SPECIAL ARTICLE

Amyotrophic Lateral Sclerosis Quality Measurement Set 2022 Update

Quality Improvement in Neurology

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The estimated prevalence of amyotrophic lateral sclerosis (ALS) is approximately 5.2–7.9 people per 100,000 in the United States,[1,2] with a worldwide ALS estimate of 4.42 per 1,000,000 population.[3] Patients with ALS have progressive arm and leg weakness, speech, swallowing, and respiratory impairments, and frequent cognitive/behavioral dysfunction. Median tracheostomy-free survival from onset of weakness is 34.7 months, but progression rates vary substantially between individuals.[4] Although pharmacologic treatment options remain limited, judicious use of noninvasive ventilation, adequate nutritional support, and multidisciplinary care serve as the background for a landscape that continues to evolve with increasing availability of neuroprotective treatments and targeted genetic therapies on both a clinical[5] and research basis.[6,7]

Quality measures are an important way of quantifying care to drive improvements in how we care for patients. They may be used nationally in accountability programs and locally by multidisciplinary teams interested in benchmarking and improving how they provide evidence-based care to their patients. The development of neurology quality measurement sets ensures that practicing neurologists can get credit for the unique expert specialty care they provide, rather than being evaluated solely on universal performance indicators (e.g., smoking cessation and medication reconciliation) that are not precisely focused on the clinical management of patients with neurologic disease. The American Academy of Neurology Institute (AANI) has developed over 19 quality measurement sets spanning the diversity of neurologic diseases. The first ALS quality measurement set was published in 2013.[8] In this article, the first update to the ALS quality measurement set, which retains several quality measures and introduces new quality measures, is reported. The quality measures provided in this article do not encompass all aspects of ALS care, but they address areas in which there is a strong evidence base, in which a perceived or documented gap in care exists, and in which it appears to be feasible to measure performance or outcomes to implement changes and improve patient care.

For the purposes of this quality measurement set, we have defined ALS broadly to incorporate phenotypic variants (such as progressive muscular atrophy and primary lateral sclerosis), since similar multidisciplinary care is required. A more detailed discussion of this definition is outlined in the quality measurement set. The complete quality measurement set, ALS Quality Measurement Set 2022 Update, is available on the AAN website. It can be accessed through aan.com/practice/neuromuscular-quality-measures.

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Glossary

AANI = American Academy of Neurology Institute; **ALS** = amyotrophic lateral sclerosis; **CMS** = Center for Medicare & Medicaid Services; **FDA** = Food and Drug Administration; **FVC** = forced vital capacity; **LPHD** = lawful physician-hastened death; **MIPS** = Merit-based Incentive Payment System; **NIV** = noninvasive ventilation; **QPP** = Quality Payment Program.

Opportunities for Improvement

Patients with ALS experience a variety of symptoms beyond limb weakness that can affect daily function. A recent survey of patients with ALS and their care partners found that fatigue (76%), speech difficulty (52%), shortness of breath (45%), pain (40%), difficulty sleeping (29%), and cognitive changes (19%) were prevalent.[9] Many patients with ALS do not receive evidence-based care.[10] Multidisciplinary care clinics tend to perform better on providing guideline-directed care and addressing the broad range of symptoms that affect quality of life, but there are still areas for improvement.[10,11]

Since the release of the ALS quality measurement set in 2013, updated ALS guidelines have been released in Canada,[12] the United Kingdom,[13] and by the NEALS Bulbar Subcommittee in the United States.[14] Guidelines specifically on respiratory care of patients with ALS were also issued in Canada[15] and France.[16] These guidelines emphasized the importance of multidisciplinary care, speech and augmented communication, screening for both malnutrition and dysphagia, respiratory screening and earlier initiation of noninvasive ventilation (NIV), palliative care, and providing adequate patient and care partner support at diagnosis and throughout the disease course.

Methods

In 2020, the AANI convened a group of experts to review the ALS quality measurement set published in 2013 for need for revision based on new literature. The small group recommended an update because of new evidence and medications that affected this quality measurement set. The AANI seated an ALS quality measure development work group consisting of multidisciplinary care clinicians, patients, and care partners, charged with updating the quality measures.

