Seizure Frequency Process and Outcome Quality Measures

Quality Improvement in Neurology

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Seizure freedom is the goal for patients who experience seizures and the physicians and treatment teams who provide care for these patients. In 2017, the American Academy of Neurology Institute (AANI) seated a standing epilepsy quality measure development work group charged with developing appropriate quality improvement measures for patients with epilepsy who experience seizures. In 2018, the work group released an updated epilepsy quality measurement set that included the seizure frequency measure initially published in the 2014 measurement set.[1,2] In the 2018 publication, the work group noted that future effort was needed to move toward a more standardized capture of seizure frequency.[1] Specifically, a lack of uniformity and consistency in documentation of seizure frequency contributed to poor feasibility of the 2014 seizure frequency measure; this is also a barrier to uniform tracking of seizure frequency for seizure outcome measure collection.[1] In spring 2019, the work group determined the time was ripe to move forward to develop quality measures that would help address the gap in measuring seizure frequency for patients with epilepsy and directly capture seizure outcome data.

Opportunities for Improvement

Tracking seizure outcome is fundamental to management decisions in epilepsy care, but opportunities exist to improve the care of patients by improving seizure frequency documentation. Variation exists in how physicians and treatment teams document seizure activity.[1] For example, documentation of seizure frequency may be recorded as none, frequent, rare, 3 times a week, daily, or with the date of the patient's last seizure. Given this variation, it is difficult to track frequency over time to determine whether seizure activity is increasing or decreasing without more extensive chart review. In addition, comparison may not be possible at all if nonspecific seizure frequency descriptions are used, such as the terms "frequent" or "rare." An opportunity exists to track and measure seizure outcome data over time and improve care with these data.[3-6] This has the potential to affect not only seizure frequency, but other outcomes important to patients that are influenced by seizure control, including quality of life, disability, risk of death from causes including sudden unexpected death in epilepsy (SUDEP), and health care utilization/cost outcomes.[7] Recent efforts have been made to standardize data collection through learning health care systems and direct collaborations with electronic health record (EHR) vendors, thus demonstrating feasibility of standardized seizure frequency documentation in clinical practice.[8-10]

Glossary

Methods

Details of the AANI's full measure development process are available online.[11] These measures were developed as a supplement to the AANI's existing epilepsy quality measurement set.[1] The AANI created a standing epilepsy quality measure development work group in 2017 charged with developing appropriate quality improvement measures for patients with epilepsy who experience seizures. Details of membership and leadership changes for this work group are available in the full measurement set document available at AAN.com/practice/epilepsy-seizures-quality-measures. Members may serve for a maximum of three 2-year terms in accordance with AANI membership protocols.[11] The standing epilepsy quality measure development work group meets every 6 months to determine whether updates are needed, review implementation and testing reports, if available, and identify any supplementary resources that should be developed, such as quality improvement templates, implementation resources, or collaborative projects with other stakeholders.[11]

In spring 2019, the work group determined that it was time to move forward with 2 draft outcome measures addressing the gap in measuring seizure frequency for patients with epilepsy. The work group utilized literature previously identified from the 2017 epilepsy quality measurement set and conducted targeted literature searches for new guideline or systematic reviews released since the original search was conducted.[1]

Ideas for measure concepts were solicited from work group members and 2 concepts were prioritized for development through work group discussions (Figure 1). Not all concepts can be developed, as doing so would be burdensome, and not all concepts are feasible or supported by evidence.[2] Additional concepts considered and reasons for not advancing them were as follows:

- Seizure freedom for patients with nonintractable epilepsy: risk stratification could be applied to an overall seizure freedom measure; thus, this concept would be duplicative.
- Time seizure-free in the calendar year: concern about implementation burdens.
- Seizure freedom among patients who had a resection, ablation, or implantation surgery: feasibility concern as outpatient clinicians may lack direct EHR access to discrete data indicating the surgery date or procedure codes as would be necessary to identify the denominator in the EHR.
- Seizure freedom among patients with epilepsy on 1 antiseizure medication: feasibility concerns, as medication prescribing data are inconsistent, and some patients with low seizure frequency may not be seen in the calendar year, which would be difficult to translate into a performance rate.
- Seizure freedom among patients with convulsive epilepsy on 1 antiseizure medication: feasibility concern that medication prescribing data are inconsistent.

