A SHORT GUIDE TO THE ADVANCE CLINICAL RESEARCH NETWORK

LAST UPDATED: JULY 25, 2019

PURPOSE OF THIS DOCUMENT:

THIS DOCUMENT IS INTENDED TO BE A HIGH-LEVEL SUMMARY OF THE ADVANCE CLINICAL RESEARCH NETWORK. MORE DETAILED AND TECHNICAL INFORMATION ABOUT THE ADVANCE CLINICAL RESEARCH NETWORK 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) (Contract #1237), integrates outpatient electronic health record (EHR) data for Community Health Center (CHC) patients, and integrates hospital, health plan, and 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:

- 13 Clinical Research Networks (CRNs), such as ADVANCE
- 2 Health Plan Research Networks (HPRNs)
- Governed by an Executive Committee and a Steering Committee

ADVANCE is led by OCHIN's Practice-Based Research Network 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
- Forming strategic partnerships with health plans and hospitals that will bring inpatient data into existing outpatient data repository
- 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).

RESEARCH DATA WAREHOUSE (RDW) AND THE PCORNET COMMON DATA MODEL (CDM):

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, 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. Hospital, claims, and 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 SOURCES:

OCHIN, Inc.: Based in Portland, Oregon, OCHIN is a health center controlled network with 110 member organizations in 18 states. These members contain:

- 645 clinics
- 1,439 departments
- 10,822 providers
- 6,510 PC providers

Over 1 million patients are seen per year in member clinics, with over 4.8 million visits per year. In total, there are 3.6 million distinct patients in the OCHIN system database and 22.3 million visits.

Data partners:

- o OHSU: hospital and ambulatory data on OCHIN patients seen in their system (in development)
- o Community Vital Signs data on all OCHIN patients, supplied by the Robert Graham Center and HealthLandscape

Health Choice Network (HCN): Founded in Florida by a group of FQHCs collaborating to recover from Hurricane Andrew, HCN is similar in size to OCHIN, with a presence in 8 states.

- 509 clinics
- 25 health systems
- 1,984,131 patients

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.

- 3 clinics
- 1 health system
- 61,426 patients

UPDATING PROCESS AND FUTURE BUILD-OUT PLANS:

For each data refresh, a log table is kept to document 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.

- o Claims data will continue to be added to the ADVANCE RDW

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.

