

Accessing PCORnet's Data and Network Resources

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pcornetSM

The National Patient-Centered
Clinical Research Network

Our national clinical research system is well-intentioned but flawed

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**

But what if we could 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?**

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.**



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

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

CDRNs

ADVANCE

[Accelerating Data Value Across a National Community Health Center Network \(ADVANCE\)](#)

Oregon Community Health Information Network (OCHIN)



[Chicago Area Patient Centered Outcomes Research Network \(CAPriCORN\)](#)

The Chicago Community Trust



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



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

Kaiser Foundation Research Institute



[Research Action for Health Network \(REACHnet\)](#)

Louisiana Public Health Institute (LPHI)



[Mid-South CDRN](#)
Vanderbilt University



[National PEDSnet: A Pediatric Learning Health System](#)

The Children's Hospital of Philadelphia



[New York City Clinical Data Research Network \(NYC-CDRN\)](#)

Weill Medical College of Cornell University



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



[Patient-Centered Network of Learning Health Systems \(LHSNet\)](#)

Mayo Clinic



[Patient-oriented SCALable National Network for Effectiveness Research \(pSCANNER\)](#)

University of California, San Diego (UCSD)



[PaTH: Towards a Learning Health System](#)
University of Pittsburgh



[Scalable Collaborative Infrastructure for a Learning Healthcare System \(SCILHS\)](#)

Harvard University

PPRNs



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

University of South Florida



[ARthritis patient Partnership with comparative Effectiveness Researchers \(AR-PoWER PPRN\)](#)

Global Healthy Living Foundation



[CCFA Partners Patient Powered Research Network](#)

Crohn's and Colitis Foundation of America



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

Epilepsy Foundation



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

University of California Los Angeles



[Community-Engaged Network for All \(CENA\)](#)

Genetic Alliance, Inc.



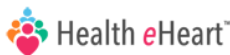
[COPD Patient Powered Research Network](#)

COPD Foundation



[DuchenneConnect Registry Network](#)

Parent Project Muscular Dystrophy



[Health eHeart Alliance](#)

University of California, San Francisco (UCSF)



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



[Interactive Autism Network](#)

Kennedy Krieger Institute



[Mood Patient-Powered Research Network](#)

Massachusetts General Hospital



[Multiple Sclerosis Patient-Powered Research Network](#)

Accelerated Cure Project for Multiple Sclerosis



[National Alzheimer's and Dementia Patient and Caregiver-Powered Research Network](#)

Mayo Clinic



[NephCure Kidney International](#)

Arbor Research Collaborative for Health



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

Duke University



[Phelan-McDermid Syndrome Data Network](#)

Phelan-McDermid Syndrome Foundation



[PI Patient Research Connection: PI-CONNECT](#)

Immune Deficiency Foundation



[Population Research in Identity and Disparities for Equality Patient-Powered Research Network \(PRIDEnet\)](#)

