Amyotrophic Lateral Sclerosis (ALS)
Quality Measurement Set 2022 Update

Approved by the ALS Quality Measurement Work Group on April 25, 2022. Approved by the AANI Quality Measure Subcommittee on May 9, 2022. Approved by AANI Quality Committee on May 24, 2022. Approved by AANI Board of Directors on June 16, 2022.

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Amyotrophic Lateral Sclerosis (ALS) Quality Measurement Set 2022 Update

There is opportunity to improve the quality of care provided for patients with ALS and their care partners.[1]

The Centers for Disease Control and Prevention (CDC) National Amyotrophic Lateral Sclerosis (ALS) Registry diagnostic category, epidemiologically definite ALS, defines a set of patients with various ALS phenotypes characterized by a specific validated algorithm to integrate patients coming from administrative datasets (commercial insurance, Medicare Advantage, Medicare, Department of Veteran Affairs, patient web-portal self-report).[2] Prior to the development of this CDC "epidemiologically definite" category, the 1997 Riluzole Advisory[3] and the 1999 and 2009 AAN ALS practice parameters[4,5] used all categories of ALS diagnostic certainty defined by the World Federation of Neurology "El Escorial" criteria for the diagnosis of ALS to include all ALS phenotypes.[6] Recently an international consensus clarified this consolidation of the characteristics of the different ALS phenotypes under the diagnosis of ALS in the Gold Coast Criteria for the diagnosis of ALS.[7]

It is estimated that ALS affects approximately 5.2 people per 100,000 in the United States, and in 2016, there were 16,424 persons identified as having epidemiologically definite ALS.[2,8] The exact number of people in the United States diagnosed with ALS is unknown, but it is estimated that each year doctors diagnosis about 5,000 individuals.[9] In a systematic review of prevalence data for ALS, it was found that worldwide ALS prevalence was 4.42 per 1,000,000 population.[10]

Six measures were drafted to capture and measure clinician process and outcomes for patients with ALS:

ALS Quality Measurement Set – 2022 Update
ALS support services
Disease modifying pharmacotherapy (DMP) discussion with patients with ALS
Screening for malnutrition and dysphagia and appropriate referral for patients with ALS
Screening for respiratory impairment and appropriate intervention for patients with ALS
ALS multidisciplinary care plan developed or updated
ALS patient care preferences

Measure Development Process

In 2020, the American Academy of Neurology Institute (AANI) asked a small group of experts to review the 2013 ALS quality measurement set for currency. The small group recommended an update because of new evidence and medications that affected the 2013 measurement set. The AANI seated an ad hoc ALS quality measure development work group charged with updating appropriate quality improvement measures for patients with ALS.

All work group members are required to disclose relationships with industry and other entities to avoid actual, potential, or perceived conflicts of interest (Appendix A). Seated work group members were instructed to abstain from voting on individual measure concepts if a conflict was present.

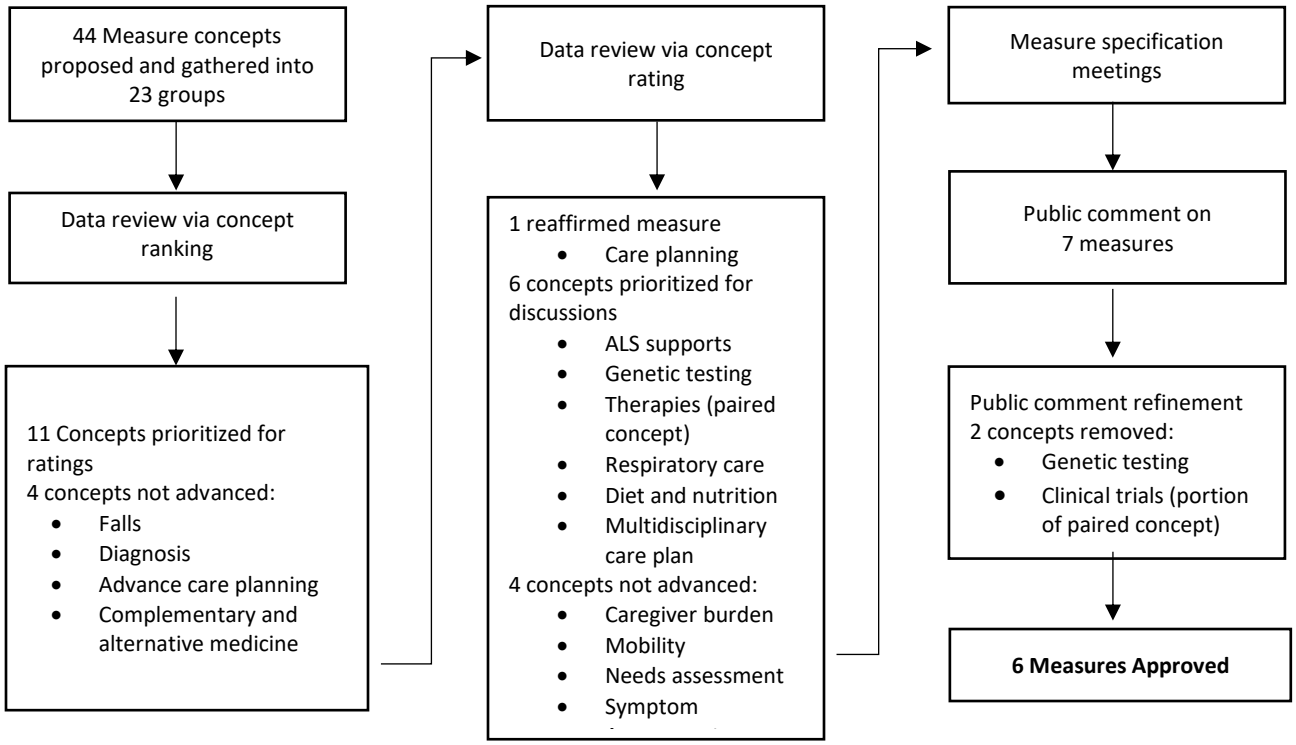
An initial literature search was conducted with the help of a medical librarian and resulted in 925 abstracts identified from EMBASE and MEDLINE. The literature search results were winnowed to 279 articles. These articles included potential guidelines, systematic reviews, meta-analyses, articles containing 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 measure, which is also known as CMS Quality Payment Program (QPP) measure 386.

It is impossible to develop a comprehensive quality measurement set that addresses all the concerns patients with ALS would value. Large measurement sets also pose a challenge for treatment teams to implement and

monitor for quality improvement work. At the start of this update, work groups members were instructed to help winnow draft concepts to focus on measures that were supported by evidence, feasible to implement, and meaningful in practice.

These measures will be reviewed triennially to determine if updates are needed to the measurement set. Full details of the AAN's measure development process are available online.[11] The measures in this set are being made available without any prior testing. The AAN encourages testing of this measurement set for feasibility and reliability by organizations or individuals positioned to do so. **Only following measure testing will measures be eligible for potential submission to Centers for Medicare & Medicaid Services (CMS) for consideration in Quality Payment Program's (QPP) Merit-based Incentive Payment System (MIPS) and the National Quality Forum for possible endorsement.** Prior to any submission, beta testing will need to occur.

The following image summarizes the steps in the measure development process.



Other Measure Concepts

The 2013 ALS Quality Measurement Set was identified for update during the triennial review of evidence.

Amyotrophic Lateral Sclerosis Quality Measurement Set - 2013
ALS multidisciplinary care plan developed or updated
Disease-modifying pharmacotherapy (DMP) for ALS discussed
ALS cognitive and behavioral impairment screening
ALS symptomatic therapy treatment offered
ALS respiratory insufficiency querying and referral for pulmonary function testing
ALS noninvasive ventilation treatment for respiratory insufficiency discussed
ALS screening for dysphagia, weight loss and impaired nutrition
ALS nutritional support offered
ALS communication support referral
ALS end-of-life planning assistance
ALS falls querying

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

1. Patients who were screened for issues with secretions and noninvasive ventilation 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 (SLP) or assistive technology specialist to discuss locked-in syndrome

The 23 concept groupings addressed advance care planning, ALS supports, aspiration, assistive technology, caregiver burden, clinical trials, cognition, communication, diagnosis, diet and nutrition, DMP, exercise, falls, fatigue, foot drop, gait/motor assessment, genetic testing, home safety, multidisciplinary care, respiratory assessment, spasticity, symptom assessment, ventilation monitoring.

The work group ranked these concepts for development using a modified Delphi process to prioritize concepts that were meaningful for quality improvement, supported by evidence, and feasible to collect. After reviewing initial rankings, the work group revised the concepts into 12 groupings for further consideration. During this discussion, work group members agreed to remove the diagnosis concept. The work group members noted feasibility concerns of capturing data 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. Advance care planning and falls measures were removed from consideration as there are existing measures that clinicians may use for patients with ALS. These measures are included in the AANI's comprehensive neurology measurement set.[12] Additionally, there is a cross-cutting quality-of-life outcome measure that may be of interest to clinicians.[13] The work group also noted that guidelines and more research are needed to address functional and integrative nutrition, specialized diets, and supplements, which could be considered for measure concepts in future iterations of this measurement set.

The work group then rated the remaining 12 concepts for feasibility, evidence, and meaningfulness for quality improvement. The 12 concepts moved forward for modified Delphi rating were ALS supports, caregiver burden, clinical trial, diet and nutrition, DMP, genetic testing, mobility, multidisciplinary care, needs assessment, respiratory care, and symptom assessment.

Following review of ratings, the work group did not advance caregiver burden, mobility, needs assessment, and symptom assessment. It was noted that a caregiver burden measure would be difficult to implement given documentation concerns. Information on caregiver burden screens is infrequently documented in a patient chart. Additionally, individual planning would need to occur to best address caregiver burden. For example, a patient and their care partner may benefit more from linkage to physical therapy to learn how to appropriately transfer and avoid injury than from a standard discussion on burnout. It would be difficult to quantify in the way that is meaningful for measurement as a personalized approach needed for patients and there is potential to burden clinicians to change documentation practices for feasibility to collect data. The work group did not develop mobility, needs assessment, or symptom assessment noting these concepts may be addressed through the multidisciplinary care umbrella. These concepts are of high value, but it is impossible to create math equations to address quality of care for all aspects of care. It is important that clinicians are performing standard speech-language pathology assessment, referring patients for speech banking as soon as they are diagnosed, having ongoing mobility, foot drop, and falls assessment in the multidisciplinary or interdisciplinary framework. The work group was charged with identifying and creating quality measures that are feasible to capture, meaningful for quality improvement, and supported by evidence. This is a difficult process, and many concepts could not be developed based on AANI development constraints.

Following the winnowing of concepts, the work group then proceeded to meet virtually to discuss 6 measure concepts:

- Therapies (addressing 2 potential components)
  - DMP
  - Clinical trials (removed following public comment)
- ALS supports
- Dietetic/nutrition care
- Genetic testing (removed following public comment)
- Multidisciplinary care (noting that some concepts not advanced maybe incorporated into this concept)
- Respiratory care—The work group discussed 2 potential concepts. The first focused on early intervention which was advanced for public comment and the second addressed patients who were started on non-invasive ventilation who were screened regularly for secretions, mask/device settings, tolerability and communication concerns. The work group tried to combine both concepts, but the denominator populations were sufficiently different requiring 2 measures, and it was noted that collection of both would pose a large burden on clinicians and practices. The concept may be revisited and developed in a future iteration of this measurement set.

Following the public comment, responses were drafted for individuals who commented, and measures refined as appropriate.

The work group removed the "Genetic testing offered following genetic counseling for patients with ALS" from further development following public comment because of lack of published evidence that this is best practice. Nevertheless, work group members recognize the value of routinely offering genetic testing to all patients with ALS patients, with the potential to identify a genetic cause for disease in 10-15% of all patients (irrespective of the presence of a family history), the potential implications for family members if a genetic cause of disease is identified, and the opportunity that a positive genetic test result would yield for participation in the growing number of observational studies and clinical trials focused on the genetic ALS population.[14-17] It is hoped that in future updates of this measurement set the concept will be reassessed for development as evidence evolves. The work group is aware of 1 consensus guideline project in process that would be beneficial for future measure development.

The work group removed the "Clinical trials (CTs) or expanded access programs (EAPs) discussion for patients with ALS" measure from further development following public comment given lack of published evidence that this is best practice. It is hoped that in future updates of this measurement set the concept will be reassessed for development as evidence evolves.

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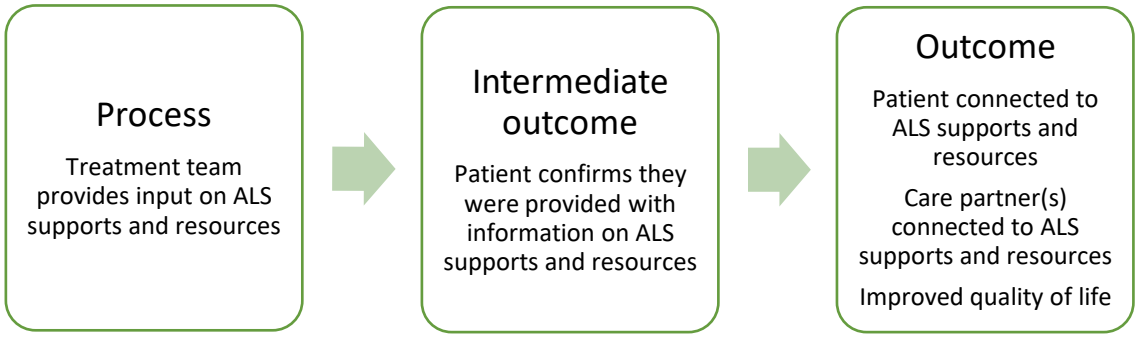
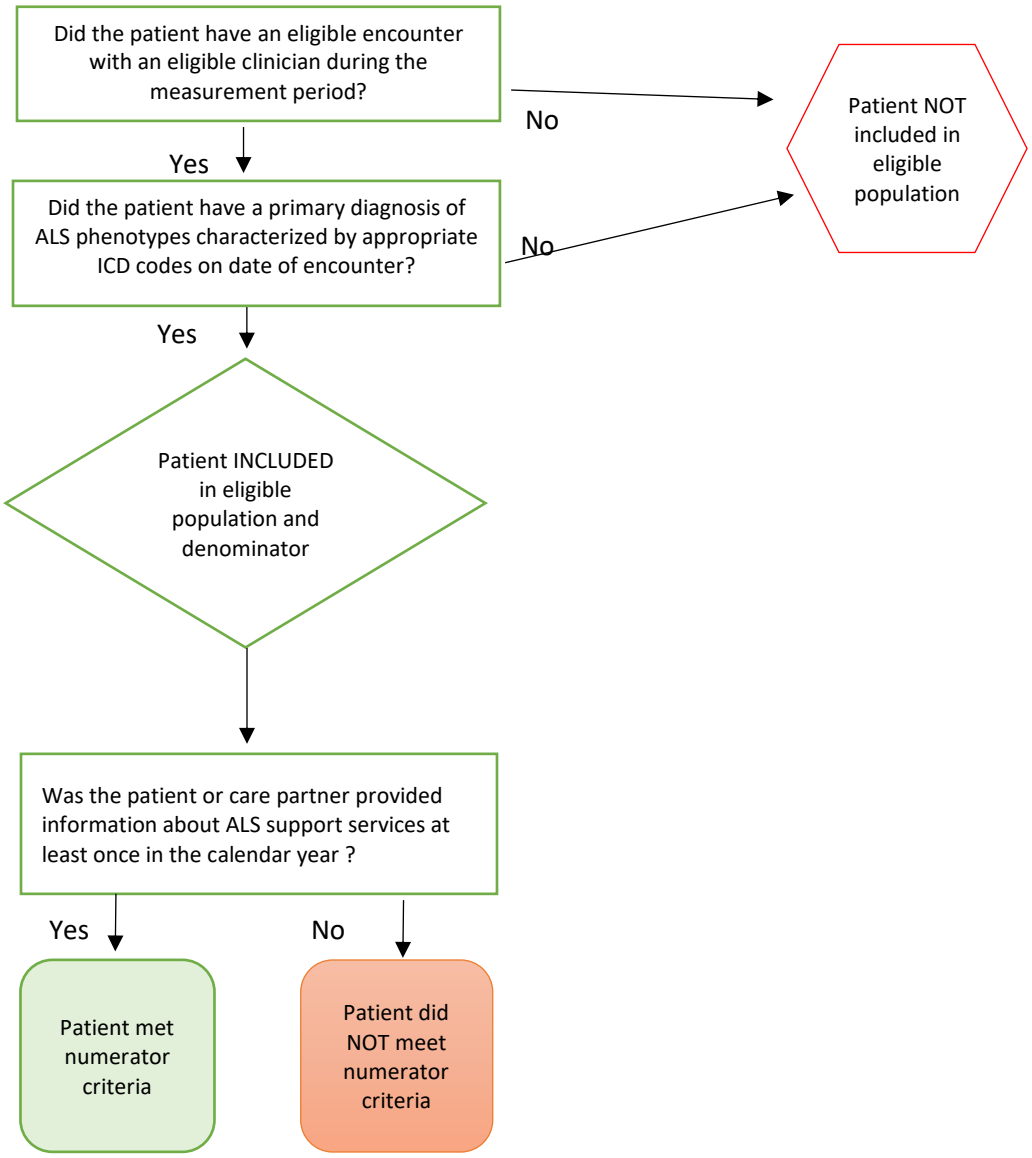
Measure Title	Amyotrophic lateral sclerosis (ALS) support services	
Description	Percentage of patients or care partners of patients diagnosed with ALS provided information about ALS support services at least once annually.	
Measurement Period	January 1, 20xx to December 31, 20xx	
Eligible Population	**Eligible Providers**	Medical doctor (MD), doctor of osteopathy (DO), advanced practice registered nurse (APRN), case manager, clinic coordinator, medical assistant, nurse, physical therapist, physician assistant (PA), occupational therapy practitioner, office assistant, registered dietitian nutritionist, respiratory therapist, speech-language pathologist, social worker
	Care Setting(s)	Outpatient care
	Ages	All
	Event	Office or telehealth encounter
	Diagnosis	ALS phenotypes characterized by appropriate ICD codes
Denominator	Patients or care partners of patients diagnosed with ALS phenotypes characterized by appropriate ICD codes	
Numerator	Patients or care partners provided information on ALS support services[a] at least once annually. NOTE: The following list of resources was developed at time of publication and may not be current. The work group is unable to provide an exhaustive list of supports and resources as this information will evolve over time. Further, treatment team members should individualize support and resource suggestions for each patient. For example, some patients may benefit from linkage to ALS community groups, while others may benefit more from provision of resources about how to effectively care for the patient to the primary care partner. Patients and care partners who do not speak or read English will also require individualized intervention to ensure written materials that meet their needs are provided. For measurement purposes this should occur at least once in the calendar year to ensure individualized resources are meeting patient and care partner needs but may need to occur more often to meet individual needs. The work group has identified the following supports and resources that could be useful: • ALS Association (https://www.als.org/) • I AM ALS (https://iamals.org/) • Your ALS Guide (youralsguide.com) • Les Turner ALS Foundation Education (https://lesturnerals.org/als-decision-tools-guides-and-webinars/) • Team Gleason (http://www.teamgleason.org) • National ALS Registry (https://www.cdc.gov/als/Default.html) • National Institute of Neurological Disorders and Stroke (NINDS) (https://www.ninds.nih.gov/Disorders/All-Disorders/Amyotrophic-Lateral-Sclerosis-ALS-Information-Page) • Muscular Dystrophy Association (https://www.mda.org/disease/amyotrophic-lateral-sclerosis) • International Alliance of ALS/MND Associations (https://www.als-mnd.org) • I AM ALS Signal (www.iamals.org/alssignal) • ALS Therapy Development Institute (https://www.als.net/als-research/als-clinical-trials/)	

