

# PCORI and PCORnet Phase 3

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# About PCORI

- An independent research institute authorized by Congress in 2010 and governed by a 21-member Board of Governors representing the entire healthcare community
- Funds comparative clinical effectiveness research (CER) that engages patients and other stakeholders throughout the research process
- Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns



# 2019 Reauthorization Legislative Research Priorities

Topics > Intellectual and/or Developmental Dis...

## Intellectual and/or Developmental Disabilities



As part of the 2019 legislation that reauthorized PCORI's funding for 10 years, Congress included research on intellectual and developmental disabilities as a priority topic for PCORI.

Topics > Maternal Morbidity and Mortality

## Maternal Morbidity and Mortality



As part of the 2019 legislation that reauthorized PCORI's funding for 10 years, Congress included research on maternal morbidity as a priority topic for PCORI.

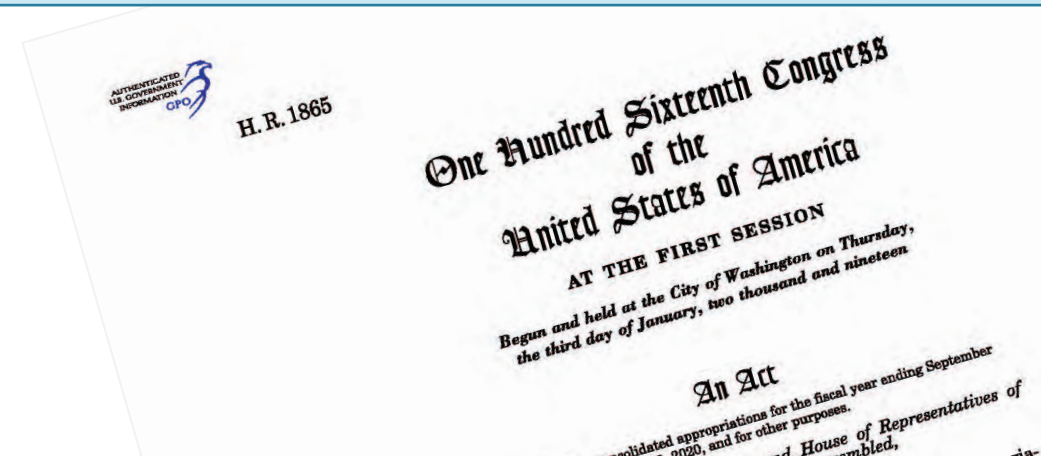
# Full Range of Outcomes

PCORI's reauthorizing legislation directs PCORI to capture, as appropriate, the full range of outcomes data in the course of our research studies.

This includes economic and cost data related to the utilization of health care services, but also outcomes and measures of cost and burden important to patients.

## Potential Burdens and Economic Impacts Include:

- Medical out-of-pocket costs, including health plan benefit and formulary design;
- Non-medical costs to the patient and family, including caregiving;
- Effects on future costs of care;
- Workplace productivity and absenteeism; and
- Healthcare utilization

