



Advisory Panel on Healthcare Delivery and Disparities Research Winter 2019 Meeting Summary

December 6, 2019

OVERVIEW

On December 6, 2019 the PCORI Advisory Panel on Healthcare Delivery and Disparities Research (HDDR) held its 14th meeting in Washington, DC. The HDDR Advisory Panel's 18 members include patients, caregivers, and patient advocates; clinicians; researchers; and representatives from industry, hospitals and healthcare systems, and payers. The meeting was open to the public via webinar, and meeting materials have been posted to the PCORI website.

At the meeting, the panel heard updates from PCORI's HDDR Program. PCORI awardees shared results of their PCORI-funded research initiatives, engaging in collaborative discussion with the Panel members on shaping further efforts, applying lessons learned, and disseminating results. During the second half of the meeting, the panel discussed two seminal topic areas: suicide prevention and maternal morbidity and mortality.

HDDR PROGRAM UPDATES

Steve Clauser, Director of PCORI's HDDR Program, reported that PCORI has awarded more than \$925 million to date to fund 220 comparative effectiveness research (CER) studies in HDDR. Dr. Clauser also updated the panel on recent awards. Between August 2019 and November 2019, 7 new HDDR awards consisted of 4 Improving Healthcare Systems and 3 Addressing Disparities Broad awards.

The panel also heard about HDDR's Research and Learning Networks, designed to help investigators improve their research and to assist PCORI in sharing information on these topics. Notably, the Journal of Palliative Medicine published the protocols from all nine Palliative Care Learning Network studies in August 2019. In addition, the Telehealth Portfolio Synthesis and Analysis Group is currently supporting manuscripts spearheaded by PCORI PIs on 3 topic areas; addressing disparities through telehealth, examining evidence gaps in the use of mHealth for self-management of chronic disease, and challenges in addressing large, multi-site, multi-state pragmatic trials in telemedicine

Report Back: Assessment of Comparative Effectiveness, Research Gaps on Aging in Place
Sindhura Gummi, Senior Program Associate, updated the panel on an initiative to categorize and communicate PCORI's investment in CER focused on aging in place. During the [Fall 2018 meeting](#), the HDDR advisory panel provided input on PCORI's draft conceptual framework on aging place to guide the portfolio analysis, and discussed target populations, relevant interventions and key outcomes. PCORI has invested \$208 million in 10 CER studies that will provide evidence to promote aging in place for

older adults. PCORI's research portfolio covers important decisional dilemmas, but CER evidence gaps remain (e.g., environmental interventions, transportation and housing). There is also a clear need for additional research on informal caregiver interventions and outcomes.

Discussion

The HDDR Advisory Panel provided suggestions for PCORI to strengthen their aging in place portfolio including:

- Examining the differences between rural and urban environments
- Exploring the impact of technology for caregivers of seniors
- Considering caregiver burden for enrollment in research
- Exploring studies that assess personnel gaps in intervention research that align with CER
- Considering cultural differences in family structure and caregiving

Only a few studies in PCORI's aging in place portfolio are complete. As a next step, PCORI plans to explore caregiver-related interventions that could be potential avenues for CER. This topic may be revisited in future HDDR Advisory Panel meetings.

HDDR AWARDEE PRESENTATIONS ON STUDIES WITH MIXED RESULTS

Pathways to American Indian and Alaska Native Wellness: Comparative Effectiveness of Two Approaches to Diabetes Prevention

Jan Vasquez, MPH and Lisa Goldman-Rosas, PhD presented results of a [PCORI-funded study](#) which compared two approaches to diabetes prevention among urban American Indians/Alaskan Natives. While the enhanced intervention was not superior to the standard intervention, the study resulted in important findings and lessons learned for future research. For example, they learned that social determinants of health like transportation, offering a welcoming space for physical activity and utilizing trained facilitators contributed to the success of both arms. The study team also formed a successful partnership with a community partner, Pathways to American Indian and Alaska Native Wellness (AAAW) and collaborated with an American Indian Community Action Board to guide the research study. Evaluation of this partnership revealed a high level of trust between board members and Stanford research staff.

