

A Short Guide to the ADVANCE Clinical Research Network (CRN)

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Purpose of this Document

This document is a high-level summary of the Accelerating Data Value Across a National Community Health Center Network (ADVANCE) Clinical Research Network (CRN). More detailed and technical information about the ADVANCE CRN and its contents is available in the “ADVANCE User Manual and Data Dictionary.”

Overview of ADVANCE

The ADVANCE CRN, funded by the Patient-Centered Outcomes Research Institute (PCORI), integrates outpatient electronic health record (EHR) and community data for community-based health care organization (CHCO) patients across the United States. The goal of ADVANCE is to build and maintain a network of community-based health care organizations to strengthen inclusion of populations systemically underserved and underrepresented in research.

The ADVANCE Data Warehouse is the nation’s most comprehensive data set on community-based health care organizations and the populations they serve, including people who are publicly insured, uninsured, or underinsured. ADVANCE is one of eight large Clinical Research Networks (CRNs) in the Patient Centered Outcomes Research Institute’s (PCORI) distributed research network, called PCORnet. The goal of PCORnet is to create a national network of representative data for conducting clinical outcomes research.

Background

The PCORI-sponsored Patient-Centered Clinical Research Network (PCORnet) was created in 2014 to improve the nation’s capacity to conduct comparative effectiveness research by creating a large, highly representative electronic data infrastructure for conducting clinical outcomes research. PCORnet consists of:

- 8 Clinical Research Networks (CRNs), including ADVANCE
- A Steering Committee comprised of PCORnet member networks and patient representatives
- 1 Coordinating Center with leaders from: Children’s Hospital of Philadelphia, Duke University, and Vanderbilt University Medical Center

ADVANCE is led by OCHIN in partnership with Health Choice Network (HCN), Fenway Health, and Oregon Health and Science University (OHSU). ADVANCE is:

- A national network of community-based health care organizations
- Building a network of community-based health care organizations with longitudinal outpatient EHR data on patients seen since 1/1/2012
- Integrating community-level data to help assess environmental/external factors that impact health

All data stored in the ADVANCE Data Warehouse (DW) contain coded patient IDs. Crosswalks to actual patient identifiers are kept in a secure location for patient de-duplication during data loads and for use by analytical staff as needed for approved research protocols (e.g., re-identification for a clinical trial).

The ADVANCE Data Warehouse (DW) and the PCORnet® Common Data Model (CDM):

The ADVANCE Data Warehouse (DW) is an expansion of the PCORnet Common Data Model (CDM). The DW contains all tables and fields defined for the PCORnet CDM, plus additional tables and fields that the ADVANCE CRN includes to support health equity research. These fields are elements unique to CHCOs that collect data for HRSA Uniform Data System (UDS) and other CHCO-related reporting purposes, which are typically not collected by non-CHCO clinics. These fields include the Federal Poverty Level (FPL), patient primary language, migrant/seasonal worker status, homeless status, veteran status, and others. DW data are cleaned, validated, and research-ready.

DW and CDM Patient Inclusion Criteria:

Data are included from the ADVANCE ambulatory data partners (OCHIN, Fenway, HCN, and OHSU) on any patient seen in their respective systems who was defined as “active” at the time of a data extract. Patients are active if they have had a primary care, behavioral health, or dental visit in one of the network’s clinics within the past three years as of the date of the data extract. For each active patient, all available historic data are then included in the DW as far back in time as available. In addition, geographic data, referred to as Community Vital Signs (CVS), are then also included for patients seen in the OCHIN and HCN networks.

ADVANCE started loading patients on 1/1/2015, so the DW includes patients deemed as “active” starting on 1/1/2012. Any patients that become inactive over time (i.e., were included in the DW as “active” after 1/1/2012 but not seen in the past three years as of any given extract date) are not removed from the DW but are flagged as “inactive”. Primary data collected through encounters for neonates (<28 days old) and incarcerated patients are excluded from the ‘research-ready’ CDM format Limited Data Set.

Mortality Data:

ADVANCE receives mortality data from two sources through Datavant: the National Technical Information Service (NTIS) Social Security Administration’s Death Master File (SSADMF) and ObituaryData.com. The SSADMF contains death records aggregated from death certificates and reporting from family members, and ObituaryData.com contains death records aggregated from funeral homes, newspapers, and other public and private obituary sources.

The death records are matched to patient records in ADVANCE datasets in a privacy-preserving manner, improving the quality of mortality data available in the EHR. Datasets utilizing mortality data from Datavant will include one additional field called Datavant Date of Death, a date field that includes the exact date of death. Note that there is no additional data available such as cause of death.

The PCORnet® COVID-19 Common Data Model (COVID-19 CDM):

The COVID-19 CDM is a separate data warehouse from the ADVANCE DW. The COVID-19 CDM contains all tables and fields defined for the PCORnet CDM but includes only patients who are either 1) COVID-19 positive, or 2) suspected of being positive but tested as COVID-19 negative.

