Common Data Elements in Epilepsy Research: Development and Implementation of the NINDS Epilepsy CDE Project

David W Loring, *Emory University*
Daniel H. Lowenstein, *University of California San Francisco*
Nicholas M. Barbaro, *University of California San Francisco*
Brandy E. Fureman, *National Institute of Neurological Disorders and Stroke*
Joanne Odenkirchen, *National Institute of Neurological Disorders and Stroke*
Margaret P. Jacobs, *National Institute of Neurological Disorders and Stroke*
Joan K. Austin, *Indiana University*
Dennis J. Dlugos, *University of Pennsylvania*
Jacqueline A. French, *New York University*
William Davis Gaillard, *George Washington University*

Only first 10 authors above; see publication for full author list.

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David W. Loring[1,2], **Daniel H. Lowenstein**[3], **Nicholas M. Barbaro**[3,4], **Brandy E. Fureman**[5], **Joanne Odenkirchen**[5], **Margaret P. Jacobs**[5], **Joan K. Austin**[6], **Dennis J. Dlugos**[7,8], **Jacqueline A. French**[9], **William Davis Gaillard**[10], **Bruce P. Hermann**[11], **Dale C. Hesdorffer**[12], **Steven N. Roper**[13], **Anne C. Van Cott**[14,15], **Stacie Grinnon**[16], and **Alexandra Stout**[16]

[1]Department of Neurology, Emory University, Atlanta, GA

[2]Department of Pediatrics, Emory University, Atlanta, GA

[3]Department of Neurology, University of California San Francisco, San Francisco, CA

[4]Department of Neurosurgery, University of California San Francisco, San Francisco, CA

[5]National Institute of Neurological Disorders and Stroke, Bethesda, MD

[6]School of Nursing, Indiana University Purdue University, Indianapolis, IN

[7]Division of Neurology, The Children's Hospital of Philadelphia, Philadelphia, PA

[8]Department of Neurology, University of Pennsylvania School of Medicine, Philadelphia, PA

[9]Department of Neurology, New York University, New York, NY

[10]Center for Neuroscience, Children's National Medical Center, George Washington University, Washington, DC

[11]Department of Neurology, University of Wisconsin School of Medicine and Public Health, Madison, WI

[12]Department of Epidemiology, Columbia University, New York, NY

[13]Department of Neurosurgery, University of Florida, Gainesville, FL

[14]Neurology Division, VA Pittsburgh Healthcare System, Pittsburgh, PA

[15]Department of Neurology, University of Pittsburgh, Pittsburgh, PA

[16]KAI Research Inc., Rockville, MD

Summary

The Common Data Element (CDE) Project was initiated in 2006 by the National Institute of Neurological Disorders and Stroke (NINDS) to develop standards for performing funded neuroscience-related clinical research. CDEs are intended to standardize aspects of data collection, decrease study start-up time, and provide more complete, comprehensive, and equivalent data across studies within a particular disease area. Therefore, CDEs will simplify data sharing and data aggregation across NINDS-funded clinical research, and where appropriate, facilitate the

Correspondence: David W. Loring, Ph.D., Department of Neurology, Emory University, 101 Woodruff Circle, Suite 6000, Atlanta, GA 30322, (404) 727-4116, dloring@emory.edu.

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development of evidenced-based guidelines and recommendations. Epilepsy-specific CDEs were established in nine content areas: (1) Antiepileptic Drugs (AEDs) and Other Antepileptic Therapies (AETs),)2) Comorbidities, (3) Electrophysiology, (4) Imaging,(5) Neurological Exam, (6) Neuropsychology,(7) Quality of Life, (8) Seizures and Syndromes, and (9) Surgery and Pathology. CDEs were developed as a dynamic resource that will accommodate recommendations based on investigator use, new technologies, and research findings documenting emerging critical disease characteristics. The epilepsy-specific CDE initiative can be viewed as part of the larger international movement toward "harmonization" of clinical disease characterization and outcome assessment designed to promote communication and research efforts in epilepsy. It will also provide valuable guidance for CDE improvement during their further development, refinement, and implementation. This article describes the NINDS CDE Initiative, the process used in developing Epilepsy CDEs, and the benefits of CDEs for the clinical investigator and NINDS.

