NAEC Surgical Data Collection Program

Frequently Asked Questions

This document is a resource to help center staff navigate the Surgery Data Collection Form and understand the program. Questions are organized in the order you will encounter them during data entry. ***This was most recently updated on September 15, 2026.*** *If you have additional questions and cannot find the answer here, please contact NAEC at info@naec-epilepsy.org.*

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1. Program Overview

Q: What is the NAEC Surgical Data Collection Program?

A: The Surgical Data Collection Program (Surgical Program) is a new data collection initiative in which NAEC-accredited epilepsy centers submit de-identified data on individual surgical procedures they perform. The program builds on a successful pilot conducted with 15 centers from 2022 to 2025. The goal is to gather and aggregate data on surgical epilepsy treatment methods and outcomes to strengthen NAEC's accreditation program and improve processes and patient care. NAEC will share aggregate data with member centers, enabling benchmarking and comparison against the broader group.

Q: Which centers are required to participate?

A: All Level 4 NAEC-accredited centers are required to submit data on all surgeries performed in 2026, with the exception of VNS battery replacements. Level 3 centers that perform VNS or other surgeries will not be included in the program in 2026.

Q: What is the deadline for submitting 2026 surgery data? What is the starting point for surgical cases?

A: The deadline for submitting data on all surgeries performed in 2026 is January 31, 2027. Although we are launching the program in May, NAEC expects centers to submit data for all surgeries going back to January 1, 2026. NAEC strongly encourages centers to begin entering data as surgeries occur throughout 2026 rather than waiting until the deadline.

Q: What happens if our center does not submit data?

A: Level 4 centers that do not upload any data will be conditionally accredited in 2027. Centers that are unable to upload all of their surgical data for 2026 will need to submit their aggregate surgical data in their Center Annual Report for 2027. Participation in the surgical data collection program will not impact Level 3 center accreditation in 2027.

Q: Is this in addition to the existing Center Annual Report?

A: Yes. The Surgical Program is a new requirement separate from the Center Annual Report (CAR). All centers will still complete the CAR though centers that submit all of their surgical cases into the Surgical Program will be excused from completing the aggregate surgical data chart in the form. However, centers that are unable to submit complete data through the portal will be required to submit aggregate surgical data via the CAR instead.

Q: What will NAEC do with the data?

A: NAEC will use the de-identified data to: support, evaluate, and improve its accreditation process; provide confidential benchmarking feedback to participating centers; and support research and data analytics on surgical outcomes and epilepsy care. NAEC follows its existing Data and Survey Policy, which precludes sharing data that is center-specific or that could identify a contributing center. A Surgical Data Governance Committee is being established to further define rules and processes for data use.

Q: Will centers be able to see how they compare to other centers?

A: Yes. Centers will have access to their own data and will be able to benchmark against aggregate data from the broader group. Benchmarking data is de-identified with respect to both patients and contributing centers, so individual center identities will not be revealed in shared comparisons.

Q: Does the Surgical Program replace having to upload de-identified surgical reports during the full accreditation process?

A: No, centers will still be required to upload de-identified surgical reports if they are going through the full accreditation process in 2027 (that begins in fall 2026). In future years, NAEC may stop requiring centers to upload de-identified surgical reports. NAEC will notify members if this process changes.

Q: Do de-identified surgical reports need to be uploaded to the Surgical Data Collection Form?

A: No, centers do not need to upload de-identified reports with the Surgical Data Collection Form. Only the form itself must be added.

Q: What documents are best to share with my institution to get their approval to participate?

A: The program overview document has a high-level explanation for the goals of the program, how data will be used, etc. You may also wish to share the HIPAA de-identification certification, letter regarding legal agreements, and the NAEC Data and Survey Policy that governs use of and access to all data collected by NAEC.

Q: Where can I find the data dictionary?

A: The data dictionary may be found as a PDF download on the NAEC website.

Q: What is the minimum number of surgical procedures centers must report for accreditation purposes?

A: For the 2027 Accreditation Process, level 4 centers must upload at least 1 case. Centers that do not upload at least one case will be conditionally accredited.

