

NIH CDE Repository, CDE Governance, and RFI

Robin Taylor, MLIS
National Library of Medicine
March 2024



National Library of Medicine

Today's presentation

- NIH CDE Repository
- NIH CDE Governance
- Request for Information (RFI)

NIH CDE Repository

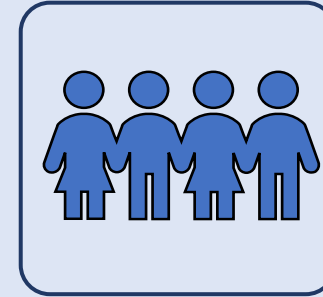
What is a common data element?



A standardized,
precisely-defined
question



Paired with a set of
specific allowable
responses



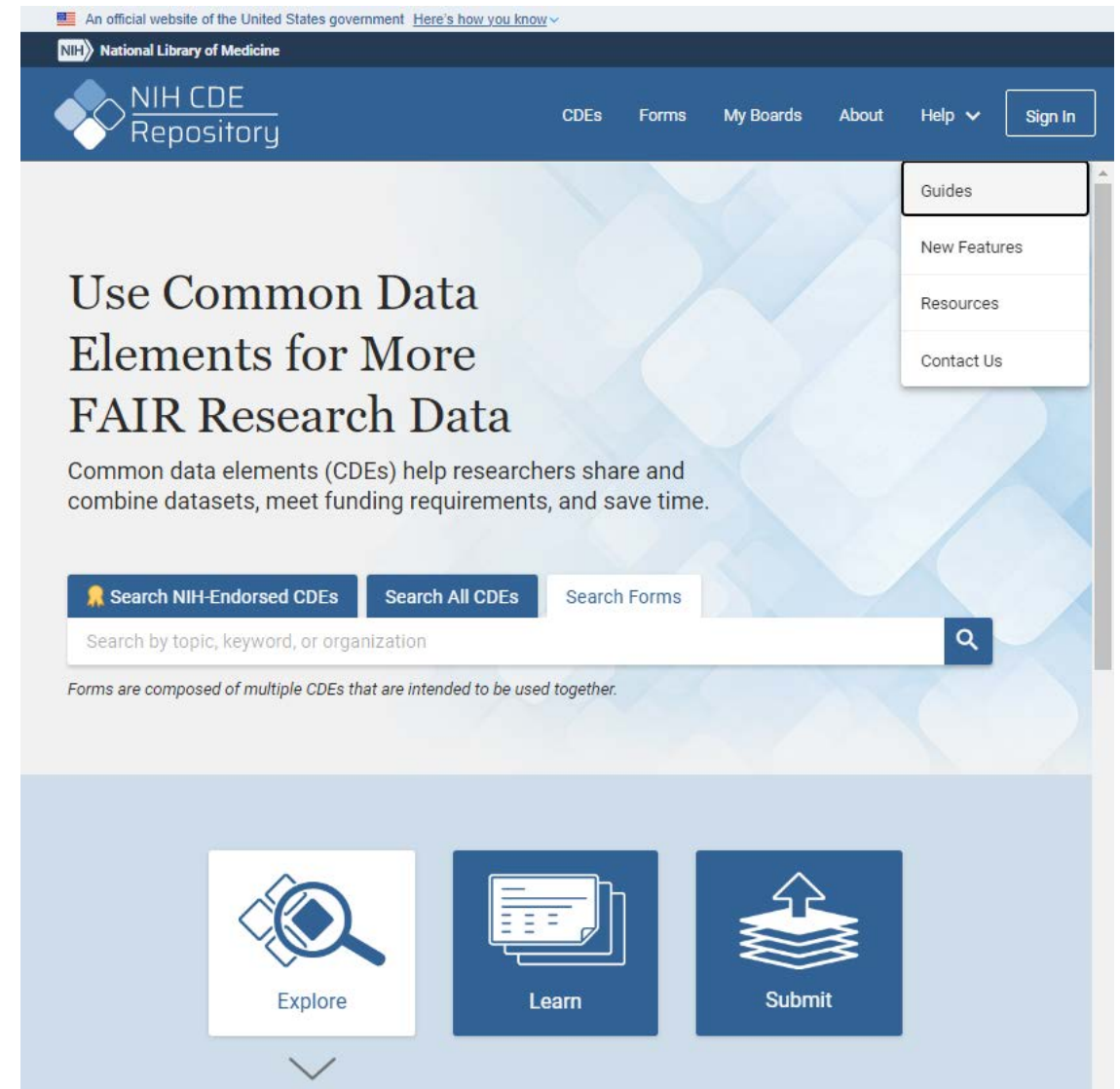
Used systematically
across different sites,
studies, or clinical
trials to ensure
consistent data
collection

