

REMINDER: Action Needed by November 29th & ODS Symposium Executive Summary

National Cancer Institute sent this bulletin at 11/21/2024 09:30 AM EST

News from NCI's Office of Data Sharing

Subscribe to the Newsletter

November 2024

Action Needed: Add your voice by November 29th

Please [consider adding your critical scientific and cancer clinical care insights](#) on an important [proposed federal rule](#) that could affect how data, particularly omics data, are shared internationally. **All feedback is needed by Friday November 29th.**

The Justice Department seeks specific feedback (e.g. general comments or concerns, real world examples, scientific risk and assessment considerations on the proposed rule for omics) from the broad community including **genomics experts, government funded scientists, health/omics data industry, patient advocates, organizations and entities** potentially affected by the proposed rule, and others with interest in the rule or expertise on data security and cybersecurity. The public may submit written comments on the NPRM at www.regulations.gov.

Critical Resources:

- [Link for comments](#)
- [Notice of Proposed Rulemaking \(NPRM\)](#)
- [DOJ Fact Sheet](#)
- [DOJ Press Release](#)
- [Presidential Executive Order](#)

Please [email the Office of Data Sharing](#) with any specific questions.

Data Sharing Symposium Executive Summary

The National Cancer Institute (NCI) Office of Data Sharing (ODS) Annual Data Sharing Symposium brought the cancer community together to work on critical data sharing efforts. The symposium provided an opportunity to discuss successes and challenges; identify knowledge gaps and evolving needs; and explore solutions that align community efforts to benefit the majority.

ODS Director, Dr. Jaime Guidry Auvil, welcomed participants, outlined the symposium agenda, provided a brief history of the inaugural ODS symposium, and highlighted key achievements from the past year. These accomplishments included updated features in the [Index of NCI Studies](#), ongoing activities of the [Childhood Cancer Data Initiative](#), and collaborations with key NCI programs through workshops focused on clinical and phenotypic data types.

Dr. Adam Resnick, Director of the Center for Data-Driven Discovery in Biomedicine at Children's Hospital of Philadelphia, delivered the "Keynote Address", emphasizing the transformative impact of data sharing in pediatric cancer and congenital birth defect research. He underscored the importance of partnership and collaboration, noting how the ODS team's support enabled the program to release data within 6 months of generation—a milestone achievement in accelerating research progress.

Following the keynote, an expert panel discussed best practices and key challenges associated with data sharing within a "Learning Health System". The discussion focused on leveraging technology, navigating legal considerations, and fostering collaborations to improve patient care. Dr. Catherine Lerro (FDA) highlighted the role of FDA in utilizing the real-world data to inform regulatory decisions. Ms. Reda Wilson (CDC), described the agency's critical work in cancer surveillance, data sharing and support for cancer registries. Dr. Patricia Bright, FDA, provided an overview of the FDA Sentinel System, a medical product safety surveillance system designed for post market risk identification and analysis.

In the session on "Data Reuse", Drs. Matt Wyczalkowski (University of Washington), Katie Campbell (Broad Institute), Larry Kushi (Kaiser Permanente), and Hai Hu (Chan Soon-Shiong Institute of Molecular Medicine) shared their innovative research leveraging a variety of data types. They discussed how clinical, genomic, small molecule screening, epidemiological, proteogenomic data are being integrated to advance understanding and treatment of cancer.

During the afternoon, participants had the opportunity to engage with ODS staff and other attendees in small group discussions on critical topics in data sharing. Symposium attendees participated in breakout sessions, either in person or virtually to discuss how the culture of biomedical data sharing can evolve to improve secondary use. The discussions focused on perspectives of equity, access, or infrastructure, brainstorming strategies to address existing barriers.

On day 2, panelists highlighted key policy considerations for the development and use of AI in research, and initiatives at the FDA and NIH. Panelists included Drs. Juli Klemm (NCI), Ellen Wann (NIH), Ravi Samala (FDA), Sean Mooney (NIH) and Ravi Veerasamy (NIDDK). They discussed a wide range of topics, including policy considerations, safeguarding data and privacy, ensuring ethical standards, mitigating biases in biomedical AI, and the future of AI in data sharing.

Over a "Fireside Chat" Dr. Warren Kibbe, NCI Deputy Director for Data Science and

Strategy, and Ms. Amanda Haddock, President of the Dragon Master Initiative, shared their personal connections to cancer and discussed the value of connecting data across different lines of research. They emphasized the importance of making data accessible, intuitive, and simple to use particularly for clinicians, basic science researchers, and patients.

During the "Exploring Technology" session, representatives from several NIH-supported resources, demoed [tools and platforms](#), showcasing the valuable data and services available through these repositories. In a collaborative afternoon session, celebrating 10 years of the "NCI Cancer Research Data Commons (CRDC)", CRDC colleagues reviewed how CRDC supports the research community. They highlighted the CRDC's role across the entire NCI data lifecycle — from developing data management and sharing plans to data submission, access, use (analysis and tools), and retention. The session concluded with a panel addressing how CRDC meets the "desired characteristics" of repositories as outlined in NIH's guidance on selecting a repository for sharing data from NIH-supported research.

In summary, the ODS Annual Data Sharing Symposium underscored the transformative potential of collaboration and innovation in advancing data sharing practices across the biomedical research community. These collective efforts are paving the way toward accelerated research progress and a unified vision for improved patient outcomes.

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

National Cancer Institute | National Institutes of Health | U.S Department of Health & Human Services | [USA.gov](#)

[Manage your subscriptions](#)

Subscribe to updates from National Cancer Institute

Email Address e.g. name@example.com

Share Bulletin



Powered by



[Privacy Policy](#) | [Cookie Statement](#) | [Help](#)