

NATIONAL QUALITY FORUM

Measure Submission and Evaluation Worksheet 5.0

This form contains the information submitted by measure developers/stewards, organized according to NQF's measure evaluation criteria and process. The evaluation criteria, evaluation guidance documents, and a blank online submission form are available on the [submitting standards web page](#).

NQF #: 1954	NQF Project: Neurology Project
(for Endorsement Maintenance Review)	
Original Endorsement Date:	Most Recent Endorsement Date: Last Updated Date: Oct 21, 2015
BRIEF MEASURE INFORMATION	
De.1 Measure Title: Documentation of Etiology of Epilepsy or Epilepsy Syndrome	
Co.1.1 Measure Steward: American Academy of Neurology	
De.2 Brief Description of Measure: All visits for patients with a diagnosis of epilepsy who had their etiology of epilepsy or with epilepsy syndrome(s) reviewed and documented if known, or documented as unknown or cryptogenic	
2a1.1 Numerator Statement: Patient visits with etiology of epilepsy or with epilepsy syndrome(s) reviewed and documented if known, or documented as unknown or cryptogenic.	
2a1.4 Denominator Statement: All visits for patients with a diagnosis of epilepsy.	
2a1.8 Denominator Exclusions: None	
1.1 Measure Type: Process 2a1. 25-26 Data Source: Administrative claims, Electronic Clinical Data : Electronic Health Record 2a1.33 Level of Analysis: Clinician : Individual	
1.2-1.4 Is this measure paired with another measure? No	
De.3 If included in a composite, please identify the composite measure (title and NQF number if endorsed):	

STAFF NOTES (issues or questions regarding any criteria)
Comments on Conditions for Consideration:
Is the measure untested? Yes <input checked="" type="radio"/> No <input checked="" type="radio"/> If untested, explain how it meets criteria for consideration for time-limited endorsement:
1a. Specific national health goal/priority identified by DHHS or NPP addressed by the measure (check De.5): 5. Similar/related endorsed or submitted measures (check 5.1): Other Criteria:
Staff Reviewer Name(s):

1. IMPACT, OPPORTUNITY, EVIDENCE - IMPORTANCE TO MEASURE AND REPORT

See Guidance for Definitions of Rating Scale: H=High; M=Moderate; L=Low; I=Insufficient; NA=Not Applicable
 Created on: 10/27/2015 at 06:43 AM

Importance to Measure and Report is a threshold criterion that must be met in order to recommend a measure for endorsement. All three subcriteria must be met to pass this criterion. See [guidance on evidence](#).

Measures must be judged to be important to measure and report in order to be evaluated against the remaining criteria. (evaluation criteria)

1a. High Impact: H O M O L O I O

(The measure directly addresses a specific national health goal/priority identified by DHHS or NPP, or some other high impact aspect of healthcare.)

De.4 Subject/Topic Areas (Check all the areas that apply): [Neurology](#)

De.5 Cross Cutting Areas (Check all the areas that apply): [Health and Functional Status](#), [Health and Functional Status : Development/Wellness](#), [Safety](#), [Safety : Medication Safety](#)

1a.1 Demonstrated High Impact Aspect of Healthcare: [Affects large numbers](#), [A leading cause of morbidity/mortality](#), [Patient/societal consequences of poor quality](#)

1a.2 If "Other," please describe:

1a.3 Summary of Evidence of High Impact (Provide epidemiologic or resource use data):

The natural history, selection of treatment, expected response to treatment, and content of counseling are determined by the etiology of epilepsy or epilepsy syndrome (Commission on Classification 1989). Therefore, the etiology of epilepsy or epilepsy syndrome should be determined at the initial visit. Epilepsy is a chronic condition in which treatments must be instituted over long durations, such as achieving maximum tolerated doses of antiepileptic drugs. Since it is often a relatively long interval between starting an intervention and determining if it is effective, the etiology of epilepsy or syndrome should be reviewed at each visit to determine if an alternative therapy is warranted.

Etiology of epilepsy is a factor in determining cognitive function and intellectual changes over time. The main distinction is between symptomatic epilepsy (which has an identified cause such as stroke or cortical dysplasia) and idiopathic epilepsy (which has no identified cause other than genetic factors).

Lennox recognized that cognitive function was twice as likely to deteriorate in the presence of a known cause of epilepsy even if the idiopathic group had more frequent seizures.

In another study, children with idiopathic epilepsy were more likely to conform to the expected normal distribution of intellectual ability for their age.

A third study demonstrated that patients with symptomatic epilepsy had a mean 6-point drop in IQ during follow-up periods between 1 and 9 years. A group of normal controls had a drop of 0.7 points.

More recent work has confirmed the poorer prognosis in patients with symptomatic epilepsy. In a longitudinal study of a group of 72 patients with epilepsy, those with the symptomatic form had a significantly lower IQ (89.1) than those with idiopathic epilepsy (102.5) on initial evaluation.²³ At their last evaluation, the symptomatic group scored 88.9, versus 104.1 for the idiopathic group.

The etiology of epilepsy is a major determinant of clinical course and prognosis, yet the current classifications of epilepsy do not list etiology in any detail. In this article, a classification (database) of the etiologies of epilepsy is proposed. In this scheme, the etiology of epilepsy is divided into four categories: idiopathic, symptomatic, provoked, and cryptogenic. These are defined and subcategories are proposed. A commentary addressing the following points is included: problems associated with assigning causation, symptomatic versus idiopathic epilepsy, focal versus generalized epilepsy, acquired epilepsy, acute symptomatic epilepsy, risk factor analysis, provoked epilepsy genetic and developmental epilepsy, and epilepsy as a disease not a symptom. (Shorvon)

From the IOM Epilepsies Across the Spectrum 2012 Report

“Cases of epilepsy that have a known etiology have a worse overall prognosis, more commonly involve persistent seizures, and have a higher mortality rate than cases in which the cause is unknown (Forsgren et al., 2005b; Hauser et al., 1998). Less than half of all newly diagnosed cases of epilepsy have a known structural or metabolic cause (Adelöw et al., 2009; Forsgren et al., 2005a; Hauser et al., 1993).

Among people with newly diagnosed epilepsy, the predominant known causes are stroke, neurodegenerative diseases such as dementia and multiple sclerosis, primary brain tumors or the spread of cancer from another site to the brain, and TBI (Annegers and Coan, 2000; Hauser et al., 1993; Herman, 2002; Hesdorffer et al., 1996a; Kelley and Rodriguez, 2009). Other known causes are rarer but confer a strong risk for developing epilepsy: brain infections, such as meningitis, encephalitis, and neurocysticercosis; pre- and perinatal injury; intellectual disability; cerebral palsy; and autism spectrum disorders (Annegers et al., 1988; Bergamasco et al., 1984; Carpio et al., 1998; Nelson and Ellenberg, 1987; Rocca et al., 1987; Tuchman and Rapin, 2002; Van der Berg and Yerushalmy, 1969). A recent study by Crump and colleagues (2011) found that preterm birth is associated with an increased risk of epilepsy in adulthood.

Identifying causes of epilepsy is the first step in primary prevention. Prevention of posttraumatic epilepsy has been attempted through indirect means and planned interventions. Efforts to prevent epilepsy from developing after TBI have involved randomized clinical trials of drug therapies; regrettably, these have not been successful (Temkin et al., 1990, 1999, 2007). Prevention of epilepsy after TBI is a complex problem, because the types, location, and extent of brain injury vary widely, and the process of epileptogenesis after TBI is not well understood. The heterogeneity of TBI has hindered the development of effective interventions to prevent poor functional outcomes in general. A systematic review of the literature found that only a third of randomized clinical trials of interventions to prevent negative health outcomes after TBI have been successful, underscoring the complexity of this injury (Hernández et al., 2005). Currently, the prevention of TBI itself allows the best opportunity to prevent post-traumatic epilepsy.

