

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 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 Accelerating Data Value Across a National Community Health Center Network (ADVANCE) Clinical Research Network (CRN), funded by the Patient-Centered Outcomes Research Institute (PCORI), integrates outpatient electronic health record (EHR) data for Community Health Center (CHC) patients across the United States and integrates community data for these patients. The ADVANCE CRN serves as a ‘community laboratory’ for engaging vulnerable patients in people-centered research. As the nation’s largest safety-net community laboratory, consisting of researchers, patients and clinicians, ADVANCE works to improve health outcomes, policy, and primary care research among vulnerable and underserved populations utilizing rigorous scientific methods.

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:

- 9 Clinical Research Networks (CRNs), such as ADVANCE
- 2 Health Plan Research Networks (HPRNs)
- A Steering Committee comprised of PCORnet member networks and patient representative
- 3 Coordinating Centers: Harvard Pilgrim, Duke, and Academy Health

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

- A national network of CHC healthcare systems
- Building a ‘community laboratory’ of CHCs with longitudinal outpatient EHR data on patients seen since 1/1/2012
- Bringing in community-level data to help assess environmental/external factors that impact health

All data stored in the ADVANCE Research Data Warehouse (RDW) 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 Research Data Warehouse (RDW) and the PCORnet® Common Data Model (CDM):

The ADVANCE Research Data Warehouse (RDW) is an expansion of the PCORnet Common Data Model (CDM). The RDW 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 CHCs that collect data for HRSA Uniform Data System (UDS) and other CHC-related reporting purposes, which are typically not collected by non-CHC clinics. These fields include the Federal Poverty Level (FPL), patient primary language, migrant/seasonal worker status, homeless status, veteran status, and others. RDW data are cleaned, validated, and research-ready.

RDW 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 networks’ 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 RDW 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 network.

ADVANCE started loading patient on 1/1/2015, so the RDW includes patients deemed as “active” starting on 1/1/2012. Any patients that become inactive over time (i.e., were included in the RDW 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 RDW but are flagged as “inactive”. Incarcerated patients and their encounters are excluded from the CDM.

Datavant Death Index (DDI):

The DDI is a combined dataset of death records assembled from government death records and third-party obituary data (e.g. funeral homes, newspapers) that can be linked to patient records in ADVANCE datasets in a privacy-preserving manner, improving the quality of mortality data. Datasets utilizing DDI will include one additional field called Date of Death, a date field that includes the month and year of death and the day portion set to “01”. 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 RDW. The COVID-19 CDM contains all tables and fields defined for the PCORnet CDM but includes only patients who are COVID-19 positive, suspected of being positive, and 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 RDW/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 RDW 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 vulnerable patients across the country. The ADVANCE RDW 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 health organizations of varying sizes, each with their 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):

- 7,471,358 total distinct patients over all time
- 4,785,251 distinct patients with a visit within the last 3 years
- 4,047,747 distinct patients with a medical ambulatory visit in the last 3 years
- Clinic sites in 31 states
- 182 health systems containing 1,688 clinic sites

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

OCHIN, Inc.: Based in Portland, Oregon, OCHIN is a Health Center-Controlled Network (HCCN). The OCHIN cohort within the ADVANCE RDW includes:

- 4,810,946 total distinct patients over all time
- 3,320,057 distinct patients with a visit within the last 3 years
- 2,950,681 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 28 states
- 155 member organizations with 1,172 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:

- 2,547,367 total distinct patients over all time
- 1,384,269 distinct patients with a visit within the last 3 years
- 1,019,175 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 8 states
- 25 health systems with 510 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 RDW includes:

- 77,615 distinct patients over all time
- 46,026 distinct patients with a visit within the last 3 years
- 46,026 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 1 state
- 1 health system with 3 clinics

Oregon Health & Science University (OHSU) Department of Family Medicine: OHSU is the 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 RDW contains data from the Federally Qualified Health Centers (FQHCs) within the OHSU health system:

- 35,430 distinct patients over all time
- 34,899 distinct patients with a visit within the last 3 years
- 31,865 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 1 state
- 1 health system with 3 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 RDW to meet future data needs.

