

# NIH CDE Repository

Updates and Future Directions

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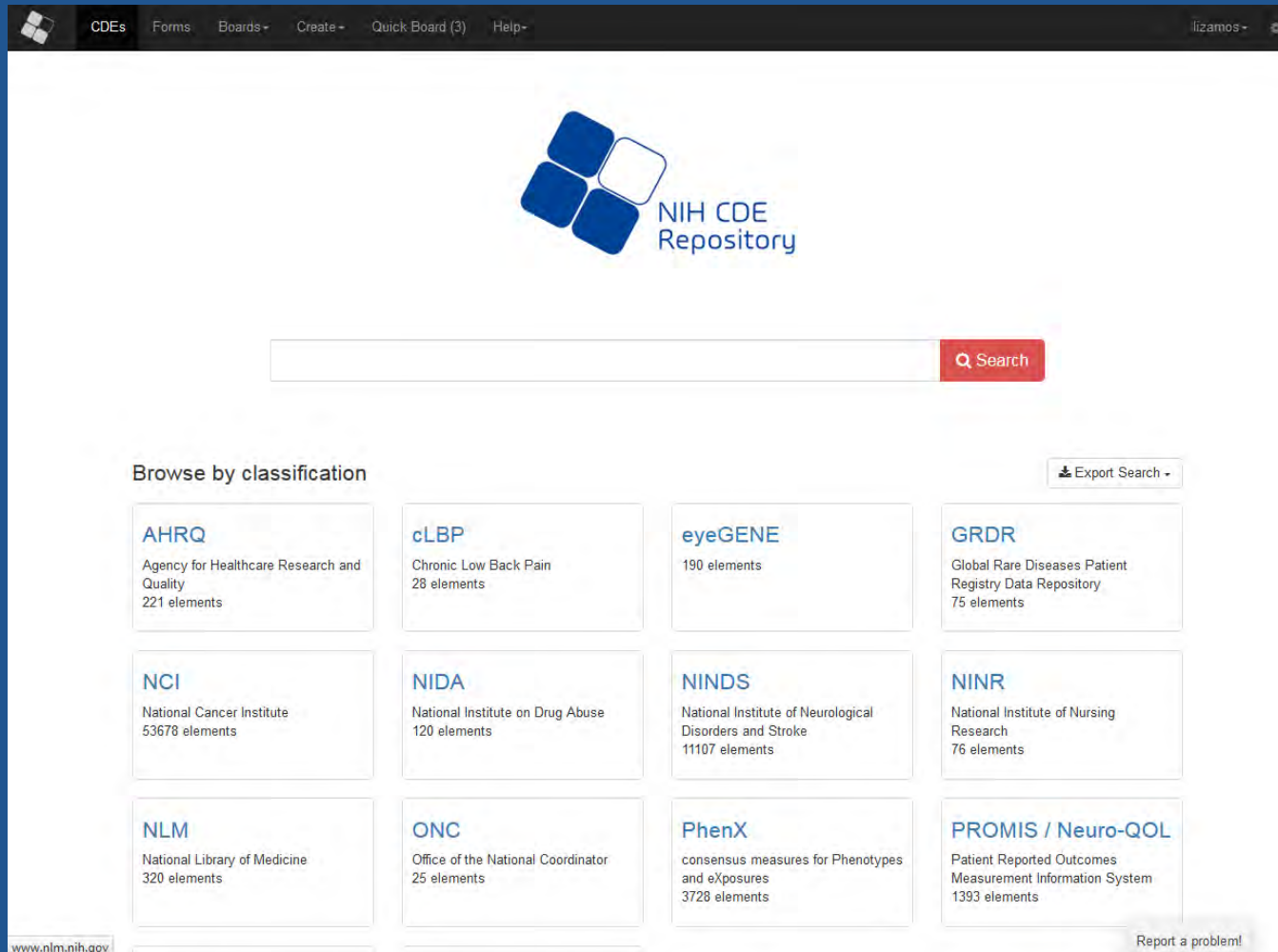
National Library of Medicine

National Institutes of Health

U.S. Department of Health and Human Services



# The NIH CDE Repository is a tool to search across initiatives



- NIH recommended/required CDEs and Forms
- Search, retrieve and reuse CDEs and Forms
- Create/harmonize
- Share and collaborate

