NIH Toolbox is a multidimensional set of brief measures assessing cognitive, emotional, motor and sensory function from ages 3 to 85, meeting the need for a standard set of measures that can be used as a “common currency” across diverse study designs and settings.

NIH Toolbox monitors neurological and behavioral function over time, and measures the domain constructs across developmental stages. This facilitates the study of functional changes across the lifespan, including evaluating intervention and treatment effectiveness.

The website includes material requirements, administration instructions, and scoring manual for each of the tests across the four domains. No-disease specific scoring and interpretation data is available. Normative data is to be published soon, per the website.

Toolbox measures are accessed through the Assessment Center, a free, online data collection tool that enables researchers to create study-specific websites for capturing participant data securely online.

Among other important features, Assessment Center also enables:

- Downloading library instruments for administration on paper
- Customization of items or instruments (e.g., format, randomization, skip patterns)
- Real-time scoring of CATs and short forms
- Storage of protected health information (PHI) in a separate, secure database
- Automated accrual reports
- Real-time data export
- Ability to capture endorsement of online consent forms

Sample items:

- Cognitive: Flanker Inhibitory Control and Attention Test, Picture Vocabulary Test
- Emotional: Perceived Stress CAT, Self-Efficacy Survey
- Motor: 9-Hole Peg Test, 2-Minute Walk Test
- Sensory: Visual Acuity Test, Words in Noise Test
The purpose of the CDE Project is to standardize the collection of investigational data in order to facilitate comparison of results across studies and more effectively aggregate information into significant metadata results.

The goal of the National Institute of Neurological Disorders and Stroke (NINDS) CDE Project specifically is to develop data standards for clinical research within the neurological community. Central to this project is the creation of common definitions and data sets so that information (data) is consistently captured and recorded across studies.

The NINDS, part of the National Institutes of Health (NIH), is the leading funder of clinical studies of the brain and nervous system in the United States. To harmonize data collected from clinical studies, the NINDS Office of Clinical Research is spearheading the effort to develop CDEs in neuroscience.

This Web site outlines these data standards and provides accompanying tools (ex: case report forms, references, etc.) to help investigators and research teams collect and record standardized clinical data.

CDEs are developed by working groups convened by the NINDS, consisting of national and international experts from leading academic and government research centers.

The NINDS first developed a set of general CDEs commonly collected in all clinical studies (ex: medical history, demographic information, medication, etc.). Now under development are pediatric and adult disease-specific CDEs in the following:

- Spinal cord injury
- Traumatic brain injury
- Epilepsy
- Stroke
- Parkinson’s disease
- Friedreich’s ataxia
- Multiple sclerosis
- Huntington’s disease
- Amyotrophic lateral sclerosis
- Headache
- Neuromuscular disorders
Neuro-QoL is a set of self-report measures that assesses the health-related quality of life (HRQOL) of adults and children with neurological disorders.

Neuro-QoL is comprised of item banks and scales that evaluate symptoms, concerns, and issues that are relevant across disorders - along with measures that assess areas most relevant for specific patient populations.

Neuro-QoL is intended for use in clinical trials, observational research, comparative effectiveness research, and population surveys.

Available as short from PDFs or as CATs through the Assessment Center. Website contains training videos with instruction for administration and education on item response theory and computer adaptive tests.