Advisory Panel on Addressing Disparities: In-Person Meeting

May 17th, 2017

9:00 AM – 5:00 PM ET

Welcome, Introductions, and Setting the Stage

Steve Clauser, PhD, MPA

Program Director, *Healthcare Delivery and Disparities Research*

Cheryl Pegus, MD, MPH,

Chair, Addressing Disparities Advisory Panel

Elizabeth A. Jacobs, MD, MAPP, FACP

Co-Chair, Addressing Disparities Advisory Panel

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

Agenda Item	Time
Welcome, Introductions, and Setting the Stage	9:00 AM
Healthcare Delivery and Disparities Research: Linking the Improving Healthcare Systems and the Addressing Disparities Programs	9:15 AM
Break	10:45 AM
Awardee Presentation: An Emergency Department-to-Home Intervention to Improve Quality of Life and Reduce Hospital Use	11:00 AM
Lunch	12:00 PM
Topics Under Consideration: Glaucoma	1:00 PM
Addressing Disparities Program Update: Broad Portfolio	1:30 PM
Break	2:45 PM
PCORI's Asthma Research Framework	3:00 PM
Addressing Disparities Panelist Presentation: Health Disparities at the Intersection of Disabilities, Race, and Ethnicity	3:45 PM
Wrap Up and Next Steps	4:15 PM
Recognition of Panelists' Service	4:30 PM
Adjourn	5:00 PM

Introductions

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

Introductions (cont.)

Cheryl Pegus, MD, MPH *(Chair)*

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

Representing: Patients, Caregivers, and Patient Advocates

Introductions (cont.)

Elizabeth A. Jacobs, MD, MAPP, FACP ***(Co-Chair)***

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

Representing: Researchers

Introductions (cont.)

Terrie Black DNP, MBA, BSN, RN, CRRN, FAHA

Clinical Assistant Professor, *University of Massachusetts, Amherst;*
Nurse Surveyor, *The Joint Commission*

Representing: Clinicians

Introductions (cont.)

Alfiee M. Breland-Noble, PhD, MHSc

Director, The AAKOMA Project, *Georgetown University Medical Center*,
Associate Professor, Psychiatry, *Georgetown University Medical Center*

Representing: Researchers

Introductions (cont.)

Ronald Copeland, MD, FACS

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

Representing: Health Systems

Introductions (cont.)

Deidra C. Crews, MD, ScM, FASN, FACP

Associate Professor of Medicine in the Division of Nephrology, *Johns Hopkins University;*

Associate Vice Chair for Diversity and Inclusion of the Department of Medicine, *Johns Hopkins University School of Medicine*

Representing: Clinicians

Introductions (cont.)

Martina Gallagher, PhD, MSN, BSN

Assistant Professor, *University of Texas Health Science Center*

Representing: Clinicians

Introductions (cont.)

Sinsi Hernández-Cancio, JD

Director of Health Equity, *Families USA*

Representing: Patients, Caregivers, and Patient Advocates

Introductions (cont.)

Grant Jones

Founder, Executive Director, *Center for African American Health*

Representing: Patients, Caregivers, and Patient Advocates

Introductions (cont.)

Christine Joseph, PhD, MPH

Senior Epidemiologist, *Henry Ford Health System*;

Director, *Henry Ford Health System Health Disparities Research Collaborative*

Representing: Researchers

Introductions (cont.)

Patrick Kitzman, PhD, MS

Associate Professor, Physical Therapy, *University of Kentucky*

Representing: Clinicians

Introductions (cont.)

Donald Klepser, PhD, MBA

Associate Professor, *University of Nebraska Medical Center*

Representing: Researchers

Introductions (cont.)

Barbara L. Kornblau, JD, OTR/L

CEO, *Coalition for Disability Health Equity*

Representing: Patients, Caregivers, and Patient Advocates

Introductions (cont.)

Ana Maria Lopez, MD, MPH, FACP

Associate Vice President for Health Equity and Inclusion, *University of Utah Health Sciences;*

Director of the Collaboration and Engagement Team (CTSA); *University of Utah*

Representing: Clinicians

Introductions (cont.)

Kenneth Mayer, MD

Medical Research Director, Co-Chair, *The Fenway Institute;*
Professor, *Harvard Medical School and School of Public Health*

Representing: Researchers

Introductions (cont.)

Doriane C. Miller, MD

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

Representing: Patients, Caregivers, and Patient Advocates

Introductions (cont.)

Alan R. Morse, JD, PhD

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

Representing: Health Systems

Introductions (cont.)

Umbereen S. Nehal, MD, MPH

Assistant Professor, *University of Massachusetts Medical School*; Physician, *Boston Medical Center*

Representing: Payers

Introductions (cont.)

Tung Nguyen, MD

Special Government Employee, *Department of Education;*

Endowed Chair in General Internal Medicine, Professor of Medicine, *University of California San Francisco (UCSF)*

Representing: Researchers

Introductions (cont.)

Danielle Pere, MPM

Associate Executive Director, *American College of Preventive Medicine*

Representing: Clinicians

Introductions (cont.)

Elinor Schoenfeld, PhD

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

Representing: Researchers

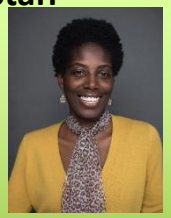
Healthcare Delivery and Disparities Research Program Staff

Addressing Disparities Advisory Panel Staff

Steve Clauser, PhD, MPA ◇ ●
Program Director

Ayodola Anise, MHS ◇
Program Officer

Kaitlynn Robinson-Ector, MPH ◇
Program Associate



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Sr. Admin Assistant

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Senior Program Officer

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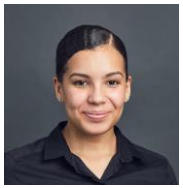
Program Manager

Julia Anderson, MEM, MPH ◇
Program Associate

Neeraj Arora, PhD ●
Associate Director



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Program Associate

Candace Hall, MA ●
Program Associate

Els Houtsmuller, PhD ●
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Senior Advisor

Gyasi Moscou-Jackson, PhD ●
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Jeanne Murphy, PhD, CNM ●
Program Officer

Allie Olender ●
Program Assistant

Carly Parry, PhD, MSW ●
Senior Advisor

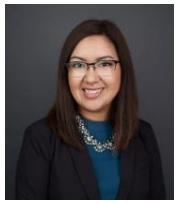
Stephanie Parver, MPH ●
Program Associate

◇ = Addressing Disparities National Priority Area

● = Improving Healthcare Systems National Priority Area

Soknorntha Prum, MPH ◇
Program Associate

Aaron Shifreen ●
Program Assistant



Marisa Torres, MPH ◇
Program Associate

Jamie Trotter, ●
Program Associate

Healthcare Delivery and Disparities Research: Linking the Improving Health Systems and Addressing Disparities Programs

Steve Clauser, PhD, MPA

Program Director, Healthcare Delivery and Disparities Research

Overview of Presentation

- Introduce the Healthcare Delivery and Disparities Research Program
- Discuss the Improving Healthcare Systems Research Priority Area
- Discuss the Addressing Disparities Program Research Priority Area
- Highlight synergies within the Healthcare Delivery and Disparities Research Program portfolio
- Discuss short- and intermediate-term next steps for the Healthcare Delivery and Disparities Research Program

Discussion Questions

1. Are there additional strategies PCORI should consider for advancing Addressing Disparities funding initiatives within the HDDR Program?
2. Within the HDDR Program, what are the risks and opportunities for the Addressing Disparities research priority area and the portfolio?
3. How do we effectively communicate the studies funded and their results in the individual research priority areas and the HDDR portfolio?
4. What are other combined HDDR program mission statements that we should consider?
5. How effective are the current Addressing Disparities and Improving Healthcare Systems frameworks in highlighting and explaining the program mission and aims?
6. What considerations should we be making in developing a framework for the HDDR program?

Overview of PCORI

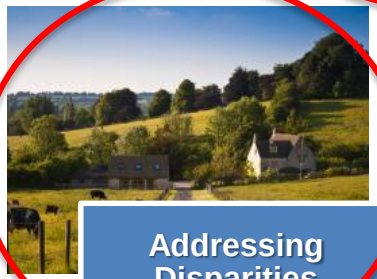
PCORI's MISSION

PCORI helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from **research guided by patients, caregivers and the broader health care community.**

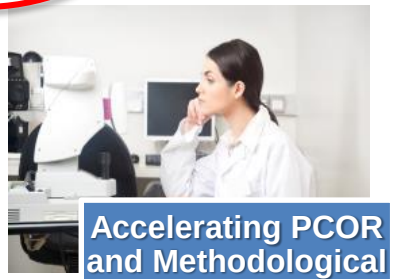
Assessment of Prevention, Diagnosis, and Treatment Options

Improving Healthcare Systems

Communication & Dissemination Research

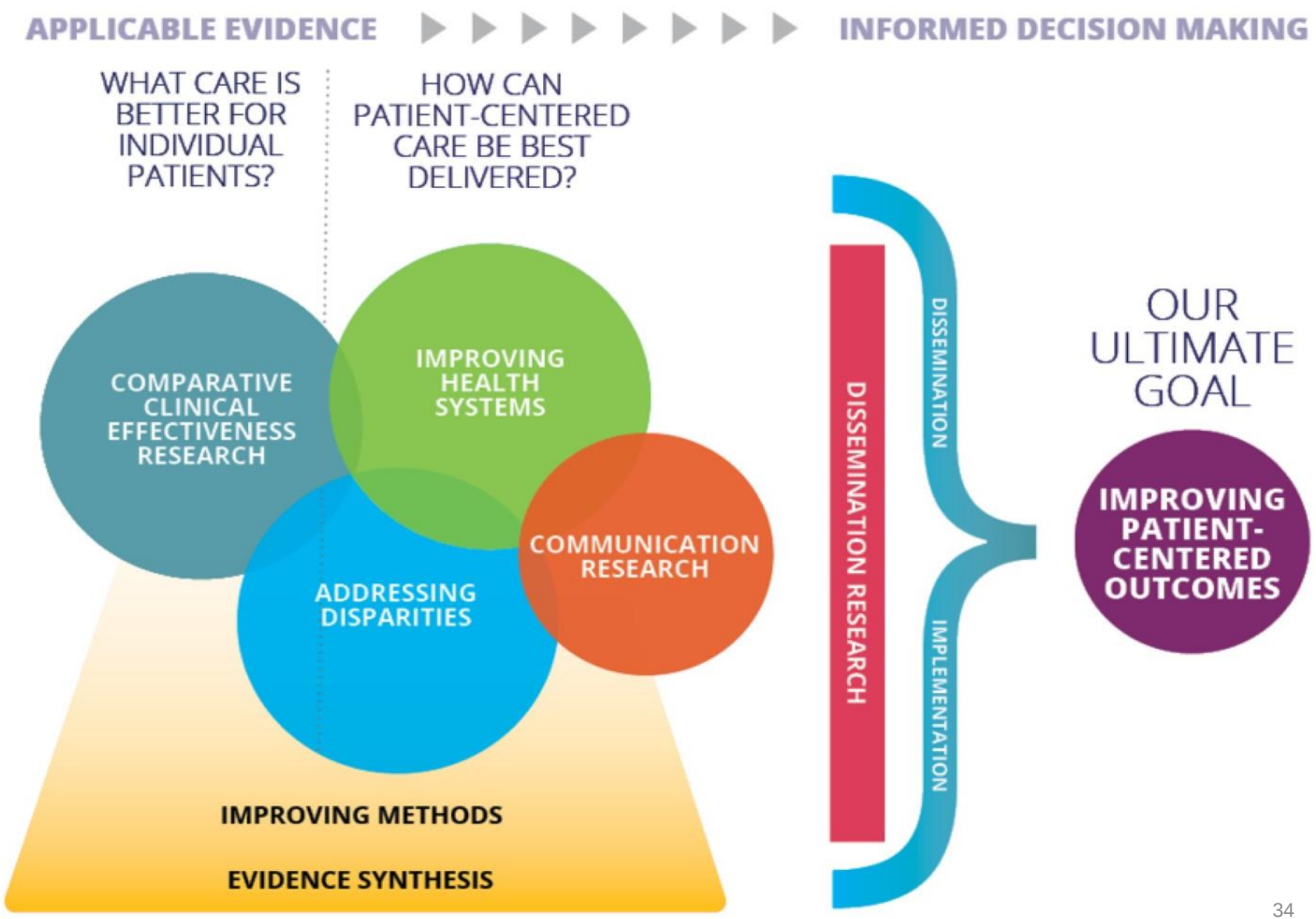


Addressing Disparities



Accelerating PCOR and Methodological Research

PCORI RESEARCH FRAMEWORK



Improving Healthcare Systems Research Priority Area

Improving Healthcare Systems (IHS) Mission Statement

PCORI's Vision, Mission, Strategic Plan

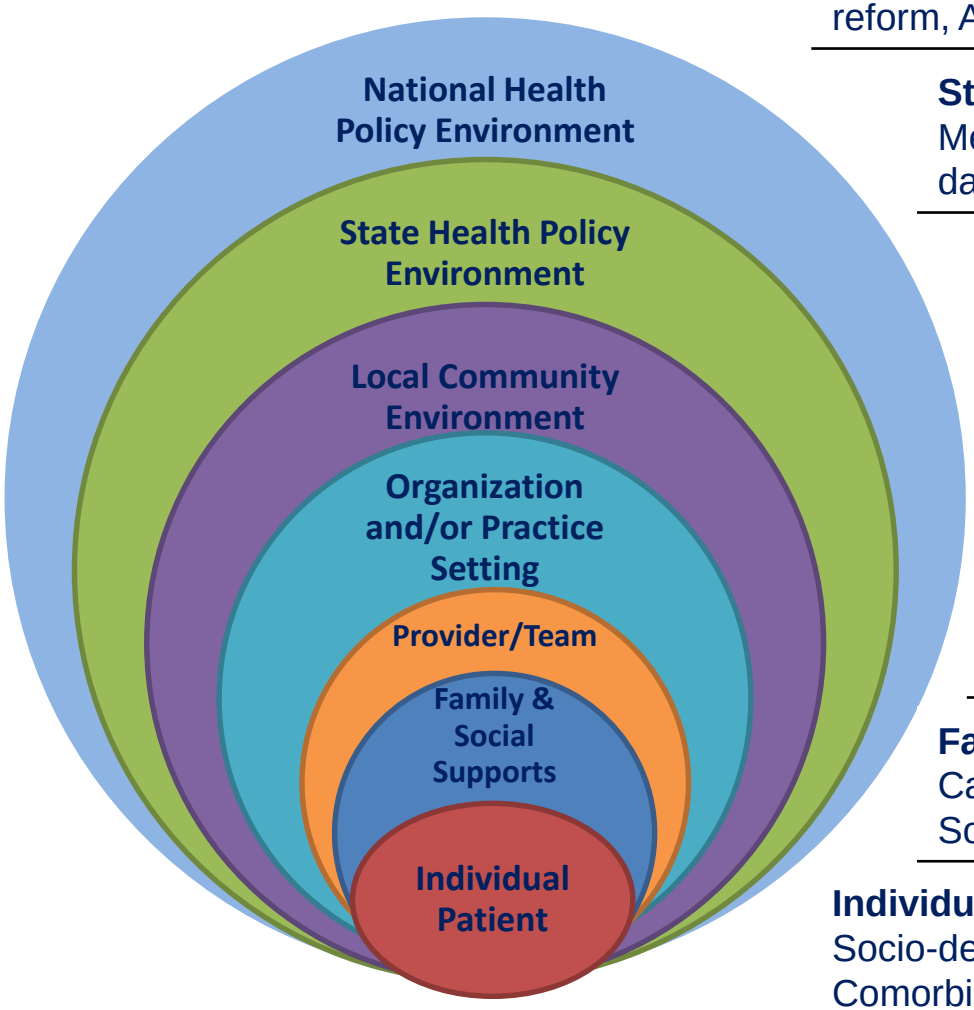
Program's Mission Statement

Compare healthcare system interventions that are intended to **optimize** the **quality**, **outcomes**, and/or **efficiency** of patient care

Program's Guiding Principle

To support studies of the comparative effectiveness of alternative features of healthcare systems that will **provide information of value to patients, their caregivers and clinicians, as well as to healthcare leaders, regarding which features of systems lead to better patient-centered outcomes**

IHS: Model for Systems Levels and Interventions



National Health Policy Environment
Medicare reimbursement, Federal health reform, Accreditations, etc.

State Health Policy Environment
Medicaid reimbursement, Hospital performance data

Local Community Environment
Community-based resources, Local hospital services, Local professional norms, etc.

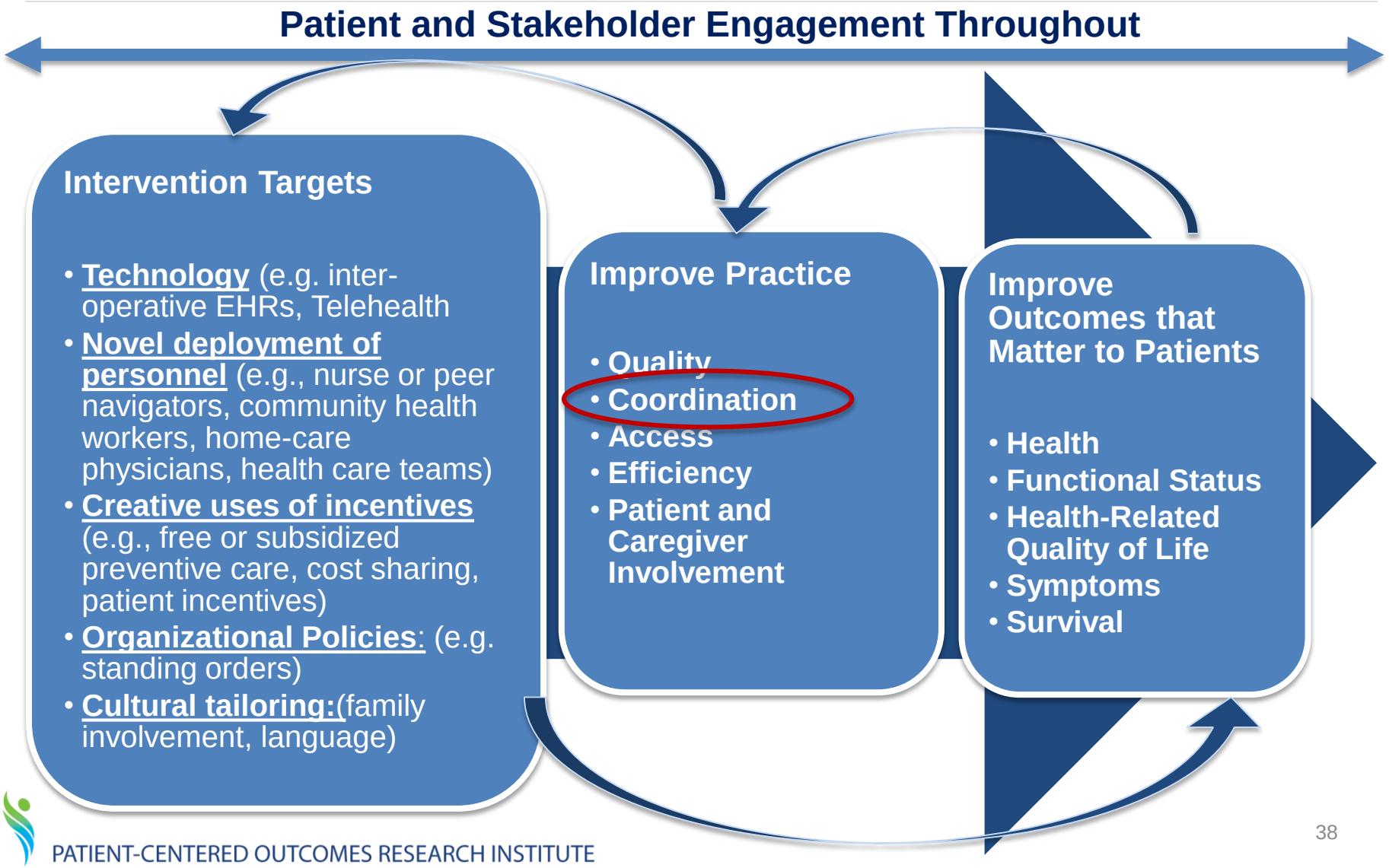
Organization and/or Practice Setting
Organizational leadership, Delivery system design, Clinical decision support, etc.

Provider/Team
Communication skills, cultural competency, staffing mix, team culture, role definition, etc.

Family & Social Supports
Caregivers, Friends, Network support, Social Media, etc.

Individual Patient
Socio-demographics, Insurance coverage, Comorbidities, Patient care preferences, Behavioral factors, Cultural perspectives

IHS: Strategic Framework



PCORI Funding Opportunities

- **Broad:**
  - Small ($1.5M, 3 year) investigator-initiated studies 2 cycles per year; competitive LOIs
  - Large ($5M, 5 year) investigator-initiated studies; 2 cycles per year; competitive LOIs (Improving Healthcare Systems only funding opportunity)
- **Pragmatic**:
  - $10M, 5 year head-to-head comparisons in large, representative study populations and settings; 3 cycles per year
  - PCORI, IOM, and AHRQ CER priorities
- **Targeted:**
  - Largest and require greatest specificity; range from $5M - $30M; often collaborations with other organizations; ad hoc funding
- **Natural Experiments:**
  - One time announcement (Improving Healthcare Systems only funding opportunity)

The IHS Portfolio Overview *(as of May 2017)*

Funding Mechanism	N of Projects	Total Funding
Broad	78	$209 million
Pragmatic	7	$90 million
Targeted	4	$65 million
Natural Experiments	3	$7 million
Total	**92**	**$371 million**

New IHS Projects – Awarded Dec. 2016

Project Title	PI Name	Institution
Expanding Access to Home-based Palliative Care through Primary Care Medical Groups	Susan Enguidanos, PhD, MPH	University of Southern California
Comparing Patient-Centered Outcomes for Adults and Children with Asthma in High-Deductible Health Plans with and without Preventive Drug Lists	Alison Galbraith, MD, MPH	Harvard Pilgrim Health Care, Inc.
Ambulatory Cancer Care Electronic Symptom Self-Reporting (ACCESS) for Surgical Patients	Andrea Pusic, MD, MS	Memorial Sloan Kettering Cancer Center
Improving Patient-Centered Communication in Primary Care: A Cluster Randomized Controlled Trial of the Comparative Effectiveness of Three Interventions	Ming Tai-Seale, PhD, MPA	Palo Alto Medical Foundation Research Institute

New PCS Projects – Awarded March 2017

Project Title	PI Name	Institution
A Simple Large Trial of Patient-Centered Care for Opioid Use Disorders in Federally Qualified Healthcare Centers and Specialty Care Settings	David Gastfriend, MD	Treatment Research Institute
Improving Transition from Acute to Post-Acute Care following Traumatic Brain Injury*	Jeanne Hoffman, PhD	University of Washington

