

Quality improvement in neurology: AAN epilepsy quality measures

Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology



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For the American
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Epilepsy Measure
Development Panel
and the American
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ABSTRACT

Objective: Epilepsy is a common neurologic condition with significant personal, societal, medical, and economic burdens. There are considerable gaps in the quality of care delivered. Measuring the quality of care delivered is the first step to its improvement. Performance measures are easily identified and quantitated ways to assess whether specific activities were carried out during a patient encounter. Therefore, epilepsy performance measures were derived through a standardized systematic process and may be the basis for pay-for-performance initiatives and maintenance of certification requirements.

Methods: Epilepsy measures were developed through the American Medical Association–convened Physician Consortium for Performance Improvement (PCPI) independent measure development process, which marked the first time a medical specialty society followed this process. Guidelines, measures, and consensus papers reviewed for the period 1998 to 2008 using the National Guidelines Clearinghouse, the National Quality Measures Clearinghouse, PubMed, MEDLINE, and the Cochrane Library were evaluated using a framework to determine the acceptability of each guideline or other evidence review document for measures development. Recommendation statements based on level of evidence, importance, validity, and gap in care were developed into candidate measures. A panel of experts from representative organizations vetted the measures. A period of public comment was followed by approval from the American Academy of Neurology and the PCPI.

Results: Literature search identified 160 relevant recommendation statements from 19 guidelines and 2 consensus papers. Systematic assessment resulted in 20 recommendation statements that were refined to 8 candidate measures by the expert panel. The measures are relevant to seizure type and frequency, etiology or epilepsy syndrome, EEG, neuroimaging, antiepileptic drug side effects, safety issues, referral for refractory epilepsy, and issues for women of child-bearing potential.

Conclusion: There is a reasonable evidence base, and consensus for, deriving performance measures for quality of epilepsy care. It is anticipated that implementation of these performance measures will improve care for patients with epilepsy if adopted by providers. *Neurology*® 2011;76:94–99

GLOSSARY

AAN = American Academy of Neurology; **AED** = antiepileptic drug; **AMA** = American Medical Association; **CPT II** = Current Procedural Terminology; **PCPI** = Physician Consortium for Performance Improvement; **PQRI** = Physician Quality Reporting Initiative.

Epilepsy is a common and widely recognized neurologic condition, but it is often poorly understood, misdiagnosed, and improperly treated. Epilepsy is surprisingly common; approximately 3% of the American population will develop epilepsy by age

75.¹ The deficits in quality of life due to epilepsy and its treatment are comparable to conditions such as diabetes, heart disease, and depression for people with active epilepsy.² Epilepsy causes considerable medical distress and an enormous economic burden.

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Supplemental data at
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Epilepsy measurement set approved by the AAN Epilepsy Measure Development Panel on July 7, 2009; by the AAN Quality Measurement and Reporting Subcommittee on July 8, 2009; by the AAN Practice Committee on July 15, 2009; and by the AAN Board of Directors on August 10, 2009. The full membership of the AMA–convened PCPI approved the measurement set on March 9, 2010.

Disclosure: Author disclosures are provided at the end of the article.

The annual direct costs per patient are more than \$11,000 and indirect costs are more than \$3,000 in some settings.³

The epilepsy treatment gap is defined as the proportion of people with epilepsy who require treatment but who do not receive it.⁴ There are racial, ethnic, and socioeconomic disparities in access to treatment, especially surgery.⁵ A lack of specialty care may lead to delayed recognition of seizures and inadequate treatment.⁶ Thus, there is a large disparity between care that should be delivered and the care that is actually delivered. A performance measurement set for epilepsy has the potential to improve care and increase the quality of life for those who have epilepsy.

Medical professionals vary in their skill and approach to diagnosing epilepsy, determining seizure type, identifying causation, and administering appropriate therapy. A uniform performance measurement set is needed to clarify these roles and to determine how best to establish evidence-based standards of care.

