



Advisory Panel on Addressing Disparities Meeting Summary

Overview

On June 8, 2016, the PCORI Advisory Panel on Addressing Disparities (AD) held its tenth 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, offered a snapshot of the current AD funded portfolio. She announced two new projects awarded through the Broad PCORI Funding Announcement (PFA): *Comparing the Effectiveness of Clinicians and Paraprofessionals to Reduce Disparities in Perinatal Depression* and *Virtual Evidence-based Healthcare for Underserved Patients with Down Syndrome*. Dr. Parag Aggarwal, Senior Program Officer for the AD Program, presented an update on AD's newest Targeted PFA on Sickle Cell Disease and progress on the topic of HIV.

Dr. Elizabeth Jacobs, member of the AD Advisory Panel, presented on the Impact of Language Barriers on Health and Health Outcomes. Dr. Leah Karliner presented on her PCORI-funded project, *Clinician Language Concordance and Interpreter Use*. The panel then heard from Ms. Lia Hotchkiss and Ms. Courtney Clyatt with the Engagement team at PCORI about the Eugene Washington Engagement Award and the Pipeline to Proposal Award Programs.

Ms. Ayodola Anise, Program Officer for the AD Program, and Dr. Elizabeth Houtssteller, Senior Program Officer for the Improving Healthcare Systems Program, led a discussion on their preliminary work on the topic on Autism. The day concluded with the recognition of the seven panelists whose terms ended and the chairs who concluded their service on the panel.

The next in-person meeting will be held on October 24th, 2016 in Washington, DC.

Related Information

- [About this Advisory Panel](#)

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

Addressing Disparities Portfolio

Dr. Romana Hasnain-Wynia, Director of the Addressing Disparities (AD) program, provided a review of the AD portfolio including studies funded through the Broad, Targeted, and Pragmatic Clinical Studies funding announcement. To date, the AD program has funded **63** projects across 21 states, totaling more than **\$178** million. She then announced two new projects awarded through the Broad PCORI funding announcement (PFA):

- 1) [*Comparing the Effectiveness of Clinicians and Paraprofessionals to Reduce Disparities in Perinatal Depression*](#)
- 2) [*Virtual Evidence-based Healthcare for Underserved Patients with Down Syndrome*](#)

Sickle Cell Disease

Dr. Parag Aggarwal, Senior Program Officer for the AD Program, updated the panel on the newly approved Targeted PFA, [*Management of Care Transitions for Emerging Adults with Sickle Cell Disease \(SCD\)*](#). The panel discussed the general topic of SCD at the [July 2015 meeting](#) and again during the [October 2015 meeting](#) when they reviewed the topic brief.

For this PFA, PCORI seeks to fund up to three (3) cluster randomized controlled trials (RCTs), which will compare the effectiveness of established transition coordination models for emerging adults (e.g., 16-25 years of age) with SCD transitioning from pediatric to adult care.

The PCORI Online system will open on August 15th, 2016 for the submission of Letters of Intents (LOIs). Applications are due on December 19th, 2016, with awards expected to be announced in June 2017.

Panelists offered the following comments:

- Results from studies on SCD transitions may have broader application to other conditions. PCORI staff should take care to analyze projects funded in one condition to identify commonalities for treatments and interventions across other conditions.
- Studies that look at leveraging existing Hemophilia clinics to treat patients with SCD may be of interest to PCORI; however, given that these two conditions affect different populations who do not live in the same areas, Hemophilia clinics may not be accessible to SCD patients.
- The Centers for Disease Control and Prevention (CDC) have done some work in the area of blood disorders and should continue to be actively engaged in efforts on SCD.

HIV

Dr. Aggarwal reminded the panel of the two concept summaries developed by the CDC on HIV that they reviewed at the [July 2015 meeting](#). With support from the panel and approval from PCORI leadership, the AD program commissioned a topic brief on, [*Comparative effectiveness of interventions of different models of early detection, identification, treatment and retention to improve outcomes for patients with HIV who are at risk for experiencing disparities*](#), which was discussed at the [February 2016 meeting](#). AD



staff is in the process of collecting potential CER questions on this topic from the panel and looking to collaborate with other agencies to identify areas for synergy.

