

# Quality improvement in neurology

## Neurology Outcomes Quality Measurement Set

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One in 6 Americans live with a neurologic disease.<sup>1-3</sup> Recent evidence suggests that the number of people dying from and affected by these disorders has increased substantially in the past 25 years, contributing to a higher health loss across the lifespan.<sup>2</sup> The American Academy of Neurology's (AAN's) mission is in part to promote the highest-quality patient-centered neurologic care for these patients, and the AAN's leadership in quality improvement initiatives and developing outcome measures is a conveyance of this mission. Quality, as defined by the National Academy of Medicine, is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."<sup>4</sup> Quality improvement is "systematic, data-guided activities designed to bring about immediate improvements in health care delivery" and is considered "an intrinsic part of normal health care operations."<sup>5</sup> Data from outcome measures can be effectively used to establish a baseline of care quality delivered within a given health care unit (e.g., multispecialty group)<sup>5,6</sup> and guide the implementation and ongoing evaluation of quality improvement initiatives intended to improve care quality and delivery.<sup>6</sup> Increasing demands to provide health care outcomes data from patients and payers and the need for neurologic providers to have these data available to assist in care planning necessitated the AAN's former Quality and Safety Subcommittee to recommend the seating of a small work group to develop neurologic outcome quality measures, which would be applicable broadly across major neurologic diseases.

Quality measures are prolific for neurology. To date, the AAN has released 15 quality measurement sets with over 139 individual measures; currently, only 14 of these developed measures are outcome or intermediate outcome measures. Other measure developers such as the PCPI Foundation, National Committee for Quality Assurance, and the Agency for Healthcare Research and Quality (AHRQ) have cross-cutting measures that affect patients with neurologic conditions. Many of these measures are process measures, which are defined in the AAN measure manual as measures that "focus on actions of health care professionals and evaluate whether these activities follow established evidence-based clinical guidelines, care protocols, and best practices."<sup>7</sup> Typically for process measures, population characteristics do not factor into comparing one health care setting to another.<sup>8</sup> To illustrate the point of process measures, the 2017 AAN Inpatient and Emergency Care Quality Measure Set included a measure related to bacterial meningitis treatment (i.e., "percentage of patients >21 years of age in whom dexamethasone 10 mg is given IV before or with the first dose of antibiotics in suspected acute bacterial meningitis").<sup>9</sup> This process measure was informed by data from

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## Glossary

AAN = American Academy of Neurology; AANI = AAN Institute; AHRQ = Agency for Healthcare Research and Quality; ALS = amyotrophic lateral sclerosis; CAHPS = Consumer Assessment of Healthcare Providers and System; QPP = Quality Payment Program; MIPS = Merit-based Incentive Payment System.

randomized controlled trials and a systematic review documenting morbidity and possibly mortality benefit of steroid administration in the treatment of bacterial meningitis.<sup>9</sup>

In comparison to a process measure, an outcome measure “address(es) critical endpoints that represent the culmination of an episode of care”<sup>7</sup> and may be more affected by patient characteristics that are beyond the control of practitioners.<sup>8</sup> Unlike process measures, which require strong guideline statements or systematic reviews to form measurement specifications, outcome measures directly assess care outcomes. These may be patient-reported outcomes, health-related quality of life, or economic outcomes. The Centers for Medicare & Medicaid Services (CMS) considers 7 categories of outcome measures in their Hospital Compare overall hospital rating, including mortality, safety of care, readmission, patient experience, effectiveness of care, timeliness of care, and efficient use of medical imaging.<sup>10</sup> Although outcome measures may be developed despite a lack of published guidelines or systematic review that establishes a standard of care for that particular care issue, they are useful ways to guide quality improvement initiative in objective and meaningful ways. For example, in 2015, the AAN Multiple Sclerosis Measure Set included an outcome measure on bladder infections.<sup>11</sup> A process measure addressing physician and provider compliance of a certain guideline-recommended therapy was not created due to the lack of a strong guideline statement indicating how treatment should be provided for bladder infections in most patients.<sup>7</sup> However, this outcome measure allows neurology practices to track the number of patients who have bladder infections, allowing an initial benchmark to be established for that practice. Providers can implement best practices and seek clinical expertise based on regional epidemiologic considerations and population characteristics. Such quality improvement initiatives can be tracked by their effect over time in reducing the incidence of bladder infections. An advantage of using an outcome measure in this scenario instead of a process measure is that it allows professionals to use their clinical judgment and individualize treatment choices for their patients encouraging patient-centered care.

