NATIONAL
QUALITY FORUM

To: Neurology Standing Committee
From: NQF Staff
Re: Neurology Off-Cycle Webinar #1
Date: June 19, 2017

Dial-In and Webinar Information

- June 19, 2017, 2:00-4:00PM ET
- Speaker Conference Line: (855)696-3824; NO CONFERENCE CODE REQUIRED
- Web Link: http://nqf.commpartners.com/se/Rd/Mt.aspx?878083

Developing a framework for Neurology through a Chronic Disease Model

Introduction

For this first webinar Neurology off-cycle work, NQF seeks the Neurology Committee's input on a framework that incorporates an approach to measurement for persons and families with needs and care that span a longitudinal time or episode and integrates the person's and family voice. The current Neurology portfolio of measures includes measures for Stroke and Dementia and most are process measures. The proposed framework is not based on a single disease but focuses on multiple chronic neurological diseases, across the age spectrum, and time span. An essential part of the framework are measures that reflect person and family engagement across conditions and time periods that will improve the quality of care and well-being for these individuals.

NQF identifies four patient reported outcomes (PRO) domains; health-related quality of life (including functional status), symptoms and symptom burden, experience of care and health behaviors. Other approaches include measures on the engagement and activation of persons and family, those to evaluate caregivers support or burden, measures to support the coordination and transitions of care, and surveys addressing quality of life and disease specific measures.

Background

Neurological conditions and injuries affect millions of Americans each year and take a tremendous toll on patients, families, and caregivers. Additionally, billions of dollars are spent on treatment, rehabilitation, and lost or reduced earnings.

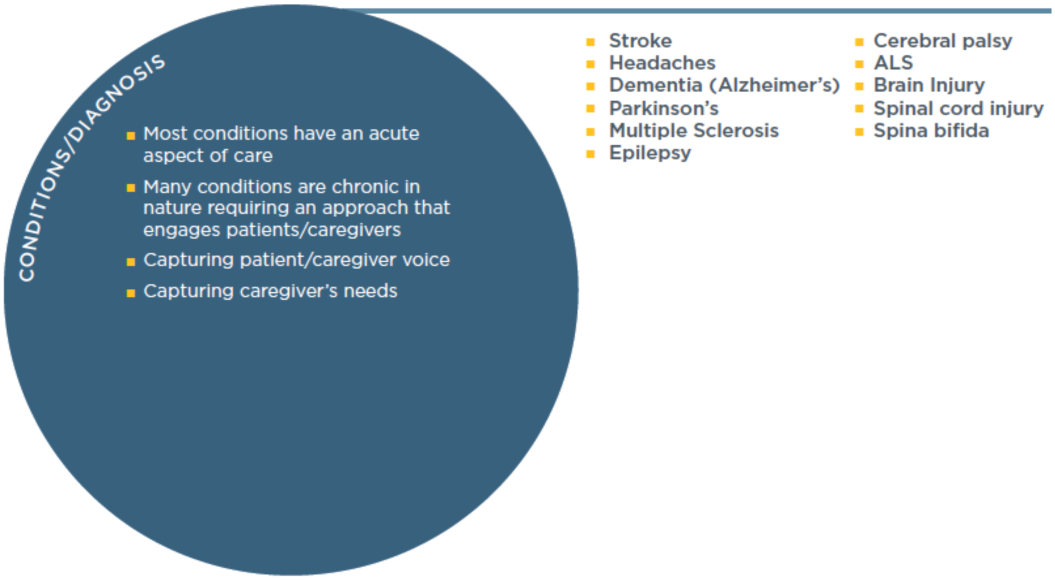
- Strokes are the fifth leading cause of death in the United States as well as a leading cause of disability. Each year, approximately 795,000 people suffer a stroke. Healthcare costs of stroke, including medications and missed days of work, are estimated at $34 billion annually.[1]
- Alzheimer's disease is the most common form of dementia with an estimated 5 million Americans living with the disease[2]. An estimated 14 million people will have Alzheimer's by 2050. In 2009, Alzheimer's disease was the fifth leading cause of death for adults ages 65 to 85. In 2010, the cost for Alzheimer's disease reached nearly $215 billion and is projected to rise to more than $500 billion annually by 2040.
- Epilepsy affects over 5 million Americans and is estimated to cost $15.5 billion each year in medical costs and lost or reduced earnings and production.[3]

