Advisory Panel on Addressing Disparities: *In-Person Meeting*

June 8th, 2016

9:00 AM – 4:15 PM

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome and Setting the Stage

Romana Hasnain-Wynia, PhD, MS

Program Director, Addressing Disparities

Doriane Miller, MD

Chair, Advisory Panel on Addressing Disparities

Grant Jones

Co-Chair, Advisory Panel on Addressing Disparities

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	Lead	Time
Addressing Disparities Program Updates	Romana Hasnain-Wynia Parag Aggarwal	9:15-10:00
Addressing Disparities Advisory Panel: Where We Have Been and Where We Are Going	Romana Hasnain-Wynia	10:00-10:30
Panelist Presentation and Discussion: Mitigating the Impact of Language Barriers on Health and Health Outcomes: What We Know and Where We Need to Go	Elizabeth Jacobs	10:30-11:00
Awardee Presentation and Discussion: Clinician Language Concordance and Interpreter Use: Impact of a Systems Intervention on Communication and Clinical Outcomes	Leah Karliner	11:00-12:00
Lunch	*All*	12:00-1:00
PCORI Eugene Washington Engagement Awards	Lia Hotchkiss	1:00-1:30
PCORI Pipeline to Proposal Awards	Courtney Clyatt	1:30-2:00

Agenda (cont.)

Agenda Item	Lead	Time
Break	*All*	2:00-2:15
Discussion of Autism Topic	Elisabeth Houtsmuller	2:15-3:00
Panelist Recognition	Romana Hasnain-Wynia	3:00-4:00
Wrap Up and Next Steps	Doriane Miller Grant Jones Romana Hasnain-Wynia	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
Sr. 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 Staff (cont.)

- Welcome the two new members to the team!

Dionna Attinson
Program Assistant

Alyzza Dill
Program Associate

Addressing Disparities Program Updates

Romana Hasnain-Wynia, PhD, MS

Program Director, Addressing Disparities

Parag Aggarwal, PhD

Senior Program Officer, Addressing Disparities

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Overview

- **Updates On**
  - Current Addressing Disparities Portfolio
  - Current Initiatives:
    - Sickle Cell Disease
    - HIV
  - October 2015 Topics Ranked by Advisory Panel
- **Questions on Program Updates**

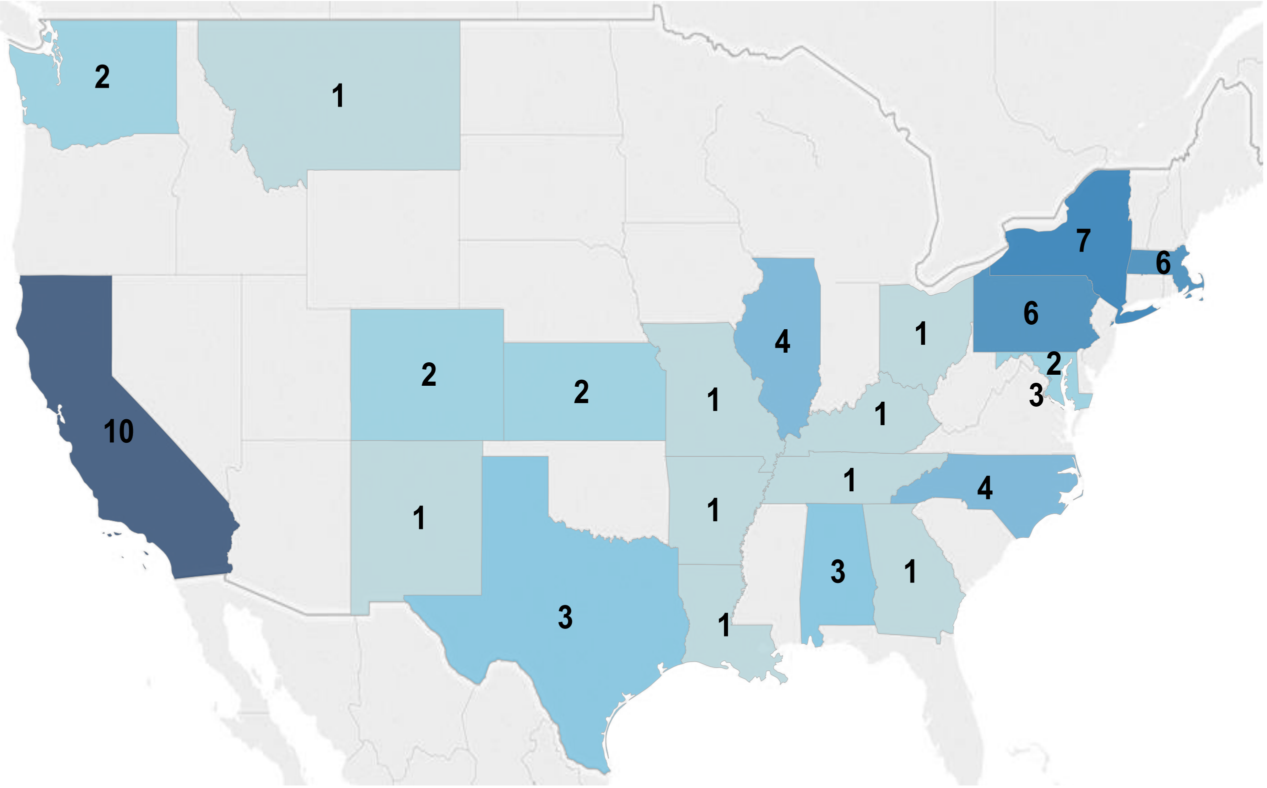
Update: Current Addressing Disparities Portfolio

Snapshot of AD Funded Projects

Number of Projects:
63

Amount Awarded:
$178 million

Number of States Where We are Funding Research:
21 (plus the District of Columbia)



Current AD Portfolio

Broad

- **49** projects

Targeted

- **8** projects under *Treatment Options for Uncontrolled Asthma In African Americans and Hispanics/Latinos* Announcement
- **2** projects under *Obesity Treatment Options Set in Primary Care for Underserved Populations* Announcement
- **2** projects under *Testing Multi-Level Interventions to Improve Blood Pressure Control in Minority Racial/Ethnic, Low Socioeconomic Status, and/or Rural Populations*

Pragmatic

- **2** projects:
  - *Patient Empowered Strategy to Reduce Asthma Morbidity in Highly Impacted Populations (PESRAMHIP)*
  - *Integrated Versus Referral Care for Complex Psychiatric Disorders in Rural FQHCs*

Addressing Disparities Health Conditions

Condition	Number
Mental/Behavioral Health	14
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
Functional Limitation and Disabilities	1
Other	9
Grand Total	**63**

New Projects Awarded through Broad PFA

- *Comparing the Effectiveness of Clinicians and Paraprofessionals to Reduce Disparities in Perinatal Depression*
  - **PI**: Darius Tandon
  - **Organization**: Northwestern University
  - **Budget**: $2.1M
  - **Objective**: To compare the effectiveness of an intervention (Mothers & Babies) that is delivered by paraprofessionals versus mental health clinicians on preventing the onset of major depression and worsening of depressive symptoms among perinatal women

Topic Previously Prioritized by the Panel: Interventions for Improving Perinatal Outcomes

New Projects Awarded through Broad PFA (cont.)

- *Virtual Evidence-based Healthcare for Underserved Patients with Down Syndrome*
  - **PI**: Brian Skotko
  - **Organization**: Massachusetts General Hospital
  - **Budget**: $2.1M
  - **Objective**: To compare the effectiveness of a technology intervention that provides customized clinical advice for Down Syndrome patients versus primary care alone on adherence to national guidelines for Down Syndrome patients and quality of life for patients and caregivers.

Topic Previously Prioritized by the Panel: Improving Quality of Care for Individuals with Disabilities

Update on Newest Approved Targeted Initiative: Sickle Cell Disease

Sickle Cell Disease: Topic Recap and Overview

- General topic was first discussed with the panel at the July 2015 meeting
- The Addressing Disparities program developed a topic brief,, “Management of Sickle Cell Disease,” and presented to the Advisory Panel for feedback on October 21, 2015
    - The panel was very enthusiastic and gave a strong endorsement to move forward with this topic
- The topic has evolved and been refined significantly since it was last discussed with the panel

Overview: Sickle Cell Disease (SCD)

- SCD is a chronic genetic disorder affecting the body's red blood cells and induces a series of disease-related complications, such as acute chest syndrome, pain crises, and stroke
- Between 70,000-100,000 Americans, predominantly African Americans, have SCD (concentrated in the South and East)
  - Early onset disease (5-6 months of age)
  - Average lifespan ranges between 36 and 56 years
  - **The emerging adult population (ages 16-25) is particularly vulnerable to worsened health outcomes during the time of transition from pediatric to adult care**
- By age 45, SCD patients average ~150 hospital visits, and will have accrued almost $1 million in medical expenses

Care Transitions in Emerging Adults

- **For emerging adults with SCD, transition in care is a life-changing** and continuous process
  - Very different from traditional transition models (e.g., from hospital to home)
  - Children with SCD are now living into adulthood, thus the burden of SCD-related morbidity and mortality has shifted to emerging adults
    - High rates of comorbid conditions (e.g., asthma, restrictive lung disease, cardiac dysfunction and renal dysfunction)
    - Cumulative disease effects

Care Transitions in Emerging Adults (cont.)

- **Quality of care decreases from pediatrics to adult care**
  - Challenges with access to specialists (e.g., hematologists)
    - **~60%** on Medicaid; limits access to specialists
  - Adult care clinicians report **dissatisfaction** with the quality of care they can provide
  - Patients report **dissatisfaction** with quality of care they receive

Care Transitions in Emerging Adults (cont.)

- **Emerging adults become disengaged from the healthcare system**
  - Loss of usual source of care
    - Decrease in routine preventative and screening visits (for chronic blood transfusions, hydroxyurea treatments, vaccines)
    - More likely to seek care for acute medical events in emergency department
      - **5.0** emergency department visits per year vs. **3.3** in other SCD age groups

Potential to Leverage NHLBI and PCORnet

- Targeted PFA can be actively distributed within soon-to-be-funded NHLBI SCD research consortia

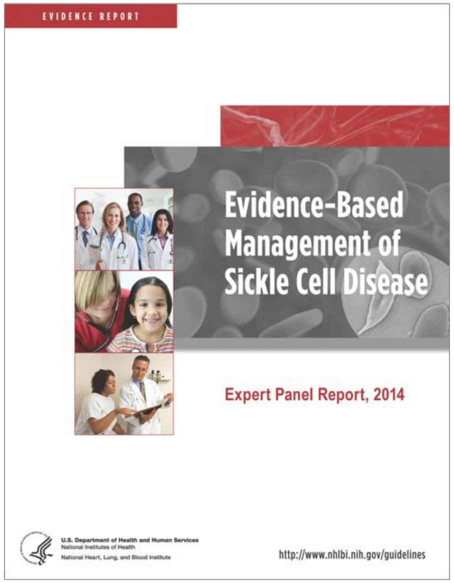
- Applicants may potentially collaborate with, and access data from, PCORnet (CDRNs) across the SCD cohorts
  - Three CDRNs have already collected data on 3000+ SCD patients

Collaboration with NHLBI or PCORnet CDRNs would be encouraged, but not required. All are welcome to apply.

Evidence Gaps: Sickle Cell Disease

- Current guidelines are based on **weak evidence** and/or **consensus-based opinion**

- SCD-related complications are highest among **emerging adults,** but there is a lack of evidence about how to improve the care transition process and outcomes



EVIDENCE REPORT

Evidence-Based Management of Sickle Cell Disease

Expert Panel Report, 2014

U.S. Department of Health and Human Services
National Institutes of Health
National Heart, Lung, and Blood Institute

http://www.nhlbi.nih.gov/guidelines

- Further research is needed to **help to fill gaps** to improve care processes and outcomes for individuals with SCD
  - There are **no current CER trials** for care transitions for individuals with SCD
    - Necessary to improve healthcare and health outcomes for vulnerable population when evidence base is weak

Summary of March 7th Workgroup

- 38 stakeholders submitted **59** questions prior to workgroup meeting

- Staff refined and consolidated the questions into two topic areas: *Care Transitions* and *Pain Management*

- By consensus, each breakout group (care transitions and pain management) identified three potential comparative effectiveness questions, for a total of six potential questions. This PFA focuses on the most important one.

4 patients

7 clinicians

2 hospitals/systems

4 industry

2 payers

1 policymakers

18 researchers

Proposed Research Question & Study Details

- **Research Question:** What is the comparative effectiveness of established transition coordination models for emerging adults with SCD transitioning from pediatric to adult care?

- **Population:** Emerging adults (e.g., 16-25 years of age) with SCD
  - SCD patients typically transition from pediatric to adult care between 16-18 years of age (timing varies based on needs and readiness)
  - Pediatricians may continue to see patients through college
  - By 26 years of age, emerging adults are no longer covered by their parents' insurance
    - Interest in older age (up to 30 years of age) range to assess issues related to insurance transitions for emerging adults

Proposed Research Question & Study Details (cont.)

Interventions and Comparators:

- Interventions must incorporate patients, care givers, and clinicians
- Interventions should be patient-facing, with robust patient engagement
- Direct comparisons of efficacious or commonly used transition coordination interventions
  - Examples could include (but are not limited to):
    - Co-located pediatric and adult care providers;
    - Clinic-based transition coordinator;
    - Virtual consultation (telehealth) with provider or specialist;
    - Use of mHealth (e.g., mobile apps, text messaging)
  - An appropriate comparator may be usual care or standard of care
- Evidence of efficacy in other diseases (e.g., diabetes, cystic fibrosis, congenital heart disease) and transition models may be used

Proposed Research Question & Study Details (cont.)

- **Outcomes:**
  - Health related quality of life (e.g., physical and mental health), depression, patient activation/self-management, patient satisfaction and experiences of care, social functioning (e.g., missed days from work and school)
  - Number of hospitalizations and number of days hospitalized due to complications (e.g., pain crises, strokes, comorbid conditions), measures of emergency department use
- **Study Design:** Cluster RCT with sufficient sample size and/or clusters to power study
- **Setting(s):** Outpatient settings including primary care practices, patient-centered medical homes, specialty SCD clinics
- **Timing:** Maximum 5 year study
- **Research Commitment:** Up to 3 studies, $25M (total costs)

SCD Timeline and Next Steps

- Board of Governors approved this topic for a tPFA on May 23, 2016
- Pre-announcement to stakeholders released on May 24, 2016

- Refine research question and develop tPFA
- tPFA to be released on August 15, 2016
- Applications due on December 19, 2016
- Awards announced in May 2017

Update of Topic in Pipeline: HIV

HIV Update

- **Progress to Date:**
  - At July 2015 meeting, the panel reviewed 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 panel's input and approval from PCORI's Science Oversight Committee, 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*
    - Discussed at the February 2016 meeting

HIV Update (cont.)

- **Next Steps:**
  - Collecting potential CER questions in this area from the panel
  - Collaborating with multiple agencies and looking for areas of synergy

Update: October 2015 Topics Ranked by Advisory Panel

Updates on October 2015 Ranked Topics

- Ten (**10**) topics were submitted by the panel for discussion during the October 2015 webinar and ranked in early 2016
- Top four topics ranked by Advisory Panel:
  1. *Compare the effectiveness of approaches (e.g., telephone management post discharge, clinic visits, telephone management, supportive services) to prevent hospital readmission for patients at high risk for readmission including racial/ethnic minorities, patients with limited English proficiency, patients with low health literacy, underinsured, and others?*
  2. *What is the comparative effectiveness of different patient-centered approaches to care coordination for patients at high risk of hospitalization/ED usage including racial/ethnic minorities, patients with limited English proficiency, patients with low health literacy, underinsured, and others?*
  3. *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.*
  4. *Comparative effectiveness of eye drops vs. laser trabeculoplasty to reduce excess morbidity from glaucoma in black and Hispanic individuals.*

Topic 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 proficiency, patients with low health literacy, underinsured, and others?*
- **Considerations:**
  - Topic not specific enough

Topic 2

- *What is the comparative effectiveness of different patient-centered approaches to care coordination for patients at high risk of hospitalization/ED usage including racial/ethnic minorities, patients with limited English proficiency, patients with low health literacy, underinsured, and others?*
- **Considerations:**
  - Current investment in this area:
    - **tPFA on Sickle Cell Disease**: *What is the comparative effectiveness of established transition coordination models for emerging adults with SCD transitioning from pediatric to adult care?*
      - Key Outcomes: Hospitalizations and ED Use

Topic 3

- *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.*
- **Considerations:**
  - Current investment in this area:
    - **Skotko**: *Virtual Evidence-based Healthcare for Underserved Patients with Down Syndrome (2016)*
      - Compares the effectiveness of a technology intervention that provides customized clinical advice for Down Syndrome patients versus primary care alone
      - Increasing the quality of care for children with down syndrome
      - Integrating guideline-based care into PCP to increase access
  - Discussion of autism topic

Topic 4

- *Comparative effectiveness of eye drops vs. laser trabeculoplasty to reduce excess morbidity from glaucoma in black and Hispanic individuals.*
- **Considerations:**
  - Will commission topic brief by the end of the year

Questions?