In this chapter epilepsy due to unknown, genetic, or presumed genetic causes is called “epilepsy of unknown etiology” for simplicity. The majority of new-onset cases of epilepsy are of unknown etiology (Adelöw et al., 2009; Forsgren et al., 2005; Hauser et al., 1993). The assumption is that etiologies exist but have not yet been detected. While the risk for continued seizures is relatively lower in epilepsy of unknown etiology than in epilepsy due to structural or metabolic causes and early mortality is lower (Forsgren et al., 2005b; Hauser et al., 1998), there are risk factors for continued seizures and for increased mortality long after the diagnosis of epilepsy, suggesting that such cases are not benign. Moreover, increasing numbers of genetic mutations are being discovered that result in catastrophic epilepsies, such as Dravet syndrome and other severe epilepsy syndromes with onset in infancy (Carranza Rojo et al., 2011).

Although several risk factors for developing epilepsy of unknown etiology have been elucidated recently, including mental health conditions and migraine (Hesdorffer et al., 2004, 2006; Ludvigsson et al., 2006; Ottman and Lipton, 1994), evidence that would support causality is lacking. It is possible that genes may be discovered to explain the occurrence of some of these epilepsies or that other factors common to both epilepsy and the risk factors may be found that contribute to the occurrence of these disorders.

Epilepsy and Seizure Statistics

- Epilepsy and seizures affect nearly 3 million Americans of all ages, at an estimated annual cost of \$17.6 billion in direct and indirect costs.
- Approximately 200,000 new cases of seizures and epilepsy occur each year.
- Ten percent of the American population will experience a seizure in their lifetime.

Health condition statistics are typically expressed in terms of incidence and prevalence in a particular

population within a specific period of time. Incidence is a measure of the number of new cases of a medical condition that occur in the population during a measured amount of time, usually one year. Prevalence is defined as the total number of existing cases of a disease in a specific population at a stated point in time. In any one day, at a certain time, there are a specific number of people with a certain disorder.

There is no central registry of cases of epilepsy or seizures in the United States. Epidemiologists base their estimates on peer-reviewed studies of medical records at specific institutions or in defined local communities. Surveys of physicians and patients, self reporting, and studies in matched populations or segments of populations overseas may also be taken into account.

From this mixture of sources, leading experts in the field have arrived at the following estimates of the incidence and prevalence of seizures and epilepsy in the United States:

Incidence -- Seizures:

- 300,000 people have a first convulsion each year.
- 120,000 of them are under the age of 18.
- Between 75,000 and 100,000 of them are children under the age of 5 who have experienced a febrile (fever-caused) seizure.

Incidence -- Epilepsy:

- 200,000 new cases of epilepsy are diagnosed each year.
- Incidence is highest under the age of 2 and over 65.
- 45,000 children under the age of 15 develop epilepsy each year.
- Males are slightly more likely to develop epilepsy than females.
- Incidence is greater in African American and socially disadvantaged populations.
- Trends show decreased incidence in children; increased incidence in the elderly.
- In 70 percent of new cases, no cause is apparent.
- 50 percent of people with new cases of epilepsy will have generalized onset seizures.
- Generalized seizures are more common in children under the age of 10; afterwards more than half of all new cases of epilepsy will have partial seizures.

Prevalence -- Epilepsy:

- Prevalence of active epilepsy (history of the disorder plus a seizure or use of antiepileptic medicine within the past 5 years) is estimated as nearly 3 million in the United States.
- Prevalence tends to increase with age.
- 326,000 children through age 15 have epilepsy.
- More than 300,000 persons over the age of 65 have epilepsy.
- Higher among racial minorities than among Caucasians.
- Cumulative incidence (risk of developing epilepsy):
- By 20 years of age, one percent of the population can be expected to have developed epilepsy.
- By 75 years of age, three percent of the population can be expected to have been diagnosed with epilepsy, and ten percent will have experienced some type of seizure.

Epilepsy risk in special populations:

The basic, underlying risk of developing epilepsy is about one percent. Individuals in certain populations are at higher risk. For example, it is estimated that epilepsy can be expected to develop in:

- 25.8 percent of children with mental retardation
- 13 percent of children with cerebral palsy
- 50 percent of children with both disabilities
- 10 percent of Alzheimer patients
- 22 percent of stroke patients
- 8.7 percent of children of mothers with epilepsy

- 2.4 percent of children of fathers with epilepsy
- 33 percent of people who have had a single, unprovoked seizure

1a.4 Citations for Evidence of High Impact cited in 1a.3: Commission of Classification and Terminology of the International League Against Epilepsy. Proposal for revised classification of epilepsies and epileptic syndromes. *Epilepsia* 1989;30:389-399.

Epilepsy Foundation of America Statistics Incidence and Prevalence
<http://www.epilepsyfoundation.org/aboutepilepsy/whatisepilepsy/statistics.cfm>

Adapted from: Devinsky O and Tarulli A. Progressive cognitive and behavioral changes in epilepsy. In: Devinsky O and Westbrook LE, eds. *Epilepsy and Developmental Disabilities*. Boston: Butterworth-Heinemann; 2001;133–149.

Institute of Medicine Report "Epilepsy Across the Spectrum: Promoting Health and Understanding"
<http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>

Shorvon, S. D. (2011), The causes of epilepsy: Changing concepts of etiology of epilepsy over the past 150 years. *Epilepsia*, 2011; 52(6): 1033–1044

1b. Opportunity for Improvement: H● M● L● I●

(There is a demonstrated performance gap - variability or overall less than optimal performance)

1b.1 Briefly explain the benefits (improvements in quality) envisioned by use of this measure:

The etiology of epilepsy is a major determinant of clinical course and prognosis, yet the current classifications of epilepsy do not list etiology in any detail. In this article, a classification (database) of the etiologies of epilepsy is proposed. In this scheme, the etiology of epilepsy is divided into four categories: idiopathic, symptomatic, provoked, and cryptogenic. These are defined and subcategories are proposed. A commentary addressing the following points is included: problems associated with assigning causation, symptomatic versus idiopathic epilepsy, focal versus generalized epilepsy, acquired epilepsy, acute symptomatic epilepsy, risk factor analysis, provoked epilepsy genetic and developmental epilepsy, and epilepsy as a disease not a symptom.

1b.2 Summary of Data Demonstrating Performance Gap *(Variation or overall less than optimal performance across providers): [For Maintenance – Descriptive statistics for performance results for this measure - distribution of scores for measured entities by quartile/decile, mean, median, SD, min, max, etc.]* QUIET Indicator Study. Indicators #4 was used as support for this measure. The 2011 Pugh et al. study on quality of care for adults with epilepsy showed the proportion of patients receiving quality indicator concordant care by setting for all settings for quality indicator #4 (if a patient is thought to have a diagnosis for epilepsy then the diagnosis should include a best estimate of seizure types) was 44.62%. Overall for patients with chronic epilepsy the quality indicator concordant care was only provided 45.07% of the time.

From the 2012 IOM Report *Epilepsies Across the Spectrum*.

The potential array of risk factors for epilepsy of unknown etiology is incompletely understood and elucidated. This is a significant gap in knowledge pertaining to more than half of all new cases of epilepsy. Further epidemiological studies can help to close this gap by examining other potential risk factors for developing epilepsy in the absence of established causes and can examine factors such as stress

that may contribute to the association between low socioeconomic status and risk for developing epilepsy. As knowledge accumulates, it may be possible to consider ways to prevent some of these cases, but this is a hope for the future.

