PCORnet®: An Introduction

PCORnet® has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®)

Unite data and communities for faster, more targeted research

One PCORnet®, Many Possibilities

PCORnet is a national resource, funded by PCORI, where high quality health data, patient partnership, and research expertise deliver fast, trustworthy answers that advance health outcomes.

- **Real-world evidence studies**
- **Comparative effectiveness research**
- **Population health research**
- **Pragmatic research**
- **Health systems research**
- **And more**

More Than a Data Network

Access to patient partners and **thousands of clinicians** with expert knowledge of PCORnet-enabled data = meaningful research targets and faster answers.

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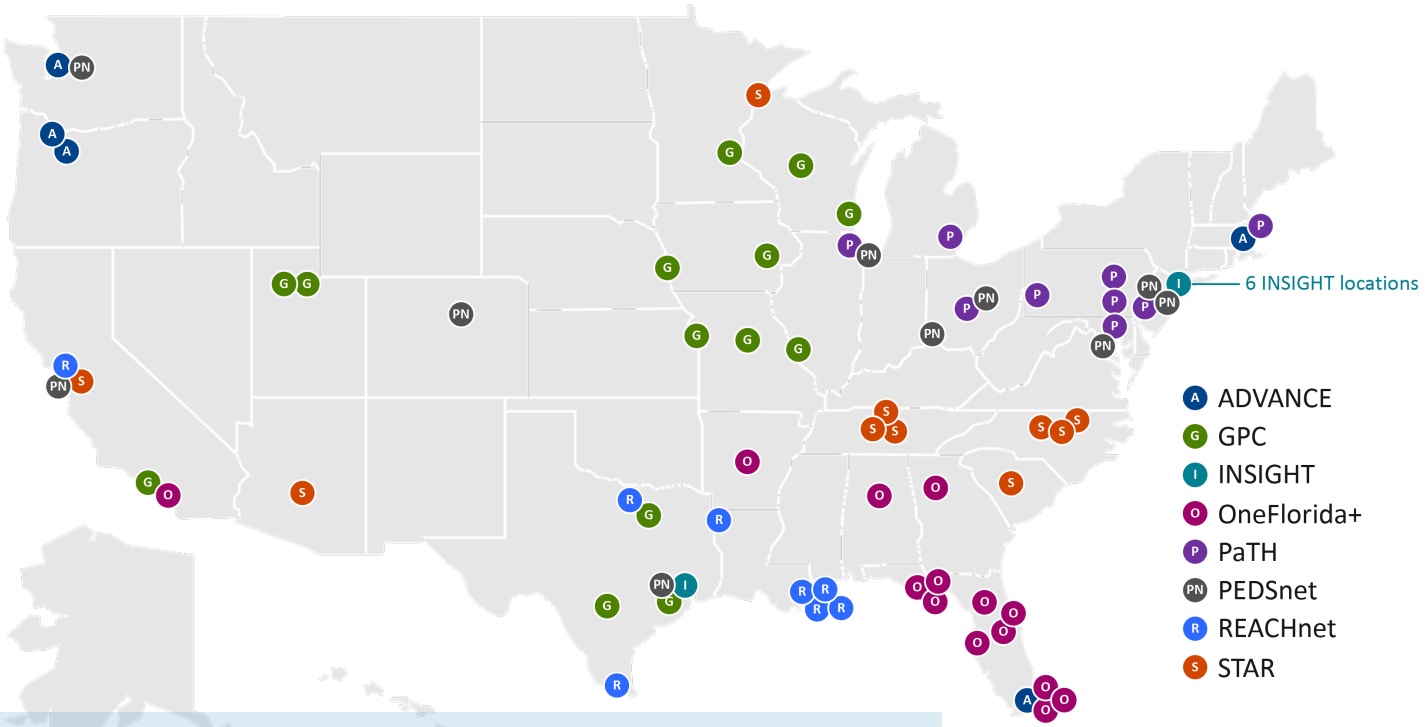
Data Insights via PCORnet®

PCORnet® Clinical Research Network locations

PCORnet infrastructure offers access to real-world data through partnerships with Clinical Research Networks (CRNs)



What are Clinical Research Networks?

CRNs are groups of diverse healthcare institutions across the U.S., from large academic health centers to local community clinics, united by a commitment to speed patient-centered research via PCORnet.

