

PCORI Advisory Panel on Healthcare Delivery and Disparities Research

Winter 2021 Meeting

December 9, 2021



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.
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COI Statement



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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 & Introductions

Panel Leadership



- **Alicia Arbaje, MD, MPH, PhD**
HDDR Advisory Panel Co-Chair
- **Jane Kogan, PhD**
HDDR Advisory Panel Co-Chair
- **Carly Khan, PhD, RN, MPH**
Associate 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 (New Panelist)**
President, Sick Cells
- **Brandi Ring, MD, FACOG, FAWM** Baylor
College of Medicine, Texas Children's Hospital
- **Diana Cejas, MD, MPH (New Panelist)**
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
- **Kelly Buckland, MS (New Panelist)**
Senior Advisor on Disability to the Assistant
Secretary for Policy at the US Department
of Transportation

HDDR Advisory Panel Members



- **Kristina Cordasco, MD, MPH, MSHS** VA Health Services Research Center for the Study of Healthcare Innovation, Policy and Practice
- **Marissa D. Sanders, MPH, CPHRM** Manager, Quality Assessment, American Dental Association
- **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)

- 11:15AM HDDR Program Updates and Discussion
- 12:00PM Lunch Break
- 12:30PM Improving Hypertension Management and Control
- 1:15PM Social Needs Interventions: New Interactive Evidence Map
- 2:00PM Break
- 2:15PM Achieve Health Equity: Community-Driven Research Approaches
- 3:15PM Strategic Planning: Research Agenda
- 3:45 PM Wrap-Up and Next Steps
- 4:00PM Adjourn



See supplemental materials I

Healthcare Delivery and Disparities Research Program

Update & Discussion

Carly Khan, PhD, RN, MPH

Associate Director, Healthcare Delivery and Disparities Research

Healthcare Delivery and Disparities Research Team



Steve Clauser,
PhD, MPA
Program Director



Els Houtssteller, PhD,
Associate Director



Neeraj Arora, PhD
Associate Director



Allison Ambrosio,
MPH
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Carly Khan, PhD,
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Meghana Aruru,
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Senior Manager,
Program Officer



Kelly Dunham, MPP
Strategic Initiatives
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Aaron Shifreen,
MBA,
Program Manager



Elizabeth Zofkie
MPH
Program Manager



Jessica Robb, MPH, Soknornthra Prum,
MPH, Senior
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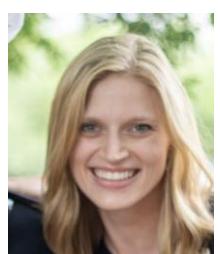
Soknornthra Prum,
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Program Associate



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Natasha Kurien, MPH,
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Rachel Kotiah,
Sr. Administrative
Assistant



Rachel Barnes,
Project Assistant



Charlotte Freifeld,
Project Assistant

Welcome New HDDR Staff



**Kisha Coa, PhD,
MPH,
Program Officer**



**Jessica Robb, MPH,
Program Manager**



**Louisa Fresquez
Hudson, MS,
Program Associate**



**Ariel Lewis, MPH,
BSN, RN
Program Associate**



**Natasha Kurien, MPH,
Program Associate**

HDDR Updates

- Research Awards
- Palliative Care Research Network
- Priority Initiatives
 - Maternal Morbidity and Mortality
 - Intellectual and Developmental Disabilities
- 2021 PCORI Annual Meeting

Research Awards: Current HDDR Portfolio



**PCORI HAS AWARDED OVER
\$1 BILLION TO FUND 277
COMPARATIVE EFFECTIVENESS STUDIES IN
HEALTHCARE DELIVERY AND DISPARITIES RESEARCH.**

As of December 2021

Funding Mechanism	# of Projects
Broad	203
Pragmatic	23
Targeted	48
PLACER	3

New Research Awards



Recent Awards

4

Improving Healthcare Systems
Broad PFA Awards

11

Addressing Disparities Broad PFA Awards

3

Phased Large Awards for Comparative
Effectiveness Research (PLACER)

4

Suicide Prevention (Brief Interventions for
Youth) Awards

2

Pragmatic Clinical Studies Awards

*AWARDED July,
September, & December
2021



See supplemental materials III

Social Determinants of Health



- **Vida Sana y Completa Trial: Treating Obesity and Food Insecurity Among Latina Women**
 - Lisa Rosas, PhD, MPH
 - Board of Trustees of the Leland Stanford Junior University
 - Budget: \$4,246,721
 - Compares two approaches to addressing obesity and food insecurity among Latina women in primary care: Vida Sana (obesity intervention) or Vida Sana y Completa (with intervention for food insecurity).
 - Stakeholders include patients, providers and healthcare system leaders.
 - **Effectiveness of Mode of Meal Delivery on the Ability of Homebound Older Adults to Remain in the Community**
 - Kali Thomas, PhD
 - Brown University School of Public Health
 - Budget: \$4,053,786
 - Evaluates the most effective and preferred type of meal delivery for older adults to improve quality of life and help them remain in their community.
 - Will inform patients, families, and healthcare entities that contract organizations for patient meal delivery
 - Stakeholders include Meals on Wheels, meal delivery drivers, patients and geriatric clinicians.

Suicide Prevention TPFA:

Comparative Effectiveness of Two Culturally Centered Suicide Interventions for Alaska Native Youth



- Elizabeth D'Amico, PhD
- RAND Corporation
- Budget: \$8,577,038
 - Proposes to adapt Qungasvik Prevention model with Motivational Interviewing Social Network intervention as brief intervention for Alaska Native youth at high risk for suicide.
 - Will inform communities on how to use culturally-centered interventions to unlock local support networks that impact suicide behavior and associated risk and protective factors to improve individual outcomes
 - Tribal Oversight Groups guide research planning, conduction, and dissemination
 - Regional “wellness teams” will inform cultural adaptations and norms, measurements, recruitment, and community engagement

Pragmatic Clinical Studies: Comparative Effectiveness of Online Cognitive Behavioral Therapy vs. an Online Single-Session Pain Relief Skills Class of Chronic Pain



- Beth Darnall, PhD
- Stanford University
- Budget: \$10,321,008
 - Compares online cognitive behavioral therapy and online “Empowered Relief” sessions in patients with a variety of chronic conditions across the US, including older adults with Medicare/Medicaid, racial and ethnic minorities, and individuals living in rural areas
 - Results will inform shared decision-making, provide data on pain treatment dose frequency, advise national policy, and help patients choose the best pain treatment while reducing financial burden for low-income communities.