Types of Seizures and Syndromes

Although much remains to be learned about the neuroscience of the epilepsies and the causes of specific types of epilepsy, in general, seizures are caused by abnormal, excessive, and hypersynchronized neuron discharges in the brain (McNamara, 1994; Pitkanen and Lukasiuk, 2011). These discharges can involve widespread areas of the brain simultaneously or be focused in one specific area. The effects of seizures on a person's health and well-being depend on the location and extent of the nerve cells involved; as a result, seizures can range from mild (such as a momentary loss of awareness) to severe (such as body convulsions).

Defining and categorizing the multiple types of epilepsy can be difficult. In 1964, the International League Against Epilepsy (ILAE) developed a classification system for epilepsy seizures and syndromes that continues to be updated (Arnautova and Nesmeianova, 1964; Berg et al., 2010). Because of the complex and disparate nature of where and to what extent the brain is affected by seizures, the epilepsies can be categorized according to multiple dimensions:

- Seizure type—Seizures are classified into two major categories: (1) focal seizures that originate in a network of neurons limited to one hemisphere of the brain and (2) generalized seizures that originate in a network of neurons that is distributed to both brain hemispheres (Berg et al., 2010). Seizures also can be categorized as of unknown type. Box 1-2 provides an overview of seizure types.
- Syndromes—Berg and colleagues (2010) recently defined a syndrome as “a complex of clinical features, signs, and symptoms that together define a distinctive, recognizable clinical disorder” (p. 681). Often a syndrome is characterized by a typical age of onset, specific characteristics of the electroencephalogram (EEG), and seizure types. Table 1-3 provides an overview of a few of the many epilepsy syndromes.

Etiology background

For example, accurate and detailed surveillance data on the etiologies of, and risk factors for, epilepsy are needed in order to identify opportunities for public health efforts to prevent epilepsy from developing in the first place or to prevent a range of possible consequences. Furthermore, because the burden of the comorbidities often outweighs that of the epilepsy itself, surveillance of its comorbidities is also crucial to appropriate targeting of public health interventions. Currently, gaps in data collection prevent accurate and timely information to monitor and evaluate these basic public health dimensions of the epilepsies, one of the most common neurological disorders in the United States.

Wick P, Fountain N. Patient reported clinician adherence to Epilepsy Performance Measures of Quality of Care. (Before the publication of the Quality Measures) Poster. Epilepsy Meeting Dec 2010.

Patient reported adherence of their physician to the quality measure (Strongly Agree, Agree; Disagree, & Strongly Disagree not noted here)
Epilepsy Syndrome (48% Strongly Agree, 33% Agree)

1b.3 Citations for Data on Performance Gap: [For Maintenance – Description of the data or sample for measure results reported in 1b.2 including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included]

Pugh MJ, Berlowitz DR, Rao JK Et al. The quality of care for adults with epilepsy: an initial glimpse using the QUIET measure BMC Health Services Research 2011, 11:1 <http://www.biomedcentral.com/1472-6963/11/1>

Institute of Medicine Report "Epilepsy Across the Spectrum: Promoting Health and Understanding" <http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>

Fountain NB, Van Ness PC, Swain-Eng R, et al. Quality improvement in neurology: AAN epilepsy quality measures. Neurology 2011;76:94-99.

Wicks P, Massagli M, Frost J, et al. Sharing health data for better outcomes on PatientsLikeMe. J Med Internet Res 2010;12:e19.

Gumnit R. We are Failing Our Patients: Guidelines and Quality Measures Epilepsia Accessed 09/24/12. <http://www.mincep.com/pdfs/publications/Epilepsia%20Editorial%20We%20Are%20Failing%20Our%20Patients.pdf>

1b.4 Summary of Data on Disparities by Population Group: [*For Maintenance – Descriptive statistics for performance results for this measure by population group*]

A study in the Harlem neighborhood of New York City found epilepsy prevalence to be higher in Hispanics than in non-Hispanics and a higher prevalence of active epilepsy³ in whites than in blacks, although the prevalence of lifetime epilepsy⁴ was higher in blacks compared to whites (Kelvin et al., 2007). In this community, there were racial and ethnic disparities in care; blacks were more likely to receive care in the emergency department compared to whites and Hispanics. Similarly, Hope and colleagues (2009) found that blacks and Hispanics were more likely than whites to be diagnosed in an emergency department, and blacks were more likely to receive a suboptimal seizure medication. Differences in care for prevalent epilepsy were also observed in residents of Alabama and surrounding states, where blacks were 60 percent less likely than non-Hispanic whites to undergo epilepsy surgery after receiving electroencephalograph (EEG) monitoring as part of a surgical evaluation, an association that persisted after controlling for factors such as SES and medical insurance coverage (Burneo et al., 2005). The degree to which differences in epilepsy incidence and prevalence in different racial and ethnic groups reflect differences in socioeconomic status is unknown. Also unknown is the degree to which the treatment gap contributes to the higher epilepsy prevalence in some subgroups.

Wick P, Fountain N. Patient reported clinician adherence to Epilepsy Performance Measures of Quality of Care. (Before the publication of the Quality Measures) Poster. Epilepsy Meeting Dec 2010.

There are some patient reported differences in physician adherence to quality measures by the type of clinician. N=221 overall.

•Epilepsy syndrome: 91% adherence (epileptologist); 79 adherence (neurologist); 80% adherence (PCP); 88% adherence (Other clinician); p-value 0.062

1b.5 Citations for Data on Disparities Cited in 1b.4: [*For Maintenance – Description of the data or sample for measure results reported in 1b.4 including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included*]

Institute of Medicine Report "Epilepsy Across the Spectrum: Promoting Health and Understanding" <http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>

Wick P, Fountain N. Patient reported clinician adherence to Epilepsy Performance Measures of Quality of Care. (Before the publication of the Quality Measures) Poster. Epilepsy Meeting Dec 2010.

1c. Evidence (*Measure focus is a health outcome OR meets the criteria for quantity, quality, consistency of the body of evidence.*)

Is the measure focus a health outcome? Yes ☒ No ☐ **If not a health outcome, rate the body of evidence.**

Quantity: H ☐ M ☐ L ☐ I ☐ **Quality:** H ☐ M ☐ L ☐ I ☐ **Consistency:** H ☐ M ☐ L ☐ I ☐

Quantity	Quality	Consistency	Does the measure pass subcriterion1c?
M-H	M-H	M-H	Yes <input checked="" type="radio"/>
L	M-H	M	Yes <input checked="" type="radio"/> IF additional research unlikely to change conclusion that benefits to

