

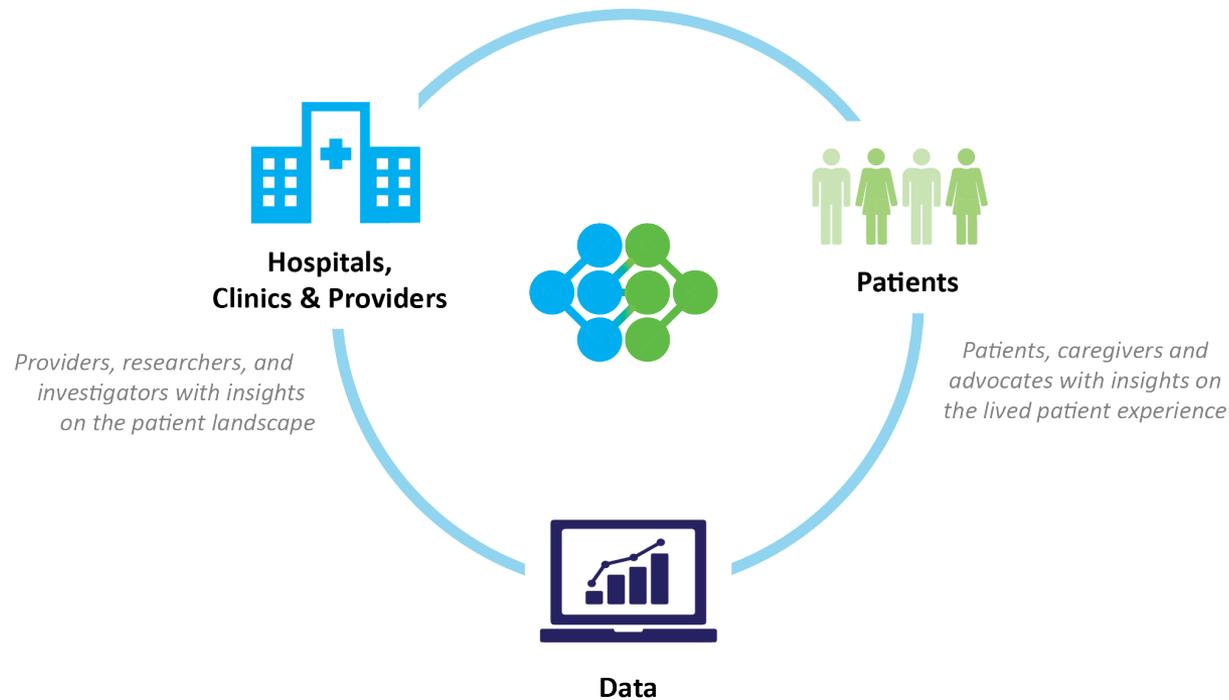
PCORnet[®]: An Introduction



An Overview for Industry Stakeholders, Academic Audiences, and Health Services Researchers

What happens when communities and data unite for better research?

Trust is built. Answers are accelerated. Health improves.



EHRs, claims, and patient-reported data with insights on daily encounters of 66 million people

The PCORnet[®] story

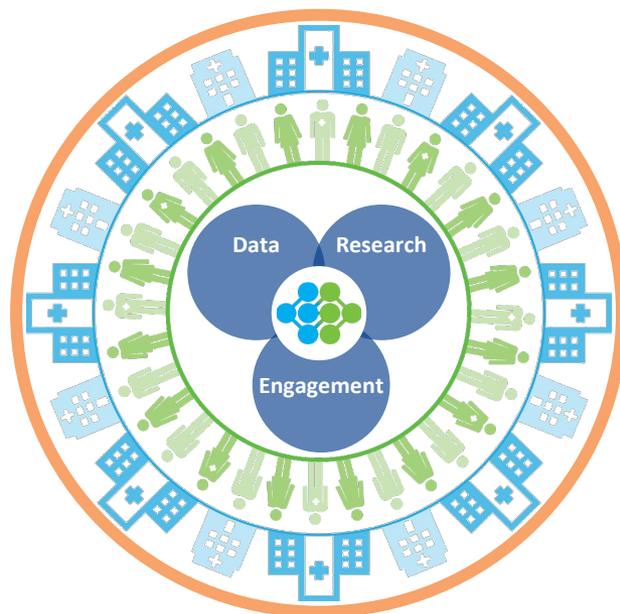
PCORI saw room for improvement in clinical research:

