

Neuromuscular Disease CDE Revision History Document

Contents

April 2025 Revisions.....	2
September 2024 Revisions.....	2
August 2022 Revisions	3
January 2020 Revisions	3
April 2015 Revisions.....	3
March 2015 Revisions.....	3
February 2015 Revisions.....	4
January 2015 Revisions	4
November 2014 Revisions	4
September 2014 Revisions.....	4
August 2014 Revisions	4
July 2014 Revisions	4
June 2014 Revisions.....	4
May 2014 Revisions	4
April 2014 Revisions.....	4
March 2014 Revisions.....	4
February 2014 Revisions.....	4
January 2014 Revisions	5
Overview	5
Form Status Changes:	5
December 2013 Revisions.....	13
September 2013 Revisions.....	13
Overview	13
Form Status Changes:	13
Detailed Form Revisions:	13

Neuromuscular Disease CDE Revision History Document

April 2025 Revisions

The Notices of Copyright were updated on the NMD Data Standards webpage in the following Outcome and Endpoints Domain; Subdomains:

- Outcomes and Endpoints; Functional Outcomes Domain; Subdomain
 - Stair Climb

September 2024 Revisions

The Notices of Copyright were updated on the NMD Data Standards webpage in the following Outcome and Endpoints Domain; Subdomains:

- Outcomes and Endpoints; Assessing Comorbidities Domain; Subdomain
 - Child Health Questionnaire (CHQ)
- Outcomes and Endpoints; Emotional and Cognitive Status Domain; Subdomain
 - McGill Pain Questionnaire (MPQ)
- Outcomes and Endpoints; Functional Outcomes Domain; Subdomain
 - 10 Meter Timed Walk
 - 6 Minute Walk Test
 - Barthel Index
 - Jebsen-Taylor Hand Function Test
 - Purdue Pegboard
 - Timed Up and Go (TUG)
- Outcomes and Endpoints; Muscle Strength Testing Domain; Subdomain
 - Pinch Strength
 - Manual Muscle Testing-Using the Medical Research Council Muscle Grading
 - Maximum Voluntary Isometric Contraction (MVIC)
- Outcomes and Endpoints; Other Non-Motor Domain; Subdomain
 - Quantitative Sudomotor Axon Reflex Test (QSART)
- Outcomes and Endpoints; Pediatric Domain; Subdomain
 - Bayley Scales of Infant Development (Bayley III, BSID)
 - Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery VMI)
 - California Verbal Learning Test - Children (CVLT-C)
 - Child Behavior Checklist (CBCL)
 - Clinical Evaluation of Language Fundamentals - Fifth Edition (CELF-5)
 - Comprehensive Test of Phonological Processing (CTOPP)
 - Mullen Scales of Early Learning (MSEL)
 - Peabody Picture Vocabulary Test 4th Edition (PPVT-4)
 - Pediatric Evaluation of Disability Inventory (PEDI)
 - Social Communication Questionnaire (SCQ)
 - Social Skills Rating Scale (SSRS)

Neuromuscular Disease CDE Revision History Document

- Tasks of Executive Control (TEC)
- Wechsler Abbreviated Scale of Intelligence (WASI)
- Wechsler Intelligence Scale for Children-V (WISC-V)
- Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III)
- Wide Range Assessment of Memory and Learning, Second Edition (WRAML-2)
- Woodcock-Johnson III Test of Cognitive Abilities
- Outcomes and Endpoints; Quality of Life/Patient Reported Outcomes Domain; Subdomain
 - EuroQoL-5 Dimension Questionnaire (EQ-5D)
 - Nottingham Health Profile (NHP)
 - Quality of Life in Neurological Disorders (Neuro-QOL)
 - Short Form 36-Item Health Survey (SF-36)
- The following updates were made to the Neuromuscular Disease Highlight Summary Document
 - The Notice of Copyright, Test for Executive Control (TEC), was corrected to Tasks of Executive Control.
 - The Notice of Copyright, Nottingham Health Profile (NHP), was added to the Outcomes and Endpoints Domain; Subdomain Quality of Life/ Patient Reported Outcomes as Supplemental.