			patients outweigh harms: otherwise No
M-H	L	M-H	Yes IF potential benefits to patients clearly outweigh potential harms: otherwise No
L-M-H	L-M-H	L	No
Health outcome – rationale supports relationship to at least one healthcare structure, process, intervention, or service			Does the measure pass subcriterion1c? Yes IF rationale supports relationship
<p>1c.1 Structure-Process-Outcome Relationship (<i>Briefly state the measure focus, e.g., health outcome, intermediate clinical outcome, process, structure; then identify the appropriate links, e.g., structure-process-health outcome; process- health outcome; intermediate clinical outcome-health outcome</i>):</p> <p>Epilepsy is a chronic condition in which treatments must be instituted over long durations, such as achieving maximum tolerated doses of antiepileptic drugs. Since it is often a relatively long interval between starting an intervention and determining if it is effective, the etiology of epilepsy or syndrome should be reviewed at each visit to determine if an alternative therapy is warranted. By reviewing and documenting the etiology of epilepsy or epilepsy syndrome with the patient at every visit the clinician can determine the appropriate treatment, understand the expected response to treatment and provide appropriate content for counseling the patient. The outcome for the patient is better symptom management, appropriate treatment and improved quality of life. This measure may also lead a reduction in overuse and misuse of treatments because the etiology/epilepsy will be reviewed and documented at every visit.</p> <p>The American Academy of Neurology has preliminary data from the implementation of these measures into the Maintenance of Certification Performance in Practice (NeuroPI) Epilepsy Module. There have been 291 physicians to date who have enrolled in Epilepsy module. However, the extrapolation of data from this module is not yet appropriate as the sample size is believed to be too small to be able to provide generalizable data. However, by the time this measure comes back to the NQH for the end of the Temporary Endorsement period (estimated by 1/2014) there will be additional data available to support the link of this measure to the desired patient outcomes. In addition, we will have some data back from the CECity registry database, which just went live in August 2012, by 1/2014 to add additional support to this measure.</p> <p>1c.2-3 Type of Evidence (<i>Check all that apply</i>): Clinical Practice Guideline, Other Indicator Paper</p> <p>1c.4 Directness of Evidence to the Specified Measure (<i>State the central topic, population, and outcomes addressed in the body of evidence and identify any differences from the measure focus and measure target population</i>): Central topic: Epilepsy Population: Individuals diagnosed with epilepsy or thought to have epilepsy Outcomes: reviewing etiology of epilepsy or epilepsy syndrome. No noted difference from the measure focus and measure target population</p> <p>1c.5 Quantity of Studies in the Body of Evidence (<i>Total number of studies, not articles</i>): 2 guideline recommendations and 1 indicator paper. Systematic review not available any of the guidelines/indicator papers.</p> <p>1c.6 Quality of Body of Evidence (<i>Summarize the certainty or confidence in the estimates of benefits and harms to patients across studies in the body of evidence resulting from study factors. Please address: a) study design/flaws; b) directness/indirectness of the evidence to this measure (e.g., interventions, comparisons, outcomes assessed, population included in the evidence); and c) imprecision/wide confidence intervals due to few patients or events</i>): The guideline/indicator authors did not provide an explicit process</p>			

or documentation of a process like GRADE whereby precision, directness, etc were detailed in a systematic review to demonstrate the quality of the body of evidence for this measure. The available information from the guideline/indicator paper is provided below.

SIGN "The seizure type(s) and epilepsy syndrome should be identified" (Level C)

It's important to make the distinction between idiopathic generalised epilepsies (IGEs) and focal (localisation-related) epilepsies, as this affects treatment choices, investigation, prognosis and counseling. Identifying the aetiology is important in focal epilepsies.

The onset of IGEs is unusual over the age of 25. The most common IGEs in adolescence are juvenile myoclonic epilepsy (generalised tonic-clonic seizures with myoclonic seizures on waking, sometimes with absence seizures, with photoparoxysmal response in 30% of cases), early morning tonic-clonic seizures in adolescence, and juvenile-absence epilepsy. These phenotypes may overlap.

NICE

Determine: Seizure type(s), epilepsy syndrome, etiology and co-morbidity. (level C) NICE 2004

Evidence statements

The classification of epilepsy relies on evidence from expert committee reports (International League Against Epilepsy). At present the established classification system is undergoing review and current proposals have the status of 'work in progress'. (IV)

Failure to correctly classify the epilepsy syndrome can lead to inappropriate treatment and persistence of seizures. (III)

Details

Overview of classification systems

The classification of epilepsy has long been a subject of contention. The problem is due to the fact that epilepsy is not a single disease entity; rather, it is a symptom of a range of underlying neurological disorders. The clinical presentation depends on a number of factors, chiefly: the part of the brain affected, the pattern of spread of epileptic discharges through the brain, the cause of the epilepsy and the age of the individual.

Classification has thus tended to focus on both the clinical presentation (type of epileptic seizure), and on the underlying neurological disorder (epilepsies and epileptic syndromes).³ The first epilepsy classifications did not distinguish between syndromes and seizures. Terms such as grand mal and petit mal were used, respectively, to classify epilepsy presenting with tonic-clonic seizures and those with 'small attacks' such as absences. The first attempt to classify the epilepsies was carried out by Gastaut.¹¹² His work formed the basis for the Commission on the Classification and Terminology of the International League against Epilepsy (ILAE) standardised classifications and terminology for epileptic seizures and the epilepsies and epileptic syndromes developed in the 1970s and 1980s.^{113;114} (Table 5, Table 6).

Although the ILAE 1981 and 1989 classifications remain in common use they have been the subject of criticism and debate. They have been criticised for:

- being unsatisfactory for epidemiological research⁴
- placing undue emphasis on the types of case referred to tertiary centres¹¹⁵
- placing undue emphasis on the role of the EEG at the expense of newer techniques such as MRI⁴
- not classifying epileptic seizures according to what a individual or eyewitness reports happens during a seizure (ictal semiology).¹¹⁶

In response to concerns about the existing classification systems the ILAE in 1997 undertook to make a revision of classification a priority and set up a Task Force of experts in the field to address this issue. This group first reported in 2001.¹ The Task Force argued that it was not possible to replace the current

international classifications^{113;114} with similar revised and updated classifications that would be universally accepted and meet all the clinical and research needs such a formal organizational system would be expected to provide. Instead, they proposed that clinicians and researchers should use a multi-axial diagnostic scheme (Table 7).

Epileptic seizures and epilepsy syndromes are to be described and categorised in individuals according to a system that uses standardised terminology, and that is sufficiently flexible to take into account the following practical and dynamic aspects of epilepsy diagnosis:

1. Some individuals cannot be given a recognized syndromic diagnosis;
2. Seizure types and syndromes change as new information is obtained;
3. Complete and detailed descriptions of ictal phenomenology are not always necessary;
4. Multiple classification schemes can, and should, be designed for specific purposes (for example, communication and teaching; therapeutic trials; epidemiologic investigations; selection of candidates for surgery; basic research; genetic characterizations).

1c.7 Consistency of Results across Studies (*Summarize the consistency of the magnitude and direction of the effect*): Studies are consistent that the etiology of epilepsy or epilepsy syndrome should be reviewed/known.

1c.8 Net Benefit (*Provide estimates of effect for benefit/outcome; identify harms addressed and estimates of effect; and net benefit - benefit over harms*):
No harms were demonstrated.

1c.9 Grading of Strength/Quality of the Body of Evidence. Has the body of evidence been graded? **Yes**

1c.10 If body of evidence graded, identify the entity that graded the evidence including balance of representation and any disclosures regarding bias: NICE National Collaborating Centre for Primary Care. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): Royal College of General Practitioners; 2004 Oct.

Rating Scheme for Strength of the Evidence

Ia-Systematic review or meta-analysis of randomized controlled trials

Ib-At least one randomized controlled trial

Ila-At least one well-designed controlled study without randomization

Ilb-At least one well-designed quasi-experimental descriptive studies, such as a cohort study

III-Well-designed non-experimental descriptive studies, case-control studies, and case studies

IV-Expert committee reports, opinions and/or clinical experience of respected authorities

Rating Recommendations

A* Directly based on category I evidence (meta-analysis of randomized controlled trials (RCTs) or at least one RCT)

B* Directly based on category II evidence (at least one controlled study without randomization or at least one other quasi-experimental study) or extrapolated from category I evidence

C* Directly based on category III evidence (non-experimental descriptive studies) or extrapolated from category I or II evidence

D* Directly based on category III evidence (expert committee reports or opinions and/or clinical experience of respected authorities) or extrapolated from category I, II or III evidence

N Recommendation taken from NICE guideline or technology appraisal guidance

SIGN (1): SIGN 70: Diagnosis and Management of Epilepsy in Adults. A National Clinical Guideline. Edinburgh (Scotland) 2003 April p.49. Under revision as of June 2008.

