Welcome!

Please be seated by 8:55 AM ET

The webinar will go live at 9:00 AM ET

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Advisory Panel on Addressing Disparities: In-Person Meeting

February 9th, 2016

9:00 AM – 4:15 PM

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Welcome and Setting the Stage

Romana Hasnain-Wynia, PhD, MS

Program Director, Addressing Disparities

Doriane Miller, MD

Chair, Addressing Disparities Advisory Panel

Grant Jones

Co-Chair, Addressing Disparities Advisory Panel

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Housekeeping

- Today's meeting is open to the public and is being recorded.
  - Members of the public are invited to listen to the teleconference and view the webinar.
  - Meeting materials can be found on the PCORI website
  - 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.

Housekeeping (cont.)

- We ask that panelists stand up their tent cards when they would like to speak and use the microphones.

- Please remember to state your name when you speak.

- **Chair Statement on COI and Confidentiality**

Agenda

Agenda Item	Time
Addressing Disparities Program Updates New Chief Science Officer Targeted Topics Funding in Priority Areas	9:15-10:00
AD Broad Portfolio: Taking a Closer Look	10:00-11:00
Awardee Presentation: A Patient-Centered Intervention to Increase Screening of Hepatitis B and C Among Asian-Americans	11:00-12:00
Lunch	12:00-1:00
Overview of PCORnet and Its Cohorts	1:00-1:45
PCORI's Asthma Portfolio and Evidence to Action Network (E2AN)	1:45-2:15
Break	2:15-2:30
Dissemination of PCORI Research Findings	2:30-3:00
HIV Topic Brief Discussion	3:00-4:00
Wrap Up and Next Steps	4:00-4:15

Introductions

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

Introductions (cont.)

Alfiee M. Breland-Noble, MHSc, PhD

Director, The AAKOMA Project, *Georgetown University Medical Center*;
Associate Professor, 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, *University of Nevada School of Medicine*

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, *University of Wisconsin*

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*
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 International*
Adjunct Professor of Opthalmology, *Columbia University*

Representing: Health Systems

Introductions (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

Introductions (cont.)

Danielle Pere, MPM

Associate Executive Director, *American College of Preventive Medicine*

Representing: Clinicians

Introductions (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

Introductions (cont.)

Russell Rothman, MD, MPP

Assistant Vice Chancellor, Population Health Research, *Vanderbilt University*
Director, Center for Health Services Research, *Vanderbilt University*
Professor, Internal Medicine, Pediatrics and Health Policy, *Vanderbilt University*

Representing: Researchers

Introductions (cont.)

Mary Ann Sander, MBA, MHA, NHA

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

Representing: Researchers

Introductions (cont.)

Elinor R. Schoenfeld, PhD

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

Representing: Researchers

Introductions (cont.)

Deborah Stewart, MD

Medical Director, *Florida Blue*

Representing: Clinicians

Addressing Disparities Program Staff


Romana Hasnain-Wynia, MS, PhD
Program Director


Parag Aggarwal, PhD
Senior Program Officer


Ayodola Anise, MHS
Program Officer


Mira Grieser, MHS
Program Officer


Cathy Gurgol, MS
Program Officer


Soknorntha Prum, MPH
Program Associate


Tomica Singleton
Sr. Administrative Assistant


Mychal Weinert
Program Associate

Addressing Disparities Program Updates

Romana Hasnain-Wynia, PhD, MS

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Overview

- **Updates On:**
  - PCORI’s New Chief Science Officer
  - Our Targeted Initiatives:
    - Obesity
    - Hypertension
    - Pragmatic Clinical Studies
    - Sickle Cell Disease
  - Funding in Priority Areas
  - Questions on Program Updates

Later in the day:
Mira Grieser and Cathy Gurgol will be giving an update on the Broad portfolio

Ayodola Anise will be giving an update on the Asthma portfolio and the Evidence to Action Network (E2AN)

Update: PCORI's New Chief Science Officer

New Chief Science Officer

- New Chief Science Officer started January 2016
  - **Evelyn P. Whitlock, MD, MPH**
    - Previously the Senior Investigator and Senior Director, Evidence-Based Medicine Research, at the Center for Health Research at Kaiser Permanente Northwest
    - Nationally recognized expert in evidence-based medicine and health policy

Update: Obesity Treatment Options

Summary of Obesity Portfolio

Project Title	Org.	Target Population(s)	Number of Study Pts	Primary Outcome	Start Date
The Louisiana Trial to Reduce Obesity in Primary Care	Pennington Biomedical Research Center	African Americans; low socio-economic individuals	1,080	Percent change in body weight from baseline	January, 2015
Midwestern Collaborative for Treating Obesity in Rural Primary Care	University of Kansas Medical Center	Rural; low socio-economic individuals	1,400	Weight loss at 24 months	January, 2015

Progress

- Collaboration between trials
  - Common Baseline and Follow up Measures:
    - QOL (SF-12)
    - Impact of Weight on QOL (IWQOL)
    - Depression (PHQ-9)
    - Physical Activity (Modifiable Activity Questionnaire)
    - Energy screener (dietary intake questionnaire)
    - Patient satisfaction
    - Weight, Blood pressure, glucose, lipids
  - Common Primary Outcome
- Project preliminary work is complete
  - Stakeholder input obtained
  - Study Protocols are finalized and IRB-approved
  - Sites are on-board (IRB approvals, subcontracts executed)
  - Interventions are finalized
  - Recruitment plans are documented

Next Step – Recruitment!

- Recruitment begins this quarter for both trials

Update: Multi-Level Interventions to Improve Blood Pressure Control in Minority Racial/Ethnic, 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

- **Resulted in funding of 2 hypertension trials (Total Funds Awarded: $23.5M)**
    - Funding announcement based on 2 topics prioritized by the AD panel in April 2013

Summary of Hypertension Portfolio

Project Title	Org.	Target Population(s)	No. of Study Pts. (No. of Sites)	Primary Outcome	Start Date
Collaboration to Improve Blood Pressure in the US Black Belt – Addressing the Triple Threat	University of Alabama	Rural populations; African Americans; low socio-economic individuals	2,000 (80 practices)	Blood pressure control	September 2015
Comparative Effectiveness of Health System vs. Multi-level Interventions to Reduce Hypertension Disparities	Johns Hopkins University	African Americans and Hispanics/ Latinos; low socio-economic individuals	1,890 (30 primary care clinics including FQHCs)	Percent of patients with blood pressure under control	September 2015

Progress

- Collaboration between trials
  - In process of identifying common baseline and follow up measures
    - Potential harmonization around
      - Health-related QOL
      - Medication adherence
      - Safety/side effects
      - Depression
      - Physical activity
  - Common primary outcome
- Project preliminary work is underway
  - Stakeholder input is continuously being obtained
  - Study Protocols and interventions are in development
    - Draft protocols due February 2016
- 1 DSMB for both studies
  - Members have experience in health and health care disparities and hypertension identified

Update: Pragmatic Clinical Studies

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.*

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: Sickle Cell Disease

Management of Sickle Cell Disease

- The Addressing Disparities program presented the topic brief, “Management of Sickle Cell Disease,” to the Advisory Panel for feedback on October 21st, 2015.
  - The panel was very enthusiastic and gave a strong endorsement to move forward with this topic.
- On November 17th, 2015, PCORI’s Scientific Oversight Committee approved staff to move forward with a multi-stakeholder workgroup in this area
- The workgroup, to be held March 7th, 2016, will focus on two key areas:
  - Transitions in Care, and
  - Pain Management