COVID-19 CDM Patient Inclusion Criteria*:

The base criteria for patient inclusion in the COVID-19 CDM are the same as those of the primary ADVANCE DW/CDM, but with the following additional requirements:

- Patients must have one or more COVID and COVID related diagnoses on or after 1/1/2020,
- OR patients must have at least one or more records of certain COVID-related specified lab tests (does not have to be a positive result),
- OR a patient had a prescription for Remdesivir.

*PLEASE SEE THE DATA DICTIONARY FOR A COMPLETED LIST OF COVID-19 INCLUSION CODES.

ADVANCE and its Partners

The ADVANCE DW includes data from two healthcare networks (OCHIN and HCN) and two healthcare organizations (Fenway Health and OHSU). All clinics represented within ADVANCE provide care for low-income, uninsured, and medically vulnerable patients across the country. The ADVANCE DW contains data from all OCHIN member organizations for patients seen since 1/1/2012, including both current and former members.

OCHIN and HCN are networks of healthcare organizations and community-based health care organizations of varying sizes, each with its own clinics, providers, and patients. Fenway Health and OHSU are themselves healthcare organizations containing two to four ambulatory clinics each.

ADVANCE overall statistics (incl. all partners):

- 13,216,058 total distinct patients over all time
- 11,850,463 distinct patients with a visit within the last 3 years
- 7,960,028 distinct patients with a medical ambulatory visit in the last 3 years
- Clinic sites in 40 states
- 263 health systems containing 2,808 clinics

Following is information for each partner organization within ADVANCE. More information is available on each organization's web site:

OCHIN, Inc.: OCHIN is a nonprofit leader in equitable health care innovation and a trusted partner to a growing national provider network. The OCHIN cohort within the ADVANCE DW includes:

- 8,142,723 total distinct patients over all time
- 5,767,584 distinct patients with a visit within the last 3 years
- 5,259,769 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 37 states
- 240 member organizations with 2,285 clinics

Health Choice Network (HCN): HCN is a Health Center-Controlled Network (HCCN) founded in Florida by a group of FQHCs collaborating to recover from Hurricane Andrew. The HCN cohort contains:

- 3,513,831 total distinct patients over all time
- 1,556,631 distinct patients with a visit within the last 3 years
- 1,083,222 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 8 states
- 25 health systems with 514 clinics

Fenway Health: Founded in 1971 as a free community clinic for the Fenway neighborhood of Boston, Fenway Health serves Boston’s lesbian, gay, bisexual and transgender community and the greater Fenway neighborhood. The Fenway cohort of the DW includes:

- 90,246 distinct patients over all time
- 41,726 distinct patients with a visit within the last 3 years
- 41,726 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 1 state
- 1 health system with 4 clinics

Oregon Health & Science University (OHSU) Department of Family Medicine: OHSU is Oregon’s only academic health center. It offers an array of services as the state’s most comprehensive health care provider, from the education of the next generation of clinicians and biomedical researchers to achieving breakthroughs and innovations in multiple fields of health care. The ADVANCE DW contains data from the Federally Qualified Health Centers (FQHCs) within the OHSU health system:

- 1,469,258 distinct patients over all time
- 594,087 distinct patients with a visit within the last 3 years
- 526,116 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 1 state
- 1 health system with 5 clinics

Data Refresh Timelines

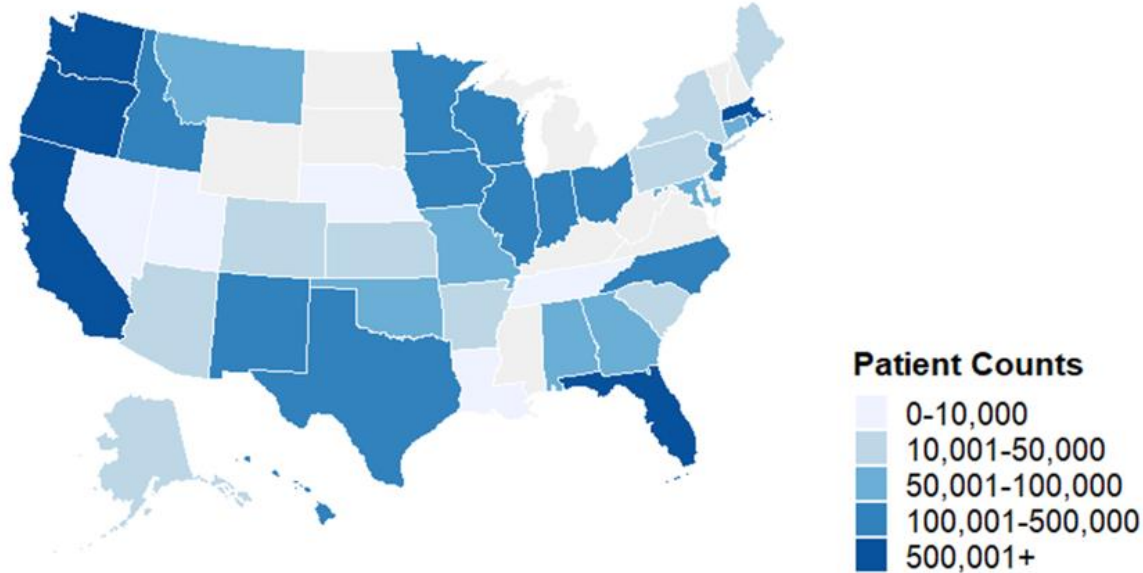
For each data refresh, a log table is kept which documents any unexpected data changes. Data profiles of all tables and fields in the CDM are run regularly to identify potential data quality issues at the field level. We are building out the breadth of the data and continuing to explore the expansion of the DW to meet future data needs.

