

# Standardize Your Research Data with the NIH Common Data Element Repository

December 12, 2024

National Library of Medicine



National Library of Medicine

# Before We Start

- Captions: click Show Captions button
- Chat:
  - Send questions to EVERYONE
  - Find the chat now and share your organization and role/title
- Handout: link in chat
- Reactions: give me a thumbs up!



# Agenda

- Introduction to CDEs
- Searching the CDE-R
- Saving CDEs for later
- How to get help



# Poll: You & CDEs



# Participant Organization

Your Responses	Standardized Responses
National Library of Medicine	NLM
NHLBI	NHLBI
AHRQ	AHRQ
National Cancer Institute (NCI)	NCI
Nat. Instit. Of Drug Abuse	NIDA
NLM	NLM
NEI (National Eye Institute)	NEI

# Familiarity with CDEs

## Data Set 1

Response	# of Participants
A	6
B	10
C	12
D	5
E	9

## Data Set 2

Free Text Responses	Participants
I'm super familiar with CDEs, use them all the time	Participant 1
Not familiar at all	Participant 2
Unfamiliar	Participant 3
I know a little about them but not a lot	Participant 4
I know a bit but I have a lot of questions; for example...	Participant 5

# Common Data Elements (CDEs) Definition

**Common Data Elements (CDEs)** are standardized, precisely defined questions paired with a set of specific allowable responses, used systematically across different sites, studies, or clinical trials to ensure consistent data collection.

# Example: Usual Place of Care

- **Standardized, precisely defined question:** Is there a place that you USUALLY go to when you are sick or need advice about your health? Select all that apply.
- **Specific allowable responses:**
  - A doctor's office or community health center or hospital-based clinic
  - Walk-in clinic, urgent care, or retail clinic in a pharmacy or grocery store
  - Emergency room
  - A VA Medical Center or VA outpatient clinic
  - Some other place
  - Does not go to one place most often
  - Don't know



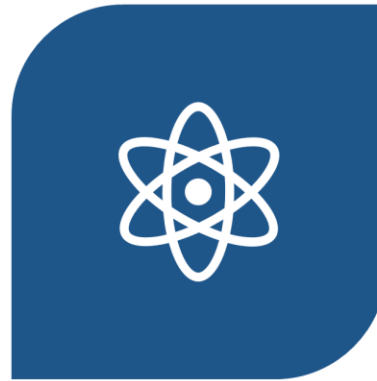
# Example: Date of Chest Examination

- **Standardized precisely defined question:** “What was the date of the imaging examination?”
- **Specific allowable response:** Date
  - mm/dd/yyyy

