



MEETING SUMMARY

Advisory Panel on Healthcare Delivery and Disparities Research Meeting Summary

May 16, 2019

[About This Advisory Panel](#) | [Meeting Details and Materials](#)

OVERVIEW

On May 16, 2019, the PCORI Advisory Panel on Healthcare Delivery and Disparities Research (HDDR) held its 13th meeting in Washington, DC.

The HDDR Advisory Panel's 23 members include patients, caregivers, and patient advocates; clinicians; researchers; and industry, hospital and healthcare system, and payer representatives. The meeting was open to the public via webinar, and meeting materials were posted to the PCORI website in advance.

At the meeting, the panel heard updates from PCORI's HDDR Program. After learning about PCORI's mental health portfolio, the panel separated into breakout groups to develop recommendations for enhancing this portfolio. Representatives of each group then summarized the research gaps they had identified, populations to include in PCORI-funded research, and mental health topics and conditions to address in future PCORI studies. After lunch, the HDDR Advisory Panel again separated into breakout groups to develop recommendations for PCORI's health systems and health disparities research and planning for the next authorization cycle. A presentation from a PCORI-funded investigator highlighted health disparities in sexual and gender minorities (SGMs) and the importance of collecting data on sexual orientation and gender identity (SOGI). The final session focused on PCORI's asthma portfolio and a PCORI-funded effort to translate the results of PCORI's asthma research into policy.

HDDR PROGRAM UPDATES

Steve Clauser, Ph.D., M.P.A., Director of PCORI's HDDR Program, reported that PCORI has awarded more than \$824 million to date to fund 214 comparative effectiveness research (CER) studies in HDDR. Dr. Clauser also updated the panel on recent awards. Between November 2018 and April 2019, 15 new HDDR awards consisted of 2 Improving Healthcare Systems and 6 Addressing Disparities Broad awards, 3 Pragmatic Clinical Study awards, and 4 Targeted funding awards.

The panel also heard about HDDR's five Research and Learning Networks, designed to help investigators improve their research and to assist PCORI in sharing information on these topics. Notably, a midterm review of the Natural Experiments Network for Improved Prevention and Treatment for Patients with Type II Diabetes is underway. In addition, the *Journal of Palliative Medicine* will publish the protocols from

all nine Palliative Care Learning Network studies. The Telehealth Portfolio Synthesis and Analysis Group also recently held telehealth webinars for funded investigators.

PCORI'S MENTAL HEALTH PORTFOLIO

Elisabeth Houtssteller, Ph.D., Associate Director, reported that mental illness affects one in five children and adults and is the leading cause of disease burden in the United States. Although evidence-based treatments are available, fewer than half of patients receive these treatments, and rates are even lower among patients who are black, Hispanic, or Asian. To date, PCORI has awarded \$320 million to fund 78 CER studies on mental health, a greater investment than for any other health condition.

Candace Hall, M.A., Program Associate, explained that 48 of PCORI's 78 mental health studies are in the HDDR portfolio, and most of these studies focus on improving patient access to mental health services. Rebecca Chanis, M.S.P.H., M.A., Program Associate, reported that PCORI has funded 16 studies on tele-mental health care (e.g., text messaging or Skype calls in participant homes or provider offices). Tshema Nash, M.P.H., Program Associate, reported that PCORI has funded 22 studies on depression, including 13 in understudied, vulnerable populations. Afterward, Dr. Houtssteller posed three questions to the group:

- (1) Are there underrepresented populations or conditions in PCORI's mental health portfolio?
- (2) Which parts of this presentation were helpful, which were not, and are there additional variables to include?
- (3) Which mental health sub-portfolios should PCORI focus on next and which criteria should we use?

BREAKOUT SESSION: REVIEW OF KEY QUESTIONS RELATED TO MENTAL HEALTH

HDDR Advisory Panel members separated into three breakout groups to discuss the questions that Dr. Houtssteller had posed.

Mental health research gaps identified by the breakout groups

- Impact of mental health screening, screening tools used, and whether screening tools need to be tailored to different populations
- Stressors (e.g., racism, comorbidities, lack of running water) affecting populations with mental health conditions
- Pathways to treatment for different populations and their impact on studies and outcomes

The breakout groups recommended including caregivers, people with limited English proficiency, SGM populations, and people with disabilities in future studies. PCORI research topics that can affect mental health outcomes include the impact of racism, race, age, and clinician/patient concordance on diagnoses given and treatments offered. The breakout groups also recommended that PCORI fund research on the relationships between mental health and lifelong trauma, immigration status, lack of insurance, and criminal justice system interactions. Conditions to study were autism, dementia, anxiety, and mental illness that results from chronic or rare diseases.

PCORI REAUTHORIZATION UPDATE

Andrew Hu, M.P.P., Director of Public Policy and Government Relations for PCORI, led a closed session about congressional reauthorization of PCORI, whose current authorization ends on September 30, 2019.

FUTURE DIRECTIONS FOR PCORI'S HEALTH SYSTEMS AND DISPARITIES RESEARCH

Parag Aggarwal, Ph.D., Associate Director, explained that although PCORI's new authorizing legislation is to be determined, PCORI should start planning for its next authorization cycle now. Carly Parry, Ph.D., M.S.W., M.A., Senior Advisor, listed some of the issues considered in PCORI's planning, specifically niches to target or how to conduct funding future research.

