PCORI Advisory Panel on Healthcare Delivery and Disparities Research

Spring 2019 Meeting

May 16, 2019
9am-5pm

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Housekeeping

- Webinar is available to the public and is being recorded
- Members of the public are invited to listen to this 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
- Chair Statement on COI and Confidentiality

1.

Welcome and Introductions

Panel Leadership

- Umbereen Nehal, MD, MPH
  HDDR Advisory Panel Co-Chair

- Craig Umscheid, MD, MSCE
  HDDR Advisory Panel Co-Chair

- Steven Clauser, PhD, MPA
  Director, Healthcare Delivery and Disparities Research Program

HDDR Advisory Panel Members

- **Rebecca Aslakson, MD, PhD ***
  Associate Professor, Stanford University
- **Leah Backhus, MD, MPH ***
  Associate Professor, Veterans Affairs and Stanford University
- **Nadine Barrett, MA, MS, PhD**
  Director of the Office of Health Equity & Disparities, Duke Cancer Institute
- **Ignatius Bau, JD**
  Independent Health Policy Consultant
- **Terri Black, DNP, MBA, BSN, RN, CRRN, FAHA**
  Clinical Assistant Professor – Nursing, University of Massachusetts and Nurse Reviewer, The Joint Commission
- **Danielle Brooks, JD**
  Senior Consultant and Director of Patient Engagement, WiseThink Health Solutions; Founder & CEO, Bridges
- **Deidra Crews, MD, ScM, FASN, FACP**
  Associate Professor of Medicine, Johns Hopkins University School of Medicine
- **Cheryl Holly, EdD, MED, RN ***
  Professor, Rutgers School of Nursing
- **Christine Joseph, PhD, MPH**
  Epidemiologist, Henry Ford Health System
- **Donald Klepser, MBA, PhD ***
  Associate Professor, University of Nebraska Medical Center
- **Ana Maria Lopez, MD, MPH, FACP**
  Associate Vice President Professor, University of Utah Health Sciences
- **Umbereen Nehal, MPH, MD**
  Chief Medical Officer, Community Healthcare Network

*indicates panelist not in attendance

HDDR Advisory Panel Members

- **Tung Nguyen, MD**
  Chair in General Internal Medicine and Professor of Medicine, University of California, San Francisco School of Medicine
- **Mary Grace Pagaduan, MPH**
  Independent Consultant, March of Dimes Foundation
- **Carmen Pace, BSN, LPN, MPA, RN**
  Facing Our Risk of Cancer Empowered (FORCE)
- **Kathy Phipps**
  Community Health Worker, Memorial Hermann Health System
- **Rachel Raia, MPH**
  Manager, Client Consulting, Blue Cross Blue Shield of Texas
- **Alexis Snyder, BA**
  Patient/Family Advisor
- **Craig Umscheid, MD, MSCE**
  Chief Quality and Innovation Officer, Vice President for Healthcare Delivery Science, Director, Center for Healthcare Delivery Science and Innovation, University of Chicago Medicine
- **Barbara Warren, Psy.D**
  Director for LGBT Programs and Policies in the Office for Diversity and Inclusion, Mount Sinai Health System and Assistant Professor of Medical Education
- **Mitzi Wasik, PharmD**
  Medical Stars Business Lead, Aetna
- **Frank Wharam, MBCHB, MPH**
  Associate Professor, Harvard Pilgrim Health Care Institute
- **Nancy Yedlin, MPH**
  Vice President, Donaghue Foundation

*indicates panelist not in attendance

Guests

- Andrew Hu, MPP
  - PCORI, Director, Public Policy and Government Relations
- Kenneth Mayer, MD
  - The Fenway Institute, Medical Research Director
  - Harvard Medical School and School of Public Health, Professor
- Sinsi Hernández-Cancio, JD
  - Families USA, Director of the Center on Health Equity Action for System Transformation

Healthcare Delivery and Disparities Research Staff

Steve Clauser, PhD, MPA
Program Director

Neeraj Arora, PhD
Associate Director

Els Houtsmuller, PhD
Associate Director

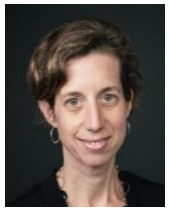
Parag Aggarwal, PhD
Associate Director

Ayodola Anise, MHS
Sr. Program Officer

Penny Mohr, MA
Senior Advisor

Carly Parry, PhD, MSW
Senior Advisor

Gyasi Moscou-Jackson, PhD
Program Officer



Mira Grieser, MHS
Program Officer

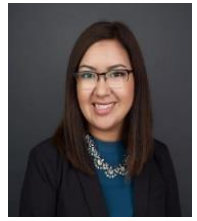
Mari Kimura, MS, PhD
Program Officer

Andrea Brandau, MPP
Program Officer

Carly Khan, PhD, MPH, RN
Program Officer

Cathy Gurgol, MPH
Sr. Program Officer

Allison Ambrosio, MPH
Program Manager

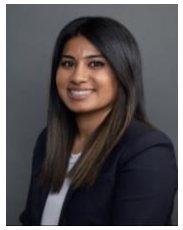


Marisa Torres-Ruis, MPH
Sr. Program Associate

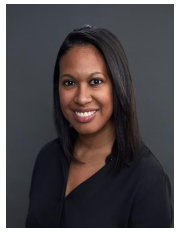
Soknorntha Prum, MPH
Sr. Program Associate

Stephanie Parver, MPH, CPHQ
Sr. Program Associate

Kaitlynn Robinson-Ector, MPH
Program Associate



Sindhura Gummi, MPH
Program Associate

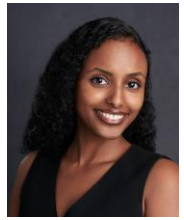


Candace Hall, MA
Program Associate

Maggie Holly
Program Associate

Aaron Shifreen
Program Associate

Rebecca Chanis, MA, MSPH
Program Associate



Metti Duressa
Program Assistant

New HDDR Staff

Tshema Nash
Program Associate

Robin Goins
Senior Administrative Assistant

Rachel Kotiah
Senior Administrative Assistant

2.

Agenda

Umbereen Nehal, MD, MPH

HDDR Advisory Panel Co-Chair

Craig Umscheid, MD, MSCE

HDDR Advisory Panel Co-Chair

Agenda

Morning Agenda

- 9:00 AM Welcome and Introductions
- 9:15 AM Healthcare Delivery and Disparities Research Program Updates
- 10:00 AM Exploring the PCORI Mental Health Portfolio
- 10:30 AM 15-Minute Break
- 10:45 AM Morning Breakout Groups
- 11:30 AM Regroup, Report Back
- 12:00 PM Lunch & PCORI Reauthorization Update

Agenda

Afternoon Agenda

- 1:15 PM PCORI's Future Directions for Health Systems and Disparities Research
- 1:30 PM Afternoon Breakout Groups
- 2:15 PM Regroup, Report Back
- 2:45 PM 15-Minute Break
- 3:00 PM Improving Healthcare Systems to Promote Health Equity for Sexual and Gender Minority Patients
- 3:45 PM Going from Evidence to Action: How PCORI's Asthma Portfolio Can Lead to Changes in Practice and Policy
- 4:45 PM Wrap-up and Next Steps
- 5:00 PM Adjourn

3.

Healthcare Delivery and Disparities Research Program Updates

Steve Clauser, PhD, MPA

Director, Healthcare Delivery and Disparities Research Program

HDDR Updates

- New Research Awards
- Research and Learning Networks
- In The Pipeline

New Research Awards

New Research Awards

PCORI HAS AWARDED OVER

$824 MILLION TO FUND 214

COMPARATIVE EFFECTIVENESS STUDIES IN HEALTHCARE DELIVERY AND DISPARITIES RESEARCH.

AS OF APRIL 2019

Funding Mechanism	# of Projects	Funding
Broad	163	$408 Million
Pragmatic	18	$210 Million
Targeted	33	$206 Million

New Research Awards

Recent Awards

- 2 Improving Healthcare Systems Broad Awards
- 6 Addressing Disparities Broad Awards
- 3 Pragmatic Clinical Study Awards
- 4 Targeted Funding Awards

*AWARDED NOVEMBER 2018 – APRIL 2019

New Broad Awards:
Improving Healthcare Systems

Study Title	PI Name	Site
Patient-Centered Enhancements in School Behavioral Health: A Randomized Trial	Mark Weist	University of South Carolina
Comparative Effectiveness of Direct Admission & Admission through Emergency Departments for Children	JoAnna Leyenaar	Trustees of Dartmouth College

New Broad Awards:
Addressing Disparities Awards

Study Title	PI Name	Site
Reducing Oral Health Disparities of Older Adults: Comparative Effectiveness of 2 Treatments	Suchitra Nelson	Case Western Reserve University
Reducing Disparities in Behavioral Health Treatment for Children in Primary Care	Thomas Power	Children's Hospital of Pennsylvania
Peer Online Motivational Interviewing for Sexual and Gender Minority Male Survivors	Joan Cook	Yale University
Leveraging mHealth and Peers to Engage African-Americans and Latinos in HIV Care (LEAN)	Kathleen Page	Johns Hopkins School of Medicine
Greenlight Plus Study: A Randomized Study of Approaches to Early Childhood Obesity Prevention	Russell Rothman	Vanderbilt University Medical Center
Comparing Approaches to Enhanced Prenatal Care to Improve Maternal and Child Health in Central California	Miriam Kuppermann	University of California, San Francisco

New Pragmatic Clinical Studies

- Pragmatic Clinical Studies and Large Simple Trials to Evaluate Patient-Centered Outcomes

Study Title	PI Name	Site
Scaling Up Psychological Treatments for Perinatal Depression and Anxiety Symptoms via Telemedicine	Daisy Singla	Sinai Health System (Canada)
Comparing Smoking Cessation Interventions among Underserved Patients Referred for Lung Cancer Screening	Scott Halpern	University of Pennsylvania
A Multi-Site Study to Compare the Outcomes of Psychiatric Treatment of Suicidal Adolescents in Different Treatment Settings	Drew Barzman	Cincinnati Children's Hospital Medical Center

New Targeted Award:
Medication-Assisted Treatment (MAT)

- Targeted Funding Announcement: Medication-Assisted Treatment Delivery for Pregnant Women with Substance Abuse Disorders Involving Prescription Opioids and/or Heroin

Study Title	PI Name	Site
Support Models for Addiction Related Treatment	Kimberly Yonkers	Yale University School of Medicine

New Targeted Awards:
Office-Based Opioid Treatment (OBOT)

- Targeted Funding Announcement: Psychosocial Interventions with Office-Based Opioid Treatment for Opioid Use Disorder

Study Title	PI Name	Site
Comparative Effectiveness of Significant Other-Enhanced OBOT and OBOT in Primary Care	Karen Osilla	RAND Corporation
Contingency Management to Enhance Office-Based Buprenorphine Treatment for Opioid Use Disorder	August Holtyn	Johns Hopkins University School of Medicine
Identifying Optimal Psychosocial Interventions for Patients Receiving Office-Based Buprenorphine	David Festinger	Philadelphia College of Osteopathic Medicine

Research and Learning Networks

Research and Learning Networks

- Asthma Evidence to Action Network (AE2AN)
- Transitional Care Evidence to Action Network (TCE2AN)
- Natural Experiments Network for Improved Prevention and Treatment for Patients with Type II Diabetes (NEN)
- Palliative Care Learning Network
- Telehealth Portfolio Synthesis and Analysis Group

Palliative Care Learning Network

- HDDR has created a learning network of nine multi-site palliative care CER studies funded in FY2017 for a total investment of ~$81 million
  - Six studies focus on models of palliative care delivery
  - Three studies focus on advance care planning
- Network goals include:
  - Foster co-learning across awardee teams
  - Facilitate collective success of the projects
  - Contribute to the field via joint presentations and publications

Telehealth Research Synthesis Portfolio Group

- PCORI hosted three telehealth webinars between March and May of this year targeting funded investigators. Topics included:
  - Addressing Disparities Through Telehealth
  - Examining Evidence Gaps in the Use of mHealth for Self-Management of Chronic Disease
  - Challenges in Addressing Large, Multi-site, Multi-state Pragmatic Trials in Telemedicine
- PCORI was invited to plan a special panel on Addressing Disparities Through Telehealth for the upcoming Academy Health meeting in June.
- Telehealth portfolio presented to PCORI's Board of Governors this past week.

In the Pipeline

Upcoming Awards

2018 Cycle 3 Broad PFA

- Addressing Disparities: Up to $8M funds available
- Improving Healthcare Systems: Up to $16M funds available
- PFA Published: October 2018
- Projected award date: **August 2019**

2019 Cycle 1 Broad PFA

- Addressing Disparities: Up to $8M funds available
- Improving Healthcare Systems: Up to $16M funds available
- PFA Published: January 2019
- Projected award date: **October 2019**

2019 PCORI Annual Meeting

Breakout Sessions. Several breakout sessions are expected to feature HDDR investigators, including sessions broadly focused on chronic illness and health disparities.

Poster Presentations. HDDR Staff will invite research awardees and project partners to submit an abstract for a poster presentation.

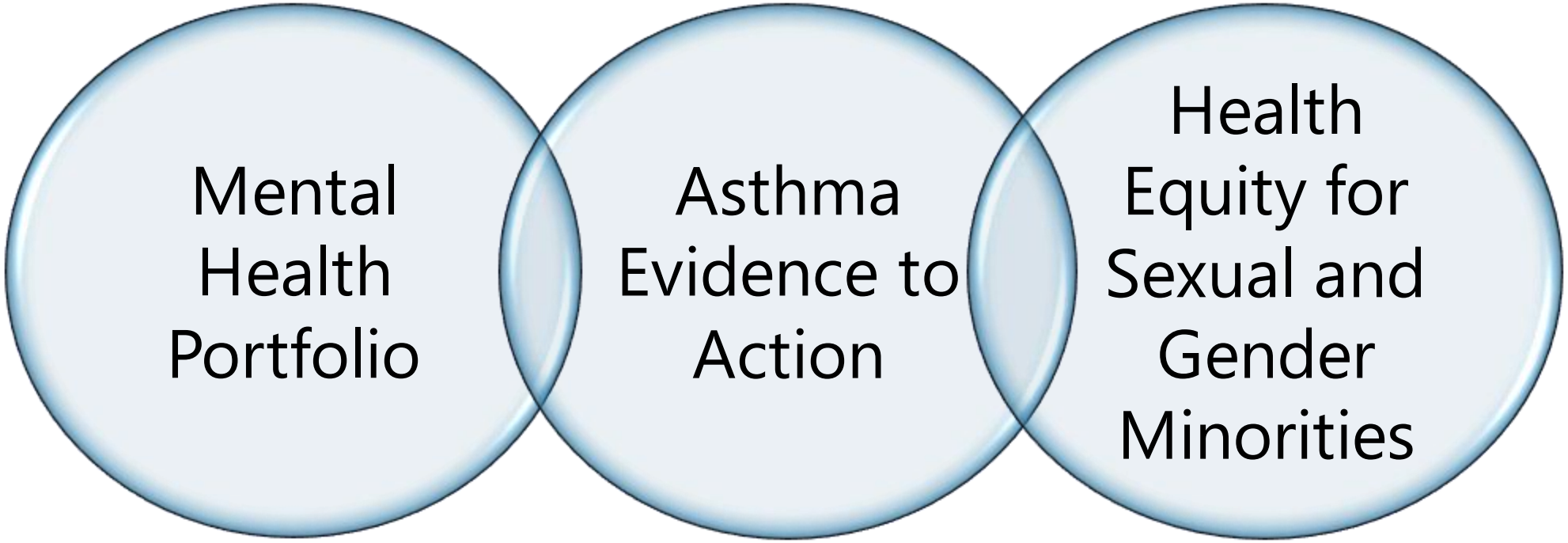
Pre-Meetings with Research Network. The PCORI Transitional Care Network and the Palliative Care Learning Network will host in-person awardee meetings in conjugation with the PCORI annual meeting.

Transitional Care Stakeholder Meeting

- PCORI will host a Fall **Transitional Care Stakeholder Meeting**
- Stakeholders will explore the unique contributions of the 25 transitional care studies in the TC-E2AN network
- The meeting will provide PCORI the opportunity to:
  - gain input on best ways to frame the portfolio and interpret its emergent findings
  - discuss measures used across the portfolio to capture the experience of transitional care from the perspective of patients and other stakeholders
  - understand what information may be needed to utilize patient-centered outcomes in decision-making

Examining Our Portfolio

- High-interest areas of the portfolio may include:



4.

PCORI's Mental Health Portfolio

PCORI Mental Health Portfolio

HDDR Advisory Panel Meeting

May 16, 2019

Rebecca Chanis, MSPH, MA
Candace Hall, MA
Els Houtsmuller, PhD

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Workgroup

Tshema Nash, MPH
Program Associate, HDDR

Rebecca Chanis, MSPH, MA
Program Associate, HDDR

Candace Hall, MA
Program Associate, HDDR

Els Houtsmuller, PhD
Associate Director, HDDR

Agenda

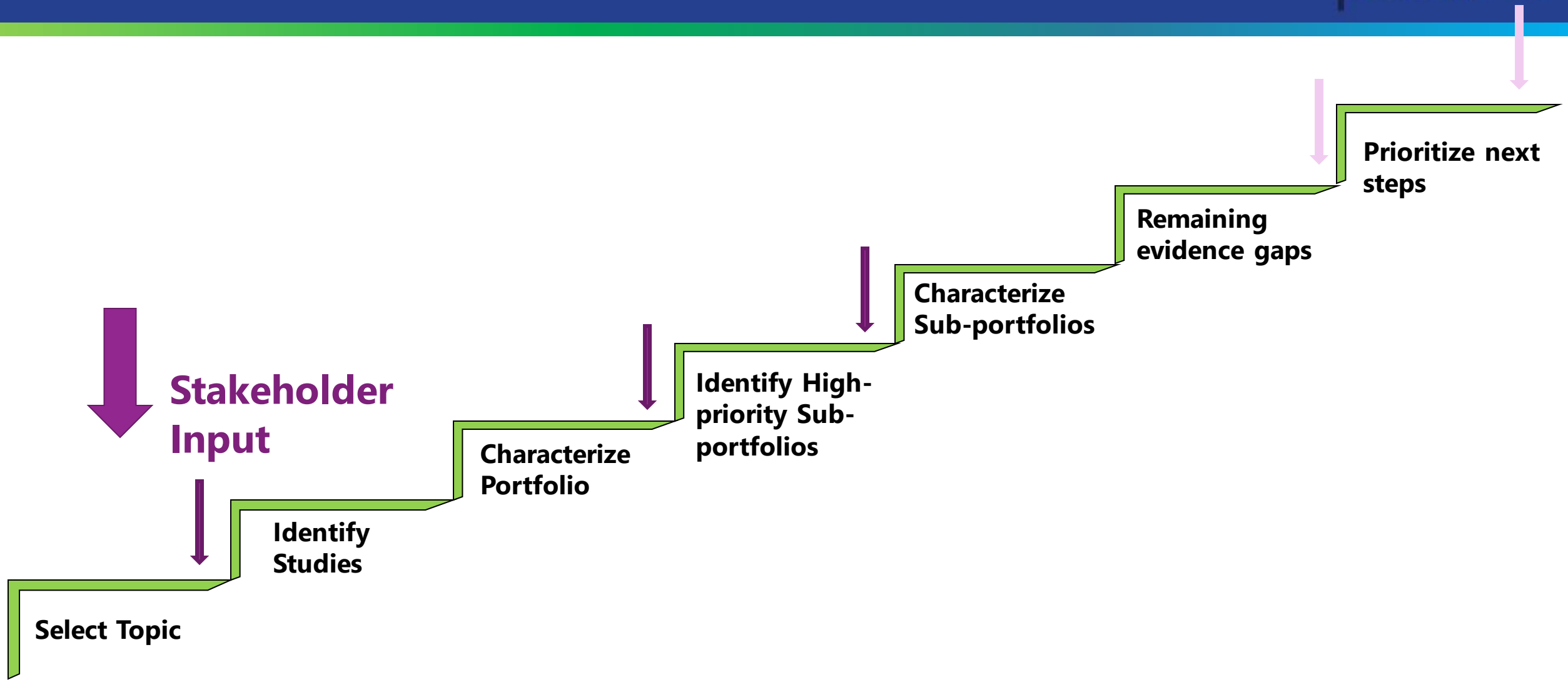
Overview	Portfolio synthesis PCORI Mental Health Portfolio
Sub-Portfolios	Three examples
Break-out Group Discussion and Report Back	Portfolio Portfolio presentation Selection topics for 'zooming in' (sub-portfolios)
Next Steps	

Portfolio Synthesis

Goals

- Which evidence gaps have we addressed?
- Which gaps should we focus on next?

Portfolio Synthesis: Process

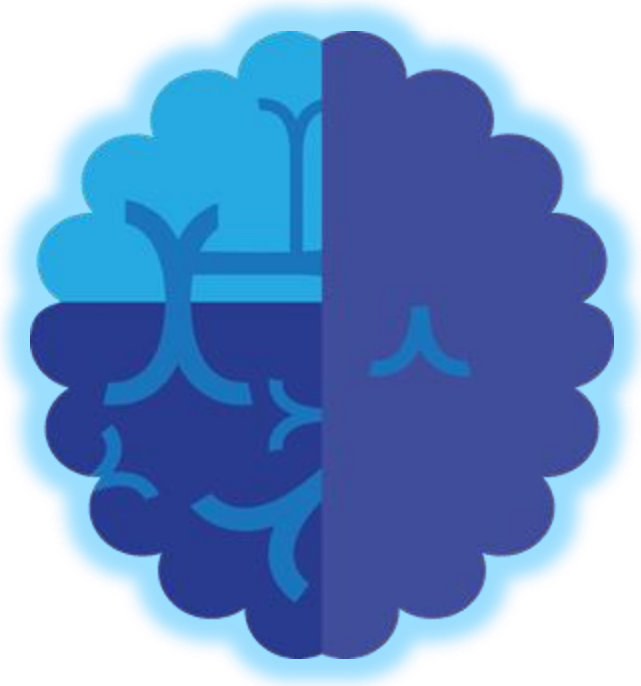


Topic Selection: Mental Health

The **high prevalence** and **heavy burden** of **mental illness** remain a major **public health concern**.