- It often doesn't answer the questions that matter most to people
- It is too expensive and too slow

PCORnet was created to make research better:

- Network of networks with curated EHR data from 66 million highly representative patients accessible for observational studies (30 million for clinical trials)
- Exceptional research teams with expertise integrating research and care
- Streamlined processes
- Patient-partnered

PCORnet is a “network of networks” that harnesses the power of partnerships



Clinical
Research
Networks
(CRNs)

+

Patient
Partners

+

Coordinating
Center

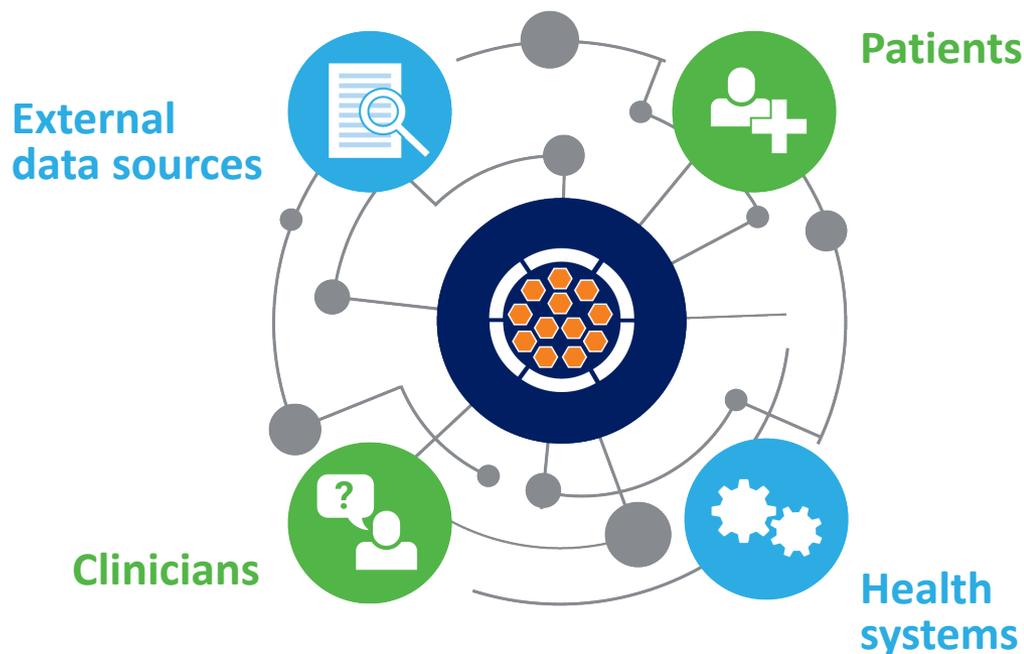
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A national infrastructure
for people-centered
clinical research



Why a network of networks works

Patients, providers, data, and systems. In the traditional research environment, each operates in a silo. In PCORnet, they unite to form a coalition.



Patients and caregivers are integrated into all phases of PCORnet-enabled research

Data drawn from millions of EHRs with growing links to patient-reported and payor data.

PCORnet connects you to thousands of clinicians and researchers can support your effort.

It starts at the PCORnet Front Door

The Front Door is the access point for stakeholders seeking to leverage the PCORnet infrastructure. Common areas of support from the Front Door are:

Study Design

- Providing preliminary data to help design proposals, effect sizes and potential study power.
- Simple preparatory research activities, such as obtaining counts for feasibility or sample size estimates + site selection counts for feasibility or sample size estimates

Network Collaborator Request

- Connecting you with collaborators within the Network to find
 - Sites for funded studies
 - Partners to co-design research leveraging PCORnet, or
 - People with specific expertise.

