NINDS Common Data Element (CDE) Project
Stroke Version 2.0 Public Review
Outcomes and Endpoints Subgroup Materials

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- Quality of Life in Neurological Disorders (Neuro-QOL)
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- Rey-Osterrieth Complex Figure Test (ROCF)
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- Stroke and Aphasia Quality of Life-39 (SAQOL-39)
- Stroke Impact Scale (SIS)
- Stroke Specific Quality of Life Scale (SS-QOL)
- Stroop Test
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- Trail Making Test (TMT), Delis-Kaplan Executive Function System (D-KEFS)
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- Wechsler Adult Intelligence Scale - Fourth Edition (WAIS-IV)
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Case Report Forms:

- Death
- Home Time
- Return to Work

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6 Minute Walk Test
(New for Stroke)

Availability	**Freely available at this website: 6 Minute Walk Test** The protocol is freely available here: 6-Minute Walk Test Protocol
Classification	**Supplemental – Highly Recommended**: Congenital Muscular Dystrophy (CMD), Facioscapulohumeral Muscular Dystrophy (FSHD) and Spinal Cord Injury (SCI) **Supplemental**: Amyotrophic Lateral Sclerosis (ALS), Cerebral Palsy (CP), Duchenne Muscular Dystrophy (DMD), Mitochondrial Disease (Mito), Myotonic Dystrophy (DM), Multiple Sclerosis (MS), Neuromuscular Disease (NMD), SCI-Pediatric (age 4 and over), Spinal Muscular Atrophy (SMA) and Stroke
Short Description of Instrument	**Background:** This test was originally developed for use in patients with cardiopulmonary disease, but has since been used in a variety of neurological conditions including MS. The 6-minute walk test (6MWT) measures the distance a patient can quickly walk on a flat, hard surface in a period of 6 minutes (the 6MWD). This evaluates the global and integrated responses of all the systems involved during exercise, including pulmonary and cardiovascular systems, systemic circulation, peripheral circulation, blood, neuromuscular units, and muscle metabolism. The 6MWT does not provide specific information on the function of each of the different organs and systems involved in exercise, or the mechanism of exercise limitation as is possible with maximal cardiopulmonary exercise testing. The self-paced 6MWT assesses the submaximal level of functional capacity. Most patients do not achieve maximal exercise capacity during the 6MWT; instead, they choose their own intensity of exercise and can stop and rest during the test. However, because most activities of daily living are performed at submaximal levels of exertion, the 6MWD may better reflect the functional exercise level for daily physical activities. **Construct measured:** Walking speed **Generic vs. disease specific**: Generic **Means of administration:** Administered in-person by a trained examiner. **Intended respondent:** Patient
Comments/Special Instructions	**MS-Specific:** Goldman et al (2008) has modified the American Thoracic Society 6MWT script (ATS 2002) for use in MS, to maximize effort and better assess motor fatigue. **Administration:** Administration time will vary depending on the patient's ability. Total administration time should be approximately 6 minutes. **SCI-Specific**: This test would not be applicable to many individuals. Even in the small minority of ASIA D cases that one

	might think of applying it to, it would still be more reasonable to use a shorter (say 2 Minute) Walk Test. **SCI-Pediatric-Specific**: Assistive devices can be used but should be kept consistent and documented.
Rationale/Justification	**Strengths/Weaknesses:** Sources of variability include the following: Factors reducing the 6MWD - Shorter height, Older age, Higher body weight, Female sex, Impaired cognition, A shorter corridor (more turns), Pulmonary disease (COPD, asthma, cystic fibrosis, interstitial lung disease), Cardiovascular disease (angina, MI, CHF, stroke, TIA, PVD, AAI), Musculoskeletal disorders (arthritis, ankle, knee, or hip injuries, muscle wasting, etc.); Factors increasing the 6MWD - Taller height (longer legs), Male sex, High motivation, A patient who has previously performed the test, Medication for a disabling disease taken just before the test, Oxygen supplementation in patients with exercise-induced hypoxemia. **CMD-Specific:** Highly recommended only for ambulatory CMD patients.
Scoring and Psychometric Properties	**Scoring:** Record the number of laps from the counter (or tick marks on the worksheet). Record the additional distance covered (the number of meters in the final partial lap) using the markers on the wall as distance guides. Calculate the total distance walked, rounding to the nearest meter, and record it on the worksheet. Most 6MWTs will be done before and after intervention, and the primary question to be answered after both tests have been completed is whether the patient has experienced a clinically significant improvement. Assistive devices can be used but should be recorded at each test. **Psychometric Properties:** The 6-min walk has good test-retest reliability in older populations (.88 <R < .94). particularly when a practice trial preceded the test trial. Convergent validity of the 6-min walk was demonstrated by its moderate correlation (.71 < r < .82) with treadmill performance. Construct validity was assessed by determining the ability of the test to detect differences between different age and activity level groups. As expected, walking scores decreased significantly across decades and were significantly lower for low-active subjects compared to high-active subjects. There was a moderate relationship between 6-min walk scores and self-reported functional ability. It was concluded that the 6-min walk can be used to obtain reasonably reliable and valid measures of physical endurance in older adults and that it moderately reflects overall physical functional performance. In healthy children, the 6-min walk test is a reliable and valid functional test for assessing exercise tolerance and endurance.
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Action Research Arm Test
(New for Stroke)

Availability	**Please visit this website for more information about the instrument: Action Research Arm Test** **The ARAT can be obtained by emailing info@saliarehab.com**
Classification	**Supplemental:** Stroke **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	Observer-rated, performance-based assessment of upper extremity function and dexterity. It evaluates a person's ability to handle objects differing in shape, size and weight.
Comments/Special Instructions	19 items in 4 subsets: Grasp (6 items) Grip (4 items) Pinch (6 items) Gross arm movement (3 items) Length of Test: 6 to 30 minutes, dependent on number of items performed.
Scoring and Psychometric Properties	**Scoring:** 4-point ordinal scale from 0 (no movement) to 3: 3: Performs test normally 2: Completes test, but takes abnormally long or has great difficulty 1: Performs test partially 0: Can perform no part of test Lyle's decision rule: Patients who achieve a maximum score on the first (most difficult) item are credited with having scored 3 on all subsequent items on that scale. If the patient scores less than 3 on the first item, then the second item is assessed. This is the easiest item, and if patients score 0 then they are unlikely to achieve a score above 0 for the remainder of the items and are credited with a zero for the other items. The maximum score on the ARTS is 57 points (possible range 0 to 57). Items can also be summed (van der Lee et al, 2002). A standardized scoring protocol has been published by Yozbatiran 2008. **Psychometric Properties:** Methodological quality of psychometric properties range from poor to excellent. Best evidence synthesis determined moderate positive evidence for using the ARAT with people without limb spasticity: intra-rater reliability (ICC 0.71 (95% CI 0.53–0.89) to 0.99 (95% CI 0.98, 0.99)); responsiveness (ROC curve 0.72–0.88, SRM 0.89); and regarding construct validity, it is a valid

	measure of activity limitation. Limited evidence for psychometric properties of the ARAT were found when used with people with upper limb spasticity for construct validity and responsiveness (ES 0.55–0.78). Gaps in evidence were found for inter and test–retest reliability, measurement error, content validity, structural validity, floor and ceiling effects.
References	Alt Murphy M, Resteghini C, Feys P, Lamers I. An overview of systematic reviews on upper extremity outcome measures after stroke. BMC Neurol. 2015 Mar 11;15:29. doi: 10.1186/s12883-015-0292-6. Bushnell C, Bettger J, Cockroft K, Cramer S, Edelen M, Hanley D, Katzan I, Mattke S, Nilsen D, Piquado T, Skidmore E, Wing K, Yenokyan G. Chronic Stroke Outcome Measures for Motor Function Intervention Trials: Expert Panel Recommendations. Circ Cardiovasc Qual Outcomes. 2015 October; 8(6 Suppl 3): S163-S169. doi: 10.1161/CIRCOUTCOMES. 115.002098. Hsueh IP, Hsieh CL. Responsiveness of two upper extremity function instruments for stroke inpatients receiving rehabilitation. Clin Rehabil. 2002;16(6):617–624. Kwakkel G, Lannin NA, Borschmann K, English C, Ali M, Churilov L, Saposnik G, Winstein C, van Wegen EE, Wolf SL, Krakauer JW, Bernhardt J. Standardized measurement of sensorimotor recovery in stroke trials: Consensus-based core recommendations from the Stroke Recovery and Rehabilitation Roundtable.Int J Stroke. 2017 Jul;12(5):451-461. doi: 10.1177/1747493017711813. Lyle RC. A performance test for assessment of upper limb function in physical rehabilitation treatment and research. Int J Rehabil Res. 1981;4(4):483–492. Pike S, Lannin NA, Wales K, Cusick A. A systematic review of the psychometric properties of the Action Research Arm Test in neurorehabilitation. Aust Occup Ther J. 2018 Oct;65(5):449-471. Yozbaritan N, Der-Yeghiaian L, Cramer SC. A Standardized Approach to Performing the Action Research Arm Test. Neurorehab Neural Re. 2007;22(1):78-90.

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Animal Naming
(New for Stroke)

Availability	The instrument is freely available at the following website: Animal Naming
Classification	**Supplemental:** Stroke
Short Description of Instrument	The Animal Naming instrument tests verbal/semantic fluency by asking the participant to list as many animals as possible in one minute.
Comments/Special Instructions	**Introduction:** “I’d like to ask a question to check your memory.” **Instruction:** “Tell me the names of as many animals as you can think of, as quickly as possible.” **Procedure:** Time for 60 seconds and record all responses. If the person stops before 60 seconds, say “Any more animals?” If the person says nothing for 15 seconds, say “A dog is an animal. “Can you tell me more animals?”
Scoring and Psychometric Properties	**Scoring**: Count the total number of animals (NOT including repetitions or non-animal words). Norms are based on age and education.
References	Lucas JA, Ivnik RJ, Smith GE, Ferman, TJ, Willis FB, Peterson, RC, Graff-Radford NR. Mayo's Older African Americans Normative Studies: Norms for Boston Naming Test, Controlled Oral Word Association, Category Fluency, Animal Naming, Token Test, Wrat-3 Reading, Trail Making Test, Stroop Test, and Judgment of Line Orientation. Clin. Neuropsychol. 2005;19(2):243-269. McKenna P, Parry R. Category specificity in the naming of natural and man-made objects: Normative data from adults and children. Neuropsych Rehabil. 1994;4(3):255-281. Rosen WG. Verbal fluency in aging and dementia. J. Clin. Neuropsychol. 1980;2(2):135-146. Tombaugh TN, Kozak J, Rees L. Normative Data Stratified by Age and Education for Two Measures of Verbal Fluency: FAS and Animal NamingArch Clin Neuropsych. 1999;14(2):167-177.

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Barthel Index

Availability	The Maryland State Medical Society holds the copyright for the Barthel Index. It may be used freely for non-commercial purposes with the primary reference cited: [Mahoney FI, Barthel D. Functional evaluation: the Barthel Index. Maryland State Med J. 1965;14:56–61. Used with permission.] Permission is required to modify the Barthel Index or to use it for commercial purposes. Shorter version of the form is available for use. Multiple language translations available – validation studies in English only. Please contact Mapi Research Trust to sign a translation agreement and to obtain Linguistic Validation Guidelines. **Contact information and permission to use:** MAPI Research Trust, Lyon, France: E-mail: PROinformation@mapi-trust.org Internet: https://mapi-trust.org/ **Information on Barthel Index:** ○ Rehab Measures: Barthel Index ○ PROQOLID
Classification	~~**Core:** Stroke~~ **Supplemental:** Multiple Sclerosis (MS), Myotonic Muscular Dystrophy (DM), Neuromuscular Disease (NMD), Stroke and Amyotrophic Lateral Sclerosis (ALS) **Exploratory:** Congenital Muscular Dystrophy (CMD), Friedreich's Ataxia (FA), and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	The Barthel Index (BI) or Barthel ADL index is a scale used to measure performance in basic activities of daily living (ADL). It uses ten variables describing ADL and mobility. A higher number is associated with a greater likelihood of being able to live at home with a degree of independence following discharge from hospital. **Purpose**: Assesses the ability of an individual with a neuromuscular or musculoskeletal disorder to care for him/herself. **Construct measured**: Activities of daily living (ADL) and mobility. **Generic vs. disease specific**: Generic.

	Means of administration: Interview (including over the phone) or observation; typically scored by a multidisciplinary team. **Intended respondent**: Patient or caregiver. **# of items**: 10. **# of subscales and names of sub-scales**: 2 – Activities of daily living, Mobility. **# of items per sub-scale**: N/A.
Comments/Special Instructions	**Background:** The BI was originally developed as an ADL assessment for long-term patients in hospital with neuromuscular or musculoskeletal disorders (Mahoney and Barthel 1965). It is one of the most widely used generic disability measures, and has been used extensively in MS. A five-item short form of the Barthel Index is also available (Hobart et al., 2001). It should be used as a record of what a patient does, not of what a patient can do.
Scoring and Psychometric Properties	**Scoring:** A patient scoring 100 is continent, feeds himself, dresses himself, gets up out of bed and chairs, bathes himself, walks at least a block, and can ascend and descend stairs. This does not mean that he is able to live alone: he may not be able to cook, keep house, and meet the public, but he is able to get along without attendant care. A score of 0 is given in all of the above activities when the patient cannot meet the criteria as defined above. According to Sinoff and Ore, scoring on the BI can be interpreted as follows: o score of 80–100, independent. o score of 60–79, needs minimal help with ADL. o score of 40–59, partially dependent. o score of 20–39, very dependent. o score of < 20, totally dependent. **Psychometric Properties:** A number of studies support the validity, reliability and responsiveness of the BI in MS. Ceiling and floor effects potentially limits its responsiveness to change in the community and long term settings. A sizable number of studies support the high reproducibility of the BI, Cronbach's reliability ranging from 0.84–0.96. Responsiveness is similar to that of the FIM. The BI is highly correlated with the FIM (Prodinger et al., 2017). The BI is considered a reliable disability scale for stroke patients. A meta-analysis by Duffy et al., (2013) found the BI to have excellent inter-rater reliability (κw, 0.93; 95% confidence interval, 0.90-0.96 random effects modeling) for standard administration after stroke. However, the scale suffers from 'ceiling effects' and therefore does not differentiate disability well among patients with higher levels of functioning. The BI also has 'floor

	effects' and is not useful in the setting of acute stroke because it typically cannot be used to measure initial stroke severity.
Rationale/Justification	**Strengths/Weaknesses:** The advantage of the BI is its simplicity. It is useful in evaluating a patient's state of independence before treatment, his progress as he undergoes treatment, and his status when he reaches maximum benefit. It can easily be understood by all who work with a patient and can accurately and quickly be scored by anyone who adheres to the definitions of items. A potential advantage of the Barthel Index is that it can be administered by patient self-report, patient interview including by telephone, or by report of a proxy able to provide reliable information (e.g., spouse, family member, or caregiver). However, there are few data confirming the equivalence of these data collection methods. **Administration:** The examination requires 5–10 minutes to complete. **Other Important Notes:** A shorter version of the form is available for use; the modified 20-point version of the BI introduced by Collin and colleagues in 1988. The modified 20-point BI is easier and quicker to administer than the 100-point BI. English and ~~Spanish~~other translations are available~~ – validation studies in English only~~. The BI is a useful tool at 30 or 90 days to assess level of assistance required for activities of daily life. There are currently no published instructions on the use of the BI to assess initial stroke disability. Pre-morbid BI is reasonable to assess on presentation, but there is a lack of data to identify how to use it to assess initial stroke presentation. Raters using this at admission or discharge should develop a standard methodology and scoring instructions for use in hospital settings.
References	**Key Reference:** Mahoney FI, Barthel D. Functional evaluation: the Barthel Index. Maryland State Med J. 1965;14:56–61. **Additional References:** Collin C, Wade DT, Davies S et al. The Barthel ADL Index: a reliability study. Int Disabil Stud. 1988;10: 61–63. D'Olhaberriague L, Litvan I, Mitsias P, Mansbach HH. A reappraisal of reliability and validity studies in stroke. Stroke. 1996;27:2331–2336. Duffy L, Gajree S, Langhorne P, Stott DJ, Quinn TJ. Reliability (inter-rater agreement) of the Barthel Index for assessment of stroke survivors: systematic review and meta-analysis. Stroke.

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Beck Anxiety Inventory (BAI)
(New for Stroke)

Availability	**Please visit this website for more information about the instrument: Beck Anxiety Inventory**
Classification	**Supplemental-Highly Recommended:** Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS) **Supplemental:** Epilepsy, Headache, Mitochondrial Disease (Mito), Stroke **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Overview:** The Beck Anxiety Inventory (BAI) measures the severity of an individual's anxiety. It is a 21-question multiple-choice self-report inventory that is used for measuring how the subject has been feeling in the last week, focusing primarily on somatic symptoms. Importantly, Raj and colleagues (2009) suggest that the BAI may overestimate anxiety severity in patients with Postural Tachycardia Syndrome (POTS). Specifically, 5 of the 21 items on the BAI are consistent with somatic orthostatic symptoms and thus could inflate the anxiety score. Therefore, special attention should be paid to the following 5 BAI items in patients with comorbid POTS: heart pounding and racing, feeling dizzy and light-headed, numbness and tingling, feeling unable to relax, and feeling unsteady. The scale is also available in Spanish. This examination is intended to assess short-term anxiety symptoms. The BAI is self-administered or verbally administered by a trained administrator, and each item is descriptive of subjective, somatic, or pain-related symptoms of anxiety. Each question has the same set of four possible answer choices. The scale takes approximately 5-10 minutes to administer and has state and trait anxiety components. Age range is 17 to 80 years. **ME/CFS Specific:** **Advantages:** Has potential to be used over the phone. **Limitations:** Rao et al. (2006) only used the - the trait version of the scale (BAIT). The scale appears to be sufficiently sensitive to assess trait anxiety and changes over time in ME/CFS patients.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The BAI items are scored on a scale between 0 and 3 and have a maximum score of 63. Total score (0–63), where Minimal Level of Anxiety (0–7); Mild Anxiety (8–15); Moderate Anxiety (16–25); Severe Anxiety (26–63). The instrument can either be manually scored or by using Pearson's proprietary Q-global scoring and reporting software.

	Psychometric Properties: The BAI is found to discriminate well between anxious and non-anxious diagnostic groups in a variety of clinical populations.
References	Beck AT. An inventory for measuring clinical anxiety: psychometric properties. J Consult Clin Psychol. 1988; 56(6): 893–897. Beck AT, Steer RA, Brown GK. Manual for The Beck Depression Inventory - Second Edition (BDI-II). San Antonio: Psychological Corporation; 1996. Beck AT, Steer RA, Ball R, Ranieri W. Comparison of Beck Depression Inventories -IA and -II in psychiatric outpatients. J Pers Assess. 1996; 67(3): 588–597. Kim DS, Park YG, Choi JH, Im S, Jung KJ, Cha YA, Jung CO, Yoon YH. Effects of Music Therapy on Mood in Stroke Patients. Yonsei Med J. 2011 Nov;52(6):977-981. Kim ES, Sun JK, Park N, Peterson C. Purpose in life and reduced incidence of stroke in older adults:'The Health and Retirement Study'. J Psychosom Res. 2013;74(5): Muntingh AD, van der Feltz-Cornelis CM, van Marwijk HW, Spinhoven P, Penninx BW, van Balkom AJ. Is the Beck Anxiety Inventory a good tool to assess the severity of anxiety? A primary care study in the Netherlands Study of Depression and Anxiety (NESDA). BMC Fam Pract. 2011;12(66). Rao AV, Bested AC, Beaulne TM, Katzman MA, Iorio C, Berardi JM, Logan AC. A randomized, double-blind, placebo-controlled pilot study of a probiotic in emotional symptoms of chronic fatigue syndrome. Gut Pathog. 2009;1(1):6. Raj V, Haman KL, Raj SR, Byrne D, Blakely RD, Biaggioni I, Robertson D, Shelton RC. Psychiatric Profile and Attention Deficits in Postural Tachycardia Syndrome. J Neurol Neurosurg Psychiatry. 2009;80(3):339-344.

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Beck Depression Inventory II (BDI-II)
(New for Stroke)

Availability	**Please visit this website for more information about the instrument: Beck Depression Inventory**
Classification	**Supplemental – Highly Recommended**: Epilepsy, Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS) **Supplemental:** Amyotrophic Lateral Sclerosis (ALS), Epilepsy, Headache, Multiple Sclerosis (MS), Parkinson's Disease (PD), Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months) and Persistent/Chronic (3 months and greater post concussion), Stroke, and Traumatic Brain Injury (TBI) **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Construct measured:** This scale measures the existence and severity of symptoms of depression. **Generic vs. disease specific**: Generic. **Means of administration:** Self-administered. **Intended respondent:** Self-Report. **# of items:** 21 items. **# of subscales and names of sub-scales:** 2 subscales: Affective and Somatic subscales. **# of items per sub-scale:** 8 for affective; 13 for somatic.
Comments/Special Instructions	The Beck Depression Inventory-II (BDI-II) developed in 1996, was derived from the BDI. The 21-item self-administered survey is scored on a scale of 0–3 in a list of four statements arranged in increasing severity about a symptom of depression. BDI-II assesses presence and intensity of mood symptoms. The scale can be divided into 2 subscales, affective symptoms (8 items) and somatic symptoms (13 items). Cut-off scores are available to classify degree of mood intensity. The scale is also available in Spanish.
Scoring and Psychometric Properties	**Scoring:** Each of the 21 items corresponding to a symptom of depression is summed to give a single score for the Beck Depression Inventory-II (BDI-II). There is a four-point scale for each item ranging from 0 to 3. On two items (16 and 18) there are seven options to indicate either an increase or decrease of appetite and sleep. Cut-off score guidelines for the BDI-II are given with the recommendation that thresholds be adjusted based on the characteristics of the sample, and the purpose for use of the BDI-II. Total score of 0–13 is considered minimal range, 14–19 is mild, 20–28 is moderate, and 29–63 is severe. This scale can be scored either manually or using the Pearson proprietary software Q-global.

	Psychometric Properties: *Feasibility:* Easy to complete, relatively short compared to interview-based assessments. *Reliability:* 1 week test-retest stability is high (.93). Internal consistency (coefficient alpha) is .92–.94 depending on the sample. *Validity:* Construct validity was high when compared to the BDI (.93).
Rationale/Justification	**ALS Specific:** **Strengths:** Easy to use, widely known, results easy to interpret. Item content improved over BDI-I to increase its correspondence with DSM-IV. **Weaknesses:** Includes several items assessing physical symptoms which may be elevated in ALS patients due to motor neuron degeneration and not depression. However non-ALS clinical studies have provided evidence of the presence of at least two factors, a cognitive-affective factor and a somatic depressive symptom factor, which is more stable than in the BDI. However, this factor structure requires confirmation in ALS. **Sensitivity to Change:** Designed to assess mood within the most recent 2-week period, so comparison across assessments should reflect change over time. **Relationships to other variables:** BDI-II scores were not correlated with functional disability (ALSFRS-R scores) (Rabkin et al., 2005) in late-stage ALS patients, but did correlate with suffering, anger, perceived caregiver burden, weariness, and negative effect. In non-ALS studies, BDI-II scores correlate with measures of hopelessness, suicidal ideation and anxiety. **Purpose of Tool:** Screening for severity of depression. **Used in:** Observational studies. **Administration time:** 5 minutes, scoring 1 minute. **Sport-Related Concussion Specific:** **Advantages:** Widely used and accepted instrument. Quantifies depressive symptoms, but is not a diagnostic instrument. Some symptoms overlap with "concussive symptoms". Any study looking at factors contributing to persistent symptoms should use this measure. **Age Range:** age 13 and older **ME/CFS Specific:** **Advantages:** Useful in ME/CFS because of the differentiation between somatic and affective symptoms. The investigator can ferret out whether mood symptoms exist or whether symptoms can be attributed mainly to the somatic symptoms of the disease. The BDI-II is a valid and reliable tool to evaluate mood in ME/CFS (Brown et al., 2012). **Limitations:** Investigators should be careful not to attribute elevations to affective reasons only as there is a large overlap

	with somatic symptoms in ME/CFS patients due to the nature of the disease.
References	Beck AT, Steer RA, Brown GK. Manual for The Beck Depression Inventory Second Edition (BDI-II). San Antonio: Psychological Corporation; 1996. Beck AT, Steer RA, Ball R, Ranieri W. Comparison of Beck Depression Inventories -IA and -II in psychiatric outpatients. J Pers Assess. 1996;67(3):588–597. Steer RA, Ball R, Ranieri WF, Beck AT. Dimensions of the Beck Depression Inventory-II in clinically depressed outpatients. J Clin Psychol. 1999;55(1):117–128. Storch EA, Roberti JW, Roth DA. Factor structure, concurrent validity, and internal consistency of the Beck Depression Inventory-Second Edition in a sample of college students. Depress Anxiety. 2004;19(3):187–189. Maizels M, Smitherman TA, Penzien DB. A review of screening tools for psychiatric comorbidity in headache patients. Headache. 2006;46 Suppl 3:S98–S109. Wang Y, Gorenstein C. Psychometric properties of the Beck Depression Inventory-II: a comprehensive review. Revista Brasileira de Psiquiatria. 2013;35(4):416–431. **ALS-Specific References:** Taylor L, Wicks P, Leigh PN, Goldstein LH. Prevalence of depression in amyotrophic lateral sclerosis and other motor disorders. Eur J Neurol. 2010;17(8):1047–1053. Rabkin JG, Albert SM, Del Bene ML, O'Sullivan I, Tider T, Rowland LP, Mitsumoto H. Prevalence of depressive disorders and change over time in late-stage ALS. Neurology. 2005;65(1):62–67. Trail M, Nelson ND, Van JN, Appel SH, Lai EC. A study comparing patients with amyotrophic lateral sclerosis and their caregivers on measures of quality of life, depression, and their attitudes toward treatment options. J Neurol Sci. 2003;209(1-2):79–85. **ME/CFS-Specific References:** Brown M, Kaplan C, Jason L. Factor analysis of the Beck Depression Inventory-II with patients with chronic fatigue syndrome. Journal of health psychology. 2012;17(6):799–808. **Stroke-Specific References:**

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Berg Balance Scale (BBS)
(New for Stroke)

Availability	Available in the public domain: Berg Balance Scale Link or The Internet Stroke Center Website Link. Please click here for more information on the Pediatric Modification of the Berg Balance Scale.
Classification	**Supplemental – Highly Recommended:** Spinal Cord Injury (SCI); not recommended for youth < 18y. **Supplemental:** Cerebral Palsy (CP), Multiple Sclerosis (MS) and Stroke **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Construct measured:** Balance function by assessing the performance of functional tasks **Generic vs. disease specific:** Generic **Means of administration:** In-person by a trained examiner **Intended respondent:** Participant **# of items:** 14 **# of subscales and names of sub-scales:** N/A **# of items per sub-scale:** N/A
Comments/Special Instructions	**Background:** The Berg Balance Scale (BBS) was developed to measure balance among stroke patients and older people with impairment in balance function by assessing the performance of functional tasks. It is a valid instrument used for evaluation of the effectiveness of interventions and for quantitative descriptions of function in clinical practice and research. This test has been validated for use in individuals with SCI, and has the advantage of being valuable for other neurologic populations. **SCI-Pediatric:** Pediatric Balance Scale, has been evaluated in children age 5–15 with known balance impairments. Shows good test-retest and inter-rater reliability. Child must be able to follow directions. It has not been evaluated specifically for children with SCI.
Rationale/Justification	**Strengths/Weaknesses:** A study by Conradsson and colleagues (2007) demonstrated that a change of 8 BBS points is required to reveal a genuine change in function between two assessments among older people who are dependent in ADL and living in residential care facilities. The BBS is appropriate for community dwelling elderly people, individuals that have suffered a stroke, and the elderly population with balance difficulties. **Administration:** Administration takes approximately 15–20 minutes.

