Seizure Frequency Process and Outcome Quality Measures

Supplement to the Epilepsy Quality Measurement Set

Approved by the Epilepsy Quality Measurement Work Group on July 1, 2021. Approved by the AANI Quality Measure Subcommittee on July 19, 2021. Approved by the AANI Quality Committee on August 2, 2021. Approved by AANI Board of Directors on August 17, 2021.

The work group thanks the American Epilepsy Society, the Child Neurology Society, the Epilepsy Foundation, My Epilepsy Story, and the National Association of Epilepsy Centers for their collaboration during public comment and their help identifying representatives for this project.

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Seizure Frequency Process and Outcome Quality Measures

Three measures were approved to capture and measure clinician process and outcomes for patients with epilepsy:

Seizure Frequency Process and Outcome Measures
Seizure Type, Frequency, and Time Since Last Seizure Recorded
Seizure Freedom **Available for quality improvement only*
Tonic Clonic Seizure Reduction **Available for quality improvement only*

Measure Development Process

In 2017, the American Academy of Neurology Institute (AANI) seated a standing epilepsy quality measure development work group (work group) who are charged with developing appropriate quality improvement measures for patients with epilepsy who experience seizures. The work group was seated for an initial 2-year term. Following the success of this pilot term, the work group continues. In 2020, the former content chair, Dr. Anup Patel, stepped down from continued service and a new chair was identified from the existing work group membership, Dr. Heidi Munger Clary. A new member, Dr. Jennifer Hopp, was seated mid-term to fill the vacancy. At the end of the 2019–2021 term, a rotation of members will occur to ensure an influx of 5 new members while 6 members remain for their third 2-year term. Members may serve for a maximum of three 2-year terms in accordance with AANI membership protocols.

Following the release of updated epilepsy quality measures in October 2018, the standing epilepsy quality measure development work group meets every 6 months to determine if updates are needed to the measurement set. Full details of the AAN's measure development process are available online.[1]

All work group members are required to disclose relationships with industry and other entities to avoid actual, potential, or perceived conflicts of interest. Seated work group members were instructed to abstain from voting on individual measure concepts if a conflict was present. See Appendix A.

In the October 2018 publication, the work group noted that future work was needed to move toward a more standardized capture of seizure frequency.[2] It is noted there is variety in how doctors and treatment teams document seizure activity. 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 compare frequency data over time to determine if activity is increasing or decreasing without chart review. An opportunity exists to track and measure seizure outcome data over time and use this data to improve care.

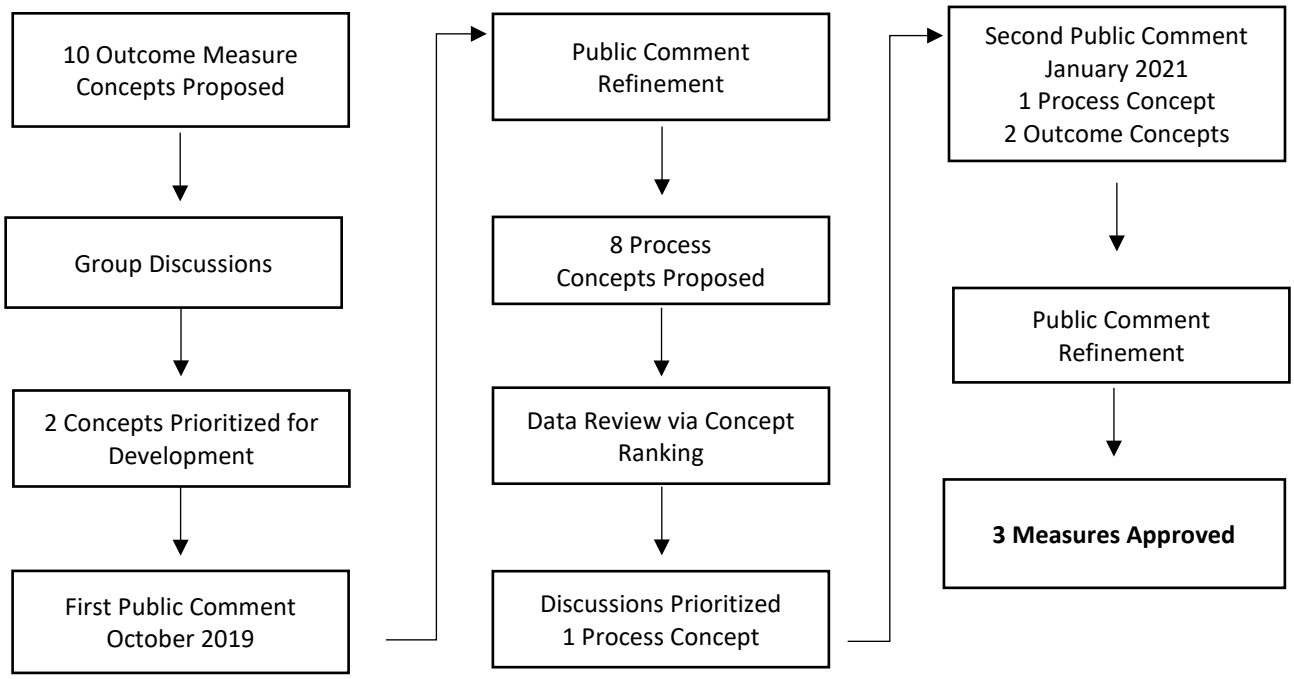
In Spring 2019, the work group determined the time was ripe to move forward with 2 draft outcome measures addressing the gap in measuring seizure frequency for patients with epilepsy. A 21-day public comment period was held in October 2019 on 2 draft seizure outcome measures. Comments were received from 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. Due to the COVID-19 pandemic, the project was temporarily halted with work resuming 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. Each of 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. Each comment was responded to and edits were incorporated as appropriate. The work group refined the seizure classification

system based on input received. Outcome measures were converted to quality improvement–only measures. This distinction indicates that the measures will be made available for implementation but will not be submitted for consideration in any accountability programs (such as payment or public reporting) at this time. The work group believes both concepts have potential to drive meaningful improvement for individual clinicians and treatment teams. It is hoped that implementation stories will be shared and the measures further refined over time to determine their value for patients with epilepsy. It is hoped that over time the measures can evolve to include risk stratification and risk adjustment strategies using data elements that are not currently available and standardized. These measures will provide a starting point for progress and are not meant to be final. Clinicians should internally benchmark performance and use those benchmarks to drive improvement over time. Not all seizures are the same and it is unclear if there will be performance variation based on patient populations, although some assumptions can be made. Implementation data would be able to drive refinements and better provide guidance on how seizure types should be addressed through potential risk stratification and adjustment.

The measures in this set are being made available without any prior testing. The AAN encourages testing of this measurement set for feasibility and reliability by organizations or individuals positioned to do so. **Only the process measure will be eligible for potential submission to CMS for consideration in the Quality Payment Program's (QPP) Merit-based Incentive Payment System (MIPS) and the National Quality Forum for possible endorsement.** Prior to any submission, beta testing will need to occur. The measurement set will be reviewed by the work group every 6 months for potential updates.

The below image summarizes the steps in the measure development process.



Other Measure Concepts

The work group discussed 7 other potential outcome concepts related to seizure outcomes, but ultimately determined these concepts were not ripe for development given feasibility issues. Those concepts included:

- Seizure freedom for patients with non-intractable epilepsy. This was proposed but dropped from further development as it was determined risk stratification could be applied to a seizure freedom measure, making a separate measure for a subset of diagnoses duplicative.
- Patients' time seizure-free in the calendar year. This concept would allow for calculation of seizure freedom for each seizure type but would prove burdensome to implement for most practices and doctors.

- Patients who had a resection, ablation, or implantation surgery that achieved seizure freedom in the calendar year. The work group noted that it would be burdensome to implement the denominator as most outpatient practices would not have access to the surgery date or codes necessary for identification of the denominator.
- Patients with epilepsy on one anti-seizure medication who are seizure-free in the calendar year. The work group noted that identification of the denominator would be difficult. Medication data in the electronic health record (EHR) lacks consistency—records often do not include start and stop date or the rationale for prescription (e.g., tegretol prescribed for headache or epilepsy), and data may be captured in different fields. Additionally, patients may not be seen in the calendar year if they have low seizure frequency. Translating this into provider performance would be difficult.
- Patients with convulsive epilepsy on one anti-seizure medication who are seizure-free in the calendar year. The work group noted that identification of the denominator would be difficult. Medication data in the EHR lacks consistency—records often do not include start and stop date or the rationale for prescription (e.g., tegretol prescribed for headache or epilepsy), and data may be captured in different fields.
- Patients with epilepsy who presented to an emergency department for seizure-related care during the calendar year. The work group noted that outpatient practices will not always have access to emergency department visit information without the patient relaying this information. Information could be identified via claims data, but such data would be delayed, preventing meaningful opportunity to drive quality improvement in practice.
- Patients with epilepsy who have increased seizure frequency referred to a comprehensive epilepsy center. The work group noted concerns that implementation could be burdensome. It would be difficult to identify the denominator given inconsistent documentation practices.

Following the first public comment period in October 2019, the work group proposed 8 potential process measure concepts for ranking. Ranking is a subjective process by work group members used to prioritize measures that are feasible to collect, meaningful to measure, and linked to improved outcomes. One measure concept incorporating 3 separate numerators was prioritized for discussion. The 7 concepts not discussed were:

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

Current AANI Epilepsy and Seizure Measures

The work group will revisit additional concepts during future updates of the epilepsy measurement set. The work group was concerned about creating too many measures in the epilepsy space resulting in practice burdens to collect data. In May 2021 in response to creation of a new seizure documentation measure, the work group unanimously voted to retire the existing seizure frequency measure from the 2017 measurement set.

Below is a summary of current epilepsy and seizure measures created by the AAN, which are available for free at AAN.com/policy-and-guidelines/quality/quality-measures2/quality-measures/epilepsy-and-seizures/

Epilepsy 2017 Update	Seizure Process and Outcome Measures	Child Neurology

Seizure Frequency – *Retired 2021*	Seizure Type, Frequency, and Time Since Last Seizure Recorded	First line treatment for infantile spasms
Counseling for Women with Epilepsy	Seizure Freedom	Rescue seizure therapy for children
Comprehensive Epilepsy Care Center Referral or Discussion	Tonic Clonic Seizure Reduction	Time to third line therapy for RCSE
Quality of Life Assessment		Neuropsychological/ neurodevelopmental screening
Quality of Life Outcome		Transition from pediatric neurology to adult neurology
Depression and Anxiety Screening		

Implementation Resources and Data Collection Burdens

The work group noted that monitoring seizure frequency and outcomes was of utmost importance to both patients with seizures and physicians and providers who treat patients with seizures. Outcomes cannot be tracked and compared without standardized seizure frequency data. 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 felt the time was right to build from the successful multicenter consortia that have implemented the 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. The AAN has ongoing efforts and will continue to collaborate with EMR vendors to improve access to structured data entry to address data collection burdens. The work group did collaborate with Logical Observation Identifiers Names and Codes LOINC to create codes for seizure data collection. More information on this collaboration is included in the *Neurology* publication. The work group appreciates this change in documentation practices is not seamless and may prove burdensome for some practices, but the potential value of this data outweighs the burdens and collection will ease over time, potentially improving efficiency.