Grading of Recommendations (Note: Only measures graded as A, B, or C were included in the table)

A: At least one meta-analysis, systematic review of randomized controlled trials (RCTs), or randomized controlled trial rated as 1++ and directly applicable to the target population; or A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results

B: A body of evidence including studies rated as 2++, directly applicable to the target population and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 1++ or 1+

C: A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or Extrapolated evidence from studies rate as 2++

D: Evidence level 3 or 4; or

Extrapolated evidence from studies rated as 2+

Levels of Evidence

1++: High quality meta-analyses, systematic reviews of randomized controlled trials (RCTs), or RCTs with a very low risk of bias

1+: Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias

1-: Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias

2++: High quality systematic reviews of case control or cohort studies. High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal

2+: Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal

2-: Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal

3: Non-analytic studies, e.g. case reports, case series

4: Expert opinion

Pugh Paper: Epilepsy Measures Work Group Grading of Evidence and Indicators

Pugh MJ, Berlowitz DR, Montouris G, Bokhour B, Cramer JA, Bohm V, Bollinger M, Helmers S, Ettinger A, Meador KJ, Fountain N, Boggs J, Tatum WO 4th, Knoefel J, Harden C, Mattson RH, Kazis L. What constitutes high quality of care for adults with epilepsy? Neurology. 2007 Nov 20;69(21):2020-7.

A: Rated as appropriate

F: Rated as feasible

N: Rated as necessary

N/A: Not Rated

Ratings

1-3 clearly appropriate/ reliable/ necessary

4-6 uncertain or equivocal

7-10 appropriate/ reliable/ necessary

1c.11 System Used for Grading the Body of Evidence: Other

1c.12 If other, identify and describe the grading scale with definitions: NICE National Collaborating Centre for Primary Care. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): Royal College of General Practitioners; 2004 Oct.

Rating Scheme for Strength of the Evidence

Ia-Systematic review or meta-analysis of randomized controlled trials

Ib-At least one randomized controlled trial

IIa-At least one well-designed controlled stud without randomization

IIb-At least one well-designed quasi-experimental descriptive studies, such as a cohort study

III-Well-designed non-experimental descriptive studies, case-control studies, and case studies

IV-Expert committee reports, opinions and/or clinical experience of respected authorities

Rating Recommendations

A* Directly based on category I evidence (meta-analysis of randomized controlled trials (RCTs) or at least one RCT)

B* Directly based on category II evidence (at least one controlled study without randomization or at least one other quasi-experimental study) or extrapolated from category I evidence

C* Directly based on category III evidence (non-experimental descriptive studies) or extrapolated from category I or II evidence

D* Directly based on category III evidence (expert committee reports or opinions and/or clinical experience of respected authorities) or extrapolated from category I, II or III evidence

N Recommendation taken from NICE guideline or technology appraisal guidance

SIGN (1): SIGN 70: Diagnosis and Management of Epilepsy in Adults. A National Clinical Guideline. Edinburgh (Scotland) 2003 April p.49. Under revision as of June 2008.

Grading of Recommendations (Note: Only measures graded as A, B, or C were included in the table)

A: At least one meta-analysis, systematic review of randomized controlled trials (RCTs), or randomized controlled trial rated as 1++ and directly applicable to the target population; or A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results

B: A body of evidence including studies rated as 2++, directly applicable to the target population and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 1++ or 1+

C: A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 2++

D: Evidence level 3 or 4; or

Extrapolated evidence from studies rated as 2+

Levels of Evidence

1++: High quality meta-analyses, systematic reviews of randomized controlled trials (RCTs), or RCTs with a very low risk of bias

1+: Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias

1-: Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias

2++: High quality systematic reviews of case control or cohort studies. High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal

2+: Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal

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N/A: Not Rated

Ratings

1-3 clearly appropriate/ reliable/ necessary

See Guidance for Definitions of Rating Scale: H=High; M=Moderate; L=Low; I=Insufficient; NA=Not Applicable

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4-6 uncertain or equivocal

7-10 appropriate/ reliable/ necessary

1c.13 Grade Assigned to the Body of Evidence: See 1c.15 or 1c.16

1c.14 Summary of Controversy/Contradictory Evidence: Not applicable

1c.15 Citations for Evidence other than Guidelines(*Guidelines addressed below*):

If a patient is thought to have a diagnosis of epilepsy then the diagnosis should include a best estimation of seizure types. (Level C 2+/Secondary) Pugh (2007)¹⁷

Pugh MJ, Berlowitz DR, Montouris G, et al. What constitutes high quality of care for adults with epilepsy? *Neurology*. 2007 Nov 20;69(21):2020-7.

This recommendation was not included in the initial development of the measure, but does support the development of this measure.

The seizure type(s) and epilepsy syndrome, aetiology, and comorbidity should be determined, because failure to classify the epilepsy syndrome correctly can lead to inappropriate treatment and persistence of seizures. [C]NICE Guideline

It is inadequate to simply diagnose an individual as having 'epilepsy'. Epilepsy should be viewed as a feature or symptom of an underlying neurological disorder and not as a single disease entity. It is important that specialists and generalists who treat individuals with epilepsy understand that epilepsy should be classified according to seizure type and epilepsy syndrome. The need to consider age-related epilepsy syndromes is particularly important in children with epilepsy. It is axiomatic that the correct classification of seizure type and epilepsy syndrome should lead to the individual with epilepsy receiving appropriate investigations, appropriate treatment, and information about the likely prognosis of the seizure type and/or syndrome.

1c.16 Quote verbatim, the specific guideline recommendation (*Including guideline # and/or page #*):

The seizure type(s) and epilepsy syndrome should be identified. (Level C) SIGN (April 2003) 23

Determine: seizure type(s), epilepsy syndrome, etiology and co-morbidity. (Level C) NICE (Oct. 2004)22

1c.17 Clinical Practice Guideline Citation: National Collaborating Centre for Primary Care. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. (Uses information from Reference 20 and 21) London (UK): Royal College of General Practitioners; 2004 Oct. Scottish Intercollegiate Guidelines Network (SIGN): SIGN 70: (1) Diagnosis and management of epilepsy in adults. A national clinical guideline. (2) Diagnosis and management of epilepsy in adults. Update to printed guideline. Scottish Intercollegiate Guidelines Network - National Government Agency [Non-U.S.]. 2003 Apr (addendum released 2004 Jun 7). Original guideline: 49 pages; Addendum: 3 pages. NGC:003832

1c.18 National Guideline Clearinghouse or other URL:

<http://guideline.gov/content.aspx?id=5963&search=epilepsy>

<http://guideline.gov/content.aspx?id=5694&search=epilepsy>

http://www.ncbi.nlm.nih.gov/pubmed/17928576?ordinalpos=2&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

1c.19 Grading of Strength of Guideline Recommendation. Has the recommendation been graded? Yes

1c.20 If guideline recommendation graded, identify the entity that graded the evidence including balance of representation and any disclosures regarding bias: SIGN guideline development work group NICE guideline development work group Pugh indicator development work group. See the individual papers for disclosures.

1c.21 System Used for Grading the Strength of Guideline Recommendation: Other

1c.22 If other, identify and describe the grading scale with definitions: NICE National Collaborating Centre for Primary Care. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): Royal College of General Practitioners; 2004 Oct.

