Making Effective Use of Data Infrastructure in PCORnet®

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PCORnet® is intended to improve the nation's capacity to efficiently conduct patient-centered health research, particularly comparative clinical effectiveness research (CER), by providing a large, highly representative network of health data, research expertise, and patient insights. PCORnet has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®).

Updated
Oct 2025

Disclosures & Funding

- Nothing to disclose

- Duke University and the Children's Hospital of Philadelphia are part of the Coordinating Center for PCORnet®, which has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®). Duke University's participation in support of the Coordinating Center for PCORnet is / has been funded through PCORI Awards RI-DCRI-01-PS7, RI-DCRI-PS11-PROJ11, RI-DCRI-01-PSI, RI-DCRI-01-PS02, CC2-Duke-2016-TO8, CC2-Duke-2016-TO9, CC2-Duke-2016-TO19, CC2-Duke-2016-TO20, CC2-Duke-2016-TO18, PCORI-383-9767. CHOP's participation in the PCORnet® and PCORnet® Studies has been funded through PCORI, NIH, and CDC awards; details available on request.

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Unite Data and Communities for Faster, More Targeted Research

One PCORnet® — Many Possibilities

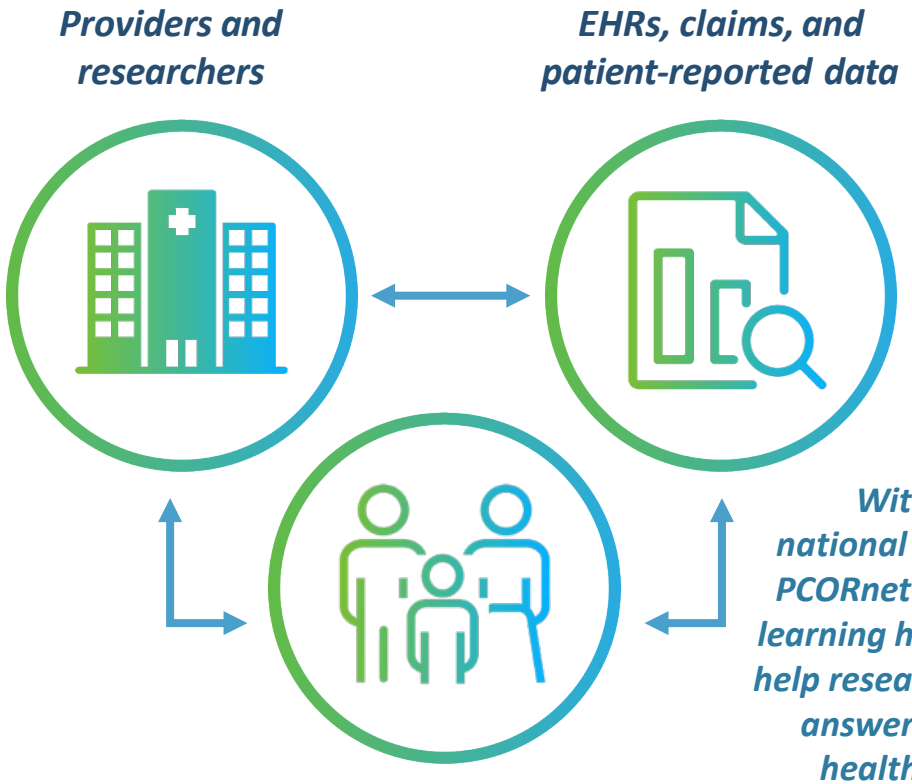
PCORnet is a national resource, funded by PCORI, that enables insights from high-quality health data, patient partnership, and research expertise to deliver fast, trustworthy answers that advance health outcomes.

Research Powered by PCORnet®

- Real-world evidence studies
- Comparative clinical effectiveness research
- Population health research
- Pragmatic research
- Health systems research
- Implementation science 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.



A Vetted National Resource

50
States

PCORnet is linked to patients in every state in the U.S.

78
PCORnet® Network Partners

8 PCORnet® Clinical Research Networks across the U.S.

47
Million People

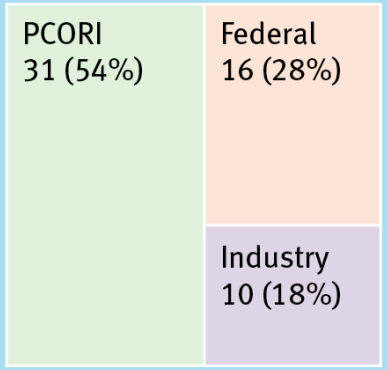
PCORnet represents data from everyday healthcare encounters with ›47 million people annually across the U.S.

991
Publications

Supported by PCORnet resources

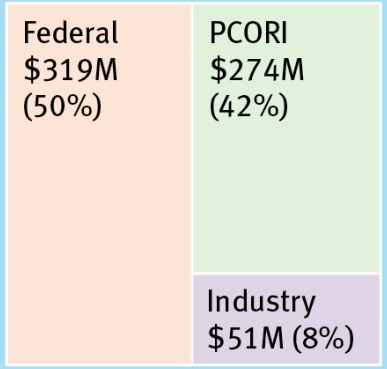
57
PCORnet® Studies

Funded by



$644
Million

PCORnet® Studies funding by source



Over the last 10 years, PCORnet® Studies have already answered critical patient-centered questions on **heart disease**, **metabolic conditions, obesity**, and more, demonstrating the power of PCORnet® to improve patient care through efficient, high-quality research.

Research that leverages this network is tapping into a **proven engine for discovery**.

Data as of August 2025

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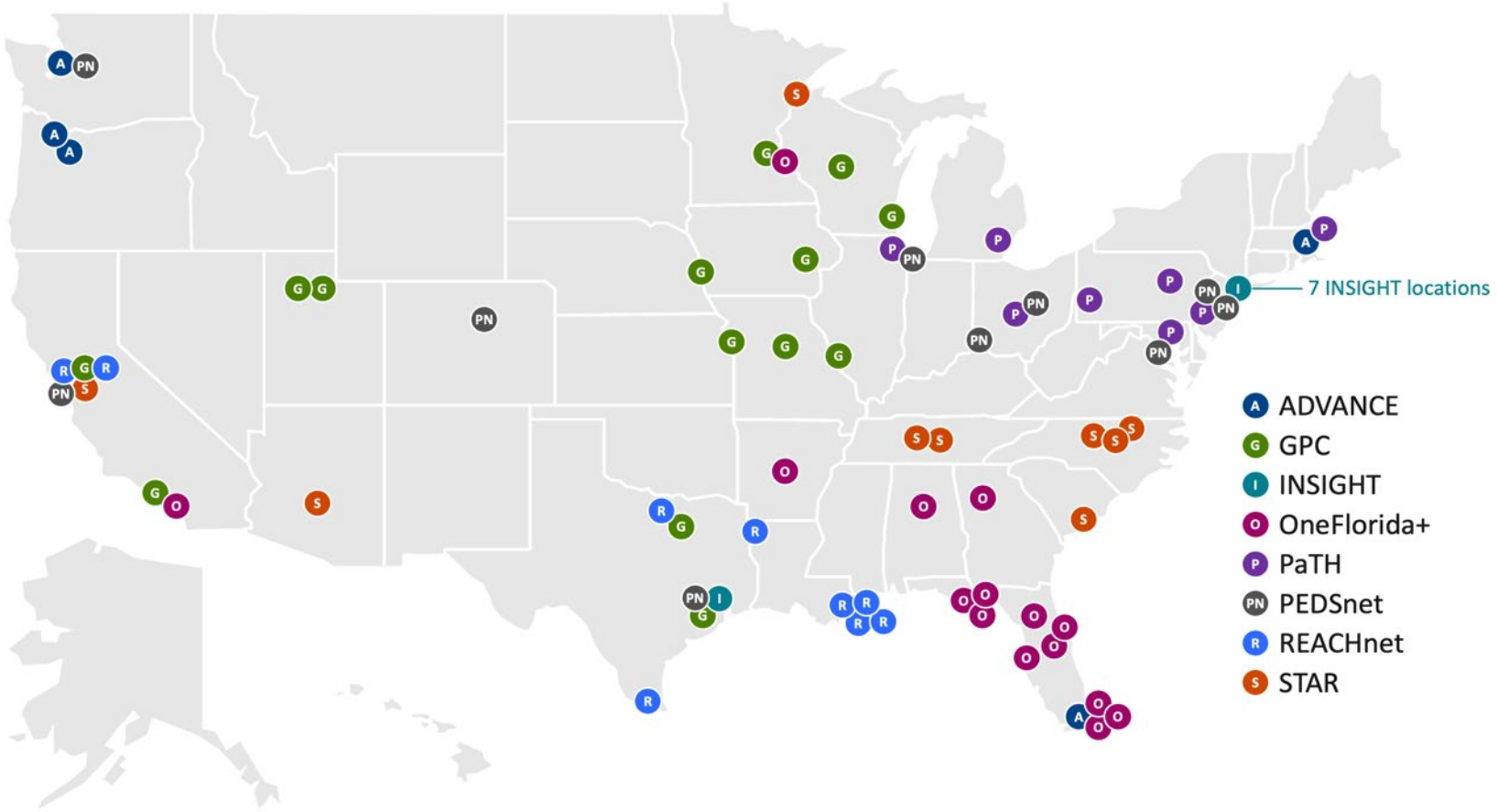
PCORnet® Clinical Research Network Locations

- Healthcare institutions from large academic health centers to local community clinics across the U.S.
- Committed to speed patient-centered research via PCORnet



What are Clinical Research Networks?