PLACER: Specialty Compared to Oncology Delivered Palliative Care for Patients with Acute Myeloid Leukemia (SCOPE-Leukemia)

- Areej El-Jawahri, MD
- Massachusetts General Hospital
- Budget: \$20,123,944
 - Compares two palliative care delivery models at 20 Palliative Care Research Cooperative sites to investigate patient quality of life and facilitators and barriers to each care model's implementation
 - Answers critical questions of how to best address palliative care needs of patients with cancer and their caregivers, and provide data on how healthcare systems can ensure availability of optimal palliative care services for their patients

Palliative Care Learning Network



- HDDR has created a learning network of nine multi-site palliative care CER studies funded in FY2017; total investment of about \$81 million
 - Six studies focus on models of palliative care delivery and three focus on 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
- Recent network activities:
 - Spring 2021
 - Meeting including biostatisticians from each study team provided opportunity to collectively discuss strategies for quantifying and accounting for COVID-19 impact to data and analytic plan for each study, and identify potential common solutions
 - Attendees requested follow-up meeting, now planned for Spring/Summer 2022
 - Upcoming convenings:
 - Planning meeting with Center for Medicare & Medicaid Innovation and PIs to discuss preliminary lessons learned from conducting large multisite palliative care trials
 - Next annual PI convening scheduled in January 2022
 - In addition to larger convenings, regular conference calls among investigators and project managers organized by PCORI will foster continued engagement and co-learning across network of study teams.

Maternal Morbidity and Mortality

Black Midwives for Black Women: Maternity Care to Improve Trust and Attenuate Structural Racism



- Kylea Liese, PhD, CNM
- University of Illinois
- Budget: \$9,998,635
- Potential Impact
 - Evaluates model of care consisting of evidence-based components designed to address health inequities in maternal mortality and morbidity with potential utility in other underserved communities (e.g., Native American/American Indian)
 - Study is highly relevant given anticipated changes in federal and state funding for maternal health
 - Study could improve health outcomes for Black women using multicomponent model of care designed to address existing health inequities across pregnancy and postpartum continuum
- Engagement
 - Strong engagement among project team and community advisory board members, including 12 Black mothers who experienced high-risk pregnancies
 - Collaboration between local and regional groups to facilitate community-based in-home visitation component of intervention

Intellectual and Developmental Disabilities

Improving the Health of Adolescents and Transition-Age Youth with IDD



- Kathleen Thomas, PhD, MPH
- University of North Carolina
- Budget: \$4,249,956
- Potential Impact
 - Study compares two peer group interventions for parents of youth with IDD: one that focuses on support and information sharing and one that adds advocacy skills training. Outcomes are measured in youth (social functioning and depression) and parents (stress, depression).
 - Caregiver support has been raised repeatedly by stakeholders as high priority
- Engagement
 - Collaboration with parents of youth with IDD in the development of research plan
 - Longstanding collaboration with providers in IDD specialty clinics

Highlights from the 2021 PCORI Virtual Annual Meeting



- Focus on PCORI's proposed National Priorities for Health and COVID-19 Pandemic
- HDDR staff organized breakout sessions on
 - COVID-19 and Dementia Care
 - Meaningful Stakeholder Engagement for Equitable Maternal Health Outcomes
 - Identifying Priorities for Research on Healthy Aging
 - Collecting Sexual Orientation and Gender Identity Data to Reduce Health Disparities
 - Engaging People with Intellectual and Developmental Disabilities in Research
- Poster sessions included many HDDR awardees

Discussion

Q&A

Lunch Break

Improving Hypertension Management and Control

Hillary Bracken, PhD, Program Officer, HDDR
Els Houtsmuller, PhD, Associate Director, HDDR



Hypertension



- Hypertension (systolic blood pressure (BP) $\geq 130\text{mmHg}$ or diastolic BP $\geq 80\text{mmHg}$ or taking medication for hypertension) affects
 - 49% of US adults and
 - 57% of Non-Hispanic Black adults
 - Significant heterogeneity in Hispanic and Asian sub-populations

Health Problems Caused by Hypertension

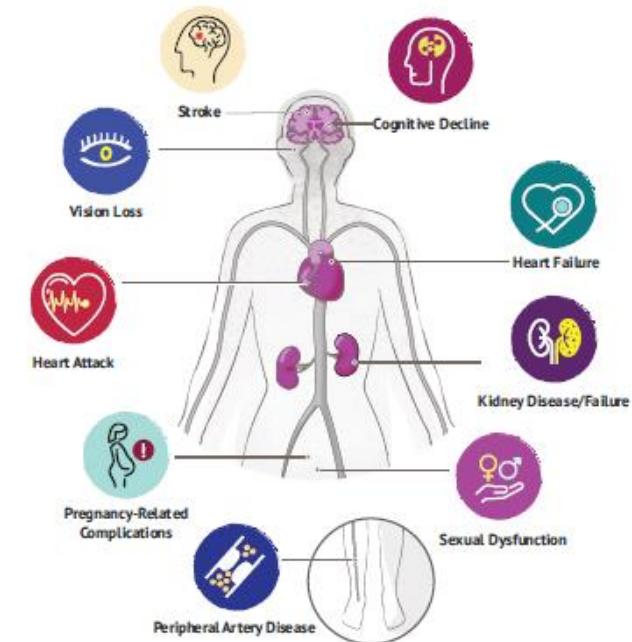


Image Source: USDHHS. Surgeon General's Call to Action on Hypertension, 2020.

Reference: [NCHS 2019](#), [CDC 2021](#)

Effective Interventions to Reduce BP, CVD Events and Mortality



- *Pharmacological*
 - Lipid-lowering and antihypertensive drug therapies for primary prevention
- *Non-pharmacological*
 - Lifestyle interventions for cardiovascular preventive treatment
 - Smoking cessation
 - Weight loss, DASH diet

Blood Pressure Control



- Despite the availability of proven approaches to lower BP, only about **1 in 4 adults** with hypertension have their condition under control¹ (CDC 2021)

[1] Controlled is defined as having a BP<130/80. CDC 2021.

