

NINDS Common Data Elements

Harmonizing information. Streamlining research.



If you have general questions about the CDE Project or more specific questions about the development of CDEs for a certain disease area, please contact the NINDS CDE Project Officer, Joanne Odenkirchen, MPH at odenkirj@ninds.nih.gov.

NINDS Common Data Element Project

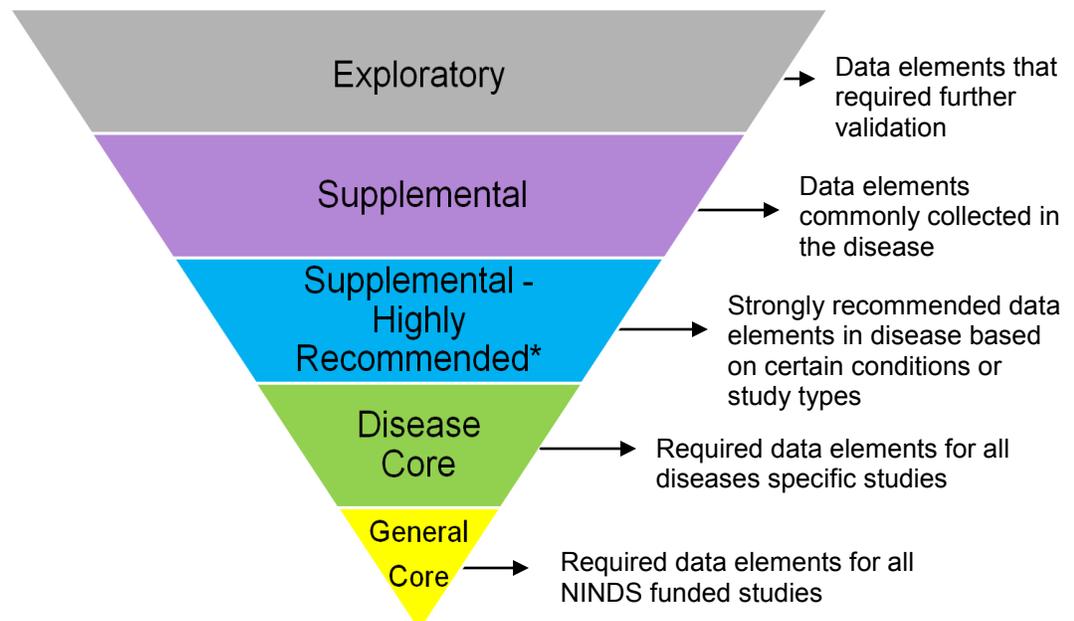
NINDS expects the clinical research it funds to meet the highest standards of scientific rigor, yet appreciates the burden that extensive data collection puts on investigators and study participants. Further, the Institute leadership recognizes that investigators independently identify data elements and forms for each study, many of which could be common across studies. As part of its effort to facilitate research of the highest quality, yet streamline clinical trial data collection in neurological studies, NINDS continues to advance its Common Data Element (CDE) Project. The CDE Project seeks to standardize the way data are collected across the neuroscience research community. Central to the project is the identification of common definitions and terminology.

By identifying CDEs in a standardized format and by developing common documentation and case report forms, the NINDS hopes to facilitate the development of data collection tools; to reduce study start-up time; to promote systematic data collection; to improve data quality and to facilitate data sharing across clinical research studies.

What do you need to know to use the CDEs?

1. Review the NINDS CDE Web site: www.commondataelements.ninds.nih.gov.
2. Contact the NINDS Project Officer, Joanne Odenkirchen, MPH at (odenkirj@ninds.nih.gov) to set up a time to discuss using the CDEs and to arrange for technical assistance.
3. Share your final or near final protocol with NINDS so the Institute and its contractor can tailor a CDE training session to your study.
4. Send the NINDS Project Officer and the contractor (NINDSCDE@emmes.com) any initial questions or comments you may have about the CDEs or the Web site prior to your scheduled training session.

CDE Classification Definitions



* Classification term of "Basic" used for Traumatic Brain Injury CDEs

Which CDEs should you use in your Amyotrophic Lateral Sclerosis (ALS) study?

1. Strongly encouraged to use the General Core CDEs.
2. Pick Additional Supplemental—Highly Recommended, Supplemental and Exploratory CDEs that are applicable to your study.

Tips for Accessing the CDEs

Find and download CDEs from <http://www.commondataelements.ninds.nih.gov/>
The NINDS CDE Web site has four main locations to access the CDEs:

1. **ALS CDE page** – http://www.commondataelements.ninds.nih.gov/ALS.aspx#tab=Data_Standards
2. **CDE Catalog tool** – <http://www.commondataelements.ninds.nih.gov/CDE.aspx>
3. **CRF Library tool** – <http://www.commondataelements.ninds.nih.gov/CRF.aspx>
4. **Form Builder tool** – <http://www.commondataelements.ninds.nih.gov/FormBuilder.aspx>

The screenshot shows the NINDS Common Data Elements website. At the top, there is a navigation bar with links for PROJECT OVERVIEW, CDE SEARCH, CRF SEARCH, FORM BUILDER, and CONTACT. The main header features the NINDS logo and the text "NINDS Common Data Elements" with the tagline "Harmonizing Information. Streamlining Research." Below the header, there are three main sections: "Streamline Your Neuroscience Clinical Research" (highlighted in red), "Launch Your Own Studies Faster", "Incorporate CDEs Into Systems", and "Learn About the CDE Project". On the right side, there is a sidebar with a list of CDEs, including "General (CDEs that cross diseases)", "Amyotrophic Lateral Sclerosis", "Epilepsy", "Friedreich's Ataxia", "Headache", "Huntington's Disease", "Mitochondrial Disease NEW", "Multiple Sclerosis", and "Neuromuscular Diseases". At the bottom, there are logos for NINDS, NIH, and USA.gov, along with a page update date of February 26, 2015.

This block contains three screenshots of the NINDS CDE tools. The top-left screenshot shows the "CDE Catalog" search interface, which includes fields for Disease, Sub-Disease, Domain, Sub-Domain, CRF Module, Classification, CDE Name, and Keywords, along with checkboxes for "From © or TM:" and "Population:". The top-right screenshot shows the "CRF Library" search interface, which includes fields for Disease, Sub-Disease, Domain, Sub-Domain, © or TM, and Keyword. The bottom-right screenshot shows the "CRF Library for Form Builder" search interface, which is identical to the CRF Library search interface.

Submitting Feedback

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

- **Submit feedback form** through Web site – <http://www.commondataelements.ninds.nih.gov/Feedback.aspx>
- **Email** – NINDSCDE@emmes.com for NINDS CDE Team; odenkirj@ninds.nih.gov for NINDS CDE Project Officer.
- **Phone/Webinar** – arrange follow-up teleconference/webinar to review your comments.