pcornet
The National Patient-Centered Clinical Research Network

The Children's Hospital of Philadelphia

https://www.chop.edu/

PCORnet® Network Partner in PEDSnet since 2013

The purpose of this Site Profile is to provide an overview of the basic research processes at The Children's Hospital of Philadelphia. This profile can help you understand: the types of patients within the electronic medical records; current PCORnet® Study participation; patient recruitment methods and institutional procedures related to Institutional Review Board and contracting; and data linkages.

Table 1. Characteristics of the patient population between January 1 – December 31, 2024

The characteristics of the patient population presented in this table are based on data from the health system's electronic health records mapped to the PCORnet® Common Data Model as of September 2025 and do not reflect any public-facing or official characteristics reported by the health system or its partners. This data can be used to help inform researchers of the types of patients, care settings, and location data that are available for research.

Unique Patient Records	500,001-1,000,000 [presented as range]
AGE IN YEARS	**%**
Children 0-9	57%
Children 10-19	41%
Adults 20-34	2%
Adults 35-54	<1%
Adults 55-64	<1%
Adults 65-74	<1%
Adults 75+	<1%
SEX	
Female	49%
Male	51%
Unknown	<1%
Missing	0%
RACE	
White	52%
Black or African American	21%
Asian	5%
Multiple race	5%
American Indian or Alaska Native	<1%
Native Hawaiian or Other Pacific Islander	<1%
Unknown	16%
Missing	<1%
HISPANIC	
No	85%
Yes	11%
Unknown	2%
Missing	1%
CARE SETTING – *patients may have more than one encounter type*	
Ambulatory Visit	91%
Emergency Department	20%
Telehealth	7%
Inpatient hospital stay	12%
Emergency to inpatient	0%
Observation stay	1%
Non-acute institutional stay	0%
AREA DEPRIVATION INDEX	
Quartile 1 (Highest Socioeconomic Status)	61%
Quartile 2	13%
Quartile 3	7%
Quartile 4 (Lowest Socioeconomic Status)	19%
Missing	<1%

RURAL-URBAN RESIDENCE	
Metropolitan/Urban area	99%
Micropolitan/Large rural area	1%
Small town	<1%
Isolated rural area	<1%
Missing	<1%
US STATE*	
New Jersey	19%
Pennsylvania	79%

**For state data, the site profile report will only list states with ≥ 10% of the patients.*

PCORnet® Study Leadership (Studies listed below where The Children's Hospital of Philadelphia is the lead site)

Consented Studies (interventional trials & studies with patient-reported data collection)

- Biologic Abatement and Capturing Kids' Outcomes and Flare Frequency in Juvenile Spondyloarthritis (BACK-OFF JSpA)
- Pediatric KIDney Stone (PKIDS) Care Improvement Network

Observational Studies

- Preserving Kidney Function in Children with Chronic Kidney Disease (PRESERVE)
- The RECOVER Post-Acute Sequelae of SARS-CoV-2 (PASC) Electronic Health Record (EHR) Cohort Study

Data Science

- Semantic Data Quality Standards for Multi-Center Clinical Research Studies and Networks

Engagement (for example, PCORI-funded Science of Engagement projects)

None

PCORnet® Study Participation (Studies listed below where The Children's Hospital of Philadelphia is participating)

Consented Studies (interventional trials & studies with patient-reported data collection)

- Clinical Outcomes of Medications Post Anti-TNF: Researching Effectiveness in Pediatric IBD
- Comparative Effectiveness of Palliative Surgery vs Additional Anti-Seizure Medications for Lennox-Gastaut Syndrome
- Medications and Weight Gain in PCORnet: The MedWeight Study
- The Covid-19 and Diabetes Assessment (CODA) Study

Observational Studies

- Understanding How Antibiotic Use Affects Childhood Obesity and Growth
- Understanding the Short- and Long-term Effects of Disasters and other Big Events on the Overdose Crisis
- Utilizing PCORnet to support transition from pediatric to adult centered care and reduce gaps in recommended care in patients with congenital heart disease

Data Science

- Advancing Public Health Use of Electronic Health Record Data
- USDHub: community resource for Urinary Stone Disease research

Engagement (for example, PCORI-funded Science of Engagement projects)

- Achieving Equity: Inclusion of Adults with Congenital Heart Disease (CHD) Living with Neurodevelopmental Disorders (NDDs) in Patient Centered Outcomes Research

Participant Recruitment Capabilities

Mechanisms

☒Patient portal ☒ Email ☒Post mail ☒Schedule-driven clinic intercept

Outreach

☒System-wide outreach permitted ☐Clinic-specific outreach (physician approval required)

Institutional Review Board (IRB) Policy

☒Recruitment messaging with “opt-out” language permitted

Primary Patient Groups

☐Adult ☒Pediatric ☐Safety net

Institutional Procedures

Institutional Review Board (IRB) Arrangements

☐May rely on single/central IRB for federally mandated studies only
☒May rely on single/central IRB for non-federally mandated studies
☒May accept commercial IRB review

Order of Activation

☐IRB approval required before contract execution
☐Contract execution required before IRB approval
☒IRB and contract can be executed in parallel

Administrative Efficiencies

☒Will accept PCORnet® Master Clinical Research Agreement without redlines for PCORI-funded studies
☒Has signed the PCORnet® Master Data Sharing Agreement
☒Has contracted directly with Industry funders

Linkage with Other Data Sources

Health Plan Claims	***Name(s) of Plan(s)***
☐In same or adjacent data mart with common ID	
☐Established linkage infrastructure and regulatory	
Other (non-EHR) Data	***Name(s) of Data Source(s)***
☐Linked in DataMart*	Chronic Kidney Disease in Children Study (CKiD)
☒Established linkage infrastructure and regulatory	

*DataMart refers to a specific data source consisting of data collected, captured or otherwise obtained by the health system. Each site’s PCORnet DataMart houses data standardized to the PCORnet® Common Data Model.

Children’s Hospital of Philadelphia is a Network Partner in PCORnet® which has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®). Children’s Hospital of Philadelphia’s participation in PCORnet is funded through a PCORI Award (RI-CHOP-01-PS10). 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.