- OCHIN and HCN data are updated weekly. This includes the updating of the geographic CVS linkages for OCHIN patients, and ZCTA-level linkages for HCN patients.
- Fenway and OHSU data are updated quarterly. (Fenway and OHSU patients are not linked to CVS data.)

Descriptions of DW Tables

The following table lists and describes the contents of each table (i.e., domain) in the ADVANCE DW. For a complete, detailed list of all tables and the fields within each table, see the “ADVANCE User Manual and Data Dictionary”.

Appendix A: ADVANCE Patient Distribution by Clinic's State



Health Sysems	Clinic Sites	Cities	States
263	2808	783	40

Appendix B: ADVANCE Selected Patient Characteristics

Counts are for patients in the ADVANCE DW with at least one ambulatory encounter, telemedicine, dental encounter, emergency department encounter, institutional professional consult, inpatient hospital stay, non-acute institutional stay, observational stay, or “unknown” encounter type between 1/1/2012 and 6/3/2024.

Patients by Sex:

Sex	Patients	%
Female	7,245,264	54.8%
Male	5,954,619	45.1%
No information	6,462	0.1%
Unknown	6,359	0.1%
Other	3,180	0.0%
Ambiguous	174	0.0%
Total Patients	13,216,058	100.0%

Patients by Race and Ethnicity:

Race & Ethnicity	Not Hispanic	Hispanic	Unknown Ethnicity	No Information	Refuse to Answer	Total	% Race Across All Ethnicities
White	4,306,576	3,247,606	332,740	50,768	80,275	8,017,966	60.7%
Black or African American	1,785,419	132,380	220,144	16,372	23,505	2,177,820	16.5%
Asian	507,883	21,332	26,970	10,544	7,622	574,351	4.3%
Unknown	190,729	496,933	492,217	1,036	9,528	1,190,443	9.0%
Refuse to Answer	96,507	343,476	93,164	9,558	84,060	626,765	4.7%
No Information	13,959	20,604	8,608	203,289	1,041	247,501	1.9%
Multiple race	89,510	55,882	11,566	2,196	2,942	162,096	1.2%
American Indian or Alaskan Native	69,435	45,291	6,272	876	2,209	124,083	0.9%
Native Hawaiian or Other Pacific Islander	55,344	19,604	6,806	4,574	1,473	87,801	0.7%
Other	630	5,358	200	983	61	7,232	0.1%
Total	7,115,992	4,388,467	1,198,687	300,196	212,716	13,216,058	100.0%
% Ethnicity Across All Races	53.8%	33.2%	9.1%	2.3%	1.6%	100.0%	

Patients by Age as of 06/30/2024:

Age Category	Patients	%
Unknown	41	0.0%
0-9	1,197,681	9.1%
10-19	1,900,688	14.4%
20-29	2,027,800	15.3%
30-39	2,203,825	16.7%
40-49	1,780,186	13.5%
50-59	1,502,430	11.4%
60-69	1,387,574	10.5%
70-79	789,714	6.0%
80-89	309,619	2.3%
90 or above	116,500	0.8%
Total Patients	13,216,058	100.0%

Patients by Primary Language:

Primary Language	Patients	%
English	9,750,781	73.8%
Spanish; Castilian	2,592,473	19.6%
Unknown	316,954	2.4%
Other language	236,173	1.8%
Haitian; Haitian Creole	56,264	0.4%
Chinese	53,487	0.4%
Vietnamese	52,322	0.4%
Russian	46,152	0.3%
Persian	38,923	0.3%
Portuguese	37,575	0.3%
Somali	34,954	0.3%
Total Patients	13,216,058	100.0%

Patients by Their Most Recent Federal Poverty Level (FPL):