- Healthcare institutions from large academic health centers to local community clinics across the U.S.
- Committed to speed patient-centered research via PCORnet

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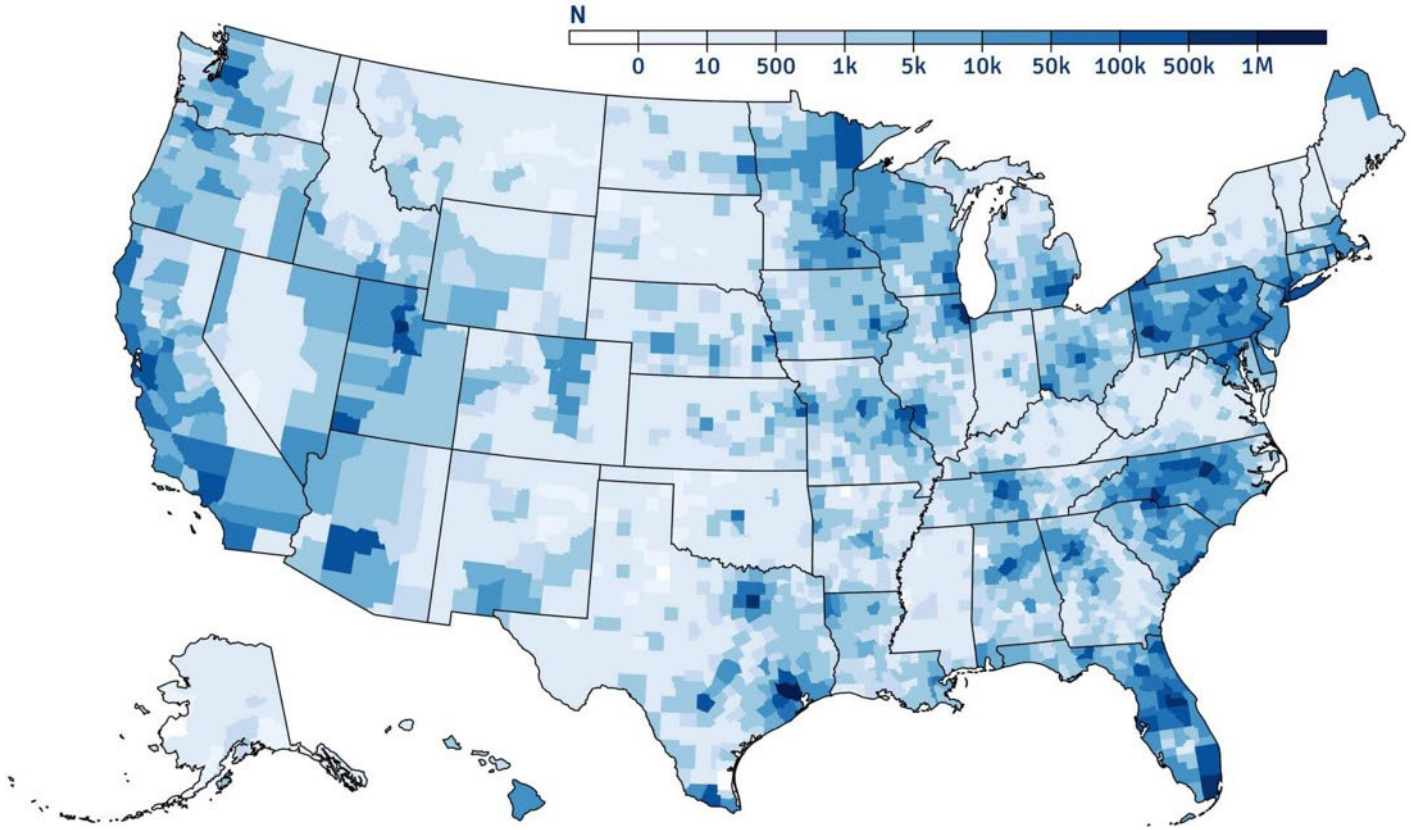
Scope of PCORnet-Accessible Data

PCORnet represents data from **everyday health care encounters with more than 47 million people** annually across the U.S., enabling large-scale, innovative, patient-centered health research



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

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PCORnet® Playbook

Your guide to using PCORnet for patient-centered research

Through this resource, you will learn:

How to use PCORnet resources to find fast, trustworthy answers to patient-centered health research questions.

How to design high-quality, large-scale research projects using PCORnet services, including engagement, data, and outreach support.

What to expect when collaborating with PCORnet® Network Partners.

Get started at pcornet.org/pcornet-playbook

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The PCORnet® Front Door

The access point for PCORnet resources and services

A “knock” on the PCORnet® Front Door can support:

STUDY DESIGN

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

DATA NETWORK REQUEST

- Get data insights from PCORnet® Clinical Research Networks
- Obtain aggregated results for informing research project development

CONNECTIONS TO NETWORK COLLABORATORS

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

PCORnet® STUDY 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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Data infrastructure in PCORnet®

The PCORnet® Common Data Model

To be useful, data have to be standardized across systems. Frequent data curation and a single language enabled by the PCORnet® Common Data Model (CDM) deliver 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 from PCORnet® Clinical Research Networks available in the PCORnet® CDM and ready for use in research

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

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Dimensions of Data Quality in PCORnet

CONFORMANCE — Data adhere to the format of the PCORnet® Common Data Model

- Fields do not contain values outside of the PCORnet® Common Data Model specification

COMPLETENESS — Values appear where we expect them

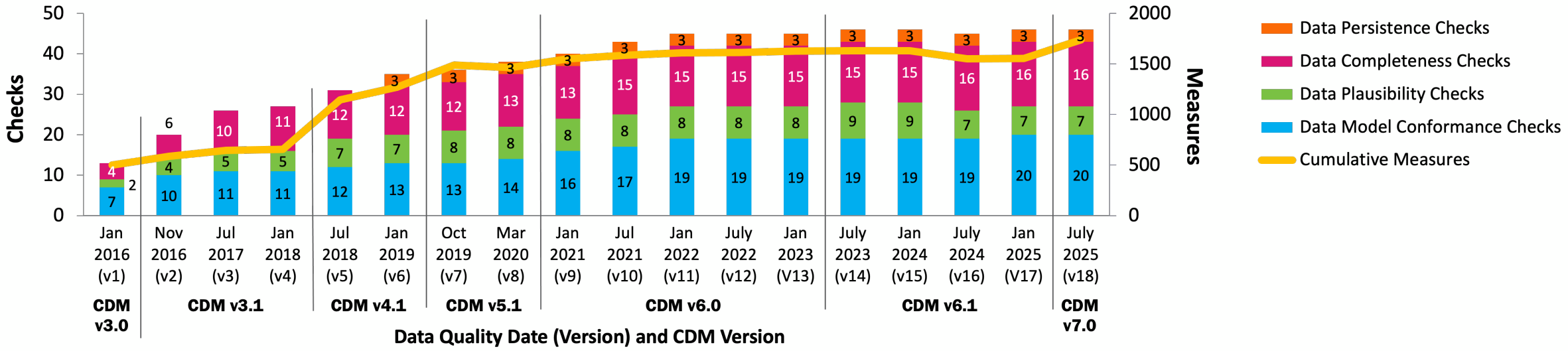
- Diagnosis codes have an associated diagnosis type (e.g., ICD-9, ICD-10, SNOMED)