Disparities in Rates of Blood Pressure Control Persist



- Rates of BP control have declined overall since 2000 with greatest declines in people of color, people without health insurance, or people without access to care. In 2018, BP was controlled in [1]
 - 8% of patients who did not report seeing a healthcare provider in the last 12 mos. vs. 47% of patients who reported seeing a healthcare provider
 - 22% of uninsured patients compared to 40-46% of patients with some form of health insurance
- National surveys show BP control is higher among non-Hispanic white adults (56%) than in non-Hispanic Black adults (49%) or Hispanic adults (47%) [2]

[1] Control defined as BP<140/90 mmHG. Muntner et al. "Trends in blood pressure control among US adults with hypertension, 1999–2000 to 2017–2018." *JAMA*. 2020

[2] NHANES survey data. Control defined as BP<130/80 [CDC, 2021](#)

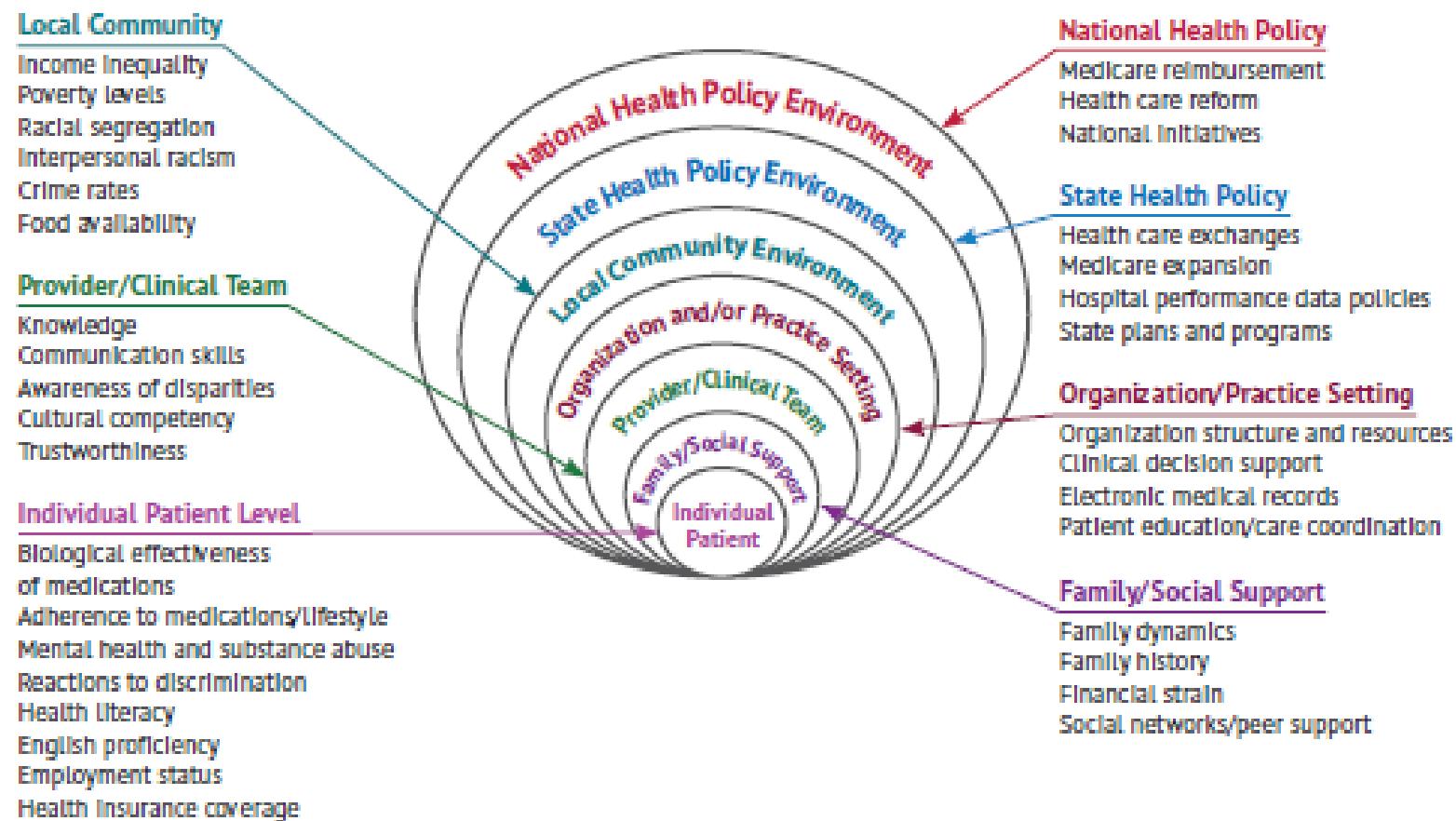
“Thus, after years of declining CVD mortality due to the broad uptake of pharmacotherapy and smoking cessation among advantaged populations, **the recent decline in the pace of progress may reflect the failure to invest adequately in closing the prevention and treatment gap among high-risk populations.**

-- NASEM, *High and Rising Mortality Rates Among Working-Age Adults*, 2021

Barriers to Eliminating Disparities in Hypertension are Complex



Figure 4. Multilevel Influences on Disparities in Hypertension Prevention and Control



Source: Mueller et al. "Reducing Racial and Ethnic Disparities in Hypertension Prevention and Control: What Will It Take to Translate Research into Practice and Policy?", *American Journal of Hypertension*, Volume 28, Issue 6, June 2015, Pages 699–716,

Strategies for Improving Hypertension Management



- Improving ***awareness***
 - The % of people who have hypertension and know they have it
- Improving ***treatment***
 - The % who have hypertension and are receiving recommended care
- Improving ***control***
 - The % who have hypertension and whose blood pressure has been lowered below specified thresholds

Interventions to Address Disparities in Hypertension Management and Outcomes



Individual-level interventions

- Strategies to improve adherence to pharmacotherapy protocols (e.g., education, cell phone applications, self-monitoring of BP and medication intake) and improve adoption and participation in lifestyle interventions for CVD preventive treatment

System and organizational interventions

- Practice facilitation, patient/clinical registries, data accountability measures such as equity dashboards, and clinical decision support tools
- Care coordination, team-based care, community health workers or pharmacists, and other community-based care models
- Low or no medication copayments; fixed-dose combination medications with low or no copayments; 90-day supply or longer medication fill supply
- Telehealth
- Race-concordant care and strategies to address implicit bias among healthcare workers

Population-level interventions

- Policies and strategies to address social needs and social determinants of health and/or environmental and policy-level barriers (e.g., health insurance)

Example CER Question: Management



- **What is the comparative effectiveness of community-based multilevel care models for blood pressure management on health and patient-centered outcomes?**
 - ***Patients with multi-morbidity*** (i.e., two or more chronic conditions)
 - ***Tailored interventions*** for communities experiencing the greatest disparities in hypertension outcomes (e.g., Black, AI/AN, Hispanic, rural, or uninsured individuals)
 - **Care models including**
 - Community health care workers and/or team-based care
 - Strategies to address social needs (e.g., active vs passive assistance) and/or healthcare-community or multi-sectoral partnerships to improve hypertension health and patient-centered outcomes

