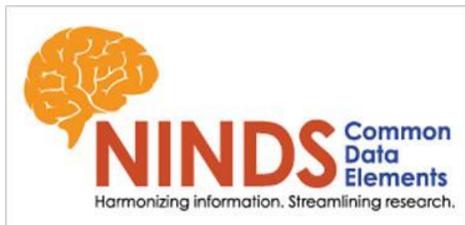


## NINDS CDE Presentations

### PRESENTATIONS IN 2018

- 1. January 2018** – International Stroke Conference, January 24–January 26, 2018, Los Angeles, CA. A Common Data Language for Clinical Research Studies: Review and Updates to the National Institute of Neurological Disorders and Stroke and National Library of Medicine Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage Common Data Elements Version 1.0 Recommendations. Poster presentation.  
**Authors:** Muniza Sheikh, MS, MBA; Sherita Ala'i, MS; Joy Esterlitz, MS; R. Loch Macdonald, MD, PhD; Jose Ignacio Suarez, MD on behalf of the SAH CDE Working Group.
- 2. February 2018** – International Neuropsychological Society 46<sup>th</sup> Annual Meeting, February 14–February 17, 2018, Washington, DC. National Institute of Neurological Disorders and Stroke, National Institutes of Health and Department of Defense Common Data Language for Clinical Research Studies: Sports-Related Concussion Common Data Element Recommendations. Poster presentation.  
**Authors:** Kristen Joseph, MA; Claudia Moy, PhD; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.
- 3. April 2018** – American Academy of Pain Management 34<sup>th</sup> Annual Meeting, April 25–April 29, 2018, Vancouver, BC, Canada. Headache Version 2.0 Common Data Element (CDE) Recommendations: Updates to the National Institute of Neurological Disorders and Stroke (NINDS) Headache CDEs. Poster presentation.  
**Authors:** Sarah Tanveer, BS; Sherita Ala'i, MS; Joy Esterlitz, MS; Michael L. Oshinsky, PhD on behalf of the Headache Version 2.0 CDE Working Group.
- 4. April 2018** – American Academy of Neurology 70<sup>th</sup> Annual Meeting, April 21–April 27, 2018, Los Angeles, CA. Common Data Elements (CDEs) for Biomechanical Devices used in Blunt Head Impact and Blast Exposure Dynamics: The National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH) and Department of Defense (DOD) Version 1.0 Recommendations. Poster presentation.  
**Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Sherita Ala'i, MS; Joy Esterlitz, MS; Kristen Joseph, MA; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices CDE Working Group.
- 5. April 2018** – American Academy of Neurology 70<sup>th</sup> Annual Meeting, April 21–April 27, 2018, Los Angeles, CA. A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke Updates to Epilepsy Common Data Element Recommendations. Poster discussion presentation.  
**Authors:** Muniza Sheikh, MS, MBA; Joan Austin, PhD, RN, FAAN; Jackie French, MD; Nicholas Barbaro, MD; Daniel Lowenstein, MD; Sherita Ala'i, MS; Sarah Tanveer, BS; Joy Esterlitz, MS; Vicky Whittemore, PhD; on behalf of the Epilepsy CDE Oversight Committee and Working Groups.
- 6. April 2018** – American Academy of Neurology 70<sup>th</sup> Annual Meeting, April 21–April 27, 2018, Los Angeles, CA. A Common Language for Clinical Research Studies: The National Institute of

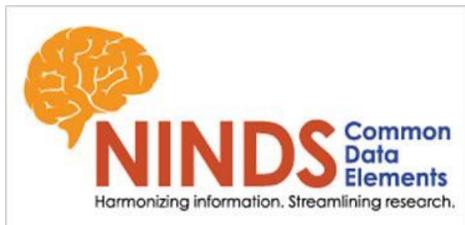


## NINDS CDE Presentations

Neurological Disorders and Stroke (NINDS) and Centers for Disease Control and Prevention (CDC) Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Common Data Elements (CDEs). Poster presentation.

