

Accessing PCORnet's Data and Network Resources

Maryan Zirkle, MD, MS, MA

Program Officer, Research Infrastructure, Patient Centered Outcomes Research Institute (PCORI)



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The National Patient-Centered Clinical Research Network

Our national clinical research system is well-intentioned but needs improvement

We are not generating the evidence we need to support the healthcare decisions that patients and their doctors have to make every day.

- ⚙ High percentage of decisions are not supported by evidence
- ⚙ Health outcomes and disparities are not improving
- ⚙ Current clinical research system faces several problems:



Too slow



Too expensive



Doesn't answer questions that matter most to people



PCORnet: the National Patient-Centered Clinical Research Network



PCORnet is **a large, highly representative, national patient-centered clinical research network**.

Our **vision** is to support a learning U.S. healthcare system and to enable **large-scale clinical research** conducted with **enhanced quality and efficiency**.

Our **mission** is to enable faster, more trustworthy clinical research that **helps people make informed health decisions**.

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With PCORnet, we have developed a nationwide functional research network that...

- ⚙️ **Creates** infrastructure, tools, and policies to support rapid, efficient clinical research
- ⚙️ **Utilizes** multiple electronic health records, insurance claims data, data reported directly by people, and other data sources
- ⚙️ **Engages** people, clinicians, and health system leaders throughout



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PCORnet embodies a “community of research” by uniting people, clinicians & systems



20
Patient-Powered Research
Networks (**PPRNs**)

+

13
Clinical Data
Research Networks
(**CDRNs**)

=

PCORnet
A national infrastructure
for people-centered
clinical research



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Clinical Data Research Networks (CDRNs)

ADVANCE	Accelerating Data Value Across a National Community Health Center Network (ADVANCE) Oregon Community Health Information Network (OCHIN)	PEDSnet A Pediatric Learning Health System The Children's Hospital of Philadelphia
CAPriCORN	Chicago Area Patient Centered Outcomes Research Network (CAPriCORN) The Chicago Community Trust	NYC-CDRN New York City Clinical Data Research Network New York City Clinical Data Research Network (NYC-CDRN) Weill Medical College of Cornell University
GPC	Greater Plains Collaborative (GPC) University of Kansas Medical Center	OneFlorida Clinical Research Consortium OneFlorida Clinical Data Research Network University of Florida
PORTAL	Kaiser Permanente & Strategic Partners Patient Outcomes Research To Advance Learning (PORTAL) Network Kaiser Foundation Research Institute	LHSNet Patient-Centered Network of Learning Health Systems (LHSNet) Mayo Clinic
REACHnet	Research Action for Health Network (REACHnet) Louisiana Public Health Institute (LPHI)	pSCANNER Patient-oriented SCALable National Network for Effectiveness Research (pSCANNER) University of California, San Diego (UCSD)
Mid-South CDRN	Mid-South CDRN Vanderbilt University	PaTH Towards a Learning Health System University of Pittsburgh
SCILHS	Scalable Collaborative Infrastructure for a Learning Healthcare System (SCILHS) Harvard University	



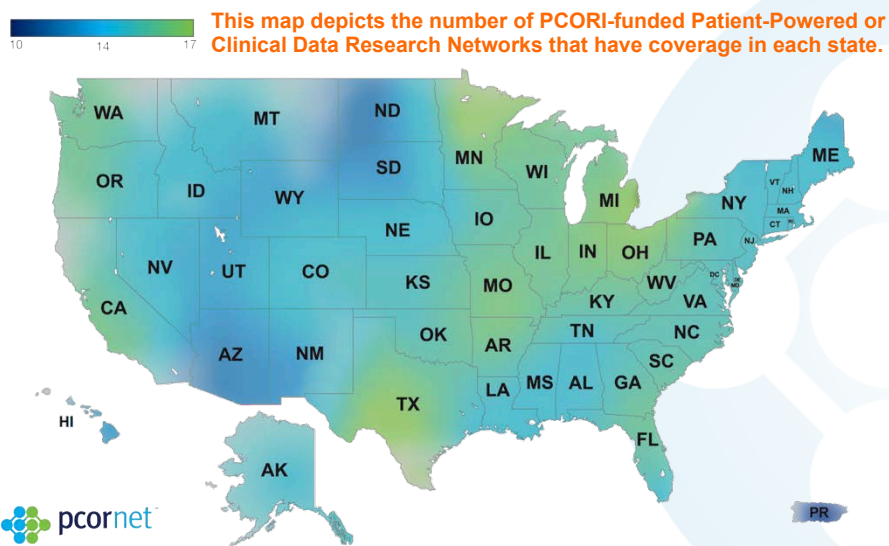
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Patient Powered Research Networks (PPRNs)