- Engaging patients in their own care has resulted in improved clinical outcomes, reduced health care consumption and improved service quality[4]. Specifically, patient engagement has been shown to improve treatment adherence, faster recovery and reduced mortality.[5] Additional research demonstrates improved service efficiency, fewer diagnostic tests and referrals, lower annual charges, and patient preference towards less costly care.[6]
- Other studies link improved service quality in engaged patients with improved communication and health literacy, greater confidence in decision-making, higher hospital staff retention rates and more satisfied patients.[7]

Characteristics of the Draft Measurement Framework for Neurological Conditions

Overall, the framework incorporates three rings that offer a new approach to measurement in Neurology. The approach uses a chronic disease focus and attempts to capture more conditions, across all ages, with a consideration of the longitudinal aspect or episode of care. The focus is less on individual conditions or diseases and more on the chronic nature of many neurological chronic diseases. The person's (patient) and caregiver's voice and engagement are a central theme across each of the rings.

Conditions/Diagnosis: The first ring includes neurological conditions and diseases. The center of the ring includes broad descriptions of the themes of conditions. The link on the outside of this ring lists the many neurological diseases to be included.



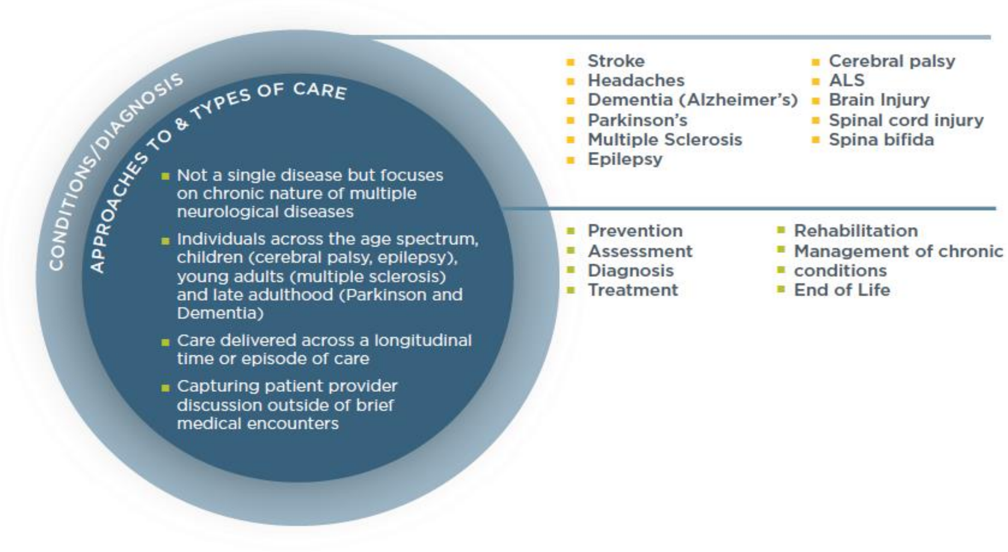
- Most conditions have an acute aspect of care
- Many conditions are chronic in nature requiring an approach that engages patients/caregivers
- Capturing patient/caregiver voice
- Capturing caregiver's needs

- Stroke
- Headaches
- Dementia (Alzheimer's)
- Parkinson's
- Multiple Sclerosis
- Epilepsy
- Cerebral palsy
- ALS
- Brain Injury
- Spinal cord injury
- Spina bifida

Discussion Questions:

- What do you think of the depiction of the framework? Do you think that a chronic disease approach is appropriate? Should we retain some of the other more acute aspects of care such as the assessment and treatment for stroke patients?
- What do you think of the conditions/disease types? Is this framework inclusive or too broad? Should some of these conditions be removed? Would you add any conditions?
- What do you think of the general statements in the circle?

