

# **Meeting Summary**

### Neurology Standing Committee – August 2017 Off-Cycle Quarterly Webinar

The National Quality Forum (NQF) convened a public webinar for the Neurology Standing Committee on Monday, August 28, 2017. An online archive of the webinar is available for playback.

#### Welcome, Introductions, and Review of Webinar Objectives

Margaret (Peg) Terry, Senior Director, NQF, and Standing Committee co-chairs David Tirschwell and David Knowlton, welcomed participants to the webinar. Christy Skipper, Project Manager, NQF, began the meeting with roll call and a review of the following meeting objectives:

- Discuss revisions to Neurology framework;
- Review NQF Measurement Prioritization criteria;
- Categorize Neurology measures according to priority level and high impact outcomes; and
- Identify gaps in Neurology portfolio.

#### **Revisions to the Neurology Framework**

Dr. Terry presented the revised Neurology framework noting the following changes:

- The framework was updated to include additional diseases/conditions, emphasize the importance of patient and caregiver voice, and show four phases of disease: Prevention & Education, Acute, Chronic, and End of Life.
- Conditions: Dr. Terry noted that many of the conditions already included in the framework were justified by global disease burden and cost of care statistics. The new revised framework lists six conditions: Stroke, Headache, Epilepsy, Dementia (Alzheimer's Disease), Parkinson's Disease, and Multiple Sclerosis. When asked ifthere were other conditions that should be included in the framework, the Committee suggested adding the following: Spinal Cord Injury (SCI), Sleep Disorders (e.g., Insomnia, Obstructive Sleep Apnea), Restless Leg Syndrome, Neuropathy, Cerebral Palsy, Essential Tremors and Amyotrophic Lateral Sclerosis (ALS).
- Prevention & Education: This phase incorporates the importance of prevention and education in reducing the risk of developing preventable neurological disease and the increasing knowledge on conditions linked to family/genetic history.
  - When asked to provide feedback, a Committee member noted that prevention and education about premature birth may be needed since it is a major contributor to cerebral palsy. Another Committee member stated there are a number of measures in development related to preclinical risk evaluations for people with familial risk for Alzheimer's disease. The Committee also mentioned that blood pressure and diabetes control for stroke patients are important to prevention and education.
- Acute Phase: The acute phase refers to the short duration of an illness and includes symptom awareness and initial detection, assessment, diagnosis, and treatment.
  - The Committee did not have specific response to this phase of the framework but did point to the American Academy of Neurology's Inpatient and Emergency Neurology Quality measurement set for reference to status epilepticus measures.
- **Chronic Phase:** The chronic phase refers to the receipt of ongoing care and treatment for neurological conditions, including symptom management and disease progression. Patient

involvement in this stage is critical in order to assess the severity of symptoms and clinical changes.

- In their discussion of the Chronic phase, a few Committee members noted that there are rehabilitative and occupational therapy measures that focus on fall risk and activity participation; such measures could apply to stroke and traumatic brain injury (TBI). Members of the committee also mentioned that there are self-efficacy measures for people with chronic conditions.
- A Committee member pointed out that performance based assessments of function may be favorable to a self-report assessment of function noting that caregivers tend to over report function, whereas the patient tends to underreport function. A performance-based measure of function could eliminate the biases introduced by the patient and the caregiver.
- Conversely, another Committee members noted another disconnect between performance based and self-report measures is that some patients may believe they are functioning at a higher level than what they really are. It was also mentioned that depression may play a role in how patients believe they are performing (e.g., a depressed patient may report a lower self-assessment of function).
- A Committee member living with a chronic neurological condition highlighted the importance of health care providers working with the patient to develop a more positive and appropriate patient attitude toward treatments that require patient reported outcomes as part of the evaluation. Additionally, the patient voice is very important in terms of assessing which treatments work best when the outcome is unknown or uncertain.
- End of Life: During this phase, patients and caregivers continue to receive symptom management from health care providers as well as support.
  - The Committee agreed with this phase of the framework and did not provide suggestions for measures that currently address end of life care.
- Patient Reported Outcomes and Patient/Caregiver Voice: Dr. Terry briefly reviewed the types
  of patient reported outcomes discussed during the first webinar. She then presented examples
  of tools, surveys, and approaches to capture the patient or caregiver voice:
  - The Neuro-QoL is a survey that evaluates symptoms, mental and cognitive health, and social health.
  - The Zarit Burden Interview (ZBI) is a caregiver self-report tool used to evaluate changes in the caregiver overtime based on the patient's condition.
  - The Electronic Stroke CarePath uses an integrated approach to stroke care and incorporates three scales: the EuroQol EQ-5D (a generic health related quality of life measure); the PHQ-9 (depression scale), and the Stroke Impact Scale – 16 (a measure of physical function). Also, patient input is sought prior to each appointment through customized questionnaires.
    - When asked whether there are other tools used to capture the patient voice, the Committee mentioned the Memory and Behavior Problem Checklist and the Clinical Dementia Rating (CDR). A Committee member noted that the Memory and Behavior Problem Checklist, a companion tool to the ZBI, may be a better measure for long term conditions such as dementia as it uses a Likert scale survey of common behavioral problems seen in individuals with dementia. The

CDR yields a score called the sum of boxes that summarizes six areas of impairment and difficulty.

