

Start-up Resource - NINDS NeuroRehab CDE Recommendations

The National Institute of Neurological Disorders and Stroke (NINDS) and other Federal agencies and international organizations have the common mission of developing data standards for clinical research. Through the efforts of subject-specific working groups, topic-driven data elements have been created. The first set of Common Data Elements (CDEs) for Rehabilitation Research in Neurological Disorders (NeuroRehab) was developed from 2020-2021, in partnership with the National Center for Medical Rehabilitation Research (NCMRR) of the National Institute of Child Health and Human Development (NICHD). The Core and Supplemental – Highly Recommended data elements to be used by an investigator when beginning a research study are listed in this resource document. Supplemental and Exploratory classifications were not utilized by the NeuroRehab CDE project.

Each CDE or instrument could be classified according to the definitions below:

General Core: A data element that is required for all NINDS funded studies.

NeuroRehab Core: A data element or measure that collects essential information applicable to all NeuroRehab clinical studies/trials across neurological disorders listed in the NINDS CDE Project. The NeuroRehab CDE Working Group subject matter experts assigned the NeuroRehab Core classification based on the criteria for selecting measurements. The NeuroRehab Core CDEs are a small subset of the available CDEs, restricted to those that the Working Group anticipated investigators would need to collect for any type of NeuroRehab clinical study. The NeuroRehab Core CDEs are required to be collected at a minimum for all NeuroRehab clinical studies. Some domains do not have any NeuroRehab Core CDEs.

NeuroRehab [Disease] Core: A data element or measure that collects essential information applicable to a specific neurological disorder that was developed by the NINDS CDE Project. The NeuroRehab [Disease] Core CDEs are recommended to be collected at a minimum when a NeuroRehab study is being conducted in a specific disease area. These data elements or measures followed the criteria for selecting measurements (reliability, validity, etc.). For example, all Stroke studies/trials must use at a minimum the NeuroRehab Stroke Core CDEs/instruments recommended for Stroke.

NeuroRehab Supplemental – Highly Recommended: A data element or measure which is considered essential based on certain conditions or study types in NeuroRehab clinical studies. Subject matter experts focused on selecting up to 3 CRF modules or instruments per subdomain within their subgroup. Following the criteria for selecting measurements, these data elements or measures are extensively validated and widely used. There are extensive psychometric properties reported (i.e., responsiveness, reliability) and evidence of use in several NeuroRehab studies. There is evidence of construct validity often using large samples and/or various supportive studies. These data elements are strongly recommended for NeuroRehab clinical studies depending on the disease area, study design, protocol or type of research involved. The NeuroRehab CDE project focused on the neurological diseases that are part of the NINDS CDE Project. Other neurological diseases and conditions identified by the subgroup are considered "gap areas". If appropriate, these data elements are also disease agnostic.



National Institute of Health (NIH) Resources:

The NINDS also strongly encourages researchers to use these NIH developed materials for NINDS-sponsored research, when appropriate. Utilization of these resources will enable greater consistency for NINDS-sponsored research studies. These tools are free of charge.

- NIH Toolbox
- Quality of Life in Neurological Disorders (Neuro-QOL)
- Patient-Reported Outcomes Measurement Information System (PROMIS)

Core CDEs for all NINDS Studies1:

Domain; Sub-Domain	CDE Name	CDE ID	Study Type
Participant Characteristics; Demographics	Birth date	C00007	All studies
Participant Characteristics; Demographics	Ethnicity USA category	C00020	All studies
Participant Characteristics; Demographics	Race USA category	C00030	All studies
Participant Characteristics; Demographics	Birth sex assigned type	C58676	All studies
Participant Characteristics; Demographics	Gender identity type	C58677	All studies
Participant Characteristics; Demographics	Medical history condition text	C00322	All studies
Participant Characteristics; Demographics	Medical history condition SNOMED CT code	C00313	All studies

Core CDEs for Infant Pediatric NeuroRehab Studies:

Domain; Subdomain	CDE Name	CDE ID
Participant Characteristics; Demographics	Education level primary caregiver USA type	C00013
Participant Characteristics; Demographics	Family income range	C00205
Participant Characteristics; Demographics	Health insurance type	C00226
Participant Characteristics; Demographics	Birth weight report value	C00311
Participant Characteristics; Demographics	Weight unit of measure	C01581
Participant Characteristics; Demographics	Household member total count	C13485
Participant Characteristics; Demographics	Health insurance other text	C18684
Participant Characteristics; Demographics	Gestational age value range	C21620

