NATIONAL QUALITY FORUM

To: Neurology Standing Committee
From: NQF Staff
Re: Neurology Off-Cycle Webinar #2
Date: August 28, 2017

Dial-In and Webinar Information

- August 28, 2017, 3:00-5:00PM ET
- Speaker Conference Line: (855) 696-3824; NO CONFERENCE CODE REQUIRED
- Web Link: http://nqf.commpartners.com/se/Rd/Mt.aspx?854454

Objectives

The objectives for today's webinar are to:

1. Discuss revisions to the Neurology Framework for Performance Measure development
2. Review NQF Measurement Prioritization criteria
3. Categorize neurology measures according to priority level and high impact outcomes
4. Identify gaps in current portfolio

Revisions to the Neurology Framework for Performance Measure Development

A measurement framework supports --*judgements about the degree to which the components of a healthcare delivery system contributes to improving health, reducing burden of illness and maximizes resources allocated to healthcare.* During the Committee's last off-cycle webinar, the Committee agreed that the framework should be updated to include neurological conditions based on global disease of burden and more emphasis on patient engagement and the patient voice. The revised framework is summarized below. See Appendix A for an illustration of the framework.

Neurological Conditions

This episode of care framework offers an approach that highlights neurology priority conditions, outlines the phases of care, incorporates the patient/caregiver voice and engagement and integrates NQF's focus on High Impact Outcomes. Two important aspects of the framework is the focus on the longitudinal chronic phase and incorporation of the patient voice and engagement throughout each phase.

The Global Burden of Disease and DALY (disability-adjusted life years) provided estimates of mortality and disability for the combined burden of neurological and cardiovascular diseases.[1] The DALY has two components: years of life lost due to premature mortality and years lived with disability. When evaluating the burden of disease using these metrics for Neurological and Cardiovascular conditions, the following six conditions represent burden internationally: Stroke (including hemorrhagic, ischemic), Headache (tension and migraine), Dementia (Alzheimer's disease), Epilepsy, Parkinson's disease and Multiple Sclerosis. Additionally, Traumatic Brain Injury (TBI) represents a significant disease burden.

US statistics demonstrate the incidence, prevalence, and costs of all seven conditions.

- Strokes are the fifth leading cause of death in the US & a leading cause of disability and cost in the US representing about $34 billion annually.[2]
- Alzheimer's (AD) disease prevalence is estimated at 5 million in US & is projected to reach 14 million by 2050 with annual costs at $215 billion annually.[3]
- Epilepsy affects over 5 million Americans and is estimated to cost $15.5 billion each year.[4]
- Parkinson's disease (PD) affects about 630,000 people in the US costs that exceeded $14.4 billion in 2010.[5]
- Multiple sclerosis (MS) affects about 400,000 people in the US with costs that range from $8,528 to $52,244 per patient per year.[6]
- 16.6% of adults 18 or older reported having migraine or other severe headaches in the last 3 months in the 2011 National Health Interview Survey.[7] The National Ambulatory Medical Care Survey/National Hospital Ambulatory Medical Care Survey showed that head pain was the fifth leading cause of ED visits overall in the U.S. and accounted for 1.2% of outpatient visits.[8]
- In 2013, about 2.8 million TBI-related emergency department (ED) visits, hospitalizations, and deaths occurred in the United States with more than 282,000 hospitalizations and 2.5 million ED visits.[9]

This is the first step in reviewing the current state of measurement in Neurology by condition.

Discussion Questions:

1. Are there any other Neurological conditions that the Committee believes should be included in the framework that represent high prevalence and incidence as well as significant cost?
2. Does the Committee wish to include any other conditions that represent specific populations such as pediatrics?
3. Is the Committee aware of any up-to-date research or evidence that offer measurement opportunities for specific conditions?

Phases of Disease

This episode of care framework presents phases that a patient with a Neurology condition may progress through from prevention to end of life (See Appendix A).

Prevention & Education – This phase highlights pre-disease time and incorporates the importance of prevention and education in reducing the risk of developing preventable neurological diseases as well as increasing knowledge about conditions that are linked to family/genetic history. Measurement in this phase may include measures that address lowering risk factors or a measure that support education on the signs of a stroke and importance of rapid treatment. It also may involve measures that support education regarding information about family history or genetic predisposition of these diseases to help with early diagnosis and treatment. The engagement of patients/family in this early phase is important. The endorsed NQF 2483 Gains in Patient Activation (PAM) Scores at 12 months captures the patient's ability to self-manage. The measure is not disease specific, but has been used with chronic conditions. The change score would indicate a change in the patient´s knowledge, skills, and confidence for self-management.

