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The NINDS CDE Project has been referenced in the following publications:

PRIMARY PUBLICATION

1. Grinnon ST, Miller K, Marler JR, Lu Y, Stout A, Odenkirchen J, Kunitz S. National Institute of Neurological Disorders and Stroke Common Data Element Project - approach and methods. Clin Trials. 2012 Jun; 9(3):322-329. PubMed PMID: 22371630.

PUBLICATIONS IN 2024

2. Schiariti V, Shierk A, Stashinko EE, Sukal-Moulton T, Feldman RS, Aman C, Mendoza-Puccini MC, Brandenburg JE; National Institute of Neurological Disorders and Stroke Cerebral Palsy Common Data Elements Oversight Committee. Cerebral palsy pain instruments: Recommended tools for clinical research studies by the National Institute of Neurological Disorders and Stroke Cerebral Palsy Common Data Elements project. Dev Med Child Neurol. 2024 May;66(5):610-622. doi: 10.1111/dmcn.15743. Epub 2023 Aug 31. PMID: 37650571; PMCID: PMC10902183.

PUBLICATIONS IN 2019

3. Suarez JI, Sheikh MK, Macdonald RL, Amin-Hanjani S, Brown RD Jr, de Oliveira Manoel AL, Derdeyn CP, Etminan N, Keller E, Leroux PD, Mayer SA, Morita A, Rinkel G, Rufennacht D, Stienen MN, Torner J, Vergouwen MDI, Wong GKC; Unruptured Intracranial Aneurysms and SAH CDE Project Investigators. Common Data Elements for Unruptured Intracranial Aneurysms and Subarachnoid Hemorrhage Clinical Research: A National Institute for Neurological Disorders and Stroke and National Library of Medicine Project. Neurocrit Care. 2019 Jun;30(Suppl 1):4-19. doi: 10.1007/s12028-019-00723-6. PubMed PMID: 31087257.
4. Bijlenga P, Morita A, Ko NU, Mocco J, Morel S, Murayama Y, Wermer MJH, Brown RD Jr; Unruptured Cerebral Aneurysms and SAH CDE Project Investigators. Common Data Elements for Subarachnoid Hemorrhage and Unruptured Intracranial Aneurysms: Recommendations from the

