

## Children’s National Hospital

<https://childrensnational.org/>

PCORnet® Network Partner in PEDSnet since 2023

The purpose of this Site Profile is to provide an overview of the basic research processes at Children’s National Hospital. 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]
<b>AGE IN YEARS</b>	<b>%</b>
Children 0-9	54 %
Children 10-19	39 %
Adults 20-34	5 %
Adults 35-54	2 %
Adults 55-64	0 %
Adults 65-74	0 %
Adults 75+	0 %
<b>SEX</b>	
Female	50 %
Male	50 %
Unknown	<1 %
Missing	0 %
<b>RACE</b>	
White	30%
Black or African American	27%
Asian	7%
Multiple race	<1%
American Indian or Alaska Native	1%
Native Hawaiian or Other Pacific Islander	<1%
Unknown	28%
Missing	7%
<b>HISPANIC</b>	
No	57%
Yes	22%
Unknown	<1%
Missing	20%
<b>CARE SETTING</b> – <i>patients may have more than one encounter type</i>	
Ambulatory Visit	95%
Emergency Department	9%
Telehealth	<1%
Inpatient hospital stay	2%
Emergency to inpatient	0%
Observation stay	2%
Non-acute institutional stay	0%
<b>AREA DEPRIVATION INDEX</b>	
Quartile 1 (Highest Socioeconomic Status)	56 %
Quartile 2	11 %
Quartile 3	4 %
Quartile 4 (Lowest Socioeconomic Status)	7 %
Missing	22 %

**RURAL-URBAN RESIDENCE**

Metropolitan/Urban area	78 %
Micropolitan/Large rural area	<1 %
Small town	<1 %
Isolated rural area	<1 %
Missing	22 %

**US STATE\***

District of Columbia	17 %
Maryland	39 %
Virginia	22 %

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

**PCORnet® Study Leadership (Studies listed below where Children’s National Hospital is the lead site)**

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

None

**Observational Studies**

None

**Data Science**

None

**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

**PCORnet® Study Participation (Studies listed below where Children’s National Hospital is participating)**

**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)
- Clinical Outcomes of Medications Post Anti-TNF: Researching Effectiveness in Pediatric IBD
- Pediatric KIDney Stone (PKIDS) Care Improvement Network

**Observational Studies**

- The RECOVER Post-Acute Sequelae of SARS-CoV-2 (PASC) Electronic Health Record (EHR) Cohort Study
- 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**

None

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

None

**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<sup>®</sup> Master Clinical Research Agreement without redlines for PCORI-funded studies
- Has signed the PCORnet<sup>®</sup> 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\*
- Established linkage infrastructure and regulatory

TriNetX

\*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<sup>®</sup> Common Data Model.

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