Accessing PCORnet’s Data and Network Resources

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

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
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?

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

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**PCORnet Structure and Decision-making Process**

Role Descriptions:

- **Executive Committee (EC):** Oversight for PCORnet operations
- **PCORnet Council:** Representative governing body for PCORnet strategy and operations; includes PCORnet’s 13 Clinical Data Research Networks (CDRNs) and 20 Patient-Powered Research Networks (PPRNs)
- **Coordinating Center (CC):** Coordinates operational activities, maintains data infrastructure, identifies research opportunities, coordinates multi-site research
PCORnet embodies a “community of research” by uniting people, clinicians & systems

PCORnet

A national infrastructure for people-centered clinical research

20 Patient-Powered Research Networks (PPRNs) + 13 Clinical Data Research Networks (CDRNs) = Clinical Data Research Networks (CDRNs)

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

OneFlorida Clinical Data Research Network
University of Florida

Greater Plains Collaborative (GPC)
University of Kansas Medical Center

Patient-Centered Network of Learning Health Systems (LHSNet)
Mayo Clinic

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

Patient-oriented SCAIable National Network for Effectiveness Research (pSCANNER)
University of California, San Diego (UCSD)

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

PaTH: Towards a Learning Health System
University of Pittsburgh

Mid-South CDRN
Vanderbilt University

National PEDSnet: A Pediatric Learning Health System
The Children’s Hospital of Philadelphia

pSCANNER

OneFlorida Clinical Data Research Network
University of Florida

PaTH

Patient-Centered Network of Learning Health Systems (LHSNet)
Mayo Clinic

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The Children’s Hospital of Philadelphia

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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

Arthritis Patient Partnership with Comparative Effectiveness Researchers (AR-POWER PPRN)
Global Living Foundation

CCFA Partners Patient Powered Research Network
Crohn’s and Colitis Foundation of America

Collaborative Patient-Centered Rare Epilepsy Network (REN)
Epilepsy Foundation

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

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

PCORnet Projects (n=18)