Example CER Question: BP Assessment



- **What is the comparative effectiveness of different strategies for BP assessment for diagnosis and management of hypertension?**
 - *Diagnostic confirmation*
 - *Management*
 - **Care models including**
 - Self-monitoring and/or monitoring with support by community health worker, nurse, or pharmacist
 - Use of manual or smart blood pressure monitors and automatic or self-report of BP monitoring data
 - Timing and mode of follow-up (office, telehealth, phone)
 - Impact on medication adherence, medication titration, duration of blood pressure control, and long term (>1 year) health outcomes

Example CER Question: Treatment



- **What is the comparative effectiveness of different BP treatment protocols?**
 - ***Pharmacological***
 - **BP thresholds and targets** for drug treatment in **younger hypertensive patients**
 - **Single-pill vs. multidrug treatment strategies** for adherence to treatment, BP control, patient-centered and clinical outcomes especially in individuals with complicated hypertension or blood pressure more than 20/10 mmHg over their goal blood pressure
 - ***Non-Pharmacological***
 - **Combinations of non-pharmacological treatments** (e.g., aerobic exercise, DASH diet, salt restriction, resistance training) for secondary BP endpoints (e.g., rate and duration of BP control and mortality due to complications of hypertension).
 - **Intervention specialist** (doctor, nurse, community health worker, peer)

Discussion Questions



Discussion Questions



- Which CER question is the most relevant?
 - Multi-level community-based management care models for populations experiencing disparities?
 - BP assessment for diagnostic confirmation and treatment?
 - Treatment?
- Which outcomes are most important to consider when considering 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 hypertension that you would like to bring up?
- Are there specific stakeholders, either individuals or organizations, that you would recommend we speak with?

Thank You!

Appendix: Hypertension - A Note on Definitions



- In 2017, ACC and AHA published new guidelines for hypertension management and defined hypertension as a BP at or above 130/80 mmHg.
 - ↓ diagnosis BP cutoff
 - ↓ treatment threshold for therapy
 - ↓ goal BP in those who qualify for therapy
- However, some US and international professional guidelines and clinical quality improvement measures maintain definition of controlled < 140/90 mmHg

2017 ACC and AHA Guidelines		
Blood Pressure Category	Systolic BP	Diastolic BP
Normal	< 120 mmHg AND	<80 mmHg
Elevated	120-129 mm Hg AND	<80 mmHg
Hypertension		
Stage 1	130-139 mmHg OR	80-89 mmHg
Stage 2	≥ 140 mmHg OR	≥ 90 mmHg

New PCORI Evidence Map

Social Need Interventions to Improve Health Outcomes

Michelle Althuis

Associate Director, Research Synthesis and New Technology

Rachael Parsons

Program Associate, Research Synthesis and New Technology



Outline of Discussion



1. Project history
2. Scope and project description
3. Presentation of the interactive evidence map
 - Evidence map features and capabilities
 - Using the evidence map to answer questions
 - ✓ Distributions and trends
 - ✓ Volume of research that could contribute to a more robust synthesis
4. Summary and discussion of your thoughts

Project History: Nomination and Project Team



- Topic was nominated by PCORI Payer Forum members
- All-star project team includes
 - Research synthesis methodologists and social needs experts
 - Visual journalists and interactive-media experience specialists
- Technical experts engaged throughout the process



Scope of Project



- Interactive repository of eligible primary studies assessing social needs interventions that ***evaluate health outcomes***
 - Displays eligible studies according to:
 - ✓ Population, intervention, outcomes
 - ✓ Study quality
 - ✓ Directionality of findings
 - Health and healthcare utilization outcomes
 - Includes 139 studies of 165 social needs interventions (last literature search 3/2021; update ongoing)

Social Needs Interventions



Address adverse social conditions that are:

1. Associated with poor health and
2. Identified or prioritized based on the patients' perspective

Eligible Social Needs Interventions



early childhood development
social isolation
legal services
employment
food insecurity
interpersonal violence
healthcare services
childcare financial strain
education
housing
transportation
utilities

Why Is This Work Important Now?



- Importance of studying social needs interventions
 - Improve health outcomes for vulnerable populations
 - Reduce disparities
 - Potentially without increasing healthcare costs

Underlying Evidence Synthesis Methodology: Scoping Review



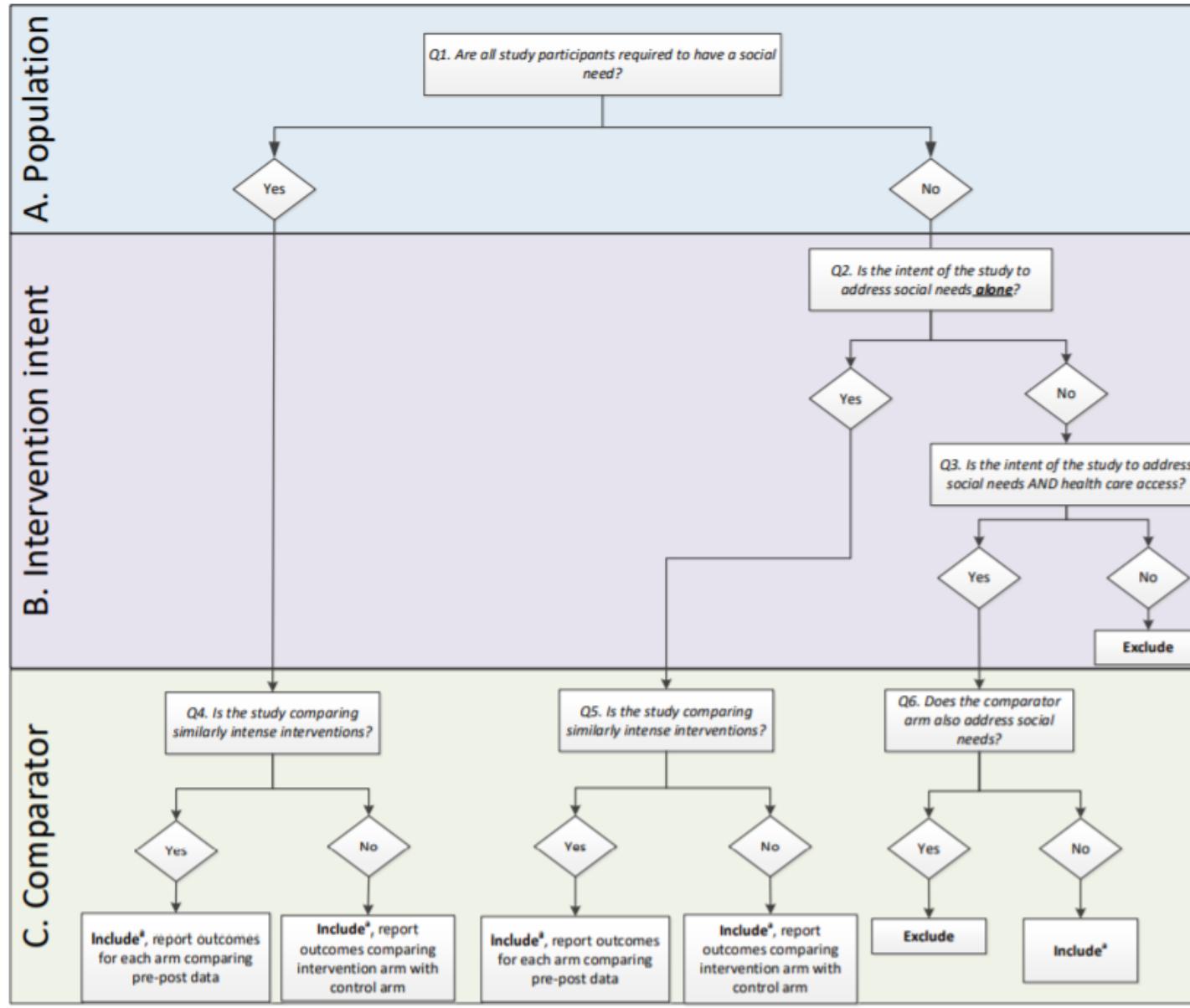
- A scoping review uses systematic methods to outline the scope and characteristics of the evidence and identify evidence gaps, ***but it stops short of full synthesis.***
- The scoping review serves as the foundation for:
 - Web-based interactive evidence map
 - Other products, including full systematic reviews on specific populations or interventions, that are important to synthesize.
- Technical Experts reviewed Research Questions, Protocol and Final Report
 - UPMC Center for High Value Health Care
 - Tufts University
 - Boston University School of Medicine
 - Health Care Cost Institute

