Accessing PCORnet's Data and Network Resources

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pcornet SM | The National Patient-Centered Clinical Research Network

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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

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But how can we improve?

What if we could **decrease the time it takes to get clinical insights?**

What if we could achieve **significant cost savings** over a traditional clinical study?

What if we could have at our fingertips **trustworthy, high-quality data** from health systems, people and partnerships to **bring people the real-world answers they seek?**

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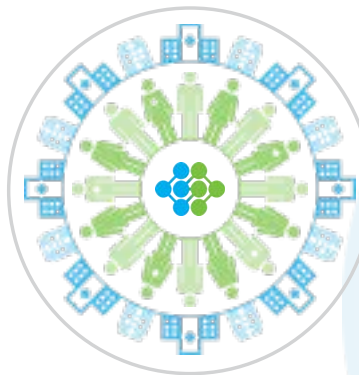
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With PCORnet, we have developed a nationwide functional research network that…

○ **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

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Patient-Powered Research Networks (**PPRNs**)	**+**	Clinical Data Research Networks (**CDRNs**)	**=**	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)

CAPriCORN
[Chicago Area Patient Centered Outcomes Research Network (CAPriCORN)](#)
The Chicago Community Trust

GPC (Greater Plains Collaborative)
[Greater Plains Collaborative (GPC)](#)
University of Kansas Medical Center

PORTAL
[Kaiser Permanente & Strategic Partners Patient Outcomes Research To Advance Learning (PORTAL) Network](#)
Kaiser Foundation Research Institute

REACHnet
[Research Action for Health Network (REACHnet)](#)
Louisiana Public Health Institute (LPHI)

[Mid-South CDRN](#)
Vanderbilt University

PEDSnet (A Pediatric Learning Health System)
[National PEDSnet: A Pediatric Learning Health System](#)
The Children's Hospital of Philadelphia

NYC-CDRN New York City Clinical Data Research Network
[New York City Clinical Data Research Network (NYC-CDRN)](#)
Weill Medical College of Cornell University

OneFlorida Clinical Research Consortium
[OneFlorida Clinical Data Research Network](#)
University of Florida

LHSNet LEARN . STUDY . TRANSLATE . DISSEMINATE
[Patient-Centered Network of Learning Health Systems (LHSNet)](#)
Mayo Clinic

pSCANNER
[Patient-oriented SCAlable National Network for Effectiveness Research (pSCANNER)](#)
University of California, San Diego (UCSD)

PaTH Network patient empowered research
[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)

ABOUT
[American BRCA Outcomes and Utilization of Testing Patient-Powered Research Network (ABOUT Network)](#)
University of South Florida

ARTHRITIS POWER
[ARthritis patient Partnership with comparative Effectiveness Researchers (AR-PoWER PPRN)](#)
Global Health Living Foundation

CCFA Partners
[CCFA Partners Patient Powered Research Network](#)
Crohn's and Colitis Foundation of America

REN Rare Epilepsy Network
[Collaborative Patient-Centered Rare Epilepsy Network (REN)](#)
Epilepsy Foundation

[Community and Patient-Partnered Centers of Excellence for Behavioral Health](#)
University of California Los Angeles

cena
[Community-Engaged Network for All (CENA)](#)
Genetic Alliance, Inc.

COPD PPRN
[COPD Patient Powered Research Network](#)
COPD Foundation

DuchenneConnect
[DuchenneConnect Registry Network](#)
Parent Project Muscular Dystrophy

Health eHeart
[Health eHeart Alliance](#)
University of California, San Francisco (UCSF)

IMPROVECARENOW
[ImproveCareNow: A Learning Health System for Children with Crohn's Disease and Ulcerative Colitis](#)
Cincinnati Children's Hospital Medical Center

IAN interactive autism network LINKING THE AUTISM COMMUNITY AND RESEARCHERS
[Interactive Autism Network](#)
Kennedy Krieger Institute

MoodNetwork
[Mood Patient-Powered Research Network](#)
Massachusetts General Hospital

iConquer MS
[Multiple Sclerosis Patient-Powered Research Network](#)
Accelerated Cure Project for Multiple Sclerosis