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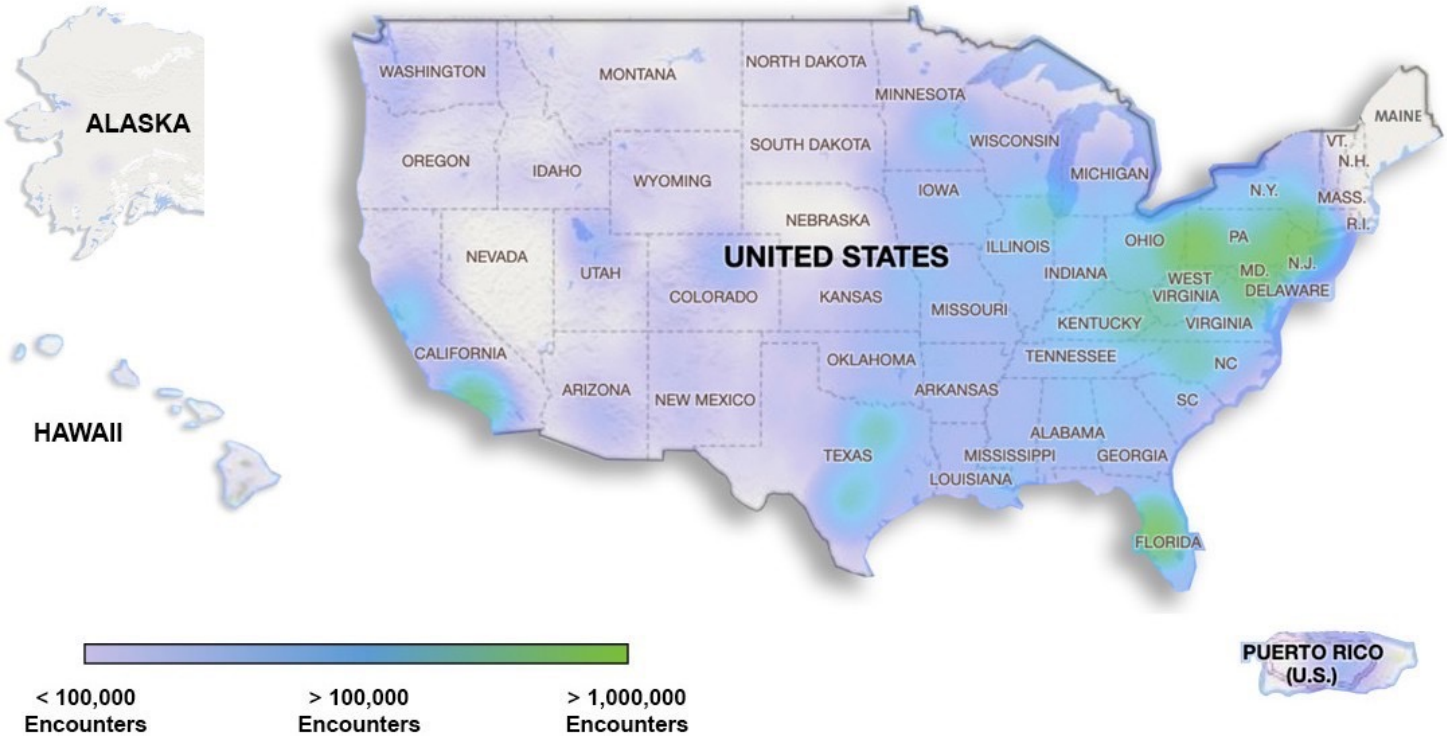
Scope of PCORnet-accessible data

PCORnet represents data from **everyday health care encounters with more than 30 million people** across the U.S. each year.



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**The data density maps illustrates single addresses that are associated with individual PCORnet Network Partner encounters.*

The PCORnet® Common Data Model

For data to be useful, it has to be standardized across systems. Frequent data curation and a single language enabled by the PCORnet® Common Data Model delivers fast insights.

