

**Measure #386: Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences – National Quality Strategy Domain: Person and Caregiver-Centered Experience and Outcomes**

**2017 OPTIONS FOR INDIVIDUAL MEASURES:**  
**REGISTRY ONLY**

**MEASURE TYPE:**  
Process

**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, hospice) at least once annually

**INSTRUCTIONS:**

This measure is to be reported a minimum of **once per performance period** for patients with a diagnosis of ALS during the performance period. This measure may be reported by 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 Reporting:**

The listed denominator criteria is used to identify the intended patient population. The numerator options included in this specification are used to submit the quality actions allowed by the measure. The quality-data codes listed do not need to be submitted for registry-based submissions; however, these codes may be submitted for those registries that utilize claims data.

**DENOMINATOR:**

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

**Denominator Criteria (Eligible Cases):**

Diagnosis for Amyotrophic Lateral Sclerosis (ICD-10-CM): G12.21

**AND**

Patient encounter during the performance period (CPT): 99201, 99202, 99203, 99204, 99205, 99212, 99213, 99214, 99215, 99304, 99305, 99306, 99307, 99308, 99309, 99310, 99318, 99324, 99325, 99326, 99327, 99328, 99334, 99335, 99336, 99337, 99354, 99355

**WITHOUT**

Telehealth Modifier: GQ, GT

**AND NOT**

**DENOMINATOR EXCLUSION:**

Patient in hospice and in terminal phase: G9758

**NUMERATOR:**

Patients who were offered assistance in planning for end of life issues (e.g., advance directives, invasive ventilation, or hospice) at least once annually

**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 and hospice.

**Numerator Options:**

***Performance Met:***

Patient offered assistance with end of life issues during the measurement period (**G9380**)

**OR**

***Denominator Exception:***

Documentation of medical reason(s) for not offering assistance with end of life issues (e.g. patient in hospice care, patient in terminal phase) during the measurement period (G9381)

**OR**

***Performance Not Met:***

Patient not offered assistance with end of life issues during the measurement period (G9382)

**RATIONALE:**

Palliative care should be adopted from the time of diagnosis. Many patients are not adequately informed about advance directives and end of life decision making and many hospice workers are not familiar with ALS. Management of the terminal phase of ALS is unsatisfactory in 33% - 61% of cases in Europe and only 8% of palliative care units are involved from the time of diagnosis. The current system of palliative care in the USA is highly decentralized. Between 60-88% of patients die in a medical facility in some countries and not at home, while over 58% of seriously ill ALS patients do not have hospice care. Approaches to end of life care vary widely and are not standardized either in timing or content.

**CLINICAL RECOMMENDATION STATEMENTS:**

- Advance directives for palliative end-of-life care should be discussed early with the patient and carers, respecting the patient's social and cultural background.<sup>1</sup>
- Offer assistance in formulating an advance care directive. (GPP)<sup>2</sup>
- Review the patients' wishes regarding their care and advance directives regularly. (Level II)<sup>3</sup>
- Re-discuss the patient's preferences for life-sustaining treatments every 6 months. (GPP)<sup>2</sup>
- Initiate discussions on end-of-life issues whenever the patient asks or "opens the door" for end-of-life information and/or interventions. (GPP)<sup>2</sup>
- Treat pain in ALS following accepted guidelines. (GPP)<sup>2</sup>
- Initiate early referral to hospice or home care teams well in advance of the terminal phase of ALS to facilitate the work of the hospice team. (GPP)<sup>2</sup>
- Discuss options for respiratory support and end-of-life issues if the patient has dyspnea, other symptoms of hypoventilation or VC <50%. (GPP)<sup>2</sup>
- Treat terminal dyspnea and/or pain with opioids alone or in combination with benzodiazepines if anxiety is present. (GPP)<sup>2</sup>

<sup>1</sup> Andersen PM, Abrahams S, Borasio GD, et al. EFNS guidelines on the Clinical Management of Amyotrophic Lateral Sclerosis (MALS) - revised report of an EFNS task force. *Eur J Neurol* 2011;19(3) 360-375 (GPP=Good Practice Point)

<sup>2</sup> 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 (GPP=Good Practice Point)

<sup>3</sup> Heffernan C., Jenkinson C, Holmes T, et al. Management of respiration in MND/ALS patients: An evidence based review. *Amyotrophic Lateral Sclerosis* 2006; 7(1):5-15

