Quality ID #386: Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences

2026 COLLECTION TYPE:
MERIT-BASED INCENTIVE PAYMENT SYSTEM (MIPS) CLINICAL QUALITY MEASURE (CQM)

MEASURE TYPE:
Process – High Priority

DESCRIPTION:
Percentage of patients diagnosed with Amyotrophic Lateral Sclerosis (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 or updated at least once annually or more frequently as clinically indicated (i.e., rapid progression).

INSTRUCTIONS:
Reporting Frequency:
This measure is to be submitted a minimum of once per performance period for denominator eligible cases as defined in the denominator criteria.

Intent and Clinician Applicability:
This measure is intended to reflect the quality of services provided for patients with diagnosed with Amyotrophic Lateral Sclerosis (ALS). This measure may be submitted by Merit-based Incentive Payment System (MIPS) eligible clinicians who perform the quality actions described in the measure based on the services provided and the measure-specific denominator coding. This measure is appropriate for use in outpatient and long-term care (e.g., nursing home, ambulatory). For each of these settings, there should be documentation in the medical record(s) that advance care planning was discussed or documented.

Measure Strata and Performance Rates:
This measure contains one strata defined by a single submission criteria.
This measure produces a single performance rate.

Implementation Considerations:
For the purposes of MIPS implementation, this patient-process measure is submitted a minimum of once per patient during the performance period. The most advantageous quality data code will be used if the measure is submitted more than once.

Telehealth:
TELEHEALTH ELIGIBLE: This measure is appropriate for and applicable to the telehealth setting. Patient encounters conducted via telehealth using encounter code(s) found in the denominator encounter criteria are allowed for this measure. Therefore, if the patient meets all denominator criteria for a telehealth encounter, it would be appropriate to include them in the denominator eligible patient population. Telehealth eligibility is at the measure level for inclusion within the denominator eligible patient population and based on the measure specification definitions which are independent of changes to coding and/or billing practices.

Measure Submission:
The quality data codes listed do not need to be submitted by MIPS eligible clinicians, groups, or third party intermediaries that utilize this collection type for submissions; however, these codes may be submitted for those third party intermediaries that utilize Medicare Part B claims data. The coding provided to identify the measure criteria: Denominator or Numerator, may be an example of coding that could be used to identify patients that meet the intent of this clinical topic. When implementing this measure, please refer to the 'Reference Coding' section to determine if other codes or code languages that meet the intent of the criteria may also be used within the medical record to identify and/or assess patients. For more information regarding Application Programming Interface (API), please refer to the Quality Payment Program (QPP) website.

DENOMINATOR:

All patients with a diagnosis of Amyotrophic Lateral Sclerosis (ALS).

DENOMINATOR NOTE:
**Signifies that this CPT Category I code is a non-covered service under the Medicare Part B Physician Fee Schedule (PFS). These non-covered services should be counted in the denominator population for MIPS CQMs.*

Denominator Criteria (Eligible Cases):
Diagnosis for Amyotrophic Lateral Sclerosis (ICD-10-CM): G12.21, G12.22, G12.23, G12.24, G12.25
AND
Patient encounter during the performance period (CPT): 92521, 92522, 92523, 92524, 92597, 92605, 92607, 92610, 92611, 92612, 92616, 96105, 96125, 98000, 98001, 98002, 98003, 98004, 98005, 98006, 98007, 98008, 98009, 98010, 98011, 98012, 98013, 98014, 98015, 99202, 99203, 99204, 99205, 99211, 99212, 99213, 99214, 99215, 99242*, 99243*, 99244*, 99245*, 99304, 99305, 99306, 99307, 99308, 99309, 99310, 99341, 99342, 99344, 99345, 99347, 99348, 99349, 99350, 99421, 99422, 99423, 99483
AND NOT
DENOMINATOR EXCLUSION:
Patient in hospice at any time during the measurement period: G9758

NUMERATOR:
Patients who were offered assistance in planning for end of life issues or whose existing end of life plan was reviewed or updated at least once annually or more frequently as clinically indicated (i.e., rapid progression).

Definition:
Assistance with end of life issues – 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.

Numerator Options:

Performance Met:	Patient offered assistance with end of life issues or existing end of life plan was reviewed or updated during the measurement period (G9380)
OR	
Performance Not Met:	Patient not offered assistance with end of life issues or existing end of life plan was not reviewed or updated during the measurement period (G9382)

RATIONALE:
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]
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]

CLINICAL RECOMMENDATION STATEMENTS:
- Be prepared to discuss end of life issues whenever people wish to do so.

