Digital Health Innovation:
Policy & Standards

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Vice-Chair, OECD Working Party on Innovation & Technology Policy
Digital Health Innovations Workshop
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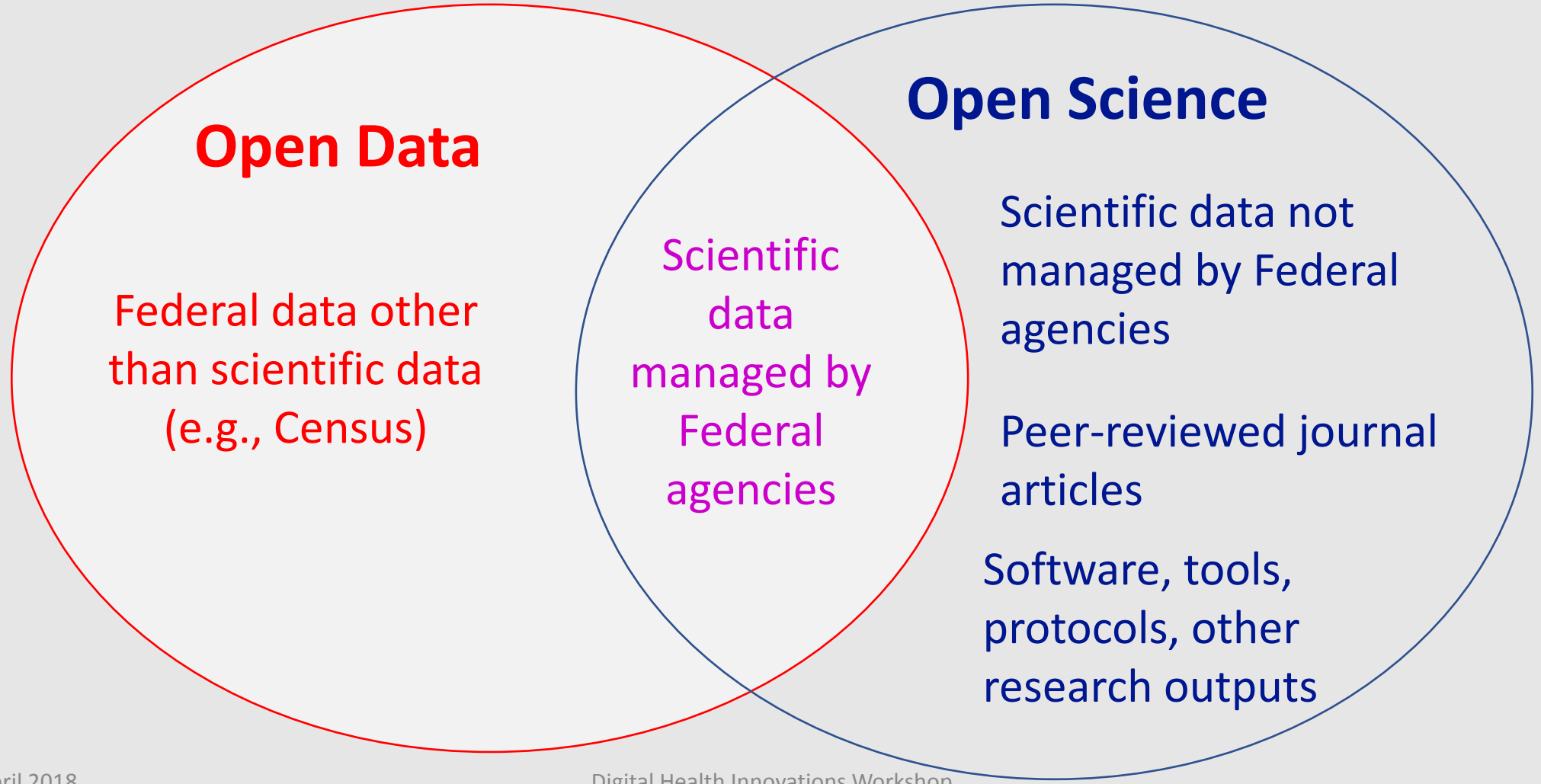
