

# Building a Patient-Centered Integrated Learning Health System



PCORI Resources and Research to Accelerate LHS in  
the Rehabilitation Research Community

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# Engagement, Methods, and Infrastructure for Patient-Centered CER – ‘A Toolkit’ to Support a Collaborative, Integrated Learning Health System

PCORI's  
Mission, Vision  
and Research  
Priorities

Accelerating  
Progress  
Towards an  
Integrated LHS

Open Data and  
Open Science  
(e.g. PCODR)

Health System  
Implementation  
Initiative  
(HSII)

Improving  
Methods and  
Methodology  
Standards

Comparative  
Clinical  
Effectiveness  
Research

Foundational  
Expectations and  
Engagement  
Activities

Workforce  
Development  
(e.g. LHS  
E-StaR)

Research,  
Data, and  
Technology  
(e.g.  
PCORnet)

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# Patient-Centered Outcomes Research Institute

Leading Funder of CER in U.S.



## PCORI®

- Funds studies designed to help people make better informed healthcare decisions
- Independent, nonprofit, research institute
- Leading funder of patient-centered comparative clinical effectiveness research (CER)





### Our Mission

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

## Key Features of Funded Research & Research-Related Projects

- Engages patients and stakeholders throughout research process
- Compares at least 2 health treatments, services or practices
- Focuses on questions most important to patients and those caring for them
- Aims to produce evidence that can be applied in practice settings





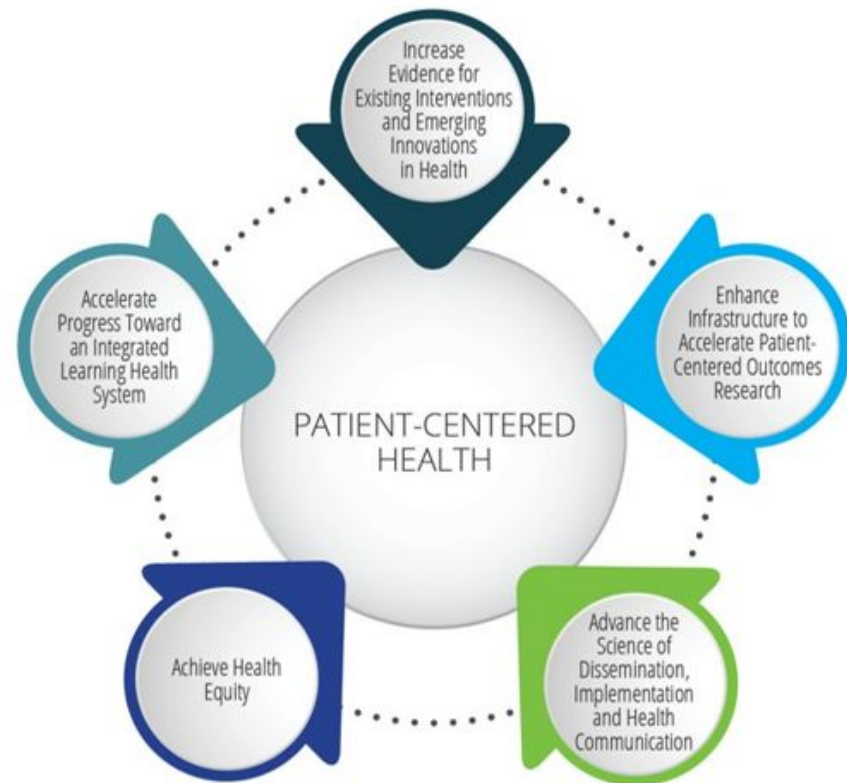
### Meaningful Patient and Stakeholder Engagement

- Patients are true partners in research
- Stakeholders across the healthcare enterprise actively and meaningfully involved throughout research process
  - Development of research priorities through to dissemination and uptake of findings



### National Priorities for Health

- Five ambitious long-term goals
- Interconnected and mutually reinforcing
- Purpose:
  - Anchor PCORI's research funding and other initiatives
  - Make a positive and significant impact on health and healthcare outcomes





# 2025 PCORI Research Award Funding Opportunities



1. Up to \$5M
2. \$5–12M

## Broad Pragmatic Studies

Investigator-initiated awards in alignment with the National Priorities for Health  
Three funding categories, including PCORnet® studies

