

Addressing Disparities Advisory Panel Webinar

October 21, 2015

2:00 PM – 4:30 PM



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome and Setting the Stage

Romana Hasnain-Wynia, PhD, MS

Program Director, Addressing Disparities

Grant Jones

Co-Chair, Addressing Disparities Advisory Panel

Doriane Miller, MD

Chair, Addressing Disparities Advisory Panel



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Housekeeping

- Today's webinar is open to the public and is being recorded.
- Members of the public are invited to listen to this teleconference and view the webinar.
- Anyone may submit a comment through the webinar chat function, although no public comment period is scheduled.
- Visit www.pcori.org/events for more information.
- Chair Statement on COI and Confidentiality



Agenda

- **Program Updates**
 - Broad Portfolio
 - Pragmatic Clinical Studies
 - Hypertension
 - HIV
- **Management of Sickle Cell Disease**
- **Refinement and Selection of Priority Topics for the Addressing Disparities Program**
- **Wrap Up and Next Steps**



Introductions

- Please quickly state the following:
 - Name.
 - Stakeholder group you represent.
 - Position title and organization.



Introductions (cont.)

Alfiee M. Breland-Noble, MHSc, PhD

Director of The AAKOMA Project and Associate Professor, Department
of Psychiatry

Georgetown University Medical Center

Representing: Researchers



Introductions (cont.)

Ronald Copeland, MD, FACS

Chief Diversity and Inclusion Officer and Senior Vice President of
National Diversity and Inclusion Strategy and Policy, Kaiser
Permanente

Representing: Hospitals and Health Systems



Introductions (cont.)

Echezona Edozie Ezeanolue, MD, MPH, FAAP, FIDSA

Associate Professor, Pediatrics and Director, Maternal-Child HIV Program, University of Nevada School of Medicine

Representing: Clinicians



Introductions (cont.)

Martina Gallagher, BSN, MSN, PhD

Assistant Professor, University of Texas Health Science Center

Representing: Clinicians



Introductions (cont.)

Martin Gould, MA, EdD

Senior Policy Analyst, US Department of the Treasury

Representing: Researchers



Introductions (cont.)

Sinsi Hernández-Cancio, JD

Director of Health Equity, Families USA

Representing: Patients, Caregivers, and Patient Advocates



Introductions (cont.)

Chien-Chi Huang, MS

Founder, Asian Breast Cancer Project
Executive Director, Asian Woman for Health

Representing: Patients, Caregivers, and Patient Advocates



Introductions (cont.)

Elizabeth A. Jacobs, MD, MAPP, FACP

Associate Vice Chair, Health Services Research in the Department of
Medicine and Population Health Science

Representing: Researchers



Introductions (cont.)

Grant Jones, BS (Co-chair)

Founder, Executive Director, Center for African American Health

Representing: Patients, Caregivers, and Patient Advocates



Introductions (cont.)

Patrick Kitzman, MS, PhD

Associate Professor, Physical Therapy, University of Kentucky

Representing: Clinicians



Introductions (cont.)

Barbara L. Kornblau, JD, OTR

CEO, Coalition for Disability Health Equity

Representing: Patients, Caregivers, and Patient Advocates



Introductions (cont.)

Kenneth Mayer, MD

Medical Research Director, Fenway Health and Professor, Harvard Medical School and School of Public Health

Representing: Researchers



Introductions (cont.)

Doriane C. Miller, MD (Chair)

Director, Center for Community Health and Vitality
University of Chicago Medical Center

Representing: Patients, Caregivers, and Patient Advocates



Introductions (cont.)

Alan R. Morse, MS, JD, PhD

President and Chief Executive Officer, Lighthouse Guild
Adjunct Professor of Ophthalmology, Columbia University

Representing: Health Systems



Introduction (cont.)

Cheryl Pegus, MD, MPH

Director of the Division of General Internal Medicine and Clinical Innovation, NYU Langone Medical Center

Representing: Patients, Caregivers, and Patient Advocates



Introduction (cont.)

Danielle Pere, MPM

Associate Executive Director, American College of Preventive Medicine

Representing: Clinicians



Introduction (cont.)

Carmen E. Reyes, MA

Center and Community Relations Manager, Los Angeles Community
Academic Partnership in Research in Aging, UCLA

Representing: Patients, Caregivers, and Patient Advocates



Introduction (cont.)