* Priority topic endorsed by IHS Advisory Panel

Addressing Disparities Research Priority Area

Addressing Disparities (AD) Mission Statement

PCORI's Vision, Mission, Strategic Plan

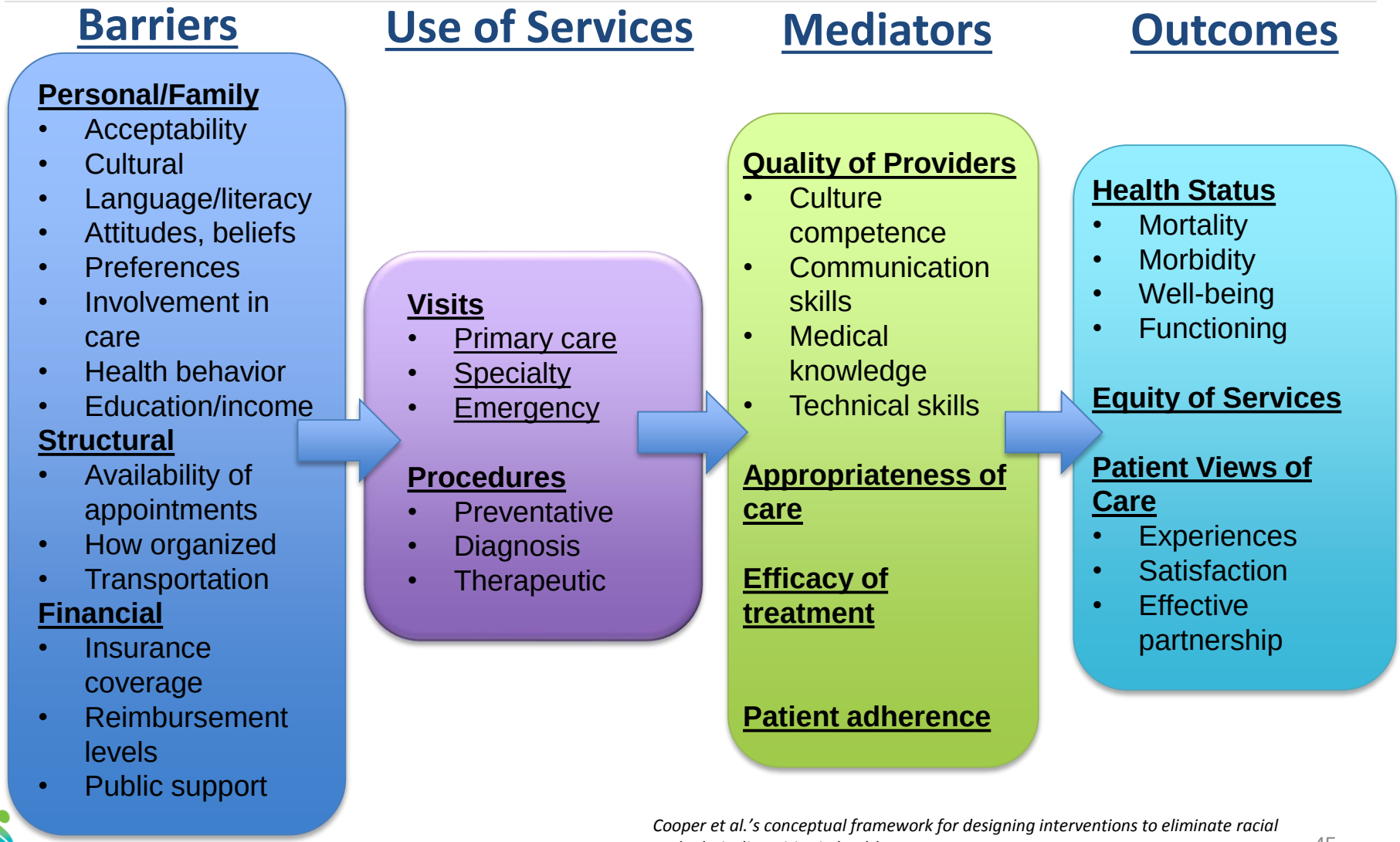
Program's Mission Statement

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

Program's Guiding Principle

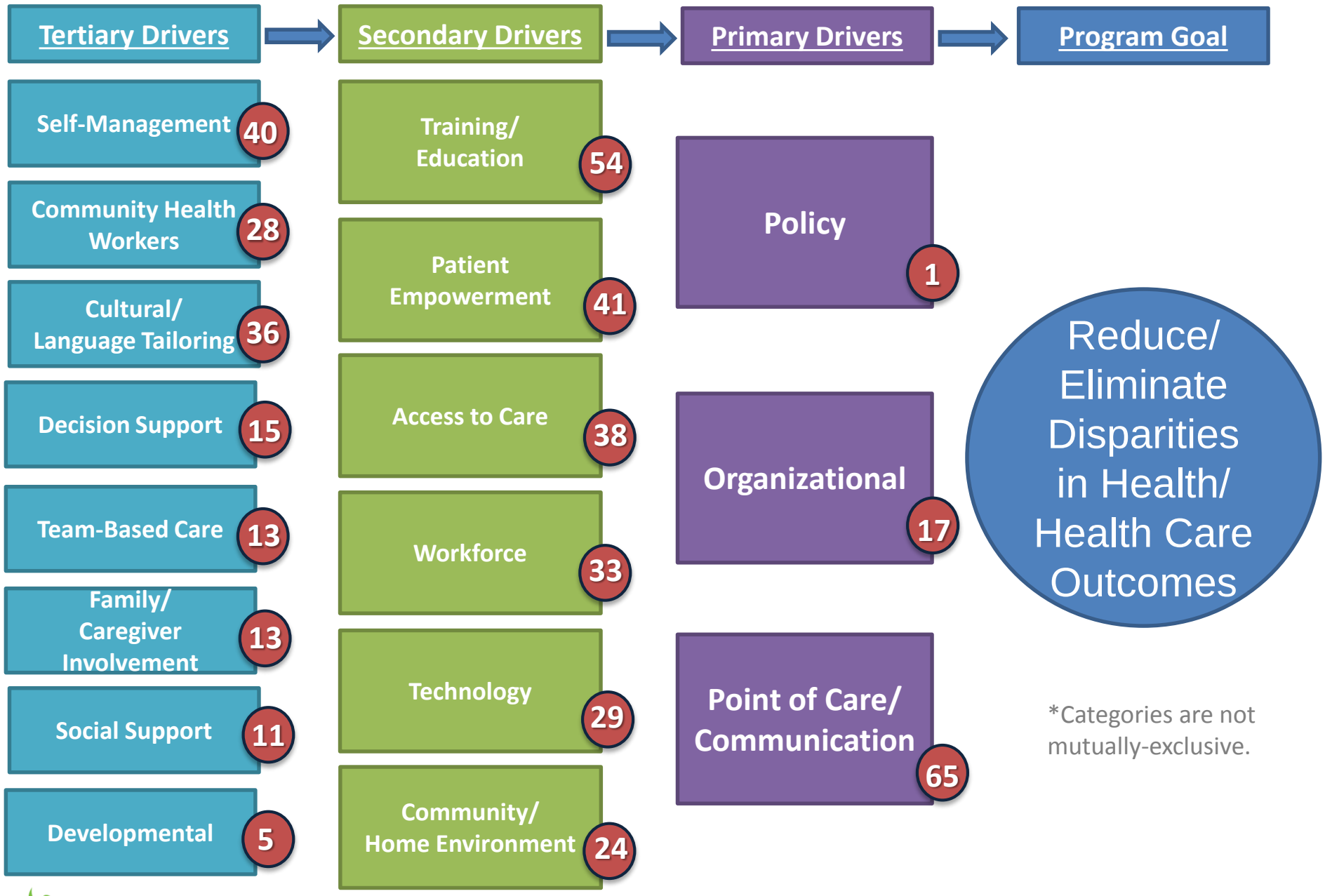
To support comparative effectiveness research that will identify best options for reducing and **eliminating disparities**

AD: Barriers and Mediators of Equitable Healthcare Framework



Cooper et al.'s conceptual framework for designing interventions to eliminate racial and ethnic disparities in health care

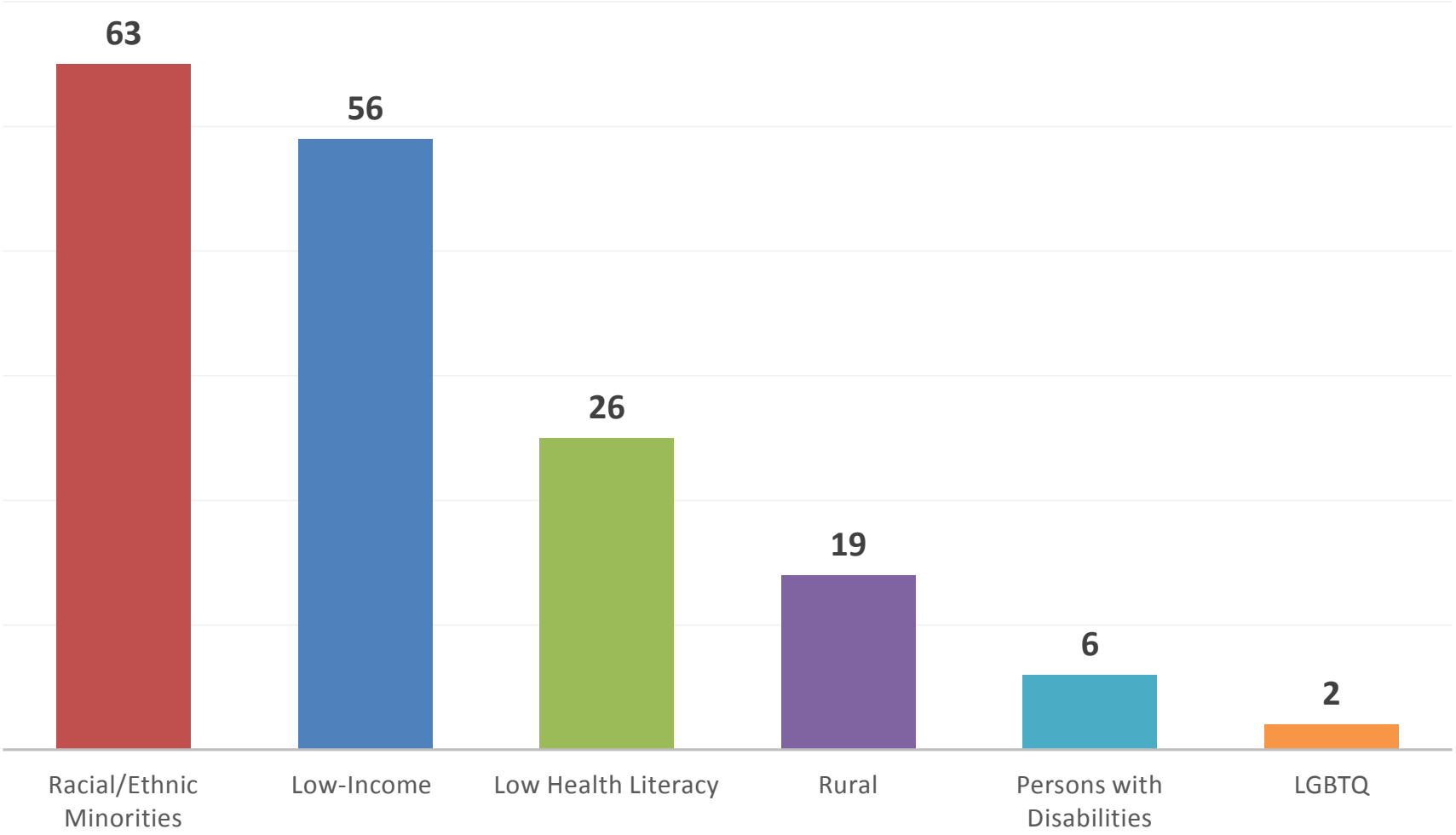
AD Driver Model



*Categories are not mutually-exclusive.

AD Populations of Interest

*not mutually exclusive



The AD Portfolio Overview *(as of May 2017)*

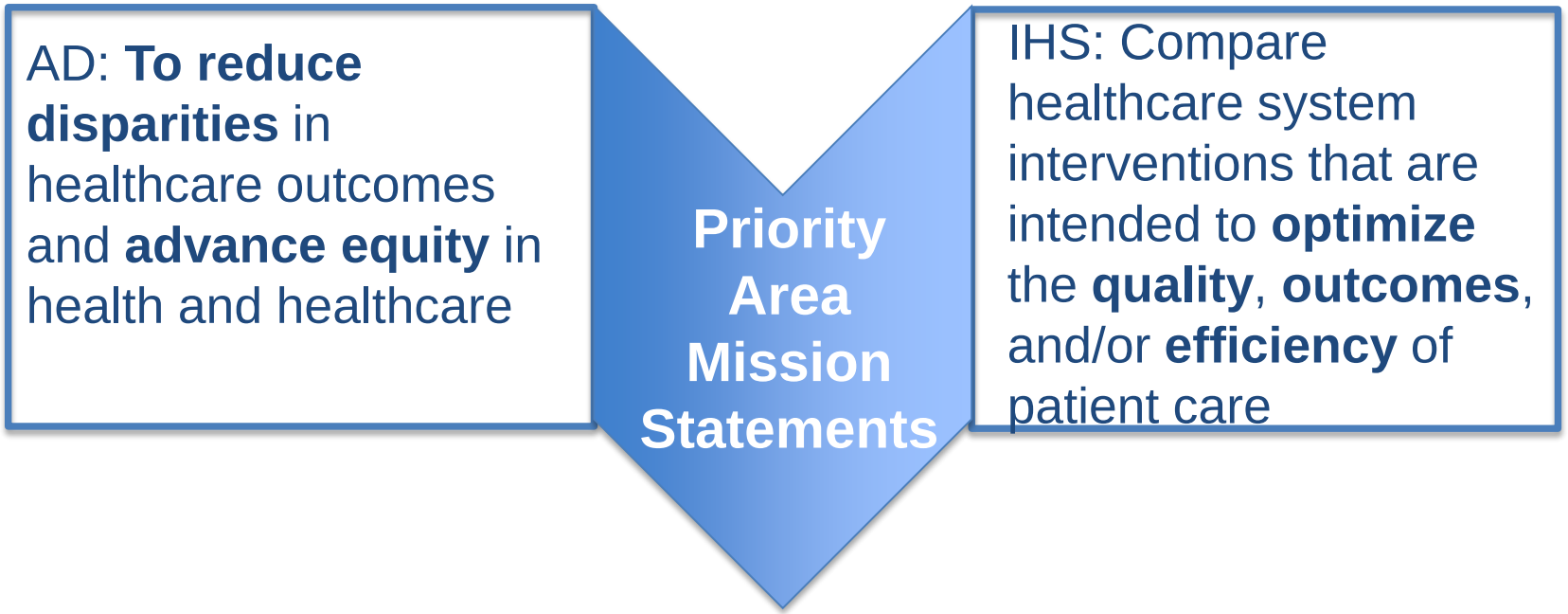
Funding Mechanism	N of Projects	Total Funding
Broad	58	$107 million
Pragmatic	2	$25 million
Targeted	12	$65 million
Total	**72**	**$197 million**

New AD Projects – Awarded Dec. 2016

Project Title	PI Name	Institution
Improving Outcomes for Low-Income Mothers with Depression: A Comparative Effectiveness Trial of Two Brief Interventions in the Patient-Centered Medical Home	Michael Silverstein, MD, MPH	Boston Medical Center
Comparative Effectiveness of Diabetes Prevention Programs	Pearl McElfish, PhD, MS, MBA	University of Arkansas for Medical Sciences
Addressing Childhood Hearing Loss Disparities in an Alaska Native Population: A Community Randomized Trial	Philip Hofstetter, MA	Norton Sound Health Corporation
A Randomized-Controlled Trial to Compare the Reach, Effectiveness, and Maintenance of Two Family-Based Childhood Obesity Treatment Programs in a Medically Underserved Region	Jamie Zoellner, PhD	Virginia Polytechnic Institute and State University

Linking the Improving Healthcare Systems and Addressing Disparities Programs

Healthcare Delivery and Disparities Research (HDDR) Program Mission Statement



HDDR Program Mission (Draft)

To support studies that compare interventions designed to improve the quality and/or efficiency of care in health care organizations that are tailored to the cultural, clinical, and and/or socio-economic needs of individual patients; and that improve health, health equity and healthcare outcomes

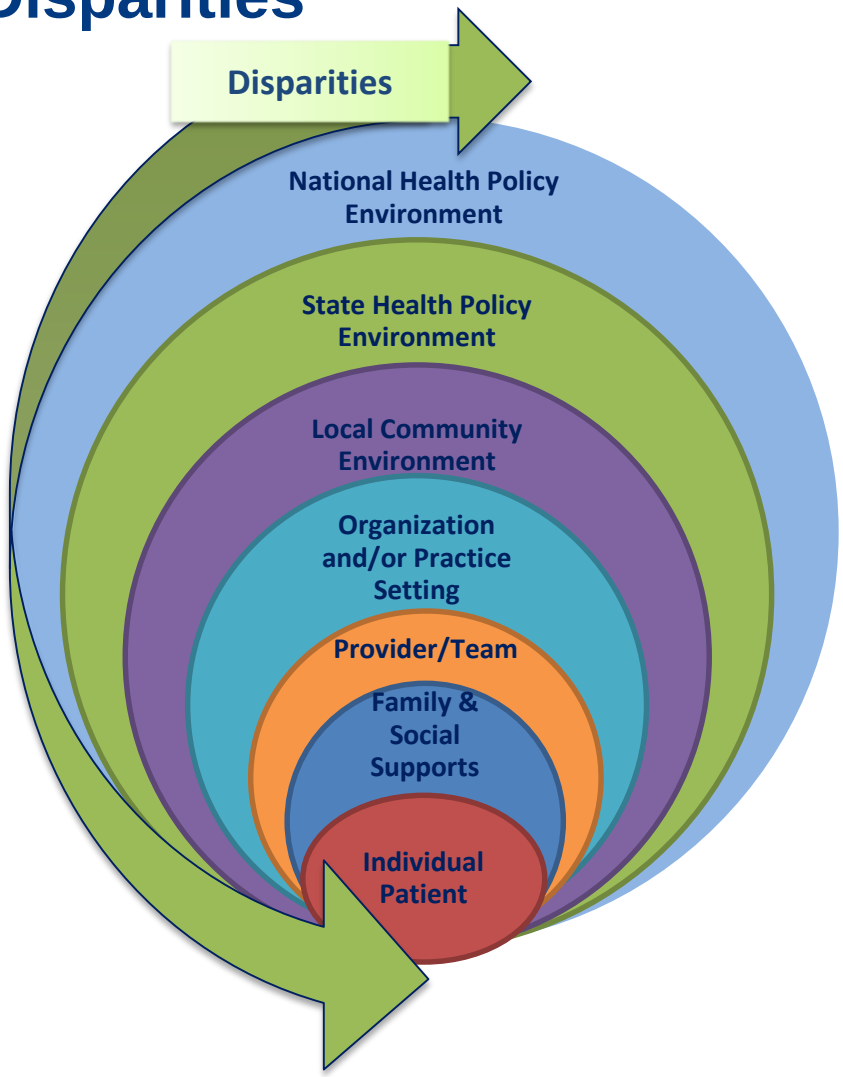
Healthcare Delivery and Disparities Research Program Projects and Funding

Number of projects**: 164**
Amount awarded**: $568 million**
Number of states represented: **34 (plus DC)**

Addressing Disparities (AD)
Number of Projects: **72**
Amount Awarded: **$197 million**

Improving Healthcare Systems (IHS)
Number of Projects: **92**
Amount Awarded: **$371 million**

PCORI Funded Studies at the Intersection of Systems and Disparities



National Health Policy Environment
Natural Experiments of the Impact of Population-Targeted Health Policies to Prevent Diabetes and Its Complications (PI: Lizheng Shi)

State Health Policy Environment
Comparative Effectiveness of State Psychotropic Oversight Systems for Children in Foster Care (PI: Stephen Crystal)

Local Community Environment
Effectiveness of Collaborative Goal-Setting Versus IMPaCT Community Health Worker Support for Improving Chronic Disease (PI: Judith Long)

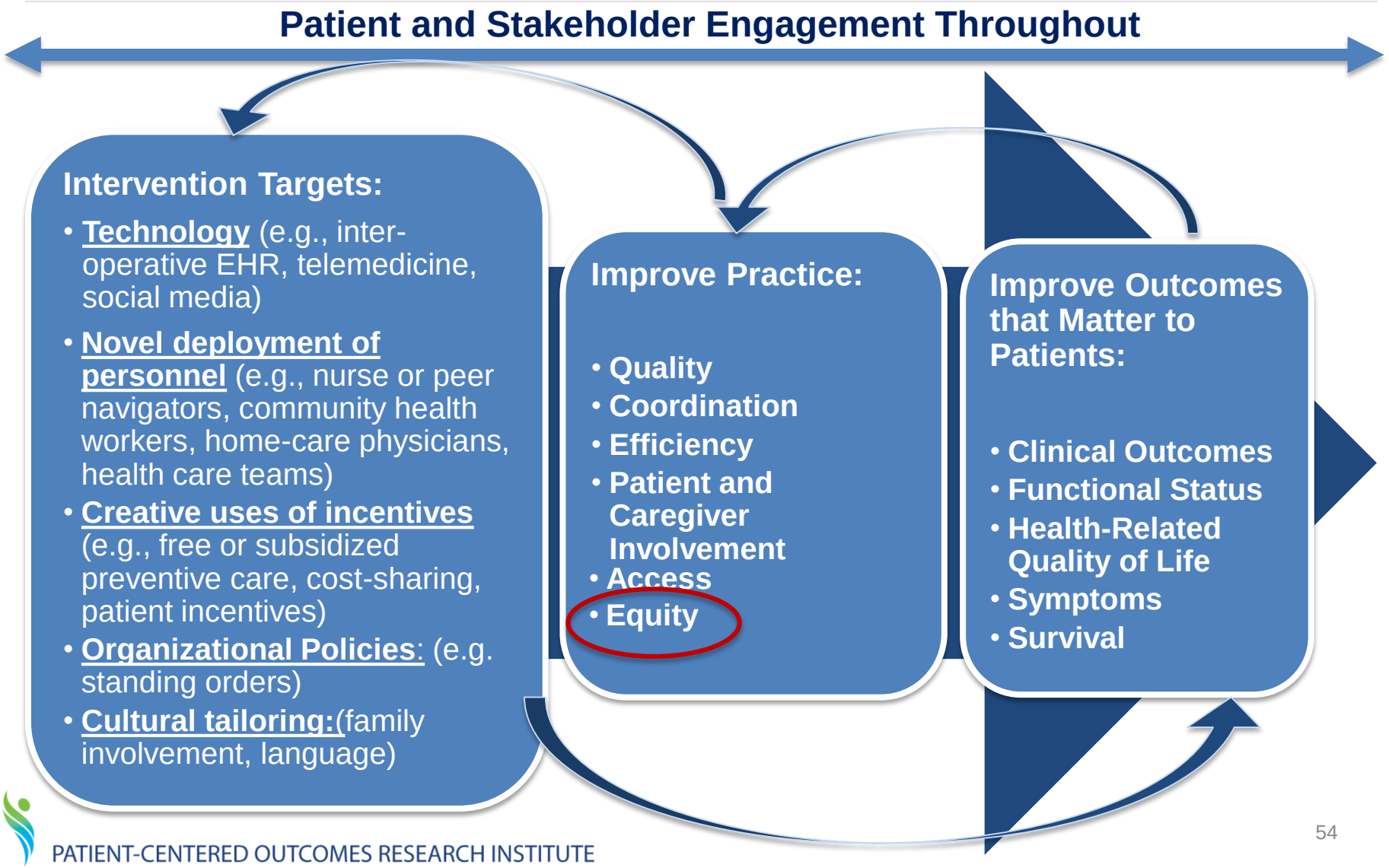
Organization and/or Practice Setting
Using the Electronic Medical Record to Improve Outcomes and Decrease Disparities in Screening for Child Physical Abuse (PI: Rachel Berger)

Provider/Team
Building a Multidisciplinary Bridge Across the Quality Chasm in Thoracic Oncology (PI: Raymond Osarogiagbon)

