Multiple sclerosis (MS) is a disabling immune-mediated disease of the CNS and considered one of the health conditions with the highest annual spending growth paid by both public and private insurance. Health care spending in the United States for MS was reported as $13.9 billion in 2016. The estimated cumulated (over 10 years) prevalence of MS among adults in the United States in 2010 was approximately 727,000. In 2017, that number was substantially higher, approximately 914,000. The prevalence is higher among women, with a female: male ratio of 2.8. Improving high-quality care for these patients can lead to improved outcomes, reduced spending, and better quality of life.

The American Academy of Neurology Institute (AANI) released the original MS quality measurement set in 2015, aimed at improving the delivery of care and outcomes for patients with MS. The AANI measure development process requires a triennial review of measures to confirm whether evidence remains current, a gap in care remains for measurement, and response to any measure implementation and testing data. A standing multidisciplinary MS quality measurement work group was seated for a 2-year term to conduct an initial review of evidence and to be available for the development of quality improvement and implementation tools. The work group members are also responsible for reviewing MS quality measure data from the AANI’s quality improvement registry: the Axon Registry.

Methods
Details of the AANI’s full measure development process are available online. A call for multidisciplinary work group members was made to representative neurologists, patients, and advocates. The application process was managed by 2 nonvoting facilitator methodologists seated from the AANI’s Quality Measurement Subcommittee and Quality Committee. Applicant subject matter expertise and measure development experience was reviewed in conjunction with review of disclosure statements to select the work group members. The AANI measure development process requires disclosure of industry relationships and other entities to avoid actual, potential, or perceived conflicts of interest. Work group members were instructed to abstain from voting on individual measure concepts if a conflict was present.

An initial literature search was conducted with the help of a medical librarian and resulted in 1,974 abstracts identified from EMBASE and MEDLINE. The literature search results were winnowed to 356 articles. These articles included potential guidelines, systematic reviews, meta-analyses, articles containing evidence of gaps in care for patients with MS, or articles summarizing patient and care partner preferences. The work group also reviewed performance data from Axon Registry and Axon Registry participant data to determine whether measures...
should be updated, reaffirmed, or retired. The work group made initial retirement, reaffirmation, and update determinations (figure). New concept proposals were submitted by work group members. These concepts were then ranked for priority in development. Following ranking, the work group met virtually to refine concepts and discuss which measures should be retired. Six concepts were edited, finalized, and individually approved for public comment.

The AANI promotes the public comment period to diverse stakeholders: physician, patient, payer, industry, and care partner organizations. Individuals who comment are not required to disclose their designations, although some voluntarily provide this information. During the 21-day public comment period, 25 individuals submitted comments. The comments received were made by physicians, advance practice providers, and neuropsychologists. One comment was submitted on behalf of the Centers for Medicaid and Medicare Services and one on behalf of a specialty society, the Inter-Organizational Practice Committee, which is composed of representatives from the American Academy of Clinical Neuropsychology/American Board of Clinical Neuropsychology, the National Academy of Neuropsychology, the American Psychological Association, the American Board of Professional Neuropsychology, and the American Psychological Association Services, Inc.

Following review of individual comments on each measure concept, the work group met to address the comments and discuss advancement of these measure concepts. The 6 measure concepts were further edited in response to public comment and finalized (table). Then the work group, AANI’s Quality Measure Subcommittee, Quality Committee, and Board of Directors voted and approved the measurement set.

**Opportunities for Improvement**

The work group developed 6 measures for the 2020 update (table). There is no requirement that all the measures in the measurement set be used. Providers and treatment teams are encouraged to identify measures that would be most meaningful to their patient population and implement those measures to drive performance improvement in practice. Practices should evaluate whether they have sufficient resources to collect the required data for quality improvement projects and how much value review of this data would bring to their organization. Collecting data on all measures may be burdensome and identifying a subset of measures may prove more meaningful to drive change in practice. Data should be collected and analyzed during an initial benchmark period, and the results used to drive meaningful changes to improve performance and overall care.

The work group reviewed the existing MS quality measures use/utilization data to make the initial retirement and update determinations (figure). Work group members were then asked to propose potential new concepts focusing on the measure concepts that are feasible to collect, do not pose an excessive burden on providers to collect data, are meaningful to quality improvement efforts, and address a known treatment or care gap. It is important to recognize the fact that it is not feasible for the work group to develop all the appropriate concepts due to resource limitations and consideration for minimizing provider reporting burden.