- 1 in 5 children and adults
  - Higher rates among homeless, LGBT, in juvenile justice systems, other
- Leading cause disease burden (DALYs, YLD)
- Estimated cost >$467 billion/yr (NIMH, 2012)
- Evidence-based treatments are available, but < 50% of patients receive treatment
  - Lower for black, Hispanic, Asian populations

TOPIC SELECTION: Mental Health



PCORI HAS AWARDED

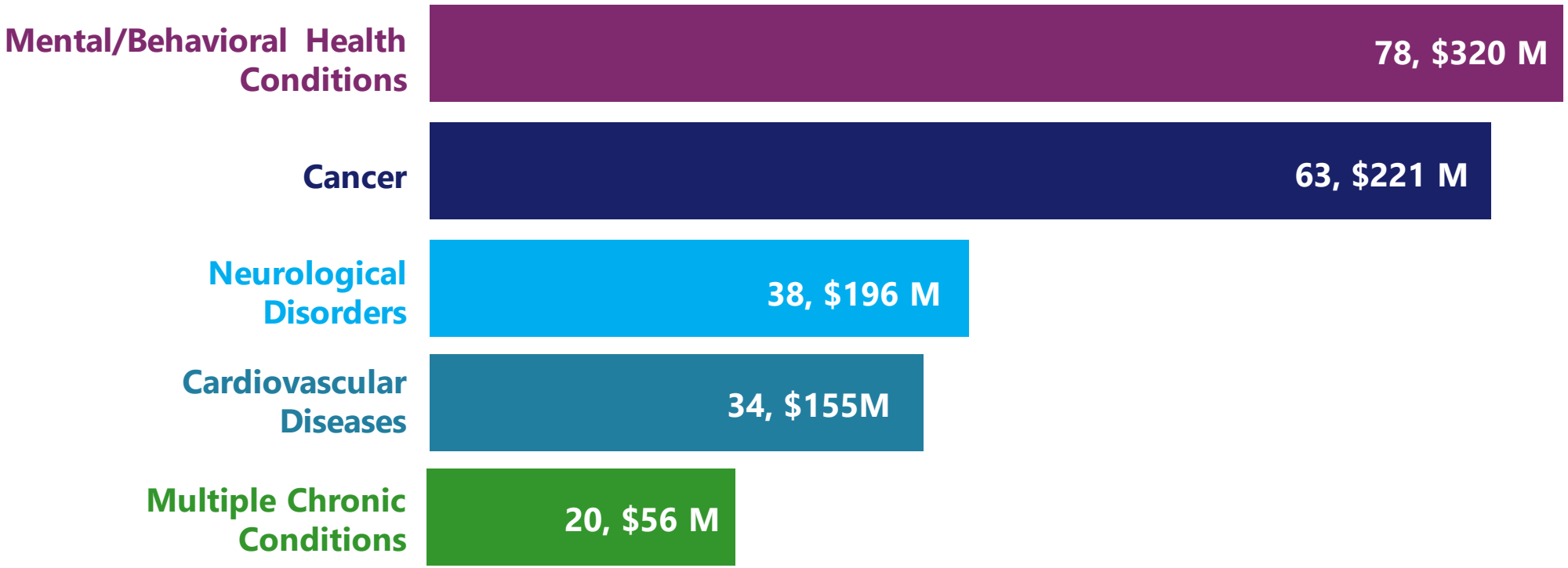
$320 MILLION TO FUND **78**

COMPARATIVE EFFECTIVENESS STUDIES ON MENTAL HEALTH

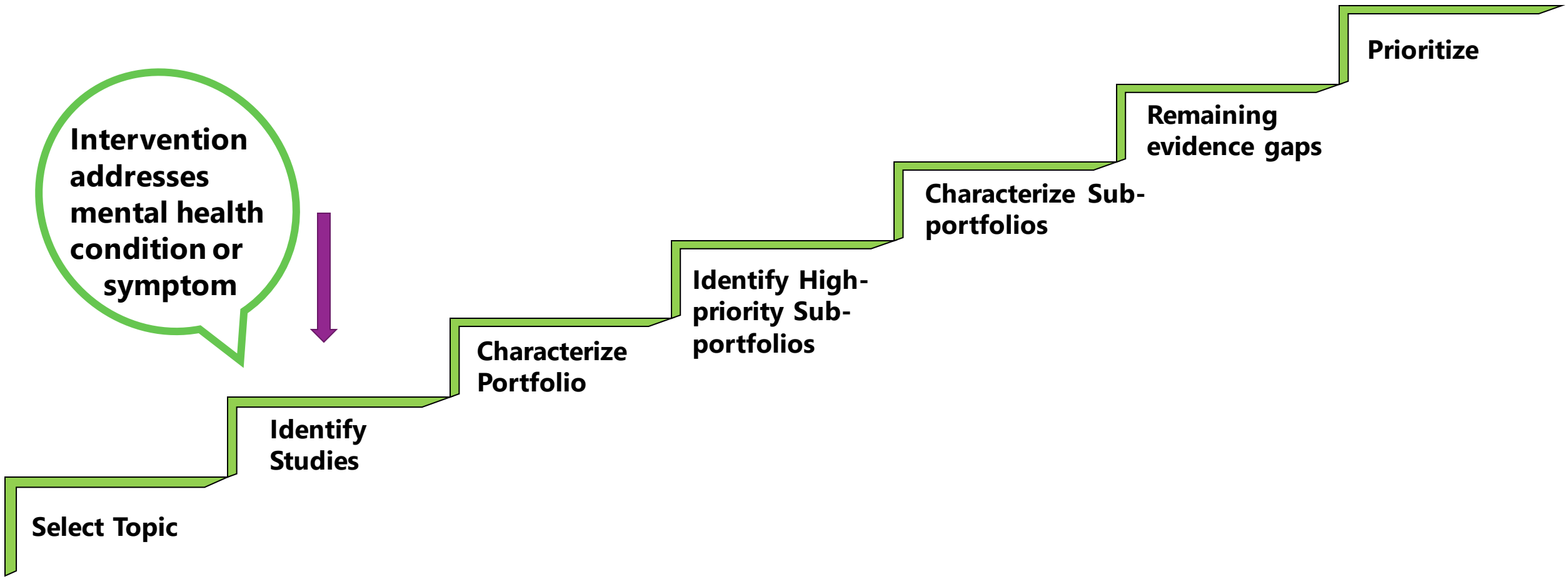
AS OF APRIL 2019

TOPIC SELECTION: Mental Health

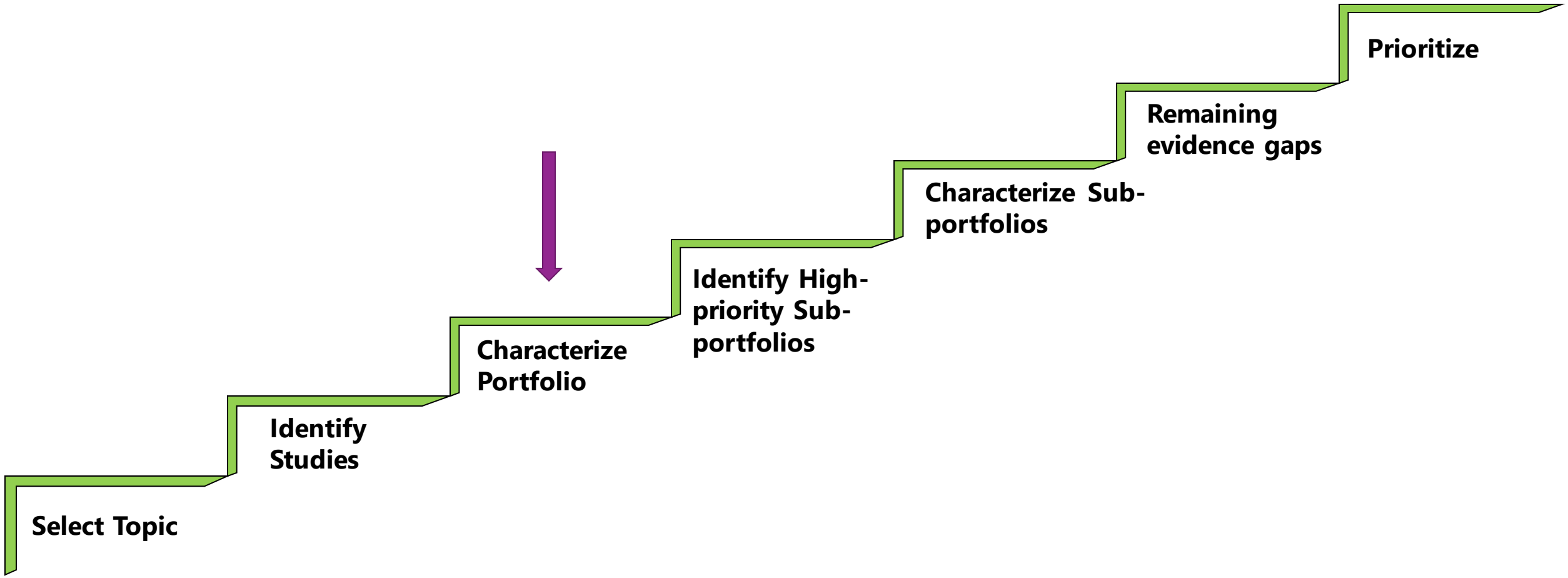
PCORI Investment Across Health Conditions



Portfolio Approach



Portfolio Approach



PCORI Mental Health Portfolio

78 studies included (48 HDDR)

$320M Investment

Study focus: improving patient access to MH services (44)

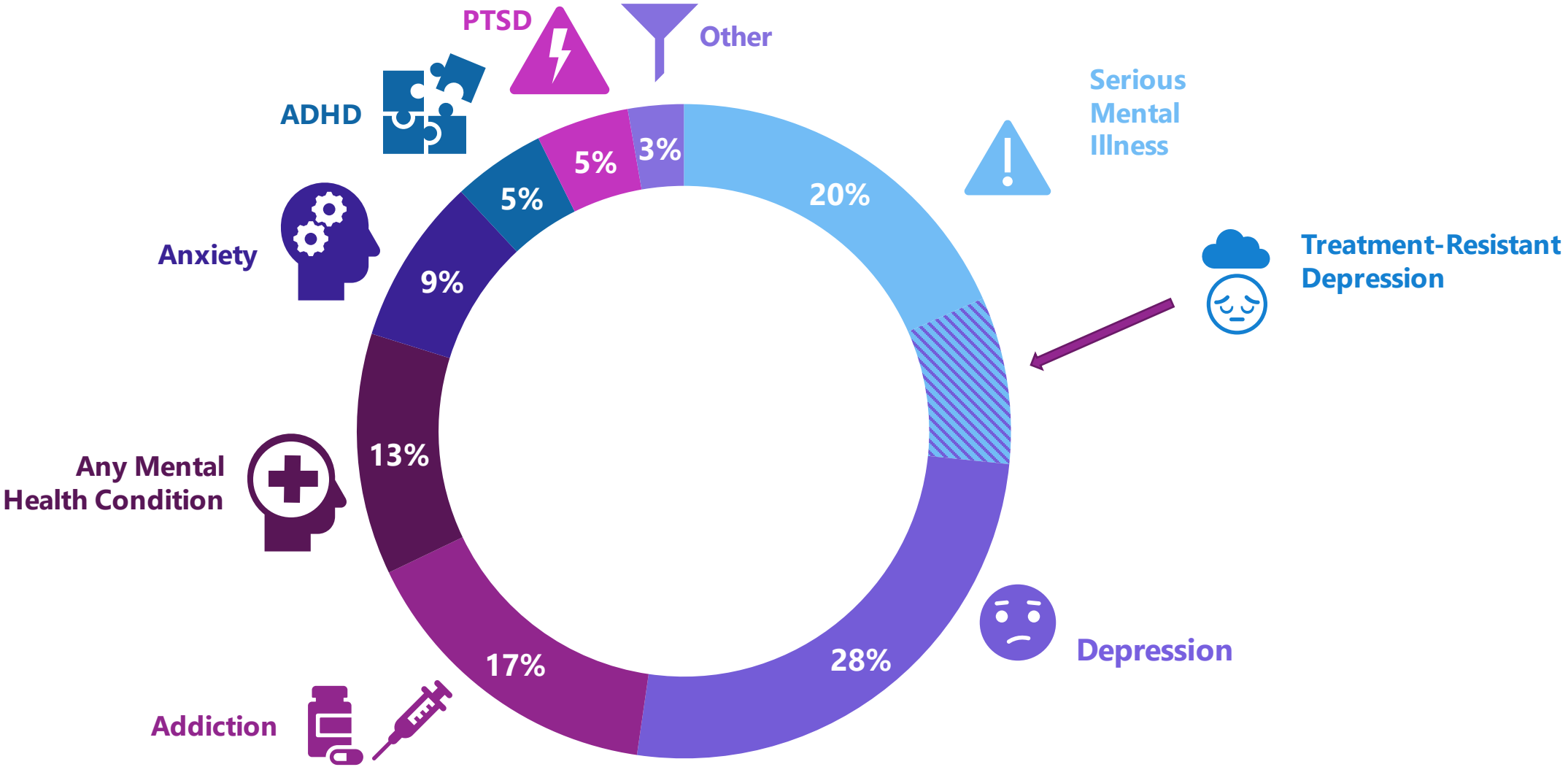
supporting primary care (25)

integrating care elsewhere (e.g., school, home) (19)

workforce (e.g., peer navigators) 18)

transitions in care (5)

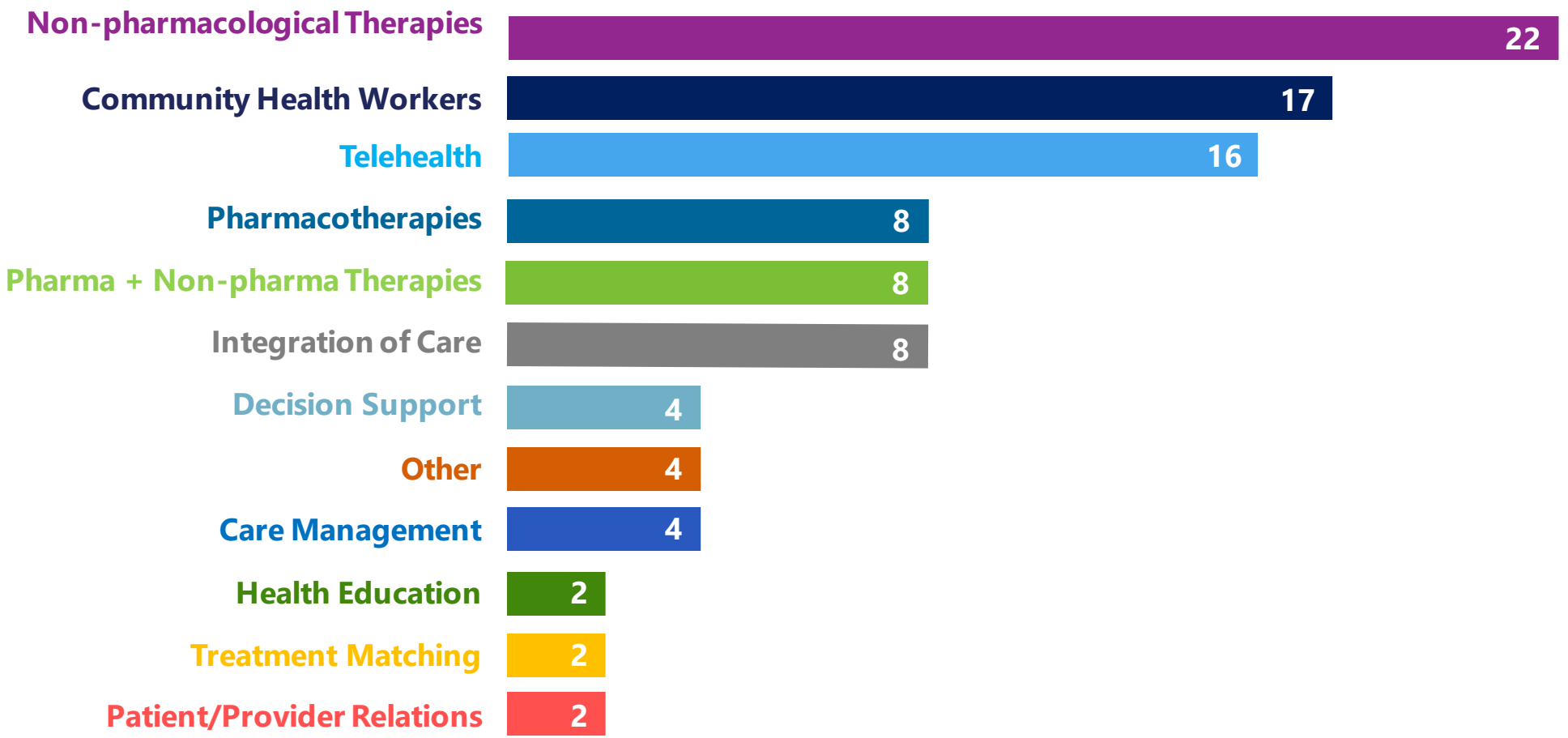
PCORI Mental Health Portfolio Conditions



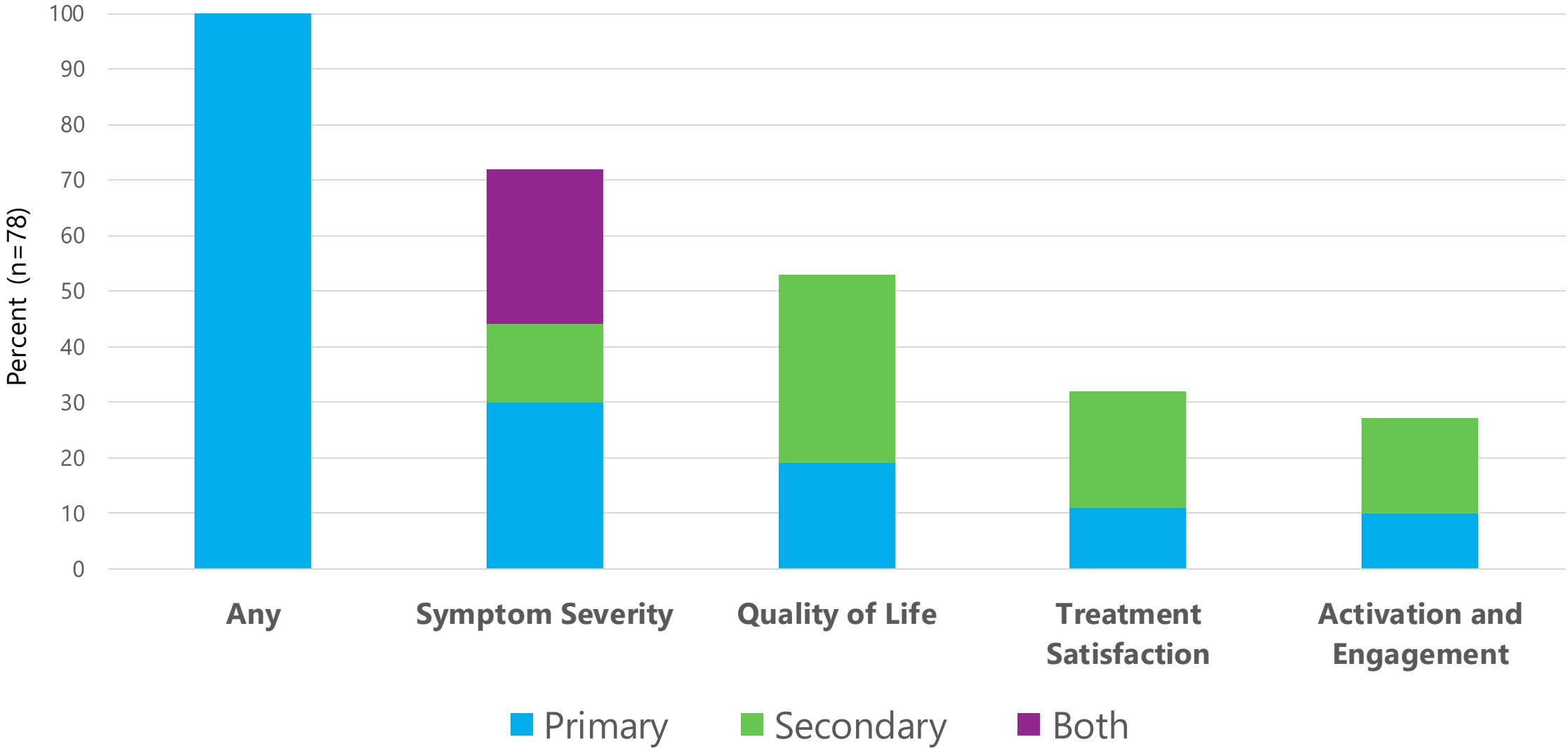
PCORI Mental Health Portfolio Populations

- Racial/Ethnic: 38
- Women: 29
- Low-Income: 22
- Children: 18
- Older Adults: 17
- General: 17
- Rural: 13
- Medicaid: 6
- Multiple Chronic Conditions: 6
- Low Health Literacy: 6
- Limited English: 6
- Sexual Minorities: 2
- Veterans/Armed Forces: 1