# Use CDEs to . . .



SAVE RESOURCES



ADVANCE SCIENCE



FOLLOW POLICIES

CDEs make  
data FAIR



Findable



Accessible



Interoperable

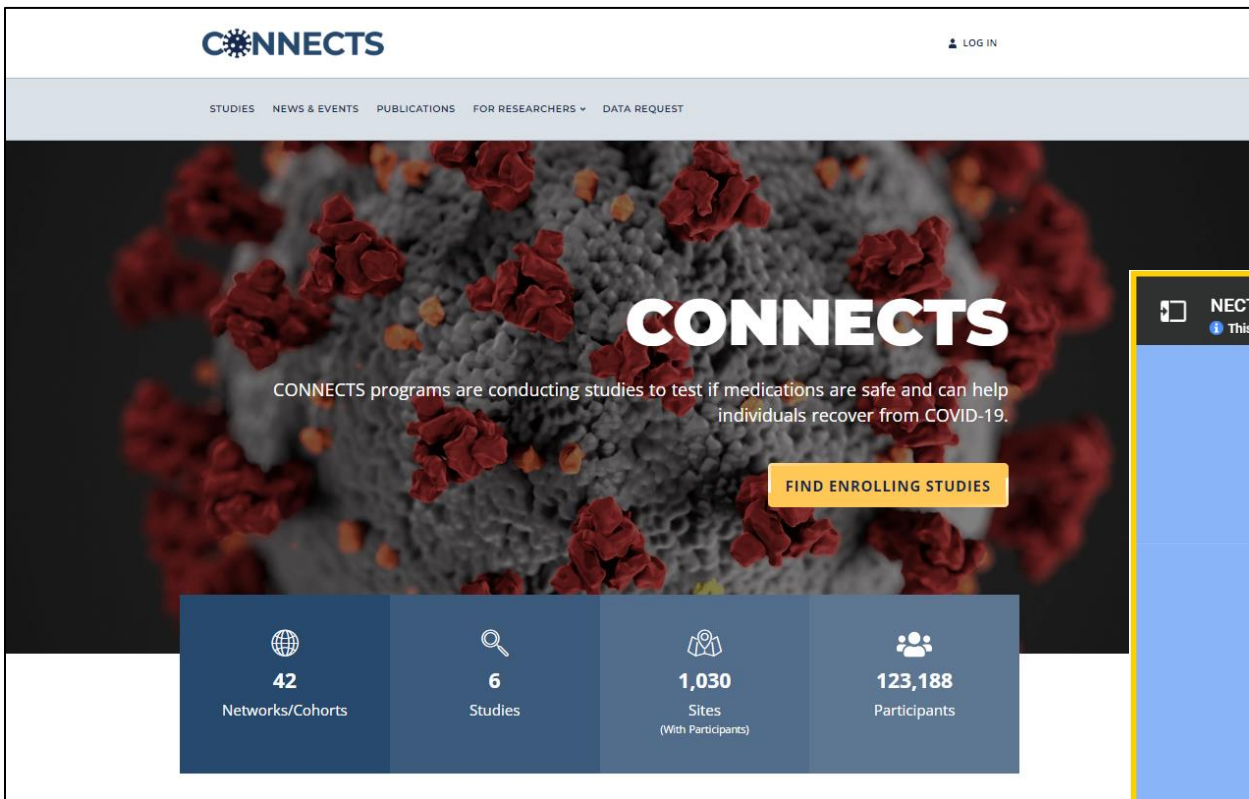


Reusable

CDEs support a compliant  
data management and  
sharing plan



# NHLBI CONNECTS







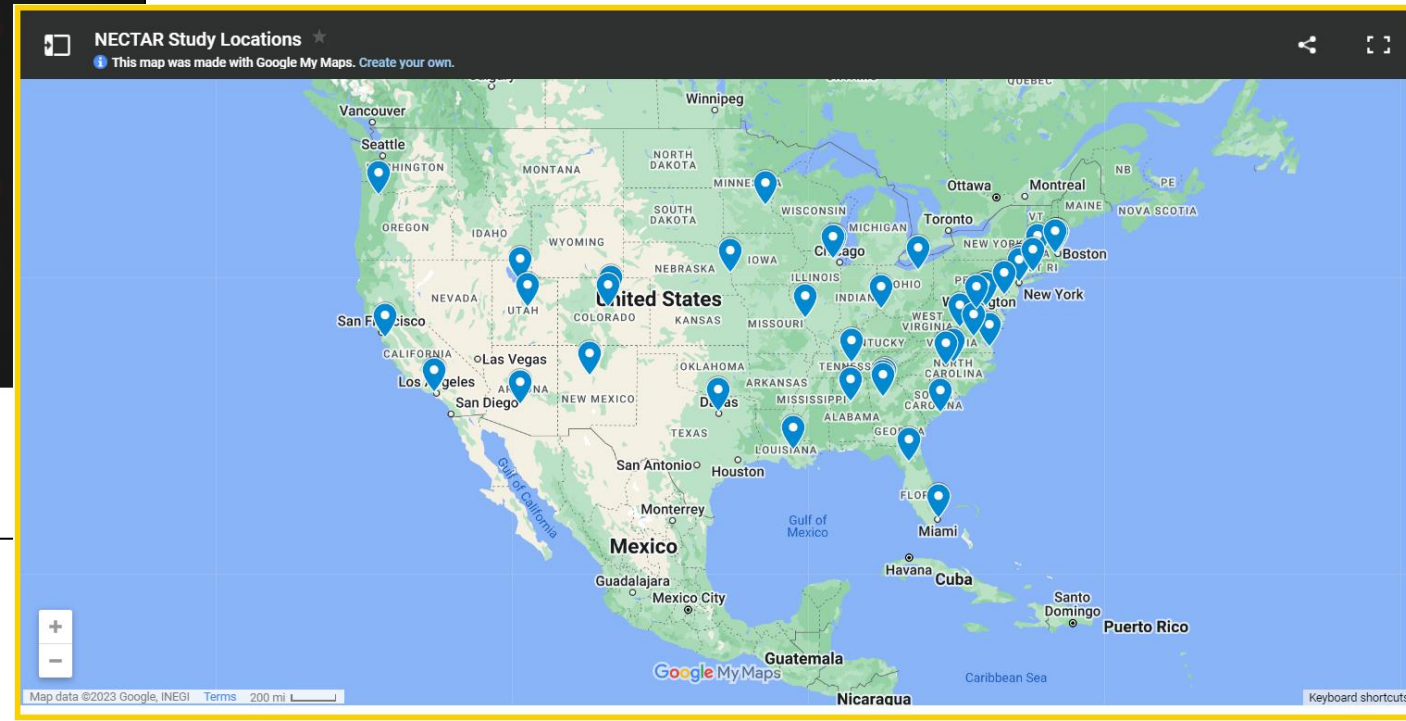
The image shows the top portion of the NHLBI CONNECTS website. At the top left is the CONNECTS logo, and at the top right is a 'LOG IN' link. Below the header is a navigation bar with links for 'STUDIES', 'NEWS & EVENTS', 'PUBLICATIONS', 'FOR RESEARCHERS', and 'DATA REQUEST'. The main content area features a background image of red and grey molecular structures. The word 'CONNECTS' is prominently displayed in large white letters. Below it, a text block reads: 'CONNECTS programs are conducting studies to test if medications are safe and can help individuals recover from COVID-19.' A yellow button labeled 'FIND ENROLLING STUDIES' is positioned below the text. At the bottom of this section are four dark blue boxes, each containing an icon and a statistic: a globe icon for '42 Networks/Cohorts', a magnifying glass icon for '6 Studies', a person icon for '1,030 Sites (With Participants)', and a group of people icon for '123,188 Participants'.

