NIH CDE Repository

Updates and Future Directions

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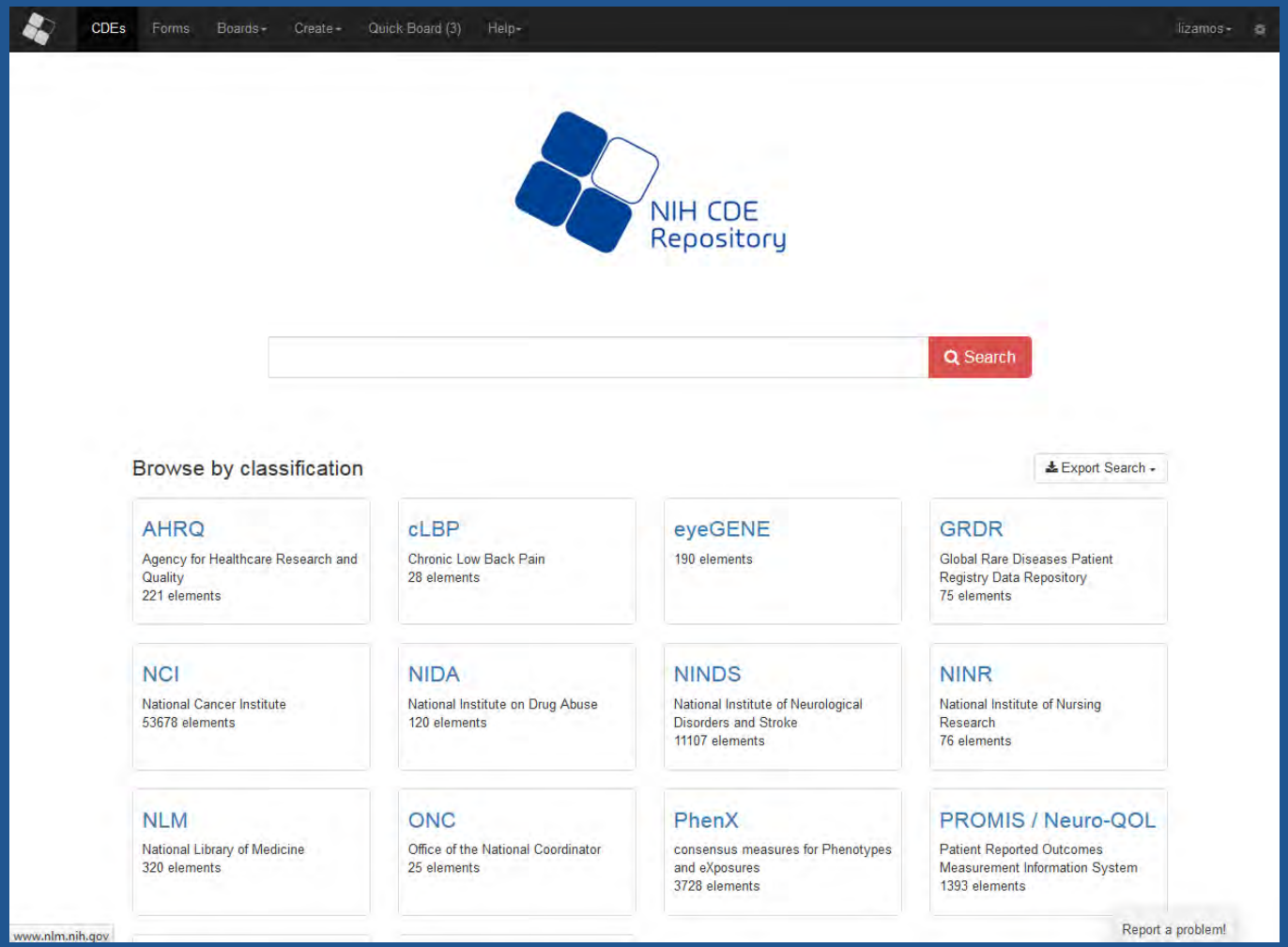
National Information Center on Health Services Research and Health Care Technology (NICHSR)
National Library of Medicine
National Institutes of Health
U.S. Department of Health and Human Services