¹ Note: Education year count C00015 is no longer a general Core CDE



Core CDEs for NeuroRehab Studies:

Domain; Subdomain	CDE Name	CDE ID
Assessments and Examinations; General and Motor	Birth date	C00007
Assessments and Examinations; General and Motor	Medical history condition start date and time	C00317
Assessments and Examinations; General and Motor	Therapy or rehabilitation type	C05130
Assessments and Examinations; General and Motor	Data collected date and time	C06005
Assessments and Examinations; General and Motor	Data source	C08147
Assessments and Examinations; General and Motor	Ambulatory status	C14639
Assessments and Examinations; General and Motor	Site name	C17402
Assessments and Examinations; General and Motor	Data unknown text	C18153
Assessments and Examinations; General and Motor	Clinical trial name	C19126
Assessments and Examinations; General and Motor	Subject ID	C19247
Assessments and Examinations; General and Motor	Study protocol name	C19256
Assessments and Examinations; General and Motor	Assessment performed date	C19500
Assessments and Examinations; General and Motor	Neurological disorder indicator	C55575
Assessments and Examinations; General and Motor	Birth sex assigned type	C58676
Assessments and Examinations; General and Motor	Gender identity type	C58677

Supplemental – Highly Recommended CDEs for NeuroRehab studies:

Domain; Subdomain	CDE Name	CDE ID
Assessments and Examinations; General and Motor	Adverse event relatedness scale	C02304
Assessments and Examinations; General and Motor	Adverse event verbatim term text	C02307
Assessments and Examinations; General and Motor	Adverse event during study indicator	C02308
Assessments and Examinations; General and Motor	Serious adverse event indicator	C02309
Assessments and Examinations; General and Motor	Adverse event CTCAE low level term name	C02310
Assessments and Examinations; General and Motor	Adverse event MedDRA lower level term code	C02311
Assessments and Examinations; General and Motor	Hypertension indicator	C05454
Assessments and Examinations; General and Motor	Pain location anatomic site	C06059
Assessments and Examinations; General and Motor	Pain location indicator	C06060