It is key that identification of opportunities to monitor and define neurologic outcomes be guided by neurology professionals. The AAN identified a gap in the existing measurement portfolio and sought to address this gap by developing cross-cutting outcome measures that may be used by neurologists and neurology providers across neurologic conditions/diseases. Three cross-cutting measures were created as a part of

this initiative (table 1). These are applicable to a broad range of neurologic conditions, including but not limited to cerebrovascular diseases, cognitive impairment and related dementias, developmental delay, headache and migraine, movement disorders, multiple sclerosis and other neuroimmunologic disorders, neoplasms of the neuroaxis, neuromuscular conditions, epilepsy, vertigo and related neuro-otologic disorders, and other neurologic illnesses.

## Opportunities for improvement

Historically, neurologic quality measures have focused on disease-specific conditions, including amyotrophic lateral sclerosis (ALS),<sup>12</sup> dementia management,<sup>13</sup> distal symmetrical polyneuropathy,<sup>14</sup> epilepsy,<sup>15</sup> essential tremor,<sup>16</sup> headache,<sup>17</sup> mild cognitive impairment,<sup>11</sup> multiple sclerosis,<sup>7</sup> muscular dystrophy,<sup>18</sup> neuro-oncology,<sup>19</sup> neurotology,<sup>20</sup> Parkinson disease,<sup>21</sup> and stroke and stroke rehabilitation.<sup>22</sup> Although there is value in delineating condition-specific measures, beginning in 2013, the AAN began exploring measures that may apply to a broad range of conditions, having released measurement sets for child neurology,<sup>23</sup> inpatient and emergency care,<sup>9</sup> and universal neurology.<sup>24</sup>

The AAN initiated the Axon Registry in 2014,<sup>25</sup> a quality improvement registry. Axon Registry participants and the CMS have identified a need for neurology outcome measures to be created.<sup>26</sup> The CMS's Quality Payment Program (QPP) Merit-based Incentive Payment System (MIPS) requires the use of quality measures to drive value-based payments.<sup>27</sup> The CMS has signaled that process measures are no longer sufficient and that outcome measures be prioritized for inclusion.

## Methods

Details of the American Academy of Neurology Institute's (AANI's) full measure development process are available online.<sup>7</sup> The AANI seated a work group comprised of Health Policy Committee members to evaluate and develop outcome measures for neurologic conditions. The work group included experts with medical economics, advocacy, measure development, and measure implementation experience. In addition, several patient representatives were included. The work group was instructed to focus on developing only outcome measures including patient-reported outcome measures, patient-reported outcome performance measures, intermediate outcome measures, and economic or efficiency outcome measures.

**Table 1** Final Neurology Outcomes Quality Measurement Set<sup>a</sup>

Concept	Title	Numerator	Denominator	Required exclusions	Allowable exclusions
<b>Patient experience and satisfaction</b>	Patient Communication Experiences for Patients with Neurologic Conditions	Patients or care partners who responded "Always" for the question "provider explained things in a way that was easy to understand."	Patients or care partners of those diagnosed with a neurologic condition who answered the question "In the last 6 months, how often did this provider explain things in a way that was easy to understand?" <sup>b</sup>	None	None
<b>Quality of life</b>	Quality of Life Outcome for Patients with Neurologic Conditions	Patients whose PROMIS Global Health-10 Score at 12 months ( $\pm 60$ days) was maintained or improved from the index score	Patients aged 18 years and older diagnosed with neurologic condition	Patients who died	Second PROMIS Global Health-10 Score not collected at 12 months ( $\pm 60$ days)
<b>Health care utilization</b>	EMG Utilization for Isolated Lower Back Pain	Patients who had an EMG for diagnosis of isolated lower back pain	Patients aged 18 and older diagnosed with isolated lower back pain	Patients who have radicular symptoms documented EMG performed by another provider	EMG clinically indicated to rule out another comorbid neurologic condition EMG ordered by another provider

Abbreviation: PROMIS = Patient-Reported Outcomes Measurement Information System.