Scoring and Psychometric Properties	**Scoring:** A five-point scale, ranging from 0–4. “0” indicates the lowest level of function and “4” the highest level of function. Total Score = 0–56. Score of 41–56 = low fall risk, 21–40 = medium fall risk, 0–20 = high fall risk. **Psychometric Properties:** Overall, the BBS appears to be a reliable tool used to measure outcomes. Berg et al demonstrated that the inter-rater reliability ICC was .99. The BBS may have a ceiling effect, and is insensitive to individuals with very high levels of balance.
References	**Key References:** Berg K, Wood-Dauphinee S, Williams JI and Gayton D. Measuring balance in the elderly: preliminary development of an instrument. Physiotherapy Canada. 1989;41:304–311. Berg KO, Wood-Dauphinee SL, Williams JI Maki B. Measuring balance in the elderly: validation of an instrument. Can J Public Health. 1992;83 Suppl 2:S7–S11. Conradsson M, Lundin-Olsson L, Lindelof N, Littbrand H, Malmqvist L, Gustafson Y, Rosendahl E. Berg balance scale: intrarater test-retest reliability among older people dependent in activities of daily living and living in residential care facilities. Phys Ther. 2007;87(9):1155–1163. **Additional References:** Bogle Thorbahn LD & Newton RA. Use of the Berg Balance Test to predict falls in elderly persons. Phys Ther. 1996;76(6):576–583; discussion 584–575. **SCI-specific:** Wirz M, Muller R, Bastiaenen C. Falls in persons with spinal cord injury: validity and reliability of the Berg Balance Scale. Neurorehabil Neural Repair. 2010;24(1):70–77. **SCI-Pediatric-specific:** Franjoine MR, Gunther JS, Taylor MJ. Pediatric balance scale: a modified version of the berg balance scale for the school-age child with mild to moderate motor impairment. Pediatr Phys Ther. 2003;15(2):114–128. **SAH-specific:** Berg K, Wood-Dauphinee S, Williams JI. The Balance Scale: reliability assessment with elderly residents and patients with an acute stroke. Scand J Rehabil Med. 1995;27(1):27–36. Nakamura DM, Holm MB, Wilson A. Measures of Balance and Fear of Falling in the Elderly: a review. Phys Occup Ther Geriatr. 1998;15(4):17–32.

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Boston Naming Test (BNT) - 30-item version

Availability	The BNT is ~~available from the Psychological Assessment Resources (PAR), 16130 North Florida Avenue, Lutz, FL 33549. For additional information, please visit~~included in the Boston Diagnostic Examination (Third Edition) available at the following website: ~~Psychological Assessment Resources~~ Pearson Assessments
Classification	**Supplemental – Highly Recommended:** Epilepsy and Stroke **Supplemental:** Mitochondrial Disease (Mito) ~~and Stroke~~ **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose** The 30-item version of the Boston Naming Test (BNT) was designed to differentiate between Alzheimer's disease (AD) and normal subjects. This version is useful for repeated assessments of a naming task, as well as in situations where administration of the complete BNT is not practical (Mack et al., 1992). **Overview** The BNT and its short forms are tasks of visual confrontation naming, sensitive to deficits in semantic retrieval. Norms for this 30-item version were developed using a registry including normal controls, mild cognitive impairment (MCI), and AD (Jefferson et al., 2007). Items have been rank ordered in terms of their ability to be named, which is thought to be correlated with their frequency. **Time** The assessment takes approximately 10 minutes. **Other Important Notes** Spanish versions of the BNT are available (Peña-Casanova et al., 2009; Ponton et al., 1996).
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring** Patients have 20 seconds to respond to each item. Each item is scored as correct, correct with semantic cues, or correct with phonemic cues. The total score is the number correct spontaneously or with semantic cues. **Psychometric Properties** Interjudge and intrajudge reliability were found to be high, average of 89.1% and 97.6% respectively. Overall reliability using a matrix agreement system adjusting for chance was 91.2% (Nicholas et al., 1998).

References	Jefferson, AL, Wong, S., Gracer, TS, Ozonoff, A, Green, RC, Stern RA. Geriatric performance on an abbreviated version of the Boston naming test. Appl Neuropsychol. 2007;14, 215–223. Mack WJ, Freed DM, Williams BW, Henderson VW. Boston Naming Test: Shortened versions for use in Alzheimer's disease. J Gerontol. 1992;47(3): 154–158. Nicholas LE, Brookshire RH, MacLennan DL, Schumacher JG, Porrazzo SA (1988). The Boston Naming Test: Revised Administration and Scoring Procedures and Normative Information for Non-Brain-Damaged Adults. Clin Aphasiology. 1988;18:103–115. Peña-Casanova J, Quiñones-Ubeda S, Gramunt-Fombuena N, Aguilar M, Casas L, Molinuevo JL, Robles A, Rodríguez D, Barquero MS, Antúnez C, Martínez-Parra C, Frank-García A, Fernández M, Molano A, Alfonso V, Sol JM, Blesa R; NEURONORMA Study Team. Spanish Multicenter Normative Studies (NEURONORMA Project): norms for Boston naming test and token test. Arch Clin Neuropsychol. 2009;24(4):343–354. Pontón MO, Satz P, Herrera L, Ortiz F, Urrutia CP, Young R, D'Elia LF, Furst CJ, Namerow N. Normative data stratified by age and education for the Neuropsychological Screening Battery for Hispanics (NeSBHIS): Initial report. J Int Neuropsychol Soc. 1996;2(2):96–104. Strauss E, Sherman EMS, Spreen O. A compendium of neuropsychological tests: administration, norms, and commentary, 3rd ed. New York: Oxford University Press; 2006, pp. 901–915.

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Brief Visuospatial Memory Test Revised (BVMT-R)
(New for Stroke)

Availability	**Please visit this website for more information about the instrument: Brief Visuospatial Memory Test – Revised.**
Classification	**Supplemental:** Cerebral Palsy (CP), Epilepsy, Multiple Sclerosis (MS), Sport-Related Concussion (SRC), Stroke, and Traumatic Brain Injury (TBI)
Short Description of Instrument	**Author:** Ralph H. B. Benedict, PhD, ABCN A measure of visuospatial memory, the Brief Visualspatial Memory Test – Revised (BVMT-R) can be used as part of a large neuropsychological battery, as a screening measure, and as a repeat measure to document changes over time. **Purpose:** Measure visuospatial memory **Age range:**18 to 79 years **Administration:** Individual **Administration time:** 45 minutes timed (includes 25-minute delay) **Scoring time:** 25 minutes
Comments/Special Instructions	The BVMT-R is designed for easy administration in clinical settings or at the bedside. Six equivalent, alternate stimulus forms consist of six geometric figures printed in a 2 x 3 array on separate pages. In three Learning Trials, the respondent views the stimulus page for 10 seconds and is asked to draw as many of the figures as possible in their correct location on a page in the response booklet. A Delayed Recall Trial is administered after a 25-minute delay. Last, a Recognition Trial, in which the respondent is asked to identify which of 12 figures were included among the original geometric figures, is administered. An optional Copy Trial may be administered to screen for severe visuoconstructive deficits and to help in scoring recall responses.
Scoring and Psychometric Properties	**Scoring:** Twelve scores may be derived from BVMT-R performance. Recall performance is recorded for each of the immediate recall trials (Trial 1, Trail 2, and Trial 3) and for the delayed recall trial (Delayed Recall).

	The recall scores are combined to form three additional summary measures of learning and memory. Recognition Hits and False Alarms are recorded during the delayed recognition task. Recognition Hits are calculated as the number of correct “YES” responses to target items, and Recognition False Alarms are calculated as the number of incorrect “yes” responses to nontarget items. **Psychometric Properties:** Reliability coefficients range from .96 to .97 for the three Learning trials, .97 for Total Recall, and .97 for Delayed Recall. Test-retest reliability coefficients range from .60 for Trial 1 to .84 for Trial 3. The BVMT-R correlates most strongly with other tests of visual memory and less strongly with tests of verbal memory.
References	Benedict, RHB. Brief visuospatial memory test - revised: Professional manual. Lutz, FL: Psychological Assessment Resources, Inc; 1997. Benedict RHB, Groninger L. Preliminary standardization of a new visuospatial memory test with six alternative forms. Clin Neuropsychol. 1995;9(1):11–16. Benedict RHB, Schretlen D, Groninger L, Dobraski M, Shpritz B. Revision of the Brief Visuospatial Memory Test: Studies of Normal Performance, Reliability, and Validity. Psychol Assess. 1996;8(2):145–153. Campanholo KR, Conforto AB, Rimkus CM, Miotto EC.Cognitive and Functional Impairment in Stroke Survivors with Basilar Artery Occlusive Disease.Behav Neurol. 2015; 971514. Tam JW, Schmitter-Edgecombe M. The role of processing speed in the Brief Visuospatial Memory Test - revised. Clin Neuropsychol. 2013;27(6):962–972.

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Canadian Occupational Performance Measure (COPM)

Availability	**Available for purchase at this website: Canadian Occupational Performance Measure (COPM)**
Classification	**Supplemental – Highly Recommended:** Cerebral Palsy (CP) **Supplemental**: Spinal Cord Injury (SCI), SCI-Pediatric (age 2 and over for parent report; age 6 and over for child report) and Stroke **Exploratory**: Spinal Muscular Atrophy (SMA) and Duchenne Muscular Dystrophy (DMD)
Short Description of Instrument	**Construct measured:** Performance and satisfaction in leisure productivity and self- care from client perspective. **Generic vs. disease specific**: Generic **Means of administration:** Typically administered by an Occupational Therapist **Intended respondent:** Participant, although a caregiver may respond on the participant's behalf **# of items:** The five most urgent problems are identified. **# of subscales and names of sub-scales:** N/A **# of items per sub-scale:** N/A
Comments/Special Instructions	**Background**: The COPM is designed to detect change in an individual's self- perception of occupational performance over time. The instrument has been validated for ages 6–65+. The COPM has been translated into over 35 ~~24~~ languages.
Scoring and Psychometric Properties	**Scoring:** Importance is ranked, performance and satisfaction are scored separately from 1–10. Scores (importance and performance and importance and satisfaction) can then be multiplied for a maximum of 100. **Psychometric Properties:** Recent studies have featured psychometric properties including clinical utility, validity and responsiveness (Eyssen et al., 2011). The results were very positive, demonstrating support for the reliability and validity of the COPM. Clinical utility, examined through several different studies supports the use of the COPM with a wide variety of clients in various settings (Dedding et al., 2004; Verkerk et al., 2006). This measure has moderate inter-rater agreement and mean performance and satisfaction score reproducibility, but poor reproducibility for separate problem scores (Eyssen et al.,2005).
Rationale/Justification	**Strengths/Weaknesses:** Some authors have commented that the tool can be time consuming and difficult to administer;

	requires the administrator to be comfortable with a patient centered approach; and due to the non-standardized interview, quality and consistency may vary between administrators. The COPM may be used for all levels and severities of injury, but may be less appropriate for acute and early Phase trials/interventions. The COPM has been well-established in adult and pediatric clinical samples (Cup et al., 2003; Dedding et al., 2004; Eyssen et al., 2005; Cusick 2006). Although it was adapted for very young children (Cusick et al., 2007), the COPM focuses assessment of performance in self-care, productivity and leisure (Law et al., 1990). The COPM has been used in SCI studies, several of which demonstrated its responsiveness to change (Mulcahey et al., 1995; Wangdell & Friden, 2010) **Administration:** Time to administer is 10–20 minutes, no equipment is required, training can be conducted by reading an article/manual.
References	**References:** Bickes MB, Deloache SN, Dicer JR, Miller SC. Effectiveness of Experiential and Verbal Occupational Therapy Groups in a Community Mental Health Setting. Occup Ther Mental Health. 2001;17(1):51–72. Bodiam, C. The Use of the Canadian Occupational Performance Measure for the Assessment of Outcome on a Neurorehabilitation Unit. Br JOccup Ther.1999;62(3):123–126. Cup EH, Scholte op Reimer WJ, Thijssen MC, & van Kuyk-Minis MA. Reliability and validity of the Canadian Occupational Performance Measure in stroke patients. Clin Rehabil. 2003;17(4):402–409. Cusick, A., Lannin, N. A., & Lowe, K. (2007). Adapting the Canadian Occupational Performance Measure for use in a paediatric clinical trial. Disabil Rehabil, 29(10), 761–766. Dedding C, Cardol M, Eyssen IC, Dekker J, Beelen A. Validity of the Canadian Occupational Performance Measure: a client-centred outcome measurement. Clin Rehabil. 2004;18(6):660–667. Eyssen IC, Beelen A, Dedding C, Cardol M, Dekker J. The reproducibility of the Canadian Occupational Performance Measure. Clin Rehabil. 2005;19(8):888-894. Eyssen IC, Steultjens MP, Oud TA, Bolt EM, Maasdam A, Dekker J. Responsiveness of the Canadian occupational performance measure. J Rehabil Res Dev. 2011;48(5):517–528.

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SCI-Pediatric-specific:
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Stroke-specific:

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Hill V, Dunn L, Dunning K, Page SJ. A pilot study of rhythm and timing training as a supplement to occupational therapy in stroke rehabilitation. Top Stroke Rehabil. 2011;18(6):728-737.

Kirton A, Andersen J, Herrero M, Nettel-Aguirre A, Carsolio L, Damji O, Keess J, Mineyko A, Hodge J, Hill MD. Brain stimulation

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Center for Epidemiologic Studies-Depression Scale (CES-D)

Availability	The instrument is freely available here: **Center for Epidemiologic Studies-Depression Scale**
Classification	**Supplemental – Highly Recommended**: Sport-Related Concussion (SRC) Acute (time of injury until 72 hours) ~~and Stroke (based on study type, disease stage and disease type)~~ **Supplemental**: Mitochondrial Disease (Mito), Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS), Multiple Sclerosis (MS), Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months) and Persistent/Chronic (3 months and greater post-concussion), Stroke, and Traumatic Brain Injury (TBI) **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose:** The Center for Epidemiologic Studies Depression Rating Scale (CES-D) is a widely used screening scale for depression and employed in stroke and cardiovascular health studies. It measures depressive feelings and behaviors occurring in the past week of a patient's life. **Overview:** The CES-D consists of 20 items, which make up six scales reflecting depressive symptomatology: depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. **Time:** Evaluation is approximately 5 minutes
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	Each item is scored on a 4-point scale ranging from 0 (rarely/none of the time) to 3 (most/all of the time). Scores for items 4, 8, 12, and 16 are reversed before summing all items to yield a total score, which can range from 0–60. Higher scores indicate more depressive symptoms. **Psychometric Properties:** The measure is reliable for assessing number, types and duration of depressive symptoms across racial, gender, and age categories, has been reported to have high internal consistency, and has been extensively validated.
Rationale/Justification	**Strengths and Weaknesses:** The CES-D is not intended as a clinical diagnostic tool and interpretations of individual scores should not be made. Group means should only be used to reference other groups. The internal reliability and consistency is good for all groups tested (Race, age, education).

	Other Important Notes: The CES-D can be self or interviewer-administered. The CES-D was developed for use in studies of the epidemiology of depressive symptomatology in the general population. Items were selected from previously validated scales and cover the major components of depressive symptomatology. The scale is not intended for a clinical diagnosis of depression. **Sport-Related Concussion Specific:** Advantages: Widely used screen for depressive symptoms. It is not a diagnostic instrument. Some of the depressive symptoms will overlap with post-concussion symptoms. It is self-administered and very brief screen. Age Range: can be used in adults, as well as children and adolescents (6–17). Less reliable in the younger children.
References	**Stroke References:** Haley WE, Roth DL, Kissela B, Perkins M, Howard, G.. Quality of life after stroke: a prospective longitudinal study. Qual Life Res. 2011; 20: 799-806. Kim J, Park E. The Factor Structure of the Center for Epidemiologic Studies Depression Scale in Stroke Patients. Top Stroke Rehabil. 2012;19(2):54-62. Parikh RM, Eden DT, Price TR, Robinson RG. The sensitivity and specificity of the Center for Epidemiologic Studies Depression Scale in screening for post-stroke depression. Int J Psychiatry Med. 1988;18(2):169–181. Ramasubbu R, Robinson RG, Flint AJ, Kosier T, Price TR. Functional impairment associated with acute poststroke depression: the Stroke Data Bank Study. J Neuropsychiatry Clin Neurosci. 1998;10(1):26–33. Shinar D, Gross CR, Price TR, Banko M, Bolduc PL, Robinson RG. Screening for depression in stroke patients: the reliability and validity of the Center for Epidemiologic Studies Depression Scale. Stroke. 1986;17(2):241–245. Steffens DC, Krishnan KR, Crump C, Burke GL. Cerebrovascular disease and evolution of depressive symptoms in the cardiovascular health study. Stroke. 2002;33(6):1636–1644. **TBI References:** Radloff, LS. The CES-D Scale: A self-report depression scale for research in the general population. App Psychol Meas. 1977;1(3):385–401.

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Color-Word Interference Test Delis-Kaplan Executive Function System (D-KEFS)
(New for Stroke)

Availability	**Please visit this website for more information about the instrument:** **Delis-Kaplan Executive Function System.**
Classification	**Supplemental:** Stroke and Traumatic Brain Injury (TBI) **Exploratory:** Sport-Related Concussion (SRC) and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	Examinee names color patches (Condition 1); reads words that denote colors printed in black ink (Condition 2); names the ink color in which color words are printed (Condition 3); switches back and forth between naming dissonant ink colors and reading the conflicting words (Condition 4). This is a subtest of the Delis-Kaplan Executive Function System (D-KEFS) which is the first nationally standardized set of tests to evaluate higher level cognitive functions in both children and adults.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** There are 24 items on each of the 3 tasks. Number of errors and time to perform the task is recorded for each trial. Researchers typically relied on a difference score between time/error on the interference task (e.g., part "C") versus the control task (part "D"). Scoring is expressed in terms of the number of seconds required to complete each of the 4 conditions. Total uncorrected and total self-corrected errors are also recorded for each condition. Trained technician can administer. Neuropsychologist needs to interpret. Administration time is 7 – 10 minutes.
Rationale/Justification	**Strengths/Weaknesses**: The battery provides an updated normative sample for a number of classic neuropsychological tests of executive function and has been widely employed in research and clinical use. Tests like the Color Word Interference Test (i.e., "Stroop" tests) have been used frequently in a wide range of patient groups thought to have executive function deficits.

	Advantages over other versions: 1) It is more brief, which has been shown to be ideal in detecting participants who have difficulty completing this task because you don't get extended practice; 2) It includes an additional training task (i.e., naming the colors of neutral words) over the original task that helps examinees establish the appropriate response set (i.e., color naming) without exposure to the interference condition; 3) it is in the public domain, and users can make up their own stimuli.
References	Delis DC, Kramer JH, Kaplan E, Holdnack J. Reliability and validity of the Delis-Kaplan Executive Function System: an update. J Int Neuropsychol Soc. 2004;10(2):301–303. McGee CL, Delis DC, Holdnack JA. Cognitive discrepancies in children at the ends of the bell curve: a note of caution for clinical interpretation. Clin Neuropsychol. 2009;23(7):1160–1172. Parmenter BA, Zivadinov R, Kerenyi L, Gavett R, Weinstock-Guttman B, Dwyer MG, Garg N, Munschauer F, Benedict RH. Validity of the Wisconsin Card Sorting and Delis-Kaplan Executive Function System (DKEFS) Sorting Tests in multiple sclerosis. J Clin Exp Neuropsychol. 2007;29(2):215–223. Spreen O, Strauss E. A Compendium of Neuropsychological Tests. 2nd Ed. New York: Oxford University Press, Inc. 1998: 477–490. Sprouse C, King J, Helman G, Pacheco-Colón I, Shattuck K, Breeden A, Seltzer R, VanMeter JW, Gropman AL. Investigating neurological deficits in carriers and affected patients with ornithine transcarbamylase deficiency. Mol Genet Metab. 2014;113(1-2):136–141. Troyer AK, Leach L, Strauss E. Aging and response inhibition: Normative data for the Victoria Stroop Test. Neuropsychol Dev Cogn B Aging Neuropsychol Cogn. 2006;13(1):20–35.

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Controlled Oral Word Association Test (COWAT) subtest of the Multilingual Aphasia Examination (MAE)
(New for Stroke)

Availability	Please visit this website for more information about the instrument: Controlled Oral Word Association Test
Classification	**Supplemental – Highly Recommended:** Epilepsy and Sport-Related Concussion (SRC) **Supplemental:** Multiple Sclerosis (MS), Stroke, and Traumatic Brain Injury (TBI)
Short Description of Instrument	The Controlled Oral Word Association Test (COWAT) is a measure of verbal fluency and is a subtest of the Multilingual Aphasia Examination (Benton, Hamsher, & Sivan, 1994). The COWAT uses the three letter set of C, F, and L to assess phonemic fluency. Individuals are given 1 min to name as many words as possible beginning with one of the letters. The procedure is then repeated for the remaining two letters (see Strauss, et al., 2006 and Benton, et al., 1994 for specific administration instructions). **Advantages**: The COWAT has a rich history of use in mild TBI and sports concussion, particularly older adolescents and adults. Quick to administer. Appears sensitive to TBI and predicts severity. Strong psychometric properties. **Limitations**: Less use with children with mild TBI, none with sports concussion. Low specificity. The abilities underlying performance on the test are varied (attention, working memory, processing speed, episodic memory), thus it is difficult to attribute impairment to a particular cognitive function. Highly influenced by premorbid verbal IQ.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The data collection form provides numbered lines on which the participant's responses can be recorded. If the participant's speed of word production is too fast to permit verbatim recording, a "+" should be recorded to indicate a correct response. Total all correct answers. **Psychometric Properties:** The reliability and validity of two qualitative scoring systems for the Controlled Oral Word Association Test [Benton, A. L., Hamsher, de S. K., & Sivan, A. B. (1983). *Multilingual aplasia examination* (2nd ed.). Iowa City, IA: AJA Associates] were examined in 108 healthy young adults. The scoring systems developed by Troyer et al. [Troyer, A. K.,

	Moscovich, M., & Winocur, G. (1997). Clustering and switching as two components of verbal fluency: Evidence from younger and older healthy adults. *Neuropsychology*, *11*, 138–146] and by Abwender et al. [Abwender, D. A., Swan, J. G., Bowerman, J. T., & Connolly, S. W. (2001a). Qualitative analysis of verbal fluency output: Review and comparison of several scoring methods. *Assessment*, *8*, 323–336] each demonstrated excellent interrater reliability (all indices at or above r_{icc} = .9). Consistent with previous research [e.g., Ross, T. P. (2003). The reliability of cluster and switch scores for the COWAT. *Archives of Clinical Psychology*, *18*, 153–164), test–retest reliability coefficients (*N* = 53; *M* interval 44.6 days) for the qualitative scores were modest to poor (r_{icc} = .6 to .4 range).
References	Beldarrain M.G.A · García-Moncó J.C.A · Quintana J.M.B · Llorens V.C · Rodeño E.C Diaschisis and Neuropsychological Performance after Cerebellar Stroke, Eur Neurol 1997;37:82–89 Benton AL, Hamsher K deS, Sivan AB. (1994). Multilingual Aphasia Examination, 3rd Edition (MAE). Accessed: 8 May 2017. Available at: http://www4.parinc.com/Products/Product.aspx?ProductID=MAE. Benton, A., & Hamsher, K (1989). Multilingual Aphasia Examination. Iowa City: AJA Associates. Chahal, N., Barker-Collo, S., Feigin, V., Cognitive and Functional Outcomes of 5-Year Subarachnoid Haemorrhage Survivors: Comparison to Matched Healthy Controls. Neuro-epidemiology, 2011, 37(1):31-8. Lezak, M.D., Howieson, D.R., Bigler, E.D., Tranel, D. Neuropsychological Assessment, 5th Ed, Oxford, New York, 2012 Miceli G, Caltagirone C, Gainotti G, Masullo C, Silveri MC. Neuropsychological correlates of localized cerebral lesions in non-aphasic brain-damaged patients. J Clin Neuropsychol. 1981;3(1):53–63. Ross TP. The reliability of cluster and switch scores for the Controlled Oral Word Association Test. Arch Clin Neuropsychol. 2003;18(2):153–164. Strauss E, Sherman EMS, Spreen O. A Compendium of Neuropsychological Tests: Administration, Norms, and Commentary, 3rd ed. New York: Oxford University Press; 2006, pp. 501–526. Tombaugh, T.N., Kozak, J., Rees. Normative Data Stratified by Age and Education for Two Measures of Verbal Fluency: FAS and Animal NamingArchives of Clinical Neuropsychology, Vol. 14, No. 2, pp. 167–177, 1999

	Troyer AK, Moscovitch M, Winocur G, Leach L, Freedman M. Clustering and switching on verbal fluency tests in Alzheimer's and Parkinson's disease. J Int Neuropsychol Soc. 1998;4(2):137–143.