FPL Category	Patients	%
100% and below	6,299,777	47.7%
101 - 150%	1,102,696	8.3%
151 - 200%	554,248	4.2%
Over 200%	972,378	7.4%
Unknown	4,286,959	32.4%
Total Patients	13,216,058	100.0%

Patients by known payer type on most recent visit:

Payer Type	Patients	%
Medicaid	4,130,152	37.8%
Uninsured	2,371,486	21.7%
Private Insurance	1,555,073	14.2%
Medicare	676,869	6.2%
Other Public Payer	299,737	2.7%
Unknown/No Information	1,901,387	17.4%
Total Patients	13,216,058	100.0%

OCHIN

Domains in DW	Description	Fields Specific to Domains
Community Vital Signs	Aggregate data of social and environmental factors that may impact patient health.	College graduates, Median income, Professional jobs, FPL levels, Unemployment, Race, Residential segregation, etc.
Condition	Representation of a patient's diagnosed and self-reported health conditions and diseases. Includes medical history and current state.	Condition ID, Report and Resolve date, Onset date, Status, Condition code, Type, and Source, etc.
Death	Reported mortality information for patients.	Source, etc.
Death Cause	The individual causes associated with a reported death.	Death cause, Code, Type, Source, and Confidence
Demographic	Current (most recently available patient information at time of data refresh) direct attributes of individual patients with at least one medical ambulatory encounter on or after 1/1/2012. No infants younger than 31 days at time of data extract.	Birth date and time, Sex, Race, Language, Family size, Income, FPL, Payor, Migrant and Homeless Status, Veteran Status, Sexual Orientation, Gender Identity, etc.
Diagnosis	Indication of the results of diagnostic processes and medical coding within healthcare delivery.	Diagnosis ID, Encounter type, Diagnosis code, type, and source
Dispensing	Outpatient pharmacy dispensing, such as prescriptions filled through a neighborhood pharmacy with a claim paid by an insurer.	Dispensing ID, Prescribing ID, NDC, Supply, Amount, etc.
Encounter	Description of the interactions between patients and providers within the context of healthcare delivery.	Encounter type, Admit and Discharge dates, Provider type, Facility location and ID, Discharge status, DRG, Migrant and Homeless status, Admitting source, Income, FPL, Payor, etc.
Enrollment	Designed to identify periods during which a person is expected to have complete data capture for one enrollment period.	Enrollment start date, end date, etc.
Family Linkage	Contains mother's patient ID where a relationship has been determined by one or more data sources and algorithms.	Mother's guarantor, Coverage, Medicaid case number, Address, etc.
General Observations	Table to store data needed for funded studies, which isn't captured in other CDM tables, such as diabetic foot exams not recorded as procedure codes in the EHR.	Provider ID, observation date, code, coding system type, numeric value, qualitative value, units, etc.
Immunization	Immunizations ordered and administered within healthcare delivery. Contains historical, patient-reported immunizations administered elsewhere.	Immunization date, CVX code, CPT code, Route, Order date, Vaccine lot number, Expiration date, etc
Lab Result	Quantitative and qualitative measurements from blood and other body specimens. These standardized measures are defined the same way across all PCORnet networks.	Lab result ID, Lab name, Specimen source, LOINC, Priority, Result, Procedure code and Type, Order and Specimen date, Result date and Time, Qualitative and Quantitative result, Unit, Range, etc.
Medication Administration	Records of medications administered to patients by healthcare providers. These administrations may take place in any settings, including inpatient, outpatient or home health encounters.	Provider ID, start / stop dates, units, etc.
Patient Reported Outcome Common Measures	Standardized measures that are defined in the same way across all PCORnet networks. Recorded at individual item level: question/statement, paired with its standardized response options.	PRO CM ID, PRO item, PRO LOINC, Response, Method, Mode, CAT, Code, etc.
Prescribing	Provider orders for medication dispensing and/or administration.	Prescribing ID, Order date and Time, Quantity, Refills, Days supply, Frequency, Basis, etc.
Procedures	Description of the discreet medical interventions and diagnostic testing, such as surgical procedures, administered within healthcare delivery.	Procedure ID, Encounter type, Procedure code and type, etc.
Surgical History	Patient's self-reported history of past surgical procedures.	Surgical history ID, History date, Procedure date, Code, Type, and Source
Vital	Vital signs (height, weight, and blood pressure) to represent a patient's current state.	Vital ID, Source, Height, Weight, BP, BMI, Smoking, Tobacco use and Type, etc.
OBS_Clin	Standardized qualitative and quantitative clinical observations about a patient	EncounterID, Obsclin_Providerid, Obsclin_Date, Obsclin_Type, Obsclin_code, etc.
OBS_Gen	Table to store everything else.	Obsgenid, Patid, Encounterid,Obsgen_providerid, Obsgen_start_date, Obsgen_type, etc.