Russell Rothman, MD, MPP

Associate Professor of Internal Medicine and Pediatrics; Director, Vanderbilt Center for Health Services Research; Chief of Internal Medicine/Pediatrics
Vanderbilt University

Representing: Researchers



Introduction (cont.)

Mary Ann Sander, MBA, MHA

Vice President, Aging and Disability Services, UPMC Community Provider Services

Representing: Researchers



Introduction (cont.)

Elinor R. Schoenfeld, PhD

Research Associate Professor of Preventive Medicine and
Ophthalmology, Stony Brook University

Representing: Researchers



Introduction (cont.)

Deborah Stewart, MD

Medical Director, Florida Blue

Representing: Clinicians



Addressing Disparities Program Staff



Romana Hasnain-Wynia, MS, PhD
Program Director



Randa Abu-Rahmeh
Program Assistant



Parag Aggarwal, PhD
Senior Program Officer



Ayodola Anise, MHS
Program Officer



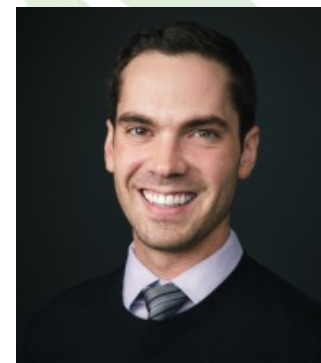
Mira Grieser, MHS
Program Officer



Cathy Gurgol, MS
Program Officer



Tomica Singleton
Sr. Administrative Assistant



Mychal Weinert
Program Associate



Addressing Disparities Program Updates

Romana Hasnain-Wynia, PhD, MS



Overview

- Updates on:
 - Broad Portfolio
 - Pragmatic Clinical Studies
 - Hypertension
 - HIV
- Questions on program updates



Update: Broad Portfolio



New Projects Awarded through Addressing Disparities Broad PFA

- 2 new projects awarded in September 2015, totaling \$3.9M

Project	Organization
<p>Addressing Racial Disparities in Implantable Cardioverter Defibrillator Therapy Via Innovative Designs (VIVID)</p> <p>CER Question: Compare the effectiveness of an educational video versus health provide counseling on the decision making process for African American individuals eligible for Implantable Cardioverter Defibrillator</p> <p>Primary Outcome: The decision to have an ICD implanted</p>	Duke University
<p>Health Disparities in Unintended Pregnancies Among Hispanic Adolescents Using a Patient-Centered Computer-Based Clinic Intervention</p> <p>CER Question: Comparative the effectiveness of Health-E You (computer application) vs general clinician training on reducing disparities in pregnancy rates of Latina adolescents</p> <p>Primary Outcomes: Current contraceptive use and contraceptive use during past 3 months</p>	University of California, San Francisco

Update: Pragmatic Clinical Studies



Newly Awarded Pragmatic Clinical Study

- This is the AD program's **first** project funded through the Large Pragmatic Studies PFA
 - Prioritized by the panel in January 2014: *Compare the effectiveness of interventions to integrate mental and behavioral health, including substance abuse treatments, into community health centers and other primary care settings to reduce disparities and advance equity.*



Newly Awarded Pragmatic Clinical Study (cont.)

- **Integrated Versus Referral Care for Complex Psychiatric Disorders in Rural Federally Qualified Health Centers (FQHCs)**
 - ***Principal Investigator:*** John Fortney
 - ***Institution:*** University of Washington
 - ***Budget:*** \$11,776,419
 - ***CER Question:*** Compare the effectiveness of primary care providers managing and treating patients with PTSD and BD using remote tele-psychiatrist consultation to providers referring patients to specialty mental health care via tele-medicine.
 - ***Primary Outcome:*** Patient self-reported health related quality of life



Update: Testing Multi-Level Interventions to Improve Blood Pressure Control in Racial/Ethnic Minority, Low Socioeconomic Status, and/or Rural Populations



Hypertension Disparities Reduction Partnership Program

- **A collaboration between the NIH (NHLBI, NINDS) and the Addressing Disparities program with goals to:**
 1. Solicit comprehensive comparative effectiveness studies testing multi-level and multi-component interventions
 2. Promote strong patient and stakeholder engagement
 3. Identify effective approaches for reducing hypertension disparities in racial and ethnic minorities, low SES populations, and/or rural populations
- **Total Funds Awarded: \$23.5M**



Hypertension Disparities Reduction Partnership Program (cont.)