**Authors:** Katelyn Gay, BS; Sherita Ala'i, MS; Joy Esterlitz, MS; Muniza Sheikh, MS, MBA; Sarah Tanveer, BS; Kristen Joseph, MA; Elizabeth R. Unger, PhD, MD; Vicky Whittemore, PhD on behalf of the ME/CFS CDE Working Group.

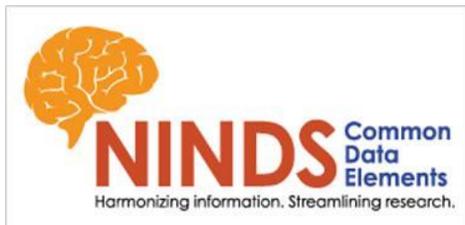
7. **April 2018** – American Academy of Neurology 70<sup>th</sup> Annual Meeting, April 21–April 27, 2018, Los Angeles, CA. Streamlining Clinical Research in Sports-Related Concussion: The National Institute of Neurological Disorders and Stroke (NINDS)/National Institutes of Health (NIH), and Department of Defense (DOD) Sport-Related Concussion Common Data Elements (CDEs). Poster presentation.  
**Authors:** Kristen Joseph, MA; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.
8. **April 2018** – American Academy of Neurology 70<sup>th</sup> Annual Meeting, April 21–April 27, 2018, Los Angeles, CA. Accelerating Headache Clinical Research Studies: The National Institute of Neurological Disorders and Stroke (NINDS) Headache Version 2.0 (V2.0). Poster presentation.  
**Authors:** Sarah Tanveer, BS; Sherita Ala'i, MS; Joy Esterlitz, MS; Michael L. Oshinsky, PhD on behalf of the Headache Version 2.0 CDE Working Group.
9. **May 2018** – 8<sup>th</sup> Annual Traumatic Brain Injury Conference, May 16–May 17, 2018, Washington, DC. Standardizing Clinical Research in Biomechanical Devices in Traumatic Brain Injury (TBI): The National Institute of Neurological Disorders and Stroke (NINDS) and Department of Defense (DoD) Common Data Elements (CDEs) Recommendations. Poster presentation.  
**Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices in TBI CDE Working Group.
10. **May 2018** – 8<sup>th</sup> Annual Traumatic Brain Injury Conference, May 16–May 17, 2018, Washington, DC. A Collaborative Approach to Streamlining Clinical Research: The National Institute of Neurological Disorders and Stroke (NINDS)/National Institutes of Health (NIH) and Department of Defense (DoD) Sport-Related Concussion Common Data Element (CDE) Recommendations. Poster presentation.  
**Authors:** Anthony Kontos, PhD; Steven Broglio, PhD, FACSM; Kathryn Schneider, PT, PhD; Elisabeth Wilde, PhD; Kristen Joseph, MA; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Katelyn Gay, BS; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.
11. **May 2018** – 2018 American College of Sports Medicine Annual Meeting, May 29–June 2, 2018, Minneapolis, MN. A Common Language for Clinical Research: NINDS/NIH and DOD Sport-Related Concussion Common Data Elements Recommendations. Poster presentation.  
**Authors:** Anthony Kontos, PhD; Steven Broglio, PhD; Harvey Levin, PhD; Kathryn Schneider, PhD; Elisabeth Wilde, PhD; Kristen Joseph, MA; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn



## NINDS CDE Presentations

Gay, BS; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.

