Advisory Panel on Addressing Disparities Meeting Summary

October 2015

Overview

On October 21, 2015, the PCORI Advisory Panel on Addressing Disparities (AD) met via teleconference, joined by AD program staff. The meeting was open to the public, and meeting materials were posted to the PCORI website in advance of the call.

PCORI staff provided updates on the AD portfolio and recent programmatic activities. The panel, which includes patients, caregivers, clinicians, researchers, providers, payers, and purchasers, then provided feedback to AD staff on a topic brief regarding the management of sickle cell disease, a topic brought to PCORI by multiple stakeholders.

The meeting concluded with discussion and refinement of 11 comparative effectiveness research (CER) questions submitted by the panel for consideration by PCORI.

The panel will reconvene in person during the first quarter of 2016.

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

Romana Hasnain-Wynia, MS, PhD, Director of the Addressing Disparities (AD) program, provided an overview of the current portfolio and recently funded projects.

Broad Portfolio

The AD program funded two new projects through the Broad PCORI funding announcement (PFA) that were approved by the PCORI Board of Governors on September 28, 2015.

- *Addressing Racial Disparities in Implantable Cardioverter Defibrillator Therapy via Innovative Designs (VIVID)*, led by Dr. Kevin Thomas of Duke University, compares the impact of an educational video versus health provider counseling, as well as the effect of racial concordance on the decision-making process for African-American patients eligible for an implantable cardioverter defibrillator.
- *Health Disparities in Unintended Pregnancies among Hispanic Adolescents Using a Patient-Centered Computer-Based Clinic Intervention*, led by Dr. Kathleen Tebb of University of California San Francisco, compares the impact of Health-E You (computer application) versus general clinician training on reducing disparities in pregnancy rates of Latina adolescents.

The AD program has now funded a total of 47 projects through the Broad PFA.

Pragmatic Clinical Studies

In August 2015, the PCORI Board of Governors approved funding for the AD program's first project through the Pragmatic Clinical Studies PFA. The study focuses on one of the topics prioritized by the Advisory Panel on AD in January 2014, "*Integration of mental and behavioral health services into the primary care of persons at risk for disparities in health care and outcomes.*"

The study, *Integrated Versus Referral Care for Complex Psychiatric Disorders in Rural Federally Qualified Health Centers (FQHCs)*, is an adaptive randomized trial led by Dr. John Fortney of University of Washington that will include 1,000 patients from rural and underserved areas. It seeks to compare the effectiveness of primary care providers managing and treating patients with post-traumatic stress disorder (PTSD) and bipolar disorder (BD) using remote tele-psychiatrist consultation to providers referring patients to specialty mental health care via tele-medicine.

Hypertension

On September 28, 2015, two trials totaling $23.5 million were awarded to compare multi-level, multi-component interventions to reduce disparities related to uncontrolled high blood pressure among African-American, Hispanic/Latino-American, and low-income and rural populations. Addressing disparities in hypertension and heart attacks in minorities and other vulnerable populations were topics prioritized by the Advisory Panel on AD in April 2013. The awards were made through the Hypertension Disparities Reduction Program Partnership, a research partnership between the AD Program at PCORI, the National Heart, Lung, and Blood Institute (NHLBI), and the National Institute of Neurological Disorders and Stroke (NINDS).

Collaboration to Improve Blood Pressure in the US Black Belt –Addressing the Triple Threat, a project led by Dr. Monica Safford of the University of Alabama at Birmingham, compares the effectiveness of practice facilitation versus telephone-based peer coaching in improving blood pressure control for 2,000 African-American patients recruited from 80 clinics in rural Alabama and North Carolina.

The second trial, *Comparative Effectiveness of Health System vs. Multi-level Interventions to Reduce Hypertension Disparities,* led by Dr. Lisa Cooper of Johns Hopkins University, seeks to compare the effectiveness of clinic-based primary care versus a collaborative, stepped approach to care, where patients first interact with a community health worker and then, if their blood pressure control does not improve, with a subspecialist (e.g., cardiologist, behavioral health specialist). The study will recruit 1,890 racial/ethnic minority, rural, and/or low-income patients across 30 primary care clinics.

HIV
An update was provided on the two topics on HIV discussed by the panel at the July 2015 meeting. Based on the feedback from the panel, the following CER questions were developed:
1. *Compare the effectiveness of interventions of different models of early detection, identification, and retention to improve outcomes for patients with HIV who are at risk for experiencing disparities (e.g., racial/ethnic minorities, men who have sex with men).*
2. *Compare the effectiveness of treatment interventions (e.g., early treatment initiation) to improve outcomes for patients with HIV who are at risk for experiencing disparities (e.g., racial/ethnic minorities, men who have sex with men).*

PCORI's Science Oversight Committee (SOC) approved these questions in September 2015. AD program staff will move forward with the development of topic briefs to explore the potential gaps that PCORI could address in these areas.