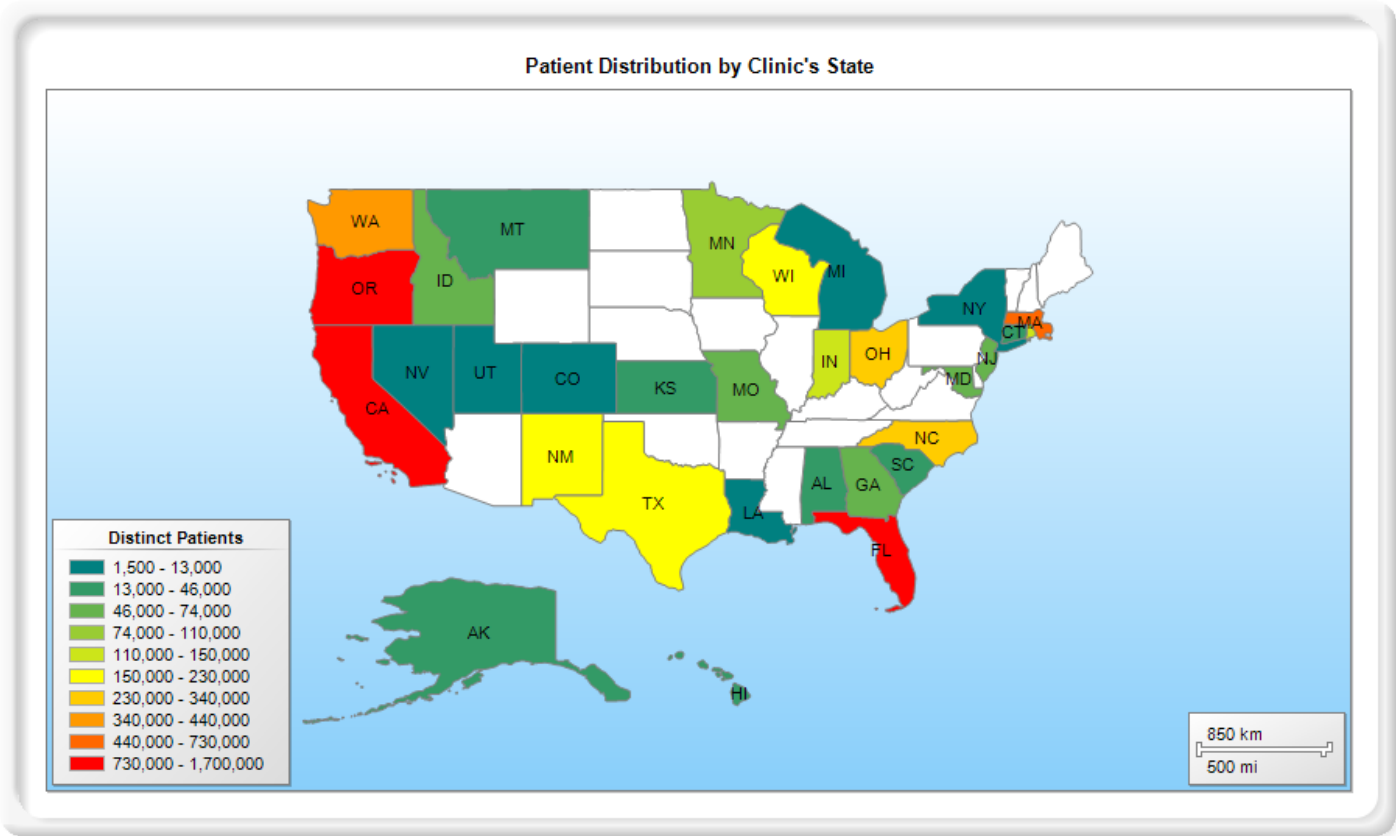
- OCHIN and HCN data are updated weekly. This includes the updating of the geographic CVS linkages for OCHIN patients, and ZCTA-level linkages for HCN patients.
- Fenway and OHSU data are updated quarterly. (Fenway and OHSU patients are not linked to CVS data.)