Source: RFI: Use of Common Data Elements (CDEs) in NIH-funded research ([NOT-LM-21-005](#))

NIH CDE Repository

The NIH CDE Repository is an **NIH-wide resource** hosted by the National Library of Medicine (NLM) since 2015.

<https://cde.nlm.nih.gov/>



The screenshot shows the homepage of the NIH CDE Repository. At the top, there is a navigation bar with the NIH logo and the text "National Library of Medicine". The main header area features the "NIH CDE Repository" logo and a navigation menu with links for "CDEs", "Forms", "My Boards", "About", "Help", and a "Sign In" button. A dropdown menu is open on the right, showing options for "Guides", "New Features", "Resources", and "Contact Us". The main content area has a large heading: "Use Common Data Elements for More FAIR Research Data". Below this, a sub-heading reads: "Common data elements (CDEs) help researchers share and combine datasets, meet funding requirements, and save time." There is a search bar with three tabs: "Search NIH-Endorsed CDEs", "Search All CDEs", and "Search Forms". The search bar contains the placeholder text "Search by topic, keyword, or organization" and a search icon. Below the search bar, a note states: "Forms are composed of multiple CDEs that are intended to be used together." At the bottom of the page, there are three large buttons: "Explore" (with a magnifying glass icon), "Learn" (with a document icon), and "Submit" (with an upload icon).

Purpose of the NIH CDE Repository

- Provide access to structured human- and machine-readable definitions of data elements that have been recommended or required by NIH Institutes and Centers for use in research and for other purposes.