The measure set has value in improving care beyond that of traditional quality assessment methods. The American Academy of Neurology (AAN) is developing a performance in practice module based upon these epilepsy measures that can be used to satisfy the American Board of Psychiatry and Neurology performance in practice maintenance of certification requirement for neurologists.⁷ The epilepsy measures also have the potential to be used in a pay-for-reporting program, such as the Centers for Medicare & Medicaid Services Physician Quality Reporting Initiative.⁸

The AAN is an established measure developer. The AAN has produced quality measures for stroke and stroke rehabilitation⁹ and Parkinson disease¹⁰ and plans to develop subsequent measurement sets for neurologic conditions. This report describes the development of quality measures for the care of epilepsy, the first set of measures developed by a medical specialty society through the American Medical Association (AMA)-convened Physician Consortium for Performance Improvement (PCPI) independent measure development process.¹¹ The PCPI consists of over 170 member organizations, including most medical specialty associations and state medical societies. PCPI guidelines specify the evidence base required for measure development.¹²

METHODS The epilepsy measure development process followed the AAN Quality Measurement and Reporting Subcommittee process manual for measure development¹⁰ and the AMA-convened PCPI review and approval process of measures developed independently by PCPI voting members.¹¹ The AAN is a voting member of the PCPI. The steps in the PCPI approval process require submitting the topic for selection, completing an evidence-based literature search, constructing draft measures,

convening an expert panel to revise candidate measures, soliciting public comments for a 30-day period, refining the final measures, and obtaining approvals from AAN committees, the AAN Board of Directors, and the PCPI full membership.

Topic selection. Epilepsy was selected as the topic because it is a clinical priority for neurology, has a high burden of illness, has demonstrated gaps in care with room for improvement, and has unexplained variations in care. Epilepsy measure development was also supported by the move toward quality improvement by medical professional societies and patient advocacy groups, including the American Epilepsy Society, the National Association of Epilepsy Centers, and the Epilepsy Foundation.

Evidence-based literature search strategy. A comprehensive search strategy to identify published guidelines, measures, and consensus papers from 1998 to 2008 was conducted using the National Guidelines Clearinghouse, the National Quality Measures Clearinghouse, PubMed, MEDLINE, and the Cochrane Library. Supplementary internet searches were carried out on relevant epilepsy Web sites.

Evidence-based evaluation supporting development and writing of measures. AAN staff screened each relevant full-text guideline or consensus paper against the PCPI framework for determining the acceptability of guidelines and other evidence review documents.¹² If the inclusion of an article based on eligibility criteria was unclear, the expert panel co-chairs and facilitators were consulted. The recommendation statements and their corresponding level of evidence (as defined by the guideline developers' rating scheme methodology) were then extracted from eligible guidelines and consensus papers. Candidate recommendations were documented, reviewed, and ranked by the co-chairs and facilitators based on face validity, feasibility to collect data, and gaps or variations in care. Measure specifications were carefully drafted with an experienced methodologist to include a full measure description, a numerator, a denominator, and applicable exclusions.

The purpose of a measure is to describe what should be performed during a patient encounter to provide quality care. The proportion of encounters meeting the measure is defined by the number of encounters properly fulfilling the measure (the numerator) divided by the number of encounters for which the measure is applicable (the denominator). Exclusions list the specific situations for which the measure does not apply based on a medical, patient, or system reason. Medical exclusions are often due to a medical contraindication. Patient reasons are often due to patient refusal of a test or intervention. System reasons are due to circumstances outside of the control of the physician or patient, such as the inability to pay for a test or intervention.

