2025 Measure Set Review (MSR): 00053-01-C-MIPS Preliminary Assessment

I. Measure Overview[1]

CMIT ID	Title
Link to CMIT measure record: 00053-01-C-MIPS	Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences
Measure Steward	**CMS Program**
American Academy of Neurology	Merit-based Incentive Payment System Link: Quality Payment Program Overview - QPP

CBE Endorsement Status	CBE Endorsement History
Not Endorsed	Never Submitted

Measure Overview
Rationale for Use: 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.[2,3.4,5,6] 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. 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

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[1] The information in these measure information sheets is sourced from the CMS Measures Inventory Tool (CMIT) and the PQM Submission Tool and Repository (STAR) Measure Database for endorsement history. This document reflects the content available as of September 2025.

[2] 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

[3] 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.

[4] 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.

[5] Phillips JN, Besbris J, Foster LA, et al. Models of outpatient neuropalliative care for patients with amyotrophic lateral sclerosis. Neurology. 2020:95:782-788

[6] 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

<table>
<tr><th colspan="2">Measure Overview</th></tr>
<tr><td colspan="2">focus of care as the disease progresses.[7,8]</td></tr>
<tr><td colspan="2">CMS-Provided Rationale for Use in Program: Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences is a high-priority patient experience of care measure and the only ALS-focused measure within MIPS. While the measure has low adoption, it is included in the Quality Care for Patients with Neurological Conditions MIPS Value Pathway (MVP), which we believe will increase adoption and allow for meaningful reporting of the measure.</td></tr>
<tr><td colspan="2">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 frequency as clinically indicated (i.e., rapid progression).</td></tr>
<tr><td colspan="2">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).
Exclusions: None</td></tr>
<tr><td colspan="2">Denominator: All patients with a diagnosis of Amyotrophic Lateral Sclerosis (ALS).
Exclusions: Patient in hospice at any time during the measurement period: G9758.</td></tr>
<tr><td>CMS Program History: This measure has been active in MIPS since 2017.</td><td>Cascade of Meaningful Measures Priority: Person-Centered Care</td></tr>
<tr><td>Measure Type: Process</td><td>Is the Measure Digital or an Electronic Clinical Quality Measure (eCQM)? Yes</td></tr>
<tr><td>Level(s) of Analysis/Measured Entity:
Clinician: Group or Practice Level</td><td>Care Setting(s):
Home Health
Hospital: Outpatient Department (HOD)
Skilled Nursing Facility (SNF)/Nursing Home
Home/Residence Visit
Telehealth</td></tr>
<tr><td>Does the Measure Fill a Statutorily Required Category for the Program? No</td><td>Is the Measure Included in Upcoming Rulemaking? No</td></tr>
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II. Measure Performance in Program

For this measure, the MSR evaluation and analysis team reviewed the publicly available datasets:

- The file 2022_puf.csv in Quality Payment Program Experience.zip (referred to as PY2022 in this assessment)
- QPP_Experience_2021.zip (referred to as PY2021 in this assessment)

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[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.

- QPP_Experience_2020.zip (referred to as PY2020 in this assessment)

Only six entities reported on this measure during performance year (PY) 2022, and the quality measure score was the same (3) for all of them. No entities reported on this measure in PY2020 or PY2021.

Due to the limited data, data analysis cannot be performed for this measure.

III. Evaluation Criteria

Meaningfulness

Importance
Guiding Questions: Does the evidence show that the focus of the measure is linked to meaningful outcomes for patients and health care organizations? Do the data demonstrate that using this measure within the quality program results in benefits that outweigh any associated burdens or costs?
The measure addresses a documented performance gap in end-of-life (EOL) planning for ALS patients, is supported by national guidelines and expert consensus, and remains relevant for quality improvement in both inpatient and outpatient settings. Clinical practice guidelines and position statements from American Academy of Neurology Institute emphasize the importance of early and ongoing EOL planning for patients with ALS. Additionally, data from the AANI Axon Registry from 2018-2020 demonstrate that, despite some improvement, a significant proportion of eligible patients are not receiving recommended care, supporting the need for continued focus on this measure for both inpatient and outpatient clinicians. Due to the limited reporting of this measure within MIPS during the lookback period, the information available is insufficient to draw conclusions about the measure's performance. **Committee Member Considerations:** Based on professional and personal experiences, consider the balance of implementation costs or burdens with the benefit of measure use within the MIPS. Committee members will have a chance to share these thoughts with the broader committee via Pre-Meeting Initial Evaluation (PIE) Forms and group discussion.
Staff Rating: Insufficient Information Available