Descriptions of RDW Tables

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

Domains in RDW	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.

Appendix A: ADVANCE Patient Distribution by Clinic's State



Health Systems	Clinic Sites	Cities	States
182	1,688	532	31

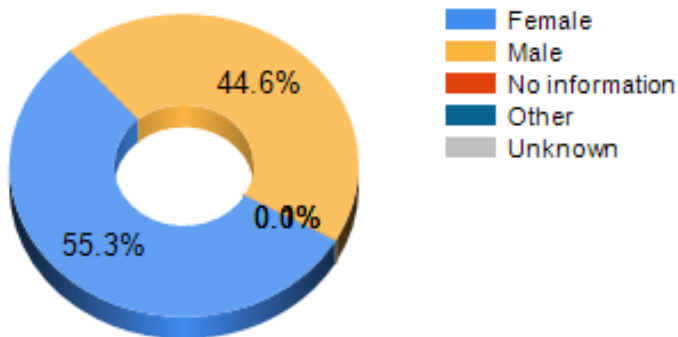
Appendix B: ADVANCE Selected Patient Characteristics

Counts are for patients in the ADVANCE RDW 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 9/30/2021.

Sex	Patients	%
Female	4,128,072	55.32%
Male	3,326,330	44.58%
No information	4,795	0.06%
Unknown	1,949	0.03%
Other	991	0.01%
Total	7,462,137	100.00%

Patients 18 and older by Condition		
Condition	Patients	%
Diabetic (Type I or II)	511,143	8.71%
Diabetic Type I	19,500	0.33%
Diabetic Type II	491,643	8.38%
Obese	1,689,792	28.81%
Obese & Diabetic (Type I or II)	280,928	4.79%
Alpha-1	427	0.01%
Total Adults	5,866,107	100.00%

Patients by Sex



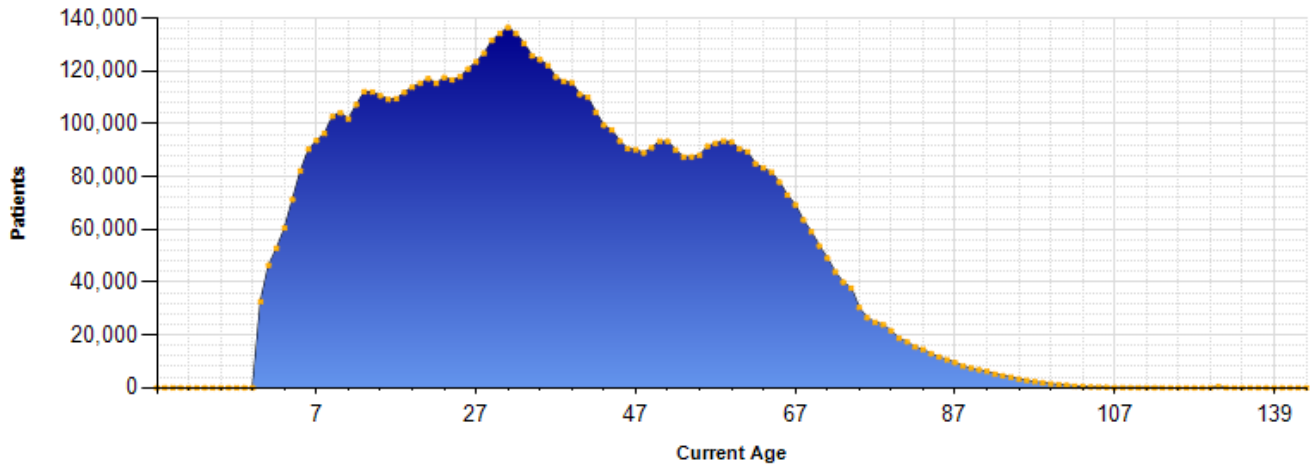
Patients by race and ethnicity:

Race \ Hispanic Ethnicity	Not Hispanic	Hispanic	Unknown Ethnicity	No information	Refuse to answer	Total	%
White	2,323,977	2,012,327	62,213	64,407	55,654	4,518,578	60.6%
Black or African American	1,270,205	81,306	19,941	25,799	36,004	1,433,255	19.2%
Asian	282,191	6,914	7,979	9,033	6,630	312,747	4.2%
Unknown	91,480	225,823	204,150	955	2,884	525,292	7.0%
Refuse to answer	62,929	194,268	3,573	9,182	43,687	313,639	4.2%
No Information	15,010	43,171	5,287	59,844	4,626	127,938	1.7%
Multiple race	58,966	47,158	1,738	3,862	4,326	116,050	1.6%
Native Hawaiian or Other Pacific Islander	32,907	12,041	1,161	331	2,951	49,391	0.7%
American Indian or Alaskan Native	29,755	20,341	1,447	490	947	52,980	0.7%
Other	269	10,469	183	1,340	10 or less	12,267	0.2%
Total	4,167,689	2,653,818	307,672	175,243	157,715	7,462,137	100.0%
%	55.9%	35.6%	4.1%	2.3%	2.1%	100.0%	

Patients by current age:

Age Category	Patients	%
Unknown	17	0.0%
0-9	729,144	9.8%
10-19	1,092,571	14.6%
20-29	1,202,276	16.1%
30-39	1,256,648	16.8%
40-49	976,774	13.1%
50-59	910,412	12.2%
60-69	772,491	10.4%
70-79	351,766	4.7%
80-89	126,639	1.7%
90-99	38,652	0.5%
99+	4,720	0.1%
Total	7,462,137	100.0%

Patients by Current Age



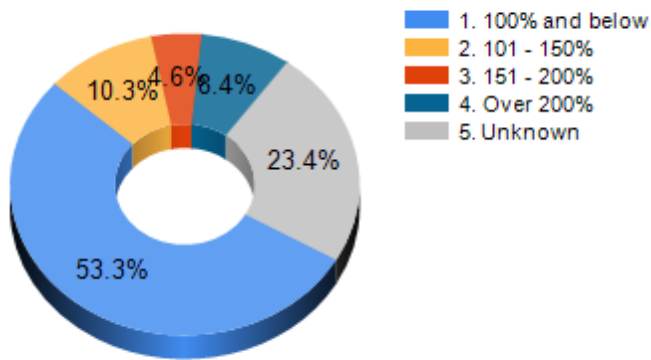
Patients by primary language:

Patients by primary language - Top 10		
Primary Language	Patients	%
English	5,429,670	72.8%
Spanish	1,481,719	19.9%
Unknown	237,267	3.2%
Other language	156,017	2.1%
Vietnamese	35,131	0.5%
Somali	28,895	0.4%
Chinese-Cantonese	25,785	0.3%
Russian	20,461	0.3%
Arabic	19,636	0.3%
Creole	14,408	0.2%
Portuguese	13,148	0.2%
Total Patients	7,462,137	100.0%

Patients by their most recent Federal Poverty Level (FPL):

FPL Category	Patients	%
1. 100% and below	3,977,047	53.3%
2. 101 - 150%	767,263	10.3%
3. 151 - 200%	344,406	4.6%
5. Unknown	1,745,074	23.4%
Total Patients	7,462,137	100.0%

Patients by FPL



Patients by known payer type on most recent visit*

Payer Type	Patients	%
Medicaid	2,665,427	35.7%
Uninsured	1,752,152	23.5%
Private Insurance	1,230,275	16.5%
Medicare	466,773	6.3%
Other Public Payer	205,858	2.8%
Private	60,006	0.8%
Managed Care	9,774	0.1%
Blue Cross	3,795	0.1%
Commercial	938	0.0%
Other	568	0.0%
Tricare	221	0.0%
Medicaid Washington	105	0.0%
Agency/Grant	74	0.0%
Veterans	48	0.0%
Worker's Comp	43	0.0%
Medicaid Other	34	0.0%
Self-Pay	26	0.0%
NonSponsored	14	0.0%
Courthold	10 or less	0.0%
Shriners	10 or less	0.0%
Total Patients	6,396,134	100.0%

*Table excludes patients with Payer Type values of 'Unknown' or 'No Information'. Total count is based on patients with payers only.