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. As part of its effort to enhance data quality, study efficiency and data sharing, NINDS has created and maintains the Common Data Element (CDE) project. NINDS CDEs are developed by clinical research experts from the community with administrative support from NINDS staff and contractors and are comprised of data items, recommended instruments and case report forms. This resource is intended to help standardize the way clinical research data are collected across the neuroscience community. Central to the project is the identification of common definitions and terminology for clinical research studies. By providing CDEs in a standardized format with documentation and case report forms, the NINDS hopes to facilitate the preparation 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?
2. Contact the NINDS Division of Clinical Research at [CRLiaison@NINDS.nih.gov](mailto:CRLiaison@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 Division of Clinical Research ([CRLiaison@NINDS.nih.gov](mailto:CRLiaison@NINDS.nih.gov)) to set up a time to discuss using the CDEs and to arrange for technical assistance. You may also contact the contractor ([NINDSCDE@emmes.com](mailto: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

- **General Core**: Required in all NINDS-funded clinical research studies.
- **Disease Core**: Required in disease-specific studies.
- **Supplemental - Highly Recommended**: Strongly recommended based on certain conditions or study types in disease-specific studies.
- **Supplemental**: Commonly collected in disease-specific studies.
- **Exploratory**: Require further validation.

*Classification term of “Basic” used for Traumatic Brain Injury CDEs*
Which CDEs should you use in your Cerebral Palsy (CP) study?

1. Strongly encouraged to use the General Core and Disease Core CDEs.
2. Pick Additional Supplemental—Highly Recommended, Supplemental and Exploratory CDEs that are applicable to your study.
3. Add data elements not found in the CDEs that are required for 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. CP CDE page – http://www.commondataelements.ninds.nih.gov/CP.aspx#tab=Data_Standards

Submitting Feedback

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

- Email – NINDSCDE@emmes.com for NINDS CDE Team; CRLiaison@NINDS.nih.gov for NINDS Division of Clinical Research.
- Phone/Webinar – Arrange follow-up teleconference/webinar to review your comments.