Essential tremor (ET) is one of the most common movement disorders in the world, with prevalence rates in the general population ranging from 0.4% to 4.6%. The incidence of ET increases with age, with the average age at onset in mid-to-late 40s. ET is estimated to affect as many as 7 to 10 million Americans. Clinically, ET is characterized by bilateral, symmetric, postural tremor in hands and forearms, with or without kinetic tremor, in the absence of abnormal posturing or task specificity. ET can also affect lower extremities, head, and voice. Symptoms may be barely noticeable, or severe and disabling.

Although tremor may affect quality of life, particularly in eating, drinking, and writing, only a proportion of patients with tremor seek medical attention. Lack of awareness and stereotypes about tremor may contribute to tremor being untreated. In addition, ET may be difficult to distinguish from other tremor syndromes, potentially leading to inaccurate diagnosis or delay in treatment.

The American Academy of Neurology (AAN) noted that opportunities exist to improve the clinical care provided to patients with ET given its high worldwide prevalence. The AAN seated a multidisciplinary work group to evaluate evidence and identify areas where quality improvement efforts could be focused and harmonized to meet patient and provider needs. The work group was tasked with identifying potential metrics or quality measures that would be meaningful in driving quality improvement efforts for general neurologists, movement disorder specialists, and care teams.

Opportunities for improvement. In a survey of over 1,000 patients with ET conducted by Louis et al., only 1 in 10 patients with ET indicated they were satisfied in their current treatment situation. When asked “If you were going to design a comprehensive approach/ideal clinical center for the treatment of tremor, which problems, aside from tremor, would you focus attention on?,” surveyed patients indicated numerous areas where additional care and support was needed. These included psychological services and support (33.9%), physical or occupational therapy (28.6%), handling embarrassment and social effects of tremor (15.8%), feelings of not being in control (13.7%), better counseling about current treatment and medications (11.9%), discussion of more treatment options or alternative treatment options (8.7%), and support groups (4.9%). Almost 12% of patients responding to the survey indicated they would like better counseling about current treatment and medications. Patients reported a need for more quantitative ways of assessing ET (12.5%) and tracking progression of the condition (12.7%). In a survey sponsored by the International Essential Tremor Foundation, members also indicated an increased need for awareness of guideline-approved treatment options. These factors, combined with debilitating effects of ET, result in a decreased quality of life, and warrant potential clinical practice improvements to ensure these needs are identified and treated as appropriate. Patient reports support further promotion of ET resources to ensure patients are connected to appropriate resources and care networks where such options might be overlooked.

The AAN work group reviewed existing guideline statements and attempted to locate research data supporting guideline use in practice. It is hoped that by developing quality measures additional information can be ascertained on clinical performance of guideline recommendations. The work group identified several areas where potential improvement efforts...
could focus, including diagnosis, pharmacologic and surgical treatment options, comorbid conditions, patient education, quality of life, and supportive therapy services. Not all areas were found to be appropriate for measure development at this time, but may be revisited in future updates. The work group concentrated efforts on creating measures for pharmacologic and surgical treatment options, ET severity, depression and anxiety, quality of life, and patient education.

METHODS Details of the AAN’s full measure development process are available online,12 and are summarized below. The AAN identified nonvoting facilitators and subject matter experts to serve as project chairs serving as a leadership team. A comprehensive literature search was conducted by a medical librarian to identify relevant evidence and guidelines. Simultaneously, work group participants were recruited. Members were selected by the leadership team through a competitive process, reviewing potential conflicts and relevant clinical or quality experience. The selected work group comprised 16 members (a list of members and contributing organizations follows this article), including physicians, patients, researchers, advanced practice providers, payers, and nursing representatives.

Work group members proposed concepts, which were prioritized for development based on known treatment gap, feasibility, and evidence to support treatment practice. The work group focused their efforts on measures that were feasible to collect, that had evidence or guideline statements supporting existing standards of care that were appropriate to measure, and for which a known treatment gap existed allowing for opportunity for improvement.

Candidate measure concepts were reviewed and edited prior to a vote to approve, reject, or abstain during an in-person meeting.13 All members disclosed potential conflicts of interest and were instructed to abstain if a potential conflict could be perceived during voting. A public comment period was held for 4 weeks, resulting in input from 33 individuals. Measure concepts were further refined prior to measurement set approvals by the work group, AAN Quality and Safety Subcommittee, AAN Practice Committee, and AAN Institute Board of Directors.

RESULTS The work group approved 6 quality measures for ET (table). Full measurement specifications are available at aan.com/practice/quality-measures/ and in appendix e-1 at Neurology.org. Providers are encouraged to identify the 1 or 2 measures that would be most meaningful for their patient populations and implement these measures to drive performance improvement in practice. There is no requirement that any measures in the set be used, nor a requirement that if one measure is used, all must be used.