August 2022 Revisions

- The CDE C00311 Birth weight report value was removed from the Prenatal and Perinatal History CRF and replaced with CDE C59019 Birth weight measurement. CDE C59019 classified as Supplemental.

January 2020 Revisions

- General Core CRF updated to replace 'Gender' question with 'Sex assigned at birth' and 'Gender identity'.
- Two new CDEs added to CRF: C58676 (Sex assigned at birth) and C58677 (Gender identity). C00035 has been removed
- Start-Up document updated to reflect these changes.

April 2015 Revisions

No changes.

March 2015 Revisions

- Revised the classification of 6 NOCs in NMD to reflect the correct classifications.
- The Start-Up Resource Listings were revised for NMD.

Neuromuscular Disease CDE Revision History Document

February 2015 Revisions

No changes.

January 2015 Revisions

- Posting of revised 508 compliant Start-Up and Highlight Summaries.
- Addition of Dr. Glen Nuckolls and removal of Dr. John Porter to the NMD Acknowledgments page.

November 2014 Revisions

No changes.

September 2014 Revisions

- Social Communication Questionnaire was moved to be under the Pediatric Subdomain in NMD.

August 2014 Revisions

No changes.

July 2014 Revisions

- Updates to the History and Acknowledgements rosters.

June 2014 Revisions

- The Committee Roster Reports in NMD were updated so that all committee members and the NINDS CDE team appear in the correct order.

May 2014 Revisions

No changes.

April 2014 Revisions

No changes.

March 2014 Revisions

No changes.

February 2014 Revisions

No changes.

Neuromuscular Disease CDE Revision History Document

January 2014 Revisions

Overview

There have been major changes to the content and structure of the Neuromuscular Disease (NMD) CDE materials in version 2.0 compared to 1.0, including the following:

Form Status Changes:

New Forms:

- Child Health Questionnaire (CHQ)
- Social Communication Questionnaire (SCQ)
- 10 Meter Timed Walk
- 6 Minute Walk Test
- Barthel Index
- Grip Strength
- Jebsen-Taylor Hand Functioning Test
- Purdue Pegboard
- Timed Up and Go (TUG)
- Manual Muscle Testing-Using the Medical Research Council (MRC) Grading Scale
- Maximum Voluntary Isometric Contraction Testing (MVIC)
- Quantitative Sudomotor Axon Reflex Test (QSART)
- Bayley Scales of Infant Development (BSID)
- Beery-Buktencia Developmental Test of Visual-Motor Integration (Berry VMI)
- Behavioral Rating Inventory of Executive Function (BRIEF)
- California Verbal Learning Test-Children (CVLT-C)
- Child Behavior Checklist (CBCL)
- Clinical Evaluation of Language Fundamentals (CELF-4)
- Comprehensive Test of Phonological Processing

Neuromuscular Disease CDE Revision History Document

- Mullen Scales of Early Learning (MSEL)
- Peabody Picture Vocabulary Test 4th Edition (PPVT-4)
- Social Skills Rating Scale (SSRS)
- Test of Executive Control (TEC)
- Wechsler Abbreviated Scale of Intelligence (WASI)
- Wechsler Intelligence Scale for Children-IV (WISC-IV)
- Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III)
- Wide Range Assessment of Memory and Learning-Second Edition (WRAML-2)
- Woodcock-Johnson III Normative Update Tests of Cognitive Intelligence (WJU III NU)
- Short Form-36 Health Survey (SF-36)
- Nottingham Health Profile (NHP)
- Quality of Life in Neurological Disorders (Neuro-QOL)

Updated Forms:

- None

Removed Forms:

- None

1 Neuromuscular Disease CDE Revision History Table

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Child Health Questionnaire (CHQ)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Social Communication Questionnaire (SCQ)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
10 Meter Timed Walk	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
6 Minute Walk Test	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Barthel Index	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Grip Strength	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Jebsen-Taylor Hand Functioning Test	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Purdue Pegboard	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Timed Up and Go (TUG)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Manual Muscle Testing-Using the Medical Research Council (MRC) Grading Scale	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Maximum Voluntary Isometric Contraction Testing (MVIC)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Quantitative Sudomotor Axon Reflex Test (QSART)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Bayley Scales of Infant Development (BSID)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Beery- Buktencia Developmental Test of Visual- Motor Integration (Berry VMI)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Behavioral Rating Inventory of Executive Function (BRIEF)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
California Verbal Learning Test-Children (CVLT-C)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Child Behavior Checklist (CBCL)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Clinical Evaluation of Language Fundamentals (CELF-4)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Comprehensive Test of Phonological Processing	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Mullen Scales of Early Learning (MSEL)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Peabody Picture Vocabulary Test 4 th Edition (PPVT-4)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Social Skills Rating Scale (SSRS)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Test of Executive Control (TEC)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Wechsler Abbreviated Scale of Intelligence (WASI)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Wechsler Intelligence Scale for Children-IV (WISC-IV)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Wide Range Assessment of Memory and Learning- Second Edition (WRAML-2)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Woodcock- Johnson III Normative Update Tests of Cognitive Intelligence (WJU III NU)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Short Form-36 Health Survey (SF-36)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Nottingham Health Profile (NHP)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form
Quality of Life in Neurological Disorders (Neuro-QOL)	2.0	1.0	Major	Notice of Copyright	A Notice of Copyright was created for this form and will replace the existing form

Neuromuscular Disease CDE Revision History Document

December 2013 Revisions

- Updated highlight summaries and start-up resource documents for NMD.

September 2013 Revisions

Overview

The NINDS website has recently expanded to incorporate four new diseases that were previously listed as sub-diseases of Neuromuscular Disease. Neuromuscular Disease will no longer list these as sub-diseases and will function independently as a new disease area.

A Start-up Resource Listing was added to the Neuromuscular Disease area to provide investigators with a set of CORE data elements to be used during a research study.

Form Status Changes:

New Forms:

- None

Updated Forms:

- None

Removed Forms:

- None

Detailed Form Revisions:

Additional specific changes to the CRF modules are detailed in the table included below.

Neuromuscular Disease CDE Revision History Document

2 Neuromuscular CDE Revision History Table

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Demographics	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Social Status	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Family History	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Medical History	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Prenatal and Perinatal History	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Surgical History	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Medical History of NMD	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Physical Examination	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Polysomnography	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Vital Signs	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Biomarkers Sample Data Guidelines	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Biospecimen Collection Guidelines for Use	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Fat Aspirate Tissue Specimens	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Gene Table and Guidelines for Use	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Laboratory Tests and Tracking	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Laboratory Tests Recommendations Table and Guidelines for Use	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Muscle Biopsy and Autopsy Tissue	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Mutation Analysis	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Nerve Biopsy	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Skin Biopsies for Qualification of Intraepidermal Nerve Fibers	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Brain Magnetic Resonance Imaging (MRI)	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Cardiac Magnetic Resonance Imaging (MRI)	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Diffusion Tensor Imaging (DTI)	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Dual-Energy X-Ray Absorptiometry (DEXA)	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Magnetic Resonance Imaging (MRI)	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Magnetic Resonance Spectroscopy (MRS)	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Echocardiogram	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Electrocardiogram (ECG)	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Electrophysiology	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Holter Examination	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Gastrointestinal Therapies	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Respiratory Interventions	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Cognitive Guidelines for Use	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Measures of Gas Exchange	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Pulmonary Assessment Master Outline and Guidelines for Use	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Pulmonary Function Testing	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.

Neuromuscular Disease CDE Revision History Document

CRF Module/ Guideline	Current Version	Previous Version	Change Classification	Change Type	Description of Change
Pediatric Cognitive Instrument Recommendations by Domain and Classification	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Pediatric Cognitive Instrument Table	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.
Death Report	1.0	N/A	Major	Updated Form	The Neuromuscular Disease CDE materials have been removed from the Neuromuscular Disease outline and updated to reflect the most recent changes in Neuromuscular Disease.