To avoid actual, potential, or perceived conflicts of interest, all work group members were required to disclose relationships with industry and other entities. Work group members were seated after confirming that disclosures did not preclude involvement as required by the AAN measure development process and instructed to abstain from voting on individual quality measure concepts if a conflict was self-identified.

An initial literature search was conducted, with the help of a medical librarian, and resulted in 925 abstracts identified from EMBASE and MEDLINE. The literature search results were winnowed to 279 articles. These articles included potential guidelines, systematic reviews, meta-analyses, articles containing evidence of gaps in care for patients with ALS, or articles summarizing patient and care partner preferences. The work group also reviewed Axon Registry® performance data on the ALS patient care preferences quality measure, which is also known as Centers for Medicare & Medicaid Services (CMS) Quality Payment Program (QPP) measure 386.

Work group members reviewed the 2013 ALS quality measurement set and input from the small expert group on review of evidence. The work group members then proposed 44 draft concepts (prior 2013 quality measure concepts and new concepts), which were gathered into 23 concept groupings. For example, 3 concepts were reviewed and grouped into ventilation monitoring:

1. Patients who were screened for issues with secretions and NIV tolerability and device data that were downloaded to look for airway obstructive events
2. Patients who were referred at least once annually to a neurologist, pulmonologist, or mental health professional to evaluate patients' interest in receiving a tracheotomy and mechanical ventilation for sustaining life
3. Patients who were dependent on a ventilator and referred at least once annually to a speech-language pathologist or assistive technology specialist to discuss locked-in syndrome

The 23 concept groupings addressed advance care planning, ALS support services (defined as written or electronic material highlighting ALS patient or care partner resources and support services), aspiration, assistive technology, care partner burden, clinical trials, cognition, communication, diagnosis, diet and nutrition, disease-modifying pharmacotherapy (DMP), exercise, falls, fatigue, foot drop, gait/motor assessment, genetic testing, home safety, multidisciplinary care, respiratory assessment, spasticity, symptom assessment, and ventilation monitoring.

The work group ranked these concepts for further development using a modified Delphi process to prioritize concepts that were meaningful for quality improvement, supported by evidence, and feasible to collect. Work group members agreed to remove the diagnosis concept, noting feasibility concerns related to data capture and limited ability to use the data to drive meaningful change at an individual clinician level because this relates to monitoring patients from symptom onset to diagnosis. The falls quality measure was

removed from consideration because there is an existing quality measure in the AANI's universal neurology quality measurement set.[17] After reviewing initial rankings, the work group revised the remaining concepts into 12 groupings for further consideration: ALS support services, care partner burden, clinical trials, diet and nutrition, DMP, genetic testing, mobility, multidisciplinary care, needs assessment, respiratory care, symptom assessment, and patient care preferences. The work group rated these remaining 12 concepts for feasibility, evidence, and meaningfulness for quality improvement.

Following review of ratings, the work group did not develop mobility, needs assessment, or symptom assessment noting that these concepts may be captured through the multidisciplinary care measure. The work group determined that a care partner burden quality measure would be difficult to implement because this is not routinely captured in clinical documentation. In addition, the work group felt that measuring care partner burden may be less meaningful than personalized interventions to improve this outcome (e.g., providing linkages to ALS support, physical and occupational therapy to address home safety, and exploration of patient care preferences). The work group strongly supports the value of all facets of the multidisciplinary care for patients with ALS, including screening and referring patients for speech and swallow therapy as soon as indicated, and conducting ongoing mobility, foot drop, and falls assessments in the multidisciplinary or interdisciplinary framework. The work group was charged with identifying and refining to the highest impact quality measures. This is a difficult process, and ultimately, many concepts could not be developed based on AANI development constraints. Measurement burden on clinicians was an additional consideration.

The quality measures were winnowed to 8 concepts:

- DMP
- Clinical trials
- ALS support service
- Dietetic/nutrition care
- Genetic testing
- Multidisciplinary care
- Respiratory care and patient care preferences

These 8 quality measures were released for public comment. Following public comment, responses were drafted for individual comments, and quality measures were refined as appropriate. The clinical trials and genetic testing quality measures were removed from consideration following public comment.

