposes but would potentially improve outcomes among an entire community.
  - A PCORI staff commented this type of research may be addressed by a multiphase model, centered on the community and the community's idea of the intervention so they are the ones driving the work.
- One panel member noted that lack of participation in research among certain populations such as Black men, may not be due to their not wanting to engage, but rather were never asked to engage in research. They went on to note the importance of engaging populations who are traditionally difficult to reach if we really want to achieve health equity.
  - A PCORI staff agreed with this point and noted there is already research to support their notion. They also cited the importance of considering who is doing the asking as that is likely to influence engagement.

Sustainability of Community-based research

- A panel member discussed the importance of sustainability for community-based projects. They noted that for projects aimed at benefitting communities, those communities may become reliant on certain services, resources, or supports. When the research funding ends, thinking about how those may be sustained in the long term is an important ethical consideration.
  - A PCORI staff noted this as an important point and discussed PCORI's desire to focus on partnership with communities and capacity building efforts.
  - Another PCORI staff commented that their point speaks to the importance of building relationships and fostering trust within communities. They went on to explain that the goals and needs of the community, even in the long term, should be part of a conceptual framework when conducting research.

Achieve Health Equity: Modeling Community-Driven Research Approaches (Part 2)

- Kelly Dunham, MPP, Senior Manager, HDDR, PCORI
- Lisa Stewart, MA, Senior Engagement Officer, Public and Patient Engagement, PCORI
- Discussion Facilitator: Alicia Arbaje, PhD, MD, MPH, Co-Chair & Jane Kogan, PhD, Co-Chair

Stewart began the second part of their presentation with an overview of stakeholder engagement activities that had taken place over the last 7 months to inform development of the new initiative. Some key considerations that emerged from those discussions included a focus on geographic context, emphasizing regional and local community interests; provision of training resources for researchers and community partners; the need for faster research and consideration of study designs beyond traditional randomized control trials (RCTs); ways to build cross sector and community partnerships while addressing the role of power and power dynamics; and the need for research to be guided by the community and their identified needs and solutions. Stewart further expounded upon these points by citing a panel at PCORI's Annual Meeting titled, "Envisioning the Next Phase of Health Equity Research at PCORI" which was led by several former members of the HDDR Advisory Panel, where they discussed many of these recommendations and key issues. Stewart encouraged the members listen to a recording of the panel's presentation which is currently posted to PCORI's website.

Dunham then reviewed PCORI's potential community-driven research approach, which includes the concept of a multi-phase funding model that would allow PCORI to foster the development of a collaborative and provide some structure to establish bidirectional partnerships between researchers and communities from the start. This multiphase approach would also include a priority setting phase and a research phase. They then shared several example research topics to illustrate the multi-phase model, noting that funding would be released as the collaborative completes each of the three phases. Dunham concluded their presentation and noted three questions for discussion on the final slide. Dunham turned the presentation over to the panel for questions and comments.

Discussion

The panel members expressed their enthusiasm for this initiative and commended PCORI for being open-minded and thoughtful when designing this approach. The following is a summary of the panel members' discussion by theme.

Partnership Phase

- One member noted they appreciated the partnership phase as its own component, noting that generally partnership building is typically rolled in to either a ramp-up phase or is part of a needs assessment. The member went on to note the importance of measuring or documenting if and how partners are creating effective and meaningful partnerships, including any potential problem areas that arose during the first phase.

    - A PCORI staff suggested this could be in the form of an MOU. The member agreed this would be a good approach.

Implementation and sustainability

- One member noted the importance of embedding implementation, both strategically and actively, throughout the multi-phase model.
- Another member echoed the prior members comment, noting that having a focused phase on understanding the barriers and facilitators of sustaining the work would be great.
- A member asked PCORI to consider the implications of withholding funding until each phase is completed. They noted it may create an uncertainty among the community as to whether the work will continue and may make it difficult to establish and sustain partnerships that from their point of view, may not be sustained over the long term.
- A second member shared an alternative perspective and noted that because the phased approach is a single award, it could set the community and research staff at ease knowing that the funding for each phase will come and does not need to be reapplied for which may offer some stability.
- A member noted the importance of capturing lessons learned and successful implementation strategies from these collaboratives and potentially sharing these across the collaboratives.

