# Passion and Mission Aligned at PCORI: Pursuing Health Impact and Equity through Engaged Research

University Hospitals Health Services Research Center

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### **Our Discussion Today**

pcori

- PCORI's Unique Approach to Health Research
- My Career Journey
- Patient and Community Engagement: Research Done Differently®
- Dissemination and Implementation: Getting Research Results to Those Who Can Use It
- Infrastructure and Health Systems: Enabling the Nation's Health Research Enterprise



#### **PCORI's Mission**





#### **Our Mission**

Help people make better-informed healthcare decisions, and improve healthcare delivery and outcomes, by producing and promoting highintegrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

## Comparative Clinical Effectiveness Research (CER)

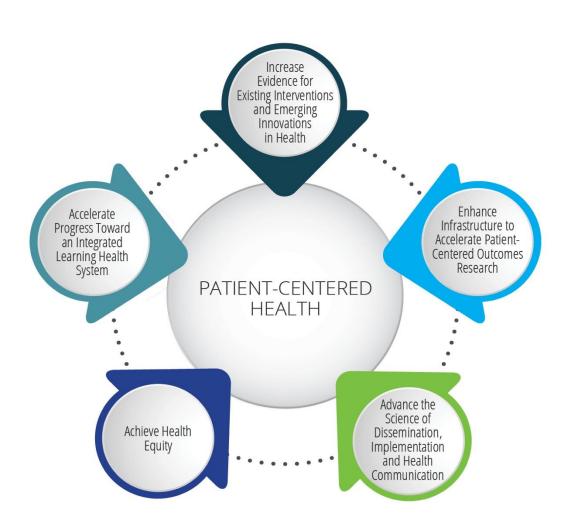


- Generates and synthesizes evidence comparing benefits and harms of at least two different methods to prevent, diagnose, treat, and monitor a clinical condition or improve care delivery
- Measures benefits in real-world populations
- Describes results in subgroups of people
- Helps consumers, clinicians, purchasers, and policy makers make informed decisions that will improve care for individuals and populations
- Informs a specific clinical or policy decision



## National Priorities for Health and Holistic Approach to Our Work

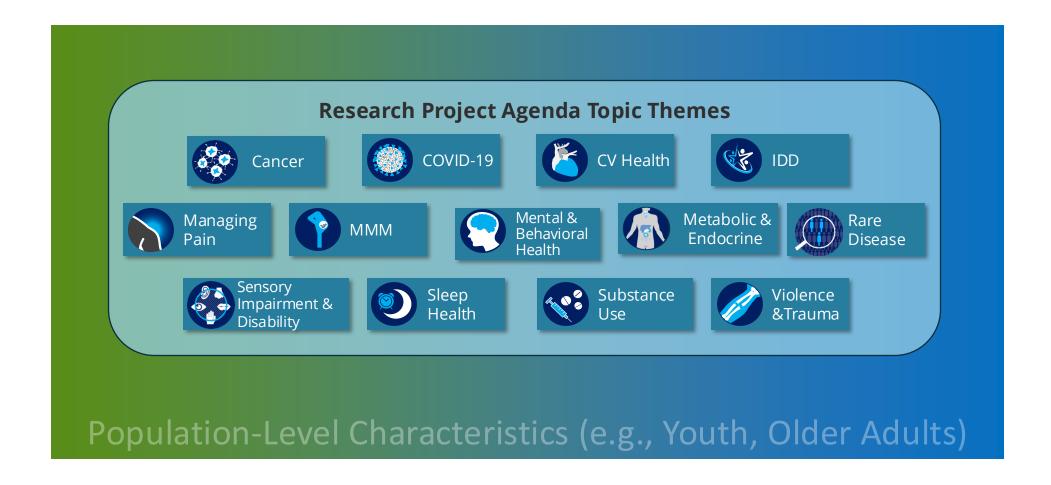






## Research Project Agenda Topic Themes Guide PCORI's Focused Funding





## **PCORI Funding Opportunities**Research and Research Related



#### Research

## **Opportunities:** *Stakeholder-Driven*

**Topics** 

**Studies:** *Funding by National* 

Priority Area
Proposals up to \$5M;
Proposals up to \$12M

### Phased Clinical Trials:

Large-scale, high-impact CER trials Proposals up to \$22M



#### **Research Related**

### Research Infrastructure:

PCORnet, Learning Health Systems

### **Engagement Projects:**

Capacity Building, Dissemination, Stakeholder Convening

#### **D&I Projects:**

Limited Competition, Shared Decision Making

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

### Fulfilling a Life's Purpose





Motivated by Disparities in Neighborhood

Bessemer, Alabama



Inspired to Leadership in Health

> Medical School



Defined
Patient-Centered
Health Care

Residency and Cardiovascular Diseases Fellowship



Revealed Pathways to Leadership in Health

Commonwealth Fund Fellowship in Minority Health Policy



Focused on National Scale & Management

NHLBI Office of the Director



**Destined to Be** 

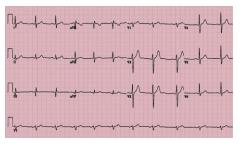
Patient-Centered Outcomes Research Institute

