

Quality improvement in neurology: Multiple sclerosis quality measures

Executive summary



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All clinicians believe they provide quality care, yet most clinicians do not directly measure quality parameters in their practice to provide verifiable health care outcomes.¹ Quality measures related to a chronic disease provide reportable and repeatable measures that can either document performance of quality care or identify gaps in care for future action/improvement. Disease-specific quality measures in neurology provide a framework that can assist clinicians in practice measurement and modification; these have the potential to benefit both subspecialist and generalist alike. Multiple sclerosis (MS) is a common, chronic, and ultimately disabling disease with multiple potential clinical intervention points during its course. It is therefore appropriate to have quality measures specific for this condition that span the course of the disease.

It is estimated that MS affects about 400,000 Americans.² MS is a costly disease, and is the leading cause of disability among young adults.^{3,4} MS can culminate in irreversible functional disability with symptoms including visual or sensory disturbances, loss of strength, tremor, ambulatory problems, loss of bladder/bowel control, fatigue, spasticity, cognitive impairment, depression, and sexual dysfunction. The median time to death is around 30 years from disease onset, which represents a reduction in life expectancy of 5–10 years.⁵

In 2014, the American Academy of Neurology (AAN) formed a multidisciplinary MS quality measurement set work group to identify and construct new quality measures aimed at improving the delivery of care and outcomes for patients with MS. In this executive summary, we report on the quality measurement set developed by the work group (table).

The full measurement set, including specifications, is available in appendix e-1 on the *Neurology*® Web site at Neurology.org. The AAN Multiple Sclerosis Quality Measurement Set includes measures that can be used in quality improvement initiatives, public reporting, payment, and maintenance of certification performance in practice programs.

OPPORTUNITIES FOR IMPROVEMENT Review of the literature showed gaps in care and areas where quality measures might be used to drive improvement in the care of patients with MS. Several studies suggest that the misdiagnosis of MS is common and can lead to patient harm, such as psychological distress, socioeconomic disadvantage, and exposure to inappropriate treatments.^{6–9} Consensus statements suggest that MRI, the most sensitive method of detecting MS disease activity, is underutilized in monitoring MS disease activity in clinical practice.^{10,11} Furthermore, current standards in most practices do not include the use of scored disability ratings, despite the availability of a wide range of validated instruments including patient self-report instruments. The use of such instruments would allow for the more accurate tracking of disease progression and disability.¹² Fall screening is also an opportunity for improvement: patients with MS have an increased risk of falls, do not spontaneously report falls to health care providers, and fall history has been shown to be a good predictor of future falls.^{13–16} Bladder infections are common in patients with MS and proper management can reduce the risk of infection, offering an opportunity for improvement.¹⁷ Despite the known benefits of exercise and physical activity, many persons with MS remain inactive, offering an

GLOSSARY

AAN = American Academy of Neurology; **DMT** = disease-modifying therapy; **ICD** = *International Classification of Diseases*; **MS** = multiple sclerosis.

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Supplemental data
at Neurology.org

Table Multiple sclerosis measurement set

1. MS diagnosis	Percentage of patients who received a new diagnosis of MS in the past 12 months who fulfilled international criteria
2. Comparison MRI within 24 months of MS diagnosis	Percentage of patients with MS who had an MRI with and without gadolinium within 24 months of diagnosis compared with a baseline MRI
3. Current MS disability scale score	Percentage of patients with MS who have an MS disability scale score documented in the medical record in the past 12 months
4. Fall risk screening for patients with MS	Percentage of patients with MS who were screened for fall risk in the past 12 months
5. Bladder infections for patients with MS	Percentage of patients with MS who have had a bladder infection in the past 12 months
6. Exercise and appropriate physical activity counseling for patients with MS	Percentage of patients with MS who were counseled on the benefits of exercise and appropriate physical activity for patients with MS in the past 12 months
7. Fatigue outcome for patients with MS	Percentage of patients with MS whose most recent score indicates results are maintained or improved on a validated fatigue rating instrument for patients with MS in the past 12 months
8. Cognitive impairment testing for patients with MS	Percentage of patients 18 years and older with MS who were tested for cognitive impairment in the past 12 months
9. Clinical depression screening for patients with MS	Percentage of patients aged 12 years and older with MS who were screened for clinical depression using an age-appropriate standardized depression screening tool at least once in the past 12 months
10. Depression outcome for patients with MS	Percentage of patients aged 12 years and older with MS whose most recent score indicates results are maintained or improved on a validated depression screening instrument for patients with MS in the past 12 months
11. Maintained or improved baseline quality of life for patients with MS	Percentage of patients with MS whose most recent score indicates results are maintained or improved on an age-appropriate quality of life tool in the past 12 months

Abbreviation: MS = multiple sclerosis.