University of California San Francisco



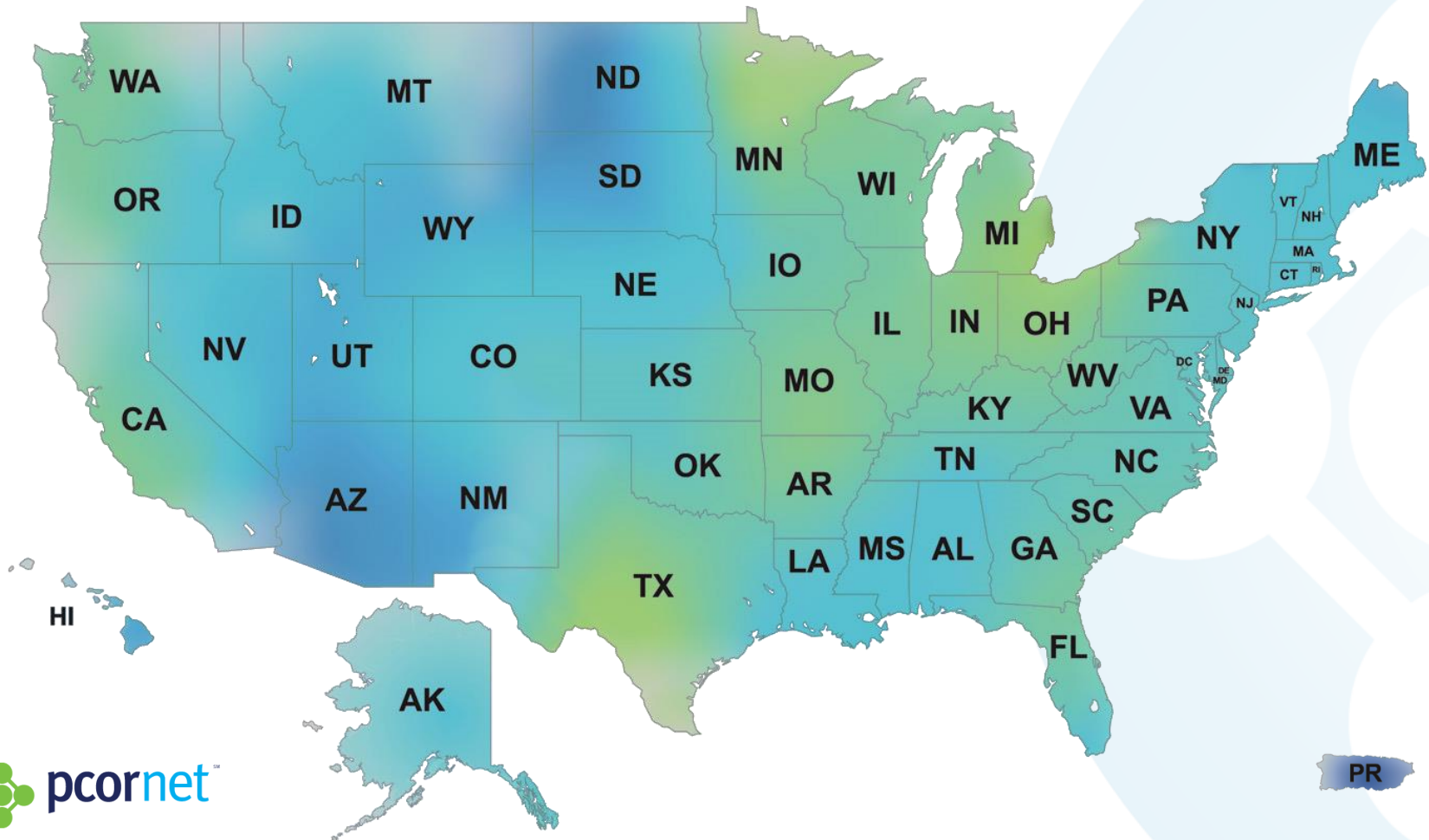
[Vasculitis Patient Powered Research Network](#)

