

University of Kansas Hospital

<http://www.kumc.edu/>

PCORnet® Network Partner in GPC since 2013

The purpose of this Site Profile is to provide an overview of the basic research processes at University of Kansas 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	6 %
Children 10-19	7 %
Adults 20-34	16 %
Adults 35-54	26 %
Adults 55-64	16 %
Adults 65-74	18 %
Adults 75+	11 %
SEX	
Female	57 %
Male	43 %
Unknown	<1 %
Missing	0 %
RACE	
White	75 %
Black or African American	10 %
Asian	<1 %
Multiple race	1 %
American Indian or Alaska Native	2 %
Native Hawaiian or Other Pacific Islander	1 %
Unknown	10 %
Missing	<1 %
HISPANIC	
No	88 %
Yes	9 %
Unknown	3 %
Missing	<1 %
CARE SETTING – <i>patients may have more than one encounter type</i>	
Ambulatory Visit	92 %
Emergency Department	10 %
Telehealth	17 %
Inpatient hospital stay	9 %
Emergency to inpatient	4 %
Observation stay	2 %
Non-acute institutional stay	<1 %
AREA DEPRIVATION INDEX	
Quartile 1 (Highest Socioeconomic Status)	36 %
Quartile 2	14 %
Quartile 3	17 %
Quartile 4 (Lowest Socioeconomic Status)	9 %
Missing	23 %

RURAL-URBAN RESIDENCE

Metropolitan/Urban area	64 %
Micropolitan/Large rural area	7 %
Small town	3 %
Isolated rural area	2 %
Missing	23 %

US STATE*

Kansas	50 %
Missouri	26 %

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

PCORnet® Study Leadership (Studies listed below where University of Kansas Hospital 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 University of Kansas Hospital 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)
- HERO Registry & Trial: Healthcare Worker Exposure Response and Outcomes
- Neuroendocrine Tumors – Patient Reported Outcomes (NET-PRO)
- 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

Observational Studies

- Comparing the Benefits and Harms of Three Types of Weight Loss Surgery -- The PCORnet® Bariatric Study
- Using PCORnet to Compare Blood Pressure Control Strategies

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

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
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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)

Social Security Death Master File (SSDMF), Digital Imaging and Communications in Medicine (DICOM), Tumor Registry, National Cardiovascular Data Registry (NCDR), North American Association of Central Cancer Registries (NAACCR)

*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.

University of Kansas Hospital is a Network Partner in PCORnet® which has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®). University of Kansas Hospital’s participation in PCORnet is funded through a PCORI Award (RI-MISSOURI-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.