Update: Funding in Priority Areas

Update on Prioritized or Discussed Topics

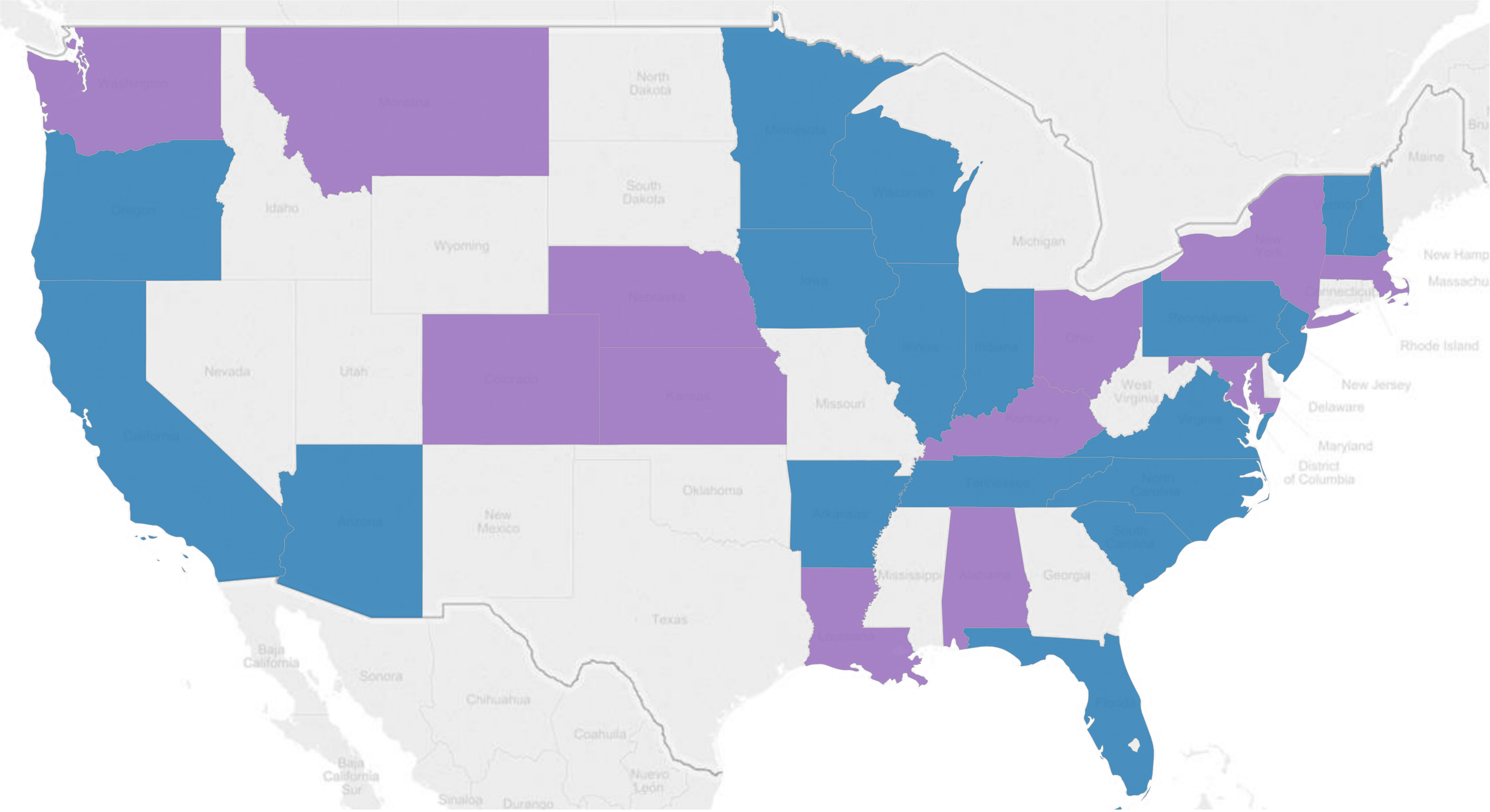
22

- **Topics Prioritized or Discussed**

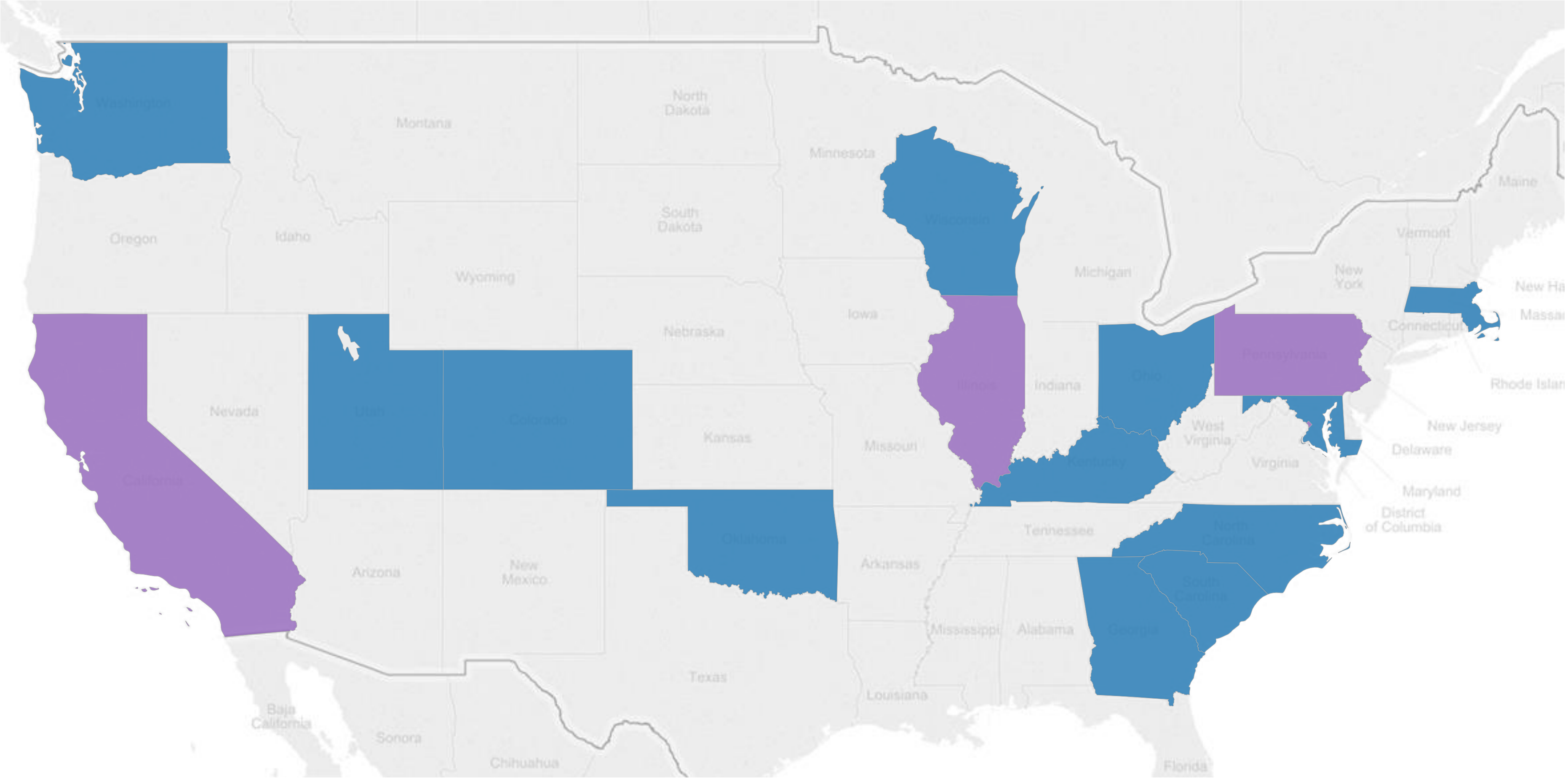
11

- **Topics Included in Funding Announcements**
  - Pragmatic Clinical Studies: **5** topics
  - Broad Portfolio: **5** topics
  - Targeted PFA: **1** topics

Funding on Rural Populations



Funding on Individuals with Disabilities



Questions on Program Updates

The AD Broad Portfolio: Taking a Closer Look

February 9, 2016

Mira Grieser, MHS
Program Officer, Addressing Disparities

Cathy Gurgol, MS
Program Officer, Addressing Disparities

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Agenda

- Program Overview
- Broad Portfolio Highlights
- Publications Update
- Q&A

Program Overview

Addressing Disparities Mission Statement

PCORI's
Vision, Mission, Strategic Plan

Program's Mission Statement

To **reduce disparities** in healthcare outcomes and **advance equity** in health and healthcare

Program's Guiding Principle

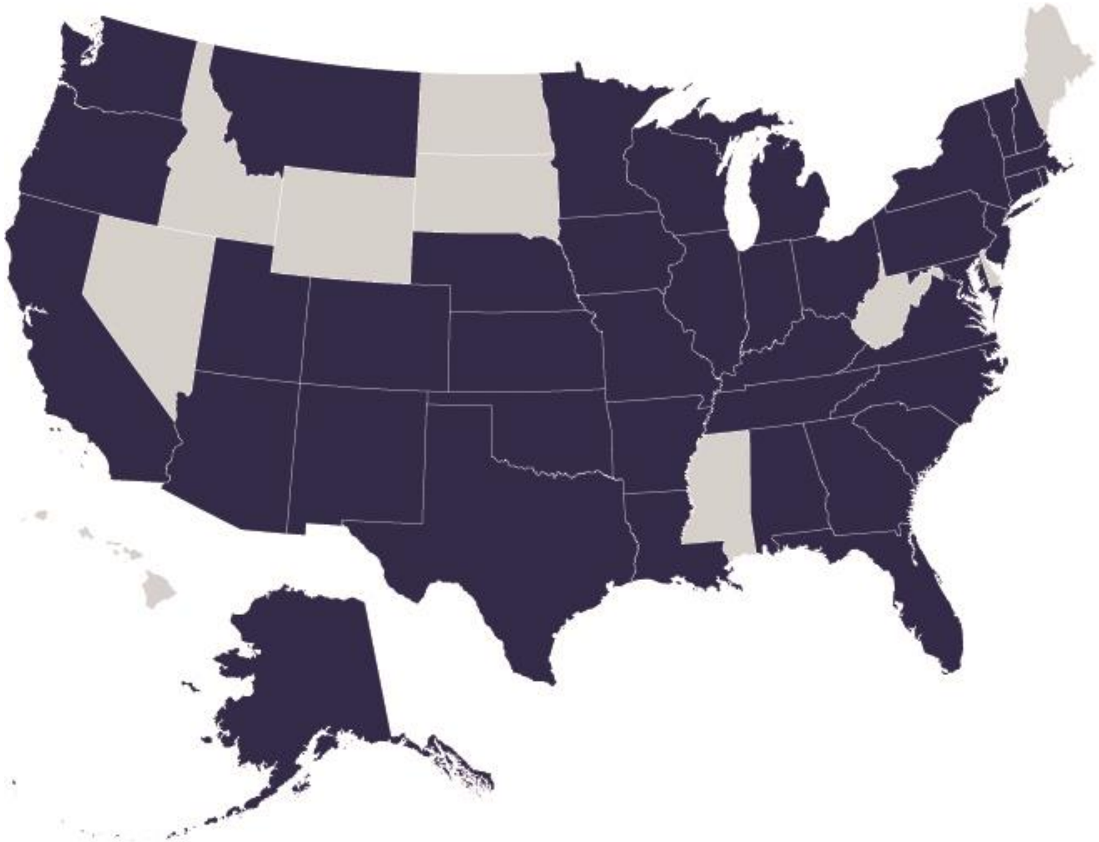
To support comparative effectiveness research that will identify best options for reducing and **eliminating disparities**

Snapshot of PCORI Funded Research Projects

Number of projects:
476

Amount awarded:
$1.25 billion

Number of states where we are funding research:
41 (plus the District of Columbia)



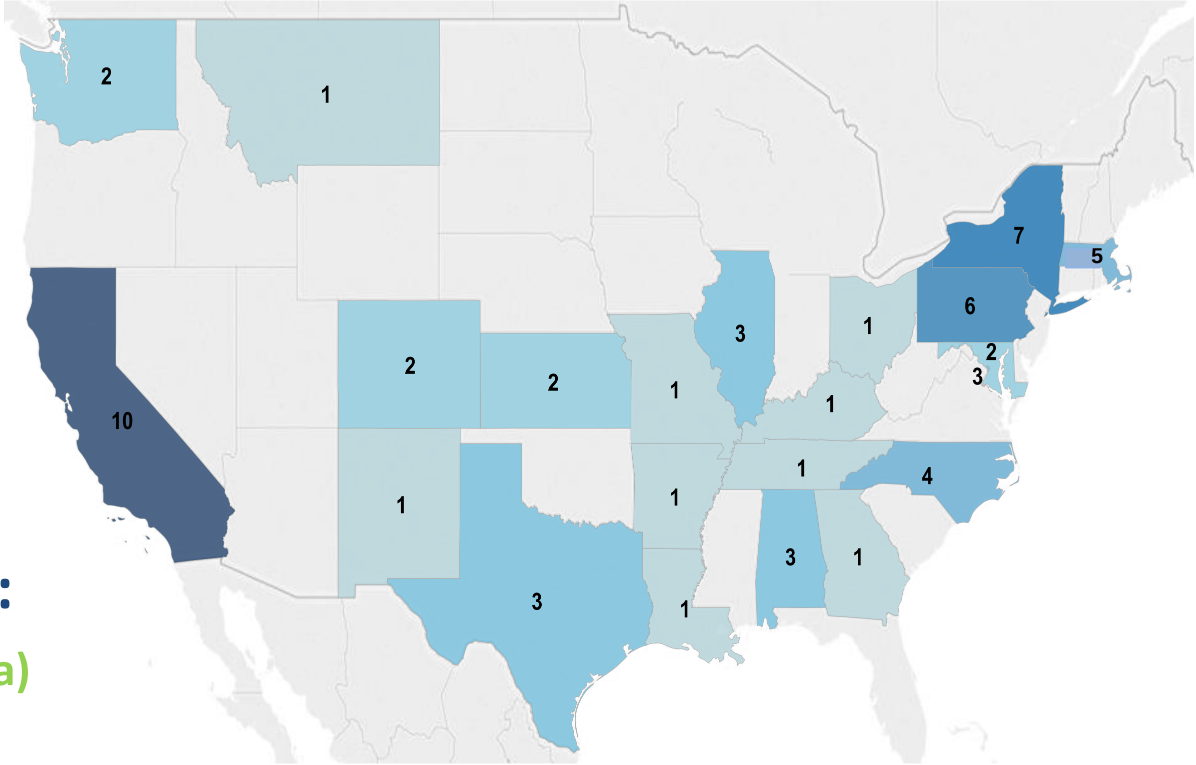
As of January 26, 2016

Snapshot of AD Funded Projects

Number of projects:
61

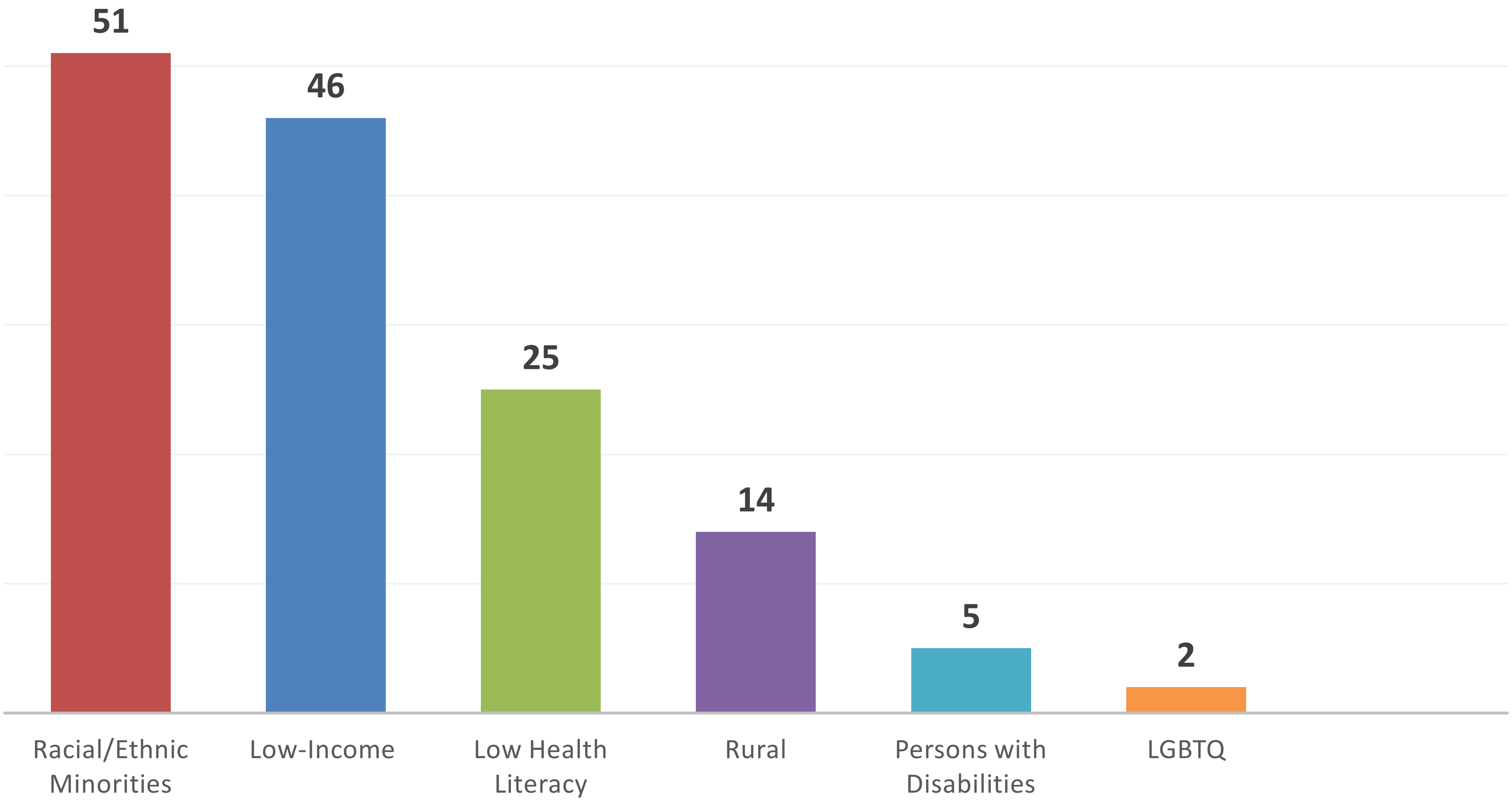
Amount awarded:
$174 million

Number of states where we are funding research:
21 **(plus the District of Columbia)**