To assist in collection of data and reduce burden, the AANI outreached LOINC to collaborate on the creation of standardized language. This was the second collaboration of this nature, and the AANI hopes that additional collaborations will occur to create or standardize codes for neurology, thereby reducing the burden on physician and clinician documentation to meet quality measure specifications.

Seizure Types: LOINC code 99311-3	**Seizure frequency:** LOINC code 99312-1	**Time since last seizure:** LOINC code 99313-9
LA32841-1: "Focal Onset - Aware" LA32842-9: "Focal Onset - Impaired Awareness" LA32843-7: "Focal Onset - to Bilateral Tonic-clonic" LA32844-5: "Generalized Onset - Motor Tonic-clonic" LA32845-2: "Generalized Onset - Other Motor" LA32846-0: "Generalized Onset - Nonmotor (Absence)" LA32847-8: "Unknown Onset (if focal or generalized)* - Motor Tonic-clonic" LA32848-6: "Unknown Onset (if focal or generalized)* - Other Motor" LA32849-4: "Unknown Onset (if focal or generalized)* - Nonmotor" LA32850-2:"Unclassified (i.e., unsure if epileptic or not)" LA32851-0: "Nonepileptic (i.e., psychogenic or physiologic)"	LA32852-8: "Innumerable (i.e., ≥ 10 per day most days)" LA32853-6: "Multiple per day (i.e., 4 days per week with ≥ 2 seizures)" LA32854-4: "Daily (i.e., 4 or more days per week)" LA32855-1: "Weekly but not daily (i.e., 1–3 per week)" LA32856-9: "Monthly but not weekly (i.e., 1–-3 per month)" LA32857-7: "At least once per year, but not every month (i.e., 10 or fewer in past 12 months)" LA32858-5: "Less than once per year" LA32859-3: "Frequency not well defined" LA4489-6: "Unknown"	LA32860-1: "Today" LA32861-9: "1–6 days ago" LA32862-7: "1–4 weeks ago" LA32863-5: "5–12 weeks ago" LA32864-3: "13–26 weeks ago" LA32865-0: "6–12 months ago (27–52 weeks ago)" LA32866-8: "13–24 months ago (53–104 weeks ago)" LA32867-6: "More than 2 years ago (more than 105 weeks ago)" LA14072-5: "Unsure"

*Unknown refers to epileptic seizures for which it is unknown whether onset is focal or generalized, using the 2017 ILAE seizure type classification.

LOINC is a common language to identify health measurements, observations, and documents and move that data across platforms from EHRs to payers, researchers, government agencies, and more. 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., Patient Health Questionnaire-9 Item [PHQ-9]).

The work group noted that multiple organizations are working on implementing standardized EHR templates to assist data collection for patients with epilepsy, further reducing burden. Templates exist or are being created for Cerner and EPIC by other stewards, and template creation is outside this work group's scope. These resources will be added at https://www.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.

The work group identified the following resources that may be helpful in implementing any seizure classification system:

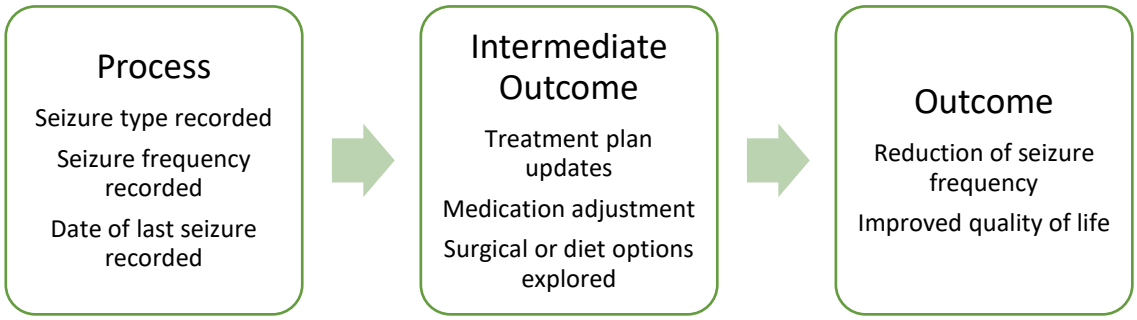
- International League Against Epilepsy (ILAE) Definition of Epilepsy. Available at: https://www.ilae.org/guidelines/definition-and-classification/definition-of-epilepsy-2014 (Accessed May 17, 2021)
- ILAE Classification of the Epilepsies (2017). Available at: https://www.ilae.org/guidelines/definition-and-classification/ilae-classification-of-the-epilepsies-2017 (Accessed May 17, 2021)
- ILAE Operational Classification of Seizure Types (2017). https://www.ilae.org/guidelines/definition-and-classification/operational-classification-2017 (Accessed May 17, 2021)
- ILAE Classification of Seizures in the Neonate: https://www.ilae.org/files/ilaeGuideline/Classification-of-seizures---modification-for-neonates-epi.16815-2021-02.pdf (Accessed May 17, 2021)

Seizure Type, Frequency, and Time Since Last Seizure Recorded

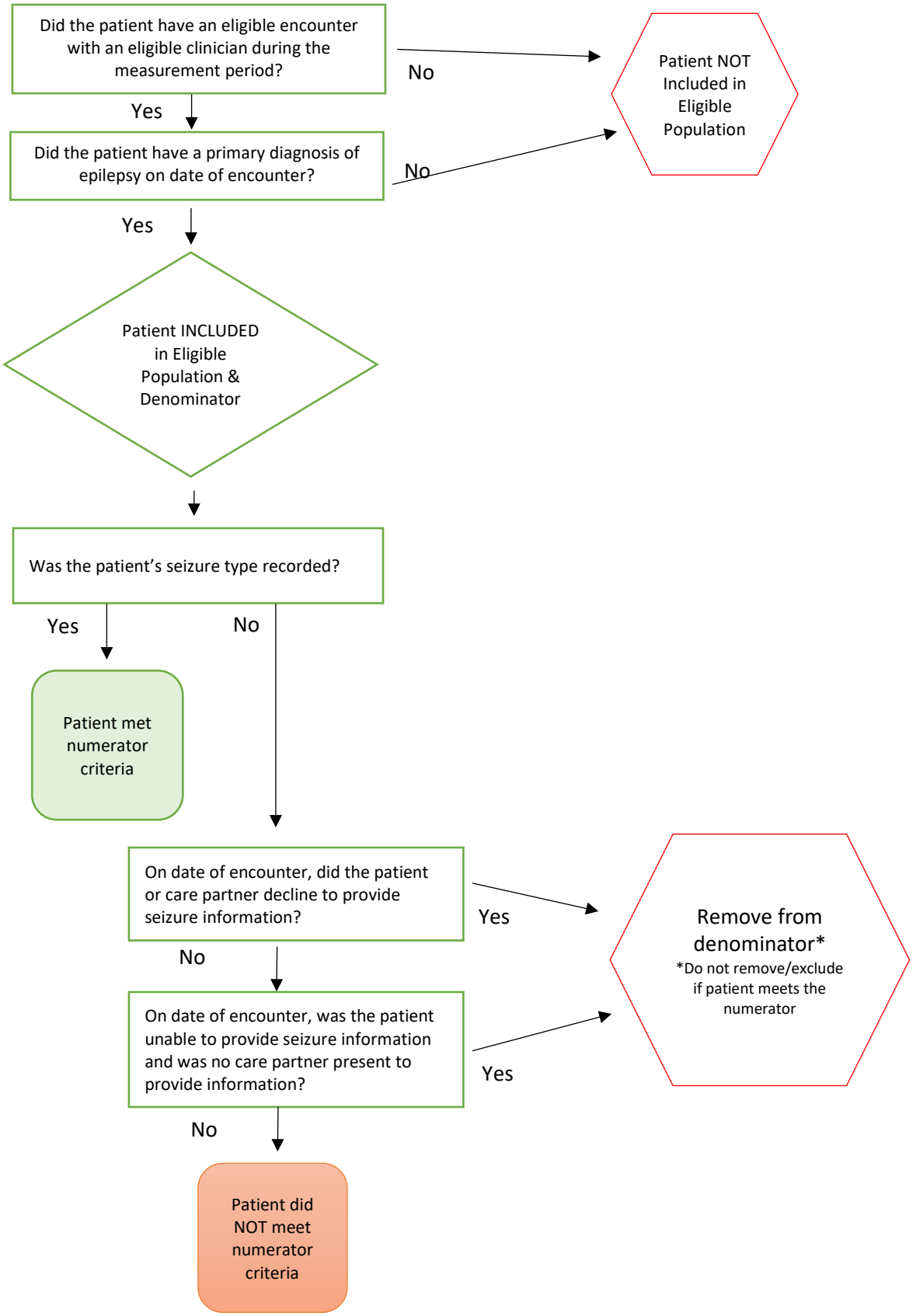
Measure Title	Seizure Type, Frequency, and Time Since Last Seizure Recorded	
Description	Percentage of patients or care partners who reported seizure type, seizure frequency for each type of seizure, and date of last seizure for each seizure type at every visit in the measurement period.	
Measurement Period	January 1, 20xx to December 31, 20xx	
Eligible Population	**Eligible Providers**	Medical Doctor (MD), Doctor of Osteopathy (DO), Physician Assistant (PA), Advanced Practice Registered Nurse (APRN)
	Care Setting(s)	Outpatient care
	Ages	All
	Event	Office or telehealth encounter
	Diagnosis	Epilepsy
Denominator	A. All visits for patients with primary diagnosis of epilepsy	
	B. All visits for patients with primary diagnosis of epilepsy	
	C. All visits for patients with primary diagnosis of epilepsy	
	D. All visits for patients with primary diagnosis of epilepsy	
Numerator	A. Patients or care partners who reported seizure type at every visit. Seizure types are defined as: • Focal Onset – Aware • Focal Onset – Impaired Awareness • Focal Onset – to bilateral tonic-clonic • Generalized Onset – Motor tonic-clonic • Generalized Onset – Other motor • Generalized Onset – Nonmotor (Absence) • Unknown Onset (if focal or generalized) – Motor tonic-clonic • Unknown Onset (if focal or generalized) – Other motor • Unknown Onset (if focal or generalized) – Nonmotor • Unclassified (i.e., unsure if epileptic or not) • Nonepileptic (i.e., psychogenic or physiologic)	
	B. Patients or care partners who reported seizure frequency for each seizure type identified in numerator A at each visit in the measurement period. Seizure frequency is defined as: • 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. Comparative words, such as “frequent,” “rare,” or “near daily,” to describe frequency cannot be used to meet the numerator.	
	C. Patients or care partners who reported time since last seizure for each seizure type identified in numerator A at each visit in the measurement period. Time since last seizure is defined as: • 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
	D. Patients or care partners who reported all 3 measure numerator components A, B, and C at each visit in the measurement period.
Required Exclusions	None
Allowable Exclusions	Component A. 1. Patient declines to provide seizure information on date of encounter. 2. Patient unable to provide seizure information on date of encounter and no care partner available to provide information or care partner information limited (i.e., nursing home or group home staff not familiar).
	Component B. 1. Patient declines to provide seizure information on date of encounter. 2. Patient unable to provide seizure information on date of encounter and no care partner available to provide information or care partner information limited (i.e., nursing home or group home staff not familiar).
	Component C. 1. Patient declines to provide seizure information on date of encounter. 2. Patient unable to provide seizure information on date of encounter and no care partner available to provide information or care partner information limited (i.e., nursing home or group home staff not familiar).
	Component D. 1. Patient declines to provide seizure information on date of encounter. 2. Patient unable to provide seizure information on date of encounter and no care partner available to provide information or care partner information limited (i.e., nursing home or group home staff not familiar).
Exclusion Rationale	Patients must be willing to provide seizure frequency or must have a knowledgeable care partner available to provide information for results to be valid.
Measure Scoring	Percentage
Interpretation of Score	Higher score indicates better quality
Measure Type	Process
Level of Measurement	Provider
Risk Adjustment	None
Risk Stratification	Not applicable
Opportunity to Improve Gap in Care	There is a known opportunity to better document seizure type and frequency for patients. The prior version of this measure did not standardize collection of data, allowing for comparative words to meet the numerator. Several quality improvement collaboratives have been formed for epilepsy and have highlighted opportunities for improved data collection and lessons learned for implementing standardized data collection.[1–4] As a result of these successes, the work group believes the time is ripe to move forward with standardized collection of data, which will in turn lead to better collection and comparison of outcome data. The work group encourages collection of seizure frequency via a diary. The measure numerator can be collected by a physician reviewing diary information and converting it into a date/last seizure quantity as required by the numerator.

