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SPECIAL ARTICLES

Quality measures for care of patients with narcolepsy: 2025 update after measure maintenance

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Narcolepsy is a chronic sleep disorder that causes overwhelming daytime sleepiness. In an effort to continue addressing gaps and variations in care in this patient population, the American Academy of Sleep Medicine Quality Measures Task Force performed quality measure maintenance on the Quality Measures for the Care of Patients with Narcolepsy (originally developed in 2015). The Quality Measures Task Force reviewed the current medical literature, including updated clinical practice guidelines and systematic literature reviews, existing narcolepsy quality measures, and performance data highlighting remaining gaps or variations in care.

Keywords: narcolepsy, quality measures, patient care

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INTRODUCTION

The quality measures for the care of narcolepsy were originally published in 2015, by the American Academy of Sleep Medicine (AASM), as part of a measure development initiative to address multiple sleep disorders.[1] Narcolepsy is a chronic sleep disorder that is marked by excessive daytime sleepiness (EDS), often manifesting as frequent and uncontrollable sleep attacks. This disorder is often underdiagnosed and delays in diagnosis are common.[2] Although pharmacologic treatments are the mainstay of evidence-based narcolepsy management, comprehensive, individually-tailored treatment strategies frequently also integrate lifestyle adjustments.

The *International Classification of Sleep Disorders*, third edition, text revision[3] was used as the narcolepsy diagnostic reference. The *International Classification of Sleep Disorders*, third edition, text revision lists 2 separate narcolepsy disorders, narcolepsy type 1 and narcolepsy type 2. Diagnostically, the 2 disorders are distinguished primarily by the presence of hypocretin deficiency or cataplexy, both present in narcolepsy type 1 and absent in narcolepsy type 2 (see **Table 1**).

METHODS

Literature review

An updated comprehensive literature search was conducted to identify current publications that addressed assessment, treatment, and follow up for this patient population. The literature review included clinical practice guidelines, systematic literature reviews, and individual studies (ie, randomized controlled trials). Searches were limited to articles published between 2018 and 2023, specific to humans, in the English language, and meeting the age criteria within the PubMed database. Publication types such as news articles, letters, editorials, and case reports were excluded. A total of 179 abstracts and 54 full journal publications were retrieved for review.

Performance data

In addition to a review of the medical literature, the Task Force searched for performance data, which may demonstrate performance gaps and/or variations in care. The quality measures have not yet been implemented in any clinical data registries and the quality measures are not included in the Merit-Based Incentive Payment System program. However, through a review of the medical literature, a survey of 35 adolescents with narcolepsy, 116 parents, and 30 sleep physicians was identified. The survey found that 94% of physicians acknowledged the importance of tracking narcolepsy quality measures, but only about one-third were actively doing so. **Figure 1** shows the percentage of sleep physicians who are currently tracking AASM narcolepsy quality measures.[4]

Existing quality measures

As a part of the measure maintenance process, the Task Force also reviewed existing quality measures and determined that there were no existing narcolepsy measures that required structural measure harmonization. The Centers for Medicare & Medicaid Services defines measure harmonization as standardizing quality measure specifications for related measures when they have the following[5]:

- The same measure focus (ie, numerator criteria)
- The same target population (ie, denominator criteria)

Table 1—ICSD-3-TR diagnostic criteria for narcolepsy type 1 and 2.

Narcolepsy Type 1	Narcolepsy Type 2
ICD-10-CM Code: G47.411	ICD-10-CM code: G47.419
Alternate names Hypocretin deficiency syndrome, narcolepsy-cataplexy, narcolepsy with cataplexy	**Alternate names** Narcolepsy without cataplexy
Diagnostic criteria Criteria A–C must be met	**Diagnostic criteria** Criteria A–E must be met
A. The patient has daily periods of irrepressible need to sleep or daytime lapses into drowsiness or sleep. B. The presence of one or both of the following: 1. Cataplexy (as defined under Essential Features) *and* either: a. Mean sleep latency of ≤ 8 minutes and 2 or more SOREMPs on an MSLT performed in accordance with current recommended protocols. b. A SOREMP (within 15 minutes of sleep onset) on nocturnal polysomnogram. 2. CSF hypocretin-1 concentration, measured by radioimmunoassay, is ≤ 110 pg/mL (using a Stanford reference sample) or less than one-third of mean values obtained in normal individuals with the same standardized assay. C. The symptoms and signs are not better explained by chronic insufficient sleep, a circadian rhythm sleep-wake disorder or other current sleep disorder, mental disorder, or medication/substance use or withdrawal.	A. The patient has daily periods of irrepressible need to sleep or daytime lapses into drowsiness or sleep occurring for at least 3 months. B. A mean sleep latency of ≤ 8 minutes and 2 or more SOREMPs on an MSLT performed in accordance with current recommended protocols. A SOREMP (within 15 minutes of sleep onset) on the preceding nocturnal polysomnogram may replace one of the SOREMPs on the MSLT C. Cataplexy is absent. D. If CSF hypocretin-1 concentration is measured by radioimmunoassay, it is either > 110 pg/mL (when using a Stanford reference sample) or more than one-third of mean values obtained in normal individuals with the same standardized assay. E. The symptoms and signs are not better explained by chronic insufficient sleep, a circadian rhythm sleep-wake disorder or other current sleep disorder, mental disorder, or medication/substance use or withdrawal.

