

Learning Objectives

Compare the differences and similarities, along with the strengths and weaknesses, of TriNetX and Epic SlicerDicer.

Create basic queries based on study protocols in TriNetX and Epic SlicerDicer to evaluate patient populations, identify cohorts, data trends, and assess key variables.

Navigate the key features of TriNetX and Epic SlicerDicer to analyze query results and access.

Understand the guidelines for accessing patient identifiable information though TriNetX and Epic SlicerDicer.

Unlock the Power of Data: Discover Why TriNetX and SlicerDicer Are Essential for Smarter Research

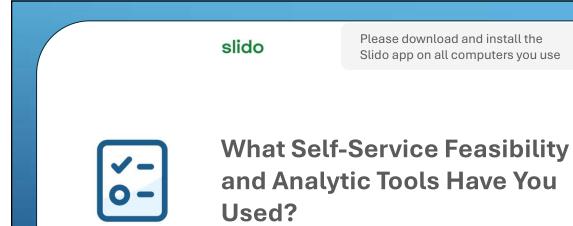
- Utilize for feasibility analysis, cohort identification and analytics.
- Develop queries for feasibility counts with de-identified data, such as demographics, location, and other variables.
- Patient identification for recruitment, following IRB approval and institution-specific guidelines.
- Conduct analytics, compare cohorts, and evaluate outcomes.

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Disclaimer: Data-Driven Insights

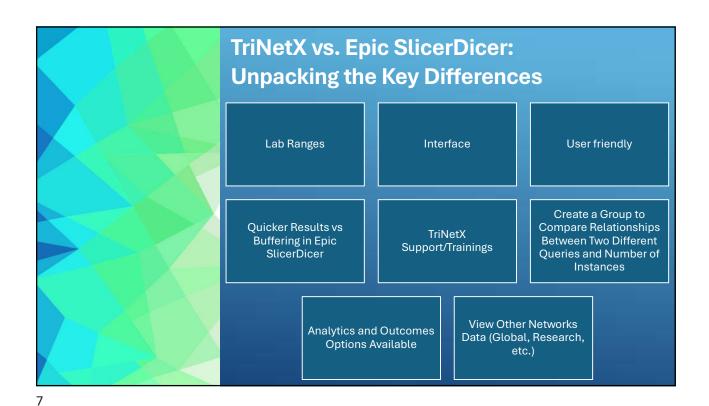
Access will vary across institutions and is subject to administrative approval or permissions.



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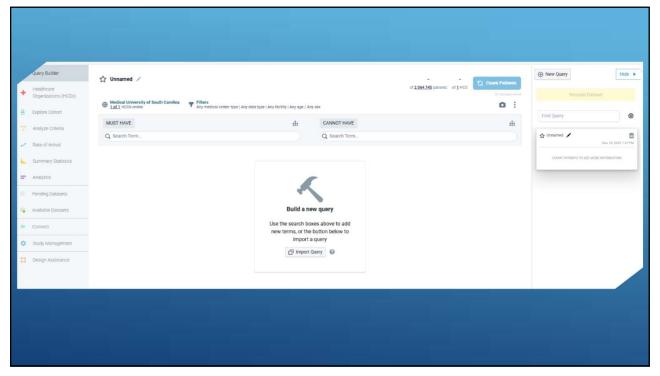


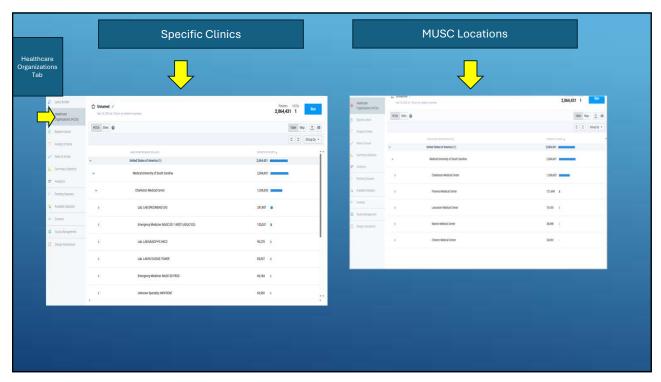
KC0 • De-identified data only. • IRB approval and data analyst (honest broker) needed to provide identifiable TriNetX: information. **Uncovering the** • Doesn't allow filtering of provider or Hidden location. Weaknesses • Doesn't have the option of "research opt out". • Research Opt Out allows data to filter out any patients that have opted out of research calls.

KC0 See design option on next slide.

