

NINDS CDE Resource
Quality of Life in Neurological Disorders (Neuro-QOL)

Availability:	<p>Although the Neuro-QOL measures have been tested in two large calibration studies with disease-based and community dwelling samples, the calibrated short forms are currently being administered in a multi-site clinical validation study. Until this study is completed and the Neuro-QOL measures are released into the public domain, investigators or groups wishing to use them in their current or future study may do so if they agree to provide the Neuro-QOL study team with item-level data derived from their respective study. This data will be used to evaluate the performance of Neuro-QOL items in different neurological conditions and trials.</p> <p>For additional information and to obtain Neuro-QOL instruments, please visit Quality of Life in Neurological Disorders Instrument Link</p> <p>See General Page for currently available Neuro-Qol Bank CDE Details.</p>
Classification:	<p>Supplemental-Highly Recommended: Congenital Muscular Dystrophy (CMD)</p> <ul style="list-style-type: none"> • Highly recommended for studies of psychosocial functioning, quality-of-life, outcome, and long-term adjustment studies. <p>Supplemental: Amyotrophic Lateral Sclerosis (ALS), Chiari I Malformation (CM) Epilepsy, Friedreich’s Ataxia (FA), Headache, Huntington’s Disease (HD), Mitochondrial Disease (Mito), Multiple Sclerosis (MS), Myasthenia Gravis (MG), Neuromuscular Disease (NMD), Parkinson’s Disease (PD), Spinal Cord Injury (SCI), Spinal Muscular Atrophy (SMA) and Traumatic Brain Injury (TBI)</p> <p>Exploratory: Duchenne Muscular Dystrophy (DMD), Facioscapulohumeral Muscular Dystrophy (FSHD), Myotonic Dystrophy (DM), and Stroke</p>
Item Bank Recommendations:	Stroke: Adult Mobility, Adult Upper Extremities, Adult Assistive Devices

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Short Description of Instrument:	<p>Purpose: The Neuro-QOL is a Patient Reported Outcome (PRO) measurement system designed for neurologically impaired populations. Neuro-QOL seeks to incorporate patient reported outcomes of functioning, such as social, psychological, and mental well-being.</p> <p>Overview: The Neuro-QOL contains 10 calibrated item banks with Likert-style items and with several banks linked with PROMIS. Item banks cover the following domains: Mobility/Ambulation, ADL/Upper Extremity, Depression, Anxiety, Positive Psychological Functioning, Stigma, Perceived and Applied Cognition (includes communication), Social Role Performance, Social Role Satisfaction, Fatigue, Personality and Behavioral Change and Sleep Disturbances.</p> <p>Time: Administered as short-forms or as Computer Adaptive Tests (CATs). Administration time is less than 5 minutes per sub domain (total time for short form across all domains is about 30 minutes).</p> <p>Scoring Patient reads Likert items on computer screen and responds. Embedded in several of the Neuro-QOL domains are a significant number of Patient-Reported Outcomes Measurement Information System (PROMIS) items. As a result, a PROMIS equivalency score can be derived for all individuals who complete the Neuro-QOL measures.</p> <p>Psychometric Properties: It is a clinically relevant and psychometrically robust health-related quality of life (HRQL) assessment tool for adults and children that is responsive to the needs of researchers in a variety of neurological disorders and settings and facilitates comparisons of data across clinical trials in different diseases.</p> <p>Other Important Notes: The Neuro-QOL is designed to be a common outcome variable across NINDS-sponsored clinical trials. It has been tested in large samples of individuals from both general and diverse, neurologically-impaired populations. Validation with stroke patients is underway. Future plans are to develop a CAT.</p> <p>Strengths: Neuro-QOL includes multiple banks and short forms that cover a variety of domains. These domains were initially developed for adult patients with ALS, multiple sclerosis, Parkinson’s disease, and stroke and for pediatric patients with epilepsy and muscular dystrophy (e.g., Duchenne Muscular Dystrophy).</p> <p>Weaknesses related to DM: The instruments include CATs, short forms, and scales. These instruments and domains were not developed specifically for myotonic dystrophy or validated in this population.</p>
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References:	<p>TBI CDE Working Group (2010). CDE Recommendations - Listing of the Core, Supplemental and Emerging Measures for each Outcome Domain.</p> <p>NINDS Common Data Elements Traumatic Brain Injury Disease page (accessed March 10, 2010).</p> <p>Neuro-QOL Bank Development and Construction. Quality of Life in Neurological Disorders (accessed March 10, 2010).</p> <p>HD: Cella, D., Nowinski, C., Peterman, A., Victorson, D., Miller, D., Lai, J.-S., & Moy, C. (2011). The Neurology Quality of Life Measurement (Neuro-QOL) Initiative. <i>Arch Phys Med Rehabil</i>, 92(Suppl 1), S28–S36.</p> <p>Carlozzi, N. E. (2010), <i>Examining Health-Related Quality of Life in Huntington’s Disease</i>. In A. W. Heinemann (Chair), <i>Advances in Outcome Measures for Neurologic Disorders</i>. Symposia presented at the ACRM-ASNR Joint Educational Conference, Montreal, Quebec, Canada.</p> <p>Carlozzi, N. E., & Tulskey, D. S. (2011). Health-related quality of life in Huntington disease. Published Abstract from the Huntington’s Disease World Congress 2011, Melbourne, Australia. <i>Clin Genetics</i>, 80 (Suppl 1), 37–38.</p> <p>Carlozzi, N. E., McGowan, H., & Tulskey, D. S. (2010). <i>Extending the Neuro-QOL to Huntington’s Disease (HD): The development of the HD-HRQOL</i>. Poster presented at the International Society for Quality of Life Research 17th Annual Conference, London, England.</p> <p>Carlozzi, N. E., & Ready, R. E. (2011). <i>Health-Related Quality of Life in Huntington’s Disease</i>. In: C. Jenkinson, M. Peters, & M. B. Bromberg (Eds.), <i>Quality of Life and Neurodegenerative Disease</i> (pp 71–81), Cambridge, UK, Cambridge University Press.</p> <p>Carlozzi, N. E. (2012). <i>Adaptations of the PROMIS and Neuro-QOL to traumatic brain injury (TBI) and Huntington disease (HD)</i>. In: D. S. Tulskey & N. E. Carlozzi (Co-Chairs), <i>Common data elements in neurological research</i>. Symposia submitted for presentation at the 40th Annual International Neuropsychological Society Meeting, Montreal, Canada.</p> <p>Carlozzi, N. E., & Tulskey, D.S. (2013). Identification of health-related quality of life (HRQOL) issues relevant to individuals with Huntington disease. <i>J Health Psychol</i>, 18(2), 212–225.</p>
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