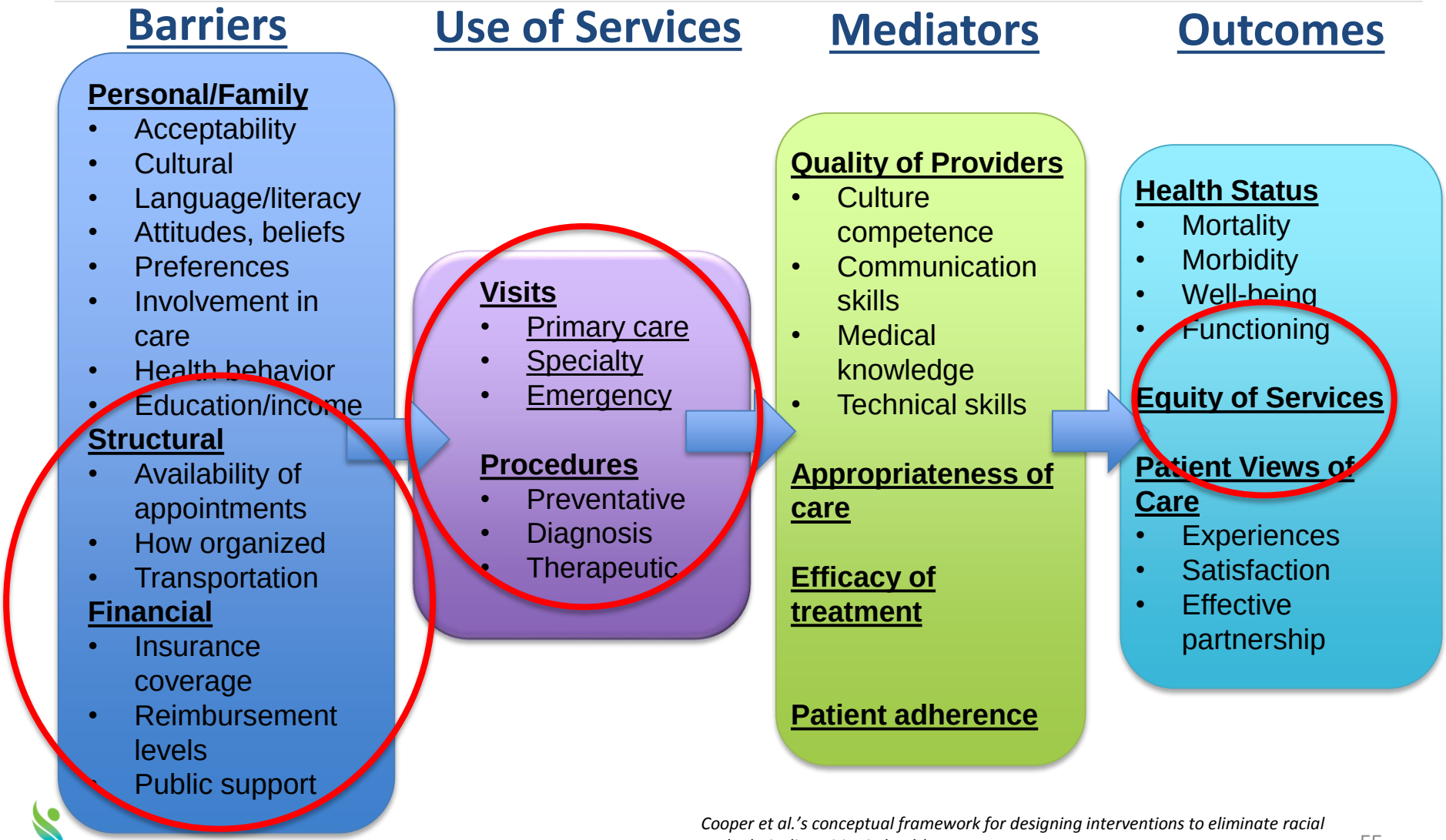
Family & Social Supports
Community Engagement for Early Recognition and Immediate Action in Stroke (CEERIAS) (PI: Shyam Prabhakaran)

Individual Patient
Addressing HIV Treatment Disparities Using a Self-Management Program and Interactive Personal Health Record (PI: Kevin Fiscella)

IHS Strategic Framework Modified for HDDR

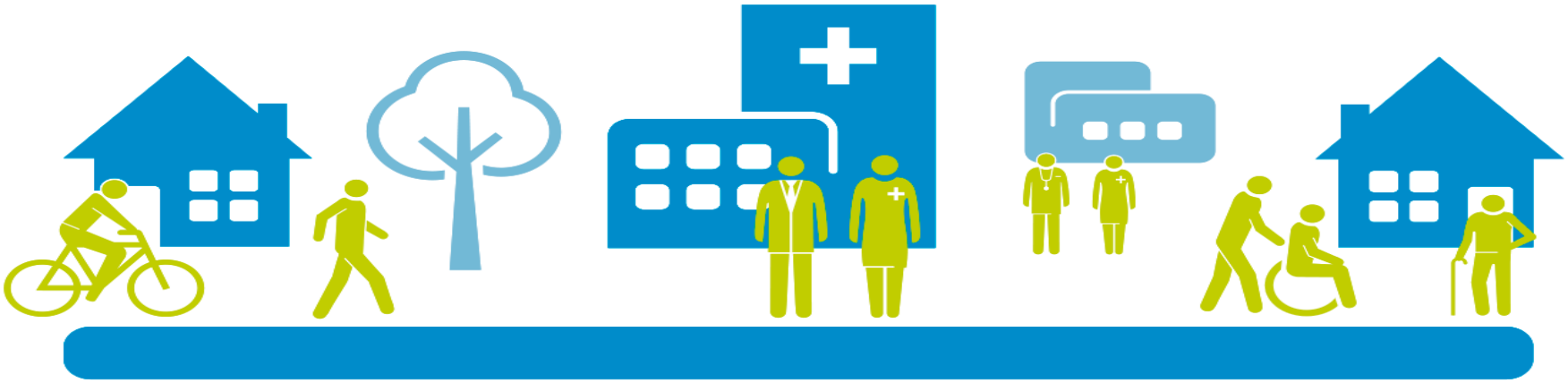


AD Barriers and Mediators of Equitable Healthcare Framework



Cooper et al.'s conceptual framework for designing interventions to eliminate racial and ethnic disparities in health care

HDDR Projects Across the Care Continuum (as of May 2017)



Addressing Disparities Research Priority Area

Prevention	Screening	Diagnosis	Treatment/ Management	Survivorship	End of Life/ Palliative Care
n= 7	n= 5	n= 0	n= 59	n= 1	n= 0

Improving Healthcare Systems Research Priority Area

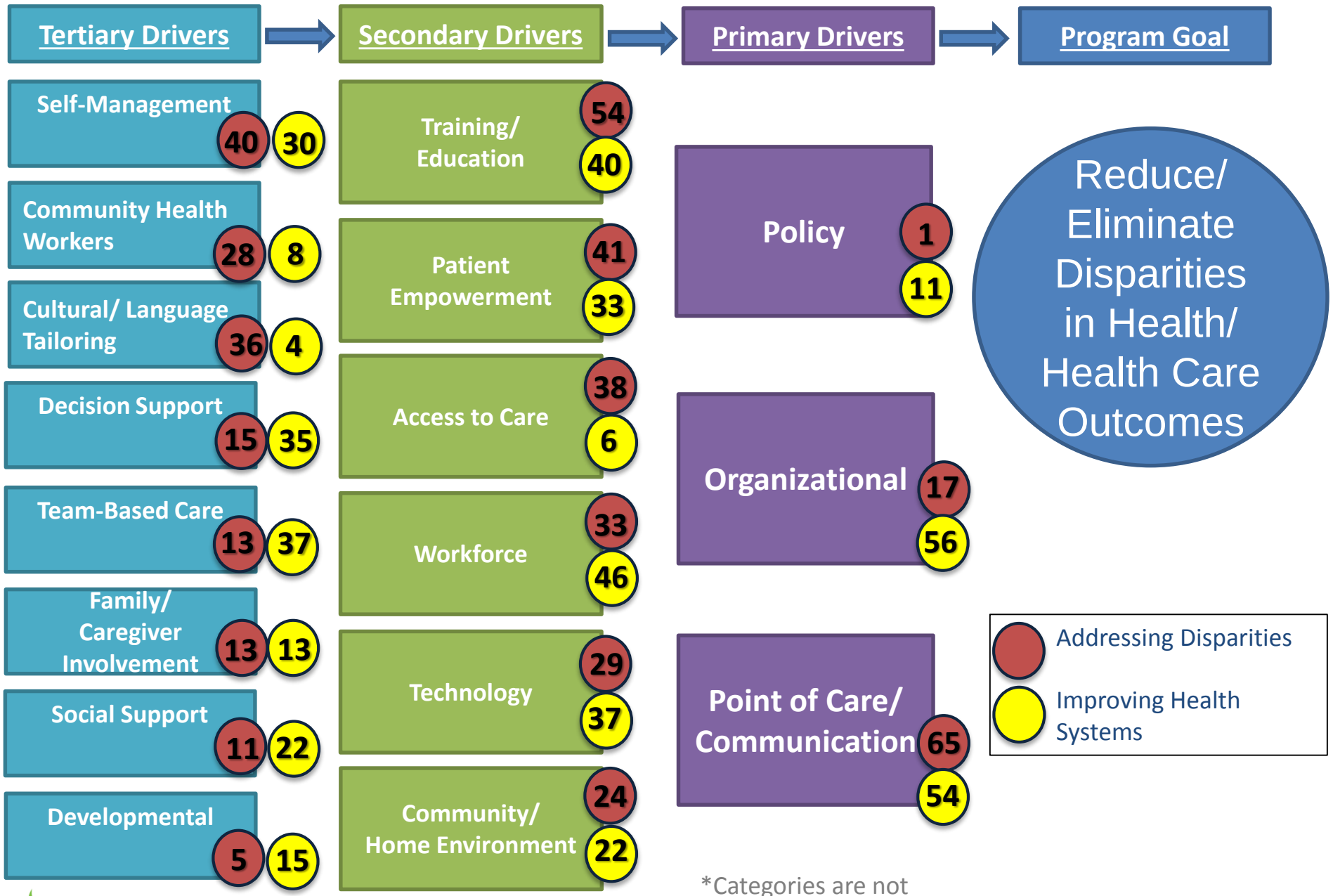
Prevention	Screening	Diagnosis	Treatment/ Management	Survivorship	End of Life/ Palliative Care
n = 7	n= 3	n= 0	n= 72	n= 3	n= 7

The HDDR funded portfolio addresses multiple phases of the healthcare continuum, ranging from prevention, and various phases of treatment, to survivorship and end of life.

Using the Care Continuum as a Strategy to Identify Gaps in Cancer Care

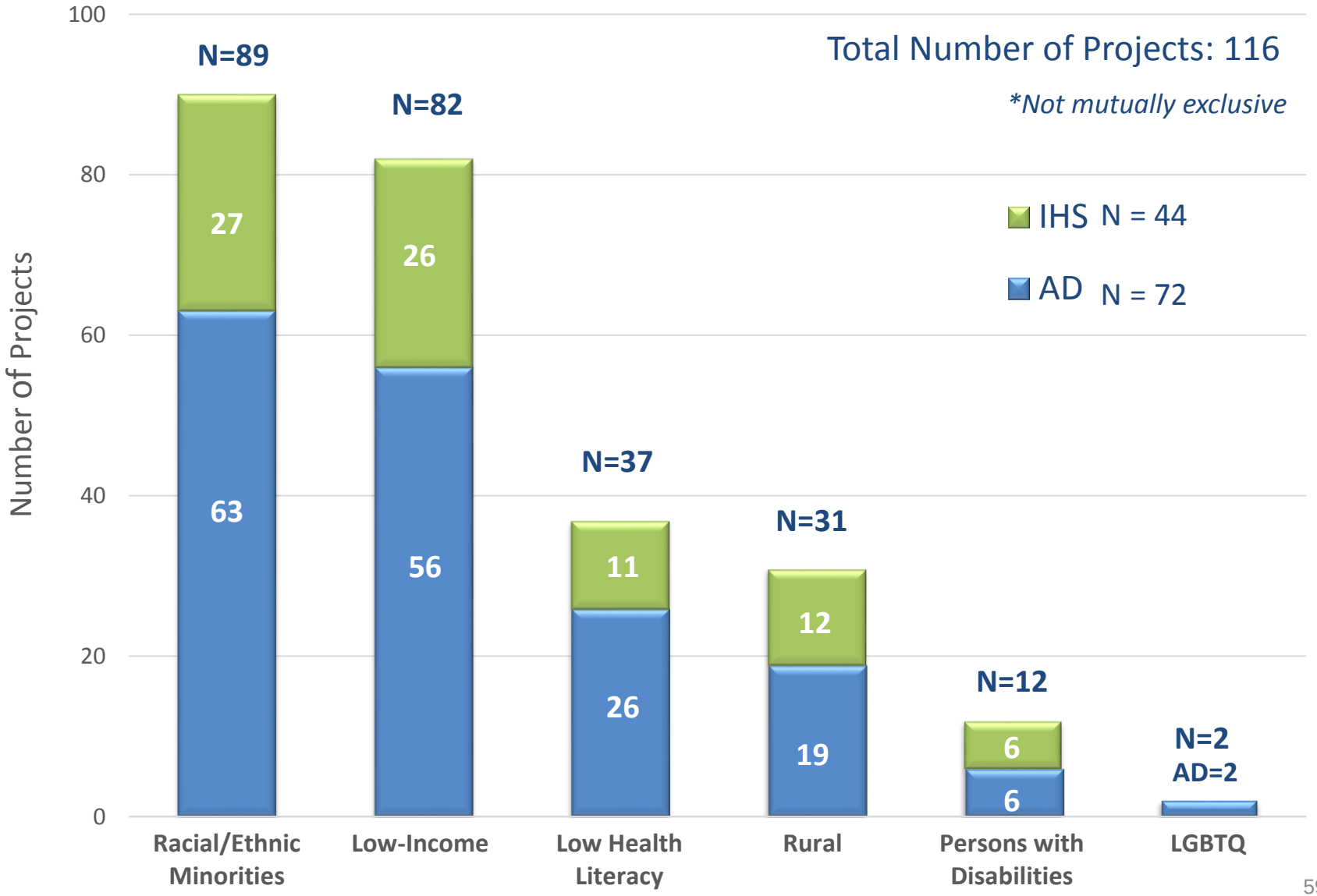
Prevention	Cultural Tailoring of Educational Materials to Minimize Disparities in HPV Vaccination (PI: Amanda Dempsey)
Screening	Increasing CRC Screening among Hispanic Primary Care Patients (PI: Ronald Myers)
Diagnosis	*****Gap Area within the AD and IHS Research Priority Areas*****
Treatment/ Management	Eliminating Patient Identified Socio-legal Barriers to Cancer Care (PI: Tracy Battaglia)
Survivorship	Nueva Vida Intervention: Improving QOL in Latina Breast Cancer Survivors and Their Caregivers (PI: Kristi Graves)
End of Life/ Palliative Care	Improving Advanced Cancer Patient-Centered Care by Enabling Goals of Care Discussions (PI: Nina Bickell)

AD Driver Model Mapped with HDDR Projects

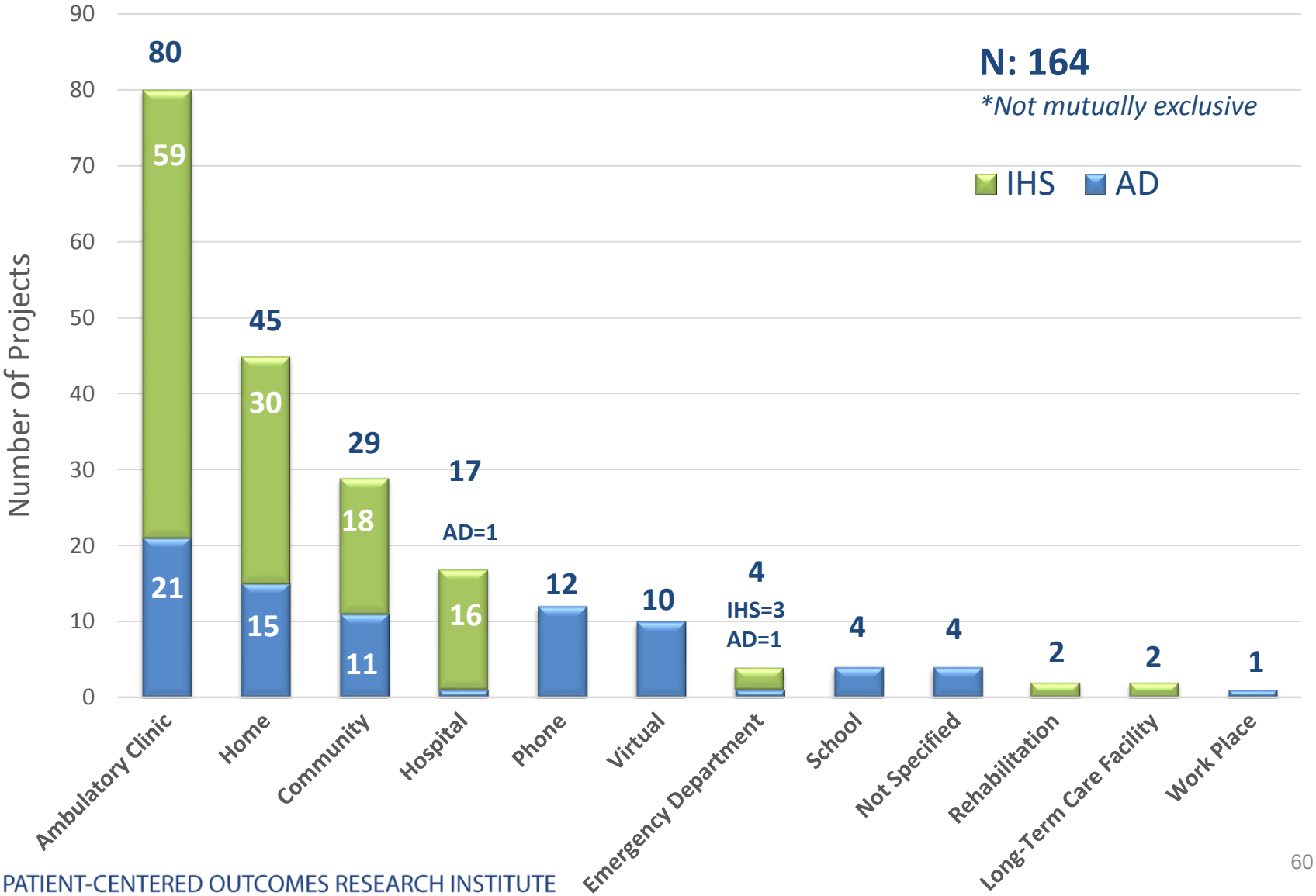


*Categories are not mutually-exclusive.

Healthcare Delivery and Disparities Research Portfolio: AD Populations of Interest



HDDR Portfolio by Intervention Settings



HDDR Portfolio by Primary Disease Focus

*as of May 2017

Using Technology to Deliver Multidisciplinary Care to Individuals with Parkinson's Disease in Their Homes

Engagement

- Patient advisory board will inform study design and implementation, particularly outreach, and patient feedback on perceived care quality will be measured

Potential Impact

- Could change practice by demonstrating the feasibility of using telemedicine to deliver high-quality care into the homes of individuals with Parkinson's disease

Methods

- Randomized controlled trial

AD Population of Interest: Persons with disabilities

Disease Focus: Neurological Disorders: Parkinson's Disease

Intervention Setting: Home

Tests the effectiveness of using telemedicine to connect patients with Parkinson's Disease to a neurologist without having to leave their homes. Key outcomes include feasibility of implementation, enhanced quality of life, and improved quality of care.

Earl Dorsey, MD, MBA,
University of Rochester
Rochester, NY

Addressing Disparities Research Project, awarded May 2013

Comparing Patient -entered Outcomes in the Management of Pain between Emergency Departments and Dedicated Acute-Care Facilities for Adults with Sickle Cell Disease

Compares patient-centered outcomes, as well as the time it takes to be treated for pain, between care received at emergency departments (EDs) and the Infusion Clinics (IC) model. ED care for SCD is marked by long delays and lack of efficacy. ICs are alternatives to ED care that provide rapid pain control and frequent reassessments.

Sophie Lanzkron, MD, MHS,
Johns Hopkins University
Baltimore, Maryland

Potential Impact

- Could change practice by demonstrating the effectiveness of the infusion clinic (IC) model to improve healthcare delivery for adults with SCD seeking care for their pain; expanding access to infusion centers will allow patients in pain to have their needs met more effectively

Engagement

- Patients living with sickle cell disease (SCD), community-based organizations, and stakeholders participated in the development and design of the study, and will continue to play a role by participating in quarterly meetings throughout the study and analysis

Methods

- Prospective observational study

AD Population of Interest: Racial/ Ethnic Minorities

Disease Focus: Rare Disease: Sickle Cell Disease

Intervention Setting: Emergency Department and Ambulatory clinic

Improving Healthcare Systems, awarded September 2014

Next Steps (Short-term): Advancement of Targeted Funding Priorities

Priority Topic Area	Topic Trajectory
Community-based Palliative Care Delivery for Adult Patients with Advanced Illnesses and their Caregivers - $48 Million Available	• Awards announced: September 2017
Managing of Care Transitions for Emerging Adults with Sickle Cell Disease - $25 Million Available	• Awards announced: September 2017
Strategies to Prevent Unsafe Opioid Prescribing in Primary Care among Patients with Acute or Chronic Non-Cancer Pain - $30 Million Available	• Awards announced: September 2017
Medication Assisted Treatment Delivery for Pregnant Women with Substance Use Disorders involving Prescription Opioids and/or Heroin - $19 Million Available	• Board approved: May 8, 2017 • Targeted funding announcement released: October 2017
Pain Management for Individuals with Sickle Cell Disease	• Targeted funding announcement released: TBD

Next Steps (Intermediate-term): Advancing Topics in the Pragmatic Clinical Studies Funding Announcements

Priority Topic
Improving outcomes in mothers and babies at risk for disparities by comparing evidence-based models of perinatal care
Clinical interventions to reduce nontraumatic lower-extremity amputations in racial or ethnic minorities and low-income populations with diabetes

Discussion Questions

1. Are there additional strategies PCORI should consider for advancing Addressing Disparities funding initiatives within the HDDR Program?
2. Within the HDDR Program, what are the risks and opportunities for the Addressing Disparities research priority area and the portfolio?
3. How do we effectively communicate the studies funded and their results in the individual research priority areas and the HDDR portfolio?
4. What are other combined HDDR program mission statements that we should consider?
5. How effective are the current Addressing Disparities and Improving Healthcare Systems frameworks in highlighting and explaining the program mission and aims?
6. What considerations should we be making in developing a framework for the HDDR program?

Break

Awardee Presentation: An Emergency Department-to-Home Intervention to Improve Quality of Life and Reduce Hospital Use

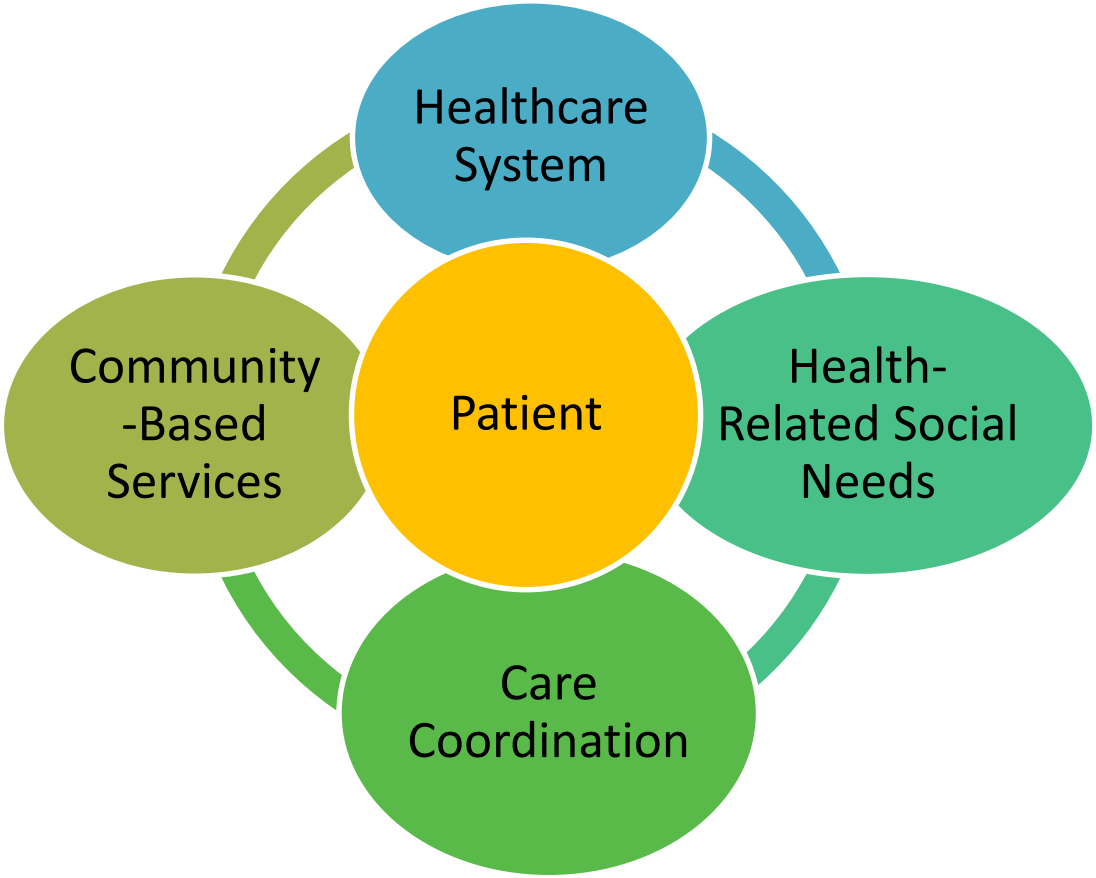
Donna Lynne Carden, MD, MPH

Professor and Director of Faculty Development for the Department of Emergency Medicine, *University of Florida*

Project Overview

Published Evidence

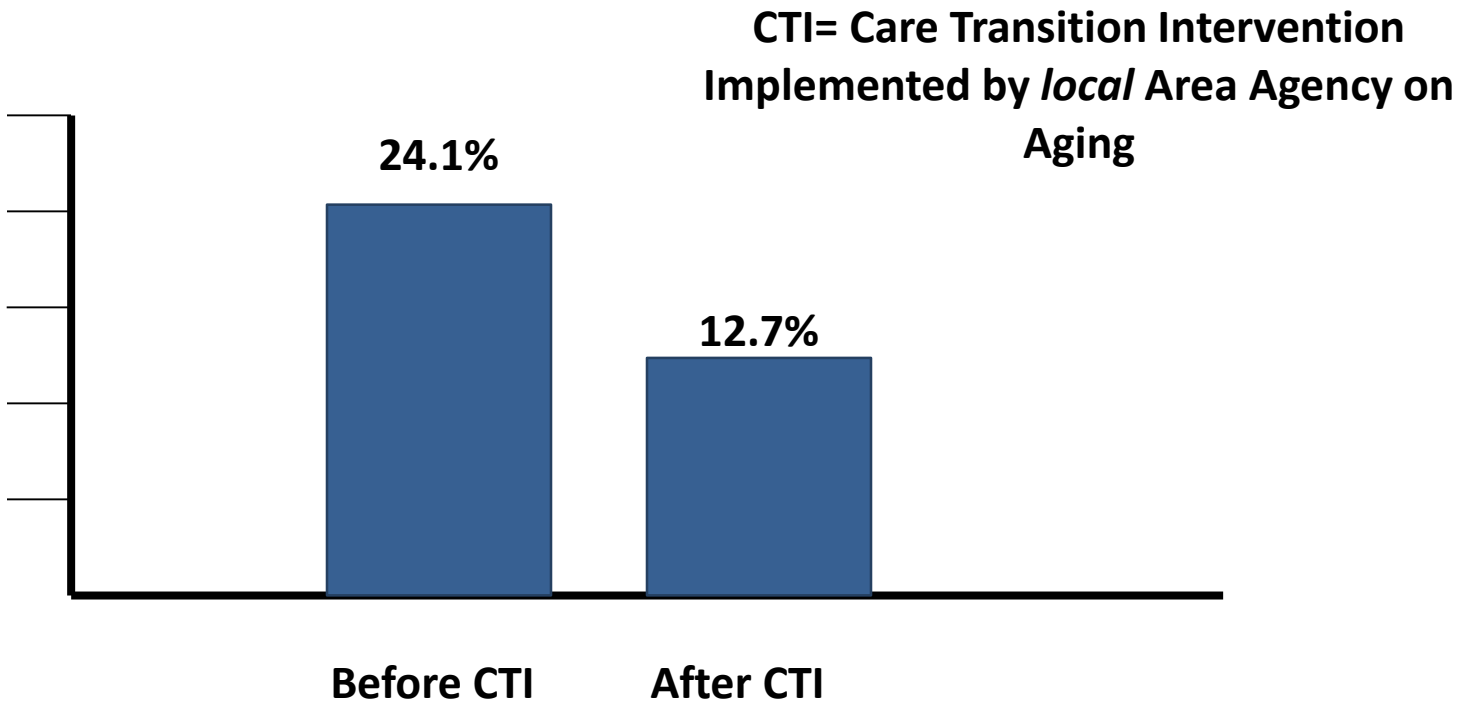
Improved care transitions, particularly for older, chronically ill Americans are a national priority.