The remaining 6 quality measures will be reviewed triennially to determine whether additional updates are needed. Full details of the AANI's quality measure development process are available online.[18] The quality measures in this set are being made available without any prior testing. The AANI encourages testing of this quality measurement set for feasibility and reliability by organizations or individuals positioned to do so. Only following testing will quality measures be eligible for potential submission to CMS for consideration in QPP Merit-based Incentive Payment System (MIPS) or MIPS Value Pathway and the National Quality Forum for possible endorsement. The Figure summarizes the steps in the quality measure development process.

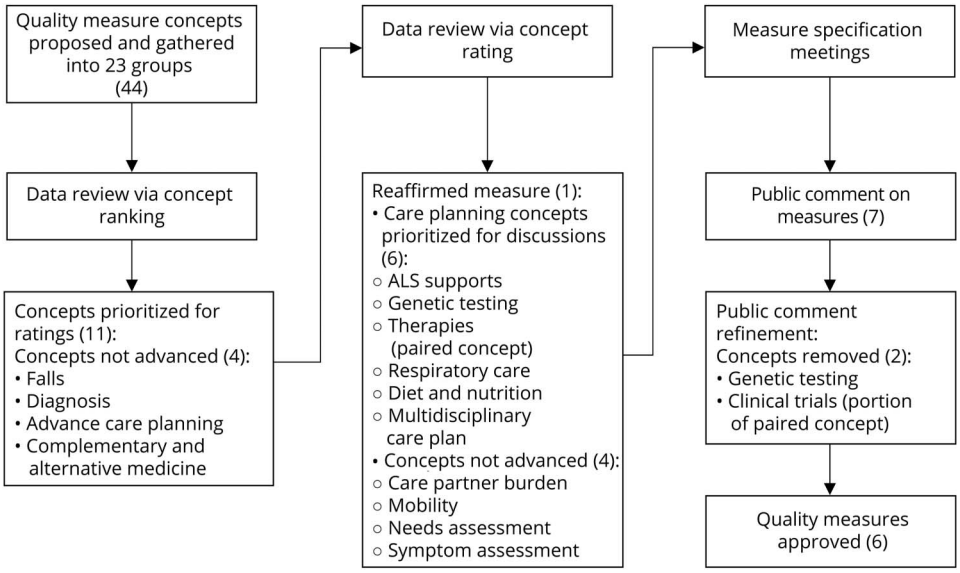
Results

Six quality measures were approved for the final 2022 updated set (see the Table): ALS support services, DMP, nutrition and dysphagia screening, respiratory screening and appropriate intervention, multidisciplinary care plan, and patient care preferences quality measures. Full quality measurement specifications are available online at aan.com/practice/quality-measures/.

Four quality measures were retired (ALS cognitive and behavioral impairment screening, ALS symptomatic therapy treatment offered, ALS communication support referral, and ALS falls querying) in favor of incorporating them under the multidisciplinary care plan to limit quality measurement burden. These quality measures are all important in the comprehensive care of the patients with ALS, but the work group felt that an emphasis on fewer, high-impact, evidence-based quality measures would drive more improvements in care. The 2 original respiratory quality measures were combined into a new quality measure (respiratory screening and appropriate intervention) with updates in both screening recommendations and indications for referral for intervention. The dysphagia, weight loss, and malnutrition quality measure was combined with the ALS nutritional support offered into a new nutrition and dysphagia screening quality measure with updated screening recommendations. ALS support services was added as a new quality measure. Disease-modifying pharmacotherapy was updated to incorporate the latest evidence and ensure that all Food and Drug Administration (FDA)-approved therapies are incorporated in the discussion to keep apace of this evolving field. The end-of-life planning assistance quality measure was reaffirmed and renamed patient care preferences. The updated quality measures include the following cross-cutting revisions: (1) consistent definition of ALS throughout, incorporating phenotypic variants, and (2) updating screening quality measures to include validated scales and tools.