Keywords

Research; Epilepsy; National Institute of Neurological Disorders and Stroke

INTRODUCTION

Funding of clinical research is a primary mission of the National Institutes of Health (NIH) and is designed to improve clinical care and reduce the burden of disease. Unfortunately, the impact of research findings has often been diminished as a result of multiple factors including incomplete or inconsistent data acquisition and reporting and, in the absence of any specific guidelines or recommendations, a variety of approaches used to characterize disease-related variables and to report clinical outcomes.

Inconsistent research reporting has been highlighted by multiple groups, resulting in the development of specific guidelines such as the Strengthening the Reporting of OBservational Studies in Epidemiology (STROBE) Statement (Vandenbroucke, et al. 2007), CONsolidated Standards of Reporting Trials (CONSORT) Statement (Begg, et al. 1996, Schulz, et al. 2010), and Standards for Reporting of Diagnostic accuracy standards (STARD) initiative(Bossuyt, et al. 2003). Although these initiatives address reporting standards, they spell out important components of good clinical research that will improve the design and conduct of new studies. As healthcare increasingly relies on evidence-based medicine to guide clinical practice, it is important for clinical researchers, whenever possible, to employ common approaches and a common vocabulary to facilitate data synthesis across multiple research projects.

Common Data Elements (CDEs) refer to data standards for conducting clinical research including common definitions and data sets. CDEs provide significant benefit to both clinical researchers and the National Institute of Neurological Disorders and Stroke (NINDS). For clinical researchers, CDEs provide guidance by identifying appropriate measures for inclusion in clinical research applications. CDEs for various disease areas have already been developed in partnership with NINDS, and their use in Phase III clinical trials is now strongly encouraged (PAR-10-198). CDEs similarly provide assurance to NINDS that appropriate metrics match their intended purpose. CDEs allow investigators to devote less space in applications for describing data collection methodology, and can be readily incorporated into case report forms (CRFs) and manuals of procedures (MOPs). Consequently, NINDS and investigators both benefit from decreasing study start-up time and effort.

CDEs insure that appropriate clinical data are consistently captured and recorded, which facilitates comparison of results across studies and allow data from different research protocols to be more effectively aggregated as metadata. CDE variables of interest can be easily extracted from a study data set and directly compared to the identical variables from other comparable studies.

BACKGROUND

Overview of CDE Project

Internal discussion about developing CDEs began at NINDS in 2006 and the CDE Project goals were first formalized on the Internet in 2007. The CDE Project is intended to develop data standards in clinical research to harmonize data collection across clinical studies. There are four primary goals of the CDE Project.

1. Disseminate standards for the collection of data from participants enrolled in studies of neurological diseases.
2. Create easily accessible tools for investigators that are needed to collect study data.
3. Encourage focused and simplified data collection to reduce burden on investigators and practice-based clinicians to increase clinical research participation.
4. Improve quality control without increasing cost by providing uniform data descriptions and tools across NINDS-funded clinical studies of treatment for neurological diseases.

There are also 4 primary CDE benefits:

1. Facilitate study start-up by allowing investigators access to appropriate data elements, definitions, and range and logic checks for forms, thereby reducing the time for study development.
2. Facilitate development of specifications for common report templates than can be submitted to oversight committees such as a Data and Safety Monitoring Boards (DSMBs) or Observational Safety Monitoring Boards (OSMBs).
3. Facilitate data sharing and data aggregation by employing standard definitions and common forms.
4. Encourage common outcome measures (e.g., functional, cognitive) that may be relevant across the neurological diseases

The process of developing CDEs across neurological diseases included the NINDS CDE Team, consisting of NINDS Program Directors and KAI Research Inc. (KAI), which was retained by NINDS as a contractor to facilitate CDE development and implementation. The CDE team identified NINDS-funded clinical trials and epidemiological studies, and study investigators were asked to provide the CRFs and MOPs used in those protocols. In addition to NINDS-funded research, the literature was examined to identify clinical reports with enrollments of at least 300 subjects. Following initial review, a “critical” core of data content areas across neurologic diseases was developed and included: (1) Demographics, (2) Inclusion/Exclusion criteria, (3) Medical history, (4) Physical exam, (5) Concomitant medications, (6) Treatment log, (7) Outcome measures or study endpoints, (8) Study discontinuation/Completion, and (9) Genetic elements.

Although several CDE measures were identified, the critical core primarily represents content areas rather than specific CDE recommendations. For example, demographics are important across clinical studies, although specific demographic characterization may differ across neurologic diseases or patient age. Inclusion/exclusion criteria will vary by disease,

and may also differ according to specific research questions being addressed. Treatment logs will reflect specific treatment interventions being investigated. Definitions of "good outcomes" differ by disease. Not all clinical research studies have a genetic component. Nevertheless, the initial CDE initiative framed important areas to address and identified initial content to be evaluated during the development of disease-specific CDEs.