Ready for Research			Available, But Still Evolving		
Demographics	Diagnoses	Procedures	Immunizations	Tumor Registry	Biosamples
Vital Signs	Labs	Clinical Observations	Social Determinants of Health	Patient-Generated Data	Genomic Results
Medication Orders & Administrations			Patient- Reported Outcomes	Natural Language Processing Derived Concepts	

Data available from Clinical Research Networks, in the PCORnet® Common Data Model and ready for use in research

Data available at some Clinical Research Networks, may or may not be in the PCORnet® Common Data Model and require additional work for use in research

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Community Engagement via PCORnet®

Engaged communities drive better, faster research

What do we mean by "communities"?

- **Patients and caregivers**, who have a seat at the table of every PCORnet® Study, engaging as coequal collaborators with health professionals
- **Clinicians/Clinic Staff**
- **Insurers**
- **Policymakers**
- **Others**

"Good studies consider all relevant evidence – and no evidence is more relevant than the community experience."
– PCORnet Steering Committee Member

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PCORnet® Compared with Other Research Networks

PCORnet infrastructure brings a full spectrum of capabilities, plus connection to communities

	Feasibility queries	Identify patient populations for trial recruitment	Coordinated data curation	Connection to patients and providers
PCORnet	●	●	●	●
ENACT	●	■	■	■
TriNetX	●	●	▲	■
OPTUM	■	●	▲	■
OHDSI	●	■	▲	▲
Sentinel	●	●	●	▲

● = capabilities ▲ = limited capabilities ■ = lacks capability

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Work with the Network

The PCORnet® Front Door

The Front Door is the Access Point for PCORnet Resources & Services

A "knock" on the Front Door can also support:

Study Design

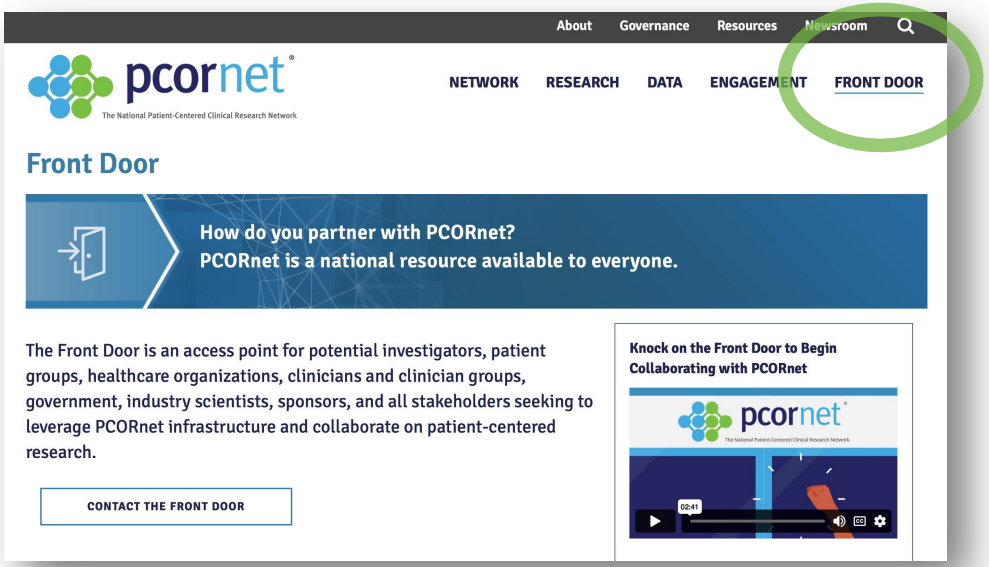
- Preliminary data for proposals, effect sizes and potential study power

Connections to Network Collaborators

- Partners to co-design research
- People with specific expertise

PCORnet Study Designation Support

- Deeper partnership with PCORnet provides access to best practice sharing, patient engagement, and transparent quality improvement initiatives