**Appendix A: ADVANCE Patient Distribution by Clinic's State**

Patient Distribution by Clinic's State
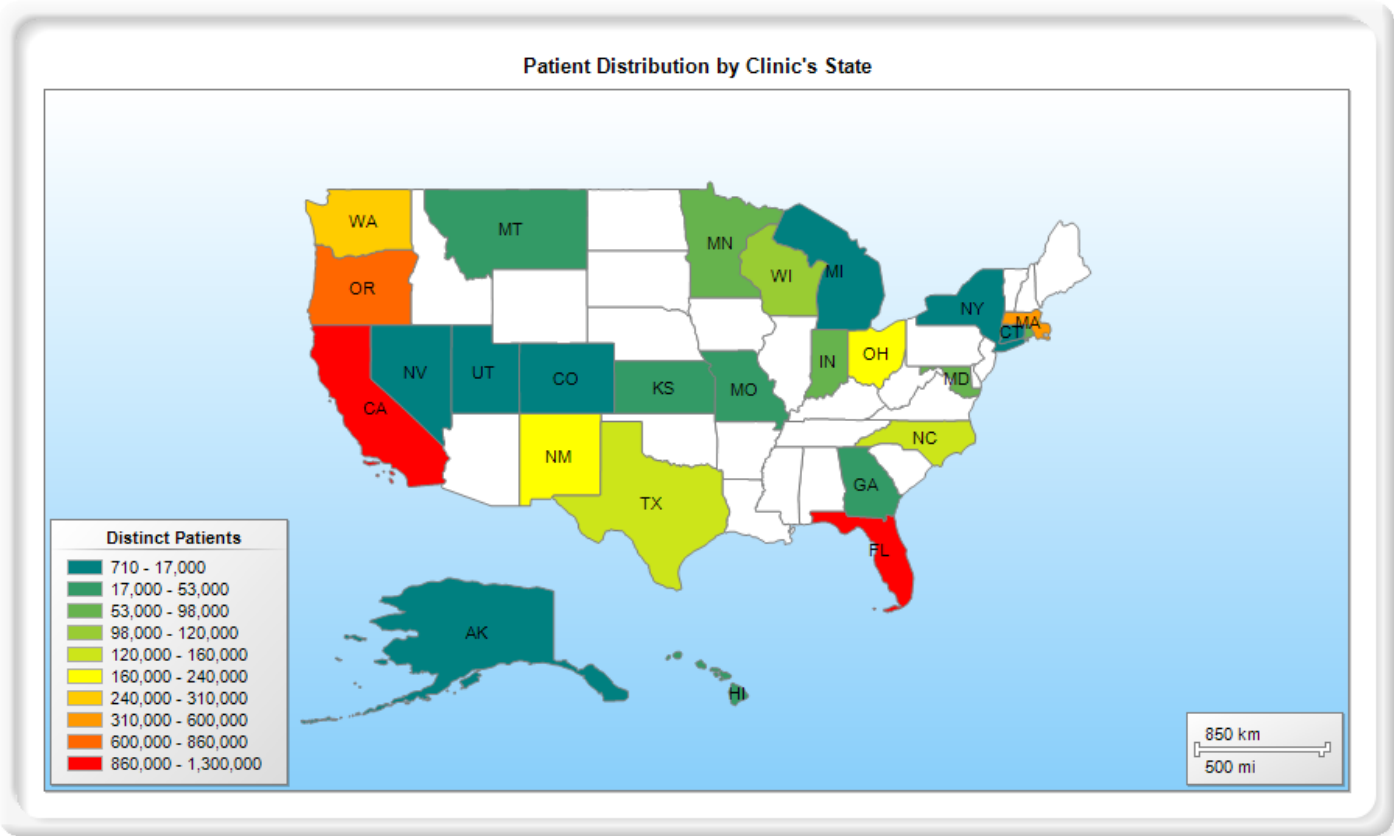
Health Systems	Clinic Sites	Cities	States
145	1249	382	26

Appendix B: ADVANCE Selected Patient Characteristics

Patients by sex and selected condition:

Sex	Patients	%
Female	2,892,171	55.59%
Male	2,308,337	44.37%
No information	1,800	0.03%
Unknown	640	0.01%
Total	**5,202,948**	**100.00%**

Patients 18 and older by Condition		
Condition	Patients	%
Diabetic (Type I ...	356,156	8.94%
Diabetic Type I	14,003	0.35%
Diabetic Type II	342,153	8.59%
Obese	1,223,780	30.71%
Obese & Diabetic (Type I or II)	200,717	5.04%
Alpha-1	310	0.01%
Total Adults	**3,984,840**	**100.00%**

Patients by Sex

Legend: Female, Male, No information, Unknown

44.4%
0.0%
55.6%
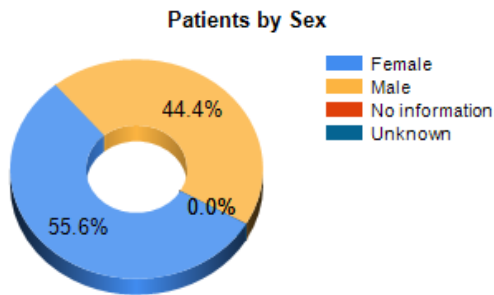
Patients by race and ethnicity:

Race \ Hispanic Ethnicity	No	Yes	Unknown	No information	Refuse to answer	Total	%
White	1,716,738	1,433,808	41,563	61,189	38,740	3,292,038	63.3%
Black or African American	906,638	51,193	12,931	26,251	27,958	1,024,971	19.7%
Asian	160,643	4,157	4,555	7,198	5,040	181,593	3.5%
Unknown	50,178	116,659	113,807	376	1,150	282,170	5.4%
Refuse to answer	32,122	103,233	1,453	3,134	18,189	158,131	3.0%
Multiple race	41,788	35,952	1,017	2,740	3,112	84,609	1.6%
No Information	16,852	41,603	4,745	39,796	5,171	108,167	2.1%
Native Hawaiian or Other	22,105	6,818	667	252	2,224	32,066	0.6%
American Indian or Alaskan	19,247	13,720	752	655	595	34,969	0.7%
Other	230	2,587	54	1,361	10 or less	4,234	0.1%
Total	2,966,541	1,809,730	181,544	142,952	102,181	5,202,948	100.0%
%	57.0%	34.8%	3.5%	2.7%	2.0%	100.0%	