PCORI Mental Health Portfolio Interventions

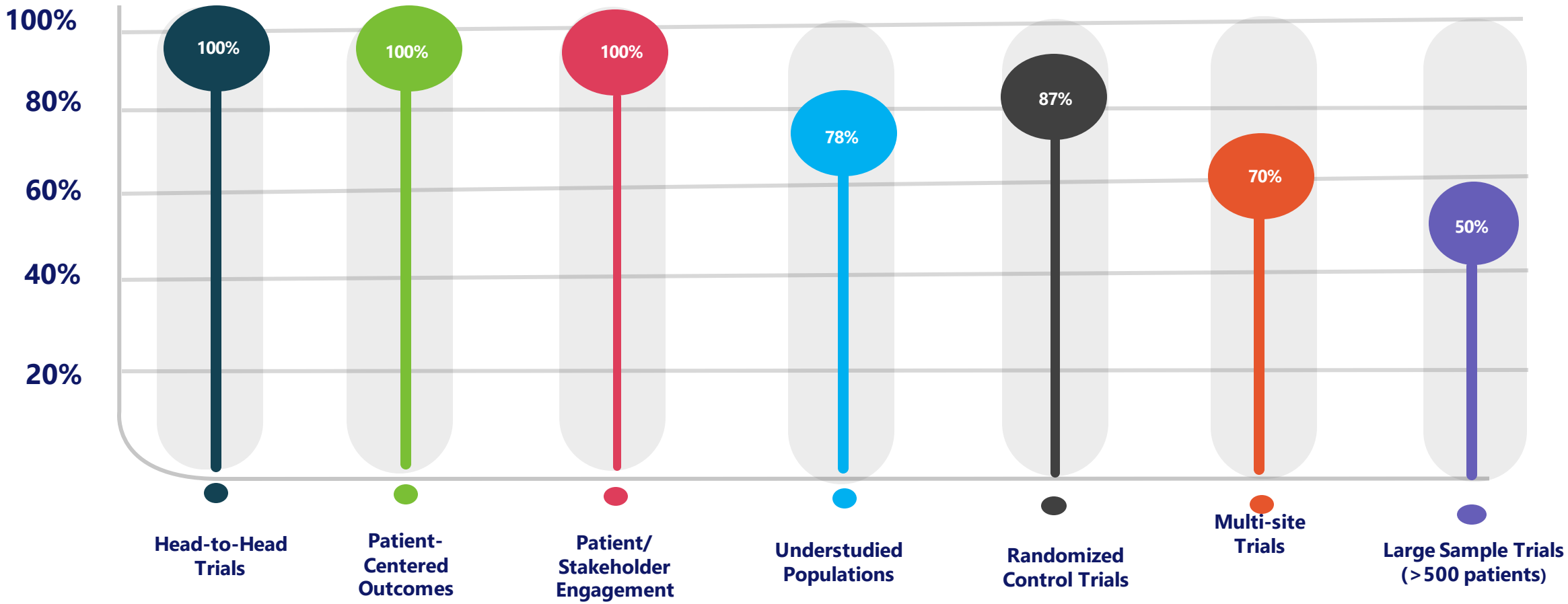


PCORI Mental Health Portfolio Patient-Centered Outcomes

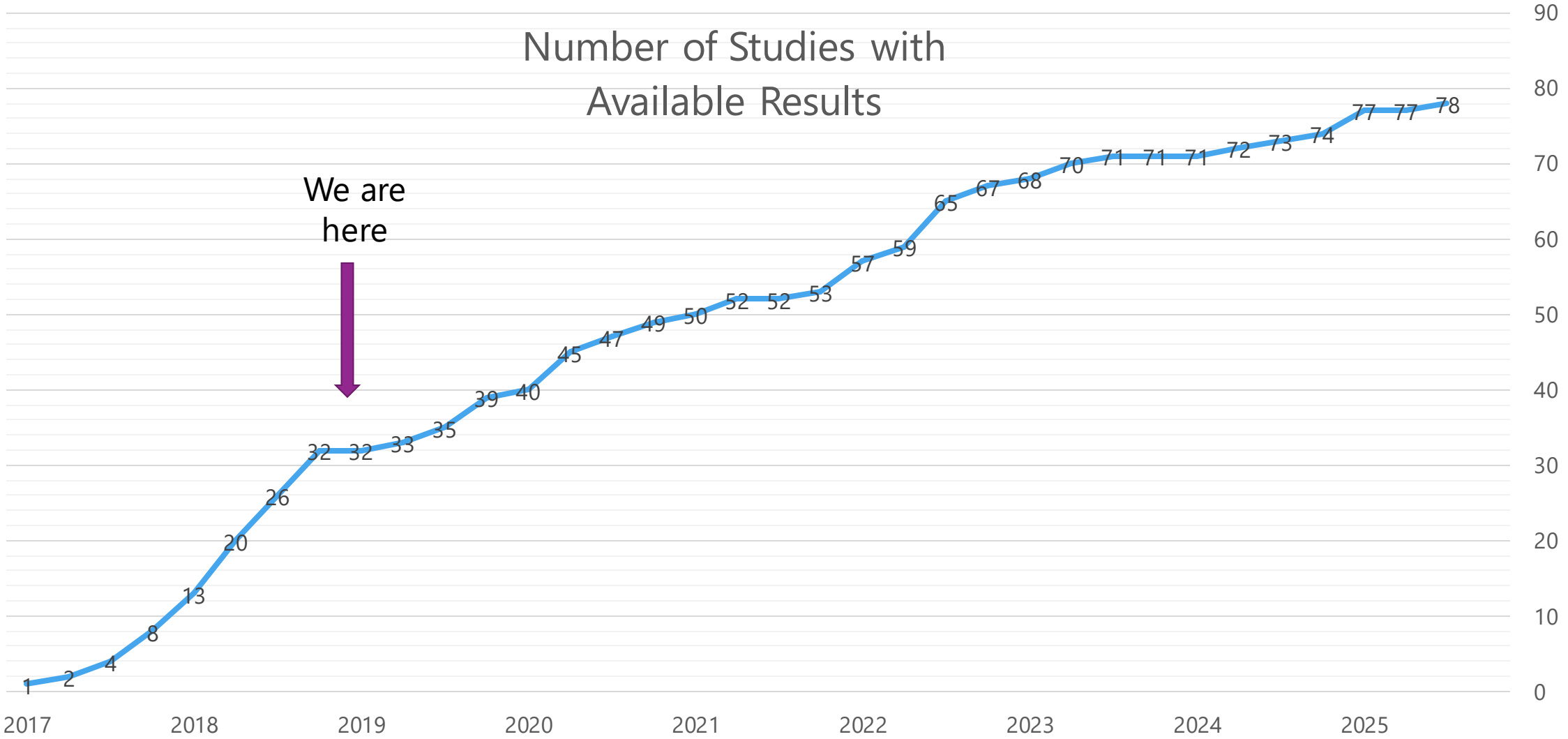


PCORI Mental Health Portfolio Study Characteristics

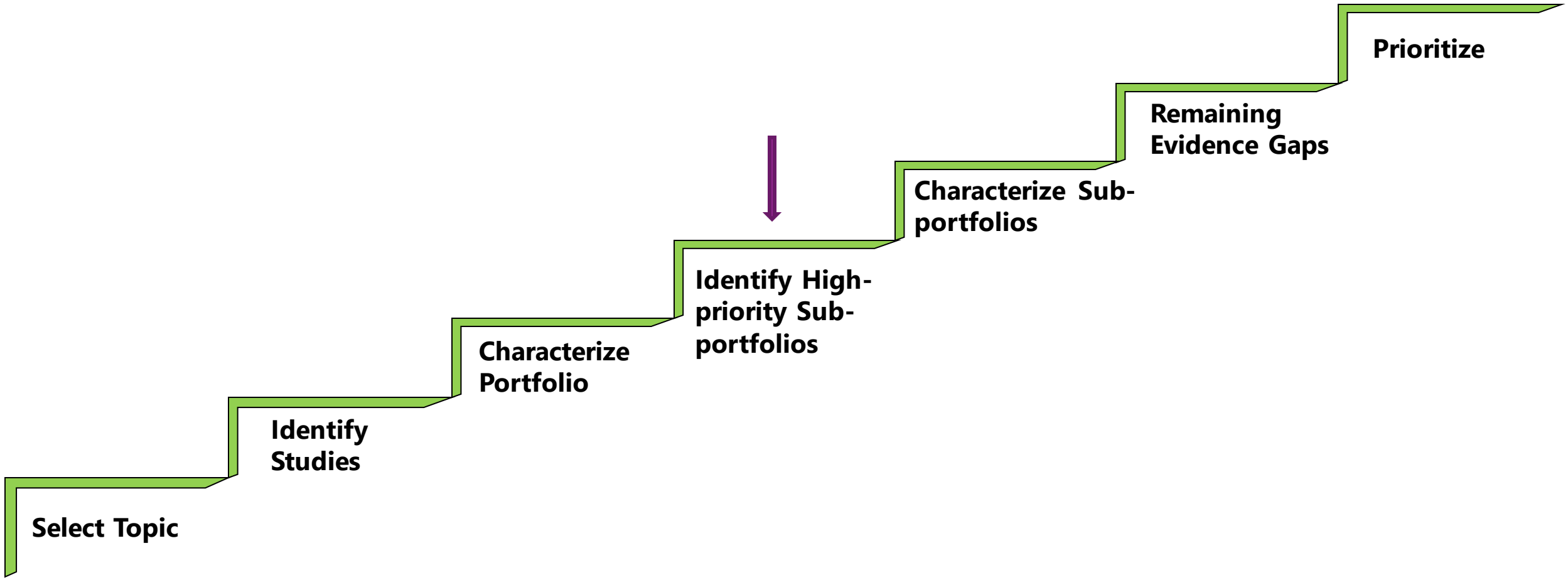
PCORI Mental Health Studies



Timeline Availability of Results



Portfolio Approach



PCORI Mental Health Portfolio

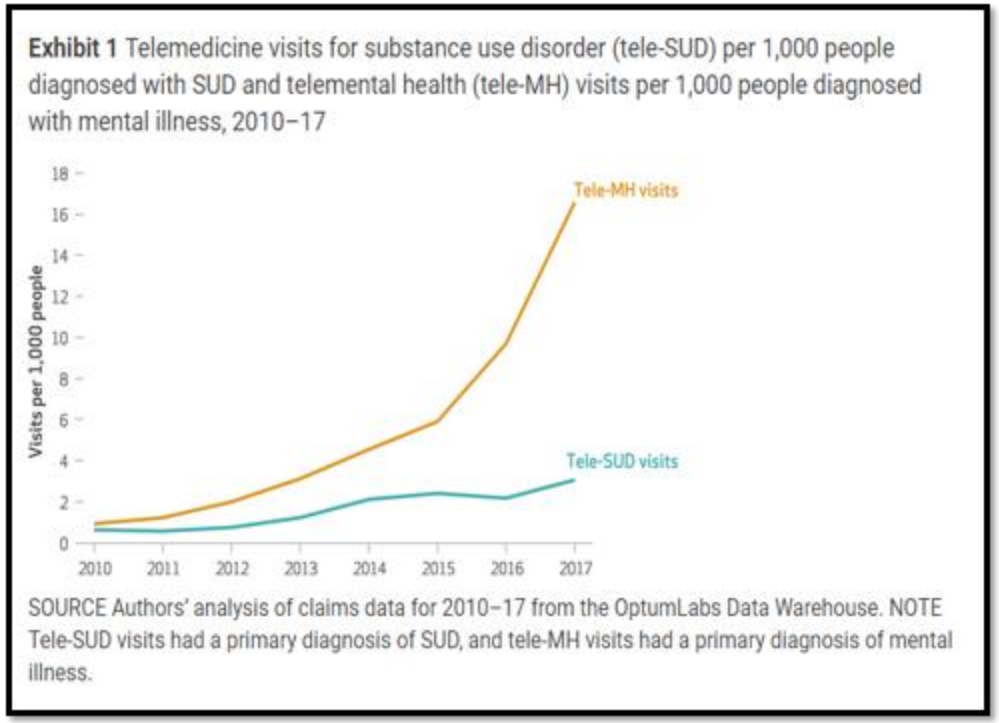
Sub-Portfolios

Sub-Portfolio: Topic Selection

Tele-mental health may address **access problems, disparities, stigma**

- Barriers to mental health care: stigma; lack of access due to financial, geographical and/or time constraints; insufficient provider availability
- Barriers disproportionately affect vulnerable populations
- **Teledelivery** of care for common mental health conditions can be as effective as face-to-face approaches…

  …but for **which conditions**, through **which media**, and **for whom**?



Haiden A. Huskamp et. al, (2018) How is Telemedicine Being Used In Opioid And Other Substance Use Disorder Treatment? http://dx.doi.org/10.1377/hlthaff.2018.05134

Sub-Portfolio: Tele-mental health Evidence Gaps

16 studies (10 in HDDR) $97 million invested

Evidence gaps (Systematic Reviews 2014-2018)

- Understudied and vulnerable populations (n = 12)
- Understudied outcomes (cost, resource use, harm; n = 9)
- Conditions other than depression/anxiety (n=7)
- Opioid addiction (n=2)
- Integration into primary care (n = 8)
- Other?

  - Design factors: Rigorous study design (n = 16)
    Including patient input in telehealth tools (n = 8)

Sub-Portfolio: Topic Selection

Depression has a **high prevalence** and **heavy burden**

- An estimated 17.3M (7%) adults and 3.2M (13%) adolescents in the US are affected (NIMH, 2019)
  - Higher for American Indian/Alaska Natives; 2 or more races; younger; female
- Leading cause of disease burden of mental health disorders (DALYs)
- Estimated cost >$210 billion/yr

Sub-Portfolio Depression Evidence Gaps

22 studies (13 in HDDR) $110 million invested

- Access/use services - 65% adults, 20% adolescents receive treatment (8)
- Understudied, vulnerable populations – disparities access/use, outcomes (13)
- Co-morbid conditions - other MH conditions, diabetes, cancer, CV (6)
- Perinatal Depression (4)
- Treatment-Resistant Depression (3)
- Other

Sub-Portfolio: Topic Selection

Serious mental illness (SMI; schizophrenia, bipolar disorder, severe depression, other)

- Serious functional impairment, substantially interfering with one or more major life activities
- An estimated 11.2M (4.5%) adults in the US are affected
  - Higher rates among females, young adults (aged 18-25), adults reporting two or more races, and sexual minority adults
- Increased mortality, morbidity, disability (life expectancy reduced 10-30 yrs)
- 67% of adults receive treatment (lower for men, adults <50, racial/ethnic minorities)

Sub-Portfolio Serious Mental Illness Evidence Gaps

21 studies (16 in HDDR) $111 million invested

- Reduction of disability, morbidity, and mortality (7)
- Access to/use of services (13)
- Understudied and vulnerable populations (rural (1), Latino (1))
- Transitions in care (3)
- Treatment-resistant Depression (3)

Sub-Portfolios

Tele-Mental Health

Depression

Serious Mental Illness

Next?

Populations, conditions, outcomes, interventions

Breakout Groups

PCORI Mental Health Portfolio

1. Underrepresented populations, conditions?

2. Presentation: Which variables are helpful? Which are not? Additional variables to include?

3. Which sub-portfolios should we focus on next? Which criteria should we use?

Breakout Session

10:30 AM – 11:30 AM

- Breakout Group 1: report to Studio E
- Breakout Group 2: report to Studio D
- Breakout Group 3: stay in the General Session Room

**Webinar will resume at 11:30 AM*

Report Back and Group Discussion

11:30 AM – 12:00 PM

Lunch and Closed Session

12:00 PM – 1:15 PM

**Webinar will resume at 1:15 PM*

6.

PCORI's Future Directions for Health Systems and Disparities Research

Setting the Stage: PCORI's Future Directions for Health Systems and Disparities Research

HDDR Advisory Panel Meeting

May 16th, 2019

Carly Parry, PhD, MSW, MA
Senior Advisor, Healthcare Delivery & Disparities Research

Parag Aggarwal, PhD
Associate Director, Healthcare Delivery & Disparities Research

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Planning for the PCORI of the Future: Health Systems and Disparities Research

Session Goals:

- Recap PCORI's investments in health systems and disparities research
- Discuss a future vision for PCORI's Healthcare Delivery and Disparities Research Program
- Propose strategies to achieve the future vision

Brief Recap: PCORI's Vision and Mission

Vision Statement from PCORI's Strategic Plan

Patients and the public have information they can use to make decisions that reflect their desired health outcomes

Mission Statement from PCORI's Strategic Plan

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

Brief Recap: HDDR's National Priorities for Research (IHS and AD)

Improving Healthcare Systems

- Compares **health system–level approaches** to improving access
- Supports patient self-care, innovative use of health information **technology**, **care coordination** for complex conditions, and effective **workforce deployment**

Addressing Disparities

- **Reduce disparities** in healthcare outcomes and **advance equity** in health and healthcare
- Support comparative effectiveness research that will identify best options for **reducing and eliminating disparities**

Assumptions About Our New Law

Purpose Statement from PCORI's Authorizing Law:

"The purpose of the Institute is to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis that considers variations in patient subpopulations, and the dissemination of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services, and [other] items."

- New authorizing law is TBD – but we should start planning!
- Assumptions guiding our conversation:
  - PCORI's mandate will still be focused on CER and remain relatively flexible
  - Our funding level will be commensurate with the current investment
  - We don't anticipate major changes in operations or funding goals; however, we may have flexibility at the margins
  - We will adjust as we learn more

Crafting The Vision

- Looking forward to PCORI in 2025 …
  - What will we have accomplished?
  - What will we be known for?

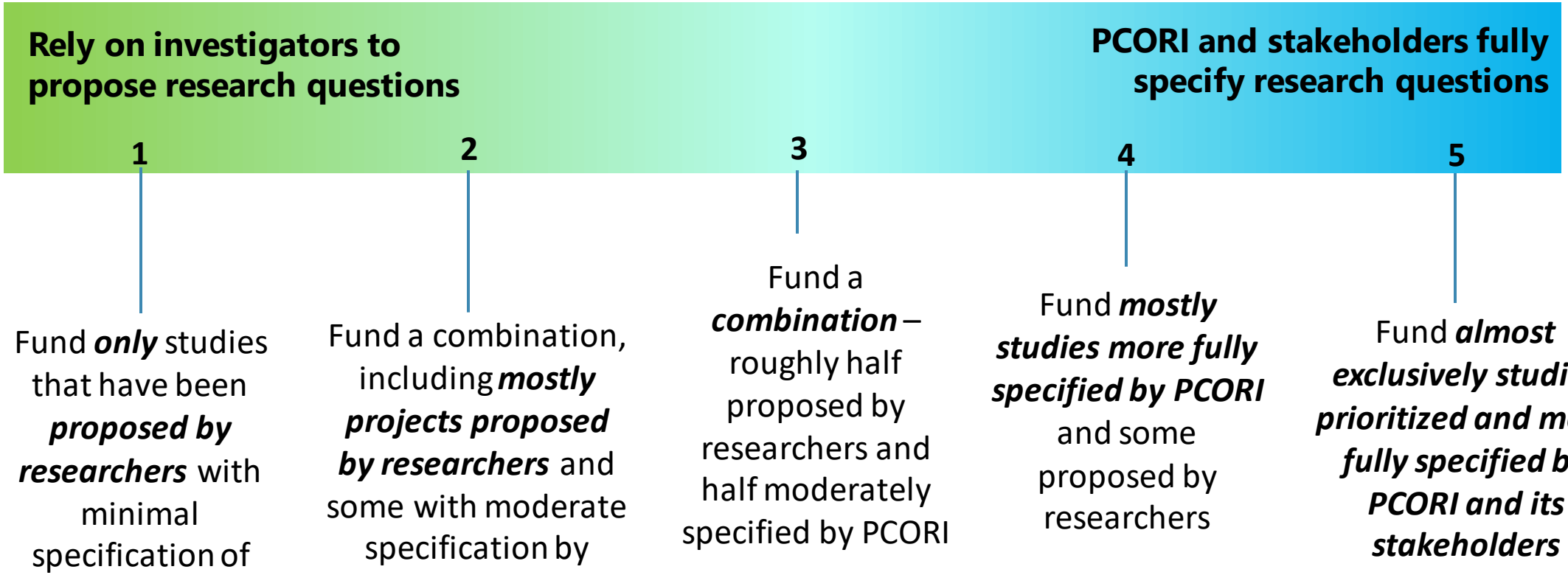
- In the breakout sessions, we will discuss your vision for the HDDR program

What is the Strategy to achieve the Vision?

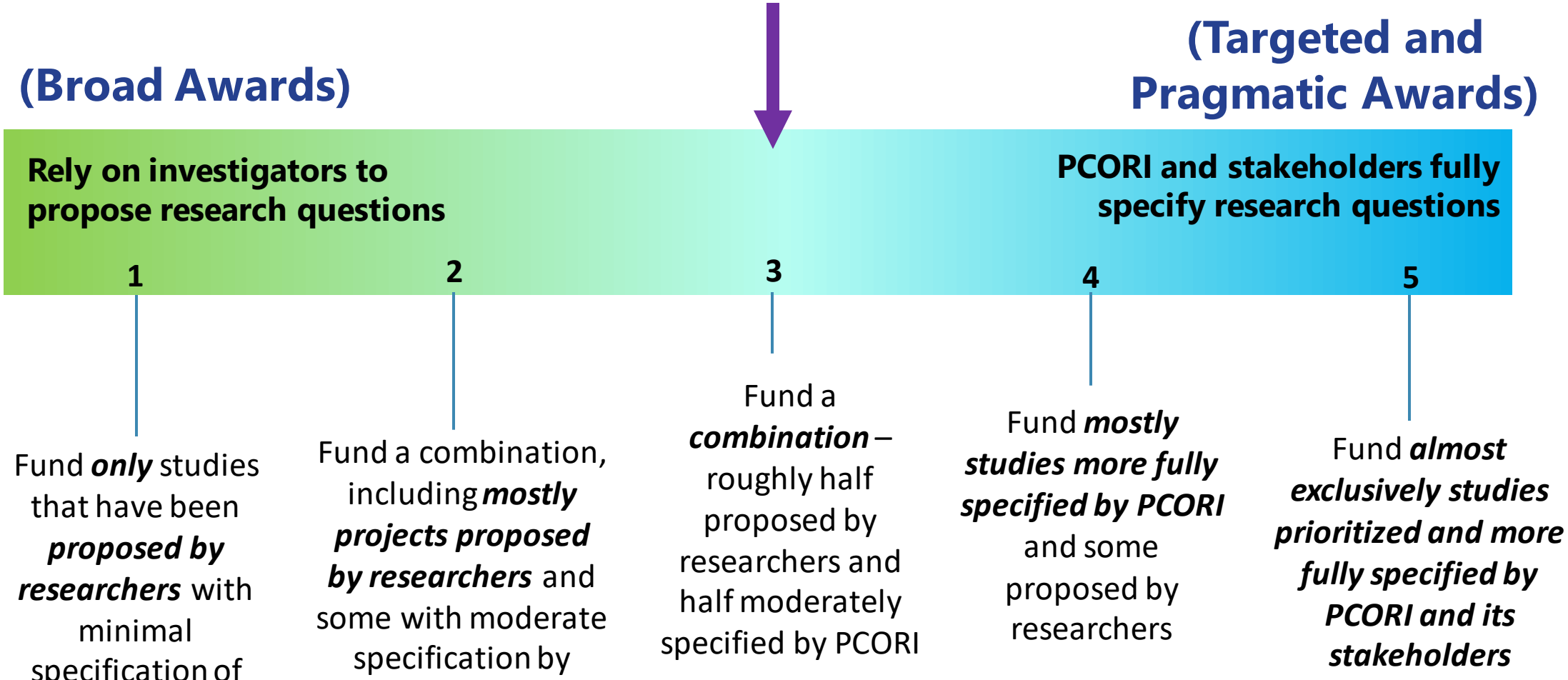
- **What should our focus (or foci) be?**
  - Given the expected size and resources, what should be our focus?
    - What areas/initiatives should we target?
    - What areas/initiatives are uniquely suited for PCORI to lead and advance fields of science and practice? (where are the niches?)

- **How should we fund this research?**
  - Investigator-initiated vs. Stakeholder-driven (targeted) research?
  - Should we support other types of research, in addition to CER?
  - Who are key stakeholders for PCORI 2.0 to consider?

The Spectrum from **Investigator-initiated** to **Stakeholder-driven research**



Where do HDDR investments fall on the spectrum today?



The Spectrum of **Research Phases**

Pilot studies are preparatory studies designed to test the performance characteristics and capabilities of study designs, measures, procedures, and other operational strategies that are under consideration.

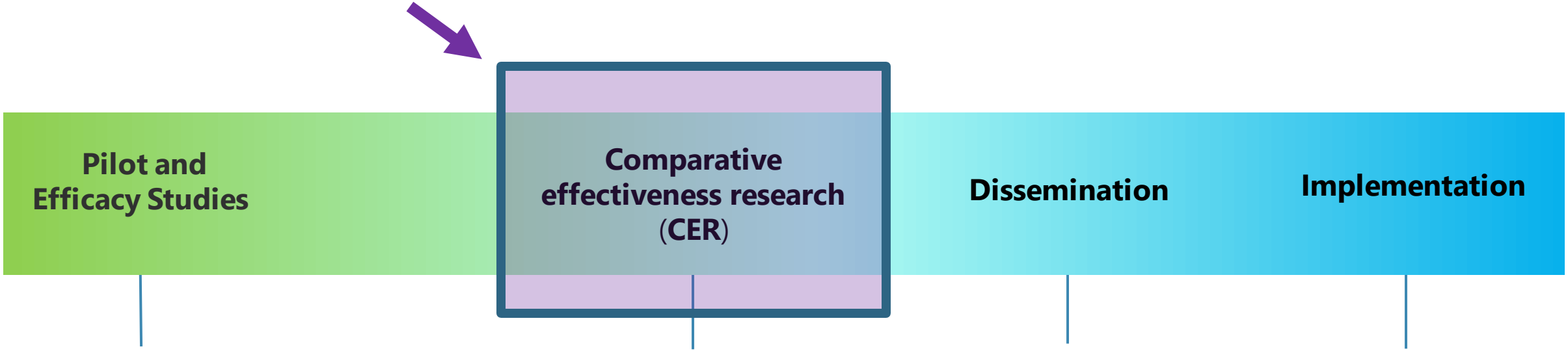
Efficacy studies determine whether an intervention produces the expected result under ideal circumstances.

Comparative effectiveness research (CER) is the real-world direct comparison of existing interventions to determine which work best for which patients and stakeholders and which can be adopted into practice.

Dissemination research is the study of targeted distribution of information and intervention materials. The intent is to understand how best to spread and sustain knowledge and the associated evidence-based interventions.

Implementation research is the scientific study of the use of strategies to adopt and integrate evidence-based health interventions into clinical and community settings in order to improve patient outcomes and benefit population health.

Where do HDDR investments fall on the spectrum today?



Pilot studies are preparatory studies designed to test the performance characteristics and capabilities of study designs, measures, procedures, and other operational strategies that are under consideration.

Efficacy studies determine whether an intervention produces the expected result under ideal circumstances.

Comparative effectiveness research (CER) is the real-world direct comparison of existing interventions to determine which work best for which patients and stakeholders and which can be adopted into practice.

Dissemination research is the study of targeted distribution of information and intervention materials. The intent is to understand how best to spread and sustain knowledge and the associated evidence-based interventions.

Implementation research is the scientific study of the use of strategies to adopt and integrate evidence-based health interventions into clinical and community settings in order to improve patient outcomes and benefit population health.

Who Are Our Stakeholders?

How has HDDR engaged stakeholders to date?

- Targeted Topic Selection
- Merit Review Panels
- Funding Collaborations
- Speakers Bureau
- Training Programs
- Advisory Panels
- Webinars and Workshops
- In-person Meetings aligned with High-Priority Topics

Breakout Session

Focusing on either PCORI's **Health Systems** or **Disparities** research:

1. What has worked well in this priority area?
2. What has not worked in this priority area?
3. What areas are uniquely suited for PCORI to lead and advance science and practice?
4. Should we support other types of research, in addition to CER?
   - Is this essential for the development of important systems and disparities research?
5. Are there critical Stakeholders we have not yet engaged in HDDR?

Breakout Session

1:30 PM – 2:15 PM

- Disparities Group: report to Studio D
- Systems Group: report to Studio E

**Webinar will resume at 2:15 PM*

Report Back and Group Discussion

2:15 PM – 2:45 PM

Afternoon Break

2:45 PM – 3:00 PM

**Webinar will resume at 3:00 PM*

7.

Improving Healthcare Systems to Promote Health Equity for Sexual and Gender Minorities

Mari Kimura, PhD
PCORI, Program Officer

Kenneth Mayer, M.D.
The Fenway Institute, Medical Research Director

HDDR studies targeting disparities in sexual and gender minority populations

n=5

PCORI studies focused on SGM: selected results

- Adil Haider, Brigham and Women's Hospital
  - Patients want their providers to know their SOGI data in the ED, contrary to provider beliefs
- Michael Goodman, Emory University
  - Transgender women receiving hormone therapy face a higher risk for stroke and blood clots than cisgender women
  - Follow-on: expanding cohort to examine effects of different doses, routes and hormone combinations
- Sari Reisner, Boston Children's Hospital (not HDDR)
  - Self-administered HPV screening as effective as clinician-delivered screening for 71% of female-to-male transgender patients, but 90% prefer self testing

Ongoing HDDR studies focused on SGM

- Joan Cook, Yale University and Amy Ellis, Nova Southeastern University
  - Does providing tailored peer-led group online psychotherapy improve depression symptoms for SGM survivors of sexual violence?
- Sari Reisner, Boston Children's Hospital
  - Does hormone therapy in primary care improve HIV outcomes for transgender adults?
- Ken Mayer, Fenway Community Health Center
  - Does intensive provider and staff training for cultural competence improve screening outcomes for SGM patients in community health centers?

Infrastructure focused on SGM

- Patient-Powered Research Network: PrideNET, UCSF
  - primary vehicle for driving SGM community engagement as research participants and co-creators of the Population Research in Identity and Disparities for Equality (PRIDE) Study
  - first nationwide SGM prospective cohort study

FENWAY HEALTH

Improving Health Care Systems to Promote Health Equity for Sexual and Gender Minority Patients

Kenneth Mayer, M.D.

PCORI Advisory Panel on Health Care Delivery and Disparities Research

May 16, 2019

Fenway Health

Independent 501(c)(3) FQHC, founded 1971

Mission: To enhance the wellbeing of the LGBT community as well as people in our neighborhoods and beyond through access to the highest quality health care, education, research and advocacy

Integrated primary care model, including HIV services and transgender health

1^0 care for >35,000 patients, about ½ LGBT; >2,000 PLHIV

The Fenway Institute

Research, Education, Policy

Clinical Trials and Data Base Research, funded by NIH, CDC, HRSA, PCORI,

Increasing awareness of health disparities over the past decade

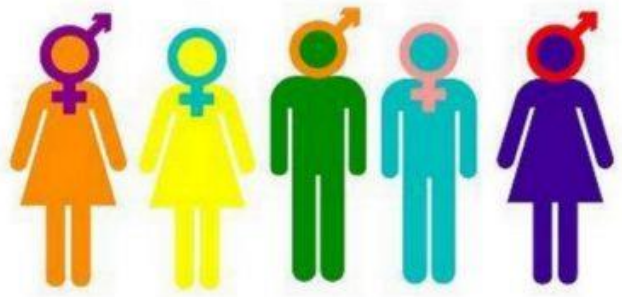
Sex and gender core determinants of health

Sex – biological differences

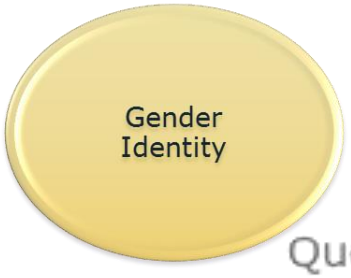
- Anatomy, chromosomes, hormones, genes, etc.

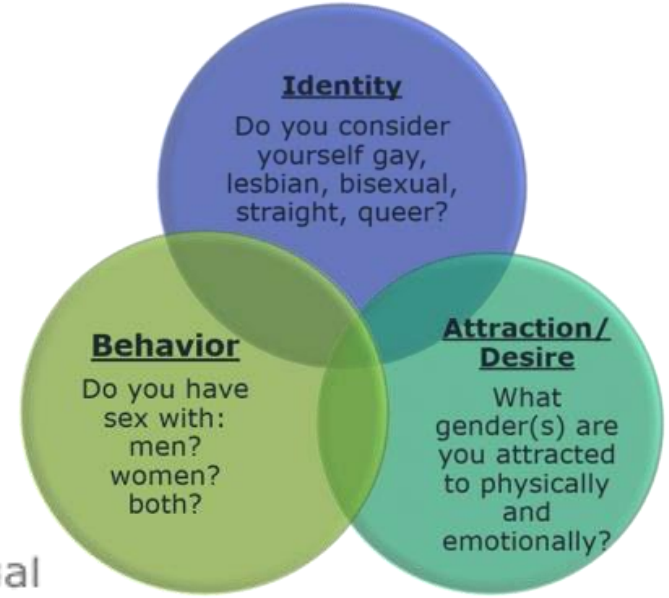
Gender – social and cultural distinctions

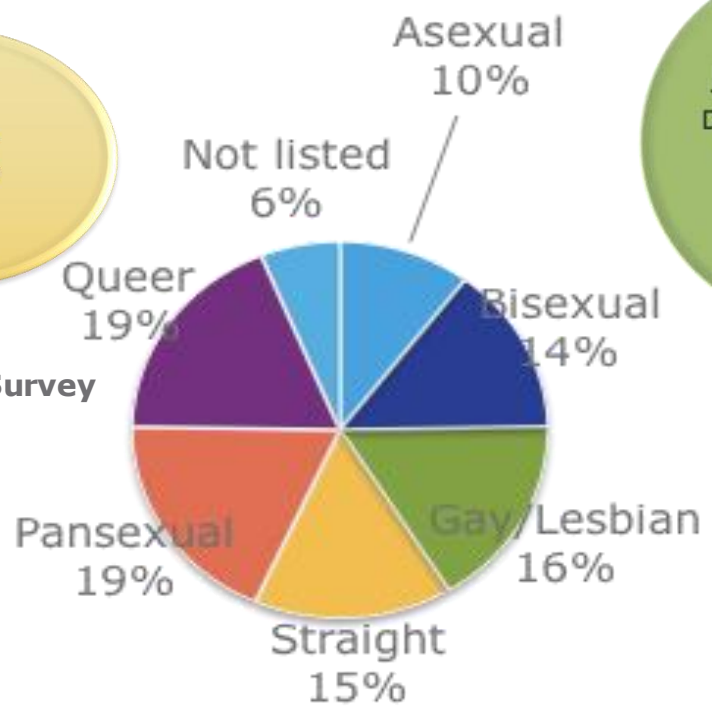
- Multidimensional
- Psychological, social, behavioral
- Gender identity, gender expression, gender roles



- Sexual Orientation is different than gender identity
- Sexual orientation can be defined by sexual identity, sexual behavior, and sexual attraction
- Identity is different than behavior!