12. **June 2018** – 2018 4<sup>th</sup> Federal Interagency Conference on Traumatic Brain Injury, June 11– June 13, 2018 Washington, DC. NIH/NINDS and the DOD CDE Recommendations: Biomechanical Devices in Head Impact and Blast Exposure Dynamics. Poster presentation.  
**Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Sherita Ala'i, MS; Joy Esterlitz, MS; Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices CDE Working Group.
13. **June 2018** – 2018 4<sup>th</sup> Federal Interagency Conference on Traumatic Brain Injury, June 11–June 13, 2018 Washington, DC. Harmonizing Data Sharing: NIH/NINDS/DOD Sport-Related Concussion Common Data Elements Version 1.0 Recommendations. Poster presentation.  
**Authors:** Kristen Joseph, MA; Steven Broglio, PhD; Anthony Kontos, PhD; Harvey Levin, PhD; Kathryn Schneider, PhD; Elisabeth Wilde, PhD; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.
14. **July 2018** – American Academy of Neurology Sports Concussion Conference, July 20–July 22, 2018, Indianapolis, IN. A Common Data Language for Biomechanical Devices used in TBI Clinical Research: The National Institute of Neurological Disorders and Stroke (NINDS) and Department of Defense (DoD) CDE Recommendations. Poster presentation.  
**Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Muniza Sheikh, MS, MBA; Joy Esterlitz, MS; Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices in TBI CDE Working Group.
15. **July 2018** – American Academy of Neurology Sports Concussion Conference, July 20–July 22, 2018, Indianapolis, IN. Streamlining Clinical Research: The National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH) and Department of Defense (DoD) Sport-Related Concussion Common Data Elements (CDE) Recommendations. Poster presentation.  
**Authors:** Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Joy Esterlitz, MS; Katelyn Gay, BS; Muniza Sheikh, MS, MBA; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.
16. **August 2018** – Neurotrauma, August 11–August 16, 2018, Toronto, Ontario. Common Data Elements for Sport- Related Concussion: NINDS/NIH Harmonization of Common Language for Clinical Research Studies Poster presentation.  
**Authors:** Kristen Joseph, MA; Carolina Mendoza-Puccini, MD; Joy Esterlitz, MS; Katelyn Gay, BS; Muniza Sheikh, MS, MBA; Patrick Bellgowan, PhD on behalf of the Sport-Related Concussion CDE Working Group.
17. **October 2018** – American Academy for Cerebral Palsy and Developmental Medicine 72<sup>nd</sup> Annual Meeting, October 9–October 13, 2018, Cincinnati, OH. The National Institute of Neurological



## NINDS CDE Presentations

Disorders and Stroke (NINDS) Updates to the Cerebral Palsy Common Data Elements Version 1.0 Recommendations. Breakfast Seminar.

**Authors:** Joline Brandenburg, MD; Robin Feldman, BS, MBA; Sherita Ala'i, MS; Joy Esterlitz, MS on behalf of the NINDS/AACPDM Cerebral Palsy CDE Oversight Committee and Working Groups.

18. **December 2018** – American Epilepsy Society 2018 Annual Meeting, November 30 – December 4, 2018, New Orleans, LA. Keeping Recommendations Current: Updates to the National Institute of Neurological Disorders and Stroke (NINDS) Epilepsy Common Data Element Recommendations.

**Authors:** Robin Feldman, BS, MBA; Joan Austin, PhD, FAAN; Jackie French, MD; Nicholas Barbaro, MD; Daniel Lowenstein, MD; Muniza Sheikh, MS, MBA; Ilar Edun, BA; Joy Esterlitz, MS; Vicky Whittemore, PhD on behalf of the Epilepsy CDE Oversight Committee and Working Groups.

### PRESENTATIONS IN 2017

19. **October 2017** – Congress of Neurological Surgeons 2017 Annual Meeting, October 7-11, Boston, MA: The National Institute of Neurological Disorders and Stroke (NINDS) Chiari I Malformation Common Data Elements (CDE) Recommendations Version 1.0.

**Authors:** Kristen Joseph, MA; Roger Kula, MD; Brandon Rocque, MD; Paolo Bolognese, MD; Cormac Maher, MD; John Heiss, MD; Allison Ashley-Koch, PhD; Dorothy Poppe, BA; Kaitlyn Esposito, BS; Joanne Odenkirchen, MPH; Robert Riddle, PhD; Sherita Ala'i, MS; Robin Feldman, BS, MBA; Ulrich Batzdorf, MD; Mark Luciano, MD, PhD

20. **September 2017** – Academy of Cerebral Palsy and Developmental Medicine (AAPDM), September 13–September 16, 2017, Montreal, Quebec, Canada: The National Institute of Neurological Disorders and Stroke (NINDS) and American Academy of Cerebral Palsy and Developmental Medicine (AAPDM) Cerebral Palsy Common Data Elements (CDE) Recommendations. Instructional Course.

