NINDS Common Data Elements

Harmonizing information. Streamlining research.

NINDS Common Data Element Project

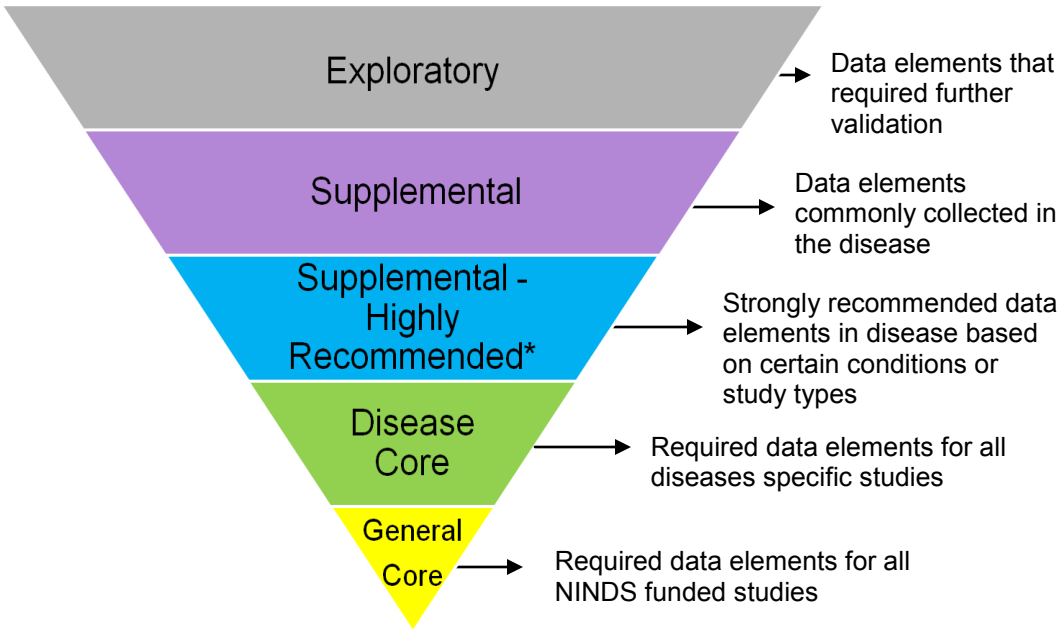
NINDS expects the clinical research it funds to meet the highest standards of scientific rigor, yet appreciates the burden that extensive data collection puts on investigators and study participants. Further, the Institute leadership recognizes that investigators independently identify data elements 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

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.

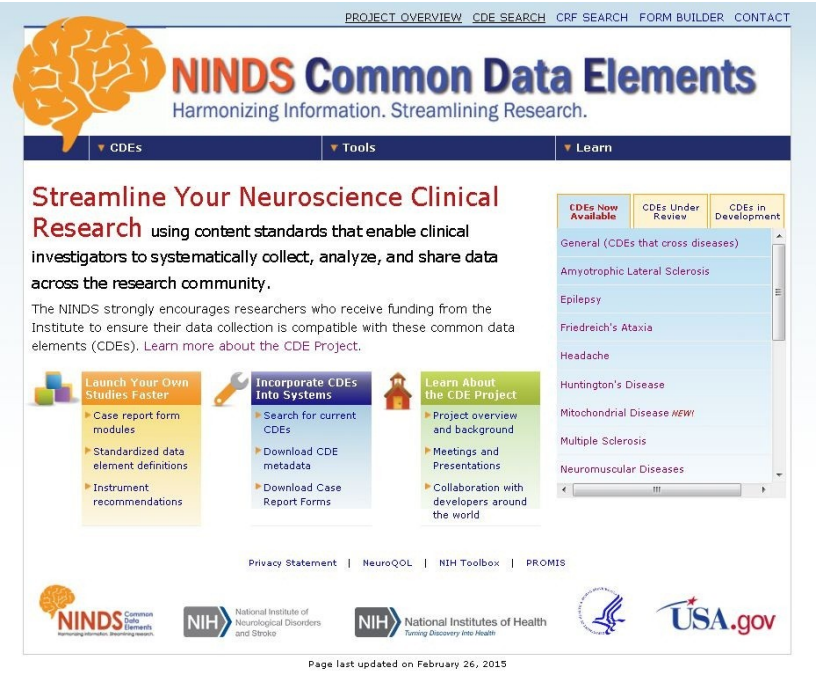
Which CDEs should you use in your Congenital Muscular Dystrophy (CMD) study?

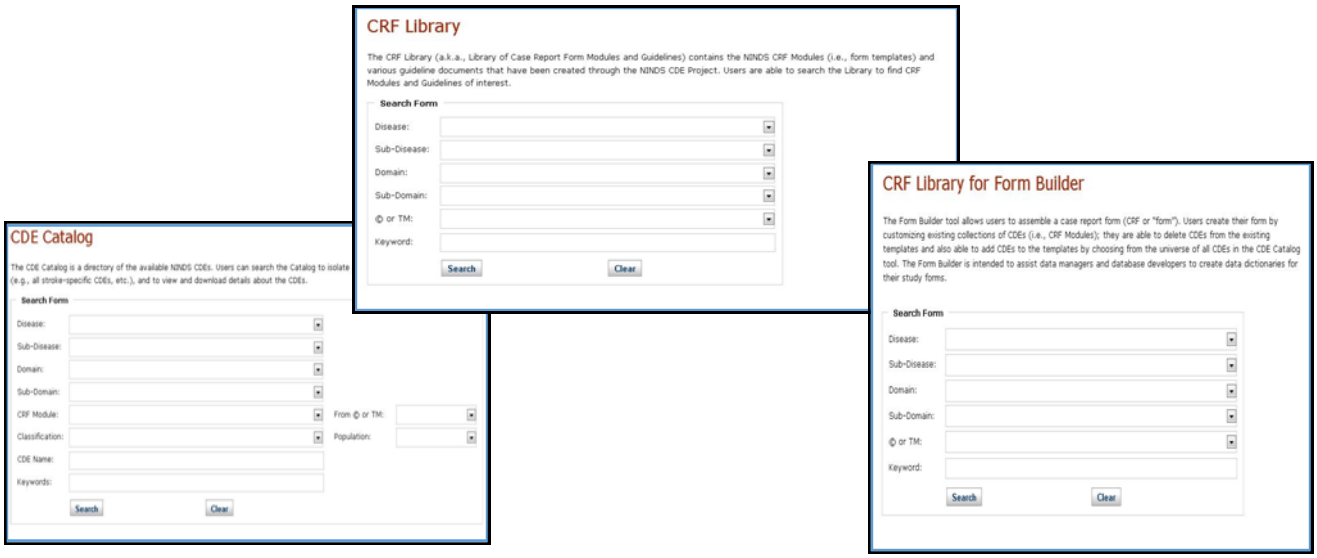
1. Strongly encouraged to use the General Core CDEs.
2. Pick Additional Supplemental—Highly Recommended, Supplemental and Exploratory CDEs that are applicable to your study.

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. **CMD CDE page** – http://www.commondataelements.ninds.nih.gov/CMD.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





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.