Guidelines for Specialized Epilepsy Centers: Report of the National Association of Epilepsy Centers Guideline Panel

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information, or procedures contained in a guideline, based on any legal theory whatsoever and whether or not there was advice on the possibility of such damages.

Abbreviations

AES=American Epilepsy Society ABRET=ABRET Neurodiagnostic Credentialing and Accreditation ACNS=American Clinical Neurophysiology Society ADHD=attention deficit hyperactivity disorder **APP=Advanced Practice Providers** ASM=anti-seizure medications CB=consensus based COI=conflict of interest DRE=drug-resistant epilepsy ECoG= electrocorticography EEG=electroencephalogram EMU=epilepsy monitoring unit fMRI=functional magnetic resonance imaging GOC=Guidelines Oversight Committee ILAE=International League Against Epilepsy MEG=magnetoencephalography NEAC=National Association of Epilepsy Centers PET=positron emission tomography PICO=Population, Intervention, Comparator, Outcome PNEE=psychogenic non-epileptic events PNES=psychogenic non-epileptic seizures PWE= people with epilepsy R.EEGT= Registered electroencephalographic technologist SAP=seizure action plan SDoH=social determinants of health SPECT=single-photon emission computerized tomography SUDEP=sudden unexplained death in epilepsy TCBS=trustworthy consensus-based statements TIAB=title/abstract VEEG= video electroencephalogram

1. Introduction and Background

Epilepsy is one of the most common chronic neurologic conditions worldwide, with an estimated prevalence of 3.4 million persons in the United States.¹ Its impact, both on an individual and societal level, is substantial. Epilepsy is associated with increased morbidity and mortality, decreased quality of life, and far-reaching socioeconomic implications.^{2,3} These risks are further elevated for approximately 30% of patients with epilepsy who have refractory seizures despite treatment with anti-seizure medications (ASM), categorized as drug-resistant epilepsy (DRE).^{4,5} As such, national and international

professional organizations advocate for comprehensive epilepsy centers to provide routine and highly specialized care for people with epilepsy (PWE).⁶⁻⁸

Comprehensive epilepsy care requires infrastructure encompassing inpatient and outpatient settings, as well as organization of a multidisciplinary care team spanning both environments. Patient-centered care begins with accurate diagnosis and pharmacologic treatment of seizures, epilepsy-related education, screening and/or management of comorbid conditions, and provision of psychosocial resources for patients and caregivers. A proportion of patients, including those with DRE, require further diagnostic testing and specialized treatments, including epilepsy surgery. Specialized epilepsy centers are also pivotal in the design and execution of research trials and other scientific advances that continue to move the field forward and improve patient outcomes.

The National Association of Epilepsy Centers (NAEC) is a non-profit association in the United States with a current membership of more than 260 epilepsy centers. NAEC was founded by a group of physicians to set a national agenda for quality care in epilepsy. NAEC published its first guidelines in 1990 to provide a basic framework for services, personnel, and facilities for in-patient care. Each decade since then, updated guidelines have expanded content to include epilepsy surgery considerations, interdisciplinary care approaches, and safety and quality measures. The 2023 Guidelines present a further evolution in this process as the first guidelines founded in an evidence-informed, consensus-based process, drawing on a broad cross-section of stakeholders including patients and caregivers. These guidelines also reflect a broader scope than previous iterations, including outpatient care, care coordination, and emphasis on the patient perspective.

Spurred by the 2012 Institute of Medicine,⁹ now known as the National Academies of Sciences, Engineering, and Medicine, report on the state of epilepsy care in the US, NAEC established in 2016 an epilepsy center accreditation program built on the foundation of existing epilepsy center guidelines. Although accreditation criteria draw upon NAEC epilepsy center guidelines for content, they are not synonymous. The NAEC board and accreditation committee review and update criteria annually based on center feedback and emerging priorities of the board. As these guidelines expand to new areas, it is recognized that many recommendations extend beyond current accreditation requirements and that center resources may limit implementation.

These 2023 guidelines outline optimal standards of care with an intent to elevate evidence-based science into standard practice. In areas that lack strong evidence, recommendations were guided by consensus from the panel of experts and highlight areas of need for additional research moving forward. The NAEC Guidelines for Specialized Epilepsy Centers are intended to be used by healthcare professionals, epilepsy center administrators, health system administrators, PWE and their caregivers, and healthcare advocates. The Guidelines can be used to determine services that should be provided, identify gaps in resources, and help patients and families assess the quality of care received. These guidelines will inform the direction of future accreditation criteria and aim to provide epilepsy centers with an expanded framework to improve processes and infrastructure to continue to advance quality care for all patients with epilepsy.

2. Methodology for the Development of the Systematic Review and NAEC Guidelines for Specialized Epilepsy Centers

In 2022 NAEC contracted with EBQ Consulting¹⁰ to develop guidelines for specialized epilepsy centers and ensure that this updated edition incorporates evidence-based trustworthy consensus-based statements (TCBS) that conform with established international standards.¹¹⁻¹⁴

When evidence is not sufficiently evolved or robust enough to support quantitative analyses for publication of evidence-based guidelines, physicians and other healthcare providers at epilepsy centers, PWE, and advocates still need guidance they can trust.¹²⁻¹⁴ The TCBS approach¹¹ produces unbiased, scientifically valid, and trustworthy guidelines through a transparent process that incorporates any available evidence-- identified through a systematic approach to reduce biases-- and expert panelists' advice. This process is necessary in non-clinical topics such as services, personnel, infrastructure, and protocols for epilepsy centers because of known pre-existing gaps in the evidence base; sample sizes are small; and the scarcity of methodologically rigorous evidence from randomized controlled trials or other high-level study designs. Thus, quantitative analyses (e.g., direct meta-analyses or network meta-analyses) are not feasible. Although this was a complete systematic review, it was performed incidental to a guideline and was not registered at <u>PROSPERO</u> (Online systematic review database).

2.1. The TCBS Process

The TCBS process,^{11,15} producing evidence-informed and consensus-based recommendations, is based on five important pillars:

- 1. Users' confidence in the panel composition and screening
- 2. Systematic and comprehensive evidence searches
- 3. Formal consensus achievement
- 4. Transparency of data and methods throughout
- 5. A rigorous review process

Composition of the panel: Structure

To ensure that the panel should represent all key stakeholder perspectives and minimize relevant conflicts of interest, an NAEC Guidelines Oversight Committee (GOC) was established to provide objective oversight of the process. Composition of the GOC drew from current and past NAEC Board members and from clinicians working at member centers.

The NAEC appointed two guideline panel co-chairs, who were both practicing epileptologists and experienced in epilepsy center accreditation process. The panel's work was overseen by a methodology consultant with extensive experience leading guideline panels and expertise in the TCBS approach.

Call for panel applications

The GOC prioritized a list of approximately 20 clinical, administrative, and patient/caregiver categories to seek a broad representation of applicants to serve on the guideline panel. A formal *Call for Applications* was sent to neurology and epilepsy professional membership societies and patient advocacy groups to recruit experts from a variety of healthcare disciplines including epileptologists, neurologists, neurosurgeons, neuroradiologists, epilepsy nurses, EEG technologists, neuropsychologists, social workers, Advanced Practice Providers, and other allied health professionals. A broad sample of PWE and their caregivers were requested to apply. More than 100 total applications were received. The NAEC staff, guidelines consultant, and GOC reviewed all applications to ensure a diversity of

demographics, geographic locations, clinical specialties, and socioeconomic contexts. Review of the applications identified missing or inadequately represented stakeholders. Specific targeted outreach to fill these gaps yielded additional neurosurgeons, a level 3 center director, a pediatric neurologist, and a psychiatrist. Despite efforts, no applications were received from clinical social workers. **Table 1**.

NAEC invited several epilepsy-related organizations to monitor the guideline development process. The American Epilepsy Society (AES) and the American Clinical Neurophysiology Society (ACNS) elected to assign a representative to monitor the work of the panel.

Conflict of interest reviews

The **NAEC Policy on Conflicts of Interest for Guidelines** [HYPERLINK: https://www.naec-epilepsy.org/wpcontent/uploads/National-Association-of-Epilepsy-Centers-Policy-on-Conflicts-of-Interest-for-Guidelines.pdf] was developed in advance of the panel application process to set rules governing guideline funding, panel composition, conflict of interest (COI) definitions, and procedures for reviewing and managing panelists' conflicts based on guideline roles and types of conflicts. The NAEC staff, guidelines consultant, and GOC reviewed all applications and COI disclosures. Conflicts that were determined to be *primary* (financial and/or relevant to the topic) but not *significant* (disqualifying) could be permitted in a minority of panel applicants whose expertise and roles were desired for the panel and who agreed to the specified terms of management based on their individual conflicts. Terms of management for participation of these applicants were that they could not draft or vote on recommendations in areas in which they had relevant conflicts, and they could not write those portions of the manuscript. All approved panelists signed letters of agreement specifying their understanding of expectations and willingness to comply with specific terms of management, when applicable. Of the final 41 panelists, 10 (24%) had terms of management related to primary COIs--less than 50%, which was the predetermined goal of the GOC.

Additional COI disclosures and reviews were conducted at relevant points in the guideline development process (eg, drafting of recommendations, the consensus achievement process, and manuscript submission for publication). One member left the panel due to a change in employment leading to a significant conflict of interest.

Funding

The sole source of funding for these guidelines was the National Association of Epilepsy Centers.

Process for panel workflow and oversight

The chairs and panelists were involved in topic organization; review and identification of relevant evidence; recommendation drafting; consensus surveys; and manuscript drafting and reviews. Based on their expertise and interests, panelists were assigned to one of six work groups for the development of guideline recommendations. Each work group included at least one PWE or caregiver. Meetings, communications, and trainings were conducted via videoconferences, emails, and electronic surveys. All panelists had the opportunity and were expected to review documents before finalization and external reviews.

2.2. Evidence Generation

The chairs and medical writer worked with NAEC staff and the EBQ Consulting team to identify the major topics of interest with components sorted into PICO¹⁶

(Populations/Interventions/Comparators/Outcomes) elements. Early in the process, a call for input on the PICO elements was solicited from NAEC members and related organizations.

