HealthMeasures
TRANSFORMING HOW HEALTH IS MEASURED

Assessing Person-Centered Health Outcomes in Stroke Patients

These recommendations are offered as a starting point for consideration. They are not necessarily the best choices for every application and do not substitute for a comprehensive literature review.

Key Domains to Consider in Stroke

A stroke's effects can be widespread or localized, severe or mild, depending upon the size and location of the area of the brain affected. However, **physical and cognitive abilities** are commonly disrupted and therefore these are key outcomes to assess. Further, difficulties in either cognitive or physical function often impact other HRQoL domains, particularly **social functioning**, making the social realm another important focus of assessment. Stroke is predominantly an adult disease. While strokes do occur in children, our recommendations are only for adult assessment.

Summary

- Recommended primary domains include physical function, cognitive function and social function.
- HealthMeasures offers brief, psychometrically sound measures for these domains.
- We recommend the use of Neuro-QOL. PROMIS contains measures of the same or similar domains as Neuro-QoL and may be useful when comparing functioning across multiple conditions.

Suggested HealthMeasures for Primary Domains in Stroke

Physical Function

Neuro-QOL includes measures of Lower Extremity (Mobility) and Upper Extremity (Fine Motor/ADLs) function. Mobility is the core measurement for survivors of cerebrovascular disease, and is highly correlated with the usual definition of "good outcome". Neuro-QOL Upper Extremity Function covers many aspects of daily life dependent on fine motor abilities, including self-care. While upper and lower motor function are often highly associated, both are important for independence and their assessment can highlight different areas to target for intervention. For performance-based assessment of physical function, we recommend NIH Toolbox Motor measures, particularly the 4m-walk (locomotion), hand dynamometer (strength) and the 9-hole pegboard (dexterity).

Cognitive Function

Patients with cerebrovascular disease may be independent for mobility but dependent due to cognitive impairment, (e.g., unable to manage a household), making this a key outcome. Neuro-QOL Cognitive Function assesses perceived difficulties in cognitive abilities as well as the application of such abilities to everyday tasks. The NIH Toolbox Cognition Battery is recommended for performance-based evaluation of language (vocabulary and reading recognition), memory, processing speed, attention and executive function.

Social Function

Many patients and caregivers regard this as a key attribute of a desirable quality of life. Neuro-QOL Satisfaction with Social Roles and Activities reflects satisfaction with work, family, friends and leisure roles and activities. As an alternative, Neuro-QoL Ability to Participate in Social Roles assesses perceived ability to perform one's usual social roles and activities.

Version Date: August 18th, 2016

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Suggested HealthMeasures for Secondary Domains in Stroke

Depression, fatigue, anxiety and disordered sleep are components of the "Post-intensive care syndrome" experienced by many survivors of cerebrovascular disease.

Secondary HealthMeasures	Description
Neuro-QOL Depression short form ***or*** CAT	Negative mood, negative views of self, negative social cognition, decreased positive affect and engagement
Neuro-QOL Anxiety short form ***or*** CAT	Thoughts and feelings related to fear, helplessness, worry and hyperarousal
Neuro-QOL Fatigue short form ***or*** CAT	Sensations ranging from tiredness to overwhelming and debilitating exhaustion
Neuro-QOL Sleep Disturbance short form ***or*** CAT	Perceptions of sleep quality, difficulties getting or staying asleep, adequacy of sleep
NIH Toolbox Emotion	Alternate PRO measures of negative affect, psychological well-being, stress and self-efficacy, social relationships
NIH Toolbox Sensation	Performance measures of vision, olfaction, audition

Stroke-relevant areas that HealthMeasures does not address include speech (motor speech production) and swallowing difficulties.

Assessment Times

The timing of assessments will vary depending on the context. After the acute phase, assessment prior to inpatient discharge can be useful for discharge and treatment planning. Pre-intervention assessment, combined with follow-up assessment at 90 days or other specified time points, can be used to monitor progress in inpatient or outpatient rehabilitation.

Primary HealthMeasures for Stroke Patients

- Neuro-QOL Lower Extremity Function
- Neuro-QOL Upper Extremity Function
- NIH Toolbox Motor Battery (ages 7+)
- Neuro-QOL Cognitive Function
- NIH Toolbox Cognition Battery
- Neuro-QOL Satisfaction with Social Roles and Activities or Neuro-QoL Ability to Participate in Social Roles

Learn More!

You can read about CATs and watch a video tutorial at the HealthMeasures.net website here!

Additional Information

The www.HealthMeasures.net website includes more information about measurement selection, data collection tools, scoring, and interpretation. Its Search for Measures tool includes access to all HealthMeasures described here. A Forum allows for questions and responses from the HealthMeasures community. The HealthMeasures team is also available for collaboration or consultation for clinical research, clinical practice, and information technology via help@healthmeasures.net. Information about the relationships between Neuro-QoL and PROMIS scores can be found at http://www.prosettastone.org/measures/Neuro-QoL/Pages/default.aspx

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Version Date: August 18th, 2016