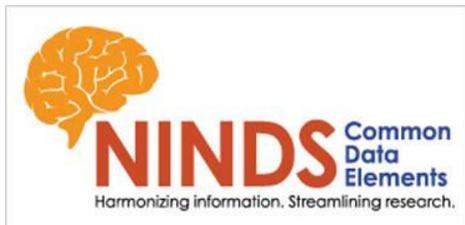
**Authors:** Joline E. Brandenburg, MD; Eileen Fowler, PhD, PT; Robin Feldman, BS, MBA; Sherita Ala'i, MS; Joy Esterlitz, MS on behalf of the NINDS/AACPDM Cerebral Palsy CDE Working Groups.

21. **September 2017** – 18th International Headache Congress, September 7–10, 2017, Vancouver, BC, Canada: Headache Version 2.0 Common Data Element (CDE) Recommendations: Updates to the National Institute of Neurological Disorders and Stroke (NINDS) Headache CDEs.

**Authors:** Sarah Tanveer, BS; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Michael L. Oshinsky, PhD on behalf of the Headache V2.0 CDE Working Group

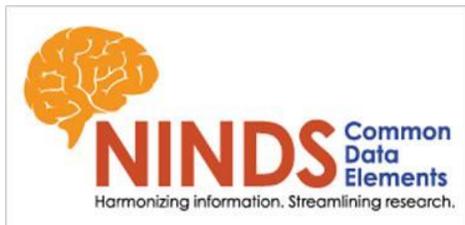
22. **July 2017** – 35<sup>th</sup> Annual National Neurotrauma Symposium, July 7-12, 2017, Snowbird, UT: Sports-Related Concussion Common Data Elements Version 1.0 Recommendations: A National Institute of Neurological Disorders and Stroke and National Institutes of Health and Department of Defense Project.

**Authors:** Kristen Joseph, MA; Claudia Moy, PhD; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.



## NINDS CDE Presentations

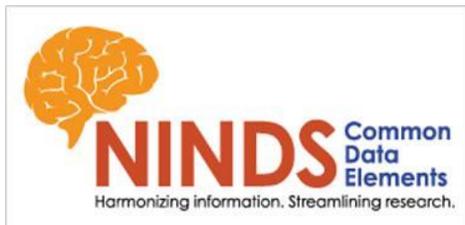
23. **July 2017** – 35<sup>th</sup> Annual National Neurotrauma Symposium, July 7-12, 2017, Snowbird, UT: Public Review of Biomechanical Devices in Traumatic Brain Injury (TBI) Common Data Elements (CDEs): The National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH) and Department of Defense (DOD) Version 1.0 Recommendations.  
**Authors:** Katelyn Gay, BS; Adam Bartsch, PhD, PE; David B. Camarillo, PhD; Carol Taylor-Burds, PhD; Sherita Ala'i, MS; Joy Esterlitz, MS; Kristen Joseph, MA; Patrick Bellgowan, PhD on behalf of the Biomechanical Devices in TBI CDE Working Group.
24. **July 2017** – American Academy of Neurology's Sports Concussion Conference, July 13-16, 2017, Jacksonville, FL: A Collaborative Project with the National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH) and Department of Defense (DOD): Sports- Related Concussion Common Data Elements Recommendations.  
**Authors:** Kristen Joseph, MA; Claudia Moy, PhD; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.
25. **June 2017** – American Headache Society (AHS) 59<sup>th</sup> Annual Scientific Meeting, June 8–11, 2017, Boston, MA: Public Review of Headache Version 2.0 Common Data Element (CDE) Recommendations: Updates to the National Institute of Neurological Disorders and Stroke (NINDS) Headache CDEs.  
**Authors:** Michael L. Oshinsky, PhD; Sarah Tanveer, BS; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Claudia Moy, PhD on behalf of the Headache V2.0 CDE Working Group.
26. **May 2017** – 7<sup>th</sup> Annual TBI Conference, May 24-25, Washington, DC: A National Institute of Neurological Disorders and Stroke and National Institutes of Health and Department of Defense Collaborative Project: Sports-Related Concussion Common Data Element Recommendations.  
**Authors:** Kristen Joseph, MA; Claudia Moy, PhD; Sherita Ala'i, MS; Joy Esterlitz, MS; Katelyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion CDE Working Group.
27. **May 2017** – Society for Clinical Trials 38<sup>th</sup> Annual Meeting, May 7–10, 2017, Liverpool, United Kingdom: A Common Data Language for Clinical Research Studies: Five (5) New Disease Recommendations from the National Institute of Neurological Disorders and Stroke, National Institutes of Health Common Data Elements Project.  
**Authors:** Joy Esterlitz, MS; Sherita Ala'i, MS; Robin Feldman, BS, MBA; Kristen Joseph, MA; Muniza Sheikh, MS, MBA; Claudia S. Moy, PhD; Sara S. Rue, MPH on behalf of the NINDS CDE Working Groups.
28. **April 2017** – Sports Neuropsychology Concussion Symposium 2017, April 27- 29, 2017, Cleveland, OH: Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke, National Institutes of Health and Department of Defense Traumatic Brain Injury Sports-Related Concussion Common Data Elements Recommendations.  
**Authors:** Steven Broglio, PhD; Kristen Joseph, MA; Sherita Ala'i, MS; Joy Esterlitz, MS; Kaitlyn Gay, BS; Patrick Bellgowan, PhD on behalf of the Sports-Related Concussion Working