Search strategies and information sources

A comprehensive and systematic search for relevant scientific literature was developed, peer-reviewed, and run in PubMed and EMBASE from January 1, 2000 to May 29, 2022. The literature search was updated on March 19, 2023. All searches were restricted to English-language and human-only studies. No exclusions based on geography were implemented. No limits were applied to the searches based on study design, reported sample size, or publication type, although some limitations were added for the subsequent screenings. Systematic reviews and guidelines were included when indexed in PubMed. Chairs proposed a few relevant articles; however, most of these were already identified through formal searching, reviewed, and approved for inclusion. The complete search strategies are available on request to info@naec-epilepsy.org.

Study selection

The reasons for acceptance/rejection of studies during screening are listed in **Table 2.** The search and screening results have been recorded and summarized in the PRISMA diagram (Figure 1).

The completed searches returned a total of 5,777 (de-duplicated) studies for title/abstract (TIAB) screening. We re-ran the search strategies to update the evidence base and identified an additional 160 articles. Screeners each independently screened one-third of the studies, and either retained or rejected each study based on their match to the pre-determined PICO-based¹⁶ elements and inclusion/exclusion criteria. Since all interventions were included in this project, no articles were rejected based on whether the study focus was an intervention or comparator, as the intention to describe treatment in epilepsy centers was best met by considering all treatments provided in that setting. Additionally, no studies were rejected during initial screening for not including outcomes from the prespecified list. (**Table 2**)

Based on the inclusion criteria (**Table 2**) set by the guideline panel chairs, the rejection rate during title and abstract review was extremely low (<20%) for the first 15% of studies screened. In view of the large number of articles identified and low rejection rate, the literature screening method was modified to identify "high interest" articles for full text review. One member of the review team (TS) reviewed all the studies and identified those that appeared to provide clear evidence in the title or abstract that they would have relevant information for one or more of the PICO elements. These "high interest" studies were then assessed by the chairs and medical writer based on title and abstract to confirm content eligibility. The two chairs independently ranked the relevance of each eligible study on a scale of 1 (most relevant) to 3 (least relevant), with studies receiving a combined summed score of 5 or less being retained. Ultimately, 175 of these studies were designated "high interest," along with 22 studies from external sources, resulting in a total of 197 final studies. The validity of this strategy can be assessed by (A) how many of the articles originally selected as "high-interest" received approval from the chairs and full-text reviewers (85%), and (B) how many of the articles not selected as "high-interest" were later brought into the guideline based on feedback from the panelists (less than 1%). Further details related to the flow of screening references are included in the PRISMA diagram.

Risk of bias in individual studies

Other than the study design limitations placed on the literature search and screenings (case studies, case series, and studies with n<10 were rejected), no additional exclusions were made based on methodologic quality of the research studies. No formal quantitative analyses were conducted, and no risk of bias assessments were made of individual study quality.

Data extraction and development of evidence tables

Panelists were then tasked with extracting relevant data into evidence tables in their areas of expertise. These panelists received video and written instructions from the Senior Methodologist (TS) and specific evidence tables created for each extractor. A consulting data analyst then performed reliability checks on a randomly selected 20 percent sample of the articles. The results were mixed with some topics (e.g., surgery, imaging, electrodiagnostic services, and PNEE) extracted very well (up to 100% correct) while in other topics important information was missed. In consultation with the chairs, the decision was made to have the chairs and consulting methodologist re-extract articles in several topic areas for volunteer extractors. This decision was based on review of a sample of two articles by each of the volunteer extractors,-and when found to have missing or erroneous extractions, triggered re-extractions of all of their assigned studies. Evidence summaries were created by the Senior Methodologist. Evidence tables and summaries are available upon request to info@naec-epilepsy.org.

2.3. Formal Consensus Achievement through Delphi Techniques

The Delphi technique is a well-accepted process for soliciting feedback and achieving the consensus of a panel regardless of availability of quantitative data.¹⁷ There are several methods of developing consensus statements,¹⁸⁻²¹ but the modified Delphi (mDelphi) approach for guideline recommendations allows consideration of the evidence base as well as expert opinion while suppressing the introduction of group interaction bias. The NAEC used the TCBS approach, which is used by several medical professional societies,²²⁻²⁴ to bring precision and transparency to the consensus achievement process for the multi-stakeholder panel of experts.^{21,25} As with quantitatively-supported evidence-based guidelines, this approach includes a rigorous review of both methods and content by internal and external stakeholders of all types.

Recommendation development

The initial recommendations were drafted based on the evidence that was provided to the panelists as evidence summaries, as well as the experience and expertise of the work group panelists. These panelists were trained in writing actionable and implementable recommendations. The qualitative evidence summaries, along with the Evidence-to-Decision Framework²⁶ questions, were used by the work groups to draft the recommendations.

The evidence summaries were later shared with the entire panel, which convened via teleconference to discuss the evidence and receive instructions on the Delphi process. The panelists were not permitted to discuss the specific details of the drafted recommendations to avoid the occurrence or even the perception of group interaction bias. Panelists were permitted to suggest topics for additional

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recommendations that did not appear in the list. The panel chairs were tasked with drafting new recommendations to address the identified gaps before the first mDelphi survey round.

Delphi surveys

The modified Delphi surveys were conducted for all guideline recommendations using SurveyMonkey[™], with all responses remaining anonymous except to the independent administrator (MG) who created and managed the process. All panelists received training on the TCBS approach, written reminders of the process and rules, and instructions on the first page of the surveys.

A priori rules and processes

Following the drafting of the recommendations, each set of recommendations went through the modified Delphi consensus process. Several *a priori* decisions were determined by the GOC to guide the modified Delphi process, including:

- Up to three rounds of Delphi surveys to achieve consensus
- An 85% minimum response rate for each survey round based on eligible voting panelists
- An 80% threshold of voters indicating agreement or strong agreement for achieving consensus
- Recommendations achieving consensus in the first or second round were not revoted on in subsequent rounds.
- No minority reports were permitted, although all panelists had the opportunity and were encouraged to express their opinions during each round of the mDelphi surveys for each recommendation.

Panelists were encouraged to respond completely to all recommendations in every round of the surveys. The healthcare professionals were advised to base their level of agreement or disagreement on the evidence and their experience treating people with epilepsy. The PWEs and caregiver panelists were asked to make similar judgments based on the evidence and their experience as patients, care providers, and advocates in the healthcare system.

All recommendations achieved consensus in the first round, however the chairs made minor revisions to seven recommendations based on the comments provided by the survey respondents and drafted one additional recommendation. The revised recommendations and a single new recommendation were then submitted for the next round of voting and all achieved consensus, for a total of 52 final recommendations. Survey tallies with the degree of consensus for each recommendation are available on request (info@naec-epilepsy.org).

2.4. Finalization of the Recommendations and Manuscript

Finalizing the recommendations

All recommendations were incorporated within the relevant section of the manuscript and numbered accordingly. All remarks are considered integral to the recommendations themselves and therefore included as part of the recommendations. In future uses, if guideline recommendations are uploaded

into digital platforms, incorporated into separate lists, or otherwise removed from this full guideline publication, the remarks should always be kept with the rest of the recommendation as a single unit.

Review and finalization of the manuscript

The final manuscript underwent extensive review first by the panelists, chairs, medical writer, and staff. Subsequent review was performed by the GOC, NAEC Board, and monitoring organizations. Comments at each stage of the review were considered by the chairs. Modifications were made when relevant. No editing or changes to the recommendations or remarks were permitted.

2.5. Limitations of the Methodology

Single screening and single data extractions, rather than dual screening and extractions with adjudication, were necessary compromises due to the high volume of articles identified and organizational constraints. Critical appraisals of the evidence quality and feasibility assessments for quantitative analyses were ruled out in advance.

2.6. Future Plans for Updates

With this edition, *Guidelines for Specialized Epilepsy Centers: Report of the National Association of Epilepsy Centers Guideline Panel* have advanced considerably and comply with current standards^{12,13} for guideline development using the TCBS approach.¹¹ NAEC is considering following the living guideline model to maintain the currency of these guidelines in future efforts. As additional research is conducted in the field of epilepsy, as methods standardize, and as knowledge grows, published data should become more homogeneous and quantifiable, permitting evidence-based guideline updates in many of the content areas.^{11,15}

NAEC will determine how to proceed in reviewing all recommendations over time and will establish specific criteria and processes for this review and potential updated recommendations. NAEC will consider additional efforts that follow the advancing work of several international initiatives to provide recommendations for digital platforms and to support implementation.

EPILEPSY CENTER GUIDELINE RECOMMENDATIONS

The 52 recommendations of the Guidelines Panel are presented below in Sections 3-5. They are organized into three categories for ease of review, although many may be relevant to more than one topic. Most recommendations were informed by the evidence review and the introduction to each section discusses some of the relevant literature. However, the introductions are not intended to be a comprehensive summary of all supportive data. Because the evidence base was extensive and comprised a wide range of sources, the panel chose not to grade the quality of individual studies. Consequently, all recommendations are considered consensus based (CB).