- Working Group on Subject Characteristics. *Neurocrit Care*. 2019 Jun;30(Suppl 1):20-27. doi: 10.1007/s12028-019-00724-5. PMID: 31077079.
5. Damani R, Mayer S, Dhar R, Martin RH, Nyquist P, Olson DM, Mejia-Mantilla JH, Muehlschlegel S, Jauch EC, Mocco J, Mutoh T, Suarez JI; Unruptured Intracranial Aneurysms and SAH CDE Project Investigators. Common Data Element for Unruptured Intracranial Aneurysm and Subarachnoid Hemorrhage: Recommendations from Assessments and Clinical Examination Workgroup/Subcommittee. *Neurocrit Care*. 2019 Jun;30(Suppl 1):28-35. doi: 10.1007/s12028-019-00736-1. PMID: 31090013.
 6. de Oliveira Manoel AL, van der Jagt M, Amin-Hanjani S, Bambakidis NC, Brophy GM, Bulsara K, Claassen J, Connolly ES, Hoffer SA, Hoh BL, Holloway RG, Kelly AG, Mayer SA, Nakaji P, Rabinstein AA, Vajkoczy P, Vergouwen MDI, Woo H, Zipfel GJ, Suarez JI; Unruptured Aneurysms and SAH – CDE Project Investigators. Common Data Elements for Unruptured Intracranial Aneurysms and Aneurysmal Subarachnoid Hemorrhage: Recommendations from the Working Group on Hospital Course and Acute Therapies-Proposal of a Multidisciplinary Research Group. *Neurocrit Care*. 2019 Jun;30(Suppl 1):36-45. doi: 10.1007/s12028-019-00726-3. PMID: 31119687.
 7. Chou SH, Macdonald RL, Keller E; Unruptured Intracranial Aneurysms and SAH CDE Project Investigators. Biospecimens and Molecular and Cellular Biomarkers in Aneurysmal Subarachnoid Hemorrhage Studies: Common Data Elements and Standard Reporting Recommendations. *Neurocrit Care*. 2019 Jun;30(Suppl 1):46-59. doi: 10.1007/s12028-019-00725-4. PMID: 31144274.
 8. Hackenberg KAM, Etminan N, Wintermark M, Meyers PM, Lanzino G, Rüfenacht D, Krings T, Huston J 3rd, Rinkel G, Derdeyn C; Unruptured Intracranial Aneurysms and SAH CDE Project Investigators. Common Data Elements for Radiological Imaging of Patients with Subarachnoid Hemorrhage: Proposal of a Multidisciplinary Research Group. *Neurocrit Care*. 2019 Jun;30(Suppl 1):60-78. doi: 10.1007/s12028-019-00728-1. PMID: 31115823.
 9. Wong GKC, Daly JJ, Rhoney DH, Broderick J, Ogilvy C, Roos YB, Siddiqui A, Torner J; Unruptured Intracranial Aneurysm and SAH CDE Project Investigators. Common Data Elements for Unruptured Intracranial Aneurysm and Subarachnoid Hemorrhage Clinical Research: Recommendations from the Working Group on Long-Term Therapies. *Neurocrit Care*. 2019 Jun;30(Suppl 1):79-86. doi: 10.1007/s12028-019-00727-2. PMID: 31077078.
 10. Hackenberg KAM, Algra A, Salman RA, Frösen J, Hasan D, Juvela S, Langer D, Meyers P, Morita A, Rinkel G, Etminan N; Unruptured Aneurysms and SAH CDE Project Investigators. Definition and Prioritization of Data Elements for Cohort Studies and Clinical Trials on Patients with Unruptured Intracranial Aneurysms: Proposal of a Multidisciplinary Research Group. *Neurocrit Care*. 2019 Jun;30(Suppl 1):87-101. doi: 10.1007/s12028-019-00729-0. PMID: 31102238.
 11. Luciano MG, Batzdorf U, Kula RW, Rocque BG, Maher CO, Heiss J, Martin BA, Bolognese PA, Ashley-Koch A, Limbrick D, Poppe DJ, Esposito KM, Odenkirchen J, Esterlitz JR, Ala'i S, Joseph K, Feldman RS, Riddle R; Chiari I Malformation Common Data Element Working Group. Development of Common Data Elements for Use in Chiari Malformation Type I Clinical Research: An NIH/NINDS Project. *Neurosurgery*. 2019 Dec 1;85(6):854-860. doi: 10.1093/neuros/nyy475. PMID: 30690581; PMCID: PMC7054710.

PUBLICATIONS IN 2018

12. Lawlor MW, Iannaccone ST, Mathews K, Muntoni F, Alai-Hansen S, Odenkirchen JC, S Feldman R; CMD Working Group. NINDS Common Data Elements for Congenital Muscular Dystrophy Clinical Research: A National Institute for Neurological Disorders and Stroke Project. *J Neuromuscul Dis.* 2018;5(1):75-84. doi: 10.3233/JND-170248. PubMed PMID: 29480213.
13. Schiariti V, Fowler E, Brandenburg J, Levey E, McIntyre S, Sukal-Moulton T, Ramey S, Rose J, Sienko S, Stashinko E, Vogtle L, Feldman RS, Koenig J, On behalf of the AACPDM Cerebral Palsy CDE Working Groups. A Common Data Language for Clinical Research Studies: The National Institute of Neurological Disorders and Stroke and American Academy for Cerebral Palsy and Developmental Medicine Cerebral Palsy Common Data Elements Version 1.0 Recommendations. *Developmental Medicine and Child Neurology.* 2018;60(10):976-986. Pubmed PMID:29542813.
14. Broglio SP, Kontos AP, Levin H, Schneider K, Wilde EA, Cantu RC, Feddermann-Demont N, Fuller GW, Gagnon I, Goia GA, Giza C, Griesbach GS, Leddy JJ, Lipton ML, Mayer AR, McAllister TW, McCrea M, McKenzie LB, Putukian M, Signoretti S, Suskauer SJ, Tamburro R, Turner M, Yeates KO, Zemek R, Ala'I S, Esterlitz, J, Gay K, Bellgowan PSF, Joseph K, On behalf of the Sport-Related Concussion CDE Working Group. The National Institute of Neurological Disorders and Stroke and Department of Defense Sport-Related Concussion Common Data Elements Version 1.0 Recommendations. *J Neurotrauma.* 2018;35(23):2776-2783. Pubmed PMID: 29717643.
15. Oshinsky ML, Tanveer S. Improving research through NINDS Headache Common Data Elements. *Cephalalgia.* 2018 Dec;38(14):2083-2084. doi: 10.1177/0333102418773076. Epub 2018 Apr 24. PubMed PMID: 29688036.

