

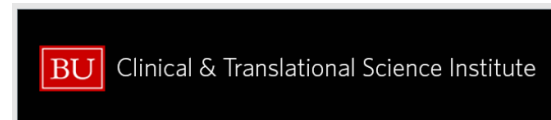
# BU-CTSI Clinical Research Informatics Tools and Resources Update

December 15, 2021

William G. Adams, MD

Professor of Pediatrics

BU-CTSI Director of Biomedical Informatics Core



The Boston University Clinical and Translational Sciences Institute Biomedical Informatics Core (BU-BIC) seeks to work with the BU/BMC research community to improve access to and use of clinical data from Boston Medical Center, affiliated Community Health Centers, and other research institutions nationally and internationally. This webinar will provide an update on current data resources, tools and consultation services so that attendees will better understand what is available and how they can be used for research.

Note: This webinar is being recorded



# About Us

We provide tools, services, and resources to clinical investigators to maximize the impact of discoveries and speed the translation of research into improved patient care through collaborative approaches.



## About Us →

What is Translational Science?

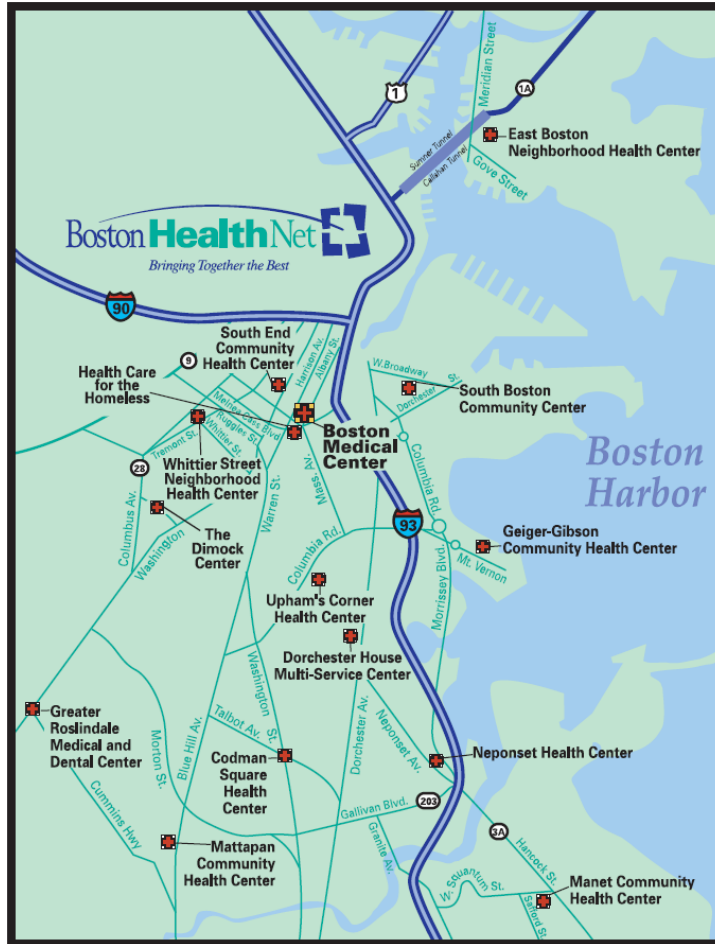
Accomplishments

Applicant		Figure 1: Boston University Clinical and Translational Science Institute					
Partner & Affiliates		HealthCore: New England Research Institute (A)	Boston Accountable Care Organization (A)	Boston Medical Center Healthcare Systems (P)	Boston HealthNet (A)	VA Boston Health System (A)	Edith Nourse Rogers Memorial Veterans Hospital (A)

# Our Vision for Informatics

- Data are accessible - privacy is protected
- Broadest possible array of health data available for research
- Researchers focus on questions more than queries
- Data and tools are standardized so they can be shared
- Advancing health equity is foundational

# Our “EcoSystem”



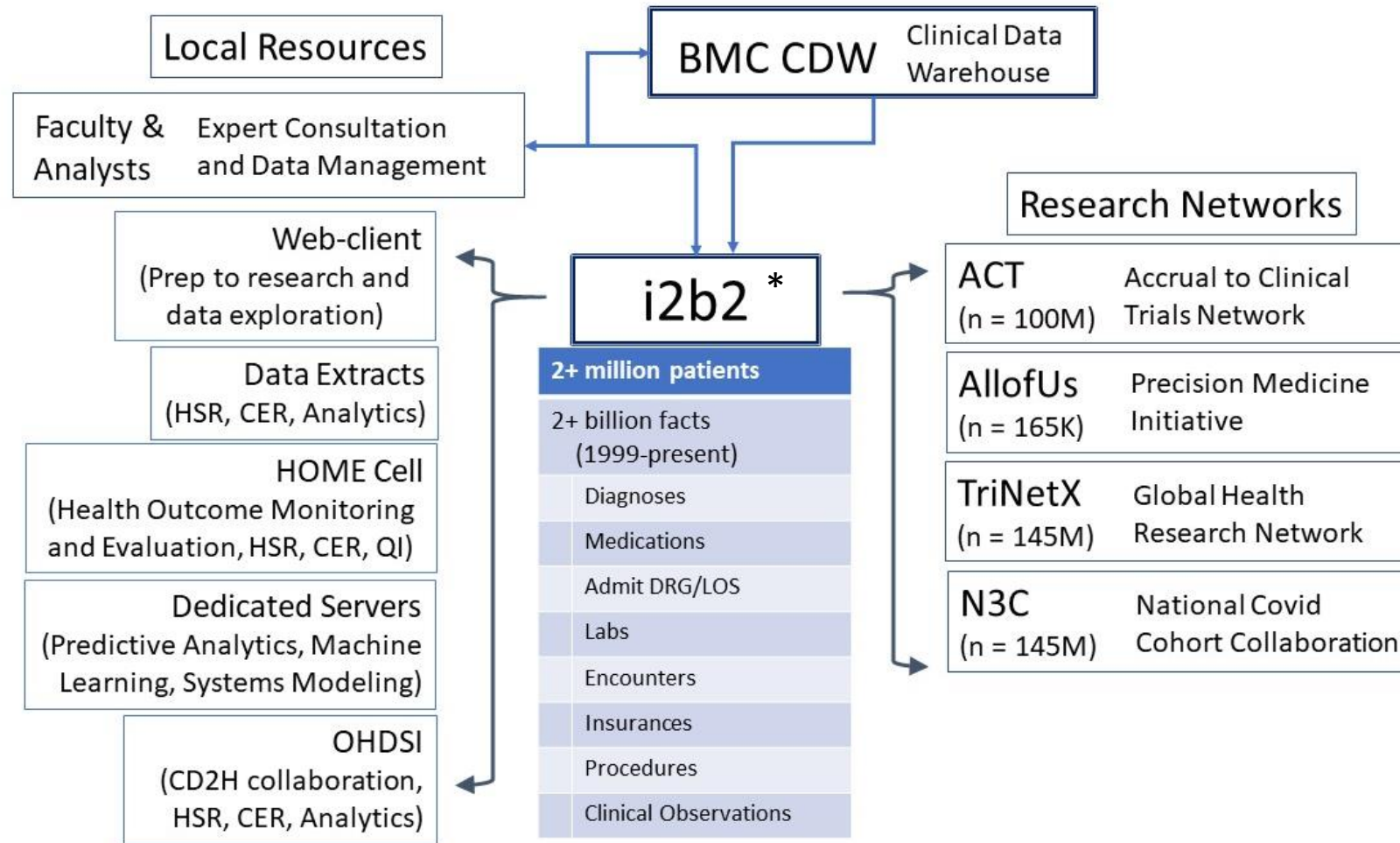
- BMC is largest safety net provider in New England
- Nearly all CHCs are FQHCs
- EHR-based care
  - BMC since 1999
  - CHCs since 2003
- Epic EHR in use at nearly all sites since 2015 (three instances)

# Agenda

- Tools and Resources
  - BMC Clinical Data Warehouse (CDW)
  - i2b2, SHRINE, ACT Network
  - TriNetX
  - NC3
  - Consultation Service
- Data for Equity (D4E) Project