Management of Sickle Cell Disease
Dr. Hasnain-Wynia and Dr. Parag Aggarwal, Senior Program Officer on the AD team, presented PCORI's work to date with sickle cell disease (SCD) and the topic brief developed by the AD team in this area.

Thus far, PCORI has invested $8.1 million, across five projects, in SCD-related research. Additionally, three clinical data research networks (CDRNs) in PCORnet are developing a rare disease cohort specific to SCD. Due to the cross-cutting nature of the topic, there may be an opportunity for several PCORI programs to collaborate on this initiative.

Additionally, NHLBI recently released a funding announcement titled "*Using Implementation Science to Optimize Care of Adolescents and Adults with Sickle Cell Disease*" that aims to fund research that will improve the quality of care for individuals with SCD. PCORI plans to work collaboratively with NHLBI and leverage their ongoing work in this topic area.

Based on literature reviews, expert discussions and discussions with PCORI leadership, the following broad CER questions were developed:

1. *What is the comparative effectiveness of different models of care for children with SCD transitioning from pediatric to adult care?*
2. *What is the comparative effectiveness of different approaches to facilitate better management and improve patient-centered and clinical outcomes during transition from pediatric to adult care taking into consideration patient and family, clinician, health system, and community factors?*
3. *What is the comparative effectiveness of interventions to improve the treatment and management of acute pain crises in patients with SCD?*

The panel members raised important points to consider as PCORI staff move forward with next steps:
- The PCORI funded Mid-South Clinical Data Research Network has a cohort (n=400) of sickle cell disease (SCD) patients who have been surveyed about their suggested priorities for future research and their interest to participate in research studies. PCORI staff should consider ways to leverage this cohort.
- Stakeholders should be contacted to provide input related to transitions in care as well as adherence.
- Issues of clinician discrimination in the management of patients with SCD in acute pain crisis should be addressed.
- In addition to pain management and care transitions, other complications, such as acute chest syndrome, may be outcomes of interest.
- The healthcare delivery system and the health plan patients are enrolled in should be captured in a study to determine if these factors influence the quality of care received.

The panel suggested a number of stakeholders from whom PCORI program staff could obtain further input:
- The Sickle Cell Disease Association of America
- Have a Heart for Sickle Cell Disease
- Cincinnati Children's Hospital (community-engaged researchers)

Refinement and Selection of Priority Topics for the Addressing Disparities Program

Prior to the meeting, panelists were each asked to submit one priority research question relevant to reducing and eliminating disparities in healthcare outcomes that could later be prioritized using PCORI criteria. Eleven topics were submitted and each panelist introduced their respective topic and provided a rationale for why PCORI should explore this topic. The entire panel then discussed and, where applicable, refined these topics. The topics are listed below.

1. *Comparative effectiveness of eye drops vs. laser trabeculoplasty to reduce excess morbidity from glaucoma in black and Hispanic individuals.*
2. *What are the comparative benefits and risks of utilizing tailored HIPAA-compliant texting, telephonic management, or email outreach in the management of glucose monitoring of underserved populations with limited provider access in communities?*
3. *Compare the effectiveness of approaches (e.g., telephone management post-discharge, clinic visits, telephone management, supportive services) to prevent hospital readmission for patients*

at high risk for readmission including racial/ethnic minorities, patients with limited English proficiency, patients with low health literacy, underinsured, and others.

4. *What is the comparative effectiveness of different patient-centered approaches to care coordination for patients at high risk of hospitalization/ED usage including racial/ethnic minorities, patients with limited English proficiency, patients with low health literacy, underinsured, and others?*

5. *In low social economic status/high-risk population with prediabetes, compare the effectiveness of the diabetes prevention program (DPP) versus metformin in preventing or delaying type 2 diabetes.*

6. *Compare the effectiveness of interventions to improve the provision of prevention and primary care to people with disabilities, including strategies to assure basic primary care interventions are provided to people with mobility impairments, sensory impairments, intellectual disabilities, and mental health disabilities.*

7. *Compare the effectiveness of strategies to improve communication between clinicians and patients with disabilities, including strategies to effectively tailor communication according to both cognitive and sensory abilities.*

8. *What are the comparative benefits and risks to people with disabilities (e.g., functional limitations) in using various models (e.g., OpenNotes Program, Blue Button Program) of health information technology to access their health programs, information, and activities?*

9. *Compare the effectiveness of interventions to reduce low-value/potentially harmful care among older adults, including provider-level and patient-level strategies to improve shared decision making.*

10. *Compare the effectiveness of strategies (e.g., mode of delivery [in-person, web-based, telephonic], patient/provider communication strategies) to provide interpreter services to providers and patients when the patient has limited English proficiency.*

Wrap-Up and Next Steps

AD staff will send a survey to the panel to rank the discussed topics. Once the results are obtained, the top two to three topics will be shared with the panel, and staff will begin exploring key research gaps and priority questions in these areas.

The panel will reconvene in person in February 2016.