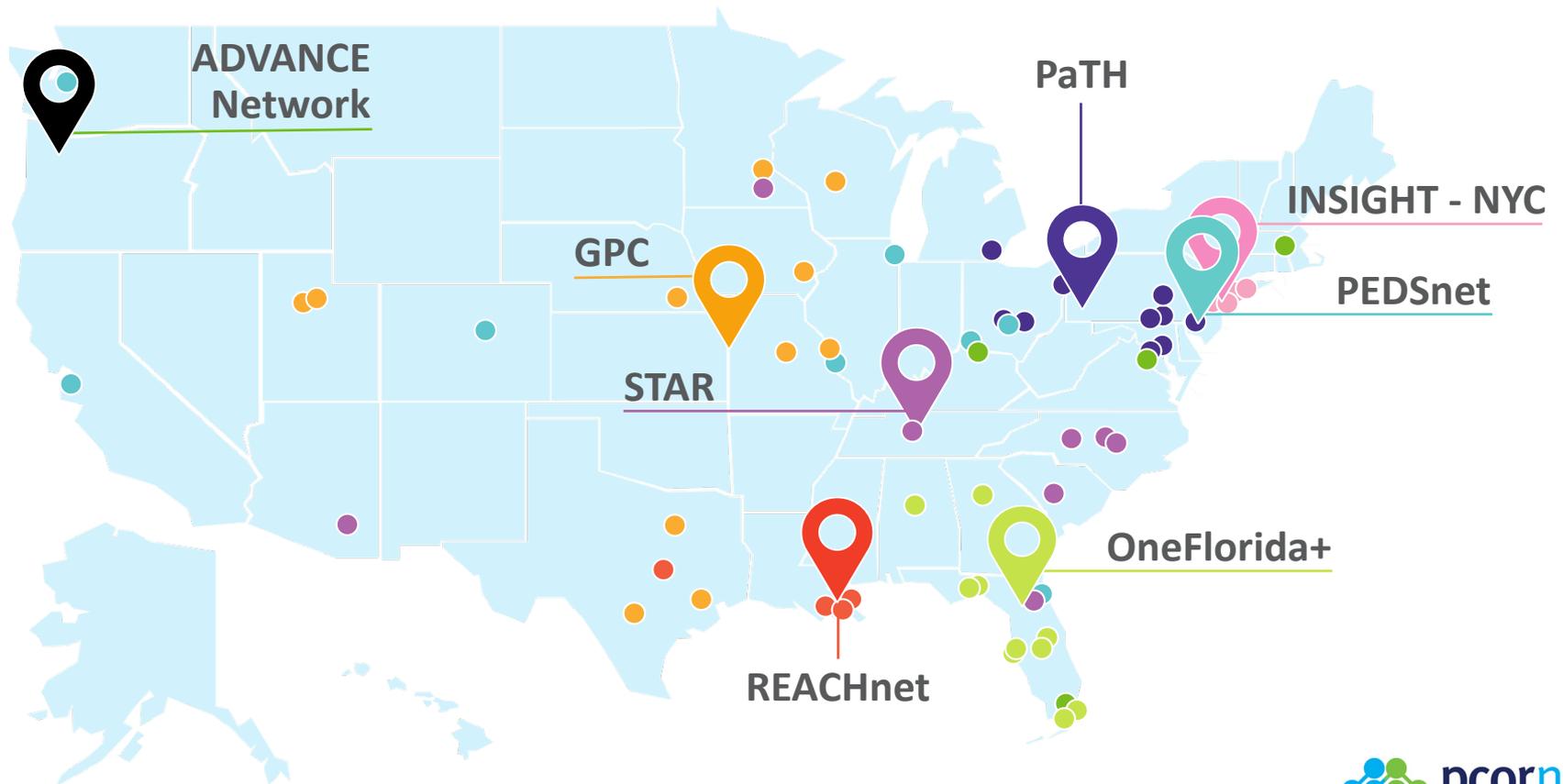
PCORnet Study Designation

- Supporting your patient-centered study post-award through deeper collaboration and transparent quality improvement initiatives.