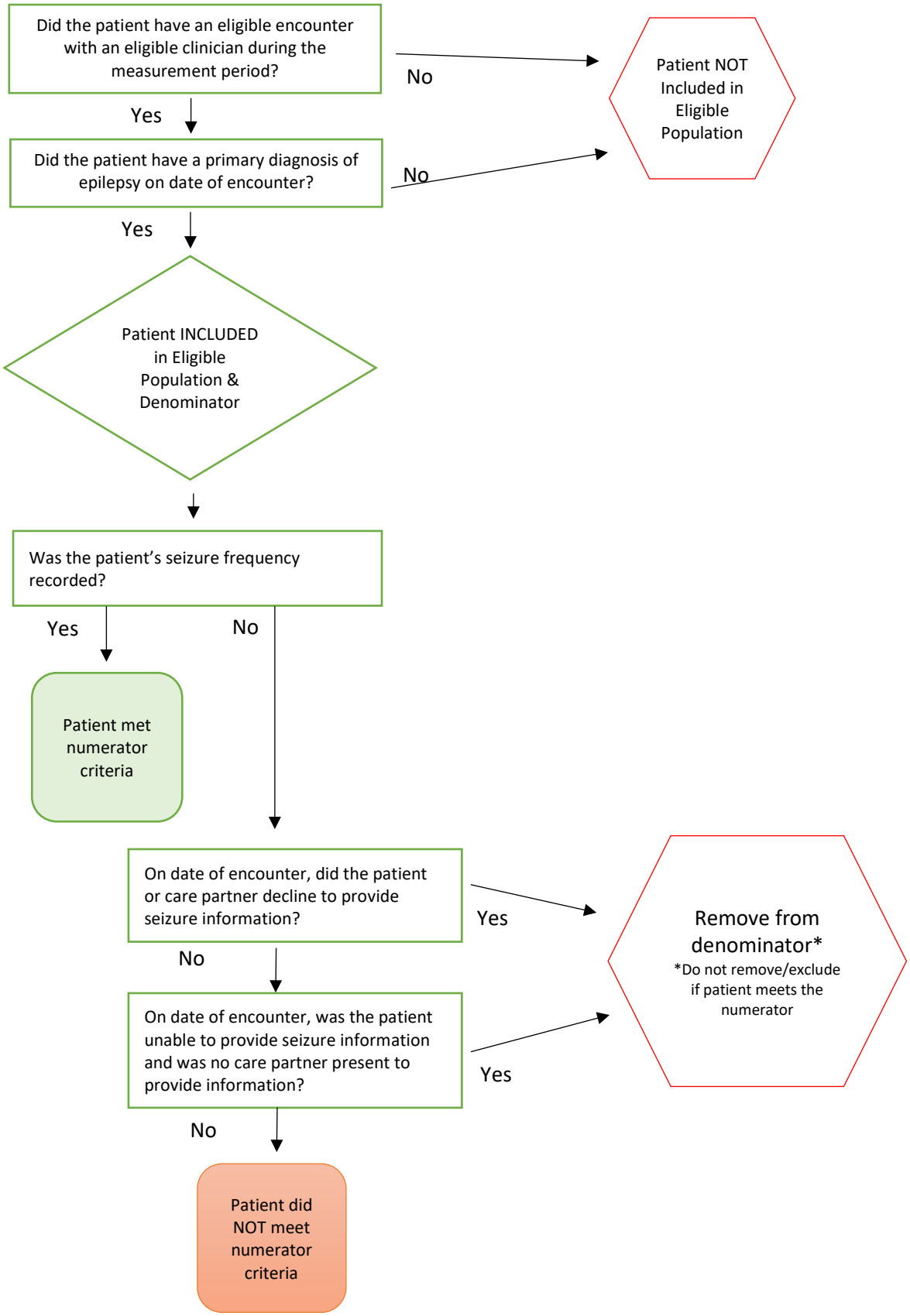
	In assessments of collection of the prior version of the measure, Fitzsimons, et al. found that seizure frequency was reported 88% of the time and etiology reported 58% of the time when reviewing 160 electronic health records.[5] Debs, et al., recently reviewed 777 charts and identified that seizure frequency data was missing from 35% (259) of charts indicating a continued gap in care.[6] While an assessment of nurse practitioner vs physician data collection of epilepsy measures found performance was around 90% for seizure frequency.[7] These studies support the existence of continued variation in charting practices. Moura, et al., conducted 88 patient interviews to compare patient perceptions to physician-documented quality of care for epilepsy and noted, "incongruence between physician and patient reports was found even in clinical measures related to etiology and seizure type, emphasizing potential gaps in patient education and counseling."[8] The intent of component D is to provide an all-or-none measure bundle for practices and clinicians who have high performance rates of individual components. This data may be helpful for some users providing an overall measurement of clinician process. Collection of all three components has high value and should be collected for patients. 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 focus and indication of commitment to the highest quality of care. Clinicians and practices starting out 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 work group evaluated potential use of date extraction to meet numerator performance for time since last seizure. EHR use and storage of dates is not standard across platforms. As a result, the work group cannot dictate date collection. Although this strategy to collect performance using date extraction can be evaluated by individual implementers and their EHR capabilities, the AAN work group cannot advise one strategy or algorithm to accomplish this without further advances of natural language processing, standardized data storage, and/or artificial intelligence. The work group believes there is a clinical benefit to documenting a duration since last seizure rather than just the date, as this information is useful when assessing treatment plan changes and counseling recommendations such as return to driving or medication tapering.
For Process Measures Relationship to Desired Outcome	The following clinical recommendation statements are quoted verbatim: • "The seizure type(s) and epilepsy syndrome, aetiology, and co-morbidity should be determined, because failure to classify the epilepsy syndrome correctly can lead to inappropriate treatment and persistence of seizures."[9] • "When a patient with epilepsy receives follow-up care, then an estimate of the number of seizures since the last visit and assessment of drug side-effects should be documented. (Level D 1+/ Primary)"[10] Collection of seizure type, frequency, and date of last seizure may lead to better outcomes. In an assessment to determine if tracking multiple epilepsy quality metrics led to improved seizure control, it was found that average quality of care, but not defect-free care, was associated with seizure control while controlling for the effect of subspecialty involvement as a possible confounding variable.[11]

	
Harmonization with Existing Measures	The AANI's prior seizure frequency measure was retired in May 2021. There are no known similar measures.
References	1. Smith JR, Jones FJS, Fureman BE, et al. Accuracy of ICD-10-CM claims-based definitions for epilepsy and seizure type. Epilepsy Res. 2020;166:106414. 2. Jones FJS, Smith JR, Ayub N, et al. Implementing standardized provider documentation in a tertiary epilepsy clinic. Neurology. 2020; 95(2):e213-e233. 3. Grinspan ZM, Patel AD, Shellhaas RA, et al. Design and implementation of electronic health record common data elements for pediatric epilepsy: Foundations for a learning health care system. Epilepsia 2021; 62:198-216. 4. Donahue MA, Herman ST, Dass D, et al. Establishing a learning healthcare system to improve health outcomes for people with epilepsy. Epilepsy & Behavior 2021; 117: 107805 5. Fitzsimons M, Dunleavy B, O'Byrne P, et al. Assessing the quality of epilepsy care with an electronic patient record. Seizure 2013; 22:604-610. 6. Debs A, Gedela S, and Patel AD. Continued Gaps in Seizure Frequency Documentation. Journal of Pediatric Epilepsy. 2020 DOI: 10.1055/s-0040-1715461 7. Hill CE, Thomas B, Sansalone K, et al. Improved availability and quality of care with epilepsy nurse practitioners. Neurology Clinical Practice. 2017; 7(2):109-117. 8. Moura LMVR, Carneiro T, Thorn EL, et al. Patient perceptions of physician-documented quality care in epilepsy. Epilepsy & Behavior 2016;62:90-96. 9. National Institute of Clinical Health and Excellence. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care (update). 2012. Clinical guideline 137. Available at: https://www.nice.org.uk/guidance/cg137 Accessed on October 15, 2020. 10. Pugh MJ, Berlowitz DR, Montouris G, et al. What constitutes high quality of care for adults with epilepsy? Neurology 2007;69:2020-2027. 11. Moura LMVR, Yacaman Mendez D, De Jesus J, et al. Association with adherence to epilepsy quality standards with seizure control. Epilepsy Research. 2015; 117:35-41.