University of Pennsylvania

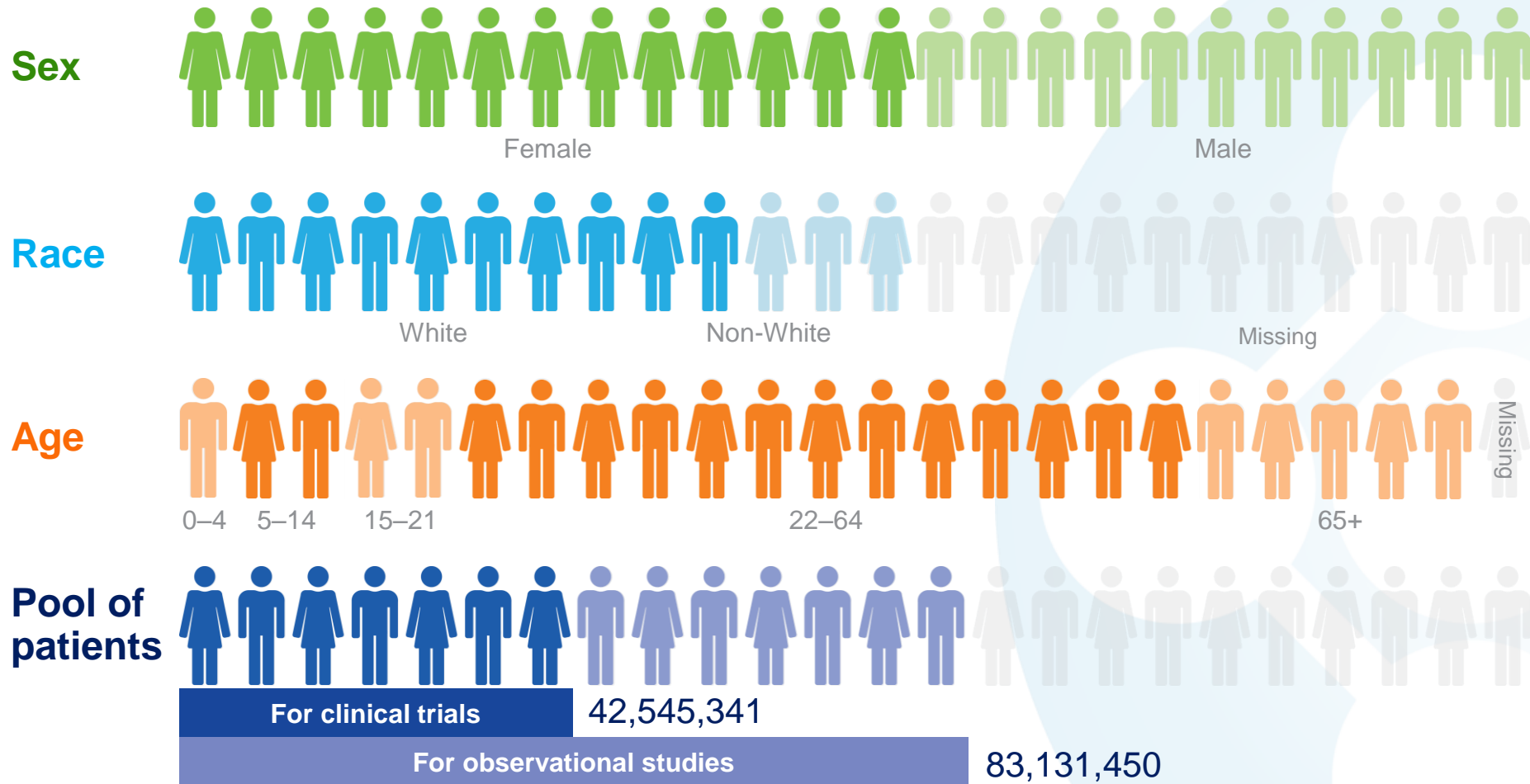
With coverage in every state — PCORnet represents thousands of conditions