UF UNIVERSITY of FLORIDA
The Foundation for The Gator Nation

Project Overview

Community Partners' Perspective



Care Transition Interventions Implemented in Admitted Patients Reduce Hospital Readmissions

Project Overview

Gaps in Knowledge Addressed by this Project

- U.S. emergency departments (ED) treat 130 million patient visits annually
- ED visits are *critical inflection or crisis points* in the patient's health trajectory
- Most transition efforts have focused on hospital discharges
- Better transitions into and out of the ED could result in more efficient resource utilization and a more seamless patient experience.
    - National Quality Forum

Project Overview

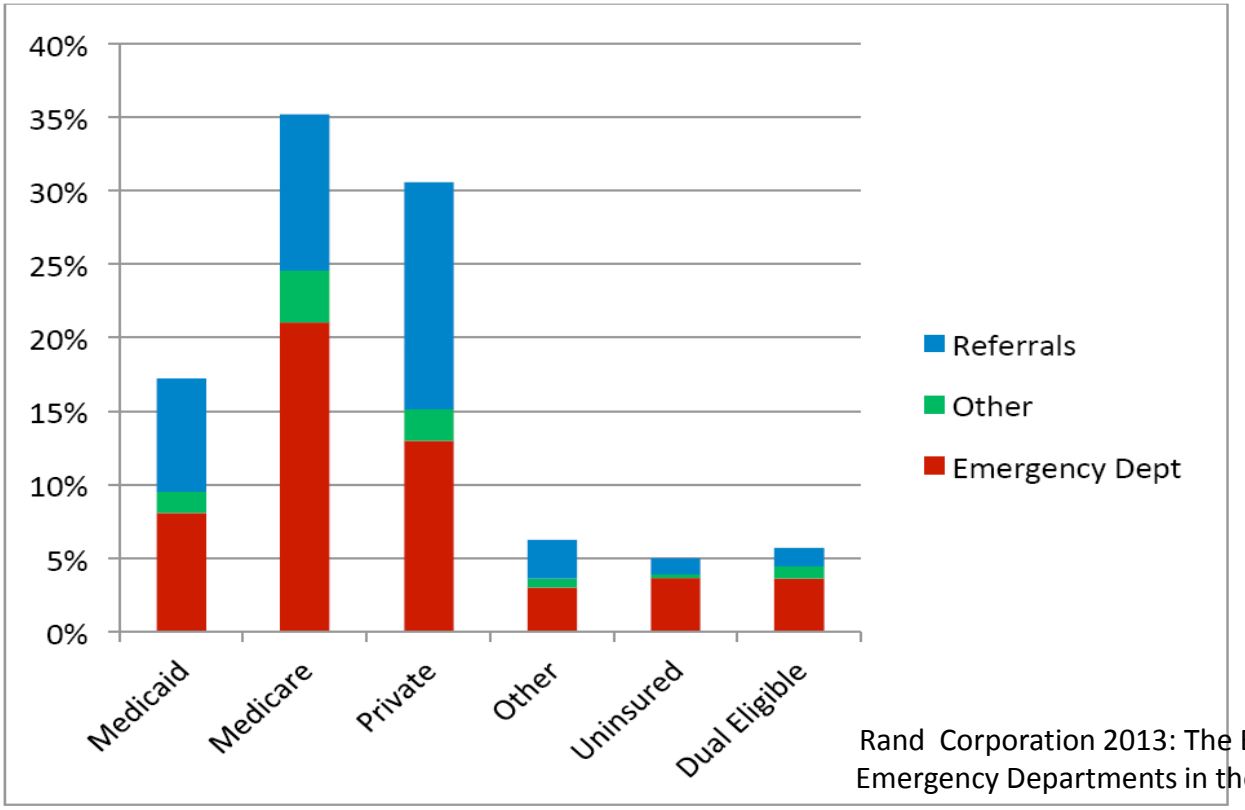
Patient and Stakeholder Engagement

- Partnered with:
  - Patients and Non-Professional Caregivers with recent ED visits
  - Community-Based Organizations (Area Agencies on Aging) in Gainesville and Jacksonville
  - Health Service Researchers and Emergency Physicians
  - Health System Managers
  - CMS Contractors


Original PCORI shortened

Project Overview

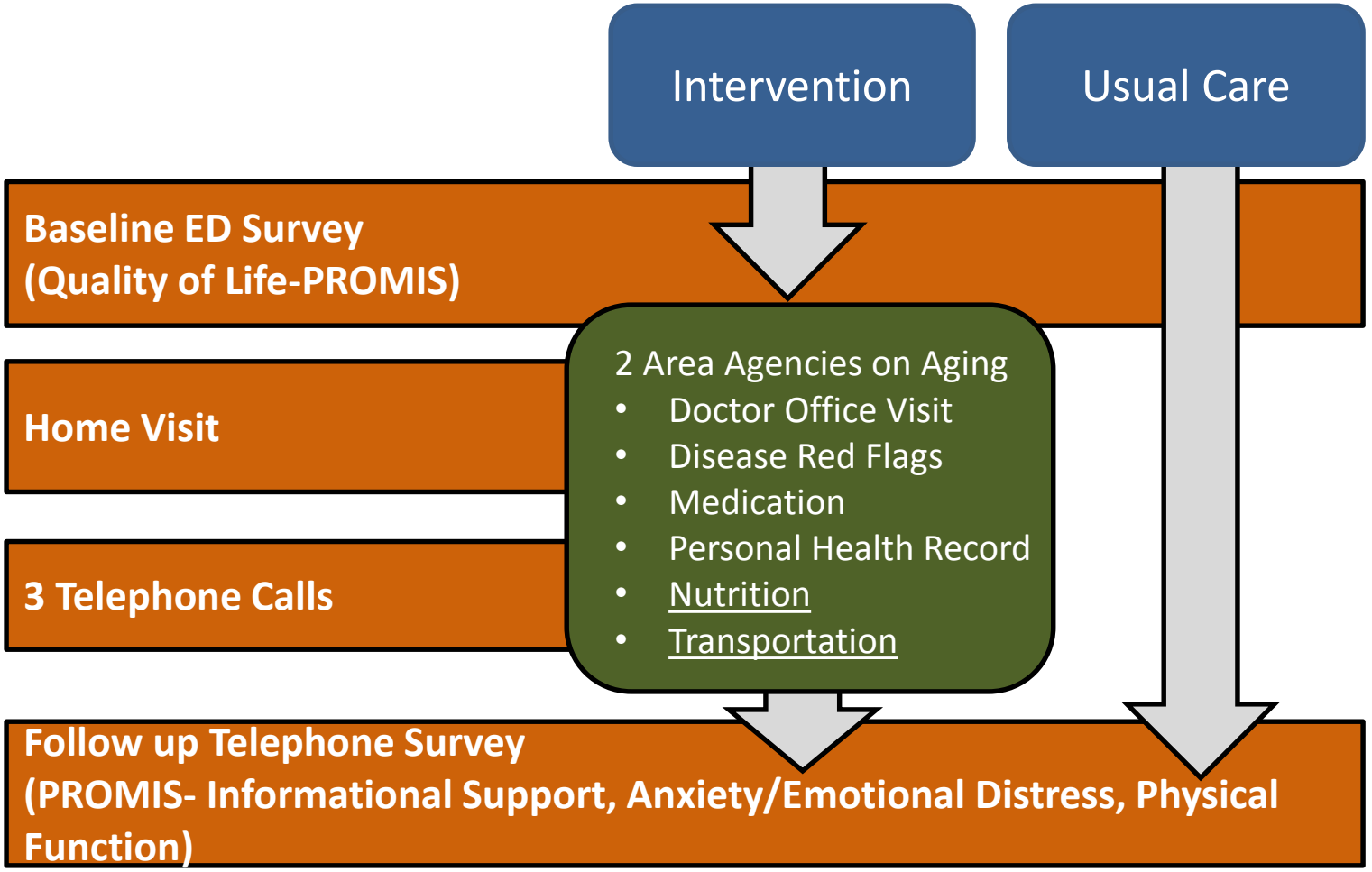
Clinician Partners' Perspective



Rand Corporation 2013: The Evolving Role of Emergency Departments in the United States.

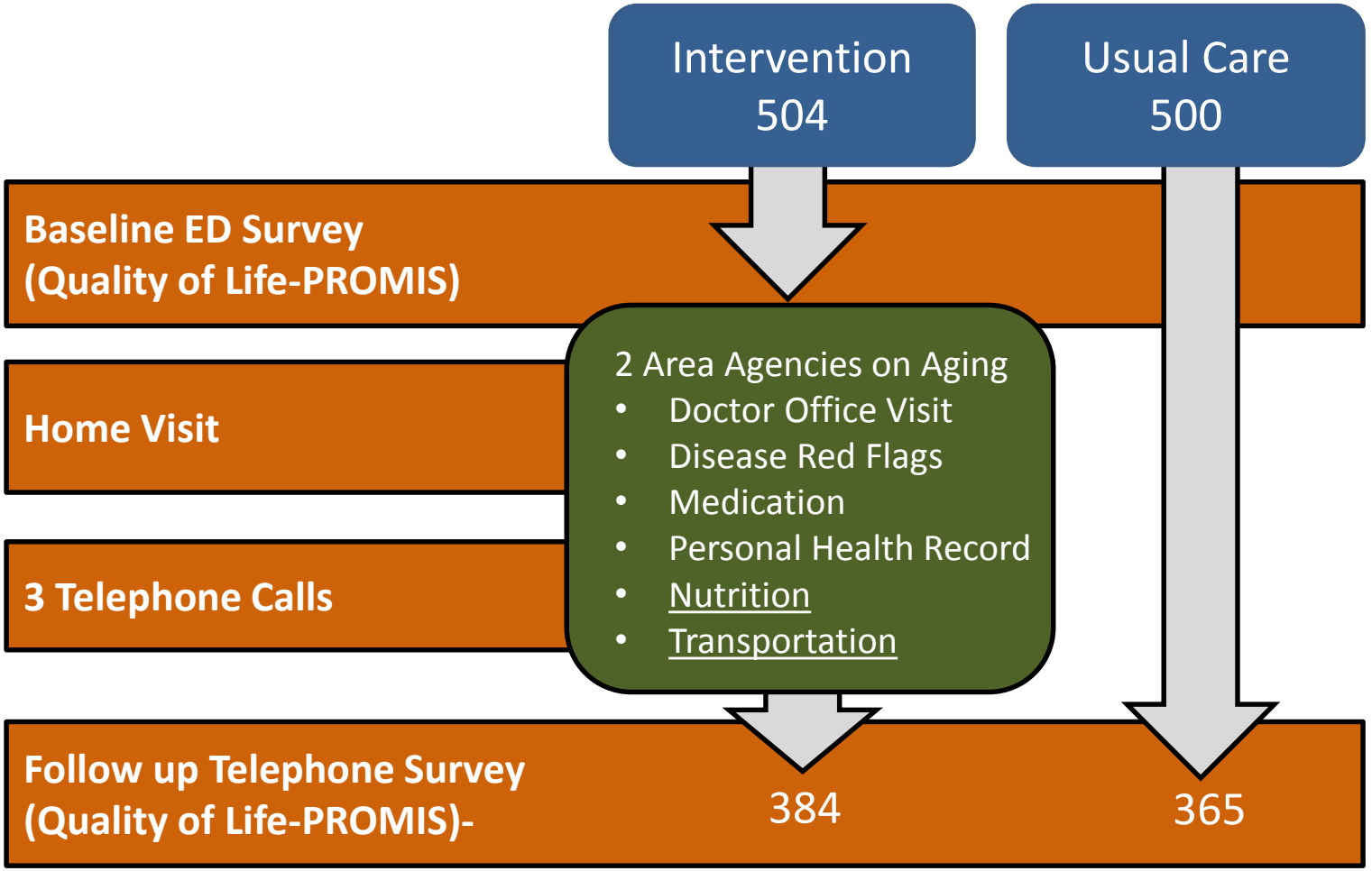
Most Medicare Beneficiaries Enter the Hospital Through the ED

Project Overview:
Mixed Methods Study Design



Aim 1- Quantitative analysis using RCT design and assessing Quality of life and Health Service Use; **Aim 2:** Qualitative analysis of In-Depth Interviews

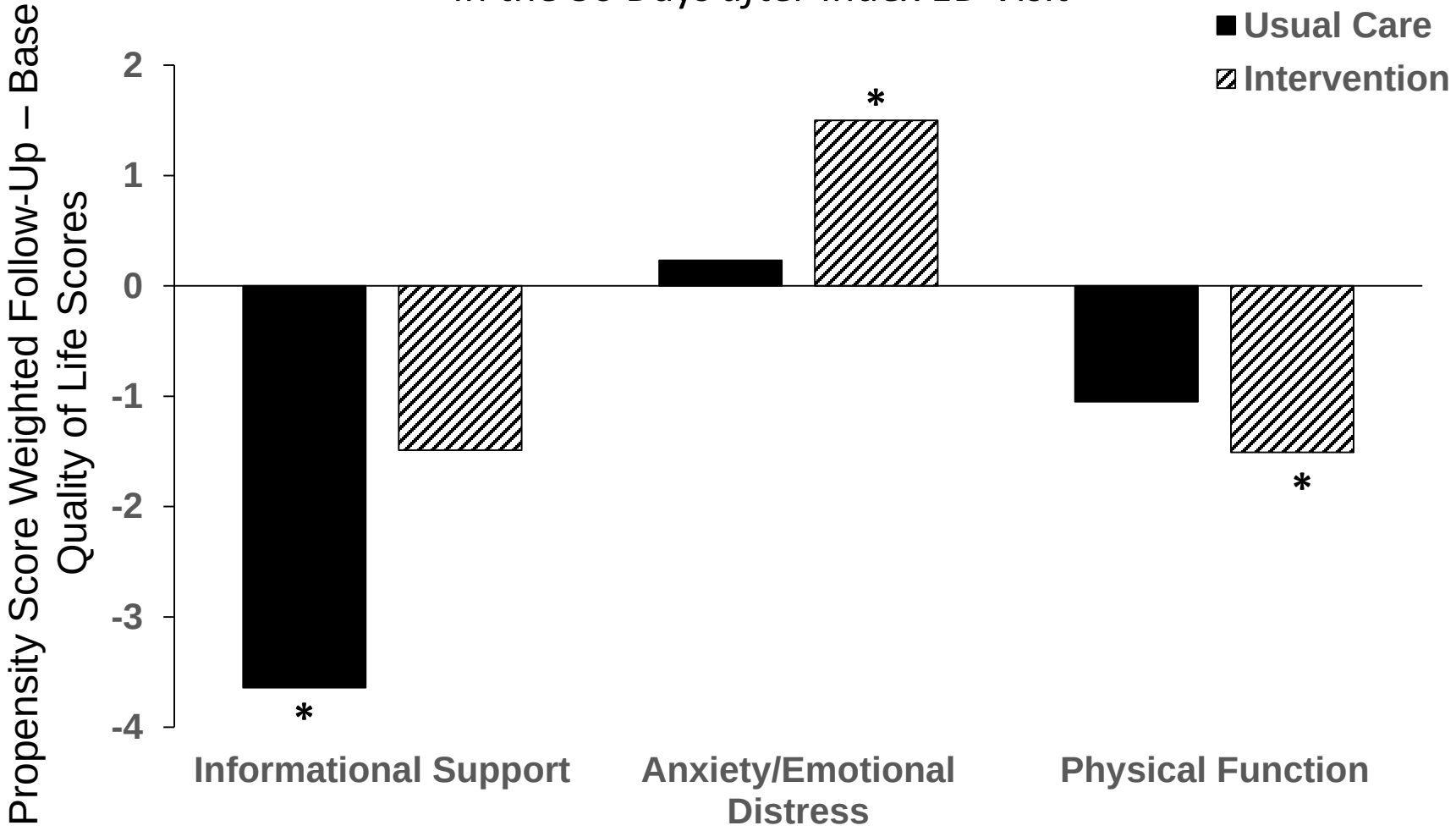
Randomized Controlled Trial- Aim 1



Aim 1- Quality of life- PROMIS measures- *Informational Support; Anxiety/Emotional distress; Physical Function*

Project Findings:

Change in Self-Reported Quality of Life
In the 30 Days *after* Index ED Visit



Lessons Learned

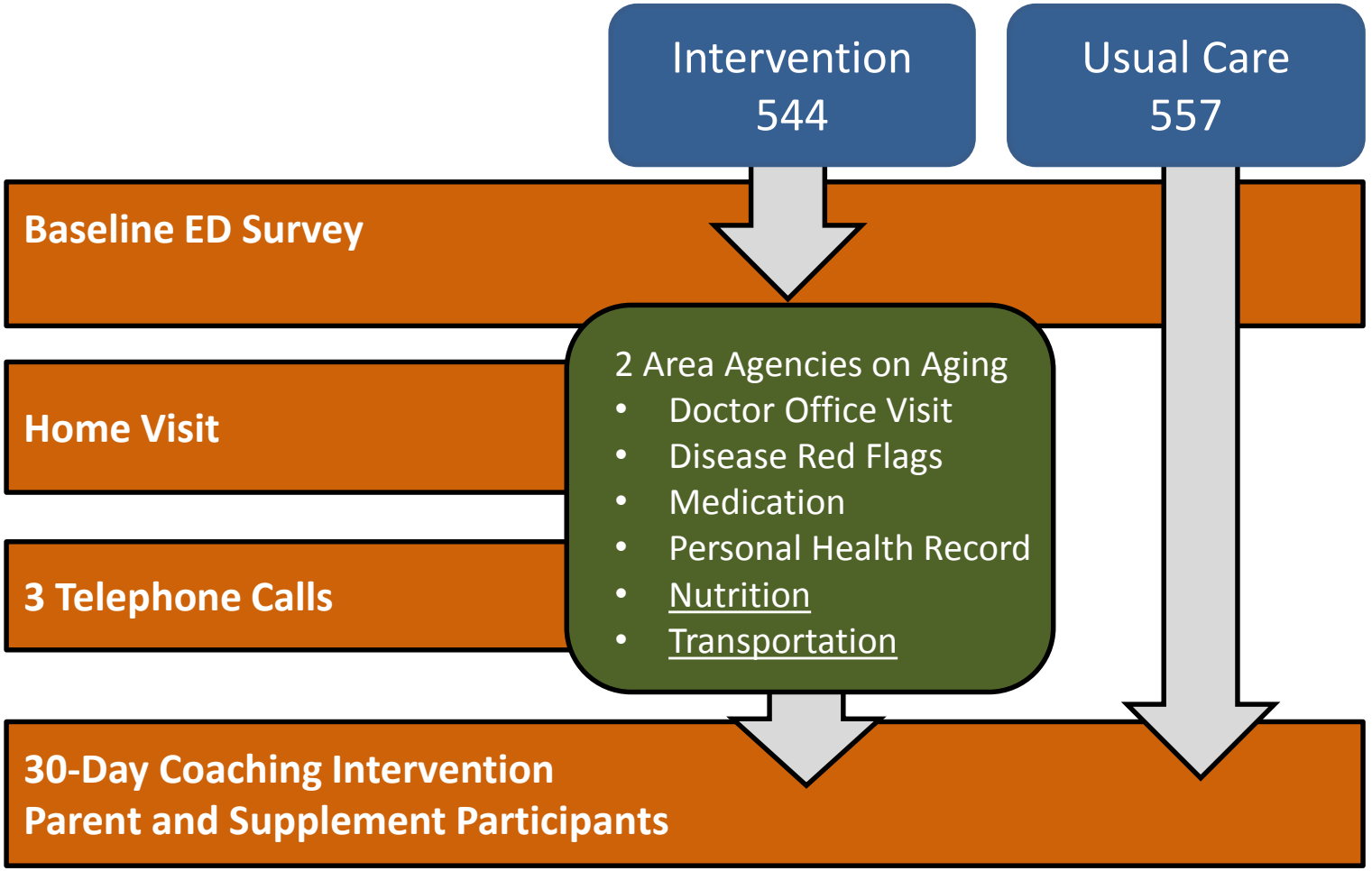
Project Lessons Learned

- During a healthcare crisis associated with an ED visit, quality of life is highest at the time of ED visit and falls over the next several weeks

- During a healthcare crisis associated with an ED visit, patient engagement is also highest at the time of the ED visit and falls over the next several weeks

- Older, chronically ill individuals will likely continue to make ED visits

Randomized Controlled Trial- Aim 1



Aim 1: Health Service Use (Medicare Claims)

Health Service Use

Medicare A and B Claims

Cohort Description	
Unique ED patients enrolled (parent and supplement)	1321
Unique Medicare beneficiaries identified through	1318
No CMS Claims identified	< 11
No matched claim for date of index ED visit	49 (3.9%)
Initial Cohort	1263 (95.5%)
Not enrolled in Medicare A and B in the year prior to the index ED visit	162 (12.8%)
Final Cohort	1101 (87.7%)