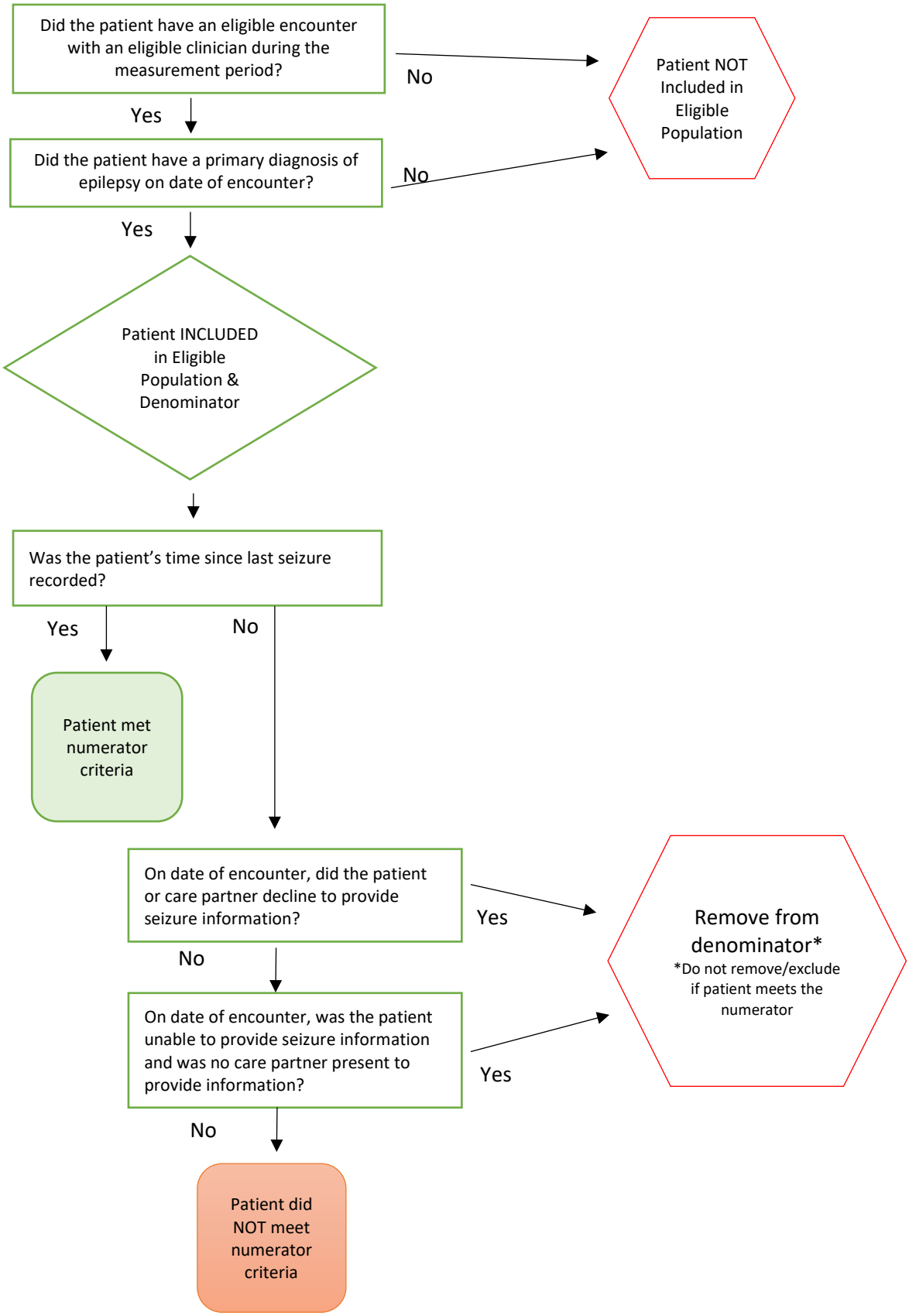
Seizure Type, Frequency, and Time Since Last Seizure Recorded Measure Flow: Component A
Note: This measure is calculated at every visit.



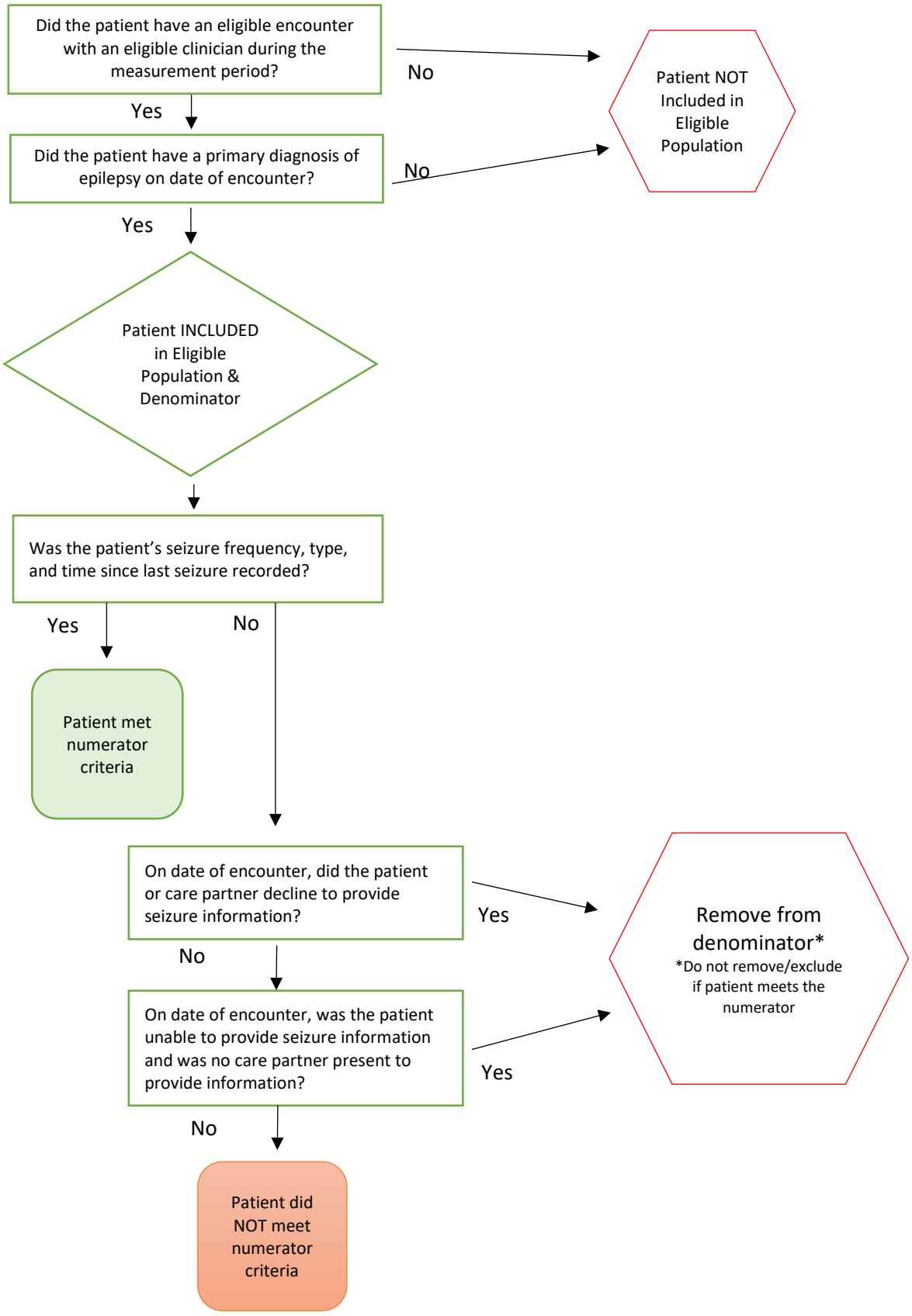
Seizure Type, Frequency, and Time Since Last Seizure Recorded Measure Flow: Component B
Note: This measure is calculated at every visit.



Seizure Type, Frequency, and Time Since Last Seizure Recorded Measure Flow: Component C
Note: This measure is calculated at every visit.



Seizure Type, Frequency, and Time Since Last Seizure Recorded Measure Flow: Component D
Note: This measure is calculated at every visit.



Seizure Type, Frequency, and Time Since Last Seizure Recorded 2021 Code Systems and Descriptions
The below code systems and code descriptions were developed by the work group in 2021. This information may evolve over time as CPT, ICD-10, and LOINC codes evolve. Please contact quality@aan.com for the most up to date coding resources for measure implementation.

Code System	Code	Code Description
Denominator		
CPT	99201-99205	Office or Other Outpatient Visit – New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit – Established Patient (E/M Codes)
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
AND		
ICD-10	G40.001	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, not intractable, with status epilepticus
ICD-10	G40.009	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, not intractable, without status epilepticus
ICD-10	G40.011	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, intractable, with status epilepticus
ICD-10	G40.019	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, intractable, without status epilepticus
ICD-10	G40.101	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, not intractable, with status epilepticus
ICD-10	G40.109	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, not intractable, without status epilepticus
ICD-10	G40.111	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, intractable, with status epilepticus
ICD-10	G40.119	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, intractable, without status epilepticus
ICD-10	G40.201	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, not intractable, with status epilepticus
ICD-10	G40.209	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, not intractable, without status epilepticus
ICD-10	G40.211	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, with status epilepticus
ICD-10	G40.219	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, without status epilepticus
ICD-10	G40.301	Generalized idiopathic epilepsy and epileptic syndromes, not intractable, with status epilepticus
ICD-10	G40.309	Generalized idiopathic epilepsy and epileptic syndromes, not intractable, without status epilepticus
ICD-10	G40.311	Generalized idiopathic epilepsy and epileptic syndromes, intractable, with status epilepticus
ICD-10	G40.319	Generalized idiopathic epilepsy and epileptic syndromes, intractable, without status epilepticus
ICD-10	G40.A01	Absence epileptic syndrome, not intractable, with status epilepticus
ICD-10	G40.A09	Absence epileptic syndrome, not intractable, without status epilepticus
ICD-10	G40.A11	Absence epileptic syndrome, intractable, with status epilepticus
ICD-10	G40.A19	Absence epileptic syndrome, intractable, without status epilepticus
ICD-10	G40.B01	Juvenile myoclonic epilepsy, not intractable, with status epilepticus
ICD-10	G40.B09	Juvenile myoclonic epilepsy, not intractable, without status epilepticus
ICD-10	G40.B11	Juvenile myoclonic epilepsy, intractable, with status epilepticus
ICD-10	G40.B19	Juvenile myoclonic epilepsy, intractable, without status epilepticus