- The Committee also discussed the use of global measures versus conditionspecific measures and suggested that it may be more valuable to look at measures specific to individual conditions. The Committee noted that conditionspecific measures may capture symptoms that are unique to a particular population.
- A Committee member noted that the Neuro-QoL survey cannot roll up the individual scores into a single score to give an overall assessment of quality of life.
- Some Committee members pointed out that the Stroke Impact Scale-16 (a scale that is part of the Electronic Stroke CarePath tool), is more predictive of falls than performance-based measures; further emerging data suggest the tool is highly predictive of preventing bad falls for the patient. It was indicated that the CarePath tool double counts depression since it uses both the PHQ-9 and the EQ-5D.
- A Committee member suggested that the Food and Drug Administration's requirements for PROs offers guidance that may inform NQF in this work on these important outcomes.

#### **NQF** Prioritization

Dr. Terry then briefly introduced NQF's new strategic initiative around measure prioritization. Jean-Luc Tilly, Senior Data Analytics Manager, NQF, explained that this initiative is a component of NQF's strategic plan as NQF is looking to take on more of a leadership role in measurement science and drive quality improvement through measurement. Mr. Tilly noted that the measure prioritization efforts will only enhance NQF's endorsement process and allow for more targeted identification and focus on measurement gaps. Throughout the presentation, Mr. Tilly emphasized that this initiative is in the pilot stage and the Committee's feedback was especially important in order to refine the process.

After an environmental scan led by Helen Burstin, Chief Scientific Officer, NQF and feedback from the Consensus Standards Approval Committee (CSAC), NQF members, standing committees, and the Measure Applications Partnership (MAP), four criteria were established:

- Outcome-focused;
- Improvable and actionable;
- Meaningful to patients, and caregivers; and
- Support systemic/integrated view of care.

Mr. Tilly described how these criteria come together to sort measures into four different tiers shown below. The first level of the hierarchy (top of the pyramid) identifies a parsimonious set of "high-impact outcomes" that address seven particular health outcomes: mortality and functional status, patient experience, total cost, preventable harm/complications, prevention/healthy behaviors, access, and equity. The second level of the pyramid identifies "driver measures" which are related to the high impact outcome measures. Driver measures drive towards high performance on high impact outcomes. Mr. Tilly noted that these measures may be scarce and may not be included within the neurology portfolio. Priority measures at the third level may be potentially limited if they are focused on a

particular care setting or condition. The bottom of the pyramid identifies improvement measures that may have a causal relationship to the priority measures, and then in turn to driver measures. Mr. Tilly noted that some measures may not fall into any level of the hierarchy although they may be NQF endorsed. Mr. Tilly ended the discussion with a conceptualization of total harm in terms of the hierarchy.



Dr. Terry then explained how measures within the Neurology portfolio are categorized within the hierarchy. These details are below along with the Committee's discussion.

Measure Prioritization Level	Measure Number and Title
<b>Priority Measures for Stroke</b>	#0437: STK-04 Thrombolytic Therapy
(Health Outcomes)	#1952: Time to Intravenous Thrombolytic Therapy
	#0467: Acute Stroke Mortality
	#2877: Hybrid hospital 30-day, all-cause, risk-standardized
	mortality rate (RSMR) following acute ischemic stroke with risk
	adjustment for stroke severity

- The Committee questioned the categorization of the stroke measures based on condition when two measures looking at a process (NQF #0437 and #1952) and the other two focus on outcomes (NQF #0467 and #2877). Dr. John Bernot, Senior Director, NQF, acknowledged this reflection and noted that a weighted scale may be developed to address issues such as this. Dr. Bernot also clarified that stroke mortality measures (NQF #0467 and 2#877) would not necessarily be considered a driver measure for health outcomes since they are disease specific measures.
- Another Committee member noted that categorizing the process and outcome measures together could make sense since they are appropriate for different settings.

Measure Prioritization Level	Measure Number and Title
Improvement Measures for	#0507: Diagnostic Imaging: Stenosis Measurement in Carotid
Stroke (Health Outcomes)	Imaging Reports
	#2864: CSTK-01: National Institutes of Health Stroke Scale (NIHSS)
	Score Performed for Ischemic Stroke Patients
	#2866: CSTK-03: Severity Measurement Performed for
	Subarachnoid Hemorrhage (SAH) and Intracerebral Hemorrhage
	(ICH) Patients (Overall Rate)
	#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

The Committee agreed with the stroke measures prioritized for improvement. Given the discussion around the priority measures for stroke listed above, the Committee agreed to move NQF #0437 and #1952 to the Improvement level. Tangential to the topic was a Committee member's opinion that NQF #2864 should not be a quality initiative just because it is easy to measure. The Committee member also noted that NQF #2864 only adds to the "door-to-needle time" for patients experiencing ischemic stroke.