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Assessments and Examinations; General and Motor Assessments and Examination Data; Devices Assessments and Examinations Colo712 Assessments and Examinations Data; Devices Assessments and Examinations Data; Devices Assessment Assessment Status Assessments and Examination Colo712 Assessments and Examinations Data; Devic	Assessments and Examinations; General and Motor	Diabetes mellitus medical history indicator	C53062
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Assessments and Examinations; General and Motor Gender identity type other text C58781 Treatment/Intervention Data; Devices Walking difficulty level status C10701 Treatment/Intervention Data; Devices Walking difficulty age support first needed value Treatment/Intervention Data; Devices Walking difficulty age permanent support started value C10706 Treatment/Intervention Data; Devices Walking difficulty age permanent support started value C10707 Treatment/Intervention Data; Devices Walking difficulty age permanent support started value C10708 Treatment/Intervention Data; Devices Walking assistive device indicator C10709 Treatment/Intervention Data; Devices Walking 1 cane use indicator C10710 Treatment/Intervention Data; Devices Walking cane use age started value C10711 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10714 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use age started value C10718 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator C10710 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721	Assessments and Examinations; General and Motor	Sleep problem diagnosis type	C57102
Treatment/Intervention Data; Devices Walking difficulty age support first needed value C10706 Treatment/Intervention Data; Devices Walking difficulty age permanent support started value C10707 Treatment/Intervention Data; Devices Wheelchair primary mobility means age value C10708 Treatment/Intervention Data; Devices Walking assistive device indicator C10709 Treatment/Intervention Data; Devices Walking 1 cane use indicator C10710 Treatment/Intervention Data; Devices Walking cane use age started value C10711 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value Treatment/Intervention Data; Devices Walker use indicator Treatment/Intervention Data; Devices Walker use indicator Treatment/Intervention Data; Devices Walker use age started value Treatment/Intervention Data; Devices Wheelchair use indicator Treatment/Intervention Data; Devices Wheelchair use age started value Treatment/Intervention Data; Devices Walking other assistive device use indicator Treatment/Intervention Data; Devices Walking other assistive device use age started value Treatment/Intervention Data; Devices Walking other assistive device use age started value Treatment/Intervention Data; Devices Walking other assistive device use age started value Treatment/Intervention Data; Devices Walking other assistive device use age started value	Assessments and Examinations; General and Motor	Birth sex assigned type other text	C58780
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Treatment/Intervention Data; Devices Walking difficulty level status C10701 Treatment/Intervention Data; Devices Walking own unable reason C10702 Treatment/Intervention Data; Devices Walking difficulty age support first needed value C10706 Treatment/Intervention Data; Devices Walking difficulty age permanent support started value C10707 Treatment/Intervention Data; Devices Wheelchair primary mobility means age value C10708 Treatment/Intervention Data; Devices Walking assistive device indicator C10709 Treatment/Intervention Data; Devices Walking 1 cane use indicator C10710 Treatment/Intervention Data; Devices Walking use 2 cane crutch indicator C10712 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10714 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Wheelchair use indicator C10718 Treatment/Intervention Data; Devices Wheelchair use indicator C10719 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721	Treatment/Intervention Data; Devices	Fall rate	C10697
Treatment/Intervention Data; Devices Walking own unable reason C10702 Treatment/Intervention Data; Devices Walking difficulty age support first needed value C10706 Treatment/Intervention Data; Devices Walking difficulty age permanent support started value C10707 Treatment/Intervention Data; Devices Walking assistive device indicator C10709 Treatment/Intervention Data; Devices Walking assistive device indicator C10709 Treatment/Intervention Data; Devices Walking 1 cane use indicator C10710 Treatment/Intervention Data; Devices Walking cane use age started value C10711 Treatment/Intervention Data; Devices Walking use 2 cane crutch indicator C10712 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use indicator C10719 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721	Treatment/Intervention Data; Devices	Sitting ability status	C10699
Treatment/Intervention Data; Devices Walking difficulty age support first needed value C10706 Treatment/Intervention Data; Devices Walking difficulty age permanent support started value C10707 Treatment/Intervention Data; Devices Wheelchair primary mobility means age value C10708 Treatment/Intervention Data; Devices Walking assistive device indicator C10709 Treatment/Intervention Data; Devices Walking 1 cane use indicator C10710 Treatment/Intervention Data; Devices Walking cane use age started value C10711 Treatment/Intervention Data; Devices Walking use 2 cane crutch indicator C10712 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use indicator C10718 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721	Treatment/Intervention Data; Devices	Walking difficulty level status	C10701
Treatment/Intervention Data; Devices Walking difficulty age permanent support started value C10707 Treatment/Intervention Data; Devices Wheelchair primary mobility means age value C10708 Treatment/Intervention Data; Devices Walking assistive device indicator C10709 Treatment/Intervention Data; Devices Walking 1 cane use indicator C10710 Treatment/Intervention Data; Devices Walking cane use age started value C10711 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use indicator C10719 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721	Treatment/Intervention Data; Devices	Walking own unable reason	C10702
Treatment/Intervention Data; Devices Wheelchair primary mobility means age value C10708 Treatment/Intervention Data; Devices Walking assistive device indicator C10719 Treatment/Intervention Data; Devices Walking 1 cane use indicator C10710 Treatment/Intervention Data; Devices Walking cane use age started value C10711 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use indicator C10718 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Walking difficulty age support first needed value	C10706
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Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Walking 1 cane use indicator Treatment/Intervention Data; Devices Walking cane use age started value C10711 Treatment/Intervention Data; Devices Walking use 2 cane crutch indicator Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use indicator C10718 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10722	Treatment/Intervention Data; Devices	Wheelchair primary mobility means age value	C10708
Treatment/Intervention Data; Devices Walking cane use age started value C10711 Treatment/Intervention Data; Devices Walking use 2 cane crutch indicator C10712 Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use indicator C10718 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Walking assistive device indicator	C10709
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Treatment/Intervention Data; Devices Walking cane or crutches pair use age started value C10713 Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Wheelchair use indicator C10715 Treatment/Intervention Data; Devices Wheelchair use age started value C10718 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Walking cane use age started value	C10711
Treatment/Intervention Data; Devices Walker use indicator C10714 Treatment/Intervention Data; Devices Walker use age started value C10715 Treatment/Intervention Data; Devices Wheelchair use indicator C10718 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Walking use 2 cane crutch indicator	C10712
Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Wheelchair use indicator Treatment/Intervention Data; Devices Wheelchair use age started value C10718 Treatment/Intervention Data; Devices Walking other assistive device use indicator Treatment/Intervention Data; Devices Walking other assistive device use age started value C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Walking cane or crutches pair use age started value	C10713
Treatment/Intervention Data; Devices Wheelchair use indicator C10718 Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Walker use indicator	C10714
Treatment/Intervention Data; Devices Wheelchair use age started value C10719 Treatment/Intervention Data; Devices Walking other assistive device use indicator Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Walker use age started value	C10715
Treatment/Intervention Data; Devices Walking other assistive device use indicator C10720 Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Wheelchair use indicator	C10718
Treatment/Intervention Data; Devices Walking other assistive device use age started value C10721 Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Wheelchair use age started value	C10719
Treatment/Intervention Data; Devices Walking primary assistive device daily use duration C10722	Treatment/Intervention Data; Devices	Walking other assistive device use indicator	C10720
	Treatment/Intervention Data; Devices	Walking other assistive device use age started value	C10721
Treatment/Intervention Data; Devices Position device use indicator C12673	Treatment/Intervention Data; Devices	Walking primary assistive device daily use duration	C10722
	Treatment/Intervention Data; Devices	Position device use indicator	C12673