	• *Brain & Life* (https://www.brainandlife.org/disorders-a-z/amyotrophic-lateral-sclerosis-als/)
	• Regional resources may include:
	  ○ The Les Turner ALS Foundation (https://lesturnerals.org/)
	  ○ ALS Hope Foundation (https://www.alshf.org/)
	  ○ Compassionate Care ALS (https://ccals.org/)
	  ○ Project ALS (https://projectals.org/)
	  ○ Joan Dancy & PALS Foundation (http://joandancyandpals.org/)
	  ○ ALS Association (https://www.als.org/) - Regional resources may include PALS for Life
	
	[a]ALS supports services is defined as written or electronic material highlighting ALS patient or care partner services, which should be individualized, that is shared physically or digitally with patients or care partners.

Required Exclusions	None
Allowable Exclusions	None
Exclusion Rationale	Not applicable
Measure Scoring	Percentage
Interpretation of Score	Higher score indicates better quality
Measure Type	Process
Level of Measurement	Provider
Risk Adjustment	None
Risk Stratification	Not applicable
Opportunity to Improve Gap in Care	National Institute for Health and Care Excellence guidelines support linking ALS patients and their caregivers to ALS supports and resources.[1] There is an opportunity to improve the linkage for patients and care partners to ALS supports and resources. Resource information is most useful for patients when presented at key points in their disease course, especially shortly after diagnosis. The work group notes that delivery of this information can be overwhelming in a typical clinic visit. Printed materials are helpful to ensure patients and care partners are able to connect with resources after the visit. This information may be delivered by a variety of professionals (see list of eligible providers above), and it is noted that for performance measurement this action may be attributed to the treating clinician through use of a planned visit model or after visit summary.
Relationship to Desired Outcome	Linkage to support groups has been demonstrated to improve outcomes for other disease states and it is anticipated that similar linkages for patients and care partners with ALS will lead to improved outcomes.[2] Cordesse, et al., supports that an established connection to network care can improve outcomes for patients with ALS.[3] Care partners for patients with ALS are known to develop psychological difficulties that increase over time and are affected by social supports.[4] It has been shown in one study[3] that by providing ALS support service resources to patients and care partners, a connection will be made to

	additional social supports and improve quality of life and reduce social isolation and psychological distress. 
Harmonization with Existing Measures	There are no known similar measures.
References	1. National Institute for Health and Care Excellence. (NICE) Motor neurone disease: assessment and management. NICE guideline NG 42. Published: February 24, 2016. Last updated: July 23, 2019. Available at https://www.nice.org.uk/guidance/NG42 Accessed on August 18, 2021. 2. Giri PC, Stevens GJ, Merrill-Henry J, et al. Participation in pulmonary hypertension support group improves patient-reported health quality outcomes: a patient and caregiver survey. Pul Circ. 2021;11(2):20458940211013258. 3. Cordesse V, Sidorok F, Schimmel P, et al. Coordinated care affects hospitalization and prognosis in amyotrophic lateral sclerosis: a cohort study. BMC Health Services Research. 2015;15:134. 4. Goldstein LH, Atkins L, Landau S, et al. Predictors of psychological distress in carers of people with amyotrophic lateral sclerosis: a longitudinal study. Psychological Medicine. 2006; 36:865-875.

ALS support services: Measure flow



ALS support services: 2022 code systems and descriptions

The below code systems and code descriptions were developed by the work group in 2022. This information may evolve over time as Current Procedural Terminology (CPT), International Classification of Diseases, Tenth Revision (ICD-10), and Logical Observation Identifiers Names and Codes (LOINC) codes evolve. Please contact quality@aan.com for the most up to date coding resources for measure implementation.

Code System	Code	Code Description
Denominator		
CPT	92507	Treatment of speech, language, voice, communication, and/or auditory processing disorder
CPT	92522	Evaluation of speech sound production (e.g., articulation, phonological process, apraxia, dysarthria)
CPT	92523	Evaluation of speech sound production (e.g., articulation, phonological process, apraxia, dysarthria); with evaluation of language comprehension and expression (e.g., receptive and expressive language)
CPT	92524	Behavioral and qualitative analysis of voice and resonance
CPT	92526	Treatment of swallowing dysfunction and/or oral function for feeding
CPT	92605	Evaluation for prescription of non-speech-generating augmentative and alternative communication device
CPT	92606	Therapeutic services for the use of non-speech-generating augmentation and alternative communication device
CPT	92607	Evaluation for prescription for speech-generating augmentative and alternative communication device, face-to-face with the patient
CPT	92609	Therapeutic services for the use of speech-generating device
CPT	92610	Evaluation of oral and pharyngeal swallowing function
CPT	97161-97164	Physical Therapy Evaluation
CPT	97165-97168	Occupational Therapy Evaluation
CPT	97802-97804	Medical Nutrition Therapy
CPT	99202-99205	Office or Other Outpatient Visit - New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit - Established Patient (E/M Codes)
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
AND		
ICD-10-CM	G12.21	Amyotrophic lateral sclerosis
ICD-10-CM	G12.22	Progressive bulbar palsy
ICD-10-CM	G12.23	Primary lateral sclerosis
ICD-10-CM	G12.24	Familial motor neuron disease
ICD-10-CM	G12.25	Progressive spinal muscle atrophy
SNOMED	86044005	Amyotrophic lateral sclerosis (disorder)
SNOMED	1201863001	Amyotrophic lateral sclerosis type 1 (disorder)
SNOMED	1201950008	Amyotrophic lateral sclerosis type 3 (disorder
SNOMED	784341001	Amyotrophic lateral sclerosis type 4 (disorder)
SNOMED	1204334005	Amyotrophic lateral sclerosis type 6 (disorder)
SNOMED	1204349002	Amyotrophic lateral sclerosis type 7 (disorder)
SNOMED	1204350002	Amyotrophic lateral sclerosis type 8 (disorder)
SNOMED	1204351003	Amyotrophic lateral sclerosis type 9 (disorder)
SNOMED	1208412003	Amyotrophic lateral sclerosis type 10 (disorder)
SNOMED	54304004	Progressive bulbar palsy (disorder)

SNOMED	230246005	Progressive bulbar palsy of childhood (disorder)
SNOMED	699866005	Progressive bulbar palsy with sensorineural deafness (disorder)
SNOMED	81211007	Primary lateral sclerosis (disorder)
SNOMED	717964007	Juvenile primary lateral sclerosis (disorder)
SNOMED	49793008	Hereditary motor neuron disease (disorder)
Denominator – Required Exclusions		
None		
Denominator – Allowable Exclusions		
None		
Numerator		
SNOMED	734277005	Provision of written information about social support (procedure)
SNOMED	710156000	Promotion of social support (procedure)
SNOMED	315042007	Social support (regime/therapy)
SNOMED	734306004	Discussion about social support (procedure)
SNOMED	386229000	Caregiver support (regime/therapy)
SNOMED	365497005	Finding of neighborhood care support (finding)
SNOMED	726052009	Caregiver focused education and support program (situation)
SNOMED	224475003	Detail of care and support circumstances and networks (observable entity)
SNOMED	702982008	Referral to voluntary support service for caregivers (procedure)

The presence of key phrases in the clinical notes may meet the numerator component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®:

- "Patient provided written information on ALS support services"
- "Care partner provided written information on ALS support services"
- "Patient provided information on ALS Association"
- "Care partner provided information on ALS Association"
- "Patient provided ALS Association information"
- "Care partner provided ALS Association information"
- "Patient provided information on I AM ALS"
- "Care partner provided information on I AM ALS"
- "Patient provided I AM ALS information"
- "Care partner provided I AM ALS information"
- "Patient provided information on Your ALS Guide"
- "Care partner provided information on Your ALS Guide"
- "Patient provided Your ALS Guide information"
- "Care partner provided Your ALS Guide information"
- "Patient provided information on Les Turner"
- "Care partner provided information on Les Turner"
- "Patient provided Les Turner information"
- "Care partner provided Les Turner information"
- "Patient provided information on National ALS Registry"
- "Care partner provided information on National ALS Registry"
- "Patient provided National ALS Registry"
- "Care partner provided information on National ALS Registry"
- "Patient provided information on NINDS ALS"
- "Care partner provided information on NINDS ALS"
- "Patient provided NINDS ALS information"

- “Care partner provided NINDS ALS information”
- “Patient provided information on MDA”
- “Care partner provided information on MDA”
- “Patient provided MDA information”
- “Care partner provided MDA information”
- “Patient provided information on International Alliance of ALS”
- “Care partner provided information on International Alliance of ALS”
- “Patient provided International Alliance of ALS information”
- “Care partner provided International Alliance of ALS information”
- “Patient provided information on Team Gleason”
- “Care partner provided information on Team Gleason”
- “Patient provided Team Gleason information”
- “Care partner provided Team Gleason information”
- “Patient provided information on I AM ALS Signal”
- “Care partner provided information on I AM ALS Signal”
- “Patient provided I AM ALS Signal information”
- “Care partner provided I AM ALS Signal information”
- “Patient provided information on ALS Therapy Development Institute”
- “Care partner provided information on ALS Therapy Development Institute”
- “Patient provided ALS Therapy Development Institute information”
- “Care partner provided ALS Therapy Development Institute information”
- “Patient provided information on Project ALS”
- “Care partner provided information on Project ALS”
- “Patient provided Project ALS information”
- “Care partner provided Project ALS information”
- “Patient provided information on PALS Foundation”
- “Care partner provided information on PALS Foundation”
- “Patient provided PALS Foundation information”
- “Care partner provided PALS Foundation”
- “Patient provided information on PALS for Life”
- “Care partner provided information on PALS for Life”
- “Patient provided PALS for Life information”
- “Care partner provided PALS for Life information”
- “Patient provided information on ALS Hope Foundation”
- “Care partner provided information on ALS Hope Foundation”
- “Patient provided ALS Hope Foundation information”
- “Care partner provided ALS Hope Foundation information”
- “Patient provided information on Compassionate Care ALS”
- “Care partner provided information on Compassionate Care ALS”
- “Patient provided Compassionate Care ALS information”
- “Care partner provided Compassionate Care ALS information”
- "Patient provided written information on regional ALS support services”
- "Care partner provided written information on regional ALS support services”

Disease-Modifying Pharmacotherapy (DMP) Discussion with Patients with Amyotrophic Lateral Sclerosis (ALS)