Readers are encouraged to view complete measure definitions and specifications in appendix e-1. The appendix also addresses how the measures will address opportunities for improvement.

opportunity for improvement.^{18,19} Fatigue occurs in about 80% of persons with MS and has an impact on physical activity and daily functioning.²⁰ Behavioral strategies and medications can improve fatigue, offering an opportunity for improvement.²¹ Cognitive impairment is reported by 40%–70% of patients with MS, yet the most widely used screening tool for cognitive function, the Mini-Mental State Examination, is insensitive to the changes most commonly found in patients with MS.^{22–24} Cognitive rehabilitation has been shown to be beneficial in patients with MS, providing an opportunity for improvement if cognitive complaints are ascertained. Depression is common in patients with MS but is underdiagnosed and undertreated.²⁵ Use of simple screening tools could increase the recognition of depression and thus the use of appropriate

treatments. MS has a negative impact on quality of life that can be improved by the proper use of disease-modifying and symptomatic therapies.⁴ Monitoring quality of life provides a way to assess a patient's overall management.

METHODS Project leadership for the MS quality measurement set was provided by the AAN, who has designed and coordinated several quality measurement sets, including headache, 2013 epilepsy update, and amyotrophic lateral sclerosis.^{26–28} Details of the full AAN measurement development process are available online.²⁹

The AAN aimed to convene a cross-specialty and multidisciplinary expert work group, and therefore solicited a broad representation of key stakeholders by inviting nominations for expert panel members from physician and nonphysician associations, MS patient and caregiver advocacy organizations, health plans, and large group employers. The selected work group consisted of 23 members (a list of work group members and contributing organizations follows this article): 6 MS specialists, 3 patient organization representatives, 3 nurse practitioners, 2 rehabilitation specialists, 1 occupational therapist, 1 physical therapist, 1 psychiatrist, 1 neuropsychologist, 1 insurance plan representative, 1 patient representative, and 3 facilitators. All work group members are required to disclose potential conflict of interests and completed an application summarizing experiences and interest.

The co-chairs independently select members from the pool of qualified specialists and experts who respond to the nomination call. The selection was based on the nominee's experience in performance measures, quality improvement, and clinical activities. In addition, requests for nominations were sent to relevant physician organizations and patient advocacy groups. Large health care organizations or insurers were also invited to nominate individuals for the work group.

The work group followed the AAN measure development process, which requires completing an evidence-based literature search, drafting candidate measures and technical specifications, establishing a multidisciplinary work group adhering to the AAN conflict of interest policy, convening in person to review candidate measures, refining and discussing the candidate measures, soliciting public comments on approved measures during a 30-day period, refining the final measures according to input received during the public comment period and corresponding technical specifications, and obtaining approvals from the work group, AAN Quality and Safety Subcommittee, AAN Practice Committee, and AAN Institute Board of Directors.²⁹

The work group sought to develop measures to support the delivery of high-quality care and to improve patient outcomes. A rigorous review of the evidence occurred. The co-chairs and facilitators, guided by a medical librarian, conducted a comprehensive search identifying over 557 abstracts and winnowing results to locate 13 guidelines and 1 consensus paper used as the evidence base for the measures developed.

The work group also strove to balance the burdens of measures on clinicians and patients against the benefit of these measures in guiding quality care. The AAN will update these measures on an ongoing basis every 3 years, and thus the measure set provides a working framework for measurement, rather than a long-term mandate.

RESULTS The work group met on June 30, 2014, discussing and voting to approve 13 candidate

measures for public comment. Following public comment, the measurement set was revised and the work group ultimately approved 11 measures for inclusion in the AAN 2015 Multiple Sclerosis Quality Measurement Set (table).

It is impossible for one quality measurement set to address all quality of care issues in MS. The measures developed reflect consensus decisions about how gaps in care could be improved and where clinical evidence exists to support the measures. The measures primarily are intended for use in quality improvement efforts. The final measures span the natural history of MS from diagnosis to later disability. Two measures explicitly were not recommended for use in accountability programs (Multiple Sclerosis Diagnosis and Comparison MRI Within 24 Months of MS Diagnosis) due to the potential burden of locating information via chart review.