Domain; Subdomain	CDE Name	CDE ID
Treatment/Intervention Data; Devices	Mobility device use indicator	C12679
Treatment/Intervention Data; Devices	Orthosis use indicator	C12682
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Treatment/Intervention Data; Devices	Therapy or rehabilitation received status	C14286
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Domain; Subdomain	CDE Name	CDE ID
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Treatment/Intervention Data; Devices	Therapy rehabilitation session other text	C19066
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Treatment/Intervention Data; Devices	Discipline types	C19140
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Treatment/Intervention Data; Devices	Fall details assistive device type	C21639
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Treatment/Intervention Data; Devices	Back brace indicator	C21654
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Treatment/Intervention Data; Devices	Communication device new provide indicator	C22609
Treatment/Intervention Data; Devices	Communication device type	C22610
Treatment/Intervention Data; Devices	Communication device other text	C22611
Treatment/Intervention Data; Devices	Home modification provide indicator	C22612
Treatment/Intervention Data; Devices	Home modification durable medical equipment type	C22613
Treatment/Intervention Data; Devices	Home medical equipment other text	C22614
Treatment/Intervention Data; Devices	Gross Motor Function Classification System (GMFCS) - Level scale	C22899



Domain; Subdomain	CDE Name	CDE ID
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Treatment/Intervention Data; Devices	Physical therapy adaptive equipment orthotic session type	C22908
Treatment/Intervention Data; Devices	Physical therapy orthoses type	C22911
Treatment/Intervention Data; Devices	Walker use type	C56951
Treatment/Intervention Data; Devices	Crutch use type	C56952
Treatment/Intervention Data; Devices	Cane stick use type	C56953
Treatment/Intervention Data; Devices	Dynamic upper extremity orthosis splint use frequency type	C56954
Treatment/Intervention Data; Devices	Transfer transportation device use indicator	C58470
Treatment/Intervention Data; Devices	ADL device use indicator	C58471
Treatment/Intervention Data; Devices	Mobility device use frequency type	C58473
Treatment/Intervention Data; Devices	Mobility device use distance type	C58474
Treatment/Intervention Data; Devices	Mobility device use location type	C58475
Treatment/Intervention Data; Devices	Mobility device use location type other text	C58476
Treatment/Intervention Data; Devices	Cane stick use laterality type	C58477
Treatment/Intervention Data; Devices	Orthosis laterality type	C58479
Treatment/Intervention Data; Devices	AFO type	C58480
Treatment/Intervention Data; Devices	Dynamic upper extremity orthosis splint use anatomic site	C58481
Treatment/Intervention Data; Devices	Static upper extremity orthosis splint use frequency type	C58482
Treatment/Intervention Data; Devices	Static upper extremity orthosis splint use anatomic site	C58483
Treatment/Intervention Data; Devices	Dynamic lower extremity stretch orthosis splint use frequency type	C58484
Treatment/Intervention Data; Devices	Dynamic lower extremity stretch orthosis splint use anatomic site	C58485
Treatment/Intervention Data; Devices	Static lower extremity stretch orthosis splint use frequency type	C58486
Treatment/Intervention Data; Devices	Static lower extremity stretch orthosis splint use anatomic site	C58487