PUBLICATIONS IN 2017

16. Karaa A, Rahman S, Lombès A, Yu-Wai-Man P, Sheikh MK, Alai-Hansen S, Cohen BH, Dimmock D, Emrick L, Falk MJ, McCormack S, Mirsky D, Moore T, Parikh S, Shoffner J, Taivassalo T, Tarnopolsky M, Tein I, Odenkirchen JC, Goldstein A; Mito Working Group Member Participants... Common data elements for clinical research in mitochondrial disease: A National Institute for Neurological Disorders and Stroke project. *J Inherit Metab Dis.* 2017 Mar 16. doi: 10.1007/s10545-017-0035-5.
17. Mulcahey MJ, Vogel LC, Sheikh M, Arango-Lasprilla JC, Augutis M, Garner E, Hagen EM, Jakeman LB, Kelly E, Martin R, Odenkirchen J, Scheel-Sailer A, Schottler J, Taylor H, Thielen CC, Zebracki K. Recommendations for the National Institute for Neurologic Disorders and Stroke spinal cord injury common data elements for children and youth with SCI. *Spinal Cord.* 2017 Apr;55(4):331-340. doi: 10.1038/sc.2016.139. Epub 2016 Nov 15. PMID: 27845358.

PUBLICATIONS IN 2016

18. Sheehan J, Hirschfeld S, Foster E, Ghitza U, Goetz K, Karpinski J, Lang L, Moser RP, Odenkirchen J, Reeves D, Rubinstein Y, Werner E, Huerta M. Improving the value of clinical research through the use of Common Data Elements. *Clin Trials.* 2016 Dec;13(6):671-676. doi: 10.1177/1740774516653238. Epub 2016 Jun 15. PMID: 27311638; PMCID: PMC5133155.
19. Shapiro E, Bernstein J, Adams HR, Barbier AJ, Buracchio T, Como P, Delaney KA, Eichler F, Goldsmith JC, Hogan M, Kovacs S, Mink JW, Odenkirchen J, Parisi MA, Skrinar A, Waisbren SE, Mulberg AE. Neurocognitive clinical outcome assessments for inborn errors of metabolism and other

rare conditions. *Mol Genet Metab.* 2016 Jun;118(2):65-9. PubMed PMID: 27132782.

20. Dastgir J, Rutkowski A, Alvarez R, Cossette SA, Yan K, Hoffmann RG, Sewry C, Hayashi YK, Goebel HH, Bonnemann C, Lawlor MW. Common Data Elements for Muscle Biopsy Reporting. *Arch Pathol Lab Med.* 2016 Jan;140(1):51-65. doi: 10.5858/arpa.2014-0453-OA. Epub 2015 Jul 1. PMID: 26132600; PMCID: PMC4975562.

PUBLICATIONS IN 2015

21. Biering-Sørensen F, Alai S, Anderson K, Charlifue S, Chen Y, DeVivo M, Flanders AE, Jones L, Kleitman N, Lans A, Noonan VK, Odenkirchen J, Steeves J, Tansey K, Widerström-Noga E, Jakeman LB. Common data elements for spinal cord injury clinical research: a National Institute for Neurological Disorders and Stroke project. *Spinal Cord.* 2015 Apr; 53(4):265-277. PubMed PMID: 25665542.
22. Biering-Sørensen F, Noonan V, and Odenkirchen J. International spinal cord injury data sets and the National Institute of Neurological Disorders and Stroke common data elements project. In: Chhabra HS, ed. *ISCOs Textbook of Comprehensive Management of Spinal Cord Injuries.* 1st ed. New Delhi: Wolters Kluwer (India) Pvt., Ltd; 2015:1121-1160.