### Passion and Mission Align at PCORI



#### PCORI's Mission and Vision ...

- Aligned with my personal and professional vision
   To promote excellence in health and health care in a
   manner that is patient-centered and engages all
   parties to contribute to shared goals
- Aligned with my passion
   Close to the front line of health care and patients, guiding research that fuels health impact and health policy decisions
- Aligned with my personal values
   Commitment to patients and stakeholder communities









Organizational Leader and Manager



Health Policy Advocate

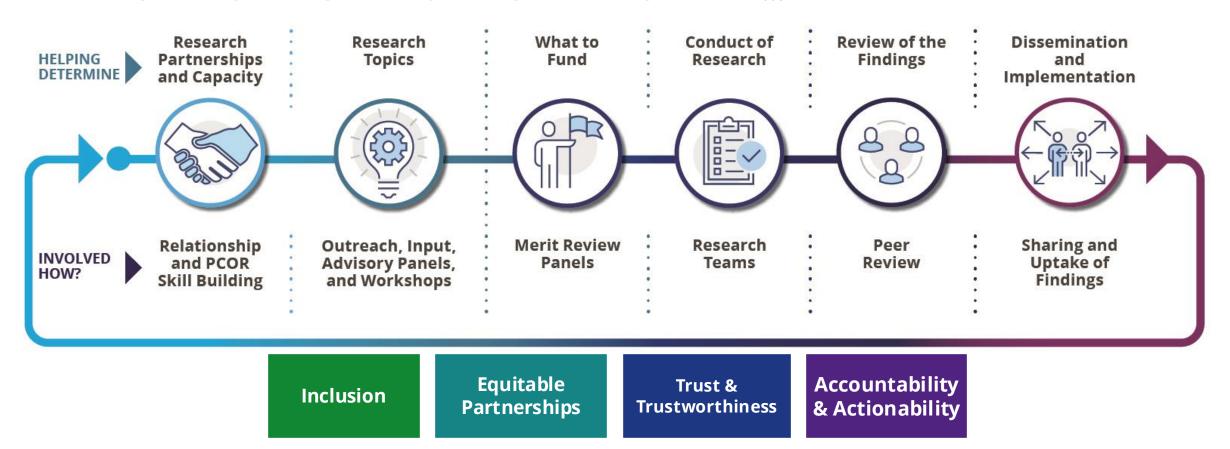
### Research Done Differently®

PCORI's Approach to Engagement at Every Step of the Process



#### **Engagement in Research**

#### PATIENTS AND OTHER STAKEHOLDERS ARE INVOLVED IN...



### **Moving Toward Health Equity**

#### Engagement as a Tool and Lessons Learned





Engagement facilitates recruitment and retention overall



It is never too late to start engaging patients, communities, and stakeholders



Trustworthiness and trust are essential for effective partnerships



Trust may be one component of low recruitment or enrollment of underserved participants



Underserved populations' unequal participation in clinical trials has multiple and complex root causes



Meet underserved populations in their communities; utilize expertise of trusted community brokers

#### Foundational Expectations for Partnerships





Diversity & Representation



Early & Ongoing Engagement



Dedicated Funds for Engagement & Partner Compensation



Build Capacity to Work as a Team



Meaningful Inclusion of Partners in Decision-Making



Ongoing Review & Assessment of Engagement

### Overcoming Challenges in Community-Engaged Research



#### Tips for Building Effective Multi-Stakeholder Research Teams

#### **Explore PCORI's Free Resources for:**

- Establishing best practices
- Defining roles and responsibilities
- Making effective group decisions
- Planning for collaboration
- Sustaining engagement
- And More!

PCORI.org/Research-Teams



#### New to Patient-Centered Outcomes Research?

- Explore our Research Fundamentals
- Free, self-paced, online training
- Easy to understand modules
- Helps people better understand the healthcare research process and to learn how to get involved in PCOR!

