

## IDENTIFIED VERSUS DE-IDENTIFIED

### De-identified

All patient data provided to TriNetX by Stony Brook institutions has been de-identified before being sent to TNX. Other institutions' data is also de-identified, or represents a Limited Data Set.

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 patients having rare conditions making them easily identifiable.

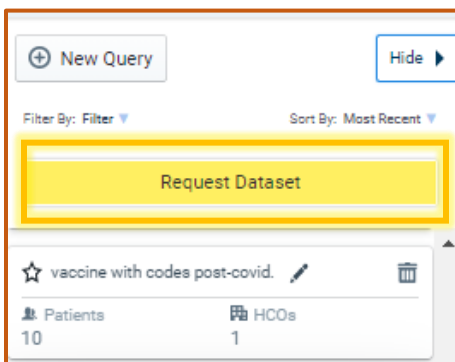
Any dataset you request in TNX from either Stony Brook or the larger Research Network will be de-identified data.

### Identified

Your cohort's 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. However, you will not be able to match up those patient identifiers with your de-identified dataset.

## GETTING DATASETS

De-identified datasets can be exported out of the platform by Stony Brook TNX support. If you are interested in getting data for cohorts, click "Request Dataset" in the relevant study query, and an email will be sent to SBM internal TNX support. You can request datasets for more than one query.



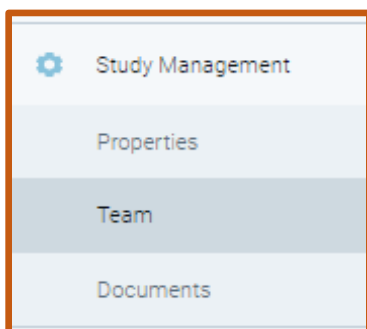
Be sure to name your study and the queries for the datasets you request. Stony Brook-only data can be retrieved by SBM internal TNX support, and can be received typically within 3 days. Datasets from the larger Research Network must be requested from TNX by SBM internal TNX support, and will take at least one week to receive.

## GETTING IDENTIFIED PATIENTS

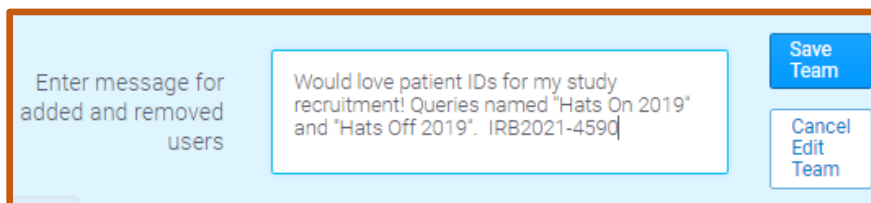
Patients in your cohort can be identified by SBM internal TNX support (Honest Broker) with the proper IRB approvals. Your query must reflect the meaning of the inclusion and exclusion criteria approved by the IRB.

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.

Remember that we cannot then link the patient identifications to your de-identified dataset. However, with IRB approval, you can use those identified patient MRNs to request datasets from SBM IT or do chart reviews.



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.



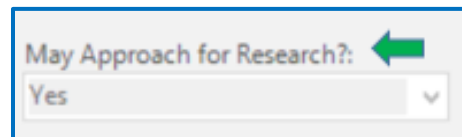
### IRB Considerations

Before requesting Patient IDs, be sure you have the approval to do so – such as an IRB-approved HIPAA Preparatory to Research Form or HIPAA Waiver of Authorization for your study.

**Note:** Our Stony Brook TriNetX internal website has the approved template HIPAA Waiver of Authorization for the use of TNX for recruitment in the documentation section.

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

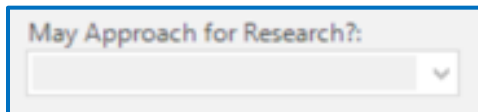
A. Patients with a “Yes” answer logged in their EMR to being contacted about research may be identified to a Study Team Member from any department, regardless of that patient’s Treatment provider.



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:

A screenshot of a dropdown menu with the text "May Approach for Research?" above it. The dropdown is currently closed, showing a small downward arrow on the right side.

- the Study Team’s department IF the patient has been seen by anyone in that department  
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](http://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

