# MEASURE #7
Referral to Comprehensive Epilepsy Center

## Measure Description
Percent of all patients with a diagnosis of treatment resistant (intractable) epilepsy who were referred for consultation to a comprehensive epilepsy center* for additional management of epilepsy.

## Measure Components

### Numerator Statement
Patients who were referred for consultation to a comprehensive epilepsy center* for additional management of epilepsy.

*Comprehensive Epilepsy Care Center: Epilepsy centers that provide comprehensive diagnostic and treatment modalities and access to multidisciplinary teams to address comorbidities that are common in epilepsy. The National Association of Epilepsy Centers has provided details of the essential services, personnel, and facilities at comprehensive epilepsy centers. In general, comprehensive centers will provide diagnostic evaluation including inpatient video electroencephalogram (EEG) monitoring, epilepsy surgery evaluation, access to epilepsy surgery, and staff to address psychiatric and psychosocial issues.

### Denominator Statement
All patients with a diagnosis of treatment resistant (intractable) epilepsy.*

*Treatment resistant (intractable) epilepsy is defined as “failure of adequate trials of two tolerated, appropriately chosen and used antiepileptic drug schedules to achieve sustained seizure freedom.”

### Denominator Exceptions
- Patient is already being seen at a comprehensive epilepsy care center.
- Patient has been evaluated within the past 2 years.
- Patient declined referral.
- Patient has non-disabling seizures. Non-disabling is defined by the treating provider and patient.

### Supporting Guideline & Other References
The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines or are summaries from the referenced clinical articles and represent the evidence base for the measure:

- If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, children, young people and adults should be referred to tertiary services soon* for further assessment. Referral should be considered when one or more of the following criteria are present:
  - The epilepsy is not controlled with medication within 2 years.
  - Management is unsuccessful after two drugs.
  - A child, young person or adult experiences, or is at risk of, unacceptable side effects from medication.
  - There is a unilateral structural lesion.
  - There is psychological and/or psychiatric co-morbidity.
  - There is diagnostic doubt as to the nature of the seizures and/or seizure syndrome. (Level IIb)
- At the review, children, young people and adults should have access to: written and visual information; counseling services; information about voluntary organizations; epilepsy specialist nurses; timely and
appropriate investigations; referral to tertiary services including surgery, where appropriate. (Level Ib & III)³

- Information should be provided to children, young people and adults and families and/or care givers as appropriate about the reasons for considering surgery. The benefits and risks of the surgical procedure under consideration should be fully explained before informed consent is obtained. (Level III)³

- If the diagnosis or seizure type remains unclear after the initial evaluations, or the patient has recurrent seizures THEN the patient should be referred to the next level of epilepsy care.⁴

- If your seizures have not been brought under control after three months of care by a primary care provider (family physician, pediatrician), further neurologic intervention by a neurologist, or an epilepsy center if locally available, is appropriate.¹

- If you are seeing a general neurologist, and your seizures have not been brought under control after 12 months, you should insist upon a referral to a specialized epilepsy center with an epileptologist.¹

- Among patients with newly intractable disabling mesial temporal lobe epilepsy (MTLE), resective surgery plus Antiepileptic Drug (AED) treatment resulted in a lower probability of seizures during year 2 of follow-up than continued AED treatment alone.⁵

- Surgical treatment resulted in greater reduction in seizure frequency compared to medical therapy and was a cost-effective treatment option in children with intractable epilepsy.⁶

- Despite Class I evidence and subsequent practice guidelines, the utilization of lobectomy has not increased from 1990 to 2008. Surgery continues to be heavily underutilized as a treatment for epilepsy, with significant disparities by race and insurance coverage. Patients who are medically refractory after failing 2 antiepileptic medications should be referred to a comprehensive epilepsy center for surgical evaluation.⁷

- Uncontrolled epilepsy was associated with significantly greater healthcare resource utilization, and higher rates of negative outcomes compared to well-controlled epilepsy.⁸

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<th>Rationale for the Measure:</th>
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<td>Referral to a comprehensive epilepsy center is needed to ensure patients are properly evaluated for epilepsy surgery, have access to ancillary epilepsy resources, and for the use of alternative epilepsy therapies as these treatments are efficacious and may not be provided in general practice.⁹ Epilepsy resective surgery is a potential curative procedure. The superiority of resective epilepsy surgery for control of treatment resistant (intractable) epilepsy over standard medical care has been demonstrated through randomized controlled trials.¹⁰</td>
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Further, alternative treatments for epilepsy, such as neurostimulation, dietary therapy, felbamate and vigabatrin, are prescribed almost exclusively at epilepsy centers as they have been restricted to patients with treatment resistant (intractable) epilepsy for whom the benefit outweighs the risk for these treatments.
Since a surgical evaluation and other available resources for treatment resistant (intractable) epilepsy can only be performed at a comprehensive epilepsy center, patients with treatment resistant (intractable) epilepsy should be referred for management. These patients will need periodic re-evaluation at a comprehensive epilepsy center to determine whether a new intervention is needed, such as new epilepsy surgery techniques, devices, or an alternative anti-seizure medication.