Panel formation. The AAN solicited a broad representation of stakeholders on the expert panel by inviting nominations for expert panel members from physician associations, epilepsy patient advocacy groups, health plans, and large group employers. Two methodologists and one support staff were provided by the PCPI as required by the PCPI review and approval process for measurement sets developed independently by PCPI voting members. Twenty-eight epilepsy specialists from the AAN epilepsy section responded to a call for serving on the panel and were independently screened by the co-chairs based on their experience in performance measures, quality improvement, and clinical activities. The final panel consisted of 40 members (see end of manuscript for list of contributing organizations): 12 epilepsy specialists, 1 facilitator, 6 patient organization representatives, 1 family physician, 1 pediatrician, 1 neurosurgeon, 1

Table Measure title and description of final 8 epilepsy measures approved by the AAN and the PCPI

Measure title and description
No. 1: Seizure type and current seizure frequency All visits with the type(s) of seizure(s) and current seizure frequency for each seizure type documented in the medical record.
No. 2: Documentation of etiology of epilepsy or epilepsy syndrome All visits with the etiology of epilepsy or epilepsy syndrome reviewed and documented if known, or documented as unknown or cryptogenic.
No. 3: EEG results reviewed, requested, or test ordered All initial evaluations with the results of at least one EEG reviewed or requested, or if EEG was not performed previously, then an EEG ordered.
No. 4: MRI/CT scan reviewed, requested, or scan ordered All initial evaluations with the results of at least one MRI or CT scan reviewed or requested or, if a MRI or CT scan was not obtained previously, then a MRI or CT scan ordered (MRI preferred).
No. 5: Querying and counseling about antiepileptic drug side effects All visits where patients were queried and counseled about antiepileptic drug side effects and the querying and counseling was documented in the medical record.
No. 6: Surgical therapy referral consideration for intractable epilepsy All patients with a diagnosis of intractable epilepsy who were considered for referral for a neurologic evaluation of appropriateness for surgical therapy and the consideration was documented in the medical record within the past 3 years.
No. 7: Counseling about epilepsy specific safety issues All patients who were counseled about context-specific safety issues, appropriate to the patient's age, seizure type(s) and frequency(ies), occupation and leisure activities, etc. (e.g., injury prevention, burns, appropriate driving restrictions, or bathing) at least once per year.
No. 8: Counseling for women of childbearing potential with epilepsy All female patients of childbearing potential (12-44 years old) diagnosed with epilepsy who were counseled about epilepsy and how its treatment may affect contraception and pregnancy at least once per year.

Abbreviations: AAN = American Academy of Neurology; PCPI = Physician Consortium for Performance Improvement.

neurophysiologist, 1 emergency medicine physician, 1 radiologist, 1 psychologist, 1 neuroimaging specialist, 1 child neurologist, 1 neuropsychologist, 1 nuclear medicine specialist, 3 staff, 1 PCPI representative, 2 methodologists, and 4 insurance group representatives. All panel members completed the AAN measurement development conflict of interest disclosure.

RESULTS The literature search identified 160 relevant recommendation statements from 19 guidelines¹³⁻³¹ and 2 consensus papers.³²⁻³³ Review by the co-chairs and facilitator resulted in 20 recommendation statements that were rated highest on importance, validity, strength of evidence, and gaps in care to serve as the evidence base for 12 candidate measures. The panel revised the draft measures and

eliminated 4 of the measures at the face-to-face meeting on October 3, 2008. The remaining 8 measures were posted for a 30-day public comment. A total of 291 comments were received from physicians, patients, insurers, and other interested individuals which further refined the draft measures. The 8 final measures were approved by the AMA Performance Measurement Advisory Group for CPT II codes on June 18, 2009. The final measurement set was approved by the expert panel, appropriate AAN committees, and the AAN Board of Directors. As was required in the PCPI independent measure developer agreement, the PCPI also approved the measures on March 9, 2010. This measurement set will be revised periodically with an extensive review every 3 years.

Brief measure titles and measure statements for each of the 8 epilepsy quality measures are listed in the table. For the full measure specifications see appendix e-1 on the *Neurology*[®] Web site at www.neurology.org. The measure statement contains the denominator and numerator for each measure. The appropriate exclusions for each measure are found in the full measure specifications (appendix e-1).