Panelists offered the following comments:

- In addition to treatment, PCORI should consider studies of prevention, as new methods such as pre-exposure prophylaxis should be compared to other strategies.
- Other stakeholders to engage include the Substance Abuse and Mental Health Services Administration.

Update on Topics Ranked by Panel at October 2015 Meeting

Dr. Hasnain-Wynia provided an update on the topics submitted by the panel for discussion at the October 2015 meeting. A total of 10 topics were submitted and then ranked by the panel. The following four (4) topics were highly ranked:

1. Compare the effectiveness of approaches (e.g. 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 language proficiency, patients with low health literacy, underinsured, and others.
2. What is the comparative effectiveness of different patient-centered approaches to care coordination for patients at high risk of hospitalization/emergency department (ED) dosage including racial/ethnic minorities, patients with limited English proficiency, patients with low health literacy, underinsured and others?
3. Compare the effectiveness of intervention 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.
4. Comparative effectiveness of eye drops vs. lasertrabeculoplasty to reduce excess morbidity from glaucoma in black and Hispanic individuals.

The most highly ranked topic on readmission was considered not specific enough by AD staff, thus program staff will review the literature and examine how more specificity can be added to this topic to elicit comparative effectiveness questions aimed at reducing disparities. The 2nd highly ranked topic is currently being addressed by a recent targeted PFA on SCD. The PFA is focused on established transition coordination models, and the outcomes of studies funded will include hospitalizations and ED use. The 3rd ranked topic is currently being addressed through the recent funding of the study [Virtual Evidence-based Healthcare for Underserved Patients with Down Syndrome](#). AD staff will commission a topic brief on the 4th ranked topic, *Comparative effectiveness of eye drops vs. lasertrabeculoplasty to reduce excess morbidity from glaucoma in black and Hispanic individuals*, this fall.

Panelists suggested that focusing more on topics with broader applicability across multiple conditions, such as readmissions, rather than addressing one condition, may help to address disparities. Dr. Hasnain-Wynia stressed that PCORI's mandate, as directed by the Board of Governors, is on concrete



CER questions on disease-specific conditions. She indicated that staff will review the AD and PCORI portfolios to understand how readmissions is being addressed by funded studies and to explore potential opportunities to fund CER on this topic.

Addressing Disparities Advisory Panel: Where We Are and Where We Are Going

Dr. Hasnain-Wynia reviewed the purpose and goals of the panel and highlighted areas where the panel provided significant feedback since its inception. She then discussed where PCORI is going as an organization and where the AD Advisory Panel, will be directing its efforts moving forward.

Panelist Presentation: Mitigating the Impact of Language Barriers on Health and Health Outcomes

Dr. Elizabeth Jacobs, a current AD panel member, presented her findings on a systematic review conducted from 2003-2015 on literature related to language barriers in healthcare settings. The purpose of this study was to review the state of the literature before and after a major change in national policy guidance in the U.S that affected the ability of patients with limited English proficiency (LEP) to access language services. Her research revealed that the number of publications over this time period increased from 136 manuscripts to 426, indicating an increased focus on addressing language barriers. The studies identified in the systematic review were largely descriptive, identifying the existence of language barriers. Additional research focused on the influence of language concordant care on patient outcomes is needed.

Members of the panel provided the following comments:

- The relationship between cultural and linguistic barriers are very much entwined. Interpreters can serve as cultural and linguistic navigators.
- Deaf or hard of hearing patients may face similar challenges. While the challenges that this population face remain distinct, there may be applicable lessons learned from addressing language barriers.

Awardee Presentation: Clinician Language Concordance and Interpreter Use: Impact of a Systems Intervention on Communication and Clinical Outcomes

Dr. Leah Karliner, an awardee funded through the AD program, presented her project, [Clinician Language Concordance and Interpreter Use: Impact of a Systems Intervention on Communication and Clinical Outcomes](#). The project seeks to compare communication and clinical outcomes for patients with LEP before and after the implementation of the Language Access Systems Improvement (LASI) initiative, which certifies bilingual clinicians to use their non-English language skills directly with patients and simultaneously increases access to professional interpreters via videoconferencing.