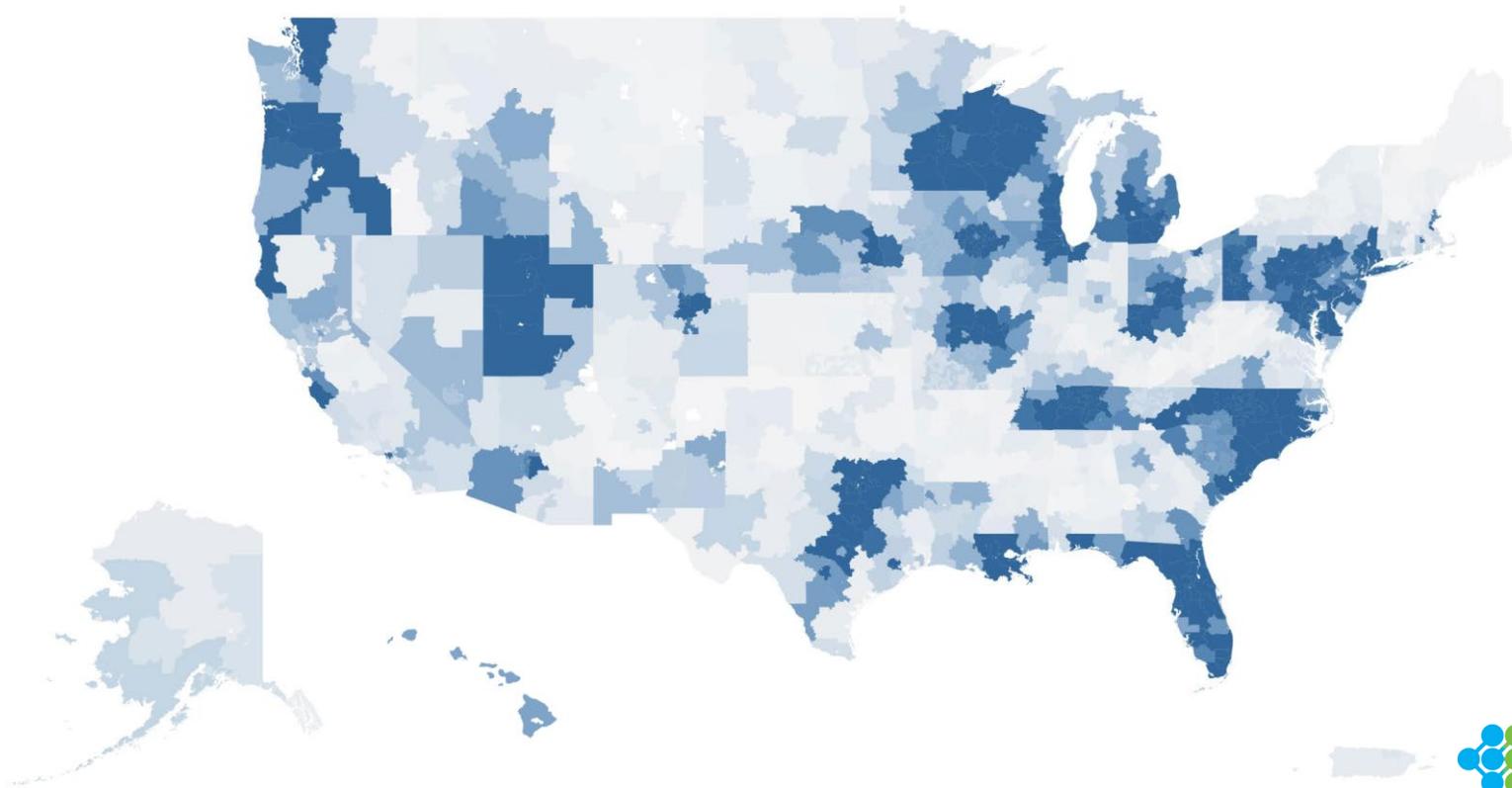
Discover how our data partners can support you

The PCORnet solution offers access to real-world data. PCORnet-partnered CRNs can help users conduct research more efficiently.



