

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

Updated: 11/4/2019 Purpose of the Document:

This document is intended to be a high-level summary of the ADVANCE 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 [People-Centered Research Foundation \(PCRF\)](https://pcrfoundation.org/) (Contract #1237), integrates outpatient electronic health record (EHR) data for Community Health Center (CHC) patients, and integrates community data for these patients. The CRN serves as a ‘community laboratory’ for engaging vulnerable patients in People-Centered Research (PCRF, <https://pcrfoundation.org/>). 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:

PCORI’s National Patient-Centered Clinical Research Network, called PCORnet, was created 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. PCRF was established to continue the successful work of PCORnet, utilizing this national network of data centers to improve the healthcare and the performance of health care delivery systems.

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 representatives

ADVANCE is led by OCHIN’s Practice-Based Research Network (PBRN) in partnership with Health Choice Network (HCN), Fenway Health, Oregon Health and Science University (OHSU), and the Robert Graham Center. We are:

- A national network of CHC 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) are de-identified. 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 protocols (e.g., re-identification for a clinical trial).

The ADVANCE Research Data Warehouse (RDW) is an expansion of the Common Data Model (CDM). The RDW contains all tables and fields defined for the PCORnet CDM, plus additional fields that the ADVANCE CRN decides to include for research purposes. These fields are elements unique to CHCs that collect data for Uniform Data System (UDS) and other CHC-related reporting purposes, which are typically not collected by non-CHC clinics. These fields include Federal Poverty Level, patient primary language, migrant/seasonal worker status, homeless status, and so on. RDW data are cleaned, validated, and research-ready.

Patient Inclusion Criteria:

Data are included from the ADVANCE ambulatory data partners (OCHIN, HCN, OHSU and Fenway) 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 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 possible. Community vital signs data are then included for those patients.

We started extracting patients on 1/1/2015, so the RDW includes patients deemed as “active” as of 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”.

Data Partners:

OCHIN, Inc.: Based in Portland, Oregon, OCHIN is a health center controlled network

- 3,332,813 distinct patients over all time
- 2,408,132 distinct patients with a visit within the last 3 years
- 2,120,310 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 20 states
- 110 member organizations with 645 clinics and 1,431 departments
- 10,822 providers and 6,510 primary care providers

Health Choice Network (HCN): Is a health center controlled network founded in Florida by a group of FQHCs collaborating to recover from Hurricane Andrew.

- 2,052,153 distinct patients over all time
- 1,296,337 distinct patients with a visit within the last 3 years
- 1,065,453 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 8 states
- 25 health systems with 506 clinics

Fenway Health: Founded in 1971 as a free community clinic for the Fenway neighborhood of Boston; it now serves Boston's lesbian, gay, bisexual and transgender community, and the greater Fenway neighborhood.

- 61,434 distinct patients over all time
- 40,655 distinct patients with a visit within the last 3 years
- 40,655 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 is the state's only academic health center. It provides an uncommon array of services from providing the state's most comprehensive health care, to educating the next generation of clinicians and biomedical researchers, to achieving breakthroughs and innovations.

- 34,542 distinct patients over all time
- 22,256 distinct patients with a visit within the last 3 years
- 19,536 distinct patients with a medical ambulatory visit in the last 3 years
- Member clinics in 1 state
- 1 health system with 2 clinics

Data Refresh Timeline:

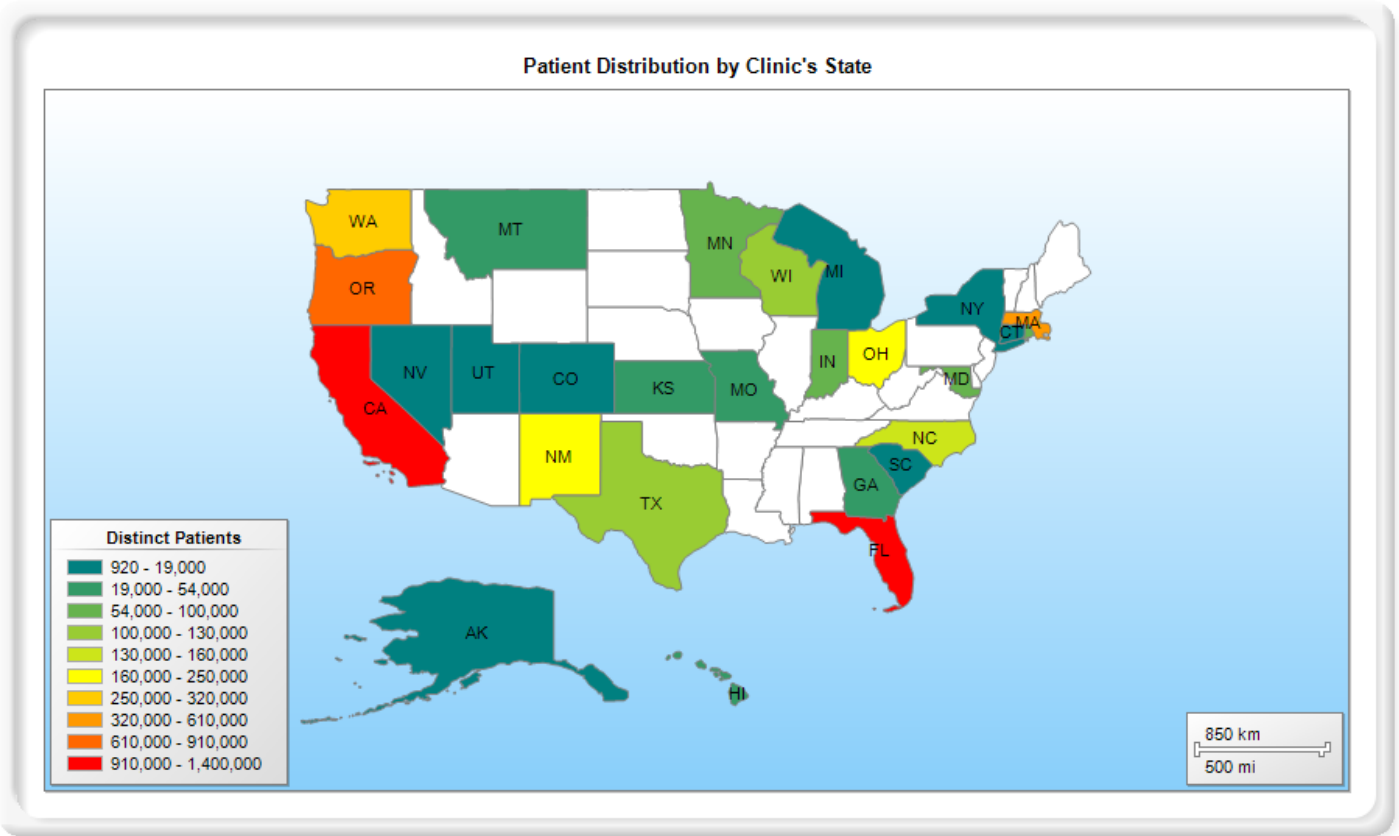
For each data refresh, a log table is kept documenting any unexpected data changes. Data profiles of all tables and fields in the CDM are run regularly to identify potential data quality issues at the field level. We are building out the breadth of the data and we are continuing to explore expanding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

OCHIN data are updated weekly, all other data (from data partners) are updated at least quarterly.

The following table lists and describes the contents of each table in the ADVANCE RDW. For a complete, detailed list of all tables and the fields within each table, see the ADVANCE RDW 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.

Appendix A: ADVANCE Patient Distribution by Clinic's State



Health Systems	Clinic Sites	Cities	States
148	1287	396	27

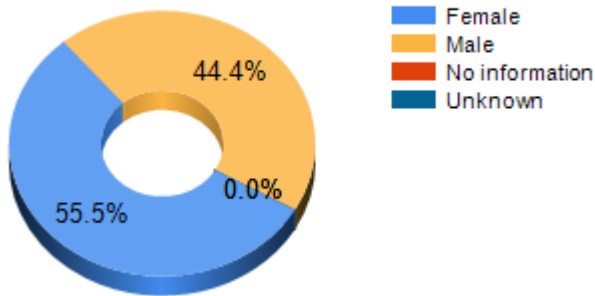
Appendix B: ADVANCE Selected Patient Characteristics

Patients with Ambulatory Visit,Dental,Emergency Department,Institutional Professional Consult,Inpatient Hospital Stay,Non-Acute Institutional Stay,No Information,Other Ambulatory Visit,Observational Stay,Other,Unknown encounter(s) between 1/1/2012 and 9/30/2019

Sex	Patients	%
Female	3,024,368	55.54%
Male	2,417,934	44.41%
No information	2,090	0.04%
Unknown	711	0.01%
Total	5,445,103	100.00%

Patients 18 and older by Condition		
Condition	Patients	%
Diabetic (Type I or II)	374,695	8.98%
Diabetic Type I	14,598	0.35%
Diabetic Type II	360,097	8.63%
Obese	1,278,983	30.66%
Obese & Diabetic (Type I or II)	210,434	5.04%
Alpha-1	301	0.01%
Total Adults	4,171,750	100.00%