Acute Phase –While this phase can describe the nature of an illness such as sudden onset or severity, it can also refer to the duration such as short duration. For the purposes of the framework, short duration is the most applicable description. This includes symptom awareness and initial detection, assessment, diagnosis and treatment. A number of measures in the current portfolio fall into the acute phase. These include measures that evaluate symptoms of stroke and treatment intervention. During this phase, the incorporation of the patient's voice and input about symptoms could facilitate the accuracy of a diagnosis and treatment.

Chronic Phase – In this phase, patients receive ongoing care and treatment including symptom management and disease progression. Several measures in the portfolio address the issue of disease progression and management of the symptoms. These include the measure of ongoing assessment of patients with dementia as a measure that addresses patients' with symptoms of dementia without a diagnosis. The introduction of the patient involvement in this stage is critical to "support patient provider engagement by assessing the severity of symptoms, providing information to track the impact of treatment on patient outcomes as well as helping the patient and provide to prioritize discussions for future …" [10] Although technology can be a barrier to achieving these goals, measurement approaches are underway. The Knowledge Program developed by the Cleveland Clinic Neurology Institute is an example of the program that captures and uses patient reported outcomes including the Patient Health Questionnaire 9 as part of the electronic data system.

End of Life – During this phase, patients and caregivers continue to receive symptom management as well as support of both patients and caregivers. Currently, there are no measures in the Neurology portfolio to address this phase. Other portfolios, specifically Palliative Care may have has measures that address symptom management across all diseases and conditions.

Discussion Questions

1. Is the Committee aware of approaches underway in your communities or health systems that incorporate the patient voice during the chronic disease phase?
2. Is the Committee aware of any measures currently that address end- of life care for neurology patients?

The review of the phases offers another view of where measures falls as well as the possibility for approaches in patient and caregiver engagement.

Patient and Caregiver Voice and Engagement

The engagement of patient and caregiver measurement is evolving. At NQF, there is a recognition that the patient voice and patient reported outcomes are important components to capture. There are several types of patient reported outcomes:

- **Health-Related Quality of Life:** HRQL is a multidimensional construct encompassing physical, social, and emotional well-being associated with illness and its treatment.
- **Functional Status:** Functional status refers to a patient's ability to perform both basic and more advanced (instrumental) activities of daily living
- **Symptoms and Symptom Burden:**
  - *Symptoms* such as fatigue and pain intensity are key domains for PROMs. Symptoms are typically negative, and their presence and intensity are best assessed through patient report.
  - *Symptom burden* captures the combination of both symptom severity and impact experienced with a specific disease or treatment.

- **Health Behaviors:** Although health behaviors may be considered predictors of health outcomes, they are also health outcomes in their own right in the sense that health care interventions can have an impact on them.
- **Patient Experience:** Measurement of patient ratings is a complex concept that is related to perceived needs, expectations of care, and experience of care. Patient ratings can cover the spectrum from patient engagement, to experience, to shared decision making, to self-management to full activation.

Table 1 below lists three examples of tools, surveys and approaches to capture the patient or caregiver voice. The first two, the Neuro-QoL and the Zarit Burden interview, are surveys and tools to assess patient symptoms, caregiver self-report tool of caregiver burden, and a third that incorporates multiple approaches to incorporate PRO in a care pathway using an external IT platform. The last example, the Electronic Stroke CarePath uses several approaches and scales to capture patient reported outcome through complex technology and systems for stroke patients.

Table 1. Examples of PRO Tools and Approaches

Examples of PRO Tools and Approaches	Description
Neuro-QoL-health-related quality of life (HRQOL) survey[11]	• Quality of life (HRQL) surveys that can be used for multiple neurological conditions for adults and pediatric patients. • Neurological conditions include stroke, multiple sclerosis, Parkinson's disease, epilepsy, amyotrophic lateral sclerosis (ALS), and muscular dystrophy. • Evaluates symptoms, mental and cognitive health, and the social health of the patient. • Not a measure, it is a survey that can be incorporated into a measure
Zarit Burden Interview (ZBI)[12]	• A caregiver self-report tool with 22 items rated on a five point scale, from 0 (Never) to 4 (Always). Testing is underway using a shorter 12 item survey of strain and personal burden. • This is not a measure but this tool can be used in a measure to evaluate changes over time. The ZBI has been used to measure change over time as a result of the condition of the person being cared for.
Electronic Stroke CarePath[13]	• From the Cleveland Clinic Neurology Knowledge Program, Neurology Institute and Information Technology Division • Integrated Approach to Stroke Care (ischemic). • Disease specific care pathways with PRO incorporated through separate IT platform • Complex data collection in use in outpatient phase • Data feeds from scheduling, and the EHR allows for customized questionnaires to the patient • Data captured in in the waiting room or computer at home before the appointment • Patient completes three scales