<table>
<thead>
<tr>
<th>Network Lead</th>
<th>PI</th>
<th>Title</th>
<th>Study Phase</th>
<th>Sponsor</th>
</tr>
</thead>
<tbody>
<tr>
<td>PORTAL</td>
<td>David Arterburn</td>
<td>PCORnet Bariatric Study</td>
<td>Awarded, Planning</td>
<td>PCORI: $4.5 million</td>
</tr>
<tr>
<td>CC-HPHC</td>
<td>Jason Block</td>
<td>Obesity-Short and Long-Term Effects of Antibiotics on Childhood Growth</td>
<td>Awarded, Planning</td>
<td>PCORI: $4.5 million</td>
</tr>
<tr>
<td>COPD</td>
<td>Jerry Krishnan</td>
<td>RELIANCE: Rolflumilast or Azithromycin to Prevent COPD Exacerbations</td>
<td>Awarded, Planning</td>
<td>PCORI: $13.7 million</td>
</tr>
<tr>
<td>University of Wisconsin-Madison</td>
<td>Scott Solomon, Orly Vardeny</td>
<td>Influenza Vaccine to Effectively Stop Cardio Thoracic Events and Decompensated heart failure (INVESTED)</td>
<td>Awarded, Planning</td>
<td>PCORI: $1.3 million</td>
</tr>
<tr>
<td>ImproveCareNow</td>
<td>Michael Kappelman</td>
<td>COMBINE: AntiTNF Monotherapy versus Combination Therapy with Low Dose Methotrexate in Pediatric Crohn’s Disease</td>
<td>Awarded, Planning</td>
<td>PCORI: $7.8 million</td>
</tr>
<tr>
<td>OneFlorida</td>
<td>Bill Hogan</td>
<td>Surveillance for Microcephaly</td>
<td>Proposal</td>
<td>FDA/Reagan-Udall/PCORI: $500K</td>
</tr>
<tr>
<td>CAPnCORN</td>
<td>William Trick</td>
<td>Antimicrobial Use and Reporting</td>
<td>Proposal</td>
<td>FDA/Reagan-Udall/PCORI: $500K</td>
</tr>
<tr>
<td>CC-Duke</td>
<td>Sreekanth Venugopal</td>
<td>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</td>
<td>Proposal</td>
<td>FDA/Reagan-Udall/PCORI: $500K</td>
</tr>
</tbody>
</table>
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<thead>
<tr>
<th>Network Lead</th>
<th>PI</th>
<th>Title</th>
<th>Study Phase</th>
<th>Sponsor</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPPRN</td>
<td>Bowen Chung</td>
<td>Resiliency Education to Reduce Depression Disparities</td>
<td>Awarded, Planning</td>
<td>PCORI: $2.5 million</td>
</tr>
<tr>
<td>AR-PoWER</td>
<td>Jeffrey Curtis</td>
<td>Harnessing PCORnet to Study Comparative Effectiveness and Safety Biologic Therapies</td>
<td>Awarded, Planning</td>
<td>PCORI: $2.5 million</td>
</tr>
<tr>
<td>COPD</td>
<td>David Mannino</td>
<td>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)</td>
<td>Awarded, Planning</td>
<td>PCORI: $2.48 million</td>
</tr>
<tr>
<td>CCFA Partners</td>
<td>James Lewis</td>
<td>Comparative Effectiveness of Specific Carbohydrate and Mediterranean Diets to Induce Remission in Patients with Crohn’s Disease</td>
<td>Awarded, Planning</td>
<td>PCORI: $2.5 million</td>
</tr>
<tr>
<td>MOOD</td>
<td>Andrew Nierenberg</td>
<td>Healthy Hearts Health Minds: A PPRN Demonstration Pragmatic Trial</td>
<td>Awarded, Planning</td>
<td>PCORI: $2.49 million</td>
</tr>
<tr>
<td>GPC</td>
<td>Maureen Smith</td>
<td>Variation in Case Management Programs and Their Effectiveness in Managing High-Risk Patients for Medicare ACOs</td>
<td>Awarded, Planning</td>
<td>PCORI: $1.4 million</td>
</tr>
<tr>
<td>ADVANCE</td>
<td>Scott Fields</td>
<td>The Impact of Patient Complexity on Healthcare Utilization</td>
<td>Awarded, Planning</td>
<td>PCORI: $1 million</td>
</tr>
<tr>
<td>PEDSnet</td>
<td>Kathleen Walsh</td>
<td>Automating Quality and Safety Benchmarking for Children: Meeting the Needs of Health Systems and Patients</td>
<td>Awarded, Planning</td>
<td>PCORI: $670,000</td>
</tr>
<tr>
<td>NYC-CDRN</td>
<td>Rainu Kaushal</td>
<td>Identifying and Predicting Patients with Preventable High Utilization</td>
<td>Awarded, Planning</td>
<td>PCORI: $1.2 million</td>
</tr>
</tbody>
</table>

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

PCORnet represents:

~90 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

Underpinned by a Common Data Model (PCORnet CDM)

Data domains in the CDM

Domains that can be added
Underpinned by a Common Data Model (PCORnet CDM)

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

### Common Data Model

<table>
<thead>
<tr>
<th>Ambulatory Visit (AV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Department (ED)</td>
</tr>
<tr>
<td>ED Admit to Inpatient (EI)</td>
</tr>
<tr>
<td>Inpatient Hospital (IP)</td>
</tr>
<tr>
<td>Non-Acute Inst. Stay (IS)</td>
</tr>
<tr>
<td>Other Ambulatory (OA)</td>
</tr>
<tr>
<td>Other (OT)</td>
</tr>
<tr>
<td>Unknown (UN)</td>
</tr>
<tr>
<td>No Information (NI)</td>
</tr>
<tr>
<td>(null)</td>
</tr>
<tr>
<td>Ambulatory Visit (AV)</td>
</tr>
</tbody>
</table>

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

### 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>
</tr>
</thead>
<tbody>
<tr>
<td>0-20</td>
<td>27.6%</td>
<td>27.0%</td>
</tr>
<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>
</tr>
<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>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th></th>
<th></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></th>
<th></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></th>
<th></th>
</tr>
</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 (50 Data Marts)

<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

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
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.)

What do Collaborative Research Groups (CRGs) do?

- Membership
- Leadership/Management
- Communication
- Data Science
- Study Catalyst
- Front Door
- Research Priorities
### Current PCORnet CRGs:

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<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, CAPriCORN</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
Administrative Efficiencies

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

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
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

A Front Door is opening…
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
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.

Twitter: @PCORnetwork

YouTube:

PCORI YouTube Playlist

Vimeo:

PCORI Vimeo Playlist

Questions or Comments?

mzirkle@pcori.org