

PCORI Advisory Panel on Healthcare Delivery and Disparities Research

Spring 2022 Meeting

May 11, 2022

Housekeeping

- This webinar will be recorded.
- Members of the public can listen to this webinar live or view the recording on the PCORI website.
- Meeting materials will be posted on the PCORI website after the meeting.
- Anyone may submit a comment through the webinar question function, although no public comment period is scheduled.
- Visit www.pcori.org/events for more information.

COI Statement



Disclosures of conflicts of interest of members of the HDDR Advisory Panel are publicly available on PCORI's website and are required to be updated annually. Members of this Panel are also reminded to update conflict of interest disclosures if the information has changed by contacting your staff representative (rbarnes@pcori.org).

If this Panel will deliberate or take action on a manner that presents a conflict of interest for you, please inform the Chair(s) so we can discuss how to address the issue. If you have questions about conflict of interest disclosures or recusals relating to you or others, please contact your staff representative.

Welcome

Nakela Cook, MD, MPH
Executive Director



Panel Leadership

- **Alicia Arbaje, MD, MPH, PhD**
HDDR Advisory Panel Co-Chair
- **Jane Kogan, PhD**
HDDR Advisory Panel Co-Chair
- **Steve Clauser, PhD, MPA**
Program Director, Healthcare Delivery and Disparities Research Program

HDDR Advisory Panel Members

- **Ana Lopez, BSN, RN**
Facing Our Risk of Cancer Empowered (FORCE)
- **Ashley Valentine, MS**
President, Sick Cells
- **Brandi Ring, MD, FACOG, FAWM**
Baylor College of Medicine, Texas Children's Hospital
- **Diana Cejas, MD, MPH**
Assistant Professor, UNC Chapel Hill School of Medicine
- **Jeffrey Oliver, MBA**
Training by Seeds, LLC
- **Jennifer Potter, MD**
Professor, Beth Israel Deaconess Medical Center
- **Kathleen Kieran, MD, MSc, MME**
Physician, Seattle Children's Hospital
- **Kristina Cordasco, MD, MPH, MSHS**
VA Health Services Research Center for the Study of Healthcare Innovation, Policy and Practice



See supplemental materials II

HDDR Advisory Panel Members



- **Marissa D. Sanders, MPH, CPHRM**
Manager, Quality Assessment, American Dental Association
- **Nicole LeBlanc (*New Panelist*)**
Person-Centered Advisory and Leadership Group Coordinator, National Center on Advancing Person-Centered Practices and Systems
- **Rainu Kaushal, MD, MPH**
Professor of Healthcare Policy and Research, New York-Presbyterian Hospital
- **Thomas James, III, MD**
Chief Medical Officer, Passport Health Plan by Molina Healthcare
- **Varleisha Gibbs, PhD, OTD, OTR/L**
Vice President, Practice Engagement and Capacity Building, American Occupational Therapy Association, Inc.
- **Xiaoduo Fan, MD**
Associate Professor, Psychiatry, University of Massachusetts Medical School

Agenda

(Times in Eastern)

- 11:30 AM Update on Strategic Planning: PCORI's Strategic Plan
- 12:00 PM Designing Research Collaboratives to Support Equitable Comparative Effectiveness Research: Promoting Healthy Pregnancy
- 12:50 PM Midday Check-In
- 1:00 PM Lunch Break
- 1:30 PM PCORI's Targeted Funding Announcement on Healthy Aging – Overview & Feedback
- 2:35 PM Addressing Health Disparities Faced by Sexual and Gender Minorities: Developing a Special Area of Emphasis
- 3:30 PM HDDR Program Updates
- 3:45 PM End of Day Check-In
- 4:00 PM Wrap-Up

 [See supplemental materials I](#)

Update on Strategic Planning: PCORI's Strategic Plan

Steven Clauser, PhD, MPA
Program Director, HDDR

 See supplemental materials V

Purpose

- Share overview of where we are in the strategic planning process
- Begin discussions with this panel on implementation planning

Structure

- Highlight key accomplishments related to strategic planning
- Outline structure of the Strategic Plan
- Hear initial thoughts from panel members related to implementation planning

Adopted National Priorities for Health



Increase Evidence for Existing Interventions and Emerging Innovations in Health

Goal: Strengthen and expand ongoing comparative clinical effectiveness research focused on both existing interventions and emerging innovations to improve healthcare practice, health outcomes, and health equity.



Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research

Goal: Enhance the infrastructure that facilitates patient-centered outcomes research to drive lasting improvements in health and transformation of both the research enterprise and care delivery.



Advance the Science of Dissemination, Implementation, and Health Communication

Goal: Advance the scientific evidence for and the practice of dissemination, implementation, and health communication to accelerate the effective sharing of comparative clinical effectiveness research results for public understanding and uptake into practice.



Achieve Health Equity

Goal: Expand stakeholder engagement, research, and dissemination approaches that lead to continued progress toward achieving health equity in the United States.



Accelerate Progress Toward an Integrated Learning Health System

Goal: Foster actionable, timely, place-based, and transformative improvements in patient-centered experiences, care provision, and ultimately improved health outcomes through collaborative, multisectoral research to support a health system that understands and serves the needs and preferences of individuals.

When We Last Spoke

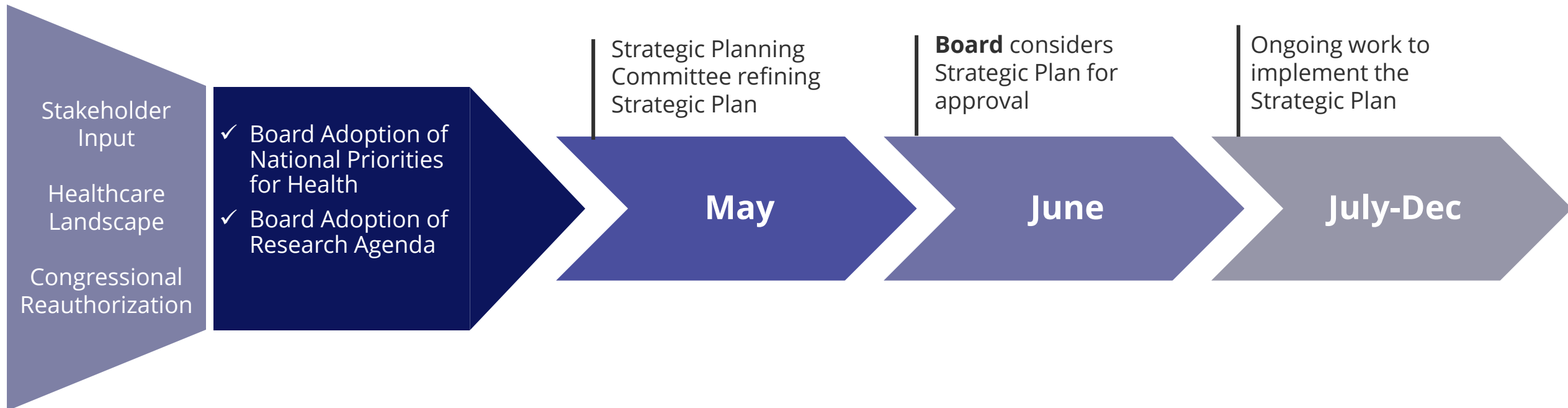
- This panel considered the proposed Research Agenda and how it could support a research portfolio to meet current and future needs
- Panel members shared insights regarding PCORI's future work including:
 - The importance of communicating evidence and research findings to the public
 - Aligning future work with others in the health research space (e.g., funders, health organizations)
 - Considering research areas and measures that reflect conditions and outcomes that matter most to stakeholders and that are relevant to a range of individuals to minimize bias
- This was integrated with input from other convenings, meetings, and discussions

Adopted Research Agenda

Fund comparative clinical effectiveness research that:

- ▶ Fills patient- and stakeholder-prioritized evidence gaps and is representative and inclusive of diverse and underrepresented patient populations and settings
- ▶ Advances the achievement of health equity and elimination of disparities with an emphasis on overcoming the effects on health and healthcare outcomes of racism, discrimination, and bias
- ▶ Builds the evidence base for emerging interventions by leveraging the full range of data resources and partnerships
- ▶ Examines the diverse burdens and clinical and economic impacts important to patients and other stakeholders
- ▶ Focuses on health promotion and illness prevention by addressing health drivers that occur where people live, work, learn, and play
- ▶ Integrates implementation science and advances approaches for communicating evidence so the public can access, understand, and act on research findings

Anticipated Timeline



Developing a Comprehensive Approach

- Core Strategic Plan document
- Digital format (e.g., clickable, interactive webpages)
- Printable “at-a-glance” handouts (e.g., two-page PDFs)

Accessibility



- Demonstrate how PCORI achieves its mission
- Opportunity for stakeholders to see themselves in PCORI’s vision
- Serve as a communication tool
- Serve as the basis for PCORI’s next phase

Purpose



- Patients and caregivers
- Researchers and clinicians
- Congress and GAO
- Healthcare purchasers, payers, industry, hospitals and other health systems
- Broader health community

Audiences



Outline of Substantive Components in Strategic Plan



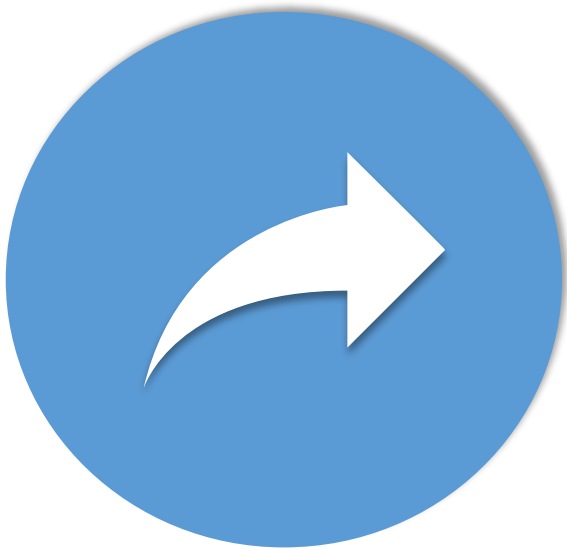
- **Introduction and a Bold Vision for PCORI's Second Decade**
 - Shares, briefly, PCORI's history and how we envision continuing our work such as the continued importance of diversity, equity, and inclusion and being responsive to an evolving health care and research landscape
- **A Holistic Approach to Generating and Disseminating Patient-Centered CER**
 - Describes comprehensive set of activities (e.g., funding CER, engagement, D&I, infrastructure) that flow from the National Priorities for Health and facilitate the generation and dissemination of evidence to improve clinical decision making
 - Includes the National Priorities for Health and Research Agenda
- **Measuring Success and Monitoring Progress**
 - Provides general approach for assessing PCORI's progress towards the National Priorities for Health

Moving Towards Implementation Planning

- We are excited to *begin discussions* with Advisory Panels related to implementation planning. To start, we would like your input on strategic opportunities related to the Research Project Agenda (RPA).
- We are particularly interested in hearing about promoting an effective, transparent process for developing the RPA. Currently, this in a *transition* and we are considering opportunities to revise the process with an eye towards enhancing ability to be *nimble, adaptive, and responsive* to changes in the health environment.
- Aim for Research Project Agenda process that is:
 - Stakeholder-Driven
 - Responsive
 - Transparent
 - Systematic
 - Efficient



Anticipated Next Steps



Use feedback garnered from discussions to inform our process considerations along with actionable steps for implementation

Share update on process development with this panel at a future meeting

Beginning Discussions to Help Inform Implementation Planning

- What are meaningful ways to engage with stakeholder communities represented on this panel to solicit ideas and inform topic development (e.g., convenings, surveys, webinars)?
- What does a responsive, transparent Research Project Agenda development process look like from your perspective?
- Given the broad, integrated nature of the adopted National Priorities for Health and Research Agenda, how could PCORI demonstrate relevance to stakeholder communities represented by this panel?
- Based on this panel's expertise in healthcare delivery and equity of care, what are this panel's suggestions to stay up to date on emerging issues in this space?



Update on the Health Equity Initiative

Enhanced Awards to Support Equitable Comparative Effectiveness Research: Improving Maternal Outcomes for At-Risk Populations

Kelly Dunham, MPP, Senior Manager, HDDR

Vivian Towe, PhD, MSc, MA, Program Officer, HDDR

Andrea Brandau, MPP, Program Officer, HDDR

Purpose of Today's Presentation

- Provide an update on the Health Equity Initiative
- Share topic focus: *improving maternal outcomes for at-risk populations*
- Gather feedback from the panel on the scope and scalability of the initiative

Expanding Beyond the Individual to Focus on Community Health

- “Health equity and health disparities are intertwined. Health equity means social justice in health (i.e., no one is denied the possibility to be healthy for belonging to a group that has historically been economically/socially disadvantaged). Health disparities are the metric we use to measure progress toward achieving health equity.”
Braveman P. What are health disparities and health equity? We need to be clear. *Public Health Rep.* 2014
- To achieve this, we must address and remove inequitable structures, policies, and practices that impact health

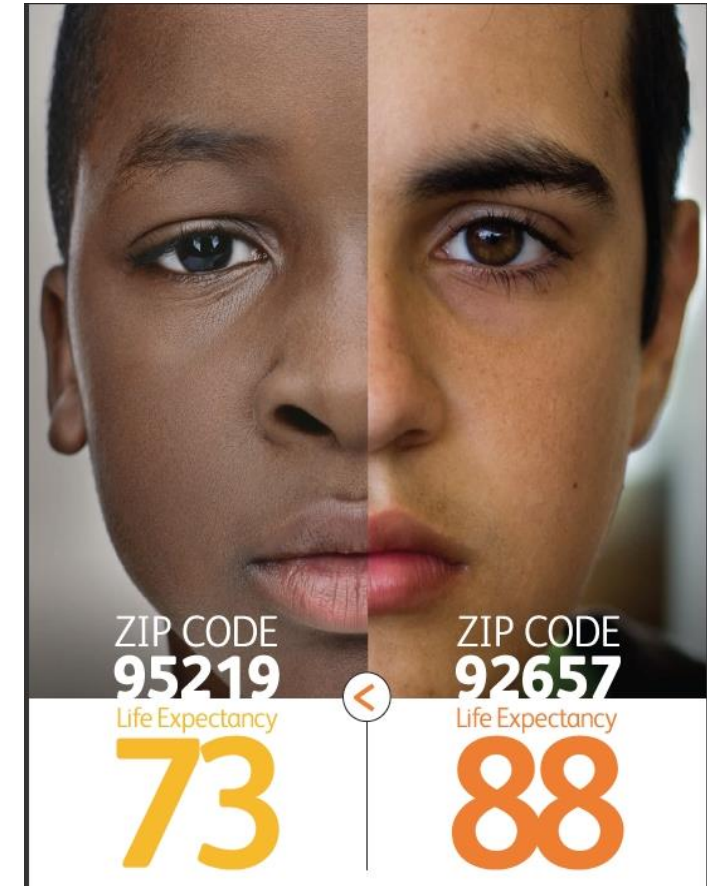


Image from “Health Happens Here” campaign, sponsored by The California Endowment

A Call for Funders to Move Upstream: The National Academies of Science, Engineering and Medicine (NASEM) Consensus Reports



NASEM Consensus Recommendations:

- Support community capacity building and prioritize equity in the SDOH through [investments in low-income and minority communities](#)
- Research on the [effectiveness and implementation of social care practices](#), including the integration of social care and health care
- PCORI and other funders should encourage payers, providers, and delivery systems to incorporate a [range of study designs and methods that include rapid learning cycles and experimental trials](#)
- Extend education and [training initiatives to include social care workforce](#)
- Support [transdisciplinary research approaches](#)

NASEM, *Communities in Action: Pathways to Health Equity* (2017)

NASEM, *Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation's Health* (2019)

Our opportunity:

- To increase evidence for and uptake of strategies for advancing health equity for **under-resourced communities** in the United States

Develop initiative informed by PCORI's strategic plan:

- *Achieve Health Equity*, one of PCORI's National Priorities for Health
 - Fosters innovation by developing enhanced engagement models and a learning network that includes communities and investigators
 - Integrates researchers and communities to optimize relevance and benefits to communities
 - Addresses health drivers that occur where people live, work, learn, and play
 - Addresses maternal morbidity and mortality, a high priority health equity issue to stakeholders

Stakeholder Engagement to Date: A Sample

- A few organizations with whom we've engaged
- Not an exhaustive list



High Stakeholder Enthusiasm about PCORI Leading a Health Equity Initiative



PCORI is well-positioned to do health equity research in which we move from community engagement toward community integration into research

Stakeholders emphasized need to elevate community's role in decision-making in research to ensure that the community directly benefits from the research

More comparative effectiveness research is needed in the context of health equity; few initiatives exist that support clinical trials with meaningful community involvement

PCORI can focus on innovation in community partnership development and integration in a way other funders may not

Flexibility in research aims is critical for communities to determine which research priorities are right for them and to obtain community buy-in

Two-Pronged Approach

- We are considering a two-pronged funding approach to advance this initiative: 1) a **research mechanism for specific topics supported by existing partnerships**, and 2) **emerging partnership awards**:
 - 1) **Enhanced research mechanism to advance equitable CER:**
 - Established researcher-community partnerships
 - Multicomponent and multilevel interventions addressing both social and structural determinants of health AND patient-level health risks/conditions
 - Learning community of investigators and community partners
 - Training opportunities for researchers from underrepresented communities
 - Support awardees with a technical assistance contractor
 - Real-time evaluation
 - Topic-specific focus

2) Emerging Partnerships Initiative is under development

Topic Focus

Improving Maternal Outcomes for At-Risk Populations

Multicomponent Models of Care to
Reduce Maternal Morbidity and Mortality

To-Date and Future Maternal Morbidity and Mortality Comparative Effectiveness Research Funding

Special Area of Emphasis focused on
**Increasing Access to and
Continuity of Patient-centered
Maternal Care**
in its Broad funding announcement

- 3 studies funded (\$26M)

Postpartum



Targeted Funding Announcement
focused on

**Improving Postpartum Maternal
Outcomes for Populations
Experiencing Disparities**

- 1 study funded (\$20M)
- Re-release Cycle 2 2022

Maternal Care



Maternal Morbidity and Mortality (MMM)

- Congressionally mandated
- Health equity
 - Optimally suited for initiative

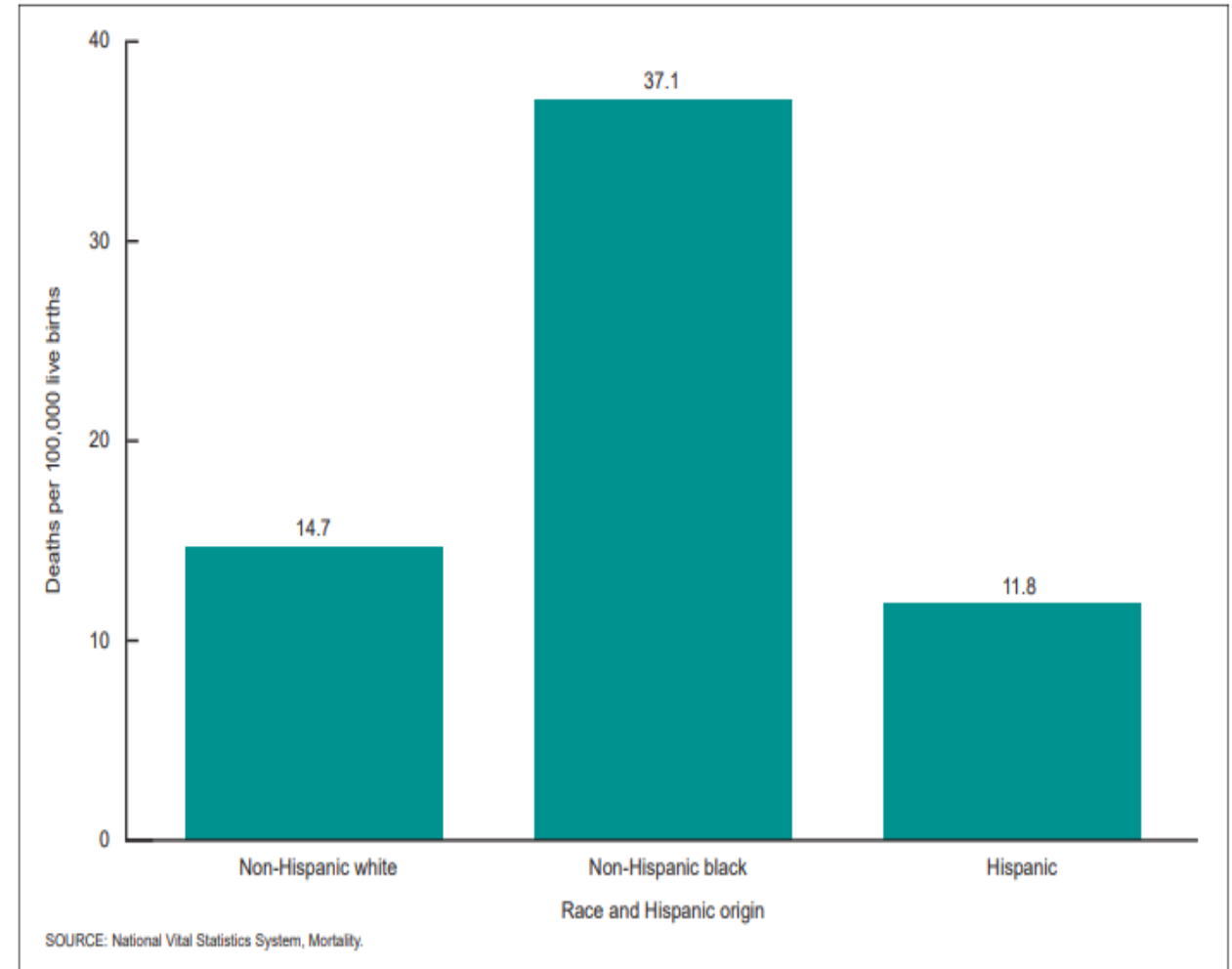
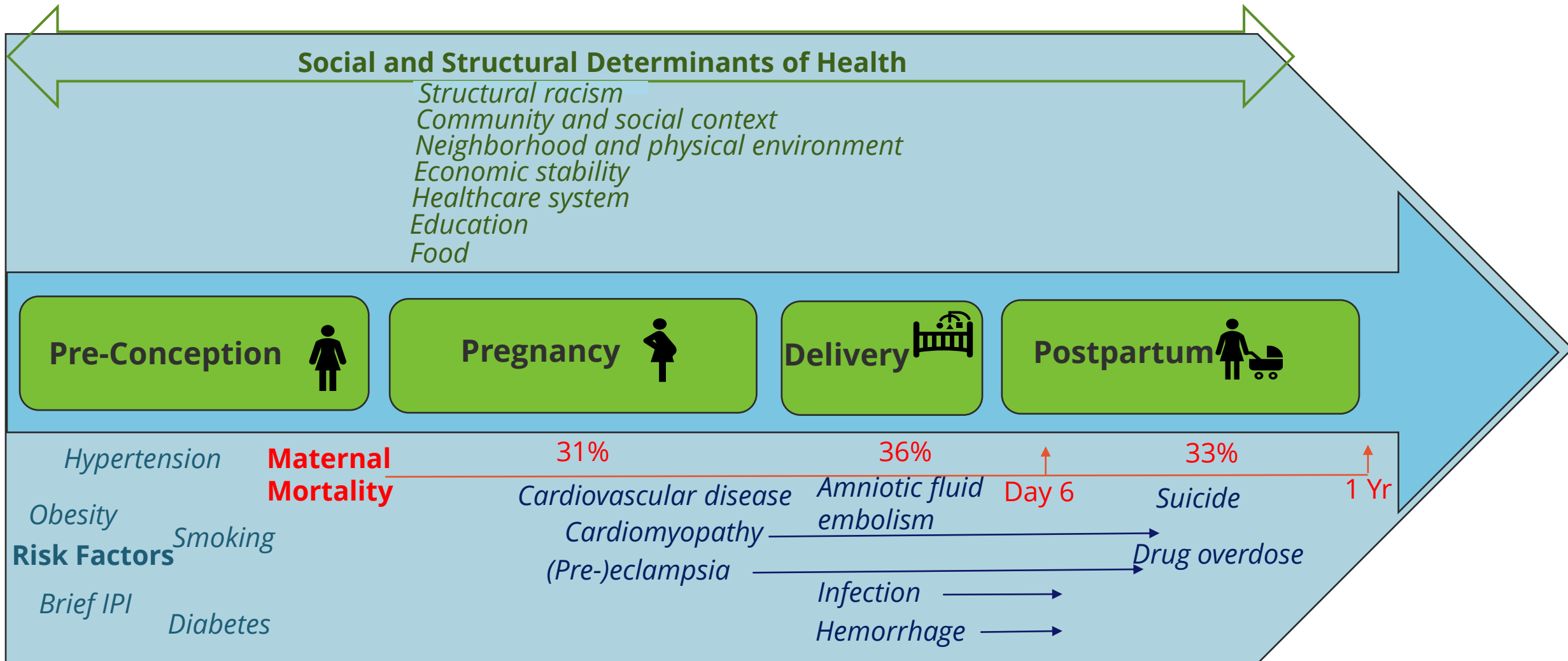
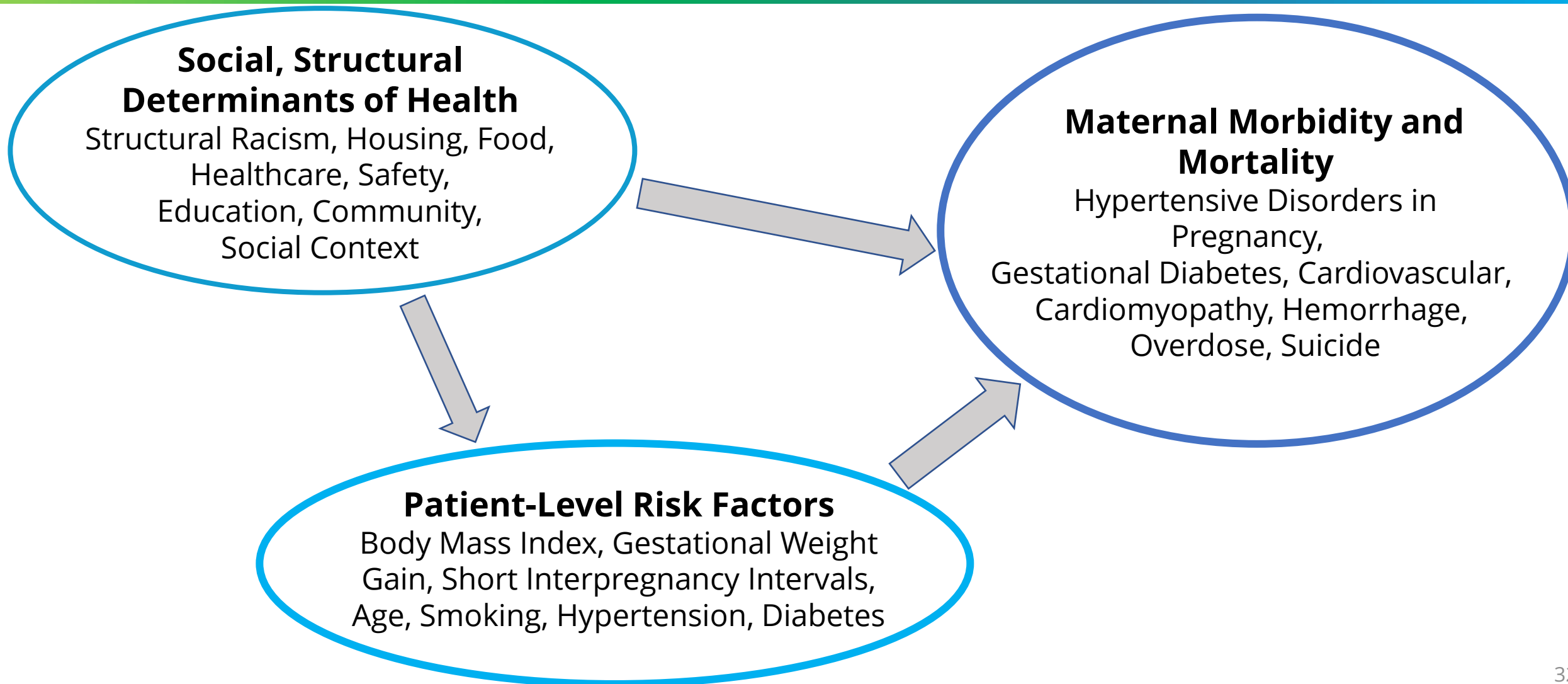