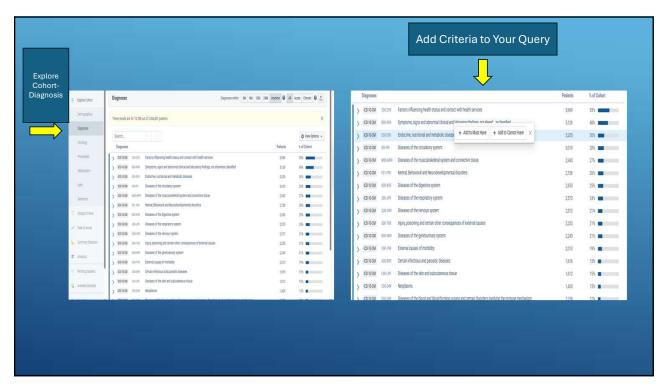
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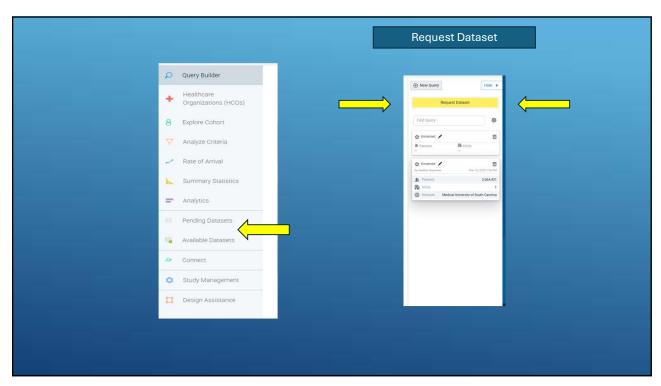