Addressing Disparities Populations of Interest

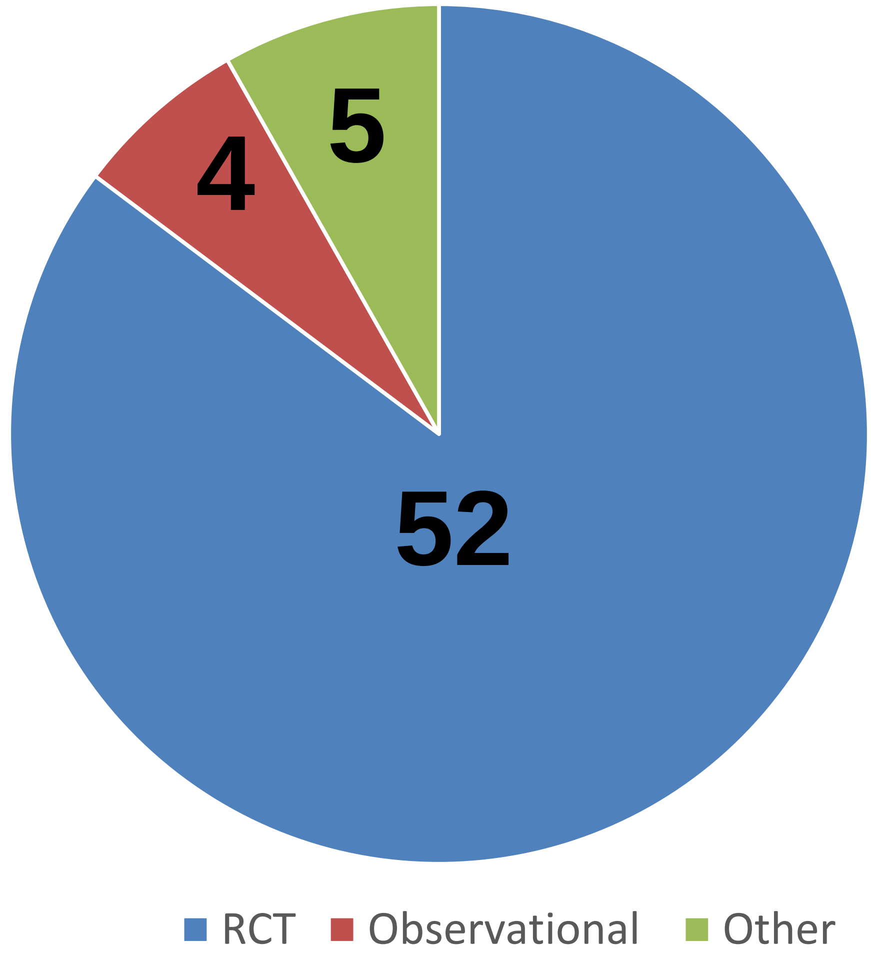
*not mutually exclusive



Addressing Disparities Health Conditions

Condition	Number
Mental/Behavioral Health	13
Respiratory Diseases	10
Cardiovascular Health	8
Nutritional and Metabolic Disorders	5
Neurological Disorders	5
Multiple/co-morbid chronic conditions	4
Cancer	3
Reproductive and Perinatal Health	2
Liver Disease	2
Other	9
Grand Total	**61**

Addressing Disparities Methods



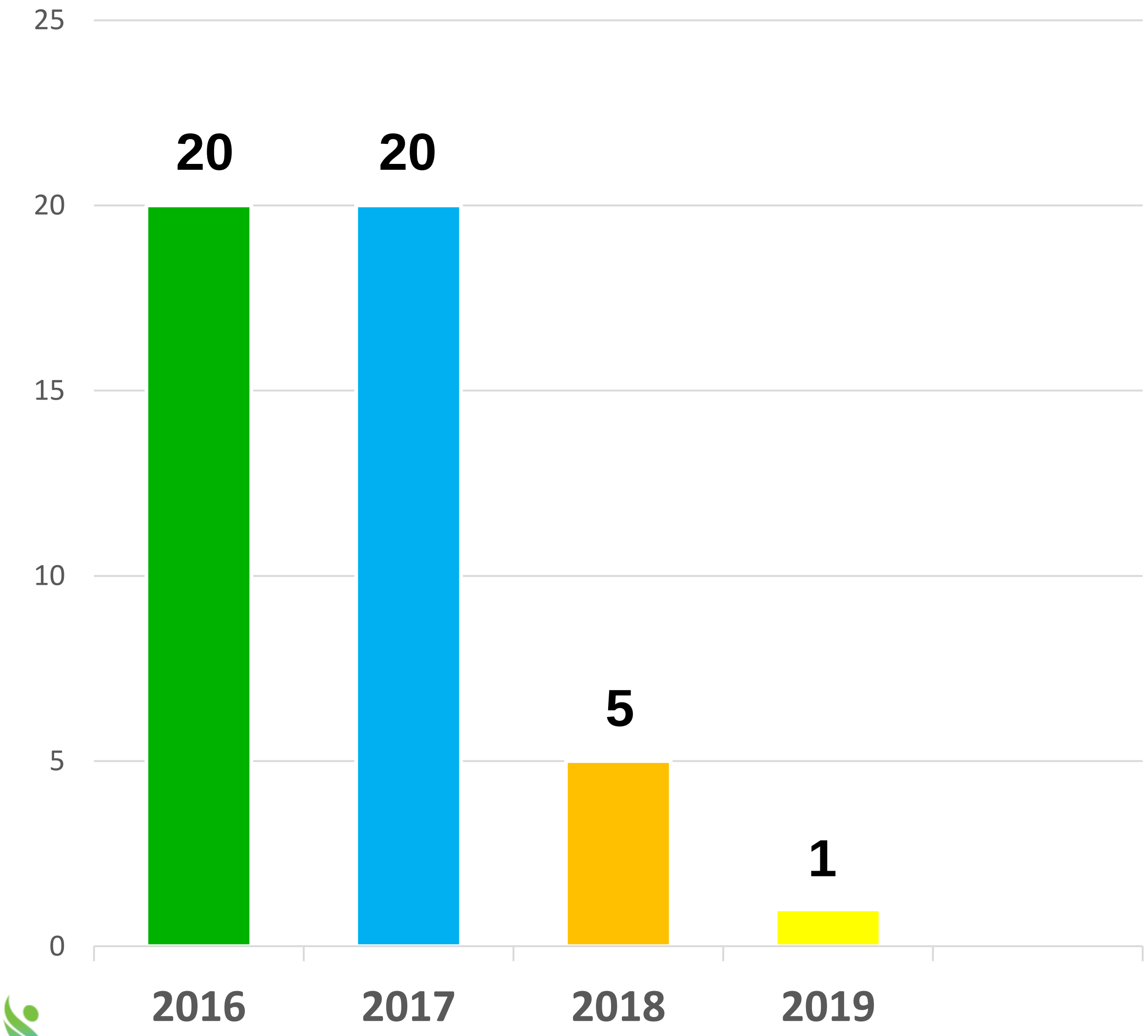
Broad Portfolio Highlights

Snapshot of Broad Portfolio

- General parameters:
  - Investigator-initiated
  - 3 years duration
  - Budget: $1.5 million (direct costs)

- Current status:
  - Funded 47 projects
  - $84 million investment

Broad Funded Projects Ending by Year



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A Deeper Look into AD Broad Projects

Selected Themes in the AD Broad Portfolio

Diabetes Treatment and Prevention

Chronic Pain Treatment

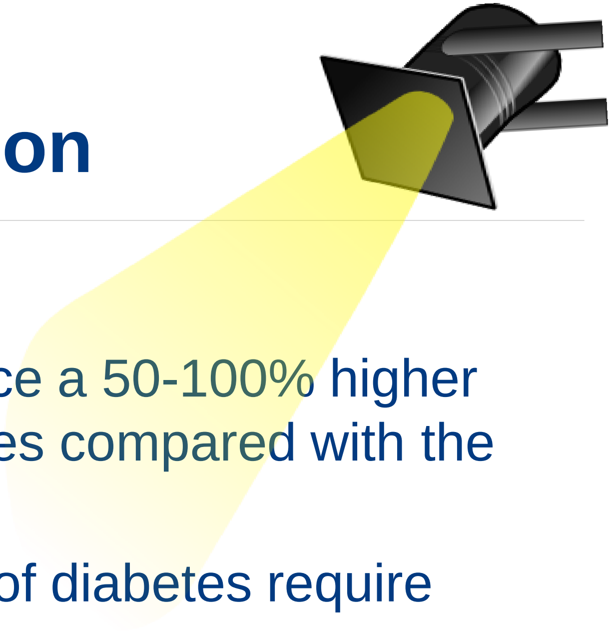
Disabilities

Care Transitions

LGBTQ Populations

Diabetes Treatment and Prevention

Diabetes Treatment and Prevention



- **Background**
  - Populations at risk for disparities experience a 50-100% higher burden of illness and mortality from diabetes compared with the general population.
  - Primary prevention and self-management of diabetes require significant lifestyle changes.

Diabetes Treatment and Prevention

Project	Intervention	Target Population	Disparity addressed
A Patient-Centered Approach for Improving Diabetes Prevention (CA)	Enhanced Diabetes Prevention Program	American Indian and Alaska Native (AIAN)	Diabetes prevention in vulnerable population
Using DSME to Reduce Disparities (AR)	Extended Family Model of Diabetes Self-Management Education	US Pacific Islander	Diabetes self-management in vulnerable population

Decisional Dilemma: Diabetes

Urban American Indian with risk factors for diabetes: *Should I participate in an enhanced Diabetes Prevention Program (DPP) that also addresses grief, historical trauma, and depression that are prevalent in my community or should I participate in a standard DPP? The enhanced program may be more effective in managing my risk factors; however, it may bring up issues that are difficult to deal with. How can I determine the best course of action for me?*

US Marshallese individual with diabetes*: What can I do to manage my condition? Is participating in a Diabetes Self-Management Education program along with my family likely to give me greater benefits than a traditional DSME program would? The Family model is tailored to my culture, but the traditional program is less of a commitment for me and my family.*

A Patient-Centered Approach for Improving Diabetes Prevention (CA)

- **Research question:**
  - How does a Diabetes Prevention Program (DPP) that addresses psychosocial issues compare with a standard DPP in addressing the needs of a high-risk urban American Indian population?

