



# **TriNetX** From Cohort Identification to Enterprise Research Asset Thursday, July 18th, 2024





UC, UCMC, UC Health, UCP, UCPC, West Chester, Drake – you hear these names and abbreviations on a daily basis, but do you know what they really mean?
 Are these all the same legal entity or are they separate organizations all together? Join Daniel Brummett, Executive Director of Finance and Operations for the College of Medicine and Chief Financial Officer for UC Physicians Inc. as he presents "The UC 'Family' – Who We Are and How We Work Together".
 During the presentation you will learn about our various corporate entities, how they are structured from a legal and tax perspective, and the various and unique ways that we work together as part of the UC Family.





# **Today's Presentation:**

## TriNetX: From Cohort Identification to Enterprise Research Asset

TriNetX has been a popular research discovery tool at UC since 2016. There have been over 45,000 queries since it went live. Added functionality includes participation in the Research Network with scores of other institutions and a denominator of over 130 million subjects enabling Real World Evidence (RWE) studies. Features in development now include Privacy Protecting Record Linkage (PPRL), third-party claims data, death registry, Natural Language Processing (NLP), and OMOP data warehouse.

## Rodrigo Octávio Deliberato, MD, MSc, PhD

Chief Research Information Officer Professor - Department of Biostatistics, Health Informatics and Data Science (BHIDS) University of Cincinnati College of Medicine

## **Brett M. Harnett, MS-IS**

Asst. Professor, Field Service Director, Center for Health Informatics Department of Biomedical Informatics (BMI) VA Research Affiliate Adjunct Faculty CCHMC University of Cincinnati



From Blood and Guts To Bits and Bytes

## TriNetX: From Cohort Identification to Enterprise Research Asset

Brett Harnett, MS-IS Asst. Professor, Field Service Department of Biostatistics, Health Informatics and Data Science brett.harnett@uc.edu

July 18, 2024



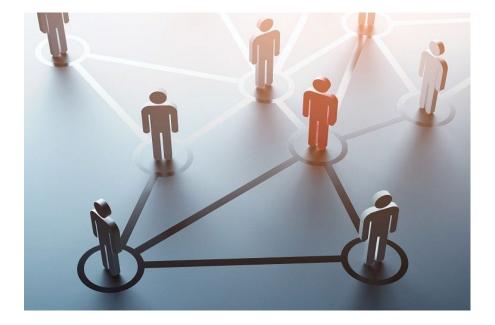
I have no actual or potential conflict of interest in relation to content of this presentation.







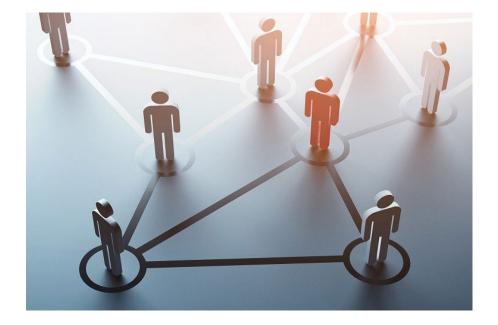




A network where HCOs supply de-identified patient data so pharmaceutical firms and CROs can identify sites with certain patient populations. Also, the ability for researchers to use the same user interface to explore, analyze and publish.







In 2023, we arranged with TriNetX for their platform and evolving tools to be a technical cornerstone of the UC/UC Health research architecture.



## CHI Services / Data from Epic / Study Feasibility using TriNetX



Center for Health Informatics (CHI) portal

### Study Feasibility using TriNetX

TriNetX can find patient cohort counts defined by clinical criteria such as diagnoses, demographics, clinical procedures, lab results and medications. These queries can be used for feasibility, subject recruitment, hypothesis generation, or defining a clinical data extract for analysis. The CHI can "reverse engineer" queries to provide identifiers for subject recruitment. If TriNetX does not have the detailed elements required, we will escalate the request to a search directly within Epic. (See 'Study Feasibility directly from Epic').

## https://live.trinetx.com/

TriNetX is a free, self-service tool. The fees associated with this service is for the CHI to help you access data should you need that.

You can learn more about TriNetX and request user credentials on the <u>CCTST website</u>. You will first need to create a free CCTST membership if not already a member.

Join the CCTST Request TriNetX User Credentials



Jul 10, 2024 at 11:47 am by Brett Harnett	Patients 200	HCOs 1 Count Patients
University of Cincinnati Medical Center 1 of 1 HCOs online	Any country 1 country in the network	All changes saved Any age / Any sex 1,404,390 patients on network
MUST HAVE	CANNOT HAVE	::::
Q Search Term	Q Search Term	
Ungrouped Terms		
MUST HAVE	CANNOT HAVE	
ICD-10-CM K52.3 Indeterminate colitis	240 ICD-10-CM N18 C	hronic kidney disease (CKD) 57,500
	1	