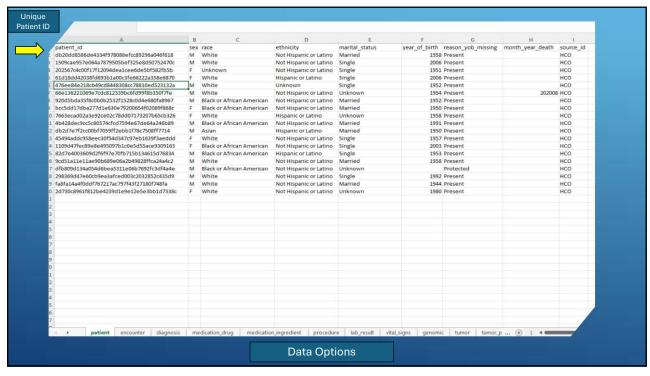


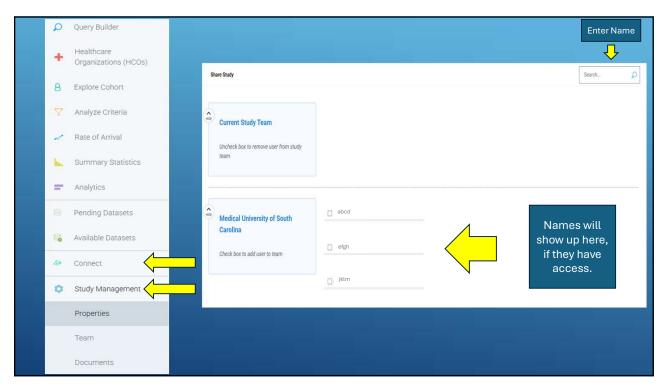


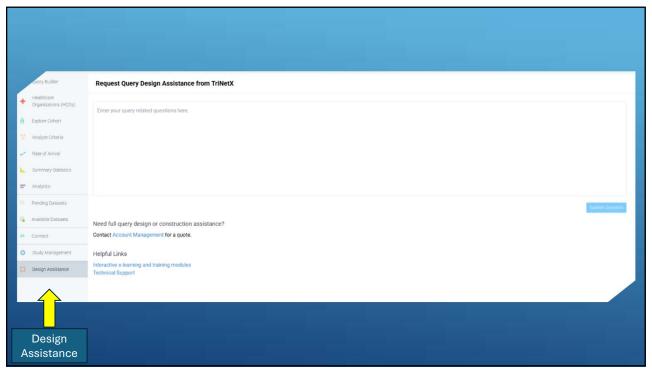


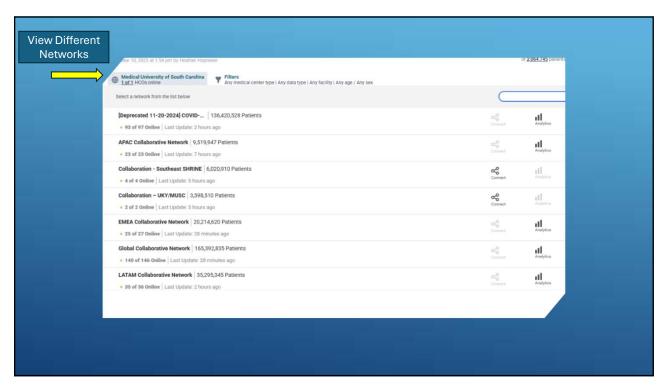


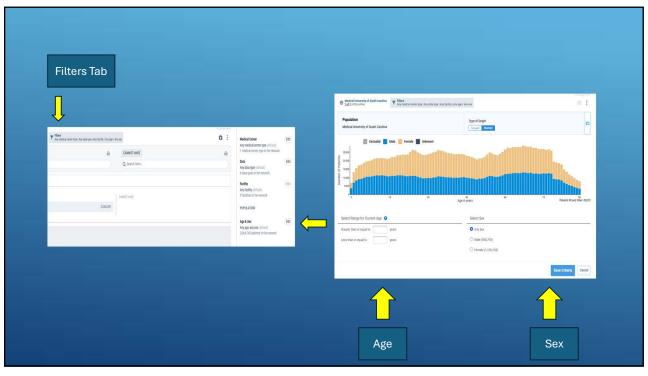


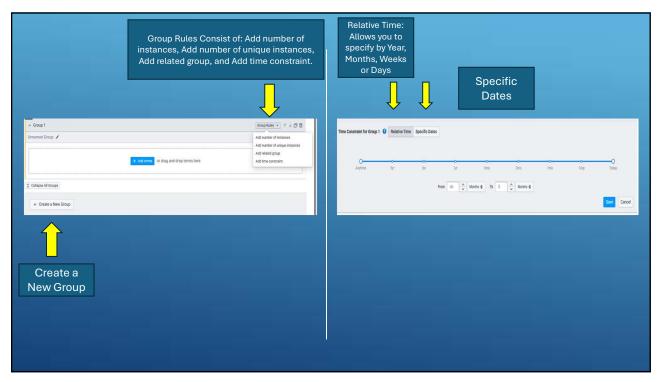


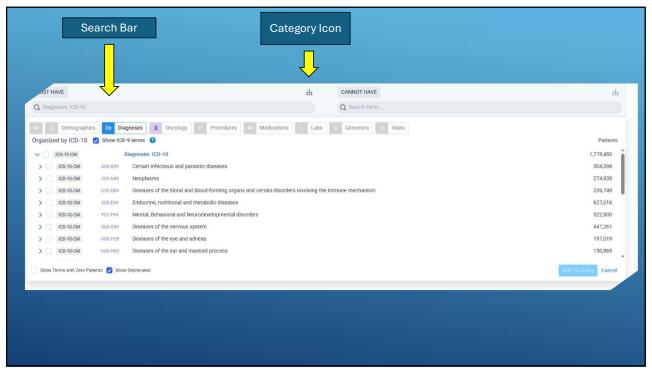


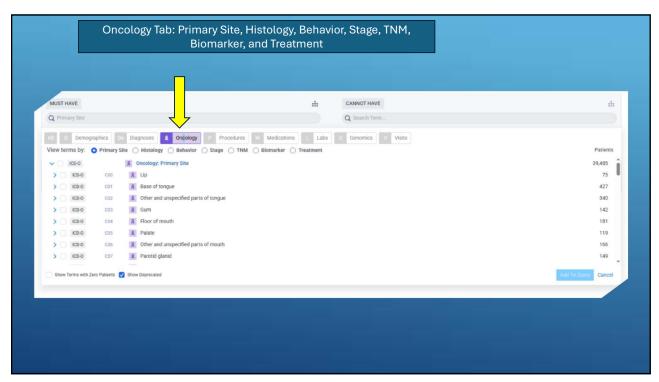


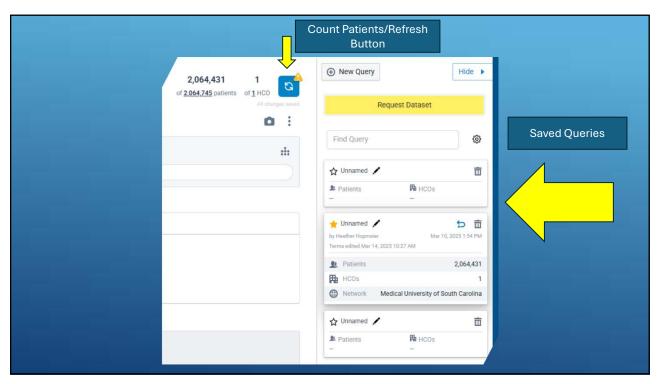












slido

Please download and install the Slido app on all computers you use





Requesting a Dataset (bright yellow button) will provide you with an identifiable patient report.

True/False

(i) Start presenting to display the poll results on this slide.

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Where would you find the clinic locations of where patients have been seen on the left-hand side bar?

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Out of the options below, what is TriNetX not able to use in the query as a filter?

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TriNetX does NOT allow Lab Ranges to be entered into the query? True/False

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How do you save a query in TriNetX?

