

## NINDS/NICHD-NCMRR NeuroRehab CDE Project Communication Subgroup Summary

The Communication subgroup reviewed existing NINDS CDE recommendations within the assigned subdomains: Deafness and Communication Disorders; Language; Language and Communication; Speech Language and Communication; Dysphagia. It was noted that dysphagia is not a construct within communication but would be within this subgroup’s purview. The primary focus was on outcome measures rather than patient descriptors.

The Chairs divided the measures for review into subdomain groups. Subgroup members were assigned measures for review based on their subject matter expertise. Reviewers were asked to rate the measures individually before conferring with others assigned to the same measures to reach a consensus on recommendations.

In addition to the NeuroRehab project instrument selection and classification criteria, the subgroup considered the following in their selection of instruments:

- patient/tester burden
- multidimensionality vs. unidimensionality
- practice effects
- use as a one-time assessment vs. use multiple times in longitudinal studies.

For this initial phase of the NeuroRehab CDE project, the working group was asked to identify existing NIH/NINDS CDEs within the Core and Supplemental – Highly Recommended classifications. Up to three Supplemental – Highly Recommended instruments/CRFs per subdomain could be recommended. The Supplemental and Exploratory classifications were out of scope. Any additional new CDEs, revisions to the subdomain structure, or recommendations within the Supplemental and Exploratory classifications would be considered gaps. The identified gap areas will help inform future phases of the NeuroRehab CDEs. The subgroups identified gap areas are discussed below.

The subgroup focused on recommendations for the adult population. A separate Infant Pediatrics subgroup was responsible for making recommendations for the pediatric population.

The subgroup recommended the following instruments as Supplemental – Highly Recommended within the indicated subdomains.

Subdomain	Instrument
Dysphagia	Huntington's Disease Dysphasia Scale
	Quality of Life in Swallowing Disorders (SWAL-QOL)
	Swallowing Disturbance Questionnaire (SDQ)
Speech	Acoustic Analysis of Speech
	Voice Handicap Index (VHI)
Language	Western Aphasia Battery Revised
Communication	Stroke and Aphasia Quality of Life-39 (SAQOL-39)

Issues unique to instrument selection in NeuroRehab include sensitivity to change, therapeutic response, repeated use of measures, and availability of multiple versions.

To date, CDEs related to Communication have been identified as part of disease- or condition-specific CDE projects only (e.g., TBI). No project to date has comprehensively identified and classified Communication CDEs. In addition, no project yet has identified and classified Communication CDEs using an appropriate theoretical paradigm. As a result, the existing set of Communication CDEs is limited in terms of scope and utility, likely affecting their use by the research community. The Communication subgroup of the NeuroRehab CDEs project recognizes this and highly recommends that NIH initiate a comprehensive Communication CDEs project to address these limitations.

For existing CDE projects, it is recommended that new sub-domains be established to classify existing Communication CDEs, as existing sub-domains are too general and/or redundant (e.g., "Deafness and Communication"; "Speech, Language, and Communication"; "Language and Communication"). New Communication sub-domains should represent the full range of Communication constructs while remaining understandable to researchers without expertise in Communication. Example sub-domains using a classification scheme based upon the American Speech-Language Hearing Association National Outcomes Measurement System are listed below:

- Cognitive-Communication
- Emergent Literacy
- Fluency
- Functional Reading
- Hearing
- Multi-Modal Functional Communication
- Pediatric Reading Comprehension
- Pragmatics
- Speech Intelligibility
- Spoken Language Comprehension
- Spoken Language Expression
- Voice
- Writing

In addition, it is recommended that "Swallowing/Feeding" be a separate sub-domain and Swallowing/Feeding CDEs not be categorized under "Communication" or similar sub-domains.