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

Romana Hasnain-Wynia, PhD

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Purpose of the Panel

- Per the Charter:
  - “The Advisory Panel on Addressing Disparities (“AD Panel”) will advise and provide recommendations to PCORI’s Board of Governors, Methodology Committee, and staff to help **plan**, **develop**, **implement**, **improve**, and **refine** efforts toward meaningful patient-centered research. The AD Panel will not serve in an official decision-making capacity, but its recommendations and advice will be taken into consideration by the Institute’s Board of Governors, Methodology Committee, and staff.”

Goals of the Panel

- The goals of the Advisory Panel on Addressing Disparities are to:

1. **Identify** and **prioritize** critical research questions for possible funding initiatives under PCORI's "health disparities" research program, as well as help to **refine** topics in the pipeline; and

2. Provide ongoing feedback and advice on **evaluating** and **disseminating** the research conducted under this program.

Addressing Disparities Advisory Panel Activities

Goal 1: Identify and prioritize critical research questions for possible funding initiatives under PCORI's "health disparities" research program, as well as help to refine topics in the pipeline

- Examples of your work in this area:
  - Provided key topics and CER questions for consideration
  - Discussed a total of **33** topics
    - Of the 33 topics, more than half (**18**) resulted in:
      - Targeted PFAs, priority topics in the Pragmatic Clinical Studies PFA, areas of interest in the Broad PFA
  - Refined priority topics and CER questions
    - HIV
    - Sickle cell disease
    - Immunotherapy for Asthma

Addressing Disparities Advisory Panel Activities (cont.)

Goal 2: Provide ongoing feedback and advice on evaluating and disseminating the research conducted under this program

- Areas where you provided significant feedback:
  - The Addressing Disparities Framework and Driver Model
  - Areas for clarity and synergies around funded projects
  - Clusters of projects on CHWs, obesity, chronic pain, diabetes prevention
  - The Asthma Evidence to Action Network (E2AN)
  - Highlighting populations that require additional investment
  - Identifying geographic locations for PCORI funding

Where PCORI Is Going

- As PCORI has evolved, we are now moving towards:
  - Focusing more on funding research that complements or fills gaps in our current portfolio and less on prioritization
  - Identifying evidence gaps and CER questions from evidence syntheses, systematic reviews, and practice guidelines
  - Evaluating the impact of the portfolio and of clusters of funded research with results
  - Continuing to build upon collaborations with external organizations (e.g., NIH, CDC, AHRQ)
  - Increasing investment for head-to-head CER studies, and how best to integrate disparities populations

Role of the Panel Moving Ahead

- Addressing Disparities staff will **continue** working with the panel to:
  - Evaluate and provide feedback on key findings from studies with results (e.g., potential impact of CHW portfolio, how asthma results inform and improve adherence to national guidelines)
  - Assist in the identification of key research questions to complement and fill gaps in the portfolio
    - Provide feedback on specific research questions and study designs (e.g., comparators, decisional dilemmas)
    - Focus on head-to-head CER trials
  - Assess the overall impact of the portfolio
  - Identify considerations for dissemination and implementation

Questions?

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

What we Know and Where we Need to Go

Elizabeth A. Jacobs, MD MPP
Professor, Departments of Medicine , Population Health Sciences, and Emergency Medicine
Associate Vice Chair, Department of Medicine
UW School of Medicine and Public Health

PCORI Advisory Panel
June 8, 2016

http://www.youtube.com/watch?v=twINuqacDdY&list=UU-M45Po-rDEq-ZcDlNOY0_g&index=2&feature=plcp

Language Barriers to Access to Health Care

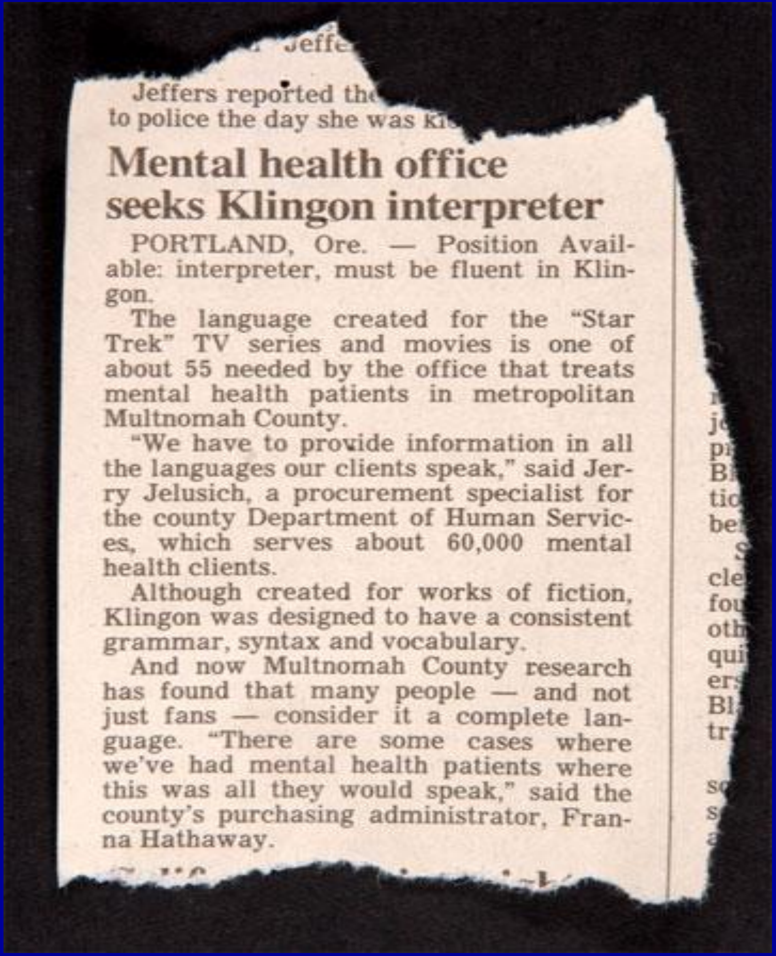
- 25 million US residents speak English less than “very well”

- Many health care organizations do not provide adequate linguistic access services

- This puts limited English proficient patients and their providers at risk

Illustration by Matt Sweitzer

Title VI of The Civil Rights Act



Jeffers reported th
to police the day she was ki

Mental health office seeks Klingon interpreter

PORTLAND, Ore. — Position Available: interpreter, must be fluent in Klingon.

The language created for the "Star Trek" TV series and movies is one of about 55 needed by the office that treats mental health patients in metropolitan Multnomah County.

"We have to provide information in all the languages our clients speak," said Jerry Jelusich, a procurement specialist for the county Department of Human Services, which serves about 60,000 mental health clients.

Although created for works of fiction, Klingon was designed to have a consistent grammar, syntax and vocabulary.

And now Multnomah County research has found that many people — and not just fans — consider it a complete language. "There are some cases where we've had mental health patients where this was all they would speak," said the county's purchasing administrator, Franna Hathaway.

Snapshots

It's a good thing Chuck raised his voice, because Pedro understood loud English.

“I need an interpreter. Send in someone who speaks jargon.”

What Do We Know?

Where to We Need to Go?

Speaking Your Patient’s Language

- “…you feel more comfortable with a doctor that speaks your same language because in that way they can explain to you better and you can understand them more.”

- “The language is a very basic issue because [if] the doctor speaks a little Spanish and the patient speaks a little English there are times when it can get lost, then the trust gets lost…”

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Changes in research on language barriers in health care since 2003: A cross-sectional review study☆

Rebecca J. Schwei [a,*], Sam Del Pozo [b], Niels Agger-Gupta [c], Wilma Alvarado-Little [d], Ann Bagchi [e], Alice Hm Chen [f], Lisa Diamond [g,h], Francesca Gany [g], Doreena Wong [i], Elizabeth A. Jacobs [a,j]

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[b] *White Memorial Medical Center, Los Angeles, CA, USA*
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[g] *Department of Psychiatry & Behavioral Sciences & Department of Medicine, Memorial Sloan-Kettering Cancer Center, New York, NY, USA*
[h] *Department of Healthcare Policy and Research, Weil Cornell Medical College, New York, NY, USA*
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ARTICLE INFO

Keywords:
Cross sectional review
Language barriers
Limited English proficiency
Policy change

ABSTRACT

Background: Understanding how to mitigate language barriers is becoming increasingly important for health care providers around the world. Language barriers adversely affect patients in their access to health services; comprehension and adherence; quality of care; and patient and provider satisfaction. In 2003, the United States (US) government made a major change in national policy guidance that significantly affected limited English proficient patients' ability to access language services.

Objective: The objectives of this paper are to describe the state of the language barriers literature inside and outside the US since 2003 and to compare the research that was conducted before and after a national policy change occurred in the US. We hypothesize that language barrier research would increase inside and outside the US but that the increase in research would be larger inside the US in response to this national policy change.

Methods: We reviewed the research literature on language barriers in health care and conducted a cross sectional analysis by tabulating frequencies for geographic location, language group, methodology, research focus and specialty and compared the literature before and after 2003.

Results: Our sample included 136 studies prior to 2003 and 426 studies from 2003 to 2010. In the 2003–2010 time period there was a new interest in studying the providers'

Purpose

- To review the state of investigation on the literature before and after a policy change in the US

- We hypothesized that research on language barriers would dramatically increase after this policy change in 2003, particularly in the US

Methods

- Systematic review from 2003-2015

- Evaluated
  - Number
  - Foci
    - Access
    - Comparison
    - Interpreting practice
    - Outcomes
    - Patient satisfaction
  - Provider type studied

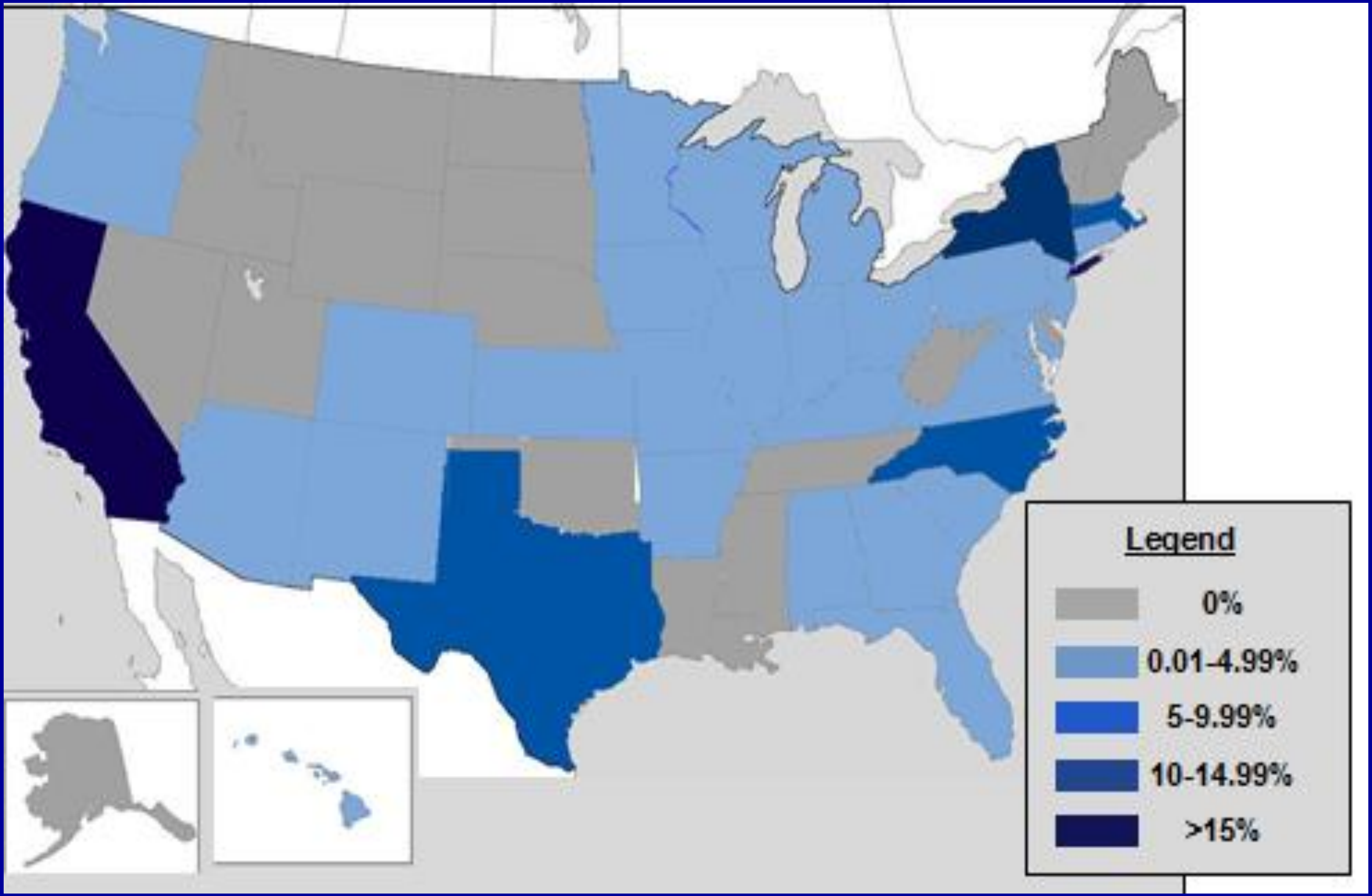
Change in Number of Publications

Geographic Study Location Pre and Post 2003 (%, n)

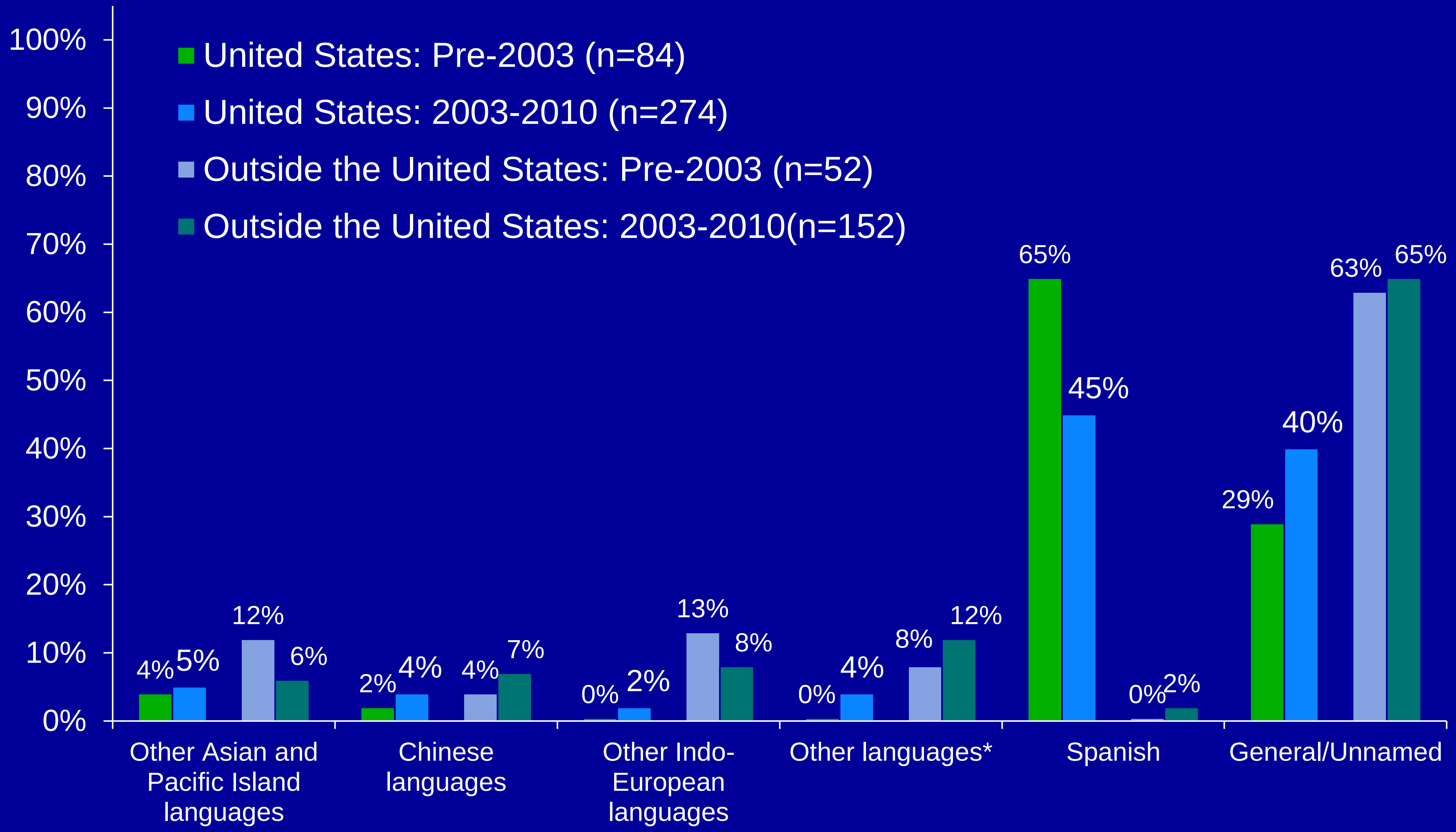
Country	Pre -2003 (n=136)	2003-2010 (n=426)	Change in proportional contribution (%)
Australia	12%, 16	6%, 26	-6%
Canada	3%, 4	8%, 33	5%
Other*	8%, 11	14%, 61	6%
United States	62%, 84	64%, 274	2%
United Kingdom	15%, 21	8%, 32	-7%