[cde.nlm.nih.gov](http://cde.nlm.nih.gov)



# New Features

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# Comments on CDEs and Forms

The screenshot displays the NIH CDEs and Forms interface. At the top, a navigation bar includes links for CDEs, Forms, Boards, Create, Quick Board (3), and Help. The user 'lizamos' is logged in. The main heading is 'Difficulty seeing side'. Below this, a row of buttons includes Export, Add to Quick Board, Add to Board, Copy, and Discuss. A red arrow points to the Discuss button. On the left, a sidebar menu lists various tabs: General (selected), Detail, Permissible Values, Naming (highlighted with a red arrow), Classification, Mesh Topic, Concepts, Reference Documents, Properties, Identifiers, Attachments, and History. The main content area shows 'General Details' for the CDE, including its Name, Steward (NEI), Definition, Used By, SDC View, Created date, Updated date, and Created By. Below this, the 'Registration State' is shown as 'Incomplete' with an 'Edit' button. At the bottom of the details section are buttons for 'Linked Forms', 'More Like This', 'Linked Boards', and 'Data Set'. On the right, a 'Join the discussion...' text box is followed by a 'Post Comment' button. Below this, two comments are visible: one from 'lizamos' dated 01/03/2017 @ 4:05PM asking 'Should this be "side streets" not site streets?' and another from 'ludetc' dated 10/31/2017 @ 4:08PM replying 'Yes, I think it's a typo'. A 'Reply to this comment' text box is at the bottom of the comment section.

Difficulty seeing side

Export Add to Quick Board Add to Board Copy Discuss

General Details

Name: Difficulty seeing side  
Steward: NEI  
Definition:  
Used By:  
SDC View: SDC View  
Created: 01/03/2017 @ 4:02PM  
Updated: 03/23/2017 @ 10:40AM  
Created By: lizamos

Registration State: Edit

Registration Status: Incomplete

Linked Forms More Like This Linked Boards Data Set

Join the discussion...

Post Comment

lizamos 01/03/2017 @ 4:05PM  
Should this be "side streets" not site streets?

ludetc 10/31/2017 @ 4:08PM  
Yes, I think it's a typo

Reply to this comment

# Add reviewers and collaborators to your Boards

**Demographics**

In progress 10/31/2017 End Review Share Discuss

Table View Export Board Classify All CDEs Create Form

**↓ Race OMB.1997** Candidate

The race of a person based on the Office of Management and Budget (OMB), Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (Oct. 30, 1997).

Used By: NLM ONC  
Steward: NLM

Value	Code Name	Code
Native Hawaiian or Other ...	Native Hawaiian or Other ...	2076-8
American Indian or Alaska...	American Indian or Alaska...	1002-5
Asian	Asian	2028-9
Black or African American	Black or African American	2054-5

(6 total) See full list in Detailed View

**↑ ↓ ⤴ Marital status** Qualified

Used By: ONC  
Steward: LOINC  
Source: LOINC

Value	Code Name	Code
1	Married	LA48-4
2	Widowed	LA49-2
3	Divorced	LA51-8
4	Separated	LA4288-2

(8 total) See full list in Detailed View

Join the discussion...

