



## NINDS CDE Presentations

### PRESENTATIONS IN 2016

1. **February 2016** – International Stroke Conference Feb. 22-24, 2017, Houston, Texas: Updating the Structure of Stroke Clinical Research Data: Version 2 of the Stroke Common Data Elements from the National Institutes of Health/National Institute of Neurological Disorders and Stroke.  
**Authors:** Joanne Odenkirchen, MPH; Scott Janis, PhD; Jeffrey L. Saver, MD; Steven Warach, MD, PhD; Thomas G. Broth, MD; Ralph L. Sacco, MD, MS, FAHA, FAAN; Muniza Sheikh, MS, MBA; Sherita Ala'i, MS; Joy Esterlitz, MS

### PRESENTATIONS IN 2015

1. **December 2015** - American Epilepsy Society, December 5–8, 2015, Philadelphia, PA: A Common Data Language for Clinical Research Studies: The NINDS Common Data Elements.  
**Authors:** Joanne Odenkirchen, MPH NINDS Office of Clinical Research; Joy Esterlitz, MS and Muniza Sheikh, MS, MBA
2. **June 2015** – United Mitochondrial Disease Foundation. Mitochondrial Medicine 2015, June 17–20, 2015, Herndon, Virginia. A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke (NINDS) Mitochondrial Disease Common Data Elements (CDE) Publication of Version 1.0 Recommendations [Poster Presentation].  
**Authors:** Joanne Odenkirchen, MPH; Sherita Ala'i, MS, Muniza Sheikh MS, MBA and Joy Esterlitz, MS on behalf of the NINDS Mitochondrial Disease CDE Working Groups.
3. **May 2015** – The 4<sup>th</sup> ISCos and ASIA Joint Scientific Meeting, May 14–16, 2015, Montreal, Canada. Public Review: NINDS Spinal Cord Injury Common Data Elements Recommendations.  
**Author:** Joanne Odenkirchen, MPH
4. **April 2015** – U.S. Food and Drug Administration meeting Public Workshop on Assessment of Neurocognitive Outcomes in Inborn Errors of Metabolism and Advancing the Development of Pediatric Therapeutics: Assessment of Neurocognitive Outcomes, April 16–17, 2015. Silver Spring, Maryland. NINDS Common Data Element (CDE) Project – Inborn Errors in Metabolism.  
**Author:** Joanne Odenkirchen, MPH
5. **April 2015** – American Academy of Neurology (AAN) 67<sup>th</sup> AAN Annual Meeting, April 18–25, 2015, Washington, DC. Public Review: The National Institute of Neurological Disorders and Stroke (NINDS) Congenital Muscular Dystrophy (CMD), Facioscapulohumeral Muscular Dystrophy (FSHD) and Myotonic Dystrophy (DM) Common Data Elements (CDE) Recommendations.  
**Authors:** Joanne Odenkirchen, MPH; Marybeth Montoro MPH; Sherita Ala'i, MS; Joy Esterlitz, MS; Elizabeth McNeil, MD, MSc, Robin Conwit, MD on behalf of The NINDS CDE CMD, FSHD and DM Working Groups
6. **February 2015** – American Heart Association/American Stroke Association 2015 International Stroke Conference and State-of-the-Science Stroke Nursing Symposium, February 10–12, 2014, Nashville, Tennessee. A Common Data Language for Clinical Research Studies: The NINDS Common Data Elements.  
**Authors:** Joanne Odenkirchen, MPH; Joy Esterlitz, MS; Sherita Ala'i, MS and Muniza Sheikh, MS, MBA on behalf of the NINDS Stroke Working Groups

### PRESENTATIONS IN 2014

1. **December 2014** – NIH Nutritional Interventions in Primary Mitochondrial Disorders: Developing an Evidence Base Workshop, December 2–3, 2014, Bethesda, Maryland. The National Institute of Neurological Disorders and Stroke (NINDS) Mitochondrial Disease Common Data Elements (CDE) Recommendations.