## NINDS CDE Presentations

Groups.

29. **April 2017** – American Academy of Neurology Annual Meeting, April 22–28, 2017, Boston, MA: Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke (NINDS) and American Academy for Cerebral Palsy and Developmental Medicine (AAPDM) Cerebral Palsy Common Data Elements Version 1.0 Recommendations.  
**Authors:** Robin Feldman, BS, MBA; Joanne Odenkirchen, MPH; Sherita Ala'i, MS; Joy Esterlitz, MS; Tracy Burr on behalf of the NINDS/AACPDM Cerebral Palsy CDE Working Groups.
30. **April 2017** – American Academy of Neurology Annual Meeting, April 22–28, 2017, Boston, MA: Chiari I Malformation Common Data Element Project: The National Institute of Neurological Disorders and Stroke (NINDS) Chiari I Malformation Common Data Elements (CDE) Recommendations Version 1.0 Website Release.  
**Authors:** Sherita Ala'i, MS; Joanne Odenkirchen, MPH; Kristen Joseph, MA; Robin Feldman, BS, MBA; Kaitlyn M. Esposito, BS; Dorothy Poppe, BA on behalf of the Chiari I Malformation CDE Working Groups.
31. **April 2017** – American Academy of Neurology Annual Meeting, April 22–28, 2017, Boston, MA: Headache Version 2.0 Common Data Element (CDE) Recommendations: Update of the National Institute of Neurological Disorders and Stroke (NINDS) Headache CDEs.  
**Authors:** Sarah Tanveer, BS; Joanne Odenkirchen, MPH; Sherita Ala'i, MS; Joy Esterlitz, MS; Michael L. Oshinsky, PhD on behalf of the Headache V2.0 CDE Working Groups.
32. **April 2017** – American Academy of Neurology Annual Meeting, April 22–28, 2017, Boston, MA: A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke, National Institutes of Health and Department of Defense Traumatic Brain Injury Sports Concussion Common Data Elements Version 1.0 Recommendations.  
**Authors:** Kristen Joseph, MA; Joanne Odenkirchen, MPH; Sherita Ala'i, MS; Joy Esterlitz, MS; Sarah Tanveer, BS; Patrick Bellgowan, PhD on behalf of the Sports Concussion CDE Working Group.
33. **April 2017** – American Academy of Neurology Annual Meeting, April 22–28, 2017, Boston, MA: A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke and National Library of Medicine Unruptured Cerebral Aneurysms and Subarachnoid Hemorrhage Common Data Elements Version 1.0 Recommendations.  
**Authors:** Muniza Sheikh, MS, MBA; Sherita Ala'i, MS; Joy Esterlitz, MS; Liz Amos, MLIS; Christophe Ludet, MS; Joanne Odenkirchen, MPH; Jose Ignacio Suarez, MD on behalf of the SAH CDE Working Group.
34. **February 2017** – International Stroke Conference, Feb. 21–24, 2017, Houston, TX: A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke and National Library of Medicine Cerebral Aneurysms and Subarachnoid Hemorrhage



## NINDS CDE Presentations

Common Data Elements Version 1.0 Recommendations.