From *International Classification of Sleep Disorders*, third edition, text revision. Copyright American Academy of Sleep Medicine, used with permission. CSF = cerebrospinal fluid, ICD-10-CM = *International Classification of Diseases*, tenth revision, clinical modification, MSLT = Multiple Sleep Latency Test, SOREMP = sleep-onset rapid eye movement period.

- Elements that apply to many measures (eg, age designation for children)

Unintended consequences

There were no known unintended consequences identified as a result of reporting the narcolepsy quality measures.

Review and approval

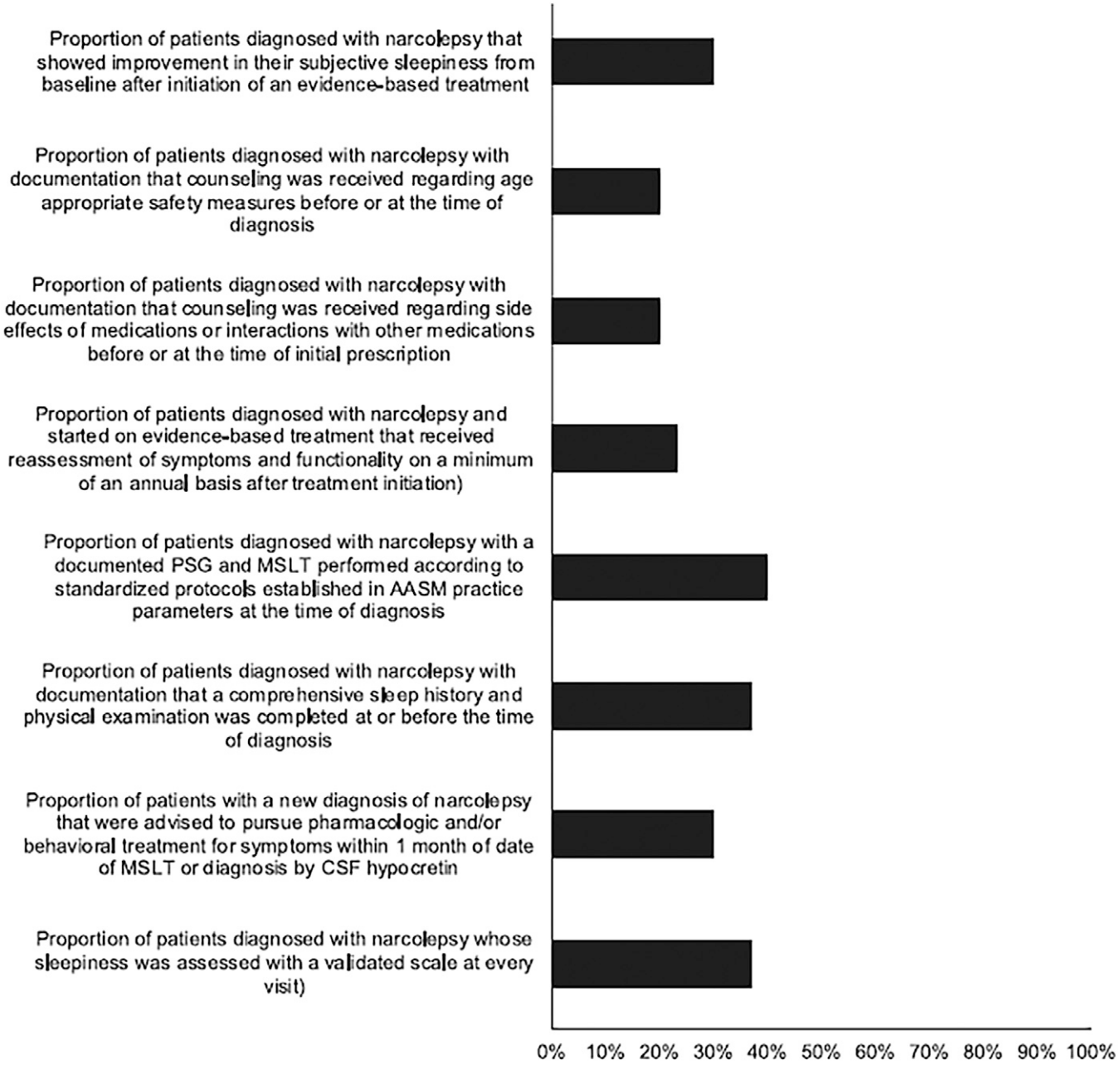
The updated measures were initially revised by the Task Force and approved for public comment by the AASM Board of Directors. The measures were then posted on the AASM website for a 30-day public comment period and were simultaneously shared with several medical specialty societies for an additional peer review, to ensure that all relevant stakeholders had an opportunity to provide feedback. The Task Force reviewed all stakeholder feedback and made additional revisions, where deemed appropriate. The final revised measures were approved for publication and implementation by the AASM Board of Directors. A driver diagram of the final measures is shown in **Figure 2**.

