

NINDS/NICHD-NCMRR NeuroRehab CDE Project Motor Function Subgroup Summary

Teleconference meetings between subgroup members produced the consensus that the International Classification of Functioning, Disability and Health (ICF) would be a suitable taxonomy for Motor Function Common Data Elements (CDEs).

The ICF is a framework for describing and organizing information on functioning and disability. Using the ICF as the Motor Function CDE taxonomy provides a framework for describing and organizing information, standardized language, and a conceptual basis for the definition and measurement of health and disability, factors important for the development and review of Motor function data standards for NeuroRehab. (https://www.cdc.gov/nchs/data/icd/ICFOverview_FINALforWHO10Sept.pdf)

With the ICF taxonomy as guidance, the Motor Function subgroup aimed to identify measures that address the varying levels of functionality in subjects in neurorehabilitation trials, including impairment to body structure and function, impairment to activity, and impairment to participation.

It was determined by the subgroup that the ICF provides a common frame of reference for Motor Function researchers and peers and to guide future Motor Function development efforts. NeuroRehab Motor Function research areas such as Voluntary/Involuntary Motor Function, Motor Response, Motor Resistance, Postural Motor Function, and Sensory Motor Control/Perception need to be accurately captured by CDEs to produce the quality data needed to advance research and improve outcomes. It is the subgroup's intention that the ICF taxonomy guide future efforts of Motor Function CDEs. Early in the CDE selection process, the subgroup decided that after the selection of Motor Function instruments, appropriate ICF taxonomy levels will be assigned.

There is a separate subgroup for infants/pediatrics. Any measures that are exclusively infant/pediatric were forwarded to the Infant Pediatrics subgroup for their consideration.

The Motor Function subgroup focused on CDEs developed for primarily adult populations. Some of the measures included for recommendation have more validity and supportive data for certain disease areas or NeuroRehab populations. These factors were considered heavily during subgroup review and are captured within the Notice of Copyright documents for NeuroRehab Supplemental – Highly Recommended measures.

NeuroRehab CDE – Motor Function Subgroup Recommendations

The following instruments were selected for NeuroRehab Supplemental – Highly Recommended Classification within existing NINDS CDE subdomains:

Functional Outcomes Subdomain

- 10 Meter Timed Walk
- Box and Blocks Test of Manual Dexterity
- Timed Up and Go (TUG)

Physical Function Subdomain

- 2 Minute Walk Test
- 6 Minute Walk Test
- Borg Rating of Perceived Exertion (RPE) Scale

Trunk Control/Balance Subdomain

- Activities Specific Balance Confidence Scale (ABC-Scale)
- Berg Balance Scale (BBS)
- Mini-Balance Evaluation Systems Test (Mini-BESTest)

Future Recommendations and NINDS CDE Subdomain Resolution

Through review and discussion, the subgroup identified that the existing available NINDS CDE subdomains cannot effectively capture the contents from the NeuroRehab perspective and can only broadly define the recommended measures. The measures within these seven subdomains would effectively fall under the primary subdomain of Motor Function, requiring future expansion or additions to available list.

During the subgroup review of assigned NINDS CDE measures, subgroup members identified seven categories to accurately organize Motor Function measures for NeuroRehab.

- Walking Speed
- Walking Endurance
- Intensity of Physical Activity
- Functional Mobility
- Balance
- Upper Limb
- General Motor Function

The Project Guidance document allows for the inclusion of 3 measures per NINDS CDE NeuroRehab subdomain, and subgroup review placed these measures beyond the defined threshold. To retain measures assigned to the new subdomains for inclusion, measures were also assigned secondary NINDS CDE subdomains where appropriate, as recommended NeuroRehab Supplemental – Highly recommended measures.

An important concern for the Motor Function subgroup was that recommended measures are compatible with the ICF taxonomy. Each of these measures is labeled with the appropriate ICF level, below. It is the subgroup’s intention that the ICF taxonomy guide future efforts of Motor Function CDEs.

Test	Motor Function Subdomain	Secondary CDE Subdomains	ICF level
10-meter Timed Walk	Walking Speed	Performance Measures, Physical Function, Functional Outcomes	Activity – Capacity
Timed 25-foot Walk	Walking Speed	Performance Measures, Physical Function, Functional Outcomes	Activity – Capacity

Test	Motor Function Subdomain	Secondary CDE Subdomains	ICF level
6-minute Walk Test	Walking Endurance	Performance Measures, Physical Function, Functional Outcomes	Activity – Capacity
2-minute Walk Test	Walking Endurance	Performance Measures, Physical Function, Functional Outcomes	Activity – Capacity
Borg Rating of Perceived Exertion	Intensity of Physical Activity	Physical Function	Impairment– Self-perceived
Five Times Sit to Stand	Functional Mobility	Performance Measures, Physical Function, Functional Outcomes, Muscle Strength Testing	Activity – Capacity
Timed Up and Go	Functional Mobility	Performance Measures, Physical Function, Functional Outcomes	Activity – Capacity
Berg Balance Scale	Balance	Performance Measures, Physical Function, Functional Outcomes, Trunk Control/Balance	Activity – Capacity
Mini-BESTest	Balance	Performance Measures, Physical Function, Functional Outcomes, Trunk Control/Balance	Activity – Capacity
Activities Specific Balance Confidence Scale	Balance	Performance Measures, Physical Function, Functional Outcomes, Trunk Control/Balance	Self-efficacy Related to Activity Performance in Daily Life
Box and Blocks Test	Upper Limb	Performance Measures, Physical Function, Functional Outcomes	Activity – Capacity
Nine-Hole Peg Test	Upper Limb	Performance Measures, Physical Function, Functional Outcomes	Activity – capacity

Test	Motor Function Subdomain	Secondary CDE Subdomains	ICF level
PROMIS/Neuro-QOL Upper Extremity Domains	Upper Limb	Performance Measures, Physical Function, Functional Outcomes	Activity – Performance, Self-perceived.
PROMIS Mobility Domain	General Motor Function	Performance Measures, Physical Function, Functional Outcomes	Activity – Performance, Self-perceived.

The pre-existing subdomains are somewhat confusing and highly overlapping. The subgroup recommends that subdomain revision would be an important activity for future NeuroRehab Working Groups and the NINDS CDE Team at some point in the future. This process would serve to likely reduce the number of overlapping subdomains and to provide clear operational definitions.

Gap Outcome Measures/Instruments

The following measures were identified by the subgroup to be considered for future inclusion. Project Guidance allows for the inclusion of 3 measures per NINDS CDE NeuroRehab subdomain, and subgroup review placed these measures beyond the defined threshold.

- Timed 25-foot Walk
- Five Times Sit to Stand
- Nine-Hole Peg Test
- PROMIS/Neuro-QOL Upper Extremity Domains
- PROMIS Mobility Domain
- Fugl-Meyer Assessment

The following measures, with remarks below, are recommended for future consideration as they are not currently included with the existing NINDS CDEs:

- Wolf Motor Function Test – Widely used; only functional scale recommended here. Generates time, quality of movement, and strength-based scores. Needs some guidance about incomplete tasks, normalization, etc.
- SIS-hand – A 5-item hand subscale of the Stroke Impact Scale (SIS).
- Chedoke Arm and Hand Activity Inventory – The Chedoke Arm and Hand Activity Inventory (CAHAI) is a validated, upper-limb measure that uses a 7-point quantitative scale in order to assess functional recovery of the arm and hand after a stroke. The purpose of this measure is to evaluate the functional ability of the paretic arm and hand to perform tasks that have been identified as important by individuals following a stroke.