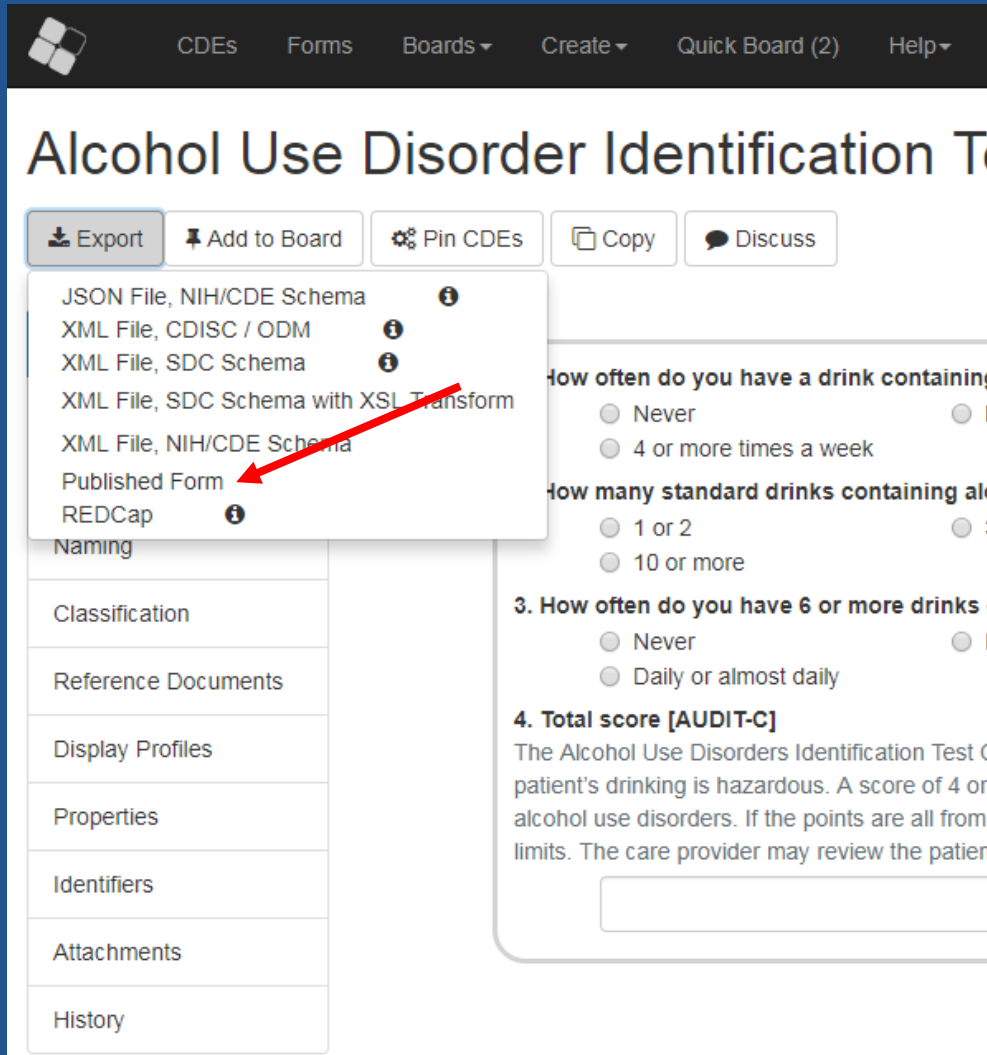
Post Comment

lizamos  
10/31/2017 @ 11:22AM

Maybe include housing status?

Reply to this comment

# “Published Form” export to specified end point



The screenshot shows the NIH CDE Repository interface for the 'Alcohol Use Disorder Identification Test'. The top navigation bar includes 'CDEs', 'Forms', 'Boards', 'Create', 'Quick Board (2)', and 'Help'. The main title is 'Alcohol Use Disorder Identification Test'. Below the title, there are buttons for 'Export', 'Add to Board', 'Pin CDEs', 'Copy', and 'Discuss'. The 'Export' button is highlighted, and a dropdown menu is open, showing the following options: 'JSON File, NIH/CDE Schema', 'XML File, CDISC / ODM', 'XML File, SDC Schema', 'XML File, SDC Schema with XSL Transform', 'XML File, NIH/CDE Schema', 'Published Form', and 'REDCap'. A red arrow points to the 'Published Form' option. The left sidebar contains a list of tabs: 'Naming', 'Classification', 'Reference Documents', 'Display Profiles', 'Properties', 'Identifiers', 'Attachments', and 'History'. The main content area displays the 'Alcohol Use Disorder Identification Test' form, which includes questions about alcohol consumption and a total score calculation.

- Many existing export formats
- This published export will generate a published version of this form that will submit data to the endpoint of your choice.
- You will need to ensure that your endpoint meets your own security standards.
  - Example: Google Spreadsheet (via a Google Script published as a web app).
- **Note:** NIH CDE Repository will not have access to any data submitted.