## Most basic level -Local cohort counts



+ Create a New Group



📩 Unnamed 🖉

Number of Patients



### Healthcare Organizations + (HCOs)

8 Explore Cohort



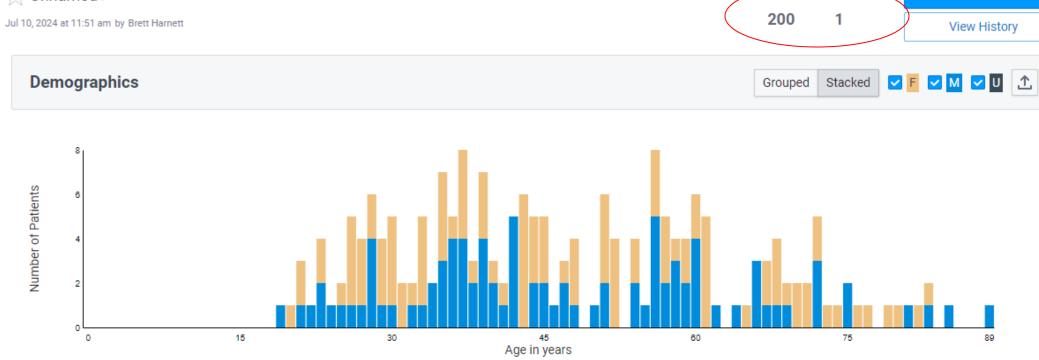
Medications

Labs

Genomics

- $\nabla$ Analyze Criteria
- Rate of Arrival . No.
- Summary Statistics h.
- Analytics
- Pending Datasets
- Available Datasets

-



Patients 90 and Older: 2

Total Patients	Minimum Age	Maximum Age	Mean Age	Standard Deviation
200	19	90	48	17

Sex	
Female	55.00%
Male	45.00%
Unknown	0.00%
Ethnicity	
Not Hispanic or Latino	95.00%
Hispanic or Latino	5.00%

Race	
White	80.00%
Black or African Americ	20.00%
American Indian or Ala	5.00%
Asian	5.00%
Other Race	5.00%
Unknown Race	5.00%
Native Hawaiian or Oth	0.00%

Patients

🔎 Query	Build	er
---------	-------	----

Healthcare Organizations (HCOs)

Explore Cohort

Demographics

Diagnoses

Oncology

Procedures

Medications

Labs

Genomics

√ Analyze Criteria

Rate of Arrival

Summary Statistics

Analytics

Pending Datasets

📩 Unnamed 🌶

Jul 10, 2024 at 11:51 am by Brett Harnett

Patients HCOs Run
200 1 View History

Diagı	noses		Diagnoses within 3M 6M 12M 24M	Anytime	All Acute Cl	nronic	9	Ľ
				Search		~ ~		)
Dia	agnoses			Patients	% of C	ohort		
<b>v</b> 10	CD-10-CM	K00-K95	Diseases of the digestive system	200	100%			
>	ICD-10-CM	K50-K52	Noninfective enteritis and colitis	200	100%			
>	ICD-10-CM	K55-K64	Other diseases of intestines	170	85%			5
>	ICD-10-CM	K20-K31	Diseases of esophagus, stomach and duodenum	130	65%			
>	ICD-10-CM	K90-K95	Other diseases of the digestive system	110	55%			
>	ICD-10-CM	К70-К77	Diseases of liver	60	30%			
>	ICD-10-CM	K80-K87	Disorders of gallbladder, biliary tract and pancreas	60	30%			
>	ICD-10-CM	K40-K46	Hernia	50	25%			
>	ICD-10-CM	K65-K68	Diseases of peritoneum and retroperitoneum	40	20%			
>	ICD-10-CM	К00-К14	Diseases of oral cavity and salivary glands	30	15%			
>	ICD-10-CM	K35-K38	Diseases of appendix	10	5%			
> 10	CD-10-CM	Z00-Z99	Factors influencing health status and contact with health services	200	100%			I
> 10	CD-10-CM	R00-R99	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	190	95%			I
> 10	CD-10-CM	E00-E89	Endocrine, nutritional and metabolic diseases	160	80%			7
> 10	CD-10-CM	D50-D89	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	140	70%			
> 10	CD-10-CM	F01-F99	Mental, Behavioral and Neurodevelopmental disorders	140	70%			1

🗟 Available Datasets 🗸

Connect Custom Terms E	Browse Network	Discover ~			
Get / Query Builder					
Jul 10, 2024 at 11:54 am by Brett Harnett			Patients HC0 1,610 1	Count Patien	ts ••••
University of Cincinnati Medical Center	r	Any country 1 country in the	e network	Any age / Any sex 1,404,390 patients on network	All changes saved
MUST HAVE		::::	CANNOT HAVE		:#:
Q Search Term			Q Search Term		
Ungrouped Terms					
MUST HAVE		c	CANNOT HAVE		
ICD-10-CM C25.9 Malignant neop pancreas, unspe		2,140	Deceased		37,350
-					

Most Basic Level Local cohort count (with Cancer Staging)