3. Inpatient Services

3.1. EMU/Electrodiagnostic Services

3.1.1. EMU Infrastructure and Personnel

The mission of a specialized epilepsy center is to provide comprehensive diagnostic and treatment services to people with epilepsy.⁶ A key component in this endeavor is an epilepsy monitoring unit (EMU) that delivers high quality care, supported by a multidisciplinary team of specialty-trained professionals and a comprehensive electrodiagnostic laboratory.^{6,27,28} Video-EEG (VEEG) monitoring is an essential tool for managing the care of complex epilepsy patients, for discriminating between epileptic and non-epileptic events when the diagnosis is in question, and for evaluating candidates for epilepsy surgery.²⁹

To allow for optimal patient observation and seizure recognition, an EMU must have continuous video recording, remote-controlled cameras, patient-activated event buttons, and alarms.³⁰⁻³³ Trained reviewers should provide continuous observation³²⁻³⁵ and the EEG should be accessible from a central server for prompt review^{35,36} VEEG monitoring studies performed in such an EMU improve patient safety and have a significantly higher likelihood of establishing a diagnosis than those performed in a less-structured setting³⁷. The number of seizures captured on VEEG monitoring and patient outcomes also improves with higher levels of staff training.^{28,34}

While published consensus states that EMU staff should have specialized training in seizure recognition and epilepsy care,^{6,27,32,35,38} no national standards for epilepsy nursing education exist. In addition, only limited data regarding ideal nurse-to-patient ratios are available; and the optimal ratio may vary depending on patient acuity.^{33,35} Given the considerable variation in staffing models among centers, the scope of education for nurses and nursing assistants should be tailored to their individual roles in each center.³⁸ Externally developed curricula such as the American Epilepsy Society's on-line *EMU Caring* program or the American Association of Neuroscience Nurses' *Certificate Program for the Seizure and Epilepsy Healthcare Professional in a Comprehensive Epilepsy Center* are useful to supplement local educational initiatives and create consistency among centers.^{39,40}

For EEG technologists, certification by ABRET Neurodiagnostic Credentialing and Accreditation is a nationally recognized standard for neurodiagnostic knowledge and performance. ABRET has established the R.EEG T. as a foundation credential for EEG technologists, and also offers advanced credentials CLTM and NA-CLTM for technologists focused on continuous video-EEG monitoring. Ideally, all technologists would have the highest level of training and certification; however, this goal is constrained by the limited availability of trained technologists and existing epilepsy center practices. In accordance with previous guideline recommendations,^{6,27} the panel's consensus opinion was that all epilepsy centers should have registered EEG technologists on their staff, but there is insufficient evidence to recommend a specific number.

Similarly, although limited data suggest that seizure recognition increases when the EMU uses trained EEG technologists for the continuous observation of the VEEG³⁴ and that a lower ratio of VEEG studies per technologist is preferable to having a single technologist monitoring a high number of studies,³³ existing center practices vary. Some centers use trained observers to supplement technologists. Current literature supports the need for continuous observation of VEEG monitoring studies,^{32,33,35,41} but data

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are insufficient to support recommendations regarding the type of observer or the ratio of studies to observer.

Expertise in interpretation of VEEG monitoring and in management of the diversity of epileptic disorders, comorbidities, and disorders mimicking epilepsy exceeds the training of most general neurologists. Epilepsy center physicians should have subspecialty fellowship education, for example in clinical neurophysiology or epilepsy, and subspecialty board certification.^{6,27} Similarly, caring for children with epilepsy requires specialty expertise including pediatric training. Care of patients in the EMU is a complex undertaking requiring coordinated efforts by team members and experience responding to convulsions and postictal agitation. Though data on the impact of volume in EMU care is lacking, in other complex medical conditions, such as congestive heart failure, high volume centers achieve shorter length of stay and decreased mortality compared to low volume centers.⁴² There should be an adequate yearly volume of EMU patients to ensure the EMU team has regular daily experience caring for epilepsy patients. This is particularly true for physicians interpreting EEGs and performing other epilepsy-related procedures.^{8,43,44}

1. Recommendation: All epilepsy centers should have an epilepsy monitoring unit (EMU), which is a dedicated inpatient location for performing 24-hour continuous video-EEG monitoring for seizure classification or localization. **CB**

Remark: The EMU should be staffed with epilepsy-trained nurses and nursing assistants. The nurse-to-patient ratio should be adequate to ensure safety and rapid response to seizures. **CB**

Remark: Patient rooms in the EMU should have remote-control video cameras with 24/7 recording available that are movable by observers to keep the patient on video continuously. **CB**

Remark: Video and EEG data should be captured and sent to a central location and be readily available to the physician reviewer in real time. **CB**

Remark: All EMU rooms should have a patient-activated event button and alarm. **CB** Remark: Centers should have registered EEG technologists (R.EEGT) on staff. **CB**

2. Recommendation: All epilepsy centers should have 24/7, continuous, real-time supervision of ongoing VEEG studies in the EMU. **CB**

Remark: Supervision should be performed by a trained observer watching VEEG studies with no other concurrent responsibilities. The trained observer may be an EEG technologist. **CB**

Remark: Trained observers must have direct access to nurses and physicians caring for the patient. If the observer is not an EEG technologist, trained observers must have direct access to a supervising EEG technologist. **CB**

Remark: Trained observers should be provided patient-specific seizure descriptions and considerations to assist them in seizure recognition. **CB**

Remark: The ratio of trained observers to VEEG studies being monitored should be adequate for timely recognition of seizures and patient-related events. **CB**

3. Recommendation: All epilepsy centers should have physicians with sufficient training and expertise to provide optimal care. **CB**

Remark: Center physicians should have board certification in epilepsy or clinical neurophysiology. **CB**

Remark: Centers treating children should have at least one pediatric epilepsy specialist on staff with board certification in epilepsy or clinical neurophysiology as well as neurology with special qualifications in child neurology. **CB**

4. Recommendation: All epilepsy centers should have sufficient volume of patients admitted to the EMU to maintain the expertise of the epilepsy care team. **CB**

3.1.2. EMU Protocols and Safety

Patients referred to epilepsy monitoring units often have poorly controlled epilepsy or seizures that have changed in frequency or character. They are often at high risk for status epilepticus and alterations in respiratory and or cardiac function related to seizures or the postictal state.⁴¹ Epilepsy monitoring units must be prepared to manage these epilepsy-related emergencies with emergency medications and equipment and with an immediately available provider or emergency medical team who can be called to the bedside.^{6,27,32} Published data are limited, but monitoring of ECG and oxygen saturation may be appropriate for high-risk patients.⁴¹ Centers with pediatric patients should have specific protocols addressing the different medications and dosages used for different ages and weights and for the different seizure types seen in childhood epilepsy and other pediatric resources, especially child life specialists.

More commonly, adverse events in the EMU are due to seizure-related falls or injuries,^{41,45} which can be exacerbated by postictal agitation.⁴⁵ The EMU should be designed with seizure precautions and safety measures in mind.^{6,27,31,32,46-48} The risk of adverse events is increased in the setting of medication withdrawal,⁴¹ so centers should have a formal protocol to address safe reduction of ASM. Utilization of standardized protocols to anticipate and address adverse events in the EMU and for acute seizure management are widely recommended as essential safety measures, ^{6,31,35,41,49-51} although many centers lack relevant protocols⁵² and center practices vary significantly.^{49,52,53} The absence of a consistent approach to EMU practice not only places patients at risk, but also creates a difficult situation for nurses and other staff.⁵²

A standardized admission order set for the EMU is an efficient way to ensure that center protocols are consistently applied. Seizure precautions and safety measures should be included in admission orders for all patients regardless of whether they suffer from epileptic seizures or non-epileptic events.^{31,50} In addition to ensuring safety, standardized protocols can also enhance the diagnostic utility of EMU studies by ensuring consistency in testing speech, memory, motor function, and level of consciousness during and after seizures.^{29,41,50,51,54} Ictal and postictal assessments require close monitoring of patients for prompt seizure identification³⁵ and underscores the importance of staff education in seizure recognition for both safety and diagnostic evaluation.⁵²

5. Recommendation: All epilepsy centers should have EMUs that are equipped to handle epilepsy-related emergencies. **CB**

Remark: Emergency medications and equipment (such as supplemental oxygen, suction) for seizures or status epilepticus should be available in the EMU. **CB** Remark: All centers should implement a written protocol for managing status epilepticus and acute repetitive or prolonged seizures. **CB** Remark: Qualified providers or a rapid response team must be available in-house to manage seizure emergencies at all times. **CB** 6. Recommendation: All epilepsy centers should implement written protocols regarding response to events that occur in the EMU. **CB**

Remark: A trained observer must be present to identify seizures and initiate a medical response promptly. **CB**

Remark: Centers should have a written protocol for testing speech, memory, level of consciousness, and motor function during and following a seizure. **CB**

Remark: All epilepsy centers should take efforts to minimize risk due to injury and falls. **CB**

Remark: All epilepsy centers should have a protocol for responding to postictal agitation, including education for responders on how to work with these patients. **CB**

7. Recommendation: All epilepsy centers should have a standard set of admission orders and protocols for patients admitted to the EMU. **CB**

Remark: Centers should have a written protocol that addresses the number or duration of seizures over a given period that require physician notification and include measures to be taken if number, duration, or severity of seizures observed is excessive. These instructions should also be included in the admission orders. **CB**

Remark: All centers should have a written protocol that addresses safe medication reduction to increase seizure yield. **CB**

Remark: All EMU patients should have a documented plan for seizure response including rescue medications. **CB**

8. Recommendation: All epilepsy centers caring for children should have pediatric-specific protocols and resources. **CB**

Remark: Child life specialists play an important role in caring for children in the EMU and should be part of the epilepsy care team. **CB**

Remark: Centers with pediatric patients should modify all EMU protocols including, but not limited to, age-appropriate safety measures and medication dosage. **CB**

3.1.3. Communication and Reporting

Many published guidelines for epilepsy centers focus on optimizing clinical procedures and safety measures. While these are essential components for delivering high quality care, the needs of the patient are often overlooked. In addition, the timely sharing of results to referring physicians may not be adequately considered. Studies addressing these important areas are limited, but in 2012 Schafer, et al published an expert consensus guideline that recognized the importance of communication with patients and caregivers as an essential component for ensuring patient safety.³² The resulting guidelines recommended pre-admission education for patients and families, and inpatient assessment for additional educational needs. In some circumstances, the primary care provider or referring specialist may be the best person to counsel and prepare the patient and family for admission.³² Additional patient and caregiver education was recommended prior to discharge. The current panel agreed with the importance of ongoing communication with patients and caregivers not only around admission and discharge, but throughout the EMU stay. A timely report of EMU findings, utilizing standard classification and terminology is also essential for communication with the referring provider and with additional specialists if needed in the future.⁵⁵

9. Recommendation: All epilepsy centers should provide EMU reports that meet ACNS standards. **CB**

Remark: Reports should use standard classification of seizure and epilepsy type. **CB** Remark: Reports should be generated in a timely fashion. **CB**

10. Recommendation: Centers should provide patient and caregiver education in preparation for EMU admission. **CB**

11. Recommendation: Centers should regularly inform EMU patients and/or caregivers of important findings in their evaluation and changes in the care plan. **CB**

