

This data dictionary applies to TriNetX's de-identified dataset. Access to and utilization of this dataset is subject to entering into a data use agreement with TriNetX. Any use, disclosure or publication of the dataset or any derivatives thereof will be governed by the terms, conditions and restrictions set forth in the Dataset Terms of Use.

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TriNetX Data Overview

TriNetX datasets provide researchers access to de-identified patient data from networks of healthcare organizations (HCO) and other data providers.

Below are a set of questions and answers that describe the overall characteristics of TriNetX data.

What kind of data comes in a TriNetX dataset?

TriNetX datasets are comprised of clinical patient data such as demographics, diagnoses, procedures, labs, and medications. This is commonly referred to as real-world data (RWD).

The data in TriNetX datasets are:

- Primarily from HCOs electronic medical record (EMR) systems
- Collected for the primary purpose of providing care to patients

The data in TriNetX datasets are not:

- Claims data, data primarily collected for the purposes of billing
- Data collected for the purposes of randomized clinical trials

Where does the data in a TriNetX dataset originate?

Data in TriNetX datasets comes from HCOs and other data providers. The data these entities provide primarily comes from:

- EMR systems
 - Structured data
 - Unstructured data processed by Natural Language Processing (NLP) technology
- Cancer registries
- Other sources (e.g., genomic data from third party genomic testing labs)

What are the characteristics of the HCOs that provide TriNetX with data?

The majority of the HCOs are large academic medical institutions with both inpatient and outpatient facilities. Most of these HCOs are adult acute-care hospitals with multiple facilities and locations. All HCOs are currently located within the United States.

HCOs provide TriNetX with both inpatient and outpatient data. The data they provide is representative of the entire patient population at the HCO. Most HCOs provide an average of seven years of historical data.

How is data transformed from its original source?

TriNetX typically receives data from HCOs and other data providers in one of two ways:

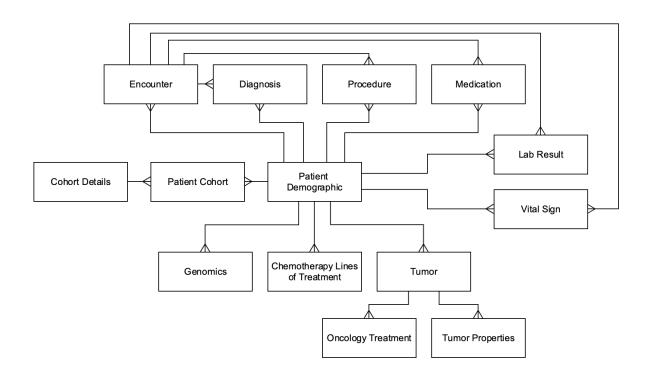
- 1. TriNetX ingests data directly from an HCO's research repository (e.g., i2b2) into the TriNetX environment
- 2. An HCO or data provider sends TriNetX data extracts in the form of CSV files

TriNetX maps the data to a standard and controlled set of clinical terminologies. The data is then transformed into a proprietary data schema. This transformation process includes an extensive data quality assessment that includes 'data cleaning' that rejects records that don't meet the TriNetX quality standards.

How fresh (up to date) is the data?

One of the distinguishing characteristics of the TriNetX dataset is that it is continuously refreshed. HCOs and other data providers update their data at various times with over 80% refreshing in 1, 2, or 4-week frequency intervals. The average lag time for an HCO's source data refresh is one month.

Data Tables Relationship



Patient Demographic Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
sex	VARCHAR	М	The biological sex of the patient. Possible values are M, F, Unknown.
race	VARCHAR	White	The race of the patient. Possible values are American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, White, Unknown.
ethnicity	VARCHAR	Hispanic	The ethnicity (cultural background) of the patient. Possible values are Hispanic or Latino, Not Hispanic or Latino, Unknown.
year_of_birth	BIGINT	1958	The birth year of the patient. May be blank if the birth year occurred more than 90 years before the year the dataset was created.
age_at_death	BIGINT	57	The age at the time of the patient's death. If a patient's age at death is above 90, the age at death is rounded to 90 in order to protect patient privacy.
postal_code	VARCHAR		The postal code of the patient. Only available on Diamond network data.