Approaches To & Types of Care: In this ring, the types of care delivered to Neurology patients, from prevention to end of life with an emphasis on chronic disease management is shown.



- Not a single disease but focuses on chronic nature of multiple neurological diseases
- Individuals across the age spectrum, children (cerebral palsy, epilepsy), young adults (multiple sclerosis) and late adulthood (Parkinson and Dementia)
- Care delivered across a longitudinal time or episode of care
- Capturing patient provider discussion outside of brief medical encounters

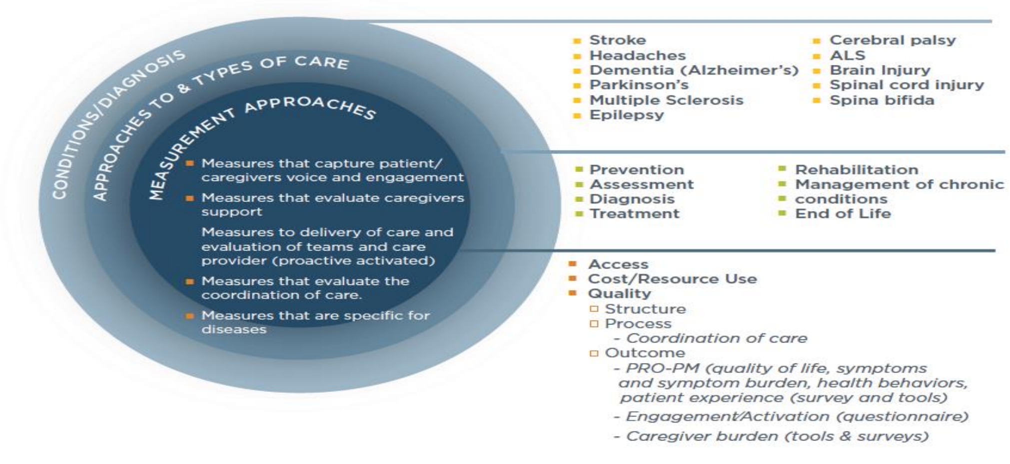
- Stroke
- Headaches
- Dementia (Alzheimer's)
- Parkinson's
- Multiple Sclerosis
- Epilepsy
- Cerebral palsy
- ALS
- Brain Injury
- Spinal cord injury
- Spina bifida

- Prevention
- Assessment
- Diagnosis
- Treatment
- Rehabilitation
- Management of chronic conditions
- End of Life

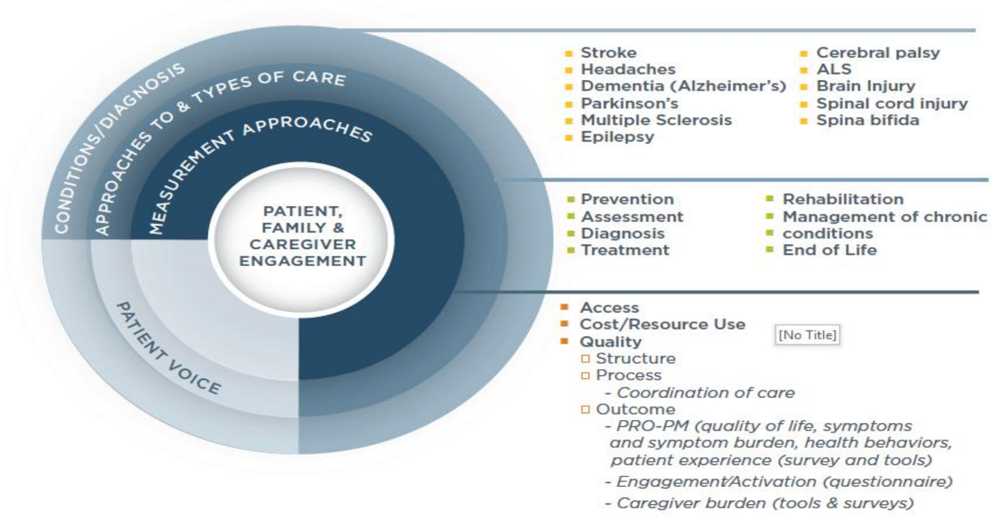
Discussion Questions:

- What do you think of the types of neurological care? What would you change?
- What do you think about the emphasis of measures that focus on chronic conditions? Note that some measures may cross other NQF Committee work for diseases that are primarily chronic in nature.
- Do you think it would be helpful to include a longitudinal approach to care? Why?
- Is it important to reflect the broad age spectrum for these diseases? Why?
- Would it be helpful to capture patient provider discussion outside of a brief medical encounter? Why?
- Are there any other approaches to or types of care to add or take away?

Measurement approaches: This last ring shows approaches to measurement. Some themes of the measurement are listed below.



Patient, Family, & Caregiver Engagement: The person's (patient) and caregiver's voice and engagement are a central theme across each of the rings.



Patient Reported Outcomes

NQF endorses performance measures. The following definitions are used to clarify the distinction between patient-level patient-reported outcome measures and performance measures to assess the quality of care provided by accountable healthcare entities.

Patient-reported outcome (PRO): Any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.

PRO patient-level measure/instrument: Tools to assess health condition (e.g., health status and status of physical, mental, and functioning) as perceived by the patient obtained by directly asking the patient to self-report (e.g., PHQ-9).

Performance measure: Numeric quantification of healthcare quality for a designated accountable healthcare entity, such as hospital, health plan, nursing home, clinician, etc.

PRO-based performance measure: A performance measure that is based on patient-reported outcome data aggregated for an accountable healthcare entity (e.g., percentage of patients in an accountable care organization whose depression score as measured by the PHQ-9 improved).

Concept	Patients with Clinical Depression	Persons with Intellectual or Developmental Disabilities
PRO	Symptom: depression	Functional Status-Role: employment
PROM	PHQ-9 © , a standardized *tool* to assess depression	Single-item measure on National Core Indicators Consumer Survey: Do you have a job in the community?
PRO-PM	Percentage of patients with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow up of PHQ-9 score <5 at 6 months (NQF #0711)	The proportion of people with intellectual or developmental disabilities who have a job in the community

Discussion Questions:

The proposed new framework shifts the focus from primarily process measures for specific conditions to a broader focus that incorporates PRO-PM measures, engagement measures, and possibly measures of burden.

- Do you think this proposed direction in Neurology measurement should be a goal?
- What do you think about PRO-PM? Do you think that the use of surveys and tools to capture the patient and caregiver voice is important? Surveys present measurement challenges –individuals and caregivers need to be asked questions about care and their own experiences-as opposed to

the use of claims or other administrative claims. How can feasibility be addressed with these challenges?

- While many of the current measures are disease specific process measures, is there a way to incorporate the patient and caregiver voice into these measures?
- How can the framework address the many measures that are disease specific process measures, while moving in the direction of a broader patient and caregiver voice? These disease specific measures are important to improving quality.
- Are there any other issues or suggestions for this framework?

Examples of Person and Caregiver Measures

NQF #2483: Gains in Patient Activation (PAM) Scores at 12 Months

The Patient Activation Measure® (PAM®) is a 10 or 13 item questionnaire that assesses an individual´s knowledge, skill and confidence for managing their health and health care. The measure assesses individuals on a 0-100 scale. There are 4 levels of activation, from low (1) to high (4). The measure is not disease specific, but has been successfully used with a wide variety of chronic conditions, as well as with people with no conditions. The performance score would be the change in score from the baseline measurement to follow-up measurement, or the change in activation score over time for the eligible patients associated with the accountable unit.

The outcome of interest is the patient's ability to self-manage. High quality care should result in gains in ability to self-manage for most chronic disease patients. The outcome measured is a change in activation over time. The change score would indicate a change in the patient´s knowledge, skills, and confidence for self-management. A positive change would mean the patient is gaining in their ability to manage their health.