The work group noted that although many validated clinical rating scales exist to support improvement work, there was little support for one specific scale across populations and providers. As a result, for measures where a scale or tool was required to satisfy the measure (e.g., Annual Assessment of ET Severity), a finite list of potential scales and tools was provided. These scales and tools will be revisited over time, but allow for data to be pulled automatically should a measure be incorporated into a registry, such as the AAN’s Axon Registry.10

In addition to the 6 measures developed and approved, the work group strongly suggests all providers assess patients with ET for unhealthy alcohol use, as alcohol may improve ET. The work group declined to develop a new measure to address this concern given the existence of a current PCPI Foundation measure that is applicable to this population. This measure requires assessing all patients aged 18 years and older for unhealthy alcohol use with the Alcohol Use Disorders Identification Test (AUDIT) Screening Instrument, Alcohol Use Disorders Identification Test—Consumption (AUDIT-C) Screening Instrument, or Single Question Screening, and for those identified as an unhealthy alcohol user, providing brief counseling. Full measure specifications are available at thepcpi.org/programs-initiatives/measurement-science.14 The PCPI Foundation measure has been endorsed by the National Quality Forum (#2152) and is currently utilized in the Centers for Medicare and Medicaid Services (CMS) pay-for-reporting Physician Quality Reporting System.14

The work group also proposed and considered additional measures. Ultimately these measures were not included in this measurement set, but the concepts will be retained for future measurement set updates as more evidence may support development or a treatment gap in care at that time. These topics included the following:

1. Annual diagnostic review—Following the public comment period, the proposed annual diagnostic review measure was not further developed. The work group decided through a voting process that further development of the measure would place burden on the provider to either change documentation practices with little added benefit to patient care or place burden on the provider to review all medical records manually to locate the data to meet the measure.

2. Prior to public comment, the work group evaluated the possibility of addressing diagnostic needs via a DaTscan. DaTscan is the first and only Food and Drug Administration (FDA)—approved imaging agent that provides a visual method to differentiate between Parkinson disease and ET. The work group did not pursue development of the measure, as use of DaTscan cannot definitively confirm a diagnosis of ET. It is anticipated this issue will be reviewed in the next update to evaluate feasibility of developing a measure that will help providers address the diagnostic needs of patients who may exhibit signs of both Parkinson disease and ET.
3. Outcome measures for tremor severity and quality of life—The work group believed these concepts were of high value, but ultimately determined it would be impractical to implement at this time, resulting in development of process measures for these issues. It is hoped that a universal tool will arise in the field to allow for efficient assessment of patient satisfaction with treatment and monitoring of tremor severity while minimizing patient and clinician burden.

