

# Inaugural ODS Webinar & New Dataset Exploration Feature in the Index of NCI Studies (INS)

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## News from NCI's Office of Data Sharing

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December 2024

### ODS Webinar: Navigating Data Access and Best Practices

We are excited to invite you to NCI's Office of Data Sharing (ODS) inaugural webinar on January 15<sup>th</sup>, 2025! The goal is to support broad data sharing and reuse that benefits the entire cancer community. This event will cover best practices for accessing controlled data and highlight updates on the new NIH security guidelines, effective January 25, 2025.

Join us as we explore:

- Mission and objectives of Office of Data Sharing (ODS)
- Best practices for requesting controlled-access NCI-supported datasets
- Overview and demo of the Index of NCI Studies (INS)

**Speakers:** Dr. Jaime Guidry Auvil, Dr. Freddie Pruitt, and Mr. Zachary Dorman

**Webinar Date:** Wednesday, January 15, 2025

**Webinar Time:** 12:00 – 1:00 PM ET

[Register now.](#)

**Don't miss out!** This is a fantastic opportunity to connect with ODS staff and gain insights into accessing and leveraging data to advance cancer research!

### New Dataset Exploration Feature in the Index of NCI Studies (INS)

The Index of NCI Studies (INS) has launched a pilot feature for dataset exploration, [now available](#).

This initial release includes 871 NCI-supported datasets from the database of Genotypes and Phenotypes (dbGaP), marking the first step toward expanding dataset search capabilities. Users can now search for datasets using free text or filters (e.g., primary disease) with matched terms highlighted in results. Each dataset includes a detailed page with summary metadata, such as principal investigators, funding sources, data use limitations, and related publications. For more information on this release, please see the full [release notes](#).

We invite you to explore this pilot dataset search feature and share your feedback at [nciofficeofdatasharing@mail.nih.gov](mailto:nciofficeofdatasharing@mail.nih.gov) to help improve this tool for the research community!

## Announcements

**Notice of Special Interest (NOSI): Administrative Supplement for Research and Capacity Building Efforts Related to Bioethical Issues (Admin Supp Clinical Trial Optional). [NOT-OD-25-015](#)**

NIH is interested in applications that identify, analyze, and/or address bioethical issues. The proposed bioethics question, issue, or topic must be clearly articulated and applicants must explain how proposed bioethics activities are related to the scope of the specific aims of the parent grant. The expiration date: January 24, 2025.

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**United States Core Data for Interoperability (USCDI+) Seeks Feedback on Adverse Event Data Elements**

NCI, the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology and the U.S. Food and Drug Administration have released the USCDI+ Cancer Immune-related Adverse Events (irAE) draft data set. To submit your comments, visit the [USCDI+ Platform](#). **The public comment period ends January 10, 2025.**

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**Implementation Update for Data Management and Access Practices Under the Genomic Data Sharing Policy**

The National Institutes of Health (NIH) is updating two practices under the NIH Genomic Data Sharing (GDS) Policy to continue to promote responsible data management and access. **This implementation update will take effect on January 25, 2025.** These changes are to ensure GDS Policy implementation continues to evolve alongside changing practices for collecting, sharing, and using controlled-access human genomic data and include: (1) modernizing security standards provided in the “[NIH Security Best Practices for Controlled-Access Data Subject to the NIH Genomic Data Sharing \(GDS\) Policy](#)”; and (2) establishing minimum expectations for access to controlled-access data by developers.

NIH’s Office of Science Policy has recently posted some [helpful FAQs](#) that will be updated over time as implementation guidance evolves.

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NLM will once again offer the live class, ***Standardize Your Research with the NIH CDE Repository***, next Thursday, December 12, 1:00-2:30 PM ET. [Register here.](#)

If you cannot attend live, you may still register to receive the recording after the event. ODS will also distribute the materials once they become available.

Through live demonstrations and hands-on exercises, this course will introduce you to CDEs and the NIH CDE-R.

The course begins with an in-depth introduction to CDEs and examples of how researchers are already using them. Then, you'll see how to search the repository and practice searching on your own. CDE-R staff will be in attendance to answer your questions.

Consider attending this course if you:

- Want to standardize the data you collect so it can be easily shared with colleagues and other researchers.
- Have been awarded a grant that requires the use of CDEs

- Have been awarded a grant that requires the use of CDEs.
- Have heard that CDEs can be part of a compliant data management and sharing plan.
- Assist researchers with the research data management lifecycle.

Common data elements (CDEs) are standardized, precisely defined questions paired with a specific set of allowable responses, used systematically across different sites, studies, or clinical trials to ensure consistent data collection. The [National Institutes of Health \(NIH\) Common Data Element Repository \(CDE-R\)](#) provides access to CDEs that have been recommended or required by NIH Institutes and Centers for use in research and for other purposes.

## Meetings

### Happening now:

- CCDI Webinar – MCI Update: Pediatric Soft Tissue Sarcomas. December 10, 2024, 1:00 PM – 2:00 PM ET. [Registration.](#)
- Optimizing the Use of Real-World Evidence in Regulatory Decision-Making for Drugs and Biological Products. December 12, 2024, 12:30 PM – 5:00 PM ET. [Registration.](#)
- "Opportunities to Advance Research for Children, Adolescents, and Young Adults with Cancer through Secondary Data Sharing in the New National Childhood Cancer Registry Data Platform" National Childhood Cancer Registry. December 13, 2024, 12:00 PM – 1:00 PM ET. [Registration.](#)
- Building Access to Tomorrow's Medicines: bringing together humans, robots, and artificial intelligence - A Workshop. February 20 – 21, 2025. [Registration.](#)

### Past meetings:

- Advancing Data Sharing to Strengthen One Health Effectiveness: Solving the Puzzle with Mismatched Pieces. October 31, 2024. [Recording.](#)
- CCDI Webinar: Live Demo: NCCR Data Platform. November 12, 2024. [Recording.](#)

We'd love to hear from you! Contact the ODS team at: [nciofficeofdatasharing@mail.nih.gov](mailto:nciofficeofdatasharing@mail.nih.gov)

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