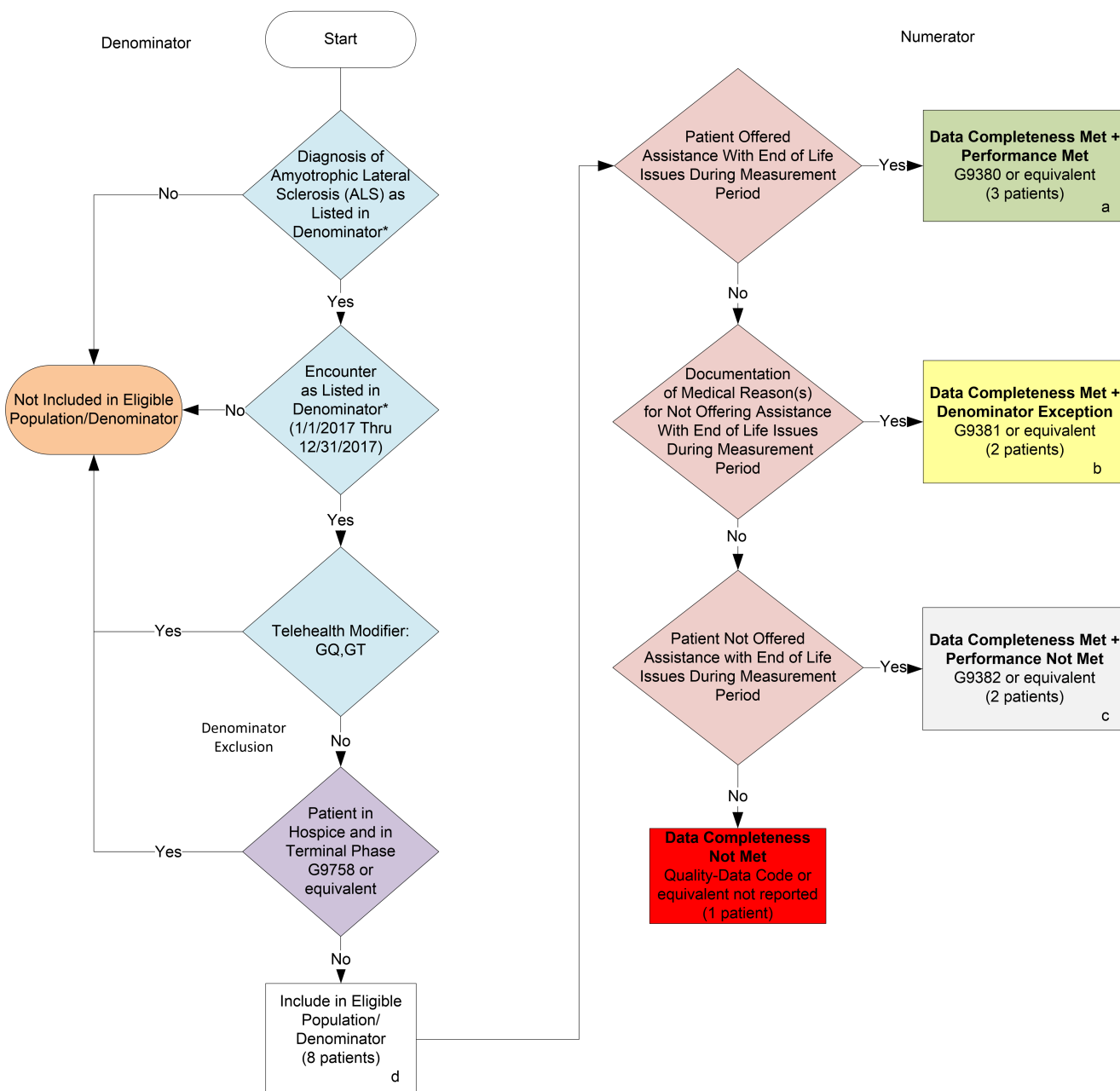
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## 2017 Registry Individual Measure Flow #386: Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences



### SAMPLE CALCULATIONS:

#### Data Completeness=

Performance Met (a=3 patients) + Denominator Exception (b=2 patients) + Performance Not Met (c=2 patients) = 7 patients = 87.50%  
Eligible Population / Denominator (d=8 patients) = 8 patients

#### Performance Rate=

Performance Met (a=3 patients) = 3 patients = 60.00%  
Data Completeness Numerator (7 patients) – Denominator Exception (b=2 patients) = 5 patients

\* See the posted Measure Specification for specific coding and instructions to report this measure.