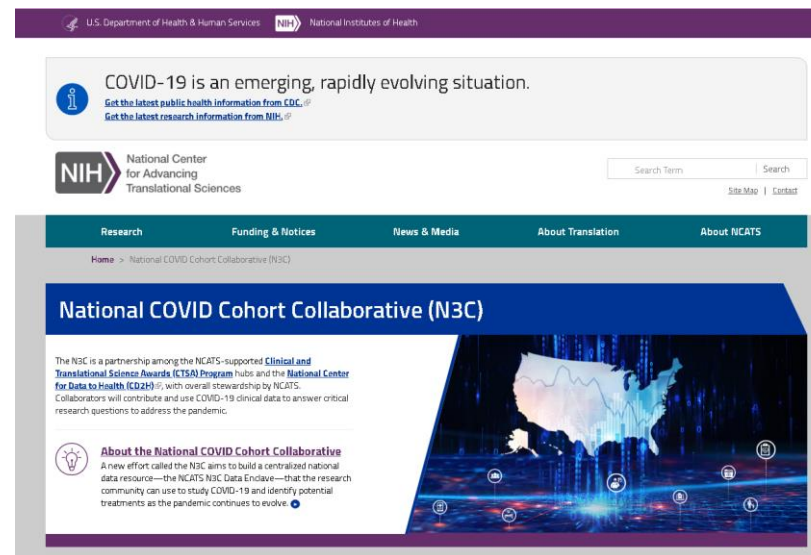
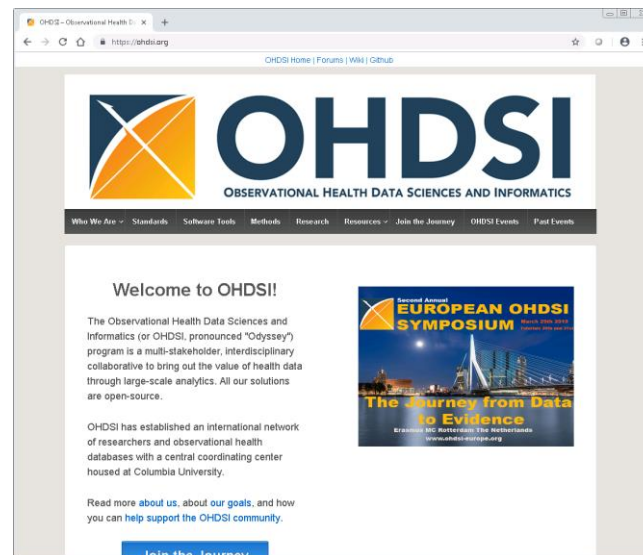
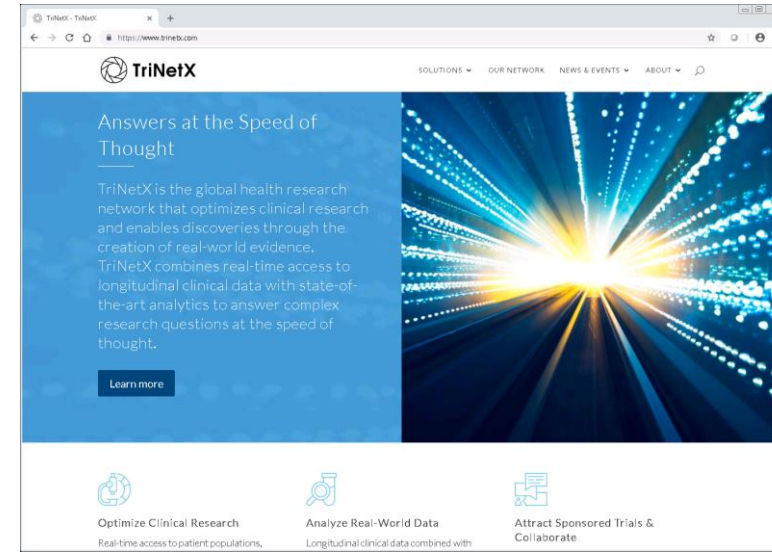
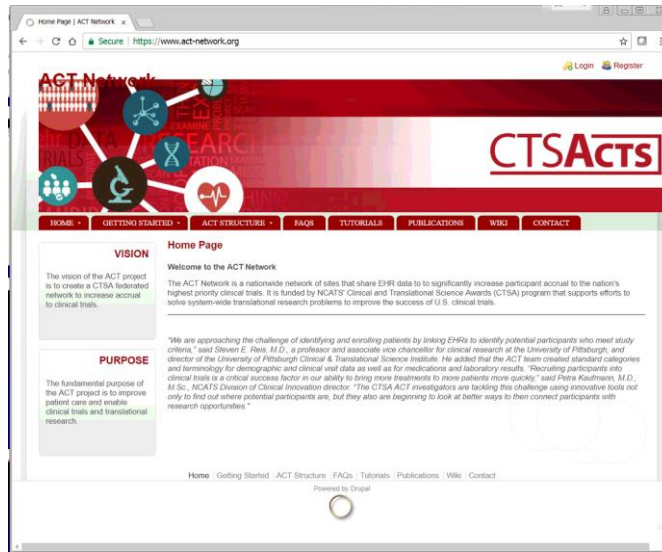
(Please chat in questions – we will address as many as possible at the end)

# BU-CTSI Clinical Data Resources and Networks



\* de-identified limited dataset

# Our National Networks






# BMC Clinical Data Warehouse (CDW)

- BMC CDW research infrastructure has grown with support from BMC and ACO
- 3 FTE research data analysts
- Specialized focusing on ACO analytics and HSR
- With COVID, group became the primary point of contact for all COVID-related CDW work
- Fee for service model supports ongoing work and scalability
- Requests should be directed to: [CDW@bmc.org](mailto:CDW@bmc.org)
- Or...

BU Data Request Form | Office of Hu x +

https://www.bumc.bu.edu/ohra/using-bmc-and-chc-data-for-research-purposes/data-request-form/ ☆ ☆ 📄 👤 ⋮

BMC Webmail Amazon.com: Onlin... Netflix CITI - Collaborative... Greenstone Garden... BU INSPIR II | Institutio... COVID-19 State an...



## Important Announcement

12 June, 2020 at 5:17 PM

Visit [Back2BU](#) for the latest updates and information on BU's response to COVID-19.

**Boston University Medical Campus and Boston Medical Center:**  
Office of Human Research Affairs

About Us HRPP Policies **Clinical Data Warehouse** Required Training Audits Limited Funding Opportunities ClinicalTrials.gov OHRA CRRO IRB 🔍

**COVID-19 (Novel Coronavirus): Please click here for FAQs: [Impact of COVID-19 on Human Subjects Research](#)**

## Data Request Form

### Clinical Data Warehouse Services Request

Please use this form to submit a CDW Data Request. *If you are interested in speaking with CDW personnel about your study or request, email [cdw@bmc.org](mailto:cdw@bmc.org) and request a consultation.*

**Please provide the following information about your request Please select the type(s) of your request: \***

- Counts Information
- Recruitment Study
- Retrospective Study
- Other

**Brief description of your request: \***

- About Us
- HRPP Policies
- Clinical Data Warehouse
  - Using BMC and CHC data for research purposes
- Policies and Procedures
- Data Request Form
- Protecting Security of Research Data
- Fees
- Required Training
- Audits
- Limited Funding Opportunities

# i2b2

- “Informatics for Integrating Biology with the Bedside”
- Open-source software based on the MGH Research Patient Data Repository (RPDR)
- Collection of modules or “cells” constitute the i2b2 “hive”
  - De-identified clinical data repository
  - Data linked to standardized vocabularies
  - Web-based query and analytic tools
- Available at BMC/BUMC since 2009

# i2b2 Core Data Elements

- Patients
- Observations (Facts)
- Concept Libraries (Ontologies)

# i2b2 Star Schema

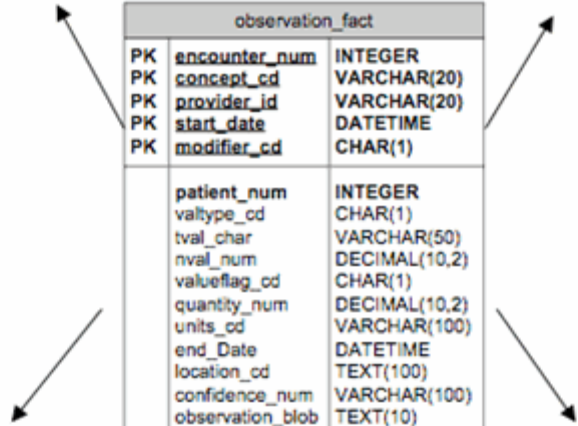
visit_dimension		
PK	encounter_num	INTEGER
PK	patient_num	INTEGER
	inout_cd	VARCHAR(10)
	location_cd	VARCHAR(100)
	location_path	VARCHAR(700)
	start_date	DATETIME
	end_date	DATETIME
	visit_blob	TEXT(10)

patient_dimension		
PK	patient_num	INTEGER
	vital_status_cd	VARCHAR(10)
	birth_date	DATETIME
	death_date	DATETIME
	sex_cd	CHAR(10)
	age_in_years_num	INTEGER
	language_cd	VARCHAR(100)
	race_cd	VARCHAR(100)
	marital_status_cd	VARCHAR(100)
	religion_cd	VARCHAR(100)
	zip_cd	VARCHAR(20)
	statecityzip_path	VARCHAR(200)
	patient_blob	TEXT(10)

observation_fact		
PK	encounter_num	INTEGER
PK	concept_cd	VARCHAR(20)
PK	provider_id	VARCHAR(20)
PK	start_date	DATETIME
PK	modifier_cd	CHAR(1)
	patient_num	INTEGER
	valtype_cd	CHAR(1)
	tval_char	VARCHAR(50)
	nval_num	DECIMAL(10,2)
	valueflag_cd	CHAR(1)
	quantity_num	DECIMAL(10,2)
	units_cd	VARCHAR(100)
	end_date	DATETIME
	location_cd	TEXT(100)
	confidence_num	VARCHAR(100)
	observation_blob	TEXT(10)

concept_dimension		
PK	concept_path	VARCHAR(700)
	concept_cd	VARCHAR(20)
	name_char	VARCHAR(2000)
	concept_blob	TEXT(10)

provider_dimension		
PK	provider_path	VARCHAR(800)
	provider_id	VARCHAR(20)
	name_char	VARCHAR(2000)
	provider_blob	TEXT(10)



## Staging Area (PHI containing data)

Billing Data – Site 2							
MRN	Visit_date	Location	Dx1	Dx2	CPT1	CPT2	PrimIns
ABCD	2/15/2010	PediPulm	123.4	125.8	90214	90213	Uninsured
ABCD	2/15/2010	MCV	70				