+ Create a New Group

Query Builder       Patients       HCOS       Run         Heathrcare organizations (HOOS)       Jul 10, 2024 at 11:56 am by Brett Hametti       Jul 10, 2024 at 11:56 am by Brett Hametti       Jul 10, 2024 at 11:56 am by Brett Hametti       View History         Explore Cohort       Oncology       Oncology within       M 6M       12M       2MM Anytime © ①         Demographics       © Expand All       Search       Image: Colort       Image: Colort					
Healthcare Organizations (HCOS)       Jul 10, 2024 at 11:56 am by Brett Hamett       1,610       1       View History         Explore Cohort       Oncology       Oncology within       3M       6M       12M       24M       Anytime       •         Demographics       • Expand All       Search       • • • • • • • • • • • • • • • • • • •	O Query Bu			Patients HCOs	Run
Explore Cohort Oncology   Demographics	l Organiza			1,610 1	View History
Diagnoses       Patients       % of Cohort         Oncology       680       42%         Procedures       680       42%         Medications       680       42%         Labs       680       42%         Genomics       > Stage       680       42%         Analyze Criteria       > TNM       660       41%         Rate of Arrival       Patients       % of Cohort		Cohort	Oncology	Oncology within 3M 6M 1	2M 24M Anytime 🕜 🟦
Primary Site       Primary Site       Patients       % of Cohort         Procedures       > Histology       Patients       % of Cohort         Medications       680       42%	Demogra	aphics	Expand All	Search	$\sim$ $\vee$ $\times$
Procedures       Patients       % of Cohort         Medications       Patients       % of Cohort         Labs       > Behavior       680       42%         Genomics       > Stage       660       40%         Analyze Criteria       > TNM       % of Cohort         Rate of Arrival       Patients       % of Cohort         Biomarker       1100       71%			> Primary Site		
Labs     > Behavior     680     42%       Genomics     > Stage     650     40%       Analyze Criteria     > TNM     660     41%       Rate of Arrival     Patients     % of Cohort			> Histology		
Genomics       Patients       % of Cohort         Analyze Criteria       Analyze Criteria       Patients       % of Cohort         Rate of Arrival       Filmmarker       660       41%		ons	> Behavior		
> TNM       660       41%         Rate of Arrival       Patients       % of Cohort         > Biomarker       1 100       74%		cs	> Stage		
Rate of Arrival Patients % of Cohort Biomarker	Analyze	Criteria	> TNM		
Summary Statistics 1,190 74%	<ul> <li>Rate of A</li> </ul>	Arrival		N I N	
	h. Summar	y Statistics	> Biomarker	1,190	74%



## Research Network: Increase the *n* from 1.3M to over 130M

					ogin
O TriNetX	solutions 🗸	OUR NETWORK	NEWS & EVENTS $\checkmark$	ABOUT 🗸	Q

TriNetX Research<sup>™</sup>

Hypothesize and Answer Complex Research Questions About Patient Outcomes & Treatment Effectiveness

- Access longitudinal clinical and genomic data
- Explore and compare cohorts, review cohort characteristics and compare outcomes of interest
- License and download billions of up-to-date, de-identified clinical facts for analysis with your own analytic tools





Comparative Study > Lancet Psychiatry. 2021 May;8(5):416-427. doi: 10.1016/S2215-0366(21)00084-5. Epub 2021 Apr 6.

## 6-month neurological and psychiatric outcomes in 236 379 survivors of COVID-19: a retrospective cohort study using electronic health records

Maxime Taquet <sup>1</sup>, John R Geddes <sup>1</sup>, Masud Husain <sup>2</sup>, Sierra Luciano <sup>3</sup>, Paul J Harrison <sup>4</sup> Affiliations **+** expand

PMID: 33836148 PMCID: PMC8023694 DOI: 10.1016/S2215-0366(21)00084-5 Free PMC article

### Abstract

**Background:** Neurological and psychiatric sequelae of COVID-19 have been reported, but more data are needed to adequately assess the effects of COVID-19 on brain health. We aimed to provide robust estimates of incidence rates and relative risks of neurological and psychiatric diagnoses in patients in the 6 months following a COVID-19 diagnosis.

Methods: For this retrospective cohort study and time-to-event analysis, we used data obtained from the TriNetX electronic health records network (with over 81 million patients). Our primary cohort comprised patients who had a COVID-19 diagnosis; one matched control cohort included patients diagnosed with influenza, and the other matched control cohort included patients diagnosed with any respiratory tract infection including influenza in the same period. Patients with a diagnosis of COVID-19 or a positive test for SARS-CoV-2 were excluded from the control cohorts. All cohorts included patients older than 10 years who had an index event on or after Jan 20, 2020, and who were still alive on Dec 13, 2020. We estimated the incidence of 14 neurological and psychiatric outcomes in the 6 months after a confirmed diagnosis of COVID-19: intracranial haemorrhage; ischaemic stroke; parkinsonism; Guillain-Barré syndrome; nerve, nerve root, and plexus disorders; myoneural junction and muscle disease; encephalitis; dementia; psychotic, mood, and anxiety disorders (grouped and separately); substance use disorder; and insomnia. Using a Cox model, we compared incidences with those in propensity score-matched cohorts of patients with influenza or other respiratory tract infections. We investigated how these estimates were affected by COVID-19 severity, as proxied by hospitalisation, intensive therapy unit (ITU) admission, and encephalopathy (delirium and related disorders). We assessed the robustness of the differences in outcomes between cohorts by repeating