An example is provided to illustrate the use of a measure. For measure 1, “Seizure type(s) and current seizure frequency(ies),” the eligible patient population (denominator) is all patients with a diagnosis of epilepsy as identified by the International Classification of Diseases–9 codes for epilepsy (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). The denominator also specifies that this measure must be completed at all visits. In order to complete the measure (numerator), the clinician must specify seizure type and current seizure frequency for each seizure type in the medical record for all visits during the measurement period or document the CPT II code 1200F. This measure has 2 types of applicable exclusions: a medical reason (e.g., patient is unable to communicate and an informant is not available) and a patient reason (e.g., patient or informant refuses to answer or comply with the request). The medical reason and patient reason may be documented in the medical record and the result coded as 1200F-1P and 1200F-2P, respectively.

Measure 1 was developed because it is intended to address the problem that many patients and physicians may generalize about seizure control and miss opportunities to intervene to improve seizure control. For example, when patients say they are “doing well,” they may not mean they are seizure-free, but rather that they are continuing to have seizures at the same rate as before. Thus, the only way to assess current seizure control is to ask the patient directly and specify it in the medical record. Documenting fre-

quency for each seizure type is necessary because some seizure types are more disabling than others and may require more or less attention.

Measure 2 requires specification of the etiology or epilepsy syndrome. This is required for high-quality medical care, because some etiologies, such as tumors, require regular follow-up and others might suggest eventual resolution, such as childhood absence epilepsy.

Measure 3 requires an EEG for all patients with epilepsy since an EEG is necessary to characterize the epilepsy syndrome which often predicts the natural history, treatment, and response. This measure does not require an EEG to be performed at each initial encounter because review of a prior EEG may be adequate. Although the measure addresses EEG availability at initial evaluation, it should not be interpreted to mean that additional EEGs are never necessary in the evaluation of epilepsy.

Measure 4 requires neuroimaging for all patients with epilepsy but allows for exclusions when neuroimaging is not indicated, such as for known idiopathic generalized epilepsy syndromes that are known to lack neuroimaging abnormalities. MRI is preferred to CT because of a much higher sensitivity to abnormalities that cause epilepsy.

Measure 5 requires inquiry about antiepileptic drug (AED) side effects at each visit. It is important to note that, like all of the measures, measure 5 requires documentation of the conversation about AED side effects. Documenting this discussion in the medical record may be a new practice for many physicians. This measure may increase the burden of documentation, but it is anticipated that the improvement in quality of care will outweigh the increase in documentation burden.

Measure 6 applies only to patients with intractable epilepsy. It is intended to assess whether these patients have been considered for referral to a higher level of care on a regular basis, which usually means consideration of referral for epilepsy surgery evaluation. Although it may seem burdensome to require documentation of this every 3 years, changes in technology and surgical techniques are changing rapidly. Patients who are not candidates for surgery now may be in a few years. Patients already followed at a tertiary care referral center can meet this measure by stating that a presurgical evaluation has already been performed (or surgery performed) or the reasons why the patient is not a surgical candidate. Patients who are not candidates for surgery now may be in a few years so periodic review is prudent even at a tertiary care facility.

Measure 7 concerns counseling about safety-related issues for patients with epilepsy. Despite the

lack of high-level recommendation statements to support this measure, as is the case with most safety measures, there is a significant need for this measure to meet the gaps in care for this patient population.

Measure 8 concerns counseling about epilepsy treatment effects on contraception and pregnancy. It applies only to women of childbearing potential. It is sometimes difficult to identify these women from coding-based databases. Thus, an age range is specified but patients can be excluded from the measure if they do not have childbearing potential for any reason.