Underlying Evidence Synthesis Methodology: Additional Details



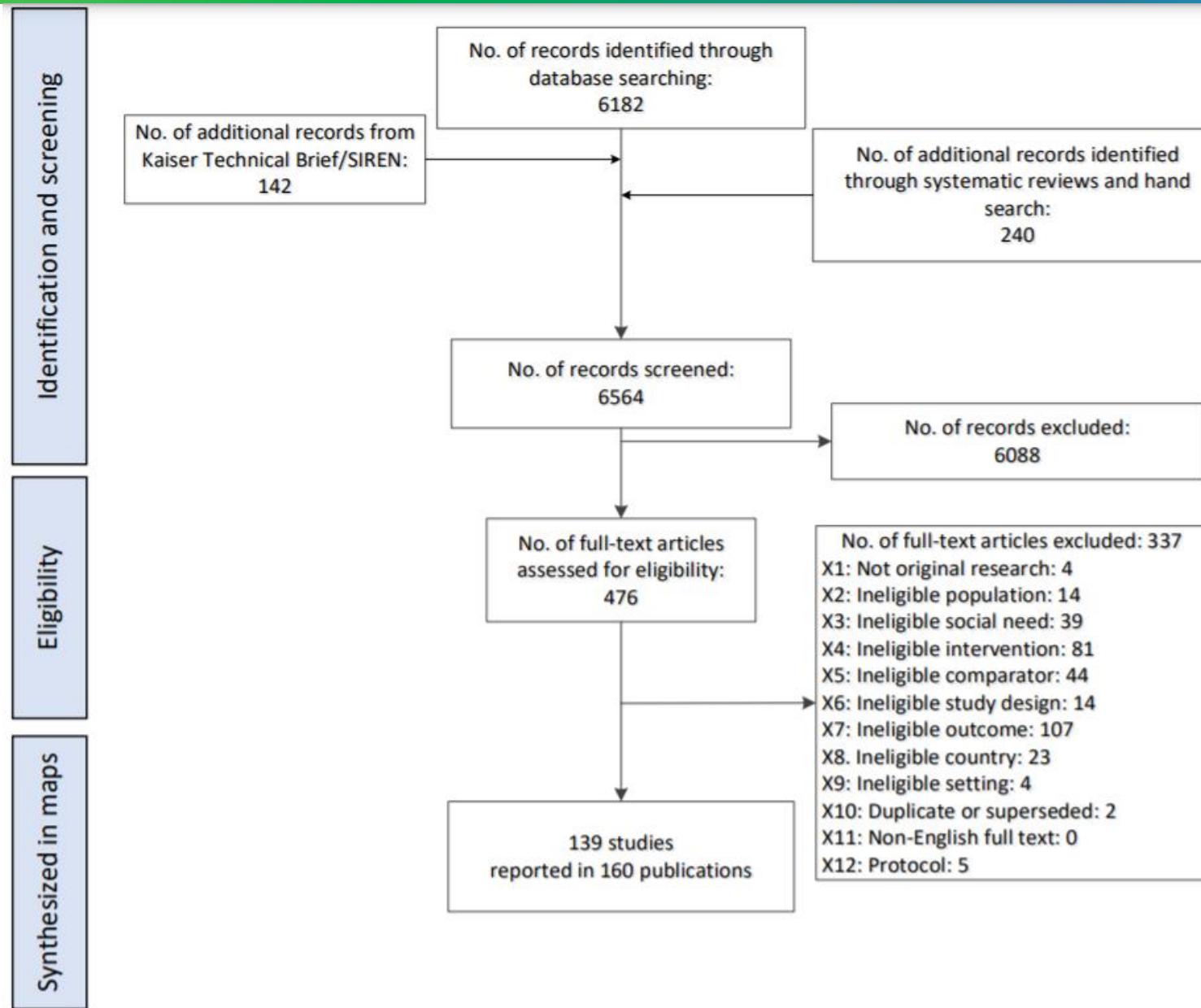
- Dual screening for inclusion of studies where the *intent* was to address social needs
 - Recruited participants with social needs or intervention designed to address needs
 - Permitted conclusions about effect of intervention on health outcomes
- **Adjustment** (altering clinical care to accommodate social barriers) and **assistance** (connecting patients with social care resources) interventions
 - Individual or healthcare system level
- Studies rated for quality using Cochrane risk of bias or ROBINS-I tools, except for studies evaluated as pre-post designs
- Directionality for results of individual outcomes
 - Example: study reports consistently positive and statistically significant results favoring experimental arm, review team reported result as positive

Inclusion and Exclusion Flow Diagram



*if study meets all other eligibility criteria.