**CONNECTS**

CONNECTS programs are conducting studies to test if medications are safe and can help individuals recover from COVID-19.

[FIND ENROLLING STUDIES](#)

 <b>42</b> Networks/Cohorts	 <b>6</b> Studies	 <b>1,030</b> Sites (With Participants)	 <b>123,188</b> Participants
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# PubMed

An official website of the United States government [Here's how you know](#)

NIH National Library of Medicine  
National Center for Biotechnology Information

Log in

PubMed® 36842617 Search

Advanced Create alert Create RSS User Guide

Found 1 result for 36842617 Save Email Send to Display

> Arch Phys Med Rehabil. 2023 Jul;104(7):1072-1080.e1. doi: 10.1016/j.apmr.2023.02.003. Epub 2023 Feb 25.

**Cross-Walk Comparison of the DVBIC-TBICoE and LIMBIC-CENC Combat-Related Concussion Prospective Longitudinal Study Datasets**

Treven C Pickett<sup>1</sup>, William C Walker<sup>2</sup>, Sara M Lipka<sup>3</sup>, Rael T Lange<sup>4</sup>, Tracey A Brickell<sup>4</sup>, Travis A Dittmer<sup>5</sup>, Johanna M Smith<sup>4</sup>, David X Cifu<sup>6</sup>, Louis M French<sup>7</sup>

Affiliations + expand  
PMID: 36842617 DOI: 10.1016/j.apmr.2023.02.003

**Abstract**

**Objective:** To describe and compare cohorts between 2 large, longitudinal, federally-funded TBI studies of Service members and veterans across demographic, self-report, and neuropsychological