The proposed new concepts addressed multiple facets of MS care and patient experience, including but not limited to comorbidities, anxiety, gait, caregiver burden, spasticity, swallowing and dysphagia, reproductive health, employment, lifestyle management, rehabilitation, and pain. It is not reasonable to create a measurement set to address all these needs as doing so would place a burden on physicians and treatment teams to collect necessary data. Through a Modified Delphi Process using 1 round of ranking, work group members prioritized 3 newer concepts for discussion. Two concepts on disease-modifying therapy (DMT) and fatigue screening were developed for public comment. One concept on relapse or disability monitoring for patients with MS was not. The concept of measuring relapse and disability monitoring was identified as being of high value to all involved in MS care. The work group plans to monitor evidence related to these measures, advances in electronic medical record coding capabilities for capturing MS-related symptoms and comorbidities, and physician documentation practices to determine whether a measure incorporating relapse or disability can be developed during a future update of the measurement set.

**Results**

Six measures were developed in the 2020 update (table): MRI monitoring for patients with MS; DMT’s monitoring for patients with MS; bladder, bowel, and sexual dysfunction screening and follow-up for patients with MS; cognitive impairment screening and follow-up for patients with MS; fatigue screening and follow-up for patients with MS; and exercise and appropriate physical activity counseling for patients with MS.

Seven measures were retired (figure): MS diagnosis; current MS disability scale score; fall risk screening for patients with
MS; fatigue outcome for patients with MS; clinical depression screening for patients with MS; depression outcome for patients with MS; maintained or improved baseline quality of life for patients with MS. Full measurement specifications are available online at aan.com/policy-and-guidelines/quality/quality-measures2/quality-measures/multiple-sclerosis/.

This is the first update to the 2015 measurement set and it is anticipated that future iterations will continue to evolve as more implementation and testing data and user feedback become available. The measurement set includes measures that require the use of validated screening tools. The work group discussed and determined that multiple tools should be offered to allow providers to determine which tool best meets their individual practice needs. The length of time needed to complete the tools in practice will vary. The work group tried to identify brief screening tools completed in 5–10 minutes when possible and examples are provided below on using a planned visit model to reduce implementation burden on physicians. Use of standardized tools requires rigorous adherence to the methods. Physicians should be adept at methods before implementing a quality measure that requires use of a standardized tool. Tools may be subject to copyright and require licensing fees. The work group notes that effective September 2020 Montreal Cognitive Assessment use requires completion of a proprietary examination and fee.

The work group reviewed the 2015 MS measures after a pragmatic review of current evidence. New measures were developed based on important areas of MS care that the work group believed were not adequately reflected in prior measures, weighing the important factors of measurability within an electronic medical record framework, burden on the health care team of measurement, and whether there was a gap in care related to the measure. Four of the 6 updated measures related to symptoms or activities, reflecting an increased focus on measures that were important to the patients with MS. A new measure on monitoring of DMT reflected their importance within the field of MS care, and another new measure on MRI monitoring reflected the central role of MRI surveillance in assessing patients for subclinical disease. Other measures that were not adopted did not meet this framework for selection.

MRI monitoring for patients with MS captures the percentage of patients who had a brain MRI scan in the last 24 months and care management decisions updated. This measure is not intended to monitor baseline or re-baseline activity specifically. The measure is intended to address a gap in care for patients and prompt providers to consider modifying management decisions based on imaging results. The MRI changes may not always prompt treatment modifications, but providers consider the MRI data to assess whether they are indicated in an individual patient. The work group discussed and agreed upon the 24-month period. The specific 24-month time frame for imaging was rigorously discussed; ultimately this timeframe was chosen to help accommodate reasonable variations that affect patient care such as gaps in insurance coverage, cost, availability of MRI in rural communities, and access to a neurologist in rural communities. There are patients with MS who may require more frequent MRI studies to monitor for progressive multifocal leukoencephalopathy such as those prescribed natalizumab, patients with clinical disease activity, or those switching DMTs; these patients should be treated in accordance with current guideline statements.

DMT monitoring for patients with MS captures the percentage of patients with MS prescribed a DMT who were screened for side effects and compliance/adherence. By screening and monitoring patients with MS prescribed DMTs, clinicians will be able to identify patients with side effects and patients who are not adhering to treatment. Once these issues are identified, clinicians will be able to modify/
alter treatment plans or propose measures to address side effects and compliance/adherence issues to help improve outcomes and quality of life. This current measure is focused on monitoring patients following the initiation of a new DMT during the measurement period. Future iterations of the measure may evolve over time to include continued monitoring for all DMTs. The work group will assess feasibility, documentation burden, and unintended consequences during future reviews.