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Grading of Recommendations (Note: Only measures graded as A, B, or C were included in the table)

A: At least one meta-analysis, systematic review of randomized controlled trials (RCTs), or randomized controlled trial rated as 1++ and directly applicable to the target population; or A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results

B: A body of evidence including studies rated as 2++, directly applicable to the target population and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 1++ or 1+

C: A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 2++

D: Evidence level 3 or 4; or

Extrapolated evidence from studies rated as 2+

Levels of Evidence

1++: High quality meta-analyses, systematic reviews of randomized controlled trials (RCTs), or RCTs with a very low risk of bias

1+: Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias

1-: Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias

2++: High quality systematic reviews of case control or cohort studies. High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal

2+: Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal

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4: Expert opinion

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A: Rated as appropriate

F: Rated as feasible

N: Rated as necessary

N/A: Not Rated

Ratings

1-3 clearly appropriate/ reliable/ necessary

4-6 uncertain or equivocal

7-10 appropriate/ reliable/ necessary

1c.23 Grade Assigned to the Recommendation: see 1c.15 or 1c.16

1c.24 Rationale for Using this Guideline Over Others: The evidence provided concurred and met a demonstrated gap in care with the potential for high positive impact for patients with epilepsy.

Based on the NQF descriptions for rating the evidence, what was the developer's assessment of the quantity, quality, and consistency of the body of evidence?

1c.25 Quantity: **Moderate** 1c.26 Quality: **Moderate** 1c.27 Consistency: **High**

1c.28 Attach evidence submission form:

1c.29 Attach appendix for supplemental materials:

Was the threshold criterion, *Importance to Measure and Report*, met?

(1a & 1b must be rated moderate or high and 1c yes) Yes ☒ No ☒

Provide rationale based on specific subcriteria:

For a new measure if the Committee votes NO, then STOP.

For a measure undergoing endorsement maintenance, if the Committee votes NO because of 1b. (no opportunity for improvement), it may be considered for continued endorsement and all criteria need to be evaluated.

2. RELIABILITY & VALIDITY - SCIENTIFIC ACCEPTABILITY OF MEASURE PROPERTIES

Extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of care when implemented. (**evaluation criteria**)

Measure testing must demonstrate adequate reliability and validity in order to be recommended for endorsement. Testing may be conducted for data elements and/or the computed measure score. Testing information and results should be entered in the appropriate field. Supplemental materials may be referenced or attached in item 2.1. See [guidance on measure testing](#).

S.1 Measure Web Page (*In the future, NQF will require measure stewards to provide a URL link to a web page where current detailed specifications can be obtained*). Do you have a web page where current detailed specifications for this measure can be obtained? **Yes**

S.2 If yes, provide web page URL: <http://www.aan.com/globals/axon/assets/9079.pdf>

2a. RELIABILITY. Precise Specifications and Reliability Testing: H ☒ M ☒ L ☒ I ☒

2a1. Precise Measure Specifications. (*The measure specifications precise and unambiguous.*)

See Guidance for Definitions of Rating Scale: H=High; M=Moderate; L=Low; I=Insufficient; NA=Not Applicable

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2a1.1 Numerator Statement *(Brief, narrative description of the measure focus or what is being measured about the target population, e.g., cases from the target population with the target process, condition, event, or outcome):*

Patient visits with etiology of epilepsy or with epilepsy syndrome(s) reviewed and documented if known, or documented as unknown or cryptogenic.

2a1.2 Numerator Time Window *(The time period in which the target process, condition, event, or outcome is eligible for inclusion):*

All visits during the reporting period (typically 12 months)

2a1.3 Numerator Details *(All information required to identify and calculate the cases from the target population with the target process, condition, event, or outcome such as definitions, codes with descriptors, and/or specific data collection items/responses):*

Report the CPT Category II, Documentation of Etiology of Epilepsy or Epilepsy Syndrome, in development designated for this numerator 1205F.

CPT II 1205F–8P: Etiology of epilepsy or epilepsy syndrome(s) not reviewed and documented, reason not otherwise specified

2a1.4 Denominator Statement *(Brief, narrative description of the target population being measured):*

All visits for patients with a diagnosis of epilepsy.

2a1.5 Target Population Category *(Check all the populations for which the measure is specified and tested if any):* Senior Care

2a1.6 Denominator Time Window *(The time period in which cases are eligible for inclusion):*

All visits during the reporting period (typically 12 months)

2a1.7 Denominator Details *(All information required to identify and calculate the target population/denominator such as definitions, codes with descriptors, and/or specific data collection items/responses):*

CPT ®Procedure Codes: 99201, 99202, 99203, 99204, 99205, 99212, 99213, 99214, 99215, 99241, 99242, 99243, 99244, 99245, 99304, 99305, 99306, 99307, 99308, 99309

AND

ICD-9 diagnosis codes: 345.00, 345.01, 345.10, 345.11, 345.40, 345.41, 345.50, 345.51, 345.60, 345.61, 345.70, 345.71, 345.90, 345.91

2a1.8 Denominator Exclusions *(Brief narrative description of exclusions from the target population):*

None

2a1.9 Denominator Exclusion Details *(All information required to identify and calculate exclusions from the denominator such as definitions, codes with descriptors, and/or specific data collection items/responses):*

Not applicable.

2a1.10 Stratification Details/Variables *(All information required to stratify the measure results including the stratification variables, codes with descriptors, definitions, and/or specific data collection items/responses):*

None.

2a1.11 Risk Adjustment Type *(Select type. Provide specifications for risk stratification in 2a1.10 and for statistical model in 2a1.13):* No risk adjustment or risk stratification **2a1.12 If "Other," please describe:**

2a1.13 Statistical Risk Model and Variables (*Name the statistical method - e.g., logistic regression and list all the risk factor variables. Note - risk model development should be addressed in 2b4.*):

2a1.14-16 Detailed Risk Model Available at Web page URL (or attachment). Include coefficients, equations, codes with descriptors, definitions, and/or specific data collection items/responses. Attach documents only if they are not available on a webpage and keep attached file to 5 MB or less. NQF strongly prefers you make documents available at a Web page URL. Please supply login/password if needed:

2a1.17-18. Type of Score:

2a1.19 Interpretation of Score (*Classifies interpretation of score according to whether better quality is associated with a higher score, a lower score, a score falling within a defined interval, or a passing score*):

2a1.20 Calculation Algorithm/Measure Logic(*Describe the calculation of the measure score as an ordered sequence of steps including identifying the target population; exclusions; cases meeting the target process, condition, event, or outcome; aggregating data; risk adjustment; etc.*):

2a1.21-23 Calculation Algorithm/Measure Logic Diagram URL or attachment:

2a1.24 Sampling (Survey) Methodology. If measure is based on a sample (or survey), provide instructions for obtaining the sample, conducting the survey and guidance on minimum sample size (response rate):

2a1.25 Data Source (*Check all the sources for which the measure is specified and tested*). If other, please describe:

[Administrative claims](#), [Electronic Clinical Data : Electronic Health Record](#)

2a1.26 Data Source/Data Collection Instrument (*Identify the specific data source/data collection instrument, e.g. name of database, clinical registry, collection instrument, etc.*): [PQRS 2012 Epilepsy: Documentation of Etiology of Epilepsy or Epilepsy Syndrome Data Collection Sheet](#).

www.physicianconsortium.org

Patients Like Me www.patientslikeme.com

NeuroPI: www.aan.com/practice/pip

2a1.27-29 Data Source/data Collection Instrument Reference Web Page URL or Attachment: [URL](#)

<http://www.aan.com/globals/axon/assets/9079.pdf> [http://www.ama-](http://www.ama-assn.org/ama1/pub/upload/mm/pqrs/2012-measure267-worksheet.pdf)

[assn.org/ama1/pub/upload/mm/pqrs/2012-measure267-worksheet.pdf](http://www.ama-assn.org/ama1/pub/upload/mm/pqrs/2012-measure267-worksheet.pdf) <http://www.aan.com/practice/pip/>

www.physicianconsortium.org

2a1.30-32 Data Dictionary/Code Table Web Page URL or Attachment:

2a1.33 Level of Analysis (Check the levels of analysis for which the measure is specified and tested):

Clinician : Individual

2a1.34-35 Care Setting (Check all the settings for which the measure is specified and tested):

Ambulatory Care : Clinician Office/Clinic, Post Acute/Long Term Care Facility : Inpatient Rehabilitation Facility, Post Acute/Long Term Care Facility : Long Term Acute Care Hospital, Post Acute/Long Term Care Facility : Nursing Home/Skilled Nursing Facility

2a2. Reliability Testing. (Reliability testing was conducted with appropriate method, scope, and adequate demonstration of reliability.)