PLAUSIBILITY — Values that appear make sense

- Less than 5% of records are associated with a future date

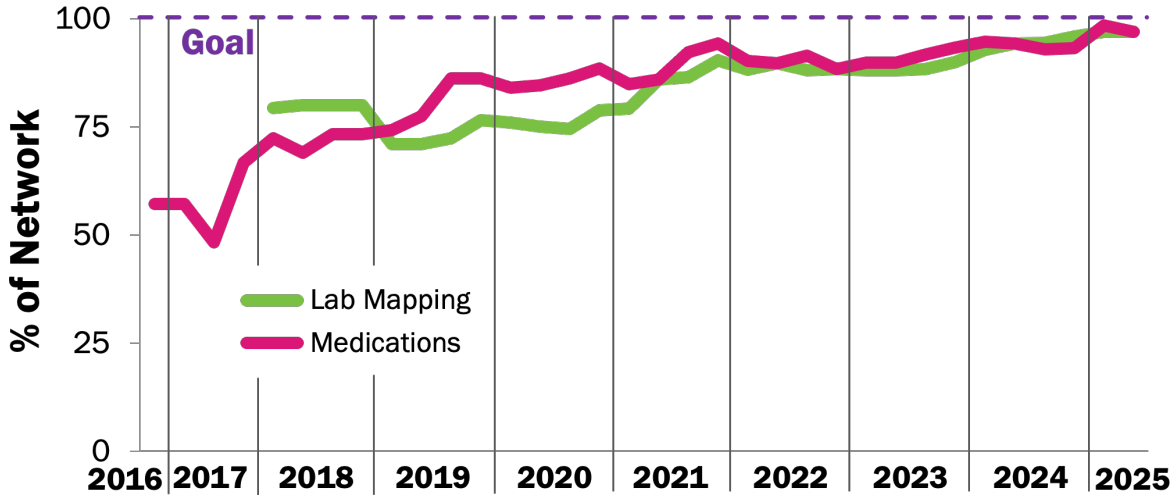
PERSISTENCE — Patients / records do not disappear between refreshes

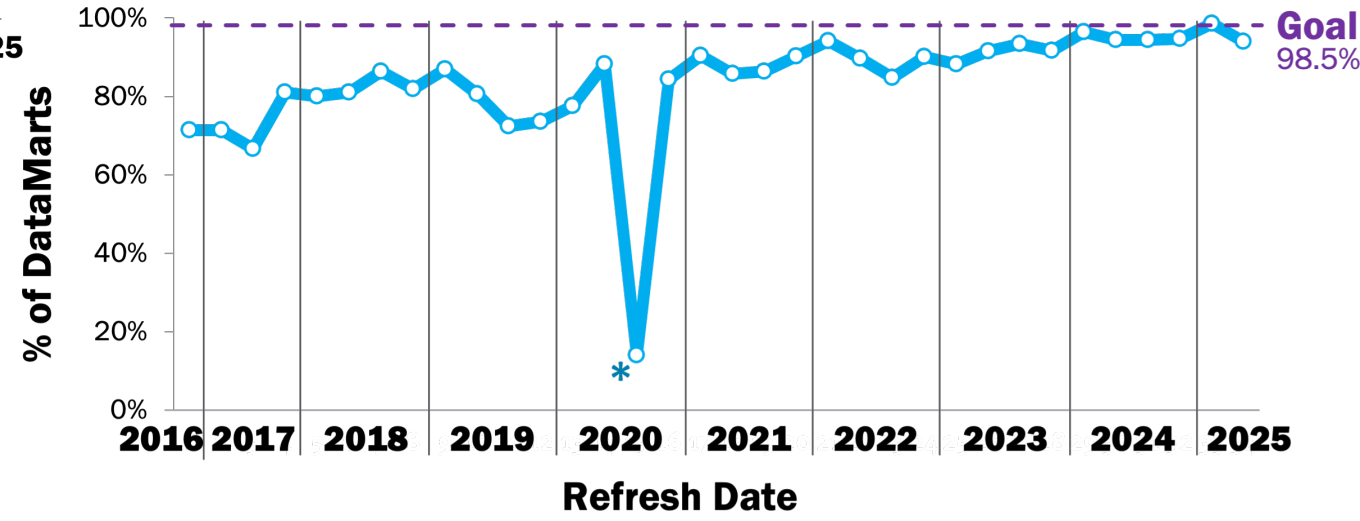
- Less than a 5% decrease in the number of patients or records in a PCORnet® Common Data Model table between refreshes



Growth in foundational data quality checks over time. Checks: Rules such as "Values must conform to PCORnet® CDM specifications." Measures: The number of PCORnet® CDM tables and/or fields affected by the checks. Data as of August 5, 2025

Improving network performance – data mapping & latency





EHR DataMarts with an encounter latency of ≤ 3 months

PCORnet Query Types – Prep-to-Research

- **Univariate statistics from data curation**
  - The Coordinating Center for PCORnet® has access to hundreds of univariate statistics about data within each site's PCORnet® CDM
  - These results can be used answer simple questions and provide a basic overview of data availability for the aggregate PCORnet population

- **Aggregate cohort queries (PCORnet® Front Door Queries)**
  - Generate aggregate counts for patient cohorts based on a set of inclusion / exclusion criteria (typically related to an index event)
  - Results can be aggregated at the network or DataMart-level, depending on use case

- For most studies, the answer to whether enough patients exist across PCORnet is "yes"

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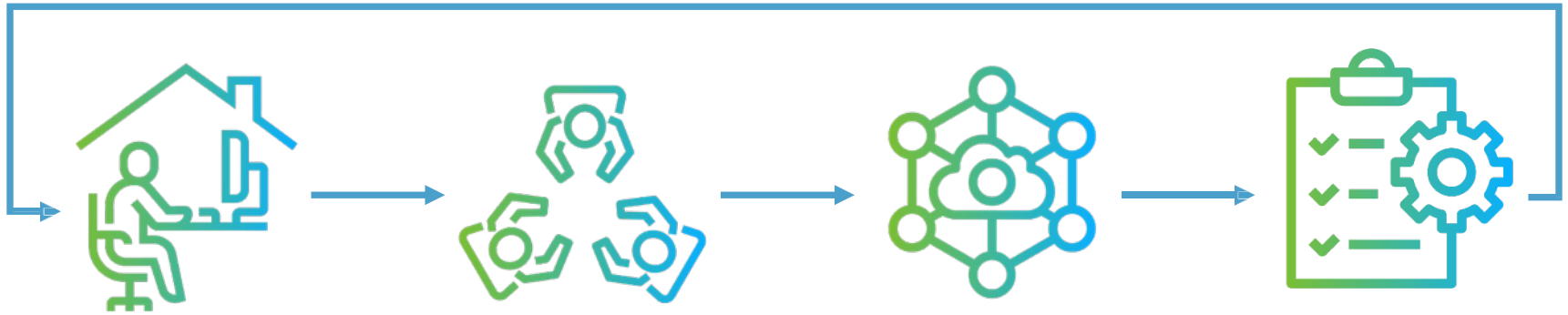
Distributed Query Infrastructure (Prep-to-Research Example)



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

Step 2
The Coordinating Center for PCORnet® 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 PCORnet® Network Partners via a secure web portal

Step 4
PCORnet® Network Partners provide a report, 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.

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PCORnet® Population Insights

Each year, PCORnet connects researchers with health data from everyday healthcare encounters with nearly 47 million people nationwide through eight PCORnet® Clinical Research Networks (CRNs) and over 70 partner organizations participating in PCORnet.

Access to broad data through PCORnet helps researchers design and implement large-scale, innovative, patient-centered health research.

The following data visualizations illustrate a snapshot of PCORnet data resources from January 1, 2024 – December 31, 2024, unless otherwise noted.

DEMOGRAPHICS | CARE SETTING | GEOGRAPHIC

Demographics

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Demographics

Total Number of unique patients: 46,797,628

Data from PCORnet resources represent encounters with a diverse patient population from across the U.S. and include a wide range of ages, races, and ethnicities for males and females. The data are from patients with at least 1 face-to-face encounter and a recorded diagnosis in 2024.

Race

American Indian or Alaska Native	284,495 (1%)
Asian	1,947,263 (4%)
Black or African American	7,364,299 (16%)
Native Hawaiian or Other Pacific Islander	114,114 (<1%)
White	28,668,290 (61%)
Multiple race	565,603 (1%)

~7,853,564 (17%) unknown or missing

Age (years)

Mean	40.3 (±22.7)
Children 0-9	6,854,362 (15%)
Children 10-19	5,774,710 (12%)
Adults 20-34	7,537,127 (16%)
Adults 35-54	10,676,750 (23%)
Adults 55-64	5,917,151 (13%)
Adults 65-74	5,756,235 (12%)
Adults 75+	4,281,293 (9%)

Sex

Female	26,295,324 (56%)
Male	20,481,961 (44%)

~20,343 (<1%) unknown or missing

Ethnicity

Hispanic	7,368,948 (16%)
Non-Hispanic	32,632,438 (70%)

6,796,242 (15%) unknown or missing

Explore Population Insights Reports

Data accessed through PCORnet include topical reports based on services performed by healthcare professionals in an ambulatory care or outpatient settings.