ALZHEIMER'S PPRN
[National Alzheimer's and Dementia Patient and Caregiver-Powered Research Network](#)
Mayo Clinic

NEPHCURE Kidney International Saving Kidneys · Saving Lives
[NephCure Kidney International](#)
Arbor Research Collaborative for Health

PARTNERS
[Patients, Advocates and Rheumatology Teams Network for Research and Service (PARTNERS) Consortium](#)
Duke University

[Phelan-McDermid Syndrome Data Network](#)
Phelan-McDermid Syndrome Foundation

PI CONNeCT IDF Patient Powered Research
[PI Patient Research Connection: PI-CONNECT](#)
Immune Deficiency Foundation

THE PRIDE STUDY
[Population Research in Identity and Disparities for Equality Patient-Powered Research Network (PRIDEnet)](#)
University of California San Francisco

V PPRN
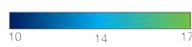[Vasculitis Patient Powered Research Network](#)
University of Pennsylvania

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PCORnet Projects (n=18)

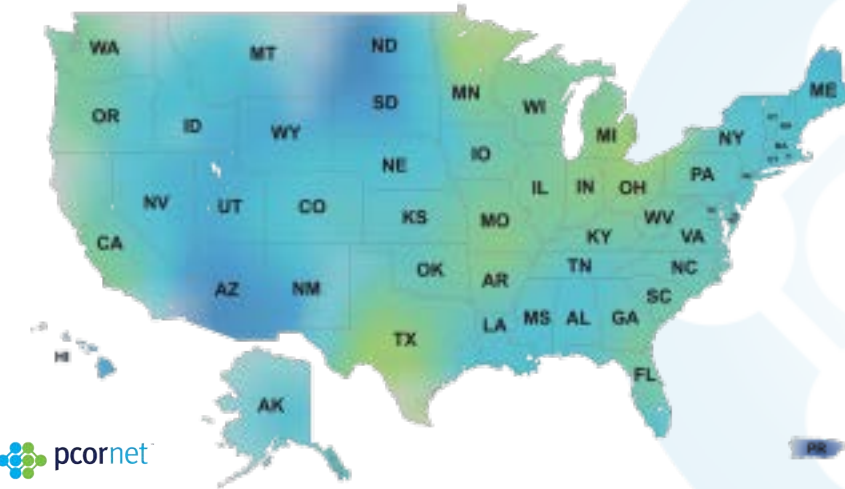| Network Lead	PI	Title	Study Phase	Sponsor
CC-Duke	Adrian Hernandez, Matthew Roe	ADAPTABLE: Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-Term Effectiveness	Enrolling	PCORI: $14 million
PORTAL	David Arterburn	PCORnet Bariatric Study	Awarded, Planning	PCORI: $4.5 million
CC-HPHC	Jason Block	Obesity-Short and Long-Term Effects of Antibiotics on Childhood Growth	Awarded, Planning	PCORI: $4.5 million
COPD	Jerry Krishnan	RELIANCE; Roflumilast or Azithromycin to Prevent COPD Exacerbations	Awarded, Planning	PCORI: $13.7 million
University of Wisconsin-Madison	Scott Solomon Orly Vardeny	INfluenza Vaccine to Effectively Stop Cardio Thoracic Events and Decompensated heart failure (INVESTED)	Awarded, Planning	PCORI: $1.3 million
ImproveCare Now	Michael Kappelman	COMBINE; AntiTNF Monotherapy versus Combination Therapy with Low Dose Methotrexate in Pediatric Crohn's Disease	Awarded, Planning	PCORI: $7.8 million
OneFlorida	Bill Hogan	Surveillance for Microcephaly	Proposal	FDA/Reagan-Udall/PCORI: $500K
CAPriCORN	William Trick	Antimicrobial Use and Reporting	Proposal	FDA/Reagan-Udall/PCORI: $500K
CC-Duke	Sreekanth Vemulapalli	Improving Data Completeness and Expanding Available Data Elements in the TVT Registry through the use of Electronic Health Record Based Data: Linking the TVT Registry and PCORnet	Proposal	FDA/Reagan-Udall/PCORI: $500K