REVISED QUALITY MEASURES

Overall revisions

The Task Force reviewed the Narcolepsy quality measure set and discussed maintaining consistency through its entirety. Throughout the 2015 narcolepsy quality measure set, there was an exception criterion for patients under 6 years old. Although the diagnosis is not common for those 5 years of age and under,[3] the Task Force removed this exclusion and revised the narcolepsy measures to apply to all patients with a narcolepsy diagnosis, regardless of age. To remain in alignment with the other AASM quality measures, the Task Force replaced "validated scale" with "validated sleepiness instrument" throughout the measure set. In measures where sleepiness is assessed, the following definition was applied to provide clarification, "for the purposes of this measure, validated sleepiness instruments include, but are not limited to: Epworth Sleepiness Scale, Epworth Sleepiness Scale modified, Stanford Sleepiness Scale, Karolinska Sleepiness Scale, Cleveland Adolescent Sleepiness Questionnaire, Pediatric Daytime Sleepiness Scale, Narcolepsy severity scale, or a Visual Analog Scale." Additionally, the notation, "a global summary of clinician interpretation of the validated sleepiness instrument should be documented in the patient's medical record" was attached to address the importance of documenting results derived from any of the validated sleepiness instruments. In measures that highlight evidence-based pharmacologic treatment, the following definition was used: "for the purposes of this measure, evidence-based pharmacologic treatments may include but are not limited to Modafinil, Pitolisant, Sodium Oxybate, Solriamfetol, Armodafinil, Dextroamphetamine, and Methylphenidate."[6] The Task Force also included a note to indicate that "Evidence-based pharmacologic treatment may also include medications that have been FDA approved for the treatment of narcolepsy since the most recent AASM clinical practice guideline publication."

Figure 1—Percentage of sleep physician respondents who reported currently tracking the listed individual quality measures published by the AASM.



From Ingram et al.[4] Copyright AASM, used with permission. AASM = American Academy of Sleep Medicine, CSF = cerebrospinal fluid, MSLT = Multiple Sleep Latency Test, PSG = polysomnography.

Outcome measure #1—reduce EDS

2015 measure description

Proportion of patients diagnosed with narcolepsy that showed improvement in their self-reported sleepiness from baseline after initiation of an evidence-based treatment.

