

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):

- 13,739,257 total distinct patients over all time
- 8,245,726 distinct patients with a visit within the last 3 years
- 7,205,489 distinct patients with a medical ambulatory visit in the last 3 years
- Clinic sites in 40 states
- 275 health systems containing 2,721 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:

- 8,593,798 total distinct patients over all time
- 6,093,758 distinct patients with a visit within the last 3 years
- 5,590,665 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 37 states
- 248 member organizations with 2,198 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:

- 3,584,752 total distinct patients over all time
- 1,550,426 distinct patients with a visit within the last 3 years
- 1,072,808 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:

- 91,449 distinct patients over all time
- 41,137 distinct patients with a visit within the last 3 years
- 41,137 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:

- 1,469,193 distinct patients over all time
- 560,405, distinct patients with a visit within the last 3 years
- 500,879 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

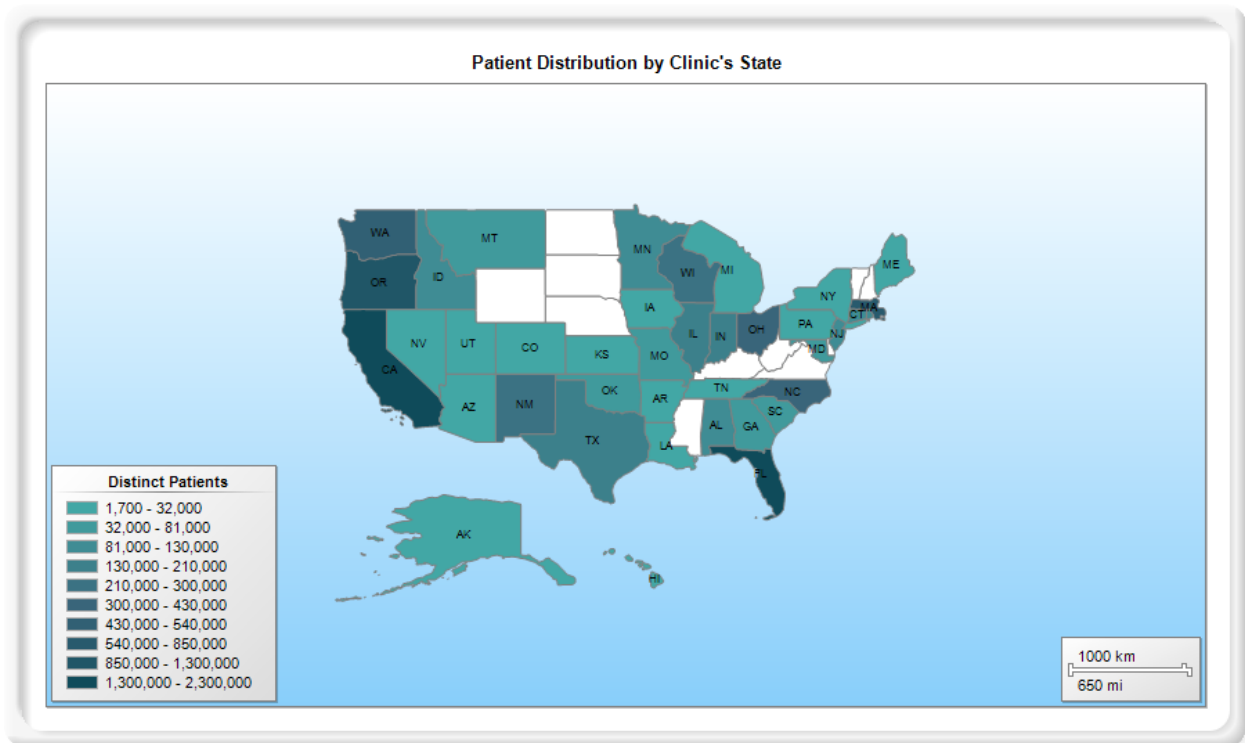
For each data refresh, a log table is kept which documents any unexpected data changes. Data profiles of all tables and fields in the CDM are run regularly to identify potential data quality issues at the field level. We are building out the breadth of the data and continuing to explore the expansion 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 Systems	Clinic Sites	Cities	States
275	2721	758	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 9/30/2024.

Patients by Sex:

Sex	Patients	%
Female	7,532,173	54.8%
Male	6,190,358	45.1%
No information	6,693	0.1%
Unknown	6,460	0.1%
Other	3,404	0.0%
Ambiguous	169	0.0%
Total	13,739,257	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	4,463,765	3,386,464	343,074	51,192	84,733	8,329,228	60.6%
Black or African American	1,857,165	138,179	223,796	16,611	24,500	2,260,251	16.5%
Asian	525,459	23,534	28,125	10,569	8,258	595,945	4.3%
Unknown	197,125	522,851	512,955	1,101	10,276	1,244,308	9.1%
Refuse to Answer	97,890	357,928	95,855	9,616	88,558	649,847	4.7%
No Information	14,063	20,772	8,674	214,829	1,054	259,392	1.9%
Multiple race	94,448	57,277	11,838	2,215	3,129	168,907	1.2%
American Indian or Alaskan Native	76,753	48,483	6,763	868	2,481	135,348	1.0%
Native Hawaiian or Other Pacific Islander	55,705	20,054	6,965	4,516	1,478	88,718	0.6%
Other	660	5,327	275	989	62	7,313	0.1%
Total	7,383,033	4,580,869	1,238,320	312,506	224,529	13,739,257	100.0%
% Ethnicity Across All Races	53.7%	33.3%	9.0%	2.3%	1.6%	100.0%	

Patients by Age as of 9/30/2024:

Age Category	Patients	%
Unknown	38	0.0%
0-9	1,247,149	9.1%
10-19	1,985,424	14.5%
20-29	2,105,569	15.3%
30-39	2,288,166	16.7%
40-49	1,853,808	13.5%
50-59	1,552,589	11.3%
60-69	1,436,744	10.5%
70-79	825,121	6.0%
80-89	322,907	2.4%
90 or above	121,738	0.9%
Total	13,739,257	100.0%

Patients by Primary Language:

Primary Language	Patients	%
English	10,105,160	73.5%
Spanish; Castilian	2,721,233	19.8%
Unknown	329,747	2.4%
Other language	246,802	1.8%
Haitian; Haitian Creole	62,827	0.5%
Chinese	54,876	0.4%
Vietnamese	53,518	0.4%
Russian	48,086	0.3%
Persian	41,802	0.3%
Portuguese	38,957	0.3%
Arabic	36,249	0.3%
Total Patients	13,739,257	100.0%

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

FPL Category	Patients	%
100% and below	6,571,935	47.8%
101 - 150%	1,138,473	8.3%
151 - 200%	579,180	4.2%
Over 200%	998,102	7.3%
Unknown	4,451,567	32.4%
Total Patients	13,739,257	100.0%

Patients by known payer type on most recent visit

Payer Type	Patients	%
Medicaid	5,386,624	39.2%
Uninsured	2,835,077	20.6%
Private Insurance	2,101,420	15.3%
Medicare	881,933	6.4%
Other Public Payer	309,641	2.3%
Unknown/No Information	2,224,562	16.2%
Total Patients	13,739,257	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.