Download the full PCORnet® CRNs Population Insights Report.

PCORnet is a large, distributed "network of networks" funded by PCORI to improve the nation's capacity to efficiently conduct health research, particularly patient-centered comparative clinical effectiveness research (CER).

At the time of this report, PCORnet® Network Partners include PCORnet® Clinical Research Networks (CRNs) with more than 70 data-contributing sites in addition to patient partners and the Coordinating Center for PCORnet®. Collectively, these data-contributing sites consist of more than thirteen thousand clinical sites connected to nearly 47 million patients in the U.S. Clinical sites include large academic health systems, hospitals, federally qualified health centers, and community clinics.

This report describes the results of a data query of the patient population with at least 1 face-to-face encounter and a recorded diagnosis code (e.g., ICD-10) at a health care setting across PCORnet between January 1 – December 31, 2024. The query results will enhance public awareness of the population of patients across sites participating in PCORnet that potentially would be available for future health care research.

Topical Reports

Gene Therapy

Intellectual and Developmental Disabilities

Maternal Morbidity and Mortality

Mental and Behavioral Health

Pediatric Population

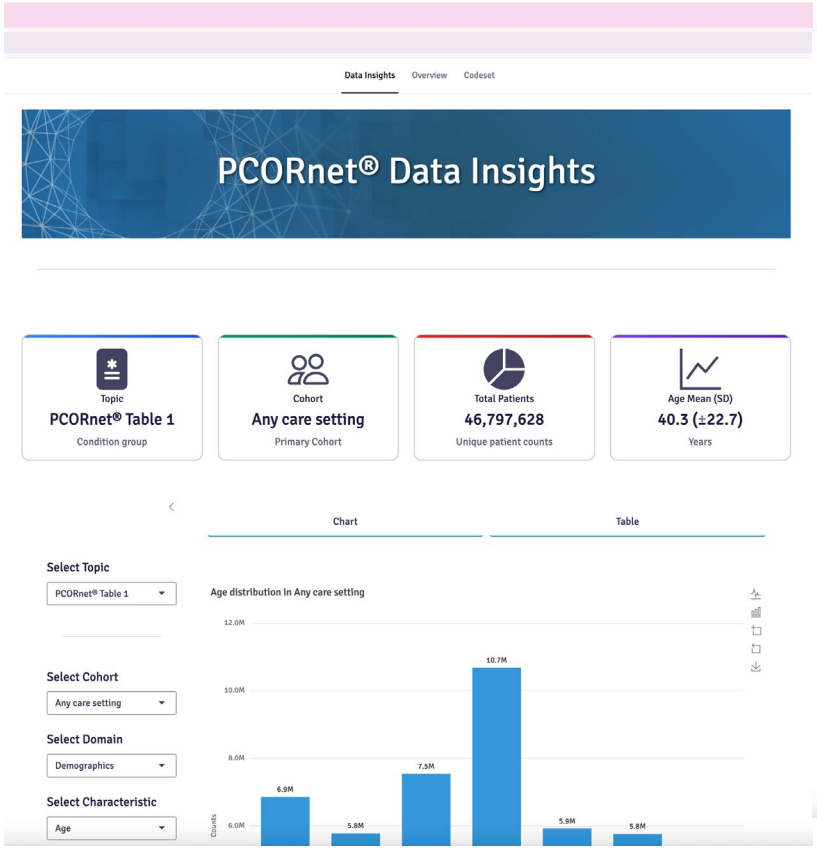
Telehealth

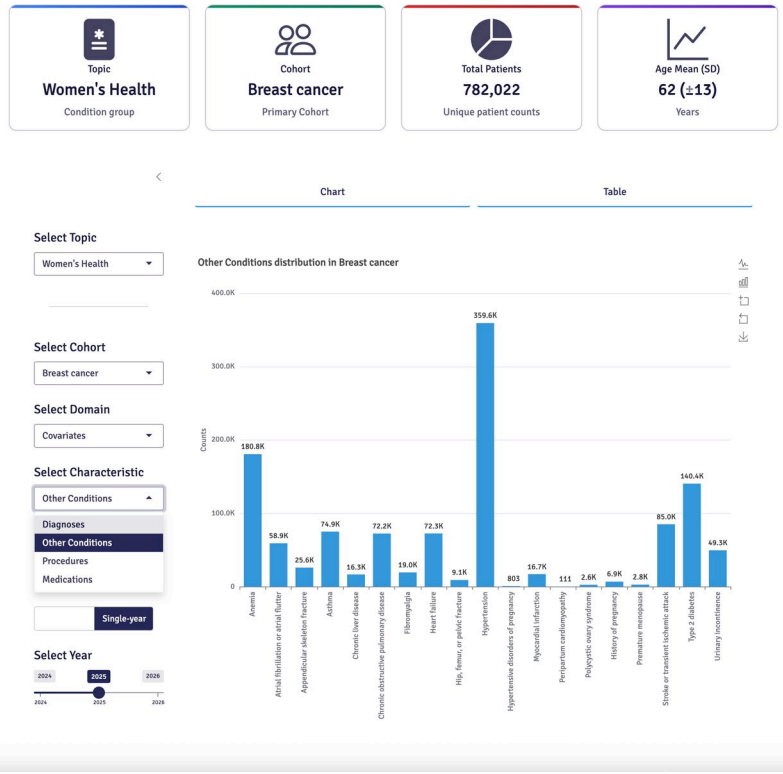
Women's Health

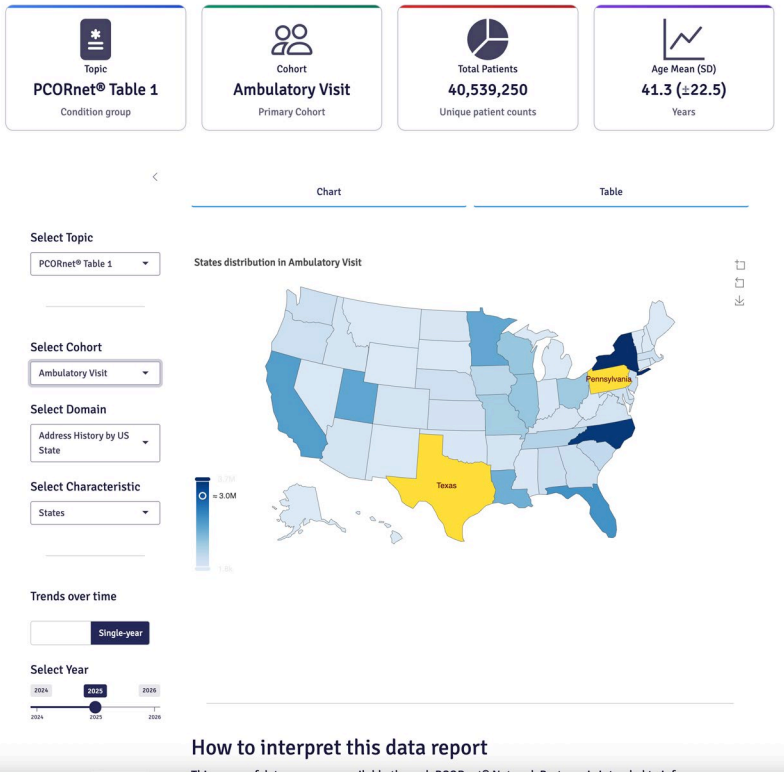
Your research can go further, faster with PCORnet. Start the conversation about how the network can support your research at the PCORnet® Front Door.

KNOCK ON THE PCORNET® FRONT DOOR TO GET STARTED

Coming Soon - Additional Visualizations







Increasing ease of navigation in complex results

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Coming Soon – Query Tools Repository

FD2091: Pediatric Cohort Characterization

Created:
2024-07-22

Subjects
Query Development

Publisher
PCORnet®

Abstract
This query aimed to characterize the prevalence of hea
population demographic characteristics, healthcare us
tions and procedures, during the query period of Janua

Description
This query identified population demographic characte
the prevalence of specified health conditions, healthca
common medications and procedures within the PCOR
2016 to December 31, 2023.

```
This query identified unique patients wi
Denominator Cohorts: At least 1 face-to-
Condition Cohorts: At least 1 face-to-fa

Cohorts included:
1. Pediatric denominator
2. Attention Deficit Hyperactivity Disor
3. Asthma
4. Autism Spectrum Disorder
5. Cystic Fibrosis
6. Chronic Kidney Disease
7. Congenital Heart Disease
8. Down Syndrome
9. Muscular Dystrophy
10. Epilepsy/Seizure disorder
11. Hypertension
12. Inflammatory Bowel Disease (Crohn's,
13. Sickle Cell Anemia
14. Type 1 Diabetes
15. Type 2 Diabetes
16. Any Pediatric Cancers
17. Full (pediatric and adult) denominat
```

Concept Set Search Results

Now showing 1 - 10 of 58

Concept Set
Wellness Visit
(2024-06-06) Children's Hospital of Philadelphia
This concept set was created to identify patients with a wellness visit for a prep-to-rese

Concept Set
Hypertension
(2024-06-10) Children's Hospital of Philadelphia
This concept set is intended to identify patients with a diagnosis of hypertension for a p
query.