*Austria, Belgium, Chile, Egypt, Germany, Greece, India, Ireland, Israel, Italy, Japan, Kuwait, Mexico, New Zealand, Nigeria, Norway, Papa New Guinea, Saudi Arabia, Singapore, South Africa, Spain, Sweden, Switzerland, Thailand and The Netherlands

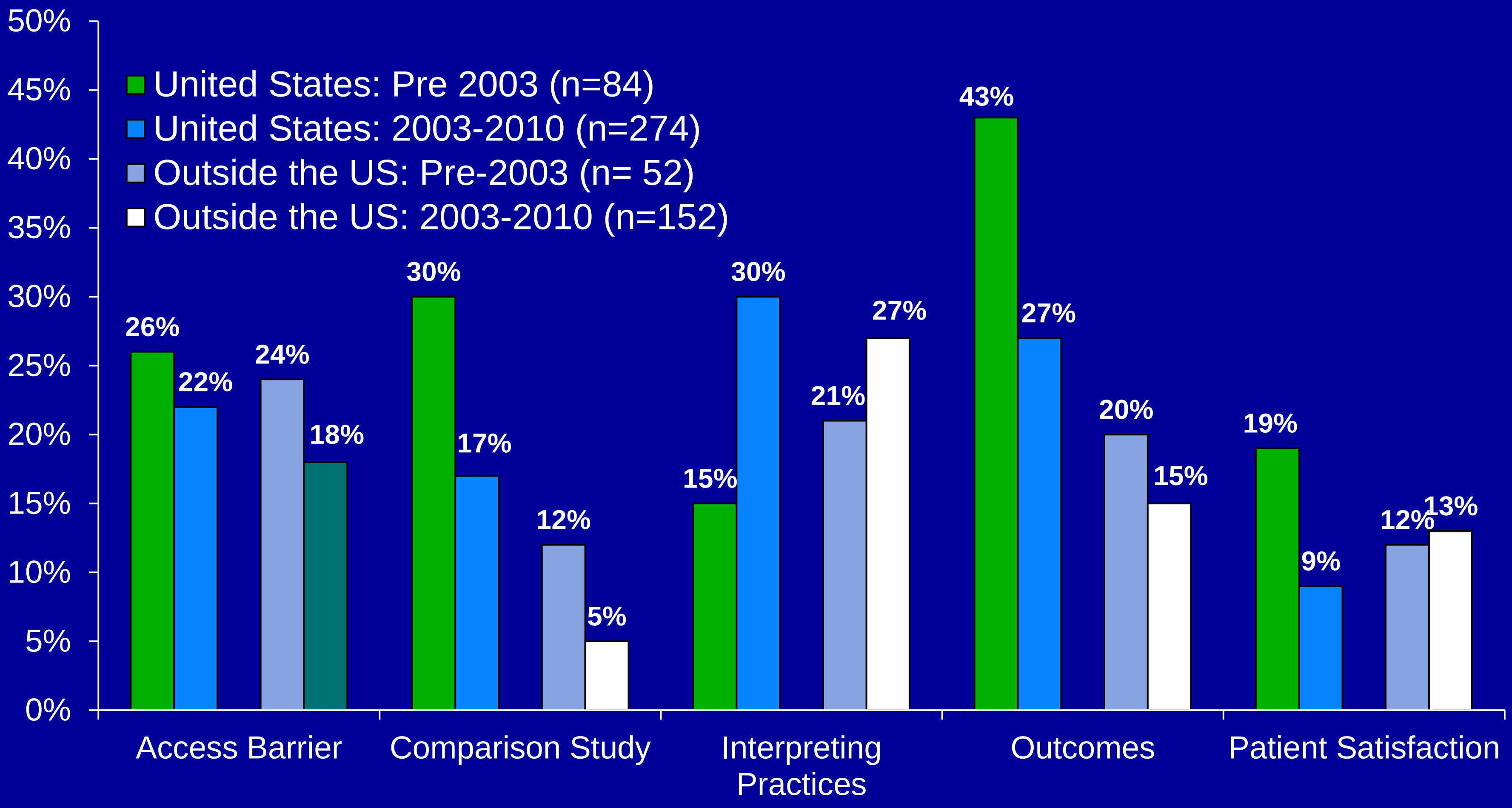
Distribution by State in the US



What Languages are Studied?



Foci of Research Topic



Providers Studied?

	United States (n=33)	Outside United States (n=39)
Care Workers	0%, 0	8%, 3
Interpreters	9%, 3	3%, 1
Nurse Educators	0%, 0	8%, 3
Nurse Practitioner	12%, 4	5%, 2
Nursing Assistants	3%, 1	0%, 0
Occupational Therapists	0%, 0	3%, 2
Pharmacists	3%, 1	23%, 9
Physical Therapists	3%, 1	3%, 1
Physician Assistant	9%, 3	0%, 0
Physicians	39%, 13	18%, 7
Registered Nurses	24%, 8	46%, 18
Social Workers	0%, 0	3%, 1
Students	36%, 12	18%, 7
Other**	6%, 2	23%, 9

*The listed provider types are those that have been studied in the literature and are not meant to be an exhaustive list

**Child welfare workers, clinical practice managers, health professionals generally, health visitors, midwives, radiation therapists, sexual health counselors

Could PCORI Contribute?

A Very Patient-Centered Topic

“I wanted to ask them about my illness. I couldn’t because there was no one to help me [communicate].”

Impact of the Condition on Individuals and Populations

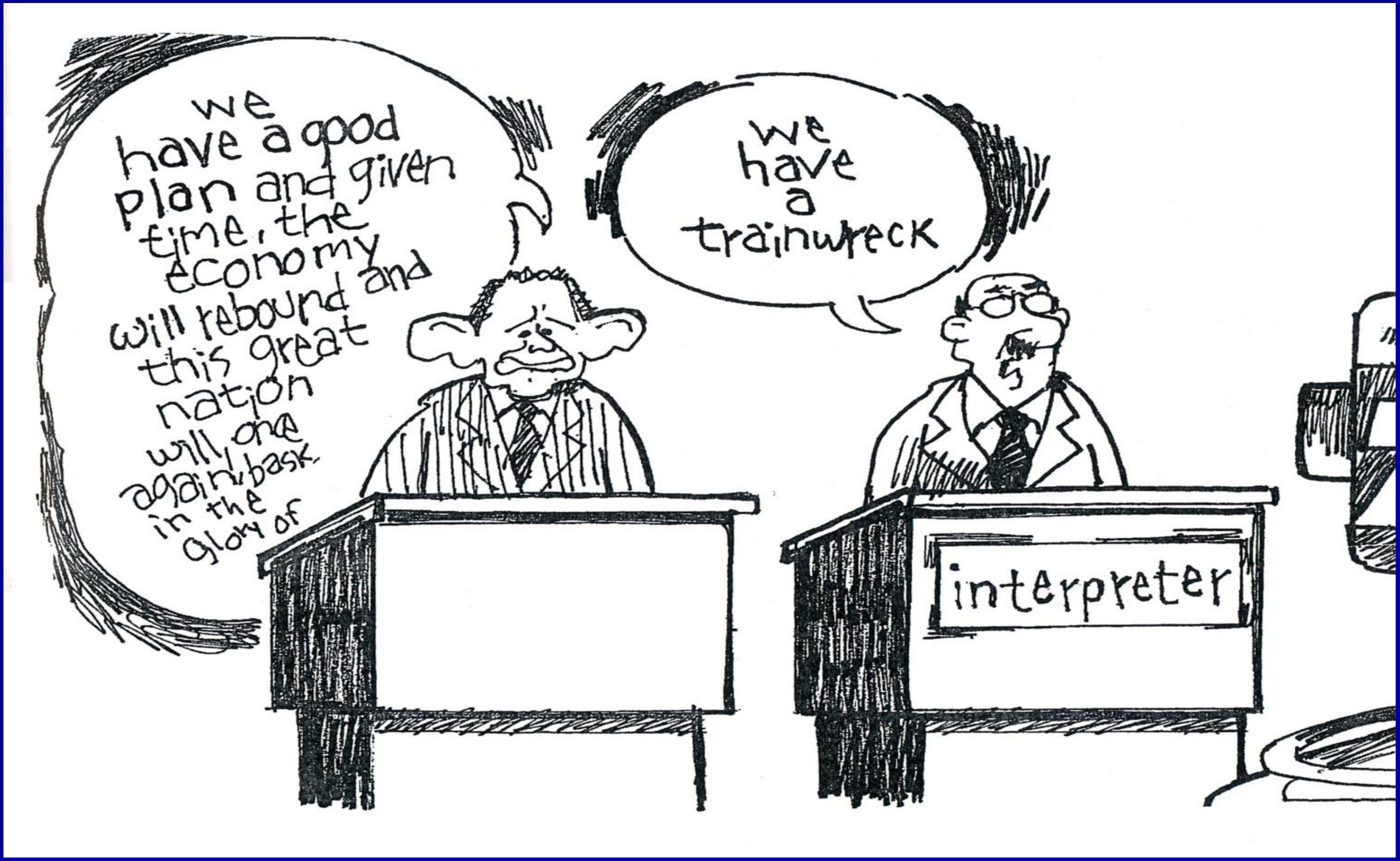
- Language barriers have been linked to numerous disparities in health and health care

- These disparities are linked to increased morbidity, mortality, and loss of productivity

Options for Addressing the Issue

- Bilingual providers
- Professional interpreters
  - Face-to-face
  - Telephonic
  - Video
- Dual-role interpreters
- Ad hoc interpreters

Likelihood of Implementation in Practice



Durability of Information

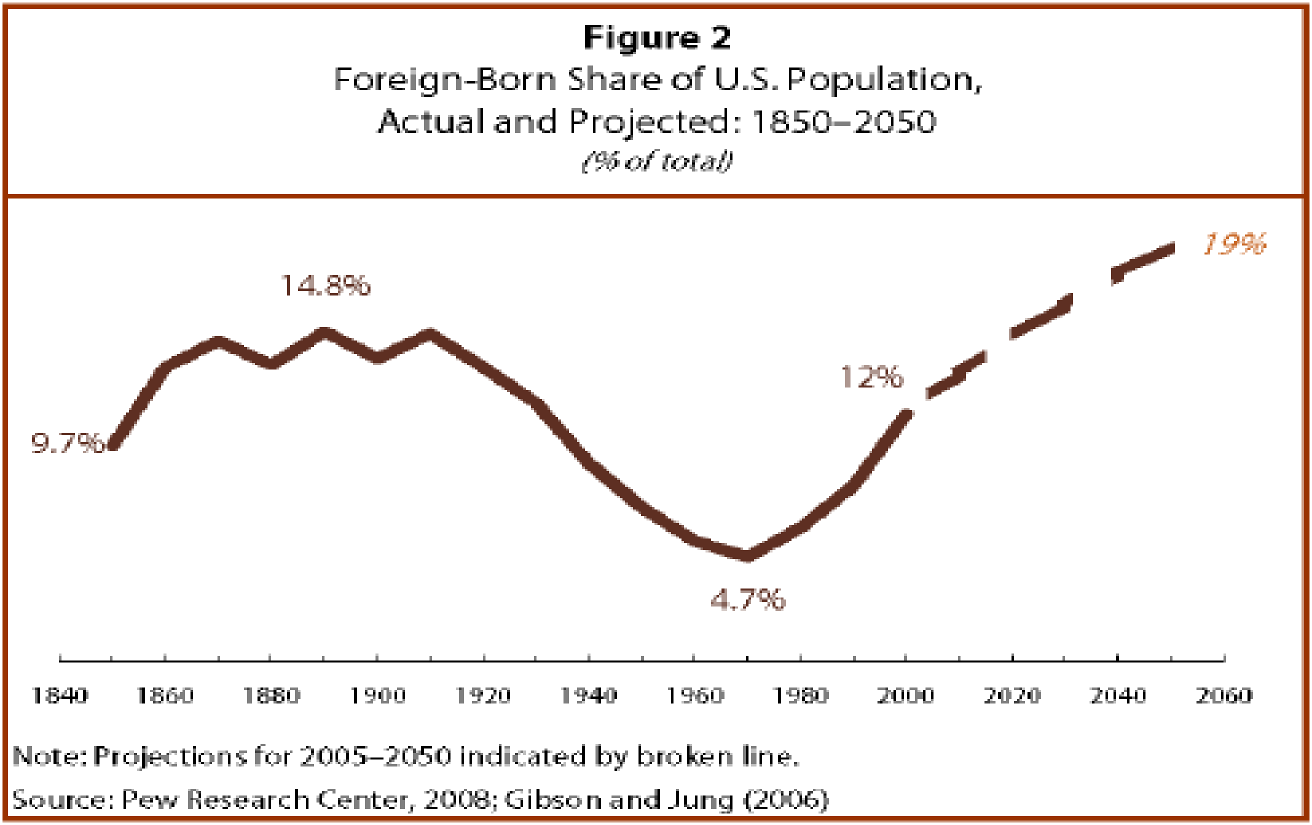


Figure 2

Foreign-Born Share of U.S. Population, Actual and Projected: 1850–2050

(% of total)

Note: Projections for 2005–2050 indicated by broken line.

