

# Welcome to the NINDS Common Data Element Project

Streamline Your Neuroscience Clinical Research using **content standards** that enable clinical investigators to **systematically collect, analyze, and share data** across the research community.

## NINDS CDE Disorders

Cerebral Palsy  
Chiari I Malformation  
Epilepsy  
Headache  
Huntington's Disease  
Mitochondrial disease  
Multiple Sclerosis  
Myalgic Encephalomyelitis/  
Chronic Fatigue Syndrome  
Parkinson's Disease  
Spinal Cord Injury  
Traumatic Brain Injury  
Sport-Related Concussion

**NeuroMuscular Diseases:**  
Amyotrophic Lateral Sclerosis  
Congenital Muscular Dystrophy  
Duchenne/Becker Muscular  
Dystrophy  
FacioScapuloHumeral Muscular  
Dystrophy  
Friedreich's ataxia  
Myasthenia Gravis  
Myotonic Dystrophy  
Spinal Muscular Atrophy  
Stroke  
Unruptured Cerebral Aneurysms  
& SubArachnoid Hemorrhage

# NINDS

Harmonizing information.  
Streamlining research.

**Common  
Data  
Elements**



# How to utilize the CDEs

Visit the NINDS CDE website: [www.commondataelements.ninds.nih.gov](http://www.commondataelements.ninds.nih.gov)



## CDE Catalog

Users can search the Catalog to isolate a subset of the CDEs and to view and download details about the CDEs.



## Library

The CRF Library contains the NINDS CRF Modules and various guideline documents that have been created through the NINDS CDE Project.



## Form Builder

The Form Builder is intended to assist data managers and database developers to create data dictionaries for their study forms.

- Contact the NINDS CDE Project Officer, Carolina Mendoza-Puccini, MD ([carolina.mendoza-puccini@nih.gov](mailto:carolina.mendoza-puccini@nih.gov)) to set up a time to discuss using the CDEs and to arrange for technical assistance.
- Share your final or near final protocol with NINDS so the Institute and its contractor can tailor a CDE training session to your study.
- Send the NINDS CDE Project Officer and the contractor ([NINDSCDE@emmes.com](mailto:NINDSCDE@emmes.com)) any initial questions or comments you may have about the CDEs or the website prior to your scheduled training session.

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## Connect with Us

We want to hear your feedback and are open to receiving it in a variety of formats:

- **Submit feedback form** through the website: [https://www.commondataelements.ninds.nih.gov/connect\\_with\\_us](https://www.commondataelements.ninds.nih.gov/connect_with_us)
- **Email** – [NINDSCDE@emmes.com](mailto:NINDSCDE@emmes.com) for NINDS CDE Team; [carolina.mendoza-puccini@nih.gov](mailto:carolina.mendoza-puccini@nih.gov) for the NINDS CDE Project Officer
- **Phone/Webinar** – Contact [NINDSCDE@emmes.com](mailto:NINDSCDE@emmes.com) to arrange a follow-up teleconference/webinar to review your comments