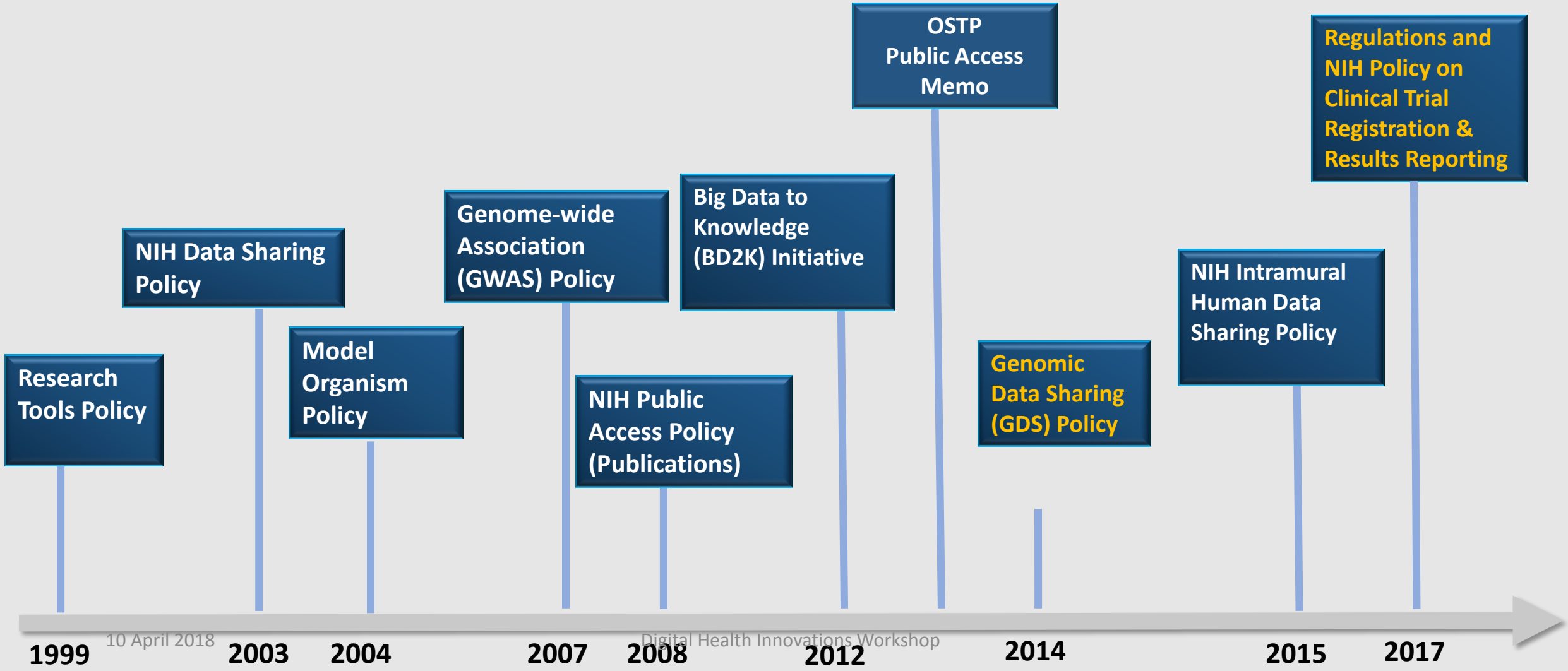
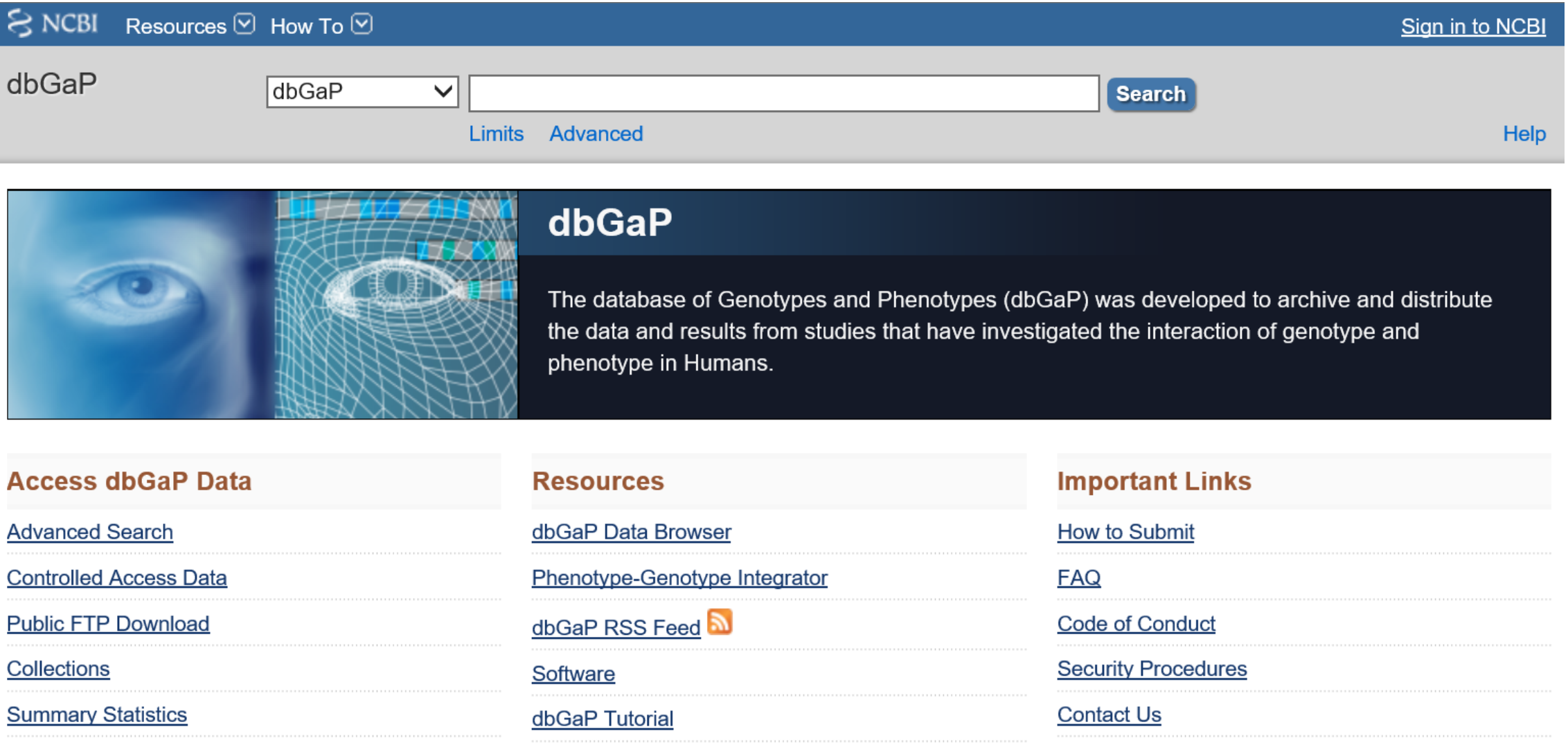
U.S. National Library of Medicine