- **Study design & comparators:**
  - RCT with 204 patients, randomized into:
    - 16-week enhanced DPP (includes 4 visits to mental health counselor, participation in traditional healing workshops)
    - 16-week standard DPP

- **Project snapshot:**
  - Longstanding and highly engaged American Indian Advisory Board
  - Project has become a model for other local groups wanting to incorporate community engagement.
  - Local safety net health system interested in results

Using DSME to Reduce Disparities (AR)

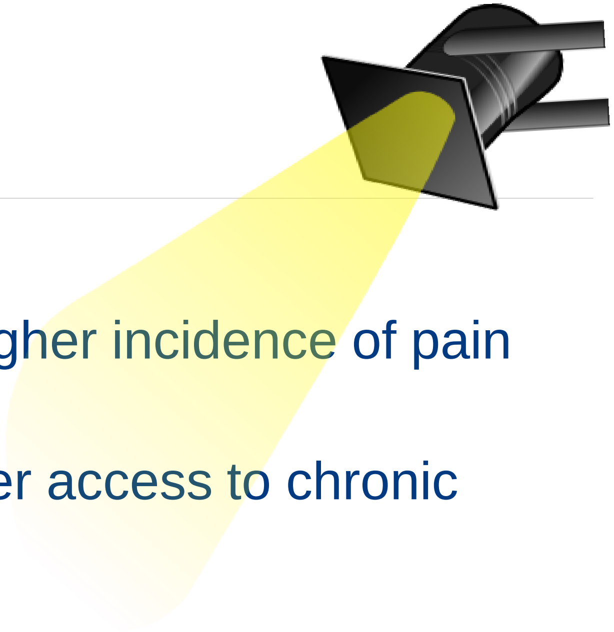
- **Research question**:
  - Diabetes Self-Management Education (DSME), an evidence-based intervention, has not been successfully implemented in the US Marshallese population. Can a culturally-adapted DSME that includes a family-based component be effective in management of diabetes in a US Marshallese population?

- **Study design & comparators:**
  - RCT with 250 US Marshallese participants with diabetes randomized into:
    - DSME with Extended Family Model
    - Traditional DSME

- **Project snapshot:**
  - Responding to unmet need for DSME in US Marshallese communities
    - In the Extended Family arm, study enrolls family members in addition to the diabetic participant. About 20% of participating family members were found with previously undiagnosed diabetes.
  - Strong community engagement has helped establish trust.

Chronic Pain Treatment

Chronic Pain Treatment



- **Background**
  - Populations at risk for disparities have a higher incidence of pain compared with general population.
  - Populations at risk for disparities have lower access to chronic pain treatment due to:
    - pain intensity underreporting
    - provider perceptions
    - treatment availability
    - other factors such as transportation to care facilities, cost.

Chronic Pain Treatment

Project	Intervention	Target Population	Disparity addressed
Psychosocial Treatments for Chronic Pain (AL)	Group Cognitive Behavioral Therapy, Group Education	Low income; African American	Pain Management
Acupuncture Approaches (NY)	Acupuncture	Low income, African American, Latino	Access to Care
Pain Coping Skills Training (NC)	Cognitive Behavioral Therapy	African American	Pain Management
Integrative Medicine Group Visits (MA)	Group Integrative Medicine	Low income; African American	Pain Management

Decisional Dilemma

***Low-income African American with chronic pain**: Should I participate in a group cognitive behavioral therapy program or a group education program, or receive standard medical care to treat pain? The CBT and education programs are time intensive but usual treatment may not help me deal with my pain effectively.*

***Healthcare system**: In determining whether to provide acupuncture, we need to understand differences in benefits and risks between individual and group acupuncture settings. Although group acupuncture can be offered for a fraction of the resources, does it offer a comparable benefit to patients in pain reduction and satisfaction?*

Literacy-Adapted Psychosocial Treatments for Chronic Pain (AL)

- **Research question:**
  - In individuals with chronic pain, does participating in a health literacy–adapted psychosocial treatment group improve pain intensity and physical functioning when compared with a group receiving standard medical care?

- **Study design & comparators:**
  - RCT; 294 African Americans with low socio-economic status receiving care at an FQHC randomized into:
    - Group Cognitive Behavioral Therapy
    - Group Education
    - Primary Care treatment as usual

- **Project snapshot:**
  - Working closely with health center which helped project team gain trust in the community.
  - Project is considering ways to become sustainable in FQHCs

Acupuncture Approaches to Decrease Disparities in Pain Treatment (NY)

- **Research question:**
  - Is acupuncture delivered in a group setting for participants with chronic pain at least as effective as acupuncture delivered in an individual setting?

- **Study design & comparators:**
  - RCT with 700 low-income adults at 6 FQHC sites in NYC randomized into:
    - 12 weekly sessions of group acupuncture
    - 12 weekly sessions of individual acupuncture

- **Project snapshot:**
  - High numbers of provider referrals indicate large unmet for pain management.
  - High level of enthusiasm from patients and providers
  - Project helped implement mechanism for credentialing licensed acupuncturists at sites; improves potential for sustainability.
  - Creation of treatment manual for group approach by stakeholders from the national acupuncture community, an important contribution to the field.

Disability

Disabilities

Study	Intervention	Target Population	Disparity addressed
Peer Health Navigation for SMI (CA)	Peer Health Navigation	Racial/ethnic minorities	Skills gained to manage healthcare
Integrated Care and Peer Navigators for Latinos with SMI (IL)	Peer Health Navigation	Low-income; Latinos	Utilization of health care
Access to and Satisfaction with Care for People with Disabilities (PA)	Compares people with disabilities to people without disabilities	Disabilities (functional impairment)	Access to health care
Self-management of Urinary Symptoms and Urinary Tract Infections (DC)	Self-management using probiotics	Individuals with spinal cord injury or spina bifida	High disease burden in population

Disability: Serious Mental Illness (SMI)

- **Background**
  - Individuals with SMI have significant disease burden with high rates of co-occurring illnesses that are often undiagnosed, untreated, or under-treated.
    - Individuals with SMI face barriers to accessing and using health care services.
  - Poor health outcomes are compounded for populations at risk for disparities.

Decisional Dilemma: Serious Mental Illness (SMI)

***Individual with serious mental illness**: I would like to manage my healthcare better. Should I participate in a program where my peers help me gain the knowledge I need or continue receiving standard treatment from the community mental health clinic? The peer program is time intensive but standard care may not be effective in meeting my healthcare needs.*

Peer Health Navigation: Reducing Disparities in Health Outcomes for SMI (CA)

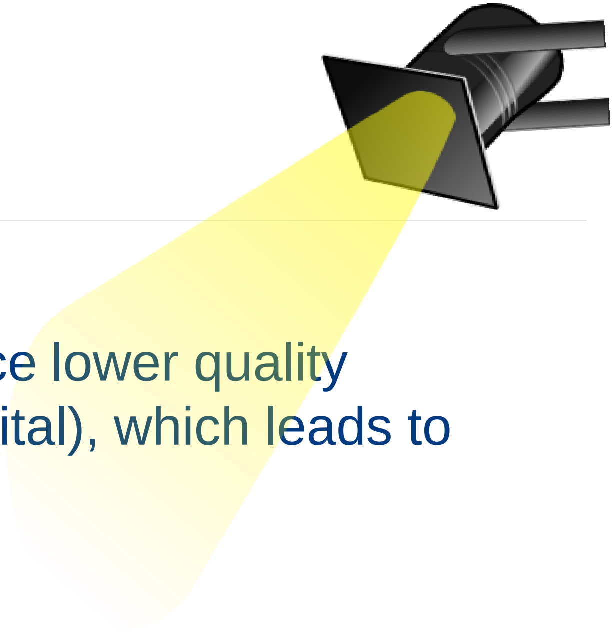
- **Research question:**
  - To what degree can peer health navigation impact the health disparities of people with serious mental illness?

- **Study design & comparators:**
  - RCT with 123 low income individuals with serious mental illness:
    - Bridge Intervention: Patient navigator intervention
    - Mental health treatment at community-based health clinic.

- **Project Snapshot:**
  - High satisfaction of intervention participants
  - Developed resources to help train peer navigators.
  - Results expected early 2016.

Care Transitions

Care Transitions



- **Background**
  - Populations at risk for disparities experience lower quality discharge planning (ED and inpatient hospital), which leads to worse outcomes:
    - Increased rehospitalizations
    - Increased subsequent ED visits
  - Effective and efficient discharge planning, primarily used in the general population, may be adapted for populations at risk for disparities to improve outcomes.

Care Transitions

Project	Intervention	Target Population	Disparity Addressed
ROADMAP (MT)	Patient-centered discharge model	Rural/Frontier	Access to care
GUIDED (TN)	Tailored ED discharge	Racial/ethnic minorities; low-income	Access to care

Decisional Dilemma: ROADMAP

***Hospital system**: What is the best way to implement discharge plans for people being discharged to their rural community. Should we adopt an individualized, patient-centered approach to discharging patients, or continue with the standard discharge model? The individualized approach could be more resource intensive, but the standard model may not meet the needs of rural patients, which could cause worse outcomes and rehospitalization.*

Reducing Disparities in Rural Communities with Discharge Model of Active Planning (ROADMAP) (MT)

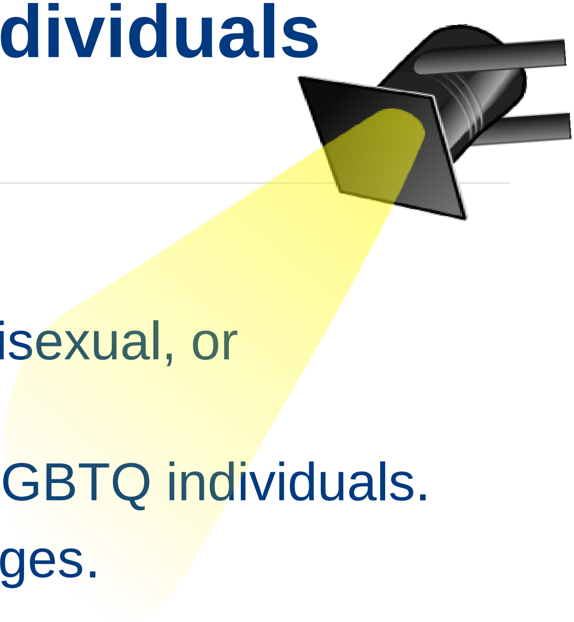
- **Research question:**
  - What are the components of a patient centered discharge planning process for rural patients that would meet the standards of healthcare delivery (system) and the patients' needs?

- **Study design & comparators:**
  - Quasi-experimental with 146 participants from 4 regional referral hospitals:
    - Patient-centered discharge planning
    - Standard discharge planning

- **Project snapshot:**
  - Manual of procedures and other study materials ready for sharing with other hospitals.
  - Public comments to incorporate rural perspective on CMS' new guidelines for discharge planning.

LGBTQ Populations

Health Disparities Among LGBTQ Individuals (AD Target population)



- **Background**
  - 9 million individuals identify as lesbian, gay, bisexual, or transgender in US.
  - Well-documented health disparities exist for LGBTQ individuals.
  - Research to address disparities is in early stages.

LGBTQ Populations

Project	Study	Target Population	Study design	Target Sample Size	Disparity Addressed
Transgender Study (GA)	Morbidity and mortality outcomes in transgender individuals	LGBTQ; low-income	Observational	9000	Generating critical data on morbidity and mortality
EQUALITY Study (MA)	Collecting sexual orientation / gender identity information in the ED	LGBTQ	Quasi-experimental	2030	Standardized data collection

Projects with LBGTQ populations

- **Transgender Study**
  - Cohort studies evaluating physical health outcomes among transgender individuals are rare.
  - Largest study ever done evaluating health outcomes in transgender individuals.
  - Detailed methods developed to determine transgender status using the EHR.

- **EQUALITY Study**
  - Developed 2 methods for collecting sexual orientation/ gender identity information in the ED
  - Currently testing these approaches in 4 hospitals in Baltimore and Boston
  - Extensive involvement of advisory board

Publications Update

Publications Statistics

- 52 manuscripts are in progress
- 9 manuscripts published so far
  - All report on incorporating patient and healthcare stakeholder engagement into research and discuss the influence of these individuals on the research project.
  - 7 also focus on project methods/design
  - Two are directed toward patient-stakeholder groups and advise them on how to establish effective partnerships with researchers.

Q&A

A Patient-Centered Intervention to Increase Screening of Hepatitis B and C Among Asian-Americans

Tung Nguyen, MD

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Setting the Scene: Telehealth

- **Telehealth:** use of medical information exchanged from one site to another via electronic communications.
- The AD program has funded 14 projects that use telehealth to improve health outcomes:
    - Populations represented: racial/ethnic minorities (Latinas, AA, Zuni Indians), low-income groups, rural, LGBTQ, low health literacy/numeracy and limited English proficiency,
    - Conditions being addressed : Cardiovascular Health, Stroke, Infectious Diseases, Chronic Diseases, Reproductive Health

Health Within Reach:
Patient and Stakeholder Engagement to Reduce Health Disparities

Tung Nguyen, MD,
Professor of Medicine, University of California San Francisco
Director, Asian American Research Center on Health

February 9, 2016

Patient-Centered Research Outcomes Institute (PCORI) AD-12-11-4615

ARCH

HEALTH
Within Reach

Division of
General Internal Medicine

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, SCHOOL OF MEDICINE

General Considerations

- What do we mean by “patient-centered”?
- Can “patient-centered” approaches worsen health and healthcare disparities?
- What can we do to ensure that patient-centered outcomes research reduce health and healthcare disparities?