Remark: Patients and/or caregivers should be updated daily with interval results from VEEG and other diagnostic tests and changes in treatment. **CB** Remark: Information in EMU reports should be shared with patients and caregivers, including a verbal conference with patient and caregiver to discuss preliminary findings prior to discharge. **CB**

12. Recommendation: Centers should provide EMU discharge planning and education that is shared with patients and caregivers, including safe medication resumption or guidance on new medication, follow-up care, and contact information. **CB**

3.2. Surgery

Approximately one-third of people with epilepsy continue to have drug-resistant seizures despite trying multiple anti-seizure medications. They experience increased morbidity and mortality and decreased independence and autonomy. Epilepsy surgery comprises several safe and effective treatment options that remain underutilized both in children and adults⁵⁶⁻⁶¹ despite the value of surgery being demonstrated in numerous studies and affirmed in prior guidelines.⁶²

3.2.1. Pre-surgical Screening and Candidate Selection

Identification of patients who may benefit from surgical therapies requires a concerted effort by epilepsy programs. However, the process of directing patients to epilepsy surgery is fraught with numerous challenges and complexities that delay or preclude surgical referral, including disparities in referral to epilepsy surgery based on race and other social determinants of health.^{27,63-65}

Weighing potential risks and benefits of different surgical treatments as well as pre-surgical planning of intracranial EEG studies requires integration of a range of patient information and data and requires the expertise of multiple clinical specialties. The recommendation of a particular surgery or choice of surgeries must include consideration of not only the details of electrophysiology, neuroradiology, and surgical anatomy, but should also weigh the patient's neurocognitive status, psychiatric state, psychosocial stressors, and support network. The most effective way to integrate these perspectives is through a multidisciplinary surgical conference.

Multidisciplinary surgical conferences with expert personnel including neurologists, neurosurgeons, neuropsychologists, and neuroradiologists, among others, result in effective treatment recommendations based on consensus, integration of multimodal image evaluations, and complex pre-

surgical assessments.⁶⁶⁻⁶⁹ Regular collaboration and clear communication through multidisciplinary conferences also expedite critical preoperative diagnostic testing and surgery.⁷⁰

An implicit tenet of patient-centered care is that patients should be advised of and receive recommendations for all surgery options likely to benefit the patient. Multidisciplinary conferences should consider all surgeries that may benefit a patient, not only those available in a particular center. Centers should facilitate referrals to other epilepsy surgery programs in cases where a recommended surgery cannot be performed at their own center.

13. Recommendation: All epilepsy centers should regularly screen patients for drug resistant epilepsy and refer such patients to multidisciplinary surgical conference for consideration of epilepsy surgery. **CB**

Remark: Referrals for epilepsy surgery evaluation should be made in a timely manner. **CB**

Remark: Epilepsy surgery includes resective, disconnection, ablative, intracranial and extracranial neurostimulation procedures, and placement of intracranial electrodes. **CB** Remark: Patients who were previously evaluated for epilepsy surgery but did not proceed to surgery should continue to be screened regularly. **CB**

14. Recommendation: All centers that perform epilepsy surgery should have a formal presurgical conference with the multidisciplinary team to evaluate and plan for each patient referred for epilepsy surgery. **CB**

Remark: The surgical epilepsy care team includes neurosurgeons, neuropsychologists, epileptologists, EEG technologists, nurses, neuroanesthesiologists, psychiatrists, neurophysiologists, neuroradiologists, case managers, and/or patient advocates. The neurosurgeon, neuropsychologists, epileptologists, and neuroradiologists should attend the pre-surgical conferences consistently, with others attending as appropriate. **CB**

15. Recommendation: Multidisciplinary surgical conferences should be able to appropriately screen patients for all epilepsy surgery options and recommend the best procedure for controlling a patient's epilepsy without regard to whether it is performed at the center. Centers that do not perform specific epilepsy surgical procedures should refer patients to a center that performs those procedures, when appropriate. **CB**

Remark: Centers that only perform extracranial neurostimulation procedures (eg, VNS) should have a referral arrangement whereby candidates for these procedures are presented at a multidisciplinary conference at the partner center that performs the full range of epilepsy surgical procedures. **CB**

Remark: Centers that lack experience in performing certain procedures in children should refer patients to a center that regularly performs those procedures. **CB** Remark: Centers that receive referrals from other programs should not replicate the evaluation unnecessarily and should involve the referring provider in decision-making. **CB**

3.2.2. Intracranial Surgery

Optimal outcomes of epilepsy surgery are predicated on accurate identification of seizure onset regions and key pathways of seizure spread. Because epilepsy is a heterogeneous disorder where involved brain

regions and circuits differ significantly from one patient to the next, individualized assessment and surgical planning including intracranial recordings are essential to achieve best outcomes. International consensus criteria for pediatric epilepsy surgery identify the ability to perform invasive EEG recording, including stereo-EEG and subdural electrode placements, as integral functions of the highest level of surgical epilepsy care.⁴³ Although intracranial EEG and scalp EEG activity share a common origin in the brain, key differences distinguish intracranial compared scalp EEG recordings, thus requiring the attention of clinicians with significant experience interpreting intracranial EEGs.

To minimize complications in neurosurgical patients who have implanted intracranial electrodes, meticulous attention to the details of care is required. The use of clinical protocols has become an established and reliable tool for ensuring optimal outcomes in surgery and in medicine more broadly.⁷¹ Centers should have written protocols that govern the care of patients undergoing intracranial EEG with the goal of minimizing the risks inherent to monitoring seizures in patients with intracranial instrumentation. These protocols should include guidelines for the care of head dressings; patient safety and fall risk mitigation; measures to prevent post-operative infections and other potential complications; safety in the setting of anti-seizure medication withdrawal; mitigation of the risk of provoking seizures during mapping as part of extra-operative electrocorticography (ECoG); and neurophysiological equipment standards.^{27,41,72} Compared to scalp EEG, where standardized electrode I placement is used universally on all patients, the location of intracranial EEG electrodes is variable among patients. Because knowledge of precise electrode location will ultimately inform the targeting of therapeutic ablative, resective, or neuromodulatory surgeries, clinicians must know the precise locations of intracranial electrodes when interpreting intracranial EEG studies.

The number of brain regions that can be implanted for long-term recording of seizures is limited, so intracranial recordings can only sample a small percentage of the brain. Intraoperative electrocorticography allows recording of additional brain regions under a recording electrode placed by the surgeon on the surface of the exposed brain during resective surgery. By moving the recording electrode during an operation, a surgeon can assess the presence of epileptic activity in brain regions that were not implanted with intracranial electrodes previously. Evidence indicates that these recordings are informative for prognosis.⁷³⁻⁷⁵

16. Recommendation: All epilepsy centers that perform intracranial surgery should have the capability of performing 24-hour video-EEG monitoring with intracranial electrodes, including stereo EEG and subdural electrodes. **CB**

Remark: All centers that perform intracranial monitoring should have epileptologists with sufficient volume of cases to maintain expertise in interpretation of intracranial EEGs. **CB**

Remark: All centers should have written protocols governing care for patients undergoing video EEG monitoring with intracranial electrodes, including care of head dressings and measures to prevent postoperative infections or other complications. **CB** Remark: All centers that place intracranial electrodes should have capabilities for electrode localization, including use of 3D reconstruction. **CB**

17. Recommendation: All centers that perform resective surgeries should have the ability to perform intraoperative electrocorticography to identify epileptogenic tissue. **CB** Remark: Electrocorticography should be interpreted by epileptologists or neurophysiologists with sufficient volume of cases to maintain expertise. **CB**

3.2.3. Identification of Eloquent Brain Regions

Surgical planning requires the identification of functional cortical regions where resection or ablation would produce unacceptable morbidity. Treatment via neurostimulation should be considered as an alternative means of controlling seizures without producing deficit. With accurate functional mapping, a neurosurgeon may safely and maximally remove brain regions giving rise to seizures while minimizing risk to functional cortical regions. Preoperatively, lateralization of eloquent language function may be determined noninvasively with fMRI, MEG, or with the intracarotid sedative administration, the Wada test. In patients undergoing surgery, intra-operative and extra-operative functional mapping are used to delineate the brain regions that perform critical motor, sensory, behavioral, and language functions.

The selection of appropriate tasks to perform during functional mapping is essential for accurate and informative results. Neuropsychologists are the clinical specialists most familiar with designing questions, objects, and tasks that probe the different cognitive functions distributed across the cortex, so they should be involved in the design of testing protocols. When feasible, the participation of a neuropsychologist in functional mapping allows adjustment of test questions and tasks in response to patient performance.

 Recommendation: Centers that perform intracranial surgeries should have the ability to perform functional mapping, including motor, sensory, language, and behavioral modalities. CB Remark: Functional mapping procedures include cortical stimulation and evoked potential recording. CB

Remark: Centers should have written protocols for functional mapping that address methodology, safety, and risk of provoking seizures during mapping. **CB** Remark: Center protocols for mapping language and behavioral modalities should be drafted in consultation with a neuropsychologist. When possible, a neuropsychologist should be present during the mapping procedure. **CB**

Remark: Centers should have capability of performing intraoperative functional mapping to maximize possibility of seizure freedom while mitigating risk of iatrogenic injury. **CB**

Remark: Centers that use intracranial electrodes should have the capability of performing extra-operative functional mapping for surgical planning. **CB**

19. Recommendation: All centers that perform surgery should have the ability to pre-operatively assess language dominance and memory. **CB**

3.2.4. Surgical Training and Experience

Surgical treatment of epilepsy requires the surgeon's mastery of numerous specialized techniques and knowledge that together have the goal of disrupting brain regions and circuits responsible for seizures while preserving critical brain functions. The importance of specialized skills in epilepsy surgery, and hence the need for specialized training for neurosurgeons performing such procedures, is increasingly recognized.⁷⁶⁻⁷⁹ Observational data demonstrate that the addition of a sub-specialty-trained functional neurosurgeon dedicated to epilepsy surgery improved both the volume of patients referred to epilepsy surgery and surgical outcomes.⁸⁰ In North America, board certification serves as a marker of surgeon

training and experience. Surgeons from outside North America may have equivalent training and experience without board certification.

