

# Resource Summary Report

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## NINDS Common Data Elements

RRID:SCR\_006577

Type: Tool

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### Proper Citation

NINDS Common Data Elements (RRID:SCR\_006577)

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### Resource Information

**URL:** <http://www.commondataelements.ninds.nih.gov>

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**Description:** The purpose of the NINDS Common Data Elements (CDEs) Project is to standardize the collection of investigational data in order to facilitate comparison of results across studies and more effectively aggregate information into significant metadata results. The goal of the National Institute of Neurological Disorders and Stroke (NINDS) CDE Project specifically is to develop data standards for clinical research within the neurological community. Central to this Project is the creation of common definitions and data sets so that information (data) is consistently captured and recorded across studies. To harmonize data collected from clinical studies, the NINDS Office of Clinical Research is spearheading the effort to develop CDEs in neuroscience. This Web site outlines these data standards and provides accompanying tools to help investigators and research teams collect and record standardized clinical data. The Institute still encourages creativity and uniqueness by allowing investigators to independently identify and add their own critical variables. The CDEs have been identified through review of the documentation of numerous studies funded by NINDS, review of the literature and regulatory requirements, and review of other Institute's common data efforts. Other data standards such as those of the Clinical Data Interchange Standards Consortium (CDISC), the Clinical Data Acquisition Standards Harmonization (CDASH) Initiative, ClinicalTrials.gov, the NINDS Genetics Repository, and the NIH Roadmap efforts have also been followed to ensure that the NINDS CDEs are comprehensive and as compatible as possible with those standards. CDEs now available: \* General (CDEs that cross diseases) Updated Feb. 2011! \* Congenital Muscular Dystrophy \* Epilepsy (Updated Sept 2011) \* Friedreich's Ataxia \* Parkinson's Disease \* Spinal Cord Injury \* Stroke \* Traumatic Brain Injury CDEs in development: \* Amyotrophic Lateral Sclerosis (Public review Sept 15 through Nov 15) \* Frontotemporal Dementia \* Headache \* Huntington's Disease \* Multiple Sclerosis \* Neuromuscular Diseases \*\* Adult and pediatric working groups are being finalized and these groups will focus on: Duchenne Muscular Dystrophy, Facioscapulohumeral Muscular Dystrophy, Myasthenia Gravis, Myotonic Dystrophy, and Spinal Muscular Atrophy The following tools are available through this portal: \* CDE Catalog - includes the

universe of all CDEs. Users are able to search the full universe to isolate a subset of the CDEs (e.g., all stroke-specific CDEs, all pediatric epilepsy CDEs, etc.) and download details about those CDEs. \* CRF Library - (a.k.a., Library of Case Report Form Modules and Guidelines) contains all the CRF Modules that have been created through the NINDS CDE Project as well as various guideline documents. Users are able to search the library to find CRF Modules and Guidelines of interest. \* Form Builder - enables users to start the process of assembling a CRF or form by allowing them to choose the CDEs they would like to include on the form. This tool is intended to assist data managers and database developers to create data dictionaries for their study forms.

**Abbreviations:** NINDS CDEs

**Synonyms:** National Institute of Neurological Disorders and Stroke CDEs, NINDS NINDS Common Data Elements: Harmonizing information. Streamlining research.

**Resource Type:** data or information resource, database, narrative resource, standard specification

**Defining Citation:** [PMID:20583225](#)

**Keywords:** common data element, neuroscience, clinical, human, adult, pediatric, disease, disorder, data standard

**Funding:** NINDS contract N01-NS-7-2372

**Resource Name:** NINDS Common Data Elements

**Resource ID:** SCR\_006577

**Alternate IDs:** nif-0000-10000

**Record Creation Time:** 20220129T080237+0000

**Record Last Update:** 20260821T193759+0000

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## Ratings and Alerts

No rating or validation information has been found for NINDS Common Data Elements.

No alerts have been found for NINDS Common Data Elements.

