



T1DX-QI Center

Data Share Journey

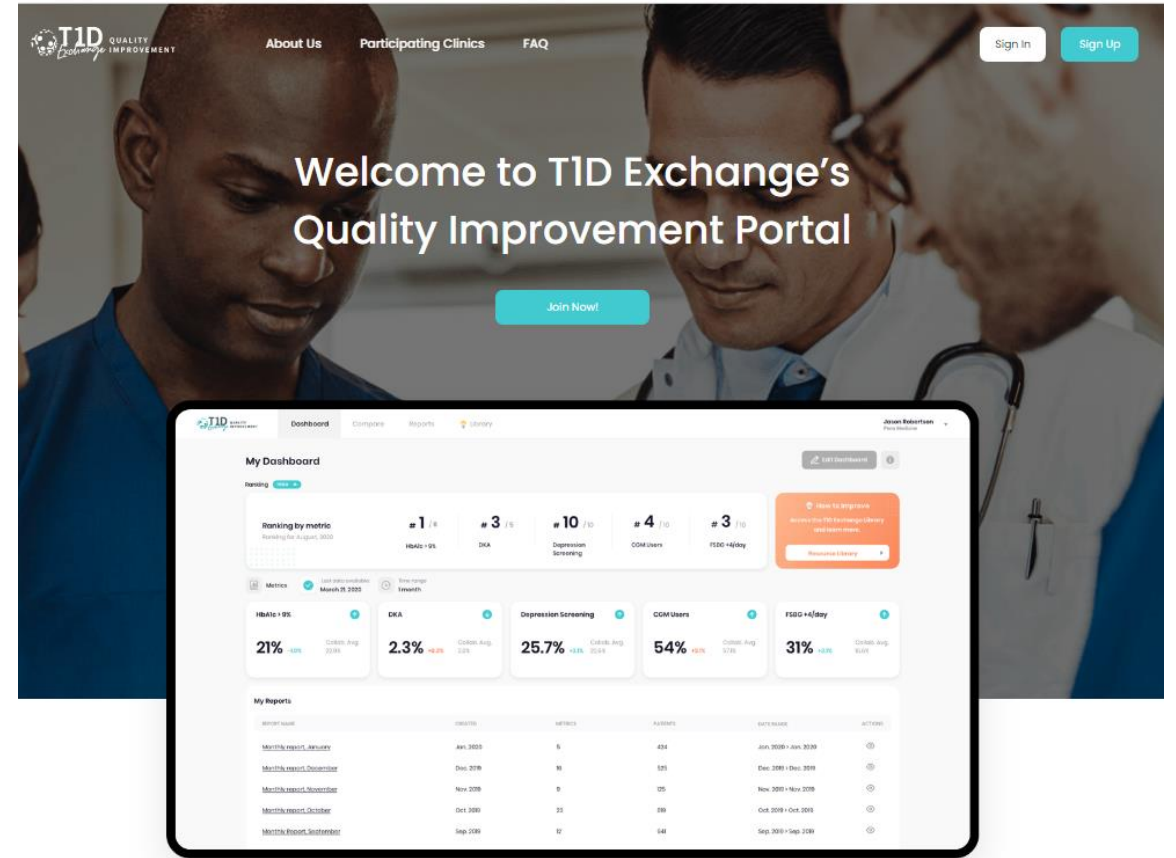
# Welcome!

T1D Exchange Quality Improvement Collaborative (T1DX-QI) is a type 1 diabetes (T1D) learning health system (LHS) of over 55 pediatric and adult endocrinology centers across the US.

**T1DX-QI Center'** share their EMR data with T1DX-QI to generate real-world evidence and demonstrate improved clinical outcomes using QI methods.

This presentation describes the integration of the center' real-world data into national learning health system: T1DX-QI portal. This presentation is limited to the data journey to the portal and does not present how it is used to drive collaborative change.

With considerable variability in documentation practices, especially in collecting diabetes-related data variables, the T1DX-QI Data Science Committee have developed Data Specification to enable data sharing, analysis and research.



# Data Specification

Specifications maintained by the T1DX-QI Data Science Committee, which is made up of selected principal investigators and data analysts.

These specifications consist of over 120 unique variables across seven data category -

- 1) Patients,
- 2) Providers,
- 3) Encounters,
- 4) Observations,
- 5) Conditions,
- 6) Medications, and
- 7) Diabetes.

NOTE – Limited data set from Center's EMR database(s) is shared with T1DX-QI and contains de-identified patient-level information. Under PHI, the requested collection is restricted to only dates and 5-digit zip codes.

