Seattle Children's Research Institute

https://www.seattlechildrens.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 Seattle Children's Research Institute. 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]
AGE IN YEARS	**%**
Children 0-9	58 %
Children 10-19	39 %
Adults 20-34	2 %
Adults 35-54	1 %
Adults 55-64	<1 %
Adults 65-74	<1 %
Adults 75+	0 %
SEX	
Female	48 %
Male	52 %
Unknown	<1 %
Missing	0 %
RACE	
White	46%
Black or African American	7%
Asian	12%
Multiple race	9%
American Indian or Alaska Native	1%
Native Hawaiian or Other Pacific Islander	1%
Unknown	24%
Missing	<1%
HISPANIC	
No	72%
Yes	20%
Unknown	8%
Missing	<1%
CARE SETTING – *patients may have more than one encounter type*	
Ambulatory Visit	74%
Emergency Department	38%
Telehealth	13%
Inpatient hospital stay	2%
Emergency to inpatient	2%
Observation stay	4%
Non-acute institutional stay	0%
AREA DEPRIVATION INDEX	
Quartile 1 (Highest Socioeconomic Status)	Not reported
Quartile 2	Not reported
Quartile 3	Not reported
Quartile 4 (Lowest Socioeconomic Status)	Not reported
Missing	Not reported

RURAL-URBAN RESIDENCE	
Metropolitan/Urban area	92 %
Micropolitan/Large rural area	5 %
Small town	1 %
Isolated rural area	1 %
Missing	<1%
US STATE*	
Washington	96 %
**For state data, the site profile report will only list states with ≥ 10% of the patients.*	

PCORnet® Study Leadership (Studies listed below where Seattle Children's Research Institute 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 Seattle Children's Research Institute 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

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

Data Science

None

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

- Measurement Matters: Refining and Validating a Patient-Centered Outcomes Research Engagement Measure

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 - IRB

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*	External medications and mother-baby
☒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.

Seattle Children's Research Institute is a Network Partner in PCORnet® which has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®). Seattle Children's Research Institute'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.