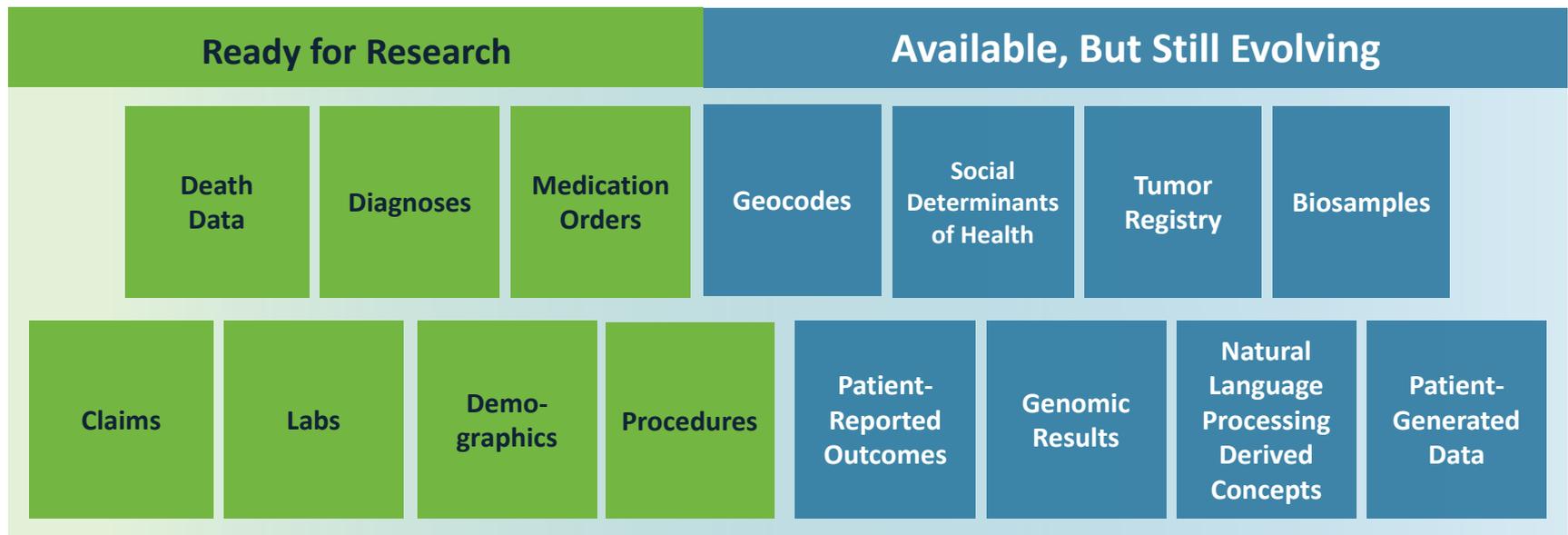
Access data on a national scale

Those encounters with 66 million people result in data available throughout the nation in all types of communities. This map represents data from the PCORnet-partnered Clinical Research Networks.



Next, the data must be usable

Lots of data is great, but for it to be useful it has to be standardized across systems. The PCORnet Common Data Model standardizes data into a single language, enabling fast insights, including:



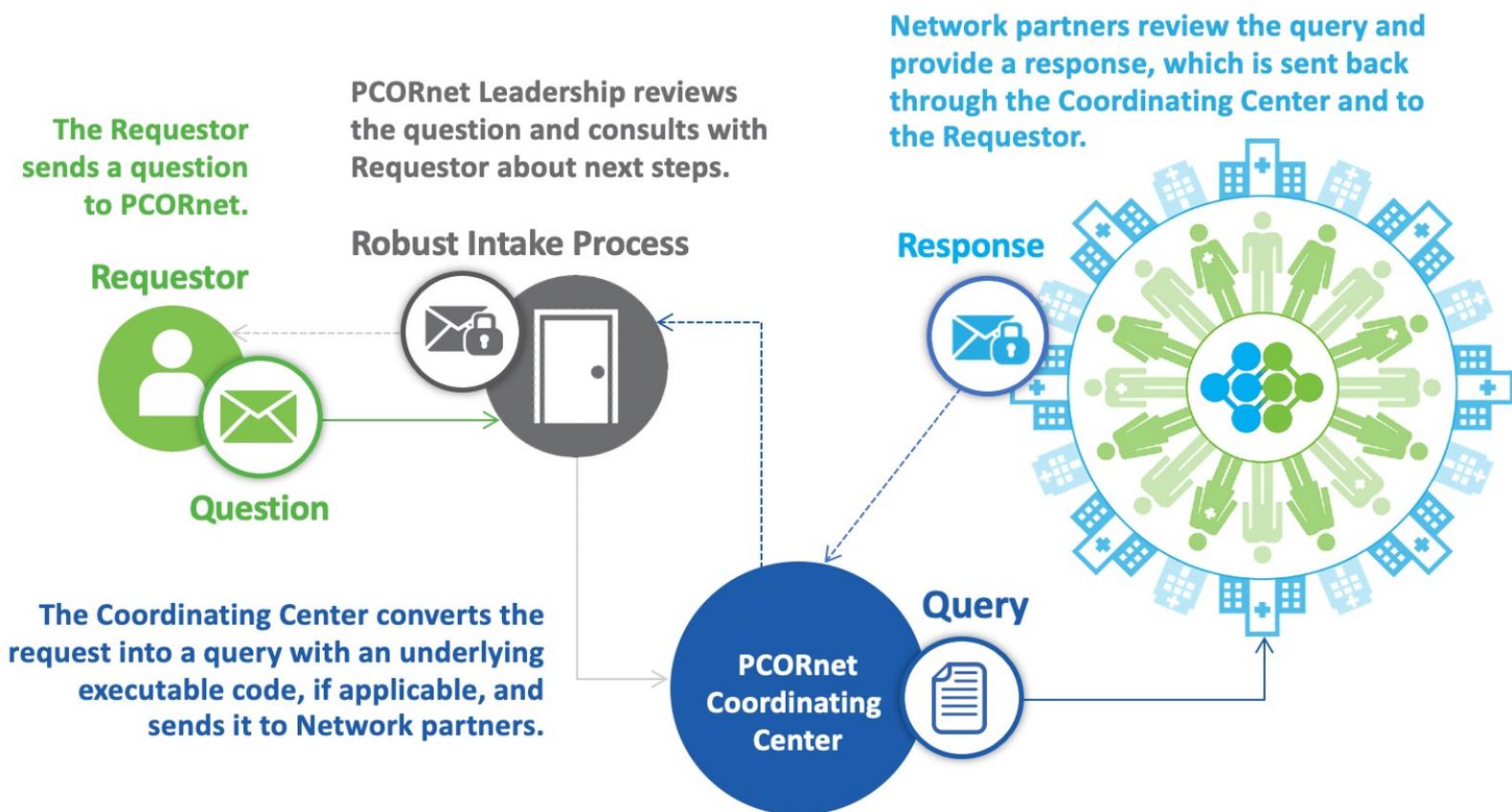
Data available from several Clinical Research Networks, in the PCORnet Common Data Model and ready for use in research.

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.



A secure infrastructure to make real-world data accessible

PCORnet was developed with a secure and streamlined infrastructure that offers researchers a simple process for querying the accessible data and deriving efficient insights.



Patients are at the center of all PCORnet-enabled research

“Good studies consider all relevant evidence – and no evidence is more relevant than the patient experience.” – PCORnet Steering Committee Member

From the Researcher Perspective

- Patients offer important context, directly informing understanding of a condition, its effects, and the burden of illness
- Patients can identify processes or procedures that research participants may find too burdensome, allowing researchers to amend and potentially boost study enrollment
- Patients ensure endpoints are meaningful, helping researchers deliver results that will improve the patient experience
- Patients can mobilize patient groups for participation in clinical trials
- Patients are essential partners in helping to disseminate results in a way that is clear to diverse communities



From the Patient Perspective

- Partnering in research empowers patients and caregivers to set the research agenda, advocating for prioritization of questions that matter to their community
- Patient partners can influence meaningful changes to study designs, giving these projects the best chance of success
- Patient partners report positive experiences in participating in and contributing to research that leads to improved clinical answers
- Patients drive adoption of actionable findings and meaningful changes in clinical care



Statins & dementia: A pragmatic trial

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?

PCORnet's Strength

PCORnet offered a **“one stop shop”** process for capturing three complementary sources of data (Medicare data, EHR data, and survey data) that would have been cumbersome in more traditional research.