PUBLICATIONS IN 2013

23. Hicks, R. The International TBI Common Data Elements Project: Getting Farther, Faster. The Challenge, Summer 2013;7(3):6-7.
24. Yue JK, Vassar MJ, Lingsma H, Cooper SR, Yuh EL, Mukherjee P, Puccio AM, Gordon W, Okonkwo DO, Valadka A, Schnyer DM, Maas A, Manley GT, Casey SS, Cheong M, Dams-O'Connor K, Hricik AJ, Knight EE, Kulubya ES, Menon D, Morabito DJ, Pacheco JL, Sinha TK. Transforming research and clinical knowledge in Traumatic Brain Injury (TRACK-TBI) Pilot: Multicenter implementation of the common data elements for traumatic brain injury. *J Neurotrauma.* 2013 Nov; 30(22):1831-1844. PubMed PMID: 23815563.
25. Hicks R, Giacino J, Harrison-Felix CL, Manley GT, Valadka A, and Wilde EA. Progress in developing common data elements for traumatic brain injury research: version two – The end of the beginning. *J Neurotrauma.* 2013 Nov; 30(22): 1852-1861. PubMed PMID: 23725058.
26. Sherman AV, Gubitza AK, Al-Chalabi A, Bedlack R, Berry J, Conwit R, Harris BT, Horton DK, Kaufmann P, Leitner ML, Miller R, Shefner J, Vonsattel JP, Mitsumoto H. 2013. Infrastructure resources for clinical research in amyotrophic lateral sclerosis. *Amyotroph Lateral Scler Frontotemporal Degener.* 2013 May; 14 Suppl 1:53-61. PubMed PMID: 23678880.
27. Okonkwo DO, Yue JK, Puccio AM, Panczykowski D, Inoue T, McMahon PJ, Sorani MD, Yuh EL, Lingsma H, Maas A, Valadka A, Manley GT. 2013. GFAP-BDP as an acute diagnostic marker in traumatic brain injury: Results from the prospective transforming research and clinical knowledge in traumatic brain injury study. *J Neurotrauma.* 2013 Sep; 30(17): 1490-1497. PubMed PMID: 23489259.
28. Lynch DR, Pandolfo M, Schulz JB, Perlman S, Delatycki MB, Payne RM, Shaddy R, Fischbeck KH, Farmer J, Kantor P, Raman SV, Hunegs L, Odenkirchen J, Miller K, Kaufmann P. Common data elements for clinical research in Friedreich's ataxia. *Mov Disord.* 2013 Feb; 28(2):1-5. PubMed PMID: 23239403
29. Yuh EL, Mukherjee P, Lingsma HF, Yue JK, Ferguson AR, Gordon WA, Valadka AB, Schnyer DM, Okonkwo DO, Maas AIR, Manley GT; TRACK-TBI Investigators. Magnetic resonance imaging improves 3-month outcome prediction in mild traumatic brain injury. *Ann Neurol.* 2013 Feb; 73(2):224-235, 2013. PubMed PMID: 23224915.

