



## Advisory Panel on Healthcare Delivery and Disparities Research Program Meeting Summary

January 2019

### Overview

On November 15, 2018 the PCORI Advisory Panel on Healthcare Delivery and Disparities Research (HDDR) held its third meeting in Washington, DC.

Fourteen of 21 returning panelists attended and were joined by three new members for the first time who replaced outgoing members who had fulfilled their term of service by the prior meeting. The 24-member multi-stakeholder panel includes patients, caregivers, clinicians, researchers, providers, payers, and representatives of healthcare systems. The meeting was open to the public via teleconference, and meeting materials were posted to the PCORI website in advance.

Steve Clauser, PhD, MPA (Program Director) and the co-chairs, Umbereen Nehal, MD, MPH, and Craig Umscheid, MD, MSCE, kicked off the meeting with introductions of panelists and PCORI staff, as well as a brief review of each HDDR priority area (Addressing Disparities and Improving Healthcare Systems). A team of HDDR staff presented the latest iteration of the HDDR Conceptual Framework, informed by panel volunteers. Then, following a presentation about the initial analysis of PCORI's geriatrics portfolio, panelists broke into small groups and worked collaboratively to refine the definition of the concept of "aging in place." Before lunch, Clauser gave a more in-depth review of recent program activities and additions to the funded portfolio since the last meeting. In the afternoon, the panel heard from a representative of AHRQ who has worked with HDDR staff to develop the PCORI/AHRQ Learning Health Systems K12 awards, followed by an update on the portfolio analysis of the Addressing Disparities portfolio that was begun at the prior meeting. The day ended with a small poster session, featuring posters authored by HDDR staff and presented at recent meetings.

### Related Information

- [About this Advisory Panel](#)
- [Meeting Details and Materials](#)
- [PCORI Healthcare Delivery and Disparities Research Program](#)

The Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created to help people make informed healthcare decisions.

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## Introductions

HDDR program staff and 14 returning members in attendance welcomed three new members:

- Kathy Phipps
- Carmen Pace, MPA/HCA, BSN, RN
- Barbara Warren, PsyD

The now 24-member panel represents a multi-stakeholder group that includes patients, caregivers, clinicians, researchers, providers, payers, healthcare systems representatives, and purchasers.

## Where Have We Been, and Where Are We Now?

Steve Clauser, Director of the Healthcare Delivery and Disparities Research Program reviewed the fusion of the IHS and AD Advisory Panels in December 2017, Targeted funding announcements in each priority area, past advisory panel activities, and priorities for the coming year.

- The IHS and AD priority areas merged in the fall of 2016, creating the Healthcare Delivery and Disparities Research Program, with the mission to focus on comparing patient-centered approaches to improve the equity, effectiveness, and efficiency of care.
- As of August 2018, the AD program has funded a total of 84 studies, for a total of \$256 million, which includes 66 studies from the Broad PCORI funding announcement for \$124 million, four studies from the Pragmatic Clinical studies funding announcement for \$49 million, and 14 studies from Targeted funding announcements, for \$83 million. The IHS program has funded a total of 121 studies for a total of \$590 million, which includes 89 studies from the Broad PCORI funding announcement for \$262 million, 14 studies from the Pragmatic Clinical Studies funding announcement for \$168 million, 15 studies from Targeted funding announcements for \$152 million, and three Natural Experiments, for \$7 million. The AD portfolio hosts four Targeted funding announcements, while the IHS portfolio has seven, covering a vast array of priorities and patient populations.
- In 2018, the IHS portfolio gained three studies addressing opioid abuse through two Targeted funding announcements, with one study on Unsafe Opioid Prescribing, and two studies on Medication-Assisted Treatment (MAT) Delivery for Pregnant Women with Substance Abuse Disorders Involving Prescription Opioids and/or Heroin. More awards are anticipated on opioid use disorders through a new Targeted funding announcement on Psychosocial Interventions with Office-Based Opioid Treatment for Opioid Use Disorder, and the reissuance of the funding announcement for Medication-Assisted Treatment (MAT) Delivery for Pregnant Women with Substance Abuse Disorders Involving Prescription Opioids and/or Heroin.
- As of September 2018, 117 PCORI studies, including 47 from HDDR, have research results peer-reviewed and publicly available. That number is expected to increase rapidly in the coming year.
- Clauser noted that prior advisory panels have weighed in on potential priority topics that later became Targeted funding announcements or special emphasis topics for Broad funding announcements. The IHS Targeted funding announcements for Models of Palliative Care