Domain; Subdomain	CDE Name	CDE ID
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Treatment/Intervention Data; Devices	Position device type other text	C58490
Treatment/Intervention Data; Devices	Activity daily living device type	C58491
Treatment/Intervention Data; Devices	Bath device type	C58492
Treatment/Intervention Data; Devices	Activity Daily Living device type other text	C58493
Treatment/Intervention Data; Devices	Bath device type other text	C58494
Treatment/Intervention Data; Devices	Toilet device type	C58495
Treatment/Intervention Data; Devices	Toilet device type other text	C58496
Treatment/Intervention Data; Devices	Transfer transportation device type	C58497
Treatment/Intervention Data; Devices	Transfer transportation device type other text	C58498
Treatment/Intervention Data; Devices	Transfer device type	C58499
Treatment/Intervention Data; Devices	Transportation device type other text	C58500
Treatment/Intervention Data; Devices	Transportation device type	C58501
Treatment/Intervention Data; Devices	Communication devices category type	C58502
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Treatment/Intervention Data; Devices	Speak communication device type other text	C58505
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Treatment/Intervention Data; Devices	Android application text	C58507
Treatment/Intervention Data; Devices	Dedicate speech generating device manufacturer name	C58508
Treatment/Intervention Data; Devices	Dedicate speech generating device name	C58509
Treatment/Intervention Data; Devices	Nonspeak communication device type	C58510
Treatment/Intervention Data; Devices	Nonspeak communication device type other text	C58511
Treatment/Intervention Data; Devices	Access communication device type	C58512
Treatment/Intervention Data; Devices	Access communication device type other text	C58513
Treatment/Intervention Data; Devices	Dynamic upper extremity orthosis splint frequency use laterality type	C58567
Treatment/Intervention Data; Devices	Dynamic upper extremity orthosis splint use anatomic site laterality type	C58568
Treatment/Intervention Data; Devices	Static upper extremity orthosis splint frequency use laterality type	C58569



