National Association NAEC of Epilepsy Centers

NAEC Board Policy Related to the Release of NAEC Data and Surveying NAEC Members for Research and/or Publications – Adopted December 7, 2025

Background: NAEC periodically gets requests for data on epilepsy centers as well as requests to survey member centers for research purposes. These requests come from NAEC members, academics involved in research, sister non-profit organizations interested in information on epilepsy care and from epilepsy device and drug manufacturers. NAEC evaluates requests for data and to survey its member center directors on a case-by-case basis, evaluating if the topic is complementary to NAEC's mission to improve and promote the quality of specialized epilepsy care.

Annually, NAEC holds a webinar and distributes a slide set to NAEC Members of the annual presentation of the data NAEC collects through its accreditation process. In addition, NAEC has conducted surveys of its members with the goal of furthering its mission of improving epilepsy care through its epilepsy center accreditation program. NAEC has worked with members to directly sponsor analysis and publication of its data. In these circumstances, NAEC creates a Memorandum of Understanding with the lead researcher or center to govern the use and confidentiality of the data.

NAEC Policy: The policies below will guide NAEC staff and leadership in determining access to and the release and publication of NAEC data for research purposes and requests to survey NAEC centers. The policy does not apply to requests from member centers for aggregate data to benchmark activity at their centers (i.e. EMU average length of stay). NAEC will post this policy on its website and inform NAEC members to make them aware of the opportunity to request the use of NAEC's data or to survey its members.

Section 1 – Access to NAEC data: Access to NAEC data will be determined on a case-by-case basis outlined in Sections 2 - 5. All members of NAEC are eligible to apply for access to NAEC data. Members of academic organizations (such as universities, foundations, and think tanks), advocacy groups (such as the Epilepsy Foundation and other groups) and other not-for-profit/nongovernmental organizations are also eligible to apply. Applications from for-profit companies will require a two-thirds positive majority vote of the full NAEC Board prior to release of NAEC data.

Section 2 – Procedure for applying to access NAEC data:

The application for access to NAEC data for research purposes include:

- Cover letter describing specific NAEC data being requested, needed involvement of NAEC staff, and timeline for publication.
- Written proposal to include purpose of the request and research question, introduction of problem, proposed methodology and data analysis. No more than 5 pages, double-spaced, 11-size font.
- 1-page NIH-style biosketch of the applicant and a list of other members of the applicant's team along with their skill set. The inclusion of essential skill sets required for proper data analysis is crucial in the approval of data requests.

Section 3 – NAEC Review of Survey and Data Requests: NAEC's Officers will evaluate all requests for accessing NAEC's data and surveying its members. All requests will be scored by evaluating their relationship to NAEC's mission to improve and promote the quality of specialized epilepsy care, the research team, the timeline for publication and the needed level of engagement of NAEC staff. A request may be denied if a similar proposal was previously approved.

Unanimous decisions of the Officers are final. In the event of opposing opinions, the majority opinion should be adopted, though if the dissenting member feels strongly about the significance and impact of the proposal, he/she may request a discussion by the full Board. The majority opinion of the full Board will be final.

NAEC Staff with input from the NAEC Officers will serve as a liaison with the applicant in obtaining the appropriate data or survey process and in working through all phases of manuscript preparation and review.

Section 4 - NAEC data to be released: Only aggregate data from NAEC members can be released. All data will be de-identified in terms of site of origination. No center-specific data will be released. Applications may conceivably request information from specific regions or states. In those circumstances, in order to maintain the goal of de-identification, those regional data released must include, in aggregate form, data from at least four (4) centers.

Section 5 – Procedure for publication of NAEC data

- The applicant will allow NAEC access to all analyses and findings which used NAEC data.
- Manuscripts containing NAEC data or analyses derived from NAEC data must be reviewed and approved by the NAEC Board prior to submission for peer review.
- Manuscripts containing NAEC data or analyses of NAEC data must specifically attribute NAEC and the Medical Directors of NAEC Member Centers.

Section 6 – Requests to Survey NAEC Centers: NAEC will consider requests to survey member centers on a case-by-case basis following the parameters outlined in sections 1 - 5 related to accessing NAEC data.

Section 7 – NAEC Sponsored Research and Surveys: NAEC will continue its practice of endorsing and sponsoring NAEC member surveys and analysis, and publications related to the data collected through its accreditation process. As the final part of the review process of the NAEC Officers and/or Board will determine whether to directly sponsor a survey or analysis of NAEC data.