Learn More About the Front Door

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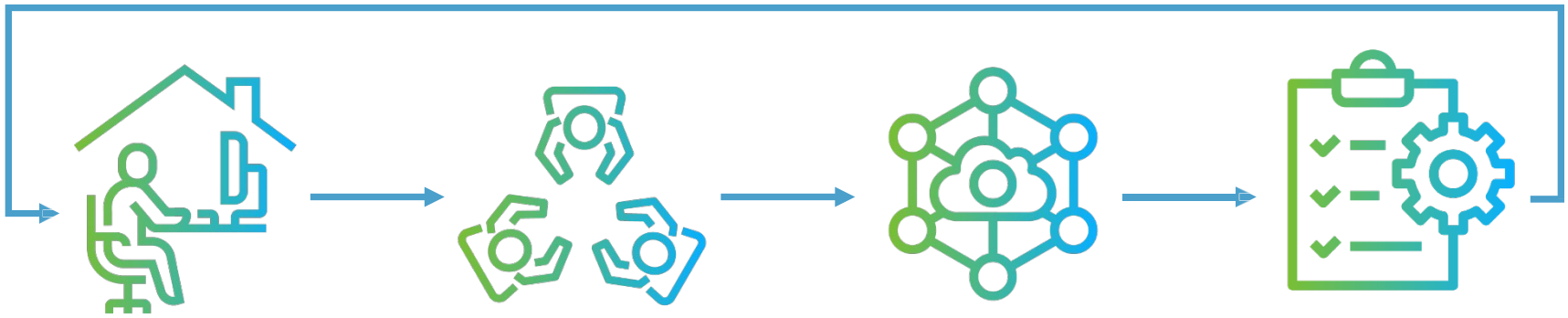
A secure infrastructure makes real-world data accessible



Step 1
The Requestor submits a question through the PCORnet® Front Door

Step 2
The Coordinating Center reviews the question and consults with the Requestor about next steps

Step 3
The Coordinating Center converts the request into a query and sends it to Network Partners via a secure portal in the Cloud

Step 4
Network Partners provide a response, which is sent back through the Coordinating Center to the Requestor

Requestor queries are sent to the data — and answers, not data, are sent back to requestors.

Read the PCORnet® Privacy Statement

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Use Cases

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PREVENTABLE

Pragmatic Evaluation of Events and Benefits of Lipid- Lowering in Older Adults

The Question

Can taking a commonly used heart medication prevent dementia in adults over the age of 75?

Strength of PCORnet®

A "one stop shop" for capturing 3 complementary sources of data (Medicare, EHR, & survey)

" I appreciate that PREVENTABLE is looking at a commonly prescribed drug to see if it could benefit seniors."
Minnie Jefferson, Patient Advisor

Study Snapshot

- **Pragmatic trial**
- **20,000 patients** aged 75 and older
- **100 U.S. sites** partnered with PCORnet & the National Veterans Affairs Network
- **Pragmatic design** used existing EHR/Medicare data plus phone surveys. Medications shipped directly to patients

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PREVENTABLE

Pragmatic Evaluation of Events and Benefits of Lipid- Lowering in Older Adults

IMPACT

- Because of the pragmatic trial design, only one amendment was needed to the study protocol to respond to COVID-19
- Embedded expertise in PCORnet fueled rapid enrollment of the largest trial in people aged 75+ to date. Broad dissemination via *New York Times* article, AARP publications, & local senior guides

Takeaway

PCORnet can effectively support pragmatic studies in challenging populations where participation is a barrier.

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ADAPTABLE

Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-Term Effectiveness

The Questions

1. *Which aspirin dose offers the right balance of effectiveness and minimal risk of bleeding?*
2. *Can PCORnet be used to find the answer using a clinical trial model wherein patients are drivers of engagement?*

Strength of PCORnet®

Adaptors: Nine patient partners from ADAPTABLE's clinical research networks.

- Offered study guidance
- Embedded at every study step, from study concept to completion and dissemination

Study Snapshot

- Pragmatic clinical trial
- **15,000 patients** living with heart disease
- Randomly assigned (1:1 ratio)
- Aspirin Dose- 81 mg/day vs. 325 mg/day

"I have lost three friends to heart disease; I don't want to lose more."
Ken Gregorie, Adaptor

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ADAPTABLE

Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-Term Effectiveness

ADAPTORS CONTRIBUTED TO 3 KEY EFFORTS:

Newsletter for Enrolled Patients:

Quarterly, included study updates plus patients' personal stories

493 participants have shared their personal story to date

Study Communication:

Revised study materials to make them more understandable for a patient audience and coached the study team at limited sites in mock calls to potential participants

Clinician Engagement:

Adaptors educated clinicians on what aspects of ADAPTABLE were engaging to them to improve participation rates

Over 15,000 patients enrolled from 40 sites over 38 months

Results published May 2021, *New England Journal of Medicine*

Takeaway

PCORnet infrastructure supports patient partner engagement that can fortify your study's efforts and contribute to faster enrollment and improved retention.