ICD-10	G40.401	Other generalized epilepsy and epileptic syndromes, not intractable, with status epilepticus
ICD-10	G40.409	Other generalized epilepsy and epileptic syndromes, not intractable, without status epilepticus
ICD-10	G40.411	Other generalized epilepsy and epileptic syndromes, intractable, with status epilepticus
ICD-10	G40.419	Other generalized epilepsy and epileptic syndromes, intractable, without status epilepticus
ICD-10	G40.42	Cyclin-Dependent Kinase-Like 5 Deficiency Disorder
ICD-10	G40.501	Epileptic seizures related to external causes, not intractable, with status epilepticus
ICD-10	G40.509	Epileptic seizures related to external causes, not intractable, without status epilepticus
ICD-10	G40.801	Other epilepsy, not intractable, with status epilepticus
ICD-10	G40.802	Other epilepsy, not intractable, without status epilepticus
ICD-10	G40.803	Other epilepsy, intractable, with status epilepticus
ICD-10	G40.804	Other epilepsy, intractable, without status epilepticus
ICD-10	G40.811	Lennox-Gastaut syndrome, not intractable, with status epilepticus
ICD-10	G40.812	Lennox-Gastaut syndrome, not intractable, without status epilepticus
ICD-10	G40.813	Lennox-Gastaut syndrome, intractable, with status epilepticus
ICD-10	G40.814	Lennox-Gastaut syndrome, intractable, without status epilepticus
ICD-10	G40.821	Epileptic spasms, not intractable, with status epilepticus
ICD-10	G40.822	Epileptic spasms, not intractable, without status epilepticus
ICD-10	G40.823	Epileptic spasms, intractable, with status epilepticus
ICD-10	G40.824	Epileptic spasms, intractable, without status epilepticus
ICD-10	G40.833	Dravet syndrome, intractable, with status epilepticus
ICD-10	G40.834	Dravet syndrome, intractable, without status epilepticus
ICD-10	G40.89	Other seizures
ICD-10	G40.901	Epilepsy, unspecified, not intractable, with status epilepticus
ICD-10	G40.909	Epilepsy, unspecified, not intractable, without status epilepticus
ICD-10	G40.911	Epilepsy, unspecified, intractable, with status epilepticus
ICD-10	G40.919	Epilepsy, unspecified, intractable, without status epilepticus
ICD-10	R56.9	Unspecified convulsions
Denominator – Required Exclusions		
None		
Denominator – Allowable Exclusions		
SNOMEDCT	288576002	Unable to communicate (finding)
SNOMEDCT	105480006	Refusal of treatment by patient (situation)
Numerator – Component A		
LOINC	99311-3	Seizure Onset
LOINC	LA32841-1	“Focal Onset - Aware”
LOINC	LA32842-9	"Focal Onset - Impaired Awareness”
LOINC	LA32843-7	“Focal Onset - to Bilateral Tonic-clonic"
LOINC	LA32844-5	“Generalized Onset - Motor Tonic-clonic"
LOINC	LA32845-2	"Generalized Onset - Other Motor"
LOINC	LA32846-0	"Generalized Onset - Nonmotor (Absence)"
LOINC	LA32847-8	"Unknown Onset (if focal or generalized)* - Motor Tonic-clonic"
LOINC	LA32848-6	“Unknown Onset (if focal or generalized)* - Other Motor"
LOINC	LA32849-4	"Unknown Onset (if focal or generalized)* - Nonmotor"
LOINC	LA32850-2	“Unclassified (i.e., unsure if epileptic or not)"
LOINC	LA32851-0	"Nonepileptic (i.e., psychogenic or physiologic)"
Numerator – Component B		
LOINC	99312-1	Seizure Frequency
LOINC	LA32852-8	"Innumerable (i.e., ≥ 10 per day most days)"

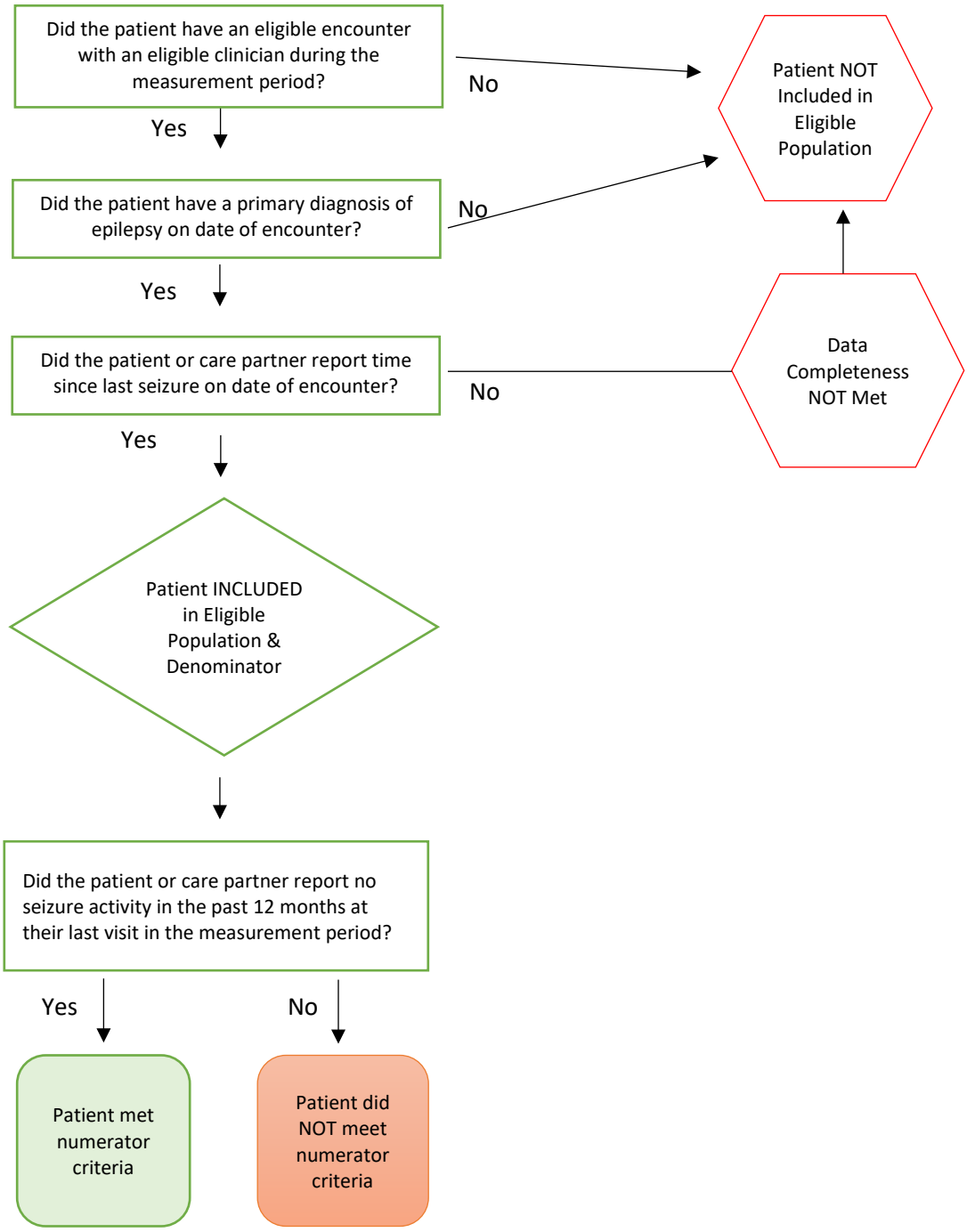
LOINC	LA32853-6	"Multiple per day (i.e., 4 days per week with ≥ 2 seizures)"
LOINC	LA32854-4	"Daily (i.e., 4 or more days per week)"
LOINC	LA32855-1	"Weekly but not daily (i.e., 1–3 per week)"
LOINC	LA32856-9	"Monthly but not weekly (i.e., 1–3 per month)"
LOINC	LA32857-7	"At least once per year, but not every month (i.e., 10 or fewer in past 12 months)"
LOINC	LA32858-5	"Less than once per year"
LOINC	LA32859-3	"Frequency not well defined"
LOINC	LA4489-6	"Unknown"
Numerator – Component C		
LOINC	99313-9	Time Since Last Seizure
LOINC	LA32860-1	"Today"
LOINC	LA32861-9	"1–6 days ago"
LOINC	LA32862-7	"1–4 weeks ago"
LOINC	LA32863-5	“5–12 weeks ago"
LOINC	LA32864-3	"13–26 weeks ago"
LOINC	LA32865-0	"6–12 months ago (27–52 weeks ago)"
LOINC	LA32866-8	"13–24 months ago (53–104 weeks ago)"
LOINC	LA32867-6	"More than 2 years ago (more than 105 weeks ago)"
LOINC	LA14072-5	“Unsure”
Numerator – Component D		
LOINC	99311-3	Seizure Onset
LOINC	LA32841-1	“Focal Onset - Aware”
LOINC	LA32842-9	"Focal Onset - Impaired Awareness”
LOINC	LA32843-7	“Focal Onset - to Bilateral Tonic-clonic"
LOINC	LA32844-5	“Generalized Onset - Motor Tonic-clonic"
LOINC	LA32845-2	"Generalized Onset - Other Motor"
LOINC	LA32846-0	"Generalized Onset - Nonmotor (Absence)"
LOINC	LA32847-8	"Unknown Onset (if focal or generalized)* - Motor Tonic-clonic"
LOINC	LA32848-6	“Unknown Onset (if focal or generalized)* - Other Motor"
LOINC	LA32849-4	"Unknown Onset (if focal or generalized)* - Nonmotor"
LOINC	LA32850-2	“Unclassified (i.e., unsure if epileptic or not)"
LOINC	LA32851-0	"Nonepileptic (i.e., psychogenic or physiologic)"
LOINC	99312-1	Seizure Frequency
LOINC	LA32852-8	"Innumerable (i.e., ≥ 10 per day most days)"
LOINC	LA32853-6	"Multiple per day (i.e., 4 days per week with ≥ 2 seizures)"
LOINC	LA32854-4	"Daily (i.e., 4 or more days per week)"
LOINC	LA32855-1	"Weekly but not daily (i.e., 1–3 per week)"
LOINC	LA32856-9	"Monthly but not weekly (i.e., 1–3 per month)"
LOINC	LA32857-7	"At least once per year, but not every month (i.e., 10 or fewer in past 12 months)"
LOINC	LA32858-5	"Less than once per year"
LOINC	LA32859-3	"Frequency not well defined"
LOINC	LA4489-6	"Unknown"
LOINC	99313-9	Time Since Last Seizure
LOINC	LA32860-1	"Today"
LOINC	LA32861-9	"1–6 days ago"
LOINC	LA32862-7	"1–4 weeks ago"
LOINC	LA32863-5	“5–12 weeks ago"
LOINC	LA32864-3	"13–26 weeks ago"
LOINC	LA32865-0	"6–12 months ago (27–52 weeks ago)"
LOINC	LA32866-8	"13–24 months ago (53–104 weeks ago)"
LOINC	LA32867-6	"More than 2 years ago (more than 105 weeks ago)"
LOINC	LA14072-5	“Unsure”