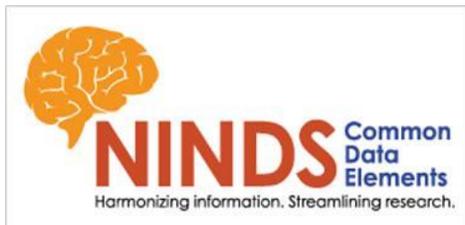
**Authors:** Joanne Odenkirchen, MPH; Liz Amos, MLIS; Christophe Ludet, MS; Muniza Sheikh, MS, MBA; Sherita Ala'i, MS; Joy Esterlitz, MS; Jose Ignacio Suarez, MD on behalf of the SAH and Unruptured Cerebral Aneurysms CDE Working Group.

### PRESENTATIONS IN 2016

35. **October 2016** – 12th International IACFS/ME Research and Clinical Conference: Emerging Science and Clinical Care, October 27-30, 2016, Fort Lauderdale, Florida: Common Data Elements (CDEs) for Standardized Testing and Clinical Studies.  
**Authors:** Elizabeth R. Unger, PhD; Vicky Whittemore, PhD; Joy Esterlitz, MS
36. **September 2016** – American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) 70th Annual Meeting, September 20–24, 2016, Hollywood, FL: Common Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke/American Academy for Cerebral Palsy and Developmental Medicine Common Data Elements V1.0 Recommendations.  
**Authors:** Joanne Odenkirchen, MPH; Tracy Burr, CAE; Sherita Ala'i, MS; Joy Esterlitz, MS; Robin Feldman, BS, MBA
37. **September 2016** – Myotonic Dystrophy Foundation 2016 Annual Conference, September 15 – 17, 2016, Arlington, VA: A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke Myotonic Dystrophy Common Data Elements Version 1.0 Recommendations.  
**Authors:** Joanne Odenkirchen, MPH; Sherita Ala'i, MS; Robin Feldman, BS, MBA; Joy Esterlitz, MS; Muniza Sheikh, MS, MBA on behalf of the NINDS Myotonic Dystrophy CDE Working Groups.
38. **September 2016** – 55th International Spinal Cord Society (ISCoS) Annual Scientific Meeting in Vienna, Austria, September 14 – 16, 2016: Pediatric SCI Common Data Element (CDE) Recommendations: Updates to the National Institute of Neurological Disorders and Stroke SCI CDEs.  
**Authors:** Joanne Odenkirchen, MPH; Lyn Jakeman, PhD; MaryJane Mulcahey, PhD, OTR/L; Lawrence C. Vogel, MD; Muniza Sheikh, MS, MBA; Sherita Ala'i, MS; Joy Esterlitz, MS; on behalf of the SCI Pediatric CDE Working Group.
39. **February 2016** – International Stroke Conference Feb. 17–19, 2016, Los Angeles, CA: 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

40. **December 2015** – American Epilepsy Society, December 5–8, 2015, Philadelphia, PA: A Common Data Language for Clinical Research Studies: The NINDS Common Data Elements.



## NINDS CDE Presentations

**Authors:** Joanne Odenkirchen, MPH; Joy Esterlitz, MS; Muniza Sheikh, MS, MBA

41. **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; Joy Esterlitz, MS on behalf of the NINDS Mitochondrial Disease CDE Working Groups.

42. **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

43. **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

44. **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.

45. **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.