BREAKOUT GROUPS AND GROUP DISCUSSION

The HDDR Advisory Panel formed two breakout groups to discuss the same sets of questions for health systems research or health disparities research.

Addressing Disparities

Responses to the five questions by the health disparities breakout group are summarized below.

1. What has worked well in this priority area?
 - Research designed to reduce or eliminate health disparities in clinical settings
 - A single advisory panel focused on both health disparities and health care delivery
 - National and international impact on recognition of the importance of stakeholder engagement
2. What has not worked in this priority area?
 - Insufficient awareness of PCORI among potential applicants
 - Engagement of vulnerable populations that are not typically involved in PCORI-funded research
3. What areas are uniquely suited for PCORI to lead and advance science and practice?
 - Technical assistance on stakeholder engagement
 - Patient care experiences
 - Which components of a multicomponent intervention make a difference
 - Interventions that target multiple diseases
4. Should PCORI support other types of research, in addition to CER?
 - Small grants for infrastructure interventions embedded in health systems that could result in rapid changes
 - Health care research centers embedded in integrated health systems supported by matching funds from PCORI and the systems
5. Are critical stakeholders not yet engaged in HDDR?
 - Populations not typically engaged in research, educators, local government agencies

Improving Healthcare Systems

The responses of the health systems breakout group are listed below.

1. What has worked well in this priority area?
 - Focus on many different populations and on all stages of the research process
2. What has not worked in this priority area?
 - Focus on questions that affect small populations
 - Research on technologies that could become outdated
3. What areas are uniquely suited for PCORI to lead and advance science and practice?
 - Research on interventions that can be rapidly implemented
 - Pilot studies of an intervention's implementation, followed by more research for successful pilot studies
 - Transition from research to implementation by stakeholders
 - More research that is embedded in health systems
4. Should PCORI support other types of research, in addition to CER?
 - Research that will result in changes, such as in employer-sponsored health insurance
 - Research focused on natural experiments by payers and states
5. Are critical stakeholders not yet engaged in HDDR?
 - School systems, houses of worship, employers, and payers
 - Center for Medicare and Medicaid Innovation, private foundations

IMPROVING HEALTH CARE SYSTEMS TO PROMOTE HEALTH EQUITY FOR SEXUAL AND GENDER MINORITIES

Mari Kimura, Ph.D., M.S., Program Officer at PCORI, explained that 5 of the 214 HDDR studies funded to date target SGM populations. These studies have shown that patients want their emergency department providers to know their sexual orientation and gender identity (SOGI) status, transgender women receiving hormone therapy have a higher risk of stroke and blood clots than cisgender women, and self-administered human papillomavirus screening is as effective as clinician-delivered screening for most female-to-male transgender patients.

Kenneth Mayer, M.D., Medical Research Director of Fenway Health, is leading a PCORI-funded [randomized controlled trial](#)¹ at 12 community health centers to determine the impact on care of cultural competence training for health care providers and clinic staff. Six centers are receiving 2 days of on-site

¹ <https://www.pcori.org/research-results/2017/how-does-training-healthcare-providers-discuss-sexual-orientation-and-gender>

training for administrators and staff on providing care that respects SGM patients' preferences, needs, and values and how to collect SOGI information. Staff at centers in the other group can participate in an optional one-time webinar that covers the same topics. The complete presentation can be found [here](#).

HOW PCORI'S ASTHMA PORTFOLIO CAN LEAD TO CHANGES IN PRACTICE AND POLICY

PCORI's Asthma Portfolio

Ayodola Anise, M.H.S., Program Officer, explained that 25 million Americans have asthma, and 10 Americans die of this disease every day. The asthma burden is highest in racial and ethnic minority and low-income populations. PCORI has invested \$46 million in 13 CER studies of asthma. Nine of the studies are complete, and the results for several are publicly available.

The presentation focused on the role of community health workers/peer navigators in the nine completed asthma studies. These studies found that community health workers consistently improved medication adherence among racial and ethnic minorities, but their impact on outcomes like asthma control and health-related quality of life was mixed. The strongest impact on asthma-related outcomes occurred when community health workers were combined with clinical decision support to provide patient education and support through home visits.

Evidence for Equity Initiative

Sinsi Hernández-Cancio, J.D., Director of the Center on Health Equity Action for System Transformation at Families USA, reported that the [Evidence for Equity Initiative](#)² is translating selected PCORI-funded research project findings into policy recommendations. Policy recommendations for asthma are now available in a report, [Advancing Health Equity through Better Evidence for Asthma Care: Translating Patient-Centered Outcomes Research Learnings into Equity-Focused Policy](#),³ based on six PCORI-funded studies.

Discussion

The HDDR Advisory Panel identified opportunities for PCORI to fund research on the following asthma topics:

- Translation of asthma study findings into real-world settings
- Important issues for clinical asthma guidelines, such as allergen reduction in homes
- The value of lifestyle modification recommendations
- Assessment of findings by race and ethnicity, housing status, and food status

WRAP UP AND NEXT STEPS

Dr. Clauer summarized the HDDR Advisory Panel's next steps from the meeting:

- Consider creating a subgroup of advisory panel members to advise PCORI on its mental health portfolio

² <https://familiesusa.org/initiatives/evidence-equity-initiative>

³ <https://familiesusa.org/product/advancing-health-equity-through-better-evidence-asthma-care-translating-patient-centered>

- Explore the longer-term feasibility of collecting SOGI data in all PCORI studies, consider creating a subgroup of advisory panel members to advise PCORI on SGM research