Up to \$750K

## Methods

Improve use of AI and ML, improve study design, support data research networks, Ethical and human subject protections in CER

1. Up to \$500K
2. Up to \$1.5M

## Science of Engagement

Two funding categories: Development and validation of measures  
Development and testing of engagement techniques

Variable

## Topical/Targeted

Stakeholder-driven topics, issues, and questions of national significance

Up to \$22M  
for feasibility  
and  
full-scale study  
phases

## Phased Large Awards for Comparative Effectiveness Research

Large, meritorious, and innovative studies with some risks (Cycles 2 & 3)

## 2025 Funding Cycle LOI Deadlines

Cycle 1: January 14

Cycle 2: May 13

Cycle 3: September 23

\*All funds and timeline noted above are subject to change

# Understanding the Components of an Integrated Learning Health System

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# Mobilizing Learning Health Systems in Rehabilitation Opportunities for LHS Infrastructure and Research

## Opening the Black Box of Rehabilitation Interventions

Alan M Jette 


*Physical Therapy*, Volume 100, Issue 6, June 2020, Pages 883–884, <https://doi.org/10.1093/ptj/pzaa078>

## Evaluating Completeness of Discrete Data on Physical Functioning for Children With Cerebral Palsy in a Pediatric Rehabilitation Learning Health System

Nikolas J Koscielniak, PhD , Carole A Tucker, PT, PhD, Andrew Grogan-Kaylor, PhD, Charles P Friedman, PhD, Rachel Richesson, PhD, Josh S Tucker, MS, Gretchen A Piatt, PhD

*Physical Therapy*, Volume 102, Issue 1, January 2022, pzab234, <https://doi.org/10.1093/ptj/pzab234>

## Advancing Rehabilitation Practice Using Embedded Learning Health System Researchers

Joshua K Johnson, PT, DPT, PhD , Mary Stilphen, PT, DPT, Daniel L Young, PT, DPT, PhD, Michael Friedman, PT, MBA, Robin L Marcus, PT, PhD, FAPTA, Christopher S Noren, OTR/L, Hallie Zeleznik, PT, DPT, Janet K Freburger, PT, PhD, FAPTA

*Physical Therapy*, Volume 101, Issue 6, June 2021, pzab029, <https://doi.org/10.1093/ptj/pzab029>

## Learning Health Systems

Open Access

COMMENTARY |  Open Access |    

### Socio-technical infrastructure for a learning health system

Charles P. Friedman , Edwin A. Lomotan, Joshua E. Richardson, Jennifer L. Ridgeway

First published: 16 January 2024 | <https://doi.org/10.1002/lrh2.10405> | Citations: 2

## Learning Health Systems

Open Access

EXPERIENCE REPORT |  Open Access

### The SHOnet learning health system: Infrastructure for continuous learning in pediatric rehabilitation

Nikolas Koscielniak, Diane Jenkins, Sahar Hassani, Cathleen Buckon, Joshua S. Tucker, Susan Sienko, Carole A. Tucker 

First published: 15 February 2022 | <https://doi.org/10.1002/lrh2.10305>



## Health Policy

Volume 135, September 2023, 104866



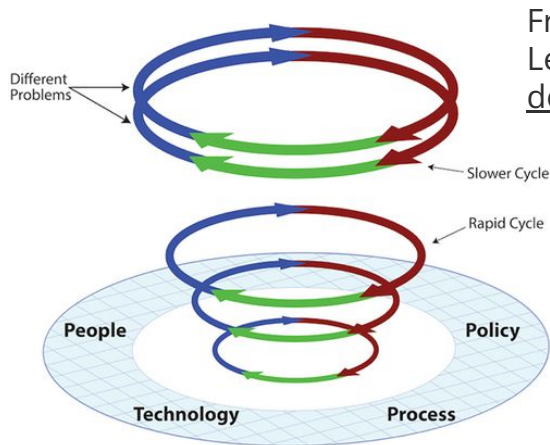
Policy Comment

## The Learning Rehabilitation System: Strengthening an intersectoral strategy to improve functioning of an ageing population

Jerome Bickenbach <sup>a b</sup>, Sara Rubinelli <sup>a b</sup>, Carla Sabariego <sup>a b</sup>, Gerold Stucki <sup>a b</sup> 