<sup>a</sup> Please refer to [aan.com/policy-and-guidelines/quality/quality-measures2/quality-measures/](http://aan.com/policy-and-guidelines/quality/quality-measures2/quality-measures/) for further definitions.<sup>7</sup>

The work group held initial meetings to brainstorm potential outcome concepts and proposed 19 measure concepts. Work group members were encouraged to rank these conceptual measures and focus on developing measures that are feasible to collect, do not pose an excessive burden on providers and practices to collect data, are meaningful to quality improvement efforts, and address a known treatment gap. The group came up with an additional 52 concepts during first round ranking discussions of the 19 proposed measures. The 71 concepts were grouped together during the second round of rankings to reduce internal competition for similar concepts. For example, 14 separate patient experience and satisfaction concepts were proposed by the group; these were consolidated into 1 patient experience/satisfaction grouping. Three separate concepts centered on medications, including ones focusing on improved adherence, reduction of side effects, and reduction of overmedication were grouped into 1 medication use grouping.

After the final review of rankings, 5 concepts were advanced for further development. Those concepts were patient experience/satisfaction, medications used to treat neurologic conditions, quality of life, depression, and health care utilization.

During the conversations on patient experience/satisfaction measure, the work group proactively focused on harmonizing the measure with existing patient surveys being collected by many neurology practices to reduce burden of collecting new data or additional patient surveys. The group proposed 2 measures within the concept of patient experience/satisfaction—one for adult care and another for child and adolescent care and focused on provider communication as the

patient-centered outcome that providers can easily influence and improve.

When discussing medications used to treat neurologic conditions measure, the work group focused on the reduction of medication side effects, proposing 2 initial drafts—one focused on patient-reported side effects and another on the improvement of the rates of side effects reported. Only the measure focused on patient-reported side effects was advanced for public comment, given feasibility concerns on monitoring and measuring the change of patient-reported side effects over time.

The work group agreed on the value in measuring quality of life for patients, especially given the chronic nature of many neurologic disorders, with several conditions being incurable, progressive, and/or degenerative. The group focused discussions on existing quality of life measures, the different types of quality of life tools, and the potential of excluding certain diagnoses, specifically terminal diagnoses (e.g., ALS and Huntington disease), from the measure. Based on these discussions, a measure focused on maintaining or improving quality of life was advanced for public comment.

While discussing depression as a potential measure, the work group agreed in the value of a depression outcome measure due to high incidence of depression as a comorbidity in neurologic disorders. Discussions also focused on potential harmonization with other existing depression outcome measures and potential burden this type of measure may place on providers. Based on these discussions, a measure focused on progression to depression remission was advanced for public comment.

During conversations on the proposed measure on health care utilization, it became apparent that measuring outcomes related to this concept such as emergency department visits, unplanned inpatient admissions, and cost of care would not be feasible to collect without substantial provider and practice burden. There were overarching concerns that measuring these outcomes may be outside the capacity of the neurology provider. Furthermore, the data collected, even if feasible, may not occur in a timely fashion for most practices and hence would limit the ability for these data to drive quality improvement initiatives. The work group reviewed the Choosing Wisely initiative for recommendations applicable to neurology that were ideally endorsed by other national societies.<sup>28,29</sup> The work group focused on EMG use for isolated lower back pain as a result.<sup>30</sup>

These 6 concepts were developed into draft measurement specifications, and each was voted on individually confirming work group consensus to seek public comment:

1. Patient communication experience for adult patients with neurologic conditions
2. Patient communication experience for child and adolescent patients with neurologic conditions
3. Patient-reported unacceptable or concerning side effects from medications prescribed for a neurologic condition
4. Quality of life outcome for patients with neurologic conditions
5. Progress toward depression remission for patients with neurologic conditions
6. EMG utilization for patients with isolated lower back pain

A 21-day public comment period was held. Forty-nine individuals provided comments, 18 of which were entered on behalf of medical societies or industry partners (table 2).