- Provide support and advice on advance care planning for end of life. Topics to discuss may include:
    - What could happen at the end of life, for example, how death may occur
    - Providing anticipatory medicines in the home
    - Advance care planning, including Advance Decisions to Refuse Treatment (ADRT) and Do Not Attempt Resuscitation (DNACPR) orders, and Lasting Power of Attorney
    - How to ensure advance care plans will be available when needed, for example, including the information on the person's Summary Care Record.
    - When to involve specialist palliative care.
    - Areas that people might wish to plan for, such as:
- What they want to happen (for example, their preferred place of death)
- What they do not want to happen (for example, being admitted to hospital)
- Who will represent their decisions, if necessary
- What should happen if they develop an intercurrent illness.
- Think about discussing advance care planning with people at an earlier opportunity if you expect their communication ability, cognitive status or mental capacity to get worse.
- Offer people the opportunity to talk about, and review any existing ADRT, DNACPR orders and Lasting Power of Attorney when interventions such as gastrostomy and non-invasive ventilation are planned.
- Provide additional support as the end of life approaches, for example, additional social or nursing care to enable informal carers and family to reduce their carer responsibilities and spend time with the person with MND [motor neuron disease].
- Towards the end of life ensure there is prompt access to the following, if not already provided:
    - A method of communication that meets the person's needs, such as an AAC system.
    - Specialist palliative care.
    - Equipment, if needed, such as syringe drivers, suction machines, riser-recliner chair, hospital bed, commode and hoist.
    - Anticipatory medicines, including opioids and benzodiazepines to treat breathlessness, and antimuscarinic medicines to treat problematic saliva and respiratory secretions.

REFERENCES:

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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.

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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.

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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.

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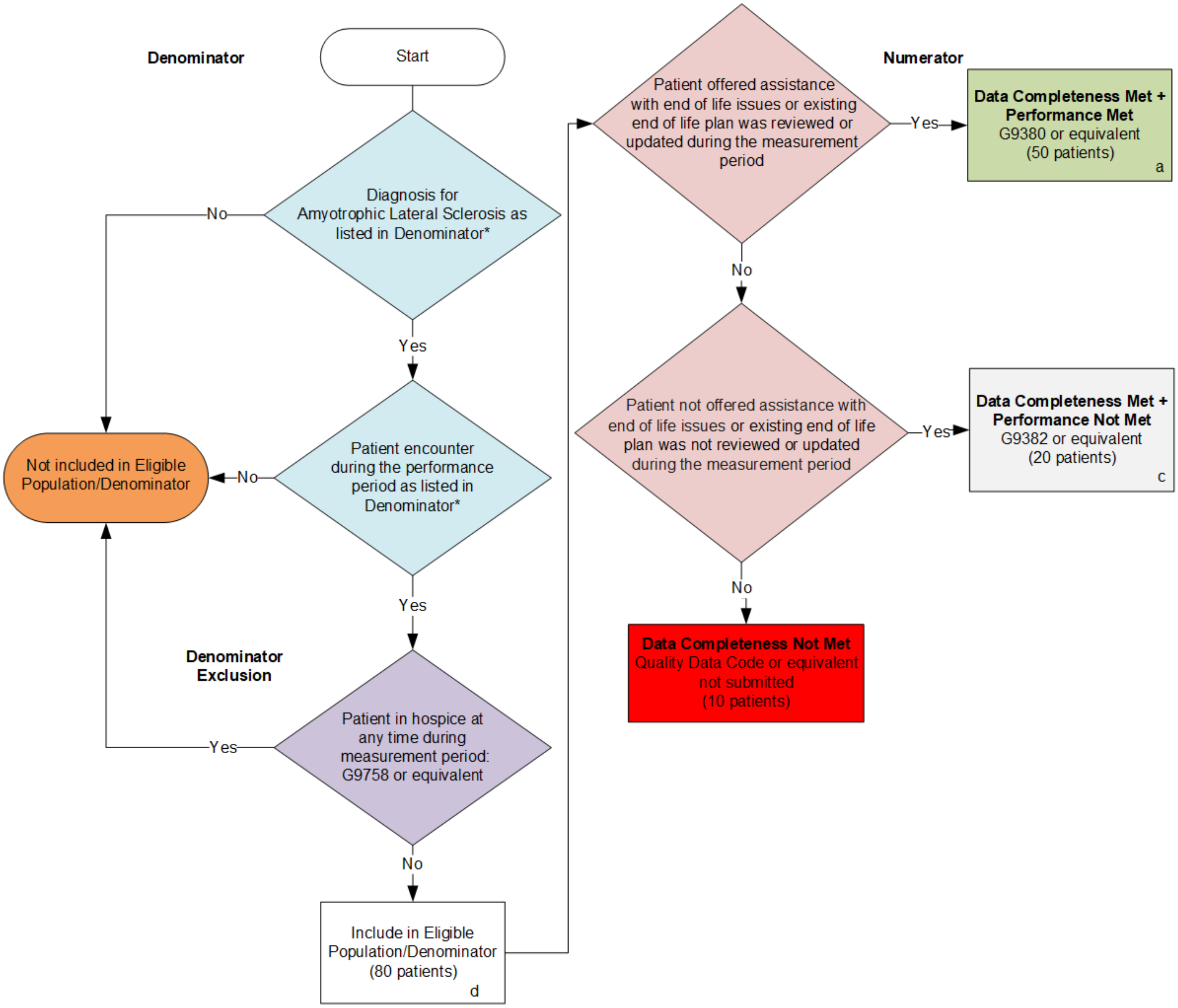
2026 Clinical Quality Measure Flow for Quality ID #386: Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences

Disclaimer: *Refer to measure specification for specific coding and instructions to submit this measure.*



SAMPLE CALCULATIONS

Data Completeness=

Performance Met (a=50 patients) + Performance Not Met (c=20 patients) = 70 patients = **87.50%**
Eligible Population / Denominator (d=80 patients) = 80 patients

Performance Rate=

Performance Met (a=50 patients) = 50 patients = **71.43%**
Data Completeness Numerator (70 patients) = 70 patients

*See the posted measure specification for specific coding and instructions to submit this measure.
NOTE: Submission Frequency: Patient-Process

The measure diagrams were developed by CMS as a supplemental resource to be used in conjunction with the measure specifications. They should not be used alone or as a substitution for the measure specification.
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2026 Clinical Quality Measure Flow Narrative for Quality ID #386: Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences

Disclaimer: *Refer to the measure specification for specific coding and instructions to submit this measure.*

1. Start with Denominator
2. Check *Diagnosis for Amyotrophic Lateral Sclerosis (ALS) as listed in Denominator**:
    a. If *Diagnosis for Amyotrophic Lateral Sclerosis (ALS) as listed in Denominator** equals No, do not include in *Eligible Population/Denominator*. Stop processing.
    b. If *Diagnosis for Amyotrophic Lateral Sclerosis (ALS) as listed in Denominator** equals Yes, proceed to check *Patient encounter during the performance period as listed in Denominator**.
3. Check *Patient encounter during the performance period as listed in Denominator**:
    a. If *Patient encounter during the performance period as listed in Denominator** equals No, do not include in *Eligible Population/Denominator*. Stop processing.
    b. If *Patient encounter during the performance period as listed in Denominator** equals Yes, proceed to check *Patient in hospice at any time during measurement period*.
4. Check *Patient in hospice at any time during measurement period*:
    a. If *Patient in hospice at any time during measurement period* equals Yes, do not include in *Eligible Population/Denominator*. Stop processing.
    b. If *Patient in hospice at any time during measurement period* equals No, include in *Eligible Population/Denominator*.
5. Denominator Population:
    - Denominator Population is all Eligible Patients in the Denominator. Denominator is represented as Denominator in the Sample Calculation listed at the end of this document. Letter d equals 80 patients in the Sample Calculation.
6. Start Numerator
7. Check *Patient offered assistance with end of life issues or existing end of life plan was reviewed or updated during measurement period*:
    a. If *Patient offered assistance with end of life issues or existing end of life plan was reviewed or updated during measurement period* equals Yes, include in *Data Completeness Met and Performance Met*.
        - *Data Completeness Met and Performance Met* letter is represented in the Data Completeness and Performance Rate in the Sample Calculation listed at the end of this document. Letter a equals 50 patients in the Sample Calculation.
    b. If *Patient offered assistance with end of life issues or existing end of life plan was reviewed or updated during measurement period* equals No, proceed to check *Patient not offered assistance with end of life issues or existing end of life plan was not reviewed or updated during measurement period*.
8. Check *Patient not offered assistance with end of life issues or existing end of life plan was not reviewed or updated during measurement period*:

   a. If *Patient not offered assistance with end of life issues or existing end of life plan was not reviewed or updated during measurement period* equals Yes, include in the *Data Completeness Met and Performance Not Met*.

      - *Data Completeness Met and Performance Not Met* letter is represented in the Data Completeness in the Sample Calculation listed at the end of this document. Letter c equals 20 patients in the Sample Calculation.

   b. If *Patient not offered assistance with end of life issues or existing end of life plan was not reviewed or updated during measurement period* equals No, proceed to check *Data Completeness Not Met*.

9. Check *Data Completeness Not Met*:

   - If *Data Completeness Not Met*, the Quality Data Code or equivalent was not submitted. 10 patients have been subtracted from the Data Completeness Numerator in the Sample Calculation.

Sample Calculations

Data Completeness equals Performance Met (a equals 50 patients) plus Performance Not Met (c equals 20 patients) divided by Eligible Population/Denominator (d equals 80 patients). All equals 70 patients divided by 80 patients. All equals 87.50 percent.

Performance Rate equals Performance Met (a equals 50 patients) divided by Data Completeness Numerator (70 patients). All equals 50 patients divided by 70 patients. All equals 71.43 percent.

*See the posted measure specification for specific coding and instructions to submit this measure.

NOTE: Submission Frequency: Patient-Process

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