| Intended Users: | Information Professionals | Researchers |
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# Product: NIH CDE Repository

**Description:** The NIH CDE Repository is a repository of common data elements (CDEs) recommended or required for use by NIH institutes and centers. A CDE is a standardized, precisely-defined question (i.e., variable) paired with specific rules for allowable responses. CDEs may be used in data collection instruments across multiple datasets, research sites, studies, etc. The CDEs in the NIH CDE Repository provide standards for how medical questionnaires or surveys are structured so that questions and responses are captured in a consistent way across different studies, organizations, and disciplines. Data that is collected, represented, and organized in consistent ways is easier to share and reuse later on. The NIH CDE Repository helps researchers follow FAIR (Findable, Accessible, Interoperable, Reusable) data principles and supports open science.

**Popular uses of this product:**

| Information Professionals | Researchers |
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| • Incorporate information about the NIH CDE Repository into presentations or outreach regarding FAIR or open science practices.<br>• Use CDEs to standardize data collection efforts and make data more interoperable and reusable. | • Find standardized forms, questionnaires, and response options to conduct research studies.<br>• Use CDEs to standardize possible responses on medical survey questions.<br>• Reduce time needed to normalize and clean data. |

**Key Points:**

1. CDEs can be used with other tools and practices to promote open science and open data practices.
2. The NIH CDE Repository is a collection of common data elements that are recommended by NIH institutes and centers. Content includes standardized forms, questions, responses, and other data elements that work to unify practices for collecting health data. For example, when asking about a patient's drinking habits, the NIH CDE Repository provides example forms with standardized questions such as "Select the number of alcoholic drinks you consume per week", with preset responses ranging from 0 to 7+. This reduces the number of ways people can respond and helps make data more interoperable.
3. CDEs marked with a gold award ribbon are endorsed by NIH. These CDEs meet the criteria set by the NIH Scientific Data Council for creating high-quality "computation-ready" data.

**Potential Predicaments:**

1. The site is free, but people must have an account to access certain features. They can request an account through NIH or their organization's third-party credentials.
2. The site does not offer a way to store or record data; it only provides guidance on CDEs to standardize the collection of clinical data.

**Teaching Examples:**

1. On the homepage, have participants search through all CDEs for "education." Compare "Education level" from NEI and "Current Educational Attainment" from Project 5, which is endorsed by NIH. Have participants discuss why they would use one CDE over the other and how that CDE helps to keep data organized, interoperable, and reusable.

**Real Life Examples:**

1. A researcher and a librarian are conducting a systematic review on depression. They want to compare the data captured between the studies. They use the NIH CDE Repository to verify if the questionnaires used in the studies used the same measurements.
2. A researcher is studying smoking cessation. To standardize their data collection efforts, they use the NIH CDE Repository to find the PhenX- smoking quit attempts protocol. They use these standardized measures to collect data about people's smoking cessation attempts.

**More Information:**

About NIH CDE Repository  Help Guides  Common Data Elements Learning Course

**Related Resources:**

U.S. Core Data for Interoperability  FAIR Data Principles  CARE Indigenous Data