Additionally, Dr. Karliner described the problems associated with poor quality communication between patients with LEP and clinicians, including less adherence to medications, decreased patient satisfaction, and less patient-centered care. Members of the LEP population speak many languages, and this population is projected to increase in size over time, creating additional urgency to address the issue.

Eugene Washington PCORI Engagement Award Program Overview

Ms. Lia Hotchkiss, Director of the [Eugene Washington PCORI Engagement Awards program](#), gave an overview of the program. The program seeks to fund projects that will build a community better able to participate in patient-centered comparative effectiveness research (CER). Projects funded under this initiative are meant to:

- Build knowledge base about how patients and other stakeholders want to participate in patient-centered outcomes research (PCOR)/CER or receive research findings;
- Implement training or skill development initiatives to build capacity for engaging in PCOR/CER; and/or
- Strengthen channels for disseminating PCOR/CER findings.

The ultimate goal is for these projects to produce deliverables that are useful to awardees, PCORI, and the broader PCOR community.

Two panelists with Eugene Washington Engagement Awards, Dr. Alfiee M. Breland-Noble and Dr. Patrick Kitzman, spoke to their experiences with their projects.

Pipeline to Proposal (P2P) Awards Program

Ms. Courtney Clyatt, Program Officer on the Engagement team at PCORI, provided an overview of the [Pipeline to Proposal \(P2P\) program](#). This program aims to build capacity and cultivate the development of proposals with sound scientific rigor and robust patient engagement. Ms. Clyatt clarified that these awards are not research awards. Rather, they are intended to foster capacity building for PCOR in the community before a study plan is even developed.

P2P funding consists of three (3) progressive tiers (Tier I, II and III), with the goal to help awardees to eventually to develop a patient-centered research proposal.

Discussion of Autism Topic

Ms. Ayodola Anise, Program Officer with the AD team, recapped the previous discussion of the panel on the topic of Autism. Dr. Elisabeth Houtsmuller, Senior Program Officer with the Improving Healthcare Systems program, then provided background on the development of her program's autism brief. The panel discussed potential CER questions for early interventions on Autism Spectrum Disorders (ASD) through the lens of PCORI discussion criteria.

The panel had the following comments about the topic and potential CER questions:

- The age of diagnosis should be considered, as not all children with an autism diagnosis receive treatment early. Interventions for older children should also be considered, as delayed diagnosis for African American children may result from misdiagnosis.
- For racial/ethnic minorities whose children are screened and have ASD, it will be important to have resources available for them. They may also require advocates to assist with navigating the system.
- In addition to taking place in the clinic setting, screening should also occur in non-traditional and non-medical locations (e.g., day cares, schools, YMCAs, churches). School nurses, specifically, can be a potential resource for both screening and connecting families to resources.
- Community education and increasing awareness about the facts of ASD are key, as there is stigma and fear associated with ASD. Communities should be educated to focus on prevention.
- Dose effect of interventions and minimum thresholds to see an effect should be assessed in CER studies. Additionally, studies should take into account that there are different levels of autism.

Panelist Recognition

Doriane Miller and Grant Jones will conclude their tenure as chair and co-chair, but will continue as members of the panel for the remainder of their terms. Dr. Hasnain-Wynia thanked them for their leadership of the ADAP.

Dr. Hasnain-Wynia also recognized and thanked seven panel members concluding their terms of service:

- Deborah Stewart (in absentia)
- Chien-Chi Huang
- Carmen Reyes (in absentia)
- Russel Rothman (in absentia)
- Mary Ann Sander
- Martin Gould (in absentia)
- Echezona Ezeanolue

Wrap Up and Next Steps

The next in-person panel meeting will be held October 24th, 2016 in Washington DC. At this meeting, there will be seven new panel members, and the panel will have a new chair and co-chair.