Stanford Children's Health

https://www.stanfordchildrens.org/

PCORnet® Network Partner in PEDSnet since 2022

The purpose of this Site Profile is to provide an overview of the basic research processes at Stanford Children's Health. 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	45 %
Children 10-19	36 %
Adults 20-34	11 %
Adults 35-54	7 %
Adults 55-64	1 %
Adults 65-74	<1 %
Adults 75+	<1 %
SEX	
Female	56 %
Male	44 %
Unknown	<1 %
Missing	0 %
RACE	
White	28%
Black or African American	2%
Asian	19%
Multiple race	5%
American Indian or Alaska Native	<1%
Native Hawaiian or Other Pacific Islander	1%
Unknown	41%
Missing	5%
HISPANIC	
No	52%
Yes	24%
Unknown	19%
Missing	5%
CARE SETTING – *patients may have more than one encounter type*	
Ambulatory Visit	86%
Emergency Department	16%
Telehealth	15%
Inpatient hospital stay	7%
Emergency to inpatient	0%
Observation stay	1%
Non-acute institutional stay	0%
AREA DEPRIVATION INDEX	
Quartile 1 (Highest Socioeconomic Status)	79 %
Quartile 2	7 %
Quartile 3	7 %
Quartile 4 (Lowest Socioeconomic Status)	5 %
Missing	1 %

RURAL-URBAN RESIDENCE	
Metropolitan/Urban area	96 %
Micropolitan/Large rural area	4 %
Small town	<1%
Isolated rural area	<1%
Missing	<1%
US STATE*	
California	99 %

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

PCORnet® Study Leadership (Studies listed below where Stanford Children's Health 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 Stanford Children's Health 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)
- Comparative Effectiveness of Palliative Surgery vs Additional Anti-Seizure Medications for Lennox-Gastaut Syndrome
- 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

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

[+] *For truly industry sponsored CT, Stanford's contracts team will not sign contract until IRB approval is in place*

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	No large-scale linkage available between electronic health record data and claims data, site able to link data when approved for IRB-supported research. Site participates in nation-wide analyses of claims data by contributing claims data to Children's Hospital Association (CHA). Data identified in these studies can be linked back to electronic health record data.
Other (non-EHR) Data	***Name(s) of Data Source(s)***
☐Linked in DataMart* ☐Established linkage infrastructure and regulatory	- Site developed de-identification of bedside monitoring data (https://med.stanford.edu/starr-wave/learn.html). - Site processes proprietary Philips Patient Information Center (PIC) ix data to standard physionet compatible format for ease of research use. - Research IT patient centered data collection capabilities: ▪ Stanford REDCap: A general purpose data collection platform (https://redcap.stanford.edu/) ▪ Stanford mHealth: Mobile application data and Apple watch data collection (https://med.stanford.edu/mhealth.html) ▪ CHOIR learning health platform: Primarily for deep longitudinal surveys: (https://choir.stanford.edu/)

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*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.

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