Concept Set
Extracorporeal Membrane Oxygenation
(2024-06-14) Children's Hospital of Philadelphia; Patient-Centered Outcomes Researcl
This concept set was developed to identify patients with a extracorporeal membrane ox
dure for a prep-to-research query.
Show more

Concept Set
Congenital Heart Disease
(2024-06-05) Children's Hospital of Philadelphia
This concept set was created to identify patients with a diagnosis of Congenital Heart D
to-research query.

Concept Set
Heart Transplant
(2024-06-06) Children's Hospital of Philadelphia; Patient-Centered Outcomes Researcl
This concept set was developed to identify patients with a heart transplant procedure f
research query.
Show more

Continuous Renal Replacement Therapy

Created:
2024-06-12

Files
px_renal_replcmnt_therapy.csv (1.34 KB)

Subjects
Prep-for-Research
Clinician Reviewed

Publisher
PCORnet

Abstract
This concept set was created to identify patients with a continuous renal replacement therapy procedure for a prep-to-research query.

Reviewers
Utidjian, Levon

Affiliations
Children's Hospital of Philadelphia

Provenance
FD2091: Pediatric Cohort Characterization (Koscielniak, Nik: PCORI)

FD2216: IDD Rerun (IDD Workgroup)

Description
The code set was developed via string searches of the PEDSnet extension of the OMOP vocabulary concept table. The domain was restricted to procedure and vocabulary was restricted to CPT, HCPCS, and ICD-10-PCS codes. The concept set was reused without modification in two query requests, FD2091 and FD2216.

Vocabularies
CPT4 , ICD-10-PCS

Clinical Subject Heading
ContinuousRenal Replacement Therapy , Renal Replacement Therapy , Extracorporeal Circulation

Related Projects
Research Project
FD2091: Pediatric Cohort Characterization

Research Project
FD2216: Intellectual and Developmental Disabilities

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PCORnet Query Types – Study Queries

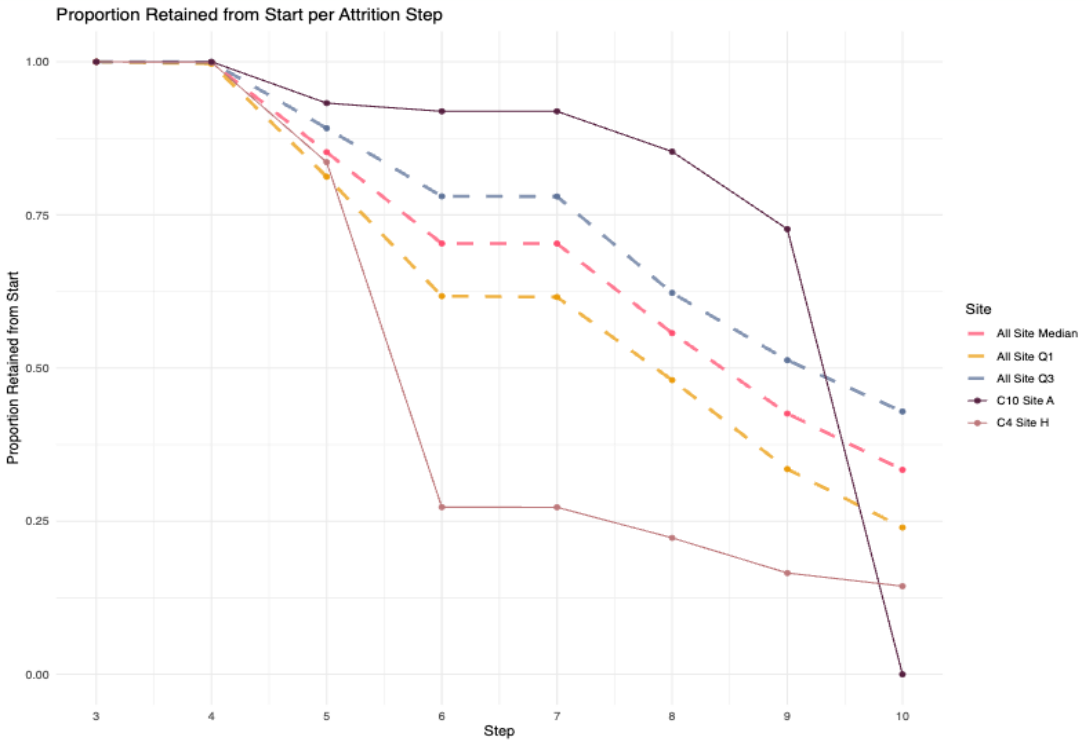
Study-specific data extracts

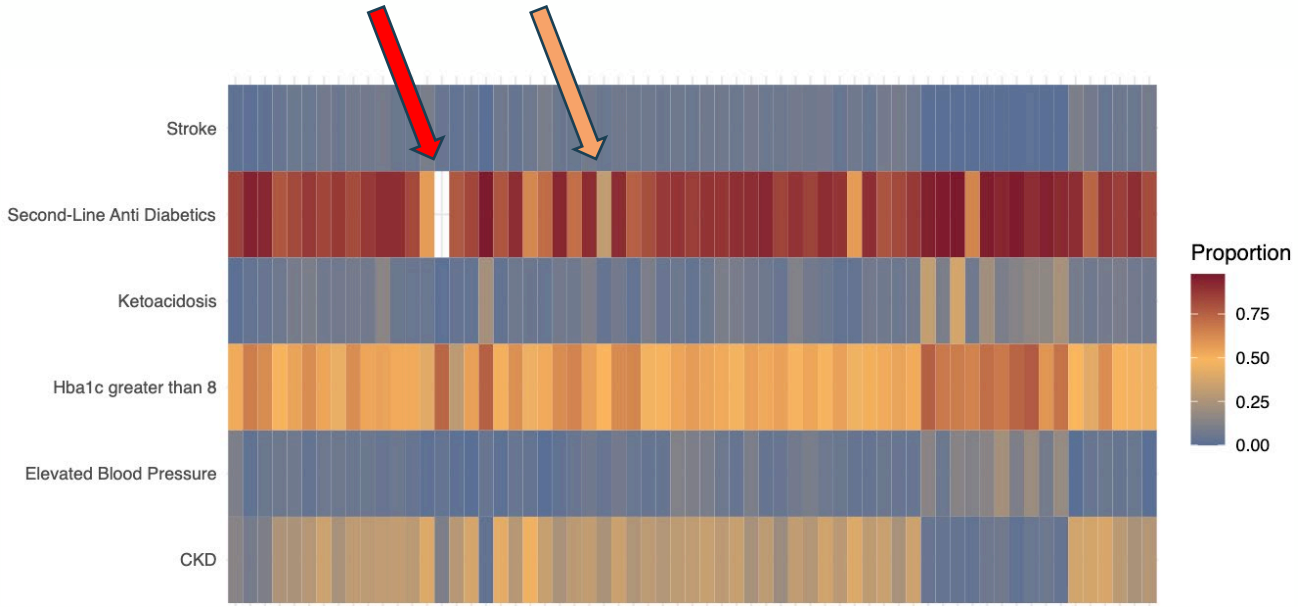
- Extracts of patient-level data for defined cohorts
- Can be based on inclusion/exclusion criteria (e.g., observational study) or for enrolled participants (e.g., pragmatic trial)

Study-specific data characterization

- Each study operates on specific variables
- General characteristics do not predict specific characteristics
- Study-focused assessment of data fitness is critical

Understanding Study Data





21

PCORnet Study Data

Cost of queries will depend on several factors

- Number of sites and number of extracts/year
- Whether the query requires data elements that are not included in the PCORnet® CDM and the degree of standardization of those data in the EHR (e.g., pulmonary function tests, flowsheets, ventilator use)

Studies may still need to obtain supplemental data

- Additional clinical data
- Chart abstraction
- Prospective data collection
- Linkage to external sources

Record Linkage Within PCORnet

- Through a 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 identifiers into **de-identified tokens** that can be securely shared with the Coordinating Center

- These tokens can be used to deduplicate patients and/or link with other sources:
  - Administrative claims
  - Data from health registries
  - Other healthcare systems
  - Other real-world data sources

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PCORnet® Study examples – data infrastructure

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, & surveys)

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

Minnie Jefferson, Patient Advisor

Study Snapshot

- **Largest trial** to date in people age 75+
- Over **9,000 enrolled** so far, with a goal to include **up to 20,000**
- **Pragmatic design** uses existing Medicare and EHR data, plus data from phone surveys. Study drugs are shipped directly to patients.