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### Abstract

Conflict of interest statement

Figures

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References

Publication types

Because UC contributes to the TriNetX platform, researchers can access not only for our local UC Health population, but also over data from scores of other HCOs currently130M patients across the global Research Network. At no cost.\*

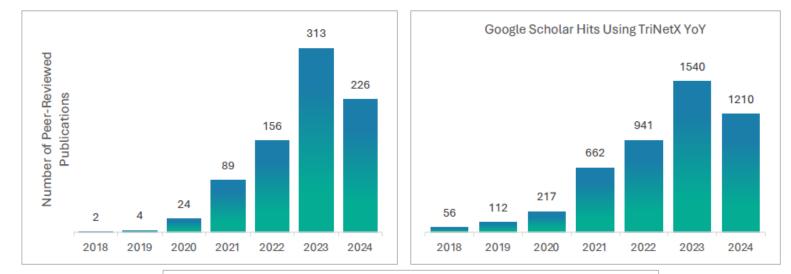
## This is Real-World Evidence

\* Except for CHI processing fees if data is needed



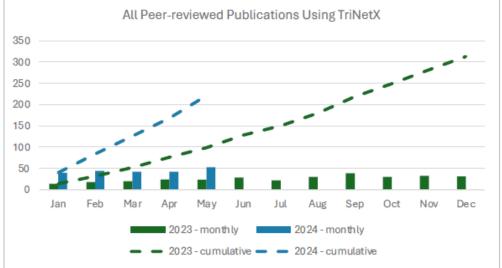
# Publications using TriNetX (May 2024)

Peer-Reviewed Publications to Date: 814 Google Scholar Hits to Date: 5,420



## Past 3 Month Snapshot:

Peer-Reviewed Publications in March 2024: **42** Peer-Reviewed Publications in April 2024: **42** Peer-Reviewed Publications in May 2024: **53** 



For full list of publications to date, visit https://www.trinetx.com/publications/



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# Publications using TriNetX (May 2024)

## naturemedicine

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nature > nature medicine > articles > article

Article | Published: 05 January 2024

### Association of semaglutide with risk of suicidal ideation in a real-world cohort

William Wang, Nora D. Volkow 🖾, Nathan A. Berger, Pamela B. Davis, David C. Kaelber & Rong Xu 🖻

### Nature Medicine 30, 168-176 (2024) Cite this article

9802 Accesses | 19 Citations | 1140 Altmetric | Metrics



Global health

Bidirectional associations between COVID-19 and psychiatric disorder:

Maxime Taquet, PhD • Sierra Luciano, BA • Prof John R Geddes, FRCPsych • Prof Paul J Harrison, FRCPsych 🙎 🖾

retrospective cohort studies of 62 354 COVID-19 cases in the USA

Multimedia.

🗠 Download Full Issue

Events

About

**EP Europace** EHJ Arrhythmias and Electrophysiology

under anticoagulation a

Published: 07 June 2023 Article history -

Gregory Y H Lip 🕿 👘 Author Notes

Article Navigation

JOURNAL ARTICLE



### JAMA Dermatology

Risk of diabetic retinopathy and diabetic macular

diabetes: a real-world data study from a global

oedema with sodium-glucose cotransporter 2 inhibitors and glucagon-like peptide 1 receptor agonists in type 2

Enter Search Term

## Association of Rituximab With Risk of Long-term Cardiovascular and Metabolic Outcomes in Patients With Pemphigus

Search All

Khalaf Kridin, MD, PhD<sup>1,2,2</sup>; Noor Mruwat, PhD<sup>2</sup>; Ralf J, Ludwig, MD<sup>1,4</sup>

### Author Affiliations | Article Information

JAMA Dermatol. 2023;159(1):56-61. doi:10.1001/jamadermatol.2022.5182

## Journal of Hematology & Oncology

Submit manuscript 🗇 Home About Articles Submission Guidelines

### JOURNAL ARTICLE ACCEPTED MANUSCRIPT

Risk of myocardial infarction and ischemic stroke in individuals with

first-diagnosed paroxysmal vs. non-paroxysmal atrial fibrillation

George Ntaios 🛎, Dimitrios Sagris, Benjamin J R Buckley, Stephanie L Harrison, Azmil Abdul-Rahim, Philip Austin,

EP Europace, Volume 25, Issue 6, June 2023, euad143, https://doi.org/10.1093/europace/euad143

Morbidity and mortality risks associated with valproate withdrawal in young men and women with epilepsy a Gashirai K Mbizvo 🗟 , Tommaso Bucci, Gregory Y H Lip, Anthony G Marson 🛛 Author Notes

Home > Diabetologia > Article

federated database

Article | Open access | Published: 08 April 2024

Volume 67, pages 1271–1282, (2024) Cite this article

### Correspondence Open access Published: 19 July 2023

## Large-scale real-life analysis of survival and usage of therapies in multiple myeloma

N. Lopez-Muñoz, G. Hernández-Ibarburu 🖾, R. Alonso, J. M. Sanchez-Pina, R. Avala, M. Calbacho, C. Cuellar, M. T. Cedena, A. Jiménez-Ubieto, R. Iñiquez, M. Pedrera, J. Cruz, L.