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Delis-Kaplan Executive Function System (D-KEFS)

Availability	**Please visit this website for more information about the instrument: Delis-Kaplan Executive Function System (D-KEFS)**
Classification	**Supplemental – Highly Recommended**: Cerebral Palsy (CP), Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS) for overall executive function and Stroke (based on study type, disease stage and disease type) **Supplemental**: Epilepsy, Huntington's Disease (HD), Mitochondrial Disease (Mito), Multiple Sclerosis (MS), Sport-Related Concussion (SRC), and Traumatic Brain Injury (TBI). **Exploratory**: Friedreich's Ataxia (FA)
Short Description of Instrument	The Delis-Kaplan Executive Function System™ (D-KEFS™) is the first nationally standardized set of tests to evaluate higher level cognitive functions in both children and adults. With nine stand-alone tests, the D-KEFS™ comprehensively assesses the key components of executive functions believed to be mediated primarily by the frontal lobe. **Engaging Materials:** Its game-like format is engaging for examinees, encouraging optimal performance without providing "right/wrong" feedback that can create frustration in some children and adults. **Multiple Uses**: • Assess the integrity of the frontal system of the brain • Determine how deficits in abstract, creative thinking may impact daily life • Plan coping strategies and rehabilitation programs tailored to each patient's profile of executive-function strengths and weaknesses **Two Forms:** D-KEFS™ offers two forms: The Standard Record Forms include all nine D-KEFS™ tests, while the Alternate Record Forms include alternate versions of D-KEFS™ Sorting, Verbal Fluency, and 20 Questions Tests. An alternate set of Sorting Cards is also available. **Correlates with the California Verbal Learning Test–II (CVLT-II):** D-KEFS™ is correlated with the CVLT–II, providing information concerning the role of memory on D-KEFS™ performance.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** Each subtest generates one or more scaled scores and percentiles characterizing performance in relation to typically performing controls. Administrators can also elect to calculate

	optional process scores that provide cumulative percentile ranks characterizing performance strategies. Contrast scores are also available within each subtest to assess the degree to which performance is affected by aspects of cognitive functioning (e.g., motor speed or inhibition or cognitive flexibility). Scoring may either be done manually or using computer software. **Psychometric Properties:** D-KEFS is a well-designed test of frontal lobe functioning which measures a broad range of neuropsychological abilities. The D-KEFS has good validity for detecting executive dysfunction.
Rationale/Justification	**Strengths/Weaknesses:** The battery provides an updated normative sample for several classic neuropsychological tests of executive function and has been widely employed in research and clinical use. **Mitochondrial Disease-Specific:** **Advantages:** Analogous subtests (Stroop/Color Word, Trail Making Test) have been found to differentiate individuals with symptomatic mitochondrial disorders from asymptomatic carriers and controls (Sprouse et al., 2014). The test has been validated for use in a variety of populations including multiple sclerosis, Parkinson's Disease, and Autism Spectrum Disorders, suggesting that it is a valid measure for use in a mitochondrial disorder population as well (Delis et al., 2004). Materials are engaging, and clinicians and researchers can select a subset of tests within the battery to assess specific executive skills that are of interest to them providing an opportunity to minimize fatigue. Selected subtests of the D-KEFS have been shown to differentiate performance in individuals with multiple sclerosis, even after controlling for depression, suggesting that this may be a more sensitive instrument for detecting executive dysfunction than other instruments in populations, like mitochondrial disorder, that may be at higher risk of developing co-occurring psychiatric symptoms (Parmenter et al., 2007). **Limitations:** The test is normed for use in those aged 8 and above and is fairly demanding in terms of language skills. The Tower subtest is particularly demanding of fine motor speed and coordination, and the Verbal Fluency and Color-Word Interference subtests require rapid verbal responding. It is not appropriate to administer to individuals with lower IQs or to individuals with more motor involvement. The instrument may be slightly less sensitive than other measures for executive dysfunction in pediatric medical populations (Parrish et al., 2007), and test scores may exaggerate discrepancies between IQ and executive dysfunction for individuals at the very high and very low end of the IQ distribution (McGee et al., 2009) **Sport-Related Concussion-Specific:** **Trail Making Test: Advantages:** The D-KEFS trail making test represents one of a battery of updated and newly normed executive tests. The trail making test in this iteration allows for a process

	based analysis of the specific difficulty that drives potential poor performance on the switching aspect of Trails B. Well normed versions of pre-existing tests of executive function. Some of the subtests have been used with TBI, though less published with mild TBI. Adults > children. **Limitations:** While thorough, the measure is long to administer and there are no studies in mild traumatic brain injury demonstrating comparative superiority to the traditional Trail Making Test. **Verbal Fluency: Advantages**: The D-KEFS Verbal Fluency task assess phonemic and categorical fluency but adds a category switching paradigm, increasing cognitive demand and adding a further executive component to this language generation task. **Limitations:** Though used widely with individuals with neurologic disorders, this is not specific to concussion nor has it been tested in this population. Age Range: 8–89 years **ME/CFS-Specific:** Recommended modules for ME/CFS are: Color-Word-Interference Test, Trail Making Test, and Verbal Fluency. No summary score available if only these components are administered, but standard scores provide good interpretative guidance. This test is highly recommended, because in addition to individual subtest scores, it provides an algorithm to predict the overall executive function score from the 3 subtests mentioned above. These three components take 15-20 minutes to complete.
References	Delis DC, Kaplan E, Kramer JH. Delis-Kaplan Executive Function System™ (D-KEFS™) [Internet] 2001. Delis DC, Kramer JH, Kaplan E, Holdnack J. Reliability and validity of the Delis-Kaplan Executive Function System: an update. J Int Neuropsychol Soc. 2004;10(2):301–303. McGee CL, Delis DC, Holdnack JA. Cognitive discrepancies in children at the ends of the bell curve: a note of caution for clinical interpretation. Clin Neuropsychol. 2009;23(7):1160–1172. Parmenter BA, Zivadinov R, Kerenyi L, Gavett R, Weinstock-Guttman B, Dwyer MG, Garg N, Munschauer F, Benedict RH. Validity of the Wisconsin Card Sorting and Delis-Kaplan Executive Function System (DKEFS) Sorting Tests in multiple sclerosis. J Clin Exp Neuropsychol. 2007;29(2):215–223. Shunks AW, Davis AS, Dean RS. Review of the Delis Kaplan Executive Function System (D-KEFS). Applied Neuropsychology. 2006;13(4):275-279. Sprouse C, King J, Helman G, Pacheco-Colon I, Shattuck K, Breeden A, Seltzer R, VanMeter JW, Gropman AL. Investigating neurological deficits in carriers and affected patients with ornithine

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Fugl-Meyer Assessment
(New for Stroke)

Availability	**This instrument is freely available: Fugl-Meyer Assessment**
Classification	**Supplemental-Highly Recommended**: Stroke **Exploratory**: Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	This is a post-stroke assessment of motor function. Five domains assessed: Motor function: Upper and lower extremities Sensory function Balance - standing and sitting, sensation Joint range of motion Joint pain
Comments/Special Instructions	Time to administer: 30–45 minutes Administration mode: paper/pencil
Scoring and Psychometric Properties	**Scoring:** Items are scored on a 3-point ordinal scale with a maximum score of 226 points: 0: cannot perform 1: performs partially 2: performs fully MCID = 4.5 – 7.0 points **Psychometric Properties:** The overall reliability is high (overall intraclass correlation coefficient=.96), and the intraclass correlation coefficients for the subsections of the assessment vary from .61 for pain to .97 for the upper extremity.
References	Alt Murphy M, Resteghini C, Feys P, Lamers I. An overview of systematic reviews on upper extremity outcome measures after stroke. BMC Neurol. 2015 Mar 11;15:29. doi: 10.1186/s12883-015-0292-6. Bushnell C, Bettger J, Cockroft K, Cramer S, Edelen M, Hanley D, Katzan I, Mattke S, Nilsen D, Piquado T, Skidmore E, Wing K, Yenokyan G. Chronic Stroke Outcome Measures for Motor Function Intervention Trials: Expert Panel Recommendations. Circ Cardiovasc Qual Outcomes. 2015 October; 8(6 Suppl 3): S163-S169. doi: 10.1161/CIRCOUTCOMES. 115.002098. Duncan PW, Goldstein LB, Horner RD, Landsman PB, Samsa GP, Matchar DB. Similar motor recovery of upper and lower extremities after stroke. Stroke. 1994;25(6):1181–1188.

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Functional Independence Measure

Availability	The FIM is proprietary. For further information about obtaining the scale, syllabus, and training materials please contact: Uniform Data System for Medical Rehabilitation 270 Northpointe Parkway, Suite 300 Amherst, New York 14228 (716) 817-7800 FAX (716) 568-0037 email:info@udsmr.org Web site:Please click here for more information about the Functional Independence Measure
Classification	**Supplemental**: Chiari I Malformation (CM), Multiple Sclerosis (MS), Stroke, and Traumatic Brain Injury (TBI) **Exploratory**: Cerebral Palsy (CP), Friedreich's Ataxia (FA) and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose**: The FIM measures degree of independence in activities of self-care, sphincter control, transfers, locomotion, communication, and cognition. **Overview**: The FIM emerged from a thorough developmental process overseen by a National Task Force of rehabilitation research. The National Task force reviewed 36 published and unpublished functional assessment scales before agreeing on an instrument. The FIM is an 18-item ordinal scale, used with all diagnoses within a rehabilitation population. It is viewed as most useful for assessment of progress during inpatient rehabilitation. FIM was originally an acronym for "Functional Independence Measure". It is still often cited as this in the literature. The current owners of the FIM instrument have decided that the acronym FIM no longer stands for anything and should be referred to only as FIM. **Time**: Evaluation time is 20–30 minutes.
Comments/Special Instructions	The FIM may be completed by rehabilitation clinicians as an observational scale, or by trained paraprofessionals or family members. It can be administered by trained interviewers as a self report or proxy report instrument, in person or by phone. FIM certification is available and required to officially utilize the tool. A detailed manual guides scoring, based on operationally-defined functional abilities. Most appropriate for Severe and Moderate Disability levels of GOSE; ceiling effects limit utility in Good Recovery. The FIM is imbedded in the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI). Thus if the IRF-PAI is administered it is not necessary to separately administer the FIM.

	The alpha FIM is a subset that has been used in the acute patient setting to assess which patients are appropriate for discharge to a rehabilitation setting. The alpha FIM may be worth exploring in Phase III trials that include assessments of appropriateness of different post-discharge destinations.
Scoring and Psychometric Properties	Scores range from 1 (total or >75% assistance) to 7 (complete independence). The total of the 18 items is the patient's total score, which ranges from 18–126. Scores may be used raw or converted to interval scores. **Psychometric Properties**: Inter-rater reliability was found to be high for the total score and moderate to substantial for items assessing physical disability, except for the item concerned with assessing independence in walking or in wheelchair. The inter-rater agreement of FIM items in the communication and social cognition subsections was only fair (Hamilton et al., 1991). The internal consistency of the FIM assessment scale was found to be high overall and for patients grouped by impairment, but low for the locomotion subscale (Dodds et al., 1993). Minimal clinically importance difference relative to physician assessment has been established for total score and motor and cognitive subscores in post inpatient rehabilitation stroke patients (Beninato et al., 2006).
References	Granger CV. The emerging science of functional assessment: our tool for outcomes analysis. Arch Phys Med Rehabil 1998;79(3):235–240. **Additional References:** Beninato M, Gill-Body KM, Salles S, Stark PC, Black-Schaffer RM, Stein J. Determination of the minimal clinically important difference in the FIM instrument in patients with stroke. Arch Phys Med Rehabil. 2006;87(1):32–39. Dodds TA, Martin DP, Stolov WC, Deyo RA. A validation of the functional independence measurement and its performance among rehabilitation inpatients. Arch Phys Med Rehabil. 1993;74(5):531-536. Hamilton BB, Laughlin JA, Granger CV, Kayton RM. Interrater agreement of the seven-level Functional Independence Measure (FIM). (abstract) Arch Phys Med Rehabil 1991;72:790. McDowell I, Newell C. Measuring Health: A Guide to Rating Scales and Questionnaires. New York: Oxford University Press, 1987. Wright, J. (2000). The FIM(TM). The Center for Outcome Measurement in Brain Injury. http://www.tbims.org/combi/FIM (accessed October 21, 2016).

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Generalized Anxiety Disorder (GAD-7)
(New for Stroke)

Availability	**The instrument is freely available here: Generalized Anxiety Disorder Instrument**
Classification	**Supplemental- Highly Recommended:** Epilepsy in studies assessing anxiety, Headache **Supplemental:** Mitochondrial Diseases (Mito), Spinal Cord Injury (SCI), Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months) and Persistent/Chronic (3 months and greater post concussion) **Exploratory:** SCI-Pediatric (ages 12 and older, but currently there is no pediatric data), Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH), and Stroke
Short Description of Instrument	**Purpose:** The Generalized Anxiety Disorder (GAD-7) is a scale that can be used for assessing anxiety severity in clinical practices and in research. **Description:** This is a brief scale with good reliability. Questions relate to the frequency of anxiety-related symptoms over the past two weeks. **Time Estimates:** 5–10 minutes. **Intended Respondent:** Patient
Comments/Special Instructions	**Comments:** The GAD-7 is based on a large sample size, can be used in diverse clinical and research settings and it can be generalized to primary care. But it focuses only on one anxiety disorder, though many more exist, and further evaluation of the patient should be considered for diagnosis. However, the same cut-off score has been shown to be good at detecting other anxiety disorders. Increasing scores are associated with multiple domains of functional impairments, supporting its construct validity. Adult patients (n=965) recruited from 15 primary health clinics participated in a study (Spitzer et al., 2006) investigating the psychometric properties of the GAD-7. The GAD-7 demonstrated excellent internal consistency (Cronbach alpha=.92) and test-retest reliability (intraclass correlation = 0.83). Most patients diagnosed with Generalized Anxiety Disorder (GAD) (89%) were above the cut-off point of 10, and most patients without GAD (82%) were below 10. At a cut point of 10 or greater, sensitivity and specificity both exceed 0.80. Thus, a score of 10 represents a reasonable cut-off point for identifying cases of GAD, whereas the

	scoring ranges of 5–9, 10–14, and 15–21 could represent mild, moderate and severe GAD. **SCI-Pediatric specific:** Normative data is with the adult population.
Scoring and Psychometric Properties	**Scoring:** 7; scoring ranging from 0–3 for each. Total Score (0–21). **Psychometric data in SCI populations** is mostly lacking. However, a recent study (Kisala et al., 2015) compared the GAD-7 with the SCI-QOL Anxiety and GAD-7 and found a correlation of 0.67 and reliability of 0.85 for the GAD-7 providing some support of its use after SCI.
References	Kisala PA, Tulsky DS, Kalpakjian CZ, Heinemann AW, Pohlig RT, Carle A, & Choi SW. Measuring anxiety after spinal cord injury: Development and psychometric characteristics of the SCI-QOL Anxiety item bank and linkage with GAD-7. J Spinal Cord Med. 2015;38(3):315–325. Kroenke K, Spitzer RL, Williams JB, & Lowe B. The Patient Health Questionnaire Somatic, Anxiety, and Depressive Symptom Scales: a systematic review. Gen Hosp Psychiatry. 2010;32(4):345–359. Schmid AA, Arnold SE, Jones VA, Ritter MJ, Sapp SA, Van Puymbroeck M. Fear of Falling in People with Chronic Stroke. Am J Occup Ther. 2015;69(2): 6903350020p1–6903350020p5. Schmid AA, Yaggi HK, Burrus NB, McClain V, Austin C, Ferguson J, Fragoso C, Sico JJ, Miech EJ, Matthias MS, Williams LS, Bravata DM. Circumstances and consequences of falls among people with chronic stroke. J Rehabil Res Dev. 2013;50(9):1277-1286. Spitzer RL, Kroenke K. Williams JB, Lowe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006;166(10):1092–1097.

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Glasgow Outcome Scale (GOS)

Availability	**The Glasgow Outcome Scale is freely available: Glasgow Outcome Scale.**
Classification	**Supplemental**: Stroke, TBI, Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose:** The Glasgow Outcome Scale was developed to define broad outcome categories for people who sustain acute brain damage from head injury or non-traumatic brain insults.1 The scale reflects disability and handicap rather than impairment; that is, it focuses on how the injury has affected functioning in major areas of life rather than on the particular deficits and symptoms caused by injury.2 It is not intended to provide detailed information about the specific difficulties faced by individual patients, but to give a general index of overall outcome. **Overview**: The GOS is a one item scale with 5 possible ratings (Dead, Vegetative State, Severe Disability, Moderate Disability, and Good Recovery). **Time**: Depending on prior familiarity with the patient, the scale can be completed in as little as 5 minutes. **Other Important Notes**: Some have questioned the validity of the GOS with children; there is an adaptation that can be used with children.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** Ratings for the GOS range from 1 to 5 (Dead to Good Recovery). The GOS is generally rated by a clinician or research assistant who is familiar with the patient or who conducts a structured interview to obtain needed information. **Psychometric Properties**: An inter-rater reliability study of the structured interview found the standard format of the GOS assessment within a written protocol is practical and reliable. This scales are very commonly used to predict global outcomes and there is an extensive literature demonstrating reliability and validity for the GOS.
References	Hacke W, Kaste M, Bluhmki E, Bozman M, Davalos A, Guidetti D, Larrue V, Lees KR, Medeghri Z, Machnig T, Schneider D, von Kummer R, Wahlgren N, Toni D. Thrombolysis with Alteplase 3 to 4.5 Hours after Acute Ischemic Stroke. N Engl J Med. 2008; 359: 1317-1329.

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Grooved Pegboard Test
(New for Stroke)

Availability	**Available for purchase from Lafayette Instrument: Grooved Pegboard Test**
Classification	**Supplemental**: Epilepsy, Multiple Sclerosis (MS), Stroke, and Traumatic Brain Injury (TBI) **Exploratory:** Sport-Related Concussion (SRC) and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Construct measured**: Finger and manual dexterity **Generic vs. disease specific**: Generic **Intended respondent**: Patients 20-85 years old **# of items**: 25 pegs **# of subscales and names of sub-scales**: N/A **# of items per sub-scale**: N/A
Comments/Special Instructions	**Background**: The Grooved Pegboard is a manipulative dexterity test. This unit consists of 25 holes with randomly positioned slots. Pegs, which have a key along one side, must be rotated to match the hole before the can be inserted. This test requires more complex visual-motor coordination than most pegboards.
Rationale/Justification	**Strengths/Weaknesses**: The Grooved Pegboard required longer administration time and was challenging for the youngest children and oldest adults. **Administration**: Each trial takes seconds; a trial may be discontinued if it takes more than 5 minutes. **TBI Rationale:** The GPT is a widely used test of fine motor skill that has proven sensitive to the effects of TBI **Epilepsy Rationale:** Motor speed may be assessed by a variety of procedures including measures of reaction time (Thompson& Trimble, 1983) or more conventional measures of motor speed used in clinical neuropsychological evaluations (Grooved Pegboard, Finger Tapping). While reaction time measures are perhaps extremely pure motor speed measures and have been used in epilepsy

	research (Thompson & Trimble, 1983), they are not widely used clinically and have limited normative data. More conventional clinical measures have the advantage of familiarity and strong normative databases and are brief and direct in administration time and directions. Grooved Pegboard was selected due to its widespread use and its purported greater sensitivity to lateralized brain impairment than other motor speed measures such as finger tapping. Importantly, one of the reasons that finger tapping was not selected is that it has historically been given with various sets of instructions and the timing of each 10 second trial introduces significant measurement error. Grooved pegboard has been effectively used to characterize fine motor speed in multiple epilepsy studies. **SAH Rationale:** The GPT has been used in various SAH studies, including large scale prospective trials such as the IHAST, and institutional databases such as from the Columbia group. It is well-normed and reference values are available for the age range of SAH patients. For these reasons, the Swiss national standard of neuropsychological assessment after SAH includes the GPT.
Scoring and Psychometric Properties	**Scoring**: For the right hand trial, the examiner demonstrates that the pegs are placed from subject's left to right, and from right to left for the left hand trial. The dominant hand trial is administered first, followed by the nondominant hand trial. Only one peg is to be picked up at a time and the subject should immediately be told if more than one is picked up. Also, only one hand is to be used. If necessary, the board should be held steady for the patient. In the case of severe motor impairment, the subject should attempt the task just to see if any of the pegs can be put in. Any factor that may effect the subject's performance should be noted, e.g. sore finger, bandage, etc. Record, in seconds, the length of time required to perform each trial beginning when the subject starts the task until the last peg is put in, or the test is discontinued. A trial may be discontinued after five minutes. In such cases, the difficulty is described and the scores are given "A" flags indicating an incomplete test. The second score is the number of "drops" made during each trial. A "drop" is any unintentional drop of a peg from the time the subject attempts to pick up the peg from the try until it is placed correctly in the hole. If one peg is turned with the hand not being tested, this is noted. If, however, this occurs more than once, the score is given a "D" flag for a nonstandard assessment. The third score is the number of pegs correctly placed in the holes for each trial. For each hand, the three scores are summed (the total time, total

	number of drops and the total number of pegs correctly placed in the board) to get complete score. The examiner encourages the subject to perform the task as quickly as possible, telling him or her to speed up if necessary. The pegs must be put in the board in the exact order and in the correct direction. The task is performed once with the dominant and then once with the non-dominant hand. **Psychometric Properties**: The Grooved Pegboard had good test-retest reliability (0.91 and 0.85 for right and left hands, respectively). The Grooved Pegboard correlated with BOT at -0.50 to -0.63 and with Purdue Pegboard at -0.73 to -0.78.
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Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)

Availability	The instrument is freely available here: Australian National University Centre for Research on Ageing, Health and Wellbeing
Classification	**Supplemental:** Mitochondrial Disease (Mito) and Stroke
Short Description of Instrument	**Purpose** The short form IQCODE is a subjective rating scale that captures informant ratings of change in cognitive function from premorbid function. **Overview** The questionnaire is designed to assess cognitive decline and dementia in the elderly. It is filled out by a relative or friend who has known the elderly person for ten years or more. **Time** The assessment takes approximately 10-15 minutes. **Other Important Notes** The IQCODE is relatively unaffected by education and pre-morbid ability or by proficiency in the culture's dominant language. It is affected by informant characteristics such as depression and anxiety in the informant and the quality of the relationship between the informant and the subject.1
Comments/Special Instructions	Information from the IQCODE and the Mini-Mental State Examination can be combined in the DemeGraph to aid in assessing for dementia.
Scoring and Psychometric Properties	**Scoring:** The score for each question is added together and then divided by the number of questions. For the Long IQCODE, divide by 26; for the Short IQCODE, divide by 16. Scores range from 1 to 5. A score of 3 means that the subject is rated on average as “no change”, 4 “a bit worse”, 5 “much worse”.1 **Psychometric Properties:** The questionnaire has high reliability and measures a single general factor of cognitive decline. It validly reflects past cognitive decline, performs at least as well at screening as conventional cognitive screening tests, predicts incident dementia, and correlates with a wide range of cognitive tests.2

References	Jorm, A.. A short form of the informant questionnaire on cognitive decline in the elderly (IQCODE): Development and cross-validation. Psychol Med. 1994;24: 145-153. Jorm A. The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): a review. International Psychogeriatrics. 2004;16: 1-19.

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King's Outcome Scale for Childhood Head Injury (KOSCHI)

Availability	This scale is in the public domain. The KOSCHI categories and definitions can be found at PLEASE CLICK HERE FOR MORE INFORMATION
Classification	**Exploratory:** Stroke
Short Description of Instrument	**Purpose** The KOSCHI provides a practical scale for pediatric head injury which enables clinicians to describe rate and extent of recovery and evaluate the effects of service and research interventions. **Overview** The King's Outcome Scale for Childhood Head Injury (KOSCHI) is a specific pediatric adaptation of the original adult Glasgow Outcome Scale (GOS). The KOSCHI expands the five category GOS to provide increased sensitivity at the milder end of the disability range. **Time** Assessment takes approximately 1-2 minutes. **Other Important Notes** The scale was originally designed for children aged 2 to 16 years of age, but there is no reason why it should not be used under the age of 2 years with the understanding that problems in this young age group are commonly underestimated.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring** There are five categories which include: (1) Death, (2) Vegetative, (3) Severe Disability, (4) Moderate Disability, (5) Good Recovery. The measure is scored by selecting the appropriate category that corresponds to the patient's prognosis. **Psychometric Properties** Modest inter-rater reliability was observed. Thus the authors recommend that if the KOSCHI is used in clinical or research practice, a team of potential observers perform pilot comparisons of their rating practices to ensure that they are scoring consistently.
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Modified Rankin Scale (mRS)

Availability	The van Swieten mRS scale is in the public domain and a free training program was prepared by Professor KR Lees in association with the Media Services Department of the University of Glasgow to certify physicians, nurses, and first responders on how to use the mRS scale. The program consists of a series of digital video recordings and accompanying written material which includes a self paced Instruction-Demonstration module and the certification modules. However, sponsors and institutions wanting to use this program to document rater competency, interater reliability and educational compliance for their studies, programs and clinical trials must obtain copyright permissions as clinical trials will need additional documentation in order to comply with regulatory requirements. ~~For additional information about the mRS training programs for healthcare professionals and for clinical research teams, visit t~~The Modified Rankin Scale ~~website~~can be found here: Modified Rankin Scale.
Classification	**Supplemental - Highly Recommended**: Unruptured Cerebral Aneurysm and Subarachnoid Hemorrhage (SAH) and Stroke (based on study type, disease stage and disease type) **Exploratory**: Myasthenia Gravis (MG)
Short Description of Instrument	**Purpose:** The modified Rankin Scale (mRS) is a scale commonly used for measuring the degree of disability or dependence in the daily activities of individuals who have suffered a stroke, and it has become the most widely used clinical outcome measure for stroke clinical trials. **Overview:** The mRS was originally introduced in 1957 by Rankin, and first modified to its currently accepted form by Prof. C. Warlow's group at Western General Hospital in Edinburgh for use in the UK-TIA study in the late 1980s. The first publication of the current modified Rankin Scale was in 1988 by van Swieten, et al., who also published the first interobserver agreement analysis of the modified Rankin Scale. **Time:** The assessment requires 5 minutes to complete. **Prestroke Scoring:** On a scale from 0 to 5; Score=6 is not possible as someone would not be in a study if they were dead at presentation. For Score=1, symptoms may refer to those of a prior stroke in patients with a past history of stroke.

