

## Colorado Children's Hospital

<https://www.childrenscolorado.org/>

PCORnet® Network Partner in PEDSnet since 2013

The purpose of this Site Profile is to provide an overview of the basic research processes at Colorado Children’s 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	100,001-500,000 [presented as range]
<b>AGE IN YEARS</b>	<b>%</b>
Children 0-9	57 %
Children 10-19	37 %
Adults 20-34	4 %
Adults 35-54	1 %
Adults 55-64	<1 %
Adults 65-74	<1 %
Adults 75+	<1 %
<b>SEX</b>	
Female	49 %
Male	51 %
Unknown	<1 %
Missing	0 %
<b>RACE</b>	
White	69%
Black or African American	7%
Asian	3%
Multiple race	5%
American Indian or Alaska Native	1%
Native Hawaiian or Other Pacific Islander	<1%
Unknown	16%
Missing	0%
<b>HISPANIC</b>	
No	64%
Yes	33%
Unknown	2%
Missing	<1%
<b>CARE SETTING</b> – <i>patients may have more than one encounter type</i>	
Ambulatory Visit	72%
Emergency Department	44%
Telehealth	10%
Inpatient hospital stay	5%
Emergency to inpatient	0%
Observation stay	3%
Non-acute institutional stay	0%
<b>AREA DEPRIVATION INDEX</b>	
Quartile 1 (Highest Socioeconomic Status)	52 %
Quartile 2	11 %
Quartile 3	14 %
Quartile 4 (Lowest Socioeconomic Status)	6 %
Missing	18 %

<b>RURAL-URBAN RESIDENCE</b>	
Metropolitan/Urban area	77 %
Micropolitan/Large rural area	2 %
Small town	2 %
Isolated rural area	1 %
Missing	18 %
<b>US STATE*</b>	
Colorado	79 %

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

**PCORnet® Study Leadership (Studies listed below where Colorado Children’s 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)**

None

**PCORnet® Study Participation (Studies listed below where Colorado Children’s 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
- Comparative Effectiveness of Palliative Surgery vs Additional Anti-Seizure Medications for Lennox-Gastaut Syndrome
- HERO Registry & Trial: Healthcare Worker Exposure Response and Outcomes
- Medications and Weight Gain in PCORnet: The MedWeight Study
- Pediatric KIDney Stone (PKIDS) Care Improvement Network
- The Covid-19 and Diabetes Assessment (CODA) Study

**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
- Understanding How Antibiotic Use Affects Childhood Obesity and Growth
- 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**

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

**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**

- In same or adjacent data mart with common ID  
 Established linkage infrastructure and regulatory

**Name(s) of Plan(s)**

**Other (non-EHR) Data**

- Linked in DataMart\*  
 Established linkage infrastructure and regulatory

**Name(s) of Data Source(s)**

Colorado Immunization Information System (CIIS);  
DataVant

\*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.

Colorado Children's 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>). Colorado Children'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.