

Johns Hopkins University

<https://ictr.johnshopkins.edu/service/collaborations/pcori-pcornet-path-network/>

PCORnet® Network Partner in PaTH since 2013

The purpose of this Site Profile is to provide an overview of the basic research processes at Johns Hopkins University. 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 | 500,001 – 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 | 14 % |
| Adults 75+ | 12 % |
| SEX | |
| Female | 57 % |
| Male | 43 % |
| Unknown | <1 % |
| Missing | <1 % |
| RACE | |
| White | 57% |
| Black or African American | 25% |
| Asian | <1% |
| Multiple race | <1% |
| American Indian or Alaska Native | <1% |
| Native Hawaiian or Other Pacific Islander | <1% |
| Unknown | 11% |
| Missing | 7% |
| HISPANIC | |
| No | 67% |
| Yes | 2% |
| Unknown | 4% |
| Missing | 27% |
| CARE SETTING – <i>patients may have more than one encounter type</i> | |
| Ambulatory Visit | 84% |
| Emergency Department | 21% |
| Telehealth | 17% |
| Inpatient hospital stay | 6% |
| Emergency to inpatient | 0% |
| Observation stay | 0% |
| Non-acute institutional stay | 0% |
| AREA DEPRIVATION INDEX | |
| Quartile 1 (Highest Socioeconomic Status) | 0 % |
| Quartile 2 | 0 % |
| Quartile 3 | 0 % |
| Quartile 4 (Lowest Socioeconomic Status) | 0 % |
| Missing | 100 % |

RURAL-URBAN RESIDENCE

| | |
|-------------------------------|-------------------|
| Metropolitan/Urban area | 0 % |
| Micropolitan/Large rural area | 0 % |
| Small town | 0 % |
| Isolated rural area | 0 % |
| Missing | 100 % |
| US STATE* | Data not reported |

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

PCORnet[®] Study Leadership (Studies listed below where Johns Hopkins University 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 Johns Hopkins University is participating)

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

- ACTIV-6: COVID-19 Study of Repurposed Medications
- Aspirin Dosing: A Patient-Centric Trial Assessing Benefits and Long-term (ADAPTABLE)
- 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
- Cognitive Behavioral Therapy and Real-Time Pain Management Intervention for Sickle Cell via Mobile Applications (CaRISMA)
- Comparative Effectiveness of Prophylactic ICD versus Non-ICD Therapy in Contemporary Heart Failure Patients with a Low Risk for Arrhythmic Death (CONTEMP-ICD)
- Greenlight Plus Study: A Randomized Study of Approaches to Early Childhood Obesity Prevention - Phase 2
- HERO Registry & Trial: Healthcare Worker Exposure Response and Outcomes
- Outcomes Database to Prospectively Assess Changing Therapy Landscape in Renal Cell Carcinoma (ODYSSEY RCC)
- Pragmatic Evaluation of Events and Benefits of Lipid-Lowering in Older Adults (PREVENTABLE)
- PRECIDENTD - PREvention of Cardiovascular and DiabEtic kidNey disease in Type 2 Diabetes
- REDucing future fractureS and improving ouTcomes of fRagility fracture (RESTORE)
- The Covid-19 and Diabetes Assessment (CODA) Study
- VictORION-INCLUSION: Evaluating Inclisiran for Cholesterol Management in Heart Disease (V-INCLUSION)

Observational Studies

- A Patient-Centered PaTH to Addressing Diabetes
- Cardiovascular Multicenter Observational Investigation of Lipid Care in the United States-2 (cvMOBIUS2)
- Comparing the Benefits and Harms of Three Types of Weight Loss Surgery -- The PCORnet[®] Bariatric Study
- Empagliflozin Diabetic Kidney Disease (Empa DKD)
- Estimating the Burden of Nonalcoholic Steatohepatitis Using a Multistate Electronic Health Record Data Network
- Preserving Kidney Function in Children with Chronic Kidney Disease (PRESERVE)
- Understanding the Short- and Long-term Effects of Disasters and other Big Events on the Overdose Crisis
- Using PCORnet to Compare Blood Pressure Control Strategies

Data Science

- Advancing Public Health Use of Electronic Health Record Data

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)

Centers for Medicare & Medicaid Services (CMS), project-specific, Datavant

Other (non-EHR) Data

Linked in DataMart*
 Established linkage infrastructure and regulatory

Name(s) of Data Source(s)

SureScripts, Mortality data, State vaccine registry

*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.

Johns Hopkins University is a Network Partner in PCORnet® which has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®). Johns Hopkins University’s participation in PCORnet is funded through a PCORI Award (RI-PITT-01-PS8). 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.