# Multiple Definitions of a Learning Health System

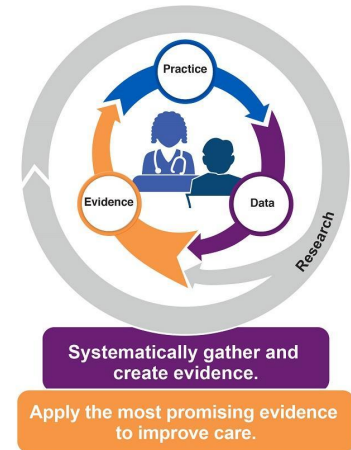
- The “alignment of science, informatics, incentives, and culture for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience.”
  - [\*Institute of Medicine Roundtable on Evidence-Based Medicine: The Learning Healthcare System: Workshop Summary, 2007\*](#)



Friedman, et al, 2024,  
Learning Health Systems.  
[doi:10.1002/lrh2.10405](https://doi.org/10.1002/lrh2.10405)

Agency for Healthcare Research  
and Quality (AHRQ).  
Learning Health Systems

## Learning Health Systems



# Operationalizing and Investing in LHS to Help People Make Informed Health Decisions

	Mission-Commitment to “Continuous Learning”	Process Model	Organizational Model	Integrated system design	LHS Initiative or Named/ Designated Program w/Embedded Research	Dedicated resources			
						IT and data	Work-force	Community Engagement	D&I
“Learning” health system	X					X	X		
Learning health system approach		X				X	X		
Learning health system model			X			X	X		
Learning Health System (organization)				X		X	X		
Integrated Learning Health System (by discipline or patient population)				X	X	X	X		X
National Learning Health System	X	?		?		X	X		X
Patient-Centered Learning Health System	X	X	X	?	?	X	X	X	X



# What We Talk About When We Talk About LHS - Dimensions of Infrastructure

<i>LHS Infrastructure Model Dimensions</i>	<i>Health Information System Maturity Model**</i>	<i>LHS Researcher Core Competencies</i>	<i>PCORnet® Maturity Model</i>	<i>FDA Sentinel Maturity Model</i>	<i>Freidman (2022)</i>	<i>Lannon et. Al (2021)</i>
<b>Governance/Policy</b>	Data Governance; Consent/Privacy	Ethics in Implementation	Governance	Governance	Policy	Governance and Management
<b>Research/Analysis</b>		Research Questions and Evidence	Research	Analytical tools and technology		Science
<b>Data and Technology</b>	Technical Dimensions (Information Quality; Transport; Security; Transaction/Query)	Informatics	X		Technology	Data and Analytics
<b>Patient and Community Engagement</b>	Stakeholder Governance; Participation	Engagement and Leadership	Engagement			Engagement and Community Building
Diversity, Equity, and Inclusion		Equity and Justice	X			
Quality Improvement						X
Sustainability	X			Strategy and Value		
System Science		X				
Research Methods		X		Methods		
Improvement Implementation Science		X				
Operations	Usability/ Workflow		X	Process	Process	
Partnerships & Public Awareness			X			
People				Talent and Organization	X	Systems of Leadership

\* Columns indicate 'X' where the language in the source is an exact match. Differences in language are reflected in the columns in the event the concept appeared to overlap but did not use the same exact verbiage\*\*Alignment/Duplication is included in the HIS model, but was not highly relevant to LHS infrastructure

# October 2023 LHS Data Services Convening

- PCORI convened leading experts in data and knowledge infrastructure services to discuss opportunities to reduce balkanization of data communities in support of an integrated LHS
- Goals of the convening:
  1. Build awareness and characterize the landscape of health data infrastructure and innovation across the health data ecosystem that can support data services for an integrated LHS;
  2. Identify opportunities and challenges to implementing activities to support an integrated LHS, including technical and policy considerations which could be organized into a cohesive health data services infrastructure to guide collaboration.
  3. Define core data services to support LHS and advance patient-centered clinical comparative effectiveness research (CER).
  4. Recommend action items to develop a collaborative approach and engage collaborators to develop core health data services that support an integrated LHS. This may include developing a framework for supporting evidence generation in a timely fashion through cooperation, developing measures of data quality, services to reduce disparities and promote health equity, and sharing data analysis methods.