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**Authors:** Joanne Odenkirchen, MPH; Sherita Ala'i, MS; Amanda Suller; Marybeth Montoro, MPH, Muniza Sheikh, MS/MBA and Joy Esterlitz, MS on behalf of the NINDS Mitochondrial Disease CDE Working Groups

2. **September 2014** – International Spinal Cord Society Annual Scientific Meeting, September 2–4, 2014, Maastricht, The Netherlands. Public Review: The National Institute of Neurological Disorders and Stroke (NINDS) Spinal Cord Injury Common Data Elements (CDE) Recommendation.  
**Authors:** Joanne Odenkirchen, MPH; Naomi Kleitman, PhD; Fin Biering-Sørensen, MD, PhD; Susan Charlifue, PhD, FACRM; Michael DeVivo, DrPH; Linda Jones, PT, MS; Sherita Ala'i, MS; Aria Lans, MPH; on behalf of The NINDS International SCI CDE Working Group
3. **June 2014** – United Mitochondrial Disease Foundation Mitochondrial Medicine 2014, June 4–7, 2014, Pittsburgh, Pennsylvania. A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke (NINDS) Mitochondrial Disease Common Data Elements (CDE)  
**Authors:** Joanne Odenkirchen, Sherita Ala'i, Divya Nigam, and Joy Esterlitz on behalf of the NINDS Mitochondrial Disease CDE Working Groups
4. **May 2014** – Society for Clinical Trials, May 17–20, 2014, Philadelphia, Pennsylvania. A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke (NINDS) Spinal Cord Injury Common Data Elements (CDE) [Poster Presentation]  
**Authors:** Joy Esterlitz, MS; Sherita Ala'i, MS; Petra Kaufmann, PhD; Matthew McAuliffe, PhD; Matthew Beyers, MSc; Joanne Odenkirchen, MPH
5. **May 2014** – American Spinal Injury Association Annual Scientific Meeting, May 14–17, 2014, San Antonio, Texas. A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke (NINDS) Spinal Cord Injury Common Data Elements (CDE).  
**Authors:** Joanne Odenkirchen (NINDS) on behalf of the Spinal Cord Injury Common Data Element Working Group
6. **February 2014** – American Society for Experimental NeuroTherapeutics, February 20–22, 2014, Bethesda, Maryland. The National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements (CDE).  
**Authors:** Wendy Galpern (NINDS)

### PRESENTATIONS IN 2013

7. **October 2013** – 52<sup>nd</sup> Annual Scientific Meeting of International Spinal Cord Society, October 28, 2013, Istanbul, Turkey. NINDS Data Elements (CDE) Project.  
**Authors:** Joanne Odenkirchen (NINDS) on behalf of the Spinal Cord Injury Common Data Element Working Group

### PRESENTATIONS IN 2012

8. **October 2012** – American Congress of Rehabilitation Medicine, October 13, 2012, Putting TBI Common Data Elements into Practice
9. **August 2012** – Hereditary Disease Foundation's 8<sup>th</sup> biennial celebration of science, August 1-4, 2012, Facilitating Clinical Research in HD: Recommendations for Data Collection from the NINDS HD Common Data Elements Project.  
**Authors:** Wendy Galpern (NINDS) on behalf of the Huntington's Disease Common Data Element Working Group
10. **June 2012** – American Headache Society, 54<sup>th</sup> Annual Scientific Meeting, June 21-24, 2012, Developing Common Data Elements (CDEs) for Headache Clinical Research: NINDS Initiative  
**Authors:** Andrew Charles, Mitchell Brin, Joanne Odenkirchen, and Linda Porter on behalf of the



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### Headache CDE Working Group