Figure 1 Measure Development Process
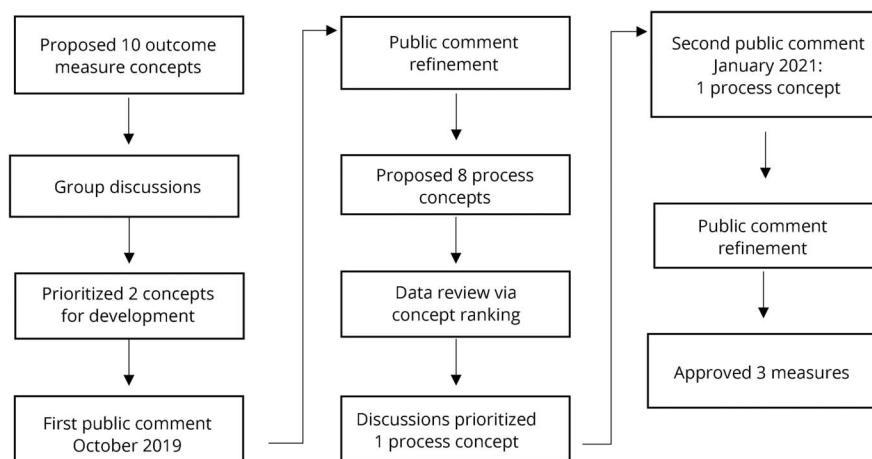
- Patients with epilepsy presenting to an emergency department for seizure-related care: feasibility concerns, as not all have access to claims data and delay in obtaining claims data prevents meaningful opportunity to drive quality improvement in practice.
- Patients with epilepsy with increased seizure frequency referred to a comprehensive epilepsy center: concern regarding implementation burdens.

A 21-day public comment period was held in October 2019 on 2 draft seizure outcome measures.[11] Comments were received from 28 individuals and organizations. The work group reviewed comments and met again. In response to public comments received on the outcome concepts, a process measure was developed to accompany the outcome concepts. The process measure was selected among 8 potential measures via a ranking process among work group members to prioritize measures that are feasible, meaningful, and linked to improved outcomes. The process measures considered but not selected were as follows:

- Seizure diary discussion
- Drug-resistant epilepsy diagnosis
- Convulsive seizure frequency recorded
- Seizure severity with a validated instrument
- Patient or care partner reported subjective seizure frequency improvement
- Seizure severity
- Patient or care partner reported subjective seizure severity improvement

Due to the COVID-19 pandemic, the project was temporarily halted, resuming work in late 2020. The work group held a second 21-day public comment period in January 2021 on 3 concepts: 2 outcome and 1 process. All the individuals who commented during the first public comment period were alerted that a process measure was developed in response to their input and were invited to review the revised measures.

The second public comment resulted in input from 39 individuals and organizations.

The work group responded to and incorporated edits to each comment as appropriate.[11] The work group refined the seizure classification system based on input received. Outcome measures were converted to quality improvement–only measures. This distinction is made to allow for the measures to be made available for implementation, while mitigating the effect of any potential unintended consequences. The measures will not be submitted for consideration in any accountability programs (such as payment or public reporting) at this time. The process measure may be submitted for consideration after measure testing confirms feasibility, reliability, and validity.

Internal approval was obtained by the work group before being reviewed and approved by the AANI's Quality Measure Subcommittee, Quality Committee, and Board of Directors.[11] The measures in this set are being made available without any prior testing. The measurement set will be reviewed by the work group every 6 months for potential updates in response to user feedback and testing reports, if available.