The final CDE products were to include:

1. Generic data elements and items in a structure that facilitates data independence
2. Data Dictionary with definitions and variable name tags
3. Template study forms in Microsoft WORD and PDF format
4. Logic and range checks
5. Manuals of Procedures (MOPs)
6. Web site that facilitates access to the CDE data elements, data dictionary, forms, and MOPS (http://www.commondataelements.ninds.nih.gov)

Development of Epilepsy CDEs

After identifying elements spanning neurological diseases, the next step in the CDE process was to develop disease-specific CDEs for epilepsy, traumatic brain injury (TBI), stroke, Parkinson disease, and spinal cord injury. The development of epilepsy-specific CDEs began in 2008 with the NINDS CDE Team drafting a list of potential Epilepsy CDE Working Group members. The Working Group included epilepsy specialists across disciplines and research backgrounds, as well as biostatisticians experienced in epilepsy research.

The Epilepsy CDE Working Group met initially at the 2008 annual meeting of the American Epilepsy Society (AES) in Seattle. During the discussion of NINDS's goal in developing CDEs for clinical studies, concern emerged that although the CDEs were intended to be guidelines, they would evolve into requirements to be included in all epilepsy studies (clinical trials and clinical research projects). An additional concern was whether all CDEs would be expected to be included in all NINDS funded projects, regardless of the specific epilepsy research question. Consequently, two tiers of CDEs were proposed since certain CDEs would not be applicable to all studies. The primary CDE tier was established for all clinical epilepsy studies (e.g., seizures and syndromes), and a secondary CDE tier was developed for selected epilepsy research (e.g., pediatric, surgical, cognitive).

The CDE areas spanning neurologic disease were used to facilitate discussion, and nine epilepsy-specific CDEs areas were subsequently identified. These include: (1) *Antiepileptic Drugs (AEDs) and Other Antiepileptic Therapies (AETs)*, (2) *Comorbidities*, (3) *Electrophysiology*, (4) *Imaging*, (5). *Neurological Exam*, (6) *Neuropsychology*, (7) *Quality of Life*, (8) *Seizures and Syndromes*, and (9) *Surgery and Pathology*. Most content areas are indeed epilepsy-specific and are not readily applicable to other neurological conditions. Working Group members volunteered to serve on specific subcommittees, and subgroup chairs were identified by the Working Group CoChairs in consultation with the NINDS CDE Team. Subcommittee composition is shown in Table 1.

Each CDE subcommittee, with members of the NINDS CDE team, met by teleconference during the first year on a schedule determined by the group's chair. Subgroup conference calls began in April 2009 and continued every 4–6 weeks through the spring of 2010. Drafts from each subcommittee were presented when the Working Group reconvened at the 2009 AES annual meeting in Boston. CDEs were modified at this meeting based upon group

feedback, and a final Working Group teleconference was conducted in February 2010. Additional modifications of the CDEs were made based upon this teleconference, with a plan of posting the final product on the Web for public commentary by July 2010. The initial work product of each group took one of two forms. Some groups created template CRFs while others recommended existing, validated instruments for specific domains of epilepsy research, along with the rationale for specific recommendations.

RESULTS

Summary of Products by Subgroup

Antiepileptic Drugs (AEDs) & Other Antiepileptic Therapies (AETs)—CRFs were developed to track AEDs, AED Resistance, AED Plasma Concentration, Non-AED Medications, Devices, Device Revision/Replacement, Implanted Devices, Seizure Diary, and Adverse Events. Selected CRFs are identified as Core, which also vary depending on whether the study is observational or interventional. The recommendations also include a survey of the available AED adverse event collection tools, which are considered as supplemental to the adverse event tracking log CRF.

Comorbidities—Recommended measures are included for Cognition, Psychiatry, and Migraine. Scales for both pediatric and adult patients are identified. The cognitive measures are described as “screening” measures and were selected in part because they could be administered without the direct on-site involvement of a clinical psychologist. Consequently, there is some divergence from tests of similar constructs recommended by the *Neuropsychology Subcommittee*.