Q: Do we need to upload the de-identified operative note and invasive EEG reports for all cases invasive EEG, resection, new VNS, RNS and DBS implantation? (NEW)

A: No, centers are not required to upload any surgical patient reports to the Surgical Reporting Program platform. However, when completing the full accreditation process, centers must upload all required documents, including patient reports, to their folder at naec.box.com.

Q: What was the experience of centers that participated in the pilot program?

A: Pilot centers had different experiences. In terms of who submitted data, it was a range from center coordinators or nurses to physicians (typically a combination among them). Center sizes and numbers of cases also varied, too; centers ranged from dozens of cases to hundreds of cases per year. The average was about 50 cases per year that were entered individually, though 8 centers entered more than 100 cases per year. Most information needed for submission is presented at the patient management conference and can be collected then. Some centers submitted data prospectively and others waited until the end of the year and entered in one batch.

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2. Privacy, HIPAA, and Institutional Compliance

Q: Do we need a Business Associate Agreement (BAA) or Data Use Agreement (DUA) with NAEC?

A: No. NAEC does not require a BAA or DUA for participation in the Surgical Program. HIPAA rules permit epilepsy centers to share de-identified patient information with accreditation entities. Because all data submitted to NAEC is fully de-identified under HIPAA, a BAA or DUA is not required or appropriate. This is consistent with NAEC's longstanding practice — NAEC has never required or signed such agreements because centers have always shared only de-identified information.

Q: How do we know the data is truly de-identified under HIPAA?

A: NAEC engaged Brad Malin, Ph.D. (Vanderbilt University), a leading expert in biomedical data privacy and HIPAA de-identification, to review and certify the surgical dataset. Dr. Malin has issued a formal opinion certifying that the data elements meet HIPAA de-identification requirements. NAEC also engaged Melissa Levine, J.D., a senior partner in the Data, Privacy and Cybersecurity practice at Hogan Lovells, a global law firm, to ensure the program is fully HIPAA-compliant. Copies of these expert opinions are available on the NAEC website.

Q: Do we need an NDA or similar confidentiality agreement?

A: No. An NDA or similar agreement is not needed or appropriate in this context. NAEC uses de-identified data in accordance with its accreditation mission and existing Data and Survey Policy. Requiring an NDA would unduly restrict NAEC's accreditation program and is not typical practice for accrediting bodies.

Q: Does submitting data to NAEC require IRB review?

A: No. IRB review is not required or relevant for the Surgical Program. IRB review applies to human subjects research, which involves interaction or intervention with individuals or the collection of individually identifiable information. The Surgical Program collects only fully de-identified data for accreditation purposes — not research — and therefore does not constitute human subjects research. IRB review is not warranted.

Q: What patient information is submitted to NAEC?

A: No individually identifiable patient information is submitted to NAEC. The data elements collected include year of birth (not full date of birth), age at diagnosis, age at surgery, sex, race, ethnicity, payer type, epilepsy classification, surgical details, and outcomes. Full dates of birth, names, medical record numbers, and other HIPAA identifiers are never submitted. These identifiers remain only in a local key document maintained at your center.

Q: What about race and ethnicity data? Are we required to submit these?

A: Race and ethnicity are optional fields in the form and are not required. NAEC recognizes that these data are not always documented in clinical notes and that collection practices vary across institutions. Enter what is available in the medical record. If the information is not documented, you may select "Unknown."

Q: What if my institution's lawyers or compliance officers still have concerns?

A: We ask that you start by sharing all of the NAEC resources with your institution – the HIPAA certification, the letter about legal agreements, the NAEC Survey and Data Use Policy, and the NAEC De-Identified Data Governance Guardrails. If your institution still has questions, please contact us at info@naec-epilepsy.org.

Q: Where is the data stored and what security level does the system meet?

A: All NAEC data – including the Surgical Report data – is stored in the cloud on US servers that have received ISO/IEC 27001:2022 certification.

Q: What guardrails does NAEC use related to data privacy, security, and access? (new)

A: NAEC has a new document outlining its data governance guardrails related to the safety, use, and sharing of the de-identified data shared in NAEC's accreditation program and the Surgical Program.

