NIH CDE Repository
Updates and Future Directions

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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
Add reviewers and collaborators to your Boards

Demographics

<table>
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<tr>
<th>Value</th>
<th>Code Name</th>
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<tbody>
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</tr>
<tr>
<td>Other</td>
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<td></td>
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<td>American Indian or</td>
<td>American Indian or Alaska</td>
<td>1002-5</td>
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<tr>
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<tr>
<td>American</td>
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(5 total) See full list in Detailed View

Marital status

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<td>4</td>
<td>Separated</td>
<td>LA288-2</td>
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</table>

(5 total) See full list in Detailed View
“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.
New Collections
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.

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 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)
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

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?

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