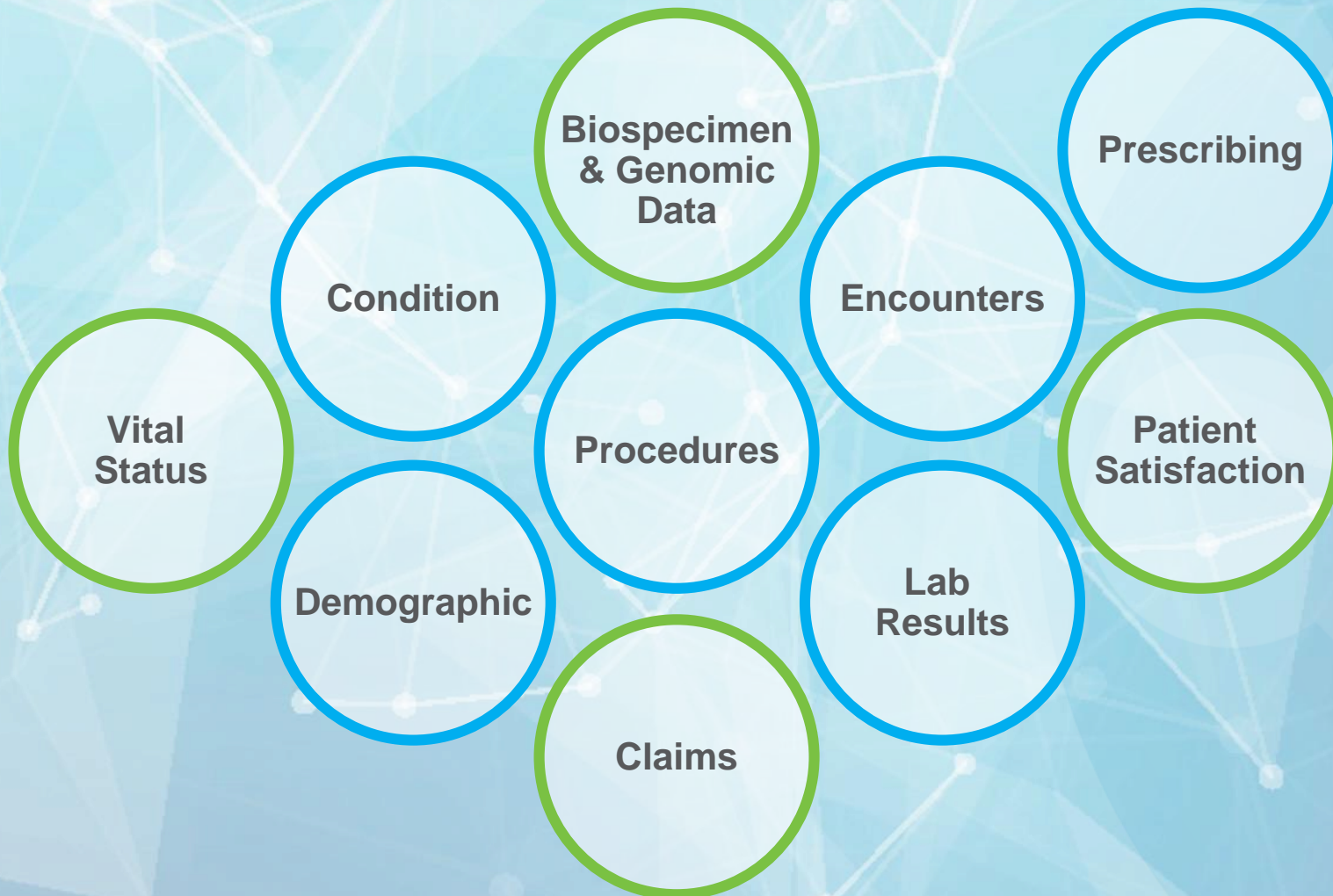
This map depicts the number of PCORI-funded Patient-Powered or Clinical Data Research Networks that have coverage in each state.