FY20 usability study takeaways

The Repository's success depends upon increased usage of CDEs across NIH



Establish **governance structure**



Implement **engagement strategies**



Deploy key **enhancements**

NIH CDE Governance

NIH CDE Governance hierarchy



NIH CDE Governance Committee Charge

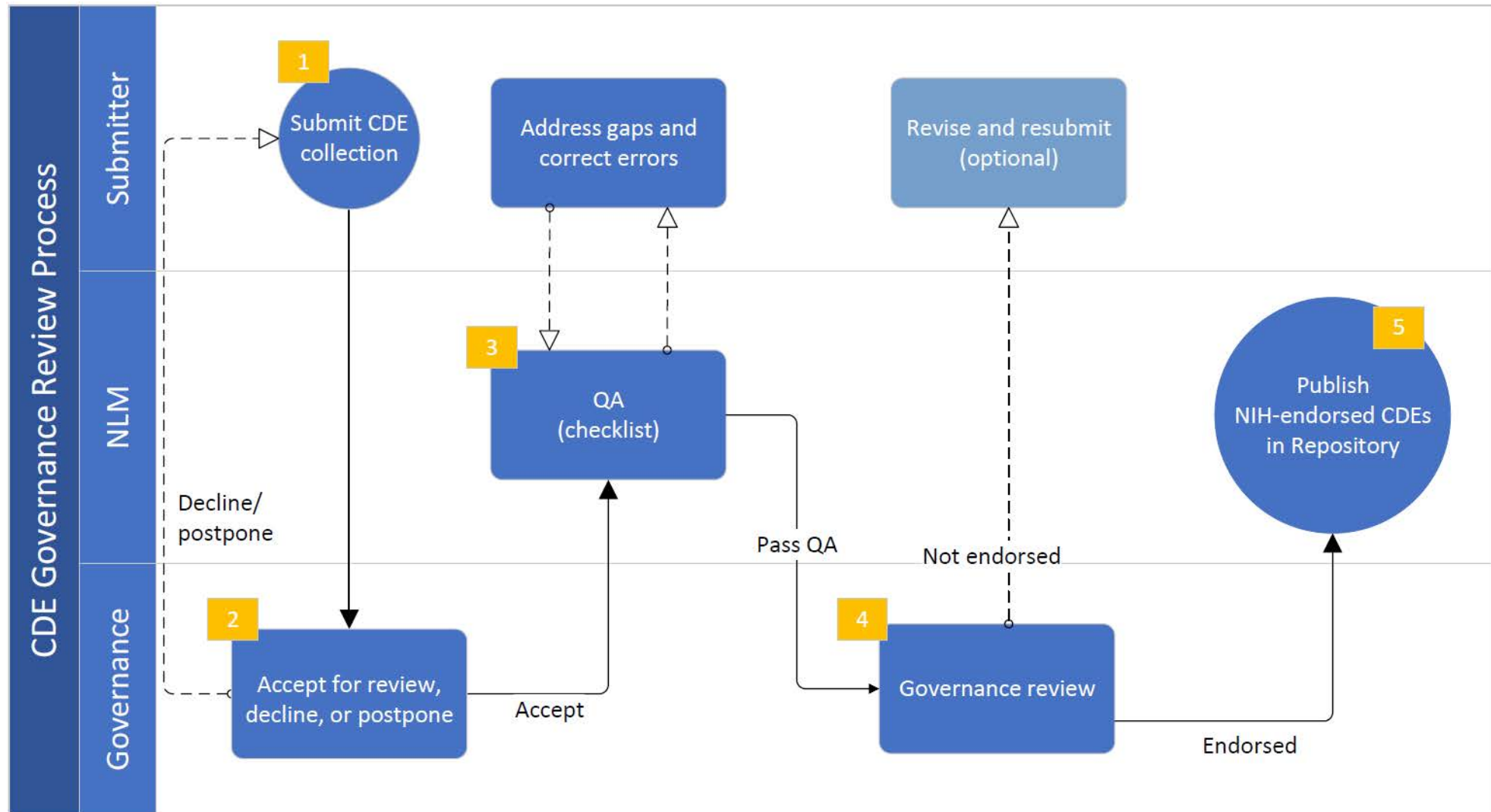
- Decide whether submitted CDEs meet criteria that merit their designation as NIH-endorsed CDEs
- Work closely with NLM on processes for depositing NIH-endorsed CDEs in the NIH CDE Repository
- Review efficacy of processes (annually)

Criteria for NIH Endorsement



Governance Committee panels endorse CDEs that meet certain criteria:

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



CDE Governance by the numbers

- NIH-Endorsed CDEs:
 - Published in NIH CDE Repository: 171 across 3 collections
 - Preparing to publish: 500+ across 2 collections
- In review pipeline: 1000+

In the NIH CDE Repository

What is in the NIH CDE Repository?

- 171 NIH-Endorsed CDEs 
- 24,158 total CDEs recommended by NIH groups
- 1,678 Forms (curated sets of CDEs)

Who is using the NIH CDE Repository?

- **Researchers**

- Search for CDEs for their projects/studies
- Export/download CDEs for use in other applications

- **Submitters**


- Explore CDEs in the Repository to see what is available
- Submit CDEs for NIH endorsement and inclusion in the Repository

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](#)

Search by topic, keyword, or organization 

NIH-endorsed CDEs have been reviewed and approved by an expert panel, and meet established criteria. They are designated with a gold ribbon. 



Explore



Learn



Submit

All CDEs

depression



ACTIVE CDE FILTERS

depression x Clear all x

REFINE CDE RESULTS

NIH-Endorsed

Collections

- Project 5 (COVID-19) (3)
- GRDR (1)
- NCI (5)
- NEI (1)
- NHLBI (72)
- NICHD (2)
- NIDA (2)
- NINDS (452)
- NINR (18)
- NLM (11)
- ONC (4)
- PhenX (27)
- PROMIS / Neuro-QOL (46)
- RADx-UP (1)
- Women's CRN (1)

Registration Status

- Standard (46)
- Qualified (552)

Data Types

- Value List (481)

Hide Filters

Table View

Summary View

Pin All

Export All

598 results. Sorted by relevance.