Bladder, bowel, and sexual dysfunction screening and follow-up for patients with MS captures the percentage of patients with MS who were screened for at least 1 of 3 symptoms: bladder, bowel, or sexual dysfunction in the past 12 months, and if screening positive had appropriate follow-up care. By screening annually for bladder, bowel, and sexual dysfunction, clinicians will be able to identify patients needing appropriate treatment to address these issues, leading to improved outcomes and better quality of life. The 2010 North American Research Committee on Multiple Sclerosis Registry data indicated that 91% of 9,341 patients with MS responding were mildly, moderately, or severely bothered by bladder, bowel, or sexual symptoms.8 Fifty percent to 90% of men with MS and 40%–80% of women with MS experience sexual dysfunction, which is significantly higher compared to the general population.9 Sexual dysfunction symptoms are often overlooked in clinical evaluations of patients with MS.9 Schairer et al.10 found that

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<td>MRI monitoring for patients with MS</td>
<td>Patients who had a brain MRI scan in the last 24 months and care management decisions updated</td>
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<td>DMT monitoring for patients with MS</td>
<td>Patients who were screened on date of encounter for DMT side effects and compliance/adherence with DMT</td>
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<td>Bladder, bowel, and sexual dysfunction screening and follow-up for patients with MS</td>
<td>Patients with MS who were screened for at least 1 of 3 symptoms: bladder, bowel, or sexual dysfunction in the past 12 months, and if screening positive had appropriate follow-up care</td>
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<tr>
<td>Cognitive impairment screening and follow-up for patients with MS</td>
<td>Patients with MS were screened for cognitive impairment in past 12 months, and if screening positive, patient was referred appropriately for further evaluation and management</td>
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<tr>
<td>Fatigue screening and follow-up for patients with MS</td>
<td>Patients with MS who were screened for fatigue in past 12 months, and if screening positive were provided appropriate follow-up</td>
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<tr>
<td>Exercise and appropriate physical activity counseling for patients with MS</td>
<td>Patients with MS counseled on the benefits of exercise and appropriate physical activity for patients with MS in past 12 months</td>
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Abbreviations: DMT = disease-modifying therapy; MS = multiple sclerosis.
The measurement period for all measures is January 1, 20xx to December 31, 20xx.
sexual dysfunction has a larger detrimental effect on mental health and quality of life related to health for patients with MS than physical disability. For this first iteration of the measure, a broad definition of screening was provided; clinicians may use a validated instrument. The work group notes these instruments are not widely used in practice. The measure may be updated in future reviews to include more specific instruments as they become more widely used in practice.

Cognitive impairment screening and follow-up for patients with MS captures the percentage of patients with MS who were screened for cognitive impairment in the past 12 months and the patients with positive screening were referred appropriately for further evaluation and management. Cognitive functioning affects life satisfaction and health-related quality of life. It is anticipated that if assessed on an ongoing basis, cognitive deficits may be identified and addressed in a timely manner. Once identified, such deficits could be treated (or patients referred to appropriate resources) and thereby help improve individuals’ quality of life. Cognitive impairment may be seen in 43%–70% of people with MS. In absence of regular objective assessment, cognitive impairment can be missed. Clinical interview and standard neurologic examination are not very sensitive to detect cognitive impairment in MS, and hence the need for a brief, accurate cognitive screening. Screening should start early, given the evidence that cognitive impairment may start early for patients with MS and appropriate referrals provided for potential positive results or changes with intervention. The Mini-Mental State Examination was not included in the list of screening tools due to concerns that the tool is not sufficiently sensitive to detect the most common cognitive deficits seen in patients with MS.

Fatigue screening and follow-up for patients with MS captures the percentage of patients 18 years and older with diagnosis of MS who were screened for fatigue in past 12 months, and if screening positive, were provided appropriate follow-up. The desired outcome is to reduce or eliminate fatigue in patients with MS; however, as the cause of fatigue can be multifactorial, the immediate goal is to identify and address fatigue so the proper interventions can be undertaken/pursued. The measure will provide an incentive for providers to identify and manage fatigue in patients with MS. Fatigue occurs in about 80% of patients with MS, causing decreased physical activity and level of daily functioning. It is anticipated that addressing fatigue with appropriate follow-up measures may result in increased ability to function at work and home and in improved quality of life for patients with MS.