Source: Pew Research Center, 2008; Gibson and Jung (2006)

http://www.pewhispanic.org/2008/02/11/us-population-projections-2005-2050/


BİYAN
YASHAKKURATU
GRACIAS
THANK
SUKSAMA
ARIGATO
SHUKURIA
YOU
GRAZIE
MEHERBANI
BOLZİN
MERCI


Gracias por su visita
Thanks for calling
Merci de votre visite
McDonald's
Gràcies p
Danke fü
Grazie p

University of California
San Francisco
advancing health worldwide™

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

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Associate Professor of Medicine

Multiethnic Health Equity Research Center

Division of General Internal Medicine

Department of Medicine

June 8, 2016

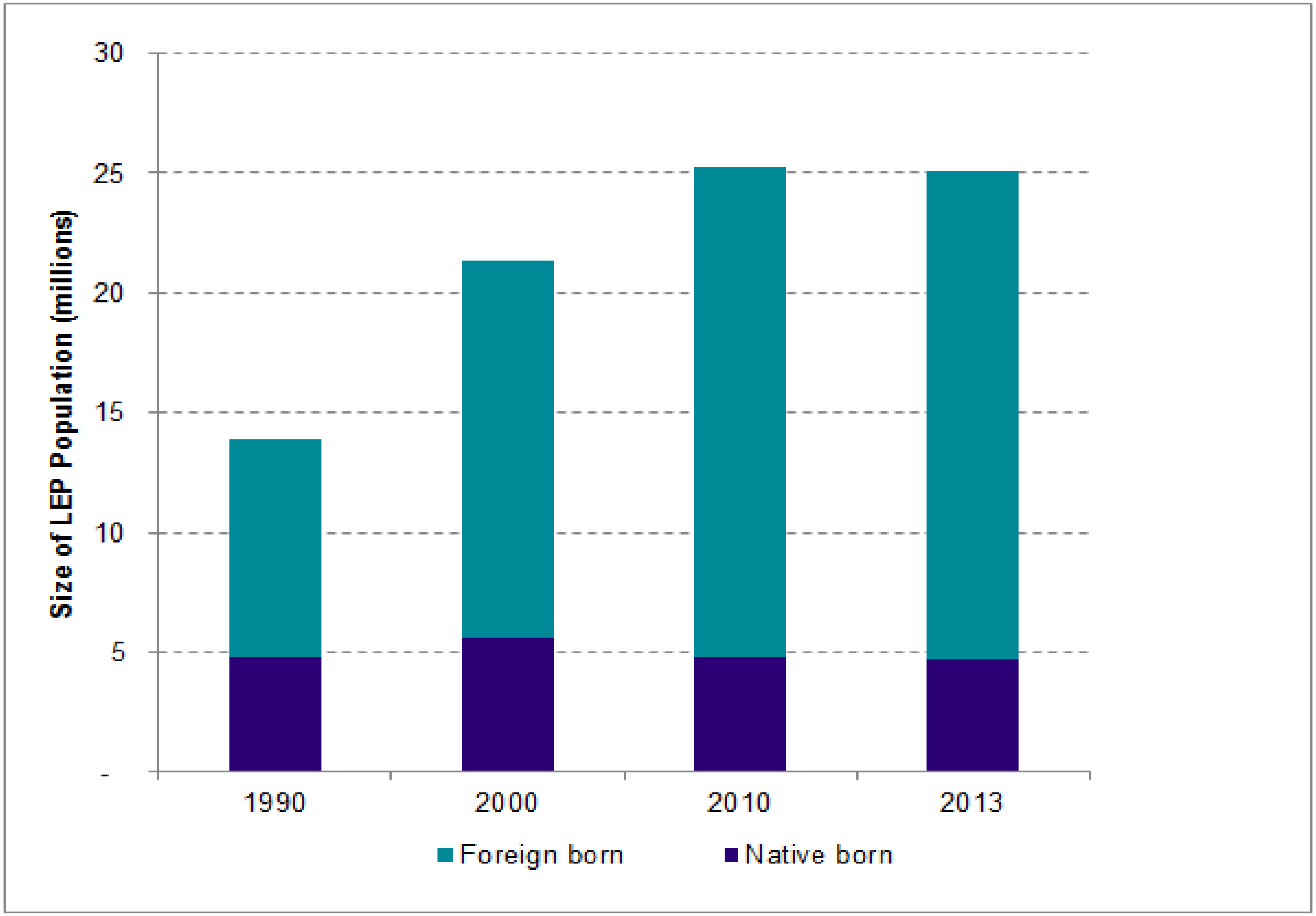
PCORI AD-1409-23627

The Problem

- Poor quality communication between patients with limited English proficiency (LEP) and clinicians:
  - Less adherence to medications
  - Decreased patient satisfaction with care
  - Less patient-centered care
  - More reports of negative clinical experiences
  - Interferes with development of trust
  - Impedes patients’ ability to engage in joint decision-making and self-management

The Challenge

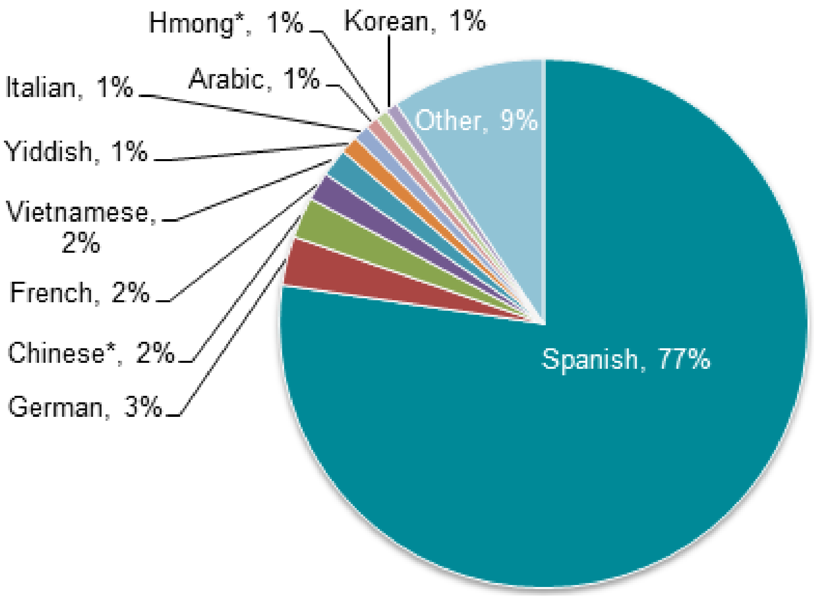
LEP population in US is growing



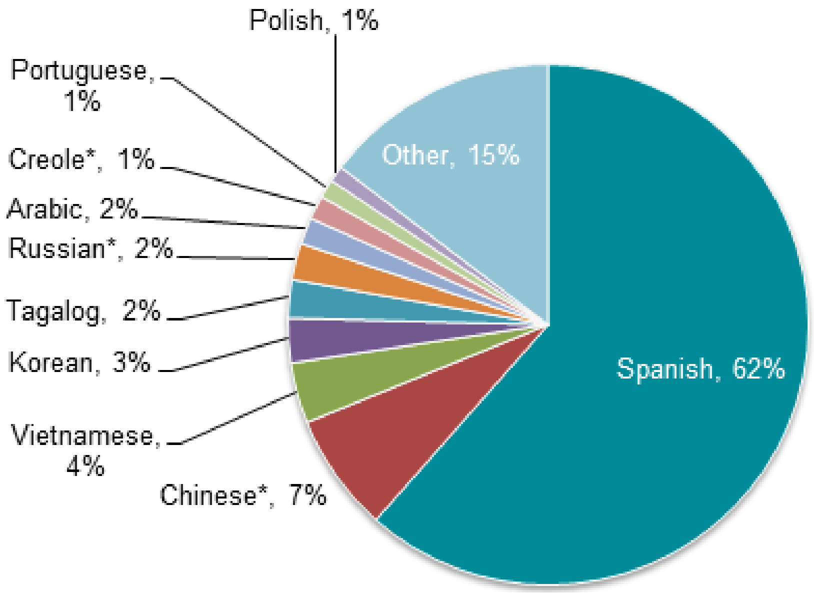
Source: Migration Policy Institute (MPI) tabulations from the U.S. Census Bureau's 1990 and 2000 Decennial Censuses and 2010 and 2013 American Community Surveys (ACS).

Many languages

Native-Born LEP Population



Foreign-Born LEP Population



The Solution

- Language concordance
  - Fully language concordant clinicians are not sufficient in number
  - Some believe their limited language skills are good enough
  - When get in over their heads don’t know how to switch gears

- Professional interpretation
  - Professional interpreters have been shown to improve quality of care and clinical outcomes, but access to them is challenging

Professional Interpreters

- Why is access so challenging?
  - Unfunded mandate from the Federal government (Title VI Civil Rights Act)
  - Quality of audio over telephone can be challenging
  - Wait times for in-person professional interpreters
  - Interpreters need to leave to get to another appointment when a visit starts late or runs over scheduled time
  - Patients often bring family members for the purposes of interpreting; clinicians follow along
  - In busy clinical environments, can feel easier not to use an interpreter

Multiple Modalities: Making Access Easy

- In-person interpretation
  - Gold-standard, but cannot provide enough access
- Telephonic interpretation
  - Convenient, particularly for brief interactions, rarer languages, may not be as good for complex interactions
- Video medical interpretation (VMI/VRI)
  - Convenient, preserves visual cues/human interaction, works for more complex interactions, requires high quality video and audio to work well

Systems Intervention in Acute Hospital

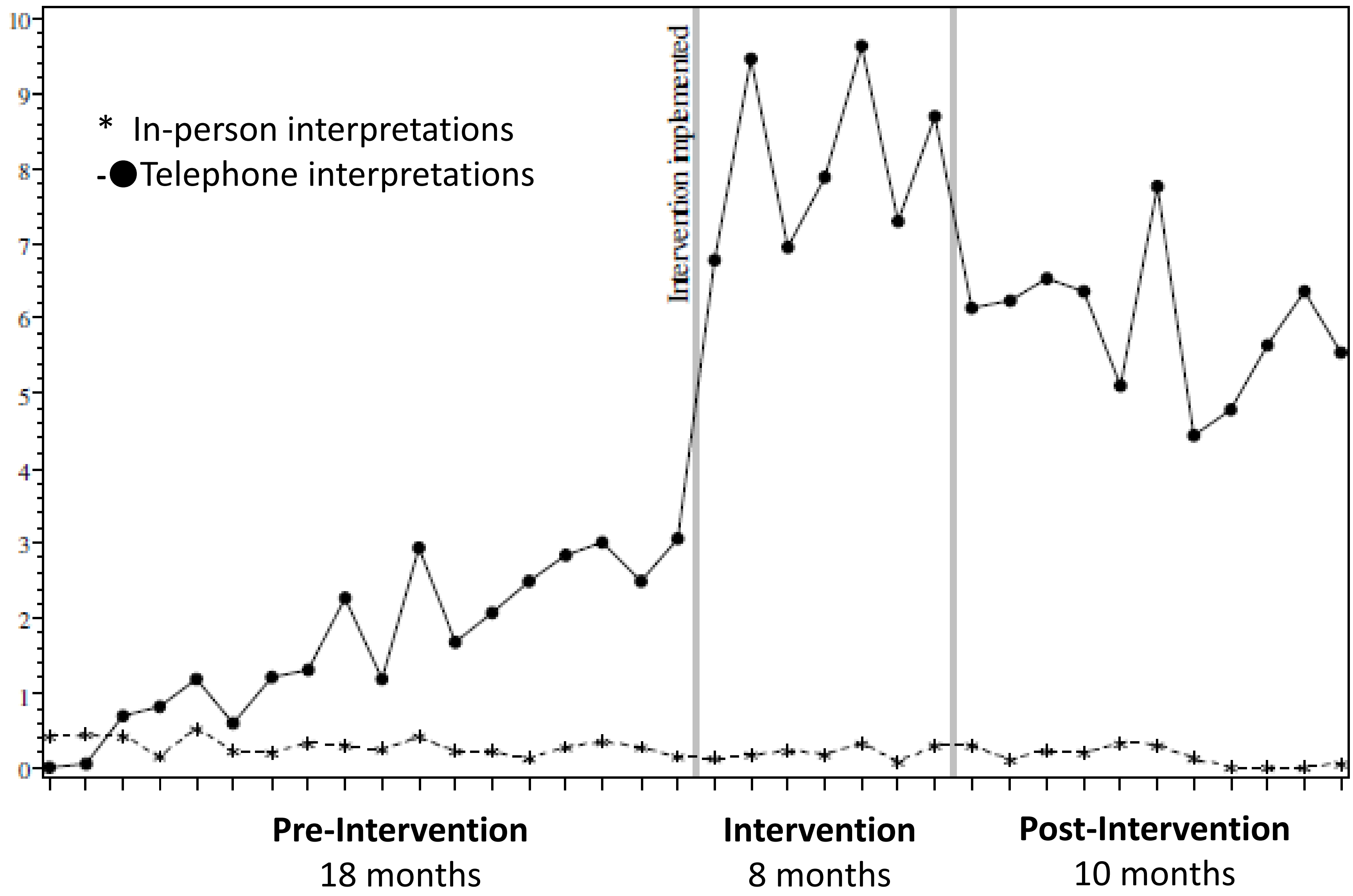
- **Intervention:** Dual-handset interpreter telephone at every bedside (Bedside Interpreter Intervention)

Prior to the intervention: usual care communication

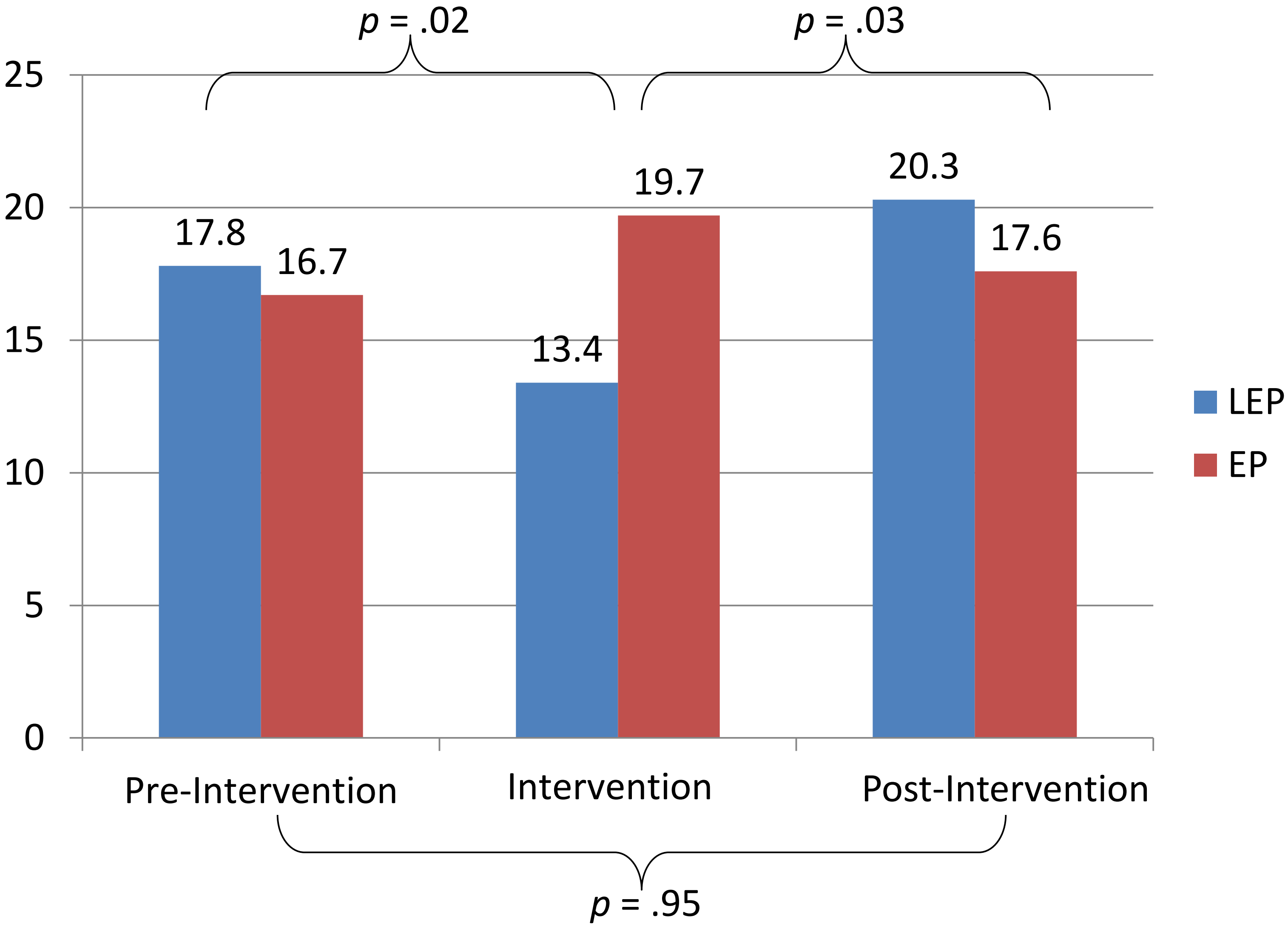
--in-person staff interpreters scheduling during usual business hours

--slowly increasing number of dual-handset interpreter phones

This work was funded by the National Institute on Aging (R01 AG038684)



Average monthly interpreted encounters standardized to number of monthly discharges for limited English proficient (LEP) patients



Observed 30-day readmission rates (%) for LEP and EP groups

Multivariate Results

Odds of readmission for LEP group compared to EP group during three time periods	
Pre-Intervention	1.07; 95% CI 0.85-1.35
Intervention	**0.64; 95% CI 0.43-0.95**
Post-Intervention	1.09; 95% CI 0.80-1.48

Adjusted for: age, sex, insurance, discharge calendar month, principal diagnosis category, severity of Illness score, ICU stay

Convenient Access Improved Consent Experience

- Interviews with Chinese and Spanish-speaking patients before and after subsequent intervention roll-out on three surgical and cardiovascular floors