PUBLICATIONS IN 2012

30. Biering-Sørensen F, Charlifue S, Devivo MJ, Grinnon ST, Kleitman N, Lu Y, Odenkirchen J. Using the Spinal Cord Injury Common Data Elements. *Top Spinal Cord Inj Rehabil.* 2012 Winter; 18(1):23-27. PubMed PMID: 22408366.
31. Grinnon ST, Miller K, Marler JR, Lu Y, Stout A, Odenkirchen J, Kunitz S. National Institute of Neurological Disorders and Stroke Common Data Element Project - approach and methods. *Clin Trials.* 2012 Jun; 9(3):322-329. PubMed PMID: 22371630.
32. Saver JL, Warach S, Janis S, Odenkirchen J, Becker K, Benavente O, Broderick J, Dromerick A, Duncan P, Elkind MSV, Johnston K, Kidwell CS, Meschia JF, Schwamm L, for the NINDS Common Data Element Working Group. Standardizing the Structure of Stroke Clinical and Epidemiological Research Data: The NINDS Stroke Common Data Element (CDE) Project. *Stroke.* 2012 Apr; 43(4):967-973. PubMed PMID: 22308239.
33. Gerring JP, Wade S. The Essential Role of Psychosocial Risk and Protective Factors in Pediatric TBI Research. *J Neurotrauma.* 2012 Mar; 29: 621-628. PubMed PMID: 22091875.
34. Duhaime AC, Holshouser B, Hunter JV, Tong K. Common Data Elements for Neuroimaging of Traumatic Brain Injury: Pediatric Considerations. *J Neurotrauma.* 2012 Mar; 29(4): 629-633. PubMed PMID: 21671798.
35. Miller AC, Odenkirchen J, Duhaime AC, Hicks R. Common Data Elements for Research on Traumatic Brain Injury - Pediatric Considerations. *J Neurotrauma.* 2012 Mar; 29(4): 634-638. PubMed PMID: 22091862.
36. Adelson PD, Pineda J, Bell MJ, Abend NS, Berger RP, Giza CC, Hotz G, Wainwright M; Pediatric TBI Demographics and Clinical Assessment Working Group. Common data elements for pediatric traumatic brain injury: Recommendations from the working group on demographics and clinical assessment. *J Neurotrauma.* 2012 Mar; 29(4): 639-653. PubMed PMID: 21939389.
37. Hunter JV, Wilde EA, Tong KA, Holshouser BA. Emerging imaging tools for use with traumatic brain injury research. *J Neurotrauma.* 2012 Mar; 29(4): 654-671. PubMed PMID: 21787167.
38. Berger RP, Beers SR, Papa L, Bell M. Common Data Elements for Pediatric Traumatic Brain Injury: Recommendations from the Biospecimens and Biomarkers Workgroup. *J Neurotrauma.* 2012 Mar; 29(4): 672-677. PubMed PMID: 22106839.
39. McCauley SR, Wilde EA, Anderson VA, Bedell G, Beers SR, Campbell TF, Chapman SB, Ewing-Cobbs L, Gerring JP, Gioia GA, Levin HS, Michaud LJ, Prasad MR, Swaine BR, Turkstra LS, Wade SL, Yeates KO. Recommendations for the Use of Common Outcome Measures in Pediatric Traumatic Brain Injury Research. *J Neurotrauma.* 2012 Mar; 29(4): 678-705. PubMed PMID: 21644810.

PUBLICATIONS PRIOR TO 2012

40. Loring D, Lowenstein D, Barbaro N, Fureman B, Odenkirchen J, Jacobs M, Austin J, Dlugos D, French J, Gaillard W, Hermann B, Hesdorffer D, Roper S, VanCott A, Grinnon S, Stout A. Common data elements in epilepsy research: Development and implementation of the NINDS epilepsy CDE project. *Epilepsia.* 2011 Jun; 52(6):1186-1191. PubMed PMID: 21426327.
41. Maas AI, Harrison-Felix CL, Menon D, Adelson PD, Balkin T, Bullock R, Engel DC, Gordon W, Langlois-Orman J, Lew HL, Robertson C, Temkin N, Valadka A, Verfaellie M, Wainwright M, Wright

