

Washington University in St. Louis

<https://wustl.edu/>

PCORnet® Network Partner in GPC since 2018

The purpose of this Site Profile is to provide an overview of the basic research processes at Washington University in St. Louis. 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	>1,000,000 [presented as range]
AGE IN YEARS	%
Children 0-9	13 %
Children 10-19	11 %
Adults 20-34	14 %
Adults 35-54	23 %
Adults 55-64	14 %
Adults 65-74	15 %
Adults 75+	10 %
SEX	
Female	58 %
Male	42 %
Unknown	<1 %
Missing	0 %
RACE	
White	75 %
Black or African American	20 %
Asian	2 %
Multiple race	0 %
American Indian or Alaska Native	<1 %
Native Hawaiian or Other Pacific Islander	<1 %
Unknown	2 %
Missing	<1 %
HISPANIC	
No	95 %
Yes	2 %
Unknown	2 %
Missing	1 %
CARE SETTING – <i>patients may have more than one encounter type</i>	
Ambulatory Visit	87 %
Emergency Department	22 %
Telehealth	23 %
Inpatient hospital stay	10 %
Emergency to inpatient	0 %
Observation stay	2 %
Non-acute institutional stay	0 %
AREA DEPRIVATION INDEX	
Quartile 1 (Highest Socioeconomic Status)	37 %
Quartile 2	20 %
Quartile 3	17 %
Quartile 4 (Lowest Socioeconomic Status)	15 %
Missing	10 %

RURAL-URBAN RESIDENCE

Metropolitan/Urban area	76 %
Microropolitan/Large rural area	6 %
Small town	6 %
Isolated rural area	1 %
Missing	10 %

US STATE*

Illinois	25 %
Missouri	63 %

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

PCORnet® Study Leadership (Studies listed below where Washington University in St. Louis is the lead site)

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

None

Observational Studies

None

Data Science

None

Engagement

None

PCORnet® Study Participation (Studies listed below where Washington University in St. Louis is participating)

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

- A Comparative Effectiveness Study of Oral Medications Used for Migraine Prevention: The APT Comparison Study
- 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
- Medications and Weight Gain in PCORnet: The MedWeight Study
- Pediatric KIDney Stone (PKIDS) Care Improvement Network
- Pragmatic Evaluation of Events and Benefits of Lipid-Lowering in Older Adults (PREVENTABLE)
- REDucing future fractureS and improving ouTcomes of fRagility fracture (RESTORE)
- VictORION-INCLUSION: Evaluating Inclisiran for Cholesterol Management in Heart Disease (V-INCLUSION)

Observational Studies

- Understanding How Antibiotic Use Affects Childhood Obesity and Growth

Data Science

None

Engagement

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)

Medicare claims linked to Common Data Model (CDM), hospital tumor registry, and social/geographic data in a centralized repository maintained at the University of Missouri (“GROUSE”)

Other (non-EHR) Data

- Linked in DataMart*
 Established linkage infrastructure and regulatory

Name(s) of Data Source(s)

North American Association of Central Cancer Registries (NAACCR) data, Social Security (SS) death data, Slide and radiological imaging metadata, (Some) genomic labs, Geocoded census data

*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.

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