Depression

Never Rarely Sometimes Often Always

Qualified

Steward: GRDR
Used By: GRDR
Source: GRDR

Depression

Qualified

Steward: RADx-UP
Used By: RADx-UP

Value	Code Name	Code
1	Yes	
0	No	

PROMIS - Emotional Distress depression depressed scale

Scale related to the individual feeling **depressed**, as part of the PROMIS Emotional Distress **Depression**

Qualified

Steward: NINDS
Used By: NINDS

Value	Code Name	Code
5	always	
4	Often	
3	Sometimes	
2	Rarely	

Dysphoria - depression



All CDEs

depression



ACTIVE CDE FILTERS

depression x

NLM x

Clear all x

REFINE CDE RESULTS

NIH-Endorsed

Collections

NLM

PHQ9 (11)

Registration Status

Standard (11)

Data Types

Value List (10)

Number (1)

Hide Filters

Table View

Summary View

Pin All

Export All

11 results. Sorted by relevance.

Feeling down, depressed, or hopeless in last 2 weeks [Reported.PHQ]

Score of how much the subject has been feeling down and **depressed** in the past two weeks, as part of the Patient Health Questionnaire (PHQ).

Standard	Value	Code Name	Code
Steward: NLM	0	Not at all	LA6568-5
Used By: NINDS, ONC, NLM	1	Several days	LA6569-3
Source: LOINC	2	More than half t...	LA6570-1
	3	Nearly every day	LA6571-9

Patient Health Questionnaire 9 item (PHQ-9) total score [Reported]

The PHQ-9 is the standard (and most commonly used) [...] Interpretation: 1-4 = Minimal **depression**; 5-9 = Mild **depression**; 10-14 = Moderate **depression**; 15-19 = Moderately severe **depression**; 20-27 = Severed **depression**

Standard

Steward: NLM

Used By: NINDS, NLM

Source: LOINC

A typical CDE record

- CDE name & definition
- Question text
- Data type (e.g., number, text)
- Steward (submitter)
- Permissible values
- Concept and terminology codes
- Other identifiers
- Related content
- Copyright/license information (Forms only)

The screenshot shows the NIH CDE Repository interface. At the top, there is a navigation bar with the NIH logo, 'National Library of Medicine', and 'NIH CDE Repository'. The main content area is titled 'Oxygen support' and includes a 'Question Text' section with the text: 'Was the participant receiving oxygen support on this day?'. Below this is a 'Definition' section explaining the concept of oxygen support status. The 'Data Type' is listed as 'Value List', and the 'Steward' is 'NHLBI'. A 'Permissible Value' table is provided, listing three categories: YES, NO, and UNKNOWN, each with its definition, PV Concept Identifier, PV Terminology Sources, Codes for PVs, and PV Code Systems.

ON THIS PAGE

- CDE Summary**
- Data Type Details
- Permissible Value
- VSAC Value Set
- CDE Details
- Other Names & Definitions
- Concepts
- Identifiers
- Properties
- Classification
- Related Content
- Submission Information
- Status
- History

Pin to Board Export Discuss

3 Views Updated: 12/12/2022

Oxygen support

Question Text
Was the participant receiving oxygen support on this day?

Definition
Oxygen Support Status - On this day, whether the patient received inhalation of oxygen aimed at restoring toward normal any pathophysiologic alterations of gas exchange in the cardiopulmonary system, as by the use of a respirator, nasal catheter, tent, chamber, or mask

Data Type: Value List
Steward: NHLBI
Origin:

Data Type Details
Data Type: Value List

Permissible Value

PV Labels	PV Definitions	PV Concept Identifiers	PV Terminology Sources	Codes for PVs	PV Code Systems
YES	The affirmative response to a question	C1705108	UMLS	C49488	NCI
NO	The non-affirmative response to a question	C1298908	UMLS	C49487	NCI
UNKNOWN	Not known, observed, recorded; or reported as unknown by the data contributor	C0439673	UMLS	C17998	NCI

Feeling down, depressed, or hopeless in last 2 weeks [Reported.PHQ]

Question Text

Feeling down, depressed, or hopeless?