Seizure Freedom

Measure Title	Seizure Freedom	
Description	Percentage of patients or care partners who reported no seizure activity at their visit in the measurement period. *This measure is intended for quality improvement only. It is not appropriate for use in accountability or payer programs.*	
Measurement Period	January 1, 20xx to December 31, 20xx	
Eligible Population	**Eligible Providers**	Medical Doctor (MD), Doctor of Osteopathy (DO), Physician Assistant (PA), Advanced Practice Registered Nurse (APRN)
	Care Setting(s)	Outpatient care
	Ages	All
	Event	Office visit or telehealth encounter
	Diagnosis	Epilepsy
Denominator	Patients diagnosed with epilepsy	
Numerator	Patients or care partners who reported no seizure activity in the past 12 months at their last visit in the measurement period.	
Required Exclusions	None	
Allowable Exclusions	None	
Exclusion Rationale	Not applicable	
Measure Scoring	Percentage	
Interpretation of Score	Higher score indicates better quality	
Measure Type	Outcome	
Level of Measurement	Provider	
Risk Adjustment	None	
Risk Stratification	The work group anticipates annual performance rate results will be stratified by intractable (treatment resistant) epilepsy diagnoses (i.e., intractability ICD-10 or LGS diagnoses). Data will need to be collected and then analyzed to support if stratification can occur by ICD codes. It is suspected that coding practices would support such stratification, although there may be unintended consequences (e.g., providers are not coding intractability) that prevent meaningful stratification. Approximately 1/3 of patients will not reach seizure freedom or remission despite treatment.[1, 2]	
Opportunity to Improve Gap in Care	Seizure freedom and remission is the desired outcome for patients with epilepsy and has been linked to improved quality of life.[3] 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." It is hoped this current measure will result in greater consistency in documentation of seizure freedom in the medical record as well as types of intractable epilepsy to allow for stratification of results.	

	The seizure type and current seizure frequency measure was previously adopted by the Centers for Medicare & Medicaid Services (CMS) for use in their Physician Quality Reporting System (PQRS) but retired from further use as documentation of seizure frequency is considered standard of care. However, research continues to support an opportunity to improve documentation of seizure frequency in practice.[4–9] The work group evaluated potential use of date extraction to meet the numerator. EHR use and storage of dates is not standard across platforms. As a result, the work group cannot dictate date collection. Although this strategy to collect performance using date extraction can be evaluated by individual implementers and their EHR capabilities, the work group cannot advise one strategy or algorithm to accomplish this without further advances of natural language processing, standardized data storage, and/or artificial intelligence.
Harmonization with Existing Measures	There are no known outcome measures addressing seizure freedom.
References	1. Hughes DM, Bonnett LJ, Czanner G, et al. Identification of patients who will not achieve seizure remission within 5 years on AEDs. Neurology 2018; 91(22):e2035-e2044 2. Wassenaar M, Leijten FSS, Egberts TCG, et al. Prognostic factors for medically intractable epilepsy: A systematic review. Epilepsy Research 2013; 106(3): 301-310. 3. Birbeck GL, Hays RD, Cui X, et al. Seizure reduction and quality of life improvements in people with epilepsy. Epilepsia. 2002; 43: 535-538. 4. Groenewegen A, Tofighy A, Ryvlin P, et al. Measures for improving treatment outcomes for patients with epilepsy – Results from a large multinational patient-physician survey. Epilepsy & Behavior. 2014; 34: 58-67. 5. Moura LMVR, Yacaman Mendez D, De Jesus J, et al. Association of adherence to epilepsy quality standards with seizure control. Epilepsy Research. 2015; 117: 35-41. 6. Blachut B, Hoppe C, Surges R, et al. Counting seizures: The primary outcome measure in epileptology from the patients' perspective. Seizure. 2015; 29: 97-103. 7. Pourdeyhimi R, Wolf BJ, Simpson AN, et al. Adherence to outpatient epilepsy quality indicators at a tertiary epilepsy center. Epilepsy & Behavior. 2014; 39:26-32. 8. de la Morena Vicente MA, Ballesteros Plaza L, Martín García H, et al. Quality measures in neurology consult care for epileptic patients. Neurología. 2014;29(5):267—270 9. Fitzsimons M, Dunleavy B, O'Byrne P, et al. Assessing the quality of epilepsy care with an electronic patient record. Seizure. 2013; 22: 604-610.

Seizure Freedom Measure Flow



Seizure Freedom 2021 Code Systems and Descriptions

The below code systems and code descriptions were developed by the work group in 2021. This information may evolve over time as CPT, ICD-10, and LOINC codes evolve. Please contact quality@aan.com for the most up to date coding resources for measure implementation.

Code System	Code	Code Description
Denominator		
CPT	99201-99205	Office or Other Outpatient Visit – New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit – Established Patient (E/M Codes)
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
AND		
ICD-10	G40.001	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, not intractable, with status epilepticus
ICD-10	G40.009	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, not intractable, without status epilepticus
ICD-10	G40.011	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, intractable, with status epilepticus
ICD-10	G40.019	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, intractable, without status epilepticus
ICD-10	G40.101	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, not intractable, with status epilepticus
ICD-10	G40.109	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, not intractable, without status epilepticus
ICD-10	G40.111	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, intractable, with status epilepticus
ICD-10	G40.119	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, intractable, without status epilepticus
ICD-10	G40.201	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, not intractable, with status epilepticus
ICD-10	G40.209	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, not intractable, without status epilepticus
ICD-10	G40.211	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, with status epilepticus
ICD-10	G40.219	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, without status epilepticus
ICD-10	G40.301	Generalized idiopathic epilepsy and epileptic syndromes, not intractable, with status epilepticus
ICD-10	G40.309	Generalized idiopathic epilepsy and epileptic syndromes, not intractable, without status epilepticus

ICD-10	G40.311	Generalized idiopathic epilepsy and epileptic syndromes, intractable, with status epilepticus
ICD-10	G40.319	Generalized idiopathic epilepsy and epileptic syndromes, intractable, without status epilepticus
ICD-10	G40.A01	Absence epileptic syndrome, not intractable, with status epilepticus
ICD-10	G40.A09	Absence epileptic syndrome, not intractable, without status epilepticus
ICD-10	G40.A11	Absence epileptic syndrome, intractable, with status epilepticus
ICD-10	G40.A19	Absence epileptic syndrome, intractable, without status epilepticus
ICD-10	G40.B01	Juvenile myoclonic epilepsy, not intractable, with status epilepticus
ICD-10	G40.B09	Juvenile myoclonic epilepsy, not intractable, without status epilepticus
ICD-10	G40.B11	Juvenile myoclonic epilepsy, intractable, with status epilepticus
ICD-10	G40.B19	Juvenile myoclonic epilepsy, intractable, without status epilepticus
ICD-10	G40.401	Other generalized epilepsy and epileptic syndromes, not intractable, with status epilepticus
ICD-10	G40.409	Other generalized epilepsy and epileptic syndromes, not intractable, without status epilepticus
ICD-10	G40.411	Other generalized epilepsy and epileptic syndromes, intractable, with status epilepticus
ICD-10	G40.419	Other generalized epilepsy and epileptic syndromes, intractable, without status epilepticus
ICD-10	G40.42	Cyclin-Dependent Kinase-Like 5 Deficiency Disorder
ICD-10	G40.501	Epileptic seizures related to external causes, not intractable, with status epilepticus
ICD-10	G40.509	Epileptic seizures related to external causes, not intractable, without status epilepticus
ICD-10	G40.801	Other epilepsy, not intractable, with status epilepticus
ICD-10	G40.802	Other epilepsy, not intractable, without status epilepticus
ICD-10	G40.803	Other epilepsy, intractable, with status epilepticus
ICD-10	G40.804	Other epilepsy, intractable, without status epilepticus
ICD-10	G40.811	Lennox-Gastaut syndrome, not intractable, with status epilepticus
ICD-10	G40.812	Lennox-Gastaut syndrome, not intractable, without status epilepticus
ICD-10	G40.813	Lennox-Gastaut syndrome, intractable, with status epilepticus
ICD-10	G40.814	Lennox-Gastaut syndrome, intractable, without status epilepticus
ICD-10	G40.821	Epileptic spasms, not intractable, with status epilepticus
ICD-10	G40.822	Epileptic spasms, not intractable, without status epilepticus
ICD-10	G40.823	Epileptic spasms, intractable, with status epilepticus
ICD-10	G40.824	Epileptic spasms, intractable, without status epilepticus
ICD-10	G40.833	Dravet syndrome, intractable, with status epilepticus
ICD-10	G40.834	Dravet syndrome, intractable, without status epilepticus
ICD-10	G40.89	Other seizures
ICD-10	G40.901	Epilepsy, unspecified, not intractable, with status epilepticus
ICD-10	G40.909	Epilepsy, unspecified, not intractable, without status epilepticus
ICD-10	G40.911	Epilepsy, unspecified, intractable, with status epilepticus
ICD-10	G40.919	Epilepsy, unspecified, intractable, without status epilepticus
ICD-10	R56.9	Unspecified convulsions
Denominator Required Exclusions		
None		
Denominator Allowable Exclusions		
None		
Numerator		
LOINC	99312-1	Seizure Frequency
LOINC	LA32858-5	"Less than once per year"
LOINC	99313-9	Time Since Last Seizure

LOINC	LA32866-8	"13–24 months ago (53–104 weeks ago)"
LOINC	LA32867-6	"More than 2 years ago (more than 105 weeks ago)"