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BP Control Laboratory

A Reusable Platform for Efficient Surveillance and Comparative Effectiveness Research

The Question

Can PCORnet support a reusable platform to reduce patient/investigator burden and streamline evidence generation around new programs or technologies designed to help improve blood pressure control?

Strength of PCORnet®

- Broad reach into a large percentage of the U.S. population
- Established connections across major health systems
- Shared Common Data Model to standardize disparate electronic health record (EHR) data codes

Study Snapshot

- **Platform supported three demonstration studies:**
- **BP Track**, a national surveillance project
- **BP MAP**, a cluster randomized controlled trial
- **BP Home**, an individual level randomized controlled trial

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BP Control Laboratory

A Reusable Platform for Efficient Surveillance and Comparative Effectiveness Research

- Pragmatic design allowed for direct patient engagement and collection of patient-generated health data (Eureka)
- Assessed EHR data from 25 participating health systems via PCORnet

- Development of the novel platform was featured in *Circulation: Cardiovascular and Quality Outcomes*
- Results from BP Track featured in the *Journal of American Heart Association*
- Results from BP Home featured *in JAMA Internal Medicine*

Takeaway

PCORnet can be used to accelerate evidence generation and translation of innovative healthcare delivery solutions into major population health benefits.

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CDC COVID-19 Collaboration

Shaping the national understanding of COVID-19

The Question

Can the PCORnet infrastructure be used for real-time reporting and surveillance of COVID-19 patterns across the country?

Strength of PCORnet®

Partnership with diverse health systems that hold electronic records for health encounters for more than 30 million people across the U.S. each year

Project Snapshot

- **Surveillance effort** in collaboration with CDC
- **Bi-weekly exploration** of deidentified records for more than half a million patients with a COVID-19 diagnosis or respiratory condition

" As a massive research network that can capture information from many healthcare systems, PCORnet has an important role to play during a pandemic response."

Tom Carton, PCORnet Steering Committee

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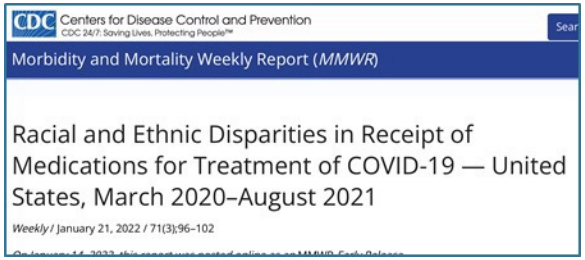
CDC COVID-19 Collaboration

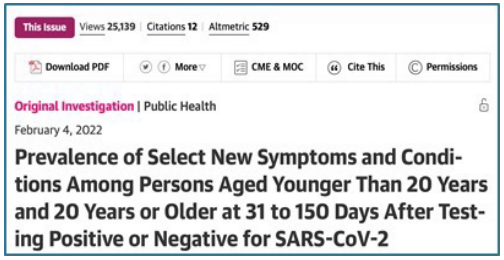
Shaping the national understanding of COVID-19

IMPACT

- Answered crucial questions relevant to public health via numerous journal publications



Racial and ethnic disparities in the use of monoclonal antibodies



Understanding "long COVID"

Myocarditis and pericarditis rates after COVID-19 vaccination

Takeaway

PCORnet can effectively support national surveillance studies with near-real-time reporting to unlock valuable insights in times of crisis when answers can't wait.

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PCORnet® Resources

- Materials developed using the Network are shared to promote lessons learned and best practices via the Resources page on **PCORnet.org**.

- Resources are sorted by Research, Data, and Engagement and searchable by keyword. They include **engagement case studies**, **lay audience glossaries**, the **PCORnet® Common Data Model**, and more.

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Learn More

Work with the Network

Visit **www.pcornet.org**

to get started!

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Appendix

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How is data linked while being kept secure?