Measure Titles	Disease-modifying pharmacotherapy (DMP) discussion with patients with amyotrophic lateral sclerosis (ALS)	
Descriptions	Percentage of patients with a diagnosis of ALS with whom the clinician discussed DMP (i.e., riluzole, edaravone, sodium phenylbutyrate/taurursodial, or other medication approved by the Food and Drug Administration [FDA]) at least once annually.	
Measurement Period	January 1, 20xx to December 31, 20xx	
Eligible Population	**Eligible Providers**	Medical doctor (MD), doctor of osteopathy (DO), advanced practice registered nurse (APRN), physician assistant (PA)
	Care Setting(s)	Outpatient care
	Ages	All
	Event	Office or telehealth encounter
	Diagnosis	ALS phenotypes characterized by appropriate ICD codes
Denominator	Patients diagnosed with ALS phenotypes characterized by appropriate ICD codes	
Numerator	Patients with whom the clinician discussed DMP (i.e., riluzole, edaravone, sodium phenylbutyrate/taurursodial, or other FDA-approved medication) at least once annually. NOTE: The list of medication names above is based on clinical guidelines and other evidence at time of publication and may not be current. Medications approved for treatment are rapidly evolving, and clinicians should confirm with the FDA which medications are currently approved for use in patients diagnosed with ALS since the release of this measurement set. Clinicians and health care professionals should also refer to the FDA web site page entitled "Drug Safety Communications" for up-to-date drug recall and alert information when prescribing medications.	
Required Exclusions	None	
Allowable Exclusions	None	
Exclusion Rationale	Not applicable	
Measure Scoring	Percentage	
Interpretation of Score	Higher score indicates better quality	
Measure Type	Process	
Level of Measurement	Provider	
Risk Adjustment	None	
Risk Stratification	Not applicable	
Opportunity to Improve Gap in Care	Multiple DMPs have been approved by the FDA for treatment of ALS, and it is expected that additional DMPs will be developed and approved in the coming years. There remains opportunity to improve access and use of DMPs for patients with ALS. Riluzole use ranges from a low of 38% of ALS patients in Muscular Dystrophy Association ALS Clinics to 63% of participants in the Centers for Disease Control and Prevention ALS Registry with 13% of patients stopping riluzole.[1,2] ALS patients participating in clinical trials entered into the PRO-ACT database have higher use of riluzole at 78%.[3] Edaravone use ranges from 19% in the USA safety database to 27% in a Veterans Affairs database.[4,5] In one	

	clinical trial, edaravone use was 25%.[6] Sodium phenylbutyrate/taurursodiol has been recently approved by the FDA and demonstrated to slow functional decline.[7]
For Process Measures Relationship to Desired Outcome	It is expected 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. Clinical practice guidelines support the use of riluzole.[8-10] Additional DMPs have been released and approved by the FDA since the 2009 American Academy of Neurology practice parameter update was published. Edaravone use is supported through Class I and II studies.[10-16] Patients with ALS participating in clinical trials may have a prolonged survival associated with higher use of DMPs (riluzole 78%, edaravone 25% [Class III evidence])[3,6,17] compared with nonparticipants. 
Harmonization with Existing Measures	There are no known similar measures.
References	1. Muscular Dystrophy Association MOVR data hub (neuroMuscular ObserVational Research) 2018. Highlights of the MDA U.S. Neuromuscular Disease Registry (2013-2016) Available at: https://www.mda.org/sites/default/files/MDA-Registry-Report-Highlights-Digital_9-2018.pdf Accessed on October 19, 2021. 2. Raymond J, Oskarsson B, Mehta P, et al. Clinical characteristics of a large cohort of US participants enrolled in the National Amyotrophic Lateral Sclerosis (ALS) Registry, 2010-2015. Amyotroph Lateral Scler Frontotemporal Degener. 2019;20(5-6):413-420. 3. Atassi N, Berry J, Shui A, et al. The PRO-ACT database: design, initial analyses, and predictive features. Neurology. 2014;83(19):1719-25. 4. Jackson C, Heiman-Patterson T, Kittrell P, et al. Radicava (edaravone) for amyotrophic lateral sclerosis: US experience at 1 year after launch. Amyotroph Lateral Scler Frontotemporal Degener. 2019;20(7-8):605-610. 5. Vu M, Tortorice K, Zacher J, et al. Assessment of Use and Safety of Edaravone for Amyotrophic Lateral Sclerosis in the Veterans Affairs Health Care System. JAMA Netw Open. 2020;3(10):e2014645. 6. Shefner JM, Andrews JA, Genge A, et al. A Phase 2, Double-Blind, Randomized, Dose-Ranging Trial Of Reldesemtiv In Patients With ALS. Amyotroph Lateral Scler Frontotemporal Degener. 2021;22(3-4):287-299. 7. Paganoni S, Macklin EA, Hendriz S et al. Trial of sodium phenylbutarate-taurursodiol for Amyotrophic Lateral Sclerosis. NEJM. 2020; 383:919-930.

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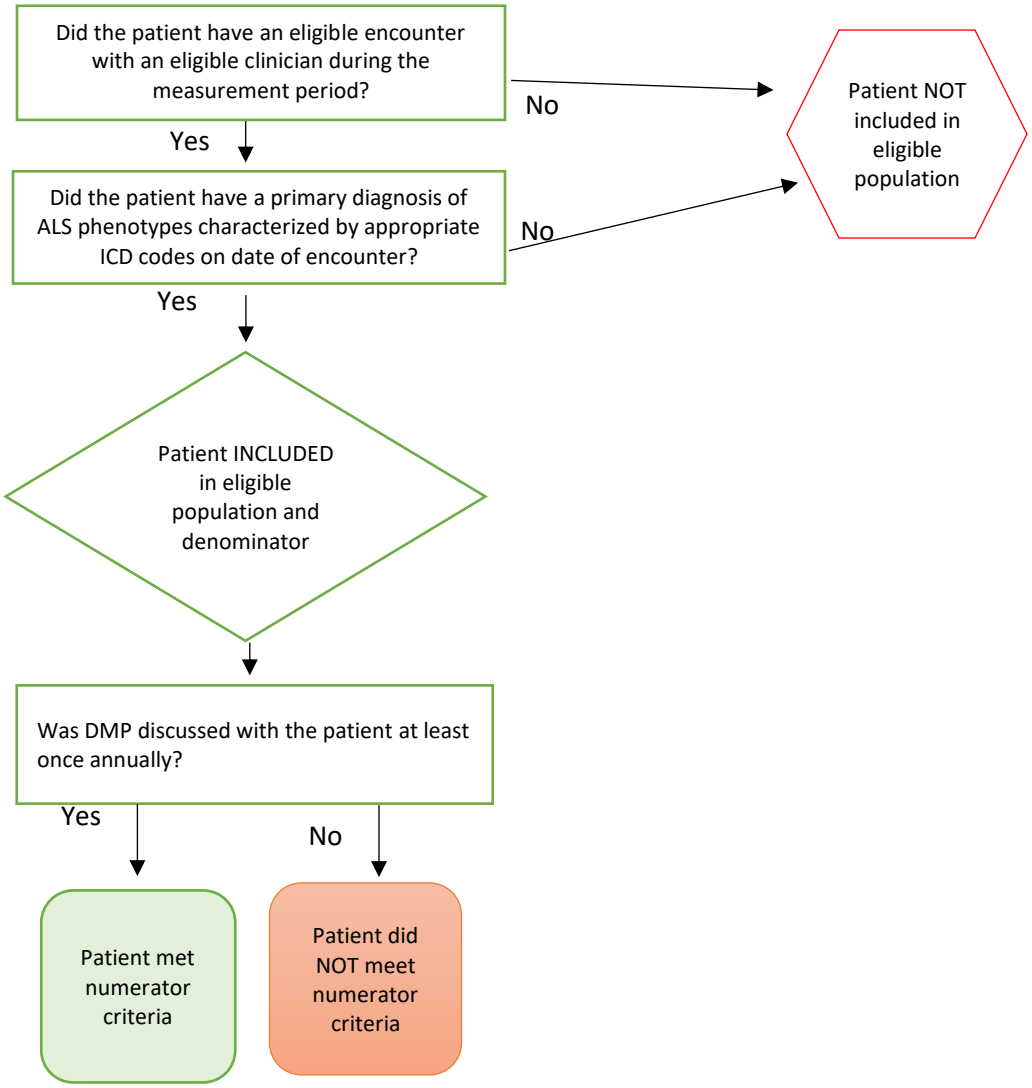
17. Chiò A, Canosa A, Gallo S, et al; PARALS group. ALS clinical trials: do enrolled patients accurately represent the ALS population? Neurology. 2011;77(15):1432-7.

DMP discussion with patients with ALS: Measure flow



DMP discussion with patients with ALS: 2022 code systems and descriptions

The below code systems and code descriptions were developed by the work group in 2022. This information may evolve over time as Current Procedural Terminology (CPT), International Classification of Diseases, Tenth Revision (ICD-10), and Logical Observation Identifiers Names and Codes (LOINC) codes evolve. Please contact quality@aan.com for the most up to date coding resources for measure implementation.

Code System	Code	Code Description
Denominator		
CPT	99201-99205	Office or Other Outpatient Visit - New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit - Established Patient (E/M Codes)
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
AND		
ICD-10-CM	G12.21	Amyotrophic lateral sclerosis
ICD-10-CM	G12.22	Progressive bulbar palsy
ICD-10-CM	G12.23	Primary lateral sclerosis
ICD-10-CM	G12.24	Familial motor neuron disease
ICD-10-CM	G12.25	Progressive spinal muscle atrophy
SNOMED	86044005	Amyotrophic lateral sclerosis (disorder)
SNOMED	1201863001	Amyotrophic lateral sclerosis type 1 (disorder)
SNOMED	1201950008	Amyotrophic lateral sclerosis type 3 (disorder
SNOMED	784341001	Amyotrophic lateral sclerosis type 4 (disorder)
SNOMED	1204334005	Amyotrophic lateral sclerosis type 6 (disorder)
SNOMED	1204349002	Amyotrophic lateral sclerosis type 7 (disorder)
SNOMED	1204350002	Amyotrophic lateral sclerosis type 8 (disorder)
SNOMED	1204351003	Amyotrophic lateral sclerosis type 9 (disorder
SNOMED	1208412003	Amyotrophic lateral sclerosis type 10 (disorder)
SNOMED	54304004	Progressive bulbar palsy (disorder)
SNOMED	230246005	Progressive bulbar palsy of childhood (disorder)
SNOMED	699866005	Progressive bulbar palsy with sensorineural deafness (disorder)
SNOMED	81211007	Primary lateral sclerosis (disorder)
SNOMED	717964007	Juvenile primary lateral sclerosis (disorder)
SNOMED	49793008	Hereditary motor neuron disease (disorder)
Denominator – Required Exclusions		
None		
Denominator – Allowable Exclusions		
None		
Numerator		
SNOMED	395085009	Discussed with patient (situation)
SNOMED	183093006	Had a chat to patient (situation)
CPT II	4540F	Disease modifying pharmacotherapy discussed
CPT II	4540F1	Disease modifying pharmacotherapy discussed
The presence of a new RxNorm code listed below on the date of the visit would signify that a discussion of DMP occurred.		
RXNORM	35623	Riluzole
RXNORM	152915	Riluzole 50 MG Oral Tablet [Rilutek]
RXNORM	368026	Riluzole Oral Tablet [Rilutek]
RXNORM	565105	Riluzole 50 MG [Rilutek]
RXNORM	1184724	Rilutek Oral Product

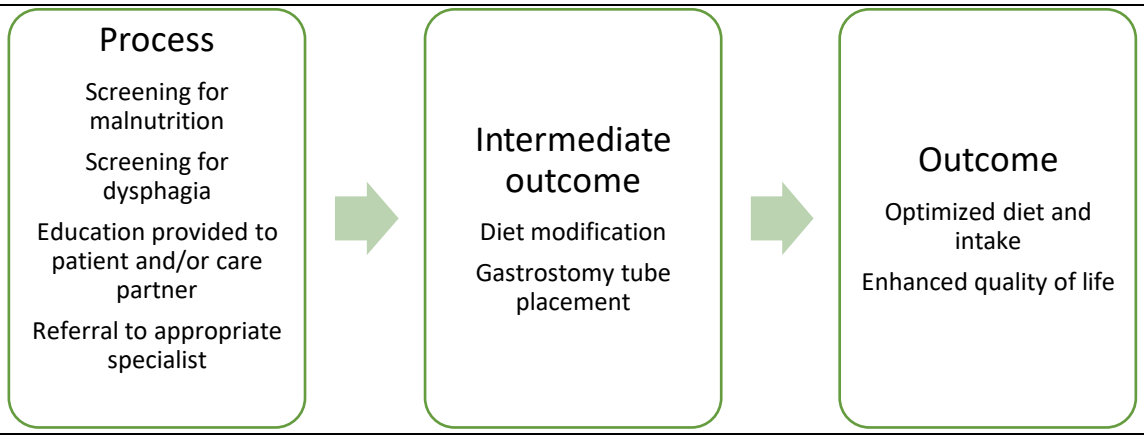
RXNORM	1184725	Rilutek Pill
RXNORM	196501	Rilutek
RXNORM	2059264	Tiglutik Oral Liquid Product
RXNORM	2059265	Tiglutik Oral Product
RXNORM	2059261	Tiglutik
RXNORM	2059262	Riluzole 5 MG/ML [Tiglutik]
RXNORM	2059263	Riluzole Oral Suspension [Tiglutik]
RXNORM	2059266	Riluzole 5 MG/ML Oral Suspension [Tiglutik]
RXNORM	2267567	Exservan
RXNORM	2267568	Riluzole 50 MG [Exservan]
RXNORM	2267572	Riluzole 50 MG Oral Film [Exservan]
RXNORM	2269644	Riluzole Oral Film [Exservan]
RXNORM	2267570	Exservan Oral Product
RXNORM	2269645	Exservan Oral Film Product
RXNORM	1921877	Edaravone
RXNORM	1921883	Edaravone 0.3 MG/ML [Radicava]
RXNORM	1921884	Edaravone Injection [Radicava]
RXNORM	1921882	Radicava
RXNORM	2613974	sodium phenylbutyrate 3000 MG / taurursodiol 1000 MG Powder for Oral Suspension [Relyvrio]

The presence of key phrases in the clinical notes may meet the numerator component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®:

- "Patient DMP options reviewed"
- "Patient DMP changed following discussion"
- "Patient provided DMP counseling"
- "Discussed riluzole during visit"
- "Discussed riluteck during visit"
- "Discussed tiglutik during visit"
- "Discussed exservan during visit"
- "Discussed edaravone during visit"
- "Discussed radicava during visit"
- "Discussed radicut during visit"
- "Discussed albrioza during visit"
- "Discussed relyvrio during visit"
- "Discussed sodium phenylbutyrate/taurursodiol during visit"

Measure Title	Screening for malnutrition and dysphagia and appropriate referral for patients with amyotrophic lateral sclerosis (ALS)	
Description	Percentage of patients with ALS who were screened every 3 months (± 30 days) for malnutrition and dysphagia and, if screening positive (reporting signs and symptoms of declining nutrition status and/or dysphagia), referral to appropriate specialist documented on date of positive screening.	
Measurement Period	January 1, 20xx to December 31, 20xx	
Eligible Population	**Eligible Providers**	Medical doctor (MD), doctor of osteopathy (DO), advanced practice registered nurse (APRN), physical therapist, physician assistant (PA), occupational therapy practitioner, registered dietitian nutritionist (RDN), speech-language pathologist (SLP)
	Care Setting(s)	Outpatient care
	Ages	All
	Event	Office or telehealth encounter
	Diagnosis	ALS phenotypes characterized by appropriate ICD codes
Denominator	Patients diagnosed with ALS phenotypes characterized by appropriate ICD codes	
Numerator	Patients who were screened every 3 months (± 30 days) for malnutrition[a] and dysphagia[b] and, if screening result was positive (reporting signs and symptoms of declining nutrition status and/or dysphagia), referral to appropriate specialist[c] documented on date of positive screening. [a]Malnutrition screening is defined as an assessment that addresses at least 2 components: unintended weight loss, dehydration, temporal wasting, and/or other visual signs of malnutrition OR administering any one of these tools: • Nutrition Risk Score (NRS) (NRS-2002)[1] • Malnutrition Universal Screening Tool (MUST)[1] • Mini-Nutrition Assessment - Short Form (MNA-SF)[1] • Malnutrition Screening Tool (MST)[1] • Simple 2 Part Tool & Malnutrition Screening Tool[1] [b]Dysphagia screening is defined as administering any one of these tools: • Eating Assessment Tool-10 (EAT-10)[2] • ALS Severity Scale – Swallowing Subscale[2] • Neuromuscular Disease Swallow Status Scale (NdSSS)[2] • Oral motor exam (I&I Test)[2] • Iowa Oral Performance Instrument (IOPI)[2] • Center for Neurologic Study Bulbar Function Scale (CNS-BFS)[2] • Yale Swallow Protocol[2] • Revised SwalQoL-FS[2] • Revised ALS Functional Rating Scale (ALSFRS-R) Items 3 & 5[4] [c]Referral to appropriate specialist is defined as referral to specialist as indicated in the current NEALS bulbar dysfunction guideline.[2] Individuals being seen at a multidisciplinary clinic do not need additional referral and meet the numerator.	
Required Exclusions	None	
Allowable Exclusions	• Patient declines malnutrition screening or follow-up • Patient declines dysphagia screening or follow-up	
Exclusion Rationale	Patients need to be willing to complete screening for impairment to be identified and, patients may decline referral due to patient care preferences despite screening positive,	

	which would warrant exclusion from calculation. Patients without insurance may decline screening and referral and would also be appropriate to exclude as a result.
Measure Scoring	Percentage
Interpretation of Score	Higher score indicates better quality
Measure Type	Process
Level of Measurement	Provider
Risk Adjustment	None
Risk Stratification	Not applicable
Opportunity to Improve Gap in Care	Evidence supports an opportunity to improve screening for malnutrition and dysphagia symptoms and improve intervention for patients with concerns identified.[3-7] Patients should be screened by an appropriately trained clinician (e.g. RDN, SLP) or via validated tools for malnutrition and dysphagia as soon as possible; this may occur at initial workup for suspected ALS, at the first visit during which ALS is diagnosed, or at the first feasible visit for patients diagnosed with ALS. These screenings should be conducted at least every 3 months (± 30 days) and may be done more frequently to meet individual patient needs. Any properly trained health professional can use the above-mentioned validated screening tools to conduct the initial screening and refer the patient and care partner to the appropriate professional for education and counseling as indicated.[2,8-10] When defining malnutrition screening, the work group noted that muscle wasting and grip strength are cardinal signs and symptoms of ALS progression and are frequently documented outside of a malnutrition screening. As a result, these terms were excluded from the list of malnutrition screening components intentionally because including it may artificially inflate performance rates. The measure will be monitored for unintended consequences and updates discussed at the next triennial review. Clinicians are encouraged to assess for muscle wasting and grip strength as part of the malnutrition screening. The work group notes there may be a chance of false-positive screening results as an unintended consequence of measurement. False-positive results are preferrable to the alternative of missed opportunities for earlier intervention. 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 physicians.[3,7,11] Use of standardized tools requires rigorous adherence to the methods. Physicians and clinicians should be adept at methods before implementing a quality measure that requires use of a standardized tool. Tools may be subject to copyright and require licensing fee.
For Process Measures Relationship to Desired Outcome	Guidelines support the screening for malnutrition and dysphagia symptoms and intervention following positive screening.[2,8-10] It is expected that by screening early and often for malnutrition and dysphagia symptoms, patients will have earlier and increased access to appropriate specialists to help address patient-specific symptoms. By addressing patient-specific symptoms earlier, increased interventions may be provided that can lead to prolonged survival and improved quality of life.[12-18]