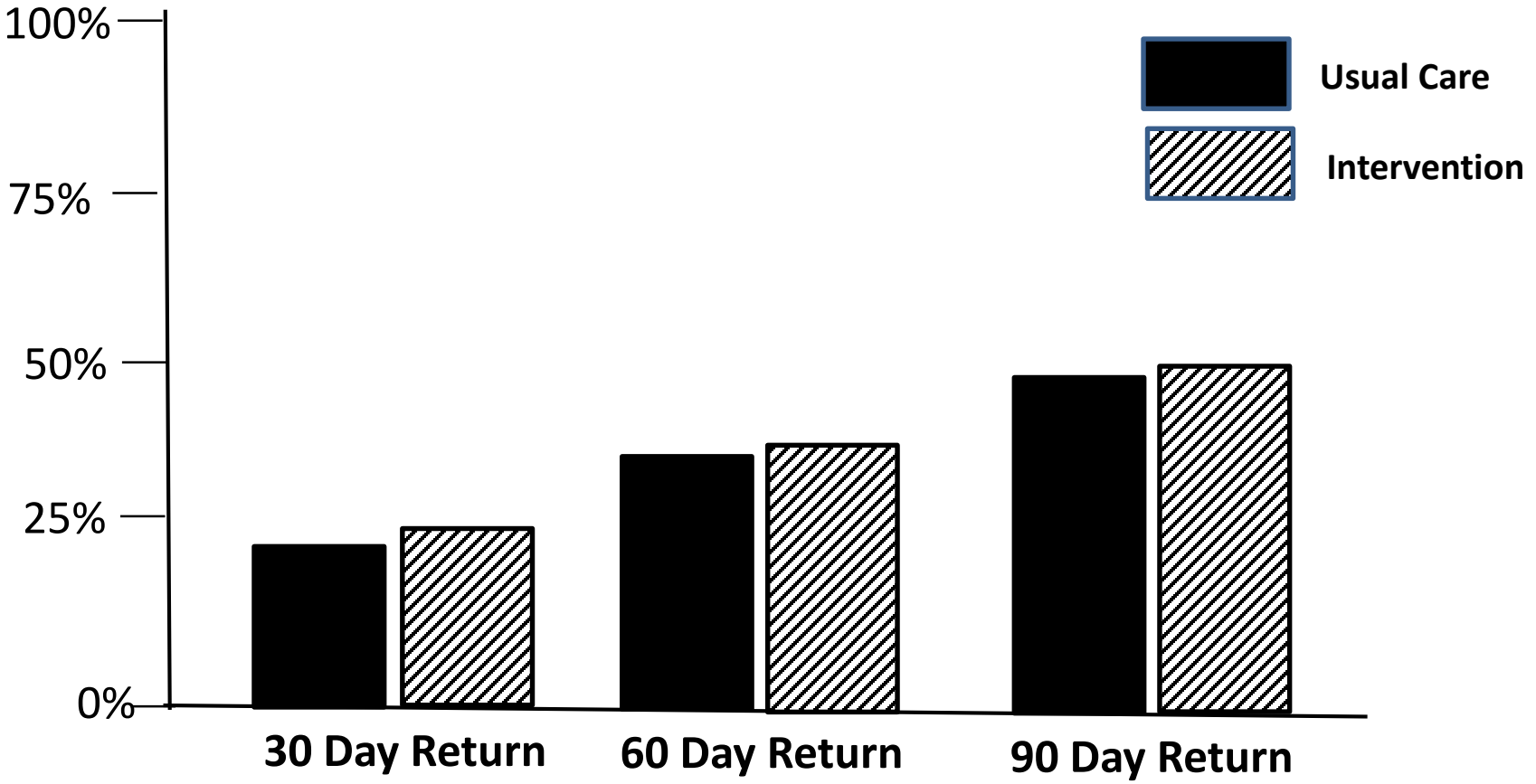
Health Service Use

Patient Demographics

	Overall (N=1101) %	Usual Care (n=544) %	Intervention (n=557) %	p-value
Mean Age (SD)	72.6 (8.5)	72.8 (8.6)	72.5 (8.4)	0.49
Gender				
Male	38.2	36.6	39.7	0.29
Female	61.9	63.4	60.3	
Non-White				
Yes	50.3	50.9	49.7	0.69
No	49.7	49.1	50.3	
Medicaid	42.9	41.9	43.8	0.16
Private	26.8	26.1	27.5	
Other Insurance	15.5	18.0	13.1	
Medicare Only	14.8	14.0	15.6	

	Overall (N=1101) %	Usual Care (n=544) %	Intervention (n=557) %	p-value
Chronic Conditions* **				
CHF	19.6	18.0	21.2	0.20
Valvular Disease	7.1	7.7	6.5	0.48
Pulmonary Circ Disease	4.3	3.7	4.9	0.37
Peripheral Vascular Disease	12.0	12.0	12.0	1.00
Paralysis	1.9	2.0	1.8	0.83
Other Neurological Disorders	11.5	12.0	11.1	0.71
Chronic Pulmonary Disease	29.0	28.5	29.4	0.74
Diabetes (No Complications)	33.2	32.4	34.1	0.56
Diabetes (Complications)	15.3	15.4	15.1	0.93
Hypothyroidism	17.4	17.1	17.8	0.81
Renal Failure	23.0	20.6	25.3	0.06
Liver Disease	5.1	5.0	5.2	0.89
Solid Tumor (No Mets)	4.3	4.8	3.8	0.46
Rhematoid Arthritis	5.0	5.7	4.3	0.33
Coagulopathy	4.4	5.0	3.8	0.38
Obesity	17.0	16.4	17.6	0.63
Weight Loss	6.1	6.1	6.1	1.00
Fluid & Elctrolyte Disorders	25.7	25.2	26.2	0.73
Deficiency Anemias	25.6	27.2	24.1	0.24
Psychoses	2.9	3.7	2.2	0.15
Depression	3.1	2.9	3.2	0.86
Hypertension	73.7	71.7	75.6	0.15

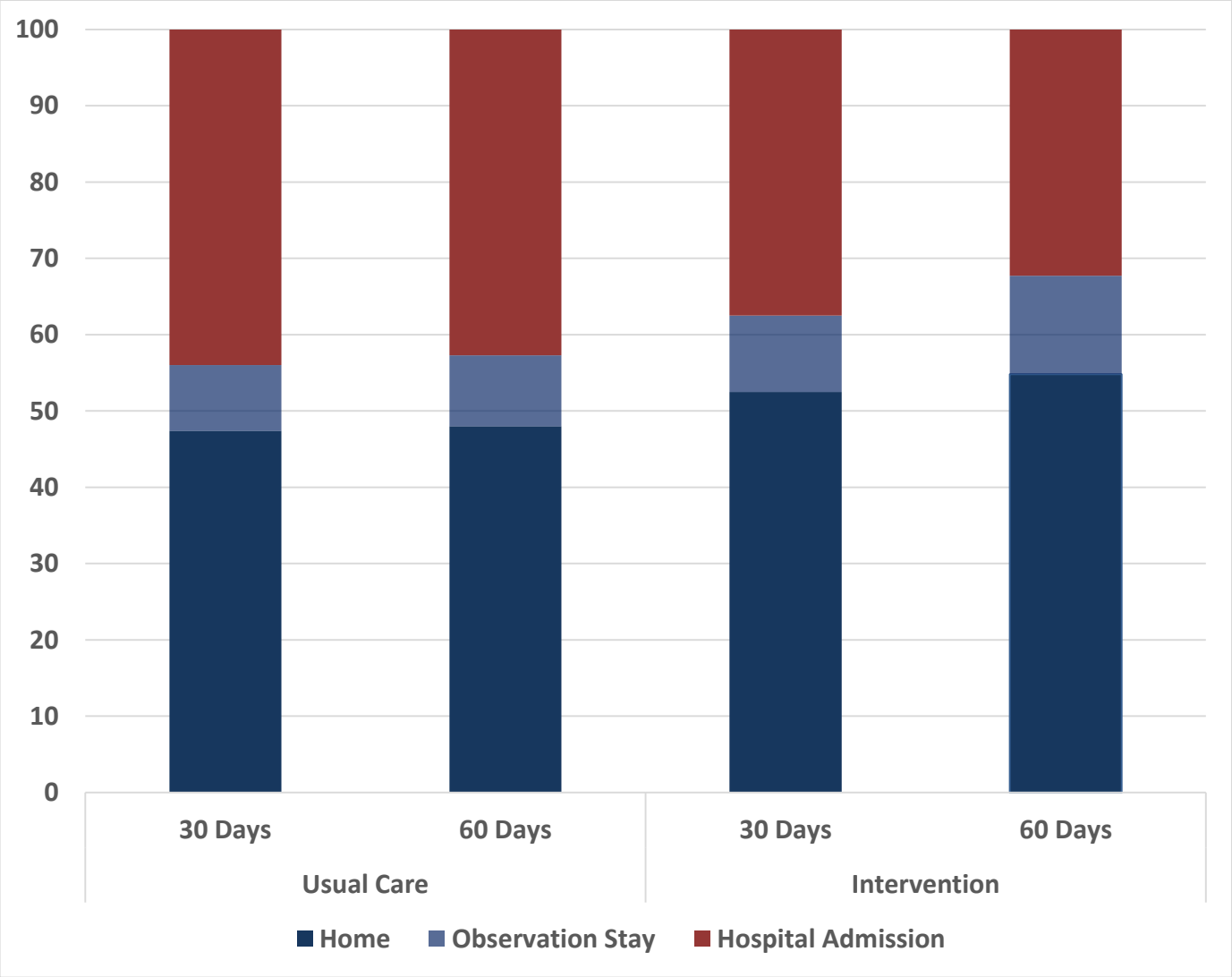
Return to the ED Within 30, 60, or 90 Days of Index ED Visit



ED Disposition 30, 60, and 90 Days *After* Index ED Visit

	Overall	Usual Care	Intervention	p-value
30 Days (n=375)				0.44
Observation Stay	9.3	8.6	10.0	
Hospital Admission	40.5	44.0	37.5	
Home	50.1	47.4	52.5	
60 Days (n=627)				**0.02**
Observation Stay	11.2	**9.3**	**12.9**	
Hospital Admission	37.3	**42.7**	**32.3**	
Home	51.5	**48.0**	**54.8**	
90 Days (N=800)				0.11
Observation Stay	12.0	10.9	13.0	
Hospital Admission	34.4	38.0	31.1	
Home	53.6	51.1	55.9	

ED Disposition 30 and 60 Days *After* Index ED Visit



Outpatient and Hospital-Based Care *After* the Index ED Visit

	Overall	Usual Care	Intervention	p-value
1+ ED Visit				
30 Days	23.5	22.8	24.2	0.57
60 Days	35.7	34.8	36.5	0.57
90 Days	44.9	43.5	46.3	0.40
1+ Inpatient Stay				
30 Days	15.0	14.3	15.6	0.55
60 Days	21.4	21.2	21.6	0.87
90 Days	27.3	26.4	28.3	0.51
1+ Outpatient Visit by Days Post-Index ED				0.38
None	20.7	23.4	18.1	
1-7 Days	38.2	38.1	38.4	
8-14 Days	21.6	19.3	23.9	
15-21 Days	11.7	11.4	12.0	
22-30 Days	7.7	7.9	7.5	
1+ Outpatient Visit Within 30 Days of Index ED	**79.3**	**76.7**	**81.9**	**0.03**

†Bolded values indicate significant differences between a given characteristic and intervention/Usual Care group ($p<0.05$)

Outpatient and Hospital-Based Care *Prior* to the Index ED Visit

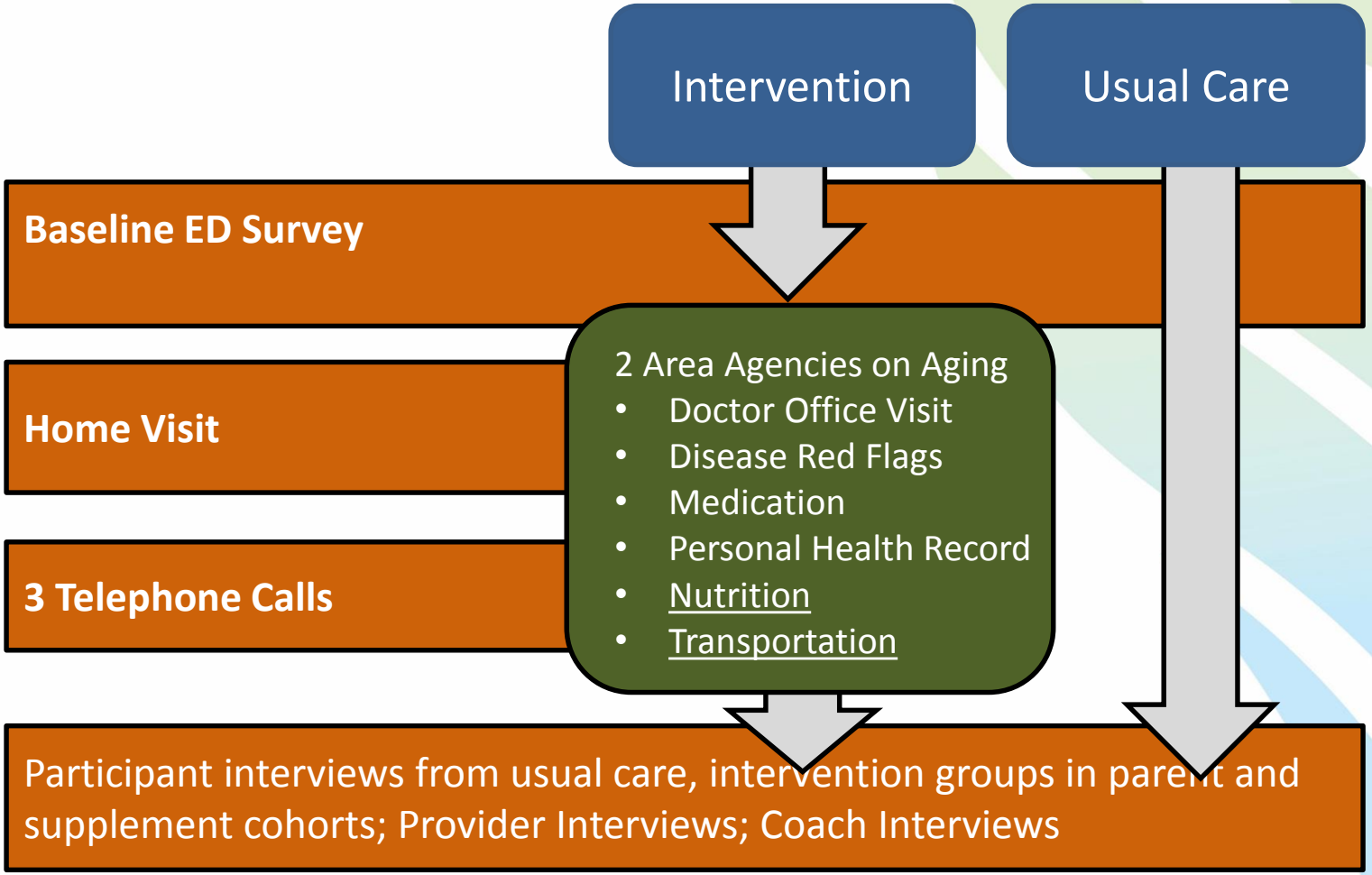
	Overall (N=1101) %	Usual Care (n=544) %	Intervention (n=557) %	p-value
Outpatient Visit				
30 Days	68.9	70.0	67.9	0.44
60 Days	76.1	75.9	76.3	0.88
90 Days	71.9	73.5	70.4	0.24
ED Visit				
30 Days	26.7	29.2	24.2	0.06
60 Days	34.2	37.1	31.2	**0.04**
90 Days	36.4	36.7	35.2	0.39
Inpatient Stays				
30 Days	11.9	13.1	10.8	0.24
60 Days	16.9	17.8	16	0.41
90 Days	19.6	20.6	18.7	0.42

†Bolded values indicate significant differences between a given characteristic and intervention/Usual Care group ($p<0.05$)

Project Findings

- An ED-initiated coaching intervention does not reduce 30, 60, or 90-day return ED visits
- The coaching intervention significantly increases follow-up doctor visits during the 30-day coaching window
- Significantly fewer coached patients who return to the ED within 60 days of index ED visit are hospitalized
- Overall admission rates are unchanged
  - Did coaching increase patients' awareness of unmet health needs?

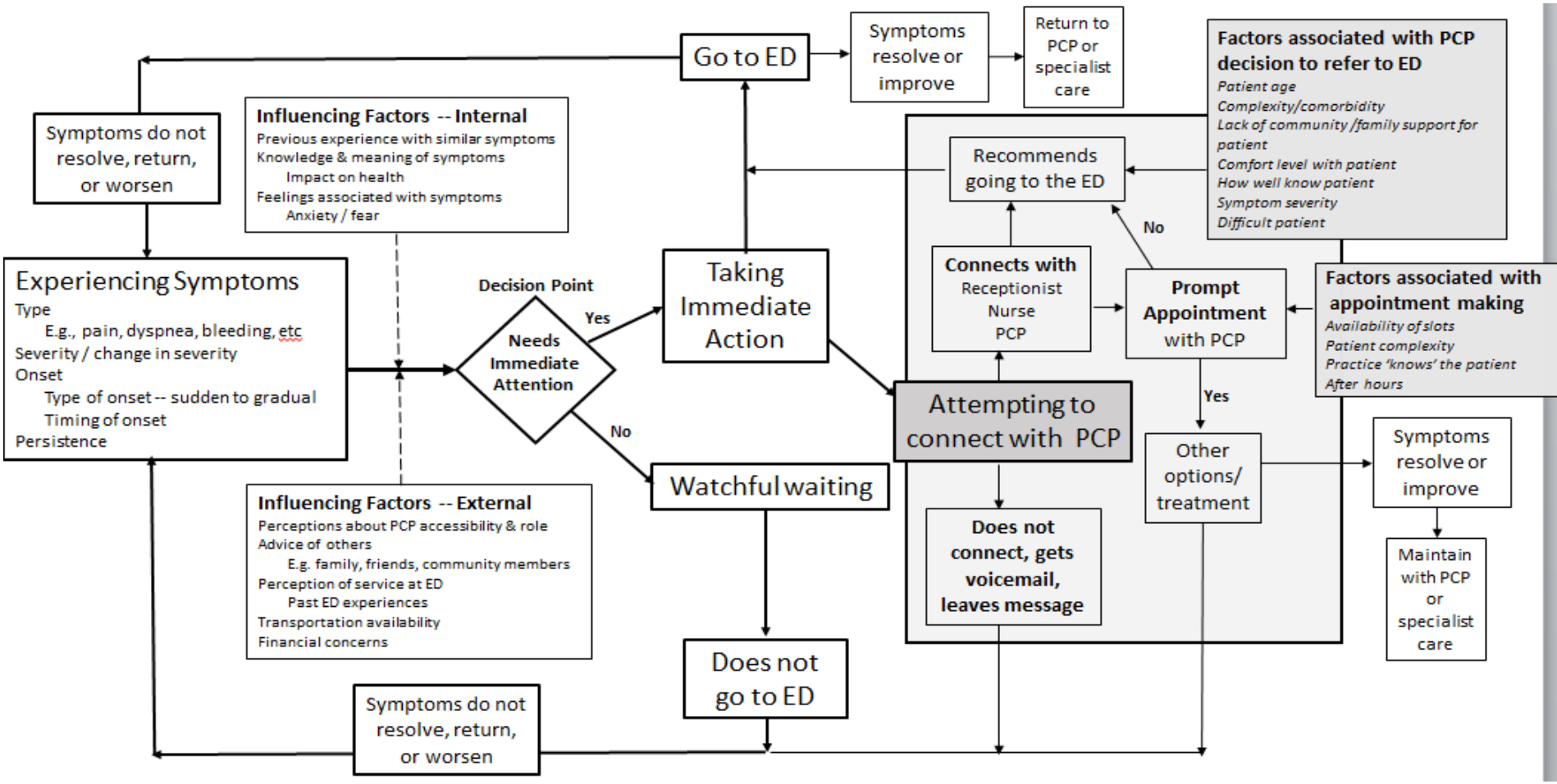
Qualitative Analysis of In-depth Interviews-Aim 2



Aim 2: Qualitative analysis of In-Depth Interviews with participants, providers and coaches

Project Findings:

Deciding to Visit the ED



Lessons Learned

Project Lessons Learned

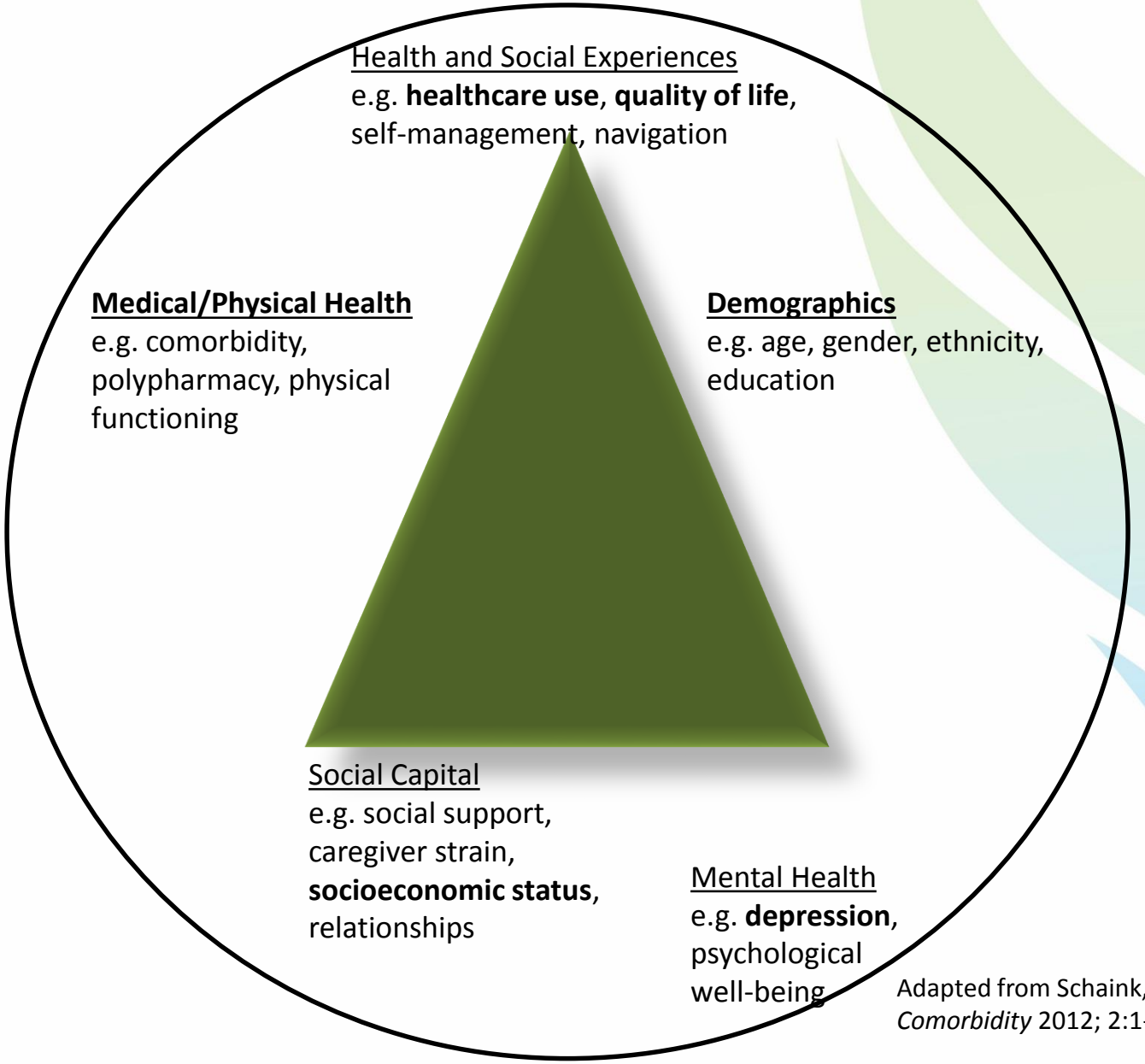
- Improved understanding of the key drivers of ED use for chronically ill, older adults
  - Older, chronically ill adults make rational and appropriate choices when seeking ED care
  - Expecting patients to differentiate emergent from less-urgent symptoms is unrealistic
  - Patients often have difficulty connecting with the primary care doctor or are advised to seek ED care by their physician
  - Contextual factors (social support, residential safety, transportation, finances) influence ED care-seeking

Background to Supplement

- As experience with transitional care interventions has grown, interest has also increased in risk prediction strategies that allow targeting and tailoring of interventions to patients most likely to benefit

- Preliminary findings from interviewing patients in their homes suggests considerable variation in patient complexity

- Coaches suggest "one size does not fit all" when considering program impact on patients' needs and healthcare seeking behavior



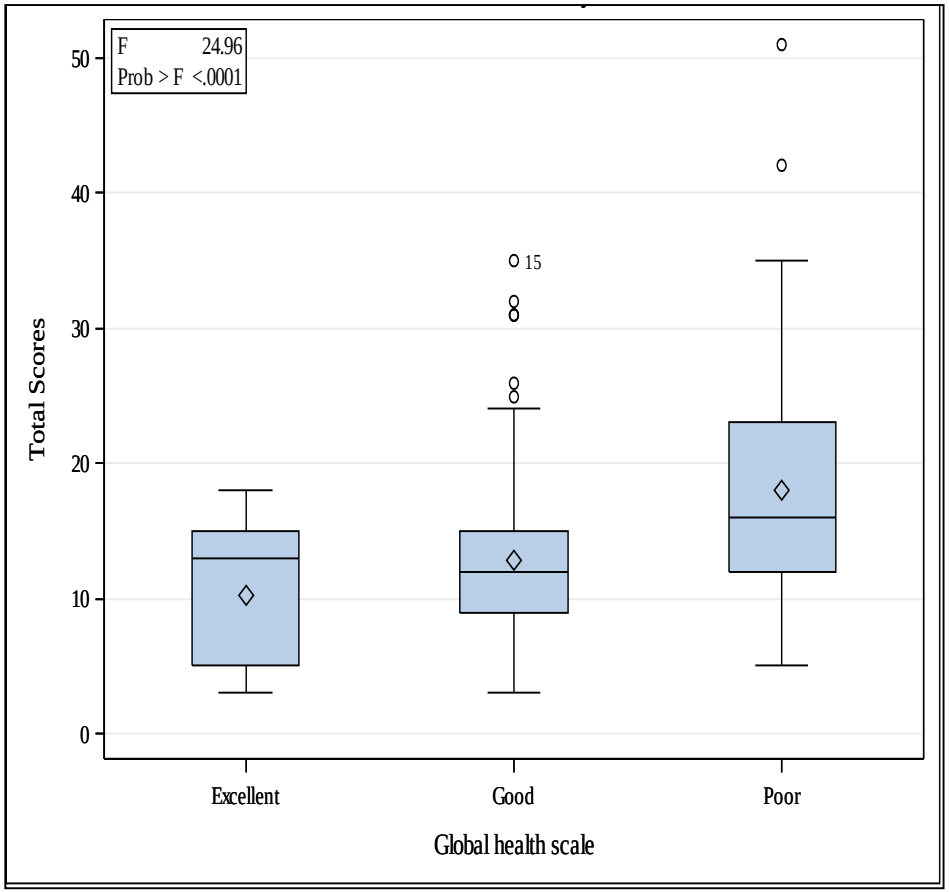
Adapted from Schaink, et al. *Journal of Comorbidity* 2012; 2:1-9

Biological, Psychological, Social and Health System Complexity

INTERMED Self-Assessment Survey (IMSA)

- Four domains:
  - Physical Health
  - Handling Problems and Stress
  - Social Support
  - Healthcare Experience
- The higher the score, the more complex the patient
- Scoring on a 0-3 scale:
  - 0 = No vulnerability/need
  - 1 = Mild vulnerability/need for monitoring or prevention
  - 2 = Moderate vulnerability/need for treatment or inclusion in treatment plan
  - 3 = Severe vulnerability/need for immediate or intensive treatment

IMSA scores and Global health scale



Global health scale:

In general, would you say your health is…

- ❑ Excellent
- ❑ Good
- ❑ Poor

Individuals with lower total survey scores were more likely to state their health is excellent.