2.25 increased odds of reporting an adequate consent experience after roll-out*

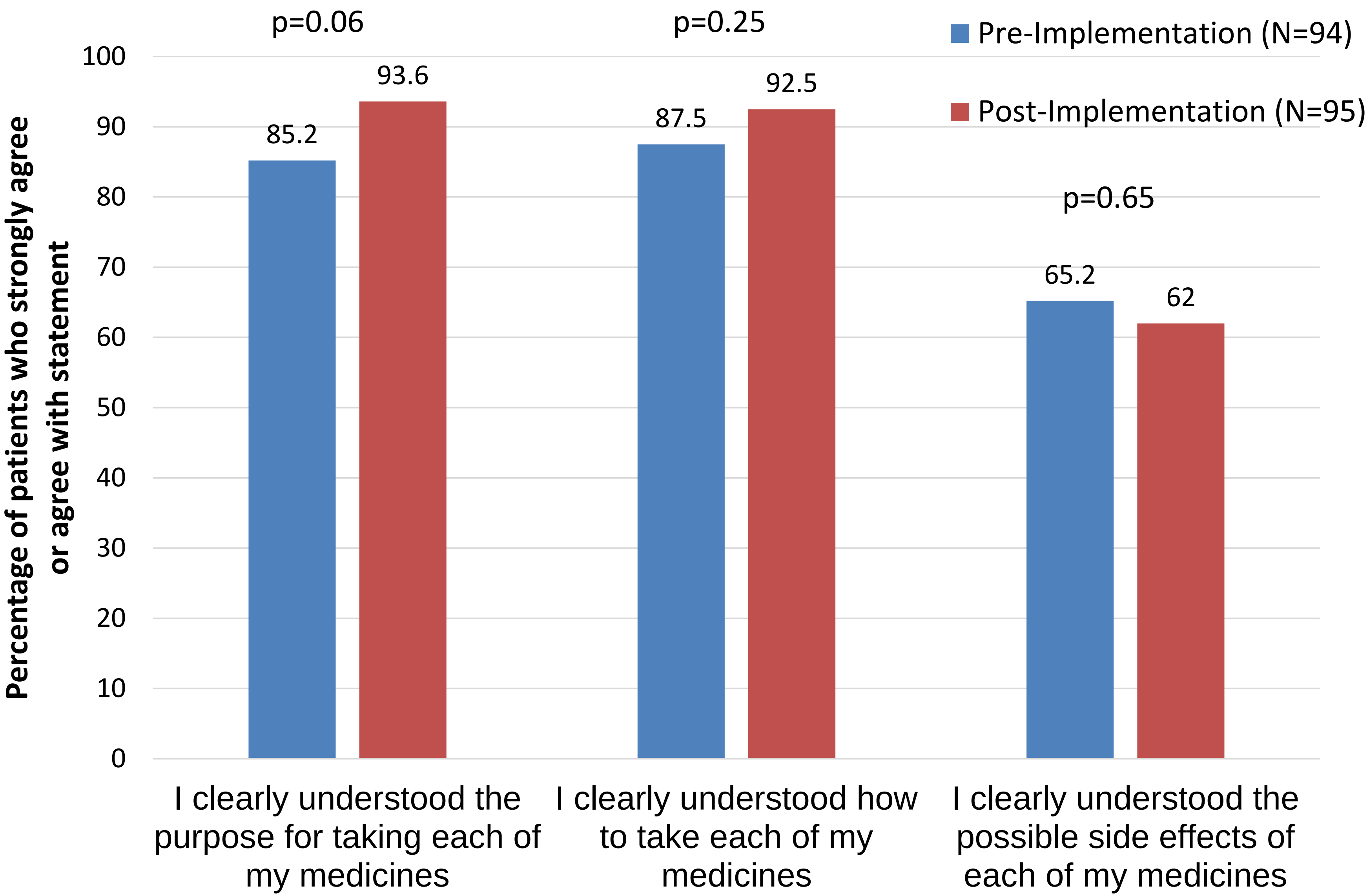
--understood purpose of procedure

--understood risks

--had all questions answered

*adjusted for propensity to be in pre- or post-group

Did not impact medication understanding at discharge



Lessons Learned

- Convenient access increases professional interpreter utilization

- Access is necessary but not sufficient to ensure utilization for all communication

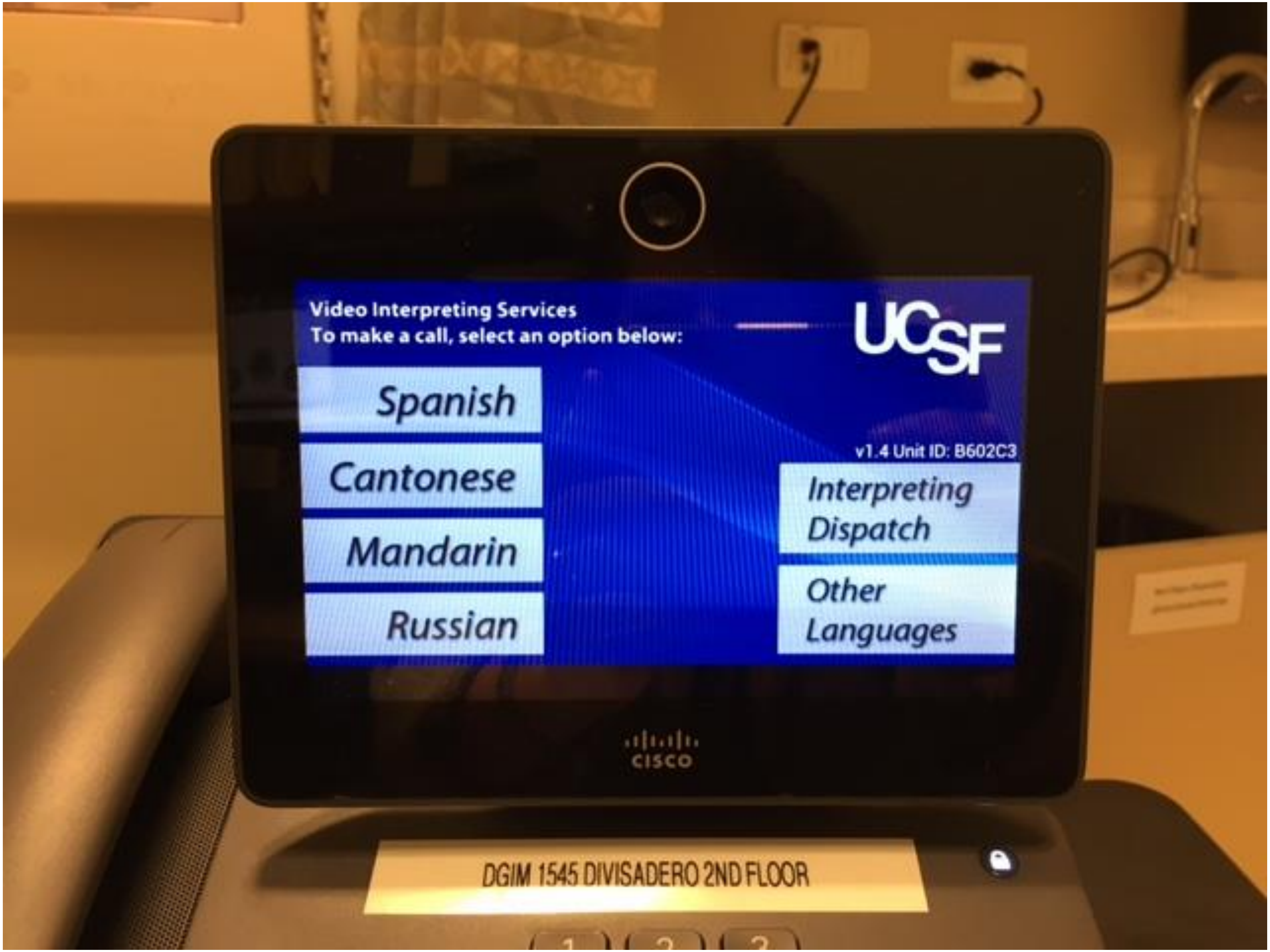
- Need to combine it with a cultural shift
- Unclear impact on use of partial-language skills for clinical communication

- Helpful to have an English-speaking comparison group

Language Access System Improvement (LASI)

Two-pronged improvement @ UCSF 2014-2015

- Video-conferencing Medical Interpretation (VMI)
  - On-demand access to remote professional interpreter
- Bilingual clinician certification program
  - Encouraging clinicians who have bilingual skills to take proficiency test
  - Encouraging those with no/inadequate skills to use professional interpreters



Video Interpreting Services
To make a call, select an option below:

Bilingual Clinician Certification

- Sent survey to all clinicians at UCSF
- Asked if they use a non-English language to communicate clinician information with patients
- If no, reminded to use professional interpreters

- If yes, which language(s)
- For each language, what ability?
  - Excellent
  - Very Good
  - Good

  - Fair
  - Poor
- In top three categories, qualify for proficiency testing
- Fair/Poor reminded to use professional interpreters

Excellent	Speaks proficiently, equivalent to that of an educated speaker, and is skilled at incorporating appropriate medical terminology and concepts into communication. Has complete fluency in the language such that speech in all levels is fully accepted by educated native speakers in all its features, including breadth of vocabulary and idioms, colloquialisms, and pertinent cultural references.

Language Access System Improvement (LASI)

Unique opportunity to evaluate whether changes in the way that language assistance is provided combined with a cultural shift to certify bilingual clinicians can have a positive impact on outcomes important to patients

Communication outcomes during a visit

rapport, respect, patient-centeredness, trust

Proximal communication outcomes

understanding of next steps after a visit

Intermediate clinical outcomes

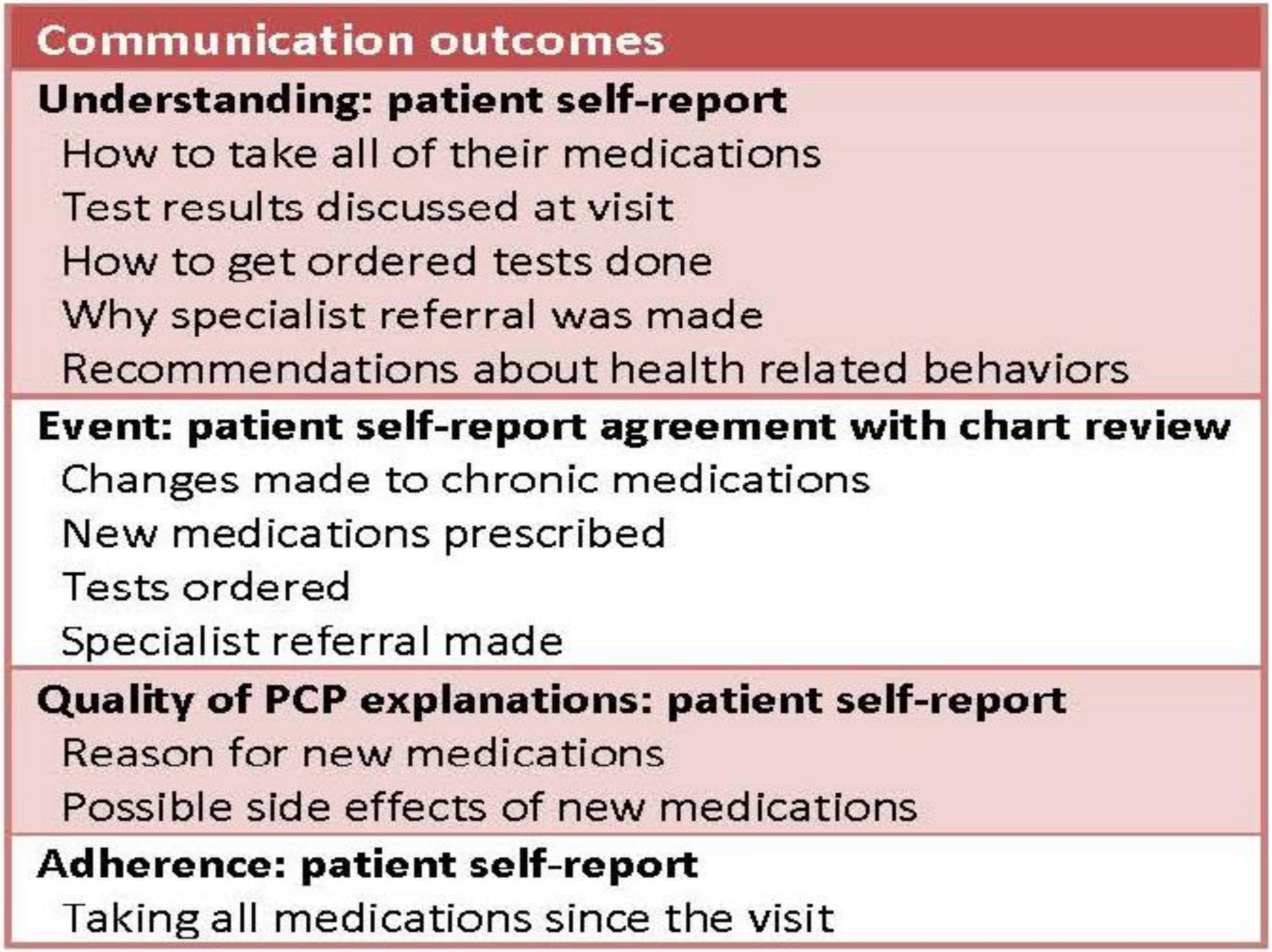
guideline goals for chronic disease management

Clinical outcomes

prevention of strokes, heart attacks, diabetes complications

Study Aims

- **Aim 1**: To evaluate the impact of the LASI initiative on communication outcomes with a natural experiment pre-post design (telephone interviews and chart review)



Communication outcomes
Understanding: patient self-report
How to take all of their medications
Test results discussed at visit
How to get ordered tests done
Why specialist referral was made
Recommendations about health related behaviors
Event: patient self-report agreement with chart review
Changes made to chronic medications
New medications prescribed
Tests ordered
Specialist referral made
Quality of PCP explanations: patient self-report
Reason for new medications
Possible side effects of new medications
Adherence: patient self-report
Taking all medications since the visit

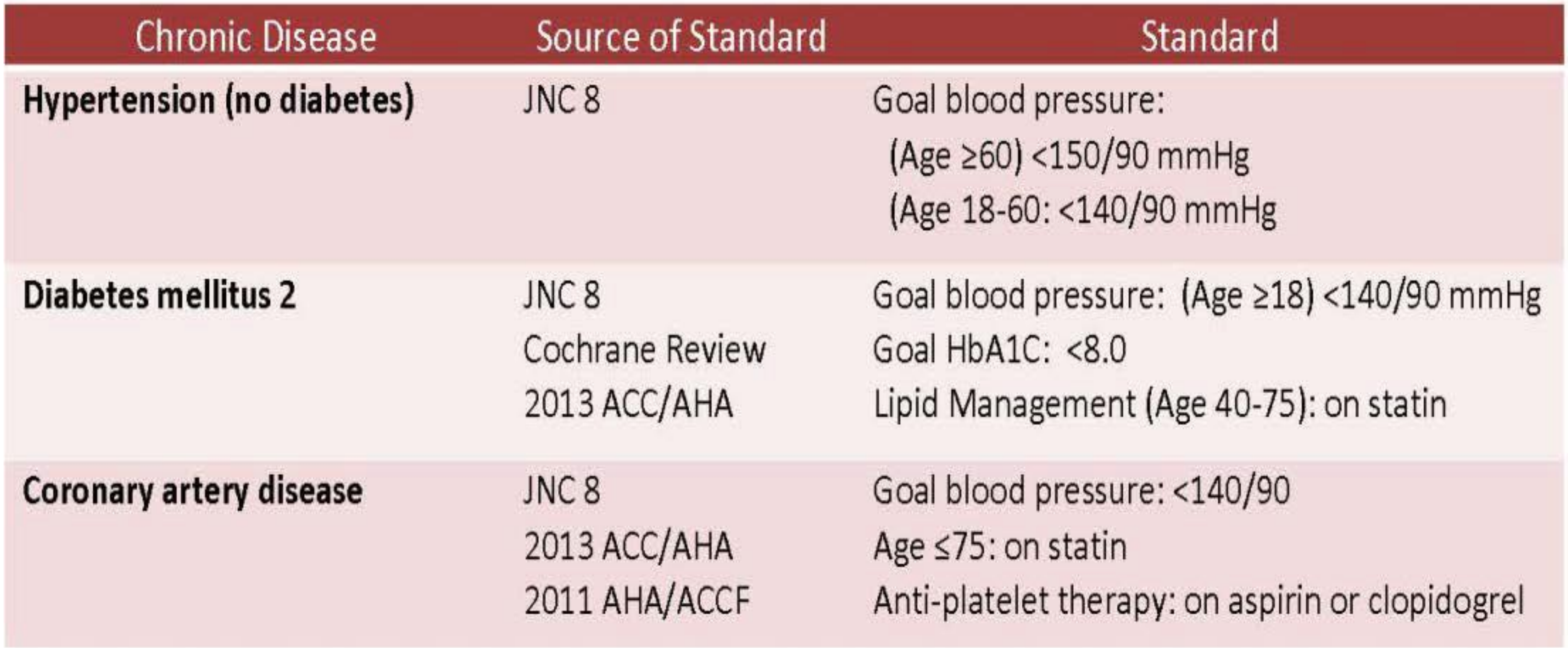
Audiotaping

- **Aim 2a**: To describe different communication elements for VMI mediated, language concordant, and partially concordant encounters using the Roter Interaction Analysis System (RIAS)
  - patient-centeredness, interpersonal influence, problem solving, reciprocity, information exchange

- **Aim 2b**: To validate an observational checklist designed to certify bilingual clinicians to communicate clinical information directly with patients and families in a non-English language

Electronic Medical Record Database

- **Aim 3**: To evaluate the impact of the LASI initiative on clinical outcomes using longitudinal data from the Electronic Medical Record (EMR)



Chronic Disease	Source of Standard	Standard
Hypertension (no diabetes)	JNC 8	Goal blood pressure: (Age ≥60) <150/90 mmHg (Age 18-60: <140/90 mmHg
Diabetes mellitus 2	JNC 8 Cochrane Review 2013 ACC/AHA	Goal blood pressure: (Age ≥18) <140/90 mmHg Goal HbA1C: <8.0 Lipid Management (Age 40-75): on statin
Coronary artery disease	JNC 8 2013 ACC/AHA 2011 AHA/ACCF	Goal blood pressure: <140/90 Age ≤75: on statin Anti-platelet therapy: on aspirin or clopidogrel

Methods

Four main sources of data collection

1. Clinician self-reported language data and proficiency test results (from UCSF Health data collection)
2. Patient telephone interviews after a primary care visit/chart review
    - -assess patient experience and understanding of post-visit plans
3. Audiotapes of primary care visits
    - -assess communication elements across modalities of communication (VMI, concordant, partially concordant)
    - -testing observational proficiency checklist
4. Electronic medical record database
    - -evaluate longitudinal impact on chronic disease management

Planned primary care patient population

- Interviews:

  Pre- LASI: Chinese and Spanish speaking patients (320)

  Post-LASI: Chinese and Spanish speaking patients (640)

  English speaking patients as comparison group (640)

- Audiotapes

  230 primary care visits (180 LEP and 50 EP)

- EMR database analysis

  1500 Chinese and Spanish speaking patients

  matched English speaking comparison group

What Questions Might We Answer?