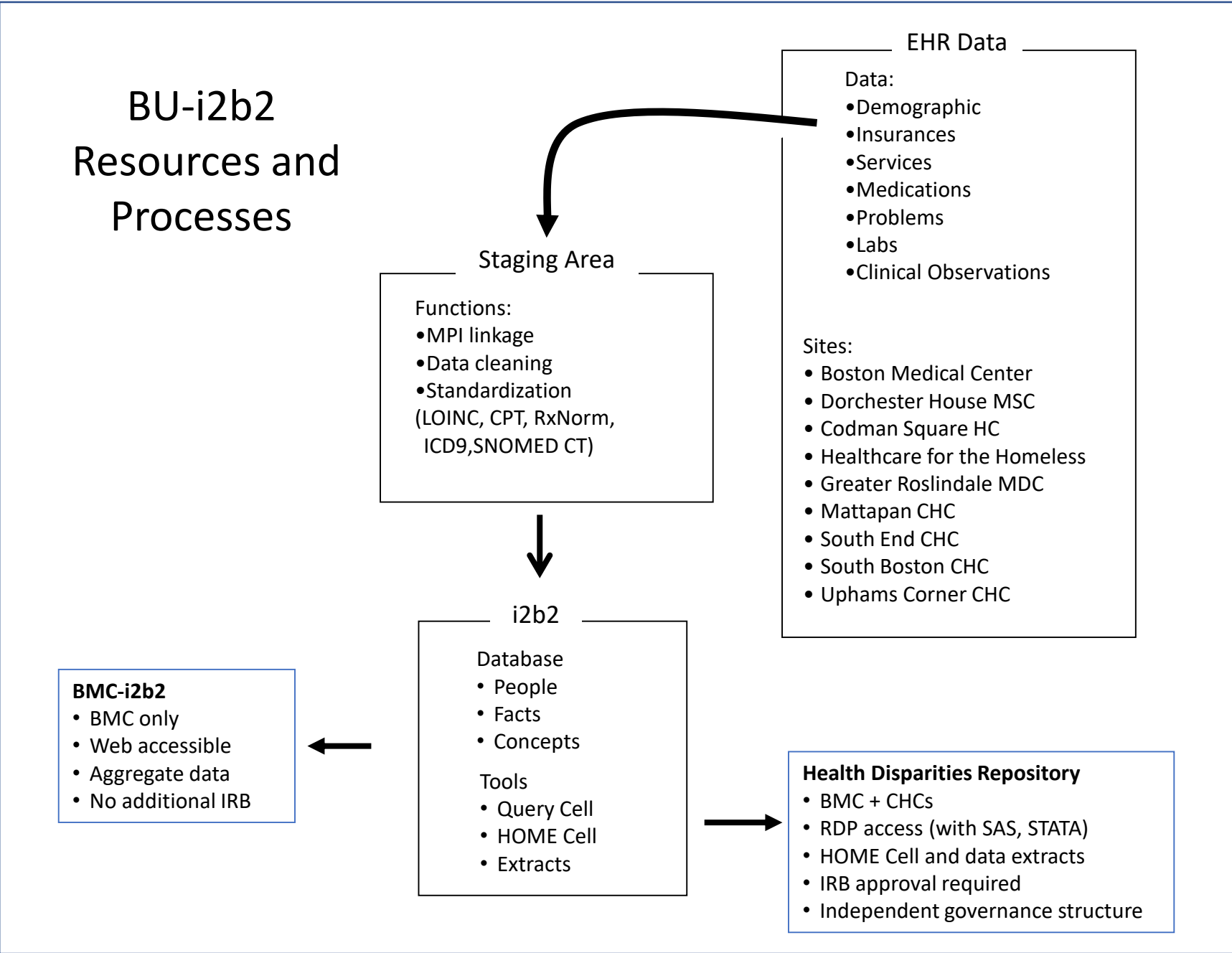
Link Table		
ID	MRN	Site
12	1234	Site1
12	ABCD	Site2

## i2b2 Repository (de-identified data)



Patients				
ID	Birth_Date	Sex_Cd	Race_Cd	...
12	11/07/2000	M	B	

Observation_facts						
ID	Concept_Cd	Start_Date	Value	Location_Cd	End_Date	...
12	PrimCareVis	1/22/2010	Site1	Site1		
12	Dx	1/22/2010	123.4	Site1		
12	Dx	1/22/2010	125.8	Site1		
12	Proc	1/22/2010	90124	Site1		
12	Proc	1/22/2010	90254	Site1		
12	Ins	1/22/2010	Medicaid	Site1		
12	PediPulm	2/22/2010	Site2-PediPulm	Site2		
12	Dx	2/22/2010	123.4	Site2		
12	Hct	2/22/2010	11.1	Site2		
12	MCV	2/22/2010	70	Site2		



# i2b2 Compatible Data

- Demographics
- Problems/Diagnoses
- Medications
- Clinical Observations
- Procedures
- Laboratory Data
- Genomic Data
- Much more...



i2b2 Web Client

Not secure | ctsi1/webclient/

**i2b2 Query & Analysis Tool** Project: BMC User: Bill Adams Find Patients | Analysis Tools | Message Log | Help | Logout

**Navigate Terms** Find

- Admissions
- Clinical Ontologies
- Demographics
  - Age - 1064994
    - >= 65 years old - 217239
    - >= 85 years old - 59217
    - 0-9 years old - 38501
    - 10-17 years old - 50720
    - 18-34 years old - 247542
    - 35-44 years old - 204184
    - 45-54 years old - 165323
    - 55-64 years old - 141603
    - 65-74 years old - 98621
    - 75-84 years old - 59409
    - [not recorded - 0]

**Workplace**

- aale
- alcc
- algniv
- alschmal
- alwalkey
- alweinst
- amgarg
- amsobota
- anegloff
- anfarrel
- anking
- aucalder
- badams
- biadams

**Previous Queries** Find

- 18-34 years old@16:55:34
- 65-74-Chron-NEPHR
- HOME:miketst2 [5-15-2017] [mimendis]
- HOME:miketst [5-15-2017] [mimendis]
- BMC\_HOME\_PLUGIN16\_16\_2017[mimendis]

**Query Tool**

Query Name: 18-34 years old@16:55:34

Temporal Constraint: Treat all groups independently

Group 1			Group 2			Group 3		
Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude
Treat Independently			Treat Independently			Treat Independently		
18-34 years old - 247542								

↑

**Facts**

one or more of these AND drop a term on here

Counts

Run Query Clear 1 Group New Group

Show Query Status **Graph Results** Query Report

Number of patients

**247542**

For Query "18-34 years old@16:55:34"

# i2b2 Recent Additions

- PHQ
- PHQ-9 Depression Scale
- Postpartum Depression Scale
- PSC - 17
- [RiskAssessment
- RiskAssessment and Protective Factors
- SCAT3 - Child (5-12)
- SCAT3 - Over 12 years
- Screen for Child Anxiety Related Disorders (SCARED)
- Screenings
- Sickle Cell
- SpiritualAssessment
- Spiritual Care Assessment
- Spiritual Care Interventions
- SRS II - Social Responsiveness Scale
- Suicidality
- Suicide Risk
- Target Low Back Pain Screening Tool
- THRIVE Survey
  - 01. Patient Response
  - 02. Patient's Language (Reading)
  - 03. HOMELESS SCREENING
  - 04. FOOD
  - 05. AFFORDING MEDICATIONS
  - 06. TRANSPORTATION
  - 07. UTILITIES
  - 08. PATIENT CAREGIVING
  - 09. EMPLOYMENT
  - 10. EDUCATION
  - 11. RESOURCES
- Vanderbilt F/U Parent
- Vanderbilt F/U Teacher
- Vanderbilt Initial Parent
- Vanderbilt Initial Teacher
- Wender Utah Rating Scale for ADHD
- WIAT-III
- WISC IV - Wechsler Intelligence Scale for Children IV
- Withdrawal Assessment Tool
- Woodcock Johnson Measure
- Wound Assessment/Care
- WPPSI (WENCHSLER PRESCHOOL AND PRIMARY SCALE OF INTELLIGENCE
- Yale-Brown Obsessive Compulsive Scale
- Immunizations (Fnic) - 263660

# SHRINE

Journal List > J Am Med Inform Assoc > v.16(5); Sep-Oct 2009 > PMC2744712

[Alerts](#) | [Author Instructions](#) | [Submit](#) | [About](#)

JAMIA

Journal of the American Medical Informatics Association

[J Am Med Inform Assoc](#). 2009 Sep-Oct; 16(5): 624–630.

PMCID: PMC2744712

doi: [10.1197/jamia.M3191](https://doi.org/10.1197/jamia.M3191)

PMID: [19567788](https://pubmed.ncbi.nlm.nih.gov/19567788/)

## The Shared Health Research Information Network (SHRINE): A Prototype Federated Query Tool for Clinical Data Repositories

[Griffin M. Weber](#), MD, PhD, <sup>a, c, \*</sup> [Shawn N. Murphy](#), MD, PhD, <sup>d</sup> [Andrew J. McMurry](#), MS, <sup>b, e</sup>

[Douglas MacFadden](#), MS, <sup>e</sup> [Daniel J. Nigrin](#), MD, MS, <sup>b, e</sup> [Susanne Churchill](#), PhD, <sup>c</sup> and [Isaac S. Kohane](#), MD, PhD <sup>b, d, e</sup>

Home Page | ACT Network x

Secure | <https://www.act-network.org>

Login Register

# ACT Network

# CTSA ACTS

HOME GETTING STARTED ACT STRUCTURE FAQs TUTORIALS PUBLICATIONS WIKI CONTACT

## Home Page

### VISION

The vision of the ACT project is to create a CTSA federated network to increase accrual to clinical trials.

### PURPOSE

The fundamental purpose of the ACT project is to improve patient care and enable clinical trials and translational research.