Acknowledging the rapid movement to adopt telemedicine, all the quality measures have been updated to include telehealth or in-person encounters. Access to the limited number of ALS specialized clinics may involve long-distance travel, which may be a barrier for some patients. Previous studies have demonstrated that telemedicine is generally viewed favorably by patients, care partners, and the multidisciplinary team,[19,20] and outcomes are similar as compared with patients receiving in-person care.[21] Anecdotally, there continues to be a gap in inpatient care of patients with ALS, particularly

Figure Amyotrophic Lateral Sclerosis Quality Measurement Set 2022 Update Process Flow



related to appropriate respiratory screening and intervention, and we have included inpatient encounters (along with office and telehealth encounters) as eligible events for screening for respiratory impairment and appropriate intervention.

A few technical updates were made and harmonized across the quality measures. In the previous quality measurement set, lack of insurance coverage was included as a necessary exclusion for some (multidisciplinary care plan, nutrition screening, and cognitive screening) but not all quality measures. After extensive discussion among the work group members, lack of insurance was removed as a necessary exclusion for any of the quality measures. The work group members felt that insurance status would not preclude discussion of evidence-based recommendations and would prompt clinicians to seek assistance in finding patient support resources, including help in applying for insurance coverage options through Medicaid or Medicare with ALS as a qualifying condition.

ALS Support Services

Studies have found that stress levels among ALS care partners are high, and patients and their care partners have many fears about the future.[9] NIH guidelines support linking patients with ALS and their care partners to ALS supports and resources. Linkage to support groups has been demonstrated to improve outcomes for other diseases,[22] and it is anticipated that similar linkages for patients and care partners with ALS will lead to improved outcomes. Qualitative studies have shown that ALS societies help fill perceived care gaps and serve as an essential supplementary source of information about the disease, available treatments including investigational drugs, and how to navigate the health care system.[23] One study found that a community care coordinator reduced hospitalizations and improved survival for patients with ALS.[24] Care partners for patients with ALS are at risk of significant psychological distress that typically increases over time and is affected by social supports.[25] Previous studies have found that support groups lessened care partner feeling of isolation and empowered them to feel more prepared to care for their relative.[26,27]

Disease-Modifying Pharmacotherapy Discussion

Clinical practice guidelines[12,28-30] and more recent evidence[31,32] support the use of riluzole, and yet it is underprescribed even in specialized clinics, with use ranging from 38% to 86%.[33,34] Additional DMPs have been released and approved by the FDA since the ALS quality measurement set was released. Recent studies also suggest benefit from edaravone and sodium phenylbutyrate/taurursodiol.[5,35-37] This quality measure was updated to incorporate this evidence and ensure that all FDA-approved therapies are incorporated in the discussion given this rapidly evolving field. We anticipate that by tracking discussions regarding DMP, patients will have earlier and increased access to appropriate patient-specific interventions and therapies that can lead to prolonged survival and improved quality of life.

Screening for Malnutrition and Dysphagia and Appropriate Referral

Guidelines support screening for malnutrition and dysphagia symptoms and intervention following positive screening.[12,14,28,38] There is an opportunity to improve the timing and consistency of screening for malnutrition and dysphagia symptoms for patients with ALS.[14,39] By routinely screening for malnutrition and dysphagia symptoms, patients should have earlier and increased access to appropriate specialists to help address specific symptoms. By addressing symptoms earlier, clinicians may provide interventions that will lead to prolonged survival and improved quality of life.[40,41] Screening for malnutrition and dysphagia and

