Multiple Sclerosis Quality-of-Care Performance Measure

NATIONAL QUALITY FORUM

WHAT IS THE PROJECT?

Multiple Sclerosis (MS) is an unpredictable disease of the central nervous system with a spectrum of diverse symptoms. This makes development of quality measures for persons with MS challenging and means that understanding a patient's preferences, values, and choices with respect to his or her unique symptoms and quality of life is critical to defining the most meaningful outcomes. Given the nature of the condition and the scarcity of quality measures to assess care for patients with MS, there is a need to develop more measures in this area.

This NQF Measure Incubator™ project seeks to facilitate the development of a performance measure for MS that reflects the outcomes that are most important to individuals with MS and uses information collected directly from those patients (i.e., patient-reported outcomes or PROs).

As a first step, NQF convened a Measure Incubator strategy session with a multistakeholder Expert Panel in late 2016. In this session, participants worked to identify a PRO measure concept that could be turned into a measure of performance for care of individuals with MS. The Panel recognized the value of periodic assessments of PROs paired with timely action by the clinician in improving patient care and advancing performance measurement for MS. The Expert Panel also noted the need for flexibility in accommodating patient preferences while not unduly burdening patients or providers.

Building on the findings from the strategy session, the project entered the measure development phase. The measure developer is gathering additional data from persons with MS to further refine the measure concept. Working with clinical practice sites, the developer will test a performance measure focused on patient-reported outcomes in the clinical setting.

WHO IS INVOLVED?

NQF has engaged diverse stakeholders in this Measure Incubator project, including individuals with MS, specialty society representatives, providers, and experts in PRO research and measure development. Drs. David Cella, Cindy Nowinski, and Aaron Kaat of **Northwestern University** and Dr. Anne Deutsch (of **Shirley Ryan Abilitylab** and **RTI International**) will develop and test a performance measure assessing the use of an MS-specific PRO in clinical care based on the recommendations of the Panel.

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WHAT IS THE ENVISIONED OUTCOME?

At the strategy session, the Panel determined that it is too early to develop a specific PRO performance measure (PRO-PM) given the limited evidence on what symptoms and outcomes are most meaningful to patients with MS. The measure developers are compiling an MS-specific patient-reported outcome measure (PROM) using existing validated instruments, such as the Neuro-QoL, and patient input. Using the Neuro-QoL, the developers are working on a performance measure that evaluates whether the measured entity has reviewed and acted on patient-reported information during MS care. The measure developers will also test the tool and performance measure in clinical practice sites. This project will be completed in mid-2019.

The resulting measure will be a critical first step toward development of outcome measures for persons with MS that reflect the voice of the patient.

To learn more about this project, the **Measure Incubator™**, **Learning Collaborative**, or how to incubate a measure, please contact NQF at **incubator@qualityforum.org.**