Patient-Centered Approach

- Who sees being a patient as his/her most important characteristic?
- What happens when the way to health is centered in healthcare settings?

"…for all the knowledge gained, the medicalization of misery is yet another way to avoid talking about impoverishment, destitution, and inequality." Jill Lepore

Can Patient-Centered Approaches Worsen Disparities?

- Decision-making
  - Health literacy and numeracy
  - Culture and language
  - Complex decision-making in a complex life

- Technological approaches
  - Electronic health records and non-verbal communication
  - Patient portals and unintended consequences
  - Mobile applications and the digital divide

Health Within Reach Framework

Asian Americans

- Asian Americans fastest growing racial group
  - 18 million and growing
  - 1 out of 17 Americans is Asian
- 66% born outside the U.S, and 50% of foreign-born came after 1990
  - Since 2008, # of immigrants from Asia > # from Latin America
- 37% are limited English proficient: Chinese: 48%, Vietnamese: 55%

Scientific and Community Needs

- USPSTF recommends screening for hep B among immigrants from endemic areas
  - Chronic hep B rates among Asian Americans ~10-15%
    - 1/3 never had hep B screening test
- USPSTF recommends screening for hep C among at-risk and birth cohort 1945-1964
  - Few studies on Asian Americans and hepatitis C
- Liver cancer: one of few cancers rising in incidence
  - 3-8x higher among Asian Americans vs. Whites
- Very few clinical interventions to improve quality of care among Asian Americans

Health Within Reach Aims

- Develop interactive patient education video (Video Doctor) and Provider Alert to increase screening of hepatitis B and C in Asian American patients

- Evaluate the efficacy of the Video Doctor + Provider Alert intervention + Provider Panel Notification vs. Provider Panel Notification in 2 healthcare systems through provider randomized controlled trial

Health Within Reach Team

- Settings: academic medical center (UCSF) and county hospital (SFGH)

- Researchers: internists, hepatologist, psychologist

- Stakeholders:
  - San Francisco Hep B Free
  - Hepatitis B Quality Improvement Collaborative
  - Asian American Network for Cancer Awareness, Research and Training (AANCART)
  - Vietnamese Community Advisory Board
  - Patient Advisory Councils at both sites

Why Was the Team Formed?

- Passion for Asian American health and reducing health disparities
- Commitment to community-based and patient-centered work
- Common focus on viral hepatitis and liver cancer
- Complementary expertise
  - Hep B Free: community mobilization, stakeholder engagement
  - QIC: clinical systems
  - SFGH/Hepatology: clinical research, underserved, specialty
  - UCSF/General Medicine: community-based participatory research, multi-lingual interventions, prevention

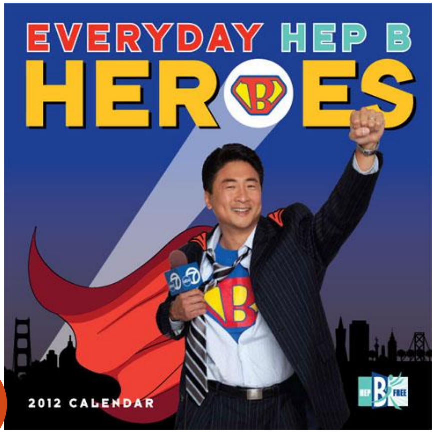
SF Hep B Free

- Launched in April 2007
- Collaborative effort between the SF Department of Public Health, AsianWeek Foundation, and Asian Liver Center at Stanford
- Target all sectors of society with the mission of institutionalizing into the medical infrastructure sustainable routine hep b screening with access to vaccination & follow-up
  - Media campaign
  - Clinician outreach
  - Community outreach
  - Policy

HEP B FREE
SAN FRANCISCO

Media Campaign & Outreach

1 in 10 Asian Americans is infected with hepatitis B, the leading cause of liver cancer. But hepatitis B can be treated, even prevented. Get the simple blood test. Stop liver cancer by stopping hepatitis B.



HEALTH
Within Reach

Policy


舊金山中華文化中心
Chinese Culture Center
San Francisco


Frank Jang


GIANTS

How Was the Team Formed?

- Hep B Free requested consultation on evaluation from UCSF
  - UCSF helped Hep B Free create a Logic Model
  - Logic Model led to conclusion that clinical quality improvement was necessary to reduce hepatitis B burden
- Hep B Free, UCSF, and SF Department of Public Health created Hepatitis B Quality Improvement Collaborative
  - Brought together all major healthcare systems in SF
  - Identified need to improve screening for hepatitis B as well as monitoring and treatment of those infected
- Identified PCORI as a potential funder

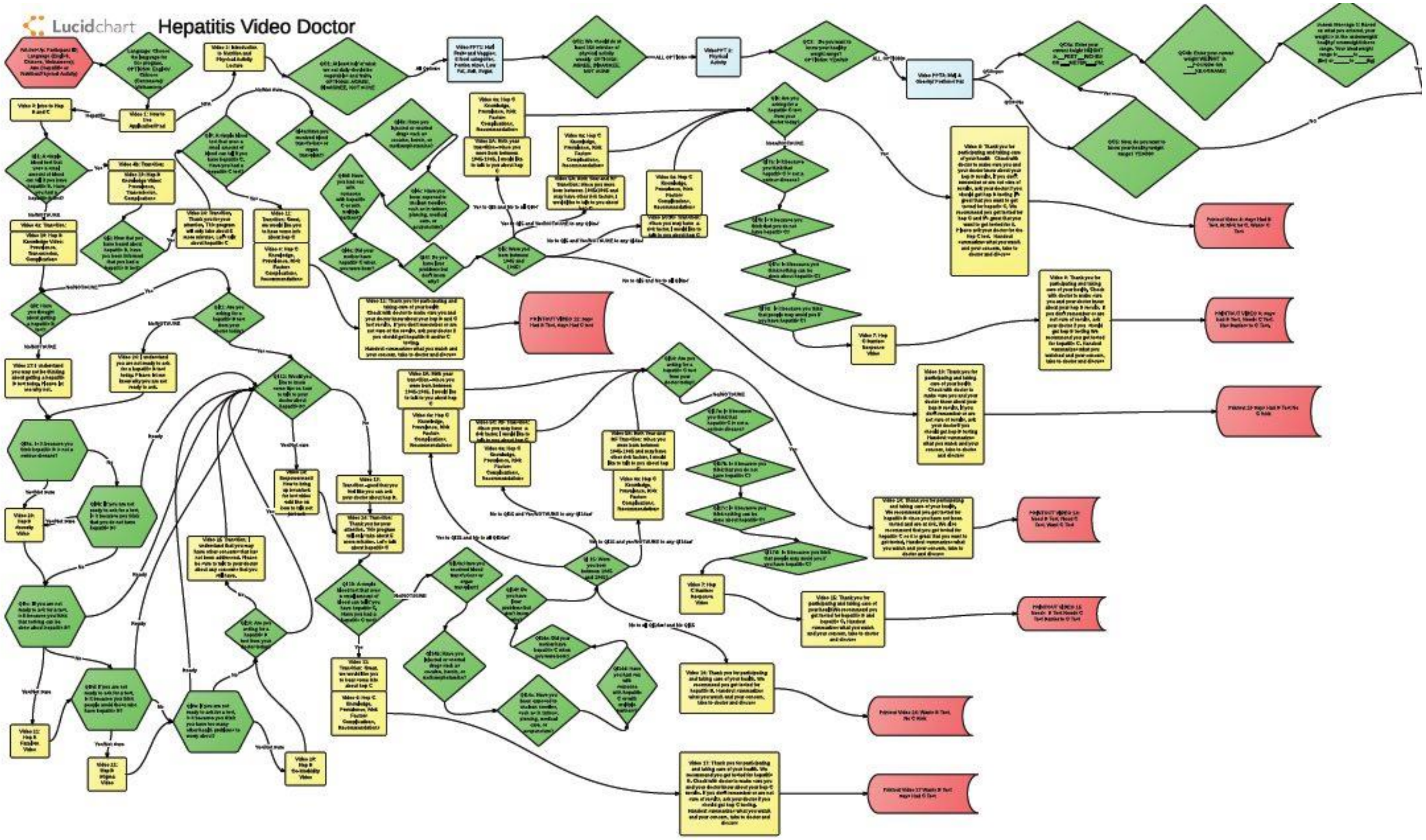
Stakeholder Input: Grant Development, Logistics, Oversight

- Identification of topic and intervention: SF Hep B Free, AANCART, Hep B QIC, Vietnamese Community Advisory Board
- Grant writing: SF Hep B Free, AANCART
- Core Team: SF Hep B Free
- Oversight/Reporting:
  - AANCART: Quarterly
  - Hep B QIC: Bimonthly
  - Vietnamese Community Advisory Board: Quarterly
  - Patient Advisory Councils: Quarterly

Stakeholder Input: Intervention

- Focus groups
  - Community members and patients to develop topics
  - Clinic staff to obtain buy-in and understand clinic logistics
- Physician interviews to understand their points of view
- Patient Advisory Councils:
  - Barriers and responses
  - Application look and feel (buttons, fonts, colors, flow)
  - Video look and feel
  - Languages
  - Control materials
  - Pilot test
- Patients: pilot test of application

Application Algorithm



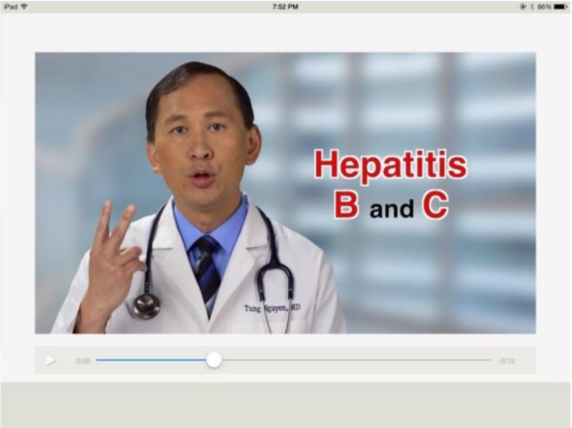
Patient Advisory Council Meeting

Application Look and Feel

HEALTH Within Reach

Application Look and Feel

Video: Choice of Doctor



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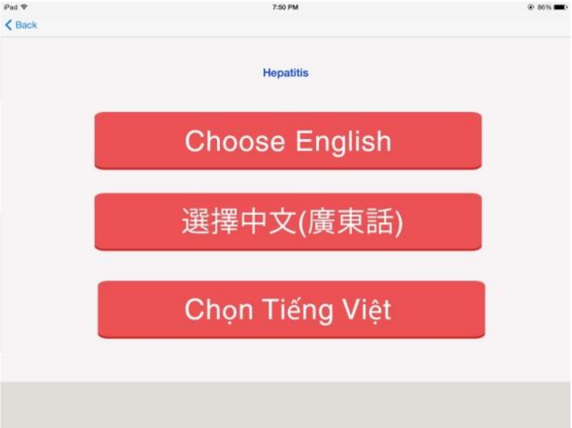
Fun?

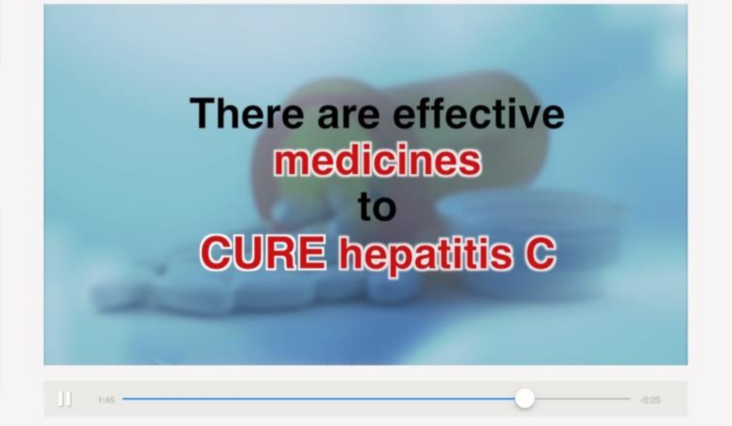
Pilot Testing

Pilot Testing

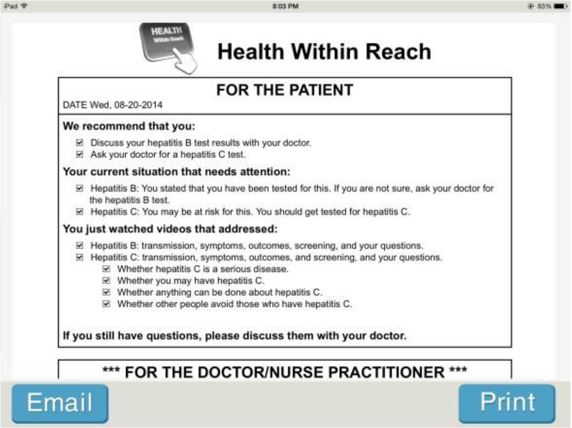
HEALTH Within Reach

Mobile App and Provider Alert





There are effective medicines to CURE hepatitis C



Health Within Reach

FOR THE PATIENT

DATE Wed, 08-20-2014

We recommend that you:

- ☑ Discuss your hepatitis B test results with your doctor.
- ☑ Ask your doctor for a hepatitis C test.