Results

Three quality measures were developed that complement existing AANI epilepsy measures (Table 1). Full measurement specifications are available online at the American Academy of Neurology website; a succinct summary of the new measures is provided in Table 2.

Seizure Type, Frequency, and Time Since Last Seizure Recorded has 4 separate components that are captured for every visit for patients with a primary diagnosis of epilepsy based on ICD codes. Component A assesses percentage of patients or care partners who reported seizure types at all

Table 1 American Academy of Neurology Institute Epilepsy and Seizure Measures

Seizure Process and Outcome Measures	Epilepsy Quality Measurement Set 2017 Update	Child Neurology Quality Measurement Set
Seizure Type, Frequency, and Time Since Last Seizure Recorded	Seizure Frequency (retired 2021)	First-line treatment for infantile spasms
Seizure Freedom	Counseling for Women with Epilepsy	Rescue seizure therapy for children
Tonic-Clonic Seizure Reduction	Comprehensive Epilepsy Care Center Referral or Discussion	Time to third-line therapy for refractory convulsive status epilepticus
	Quality of Life Assessment	Neuropsychological/neurodevelopmental screening
	Quality of Life Outcome	Transition from pediatric neurology to adult neurology
	Depression and Anxiety Screening	

Summary of American Academy of Neurology Institute epilepsy and seizure measures, as well as select child neurology measures applicable to patients with epilepsy, which are available for free at aan.com/practice/epilepsy-seizures-quality-measures.

Table 2 Description of New Quality Measures

Measure	Description
Seizure Type, Frequency, and Time Since Last Seizure Recorded	Percent of patients/care partners who reported at every visit, using categories defined in Table 3 A: Seizure type for all distinct semiologies B: Seizure frequency for all seizure types C: Time since last seizure for all seizure types D: Seizure type, seizure frequency, and time since last seizure for all seizure types at all visits
Seizure Freedom	Percent of patients/care partners reporting no seizure activity in the past 12 months at the last visit in measurement period
Tonic-Clonic Seizure Reduction	Percent of patients with current or past tonic-clonic seizures who reported lower or the same seizure frequency for tonic-clonic seizures at the last visit in the measurement period, compared to the first visit in the baseline period (prior calendar year) Seizure frequency must be documented using categories in Table 3 (seizure frequency or time since last seizure)

visits. Component B assesses percentage of patients or care partners who reported seizure frequency for each seizure type at all visits. Component C assesses percentage of patients or care partners who reported time since last seizure for each seizure type at all visits. Component D (all or none measure bundle) assesses percentage of patients or care partners who reported all 3 measure numerator components (A, B, and C) at all visits.

The work group noted that monitoring seizure frequency and outcomes was of great importance to both patients with seizures and physicians and clinicians who treat patients with seizures. Outcomes cannot be tracked and compared without standardized seizure frequency data. Individuals commenting during the first public comment period highlighted the need for a process measure to capture data systematically to ensure feasibility for subsequent outcome measures. This measure was created in response to feedback received.

The AANI's work group and Quality Measure Subcommittee has discussed documentation burdens and the need to drive change in this area. The work group believed the time was appropriate to build from the successful multicenter consortia

that have implemented data standards and move towards collection of this data for additional treatment teams that want to benchmark their quality improvement efforts to track seizure data and frequency outcomes. Seizure types, seizure frequency, and time since last seizure were defined (Table 3). Efforts were made to align these definitions with International League Against Epilepsy (ILAE) 2017 Seizure Types and Epilepsy Learning Healthcare System consortia categories for seizure frequency and time since last seizure.[8-10,12] Additional ILAE resources may be helpful in implementing any seizure classification system.[13-16]

The intent of Component D is to provide an all-or-none measure bundle for practices and clinicians who have high performance rates for individual components. These data may be helpful for some users, providing an overall measurement of clinician process. Collection of all 3 components is relevant for optimal clinical practice. All-or-none calculation requires each component be completed to meet measure performance, with equal weighting of components. These bundles are valuable, given their patient-centered commitment to the highest quality of care. Clinicians and practices starting out