# PCORI Funding for Rehabilitation Interventions

## Selected Projects Since 2014



- PCORI Funded Projects that Support a Rehabilitation LHS
  - [Creating a Manual to Better Define Rehabilitation Treatments](#) (PI: Whyte)
  - [Prehabilitation and Rehabilitation in Peripheral Artery Disease: A Randomized Exercise Intervention Trial \(PREPARE-IT\)](#) (PI: Myers)
  - [Home-based Pulmonary Rehabilitation with Health Coaching in Patients with Fibrotic Lung Disease](#) (PI: Moua)
  - [Optimizing Treatment Sequencing for Patients with Chronic, Non-Specific Low Back Pain](#) (PI: Fritz)
  - [Optimizing Care for Patients with Dementia: A comparison of two non-pharmacological treatment approaches](#) (PI: Leland)

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# PCORI Resources to Support an Integrated, Patient-Centered LHS

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# Six Foundational Expectations for Partnership



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

# New Models of Scientist Training and LHS Research with Nationwide Reach

## 16 AHRQ-PCORI LHS E-STaR Centers Programs



Institution	Program Name
Arizona State University - Tempe	Southwest Safety Net Embedded Scientist Training and Research (SSNE-STaR) Center
Beth Israel Deaconess Medical Center	Massachusetts Institute for Equity-Focused Learning Health System Science (MIELHSS)
Boston Medical Center	Boston Health Equity & community-Aligned Learning Health System (Boston-HEALHS)
Brown University	Learning Health systems training to improve Disability and chronic condition care (LeaHD)
Children's Hospital of Philadelphia	PEDSnet Scholars: A National Pediatric Learning Health System Embedded Scientist Training and Research Program
Columbia University Health Sciences	Columbia-Cornell-Einstein EQUIP+ Center for Learning Health System Science
Dartmouth College	Dartmouth Learning Health System (LHS) Embedded Scientist Training and Research (E-STaR) Center
Johns Hopkins University	Promoting Embedded Research in a Learning Health System
Kaiser Foundation Research Institute	Washington Learning Health System Embedded Scientist Training and Research Center (WA LHS E-STAR Center)
Rutgers Biomedical and Health Sciences	Learning Health System Scientist Training and Research in New Jersey (LHS STAR NJ)
University of California San Diego	UCSD Center for Learning Health Systems Science
University of California San Francisco	Learning Health System Embedded Scientist Training and Research Center
University of Michigan Ann Arbor	Michigan Embedded LHS Scientist Training and Research (MEL-STaR) Center
University of Minnesota	Learning Health System Embedded Scientist Training and Research (LHS E-STaR) of the North (LEaRN)
University of Pennsylvania	Patient-Oriented Research and Training to Accelerate Learning (Penn PORTAL)
Vanderbilt University Medical Center	Realizing Accelerated Progress, Investigation, Implementation, and Dissemination in Learning Health Systems (RAPID-LHS) Center

# Methods Program

## *Portfolio Snapshot: Size, Scope, Impact*



**148 funded projects awarded through Cycle 1 2023**

107 completed  
41 in-progress



**\$160 million budgeted across all projects**

~5% of total research funding



**Over 600 peer-reviewed publications<sup>24</sup>**

Methods publications account for ~15% of all PCORI-funded peer-reviewed publications

# Methods Program

## *Portfolio Snapshot: Size, Scope, Impact*

- Funds and duration: \$750K in direct costs/36 months
- Funding announcement published 3 funding cycles/year
- Average of approximately 40 Letters of Intent/20 applications per cycle
- **Current Program Priorities,\* Improving Methods for Conducting Patient-Centered Comparative Clinical Effectiveness Research:**
  - Methods to Improve Study Design
  - Methods to Support Data Research Networks
  - Methods to Improve Use of AI and Machine Learning in Clinical Research
  - Methods Related to Ethical and Human Subjects Protection

*\* Current priorities are under review; potential new areas will be discussed with MC in the coming months*



Consistent with PCORI's authorizing law, the Methodology Committee develops and updates methodological standards for patient-centered comparative clinical effectiveness research.