#### **Engagement Tool and Resource Repository**

- Searchable peer-to-peer repository
- Explore 400<sup>+</sup> engagement-related tools and resources developed and used by PCORI awardees
- Includes toolkits, case studies, engagement guides, training manuals, white papers, tip sheets and more



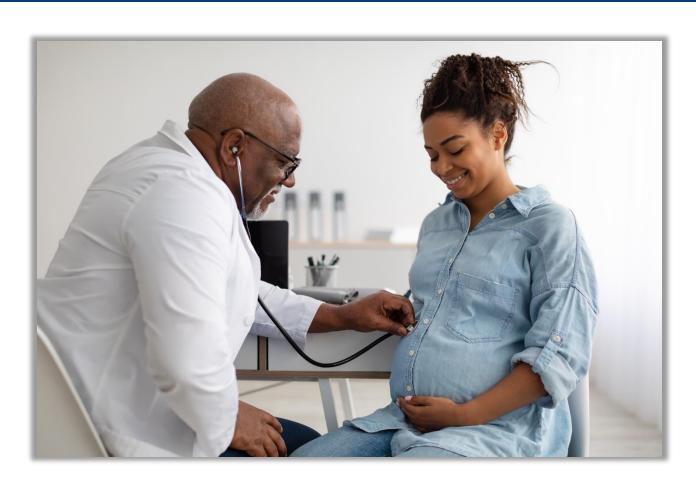


www.pcori.org/engagementresources



#### Partnering to Enhance Maternal Health





#### **Partner Awards**

- Multicomponent, multilevel interventions to address health conditions and social determinants of health to improve maternal health outcomes
- Community organizations are full partners with research organizations
- Four studies involve dozens of community partners, tens of thousands of study participants

## Healthcare Delivery Interventions in PCORI-funded CER





The Hearing Norton Sound Study

Research In

In progress; Enrollment complete

Comparing Health-System-Based and Community-Based Dementia Care for Patients and Caregivers -- D-CARE: The Dementia Care Study



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
FINAL RESEARCH REPORT

Matching Patients with Therapists to Improve Mental Health Care

Michael I. Constantino. PhD¹: Iames F. Boswell. PhD²: David R. Kraus. PhD³: Thomas Swales. PhD⁴



PATIENT-CENTERED OUTCOMES

FINAL RESEARCH REPORT

Does Daily Self-Monitoring of Blood Sugar Levels Improve Blood Sugar Control and Quality of Life for Patients with Type 2 Diabetes Who Do Not Use Insulin? – The Monitor Trial



Comparing Ways to Monitor Patients with COVID-19 at Home

## Dissemination & Implementation of Research Results Implementation Project: Results from the CODA Study DCOri

- The CODA study found that antibiotics may be as effective as surgery for adult patients with uncomplicated appendicitis
- Implementation project is putting in place a shared-decision making program at 15 hospitals about the use of antibiotics and surgery for appendicitis



#### **Long-Term Outcomes**

After three months, about 7 out of every 10 patients who took antibiotics had avoided surgery.



After a year, about 6 out of every 10 patients who took antibiotics had avoided surgery.



After three years, about 5 out of every 10 patients who took antibiotics had avoided surgery.



#### Health Systems Implementation Initiative



- Participating healthcare delivery systems lead implementation projects within their settings
- PCORI funding supports
   efforts to change practice and
   improve health care and
   outcomes based on specific
   PCORI-funded research
   findings



## PCORnet®: A National Resource to Enhance Capacity for CER



## Access to Data on a National Scale



13,000+
Clinical Sites of Care

**47M**Patient Encounters

**40+** PCORnet® Studies



- The first pragmatic trial conducted using PCORnet
- Compared aspirin 81 mg and 325 mg daily to prevent cardiovascular events
- PCORnet provided access to EHRs of >15,000 eligible patients with history of atherosclerotic cardiovascular disease
- Patient leaders known as "Adaptors" ensured patient-centeredness

### **Advancing Learning Health Systems**





#### PCORnet Infrastructure & Research

- 70+ data coordinating centers support demographic comparability
- Common Data Model facilitates national scale
- Engagement supports patient partnership



### LHS Workforce Development

- AHRQ-PCORI E-Star LHS Training Program (2023-2028)
- AHRQ-PCORI LHS K12 (2018-2023)



## Health System Implementation Initiative (HSII)

- 42 Participating Health Systems Across the Country
- Implementation projects support uptake of PCORI-funded evidence into practice

## Patient-Centered Outcomes Research Institute Get Involved



## **Several Ways to Get Involved with PCORI**

- Apply to serve on one of PCORI's five Advisory Panels
- Become a Merit Reviewer
- Become a PCORI Ambassador
- Become a Peer Reviewer
- Participate in PCORI Events



### **Thank You**

QUESTIONS?