	
Harmonization with Existing Measures	There are no known similar measures.
References	1. Evidence Analysis Library (EAL) of the Academy of Nutrition & Dietetics. Available at: https://www.andeal.org/ Accessed on November 1, 2021. 2. Pattee GL, Plowman EK, Focht Garand KL, et al. Provisional best practices guidelines for the evaluation of bulbar dysfunction in amyotrophic lateral sclerosis. Muscle Nerve. 2019; 59(5):531-536. 3. Romero-Gangonells E, Virgili-Casas MN, et al. Evaluation of Dysphagia in Motor Neuron Disease. Review of Available Diagnostic Tools and New Perspectives. Dysphagia. 2021;36(4):558-573. 4. Cedarbaum JM, Stambler N, Malta E, et al. The ALSFRS-R: a revised ALS functional rating scale that incorporates assessments of respiratory function. BDNF ALS Study Group (Phase III). J Neurol Sci. 1999;169(1-2):13-21. 5. Zhang M, Hubbard J, Rudnicki SA, et al. Survey of current enteral nutrition practices in treatment of amyotrophic lateral sclerosis. ESPEN Journal. 2013;8:e25-e28. 6. Takei K, Tsuda K, Takahashi F, et al. An assessment of treatment guidelines, clinical practices, demographics, and progression of disease among patients with amyotrophic lateral sclerosis in Japan, the United States, and Europe. Amyotroph Lateral Scler Frontotemporal Degener. 2017;18(sup1):88-97. 7. Plowman EK, Tabor L, Robison R, Gaziano, J., et al. Discriminant ability of the Eating Assessment Tool-10 to detect aspiration in individuals with amyotrophic lateral sclerosis. Neurogastroenterolo Motil. 2016; 28(1): 85-90. 8. Miller RG, Jackson CE, Kasarskis EJ, et al. Practice Parameter Update: The care of the patient with amyotrophic lateral sclerosis: Drug, nutritional, and respiratory therapies (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology. Neurology. 2009;73(15):1218-1226 9. Burgos R, Breton I, Cereda E, et al. ESPEN guideline clinical nutrition in neurology. Clinical Nutrition. 2018; 37(2):354-396. 10. Shoesmith C, Abrahao A, Benstead T, et al. Canadian best practice recommendations for the management of amyotrophic lateral sclerosis. CMAJ. 2020;192(46): e1453-e1468. 11. Cheney DM, Siddiqui MT, Litts JK, et al. The Ability of the 10-Item Eating Assessment Tool (EAT-10) to Predict Aspiration Risk in Persons With Dysphagia. Annals of Otology, Rhinology & LaryngologAnn Otol Rhinol Laryngol. 2015;124(5):351-354.

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Other articles of interest

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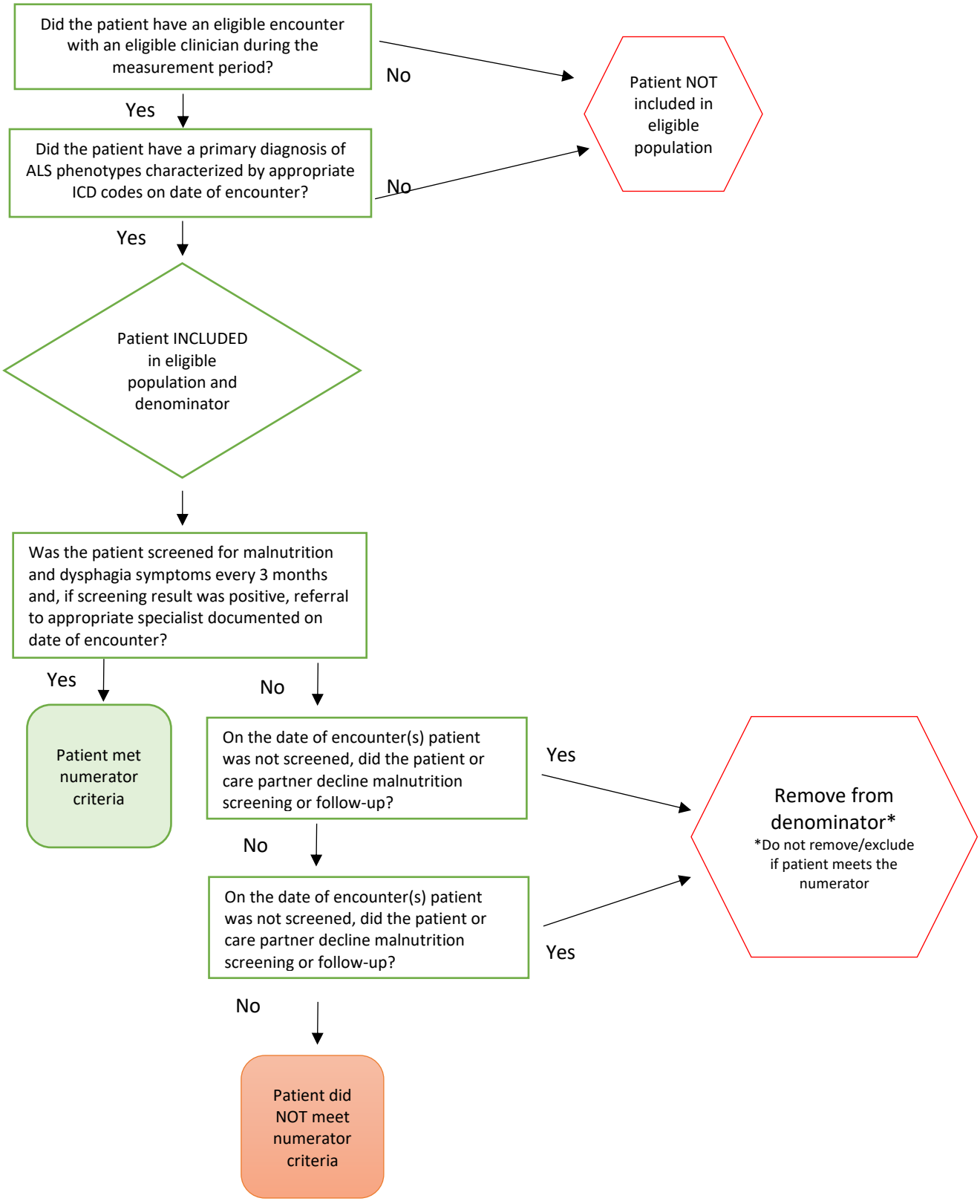
Screening for malnutrition and dysphagia and appropriate referral for patients with ALS: Measure flow



Screening for malnutrition and dysphagia and appropriate referral for patients with ALS: 2022 code systems and descriptions

The following code systems and code descriptions were developed by the work group in 2022. This information may evolve over time as Current Procedural Terminology (CPT), International Classification of Diseases, Tenth Revision (ICD-10), and Logical Observation Identifiers Names and Codes (LOINC) codes evolve. Please contact quality@aan.com for the most up to date coding resources for measure implementation.

Code System	Code	Code Description
Denominator		
CPT	92507	Treatment of speech, language, voice, communication, and/or auditory processing disorder
CPT	92522	Evaluation of speech sound production (e.g., articulation, phonological process, apraxia, dysarthria)
CPT	92523	Evaluation of speech sound production (e.g., articulation, phonological process, apraxia, dysarthria); with evaluation of language comprehension and expression (e.g., receptive and expressive language)
CPT	92524	Behavioral and qualitative analysis of voice and resonance
CPT	92526	Treatment of swallowing dysfunction and/or oral function for feeding
CPT	92605	Evaluation for prescription of non-speech-generating augmentative and alternative communication device
CPT	92606	Therapeutic services for the use of non-speech-generating augmentation and alternative communication device
CPT	92607	Evaluation for prescription for speech-generating augmentative and alternative communication device, face-to-face with the patient
CPT	92609	Therapeutic services for the use of speech-generating device
CPT	92610	Evaluation of oral and pharyngeal swallowing function
CPT	97161-97164	Physical Therapy Evaluation
CPT	97165-97168	Occupational Therapy Evaluation
CPT	97802-97804	Medical Nutrition Therapy
CPT	99201-99205	Office or Other Outpatient Visit - New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit - Established Patient (E/M Codes)
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
AND		
ICD-10-CM	G12.21	Amyotrophic lateral sclerosis
ICD-10-CM	G12.22	Progressive bulbar palsy
ICD-10-CM	G12.23	Primary lateral sclerosis
ICD-10-CM	G12.24	Familial motor neuron disease
ICD-10-CM	G12.25	Progressive spinal muscle atrophy
SNOMED	86044005	Amyotrophic lateral sclerosis (disorder)
SNOMED	1201863001	Amyotrophic lateral sclerosis type 1 (disorder)
SNOMED	1201950008	Amyotrophic lateral sclerosis type 3 (disorder
SNOMED	784341001	Amyotrophic lateral sclerosis type 4 (disorder)
SNOMED	1204334005	Amyotrophic lateral sclerosis type 6 (disorder)
SNOMED	1204349002	Amyotrophic lateral sclerosis type 7 (disorder)
SNOMED	1204350002	Amyotrophic lateral sclerosis type 8 (disorder)
SNOMED	1204351003	Amyotrophic lateral sclerosis type 9 (disorder
SNOMED	1208412003	Amyotrophic lateral sclerosis type 10 (disorder)

SNOMED	54304004	Progressive bulbar palsy (disorder)
SNOMED	230246005	Progressive bulbar palsy of childhood (disorder)
SNOMED	699866005	Progressive bulbar palsy with sensorineural deafness (disorder)
SNOMED	81211007	Primary lateral sclerosis (disorder)
SNOMED	717964007	Juvenile primary lateral sclerosis (disorder)
SNOMED	49793008	Hereditary motor neuron disease (disorder)
Denominator – Required Exclusions		
None		
Denominator – Allowable Exclusions		
SNOMEDCT	443390004	Refused (qualifier value)
SNOMEDCT	440621003	Referral declined by patient (situation)
SNOMEDCT	134385008	Referral to dietician declined (situation)
SNOMEDCT	721107007	Referral to specialist declined (situation)
SNOMEDCT	31021000119100	Screening declined (situation)
SNOMEDCT	21701000175105	Nutrition counseling declined (situation)
The presence of key phrases in the clinical notes may meet the required exclusion component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Patient declines malnutrition screening" • "Patient declines malnutrition discussion" • "Patient declines malnutrition referral" • "Patient declines dysphagia screening" • "Patient declines dysphagia discussion" • "Patient declines dysphagia referral"		
Numerator – Malnutrition screening component		
LOINC	98967-3	Nutritional Risk Screening 2002 panel
SNOMED	895537006	Mini Nutritional Assessment (assessment scale)
SNOMED	310243009	Nutritional assessment (procedure)
SNOMED	414648004	Malnutrition universal screening tool (assessment scale)
SNOMED	444297006	Malnutrition universal screening tool score (observable entity)
SNOMED	443216009	Assessment using malnutrition universal screening tool (procedure)
SNOMED	225388007	Dietary intake assessment (procedure)
SNOMED	1759002	Assessment of nutritional status (procedure)
SNOMED	1149300008	Subjective Global Nutritional Assessment for children (assessment scale)
SNOMED	410170008	Nutrition care assessment (procedure)
SNOMED	391132008	Nutritional assessment completed (situation)
SNOMED	710563008	Assessment of risk for impaired nutritional status (procedure)
The presence of key phrases in the clinical notes may meet the numerator screening component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Screened for malnutrition concerns" • "Nutrition Risk Score completed" • "NRS completed" • "NRS-2002 completed" • "Malnutrition Universal Screening Tool completed" • "MUST completed" • "Mini-Nutrition Assessment - Short Form completed" • "MNA-SF completed"		

- "Malnutrition Screening Tool completed"
- "MST completed"
- "Simple 2 Part Tool & Malnutrition Screening Tool completed"

Numerator – Dysphagia screening component

LOINC	82942-4	Swallowing [ALSFRS-R]
SNOMED	430972007	Screening for dysphagia (situation)
SNOMED	431765005	Screening for dysphagia (procedure)
SNOMED	430972007	Screening for dysphagia performed (situation)
LOINC	82954-9	Amyotrophic lateral sclerosis functional rating scale – revised [ALSFRS-R]
SNOMED	718646004	Amyotrophic lateral sclerosis functional rating scale revised (assessment scale)
SNOMED	718648003	Amyotrophic lateral sclerosis functional rating scale revised score (observable entity)
SNOMED	718645000	Amyotrophic lateral sclerosis functional rating scale revised score (procedure)
SNOMED	717684008	Yale Swallow Protocol (assessment scale)
SNOMED	716854005	Yale Swallow Protocol score (observable entity)
SNOMED	715444007	Assessment using Yale Swallow Protocol (procedure)

The presence of key phrases in the clinical notes may meet the numerator screening component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®:

- "Screened for dysphagia concerns"
- "EAT-10 completed"
- "EAT-10 score is"
- "ALS Severity Scale – Swallowing Subscale completed"
- "Neuromuscular Disease Swallow Status Scale completed"
- "NdSSS completed"
- "Oral motor exam completed"
- "I&I Test completed"
- "Iowa Oral Performance Instrument completed"
- "IOPI completed"
- "Center for Neurologic Study Bulbar Function Scale completed"
- "CNS-BFS completed"
- "Yale Swallow Protocol completed"
- "Revised SwalQoL-FS completed"
- "ALSFRS-R Item 3 & 5 completed"

Numerator – Screening and positive screening component.
Included disorder and diagnosis codes assigned on date of encounter would indicate both a screening occurred, and the findings were positive warranting follow-up care.