Exercise and appropriate physical activity counseling for patients with MS captures the percentage of patients with MS who were counseled on the benefits of exercise and appropriate physical activity in the past 12 months. This measure was reaffirmed by the work group without substantial updates. The work group reviewed use data from the Axon Registry that supports a continued gap in care being addressed with Centers for Medicare and Medicaid Services (CMS) benchmark data from 2019 indicating average performance for those reporting the measure for Merit-Based Incentive Payment System (MIPS) was 73%. Seven of the original MS quality measures were retired. Measures may be retired for multiple reasons, and retirement does not reflect a lack of value in quantifying a concept. The work group believes these concepts retain value, but measures were retired due to feasibility concerns or existence of cross-cutting measures that include patients with MS in the denominator. The AANI is encouraging quality measurement development work groups to limit the number of measures available for an individual disease topic to reduce clinician burden, focus on fewer meaningful measures for quality improvement, and allow for testing of measures to be developed. Rationales for individual measure retirement are detailed in the following:

- **MS diagnosis:** The work group retired this measure because of the large burden for data collection placed on physicians and care provider teams, including potentially requiring them to modify their documentation practices.
- **Current MS Disability Scale score:** This measure was previously incorporated in the AANI’s Axon Registry. Implementation concerns were identified as the data were being collected in the registry. It was noted that some of the disability scales approved for use in the measure would not be collected on the date of the patient visit and collected at a later follow-up visit. CMS had approved the measure for use by a Qualified Clinical Data Registry through 2019, following which CMS added a modification to include a follow-up component to the collection of the scale score. Adding a follow-up component would add another layer of complexity, reducing feasibility further. The work group also noted that an outcome measure would be difficult to develop on the topic given the varied scale use by neurologists and inconsistency of documentation by practice settings. Given these concerns, the measure was retired and discussion was held on development of a relapse or disability-related measure.
- **Fall risk screening for patients with MS:** The work group retired this measure given the existence of cross-cutting falls measures. The work group encourages providers to utilize one of the following measures to monitor and track falls and fall outcomes in practice (MIPS quality measure specifications are available at qpp.cms.gov): for patients 65 and older: MIPS quality ID #318 (Falls: Screening for Future Fall Risk), MIPS quality ID #154 (Falls: Risk Assessment), and MIPS quality ID #155 (Falls: Plan of Care); for patients 64 and younger: Axon Registry ID #64: Patient-Reported Falls and Plan of Care.
- **Fatigue outcome for patients with MS:** The fatigue outcome measure was retired due to concerns that a physician or MS treatment team has little control over changes in fatigue screening scores that are likely affected...
by multiple causes including other comorbid conditions treated by other specialists. As a result, the measure was changed to a screening and follow-up measure.

- Clinical depression screening for patients with MS and depression outcome for patients with MS: The work group retired the prior depression assessment and outcome measures given the existence of cross-cutting depression measures. The work group encourages providers to utilize one of the following measures to monitor and track depression outcomes in practice: MIPS quality ID #134: Preventive Care and Screening: Screening for Depression and Follow Up Plan (process measure for patients 12 years and older screening for depression using standardized depression screening tool, and if positive, a follow-up plan is documented); MIPS quality ID#370: Depression Remission at Twelve Months (outcome measure at 12 months for patients age 18 years and older diagnosed with major depression or dysthymia utilizing Patient Health Questionnaire–9 scores).¹⁷

- Maintained or improved baseline quality of life for patients with MS: The work group retired the prior quality of life for patients with MS measure due to the existence of cross-cutting measures addressing quality of life for patients with MS. The work group encourages providers to utilize Axon Registry ID #54: Quality of Life for Patients with Neurologic Conditions.⁶

**Discussion**

This measure set update is part of an ongoing effort to provide individual providers, practices, and health care systems with tools needed to improve the delivery of care to patients with neurologic conditions.

These MS measures do not represent all aspects of MS care but provide a framework for quality improvement in practice. Limitations of this process include incomplete feedback on the usability of these MS measures in clinical practice that the ongoing reporting in registries such as Axon Registry and learning health collaboratives may improve upon; limited information in the literature on gaps in measurable MS management activities; and lack of data on variation in practice related to new measure development that might support gap analysis. It is hoped the future refinement/modification of Axon Registry will provide a more direct feedback loop for neurologic measures set development. The American Academy of Neurology is cognizant of the need to address these limitations, and one of the explicit reasons to house the Quality Measure Subcommittee and Registry Subcommittees under the Quality Committee was to support provision of such feedback for continuous quality improvement.