3. Getting Started: Login and Access

Q: How do I log in to the data entry portal?

A: Visit naec-epilepsy.org and click the "Member Login" button in the top right of the screen. Enter your username (or email address) and password, then click "Log In." If you have forgotten your password, use the "Lost Password" link on the login page.

Q: Where do I find the Surgery Data Collection Program section after logging in?

A: After logging in, you will be directed to the Member Resources page. Under "My Centers," click on your center's name to open your Center Profile. The Surgical Program section is located on the Center Profile page and includes options for submitting new reports, viewing and editing existing reports, adding outcomes, and managing user access.

Q: What if I am associated with more than one NAEC center?

A: If you have access to multiple centers, all of them will be listed under "My Centers" on the Member Resources page. Be sure to click into the correct center before entering any data — data entered under the wrong center cannot automatically be moved.

Q: How do I add or remove staff who can access the Surgical Program portal?

A: On the Center Profile page, click the "Add/Remove Surgical Reports Users" link. The form displays users who currently have access. To remove a user, check the box next to their email address. To add a new user, enter their Name, Title, and Email Address. To add multiple users at once, click the blue "+" icon to add additional rows. When done, click Submit. NAEC staff will process access requests generally within 48 hours. If you need to resubmit the form immediately after submission, please reload the page first to reset the form.

Q: Who has authority to determine who can access the portal for our center?

A: The Center Medical Director has authority to determine who at the center can access the Surgical Program portal. Access can be different from those who have access to complete the Center Annual Report.

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4. Patient ID and the Local Key Document

Q: What is the Patient ID and how do I assign it?

A: The Patient ID is a number selected by your center to uniquely identify each patient in the NAEC database. Your center assigns this number; NAEC does not pre-assign IDs. The Patient ID must be a whole number between 0 and 10,000. Each patient at your center should have one unique Patient ID that is used consistently across all surgery entries for that patient.

Q: What is the local key document and why do we need it?

A: The local key is a simple document (we recommend an Excel spreadsheet) that your center maintains to link each NAEC Patient ID to your local patient identifiers — such as the patient's name, date of birth, and medical record number. This allows you to look up the correct Patient ID when entering subsequent surgeries for a patient and to re-identify a patient if needed for clinical purposes.

	A	B	C	D
1	NAEC Patient ID	Name	DOB	MRN
2	1	Doe, John	1/1/2001	1000000001
3	2	Doe, James	1/1/2001	1000000002
4				
5				
6				

Q: Does NAEC receive or store the local key?

A: No. The local key document always stays at your center and is never submitted to NAEC. It is a local administrative tool only.

Q: How should centers store the local key document?

A: Because the local key contains protected health information (PHI), your center should store and protect it in accordance with your institution's policies for PHI. Please follow your center's standard guidance on secure document storage.

Q: What if a patient has had multiple surgeries?

A: Use the same Patient ID for all surgeries for a given patient. When entering a new surgery for a patient already in the database, check the "Existing Patient" box on the first page of the form. Refer to your local key to look up the correct Patient ID for that patient.

Q: Will this be a rolling data report year to year or can we reuse numbers each year, for example restarting with patient ID 1 for next year?

A: This will be a rolling database with cases added to each year, so you should not reuse patient ID numbers. If you do, the database will associate reports as being for the same patient incorrectly. However your center decides to do the patient ID numbers, you must keep track and make sure that they are not repeated across your patient population.

Q: How should pediatric and adult centers of the same institution work together on the Program?

A: Centers should ensure that a procedure is only entered by one of the centers. Patient IDs should not be shared across centers (a patient's ID is tied to the center), and we are following outcomes of procedures and not patients. So it is ok if a patient shows up across multiple centers (for example, if a patient has one set of procedures as a pediatric patient and then transitions to adult care).

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5. Entering a Surgery Report — Page 1: Center Verification

Q: What should I do on the first page of the form?

A: The first page asks you to confirm two things before proceeding:

- **Reporting Center:** Verify that the center shown in the dropdown is the center at which the surgery was performed. If you are associated with multiple centers, make sure the correct one is selected.
- **Existing Patient:** Check this box if the patient receiving this surgery has previously had a surgery entered in the NAEC database. Do not check this box for a patient's first surgery entry.