	Other Important Notes: English and eleven different language translations are available. Consider employing a formal scoring system for the mRS such as the Structured Interview for the mRS, or a training program to determine the score that best describes the subject's current state.The mRS is highly reliable at pre-stroke, 30 and 90 days, and upon return to the community, but caution should be exercised when trying to apply it at hospital arrival or discharge. There are currently no published instructions on the use of the mRS to assess initial stroke disability. Raters using this at admission or discharge should develop a standard methodology and scoring instructions for use in hospital setting.
Comments/Special Instructions	Decisions about further medical management, the need for PT/OT therapy and the degree of care that a patient requires can be partially informed by the mRS, but final determinations should be made on an individual basis. The mRS is used to evaluate the degree of disability in patients who have suffered a stroke, but individual quality of life and independence are influenced by a wide variety of factors including the presence of comorbidities and socioeconomic status. The use of a structured interview may lead to increased reliability among those conducting assessments using the mRS.
Scoring and Psychometric Properties	**Scoring:** Typical Scoring: On a scale from 0 to 6; 0 indicating 'no symptoms' and 6 indicating 'death'. **Psychometric Properties:** Multiple types of evidence attest to the validity and reliability of the mRS. The reported data support the view that the mRS is a valuable instrument for assessing the impact of new stroke treatments. Inter-observer reliability of the mRS can be improved by using a structured interview, by using structured assessment forms, and by having raters undergo a multimedia training process.
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Montreal Cognitive Assessment (MoCA)

Availability	Universities/Foundations/Health Professionals/Hospitals/Clinics/Public Health Institutes: MoCA may be used, reproduced, and distributed, WITH prior written permission. The test should be made available free of charge. Commercial Entity/Pharma sponsored research: MoCA may be used, reproduced, and distributed, WITH prior written permission and Licensing Agreement. The test should be made available free of charge. **For additional information, please visit website: Montreal Cognitive Assessment.**
Classification	**Supplemental – Highly Recommended**: Stroke (based on study type, disease stage and disease type), Epilepsy and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH) **Supplemental**: Huntington's Disease (HD), Mitochondrial Disease (Mito) and Parkinson's Disease (PD)
Short Description of Instrument	**Purpose:** The MoCA screens patients who present with mild cognitive complaints and normal mini-mental state examination (MMSE) scores for mild cognitive impairment (MCI). While the MMSE is a ubiquitous cognitive screening instrument, its relative insensitivity to executive dysfunction and the focal cognitive deficits that can often been seen in stroke render it suboptimal for cerebrovascular populations. In fact, a recent study demonstrated the underestimation of cognitive deficits by the MMSE versus the MoCA in individuals with TIAs and stroke in a large population based study. **Overview:** The MoCA is a screening test of cognition with favorable psychometric properties. It screens eight domains: Visuospatial/executive, Naming, Memory, Attention, Language, Abstraction, Delayed recall, and Orientation. Time: The assessment takes approximately 10 minutes. Other Important Notes: Available in various languages (currently 31 total). Raters using this at admission or discharge should develop a standard methodology and scoring instructions for use in hospital setting.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The total possible score is 30 points (total for each domain: Visuospatial/executive – 5, Naming – 3, Memory – None, Attention – 6, Language – 3, Abstraction – 2, Delayed recall – 5, Orientation – 6). A normal score is greater than or equal to 26 points. The original suggested cut-off score [MCI or Alzheimer's disease (AD)] was any score less than 26. One point is added for an individual who has 12 years or fewer of formal education; however the total possible score

	remains the same. ~~Note that additional studies of optimizing cut-points in different populations are currently underway.~~A recent meta-analysis indicated that a score of 23 was more valid, resulting in fewer false positive. **Psychometric Properties:** There are strong validation studies emerging across patient populations (e.g., cerebrovascular, MCI/AD, Parkinson's disease).
References	Nasreddine ZS, Phillips NA, Bedirian V, Charbonneau S, Whitehead V, Collin I, Cummings JL, Chertkow H. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment.J Am Geriatr Soc. 2005;53:695–699. Luis CA, Keegan AP, Mullan M. Cross validation of the Montreal Cognitive Assessment in community dwelling older adults residing in the Southeastern US. Int J Geriatr Psychiatry. 2009;24(2):197–201. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, Cummings JL, Chertkow H. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. J Am Geriatr Soc. 2005;53(4):695–699. Naugle RI, Kawczak K. Limitations of the Mini-Mental State Examination. Cleve Clin J Med. 1989;56(3):277–281. Pendlebury ST, Cuthbertson FC, Welch SJ, Mehta Z, Rothwell PM. Underestimation of cognitive impairment by Mini-Mental State Examination versus the Montreal Cognitive Assessment in patients with transient ischemic attack and stroke: a population-based study. Stroke. 2010;41(6):1290–1293. Popović IM, Serić V, Demarin V. Mild cognitive impairment in symptomatic and asymptomatic cerebrovascular disease. J Neurol Sci. 2007;257(1-2):185–193. Zadikoff C, Fox SH, Tang-Wai DF, Thomsen T, de Bie RM, Wadia P, Miyasaki J, Duff-Canning S, Lang AE, Marras C. A comparison of the mini mental state exam to the Montreal cognitive assessment in identifying cognitive deficits inParkinson's disease. Mov Disord. 2008;23(2):297–299. Carson N, Leach L, Murphy KJ. A re-examination of Montreal Cognitive Assessment (MoCA) cutoff scores. Int J Geriatr Psychiatry. 2018 Feb;33(2):379-388. **SAH**: Schweizer TA, Al-Khindi T, Macdonald RL. Mini-Mental State Examination versus Montreal Cognitive Assessment: rapid assessment tools for cognitive and functional outcome after

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National Institutes of Health (NIH) Toolbox

Availability	Please visit this website for more information about the instrument: NIH Toolbox Website
Classification	**Supplemental** : Amyotrophic Lateral Sclerosis (ALS), Cerebral Palsy (CP), Chiari I Malformation (CM), Congenital Muscular Dystrophy (CMD),Epilepsy, Duchenne/Becker Muscular Dystrophy (DMD), Friedreich's Ataxia (FA), Facioscapulohumeral Muscular Dystrophy (FSHD), Headache, Huntington's Disease (HD), Mitochondrial Disease (Mito), Myasthenia Gravis (MG), Myotonic Muscular Dystrophy (DM), Multiple Sclerosis (MS), Neuromuscular Diseases (NMD), Parkinson's Disease (PD), Spinal Cord Injury (SCI), Spinal Muscular Atrophy (SMA), Stroke, and Traumatic Brain Injury (TBI) **Exploratory**: Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months) and Persistent/Chronic (3 months and greater post concussion) ~~and Stroke~~
Short Description of Instrument	**Purpose**: The National Institutes of Health Toolbox is part of the NIH Blueprint initiative. It seeks to assemble brief, comprehensive assessment tools that will be useful in a variety of settings with a particular emphasis on measuring outcomes in epidemiologic studies and clinical trials across the lifespan. **Overview**: The ultimate goal is to help improve communication within and between fields of biomedical research and advance knowledge by using common data elements. The battery will examine various cognitive (episodic memory, language, processing speed, working memory, executive functions, attention), emotional (negative affect, positive affect, stress and coping, social relationships), sensory (vestibular, audition, olfaction, taste, vision) and motor functions (dexterity, strength, locomotion, endurance, balance). **Time**: The evaluation will take approximately 1–2 hours to complete. **Other Important Notes**: The battery is designed to measure these domains in ages 3 through 85.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring**: The scoring varies by battery. **Psychometric Properties**: The battery has gone through extensive work to identify and pre-test the constructs to be measured. Validation is expected to be

	completed by the end of 2009 with subsequent norming planned on a very large sample.
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Neuropsychiatric Inventory Questionnaire (NPI-Q)

Availability	Copyright belongs to Jeffrey L. Cummings, MD. **For additional information and test materials, visit: Home – ePROVIDE™** Non- funded academic research: if the project is not explicitly funded, but funding comes from overall departmental funds, from the University or individual funds then fees are waived. Funded academic research, including projects receiving funding from commerce, government, EU, and commercial studies (industry, CRO, any for-profit companies) should contact Dr. Cummings via MAPI Research Trust, to negotiate fees.
Classification	**Supplemental – Highly Recommended:** Parkinson's Disease (PD) **Supplemental:** Amyotrophic Lateral Sclerosis (ALS) ~~and Stroke~~ **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH) and Stroke
Short Description of Instrument	**Purpose:** The NPI-Q is used to measure 12 categories of behavioral disturbance, in: Delusions, Hallucinations, Anxiety, Depression/Dysphoria, Agitation/Aggression, Elation/Euphoria, Disinhibition, Irritability/Lability, Apathy/Indifference, Motor Disturbance, Nighttime Behavior Problems, and Problems with Appetite/Eating. The questionnaire is completed by a caregiver and asks whether the patient exhibits each of the behaviors. **Overview:**The NPI Questionnaire is a validated caregiver completed questionnaire derived from the original NPI. The questionnaire taps behavioral symptoms commonly observed post- stroke (e.g., disinhibition, apathy, irritability). **Time:**The assessment takes approximately 10 minutes.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	The administrator ranks the severity of each behavior exhibited on a scale of 1 to 3, with 3 being the most severe. The total severity score is the sum of the severity scores obtained for each behavioral category. Additionally, the administrator ranks the patient's level of distress from each behavior, on a scale of 1 to 5, with 5 indicating the most severe level of distress. The total distress score is the sum of the distress scores obtained for each behavioral category. **Psychometric Properties:** Test-retest reliability of the NPI-Q is acceptable. The NPI-Q provides a brief, reliable, informant-based assessment of neuropsychiatric symptoms and associated caregiver distress that may be suitable for use in general clinical practice.

	The NPI-Q is a valid and reliable instrument for screening neuropsychiatric symptoms in patients with stroke and TIA (Wong et al., 2014).
Rationale/Justification	**Feasibility:** The interview is rather simple to administer, taking 5 minutes to complete. **Reliability:** Test-retest correlations for symptom and distress scores was adequate (.80 and .94 respectively). Strong interscale correlations existed between the NPI total score and the NPI-Q severity total (.91), and distress total score (.92). **Validity:** The NPI was valid when compared with scores on the MMSE, only for those patients with low MMSE scores (r=.44). **Sensitivity to Change:** Unknown. **Relationships to other variables:** The NPI-Q has limited correlation with cognitive functioning, as measured by the MMSE, particularly for patients who are only mildly impaired. It has a stronger correlation with cognitive performance, for those with moderate to severe stage cognitive decline. Its relationship to depression and other measures are unknown. **Strengths:** This scale has been widely used across many neurological disorders, allowing for comparisons. The NPI-Q is very brief, and uses no staff resources to administer. **Weaknesses:** Caregiver ratings can be biased due to misinterpretation of complex clinical syndromes that are not in the common lexicon (e.g., delusions, hallucinations, apathy). Domains are weighted towards moderate stage dementia and less relevant for early-stage changes. Low NPI-Q validity ratings were found for patients with high MMSE scores. Ratings are acquired via caregivers instead of patients or clinicians, and are therefore less sensitive to change, due to recall bias, cultural beliefs, caregiver mood, etc. The NPI-Q is not designed for the ALS population, thus making dysarthria, motor weakness, and fatigue confounds in a variety of items. Copyright fees will likely apply for funded research projects.
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NIH Stroke Scale (NIHSS)

Availability	This measurement tool is freely accessible at: NIH Stroke Scale. See here for NIH Stroke Scale Training and Certification: American Heart Association Lifelong Learning
Classification	**Disease Core:** Stroke (Ischemic Stroke only) **Supplemental - Highly Recommended**: Stroke (based on study type, disease stage and disease type) **Supplemental:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose:** The NIHSS is a 11-item neurologic examination stroke scale used to evaluate the effect of acute cerebral infarction on the levels of consciousness, language, neglect, visual-field loss, extraocular movement, motor strength, ataxia, dysarthria, and sensory loss. **Overview:** The NIHSS is a tool used to rapidly assess the effects of stroke. The NIHSS is currently being validated for pediatric stroke. **Time:** The examination requires less than 10 minutes to complete.
Comments/Special Instructions	Administer stroke scale items in the order listed. Record performance in each category after each subscale exam. Do not go back and change scores. Follow directions provided for each exam technique. Scores should reflect what the patient does, not what the clinician thinks the patient can do. The clinician should record answers while administering the exam and work quickly. Except where indicated, the patient should not be coached (i.e., repeated requests to patient to make a special effort). It is preferable for the individual item scores to be recorded in addition to the total score.
Scoring and Psychometric Properties	**Scoring:** Ratings for each stroke scale item are scored with 3 to 5 grades with 0 as normal, and there is an allowance for un-testable items. A trained observer rates the patient's ability to answer questions and perform activities. **Psychometric Properties:** The NIHSS was designed and validated for ischemic stroke. However, further research is needed to determine its advantages and its advantages over simpler scales to assess disability after

	hemorrhagic strokes. Reliability was found to be excellent overall and moderate to excellent for most individual scales. The survey can also reliably be used to assess patients through a remote television link, although it requires slightly more time to complete. The NIHSS has been modified from its initial configuration by the elimination of some aspects which showed poor reliability, and the expansion of other aspects.
References	Brott T, Harold P, Adams HP, Olinger CP, Marler JR, Barsan WG, Biller J, Spilker J, Holleran R, Eberle R, Hertzberg V, Rorick M, Moomaw CJ, Walker M. Measurements of acute cerebral infarction: a clinical examination scale. Stroke. 1989;20(7):864-870. Brott TG, Haley EC Jr., Levy DE, Barsan W, Broderick J, Sheppard GL, Spilker J, Dongable GL, Massey S, and Reed R. Urgent therapy for stroke, I: Pilot study of tissue plasminogen activator administered within 90 minutes. Stroke. 1992; 23, 632-640. Goldstein L, Bertels C, Davis J. Interrater reliability of the NIH Stroke Scale. Arch. Neurol. 1989; 46, 660-662. Kwakkel G, Lannin NA, Borschmann K, English C, Ali M, Churilov L, Saposnik G, Winstein C, van Wegen EE, Wolf SL, Krakauer JW, Bernhardt J. Standardized measurement of sensorimotor recovery in stroke trials: Consensus-based core recommendations from the Stroke Recovery and Rehabilitation Roundtable.Int J Stroke. 2017 Jul;12(5):451-461. doi: 10.1177/1747493017711813.

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Patient Health Questionnaire - 9 (PHQ-9) Depression Scale
(New for Stroke)

Availability	**Please visit this website for more information about the instrument:** **Patient Health Questionnaire 9 (PHQ-9)**
Classification	**Supplemental – Highly Recommended**: Headache, Spinal Cord Injury (SCI) and SCI-Pediatric (ages 12 and older), and Stroke **Supplemental**: Epilepsy, Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months) and Persistent/Chronic (3 months and greater post concussion), and Traumatic Brain Injury (TBI). **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	The PHQ-9 is a screening tool that is specific to depression. This 9 item measure asks participants whether and how often they have been bothered by depression related symptoms over the last two weeks.
Comments/Special Instructions	**Rationale:** PHQ-9 is a valid screening measure for major depressive disorder in people with SCI assessed during their initial inpatient rehabilitation. At a slightly higher cutoff than usual (greater than or equal to 11), the PHQ-9 has a sensitivity of 100% and a specificity of 84% and met stringent criteria for an adequate diagnostic test (Youden criterion). The PHQ-9 has also been found to be sensitive to change in the context of a clinical trial of antidepressant treatment as the “gold standard” Hamilton Depression Rating Scale and some other measures. **Sport-Related Concussion-Specific:** Well validated, widely used screening instrument for depression symptoms. Although not a diagnostic instrument, at higher cut-off levels there is a high correlation with diagnostic interviews. **Age Range:** 13 years and older
Scoring and Psychometric Properties	**Scoring:** 9 items are scored on a scale of 0 to 3, resulting in a total score of 0 to 27 for depression severity: 0 = not at all 1 = several days 2 = more than half the days 3 = nearly every day Total Scores: (Kroenke, et al., 2001) 0-4 indicates minimal depression (no treatment action required)

	5-9 indicates mild depression (watch and repeat PHQ-9 at follow-up) 10-14 indicates moderate depression (treatment plan and counseling recommended and/or pharmacotherapy) 15-19 indicates moderately severe depression (active treatment with pharmacotherapy and/or psychotherapy) 20-27 indicates severe depression (Immediate initiation of pharmacotherapy and, if severe impairment or poor response to therapy, expedited referral to a mental health specialist for psychotherapy and/or collaborative management) **Psychometric Properties:** The PHQ-9 is a valid screening measure for major depressive disorder in people with SCI assessed during their initial inpatient rehabilitation. At a slightly higher cutoff than usual (greater than or equal to 11), the PHQ-9 has a sensitivity of 100% and a specificity of 84% and met stringent criteria for an adequate diagnostic test (Youden criterion). The PHQ-9 has also been found to be sensitive to change in the context of a clinical trial of antidepressant treatment as the “gold standard” Hamilton Depression Rating Scale and some other measures.
Rationale/Justification	**Administration:** 1 to 3 minutes; paper and pencil. **SCI-specific notes:** This instrument has excellent internal consistency, as it showed promise as a tool with which to identify probable Major Depressive Disorder in people with SCI (Bombardier et al 2004). A shortened version of the PHQ-9 with just questions 1, 2 and 6 may be used to increase efficiency and reduce gender effects of the 9 item questionnaire (Graves and Bombardier, 2008).
References	Fann JR, Bombardier CH, Dikmen S, Esselman P, Warms CA, Pelzer E, Rau H, Temkin N. Validity of the Patient Health Questionnaire-9 in assessing depression following traumatic brain injury. J Head Trauma Rehabil. 2005;20(6):501–511. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med. 2001;16(9):606–613. Löwe B, Unützer J, Callahan CM, Perkins AJ, Kroenke K. Monitoring depression treatment outcomes with the patient health questionnaire-9. Med Care. 2004;42(12):1194–1201.

	Maizels M, Smitherman TA, Penzien DB. A review of screening tools for psychiatric comorbidity in headache patients. Headache. 2006;46 Suppl 3:S98–S109. **SCI-specific:** Bombardier CH, Kalpakjian CZ, Graves DE, Dyer JR, Tate DG, Fann JR. Validity of the Patient Health Questionnaire-9 in assessing major depressive disorder during inpatient spinal cord injury rehabilitation. Arch Phys Med Rehabil. 2012;93(10):1838–1845. Bombardier CH, Richards JS, Krause JS, Tulsky D, Tate DG. Symptoms of major depression in people with spinal cord injury: implications for screening. Arch Phys Med Rehabil. 2004;85(11):1749–1756. Graves DE, Bombardier CH. Improving the efficiency of screening for major depression in people with spinal cord injury. J Spinal Cord Med. 2008;31(2):177–184. **Stroke-specific:** deMan-van Ginkel JM, Gooskens F, Schepers VPM, Schuurmans MJ, Lindeman E, Hafsteindottir TB. Screening for Poststroke Depression Using the Patient Health Questionnaire. Nursing Research. 2012;61(5):333-341. Turner A, Hambridge J, White J, Carter G, Clover K, Nelson L, Hackett M. Depression Screening in Stroke: A Comparison of Alternative Measures With the Structured Diagnostic Interview for the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Major Depressive Episode) as Criterion Standard. Stroke. 2012;43(4):1000-1005.

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Patient-Reported Outcomes Measurement Information System (PROMIS)

Availability	The instrument is freely available here: PROMIS website. See General Page for currently available PROMIS Bank CDE Details.
Classification	**Supplemental – Highly Recommended**: Stroke, Congenital Muscular Dystrophy (CMD) in studies of psychosocial functioning, quality-of-life, outcome, and long-term adjustment studies. **Supplemental**: Traumatic Brain Injury (TBI), 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 Diseases (NMD), Duchenne/Becker Muscular Dystrophy (DMD/BMD), Spinal Muscular Atrophy (SMA), Parkinson's Disease (PD), ~~Stroke,~~ and Spinal Cord Injury (SCI), and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH) **Exploratory**: Cerebral Palsy (CP) Myotonic Muscular Dystrophy (DM) and Facioscapulohumeral Muscular Dystrophy (FSHD) and Sport-Related Concussion (SRC) *Headache specific subtest recommendations: Anxiety (Adult/Pediatric), Depression (Adult/Pediatric), Sleep (Adult)
Short Description of Instrument	The Patient Reported Outcomes Measurement Information System (PROMIS) Version 1.0 contains 12 calibrated item banks with likert style items (e.g., anger, anxiety, depression, fatigue (Cella et al., 2010; Garcia et al., 2007), pain (Amtmann et al., 2010), physical function, satisfaction with social activities and roles, sleep/wake disturbance (Bruni et al., 1996, 1994; Spruyt& Gozal 2011), and global health). It is part of the NIH goal to develop systems to support NIH-funded research supported by all of its institutes and centers. PROMIS measures cover physical, mental, and social health and can be used across chronic conditions. The instrument is domain-focused (domains listed above) rather than specific to a particular disease; however, a disease-customized measurement approach can be utilized by choosing the PROMIS measures most relevant to the specific disease. There would be extra time up front (compared to a standardized single measure) to select and agree upon appropriate CMD-specific items but would be worthwhile in the long term IF other researchers studying CMD agree to use the CMD specific items identified. See: PROMIS Domain Framework for pediatric and adult domains **Administration:** Computer adaptive test (CAT) or short-forms

	Time: Variable but design based on item-response theory algorithms to minimize time. The basic PROMIS instrument is available in multiple versions (10-, 29-, and 57-item versions). Ages: Pediatric self-report instruments are available for children ages 8–17 and parent proxy reports are available for children ages 5–17. Full range of self-report adult instruments. **Cost:** Free access to investigators who register and describe their study on the Assessment Center website. Currently, free use with a cooperative agreement. The goal is to grant free access in the public domain to the scientific community including the data repository, CAT, and supporting documents. This is in process. Available in Spanish and specific domains are available in multiple other languages; see PROMIS Translations for details. **Advantages:** Brief, yet reliable.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** T scores for all scales. In all cases, a high score means more of domain. For example, higher scores on the fatigue measures indicate poorer health whereas higher scores on physical functioning measure indicate better health. Standardization Population: For most domains, T-scores relate to the US General Population. See PROMIS Calibrations Testing for further details regarding sample for specific ages and domains. Scoring Manuals for PROMIS measures are available at: PROMIS Scoring Manuals. **Psychometric Properties: Substantial qualitative and quantitative evidence has been gathered that supports the validity of PROMIS measures. More information about validation is available at:** PROMIS Validation
References	Amtmann D, Cook KF, Jensen MP, Chen WH, Choi S, Revicki D, Cella D, Rothrock N, Keefe F, Callahan L, Lai JS. Development of a PROMIS item bank to measure pain interference. Pain. 2010;150(1):173–182. Bruni O, Ottaviano S, Guidetti V, Romoli M, Innocenzi M, Cortesi F, Giannotti F. The Sleep Disturbance Scale for Children (SDSC) construction and validation of an instrument to evaluate sleep disturbances in childhood and adolescence. J Sleep Res. 1996;5(4):251–261.