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https://clinicaltrials.gov/study/NCT04262206

Clinical Outcomes of Medications Post Anti-TNF: Researching Effectiveness in Pediatric IBD (COMPARE)

Background:

- Anti-TNF is first line therapy for moderate to severe pediatric IBD
- Approximately 30% of children initiating anti-TNF therapy experience treatment failure within the first two years
- Non-TNF advanced therapies have been approved for adults & are often used “off-label” for children

Project aims:

Recruit two pediatric cohorts (Crohn’s disease [CD] and ulcerative colitis [UC]) refractory to anti-TNF therapy, and a) **compare the effectiveness** of emerging therapies, b) **characterize the safety** of these treatments, and c) **explore the heterogeneity of treatment effect**s across subgroups.

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https://clinicaltrials.gov/study/NCT07198113

COMPARE – Study Details

Multi-center, prospective cohort studies

- Approximately 30 centers
- Separate cohorts for CD and UC
- 550 participants in each cohort
- 1-3 years follow–up
- Data extracts from the PCORnet® CDM, coupled with prospectively collected data via REDCap

Retrospective cohort

- Use the PCORnet® CDM to extract and analyze data at participating sites on non-enrolled patients taking emerging therapies after anti-TNF treatment to identify potential long-term side effects

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Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult-Centered Care (CHI-RON)

Goal: Combine data from EHRs, health insurance claims, and patient-reported outcomes to investigate the heterogeneity of congenital heart disease (CHD)

Project aims:

- Utilize PCORnet to establish an **ACHD surveillance system** to gather real-world data on healthcare use and co-morbidities for the various CHD subtypes.
- Determine factors associated with **gaps in recommended care**.
- Determine the **impact of gaps in care on patient reported outcomes** through linkage to the Congenital Heart Initiative.

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https://clinicaltrials.gov/study/NCT05185232

CHI-RON – Study Details

- Observational cohort study
- 13 health systems (12 PCORnet, 1 non-PCORnet) + 2 health plans
- Computable phenotype deployed to identify patients within the PCORnet® CDM
- Compared outcomes for CHD patients receiving recommended care vs. not

- Datavant record linkage software used to identify overlapping participants among health systems and then to link EHR data from the PCORnet® CDM with data from the health plans

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RECOVER

Scale	• Large sample size & longitudinal structured and notes data
Geography	• Nationally representative & readily linked to regional registries
Pragmatism	• Reflects realities of access to and provision of health care
Flexibility	• Rapid assessments & hypothesis generation
Efficiency	• Complements RECOVER clinical cohorts & clinical trial enrollment

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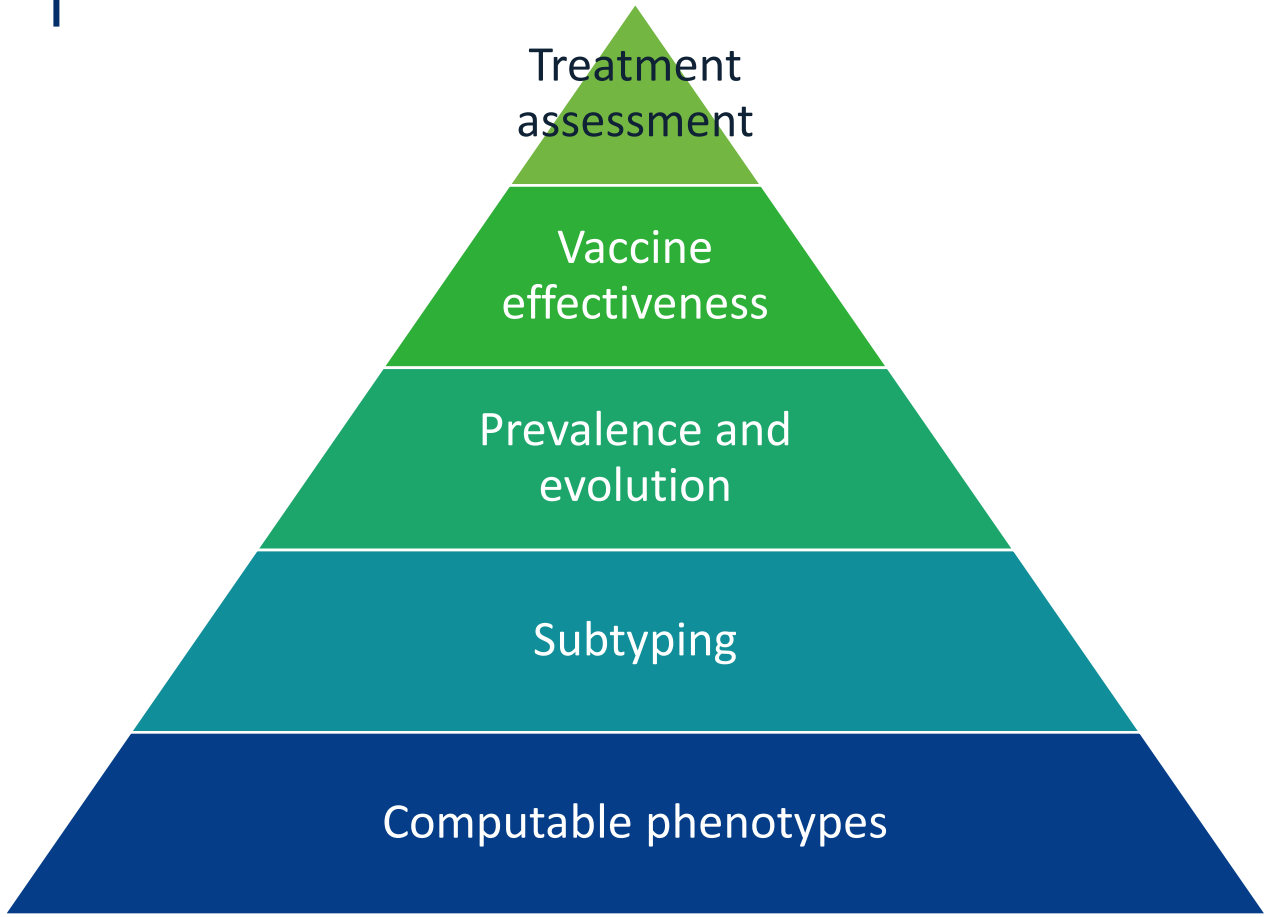
RECOVER



Information

- 37 PCORnet® network partners
- >20M Patients with COVID-19, vaccine, or look-alike
- 70M clinical notes

Structure

- Data harmonized in secure enclave
- Vaccine registry linkage
- Data model harmonized with N3C

Team

- Adult and pediatric clinical experts
- Shared informatics
- Community representatives

