

Standardize Your Research Data with the NIH Common Data Element Repository

March 29, 2023

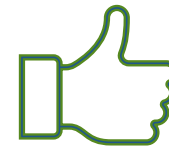
National Library of Medicine



National Library of Medicine

Before We Start

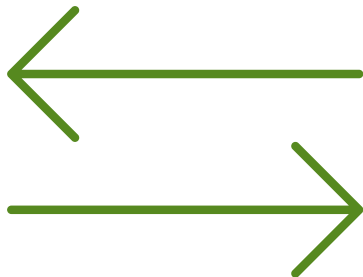
- Captions: click Closed Captions button
- Chat: send questions to EVERYONE
- Handout: link in chat
- Reactions: give me a thumbs up!



CDEs and the NIH

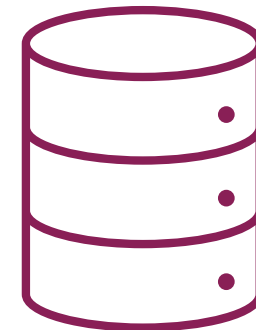
CDEs...

- Make data interoperable and support FAIR principles



CDEs...

- Support the NLM Strategic Plan for 2017-2027, the NIH Strategic Plan for Data Science, and the NIH Data Management and Sharing Policy



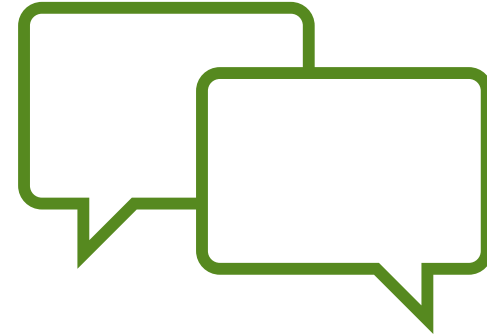
Agenda

- Defining CDEs and the CDE-R
- Preparing to search
- Locating CDEs in the CDE-R
- Saving CDEs for later
- How to get help



Chat: Introduce Yourself

- Your title/role
- Your organization



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

Comfort Level 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
Pretty comfortable	Participant 1
I know what CDEs are but that's about it	Participant 2
I've used them a lot	Participant 3
I'd say my comfort level depends on what I'm looking for. . .	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 Health Care Type

- **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	Walk-in clinic, urgent care center, or retail clinic in a pharmacy store or grocery store
Emergency room	A VA Medical Center or VA outpatient clinic
Some other place	There is NO place
Don’t know	Refused/Not reported
Unknown	

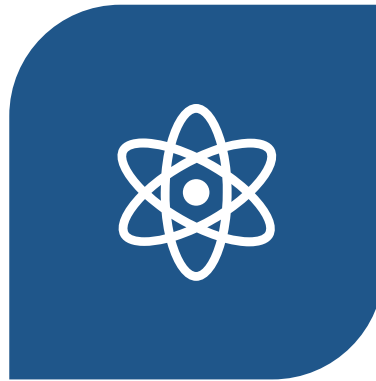
Example: Date of Chest Examination

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

Use CDEs to . . .