### Welcome to the ACT Network

The ACT Network is a nationwide network of sites that share EHR data to to significantly increase participant accrual to the nation's highest priority clinical trials. It is funded by NCATS' Clinical and Translational Science Awards (CTSA) program that supports efforts to solve system-wide translational research problems to improve the success of U.S. clinical trials.

*"We are approaching the challenge of identifying and enrolling patients by linking EHRs to identify potential participants who meet study criteria," said Steven E. Reis, M.D., a professor and associate vice chancellor for clinical research at the University of Pittsburgh, and director of the University of Pittsburgh Clinical & Translational Science Institute. He added that the ACT team created standard categories and terminology for demographic and clinical visit data as well as for medications and laboratory results. "Recruiting participants into clinical trials is a critical success factor in our ability to bring more treatments to more patients more quickly," said Petra Kaufmann, M.D., M.Sc., NCATS Division of Clinical Innovation director. "The CTSA ACT investigators are tackling this challenge using innovative tools not only to find out where potential participants are, but they also are beginning to look at better ways to then connect participants with research opportunities."*

Home | Getting Started | ACT Structure | FAQs | Tutorials | Publications | Wiki | Contact

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# Sample ACT SHRINE Query\*

The screenshot displays the SHRINE i2b2 query tool interface. On the left, a tree view shows the hierarchy of ACT terms, with 'Diabetes mellitus (e00-e13)' selected. The main area is titled 'Query Tool' and shows a query named 'Diabetes mellitus (13 of 13)'. The query is structured as follows:

Group 1	Group 2	Group 3
Date	Date	Date
Occurs > Or	Occurs > Or	Occurs > Or
Exclude	Exclude	Exclude
Diabetes mellitus (e00-e13)		

Below the query table, there are two 'AND' operators. A green box labeled 'one of more of these' is positioned under the first 'AND', and a yellow box labeled 'stop a term on here' is positioned under the second 'AND'. At the bottom, there is a search bar containing 'Diabetes counts by site - TEST' and a 'Request New Topic' button. The interface also includes navigation buttons like 'Run Query', 'Clear', and 'New Group'.

\*self-service use of i2b2 query tool for local queries available but network wide queries are done with CTSI support

# Sample ACT SHRINE Query

Query Status	Breakdowns	Export to CSV
Status of Query Diabetes mellit@13:1... at Each Institution:		Last Updated on: 05/16/2019 1:18:27 pm
BUMC	COMPLETED	Patient Count: 83390 ± 10 patients
CCHMC	COMPLETED	Patient Count: 71 ± 10 patients
Childrens Hospital Colorado	COMPLETED	Patient Count: 11887 ± 10 patients
Childrens National	COMPLETED	Patient Count: 10 ± 10 patients
Columbia University Medical Center	QUEUED	
Duke	COMPLETED	Patient Count: 155 ± 10 patients
Emory	COMPLETED	Patient Count: 10 ± 10 patients
Indiana	COMPLETED	Patient Count: 10 ± 10 patients
JHU	COMPLETED	Patient Count: 10 ± 10 patients
KUMC	COMPLETED	Patient Count: 10 ± 10 patients
Keck Medicine of USC	COMPLETED	Patient Count: 10 ± 10 patients
Kentucky	COMPLETED	Patient Count: 10 ± 10 patients
MCW	COMPLETED	Patient Count: 10 ± 10 patients
Mayo Clinic Enterprise	COMPLETED	Patient Count: 10 ± 10 patients
Medical University of South Carolina	COMPLETED	Patient Count: 10 ± 10 patients
Morehouse	COMPLETED	Patient Count: 10 ± 10 patients
NYU Langone Medical Center	COMPLETED	Patient Count: 10 ± 10 patients
Northwestern University	ERROR	
OHSU	COMPLETED	Patient Count: 10 ± 10 patients
Partners HealthCare	COMPLETED	Patient Count: 10 ± 10 patients
PennState Health	ERROR	
Stanford Medicine	COMPLETED	Patient Count: 10 ± 10 patients
The Ohio State University Wexner Medical Center	QUEUED	
UAB	COMPLETED	Patient Count: 10 ± 10 patients
UAMS	COMPLETED	Patient Count: 10 ± 10 patients
UCD	COMPLETED	Patient Count: 10 ± 10 patients
UCI	COMPLETED	Patient Count: 10 ± 10 patients
UCLA	QUEUED	
UCSD	SUBMITTED	
UCSF	COMPLETED	Patient Count: 10 ± 10 patients
UF	COMPLETED	Patient Count: 10 ± 10 patients
UIC	COMPLETED	Patient Count: 10 ± 10 patients
UNC - Chapel Hill	COMPLETED	Patient Count: 10 ± 10 patients
UPitt	COMPLETED	Patient Count: 10 ± 10 patients
UT Southwestern	COMPLETED	Patient Count: 10 ± 10 patients
UTHSCSA	COMPLETED	Patient Count: 10 ± 10 patients
UTHealth	ERROR	
University of Minnesota - AHC	COMPLETED	Patient Count: 10 ± 10 patients
VCU	COMPLETED	Patient Count: 10 ± 10 patients
Vanderbilt University Medical Center	COMPLETED	Patient Count: 10 ± 10 patients
Wash U St Louis	ERROR	
Weill Cornell Medicine	COMPLETED	Patient Count: 10 ± 10 patients

# Additional projects/activities

## BMC Projects

- BMC Cancer Registry Integration
- BP Normalization and Care
- VVV in BP, lipid, and Hgb1C
- Sickle Cell QI (children and adults)
- Sickle Cell BH
- Community-based smoking cessation
- Pneumonia rates in PCV vaccine era
- HPV vaccination and morbidity
- Algorithms for Personalized Decision Making
- Vital Village – geographic health effects
- Household Health Study
- Comparative Effectiveness of Bariatric Surgical Procedures

## I2b2 Networking

ePROS – psychotropic medication use in kids  
ePROS – on- off-label safety  
Insurance switching  
Pediatric uveitis  
Precision Medicine Initiative/All of Us

BU i2b2

sites.bu.edu/bu-i2b2/

INSPIR II » Institutional Google Settings Home - i2b2-dev i2b2@BU - Weebly Site Weebly BU-i2b2 Web Client i2b2 Dev2 Webclient My BHN Sharepoint REDCap SCHILHS i2b2 Web Client

**BU** Clinical & Translational Research Institute (CTSI)  
i2b2

Boston University Search Directory BU Today

i2b2@bu Intro to i2b2 BMC-i2b2 MHDR HOME Cell Resources

# i2b2@bu

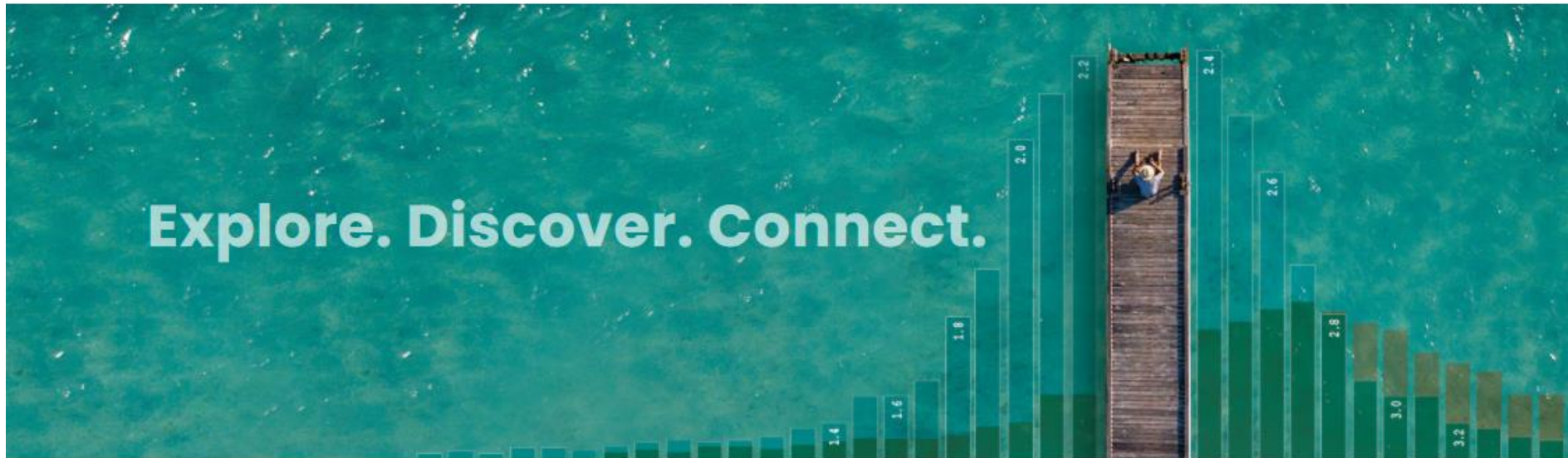
Welcome to BU-i2b2. The “Informatics for Integrating Biology with the Bedside (i2b2)” Platform at Boston University is supported by researchers at Boston University and its Clinical and Translational Science Institute (BU-CTSI). Our primary focus is on the use of de-identified electronic health data to better understand and improve the health of the residents of Boston and to develop new tools and approaches to support the effective use of i2b2 with its broader community.