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Inclusion Criteria

- 1. Ability and willingness to provide written informed consent and to comply with the study procedures.
- 2. Fluency in the language of the investigator, study staff and the informed consent.
- 3. Age 18-75 years.
- 4. Diagnosis (including imaging either prior to study entry or during screening) of primary TN as per the ICHD3 criteria confirmed by the study neurologist or a healthcare professional with expertise in TN:
 - Classical TN, purely paroxysmal
 - Classical TN with concomitant continuous pain
 - Idiopathic TN, purely paroxysmal
 - Idiopathic TN with concomitant continuous pain
- 5. Experience pain due to TN and at baseline, experience at least 3 paroxysms per day of at least intensity of 4 or more on PI-NRS during the last 7 days
- 6. Female patients are either sterile or menopausal. For female patients with childbearing potential:
 - A female patient is eligible to participate if she is not pregnant or breastfeeding and is willing to use an acceptable contraceptive method
 as described in during the study intervention period (at a minimum until 28 days after the last dose of study intervention).
 - WOCBP must have a negative highly sensitive pregnancy test (urine or serum as required by local regulations) within 28 days before the first dose of study intervention.

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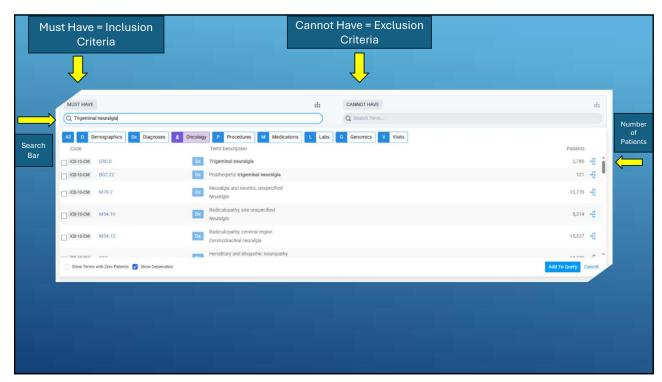
Exclusion Criteria

- Patients who express suicidal ideation or have recent history of suicidal behavior and who, in the opinion of the investigator, are at risk of harming themselves.
- Current or prior history of diagnosis of schizophrenia or chronic psychotic disorders. Patients with mood or anxiety disorders or TN-related depressive symptoms are permitted.
- History of DSM-5-defined substance dependence (Diagnostic and Statistical Manual for Mental Disorders, 5th edition) and/or substance abuse in the last six months (180 days), except for nicotine.
- Patient not willing to discontinue their current TN analgesic medication.
- Use of opioids, except for pain control on a prn basis as long as it does not exceed 2 days per week.
- Known allergic reaction to the investigational drug or one of its components.
- 7. Patients with secondary TN as per the ICHD3 criteria.

- Medication history:
- Previous treatment with basimglurant, except with the prior agreement of the medical monitor.
- Treatment with antipsychotics within six months (180 days) of screening.
- Any investigational drug within 90 days prior to initiation of study drug.

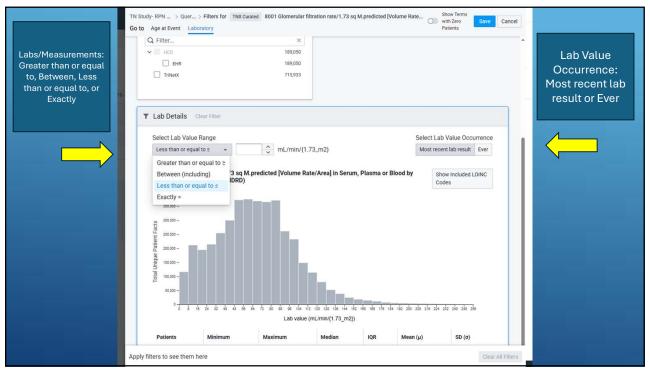
Medical status:

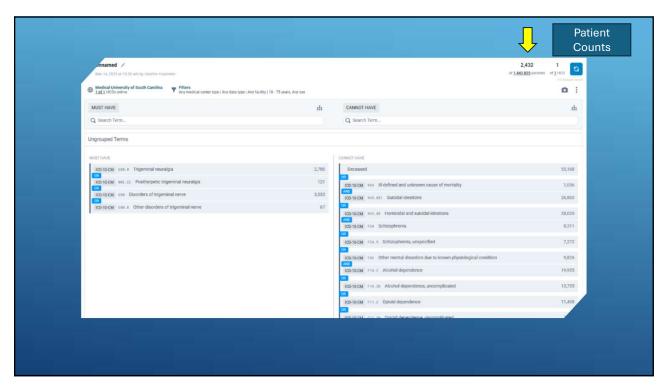
- Evidence of clinically significant, uncontrolled, unstable medical conditions or recently diagnosed cardiovascular disease, such as ischemic heart disease.
- Subject has a history of gastric, or small intestinal surgery, including gastric bypass.
- Body mass index > 39 kg/m2
- Patients with severely impaired hepatic function, ie, Child-Pugh score C.
- Patients with severe renal impairment, ie, eGFR or creatinine clearance lower than 30 mL/min.