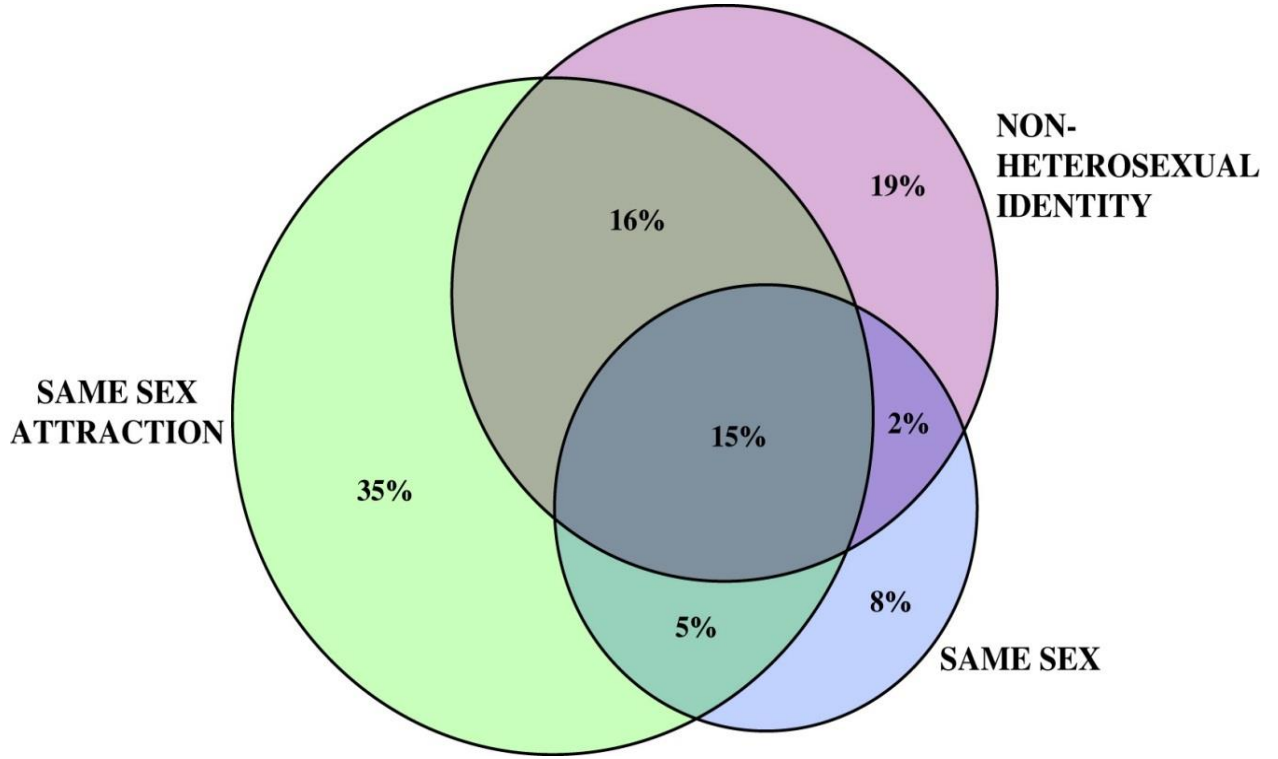






- 2015 US Trans Survey

Sexual orientation dimensions do not always align

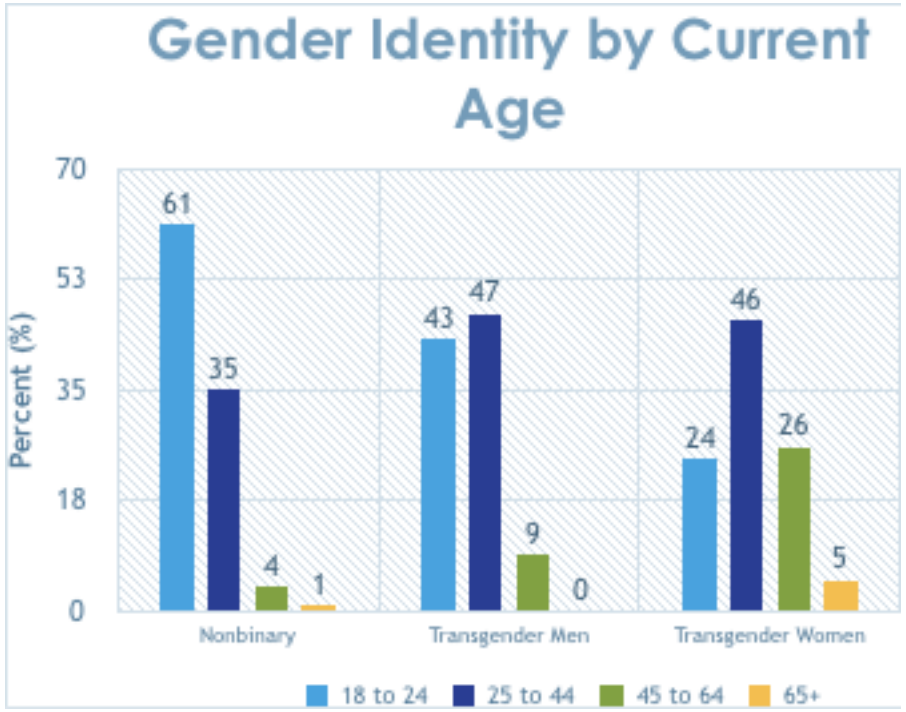


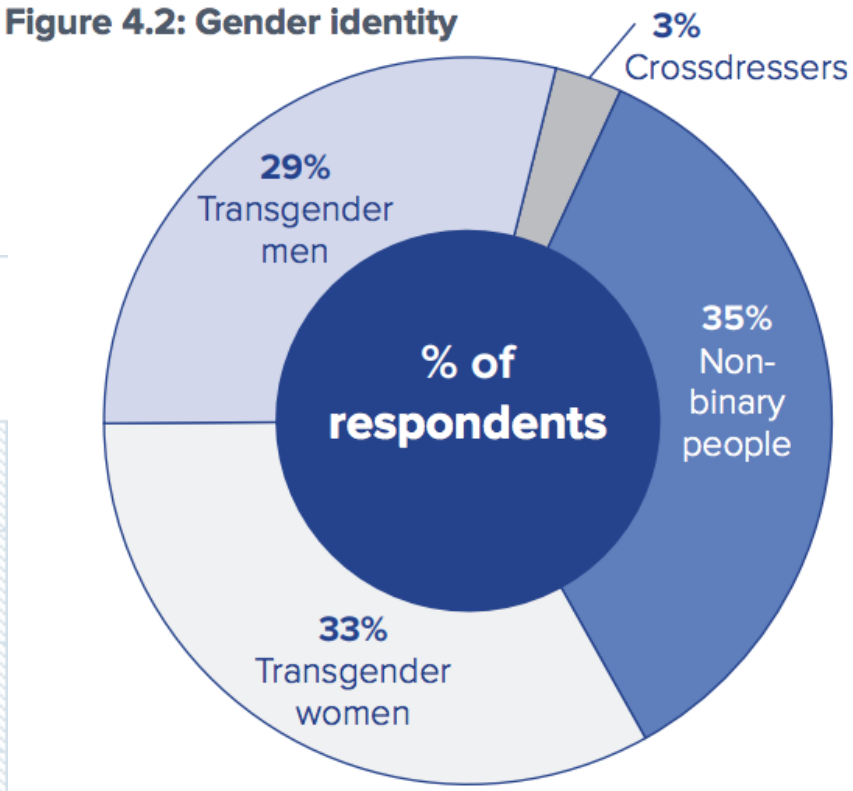
Dimensions correlate differently with health outcomes, e.g. bisexual adolescent women are more likely to report unplanned pregnancy than heterosexual women

Venn diagram of high school students who reported non-heterosexual identity (gay or lesbian, bisexual, unsure), attraction (same gender, both genders), and/or behavior (same gender, both genders) (n = 237).

Igartua K et al: Concordance and discrepancy in sexual identity, attraction, and behavior among adolescents. J Adolesc Health 2009;45(6):602-8.

Non-binary identities more common in younger people





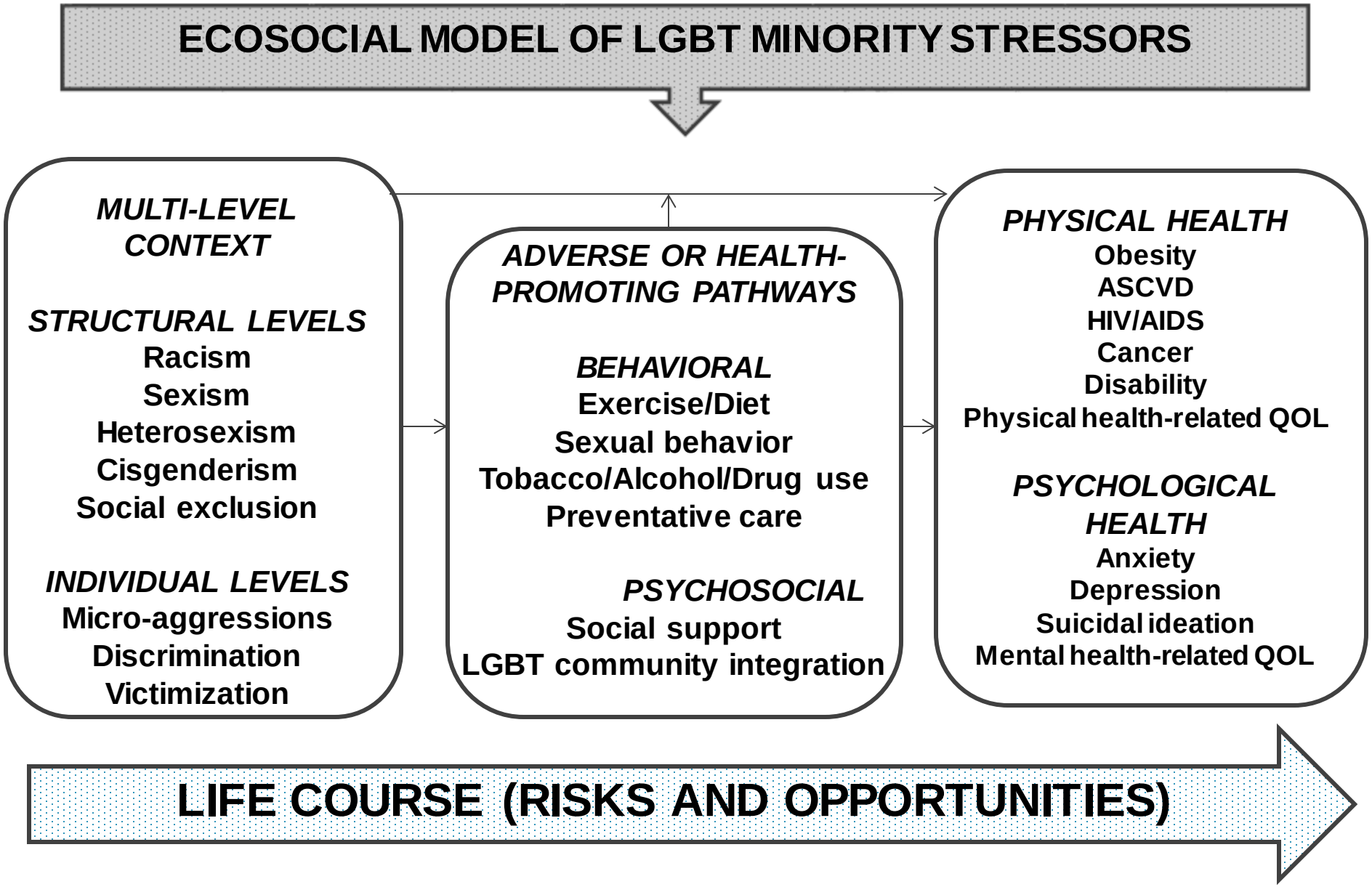
James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.

Multiple factors are associated with SGM health disparities

- Minority stressors-growing up in a non-affirming environment→internalization→adverse outcomes
- Societal rejection associated with decreased social and economic capital
- Unique sexual practices: e.g. receptive anal intercourse being most efficient for HIV transmission
- Unique exposures of transgender people to exogenous hormones
- Avoidant health care engagement→delays in seeking preventive services

- Sexual orientation and gender identity are only 2 aspects of any person's life experience
- Race/ethnicity, SES, other cultural and economic issues are also relevant to accessing and engaging in health care
- SGM people from racial and ethnic minority groups experience the **intersection** of their multiple identities
- LGBTQ racial and ethnic minority patients may experience worse health outcomes than heterosexual peers
- Example: highest US HIV rates in Black and Latino men who have sex with men
- **Microaggressions**: Staff who misgender a transgender person, or who ignore a patient's sexual orientation when they access care

Example of Intersectionality and Health Disparities: HIV and Race/Ethnicity



Adapted from Fredricksen-Goldsen et al. Am J Orthopsych 2014; 84: 656.

Primary Care & Prevention

- Sexual minority cisgender women are less likely to report having had routine Pap tests
- Sexual minority cisgender women and transgender people are at higher risk of not having health insurance
- NTDS (2016): 33% of transgender people surveyed reported postponing or foregoing preventive care
- GLMA-AMA Survey (2010): 40% of physicians surveyed had no formal LGBT health training ever, and 50% had received fewer than 5 hours of training ever

STI's

- CDC: MSM (2-4% of US population) accounted for 67% of all new HIV infections in 2016, 68% of all primary and secondary syphilis cases in 2017, and 38.5% of gonorrhea cases in 2017
- According to current estimates, around 25% of transgender women are living with HIV and more than half of black transgender women are living with HIV
- Bisexual cisgender women have an adjusted OR of 2.13 (compared to straight counterparts) for lifetime prevalence of genital herpes or genital warts

Behavioral Health

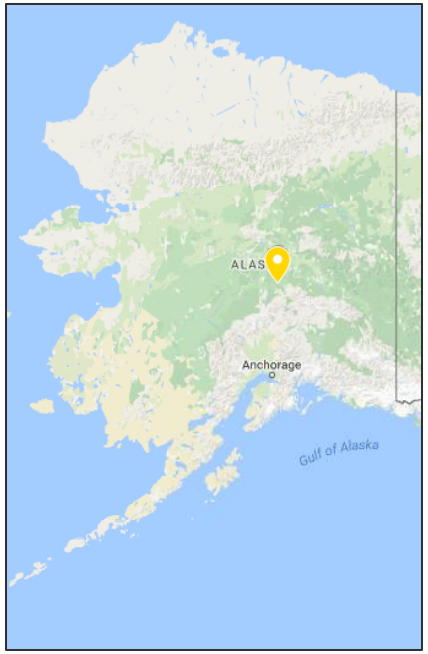
- The risk of gay and lesbian cisgender people developing depression is 1.5 to 3 times that of cisgender, heterosexual peers.
- Depression rate among transgender individuals may be as high as 44%
- Rates of substance abuse are higher among LGBT people compared to peers.
- SGM suicide attempt rate is 1.5 to 7 times the rate of peers; being “closeted” further increases that risk
- Native Americans and Latinx people are at increased risk of suicide compared with white LGBT people

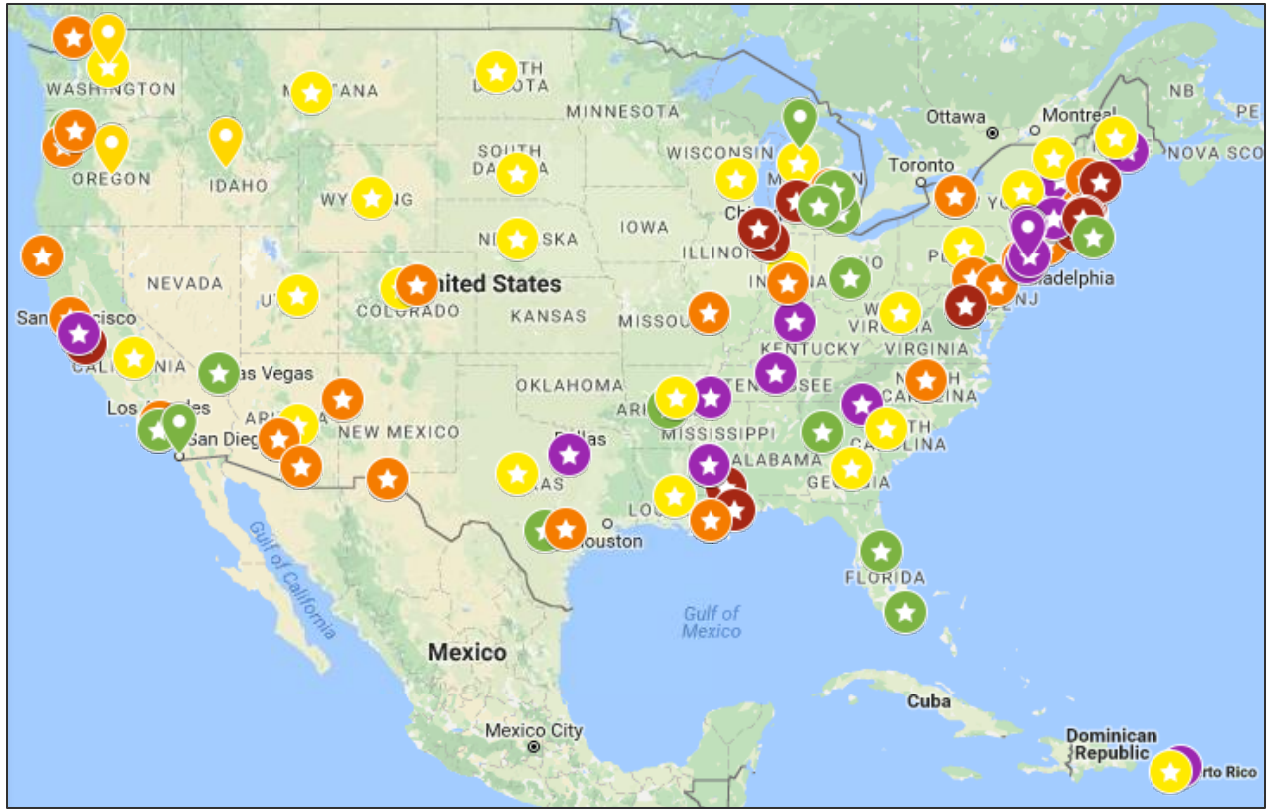
Trauma

- LGBT people account for over 17% of all hate crimes victims
- The incidence of hate crimes against transgender people is even higher
- 25-40% of LGB youth report at least one lifetime incident of emotional, physical, or sexual abuse by a same-sex partner
- 58% of transgender adults reported verbal harassment in a place of public accommodation; 24% suffered police harassment
- Rates of PTSD are higher for LGBT people than demographically matched peers

The HRSA-funded National LGBT Health Education Center offers educational programs, resources, and consultation to health care organizations with the goal of providing affirmative, high quality, cost-effective health care for lesbian, gay, bisexual, transgender and queer (LGBTQ) people.

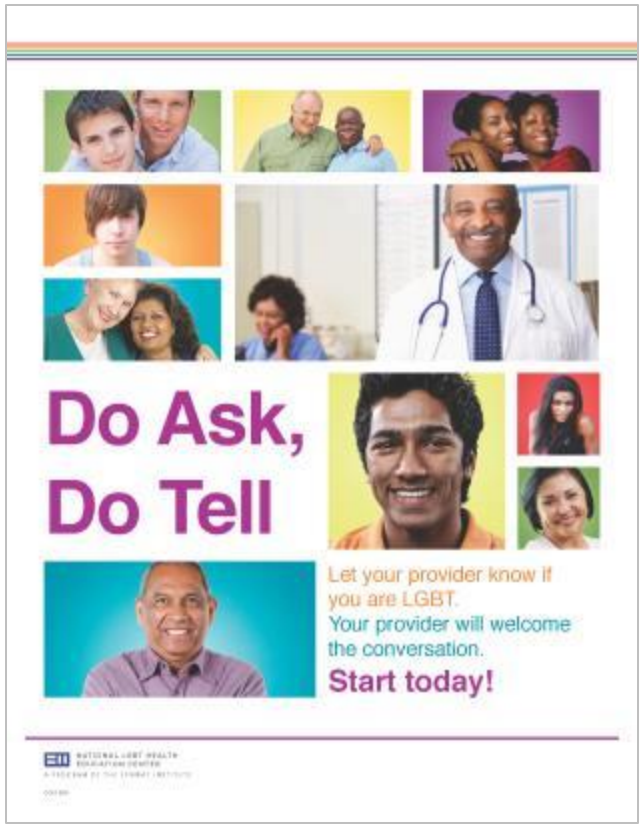
- Training and Technical Assistance
- Grand Rounds
- ECHO Programs
- On Line Learning
  - Webinars and Learning Modules
  - CE, and HEI Credit
- Resources and Publications
- www.lgbthealtheducation.org

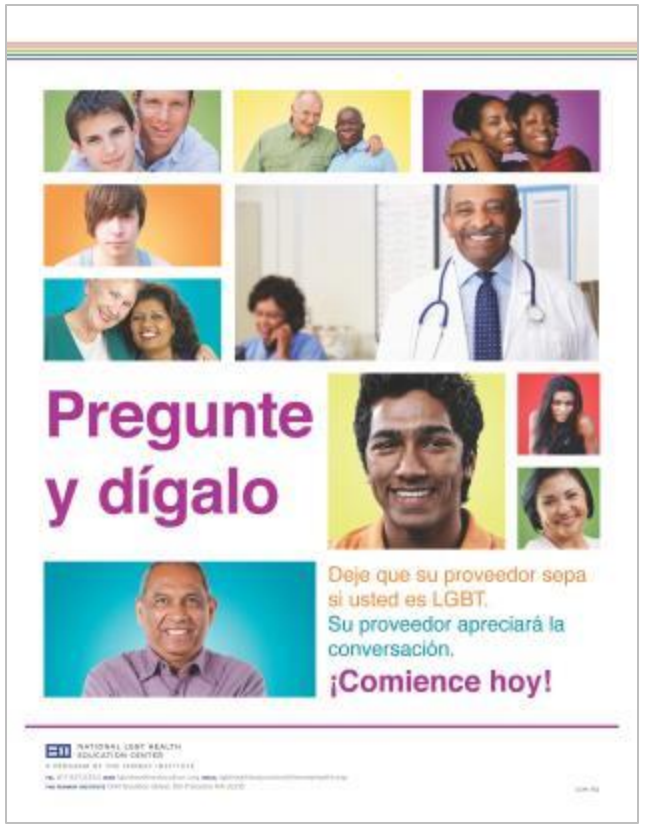




Training and Technical Assistance in 45 states, plus Washington D.C. and Puerto Rico

www.lgbthealtheducation.org





As part of your history, generally as part of social history or filling in blanks left at registration, you might simply say, “We have begun asking patients about their sexual orientation and gender identity so we can provide affirmative care.”

Another example might be, “I see you left these questions blank at registration, and I was wondering if you had questions, and whether we might talk about how you think about yourself in this regard?”

What is your current gender identity?

- □ Male
- □ Female
- □ Transgender Male/Trans Man/FTM
- □ Transgender Female/Trans Woman/MTF
- □ Gender Queer
- □ Additional Category (please specify) _____

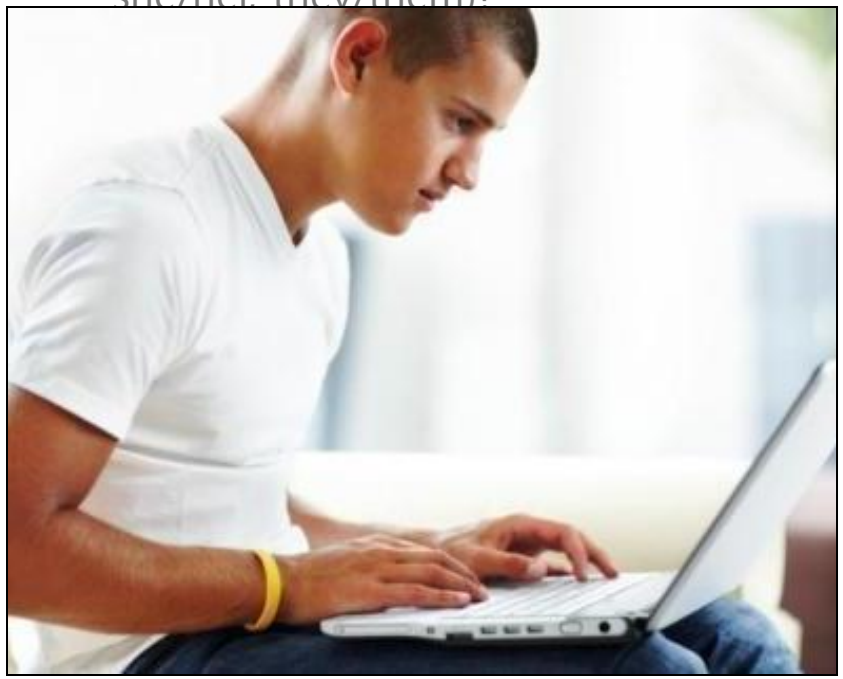
What sex were you assigned at birth?