- Topics prioritized by the AD panel in April 2013:
 - **Heart attacks among racial and ethnic minorities**—Compare the effectiveness of health interventions (including place-based interventions in community health centers) to enhance the “Million Hearts” program and reduce major vascular events among the economically disadvantaged, including racial and ethnic minorities and rural populations.
 - **Hypertension in minorities**—Compare the effectiveness of different delivery models (e.g., home blood pressure monitors, utilization of pharmacists or other allied health providers) for controlling hypertension in racial minorities.



Hypertension Disparities Reduction Partnership Program: Funded Projects

- **Collaboration to Improve Blood Pressure in the US Black Belt – Addressing the Triple Threat**
 - ***Principal Investigator:*** Monika Safford, MD
 - ***Institution:*** University of Alabama
 - ***Budget:*** \$9,494,562
 - ***CER Question:*** What is the comparative effectiveness of practice facilitation (which includes use of EMR, team care, protocols for algorithm-driven blood pressure medication management, creating registries and audit and feedback systems using EHRs, self-management support) versus telephone based peer coaching
 - ***Primary Outcome:*** Improvement in blood pressure control between baseline and follow-up between practices in any of the intervention and enhanced usual care arm



Hypertension Disparities Reduction Partnership Program: Funded Projects (cont.)

- **Comparative Effectiveness of Health System vs. Multi-level Interventions to Reduce Hypertension Disparities**
 - ***Principal Investigator:*** Lisa Cooper, MD, MPH
 - ***Institution:*** Johns Hopkins University
 - ***Budget:*** \$12,152,110
 - ***CER Question:*** What is the comparative 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).
 - ***Primary Outcome:*** Percent of patients with blood pressure under control



Update: HIV



HIV

- **Background:** The Addressing Disparities Advisory Panel reviewed two topics related to HIV at the July 2015 meeting.
- **Progress:** Based on the feedback from the panel, the topics were revised:
 - *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).*
 - *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).*
- **Next Steps:** The topics were presented to PCORI's Science Oversight Committee in September 2015. Approval was given to move forward with the development of topic briefs in this area to further explore the potential gaps and CER questions that PCORI could address.



Questions on Program Updates

Management of Sickle Cell Disease

Parag Aggarwal, PhD

Senior Program Officer, Addressing Disparities

Romana Hasnain-Wynia, PhD, MS



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Building on PCORI's Investment in Sickle Cell Disease

- **Three** CDRNs in PCORnet that are developing a rare disease cohort specific to sickle cell disease (SCD)
- PCORI has invested over **\$8.1 million**, across **5 projects**, in SCD related research
 - **Three** Broad awards
 - 2 in Assessment of Prevention, Diagnosis and Treatment Options
 - 1 in Improving Healthcare Systems
 - **One** Pipeline to Proposal
 - **One** Engagement award
- Due to the cross-cutting nature of the topic, this presents an opportunity for collaboration across **all** PCORI programs.



Leveraging Ongoing Work

- NHLBI released a funding announcement entitled “**Using Implementation Science to Optimize Care of Adolescents and Adults with Sickle Cell Disease**” in July 2015
- The goal of this initiative is to focus on improving the quality of care for individuals with SCD
- Applications are due October 2015 and awards to seven geographically diverse sites will be made in the first quarter of 2016



National Heart, Lung,
and Blood Institute



Care Transitions and SCD



- SCD-related mortality rates are highest among young adults transitioning from pediatric to adult care.
- The guidelines available for facilitating this transition are based on **weak evidence** and/or **consensus-based opinion**.
- These gaps need to be addressed, as clinicians and patients are seeking guidance about treatment options to inform decision-making to improve outcomes.



Management of Sickle Cell Disease: Potential CER Questions

- What is the comparative effectiveness of different models of care for children with SCD transitioning from pediatric to adult care?
- 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?
- What is the comparative effectiveness of interventions to improve the treatment and management of acute pain crises in patients with SCD?



Our Ask of You

- General feedback or questions on the topic?
- Suggestions for additional CER questions?
- Suggestions for additional stakeholder input?