	American BRCA Outcomes and Utilization of Testing Patient-Powered Research Network (ABOUT Network) University of South Florida		ImproveCareNow: A Learning Health System for Children with Crohn's Disease and Ulcerative Colitis Cincinnati Children's Hospital Medical Center
	ARthritis patient Partnership with comparative Effectiveness Researchers (AR-PoWER PPRN) Global Health Living Foundation		Interactive Autism Network Kennedy Krieger Institute
	CCFA Partners Patient Powered Research Network Crohn's and Colitis Foundation of America		Mood Patient-Powered Research Network Massachusetts General Hospital
	Collaborative Patient-Centered Rare Epilepsy Network (REN) Epilepsy Foundation		Multiple Sclerosis Patient-Powered Research Network Accelerated Cure Project for Multiple Sclerosis
	Community and Patient-Partnered Centers of Excellence for Behavioral Health University of California Los Angeles		National Alzheimer's and Dementia Patient and Caregiver-Powered Research Network Mayo Clinic
	Community-Engaged Network for All (CENA) Genetic Alliance, Inc.		NephCure Kidney International Arbor Research Collaborative for Health
	COPD Patient Powered Research Network COPD Foundation		Patients, Advocates and Rheumatology Teams Network for Research and Service (PARTNERS) Consortium Duke University
	DuchenneConnect Registry Network Parent Project Muscular Dystrophy		Phelan-McDermid Syndrome Data Network Phelan-McDermid Syndrome Foundation
	Health eHeart Alliance University of California, San Francisco (UCSF)		PI Patient Research Connection: PI-CONNECT Immune Deficiency Foundation
			Population Research in Identity and Disparities for Equality Patient-Powered Research Network (PRIDE.net) University of California San Francisco
			Vasculitis Patient Powered Research Network University of Pennsylvania

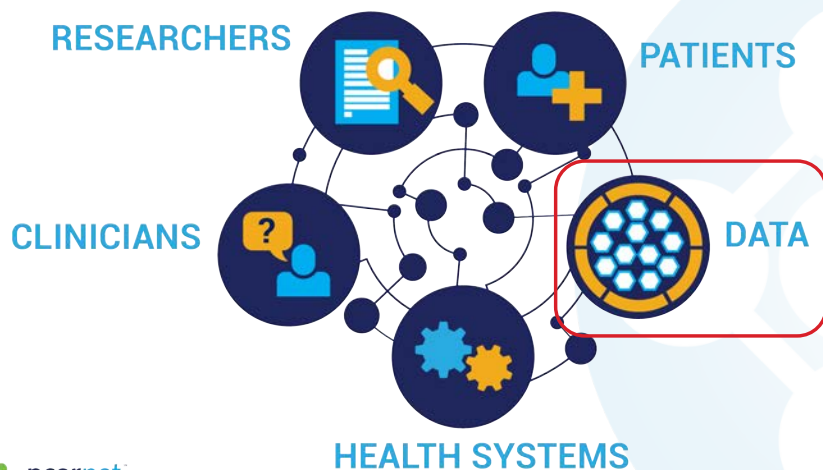
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With coverage in every state — PCORnet represents thousands of conditions