Study Snapshot

- **20,000 patients** aged 75 and older
- **100 U.S. sites** in partnership with PCORnet and the National Veterans Affairs Network
- **Pragmatic design** using existing EHR/Medicare data plus phone surveys, with medications shipped directly to patients

Statins & dementia: A pragmatic trial

PREVENTABLE,
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Lowering in Older Adults

RESULTS

- Pragmatic design meant only **one amendment** in response to COVID-19 (addition of one telehealth visit)
- PCORnet's embedded expertise fueled best practices to support **rapid enrollment**, including including mention in a *New York Times* [article](#), AARP publications, and local senior guides

The Takeaway

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

Aspirin dosing: Engagement in research

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?

PCORnet's Strength

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** who are living with heart disease
- Randomly assigned in a 1:1 ratio
- Receive an aspirin dose of **81 mg/day vs. 325 mg/day**

Faulkner M, Alikhaani J, Brown L, et al. Exploring Meaningful Patient Engagement in ADAPTABLE (Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-term Effectiveness). *Med Care*. 2018

Aspirin dosing: Engagement in research

ADAPTABLE

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

RESULTS

ADAPTORS CONTRIBUTED TO THREE KEY ENGAGEMENT EFFORTS FOR THE STUDY:

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 with only 40 sites over 38 months.
Results were published May 2021 in the *New England Journal of Medicine*.

The Takeaway

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

COVID-19 insights: A community for rapid research

HERO

(Healthcare Worker
Exposure Response and
Outcomes) Platform

The Question

Can PCORnet be used to quickly create a community of people to help address ongoing, unanswered questions related to COVID-19 and its impact on individuals working in, and affiliated with, healthcare?

PCORnet's Strength

Existing partnership with major health systems across the U.S. to support rapid creation of a robust community of healthcare workers that can deliver meaningful COVID-19 insights.

Program Snapshot

- **HERO Registry** of 30,000+ individuals working in healthcare and their communities, supporting:
 - **HERO-HCQ**, a randomized study of hydroxychloroquine or placebo to determine benefit against COVID-19
 - **HERO-TOGETHER**, 20,000 HERO members who receive COVID-19 vaccination and report on safety across two years

COVID-19 insights: A community for rapid research

HERO

(Healthcare Worker Exposure Response and Outcomes) Platform

RESULTS

HERO Registry:

- Today, **30,000+** members report on their experiences through surveys on PPE, burnout, childcare, moral injury and vaccine hesitancy
- Registry members **prioritize research topics** and can also sign up for other research leveraging the HERO Platform

HERO-HCQ:

- **1,363** HERO members randomized
- **30 days** to site activation
- **10 days** to first patient enrolled
- Results published in NEJM in August 2020

HERO-TOGETHER:

- **5,000** patients enrolled in just **six weeks**
- Today, **8,000+** patients are part of the effort to understand long-term effects of vaccines

The Takeaway

PCORnet can help you rapidly erect communities and deliver fast insights in situations when patients can't wait for answers.



How PCORnet stacks up with other data aggregators

	Feasibility queries	Identify patient populations for trial recruitment	Coordinated data curation	Connection to patients and providers
PCORnet	●	●	●	●
The ACT Network	●	●	●	●
TriNetX	●	●	●	●
OPTUM	●	●	●	●
OHDSI	●	●	●	●
Sentinel	●	●	●	●

● = capabilities ● = limited capabilities ● = lacks capability

PCORnet Resources

- Resources developed within the PCORnet network are available to everyone through the PCORnet Resources page on PCORnet.org
- Resources are sorted by Research, Data, and Engagement and are keyword searchable or can be filtered.
- Examples include common data model code; a lay audience data glossary; press release templates; and engagement case studies.

Resources

Explore our resources for improving research through better practices

Research	Data	Engagement
Explore innovative tools and models that can be used throughout every stage of your research project - from generation of a hypothesis to disseminating results.	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 best practices for engaging a variety of stakeholders throughout the research process. Engagement means active involvement of all stakeholders.
SEARCH RESEARCH	SEARCH DATA	SEARCH ENGAGEMENT

Search All Resources

Enter any keyword or phrase in the **Search** box, or use the dropdown options to narrow your search by category, network partner, resource type, and/or audience. Click **Reset** to view all resources in an unfiltered view.