Flow Chart for Article Inclusion



Project Innovation: Novel Visual



- Interviews with potential end users to ascertain
 - how the map might be used
 - types of questions the map should answer
- Two rounds of usability testing of the visual which involved both information-seeking and information-understanding tasks
 - Version 1 with 12 users: moderate-to-high graph literacy and internet experience
 - Version 2 with 42 users: 22 novices & 20 professionals with significant experience in conducting or consuming research on social determinants of health

TRANSITION: Evidence Map Features and Capabilities



pcori PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

EVIDENCE MAP
SOCIAL NEEDS INTERVENTIONS TO IMPROVE HEALTH OUTCOMES

Visualization About this evidence map

Refine data by

- Social need addressed
- Study population recruited
- Study design
- Study quality
- Intervention setting

Display by

- Population characteristics
- Type of outcome

 You'll see this icon often in this application. Clicking on it will bring up the list of studies that fulfill the options you've chosen on the menus above.

This evidence map contains information about **139 studies** on social needs interventions. **Each dot represents a study.**
The filters to the left let you show or hide studies, sort them, and color code them.
Hover over a dot to see the title of the corresponding study.
Click on any dot to see detailed information about the study.

Data last updated 3/5/2021.

Social need addressed

Social need addressed	Number of studies	View details
Childcare assistance	8	
Early childhood education and development access and quality	7	
Education assistance	25	
Employment assistance	35	
Financial strain assistance	25	
Food security assistance	35	

Summary Take Home



- Research on social needs interventions is accumulating rapidly.
- The interactive map seeks to curate studies of social needs interventions that report health outcomes.
- This repository aspires to accelerate research on social needs interventions and health equity by providing easy access to the entire body of research studies.
 - ✓ Future evidence synthesis products
 - ✓ Inform future funding opportunities and support our National Priorities

Your Thoughts!



- What are your reactions?
- Are there any questions we should consider for formal synthesis, such as a systematic review?
- What ideas do you have for improving utility of the interactive map?
- What other topics might benefit from a similar product?

Break



Achieve Health Equity: Community-Driven Research Approaches

Developing Novel Funding Models

Kelly Dunham, Senior Manager
Lisa Stewart, Senior Engagement Officer

 See supplemental materials IV



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

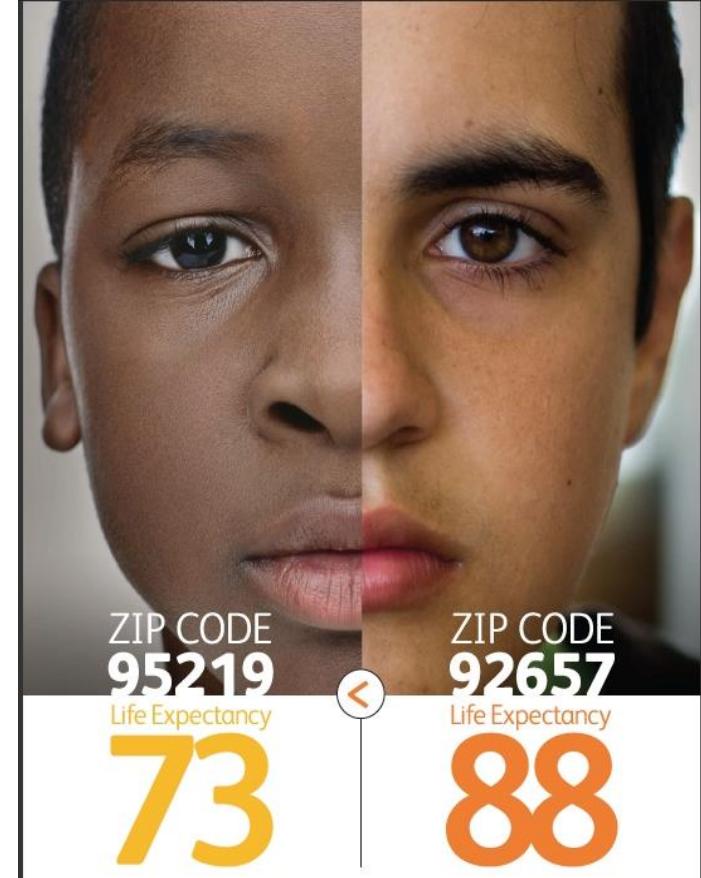


Image from "Health Happens Here" campaign, sponsored by The California Endowment

Entry points for comparative effectiveness research

Population-based interventions to address SDOH and system inequities (e.g., food insecurity, unstable housing)

Organizational interventions to address organizational processes (e.g., team-based care, telehealth)

Individual interventions to address behaviors or management of specific conditions (e.g., peers, social media)



A call for funders to move upstream: National Academies of Science, Engineering and Medicine (NASEM) Consensus Reports



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

- Support **transdisciplinary research approaches** to generate evidence on approaches for advancing equity
- Support community capacity building and prioritize equity in the SDOH through **investments in low-income and minority communities**

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

- Support 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**

What types of funding models are needed to “achieve health equity?”



Our opportunity:

- To provide evidence and stimulate uptake on strategies for advancing health equity for **underserved communities** in the United States

Considering an “enhanced program” or “community-driven research collaborative” approach:

- Risk may not be suitable to existing award mechanisms
- Need to integrate research, training, and community engagement to enhance learning
- Specialized training and investment may be needed for communities and investigators
- Need for multiple awards to develop a learning community of investigators and stakeholders to advance science and practice

Potential structure and mechanisms:

- Establish several collaboratives to support research that enhances health equity by reducing health disparities in the context of issues of racism, discrimination, and bias
- Collaboratives would include “cores” to support shared governance, community engagement, research operations, and training/capacity building
- Collaboratives could be supported by a coordinating center and external advisory group to extend learning, coordination, and impact
- Consideration of a multi-phase model (e.g., partnership to research project)

Considering the broader landscape: Stakeholder engagement to date



- **Multi-stakeholder panels (May-November 2021)**
 - Advisory Panel on Healthcare Delivery and Disparities Research
 - Advisory Panel on Patient Engagement
 - Health Equity Breakout Session, PCORI Annual Meeting
- **Payers (October-November 2021)**
 - PCORI Payer Forum
 - Medicaid Medical Directors
- **Funders (July-October 2021)**
 - National Institute on Aging (NIA)
 - National Heart, Lung, and Blood Institute (NHLBI)
 - VA Center for Health Equity Research and Promotion (CHERP) and VA Health Services Research & Development Service (HSR&D)*
 - NIH Community Engagement Alliance (CEAL) Against COVID-19 Disparities*
 - National Cancer Institute (NCI)*
 - National Institute of Minority Health and Health Disparities (NIMHD)*
 - Robert Wood Johnson Foundation*

