



NAEC Surgical Data Reporting Program Overview – May 6, 2026

Overview and Plans for Implementation in 2026

As announced in December 2024, NAEC will begin implement a new Surgical Data Collection Program (the Program) in May, 2026. The Program is based on the successful completion of a pilot program with 15 centers that submitted de-identified data on individual surgical procedures from 2022 to 2025.

Goal and Benefits of the Program

The goal of the Program is to gather and aggregate de-identified data on methods and outcomes of surgical epilepsy treatment to improve processes and patient outcomes. NAEC will share aggregate data with member centers. Centers will have access to their own data and will be able to benchmark and compare their data with all participating centers. NAEC may use this de-identified data to improve and increase the evidence basis for NAEC’s accreditation process. The Surgical Program reflects an update to NAEC’s existing process of collecting aggregate de-identified data annually from epilepsy centers for accreditation.

Center Requirements and Tie to Accreditation in 2027

Participation in the surgical data collection program is a requirement for Level 4 centers to maintain their accreditation in 2027. All level 4 centers are required to submit data on all surgeries performed in 2026, except VNS battery replacements. Level 4 centers that do not upload any data will be conditionally accredited in 2027. Centers that were 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. Level 3 centers are encouraged to participate if they perform VNS or other surgeries, but participation is optional (VNS battery replacements will not be reported).

HIPAA and Data Privacy

In preparation for the expansion of the Surgical Data Collection Program, NAEC engaged [Melissa Levine, J.D.](#), an attorney at Hogan Lovells, who is an expert in HIPAA and data privacy. She has assisted NAEC staff in developing governance documents for the program and connected NAEC with a statistician to certify that the surgical dataset is fully de-identified under HIPAA. NAEC hired [Brad Malin, Ph.D.](#), an expert in this field, to review and issue an opinion on the surgical dataset. Dr. Malin has issued a [report](#) that certifies the surgical dataset as de-identified in accordance with HIPAA requirements:

“It is my determination that the data sent by covered entities to the National Association of Epilepsy Centers, as described in this document, meets the de-identification requirements set forth in the HIPAA Privacy Rule and other related laws and regulations. This determination is based on the representation of the NAEC data management practices as of October 30, 2025.” – Brad Malin, Ph.D., Vanderbilt University

With this certification, NAEC does not need Business Associate Agreements with centers participating in the surgical data collection program. NAEC staff will follow processes outlined by these experts to ensure that data remains de-identified and that Dr. Malin’s certification is not inadvertently invalidated, following guardrails related to not re-identifying patients. [More information on why agreements like BAAs or data use](#)

agreements are not needed for the Surgical Program can be found in this (letter from NAEC's President, Dr Schuele), based on the advice of NAEC's counsel.

Commented [ER1]: Make this a link to the letter when it is finalized

Governance and Use of Data

The NAEC Board has agreed to initial guidelines on the use of the surgical program data:

- NAEC will consider sharing this de-identified data set with its members, sister organizations, and researchers following its [Data and Survey Policy](#). This existing policy precludes NAEC from sharing data that is center-specific or could identify a center.
- NAEC may use and/or share the de-identified dataset for the following purposes:
 - To evaluate, support, and improve NAEC's accreditation process
 - For providing confidential feedback to participating centers for benchmarking and comparison with the broader group
 - For research and data analytics on surgical outcomes, epilepsy care and treatment to benefit epilepsy centers

Logistics and Timing of Data Submission in 2026

Centers will submit data using a new portal in the NAEC website, similar to how they complete the Center Annual Report. Center Medical Directors will have authority to determine who at their center can have access to the portal (can be different than people who have access to complete the Center Annual Report, for example).

Here is the timeline for release of more details about the program and submission of data in 2026 in preparation for the 2027 NAEC Accreditation Process:

- **March:** NAEC shares with centers an overview and timeline for the program, the HIPAA certification report, and the data dictionary to assist members who wish to prospectively gather data about their 2026 surgeries.
- **May:** NAEC launches the program and opens the data portal for all members to participate. NAEC will hold a webinar and "Office Hours" to teach centers how to upload data.
- **April – July:** NAEC members are encouraged to start submitting data to ensure that they have appropriate access to the database. NAEC will continue regularly scheduled "Office Hours" to answer center questions on data collection and logistics.
- **September:** Staff will assess participation of centers via the website and check in with centers that have not uploaded any data to learn about challenges and barriers to participation.
- **January 31, 2027:** Deadline for submission of data on all surgeries performed in 2026 except VNS battery replacements.

Important Documents on Surgical Data Reporting Program

[Surgical Data Dictionary](#)

[Letter on Surgical Program Legal Issues](#)

[Certification Report of Surgical Dataset](#)

[Logistics and User Instructions](#) (portal will open May 6)