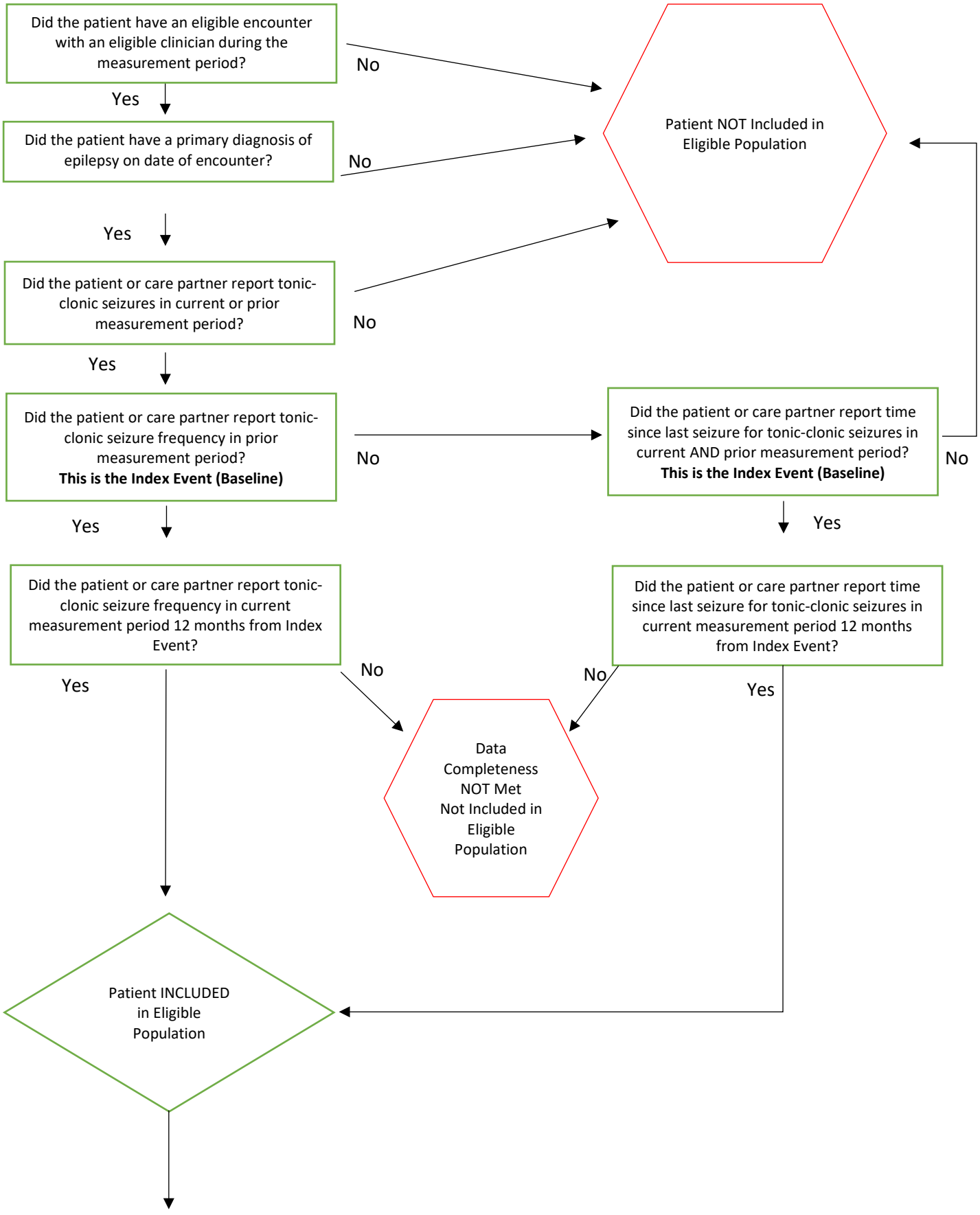
Tonic-Clonic Seizure Reduction

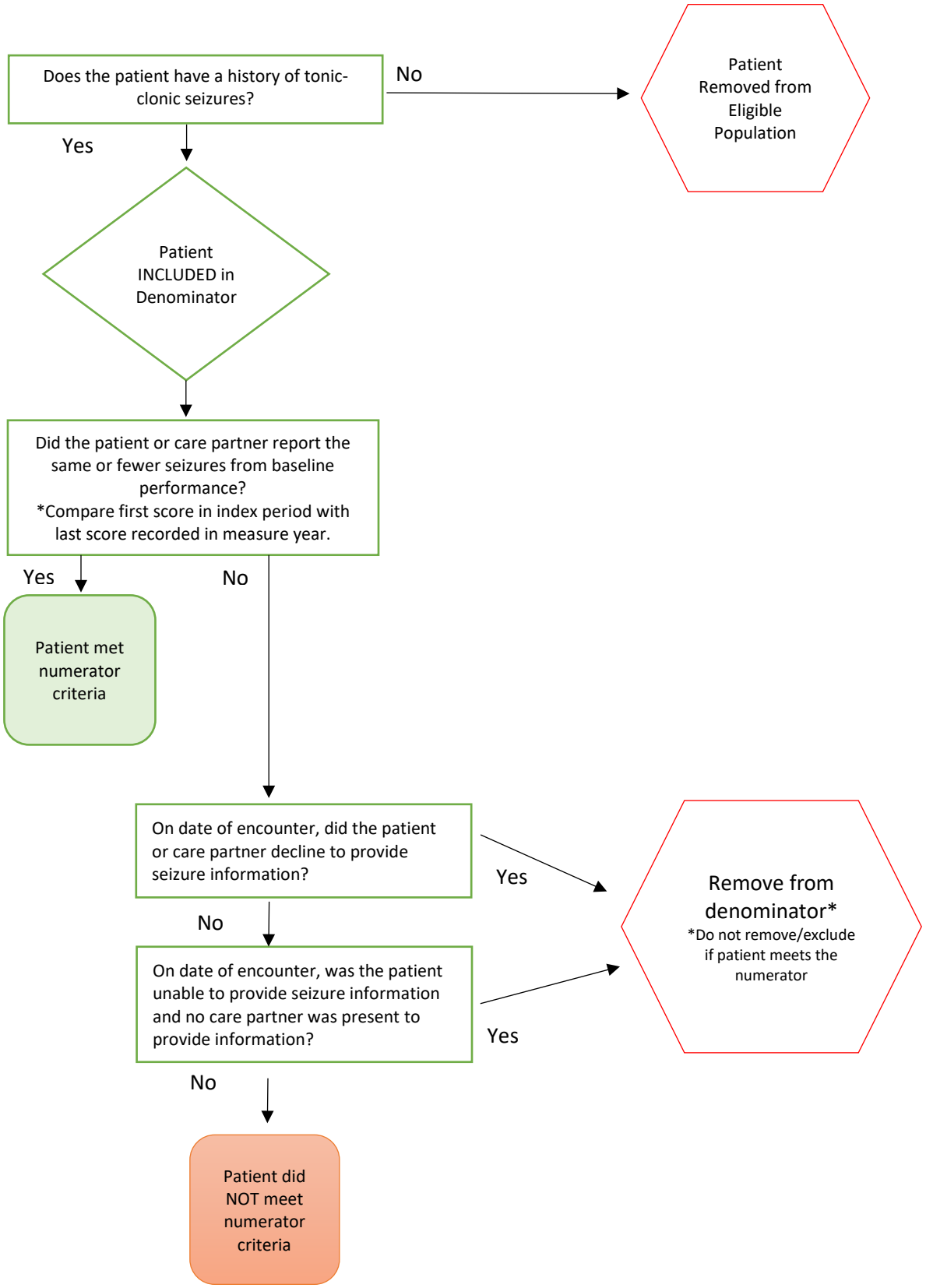
Measure Title	Tonic-Clonic Seizure Reduction	
Description	Percentage of patients experiencing tonic-clonic seizures who report the same or fewer seizures from baseline performance. This measure is intended for quality improvement only. It is not appropriate for use in accountability or payer programs.	
Measurement Period	January 1, 20xx to December 31, 20xx (See denominator identification period below.)	
Eligible Population	**Eligible Providers**	Medical Doctor (MD), Doctor of Osteopathy (DO), Physician Assistant (PA), Advanced Practice Registered Nurse (APRN)
	Care Setting(s)	Outpatient care
	Ages	All
	Event	Office visit
	Diagnosis	Convulsive seizures (see code list below). Diagnoses may also be identified via key phrase search for: • Tonic-clonic • Convulsive seizure • Grand mal • GTC • Secondary generalized seizures • Focal to bilateral tonic-clonic • Generalized – Motor tonic-clonic • Unknown (if focal or generalized) Onset – Motor tonic-clonic
Denominator	Patients diagnosed with epilepsy who have experienced or are currently experiencing tonic-clonic seizures. ***NOTE:*** *To be considered denominator eligible for this measure, the patient must have both the diagnosis of tonic-clonic seizures AND seizure frequency or time since last seizure recorded (index event) and this date occurs during denominator identification period (see below definition).*	
Denominator Identification Period	The denominator identification period (i.e., baseline performance period) occurs prior to the measurement period and is the period in which eligible patients can have an index event. The denominator identification period occurs in the calendar year (12 months) prior to the start of the current measurement period. For example, the denominator identification period for the 2022 calendar year is from 1/1/2021 to 12/31/2021. For patients with a baseline performance, there needs to be enough time following collection of seizure frequency for the patients to have the opportunity to reach comparison 12 months after that visit. The first score collected in the denominator identification period is compared to the last score recorded in the measurement assessment period. **Index Event Date:** The date on which a patient with a diagnosis of tonic-clonic seizures has either their seizure frequency or time since last seizure recorded during the denominator identification period. Patients may provide this information via screening (using a planned visit model) prior to the encounter (including the day of the encounter). **Measure Assessment Period:** The index event date marks the start of the measurement assessment period for each patient, which is 12 months (calendar year). This assessment period is fixed and does not "start over" with a higher seizure frequency count that may occur after the index event date during the 12 months (calendar year).	
Numerator	Patients who had the same or fewer quantity of seizures in the most recent 12 months compared to the prior 12 months (see denominator identification period definition above).	