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Treatment/Intervention Data; Devices Eat drink assistive device type other text C58578 Treatment/Intervention Data; Devices Mobility device use propel type C58617 Treatment/Intervention Data; Devices Mobility device use propel type other text C58618 Treatment/Intervention Data; Devices Truncal support device type C58619 Treatment/Intervention Data; Devices Truncal support device type other text C58620 Treatment/Intervention Data; Devices Truncal support device type other text C58620 Treatment/Intervention Data; Devices Stand time use type C58621 Treatment/Intervention Data; Devices Number minutes day duration C58622 Treatment/Intervention Data; Devices Number days week count C58623 Treatment/Intervention Data; Devices Transfer transportation device type use indicator C58624 Treatment/Intervention Data; Devices Tre	Treatment/Intervention Data; Devices	Activity daily living device type use indicator	C58575
Treatment/Intervention Data; Devices Mobility device use propel type C58617 Treatment/Intervention Data; Devices Mobility device use propel type other text C58618 Treatment/Intervention Data; Devices Truncal support device type C58619 Treatment/Intervention Data; Devices Truncal support device type other text C58620 Treatment/Intervention Data; Devices Stand time use type C58621 Treatment/Intervention Data; Devices Number minutes day duration C58622 Treatment/Intervention Data; Devices Number days week count C58623 Treatment/Intervention Data; Devices Transfer transportation device type use indicator C58624 Treatment/Intervention Data; Devices Communication device type use indicator C58625 Treatment/Intervention Data; Devices Transfer device type other text C58626 Treatment/Intervention Data; Devices Crutch use laterality type C58630 Treatment/Intervention Data; Devices Position device type use indicator C58631 Treatment/Intervention Data; Devices Therapy or rehabilitation received status other text C58875 Treatment/Intervention Data; Devices Assistive device use indicator C58879 Treatment/Intervention Data; Devices Assistive device type C58880	Treatment/Intervention Data; Devices	Eat drink assistive device type	C58577
Treatment/Intervention Data; Devices Mobility device use propel type other text C58618 Treatment/Intervention Data; Devices Truncal support device type C58619 Treatment/Intervention Data; Devices Truncal support device type other text C58620 Treatment/Intervention Data; Devices Stand time use type C58621 Treatment/Intervention Data; Devices Number minutes day duration C58622 Treatment/Intervention Data; Devices Number days week count C58623 Treatment/Intervention Data; Devices Transfer transportation device type use indicator C58624 Treatment/Intervention Data; Devices Communication device type use indicator C58625 Treatment/Intervention Data; Devices Transfer device type other text C58626 Treatment/Intervention Data; Devices Crutch use laterality type C58630 Treatment/Intervention Data; Devices Position device type use indicator C58631 Treatment/Intervention Data; Devices Position device type another body part specify text Treatment/Intervention Data; Devices Therapy or rehabilitation received status other text C58875 Treatment/Intervention Data; Devices Assistive device use indicator C58879 Treatment/Intervention Data; Devices Assistive device type C58880	Treatment/Intervention Data; Devices	Eat drink assistive device type other text	C58578
Treatment/Intervention Data; Devices Truncal support device type Treatment/Intervention Data; Devices Therapy or rehabilitation received status other text C58879 Treatment/Intervention Data; Devices Assistive device use indicator C58880	Treatment/Intervention Data; Devices	Mobility device use propel type	C58617
Treatment/Intervention Data; Devices Therapy or rehabilitation received status other text C58875 Treatment/Intervention Data; Devices Assistive device use indicator C58880	Treatment/Intervention Data; Devices	Mobility device use propel type other text	C58618
Treatment/Intervention Data; Devices Treatment/I	Treatment/Intervention Data; Devices	Truncal support device type	C58619
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Treatment/Intervention Data; Devices Assistive device use indicator C58625 Treatment/Intervention Data; Devices Assistive device type C58630 Treatment/Intervention Data; Devices Assistive device type C58632	Treatment/Intervention Data; Devices	Stand time use type	C58621
Treatment/Intervention Data; Devices Assistive device use indicator C58624 C58625 Communication device type use indicator C58630 Access communication device type another body part specify text C58632 Treatment/Intervention Data; Devices Therapy or rehabilitation received status other text C58875 Treatment/Intervention Data; Devices Assistive device use indicator C58880	Treatment/Intervention Data; Devices	Number minutes day duration	C58622
Treatment/Intervention Data; Devices Assistive device use indicator Treatment/Intervention Data; Devices Treatment/Interve	Treatment/Intervention Data; Devices	Number days week count	C58623
Treatment/Intervention Data; Devices Assistive device use indicator Treatment/Intervention Data; Devices	Treatment/Intervention Data; Devices	Transfer transportation device type use indicator	C58624
Treatment/Intervention Data; Devices Crutch use laterality type C58630 Treatment/Intervention Data; Devices Position device type use indicator C58631 Treatment/Intervention Data; Devices Access communication device type another body part specify text Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Assistive device use indicator Treatment/Intervention Data; Devices Assistive device type C58880	Treatment/Intervention Data; Devices	Communication device type use indicator	C58625
Treatment/Intervention Data; Devices Position device type use indicator C58631 Access communication device type another body part specify text Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Assistive device use indicator Treatment/Intervention Data; Devices Assistive device type C58880	Treatment/Intervention Data; Devices	Transfer device type other text	C58626
Treatment/Intervention Data; Devices Access communication device type another body part specify text Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Assistive device use indicator Treatment/Intervention Data; Devices Assistive device type C58880	Treatment/Intervention Data; Devices	Crutch use laterality type	C58630
Treatment/Intervention Data; Devices Specify text Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Treatment/Intervention Data; Devices Assistive device use indicator Treatment/Intervention Data; Devices Assistive device type C58880	Treatment/Intervention Data; Devices	Position device type use indicator	C58631
Treatment/Intervention Data; Devices Assistive device use indicator C58879 Treatment/Intervention Data; Devices Assistive device type C58880	Treatment/Intervention Data; Devices	7.	C58632
Treatment/Intervention Data; Devices Assistive device type C58880	Treatment/Intervention Data; Devices	Therapy or rehabilitation received status other text	C58875
	Treatment/Intervention Data; Devices	Assistive device use indicator	C58879
Treatment/Intervention Data; Devices Assistive device other text C58882	Treatment/Intervention Data; Devices	Assistive device type	C58880
	Treatment/Intervention Data; Devices	Assistive device other text	C58882



Domain; Subdomain	CDE Name	CDE ID
Treatment/Intervention Data; Devices	Walking primary assistive device daily use duration not	C59011
Treatment, intervention bata, bevices	applicable status	C33011

General Core for all Studies:

Investigators should review the FDA's "Guidance for Industry: Suicidal Ideation and Behavior: Prospective Assessment of Occurrence in Clinical Trials" for the most up-to-date information about suicidal ideation and behavior. One scale that FDA suggests is the Columbia Suicide Severity Rating Scale (C-SSRS) (available at Columbia Suicide Severity Rating Scale Website).