Conformance
Guiding Question: Do measure components and specifications align with the measure intent and target population?
The intent of this measure is to enhance end-of-life planning for patients with ALS by assessing the percentage who receive EOL planning support or have their neuropalliative care plans updated annually in home health, skilled nursing facility, and outpatient settings. The specifications align with this intent: the numerator includes patients offered EOL planning assistance or whose plans were reviewed or updated at least annually, or more often if disease progression is rapid. The denominator includes all ALS patients except those in hospice during the measurement period, as their EOL plans are likely already in effect. This measure supports two MIPS objectives: to improve care for Medicare beneficiaries and to educate, engage, and empower patients as active members of their care team. **Committee Member Considerations:** Committee members should review the list of active measures within this CMS program in the appendix and consider this measure's alignment with the set. The appendix lists all active measures reported in relevant specialty sets.
Staff Rating: Met

Feasibility

Guiding Question: Are the tools, processes, and people necessary to implement and report on the measure reasonably available for measured entities in the CMS program?

This measure is broadly reportable by any clinician, group, or TIN (tax identification number) because it is not a Qualified Clinical Data Registries (QCDR) measure, and MIPS Clinical Quality Measures (CQMs) allow flexibility in how data are collected and supported within reporting systems. The numerator can be documented using various coding systems (SNOMED, ICD-10, CPT, LOINC), FHIR artifacts such as the PACIO Advance Directive Guide, and USCDI V5 data elements.

Committee Member Considerations: Committee members with experience implementing this or similar measures in acute care hospital settings should reflect on potential challenges to feasibility of data collection and reporting.

Staff Rating: Met

Validity

Guiding Question: Do the data and/or logic support the idea that the measured entity can improve their performance on the measure?

While performance data is not available for the lookback period, there is evidence that changes in clinical practice can improve performance on this measure from prior research conducted in the Axon Registry. Entities that have implemented EOL-focused processes for supporting patient care preferences have shown improvement, supporting the measure's validity.

Committee Member Considerations: Committee members with experience implementing this or similar measures in clinical settings should reflect on potential methods to promote patient care preferences in EOL planning conversations and care plans.

Staff Rating: Met

Reliability

Guiding Question: Does the evidence show that changes in measure performance are due to improvements in quality of care? In other words, do the data demonstrate that variation in measure performance is linked to changes made to processes or behaviors to improve care?

Available data was insufficient to estimate reliability for this measure within the program.

Staff Rating: Insufficient Information Available

Usability

Guiding Questions: Are there any known barriers or facilitators that determine whether the person or entity could improve on the measure focus? Are these barriers addressable?

Variation in resource availability and staffing across entities may limit some organizations' ability to improve on the measure. This measure demonstrates strong usability and feasibility for clinicians participating in the MIPS program. Providers who elect to report this measure are unlikely to face significant barriers to implementation or data submission, as its design aligns well with routine clinical workflows and offers greater flexibility compared to mandatory reporting requirements.

Usability
Committee Member Considerations: Based on professional/personal experiences, committee members should consider any barriers to using this measure for certain measured entities as well as any potential facilitators that might promote usability within the program.
Rating: Insufficient Information Available

Data Stream Parsimony

Data Stream Parsimony
Guiding Question: Does the data flow required for the measure promote non-burdensome data collection and reporting?
Based on available information, there is minimal burden or redundancy in data collection and reporting for this measure within the relevant specialty sets for MIPS. **Committee Member Considerations:** Based on professional/personal experiences, committee members should reflect on any additional barriers to the clinical data flow that collection may add as well as potential mitigation strategies.

Patient Journey

Patient Health Journey
Guiding Question: Does the measure address the appropriate aspects of care to align with the patient health care journey?
By promoting EOL planning around patient preferences, the measure encourages active patient participation in care decisions and aligns with best practices for patient-centered EOL care. **Committee Member Considerations:** Based on professional/personal experiences, committee members should consider if the measure identifies an appropriate and critical time to engage patients in EOL planning. Reflect on whether this timepoint is meaningful to patients and any potential barriers or burdens associated with this timepoint in the care journey.