Encounter Table

Data Element	Data Type	Sample Data	Description
encounter_id	VARCHAR	987654321	The unique ID for the encounter (de-identified).
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
start_date	DATETIME (YYYYMMDD)	20110315	The date the encounter began.
end_date	DATETIME (YYYYMMDD)	20110318	The date the encounter ended.
type	VARCHAR	АМВ	The care setting of the encounter. Possible values are Ambulatory (AMB), Emergency (EMER), Field (FLD), Home Health (HH), Inpatient Encounter (IMP), Inpatient Acute (ACUTE), Inpatient Non-acute (NONAC), Observation (OBSENC), Pre-admission (PRENC), Short Stay (SS), Virtual (VR). These values are based on HL7 v3 Value Set ActEncounterCode.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the encounter start or end date was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Diagnosis Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
encounter_id	VARCHAR	987654321	The unique ID for the encounter (de-identified).
code_system	VARCHAR	ICD-10-CM	The name of the code system in which this diagnosis is coded. Possible code systems are ICD-9-CM, ICD-10-CM.
code	VARCHAR	E11	The diagnosis code.
date	DATETIME (YYYYMMDD)	20110315	The date the diagnosis was recorded.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the diagnosis was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Procedure Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
encounter_id	VARCHAR	987654321	The unique ID for the encounter (de-identified).
code_system	VARCHAR	ICD-10-PCS	The name of the code system in which this procedure is coded. Possible code systems are ICD-9-CM, ICD-10-PCS, CPT.
code	VARCHAR	03CJ0ZZ	The procedure code.
date	DATETIME (YYYYMMDD)	20150314	The date the procedure was recorded.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the procedure was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Medication Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
encounter_id	VARCHAR	987654321	The unique ID for the encounter (de-identified).
code_system	VARCHAR	RxNorm The name of the code system in which this medication is coded. The code system is RxNorm.	
code	VARCHAR	26225	The medication code.
start_date	DATETIME (YYYYMMDD)	20120914	The date the medication order, prescription, or administration was recorded.
route	VARCHAR	Oral Product	The route of administration. Possible values are Drug implant, Inhalant, Injectable, Intraperitoneal, Nasal, Ophthalmic, Oral, Otic, Rectal, Topical, Urethral, Vaginal, Unknown.
brand	VARCHAR	Zofran	The medication brand.
strength	VARCHAR	4 mg	The medication strength.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the medication was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Lab Result Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (deidentified).
encounter_id	VARCHAR	987654321	The unique ID for the encounter (deidentified).
code_system	VARCHAR	LOINC	The name of the code system in which this lab observation is coded. The code system is LOINC.
code	VARCHAR	2885-2	The code representing the lab test.
date	DATETIME (YYYYMMDD)	20120914	The date the test result was recorded.
lab_result_num_val	DECIMAL	7	The lab result for numeric results.
lab_result_text_val	VARCHAR	Positive	The lab result for text results.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the lab result was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Vital Sign Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
encounter_id	VARCHAR	987654321	The unique ID for the encounter (de-identified).
code_system	VARCHAR	LOINC	The name of the code system in which this vital sign is coded. The code system is LOINC.
code	VARCHAR	8302-2	The code representing the vital sign.
date	DATETIME (YYYYMMDD)	20120914	The date the vital sign was recorded.
value	VARCHAR	72	The value of this vital sign.
text_val	VARCHAR	Positive	The value for text results.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the vital sign was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Tumor Properties Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (deidentified).
diagnosis_date	DATETIME (YYYYMMDD)	20120914	The date of the original primary cancer diagnosis.
observation_date	DATETIME (YYYYMMDD)	20121114	The date the property was recorded.
tumor_site_code_system	VARCHAR	ICD-O	The name of the code system in which the tumor site is coded. The code system is ICD-O.
tumor_site_code	VARCHAR	C50	The tumor site code.
morphology_code_system	VARCHAR	ICD-O	The name of the code system in which morphology is coded. The code system is ICD-O.
morphology_code	VARCHAR	8500/3	The morphology code.
tumor_property_code_system	VARCHAR	TriNetX – Tumor Property	The name of the code system in which the tumor property is coded. The code system is TriNetX. This is a code system created by TriNetX for oncology specific factors.
tumor_property_code	VARCHAR	CSF07- Colon 060	The code that indicates the type of tumor property.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the tumor property was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Oncology Treatment Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
diagnosis_date	DATETIME (YYYYMMDD)	20120914	The date of the primary cancer diagnosis.
tumor_site_code_system	VARCHAR	ICD-O	The name of the code system in which the tumor site is coded. The code system is ICD-O.
tumor_site_code	VARCHAR	C50	The tumor site code.
morphology_code_system	VARCHAR	ICD-O	The name of the code system in which morphology is coded. The code system is ICD-O.
morphology_code	VARCHAR	8500/3	The morphology code.
oncology_treatment_start_date	DATETIME (YYYYMMDD)	20121001	The start date of the course of oncology treatment.
oncology_treatment_code_system	VARCHAR	TriNetX – Oncology Treatment	The name of the code system in which the oncology treatment is coded. The code system is TriNetX. This is a code system created by TriNetX for oncology treatment.
oncology_treatment_code	VARCHAR	1390 1	The code for the oncology treatment.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the oncology treatment was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Tumor Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
diagnosis_date	DATETIME (YYYYMMDD)	20120914	The date of the original primary cancer diagnosis.
observation_date	DATETIME (YYYYMMDD)	20121114	The date the property was recorded.
tumor_site_code_system	VARCHAR	ICD-O	The name of the code system in which the tumor site is coded. The code system is ICD-O.
tumor_site_code	VARCHAR	C50	The tumor site code.
morphology_code_system	VARCHAR	ICD-O	The name of the code system in which morphology is coded. The code system is ICD-O.
morphology_code	VARCHAR	8500/3	The morphology code.
stage_code_system	VARCHAR	TriNetX – Oncology Stage	The name of the code system in which the tumor stage is coded. The code system is TriNetX. This is a code system created by TriNetX for tumor stages.
stage_code	VARCHAR	2b	The code for the tumor stage.
tumor_size	VARCHAR	T2	The code for the size of tumor.
number_of_lymph_nodes	VARCHAR	N1	The code for the degree of spread to regional lymph nodes.
metastatic	VARCHAR	М0	The code for the presence of metastatis.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the tumor entry was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Chemotherapy Lines of Treatment Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
start_date	DATETIME (YYYYMMDD)	20150314	The date the chemotherapy line of treatment was determined to start.
line	BIGINT	1	The sequential order of chemotherapy regimens. Possible values are 1, 2, 3, 4, or 5 with 1 = the first regimen and 5 = the last regimen. These lines are derived by TriNetX.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the chemotherapy line of treatment was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Genomics Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (deidentified).
code_system	VARCHAR	HGVS	The name of the code system in which genomic data is coded. The syntax of the code conforms to HGVS.
code	VARCHAR	BRAF p.V600E c.1799T>A	Variant description.
test_date	DATETIME (YYYYMMDD)	20120914	The date the genetic test was recorded.
derived_by_TriNetX	BOOLEAN	Т	Flag that indicates whether the genomic data was derived by TriNetX. Possible values are T for TRUE and F for FALSE.

