



## Advisory Panel on Addressing Disparities Meeting Summary

### Overview

On February 9, 2016, the PCORI Advisory Panel on Addressing Disparities (AD) held its ninth meeting in Washington, DC.

The 21-member panel includes patients, caregivers, clinicians, researchers, providers, payers, and purchasers. The panel was joined by AD program staff. The meeting was open to the public via teleconference, and slides and meeting materials are available on the PCORI website.

Dr. Romana Hasnain-Wynia, Director of the AD Program, provided updates on program initiatives, including studies underway on obesity treatment options, hypertension control and a study awarded through the pragmatic clinical studies funding announcement. The updates also included updates on the progress with the sickle cell disease topic as well as other topics previously discussed by the panel. Staff presented an analysis of projects funded through the AD Broad funding announcement and themes that have emerged. Dr. Tung Nguyen, an awardee funded through the AD program, described his PCORI-funded study comparing interventions for increasing hepatitis B and C screening in Asian Americans. The panel heard presentations from other PCORI staff on PCORnet, dissemination and implementation of PCORI research results, and the PCORI and AD asthma portfolio. The day concluded with a discussion of a topic brief focusing on HIV, an area for which the panel expressed strong support.

The next in-person meeting will be held in the summer of 2016.

### Related Information

- [About this Advisory Panel](#)
- [Meeting Details and Materials](#)
- [Advisory Panel on Addressing Disparities October 2015 Meeting](#)
- [PCORI Addressing Disparities Program](#)
- [Stakeholder Workshop on Research Questions for Sickle Cell Disease](#)
- [Intervention to Increase Screening of Hepatitis B and C in Asian Americans](#)
- [PCORnet, the National Patient-Centered Clinical Research Network](#)
- [PCORI's Peer Review Process for Public Release of Research Findings](#)
- [PCORI HIV Topic Brief](#)

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

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## Program Updates

Dr. Hasnain-Wynia, Director of the Addressing Disparities (AD) program, introduced Dr. Evelyn P. Whitlock, [PCORI's new Chief Science Officer](#). Dr. Hasnain-Wynia provided updates on studies funded through the program's targeted announcements on obesity treatment options and hypertension control, as well as a pragmatic clinical trial managed by the AD program. Details on these projects are available on the [PCORI website](#). Updates were also provided on the status of the 22 topics the panel has reviewed from 2013 to 2015, 11 of which have been incorporated into the Broad, Pragmatic Clinical Studies or targeted funding announcements.

A multi-stakeholder workgroup on sickle cell disease management will take place on March 7, 2016. The workgroup is a PCORI cross-departmental initiative led by the AD program. Panelists were invited to listen to the workgroup via webinar.

The panel offered the following suggestions on the program updates:

- Identify opportunities for the investigators of the targeted obesity awards and the [National Diabetes Prevention Program](#) of the Centers for Disease Control and Prevention (CDC) to exchange data and findings
- Encourage the obesity awardees to include family-focused interventions
- Consider use of hemophilia clinics and strategies for treating pain for patients with sickle cell disease
- Examine the intersections among various populations at risk for disparities in the AD portfolio, such as looking at Hispanics/Latinos who also are of low socioeconomic status
- Encourage researchers in Florida to submit proposals to the AD program

## AD Broad Portfolio: Taking a Closer Look

Cathy Gurgol and Mira Grieser, Program Officers on the AD team, provided an overview of the 47 investigator-initiated projects (totaling \$84M) funded within the AD broad portfolio. They discussed the themes that emerged through analysis of the portfolio (i.e., diabetes treatment and prevention, chronic pain treatment, disabilities, care transitions, and LGBTQ populations) and provided examples of studies in each theme. Details on these projects are available on the [PCORI website](#). Nine [manuscripts](#) have been published with interim results from these projects, and 52 more are in preparation.