- □ Male
- □ Female
- □ Decline to Answer

What name do you use?

What name is on your insurance records?

What are your pronouns (e.g. he/him, she/her, they/them)?



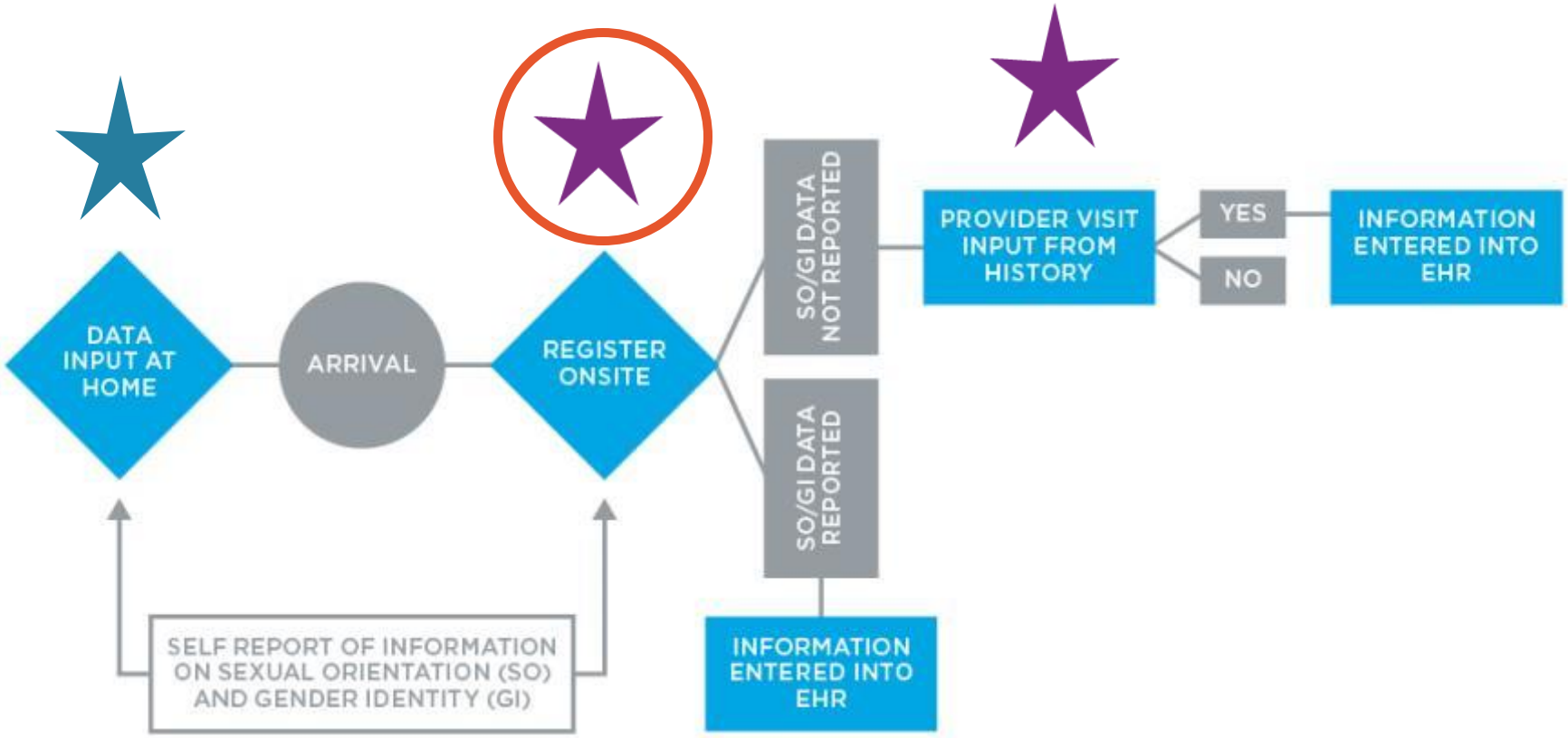
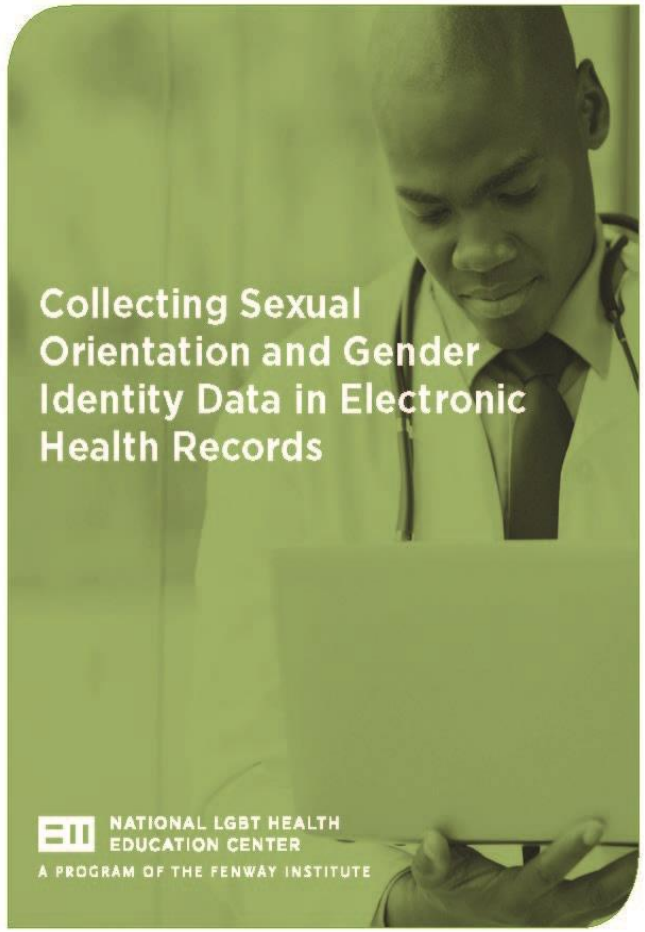
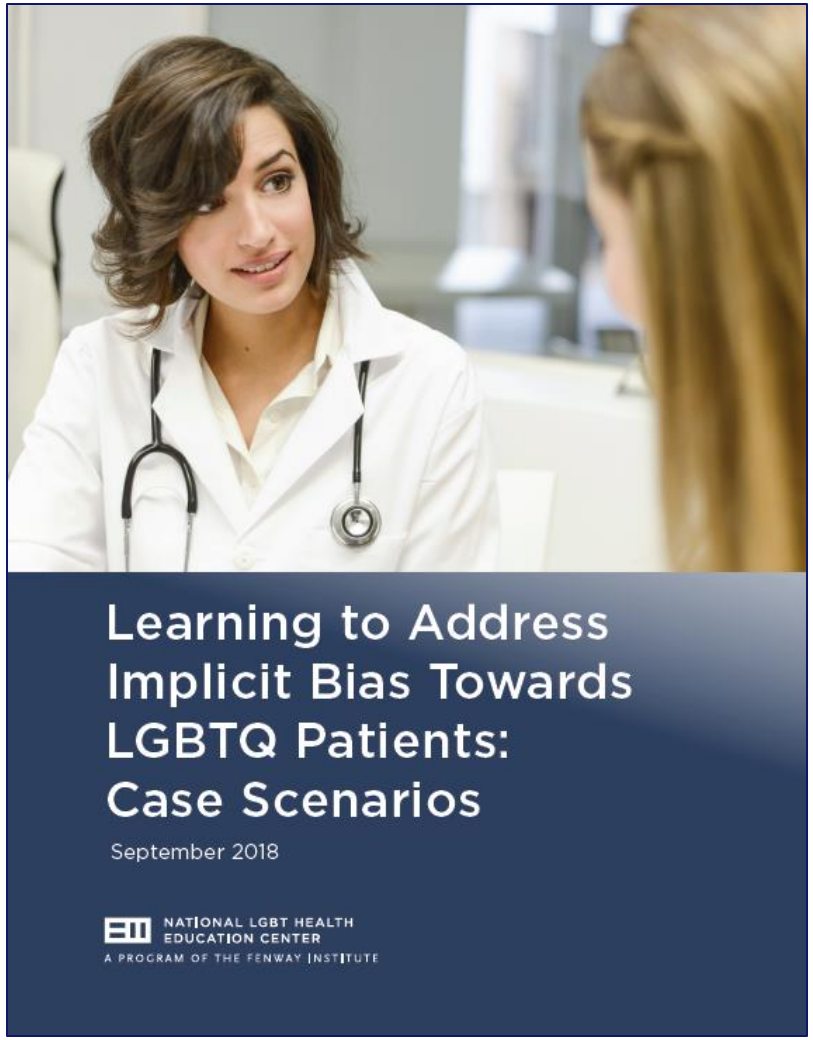


Fig. 2. Diagram from "Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health."[13]



www.lgbthealtheducation.org/topic/sogi/



- LGBTQ concepts and common terms
- LGBTQ health disparities
- Implicit Bias
- Communicating with cultural humility
- SO/GI data collection
- Confidentiality and privacy

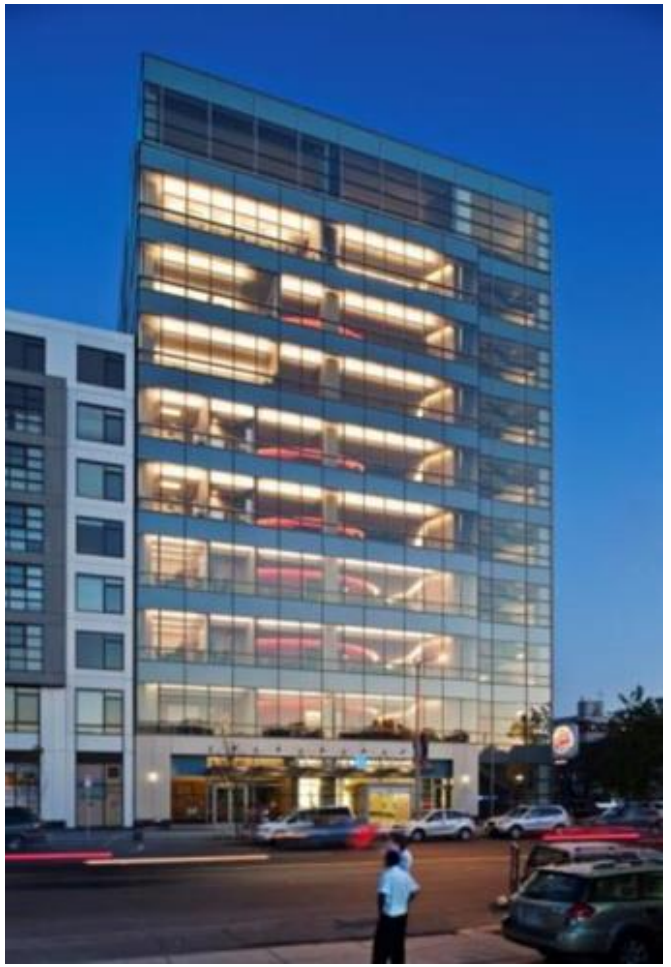
Of SGM Patients Through Cultural Competence Training For Staff Of FQHCs

- PCORI investigator-initiated grant
- RCT of 12 FQHCs
- 6 received intensive staff education through Fenway Ed Center, 6 are SOC (weblink to video)
- Outcome measures will include:
  - -↑ enumeration of SGM patients (UDS)
  - -↑ SGM patients receiving appropriate services
  - -↑ SGM and staff satisfaction (interviews)

Considerations for the Panel:
Much is Not Known

- Optimal ways to engage SGM patients in 1^0 care
- Clinical effectiveness of different approaches to cancer and behavioral health screening of sexual and gender minority patients
- Optimal hormonal and surgical care for gender non-conforming patients
- Best practices for management of gender transitions in youth and adults
- Decision support tools in EHRs to optimize care for sexual and gender minority patients

- Chris Grasso
- Matteo Peretti
- Stephanie Loo
- Alex Keuroghlian
- Dana King
- Deirdre O’Donnell
- Sean Cahill
- Mari Kimura
- Maggie Jalowsky
- PCORI



Discussion Questions

1. How can PCORI help our awardees identify SGM study participants?
2. How feasible is it to measure heterogeneity of treatment effects in SGM study participants?
3. How can we best address evidence gaps for SGM patients?

8.

Going from Evidence to Action: How PCORI's Asthma Portfolio Can Lead to Changes in Practice and Policy

RESEARCH DONE DIFFERENTLY

What we're learning from the PCORI asthma portfolio

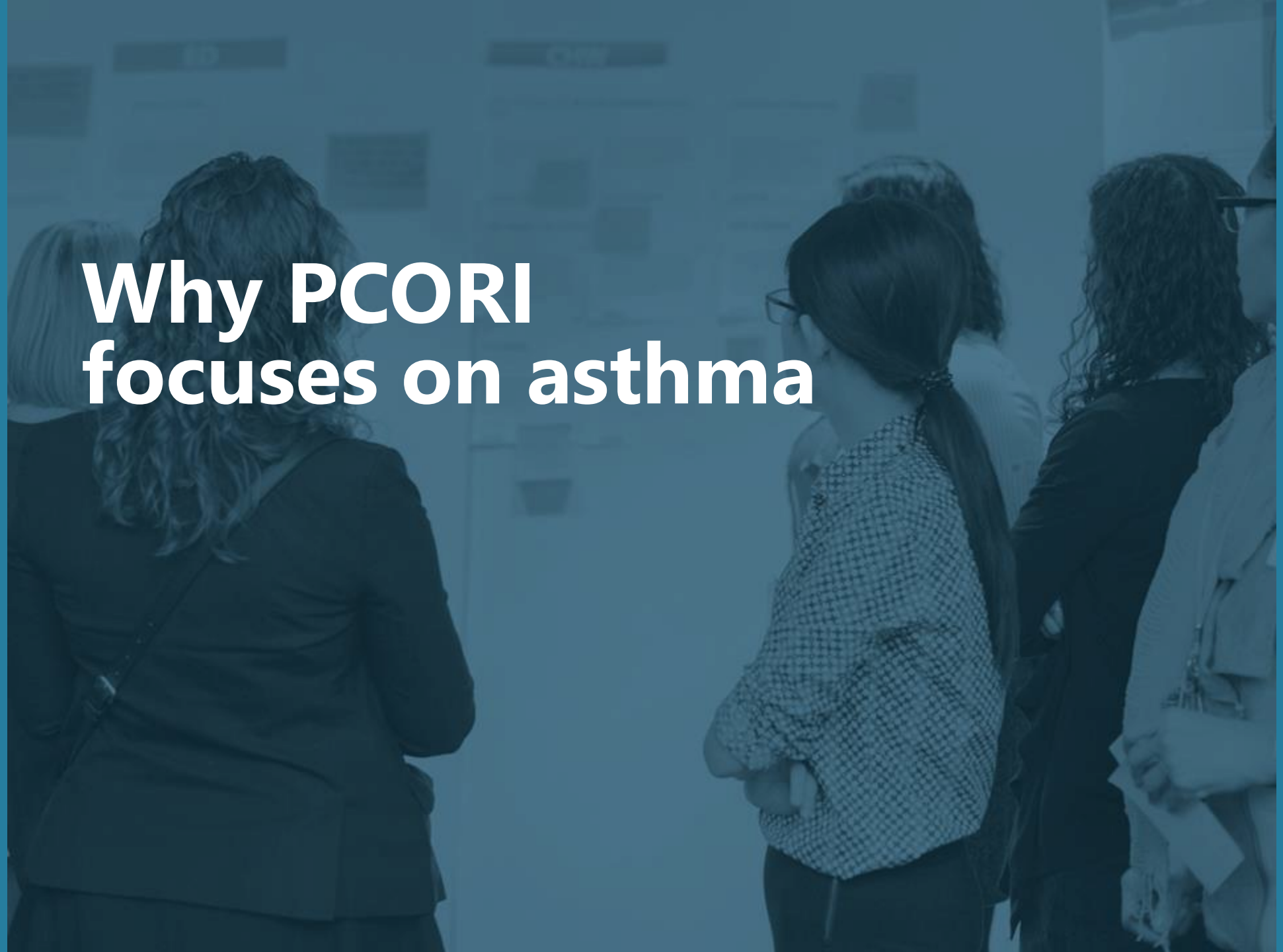
May 16, 2019

Ayodola Anise, MHS
Senior Program Officer
Healthcare Delivery and Disparities Research Program

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Discussion Questions

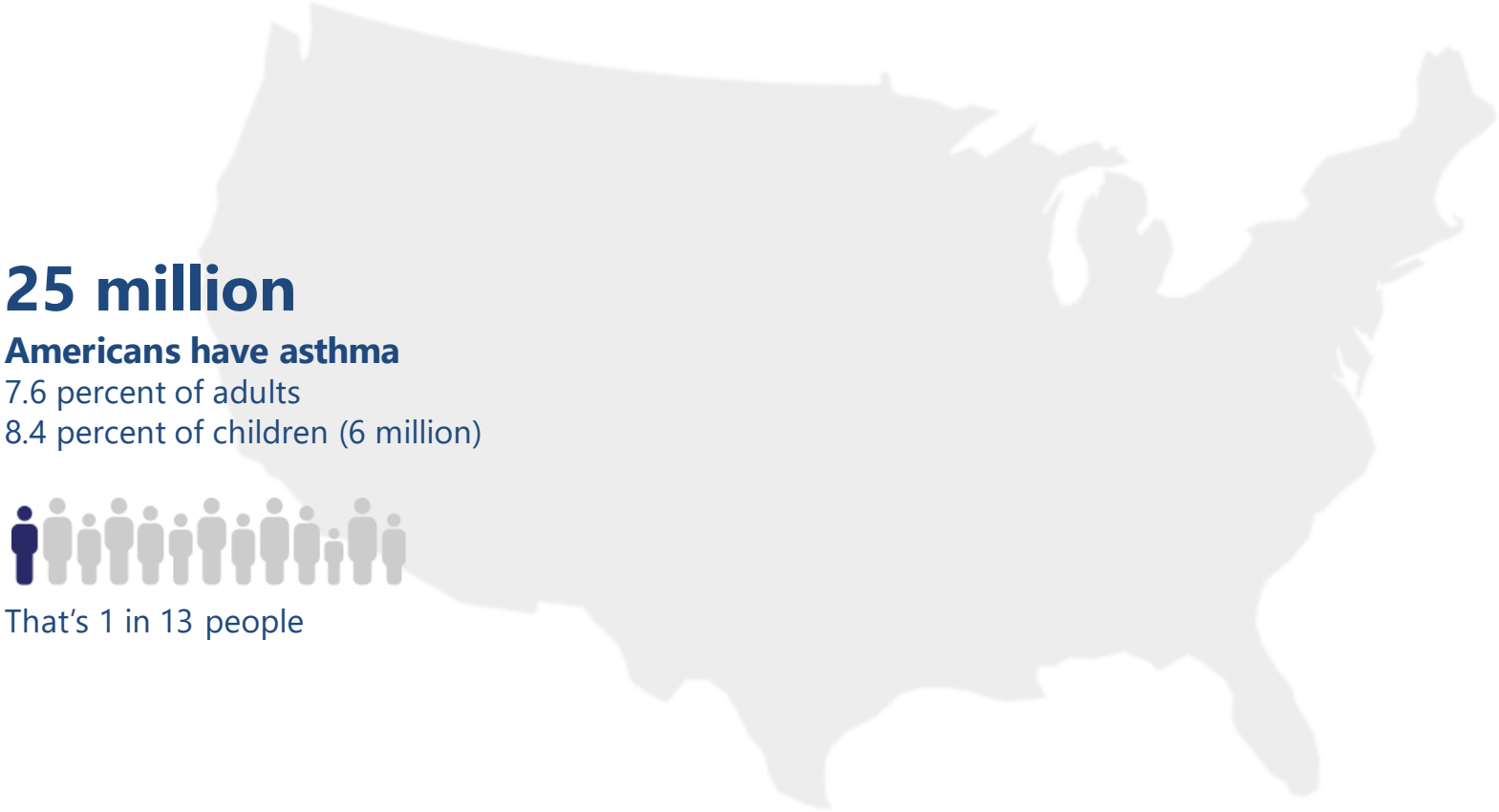
- The studies in the asthma portfolio provide information on strategies to improve patient and provider adherence to the NAEPP Guidelines. **How should PCORI and other stakeholders make these strategies and implementation successes and challenges available to stakeholders?**
- We hear from multiple stakeholders that one study is not enough to change practice. **How could PCORI and other stakeholders leverage these study findings to change practice?**
- Translating research findings into actionable policy recommendations is critical. **From your perspective, what could PCORI fund or do to make study findings more actionable?**



Why PCORI focuses on asthma

PCORI Asthma portfolio

Asthma is one of our most common and costly diseases



25 million

Americans have asthma

7.6 percent of adults

8.4 percent of children (6 million)

That's 1 in 13 people

1. Guidelines for the Diagnosis and Management of Asthma. Expert Panel Report 2. National Institutes of Health. National Heart, Lung, and Blood Institute, 1997.; 2. National Center for Health Statistics. Asthma Prevalence, Health Care Use and Mortality, 2000-2001 [Web Page]. 2003 Jan 28; 3. Clearing the Air: Asthma and Indoor Air Exposures. Institute of Medicine. Washington, D.C.: National Academy Press, 2000.; 4. Mannino DM, Homa DM, Akinbami LJ, Moorman JE, Gwynn C, Redd SC. Surveillance for asthma—United States, 1980-1999. MMWR Surveill Summ 2002 Mar;51(1):1-13.

PCORI Asthma portfolio

Asthma is one of our most common and costly diseases

25 million

Americans have asthma

7.6 percent of adults

8.4 percent of children (6 million)

That's 1 in 13 people

10/day

Each day, ten Americans die from asthma

Many of these deaths are avoidable with proper treatment and care.[1]

1. Guidelines for the Diagnosis and Management of Asthma. Expert Panel Report 2. National Institutes of Health. National Heart, Lung, and Blood Institute, 1997.; 2. National Center for Health Statistics. Asthma Prevalence, Health Care Use and Mortality, 2000-2001 [Web Page]. 2003 Jan 28; 3. Clearing the Air: Asthma and Indoor Air Exposures. Institute of Medicine. Washington, D.C.: National Academy Press, 2000.; 4. Mannino DM, Homa DM, Akinbami LJ, Moorman JE, Gwynn C, Redd SC. Surveillance for asthma—United States, 1980-1999. MMWR Surveill Summ 2002 Mar;51(1):1-13.