## Methodology Committee

### Members:

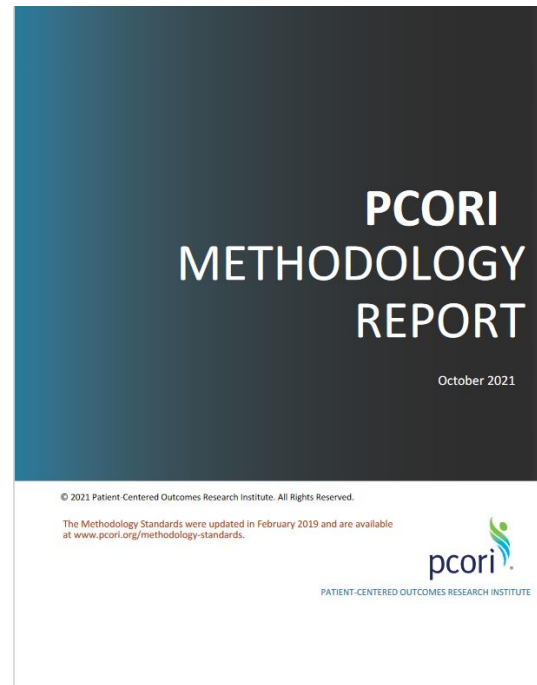
- Adam Wilcox, Ph.D. (Chair)
- Lehana Thabane, Ph.D., MSc (Vice Chair)
- Naomi Aronson, Ph.D.
- Suzanne Bakken, Ph.D., RN
- Cathy J. Bradley, Ph.D., MPA
- Matthew Fox, DSc, MPH
- Cynthia Girman, DrPH
- Larry R. Hearld, Ph.D., MSA, MBA
- Jeremy Goldhaber-Fiebert, Ph.D.
- Mark Helfand, M.D., MS, FACP
- Sally C. Morton, Ph.D.
- Shirley Wang, Ph.D., ScM
- Steven Goodman, M.D., Ph.D., MHS
- Susan Zickmund, Ph.D.
- Doris C. Lefkowitz, Ph.D. (AHRQ)
- Michael S. Lauer, M.D. (NIH)

\*\*<https://www.pcori.org/about/governance/methodology-committee>

# Methodology Standards Development & Reports

The PCORI Methodology Report includes four primary sections:

- **Section I: Patient-Centered Outcomes Research** reviews the need for methodological standards in patient-centered outcomes research.
- **Section II: Identifying and Addressing Evidence Gaps in PCOR** discusses the importance of a systematic process for prioritizing topics and determining appropriate research designs.
- **Section III: PCORI Methodology Standards** explains how PCORI developed and updated its set of **17 topics** and **67 methodology standards**, discusses each group of standards, and summarizes the justifications for the standards.
- **Section IV: Advancing Understanding and Appropriate Use of Methods for PCOR** emphasizes the role of the Methodology Standards in promoting transparency, which is a critical component of good research practices.



# Please help spread the word - Methodology Committee Nominations Open through Oct 31



- The next slate of seven (7) MC members will be considered for appointment by the Board in Spring 2025. The [Call for Nominations](#) is now open on PCORI's website.

- Methodological Areas of Particular Interest:
  - Analysis of potential burdens and economic impacts to patients and caregivers.
  - Artificial intelligence, machine learning and large language models.
  - Bioethics.
  - Data science and informatics.
  - Diversity, equity and inclusion.
  - Engagement science, including community-based participatory research.
  - Implementation science, including health system science.
  - Patient-centered measurement, including patient-reported outcomes.
  - Program evaluation.
  - Real-world data and real-world evidence.
  - Research rigor and reproducibility.
  - Social determinants of health

2  
8

- NEW THIS CYCLE: All applicants must SELF-nominate.
- All appointed MC members are required to forego the opportunity to apply for PCORI funding during their term on the MC and for a specified period of time thereafter, consistent with [PCORI's Conflict of Interest Policy Relating to PCORI Funding for Members of the Board of Governors, Members of the Methodology Committee and Employees.](#)
- Communication and messaging materials are available to support outreach

# PCORI's Policy for Data Management and Data Sharing

## Patient Centered Outcomes Data Repository (PCODR)



- **PCORI's Policy for Data Management and Data Sharing:** Stipulates the research data and data documentation from certain PCORI-funded studies be deposited in a data repository (PCODR) to facilitate data sharing.
- Since 2019, PCORI staff have worked to implement the Policy PCORI wide and build out PCODR.
- PCODR contains data from a growing number of PCORI-funded CER clinical trials covering a range of diseases and therapeutic areas (12 CER studies as of February 2024).
- The number of studies available for request will continue to grow over the coming years.

Please visit [PCORI's Data Sharing Webpage](#) for more information.