SAVE RESOURCES

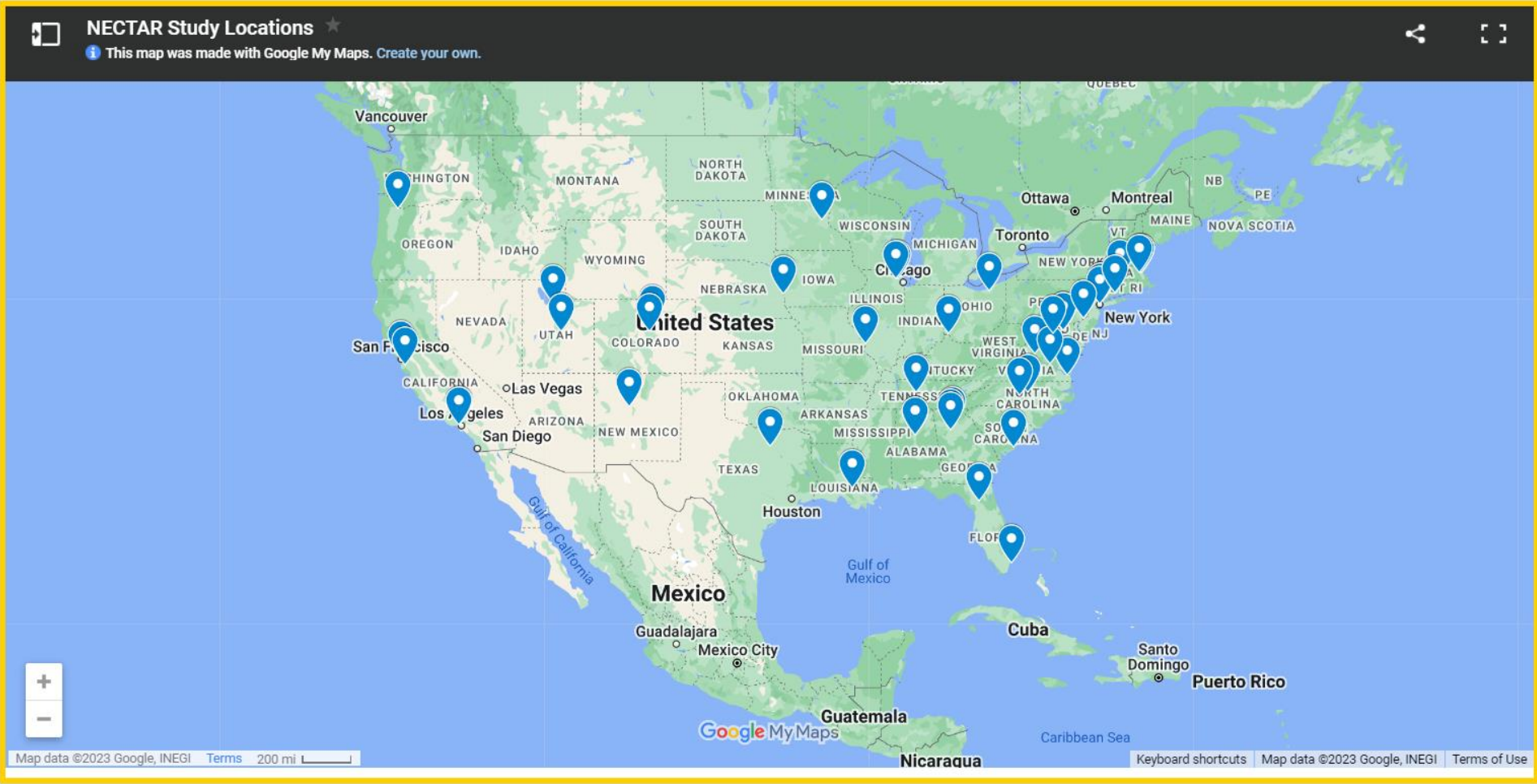


ADVANCE SCIENCE



FOLLOW POLICIES

NHLBI CONNECTS



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)

Endorsed CDE Icon



Forms Definition

A Form is a group of questions or variables 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

Example: BRICS Social Determinants of Health

- 63 total CDEs
- Includes CDEs from other Forms, like AUDIT-C Questionnaire

Check Your Understanding



Question Break One



Exercise #1

- Search within the NIH-Endorsed collection for a CDE that collects employment status of the respondent
- Put in the chat one of the permissible values for this CDE

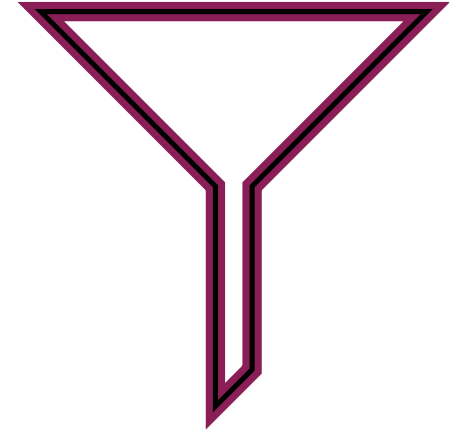


Question Break Two



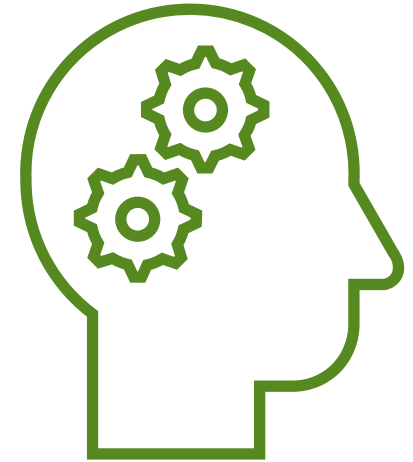
How to Narrow Your Results

- 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 Clinical Decision Support for Substance Abuse form from NIDA
- How many questions does it include? Tell me in the chat.



Exercise #3: Browsing CDEs

- What is the name of one NEI CDE collection that you can browse in the Repository? Tell me in the chat.



Question Break Three



How to Get Help

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

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
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:
[REDACTED] (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