* Key informant interview conducted by Marshall Chin

Takeaways from early stakeholder discussions



Element	Considerations
Overall design	<ul style="list-style-type: none">• Geographical context is crucial – e.g., Appalachia, urban neighborhoods• Incorporate training for researchers and community partners• Foster collaboration and communication across centers- e.g., working groups, frequent meetings, supplemental awards for cross-center projects• Consider follow-on implementation awards for research
Speed and innovation	<ul style="list-style-type: none">• Fund research beyond the traditional model, e.g., pilot funding, feasibility phase, and designs beyond RCTs• Consider rapid funding not tied to cycles and higher risk projects
Partnerships and balance of power	<ul style="list-style-type: none">• Fund transdisciplinary research which moves beyond discipline-specific approaches• Consider who is at the table from the start (intersectoral partnerships)• Rules, structure, and funding should incentivize partners to effectively collaborate
Research focus	<ul style="list-style-type: none">• Guided by community identification of needs and solutions• Requirement of conceptual model that recognizes multifactorial factors and levels• Consider type of evidence needed to impact policy and community outcomes

Addressing structural inequities in research: Feedback from the PAM Health Equity Breakout session



- Funders (PCORI) have an opportunity to advance equity through structural adjustments
 - Co-governance / Shared Leadership with Stakeholders
 - Consideration of multiple contracts to ensure financial equity and power sharing
 - Transparency and deeper involvements in the operations of research projects and programs
 - Include time for trust building and capacity building - need to go beyond research project needs
 - Locate research outside of academic centers and into community settings

["Envisioning the Next Phase of Health Equity Research at PCORI"](#)

November 17, 2021

- Lisa Goldman Rosas, PhD, MPH
- Sinsi Hernandez-Cancio, JD
- Benjamin Henwood, PhD, LCSW
- Tung Nguyen, MD
- Ashley Valentine, MRes
- Nina Wallerstein, DrPH, MPH

Moving upstream

Considering our approach



How do we get there? Consideration of a multi-phase model to foster community-driven collaboratives



Phase 1: Partnership

Lays the foundation for collaboration and ensures that partners have the capacity for subsequent phases



Phase 2: Priority Setting

Building on Phase 1, collaborative identifies gaps and research priorities



Phase 3: Research

Collaborative implements comparative effectiveness research projects on priorities identified in Phase 2, may include a feasibility phase

- Funding could be released as the collaborative completes each phase and demonstrates potential and plans for the next phase (e.g., capability, need, as the collaborative completes research protocol, etc.)

Example research topics

Specific interventions would be driven by communities



Research topics would address at least one (preferably more) of the nine NASEM-identified SDOH—education, employment, health systems and services, housing, income and wealth, physical environment, public safety, social environment, and transportation—and be:

- community-driven;
- multi-sectoral; and
- evidence-informed

Examples of potential research topics:

- Studies that compare ways to increase equitable use of community resources, including exercise facilities, greenspace, biking and walking paths, and healthy food options to improve cardiovascular health
- Studies that compare community-based approaches to increase access to healthy food and social care resources through partnerships to improve diabetes
- Studies that compare approaches to improve healthcare access to youth in low-income neighborhoods through partnerships with schools, FQHCs, nurses, and school-based health centers to address mental health disparities in teens

How should PCORI design equitable research collaboratives to achieve health equity?



- Research centers are traditionally located at academic institutions or large health systems. Can you think of novel partnership arrangements between research and non-research organizations that situate community-based organization in leadership? What is needed in terms of structure to mitigate barriers that exist in health systems or other settings?
- What are your thoughts regarding the use of a phased or multi-stage model? What would the functional statements include for each phase?
- What kinds of topics are important to achieving health equity? Should PCORI consider a more narrowly defined, topic-specific approach to this initiative, or allow communities to drive topic selection?