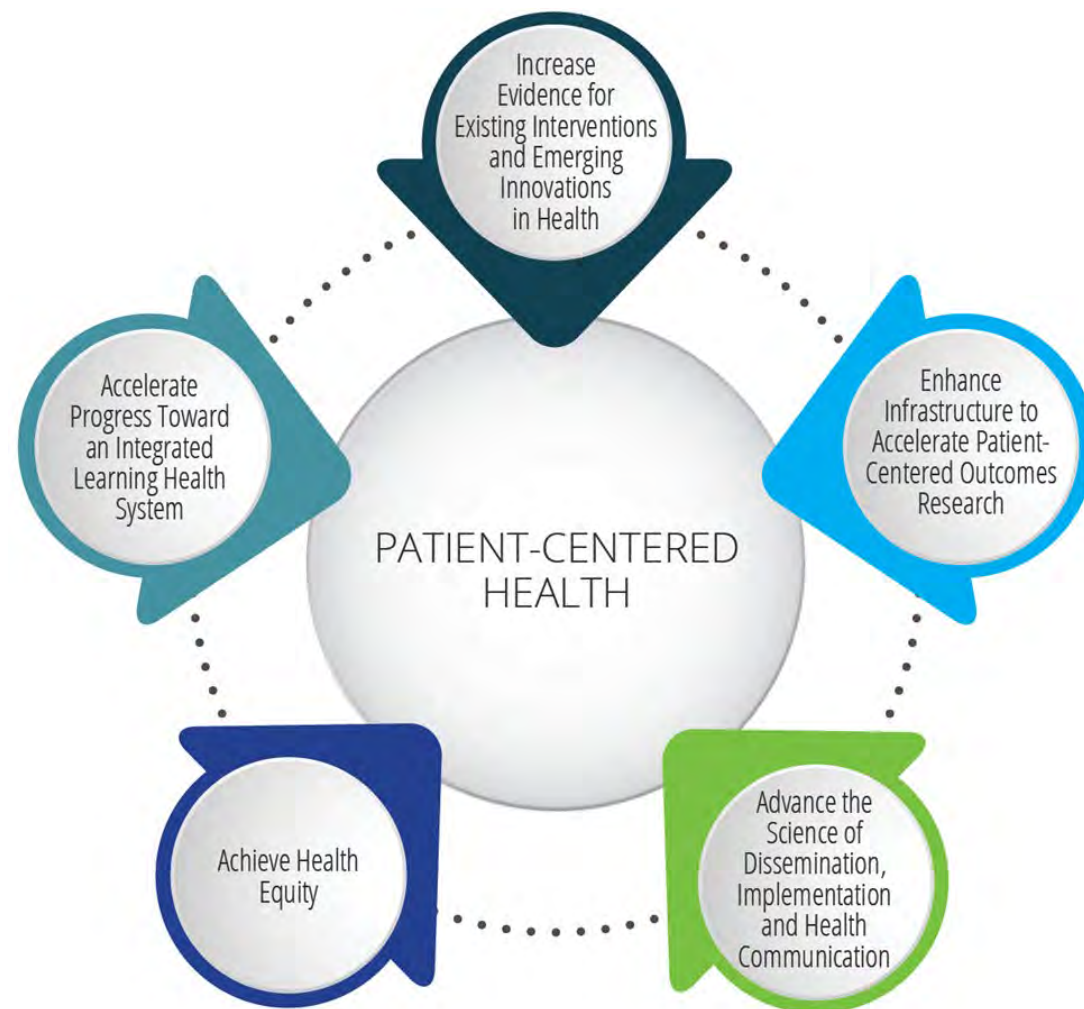


# Stakeholder and Public Input Informs PCORI's National Priorities and Research Agenda



# Proposed National Priorities for Health

- Increase Evidence for Existing Intervention Emerging Innovations in Health
- **Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research**
- Advance the Science of Dissemination, Implementation, and Health Communication
- Achieve Health Equity
- Accelerate Progress Toward an Integrated Learning Health System