Delivery and Office-Based Opioid Treatment, and the AD Targeted funding announcements for Sickle Cell Disease Therapy/Care Transitions, and Blood Pressure Control in Minority Populations are recent examples of targeted initiatives that originated in the IHS and AD Advisory Panels, respectively.

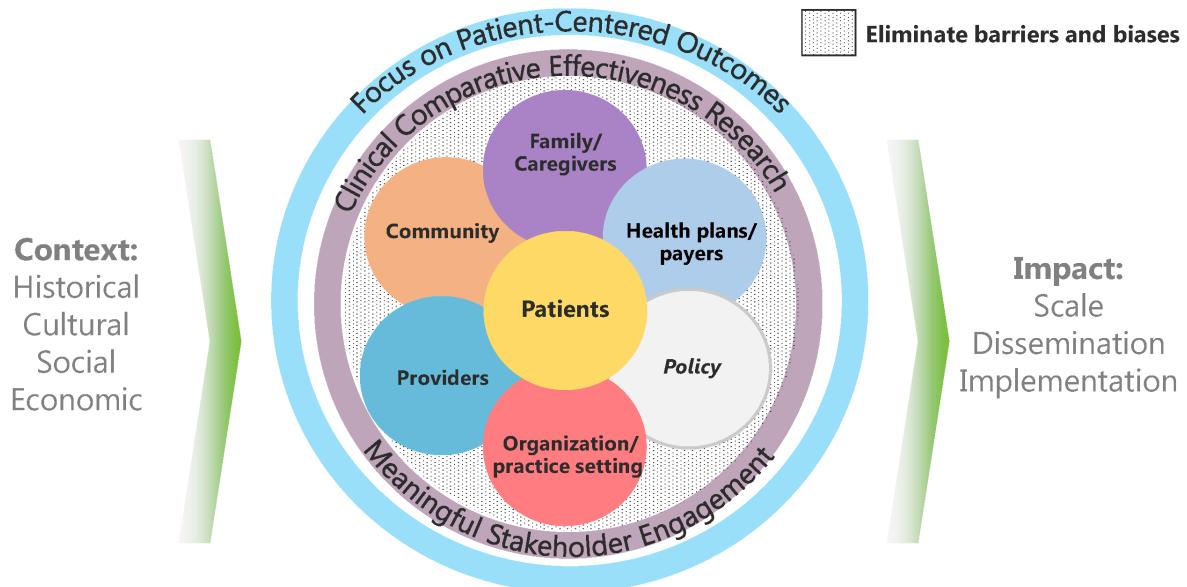
- In the future, the HDDR Advisory Panel will be asked to prioritize topics to inform targeted analyses of special populations or disease areas, identify gaps in the HDDR portfolio for future priority topic development, and inform the analytic approach and interpretation of research results.

## **HDDR Conceptual Framework: An Update**

HDDR Program Officers Carly Khan, PhD, and Mari Kimura, PhD, MS, provided an update on the HDDR Conceptual Framework, the development of which they have led over the past year. The panel saw an updated framework diagram, informed by feedback received at the April 2018 meeting and from a subset of panel volunteers who have contributed to the refinement of the framework. The framework is a tool to visualize the contributing and overlapping priorities of the disparities and health systems priorities in the HDDR program, while also revealing any gaps in priorities or areas needing further analysis. The framework places the patient at the center of our work, surrounded by the overlapping needs and priorities of families/caregivers, health plans/payers, policy makers, organization/practice setting, providers, and the community, all within the spheres of clinical comparative effectiveness research, meaningful stakeholder engagement, and focus on patient-centered outcomes and eliminating barriers and biases. The framework is viewed within historical, cultural, social, and economic contexts, with an eye toward scale, dissemination, and implementation of research findings.