	Seizure frequency must be recorded using one of the below quantity formats. Clinicians and treatment teams must use one of the quantity formats consistently for their patients to accurately calculate outcomes over time: Current seizure frequency for each tonic-clonic type: • 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 Time since last seizure for each tonic-clonic type: • 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
Required Exclusions	Patients without documentation of tonic-clonic seizures
Allowable Exclusions	1. Patient declines to provide seizure information on date of encounter. 2. Patient unable to provide seizure information on date of encounter and no care partner is available to provide information or care partner information limited (i.e., nursing home or group home staff not familiar).
Exclusion Rationale	Patients must be willing to provide seizure frequency or must have a knowledgeable care partner available to provide information for results to be valid.
Measure Scoring	Percentage
Calculation Example	Dr. Baker 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 or their care partners' reports. Ten of these patients have multiple visits with their seizure frequency data collected. For these patients, the first seizure frequency score collected in 2020 will be compared to the last seizure frequency score recorded in 2021. In 2021, Dr. Baker also sees 25 new patients who report their seizure frequency at every visit. On December 31, 2021, Dr. Baker's practice administrator completes a comparison of 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. Dr. Baker finds that 33% 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.
Interpretation of Score	Higher score indicates better quality
Measure Type	Outcome
Level of Measurement	Provider

Risk Adjustment	None. Being made available without risk adjustment. Work group will revisit during future updates to evaluate any unintended consequences over time.
Opportunity to Improve Gap in Care	Tonic-clonic seizures present a first opportunity to start measuring seizure reduction for patients with epilepsy given patients and care partners are more likely to be able to identify and recall most recent seizure activity compared to non-convulsive forms of epilepsy. Additionally, tonic-clonic seizures have the highest risk for major consequences such as a risk for sudden unexpected death from epilepsy (SUDEP).[1] It is estimated about 25% of patients with epilepsy have generalized tonic-clonic seizures, 5% have either absence or myoclonic seizures and less than 1% have atonic seizures.[2] 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 information may be accessed more readily when and if patients require coordinated care, like when a patient may present at 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.
Harmonization with Existing Measures	There are no known similar measures.
References	1. Devinsky O. Sudden unexpected death in epilepsy. New Engl J Med. 2011;365:1801-1811. 2. American Epilepsy Society. Facts and Figures. Available at: https://www.aesnet.org/for_patients/facts_figures Accessed on August 6, 2019.

Tonic-Clonic Seizure Reduction Measure Flow





Tonic Clonic Seizure Reduction Code Systems and Descriptions

Code System	Code	Code Description
Denominator		
CPT	99201-99205	Office or Other Outpatient Visit – New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit – Established Patient (E/M Codes)
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
AND		
ICD-10	G40.001	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, not intractable, with status epilepticus
ICD-10	G40.009	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, not intractable, without status epilepticus
ICD-10	G40.011	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, intractable, with status epilepticus
ICD-10	G40.019	Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, intractable, without status epilepticus
ICD-10	G40.201	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, not intractable, with status epilepticus
ICD-10	G40.209	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, not intractable, without status epilepticus
ICD-10	G40.211	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, with status epilepticus
ICD-10	G40.219	Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, without status epilepticus
ICD-10	G40.301	Generalized idiopathic epilepsy and epileptic syndromes, not intractable, with status epilepticus
ICD-10	G40.309	Generalized idiopathic epilepsy and epileptic syndromes, not intractable, without status epilepticus
ICD-10	G40.311	Generalized idiopathic epilepsy and epileptic syndromes, intractable, with status epilepticus
ICD-10	G40.319	Generalized idiopathic epilepsy and epileptic syndromes, intractable, without status epilepticus
ICD-10	G40.401	Other generalized epilepsy and epileptic syndromes, not intractable, with status epilepticus
ICD-10	G40.409	Other generalized epilepsy and epileptic syndromes, not intractable, without status epilepticus
ICD-10	G40.411	Other generalized epilepsy and epileptic syndromes, intractable, with status epilepticus
ICD-10	G40.419	Other generalized epilepsy and epileptic syndromes, intractable, without status epilepticus
ICD-10	G40.42	Cyclin-Dependent Kinase-Like 5 Deficiency Disorder
ICD-10	G40.501	Epileptic seizures related to external causes, not intractable, with status epilepticus
ICD-10	G40.509	Epileptic seizures related to external causes, not intractable, without status epilepticus

ICD-10	G40.801	Other epilepsy, not intractable, with status epilepticus
ICD-10	G40.802	Other epilepsy, not intractable, without status epilepticus
ICD-10	G40.803	Other epilepsy, intractable, with status epilepticus
ICD-10	G40.804	Other epilepsy, intractable, without status epilepticus
ICD-10	G40.811	Lennox-Gastaut syndrome, not intractable, with status epilepticus
ICD-10	G40.812	Lennox-Gastaut syndrome, not intractable, without status epilepticus
ICD-10	G40.813	Lennox-Gastaut syndrome, intractable, with status epilepticus
ICD-10	G40.814	Lennox-Gastaut syndrome, intractable, without status epilepticus
ICD-10	G40.833	Dravet syndrome, intractable, with status epilepticus
ICD-10	G40.834	Dravet syndrome, intractable, without status epilepticus
ICD-10	G40.89	Other seizures
ICD-10	G40.901	Epilepsy, unspecified, not intractable, with status epilepticus
ICD-10	G40.909	Epilepsy, unspecified, not intractable, without status epilepticus
ICD-10	G40.911	Epilepsy, unspecified, intractable, with status epilepticus
ICD-10	G40.919	Epilepsy, unspecified, intractable, without status epilepticus
ICD-10	G40.A01	Absence epileptic syndrome, not intractable, with status epilepticus
ICD-10	G40.A09	Absence epileptic syndrome, not intractable, without status epilepticus
ICD-10	G40.A11	Absence epileptic syndrome, intractable, with status epilepticus
ICD-10	G40.A19	Absence epileptic syndrome, intractable, without status epilepticus
ICD-10	G40.B01	Juvenile myoclonic epilepsy, not intractable, with status epilepticus
ICD-10	G40.B09	Juvenile myoclonic epilepsy, not intractable, without status epilepticus
ICD-10	G40.B11	Juvenile myoclonic epilepsy, intractable, with status epilepticus
ICD-10	G40.B19	Juvenile myoclonic epilepsy, intractable, without status epilepticus
ICD-10	R56.9	Unspecified convulsions
OR Documentation of Seizure Classification to identify Tonic-Clonic Seizures		
LOINC	LA32843-7	“Focal Onset - to Bilateral Tonic-clonic"
LOINC	LA32844-5	“Generalized Onset - Motor Tonic-clonic"
LOINC	LA32847-8	"Unknown Onset (if focal or generalized)* - Motor Tonic-clonic"
OR Documentation of Key Phrases to identify Tonic-Clonic Seizures		
		Tonic-clonic
		Convulsive seizure
		Grand mal
		GTC
		Secondary generalized seizures
		Focal to bilateral tonic clonic
		Generalized – Motor Tonic-Clonic
		Unknown (if focal or generalized) Onset – Motor tonic-clonic
Denominator Required Exclusions		
None		
Denominator Allowable Exclusions		
SNOMEDCT	288576002	Unable to communicate (finding)
SNOMEDCT	105480006	Refusal of treatment by patient (situation)
Numerator		
LOINC	99312-1	Seizure Frequency
LOINC	LA32852-8	"Innumerable (i.e., ≥ 10 per day most days)"
LOINC	LA32853-6	"Multiple per day (i.e., 4 days per week with ≥ 2 seizures)"
LOINC	LA32854-4	"Daily (i.e., 4 or more days per week)"
LOINC	LA32855-1	"Weekly but not daily (i.e., 1–3 per week)"
LOINC	LA32856-9	"Monthly but not weekly (i.e., 1–3 per month)"
LOINC	LA32857-7	"At least once per year, but not every month (i.e., 10 or fewer in past 12 months)"
LOINC	LA32858-5	"Less than once per year"
LOINC	LA32859-3	"Frequency not well defined"

LOINC	LA4489-6	"Unknown"
LOINC	99313-9	Time Since Last Seizure
LOINC	LA32860-1	"Today"
LOINC	LA32861-9	"1–6 days ago"
LOINC	LA32862-7	"1–4 weeks ago"
LOINC	LA32863-5	“5–12 weeks ago"
LOINC	LA32864-3	"13–26 weeks ago"
LOINC	LA32865-0	"6–12 months ago (27–52 weeks ago)"
LOINC	LA32866-8	"13–24 months ago (53–104 weeks ago)"
LOINC	LA32867-6	"More than 2 years ago (more than 105 weeks ago)"
LOINC	LA14072-5	“Unsure”

Appendix A

Work Group Member	Disclosures
Heidi Munger-Clary, MD, MPH (Subject matter chair effective February 2020)	Dr. Munger Clary reports research funding NCATS KL-2 career development award, translational pilot award; NINDS NeuroNEXT fellowship award to investigate treatment and outcome assessment for anxiety and depression in epilepsy.
S. Andrew Josephson, MD, FAAN (non-voting work group member)	No relevant disclosures for this project.
Christine Baca, MD, MSHS (non-voting work group member)	Dr. Baca reports research funding from Epilepsy Foundation/American Epilepsy Society.
Gary Franklin, MD, MPH, FAAN	No disclosures.
Susan T. Herman, MD, FAAN	Dr. Herman serves as Vice President of the National Association of Epilepsy Centers; has received research support from Neuropace, Inc., Sage Therapeutics, Acorda Therapeutics, UCB Pharma, and NIH/NINDS.
Jennifer L. Hopp, MD (new member effective April 2020)	Dr. Hopp received travel funding from the American Academy of Neurology Transforming Leaders Program, research support from NINDS, NIH/NETT, MII/TEDCO, honoraria from UpToDate, Inc., J. Kiffen Penry Epilepsy Education Programs, and consulting fees from GEROLAMO McNULTY DIVIS & LEWBART.
Inna Hughes, MD, PhD	No disclosures.
Lisa Meunier	No disclosures.
Lidia M.V.R. Moura, MD, MPH	Dr. Moura is the recipient of a Career Development Award sponsored by the American Academy of Neurology to study predictors of treatment adherence and outcomes in geriatric epilepsy; serves as Principal Investigator on a Sponsor Initiated Award by the Epilepsy Foundation, Co-principal Investigator on a project sponsored by the Centers for Disease Control and Prevention, Co-investigator on two NIH Research Project Awards, and Co-investigator on NIH P01 Award.
Brandy Parker-McFadden	No disclosures.
Anup Patel, MD (membership ended 1/2020)	Dr. Patel reports research funding from Pediatric Epilepsy Research Foundation (PERF), Upsher-Smith, LivaNova, and Greenwich Biosciences, consulting fees from Greenwich Biosciences, Supernus, LivaNova, and serves on a Scientific Advisory Board for UCB Pharma.
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Marianna Spanaki, MD, PhD, MBA	Dr. Spanaki serves on the Scientific Advisory Board SK Life Science.

[1] Quality Measurement Subcommittee. American Academy of Neurology Quality Measurement Manual 2019 Update. 24 p. Available at: https://www.aan.com/policy-and-guidelines/quality/quality-measures2/how-measures-are-developed/

[2] Patel AD, Baca C, Franklin G, et al. Quality improvement in neurology: Epilepsy Quality Measurement Set 2017 update. Neurology 2018; 91(18):829-836.