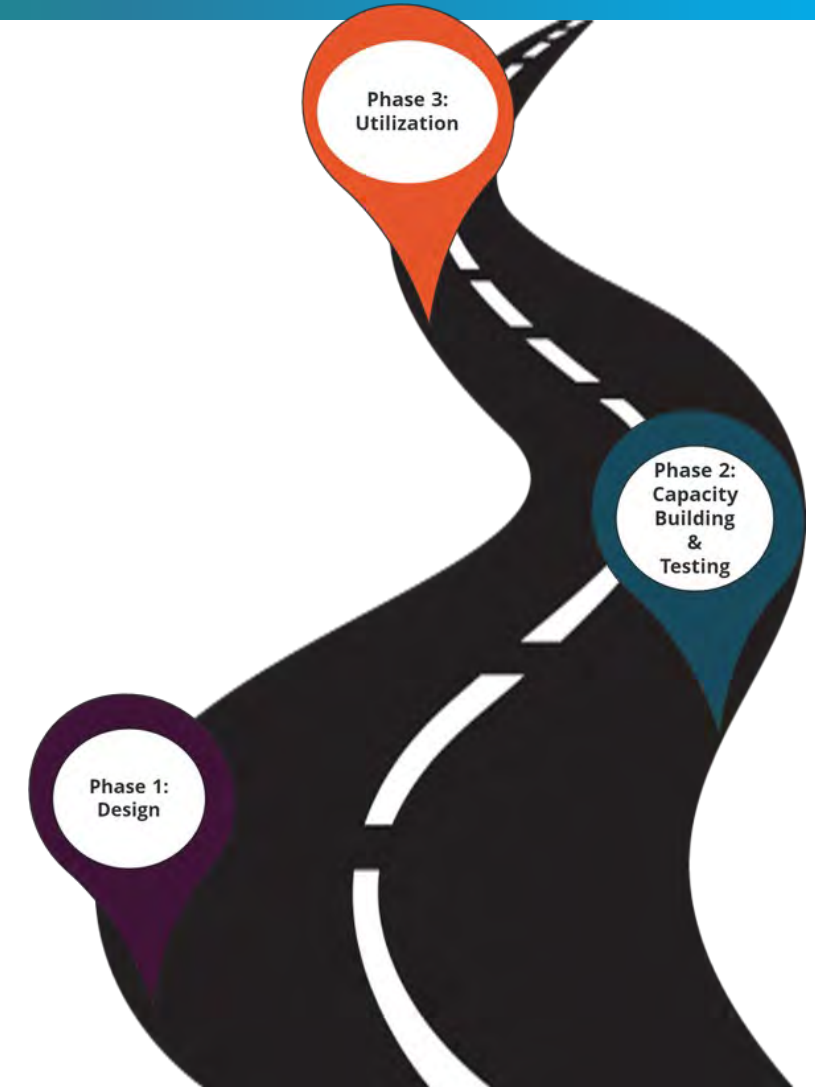


Read more [here](#).

# PCORnet<sup>®</sup>, The National Patient-Centered Clinical Network



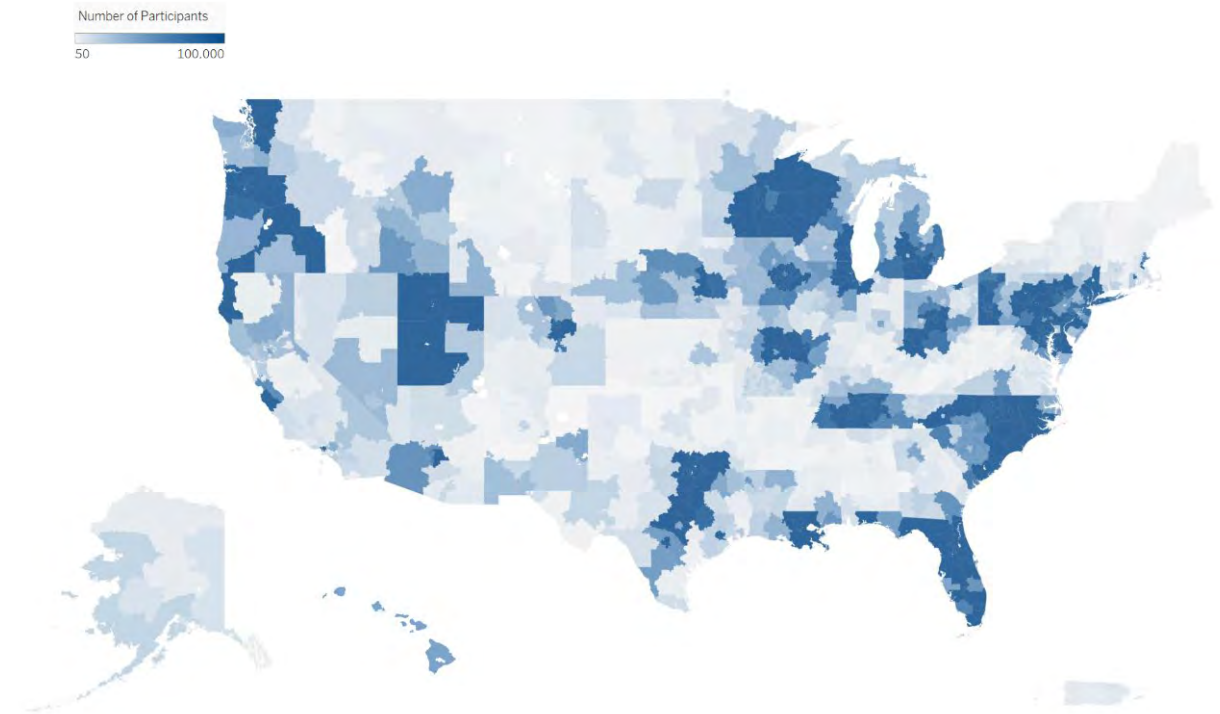
- PCORI awarded infrastructure development funds in a phased approach
  - The first phase of PCORnet was defined as a **planning and design** period to support the development of infrastructure
  - Phase 2 of PCORnet was a period of infrastructure **implementation, capacity building, and testing** through demonstration projects
  - In Phase 3, the focus will shift from infrastructure building to **utilization** of the network infrastructure for patient-centered research of national scope