Resulting in a national evidence system with unparalleled research readiness



Underpinned by a Common Data Model



Underpinned by a Common Data Model

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

SITE 1

Social Work Visit
Allied Health
Office Visit
Nurse Visit
Procedure Visit
Employee Health
Vascular Lab
Sleep Study Visit
Social Work Visit

SITE 2

Office Visit
Specimen
Postpartum Visit
Clinical Support
Initial Prenatal

SITE 3

Home Care Visit
Office Visit
Therapy Visit
Orders Only
Cardiology Testing
Hospital Encounter

Common Data Model

Ambulatory Visit (AV)
Emergency Department (ED)
ED Admit to Inpatient (EI)
Inpatient Hospital (IP)
Non-Acute Inst. Stay (IS)
Other Ambulatory (OA)
Other (OT)
Unknown (UN)
No Information (NI)
(null)
Ambulatory Visit (AV)

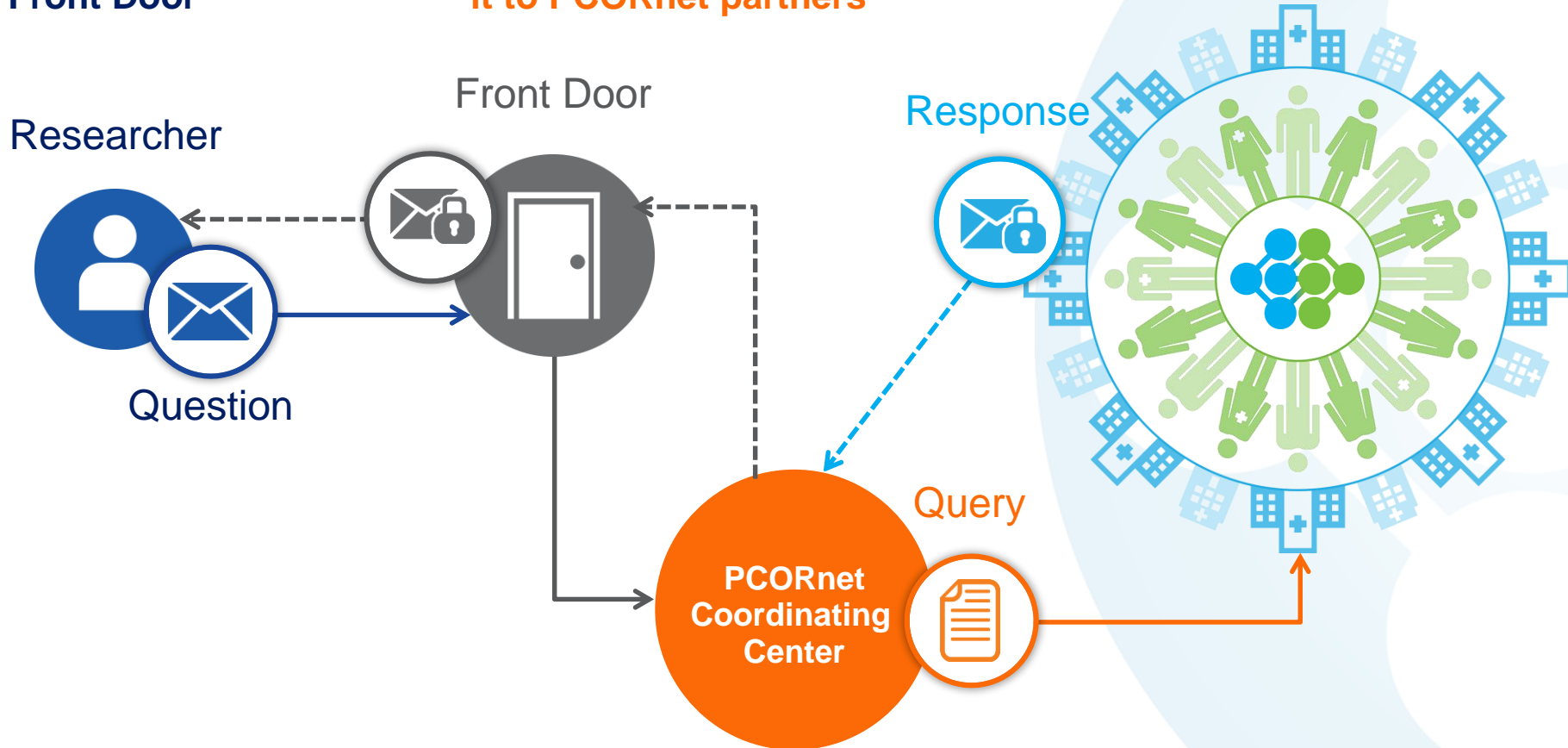
In order to be able to trust results of an analysis, need to have consistent representations

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



Demographics: Initial Results from 26 Data Marts that included 23 million persons with a 2014 encounter

	PCORnet*	2010 US Census
Age		
0-20	34%	27%
21-44	27%	34%
45-64	24%	26%
65-74	9%	7%
75+	6%	6%
Sex		
Female	55%	51%
Male	45%	49%
Race		
Black/African American	14%	13%
White	54%	72%
Other/Missing	32%	15%
Hispanic		
Yes	19%	16%
No	52%	84%
Other/Missing	29%	

**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).*

Selected Condition: Counts of Patients (23 Data Marts)

Condition	Count
Diabetes	530,000
Pulmonary Disease	1,900,000
Any Malignancy	740,000
MI	230,000
Stroke	230,000
Rheumatoid Arthritis	139,000
Ulcerative Colitis	46,000
Hypertension	3,420,000
Renal Disease	671,000
Influenza/ Pneumonia	578,000

**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*

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

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 — both organically grown and funded — in the months and years to come

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

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	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 Healthy 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



Administrative Efficiencies

- Common data sharing agreement
- Single IRB arrangement
- Streamlined contracting

Social Resources

- Governance
- Relationship network
- Engagement
- Communications



PCORnet Single IRB

SMART IRB (*formerly IRBrelay*)

- Endorsed by NCATS
- SOPs and Forms available; Electronic platform in development at Harvard
- Will be implemented among CTSA's Fall-Winter 2016

PCORnet

- SMART IRB Pilot Test
 - 14 PCORnet institutions have signed SMART IRB Master Agreement
 - Conducting evaluation of process, including cost and time requirements
- Coordinating efforts with NCATS/CTSA to implement among all PCORnet sites Fall-Winter 2016
 - Designated IRB Coordinator in Coordinating Center

Think of all the different ways you can leverage PCORnet

Faster answers to pre-research queries



SUBMIT
Data Network Request

Valuable expertise via network collaboration



SUBMIT
Request for Network Collaboration

Enhanced credibility via PCORnet study designation



SUBMIT
Request for PCORnet Study Designation

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