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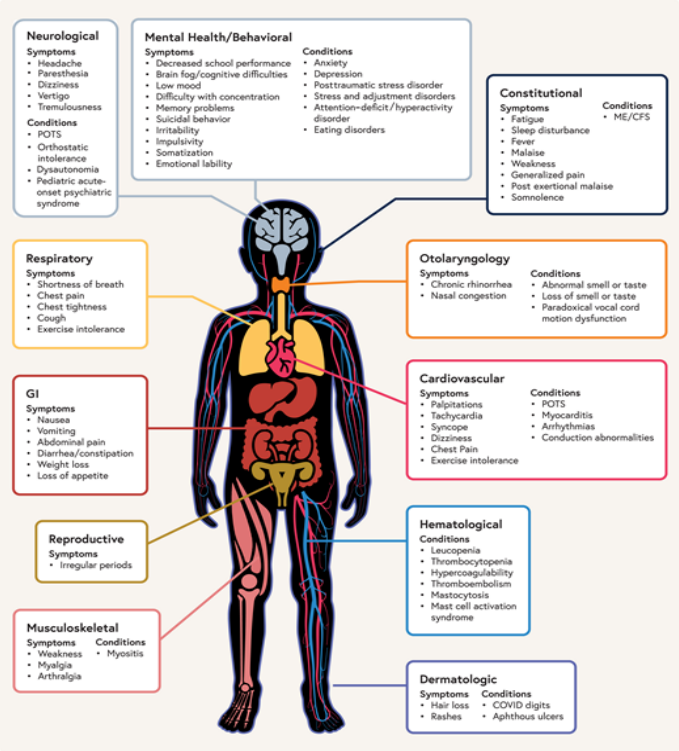
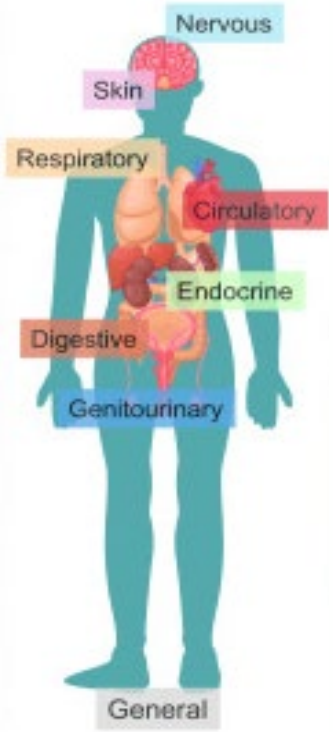
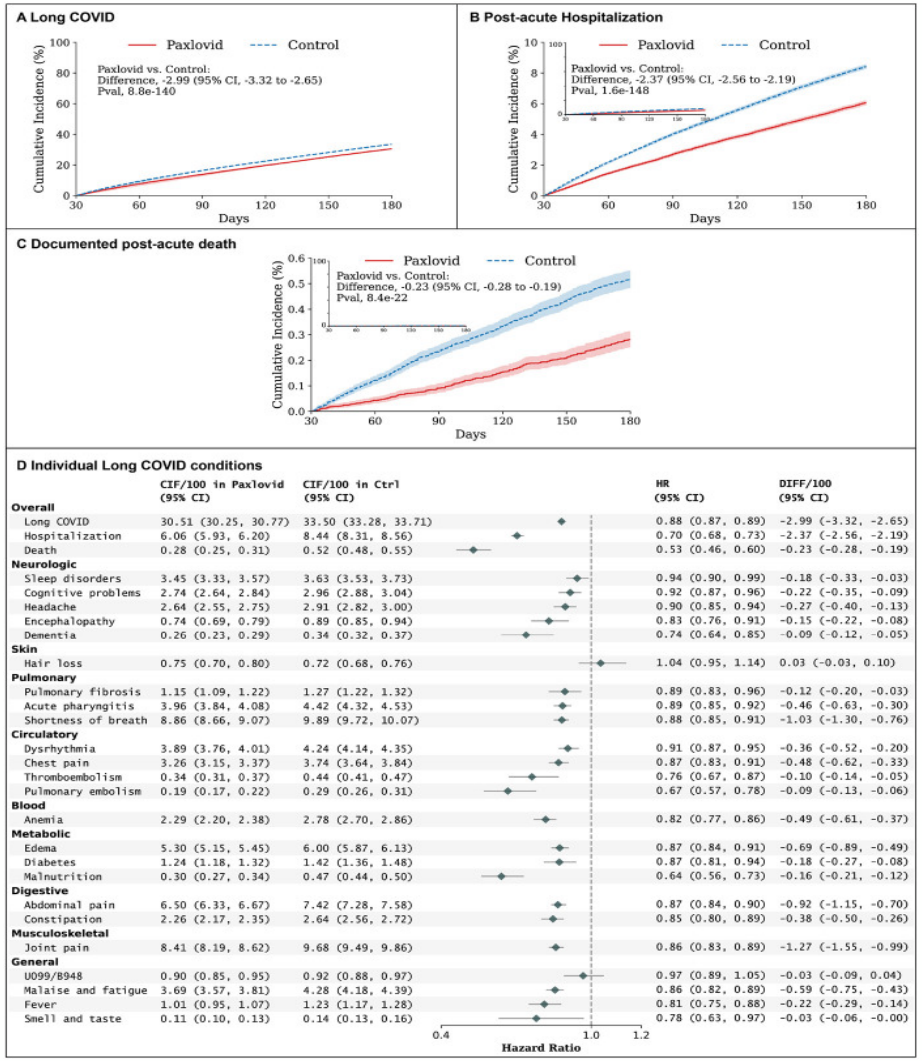
RECOVER







	CIF/100 in Paxlovid (95% CI)	CIF/100 in Ctrl (95% CI)	HR (95% CI)	DIFF/100 (95% CI)
Overall				
Long COVID	30.51 (30.25, 30.77)	33.50 (33.28, 33.71)	0.88 (0.87, 0.89)	-2.99 (-3.32, -2.65)
Hospitalization	6.06 (5.93, 6.20)	8.44 (8.31, 8.56)	0.70 (0.68, 0.73)	-2.37 (-2.56, -2.19)
Death	0.28 (0.25, 0.31)	0.52 (0.48, 0.55)	0.53 (0.46, 0.60)	-0.23 (-0.28, -0.19)
Neurologic				
Sleep disorders	3.45 (3.33, 3.57)	3.63 (3.53, 3.73)	0.94 (0.90, 0.99)	-0.18 (-0.33, -0.03)
Cognitive problems	2.74 (2.64, 2.84)	2.96 (2.88, 3.04)	0.92 (0.87, 0.96)	-0.22 (-0.35, -0.09)
Headache	2.64 (2.55, 2.75)	2.91 (2.82, 3.00)	0.90 (0.85, 0.94)	-0.27 (-0.40, -0.13)
Encephalopathy	0.74 (0.69, 0.79)	0.89 (0.85, 0.94)	0.83 (0.76, 0.91)	-0.15 (-0.22, -0.08)
Dementia	0.26 (0.23, 0.29)	0.34 (0.32, 0.37)	0.74 (0.64, 0.85)	-0.09 (-0.12, -0.05)
Skin				
Hair loss	0.75 (0.70, 0.80)	0.72 (0.68, 0.76)	1.04 (0.95, 1.14)	0.03 (-0.03, 0.10)
Pulmonary				
Pulmonary fibrosis	1.15 (1.09, 1.22)	1.27 (1.22, 1.32)	0.89 (0.83, 0.96)	-0.12 (-0.20, -0.03)
Acute pharyngitis	3.96 (3.84, 4.08)	4.42 (4.32, 4.53)	0.89 (0.85, 0.92)	-0.46 (-0.63, -0.30)
Shortness of breath	8.86 (8.66, 9.07)	9.89 (9.72, 10.07)	0.88 (0.85, 0.91)	-1.03 (-1.30, -0.76)
Circulatory				
Dysrhythmia	3.89 (3.76, 4.01)	4.24 (4.14, 4.35)	0.91 (0.87, 0.95)	-0.36 (-0.52, -0.20)
Chest pain	3.26 (3.15, 3.37)	3.74 (3.64, 3.84)	0.87 (0.83, 0.91)	-0.48 (-0.62, -0.33)
Thromboembolism	0.34 (0.31, 0.37)	0.44 (0.41, 0.47)	0.76 (0.67, 0.87)	-0.10 (-0.14, -0.05)
Pulmonary embolism	0.19 (0.17, 0.22)	0.29 (0.26, 0.31)	0.67 (0.57, 0.78)	-0.09 (-0.13, -0.06)
Blood				
Anemia	2.29 (2.20, 2.38)	2.78 (2.70, 2.86)	0.82 (0.77, 0.86)	-0.49 (-0.61, -0.37)
Metabolic				
Edema	5.30 (5.15, 5.45)	6.00 (5.87, 6.13)	0.87 (0.84, 0.91)	-0.69 (-0.89, -0.49)
Diabetes	1.24 (1.18, 1.32)	1.42 (1.36, 1.48)	0.87 (0.81, 0.94)	-0.18 (-0.27, -0.08)
Malnutrition	0.30 (0.27, 0.34)	0.47 (0.44, 0.50)	0.64 (0.56, 0.73)	-0.16 (-0.21, -0.12)
Digestive				
Abdominal pain	6.50 (6.33, 6.67)	7.42 (7.28, 7.58)	0.87 (0.84, 0.90)	-0.92 (-1.15, -0.70)
Constipation	2.26 (2.17, 2.35)	2.64 (2.56, 2.72)	0.85 (0.80, 0.89)	-0.38 (-0.50, -0.26)
Musculoskeletal				
Joint pain	8.41 (8.19, 8.62)	9.68 (9.49, 9.86)	0.86 (0.83, 0.89)	-1.27 (-1.55, -0.99)
General				
U099/B948	0.90 (0.85, 0.95)	0.92 (0.88, 0.97)	0.97 (0.89, 1.05)	-0.03 (-0.09, 0.04)
Malaise and fatigue	3.69 (3.57, 3.81)	4.28 (4.18, 4.39)	0.86 (0.82, 0.89)	-0.59 (-0.75, -0.43)
Fever	1.01 (0.95, 1.07)	1.23 (1.17, 1.28)	0.81 (0.75, 0.88)	-0.22 (-0.29, -0.14)
Smell and taste	0.11 (0.10, 0.13)	0.14 (0.13, 0.16)	0.78 (0.63, 0.97)	-0.03 (-0.06, -0.00)