NQF #2967: CAHPS Home-and Community-Based Services Measure

CAHPS Home- and Community-Based Services measures derive from a cross disability survey to elicit feedback from adult Medicaid beneficiaries receiving home and community based services (HCBS) about the quality of the long-term services and supports they receive in the community and delivered to them under the auspices of a state Medicaid HCBS program. The unit of analysis is the Medicaid HCBS program, and the accountable entity is the operating entity responsible for managing and overseeing a specific HCBS program within a given state. There are 19 measures in this new measure.

The measures consist of seven scale measures, 6 global rating and recommendation measures, and 6 individual measures:

Scale Measures
1. Staff are reliable and helpful –top-box score composed of 6 survey items
2. Staff listen and communicate well –top-box score composed of 11 survey items terry
3. Case manager is helpful - top-box score composed of 3 survey items
4. Choosing the services that matter to you - top-box score composed of 2 survey items
5. Transportation to medical appointments - top-box score composed of 3 survey items
6. Personal safety and respect - top-box score composed of 3 survey items

7. Planning your time and activities top-box score composed of 6 survey items

Global Ratings Measures
8. Global rating of personal assistance and behavioral health staff- top-box score on a 0-10 scale
9. Global rating of homemaker- top-box score on a 0-10 scale
10. Global rating of case manager- top-box score on a 0-10 scale

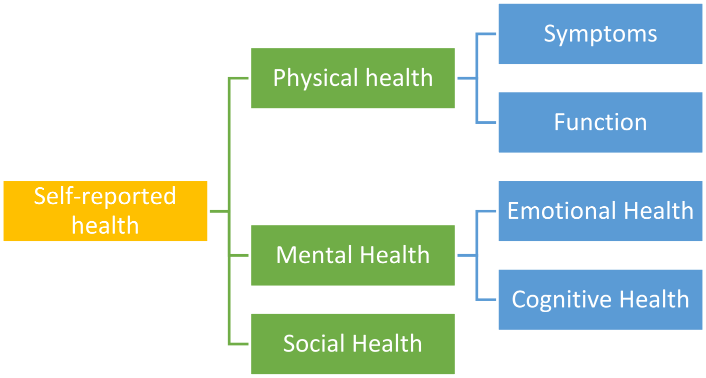
Recommendations Measures
11. Would recommend personal assistance/behavioral health staff to family and friends – top-box score on a 1-4 scale (Definitely no, Probably no, Probably yes, Definitely yes)
12. Would recommend homemaker to family and friends — top-box score on a 1-4 scale (Definitely no, Probably no, Probably yes, Definitely yes)
13. Would recommend case manager to family and friends– top-box score on a 1-4 scale (Definitely no, Probably no, Probably yes, Definitely yes)

Unmet Needs Measures
14. Unmet need in dressing/bathing due to lack of help–top-box score on a Yes, No scale
15. Unmet need in meal preparation/eating due to lack of help– top-box score on a Yes, No scale
16. Unmet need in medication administration due to lack of help– top-box score on a Yes, No scale
17. Unmet need in toileting due to lack of help– top-box score on a Yes, No scale
18. Unmet need with household tasks due to lack of help– top-box score on a Yes, No scale
Physical Safety Measure
19. Hit or hurt by staff – top-box score on a Yes, No scale

Use of Surveys

Neuro-QoL[8]

The Neuro-QoL is a set of health-related quality of life (HRQOL) surveys that can be used for multiple neurological conditions for adults and pediatric patients. Neurological conditions include but are not limited to: stroke, multiple sclerosis, Parkinson's disease, epilepsy, amyotrophic lateral sclerosis (ALS), and muscular dystrophy. Neuro-QoL evaluates symptoms, mental and cognitive health, and the social health of the patient. While this is not a measure, it is a survey that can be incorporated in to a measure. The Neuro-QoL adult domain framework is illustrated below.



Use of Tools

Zarit Burden Interview (ZBI)[9]

The Zarit Burden Interview is a caregiver self-report measure 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. The measure is useful in that results across studies can be compared; however, the length of the survey could be a deterrent.[10]

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