

Lurie Children’s Hospital

<https://www.luriechildrens.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 Lurie 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]
AGE IN YEARS	%
Children 0-9	59 %
Children 10-19	38 %
Adults 20-34	2 %
Adults 35-54	Not Reported
Adults 55-64	Not Reported
Adults 65-74	Not Reported
Adults 75+	Not Reported
SEX	
Female	47 %
Male	53 %
Unknown	Not Reported
Missing	Not Reported
RACE	
White	46%
Black or African American	11%
Asian	5%
Multiple race	4%
American Indian or Alaska Native	Not Reported
Native Hawaiian or Other Pacific Islander	Not Reported
Unknown	32%
Missing	Not Reported
HISPANIC	
No	62%
Yes	34%
Unknown	4%
Missing	Not Reported
CARE SETTING – <i>patients may have more than one encounter type</i>	
Ambulatory Visit	82%
Emergency Department	19%
Telehealth	12%
Inpatient hospital stay	3%
Emergency to inpatient	3%
Observation stay	3%
Non-acute institutional stay	Not Reported
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	98 %
Micropolitan/Large rural area	1 %
Small town	1 %
Isolated rural area	Not Reported
Missing	Not Reported
US STATE*	
Illinois	97 %

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

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

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

- Comparative Effectiveness of Palliative Surgery vs Additional Anti-Seizure Medications for Lennox-Gastaut Syndrome

Observational Studies

None

Data Science

None

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

None

PCORnet® Study Participation (Studies listed below where Lurie Children’s 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

- Comparing the Benefits and Harms of Three Types of Weight Loss Surgery -- The PCORnet® Bariatric Study
- 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

- USDHub: community resource for Urinary Stone Disease research

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[®] 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

- 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)

Linked on a project-by-project basis with nearby health systems such as Prentice Women's Hospital (re: neonates transferred from there to Lurie Children's).

*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.

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