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Patient-Reported Outcomes Measurement Information System (PROMIS)-Physical Function Assessments

Availability	Please visit this website for more information about the instrument: http://www.nihpromis.org
Classification	**~~Exploratory~~Supplemental:** Stroke
Short Description of Instrument	The Patient Reported Outcomes Measurement Information System (PROMIS) Version 1.0 contains 12 calibrated item banks with Likert style items (e.g., anger, anxiety, depression, fatigue (Cella et al., 2010; Garcia et al., 2007), pain (Amtmann et al., 2010), physical function, satisfaction with social activities and roles, sleep/wake disturbance (Bruni et al., 1996, 1994; Spruyt & Gozal 2011), and global health (Cella et al., 2010; Hays et al., 2009)). It is part of the NIH goal to develop systems to support NIH-funded research supported by all of its institutes and centers. PROMIS measures cover physical, mental, and social health and can be used across chronic conditions. The instrument is domain-focused (domains listed above) rather than specific to a particular disease; however, a disease-customized measurement approach can be utilized by choosing the PROMIS measures most relevant to the specific disease. See: PROMIS Domain Framework for pediatric and adult domains. **Purpose:** This assessment measures patient-reported outcomes related to physical function. **Overview:** Because many persons with a chronic disease will have more than one chronic condition and cannot distinguish the fraction of a problem attributable to each one, physical function items attempt to quantitate the sum of these effects, leaving the teasing out of relative contributions to the analysis stage. Physical function is conceptually multidimensional, with four related subdomains: mobility (lower extremity function), dexterity (upper extremity function), axial (neck and back function), and ability to carry out instrumental activities of daily living (IADL). **Time:** On average, respondents will answer five questions per minute, suggesting, for example, that a computerized adaptive test (CAT) administration of all nine banks with an average of five items per bank will take about ten minutes to complete. **Cost:** No licensing or royalty fees for English and Spanish PROMIS measures used in individual research, clinical practice, educational

	assessment or other application. Translations in other languages have a distribution fee. Permission is required for commercial use or integration into proprietary technology; see PROMIS Terms and Conditions of Use for details. **Age:** Adults (ages 18+), pediatric self-report (ages 8-17) and parents serving as proxy reporters for their child (youth ages 5-17). Item bank and short forms are available in Dutch, English and French. Short forms are also available in additional languages; see PROMIS Translations for details. **Other Important Notes:** There are two general options to consider when selecting a PROMIS instrument for your study: CAT or static short forms. Within these two general options are several specific considerations to guide your optimal selection. In all cases, when you create an assessment from a PROMIS bank, a score will be produced on the same common (Theta) metric which has been converted to a T-distribution based on the United States general population. The choice you make for assessment in your study should be driven by your relative interests in precision, brevity, item content, and flexibility/portability.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** Each item is rated by the difficulty the patient has experienced in completing each item in a 5-point Likert scale. A score of 1 is rated the lowest (an inability to complete the item) and a score of 5 is rated the highest (no difficulty experienced at all). Once the assessment is complete, summative scores are generated. T scores for most items. In all cases, a high score means more of domain. For example, higher scores on the fatigue measures indicate poorer health whereas higher scores on physical functioning measure indicate better health. Standardization Population: For most domains, T-scores relate to the US General Population. See PROMIS Calibrations Testing for further details regarding sample for specific ages and domains. Scoring Manuals is available at: PROMIS Physical Function Scoring Manual. **Psychometric Properties:** Validation is ongoing. The physical function item bank has demonstrated reliability, precision and construct validity as it is correlated with legacy instruments: Health Assessment Questionnaire (r=-0.80) and SF-36 (r=-0.88). It is also correlated with the 10 item

	short form (r=0.96) (Cella et al. 2010).The psychometric properties of this scale were evaluated in general and chronic disease populations (Rose et al. 2014) and in a six chronic health conditions (Schalet et al., 2016). This scale was found to have excellent internal consistency and minimal ceiling effect in a study of ischemic stroke patients by Katzan et al. (2016). The minimally important difference range in ischemic and hemorrhagic stroke patients was determined to be 2.5 to 6.5 T-score points (Lapin et al., 2018).
References	Amtmann D, Cook KF, Jensen MP, Chen WH, Choi S, Revicki D, Cella D, Rothrock N, Keefe F, Callahan L, Lai JS. Development of a PROMIS item bank to measure pain interference. Pain. 2010;150(1):173–182. Bruni O, Ottaviano S, Guidetti V, Romoli M, Innocenzi M, Cortesi F, Giannotti F. The Sleep Disturbance Scale for Children (SDSC) construction and validation of an instrument to evaluate sleep disturbances in childhood and adolescence. J Sleep Res. 1996;5(4):251–261. Bruni O, Romoli M., Innocenzi M, Giannotti F, Cortesi F and Ottaviano S. Prevalenza dei disturbi del sonno in eth scolare. In: Di Perri R., Raffaele M., Silvestri R. and Smirne S. (Eds) *11 Sonno in Italiu 1994.* Poletto Ed., Milano, 1994 163–171. Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, Amtmann D, Bode R, Buysse D, Choi S, Cook K, Devellis R, DeWalt D, Fries JF, Gershon R, Hahn EA, Lai JS, Pilkonis P, Revicki D, Rose M, Weinfurt K, Hays R; PROMIS Cooperative Group. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *J Clin Epidemiol*. 2010 Nov;63(11):1179-1194. Cella D, Yount S, Rothrock N, Gershon R, Cook K, Reeve B, Ader D, Fries JF, Bruce BRM: The patient reported outcomes measurement information system (PROMIS): progress of an NIH roadmap cooperative group during its first two years. Med Care 2007, 45:S3-S11. Garcia SF, Cella D, Clauser SB, Flynn KE, Lad T, Lai JS, Reeve BB, Smith AW, Stone AA, Weinfurt K. Standardizing patient-reported outcomes assessment in cancer clinical trials: a patient-reported outcomes measurement information system initiative. J Clin Oncol. 2007;25(32):5106–5112. Hays RD, Revicki DA, Feeny D, Fayers P, Spritzer KL, Cella D. Using Linear Equating to Map PROMIS(®) Global Health Items and the PROMIS-29 V2.0 Profile Measure to the Health Utilities Index Mark 3. Pharmacoeconomics. 2016;34(10):1015-1022.

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Pediatric Modified Rankin Scale (mRS)

(New for Stroke)

Availability	Public access. Click here for Bigi, et al version. Click here for Cnossen, et al version.
Classification	**Exploratory:** Stroke
Short Description of Instrument	**Purpose:** To assess global neurological impairment following stroke in children **Overview:** This is a modification of the adult Modified Rankins Scale (mRS) which takes into account age-related expectations of neurologic function. There are two published pediatric modifications of the mRS (Bigi, 2011; Cnossen, 2010). Neither version has been subjected to rigorous evaluation of inter-rater reliability or validity. The version published by Bigi is more comparable to the adult version of the mRS, and is the most widely used of the two versions. A comparison of the PSOM and pediatric mRS showed concordance of the two instruments in 88% of subjects when dichotomized into “good” vs “poor” outcomes (Bulger, 2011). **Time:** 5 min (scored after completing a standard clinical neurologic examination)
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** Pediatric mRS modification of Bigi, et al: 0. No symptoms at all 1. No significant disabilities despite symptoms; behavior appropriate to age and normal further development 2. Slight disability; unable to carry out all previous activities, but same independence as other age- and sex-matched children, according to gross motor function scale (Palisano et al 1997) 3. Moderate disability; requiring some help, but able to walk without assistance; in younger patients adequate motor development despite mild functional impairment, defined as reduction of 1 level on the gross motor function scale 4. Moderately severe disability; unable to walk without assistance; in younger patients reduction of at least 2 levels on the gross motor function scale 5. Severe disability; bedridden, requiring constant nursing care and attention 6. Dead Pediatric mRS, modification of Cnossen, et al:

	1. No residual disability; the child attends regular education and does not need remedial teaching 2. Mild residual disability; the child is able to attend regular education but needs remedial teaching because of mild motor disturbances, mild learning disability, or both 3. Severe residual disability; the child has a severe motor deficit (needs braces or wheelchair), severe learning disability, or both, attends a school for special education or is confined to a daily care center 4. Dead **Psychometric Properties:** N/A
References	Bigi S, Fischer U, Wehrli E, Mattle HP, Boltshauser E, Burki S, Jeannet P, Fluss J, Weber P, Nedeltchev K, El-Koussy M, Steinlin M, Arnold M Acute ischemic stroke in children versus young adults. Ann Neurol 2011;70(2): 245-254. Bulder MM, Hellmann PM, van Nieuwenhuizen O, Kappelle LJ, Klijn CJ, Braun KP Measuring outcome after arterial ischemic stroke in childhood with two different instruments. Cerebrovasc Dis 2011;32(5):463-70. Cnossen MH, Aarsen FK, Akker SLj, Danen R, Appel IM, Steyerberg EW, Catsman-Berrevoets CE. Paediatric arterial ischaemic stroke: functional outcome and risk factors. Dev Med Child Neurol. 2010;52(4):394-9. Palisano R, Rosenbaum P, Walter S, et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol 1997;39: 214-23.

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Pediatric Quality of Life Inventory (PedsQL 4.0)
(New for Stroke)

Availability	Protected by Copyright **For further questions please contact:** The PedsQL is available at http://www.pedsql.org.
Classification	**Supplemental:** Stroke
Short Description of Instrument	**Purpose:** Provide a measure of health-related quality of life. **Overview:** PedsQL is a commonly used generic HRQL measure for children. There are multiple disease-specific modules, including one for children with cerebral palsy, but none adapted or validated specifically for stroke. It is designed to evaluate children age 2-18 years, with questionnaires targeting parents as proxy responders at all ages, and patients age > 5 years completing separate questionnaires providing self-report. It is the most commonly used HrQOL instrument used in pediatric stroke outcome studies. **Time:** 15-20 min
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The instrument contains 23 items encompassing four areas: physical, emotional, social, and school. Participants respond on a Likert scale from 0 to 4. Items are reverse scored and linearly transformed to a 0 to 100 scale, with higher converted scores indicating better HRQL. The instrument provides four domain scores, two summary scores (physical and psychosocial functioning), and a total HRQL score. **Psychometric Properties:** Well-standardized and validated, good reliability and sensitivity to change, good correlations with other standardized measures of disease severity in disease-specific modules.
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Pediatric Stroke Outcome Measure Short Neuro Exam (PSOM-SNE) - Child Version (Children Aged 2 Year and Older)

Availability	***The Pediatric Stroke Outcome Measure Short Neuro Exam (PSOM-SNE) Child and Infant Versions are copyrighted by The Hospital for Sick Children Sickkids®. Permission must be obtained directly from The Hospital for Sick Children Sickkids® before use of the Pediatric Stroke Outcome Measure Short Neuro Exam (PSOM-SNE) Child and Infant Versions. Please consult the link below to obtain necessary permissions.*** Flintbox: **Flintbox** **For further questions please contact Ms. Arlene Yee:** Arlene Yee, Director Industry Partnerships& Commercialization The Hospital for Sick Children arlene.yee@sickkids.ca
Classification	**Supplemental - Highly Recommended:** Stroke
Short Description of Instrument	**Purpose:** This scale assesses neurologic deficit severity following pediatric ischemic stroke. **Overview:** The PSOM is a composite scoring system for findings on a standard clinical neurological examination. It assumes knowledge of normal age-related findings by the examiner, thus is designed to be performed by individuals with extensive training and experience in pediatric neurology.~~of clinical and radiographic information and a detailed neurologic examination~~. The measure was published in 2000. **Time:** Examination time in keeping with a standard detailed neurologic exam by a qualified child neurologist, depending on age of child and extent and nature of any abnormalities present (typically 10-15 minutes), plus time to enter findings and assign scoring in recording form and final Summary of Impressions (typically 5 minutes).~~Varies depending on the examination results for the 115 test items~~
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The ~~neurologic examination of the~~ PSOM is a system of scoring findings on a standard detailed neurologic examination by an individual with extensive experience and training in clinical child neurology. Exam findings are recorded on a form with ~~contains~~ 115 test items ordered developmentally in the areas of behavior, mental status, cranial nerves, motor functions, sensory function, cerebellar function, and gait function. At the completion of the examination, the examiner completes a final Summary of Impressions which summarizes examination findings in the form of a Likert-type rating

from 0 (no abnormality) to 2 (severe abnormality with absent function) in each of five domains. ~~deficit severity score ranging from 0 (no deficit) to 2 (severe deficit) is assigned for each of five spheres~~The five domains are: right sensorimotor (including motor, visual, hearing, and somatosensory function), left sensorimotor, language production, language comprehension, and cognitive and behavioral performance. The domain scores are summed for a total POSM score ranging from 0 (normal exam) to a maximum of 10 (severe abnormalities and loss of function in all five domains).~~The patient is assigned an overall Deficit Severity Score of normal, mild, moderate, or severe for each assessment, based on the combination of scores in the individual spheres of the PSOM.~~

Interpretation and Analysis
The original and simplest interpretation strategy assigns a subject to global outcome strata, as follows:

Scoring for Pediatric Stroke Outcome Measure (PSOM)
Adapted from (deVeber et al., 2000)

Good, Normal: Score = 0 in all five ~~spheres~~domains**†**

Good, Mild deficit: Total Score = 0.5, by definition involves mild abnormalities without functional loss in one ~~sphere~~ domain only

Poor, Moderate deficit: Total Score = 1.0-1.5, and involves scores of 0.5 in two, three, or four ~~spheres~~domains; or a Score = 1 in one ~~sphere~~ domain and 0.5 in one other ~~sphere~~domain; or a Score = 1 in one ~~sphere~~ domain only

Poor, Severe deficit: Total Score is ≥ 2.0 and involves scores of 0.5 in all five ~~spheres~~domains; or Score = 1 in one ~~sphere~~ domain plus 0.5 in two other domains~~spheres~~; or Score = 1 in at least two ~~spheres~~domains; or Score = 2 in at least one ~~sphere~~domain

Other strategies have been used by other authors to stratify total PSOM scores into four groups of increasing severity (Jordan et al 2018; Fullerton et al 2018):
0 -1.0 = no/mild impairment
1.5-3.0 = moderate impairment
3.5-6.0 = severe impairment
6.5-10.0 = profound impairment

0 = No impairment, normal function; 0.5 = minimal to mild impairment, normal function; 1 = moderate impairment, decreased function; 2 = severe impairment, loss of function.

†Right sensorimotor, left sensorimotor, language expressive, language comprehensive, and cognitive and behavior.

	Psychometric Properties: The PSOM has demonstrated reliability and validity. It has been used in several neonatal/ childhood stroke studies to assess neurological deficit severity.
References	deVeber GA, MacGregor D, Curtis R, Mayank S. Neurologic outcome in survivors of childhood arterial ischemic stroke and sinovenous thrombosis. J Child Neurol. 2000;15(5):316-324. Fullerton HJ, Stence N, Hills NK, Jiang B, Amlie-Lefond C, Bernard TJ, Friedman NR, Ichord R, Mackay MT, Rafay MF, Chabrier S, Steinlin M, Elkind MSV, deVeber GA, Wintermark M; VIPS Investigators. Focal Cerebral Arteriopathy of Childhood: Novel Severity Score and Natural History. Stroke. 2018 Nov;49(11):2590-2596. Härtel C, Schilling S, Sperner J, Thyen U. The clinical outcomes of neonatal and childhood stroke: review of the literature and implications for future research. Eur J Neurol. 2004;11(7):431-438. Jordan LC, Hills NK, Fox CK, Ichord RN, Pergami P, deVeber GA, Fullerton HJ, Lo W; VIPS Investigators. Socioeconomic determinants of outcome after childhood arterial ischemic stroke. Neurology. 2018;91(6):e509-e516. Kitchen L, Westmacott R, Friefeld S, MacGregor D, Curtis R, Allen A, Yau I, Askalan R, Moharir M, Domi T, deVeber G. The pediatric stroke outcome measure: a validation and reliability study. Stroke. 2012;43(6):1602-1608. Stacey A, Toolis C, Ganesan V. Rates and Risk Factors for Arterial Ischemic Stroke Recurrence in Children. Stroke. 2018 Apr;49(4):842-847.

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Pediatric Stroke Outcome Measure Short Neuro Exam (PSOM-SNE) - Infant Version (Infants Term Birth to Two Years)

Availability	***The Pediatric Stroke Outcome Measure Short Neuro Exam (PSOM-SNE) Child and Infant Versions are copyrighted by The Hospital for Sick Children Sickkids®. Permission must be obtained directly from The Hospital for Sick Children Sickkids® before use of the Pediatric Stroke Outcome Measure Short Neuro Exam (PSOM-SNE) Child and Infant Versions. Please consult the link below to obtain necessary permissions.*** Flintbox: **Flintbox** **For further questions please contact Ms. Arlene Yee:** Arlene Yee, Director Industry Partnerships& Commercialization The Hospital for Sick Children arlene.yee@sickkids.ca
Classification	**Supplemental - Highly Recommended:** Stroke
Short Description of Instrument	**Purpose:** This scale assesses neurologic deficit severity following pediatric ischemic stroke. **Overview:** The PSOM is a composite scoring system for findings on a standard clinical neurological examination. It assumes knowledge of normal age-related findings by the examiner, thus is designed to be performed by individuals with extensive training and experience in pediatric neurology.~~of clinical and radiographic information and a detailed neurologic examination.~~ The measure was published in 2000. **Time:** Examination time in keeping with a standard detailed neurologic exam by a qualified child neurologist, depending on age of child and extent and nature of any abnormalities present (typically 10-15 minutes), plus time to enter findings and assign scoring in recording form and final Summary of Impressions (typically 5 minutes).~~Varies depending on the examination results for the 115 test items~~
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The ~~neurologic examination of the~~ PSOM is a system of scoring findings on a standard detailed neurologic examination by an individual with extensive experience and training in clinical child neurology. Exam findings are recorded on a form with ~~contains~~ 115 test items ordered developmentally in the areas of behavior, mental status, cranial nerves, motor functions, sensory function, cerebellar function, and gait function. At the completion of the examination, the examiner completes a final Summary of Impressions which summarizes examination findings in the form of a Likert-type rating

from 0 (no abnormality) to 2 (severe abnormality with absent function) in each of five domains. ~~deficit severity score ranging from 0 (no deficit) to 2 (severe deficit) is assigned for each of five spheres~~The five domains are: right sensorimotor (including motor, visual, hearing, and somatosensory function), left sensorimotor, language production, language comprehension, and cognitive and behavioral performance. The domain scores are summed for a total POSM score ranging from 0 (normal exam) to a maximum of 10 (severe abnormalities and loss of function in all five domains).~~The patient is assigned an overall Deficit Severity Score of normal, mild, moderate, or severe for each assessment, based on the combination of scores in the individual spheres of the PSOM.~~

Interpretation and Analysis
The original and simplest interpretation strategy assigns a subject to global outcome strata, as follows:

Scoring for Pediatric Stroke Outcome Measure (PSOM)
Adapted from (deVeber et al., 2000)

Good, Normal: Score = 0 in all five ~~spheres~~domains**†**

Good, Mild deficit: Total Score = 0.5, by definition involves mild abnormalities without functional loss in one ~~sphere~~ domain only

Poor, Moderate deficit: Total Score = 1.0-1.5, and involves scores of 0.5 in two, three, or four ~~spheres~~domains; or a Score = 1 in one ~~sphere~~ domain and 0.5 in one other ~~sphere~~domain; or a Score = 1 in one ~~sphere~~ domain only

Poor, Severe deficit: Total Score is ≥ 2.0 and involves scores of 0.5 in all five ~~spheres~~domains; or Score = 1 in one ~~sphere~~ domain plus 0.5 in two other domains~~spheres~~; or Score = 1 in at least two ~~spheres~~domains; or Score = 2 in at least one ~~sphere~~domain

Other strategies have been used by other authors to stratify total PSOM scores into four groups of increasing severity (Jordan et al 2018; Fullerton et al 2018):
0 -1.0 = no/mild impairment
1.5-3.0 = moderate impairment
3.5-6.0 = severe impairment
6.5-10.0 = profound impairment

0 = No impairment, normal function; 0.5 = minimal to mild impairment, normal function; 1 = moderate impairment, decreased function; 2 = severe impairment, loss of function.

†Right sensorimotor, left sensorimotor, language expressive, language comprehensive, and cognitive and behavior.

	Psychometric Properties: The PSOM has demonstrated reliability and validity. It has been used in several neonatal/ childhood stroke studies to assess neurological deficit severity.
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Pediatric Stroke Recurrence and Recovery Questionnaire (RRQ)

(New for Stroke)

Availability	Public access: Click here to access.
Classification	**Supplemental:** Stroke
Short Description of Instrument	**Purpose:** This scale assesses neurologic deficit and functional impact of deficits following pediatric ischemic stroke. **Overview:** The Pediatric Stroke RRQ provides a means to estimate, through parent interview, the rating obtained by an in-person neurologist examination using the Pediatric Stroke Outcome Measure (PSOM). It was validated in a cohort of patients who underwent concurrent evaluation using the standard in-person PSOM examination, and parent interview using the RRQ structured questionnaire. There are additional questions to ascertain stroke recurrence. This was published in 2012 (Lo 2012). It is commonly used in combination with the PSOM to obtain more complete outcome ascertainment in longitudinal prospective cohort studies of childhood stroke (Fullerton 2016; Jordan 2018). **Time:** 10-15 minutes
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The RRQ is based on a structured interview of the parent, in which the parent is asked to rate the child's function in each of the five functional domains of the PSOM on a Likert scale of 0 (no deficit) to 2 (severe deficit with loss of function). The five domains are: right sensorimotor (including motor, visual, hearing, and somatosensory function), left sensorimotor, language production, language comprehension, and cognitive and behavioral performance. The domain scores are summed for a total RRQ score ranging from 0 (normal exam) to a maximum of 10 (severe abnormalities and loss of function in all five domains). **Interpretation and analysis:** same as for PSOM. **Psychometric Properties:** Internal consistency of the total RRQ, and intra-class correlation between total RRQ and total PSOM scores was good ($R^2 = 0.61$).
References	Fullerton HJ, Wintermark M, Hills NK, Dowling MM, Tan M, Rafay MF, Elkind MS, Barkovich AJ, deVeber GA; VIPS Investigators. Risk of Recurrent Arterial Ischemic Stroke in Childhood: A Prospective International Study. Stroke. 2016;47(1):53-9.

	Jordan LC, Hills NK, Fox CK, Ichord RN, Pergami P, deVeber GA, Fullerton HJ, Lo W; VIPS Investigators. Socioeconomic determinants of outcome after childhood arterial ischemic stroke. Neurology. 2018;91(6):e509-e516. Lo WD, Ichord RN, Dowling MM, Rafay M, Templeton J, Halperin A, Smith SE, Licht DJ, Moharir M, Askalan R, Deveber G; International Pediatric Stroke Study (IPSS) Investigators. The Pediatric Stroke Recurrence and Recovery Questionnaire: validation in a prospective cohort. Neurology. 2012;79(9):864-70.

NINDS CDE Notice of Copyright
PROMIS Scale v1.2 - Global Health
(New for Stroke)

Availability	The instrument is freely available here: PROMIS website.
Classification	**Supplemental – Highly Recommended**: Stroke
Short Description of Instrument	The Patient Reported Outcomes Measurement Information System (PROMIS) Version 1.0 contains 12 calibrated item banks with Likert style items (e.g., anger, anxiety, depression, fatigue (Cella et al., 2010; Garcia et al., 2007), pain (Amtmann et al., 2010), physical function, satisfaction with social activities and roles, sleep/wake disturbance (Bruni et al., 1996, 1994; Spruyt & Gozal 2011), and global health (Cella et al., 2010; Hays et al., 2009)). It is part of the NIH goal to develop systems to support NIH-funded research supported by all of its institutes and centers. PROMIS measures cover physical, mental, and social health and can be used across chronic conditions. The instrument is domain-focused (domains listed above) rather than specific to a particular disease; however, a disease-customized measurement approach can be utilized by choosing the PROMIS measures most relevant to the specific disease. See: PROMIS Domain Framework for pediatric and adult domains. The PROMIS Scale v1.2 - Global Health (also referred to as PROMIS-10) is a ten-item patient reported measure of physical, mental and social health. Items query general health, quality of life, physical health, mental health, satisfaction with discretionary social activities, carrying out every day physical activities, pain, fatigue, satisfaction with social roles, and emotional problems (Hays et al., 2009). **Stroke Specific:** Version 1.1 of this scale is recommended by the International Consortium for Health Outcomes Measurement Working Group as part of the Stroke Standard Set of outcome measures (Salinas et al., 2016). The psychometric properties in ischemic stroke and intracerebral hemorrhage patients, and comparison to other PROMIS domain scales were studied by Katzan and Lapin (2018). Version 1.2 of the scale includes changes to allow item response theory scoring in computer scoring applications but does not include changes to the syntax of items; see Scoring Manual for additional details. Lapin et al., 2018 found that updates to the scoring methodology did not change the conclusions of their previous validation study (Katzan and Lapin 2018). **Administration:** Fixed length scale

	Time: **Ages:** Adult (ages 18+) **Cost:** No licensing or royalty fees for English and Spanish PROMIS measures used in individual research, clinical practice, educational assessment or other application. Translations in other languages have a distribution fee. Permission is required for commercial use or integration into proprietary technology; see PROMIS Terms and Conditions of Use for details. Available in Afrikaans, Chinese-Simplified, Czech, Danish, Dutch, German, Finnish, French, Italian, Japanese, Korean, Portuguese-Br, Russian, Slovak, Spanish, Swedish, Welsh. Hebrew, Polish, Romanian and Thai translations are in progress; see PROMIS Translations for details. **Advantages:** Brief, yet reliable.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The PROMIS Scale v1.2 - Global Health has two scores: Physical Health (physical health, physical function, pain, and fatigue items) and Mental Health (quality of life, mental health, satisfaction with discretionary social activities, and emotional problem items) (Hays et al., 2009). T scores for all scales. In all cases, a high score means more of domain. For example, higher scores on the fatigue measures indicate poorer health whereas higher scores on physical functioning measure indicate better health. Standardization Population: For most domains, T-scores relate to the US General Population. See PROMIS Calibrations Testing for further details regarding sample for specific ages and domains. Scoring Manuals is available at: PROMIS Global Scoring Manual. **Psychometric Properties:** Substantial qualitative and quantitative evidence has been gathered that supports the validity of PROMIS measures. More information about validation is available at: PROMIS Validation
References	Allen J, Alpass FM, Stephens CV. The sensitivity of the MOS SF-12 and PROMIS® global summary scores to adverse health events in an older cohort. Qual Life Res. 2018;27(8):2207-2215. Amtmann D, Cook KF, Jensen MP, Chen WH, Choi S, Revicki D, Cella D, Rothrock N, Keefe F, Callahan L, Lai JS. Development of a

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Patient-Reported Outcomes Measurement Information System 29-item Health Profile (PROMIS-29)
(New for Stroke)

Availability	The instrument is freely available here: PROMIS website.
Classification	**Supplemental – Highly Recommended**: Stroke
Short Description of Instrument	The Patient Reported Outcomes Measurement Information System (PROMIS) Version 1.0 contains 12 calibrated item banks with Likert style items (e.g., anger, anxiety, depression, fatigue (Cella et al., 2010; Garcia et al., 2007), pain (Amtmann et al., 2010), physical function, satisfaction with social activities and roles, sleep/wake disturbance (Bruni et al., 1996, 1994; Spruyt & Gozal 2011), and global health (Cella et al., 2010; Hays et al., 2009)). It is part of the NIH goal to develop systems to support NIH-funded research supported by all of its institutes and centers. PROMIS measures cover physical, mental, and social health and can be used across chronic conditions. The instrument is domain-focused (domains listed above) rather than specific to a particular disease; however, a disease-customized measurement approach can be utilized by choosing the PROMIS measures most relevant to the specific disease. See: PROMIS Domain Framework for pediatric and adult domains. PROMIS-29 includes seven HRQOL domains (physical functioning, anxiety, depression, fatigue, sleep disturbance, social functioning, and pain), and the pain domain has two subdomains (interference and intensity). Each of the seven domains has four 5-level items (i.e., 16 decrements each). In addition to these items, pain intensity is assessed using a single 11-point numeric rating scale anchored between no pain (0) and worse imaginable pain (10), adding 10 additional decrements. **Administration:** Fixed length scale **Time:** Approximately 20 minutes **Ages:** Adult (ages 18+) **Cost:** No licensing or royalty fees for English and Spanish PROMIS measures used in individual research, clinical practice, educational assessment or other application. Translations in other languages have a distribution fee. Permission is required for commercial use or integration into proprietary technology; see PROMIS Terms and Conditions of Use for details.