?

Impact of LASI on Communication and Clinical Outcomes

- Does LASI shift use of inadequate language skills to use of professional interpretation?
- Does the increased access and shift in culture from LASI have a positive impact on LEP patients' understanding and knowledge of medications and follow-up plans (tests, referrals) after their primary care visit?

  …how does this compare with English speakers?
- Does LASI impact the proportion of LEP patients with chronic diseases who are at goal according to national standards for blood pressure, glycemic control, lipid and anti-platelet therapy?

Language Concordance

- How does clinician self-report of Chinese/Spanish language skills compare to patient report of that clinician’s skills?

  …to clinician performance on an oral language proficiency test?

- How does score on an observational checklist compare with patient report of clinician language skills? With clinician self-report?

Communication Analysis

- Do communication elements differ by communication modality (VMI, partial concordance, full concordance)?

  …how does this compare with English speakers?

- Are these communication elements associated with patient post-visit knowledge and self-reported understanding of medications / follow-up plans?

- Are there behaviors used by fully concordant clinicians which are then associated with enhanced rapport, respect, trust, patient-centeredness?

Progress to date

- 320 Chinese and Spanish speakers interviewed in the Spring of 2014 (pre-data collection)
- 462 patients interviewed in post-data collection (71% participation rate)
  - 221 Chinese speakers (Cantonese and Mandarin)
  - 96 Spanish speakers
  - 145 English speakers (matching English speakers within clinicians)
- Plan to start audiotaping by early August
  - 72% agree to be audiotaped at a future visit

CPEHN

California Pan-Ethnic Health Network

Building on 20 years as a champion for health equity

Team

- Advisory Collaborative on Language Access (ACLA)
- UCSF team:
  - Dr. Steven Gregorich (statistician)
  - Dr. Celia Kaplan (DrPH)
  - Sarita Pathak (project director); Ana Fernandez-Lamothe (project coordinator/lead interviewer); Karen Kuang, Andrew Rodriguez, Yina Wang
- Collaborators
  - Dr. Lisa Diamond (MSKCC)
  - Dr. Debra Roter (Johns Hopkins)

Advisory Collaborative on Language Access

- Esme Seto and Dr. Sunita Mutha, co-chairs
- Three additional patient stakeholders
  - Marynieves Diaz
  - Huiqing (Alice) Wu
  - Third in transition…
- Mateo Rutherford, Director of Language Access special projects at UCSF
- Cary Sanders, Director of Policy for California Pan-Ethnic Health Network

ACLA Events and Contributions to date

- Kickoff half-day September 28th
  - Personal and cultural sharing, project overview, vision/mission of group, communication and meeting preferences
- In-person meeting February 12th
  - Update on recruitment, presentation from Dr. Roter on communication research and RIAS
- Upcoming phone conference June 20th
  - Updates on recruitment, consultation about audio-recording protocols
- Email consultations as needed
  - Information sheet for patients
  - Feedback on telephone survey
  - Assistant with translations
  - Voting on group name
- Esme Seto, ACLA co-chair, attends team meetings once a month

Anticipated Outcomes

- Clinical data to support combining convenient access to professional interpreters with a clinician certification program to make a cultural shift toward high quality communication for LEP

  --next steps: dissemination of this model

- Identification of which communication elements during an encounter with a patient with LEP positively impact patient experience of care and clinical outcomes

  --next steps: educational program to teach clinicians to use those elements when working with an interpreter

- Validation of a direct observation proficiency checklist

  --Dissemination to provide more flexibility for bilingual clinician certification

Thank you!

Questions?

leah.karliner@ucsf.edu

Lunch

We will resume at 1:00 PM ET

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Eugene Washington PCORI Engagement Award Program Overview

Lia Hotchkiss, MPH

Program Director, Engagement Awards

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

PCORI Programmatic Funding

- Our strong emphasis on engaging patients and the broader healthcare community in all our work is evident in the criteria we have developed for the research we fund
- We also provide awards to encourage engagement of patients and other stakeholders in comparative effectiveness research
  - **Eugene Washington PCORI Engagement Awards** program encourages patients and other stakeholders to become integral members of the research process
  - **Pipeline to Proposal Awards** initiative provides seed money to encourage patients and other stakeholders to partner with researchers to study the issues that are most critical to them

Engagement Awards Team

Lia Hotchkiss, MPH
Director

Shivonne L. Laird, PhD, MPH
Program Officer

Yasmeen Long, MA
Program Officer

Alicia Thomas, MHS
Program Officer

Ivey Wohlfeld
Program Associate

Rachel Mosbacher
Fellow

Why Engage?

To influence research to be patient-centered, relevant, and useful

To establish trust and a sense of legitimacy in research findings

To encourage successful uptake and use of research results

Engagement Award Program

- A programmatic funding opportunity, launched in Feb 2014
- $20.5 million in FY 2016
- Support projects that will build a community better able to participate in PCOR/CER as well as serve as channels to disseminate study results
- Engagement Award projects will produce deliverables that are useful to awardees, PCORI, and the broader PCOR community for increasing patient and stakeholder engagement in PCOR/CER

Develop Community Skilled in PCOR

Engage Community in Research Processes

Engage Community in Dissemination

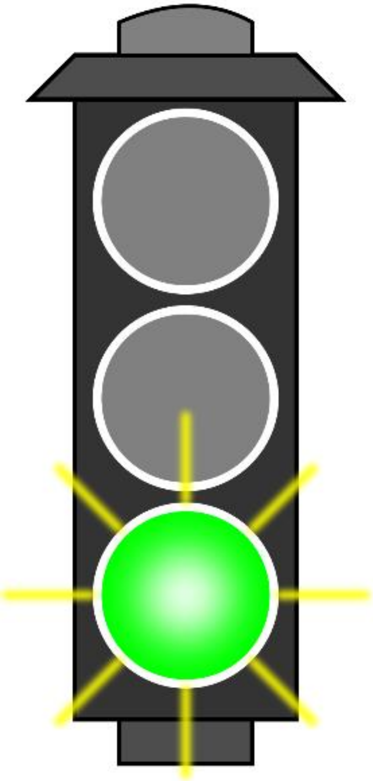
Engagement Award Overview

- Engagement Award (EA) projects
  - build **knowledge** base about how patients and other stakeholders want to participate in 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.

- Funding through an Engagement Award Initiative Notice (EAIN) supports **meetings/conferences** that align with PCORI's mission and strategic plan, and facilitate expansion of PCOR/CER in areas such as:
  - research design and methodology
  - research development
  - dissemination and implementation

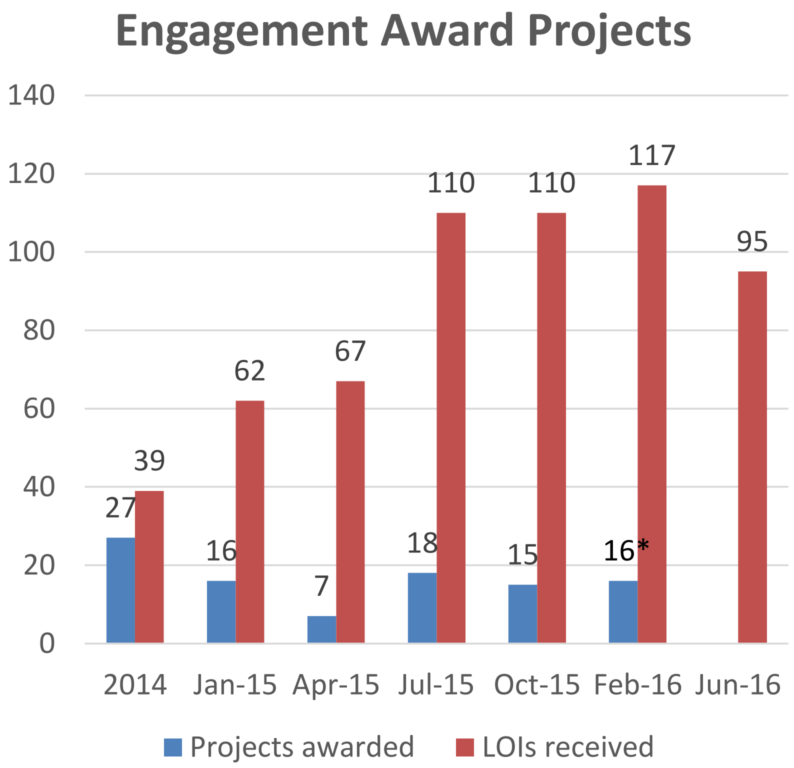
Awards of **up to $250,000** per project, up to **two years** in duration

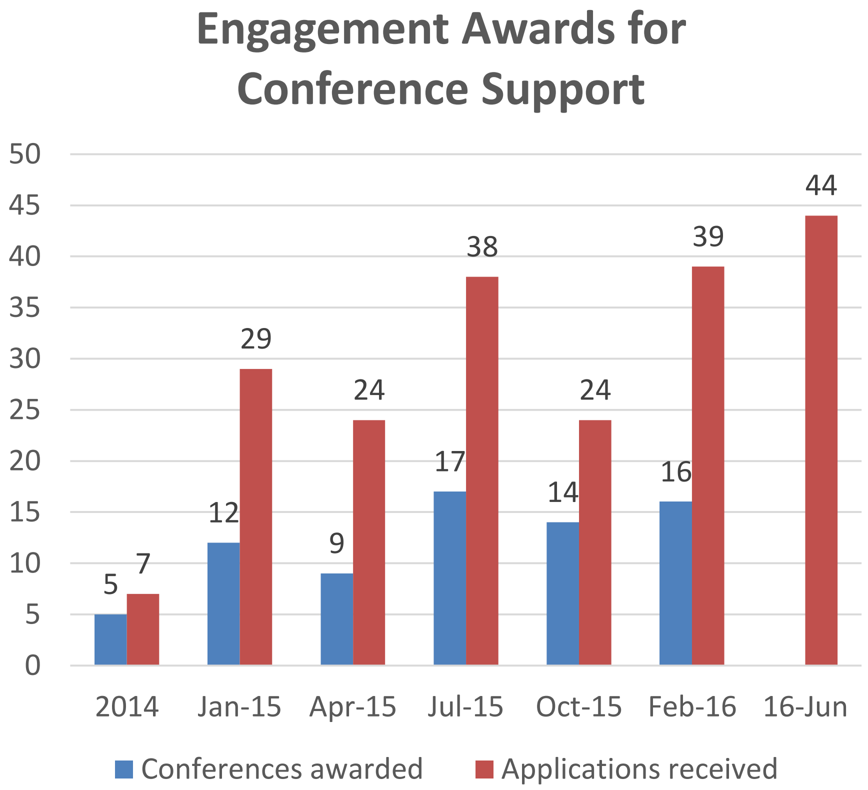
Emphasis On Planning for Dissemination of PCOR Findings



- Organizations with strong ties to end-user audiences
- To prepare to disseminate and implement PCOR/CER results
- Focus on strengthening the infrastructure and relationships necessary to actively disseminate and implement research results or products derived from PCORI studies or other high-quality PCOR/CER findings consistent with PCORI's research priorities
- Separate from Limited D&I funding opportunity
- Infrastructure and relationships developed must be sustainable with the potential to be scaled
- Information and tools generated must be generalizable and made public

Applications Received and Awards Made To Date

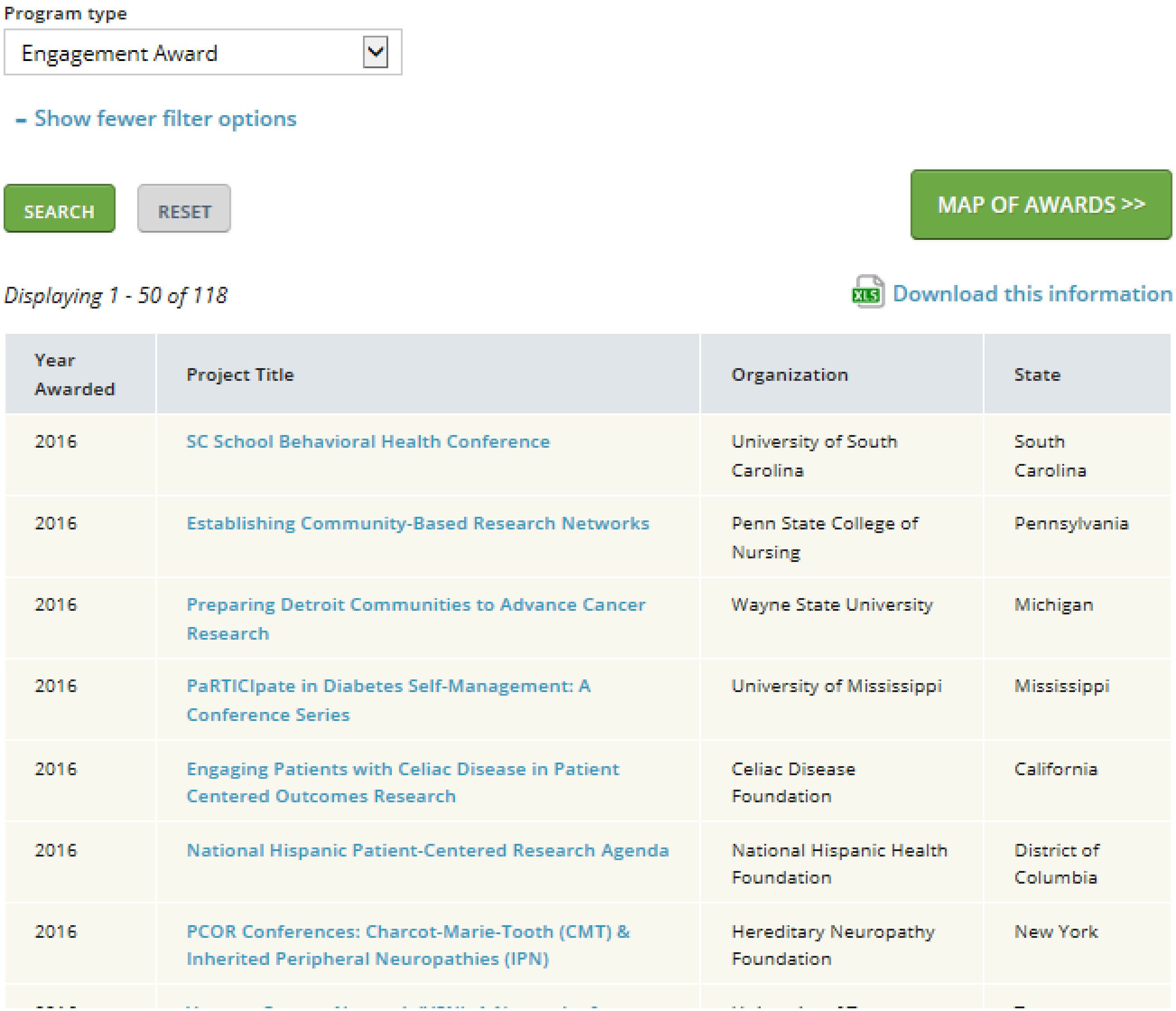

Engagement Award Projects


Engagement Awards for Conference Support

Since program launch in Feb 2014, we've selected 158 projects/conferences for awards**