Potential topic areas

- One panel member suggested thinking about differently about access and transportation, noting that often transportation and access are limited to urban areas. However, in rural areas populations are forced to drive, so looking at safe driving practices and programs which would allow older drivers and potentially neurodiverse populations to remain on the road would be a topic of interest.
- A panel member asked PCORI to expand upon what they envision the PCORI Funding Announcement (PFA) to look like and noted for this initiative applicants will need to find a balance between proposing a narrowly defined approach or allowing communities to drive the topic selection.
    - A PCORI staff offered an example of potentially focusing on a given topic such as chronic diseases, but that they are open to other suggestions.
- Another panel member shared that their institution solicits research topics from stakeholders and then they are prioritized and distilled into a list of ten or so priorities for researchers to choose from. They noted for PCORI, that may mean soliciting ideas from certain communities of interest and generating a prioritized topic list from those cited.

Engaging junior researchers

- One member noted that women and minorities are less likely to author papers and lead research projects which in turn, makes them less desirable applicants for funding. The member suggested a call for proposals specifically targeting less experienced researchers and pairing them with a more seasoned research stakeholder group to share resources and knowledge the junior researcher may not have access to otherwise. The member went on to note that private practice physicians for example who may be seeing underserved populations are uniquely poised to engage in research, however they lack the academic resources to conduct it.

Strategic Planning: Research Agenda

- Vivian Towe, PhD, MPA, PhD, MSc, MA, HDDR, PCORI
- Discussion Facilitator: Alicia Arbaje, PhD, MD, MPH, Co-Chair

Vivian Towe provided an update on PCORI's strategic planning activities. Towe first provided the scope of strategic planning activities, starting with the National Priorities for Heath, which were recently approved by PCORI's Board of Governors. The priorities were informed by a broad range of stakeholders, including the HDDR panel and are designed to be mutually reinforcing to create synergistic opportunities for progress. Towe then shared PCORI's research agenda which will serve as a framework for achieving progress on the National Priorities for Health. Six statements comprise the proposed research agenda; each was reviewed, and an illustrative example shared to provide further context.

Discussion

Communicating evidence and research findings to the public

- Two panel members noted their appreciation for the research agenda's focus on implementation science and communication of evidence and research findings to everyone in the public, including policy makers and decision leaders.
- Another member noted in regard to the communications point, it would be great to better understand what some best practices for communication and messaging of research and evidence are and how to combat misinformation and disinformation.
- Another member echoed the panel's comments and suggested PCORI build in support or suggest partnerships with health communication experts to disseminate important research findings.
- One member noted the importance of aligning PCORI's work with the work of others in this space such as the NQF who have six domains within their national quality strategy.

Important research areas

- One panel member suggested the development and or inclusion of measures that better reflect outcomes that matter most to stakeholders and are relevant to a broader range of individuals to minimize bias. The member went on to cite the example of hypertension and based on earlier discussions, are there other measures we should be using to understand high blood pressure and hypertension in patients aside from measuring blood pressure itself.
- Another panel member agreed with this comment and suggested thinking more holistically about what is measured to better understand, for example, what led someone to become hypertensive.
- One panel member suggested including insurers as stakeholders when considering important research areas for PCORI to fund, noting that they have data to inform where research may most needed.

Wrap-Up and Next Steps

- Carly Khan, PhD, MPH, RN, Associate Director, HDDR, PCORI
- Alicia Arbaje, PhD, MD, MPH Associate Professor of Medicine and Director of Transitional Care Research, Johns Hopkins University, HDDR Advisory Panel Co-Chair
- Jane Kogan, PhD Associate Chief Research and Translation Officer, UPMC Center for High-Value Health Care, HDDR Advisory Panel Co-Chair

Khan thanked the panel and presenters for a productive meeting and made special mention of PCORI staff who assisted with the planning and execution of the meeting before turning the discussion over to Kogan for final thoughts. Kogan echoed Khan's sentiments and then cited two emergent themes from the meeting which were mobilization of communities and building and fostering trust among stakeholders. Arbaje concluded the meeting by adding other key themes including considering how implicit bias may impact research, the importance of implementation in research, and inclusivity of diverse groups in research. Arbaje then reminded the panel of their next meeting in May 2022 and to complete a survey they will receive via email from PCORI.