

NAEC Guidelines Revision – Update for Membership

NAEC Guideline Panel Chairs

Susan Arnold, MD and Fred Lado, MD



Overview

- History of NAEC Guidelines
- NAEC Board Decision to Use Evidence-Informed Process to Update Guidelines
- Guideline Process to Date
 - Guideline Oversight Committee
 - Guideline Panel
- Call for Input on Topics and Timeline



NAEC's Guideline History

- NAEC's "*Guidelines for Essential Services, Personnel, and Facilities in Specialized Epilepsy Centers in the US*" *Epilepsia*
 - Originally published in 1990 to provide a “framework for a systematic, well-organized approach to subspecialty epilepsy care.” Checklist of needed elements.
 - Updates published in 2001 distinguished medical and surgical centers and in 2010 removed that distinction and provided more information on referral guidelines, team approach, safety and quality of care.



NAEC Initiates Accreditation Program Responding to Institute of Medicine

- 2013 – IOM Report recommended accreditation of epilepsy centers based on external review and validation by an external body to ensure “excellence, consistency, clarity, and transparency in the provision of epilepsy care.”
- 2015 – NAEC developed and piloted its epilepsy center accreditation program seeking public input on criteria.
- 2016 – Epilepsy Center Accreditation formalized.



2020 Guideline Review Process

- Established Guideline Work Group of NAEC Board in January 2020
- Hired a consultant (Lewin Group) to inform the Board of the current standards for developing respected guidelines in the US and internationally and to consider the potential scope of guidelines.



2020 Guideline Review Process

- Evidence review is considered an essential requirement of guideline development in 2021.
 - Insurers and policymakers look to published literature to make coverage and payment policy.
 - Revised guidelines with a literature/evidence review are needed to provide a published foundation for NAEAC’s accreditation program.
- Board decided that it should undertake an “evidence-informed, consensus-based process” using a Delphi approach.



2020 Guideline Review Process

- Developed and sent an RFP to 4 parties seeking a consultant to assist with guideline development.
- EBQ Consulting chosen due to:
 - expertise and experience with “trustworthy consensus-based, evidence-informed” guidelines.
 - process is acceptable for guideline inclusion in recognized guideline repositories.



Guideline Development Process - Oversight Committee

- Guideline Oversight Committee established
 - Chairs – Christi Heck and David Labiner
 - Members – Kevin Chapman, Lara Jehi and Stephan Schuele
- Creation of Policies and Procedures to follow in forming Panel, including conflict of interest (COI) levels and terms of management and guideline development process.



Creating Guideline Panel

- Broad Call for Applications – June 2021
 - Epilepsy Center Team Stakeholders including NAEC Members, sister provider organizations, and national organizations of other provider groups
 - Patients and Caregivers including outreach to patient organizations and individuals
- Over 100 applications received and reviewed for expertise, stakeholder type, diversity and COI.



Guideline Panel

Epileptologists*, **	17
People with Epilepsy (PWE) and Caregivers*	6
Neurosurgeon	4
EEG Technologists	4
Neuropsychologist	2
Neuroradiologist	2
Epilepsy Nurse Specialist	2
Pediatric Neurologist	1
Neuropsychiatrist	1
Epilepsy APP	1
Patient Educator	1
Center Administrator	1
PANEL TOTAL	43

* 1 level 4 ped epileptologist is also a person with epilepsy

** 9 Epileptologists are APBN Board Certified in Child Neurology, 2 are from level 3 centers

Panel Co-Chairs:

Susan Arnold, MD

Fred Lado, MD, PhD

Panelist names kept confidential until Guideline is complete



Next Steps – Panel Training and Topic Development

Panel Training this month on evidence driven guidelines and topics.

What are the important questions to ask of the scientific literature?

The research questions should include:

- The **P**opulation or target group
- The **I**ntervention or exposure
- The **C**ontrol group
- **O**utcomes



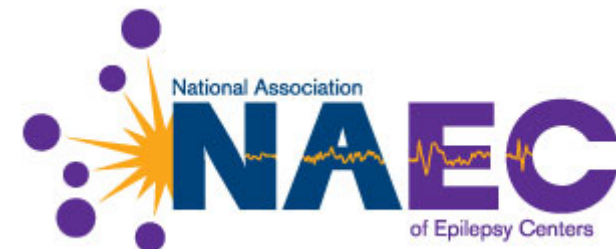
Next Steps - Guideline Recommendations

All recommendations should be written in a standard format.

- Ensures consistency, readability, understanding
- Provide as much detail as the evidence and the expertise of the panel can support:

Who	What	When	Where	How
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- The reasons WHY these recommendations are being proposed are not part of recommendations but can be included in guideline text.



Call for Guideline Topics and Timeline

- Request for input on guideline topics to go out before the end of the year to NAEC Members and other provider and patient organizations.
- Multiple virtual meetings in 2022 to determine topics and reach consensus on recommendations
- Anticipate a year long process with guideline submitted for publication by December 2022.
- Impact on accreditation likely no sooner than 2024/2025.