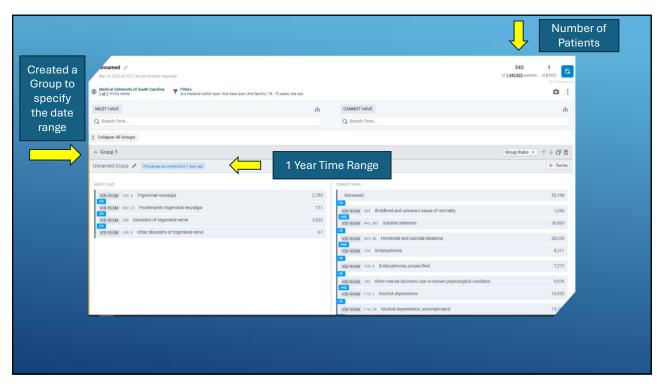








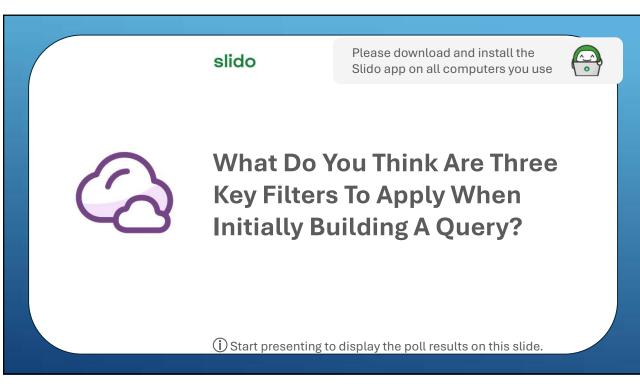




Pro Tips & Tricks for TriNetX: Unlock Your Full Potential!

- Any time you get the number "10" this can mean any number from 1-10.
- Keep a close eye on the "AND" and "OR" options when building your query. This can make a huge difference in your patient counts!
- IRB approval is needed to collect identified information. It is not required when using it for feasibility purposes to look at de-identified
- Cite TriNetX in your project if utilized.
- Best used with Google Chrome.

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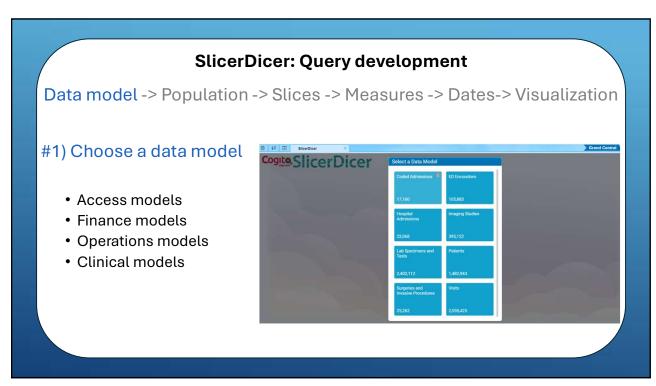


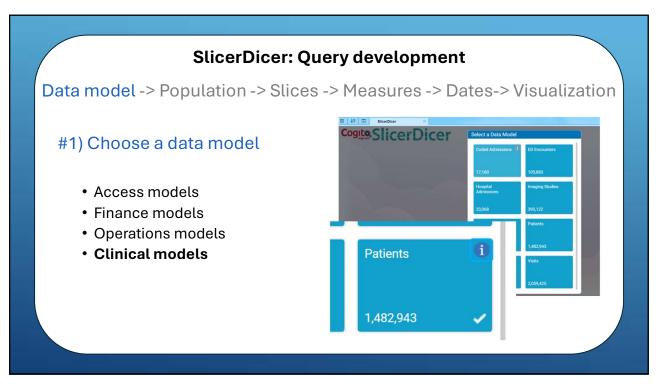
Self-service reporting from within EPIC hyperspace

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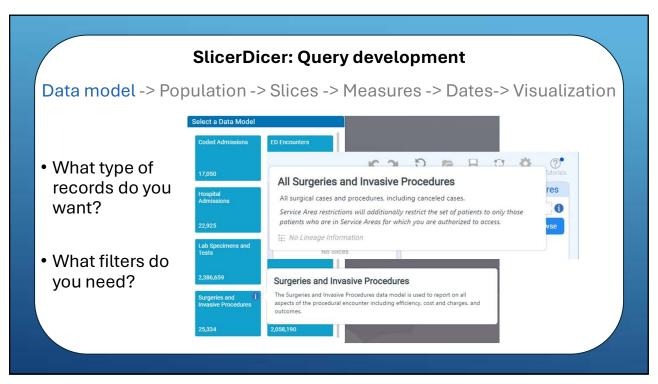
SlicerDicer: Data source

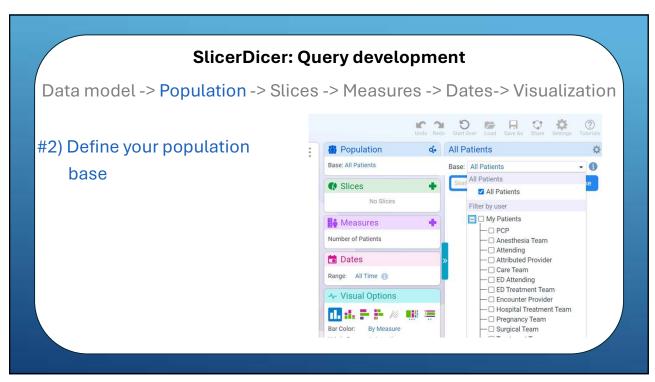
- Hospitals and healthcare organizations with EPIC
- Caboodle database (dimensional data model, updated once daily)
- Choice of record level: e.g. procedures, encounters, patients
- Self-service tool
- ✓ Aggregate data
- ✓ Individually-identifiable data (regulatory approvals required)