Q: What does "Existing Patient" mean exactly?

A: "Existing Patient" means the patient has had at least one prior surgery already entered in the NAEC Surgical Program database at your center. It does not simply mean the patient is known to your center or has been seen there before. Use your local key document to determine whether a Patient ID already exists for this patient.

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6. Entering a Surgery Report — Page 2: Patient Information

Q: What Patient ID should I enter?

A: Enter the unique number your center has assigned to this patient. For a new patient (first surgery you are entering into the database), assign the next available number in your local key and record it there. For a returning patient, look up their existing ID in the local key. Patient IDs must be whole numbers between 0 and 10,000.

Q: Why does the form ask for year of birth rather than full date of birth?

A: Collecting only the year of birth (rather than the full date) is a deliberate de-identification measure. Under HIPAA, a full date of birth is a protected identifier. Year of birth alone is not protected health information (PHI) and therefore may be submitted. We seek year of birth to assist with the program's analytical purposes.

Q: What is "Age at Diagnosis"? (UPDATED)

A: This is the patient's age in whole years at the time epilepsy was first diagnosed, not the age at first seizure or at surgery. Enter a whole number between 0 and 120. Please note, for surgical cases performed on pediatric patients, the platform cannot include “months” for patients who were than than one year old at the age of diagnosis due to HIPAA compliance.

Q: What if I don’t know the patient’s "Age at Diagnosis"? (NEW)

A: Just leave this blank if you don’t know the patient’s age at diagnosis, or if you just know a general timeframe (i.e., the patient was diagnosed in childhood but you don’t know when exactly).

Q: How should I enter Epilepsy Type?

A: Select the ILAE epilepsy type that best characterizes the patient's epilepsy: Generalized, Focal, Combined generalized and focal, or Unknown. This classification is based on the ILAE 2017 framework. If the epilepsy type is uncertain or not well characterized, select "Unknown."

Q: How should I enter Etiology? What if the patient has more than one etiology?

A: Etiology is a multiselect field — select all that apply. The available options are: Structural: Post-traumatic, Structural: Other, Genetic, Infectious, Metabolic, Immune, and Unknown. For patients with dual pathology or multiple contributing etiologies, select all relevant options.

Q: How should I handle Seizure Types if the patient has multiple seizure types?

A: Seizure Types is a multiselect field — select all seizure types the patient experiences. For example, a patient with both focal impaired awareness seizures and focal to bilateral tonic-clonic seizures should have both selected.

Q: What should I enter for Syndrome if the patient does not have a named syndrome?

A: Select "None." Syndrome is a required field, so it cannot be left blank. The extensive list of syndromes reflects the full ILAE classification; many patients undergoing epilepsy surgery will appropriately have "None" selected. You may also select “Other” and enter the syndrome in the text box.

Q: Are all fields mandatory? (UPDATED)

A: No, not all fields are mandatory. Many required fields where information may be unavailable, such as insurance status, have an “unknown” option. We encourage centers to fill out every visible question; you can click unknown if that is the appropriate response. Branching logic will mean that not every question / option will show up for every submission.

Q: Are Race, Ethnicity, and Sex required?

A: Sex, Race, and Ethnicity are not required fields. Enter what is documented in the medical record. If the information is unavailable or not documented, you may leave these blank or select "Unknown" where that option is available.

Q: Is the only option manual entry for cases? Is it possible to do a batch upload?

A: Yes, as of now, centers are required to enter each surgical case separately and manually. NAEC is exploring ways to tie the Surgical Program database more directly to EHRs and to allow more seamless data transfer in future years.

7. Entering a Surgery Report — Page 3: Surgery Information

Q: What does "Previous Treatment Surgery (including neuromodulation)" mean?

A: This asks whether the patient has previously undergone any epilepsy-related surgical treatment — including resection, ablation, disconnection, or device implantation (RNS, DBS, VNS) — prior to the current admission. This refers to any prior treatment surgery, not just procedures performed at your center. Select Yes, No, or Unknown.