11. **June 2012** – Movement Disorders Society – 16th International Congress of Parkinson’s Disease and Movement Disorders, June 17- 21, 2012, Recommendations for data collection in Huntington's disease clinical research: The NINDS Huntington's disease Common Data Elements project  
**Authors:** Wendy Galpern (NINDS) on behalf of the Huntington’s Disease Common Data Element Working Group
12. **May 2012** – European Stroke Congress, May 22-25, 2012, National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health, Stroke Common Data Elements (CDEs): Using the CDEs in Clinical Research Studies  
**Authors:** Jeffrey Saver, Steven Warach (Stroke CDE Oversight Committee Co-Chairs); Catherine Amlie-Lefond, Joseph Broderick, Colin Derdeyn, Billy Dunn., Mitchell Elkind, Lawrence Fine, Mary George, Michael Hill, Virginia Howard, Kennedy R. Lees, David Levy, Bo Norrving, Yuko Palesch, Lee Schwamm (Stroke CDE Oversight Committee Members); Pooja Khatri (Stroke CDE Working Group Member); Stacie Grinnon, Lisa Hunegs, Megan Otruba (KAI); Scott Janis, Petra Kaufmann, Joanne Odenkirchen (NINDS)
13. **March 2012** – National Ataxia Foundation- Investigator’s Meeting, March 13-16, 2012, The National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements (CDEs) for Use in Friedreich’s Ataxia Clinical Studies  
**Authors:** Martin Delatycki, Jennifer Farmer, Kenneth Fischbeck, Paul Kantor, David Lynch, Massimo Pandolfo, Mark Payne, Susan Perlman, Jorg Schulz, Robert Shaddy, Subha Raman, Petra Kaufmann, Joanne Odenkirchen, Lisa Hunegs
14. **February 2012** - American Society for Experimental NeuroTherapeutics February 22 – 25, 2012: National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Common Data Element (CDE) Project: Using the NINDS CDEs in Research Projects  
**Authors:** Lisa Hunegs, Alexandra Stout (KAI Research, Inc.), Joanne Odenkirchen (NINDS)

### PRESENTATIONS PRIOR TO 2012

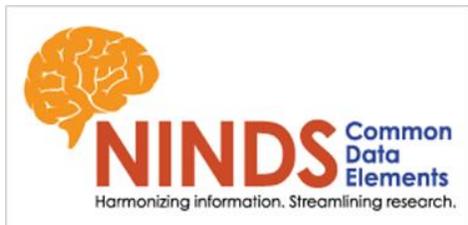
15. **December 2011** - XIX World Congress on Parkinson’s Disease and Related Disorders; December 11-14, 2011: Facilitating Clinical Research: The National Institute of Neurological Disorders and Stroke Parkinson’s disease Common Data Elements Project  
**Authors:** Caroline Tanner, Karl Kieburtz, Wendy Galpern, Mahlon DeLong, Dennis Dickson, Jordan Elm, Tatiana Foroud, Cornelia Kamp, Anthony Lang, Karen Marder, Kenneth Marek, Ronald Pfeiffer, G Webster Ross, Andrew Siderowf, and Daniel Weintraub on behalf of the NINDS PD CDE Working Group
16. **December 2011** - 2011 AES Annual Meeting; December 5, 2011: National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Common Data Element (CDE) Project: Epilepsy CDE Update (*Poster Presentation*)  
**Authors:** Stacie Grinnon, Alexandra Stout, Brandy Fureman, Joanne Odenkirchen, The Epilepsy CDE WG
17. **December 2011** - 2011 AES Annual Meeting; December 3, 2011: NINDS – Learn to Use the Epilepsy Common Data Elements (CDEs) for Clinical Research (*Public meeting*)  
**Authors:** The NINDS Epilepsy CDE Working Group; Brandy Fureman, Joanne Odenkirchen (NINDS); Stacie Grinnon, Alexandra Stout (KAI)
18. **November 2011** – Fifth Annual Huntington Disease Clinical Research Symposium; November 5, 2011: National Institute of Neurological Disorders and Stroke Huntington’s disease Common Data Elements Project



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**Authors:** Wendy Galpern on behalf of the Huntington's Disease Working Group