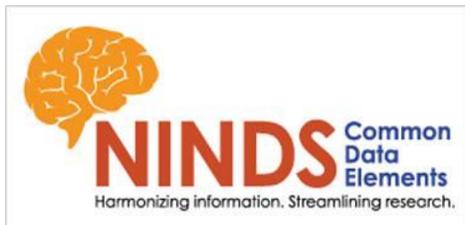
**Authors:** Joanne Odenkirchen, MPH; Joy Esterlitz, MS; Sherita Ala'i, MS; Muniza Sheikh, MS, MBA on behalf of the NINDS Stroke Working Groups.

### PRESENTATIONS IN 2014

46. **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.

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

47. **September 2014** – International Spinal Cord Society Annual Scientific Meeting, September 2–4, 2014, Maastricht, The Netherlands. Public Review: The National Institute of Neurological



## NINDS CDE Presentations

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.

48. **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, MPH; Sherita Ala'i, MS; Divya Nigam, BS; Joy Esterlitz on behalf of the NINDS Mitochondrial Disease CDE Working Groups.

49. **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).

**Authors:** Joy Esterlitz, MS; Sherita Ala'i, MS; Petra Kaufmann, PhD; Matthew McAuliffe, PhD; Matthew Beyers, MSc; Joanne Odenkirchen, MPH

50. **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.

51. **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, MD, PhD

### PRESENTATIONS IN 2013

52. **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, MPH on behalf of the Spinal Cord Injury Common Data Element Working Group.

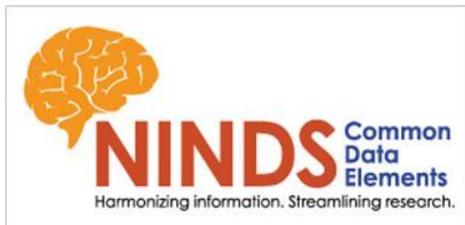
### PRESENTATIONS IN 2012

53. **October 2012** – American Congress of Rehabilitation Medicine, October 13, 2012, Putting TBI Common Data Elements into Practice.

54. **August 2012** – Hereditary Disease Foundation's 8th 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, MD, PhD on behalf of the Huntington's Disease Common Data Element Working Group.

55. **June 2012** – American Headache Society, 54th Annual Scientific Meeting, June 21-24, 2012,



## NINDS CDE Presentations

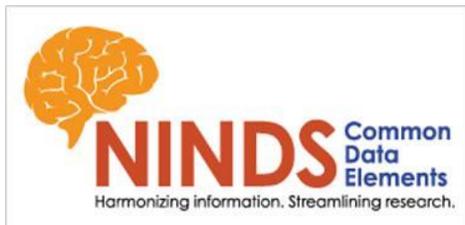
Developing Common Data Elements (CDEs) for Headache Clinical Research: NINDS Initiative.

**Authors:** Andrew Charles, MD; Mitchell Brin, MD; Joanne Odenkirchen, MPH; Linda Porter, MD on behalf of the Headache CDE Working Group.

56. **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, MD, PhD on behalf of the Huntington’s Disease Common Data Element Working Group.
57. **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, MD; Steven Warach, MD; Catherine Amlie-Lefond, MD; Joseph Broderick, MD; Colin Derdeyn, MD; Billy Dunn, MD; Mitchell Elkind, MD; Lawrence Fine, MD; Mary George, MD; Michael Hill, MD; Virginia Howard, PhD; Kennedy R. Lees, MD; David Levy, MD; Bo Norrving, PhD; Yuko Palesch, PhD; Lee Schwamm, MD; Pooja Khatri, MD; Stacie Grinnon, MS; Lisa Hunegs, MSW, MPH; Megan Otruba, BS; Scott Janis, PhD; Petra Kaufmann, MD; Joanne Odenkirchen, MPH
58. **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, MD, PhD; Jennifer Farmer, MS; Kenneth Fischbeck, MD; Paul Kantor, PhD David Lynch, MD, PhD; Massimo Pandolfo, MD; Mark Payne, MD; Susan Perlman, MD; Jorg Schulz, MD; Robert Shaddy, MD; Subha Raman, MD; Petra Kaufmann, MD; Joanne Odenkirchen, MPH; Lisa Hunegs, MSW, MPH
59. **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, MSW, MPH; Alexandra Stout; Joanne Odenkirchen, MPH

