



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 facilitated the initial 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).

PHASE 1: STRATEGY SESSION

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 discussion was informed by **broad patient input compiled by PatientsLikeMe® and NQF** from over 50,000 patients 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.

NQF engaged diverse stakeholders in this Measure Incubator project, including individuals with MS, specialty society representatives, providers, and experts in PRO research and measure development.

PHASE 2: MEASURE DEVELOPMENT

Building on the findings from the strategy session, the project entered the measure development phase in 2017. Drs. David Cella, Cindy Nowinski, and Aaron Kaat of **Northwestern University** and Dr. Anne Deutsch (of **Shirley Ryan AbilityLab** and **RTI International**) developed a performance measure assessing the use of an MS-specific PRO in clinical care based on the recommendations of the Panel. The measure development team gathered additional data from persons with MS to further refine the measure concept.

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 compiled 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 drafted a performance measure that evaluates whether the measured entity has reviewed and acted on patient-reported information during MS care. This work was completed in late 2018.

NQF closed out this project in 2018 after achieving the significant milestones above.

This work creates a solid foundation for further development and represents a critical first step toward development of outcome measures for persons with MS that reflect the voice of the patient.

This project was funded by **Biogen**. In accordance with the **NQF Measure Incubator Conflict of Interest Principles**, Biogen has not influenced the outcomes and activities associated with this project.

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