

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

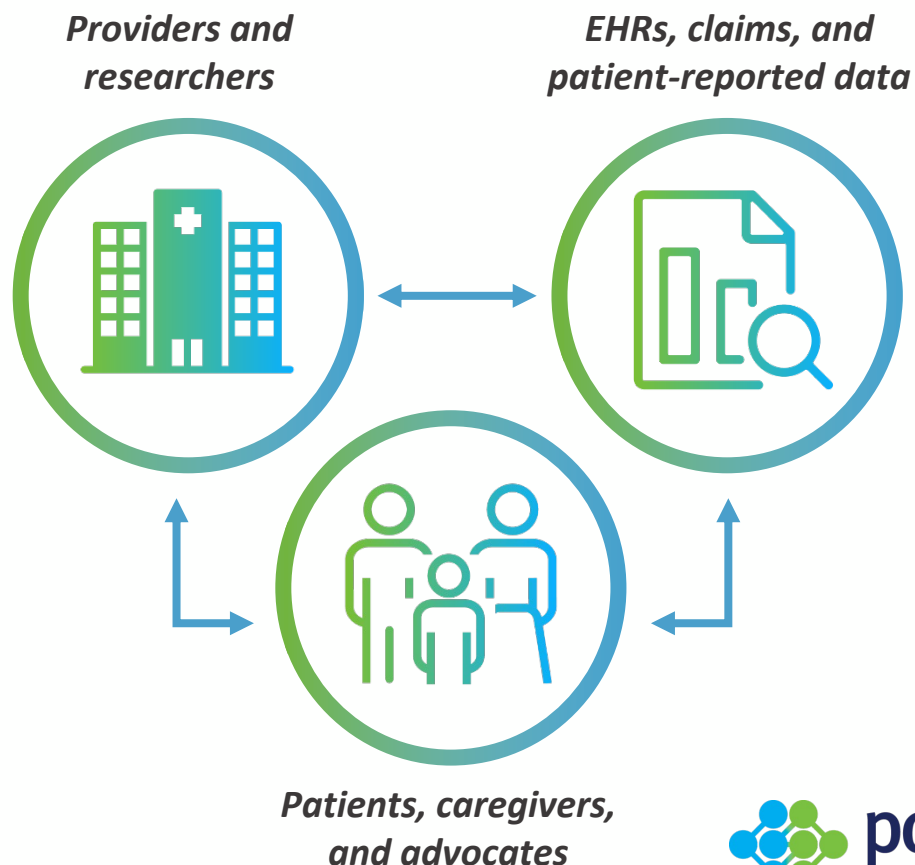
One PCORnet®, Many Possibilities

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.

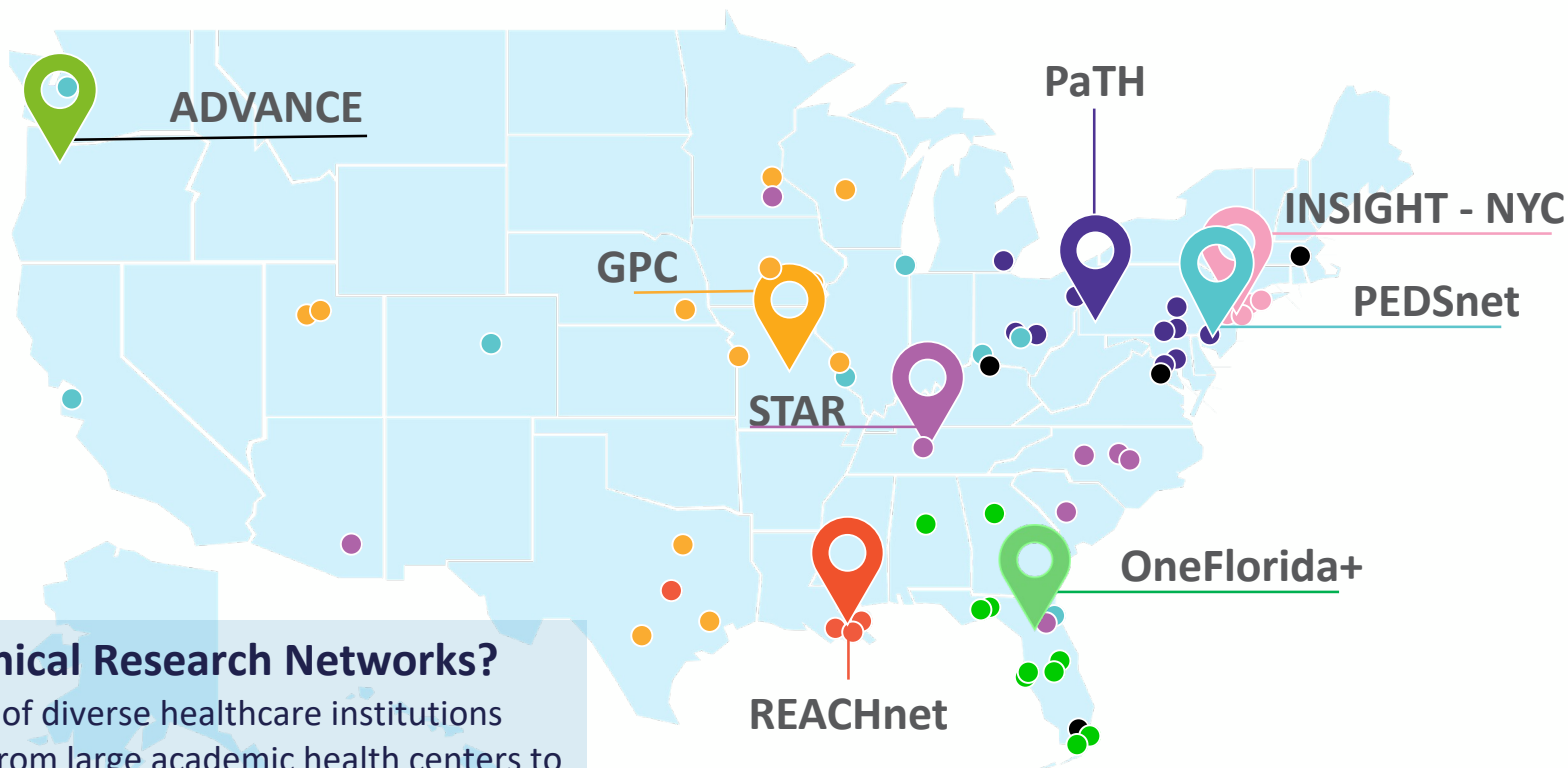


Data Insights via PCORnet®



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.