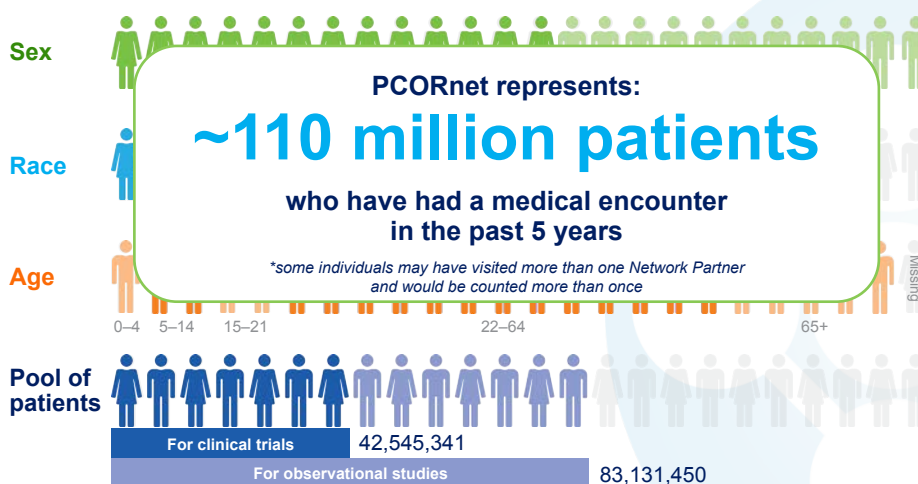
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A community of research that unites data from patients, clinicians, and systems



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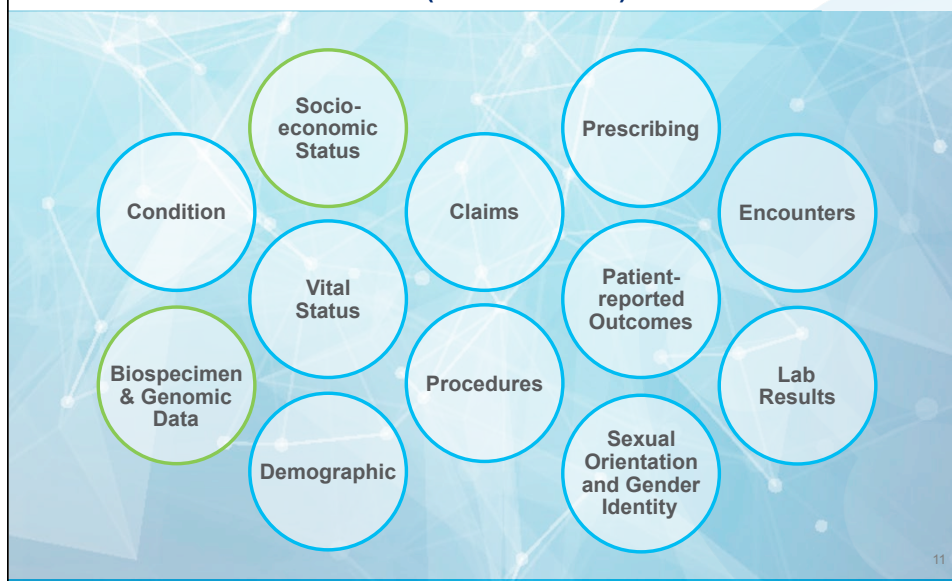
Resulting in a national evidence system with unparalleled research readiness



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Underpinned by a Common Data Model (PCORnet CDM)

- Data domains in the CDM
○ Domains that can be added



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Underpinned by a Common Data Model (PCORnet CDM)

Same data are represented differently at different institutions
(e.g., Type of Encounter)