Your current situation that needs attention:

- ☑ Hepatitis B: You stated that you have been tested for this. If you are not sure, ask your doctor for the hepatitis B test.
- ☑ Hepatitis C: You may be at risk for this. You should get tested for hepatitis C.

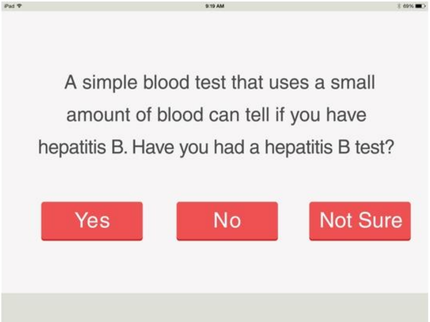
You just watched videos that addressed:

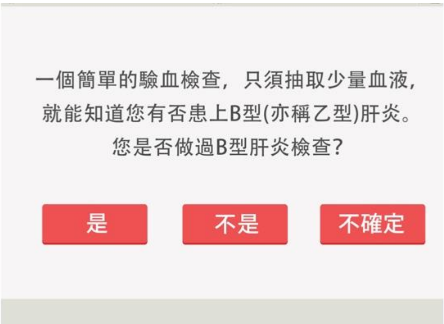
- ☑ Hepatitis B: transmission, symptoms, outcomes, screening, and your questions.
- ☑ Hepatitis C: transmission, symptoms, outcomes, and screening, and your questions.
  - ☑ Whether hepatitis C is a serious disease.
  - ☑ Whether you may have hepatitis C.
  - ☑ Whether anything can be done about hepatitis C.
  - ☑ Whether other people avoid those who have hepatitis C.

If you still have questions, please discuss them with your doctor.

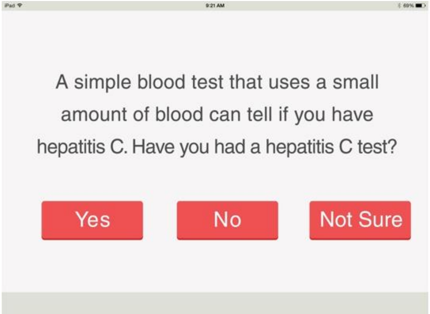
***** FOR THE DOCTOR/NURSE PRACTITIONER *****

Languages


A simple blood test that uses a small amount of blood can tell if you have hepatitis B. Have you had a hepatitis B test?


一個簡單的驗血檢查，只須抽取少量血液，就能知道您有否患上B型(亦稱乙型)肝炎。您是否做過B型肝炎檢查？

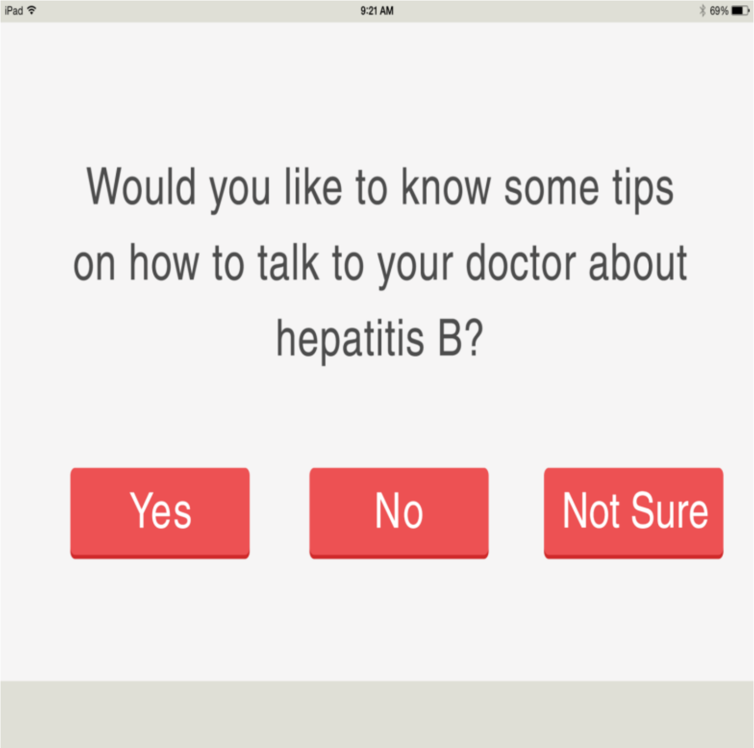

Một xét nghiệm máu đơn giản chỉ dùng một lượng nhỏ máu để có thể cho biết bạn bị bệnh viêm gan B hay không. Bạn đã làm thử nghiệm viêm gan B chưa?


A simple blood test that uses a small amount of blood can tell if you have hepatitis C. Have you had a hepatitis C test?


一個簡單的驗血檢查，只須抽取少量血液，就能知道您有否患上C型肝炎。您是否做過C型肝炎檢查？

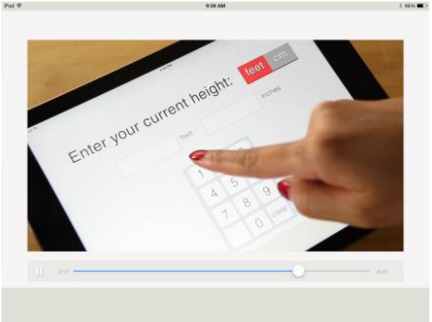

Một xét nghiệm máu đơn giản chỉ dùng một lượng nhỏ máu để có thể cho biết bạn bị bệnh viêm gan C hay không. Bạn đã làm thử nghiệm viêm gan C chưa?

Culture and Empowerment



Would you like to know some tips on how to talk to your doctor about hepatitis B?

Control Group

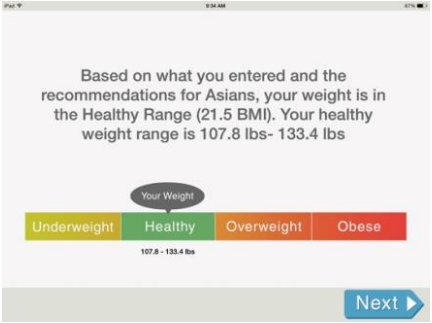


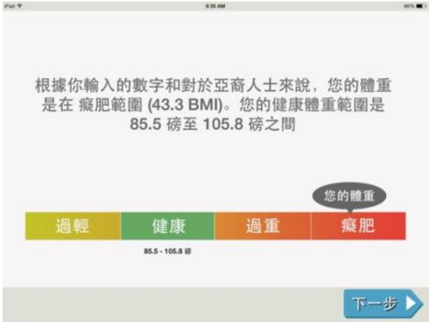

輸入您現在的身高:

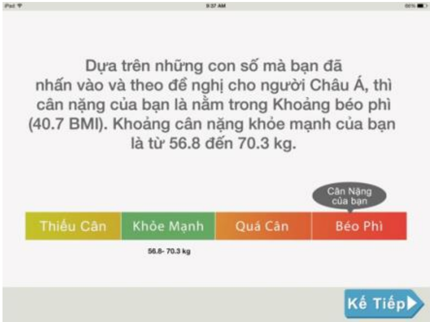
請輸入您的身高
數目應該是 4 至 6 尺之間


Chiều cao hiện giờ của bạn:

5 feet
9 inch


Based on what you entered and the recommendations for Asians, your weight is in the Healthy Range (21.5 BMI). Your healthy weight range is 107.8 lbs- 133.4 lbs


根據你輸入的數字和對於亞裔人士來說，您的體重是在 癡肥範圍 (43.3 BMI)。您的健康體重範圍是 85.5 磅至 105.8 磅之間


Dựa trên những con số mà bạn đã nhấn vào và theo để nghị cho người Châu Á, thì cân nặng của bạn là nằm trong Khoảng béo phì (40.7 BMI). Khoảng cân nặng khỏe mạnh của bạn là từ 56.8 đến 70.3 kg.

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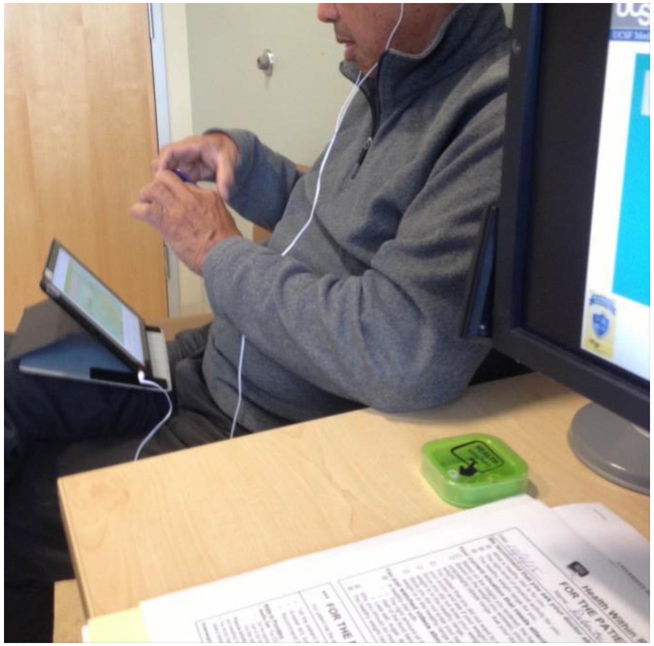
Implementation Logistics

Usability



Patient Advisory Councils Input: Implementation

- Age eligibility
- Informed consent
- Survey development
- Recruitment
- New topics of interest

Challenges

- Different perspectives and approaches
- Aligning expectations
- Communication

Addressing Challenges

- Budget
- Regular meetings
  - Food
  - Fun
- Respectful communication
  - time for discussion so everyone’s viewpoints are heard
  - problem solving not finger pointing
  - consensus decision making
- Understand that resolving challenges caused by intersection of different perspectives lead to innovation and generalizability

Recommendations About Stakeholders Engagement

- Stakeholder engagement is totally worth it!
- Trust takes time
  - Trust by proxy
- Flexibility in study design, intervention, and implementation within boundary of research integrity
- Insider/outsider research teams
- Include stakeholders from minority communities not only in PCORI disparities projects but ALL PCORI projects