Definition

Score of how much the subject has been feeling down and depressed in the past two weeks, as part of the Patient Health Questionnaire (PHQ).

Data Type: Value List

Steward: NLM

Origin:

Data Type Details

Data Type: Value List

Ids: LOINC: LL358-3 , version: 2.58

Permissible Value

The list below includes codes with synonyms, you can also view them as:

LOINC Codes

NCI Thesaurus Codes

SNOMEDCT US Codes

UMLS Codes

PV Labels	PV Definitions	PV Concept Identifiers	PV Terminology Sources	Codes for PVs	PV Code Systems
0				LA6568-5	LOINC
1				LA6569-3	LOINC
2				LA6570-1	LOINC
3				LA6571-9	LOINC

Linked Forms (5)

More like this (10)

Linked Data Set (0)

Patient Health Questionnaire - 9 (PHQ-9) Depression Scale **11 Questions**

Qualified

PHQ-9 provides a reliable and valid measure of depression severity and also yields a DSM-IV criteria based diagnosis of a depressive disorder. This 9 item measure asks subjects whether and how often t [...]

Steward: NINDS

Used By: NINDS

Maxivir Trial **33 Questions**

Incomplete

Protocol for Maxivir trial

Steward: TEST

Used By: TEST

Patient Health Questionnaire 2 item (PHQ-2) [Reported] **3 Questions**

Qualified

The Patient Health Questionnaire-2 (PHQ-2) is a shorter version of the PHQ-9 containing two screening questions: one about the frequency of depressed mood and another about loss of interest in activit [...]

Steward: NLM

Used By: ONC

ON THIS PAGE

[Preview](#)[General Details](#)[Status](#)[Other Names & Definitions](#)[Classification](#)[Display Profiles](#)[Properties](#)[Identifiers](#)[History](#)

Form: Patient Health Questionnaire 2 item (PHQ-2) [Reported]

[Export ▾](#)[Add to Board](#)[CDEs](#)

Preview

[Options ▾](#)

1. Little interest or pleasure in doing things?

 Not at all Several days More than half the days Nearly every day

2. Feeling down, depressed, or hopeless?

 Not at all Several days More than half the days Nearly every day

3. Patient Health Questionnaire 2 item (PHQ-2) total score [Reported]

The PHQ-2 is the ultra-brief depression measure (using first 2 items of PHQ-9) and ranges from 0-6. Most who use the short PHQ-2 use it for screening and not for monitoring depression

Form is copyrighted, but can be freely used. More information can be found at the provided link(s)

General Details

Name: Patient Health Questionnaire 2 item (PHQ-2) [Reported]

Description: The Patient Health Questionnaire-2 (PHQ-2) is a shorter version of the PHQ-9 containing two screening questions: one about the frequency of depressed mood and another about loss of interest in activities. A positive to either question indicates further testing is required.

Used by: ONC

Is a Bundle: No

Copyrighted: Form is copyrighted, but can be freely used. More information can be found at the provided link(s)
<https://www.phqscreeners.com/select-screener>
<https://loinc.org/55758-7/>

All CDEs

Search by topic, keyword, or organization



REFINE CDE RESULTS

NIH-Endorsed

Collections

- Project 5 (COVID-19) (125) >
- ScHARe (34) >
- AHRQ (91) >
- cLBP (4) >
- External Forms (204) >
- GRDR (75) >
- NEI (235) >
- NHLBI (2779) >
- NICHD (638) >
- NIDA (120) >
- NINDS (13863) >
- NINR (191) >
- NLM (302) >
- ONC (35) >
- PhenX (3635) >
- PROMIS / Neuro-QOL (647) >
- RADx-UP (234) >
- Women's CRN (21) >

Registration Status

- Standard (1566)
- Qualified (21475)

Data Types

- Value List (14815)

Search CDEs

Export All CDEs

Enter a phrase/text or explore CDEs by selecting a Collection.