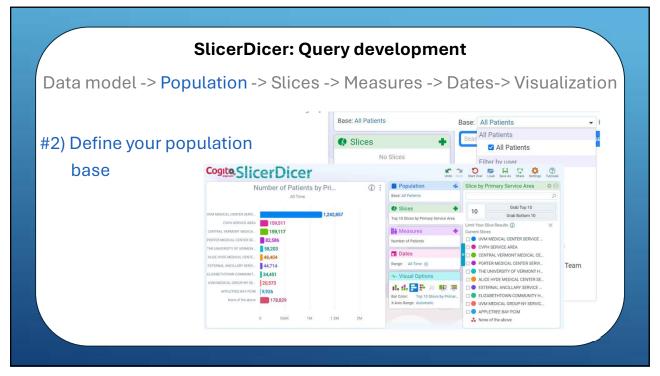


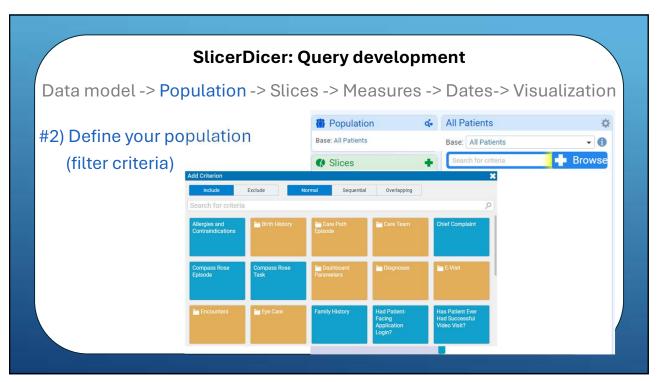




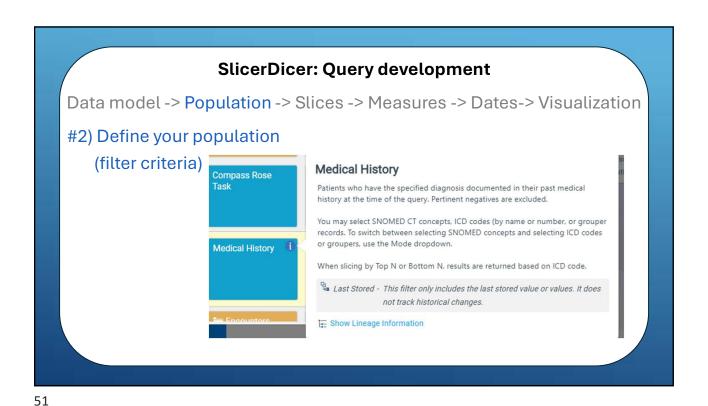






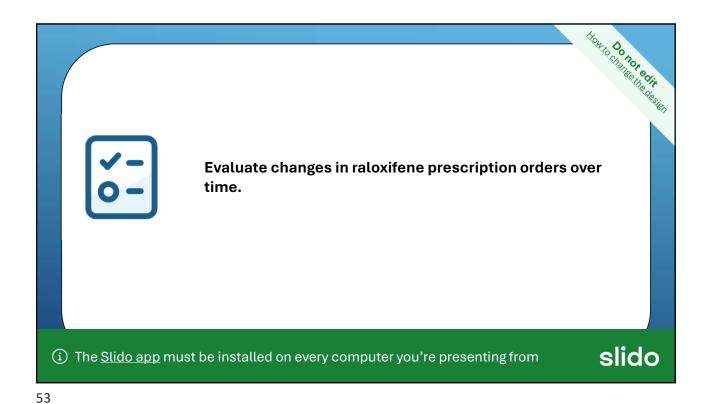


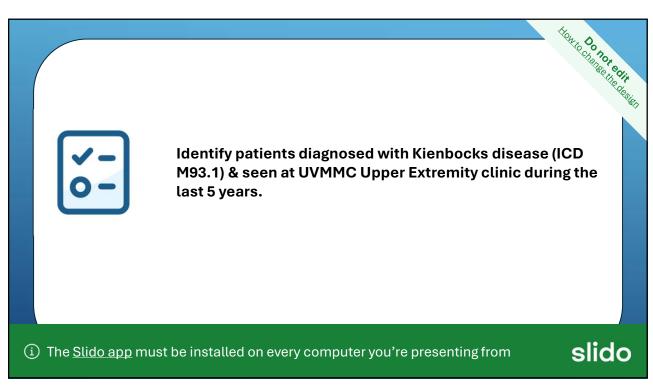


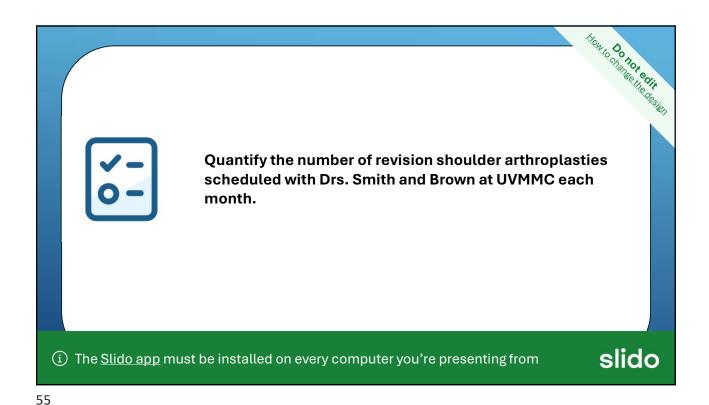


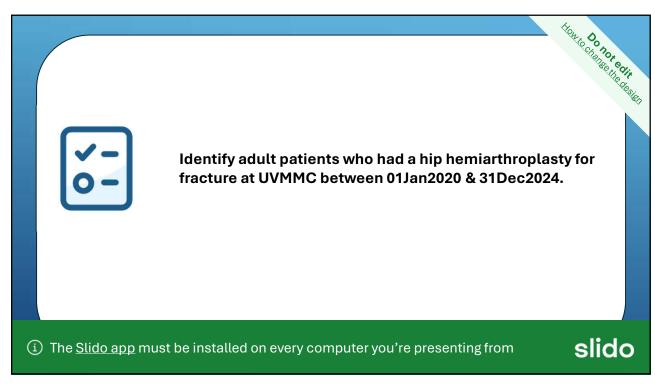
Evaluate changes in referrals to genetic counseling between 01Jan2020 & 31Dec2024.

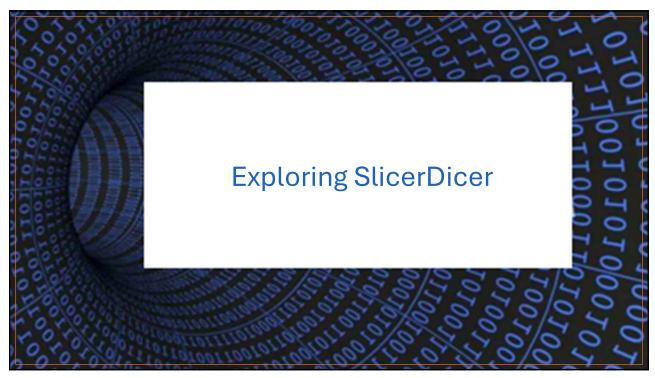
The Slido app must be installed on every computer you're presenting from