Common Data Model		
SITE 1	SITE 2	
Social Work Visit	Office Visit	Ambulatory Visit (AV)
Allied Health	Specimen	Emergency Department (ED)
Office Visit	Postpartum Visit	ED Admit to Inpatient (EI)
Nurse Visit	Clinical Support	Inpatient Hospital (IP)
Procedure Visit	Initial Prenatal	Non-Acute Inst. Stay (IS)
Employee Health		Other Ambulatory (OA)
Vascular Lab		Other (OT)
Sleep Study Visit		Unknown (UN)
Social Work Visit		No Information (NI)
		(null)
		Ambulatory Visit (AV)
	SITE 3	
	Home Care Visit	
	Office Visit	
	Therapy Visit	
	Orders Only	
	Cardiology Testing	
	Hospital Encounter	

In order to be able to trust results of an analysis, need to have consistent representations

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Demographics: Initial Results that included more than 40 million persons with a 2014 encounter

	PCORnet*	2010 US Census
Age		
0-20	27.6%	27.0%
21-44	28.1%	33.6%
45-64	26.6%	26.4%
65-74	10.1%	7.0%
75+	7.7%	6.0%
Sex		
Female	57.1%	50.8%
Male	42.9%	49.2%
Other/Missing	0.0%	
Race		
Black/African American	12.1%	12.6%
White	62.4%	72.4%
Other/Missing	25.6%	15.0%
Hispanic		
Yes	14.2%	16.3%
No	61.5%	83.7%
Other/Missing	24.2%	



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*Number of patients with given characteristic with an encounter in any care setting divided by the total number of patients with an encounter in any care setting (2014).

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Selected Condition: Counts of Patients

Condition	PCORnet*
Diabetes	750,269
Pulmonary Disease	2,837,803
Any Malignancy	1,294,158
MI	354,929
Stroke	420,802
Rheumatoid Arthritis	254,803
Ulcerative Colitis	88,029
Hypertension	5,902,641
Renal Disease	1,018,729
Influenza/ Pneumonia	869,306



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*Number of patients with condition of interest in any care setting divided by the total number of patients with an encounter in any care setting (2014).

**Most estimates are based on adults only.

***Prevalence of CKD

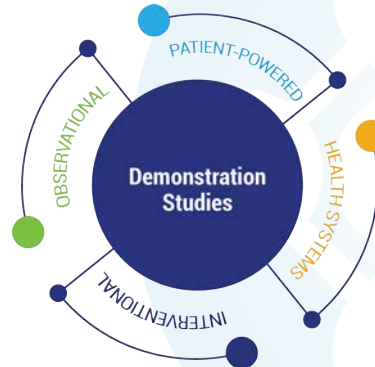
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We've tested our system's functionality in multiple research settings

14 PCORI-funded PCORnet demonstration studies are answering critical research questions while also testing the infrastructure and key functional aspects of PCORnet.

- Interventional studies
- Observational studies
- Patient-powered research network (PPRN) studies
- Health systems studies

Learn more about
PCORnet Demonstration Studies



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We've also amplified our research power with cross-network collaboration

Collaborative Research Groups: Catalyzing Multi-Network Research



- Autoimmune and Systemic Inflammatory Syndromes
- Behavioral Health
- Cancer
- Cardiovascular Health
- Diabetes and Obesity
- Health Disparities
- Health Systems, Health Policy, and Public Health
- Hospital Medicine
- Kidney Health
- Pediatrics
- Pulmonary



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Current PCORnet CRGs:

CRG Name	Administrative Prime	Participating Networks
Autoimmune and Systemic Inflammatory Syndromes	AR-PoWER PPRN	Vasculitis
Behavioral Health	NYC CDRN	CPPRN
Cancer	GPC CDRN	ABOUT, PORTAL
Cardiovascular Health	Health eHeart Alliance PPRN	LHSnet, OneFlorida
Diabetes and Obesity	Mid-South CDRN	OneFlorida
Health Disparities	ADVANCE CDRN	PRIDEnet
Health Systems, Health Policy and Public Health	NYC CDRN	OneFlorida
Hospital Medicine	pSCANNER CDRN	Mid-South, CAPriCORN
Kidney Health	NephCure PPRN	LHSnet, pSCANNER, Mid-South
Pediatrics	PEDSnet CDRN	OneFlorida
Pulmonary	COPD PPRN	PaTH