PCORI Asthma portfolio

Asthma is one of our most common and costly diseases

25 million

Americans have asthma

7.6 percent of adults

8.4 percent of children (6 million)

That's 1 in 13 people

10/day

Each day, ten Americans die from asthma

Many of these deaths are avoidable with proper treatment and care.[1]

$81.9 billion

Annual economic cost of asthma

Including medical costs and loss of work and school days.[2]

Asthma accounts for

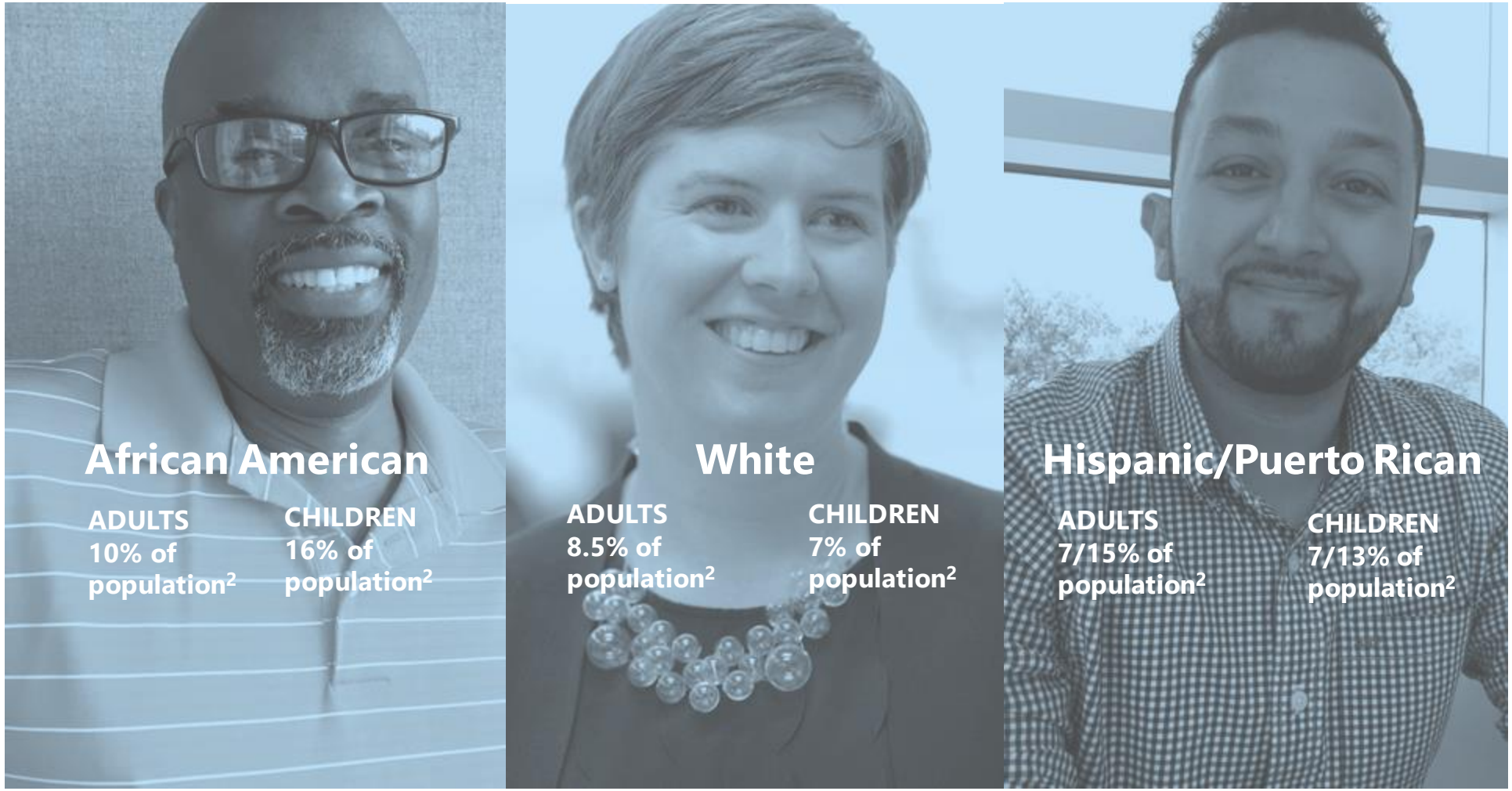
14.2 million doctor's office visits

1.8 million ER visits.[3]

13.8 million missed school days.[4]

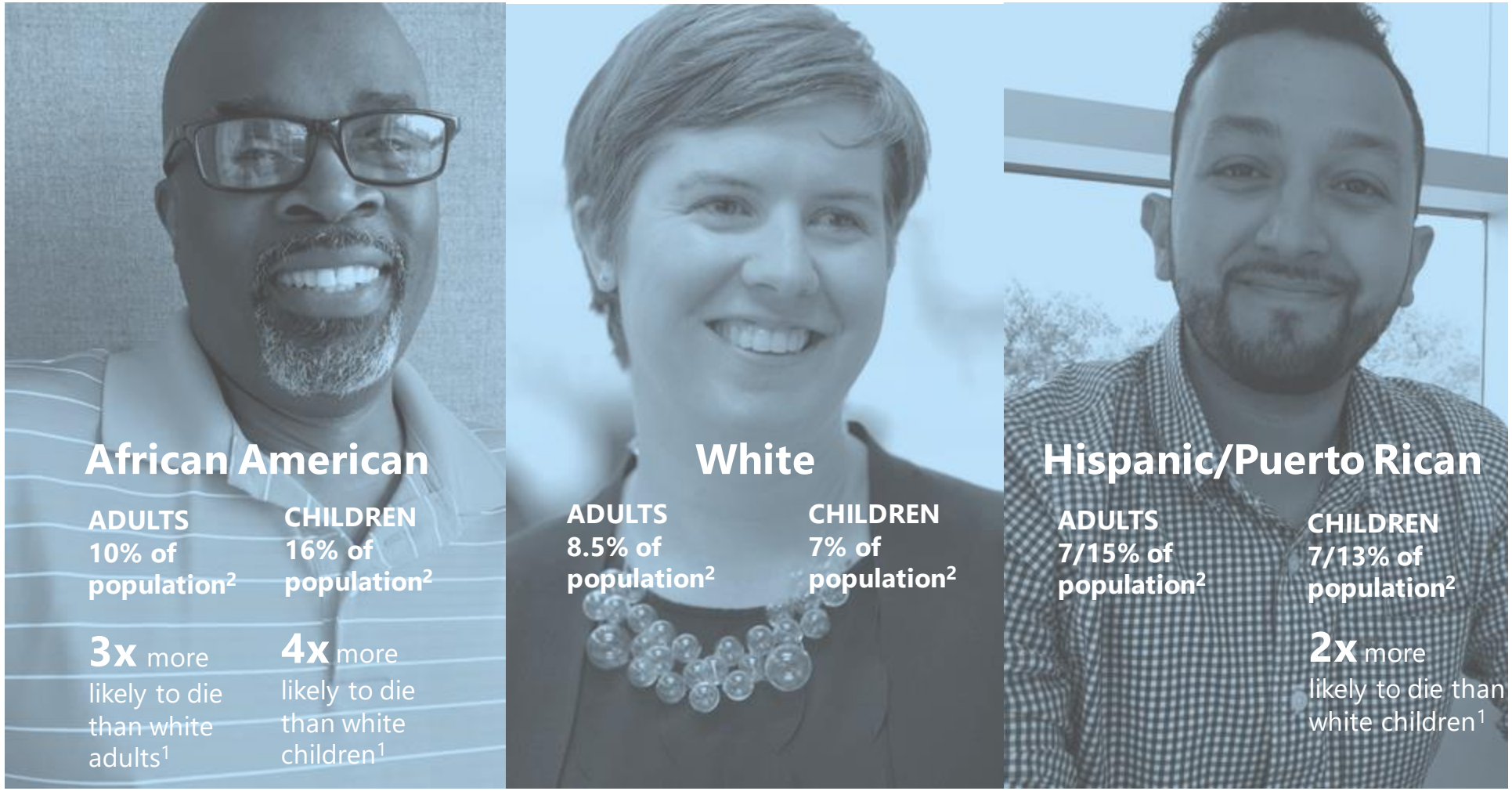
1. Guidelines for the Diagnosis and Management of Asthma. Expert Panel Report 2. National Institutes of Health. National Heart, Lung, and Blood Institute, 1997.; 2. National Center for Health Statistics. Asthma Prevalence, Health Care Use and Mortality, 2000-2001 [Web Page]. 2003 Jan 28; 3. Clearing the Air: Asthma and Indoor Air Exposures. Institute of Medicine. Washington, D.C.: National Academy Press, 2000.; 4. Mannino DM, Homa DM, Akinbami LJ, Moorman JE, Gwynn C, Redd SC. Surveillance for asthma—United States, 1980-1999. MMWR Surveill Summ 2002 Mar;51(1):1-13.

Asthma burden is highest in minority and low income populations

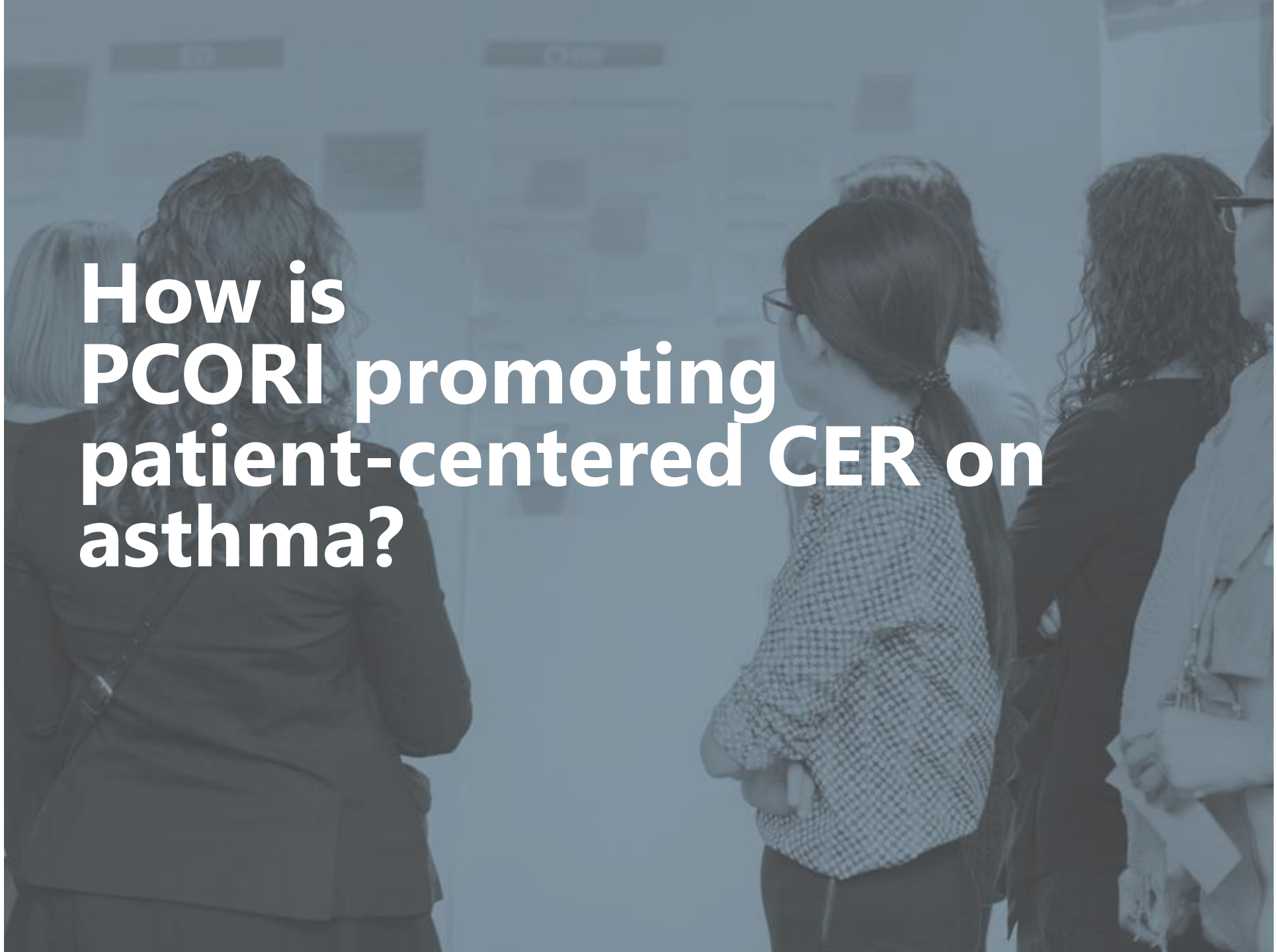


[1]https://www.cdc.gov/asthma/pdfs/Racial_Disparities_in_Childhood_Asthma.pdf
[2]https://www.cdc.gov/asthma/most_recent_data.htm

Asthma burden is highest in minority and low income populations

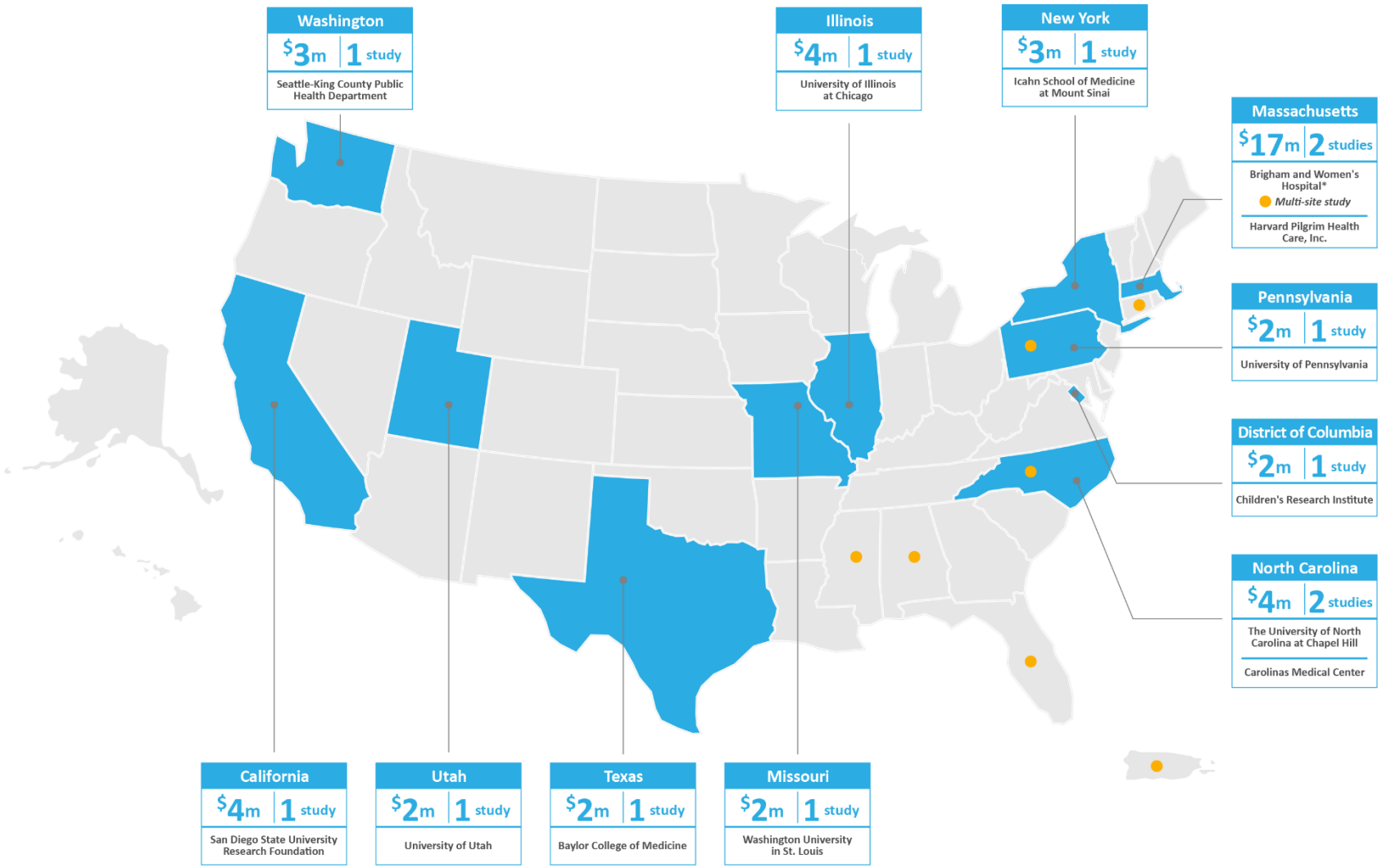


[1]https://www.cdc.gov/asthma/pdfs/Racial_Disparities_in_Childhood_Asthma.pdf
[2]https://www.cdc.gov/asthma/most_recent_data.htm



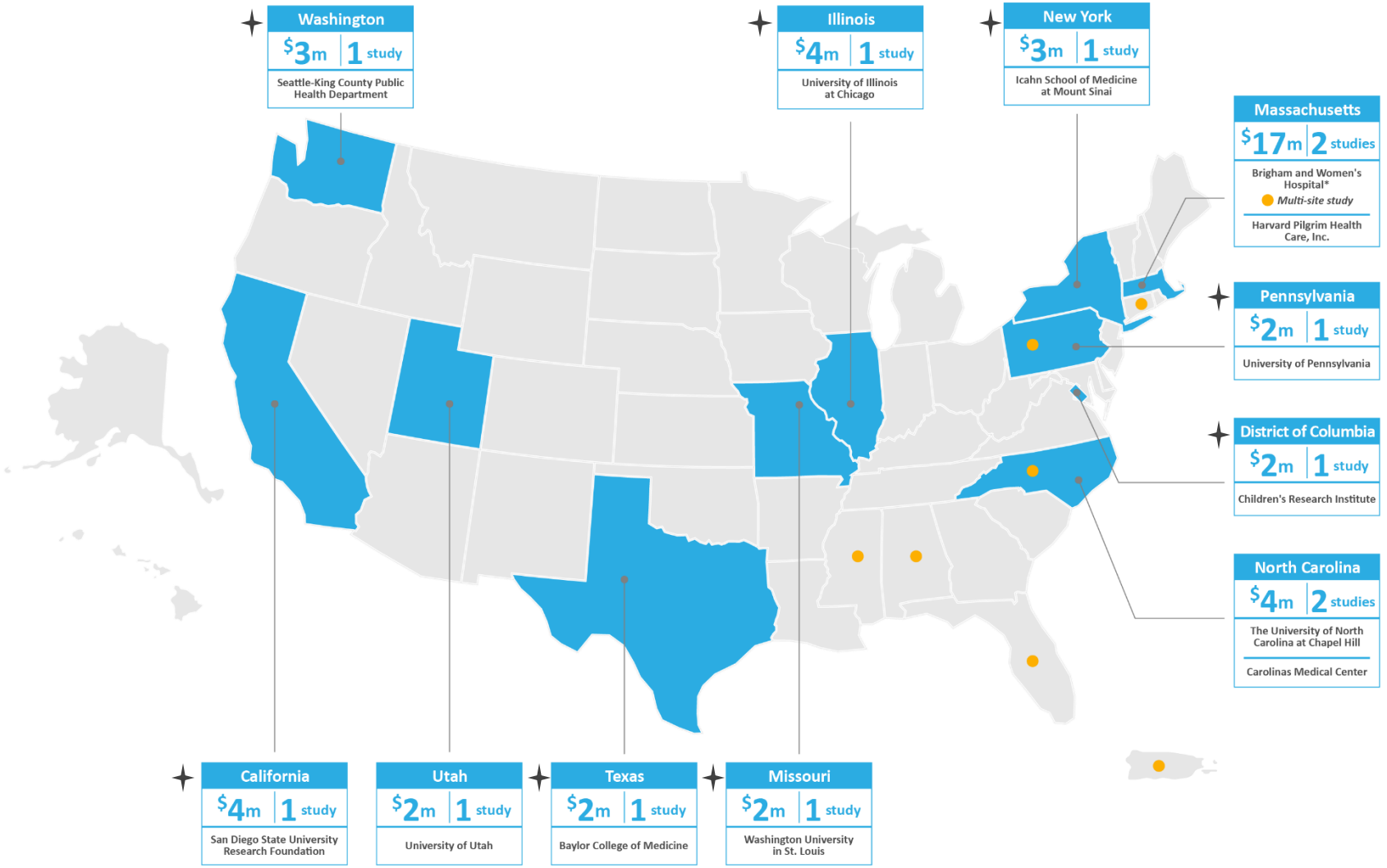
How is PCORI promoting patient-centered CER on asthma?

PCORI asthma portfolio to date
$46 Million investment in 13 CER studies



124

PCORI invests in
9 Studies to Improve Asthma Outcomes for African Americans & Hispanics/Latinos



125

PCORI's asthma portfolio targets
Evidence-based, patient-centered interventions…

MEDICATIONS + TREATMENT

Which regimes increase asthma control for whom?

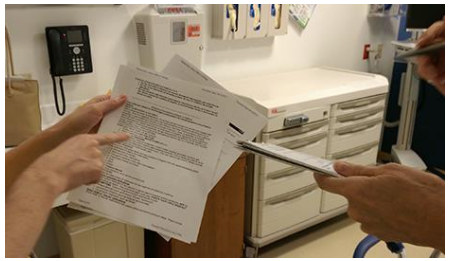
Which regimens gain the most compliance?

PATIENT/CAREGIVER EDUCATION

How much education?

Who is the best teacher?

What's the most effective mechanism?

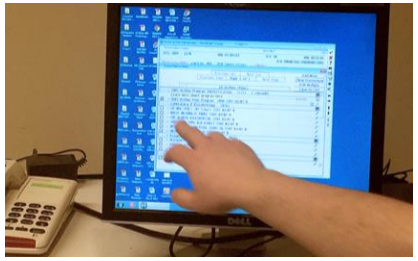


PROVIDER EDUCATION

Where is the education best placed?

Who is the best teacher?

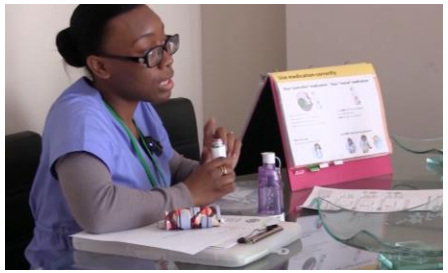
What's the most effective mechanism?



EHR/DECISION SUPPORT TOOLS

Which tools reduce practice variation?

Which tools increase guideline-based care?

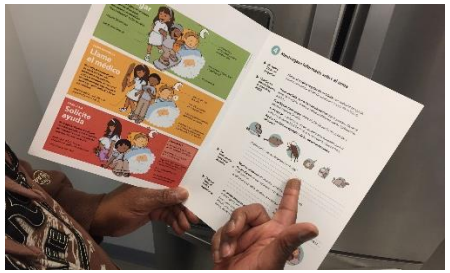


COMMUNITY HEALTH WORKERS

Where are CHWs best deployed?

What role should they play?

How many visits are required to be effective?

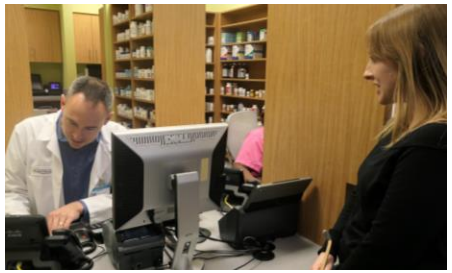


PATIENT TOOLS

Can internet tools improve access?

Can tailored tools improve comprehension?

Which tools increase adherence?



HEALTH PLAN COVERAGE

Which benefits improve adherence?

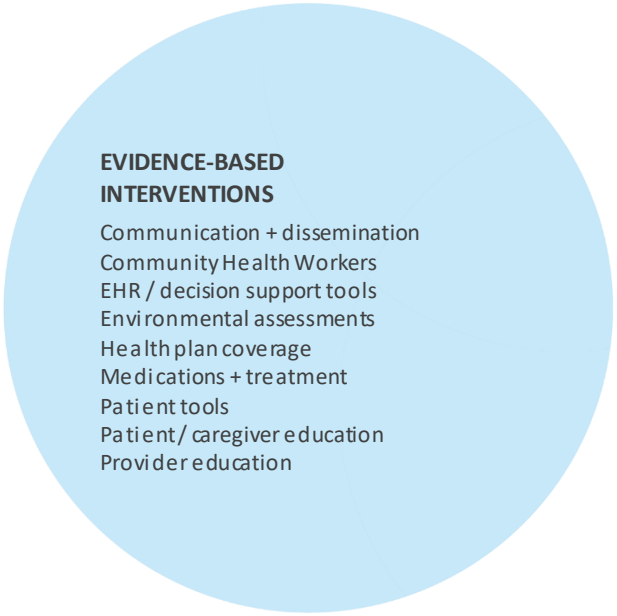
How much coverage reduces ED utilization?

ENVIRONMENTAL ASSESSMENTS

How can families learn how to mitigate triggers in the home?