Appendix: Active Measures in the Merit-based Incentive Payment System

Use in MIPS

This measure is in the following traditional MIPS specialty sets:

- Neurology
- Speech Language Pathology

This measure is in the following MIPS Value Pathways:

- Quality Care for Patients with Neurological Conditions. View this pathway at Explore MIPS Value Pathways (MVPs) - M0004 - QPP

Measures in the MIPS Neurology Specialty Set

CMIT ID	Measure Title
00037-01-C-MIPS	Advance Care Plan
00053-01-C-MIPS	*Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences*
00496-01-C-MIPS	Assessment of Cognitive Impairment or Dysfunction for Patients with Parkinson’s Disease
00497-01-C-MIPS	Assessment of Mood Disorders and Psychosis for Patients with Parkinson's Disease
00133-01-C-MIPS	Closing the Referral Loop: Receipt of Specialist Report
01803-01-C-MIPS	Connection to Community Service Provider
00185-04-E-MIPS	Dementia: Cognitive Assessment
00186-01-C-MIPS	Dementia: Education and Support of Caregivers for Patients with Dementia
00187-01-C-MIPS	Dementia: Functional Status Assessment
00188-01-C-MIPS	Dementia: Safety Concern Screening and Follow-Up for Patients with Dementia
00219-01-C-MIPS	Documentation of Current Medications in the Medical Record
00228-01-C-MIPS	Elder Maltreatment Screen and Follow-Up Plan
00243-01-C-MIPS	Epilepsy: Counseling for Women of Childbearing Potential with Epilepsy
00255-02-C-MIPS	Falls: Plan of Care
01212-02-C-MIPS	Gains in Patient Activation Measure (PAM) Scores at 12 Months
00487-01-C-MIPS	Overuse of Imaging for the Evaluation of Primary Headache
00672-02-C-MIPS	Preventive Care and Screening: Screening for Depression and Follow-Up Plan
00672-07-E-MIPS	Preventive Care and Screening: Screening for Depression and Follow-Up Plan
00595-01-C-MIPS	Preventive Care and Screening: Screening for High Blood Pressure and Follow-Up Documented
00596-10-C-MIPS	Preventive Care and Screening: Tobacco Use: Screening and Cessation Intervention

Measures in the MIPS Neurology Specialty Set	
CMIT ID	**Measure Title**
00597-02-C-MIPS	Preventive Care and Screening: Unhealthy Alcohol Use: Screening & Brief Counseling
00498-01-C-MIPS	Rehabilitative Therapy Referral for Patients with Parkinson's Disease
01664-01-C-MIPS	Screening for Social Drivers of Health
00683-02-C-MIPS	Sleep Apnea: Assessment of Adherence to Obstructive Sleep Apnea (OSA) Therapy.
00684-01-C-MIPS	Sleep Apnea: Severity Assessment at Initial Diagnosis

Measures in the MIPS Speech Language Pathology Specialty Set	
CMIT ID	**Measure Title**
01608-01-C-MIPS	Adult COVID-19 Vaccination Status
00053-01-C-MIPS	*Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences*
00496-01-C-MIPS	Assessment of Cognitive Impairment or Dysfunction for Patients with Parkinson's Disease
01803-01-C-MIPS	Connection to Community Service Provider
00186-01-C-MIPS	Dementia: Education and Support of Caregivers for Patients with Dementia
00187-01-C-MIPS	Dementia: Functional Status Assessment
00188-01-C-MIPS	Dementia: Safety Concern Screening and Follow-Up for Patients with Dementia
00219-01-C-MIPS	Documentation of Current Medications in the Medical Record
00228-01-C-MIPS	Elder Maltreatment Screen and Follow-Up Plan
00274-01-C-MIPS	Functional Outcome Assessment
00672-02-C-MIPS	Preventive Care and Screening: Screening for Depression and Follow-Up Plan
00672-07-E-MIPS	Preventive Care and Screening: Screening for Depression and Follow-Up Plan
00596-10-C-MIPS	Preventive Care and Screening: Tobacco Use: Screening and Cessation Intervention
01664-01-C-MIPS	Screening for Social Drivers of Health