i2b2 is composed of multiple interconnected software modules (called “cells”) that support a broad range of functions including data storage, concept mapping (ontologies), and data analysis. Data are stored in a de-identified format, with obscured dates and counts to protect patient privacy while supporting the needs of clinical, public health, and translational researchers. Users of BU-i2b2 can quickly perform aggregate data queries for patients who receive care at Boston Medical Center, *themselves*, using the [BMC-i2b2](#) web client. With IRB and Executive Director approval they may also use i2b2 to explore data that includes Boston Medical Center as well as Boston HealthNet Community Health Centers using the [Massachusetts Health Disparities Repository \(MHDR\)](#). Data extracts are also available with the same approvals and can be used within a secure data workspace. In addition we have developed a new software module called the “[Health Outcome Monitoring and Evaluation](#)”

## News →

[Updates](#)  
November 22, 2016





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# TriNetX at BMC/BUMC

- TriNetX is global health research network
- Primary source of support is from pharma industry
- Goals are to connect the world of drug discovery and development from:
  - Pharmaceutical company to study site
  - Investigator to patient
  - Via sharing real-world data to make clinical and observational research easier and more efficient
- Two pathways for research
  - Query tool – user-friendly self-service tool for aggregate data exploration (active at BMC)
  - Research network participation



Your organization email address



[Need to reset your password?](#)

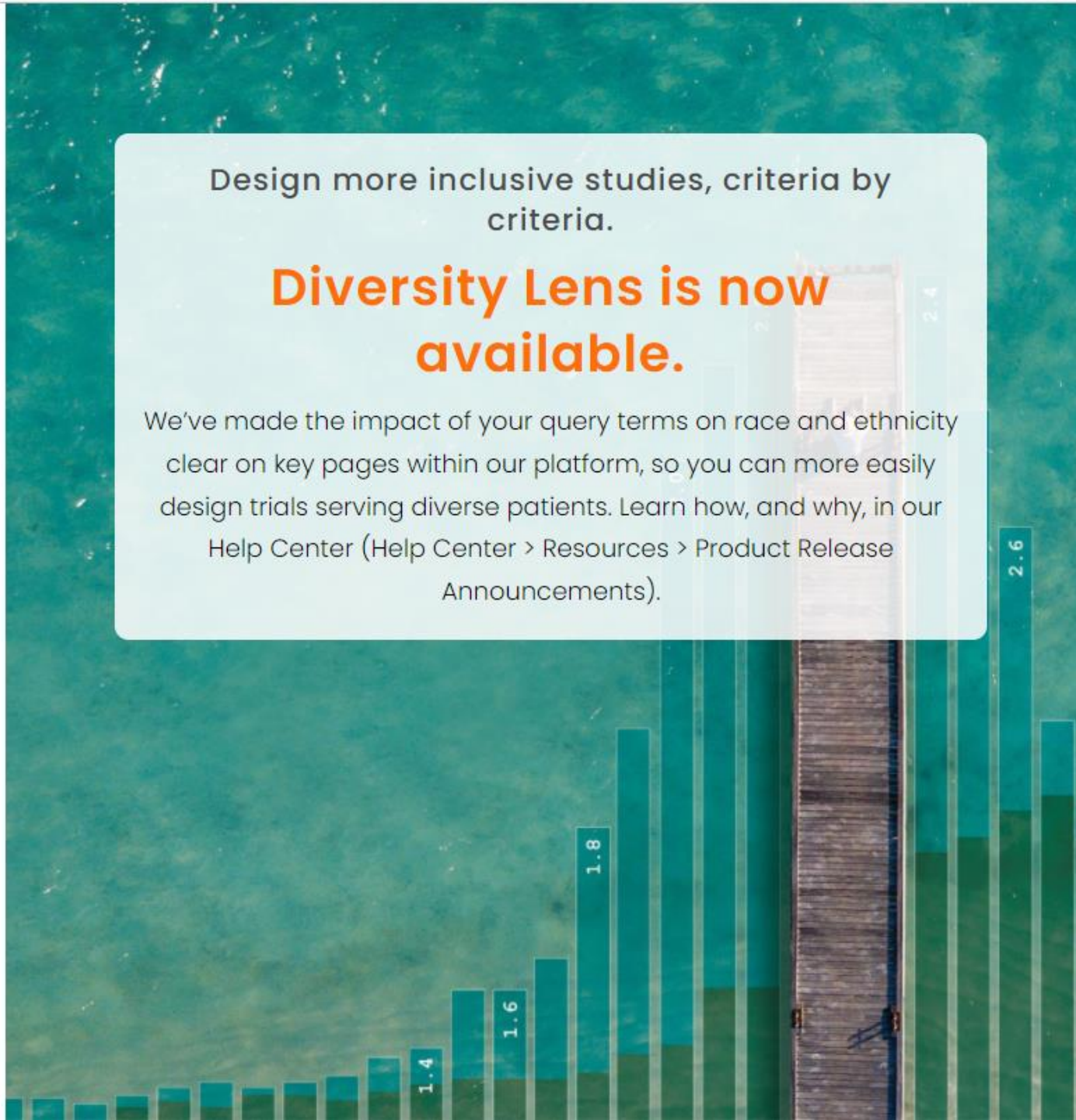
[Login >](#)

The TriNetX platform has regularly scheduled maintenance every Wednesday from 8pm to 10pm ET.

Design more inclusive studies, criteria by criteria.

## Diversity Lens is now available.

We've made the impact of your query terms on race and ethnicity clear on key pages within our platform, so you can more easily design trials serving diverse patients. Learn how, and why, in our Help Center ([Help Center > Resources > Product Release Announcements](#)).




## Create New Study

Created by on Dec 15, 2021

**\*Study Name** (required) Enter a descriptive name for the study

### Study Name

Diabetes and A1C


**\*Research Purpose**  (required) Select one or more from the list below

### Clinical Trial Research

- Design clinical trial
- Assess feasibility of clinical trial
- Identify clinical trial sites
- Recruit trial subjects

### Other Scientific Research

- Conduct health economics and outcomes research (HEOR)
- Explore patient populations
- Conduct other secondary research

 **Study Identifying Information** (optional)

# Sample Query: Diabetes and A1C Cohort

Network Boston Medical Center  
1 of 1 HCOs online

Population Any age / Any sex  
1,113,070 patients on network

MUST Have Diabetes mellitus

CANNOT Have Search Term...

All D Demographics Dx Diagnoses P Procedures M Medications L Labs G Genomics V Visits

Code	Term Description	Patients
<input checked="" type="checkbox"/> E08-E13	Dx Diabetes mellitus	86,410
<input type="checkbox"/> E11	Dx Type 2 diabetes mellitus	84,640
<input type="checkbox"/> E08	Dx Diabetes mellitus due to underlying condition	9,790
<input type="checkbox"/> E08.4	Dx Diabetes mellitus due to underlying condition with neurological complications	7,140
<input type="checkbox"/> E08.42	Dx Diabetes mellitus due to underlying condition with diabetic polyneuropathy	6,910
<input type="checkbox"/> O24		
<input type="checkbox"/> E08.9		
<input type="checkbox"/> E08.6		

Show Terms with Zero Patients

MUST Have A1c

CANNOT Have Search Term...

All D Demographics Dx Diagnoses P Procedures M Medications L Labs G Genomics V Visits

Code	Term Description	Patients
<input checked="" type="checkbox"/> TNX:LAB:9037	L Hemoglobin a1c/hemoglobin.total in blood	170,190
<input type="checkbox"/> 83036	P Hemoglobin; glycosylated (a1c)	142,100
<input type="checkbox"/> 41995-2	L Hemoglobin a1c [mass/volume] in blood	440
<input type="checkbox"/> R73.09	Dx Other abnormal glucose High hemoglobin a1c level	25,390
<input type="checkbox"/> R78.89	Dx Finding of other specified substances, not normally found in blood High hemoglobin a1c level	16,010
<input type="checkbox"/> R68.89	Dx Other general symptoms and signs Hemoglobin a1c greater than 10% indicating poor diabetic control	11,660

Show Terms with Zero Patients  Show Deprecated

Add To Query Cancel

# Sample Query: Narrowing Results Range



# Sample Query: Counting Patients

☆ Diabetes and A1C = 6+ ✎

Dec 15, 2021 at 11:01 am by Bill Adams

Patients

46,460

HCOs

1

Count Patients



All changes saved

Boston Medical Center

1 of 1 HCOs online

Any country

1 country in the network

Any age / Any sex

1,285,260 patients on network



MUST HAVE



Search Term...

CANNOT HAVE



Search Term...