Diabetologia

Aims and scope  $\rightarrow$ 

Submit manuscript →



This journal

Journals

Publish

ARTICLES | VOLUME 8, ISSUE 2, P130-140, FEBRUARY 2021

Clinical

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CHI Services / Real World Evidence Publishing (RWE) / TriNetX Research Network (RWE Data)



TriNetX Research Network (RWE Data)

There are two methods to analyze data using <u>TriNetX</u>: Online analytics are built-in the TriNetX application and can be done entirely within the interface, usually within hours or less, if you are really good. Various types of analyses can be done such as Compare Cohorts, Analyze Outcomes, Incidence and Prevalence, and Treatment Pathways. You can also build queries and then request data from the TRN. Thousands of RWE papers <u>have been published</u> just in the past few years. Data is classified as de-identified per the Privacy Rule using the Expert Determination Method, thus, no IRB approval is needed for accessing this data. A Data Use Agreement with TriNetX is required but fairly expeditious (uses DocuSign).

Note: Before you submit a request for data through the TriNetX website, you must review the <u>Policy and Procedures for accessing data and</u> <u>publishing</u>. If you do not submit a request below, the data you want from TriNetX cannot be approved.

There is no cost for the data from TriNetX, but you must also use this page to submit the request to the CHI for processing after you request your data within the TriNetX tool. There is a small fee.

You can learn more about TriNetX and request user credentials on the <u>CCTST website</u>. You will first need to create a free CCTST membership if you are not already a member.

Join the CCTST Request TriNetX User Credentials

Pricing

\$194.00

See the <u>CHI Terms of Service</u> for more details. You will receive a Work Order with the final price before work is started. *We provide subsidies on many services to CCTST members*. <u>Create your free CCTST account today!</u>

Center for Health Informatics (CHI) portal



## Accessing data from TriNetX and publishing guidelines

For security reasons, this access this document, users must be logged into the CHI Portal.

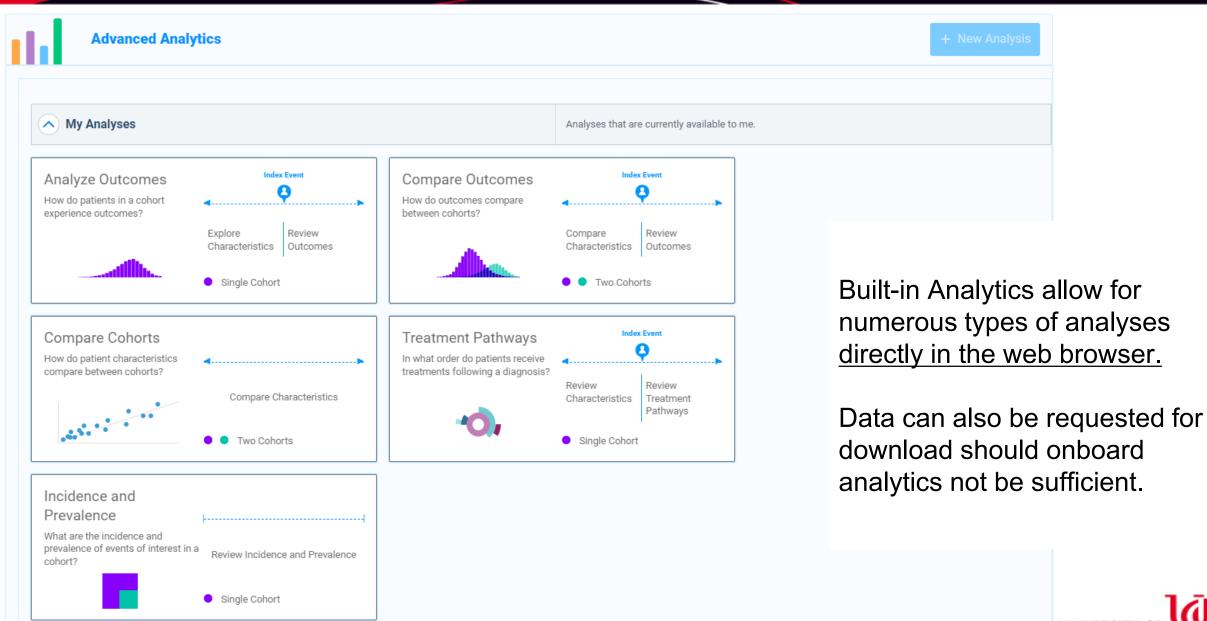
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## Introduction

TriNetX is the global health research network enabling healthcare organizations, biopharma, and contract research organizations (CROs) to collaborate, enhance trial design, accelerate recruitment, and bring new therapies to market faster.