Table 3 Seizure Measure Definitions

Seizure types: LOINC code 99311-3	Seizure frequency: LOINC code 99312-1	Time since last seizure: LOINC code 99313-9
Focal Onset–Aware Focal Onset–Impaired Awareness Focal Onset–Bilateral Tonic-Clonic Generalized Onset–Motor Tonic-Clonic Generalized Onset–Other Motor Generalized Onset–Nonmotor (Absence) Unknown Onset (if Focal or Generalized)[a]–Motor Tonic-Clonic Unknown Onset (if Focal or Generalized)[a]–Other Motor Unknown Onset (if Focal or Generalized)[a]–Nonmotor Unclassified (i.e., Unsure if Epileptic or Not) Nonepileptic (i.e., Psychogenic or Physiologic)	Innumerable (i.e., ≥10 per day most days) Multiple per day (i.e., 4 days per week with ≥2 seizures) Daily (i.e., 4 or more days per week) Weekly but not daily (i.e., 1–3 per week) Monthly but not weekly (i.e., 1–3 per month) At least once per year, but not every month (i.e., 10 or fewer in past 12 months) Less than once per year Frequency not well defined Unknown	Today 1–6 days ago 1–4 weeks ago 5–12 weeks ago 13–26 weeks ago 6–12 months ago (27–52 weeks ago) 13–24 months ago (53–104 weeks ago) More than 2 years ago (more than 105 weeks ago) Unsure

Abbreviation: LOINC = Logical Observation Identifiers Names and Codes.
[a] Unknown refers to epileptic seizures for which it is unknown whether onset is focal or generalized, using the 2017 International League Against Epilepsy seizure type classification.

collecting seizure frequency data should implement and identify which component measures were not satisfied to identify areas of practice where quality improvement can occur. Over time, it is anticipated clinicians and practices will have high performance on individual components; by moving to the all-or-none calculation, there is a shift to overall patient focus at each visit.

The AANI has ongoing efforts and will continue to collaborate with EHR vendors to improve access to structured data entry to address data collection burdens. The work group collaborated with LOINC (Logical Observation Identifiers Names and Codes) to create codes for the seizure type, frequency, and time since last seizure categories shown in Table 3. The work group appreciates this change in documentation practices is not seamless and may prove burdensome for some practices, but the potential value of the data outweighs the burdens, and collection will ease over time, potentially ultimately improving efficiency as practices adopt standardized templates and other tools.

To assist in collection of data and reduce burden, the AANI collaborated with LOINC, as mentioned above, to create standardized seizure collection language. The AANI previously submitted a request for pain assessment codes for polyneuropathy and believes creation of standardized codes for neurology will reduce clinician documentation burden.[17] LOINC is a common language to identify health measurements, observations, and documents and move the data across platforms from EHRs to payers, researchers, government agencies, and more.[18] LOINC codes exist to capture common laboratory tests (e.g., SARS-2/COVID-19 tests), clinical documents (e.g., discharge summary), and survey instruments (e.g., 9-Item Patient Health Questionnaire [PHQ-9]).[18]

After the second public comment period, which supported development of a more specific Seizure Type, Frequency, and Time Since Last Seizure Recorded measure, the prior seizure frequency measure was retired by the work group.[2]