ELSEVIER FULL-TEXT ARTICLE

ACTIONS

“ Cite

📁 Collections

SHARE

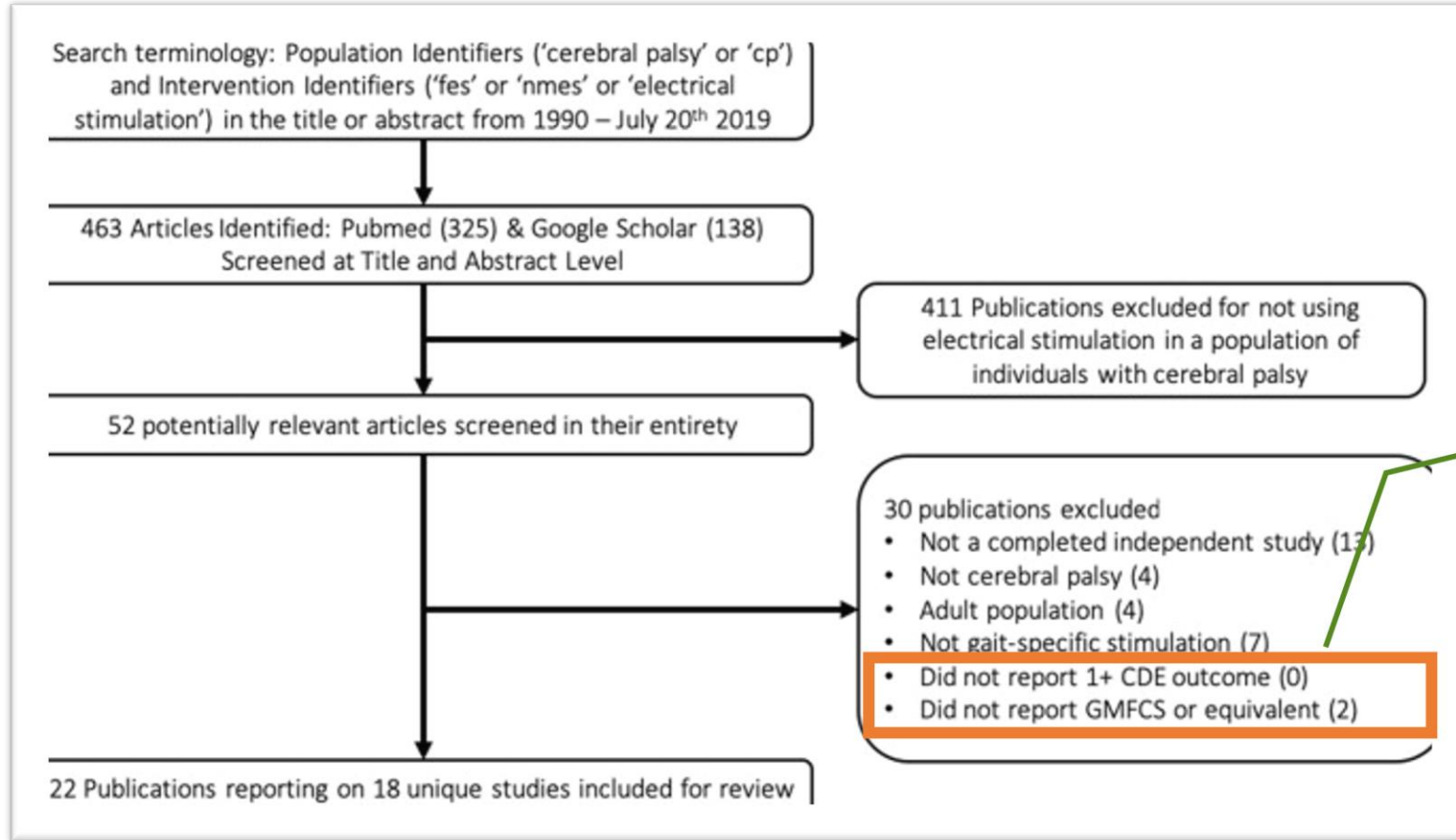
📄 📘 🔗

PAGE NAVIGATION

“This comparative analysis was enabled by heavy use of NIH common data elements in both studies.[ . .]”

Citation: Pickett TC, Walker WC, Lipka SM, Lange RT, Brickell TA, Dittmer TA, Smith JM, Cifu DX, French LM. Cross-Walk Comparison of the DVBIC-TBICoE and LIMBIC-CENC Combat-Related Concussion Prospective Longitudinal Study Datasets. Arch Phys Med Rehabil. 2023 Jul;104(7):1072-1080.e1. doi: 10.1016/j.apmr.2023.02.003. Epub 2023 Feb 25. PMID: 36842617.

# CDE Inclusion/Exclusion



Use of common data element in inclusion/exclusion criteria for a systematic review

Citation: Mooney JA, Rose J. A Scoping Review of Neuromuscular Electrical Stimulation to Improve Gait in Cerebral Palsy: The Arc of Progress and Future Strategies. Front Neurol. 2019 Aug 21;10:887. doi: 10.3389/fneur.2019.00887. PMID: 31496986; PMCID: PMC6712587.

# The NIH CDE Repository (CDE-R)

- CDEs recommended or required by NIH ICs or other organizations
- Reviewed by NIH CDE governance committee, in partnership with NIH CDE Repository Team





# NIH-Endorsed CDEs Criteria



- ✓ Clear definition of variable and measure with prompt and response
- ✓ Documented evidence of reliability and validity
- ✓ Human- and machine-readable format preferred
- ✓ Recommended/designated by a recognized NIH body (IC, committee, etc.)
- ✓ Licensing and IP status clear (prefer CC-by or open source)

# NIH-Endorsed CDE Collections



- Project 5 for translational, clinical, and applied COVID-19 research
- NHLBI CONNECTS Organ Support CDEs
- NIMHD/NINR ScHARE
- SBE CCC COVID-19 Mitigation Policy CDEs

# Form Definition

A **form** is a group of questions or variables (aka CDEs) with specified sets of allowable responses that are used as a set for particular research or clinical reasons.