Next Steps

- Present Advisory Panel comments and feedback to the Scientific Oversight Committee, a subcommittee of the PCORI Board of Governors
- Approval of Scientific Oversight Committee to convene multi-stakeholder workgroup to refine topic and CER questions



Refinement and Selection of Priority Topics for the Addressing Disparities Program

Doriane Miller, MD

Chair, Addressing Disparities Advisory Panel

Grant Jones

Co-Chair, Addressing Disparities Advisory Panel



Overview

- Prior to this webinar, each panel member was asked to contribute one high-priority research question relevant to reducing and eliminating disparities in healthcare outcomes that could later be prioritized using PCORI criteria.
- We asked that these questions:
 - Be framed as comparative research questions.
 - Reflect topics that will result in practical information to help patients and other stakeholders make informed decisions about their health care and health outcomes.
 - Clearly identify the population at risk for experiencing disparities, the options of care that should be compared, and the potential outcomes for those options.
- The goal is to arrive at consensus on the **top 2-3 questions** that should be further explored by PCORI



Topic Discussion

Rules of Engagement

- We have **7 minutes per topic** to engage in discussion.
 - The panel member who submitted the topic will have **2 minutes** to introduce their topic and provide rationale.
 - That leaves **5 minutes** for discussion.
- We are looking for **consensus** on whether AD staff should pursue topics. Please consider these questions:
 - Do you see a clear CER question for this topic?
 - Can the wording be improved to be more concrete in terms of populations and interventions being compared?
 - Do you recommend or not recommend that staff pursue the topic?
- Use the “raise hand” feature on the webinar when you want to speak OR submit questions via the chat feature.



Examples of CER Questions From Pragmatic Clinical Trials Funding Announcement

- Compare the effectiveness of various alternative delivery models (e.g., primary care, schools, mobile vans) versus the dentist's office in preventing dental caries in children in medically underserved areas.
- Compare the effectiveness of clinical interventions to reduce initiation of use of tobacco and promote tobacco cessation among populations with known tobacco disparities, including high-risk and vulnerable populations.



Topic 1

- **Question:** *Comparative effectiveness of eye drops vs. laser trabeculoplasty to reduce excess morbidity from glaucoma in black and Hispanic individuals.*
- **Panel Member:** Alan R. Morse



Topic 2

- **Question:** *What are the comparative benefits and risk of utilizing HIPAA compliant texting, telephonic management or email outreach in the management of glucose monitoring of underserved populations with limited provider access in communities?*
- **Panel Member:** Cheryl Pegus



Topic 3

- **Question:** *What are the comparative benefits and risks of web-based wellness/peer coaching programs vs. in-person group wellness/peer coaching programs for people with limited English proficiency?*
- **Panel Member:** Chien-Chi Huang



Topic 4

- **Question:** *What are the optimal approaches 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?*
- **Panel Member:** Russell Rothman



Topic 5

- **Question:** *What are the optimal 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?*
- **Panel Member:** Russell Rothman



Topic 6

- **Question:** *In low social economic status/high risk population with prediabetes, compare the utilization and efficacy of the diabetes prevention program vs metformin in preventing or delaying type 2 diabetes.*
- **Panel Member:** Dani Pere



Topic 7

- **Question:** *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.*
- **Panel Member:** Barbara Kornblau



Topic 8

- **Question:** *Compare the effectiveness of strategies to improve communication between clinicians and patient with disabilities, including strategies to effectively tailor communication according to both cognitive and sensory abilities.**
- **Panel Member:** Patrick Kitzman

* This was a topic previously reviewed by the Advisory Panel, but was not highly prioritized.



Topic 9

- **Question:** *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?*
- **Panel Member:** Martin Gould



Topic 10

- **Question:** *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.*
- **Panel Member:** Carmen Reyes



Topic 11*

- **Question:** *Compare the effectiveness of strategies to provide interpreter services to providers and patients when the patient is limited English proficient.*
- **Panel Member:** Liz Jacobs

* The AD Program recently funded a project in this area, “*Clinician Language Concordance and Interpreter Use: Impact of a Systems Intervention on Communication and Clinical Outcomes.*”



Wrap Up and Next Steps

- Shortly following the call, we will be sending out a poll for you to rank order the topics discussed.
- We are planning to have our next in-person meeting in early 2016.



Adjourn

Thank you for your participation!

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