Figure 2. Maternal mortality rates, by single race and Hispanic origin: United States, 2018

Maternal Morbidity and Mortality Framework



Maternal Morbidity and Mortality Risk Factors



Priority Question

What is the comparative effectiveness of multicomponent, multilevel interventions of perinatal care that include **strategies to address specific health risks and conditions** and **strategies to address social and structural determinants of health** for pregnant persons to improve maternal outcomes?

- Interventions in pre- and postnatal care to reduce and/or manage specific health risks and conditions (e.g., monitoring/treatment of hypertension, screening/treatment for depression, screening and continuous glucose monitoring for diabetes) and address social and structural determinants of health (e.g., housing-related, meal replacement, transportation)
- Primary outcomes: Clinical outcomes, such as composite outcomes (Severe Maternal Morbidity, SMM; Hypertensive Disorders of Pregnancy, HDP), other; Gestational Diabetes Mellitus (GDM), excess Gestational Weight Gain (GWG), Depression, Substance use, Suicidality

Discussion

- Which outcomes are most important to consider for these research questions?
- Are there any contextual factors, considerations, or potential challenges that we should be mindful of when considering clinical effectiveness research in this space?
- Are there other important issues regarding addressing health equity that you would like to bring up?
- Are there any considerations or mechanisms that would enhance scalability and learning?

Midday Check-In



www.menti.com



Lunch Break



Healthy Aging: Optimizing Physical and Mental Functioning Across the Aging Continuum – PCORI Funding Announcement

Neeraj Arora, PhD – Associate Director, HDDR

Tabassum Majid, PhD, MAgS – Program Officer, HDDR

Vivian Towe, PhD, MSc, MA – Program Officer, HDDR

Carly Khan, PhD, RN, MPH – Associate Director, HDDR

Candace Hall, MA – Program Associate, HDDR

Agenda

- Provide overview of the Healthy Aging Targeted Funding Announcement
- Solicit feedback from panel for future potential refinement and focus

Background

- Number of older adults in the U.S. is growing significantly, along with an increase in diversity by race/ethnicity
 - By 2030, 1-in-5 Americans will be age 65 or older
 - Between 2017 and 2040, the proportion of racial/ethnic minorities among older adults in the U.S. will increase by 135%
- Majority of older adults have two or more chronic conditions and experience significant burden
- Majority of older adults prefer to stay in their homes and communities for as long as they can
- Care partners play a critical role in helping older adults age in place, but experience significant caregiving burden
- The current healthcare system is not well-equipped to address the complex care needs of a rapidly growing and diverse older adult population
- The National Academy of Medicine has identified “Actualizing better health and healthcare for older adults” to be one of five vital directions for health and healthcare in 2021

PCORI Funding Announcement (PFA) Overview



Objective:

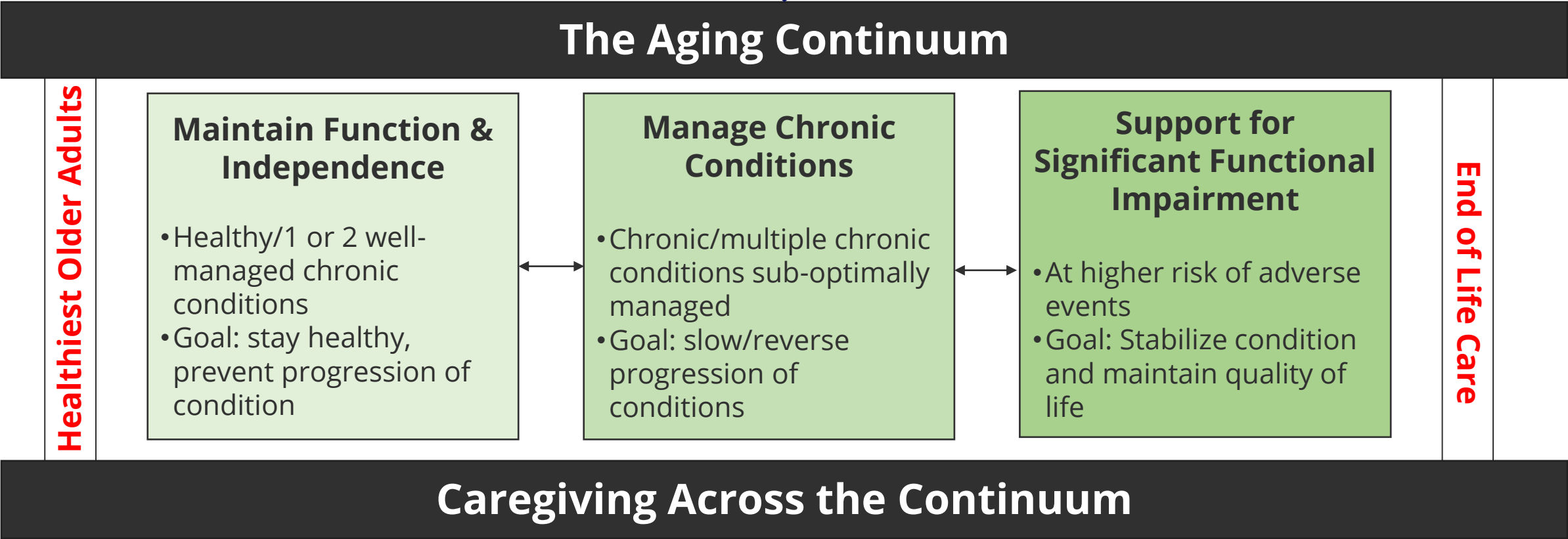
- This Targeted PFA (TPFA) on [healthy aging](#) seeks to fund high-quality comparative effectiveness research (CER) studies that aim to optimize the physical and mental functioning of community-dwelling older adults and their caregivers across the aging continuum.

- **Available Funds:** Up to \$50 million
- **Total Direct Costs:** Up to \$5 million
- **Project Duration:** Up to 5 years

Framework for Healthy Aging Funding Announcement



Interventions Optimizing Physical and Mental Functioning Across the Aging Continuum



Four primary research questions

- What are the most effective approaches to **maintaining function and independence** among older adults living in the community across different phases of the aging continuum?
- What are the most effective approaches to **facilitating management of chronic/multiple chronic conditions** among older adults living in the community?
- What are the most effective approaches to supporting older adults in the community with **significant functional (physical and/or cognitive) impairment** to maintain their quality of life?
- What are the most effective approaches to **reducing caregiver stress and improving quality of life of caregivers** caring for older adults across different phases of the aging continuum?

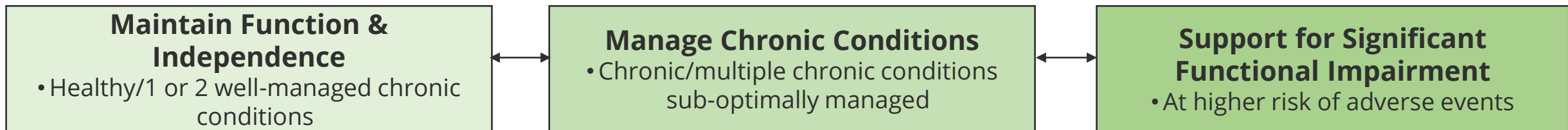
Stakeholder Engagement

Stakeholders Consulted

- National Institute on Aging (NIA)
- Agency for Healthcare Research and Quality (AHRQ)
- American Academy of Family Physicians (AAFP)
- Alliance for Aging Research (AAR)
- Caregiver Action Network (CAN)
- American Association of Retired Persons (AARP)
- National Academy for State Health Policy (NASHP)
- John A. Hartford Foundation (JAHF)
- Medicaid Medical Directors Network (MMDN)
- National Alliance for Caregiving (NAC)

Study Considerations: Target Population

- Older adults (in the domains below) & their caregivers
 - Community-dwelling participants: regular housing, assisted living, senior housing
 - Younger, non-Medicare eligible, populations considered with justification
- PCORI encourages studies that
 - Include diverse study populations such as rural-dwelling, low income, racial/ethnic groups, individuals with low health literacy, limited English proficiency, or living in unstable circumstances
 - Have broadly applicable interventions powered for heterogeneity of treatment effects (HTE) analyses



Study Considerations: Caregivers

- The PFA encouraged studies to include caregivers, as appropriate, acknowledging that requirements of caregivers vary greatly across the trajectory of caregiving, depending on the illness (type and/or severity) of the care recipient
- Caregivers: family members or close friends serving as the primary caregiver or caregivers to an older adult

Study Considerations: Study Design

- Individual or cluster randomized controlled trials
- Natural experiments
- Studies with implementation component will help with dissemination and widespread adoption of effective interventions
 - Hybrid Type 1 or 2 designs
 - Mixed methods

Study Considerations: Interventions/Comparators

- The comparison proposed must address a critical decisional dilemma to stakeholders and an evidence gap
 - Justify that the comparators are the critical ones in the current context of older adult/caregiver needs
 - Needs evidence of prior efficacy or have documentation of widespread use
 - If usual care is included as a comparator, it must be adequately justified, well defined, and sufficiently measured

Study Considerations: Outcomes

- Applications should propose well-justified outcomes that are clinically meaningful and considered important by patients and/or their caregivers and, upon which impact by proposed interventions, can be assessed during the duration of the CER study.
- Examples of possible outcomes include, but are not limited to:
 - Physical function measures (activities of daily living, instrumental activities of daily living, mobility)
 - Mental health measures (depression, anxiety, social isolation, cognitive function)
 - Older adult and caregiver quality of life and caregiver stress/burden
 - Delay to institutionalization and healthcare utilization
 - Additional clinical measures (e.g., blood pressure control, antipsychotic use)

Note: Outcomes such as self-efficacy and patient activation could be potential mediators of the impact of interventions on clinically meaningful outcomes and may be included as secondary outcomes but not as primary outcomes.

Study Considerations: Settings

- This TPFA focuses on interventions that may be delivered in outpatient clinical, home, or community-based settings.
- Study settings can include primary and specialty care clinics; homes of older adults or their caregivers; and community settings such as assisted living, senior housing, retirement facilities, and adult daycare centers.
- Studies solely taking place in institutional settings, like hospitals and nursing homes, are not considered eligible.
- Interventions may be delivered across multiple settings.
- Multisite studies (e.g., across multiple sites within a health system, preferably in diverse geographies; across multiple health care systems; across multiple communities) are required in order to support widespread implementation of effective interventions.

Key Dates

- Board approval of the Healthy Aging TPFA: June 2021
- PFA released: September 2021
- Letter of intent (LOI) deadline: October 2021
- Full application deadline: January 2022
- Merit Review: April 2022
- Board approval of proposed funding slate: July 2022
- Potential for future reissuance: TBD

AP Feedback



Example Areas for Feedback and Advice

- If we were to reissue the Healthy Aging TPFA, what revisions, refinements, or areas of focus would you recommend related to, but not limited to:
 - Specific patient populations or communities we should call out
 - Particular settings we may emphasize for intervention delivery and evaluation
 - Requirements/deliverables we may consider that would facilitate sustainability of the interventions after the study is over
 - Guidance specific to facilitating cutting edge CER on caregiver needs
 - Specific requirements for stakeholder engagement to ensure success of the proposed studies
- In general, how can we enhance our emphasis on health equity in the Healthy Aging TPFA?

