NAEC De-Identified Data Governance Guardrails
As of July 2026

Background
Since 2016, the National Association of Epilepsy Centers ("NAEC") has collected and received certain de-identified patient data from epilepsy centers as part of its process to accredit level 3 and 4 epilepsy centers. NAEC respects the privacy of patient data and has safeguards in place to prevent any center-specific data from being disclosed and patient data from being rendered identifiable. In 2026, NAEC is implementing a surgical data collection program that will collect de-identified data on a per procedure basis to further its goals of setting standards in epilepsy care and accrediting quality epilepsy centers.

NAEC receives de-identified patient data from epilepsy centers that are subject to HIPAA. Under HIPAA, information is considered de-identified where it does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual. There are two ways that data may be de-identified under HIPAA – through the safe harbor method or expert determination method. Under either method, NAEC does not have the ability to re-identify the data it receives.

The NAEC accreditation program utilizes the safe harbor method of de-identification of the patient reports submitted by centers for its existing accreditation requirements. More information on this method can be found here.

As part of NAEC's surgical data collection program (the "Program"), level 3 and 4 centers seeking NAEC accreditation will be required to share certain de-identified information on a per procedure basis. This data has been certified as de-identified under HIPAA by a statistician, consistent with the HIPAA expert determination method of de-identification. The Program will help further NAEC's goals of setting standards in epilepsy care and accrediting quality epilepsy centers.

NAEC respects the privacy of patient data and has safeguards in place to protect the de-identified patient data it receives. These De-Identified Data Governance Guardrails (these "Guardrails") explain what de-identified data centers are to share with NAEC, what NAEC intends to do with the data, and the guardrails and safeguards NAEC has in place to help protect the de-identified data and prevent it from being reidentified.

Data Collected for the Surgical Program
For the Program, participating centers will share with NAEC certain limited patient information and the number and types of surgeries performed within different age categories.

Each patient record containing the above information also will include a random code that enables NAEC to link different surgeries for the same patient.

NAEC has received an expert determination from prominent HIPAA de-identification statistician, Brad Malin, certifying that all the above data elements, including the code number, are de-identified under the HIPAA expert determination method. This means that epilepsy centers providing NAEC with the above data elements are providing only data that is considered and certified as de-identified data under HIPAA.

Safeguards and Guardrails for De-Identified Data Collected by NAEC

In addition to having the statistician certification, NAEC has technical, administrative, and physical safeguards and controls in place to protect the de-identified data and prevent re-identification. NAEC also adheres to the following guardrails:

- NAEC personnel with access to the data is limited and provided access on a need-to-know basis.
- NAEC and its personnel will not make any attempt to re-identify any of the patients who are the subjects of the de-identified data set.
- NAEC will not combine the de-identified data set with any other information, unless permitted by the statistician certification or the statistician confirms in advance that such will not impact the risk of reidentification or invalidate the certification.
- NAEC has in place policies, procedures, and controls to help prevent inappropriate access to, or use or disclosure of, the de-identified data.
- NAEC trains its workforce on these Guardrails, privacy obligations, and appropriate use and protection of data.
- NAEC will not sell the de-identified data and will not use or share de-identified data to train artificial intelligence or machine learning models or to develop commercial products.
- NAEC will not share center-specific data with other centers or third parties, unless approved by the Center Medical Director in advance in connection with a specific project.
- Any data shared with centers or other third parties for research or benchmarking will be aggregated and de-identified as to both patients and centers.

Use of De-Identified Data

NAEC will use the de-identified data set for the following purposes:

- To support accreditation of epilepsy centers;
- For research and data analytics on epilepsy centers' surgical outcomes, care, and treatment;
- To evaluate and improve NAEC's accreditation process;
- To allow centers to benchmark their individual data relative to aggregate data; and
- For other board approved educational or publication purposes.

Sharing of De-Identified Data

NAEC may share aggregated, de-identified data with other NAEC centers for benchmarking purposes and national data with all contributing centers annually or bi-annually. In certain circumstances, NAEC also may share aggregated, de-identified data with third party researchers. Prior to sharing such data, NAEC will remove reference to the originating center and aggregate the data to reduce the risk that data could be attributed to a specific center. In addition, any third-party researcher receiving data must agree to:

- refrain from taking any action to reidentify the data;
- not combine the data with other information that could increase the risk of reidentification of the data;
- limit uses and disclosures of the data to those identified purposes; and
- implement and maintain reasonable and appropriate data protection and security measures.