Measure Prioritization Level	Measure Number and Title
Improvement Measures for	#2111: Antipsychotic Use in Persons with Dementia
Dementia (Preventable	#2872: Dementia- Cognitive Assessment
Harm)	

- Although the Committee questioned the categorization of NQF #2872 as an improvement measure for preventable harm, they could not determine a better category for this measure.
- The Committee did note the importance of inappropriate use of antipsychotics captured by NQF #2111. Another Committee member suggested that when used judiciously in the "right hands" of the clinician, use of antipsychotics on dementia patients can provide better management on quality of life and caregiver burden.
- It was suggested that some of these measures may be categorized as status assessments since some measures may or may not be measuring actual improvement.

Measure Prioritization Level	Measure Name
Improvement Measure for Stroke (Preventable Harm)	#2863: CSTK-06: Nimodipine Treatment Administered

• The Committee agreed with the categorization of NQF #2863 as an improvement measure.

#### **Measurement Gaps**

Dr. Terry reviewed the measurement gaps identified during the last Committee meeting:

- Parkinson's disease, Multiple Sclerosis, Muscular Dystrophy, Alzheimer's disease, and Dementia;
- o Best practices for early diagnosis and treatment of neurological disease;

- 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
- o eMeasures to leverage the use of electronic health records (EHRs).

One Committee member observed that early intervention measures hinging on early diagnosis may not be appropriate for all conditions. The Committee member stated that there is little to no benefit of early diagnosis in patients with Parkinson's disease who have not yet experienced any symptoms. It was suggested that the benefit of early diagnosis occurs when there is an early intervention that can provide a better quality of life. Another Committee member countered that statement noting that epilepsy surgery seems to prevent sudden unexpected death in epilepsy (SUDEP), albeit for a very small population.

Dr. Terry then led the Committee through each type of health outcome and asked for feedback on potential measurement areas.

- Health outcomes (mortality and functional status): The Committee re-emphasized that mortality is an important outcome to assess for neurological conditions. From the pediatric perspective, a Committee member noted that it may be important to assess whether a child or adult could attend school or work; although these are not necessarily classic health outcomes, they are clear and in some ways testable functional outcomes.
- Patient experience: The Committee identified a <u>Health Confidence tool</u> developed by John Wasson containing a single question assessing health confidence or patient activation using a zero to 10 scale.
- Preventable harms/complications: While the Committee did not specifically describe any potential measure concepts in this area, they did raise a point, about patient reported outcomes, suggesting that there could be regional variation in how patients respond to questions about harm and complications. The Committee member cautioned that when measuring preventable harms and complication, risk weighting (statistically), is preferred to patient report. In discussing possible gaps in measurement, another Committee member noted that hospital acquired infections were a problem following stroke and other areas such as complications and bleeding in stroke patients related to secondary prevention medications.
- **Prevention/healthy behaviors:** The Committee did not describe any potential measure concepts in this area.
- **Total cost/low value care:** The Committee did not describe any potential measure concepts in this area.
- Access to needed care: In regards to stroke, the Committee noted that access to care for acute stroke interventions is measurable at the population level for instance, patients living in rural areas or that live in lower socioeconomic areas may have reduced access to care. The Committee member also suggested that measures that assess the percentage of people in a population that receive intravenous tPA could be included in this category. Another Committee member noted that access to care may also be an issue with epilepsy as patients may not have access to the tertiary and quaternary care centers that provide epilepsy surgery evaluations. Other Committee members offered that there may be value in looking at studies of telemedicine to assess access. It was also stated that it may be worth assessing time from first symptoms to diagnosis and time from diagnosis to treatment. The Committee member

suggested that people who have less access to care are going to have a much longer time period from when they note symptoms to when they can get a diagnosis. It was also noted that the metric could also indirectly capture cost issues.

• **Equity of care:** A Committee member observed that an analysis of equity of care could apply to any of the previously described six high impact outcomes. Another member noted retrospective research on Medicaid and Medicare data sets that looked at patient demographics versus care delivered.

#### **Opportunity for Public Comment**

The American Academy of Neurology (AAN) offered a public comment. The AAN encouraged the Committee to group conditions together within the measurement framework rather than listing specific diseases. The Committee agreed that this approach would make sense, although from a measurement perspective, the specificity allows greater flexibility in terms of defining how appropriate the measure is.

# PAGE 8 Appendix A. Revised Measurement Framework for Neurological Conditions



## Neurology Framework for Performance Measure Development