ICD-10	R13.10	Dysphagia, unspecified
ICD-10	R13.11	Dysphagia, oral phase
ICD-10	R13.12	Dysphagia, oropharyngeal phase
ICD-10	R13.13	Dysphagia, pharyngeal phase
ICD-10	R13.14	Dysphagia, pharyngoesophageal phase
ICD-10	R13.19	Other Dysphagia
SNOMED	40739000	Dysphagia (disorder)
SNOMED	71457002	Oropharyngeal dysphagia (disorder)
SNOMED	429975007	Oral phase dysphagia (disorder)

SNOMED	21101000119105	Pharyngal dysphagia (disorder)
SNOMED	40890009	Esophageal dysphagia (disorder)
SNOMED	736828006	Able to swallow modified diet (finding)
SNOMED	722875003	Functional dysphagia (disorder)
SNOMED	249486008	Unable to swallow (finding)
SNOMED	399122003	Swallowing problem (finding)
SNOMED	47717004	Abnormal deglutition (finding)
SNOMED	225589000	Chokes when swallowing (finding)
SNOMED	288942001	Unable to swallow food (finding)
The presence of key phrases in the clinical notes may meet the numerator screening component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Screened for dysphagia and malnutrition concerns"		
Numerator – Evidence of a positive screening		
SNOMED	161832001	Weight decreasing (finding)_
SNOMED	47563007	Nutritional deficiency (finding)
SNOMED	445261000124106	Nutrition impaired (finding)
SNOMED	284670008	Nutritionally compromised (finding)
SNOMED	129845004	At risk for imbalanced nutrition, less than body requirements (finding)
SNOMED	102635008	Acute nutritional deficiency (finding)
SNOMED	102636009	Chronic nutritional deficiency (finding)
SNOMED	366364004	Finding of nutritional status (finding)
SNOMED	87276001	Nutritional status (observable entity)
SNOMED	102492002	Failure to maintain weight (finding)
SNOMED	284670008	Nutritionally compromised (finding)
SNOMED	2492009	Nutritional disorder (disorder)
SNOMED	74116004	Nutritional muscular degeneration (disorder)
SNOMED	441971000124107	Chronic disease-related malnutrition (disorder)
SNOMED	34095006	Dehydration (disorder)
SNOMED	450316000	Severe dehydration (disorder)
SNOMED	1611000119108	Mild dehydration (disorder)
SNOMED	88092000	Muscle atrophy (disorder)
SNOMED	281583001	Nutritional wasting (disorder)
SNOMED	26544005	Muscle weakness (finding)
The presence of key phrases in the clinical notes may meet the numerator positive screening component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Malnutrition screening positive" • "Malnutrition deficit identified" • "Malnutrition services needed" • "Dysphagia identified" • "Dysphagia screening positive"		
Numerator – Follow-up component		
SNOMED	307380007	Referral to swallow clinic (procedure)
SNOMED	428461000124101	Referral to nutrition professional (procedure)
SNOMED	306173009	Referral to speech and language therapy service (procedure)
SNOMED	306360000	Referral to community-based speech and language therapist (procedure)
SNOMED	306174003	Referral to community-based speech and language therapy service (procedure)

SNOMED	3457005	Patient referral (procedure)
SNOMED	410270001	Nutritionist education, guidance, and counseling (procedure)
SNOMED	61310001	Nutrition education (procedure)
SNOMED	386373004	Nutrition therapy (regime/therapy)
SNOMED	229912004	Enteral feeding (regime/therapy)
SNOMED	448556005	Oral nutritional support (regime/therapy)
SNOMED	410172000	Nutrition care management (procedure)
SNOMED	386374005	Nutritional monitoring (regime/therapy)
SNOMED	278906000	Nutritional support (regime/therapy)
SNOMED	386372009	Nutrition management (regime/therapy)
SNOMED	278846007	Dietetic procedures (procedure)
SNOMED	895547009	Enteral nutrition intake (observable entity)
SNOMED	410402005	Nutrition surveillance (regime/therapy)
SNOMED	410403000	Nutritionist surveillance (regime/therapy)
SNOMED	709763007	Liaising with nutritionist (procedure)
SNOMED	435591000124104	Nutrition supplement therapy (regime/therapy)
SNOMED	410350005	Nutritionist case management (procedure)
SNOMED	445641000124105	Technical nutrition education (procedure)
SNOMED	413315001	Nutrition/feeding management (regime/therapy)
SNOMED	311569007	Dysphagia therapy regime (regime/therapy)
SNOMED	441041000124100	Counseling about nutrition (procedure)

The presence of key phrases in the clinical notes may meet the numerator follow-up component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®:

- "Care coordinated with multidisciplinary team"
- "Referred to SLP"
- "Evaluated by SLP"
- "SLP referral report received"
- "Referred to Registered Dietitian Nutritionist"
- "Evaluated by Registered Dietitian Nutritionist"
- "Registered Dietitian Nutritionist referral report received"
- "Referred to RDN"
- "Evaluated by RDN"
- "RDN referral report received"
- "Referred to Registered Dietitian Nutritionist"
- "Evaluated by Registered Dietitian Nutritionist"
- "Registered Dietitian Nutritionist referral report received"
- "Referred to dietitian"
- "Evaluated by dietician"
- "Dietician referral report received"

Measure Title	Screening for respiratory impairment and appropriate intervention for patients with amyotrophic lateral sclerosis (ALS)	
Description	Percentage of patients with ALS screened every 3 months (±30 days) or more frequently as clinically indicated for respiratory impairment and cough strength, and if screening result is positive for any impairments, discussed noninvasive respiratory support (e.g., noninvasive ventilation (NIV), assisted cough) with patients or referred for NIV.	
Measurement Period	January 1, 20xx to December 31, 20xx	
Eligible Population	**Eligible Providers**	Medical doctor (MD), doctor of osteopathy (DO), advanced practice registered nurse (APRN), physician assistant (PA), respiratory therapist (RT)
	Care Setting(s)	Outpatient and inpatient care
	Ages	All
	Event	Office or telehealth encounter and inpatient encounter
	Diagnosis	ALS phenotypes characterized by appropriate ICD codes
Denominator	Patients diagnosed with ALS phenotypes characterized by appropriate ICD codes	
Numerator	Patients screened every 3 months (±30 days) or more frequently as clinically indicated[a] (e.g., rapid progression) for respiratory impairment and cough strength. If screening result is positive for any of the specified impairments,[b] discussed noninvasive respiratory support (e.g., NIV, assisted cough) with patients or referred them for NIV.[c] Suggested tools for screening respiratory impairment are the respiratory subscore from the revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R); the ALS respiratory symptom scale;[1,2] pulmonary function testing, including vital capacity (VC) and maximal inspiratory pressure (MIP)/sniff nasal inspiratory pressure (SNIP); and peak cough flow. The work group notes that respiratory subscore alone should not trigger follow-up as there will be patients with a score of 1 who require discussion while others with a higher score would not warrant a discussion. [a]For inpatient care, this should be done once before discharge. [b]Any single criterion is sufficient to initiate NIV[3]: • Symptoms plus a VC < 80% (orthopnea, dyspnea, morning headache, daytime sleepiness, or unrefreshing sleep) • CO_2 measurement o Daytime/awake $PaCO_2 \geq 45$ mm Hg via arterial blood gases o End-tidal carbon dioxide/transcutaneous carbon dioxide ($ETCO_2/TCCO_2$) or venous blood gas $PCO_2 \geq 50$ mm Hg • Sleep-related oxygen saturation from any source, including polysomnography/home sleep test (HST) o ≤ 90% for ≥ 5% of the night o ≤ 88% ≥ 5 min • VC (upright or supine, either forced VC or slow VC) o ≤ 50% predicted • MIP/SNIP is less negative than the following values: o MIP ≤ –60 cm H_2O (equal or worse than) o SNIP ≤ -40 cm H_2O (equal or worse than)	

	[c]Time between positive screening result and referral should be within 4 weeks of encounter (i.e., date of encounter to 42 days postencounter).
Required Exclusions	Patient using noninvasive or invasive ventilation prior to encounter date
Allowable Exclusions	• Patient declines screening and/or referral for NIV on date of encounter • Patient unable to complete testing on date of encounter
Exclusion Rationale	Patients who are already using invasive ventilation would not need ongoing screening to determine appropriateness for NIV. Because this measure is focused on earlier identification of respiratory failure for the purposes of initiating NIV, patients already using noninvasive ventilation are excluded. Patients need to be willing to complete screening for respiratory impairment to be identified, and patients may decline referral for NIV because of patient care preferences, despite receiving a positive screening result for respiratory impairment. Patients without insurance may decline screening and referral, and it would be appropriate to exclude them as a result. There may be some situations where a patient is unable to complete testing such as having cognitive impairment or weak bulbar muscles that prevent adequate seal for pulmonary function testing, and these patients would be appropriate to exclude as a result.
Measure Scoring	Percentage
Interpretation of Score	Higher score indicates better quality
Measure Type	Process
Level of Measurement	Provider
Risk Adjustment	None
Risk Stratification	Not applicable
Opportunity to Improve Gap in Care	The measure has been updated to reflect this most recent evidence. Although use of NIV in patients with ALS and respiratory impairment has been shown to improve survival,[4,5] quality of life,[4,5] and cognitive outcomes,[6] use of NIV remains low.[7,8] This measure aims to highlight this gap. Screening respiratory function every 3 months is recommended by the most recent guidelines,[9] but the screening frequency should be individualized based on the rate of disease progression. Early initiation of NIV has been shown to prolong survival, improve adherence to NIV, and slow the rate of decline in FVC.[10-14] Recent guidelines support broadening the criteria for initiating NIV to include a higher FVC threshold to > 65% predicted if asymptomatic or > 80% FVC predicted for patients who are symptomatic with dyspnea or orthopnea and for those with nighttime respiratory dysfunction.[9] Both sets of guidelines support use of MIP, SNIP, and/or maximal expiratory pressure thresholds for consideration of NIV, and recent studies suggest that these pressure-based measurements may show an earlier steeper decline than FVC.[15,16] Patients with impaired cough flow (< 270L/min) or difficulty clearing bronchial secretions, should be recommended for cough assist devices.[9] This 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 in keeping with recent guidelines.[1,9] There is an ongoing gap related to comprehensive respiratory care of patients with ALS and respiratory impairment, including pharmacologic therapies (inhalers, 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. While important, at present the work group felt capturing all these elements would not be feasible in our current measure data collection.[9,17] The work group noted that recent guidelines also recommend reviewing and updating patient care preferences at significant time points in the patient's illness, including development of respiratory impairment.[18] Important decisions related to respiratory dysfunction include whether to initiate NIV, when to stop NIV in the disease course, whether tracheostomy is within the patient's goals of care, and 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.[19-21]
For Process Measures Relationship to Desired Outcome	Use of NIV has been shown to prolong survival and enhance quality of life.[4,5] 
Harmonization with Existing Measures	This measurement set also includes a multidisciplinary care measure that recommends including a respiratory therapist and pulmonologist as part of the multidisciplinary care team. This measure is complimentary to the multidisciplinary care measure in that screening is recommended as part of the multidisciplinary clinical evaluation, and this measure highlights the need for patients who receive a positive screening result to have a discussion of noninvasive respiratory support (e.g., NIV, assisted cough) or referral for NIV.
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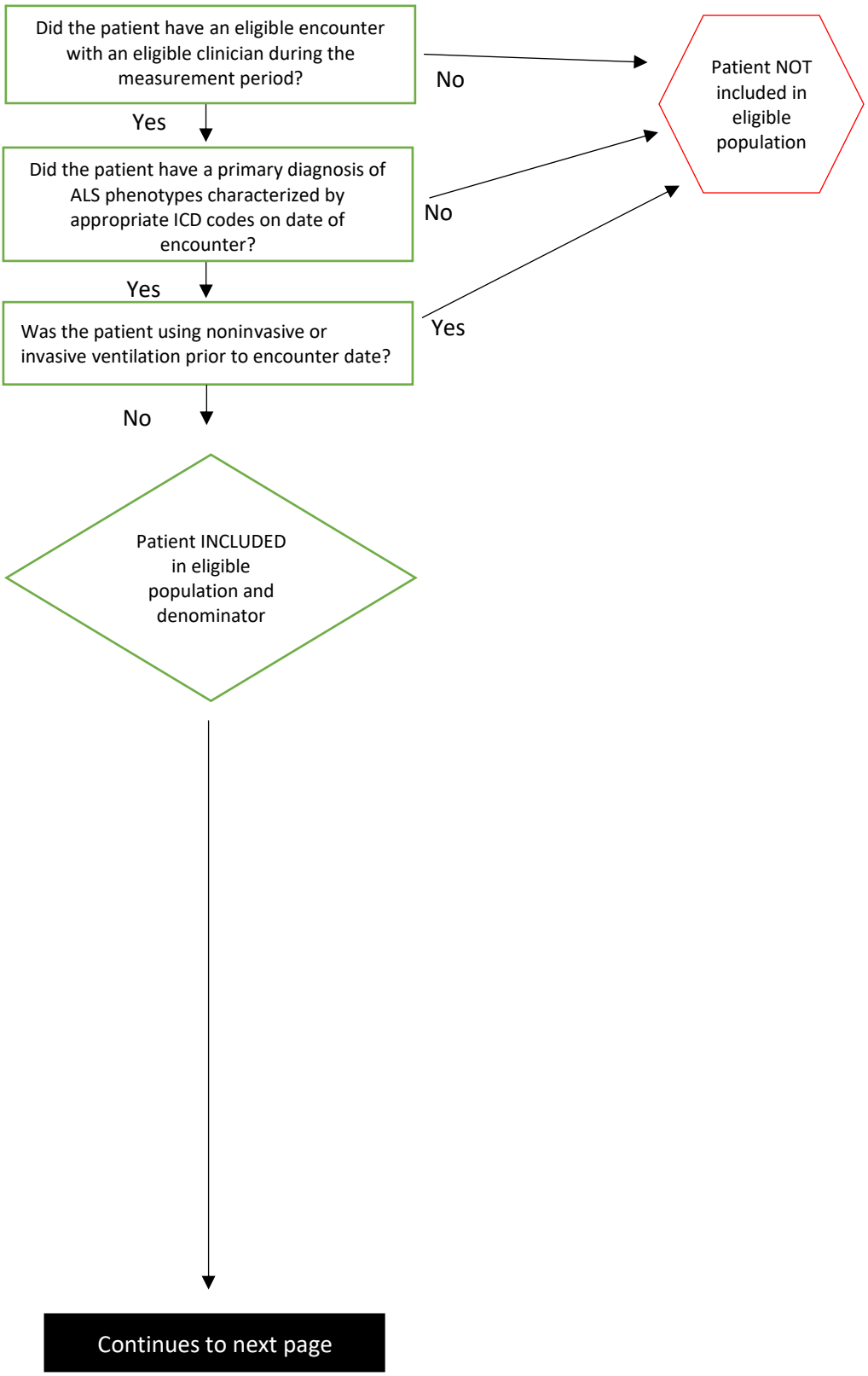
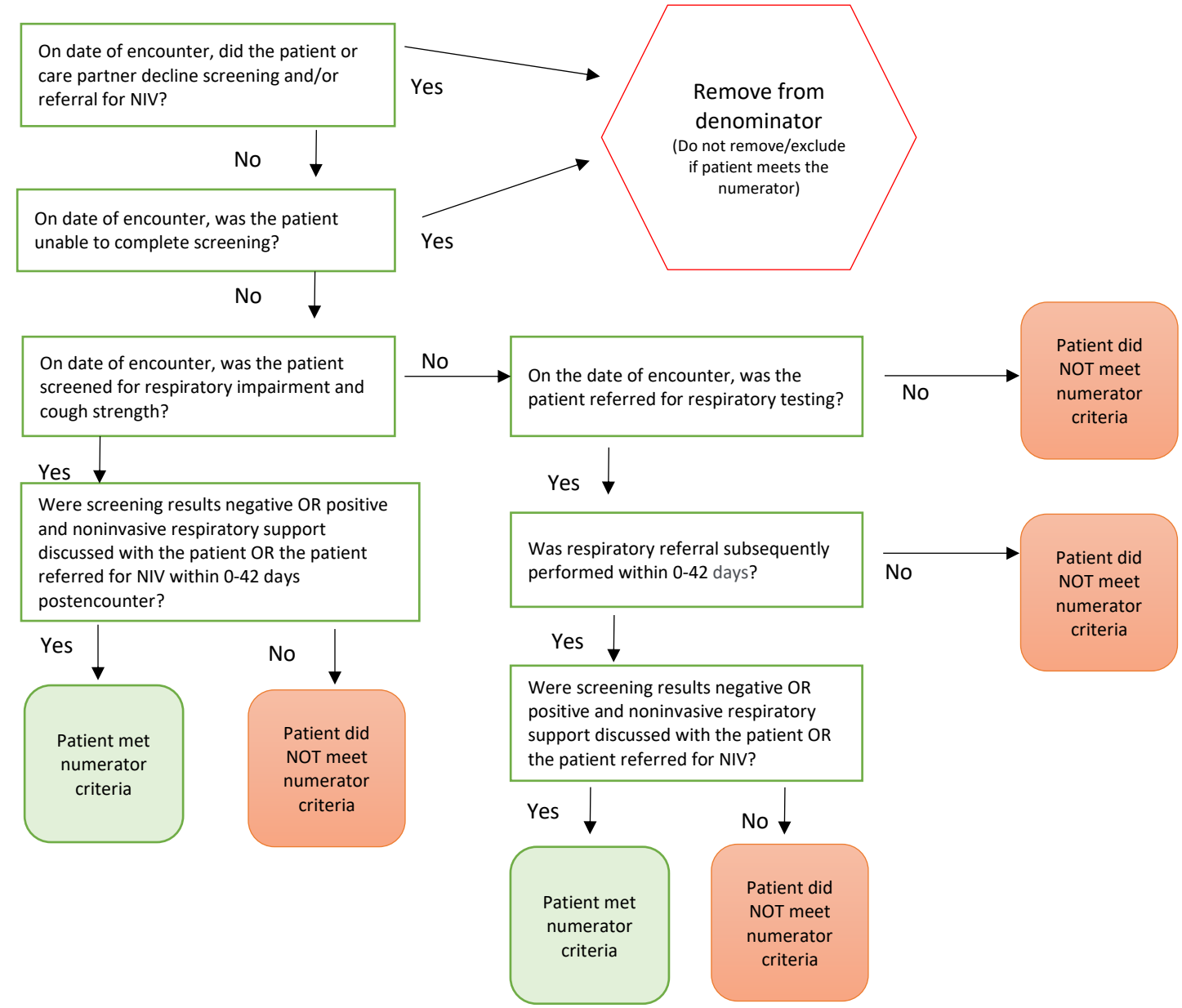
Screening for respiratory impairment and appropriate intervention for patients with ALS: Measure flow



Screening for respiratory impairment and appropriate intervention for patients with ALS: Measure flow (*continued*)



Screening for respiratory impairment and appropriate intervention for patients with ALS: 2022 Code systems and descriptions

The following code systems and code descriptions were developed by the work group in 2022. This information may evolve over time as Current Procedural Terminology (CPT), International Classification of Diseases, Tenth Revision (ICD-10), and Logical Observation Identifiers Names and Codes (LOINC) codes evolve. Please contact quality@aan.com for the most up to date coding resources for measure implementation.