Discussion

Dr. Rosas and Ms. Vazquez clarified that the research team included the evaluation of the community partnership in their Pori proposal and PCORI fully supported it. This evaluation provided community board members the opportunity to anonymously and openly express their concerns and was instrumental for understanding how to foster community partnerships. The enhanced intervention arm included the standard diabetes prevention program (DPP) with additional enhancements such as talking circles, and mental health support. The researchers learned that participants experienced challenges in attending extra activities and subsequently, the standard DPP was just as effective as the enhanced DPP. Panelists also noted the importance of considering co-morbidities and stigma with respect to weight and recommended looking at harm reduction models.

Trauma Survivors Outcomes & Support (TSOS) PCORI Studies: Harnessing Stakeholder Driven Science & the E2AN to Impact National Acute Care Policy

Doug Zatzick, MD and Peter Thomas, JD, presented results from their [PCORI-funded study](#) in the context of two decades of scientific and policy related work on patient-centered care transitions for U.S. trauma care systems. The study compared the effectiveness of care management versus enhanced usual care to prevent postinjury concerns and symptoms for hospitalized patients with serious injuries. Study results showed that the program reduced the intensity of trauma-patient concerns but did not have a strong effect on PTSD symptoms or physical function. Although the study yielded mixed results, it supported the effectiveness of patient-centered care interventions for trauma survivors which, in combination with other research results, influenced the American College of Surgeons to update guidelines for trauma care centers to recommend patient-centered strategies to facilitate transition back into the community. These are the first guidelines ever issued by the College recommending patient-centered approaches for transitional care. Dr. Zatzick and his research team are currently working on a second PCORI-funded study which compares a team-based approach with peer support with trauma surgery notification and mental health referral for trauma-injury patients with symptoms of PTSD. Mr. Thomas shared his personal experience with a traumatic injury and highlighted the value of having a peer mentor to support his recovery.

Discussion

Advisory Panel members discussed and/or recommended potential differences between veterans and civilians with traumatic injuries and whether peer support would be as effective for veterans. Dr. Zatzick agreed that the unique needs of veterans should be identified and reiterated that peer mentoring and peer support interventions have been shown to be effective in a variety of populations and settings. The panel also discussed the limitations of using a medical model when evaluating patient-centered outcomes. Social science models may be more useful for capturing a broader range of outcomes that matter to patients, especially outcomes related to social determinants of care. Some of the positive impacts of interventions such as peer-mentoring may be difficult to measure, such as empathy and patient trust. The panel recommended continuing to explore ways to capture and measure meaningful outcomes.

MATERNAL MORBIDITY AND MORTALITY, IDENTIFYING RESEARCH PRIORITIES

Cathy Gurgol, Senior Program Officer, provided an overview of maternal morbidity and mortality in the U.S. 700 women die from pregnancy-related complications yearly in the US, and Black women are 3 to 4 times more likely than white women to die from pregnancy-related complications. Black women are also twice as likely to experience severe maternal morbidity compared to white women. Reports of poor outcomes and disparities as well as significant stakeholder input have led PCORI to actively explore ways to support CER around healthcare decision-making related to maternal morbidity and mortality. Ms. Gurgol asked for feedback and recommendations from the HDDR Advisory Panel on strategies, outcomes, and/or populations that PCORI should consider for potential CER to reduce maternal mortality and morbidity.

Discussion

The HDDR Advisory Panel recommended PCORI explore the following topics related to maternal morbidity and mortality research:

- ***Bias***
 - Panelists recommended PCORI explore interventions that seek to address provider bias and patient mistrust of healthcare providers in order to reduce disparities in maternal morbidity and mortality. Unfortunately, research on outcomes and impacts of anti-bias and discrimination trainings is currently lacking. Furthermore, changes in unconscious bias is a difficult outcome to measure. However, the panel stated that patient-reported outcomes, such as patient experience of care could be measured. The lack of established efficacy makes such interventions difficult to fund, however if PCORI expands funding opportunities to include pilot interventions, they should consider the opportunity to learn which training programs can reduce provider bias. Such interventions may also shed light on the interplay between systems, providers and patients of color.
- ***Expanding Maternal Health***
 - Panelists noted that maternal health goes beyond reproductive health and this narrow focus can lead to other health issues being overlooked such as violence against women, trauma caused by discrimination, and other unique issues facing women of color. Panelists recommended considering interventions that measure stress and cortisol levels in pregnant women, consider culturally appropriate ways to integrate family into care instead of focusing only on the patient, and programs like doula support across age, ethnicity, geography and education level.
- ***Timely Care***
 - Panelists recommended research that seeks to understand and address the reasons some women do not receive timely prenatal care, including care-seeking behavior. This may include collecting data on whether the pregnancy was intended or not which is associated with lack of care.
- ***Substance use disorders***
 - Panelists noted the continuing need to focus on pregnant women with opioid and other substance use disorders.

SUICIDE PREVENTION: TOPIC DEVELOPMENT FOR TARGETED PFA

Els Houtsmuller, Associate Director, provided background on the topic of suicide prevention and an overview of PCORI's current portfolio in this area. Suicide rates in the US have increased by 33% since 1999 and certain populations, such as transgender, rural, and American Indian/Alaska Native individuals, experience higher rates of suicide. ; interventions in crisis settings such as emergency departments or mobile crisis units, brief interventions to address acute risk such as safety planning or motivational interviewing, longer-term treatments such as therapy or medications, and systems-level interventions to identify people at risk. PCORI identified suicide prevention as a topic of interest in broad funding announcements in 2019 and has funded two research studies which are currently in progress. Dr. Houtsmuller asked the Advisory panel to provide recommendations on tailored interventions for target populations, research outcomes (suicide ideation, engagement in care, coping skills, and/or quality of life) and study designs.

Discussion

The Advisory Panel shared the following recommendations for research considerations:

- ***Tailored Interventions for Target Populations***
 - Consider interventions that utilize peer-support to improve connectedness and minimize loneliness. Peer support has been shown to be effective for improving a broad range of patient outcomes.
 - Support interventions that increase resilience and other protective factors instead of focusing only on risk factors.
 - The peer respite model may have potential for tailoring for transgender women.
 - Explore bystander interventions to prevent suicide.
 - Consider workforce development interventions that train and utilize community navigators or health workers (CHWs) as a first line of defense. Due to oversaturation, PCORI has limited funding for CHW research. However, this does not rule out funding research on specific issues with broad implications (such as suicide prevention) that utilize CHWs for interventions.
 - Older adults have high rates of suicide. Consider interventions tailored to this population and their unique issues with regards to suicide risk (such as cognitive decline, retirement, social isolation, and bereavement).
 - At the systems level, research should consider the ways healthcare may unintentionally contribute to the emotional and physical pain of older adults such as prescribing medications that may make depression symptoms worse (e.g. beta blockers), and overlooking signs of depression because the symptoms may manifest themselves differently in this population, particularly for men.
- ***Outcomes***
 - Suicidal ideation and suicide attempts should be captured. Ideally this data would be available in claims and/or electronic health records.
- ***Study Design***
 - Encourage natural experiments using existing infrastructure, such as suicide hotlines and mobile crisis units.
- ***Other Considerations***
 - Views of suicide vary greatly across cultures and communities. Interventions should consider these cultural differences particularly regarding language and stigma associated with suicide and mental health. The cultural explanatory model may be helpful.
 - When assessing risk, researchers should consider prescription medicines and firearms in the home.
 - Suicide rates in Black teens have been increasing. Researchers should consider the reasons for this upward trend, including how bias and microaggressions from everyday trauma influence stress levels, particularly for black boys and teenagers.
 - Pediatric professional organizations may be ideal partner for youth suicide prevention.

WRAP UP AND NEXT STEPS

The Co-chairs and Dr. Clauser thanked the Advisory Panel for the thoughtful feedback and rich discussion. Dr. Clauser noted that these discussions are still in the beginning phases and PCORI will review and consider the feedback provided by the Advisory Panel. If any panel members have additional thoughts, feedback, or questions, they should email Juliette Price (jprice@pcori.org).