NIH CDE Repository

Updates and Future Directions

Liz Amos, MLIS
National Information Center on Health Services Research and Health Care Technology (NICHSR)
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]
New Features
Comments on CDEs and Forms

Difficulty seeing side

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

Registration State:
- Registration Status: Incomplete

- Linked Forms
- More Like This
- Linked Boards
- Data Set

Post Comment
- lizamos
  01/03/2017 @ 4:05PM
  Should this be "side streets" not "site streets"?
- lizamos
  10/31/2017 @ 4:08PM
  Yes, I think it's a typo

Reply to this comment
Add reviewers and collaborators to your Boards

Demographics

<table>
<thead>
<tr>
<th>Race OMB.1997 Candidate</th>
<th>Value</th>
<th>Code Name</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Native Hawaiian or Other...</td>
<td>Native Hawaiian or Other...</td>
<td>2076-8</td>
</tr>
<tr>
<td></td>
<td>American Indian or Alaska...</td>
<td>American Indian or Alaska...</td>
<td>1002-5</td>
</tr>
<tr>
<td></td>
<td>Asian</td>
<td>Asian</td>
<td>2028-9</td>
</tr>
<tr>
<td></td>
<td>Black or African American</td>
<td>Black or African American</td>
<td>2054-5</td>
</tr>
<tr>
<td></td>
<td>(6 total) See full list in Detailed View</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Value</th>
<th>Code Name</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>Married</td>
<td>LA48-4</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Widowed</td>
<td>LA49-2</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Divorced</td>
<td>LA51-8</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Separated</td>
<td>LA288-2</td>
</tr>
<tr>
<td></td>
<td>(8 total) See full list in Detailed View</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
“Published Form” export to specified end point

- 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.
<table>
<thead>
<tr>
<th>CDE Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Past Year Alcohol Consumption Frequency</td>
<td>How often do you have a drink containing alcohol [SAMHSA]</td>
</tr>
<tr>
<td>Patient Day Alcohol Consumption Day Alcohol Consumption Frequency Amount</td>
<td>How many standard drinks containing alcohol do you have on a typical day [SAMHSA]</td>
</tr>
<tr>
<td>Alcoholic Beverage Consumption MoreThanSixAtOneOccasionFrequency</td>
<td>How often do you have 6 or more drinks on 1 occasion [SAMHSA]</td>
</tr>
<tr>
<td>Total score [AUDIT-C]</td>
<td></td>
</tr>
</tbody>
</table>
New Collections
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
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

- 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

- 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
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?

liz.amos@nih.gov - NIH CDE Repository Lead
langl@mail.nih.gov - Assistant Director for Health Services Research Information