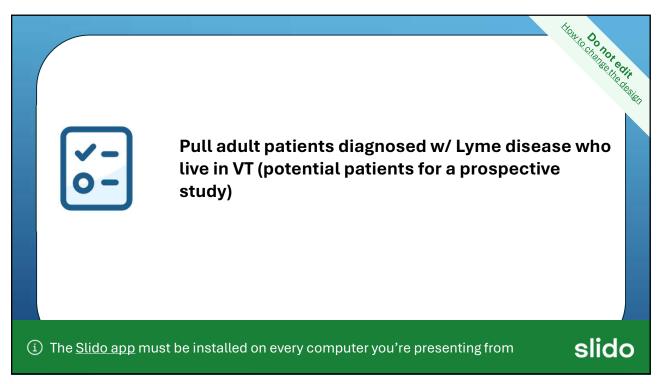


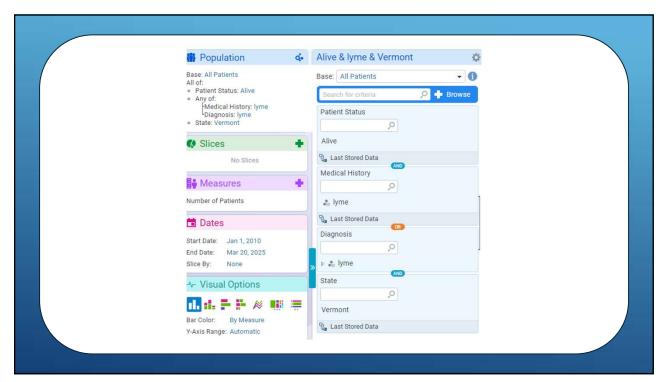


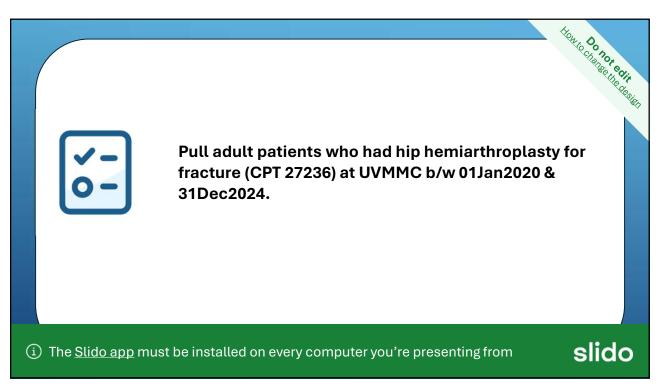


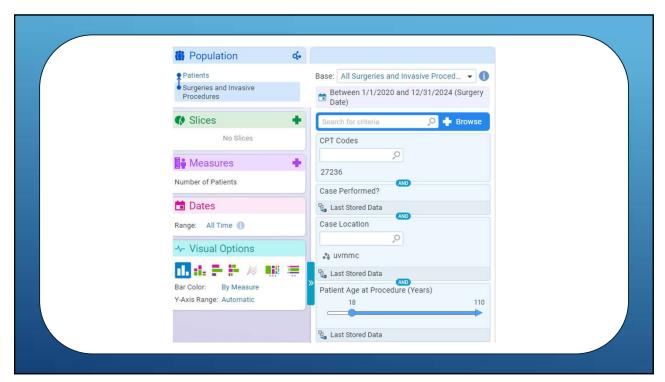


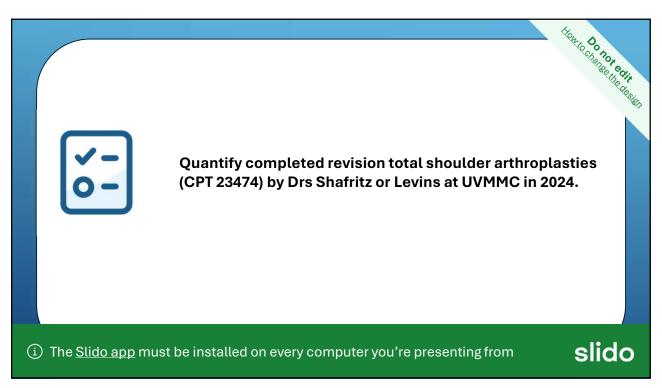


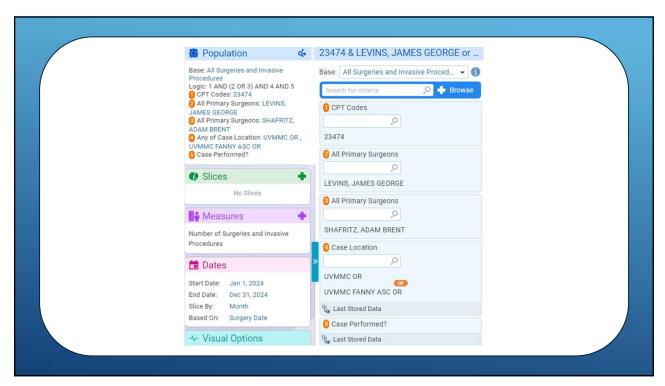


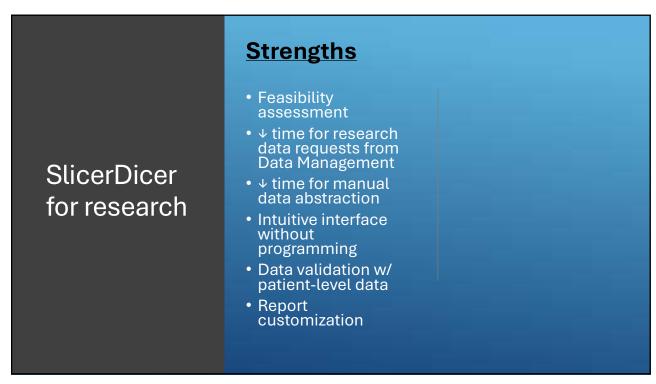












SlicerDicer for research

Strengths

- Feasibility assessment
- ↓ time for research data requests from Data Management
- ↓ time for manual data abstraction
- Intuitive interface without programming
- Data validation w/ patient-level data
- Report customization

Limitations

- Scope of data (local only)
- Scope of data (discrete data only)
- Quality of data (precision, accuracy, completion)
- Learning curve
- Statistical tools
- Line-level verification requirements
- Performance issues, depending on volume of data
- Access control

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SlicerDicer & TriNetX: Regulatory considerations

- Aggregate vs. individually-identifiable data
- HIPAA: regulates access, use, & disclosure of PHI from covered entities
- HIPAA Pathways for research:
 - ➤ Signed authorization
 - ➤ Waiver (or partial waiver) of HIPAA Authorization
 - Preparatory to research
 - > Research on decedents
 - Limited dataset obtained via third party (signed data use agreement)
 - ➤ De-identified dataset obtained via third party

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- See institutional guidance on documentation / agreements / disclosures



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Next steps:

How can you use these tools in your research studies?