1	Core Spec Change			
2	Version	Date	Description/Comments	Reason
3	0.3.0	2022-09-12	patient's: education_level added to variables along with accepted coding values non-binary added as new accepted value in gender	Capture education level of patient/Parents or Legal guardian of patient expand accepted values for gender race_1, race_2 as new columns will help capture multiple race categories for patient's
4			Observations: 93030-5 SDOH question for transportation 93033-9 SDOH question for Housing 97063-2 Family History of Diabetes	Capture SDOH response for transportation, Housing and Family History of Diabetes
5	0.2.7	2021-10-05	All Sheet: Data mapping priority added to all sheets	Classify variables based on QI metrics phases and population health
6			Providers: Allowed value in other_id_type changed to only include internal id	
7			Encounters: endo_vists added to variables medication and laboratory class added to allowed values in class variable	To indicate an encounter is from the endocrine group or non-endocrine group additional class values to capture visits for medications and lab tests
8	0.2.6	2021-06-08	Medications: Below variables are added- drug_name drug_name_generic drug_class drug_sub_calss	Capture drug name, generic name, class and sub class
9			Observations: 88124-3 88122-7 88123-5 PHQ-8 patient's: Postal code- Changed from 5-10 character to 5 character	Added 3 new surveys to capture Hunger Vital signs data Added PHQ8- for depression screening

# Prerequisites

- 1. Data Use Agreement is signed between T1D Exchange and clinic/hospital
- 2. T1D Exchange's central IRB (WCG) and Non-Human Subject Research letter of determination is shared with clinic/hospital for reference
- 3. Clinic/hospital completes internal IRB process for approval according to internal policy requirements
  - a. Clinic/hospital's IRB determines the project as QI
  - b. IRB waives requirement to patient consent.
- 4. Clinic/hospital's data security/IT office shares internal security questionnaire with T1D Exchange
  - a. T1D Exchange completes questionnaire
  - b. T1DX-QI receives approval as a trusted vendor for data mapping
- 5. Data mapping and transfer protocol
  - a. Data extraction and file creation definition.
  - b. Secure FTP is established for file transfer

# Project Team

	Task	Clinic / Hospital Department	T1DX Contact
✓	Principle Investigator	Clinic / Hospital	<b>Nicole Rioles</b> Senior Director of Clinical Partnerships and Engagement <a href="mailto:nrioles@t1dexchange.org">nrioles@t1dexchange.org</a>
✓	Collaboration Agreement	Legal	<b>Nicole Rioles</b> Senior Director of Clinical Partnerships and Engagement <a href="mailto:nrioles@t1dexchange.org">nrioles@t1dexchange.org</a>
✓	IRB Approval	Clinic / Hospital	<b>Nicole Rioles</b> Senior Director of Clinical Partnerships and Engagement <a href="mailto:nrioles@t1dexchange.org">nrioles@t1dexchange.org</a>
✓	IT / Data Transport Security Review	IT and Data Security	<b>Sukhtej Dhingra</b> Senior Director, Product Development & Data <a href="mailto:sdhingra@t1dexchange.org">sdhingra@t1dexchange.org</a>
✓	Clinic/Hospital – EMR Data Mapping	EMR Data Support	<b>Anton Wirsch</b> Lead, Data Management <a href="mailto:awirsch@t1dexchange.org">awirsch@t1dexchange.org</a>
✓	Billing / Accounting	Accounting	<b>Nicole Rioles</b> Senior Director of Clinical Partnerships and Engagement <a href="mailto:nrioles@t1dexchange.org">nrioles@t1dexchange.org</a>
✓	T1DX-QI Portal' Product Manager	Clinic / Hospital	<b>Ann Mungmode</b> Senior Product Manager <a href="mailto:amungmode@t1dexchange.org">amungmode@t1dexchange.org</a>