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You can use PCORnet for many kinds of research



Pre-research

- Feasibility queries
- Engagement
- Match-making



Interventional studies

- Clinical trials
- Pragmatic randomized clinical trials
 - e-Identification
 - e-Consent
 - e-Randomization
 - e-Follow-up
- Cluster randomization



Observational studies

- Cross-sectional
- Epidemiology
- Health services
- Comparative effectiveness or safety



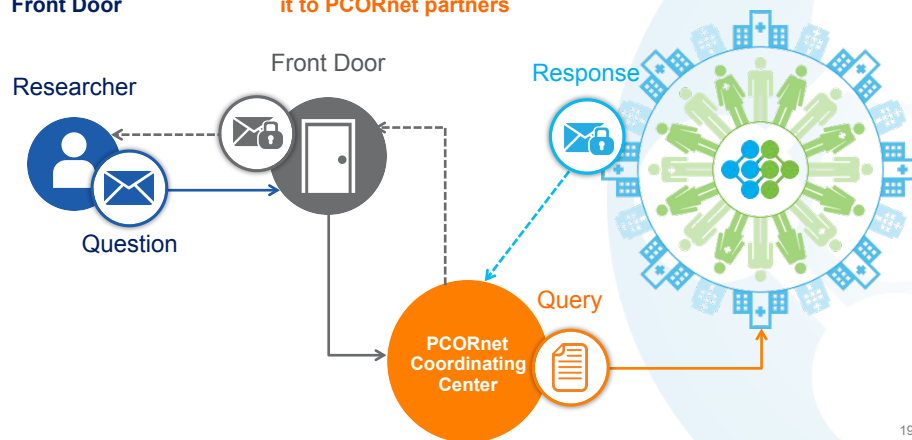
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Here's how the PCORnet® distributed research network works

The Researcher sends a question to the PCORnet Coordinating Center through the Front Door

The Coordinating Center converts the question into a query with an underlying executable code, and sends it to PCORnet partners

PCORnet partners review the query and provide a response, which is sent back through the Front Door to the Researcher



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Think of all the different ways you can leverage PCORnet

Request for Feasibility Review & Designation



SUBMIT
Request for Feasibility Review & Designation

Data Network Request



SUBMIT
Data Network Request

Request for Network Collaborators



SUBMIT
Request for Network Collaborators

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A Front Door is OPEN... take your research to the next level



- ⚙ Through PCORnet Front Door, we invite PCORnet researchers and other investigators, patient groups, healthcare organizations, clinicians or clinician groups, government and industry scientists, and sponsors to collaborate on important patient-centered clinical research studies.
- ⚙ For general questions, contact us at frontdoor@pcornet.org

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More information on PCORnet®

- ⚙ Website: www.pcornet.org
- ⚙ PCORnet Commons: <http://pcornetcommons.org/>
- ⚙ Twitter: [@PCORnetwork](https://twitter.com/PCORnetwork)
- ⚙ YouTube: [PCORI YouTube Playlist](#)
- ⚙ Vimeo: [PCORI Vimeo Playlist](#)
- ⚙ PCORnet communications contact: Jennifer.Cook@duke.edu



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PCORnet® and PCORI

About PCORnet

PCORnet, the National Patient-Centered Clinical Research Network, is an innovative initiative of the Patient-Centered Outcomes Research Institute (PCORI). The goal of PCORnet is to improve the nation's capacity to conduct clinical research by creating a large, highly representative network that directly involves patients in the development and execution of research. More information is available at www.pcornet.org.

About PCORI

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, nonprofit organization authorized by Congress in 2010. Its mission is to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions. PCORI is committed to continually seeking input from a broad range of stakeholders to guide its work. More information is available at www.pcori.org.



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Questions or Comments?

mzirkle@pcori.org



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