Epilepsy surgery in young children poses additional challenges both in the types of epilepsy encountered and the requirements for surgery in the youngest patients. In epilepsy centers serving children, pediatric neurosurgeons skilled in hemispherotomy, for example, along with pediatric anesthesiologists and critical care intensivists, are essential for the treatment of high-risk cases in infants and toddlers.⁸¹

Sufficient case volume at centers that perform epilepsy surgery is essential for maintaining the expertise of the multidisciplinary epilepsy care team. Studies across surgical and medical areas have consistently shown improved outcomes associated with higher volume^{44,82}, and the International League Against Epilepsy [ILAE] has established minimum case volume standards for epilepsy centers.^{8,43} While good outcomes certainly may be achieved at low-volume epilepsy centers, available data suggest higher odds of surgical complications at low-volume epilepsy surgical centers, as well as lower costs of care at high-volume centers.⁸³ While reliance on volume measures alone may result in unintended consequences, such as centers' performing unnecessary surgery or certain types of surgery simply to attain accreditation status,⁸⁴ minimum case volumes would enable multidisciplinary teams to maintain expertise in these complex procedures.

20. Recommendation: All centers that perform epilepsy surgery should have a neurosurgeon with specialized training and experience in epilepsy surgery. **CB**

Remark: Center neurosurgeons should be board certified or tracking toward certification in neurosurgery. **CB**

Remark: Centers that serve children should have a neurosurgeon with specialized training and experience in pediatric epilepsy surgery, including hemispherotomy. **CB**

21. Recommendation: All centers that perform epilepsy surgery should have sufficient volume of cases to maintain expertise of the multidisciplinary surgical epilepsy care team. **CB**

3.2.5. Pathology Report

Epilepsy can be due to numerous etiologies including structural, genetic, infectious, metabolic, and immune-related disorders. The specific underlying causes and mechanisms that contribute to a patient's seizures can have a significant effect on treatment strategies and prognosis. In some cases, future therapy may be informed by the pathologic diagnosis.

For instance, multiple types of malformation of cortical development (MCD) and focal cortical dysplasias (FCDs) have different histopathologic findings and associated genetic mutations.⁸⁵ For some types, the chance of seizure freedom may depend on the completeness of resection of the malformation.⁸⁶

Therefore, surgically resected tissue, including the epileptogenic zone or suspected lesion, should be examined by a neuropathologist. The formal pathology report may provide crucial information for determining the underlying cause of epilepsy, guiding treatment decisions, and ensuring optimal patient care.

22. Recommendation: All epilepsy centers that perform resective surgery should have surgical specimens analyzed by a neuropathologist who generates a formal pathology report. **CB**

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4. Diagnostic Evaluation

4.1. Neuropsychology Services

Epilepsy often has neurocognitive impacts. The presence of a seizure focus in a region of the brain may disrupt the normal cognitive processes located there. The cognitive status of patients becomes even more complex when the effects of anti-seizure medications and epilepsy surgery are considered. Resective epilepsy surgery, by its nature, introduces a lesion that may have cognitive consequences. Neuropsychological testing characterizes cognitive functions in order to anticipate the long-term effects of seizures and assess the impact of treatments. This testing assumes special importance in planning for epilepsy surgery as it provides insight into the cognitive burden of poorly controlled epilepsy, identifies cortical regions functioning below expectations, and considers potential consequences of surgical resections.^{27,87-89}

Neuropsychological testing plays an important role throughout the treatment course as it assesses the impact of seizure medications changes, treatment of mood comorbidities, epilepsy surgery, and rehabilitation needs.^{87,88,90-92} In children, testing can assist in monitoring maturation and development, which are impacted by epilepsy.⁹¹ For neuropsychological assessment to be optimally informative and cost effective, standardization of testing frequency, testing protocols, and use of validated measure of performance should be encouraged.^{90,93,94}

23. Recommendation: All epilepsy centers should have neuropsychologist(s) with training in neuropsychometric evaluation on site or by referral to perform or supervise clinical neuropsychological evaluations for patients manifesting or expressing neurocognitive symptoms or being evaluated for epilepsy surgery. **CB**

Remark: The epilepsy center should have standard protocols that address which patients require neuropsychometric evaluations. CB

Remark: Clinical neuropsychologists should be board certified or pursuing board certification. **CB**

Remark: Centers with pediatric patients should have neuropsychologists with specific training and expertise in evaluating children. **CB**

Remark: Individual tests should be performed by neuropsychologists, qualified psychometricians, or clinical staff with formal training in the administration of these tests. **CB**

4.2. Imaging Services

Brain imaging is essential for the diagnosis, treatment, and follow-up care of persons with epilepsy. Structural imaging (CT and high-resolution MRI) shows the detailed anatomy of the brain and any malformations or lesions that may be present. Every epilepsy center should have good quality CT and MRI capabilities and should use MRI protocols optimized for epilepsy.⁹⁵⁻⁹⁷

In centers that perform epilepsy surgery, availability of additional imaging modalities is essential. No randomized controlled trials compare different methods of functional imaging with regard to epilepsy surgery outcomes There is, however, consensus that functional brain imaging including PET, SPECT, and

magnetoencephalography (MEG) can localize regions of abnormal blood flow, perfusion, metabolism, or electromagnetic activity and may identify foci of epileptic activity, thereby increasing the yield of presurgical localization.⁹⁷⁻¹⁰³ In addition, functional mapping modalities can identify regions of functional cortex such as brain centers of language, movement, tactile sensation, hearing, and vision, and guide the surgical approach to resecting epileptogenic brain lesions.^{98,104,105}

Lateralization of eloquent language function may be determined noninvasively with functional magnetic resonance imaging (fMRI) or with intracarotid sedative administration, the Wada test. The Wada test also makes it possible to assess the potential impact of resective or ablative surgery on some memory functions. These tests can determine safety of surgery in the dominant hemisphere for many patients.^{92,106,107} Wada testing is clearly more invasive and has more risk than fMRI, and should be used selectively for appropriate patients when surgery may affect memory or language function and benefits of Wada testing outweigh its risks.^{27,76,89,104,107,108}

Consideration of brain development, neuroplasticity, and pediatric-specific epilepsy syndromes requires that centers serving children should have specialists with training and expertise in interpreting pediatric imaging studies. The differing behavioral needs of children also require that the imaging centers should have expertise to perform those studies safely, including capabilities for pediatric anesthesia if necessary.^{97,109}

24. Recommendation: All epilepsy centers should have CT and MRI with optimized epilepsy-specific MRI protocols. **CB**

Remark: Centers that serve children should have the capability of performing studies while the patient is under anesthesia with appropriate safety monitoring. **CB**

25. Recommendation: For centers that perform surgery, PET, SPECT, and/or MEG should be utilized when appropriate to increase the yield of pre-surgical localization of the seizure focus and assist in surgical decision making. **CB**

Remark: The multi-disciplinary surgical planning team should make the decision regarding which specific imaging modality to use. **CB** Remark: Centers that perform surgery but do not have these imaging modalities should

have the capability to arrange referrals for surgical patients. **CB**

Remark: Centers that serve children should have the capability of performing studies while the patient is under anesthesia with appropriate safety monitoring. **CB**

26. Recommendation: For centers that perform surgery, fMRI, MEG, other functional mapping modalities, and/or Wada tests with cerebral angiography should be available to assist in localization of eloquent functions. **CB**

Remark: Centers that perform surgery but do not have these imaging modalities should have the capability to arrange referrals for surgical patients as appropriate. **CB**

27. Recommendation: Centers that perform diagnostic imaging should have studies interpreted by personnel with appropriate specialty training and certification. **CB**

Remark: Centers that serve children should have studies interpreted by neuroimaging specialists with specific training and expertise in pediatric studies. **CB**

4.3. Genetic Services

Genetic testing has gained an increasingly important role in the evaluation of epilepsy, especially following the advent of next-generation sequencing technology in the early 21st century. Multiple studies have demonstrated its diagnostic utility both in children¹¹⁰⁻¹¹⁴ and in adults.¹¹⁵⁻¹¹⁸ The identification of a genetic disorder is useful in determining prognosis,¹¹⁵ and has implications both for medical management^{113,116,117} and for surgical decision-making.^{113,119} Testing should occur early in the evaluation of epilepsy, as establishing a diagnosis at a younger age may lead to more effective management and better outcomes.¹¹⁷

No current consensus on the optimal genetic testing strategy for epilepsy has been reached.^{111,112,120} Anticipated diagnostic yield, patient age at testing, and cost-effectiveness all influence test choice. Extensive evidence exists that the diagnostic yield of genetic tests is higher in individuals with drug resistant epilepsy,¹¹⁶ earlier age of seizure onset,^{110,116,117} and in certain patient subpopulations such as those with developmental epileptic encephalopathy or neurodevelopmental disabilities.^{110,116,121} Centers that implement a consistent strategy for genetic testing that reflects these factors are more likely to provide benefit to patients than those lacking an established testing protocol.¹¹⁷

The growing role of genetic testing in epilepsy care has created a need for genetic counseling services in epilepsy centers. Genetic counselors play an important role in educating patients and families regarding the meaning of test results, the features of specific genetic syndromes, the risk for recurrence, and the options for reproductive genetic diagnostic technology.^{115,121} Genetic disorders often affect multiple body systems and require comprehensive care. Consultation with a medical geneticist can play an important role in the initial diagnosis and management of a genetic epilepsy syndrome, especially in children where the full impact of the disorder may not yet be apparent.

28. Recommendation: All epilepsy centers should utilize genetic testing as part of the diagnostic workup for patients with intractable epilepsy of unknown etiology. **CB**

Remark: Genetic testing is useful in evaluation of surgical candidates. **CB** Remark: Testing can be performed by an external laboratory. **CB**

29. Recommendation: All epilepsy centers should have an established protocol to identify those patients who would most likely benefit from genetic testing, even if their seizures are well controlled. **CB**

Remark: Protocols should identify populations with a higher risk for genetic disorders, including early-onset epilepsy, developmental and epileptic encephalopathy, neurodevelopmental disabilities, and family history of epilepsy. **CB**

30. Recommendation: All epilepsy centers should offer genetic counseling from a certified genetic counselor either within the program or by referral. **CB**

Remark: All pediatric centers should have access to medical genetics consultation on site or by referral. **CB**

5. Outpatient Services

5.1. Outpatient Care

Outpatient clinic is an integral component of an epilepsy center's ability to deliver comprehensive quality care. Initial evaluation in the outpatient setting often serves as the access point into the system and facilitates a diagnosis, evidence-based treatment with anti-seizure medication, and other patient-tailored therapies including epilepsy surgery. Longitudinal outpatient care is equally important for ongoing management to mitigate seizure risks, manage medication side effects and epilepsy comorbidities, and provide psychosocial support and resources.