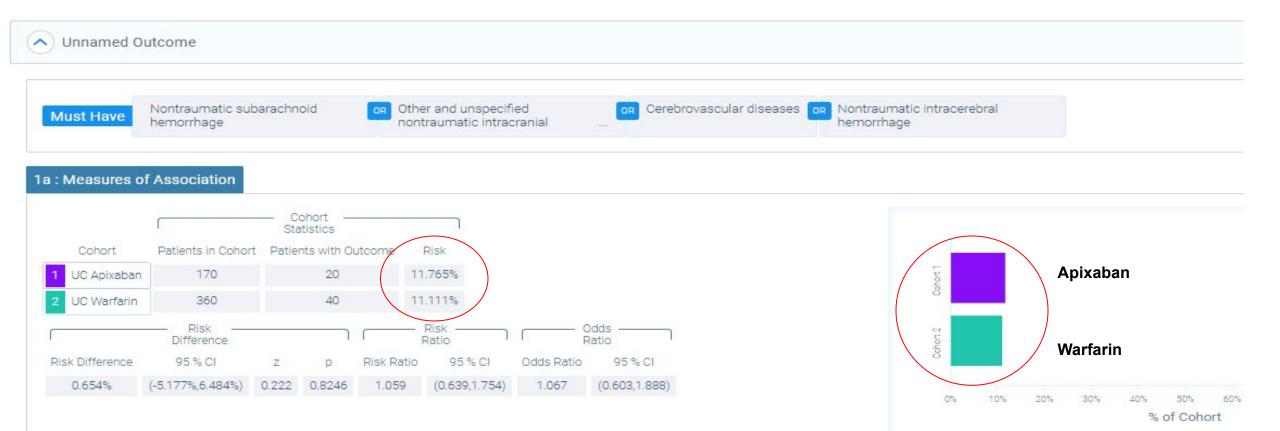


UNIVERSITY OF Cincinnati

# **Built-in Compare Outcomes Analysis**

Characteristics Diagnoses	Compare diagnoses between your co event.	phorts. Results include diagnos	es up to 365 days before index	Run
Cohort 1 UC Apixaban	170 Cohort 2 UC Warfarin			360
Diagnoses			Show What's the All O Acu	A 100 A 1
			Search	~ ~ X
Diagnoses		Patient Count	% of Cohort	Signal
> 130-152 Other forms of heart disease		150 320	88% 89%	
> 110-115 Hypertensive diseases		140 290	82% 81%	
> Z77-Z99 Persons with potential health hazards related to family and personal h	history and certain conditions influencing health status	130 300	76% 83%	
> E70-E88 Metabolic disorders		110 250	65% 69%	
> R00-R09 Symptoms and signs involving the circulatory and respiratory systems	S	90 180	53% 50%	
> Z00-Z13 Persons encountering health services for examinations		80 140	47% 39%	
> R50-R69 General symptoms and signs		70 160	41% 44%	
> 120-125 Ischemic heart diseases		60 150	35% 42%	
CARLEAT Enleadio and paraviernal disordare		50	29%	n









# Accessing TriNetX

## **ABOUT TRINETX**

TriNetX is a self-service tool that allows researchers to determine approximately how many patients in the Clinical Research Enterprise Warehouse meet certain criteria. Researchers use an intuitive user interface for selecting query criteria from UC Health's clinical (Epic) repository.

## TO USE TRINETX

https://www.cctst.org/trinetx

- Click: <u>Access TriNetX</u>.
- Read the User Agreement that is displayed and click "I Agree".
- A User account will be created and credentials emailed to you from the System Administrator.
- After you log in, click on the Help menu in the upper right and watch the short training videos (at least: Introduction to TriNetX, General Navigation and Terminology and Adding Terms).
- Begin using the TriNetX interface to create your queries. Queries time out after 5 minutes (very few should ever take that long).

## Login

Authenticate with one of these to access or create your CCTST membership:





Jse your UC or Cincinnati Children's credentials to access or create your CCTST membership.

After you accept the User Agreement, you will be contacted by the CHI with a temporary login.

Note: Authentication is managed by TriNetX, not UC/CHI.

## **User Agreement**

This User Agreement permits approved user's access to TriNetX. Your acceptance of this agreement certifies that you understand and agree to all applicable terms contained herein (you only need to agree once):

- *i*. I understand that this system was not designed, nor is it intended, to support any aspect of patient care.
- ii. I represent that I am an active, approved and registered user for UC Health clinical systems or am currently engaged in research or quality improvement activities at UC or UC Health.
- iii. I understand that the creators of TriNetX have made efforts to provide accurate, timely data but that the data may not be accurate due to data inconsistencies or errors.
- iv. I understand that due to HIPAA privacy concerns, the data is considered Protected Health Information (PHI) categorized as a Limited Data Set that includes specific dates. Query results are obfuscated (purposely clouded) where aggregate counts are small. (Exact numbers can be garnered through the Center for Health Informatics.)
- v. I agree to restrict individual queries to legitimate research topics.
- *vi.* I understand that all searches executed within the system are recorded and will be examined, as part of routine compliance audits. The identity of the user is recorded along with information related to each search executed.
- vii. I understand that I may not share my login information with any other person for any reason.
- *viii.* I have read, understood, and will comply with University of Cincinnati's computer use policy.
- ix. I have completed training in human subjects' protection.
- x. I understand that I may not use the data retrieved using TriNetX to identify or contact any individual or to attempt to learn the identity of any household, family, person, establishment or sampling unit included in these data.
- xi. I acknowledge that I will only obtain the minimum necessary data to accomplish the goals of my research or quality improvement activity.
- xii. I understand that any violation of this assurance may result in disciplinary action by UC and/or UC Health in consultation with the appropriate office(s) at these institutions.