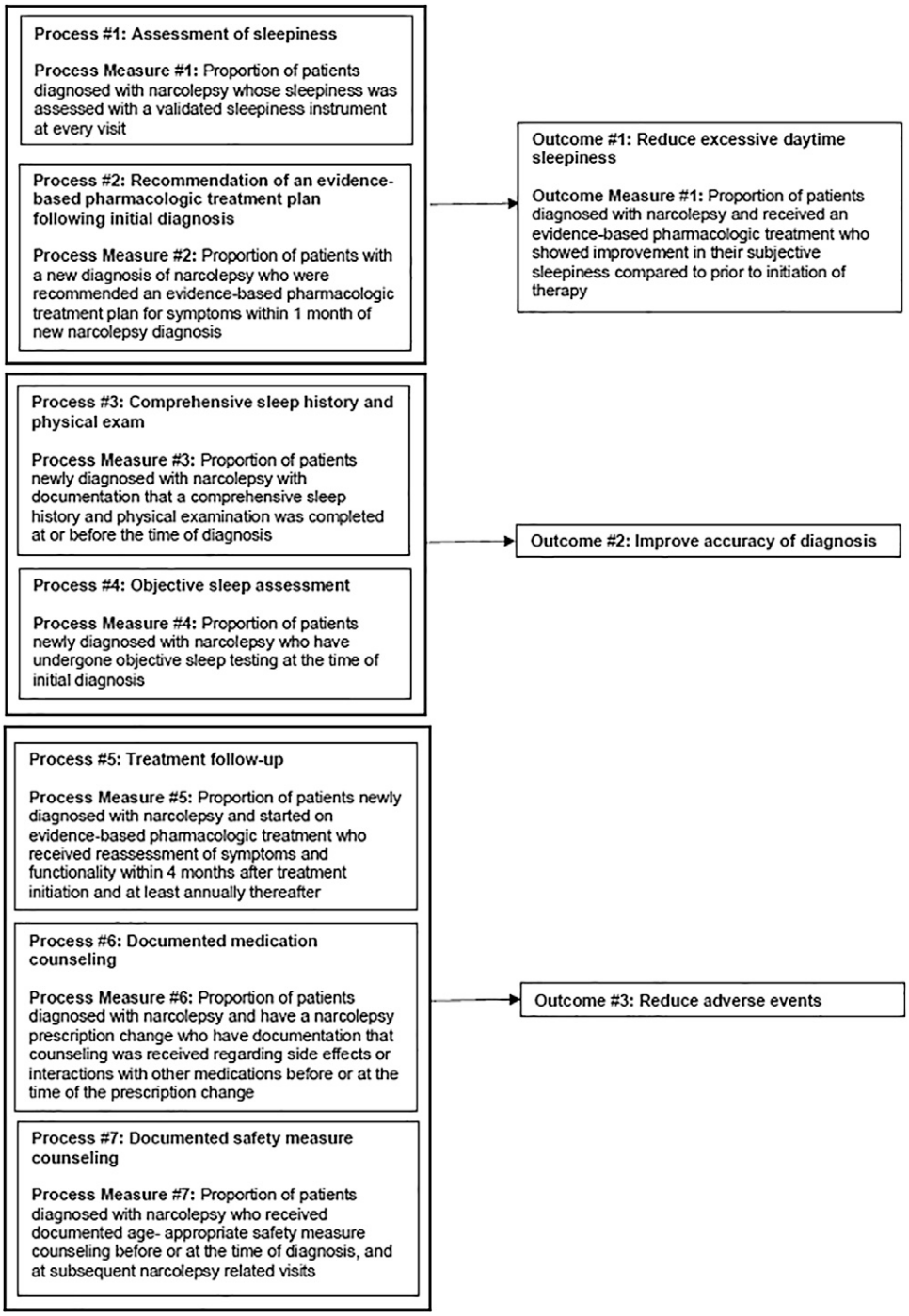
2025 revised measure description

Proportion of patients diagnosed with narcolepsy and received an evidence-based pharmacologic treatment who showed improvement in their self-reported sleepiness compared to prior to initiation of therapy.

Exceptions

- **Medical reasons:** Patients on escalating sedating medication regimen administered for comorbid conditions (eg, opioids for pain, benzodiazepines for seizures); Patients with documented contraindications to recommended evidence-based pharmacologic treatment

Figure 2—Revised narcolepsy quality measures driver diagram.



- **Patient reasons:** Patient and/or caregiver declines or is unable to complete sleepiness instrument; Patient and/or caregiver declines prescribed treatment
- **System reasons:** None

Supporting evidence and rationale for revisions

This measure was originally developed to identify patients who showed improvement in their self-reported sleepiness after the initiation of an evidence-based treatment. While the Task Force decided to largely maintain the measure description, the numerator was revised, to highlight the importance of comparing the patient's self-reported sleepiness (using a validated sleepiness instrument) before treatment to their self-reported sleepiness after treatment initiation. Clinicians must monitor EDS during ongoing treatment so that residual sleepiness may be addressed.[7] During the public comment period there was a comment that

providers often inherit patients when they move, change insurance plans, or change providers. As such, patients may not show an improvement in EDS if therapy may already be well managed. The Task Force agreed with this statement and revised the measure description to address: Proportion of patients diagnosed with narcolepsy who received an evidence-based pharmacologic treatment and showed improvement in their self-reported sleepiness ***compared to prior to initiation of therapy***.

To further clarify the measure intent, there were also edits to the exceptions. The Task Force updated the medical exceptions to read, patients on ***escalating*** sedating medications ***regimen*** administered for comorbid conditions (eg, opioids for pain, benzodiazepines for seizures); and patients ***with*** documented contraindications ***to the recommended evidence-based pharmacologic treatment***. The Task Force removed specific exceptions for patients who are intellectually disabled or cognitively impaired and patients for whom there are no validated sleepiness scales in the patient's language; however, these may be captured in the exception that was sustained for patients or caregivers who are unable to complete the scale. Because the revised measures are intended to apply to people with narcolepsy of all ages, the exclusion of patients aged < 6 years was removed.

