

NINDS CDE Project

Working group: long-term therapies

Completed by: George Wong

Date: September 29, 2016

Please answer the following questions below.

1. **Approach for selection of elements** (How did you go about drafting the recommendations and/or reviewing the current tools/instruments, and did you have any criteria for selection and classification?)

The selection of elements was derived from consensus of the expert panel of subcommittee members.

2. **Differential application to types of subarachnoid hemorrhage** (*Do the instruments/elements you recommended differ between the types of subarachnoid hemorrhage?*)

No.

3. Summary recommendations (We could consider a summary table OR each group could summarize their recommendations).

Instrument / Scale / CRF Name <i>Name and acronym of the instrument/measure that is recommended for inclusion in the CDEs</i>	Domain	Subdomain	Classification (e.g., Core, Supplemental - Highly Recommended, Supplemental, Exploratory)
Discharge Medications CRF	Disease/Injury Related Events	Discharge Information	Supplemental
Action Research Arm Test	Assessments and Examinations	General & Motor	Exploratory
Arm Motor Abilities Test	Assessments and Examinations	General & Motor	Exploratory
Berg Balance Scale	Assessments and Examinations	General & Motor	Exploratory
Chelsea Critical Care Physical Assessment Tool	Assessments and Examinations	General & Motor	Exploratory
de Morton Mobility Index (DEMMI): Elements	Assessments and Examinations	Hospital Care/Management	Exploratory
Fugl-Meyer Assessment	Assessments and Examinations	General & Motor	Exploratory
Functional Ambulation Categories	Assessments and Examinations	General & Motor	Exploratory
Functional Gait Assessment	Assessments and Examinations	General & Motor	Exploratory
Functional Independence Measure	Assessments and Examinations	General & Motor	Exploratory
London Handicap Scale	Assessments and Examinations	Hospital Care/Management	Exploratory
Mobilizing ICU Patients Safety Assessment	Assessments and Examinations	Hospital Care/Management	Exploratory

Overall Measurement Schema for ICU Acquired Weakness and Related Conditions	Assessments and Examinations	Hospital Care/Management	Exploratory
Physical Function ICU Test	Assessments and Examinations	General & Motor	Exploratory
Progressive Upright Mobility Protocol (PUMP) Plus	Assessments and Examinations	General & Motor	Exploratory
Reintegration to Normal Living	Assessments and Examinations	Hospital Care/Management	Exploratory
Rivermeade Mobility Index	Assessments and Examinations	General & Motor	Exploratory

4. **Comparison to other subarachnoid hemorrhage standards** (Are there any notable similarities/differences in the CDE recommendations as compared with other standards?)
No.

5. **Issues unique to subarachnoid hemorrhage disease** (Were there any issues encountered when developing the CDE standards which are unique to subarachnoid hemorrhage or which highlight a unique concern about subarachnoid hemorrhage data collection?)
The literature published in the field of subarachnoid hemorrhage is less and reporting standards are different among different studies.

6. **Unmet needs; unanswered questions** (What unmet need / unanswered questions were identified via the CDE process in subarachnoid hemorrhage? What areas are in need of further research and development?)
We considered that the non-uniformity is one of the reasons to hinder the reporting of data in the literature and therefore CDE recommendations are important for the development of future registries and clinical trials.