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



NIH Culture of Data and Resource Sharing




NCBI
Resources
How To
Sign in to NCBI
dbGaP
dbGaP
Search
Limits
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dbGaP
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.
Access dbGaP Data
Advanced Search
Controlled Access Data
Public FTP Download
Collections
Summary Statistics
Resources
dbGaP Data Browser
Phenotype-Genotype Integrator
dbGaP RSS Feed
Software
dbGaP Tutorial
Important Links
How to Submit
FAQ
Code of Conduct
Security Procedures
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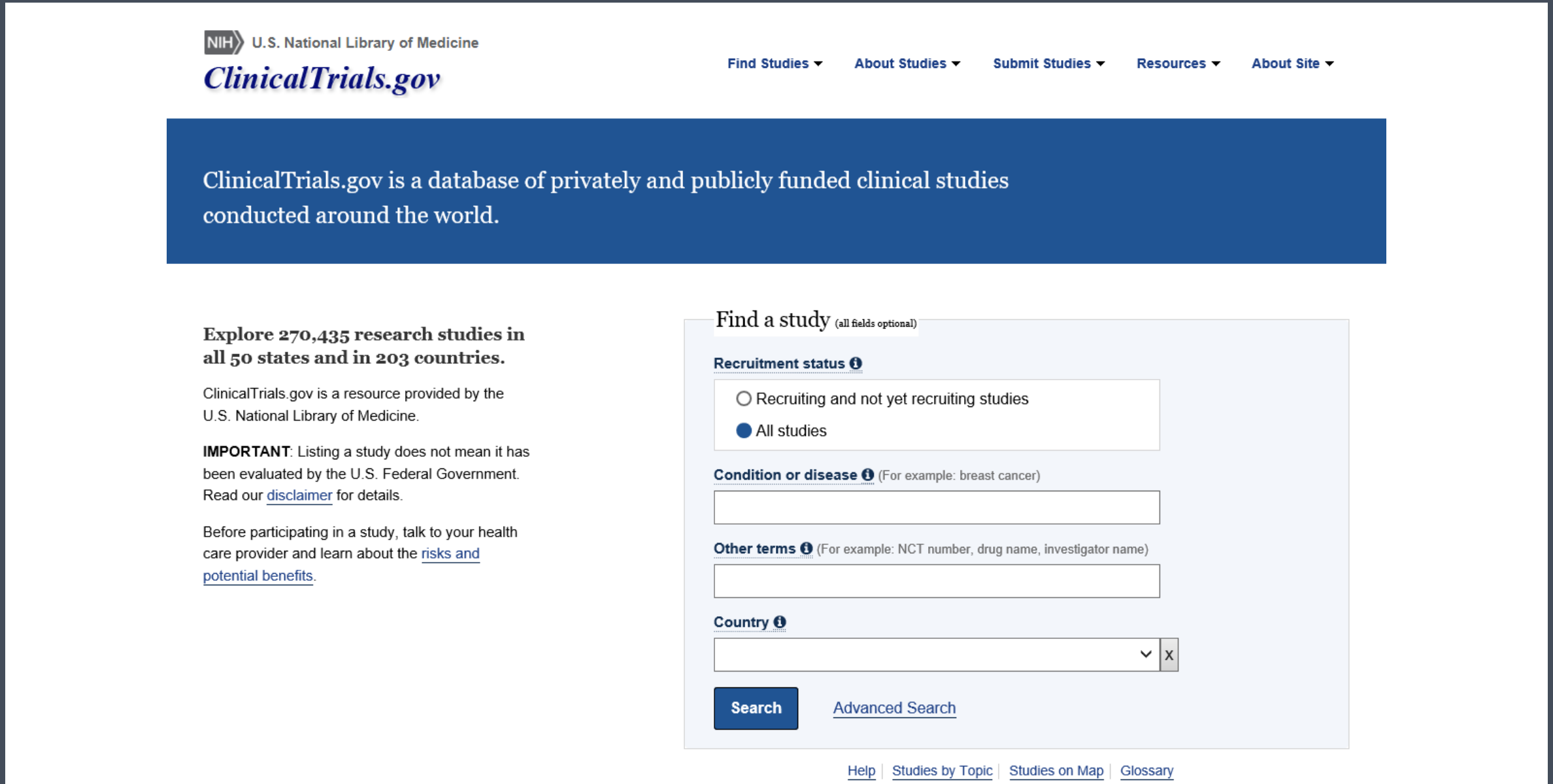
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Before participating in a study, talk to your health care provider and learn about the risks and potential benefits.
Find a study (all fields optional)
Recruitment status
Recruiting and not yet recruiting studies
All studies
Condition or disease (For example: breast cancer)
Other terms (For example: NCT number, drug name, investigator name)