	Afrikaans, Arabic, Bosnian, Bulgarian, Croatian, Czech, Dutch, English, Finnish, French, Georgian, German, Greek, Gujarati, Hebrew, Hungarian, Italian, Kannada, Kazakh, Korean, Latvian, Lithuanian, Macedonian, Malay, Malayalam, Marathi, Norwegian, Odia/Orya, Polish, Portuguese, Punjabi, Romanian, Russian, Serbian, Simplified Chinese (Mandarin), Slovak, Spanish, Swedish, Tamil, Telugu, Thai, Traditional Chinese, Turkish, Ukranian, Urdu; see PROMIS Translations for details. **Advantages:** Brief, yet reliable.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** T scores for all scales. For the PROMIS – 29 Adult Profile 2.1 instrument, an Anxiety raw score of 10 converts to a T-score of 59.5 with a standard error (SE) of 2.6 (see scoring table for the 4a short form v2.1 in Appendix 1 of the PROMIS Scoring Manual). Thus, the 95% confidence interval around the observed score ranges from 54.4 to 64.6 (T-score + (1.96*SE) or 59.5 + (1.96* 2.6). In all cases, a high score means more of domain. For example, higher scores on the fatigue measures indicate poorer health whereas higher scores on physical functioning measure indicate better health. Standardization Population: For most domains, T-scores relate to the US General Population. See PROMIS Calibrations Testing for further details regarding sample for specific ages and domains. Scoring Manuals is available at: PROMIS Global Scoring Manual. **Psychometric Properties:** Substantial qualitative and quantitative evidence has been gathered that supports the validity of PROMIS measures. More information about validation is available at: PROMIS Validation
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NINDS CDE Notice of Copyright
PTSD Checklist - Civilian (PCL-C)
(New for Stroke)

Availability	The instrument is freely available here: PTSD CheckList – Civilian Version (PCL-C)
Classification	**Supplemental**: Traumatic Brain Injury (TBI) **Exploratory**: Sport-Related Concussion (SRC) Subacute (after 72 hours to 3 months) and Persistent/Chronic (3 months and greater post concussion), Stroke, and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	There are three different versions of this checklist: Civilian, Military and Stressor Specific. The Post Traumatic Stress Disorder Checklist (PCL) is a 17-item self- report measure of the DSM-IV symptoms of PTSD. Respondents rate how much they were “bothered by a symptom” on a 5-point scale ranging from 1 (“not at all”) to 5 (“extremely”). Proper administration requires that the test taker be able to respond meaningfully to the items. The test taker must be able to see, read, and comprehend the items. Average reading difficulty is about the 6th-grade level. Age range: Most suggest 16 years and older
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The PCL can be scored in two ways: a) a total score (range 17-85), or b) using differential symptom response to follow the DSM-IV criteria (For DSM-V criteria see PCL-5). In the latter approach item ratings of 3–5 (Moderately or above) are considered symptomatic and DSM criteria are used for a diagnosis: • - Symptomatic response to at least 1 “B” item (Questions 1–5), • - Symptomatic response to at least 3 “C” items (Questions 6–12), • - Symptomatic response to at least 2 “D” items (Questions 13–17) Patient reads the items and answers on a 5-point rating scale. Interpretation requires doctoral level training in psychology. **Administration time**: 5 minutes. **Psychometric Properties:** The PCL shows good temporal stability, internal consistency, test–retest reliability, and

	convergent validity. The majority of structural validity studies support four factor models. Little is available on discriminant validity and sensitivity to change.
Rationale/Justification	The PCL provides a brief assessment of PTSD symptoms, can be used for diagnostic and severity purposes, and can be used to monitor change in response to treatment. Public domain and widely used measure.
References	Weathers, F., Litz, B., Herman, D., Huska, J., & Keane, T. (October 1993). The PTSD Checklist (PCL): Reliability, Validity, and Diagnostic Utility. Paper presented at the Annual Convention of the International Society for Traumatic Stress Studies, San Antonio, TX. Weathers FW, Litz BT, Keane TM, Palmieri PA, Marx BP, Schnurr PP. (2013). The PTSD Checklist for DSM-5 (PCL-5). Scale available from the National Center for PTSD at www.ptsd.va.gov. Blevins CA, Weathers FW, Davis MT, Witte TK, Domino JL. The Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5): Development and initial psychometric evaluation. J Trauma Stress. 2015;28:489–498. Bovin MJ, Marx BP, Weathers FW, Gallagher MW, Rodriguez P, Schnurr PP, Keane TM. Psychometric properties of the PTSD Checklist for Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (PCL-5) in veterans. Psychol Assess. 2016;28(11):1379–1391. Goldfinger JZ, Edmondson D, Kronish IM, Fei K, Balakrishnan R, Tuhrim S, Horowitz CR. Correlates of Post-traumatic Stress Disorder in Stroke Survivors. J Stroke Cerebrovasc Dis. 2014;23(5):1099-1105. Wilkins KC, Lang AJ, Norman SB. Synthesis of the psychometric properties of the PTSD checklist (PCL) military, civilian, and specific versions. Depress Anxiety. 2011 Jul;28(7):596-606. Wortmann JH, Jordan AH, Weathers FW, Resick PA, Dondanville KA, Hall-Clark B, Foa EB, Young-McCaughan S, Yarvis JS, Hembree EA, Mintz J, Peterson AL, Litz BT. Psychometric analysis of the PTSD Checklist-5 (PCL-5) among treatment-seeking military service members. Psychol Assess. 2016;28(11):1392–1403.

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Quality of Life in Neurological Disorders (Neuro-QOL)

Availability	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. For additional information and to obtain Neuro-QOL instruments, please visit Quality of Life in Neurological Disorders Instrument Link
Classification	**Supplemental-Highly Recommended**: Stroke, Congenital Muscular Dystrophy (CMD) - Highly recommended for studies of psychosocial functioning, quality-of- life, outcome, and long-term adjustment studies. **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) **Exploratory**: Cerebral Palsy (CP), Duchenne Muscular Dystrophy (DMD), Facioscapulohumeral Muscular Dystrophy (FSHD), Myotonic Dystrophy (DM), Sport-Related Concussion (SRC), ~~Stroke,~~ and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Stroke:** Adult Mobility, Adult Upper Extremities, Adult Assistive Devices **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. **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. **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). **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. **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). **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.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**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. **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.
References	Cella D, Lai JS, Nowinski CJ et al. Neuro-QOL: brief measures of health-related quality of life for clinical research in neurology. Neurology. 2012;78(23):1860-1867. doi: 10.1212/WNL.0b013e318258f744. Epub 2012 May 9. Gershon RC, Lai JS Bode R et al. Neuro-QOL: quality of life item banks for adults with neurological disorders: item development and calibrations based upon clinical and general population testing. Qual

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Carlozzi NE & Ready RE. (2011). Health-related quality of life in Huntington's Disease. In: C. Jenkinson, M. Peters, & M. B. Bromberg (Eds.), Quality of Life and Neurodegenerative Disease. Cambridge, UK: Cambridge University Press, pp. 71–81.

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NINDS CDE Notice of Copyright
Questionnaire for Verifying Stroke-Free Status (QVSFS)

Availability	Please visit this website for more information about the instrument: Questionnaire for Verifying Stroke-Free Status.
Classification	**Supplemental – Highly Recommended:** Stroke
Short Description of Instrument	**Purpose:** The Questionnaire for Verifying Stroke-Free Status (QVSFS) is a practical instrument for confirming absence of previous symptomatic stroke or transient ischemic attack in control subjects participating in stroke research. **Overview:** The QVSFS is an 8-item structured questionnaire, designed to quickly and accurately identify prospectively screened study subjects who are free of symptomatic cerebrovascular disease. **Time:** Administration time is 5 minutes or less for all subjects.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	QVSFS scores range from 0 (no questions positive) to 8 (all 8 questions positive). Subjects were considered QVSFS negative (stroke/TIA free) if their sum score was 0. If any of the 8 items were positive (sum score 1 to 8), the QVSFS was considered positive (not stroke/TIA free). Any question that was answered "unknown" was scored as a negative response. **Psychometric Properties:** The QVSFS can effectively identify stroke-free individuals with a high degree of accuracy, even in a population with a large proportion of patients with prior stroke or TIA. Accuracy for identifying subjects with stroke and/or TIA is lower, but the QVSFS may still be useful as a screening tool in that regard
References	Jones WJ, Williams LS, Meschia JF. Validating the Questionnaire for Verifying Stroke-Free Status (QVSFS) by neurological history and examination. Stroke. 2001;32(10):2232–2236. Meschia JF, Lojacono MA, Miller MJ, Brott TG, Atkinson EJ, O'Brien PC. Reliability of the questionnaire for verifying stroke-free status. Cerebrovasc Dis. 2004;17(2-3):218–223. Meschia JF, Brott TG, Chukwudelunzu FE, Hardy J, Brown RD Jr, Meissner I, Hall LJ, Atkinson EJ, O'Brien PC. Verifying the stroke-free phenotype by structured telephone interview. Stroke. 2000 31(5):1076–1080. Sung VW, Johnson N, Granstaff US, Jones WJ, Meschia JF, Williams LS, Safford MM. Sensitivity and Specificity of Stroke

	Symptom Questions to Detect Stroke or Transient Ischemic Attack. Neuroepidemiology. 2011;36(2):100-104.

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Rey Auditory Verbal Learning Test [RAVLT]
(New for Stroke)

Availability	**Please visit this website for more information about the instrument: Rey Auditory Verbal Learning Test**
Classification	**Basic:** Acute Hospitalized Traumatic Brain Injury, Moderate/Severe Traumatic Brain Injury and Concussion/Mild Traumatic Brain Injury **Supplemental:** Cerebral Palsy, Epilepsy, Multiple Sclerosis (MS), Sport-Related Concussion (SRC) Persistent/Chronic (3 months and greater post concussion), Stroke, and Epidemiology Traumatic Brain Injury (TBI) **Exploratory**: Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH) and Sport-Related Concussion (SRC) Acute (time of injury until 72 hours) and Subacute (after 72 hours to 3 months)
Short Description of Instrument	Originally developed in the 1940s, the RAVLT has evolved over the years, and several variations of the test have emerged. The standard RAVLT format starts with a list of 15 words, which an examiner reads aloud at the rate of one per second. The patient's task is to repeat all the words he or she can remember, in any order. This procedure is carried out a total of five times. Then the examiner presents a second list of 15 words, allowing the patient only one attempt at recall. Immediately following this, the patient is asked to remember as many words as possible from the first list. The RAVLT has proven useful in evaluating verbal learning and memory, including proactive inhibition, retroactive inhibition, retention, encoding versus retrieval, and subjective organization. Because the test is brief, straightforward, easy to understand, and appropriate for both children and adults (ages 7 through 89), it has gained widespread acceptance. However, until now, data about the RAVLT-norms, validity studies, different administration and scoring procedures-have been scattered in various sources. **Epilepsy Specific Information**: The RAVLT is a verbal learning test that has been used widely, both in North American and in Europe, as well as Australia (Weintrob, 2007). In addition, a Spanish version is available ((WHO-UCLA AVLT). It is structured in the same format as the CVLT (5 learning trials, distracter trial, and immediate and delayed recall of initial list), but consists of words that are not semantically related. **TBI Specific Information/Comments**: This is a performance based measure which requires the subject to understand what is required and participate in the testing. It requires a functional level in the severe disability or above on the GOS/GOSE.

	Sport-Related Concussion Specific Comments: The RAVLT has proven useful in evaluating verbal learning and memory, including proactive inhibition, retroactive inhibition, retention, encoding versus retrieval, and subjective organization. Because the test is brief, straightforward, easy to understand, and appropriate for both children and adults (aged 7 through 89), it has gained widespread acceptance. Advantages: include costs (in the public domain). The RAVLT has been translated into multiple languages including Spanish (Los Angeles Auditory Verbal Learning Test), which facilitates its use across a wider segment of the population not only in the US, but to compare across studies from other nations. The RAVLT has been widely used to characterize verbal memory in epilepsy patient series. The primarily disadvantage of the RAVLT is its normative information, with a variety of "norms" appearing in different contexts. Although meta-norms are available, the norms were not obtained in a systematic fashion such as with tests from formal test publishers. Age Range: 7–89 years
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** Different summary scores are derived from raw RAVLT scores. These include RAVLT Immediate (the sum of scores from 5 first trials (Trials 1 to 5)), RAVLT Learning (the score of Trial 5 minus the score of Trial 1), RAVLT Forgetting (the score of Trial 5 minus score of the delayed recall) and RAVLT Percent Forgetting (RAVLT Forgetting divided by the score of Trial 5). **Psychometric Properties:** This measure has good psychometric properties, is widely used, translated into multiple languages, has multiple forms, and is in the public domain. It is a legacy measure for the NIH Toolbox Episodic Memory subdomain.
Rationale/Justification	The advantages of the RAVLT include costs (in the public domain) and its purported greater sensitivity than the CVLT to lateralized temporal lobe seizure onset. The RAVLT has been translated into multiple languages including Spanish (Los Angeles Auditory Verbal Learning Test), which facilitates its use across a wider segment of the population not only in the US, but to compare across studies from other nations. The RAVLT has been widely used to characterize verbal memory in epilepsy patient series. The primarily disadvantage of the AVLT is its normative information, with a variety of "norms" appearing in different contexts. Although meta-norms are available, the norms were not

	obtained in a systematic fashion such as with tests from formal test publishers. There is no universally agreed upon recognition format for the procedure. The committee has selected one to permit consistency across studies, although there are also discussions to create a new recognition form due to certain limitations of current recognition approaches.
References	Schmidt M. Rey Auditory and Verbal Learning Test: A Handbook. Los Angeles: Western Psychological Services, 1996. Strauss E, Sherman E, Spreen O (2006). Rey Auditory Verbal Learning Test. In Compendium of Neuropsychological Tests (3rd Edition) Oxford University Press. pp. 776–807. Weintrob DL, Saling MM, Berkovic SF, Reutens DC. Impaired verbal associative learning after resection of left perirhinal cortex. Brain. 2007;130(Pt 5):1423–1431. **TBI**: Brenner LA, Terrio H, Homaifar BY, Gutierrez PM, Staves PJ, Harwood JE, Reeves D, Adler LE, Ivins BJ, Helmick K, Warden D. Neuropsychological test performance in soldiers with blast-related mild TBI. Neuropsychol. 2010;24(2):160–167. McCauley SR, Wilde EA, Anderson VA, Bedell G, Beers SR, Campbell TF, Chapman SB, Ewing-Cobbs L, Gerring JP, Gioia GA, Levin HS, Michaud LJ, Prasad MR, Swaine BR, Turkstra LS, Wade SL, Yeates KO; Pediatric TBI Outcomes Workgroup. Recommendations for the use of common outcome measures in pediatric traumatic brain injury research. J Neurotrauma. 2012;29(4):678–705. Sroufe NS, Fuller DS, West BT, Singal BM, Warschausky SA, Maio RF. Postconcussive symptoms and neurocognitive function after mild traumatic brain injury in children. Pediatrics. 2010;125(6):e1331–e1339. Wäljas M, Lange RT, Hakulinen U, Huhtala H, Dastidar P, Hartikainen K, Öhman J, Iverson GL. Biopsychosocial outcome after uncomplicated mild traumatic brain injury. J Neurotrauma. 2014;31(1):108–124. Studer M, Goeggel Simonetti B, Joeris A, Margelisch K, Steinlin M, Roebers CM, Heinks T. Post-concussive symptoms and neuropsychological performance in the post-acute period

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Rey-Osterrieth Complex Figure Test (ROCF)

Availability	**For additional information and test materials: Rey-Osterrieth Complex Figure (ROCF) Test**
Classification	**Supplemental – Highly Recommended:** Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS) **Supplemental:** Epilepsy and Stroke **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH): Copy trial for visuoperception Delayed Recall trial for memory
Short Description of Instrument	**Purpose:** The Rey-Osterrieth Complex Figure (ROCF) test requires the subject to copy a complex geometric figure, providing an index of design reproduction/graphic ability. Recall trials then tap visual memory for the stimuli. **Overview:** The ROCF is a widely used neuropsychological test for the evaluation of visuospatial constructional ability (Copy trial) and visual memory (Immediate Recall, Delayed Recall, and Recognition trials). It consists of three test conditions: Copy, Immediate Recall and Delayed Recall. Test requires the subject to copy a complex geometric figure, providing an index of design reproduction/graphic ability. A recall trial then taps visual memory for the stimuli. **Population:** 6-89 years **Time:** The assessment takes approximately 45 minutes, including a 30-minute delay interval (timed).
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** Drawings are scored based on a 36-point scoring system or a 72-point system. The 72-point system (Denman, 1984) gives more information about organizational ability. The same scoring criteria apply to all three drawing trials. Each of the 18 scoring units are scored based on accuracy and placement criteria. Unit scores range from two (accurately drawn, correctly placed) to zero (inaccurately drawn, incorrectly placed, unrecognizable, omitted). The time required to copy the figures have also been used. **Scoring Time:** 45 minutes including delay period for memory recall. Scoring of this task is very labor intensive and requires thorough training, so that may be a problem in a research setting. **Psychometric Properties:** The test has been extensively validated across populations and has well established normative standards. Intercorrelations between the ROCF and other measures, in samples of both normal and brain-damaged subjects, indicate convergent and discriminant validity. It reliably discriminates among

	brain-damaged, psychiatric, and normal subjects. In addition, the Recognition trial provides incremental diagnostic power compared to using recall trials alone.
References	Denman SB. Denman Neuropsychology Memory Scale. 1984, Charleston, SC: Sidney B. Denman. Larrabee GJ, Curtiss G. Factor structure and construct validity of the Denman Neuropsychology Memory Scale. Int J Neurosci. 1985;26(3-4):269–276. Lezak M, Howieson DB, Loring DW, Hannay HJ, Fischer JS. Neuropsychological Assessment. New York: Oxford University Press, 2004. Meyers JE, Meyers KR. Rey Complex Figure Test and Recognition Trial: Professional Manual. Lutz, FL: PAR, 1995. Rey A & Osterrieth PA. Translations of excerpts from Andre Rey's Psychological examination of traumatic encephalopathy and P.A. Osterrieth's The Complex Figure Copy Test. Clinical Neuropsychologist. 1993;7(1):4–21. van der Ham IJM, Kant N, Postma A, Visser-Meily JMA. Is Navigation Ability a Problem in Mild Stroke Patients? Insights from Self-reported Navigation Measures. J Rehabil Med. 2013;45:429-433.

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Similarities Subtest of the Wechsler Adult Intelligence Scale-Fourth Edition (WAIS-IV)
(New for Stroke)

Availability	Please visit this website for more information about the instrument: Wechsler Adult Intelligence Scale-Fourth Edition Link
Classification	Exploratory: Stroke and Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	Publication Date: 2008 Ages/Grades: Individuals 16–90 years Completion Time: 60 minutes Scores: VIQ, PIQ, and FSIQ scores The Similarities Subtest of the WAIS-IV is a verbal comprehension test that measures verbal concept formation and reasoning.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The participant is presented with two words which represent common objects or concepts and has to describe how they are similar. The scores on each item vary according to the degree to which the response describes a property applicable to both items in the pair of words. Raw scores are converted to age-corrected standard scores, with a mean of 10 and standard deviation of 3.
References	Hochstenbach JB, den Otter R, Mulder TW. Cognitive recovery after stroke: a 2-year follow-up. Arch Phys Med Rehab. 2003;84(10):1499-1504. Wechsler D. (~~1997~~2008). Wechsler adult intelligence scale-~~III~~Fourth Edition (WAIS-IV). ~~New York~~San Antonio, TX: ~~Psychological Corporation~~NCS Pearson.

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Six-Item Screener
(New for Stroke)

Availability	Please visit this website for more information about the instrument: Six-Item Screener
Classification	**Supplemental:** Stroke
Short Description of Instrument	The six-item screener is a brief instrument for identifying subjects with cognitive impairment and its diagnostic properties are comparable to the full Mini-Mental State Examination. It can be administered by telephone or face-to-face interview and is easily scored by a simple summation of errors.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** 0 to 3 points: Impairment Likely 4 to 6 points: Impairment less likely **Psychometric Properties:** Six-Item Screener is a reliable instrument for identifying subjects with cognitive impairment and its diagnostic properties are comparable to the full Mini Mental State Examination (MMSE).
References	Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC (2002). Six-Item Screener to Identify Cognitive Impairment Among Potential Subjects for Clinical Research. Medical Care. 40(9):771-781. Carpenter CR, DesPain B, Keeling TN, Shah M, Rothenberger M (2011). The Six-Item Screener and AD8 for the Detection of Cognitive Impairment in Geriatric Emergency Department Patients. Ann Emerg Med. 57(6): 653-661. Wilber ST, Carpenter CR, Hustey FM (2008). The Six-Item Screener to Detect Cognitive Impairment in Older Emergency Department Patients. J. Acad. Emerg. 15: 613-616.

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Stroke Adjudication Form

Availability	Please visit this website for more information about the instrument: http://www.regardsstudy.org/. The instrument is freely available here: Stroke Adjudication Form
Classification	**Supplemental:** Stroke
Short Description of Instrument	**Purpose**: The template stroke adjudication form from the REasons for Geographic And Racial Differences in Stroke (REGARDS) study provides a systematic way to collect data on stroke presence and subtype. **Overview:** The form was developed in conjunction with the Neurology group at Cincinnati and provides a framework for dual review and resolution of discordant adjudications to determine the presence and subtype of stroke. **Time:** The assessment time is variable, as it requires the review of medical records describing the actual event. It could vary between as few as 3 minutes, or as much as 30 minutes.
Comments/Special Instructions	This form has been utilized in a retrospective epidemiologic study of stroke.
Scoring and Psychometric Properties	**Scoring:** Scoring is based on the determination if 'stroke' is or not present, and if 'stroke' is present it further defines the stroke subtype. **Psychometric Properties:** N/A
References	Howard VJ, Cushman M, Pulley L, Gomez CR, Go RC, Prineas RJ, Graham A, Moy CS, Howard G. The REasons for Geographic and Racial Differences in Stroke study: objectives and design. Neuroepidemiology. 2005; 25: 135–143.

NINDS CDE Notice of Copyright
Stroke and Aphasia Quality of Life-39 (SAQOL-39)
(New for Stroke)

Availability	Please visit this website for more information about the instrument: Stroke and Aphasia Quality of Life-39 (SAQOL-39)
Classification	**Supplemental-Highly Recommended:** Stroke
Short Description of Instrument	Derived from the Stroke Specific Quality of Life Scale (SS-QOL) in 2003, the SAQOL-39 is the short form of the SAQOL (53 items), which is itself an adaptation of the SS-QOL (Stroke-specific Quality of life scale).
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The SAQOL-39 has 2 response formats, both based on a 5-point scale: 1=could not do it at all to 5=no trouble at all and 1=definitely yes to 5=definitely no Overall and subdomain scores can range from 1 to 5; the overall SAQOL-39 score is calculated by summing across the items and dividing by the number of items; subdomain scores are calculated the same way. **Psychometric Properties:** The SAQOL-39 is an acceptable, reliable, and valid measure of health-related quality of life (HRQL) in people with long-term aphasia.
References	Hilari K, Byng S, Lamping DL, Smith, SC. Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39): Evaluation of Acceptability, Reliability, and Validity. Stroke. 2003;34: 1944-1950. Hilari K, Lamping DL, Smith SC, Northcott S, Lamb A, Marshall J. Psychometric properties of the Stroke and Aphasia Quality of Life Scale (SAQOL-39) in a generic stroke population. Clinical Rehabilitation. 2009; 23(6):554-557.

NINDS CDE Notice of Copyright
Stroke Impact Scale (SIS)

Availability	**The SIS is copyrighted by the University of Kansas Stroke Impact Scale website. Non- English language translations are available from PROQOLID: Non-English language translations of SIS.**
Classification	**Supplemental**: Stroke **Exploratory**: Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose**: The Stroke Impact Scale is a stroke-specific, self-report, health status measure. It was designed to assess multidimensional stroke outcomes, including strength, hand function, activities of daily living/ instrumental activities of daily living (ADL/IADL), mobility, communication, emotion, memory and thinking, and participation. The SIS can be used both in clinical and research settings. **Overview**: It was designed to assess multidimensional stroke outcomes. The SIS version 3.0 includes 59 items and assesses 8 domains: Strength - 4 items, Hand function - 5 items, ADL/IADL - 10 items, Mobility - 9 items, Communication - 7 items, Emotion - 9 items, Memory and thinking - 7 items, Participation/Role function - 8 items. **Time**: There is no set time limit for this examination. The SIS can be administered in person, over the phone or by mail. **Other Important Notes**: Alternate forms of the Stroke Impact Scale include the SIS-16, developed to address the lack of sensitivity to differences in physical functioning in functional measures of stroke outcome. The SIS-16 consists of 16 items from the SIS 2.0: seven ADL/IADL items, eight Mobility items, and a single Hand Function item. The SIS and the SIS-16 has been translated by MAPI Research Institute: (Non-English language translations website) into numerous languages. The SIS-16: The SIS-16 was recently developed as a short stand alone tool for measuring the physical aspects of stroke recovery. This version implements 16 questions from the SIS 3.0 across four of the eight domains to create a short composite.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring**: The SIS is a patient-based, self-report scale in which each item is rated in a 5- point Likert scale in terms of the difficulty the patient has experienced in completing each item. A score of 1 = an inability to complete the item and a score of 5 = no difficulty

	experienced at all. Using an algorithm equivalent to the one used in the SF- 36, summative scores are generated for each domain. The SIS is scored in the following way, for each domain: Transformed Scale = [(Actual raw score - lowest possible raw score) / Possible raw score range] x 100. Both the SIS version 3.0 and the SIS-16 are available in proxy version when patients are unable to complete them. **Psychometric Properties**: The SIS is reliable, valid, and sensitive to change. Unlike the SF-36, it does not have a floor effect in stroke patients. There are clear differences when the SIS is done via proxy report versus self-report.
References	Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992;30:473–483. Duncan PW, Lai SM, Tyler, DA, Perera, S, Reker, DM, Studenski, S. Evaluation of proxy responses to the Stroke Impact Scale. Stroke. 2002;33(11):2593–2599. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, Laster L J. The Stroke Impact Scale version 2.0: Evaluation of reliability, validity, and sensitivity to change. Stroke. 1999;30:2131–2140. Duncan PW, Lai SM, Bode RK, Perea S, DeRosa JT, GAIN Americas Investigators. Stroke Impact Scale-16: A brief assessment of physical function. Neurology. 2003;60:291–296. Lin K, Fu T, Wu C, Wang Y, Liu J, Hsieh C, Lin S. Minimal Detectable Change and Clinically Important Difference of the Stroke Impact Scale in Stroke Patients. Neurorehabilit. Neural Repair. 2010;24(5):486-492.