The quality measures presented here were developed for use in quality improvement projects for patients with MS and to ensure measures specific for this condition span the course of this disabling disease. Measures developed by the work group may be submitted for consideration in CMS’s MIPS program or used by private payers to track provider performance after testing is completed. It is important to note that these are not intended to serve as a comprehensive guideline to caring for a patient with MS. The work group will be revisiting these measures periodically to ensure they remain relevant and feasible. Many other potential measures were discussed by the work group and believed to be of great importance in providing care, such as relapse or disability monitoring and patient-reported missed work or school days, but at present are not feasible to collect or pose a significant burden to the end user; as data extraction techniques change and improve, concepts not included in this finalized measure set may be considered in future revisions. Ongoing measure revision and development will continue with a multidisciplinary work group to ensure that these measures are meaningful to providers as well as the patients they care for.

**Examples of Using AANI Quality Measures in Practice**

For example, Dr. Ige is in a 5-neurologist practice, and decides to use the exercise and appropriate physical activity counseling for patients with MS measure. Dr. Ige is surprised to find a baseline performance of 35% of her patients received counseling. Dr. Ige asks the information technology support staff to put in a best practice alert in the electronic health record for recommendations on exercise and counseling for patients. The information technology staff also update the templated note to add a section and prompt for this counseling. Dr. Ige and team identify existing Internet resources for individuals with limited mobility and those with no restrictions on range of motion that can be used without need to create new materials. Dr. Ige collaborates with her medical assistant staff to provide appropriate education materials after she completes her examination in the after visit summary. After 6 months, the measure shows improvement, and 79% of patients are now receiving counseling. If reporting on this measure for MIPS, Dr. Ige’s performance is now higher than the 2020 average performance rate of 73% and would indicate a potential award of 6 points for the 2020 performance year on this quality measure.¹⁶

In another scenario, Dr. Anderson is in an academic practice with 30 neurologists and decides to use the fatigue impairment screening and follow-up for patients with MS measure to improve care. First, Dr. Anderson discovers that not all of his patients received screening and only 47% were provided follow-up care when fatigue concerns were identified. Dr. Anderson discusses results with the department chair. The practice agrees to pilot a quality improvement project for 5 patients identified with poor quality of life results. The practice pilots using a planned office visit to collect screening information prior to appointments. In the planned office visit model, Dr. Anderson’s team sends out a fatigue screening
instrument via their patient portal 3 days in advance of the appointment. Patients without access to the portal are asked to complete the screening instrument when they arrive for their appointment. Answers and scores are reviewed and entered by roaming staff for Dr. Anderson to review and use as a guide for management planning during the visit. Dr. Anderson’s team also begins hosting community support groups in the office setting, monitoring comorbid psychiatric symptoms, and assisting with access to specialist care for sleep and fatigue issues. Not all piloted interventions are successful or feasible to maintain due to cost, but after 3 months Dr. Anderson notes that 62% of his patients now receive screening and follow-up. Perfection is not the goal, but through small steps demonstrable improvements can be made.

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Dr. Rae-Grant reports currently serving as neurology editor for DynaMed, a subscription-based point of care tool for clinicians with no industry support or advertising; royalties from 2 textbooks he has published, 1 on neurology and 1 on multiple sclerosis; and organizes neurology review courses. Dr. Amezcuea reports active research support from the National MS Society, NIH NINDS, Bristol Myers Squibb Foundation, and Biogen Idec; has served as a consultant to Biogen Idec, Novartis, Alexion Pharmaceuticals, Genentech, EMD Serono, and AbbVie; and has served as primary investigator for clinical trials with MedDay, Genentech, and PCORI. Dr. English reports serving on a Board of Directors for the Consortium of Multiple Sclerosis Centers; has served as consultant to Biogen-Idec, Novartis, Sanoﬁ-Genzyme, Genentech, EMD Serono, Teva, Raptor, and AbbVie; served as speaker consultant for the MS Association of America and National MS Society; and is a founding member of Healthcare Impact Partners and HIP Nation. Dr. Garg reports no disclosures. Dr. Giesser reports royalties from 2 multiple sclerosis publications and has received a consulting fee from Greenwich Biosciences. Dr. Kelly reports no disclosures. Dr. Collazo has no disclosures relevant to this project. A. Montague, Dr. Olek, and E. Page report no disclosures. Dr. Bennett is an employee of the American Academy of Neurology. Dr. Caller has no disclosures relevant to this project. Go to Neurology.org/N for full disclosures.

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