Table 1. Correlations among IMSA scores and clinical measures

	Comorbidities (N=319) Pearson's r	Medication count (N=288) Pearson's r
Physical Health	0.34 ***	0.17 **
Handling Problems and Stress	0.36 ***	0.16 **
Social Support	0.17 **	-0.04
Healthcare Experience	0.26 ***	0.09
Total Survey Scores	0.41 ***	0.15 **

* P<0.05 ** P<0.01 *** P<0.001

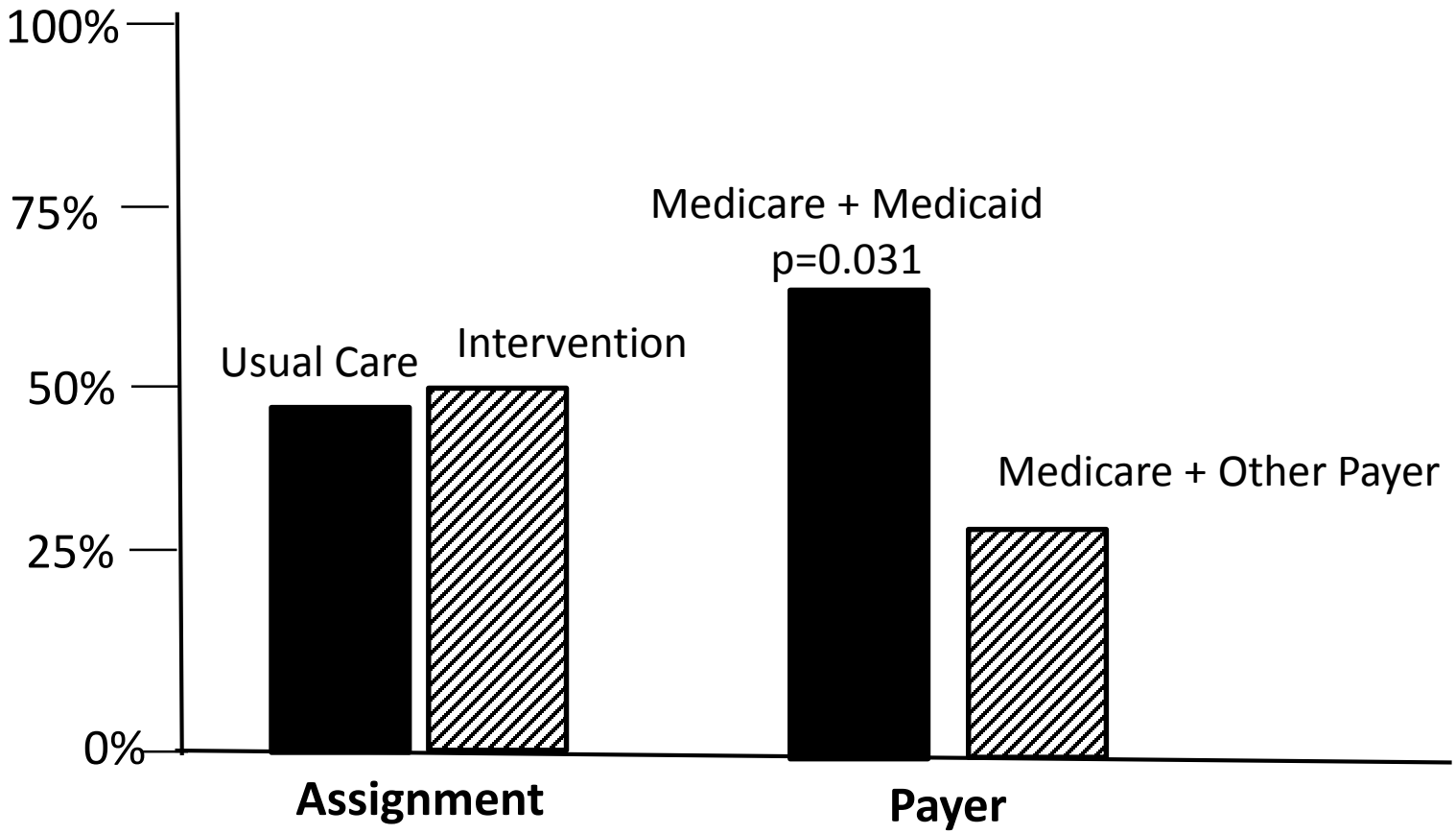
Table 2. IMSA scores between Medicaid / non-Medicaid groups

Self-reported patient complexity	Medicaid (n=111)	non-Medicaid (n=208)	P-value
	Mean (SD)	Mean (SD)	
Physical Health	9.60 (3.11)	8.94 (3.31)	0.083
Handling Problems and Stress	3.44 (3.04)	2.54 (2.57)	0.009
Social Support	1.88 (2.06)	1.30 (1.54)	0.004
Healthcare Experience	2.27 (2.46)	1.63 (2.29)	0.024
Total Survey Scores	17.19 (7.74)	14.41 (6.97)	0.002

Table3. IMSA scores by disadvantaged and non-disadvantaged groups			
	ADI (disadvantaged/Non-disadvantaged)		
Self-reported patient complexity	Disadvantaged (N=54) Mean (SD)	Non-disadvantaged (N=229) Mean (SD)	p-value
Physical Health	9.15 (3.39)	9.48 (2.94)	0.637
Handling Problems and Stress	2.84 (2.71)	2.69 (3.10)	0.483
Social Support	1.45 (1.68)	1.69 (2.04)	0.291
Healthcare Experience	1.85 (2.36)	1.98 (2.63)	0.709
Total Survey Scores	15.30 (7.32)	15.83 (8.06)	0.938

Table4. IMSA scores between health literacy groups			
	Health Literacy		
Self-reported patient complexity	Adequate (N=137) Mean (SD)	Limited (N=92) Mean (SD)	p-value
Physical Health	8.73 (2.91)	9.04 (3.79)	0.480
Handling Problems and Stress	2.51 (2.28)	2.88 (3.33)	0.320
Social Support	1.31 (1.72)	1.61 (1.69)	0.191
Healthcare Experience	1.42 (2.02)	1.86 (2.42)	0.135
Total Survey Scores	13.96 (6.53)	15.39 (8.12)	0.143

Potentially Preventable ED Visits
30 Day Return ED Visits
Ambulatory Care Sensitive Conditions



Project Findings

Supplement Project

- Patient-reported complexity score is associated with characteristics known to represent illness severity including global health status, number of chronic health conditions and medications
- Significant differences were observed between patient-reported complexity score and payer status
  - Dual eligible patients had higher self-reported complexity in the domains often *'hidden'* during a health system encounter
- No significant difference was observed in patient-reported complexity score and Area Deprivation Index, a measure of neighborhood resources.

Anticipated Benefits to the Field

- The ED holds promise as a site to deploy transitional care interventions, especially for vulnerable, hard-to-reach populations
  - Can we reduce disparities and improve outcomes?
- Better alignment of key drivers of ED use, ED-initiated transitional care interventions and relevant outcomes may become possible
  - Can we find *better* ways to address the fear and uncertainty over the cause and course of patients' symptoms that drive transitions into and out of the ED?
  - Can we provide more targeted and tailored informational support that provides robust and longer-term impacts on patients' ability to obtain, process and use health information and services

Lessons Learned

Engagement Lessons Learned

- Patient and Caregiver Engagement:
  - *Patients become empowered*
  - Patients meaningfully contributed to every phase of the research project
  - *Provided the Conceptual Framework for the Project*
- Challenges
  - Engagement does not end when the project ends

Acknowledgements

The opinions in this presentation are solely the responsibility of the authors and do not necessarily represent the views of PCORI, its Board of Governors or Methodology Committee.

Lunch

We will resume at 1: 00 PM ET

Topics Under Consideration: Glaucoma

Parag Aggarwal, PhD

Senior Program Officer, *Healthcare Delivery and Disparities Research Program*

Glaucoma Topic History

Topic Origin: *"Comparative Effectiveness of Eye Drops vs Laser Trabeculoplasty to Reduce Excess Morbidity from Glaucoma in Black and Hispanic Individuals"* identified by ADAP as a highly ranked topic.

Topic History:

- Fall of 2016, Addressing Disparities (AD) staff commissioned the topic brief.
- ADAP members Dr. Alan Morse and Dr. Tung Nguyen reviewed the resulting topic brief at the October 24, 2016 ADAP meeting.
- ADAP recommended that PCORI move forward with this topic.
- AD staff presented topic brief to SOC, 12/6/2016; subsequent questions were asked – both broad and specific.
- AD staff addressed the SOC's questions and convened expert reviewers.

SOC Questions

- Broad questions:
  - Nature of the disease and it's progression: is it too slow moving to capture outcomes in a 3-5 year study?
  - What is causing the outcome of blindness? Is it screening, late diagnosis, variability in disease progression, adherence, etc.?
  - Have any gaps in knowledge been called out in the literature?

- Specific questions:
  - Are screening practices in place?
  - Statistics among Asian American populations?
  - Outcomes for eye drops versus laser?

- Begs the question…
  - Are eye drops versus laser the right comparators?

Glaucoma Background

- Progressive vision loss that reduces quality of life; Legal blindness if left untreated
- Prevalence greatest among African, Hispanic, and Asian Americans. (Stein et al. 2011)

African A.	Hispanic A.	Asian A.	Caucasian A.
12.19%	6.4%	6.52%	5.59%

Japanese	Chinese	Filipino	Indian	Pakistani	Non-Asian
9.49%	5.75%	6.40%	7.78%	7.70%	5.91%

- Medicated eye drops and laser trabeculoplasty are effective in slowing the progression of vision loss and improving QOL.

Glaucoma - Barriers Identified

- Four primary barriers to prevention of glaucoma:

  (1) Screening/Diagnosis – getting to a clinic for an eye exam

  (2) Treatment – prescription for eye drops or laser

  (3) Medication Adherence and/or Treatment Follow-up

  (4) Trust/Communication between non-minority physician and minority patient

Recommendations & Next Steps

- The outcome should be **to slow down the progression of vision loss** and **improve patient quality of life**.
- The topic should focus on **addressing the barriers that prevent progression of glaucoma** for disparities populations.
- **Comparative interventions** can explore best options to improve:
  - Access to initial eye exams and screening
  - Physician-patient communication
  - Prescription or recommendation of best treatment option
  - Adherence to appropriate treatment
- ADAP Input
- Bring to SOC for review

Discussion

Addressing Disparities Broad Portfolio Updates and Completed Projects

Mira Grieser, MHS

Program Officer, Healthcare Delivery and Disparities Research

Addressing Disparities Broad Portfolio Updates

- **General parameters of the Broad Funding Announcement:**
  - Investigator-initiated topics
  - 3 years duration
  - $1.5 million (direct costs)

- **Funded status to date:**
  - 58 projects
  - $107 million

What is in the Broad portfolio?

- Projects targeting AD priority populations
  - Racial/ethnic minorities
  - Low income individuals
  - Rural populations
  - Limited English proficiency/ low health literacy
  - Populations with special healthcare needs (i.e. disabilities)
  - LGBTQ individuals

- Projects on various conditions:
  - Mental Health
  - Cardiovascular Health
  - Nutritional and Metabolic Disorders
  - Neurologic disorders
  - Multiple chronic conditions
  - Cancer
  - Perinatal health
  - Many others

What is in the AD Broad portfolio (cont)?

- Broad range of intervention settings:
  - Home
  - School
  - Community
  - Primary Care
  - Hospital

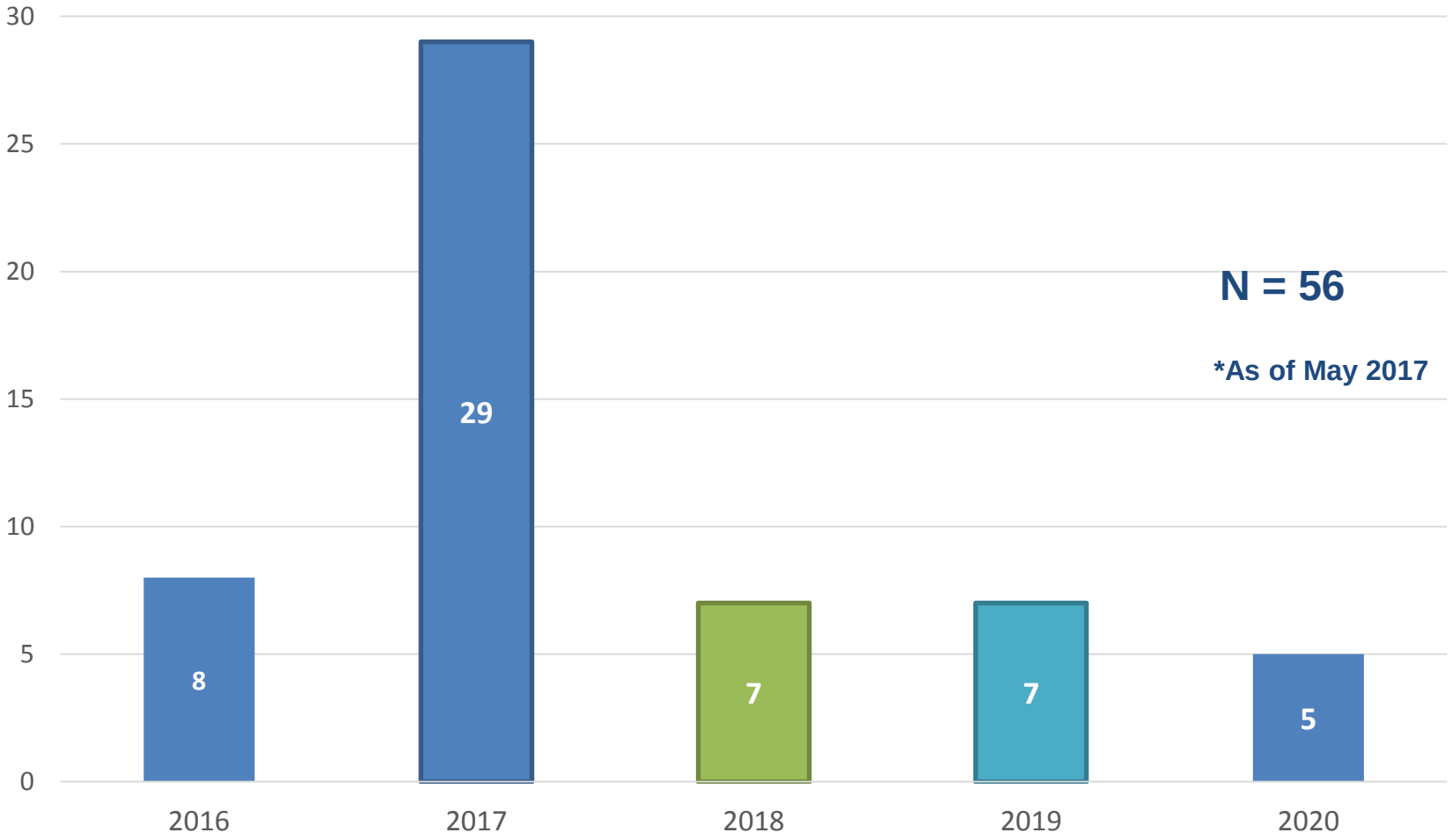
- Broad range of intervention strategies:
  - Self-management
  - CHW
  - Cultural/Language Tailoring
  - Decision Support
  - Team-Based Care
  - Family/ Caregiver Involvement
  - Social Support

New AD Projects (announced Fall 2016)

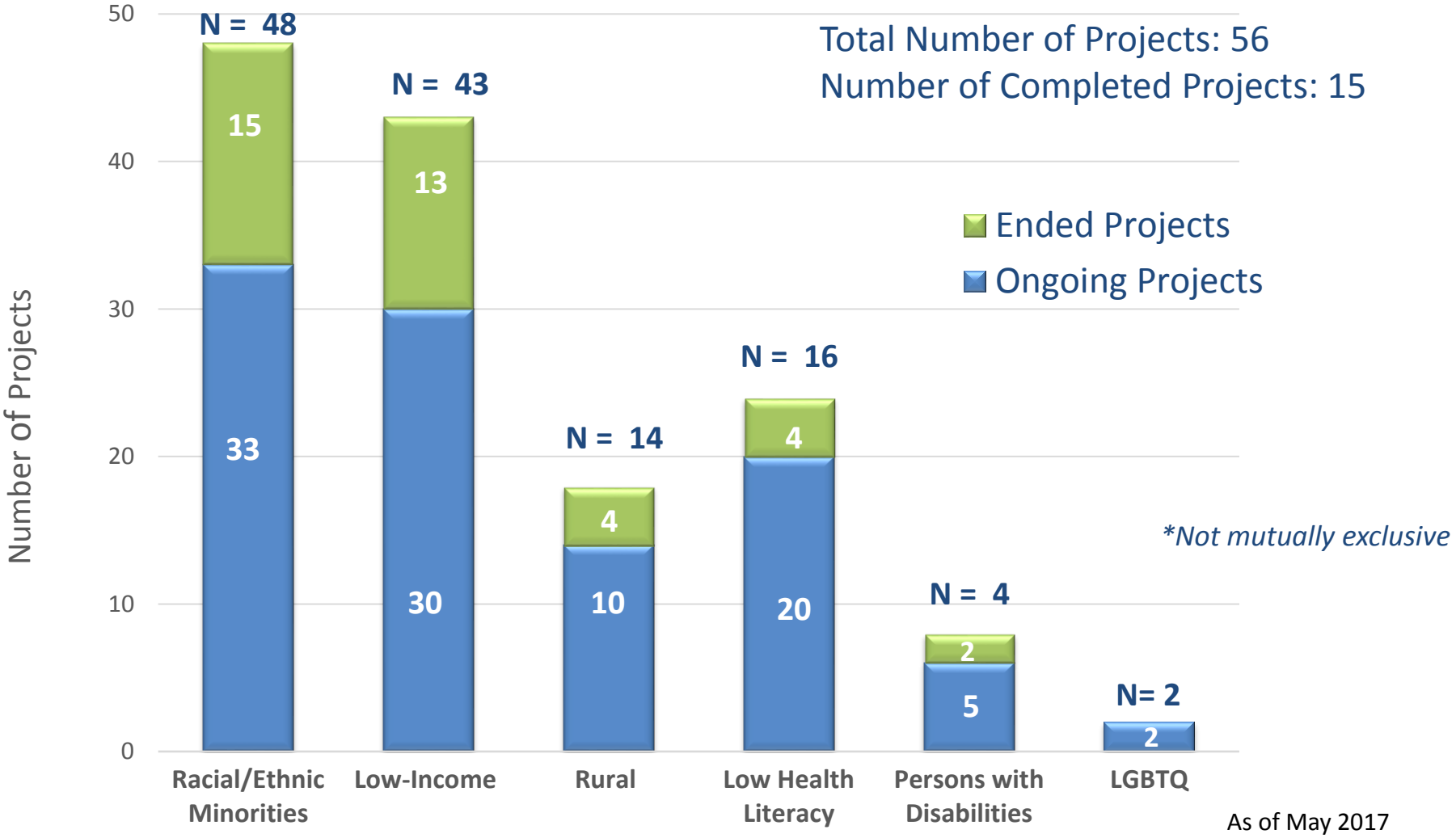
Topic	Target population	PI	Primary Aim
Perinatal depression	Low-income, African American and Latina women	Michael Silverstein, MD Boston Medical Center	Compare two brief depression intervention strategies in primary care settings to improve outcomes among low-income, minority, pregnant and post-partum women with depressive symptoms.
Childhood obesity	Low-income, Rural	Jamie Marie Zoellner, PhD, RD Virginia Tech	Compare two family-based childhood obesity treatment programs in a medically underserved region.
Diabetes	US Pacific Islander	Pearl McElfish, PhD University of Arkansas Medical Sciences	Compare a culturally-adapted vs. standard Diabetes Prevention Program-Lifestyle Intervention.
Childhood hearing loss	Rural Native Alaskans	Philip Hofstetter, MA, AuD, Norton Sound Health Corporation Susan Emmett, MD, MPH, Johns Hopkins University	Compare two school-based screening and referral processes (general primary care referral vs immediate telemedicine consult.)

AD Broads: Project Completion

AD Broad Portfolio: Project End Dates



Broad Portfolio: AD Target Populations



As of May 2017

Completed projects

After Research period is completed:

- All awardees must submit a Final Research Report
  - Required by PCORI authorizing legislation
  - Overview of entire research project with emphasis on methodology and findings
  - Undergoes peer review
  - Final version is eventually posted on PCORI website
- Awardee publications, simultaneously
- Awardees work with their stakeholders to disseminate their findings
- Awardees may apply for PCORI Dissemination & Implementation funding

- Within the AD Broad portfolio (n=56 projects)
  - 15 projects are complete
  - 10 projects have submitted Draft Final Research Report

Questions for ADAP

- How can PCORI communicate results of our funded projects?
  - Clusters of projects by topic area, target population, intervention setting
  - Individual projects
- Who should be targeted?
  - Health systems, payers, providers, families, patients

- How do we start applying these results to actual reduction of disparities in health and health care?