## Merge AUDIT-C Questionnaire Into Alcohol Use Disorder Identification Test - Consumption [AUDIT-C]

### Form fields:

☐ All ☐ None

☒ Naming

☒ Ref Documents

☒ Properties

☒ IDs

☒ Classifications

☒ Questions

### CDE fields:

☐ All ☐ None

☒ Naming

☒ Ref Documents

☒ Properties

☒ IDs

☒ Attachment

☒ Data Set

☒ Derivation Rules

☒ Sources

☒ Classifications

Retire CDE? ☐

CDE Name: Patient Past Year Alcohol Consumption Frequency



CDE Name: Patient Day Alcohol Consumption Day Alcohol Consumption Frequency Amount



CDE Name: Alcoholic Beverage Consumption MoreThan Six At One Occasion Frequency



+ Add Placeholder

CDE Name: How often do you have a drink containing alcohol [SAMHSA]

CDE Name: How many standard drinks containing alcohol do you have on a typical day [SAMHSA]

CDE Name: How often do you have 6 or more drinks on 1 occasion [SAMHSA]

CDE Name: Total score [AUDIT-C]

Cancel

Merge



CDE QuickBo

Q Side by S

☒ AUDIT-

Questions - alcohol scre active alcoh version of th scored on a 4 points. In r drinking or a Generally th safety.</p> <p> Identification AUDIT-C is :

☒ Alcohol

Questions -

# New Collections

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# LASIK Quality of Life Collaboration Project

- FDA, NEI and DOD project to better understand potential risk of severe problems that can result from LASIK.
  - Patient-Reported Outcomes with LASIK (PROWL)
    - Pre-Op and Post-Op Questionnaires
- NLM asked to create CDEs and electronic form
- [More information on scales used in PROWL Questionnaires](#)

The next few questions are about *double images*, which some people call "ghost" or "shadow" images. By double images, we mean seeing a distorted or *blurry visual image*, such as the images shown below. These images may not represent exactly what you see and your symptoms may be more or less severe than what is shown.

No double image —————→ Severe double image



46. In the last 7 days, have you seen any double images?

- ☐ Yes, but ONLY when NOT wearing glasses or contact lenses
- ☐ Yes, but ONLY when wearing glasses or contact lenses
- ☐ Yes, when wearing AND when not wearing glasses or contact lenses
- ☐ No, not at all

47. In the last 7 days, how often have you seen double images when you are wearing your best vision correction (glasses or contact lenses)?

- ☐ I do not use glasses or contact lenses
- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always



# NINR Symptom Science

- NINR first developed a set of CDEs commonly collected in all symptom studies -- Sleep, Fatigue, Pain, and Cognitive/Affect -- regardless of diagnosis.
- Along with symptoms, also included are demographic information (e.g., date of birth/ age, race, ethnicity); on participants throughout a study
- Required in specific P20 FOAs (NINR)



# Collections In Development

## NIEHS – RAPIDD Study Protocols

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- A pre-positioned protocol intended to minimize the time needed to begin collecting health data and biological samples from disaster response workers who may be exposed to environmental contaminants.
- RAPIDD includes all the documents and procedures needed to create a registry of workers.
- Rapid Acquisition of Pre- and Post-Incident Disaster Data
- Core, Basic and Enhanced Health Forms

## PCOR-TF Women's Coordinated Registry Network

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- Project with FDA, ONC, and several womens device registries
- Potential users of NLM tooling and resources



# Ongoing Projects

- Copyright analysis and workflow development
  - Environmental scan of standardized assessment instruments to determine copyright status
  - Development of workflow for contacting copyright holder
- Annotation(s) of data elements and forms to support discoverability
  - SNOMED CT (Poster Session 11/7 @ 5pm)
  - MeSH (collaboration with NLM Index Section)
- First NLM application to move to Amazon Web Services
- Continued work in deduplication, quality assurance, and harmonization



# Ongoing NIH CDE Activities

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# Current NIH CDE activity

- Task force, reporting to NIH Scientific Data Committee
- Working groups addressing need for:
  - Technical infrastructure
  - Harmonization and alignment of key data elements (race, ethnicity, etc)
  - Glossary related to CDE activities
- Exploration of linkage to variable level datasets (dbGaP)
- Natural language processing and CDEs to improve discoverability in dbGaP (Poster Session 11/7 @ 5pm)
- Exploring FHIR integration with NLM Terminology and Standards team



# Questions?

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