Cohort Details Table

Data Element	Data Type	Sample Data	Description
cohort_name	VARCHAR	Diabetes women aged 18-45	The name of the cohort included in the dataset.
cohort_number	BIGINT	1	The number of the cohort included in the dataset.
total_patient_records	BIGINT	20,000	The total number of patient records in the cohort in the dataset.

Dataset Details Table

Data Element	Data Type	Sample Data	Description
total_number_unique_patients	BIGINT	19,000	The total number of unique patient records across multiple cohorts in the dataset. A patient's record could be in a single cohort multiple times if the patient visited more than one HCO that contributed data to a cohort.
total_number_HCOs	BIGINT	7	The total number of healthcare organizations contributing data to the dataset.
date_created	DATETIME (YYYYMMDD)	20180316	The date the dataset was created.

Patient Cohort Table

Data Element	Data Type	Sample Data	Description
patient_id	VARCHAR	123456789	The unique ID for the patient (de-identified).
cohort_name	VARCHAR	Diabetes women aged 18-45	The name of the cohort in which the patient's record is included.
cohort_number	BIGINT	1	The number of the cohort in which the patient's record is included.

Standardized Terminology Table

Data Element	Data Type	Sample Data	Description
code_system	VARCHAR	RxNORM	The name of the code system in which the data element is coded.
code	VARCHAR	1191	The code for the data element.
code_description	VARCHAR	Aspirin	The textual description of the data element.
path	VARCHAR	N0000010574/N0000029132/ N0000029133/N0000029135/ 1191	The terms the data element is mapped to and the path in which those terms exist.
unit	VARCHAR	inches	The unit of measurement for a code value. This field only applies to codes in the Lab Result table and the Vital Sign table.