## Ungrouped Terms

MUST HAVE

E08-E13 Diabetes mellitus 98,080

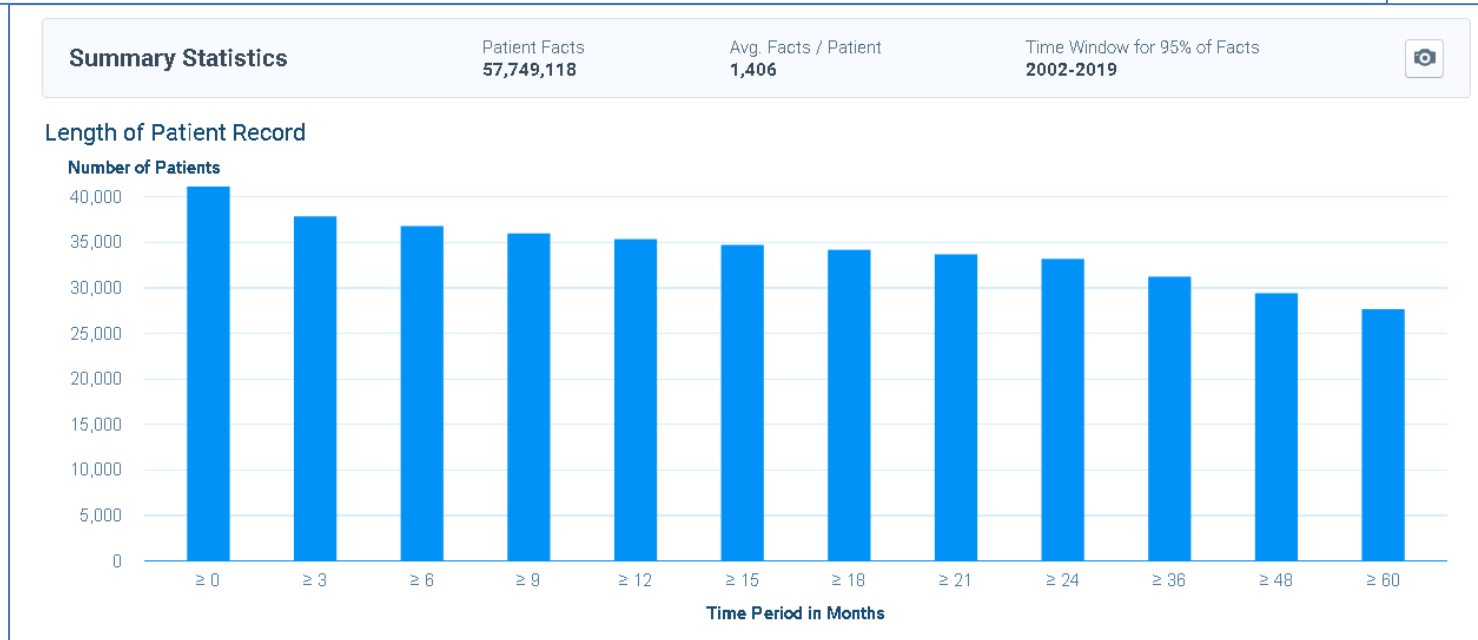
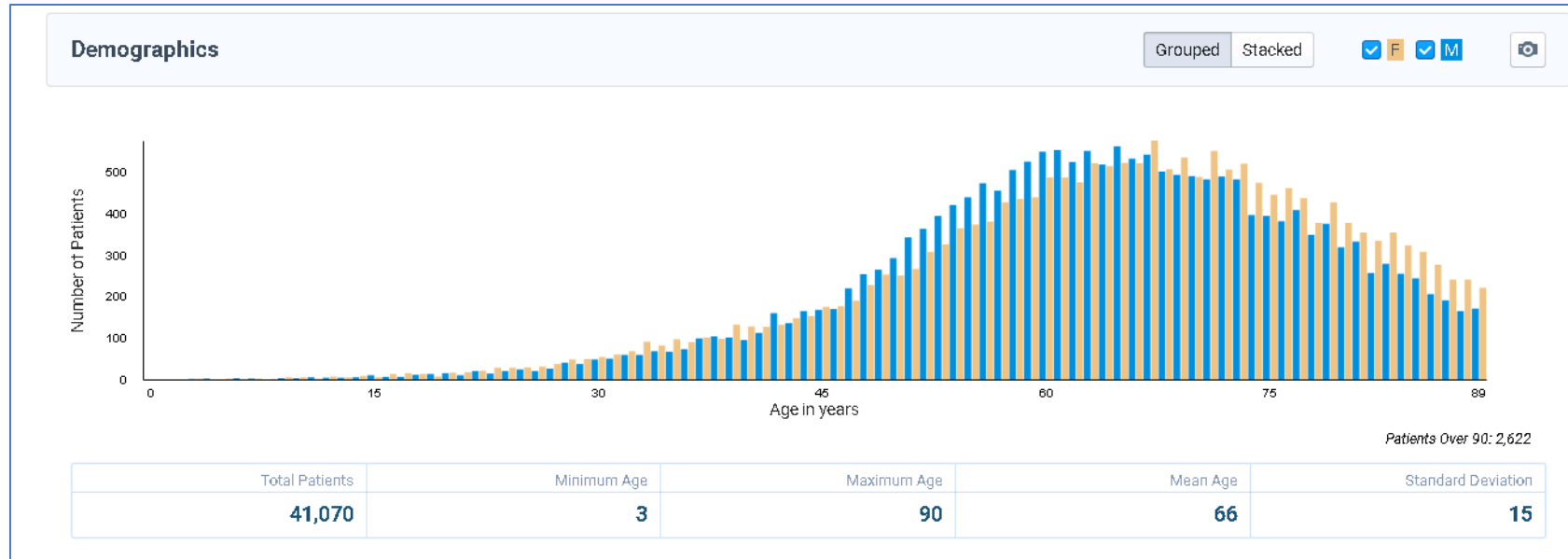
AND

9037 Hemoglobin A1c/Hemoglobin.total in Blood 196,410

> ≥ 6 %, most recent value

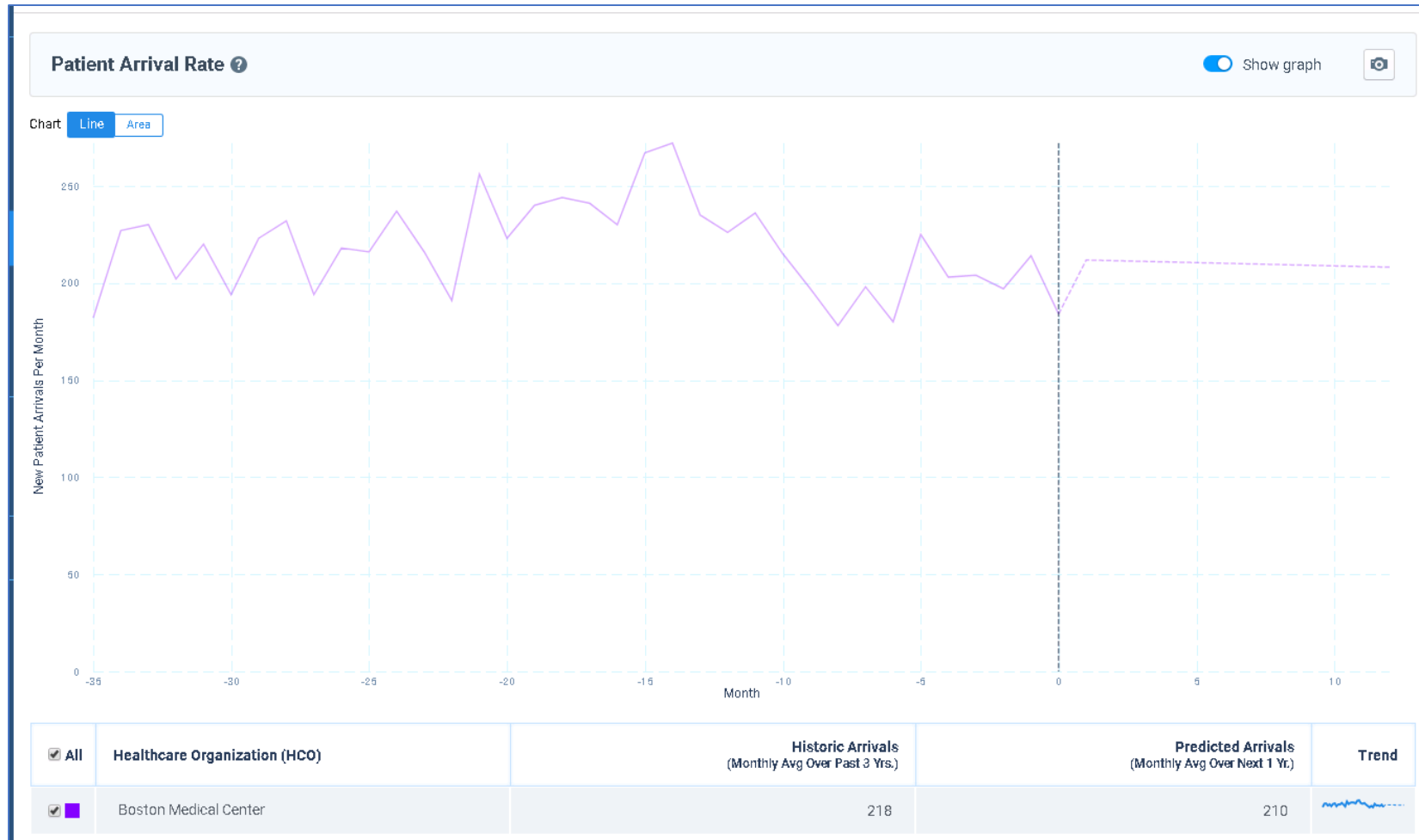
CANNOT HAVE

# Sample Query: Exploring the Cohort





# Sample Query: Predicting Arrivals



# Sample Query: Counting Patients

☆ Diabetes and A1C = 6+ ✎

Dec 15, 2021 at 11:01 am by Bill Adams

Patients

46,460

HCOs

1

Count Patients



All changes saved

Boston Medical Center

1 of 1 HCOs online



Any country

1 country in the network



Any age / Any sex

1,285,260 patients on network



MUST HAVE



Search Term...

CANNOT HAVE



Search Term...