PCORI's Investment in Sexual and Gender Minority Populations

Brendan Weintraub, MPH, CHES®
Program Associate, HDDR
he/him/his

Agenda

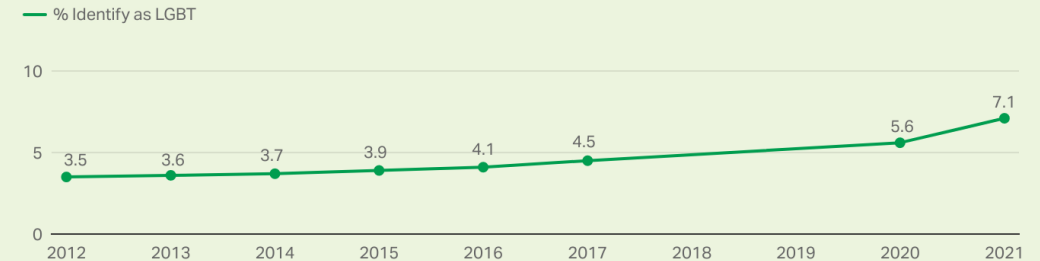
- General overview of **Sexual and Gender Minorities (SGM) in the U.S.**
- Overview of PCORI's SGM **Research and Engagement Portfolios**
- Potential **Role for PCORI in SGM Research** based on internal activities
- Breakout Rooms
- Discussion & Next Steps

Sexual and Gender Minorities in the U.S.

- **SGM** comprise lesbian, gay, bisexual, transgender, intersex, and asexual/aromatic/agender (LGBTQIA+) individuals who make up ~7.1% of the U.S. population
 - 56.8% Bisexual
 - 20.7% Gay
 - 13.9% Lesbian
 - 10% Transgender
 - 4.3% Other (e.g., queer, same-gender-loving)

Americans' Self-Identification as Lesbian, Gay, Bisexual, Transgender or Something Other Than Heterosexual

Which of the following do you consider yourself to be? You can select as many as apply. Straight or heterosexual; Lesbian; Gay; Bisexual; Transgender



--Respondents who volunteer another identity (e.g., queer, same-gender-loving; pansexual) are recorded as "Other LGBT" by interviewers. These responses are included in the LGBT estimate.

--Data not collected in 2018 and 2019.

--2012-2013 wording: Do you, personally, identify as lesbian, gay, bisexual or transgender?

GALLUP

Health Disparities within SGM Populations

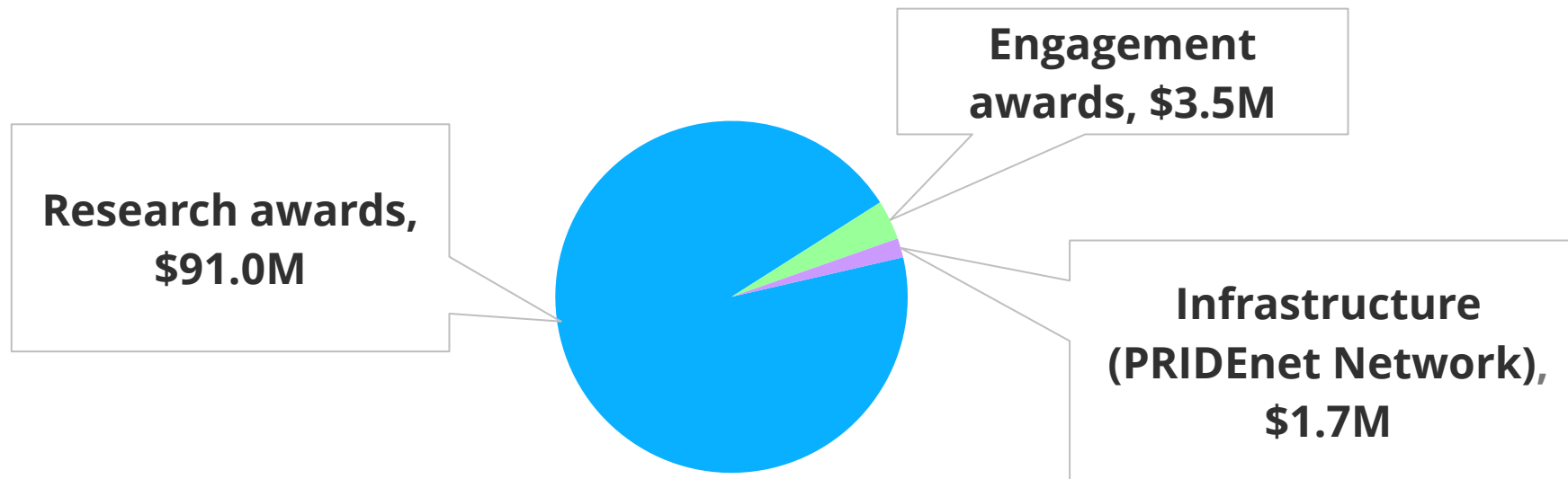
- **Intersectionality**
- Different sub-groups have different disparities ranging from elevated risk for certain infections such as HIV, to increased risk of cardiovascular disease, to elevated rates of depression and suicide
- **Critical gaps** in SGM healthcare and disparities:
 - **Lack of uptake for Sexual Orientation and Gender Identity (SOGI) data collection**
 - Paucity of effective **strategies to reduce adverse effects of implicit bias** among medical/clinical professionals working with SGM populations
 - **Approaches to reduce healthcare disparities across the lifespan**

PCORI's SGM Research and Engagement Portfolio



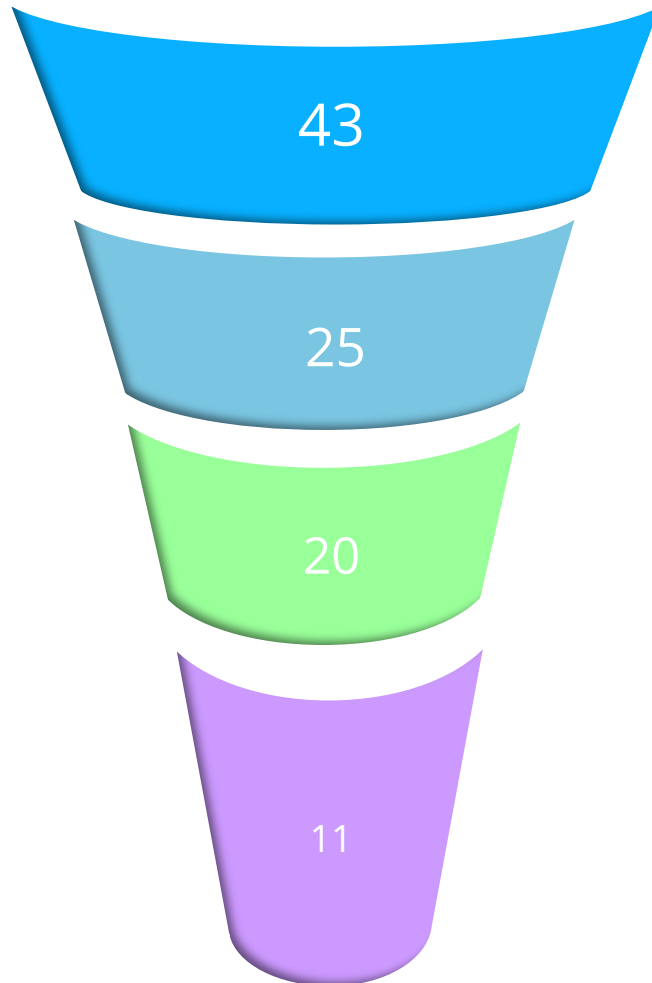
PCORI's Investment in SGM Populations

PCORI HAS AWARDED **\$96.2 MILLION** to fund **43**
COMPARATIVE CLINIC EFFECTIVENESS RESEARCH STUDIES, ENGAGEMENT PROJECTS, AND A PATIENT-
POWERED RESEARCH NETWORK ON OR RELATED TO
SGM HEALTH