NeuroRehab Core Pediatric Instruments:

- 1. Pediatric Quality of Life Inventory (PedsQL) (ages 2-18)
- 2. Strengths and Difficulties Questionnaire (SDQ), combined Full and Followup versions (ages 3-16)

NeuroRehab Sport Related Concussion Core Instruments:

- 1. Immediate Post-Concussion Assessment and Cognitive Testing (imPACT)
- 2. Post Concussion Symptom Scale

NeuroRehab Stroke Core Instrument:

1. NIH Stroke Scale (NIHSS)

NeuroRehab Supplemental – Highly Recommended Instruments:

- 1. 10 Meter Timed Walk
- 2. 2 Minute Walk Test
- 3. 6 Minute Walk Test
- 4. Acoustic Analysis of Speech
- 5. Activities Specific Balance Confidence Scale (ABC-Scale)
- 6. Alcohol Use Disorders Identification Test: Self-Report Version (AUDIT)
- 7. Alcohol, Smoking, and Substance Use Involvement Screening Test (ASSIST)
- 8. Animal Naming
- 9. Apathy Evaluation Scale
- 10. Apathy Scale (AS)
- 11. Assessment of Intelligibility of Dysarthric Speech (AIDS)
- 12. Assessment of Life Habits (Life-H)
- 13. Barthel Index
- 14. Beck Anxiety Inventory (BAI)



- 15. Beck Depression Inventory II (BDI-II)
- 16. Berg Balance Scale (BBS)
- 17. Borg Rating of Perceived Exertion (RPE) Scale
- 18. Boston Naming Test (BNT) 30-item version
- 19. Box and Blocks Test of Manual Dexterity
- 20. Brief Pain Inventory (Short Form)
- 21. Brief Symptom Inventory-18 (BSI-18)
- 22. Brief Test of Adult Cognition by Telephone (BTACT)
- 23. Brief Visuospatial Memory Test Revised (BVMT-R)
- 24. Center for Epidemiologic Studies-Depression Scale (CES-D)
- 25. Columbia Suicide Severity Rating Scale (C-SSRS)
- 26. Composite Autonomic Symptom Scale
- 27. Controlled Oral Word Association Test (COWAT) Subtest of the Multilingual Aphasia Examination (MAE)
- 28. Five-Point Test (5-PT)
- 29. Frontal Behavioral Inventory (FBI)
- 30. Frontal Systems Behavioral Scale (FrSBe)
- 31. Fugl-Meyer Assessment
- 32. Functional Gait Assessment
- 33. Functional Independence Measure
- 34. Functional Independence Measure Cognition Subscale (Cog-FIM)
- 35. Galveston Orientation and Amnesia Test (GOAT)
- 36. Generalized Anxiety Disorder (GAD-7)
- 37. Glasgow Coma Scale (GCS)
- 38. Grooved Pegboard Test
- 39. Hamilton Anxiety Rating Scale (HAM-A)
- 40. Hamilton Depression Rating Scale (HDRS)
- 41. HDQLIFE
- 42. Headache Impact Test-6 (HIT-6)
- 43. Hopkins Verbal Learning Test Revised (HVLT-R)
- 44. Hospital Anxiety and Depression Scale (HADS)
- 45. Huntington's Disease Dysphasia Scale
- 46. Impact of Event Scale (IES)
- 47. JFK Coma Recovery Scale- Revised
- 48. Judgment of Line Orientation (Benton JLO)