126

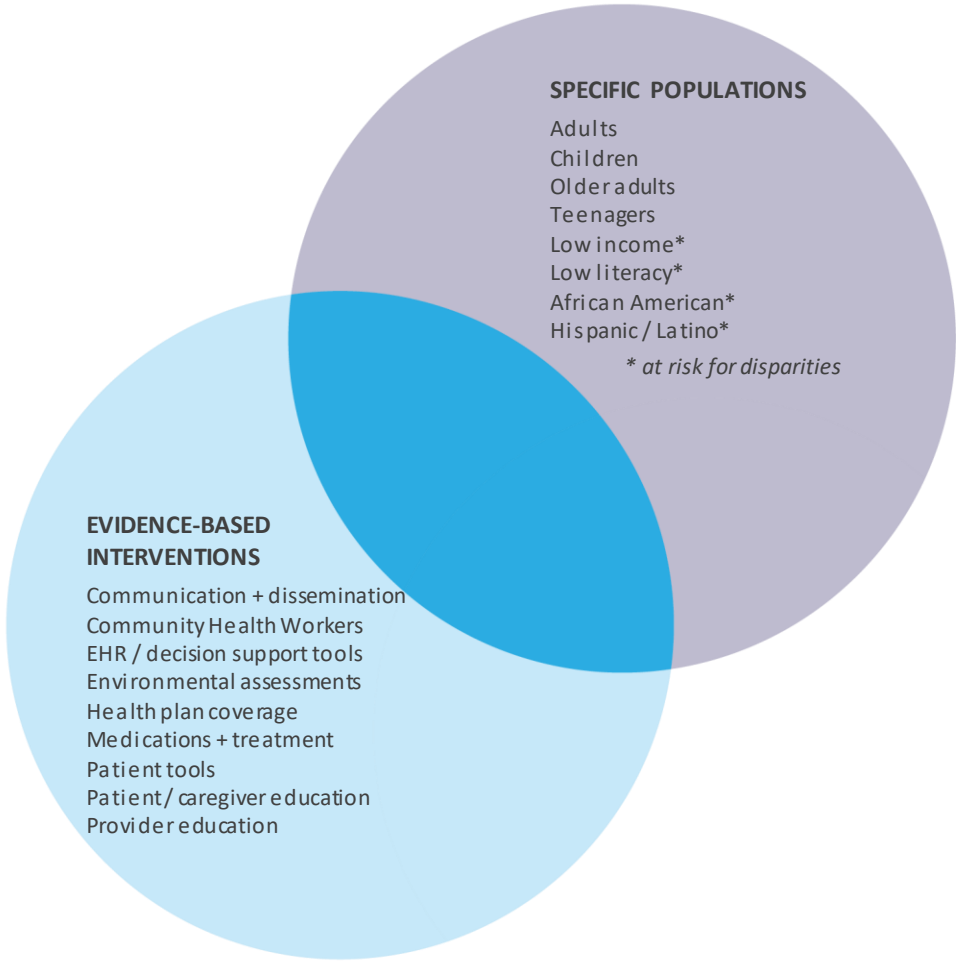
PCORI asthma portfolio
Designed to address gaps in treatment knowledge



127

PCORI asthma portfolio

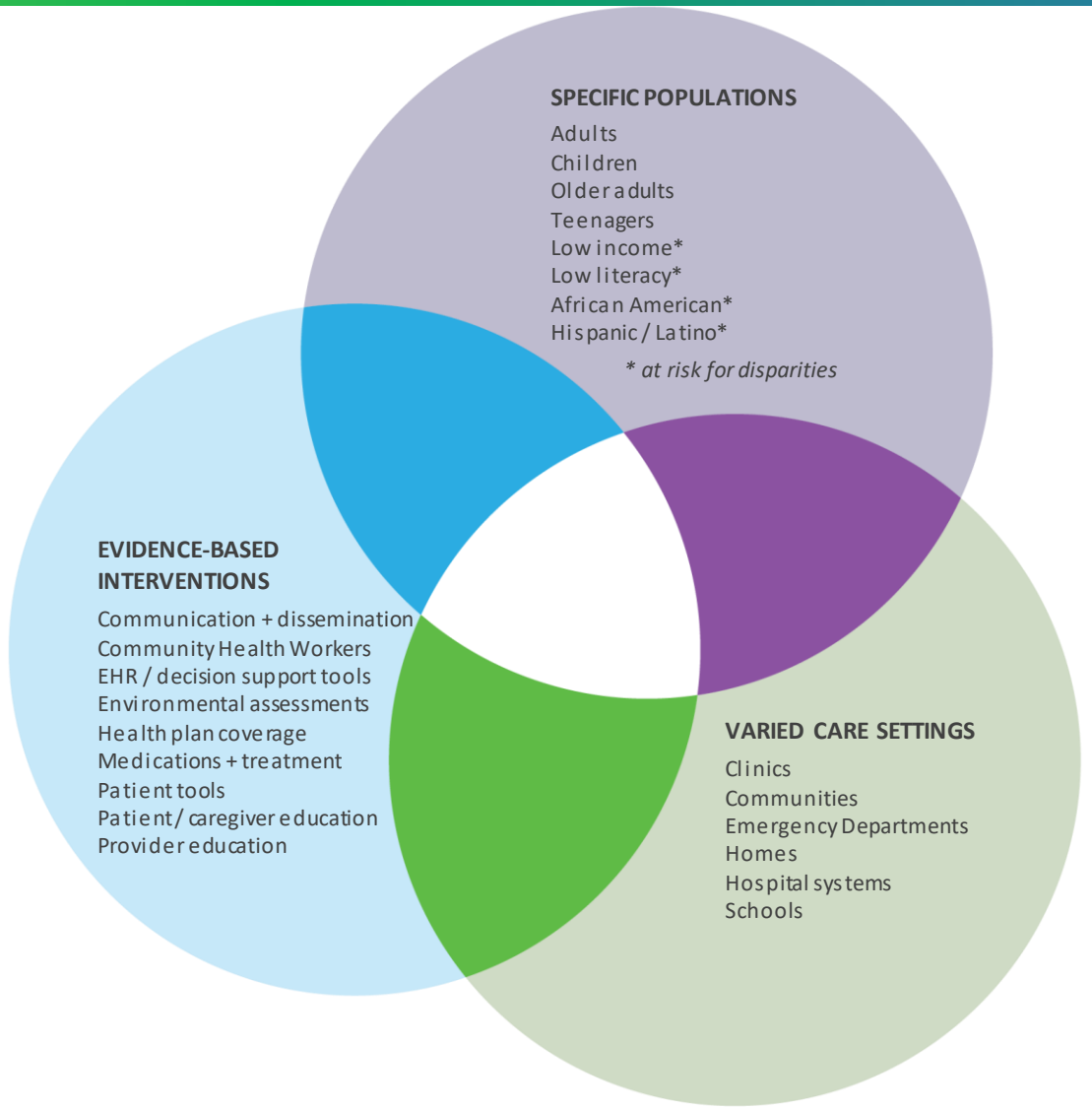
Designed to address gaps in treatment knowledge



128

PCORI asthma portfolio

Designed to address gaps in treatment knowledge



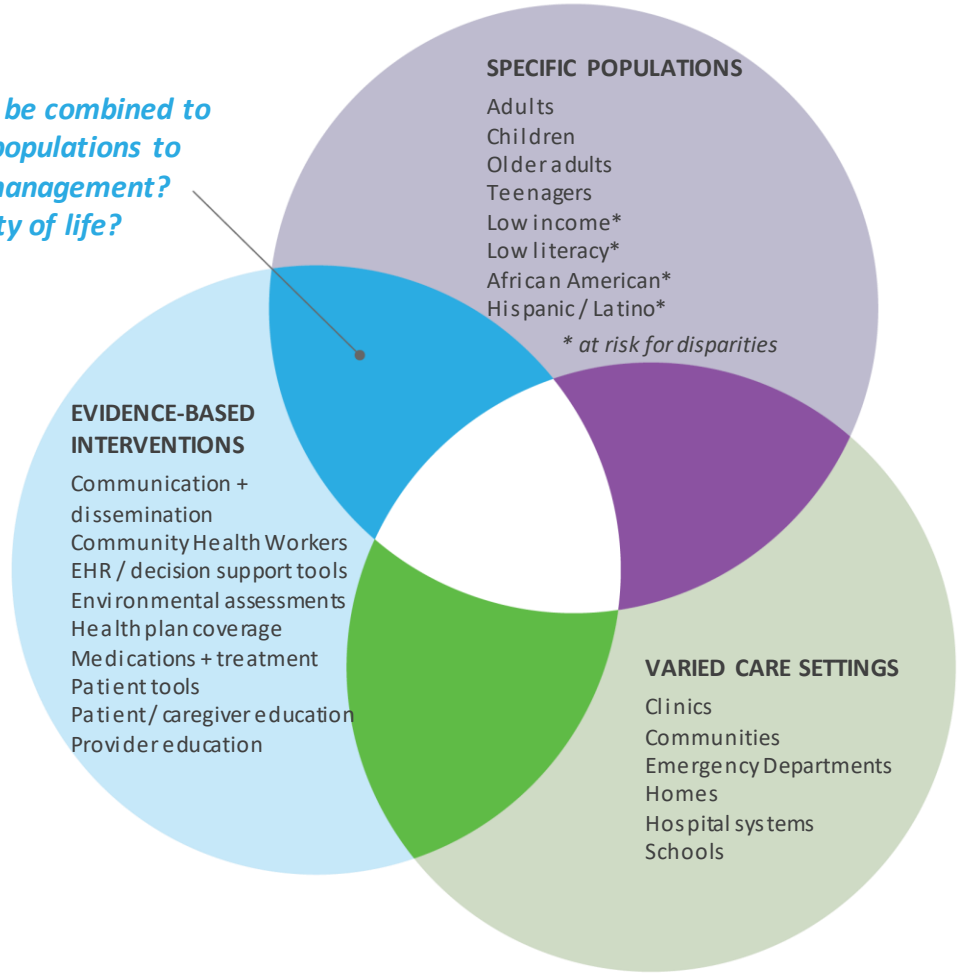
129

PCORI asthma portfolio

Designed to address gaps in treatment knowledge

KNOWLEDGE GAP 1

How can interventions be combined to better serve different populations to improve asthma self-management? Asthma control? Quality of life?



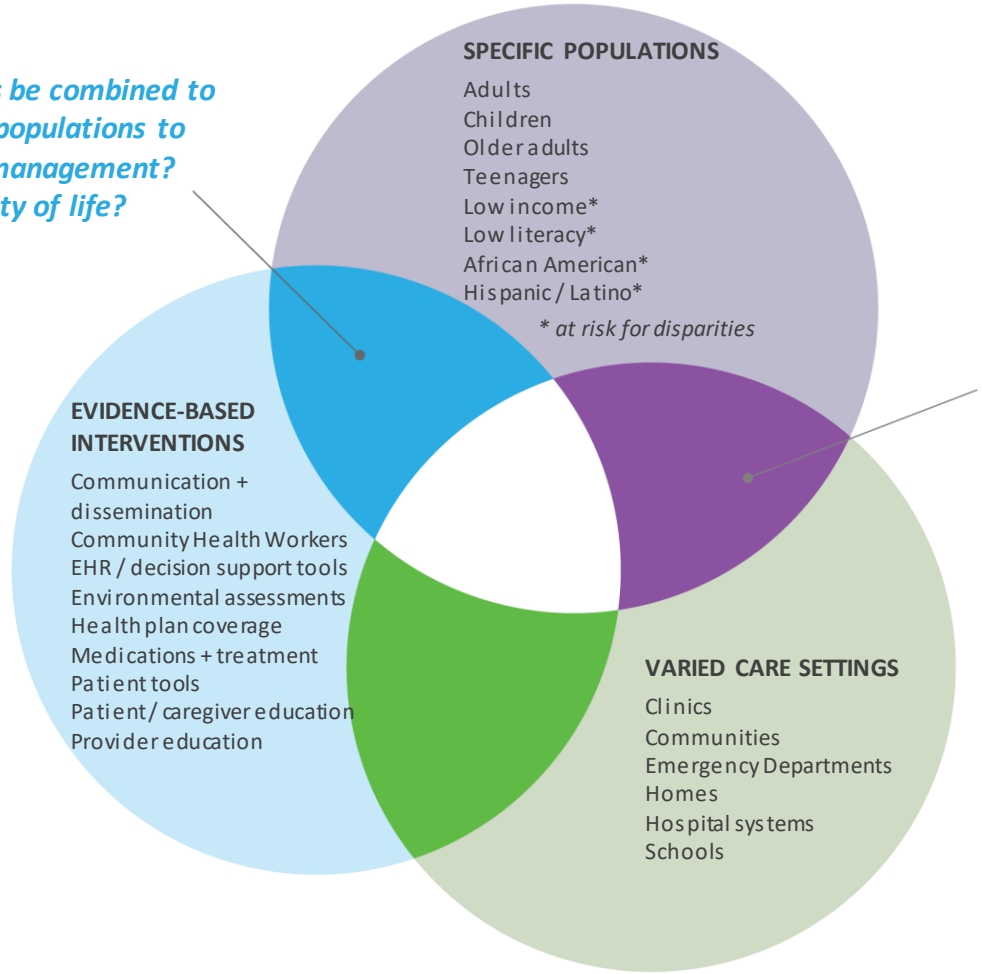
130

PCORI asthma portfolio

Designed to address gaps in treatment knowledge

KNOWLEDGE GAP 1

How can interventions be combined to better serve different populations to improve asthma self-management? Asthma control? Quality of life?



KNOWLEDGE GAP 2

What helps improve access and appropriate utilization?

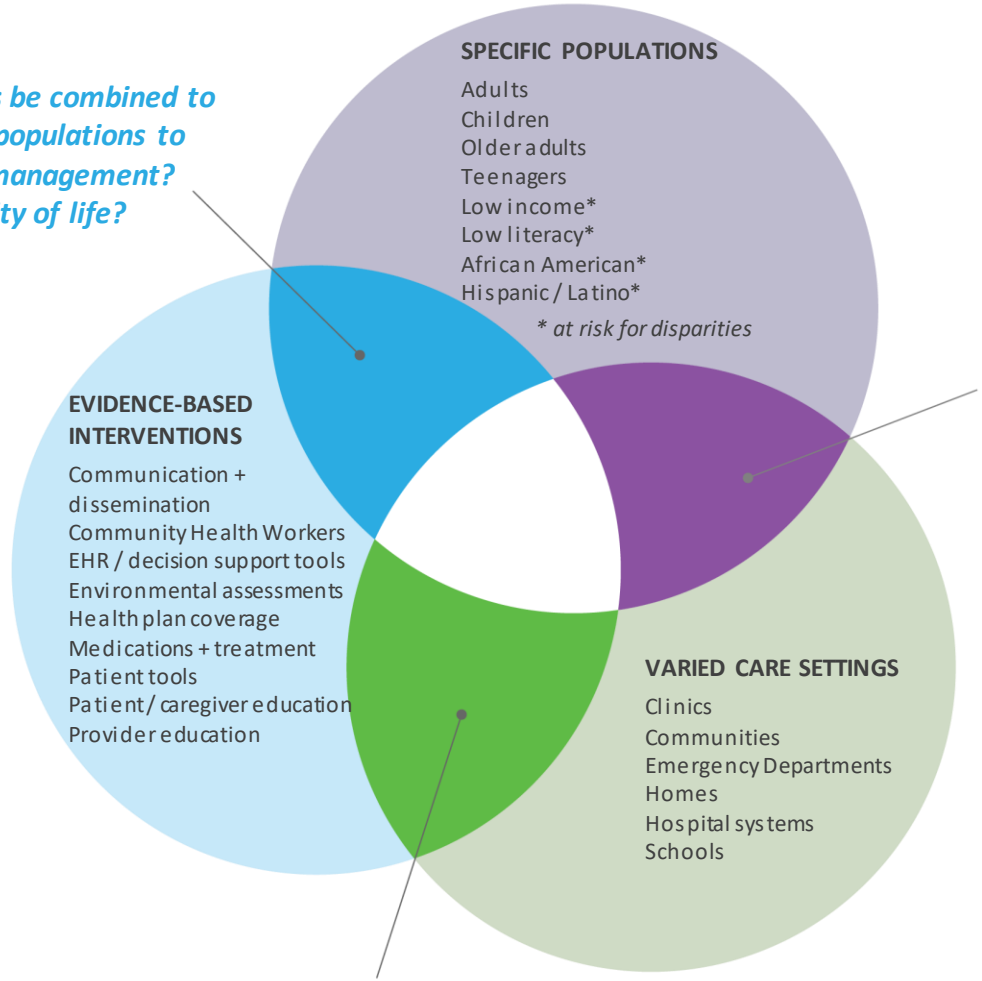
131

PCORI asthma portfolio

Designed to address gaps in treatment knowledge

KNOWLEDGE GAP 1

How can interventions be combined to better serve different populations to improve asthma self-management? Asthma control? Quality of life?



KNOWLEDGE GAP 2

What helps improve access and appropriate utilization?

KNOWLEDGE GAP 3

In which settings can interventions have the greatest impact?

How should interventions be adapted to fit real-world settings?

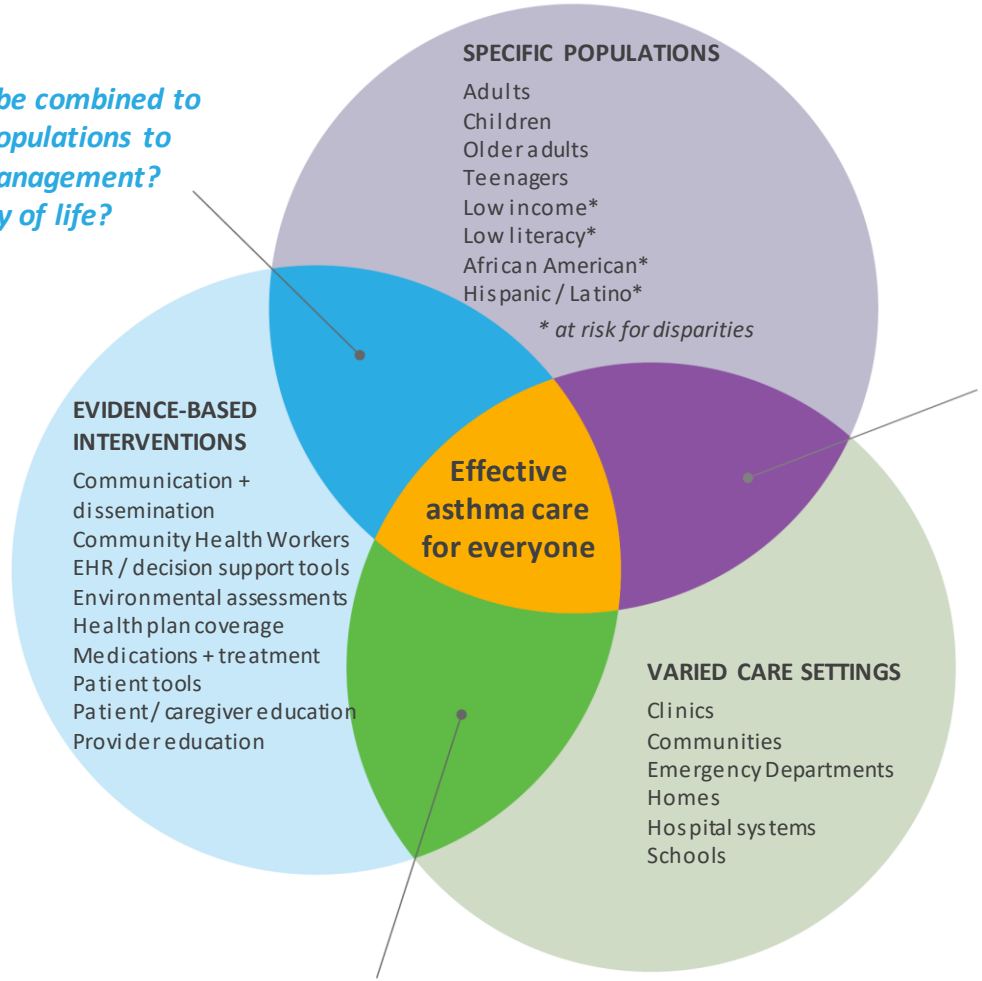
132

PCORI asthma portfolio

Designed to address gaps in treatment knowledge

KNOWLEDGE GAP 1

How can interventions be combined to better serve different populations to improve asthma self-management? Asthma control? Quality of life?



KNOWLEDGE GAP 2

What helps improve access and appropriate utilization?

KNOWLEDGE GAP 3

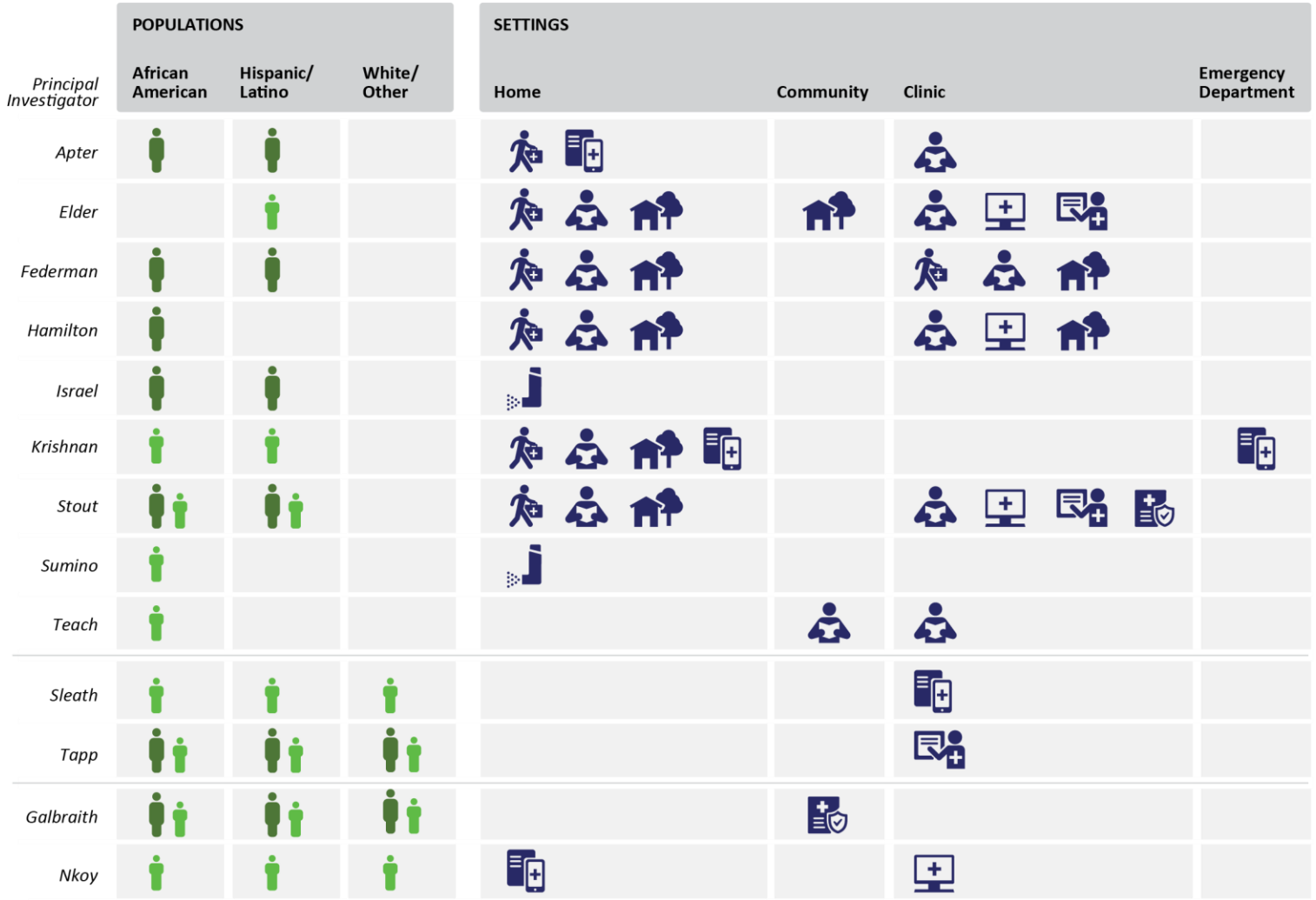
In which settings can interventions have the greatest impact?

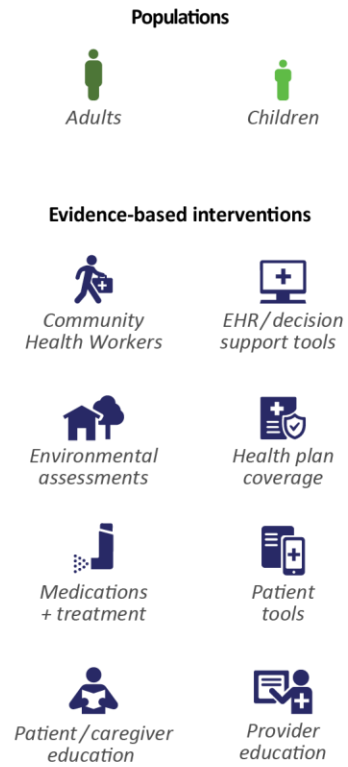
How should interventions be adapted to fit real-world settings?

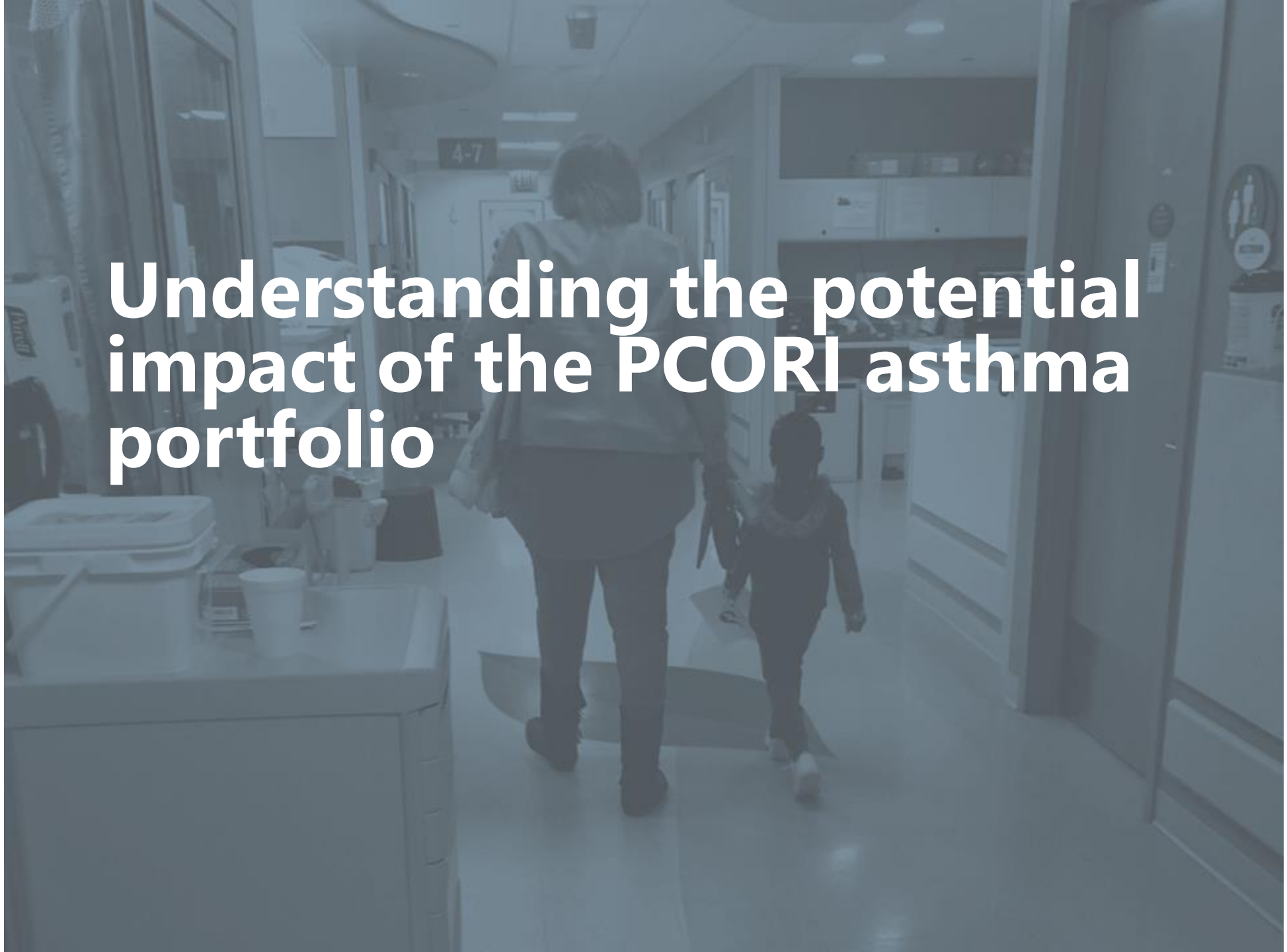
133

PCORI's asthma portfolio addresses

Which interventions work for whom, and in which setting?