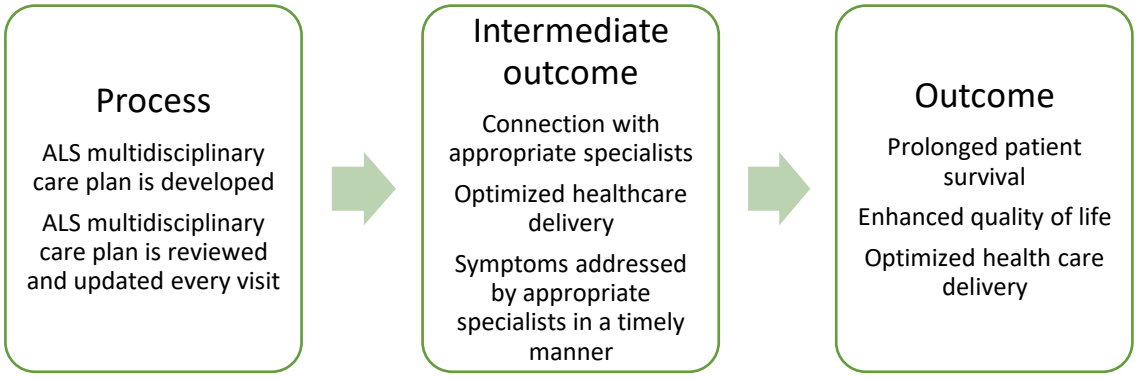
Code System	Code	Code Description
Denominator		
CPT	99091	Collection and interpretation of physiologic data
CPT	94014-94016	Patient-initiated spirometric recording per 30-day period of time
CPT	99453	Remote monitoring of physiologic parameter(s) (e.g., weight, blood pressure, pulse oximetry, respiratory fl ow rate), initial; set-up and patient education on the use of equipment)
CPT	99454	Device(s) supply with daily recording(s) or programmed alert(s) transmission, each 30 days
CPT	99457	Remote physiologic monitoring treatment management services, clinical staff/ physician/ other qualified healthcare professional time in a calendar month requiring interactive communication with the patient/caregiver during the month; initial 20 min
CPT	99458	Remote physiologic monitoring treatment management services, clinical staff/ physician/ other qualified healthcare professional time in a calendar month requiring interactive communication with the patient/caregiver during the month; additional 20 min
CPT	94726-94729	Pulmonary Diagnostic Testing, Rehabilitation, and Therapies
CPT	99202-99205	Office or Other Outpatient Visit - New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit - Established Patient (E/M Codes)
CPT	99221-99223	New or Established Patient Initial Hospital Inpatient Care Services
CPT	99231-99233	Inpatient hospital visits: Initial and subsequent
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
AND		
ICD-10-CM	G12.21	Amyotrophic lateral sclerosis
ICD-10-CM	G12.22	Progressive bulbar palsy
ICD-10-CM	G12.23	Primary lateral sclerosis
ICD-10-CM	G12.24	Familial motor neuron disease
ICD-10-CM	G12.25	Progressive spinal muscle atrophy
SNOMED	86044005	Amyotrophic lateral sclerosis (disorder)
SNOMED	1201863001	Amyotrophic lateral sclerosis type 1 (disorder)
SNOMED	1201950008	Amyotrophic lateral sclerosis type 3 (disorder
SNOMED	784341001	Amyotrophic lateral sclerosis type 4 (disorder)
SNOMED	1204334005	Amyotrophic lateral sclerosis type 6 (disorder)
SNOMED	1204349002	Amyotrophic lateral sclerosis type 7 (disorder)
SNOMED	1204350002	Amyotrophic lateral sclerosis type 8 (disorder)
SNOMED	1204351003	Amyotrophic lateral sclerosis type 9 (disorder
SNOMED	1208412003	Amyotrophic lateral sclerosis type 10 (disorder)

SNOMED	54304004	Progressive bulbar palsy (disorder)
SNOMED	230246005	Progressive bulbar palsy of childhood (disorder)
SNOMED	699866005	Progressive bulbar palsy with sensorineural deafness (disorder)
SNOMED	81211007	Primary lateral sclerosis (disorder)
SNOMED	717964007	Juvenile primary lateral sclerosis (disorder)
SNOMED	49793008	Hereditary motor neuron disease (disorder)
Denominator – Required Exclusions		
ICD 10CM	Z99.11	Dependence on respirator [ventilator] status
ICD 9CM	V46.11	Dependence on respirator, [ventilator] status
SNOMEDCT	430191008	Management of noninvasive mechanical ventilation (procedure)
SNOMEDCT	707765006	On ventilator (qualifier value)
SNOMEDCT	713655003	Dependence on non-invasive ventilation (finding)
SNOMEDCT	105501005	Dependence on enabling machine or device (finding)
SNOMEDCT	706172005	Ventilator (physical object)
SNOMEDCT	449071006	Mechanical ventilator (physical object)
SNOMEDCT	364698001	Ventilator observable (observable entity)
SNOMEDCT	371820004	Patient ventilated (finding)
SNOMEDCT	444932008	Dependence on ventilator (finding)
SNOMEDCT	152921000119101	Dependence on respiratory device (finding)
SNOMEDCT	40617009	Artificial respiration (procedure)
The presence of key phrases in the clinical notes may meet the required exclusion component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Patient using invasive ventilation" • "Patient requires IV"		
Denominator – Allowable Exclusions		
SNOMEDCT	726698006	Referral to respiratory physician declined by subject (situation)
SNOMEDCT	440621003	Referral declined by patient (situation)
SNOMEDCT	736085006	Referral to respiratory clinic declined (situation)
SNOMEDCT	386806002	Impaired cognition (finding)
SNOMEDCT	702956004	Severe cognitive impairment (finding)
SNOMEDCT	721107007	Referral to specialist declined (situation)
The presence of key phrases in the clinical notes may meet the required exclusion component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Patient declines respiratory screening" • "Patient declines NIV discussion" • "Patient declines NIV referral" • "Patient unable to complete respiratory screening" • "Unable to establish seal for screening" • "Patient's cognitive decline prevents respiratory screening"		
Numerator		
HCPCS	1503F	Patient queried about symptoms of respiratory insufficiency
HCPCS	1505F	Patient has respiratory insufficiency
HCPCS	E0600	Respiratory suction pump, home model, portable or stationary, electric
LOINC	82954-9	Amyotrophic lateral sclerosis functional rating scale - revised [ALSFRS-R]
LOINC	82952-3	Respiratory insufficiency
LOINC	82953-1	Total score [ALSFRS-R]

LOINC	81458-2	Pulmonary function test panel
SNOMEDCT	718646004	Amyotrophic Lateral Sclerosis Functional Rating Scale Revised (assessment scale)
SNOMEDCT	718645000	Assessment using Amyotrophic Lateral Sclerosis Functional Rating Scale Revised (procedure)
SNOMEDCT	718648003	Amyotrophic Lateral Sclerosis Functional Rating Scale Revised score (observable entity)
SNOMEDCT	23426006	Measurement of respiratory function (procedure)
SNOMEDCT	76572000	Measurement of lung volume (procedure)
SNOMEDCT	268379003	Vital capacity (observable entity)
SNOMEDCT	871784006	Cough peak expiratory flow measurement (procedure)
SNOMEDCT	448459000	Assessment using chronic respiratory disease questionnaire (procedure)
SNOMEDCT	422834003	Respiratory assessment (procedure)
SNOMEDCT	40617009	Artificial respiration (procedure)
SNOMEDCT	708409001	Home nebulizer therapy (procedure)
SNOMEDCT	428311008	Non-invasive ventilation (regime/therapy)
SNOMEDCT	20573003	Ineffective breathing pattern (finding)
SNOMEDCT	306275005	Referral to respiratory physician (procedure)
The presence of key phrases in the clinical notes may meet the numerator component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Screened for respiratory impairment" • "Discussed NIV"		

Amyotrophic Lateral Sclerosis (ALS) Multidisciplinary Care Plan Developed or Updated
This measure is calculated at every visit

Measure Title	Amyotrophic lateral sclerosis (ALS) multidisciplinary care plan developed or updated	
Description	Percentage of visits with patients who have a primary diagnosis of ALS during which a multidisciplinary care plan[a] was either developed (if not done previously) OR reviewed and/or updated.	
Measurement Period	January 1, 20xx to December 31, 20xx	
Eligible Population	**Eligible Providers**	Medical doctor (MD), doctor of osteopathy (DO), advanced practice registered nurse (APRN), physician assistant (PA)
	Care Setting(s)	Outpatient care
	Ages	All
	Event	Office or telehealth encounter
	Diagnosis	ALS phenotypes characterized by appropriate ICD codes
Denominator	All outpatient and telehealth visits for patients with a primary diagnosis of ALS phenotypes characterized by appropriate ICD codes	
Numerator	Visits during the calendar year during which a multidisciplinary care plan[a] was either developed (if not done previously) OR reviewed and/or updated. [a]A multidisciplinary care plan should address multiple facets of the disease, including respiratory function, nutrition, mobility, falls, mood, cognitive function, and communication. The plan should include input from a neurologist and at least 4 of the following specialists to address manifestations of disease: pulmonologist, gastroenterologist, physiatrist, social worker, occupational therapist, physical therapist, speech-language pathologist, psychologist, psychiatrist, respiratory therapist, genetic counselor, palliative care specialist, specialized nurse, dietitian, assistive technology specialist, or dentist.	
Required Exclusions	None	
Allowable Exclusions	• Patient/caregiver declines multidisciplinary care plan. • Patients identified as not in current need of multidisciplinary care planning with an early, non-debilitating form of ALS (e.g., King's Staging System, Stage 1)	
Exclusion Rationale	Exclusions are needed for patients who decline multidisciplinary care. Patients must be willing to engage in this process for results to be valid. Patients without insurance may decline screening and referral and would be appropriate to exclude as a result. There are patients who might not benefit from multidisciplinary care planning, such as those in the early stages of ALS or who are at a stage of disease that is non-debilitating (e.g., sole symptom of foot drop).	
Measure Scoring	Percentage	
Interpretation of Score	Higher score indicates better quality	
Measure Type	Process	
Level of Measurement	Provider	
Risk Adjustment	None	
Risk Stratification	Not applicable	

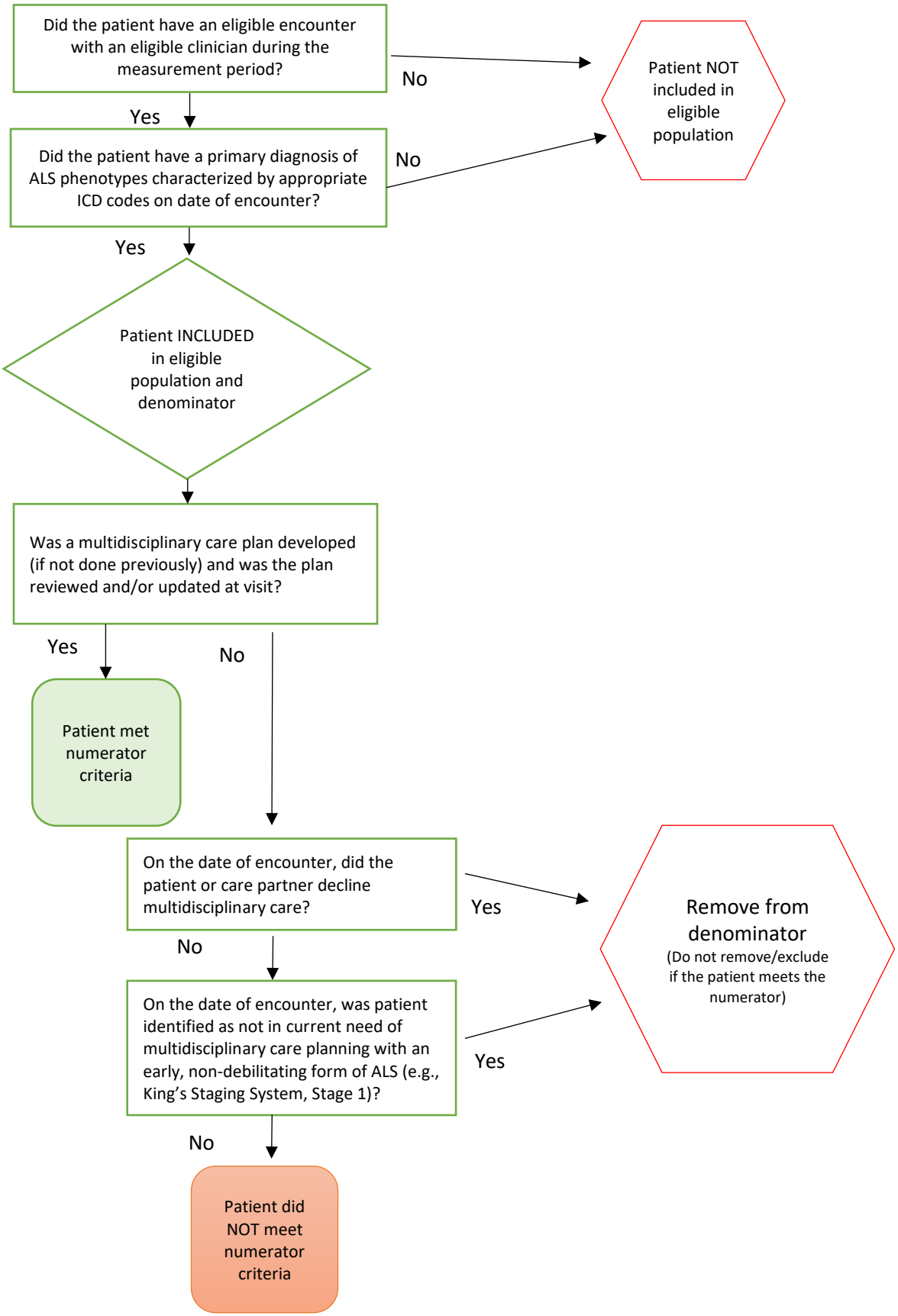
Opportunity to Improve Gap in Care	Treatments for ALS are underused, even in specialized clinics.[1,2] Studies suggest that even in tertiary care centers, there are varying degrees of adherence to the evidence-based parameters.[1-3] Studies show that there is a much higher utilization rate of evidence-based treatments in multidisciplinary clinics than in community-based care.[2,4] Data are especially indicative of underuse of riluzole (60% of patients), percutaneous endoscopic gastrostomy (9%), and noninvasive ventilation (22%), with greatest gains in use occurring in the specialized ALS clinics.[2] Implementation of a multidisciplinary protocol showed less delay in initial assessment by a nutrition specialist and lower percentage of severe malnutrition in ALS patients.[5] These important treatments lengthen life and improve quality of life, but they are neglected by many patients and health care professionals.[1,2] Access to the limited number of ALS specialized clinics may involve long-distance travel which may be a barrier for some patients. Telemedicine might be a solution to this challenge. Selkirk, et al. found that patients seen via telemedicine received the same quality of care and had similar outcomes as patients who had in-person encounters.[6] In a limited study, Schellenberg, et al. found that travel and mobility were cited by patients as a barrier to multidisciplinary care, and some patients expressed interest in telehealth services.[7] A study by Dandaba, et al. found a gap in services for older patients with ALS. These patients had less access and decreased referrals to ALS expert centers.[8] The work group evaluated expanding the eligible visits to include inpatient care but declined to expand measurement focus during this update. Inpatient clinicians are encouraged to conduct a review of treatment plans during admission. The work group also discussed excluding patients admitted to hospice, short-term nursing facilities, and palliative-care services. An exclusion was not developed after discussion because treatment planning review and updates should continue throughout the course of care.
For Process Measures Relationship to Desired Outcome	There is strong guideline support for multidisciplinary care for patients with ALS.[4,9-13] It is expected that by tracking linkage to multidisciplinary care planning and regularly updating the plan that patients will have earlier and increased access to appropriate specialists to help address patient-specific symptoms. By addressing patient-specific symptoms earlier, increased interventions may be provided that can lead to prolonged survival and improved quality of life. 
Harmonization with Existing Measures	This represents an update to the existing AAN 2012 ALS Quality Measure Set Measure #1, "ALS Multidisciplinary care plan developed or updated." There are no known similar measures.