Patients by current age:

Patients by Age Category (current age)

Age Category	Patients	%
Unknown	14	0.0%
0-9	592,023	11.4%
10-19	789,906	15.2%
20-29	856,648	16.5%
30-39	853,314	16.4%
40-49	661,627	12.7%
50-59	643,097	12.4%
60-69	503,936	9.7%
70-79	201,118	3.9%
80-89	76,477	1.5%
90-99	22,621	0.4%
99+	2,134	0.0%
Total	5,202,948	100.0%

Patients by Current Age
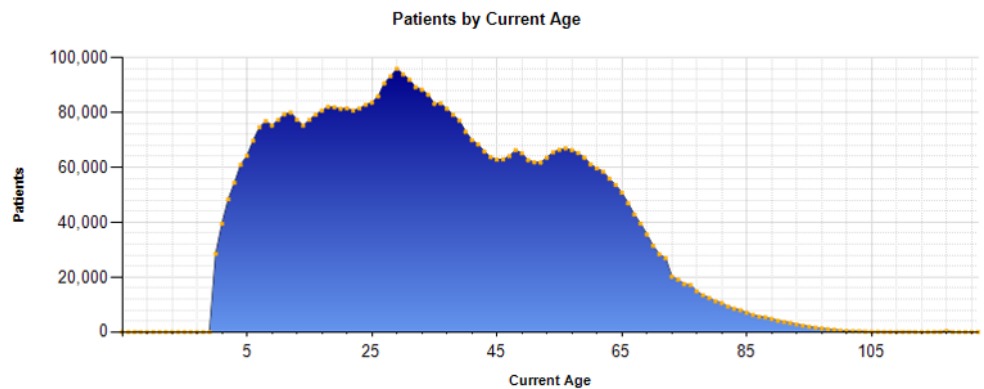
Patients by primary language:

Patients by primary language - Top 10		
Primary Language	**Patients**	**%**
English	3,801,781	73.1%
Spanish	1,011,488	19.4%
Unknown	181,091	3.5%
Other language	101,885	2.0%
Somali	24,287	0.5%
Vietnamese	21,542	0.4%
Russian	15,470	0.3%
Arabic	15,409	0.3%
Chinese-Cantonese	11,165	0.2%
Creole	10,918	0.2%
Nepali	7,912	0.2%
Total Patients	**5,202,948**	**100.0%**

Patients by their most recent federal poverty level:

FPL Category	Patients	%
1. 100% and below	2,741,841	52.7%
2. 101 - 150%	548,034	10.5%
3. 151 - 200%	232,121	4.5%
4. Over 200%	438,206	8.4%
5. Unknown	1,242,746	23.9%
Total Patients	**5,202,948**	**100.0%**

Patients by FPL

- 1. 100% and below
- 2. 101 - 150%
- 3. 151 - 200%
- 4. Over 200%
- 5. Unknown

10.5% 4.5% 8.4%
23.9%
52.7%
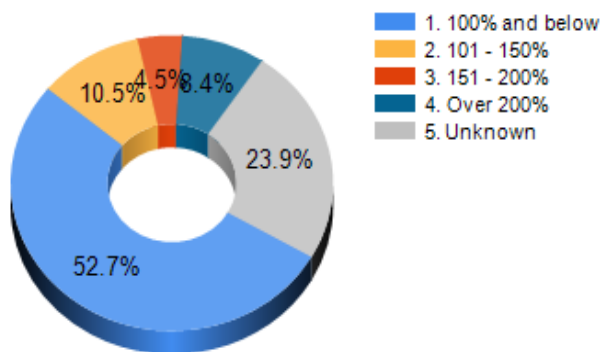
Patients by payer type on most recent visit:

Payer Type	Patients	%
Medicaid	1,901,621	36.5%
Uninsured	1,339,304	25.7%
Private Insurance	829,426	15.9%
NI	475,726	9.1%
Medicare	327,860	6.3%
Other Public Payer	275,373	5.3%
Private	48,087	0.9%
Unknown	5,551	0.1%
Total Patients	**5,202,948**	**100.0%**

Patients by Payer Type