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Stroke Specific Quality of Life Scale (SS-QOL)

Availability	The SS-QOL is in the public domain but the following reference should be cited if the scale is used: Williams LS, Weinberger M, Harris LE, Clark DO, Biller J. Development of a stroke-specific quality of life scale. Stroke 1999 Jul;30(7):1362-9. **The instrument is freely available here: Stroke Specific Quality of Life Scale.**
Classification	**Supplemental**: Stroke **Exploratory**: Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose** The SS-QOL is a patient-centered outcome measure intended to provide an assessment of health-related quality of life specific to patients with stroke. The scale domains and items were derived from a series of interviews with post-stroke patients. **Overview** Patients must respond to each question of the SS-QOL with reference to the past week. It is a self-report scale containing 49 items in 12 domains and subscales which include: Energy, Upper extremity function, Work/Productivity, Mood, Self-care, Social roles, Family roles, Vision, Language, Thinking and Personality. **Time** This scale takes approximately 10-15 minutes to complete. Other Important Notes: Training is not required, as the SS-QOL is intended to be self-administered.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:**Items are rated on a 5-point Likert scale. There are three different response sets. Patients must respond to each item using the corresponding response set as indicated on 5 point scale. Higher scores indicate better functioning. The SS-QOL yields both domain scores and an overall SS-QOL summary score. The domain scores are unweighted averages of the associated items while the summary score is an unweighted average of all twelve domain scores. **Psychometric Properties:** The SS-QOL was published and validated in 1999 by Williams, Weinberger, Harris, and Clark. One

	study suggests that the scale can be administered to patients with stroke reliably over the telephone. This scale should not be used with the following groups: Severe stroke populations. The SS-QOL has not yet been tested among patients with severe stroke. Should be used with caution in patients with aphasia. Although the modified version of the scale, the Stroke and Aphasia Quality Of Life Scale (SAQOL-39), has been validated for use in patients with long-term aphasia, it is a relatively new measure that requires further psychometric testing. Patients who require a proxy to complete. A study by Williams et al.5 compared proxy ratings of the SS-QOL to patient self administration in 225 patient-proxy pairs. Proxies rated all domains of SS-QOL lower than the patients. The intraclass correlation coefficient (ICC) for each domain ranged from poor (r = 0.30 for role function) to adequate (r = 0.59 for physical function). Proxy overall SS-QOL score was also rated lower than the patient score (3.7 versus 3.4) with an ICC of r = 0.41
References	Silva SM, Correa FI, Pereiea GS, Coelho de Morais Faria CD, Ferrari Correa JC. Construct validity of the items on the Stroke Specific Quality of Life (SS-QOL) questionnaire that evaluate the participation component of the International Classification of Functioning, Disability and Health. Disabil Rehabil. 2016; 40(2):225-231. Hilari K, Byng S, Lamping DL, Smith SC. The stroke and aphasia quality of life scale-39 (SAQOL-39): evaluation of acceptability, reliability and validity. Stroke. 2003;34 (8):1944–1950. Williams LS, Weinberger M, Harris LE, Clark DO, Biller J. Development of a stroke-specific quality of life scale. Stroke. 1999a;30(7):1362–1369. Williams LS, Weinberger M, Harris LE, Biller J. Measuring quality of life in a way that is meaningful to stroke patients. Neurology. 1999b;53:1839–1843. Williams LS, Redmon G, Saul DC, Weinberger M. (2000). Reliability and telephone validity of the Stroke-specific Quality of Life (SS-QOL) scale. Stroke. 2000;32:339-b. Williams LS, Bakas T, Brizendine E, Plue L, Tu W, Hendrie H, Kroenke K. How valid are family proxy assessments of stroke patients' health-related quality of life? Stroke. 2006;37:2081–2085.

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Stroop Test

Availability	**Please visit this website for more information about the instrument: Stroop Test** A commonly used version is the Delis-Kaplan Executive Function System (D-KEFS) Color-Word Interference Test (CWIT). The CWIT consists of the three traditional Stroop trials (color naming, color name reading, interference) as well as a fourth trial in which the subject switches back and forth between naming the dissonant ink colors and reading the conflicting color names. The stimulus booklet and forms are copyrighted and included as part of the D-KEFS test kit, but can be purchased separately from the test publisher **(Stroop Color and Word Test**).
Classification	**Supplemental – Highly Recommended:** Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS) **Supplemental:** Huntington's Disease (HD), Multiple Sclerosis (MS), Sport-Related Concussion (SRC), and Stroke
Short Description of Instrument	The Stroop test involves three trials. In the WORD trial, the subject reads words of color names (e.g., red, blue) printed in black ink. In the COLOR trial, the subject identifies colors (e.g., rectangles printed in red or blue). Finally, in the COLOR-WORD response inhibition trial, the subject must name the color in which a word is presented, while ignoring the printed word. Thus, incongruence between the word's color and identity (e.g., the word "blue" presented in red) requires inhibition and response selection. Multiple versions of the Stroop test are available (e.g., Victoria, Golden, D-KEFS, and Trenerry versions). **Construct measured:** Cognitive flexibility, attention, and processing speed **Generic vs. disease specific:** Generic **Means of administration (paper and pencil, computerized):** Paper and Computerized **Location of administration (clinic, home, telephone)**: Clinical and Research Settings **Intended respondent (patient, caregiver):** Patient **# of items:** N/A **# of subscales and names of sub-scales:** N/A
Comments/Special Instructions	**Measurements:** Type of scale used to describe individual items and total/subscale scores (nominal, ordinal, or [essentially] continuous): Continuous.

	If ordinal or continuous, explain if ceiling or floor effects are to be expected if the measure is used in specific HD Subgroups. No floor effects. Ceiling effects can be avoided if any subjects who reach the end of the page before the allotted time has elapsed are redirected to the top row and continue working until the end of the allotted time-period. Individuals with advanced disease may struggle with the interference trial. **Huntington's Disease-Specific:** The UHDRS version of the Stroop task has been most commonly used in HD research. To date, no one version of the Stroop Tests has been shown to be clearly superior to others. Intended use of instrument/ purpose of tool (cross-sectional, longitudinal, diagnostic): Assessment of cognitive function in HD cross-sectional and longitudinal studies. Sensitivity to Change/ Ability to Detect Change: (over time or in response to an intervention): In published cross-sectional (Stout et al., 2011) and internal analyses (PREDICT-HD), the test is sensitive to changes in premanifest HD, especially in individuals who are closer to an expected diagnosis. Unpublished internal analyses of 7-year longitudinal data (PREDICT) also shows changes in rates of change over time in premanifest HD on all subtests, especially color and word naming. The TRACK-HD study In a cross-sectional analysis of the Stroop WORD found that healthy controls performed significantly better on the than both the early HD and the premanifest HD groups. Longitudinally, the TRACK-HD study found significant differences in rates of change for early HD compared to controls, but did not find significant differences in rates of change for premanifest HD compared to controls. In Stroop WORD, the TRACK-HD premanifest participants may be less likely to show cognitive effects than the PREDICT-HD Premanifest participants because: (1) they are further from estimated onset based on CAG repeat length and age (Langbehn et al., 2004) and (2) they are potentially less progressed because the TRACK-HD study excluded premanifest subjects based on UHDRS motor scores >= 5. In general, cognitive tests will be more effective metrics in studies of premanifest HD when the focus is on subjects that are close to onset. Meta-analysis of HD observational studies published 1993-2007 reveals both cross sectional performance differences compared to healthy controls and longitudinal change within HD groups over time for Stroop Reading and Stroop Color that is evident in both premanifest and Early HD. The Stroop Interference findings are less impressive, with smaller cross sectional effect sizes and no significant longitudinal effects (see below).

Scoring and Psychometric Properties	**Scoring:** Scoring for each trial type is based on the number of correct responses in a fixed amount of time, typically within 45 seconds (Golden, 1975). Higher scores indicate better cognitive performance. Standardization of scores to a reference population (z scores, T scores): Raw scores can be converted to t scores for different ranges of age and years of education, depending on norms used. Studies reporting raw scores should control for age and education. If scores have been standardized to a reference population, indicate frame of reference for scoring (general population, HD subjects, other disease groups). General population (5-90 years of age; education levels of 2 to 20 years). **Psychometric Properties:** **Reliability:** High reliability across different versions. **Test-retest or intra-interview (within rater) reliability (as applicable):** Test-retest reliabilities cover periods of 1 minute to 10 days. Reliabilities for Word, Color, and Color-Word are respectively .88, .79 and .71 (Jensen, 1965) and .89, .84., and .73 (Golden, 1975). **Inter-interview (between-rater) reliability (as applicable):** Internal consistency: Correlations among the subtests are moderate to high (.71 to .84) (Chafetz and Mathew, 2004). **Statistical methods used to assess reliability:** Intraclass correlations Reliability data from the CAB study will be available for the Stroop Word condition of this task by end of 2012 for 100 control, 100 premanifest, and 50 early HD subjects. **Construct validity:** The interference score correlates well with measures of attention and prepotent response inhibition (May and Hasler, 1998) **Known Relationships to Other Variables (e.g., gender, education, age):** May not be valid in color-blind individuals. The color-word interference score is vulnerable to aging (Mitrushina et al., 2005). Age and education should be controlled if reporting raw scores. **Diagnostic Sensitivity and Specificity, if applicable (in general population, HD population- premanifest/ manifest, other disease groups):** Cross-Sectional sensitivity in PreHD

	(Group: Effect Size, P value, # of studies/ total # of HD participants across studies) Cross-Sectional sensitivity in HD (Group: Effect Size, P value, # of studies/total # of HD participants across studies) Longitudinal sensitivity within subjects (Group: Effect Size, P value, # of studies/ total # of HD participant across studies) Stroop Reading All Pre: -0.44, 0.001, 13/242; Near Pre:-0.65, 0.001, 4/152 Early: -1.29, <0.001, 10/220 Dx: -0.65, 0.022, 4/115; Near Pre: -0.61, <0.001, 2/160; All Pre: -0.47, <.003, 4/180 Stroop Colour All Pre: -0.44, 0.002, 14/260; Near Pre: -0.87, 0.001, 4/152 Early: -1.35, <0.001, 9/207 Dx: -0.79, 0.008, 3/102; Near Pre: -0.44, 0.001, 2/160; All Pre: -0.34, 0.001, 4/180 Stroop Interference All Pre: -0.24, 0.065, 18/332; Near Pre: -0.64, 0.004, 5/158 Early: -1.09, <0.001, 10/184 Dx: -0.15, 0.108, 4/115; Near Pre: -0.3, 0.215, 2/159; All Pre: 0, .999, 5/212
Rationale/Justification	**Strengths:** The color and word subtest are particularly sensitive in cross-sectional and longitudinal studies of premanifest and early manifest HD. Task has been tested at sites in the United States, Canada, United Kingdom, Australia, Germany, and Spain. Task is easy to administer. Well established neuropsychological test measure with some literature in mild TBI and sport concussion. **Weaknesses:** N/A **Special Requirements for administration:** A stopwatch is required. **Administration Time:** Assessment takes approximately 2 minutes for each of the three trial types. **Translations available:** Spanish (Golden Version), Cantonese (Victoria Version). The UHDRS version is available in several European languages including: Czech, Danish, Dutch, Finnish, French, German, Italian, Norwegian, Polish, Portuguese, Spanish and Swedish.
References	Golden, CJ. Stroop Color and Word Test: A Manual for Clinical and Experimental Uses. Chicago, Illinois: Skoelting, 1978, pp. 1–32.

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Telephone Interview for Cognitive Status (TICS)

Availability	The TICS is available from the Psychological Assessment Resources (PAR). **For additional information, please visit: Telephone Interview For Cognitive Status**.
Classification	**Supplemental**: Stroke **Exploratory**: Unruptured Cerebral Aneurysm and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose**: The Telephone Interview for Cognitive Status (TICS) is a brief, standardized test of cognitive functioning that was developed for use in situations where in-person cognitive screening is impractical or inefficient (e.g., large-scale population screening, epidemiological surveys, with patients who are unable to appear in person for clinical follow-up). It is also helpful in the diagnosis of documenting progressive impairment, and might also identify incident disease in research populations. **Overview**: The TICS is designed to be administered using the telephone, however, it also may be administered face-to-face. The TICS is particularly useful for examining visually impaired individuals and individuals who are unable to read or write, since it does not require vision. The TICS is very brief and tests many of the basic cognitive functions affected by dementia, consisting of an 11-items, that assess a variety of cognitive domains affected by dementing disorders, including orientation to time and place, receptive and expressive language functions, immediate verbal memory, calculation, and verbal abstraction. It successfully differentiates carefully diagnosed Alzheimer's disease patients from healthy spouse controls and demonstrates high test-retest reliability in these populations. **Time**: The test usually takes less than 10 minutes to administer and score.
Comments/Special Instructions	The TICS has a modified version, TIC-m, which eliminates items that are difficult to verify in epidemiological study, and also includes a delayed recall procedure in an attempt to increase sensitivity. Before administering the telephone interview, the examiner must speak with someone at the same location (e.g., family member, caregiver) who will serve as a proctor to ensure that the

	environment is appropriate for testing and that the examinee is able to hear spoken language at a spoken volume. All examinee responses are recorded verbatim.
Scoring and Psychometric Properties	**Scoring:** The individual item scores are summed to obtain the TICS Total score, ranging from 0–41. **Psychometric Properties:** The TICS has a high test-retest reliability and excellent sensitivity and specificity for the detection of cognitive impairment. Among elderly populations, TICS scores approximate a normal distribution and are not subject to the ceiling effects that limit the usefulness of many mental status examinations.
Rationale/Justification	The TICS has been used as a neurocognitive screening tool in large-scale SAH studies such as the International Study of Unruptured Intracranial Aneurysms (ISUIA) and institutional protocols (e.g., by the Columbia group). While neuropsychological outcome is best tested in a face-to-face interview, telephone-based assessments might be the only feasible assessment, depending on the type of study.
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Token Test
(New for Stroke)

Availability	**Please visit this website for more information about the instrument: Token Test.**
Classification	**Supplemental**: Stroke and Unruptured Cerebral Aneurysm and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Purpose**: The Token Test is used to assess auditory comprehension in persons with developmental and acquired disorders affecting language. The examinee provides a gestural response in response to a verbal command.
Comments/Special Instructions	The Token Test is excellent for detecting mild auditory comprehension deficits, but less useful for assessing other aspects of auditory comprehension (such as semantic comprehension) or functional communication.
Scoring and Psychometric Properties	**Scoring**: The test is scored on a scale of 0–163. ~~A sample of a Token test scoring sheet can be found on the web link provided above.~~ The mean score for adults (and adolescent 14 years or older) is 161. Scores lower than 157 are virtually absent in a normal adult population. **Psychometric Properties:** The test shows excellent and good inter-rater reliability, while some parts have lower coefficients.
References	De Renzi E, Vignolo LA. The token test: A sensitive test to detect receptive disturbances in aphasics. Brain 1962;85:665–678. **Additional References:** Alkhamra RA, Al-Jazi AB. Validity and reliability of the Arabic Token Test for children. Int J Lang Commun Disord. 2016 Mar;51(2):183-91. Becker F, Reinvang I. Event-related potentials indicate bi-hemispherical changes in speech sound processing during aphasia rehabilitation. J Rehabil Med. 2007;39:658–661. Franceschini M, Agosti M, Cantagallo A, Sale P, Mancuso M, Buccino G. Mirror neurons: action observation treatment as a tool in stroke rehabilitation. Eur J Phys Rehabil Med. 2010;46:517-523. Hula W, Doyle PJ, McNeil MR, Mikolic JM. Rasch modeling of revised token test performance: validity and sensitivity to change. J Speech Lang Hear Res. 2006 Feb;49(1):27-46. McNeil MR, Pratt SR, Szuminsky N, Sung JE, Fossett TR, Fassbinder W, Lim KY. Reliability and validity of the computerized Revised Token Test: comparison of reading and listening versions in persons with and without aphasia. J Speech Lang Hear Res. 2015

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Trail Making Test (TMT), Delis-Kaplan Executive Function System (D-KEFS)
(New for Stroke)

Availability	Please click here for more information: Trail Making Test
Classification	**Supplemental – Highly Recommended:** Huntington's Disease (HD) – for Cognitive Assessment and Sport-Related Concussion (SRC) **Basic:** Acute, Moderate and Mild Traumatic Brain Injury (TBI) **Supplemental:** Stroke, Epidemiology TBI **Exploratory:** Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Summary/Overview of Instrument:** The first part of Trail Making Test (TMT) test, TMT-A, requires the subject to rapidly sequence numbers from 1 through 25, with the score being the time to complete the task. The second part, TMT-B, is a more difficult cognitive flexibility task requiring the subject to follow a sequential pattern while shifting cognitive sets, sequencing from 1 to 13 while switching between numbers and letters (i.e., 1-A-2-B-3-C,…), with the score being the time to complete the task. The utility and psychometric properties of the Trails B are so well accepted that it is one of the few measures that it is used across neurologic and psychiatric clinical and research patient populations. **Construct measured:** Psychomotor speed and executive functions **Generic vs. disease specific:** Generic **Intended use of instrument/purpose of tool:** The Trail Making Test is a measure of psychomotor speed, visual scanning, and executive ability. **Means of administration (paper and pencil, computerized):** Written **Location of administration** (clinic, home, telephone): Clinical setting **Intended respondent (patient, caregiver):** Patient **# of items:** N/A **# of subscales and names of sub-scales:** N/A
Comments/Special Instructions	N/A

Scoring and Psychometric Properties	**Scoring:** Scoring of A and B are reported as the number of seconds required to complete the task. Higher scores indicate greater impairment. Performance varies by age and education, and thus normative standards are used to classify patient performance. Errors affect the patient's score only in that the correction of errors is included in the completion time for the task. If a patient has not completed both parts after five minutes, it is unnecessary to continue the test. In addition to the direct scores, the B-A difference score, the B:A ration, and the B-A/A proportional score have also been used as indicators of certain cognitive operations or specific markers of brain damage (Sanchez- Cubillo et al., 2009). Note: Parts A & B must be completed together and in the correct order for test administration to be valid. Standardization of scores to a reference population: Raw scores (time to complete) are converted to scaled scores (0–19). Scale score is converted to t score by sex, education, age, and ethnicity. Norms are from the Halstead-Reitan Battery (Heaton et al., 2004). **Psychometric Properties:** Test-retest or intra-interview (within rater) reliability (as applicable): For intervals of 3 weeks to 1 year, test-retest reliability is moderate to high for Part A (r=0.36–0.79) and Part B (r=0.44–0.89) (Bornstein et al., 1987, Matarazzon et al., 1974, Dikmen et al., 1999). Inter-interview (between-rater) reliability (as applicable): Interrater reliability has been found to be high for both Part A r=(0.94) and Part B (r=0.90). Statistical methods used to assess reliability: Correlational analyses and reliability coefficients. The HD-CAB is a cognitive battery designed specifically for use in late premanifest and early HD clinical trials. This six test assessment battery which includes the Trail Making B test was found be sensitive to disease status and reliable in an observational study in 105 control, 103 premanifest-HD, and 55 early HD subjects (Stout et al., 2014). Content validity: Part A and B correlate moderately (r=0.31) (Heilbronner et al., 1991). Construct validity: Subtests correlate with visual search tasks (Ehrenstein et al., 1982). In a study by Sanchez-Cubillo and colleagues (2009) suggested that the TMT-A mainly requires visuoperceptual abilities, while the TMT-B requires "primarily working member and secondarily task-switching ability". Sensitivity to Change/Ability to Detect Change (over time or in response to an intervention): In published cross-sectional (Stout et al., 2011) and internal analyses (PREDICT-HD), Parts A and B are sensitive to impairments in premanifest HD, especially Part B in individuals who are closer to an expected diagnosis. Unpublished internal analyses of 7-year longitudinal data (PREDICT) show

	differences in rates of longitudinal change in premanifest HD on both subtests, but especially Part A, compared to gene negatives. Cross sectionally, the TRACK-HD study found that healthy controls performed significantly better than both the early HD and the premanifest HD groups. Longitudinally, the TRACK-HD study found significant differences in rates of change for early HD compared to controls, but did not find significant differences in rates of change for premanifest HD compared to controls. The TRACK-HD premanifest participants may be less likely to show cognitive effects than the PREDICT-HD Premanifest participants because 1) they are further from estimated onset based on CAG repeat length and age (Langbehn et al., 2004) and 2) they are potentially less progressed in actuality because the TRACK-HD study excluded premanifest subjects based on UHDRS motor scores >= 5. Generally speaking, cognitive tests will be more effective metrics in studies of premanifest HD when the focus is on subjects that are close to onset. Known Relationships to Other Variables (e.g., gender, education, age): Performance declines with IQ and educational level (Diaz-Asper et al., 2004; Clark et al, 2004; Hester et al., 2005). Diagnostic Sensitivity and Specificity, if applicable (in general population, HD population- premanifest/ manifest, other disease groups): Well-established in multiple disease groups. (See Strauss, Sherman, & Spreen, 2006 or Mitrushina et al., 2005 for details). O'Rourke et al. (2011) showed sensitivity to detect differences between prodromal HD and gene negative controls.
Rationale/Justification	**Strengths:** Parts A and B are sensitive in cross-sectional and longitudinal studies of prodromal HD. Task has been tested at sites in the United States, Canada, United Kingdom, Australia, Germany, and Spain. **Weaknesses:** The examiner must carefully monitor a participant's performance to accurately ~~score errors~~detect errors. The reliability of test administration can vary by examiner's reaction time in noticing errors and pointing them out, which introduces imprecision. More severe motor impairment may influence results. Participants who are very cognitively impaired may not be able to complete the task, which must be dealt with statistically (e.g., set a maximum time for noncompleters). **Availability:** In the Public domain, May be photocopied, though there are versions available for purchase. **Special Requirements for administration:** Stopwatch. **Administration Time:** 10 minutes.
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	Strauss, E., Sherman, E. M. S., & Spreen, O. (2006). Comprehensive Trail Making Test (CTMT) A Compendium of Neuropsychological Tests (pp. 557–561). New York: Oxford University Press. Specialty Automated Systems Corporation offers an online version of the Trail Making Test. For more information, visit: Trail Making Test.

NINDS CDE Notice of Copyright
Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P)
(New for Stroke)

Availability	**Please visit this website for more information about the instrument: Utrecht Scale for Evaluation of Rehabilitation-Participation.**
Classification	**Exploratory**: Stroke, Unruptured Cerebral Aneurysm and Subarachnoid Hemorrhage (SAH)
Short Description of Instrument	**Description**: The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) is a self-report questionnaire used to measure participation and has been used in patients with stroke. Consists of 3 scales: (1) frequency of participation (objective level of participation): 11 items (2) participation restrictions experienced (subjective rating of participation): 11 items (3) satisfaction with participation (subjective rating of participation): 10 items Frequency scale consists of two parts: Part A (vocational activities) measures the number of hours in a regular week spent on paid work, unpaid work, education, and housekeeping Part B (leisure and social activities) measure the frequency of sports and physical exercise, going out, making day trips, leisure activities at home, visiting family or friends, receiving visits from family or friends, and contact by computer or telephone during the last 4 weeks. Restriction scale: Items on difficulties experienced with vocational, leisure, and social activities. This scale asks patients to rate the severity of the restrictions of participation caused by the stroke. Satisfaction scale: Items about satisfaction with vocational, leisure, and social activities. The USER-P covers the International Classification of Functioning, Disability and Health (ICF) chapters 6 – 9.
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The scores for the three scales are as follows: Frequency of participation (0 – 55): Part A: 0 = none at all; 5 = 36 hours or more Part B: 0 = not at all; 5 = 19 times or more Participation restriction (0 – 33): 0 = not possible to perform; 3 = performed with difficulty

	Satisfaction with participation (0 – 40) 0 = very dissatisfied; 4 = very satisfied The scores are combined for a sum score ranging from 0 to 100, with a higher score indicating a higher level of participation, meaning a higher frequency, less restrictions experienced, and more satisfaction.
Rationale/Justification	The USER-P is a valid measure to rate objective and subjective participation in persons with physical disabilities.
References	Post MW, van der Zee CH, Hennink J, Schafrat CG, Visser-Meily JM, van Berlekom SB. Validity of the utrecht scale for evaluation of rehabilitation-participation. Disabil Rehabil. 2012;34(6):478–485. Van der Zee CH, Priesterbach AR, Van der Dussen L, et al. Reproducibility of three self-report participation measures: the ICF Measure of Participation and Activities Screener, the Participation Scale, and the Utrecht Scale for Evaluation of Rehabilitation-Participation. J Rehabil Med. 2010;42:752–757. Van der Zee CH, Visser-Meily JMA, Lindeman E, Kappelle LJ, Post, MWM. Participation in the Chronic Phase of Stroke. Top Stroke Rehabil. 2015;20(1):52-61.