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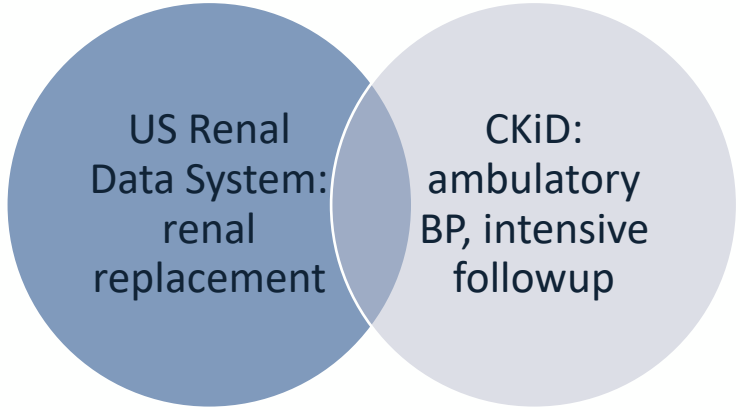
Compare the effects of renin-angiotensin-aldosterone system inhibition (RAASi) versus calcium channel blockade (CCB) on kidney function among children with chronic kidney disease and hypertension

15 institutions, 5 CRNs

20,100 children with CKD

5.5 years median followup

External Data Linkage:



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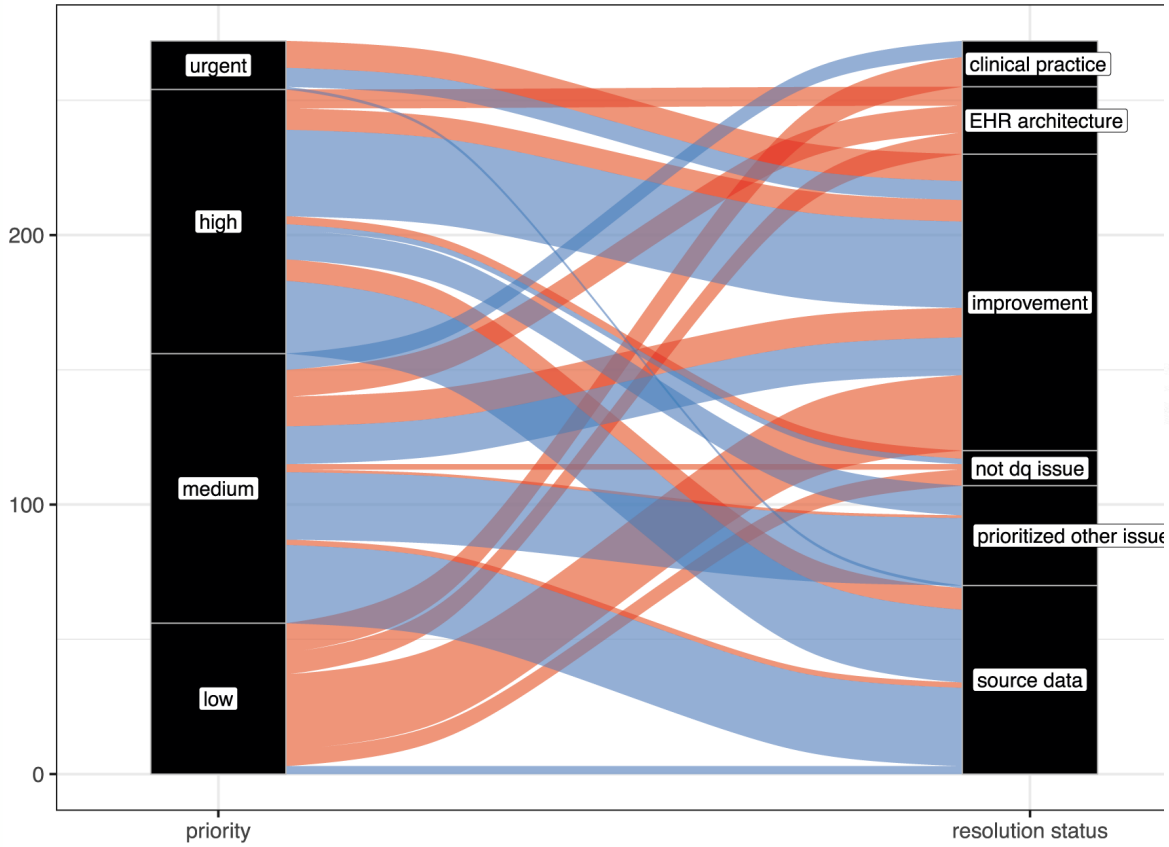

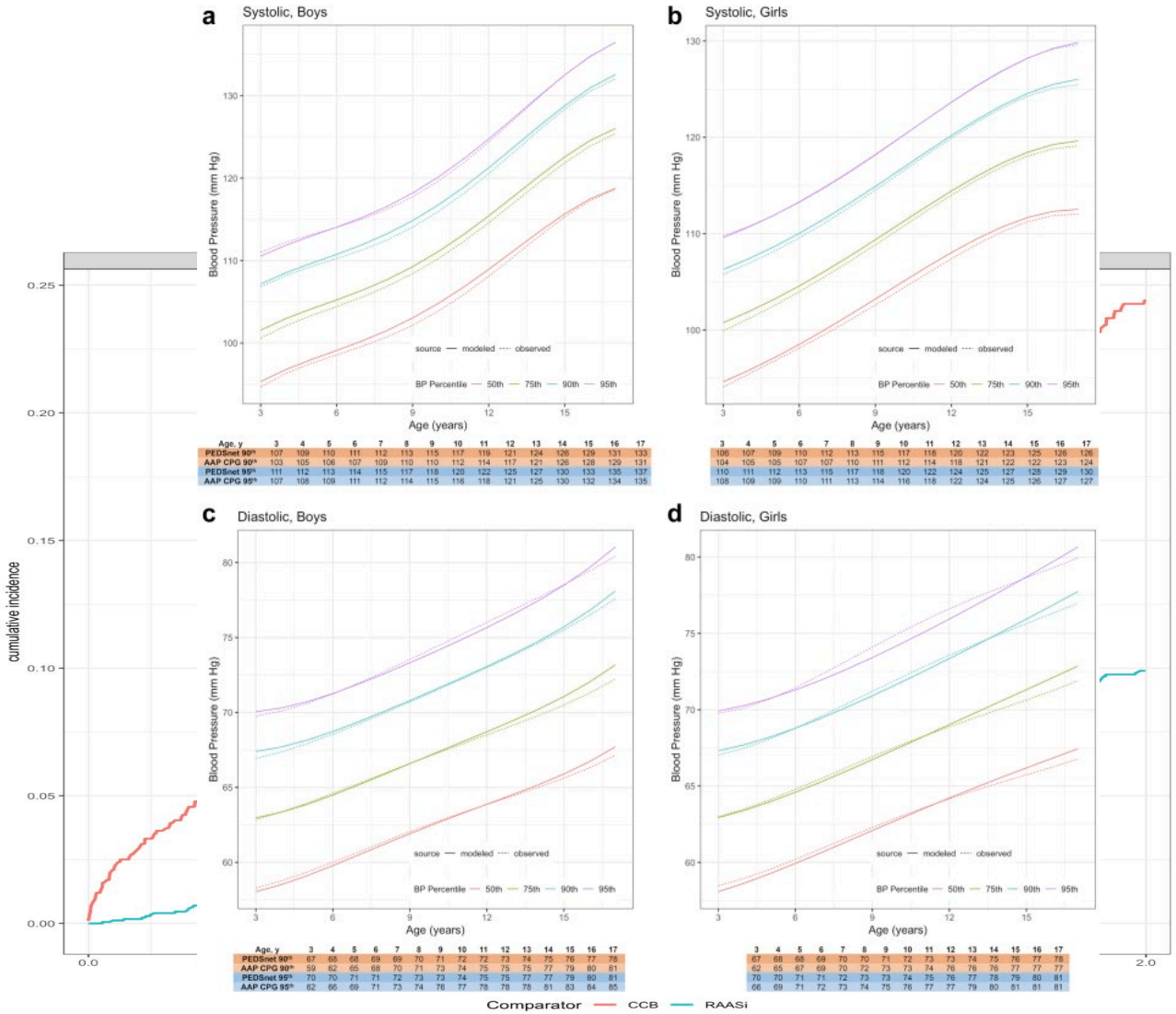

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