Following review of this information and the individual comments on each measure concept, the work group met to discuss advancement of these measure concepts. The work group dropped 2 measures from further development—the patient-reported unacceptable or concerning side effects from medications for a neurologic condition and progress toward

depression remission for patients with neurologic conditions from further development (figure). The work group combined the adult and child and adolescent patient communication experience measures for 1 comprehensive measure. Three measure concepts were modified in response to public comment and finalized (table 1). Then, the work group and AANI's Quality Measure Subcommittee, Quality Committee, and Board of Directors voted and approved the measurement set.

## Results

The work group approved 3 measures (table 1). Full measurement specifications are available online at [aan.com/practice/quality-measures/](http://aan.com/practice/quality-measures/).<sup>7</sup> A brief synopsis of the AAN's approach to final delivery of these outcome measure sets where specific considerations were discussed is summarized below.

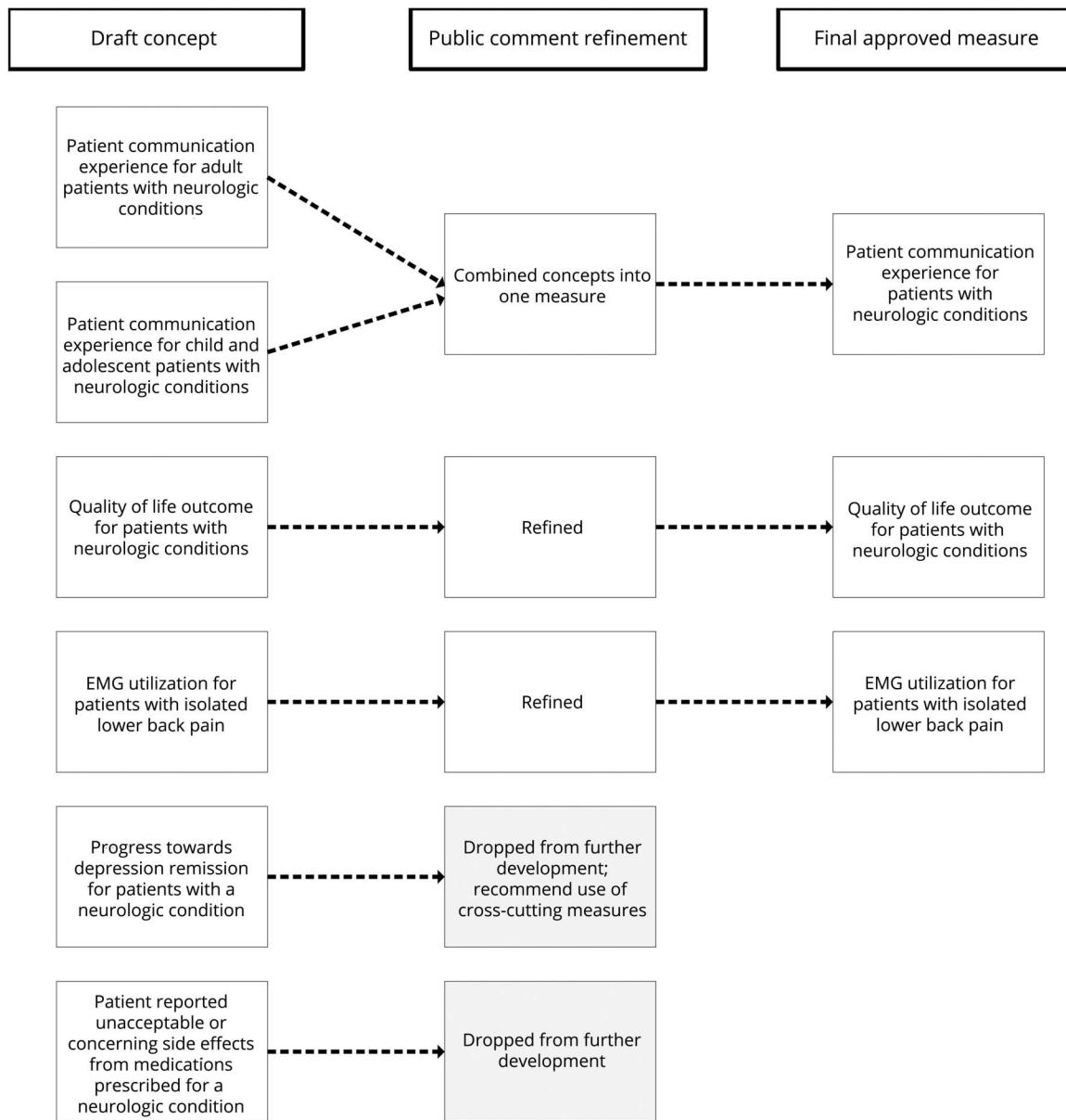
### Patient communication experience for patients with neurologic conditions