Country
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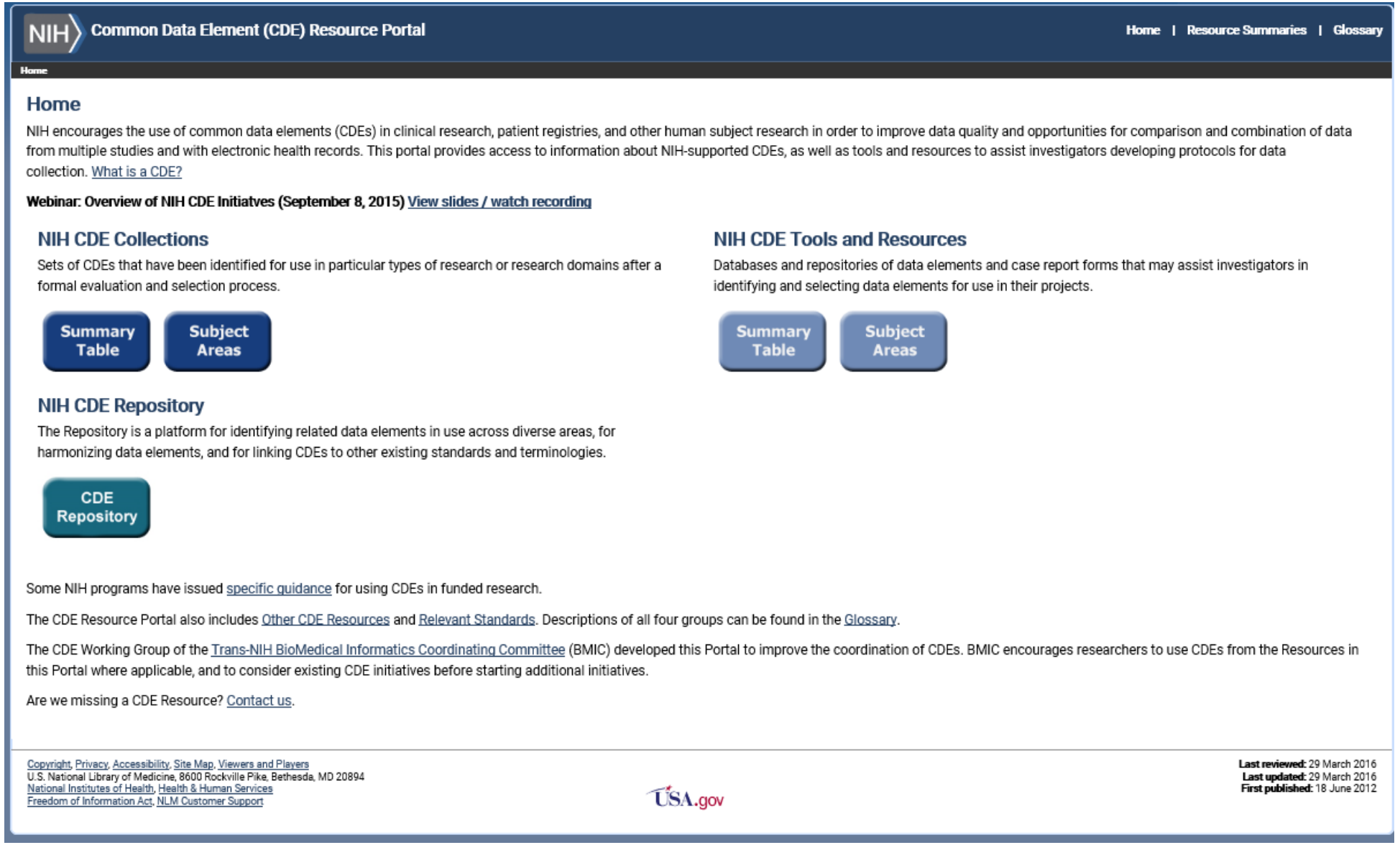
Studies by Topic
Studies on Map
Glossary

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


NIH
Common Data Element (CDE) Resource Portal
Home | Resource Summaries | Glossary
Home
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 Initiatves (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.
Summary Table
Subject Areas
NIH CDE Tools and Resources
Databases and repositories of data elements and case report forms that may assist investigators in identifying and selecting data elements for use in their projects.
Summary Table
Subject Areas
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.
CDE Repository
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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A Platform for Biomedical Discovery and Data-Powered Health

Strategic Plan 2017-2027

https://www.nlm.nih.gov/pubs/plan/lrp17/NLM_StrategicReport2017_202

Thank you

www.nlm.nih.gov