Table ALS Quality Measurement Set 2022 Update

Title	Numerator	Denominator	Required exclusions	Allowable exclusions
ALS support services	Patients or care partners provided information on ALS support services at least once annually	Patients or care partners of patients diagnosed with ALS phenotypes characterized by appropriate *ICD* codes	None	None
DMP discussion with patients with ALS	Patients with whom the clinician discussed DMP (i.e., riluzole, edaravone, or other FDA-approved medication) at least once annually	Patients diagnosed with ALS phenotypes characterized by appropriate *ICD* codes	None	None
Screening for malnutrition and dysphagia and appropriate referral for patients with ALS	Patients who were screened every 3 mo (±30 d) for malnutrition and dysphagia and, if screening result was positive (reporting signs and symptoms of declining nutrition status and/or dysphagia), referral to appropriate specialist documented on date of positive screening	Patients diagnosed with ALS phenotypes characterized by appropriate *ICD* codes	None	The patient declines malnutrition screening or follow-up The patient declines dysphagia screening or follow-up
Screening for respiratory impairment and appropriate intervention for patients with ALS	Patients screened every 3 mo (±30 d) or more frequently as clinically indicated (e.g., rapid progression) for respiratory impairment and cough strength. If the screening result is positive for any of the specified impairments, discussed noninvasive respiratory support (e.g., NIV and assisted cough) with patients or referred them for NIV; the time between the positive screening result and referral/discussion should be 4 wk (±14 d)	Patients diagnosed with ALS phenotypes characterized by appropriate *ICD* codes	Patients using NIV or invasive ventilation prior to the encounter date	The patient declines screening and/or referral for NIV on the date of encounter The patient unable to complete testing on the date of encounter
ALS Multidisciplinary Care Plan Developed or Updated (calculated at every visit)	Patients for whom a multidisciplinary care plan was either developed (if not done previously) or reviewed and/or updated at every visit during the calendar year	All outpatient and telehealth visits for patients with a primary diagnosis of ALS phenotypes characterized by appropriate *ICD* codes	None	The patient/care partner declines the multidisciplinary care plan. Patients identified as not in current need of multidisciplinary care planning with an early, nondebilitating form of ALS (e.g., King's Staging System, Stage 1)
ALS patient care preferences	Patients who were offered assistance in planning for end-of-life issues (e.g., advance directives, invasive ventilation, lawful physician-hastened death, or hospice) or whose existing end-of-life plan was reviewed and updated at least once annually or more frequently as clinically indicated (i.e., rapid progression) Assistance with end-of-life issues is defined as an assessment of patient concerns, desires, and needs relating to end-of-life issues. Based on the patient's disease progression, this may include discussions regarding invasive ventilation, advance directives, lawful physician-hastened death, or hospice.	Patients diagnosed with ALS phenotypes characterized by appropriate *ICD* codes	Admitted to hospice	Annual discussion is not clinically indicated.

Abbreviations: ALS = amyotrophic lateral sclerosis; DMP = disease-modifying pharmacotherapy; FDA = Food and Drug Administration; *ICD* = *International Classification of Diseases*; NIV = noninvasive ventilation.

referral to appropriate specialists were combined into a single quality measure. Suggested validated screening tools for both malnutrition and dysphagia were added. The work group tried to identify brief screening tools completed in 5–10 minutes when possible and decided that the EAT-10 or SwalQoL revised FS could be implemented using a planned visit model to reduce implementation burden on allied health professionals.[42-44]

Screening for Respiratory Impairment and Appropriate Intervention

Although the use of NIV in patients with ALS and respiratory impairment has been shown to improve survival,[45,46] quality of life,[45,46] and cognitive outcomes,[47] the use of NIV remains low.[48,49] In addition, recent guidelines support earlier initiation of NIV at a higher forced vital capacity (FVC) threshold (>65% predicted if asymptomatic or >80% FVC predicted for patients who are symptomatic with dyspnea or orthopnea and for those with nighttime respiratory dysfunction).[12] Patients with impaired cough flow (<270 L/min) or difficulty clearing bronchial secretions should be recommended for cough assist devices.[12] The quality measure has been updated to reflect the growing evidence for early NIV. The workgroup incorporated and expanded positive screening impairments that would support referral for NIV in keeping with the recent recommendations of the American Thoracic Society.[50] Screening for respiratory impairment and referral for noninvasive respiratory support (NIV and cough assist) were combined into a single quality measure. This quality measure is intended to capture the most critical existing gap in identifying respiratory dysfunction and early initiation of NIV and cough assist if it is within the patient's care preferences.[12,50] There is a persistent gap related to comprehensive respiratory care of patients with ALS, including pharmacologic therapies (inhalers and nebulization), devices (high-frequency chest wall oscillations, incentive respiratory training, lung volume recruitment, suction machine, nebulizer, mouthpiece ventilation, etc), and appropriate respiratory therapist, physician, and technical support.[12,51] Although important, at present, the work group felt capturing all these elements would not be feasible in our current quality measure data collection. In addition, there is a significant improvement opportunity related to optimization of NIV following initiation to address comfort, secretions, and other key factors that drive nonadherence.[52] The work group believes that these additional concepts merit further consideration in future updates. Finally, the work group acknowledges the need for more training and expertise (specialized neuromuscular pulmonologists and respiratory therapists) to better address the treatment gaps in this rapidly moving field.[51]