# The Network is National in Scope

- PCORnet is a federated network of networks representing a large array of health care systems, a range of care settings, and a large segment of the American population
- Participating networks have developed a high level of trust and a shared commitment to patient-centered clinical research
- The breadth permits PCORnet to be a valuable resource for large, impactful studies, national in scope, not easily implemented without pre-existing infrastructure

## PCORnet is National in Scope





# The Patient is at the Center

- A culture of patient centeredness permeates PCORnet at every level – through every participating network and at all stages of the research process
- The culture advances PCORI’s core mission to transform clinical research throughout the nation by integrating patients as essential partners
- Its influence extends well beyond the impact of a project-by-project approach







## PCORnet is Patient-Centric



# Data can be Linked to the Patient

- PCORnet's Common Data Model is unique in that its distributed structure permits direct connections to patients and providers and re-access of primary data with appropriate privacy and confidentiality protections, consistent with legal requirements
- The connectedness is possible because of the established trust between participating network partners within this federated network

## PCORnet Facilitates Connections to Patients

	Feasibility queries	Identify patient populations for trial recruitment	Coordinated data curation	Connection to patients and providers
	●	●	●	●
	●	●	◐	◐
	●	●	◐	○
	○	●	◐	○
	●	○	◐	◐
	●	●	●	◐

# PCORI Prioritizing Principles for Infrastructure Funding Relating to PCORnet



## Patient-Centered

- I. Strengthen the central role of patient and caregiver engagement to produce true partnership in the full research process
- II. Attend to and strengthen the diversity of the patient populations served and the inclusion of care sites that serve underserved populations

## National Scope

- III. Recognize and strengthen the unique ability of PCORnet to generate definitive evidence through studies of national scope; prioritize investments that strengthen that capability particularly for studies focused on PCORI *Strategic Research Priorities*
- IV. Build on the unique capabilities of the PCORnet data structures, prioritizing investments that will align with the PCORI *Strategic Research Priorities*

## Governance and Partnerships

- V. Continue to develop the shared governance model which builds trust among participating networks and is coupled with close milestone-based monitoring of PCORI's infrastructure funds. As appropriate, encourage the development of mechanisms for cost recovery for infrastructure use related to projects supported by other funders
- VI. Recognize the importance of optimum distribution of core coordinating functions, with the dual goals of optimizing effective network function and capitalizing on the distributed expertise and capabilities of this complex network
- VII. Recognize, enable and promote the value of PCORnet to contribute to a learning health care system through effective partnerships with all stakeholders. Strengthen the educational resources needed to achieve this goal
- VIII. Recognize, enable and optimize the value of PCORnet for building partnerships with Federal Health Agencies

# Phase 3 Funding Announcements



The screenshot shows the PCORI website with the following elements:

- Header: PCORI logo and navigation links (BLOG, NEWSROOM, FIND IT FAST, HELP CENTER, SUBSCRIBE, CAREERS, CONTACT US).
- Search bar: A search input field with a magnifying glass icon.
- Navigation bar: A dark blue bar with white text for ABOUT US, RESEARCH & RESULTS, TOPICS, ENGAGEMENT, FUNDING OPPORTUNITIES, and MEETINGS & EVENTS.
- Breadcrumbs: Funding Opportunities > Optimizing Infrastructure for Conduct...
- Content area: A large heading "Optimizing Infrastructure for Conducting Patient-Centered Outcomes Research: PCORnet, The National Patient-Centered Clinical Research Network -- Phase 3 -- Cycle 1 2021" with social media icons (Twitter, Facebook, LinkedIn, and a plus sign) to its right. Below the heading, a light blue box contains the text: "Full applications were due on Tuesday, April 6, 2021, by 5:00 p.m. ET."
- Left sidebar: A vertical list of links: Funding Opportunities, What & Who We Fund, What You Need To Know To Apply, Applicant Resources, and Merit Review.

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- Breadcrumbs: Funding Opportunities > Limited PCORI Funding Announcement: C...
- Content area: A large heading "Limited PCORI Funding Announcement: Coordinating Center Functions to Advance Phase 3 of PCORnet®, the National Patient-Centered Clinical Research Network -- Cycle 2 2021" with social media icons (Twitter, Facebook, LinkedIn, and a plus sign) to its right. Below the heading, a light blue box contains the text: "Letters of Intent were due Tuesday, June 1, 2021, by 5:00 p.m. ET. Full applications were due Tuesday, August 10, 2021, by 5:00 p.m. ET."
- Left sidebar: A vertical list of links: Funding Opportunities, What & Who We Fund, What You Need To Know To Apply, Applicant Resources, Merit Review, and Awardee Resources.

# PCORI Data Convenings



- Identify specific strategies to enhance the PCORnet data infrastructure that would align with PCORnet Prioritizing Principles and PCORI's Strategic Research Priorities
- Increase visibility of PCORnet and encourage a dialog with experts who are advancing the field
- Topics
  - Social Determinants of Health
  - Patient Reported Outcomes
  - CMS Data Access

The screenshot shows a webpage for an event. At the top left is the NORC logo, which includes a star icon and the text "NORC at the University of Chicago". The main title of the event is "Expanding Social Determinants of Health Data across PCORnet®". Below the title, it says "You're Invited!" and provides a brief description of the event's purpose: "PCORnet, the National Patient-Centered Clinical Research Network, is a PCORI-funded initiative with the goal of developing infrastructure to enable patient centered comparative effectiveness research (CER) to be conducted faster and more efficiently. Please join us for a discussion exploring opportunities to enhance social determinants of health (SDOH) data within the PCORnet data infrastructure." There are three buttons: "White Paper (Available Soon)", "Register Here", and "View Agenda". Below these are three bullet points: "Discuss the current status of SDOH data collection by PCORnet network partners", "Discuss opportunities to optimize accessibility and availability of individual-level, population-level, and community-based SDOH data to support PCORnet research", and "Engage stakeholders on short-term and long-term infrastructure priorities to enhance SDOH data capture for network-wide research". The "Featured Speakers" section lists six individuals with their photos and titles: Erika Cottrell, PhD, MPP (Investigator, OCHIN; Assistant Professor, Oregon Health & Science University); Jon Puro, MPA/HA (Director of Research Informatics and Data Governance, OCHIN; Principal Investigator, ADVANCE); Thomas Carton, PhD, MS (Chief Data Officer, Louisiana Public Health Institute; Principal Investigator, REACHnet); Laura Gottlieb, MD, MPH (Founding Co-Director, SIREN; Professor, Family and Community Medicine, University of California, San Francisco); Keith Marsolo, PhD (Associate Professor, Department of Population Health Sciences, Duke University School of Medicine); and Betsy Shenkman, PhD (Chair and Professor, Department of Health Outcomes & Biomedical Informatics, University of Florida College of Medicine; Principal Investigator, OneFlorida).

# Changes for Phase 3

- Master Funding Contract
  - Single master funding agreement with the possibility of multiple Project Statements under it
  - Phase 3 CRN project will be first Project Statement
  - Additional infrastructure project funding can be added in additional Project Statements
- Increased attention to performance
  - Data quality
  - Research participation
  - Corresponding Phase 3 milestones

# Questions?