- 49. Letter-Number Sequencing Subtest
- 50. Medical Symptom Validity Test (MSVT)
- 51. Mini-Balance Evaluation Systems Test (Mini-BESTest)
- 52. Mini-Mental State Examination (MMSE)
- 53. Montreal Cognitive Assessment (MoCA)
- 54. Myotonic Dystrophy Health Index (MDHI)
- 55. Neuro-QOL Adult Bank Sleep Disturbance
- 56. NIH Toolbox Emotional Battery
- 57. NIH Toolbox Cognitive Battery
- 58. NIH Toolbox Flanker Inhibitory Control Attention Test
- 59. Parkinson's Disease Quality of Life Scale (PDQUALIF)
- 60. Patient Health Questionnaire 9 (PHQ-9) Depression Scale
- 61. Patient-Reported Outcomes Measurement Information System (PROMIS)
- 62. Processing Speed Index of the Wechsler Adult Intelligence Scale-Fourth Edition (WAIS-IV)
- 63. PROMIS Scale v1.2 Global Health
- 64. PROMIS v2.0 Satisfaction With Social Roles and Activities
- 65. PROMIS-29 Profile
- 66. PROMIS Ability to Participate Item Bank and Short Forms (PROMIS Item Bank v2.0 Ability to Participate in Social Roles and Activities; PROMIS Short Form v2.0 Ability to Participate in Social Roles and Activities 4a; PROMIS Short Form v2.0 Ability to Participate in Social Roles and Activities 6a; PROMIS Short Form v2.0 Ability to Participate in Social Roles and Activities 8a)
- 67. PROMIS Alcohol Use Item Banks (PROMIS Bank v1.0 Alcohol Negative Expectancies)
- 68. PROMIS Anxiety Item Bank (PROMIS Bank v1.0 Anxiety)
- 69. PROMIS Cognitive Function Item Banks (PROMIS Bank v2.0 Cognitive Function; PROMIS Bank v2.0 Cognitive Function Abilities)
- 70. PROMIS Depression Item Bank (PROMIS Bank v1.0 Depression)
- 71. PROMIS Dyspnea Item Banks (PROMIS Bank v1.0 Dyspnea Functional Limitations)
- 72. PROMIS Pain Behavior Item Bank and Short Form (PROMIS Bank v2.0 Pain Behavior)
- 73. PROMIS Pain Interference Item Bank (PROMIS Bank v1.1 Pain Interference)
- 74. PROMIS Self-Efficacy for Managing Chronic Conditions Item Bank (PROMIS Bank v1.0 Self-Efficacy for Managing Emotions)
- 75. PROMIS Sleep Item Banks (PROMIS Bank v1.0 Sleep Disturbance; PROMIS Bank v1.0 Sleep-Related Impairment)
- 76. PTSD Checklist for DSM-5 (PCL-5)
- 77. Quality of Life in Neurological Disorders (Neuro-QOL)
- 78. Quality of Life in Swallowing Disorders (SWAL-QOL)
- 79. Repeatable Battery for Assessment of Neuropsychological Status (RBANS)
- 80. Rey Auditory Verbal Learning Test (RAVLT)



- 81. Rey-Osterrieth Complex Figure Test (ROCF)
- 82. Rivermead Post-Concussive Symptoms Questionnaire (RPQ)
- 83. Short Form 36-Item Health Survey (SF-36)
- 84. Spinal Cord Injury Quality of Life (SCI-QOL)
- 85. Stroke and Aphasia Quality of Life-39 (SAQOL-39)
- 86. Stroop Test
- 87. Structured Clinical Interview for DSM-5 Axis I Disorders Research Version (SCID-5-RV)
- 88. Swallowing Disturbance Questionnaire (SDQ)
- 89. Symbol Digit Modalities Test
- 90. Telephone Interview for Cognitive Status (TICS)
- 91. Test of Memory Malingering (TOMM)
- 92. Test of Premorbid Functioning
- 93. Timed Up and Go (TUG)
- 94. Token Test
- 95. Trail Making Test
- 96. Traumatic Brain Injury Quality of Life (TBI-QOL)
- 97. Victoria Symptom Validity Test (VSVT)
- 98. Voice Handicap Index (VHI)
- 99. Wechsler Adult Intelligence Scale Fourth Edition (WAIS-IV)
- 100. Wechsler Adult Intelligence Scale-Fourth Edition (WAIS-IV) Digit Span Subtest
- 101. Western Aphasia Battery Revised
- 102. Word Reading Subtest of the Wide Range Achievement Test (WRAT-4)
- 103. World Health Organization Quality of Life Assessment (WHOQOL-BREF)

For the complete list of NINDS CDE recommendations for NeuroRehab, please see the NINDS CDE website.