## Ungrouped Terms

MUST HAVE

E08-E13 Diabetes mellitus 98,080

AND

9037 Hemoglobin A1c/Hemoglobin.total in Blood 196,410

> ≥ 6 %, most recent value

CANNOT HAVE

☆ Diabetes and A1C = 6+ ✎

Dec 15, 2021 at 11:01 am by Bill Adams

Patients

46,460

HCOs

1

 Count Patients



All changes saved

Research  
56 of 57 HCOs online ^

Any country  
6 countries in the network v

Any age / Any sex  
81,221,267 patients on network v



Select a network from the list below

**Boston Medical Center** | 1,285,260 Patients

● 1 of 1 Online | Last Update: 12 days ago



Trial Connect



Analytics



Data sets

**COVID-19 Research Network** | 89,206,888 Patients

● 65 of 66 Online | Last Update: 4 hours ago



Trial Connect



Analytics



Data sets

**Diamond Network** | 212,777,108 Patients

● 92 of 92 Online



Trial Connect



Analytics



Data sets

**EMEA Collaborative Network** | 11,201,788 Patients

● 18 of 18 Online | Last Update: 24 minutes ago



Trial Connect



Analytics



Data sets

**Global Collaborative Network** | 89,069,623 Patients

● 73 of 75 Online | Last Update: 24 minutes ago



Trial Connect



Analytics



Data sets

**LATAM Collaborative Network** | 2,380,597 Patients

● 5 of 5 Online | Last Update: 2 days ago



Trial Connect



Analytics



Data sets

**Research** | 81,221,267 Patients

● 56 of 57 Online | Last Update: 4 hours ago



Trial Connect



Analytics



Data sets

# ☆ Diabetes with A1C 6+ Research Network

Dec 15, 2021 at 11:06 am by Bill Adams

Patients  
**2,187,359**

HCOs  
**52**

**Count Patients**



All changes saved

Research  
56 of 57 HCOs online

Any country  
6 countries in the network

Any age / Any sex  
81,221,267 patients on network



MUST HAVE

Search Term...

CANNOT HAVE

Search Term...

## Ungrouped Terms

MUST HAVE

E08-E13 Diabetes mellitus 5,576,220

AND

9037 Hemoglobin A1c/Hemoglobin.total in Blood 9,034,516

> ≥ 6 %, most recent value

CANNOT HAVE

New Query

Hide

Filter By:

Sort By: Most Recent

Request Dataset

☆ Diabetes with A1C 6+ Research Network   
by Bill Adams Dec 15, 2021 11:06 AM

Patients 2,187,359

HCOs 52

Network Research

☆ Diabetes and A1C = 6+

Patients 46,460 HCOs 1

☆ Diabetes and A1C

Patients 65,030 HCOs 1

TRINETX RESEARCH™

Analyze Data.  
Generate Evidence.  
Take Action.



### Research-Ready Real-World Data

Eliminates the cost, complexity, and lengthy timelines associated with licensing, mapping, normalizing, and hosting multiple third-party data sets.



### On-Demand Real-World Evidence Generation

Quickly gain real-world insights into how patients are treated and their health outcomes or conduct full protocol-driven observational research studies in a fraction of the usual time.



### Elegant UI with Research Workflow

Intuitive interface for those without advanced data training and robust statistical analysis capabilities for experienced epidemiology and outcomes research professionals.



### Global and Diverse Healthcare Databases

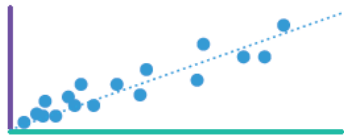
Conduct region-specific studies compliant with local privacy regulations; studies using academic medical center or cardiology specialty EMRs, HemOnc registries, or our Diamond Network.

## Highly Intuitive Analytics

TriNetX combines longitudinal clinical data with powerful, self-service analytics, making it the fastest and easiest method for creating real-world evidence.

### Compare Cohorts

How do patient characteristics compare between cohorts?



←-----→  
Compare Characteristics

● ● Two cohorts

### Compare Cohorts

Investigate characteristics of patients on different treatments, in different geographies, or in different demographic groups.

- Compare the prevalence of comorbidities, laboratory results, treatments, and medications across cohorts
- Discover meaningful differences between the characteristics of two cohorts

### Analyze Outcomes

How do patients in a cohort experience outcomes?



● Single cohort

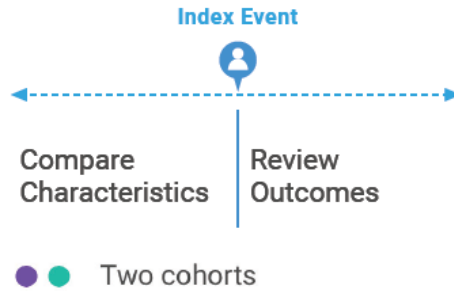
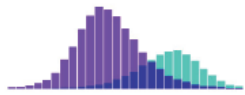
### Analyze Outcomes

Identify risk of outcomes in a cohort and use retrospective data as a control arm.

- Understand baseline characteristics and natural disease progression
- Define your cohort according to eligibility criteria of a clinical trial and use real-world data as your control arm

## Compare Outcomes

How do patients compare between cohorts?



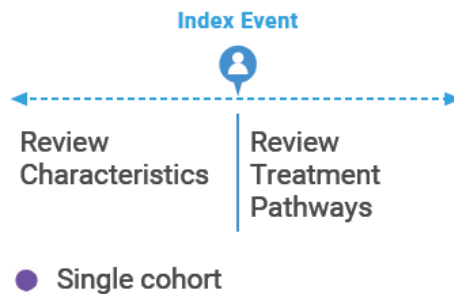
## Compare Outcomes

Conduct comparative effectiveness research with propensity score matching, stratification, and Kaplan-Meier analyses.

- Conduct retrospective observational analysis
- Compare cohorts' baseline characteristics
- Compare risk of outcomes across cohorts
- Perform time-to-event analysis

## Treatment Pathways

What is the order of patient treatments after diagnosis?



## Treatment Pathways

Analyze how patients are treated and when they switch treatments. Compare lines of treatment for any disease.

- Understand typical care pathways
- Analyze characteristics of patients who switch treatments
- Compare outcomes across different lines of treatment

# Additional TriNetX Opportunities

- TriNetX Research
  - Collaboration between 50+ HCOs
  - Aggregate queries available through query tool
  - Limited datasets (LDS) can also be requested
  - Downloads of potentially very large LDS require IRB protocol, approval, and funding
  - Next year hope to add death data claims
- Trial Connect
  - Industry partners reachout (blinded) to potential sites using aggregate counts
  - Interested sites respond to invitation for further discussion



# National COVID Cohort Collaborative (N3C)

A national resource for shared analytics

22 April 2020



National  
COVID  
Cohort  
Collaborative

# NC3 Goals

- Establish a central registry of patients who have been tested for COVID or have a clinical diagnosis of COVID.
- Harmonize COVID clinical data extracted from federated clinical repositories associated with one of several Common Data Models (CDM) (ACT/i2b2, PCORNet, OHDSI, TriNetX)
- Provide secure analytic platform for analytics using minimum required identifiers (HIPAA limited data set, de-identified, synthetic)

Additional information at: <https://ncats.nih.gov/n3c>

National Institutes of Health x

Secure | https://allofus.nih.gov


U.S. Department of Health & Human Services National Institutes of Health

NIH National Institutes of Health  
All of Us Research Program

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## The future of health begins with **All of Us**

The *All of Us* Research Program is a historic effort to gather data from one million or more people living in the United States to accelerate research and improve health. By taking into account individual differences in lifestyle, environment, and biology, researchers will uncover paths toward delivering precision medicine.

⌵

# BU-CTSI Biomedical Informatics Core Key Personnel

Investigator	Expertise	Roles
<b>William Adams</b>	CRI, Epi, i2b2	Director, clinical and population health informatics lead, manages and promotes i2b2 and OMOP networks
<b>Eric Kolaczyk</b>	CDS,ML-PA,EDS	Computational and data science lead
<b>Marc Lenburg</b>	BI	Bioinformatics lead, CRC bioinformatics liaison
<b>Rebecca Mishuris</b>	CRI, EHR, PH	EHR innovation research, ITS-liaison, Epic SME
<b>Christopher Shanahan</b>	CRI,RD	CRITC lead, app and registry SME, addiction informatics SME
<b>Ioannis Paschalidis</b>	CDS,ML-PA	Machine learning, prediction, School of Engineering liaison
<b>Belinda Borelli</b>	MH, TBC	Mobile/Digital Health lead technology-based behavior change SME
<b>Heather Hsu</b>	HSR, PH, ACO	Population Health and ACO Analytics lead, data governance
<b>Martha Werler</b>	PHI, Epi, PH	Public Health Informatics, promotes Optum and other data
<b>Adam Gower</b>	BI	Bioinformatics analytic support, OpenSesame and GeneHive

**Expertise Legend:** ACO-Accountable Care Organization, BI-Bioinformatics, CDS-Computational and Data Sciences, CRI-Clinical Research Informatics, EHR-Electronic Health Record, Encryption and Data Security (EDS), HSR-Health Services Research, i2b2-Informatics for Integrating Biology and the Bedside, ML-PA-Machine Learning/Predictive Analytics, MH-Mobile Health, OMOP-Observational Medical Outcomes Project, PH-Population Health, RD-Registry Development, SME-subject matter expert, TBC-Technology-based Behavior Change



### Important Announcement

12 June 2020 at 3:17 PM

Visit [Back2BU](#) for the latest updates and information on BU's response to COVID-19.



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## Accelerating Discoveries Toward Better Health

The BU-CTSI is a center of expertise providing tools, services and resources to clinical investigators, maximizing the impact of discoveries & speeding the translation of research into improved patient care



### SUCCESS STORY



#### Related Research Awardees

[BU CTSI Funds 21 COVID-19 Related Research Projects in 2020](#)

### RESEARCH NAVIGATOR TEAM

## Request CTSI Services

[Learn more](#)

### ANNOUNCEMENT

## BU CTSI Receives 38.3 Million Renewal from NIH

[Learn more](#)

# CTSI Services

## Contact the CTSI

Click below to request CTSI Services in support of your research or career development, and/or to ask your question.

