

Fenway Health

<https://fenwayhealth.org/>

PCORnet® Network Partner in ADVANCE since 2013

The purpose of this Site Profile is to provide an overview of the basic research processes at Fenway Health. 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	<100,000 [presented as range]
AGE IN YEARS	%
Children 0-9	1 %
Children 10-19	3 %
Adults 20-34	47 %
Adults 35-54	32 %
Adults 55-64	11 %
Adults 65-74	5 %
Adults 75+	1 %
SEX	
Female	42 %
Male	57 %
Unknown	<1 %
Missing	<1 %
RACE	
White	69 %
Black or African American	9 %
Asian	10 %
Multiple race	0 %
American Indian or Alaska Native	1 %
Native Hawaiian or Other Pacific Islander	<1 %
Unknown	10 %
Missing	<1 %
HISPANIC	
No	75 %
Yes	12 %
Unknown	5 %
Missing	8 %
CARE SETTING – <i>patients may have more than one encounter type</i>	
Ambulatory Visit	92 %
Emergency Department	0 %
Telehealth	44 %
Inpatient hospital stay	0 %
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*	
Massachusetts	97 %

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

PCORnet® Study Leadership (Studies listed below where Fenway Health 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 Fenway Health is participating)

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

None

Observational Studies

- Equity in Treatment for Asthma Between Latinos and Whites
- 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

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 Data Mart*
- Established linkage infrastructure and regulatory

Name(s) of Data Source(s)

- Veritas death index
- Encounter, insurance payer, medication, conditions, lab results, and vitals data from Beth Israel Deaconess Medical Center (for Fenway Health patients with records at the institution from 01/2007-07/2015)
- Patient Reported Outcomes data from patients participating in the Center for AIDS Research Network of Integrated Clinical Systems (CNICS) from University of Washington Data Management Core
- Decentralized Geomarker Assessment for Multi-site Studies (DeGAUSS)/Docker Desktop geocoding - includes STATE_FIPS, COUNTY_FIPS, RUCA_ZIP output from the address geocoding software
- Internal site data about provider gender and specialty

*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.

Fenway Health is a Network Partner in PCORnet[®] which has been developed with funding from the Patient-Centered Outcomes Research Institute[®] (PCORI[®]). Fenway Health's participation in PCORnet is funded through a PCORI Award (RI-OCHIN-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.