Accessing PCORnet’s Data and Network Resources

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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
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

\[ \text{20 Patient-Powered Research Networks (PPRNs)} + \text{13 Clinical Data Research Networks (CDRNs)} = \text{PCORnet} \]

A national infrastructure for people-centered clinical research

Clinical Data Research Networks (CDRNs)

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

- American BRCA Outcomes and Utilization of Testing Patient-Powered Research Network (ABOUT Network)
- Arthritis patient Partnership with comparative Effectiveness Researchers (ARM-Power PPRN)
- Global Health 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-Partnersed Centers of Excellence for Naturalist 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
- PRIDE Network
- 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.
A community of research that unites data from patients, clinicians, and systems

Resulting in a national evidence system with unparalleled research readiness

PCORnet represents:

\(~110\) million patients

who have had a medical encounter in the past 5 years

*some individuals may have visited more than one Network Partner and would be counted more than once

Pool of patients:

For clinical trials: 42,545,341

For observational studies: 83,131,450
Underpinned by a Common Data Model (PCORnet CDM)

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

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

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

<table>
<thead>
<tr>
<th>Age</th>
<th>PCORnet*</th>
<th>2010 US Census</th>
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</thead>
<tbody>
<tr>
<td>0-20</td>
<td>27.6%</td>
<td>27.0%</td>
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<tr>
<td>21-44</td>
<td>28.1%</td>
<td>33.6%</td>
</tr>
<tr>
<td>45-64</td>
<td>26.6%</td>
<td>26.4%</td>
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<tr>
<td>65-74</td>
<td>10.1%</td>
<td>7.0%</td>
</tr>
<tr>
<td>75+</td>
<td>7.7%</td>
<td>6.0%</td>
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</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>PCORnet*</th>
<th>2010 US Census</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>57.1%</td>
<td>50.8%</td>
</tr>
<tr>
<td>Male</td>
<td>42.9%</td>
<td>49.2%</td>
</tr>
<tr>
<td>Other/Missing</td>
<td>0.0%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>PCORnet*</th>
<th>2010 US Census</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black/African American</td>
<td>12.1%</td>
<td>12.6%</td>
</tr>
<tr>
<td>White</td>
<td>62.4%</td>
<td>72.4%</td>
</tr>
<tr>
<td>Other/Missing</td>
<td>25.6%</td>
<td>15.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hispanic</th>
<th>PCORnet*</th>
<th>2010 US Census</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>14.2%</td>
<td>16.3%</td>
</tr>
<tr>
<td>No</td>
<td>61.5%</td>
<td>83.7%</td>
</tr>
<tr>
<td>Other/Missing</td>
<td>24.2%</td>
<td></td>
</tr>
</tbody>
</table>

*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

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

*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
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
### Current PCORnet CRGs:

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

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
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.

Think of all the different ways you can leverage PCORnet

Request for Feasibility Review & Designation  Data Network Request  Request for Network Collaborators

SUBMIT Request for Feasibility Review & Designation
SUBMIT Data Network Request
SUBMIT Request for Network Collaborators
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

More information on PCORnet®

- Website: www.pcornet.org
- PCORnet Commons: http://pcornetcommons.org/
- Twitter: @PCORnetwork
- YouTube: PCORI YouTube Playlist
- Vimeo: PCORI Vimeo Playlist
- PCORnet communications contact: Jennifer.Cook@duke.edu
## 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](http://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](http://www.pcori.org).

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## Questions or Comments?

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[pcornet](http://pcornet.org) The National Patient-Centered Clinical Research Network