Finally, a pertinent question was raised regarding whether self-reported providers should use the same validated sleepiness instrument after the initiation of treatment that was used prior to treatment. After careful consideration, the Task Force reached a unanimous agreement that using a consistent, validated instrument across all stages of assessment will help ensure comparability and provide a more accurate evaluation of the treatment provided.

Process measure #1—assessment of sleepiness

2015 measure description

Proportion of patients diagnosed with narcolepsy whose sleepiness was assessed with a validated scale at every visit.

2025 revised measure description

Proportion of patients diagnosed with narcolepsy whose sleepiness was assessed with a validated sleepiness instrument at every visit.

Exceptions

- **Medical reasons:** None
- **Patient reasons:** Patient and/or caregiver declines or is unable to complete sleepiness instrument
- **System reasons:** None

Supporting evidence and rationale for revisions

The overall intent of this measure is still to ensure that clinicians assess sleepiness at every visit using a validated sleepiness instrument. There is no single best test to assess EDS, but clinicians can select tests validated for specific diagnostic needs.[8]

As with the exceptions for outcome measure 1, the patient reason exception for inability to complete the sleepiness instrument was maintained, but specific exclusions for patients who are intellectually disabled or cognitively impaired and patients for whom a validated instrument is not available in their primary language were removed. This change reflects the understanding sleepiness can be effectively assessed using a validated sleepiness instrument with the assistance of a caregiver if the patient is unable to complete it independently. The Task Force discussed the importance of clinicians having tools to address the needs of all patients, regardless of language barriers.

Process measure #2—recommendation of an evidence-based pharmacologic treatment plan following initial diagnosis

2015 measure description

Proportion of patients with a new diagnosis of narcolepsy that were advised to pursue pharmacologic and/or behavioral treatment for symptoms within 1 month of date of Multiple Sleep Latency Test (MSLT) or diagnosis by cerebrospinal fluid (CSF) hypocretin.

2025 revised measure description

Proportion of patients with a new diagnosis of narcolepsy who were recommended an evidence-based pharmacologic treatment plan for symptoms within 1 month of new narcolepsy diagnosis.

Exceptions

- **Medical reasons:** Patient is pregnant and/or breastfeeding; medical or psychiatric condition that precludes safe use of pharmacologic narcolepsy treatment
- **Patient reasons:** None
- **System reasons:** None

Supporting evidence and rationale for revisions

The Task Force chose to highlight "recommendation" in this measures title since clinicians can only recommend treatment; they cannot enforce patient adherence. Furthermore, while both behavioral and pharmacological treatments may be part of an individualized narcolepsy treatment plan, only the latter is supported by high level evidence-based research. To align with other AASM quality measures and current medical literature, the Task Force revised this measure to highlight the importance of recommending evidence-based pharmacologic care that assumes that behavioral issues have been addressed. Based on the updated clinical practice guidelines and absence of behavioral therapy recommendations, it was agreed upon to focus on evidence-based pharmacologic recommendations for this measure. It should also be noted that previous clinical practice guidelines were symptom-based, while the most up-to-date clinical practice guidelines and GRADE assessment focus on the disease. The original measure description indicated that to satisfy the measures criteria a patient must be advised to pursue *treatment for symptoms within 1 month of MSLT or diagnosis by CSF hypocretin*. To better align with the *International Classification of Sleep Disorders*, third edition, text revision options for diagnostic testing,[3] the Task Force revised the measure description to state, "treatment plan for symptoms within 1 month of new narcolepsy diagnosis."

According to the 2021 clinical practice guideline, recommendations for specific pharmacologic interventions for the treatment of narcolepsy in adults are modafinil, pitolisant, sodium oxybate, solriamfetol (strong), armodafinil, dextroamphetamine, methylphenidate (conditional). Conditional recommendations for pediatric patients with narcolepsy are modafinil and sodium Oxybate. There was insufficient and inconclusive evidence to make recommendations for l-carnitine, scheduled naps, selegiline, triazolam selective serotonin reuptake inhibitors and serotonin-norepinephrine reuptake inhibitors.[6] The Task Force created a definition for consistency throughout the measure. "For the purposes of this measure, evidence-based pharmacologic treatments may include but are not limited to Modafinil, Pitolisant, Sodium Oxybate, Solriamfetol, Armodafinil, Dextroamphetamine, and Methylphenidate." The Task Force also included a note in this measure to indicate that evidence-based pharmacologic treatment may also include medications that have been Food and Drug Administration approved for the treatment of narcolepsy since the most recent AASM clinical practice guideline publication. During the public comment period it was noted that behavioral (or nonpharmacologic) treatments were excluded in this measure revision since the Task Force chose to focus on pharmacological treatments however, the group agreed to include the following notation: "Note: Pharmacologic treatment is an adjunct to sleep counseling and nonpharmacologic treatments." The original measure did not include any exceptions; however, the Task Force determined it necessary to introduce the following medical exceptions, "patient is pregnant and/or breastfeeding" and "medical or psychiatric condition that precludes safe use of pharmacologic narcolepsy treatment" as acceptable exception criterion. An additional comment suggested including exceptions regarding the cost and availability of specific medication as well as specific patient occupations that might prohibit the use of the recommended medications. The Task Force considered the challenges of recommending treatments based on patient affordability, availability, or convenience, but noted the distinction between what is recommended as evidence-based (and captured in this measure) and what the patient ultimately chooses based on these patient-specific factors. Significant improvements in sleep-related patient reported outcomes were seen with pharmacotherapy use, regardless of diagnosis or treatment type, highlighting the importance of individualized prescribing decisions for this population.[9]