Q: What year should I enter for Year of Surgery?

A: Enter the calendar year in which the surgery being reported was performed.

Q: What is "Intent of Surgery"?

A: Select the primary intent of the surgical procedure:

- **Curative:** the goal is seizure freedom or significant seizure reduction
- **Palliative:** the goal is to reduce seizure burden without expectation of seizure freedom (e.g., corpus callosotomy, neuromodulation)
- **Diagnostic:** the procedure is for diagnostic purposes only (e.g., intracranial EEG monitoring without a planned treatment surgery in the same admission)

Q: Can we start a new surgery report submission during epilepsy surgery conference, keep the window open, and then update and submit it after the surgery is done? (NEW)

A: To ensure that data are saved, we encourage you to submit an incomplete report. You can submit and then re-open to edit and enter data at any later time.

Q: How should I report a case for a patient who had no known etiology at the time of surgery (no lesion or structural cause), but then pathology showed a focal cortical dysplasia Type 1, which would fall under structural etiology? (NEW)

A: This would be best classified as a structural etiology. You may need to edit the database if previously classified as unknown etiology. You may go back and update details already entered if additional information becomes available after the first submission.

Q: How should I report a case where intracranial EEG monitoring and a treatment surgery occurred in the same admission?

A: Enter a single surgery report for the admission. For "Type of Surgery," select both the intracranial EEG type (e.g., Stereo EEG) and the treatment type (e.g., Resection, Disconnection, Ablation). For "Intent," select the intent of the treatment surgery (typically Curative or Palliative).

Q: What does "location of treatment or target" mean for an SEEG? (NEW)

A: Yes, this is asking where the depths were implanted.

Q: How should we categorize electrode removal? (NEW)

A: This would occur during the same EMU admission as the electrode placement, so it's implied in the electrode placement questions.

Q: Should we add intracranial EEG to Types of Surgery if they've had an SEEG in the past, even at other epilepsy centers? (NEW)

A: No, you should not add "intracranial EEG" in "Types of Surgery" if it was not performed during that admission. You can select "previous admission" for "intracranial EEG details" if relevant.

Q: If the SEEG was performed during a previous EMU admission, is it correct that we should not report that SEEG in the "Type(s) of Surgery"?? (NEW)

A: That is correct. If you are entering a treatment surgery that was preceded by intracranial EEG during a previous admission at any center, do not select "intracranial EEG" for type of surgery. Only select the treatment surgery performed during that admission.

Q: What are the options under "Type of Surgery" and how do they relate?

A: Type of Surgery is a multiselect field with three broad categories:

- **Intracranial EEG**: includes Stereo EEG, Grid, Strips, Depths (not SEEG), and Previous admission (for patients returning for treatment after a prior monitoring admission)
- **Neurostimulation**: for device implantation procedures (RNS, DBS, VNS) without a concurrent resection/ablation
- **Resection, Disconnection, Ablation:** for surgical treatment procedures; selecting this will prompt you to specify the type

Q: What should I select for Type of Surgery if the procedure was a device battery change?

A: For battery changes (RNS, DBS, or VNS battery change), select the appropriate device type option. Battery changes are included in the data to give a complete picture of neuromodulation activity. Note that VNS battery replacements are the one exception to the reporting requirement; Level 4 centers are not required to report VNS battery changes, though they may do so optionally.

Q: How should we report the surgical cases for patients who had more than one surgical intervention during their EMU admission? (NEW)

A: The "type of surgery" question is multi-select so all surgical interventions during a single admission can be entered.

Q: For procedures that require two separate surgeries and admissions, should these be documented as two separate entries under the same patient identifier, or should the procedures be recorded as a single entry? (NEW)

A: Yes, the procedures should be reported as two separate entries using the same patient ID.

Q: What do the options mean for cases where no treatment surgery was performed? (UPDATED)

A: Note, past versions of the FAQ and surgical database had a question about when a diagnostic admission did not result in a treatment surgery. That question has been removed from the database.

Q: What is Intraoperative ECoG?