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## Data and Source Information

**Source:** [SciCrunch Registry](#)

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## Usage and Citation Metrics

We found 32 mentions in open access literature.

**Listed below are recent publications.** The full list is available at [dkNET](#).

Huff HV, et al. (2025) Prevalence and severity of neurologic symptoms in Long-COVID and the role of pre-existing conditions, hospitalization, and mental health. *Frontiers in neurology*, 16, 1562084.

Struck AF, et al. (2025) Juvenile Myoclonic Epilepsy Imaging Endophenotypes and Relationship With Cognition and Resting-State EEG. *Human brain mapping*, 46(7), e70226.

Struck AF, et al. (2025) Cognitive and brain health in juvenile myoclonic epilepsy: Role of social determinants of health. *Epilepsia*, 66(5), 1641.

Jones CL, et al. (2025) Possible Racial Disparities in the Diagnosis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). *International journal of environmental research and public health*, 22(2).

Robba C, et al. (2023) Treatments for intracranial hypertension in acute brain-injured patients: grading, timing, and association with outcome. Data from the SYNAPSE-ICU study. *Intensive care medicine*, 49(1), 50.

Seton KA, et al. (2023) Investigating Antibody Reactivity to the Intestinal Microbiome in Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Feasibility Study. *International journal of molecular sciences*, 24(20).

Jaffa MN, et al. (2023) Common Data Elements for Disorders of Consciousness: Recommendations from the Working Group on Goals-of-care and Family/Surrogate Decision-Maker Data. *Research square*.

Gonzalez-Robles C, et al. (2023) Outcome Measures for Disease-Modifying Trials in Parkinson's Disease: Consensus Paper by the EJS ACT-PD Multi-Arm Multi-Stage Trial Initiative. *Journal of Parkinson's disease*, 13(6), 1011.

Abrams MB, et al. (2022) A Standards Organization for Open and FAIR Neuroscience: the International Neuroinformatics Coordinating Facility. *Neuroinformatics*, 20(1), 25.

Rinaldi E, et al. (2022) Harmonization and standardization of data for a pan-European cohort on SARS- CoV-2 pandemic. *NPJ digital medicine*, 5(1), 75.

Kals M, et al. (2022) A genome-wide association study of outcome from traumatic brain injury. *EBioMedicine*, 77, 103933.

Edlow BL, et al. (2021) Common Data Elements for COVID-19 Neuroimaging: A GCS-NeuroCOVID Proposal. *Neurocritical care*, 34(2), 365.

DeKosky ST, et al. (2021) Blood Biomarkers for Detection of Brain Injury in COVID-19 Patients. *Journal of neurotrauma*, 38(1), 1.

Meeuws S, et al. (2020) Common Data Elements: Critical Assessment of Harmonization between Current Multi-Center Traumatic Brain Injury Studies. *Journal of neurotrauma*, 37(11), 1283.

West AN, et al. (2020) Evidence Limitations in Determining Sexually Dimorphic Outcomes in Pediatric Post-Traumatic Hypopituitarism and the Path Forward. *Frontiers in neurology*,

11, 551923.

Koch S, et al. (2020) Randomized Trial of Combined Aerobic, Resistance, and Cognitive Training to Improve Recovery From Stroke: Feasibility and Safety. *Journal of the American Heart Association*, 9(10), e015377.

Rosenblum JS, et al. (2019) Chiari Malformation Type 1 in EPAS1-Associated Syndrome. *International journal of molecular sciences*, 20(11).

Raikes AC, et al. (2018) Diffusion Tensor Imaging (DTI) Correlates of Self-Reported Sleep Quality and Depression Following Mild Traumatic Brain Injury. *Frontiers in neurology*, 9, 468.

Camp KM, et al. (2016) Nutritional interventions in primary mitochondrial disorders: Developing an evidence base. *Molecular genetics and metabolism*, 119(3), 187.

Iro MA, et al. (2016) Immunoglobulin in the Treatment of Encephalitis (IgNiTE): protocol for a multicentre randomised controlled trial. *BMJ open*, 6(11), e012356.