Early access to comprehensive epilepsy clinic improves seizure control, developmental outcomes, and reduces the risk of premature mortality.¹²²⁻¹²⁵ Yet, there is a progressive decline in access to care. ¹²⁶ Delays in access are multifactorial, in part due to a shortage of neurologists and there is little evidence on effective interventions to decrease waiting times.^{124,126} Working within the confines of immovable constraints, epilepsy centers should prioritize resources to optimize scheduling, including development of a triage system to identify patients who need urgent evaluation, as well as providing timely communication to address patient related concerns.

During the COVID-19 pandemic, outpatient access to neurology care expanded with rapid adoption of telehealth.¹²⁷ While reimbursement and rules regarding telemedicine are still evolving, outpatient telehealth services remain an important resource. Telemedicine services can provide earlier access to specialized care and improve patient satisfaction, especially for patients in resource-limited areas.¹²⁸⁻¹³¹ For PWE who may not drive, telemedicine is already an essential tool for accessing medical care. Telemedicine has even greater potential to bring specialized care to underserved regions of the US if regulators are able to update laws concerning state-based medical licensure and interstate prescribing of antiseizure medications that are classified as controlled substances.

31. Recommendation: All epilepsy centers should optimize scheduling to achieve timely appointments both for new and existing patients. This should include triaging patients with urgent need for evaluation. **CB**

32._Recommendation: All epilepsy centers should include telehealth services as an option for outpatient care. **CB**

Remark: The center should have the appropriate infrastructure to provide telehealth services and staff training on providing secure telehealth services. **CB**

33. Recommendation: All epilepsy centers should facilitate patient communication utilizing both telephone and virtual healthcare access services with prompt response to patient concerns. **CB**

5.2. Medication Management

Anti-seizure medication (ASM) management is required for nearly all patients with epilepsy. Medication education as well as monitoring for adherence and side effects should be prioritized, as non-adherence with ASM is associated with increased morbidity, mortality, and higher healthcare-associated costs.¹³²⁻¹³⁴ Dedicated medication counseling can improve caregiver and patient knowledge and medication adherence¹³⁵ which further supports the need for multidisciplinary team members with pharmacologic

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expertise.²⁷ Cost of anti-seizure medication is also a major barrier to adherence.¹³⁶ Epilepsy centers should prioritize resources to help patients navigate financial and insurance barriers.

34. Recommendation: All epilepsy centers should regularly assess patient medication adherence and side effects as part of routine outpatient care. **CB**

Remark: Centers should have a protocol that guides assessment and documentation of medication adherence and side effects. **CB**

Remark: Centers should have personnel with expertise in pharmacology (pharmacists, epileptologists) to address side effects and increase adherence. **CB**

35. Recommendation: All epilepsy centers should have strategies to assist patients with navigating barriers to medication access. **CB**

Remark: Centers need to recognize this problem for patients and take responsibility to connect patients with available resources. **CB**

Remark: Centers should have social workers able to assist patients whose needs cannot be met by available resources. **CB**

5.3. Care Coordination

Children and adults with epilepsy often have additional social, educational, and/or complex medical needs. Care may be lifelong, spanning medical sectors, school, vocational, and in-home services. Optimal management for these patients comprises a multidisciplinary approach among medical providers, therapists, and education specialists, and social workers.¹³⁷ Care coordinators play an integral role in organizing and facilitating care for patients with high resource needs and improve family and care team satisfaction, clinical efficiencies, and patient outcomes.¹³⁸ In many centers, the tasks of a care coordinator may be split among multiple team members; however, identification of a care coordinator as a central role underscores the importance of this resource.

Adolescents are a population with unique needs in the transition period from pediatric to adult care. The American Academy of Pediatrics has advocated for the standardization of early education and coordinated care among patients with complex, chronic health conditions such as epilepsy.¹³⁹ Subsequently, national and international task forces have developed epilepsy-specific transition recommendations.^{140,141} Survey studies following implementation of transition education programs have shown benefit from providers' perspectives and improvement in patient knowledge, as well as demonstration of positive prediction in education/vocational outcomes, patient independence, and overall risk reduction.^{142,143} As such, these studies support the prioritization of provider collaboration, tailored patient education, and the benefit of a multidisciplinary epilepsy transition clinic.^{142,143}

36. Recommendation: All epilepsy centers should have a care coordinator(s) assigned to facilitate referrals for services a center does not provide, to facilitate communication between center providers and outside specialists or agencies, to ensure smooth patient transitions between inpatient and outpatient care, and to assist in transitioning from pediatric to adult epilepsy care providers. **CB**

Remark: Care coordinators may also take a direct role or assist in securing medication and treatment authorizations, home health care services, and obtaining medical equipment for outpatient use. **CB**

Remark: Some of the responsibilities of care coordination could be met by an epilepsy nurse, nurse navigator, advanced practice provider (APP), social worker, or other personnel. However, this does not replace the need for a designated care coordinator. **CB**

- 37. Recommendation: Epilepsy centers that serve children should have a well-defined protocol to facilitate transition between pediatric and adult care. **CB**
 - Remark: Transition of care includes pre-transition planning, transfer, and integration into adult care. **CB**
 - Remark: Transition education for persons with epilepsy and caregivers should begin in early adolescence. **CB**

5.4. Psychogenic Nonepileptic Events

Psychogenic nonepileptic seizures or events (PNES or PNEE), also called functional seizures, are a relatively common psychiatric disorder that presents challenges in diagnosis and treatment and often coexist with epilepsy. VEEG monitoring is the gold standard for establishing the diagnosis of PNEE⁹² which accounts for approximately 15-20% of patients referred to an EMU.¹⁴⁴ Anxiety and depression may contribute to PNEE symptoms.¹⁴⁵ Correctly diagnosing and treating these patients can improve quality of life.¹⁴⁵ Barriers to treatment are significant and lead to readmissions and untreated symptoms.¹⁴⁶ Psychological evaluation can identify factors that contribute to development of PNEE. Psychotherapy can direct treatment and development of coping strategies for these patients.¹⁴⁷ Epilepsy centers play a key role in the diagnosis of PNEE, disambiguating epileptic seizure from non-epileptic events and facilitating referral of these patients to mental health providers for ongoing treatment.²⁷ Epilepsy centers should remain connected to patients with PNEE to advise mental health providers who may be concerned about the possibility of epileptic seizures and, when necessary, to re-evaluate patients where epileptic and non-epileptic events may both be present.¹⁴⁸

38. Recommendation: All epilepsy centers should be able to provide comprehensive care for psychogenic nonepileptic events (PNEE). **CB**

Remark: Centers should have psychologists or psychiatrists with experience managing PNEE on staff or available via an established referral relationship. **CB** Remark: Epileptologists and mental health providers should discuss the diagnosis with the patient during the initial assessment period. **CB**

Remark: Center care providers should remain active in the ongoing care of patients with PNEE to minimize recurrent hospitalization and avoid confusion regarding diagnosis. **CB**

5.5. Special Populations

5.5.1. Patients with Special Needs

Patients with an increased vulnerability to the effects of seizures or who may be at greater risk for developing seizures constitute a special population that requires additional attention to mitigate heightened risks. Children with developmental disabilities develop epilepsy at higher rates than the general population and are more likely to have medical comorbidities in addition to epilepsy. These children are more likely to require more frequent follow-up visits, multispecialty care, and hospitalization. They are also more likely to exhibit behaviors that can – if not appropriately addressed –

interfere with optimal neurological evaluation and care.¹³⁷ Increasingly, the diagnostic evaluation of developmental disabilities also entails genetic testing and counseling.¹²¹

Epilepsy centers should be adequately prepared to meet the needs of this special population. Adequate preparation may in some instances entail providing a particular resource (e.g., child life specialists) as needed in the course of care. More often, adequate preparation requires careful consideration of the obstacles to care faced by children with disabilities and developing a systematic approach to overcoming these obstacles. The development of policies guiding the care of children with developmental disabilities is intended to leverage each center's knowledge of their particular setting and resources to formulate an optimal plan for their patient population and then to train staff in the implementation of these policies, thereby reducing the unpredictability and uncertainty that patients and their caregivers face when navigating medical care.

39. Recommendation: All epilepsy centers should be prepared to care for patients with special needs including those with motor, sensory, and behavioral disorders, and intellectual and developmental disabilities. **CB**

Remark: Centers should have policies guiding the accommodation of patients with intellectual and developmental disabilities, including preparation for and administration of epilepsy-related procedures. **CB**

Remark: Pediatric epilepsy centers should have trained child life specialists to help children and their caregivers in preparation for and administration of epilepsy-related procedures. **CB**

5.5.2. People with Epilepsy and Childbearing Potential

Seizures or the use of anti-seizure medications may affect fertility, contraception, pregnancy, or risk of developmental disabilities in offspring. People with epilepsy and childbearing potential constitute a special population that requires additional attention to mitigate these heightened risks. Evidence is clear that intrauterine exposure of the fetus to some anti-seizure medications, such as valproate, can significantly affect both fetal and postnatal development, often profoundly.¹⁴⁹⁻¹⁵¹ Yet, use of potentially teratogenic medications remains relatively common.^{152,153} Because pregnancies may be unplanned, optimal care requires that counseling and pregnancy planning take place as part of routine care.¹⁵³ The 2017 Epilepsy Quality Measures of the American Academy of Neurology endorsed the importance of counselling on pregnancy-related topics and folate supplementation for women with epilepsy of childbearing age.