Search...
Filter Categories
Resource Type
Network Partners
Audience
Reset

Resource Type: Guide, Plan
Audience: Researchers, Hospitals and Health Systems, Clinicians, Industry, Payers, Patients

Rapid and Collaborative Response to COVID-19

Researchers responded rapidly and collaboratively to answer COVID-19 questions by using PCORnet resources including a flexible coordinating center, a common data model, research-ready networks, and existing research studies that pivoted quickly. Researchers can use this resource to demonstrate how the resources of PCORnet can be used for studies that require fast answers.

RESEARCH

Resource Type: Presentation/Webinar
Audience: Training Institutions, Researchers, Hospitals and Health Systems, Industry, Patients, Policy Makers

Building Stakeholder Capacity to Engage around Technical Content

This webinar could be a helpful resource for researchers and organizations working to engage patients in discussions and decision-making related to complex and highly technical topics. Panelists Monique Does (Kaiser Permanente) and Liz Salm (OpenNotes) discuss tools and strategies for engaging stakeholders in research data and methodology topics, and their own experiences with this type of engagement from a researcher and patient/researcher perspective. Greg Merritt (PaTH Network) moderates.

ENGAGEMENT

Resource Type: Presentation/Webinar
Audience: Researchers, Hospitals and Health Systems, Industry, Patients, Policy Makers

Engaging Patient/Partner

can be used by researchers in learning more about using engage patients and other elites Shilpa Venkataschalam Iyengar tools to support patient and explore the opportunity and sustaining these ke moderates the session.

ENGAGEMENT

Resource Type: Guide, Governance
Audience: Researchers, Clinicians, Hospitals and Health Systems, Industry

HERO Data Dictionary

Use this resource to review information, content, format, and structure of the HERO (Healthcare Worker Exposure Response & Outcomes) Research database and the relationship between its elements.

DATA

Resource Type: Presentation/Webinar
Audience: Training Institutions, Researchers, Hospitals and Health Systems, Industry, Patients, Policy Makers

Successful engagement approaches across networks

Researchers and organizations seeking information on engagement approaches can use this webinar as a resource. This recorded webinar features the PCORnet Engagement Workgroup and their efforts to develop a set of core principles for the network, the process followed for generating the principles, and next steps for implementation across PCORnet.

ENGAGEMENT

Resource Type: Presentation/Webinar
Audience: Training Institutions, Researchers, Hospitals and Health Systems, Industry, Patients, Policy Makers

Supporting Diverse & Inclusive Engagement

These slides can be used by researchers and organizations to inform policies and programs for increasing underrepresented population engagement in research and governance. Panelists Carolyn Shimmin, George and Fay Yee, and Freddie White Johnson discussed creating an inclusive environment for engagement, strategies for stakeholder retention, and the importance of community-centered approaches. Lisa Stewart moderated.

ENGAGEMENT

Resource Type: Template
Audience: Researchers, Hospitals and Health Systems, Industry

Research Findings for the Community

The PaTH Clinical Research Network (CRN) designed this template as a guide for sharing the results of a published article with the general public.

ENGAGEMENT

Resource Type: Guide, Governance
Audience: Researchers, Clinicians, Hospitals and Health Systems, Industry

Daquetry

The PaTH Clinical Research Network (CRN) Department of Bio-Medical Informatics team developed Daquetry a tool used to deploy code, as well as to automate and archive network-wide Quality Assurance queries. The code is publicly available and may be useful to support other CRNs data processes.

DATA

How can PCORnet help you?

PCORnet-enabled studies are answering critical research questions. What questions can PCORnet help answer for you?

While PCORnet is fit for a broad range of research types, research conducted using the Network's resources has been focused on studies like:



Real-world evidence studies



Health systems research



Population health research



Pragmatic clinical trials



Studies on how to best engage patients in research

Learn More.



Work with PCORnet.

Visit us at **www.pcornet.org**
to get the relationship started.