# How can the Research Community Use Patient Centered Outcomes Data Repository (PCODR)?

Discover, Access, & Analyze  
Comparative Clinical Effectiveness  
Research Data

PATIENT-CENTERED  
OUTCOMES  
DATA REPOSITORY

- PCORI funded PCODR to **improve** the capacity to **conduct** patient-centered comparative clinical effectiveness research (CER) to
  - *Facilitate reproduction of analyses to increase the integrity of PCORI-funded CER*
  - *Build on study findings or integrate data from multiple studies to **generate new evidence***
- All interested investigators may submit requests to access de-identified data from a growing number of patient-centered CER studies on topics including
  - Lower back pain,
  - Stroke,
  - Cardiovascular, and
  - Mental health.



# PCORI Health System Implementation Initiative (HSII)

## HSII in 3 Steps

### Step 1

Health systems apply to become **HSII Participants** (no funding, 7-year term)



### Step 2

HSII Participants undertake **Capacity Building Projects** (Budgets ≤ \$500K)

Projects supporting HSII Participants' efforts to prepare for HSII Implementation Projects. For example,

- Planned implementation approaches
- Mechanisms for patient and community groups to inform upcoming implementation efforts
- Improving data infrastructure for program evaluation

Capacity Building Projects awarded Summer 2023. (Note: projects were not required.)

### Step 3

HSII Participants undertake **Implementation Projects** (Budgets ≤ \$500K - \$5 Million)

Two Calls for Proposals (CFPs) released so far (Oct. 2023, May 2024).

Eligible evidence topics:

- Intensive Lifestyle Treatment for Weight Loss in Primary Care
- Appropriate Antibiotic Prescribing for Children with ARTIs
- <sup>3</sup>Addressing Hypertension in Adults<sup>†</sup>
- Monitoring ePROs During Cancer Treatment<sup>†</sup>

First set of projects under the first CFP will be awarded Fall 2024.

# PCORnet<sup>®</sup>



An established network to support  
Research Done Differently – capable of  
conducting national-scale studies designed  
to help people make better  
informed healthcare decisions

# PCORnet<sup>®</sup> Contributes to PCORI's Mission and National Priorities for Health at Multiple Levels



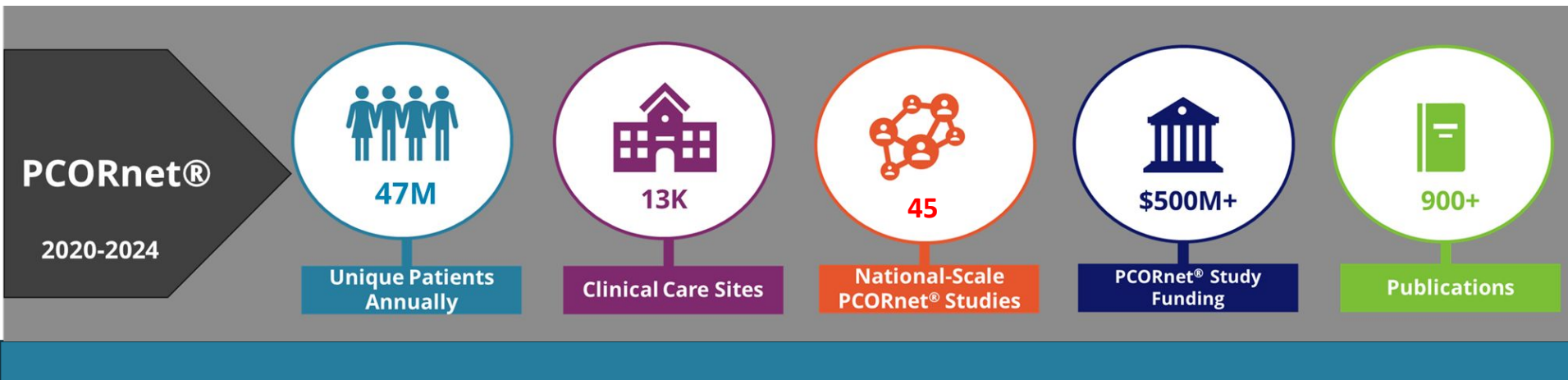
## PCORnet

- Supports national-scale studies designed to help people make better informed healthcare decisions
- Catalyst for *Research Done Differently*
  - Embeds patient partnership and community engagement in all components of the network
  - Enhances capacity to conduct health research with real world data
  - Builds reusable infrastructure and capacity for continuous improvement at local, regional, and national levels
  - One point of entry: [www.pcornet.org/frontdoor](http://www.pcornet.org/frontdoor)