DISCUSSION Quality measures can demonstrate the high quality of care that physicians already provide or they can be an impetus for physicians to provide higher quality care. Epilepsy performance measures can improve epilepsy care by resolving simple gaps in care. The 8 epilepsy measures are intended to be implemented in daily practice and can be used for quality improvement programming and activities.

Development of the epilepsy measures marks the first time a medical specialty society has developed a performance measurement set through the PCPI independent measurement development process.¹¹ Following this process, the PCPI supplied the AAN methodologists, an AMA-PCPI staff representative, and the opportunity for vetting and approval of the measures by the full PCPI membership. The AAN gained methodologic support, national recognition of its measures, and vetting of measures by over 170 medical specialty societies. By initiating development, the AAN is able to have direct input into measures in order to keep them relevant to neurologists.

The epilepsy measures are written using a lexicon or format that is intended to facilitate implementation of measures derived from guidelines (the evidence base) by clinicians in practice. Each measure identifies the patient population eligible for the measure (e.g., all patients with a diagnosis of epilepsy) and identifies the temporal application (e.g., at least annually). Once the clinician determines whether a patient is eligible, then the measure states how it is fulfilled (e.g., documentation that the etiology of epilepsy or epilepsy syndrome was reviewed). Physicians who use the measures can easily implement a method to identify the relevant patients to be considered for the measure and then determine how to conduct the assessment of whether the measure was fulfilled.

Widespread adoption of these performance measures for epilepsy care has the potential to substantially improve quality of care for patients with epilepsy at all levels of health care delivery. Many epilepsy patients receive most of their epilepsy care

from primary care doctors who are likely to find many of the measures useful in improving their epilepsy care. General neurologists may be able to improve care by following the measures they are not currently addressing or documenting. Even epileptologists, who seem most likely to follow the measures, may improve their care by uniformly applying all of the measures. Thus, the measures are likely to improve the quality of epilepsy care for many patients and future testing of these measures will focus on identifying the degree to which implementation of the measures improves care.

EPILEPSY MEASURE DEVELOPMENT PANEL

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ican Psychological Association, American Society of Neuroimaging, Child Neurology Society, National Academy of Neuropsychology, National Organization of Rare Disorders, Society of Nuclear Medicine, American Medical Association convened Physician Consortium for Performance Improvement, Kresowik Consulting, UnitedHealth Group, Inc., Anthem Blue Cross Blue Shield, Humana, and Aetna, Inc.

DISCLOSURE

Dr. Fountain serves on the National Association of Epilepsy Centers Board of Directors; has received funding for travel from UCB; serves on the editorial board of *Epilepsy Currents*; estimates that 10% of his clinical effort at the University of Virginia EEG Lab is spent on EEG interpretation; and receives research support from UCB, Vertex Pharmaceuticals, Sepracor Inc., Medtronic, Inc., NeuroPace, Inc., and the NIH (R01 NS 058634-01A2m [Site PI] and U01 NS 053998 [Site PI]). Dr. Van Ness is a board member for the National Association of Epilepsy Centers; serves on scientific advisory boards for Cyberonics, Inc. and Lundbeck Inc.; serves on the editorial board of *Archives of Neurology*; estimates that 33% of his clinical effort at University of Texas Southwestern Medical Center is spent on epilepsy monitoring; and receives research support from UCB, NeuroPace, Inc., and Eisai Inc. R. Swain-Eng is a full-time employee of the American Academy of Neurology. S. Tonn is a full-time employee of the American Academy of Neurology (AAN) and served as project director for AAN grants from Pfizer Inc. and the CDC. Dr. Bever serves on the editorial board of the *MS Quarterly Report*; is listed as a coinventor on and receives royalties from Abraxis BioScience, Inc. for a pending patent re: Use of hematogenous stem cells in neuronal replacement therapy and gene delivery; receives royalties from the publication of *Ambulatory Medicine*, 7th ed (Lippincott Williams & Wilkins, 2006); and has received research support from the Department of Veterans Affairs and the National MS Society.

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