* currently under review
**as of June 6, 2016; inc. 25 PPLN D&I awards

What We’ve Funded
(Research and Results Tab on PCORI Website)



Program type

Engagement Award

Displaying 1 - 50 of 118

Year Awarded	Project Title	Organization	State
2016	SC School Behavioral Health Conference	University of South Carolina	South Carolina
2016	Establishing Community-Based Research Networks	Penn State College of Nursing	Pennsylvania
2016	Preparing Detroit Communities to Advance Cancer Research	Wayne State University	Michigan
2016	PaRTICIpate in Diabetes Self-Management: A Conference Series	University of Mississippi	Mississippi
2016	Engaging Patients with Celiac Disease in Patient Centered Outcomes Research	Celiac Disease Foundation	California
2016	National Hispanic Patient-Centered Research Agenda	National Hispanic Health Foundation	District of Columbia
2016	PCOR Conferences: Charcot-Marie-Tooth (CMT) & Inherited Peripheral Neuropathies (IPN)	Hereditary Neuropathy Foundation	New York

Engagement Award Focus on Addressing Disparities

- Reviewers consider each proposed project's focus on and engagement of vulnerable/underserved populations
- Applicant completes LOI field (in SalesForce) - "Vulnerable/Underserved Pop Focus"
  - children 0-12, 13-18, 18-21; adults >65; disabled persons; African Americans; Hispanic/Latino; American Indian; Pacific Islander; Asian; rural pop; urban pop; veteran; women; LGBT; low income; low health literacy; other; chronic conditions; rare disease; genetic makeup affect medical outcomes

- Conducted initial review of funded Engagement Awards and found that 90 of 158 (**57%**) include vulnerable/underserved population; formal portfolio analysis to be conducted this fall

Sample of Engagement Awards

- **Racial and ethnic minorities**
  - *The Gathering for Pacific Islander Health*
  - *A Gathering of Good Minds: Engaging Native Americans in Wellness*
  - *National Hispanic Patient-Centered Research Agenda*
- **Rural populations**
  - *Virtual Rural Oncology Community (V-ROC)*
  - *Rural Patient and Provider Perspectives on the Patient Centered Medical Home Model*
- **Individuals with disabilities**
  - *Workshops to Transform the Health Care of Women with Disabilities*
  - *Speak for Yourself: Patient-Centered Research Network for People with Disabilities & Their Families*

Familiar Engagement Award Projects

- **Alfiee M. Breland-Noble, PhD, MHSc**
  - ***Engaging Black Faith Communities to Address Mental Health Disparities via Curriculum Development***
    - Project to increase the capacity of faith communities, youth, and stakeholders to lead, design, and conduct their own PCOR/CER studies
    - Develop a training curriculum to prepare African American youth patients/advocates, faith and community leaders in the basic tenets of PCOR, CER and CBPR
- **Patrick Kitzman, MS, PhD**
  - ***Healthcare Decision Making of Adults Living in Rural Communities with Acquired Neurologic Conditions***
    - Project will determine what information SCI, TBI, and stroke patients and healthcare providers in rural communities need to make clinical and health decisions and where they access this information.
    - Develop a model for engaging these individuals to participate, utilizing PCOR/CER to develop health-related questions that are relevant to improving their healthcare decision-making and health outcomes

How to Submit Applications

- http://www.pcori.org/funding-opportunities

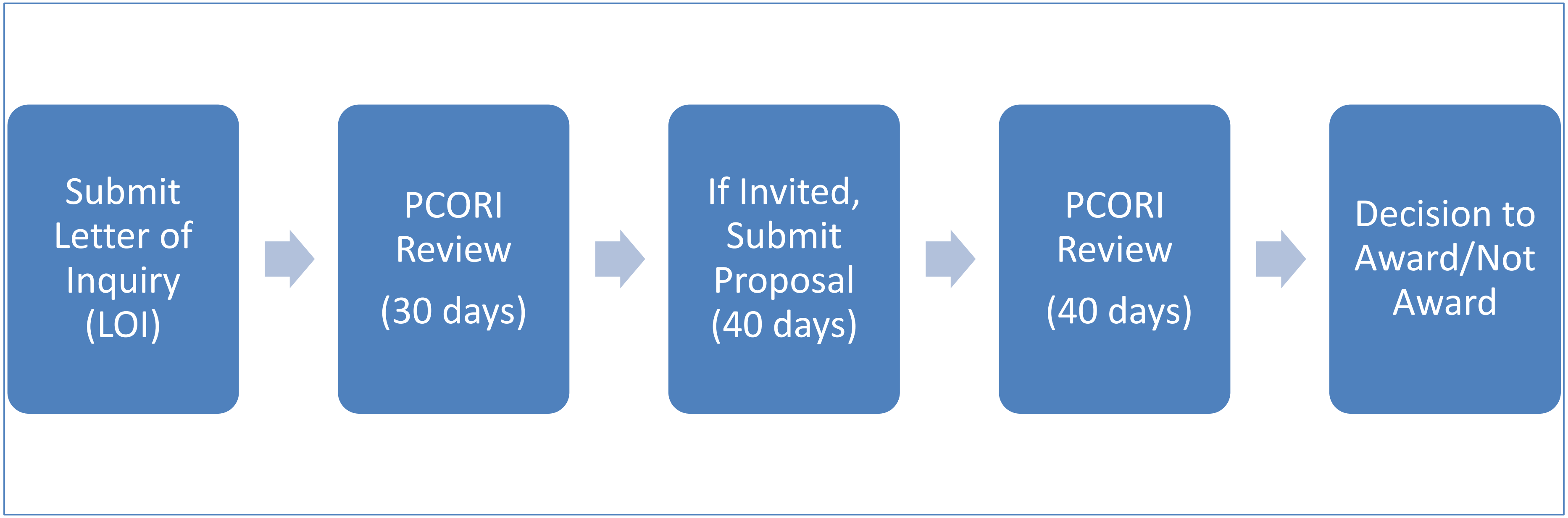
Engagement Award: Knowledge, Training and Development, and Dissemination Awards

Key Deadlines	Type	Funds Available	Total Costs
LOI: June 1, 2016 by 5 p.m. ET **Application:** Full proposals are due 40 days after review and approval of the LOI.	Program Award		Award total costs may not exceed $250,000

Engagement Award (EAIN): Research Meeting and Conference Support

Key Deadlines	Type	Funds Available	Total Costs
LOI: Not required **Application:** June 1, 2016 by 5 p.m. ET	Program Award		One-time award total costs must not exceed $50,000 and multi-year award total costs may not exceed $250,000.

Review Process



- If applying for meeting/conference support, you do not need to submit a Letter of Inquiry (LOI); applicants proceed directly to submitting a full proposal.
- The funding cycle deadlines for both LOIs and proposals for meeting/conference support are: February 1, June 1, and October 1.
- Applications are reviewed by PCORI's Engagement Department, Contracts Management and Administration, and other PCORI internal staff, as needed.

Engagement Awards NOT Intended to Support:

- Projects solely intended to improve patient engagement in healthcare service delivery, patient self-care, or patient-centeredness of care (e.g., shared decision making)
- Projects intended to increase the number of patients who agree to be research subjects or participants
- Research projects
- Planning or pilot studies
- Projects designed solely to validate tools or instruments
- Delivery of health care
- Development of registries or recruitment of research or registry participants
- Development of decision support tools or clinical practice guidelines
- Meetings that don't focus on PCOR or CER
- Full-fledged projects to translate PCORI research findings into products and/or disseminate PCORI research results
- Projects proposed by PCORI-funded investigators to prepare for applying (i.e. "bridge funding") to the Limited PCORI Funding Announcement: Dissemination and Implementation

Thank you!

Contact Information:

Lia Hotchkiss, MPH
Program Director, Eugene Washington PCORI Engagement Awards
Patient-Centered Outcomes Research Institute (PCORI)
1828 L Street, NW 9th Floor
Washington, DC 20036

Telephone: 202-494-3441
Email: lhotchiss@pcori.org

Visit: http://www.pcori.org/funding-opportunities/programmatic-funding/eugene-washington-pcori-engagement-awards

Pipeline to Proposal (P2P) Awards Program

Courtney Clyatt, MA, MPH

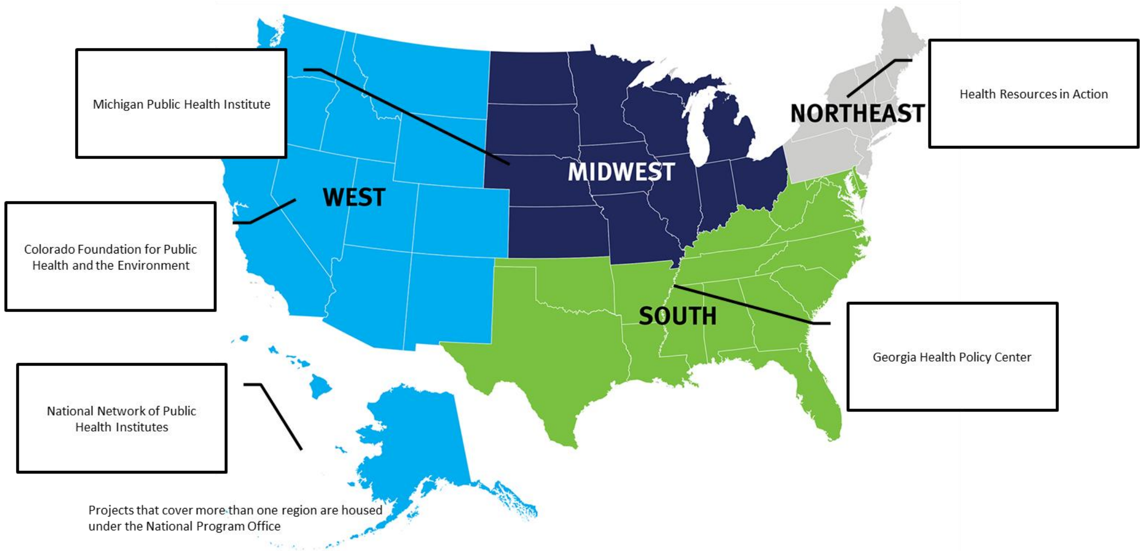
Program Officer, Engagement

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

P2P Program Team

PCORI Staff

Pipeline Award Program Offices



Michigan Public Health Institute

Colorado Foundation for Public Health and the Environment

National Network of Public Health Institutes

Health Resources in Action

Georgia Health Policy Center

Projects that cover more than one region are housed under the National Program Office

P2P Program Overview

P2P Mission and Purpose

- **Mission:** The P2P program aims to build a national community of patient, stakeholder, and researcher partnerships that have the expertise and passion to participate in patient-centered outcomes research within their communities that leads to high-quality research. In addition, the P2P program is a funding mechanism to develop and strengthen the engagement in proposals submitted for funding**.**

- **Purpose:** Build capacity and cultivate the development of proposals with sound scientific rigor and **robust patient engagement**.

P2P Award Goals

- Successfully establish an infrastructure for patients, caregivers, and other stakeholders to increase CER information and engagement in research.
- Strengthen relationships between researchers, patients and stakeholders, particularly in communities that have been underrepresented in research.
- Build capacity for researcher/non-research partnerships to create research questions and submit PCOR research proposals that can be considered for PCOR funding.

P2P Awards Are Not Research Awards

- Activities should not include:
  - Conducting a small research study
  - Conducting a pilot study
  - Conducting a formal evaluation of a program, tool or intervention
  - Validating a program, tool or intervention
  - Gathering pilot data
  - Activities requiring IRB approval or the informed consent of participants

P2P Awards Strengthen the PCORI Research Enterprise

PCORI Research Process

Pre-planning

Plan Study

Conduct Study

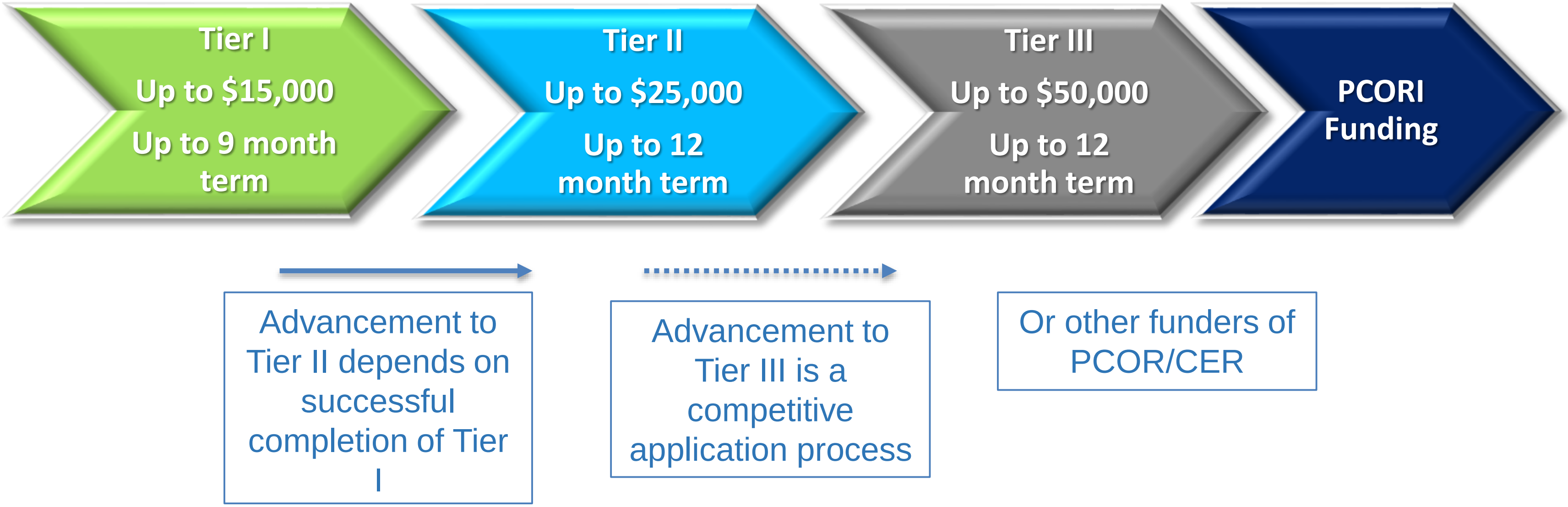
Disseminate Study Results

Implement Study Results

1) P2P helps foster capacity building for PCOR in the community before a study plan is even developed. This enables underserved/minority and otherwise “missing” communities to actively engage in the research process.

2) It has been shown that when patient partners are engaged early on and throughout the research process, they are more likely to help in the implementation and dissemination of study results in their communities.

Progressive Pipeline - Three-Tiered Process



Tier I

Up to $15,000

Up to 9 month term

Tier II

Up to $25,000

Up to 12 month term

Tier III

Up to $50,000

Up to 12 month term

PCORI Funding

Advancement to Tier II depends on successful completion of Tier I

Advancement to Tier III is a competitive application process

Or other funders of PCOR/CER

What’s New in the Pipeline?

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Independent Tier III

Tier III

Up to $50,000

Up to 9 month term

PCORI Funding

Purpose of Funding – Proposal development, targeting advanced potential research partnerships (those who are “almost there”) that could benefit from working with awardee partners to draft a strong patient engagement plan to enhance a rigorous science proposal.

Eligibility for Independent Tier III

Independent Tier III, applicants must have well-formed research partnerships that include at least one patient and one researcher. Patients or researchers can serve as the project lead.

Teams Encouraged to Apply

- Those who have submitted proposals to PCORI and were not funded but received recommendations from PCORI to strengthen their Engagement Plan
- Those whose topics of interest are aligned with PCORI science funding priorities
- Those whose partners or populations of interest are aligned with populations who are typically underrepresented in research

Award Activities

The ultimate goal of Independent Tier III Award is to form a robust patient-centered research proposal with a partnership team of patients and researchers.

Independent Tier III Award Activities

- Finalized and thorough governance document that describes how all partners engage, and have equal contribution in, decision-making and strategic planning
- List of ideas developed by all partners that will drive changes, additions, and improvements in the team's proposed research project
- A workplan that describes how the partners will work collectively to develop a patient-centered research proposal for a full PCORI application .
- LOI submitted for a broad PCORI funding announcement (PFA)
- Draft proposal for a PFA

Application Timeline

- The graphic below shows the important dates for the Independent Tier III

LOI Deadline

Application Deadline

Project Start Date

6/30/2016

8/15/2016

9/30/2016

11/30/2016

2/1/2017

Application Portal Opens

Awards Announced

Project Locations and Population Focus

Strengthening PCOR Nationwide

Our *Pipeline to Proposal Awards* encourage PCOR in comparative clinical effectiveness research.