40. Recommendation: All epilepsy centers should provide counseling to people with epilepsy and childbearing potential on the impact of epilepsy and anti-seizure medications on contraception and pregnancy. **CB**

Remark: Counseling should include the importance of folate supplementation for people with epilepsy and childbearing potential. **CB**

5.6. Patient Education

Given the chronicity and complexity of epilepsy, education for patients and caregivers is a cornerstone of quality care.¹⁵⁴ People with epilepsy want access to information including epilepsy diagnosis and medication management, treatment options and outcomes, psychosocial impact (employment, driving),

and comorbidities.¹⁵⁵ Relatedly, effective patient education leads to improved epilepsy knowledge, coping skills and sense of wellbeing, and anti-seizure medication adherence.¹⁵⁵⁻¹⁵⁸

Treatment action plans are a self-management tool for acute exacerbations of chronic diseases including epilepsy.¹⁵⁹ Seizure action plans (SAP) provide timely instruction for seizure emergencies, increasing patient/caregiver comfort level with acute seizure care.¹⁶⁰ A single randomized control trial showed implementation of SAP did not lead to difference in health care utilization;¹⁶⁰ however, this remains a postulated benefit.^{159,161} As such, expert opinion consensus recommends SAPs to help guide treatment of seizure emergencies for all PWE.^{159,161}

Sudden unexplained death in epilepsy (SUDEP) is a rare but catastrophic risk among people with epilepsy. While the pathophysiology is not completely understood, known risk factors and preventative interventions are well-established.¹⁶² Literature strongly demonstrates that patients and caregivers want their neurologist to discuss SUDEP, preferably at time of diagnosis and in person.^{163,164} Joint clinical guidelines from the American Academy of Neurology and American Epilepsy Society recommend SUDEP counseling for all PWE and caregivers.¹⁶⁵

Education topics are wide-ranging and cannot be comprehensively covered in any single clinic or inpatient visit. External resources are an essential adjunct to provide additional patient-tailored education and/or community support. To increase access, epilepsy centers should provide written materials in English and other frequently used languages within the center's community.

41. Recommendation: All epilepsy centers should provide epilepsy-specific patient educational materials and referrals to support groups and community resources. CB Remark: Educational materials should cover the broad spectrum of needs and include materials for people with new-onset epilepsy, people affected by common comorbidities of epilepsy, and people with complex needs including those contemplating epilepsy surgery. CB

42. Recommendation: All epilepsy centers should provide patients with individualized written seizure safety management plans including seizure precautions, recognition, triggers, first aid, and rescue medications. **CB**

43. Recommendation: All epilepsy centers should provide PWE and caregivers with information on the risks of SUDEP and life-threatening events related to epilepsy. **CB**

5.7. Social Determinants of Health and Interpretation Services

The Centers for Disease Control and Prevention, adopting the World Health Organization's definition, describes social determinants of health (SDoH) as the nonmedical factors that influence health outcomes.¹⁶⁶ Fixed demographic factors such as race, ethnicity, gender, and age are linked to social factors that negatively affect care delivery and appropriate resource distribution in PWE.¹⁶⁷ These demographic factors, along with socioeconomic status, rural versus urban dwellers, non-English speakers, and proximity to an epilepsy center, are major SDoH affecting this population.¹⁶⁸⁻¹⁷² Similar delays in access to care are seen in PWE with other sociodemographic correlates, such as lower educational attainment, limited health literacy, higher under- or unemployment, and those under- or uninsured.¹⁶⁸

Historical health disparities, discrepancies, and inequities experienced by African Americans, Hispanics, non-English speakers, Asian/Pacific Islanders, and Native Americans have persisted in PWE.¹⁷³⁻¹⁷⁵ Reasons for higher epilepsy prevalence in similar sociodemographic and socioeconomic populations are likely multifactorial.¹⁷⁶⁻¹⁷⁸ These multilayered, interconnected SDOH affect time to diagnosis, syndrome-specific anti-seizure medication management, anti-seizure medication adherence, time to pre-surgical evaluation, and time to surgery.^{9,168,169,172,179-181} The prevalence of epilepsy surgery is also lower among African Americans, Hispanics, and non-English speakers compared to their White, English-speaking counterparts.¹⁸² The negative interplay of cultural norms, physician-patient relationships, cultural sensitivity, and stigma in patients' and families' decision-making cannot be overstated.¹⁷⁵ This ongoing problem of higher prevalence yet delayed access to care must be urgently addressed. Fortunately, studies have shown that once patients get to epilepsy centers, treatment gaps may be lessened.¹⁸³ Awareness of SDoH, education, and outreach are therefore key contributors to improving overall epilepsy care delivery in the United States.

44. Recommendation: All epilepsy centers should assess the impact of social determinants of health on patients and offer referral for support services when necessary. **CB**

45. Recommendation: Centers should offer interpretation services and written translation for patients and caregivers with language barriers. **CB**

Remark: Educational materials should be available in English and in other frequently used languages in the center's community. **CB**

Remark: Patient-specific materials, such as patient care instructions and seizure action plans, should be written in the patient's preferred language, or if not available, interpreter services should be used to verbally communicate information to patients. **CB**

5.8. Psychosocial Services

Psychosocial services encompass a range of medical and psychological support that contributes to comprehensive care for persons with epilepsy. Epilepsy is well known to include comorbidities that can include inattention, cognitive difficulties, mood disorder, anxiety, or perceptual problems. Sometimes the symptoms may coalesce into psychiatric illness such as major depression or attention deficit hyperactivity disorder (ADHD). Symptoms of anxiety or mood lability may even be constituents of ictal or peri-ictal periods and may be difficult to isolate from seizure events. Skilled mental health clinicians are essential components of the epilepsy care team in order to address comorbidity.¹⁸⁴ Treatment of mental health conditions may even improve epilepsy itself.^{144,185}

A comprehensive care approach for epilepsy may include consultation with psychiatry, neuropsychology, and social work services in addition to the primary epilepsy team. Treatment studies have reinforced the notion that epilepsy care that incorporates psychosocial services may improve overall outcomes and improved quality of life for children and adults with epilepsy.¹⁸⁶⁻¹⁸⁸ Sophisticated epilepsy centers need to include psychiatric, psychological, and social work services to complement specialized epilepsy care.¹⁸⁹

46. Recommendation: All centers should regularly screen patients for behavioral health comorbidities and offer referrals for treatment when necessary. **CB** Remark: All centers should screen for depression and anxiety and utilize standardized screening tools if appropriate. CB
Remark: All centers should have established referral processes for behavioral health counseling and psychiatric services. CB
Remark: Centers serving children should screen for learning and behavioral concerns and attention deficit disorders. CB
Remark: Centers serving children should have trained child life specialists to help children and their caregivers cope with the stress of chronic illness. CB

47. Recommendation: All epilepsy centers should have a licensed clinical social worker on staff to assess and address, as appropriate, the disproportionate impact epilepsy has on educational, social, emotional, and vocational needs. **CB**

Remark: Although primary assessment of educational needs is usually done by the school system or by a neuropsychologist, a social worker plays an important role in addressing how children and their caregivers can access school services. **CB**

5.9. Dietary Therapy Services

Dietary therapy has a long history of use in the management of childhood epilepsy, with welldocumented evidence for efficacy.¹⁹⁰⁻¹⁹⁶ There is inconsistent evidence regarding cost effectiveness.^{191,196} Dietary therapy is a treatment of choice for certain genetic syndromes¹⁹² and has a role in the management of refractory epilepsy in infants.¹⁹⁷ More recently, dietary therapy has also been shown to be effective in adults with epilepsy.^{197,198}

Ketogenic diet therapy is often unpalatable, and patients treated with dietary therapy have high rates of non-adherence and early discontinuation, even when the diet has improved seizure control.^{192,193,199} It is also associated with significant adverse effects, typically requiring inpatient monitoring during the initiation of therapy, and regular outpatient monitoring with periodic laboratory testing thereafter.^{191-193,200} Less restrictive diets, such as the modified Atkins or low glycemic index diets, appear to be better tolerated than the traditional ketogenic diet and have also shown efficacy in seizure reduction; however, adherence remains a problem.^{193,199} Registered dietitians play an important role in initiation and subsequent management of all forms of dietary therapy.^{193,195,199,200}

48. Recommendation: All epilepsy centers that offer dietary therapy should have a registered dietitian with expertise in managing dietary therapies. **CB**

49. Recommendation: Pediatric epilepsy centers should have a ketogenic diet program for treatment of epilepsy within the center or by referral, which must include both an epileptologist and a registered dietitian. **CB**

Remark: Centers need a protocol for initiation of the ketogenic diet and for monitoring for adverse events. **CB**

Remark: Centers may utilize advanced practice providers and nurses trained in the ketogenic diet to manage patients. **CB**

5.10. Rehabilitation Services

Rehabilitation services are an essential component of comprehensive epilepsy care to address common neurodevelopmental and neuropsychiatric comorbidities in PWE. Wide-ranging physical and cognitive impairments have a significant impact on quality of life affecting early childhood development, physical mobility, school performance, social interactions, employment, driving, and independent living. Recognition of importance and recommendations for screening and treatment resources have been highlighted in previous national and international epilepsy guidelines.^{27,201,202} Screening for developmental and cognitive concerns is often part of an initial neurology visit. In many cases, this could incorporate additional sources of information such as reports from school, employer, and/or a primary care provider or other specialist's developmental screening.