	▪ generic health-related quality of life measure (EuroQol EQ-5D)[14], ▪ Patient depression screen (Patient Health Questionnaire 9)[15], ▪ Measure of physical function (Stroke Impact Scale-16)[16] • Physicians compared data and correlated their assessment and the patient’s report

Discussion Questions

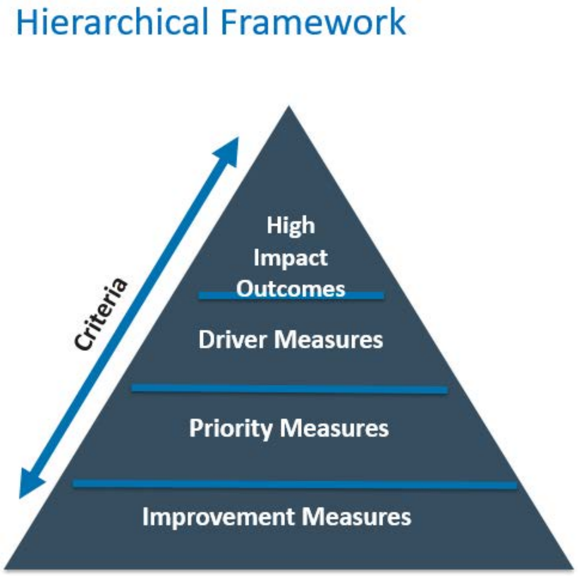
1. Is the Committee aware of or has the Committee used tools, surveys or other methods to capture patient input or patient voice during or after care delivery?
2. If so, has the capture of patient input been helpful? Are there issues in capturing patient input?
3. If the Committee agrees that patient input or patient voice are important, what are the most important aspects of care that should be measured (symptoms, depression, patient experience, etc.)?

NQF Prioritization Criteria

A goal at NQF is to prioritize measures that matter across all topic areas. To achieve that end, work is underway at NQF to support the development of an approach to identify the best measures for accountability and improvement as well as reduce burden on physicians and clinicians. The prioritization criteria is based on an environmental scan of prioritization efforts across the US and the world. Through an iterative process that involved input from the public, experts, committee members and organizational members, four prioritization criteria were selected. These criteria are summarized below.

1. **Outcome-focused**: Preference for outcome measures and measures with a strong link to improved outcomes and costs.
2. **Improvable and actionable**: Preference for actionable measures with a demonstrated need for improvement and evidence-based strategies for doing so.
3. **Meaningful to patients and caregivers**: Preference for person-centered measures with meaningful and understandable results for patients and caregivers.
4. **Support systemic/integrated view of care**: Preference for measures that reflect care that spans settings, providers, and time to ensure that care is improving within and across systems of care.

NQF will use these criteria to identify measures across a hierarchical measurement framework. One goal of this work is to prioritize the measures in the Neurology portfolio by four levels. The four levels of measurement are described below. NQF staff performed an initial review and classified each measure. NQF is seeking input by the Neurology Committee on this classification. This is the first step towards identifying the status of measurement in Neurology as well as identifying gaps.



- The first level of the hierarchy (top of the pyramid) identifies a parsimonious set of “high-impact outcomes.”
- The second level of the pyramid identifies “driver measures” that can be used to drive toward higher performance on the high impact outcomes. These measures are based on healthcare accountability metrics within the health care system.
- The third level of the pyramid identifies “priority measures” within specific settings and conditions that would also contribute to improved performance of the high-level outcomes.
- The fourth level (bottom of the pyramid) identifies a set of “internal improvement” measures. Measures used for accountability may be disconnected from measures used to drive internal improvement. Improvement measures that tie back to high impact measures could help in focusing improvement activities.

Additionally, NQF staff classified measures according to which high impact outcome they most directly addressed. These high impact outcomes would be used to assess the quality and value of the overall healthcare system and its contribution to health, quality, and value (see Table 2). This set of “high impact outcomes” aligns with other national efforts, closely mirroring the domains of the National Quality Strategy. We are asking the Committee to review the preliminary work completed by the staff and offer recommendations for changes of the categories.