# PCORnet® By the Numbers

A national resource where high-quality health data, patient partnership, and research expertise deliver fast, trustworthy answers that advance health outcomes



# PCORnet® Clinical Research Network Sites

(as of August 2024)



1. Fenway Health
2. Health Choice Network
3. OCHIN
4. Oregon Health & Science University Hospital System\*
5. The University of Washington\*



6. Allina Health
7. Intermountain Healthcare
8. Marshfield Clinic Research Institute
9. Medical College of Wisconsin
10. University of California, Los Angeles\*
11. University of Iowa Healthcare
12. University of Kansas Hospital
13. University of Missouri
14. University of Nebraska Medical Center
15. University of Texas Health Science Center at Houston
16. University of Utah Health
17. UT Health San Antonio
18. UT Southwestern Medical Center
19. Washington University in St. Louis



20. Columbia
21. Houston Methodist\*
22. Montefiore
23. Mount Sinai
24. New York University Langone Health
25. New York-Presbyterian
26. Weill Cornell Medicine



27. AdventHealth Orlando
28. Bond Community Health Center, Inc.
29. Emory University
30. Florida Medicaid
31. Jackson Health System\*
32. Nicklaus Children's Hospital (NCH)
33. Orlando Health
34. Tallahassee Memorial Healthcare and Capital Health Plan
35. University of Alabama at Birmingham
36. University of Arkansas for Medical Sciences\*
37. University of California, Irvine\*
38. University of Florida and University of Florida Health
39. University of Miami and UHealth
40. University of South Florida and Tampa General Hospital



41. Boston Medical Center\*
42. Geisinger Health
43. Johns Hopkins University
44. Ohio State University
45. Penn State University
46. Rush University Medical Center\*
47. Temple University
48. University of Michigan
49. University of Pittsburgh



3  
5

**Coordinating Center for PCORnet®**

60. Baylor Scott & White Health (BSWH)
61. DHR Health Inst. for Research and Development\*
62. Louisiana Public Health Institute (Lead)
63. Ochsner Health
64. Ochsner LSU Health Shreveport\*
65. Tulane Medical Center
66. University Medical Center New Orleans
67. University of California, San Francisco\*
68. Duke University
69. Essentia Health\*
70. Health Sciences South Carolina
71. Mayo Clinic
72. Meharry Medical College
73. Stanford Healthcare\*
74. University of North Carolina at Chapel Hill
75. Vanderbilt Health Affiliated Network
76. Vanderbilt University Medical Center
77. Wake Forest University Health Sciences

1. The Children's Hospital of Philadelphia
2. Vanderbilt University Medical Center
3. Duke University

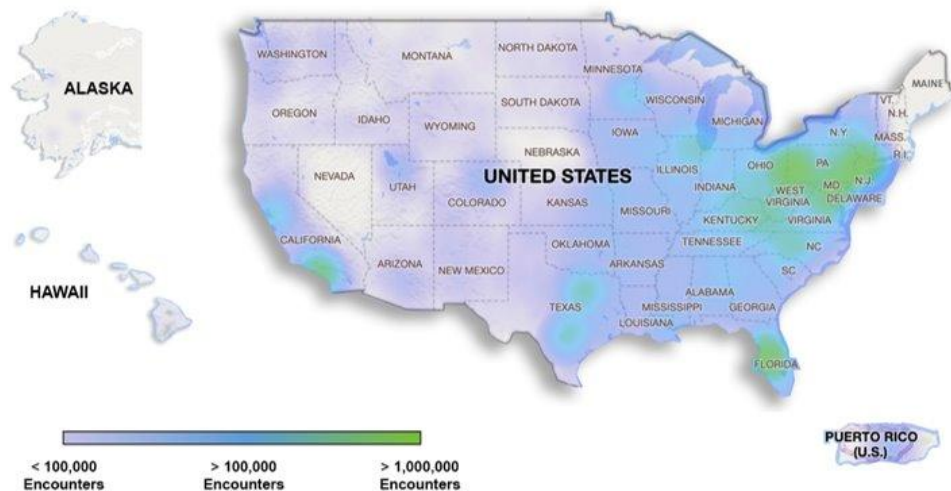
Shading indicates CTSI hubs  
\*New CRN sites  
Highlight= NCATS Hub Awardees