Project Results

Mental Health
Colorectal cancer screening
LGBTQ health

Serious Mental Illness (SMI) & Peer Navigation:

John Brekke, PhD — **University of Southern CA**
Patrick Corrigan, PsyD — **Illinois Institute of Technology**

- **The disparity:**
  - Individuals with SMI have high rates of co-morbidities that are often undiagnosed, untreated, or under-treated.
  - Need for interventions for racial/ethnic minority individuals with SMI

- **Research question:** Can peer navigation improve access to primary care (and other outcomes) for individuals with SMI?
- **Study design/Target population**: RCTs; participants were mostly (CA) or exclusively (IL) Latino

- **Findings**: Compared with the usual care group, the group receiving peer navigation had more positive health outcomes including:
  - Better access and use of primary care
  - Better quality relationship between PCP and patient
  - Increased confidence in self management skills / increased empowerment
  - Better QoL
- **Potential Impact**:. Both studies found evidence that point to benefits of peer navigator intervention for improving outcomes for Latino individuals with SMI.

Kelly E et al. ***Integrating behavioral healthcare for individuals with serious mental illness: A randomized controlled trial of a peer health navigator intervention.*** Schizophr Res. 2017 Apr;182:135-141.

Increasing CRC Screening among Hispanic Primary Care Patients

PI: Ronald Myers, DSW, PhD **Thomas Jefferson University**

- **The disparity:**
  - Colorectal cancer (CRC) screening rates are significantly lower in Hispanics than in non-Hispanic whites (47% and 62% respectively).
  - A mailed intervention (a stool blood test kit, instructions for scheduling a screening colonoscopy) is an established way to promote CRC screening.
  - This study tests a new method to maximize CRC screening rates in Hispanic patients.
- **Methods:**
  - **Research Question:** Can a telephone-based decision support and navigation intervention boost CRC screening rates in Hispanic patients?
  - **Comparators:**
    - Mailed kit + decision support and navigation
    - Mailed kit only.
  - **Sample:** n=400 Hispanic patients age 50-75 years, non-adherent to CRC screening
  - **Primary outcome:** CRC screening adherence within 12 months after recruitment to study.
- **Findings:**
  - The decision support and navigation arm shows a substantial increase in CRC screening rates at 6 months compared with the mailed kit only.

EQUALITY Study

PI: Adil Haider, MD, MPH **Brigham & Women's Hospital**

- **Background:** Multiple recommendations for healthcare settings to collect sexual. orientation information.
  - No clear guidelines or best practices
  - Many providers question whether patients want to disclose information

- **Objective:**
  - To develop and test approaches for routinely collecting SOGI in an ED setting.

- **Phase 1 Methods** (exploratory sequential mixed methods):
  - in-depth interviews
  - national survey with 1516 patients (LGBTQ and straight) and 429 providers (nurses and physicians)

- **Findings**:[1]
  - 77.8% of providers thought that patients would refuse to disclose SO.
  - 10.3% of patients reported that they would refuse to disclose SO.
  - Both groups favored non-verbal self-reporting (i.e. paper or electronic formats) over verbal self-reporting.

[1] Haider AH, Schneider EB, Kodadek LM, Adler RR, Ranjit A, Torain M, Shields RY, Snyder C, Schuur JD, Vail L, German D, Peterson S, Lau BD. Emergency Department Query for Patient-Centered Approaches to Sexual Orientation and Gender Identity The EQUALITY Study. *JAMA Intern Med.* Published online April 24, 2017. doi:10.1001/jamainternmed.2017.0906125

Discussion

- How can PCORI communicate results of our funded projects?
  - Clusters of projects by topic area, target population, intervention setting
  - Individual projects
- Who should be targeted?
  - Health systems, payers, providers, families, patients

- How do we start applying these results to actual reduction of disparities in health and health care?

Break

PCORI's Asthma Research Framework

Ayodola Anise, MHS

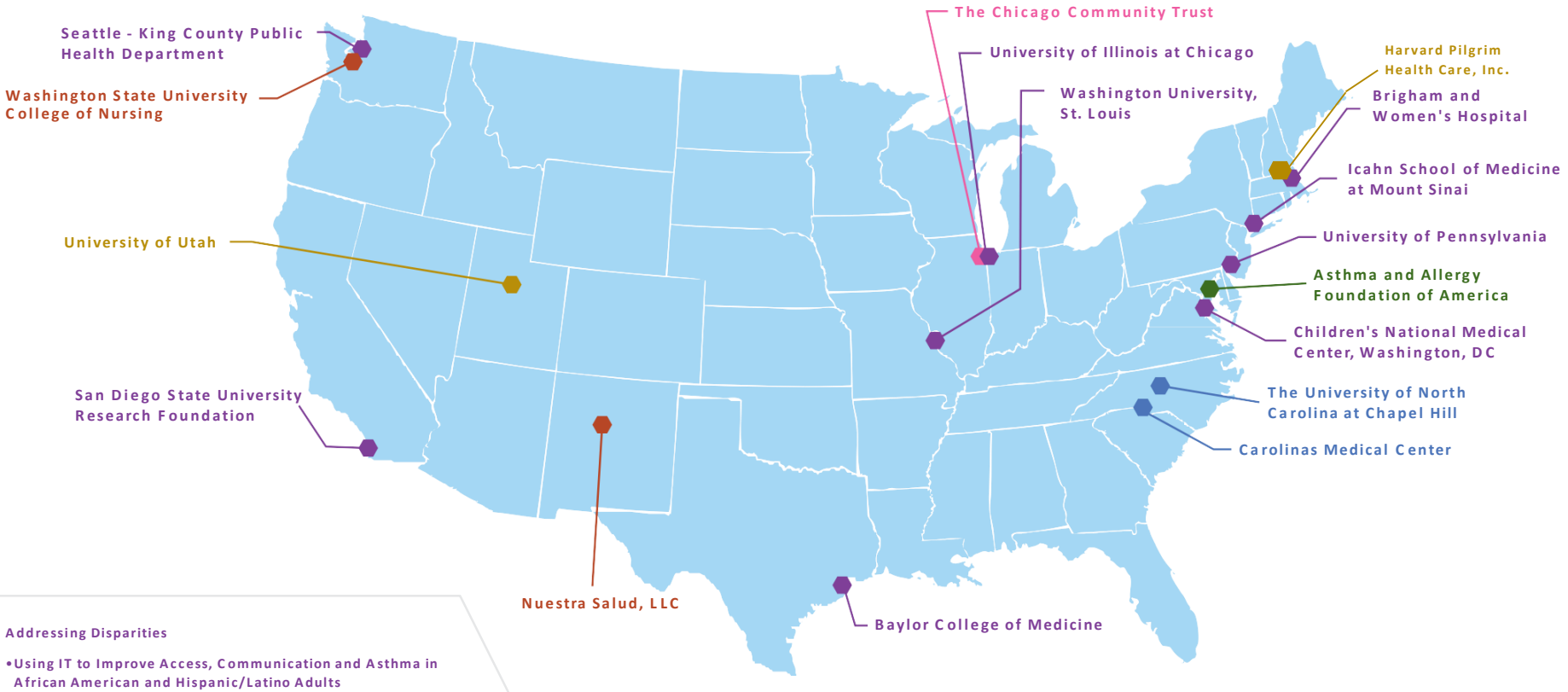
Program Officer, *Healthcare Delivery and Disparities Research*

Roadmap

- Provide background on the Asthma Evidence to Action Network (E2AN)
- Discuss the potential impact of the Asthma E2AN
- Provide update on the 2017 Asthma E2AN activities
- Discuss the draft Asthma E2AN Framework

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.



Addressing Disparities

- **Using IT to Improve Access, Communication and Asthma in African American and Hispanic/Latino Adults**
  University of Pennsylvania | Andrea Apter, MD, MA, MSc
- **Imperial County Asthma CER Project (RESPIRA)**
  San Diego State University Research Foundation | John Elder, MPH, PhD
- **Clinic-Based vs. Home-Based Support to Improve Care and Outcomes for Older Asthmatics (SAMBA)**
  Icahn School of Medicine at Mount Sinai | Alex Federman, MD, MPH
- **The Houston Home-based Integrated Intervention Targeting Better Asthma Control (HIIT-BAC) for African Americans**
  Baylor College of Medicine | Winifred J. Hamilton, PhD
- **Patient Empowered Strategy to Reduce Asthma Morbidity in Highly Impacted Populations (PESRAMHIP)**
  Brigham and Women's Hospital | Elliot Israel, MD
- **The Coordinated Healthcare Interventions for Childhood Asthma Gaps in Outcomes (CHICAGO) Trial**
  University of Illinois at Chicago | Jerry Krishnan, MD, PhD
- **Guidelines to Practice (G2P): Reducing Asthma Health Disparities through Guideline Implementation**
  Seattle - King County Public Health Department | James Stout, MD, MPH
- **Preference and Effectiveness of Symptom-Based Adjustment of Inhaled Corticosteroid Therapy in African American Children (ASIST)**
  Washington University, St. Louis | Kaharu Sumino, MD, MPH
- **Improving Asthma Outcomes through Stress Management**
  Children's National Medical Center, Washington, DC | Stephen Teach, MD, MPH

Communications and Dissemination Research

- **Using Question Prompt Lists During Pediatric Asthma Visits to Increase Adolescent Involvement**
  The University of North Carolina at Chapel Hill | Betsy Lynn Sleath, PhD
- **Comparing Traditional and Participatory Dissemination of a Shared Decision Making Intervention**
  Carolinas Medical Center | Hazel Tapp, PhD

Improving Healthcare Systems

- **Redesigning Ambulatory Care Delivery to Enhance Asthma Control in Children**
  University of Utah | Flory Nkoy, MD, MS, MPH
- **Redesigning Ambulatory Care Delivery to Enhance Asthma Control in Children**
  Harvard Pilgrim Health Care, Inc. | Alison Amidei Galbraith, MD, MPH

Engagement, Pipeline to Proposals Awards (Tier I, Tier II)

- **The Hispanic Family Asthma Outcomes Research Network**
  Nuestra Salud, LLC | Jorge Otero
- **Promoting Patient-Centered Research in the Puget Sound Asthma Coalition**
  Washington State University College of Nursing | Julie Postma, PhD

Engagement Award Program

- **Training Patients with Asthma to Understand and Participate in Patient-Centered Outcomes Research**
  Asthma and Allergy Foundation of America | James Bender

Infrastructure CDRN in PCORNet (Phase I, Phase II)

- **Chicago Area Patient-Centered Outcomes Research Network (CAPriCORN)**
  The Chicago Community Trust | Terry Mazany, MA, MBA

Potential Impact of the Asthma E2AN

- **Increase capacity** of researchers and patient and stakeholder partners in the Asthma E2AN to engage in **patient-centered outcomes research**.
- **Speed the implementation** and use of patient-centered outcomes research **evidence**.
- Provide a cohort of projects to measure the **uptake and usefulness of evidence** by end users outside of the research projects.

Asthma E2AN Activities in 2017

- Held in-person meeting on March 27-28 in Arlington, VA
  - Began capturing the stories around the projects
  - Identified early impacts of projects prior to research results being available
  - Developed and presented a draft framework to better describe portfolio and potential impact of the portfolio
- Began to brainstorm activities to support the Asthma E2AN
  - Webinars
  - Evidence synthesis/mapping
  - Data aggregation

Purpose of the Asthma Portfolio Framework

- To share how PCORI's investment can have an impact on improving asthma outcomes and reducing disparities in asthma
- So awardees and researchers can talk about where their projects fit into PCORI's asthma portfolio
- To inform future asthma research – it will allow us to make reasoned and defensible choices about unexplored areas of asthma research

Discussion Questions

1. How can the framework be more reflective of PCORI's focus on comparative effectiveness research and patient-centeredness?
2. How can the framework achieve a better balance of granular verses general information?
3. What considerations should be discussed for using different frameworks for various audiences?
4. How can the "Drivers of Practice Change" be more aligned with the mechanisms that facilitate practice change?
5. Are the organizational components of the framework (i.e., headings, content) appropriate?

Draft Framework for PCORI's Asthma Portfolio

Impact

- Improve Asthma Outcomes
- Reduce Asthma Disparities

Drivers of Practice Change

- Quality Measures
- Guideline Adherence
- Technology
- Coverage and Payment Policy
- Sustainability
- Feasibility of Implementation

Outcomes

Patient-Reported

- Asthma Quality of Life
- Asthma Control
- Symptom-free Days
- General Health Status
- Patient-Clinician Shared Decision-Making
- Patient Satisfaction
- Missed School or Work
- Medication Use
- Caregiver Satisfaction
- Psychosocial Stress

Clinical

- Pulmonary Function
- Asthma Exacerbations
- Medication Use
- Medical Resource Utilization

Engagement

- Patient Perception of Involvement
- Patient Engagement in CER & PCOR
- Clinical Team Involvement

Qualitative

- Focus Groups
- In-Depth Interviews
- Other (e.g., Early Impacts)

Strategies

Interventions

- Tools (e.g., asthma action plan)
- Patient & Clinician Education
- EHR (e.g., decision support tools)
- Environmental Assessments
- Community Health Worker
- Medication
- Practice Redesign

Communication & Dissemination

- SDM Tools
- Passive/Active Diffusion
- Practice Adaptation

Patient-Stakeholder Engagement in Research

- Increasing Outreach
- Better Engagement

Stakeholders

- Patients
- Caregivers
- Clinicians
- Researchers
- Purchasers
- Payers
- Industry
- Hospitals
- Health Systems
- Policy Makers
- Training Institutions

Barriers

Asthma Care

- Access
- Quality
- Health Related Behaviors
- Physical Environment
- Socioeconomic Factors (e.g., racial, cultural, literacy considerations)

Communication & Dissemination

- Shared Decision Making
- Visit Involvement
- Provider Buy-in
- Practice Culture/Variation
- Team Interaction
- Journals & Publications
- Clinician Factors (e.g. priorities, time)
- Strategies to Get Findings to End-Users

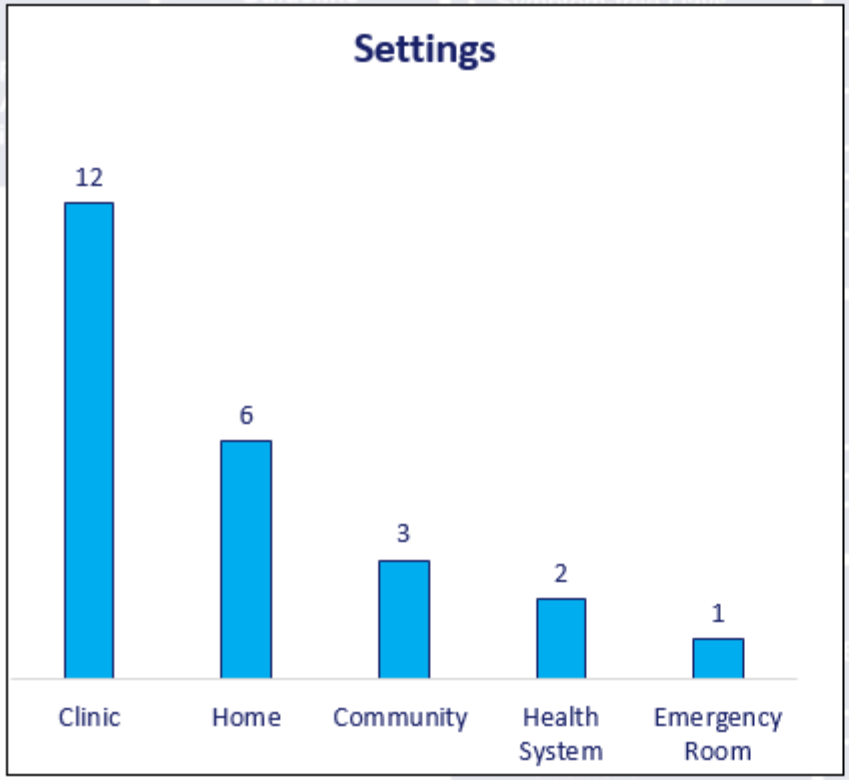
Engagement

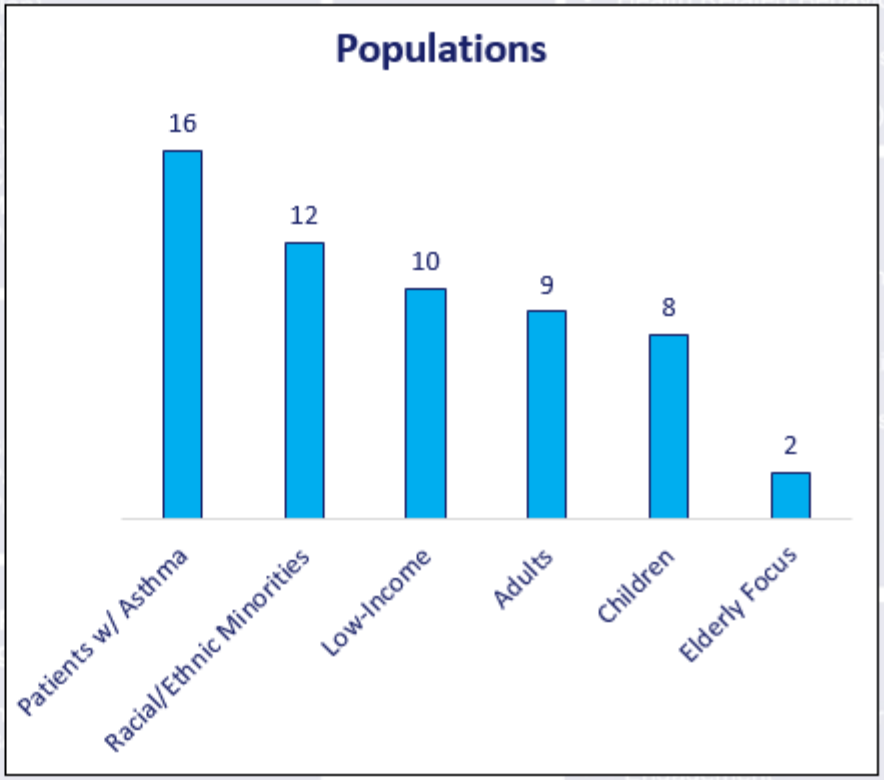
- Patient/Stakeholder Involvement in Research
- Metrics to Measure Engagement

Infrastructure to Conduct Research

- Recruitment/Retention
- Materials/Tools Developed

Draft Framework for PCORI's Asthma Portfolio





Setting and Population categories are not mutually exclusive

Discussion Questions

1. How can the framework be more reflective of PCORI's focus on comparative effectiveness research and patient-centeredness?
2. How can the framework achieve a better balance of granular verses general information?
3. What considerations should be discussed for using different frameworks for various audiences?
4. How can the "Drivers of Practice Change" be more aligned with the mechanisms that facilitate practice change?
5. Are the organizational components of the framework (i.e., headings, content) appropriate?
6. Anything else?

Addressing Disparities Panelist Presentation: Health Disparities at the Intersection of Disabilities, Race, and Ethnicity

Barbara Kornblau, JD, OTR/L

CEO, *Coalition for Disability Health Equity*

Health Disparities at the Intersection of Race/Ethnicity and Disability.

Barbara L. Kornblau, JD, OTR
Coalition for Disability Health Equity
Florida A&M University

What does disability mean?

- Does not mean you are sick or unhealthy
- It is not a bad outcome
- It is a difference that people live with

Percent of PWD

- "Disability is an emerging field within public health; people with significant disabilities account for more than 12% of the US population."

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (January 01, 2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health, 105,* 198-206.

PWD Experience Health Disparities

- "[p]eople with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities."

  - National Council on Disability (NCD), (2009) *The Current State of Health Care for People with Disabilities*.

PWD Meet the Criteria for Health Disparity Population

- "The available evidence documents that people with disabilities meet all the criteria for a disparity population with disabilities were institutionalized and marginalized.
- They experience documented differences in health outcomes at the population level that relate to higher rates of unmet health care needs, unhealthy lifestyle behaviors, mental health and chronic diseases, and social determinants of poor health.
- Finally, many of these differences are recognized as avoidable and disproportionately affect this population." (Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R., 2015)

- “People with disabilities are over-represented in many target populations for public health intervention—from smoking to obesity to injury prevention—yet their presence in these target groups is not recognized nor accommodated.”

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R., 2015)

- “As a group, people with disabilities experience more chronic diseases and conditions, and experience them at earlier ages”

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R., 2015)

The Evidence….

- Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases, such as asthma, diabetes, cancer, heart disease and cardiopulmonary conditions.
  - (Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007)

- Inaccessible medical equipment and lack of trained physicians, dentists, and other health professionals prevent individuals with disabilities from receiving the basic primary and preventive care,
  - such as getting weighed, preventative dental care, pelvic exams, x-rays, physical examinations, colonoscopies, and vision screenings.
  - (Kirschner, Breslin, & Iezzoni, 2007; Chan, Doctor, MacLehose, et al. (1999); Manderscheid R., Druss B., & Freeman E . 2007)

- People who are deaf or experience significant problems hearing report they were 3x as likely to report fair or poor health compared with people without hearing impairments. (NCD, 2009).
- They have difficulty communicating with primary care providers who don't want to pay interpreters or "bother" with a Telecommunication Device for the Deaf (TDD).

- 27% of adults with major physical and sensory impairments are obese, compared with 19% among those without major impairments (Iezzoni, 2009).
- Individuals with intellectual disabilities must contact 50 physicians before they can find one trained to treat them. (Corbin, Holder, & Engstrom, 2005)
- 4.6% of deaf people are infected with HIV/AIDS
- 50% of those with TBI or spinal cord injuries are substance abusers (Curtis& Heaphy, 2009)

- 1997 IOM report *Enabling America:*
  - federal research effort in the area of disability was inadequate.
- 2005 U.S. Surgeon General:
  - issued a *Call to Action* and warned of the need to address disability-based health disparities in access to clinical care, prevention and wellness, and public health services.
- 2007 IOM report, *The Future of Disability in America:*
  - research spending on disability is miniscule for & future needs & Numbers likely to rise with aging baby boomers.

Disability

- People with disabilities have difficulties with basic actions:
  - Functional limitations
  - Limitations in vision or hearing
  - Cognitive limitations
  - Use of assistive technology

Complex activity limitations

- Within the sample of people with disabilities, some also have complex activity limitations:
  - ADL/IADL limitations
  - Limitations in work, social, or recreational activities

- CDC reports approximately 62 million (30%) Americans experience either some difficulty with “basic” movement, or cognitive, sensory, or emotional problems.
- About 14% of people experience “complex activity limitations” in their ability to participate in society, including maintaining a household, working, and pursuing hobbies. (NHIS Data)
  - Altman, Barbara & A. Bernstein, Disability and Health in the United States, 2001-2005” (Hyattsville, MD: National Center for Health Statistics, 2008) at 5. (Yee, 2011)

The double burden

- "Aside from the public health issues that most racial/ethnic minorities face, minorities with disabilities experience additional disparities in health, prejudice, discrimination, economic barriers, and difficulties accessing care as a result of their disability—in effect, they face a "double burden."

HHS Advisory Committee on Minority Health, *Assuring Health Equity for Minority Persons with Disabilities: A Statement of Principles and Recommendations (July 2011) at 11.*

Amplifying Phenomenon

- "Individuals from minority racial/ethnic groups who also have disabilities confront an enormous health disparity amplifying phenomenon."