It assesses the percentage of patients with neurologic conditions or their care partners who reported that the provider always explained things in a way that was easy to understand. Initially, the work group proposed 2 separate measures focusing on adult and child and adolescent populations, but the 2 concepts were combined to form a unified measure assessing patient or care partner perception of provider communication. The work group chose to use survey data from the AHRQ Consumer Assessment of Healthcare Providers and Systems (CAHPS) program as a base for the numerator, given that the (1) current collection of this data is ongoing within multiple neurologic practices; (2) survey is free, available in the public domain, and designed to capture the patient-reported experience with their care and is not disease specific, thereby allowing for comparisons among patients with various neurologic conditions (e.g., patients with neuropathy compared with migraine) and comparisons between patients with neurologic and non-neurologic conditions (e.g., patients with stroke compared with those with myocardial infarction); and (3) the AHRQ provides guidance and resources to promote quality improvement initiatives by invested health care audiences (e.g., the CAHPS Ambulatory Care Improvement Guide).<sup>31</sup>

**Table 2** Public comment responses

Questions posted (N = no. of respondents)	Strongly agree	Agree	Disagree	Strongly disagree	Not applicable
The measurement set is important to me, my patients, my organization, or health care system (N = 41)	14 (34.1%)	21 (51.2%)	1 (2.4%)	5 (12.2%)	0
The wording of the measures is clear (N = 39)	4 (10.3%)	27 (69.2%)	6 (15.4%)	2 (5.1%)	0
Questions posted (N = no. of respondents)	Agree some information is collected	Some information is collected	Disagree	Unsure	
Information required for these measures is currently collected by health care professionals in your organization (N = 38)	7 (18.4%)	18 (47.4%)	7 (18.4%)	6 (15.8%)	

**Figure** Evolution and workflow of the development of the outcome measure set



The AHRQ defines different gradations of compliance of a measure set into “always,” “usually,” “sometimes,” and, “never.” The work group chose to use AHRQ’s “always” standard vs changing the standard to the next level response of “usually.” The work group noted that “always” is a reasonable standard for quality measurement, highlighting the critical impact of provider communication necessary for better outcomes in our patients, and is currently the standard upheld by the AHRQ (See CMS QPP MIPS #321 available at [qpp.cms.gov](http://qpp.cms.gov)).<sup>32</sup> It would not be reasonable for providers, practices, or payers to have 100% performance on this quality measurement, especially given that the goal of implementing this (and other) quality measures is to establish an individual benchmark in the first measurement period and drive performance improvement over time in subsequent measurement periods. Maintaining the always standards harmonizes with

existing measurement and reduces provider burden to track separate data for an AAN developed measure.