### Table 2016 Essential tremor measurement set

<table>
<thead>
<tr>
<th>Title</th>
<th>Description</th>
<th>Numerator</th>
<th>Denominator</th>
<th>Exclusions</th>
<th>Exclusion rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pharmacologic treatment for patients with ET</strong></td>
<td>Percentage of patients aged 18 years or older with ET whose pharmacologic treatment options were discussed at least once in the 12-month measurement period</td>
<td>Patients for whom pharmacologic treatment options were discussed at least once in the 12-month measurement period</td>
<td>Patients 18 years and older with a diagnosis of ET</td>
<td>Patient declines discussion</td>
<td>It is appropriate to exclude patients who decline to discuss pharmacologic options; in addition, a discussion on treatment options cannot be held with those who have an impairment preventing participation without the presence of a caretaker</td>
</tr>
<tr>
<td><strong>Surgical evaluation for patients with ET</strong></td>
<td>Percentage of patients aged 18 years or older diagnosed with medically refractory ET for whom available guideline-appropriate surgical treatment options were discussed least once in the 12-month measurement period</td>
<td>Patients aged 18 years or older diagnosed with medically refractory ET for whom available guideline-appropriate surgical treatment options were discussed least once in the 12-month measurement period</td>
<td>Patients aged 18 years or older with a diagnosis of ET</td>
<td>Patient declines discussion</td>
<td>It is appropriate to exclude patients who decline surgical options and those who have already undergone a surgical treatment intervention; it is appropriate to exclude those who are believed to not be surgical candidates due to unacceptable surgical risks; patients connected to care at a movement disorder center and who have been evaluated in prior 2-year period are removed to reduce duplicative conversations with the patient on surgical treatment options</td>
</tr>
<tr>
<td><strong>Annual assessment of ET severity</strong></td>
<td>Percentage of patients aged 18 years or older with ET whose tremor severity was assessed annually and recorded at least once in the 12-month measurement period</td>
<td>Patients aged 18 years or older with ET whose tremor severity was assessed annually and recorded in the 12-month measurement period</td>
<td>Patients 18 years and older with a diagnosis of ET</td>
<td>None</td>
<td>Not applicable</td>
</tr>
<tr>
<td><strong>Annual screening of depression and anxiety for patients with ET</strong></td>
<td>Percentage of patients aged 18 years or older with ET for whom annual screening for depression and anxiety were conducted at least once in the 12-month measurement period</td>
<td>Patients for whom annual screening for depression and anxiety were conducted at least once in the 12-month measurement period</td>
<td>Patients 18 years and older with a diagnosis of ET</td>
<td>Patient is unable to participate in examination (i.e., advanced stage dementia, profound psychosis, neurodevelopmental disorder, brain injury encephalopathy, or hydrocephalus) and caretaker not present</td>
<td>An assessment of depression and anxiety cannot be conducted for patients with an impairment preventing participation without the presence of a caretaker</td>
</tr>
<tr>
<td><strong>Annual assessment of quality of life for patients with ET</strong></td>
<td>Percentage of patients aged 18 years and older diagnosed with ET who were assessed annually for quality of life in the 12-month measurement period</td>
<td>Patients 18 years and older diagnosed with ET who were assessed annually for quality of life in the 12-month measurement period</td>
<td>Patients 18 years and older with a diagnosis of ET</td>
<td>Patients who are unable or decline to complete quality of life instrument</td>
<td>Quality of life is a subjective symptom that requires patient cooperation to assess</td>
</tr>
<tr>
<td><strong>Promotion of ET resources</strong></td>
<td>Percentage of patients aged 18 years and older with ET who were provided information on relevant patient support groups, advocacy groups, or ET-specific education in the 12-month measurement period</td>
<td>Patients aged 18 years and older who were provided information on relevant patient support groups, advocacy groups, or ET-specific education in the 12-month measurement period</td>
<td>Patients 18 years and older with a diagnosis of ET</td>
<td>None</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

**Abbreviation:** ET = essential tremor.

These measures were approved by the work group. There is no requirement that all measures in the measurement set be used. Providers are encouraged to identify the 1 or 2 measures that would be most meaningful for the patient population and implement these measures to drive performance improvement in practice.

*The work group strongly suggests all providers screen for unhealthy alcohol use in this population using the Preventative Care and Screening: Unhealthy Alcohol Use: Screening & Brief Counseling measure (National Quality Forum measure #2152)."
4. Botulinum toxin—The work group discussed development of a potential measure for vocal, head, and limb tremor, but there was a lack of strong evidence and guideline statements. Hopefully, additional research will be conducted to demonstrate the efficacy of this treatment option for consideration as a potential measure in the future.

5. Speech, occupational, and physical therapy—The work group discussed development of a measure addressing referrals to speech, occupational, and physical therapy services, but there were no strong evidence statements linking these services to improved outcomes. In addition, a patient-reported outcome measure was not appropriate for development given the lack of validated instruments to gather outcomes in these settings.

6. Exercise and relaxation—There is insufficient published evidence to support development of these measures at this time. There are small studies (n = 10 patients with ET in active treatment group) supporting resistance training and biofeedback (n = 3 patients in active treatment group). However, these small samples cannot be generalized to patients with ET, and more research and systematic reviews on these issues are needed to support development of future measures.

7. Intermediate medication stabilization outcome—The work group discussed development of this measure, which was subsequently dropped from further development given the lack of evidence to support therapeutic blood ranges for current medications used to treat ET. Although such ranges exist for seizure control, it is not appropriate to apply these ranges to patients with ET.

8. Vocal tremor—The work group discussed development of a measure assessing if a patient identified with vocal tremor was informed of available treatment options. The work group discussed that the current level of evidence and absence of guideline statements did not meet criteria for measurement development.

9. Cognitive impairment—The work group discussed development of a potential measure addressing clinician assessment for cognitive impairment, but evidence was lacking supporting the need for this assessment on all patients with ET. Further research is needed regarding the association of ET and cognitive impairment.

10. Ultrasound—The US FDA has approved MRI-guided focused ultrasound, a noninvasive method to treat ET that is unresponsive to medical management. Many individuals commented on the lack of a measure addressing ultrasound use. Current guideline statements do not address high-energy ultrasound use, but it is anticipated that this will be addressed in future updates of the measurement set following development of guidelines addressing ultrasound use for treatment of ET.