Common Data Linkage

- Through strategic collaboration, PCORnet® Network Partners worked to establish a **secure** and **standardized** privacy-preserving record linkage (PPRL) infrastructure that is **reusable** and **scalable**
- Each PCORnet network site uses software that converts data into **de-identified tokens** that can be securely shared with the Coordinating Center for PCORnet
- The tokens are included in a table that is associated with each site's **Common Data Model**
- From there, the Coordinating Center uses a **matching software** to determine whether a patient's data exists at more than one site (duplicative data)

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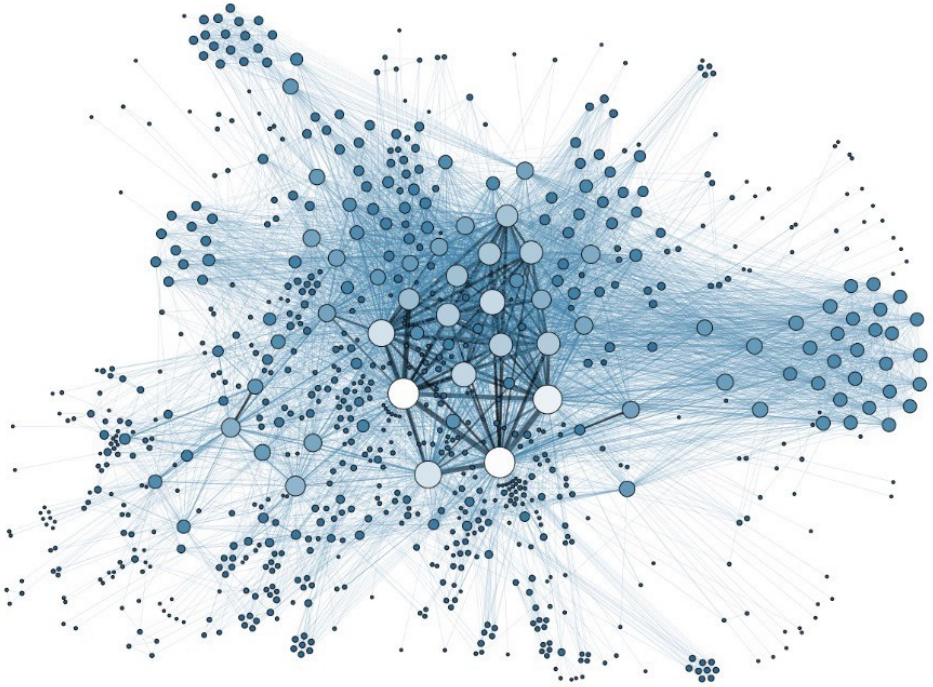
What types of data have PCORnet® Network Partners linked using PPRL ?

- Claims data
- Data included in health registries
- Data that has been duplicated across healthcare systems



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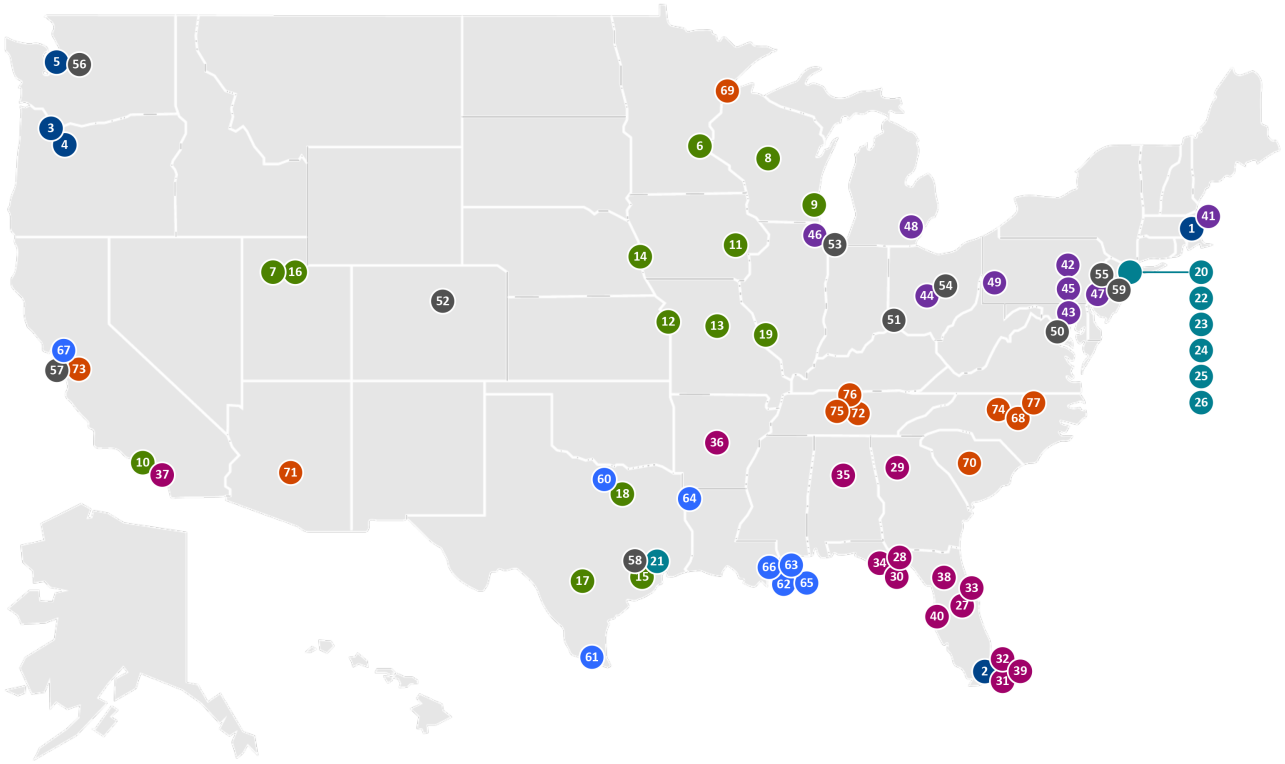
PCORnet® Clinical Research Network Locations



