Digital Health Innovation: Policy & Standards

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U.S. Policies Promote Open (Government) Data and Open Science

Open Data

- Federal data other than scientific data (e.g., Census)

Open Science

- Scientific data not managed by Federal agencies
- Peer-reviewed journal articles
- Software, tools, protocols, other research outputs

Scientific data managed by Federal agencies

Software, tools, protocols, other research outputs
NIH Culture of Data and Resource Sharing

- NIH Data Sharing Policy
- Model Organism Policy
- Genome-wide Association (GWAS) Policy
- NIH Public Access Policy (Publications)
- Big Data to Knowledge (BD2K) Initiative
- OSTP Public Access Memo
- Genomic Data Sharing (GDS) Policy
- NIH Intramural Human Data Sharing Policy
- Regulations and NIH Policy on Clinical Trial Registration & Results Reporting
The database of Genotypes and Phenotypes (dbGaP) was developed to archive and distribute the data and results from studies that have investigated the interaction of genotype and phenotype in Humans.
ClinicalTrials.gov is a database of privately and publicly funded clinical studies conducted around the world.

Explore 270,435 research studies in all 50 states and in 203 countries.

ClinicalTrials.gov is a resource provided by the U.S. National Library of Medicine.

IMPORTANT: Listing a study does not mean it has been evaluated by the U.S. Federal Government. Read our disclaimer for details.

Before participating in a study, talk to your health care provider and learn about the risks and potential benefits.
Health data standards

• Standards designated for use in Electronic Health Records
  • SNOMED-CT – Clinical Terminology
  • LOINC – Lab results and observations
  • Rx-NORM – drug names

• International Health Data Standards Organization – SNOMED International
  • 29 Members
  • 5000 affiliate individual and organizations

• UMLS – Unified medical language system
  • Compendium of controlled vocabularies in the biomedical sciences
  • Developed by U.S. National Library of Medicine
Home
NIH encourages the use of common data elements (CDEs) in clinical research, patient registries, and other human subject research in order to improve data quality and opportunities for comparison and combination of data from multiple studies and with electronic health records. This portal provides access to information about NIH-supported CDEs, as well as tools and resources to assist investigators developing protocols for data collection. What is a CDE?

Webinar: Overview of NIH CDE Initiatives (September 8, 2015) View slides / watch recording

NIH CDE Collections
Sets of CDEs that have been identified for use in particular types of research or research domains after a formal evaluation and selection process.

NIH CDE Repository
The Repository is a platform for identifying related data elements in use across diverse areas, for harmonizing data elements, and for linking CDEs to other existing standards and terminologies.

Some NIH programs have issued specific guidance for using CDEs in funded research.

The CDE Resource Portal also includes Other CDE Resources and Relevant Standards. Descriptions of all four groups can be found in the Glossary.

The CDE Working group of the Trans-NIH Biomedical Informatics Coordinating Committee (BMIC) developed this Portal to improve the coordination of CDEs. BMIC encourages researchers to use CDEs from the Resources in this Portal where applicable, and to consider existing CDE initiatives before starting additional initiatives.

Are we missing a CDE Resource? Contact us.

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National Institutes of Health, Health Information, U.S. Government Services
Freedom of Information Act, NCI Customer Support

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A Platform for Biomedical Discovery and Data-Powered Health

Strategic Plan 2017-2027

Thank you

www.nlm.nih.gov