2a2.1 Data/Sample (Description of the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included):

Not completed.

2a2.2 Analytic Method (Describe method of reliability testing & rationale):

Not completed.

2a2.3 Testing Results (Reliability statistics, assessment of adequacy in the context of norms for the test conducted):

Not completed.

2b. VALIDITY. Validity, Testing, including all Threats to Validity: H● M● L● I●

2b1.1 Describe how the measure specifications (measure focus, target population, and exclusions) **are consistent with the evidence cited in support of the measure focus (criterion 1c) and identify any differences from the evidence:**

Not completed.

2b2. Validity Testing. (Validity testing was conducted with appropriate method, scope, and adequate demonstration of validity.)

2b2.1 Data/Sample (Description of the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included):

Not completed.

2b2.2 Analytic Method (Describe method of validity testing and rationale; if face validity, describe systematic assessment):

Not completed.

2b2.3 Testing Results (Statistical results, assessment of adequacy in the context of norms for the test conducted; if face validity, describe results of systematic assessment):

Not completed.

POTENTIAL THREATS TO VALIDITY. (All potential threats to validity were appropriately tested with adequate results.)

2b3. Measure Exclusions. (Exclusions were supported by the clinical evidence in 1c or appropriately tested with results demonstrating the need to specify them.)

2b3.1 Data/Sample for analysis of exclusions (Description of the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included):

Not completed.

2b3.2 Analytic Method (Describe type of analysis and rationale for examining exclusions, including

exclusion related to patient preference):

Not completed.

2b3.3 Results (Provide statistical results for analysis of exclusions, e.g., frequency, variability, sensitivity analyses):

Not completed.

2b4. Risk Adjustment Strategy. (For outcome measures, adjustment for differences in case mix (severity) across measured entities was appropriately tested with adequate results.)

2b4.1 Data/Sample (Description of the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included):

Not completed.

2b4.2 Analytic Method (Describe methods and rationale for development and testing of risk model or risk stratification including selection of factors/variables):

Not completed.

2b4.3 Testing Results (Statistical risk model: Provide quantitative assessment of relative contribution of model risk factors; risk model performance metrics including cross-validation discrimination and calibration statistics, calibration curve and risk decile plot, and assessment of adequacy in the context of norms for risk models. Risk stratification: Provide quantitative assessment of relationship of risk factors to the outcome and differences in outcomes among the strata):

Not completed.

2b4.4 If outcome or resource use measure is not risk adjusted, provide rationale and analyses to justify lack of adjustment: Not completed.

2b5. Identification of Meaningful Differences in Performance. (The performance measure scores were appropriately analyzed and discriminated meaningful differences in quality.)

2b5.1 Data/Sample (Describe the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included):

Not completed.

2b5.2 Analytic Method (Describe methods and rationale to identify statistically significant and practically/meaningfully differences in performance):

Not completed.

2b5.3 Results (Provide measure performance results/scores, e.g., distribution by quartile, mean, median, SD, etc.; identification of statistically significant and meaningfully differences in performance):

Not completed.

2b6. Comparability of Multiple Data Sources/Methods. (If specified for more than one data source, the various approaches result in comparable scores.)

2b6.1 Data/Sample (Describe the data or sample including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included):

Not completed.

2b6.2 Analytic Method (Describe methods and rationale for testing comparability of scores produced by the different data sources specified in the measure):

Not completed.

2b6.3 Testing Results (Provide statistical results, e.g., correlation statistics, comparison of rankings;

assessment of adequacy in the context of norms for the test conducted):

Not completed.

2c. Disparities in Care: H ☐ M ☐ L ☐ I ☐ NA ☐ (If applicable, the measure specifications allow identification of disparities.)

2c.1 If measure is stratified for disparities, provide stratified results (Scores by stratified categories/cohorts): Not completed.

2c.2 If disparities have been reported/identified (e.g., in 1b), but measure is not specified to detect disparities, please explain:

Not completed.

2.1-2.3 Supplemental Testing Methodology Information:

Steering Committee: Overall, was the criterion, *Scientific Acceptability of Measure Properties*, met? (Reliability and Validity must be rated moderate or high) Yes ☐ No ☐

Provide rationale based on specific subcriteria:

If the Committee votes No, STOP

3. USABILITY

Extent to which intended audiences (e.g., consumers, purchasers, providers, policy makers) can understand the results of the measure and are likely to find them useful for decision making. (**evaluation criteria**)

C.1 Intended Actual/Planned Use (Check all the planned uses for which the measure is intended):

Payment Program, Professional Certification or Recognition Program, Public Reporting, Quality Improvement (Internal to the specific organization), Regulatory and Accreditation Programs

3.1 Current Use (Check all that apply; for any that are checked, provide the specific program information in the following questions): Public Reporting, Payment Program, Professional Certification or Recognition Program, Regulatory and Accreditation Programs, Quality Improvement (Internal to the specific organization)

3a. Usefulness for Public Reporting: H ☐ M ☐ L ☐ I ☐

(The measure is meaningful, understandable and useful for public reporting.)

3a.1. Use in Public Reporting - disclosure of performance results to the public at large (If used in a public reporting program, provide name of program(s), locations, Web page URL(s)). If not publicly reported in a national or community program, state the reason AND plans to achieve public reporting, potential reporting programs or commitments, and timeline, e.g., within 3 years of endorsement: **[For Maintenance** – If not publicly reported, describe progress made toward achieving disclosure of performance results to the public at large and expected date for public reporting; provide rationale why continued endorsement should be considered.]

All of three epilepsy measures are currently in use in the 2012 Physician Quality Reporting System program. They have also been implemented in the CE City Registry, a CMS qualified registry for PQRS, so that physicians can complete the registry and individual claims based measures. In addition, these measures were used as the basis for the American Academy of Neurology's Maintenance of Certification Performance in Practice (NeuroPI) Epilepsy Module. Moreover, we know that www.patientslikeme.com has added these measures to their patient portal, which is a resource patients use to understand their own

healthcare. These measures were also supported by the National Association of Epilepsy Centers and the Epilepsy Foundation of America. Although we do not have specific data to identify which physicians are using these measures, we do know that many of their members have told the AAN that they are aware of these measures and are using them in their practices.

3a.2. Provide a rationale for why the measure performance results are meaningful, understandable, and useful for public reporting. If usefulness was demonstrated (e.g., focus group, cognitive testing), describe the data, method, and results: CMS has no yet reported back any data from PQRS 2012 program

3.2 Use for other Accountability Functions (payment, certification, accreditation). If used in a public accountability program, provide name of program(s), locations, Web page URL(s): PQRS website
NeuroPI for Board certification for Performance in Practice requirement

3b. Usefulness for Quality Improvement: H M L I

(The measure is meaningful, understandable and useful for quality improvement.)

3b.1. Use in QI. If used in quality improvement program, provide name of program(s), locations, Web page URL(s):

[For Maintenance – If not used for QI, indicate the reasons and describe progress toward using performance results for improvement].

