Standardize Your Research Data with the NIH Common Data Element Repository

October 18, 2023

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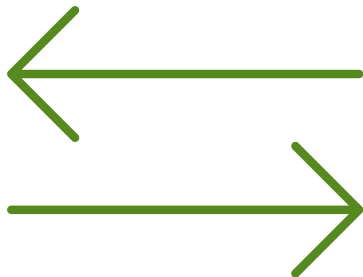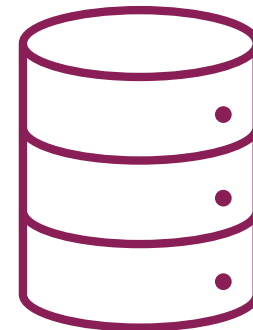
CDEs and the NIH

CDEs…
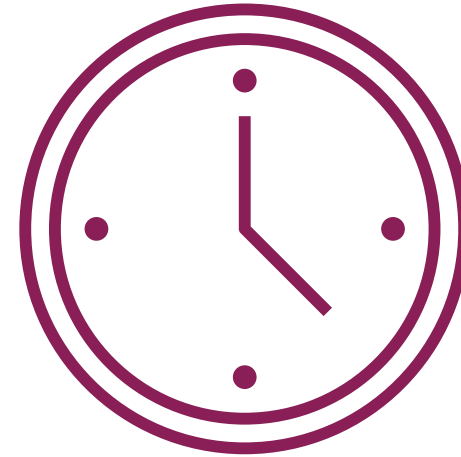
- Make data interoperable and support FAIR principles

CDEs…

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

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Agenda

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

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	

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Example: Date of Chest Examination

- **Standardized precisely defined question: "**What was the date of the imaging examination?"

- **Specific allowable response:** Date
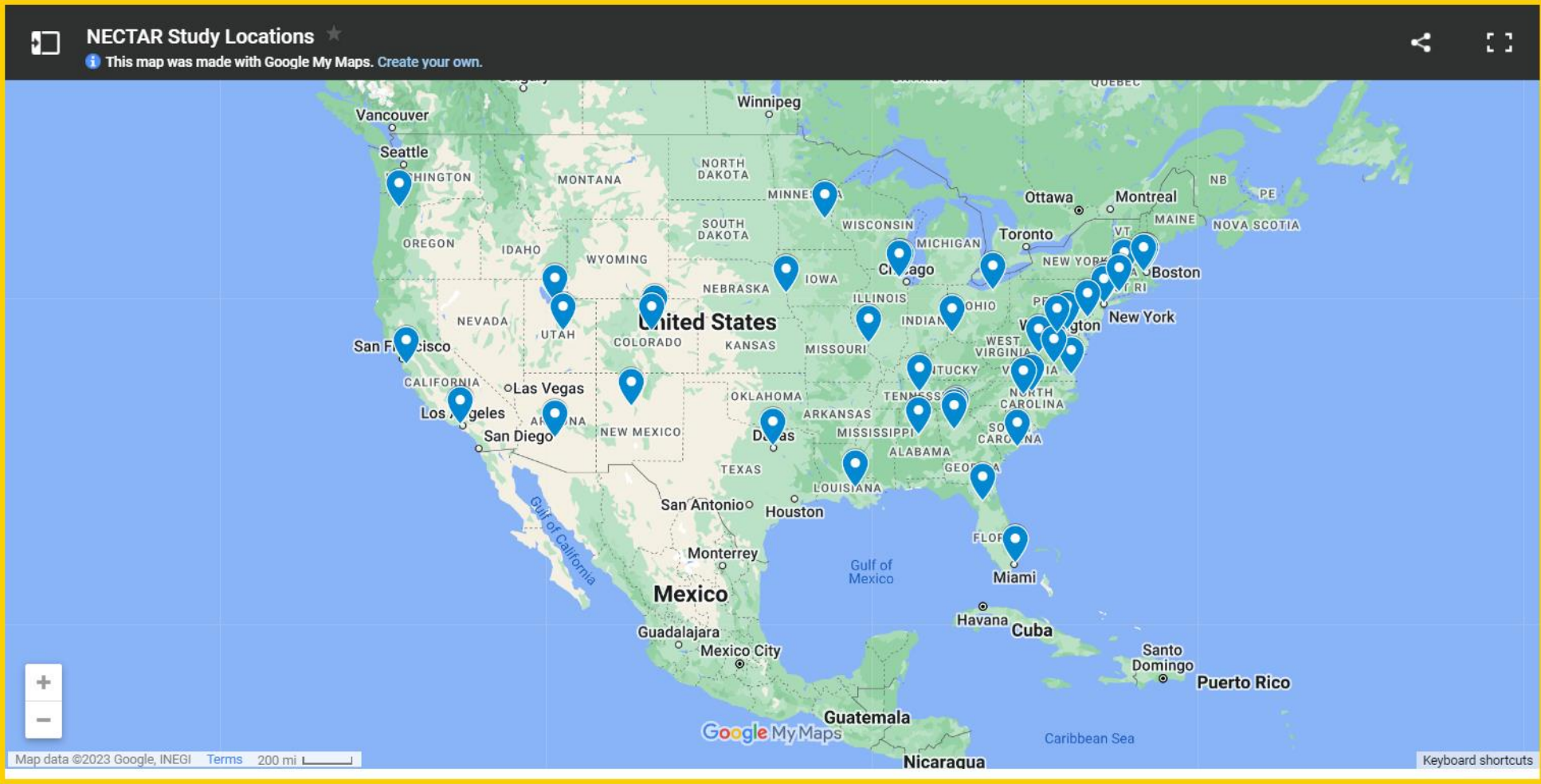
Use CDEs to. . .

