



**Data Elements for NAEC Surgical Data Collection Program  
As of May 11, 2026**

***Note: This is provided as a resource to help NAEC centers organize their data collection, but all surgical data must be uploaded via the data portal on the NAEC website.***

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1. Previous Patient
  - a. Yes
  - b. No

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2. Patient ID
3. Patient Year of Birth
4. Age at Diagnosis
5. Sex
  - a. Female
  - b. Male
  - c. Non-binary
  - d. Unknown
6. Race
  - a. American Indian or Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian or Other Pacific Islander
  - e. White
  - f. Multiracial
  - g. Unknown
7. Ethnicity
  - a. Hispanic or Latino
  - b. Not Hispanic or Latino
  - c. Unknown
8. Etiology (multiselect)
  - a. Structural
  - b. Genetic or presumed genetic
  - c. Infectious
  - d. Metabolic
  - e. Immune
  - f. Unknown
9. Structural etiology (branched from 8a)
  - a. Aneurysm
  - b. AVM
  - c. Cavernoma

- d. Encephalocele
  - e. HIE
  - f. Malformation of cortical development
  - g. Mesial temporal sclerosis
  - h. Neoplasia
  - i. Neurocutaneous syndromes
  - j. Stroke
  - k. TBI
  - l. Other
10. Epilepsy type
- a. Generalized
  - b. Focal
  - c. Combined generalized and focal
  - d. Unknown
11. Seizure types (multiselect)
- a. Focal aware nonmotor
  - b. Focal aware motor
  - c. Focal impaired awareness nonmotor
  - d. Focal impaired awareness motor
  - e. Focal to bilateral tonic clonic
  - f. Generalized tonic clonic
  - g. Generalized other motor
  - h. Generalized nonmotor
  - i. Other/unknown
12. Syndrome
- a. None
  - b. Mesial temporal lobe epilepsy with hippocampal sclerosis (MTLE-HS)
  - c. Lennox-Gastaut syndrome (LGS)
  - d. CDKL5-DEE
  - e. Childhood absence epilepsy (CAE)
  - f. Childhood occipital visual epilepsy (COVE)
  - g. Developmental epileptic encephalopathy with spike-and-wave activation in sleep (DEE-SWAS)
  - h. Dravet syndrome (DS)
  - i. Early infantile developmental and epileptic encephalopathy (EIDEE)
  - j. Epilepsy in infancy with migrating focal seizures (EIMFS)
  - k. Epilepsy with auditory features (EAF)
  - l. Epilepsy with eyelid myoclonia (EEM)
  - m. Epilepsy with generalized tonic-clonic seizures alone (GTCA)
  - n. Epilepsy with myoclonic absence (EMA)
  - o. Epilepsy with myoclonic atonic seizures (EMAtS)
  - p. Epilepsy with reading-induced seizures (EwRIS)
  - q. Epileptic encephalopathy with spike-and-wave activation in sleep (EE-SWAS)
  - r. Familial focal epilepsy with variable foci (FFEVF)

- s. Familial mesial temporal lobe epilepsy (FMTLE)
- t. Febrile infection-related epilepsy syndrome (FIRES)
- u. Gelastic seizures with hypothalamic hamatoma (GS-HH)
- v. Genetic epilepsy with febrile seizures plus (GEFS+)
- w. Glucose transporter 1 deficiency syndrome (GLUT1DS)
- x. Hemiconvulsion-hemiplegia-epilepsy syndrome (HHE)
- y. Infantile epileptic spasms syndrome (IESS)
- z. Juvenile absence epilepsy (JAE)
- aa. Juvenile myoclonic epilepsy (JME)
- bb. KCNQ2-DEE
- cc. Myoclonic epilepsy in infancy (MEI)
- dd. PCDH19 clustering epilepsy
- ee. Photosensitive occipital lobe epilepsy (POLE)
- ff. Progressive myoclonus epilepsies (PME)
- gg. Pyridoxine 5-phosphate deficiency (PSPD-DEE)
- hh. Pyridoxine-dependent (PD-DEE)
- ii. Rasmussen syndrome (RS)
- jj. Self-limited epilepsy with autonomic seizures (SeLEAS)
- kk. Self-limited epilepsy with centrottemporal spikes (SeLECTS)
- ll. Self-limited familial neonatal-infantile epilepsy (SeLFNIE)
- mm. Self-limited infantile epilepsy (SeLIE)
- nn. Self-limited neonatal epilepsy (SeLNE)
- oo. Sleep-related hypermotor epilepsy (SHE)
- pp. Sturge Weber syndrome (SWS)

**PAGE 3**

- 13. Previous treatment surgery (including neuromodulation)
  - a. Yes
  - b. No
  - c. Unknown
- 14. Year of Surgery
- 15. Age at time of surgery
- 16. Primary Payer
  - a. Private
  - b. Medicare
  - c. Public (not Medicare)
  - d. Other
  - e. Unknown
- 17. Types of Surgery
  - a. Intracranial EEG
  - b. Neurostimulation
  - c. Resection, Disconnection, Ablation
- 18. Intracranial EEG details (multiselect, branched from 17a)
  - a. None

- b. Previous admission (do not select other options)
  - c. Stereo EEG
  - d. Grid
  - e. Strips
  - f. Depths (not stereo EEG)
  - g. Unknown
19. Neurostimulation Details (multiselect, branched from 17b)
- a. RNS placement (or lead change)
  - b. DBS placement
  - c. VNS placement
  - d. RNS battery change (without lead change)
  - e. DBS battery change
  - f. VNS battery change
20. Resection, Disconnection, Ablation Details (multiselect, branched from 17c)
- a. Lesionectomy
  - b. Lesionectomy plus
  - c. Anterior temporal lobectomy
  - d. Anterior temporal lobectomy plus
  - e. Selective Amygdalohippocampectomy
  - f. Neocortical resection
  - g. Multi-lobar resection
  - h. Hemispherectomy/otomy
  - i. Open Corpus callosotomy
  - j. Laser Corpus callosotomy
  - k. Laser ablation
  - l. Radiofrequency ablation
  - m. Multiple subpial transections
21. Intent of Surgery
- a. Curative
  - b. Palliative
  - c. Diagnostic
  - d. Battery Change
22. Intraoperative ECOG
- a. Yes
  - b. No
  - c. Unknown
23. Location of resection or device placement (multiselect)
- a. Bilateral
  - b. Medial temporal
  - c. Temporal neocortical
  - d. Frontal
  - e. Parietal
  - f. Occipital
  - g. Insula

- h. Thalamus: Anterior nucleus
  - i. Thalamus: Centromedian
  - j. Thalamus: Pulvinar
  - k. Other
24. Complications (multiselect)
- a. None
  - b. Symptomatic intracranial hemorrhage
  - c. Operative site infection
  - d. Unexpected temporary (< 6 month) neurological deficit
  - e. Unexpected permanent (> 6 month) neurological deficit
  - f. Readmission or reoperation or prolonged length of stay
  - g. Death
  - h. Other (please comment)
25. Please Describe Other Complications
26. Additional Comments

### OUTCOMES PAGE

27. Time post-surgery (months)
28. Engel Outcome
- a. N/A
  - b. I
  - c. II
  - d. III
  - e. IV
  - f. Death
29. ILAE Score
- a. N/A
  - b. 1
  - c. 2
  - d. 3
  - e. 4
  - f. 5
  - g. 6
  - h. Death