### Opportunity for Improvement

Patients with treatment resistant (intractable) epilepsy are not being referred for epilepsy surgery evaluation; the average duration of epilepsy before surgery in almost all trials is nearly 20 years.\(^\text{11,12}\) A delay in referrals exists despite guidelines and quality measures recommending early referral.\(^\text{13-17}\) Rates of lobectomy have not increased with significant disparities by race and insurance coverage.\(^\text{7}\) This is convincing evidence that patients are not being referred to an epilepsy center for consideration of surgery and other interventions.

The implementation of a quality measure is likely to improve general awareness and encourage specific education for reinforcement to providers and patients about the efficacy of referral to a comprehensive epilepsy center. For example, implementation of an epilepsy quality measure checklist increased surgical referral from 3% to 14% in one clinic.\(^\text{18}\)

### References


<table>
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<tr>
<th>Measure Designation</th>
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| **Measure purpose** | ☒ Quality improvement  
| | ☒ Accountability  
| | ☒ MOC  |
| **Type of measure** | ☒ Process  
| | ☐ Outcome  
| | ☐ Structure  |
| **Level of Measurement** | ☒ Individual Provider  
| | ☐ Practice  |
| **National Quality Strategy Domains** | ☒ Patient and Family Engagement  
| | ☒ Patient Safety  
| | ☒ Care Coordination  
| | ☐ Population/Public Health  
| | ☐ Efficient Use of Healthcare Resources  
| | ☐ Clinical Process/Effectiveness  |
| **Care setting** | ☒ Outpatient  
| | ☐ Inpatient  
| | ☐ Emergency Departments and Urgent Care  |
| **Data Sources** | ☒ Electronic health record (EHR) data  
| | ☒ Administrative Data/Claims  |

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### Technical Specifications: Electronic Health Record (EHR) Data

The AAN is in the process of creating code value sets and the logic required for electronic capture of the quality measures with EHRs. A listing of the quality data model elements, code value sets, and measure logic (through the CMS Measure Authoring Tool) for each of the epilepsy measures will be made available at a later date.

### Technical Specifications: Electronic Administrative Data (Claims)

Administrative claims data collection requires users to identify the eligible population (denominator) and numerator using codes recorded on claims or billing forms (electronic or paper). Users report a rate based on all patients in a given practice for whom data are available and who meet the eligible population/denominator criteria.

<table>
<thead>
<tr>
<th>Denominator (Eligible Population)</th>
<th>ICD-9 and ICD-10 Diagnosis Codes:</th>
<th>ICD-9 Codes</th>
<th>ICD-10 Codes</th>
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<tr>
<td>345.01, generalized nonconvulsive epilepsy, with intractable epilepsy</td>
<td>G40.A19 absence epileptic syndrome, intractable, without status epilepticus</td>
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<td>345.41, Localization-related (focal) (partial) epilepsy and epileptic syndromes with complex partial seizures, with intractable epilepsy</td>
<td>G40.219 Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, without status epilepticus</td>
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<tr>
<td>345.51, Localization-related (focal) (partial) epilepsy and epileptic syndromes with simple partial seizures, with intractable epilepsy</td>
<td>G40.119 Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, intractable, without status epilepticus</td>
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<tr>
<td>345.61, Infantile spasms, with intractable epilepsy</td>
<td>G40.824 Epileptic spasms, intractable, without status epilepticus</td>
<td></td>
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<tr>
<td>345.71, Epilepsia partialis continua, with intractable epilepsy</td>
<td>G40.119 Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures, intractable, without status epilepticus</td>
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**AND**

CPT E/M Service Code:

- 99201, 99202, 99203, 99204, 99205 (Office or other outpatient visit-New Patient);
- 99211, 99212, 99213, 99214, 99215 (Office or other outpatient visit-Established Patient);
- 99241, 99242, 99243, 99244, 99245 (Office or Other Outpatient Consultation-New or Established Patient)