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PCORnet Projects

Network Lead	PI	Title	Study Phase	Sponsor
CPPRN	Bowen Chung	Resiliency Education to Reduce Depression Disparities	Awarded, Planning	PCORI: $2.5 million
AR-PoWER	Jeffrey Curtis	Harnessing PCORnet to Study Comparative Effectiveness and Safety Biologic Therapies	Awarded, Planning	PCORI: $2.5 million
COPD	David Mannino	Monitoring and Peer Support to Improve Treatment Adherence and Outcomes in Patients with Overlap Chronic Obstructive Pulmonary Disease and Sleep Apnea via a Large PCORnet Collaboration (O2VERLAP)	Awarded, Planning	PCORI: $2.48 million
CCFA Partners	James Lewis	Comparative Effectiveness of Specific Carbohydrate and Mediterranean Diets to Induce Remission in Patients with Crohn's Disease	Awarded, Planning	PCORI: $2.5 million
MOOD	Andrew Nierenberg	Healthy Hearts Health Minds: A PPRN Demonstration Pragmatic Trial	Awarded, Planning	PCORI: $2.49 million
GPC	Maureen Smith	Variation in Case Management Programs and Their Effectiveness in Managing High-Risk Patients for Medicare ACOs	Awarded, Planning	PCORI: $1.4 million
ADVANCE	Scott Fields	The Impact of Patient Complexity on Healthcare Utilization	Awarded, Planning	PCORI: $1 million
PEDSnet	Kathleen Walsh	Automating Quality and Safety Benchmarking for Children: Meeting the Needs of Health Systems and Patients	Awarded, Planning	PCORI: $670,000
NYC-CDRN	Rainu Kaushal	Identifying and Predicting Patients with Preventable High Utilization	Awarded, Planning	PCORI: $1.2 million

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With coverage in every state — PCORnet represents thousands of conditions
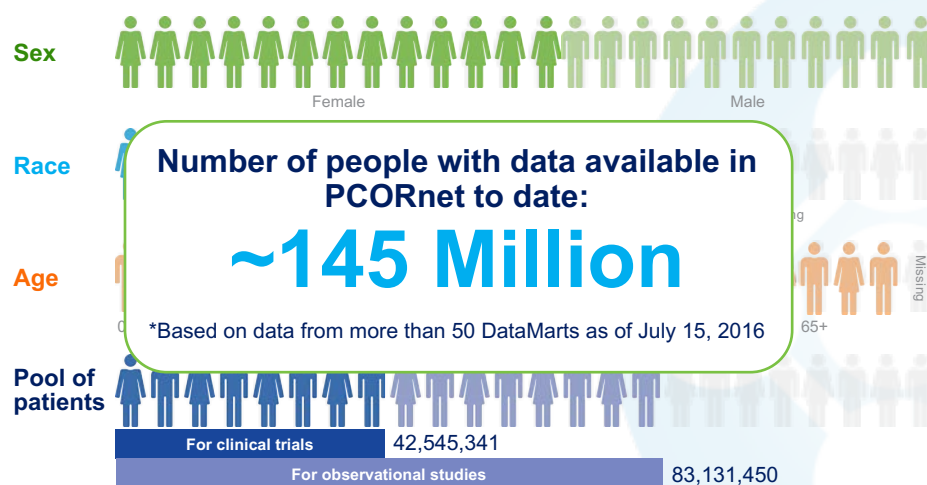
This map depicts the number of PCORI-funded Patient-Powered or Clinical Data Research Networks that have coverage in each state.
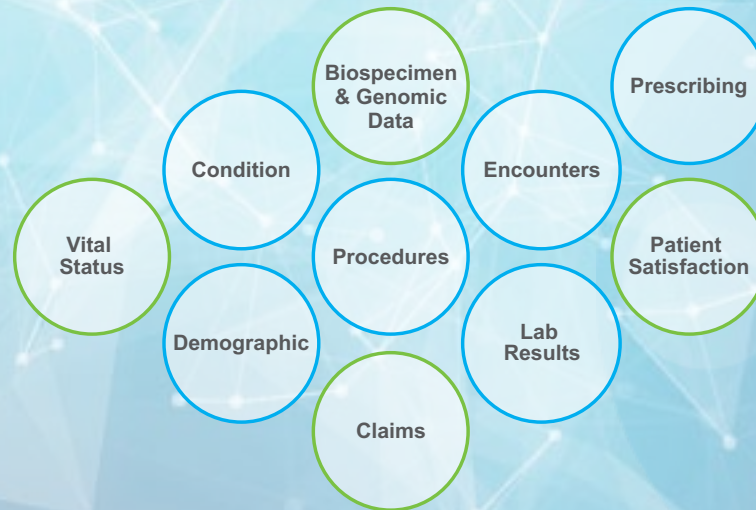
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Resulting in a national evidence system with unparalleled research readiness