- DW, Schwab K. Standardizing data collection in traumatic brain injury. *J Neurotrauma*. 2011 Feb; 28(2):177-187. PubMed PMID: 21162610.
42. Biering-Sørensen F, Charlifue S, DeVivo MJ, Grinnon ST, Kleitman N, Lu Y, Odenkirchen J. Incorporation of the International Spinal Cord Injury Data Set Elements into the National Institute of Neurological Disorders and Stroke Common Data Elements. *Spinal Cord*. 2011 Jan; 49(1):60-64. PubMed PMID: 20733589.
 43. Loring, DW & Hermann, BP. Neuropsychology and the epilepsy common data element project. In: Helmstaedter, C, Lassonde, M, Hermann, B, Kahane, P, and Arzimanoglou, A. (eds.) *Neuropsychology in the Care of People with Epilepsy*. Paris: John Libbey Eurotext; 2011: 59-68.
 44. Menon DK, Schwab K, Wright DW, Maas AI; Demographics and clinical assessment working group of the International and Interagency Initiative toward Common Data Elements for Research on Traumatic Brain Injury and Psychological Health. Position statement: definition of traumatic brain injury. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1637-1640. PubMed PMID: 21044706.
 45. Maas AI, Harrison-Felix CL, Menon D, Adelson PD, Balkin T, Bullock R, Engel DC, Gordon W, Orman JL, Lew HL, Robertson C, Temkin N, Valadka A, Verfaellie M, Wainwright M, Wright DW, Schwab K. Common data elements for traumatic brain injury: recommendations from the interagency working group on demographics and clinical assessment. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1641-1649. PubMed PMID: 21044707.
 46. Wilde EA, Whiteneck GG, Bogner J, Bushnik T, Cifu DX, Dikmen S, French L, Giacino JT, Hart T, Malec JF, Millis SR, Novack TA, Sherer M, Tulskey DS, Vanderploeg RD, von Steinbuechel N. Recommendations for the use of common outcome measures in traumatic brain injury research. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1650-1660.e17. PubMed PMID: 21044708.
 47. Duhaime AC, Gean AD, Haacke EM, Hicks R, Wintermark M, Mukherjee P, Brody D, Latour L, Riedy G; Common Data Elements Neuroimaging Working Group Members, Pediatric Working Group Members. Common data elements in radiologic imaging of traumatic brain injury. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1661-1666. PubMed PMID: 21044709.
 48. Manley GT, Diaz-Arrastia R, Brophy M, Engel D, Goodman C, Gwinn K, Veenstra TD, Ling G, Ottens AK, Tortella F, Hayes RL. Common data elements for traumatic brain injury: recommendations from the biospecimens and biomarkers working group. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1667-1672. PubMed PMID: 21044710.
 49. Nash WP, Vasterling J, Ewing-Cobbs L, Horn S, Gaskin T, Golden J, Riley WT, Bowles SV, Favret J, Lester P, Koffman R, Farnsworth LC, Baker DG. Consensus recommendations for common data elements for operational stress research and surveillance: report of a federal interagency working group. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1673-1683. PubMed PMID: 21044711.
 50. Kaloupek DG, Chard KM, Freed MC, Peterson AL, Riggs DS, Stein MB, Tuma F. Common data elements for posttraumatic stress disorder research. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1684-1691. PubMed PMID: 21044712.
 51. Whyte J, Vasterling J, Manley GT. Common data elements for research on traumatic brain injury and psychological health: current status and future development. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1692-1996. PubMed PMID: 21044713.
 52. Thurmond VA, Hicks R, Gleason T, Miller AC, Szufliata N, Orman J, Schwab K. Advancing integrated research in psychological health and traumatic brain injury: common data elements. *Arch Phys Med Rehabil*. 2010 Nov; 91(11):1633-1636. PubMed PMID: 21044705.

NINDS CDE Publications

53. Haacke EM, Duhaime AC, Gean AD, Riedy G, Wintermark M, Mukherjee P, Brody DL, DeGraba T, Duncan TD, Elovic E, Hurley R, Latour L, Smirniotopoulos JG, Smith DH. Common data elements in radiologic imaging of traumatic brain injury. *J Magn Reson Imaging*. 2010 Sep; 32(3):516-543. PubMed PMID: 20815050.
54. Stone K. NINDS common data element project: A long-awaited breakthrough in streamlining trials. *Ann Neurol*. 2010 Jul; 68(1):A11-A13. PubMed PMID: 20583225.
55. Traumatic brain injury: time to end the silence. *Lancet Neurol*. 2010 Apr; 9(4):331. PubMed PMID: 20298955.
56. Miller G. Neuroscience. New guidelines aim to improve studies of traumatic brain injury. *Science*. 2010 Apr 16; 328(5976):297. PubMed PMID: 20395488.