As surveys are currently collected and aggregated without linkage to a specific patient, the work group noted a challenge to linking responses from a specific patient to their treating provider. This quality measure would require a modification of data collection. Other considerations in implementing this quality measure include promoting willingness of patients and care partners to feel comfortable communicating responses reflective of their care, providers fostering an environment that minimizes potential response bias, and understanding how patients, care partners, and clinicians work together and use this means of communication in meaningful ways. Although implementing this quality measure may introduce a potential burden within a busy practice, the work group felt

as if the opportunity to improve delivery of care based on responses from patient and care partners would be worth the investment.

### Quality of life outcome for patients with neurologic conditions

It assesses the percentage of patients whose quality-of-life assessment results are maintained or improved during the measurement period. The work group discussed exclusions, potential value, and unintended consequences of excluding specific neurologic conditions such as ALS and Huntington disease. The work group ultimately determined that there would be value in continued assessment of quality of life for those with a terminal illness and/or neurodegenerative disease. Given data demonstrating that patient outcome measures reported within palliative care populations enhance patients' quality of life,<sup>33</sup> including patients with the aforementioned neurologic diseases, would allow for opportunities identify unmet or underappreciated patient needs and improve quality of life throughout disease stages. It was also noted that if a neurologist is working strictly with an ALS population, the benchmarks identified would be meaningful and could drive change over time.

The AANI has implemented this quality-of-life outcome measure into the Axon Registry (Axon Number 40, CMS Assigned Number 54)<sup>34</sup> and will monitor over time for potential unintended consequences and potential to use disease state as a specific risk adjustment tool. The work group released the measure using 1 specific patient-reported outcome tool, the Patient-Reported Outcomes Measurement Information System Global Health-10.<sup>35</sup> Inclusion of additional tools will be assessed at future updates. The measure was rolled out with 1 tool allowing for comparable results over time, and as evidence grows to support linking and comparing of multiple tools over time through resources such as PROsetta Stone,<sup>36</sup> additional tools may be added to meet the numerator.

### EMG utilization for patients with isolated lower back pain

It assesses the percentage of patients with isolated lower back pain who had an EMG. This is an inverse measure where a lower score is indicative of better care.<sup>28–30</sup> The work group discussed in-depth required and allowable exclusions and asked for commenters to weigh-in on the appropriateness of removing patients who had an EMG ordered by another provider. The work group ultimately decided to maintain an allowable exclusion for patients who had an EMG ordered by another provider. An allowable exclusion can only help performance. Patients who did not have an EMG performed will be included in calculation of the numerator. If there is evidence that an EMG was performed, the record will then be reviewed to determine if an EMG was ordered by another provider. If yes, the patient is then removed from the denominator, improving the overall quality score.

The plan is to maintain the exclusion list and assess for unintended consequences over time. The work group is concerned that the exclusion list may potentially affect the ability to drive meaningful change in practice, hence the need to study results over time to determine the impact of implementing this measure. The work group hopes that neurology practices will engage and educate their referring peers to discuss appropriate use of EMG and share didactic materials (e.g., Neurology Choosing Wisely recommendations)<sup>30</sup> if there is a noted trend of inappropriate referrals over time and use this measure to enhance care in patients with isolated back pain.

The work group chose to drop the following 2 measures from further development following the public comment period due to several reasons that are detailed below.

### Patient-reported unacceptable or concerning side effects from medications for a neurologic condition

The measure was dropped from further development due to the data collection challenges that currently exist. There is currently no widely adopted patient-reported outcome tool that collects side effects or adverse events for neurologic medications. In addition, there are challenges to attribute side effects or adverse events to a specific medication when patients may be prescribed multiple medications, which may or may not interact with one another or may have neurologic condition symptoms that mirror medication side effects, such as drowsiness or fatigue. The work group noted that there is an opportunity to develop a better side effect or adverse event tool for use in neurologic populations. Although some currently exist for epilepsy, headache, and pain management, there remains a gap in collecting these data. The work group hopes that advances in data collection are made allowing for development of a measure in the future.