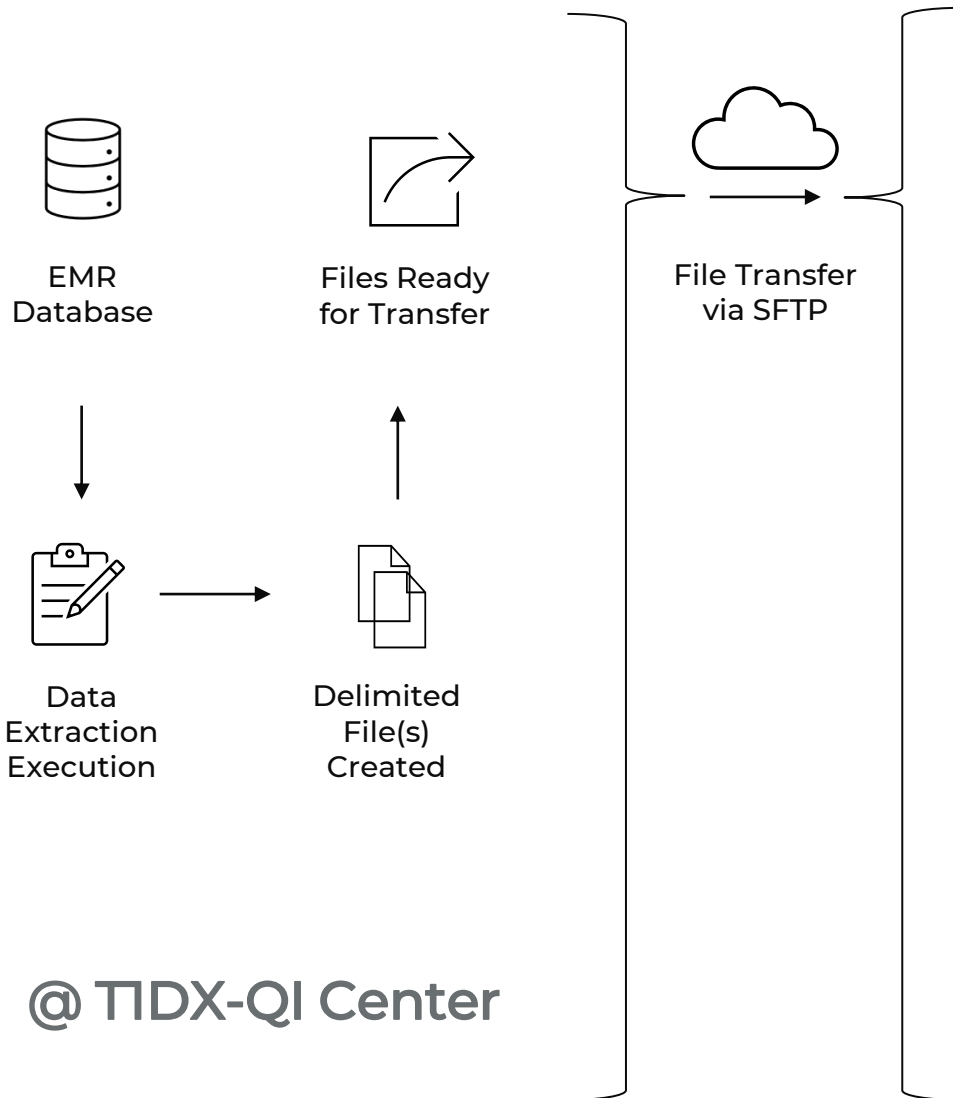
# Integration Project



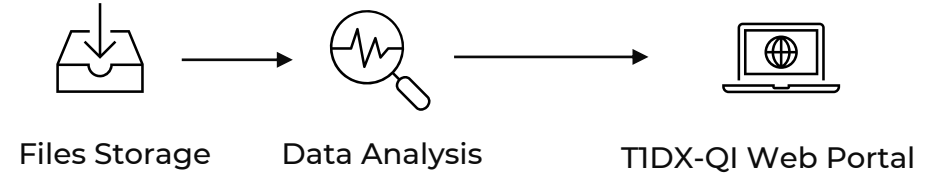
## Cross-functional Team –

1. TIDX' Integration Group
2. Center' EMR Data Group
3. Consultants (as required)
4. Center' IT/IS Group (as required)

# Data Flow & Security



@ TIDX-QI Center



LOCATION	Amazon S3	Amazon Athena / Tableau Server	Amazon EC2 / PostgreSQL	
ENCRYPTION	S3 managed keys (SSE-S3)	S3 managed keys (SSE-S3)	256-bit AES-GCM key	
AUTHENTICATION	SSH Keys	MFA (Azure AD) & VPN/VDI	JWT / MFA	
DATA FORMAT	Delimited File(s)	Delimited File(s) / PostgreSQL	Aggregated Data	TIDX-QI Center Data
USER(S)	Data Integration Team	Data Research Team Data Support Team	Product Team All TIDX-QI Centers Stakeholders	Product Team Only TIDX-QI Center Stakeholders

@ TIDX - QI



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