*includes projects conducting subgroup analyses in SGM individuals

PCORI's SGM Portfolio: Overview



- Total awards in portfolio

- Awards focused on Healthcare Delivery for SGM populations

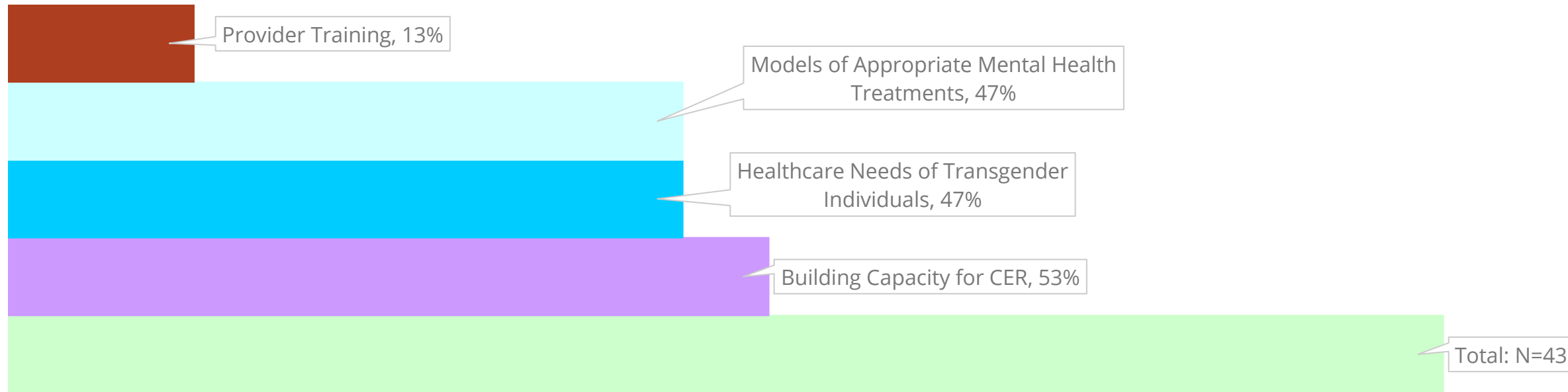
- Awards focused on Mental Health care in SGM populations

- Awards focused on HIV care in SGM populations

**categories not mutually exclusive*

PCORI's SGM Portfolio: Common Themes

Common Themes across Portfolio (n=43)



**categories not mutually exclusive*

Highlighted Study: Examining Health Outcomes for People Who Are Transgender

Study Title: Comparative Risks and Benefits of Gender Reassignment Therapies

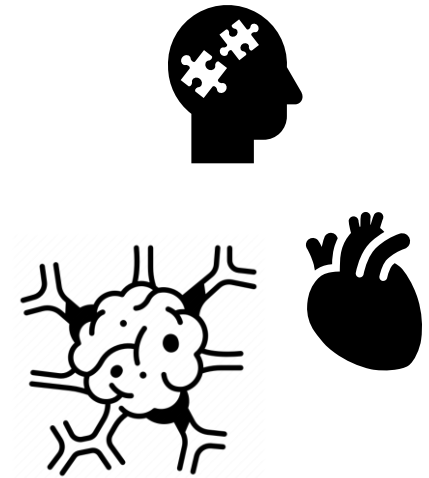
Principal Investigator: Michael Goodman, MD, MPH, Emory University

Study findings:

1. Nearly all mental health conditions were more common among transgender people than cisgender people (who aren't transgender).
2. Compared with cisgender men, transgender women had a lower risk of prostate cancer and a higher risk of cancers that arise from endocrine glands, such as thyroid cancer.
3. Transgender women who received estrogen had a higher risk of blood clots and strokes compared with men and women who aren't transgender. Their risk for blood clots and strokes increased over time.

Study Design: Observational study (cohort and cross-sectional)

This Study of Transition, Outcomes, and Gender (STRONG) cohort represents one of the largest U.S. cohorts of transgender people.





LGBTQ teens are **six** times more likely to experience symptoms of **depression** than their heterosexual counterparts.

Engagement Award for Dissemination

Project Title: Management of Mental Health Problems Among Gender Non-conforming Youth

Project Lead: Michael Goodman, MD, MPH, Emory University

Doctors, family members, and school staff need to know about dangers facing transgender children and adolescents and take steps to reduce these dangers.

Objective: **educate healthcare providers, parents, and school counselors about risks facing transgender children and adolescents**, and to let them know about available ways of reducing these risks.

The project team will work with community partners to develop and distribute educational materials to partner organizations:

- Mental Health Research Network
- World Professional Association for Transgender Health
- American School Counselor Association

Management of Mental Health Problems Among Gender Non-conforming Youth



Project Summary

Background: The project team's recent study, which was supported by the Patient-Centered Outcomes Research Institute, showed that mental health diagnoses were several times more common among transgender children and adolescents than among nontransgender kids of the same age. The results were particularly worrisome for self-injury and suicidal thoughts.

Proposed Solution to the Problem: Doctors, family members, and school staff need to know about dangers facing transgender children and adolescents and take steps to reduce these dangers.

Objectives: The goal of this project is to educate healthcare providers (doctors and nurses), parents, and school counselors about risks facing transgender children and adolescents, and to let them know about available ways of reducing these risks.

<https://www.pcori.org/research-results/2018/management-mental-health-problems-among-gender-non-conforming-youth>

Further CER opportunities in SGM populations



Opportunities for CER

- Based on literature, current portfolio, and stakeholder discussions, three potential areas for comparative effectiveness research were noted:
 - **Testing/evaluating different validated approaches to collecting sexual orientation and gender identity data**
 - **SGM health education and training to address provider discrimination and patient mistrust**
 - **Effective community-based/culturally competent sexual health care management models to either increase engagement in care, and/or focus on sexual health in understudied SGM populations**

Questions to Consider

- In addition to the three areas identified, what are other salient opportunities for meaningful comparative effectiveness research?
- What other stakeholder partners (e.g., patients, clinicians, regulators) are important to engage?
- What is the best way to get the word out among researchers and others working in this population?

Healthcare Delivery and Disparities Research Program Update & Discussion

Steven Clauser, PhD, MPA
Program Director, HDDR

Healthcare Delivery and Disparities Research Team



Steve Clauser,
PhD, MPA
Program Director



Els Houtsmuller,
PhD
Associate Director



Neeraj Arora,
PhD
Associate Director



Allison Ambrosio,
MPH
Associate Director



Carly Khan, PhD,
MPH, RN
Associate Director



Sarah Ruiz, PhD
Senior Program
Officer



Mira Grieser,
MHS
Program Officer



Mari Kimura, MS,
PhD
Program Officer



Andrea Brandau,
MPP
Program Officer



Vivian Towe, PhD,
MSc, MA
Program Officer



Tabassum Majid,
PhD, MAgS
Program Officer



Meghana Aruru,
PhD
Program Officer



Hillary Bracken,
PhD, MHS, MA
Program Officer



Kisha Coa, PhD,
MPH
Program Officer



Kelly Dunham, MPP
Senior Manager,
Strategic Initiatives



Aaron Shifreen,
MBA
Program Manager



Elizabeth Zofkie,
MPH
Program Manager



Jessica Robb,
MPH
Program Manager



Soknorntha Prum,
MPH, Senior
Program Associate



Juliette Price,
MPH
Program Associate



**Brendan
Weintraub, MPH**
Program Associate



Marissa Coyle,
MPH
Program Associate



Avani Hegde,
MPH
Program Associate



**Shreeya
Khatiwada, MPH**
Program Associate



**Marina
Brandman, MPH**
Program Associate



**Louisa Fresquez
Hudson, MS**
Program Associate



Candace Hall,
MA
Program Associate



Ariel Lewis, MPH,
BSN, RN
Program Associate



Natasha Kurien,
MPH
Program Associate



Rachel Kotiah
Sr. Administrative
Assistant



Rachel Barnes
Project Specialist



Charlotte Freifeld
Project Specialist

Welcome New HDDR Staff



Sarah Ruiz, PhD
Senior Program Officer



Mira Grieser, MHS
Program Officer



**Shreeya Khatiwada,
MPH**
Program Associate



Marina Brandman, MPH
Program Associate

HDDR Updates

- Research Awards
- Palliative Care Research Network
- Learning Health Systems
- 2022 PCORI Annual Meeting