Number of projects awarded:

Tier I – 77

Tier II – 71

Amount awarded:

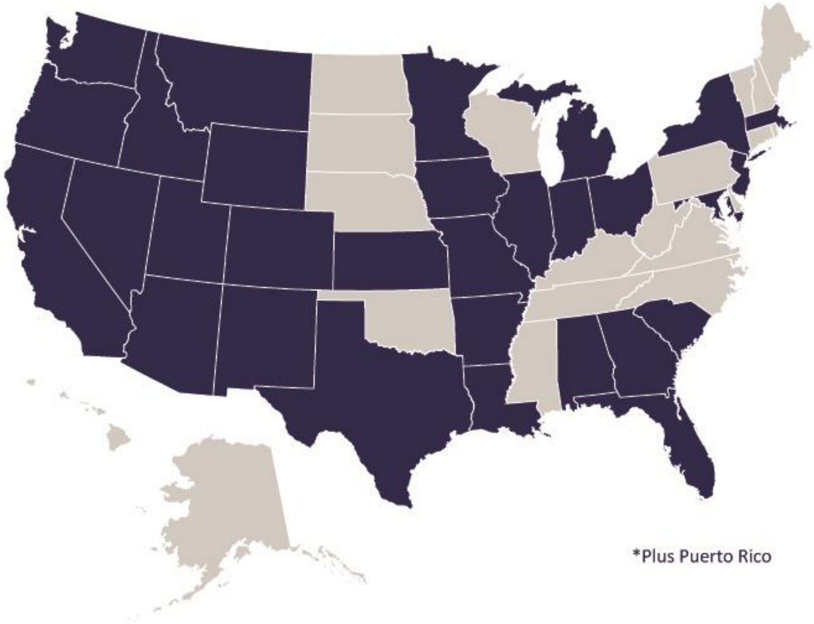
$2,911,435

(Tier I Cycles 1 & 2 and Tier II Cycle 1)

Number of states where we are funding projects:

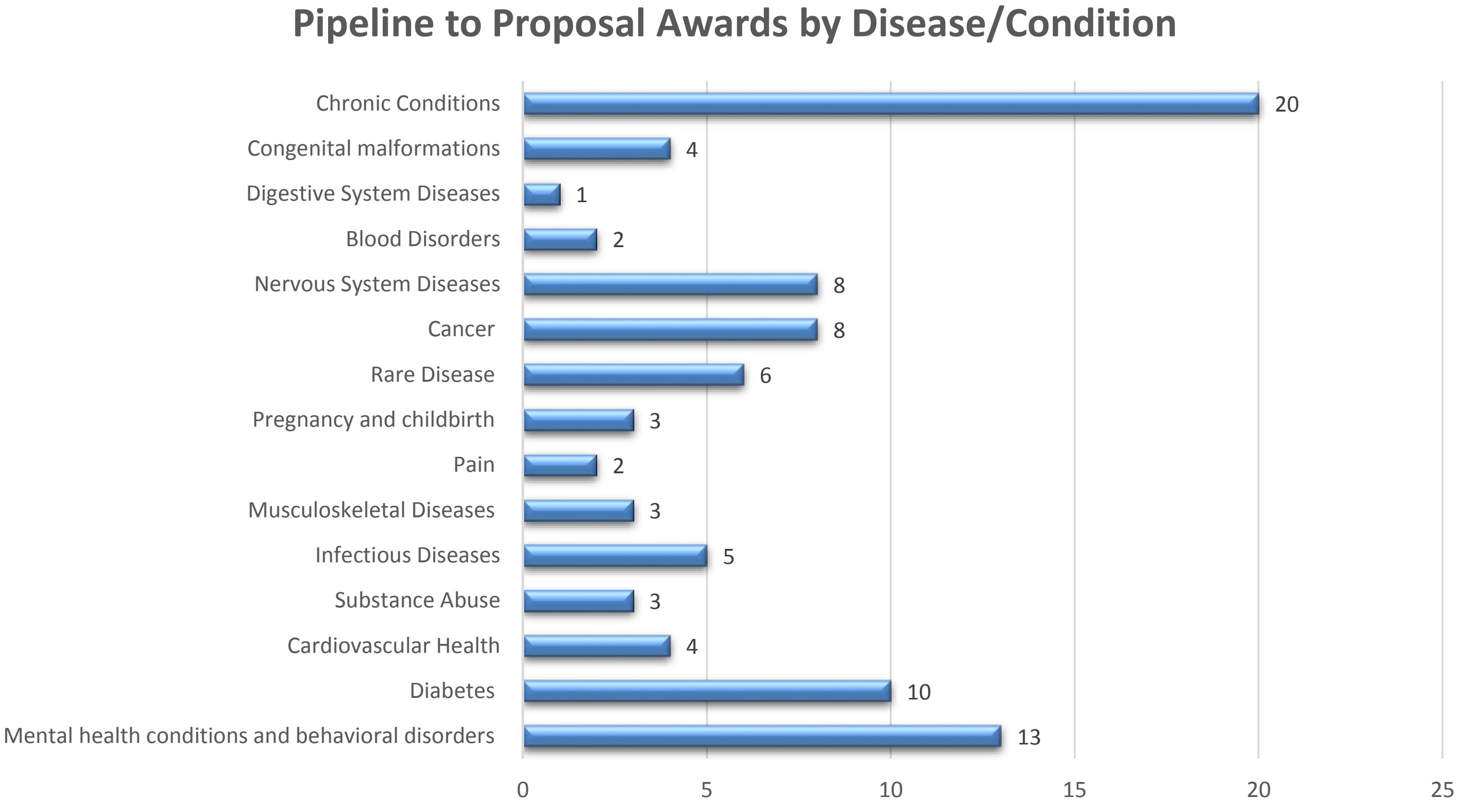
30 states, District of Columbia and Puerto Rico

As of May 1, 2016

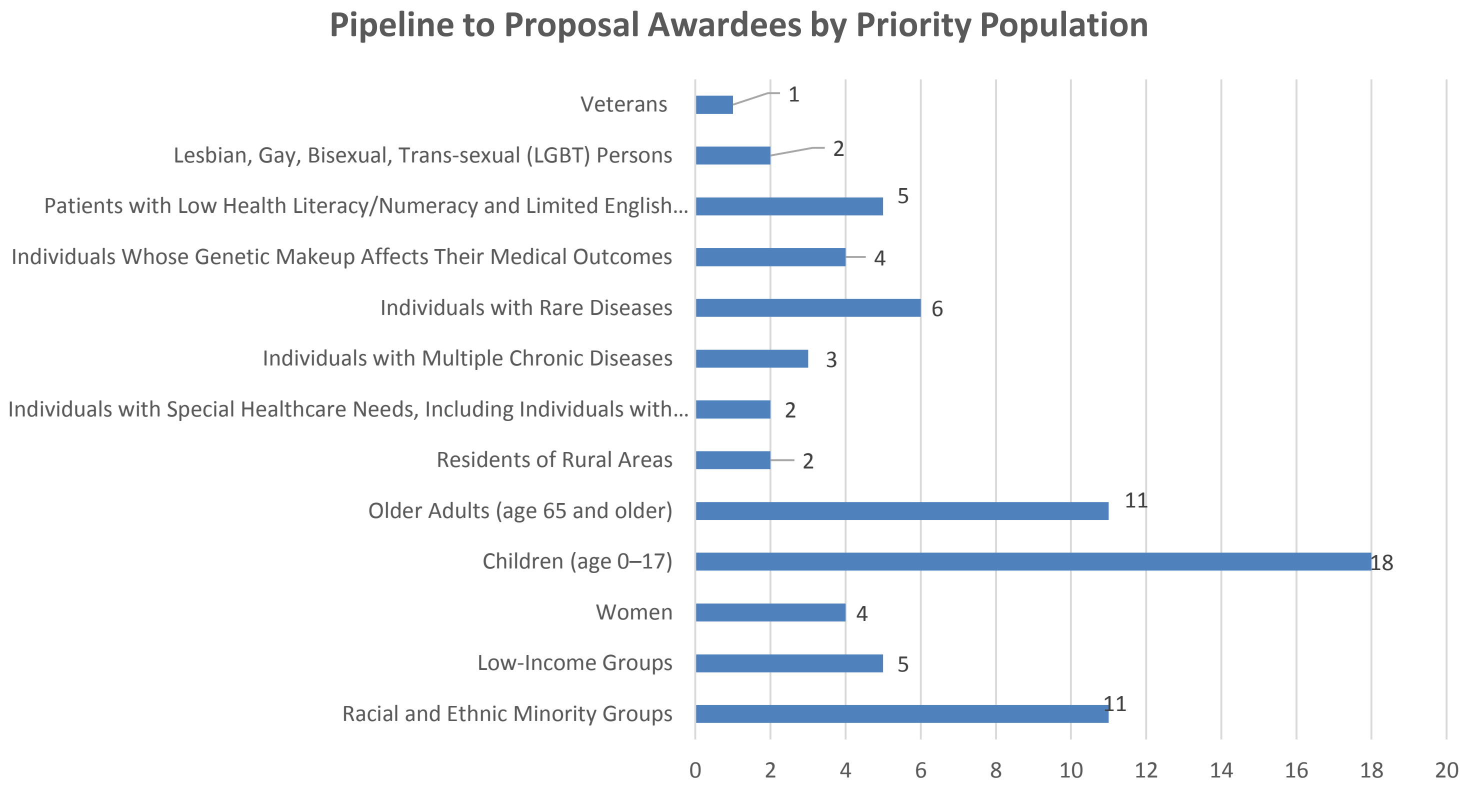


*Plus Puerto Rico

Pipeline to Proposal Awards by Disease/Condition



Pipeline to Proposal Awardees by Priority Population



P2P Projects That May Be of Interest

Sample of P2P Awards focusing on Addressing Disparities

Racial and ethnic minorities

- *Supporting Latino Families with Children with Spina Bifida*
- *Engaging American Indian and Spanish-Speaking Families and Sharing Family Wisdom to Reduce Childhood Obesity*
- *Unchung Nation's Initiative to End Diabetes (UNITED)*
- *We'll Take the Village: Engaging the Community to Better Health (sickle cell disease)*

Rural populations

- *Primary Care Integrated Addiction Treatment Services in Rural Iowa*
- *I Have a Voice! Empowering Mental Health Consumers to Engage in a Patient-Centered Research Community to Improve Options for Mental Health Recovery Support*

Individuals with disabilities

- *Improving Oral Health for Vulnerable Populations - Individuals with Intellectual and Developmental Disabilities*

P2P Projects participating in E2AN

- *The Hispanic Family Asthma Outcomes Research Network*
  - Nuestra Salud, LLC (NS), serves the Hispanic and Spanish-speaking population of New Mexico. Lung health, particularly asthma care in children and smoking cessation, has been surfacing as an issue that our community would like to address.. As an advocate organization, our staff, families, and patients need training and support to build our capacity to participate more fully in developing comparative effectiveness research (CER) questions, participate in the design and evaluation of the research findings, and make sure our efforts are valued.

- *Promoting Patient-Centered Research in the Puget Sound Asthma Coalition*
  - Washington State University College of Nursing. The purpose of this project is to promote patient-centered research in the Puget Sound Asthma Coalition (PSAC). The PSAC is a multi-organizational effort to improve the quality of life for individuals, families, and communities affected by asthma.

Questions?

Thank You!

Courtney Clyatt,
Program Officer, Patient Engagement

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Break

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Discussion of Autism Background Brief

Elisabeth Houtsmuller, PhD
Senior Program Officer, Improving Healthcare Systems

Ayodola Anise, MHS
Program Officer, Addressing Disparities

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PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Background on Development of Autism Topic

- Topic Brief previously discussed by our panel in September 2014:

  Compare the Effectiveness of Disease Identification/Risk Assessment for Autism Spectrum Disorders and Therapeutic Strategies (e.g., Behavioral or Pharmacologic Interventions, the Combination of the Two) for Different Autism Spectrum Disorders among Populations Likely to Experience Disparities (i.e., Racial/Ethnic Minorities, Rural Populations, Low SES Populations)
- A literature search in 2014 focused on identification and diagnosis of autism spectrum disorders found little evidence of efficacious interventions
- The Improving Healthcare Systems program at PCORI is reintroducing this topic and is moving forward with a background brief in this area
  - This presents opportunities for program collaboration and for both the Improving Healthcare Systems and Addressing Disparities Advisory Panels to provide input on the topic

Autism Diagnosis and Disparities

- 1 in 68 children affected, substantial burden to individual and family
- Early diagnosis critical: early intensive intervention emphasized
- Disparities
  - Estimated prevalence higher for white children than for African American and Hispanic children (1 in 64 vs 1 in 76 vs 1 in 99).
  - African American and Hispanic children are likely to be diagnosed at later age than white children.
  - African American children spend more time in treatment before receiving an ASD diagnosis, three times more likely to receive incorrect diagnosis before ASD diagnosis than white children.
  - African American and Hispanic children more likely to have comorbid intellectual disability than white children.

Autism Diagnosis and Disparities (cont.)

- Disparities presumed to result from diagnostic bias providers, differences care seeking, access disparities.

- Disparities in diagnosis lead to disparities in treatment

- Racial and ethnic minority families, low SES families with child with ASD have reduced access to care and specialty care, reduced quality of care
  - African American and Hispanic children with ASD diagnosis enter treatment at a later age than white children

- Many studies conclude routine *screening* for autism in early childhood must be implemented for all children, specifically minorities and those of low SES.

Screening Prevalence and Recommendations

- CDC, American Academy of Pediatrics recommend screening for ASD at 18 and 24-month well-child visits

- Prevalence of ASD screening in US varies; most surveys suggest less than 60% of clinicians screen for ASD.

- Recent US Preventive Services Task Force recommendation regarding screening for ASD in young children (18 months-3 years) Feb 2016:
  - Insufficient evidence to assess benefits and harms *when no concerns have been raised by parents or clinicians*
  - Adequate evidence that current screening instruments can detect ASD

Considerations for Recommendations and Potential CER Questions

- How do we (PCORI) reduce disparities?
  - Does universal screening lead to health outcomes improvements in populations with low socioeconomic status and minority populations? (USPSTF recommends)

- In the absence of universal screening, how can we reduce disparities?
  - Small studies suggest
    - *non-traditional forms of screening* may increase identification of ASD in low-income and racially and ethnically diverse children
    - *family navigation* reduces time to diagnostic resolution for low-income ethnic/racial minority families .

PCORI Discussion 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?

Early Interventions ASD: Applied Behavior Analysis

- Applied Behavior Analysis (ABA)-based early intensive interventions
  - Widely used
    - widely accepted by healthcare professionals
    - insurance coverage required in at least 30 states
  - Supported by some research; improvements in critical academic and life skills and reductions in restricted and maladaptive behaviors
  - Encourage positive behavior, discourage negative behavior

Early Interventions ASD
Applied Behavior Analysis (cont.)

- Delivery of ABA early intensive intervention:
- where: at home, in school, in specialist clinic
- who: behavior therapist, behavior analyst, school staff (general educators, special educators, teaching assistants), paraprofessionals, parents.

- AHRQ review 2014: evidence for ABA, Intensive Parent Training Programs, Social skills interventions, Joint Attention interventions, but need remains for studies of interventions across settings.

- Systematic review/meta-analysis: early ABA improves spoken-language outcomes for children with ASD; largest effects for parent plus clinician implementing the intervention (Hampton and Kaiser, 2016)

- PCORI twitter chat autism April 2016

Potential CER Questions

- Does the effectiveness of early interventions based on applied behavior analysis (ABA) differ when delivered at school, in a specialist's office, in a community setting or at home for children with a diagnosis of ASD and different levels of severity of core symptoms?

- What is the comparative effectiveness of early ABA interventions delivered by behavior therapists, behavior analysts, paraprofessionals, school staff and parents to children with a diagnosis of ASD and different levels of severity of core symptoms?

PCORI Discussion Criteria

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Panelist Recognition

Thank You!

- We would like to give a special thanks to those members whose terms end this year:
  - Deborah Stewart
  - Chien-Chi Huang
  - Carmen Reyes
  - Russell Rothman
  - Mary Ann Sander
  - Martin Gould
  - Echezona Ezeanolue

- We'd also like to thank our chair and co-chair, **Doriane Miller** and **Grant Jones**, for leading our panel for the past 3 years

Wrap Up and Next Steps

- Our next in-person meeting will be held in Washington, DC on **Monday, October 24th**
- **Addressing Disparities Advisory Panel Membership**
  - We will be welcoming up to 7 new members
  - We will be selecting a new chair and co-chair
  - Board approval of chair, co-chair, and new members on August 16th

Adjourn

Thank you for your participation!

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