Seizure Freedom calculates the percentage of patients or care partners who reported no seizure activity at their visit in the measurement period. Seizure freedom is the desired outcome for patients with epilepsy and has been linked to improved quality of life.[19] Approximately one-third of patients will not reach seizure freedom despite treatment.[20,21] Patients, care partners, physicians, and treatment teams should be documenting seizure frequency and types of seizures to track progress towards the goal of seizure freedom. The American Academy of Neurology's Axon Registry tracks current seizure frequency documentation (Axon 03), but due to inconsistent documentation practices throughout the United States, comparison and longitudinal data on seizure freedom cannot be generated. For example, practices may document seizures are "frequent," "better than prior visit," "weekly," or "rare." In response to this review of experience from the Axon Registry, the work group designed the Seizure Freedom measure to foster greater consistency of documentation of seizure freedom in the

medical record. It is also hoped that this measure will foster accurate intractable epilepsy coding to allow for stratification of results. The work group anticipates annual performance rate results for this measure will be stratified by intractable (treatment-resistant) epilepsy diagnoses (i.e., intractability or Lennox-Gastaut syndrome diagnoses). Data will need to be collected and then analyzed to support whether stratification is feasible using ICD codes. It is suspected that coding practices would support such stratification, although there may be unintended consequences (e.g., clinicians are not coding intractability) that prevent meaningful stratification. This will be evaluated every 6 months by the work group, and the quality improvement–only status of this measure will reduce any potential effect of unintended consequences and facilitate future measure optimization.

Feedback from a few public commenters suggested not to include all types of epilepsy and to modify the measure to percentage of patients who obtained seizure freedom in the measurement period. The work group did not modify the measure and noted the larger Seizure Freedom measure would create a data set with the ability to risk stratify and evaluate a subset of the larger data collected to determine the percentage of patients who became seizure-free in the past 12 months.

Tonic-Clonic Seizure Reduction calculates the percentage of patients experiencing tonic-clonic seizures who report the same or fewer seizures from baseline performance. Tonic-clonic seizures present a first opportunity to start measuring seizure reduction for patients with epilepsy, given that patients and care partners are more likely to be able to identify and recall the most recent tonic-clonic seizure activity compared to nonconvulsive forms of epilepsy. In addition, tonic-clonic seizures have the highest risk for major consequences, such as a risk for SUDEP.[22,23] It is estimated that about 25% of patients with epilepsy have tonic-clonic seizures, 5% have either absence or myoclonic seizures, and fewer than 1% have atonic seizures.[24]

Tracking seizure frequency for patients with tonic-clonic seizures over time with consistent documentation style will result in better opportunities to improve care and treatment planning. By standardizing documentation styles, it is anticipated that information may be accessed more readily when and if patients require coordinated care, such as when a patient may present to an emergency room, or when communicating between specialist and primary care practices. The work group believes that closer monitoring of seizure frequency will result in improved communication about treatment plan options that may result in decreased seizures over time. The work group considered whether improvement only (rather than same or improved frequency) should meet the numerator for this measure. Given the categorical definition of seizure frequency and time since last seizure (Table 3), a measure requiring improvement only would omit persistently seizure-free patients from the numerator, and thus same or improved seizure frequency was favored by the work group for the numerator definition. See Figure 2 for a calculation

Figure 2 Tonic-Clonic Seizure Reduction Measure Example

This measure requires tracking data over two calendar years to establish a baseline in calendar year 1 and then evaluate performance in calendar year 2. An example better illustrates how to calculate.

- A neurologist sees 100 patients between January 1 and December 31, 2020, who are diagnosed with epilepsy and who experience tonic-clonic seizures. Each of these patients had their seizure frequency recorded in the 2020 calendar year. Thirteen of these patients are seen multiple times in 2020 and their seizure frequency is recorded at every visit.

- In 2021, all 100 patients return for further care and seizure frequency is again captured by their own report, or report of their care partners. Ten of these patients have multiple visits with their seizure frequency data collected. For these patients, the first tonic-clonic seizure frequency score collected in 2020 will be compared to the last tonic-clonic seizure frequency score recorded in 2021. In 2021, the neurologist also sees 25 new patients who report their seizure frequency at every visit.

- On December 31, 2021, her practice administrator completes a comparison of tonic-clonic seizure frequency report for 2021 from 2020. The 25 new patients seen in 2021 are not included in the measure calculation, as they do not have the required baseline or index event to make a comparison. She finds that 53% of her patients have the same or fewer tonic-clonic seizures at the last reported seizure frequency captured in 2021, compared to their first reported seizure frequency captured in 2020.

example of an individual clinician's performance on this outcome measure.