Strategic Planning: Proposed Research Agenda

Vivian Towe, PhD, MSc, MA

Program Officer

Healthcare Delivery and Disparities Research

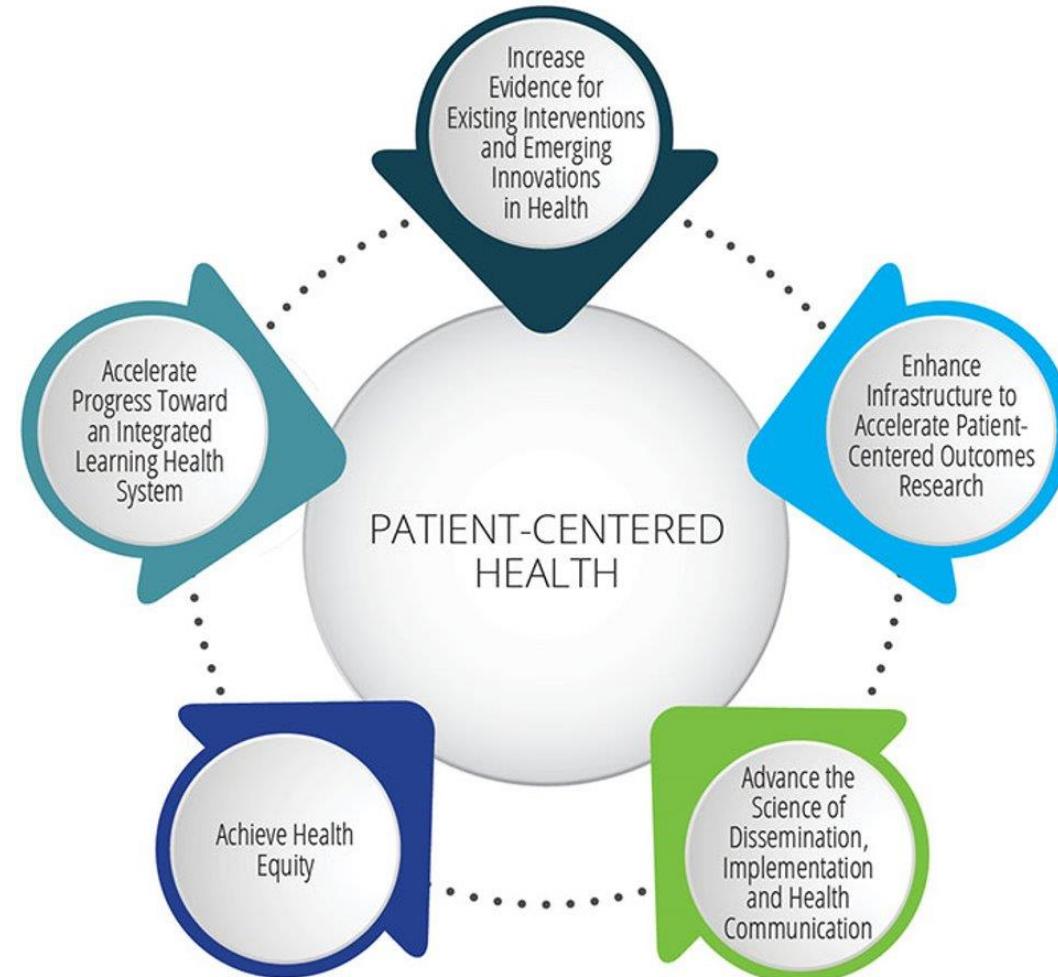
Scope of Strategic Planning Activities

- **National Priorities for Health**
- **Research Agenda**
- Strategic principles for PCORnet® phase 3
- Methodology Committee focus for PCORI's next phase
- Commitment Planning and strategies to increase funding
- Scenario Planning based on the changes in landscape and environment
- Priorities from reauthorizing law
 - Maternal morbidity and mortality
 - Intellectual and developmental disabilities
 - Full range of outcomes data
- Monitoring progress and measuring success



Strategic Planning

Adopted National Priorities for Health



Research Agenda: A Component of the Strategic Plan



- The **strategic plan** centers on achieving the National Priorities for Health, and the Research Agenda is one major component of the plan. The strategic plan aims to describe all the various components and present a cohesive vision for PCORI's future activities.
- The **Research Agenda** provides a framework for achieving progress on the National Priorities for Health specifically through the strategy of funding comparative clinical effectiveness research (CER). The Research Agenda helps guide the development of continuously relevant **Research Project Agenda** via an on-going, stakeholder-engaged process.
- PCORI utilizes other strategies in addition to funding CER (for example, Dissemination & Implementation) to achieve the National Priorities for Health, and these will be described in other components of the strategic plan.

Creation of the Research Agenda



Proposed Research Agenda



- Fund research that fills patient- and stakeholder-prioritized evidence gaps and is representative of diverse patient populations and settings
- Fund research that aims to achieve health equity and eliminate health and healthcare disparities
- Fund research that builds the evidence base for emerging interventions by leveraging the full range of data resources and partnerships
- Fund research that examines the diverse burdens and clinical and economic impacts important to patients and other stakeholders
- Fund research that focuses on health promotion and illness prevention by addressing health drivers that occur where people live, work, learn, and play
- Fund research that integrates implementation science and that advances approaches for communicating evidence so the public can access, understand, and act on research findings

Proposed Research Agenda and Examples for Supporting Context



Research Agenda Statement:

Fund research that fills patient- and stakeholder-prioritized evidence gaps and is representative of diverse patient populations and settings

Illustrative Examples

- Research on topics and outcomes of high relevance and value to patient and stakeholder communities that generates timely evidence to inform decisions
- Research that recruits study participants that are representative of communities most affected by conditions being studied and are representative of the diversity of the nation in order to understand potential differences in treatment effects and outcomes across populations
- Research that involves investigators that reflect the population or community where the research is conducted and for whom the research is intended

Research Agenda Statement:

Fund research that aims to achieve health equity and eliminate health and healthcare disparities

Illustrative Examples

- Research across conditions, populations, and subpopulations on topics where disparities in health outcomes occur
- Research on innovations for health systems that drive practice change to promote equitable care and eliminate discriminatory health care practices
- Research that supports and develops the talent of diverse, early career investigators and the health care workforce

Proposed Research Agenda and Examples for Supporting Context- Continued



Research Agenda Statement:

Fund research that builds the evidence base for emerging interventions by leveraging the full range of data resources and partnerships

Illustrative Examples

- Research that leverages evidence synthesis and stakeholder engagement to meet the evidentiary needs of federal, state, and local policymakers and stakeholders
- Research on innovations identified through relationships with federal partners including the FDA, CMS, NIH, VA, CDC, and AHRQ
- Research using optimized methods of data capture that are inclusive of diverse sources of real-world information (including patient-provided data)

Research Agenda Statement:

Fund research that examines the diverse burdens and clinical and economic impacts important to patients and other stakeholders

Illustrative Examples

- Research that engages patients, caregivers, and other key stakeholders in identifying important outcomes, unintended consequences, burden, and economic impacts
- Research that assesses the full range of factors that influence health outcomes, such as patient preferences, economic issues, practice variation, and disparities in the delivery of care

Proposed Research Agenda and Examples for Supporting Context- Continued



Research Agenda Statement:

Fund research that focuses on health promotion and illness prevention by addressing health drivers that occur where people live, work, learn, and play

Illustrative Examples

- Research in cross-sector collaboration with organizations with expertise in the social determinants of health (e.g., economic stability; education access and quality; health care access and quality; neighborhood and built environment; social and community context)
- Research on upstream topics such as social determinants of health, public health, and policies or programs that influence population-level health
- Research that examines the use of and investment in health-promoting resources in the community

Research Agenda Statement:

Fund research that integrates implementation science and that advances approaches for communicating evidence so the public can access, understand, and act on research findings

Illustrative Examples

- Research that studies the effectiveness of ways to get information to the right people, at the right time, in the right way that addresses cultural and other tailoring, modes of communication, and appropriate messengers for specific populations
- Research on approaches for rapid dissemination of evidence to inform the immediate decisional needs of patients, clinicians, health systems, and other stakeholders
- Research on the effectiveness of implementation strategies that have potential for accelerating the uptake of evidence into practice
- Research that assesses methods for explaining uncertainty, applicability, and communicating risk, including approaches for tailoring these methods for diverse populations

Hearing from the Panel



Discussion Questions



1. How might the proposed Research Agenda meet future needs for PCORI's strategy of funding CER?
2. How could the proposed Research Agenda support a research portfolio that is inclusive of this panel's topics of interest?
3. Is there an important research area that you would like to see better reflected in the proposed Research Agenda?
4. What kinds of research portfolios will be important to support the specific Statements?



Proposed Research Agenda

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- Fund research that integrates implementation science and that advances approaches for communicating evidence so the public can access, understand, and act on research findings

Survey



Wrap-Up and Next Steps

Alicia Arbaje & Jane Kogan
HDDR Advisory Panel Co-Chairs

Carly Khan
Associate Director, Healthcare Delivery
and Disparities Research Program

Meeting Adjourned