Tung.Nguyen@ucsf.edu

www.asianarch.org

ARCH

Lunch

We will resume at 1:00 PM ET

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

PCORnet Cohorts: Summary and Status

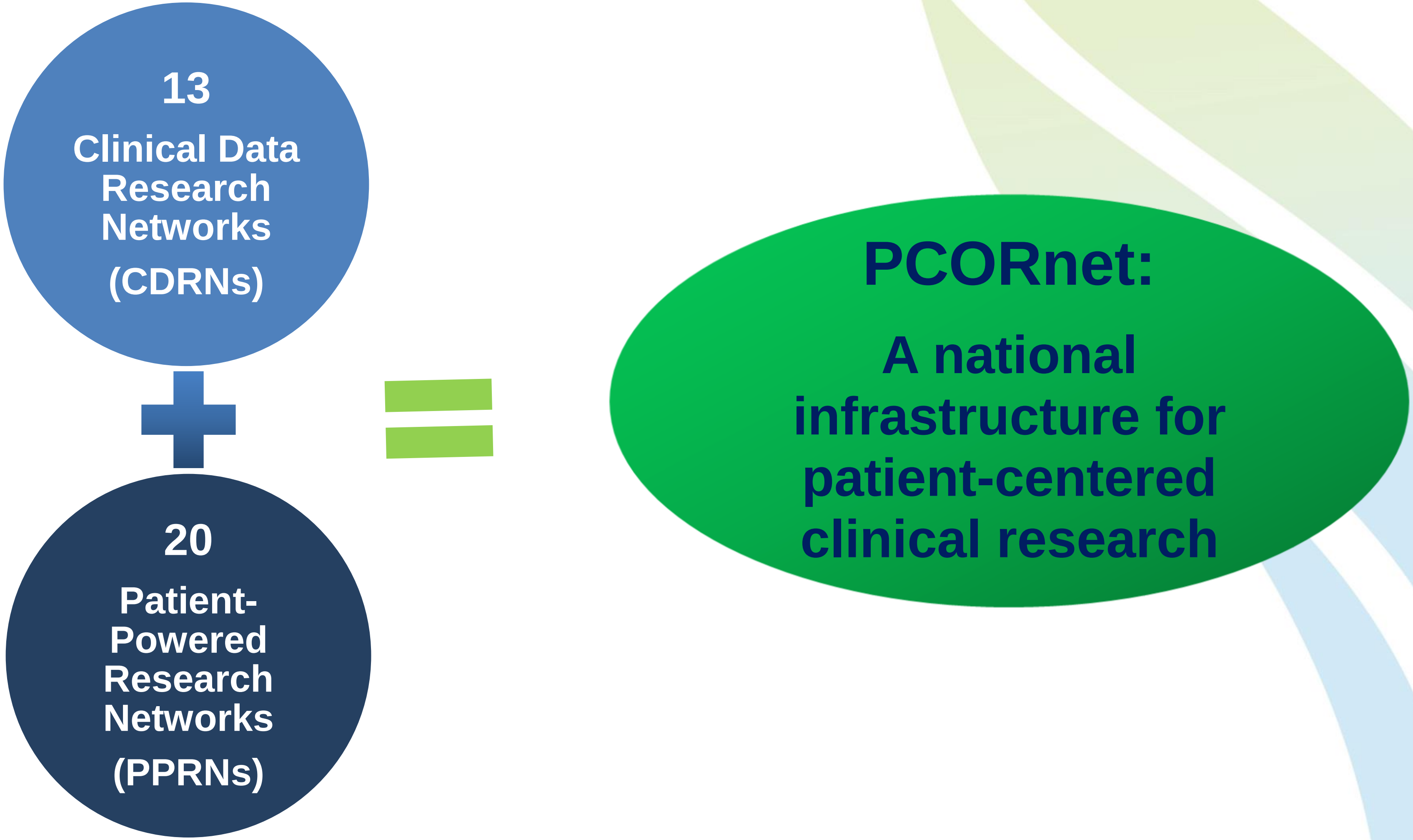
Focus on CDRNs and Rare Diseases

Maryan Zirkle, MD, MS, MA
Program Officer, Infrastructure
Patient Centered Outcomes Research Institute

Why did PCORI establish PCORnet?

- 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.
- PCORnet is made up of Clinical Data Research Networks (CDRNs) and Patient Powered Research Networks (PPRNs).

PCORnet unites *system-based* and *patient-driven* research networks



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Clinical Data Research Networks

(CDRNs)

+

20

Patient-Powered Research Networks

(PPRNs)

=

PCORnet:

A national infrastructure for patient-centered clinical research

PCORnet CDRN Common Disease Cohorts

Network	PI Name	Disease/Condition
ADVANCE	Jennifer DeVoe	Diabetes
CAPriCORN	Terry Mazany	Weight, asthma, anemia
GPC	Russ Waitman	Breast cancer
REACHnet	Tom Carton	Diabetes
LHSNet	Veronique Roger	Heart failure
Mid-South CDRN	Russell Rothman	Coronary heart disease with recent encounter
NYC-CDRN	Rainu Kaushal	Diabetes
OneFlorida	Elizabeth Shenkman	Hypertension
PaTH	Kathleen McTigue	Atrial fibrillation
PEDSNet	Chris Forrest	Inflammatory bowel disease
PORTAL	Elizabeth McGlynn	Colorectal cancer
pSCANNER	Lucila Ohno-Machado	Congestive heart failure
SCIHLS	Ken Mandl	Knee osteoarthritis

PCORnet PPRN Common Disease and Community Networks

Network	PI Name	Disease/Condition
MS-PPRN	Robert McBurney	Multiple sclerosis
ABOUT	Rebecca Sutphen	Hereditary Breast, Ovarian, Pancreatic, Prostate, Melanoma, and Related Cancers
AD-PCPRN	Ron Peterson	Alzheimer’s disease and dementia
AR-PoWER	Seth Ginsberg	Rheumatoid arthritis and spondyloarthritis
CCFA Partners	Michael Kappelman	Inflammatory Bowel Disease, including Crohn's disease and ulcerative colitis
COPD	John Walsh	Chronic obstructive pulmonary disease
CPPRN	Kenneth Wells	Behavioral health in under-resourced communities
IAN	Kiely Law	Autism spectrum disorders
Health eHeart	Mark Pletcher	Cardiovascular health
Mood Network	Andy Nierenberg	Individuals with mood disorders
PRIDEnet	Mitchell Lunn	Sexual and gender minorities

PCORnet CDRN Rare Disease Cohorts

Network	PI Name	Disease/Condition
ADVANCE	Jennifer DeVoe	Alpha-1-antitrypsin deficiency
CAPriCORN	Terry Mazany	Sickle cell disease; recurrent *C. difficile* colitis
GPC	Russ Waitman	Amyotrophic lateral sclerosis (ALS)
REACHnet	Tom Carton	Sickle cell disease; rare cancers
LHSNet	Veronique Roger	Osteogenesis imperfecta
Mid-South CDRN	Russell Rothman	Sickle cell disease
NYC-CDRN	Rainu Kaushal	Cystic fibrosis
OneFlorida	Elizabeth Shenkman	Duchenne muscular dystrophy
PaTH	Kathleen McTigue	Idiopathic pulmonary fibrosis
PEDSNet	Chris Forrest	Hypoplastic left heart syndrome
PORTAL	Elizabeth McGlynn	Severe congenital heart disease
pSCANNER	Lucila Ohno-Machado	Kawasaki disease
SCIHLS	Ken Mandl	Pulmonary arterial hypertension

PCORnet PPRN Rare Disease Networks

Network	PI Name	Disease/Condition
REN	Janice Buelow	Rare epilepsies
NephCure	Elizabeth Cope	Primary nephrotic syndrome
V-PPRN	Peter Merkel	Vasculitis
PMS-DN	Megan O’Boyle	Phelan-McDermid syndrome
DCN	Ann Lucas	Duchenne and Becker muscular dystrophy
PARTNERS	Laura Schanberg	Pediatric rheumatology
PI-CONNECT	Kathleen Sullivan	Primary immunodeficency
CENA	Sharon Terry	Multiple conditions
ICN	Peter Margolis	Inflammatory bowel disease

Focus: CDRNs and Rare Diseases
Phase I: CDRN PFA Requirements for Rare Disease Cohort

- **Identify, characterize, and recruit** a rare disease cohort with defined conditions or symptoms using available electronic data.
- Rare disease was defined by a prevalence of **less than one per 1,500 persons** in the United States.
- Applicants were encouraged to **reach out to and collaborate with the appropriate rare disease organization(s)** to identify and include additional individuals with the condition.
- Expected to work with other funded networks to ensure that methods of cohort construction use **data standards that support interoperability** and construction of similar cohorts elsewhere.
- The cohort must be **contacted and recruited** to participate in the cohort and in a brief baseline **survey**.
  - The survey must assess the patient’s <u>level of interest in participating in research</u> related to the condition being studied, including:
    - Interest in participating in randomized trials should an appropriate one be launched
    - Interest in participating in network development and governance
    - Interest in communicating with other patients about possible uses of the network

Focus CDRNs and Rare Diseases
Phase II: CDRN PFA Requirements for Rare Disease Cohort

- Cohort identification and **preliminary analyses by running standardized queries against analysis-ready, standardized data.**
- Continue development of the rare disease specific cohort initiated in Phase I, including:
  - Description of **planned expert working groups** during Phase II,
  - Projected **status of the cohort by the end of Phase II** (e.g., number of individuals expected to be accrued)
  - **Data** elements available
  - Ability to **contact individuals** for participation in research
  - Expectations and commitment for **research funding**

Themes of CDRN Rare Disease Cohorts

- **Establishing Advisory Groups**
  - Includes patients, caregivers, clinicians, and researchers
- **IRB**
  - Slow to start: Various differences in local institutional practices
- **Identification**
  - Using computable phenotypes is not always accurate; results in false positives
- **Recruitment and Consent**
  - Populations can be accustomed to f2f recruitment and respond favorable to this methodology
  - Time intensive work toward novel, streamlined approach whereby patients could opt-out at the time of the recruitment
- **Data Collection: EMR and Survey**

Next Steps

Creating Template Table for Cohorts

I. Computable Phenotype

II. Pan-Disease Elements

  a) Completeness

  b) Demographics

  c) Coverage

III. Survey Elements

  a) Approach for ID

  b) Patients contacted

  c) Patients surveyed

  d) Response rate

  e) Participation

IV. Condition-Specific Elements

Questions/Comments/Feedback

What other information would be useful?

PCORI's Asthma Portfolio and Asthma Evidence to Action Network

Ayodola Anise, MHS

Program Officer, Addressing Disparities

pcori®

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Overview

- Describe newly funded pragmatic comparative effectiveness trial on asthma within AD Program
- Provide summary of existing asthma portfolio and how new project is complementary
- Update on Asthma Evidence to Action Network and next steps

Newly Funded Pragmatic Trial within AD Program

Patient Empowered Strategy to Reduce Asthma Morbidity in Highly Impacted Populations (PI: Elliot Israel; Brigham and Women's Hospital)

- **Budget:** $13,857,838
- **Research Question:** Does symptom-based use of inhaled corticosteroids (ICS) reduce asthma exacerbations compared to daily use of ICS?
- **Population:** African American and Hispanic/Latino patients between the ages of 18-75 years with asthma who use ICS or had an exacerbation in the past year
- **Intervention:** Patient-Activated Reliever-Triggered ICS (PARTICS) approach plus provider-educated standard of care
  - Use of ICS + short-acting beta-agonist (SABA) reliever only when asthma symptoms are present
- **Comparator:** Daily use of ICS + long-acting beta-agonist (LABA) plus provider-educated standard of care (regardless of presence of asthma symptoms)
- **Sample Size:** 1200 African American and Hispanic/Latino patients
- **Primary Outcome:** Asthma exacerbations

Newly Funded Pragmatic Trial within AD Program (cont.)

- **Potential Impact**
  - Previous efficacy studies have suggested that the PARTICS approach is better at reducing exacerbations compared to using asthma medications every day; however, there have not been any comparative effectiveness studies in a real-world setting
  - The National Asthma Education Prevention Program guideline committee has been hesitant to adopt the PARTICS approach as a formal recommendation because of the lack of effectiveness evidence
  - Therefore, the proposed pragmatic study is patient-centered, leverages the methods by which patients prefer to take their medications, and would be easy for patients and providers to implement. Study results have the strong potential to influence practice guidelines
    - “A study such as [this], performed in a large diverse population, with important outcomes…would strongly enhance the incorporation of such an approach into the NAEPP guideline recommendations.” (Dr. William Busse, past chairperson of the NAEPP Guideline Committee)

New Study Complements PCORI's Existing Asthma Portfolio

- **Eleven funded projects on Asthma in the PCORI Broad and Targeted portfolio**
  - Eight projects within AD Program focused on improving asthma outcomes for African American and Hispanics/Latino populations ($23.2M)
  - Three funded projects on Asthma in Broad portfolios of other PCORI research programs ($5.9M)

- **The proposed study complements the portfolio by:**
  - Adding a pragmatic study focusing on medication use in a head-to-head trial for African American and Hispanics/Latino adults with asthma
  - Leveraging actual patient patterns of medication use that could directly influence NAEPP guidelines

Asthma Evidence to Action Network

- **Goals:**
  - **Engage asthma awardees**, including researchers, patients and stakeholder partners, and **facilitate cross-learning** between funded projects across PCORI.
  - **Link asthma awardees with end users** to enhance relevance of evidence and increase the likelihood of uptake of findings.
- **Participants include asthma awardee from across PCORI departments and program areas**
  - 12 patient-centered CER studies
  - 2 Pipeline to Proposal Awards
  - 1 Clinical Data Research Network in PCORnet includes asthma cohort
  - 1 Engagement Award

