Standardize Your Research Data with the NIH Common Data Elements Repository
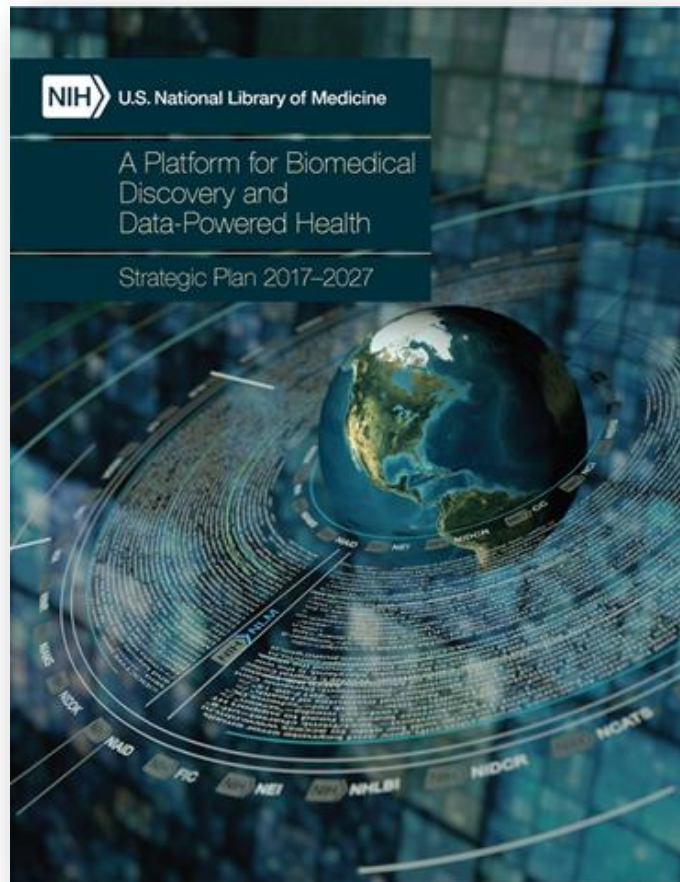
October 4, 2022

National Library of Medicine

CDEs and the NLM

NIH U.S. National Library of Medicine

A Platform for Biomedical Discovery and Data-Powered Health

Strategic Plan 2017–2027

- CDEs:
  - Make data interoperable and support FAIR principles
  - Support the NLM Strategic Plan for 2017-2027 and NIH Strategic Plan for Data Science

Agenda

✏️ Defining CDEs and the CDE-R

🔍 Preparing to search

🎯 Locating CDEs in the CDE-R

⏰ Saving CDEs for later

🤝 How to get help

You & CDEs: Part 1

- Your title/role

- Your organization

You & CDEs: Part 2

What is your comfort level with using CDEs? Enter the letter in the chat that corresponds to your answer.

A. Very comfortable! I use them all the time.

B. Kind of comfortable. I've used them before, but it was a challenge

C. Somewhat uncomfortable. I've attempted to use them but it wasn't successful.

D. I know what CDEs are, but I've never used them

E. I don't even know what CDEs are!

Participant Organization

Sample Original Responses	Standard 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 comfortable 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 Definition

Common Data Elements (CDEs) are <u>standardized</u>, <u>precisely defined</u> questions paired with a set of <u>specific</u> <u>allowable</u> responses, used systematically across different sites, studies, or clinical trials to ensure <u>consistent</u> 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 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 responses:

- Date

Use CDEs to. . .
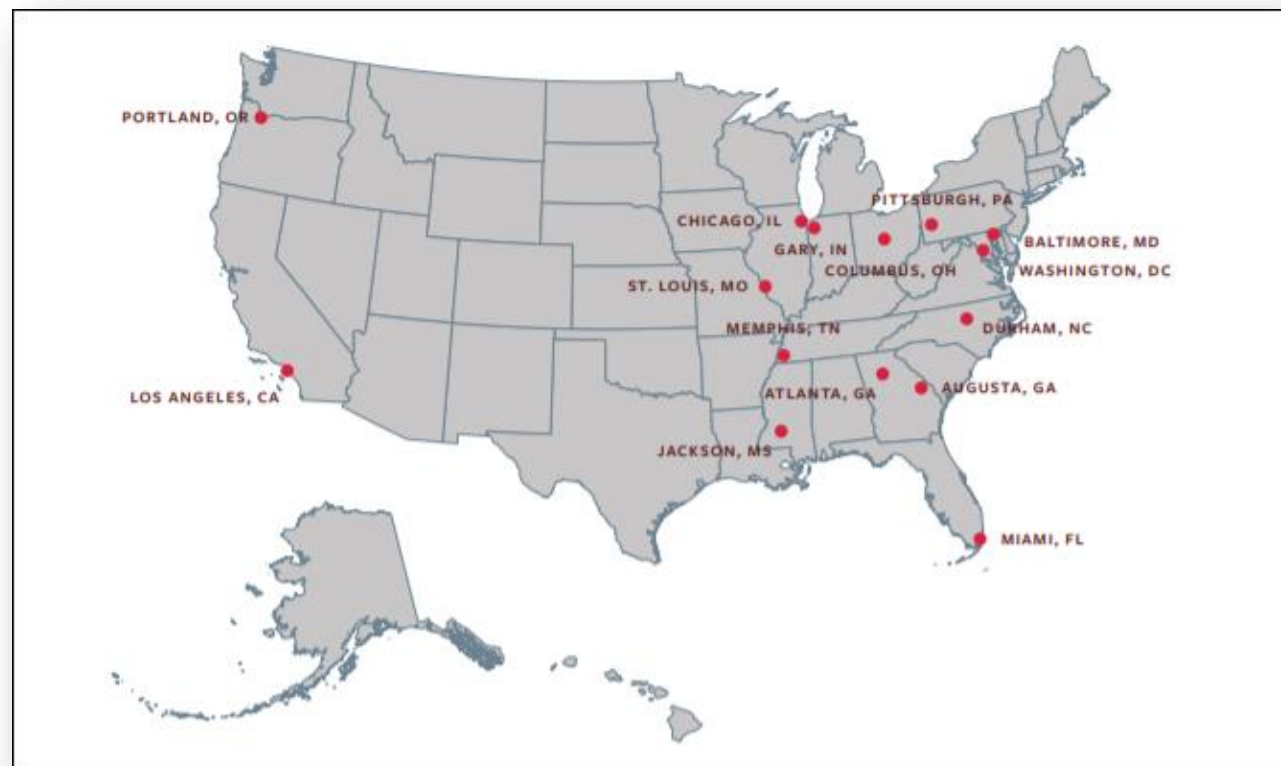

SAVE RESOURCES
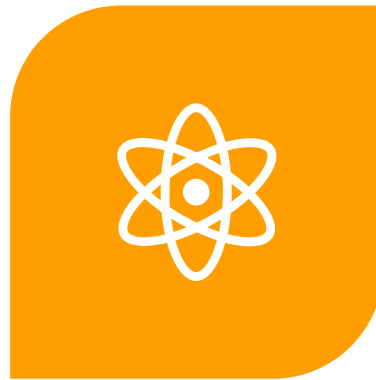
ADVANCE SCIENCE

FOLLOW POLICIES

CDEs at the NHLBI

The NIH CDE Repository (CDE-R)

NIH-Endorsed CDEs Criteria

- Clear definition of variable, 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 set 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

Exercise #1

- Search within the NIH-Endorsed collection for a CDE that collects employment status of the respondent

- Raise your hand when you've found it

- Put in the chat one of the permissible values for this CDE

Exercise #2

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

- How many questions does it include? Tell me in the chat.
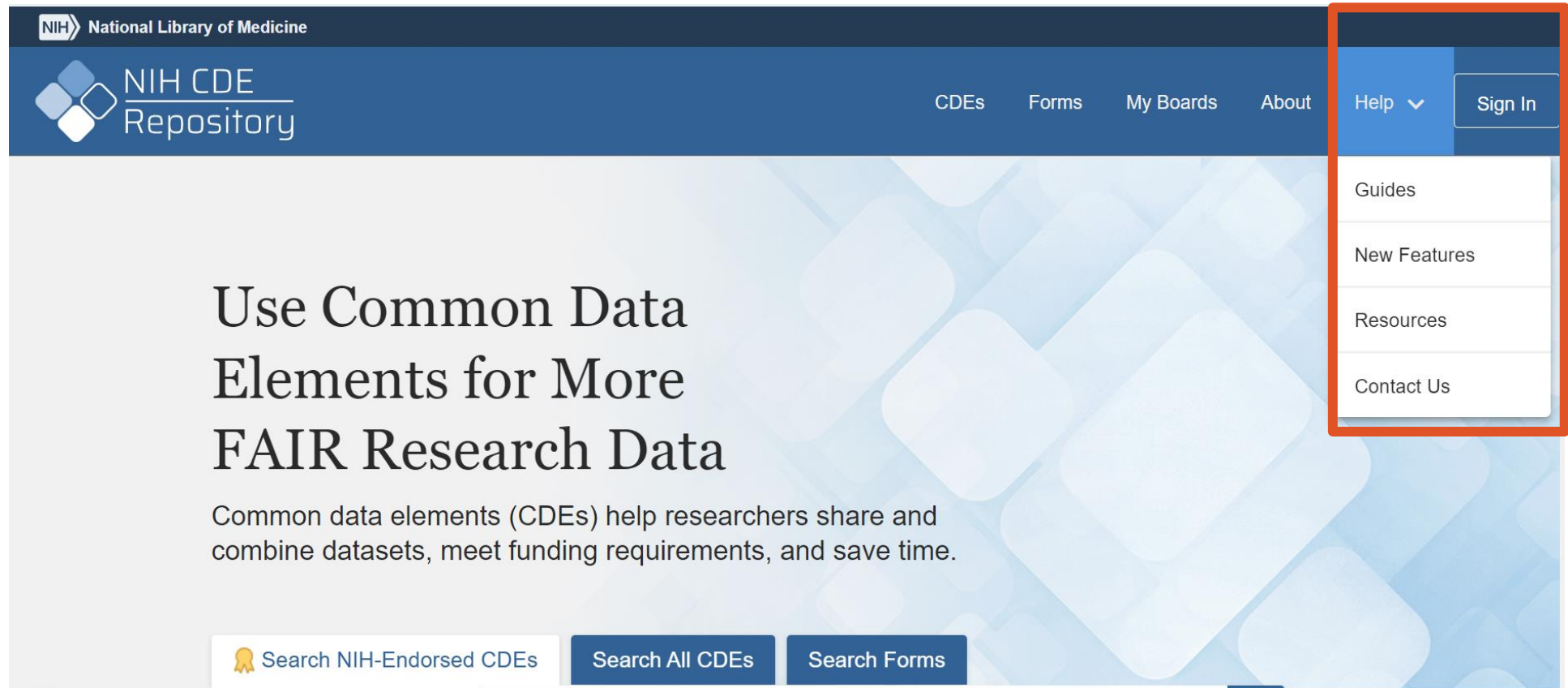
Exercise #3: Browsing CDEs

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

How to Get Help