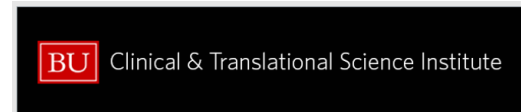
**Request CTSI Services**



**Ask a Question**



# Data for Equity (D4E)



## Contributions to Health Outcome Composite Score\*:

- 47% socio-economic factors
- 34% health behaviors
- **16% *clinical care***
- 3% physical environment

\*Hood et al / Am J Prev Med 2016;50(2):129–135



Social Determinants of Health | Healthy People 2020



# Boston Medical Center launches new plan to address racial disparities in health care

By Priyanka Dayal McCluskey Globe Staff, Updated November 16, 2021, 10:27 a.m.



Dr. Thea James, left, and Elena Mendez-Escobar are the codirectors of Boston Medical Center's new Health Equity Accelerator. SUZANNE KREITER/GLOBE STAFF

Boston Medical Center, the safety-net hospital where the majority of patients identify as people of color, is launching a broad new effort to pinpoint racial inequities in health care and work to eliminate those disparities for Black and brown people.

The initiative announced Tuesday, called the [Health Equity Accelerator](https://www.bmc.org/health-equity-accelerator), will bring together researchers and clinicians and include feedback from patients to address longstanding discrepancies in health care and outcomes.

## The Health Equity Accelerator at BMC

Transform healthcare to deliver health justice and well being

Clinical care

Research & education

Community & SDoH

Policy and advocacy

Health inequity areas



Maternal and child health



Infectious diseases



Behavioral health



Chronic conditions



Oncology & ESRD

[www.bmc.org/health-equity-accelerator](https://www.bmc.org/health-equity-accelerator)

# OHDSI/OMOP Common Data Model\*

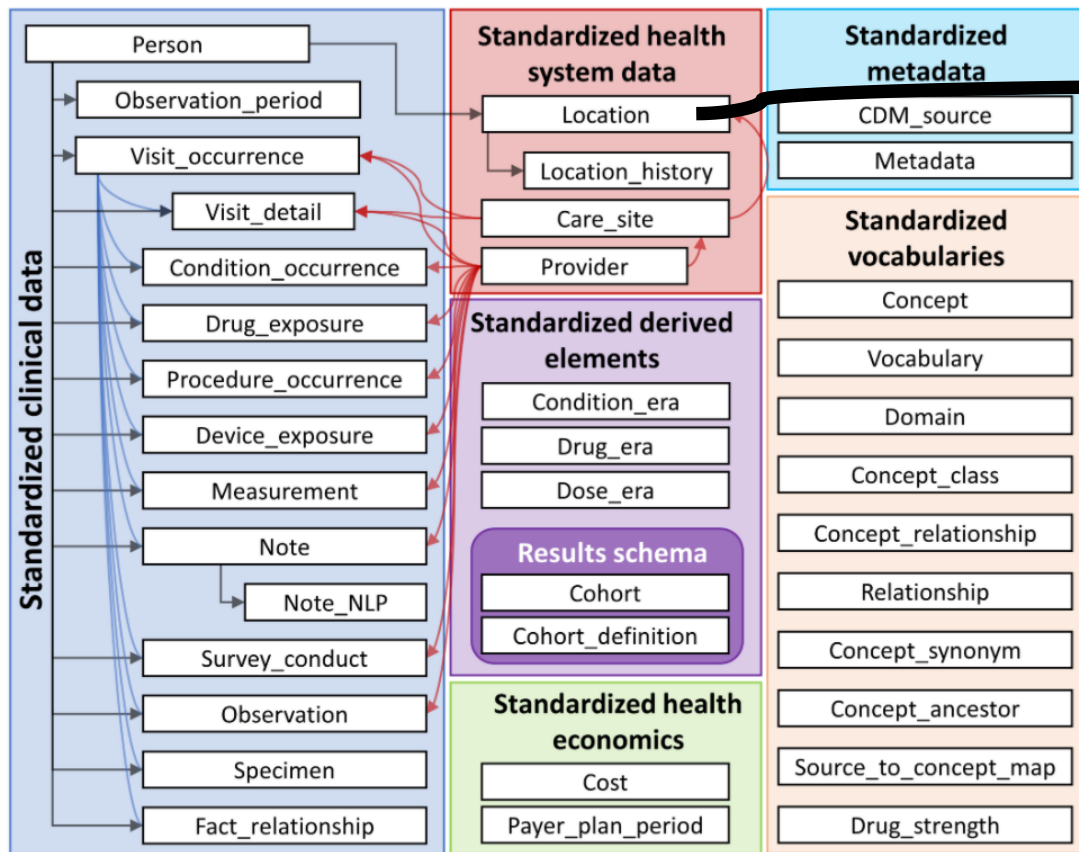
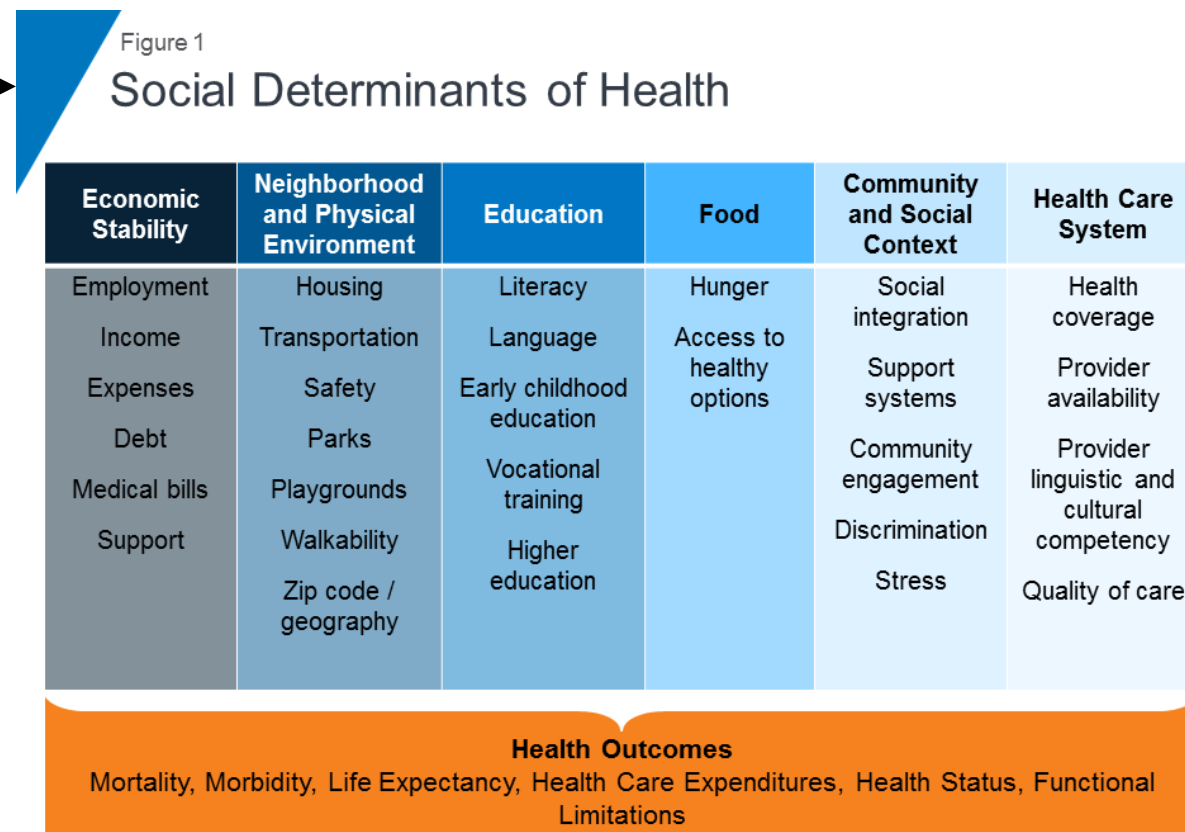


Figure 4.1: Overview of all tables in the CDM version 6.0. Note that not all relationships between tables are shown.



\*Used by N3C, AllofUs, many other academic institutions



# OHDSI

OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS

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## Welcome to OHDSI!

The Observational Health Data Sciences and Informatics (or OHDSI, pronounced "Odyssey") program is a multi-stakeholder, interdisciplinary collaborative to bring out the value of health data through large-scale analytics. All our solutions are open-source.

OHDSI has established an international network of researchers and observational health databases with a central coordinating center housed at Columbia University.

Read more [about us](#), about our [goals](#), and how you can [help support the OHDSI community](#).

## 2020 OHDSI Symposium

Our 2020 OHDSI Global Symposium brought together a global research community for 18 hours of open science, international collaboration and community fun. The day included research presentations from community members, panels that brought together leaders from major healthcare organizations, as well as network sessions, the annual collaborator showcase, and plenty more. Check it all out at the link below.

[2020 OHDSI Global Symposium](#)

## OHDSI Work Around COVID-19

# Data for Equity (D4E) Platform - 2022

- 20-year integrated clinical dataset
  - CHCs and BMC
- Rich location-based data
- Common data governance
- Common data model (OMOP CDM)
- Shared software and analytic code
- Open-source learning community (OHDSI)
- De-identified population level research
  - HSR, CER, ML, AI, QI



Clinical & Translational Science Institute

Thank you for joining us today!

For additional questions please contact:

Nicholas Trombley ([nst5775@bu.edu](mailto:nst5775@bu.edu))

Bill Adams ([badams@bu.edu](mailto:badams@bu.edu))

(or visit the BU-CTSI website and put in a request)