The panel appreciated the progress staff had made in responding to their earlier feedback, but suggested that more attention should be placed on the audience(s) the framework relates to, as a final step in considering final revisions.

## Healthcare Delivery and Disparities Research Conceptual Framework



### Aging in Place: Refining the Topic for a Portfolio Analysis

HDDR Program Officer Gyasi Moscou-Jackson, PhD, MS, RN, and Program Associate Sindhura Gummi, MPH, introduced their analysis of PCORI's portfolio of studies on geriatrics issues and aging, identified as a priority by PCORI staff and stakeholders. In particular, they sought the panel's input on conceptualizing the interventions that qualify as promoting "Aging in Place," which was identified as a critical subgroup of studies in the geriatrics portfolio. Panelists met in small groups to further refine the priority of aging in place, with the following feedback provided to the entire panel and staff:

- The panel confirmed their enthusiasm for the analysis of this topic.
- Clarity was requested on the necessity of a portfolio analysis of this topic, and the intended audience.
- Encouragement to consider expanding the population to include people with disabilities
- Importance of considering disparities in geriatrics care, specifically with regard to cultural norms on the process of aging
- Should the care setting include public housing, or other community-based housing options?  
How does the setting affect the delivery of various interventions?
- How are the goals of care assessed in the context of aging in place?
- Workforce—how can different kinds of providers and community members help older populations remain in their homes?



PCORI staff appreciated the feedback and plans to incorporate these responses into future refinement of this portfolio.

## **State of HDDR: Program Update from Steve Clauser**

Program Director Steve Clauser presented a deeper dive into HDDR program activities since the last AP meeting, with particular attention to recently awarded studies and the recently released Targeted funding announcements for studies on opioid use disorders. He reviewed the ongoing portfolio analyses that HDDR staff have worked on this year, and shared the considerable participation of program staff in the 2018 PCORI Annual Meeting. Clauser went through the growing list of research communities and learning networks that are supported by HDDR staff, such as the Asthma Evidence to Action Network, the Palliative Care Learning Network, the Telehealth Portfolio Synthesis and Analysis Group, the Transitional Care Evidence to Action Network, and the Natural Experiments Network. He also introduced PCORI's new partnership with AHRQ (Agency for Healthcare Research and Quality) to train the next generation of health systems/CER researchers—which the panel heard more about later in the day.

## **AHRQ/PCORI Learning Health System K12 Mentored Career Development Program: Genesis, Overview, and Roadmap**

HDDR Senior Advisor Carly Parry, PhD, MSW, MA, and AHRQ Senior Fellow Jean Hsieh, MD, presented an overview of the newly founded partnership between PCORI and AHRQ to support emerging health systems researchers. The purpose of the K12 Intuitional Mentored Career Development Program is to train clinical and research scientists to conduct PCOR within learning health systems (LHS) focused on generation, adoption, and application of evidence to improve the quality of care and patient outcomes. The program draws upon the PCORI Methodology Standards to guide the curriculum, and leverages AHRQ's expertise in implementing funding programs and PCORI's expertise in conducting patient-centered outcomes research and managing learning collaboratives.

The LHS award supports 11 Centers of Excellence throughout the country, for up to five years, for about \$800,000/year in annual costs per project, across 40 scholars in Year 1, which will grow to 90 scholars over the five-year program. The Centers of Excellence include: Albert Einstein College of Medicine, Children's Hospital of Philadelphia, Indiana University School of Medicine, Kaiser Permanente Washington Health Research Institute, Northwestern University, Oregon Health and Science University, University of California, Los Angeles, University of California, San Francisco, University of Minnesota, University of Pennsylvania, and Vanderbilt University Medical Center. The learning collaborative that will develop as part of the partnership will serve as a forum to promote cross-institutional scholar/mentor interactions, collaboration across institutions on project best practices, and will result in a shared curriculum of training health systems research that could be expanded to other health systems.



The presentation generated considerable discussion and suggestions for learning curriculum that the LHS staff will take back to the principal investigators for consideration. PCORI and AHRQ promised to provide regular updates for the panel as this initiative proceeds.