NOTE: Reporting Frequency - Patient-process

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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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**2017 Registry Individual Measure Flow**  
**#386: Amyotrophic Lateral Sclerosis (ALS) Patient Care Preferences**

Please refer to the specific section of the Measure Specification to identify the denominator and numerator information for use in reporting this Individual Measure.

1. Start with Denominator
2. Check Patient Diagnosis:
  - a. If Diagnosis of Amyotrophic Lateral Sclerosis (ALS) as Listed in Denominator equals No, do not include in Eligible Patient Population. Stop Processing.
  - b. If Diagnosis of Amyotrophic Lateral Sclerosis (ALS) as Listed in the Denominator equals Yes, proceed to check Encounter Performed.
3. Check Encounter Performed:
  - a. If Encounter as Listed in the Denominator equals No, do not include in Eligible Patient Population. Stop Processing.
  - b. If Encounter as Listed in the Denominator equals Yes, proceed to check Telehealth Modifier.
4. Check Telehealth Modifier:
  - a. If Telehealth Modifier equals Yes, do not include in Eligible Patient Population. Stop Processing.
  - b. If Telehealth Modifier equals No, proceed to Patient in Hospice and in Terminal Phase.
5. Check Patient in Hospice and in Terminal Phase:
  - a. If Patient in Hospice and in Terminal Phase equals Yes, do not include in Eligible Patient Population. Stop Processing.
  - b. If Patient in Hospice and in Terminal Phase equals No, include in the Eligible Population.
6. Denominator Population:
  - a. 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 8 patients in the sample calculation.
7. Start Numerator
8. Check Patient Offered Assistance with End of Life Issues During Measurement Period:
  - a. If Patient Offered Assistance with End of Life Issues During Measurement Period equals Yes, include in Data Completeness Met and Performance Met.
  - b. 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 3 patients in Sample Calculation.

- c. If Patient Offered Assistance with End of Life Issues During Measurement Period equals No, proceed to Documentation of Medical Reason(s) for Not Offering Assistance with End of Life Issues During Measurement Period.
9. Check Documentation of Medical Reason(s) for Not Offering Assistance with End of Life Issues During Measurement Period:
  - a. If Documentation of Medical Reason(s) for Not Offering Assistance with End of Life Issues During Measurement Period equals Yes, include in Data Completeness Met and Denominator Exception.
  - b. Data Completeness Met and Denominator Exception letter is represented in the Data Completeness and Performance Rate in the Sample Calculation listed at the end of this document. Letter b equals 2 patients in the Sample Calculation.
  - c. If Documentation of Medical Reason(s) for Not Offering Assistance with End of Life Issues During Measurement Period equals No, proceed to Patient Not Offered Assistance with End of Life Issues During Measurement Period.
10. Check Patient Not Offered Assistance with End of Life Issues During Measurement Period:
  - a. If Patient Not Offered Assistance with End of Life Issues During Measurement Period Yes, include in the Data Completeness Met and Performance Not Met.
  - b. 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 2 patients in the Sample Calculation.
  - c. If Patient Not Offered Assistance with End of Life Issues During Measurement Period equals No, proceed to Data Completeness Not Met.
11. Check Data Completeness Not Met:
  - a. If Data Completeness Not Met, the Quality Data Code or equivalent was not reported. 1 patient has been subtracted from the data completeness numerator in sample calculation.

#### **SAMPLE CALCULATIONS:**

##### **Data Completeness=**

$$\frac{\text{Performance Met (a=3 patients)} + \text{Denominator Exception (b=2 patients)} + \text{Performance Not Met (c=2 patients)}}{\text{Eligible Population / Denominator (d=8 patients)}} = \frac{7 \text{ patients}}{8 \text{ patients}} = 87.50\%$$

##### **Performance Rate=**

$$\frac{\text{Performance Met (a=3 patients)}}{\text{Data Completeness Numerator (7 patients) – Denominator Exception (b=2 patients) = 5 patients}} = \frac{3 \text{ patients}}{5 \text{ patients}} = 60.00\%$$