References	1. Bradley WG, Anderson F, Gowda N, Miller RG. Changes in the management of ALS since the publication of the AAN ALS practice parameter 1999. Amyotroph Lateral Scler Other Motor Neuron Disord 2004; 5:240-44. 2. Miller RG, Anderson F, Brooks BR, set al. ALS CARE Study Group. Outcomes research in amyotrophic lateral sclerosis: lessons learned from the amyotrophic lateral sclerosis clinical assessment, research, and education database. Ann Neurol 2009; 65(1):S24-8. 3. Marin B, Beghi E, Vial C, et al. Evaluation of the application of the European guidelines for the diagnosis and clinical care of amyotrophic lateral sclerosis (ALS) patients in six French ALS centres. Eur J Neurol. 2016; 23(4):787-795. 4. Miller RG, Jackson CE, Kasarskis EJ, et al. Practice Parameter update: The care of the patient with amyotrophic lateral sclerosis: Multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology. Neurology. 2009:73(15):1227-1233 5. López-Gómez JJ, Torres-Torres B, Gómez-Hoyos E, et al. Influence of a multidisciplinary protocol on nutritional status at diagnosis in amyotrophic lateral sclerosis. Nutrition. 2018;48:67-72. 6. Selkirk SM, Washington MO, McClellan F, et al. Delivering tertiary centre speciality care to ALS patients via telemedicine: a retrospective cohort analysis. Amyotroph Lateral Scler Frontotemporal Degener. 2017;18(5-6):324-332. 7. Schellenberg, et al. 2018 - Patient perspectives on transitioning to amyotrophic lateral sclerosis multidisciplinary clinics. Interesting patient perspectives of advantages and disadvantages but only 15 patients. Pros reported by patients were convenience, clinical expertise, provider communication, access to research, and advocacy potential. Major barriers cited were travel and mobility, some patients expressed interest in telehealth. 8. Dandaba M, Couratier P, Labrunie A, et al. Characteristics and prognosis of oldest subjects with amyotrophic lateral sclerosis. Neuroepidemiology. 2017;491(1-2):64-73. 9. Andersen PM, Borasio GD, Dengler R, et al. EFNS task force on management of amyotrophic lateral sclerosis: guidelines for diagnosing and clinical care of patients and relatives. European J of Neurology 2005;12:921-938 10. Heffernan C, Jenkinson C, Holmes T, et al. C. Management of respiration in MND/ALS patients: An evidence based review. Amyotrophic Lateral Sclerosis 2006; 7(1):5-15. 11. Tripodoro VA, De Vito EL. Management of dyspnea in advanced motor neuron diseases. Curr Opin Support Palliat Care 2008; 2(3):173-9. 12. National Institute for Health and Care Excellence. (NICE) Motor neurone disease: assessment and management. NICE guideline NG 42. Published: February 24, 2016. Last updated: July 23, 2019. Available at https://www.nice.org.uk/guidance/NG42 Accessed on August 18, 2021. 13. Shoesmith C, Abrahao A, Benstead T, et al. Canadian best practice recommendations for the management of amyotrophic lateral sclerosis. CMAJ. 2020;192(46): e1453-e1468. Other references of interest • Howard I, Potts A. Interprofessional Care for Neuromuscular Disease. Curr Treat Options Neurol. 2019 Jul 1;21(8):35. • de Almeida FEO, do Carmo Santana AK, de Carvalho FO. Multidisciplinary care in Amyotrophic Lateral Sclerosis: a systematic review and meta-analysis. Neurol Sci. 2021 Mar;42(3):911-923.

	• Kasarskis EJ, Elza TA, Bishop NG, Spears AC. The amyotrophic lateral sclerosis (ALS) support network of Kentucky: an informational support group using interactive video. J Neurol Sci. 1997 Oct;152 Suppl 1:S90-2. • Paganoni S, Simmons Z. Telemedicine to innovate amyotrophic lateral sclerosis multidisciplinary care: The time has come. Muscle Nerve. 2019 Jan;59(1):3-5. • Cardoso S, Meneton P, Aimé X, et al. Use of a modular ontology and a semantic annotation tool to describe the care pathway of patients with amyotrophic lateral sclerosis in a coordination network. PLoS One. 2021 Jan 6;16(1):e0244604.

ALS multidisciplinary care plan developed or updated: Measure flow

This measure is calculated at every visit.



ALS multidisciplinary care plan developed or updated: 2022 Code systems and descriptions

The following code systems and code descriptions were developed by the work group in 2022. This information may evolve over time as Current Procedural Terminology (CPT), International Classification of Diseases, Tenth Revision (ICD-10), and Logical Observation Identifiers Names and Codes (LOINC) codes evolve. Please contact quality@aan.com for the most up to date coding resources for measure implementation.

Code System	Code	Code Description
Denominator		
CPT	99201-99205	Office or Other Outpatient Visit - New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit - Established Patient (E/M Codes)
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
AND		
ICD-10-CM	G12.21	Amyotrophic lateral sclerosis
ICD-10-CM	G12.22	Progressive bulbar palsy
ICD-10-CM	G12.23	Primary lateral sclerosis
ICD-10-CM	G12.24	Familial motor neuron disease
ICD-10-CM	G12.25	Progressive spinal muscle atrophy
SNOMED	86044005	Amyotrophic lateral sclerosis (disorder)
SNOMED	1201863001	Amyotrophic lateral sclerosis type 1 (disorder)
SNOMED	1201950008	Amyotrophic lateral sclerosis type 3 (disorder
SNOMED	784341001	Amyotrophic lateral sclerosis type 4 (disorder)
SNOMED	1204334005	Amyotrophic lateral sclerosis type 6 (disorder)
SNOMED	1204349002	Amyotrophic lateral sclerosis type 7 (disorder)
SNOMED	1204350002	Amyotrophic lateral sclerosis type 8 (disorder)
SNOMED	1204351003	Amyotrophic lateral sclerosis type 9 (disorder
SNOMED	1208412003	Amyotrophic lateral sclerosis type 10 (disorder)
SNOMED	54304004	Progressive bulbar palsy (disorder)
SNOMED	230246005	Progressive bulbar palsy of childhood (disorder)
SNOMED	699866005	Progressive bulbar palsy with sensorineural deafness (disorder)
SNOMED	81211007	Primary lateral sclerosis (disorder)
SNOMED	717964007	Juvenile primary lateral sclerosis (disorder)
SNOMED	49793008	Hereditary motor neuron disease (disorder)
Denominator – Required Exclusions		
None		
Denominator – Allowable Exclusions		
SNOMEDCT	443390004	Refused (qualifier value)
SNOMEDCT	408558009	Multidisciplinary team falls assessment declined (situation)
The presence of key phrases in clinical notes may meet the numerator component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Patient declines multidisciplinary care referral" • "Care partner declines multidisciplinary care referral" • "Patient does not have insurance coverage for multidisciplinary care services"		
Numerator		
CPT	0580F	Multidisciplinary care plan developed or updated
SNOMEDCT	708004003	Multidisciplinary review (procedure)
SNOMEDCT	312384001	Multidisciplinary assessment (procedure)

SNOMEDCT	700431008	Multidisciplinary assessment of care needs (procedure)
SNOMEDCT	408423009	Multidisciplinary team falls assessment (procedure)
SNOMEDCT	408555007	Multidisciplinary team falls assessment done (situation)
SNOMEDCT	444804000	Multidisciplinary care conference report (record artifact)
SNOMEDCT	408458006	Specialist multidisciplinary team (qualifier value)
SNOMEDCT	410149002	Professional / ancillary services assessment (procedure)
SNOMEDCT	225971008	Liaising with multidisciplinary team (procedure)
SNOMEDCT	711069006	Coordination of care plan (procedure)
SNOMEDCT	225297008	Care planning and problem-solving actions (procedure)
SNOMEDCT	713126005	Coordination of case conference (procedure)
SNOMEDCT	713108007	Provide status report to multidisciplinary team (procedure)
SNOMEDCT	384682003	Multidisciplinary care conference (procedure)
SNOMEDCT	389064003	Team conference (procedure)

The presence of key phrases in the clinical notes may meet the numerator component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®:

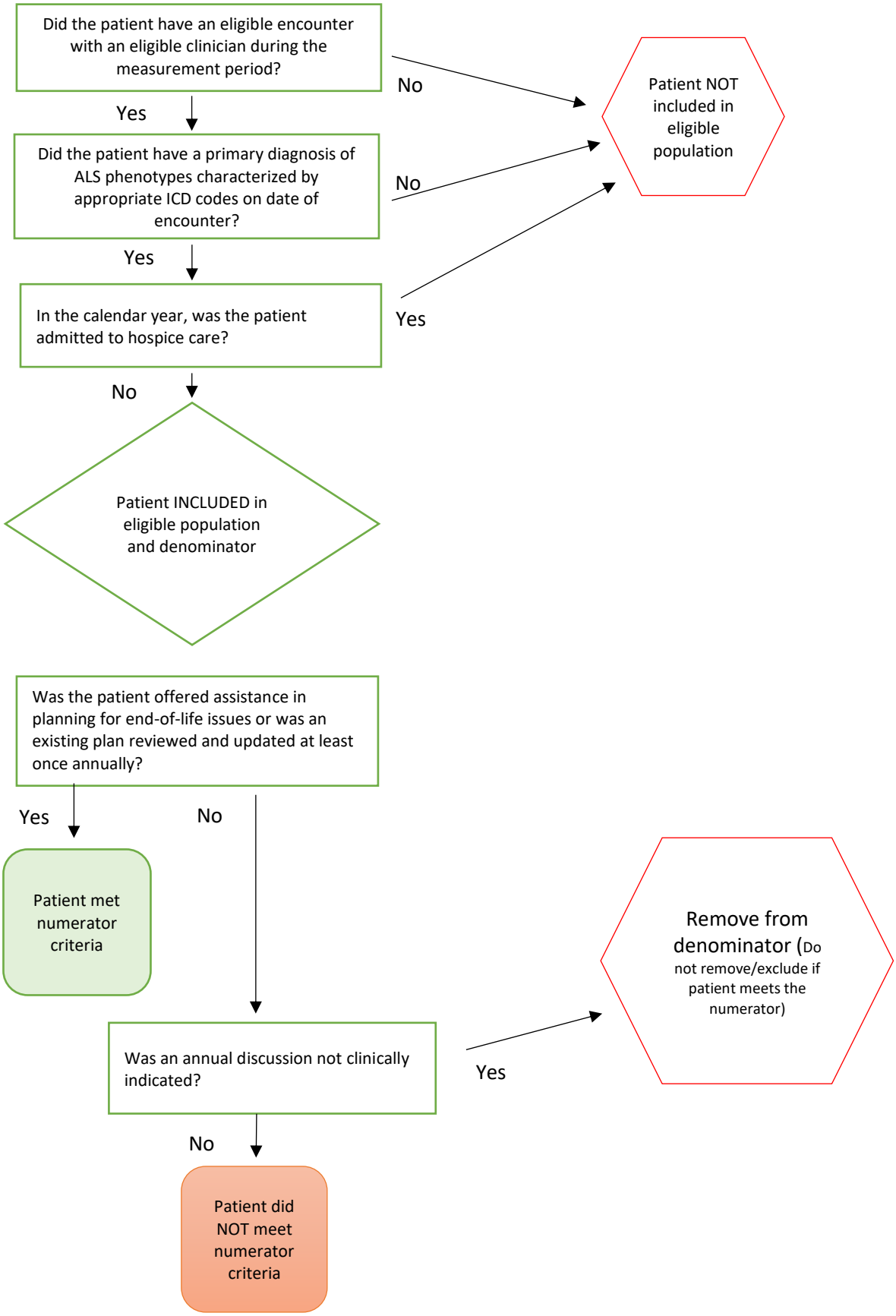
- "Patient multidisciplinary care plan developed"
- "Patient multidisciplinary care plan reviewed"
- "Patient multidisciplinary care plan updated"