Current literature also supports special consideration for patients undergoing epilepsy surgery evaluation and treatment. Previous studies have shown post-operative rehabilitation improves employment status,²⁰³⁻²⁰⁵ patient satisfaction,²⁰⁶ and that cognitive "pre-habilitation" programs prior to epilepsy surgery can prepare patients for predicted post-operative changes and help tailor post-surgical rehabilitation planning.⁹² Prescriptive recommendations for rehabilitation program logistics are limited. One study found that programs with a specialized epilepsy design for vocational services had better success than federal programs.²⁰⁷

50. Recommendation: All centers should have a protocol addressing regular screening for neurodevelopmental and cognitive co-morbidities in patients with epilepsy, with referrals for appropriate rehabilitation services. **CB**

Remark: Pediatric epilepsy centers should screen for developmental disorders and speech and language disorders for patients of all ages; they should screen school-aged children for learning and attention disorders. **CB**

Remark: Adult epilepsy centers should screen all patients for cognitive and vocational issues. **CB**

51. Recommendation: All centers should provide physical, occupational, and speech therapy services within the center or by referral. **CB**

Remark: All centers should provide services for cognitive and language disorders, common comorbidities of epilepsy, as part of comprehensive care. **CB** Remark: Centers should offer referrals for physical medicine and rehabilitation consultation when needed. **CB**

52. Recommendation: All epilepsy centers should anticipate potential rehabilitative needs for patients undergoing epilepsy surgery and include appropriate pre-operative assessment to plan for pre- and post-surgical therapy services. **CB**

Remark: For patients undergoing epilepsy surgery, centers should provide physical, occupational, and speech therapy services as part of their pre- and post-surgical care. **CB**

Remark: Centers should utilize pre-surgical neuropsychological testing to direct or guide planning for pre- and post-surgical therapy services. **CB**

6. Conclusion

The recommendations of the *Guidelines for Specialized Epilepsy Centers: Report of the National Association of Epilepsy Centers Guideline Panel* are the product of a diverse panel. The inclusion of voices from a broad spectrum of epilepsy center stakeholders, including those of patients and caregivers, led to a new focus on education and communication--topics that were outside the scope of prior NAEC guidelines. Although these areas are often addressed by providers on an individual basis, reports from PWE and caregivers, supported by input from nurses and EEG technologists, underscored the need for centers to take a more active role in creating uniform standards to ensure all center patients receive adequate information.

The current guidelines also reflect the first time that the NAEC has gone beyond the field of neurology to seek input from other medical specialists and allied health personnel. This is exhibited in a greater emphasis on multidisciplinary care conferences, screening for comorbidities of epilepsy, and providing access to other specialty services in addition to the core epilepsy center components of outpatient care, diagnostic procedures, and epilepsy surgery. Consensus opinion from a diversity of stakeholders strengthens the weight of the guideline recommendations in areas where the evidence base is limited. The panel recognized that the landscape of epilepsy care extends beyond the EMU and outpatient clinic; and, while the current recommendations can only address those areas directly under Epilepsy Center control, centers would benefit from working in concert with other members of their multidisciplinary teams to ensure patients and caregivers remain informed and engaged throughout all aspects of their medical care.

Greater participation of epilepsy centers in data collection and outcomes reporting is needed to advance research into optimal epilepsy care. Connecting outcomes to the implementation of the recommendations in these guidelines will be especially valuable. As further data become available, the current guidelines will need to be adapted to reflect new information. The National Association of Epilepsy Centers is considering adopting a living guidelines model as a means for updating individual recommendations as new relevant evidence becomes available.^{11,12,208-211}

The fundamental purpose of these guidelines is to advance the quality of epilepsy care by outlining the essential services needed for a comprehensive epilepsy center and the optimal manner for their delivery. The current recommendations reflect the contributions from a broad panel of expert opinions and a comprehensive review of existing data. They are designed to facilitate incorporation of future advances and research. As a result, this information will provide ongoing support for epilepsy centers to obtain adequate resources for their programs and for people with epilepsy and their caregivers to assess the quality of care they receive.

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Endorsements

The Guidelines for Specialized Epilepsy Centers: Report of the National Association of Epilepsy Centers Guideline Panel was approved by National Association of Epilepsy Centers' Board of Directors.

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Table 1. Panel Composition

2 epileptologists, panel co-chairs14 additional adult and pediatric epileptologists1 pediatric neurologist4 neurosurgeons2 neuroradiologists1 neuropsychiatrist2 neuropsychologists3 EEG technologists1 pediatric nurse practitioner2 epilepsy nurse specialists1 patient educator1 epilepsy center administrator7 persons living with epilepsy (PWE) or caregivers (1 is also an epileptologist)41 total panelists

Table 2: PICO-Based Inclusion/Exclusion Criteria for LiteratureScreening

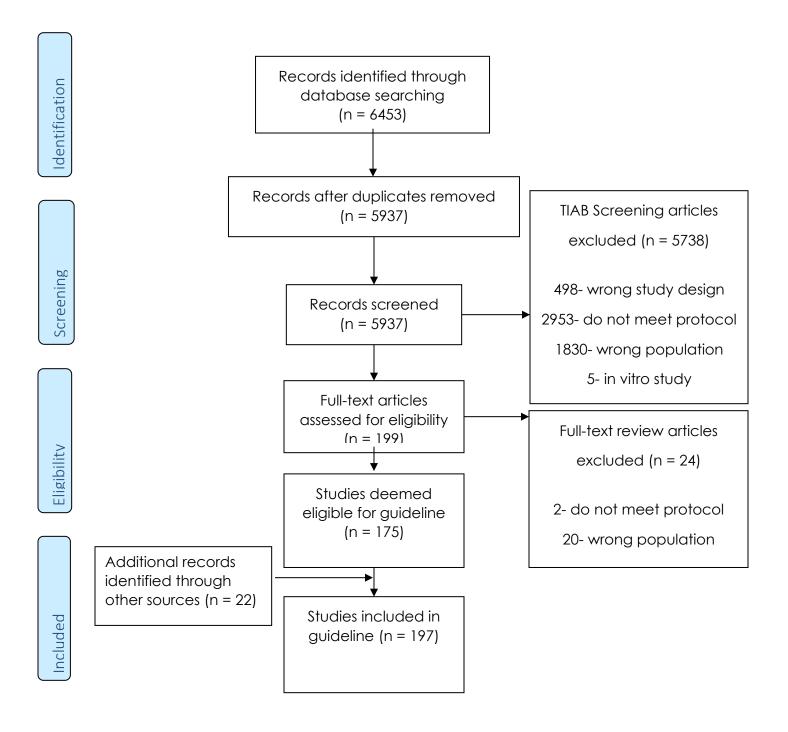
Participants	Among patients with:
Participants	 Epilepsy (controlled or uncontrolled)
	Recurrent seizure-like events
	Suspected epilepsy based on multiple episodes
	 Receiving treatment at epilepsy centers including a focus on: Inpatient (epilepsy monitoring unit, exclude ICU monitoring for complex neurological conditions other than epilepsy) Outpatient (office-based clinic care, telehealth) Accreditation level
	 Patient characteristic (adult, pediatric, mixed)
	 Geographic setting (rural medically underserved, urban medically underserved, suburban, rural not medically underserved, urban not medically underserved)
	Subgroups of interest: Age 65+, pediatric patients, women, rare epilepsy syndromes/conditions
Interventions	Services including but not limited to:
	 Electrodiagnostic (eg, 24-hour video-EEG with either surface electrodes or sphenoidal electrodes, intracarotid amobarbital [Wada] testing, functional cortical mapping, evoked potential recording capable of being safely used with intracranial electrodes, electrode localization) Neurosurgery (eg, emergency or elective including biopsy and removal of incidental lesions, treatment of cerebral complications of epileptic seizures, stereotactic techniques, management of surgical complications, corpus callosotomy) Imaging (eg, computerized axial tomography, cerebral angiography, interictal positron emission tomography, fMRI) Pharmacological expertise (eg., quality-assured anticonvulsant serum drug levels) Neuropsychological (eg, comprehensive test batteries for cerebral dysfunction) Psychosocial services (eg, inpatient and outpatient psychological services for assessment and treatment of chronic epilepsy) Rehabilitation (eg, physical, occupational, speech therapy) Access to higher level care (eg, ICU, anesthesia, emergency resuscitative equipment) Care coordination (eg, medication authorizations, home medical equipment, transition from inpatient to outpatient) Genetic testing and counselling Patient and caregiver education

	•Services for special populations (eg, language interpretation
	services, rare epilepsies)
	Essential elements of the inpatient epilepsy monitoring unit
	including but not limited to:
	•The design and layout of the physical space to provide access,
	observation and monitoring needs of patients, and safety considerations
	•The equipment needed to carry out services
	Data collection protocols and management
	•Additional facility protocols (eg, transportation, fall prevention,
	medication reduction, standard order set)
	Personnel including but not limited to:
	•Epilepsy specialists
	 Providers associated with neurosurgery
	 Providers associated with diagnostic testing
	Psychosocial and care coordinators
	•Nursing
	Advance practice providers
Comparators	Not applicable (include all)
Outcomes and	 Any center outcomes including but not limited to:
Outcome Measures	- Center-wide clinical outcomes determined from datasets
	-Reduced hospitalizations, morbidity, or mortality [over a period of
	time]
	 Non-clinical outcomes including but not limited to:
	-Patient volumes
	-Financial outcomes
	-Staff turnover rates
	-Number of times the center was sued
	-Patient complaints
	-Patients signing out or leaving prematurely due to
	dissatisfaction with care or requesting a new source of care
	-Patient satisfaction
	-Press Gainey scores, wait times for appointments, in-clinic wait,
	return of phone calls
	Patient outcomes including but not limited to:
	-Seizure frequency
	-Seizure freedom
	-Emergency department visits
	-Hospital readmission
	-Quality of life
	-Functional status
	-Behavioral health
	-Mortality
	-Education/employment status
Timing	Any
Study designs	Keep:
Juny uesigns	• RCT (Phase 1-4)
	• NCI (FIIdSE 1-4)

	 Non-randomized clinical trials (Phase 1-4)
	 Observational, non-comparative
	 Observational studies, comparative
	Cross-sectional
	Prospective cohort
	Retrospective cohort
	 Non-concurrent cohort
	 Systematic reviews/meta-analyses
	Pooled analyses
	Case-control
	Reject (wrong study design):
	Case reports/series
	 Prognostic course/factor studies
	Modeling studies
	Pre-clinical
	Narrative reviews
	Reject (other reason for rejection):
	• In vitro
	• Not a clinical study
	 Not a treatment study
	Animal studies
	Non-English
	Duplicate publication
Notes	Despite a long intervention list, any intervention/institution
	characteristic is acceptable.
	Despite a long outcome list, any outcome reported is
	acceptable.
	Hierarchy is to reject all non-epilepsy studies for <i>wrong</i>
	<i>population</i> > reject studies with no new data for <i>not</i> a <i>clinical</i>
	study > reject studies with no center information for wrong
	intervention
	intervention



Figure 1. PRISMA flow diagram for NAEC Guidelines for Specialized Epilepsy Centers.



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