Discussion

The work group believes that these new outcome measures have the potential to drive meaningful improvement for individual clinicians and treatment teams caring for patients with epilepsy. It is hoped that implementation stories will be shared and the measures refined over time to determine their value for patients. These new measures will provide a starting point for progress and are not meant to be final. For example, over time these measures may evolve to include risk stratification and risk adjustment strategies using data elements that are not currently available and standardized, although much ongoing research is dedicated to this topic.

Individual clinicians should internally benchmark performance using these metrics and use these data to drive improvement over time, as a component of institutional or individual quality improvement efforts, or in individualized efforts to meet maintenance of certification. It is unclear whether there will be performance variation based on patient populations, but given the variety of seizure types and clinical scenarios for patients with epilepsy, it is likely. Implementation data will be able to drive refinements of these measures.

The work group noted that multiple organizations are working on implementing standardized EHR templates to assist in data collection for patients with epilepsy, further reducing the reporting burden for clinicians; these may also potentially include automated outcome measure calculations based on process measure documentation tools. Templates exist or are being created for Cerner and EPIC by other stewards, for example, although this template creation is outside this work group's scope. These resources will be added to AAN.com/policy-and-guidelines/quality/quality-measures2/quality-measures/epilepsy-and-seizures/ as they become known to the work group and if they are available for use without copyright or license concerns. Strategies involving patient-reported questionnaires on seizure frequency and time since last seizure that are reviewed with clinicians have been employed by learning health care system efforts[25-28]; similar strategies could be considered more broadly to reduce clinician burden.

The work group acknowledges potential limitations of these measures and will monitor for unintended consequences every 6 months. For example, while the measures are intended to drive meaningful improvement in seizure outcomes, the work group recognizes that factors out of a clinician's control may contribute to poor seizure outcomes for some patients, and in some situations it may be beneficial to prioritize other factors such as minimizing adverse effects or surgical risks over maximizing seizure control. Furthermore, the work group acknowledges the limitations of patient/care partner report or diary-based seizure frequency reporting and that many seizures go unrecognized or unreported. However, standardized frequency documentation and outcome tracking has the potential to improve current practice despite these limitations. Whereas outcome metrics such as these will lead to healthy debate among neurologists, their intent is to improve the management of patients with epilepsy and serve as a reminder that we can all strive for better seizure control and better lives for those who entrust us with their care.

Publication History

Appendix Authors

Name	Location	Contribution
Heidi Munger Clary, MD, MPH	Neurology, Wake Forest School of Medicine, Winston-Salem, NC	Subject matter chair effective February 2020; concept and design, acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content, and supervision including responsibility for conduct and final approval

Appendix *(continued)*

Name	Location	Contribution
S. Andrew Josephson, MD	Neurology, Weill Institute for Neurosciences, University of California San Francisco	Facilitator chair; concept and design, acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content, and supervision including responsibility for conduct and final approval
Gary Franklin, MD, MPH	Quality Improvement measure expert, University of Washington, Seattle	Work group member; acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content
Susan T. Herman, MD	Neurology, Barrow Neurological Institute, Phoenix, AZ	Work group member; acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content
Jennifer L. Hopp, MD	Neurology, University of Maryland School of Medicine, Baltimore	Work group member; acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content
Inna Hughes, MD, PhD	Neurology, University of Rochester, NY	Work group member; acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content
Lisa Meunier	Epilepsy Foundation of Minnesota, Minneapolis, MN	Work group member; acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content
Lidia M.V.R. Moura, MD, PhD, MPH	Neurology, Massachusetts General Hospital; Neurology, Harvard Medical School, Boston, MA	Work group member; acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content
Brandy Parker-McFadden	My Epilepsy Story, Nashville, TN	Work group member; acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content

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