## PRESENTATIONS PRIOR TO 2012

61. **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, MD, PhD; Karl Kieburtz, MD, PhD; Wendy Galpern, MD, PhD; Mahlon DeLong, MD; Dennis Dickson, MD; Jordan Elm, PhD; Tatiana Foroud, PhD; Cornelia Kamp, MBA; Anthony Lang, MD; Karen Marder, MD, MPH; Kenneth Marek, MD; Ronald Pfeiffer, MD; G Webster Ross, MD; Andrew Siderowf, MD; Daniel Weintraub, MD on behalf of the NINDS Parkinson’s Disease Common Data Element Working Group.
62. **December 2011** - 2011 AES Annual Meeting; December 5, 2011: National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Common Data

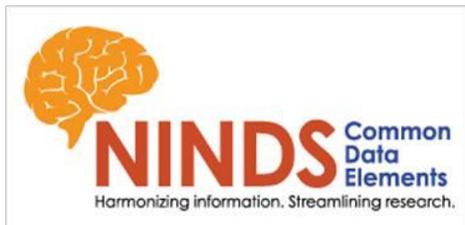


## NINDS CDE Presentations

Element (CDE) Project: Epilepsy CDE Update. (*Poster Presentation*)

**Authors:** Stacie Grinnon, MS; Alexandra Stout, Brandy Fureman, PhD; Joanne Odenkirchen, MPH on behalf of the Epilepsy Disease Common Data Element Working Group.

63. **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, PhD; Joanne Odenkirchen, MPH; Stacie Grinnon, MS, Alexandra Stout
64. **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.  
**Authors:** Wendy Galpern, MD, PhD on behalf of the Huntington’s Disease Working Group.
65. **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, MD, PhD on behalf of the Huntington’s Disease Working Group.
66. **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, MD; Susan Charlifue, PhD; Michael J. DeVivo, DrPH; Stacie T. Grinnon, MS; Naomi Kleitman, PhD; Joanne Odenkirchen, MPH
67. **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, MD, PhD on behalf of the NINDS Parkinson’s Disease Common Data Element Working Group.
68. **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, MD; Kyra Becker, MD; Oscar Benavente, MD; Joseph Broderick, MD; Alexander Dromerick, MD; Pamela Duncan, PhD; Karen Johnston, MD; Chelsea Kidwell, MD; James Meschia, MD; Lee Schwamm, MD; Stacie Grinnon, MS, Lisa Hunegs, MSW, MPH; Scott Janis, PhD; Joanne Odenkirchen, MPH; Steven Warach, MD, PhD
69. **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, MD, PhD; Jennifer Farmer, MD; Kenneth Fischbeck, MD; Wendy Galpern, MD, PhD; Lisa Hunegs, MSW; MPH; Paul Kantor, PhD; Petra Kaufmann, MD; David Lynch, MD; Kristy Miller, MPH; Joanne Odenkirchen, MPH; Massimo Pandolfo, MD; Mark Payne, MD; Susan Perlman, MD Jorg Schulz, MD; Robert Shaddy, MD; Subha Raman, MD
70. **April 2011** – American Academy of Neurology (AAN); April 9-16, 2011, National Institute of



## NINDS CDE Presentations

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, MS; Kristy Miller, MPH; Petra Kaufmann, MD; Wendy Galpern, MD, PhD; Joanne Odenkirchen, MPH

71. **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, MS; Lisa Hunegs, MSW, MPH; Joanne Odenkirchen, MPH
72. **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, MS, Lisa Hunegs, MSW, MPH; Alexandra Stout, Brandy Fureman, PhD; Joanne Odenkirchen, MPH
73. **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, MS; Kristy Miller, MPH; Patti Shugarts, Yun Lu, PhD; Dianne Reeves, Joanne Odenkirchen, MPH
74. **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, RN, MSN; Joanne Odenkirchen, MPH
75. **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, MS; Alex Stout; Joanne Odenkirchen, MPH
76. **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, MPH; Stacie T. Grinnon, MS; Joanne Odenkirchen, MPH