The work group acknowledges the recent guideline recommendations to review and update patient care preferences at significant time points in the patient's illness, including development of respiratory impairment.[13] Important decisions related to respiratory dysfunction include (1) whether to initiate NIV, (2) when to stop NIV in the disease course, (3) whether tracheostomy is within the patient's goals of care, and (4) discussion of potential evolution to locked-in syndrome while on ventilatory support so that patients and families can anticipate each stage and determine their care preferences.[53-55]

Multidisciplinary Care Plan

Multidisciplinary care for patients with ALS has been demonstrated to improve survival and quality of life.[56,57] The original quality measure calls for a neurologist and at least 4 of the following specialists to provide input to the plan: pulmonologist, gastroenterologist, physiatrist, psychiatrist, social worker, occupational therapist, physical therapist, speech-language pathologist, psychologist, respiratory therapist, genetic counselor, palliative care specialist, specialized nurse, dietician, or dentist. In this update, an assistive technologist was added as a clinician to this quality measure given their essential role in supporting functional abilities in patients with ALS, including communication technologies such as voice banking, speech generating devices, gaze control systems, and brain-computer interfaces.[58,59] The work group anticipates that advances in smart home technology and environmental controls will continue to evolve and hopes that further studies will support their role in care for patients with ALS potentially resulting in guideline statements. The work group affirms that cognitive and behavioral impairment in ALS are often underappreciated and can lead to significant care partner burden and affect adherence to the therapy plan.[60] It was felt that screening for cognitive and behavioral impairment best fit under the multidisciplinary care plan, and this quality measure was updated to incorporate several cognitive and behavioral screening tools. The workgroup updated the quality measure frequency to indicate that the multidisciplinary care plan should be developed, reviewed, and/or updated at every visit to reflect the need for reassessment of the care plan at every encounter. Patients with early-stage ALS (Kings Stage I) were added as an allowable exclusion.

Patient Care Preferences

Guidelines continue to stress the importance of end-of-life planning for patients with ALS and their care partners. In 2022, the AANI released a position statement, Clinical Guidance in Neuropalliative Care, that encourages clinicians to engage patients in neuropalliative planning at an early stage, given the poor prognosis and likelihood of difficulty expressing a desire to shift the focus of care as the disease progresses.[e1] The UK NICE guidelines emphasize the importance of eliciting patient care preferences at key points in disease progression (diagnosis, onset of dysphagia, onset of respiratory impairment, etc).[13] We renamed the end-of-life planning quality measures to capture the broader importance of advance care planning at all stages of disease.

Since the end-of-life planning in ALS quality measure was adopted by the CMS in QPP, the quality measure has not been identified as topped out, which CMS defines as little or no room for improvement in scores. The quality measure was also implemented in AANI's Axon Registry®, and review of average performance scores provided by AANI staff indicated a continued gap in care, with average performance ranging from 49%

to 74% in 2018–2020. Recent evidence supports that there is a continued opportunity for improvement.[e2,e3,e4-e7] In addition, we note that there is an ongoing need for research in the most effective, evidence-based communication strategies.[e2]

Lawful physician-hastened death (LPHD) was added as one of the key assistance types.[e7,e8] We note that neurologists can but are not obligated to provide assistance in LPHD.[e9] The frequency of end-of-life discussions was updated in keeping with the other quality measures in this set to at least once annually or more frequently as clinically indicated.