SAVE RESOURCES
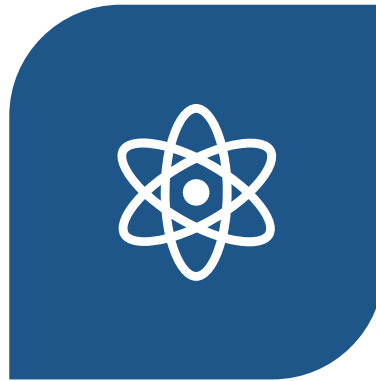
ADVANCE SCIENCE

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)

Form 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

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

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Review

5. Find <u>CDEs, Forms, and Bundles</u> in the CDE-R

6. <u>Endorsed</u> CDEs have been reviewed and approved by the NIH.

7. In the CDE-R, a bundle is a form that is indivisible and individual CDEs pulled from them are not considered valid.

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
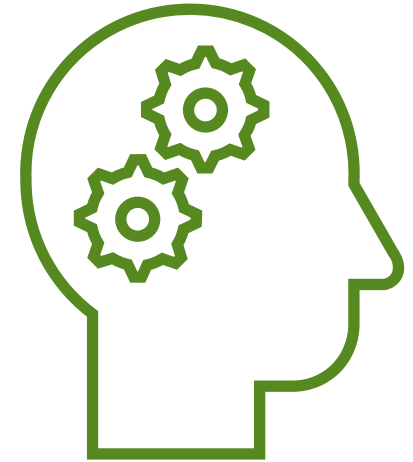
How to Narrow Your Results

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

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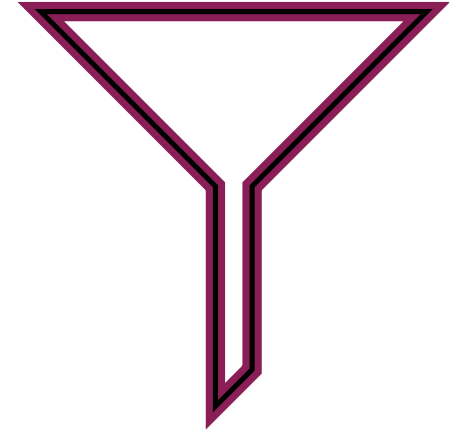
Exercise #2