NeuroPI-NeuroPI clinical modules are designed to help neurologists meet the American Board of Psychiatry and Neurology (ABPN) Part 4 performance in practice requirement for Maintenance of Certification (MOC). There is a epilepsy module that includes this quality measure. 291 individuals have started using this measure in the program.

CECity PQRI Wizard

Physician Quality Reporting System (2012) program measure

Patients Like Me website www.patientslikeme.com

3b.2. Provide rationale for why the measure performance results are meaningful, understandable, and useful for quality improvement. If usefulness was demonstrated (e.g., QI initiative), describe the data, method and results:

We have not yet received any results from these QI initiatives.

Overall, to what extent was the criterion, Usability, met? H M L I

Provide rationale based on specific subcriteria:

4. FEASIBILITY

Extent to which the required data are readily available, retrievable without undue burden, and can be implemented for performance measurement. (evaluation criteria)

4a. Data Generated as a Byproduct of Care Processes: H M L I

4a.1-2 How are the data elements needed to compute measure scores generated? (Check all that apply).

Data used in the measure are:

generated by and used by healthcare personnel during the provision of care, e.g., blood pressure, lab value, medical condition

4b. Electronic Sources: H M L I

4b.1 Are the data elements needed for the measure as specified available electronically (Elements that are needed to compute measure scores are in defined, computer-readable fields): No data elements are in electronic sources

4b.2 If ALL data elements are not from electronic sources, specify a credible, near-term path to electronic capture, OR provide a rationale for using other than electronic sources: Currently this measure has been specified for administrative claims (with CPT II codes). The AAN has contracted with two separate consultants to learn the process to develop eSpecifications, code value sets and develop eMeasures. The training was complete as of 9/25/12 and the measures will be full specified for eMeasures by December 2012.

4c. Susceptibility to Inaccuracies, Errors, or Unintended Consequences: H ☐ M ☐ L ☐ I ☐

4c.1 Identify susceptibility to inaccuracies, errors, or unintended consequences of the measurement identified during testing and/or operational use and strategies to prevent, minimize, or detect. If audited, provide results:

Testing has not begun yet but will be completed by January 2014. Strategies to prevent, minimize or detect unintended consequences will be identified during testing in 2013. Operational use of this measure has not identified any inaccuracies, errors or unintended consequences of measurement.

4d. Data Collection Strategy/Implementation: H ☐ M ☐ L ☐ I ☐

A.2 Please check if either of the following apply (regarding proprietary measures):

4d.1 Describe what you have learned/modified as a result of testing and/or operational use of the measure regarding data collection, availability of data, missing data, timing and frequency of data collection, sampling, patient confidentiality, time and cost of data collection, other feasibility/implementation issues (e.g., fees for use of proprietary measures):

Testing has not begun yet but will be completed by January 2014. Operational use of this measure helped identify the need for a registry to simplify usage of measures (available via the CECity registry as of 8/2012). No other problems or issues have been identified.

Overall, to what extent was the criterion, *Feasibility*, met? H ☐ M ☐ L ☐ I ☐

Provide rationale based on specific subcriteria:

OVERALL SUITABILITY FOR ENDORSEMENT

Does the measure meet all the NQF criteria for endorsement? Yes ☐ No ☐

Rationale:

If the Committee votes No, STOP.

If the Committee votes Yes, the final recommendation is contingent on comparison to related and competing measures.

5. COMPARISON TO RELATED AND COMPETING MEASURES

If a measure meets the above criteria and there are endorsed or new related measures (either the same measure focus or the same target population) or competing measures (both the same measure focus and the same target population), the measures are compared to address harmonization and/or selection of the best measure before a final recommendation is made.

5.1 If there are related measures (either same measure focus or target population) or competing measures (both the same measure focus and same target population), list the NQF # and title of all related and/or competing measures:

5a. Harmonization

5a.1 If this measure has EITHER the same measure focus OR the same target population as NQF-endorsed measure(s): Are the measure specifications completely harmonized?

5a.2 If the measure specifications are not completely harmonized, identify the differences, rationale, and impact on interpretability and data collection burden:

5b. Competing Measure(s)

5b.1 If this measure has both the same measure focus and the same target population as NQF-endorsed measure(s):

Describe why this measure is superior to competing measures (e.g., a more valid or efficient way to measure quality); OR provide a rationale for the additive value of endorsing an additional measure. (Provide analyses when possible):

CONTACT INFORMATION

Co.1 Measure Steward (Intellectual Property Owner): American Academy of Neurology, 201 Chicago Avenue, Minneapolis, Minnesota, 55415

Co.2 Point of Contact: Amy, Bennett, abennett@aan.com, 612-928-6072-

Co.3 Measure Developer if different from Measure Steward: American Academy of Neurology, 201 Chicago Avenue, Minneapolis, Minnesota, 55415

Co.4 Point of Contact: Amy, Bennett, abennett@aan.com, 612-928-6072-

Co.5 Submitter: Amy, Bennett, abennett@aan.com, 612-928-6072-, American Academy of Neurology

Co.6 Additional organizations that sponsored/participated in measure development:
American Epilepsy Society, Epilepsy Foundation of America, National Association of Epilepsy Centers, American Academy of Family Physicians, American Clinical Neurophysiology Society, American College of Emergency Physicians, American College of Radiology, American Psychological Association, American Society of Neuroimaging, Child Neurology Society, National Academy of Neuropsychology, National Organization of Rare Disorders, Society of Nuclear Medicine, AMA convened Physician Consortium for Performance Improvement, Methodology Consultants, Insurance representatives from UnitedHealth Care (now OptumHealth), Wellpoint, Humana and Aetna.

Co.7 Public Contact: Rebecca, Swain-Eng, MS, rswaineng@aan.com, 612-928-6121-, American Academy of Neurology

ADDITIONAL INFORMATION

Workgroup/Expert Panel involved in measure development

Ad.1 Provide a list of sponsoring organizations and workgroup/panel members' names and organizations. Describe the members' role in measure development.

Co-Chairs: Nathan Fountain MD, Paul Van Ness, MD

American Academy of Neurology Facilitator: Christopher Bever Jr., MD

American Academy of Neurology Representatives: Jeffrey Buchhalter, MD; Andres Kanner, MD; K. Babu Krishnamurthy, MD; Susan Naselli, MD; Piotr Olejniczak, MD

Rita Richardson, MD; Joseph Sirven, MD; Michael Sperling, MD; John Stern, MD

American Epilepsy Society: Allan Krumholz, MD and Paul Levisohn, MD

Epilepsy Foundation of America: Gregory L. Barkley, MD, FAAN and Michael C. Smith, MD

National Association of Epilepsy Centers: David Labiner, MD and Thaddeus Walczak, MD

American Academy of Family Physicians: Mark Potter, MD

American Academy of Pediatrics: Dennis Dlugos, MD

American Academy of Neurological Surgeons/Congress of Neurological Surgeons:
Joshua Rosenow, MD
American Clinical Neurophysiology Society: William Tatum IV, DO
American College of Emergency Physicians: Andrew Jagoda, MD

Ad.2 If adapted, provide title of original measure, NQF # if endorsed, and measure steward. Briefly describe the reasons for adapting the original measure and any work with the original measure steward:

Measure Developer/Steward Updates and Ongoing Maintenance

Ad.3 Year the measure was first released: 2010

Ad.4 Month and Year of most recent revision: 02, 2013

Ad.5 What is your frequency for review/update of this measure? Large review and update every 3 years. Smaller reviews as needed.

Ad.6 When is the next scheduled review/update for this measure? 02, 2013

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