ADVANCE
1. Fenway Health
2. Health Choice Network
3. OCHIN
4. Oregon Health & Science University Hospital System
5. The University of Washington

GPC
6. Allina Health
7. Intermountain Healthcare
8. Marshfield Clinic Research Institute
9. Medical College of Wisconsin
10. University of California, Los Angeles
11. University of Iowa Healthcare
12. University of Kansas Hospital
13. University of Missouri
14. University of Nebraska Medical Center
15. University of Texas Health Science Center at Houston
16. University of Utah Health
17. UT Health San Antonio
18. UT Southwestern Medical Center
19. Washington University in St. Louis

INSIGHT
20. Columbia
21. Houston Methodist
22. Montefiore
23. Mount Sinai
24. New York University Langone Health
25. New York-Presbyterian
26. Weill Cornell Medicine

OneFlorida+
27. AdventHealth Orlando
28. Bond Community Health Center, Inc.
29. Emory University
30. Florida Medicaid
31. Jackson Health System
32. Nicklaus Children's Hospital (NCH)
33. Orlando Health
34. Tallahassee Memorial Healthcare and Capital Health Plan
35. University of Alabama at Birmingham
36. University of Arkansas for Medical Sciences
37. University of California, Irvine
38. University of Florida and University of Florida Health
39. University of Miami and UHealth
40. University of South Florida and Tampa General Hospital

PaTH
41. Boston Medical Center
42. Geisinger Health
43. Johns Hopkins University
44. Ohio State University
45. Penn State University
46. Rush University Medical Center
47. Temple University
48. University of Michigan
49. University of Pittsburgh

PEDSnet
50. Children's National Hospital
51. Cincinnati Children's Hospital
52. Colorado Children's Hospital
53. Lurie Children's Hospital
54. Nationwide Children's Hospital
55. Nemours
56. Seattle Children's Research Institute
57. Stanford Children's Health
58. Texas Children's Hospital
59. The Children's Hospital of Philadelphia (CC)

REACHnet
60. Baylor Scott & White Health (BSWH)
61. DHR Health Institute for Research and Development
62. Louisiana Public Health Institute (Lead)
63. Ochsner Health
64. Ochsner LSU Health Shreveport
65. Tulane Medical Center
66. University Medical Center New Orleans
67. University of California, San Francisco

STAR
68. Duke University (CC)
69. Essentia Health
70. Health Sciences South Carolina
71. Mayo Clinic
72. Meharry Medical College
73. Stanford Healthcare
74. University of North Carolina at Chapel Hill
75. Vanderbilt Health Affiliated Network
76. Vanderbilt University Medical Center (CC)
77. Wake Forest University Health Sciences