A: Intraoperative electrocorticography (ECoG) refers to direct cortical recording performed in the operating room during a resection or ablation to help guide the extent of the surgical intervention. Select Yes, No, Unknown, or N/A (for cases where no resection or ablation was performed).

Q: How should I report complications?

A: Complications is a multiselect field. Select all that apply. The options include: None, Symptomatic intracranial hemorrhage, Operative site infection, Unexpected temporary neurological deficit (resolving within 6 months), Unexpected permanent neurological deficit (persisting beyond 6 months), Readmission or reoperation or prolonged length of stay, Death, and Other. If you select "Other," you will be prompted to describe the complication in a free text field (maximum 200 characters).

> *Note that expected neurological deficits — those anticipated as part of the planned surgical approach and discussed with the patient — should not be entered as complications. Only unexpected deficits are reportable complications.*

Q: What should go in the "Additional Comments" field?

A: The Additional Comments field is a free text area for any information about the case that is not captured by the structured fields. Use it for clinical context, clarifications, or anything you feel is relevant for understanding the case. This field is optional.

Q: Should we enter the previous epilepsy surgeries in the “comments” section? (NEW)

A: You can but don’t have to enter previous surgeries in the comments section. You should use the same ID for the patient if one of their previous surgeries has been entered into the database

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8. Entering Outcomes

Q: When and how do I enter outcomes? (UPDATED)

A: Outcomes are entered separately from the initial surgery report, after sufficient follow-up time has elapsed (e.g., 12 months). From the Surgery Reports dashboard, locate the patient's surgery entry and click "View/Add Outcomes" in that row. Alternatively, click "Open Report" to open the full surgery record in a new browser tab, where the outcomes form is also accessible. Centers are not required to report outcomes as part of the 2027 accreditation process.

Q: What outcomes are collected, and at what time points?

A: Both Engel Outcome and ILAE Score are collected. The program collects outcomes at 12 months and 24 months post-surgery. You can add outcomes at each time point as they become available — the outcomes table for each surgery will accumulate entries over time. Both Engel and ILAE are required fields when adding an outcome.

Q: How do I enter the time post-surgery field?

A: Enter the approximate number of months elapsed since the surgery at the time of the follow-up assessment. For a 12-month follow-up, enter 12; for a 24-month follow-up, enter 24. The field accepts whole numbers.

Q: What are the Engel outcome options?

A: The Engel scale options are: Class I (seizure free or rare disabling seizures), Class II (worthwhile improvement), Class III (worthwhile improvement uncertain), Class IV (no worthwhile improvement), and N/A.

Q: What are the ILAE outcome options?

A: The ILAE outcome scale options are: 1 (completely seizure free), 2 (50% or greater reduction in seizure days), 3 (less than 50% reduction in seizure days), 4 (no worthwhile change), 5 (greater than 50% increase in seizure days), 6 (death), and N/A.

Q: What if outcome data is not available at 12 or 24 months?

A: If outcome information is not available at a given time point — for example, if the patient was lost to follow-up or the patient had a different surgery — you may select N/A for both Engel and ILAE. Do not leave outcome entries blank; use N/A to indicate the data is unavailable rather than omitting the entry.

Q: Are centers expected to input the data at a certain time? Does NAEC expect centers to review each surgery at 6 and 12 months for complications and outcomes?

A: Centers can edit or update complications or outcomes at any point in time, though we encourage centers to gather data at 6 and 12 months post-procedure. Those are guidelines, however – it is ok if centers submit outcome data at different times.

Q: Does NAEC have any guidelines or recommendations for how to collect data on outcomes – such as via clinic visits, phone calls, etc?

A: Centers can use regular post-surgery appointments, chart reviews, or specific patient outreach to gather this information. NAEC is only seeking basic outcome data (Engel and ILAE) but we encourage centers to gather additional data. This document has the required data elements for the entire Surgical Program and this is a post-surgery questionnaire template.

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9. Viewing, Editing, and Exporting Your Data

Q: How do I find and review previously entered surgery reports?

A: From your Center Profile, the Surgical Program section displays a table of all existing surgery reports. You can filter by Year of Surgery, Type of Surgery, or Patient ID and click Search to narrow results. The table shows Patient ID, Year of Surgery, Surgery Details, Age at Diagnosis, Sex, and Race for each entry.

