DATA FROM TRINETX

IDENTIFIED VERSUS DE-IDENTIFIED

Patient data provided to TriNetX by institutions have been de-identified before being sent to TNX, or represents a Limited Data Set.

De-identified

Patient data in TNX from any network is considered de-identified as long as it stays within the platform for review or analyses.

Any dataset you request in TNX from the larger Research or Linked Networks is also considered de-identified data.

Some TNX precautions to prevent identifying patients are:

Sensitive Codes. Some query terms are considered too identifiable, and are restricted for use in TNX analytics. Examples include certain BMIs or Assault.

Patient Counts Rounding. When you click to Count Patients for your query within the Stony Brook network, the number will always be divisible by 10. This safeguards a patient having a rare condition making them easily identifiable.
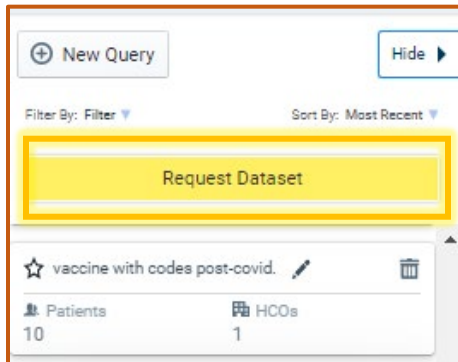
Limited Dataset

Any dataset you request in TNX from the Stony Brook University Network will be a Limited Data Set. This type of dataset includes *some* of the 18 Protected Health Information unique identifiers. In this case, our Stony Brook datasets from TriNetX include true dates of services and diagnoses. For that reason, you will need IRB exempt designation for your protocol and you will need to submit the Limited Data Set Form with your IRB.

Identified

Your Stony Brook University Network cohort patients CAN be identified with proper IRB approval. Each patient in the TNX platform has a synthetic identifier, and an Honest Broker can re-identify that patient cohort on your behalf.

GETTING DATASETS

Datasets can be generated for download from the platform by Stony Brook and TNX support. If you are interested in getting data for cohorts, click "Request Dataset" in your study and select the relevant study query. An email will be sent to SBM internal TNX support. You can request datasets for more than one query, but be aware that selecting more than one cohort for a dataset will merge those cohorts within that dataset. To have a separate dataset per query, request each cohort dataset individually.

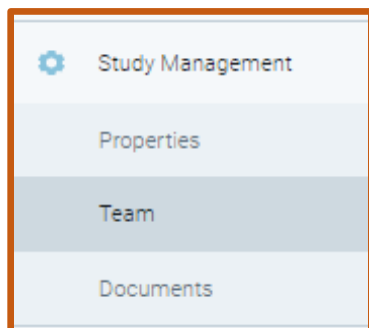Be sure to <u>name your study and the queries</u> for the datasets you request.

Stony Brook-only datasets will be processed by SBM internal TNX support, and can be received typically within 3 days. This process includes a review of your IRB to confirm that the Limited Data Set Form is submitted and that your defined cohort is reflected in your protocol.

Research or Linked Network Datasets must be requested from TNX by SBM internal TNX support, and will take at least 2 weeks to receive. These dataset requests do not require and IRB, as they are de-identified.
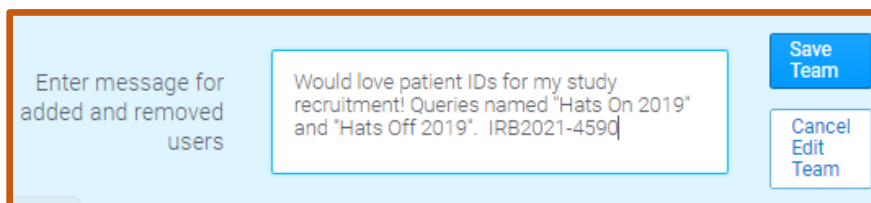
GETTING IDENTIFIED PATIENTS

Patients in your cohort can be identified by SBM internal TNX support (Honest Broker) with the proper IRB approvals. Your query must reflect the meaning of your inclusion and exclusion criteria approved by the IRB.

You might want to identify patients for retrospective or prospective chart reviews, reviews preparatory to research, or subject recruitment. Each patient in the platform has a synthetic identifier that can be re-matched to a patient at Stony Brook.

Share your study with Melanie Keister by adding her to your Study Team, and write within the provided message area that you are requesting Patient IDs.
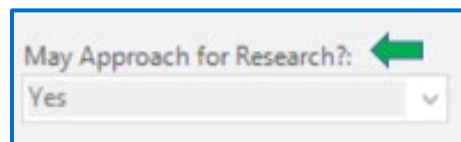
IRB Considerations

Before requesting Patient IDs, be sure you have the approval to do so. Visit www.stonybrookmedicine.edu/trinetx for SBU IRB protocol and form templates, such as for Retrospective Chart Reviews, Limited Dataset Exempt Protocols, and the HIPAA Waiver of Authorization for the use of TNX for recruitment.

DATA FROM TRINETX

The criteria used by the Honest Broker in choosing which patients to identify for recruitment are:

A.   Patients with a "Yes" answer logged in their EMR to being contacted about research may be identified to a Study Team Member from any department, regardless of that patient's Treatment provider.

B.   Patients with a "No" answer logged in their EMR to being contacted about research may only be identified to their treatment provider about a study. Study Team may be given the name of the patient's treatment provider only.

C.   Patients with an "Unable to Obtain" or "Blank" answer may be identified to:

- the investigator's department IF the investigator sees patients in the same building and practice as patient's treatment provider, and it is reasonable to assume the investigator would care for patient in that provider's absence.

  OR

- another department in which the patient has been seen, if that other department has agreed to assist in recruitment for the Study Team. Study Team may be given the name of the patient's treatment provider only.

STONY BROOK TRINETX: WWW.STONYBROOKMEDICINE.EDU/TRINETX

Visit our internal site for more supporting resources and information about the platform.

https://www.stonybrookmedicine.edu/trinetx

The documentation section houses such things as:

- TNX Sample Data File
- TNX Data Dictionaries
- Sensitive terms restricted to protect PHI in datasets
- Statement of Liability Data Use Agreement
- SBM Template for IRB HIPAA Waiver for Subject Recruitment
- Limited Dataset Exempt Protocol Template
- Code Lookups for ICD, CPT, and LOINC