The NIH CDE Repository hosts **23041 CDEs** from **18 Collections**. We provide access to structured human and machine-readable definitions of data elements that have been recommended or required by NIH Institutes and Centers and other organizations for use in research and for other purposes.

Collections

<p> Project 5 (COVID-19)</p> <p>For translational, clinical, and applied COVID-19 research</p> <p style="text-align: right;">125 elements</p>	<p> ScHARe</p> <p>Science Collaborative for Health disparities and Artificial intelligence bias REDuction Source</p> <p style="text-align: right;">34 elements</p>
<p>AHRQ</p> <p>Agency for Healthcare Research and Quality</p> <p style="text-align: right;">91 elements</p>	<p>cLBP</p> <p>Chronic Low Back Pain Source</p> <p style="text-align: right;">4 elements</p>
<p>External Forms</p> <p>External Forms</p> <p style="text-align: right;">204 elements</p>	<p>GRDR</p> <p>Global Rare Diseases Patient Registry Data Repository Source</p> <p style="text-align: right;">75 elements</p>
<p>NEI</p> <p>National Eye Institute</p>	<p>NHLBI</p> <p>National Heart, Lung and Blood Institute</p>



REFINE FORM RESULTS

Collections ^

- Project 5 (COVID-19) (30) >
- ScHARe (9) >
- AHRQ (9) >
- External Forms (24) >
- NEI (8) >
- NHLBI (88) >
- NICHD (15) >
- NIDA (12) >
- NINDS (1136) >
- NINR (18) >
- NLM (30) >
- ONC (5) >
- PhenX (283) >
- PROMIS / Neuro-QOL (61) >
- Women's CRN (1) >

Copyright Status ^

- Public domain, free to use (829)
- Copyrighted, but free to use (641)
- Copyrighted, with restrictions (208)

Registration Status ^

- Qualified (1678)

Search Forms

Export All Forms

Enter a phrase/text or explore Forms by selecting a Collection.

The NIH CDE Repository hosts **1678 Forms** from **15 Collections**. We provide access to structured human and machine-readable definitions of data elements that have been recommended or required by NIH Institutes and Centers and other organizations for use in research and for other purposes.

Collections

Project 5 (COVID-19)

For translational, clinical, and applied COVID-19 research

30 elements

ScHARe

Science Collaborative for Health disparities and Artificial intelligence bias REduction Source

9 elements

AHRQ

Agency for Healthcare Research and Quality

9 elements

External Forms

External Forms

24 elements

NEI

National Eye Institute

8 elements

NHLBI

National Heart, Lung and Blood Institute
Cure Sickle Cell Initiative
Source

88 elements

NICHD

Ernie Kennedy Shriver National Institute of Child Health and Human Development

NIDA

National Institute on Drug Abuse

CDE Resources

NIH CDE Repository: <https://cde.nlm.nih.gov/>

Common Data Elements: Standardizing Data Collection

- [Self-paced tutorial](#) on CDE basics

Standardize Your Research Data with the NIH CDE Repository

- [Recording](#) of October 2022 live class
- [On-demand training](#) version of this class

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

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

Search by topic, keyword, or organization

Forms are composed of multiple CDEs that are intended to be used together.

Explore Learn Submit

Request for Information

2021 NLM Request for Information: Use of CDEs in NIH-Funded Research

- Most responses came from researchers
- Most comments were about CDE guidance, tools, infrastructure, and incentives
- Other comments were about challenges to adopting CDEs and current use of CDEs

<https://grants.nih.gov/grants/guide/notice-files/NOT-LM-21-005.html>

Request for Information: Common Data Elements

- Soliciting public input on core data elements (CDEs) for NIH-funded research.
- CDEs ensure standardized data collection, enhancing interoperability and facilitating knowledge discovery.
- Challenges in CDE adoption include duplicative sources and the need for mapping technologies.

Due Date: April 20, 2024.



Read the RFI here:
<https://bit.ly/3T3Q3U3>

thank you!

robin.taylor@nih.gov