



NAEC and Guideline Development Background Information

ABOUT NAEC

NAEC is a non-profit association with a membership of more than 260 specialized epilepsy centers in the United States. NAEC was founded in 1987 by physicians committed to setting a national agenda for quality epilepsy care. NAEC published its first iteration of its *Guidelines for Essential Services, Personnel, and Facilities in Specialized Epilepsy Centers* in 1990. The Association continues its work to develop standards of care and promote their adoption by epilepsy centers through its accreditation program. NAEC pursues an active agenda, educating public and private insurers, policymakers, and government officials about the complexities of and need for patient access to specialized epilepsy services.

NAEC's mission is to support epilepsy centers in delivering quality comprehensive care to people with epilepsy, by setting standards of care, advocating for access to high quality epilepsy center services, and providing knowledge and resources to its member centers. More information about NAEC and its member centers can be found at www.naec-epilepsy.org.

Since its formation, NAEC has focused its efforts on developing standards of epilepsy care. Prior to initiating its accreditation process, NAEC required that member centers complete a self-designation report and provide the names of key personnel and the diagnostic and treatment services provided.

The Institute of Medicine (IOM), as part of its 2012 published report, [*Epilepsy Across the Spectrum: Promoting Health and Understanding*](#), recommended that "NAEC and American Epilepsy Society establish criteria and a process with independent external review mechanisms for the accreditation of epilepsy centers and that accredited centers should form a network that includes data sharing, clinical trial and other research networking, professional education and other activities." The NAEC Board spent two years following the publication of the report reviewing models for accrediting centers and evaluating ways to strengthen its process of evaluating and recognizing level 3 and 4 epilepsy centers.

In 2014, the NAEC Board developed a more formal accreditation process with expanded criteria, which was implemented in 2015. Centers are now required to submit documents to validate their responses to the online Annual Report and NAEC verifies the certifications for epilepsy center personnel with relevant boards and certification bodies. Today, NAEC's accreditation process serves two purposes: 1) to define and incentivize standards of care for comprehensive epilepsy care; and 2) serve as an avenue to collect data on the types and volume of services provided by specialized epilepsy centers.

BACKGROUND ON THE DEVELOPMENT OF AN NAEC GUIDANCE DOCUMENT

There is consensus among NAEC Board Members that a revision of NAEC's *Guidelines for Essential Services, Personnel, and Facilities in Specialized Epilepsy Centers* is necessary as the last version, published in 2010, is outdated and no longer reflects the center criteria utilized by NAEC to accredit level 3 and 4 epilepsy centers. In addition, the Board believes the Guidelines document is too narrowly focused on inpatient hospital services provided in hospital epilepsy monitoring units, excluding the significant chronic care management provided by centers on an outpatient basis.

The NAEC Board began discussions in 2020 on how to update the current published document to better align it with NAEC's well-recognized center accreditation program and has decided to pursue guideline development following a more rigorous approach involving a broader group of stakeholders. NAEC has contracted with [EBQ Consulting](#) to

assist the Association in developing an evidence-informed guidance document that reflects the desired quality, safety, and practice standards of level 3 and level 4 epilepsy centers, aligned with NAEC's accreditation program. EBQ has significant experience in evidence-based and evidence-informed guidelines. They provide a team of highly educated, skilled, and experienced methodologists, data analysts, medical librarians, and project managers.

In developing this NAEC Guideline, the Association will use a formal process to identify, evaluate, and prioritize the key elements of epilepsy center care with a multi-disciplinary group of stakeholders including experts in all aspects of epilepsy and healthcare delivery, and patients, caregivers, and advocates. The development of the guideline document will follow a transparent process that incorporates existing evidence-based literature, supplemental data from accredited epilepsy centers collected via surveys, and the knowledge of the experienced panelists.

PROJECT SCOPE

The Guideline development process will likely span the next year to 18 months. We plan to seat the Guideline Panel by September 1, 2021 and anticipate acceptance for publication of the guideline document by the end of 2022. The main steps to creating the guidance document will include:

1. Determining the makeup of the panel to evaluate the epilepsy center parameters
2. Assuring the use of an appropriate policy for conflict-of-interest management and disclosures
3. Formulating key topics, parameters, and identifying important outcomes to be assessed
4. Conducting a systematic and comprehensive literature review to determine what evidence exists for key parameters
5. Managing a modified Delphi process to seek consensus on key recommendations
6. Drafting the guidance document
7. Identifying knowledge gaps and recommendations for future study

GUIDELINE PANEL DETAILS

NAEC anticipates that all panel meetings will be virtual and will include a training session as well as several sessions to develop the key topics of the guideline and to review the evidence identified by a literature search. Prior to the meetings, panelists will be asked to review materials and active participation is required. Panelists may also be asked to draft sections of the guidelines based on their expertise. NAEC will require a conflict-of-interest review process with initial and subsequent disclosures by applicants. There are no sources of funding for guideline development other than the NAEC and no honoraria paid to any contributors. In general, individuals chosen to participate in NAEC's Guideline Panel will be asked to:

- Participate in all scheduled panel meetings and conference calls, including panel training
- Adhere to timelines
- Review evidence tables and analyses
- Draft recommendations/suggestions, if requested to do so by the panel chair(s), based on the evidence when available
- Draft assigned sections of the manuscript and review the entire manuscript
- Participate in dissemination and implementation of the guideline

GUIDELINE PANEL APPLICATIONS

The NAEC aims to seat a panel representing all important stakeholder perspectives, including epileptologists (adult and pediatric), epilepsy surgeons, EEG technologists, epilepsy nurse specialists, social workers with epilepsy expertise, neuropsychologists, thus requesting applications from a diverse body of medical and health disciplines and patients with epilepsy and their caregivers and advocates. The Association is widely disseminating this background document and the link to the [Panel Application](#).

FOR MORE INFORMATION, please email info@naec-epilepsy.org