## **PCORI Addressing Disparities: Update from the Portfolio Analysis Team**

HDDR Program Associate Maggie Holly and Program Assistant Metti Duressa presented an update from the team working on the portfolio analysis that was presented at the April 2018 meeting. They reiterated the goals of the initiative: to identify additional gaps that may exist in our portfolio, increase the usefulness of our portfolio by “clustering” similar projects, and encourage new collaborations with stakeholders.

The working group, informed by the advisory panel, has selected federally qualified health centers (FQHCs) as the high-priority topic on which to begin the analysis. Then, they began generating analytic questions on PCORI’s role in advancing research in FQHCs, such as: How is our portfolio engaging FQHC leadership? How is our portfolio improving quality measure performance? How is our portfolio assessing and addressing social support needs?

At the time of the April 2018 meeting, the working group was seeking feedback from stakeholders (HDDR Advisory Panelists) to strengthen the analysis. Panel feedback highlighted the stakeholder priorities that were missing, and ensured the appropriate specificity in the definitions used. Between the April and November 2018 meetings, the working group collected extensive data on PCORI’s portfolio of studies in FQHCs: 27 funded awards, for more than \$129 million, in 25 states, with 35 publications to date. Eight studies focus on FQHCs in rural areas, two on LGBT persons, and 19 on racial and ethnic minority groups. The most common focus of studies in FQHCs addressed infection control and mental health issues. Then, nine key areas were identified as priorities for doing research in FQHCs: incorporating intersectionality into research, engaging patients and community members, improving quality and lowering cost, partnering to improve capacity and plan for growth, using technological solutions, tackling the social determinants of health, serving the needs of special populations, integrating behavioral health, and expanding access to care and other services.

At the November 2018 meeting, the panel provided the following feedback on the FQHC analysis of the AD portfolio:

- What makes an FQHC what it is?
- Workforce issues: are FQHCs appropriately staffed so that they are able to serve their specific population’s needs? If not, how can the workforce be supported to function at its best?
- Sustainability of interventions should be carefully considered prior to implementation, given the basic difficulties FQHCs have in accessing their patients.
- Sometimes, FQHCs are the only places certain populations can access care, and the institution needs to be able to link these patients with secondary and tertiary providers as needed. It could be interesting to study the benefits and outcomes of fostering collaborations between academic institutions and FQHCs.

- How can we extract the generalizable information from the work done in FQHCs?
- Pragmatic research studies, instead of efficacy questions, may be more adaptable to the FQHC environment due to the increased demands on clinicians in this environment.
- There is a lot to learn from FQHCs, and a lot variation within them.

## Poster Session

The following posters were presented by HDDR staff to the panel for their perusal:

- Chronic Disease Management: The Use of Chronic Care Model Elements in Patient-Centered Outcomes Research Institute's (PCORI) Comparative Effectiveness Research (CER) Trials (Kaitlynn Robinson-Ector, Marisa Torres-Ruiz, Dionna Attinson, Sindhura Gummi, Candace Hall, Ayodola Anise, Steven Clauser)
- Patient Partnerships and the Advancement of Health Equity (Soknornta Prum, Marisa Torres-Ruiz, Kaitlynn Robinson-Ector)
- Addressing National Research Priorities in Mental Health: A Systematic Analysis of the PCORI Mental Health Portfolio (Candace Hall, Terri Gleason, Elisabeth Houtssteller)
- Analysis of Cultural Tailoring in Behavioral Interventions (Marisa Torres-Ruiz, Dionna Attinson, Alyssa Hudson, Kaitlynn Robinson-Ector)
- Team-Based Models and Access to Care: Linking Underserved Communities to Health Services (Marisa Torres-Ruiz, Kaitlynn Robinson-Ector, Sindhura Gummi, Candace Hall, Gyasi Moscou-Jackson, Carly Khan, Steve Clauser)
- Collaborative Efforts Among Eight Patient-Centered Studies to Reduce Disparities in Asthma (Dionna Attinson, Julia Anderson, Ayodola Anise)

## Next Steps

Panelists interested in working on any of the initiatives presented were encouraged to get in contact with HDDR staff. At the next meeting, to be planned for some time in the spring of 2019, more information will be provided on these early initiatives, particularly efforts to disseminate research results as they become available.