Table 2. Types of High Impact Outcomes

Types of High Impact Outcomes	Translation into Patient Voice
Health Outcomes (e.g. functional status and mortality)	Are you getting better?
Patient experience (including care coordination, shared decision-making)	How was your care?
Total cost	Did you receive the care you needed and no more?
Preventable harm/complications	Did you suffer any adverse effects from your care?
Prevention/healthy behaviors	Do you need more help staying healthy?
Access	Can you get the care you need when and where you need it?
Equity	Are you getting high quality care regardless of who you are or where you live?

Table 3 shows how eleven measures within the portfolio were prioritized against the NQF criteria. Measures that were endorsed with reserve status were not included. Note that there are no driver measures and four priority measures.

For each measure below, please indicate whether the Committee agrees with the prioritization.

Table 3. Classification of Neurology Measures

Measures	High Impact Outcome	Driver Measures	Priority Measures	Improvement Measures
0437 STK-04 Thrombolytic Therapy	Health Outcomes		x	
0507 Diagnostic Imaging: Stenosis Measurement in Carotid Imaging Reports	Health Outcomes			x
1952 Time to Intravenous Thrombolytic Therapy	Health Outcomes		x	
2111 Antipsychotic Use in Persons with Dementia	Preventable Harm			x
2863 CSTK-06: Nimodipine Treatment Administered	Preventable Harm			x
2864 CSTK-01: National Institutes of Health Stroke Scale (NIHSS) Score Performed for Ischemic Stroke Patients	Health Outcomes			x
2866 CSTK-03: Severity Measurement Performed for Subarachnoid Hemorrhage (SAH) and Intracerebral Hemorrhage (ICH) Patients (Overall Rate)	Health Outcomes			x
2872 Dementia- Cognitive Assessment	Preventable harm			x
0467 Acute Stroke Mortality Rate (IQI 17)	Health Outcomes		x	
2877 Hybrid hospital 30-day, all-cause, risk-standardized mortality rate (RSMR) following acute ischemic stroke with risk adjustment for stroke severity	Health Outcomes		x	
0661 Head CT or MRI Scan Results for Acute Ischemic Stroke or Hemorrhagic Stroke Patients who Received Head CT or MRI Scan Interpretation Within 45 minutes of ED Arrival	Health Outcomes			X

Measurement Gaps

The purpose the gap discussion is to identify measurement gaps across all areas of Neurology. The assessment of gaps will include several areas to consider including high impact outcomes, conditions, and patient voice and engagement. First, the condition section includes data on prevalence, incidence, cost and burden of Neurological conditions as well as the types of measures included in the current portfolio. The next section on the phases of the disease offer a breakdown on where current measures fall and what gaps exist.

The next section highlights the use of PROM and their use or potential use with consideration of the barriers. The next section offers a review the measures in the current portfolio against the types of measures from priority to improvement. Finally, the categorization of measures by High Impact Outcome categories highlight the availability current measures and the gaps that exist.