### Important Note:

other authentication options

TriNetX uses its own authentication. You will need to get credentials before using it for the first time.

You agreed to this version of the User Agreement on 12/6/2016, 11:25:25 AM.

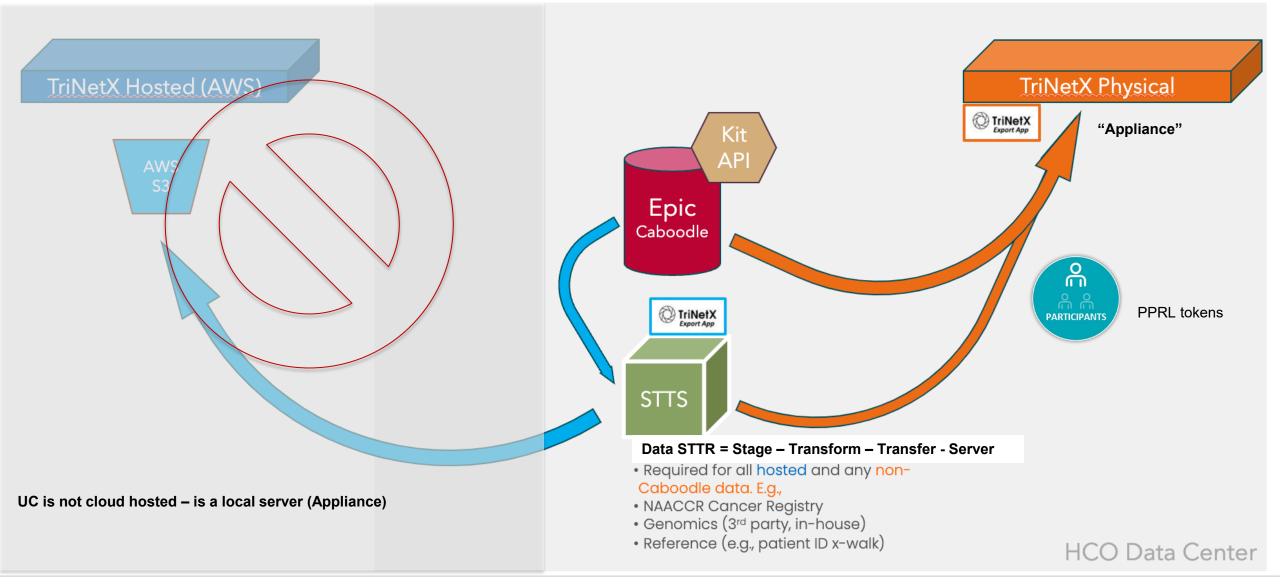


# New Capabilities in process...

- Privacy Protecting Record Linkage (De-duplication)
- Third-party claims data (e.g. pharmacy claims)
- Death registry (confirming death important for survival analyses)
- Natural Language Processing (coded concepts from notes)
- OMOP data warehouse (Observational Medical Outcomes Partnership) (harmonizing inter-institution research data warehouses)



# Flexible Architecture (Hosted or Physical)





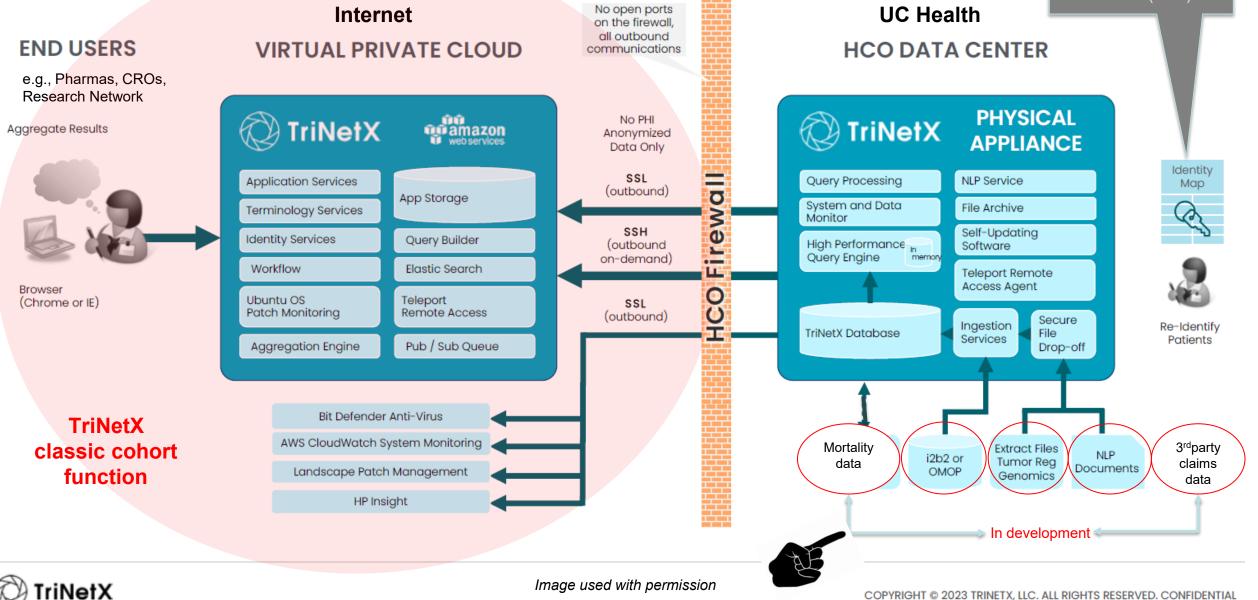
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# **Physical Appliance Architecture**