Process measure #3—comprehensive sleep history and physical exam

2015 measure description

Proportion of patients diagnosed with narcolepsy with documentation that a comprehensive sleep history and physical examination was completed at or before the time of diagnosis.

2025 revised measure description

Proportion of patients newly diagnosed with narcolepsy with documentation that a comprehensive sleep history and physical examination was completed at or before the time of diagnosis.

Exceptions

- **Medical reasons:** None
- **Patient reasons:** None
- **System reasons:** None

Supporting evidence and rationale for revisions

To effectively manage sleep disorders, it is important for providers to complete a comprehensive assessment which includes a sleep, medical and mental health history and physical examination.[10] Doing so also will allow providers to thoroughly assess a patient's comorbidities, medications, health care needs, and overall quality of life. The Task Force stressed the importance of ensuring that newly diagnosed patients have this documentation, as it is not standard practice to diagnosis a patient with narcolepsy without completing both. In this measure, the Task Force created the following definition for sleep history and examination, "for the purposes of this measure, a sleep history and examination include at minimum documentation of a thorough general physical and neurological examination, sleep-wake patterns, cataplexy, signs and symptoms suggestive of sleep-disordered breathing, current medications, and other potential comorbidities which may contribute to excessive daytime sleepiness (eg, history of traumatic brain injury or history of psychiatric conditions)."

No other substantive changes were made to the measure language.

Process measure #4—objective sleep assessment

2015 measure description

Proportion of patients diagnosed with narcolepsy with a documented polysomnography and MSLT performed according to standardized protocols established in AASM practice parameters at the time of diagnosis.

2025 revised measure description

Proportion of patients newly diagnosed with narcolepsy who have undergone objective sleep testing at the time of initial diagnosis.

Exceptions

- **Medical reasons:** None
- **Patient reasons:** None
- **System reasons:** None

Supporting evidence and rationale for revisions

Definitive diagnosis of narcolepsy can be complex and should incorporate a detailed presenting history, assessment of sleep-wake cycles, assessment of sleep deprivation, self-reported report of symptoms (questionnaires, sleep diary), and objective testing. Objective testing may include polysomnography, actigraphy, MSLT including drug-testing of urine, human leukocyte antigen typing and lumbar puncture to measure CSF hypocretin-1 (orexin) levels).[11]

Completion of an objective sleep test is an integral part of narcolepsy diagnosis. This measures description was simplified to clarify that the measure is intended for newly diagnosed

patients and to remove the highlighted polysomnography and MSLT objective sleep tests. The tests were removed to ensure that clinicians are not limited to only those 2 objective sleep tests but rather should make the diagnosis including objective testing as specified in the *International Classification of Sleep Disorders*, third edition, text revision. Because the numerator definition was broadened to include people diagnosed via CSF hypocretin-1 testing, the medical reason exception for diagnosis via hypocretin-1 testing was removed. The Task Force also removed the exception to objective testing for patients in which it is considered unsafe to stop stimulants, stimulant-like medications, and rapid eye movement suppressing medications at least 2 weeks (or 5 half-lives, whichever is longer) before MSLT (ie, antidepressants in patients prone to severe depression). Although the Task Force is aware of such circumstances, patients who cannot safely undergo any of the objective diagnostic procedures necessary to establish a diagnosis of narcolepsy should not be given a diagnosis of narcolepsy. The Task Force re-evaluated this decision during the public comment period, in response to a suggestion that patients who could not tolerate testing should be an exclusion but reaffirmed their belief that narcolepsy diagnosis must include appropriate objective testing.

Additionally, the Task Force considered retiring the measure but decided it was important to retain it because there may still be a gap in care, as reflected by their shared experiences of having patients present in practices with a diagnosis, and no documentation of an objective sleep assessment.