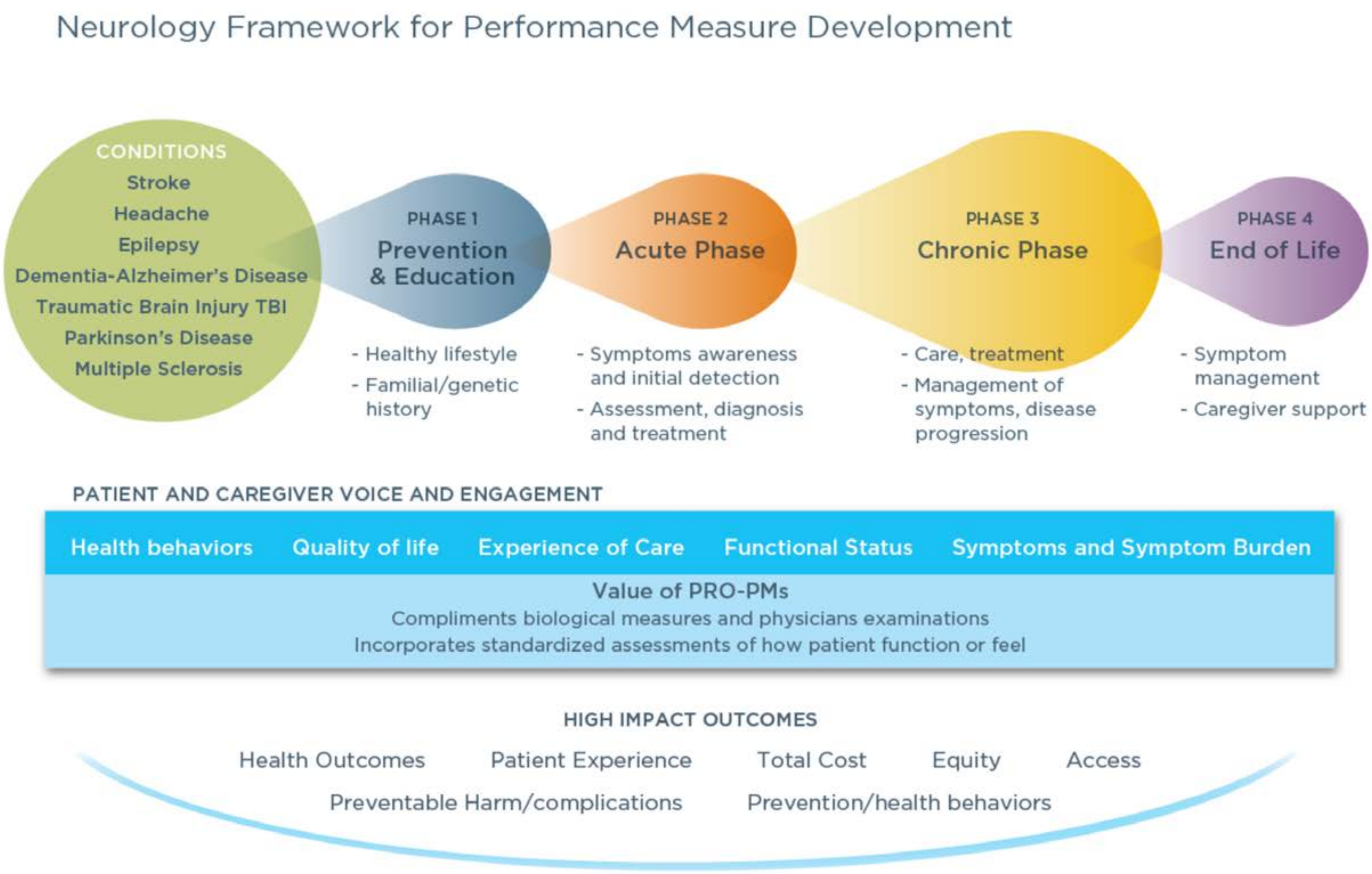
Lastly, from the prior discussion of measures, in 2016 the following measurement gaps were identified:

- Measures targeting neurological conditions: Parkinson's disease, multiple sclerosis, muscular dystrophy, Alzheimer's disease, and dementia;
- Best practices for early diagnosis and treatment of neurological diseases;
- Measures that provide disparities data on disease and treatment to inform patient care;
- Patient reported outcomes (PROs);
- Measures that continue to monitor for unintended consequences for specific populations; and
- eMeasures to leverage the use of electronic health records (EHRs).

Discussion Questions

1. Does the Committee agree that gaps identified from the last in-person meeting are still applicable? If not what would you change?
2. Is the Committee aware of measures or measure concepts for other neurological conditions?
3. Are there measures in use that address the patient voice or PROs that would be appropriate for Neurology?
4. What kinds of measures do we need to fill these gaps, specifically priority measures that will address:
    - Patient experience
    - Total cost/high-value care,
    - Access to needed care
    - Equity of care
    - Prevention/healthy behaviors

Appendix A: Neurology Framework for Performance Measure Development



Neurology Framework for Performance Measure Development

CONDITIONS
Stroke
Headache
Epilepsy
Dementia-Alzheimer's Disease
Traumatic Brain Injury TBI
Parkinson's Disease
Multiple Sclerosis

PHASE 1
Prevention & Education
- Healthy lifestyle
- Familial/genetic history

PHASE 2
Acute Phase
- Symptoms awareness and initial detection
- Assessment, diagnosis and treatment

PHASE 3
Chronic Phase
- Care, treatment
- Management of symptoms, disease progression

PHASE 4
End of Life
- Symptom management
- Caregiver support

PATIENT AND CAREGIVER VOICE AND ENGAGEMENT

Health behaviors | **Quality of life** | **Experience of Care** | **Functional Status** | **Symptoms and Symptom Burden**

Value of PRO-PMs
Compliments biological measures and physicians examinations
Incorporates standardized assessments of how patient function or feel

HIGH IMPACT OUTCOMES
Health Outcomes
Patient Experience
Total Cost
Equity
Access
Preventable Harm/complications
Prevention/health behaviors

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[8] Smitherman, TA, Burch, R, Sheikh, H, et al. The prevalence, impact, and treatment of migraine and severe headaches in the United States: a review of statistics from national surveillance studies. Headache. 2013;53(3):427-436.

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