Electrophysiology—CRFs were created to capture data in the following areas: General EEG Information, Scalp EEG, Interictal Abnormalities, Benign EEG Variants, and Ictal vEEG. These forms are considered core only for those epilepsy studies in which EEG is a critical feature (e.g., study of EEG abnormalities, use in defining epilepsy syndromes or localization for surgery).

Imaging—CRFs were developed for both structural and functional imaging. Included are forms for structural MRI, functional MRI, magnetoencephalography/magnetic source imaging (MEG/MSI), Ictal/Interictal SPECT (single photon emission computed tomography), and Interictal FDG-PET (fluoride-oxyglucose positron emission tomography). Where relevant, data acquisition parameters (including age-based MR imaging sequences) and image processing/analysis are provided.

Neurological Exam—CRFs were constructed for both the General Physical and Neurological Examination. These CRFs are general and applicable across neurological diseases, and include traditional assessment of Mental Status, Cranial Nerves, Motor, Cerebellar/Coordination, Reflexes, Gait, and Sensory Function.

Neuropsychology—Distinct recommendations were made for adolescents and adults, pediatric (6–12 years), and young pediatric (0–5 years) age groups. Although the original goal was to recommend only those instruments that have been used previously in epilepsy research, there is a very scarce literature for younger patients. In these cases, measures are recommended based upon widespread general clinical use, or recommendations from the Pediatric TBI CDE Working Group. Tests containing Spanish versions are included wherever possible. Also included are additional demographics that are important for characterizing neuropsychological performance (e.g., education), and a one-year follow-up interval is recommended.

Quality of Life—In addition to summarizing and making recommendations across multiple potential Quality of Life measures used in epilepsy research, psychometric properties are included. Recommendations are made for both adult and pediatric use.

Seizures and Syndromes—CRFs were developed based on the most recent recommendations from the International League Against Epilepsy (ILAE) to standardize Classification of Etiology, Syndromes by Age of Onset, and Classification of Seizures. Use of these forms is considered core for all epilepsy studies.

Surgery and Pathology—CRFs were generated for core use in epilepsy surgery studies. Information on type of surgery, surgical approach and monitoring, pathology, and post-operative course including complications can be captured.

Remaining Work

Although Epilepsy CDEs have been posted on the NINDS website (http://www.commondataelements.ninds.nih.gov), this is considered to be an initial step in a larger initiative to promote the adoption of CDE tools in clinical epilepsy research. The NINDS continues to invite feedback from the epilepsy research community to refine CDEs to improve their utility. Feedback will be used to guide CDEs modification to ensure that data gathering and entry for Tier 1 CDEs are not overly burdensome and do not impede clinical trial participation. Thus, like the CONSORT Statement (Schulz, Altman & Moher 2010), CDEs are expected to evolve over time, and the NINDS will maintain an up-to-date website reflecting ongoing CDE modifications and improvements

Working group members remain somewhat concerned that there will be insufficient flexibility for researchers to include study specific measures that the investigators consider to be the most appropriate to address their research question. This was explicitly addressed in some areas by stating that investigators may include alternative measures for database continuity to maintain fidelity and consistency within their own research programs. Although NINDS expects that clinical investigators will incorporate Epilepsy CDEs into their grant proposals, especially proposals for Phase III clinical trials, the Institute recognizes there are situations in which particular Epilepsy CDEs may not be the most appropriate instruments for a particular study. NINDS is committed to maintain appropriate flexibility so the most appropriate metrics can be included, and in those cases, investigators need only to describe why alternative instruments or approaches are preferable to recommended CDEs.

Lessons Learned

In addition to epilepsy, disease-specific CDEs are being developed for Traumatic Brain Injury (TBI), Stroke, and Parkinson's disease. Although complete coordination of effort across specialties was not possible, greater coordination of effort would have helped to make recommendations that could facilitate cross-disease comparisons. In addition, input from different CDE groups might have provided additional expertise that could help shape epilepsy CDE conceptualization and recommendations. For example, the TBI CDE Working Group characterized their recommendations as core, supplemental (i.e., defined similarly to conditional), or emerging elements ("emerging" is a label used to describe data elements that require further validation but may fill current gaps in the CDEs or substitute for existing CDEs once there is sufficient empirical support to classify them as core or supplemental elements). To address these discrepancies, the NINDS has assembled a CDE Oversight Committee to help guide the future direction of the Project and offer guidance on issues such as how to reconcile differences among the disease-specific CDEs. Furthermore, because additional disease-specific CDEs are developed, it is likely that certain elements that are not

currently part of the critical core may appear across the disease-specific CDEs. The Oversight Committee will help decide which CDEs should be elevated from the disease-specific level to the critical core (e.g., the CDEs from the physical/ neurological exam).