Patients by Sex

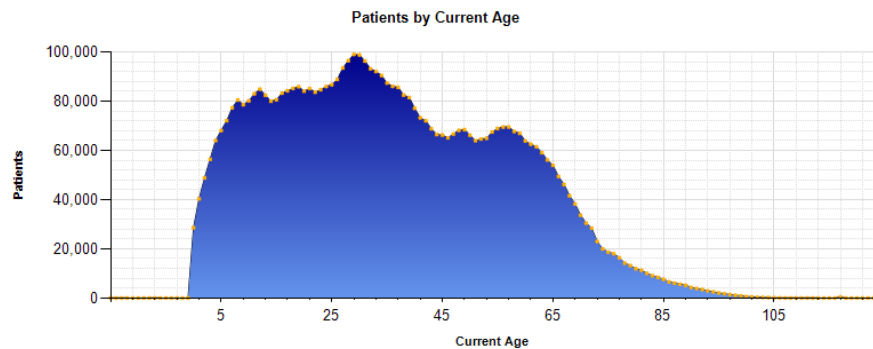


Patients by race and ethnicity:

Race \ Hispanic Ethnicity	No	Yes	Unknown	No information	Refuse to answer	Total	%
White	1,776,452	1,505,915	43,472	62,735	41,121	3,429,695	63.0%
Black or African American	945,561	53,268	13,617	28,346	29,466	1,070,258	19.7%
Asian	176,554	4,396	4,801	7,399	5,244	198,394	3.6%
Unknown	53,421	123,294	120,423	435	1,294	298,867	5.5%
Refuse to answer	33,235	107,868	1,516	3,472	19,878	165,969	3.0%
Multiple race	44,167	38,772	1,129	2,904	3,349	90,321	1.7%
No Information	16,973	43,459	4,734	42,065	5,333	112,564	2.1%
Native Hawaiian or Other Pacific Islander	23,987	7,510	706	252	2,292	34,747	0.6%
American Indian or Alaskan Native	20,327	14,606	825	679	634	37,071	0.7%
Other	346	5,472	76	1,316	10 or less	7,217	0.1%
Total	3,091,023	1,904,560	191,299	149,603	108,618	5,445,103	100.0%
%	56.8%	35.0%	3.5%	2.7%	2.0%	100.0%	

Patients by current age:

Age Category	Patients	%
Unknown	14	0.0%
0-9	614,688	11.3%
10-19	829,747	15.2%
20-29	888,114	16.3%
30-39	893,960	16.4%
40-49	692,356	12.7%
50-59	669,797	12.3%
60-69	532,387	9.8%
70-79	215,794	4.0%
80-89	81,628	1.5%
90-99	24,172	0.4%
99+	2,408	0.0%
Total	5,445,103	100.0%

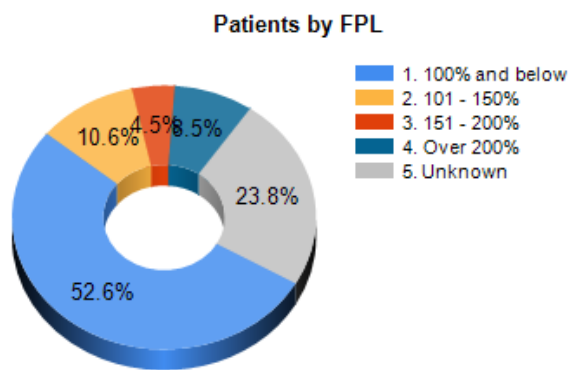


Patients by primary language:

Patients by primary language - Top 10		
Primary Language	Patients	%
English	3,966,056	72.8%
Spanish	1,068,844	19.6%
Unknown	186,338	3.4%
Other language	107,963	2.0%
Somali	24,517	0.5%
Vietnamese	23,020	0.4%
Chinese-Cantonese	17,155	0.3%
Russian	16,049	0.3%
Arabic	15,831	0.3%
Creole	11,313	0.2%
Nepali	8,017	0.1%
Total Patients	5,445,103	100.0%

Patients by their most recent federal poverty level:

FPL Category	Patients	%
1. 100% and below	2,866,332	52.6%
2. 101 - 150%	578,530	10.6%
3. 151 - 200%	246,142	4.5%
4. Over 200%	460,134	8.5%
5. Unknown	1,293,965	23.8%
Total Patients	5,445,103	100.0%



Patients by payer type on most recent visit:

Payer Type	Patients	%
Medicaid	1,981,133	36.4%
Uninsured	1,390,129	25.5%
Private Insurance	857,288	15.7%
NI	539,677	9.9%
Medicare	342,948	6.3%
Other Public Payer	279,189	5.1%
Private	48,998	0.9%
Unknown	5,741	0.1%
Total Patients	5,445,103	100.0%

Patients by Payer Type