The panel noted that the inability of LGBTQ populations to identify themselves adequately is major source of distrust and disengagement in health-care systems for these individuals. Additionally, the panel had the following suggestions:

- Develop common data standards to identify people as transgender in the [study](#) of outcomes of gender reassignment therapies
- Consider the sustainability of interventions with positive results after PCORI funding ends. PCORI staff explained that these studies are establishing the evidence base that payers use to make coverage and reimbursement decisions

- Avoid conflating patient satisfaction with quality of care and quality of life outcomes
- Encourage researchers seeking PCORI funding to collect data on LGBTQ populations
- Expand research on Asian Americans in PCORI-funded studies by encouraging researchers to partner with community-based organizations and others who address the health of this population

## Awardee Presentation: A Patient-Centered Intervention to Increase Screening of Hepatitis B and C among Asian Americans

Dr. Tung Nguyen of the University of California, San Francisco, presented his PCORI-funded [randomized, controlled trial](#). The study is comparing the effects of a mobile application combined with provider alerts to provider panel notifications on hepatitis B and C screening in Asian American adults. Several community-based organizations helped identify the study topic, develop the intervention, and write the proposal; they also oversee the study. The intervention is available in English, Mandarin, Cantonese, and Vietnamese.

The panel had the following comments on Dr. Nguyen's presentation:

- Research teams conducting studies on populations at risk for disparities must be as diverse as community partners and participants
- Technological innovations have the potential to increase disparities, as they may not be adapted for use in all populations
- Interventions cannot be patient-centered if patients can only use them with an interpreter. For this reason, community health workers and others familiar with the patient's language and culture are key
- It is important that the studies funded outside of the AD program also have a focus on disparities populations. Staff indicated that a number of studies in other PCORI programs address populations at risk for disparities

## Overview of PCORnet and Its Cohorts

Dr. Maryan Zirkle, Program Officer for the Infrastructure team at PCORI, offered a brief overview of [PCORnet, the National Patient-Centered Clinical Research Network](#). PCORnet comprises 13 *system-based* Clinical Data Research Networks (CDRNs) and 20 *patient-driven* Patient-Powered Research Networks (PPRNs). PCORnet was designed to make it faster, easier, and less costly to conduct clinical research by harnessing the power of large amounts of health data and patient partnerships. Each CDRN and PPRN conducts research on at least one common disease and at least one rare disease.

The panel suggested that the networks do the following:

- Collect information on race and ethnicity using the categories established by the [Institute of Medicine](#)
- Develop strategies to collect more accurate information on race and ethnicity



- Collect data on need for interpreters, languages spoken, disability status, LGBTQ status, and socioeconomic status
- Collaborate with insurance plans

## PCORI's Asthma Portfolio and Evidence to Action Network (E2AN)

Ayodola Anise, a Program Officer for the AD team, described a newly funded pragmatic clinical trial in the AD program titled, "[Patient empowered strategy to reduce asthma morbidity in highly impacted populations \(PESRAMHIP\)](#)." This trial is designed to compare the use of inhaled corticosteroids (ICS) and short-acting beta-agonists when asthma symptoms are present to daily use of ICS plus a long-acting beta-agonist on asthma exacerbations in 1,200 African Americans and Hispanics/Latinos.

In addition to this trial, PCORI has funded 11 other CER studies on asthma, including 8 in the AD Program focusing on African Americans and Hispanics/Latinos. The newly funded pragmatic trial complements the current asthma portfolio by focusing on medication use in a head- to-head trial for African American and Hispanics/Latino adults with asthma.

To engage all the asthma awardees funded by PCORI, including Pipeline to Proposal and Engagement awardees, the [Asthma Evidence to Action Network \(E2AN\)](#) was developed. The network has the goals of facilitating cross-learning between funded projects across PCORI and linking asthma awardees with end users to enhance relevance of evidence and increase the likelihood of uptake of findings. The next in-person annual meeting of the Asthma E2AN will take place on March 22<sup>nd</sup> – 23<sup>rd</sup> in Houston, TX.

The panel discussed the possibility of confounding in the recently funded pragmatic clinical trial. They suggested that the investigators examine how different causes of asthma exacerbations (e.g., exercise versus environmental exposures) affect asthma treatment needs.

## Dissemination of PCORI Research Findings

Dr. Joanna Siegel, Director of Dissemination and Implementation, and Jean Slutsky, Chief Engagement and Dissemination Officer and Program Director of Communication and Dissemination Research, reported on PCORI's [peer review policy](#). Draft final reports will be released within up to 13 months after a study's completion and both lay-language and clinician abstracts of these reports will be available within the following 90 days. The goal of this process is to make research findings comprehensible, useful, and available to patients and providers for healthcare decisions.