Lastly, while reviewing the numerator language, the Task Force created a definition for sleep testing: "For the purposes of this measure, sleep testing for Narcolepsy is defined as the performance of a polysomnogram (PSG) with Multiple Sleep Latency Test (MSLT) or CSF hypocretin, in accordance with the ICSD recommendations in effect at the time of the patient's initial diagnosis. Adequate sleep should be documented by sleep diary and, when available, actigraphy for 2 weeks before testing."[3]

Process measure #5—treatment follow-up

2015 measure description

Proportion of patients diagnosed with narcolepsy and started on evidence-based treatment that received reassessment of symptoms and functionality on a minimum of an annual basis after treatment initiation.

2025 revised measure description

Proportion of patients newly diagnosed with narcolepsy and started on evidence-based pharmacologic treatment who received reassessment of symptoms and functionality within 4 months after treatment initiation and at least annually thereafter.

Exceptions

- **Medical reasons:** None
- **Patient reasons:** Patient does not return for follow-up and/or transitioned to a different provider
- **System reasons:** None

Supporting evidence and rationale for revisions

There were 3 significant updates to this measure including highlighting newly diagnosed patients, evidence-based pharmacological treatment, and reassessing symptoms and functionality not only annually but also within 4 months of the treatment initiation.

The original measure did not provide clear guidance on whether the population should encompass all patients with narcolepsy or only those who are newly diagnosed. The Task Force decided to highlight newly diagnosed patients, as the intent of the measure is to ensure that patients who begin a treatment plan after initial diagnosis receive regular follow-up care and are consistently monitored to determine their response to treatment. Modifications to treatment recommendations should depend on clinical judgement, including careful follow-up discussions with patients and caregivers.[12] However, while not part of the definition of this measure, similar follow-up following new changes to treatments for existing patients is considered good clinical practice.

Secondly, the Task Force elected to emphasize evidence-based pharmacologic treatment, which are outlined in the Treatment of central disorders of hypersomnolence: an AASM clinical practice guidelines.[6] When reviewing the denominator language, the Task Force noted that the evidence-based pharmacologic treatment needed to be captured as a definition and required modification, for consistency with current literature and clinical practice guideline recommendations: "For the purposes of this measure, evidence-based pharmacologic treatments may include, but are not limited to:

- Modafinil
- Pitolisant
- Sodium Oxybate
- Solriamfetol
- Armodafinil
- Dextroamphetamine
- Methylphenidate"

This update reflects the changes in guideline recommendations. To ensure that the measure remains consistent with clinical practice guidelines and will also capture any newly recommended evidence-based pharmacologic treatments the following notation was created, "Evidence-based pharmacologic treatment may also include medications that have been FDA approved for the treatment of narcolepsy since the most recent AASM clinical practice guideline publication."

Lastly, treatment plans routinely change over time and can be affected by factors such as age, lifestyle, severity, tolerance and comorbidities. Treatment choices should be tailored to each patient's symptoms, comorbidities, tolerance and risk of potential drug interactions.[13] Regular assessment after initiation of treatment is a useful approach to drive changes in therapy such as dose adjustment or switching of medications, especially because the level of improvement may not be able to be predicted.[14]

To clarify the expectations associated with this measure and make clear the many methods one can use to reassess a patient's symptoms, the exceptions were reorganized and many of them were incorporated into the list of conditions that warrant a change in management. This restructuring was made with the understanding that none of the following exceptions should

prevent a provider from reassessing the patient's symptoms and functionality. The exceptions that were removed include: pregnancy and/or breastfeeding; medical or psychiatric conditions that preclude the safe use of pharmacological narcolepsy treatments; prohibitive costs affecting adherence; payer noncoverage of evidence-based treatments; and patient and/or caregiver refusal of treatment. The latter exception was deemed not applicable to this measure, as it focuses on treatment follow-up. Thus, patients who decline treatment would not be included in the population for this measure.

To provide further clarification, the Task Force added the following conditions to the list of those requiring a change in management:

- Lack of efficacy (or suboptimal efficacy)
- Lack of functional improvement

Process measure #6—documented medication counseling

2015 measure description

Proportion of patients diagnosed with narcolepsy with documentation that counseling was received regarding side effects of medications or interactions with other medications before or at the time of initial prescription.

2025 revised measure description

Proportion of patients diagnosed with narcolepsy and have a narcolepsy prescription change who have documentation that counseling was received regarding side effects or interactions with other medications before or at the time of the prescription change.