- Locate the Clinical Decision Support for Substance Abuse form from NIDA

- Copy and paste its copyright status into the chat.
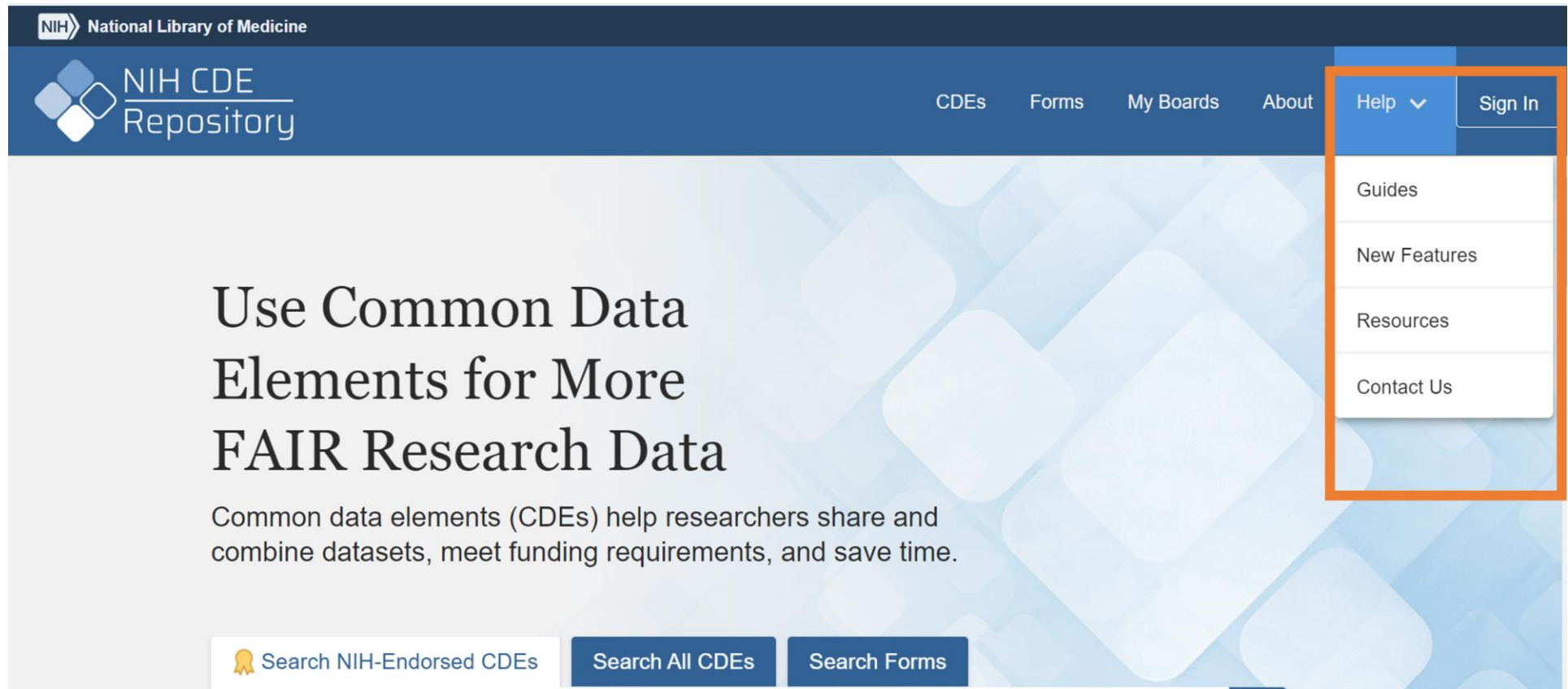
Exercise #3: Browsing CDEs

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

How to Get Help