PCORI has released a new funding announcement, [Dissemination and Implementation of PCORI Funded Patient-Centered Outcomes Research Results and Products in Real World Settings](#). This funding announcement is for awardees who have submitted their final reports to PCORI to assist with the dissemination and implementation of evidence from PCORI-funded studies.

The panel offered the following suggestions:

- Encourage awardees to collaborate with stakeholders and other local and regional partners on their dissemination plans to influence how the knowledge gained from research is disseminated

- Encourage awardees to apply for the PCORI Dissemination and Implementation awards, [Eugene Washington Engagement Awards](#), and Agency for Healthcare Research and Quality (AHRQ) awards for disseminating patient-centered outcomes research
- Refer investigators to the AHRQ [strategies](#) for communication and dissemination of health and health-care evidence to learn how to assess findings and determine which findings to disseminate
- Work with ethnic media, conferences targeted to populations at risk of disparities, and community events to disseminate research findings
- Ensure that research findings are disseminated to study participants

## HIV Topic Brief Discussion

Dr. Parag Aggarwal, Senior Program Officer in the AD Program, explained that based on input from the panel and approval from PCORI's Scientific Oversight Committee, a [topic brief](#) focusing on interventions for people with or at risk of HIV was commissioned.

Panelist Dr. Kenneth Mayer, summarized the topic brief and made the following comments:

- PCORI investigation of interventions to address HIV is timely, as effective tools are now available to control the epidemic. Evidence shows that treatment should start as soon as the infection is diagnosed, and several trials have demonstrated the benefits of pre-exposure prophylaxis (PrEP) in individuals at high risk of HIV.
- PCORI could help fill evidence gaps about the clinical effectiveness of different treatment modalities.
  - Examples include: culturally tailored interventions for communities of color and men who have sex with men, and ways to engage and retain patients with behavioral health issues (e.g., depression, substance abuse) in HIV care.

Panelist Dr. Russell Rothman, provided additional information from the topic brief and made the following comments:

- Although strong evidence supports the prevention and management of HIV, many patients with HIV, especially disparities populations, are not being identified or managed adequately.
- Patients at risk for experiencing disparities might benefit from cultural tailoring and patient navigators.
- Many studies could be proposed to improve the identification and screening of individuals at risk for HIV and enhance quality of care to reduce the burden of disease.
- If PCORI studies can identify novel ways to improve care (e.g., through informatics, telehealth, mobile tools, cultural tailoring), these approaches could be implemented in practice.
- In addition to early detection, identification, treatment, and retention, the research should address different models of early prevention and detection.

The panel had the following comments on the HIV topic brief:

- As with other health issues that are common in populations at risk for experiencing disparities, few studies address behavioral healthcare needs in individuals with or at risk of HIV
- The topic brief does not include Asian populations in the table (page 5). Too often, Asian Americans are not included in discussions of communities of color
- Data are also needed on subgroups within populations at risk of disparities, including individuals who abuse substances
- The topic brief should also address the unmet HIV-related needs of older adults and adults who are incarcerated
- The costs of HIV treatment can be high, so resources need to be used optimally
- In spite of its known efficacy, PrEP uptake is low, and the topic brief should be expanded to address ways to increase uptake
- Should this topic result in a targeted funding announcement, it should call for research teams to include individuals who understand the social and cultural needs of the target populations (i.e., members of those communities), which is necessary to maximize acceptance, uptake, and adherence
- Other potential research topics include ways to determine which patients are at risk of HIV, programs that fully engage patients with an HIV diagnosis in care, and the role of pharmacists in HIV care
- Key stakeholder groups to involve in development of this topic include: the Health Resources and Services Administration (HRSA), American Academy of HIV Medicine, HIV Medicine Association, health plans, pharmacy benefit managers, sex trafficking advocacy groups, pastors and other religious leaders, national civil rights groups, and national HIV/AIDS organizations of major racial/ethnic groups

## Wrap-Up and Next Steps

Next steps are to:

- Revise the HIV topic brief to address the panel's comments and present the brief to the Scientific Oversight Committee
- Identify the date for the next in-person advisory panel meeting for the summer of 2016
- Consider adding presentations on the [Pipeline to Proposal Awards](#) and [Eugene Washington PCORI Engagement Awards](#) to a future advisory panel meeting agenda