## Aids Recruitment!

Reverse engineer synthetic IDs to MRNs (CHI)



## Layers of TriNetX ecosystem



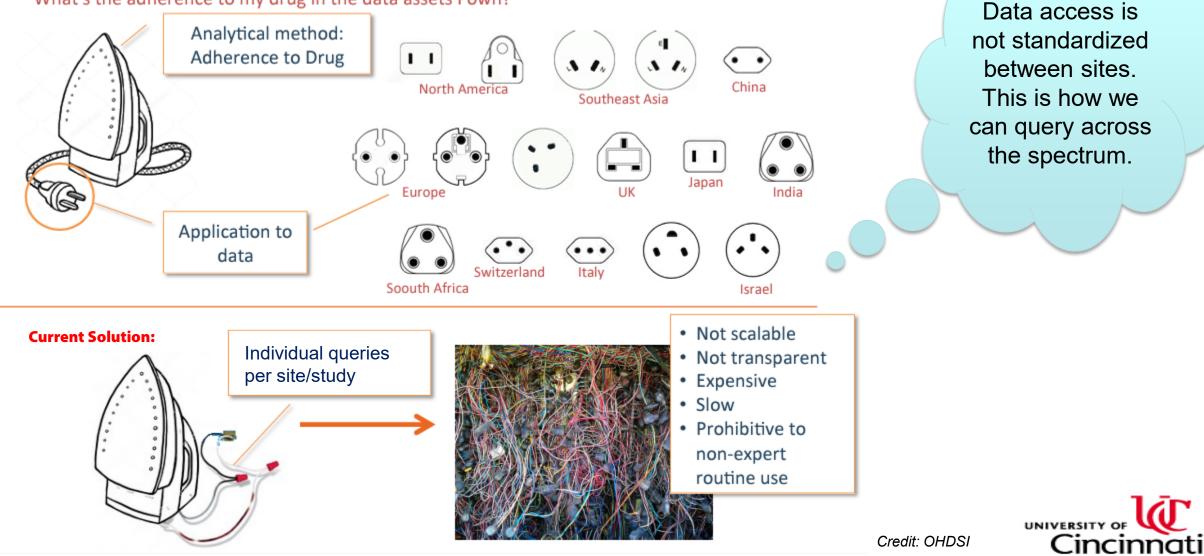




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## **OMOP Solution:**

"What's the adherence to my drug in the data assets I own?"



Definition	Concept	Sets	Generation	Reporting	Explore	Export
Print Friendly	JSON	SQL				

## Initial Event Cohort

People having any of the following:

- a drug exposure of Warfarin<sup>2</sup>
  - o for the first time in the person's history
  - with age >= 65

with continuous observation of at least 180 days prior and 0 days after event index date, and limit initial events to: earliest event per person.

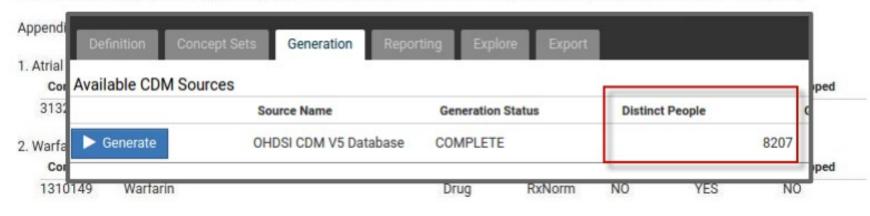
For people matching the Primary Events, include: People having all of the following criteria:

 at least 1 occurrences of a condition occurrence of Atrial fibrillation<sup>1</sup> occurring between all days Before and 1 days Before event index date

Limit cohort of initial events to: earliest event per person.

Limit qualifying cohort to: earliest event per person.

No end date strategy selected. By default, the cohort end date will be the end of the observation period that contains the index event.





## Summary

An update on development efforts with TriNetX for the research infrastructure.

TriNetX has been a popular research discovery tool at UC since 2016. There have been over 45,000 queries since it went live.

Added functionality includes participation in the Research Network with scores of other institutions and a denominator of over 130 million subjects (and growing) enabling Real World Evidence (RWE) studies.

Features in development include Privacy Protecting Record Linkage (PPRL), third-party claims data, death registry, Natural Language Processing (NLP), and OMOP data warehouse.

The architecture is securely housed at UC Health with access to the CoM.





## Thank you - Questions

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This is our Chief Information Officer. He's encrypted for security purposes.