The CDEs developed by the Epilepsy CDE Working Group are distinct from the NIH Toolbox (http://www.nihtoolbox.org). The NIH Toolbox is a recent initiative designed for use in epidemiologic studies and clinical trials across the lifespan, and consists of developing new measures of cognition, emotion, sensory, and motor function that can be administered in 2 h or less. Importantly, the Toolbox measures will be readily available at nominal cost. The NINDS envisions that over time, some instruments developed and validated through the NIH Toolbox effort may be incorporated into the Epilepsy CDEs.

DISCUSSION

Future Directions

The Epilepsy CDEs are intended to be dynamic tools that will evolve over time. NINDS and the CDE Working Group expect that initial public commentary, as well as feedback based upon their initial implementation, will be invaluable in fixing “bugs” associated with unanticipated consequences of specific recommendations. Actual use of CDE forms will help to determine whether the implementation of Tier 1 CDEs is excessively burdensome due to inclusion of constructs/elements that, although conceptually appealing at the time of CDE creation, reflect excessive detail that extends beyond what most investigators will obtain as part of efficiently run trials. The CDE Oversight committee will monitor the feedback regarding implementation issues and make recommendations for modification as needed.

CDEs should easily interface with electronic medical records, which increasingly rely on data capture forms to guide data acquisition. It is reasonable to expect that clinical researchers may be able to use these forms not only as part of a patient’s electronic medical record, but to have patient data subsequently transferred directly to the coordinating center responsible for data processing and analysis, assuming the appropriate safeguards are in place to protect confidentiality of this information. Therefore, CDEs can be conceptualized as the first step toward data pooling across multiple sites, and an epilepsy CDE informatics network could greatly facilitate collaborative research initiatives. An example of this approach is the National Cancer Institute's caBIG® (Cancer Biomedical Informatics Grid®, sponsored by the National Cancer Institute, the National Institutes of Health, and supervised by the National Cancer Institute Center for Bioinformatics and Information Technology, Rockville, M.D., U.S.A.). Importantly, the NINDS is currently conducting a pilot project to register its general/generic CDEs (i.e., those not specific to a disease) into the Cancer Data Standards Registry and Repository (caDSR). The caDSR is one of the key components of the caBIG® infrastructure. The caDSR database and tools, together with the EVS (Enterprise Vocabulary Services), are the basis of the semantic foundation for interoperable data and analytical services. If the pilot project is deemed successful the NINDS may continue with the registration of the Epilepsy CDEs into the caDSR.

The goal of harmonizing clinical research standards not only reflects North American initiatives (Hachinski, et al. 2006), but also is embraced by the international research community (Kesselring, et al. 2008, Hachinski, et al. 2010, Tomson, et al. 2010). Therefore, although the NINDS CDE Project was established for NIH-funded clinical neuroscience studies, CDEs will provide a valuable framework for discussion for the global epilepsy community (e.g., ILAE), and international feedback will provide valuable guidance for CDE improvement during their further development, refinement, and implementation. By harmonizing research techniques wherever possible, CDEs will foster collaborative

approaches across institutions by facilitating data sharing to answer questions requiring large patient samples, facilitate multicenter recruitment of conditions with uncommon disease characteristics, and minimize discrepancies in the literature related to study-specific approaches for sample characterization and outcome assessment.

References

Begg C, Cho M, Eastwood S, Horton R, Moher D, Olkin I, Pitkin R, Rennie D, Schulz KF, Simel D, Stroup DF. Improving the quality of reporting of randomized controlled trials. The CONSORT statement. Jama. 1996; 276:637–639. [PubMed: 8773637]

Bossuyt PM, Reitsma JB, Bruns DE, Gatsonis CA, Glasziou PP, Irwig LM, Lijmer JG, Moher D, Rennie D, de Vet HC. Towards complete and accurate reporting of studies of diagnostic accuracy: the STARD initiative. Bmj. 2003; 326:41–44. [PubMed: 12511463]