# PCORnet<sup>®</sup> Network Services Designed to Support Health Research



**Infrastructure and resources provided  
for full range of study designs**



**PCORnet Governance and  
Research Readiness Service**

**Engagement and Public  
Awareness Service**

**Data Service**

As of 2023, PCORnet includes >34m unique patients and  
>13,000 sites of care

# The PCORnet<sup>®</sup> Common Data Model



For data to be useful, it has to be standardized across systems. Frequent data curation and a single language enabled by the PCORnet<sup>®</sup> Common Data Model delivers fast insights.

Ready for Research			Available, But Still Evolving		
Demographics	Diagnoses	Procedures	Immunization s	Tumor Registry	Biosamples
Vital Signs	Labs	Clinical Observations	Social Determinants of Health	Patient-Generated Data	Genomic Results
Medication Orders & Administrations			Patient- Reported Outcomes	Natural Language Processing Derived Concepts	

**Data available from Clinical Research Networks, in the PCORnet<sup>®</sup> Common Data Model and ready for use in research**

**Data available at some Clinical Research Networks, may or may not be in the PCORnet<sup>®</sup> Common Data Model and require additional work for use in research**



# Public Query Reports of PCORnet® Data Resources



- PCORI initiated large national PCORnet Front Door queries to increase public awareness of PCORnet data resources and demonstrate capacity of PCORnet to support investigator-initiated research
  - **Telehealth:** [Characterizing Telehealth Visits Across Clinical Research Networks Participating in PCORnet®](#)
  - **Intellectual and Developmental Disabilities:** [Cohort of Patients with Intellectual and Developmental Disabilities Across Clinical Research Networks Participating in PCORnet®](#)
  - **Maternal Morbidity and Mortality:** [Characteristics of Pregnancy-Related Health Events Across Clinical Research Networks Participating in PCORnet®](#)
  - **Pediatric Population:** [Characteristics of the Pediatric Population Across Clinical Research Networks Participating in PCORnet®](#)

# BPS Category 3 for PCORnet® Studies



- In Cycle 2 of 2023, Category 3 was added to the Broad Pragmatic Studies (BPS) PCORI Funding Announcement (PFA) to support PCORnet® Studies that advance PCORI's National Priorities for Health
- Total direct costs  $\leq$  \$12 million, up to 5 years
- Studies must:
  - Address PCORI's National Priorities for Health
  - Include 2 or more Clinical Research Networks (CRNs)
  - Share study progress, performance metrics (e.g., Days to IRB, Number of days to first patient enrolled) monthly
  - Share best practices at least annually with the Network (e.g., PCORnet® Steering Committee), as outlined in additional PCORnet® Study milestones
  - Use PCORnet resources to improve the efficiency of the patient-centered research conducted (e.g., PCORnet® Common Data Model, single IRB, engagement resources)

# Bringing it all Together to Support: Examples of Ways PCORnet Can Support LHS in IDD and MMM

December 2023

A Roadmap for Accelerating Research in Intellectual and Developmental Disabilities Using PCORnet®



December 2023

A Roadmap for Accelerating Research to Prevent Maternal Morbidity and Mortality Using PCORnet®



- What is the comparative effectiveness of *clinic-based peer support vs community-based peer support* for individuals with IDD on *health-related quality of life, self-reported connection to community resources, and overall well-being*?
- What is the comparative effectiveness of delivering *melatonin vs behavioral therapy for sleep* among individuals with IDD on *sleep duration, sleep quality, quality of life, and other patient-reported outcome measures (PROMs)*?
- What is the comparative effectiveness of *risk-based models for the quantity and content of prenatal and postpartum care visits, relative to current recommendations, for reducing MMM*?
- What combination of providers (ie, *psychiatrists vs primary care physician vs certified nurse-midwives vs nurse practitioners vs registered nurses vs community health workers, doulas, etc*) is most effective for treatment of mood disorders during pregnancy and the postpartum period?

# Making Connections with PCORnet®



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Please contact PCORI ([pfa@pcori.org](mailto:pfa@pcori.org)) for information on funding opportunities and consultation

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