Sex

Female   Male

Race

Number of people with data available in PCORnet to date:

~145 Million

*Based on data from more than 50 DataMarts as of July 15, 2016

Age

65+

Pool of patients

For clinical trials   42,545,341
For observational studies   83,131,450

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Underpinned by a Common Data Model (PCORnet CDM)

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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	Common Data Model
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	SITE 3	Unknown (UN)
Social Work Visit	Home Care Visit	No Information (NI)
	Office Visit	(null)
	Therapy Visit	Ambulatory Visit (AV)
	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 (50 Data Marts)

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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Even more enhancements in data and expertise are coming soon

New data streams
- Claims data
- People-reported data
- Medicare data
- Registry data

More expertise
- **Collaborative research groups (CRGs)—** both organically grown and funded — in the months and years to come

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What is a Collaborative Research Group (CRG)?

⊙ A community organized to facilitate research on health condition(s) or areas of health research

⊙ Cross-cutting: includes CDRNs & PPRNs

⊙ CRGs can have Research Interest Groups
- CRG (Cardiovascular)
  - RIG 1 (Atrial fibrillation)
  - RIG 2 (Hypertension)
  - RIG n (etc.)

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What do Collaborative Research Groups (CRGs) do?

1. Membership

2. Leadership/Management

3. Communication

4. Data Science

5. Study Catalyst

6. Front Door

7. Research Priorities

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You can use PCORnet for many kinds of research

Pre-research
- Feasibility queries
- Engagement
- Match-making

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

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

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Administrative Efficiencies

- Common data sharing agreement

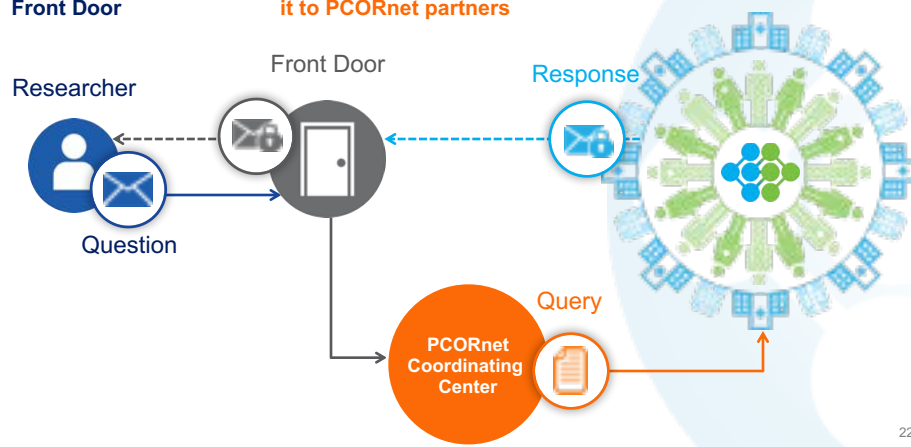- Single IRB arrangement

- Streamlined contracting

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Here's how PCORnet's 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

Front Door

Researcher

Response

Question

Query

PCORnet Coordinating Center

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Think of all the different ways you can leverage PCORnet

Faster answers to pre-research queries

Valuable expertise via network collaboration

Enhanced credibility via PCORnet study designation

SUBMIT
Data Network Request

SUBMIT
Request for Network Collaboration

SUBMIT
Request for PCORnet Study Designation

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**A Front Door is opening soon…
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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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 comparative clinical effectiveness research efficiently by creating a large, highly representative network for conducting clinical outcomes research that directly involves patients in the development and execution of the 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?

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