Additional Considerations—Patient and Care Partner Voice

Patient and care partner perspective should be incorporated in the development of quality measures because they are ultimately meant to drive improvement in patient outcomes. The previous ALS quality measurement set emphasized the need for at least annual referrals as needed for communication support, respiratory and nutrition interventions, and end-of-life planning. Many members of the work group felt that this was too infrequent given the pace of disease progression that can vary enormously between patients. Updates are reflected in this set accordingly. For instance, both the respiratory screening with appropriate intervention and the nutrition and dysphagia screening are now recommended every 3 months ±30 days or more frequently as clinically indicated. In updating the timing and frequency, balancing the need for early information while not overwhelming patients, care partners, and families, particularly at diagnosis, was carefully considered as was quality measurement burden on clinicians.[e10,e11]

Two new concepts developed merit further discussion as they were of particular interest to the patient and care partner representatives in the work group. The first, clinical trials (CTs) or expanded access program (EAP) discussion for patients with ALS was felt to be essential in ensuring that patients receive comprehensive information about all available treatments, both clinical and research based, also allowing patients to contribute to advances in research and provide hope.[e11] We note that patients with ALS participating in clinical trials may have prolonged survival, often associated with higher use of DMPs, compared with nonparticipants.[e12-e14] Ultimately, the work group removed this proposed measure from further development following public comment, given insufficient published evidence for its effect on patient outcomes. In future updates of this quality measurement set, this concept should be reassessed for development as evidence evolves.

Second, there was widespread support of a quality measure to promote universal genetic testing to expand opportunities for treatment and research. In the end, the work group removed this measure from consideration following public comment because of insufficient published evidence that this is best practice. The work group continues to support the value of routinely offering genetic testing to all patients with ALS, given the potential to identify a genetic cause for the disease (10%–15% of all patients irrespective of family history), the implications for family members if a genetic cause is identified, and the opportunity that a positive result might enable participation in the growing number of targeted treatment trials for patients with causative variants.[e15-e18] We hope that in future updates, this concept will be reassessed for further development. The work group is aware of one consensus guideline project in process that would be beneficial for future quality measure development.

Ultimately, the work group was unable to find sufficient evidence, which is required by the AANI quality measure development process, linking these to outcomes, including patient-centered outcomes, to support adoption of either quality measure. Additional research in this area is strongly needed.

Conclusion

ALS remains a devastating, incurable disease. Advances in care can nonetheless prolong life expectancy and enhance quality of life for patients and care partners. However, not all patients with ALS receive timely and comprehensive evidence-based care for their disease.

The ALS quality measures were developed using the AANI's evidence-based development process, which has been used to improve care for numerous other neurologic disorders. Implementation of these quality measures has the potential to substantially improve the quality of care for patients with ALS at all levels of health care delivery. Adoption of these quality measures in a wide variety of clinical settings helps to ensure that patients with ALS receive high-quality evidence-based treatment, regardless of where they receive their care. The quality measurement set intends to improve collaboration of care and link patients and care partners with the appropriate support and resources needed to improve quality of life and ease disease burden through their difficult journey.

A clear distinction should always be made between guidelines and quality measures. Guidelines provide robust evidence-based recommendations on providing care to a patient with a particular disease or disorder. Quality measures help to bolster adherence to guidelines by allowing the identification of variation in care delivery and providing a way to benchmark quality improvement efforts to elevate the standard of care. Quality measures are intended to be used by a wide variety of stakeholders, including health care clinicians and private and public payors following adequate testing.

These quality measures will always remain a work in progress. As new evidence comes to light and new medical literature is published, guidelines for ALS care will be updated, and, consequently, quality measures will be updated as well to ensure that the content remains up to date. Quality measures are also retired if future studies and data collection demonstrate that

little to no gap in care exists, even if evidence-based guidelines continue to support that aspect of care because a topped out quality measure cannot be used to improve care. The goal of maintaining meaningful and relevant quality measures is to improve the standard of care and ideally lead to improved lifespan and quality of life for patients with ALS.

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Appendix *(continued)*

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Appendix *(continued)*

Name	Location	Contribution
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