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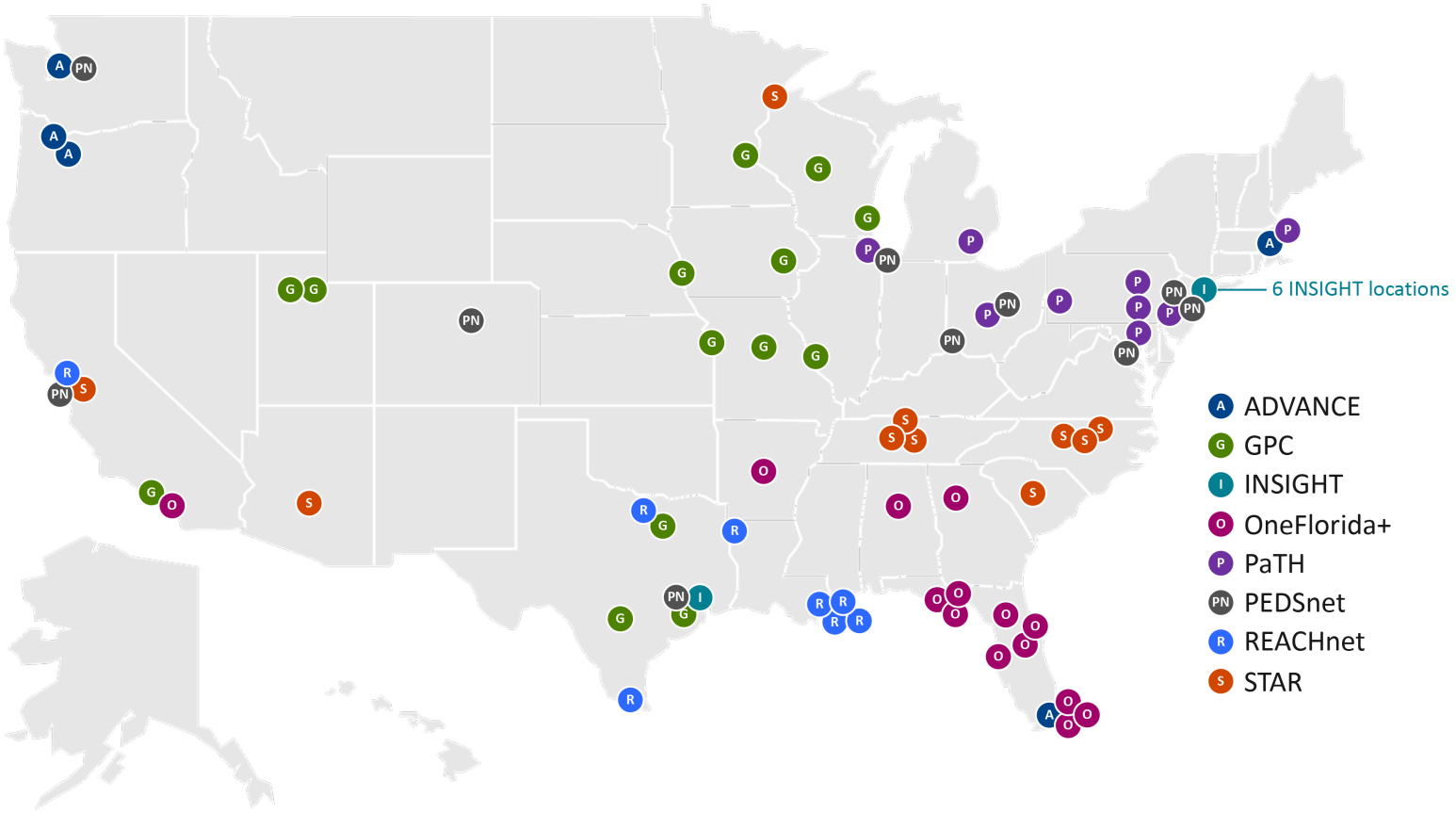

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13. University of Missouri
14. University of Nebraska Medical Center
15. University of Texas Health Science Center at Houston
16. University of Utah Health
17. UT Health San Antonio
18. UT Southwestern Medical Center
19. Washington University in St. Louis

INSIGHT
20. Columbia
21. Houston Methodist
22. Montefiore
23. Mount Sinai
24. New York University Langone Health
25. New York-Presbyterian
26. Weill Cornell Medicine

OneFlorida+
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77. Wake Forest University Health Sciences

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