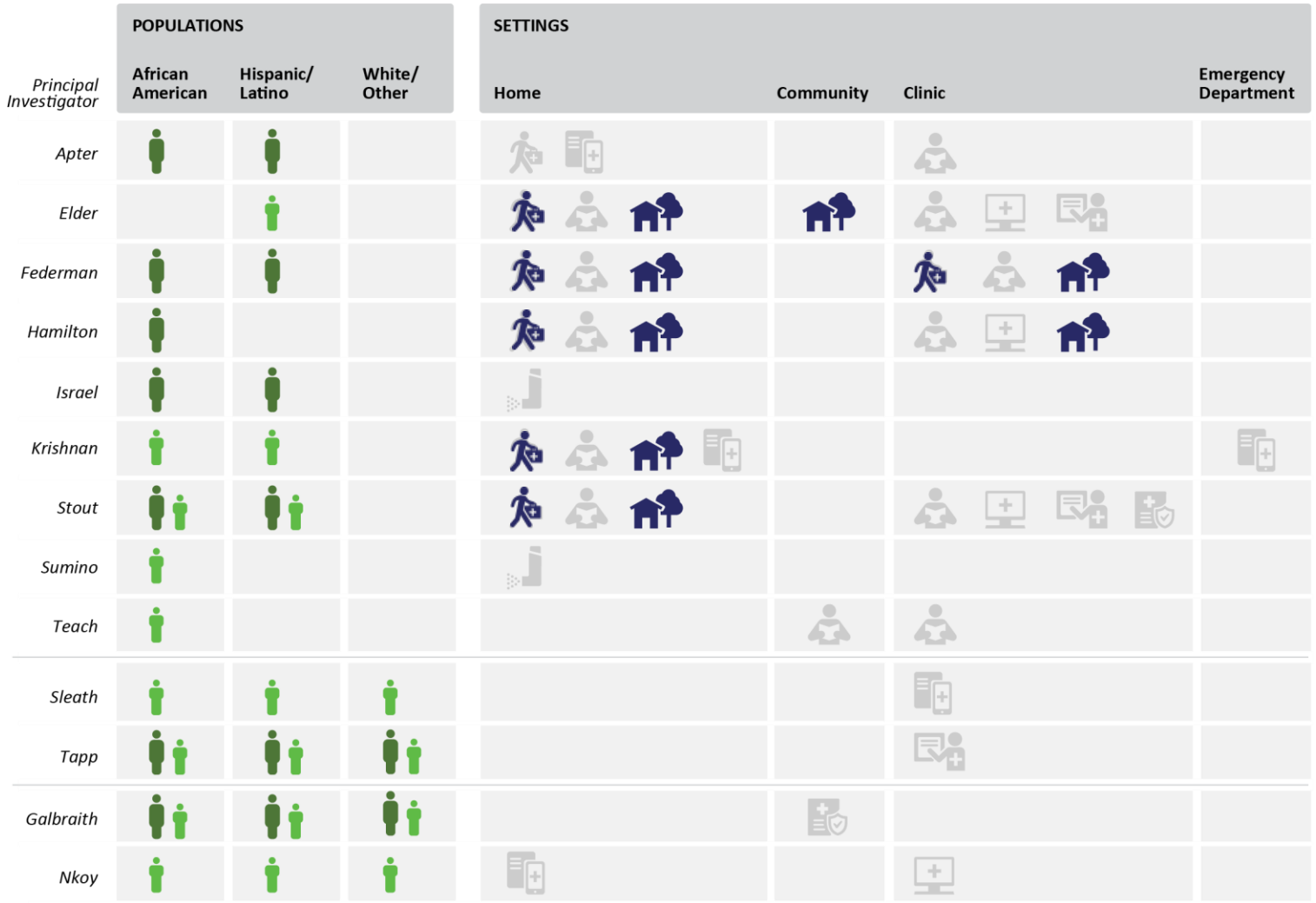




Understanding the potential impact of the PCORI asthma portfolio

PCORI asthma portfolio addresses patient/provider adherence to NAEPP Guidelines

Community health workers & environmental assessments

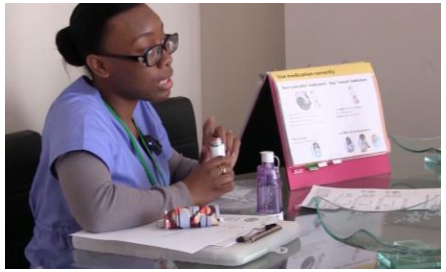


PCORI asthma portfolio addresses patient/provider adherence to NAEPP guidelines
Prescribing a community health workers (CHWs)

- CHWs, when prescribed to provide patient education and address environmental triggers, improve asthma control and quality of life compared to comparators in most of our studies
- Several studies showed improvements in medication adherence/ prescription refills
- Along with, provider education and provider support tools, CHWs may have an even greater impact on outcomes (Stout)
- For older populations (60+), CHWs in the home or care coaches in the clinic can improve asthma quality of life and asthma control (Federman)

*"I would say 70% [of my clients] have issues that are more urgent: **housing, finances, food.** They are more apt to be conscious of those things, as opposed to asthma, until it flares up."*

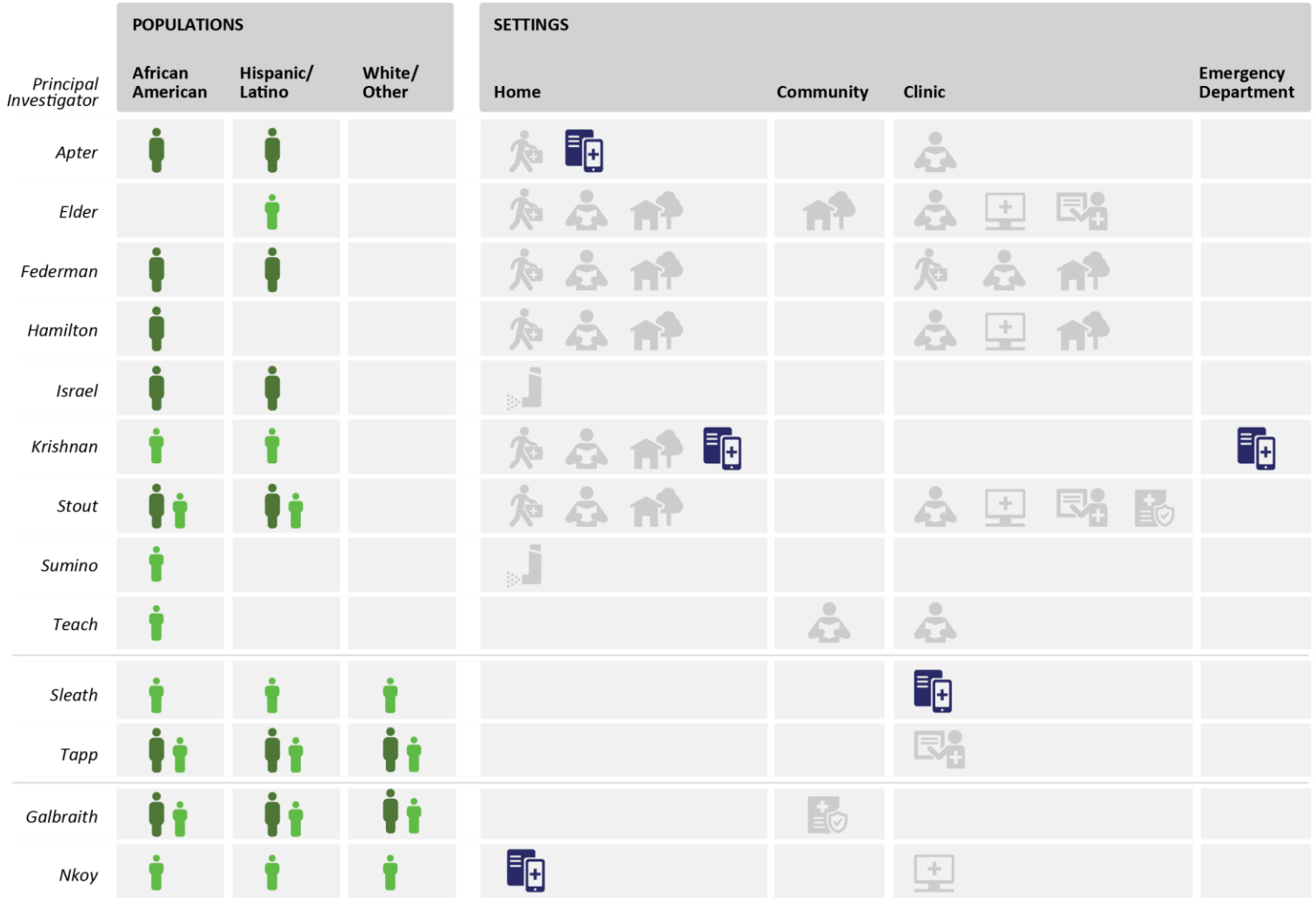
Community Health Worker



COMMUNITY HEALTH WORKERS

PCORI asthma portfolio addresses patient/provider adherence to NAEPP Guidelines

Using patient tools to support self-management education



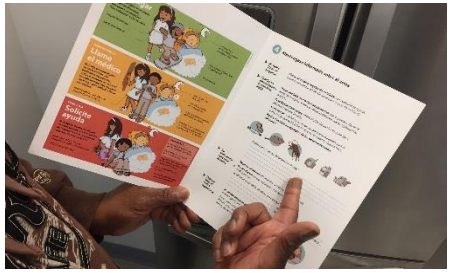
PCORI asthma portfolio addresses patient/provider adherence to NAEPP guidelines

Patient tools to support self-management education

- Patient-centered tools range from question prompt lists, electronic trackers, and detailed discharge instructions and allow for tailoring based on patient needs
- Tools can increase quality of life, reduce missed school days and work days, healthcare utilization, and oral steroid use (Nkoy)
- Tools can improves inhaler techniques, prescription refills, outpatient follow-up visits (Krishnan)
- Tools can promote shared decision making and increase youth question asking during clinical visits (Sleath)

“ The doctors will give you pamphlets, but they don’t give you a lot of education. ***You really have to take it into your own hands.*** *And that’s the really hard part—they don’t really give you much outside assistance. ”*

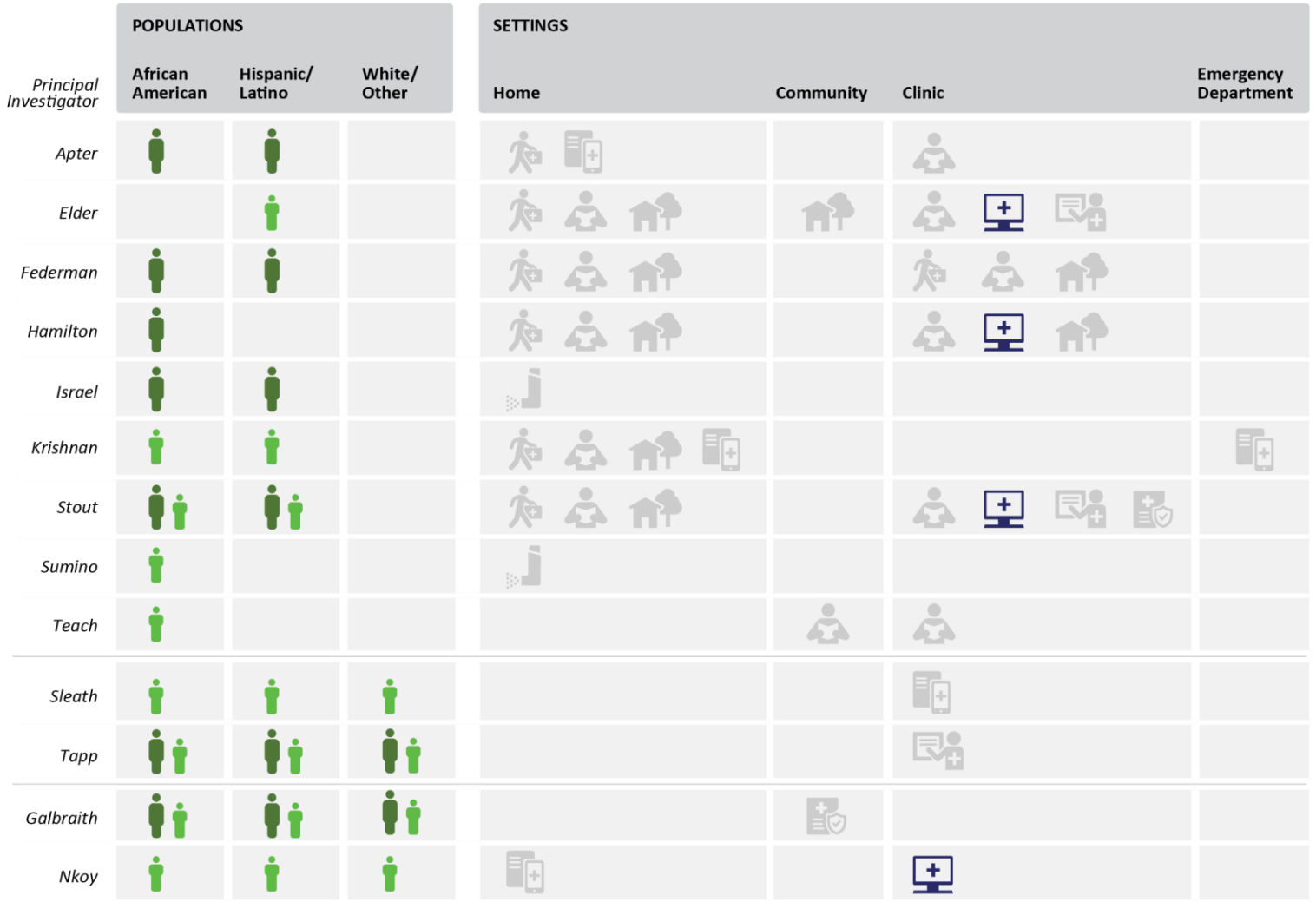
Parent of child with asthma



PATIENT TOOLS

PCORI asthma portfolio addresses patient/provider adherence to NAEPP guidelines

Using EHR/decision supports to build on provider education

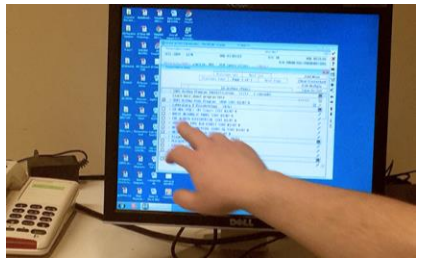


PCORI asthma portfolio addresses patient/provider adherence to NAEPP guidelines
Using EHR/decision supports to build on provider education

- System and clinical decision supports prompt guideline-based care and address the organization and delivery of asthma care
- EHR/decision supports include EHR enhancements, audit and feedback, care teams, modification to notes, care plans, and orders
- Alone, these interventions may have some promise for improving asthma outcomes; however, in conjunction with patient education and CHW home visits may lead to even better outcomes (Stout; Nkoy)

*"I'm sure you've heard from other providers that by the time a patient checks in, gives us a urine sample, has their vitals, **I have about two minutes left** to see them. "*

Outpatient provider



EHR/DECISION SUPPORT TOOLS

Real world.
Patient-centered.
Research done differently.

thank you
danke
謝謝
teşekkür ederim
gracias
спасибо
bedankt
dziękuję
obrigado
sukriya
kop khun krap
go raibh maith agat
mochchakkeram
arigatô
dakujem
grazie
terima kasih
tapadh leat
dank je
hvala
mauruuru
sagolun
takk
taiku
мерси
morci
рахмат
Баярлалаа
хвала
enkosi
sobodi
dekuji
mèsi
najis tuke
kam sah hamnida
rahmat
tanemirt
rahmet
diolch
dhanyavadagalu
shukriya
trugarez
mercé
xièxie
chnorakaloutioun
gratias ago
gràcies
sulpáy
djiere dieuf
tau
mamnun
murakoze
chokrane
tenki
obrigada
asante
manana
paldies
grazzi
mahalo
misaotra
matondo
blagodaram
vinaka
спасибі
faafetai lava
kiitos
dankie
dhanyavad
nanni
nandri
bayarlalaa
gràcie
köszönöm
akun
dankon
aciū
mersi
barka
welalin
tack
spas
kia ora
ありがとう
didi madloba
kiaoriotoo
তোমাকে ধন্যবাদ
감사합니다

CENTER ON
HEALTH EQUITY ACTION
FOR SYSTEM TRANSFORMATION
AT FAMILIESUSA

Evidence for Equity Initiative: Advancing Health Equity through Better Evidence for Asthma Care

Sinsi Hernández-Cancio
Director of the Center on Health Equity Action

Patient Centered Outcomes Research Institute
Healthcare Delivery and Disparities Research Advisory Panel

May 16, 2019

Agenda

I. Who we are

II. Evidence for Equity Initiative

III. Translating PCORI asthma research into policy recommendations

Who We Are

Families USA's Mission & Focus Areas

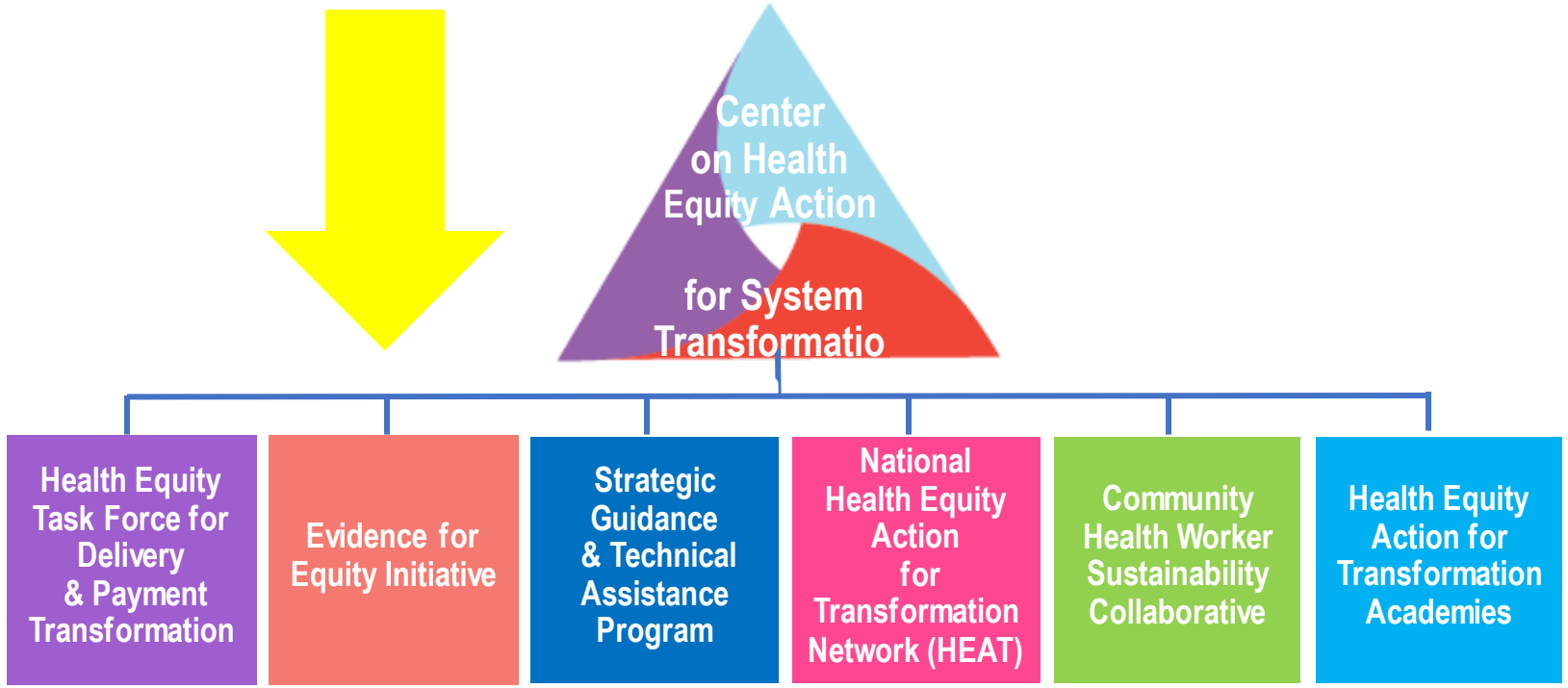
Families USA, a leading national voice for health care consumers, is dedicated to the achievement of high-quality, affordable health care and improved health for all. We advance our mission through public policy analysis, advocacy, and collaboration with partners to promote a patient-and community centered health system.

Working at the national, state and community level for over 35 years.

Center on Health Equity Action for System Transformation

- **Build and fuel a movement for equity-focused health care system transformation** by galvanizing and coordinating action among diverse organizations and community leaders.
- **Channel and translate the power of the most innovative thinking** from top thought leaders and policy experts into concrete, actionable strategies and recommendations for community leaders, stakeholders, and decision-makers to use.
- **Work with leaders who represent communities of color and other underserved groups to enhance their capacity** to elevate the urgency of tackling inequities through health system reform and engage effectively in system transformation by providing critical strategic guidance, training, tools, and technical support.

Current Initiatives



A Framework for Advancing Health Equity & Value

- Guidance on achieving meaningful inclusion of community leaders in decision making
- Rubric for assessing health equity impact of programs and policies
- Framework of six domains needing action to achieve a transformed, efficient, high value, high quality, and EQUITABLE health system
- 86 concrete policy options for the six domains, across the federal, state, and private sector levels.

Policy Domains for Achieving a Transformed, Equitable, and High Value Health Care System

The Evidence for Equity Initiative

Evidence for Equity Initiative

- Bridge gap between PCORI disparities research and the advocacy and policy making community.
- Promote the need for representative and transparent patient-centered evidence to help decision makers implement health system transformation policies that advance health equity instead of making inequities worse.
- Synthesize and translate research findings into policy recommendations to advance health equity.
- Build and strengthen dissemination and policy action structures focused on addressing disparities to facilitate increased engagement and dissemination.

Phase 1: Make the case for advocates & decision makers

The Role of Patient-Centered Outcomes Research in Improving Evidence and Advancing Health Equity

- Challenge
  - "Evidence-based" medicine is the foundation of value based care.
  - Most treatments provided in the U.S. are not well-supported by evidence (Institute of Medicine).
  - Historically, health systems and clinical research have excluded communities of color and other groups.
- Questions
  - Can health care system transformation solve for equity if the evidence it relies on is neither representative nor transparent?
  - Are we reinforcing inequities by building a system based on incomplete and biased data?

Phase 2: Synthesize results, translate, & develop policy recommendations

How do we advance from research to concrete action? POLICY

- Translation and Policy Development:
  Review select topic areas of PCORI research projects to translate learnings into policy recommendations.
  - What worked and how do we implement policies to support it?
  - What didn't work and how do we use policy to disincentivize it?
- Targeted Dissemination: brief followed by webinar
- Challenge: unavailability of public data.

Translating PCORI asthma research into policy recommendations

Topic Area: Asthma

Advancing Health Equity through Better Evidence for Asthma Care: Translating Patient-Centered Outcomes Research Learnings into Equity-Focused Policy Recommendations

- Asthma high-priority given the disparate impact in communities of color
- Limitations given availability of publicly available results.
- Cooperation with PCORI to help us contact PIs was invaluable.
- Six studies were available for analysis

Key Recommendations

1. **Researchers should stratify the results of their studies by race, ethnicity, and gender.**
    - Not all studies stratified effectiveness by race and ethnicity
    - One was focused on one particular group.

2. **Research on children should include qualitative data from parents**
    - Despite measurable objective improvements in management, parental/patient perceptions did not indicate improved outcomes.
    - Missing links in connecting parent focused intervention to improved outcomes.

3. **CHWs should be sustainably funded as valuable health interventions that address inequities and improve health outcomes**
    - 3 interventions used CHWs, all improved outcomes.

Impact: Phase 1

The Role of Patient-Centered Outcomes Research in Improving Evidence and Advancing Health Equity

- **Nearly 200 people participated in webinar**
  - 18% response rate for post webinar survey
  - Diverse mix , including nonprofits, state Medicaid offices and other state agencies unions, health care consultants, and community health clinics
  - Most were engaging in a Families USA event or webinar for the first time.
- **Increased understanding of the importance of diversity in research and in PCOR.**
  - 58% had never heard of PCOR or PCORI
  - 15% hadn't known about bias in research
  - Of those who hadn't stated that diverse evidence was "very important" to equity pre-webinar, half shifted to "very important" post webinar
  - Top additional key take-away: need for subgroup analysis (Asthma in Puerto Ricans example).

Impact: Phase 2

Advancing Health Equity through Better Evidence for Asthma Care: Translating Patient-Centered Outcomes Research Learnings into Equity-Focused Policy Recommendations

- **Nearly 75 people participated in webinar**
  - Presentation included a PI and a member of the Childhood Asthma Leadership Coalition.
  - 20% response rate for post webinar survey
  - Diverse mix: Over half (53 percent) represented community-based health centers/nonprofits, followed by national advocacy organizations.
- **Strong positive response**
  - Very highly rated overall (4.4 out of 5)
  - **100 percent** reported that our policy recommendations were useful.
  - All respondents agreed evidence was important to advance health equity prior to webinar, but 75% of those indicating “important” moved up to “very important” post webinar.
  - Most cited new piece of knowledge gained revolved around CHWs.

What's Next?

- Future Topic Areas
  - CHWs in the Fall
  - Telehealth next year

- Continue to seek opportunities to promote PCOR as a Health Equity strategy and disseminate recommendations.

- Given limited access to results, plan for updates in the future

Discussion Questions

- The studies in the asthma portfolio provide information on strategies to improve patient and provider adherence to the NAEPP Guidelines. **How should PCORI and other stakeholders make these strategies and implementation successes and challenges available to stakeholders?**
- We hear from multiple stakeholders that one study is not enough to change practice. **How could PCORI and other stakeholders leverage these study findings to change practice?**
- Translating research findings into actionable policy recommendations is critical. **From your perspective, what could PCORI fund or do to make study findings more actionable?**

Wrap Up and Next Steps

Umbereen Nehal, MD, MPH
HDDR Advisory Panel Co-Chair

Craig Umscheid, MD, MSCE
HDDR Advisory Panel Co-Chair

Steven Clauser, PhD, MPA
Director, Healthcare Delivery and Disparities Research Program

Meeting Adjourn

*Please complete and return the “Panelist Feedback’ Survey located your PCORI folder.