

HYBRID
Meeting

Advancing the Use and Development of **Common Data Elements** in Research



Natcher Conference Center
Building 45, NIH Campus
Bethesda, MD

MARCH 6-7, 2024

Office of Data Science Strategy

OD/DPCPSI

Provides NIH-wide leadership and coordination for a modernized NIH data resource ecosystem*



What We Do

Provides **leadership and coordination** on the strategic plan for data science

Develops NIH's vision for a **modernized and integrated biomedical** data ecosystem

Enhances a **diverse and talented** data science workforce

Builds strategic partnerships to advanced technologies and methods

Data Science in the next 5 years

- Improve Capabilities to Sustain the NIH Policy for Data Management and Sharing
- **Develop Programs to Enhance Human Derived Data for Research**
- Provide New Opportunities in Software, Computational Methods, and Artificial Intelligence
- Support for a Federated Biomedical Research Data Infrastructure
- Strengthen a Broad Community in Data Science

Common Data Elements

- Common data elements (CDEs) are standardized, defined questions paired with a set of specific allowable responses.
- If used systematically across different sites, studies, or clinical trials, consistent data is collected, and it becomes possible to share and compare data.
- The NIH CDE Repository currently hosts 23041 CDEs from 18 collections. Three collections (ScHARe, Project 5 (COVID-19) and NHLBI) are labeled as NIH-endorsed CDEs.



The screenshot shows the NIH CDE Repository website. At the top, there is a dark blue header with the NIH logo and "National Library of Medicine" on the left, and a "Sign In" button with a menu icon on the right. Below the header, the main content area has a light blue background with a faint grid pattern. The main heading reads "Use Common Data Elements for More FAIR Research Data". Below this, a sub-heading states: "Common data elements (CDEs) help researchers share and combine datasets, meet funding requirements, and save time." There is a search bar with the placeholder text "Search by topic, keyword, or org..." and a magnifying glass icon. Below the search bar, the word "within" is displayed. A blue button with a gold ribbon icon and the text "NIH-Endorsed CDEs" is shown. At the bottom, a paragraph explains: "NIH-endorsed CDEs have been reviewed and approved by an expert panel, and meet established criteria. They are designated with a gold ribbon." followed by a gold ribbon icon.

Request for Information: Common Data Elements (CDEs)

- Soliciting public input on core data elements (CDEs) for NIH-funded research.
- CDEs ensure standardized data collection, enhancing interoperability and facilitating knowledge discovery.
- Challenges in CDE adoption include duplicative sources and the need for mapping technologies.



Due Date: April 20, 2024.

Read the RFI here:
<https://bit.ly/3T3Q3U3>

Workshop Goals

- Assess, enhance, and broaden the development, adoption, and use of common data elements (CDEs) for research across various diseases and conditions, including, but not limited to, autoimmune diseases and immune-mediated conditions.
- Demonstrate successes and discuss strategies to encourage the adoption and use of CDEs in research, including resources, approaches, and methods.
- Engage all stakeholders—including National Institutes of Health (NIH) staff, extramural researchers, professional societies, and patient organizations—and participants from diverse professional backgrounds

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OPENING KEYNOTE

Monica M. Bertagnoli, M.D.

Director
National Institutes of Health

CLOSING KEYNOTE

Victoria Shanmugam,

MBBS, MRCP, FACR, CCD

Director
Office of Autoimmune Disease Research
National Institutes of Health

Workshop Day 1

Session I: The Value of Common Data Elements (CDEs)

This session will explore how CDEs play a crucial role in standardizing data collection methods, promoting consistency across studies, enabling comparisons between different studies with validated instruments.

Session II: Current NIH Resources for CDEs

This session will dive into the policies, trans-NIH initiatives, and resources for the identification and utilization of CDEs.

Session III: Overcoming Barriers in CDE Adoption, Mapping, and Use in Community Research

This session will center on the significance and importance of community engagement throughout the CDE development and implementation process.

Workshop Day 2

Session IV: Technical Implementation Aspects of Mapping, Transformation and Harmonization

This session will explore the technical implementation aspects of mapping, transforming, and harmonizing data, and the challenges in this process.

Session V: Approaches to Improve Interoperability

This session will spotlight approaches and challenges to utilize CDEs to facilitate and improve data interoperability and support mapping and transformation.

Session VI: Use Cases for Preparing and Applying CDEs for Intelligent Technologies

This session will explore the importance of preparing CDEs and data for AI applications and leveraging AI to enhance CDE definition and development.

NIH Director's Welcome

Monica M. Bertagnolli, M.D.
Director, National Institutes of Health