Q: How do I correct a mistake in a submitted report?

A: There are two ways to edit an existing report. First, you can use "Toggle Inline Edit" on the Surgery Reports dashboard to edit fields directly in the table view. Second, you can click "Open Report" on any entry to open the full report in a separate browser tab, where all fields can be reviewed and edited.

Q: What if I need to delete an entry entirely?

A: Each row in the Surgery Reports table has a "Delete Entry" option. Use this carefully — deletion is permanent. If you are uncertain whether to delete or correct an entry, we recommend editing rather than deleting.

Q: Can I export my center's data?

A: Yes. Your center's surgery data can be exported at any time using the CSV or Excel buttons above the Surgery Reports table. This allows you to maintain a local copy of your submissions, verify completeness, and use the data for internal quality improvement purposes. Note, as of now the only rows that export will be those showing on screen (i.e., if you are only seeing the 25 most recent surgeries, then only those will export when you hit the button).

Q: Is there a way to see a visual summary of our center's surgical data?

A: A summary dashboard with visual displays of your center's surgery data is planned as a future addition to the portal. This feature is not yet available but will be added in an upcoming update. In the meantime, centers can export data to CSV or Excel and create their own summaries.

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10. Specific Field Clarifications

Q: What is the difference between Etiology and Structural Etiology?

A: "Etiology" refers to the broad ILAE category: Structural, Genetic, Infectious, Metabolic, Immune, or Unknown. "Structural Etiology" (where applicable) is a more specific subclassification within the structural category — for example, post-traumatic, stroke, malformation of cortical development, neoplasia, or mesial temporal sclerosis. If the etiology is Structural, you will be able to select the specific structural subtype.

Q: What is the difference between Lesionectomy, Lesionectomy Plus, ATL, and ATL Plus?

A: These terms reflect the extent of the resection:

- **Lesionectomy:** removal of a discrete lesion only, with minimal surrounding tissue
- **Lesionectomy Plus:** lesionectomy with additional resection of surrounding epileptogenic cortex beyond the lesion itself
- **Anterior Temporal Lobectomy (ATL):** standard anterior temporal lobe resection, typically including mesial structures
- **ATL Plus:** anterior temporal lobectomy with additional resection beyond the standard extent

> *When in doubt about the distinction between these categories, discuss with your surgical team. Consistent interpretation across entries at your center is more important than perfect alignment with other centers, as aggregate analyses will account for this variation.*

Q: What is the difference between DEE-SWAS and EE-SWAS in the Syndrome list?

A: These represent two related but distinct ILAE syndrome classifications. DEE-SWAS (Developmental and Epileptic Encephalopathy with Spike-and-Wave Activation in Sleep) applies to patients with both a pre-existing developmental delay and the EEG pattern. EE-SWAS (Epileptic Encephalopathy with Spike-and-Wave Activation in Sleep) applies to patients in whom the EEG pattern itself is the primary driver of cognitive regression, without a pre-existing developmental condition. Select the one that best fits the patient's clinical profile.

Q: Will the seizure type terminology be updated to reflect the 2025 ILAE classification (e.g., "consciousness" instead of "awareness")?

A: The data dictionary currently uses 2017 ILAE seizure type terminology. NAEC is aware of the 2025 ILAE updates and will consider revisions to the data dictionary in future cycles. For now, please use the terminology as it appears in the form. You do not need to update your internal documentation in anticipation of changes.

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11. Getting Help

Q: What if I have a question not answered in this FAQ?

A: Please contact NAEC at info@naec-epilepsy.org. NAEC also holds regular Office Hours sessions where center staff can ask questions about data collection and form navigation. Watch for announcements about scheduled Office Hours dates.

Q: What if I notice an error or inconsistency in the data elements or form options?

A: Please report any errors, inconsistencies, or suggestions to NAEC at info@naec-epilepsy.org. Your feedback helps improve the program for all participating centers.

Thank you for your commitment to excellence in epilepsy care and your participation in the NAEC Surgical Data Collection Program!