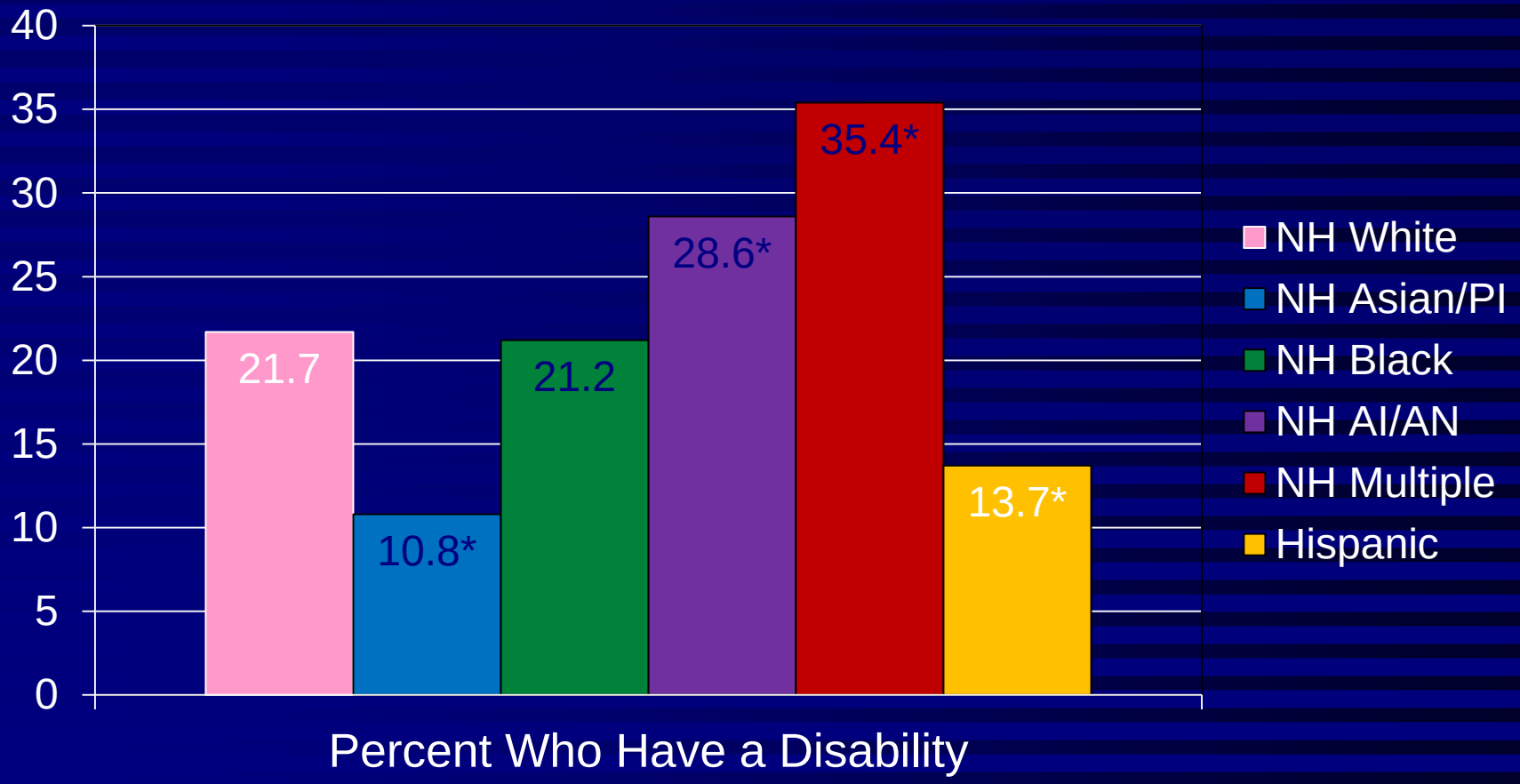
Drum C, McClain MR, Horner-Johnson W, Taitano G. Health disparities chart book on disability and racial and ethnic status in the United States. Institute on Disability, University of New Hampshire. http://www.iod.unh.edu/pdf/Health%20Disparities%20Chart%20Book_080411.pdf. Published August, 2011.

Challenging Multiplier Effect

- "The combination of a racial and ethnic minority status with the presence of a disability creates a challenging multiplier effect in several areas of health."

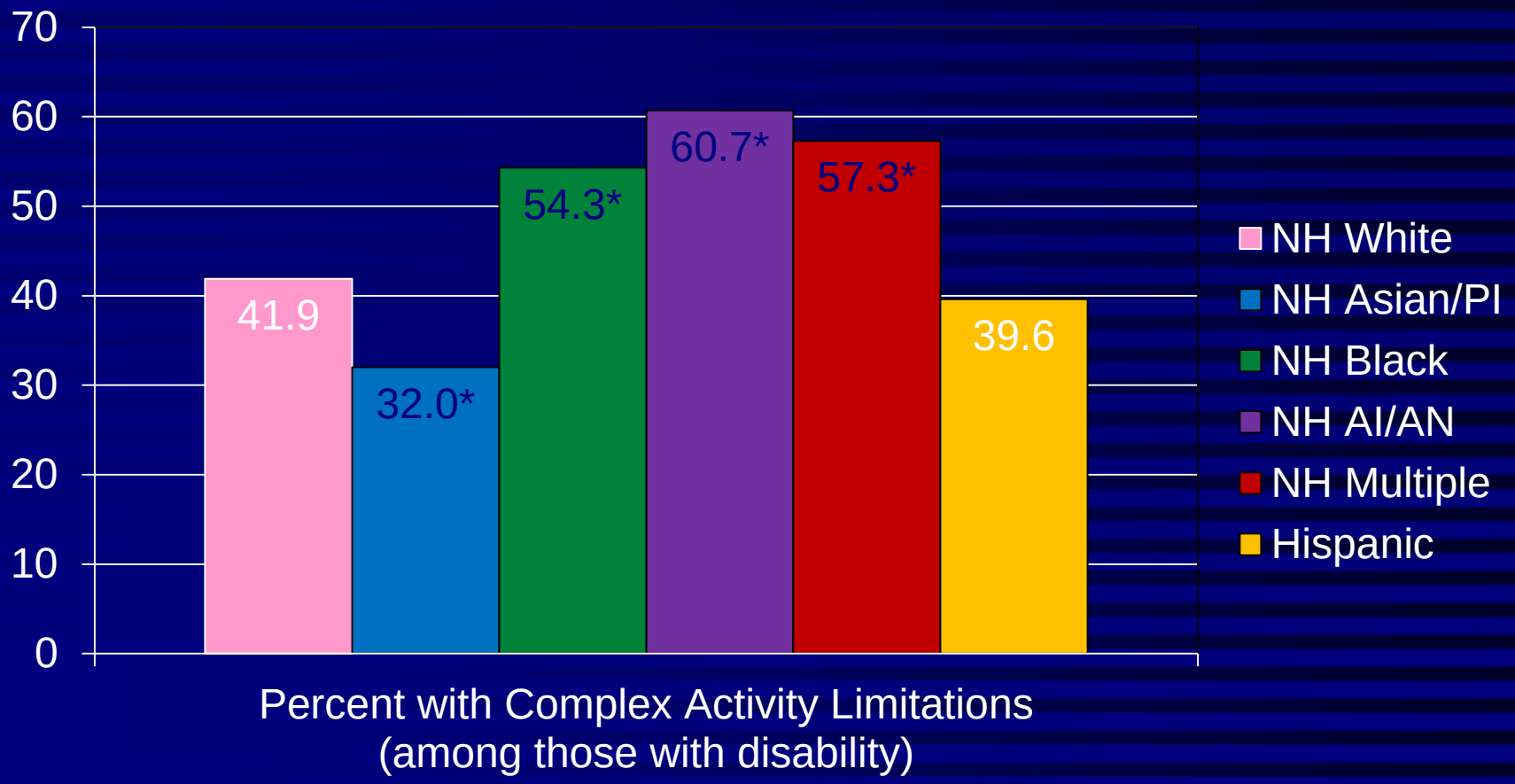
Drum, C.E., Phillips, K.G., Chiu, K., & the Data, Research, and Evaluation Committee of the Region I Health Equity Council (2015). New England Regional Health Equity Profile & Call to Action.

Disability in racial & ethnic groups



Project Intersect: Addressing Health Disparities at the Intersection of Race, Ethnicity, and Disability, which was funded by a cooperative agreement between CDC and the Association of University Centers on Disabilities Willi Horner-Johnson, PhD, PI

Complex activity limitations



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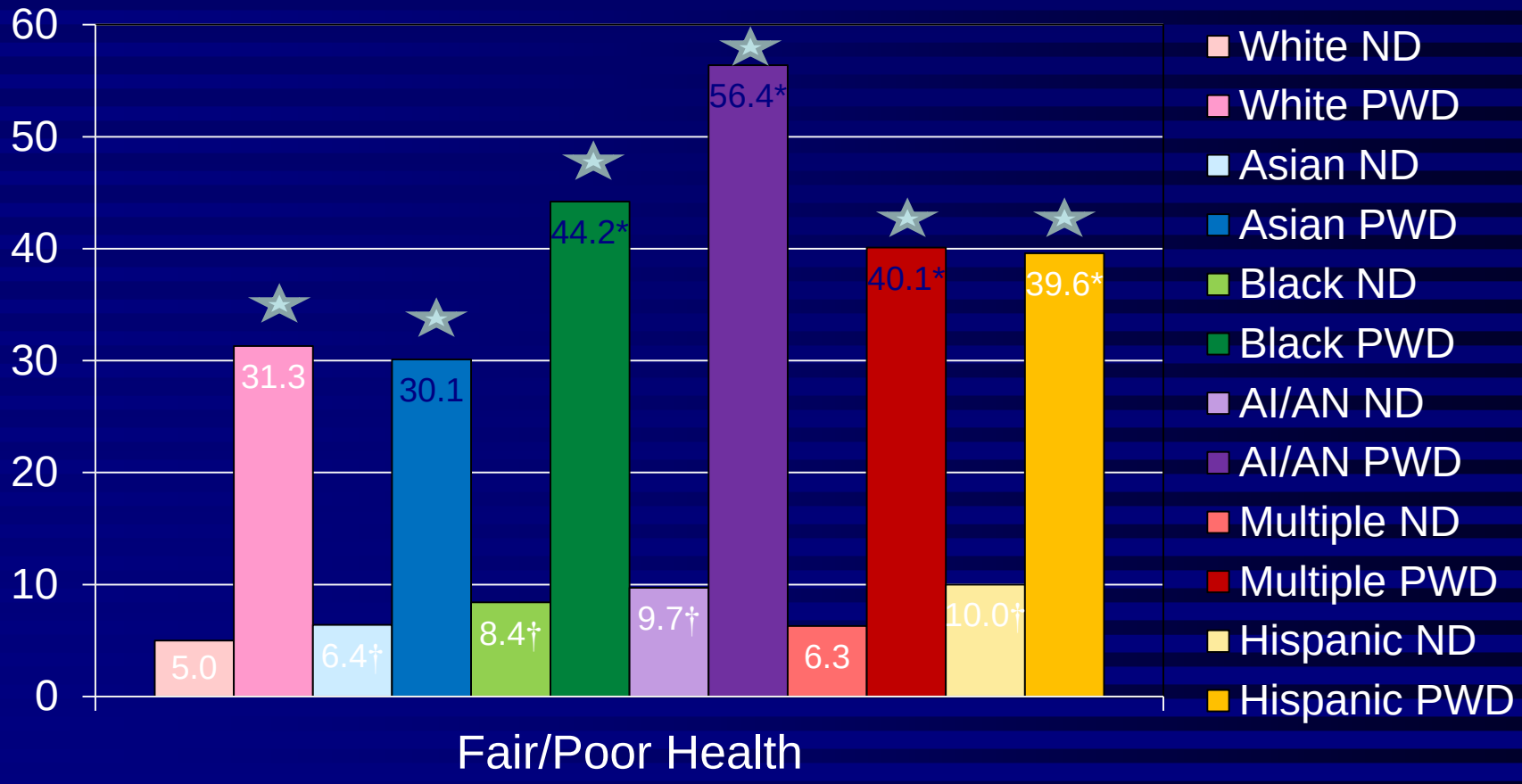
Perceived health status



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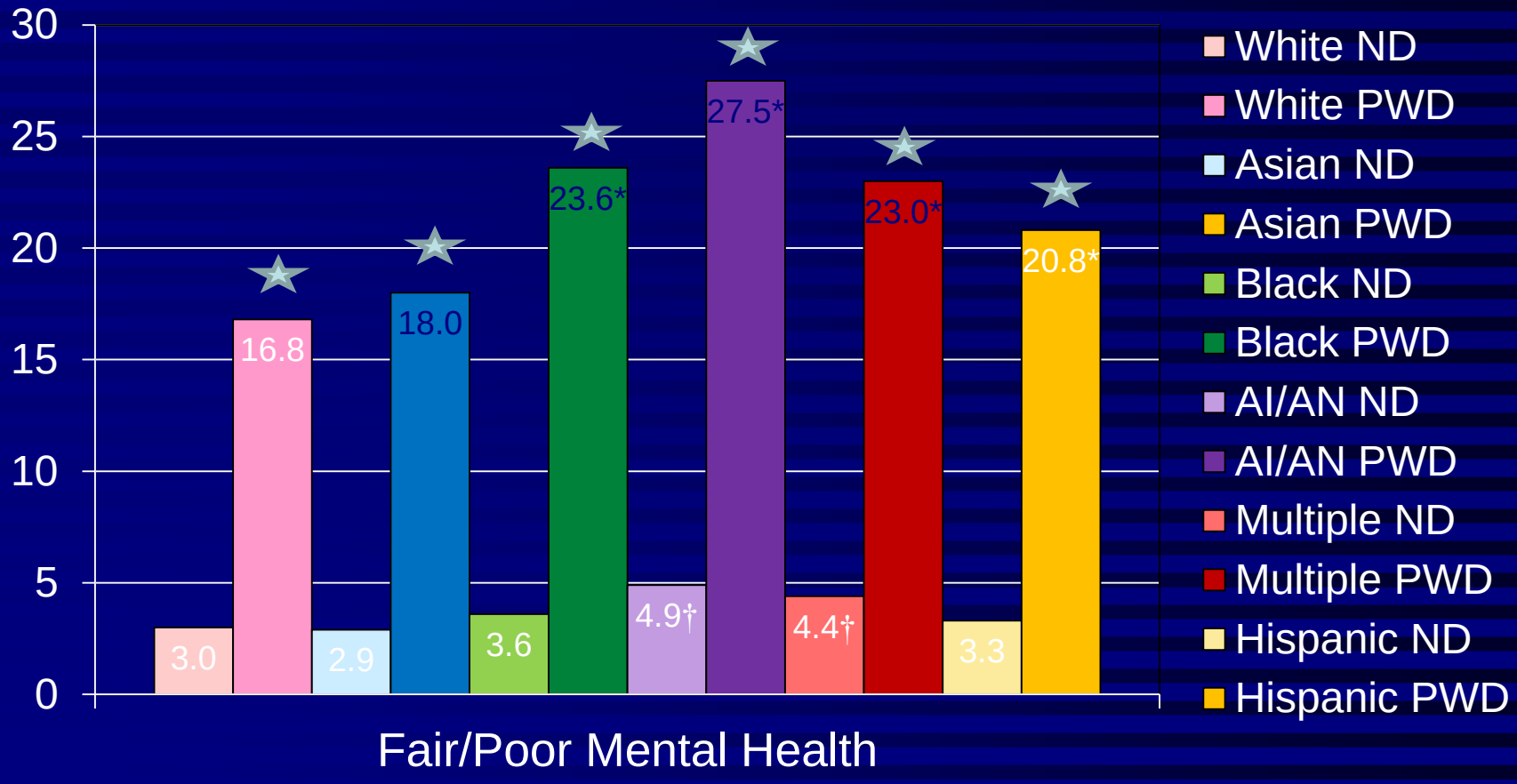
Perceived mental health status



Project Intersect: Addressing Health Disparities at the Intersection of Race, Ethnicity, and Disability, which was funded by a cooperative agreement between CDC and the Association of University Centers on Disabilities Willi Horner-Johnson, PhD, PI

Double Burden: Disability & REM

- Persons with both mobility limitations *and* minority status experienced greater health disparities than adults with minority status *or* mobility limitations alone. For example
  - worsening health,
  - depressive symptoms,
  - diabetes,
  - stroke,
  - visual impairment,
  - difficulty with activities of daily living,
  - obesity, physical activity and
  - low workforce participation. (Altman & Bernstein, 2008)

Disability + REM

- White people w/ Down syndrome in the US had a median death age of 50 in 1997,
  - median age was 25 for African Americans/Blacks, &
  - only 11 for people of other races. (Friedman, 2001 CDC)

Disability + REM

- African Americans are diagnosed more frequently with schizophrenia and less frequently with affective disorders compared with whites who exhibit the same symptoms. (SAMHSA, 2001)
- Asians are more likely to be diagnosed with schizophrenia than whites, Blacks, or Hispanics. (Chow JC, Jaffee K, Snowden L. 2003)
- Only 27% of blacks received antidepressants when first diagnosed with depression, compared with 44% of whites (SAMHSA, 2001)

Disability + REM

- Older Asian American women had the highest suicide rate—6.01 per 100,000—among older adult women of all racial-ethnic groups during 2005 and 2009

CDC.(2014). “Injury Center: Violence Prevention: National Suicide Statistics at a Glance. Suicide Rates Among Persons Ages 65 Years and Older by Race/Ethnicity and Sex, United States, 2005–2009

- There are many barriers to Asians seeking mental health including stigma, lack of language access, and lack of knowledge of community resources to mental illness goes unreported and untreated

CDC. (2013). “Suicide: Risk and Protective Factors.” Injury Prevention & Control. Atlanta, GA: CDC

Disability + REM

- The 2001 Surgeon General's report on mental health cited striking disparities in access, quality, and availability of mental health services for REM Americans
  - Surgeon General's Report on Mental Health – Culture, Race, and Ethnicity. August 26, 2001.
- People with chronic pain: African American/Black patients are prescribed fewer pain medications than whites. (Green et. al, 2009)

Increased Amputations

- African Americans and Hispanics with peripheral arterial disease and diabetes experience a greater incidence and odds of non-traumatic amputation – between 1.5 and 4 times higher – and at a higher amputation level when compared with non-Hispanic whites

Lefebvre, KM, Lavery, LA. Disparities in amputations in minorities. *Clin Orthop Relat R*. 2011; 469 (7),1941–1950. doi: 10.1007/s11999-011-1842-x.

Disparities in Diabetes

- The rate of diagnosed diabetes by race and ethnic background are
  - 15.9% of American Indians/Alaska Natives,
  - 13.2% of non-Hispanic African Americans,
  - 12.8% of Hispanics,
  - 9.0% of Asian Americans, and
  - only 7.6% of non-Hispanic whites

Centers for Disease Control and Prevention. (2014) *National Diabetes Statistics Report: Estimates of Diabetes and Its Burden in the United States.* Atlanta, GA: US Department of Health and Human Services.

Aging & Personal Tasks

- 20% of African Americans/Blacks age 70 & older lost the ability to perform personal tasks such as eating, dressing and bathing, compared to
  - 17%of Latinos and
  - 15% of whites who lost that ability (Peek, 2001)

Aging and Independent Living

- 23% of both Older African Americans and Hispanics were more likely than whites (19%) to have difficulty performing household tasks that help them live independently,
  - such as shopping, preparing meals and managing money

Disparities Summary

- People with disabilities experience health disparities (Altman & Bernstein, HP2020)
- People who are members of racial and ethnic minorities experience health disparities (HP2020)
- PWD + MREM = greater health disparities (Drum et. al, 2011)

Research Gaps

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Wrap Up and Next Steps

Panelist Recognition

Thank your for your time and commitment!

- We would like to give a special thanks to Addressing Disparities Advisory Panel members whose terms end this year:
  - Alfiee Breland-Noble
  - Martina Gallagher
  - Elizabeth Jacobs (Co-Chair)
  - Grant Jones
  - Patrick Kitzman
  - Doriane Miller
  - Alan Morse
- We would also like to thank Elizabeth A. Jacobs for serving as the Co-chair of the Addressing Disparities Advisory Panel.

Panelist Recognition - Alfiee Breland-Noble

- Director, The AAKOMA Project, Georgetown University Medical Center; Associate Professor, Psychiatry, Georgetown University Medical Center

- Represented: *Researchers*

- Alfiee M. Breland-Noble, PhD, MHSc, is an adolescent mental health disparities researcher whose work includes youth, caregivers, families, and communities. Breland-Noble's areas of research and clinical expertise include reducing disparities in depression treatment utilization and outcomes, community-based participatory research (CBPR), faith-based health promotion, developing and disseminating culturally relevant, and patient-focused methods for engaging underserved patients in research to improve the cultural relevance of the mental healthcare evidence base.

- Served as a member of the Addressing Disparities Advisory Panel since April 2014

Panelist Recognition - Martina Gallagher

- Assistant Professor, University of Texas Health Science Center
- Represented: *Clinicians*
- Martina Gallagher, BSN, MSN, PhD, is an Assistant Professor at the University of Texas Health Science Center. Her research focus is on the prevention and treatment of obesity and its cardiovascular sequelae in Latino families. She received a BSN, MS in Nursing Administration of Community and Healthcare Systems and a PhD in Clinical Nursing Research, emphasizing health promotion of Latino families, from the University of Texas Health Science Center at San Antonio. She completed a two-year postdoctoral fellowship at the University of Washington School of Nursing, where she studied basic sleep concepts, data collection, analysis, and interpretation of sleep measures in Latino community settings.
- Served as a member of the Addressing Disparities Advisory Panel since April 2014

Panelist Recognition - Elizabeth Jacobs

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

- Represented: *Researchers*

- Elizabeth A. Jacobs, MD, MAPP, FACP, is recognized as an expert on the provision of linguistically accessible and culturally competent care and has served on many expert panels. She has published numerous peer-reviewed journal articles and authored three book chapters, and she works with other investigators to design culturally specific research. Elizabeth A. Jacobs is also is a PCORI awardee. Jacobs received her MD from the University of California at San Francisco, trained as a general internist at Brigham and Women's Hospital in Boston, and completed a Robert Wood Johnson Clinical Scholars Fellowship at the University of Chicago.

- Served as a member of the Addressing Disparities Advisory Panel since April 2014

Panelist Recognition - Grant Jones

- Founder, Executive Director, Center for African American Health
- Represented: *Patients, Caregivers, and Patient Advocates*
- Grant Jones was a Senior Program Officer for the Piton Foundation in Denver, his work centered on strengthening neighborhoods and resident leadership development. There he spearheaded initiatives to expand the role of faith-based groups in neighborhood improvement and the development of the Center for African American Health. He has served on the Colorado Blue Ribbon Commission for Health Care Reform, the Metro Denver Health and Wellness Commission, the Board of Directors of the Colorado Health Foundation, and the Partnership of Academicians and Communities for Translation and the Council of the Colorado Clinical and Translational Science Institute.
- Served as a member of the Addressing Disparities Advisory Panel since April 2014 and was the former Co-Chair from June 2014 to May 2016

Panelist Recognition - Patrick Kitzman

- Director, Center for Community Health and Vitality, University of Chicago Medicine
- Represented: Clinicians
- Since 2008, Patrick Kitzman, MS, PhD, has worked with multiple state and community-based partners, as well as consumers and caregivers, to establish the Kentucky Appalachian Rural Rehabilitation Network, and serves as its director. His area of interest is the long-term health and health care for individuals with disabilities due to stroke, spinal injury, and brain injury living in Central Appalachian rural communities. He received his PhD in neuroscience from Ohio State University. After completing a two-year postdoctoral fellowship in molecular neurobiology, he completed a BS and MS in physical therapy at the University of Kentucky, and has practiced as a physical therapist in multiple healthcare settings.
- Served as a member of the Addressing Disparities Advisory Panel since April 2014

Panelist Recognition - Doriane Miller

- Director, Center for Community Health and Vitality, University of Chicago Medicine
- Represented: Patients, Caregivers, and Patient Advocates
- Doriane Miller, MD, directs The Center for Community Health and Vitality, which has the mission to improve population health outcomes for residents on the South Side of Chicago through community-engaged research, demonstration, and service models. She was a member of the 2002 Institute of Medicine committee that produced the Guidance for the National Healthcare Disparities Report and she brings over 20 years of experience as a community-based primary care provider who has worked with underserved, minority populations and has a special interest in behavioral health. She received an MD from the University of Chicago and completed a Primary Care Internal Medicine Residency and a General Medicine/Clinical Epidemiology Fellowship at the University of California, San Francisco.
- Served as a member of the Addressing Disparities Advisory Panel since April 2014 and was the former Chair from June 2014 to May 2016

Panelist Recognition - Alan Morse

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

- Represented: Health Systems

- Alan R. Morse, JD, PhD, is the President and Chief Executive Officer of Lighthouse Guild, which provides a full spectrum of integrated vision and healthcare services helping people who are blind or visually impaired, including those with multiple disabilities or chronic medical conditions. Morse is an Adjunct Professor in the Department of Ophthalmology, Columbia University; a trustee of the Healthcare Association of New York; a member of the advisory board of the McPherson Eye Research Institute, University of Wisconsin; and a member of the editorial board of the journal, Ophthalmology.

- Served as a member of the Addressing Disparities Advisory Panel since April 2014

Adjourn

Thank you for your participation!