# Example: Audit-C Questionnaire

## 1. How often do you have a drink containing alcohol?

- Two to Three Instance Per Week
- Two to Four Instance Per Month
- Four or Greater Instance Per Week
- Monthly or less
- Never

## 2. How many standard drinks containing alcohol do you have on a typical day?

- 1 or 2
- 10 or more
- 3 to 4
- 5 to 6
- 7 to 9

## 3. How often do you have six or more drinks on one occasion?

- Two To Three Instance Per Week
- Two to Four Instance Per Month
- Four or Greater Instance Per Week
- Less Than Monthly
- Monthly
- Daily
- Never
- Weekly

# Bundles definition

A **bundle** is a form that is indivisible and individual CDEs pulled from them are not considered valid.

**!** **This form is a bundle.** Bundles are indivisible. They are not considered valid and reliable if not used in their entirety, as intended.

**!** **This CDE is part of a bundle.** All CDEs within a bundle must be used together. Go to [bundle](#)

# Check Your Understanding



# Review

5. Find CDEs, Forms, and Bundles in the CDE-R
6. Endorsed CDEs have been reviewed and approved by the NIH.
7. It is TRUE that in the CDE-R, a bundle is a form that is indivisible and individual CDEs pulled from them are not considered valid.

# Questions-1?





# Exercise #1

- Search for an **NIH-Endorsed** CDE from the **ScHARe** project that collects the **health insurance** type of the respondent
- Put in the chat one of the permissible values for this CDE

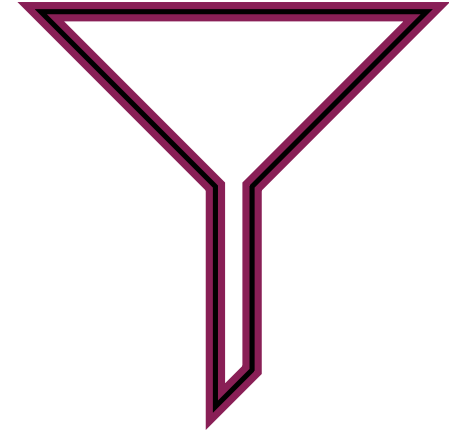


# Questions-2?



# How to Narrow Your Results

- Limit to NIH-Endorsed CDEs
- Limit to a specific Collection
- Limit to Standard under Registration Type
- Add additional terms to your search



# Exercise #2

- Locate the BRICS Social Determinants of Health form from the NINR
- Copy and paste its copyright status into the chat.



# Questions-3?



# How to Get Help



The screenshot shows the NIH CDE Repository website. The top navigation bar includes the NIH logo and the text "National Library of Medicine". Below this, the "NIH CDE Repository" logo is on the left, and navigation links for "CDEs", "Forms", "My Boards", and "About" are on the right. A "Help" dropdown menu is open, showing options for "Guides", "New Features", "Resources", and "Contact Us". A "Sign In" button is also visible. The main content area features a large heading: "Use Common Data Elements for More FAIR Research Data". Below the heading is a paragraph: "Common data elements (CDEs) help researchers share and combine datasets, meet funding requirements, and save time." At the bottom, there are three search buttons: "Search NIH-Endorsed CDEs" (with a ribbon icon), "Search All CDEs", and "Search Forms".

NIH National Library of Medicine

NIH CDE Repository

CDEs Forms My Boards About

Help Sign In

Guides

New Features

Resources

Contact Us

## Use Common Data Elements for More FAIR Research Data

Common data elements (CDEs) help researchers share and combine datasets, meet funding requirements, and save time.

Search NIH-Endorsed CDEs Search All CDEs Search Forms



# How to Get MLA CE

[Close survey](#)

Thank you for completing this evaluation survey. Your feedback will support efforts to improve future Network of the National Library of Medicine (NNLM) training sessions.

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If your training session ( ) offered Continuing Education credit from the Medical Library Association and you would like to claim it, please follow these instructions. See Step 4 for enrollment code.

1. Go to [www.medlib-ed.org](http://www.medlib-ed.org)
2. Login (for information on how to create a free MEDLIB-ED account, [visit MLA's FAQ page for further help](#)).
3. Click My Learning on the blue bar near the top of the page
4. Enter the following enrollment code in the appropriate field:  
 (please copy) 
5. Click Redeem, then Claim

If you have questions or run into problems with MEDLIB-ED, please email [MEDLIB-ED@mail.mlahq.org](mailto:MEDLIB-ED@mail.mlahq.org)