19. **September 2011** - World Congress on Huntington's Disease; September 11-14, 2011: Facilitating Clinical Research: The National Institute of Neurological Disorders and Stroke Huntington's Disease Common Data Elements Project  
**Authors:** Wendy Galpern on behalf of the Huntington's Disease Working Group
20. **June 2011** - Workshop at the International Conference on Spinal Cord Medicine and Rehabilitation; June 4-8, 2011: Using the Spinal Cord Injury Common Data Elements: A Workshop  
**Authors:** Fin Biering-Sørensen, Susan Charlifue, Michael J. DeVivo, Stacie T. Grinnon, Naomi Kleitman, Joanne Odenkirchen
21. **June 2011** – Movement Disorder Society; June 5-9, 2011: National Institute of Neurological Disorders and Stroke Parkinson's disease Common Data Elements Project  
**Authors:** Wendy Galpern on behalf of the NINDS PD CDE Working Group
22. **May 2011** – European Stroke Congress; May 24-27, 2011 National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health, Stroke Common Data Elements (CDEs): Version 1.0 Available for Use  
**Authors:** Jeffrey Saver, Kyra Becker, Oscar Benavente, Joseph Broderick, Alexander Dromerick, Pamela Duncan, Karen Johnston, Chelsea Kidwell, James Meschia, Lee Schwamm, Stacie Grinnon, Lisa Hunegs, Scott Janis, Joanne Odenkirchen, Steven Warach
23. **May 2011** – 4th International Friedreich's Ataxia Scientific Conference; May 5-7, 2011, Developing Common Data Elements for Friedreich's Ataxia Clinical Research  
**Authors:** Martin Delatycki, Jennifer Farmer, Kenneth Fischbeck, Wendy Galpern, Lisa Hunegs, Paul Kantor, Petra Kaufmann, David Lynch, Kristy Miller, Joanne Odenkirchen, Massimo Pandolfo, Mark Payne, Susan Perlman, Jorg Schulz, Robert Shaddy, Subha Raman
24. **April 2011** – American Academy of Neurology (AAN); April 9-16, 2011, National Institute of Neurological Disorders and Stroke, National Institutes of Health, Common Data Element (CDE) Project: Applying the General and Disease-specific CDEs to Clinical Research Projects (*Poster Session*)  
**Authors:** Stacie Grinnon, Kristy Miller, Petra Kaufmann, Wendy Galpern, Joanne Odenkirchen
25. **February 2011** – International Stroke Conference (ISC) 2011; February 8-11, 2011: Version 1.0 of the Stroke Common Data Elements Available for Public Use from the National Institute of Neurological Disorders and Stroke, National Institutes of Health Common Data Element Project (*Poster Session*)  
**Authors:** Stacie Grinnon, Lisa Hunegs, Joanne Odenkirchen
26. **December 2010** – 64th Annual Meeting of the American Epilepsy Society; December 3-7, 2010: National Institute of Neurological Disorders and Stroke, National Institutes of Health, Common Data Element (CDE) Project: Version 1.0 of Epilepsy CDEs Available for Use (*Poster Session*)  
**Authors:** Stacie Grinnon, Lisa Hunegs, Alexandra Stout, Brandy Fureman, Joanne Odenkirchen
27. **September 2010** – caBIG Annual Conference; September 13-15, 2010: Harmonizing the National Institute of Neurological Disorders and Stroke (NINDS) Core Common Data Elements (CDEs) with the National Cancer Institute (NCI) Cancer Biomedical Informatics Grid (caBIG) Cancer Data Standards Registry and Repository (caDSR) (*Poster session*)  
**Authors:** Stacie T. Grinnon, Kristy Miller, Patti Shugarts, Yun Lu, Dianne Reeves, Joanne Odenkirchen
28. **June 2010** – Biomedical Informatics without Borders: Implementing Interoperability; June 21-22, 2010: Harmonization of NINDS General Common Data Element (CDE) Case Report Form (CRF) Modules into the cancer Biomedical Informatics Grid (caBIG) Cancer Data Standards Registry and Repository (caDSR) (*Poster Session*)  
**Authors:** Stacie T. Grinnon, Kristy Miller, Patti Shugarts, Yun Lu, Dianne Reeves, Joanne Odenkirchen



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29. **June 2010** – Drug Information Association (DIA) Annual Meeting 2010; June 13-17, 2010: National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH) Common Data Element (CDE) Project: Exploring Partnerships in Data Standards (*Poster Session*)  
**Authors:** Stacie T. Grinnon, Alex Stout, Joanne Odenkirchen
30. **May 2010** - Society of Clinical Trials Annual Meeting (SCT); May 16-19, 2010: National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Common Data Element (CDE) Project: Developing Disease-specific CDEs (*Poster Session*)  
**Authors:** Kristy Miller, Stacie T. Grinnon, Joanne Odenkirchen