Research Awards: Current HDDR Portfolio



PCORI HAS AWARDED OVER

\$1 BILLION TO FUND 282

**COMPARATIVE EFFECTIVENESS STUDIES IN
HEALTHCARE DELIVERY AND DISPARITIES RESEARCH.**

As of May 2022

| Funding Mechanism | # of Projects |
|-------------------|---------------|
| Broad | 205 |
| Pragmatic | 24 |
| Targeted | 50 |
| PLACER | 3 |

New Research Awards

Recent Awards

2

Improving Healthcare Systems
Broad PFA Awards

1

Nonsurgical Options for Women with Urinary
Incontinence Targeted PFA (TPFA) Award

1

Improving Postpartum Maternal Outcomes for
Populations Experiencing Disparities TPFA Award

1

Pragmatic Clinical Studies Award

*AWARDED March 2022

 [See supplemental materials III](#)

Comparing Hospital to Home Transition Interventions for Children with Medical Complexity



- Patrick Brady, MD, MS
- Katherine Auger, MD, MS
- Cincinnati Children's Hospital Medical Center
- Budget: \$2,887,272
 - Compares a GET2HOME intervention to the standard of care hospital-based discharge process.
 - GET2HOME includes a pre-discharge telehealth meeting with the patient family and care team, a visual discharge task tracker to monitor progress, and a post-discharge telehealth meeting.
 - Results will inform future decision-making by clinicians, caregivers, and payers for children with complex chronic diseases to reduce rehospitalizations
 - Stakeholders include caregivers, clinicians, advocates, payers, and research experts

Comparative Effectiveness of Two Approaches to Symptom Monitoring in Hemodialysis



- Jennifer Flythe, MD, MPH
- Laura Dember, MD
- The University of North Carolina at Chapel Hill
- Budget: \$5,711,565
 - Compares SMarRT-HD to the standard of care symptom monitoring
 - SMarRT-HD includes twice monthly electronic symptom monitoring with supported medical provider follow-up
 - Results will inform best practices to monitor and address hemodialysis patient symptoms as well as ways to use patient-reported outcome measures in routine dialysis care
 - Stakeholders include patients, nephrologists, nurses, social workers, Centers for Medicare and Medicaid Services (CMS), and leading organizations in dialysis

Pragmatic Trial to Enhance Quality, Safety, and Patient Experience in COPD – EQuIP COPD



- David Au, MD, MS
- Lucas Donovan, MD, MS
- VA Puget Sound Health Care System
- Budget: \$9,085,333
 - Compares proactive population management recommendations for chronic obstructive pulmonary disease (COPD) by clinical pharmacists to proactive population management recommendations for COPD by pulmonary specialists
 - Pharmacists and pulmonologists will review patient files, detail rationale and recommendations, and create draft orders that primary care providers can endorse, modify, or delete
 - Results will inform population management of COPD by pharmacists to improve quality of life and care
 - Stakeholders include the Seattle-Denver Veteran Engagement Group and an advisory board composed of veteran patients/caregivers and national VA policy leaders in pulmonary, pharmacy, and primary care

Trauma-Informed Approach to Timely Detection and Management of Early Postpartum Hypertension



- Rafael Perez-Escamilla, PhD
- Heather Lipkind, MD
- Yale School of Public Health
- Budget: \$20,444,441
 - Compares standard of care to a remote medical model and a community health model
 - Standard of Care includes guideline-based care and anti-racism training for providers
 - Remote Medical Model includes remote blood pressure monitoring, weekly telehealth visits, and screening, referral, and treatment for mental health, blood pressure, and social needs
 - Community Health Model includes all the above with weekly visits by community health workers or doulas
 - Results will inform professional guidelines, coverage, and decisions to implement telemedicine postpartum and improve maternal outcomes
 - Stakeholders include payers, providers, hospital representatives, health administrators, and maternal health stakeholders at the local, state, and national level

Comparative Efficacy of Advanced Practice Provider Co-Management vs. Electronic Decision Support in Improving Incontinence Outcomes in a Diverse Population of Aging Women



- Jennifer Anger, MD, MPH
- University of California San Diego
- Budget: \$5,896,843
 - Compares electronic co-management to advanced practice provider (APP) co-management
 - Electronic Co-Management includes an electronic referral system in which specialists can review referrals and make recommendations if more primary care is needed before referral
 - APP Co-Management includes urinary incontinence (UI) care, patient education, and bilingual televisit-assisted patient self-management
 - Results will inform high-quality UI care in primary care as well as address disparities experienced by low-income Hispanic women receiving UI care
 - Stakeholders include patients, caregivers, primary care providers, specialists, policymakers, health systems, and national primary care organizations

Palliative Care Learning Network



- HDDR has created a learning network including several multi-site palliative care CER studies focused on models of palliative care delivery and advance care planning.
- Network goals: foster co-learning across awardee teams; facilitate collective success of the projects; contribute to the field via joint presentations and publications.
- 2021-2022 Network activities:
 - Winter 2022
 - PIs met with representatives from the Center for Medicare & Medicaid Innovation to discuss preliminary lessons learned from conducting large multisite palliative care trials.
 - Study team Biostatisticians meeting provided an opportunity to collectively discuss strategies for quantifying and accounting for the impact of COVID-19 on each study and to identify potential common solutions.
 - Upcoming convenings:
 - PI meeting planned for late Spring 2022.
 - In addition to larger convenings, regular conference calls among investigators and project managers are organized by HDDR and contractor staff to foster continued engagement and co-learning across the network.

Learning Health Systems (LHS) Initiatives



- *Agency for Healthcare Research and Quality (AHRQ)/PCORI Learning Health System Training program (K12):*
 - Year 4 of 5, \$40M initiative to train next generation of PCOR professionals
 - Interim Evaluation Findings:
 - Strong scholar and mentor participation
 - Development of robust LHS training curricula
 - Significant accomplishments and career advancement for scholars
 - Addition of healthcare equity and justice as core competency of LHS training based on input from Centers of Excellence Learning Collaborative
 - Health system engagement and support for research

- Goal of second phase of LHS Training Program: support institutions to produce next cadre of embedded LHS researchers and scientists with skills to conduct, apply, and implement PCOR to empower equitable whole-person care across the lifespan, to improve system operations, quality, and health outcomes.
- Each grant will consist of distinct components that will be evaluated in review process, such as governance, research and data; training; dissemination and implementation; and evaluation
- Research cores will focus specifically on AHRQ/PCORI primary care priorities, including improving health equity, primary care, maternal mortality and morbidity, Intellectual and Developmental Disabilities (IDD), and use of data resources like PCORnet.

- Program scholar diversity will be increased, and partnerships will be expanded to include minority-serving institutions and federally qualified health centers and health systems committed to serving underserved populations.
- LHS 2.0 approach will yield greater opportunities for awardees to execute robust embedded LHS research, transition to PCORI and AHRQ research funding mechanisms, and directly engage system's stakeholders, with opportunities for co-sponsorship.

2022 PCORI Annual Meeting



**Wednesday, October 26 –
Thursday, October 27, 2022**

In-Person and Virtual

End of Day Check-In



www.menti.com



Survey



Wrap-Up and Next Steps

Alicia Arbaje & Jane Kogan
HDDR Advisory Panel Co-Chairs

Steven Clauser
Program Director, Healthcare Delivery
and Disparities Research Program

Meeting Adjourned