**DISCUSSION** ET is among the most common movement disorders in the world, and patients may be cared for by health care providers in family medicine, internal medicine, and neurology. It is the hope of the work group that implementation of the measures will lead to quantifiable improvements in the care of patients with ET. Guidance about the annual assessment of tremor, medication, and surgical evaluation and treatment in ET is provided. In addition, these measures provide recommendations for the evaluation of depression and anxiety and quality of life in patients with ET. Finally, there are recommendations for providing patients with ET with information about support groups and online resources. The overall goal of quality measures is to guide their users to evidence-based improvements in care and, eventually, health care outcomes.

It is anticipated that select measures will be submitted for consideration in the CMS Merit-based Incentive Payment System, which replaces the previous Physician Quality Reporting System. In addition, select private payers may utilize measures to track provider performance. It is important that providers have access to ET measures in these systems to ensure performance measures are meaningful to providers as currently providers are limited to cross-cutting (i.e., measures with broader patient denominators, such as patients diagnosed with any neurologic disorder) preventative care measures. These measures may provide more meaningful data to providers to drive performance improvement in this population beyond what data gained through reporting preventative care measures could provide. The AAN will also update these measures on an ongoing basis every 3 years, allowing the measurement set to provide a working framework for measurement, rather than a long-term mandate.

Measures that include direct and indirect manifestations of the disorders are important to providers, patients, and families. In addition, measure development is moving towards cross-cutting, outcome, and patient-reported measures. Development of this measurement set is a first step toward driving performance improvement in practice for patients with ET. The measurement set will evolve over future updates to further meet provider, patient, and family needs.

**AUTHOR CONTRIBUTIONS**

Dr. Zesiewicz contributed to study concept and design, acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content, and study supervision including responsibility for conduct of research and final approval. Dr. Sullivan contributed to study concept and design, acquisition of data, analysis and/or interpretation of data, and design, acquisition of data, analysis and/or interpretation of data.
drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content, and study supervision including responsibility for conduct of research and final approval. Dr. Ponce de Leon contributed to study concept and design, acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content, and study supervision including responsibility for conduct of research and final approval. Dr. Hohler contributed to study concept and design, acquisition of data, analysis and/or interpretation of data, drafting/revising the manuscript, critical revisions of the manuscript for important intellectual content, and study supervision including responsibility for conduct of research and final approval.

ACKNOWLEDGMENT

The authors thank the ET Quality Measurement Set Work Group members for their dedication, time, energy, contributions, and work that supported the development of this manuscript: Theresa A. Zesiewicz, MD, FAAN (American Academy of Neurology); Kelly L. Sullivan, PhD, MSPH (American Academy of Neurology); Paras Bhattarai, MD, MBBS (American Academy of Neurology); Kelvin L. Chou, MD (American Academy of Neurology); Peter Hedera, MD, PhD (American Academy of Neurology); Janis M. Miyasaki, MD, FAAN (American Academy of Neurology); Diego R. Torres-Russotto, MD (American Academy of Neurology); Laurice Yang, MD (American Academy of Neurology); Margaret M. Lambert, RN, BSN, CNRN (American Association of Neuroscience Nurses); Julie Barkmeier-Kraemer, PhD, CCC-SLP (American Speech-Language-Hearing Association); Ellen Air, MD, PhD (American Academy of Neurology); Lauren Seeberger, MD, FAAN (American Society for Stereotactic and Functional Neurosurgery); Jane Orr, PT, DPT, NCS (American Society for Stereotactic and Functional Neurosurgery); Fatta B. Nahab, MD (Movement Disorder Society); Dietrich Haubenberger, MHSc, MD (National Institute of Neurologic Disorders and Stroke/NIH); Anna D. Holter, MD, FAAN (American Academy of Neurology facilitator); Marcus Ponce de Leon, MD, FAAN (American Academy of Neurology facilitator); Amy Bennett, JD (American Academy of Neurology staff); Gina Gjorvad (American Academy of Neurology staff); Katie Hengtes (American Academy of Neurology staff); Erin Lee (American Academy of Neurology staff); Karen Lundgren, MBS (American Academy of Neurology staff); Becky Schierman, MPH (American Academy of Neurology staff).

STUDY FUNDING

No targeted funding reported.

DISCLOSURE

T. Zesiewicz has received grant funding from FARA, Glaxo Smith Kline, Shire, Sagec, SNC, Adamas, Osmotica, Edison, Retrotape, Reata, and Baxalta. She has consulted for Stentiment Inc. and Agilis. K. Sullivan, M. Ponce de Leon, A. Bennett, and A. Hohler report no disclosures relevant to the manuscript. Go to Neurology.org for full disclosures.

Received January 31, 2017. Accepted in final form June 28, 2017.

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