Exceptions

- **Medical reasons:** None
- **Patient reasons:** None
- **System reasons:** None

Supporting evidence and rationale for revisions

This measure was originally implemented to capture medication counseling only at the time that the initial prescription was prescribed. The Task Force discussed at length and decided that not only is it important to counsel a patient on side effects or interactions for an initial prescription, but it is imperative to counsel at the time of any prescription change. One online survey study of people with narcolepsy type 1 and narcolepsy type 2 showed that treatment side effects are very common (72%) and medication changes are very often necessary (in 75%).[15]

During the public comment period a concern was raised that when a patient transfers care, but the previous prescription is continued, counseling should be conducted by the new sleep medicine provider, as it cannot be guaranteed that it was provided by the previous provider. Consequently, the term "newly prescribed" could inadvertently exclude these patients, potentially creating a safety gap. To address this concern the Task Force developed a formal definition to clarify what constitutes a prescription change. The definition is as follows: "For the purposes of this measure, a prescription change may include changes to the provider, dosing regimen, or medication."

Lastly, another public comment suggested that counseling should be provided to the parent or guardian when the patient is a minor. The Task Force agreed with this recommendation, and in response, a new notation was added: "Note: Counseling may be provided to parent and/or caregiver when appropriate." Patient and caregiver education is essential to ensure understanding of treatment protocols and potential adverse effects.[16]

Process measure #7—documented safety measure counseling

2015 measure description

Proportion of patients diagnosed with narcolepsy with documentation that counseling was received regarding age-appropriate safety measures before or at the time of diagnosis.

2025 revised measure description

Proportion of patients diagnosed with narcolepsy who received documented age-appropriate safety measure counseling before or at the time of diagnosis, and at subsequent narcolepsy related visits.

Exceptions

- **Medical reasons:** None
- **Patient reasons:** None
- **System reasons:** None

Supporting evidence and rationale for revisions

There is substantial evidence that excessive sleepiness in the workplace and on the highways is a serious safety hazard.[17]

Clinicians should regularly reassess safety during follow-up visits.[13] The Task Force thoroughly discussed the measure and reached a consensus that it is crucial to provide safety measure counseling to the patient as frequently as possible, after a diagnosis of narcolepsy. This revision underscores the Task Force's commitment to enhancing patient care through consistent and comprehensive counseling.

While reviewing the numerator language, the Task Force noted that safety measure counseling needed to be captured as a definition to provide clarification on components that may be applicable. "For the purposes of this measure, safety measure counseling may include but is not limited to education on: (1) appropriate medication usage and storage to avoid misuse and (2) the potential dangers of sleepiness and/or cataplexy which may occur at any time (eg while driving, biking, cooking) and cause injury."

Lastly, as with Process Measure 6, counseling should include the parent or guardian when the patient is a minor. The Task Force added the following notation, "Counseling may be provided to parent and/or caregiver when appropriate."

IMPLEMENTATION STRATEGIES

This revised set of quality measures can be used for AASM accreditation, benchmarking, quality improvement, research,

and/or incorporation into clinical data registries. Reporting these measures through a registry would generate valuable data that can be utilized for multiple purposes, including the validation of quality measures, the assessment of scientific acceptability, the establishment of benchmarking standards, the promotion of quality improvement initiatives, and the advancement of clinical research.

FUTURE DIRECTIONS

During the public comment period, there was a proposal to emphasize the significance of behavioral and lifestyle modifications—such as improvements in diet, exercise, sleep patterns, social engagement, and a sense of purpose—rather than focusing solely on pharmacologic interventions, since these are integral to overall health and well-being. The Task Force concurred with this suggestion and expressed a strong consensus that incorporating a process measure addressing nonpharmacologic approaches in the future would be valuable, particularly if future studies demonstrate the efficacy of such approaches. Potential approaches to be tested could include strategies such as maintaining consistent schedules, establishing regular sleep times, and promoting therapeutic napping. Lastly, these measures should undergo testing to assess both the feasibility in clinical settings and ability to produce meaningful outcomes. Long-term monitoring and data analysis will ensure that the desired outcomes are consistently achieved over time. This sustained evaluation will validate the measures' effectiveness and allow for adjustments that enhance positive self-reported outcome for patients.

ABBREVIATIONS

AASM, American Academy of Sleep Medicine
CSF, cerebrospinal fluid
EDS, excessive daytime sleepiness
MSLT, Multiple Sleep Latency Test

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DISCLOSURE STATEMENT

Dr. Revana is currently the principal investigator of a phase 2 clinical trial at Harmony Biosciences, LCC, and a consultant at Trend, LLC. Dr. Donald holds stock in the following entities: Becton, Dickinson and Company, Medtronic, Pfizer, and Zimmer Biomet Holdings, Inc. Dr. Junna is Secretary of the Minnesota Sleep Society Board of Directors. Ms. Crawford and Ms. Gray are employed by the American Academy of Sleep Medicine. The other authors report no conflicts of interest.