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Walking Speed

Availability	The Instrument is Freely Available Here: Walking Speed. The protocol is freely available here: 10-metre Walk Test Protocol
Classification	**Supplemental – Highly Recommended:** Stroke (based on study type, disease stage and disease type) **Supplemental:** Cerebral Palsy (CP)
Short Description of Instrument	**Purpose:** Walking speed is an indicator of function for detection of mobility impairments, risk of falls and prediction of morbidity and mortality. **Overview:** Walking speed has been chosen by a panel of experts as the standardized assessment to measure locomotion for the motor function domain of the NIH Toolbox. It has robust psychometric properties, correlates with functional ability, and predicts future health status, functional decline, discharge locations and mortality. Walking speed is assessed in meters per second. Walking speeds indicate the levels of impairment and functional levels of walking. Less than 0.4m/sec reflects severe gait impairment or household ambulation, 0.4m/sec to 0.8m/sec indicates moderate gait impairment or limited community ambulation and greater than 0.8 m/sec reflects mild impairment and ability to walk in the community. Improvement in functional levels is associated with improved activities of daily living (ADLs)/ Instrumental ADLS (IADLS) and quality of life. **Time:** Assessment takes approximately 2 to 5 minutes.
Comments/Special Instructions	**Other Important Notes:** Walking speed is an easily accessible measuring tool that is an important objective measure of patient's functional status and highly predicative of morbidity, mortality and health care utilization and is clinically interpretable.
Scoring and Psychometric Properties	**Scoring:** Start your patient at the beginning of a 6 meter line. Ask patient to walk "at a comfortable pace" to the end of the line – "Walk at a comfortable pace as if you are walking in the park". Allow participant to accelerate 1-meter and decelerate 1-meter. Time during the central 4 meters. Use a stopwatch to time from when the patient's leading limb crosses the test line and until the leading limb crosses the end test distance line. Comfortable walking speed is time to complete 4 meters, reported in m/sec (4 meters/time to complete that distance).

	Psychometric Properties: Self-selected walking speed measurement is reliable, valid, and sensitive to change.
References	Abellan van Kan G, Rolland Y, Andrieu S, Bauer J, Beauchet O, Bonnefoy M, Cesari M, Donini LM, Gillette Guyonnet S, Inzitari M, Nourhashemi F, Onder G, Ritz P, Salva A, Visser M, Vellas B. Gait speed at usual pace as a predictor of adverse outcomes in community-dwelling older people an International Academy on Nutrition and Aging (IANA) Task Force. Nutr Health Aging. 2009;13(10):881–889. Fritz S, Lusardi M. White Paper: "Walking Speed: the Sixth Vital Sign". J Geriatr Phys Ther. 2009;32(2):2–5. Guralnik JM, Ferrucci L, Pieper CF, Leveille SG, Markides KS, Ostir GV, Studenski S, Berkman LF, Wallace RB. Lower extremity function and subsequent disability: consistency across studies, predictive models, and value of gait speed alone compared with the short physical performance battery. J Gerontol A Biol Sci Med Sci. 2000;55(4):M221–M231. Perry J, Garrett M, Gronley JK, Mulroy SJ. Classification of walking handicap in the stroke population. Stroke. 1995;26(6):982–989. Richards CL, Olney SJ. Hemiparetic gait following stroke. Part II: Recovery and physical therapy. Gait Posture. 1996;(4):149-162. Schmid A, Duncan PW, Studenski S, Lai SM, Richards L, Perera S, Wu SS. Improvements in speed-based gait classifications are meaningful. Stroke. 2007;38(7):2096–2100. Steffen TM, Hacker TA, Mollinger L. Age- and gender-related test performance in community-dwelling elderly people: Six-Minute Walk Test, Berg Balance Scale, Timed Up & Go Test, and gait speeds. Phys Ther. 2002;82(2):128–137. Van Iersel MB, Munneke M, Esselink RA, Benraad CE, Olde Rikkert MG. Gait velocity and the Timed-Up-and-Go test were sensitive to changes in mobility in frail elderly patients. J Clin Epidemiol. 2008; 61(2):186–191.

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Wechsler Adult Intelligence Scale - Fourth Edition (WAIS-IV)

Availability	**Please visit this website for more information about the instrument:** **Wechsler Adult Intelligence Scale-Fourth Edition**
Classification	**Supplemental-Highly Recommended:** Cerebral Palsy (CP) and Sport-Related Concussion (SRC) **Supplemental**: Epilepsy, Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS), Mitochondrial Disease (Mito), Stroke, and Traumatic Brain Injury (TBI)
Short Description of Instrument	The WAIS-IV is a battery of tests that provides an estimate of general intellectual functioning. The WAIS-IV has 10 core subtests (Arithmetic, Block Design, Comprehension, Digit Span, Digit Symbol, Information, Letter-Number Sequencing, Matrix Reasoning, Picture Arrangement, Picture Completion, Processing Speed, Object Assembly, Similarities, Symbol Search, and Vocabulary) which make up four index scores, including the Verbal Comprehension Index (VCI), the Perceptual Reasoning Index (PRI), the Working Memory Index (WMI), and the Processing Speed Index (PSI). **Index Scores:** FSIQ, General Ability (GAI) Verbal Comprehension (VCI): The VCI is a measure of verbal concept formation, verbal reasoning, and knowledge acquired from one's environment. **Perceptual Reasoning (PRI)**: The PRI is a measure of perceptual and fluid reasoning, spatial processing, and visual-motor integration. **Working Memory (WMI)**: The WMI is a measure of working memory abilities, which involves attention, concentration, mental control and reasoning. Working memory tasks require the ability to temporarily retain information in memory, perform some operation or manipulation with it, and produce a result. **Processing Speed (PSI)**: The PSI is composed of subtests measuring the speed of mental and eye/hand coordination. The PSI provides a measure of the person's ability to quickly and correctly scan, sequence, or discriminate simple visual information. This composite also measures short-term memory, attention, and visual-motor coordination. Excellent norms, frequently revised and correlated to other Wechsler products such as the WRAT-4, DKEFS subtests and the CVLT II. **Subtests:** VCI: Similarities, Vocabulary, Information PSI: Block Design, Matrix Reasoning, Visual Puzzles WMI: Digit Span, Arithmetic

	PSI: Symbol Search, Coding **Publication Date:** 2008 **Ages:** Individuals 16:0–90:11 years **Completion Time:** 60–90 minutes **Language:** English, Spanish
Comments/Special Instructions	**Block Design Subtest: Epilepsy** **Formal IQ Testing** The WAIS-IV was released in 2008, and there are presently no peer-reviewed clinical studies of the WAIS-IV in epilepsy. Historically, the natural evolution for adopting new psychological tests following their revision occurs over an approximate 5-year transition period. For studies using Wechsler short forms derived from either the WASI or WAIS-IV/WISC-IV, the committee recommends, at a minimum, including the Vocabulary and Block Design subtests. Similarly, the committee recommends that the General Ability Index be calculated when the full WAIS-IV/WISC-IV is administered to facilitate comparisons with the FSIQ obtained with the WASI. **Visuospatial (Optional Domain)** Spatial skills, to date, have not been a primary interest in most epilepsy studies. Other than improvement following contralateral/dominant hemisphere surgery, visuospatial performances tend to remain stable. In addition, there is greater variability in tests used to measure visual spatial abilities compared to language measures (e.g., Judgment of Line Orientation, Visual Object and Space Perception, Rey-Osterreith Complex Figure copy). Rather than recommend an additional test to the CDE neuropsychology protocol, the committee is cognizant of the fact that in most cases, Block Design will be administered as part of the Wechsler IQ testing. Consequently, when an individual visual spatial task is needed, performance on the Block Design subtest can be used. For studies using the WAIS-IV, the Perceptual Reasoning Index (PRI) derived from performances on Block Design, Matrix Reasoning, and Visual Puzzles can be present. If the WASI has been used, then the PIQ, which is analogous to the WAIS-IV PRI given the absence of tests of processing speed, can be reported. **Recommended Tests:** Block Design, WAIS-IV Perceptual Reasoning Index **Digit Span Subtest: TBI** **Description:** Two sections: Digits Forward and Digits Backward **Permissible Values:** Raw score: 0–30 Scaled Score: 1–19. **Procedures:** Administered verbally. Requires minimal training. Administration time is 10 minutes. **Comments:** Adults 16–89 years

	Rationale: The Digit Span subtest is a widely used measure of auditory attention that is well-normed and sensitive to the effects of TBI **References:** Wechsler D. (1997). Wechsler adult intelligence scale-III. New York: Psychological Corporation. **Digit Span Subtest: Epilepsy** **<u>Simple Span of Attention</u>** **Purpose:** To assess immediate attention **Alternative Languages:** Spanish **Comment:** The Digit Span test differs based upon which age-appropriate measure is used. The WISC-IV assesses forward and backward digit span. The WAIS-IV also includes a Sequencing trial in which the subject is the repeat back the digits in ascending order. Nationally-representative norms are available for 16–90 (WAIS-IV) years. WAIS-IV test booklets are copyrighted and can be purchased separately from the test publisher. Permission to photocopy single pages of the booklets for an annual fee can also be arranged with the publisher. In addition to normative values, span length (maximum longest digit span) should be reported separately for forward span and backward span. Individual standard scores for sum of correct trials for forward digits, backward digits, and sequencing should also be included. For studies relying on the WAIS-IV for IQ assessment, Digit Span will be obtained as part of the WAIS-IV protocol. **Primary Dependent Measures:** Digit Span Forward (scaled score), Digit Span Backward (scaled score) **Optional Secondary Measure:** Absolute span (largest number string) for forward span and digit span **Time Estimate:** 10 minutes **Scoring Estimate:** < 5 minute **Vendor:** Pearson/PsychCorp, P.O. Box 599700, San Antonio, TX 78259 **Spanish Reference:** Peña-Casanova J, Quinones-Ubeda S, Quintana-Aparicio M, Aguilar M, Badenes D, Molinuevo JL, et al. Spanish Multicenter Normative Studies (NEURONORMA Project): norms for verbal span, visuospatial span, letter and number sequencing, trail making test, and symbol digit modalities test. Arch Clin Neuropsychol. 2009;24(4):321–341. **Digit Symbol Subtest: Stroke** **Purpose:** This test has been shown to predict group membership defined by processing speed deficits, such as brain-injured versus control samples and has been used as a sensitive outcome in studies identifying predictors of longitudinal decline in elders. **Overview:** The digit-symbol subtest measures the time to recode symbol and digit items. The test requires elements of attention, visuoperceptual processing, working memory, and psychomotor speed.

	Time: Assessment takes a few minutes to complete **Scoring:** The score is the number correctly coded from 0–133 in 120 seconds. **Psychometric Properties:** The test demonstrates strong reliability and validity coefficients. **References:** DeMonte VE, Geffen GM, May CR, & MacFarland K. Improved sensitivity of the rapid screen of mild traumatic brain injury. J Clin Exp Neuropsychol. 2009;6:1–11. Knopman DS, Mosley TH, Catellier DJ Coker LH. Atherosclerosis risk in communities study brain MRI study. Fourteen-year longitudinal study of vascular risk factors, APOE genotype, and cognition: the ARIC MRI study. Alzheimer's & Dementia. 2009;5:207–214. Wechsler D. (1997). Wechsler adult intelligence scale-III. New York: Psychological Corporation. **Letter-Number Sequencing Subtest: TBI** **Description:** This is a complex span task involving simultaneous processing. The subject is presented with a mixed list of numbers and letters and their task is to repeat the list by saying the numbers first in ascending order and then the letters in alphabetical order. **Permissible Values:** Performance on this measure is converted to scaled scores with a mean of 10 and standard deviation of 3. The scaled score is adjusted for age. **Procedures:** Requires trained examiner to administer. Administration time is 5 minutes. **Comments:** This is a performance based measure which requires the subject to understand what is required and participate in the testing. It requires a functional level in the severe disability or above on the GOS/GOSE. **Rationale:** Highest factor analytic loading on Working Memory factor. Good psychometric properties and sensitivity to severity of TBI. Legacy measure for the NIH Toolbox Working Memory Subdomain. **References:** Wechsler Adult Intelligence Scale III. Letter-Number Sequencing Subtest. Pearson Education Inc, San Antonio, TX. **Processing Speed Index Subtest: TBI** **Description:** This index is based on 2 subtests of the Wechsler Adult Intelligence Scale. For Digit Symbol, examinee must accurately fill in symbols, according to matched number-symbol pairs in a key in 120 seconds. For Symbol Search, examinee determines whether either of two target symbols match any of the symbols in a search group; examinee must respond to as many items as able in 120 seconds. **Permissible Values:** The 2 subtests yield scaled scores adjusted for age with a mean of 10 and standard deviation of 3. The WAIS PS Index is based on the 2 subtests with a mean of 100 and standard deviation of 15 adjusted for age.

	Procedures: Requires trained examiner to administer and neuropsychologist or psychologist to interpret. Administration time is 10 minutes. **Comments:** This is a performance based measure which requires the subject to understand what is required and participate in the testing. It requires a functional level in the severe disability or above on the GOS/GOSE. **Rationale:** Good psychometric properties. Sensitive to TBI and its severity. Legacy measure for NIH Toolbox Processing Speed Subdomain. **References:** Wechsler Adult Intelligence Scale III/IV. Processing Speed Index. Pearson Education Inc, San Antonio, Texas. **Symbol Search Subtest: Stroke** **Purpose:** The symbol-search subtest of the WAIS III is an indicator of processing speed and visual perception. **Overview:** The symbol-search subtest requires rapid identification of targets. Specifically, for each item the subject must search a series of five figures to see if either of two targets occur, and mark yes or no for each item. Recent fMRI findings have shown greater activity in the left dorsolateral prefrontal cortices associated with slower symbol search performance. This subtest and the Digit-Symbol subtest together comprise the Processing Speed Index of the WAIS-III. **Scoring:** The score is the number correct in 120 seconds from 0–60. **Time:** Assessment takes approximately 3 minutes. **Psychometric Properties:** The subtest has shown validity in studies of adults with various neurological disorders. **References:** Sweet LH, Paskavitz JF, OConnor MJ, Browndyke JN, Wellen JW, Cohen RA. FMRI correlates of the WAIS-III Symbol Search subtest. J Int Neuropsychol. 2005;11:471–476. Wechsler D. (1997). Wechsler adult intelligence scale-III. New York: Psychological Corporation. **Specific for Mitochondrial Disorder** **Strengths:** As noted above, the Wechsler Adult Intelligence Scale has long been considered a gold standard instrument for assessing adult intelligence in both research and clinical settings. It is widely used, reliable and well validated. Previous versions of the WAIS have been used to characterize specific phenotypic characteristics of particular mitochondrial disorders. For example, relative weaknesses in nonverbal reasoning ability in individuals with POLG1 mutations and the syndrome of mitochondrial spinocerebellar ataxia and epilepsy (Gramstad et al., 2009), though results may have been impacted by psychomotor slowing. Similarly, previous versions of the WAIS have been used as sensitive measures of generalized cognitive decline in mitochondrial disorders as a whole (Finsterer, 2009).

	Limitations: There have not yet been studies published using the most recent revision, the WAIS-IV, in individuals with mitochondrial disorder, however it has been used in studies with populations that may present with similar characteristics like multiple sclerosis, with results demonstrating that the instrument as a whole is sensitive to measuring disease-related changes in cognition over time (Ryan et al, 2012). **References:** Finsterer J.Mitochondrial disorders, cognitive impairment and dementia. J Neurol Sci. 2009;283:143–148. Gramstad A, Bindoff LA, Lillebø A, Tzoulis C, Engelsen BA. Neuropsychological performance in patients with POLG1 mutations and the syndrome of mitochondrial spinocerebellar ataxia and epilepsy. Epilepsy Behav. 2009;16(1):172–174. Ryan JJ, Gontokovsky ST, Kreiner DS, and Tree HA. Wechsler Adult Intelligence Scale-Fourth Edition performance in relapsing-remitting multiple sclerosis. J Clin Exp Neuropsychol. 2012;34 (6):571–579. **Specific for ME/CFS** In general, the subscore component profile will show average or above average values for the Verbal Comprehension and Perceptual Reasoning Components, while Working Memory and especially Processing Speed are often in the below average range. **References:** Tiersky LA, Cicerone KD, Natelson BH, DeLuca J. Neuropsychological Functioning in Chronic Fatigue Syndrome and Mild Traumatic Brain Injury: A Comparison. The Clinical Neuropsychologist. 1998;12(4):503-512. **Specific for Sport-RelatedConcussion Recommended Tests:** The Working Memory Index (WMI) and the Processing Speed Index (PSI).
Scoring and Psychometric Properties	~~Full battery can take up to 2 hours to administer.~~ **Scoring:** Hand or computer scored. Alternative subtests are available for administration to a patient who is not a native English speaker or has received their academic education elsewhere. **Psychometric Properties:** Per the Comments/Special Instructions section, the WAIS-IV subtests have shown validity in various studies.
References	Foo R, Guppy M, Johnston L. Intelligence assessments for children with cerebral palsy: a systematic review. Dev Med Child Neurol. 2013;55(10):911–918. McCrea SM, Robinson TP. Visual Puzzles, Figure Weights, and Cancellation: Some Preliminary Hypotheses on the Functional and Neural Substrates of These Three New WAIS-IV Subtests. ISRN Neurology. 2011:1-19.

	Wechsler D. (2008) Wechsler Adult Intelligence Scale, fourth edition (WAIS-IV). The Psychological Corporation; San Antonio, TX. Technical Manual: WAIS-IV Technical & Interpretive Manual Presentations: Wechsler General Ability Index, GAI, Symposium (APA 2009) Wisdom NM, Mignogna J, Collins RL. Variability in Wechsler Adult Intelligence Scale-IV subtest performance across age. Arch Clin Neuropsychol. 2012;27(4):389–397. Many studies have at least used some subtests of the WAIS IV including Digit Span forward and backward, Digit Symbols, and Vocabulary (for an estimate of verbal IQ).

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Western Aphasia Battery-Revised (WAB-R)
(New for Stroke)

Availability	Please visit this website for more information about the instrument: Western Aphasia Battery-Revised (WAB-R)
Classification	**Supplemental-Highly Recommended:** Stroke
Short Description of Instrument	The Western Aphasia Battery-Revised (WAB-R) assesses linguistic skills most frequently affected by aphasia, plus key nonlinguistic skills, and provides differential diagnosis information. Adaptable to various administration settings from hospital room to clinic, it provides a baseline level of performance to measure change over time. WAB-R is an individually administered assessment for adults with acquired neurological disorders (e.g., as a result of stroke, head injury, dementia). It classifies the type and severity of aphasia disorder (if present) and gives a clinically valid baseline for diagnosis, prognosis and research. **Age range:** 18 to 89 years **Completion time:** 30-45 minutes, additional 45-60 minutes for the reading, writing, praxis, and construction sections
Comments/Special Instructions	N/A
Scoring and Psychometric Properties	**Scoring:** The test provides a number of criterion cut scores. **Psychometric Properties:** High internal consistency measures and high test-retest reliability argue for stability of the test both because its parts contribute to the composite index and because of its temporal reliability. Inter- and intrajudge reliability are both very high, suggesting consistent scoring within and between scorers. The WAB satisfies face- and content-validity criteria. Results from the WAB and the *Neurosensory Center Comprehensive Examination for Aphasia* (NCCEA) highly correlate, indicating good construct validity. WAB AQ scores and Raven's *Coloured Progressive Matrices* scores significantly correlate, suggesting that the language portions of the WAB are not totally independent from nonverbal functioning. WAB AQ scores reliably differentiate between aphasic and control groups, with only a small overlap for high functioning anomic aphasic subjects.
References	Kertesz A. Western aphasia battery revised. San Antonio, TX: Harcourt Assessment. 2006. Shewan CM, Kertesz A. Reliability and validity characteristics of the Western Aphasia Battery (WAB). J Speech Hear Disord. 1980 Aug;45(3):308-24.

	Williamson DS, Richman M, Redmond SC. Applying the Correlation Between Aphasia Severity and Quality of Life Measures to a Life Participation Approach to Aphasia. Top Stroke Rehabil. 2015; 18(2):101-105.

Death (New for Stroke)

[*Study Name/ID pre-filled*] Site Name:

Subject ID:

1. Vital status* (choose one):

☐ Alive ☐ Dead

2. Date and Time of Death (m m /d d/ y y y y):

☐ am ☐ 24-hour clock

☐ pm

3. Date of final diagnosis (m m /d d/ y y y y):
4. Cause(s) of Death:

Table 1 Cause(s) of Death

Cause of Death (List primary cause first)	ICD-10-CM Code
Data to be filled out by site	Data to be filled out by site
Data to be filled out by site	Data to be filled out by site
Data to be filled out by site	Data to be filled out by site
Data to be filled out by site	Data to be filled out by site
Data to be filled out by site	Data to be filled out by site

5. Is the death a stroke according to the WHO definition?

☐ Yes ☐ No ☐ Unknown

6. Age at death (years):
7. Death location***:

☐ Home
☐ Home with hospice
☐ Inpatient hospice care
☐ Nursing home
☐ Hospital – inpatient stay
☐ Hospital – emergency room
☐ Other, specify:

Death CRF Instructions

General Instructions

This CRF Module is recommended to collect information on death for Stroke studies.

All elements on this CRF are classified as Supplemental, except for Vital Status* which is recommended as Disease Core and Death location*** which is recommended as Exploratory.

Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.

- Vital Status – Record the status of participant/subject as alive or dead
- Date and Time of Death – Record the date (and time) of death and verify with the death certificate if possible. The date/time should be recorded to the level of granularity known (e.g., year, year and month, complete date plus hours and minutes, etc.) and in the format acceptable to the study database. If uncertainty exists on the occurrence of death or date of death, confirm death and date of death using vital status search, such as the Social Security Death Index in the US.
- Date of final diagnosis – Enter the Date of participant's/subject's final clinical diagnosis.
- Cause(s) of Death – Record what the death certificate lists as the official cause of death.
- Death cause ICD-10-CM code - Record the cause or causes of death using explanatory text and the associated ICD-10-CM code. Include the primary cause of death first followed by any secondary causes.
- Is the event a stroke according to the WHO definition? – The indicator of whether the death is a stroke according to the WHO definition. World Health Organization definition = Rapidly developing clinical signs of focal, at times global, disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin.
- Age at death (years) – Enter the value of the subject/participant's age at death.
- Death location – Choose one.

Home Time (New for Stroke)

[Study Name/ID pre-filled]

Site Name:

Subject ID:

1. ***Length of time spent in own home or relative's home (days):

Home Time CRF Module Instructions

General Instructions

This CRF Module is recommended to collect information on time spent at home for subarachnoid hemorrhage (SAH) studies.

The element on this CRF is classified as Exploratory.

Specific Instructions

- Home Time: This has been shown to be significantly associated with post-stroke disability as measured by the Modified Rankin Scale, especially across the better recovery levels. Need for post-stroke in-patient rehabilitation factors into this outcome. It is reliable, less prone to inter-observer variability than conventional grading scales, and needs no formal training. As continuous outcome it offers powerful possibilities for statistical analysis. In addition, it can easily be understood by the patient or the public.

Reference

Quinn TC et al., Stroke. 2008 Jan;39(1):231-3. Epub 2007 Nov 21.

Return to Work (New for Stroke)

[Study Name/ID pre-filled]

Site Name:

Subject ID:

1. Type of occupation prior to stroke (four-digit code as defined by the ILO/ISCO):
2. Primary occupation prior to stroke *(Choose one)*:
   - ☐ Paid work (employed/self-employed, including military)
   - ☐ Homemaker
   - ☐ Student (including on the job training)
   - ☐ Retired (disability pension)
   - ☐ Retired (non-disability)
   - ☐ Unpaid work (volunteer)
   - ☐ Unemployed (none of the above)
   - ☐ Other, Specify
   - ☐ Unknown
3. Secondary occupation prior to stroke (Choose all that apply):
   - ☐ N/A
   - ☐ Paid work (employed/self-employed, including military)
   - ☐ Homemaker
   - ☐ Student (including on the job training)
   - ☐ Retired (disability pension)
   - ☐ Retired (non-disability)
   - ☐ Unpaid work (volunteer)
   - ☐ Unemployed (none of the above)
   - ☐ Other, Specify
   - ☐ Unknown
4. Workload prior to stroke (hours/week):
5. Type of paid occupation after stroke (four-digit code as defined by the ILO/ISCO):
6. Primary occupation after stroke *(Choose one)*:
   - ☐ Paid work (employed/self-employed, including military)
   - ☐ Homemaker
   - ☐ Student (including on the job training)
   - ☐ Retired (disability pension)
   - ☐ Retired (non-disability)
   - ☐ Unpaid work (volunteer)
   - ☐ Unemployed (none of the above)
   - ☐ Other, Specify
   - ☐ Unknown
7. Secondary occupation after stroke (Choose all that apply):
   - ☐ N/A
   - ☐ Paid work (employed/self-employed, including military)
   - ☐ Homemaker
   - ☐ Student (including on the job training)

Return to Work (New for Stroke)

[Study Name/ID pre-filled]

Site Name:

Subject ID:

- ☐ Retired (disability pension)
- ☐ Retired (non-disability)
- ☐ Unpaid work (volunteer)
- ☐ Unemployed (none of the above)
- ☐ Other, Specify
- ☐ Unknown

8. Returned to prior level of responsibilities at work:
   - ☐ Yes
   - ☐ No
   - ☐ Unknown
9. If no, explain why:
   - ☐ Reduced level of responsibilities ☐ Unemployed
   - ☐ Unknown
10. Workload after stroke (hours/week):

Return to Work CRF Module Instructions

General Instructions

This CRF contains data on returning to work that would be collected for a stroke study.

Important note: The data elements included on this CRF Module are considered Exploratory (should only be collected if the research team considers them appropriate for their study).

Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.

- Type of occupation: Enter the four-digit occupation code as defined by the International Labor Organization (ILO) and International Standard Classification of Occupations (ISCO)-08.
- Primary and secondary occupation before/after stroke: In patients with paid work before stroke, the exact type of occupation is defined using the International Standard Classification of Occupations (ISCO)-08 categories.
- Prior level of responsibilities at work: it is documented for patients that return to their previous occupation after stroke have fewer responsibilities as compared to the situation before stroke.