Hachinski V, Donnan GA, Gorelick PB, Hacke W, Cramer SC, Kaste M, Fisher M, Brainin M, Buchan AM, Lo EH, Skolnick BE, Furie KL, Hankey GJ, Kivipelto M, Morris J, Rothwell PM, Sacco RL, Smith SC Jr, Wang Y, Bryer A, Ford GA, Iadecola C, Martins SC, Saver J, Skvortsova V, Bayley M, Bednar MM, Duncan P, Enney L, Finklestein S, Jones TA, Kalra L, Kleim J, Nitkin R, Teasell R, Weiller C, Desai B, Goldberg MP, Heiss WD, Saarelma O, Schwamm LH, Shinohara Y, Trivedi B, Wahlgren N, Wong LK, Hakim A, Norrving B, Prudhomme S, Bornstein NM, Davis SM, Goldstein LB, Leys D, Tuomilehto J. Stroke: working toward a prioritized world agenda. Cerebrovasc Dis. 2010; 30:127–147. [PubMed: 20516682]

Hachinski V, Iadecola C, Petersen RC, Breteler MM, Nyenhuis DL, Black SE, Powers WJ, DeCarli C, Merino JG, Kalaria RN, Vinters HV, Holtzman DM, Rosenberg GA, Wallin A, Dichgans M, Marler JR, Leblanc GG. National Institute of Neurological Disorders and Stroke-Canadian Stroke Network vascular cognitive impairment harmonization standards. Stroke. 2006; 37:2220–2241. [PubMed: 16917086]

Kesselring J, Coenen M, Cieza A, Thompson A, Kostanjsek N, Stucki G. Developing the ICF Core Sets for multiple sclerosis to specify functioning. Mult Scler. 2008; 14:252–254. [PubMed: 17986511]

Schulz KF, Altman DG, Moher D. CONSORT 2010 statement: updated guidelines for reporting parallel group randomised trials. Bmj. 2010; 340:c332. [PubMed: 20332509]

Tomson T, Battino D, Craig J, Hernandez-Diaz S, Holmes LB, Lindhout D, Morrow J, French J. Pregnancy registries: differences, similarities, and possible harmonization. Epilepsia. 2010; 51:909–915. [PubMed: 20196792]

Vandenbroucke JP, von Elm E, Altman DG, Gotzsche PC, Mulrow CD, Pocock SJ, Poole C, Schlesselman JJ, Egger M. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): explanation and elaboration. Epidemiology. 2007; 18:805–835. [PubMed: 18049195]

Table 1

Membership in Epilepsy CDE Working Group Subcommittees

Group	Membership
Epilepsy Working GroupCo-chairs	Nicholas Barbaro, Daniel Lowenstein
Antiepileptic Drugs (AEDs) and Other Antiepileptic Treatments (AETs)	Jacqueline French (chair), Peggy Clark, James Cloyd, Tracy Glauser, Nina Graves, Daniel Lowenstein, Gerry Nesbitt
Comorbidities	Bruce Hermann (chair), Joan Austin, Anne Berg, Kristen Fowler, Tracy Glauser, W. Allen Hauser, Dale Hesdorffer, Curt LaFrance, Ruth Ottman, Shlomo Shinnar, Anne Van Cott
Electrophysiology	Anne Van Cott (chair), Dennis Dlugos, William Gaillard, Gerry Nesbitt, Susan Spencer
Imaging	William Gaillard (chair), Nicholas Barbaro, Gregory Barkley, Robert Knowlton, Ruben Kuzniecky, Susan Spencer
Neurological Exam	Dennis Dlugos (chair), Peggy Clark, Daniel Lowenstein, Christine O'Dell, David Thurman, Mariann Ward
Neuropsychology	David Loring (chair), Avital Cnaan, Marla Hamberger, Bruce Hermann, John Langfitt. Pediatric Consultants: Elisabeth Sherman, Mary Lou Smith, Michael Westerveld
Quality of Life	Joan Austin (chair), David Cella, Avital Cnaan, Kristen Fowler, Marla Hamberger, John Langfitt, Christine O'Dell
Seizures and Syndromes	Dale Hesdorffer (chair), Anne Berg, Jacqueline French, W. Allen Hauser, Shlomo Shinnar, David Thurman
Surgery and Pathology	Steven Roper (chair), Nicholas Barbaro, Robert Fisher, Susan Spencer, Samuel Wiebe
NINDS CDE Team (including KAI)	Margaret Jacobs, Brandy Fureman, Stacie Grinnon, Joanne Odenkirchen, Alexandra Stout

Please see the NINDS CDE website (http://www.commondataelements.ninds.nih.gov/Epilepsy.aspx#ack) for a complete list of current Epilepsy CDE Working Group members.