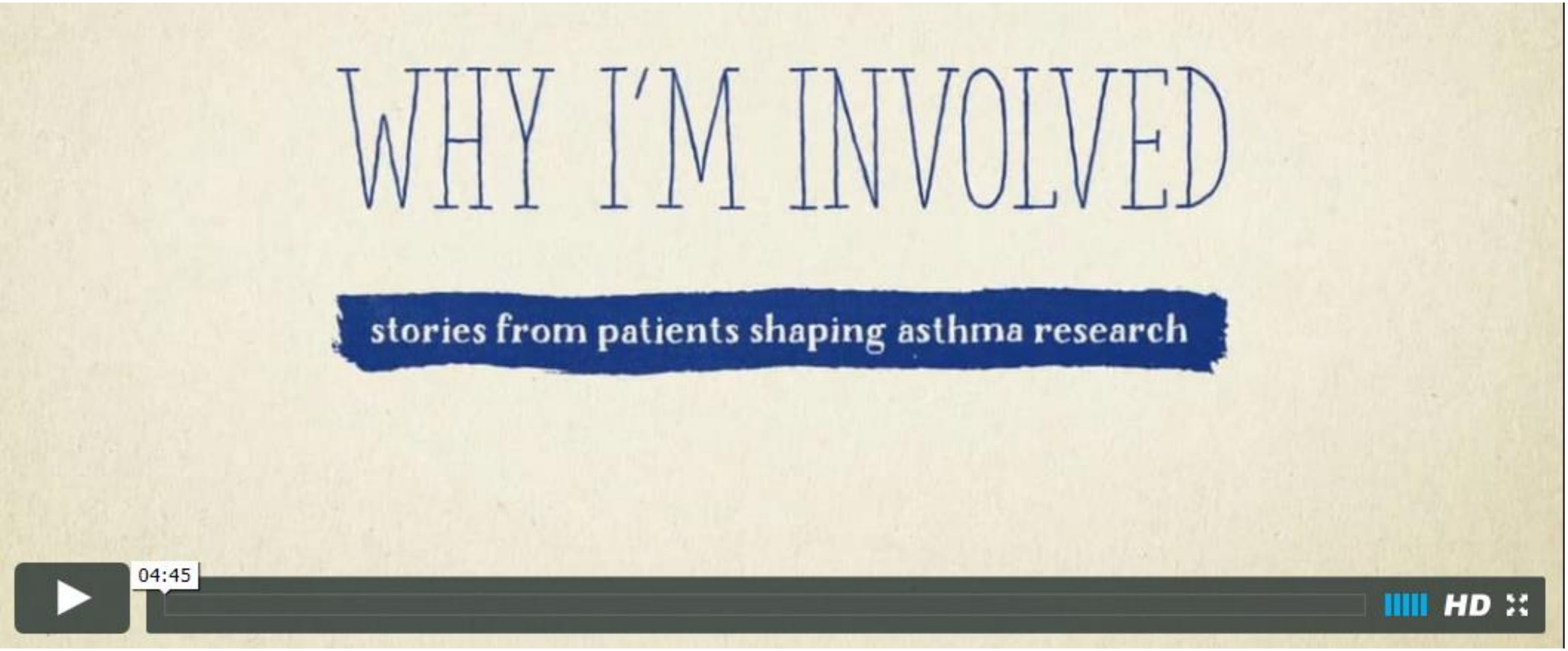
Asthma Evidence to Action Network: Accomplishments in 2015 & 2016

- Leveraged engagement of awardees by establishing four affinity groups in areas of interest to awardees or by stakeholder group (e.g., sustainability, measure alignment, disparities, patient partners)
- Developed a video that tells the story of what it’s like for patients to partner with researchers on PCORI asthma projects
- Contacted end users of asthma research representing professional societies, payers, health care/health systems, purchasers, and advocacy organizations
  - Input from end users: Syntheses of multiple studies are more valuable to end users than results from a single intervention study

Asthma Evidence to Action Network: Next Steps for 2016

- Continue engaging awardees through affinity groups
- Convene annual in-person meeting
  - March 22-23, Houston, TX
- Leverage existing relationships with Federal agencies and other stakeholders
  - National Institutes of Health
  - Centers for Disease Control and Prevention
  - Environmental Protection Agency

Viewing of Patient Partner Video*



**Video not available to Webinar participants. Video will be posted to event site with meeting summary and additional materials.*

Break

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Dissemination and Implementation of PCORI Research Findings

Joanna E. Siegel, ScD
Program Director, Dissemination and Implementation

Jean R. Slutsky, PA, MSPH
Chief Engagement and Dissemination Officer
Program Director, Communication and Dissemination Research

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Dissemination and Implementation are Complicated!

Important Considerations for Disseminating Research Findings

The primary questions and challenges to be addressed when assessing evidence include:

- ***Is the evidence ready for use and adoption now?***
  - Evidence Context

- ***What stakeholder priorities, needs, and concerns does the evidence address?***

Dissemination Activities Start Well Before Findings Are Ready

Effective dissemination and implementation start at the point of research topic selection, as emphasized by stakeholders—long before research is conducted and evidence is ready to be shared. To understand the ***needs of audiences*** who will use evidence to make health and healthcare decisions, research must address ***questions that are relevant*** to those audiences. To that end, those individuals and organizations who may partner with PCORI to disseminate and implement evidence should be engaged as ***partners from the beginning.***

PCORI's Obligation Under its Authorizing Legislation

Conduct Peer Review of Primary Research

- Assess scientific integrity
- Assess adherence to PCORI's Methodology Standards

PCORI’s Obligation Under its Authorizing Legislation *(cont.)*

Release of Research Findings

- No later than 90 days after “conduct or receipt”
- Make available to clinicians, patients, and general public
- **Make comprehensible and useful to patients and providers for healthcare decisions**
- Include considerations specific to certain sub-populations, risk factors, and comorbidities
- Describe process and methods, including conflicts of interest
- Include limitations and further research needed

Implications for PCORI Dissemination Activities

Peer Review

- Starts upon receipt of draft final report – up to 13 mos following study completion
- Awardee revises based on peer-review comments
- PCORI accepts final report

PCORI releases research results within 90 days of final report acceptance.

Implications for PCORI Dissemination Activities

Initial Release of Findings (Website Posting)

- Lay-language Abstract
- Clinician Abstract

"PCORI will post the following materials on its website no later than 90 days after the draft final research report is accepted: a 500-word abstract for medical professionals, a standardized summary of the study's results for patients and the general public, and a link to the study record on ClinicalTrials.gov (as applicable)."

Implications for PCORI Dissemination Activities

Additional Dissemination Activities:

- PCORI webinars, CME/CE
- Journal articles
- Engagement Awards for Dissemination
- Opportunities for “intermediaries” such as patient or physician organizations to disseminate and implement findings
- CDR Limited Competition Awards
- Dissemination projects in collaboration with AHRQ

Limited Competition Dissemination Funding for Current Awardees

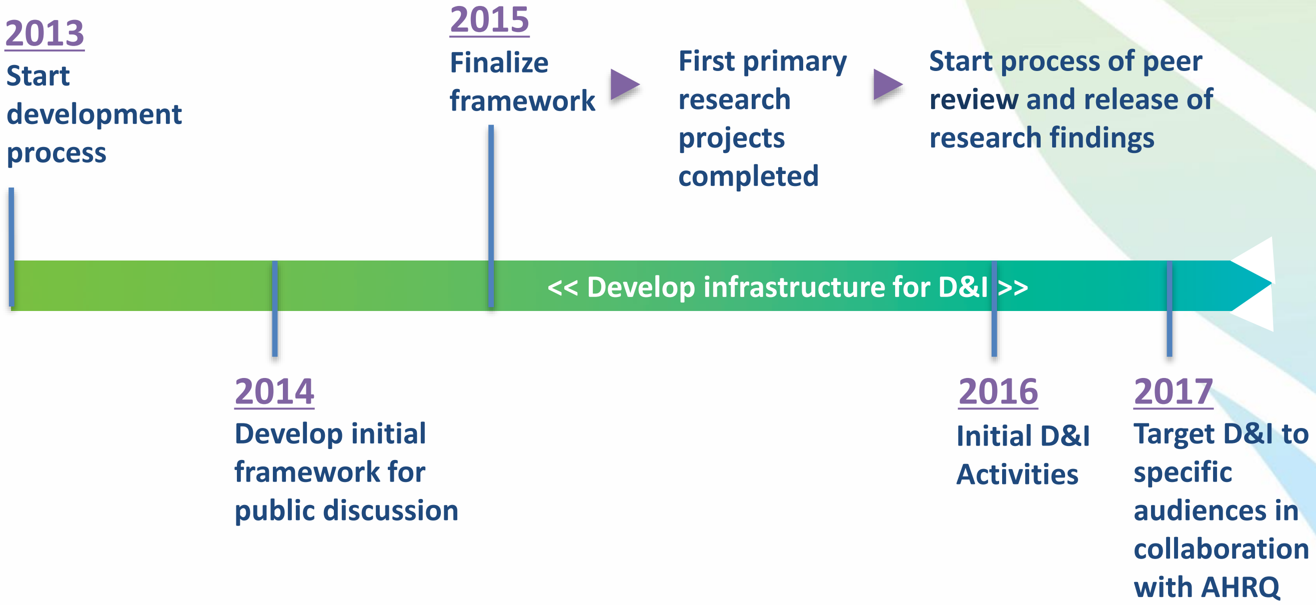
- Offers additional funding for current grantees to disseminate their research findings
- Strategies proposed for D&I of PCORI results will vary widely based on:
  - the results and/or products being disseminated
  - the populations being targeted
  - and the goals of the dissemination and implementation effort

- Designed to give PCORI awardee teams an opportunity to propose investigator initiated D&I strategies
- We seek to fund projects:
  - designed to actively disseminate and implement research results and products
  - using approaches that are informed and guided by established dissemination and implementation models and frameworks
  - in the context of real world settings
- Town Hall February 11

Continuing Need for Stakeholder Involvement for Effective Dissemination

- Clarify why findings matter to patients, clinicians, others.
- Connect with patient and clinician audiences
- Anticipate barriers to use in decision making
- Recognize opportunities for effective dissemination and implementation

Dissemination and Implementation Timeline



2013
Start development process

2014
Develop initial framework for public discussion

2015
Finalize framework ▶ First primary research projects completed ▶ Start process of peer review and release of research findings

<< Develop infrastructure for D&I >>

2016
Initial D&I Activities

2017
Target D&I to specific audiences in collaboration with AHRQ

HIV Topic Brief Discussion

Parag Aggarwal, PhD

Senior Program Officer, Addressing Disparities

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Background

- At our July 2015 meeting, we reviewed two proposals from the CDC relating to HIV:
  - *Early HIV Treatment to Optimize Patient Health and HIV Prevention: A Comparative Effectiveness Study of Immediate Antiretroviral Therapy for Persons with Acute or Early HIV Infection*
  - *Comparative Effectiveness Trial of Innovative Models for Delivering HIV Prevention and Care Services to People Living with HIV (PLWH)*
- With the panel's input, and approval from PCORI's Scientific Oversight Committee, the AD program commissioned a focused topic brief on the following:
  - ***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***

Objectives

- Today, we will be reviewing the topic brief, with the following goals:
  - Recommend whether the topic is well suited for PCORI to fund
    - Consider the prioritization criteria, and where the topic might be weak
  - Consider what specific populations/subpopulations would be important to study
  - Recommend what interventions should be compared or tested
  - Identify potential CER questions
  - List key stakeholder groups we should involve in the topic development process moving forward

PCORI Prioritization Criteria

1. **Patient-Centeredness**: Is the comparison relevant to patients, their caregivers, clinicians or other key stakeholders and are the outcomes relevant to patients?
2. **Impact of the Condition on the Health of Individuals and Populations**: Is the condition or disease associated with a significant burden in the US population, in terms of disease prevalence, costs to society, loss of productivity or individual suffering?
3. **Assessment of Current Options**: Does the topic reflect an important evidence gap related to current options that is not being address by ongoing research?
4. **Likelihood of Implementation in Practice**: Would new information generated by research be likely to have an impact in practice? (e.g., do one or more major stakeholder groups endorse the question?)
5. **Durability of information**: Would new information on this topic remain current for several years, or would it be rendered obsolete quickly by new technologies or subsequent studies?

Discussion

- Primary Discussant:
  - **Kenneth Mayer**
- Secondary Discussant:
  - **Russell Rothman**

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Next Steps

- We will continue to investigate internally and report back any progress to the panel at our next meeting

Wrap Up and Next Steps

- We plan to host our next in-person meeting this summer
  - A poll will be distributed following this meeting for dates
- New Advisory Panel applications are now being accepted
  - The deadline to apply is **March 21st**

Adjourn

Thank you for your participation!

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