The NIH CDE Repository is a tool to search across initiatives

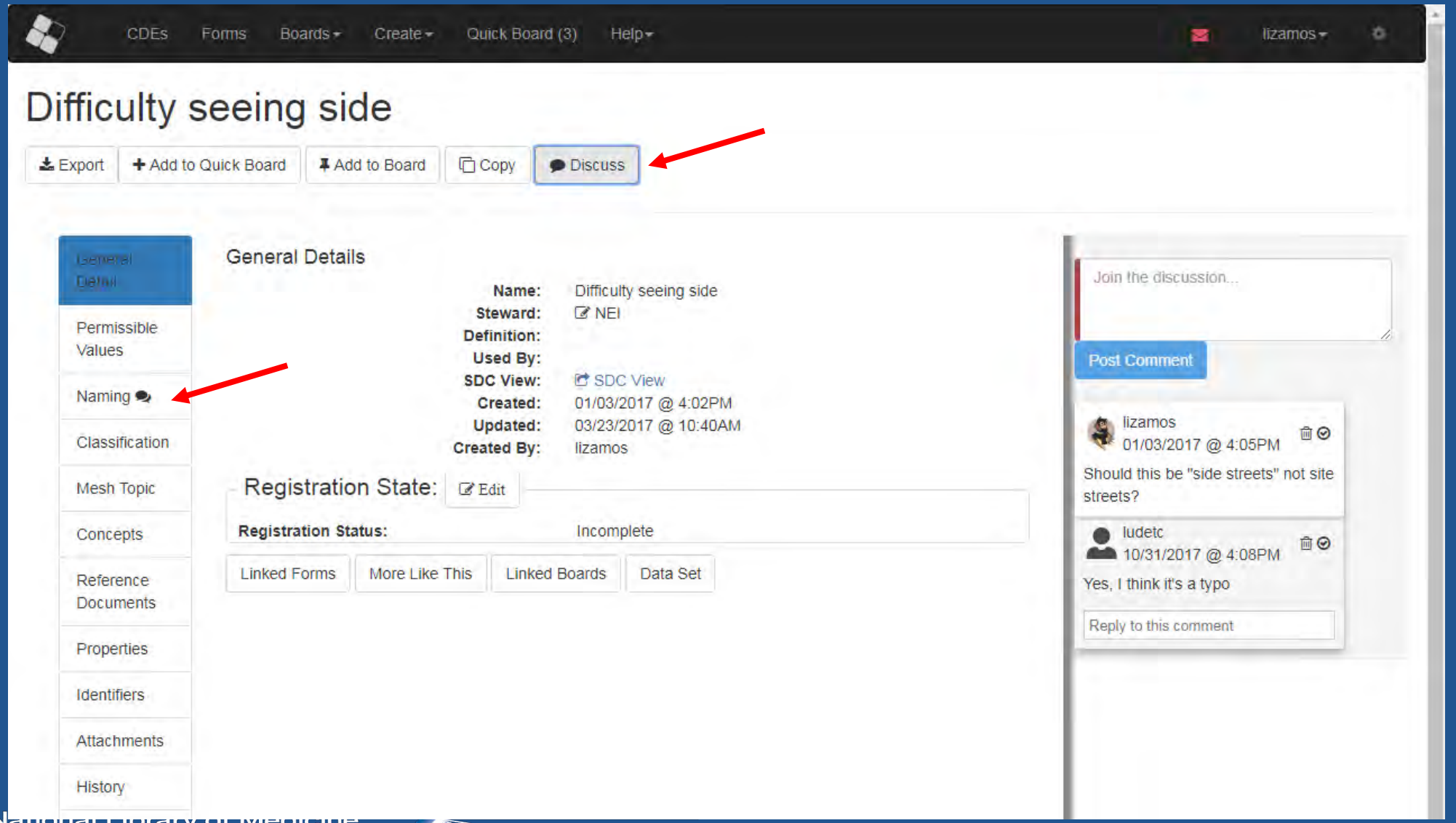


- NIH recommended/required CDEs and Forms
- Search, retrieve and reuse CDEs and Forms
- Create/harmonize
- Share and collaborate

