

University of North Carolina at Chapel Hill

<http://tracs.unc.edu/>

PCORnet® Network Partner in STAR since 2018

The purpose of this Site Profile is to provide an overview of the basic research processes at the University of North Carolina at Chapel Hill. 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	10 %
Children 10-19	9 %
Adults 20-34	16 %
Adults 35-54	25 %
Adults 55-64	15 %
Adults 65-74	15 %
Adults 75+	11 %
SEX	
Female	58 %
Male	42 %
Unknown	<1 %
Missing	<1 %
RACE	
White	64 %
Black or African American	20 %
Asian	2 %
Multiple race	0 %
American Indian or Alaska Native	2 %
Native Hawaiian or Other Pacific Islander	<1 %
Unknown	12 %
Missing	<1 %
HISPANIC	
No	87 %
Yes	9 %
Unknown	4 %
Missing	<1 %
CARE SETTING – <i>patients may have more than one encounter type</i>	
Ambulatory Visit	94%
Emergency Department	23%
Telehealth	7%
Inpatient hospital stay	4%
Emergency to inpatient	5%
Observation stay	2%
Non-acute institutional stay	0%
AREA DEPRIVATION INDEX	
Quartile 1 (Highest Socioeconomic Status)	28%
Quartile 2	17%
Quartile 3	31%
Quartile 4 (Lowest Socioeconomic Status)	24%
Missing	1%

RURAL-URBAN RESIDENCE	
Metropolitan/Urban area	74%
Micropolitan/Large rural area	18%
Small town	5%
Isolated rural area	3%
Missing	<1%
US STATE*	
North Carolina	97 %

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

PCORnet® Study Leadership (Studies listed below where the University of North Carolina is the lead site)

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

- Clinical Outcomes of Medications Post Anti-TNF: Researching Effectiveness in Pediatric IBD
- Improving Outcomes and Reducing Disparities for Patients With Inflammatory Bowel Disease Through Epidemiology and Enhanced Disease Management (PROMOTE IBD)

Observational Studies

None

Data Science

None

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

None

PCORnet® Study Participation (Studies listed below where the University of North Carolina is participating)

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

- Aspirin Dosing: A Patient-Centric Trial Assessing Benefits and Long-term (ADAPTABLE)
- Comparative Effectiveness of Palliative Surgery vs Additional Anti-Seizure Medications for Lennox-Gastaut Syndrome
- Evaluating the Comparative Effectiveness of Telemedicine in Primary Care: Learning from the COVID-19 Pandemic
- Greenlight Plus Study: A Randomized Study of Approaches to Early Childhood Obesity Prevention - Phase 1
- Greenlight Plus Study: A Randomized Study of Approaches to Early Childhood Obesity Prevention - Phase 2
- HERO Registry & Trial: Healthcare Worker Exposure Response and Outcomes
- HERO-TOGETHER: A Safety Surveillance Study of Post- Vaccination Events of Interest among People Vaccinated Against COVID- 19
- 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)
- REDucing future fractureS and improving ouTcomes of fRagility fracture (RESTORE)
- VictORION-INCLUSION: Evaluating Inclisiran for Cholesterol Management in Heart Disease (V-INCLUSION)

Observational Studies

- Bariatric Surgery Impact on Cancer Screening (BASICS)
- Comparing the Benefits and Harms of Three Types of Weight Loss Surgery -- The PCORnet® Bariatric Study
- Empagliflozin Diabetic Kidney Disease (Empa DKD)
- Preserving Kidney Function in Children with Chronic Kidney Disease (PRESERVE)
- Understanding How Antibiotic Use Affects Childhood Obesity and Growth
- 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
- 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)

Medicare, Blue Cross Blue Shield of North Carolina

Other (non-EHR) Data

Linked in DataMart*
 Established linkage infrastructure and regulatory

Name(s) of Data Source(s)

UNC Cancer Registry,
 State Death Data from North Carolina Department of Health and Human Services

*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 North Carolina at Chapel Hill is a Network Partner in PCORnet[®] which has been developed with funding from the Patient-Centered Outcomes Research Institute[®] (PCORI[®]). University of North Carolina at Chapel Hill’s participation in PCORnet is funded through a PCORI Award (RI-VUMC-01-PS9). 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.