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



5

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

Demographics	Diagnoses	Procedures
Vital Signs	Labs	Clinical Observations
Medication Orders & Administrations		

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

Available, But Still Evolving

Immunizations	Tumor Registry	Biosamples
Social Determinants of Health	Patient-Generated Data	Genomic Results
Patient- Reported Outcomes	Natural Language Processing Derived Concepts	

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

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



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

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

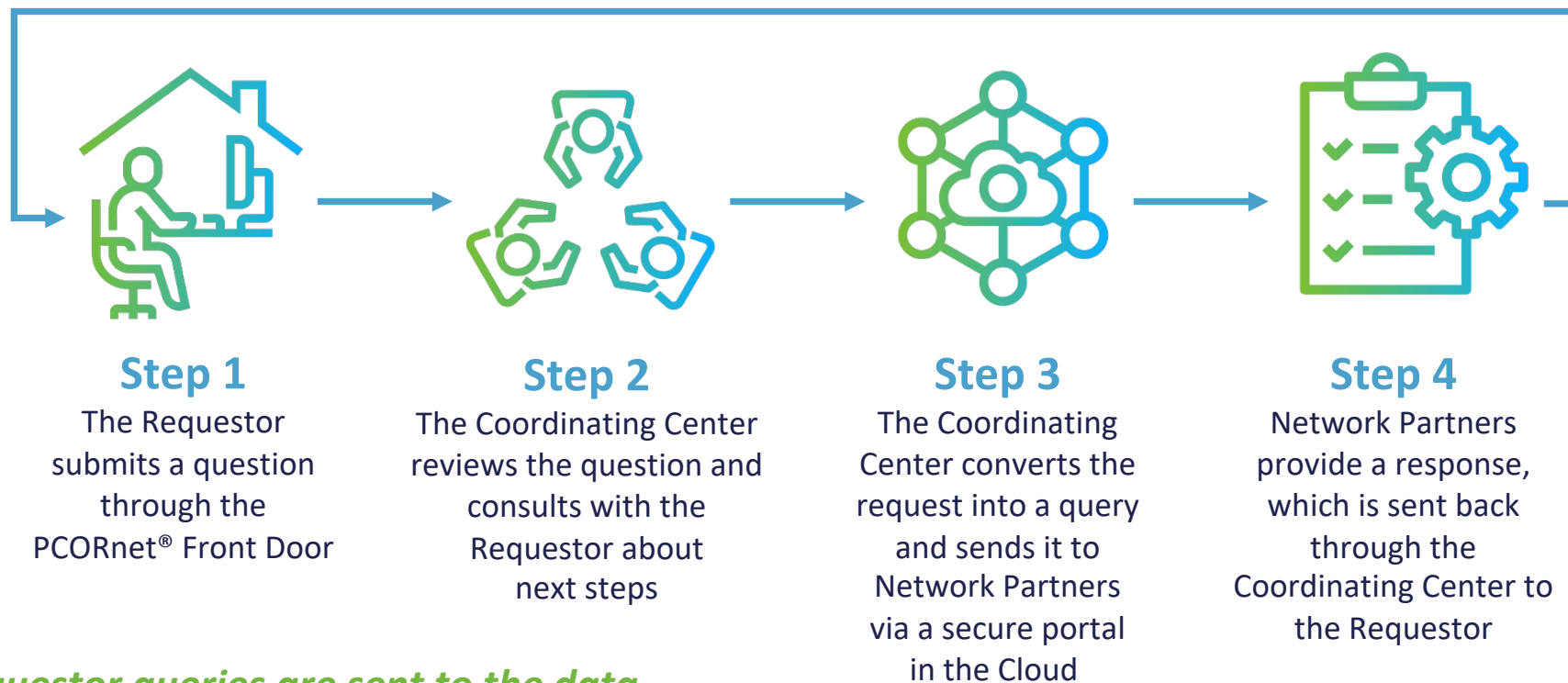
PCORnet Study Designation Support

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



[Learn More About the Front Door](#)

A secure infrastructure makes real-world data accessible



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

[Read the PCORnet® Privacy Statement](#)

Use Cases



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

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.

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

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.



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

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.

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

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.

PCORnet® Resources

- Materials developed using the Network are shared to promote lessons learned and best practices via the Resources page on [PCORnet.org](https://www.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.

Explore our resources for improving research through better practices

Research

Explore innovative tools and models that can be used throughout every stage of your research project - from generation of a hypothesis to disseminating results.

SEARCH RESEARCH

Data

Improve the quantity and quality of data used in your study with innovative resources and tools. Data networks should follow the principles of efficiency, interoperability, transparency, reproducibility, security, and inclusivity of stakeholders.

SEARCH DATA

Engagement

Search best practices for engaging a variety of stakeholders throughout the research process. Engagement means active involvement of all stakeholders.

SEARCH ENGAGEMENT

Learn More



Work with the Network
Visit www.pcornet.org
to get started!

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Appendix



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)



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