Measure Title	Amyotrophic lateral sclerosis (ALS) patient care preferences	
Description	Percentage of patients with ALS 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).	
Measurement Period	January 1, 20xx to December 31, 20xx	
Eligible Population	**Eligible Providers**	Medical doctor (MD), doctor of osteopathy (DO), advanced practice registered nurse (APRN), physician assistant (PA)
	Care Setting(s)	Outpatient care
	Ages	All
	Event	Office or telehealth encounter
	Diagnosis	ALS phenotypes characterized by appropriate ICD codes
Denominator	Patients diagnosed with ALS phenotypes characterized by appropriate ICD codes	
Numerator	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 patient's disease progression, this may include discussions regarding invasive ventilation, advance directives, lawful physician hastened death, or hospice.	
Required Exclusions	Admitted to hospice	
Allowable Exclusions	Annual discussion not clinically indicated	
Exclusion Rationale	Patients admitted to hospice would not require annual assessment of patient care preferences. There are some patients for whom an annual discussion and update of end-of-life care planning is not clinically indicated.	
Measure Scoring	Percentage	
Interpretation of Score	Higher score indicates better quality	
Measure Type	Process	
Level of Measurement	Provider	
Risk Adjustment	None	
Risk Stratification	Not applicable	
Opportunity to Improve Gap in Care	Since it was released in 2013, the quality measure has been adopted by the Centers for Medicare & Medicaid Services in their Quality Payment Program. The measure has not been identified as topped-out. The measure was also implemented in the American Academy of Neurology Institute's (AANI) Axon Registry®, and review of average performance scores indicated a continued gap in care: the 2018 average performance, excluding zero denominator from 8 clinicians, was 53.59%; the 2019 average performance, excluding zero denominator from 149 clinicians, was 48.8%; and the 2020 average	

	performance, excluding zero denominator from 105 clinicians, was 73.92%. Evidence supports there is a continued gap to address for inpatient and outpatient clinicians.[1-5]
For Process Measures Relationship to Desired Outcome	Clinical practice guidelines continue to stress the importance of end-of-life planning for patients with ALS and their care partners, but guidelines for discussions about end-of-life care for patients with ALS have not been published.[1,6,7] In 2022, the AANI released a position statement, Clinical Guidance in Neuropalliative Care, that encourages clinicians to engage 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.[8] 
Harmonization with Existing Measures	There are no known similar measures.
References	1. Genuis SK, Luth W, Campbell S, et al. Communication About End of Life for Patients Living With Amyotrophic Lateral Sclerosis: A Scoping Review of the Empirical Evidence. Front Neurol. 2021;12:683197. Mehta AK, Jackson NJ, Wiedau-Pazos M. Palliative Care Consults in an Inpatient Setting for Patients With Amyotrophic Lateral Sclerosis. Am J Hosp Palliat Care. 2021;38(9):1091-1098. 2. Mehta AK, Jackson NJ, Wiedau-Pazos M. Palliative Care Consults in an Inpatient Setting for Patients With Amyotrophic Lateral Sclerosis. Am J Hosp Palliat Care. 2021;38(9):1091-1098. 3. Hafer J, Jensen S, Wiedau-Pazos M, et al. Assessment of feasibility and utility of universal referral to specialty palliative care in a multidisciplinary amyotrophic lateral sclerosis clinic: A cohort study. Muscle Nerve. 2021;63(6):818-823. 4. Phillips JN, Besbris J, Foster LA, et al. Models of outpatient neuropalliative care for patients with amyotrophic lateral sclerosis. Neurology. 2020:95:782–788. 5. Mehta TR, Bayat E, Govindarajan R. Palliative care in amyotrophic lateral sclerosis clinics: A survey of NEALS consortium membership. Muscle Nerve. 2021;63(5):769-774. 6. National Institute for Health and Care Excellence. (NICE) Motor neurone disease: assessment and management. NICE guideline NG 42. Published: February 24, 2016. Last updated: July 23, 2019. Available at https://www.nice.org.uk/guidance/NG42 Accessed on August 18, 2021. 7. Miller RG, Jackson CE, Kasarskis EJ, et al. Practice Parameter Update: The care of the patient with amyotrophic lateral sclerosis: Drug, nutritional, and respiratory therapies (an evidence-based review): Report of the Quality Standards Subcommittee of the American Academy of Neurology 2009;73(15):1218-1226. 8. Taylor LP, Besbris JM, Graf WD, et al. on behalf of the Ethics, Law, and Humanities Committee. Clinical Guidance in Neuropalliative Care: An AAN Position Statement. Neurology. 2022; 98(10) 409-416.

	Other articles of interest: • Gordon JM, Creutzfeldt CJ. Palliative care, evidence, and ALS: The baby and the bathwater. Neurology. 2020;95(17):765-766. • Sethi A, Everett E, Mehta A, et al. The Role of Specialty Palliative Care for Amyotrophic Lateral Sclerosis. Am J Hosp Palliat Care. 2021 Sep 28:10499091211049386. • Brizzi K, Paganoni S, Zehm A, et al. Integration of a palliative care specialist in an amyotrophic lateral sclerosis clinic: Observations from one center. Muscle Nerve. 2019;60(2):137-140.

ALS patient care preferences: Measure flow



ALS patient care preferences: 2022 code systems and descriptions

The following code systems and code descriptions were developed by the work group in 2022. This information may evolve over time as Current Procedural Terminology (CPT), International Classification of Diseases, Tenth Revision (ICD-10), and Logical Observation Identifiers Names and Codes (LOINC) codes evolve. Please contact quality@aan.com for the most up to date coding resources for measure implementation.

Code System	Code	Code Description
Denominator		
CPT	99202-99205	Office or Other Outpatient Visit - New Patient (E/M Codes)
CPT	99211-99215	Office or Other Outpatient Visit - Established Patient (E/M Codes)
CPT	99241-99245	Office or Other Outpatient Consultation – New or Established Patient
CPT	99421-99423	Online digital evaluation and management service
CPT	99441-00443	Telephone evaluation and management service
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SNOMED	81211007	Primary lateral sclerosis (disorder)
SNOMED	717964007	Juvenile primary lateral sclerosis (disorder)
SNOMED	49793008	Hereditary motor neuron disease (disorder)
Denominator – Required Exclusions		
HCPCS	G9758	Admitted to hospice
HCPCS	G9858	Patient enrolled in hospice
CPT II	G9760, G9761, G9805,G9809,G9819	Patients who use hospice services any time during the measurement period.
CPT II	G9688	Patients using hospice services any time during the measurement period
CPT II	G9690	Patient receiving hospice service any time during the measurement period
CPT II	G9692	Hospice services received by patients any time during the measurement period
CPT II	G9693	Patient use of hospice services any time during the measurement period

CPT II	G9694	Hospice service utilized by patient any time during the measurement period
SNOMEDCT	103735009	Palliative care (regime/therapy)
SNOMEDCT	182964004	Terminal care (regime/therapy)
SNOMEDCT	306676000	Discharge from hospice (procedure)
SNOMEDCT	306681009	Discharge from hospice day hospital (procedure)
SNOMEDCT	170935008	Full care by hospice (finding)
SNOMEDCT	170936009	Shared care - hospice and general practitioner (finding)
SNOMEDCT	183919006	Urgent admission to hospice (procedure)
SNOMEDCT	183920000	Routine admission to hospice (procedure)
SNOMEDCT	183921001	Admission to hospice for respite (procedure)
SNOMEDCT	1891000124102	Transition from acute care to hospice (finding)
SNOMEDCT	1961000124102	Transition from hospice to home-health care (finding)
SNOMEDCT	1971000124109	Transition from hospice to acute care (finding)
SNOMEDCT	1981000124107	Transition from hospice to long-term care (finding)
SNOMEDCT	284546000	Hospice (environment)
SNOMEDCT	305336008	Admission to hospice (procedure)
SNOMEDCT	305911006	Seen in hospice (finding)
SNOMEDCT	441874000	Seen by palliative care service (finding)
SNOMEDCT	444933003	Home hospice service (qualifier value)
LOINC	100018-1	Hospice care Note
LOINC	45755-6	Hospice care [Minimum Data Set]
LOINC	54709-3	Hospice considered appropriate [CARE]
LOINC	55012-9	Hospice care in last 14 days - while not a resident [MDSv3]
LOINC	55013-7	Hospice care in last 14 days - while a resident [MDSv3]
LOINC	85595-7	Will hospice care be provided
SNOMEDCT	373066001	Yes (qualifier value)
The presence of key phrases in clinical notes may meet the required exclusion component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®: • "Patient admitted to dying care" • "Patient admitted to hospice care" • "Patient admitted to palliative care" • "Patient admitted to terminal care" • "Patient discharged home from hospice care"		
Denominator – Allowable Exclusions		
SNOMEDCT	713615000	Advance care planning declined (situation)
SNOMEDCT	716048005	Review of advance care plan declined (situation)
SNOMEDCT	714747005	Discussion about advance care planning declined (situation)
Numerator		
HCPCS	G9380	Patient offered assistance with end of life issues during the measurement period
HCPCS	G9382	Patient not offered assistance with end of life issues during the measurement period
HCPCS	4553F	Patient offered assistance in planning for end of life issues
LOINC	45473-6	Advance directive/living will completed
LOINC	45474-4	Advance directive - do not resuscitate [Minimum Data Set]
LOINC	45475-1	Advance directive - do not hospitalize [Minimum Data Set]
LOINC	45476-9	Advance directive - organ donation [Minimum Data Set]

LOINC	45477-7	Advance directive - autopsy request [Minimum Data Set]
LOINC	45478-5	Advance directive - feeding restrictions [Minimum Data Set]
LOINC	45479-3	Advance directive - medication restrictions [Minimum Data Set]
LOINC	45480-1	Advance directive - other treatment restrictions [Minimum Data Set]
LOINC	45481-9	Advance directive - none [Minimum Data Set]
LOINC	45986-7	Advance directives Set
LOINC	75320-2	Advance directive
LOINC	75787-2	Advance directive - request for intubation
LOINC	75788-0	Advance directive - request for tube feeding
LOINC	75789-8	Advance directive - request for life support
LOINC	75790-6	Advance directive - request for IV fluid and support
LOINC	75791-4	Advance directive - request for antibiotics
LOINC	75792-2	Advance directive - request for resuscitation that differs from cardiopulmonary resuscitation
LOINC	93442-2	Advance directive document format
SNOMEDCT	713580008	Review of advance care plan (procedure)
SNOMEDCT	713600001	Agreement on advance care plan (procedure)
SNOMEDCT	713603004	Advance care planning (procedure)
SNOMEDCT	713604005	Education about advance care planning (procedure)
SNOMEDCT	713662007	Discussion about advance care planning (procedure)
SNOMEDCT	713673000	Has end of life care plan (finding)
SNOMEDCT	714748000	Has advance care plan (finding)
SNOMEDCT	715016002	Advance care planning request by patient (procedure)
SNOMEDCT	736366004	Advance care plan (record artifact)
SNOMEDCT	736373009	End of life care plan (record artifact)
SNOMEDCT	425392003	Active advance directive (finding)
SNOMEDCT	310305009	Active advance directive (copy within chart) (finding)
SNOMEDCT	310302007	Advance directive discussed with patient (finding)
SNOMEDCT	310303002	Advance directive discussed with relative (finding)
SNOMEDCT	425396000	Active advance directive with verification by family (finding)
SNOMEDCT	425394002	Active healthcare will (finding)
SNOMEDCT	425395001	Active living will (finding)
SNOMEDCT	87691000119105	Comfort care only status (finding)
SNOMEDCT	697978002	Provider orders for life-sustaining treatment (record artifact)
SNOMEDCT	365870005	Finding of resuscitation status (finding)
SNOMEDCT	143021000119109	Do not resuscitate status with supporting documentation (finding)
SNOMEDCT	385763009	Hospice care (regime/therapy)
SNOMEDCT	719414000	Referral to hospice at home service (procedure)
SNOMEDCT	734280006	Provision of written information about hospice service (procedure)
SNOMEDCT	363676003	Palliative - procedure intent (qualifier value)
SNOMEDCT	773981004	Palliative care plan (record artifact)
SNOMEDCT	310073009	Palliative care service (qualifier value)
SNOMEDCT	306237005	Referral to palliative care service (procedure)

The presence of key phrases in clinical notes may meet the numerator component for the Axon Registry®. Suggested key phrases for potential use in the Axon Registry® are included below. This list is not exhaustive and will be updated annually if adopted into the Axon Registry®:

- "Advance care directive reviewed"
- "Advance directive assistance and planning"
- "Assistance in end of life planning"
- "Assistance on end of life issues"

- “Assistance on planning for hospice”
- “Has DNI form filled out”
- “Has DNR form filled out”
- “Has MOLST form filled out”
- “Has POLST form filled out”
- “Healthcare power of attorney reported”
- “Palliative care discussed”
- “Advanced directive reviewed”
- “Advance directive reviewed”
- “Advance care plan reviewed”
- “Advanced care plan reviewed”
- “Discussion about Hospice”
- “Palliative care discussed”
- “Provider offered assistance about hospice”
- “Discussion of invasive ventilation”
- “Respiratory support”
- “Terminal dyspnea”

Appendix A

Work Group Member	Disclosures
Michael Benatar, MBChB, MS, DPhil, FAAN, FANA	Dr. Benatar has received personal compensation in the range of $10,000-$49,999 for serving as a Consultant for Biogen. Dr. Benatar has received personal compensation in the range of $500-$4,999 for serving as a Consultant for Jazz Pharmaceuticals. Dr. Benatar has received personal compensation in the range of $500-$4,999 for serving on a Scientific Advisory or Data Safety Monitoring board for AveXis. Dr. Benatar has received personal compensation in the range of $5,000-$9,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Viela Bio. Dr. Benatar has received personal compensation in the range of $5,000-$9,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Immunovant. Dr. Benatar has received personal compensation in the range of $5,000-$9,999 for serving on a Scientific Advisory or Data Safety Monitoring board for SwanBio. Dr. Benatar has received personal compensation in the range of $500-$4,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Denali. Dr. Benatar has received personal compensation in the range of $500-$4,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Alexion. Dr. Benatar has received personal compensation in the range of $5,000-$9,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Roche. Dr. Benatar has received personal compensation in the range of $500-$4,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Alector. Dr. Benatar has received personal compensation in the range of $500-$4,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Sanofi. Dr. Benatar has received personal compensation in the range of $500-$4,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Novartis. The institution of Dr. Benatar has received research support from Orphazyme. Dr. Benatar has received intellectual property interests from a discovery or technology relating to health care. Dr. Benatar has received intellectual property interests from a discovery or technology relating to health care. Dr. Benatar has received intellectual property interests from a discovery or technology relating to health care.
Benjamin R. Brooks, MD	Dr. Brooks has received personal compensation in the range of $500-$4,999 for serving as a Consultant for ITF Pharma. Dr. Brooks has received personal compensation in the range of $500-$4,999 for serving as a Consultant for Mitsubishi Tanabe Pharma America. Dr. Brooks has received personal compensation in the range of $5,000-$9,999 for serving as a Consultant for Medicinova. Dr. Brooks has received personal compensation in the range of $10,000-$49,999 for serving on a Scientific Advisory or Data Safety Monitoring board for Biogen. Dr. Brooks has received personal compensation in the range of $500-$4,999 for serving on a Scientific Advisory or Data Safety Monitoring board for AB Science. Dr. Brooks has received personal compensation in the range of $500-$4,999 for serving on a Speakers Bureau for Mitsubishi Tanabe Pharma America. Dr. Brooks has received personal compensation in the range of $5,000-

	$9,999 for serving on a Speakers Bureau for Cytokinetics. The institution of Dr. Brooks has received research support from Orion. Dr. Brooks has received research support from Alexion. The institution of Dr. Brooks has received research support from Mitsubishi TanabePharma America. The institution of Dr. Brooks has received research support from Biohaven. Dr. Brooks has received personal compensation in the range of $0-$499 for serving as a Member Annual Surveillance Committee CDC National ALS Registry with Center for Disease Control Agency Toxic Substances Disease Registry. Dr. Brooks has a non-compensated relationship as a Member ALS Quality Measures Subcommittee with American Academy of Neurology that is relevant to AAN interests or activities.
Alisa Brownlee, ATP, CAPS, CLIPP, WSP	Ms. Brownlee has received personal compensation for serving as an employee of RESNA.
Tracie Caller, MD, MPH, FAAN Non-voting facilitator	Dr. Caller has nothing to disclose.
Rohit Das, MD, FAAN Non-voting facilitator	Dr. Das has received personal compensation in the range of $5,000-$9,999 for serving as an Expert Witness for janicek. The institution of an immediate family member of Dr. Das has received research support from NIH.
Nancy Giles Walters, MMSc, RDN, LDN, FAND	Ms. Walters has nothing to disclose.
Herman Green	Mr. Green has nothing to disclose.
Phil Green	Mr. Green has nothing to disclose.
Sherry Kolodziejczak, MS, OTR/L	Ms. Kolodziejczak has nothing to disclose.
Kathryn Kvam, MD	Dr. Kvam has nothing to disclose.
John Russo	Mr. Russo has nothing to disclose.
Danica Sanders, RN, BSN	Ms. Sanders has nothing to disclose.
Nadia Sethi, DDS	Dr. Sethi has received personal compensation for serving as an employee of ALS TDI. Dr. Sethi has received personal compensation in the range of $500-$4,999 for serving as a Consultant for Cytokinetics. Dr. Sethi has received personal compensation in the range of $500-$4,999 for serving as a Consultant for IONIS Pharmaceuticals. Dr. Sethi has received personal compensation in the range of $500-$4,999 for serving as a Consultant for Biogen. Dr. Sethi has received personal compensation in the range of $500-$4,999 for serving as a Consultant for Merck.
Kara Stavros, MD	Dr. Stavros has nothing to disclose.
Julie Stierwalt, PhD	The institution of Julie Stierwalt has received research support from NIH. Julie Stierwalt has received publishing royalties from a publication relating to health care. Julie Stierwalt has received publishing royalties from a publication relating to health care.

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