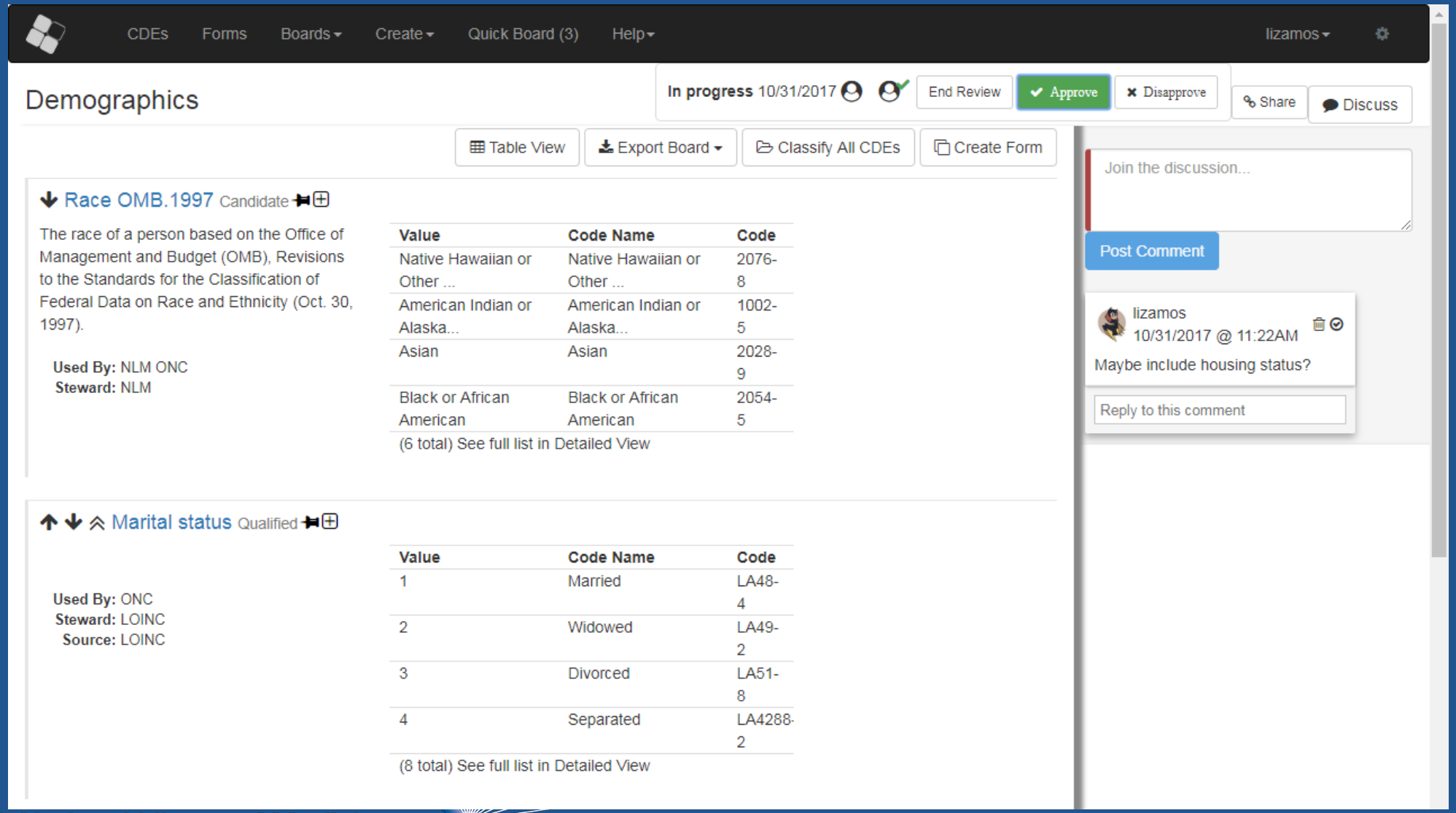
cde.nlm.nih.gov

New Features

Comments on CDEs and Forms



Add reviewers and collaborators to your Boards



“Published Form” export to specified end point

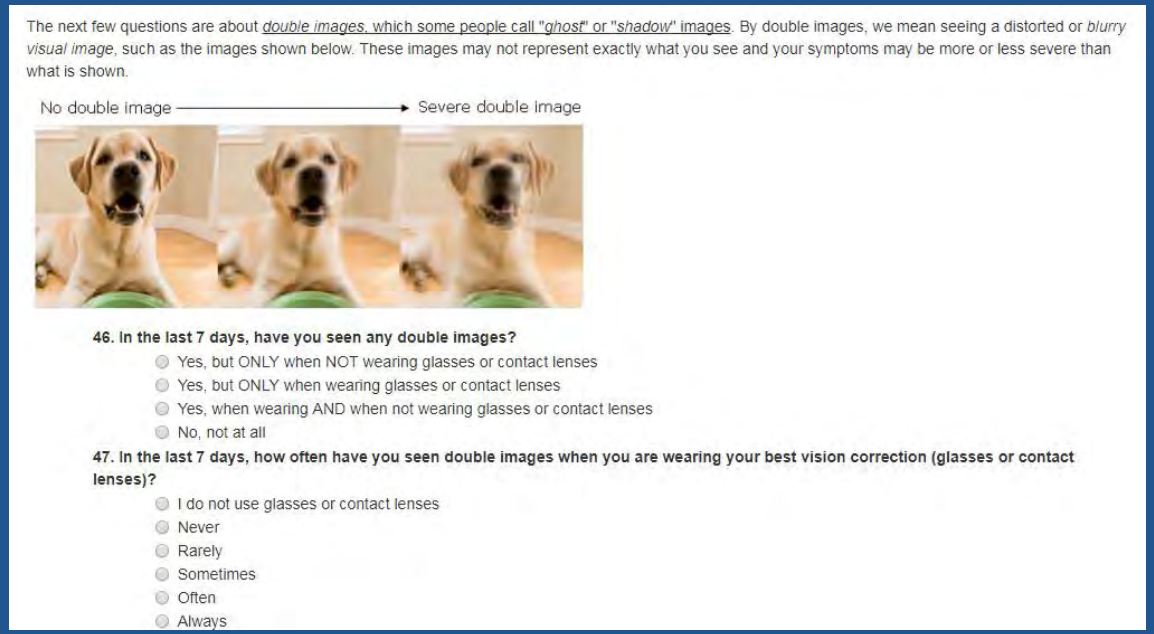
- Many existing export formats
- This published export will generate a published version of this form that will submit data to the endpoint of your choice.
- You will need to ensure that your endpoint meets your own security standards.
  - Example: Google Spreadsheet (via a Google Script published as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

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

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.

No double image → Severe double image

LASIK Quality of Life Collaboration Project (FDA site)

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)

NIH National Institute of Nursing Research
Building the Scientific Foundation for Clinical Practice

BRICS | Biomedical Research Informatics Computing System

cdRNS
Common Data Repository for Nursing Science

NINR Common Data Element Portal

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?

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