### Progress toward depression remission for patients with neurologic conditions

It was dropped from further development due to the presence of existing depression outcome measures. Rather than create an additional measure specific to neurologic populations, the work group encourages individuals interested in monitoring comorbid depression to use measures already in existence.<sup>37–39</sup> Commenters echoed concerns raised by the work group that treatment of depression is beyond the scope of care by a neurology practice, particularly solo and small practices. The AANI's prior measure development has noted that comorbid psychiatric conditions are prevalent for epilepsy,<sup>15</sup> multiple sclerosis,<sup>11</sup> Parkinson disease, stroke,<sup>22</sup> headache,<sup>17</sup> and dementia,<sup>13</sup> as each of these quality measurement sets has a process measure created for assessment of depression and/or comorbid psychiatric conditions. The work group notes a gap in neurology related to treatment of depression, given the high prevalence of depression in neurologic populations, and believes that it can be effectively addressed through team-based care. There is value in neurology practices monitoring depression values and engaging

psychiatric, psychology, and social work supports to ensure that effective treatment is provided.

## Conclusion

The AANI hopes that these measures will be meaningful for quality improvement efforts. Providers are encouraged to start small, identifying 1 or 2 measures. After choosing a measure or measures, providers should seek out key stakeholders, gauge the readiness of a given health care unit to conduct meaningful quality improvement initiatives, and identify pertinent and accessible facilitators (e.g., patient and leadership involvement) to conducting quality improvement work.<sup>6,40,41</sup> Quality measures are only one tool to improving patient care. Development and implementation of these measures is a dynamic process, and these sets will be reviewed every 3 years for potential updates. Additional measures may be added in future if there is agreement on the feasibility and value of these to quality improvement efforts in widespread applicability in improving neurologic care. Measures will be evaluated for retirement or updates based on advances in evidence, feasibility concerns, and/or changes in treatment gaps. Quality measures may also be used for accountability programs such as MIPS after appropriate testing confirms their reliability and validity as mandated by the CMS. Although it is the hope of the AANI that these quality measures are adopted by the CMS and others, the AANI does not recommend payers adopting these measures for payment programs at this time. These measures will need to be thoroughly tested within real-world clinical practice, and appropriate risk adjustment strategies will need to be developed.<sup>8</sup> The AANI recognizes that even after these outcome measures were more fully tested, that there may be a delayed uptake outside of the neurology community.

The AANI encourages the providers and practices using these measures to share their successes with their peers to drive a change in the field. Outcome measures are a huge component of value-based care and are here to stay. Ongoing engagement and feedback into outcome measure development and implementation from both providers and patients is key to optimal provider experience in using them, which will eventually translate into enhancing patient care.

## Examples of using AAN quality measures in practice

For example, Dr. Bautista is in a 5-neurologist practice and decides to use the EMG measure for lower back pain and is shocked to find a 35% ordering of EMG for isolated lower back pain. Dr. Bautista asks her information technology support to put in a best practice alert in the electronic health record for recommendations on ordering EMG, and this measure in 3 months shows only 10% of patients now getting EMG for simple back pain. If part of an Accountable Care

Organization, this practice now gets reimbursement for reducing unnecessary care.

Similarly, Dr. Yu is in an academic practice with 30 neurologists and decides to use the quality of life measure. First, Dr. Yu discovers that 47% of her patients rate their quality of life as good or better. Dr. Yu discusses results with the department chair. Arrangements are made to provide resources to patients and care partners on community support groups, low-cost transportation options, and area food shelf options in the after-visit summary. The practice agrees to pilot a quality improvement project for 5 patients identified with poor quality of life results. The practice pilots use of a patient health navigator, hosting community support groups in the office setting, monitoring comorbid psychiatric symptoms, and access to psychiatric care. Not all piloted interventions are successful or feasible to maintain due to cost, but after 6 months, Dr. Yu notes that 52% of her patients now report their quality of life as good or better. Perfection is not the goal, but through small steps, demonstrable improvements could be made for her patient population.

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## Appendix (continued)

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