Four measures are intended to be applied at the system or accountable care organization level, and these include measures to address bladder infections, fatigue, depression, and quality of life. Use of these measures to compare individual providers or practices would require the application of a valid risk adjustment methodology, which does not yet exist for MS or any other disease populations. These measures may be used for accountability at the system or accountable care organization level if the MS populations being compared are similar in demographics, socioeconomic status, and the prevalence of comorbid conditions. These measures may also be used for internal, non-publicly reported quality improvement for a patient population that is not subject to significant change, as risk adjustment or stratification would not be required. The work group determined the Cognitive Impairment Testing for Patients with MS should also apply only to the system or health plan level of care for use in accountability programs. The AAN encourages a minimum sample size of 20 for use in public reporting programs to further reduce likelihood of error. The number 20 reflects current CMS sample requirements for Hospital Compare public reporting.

At the beginning of this project, the work group determined the scope would be limited to MS, meaning that neuromyelitis optica and clinically isolated syndrome were excluded. The work group considered several other important constructs in care for people with MS, including MS relapse, spasticity, mobility, visual deficits, and disease-modifying therapy (DMT) use. Development of a relapse measure was deemed to be of high importance given the fact that reduction in the number of relapses is considered to be one of the most important desired outcomes for a patient with MS. However, potential measure drafts were noted to be potentially difficult or impossible to

measure, difficult or impossible for a practitioner to act upon, and cost-inefficient. Development of a measure related to DMT was evaluated, but there was lack of published data supporting a treatment gap in care. There were also concerns that a denominator could be accurately identified using administrative data with limitations in *ICD* coding (i.e., specifically to relapsing-remitting MS vs progressive MS). The work group began to develop measure concepts to address mobility and visual deficits, but these did not receive high enough priority for further development following the in-person meeting.

The work group announced and accepted public comments on the draft measurement set during August and September 2014. During the public comment period, 87 individuals provided over 600 comments on the draft measurement set. As a result of public comments and concern, the proposed measures on “pain assessment” and “fall follow-up plan” candidate measures were withdrawn from the final set the work group approved for public comment. The pain assessment measure was withdrawn due to concern that it unnecessarily duplicated existing measures. In its place, the work group encourages individuals to consider National Quality Forum–endorsed measure 0420 (adopted into the Physician Quality Reporting System measure 131) to address patient pain concerns. The fall follow-up measure was withdrawn due to potential difficulty locating follow-up plan documentation, which would potentially require burdensome chart review, as the information would not be easily accessed in an electronic health record.

The full measurement set specifications are available in appendix e-1.

DISCUSSION Improving the quality of health care is essential in the practice of medicine. Fundamental to these efforts to improve quality is the ability to measure care because we cannot improve what we do not measure. These measures are intended to be used by stakeholders to quantify the quality of care provided to patients with MS. There are several statewide, national, and private and public payer efforts to hold health care providers formally accountable for the quality of their care. AAN-developed measures may be considered for use in these programs as well as other public reporting programs; these measures are based on existing guidelines and in part are intended to help focus providers on these standards of care.

Just as the work on guidelines is never complete, there will always be ongoing work on a measurement set. As the medical literature is updated, guidelines will be updated, and subsequently, quality measures will be updated as well. In addition to re-reviewing the clinical

content of a measure, further validation research will be needed to measure the process–outcome link, which consists of using these measures and determining whether they lead to better health. Finally, if future studies show that there is little to no gap in care, that measure may be retired even if it has strong medical evidence to justify doing it.

The AAN is monitoring the field of quality measurement, and there are major changes under way. Some of these trends include thinking about outcomes of care in addition to process of care, focusing on patient-centered instead of clinician-centered measures, considering overuse measures in addition to underuse measures, including costs of care into the measures, and thinking about measures that can be more easily incorporated within electronic health records. None of these features was highlighted in the first AAN measures published only 5 years ago, demonstrating the speed of change in this arena. These attributes are being incorporated in AAN guidelines, and as such, the AAN Quality Measurement Subcommittee will be incorporating them in future measures.

AUTHOR CONTRIBUTIONS

Dr. Rae-Grant contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. A. Bennett contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Sanders contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Phipps contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Cheng contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Bever contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision.

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CONFLICT OF INTEREST

The American Academy of Neurology is committed to producing independent measurement sets. Significant efforts are made to minimize the potential for conflicts of interest to influence the finalized measures. Conflict of interest forms were obtained from all authors and reviewed by an oversight authority prior to project initiation. All potential conflicts of interest are resolved in accordance with the AAN's Policy on Conflicts of Interest and as described in the 2014 AAN Measurement Manual.²⁹ The AAN forbids commercial participation in, or funding of, measure development and initial distribution.

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