

# NCI ODS Workshop Series and Register for the Annual Data Sharing Symposium

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## News from NCI's Office of Data Sharing

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### Enhancing Data Reuse in Cancer Research Workshop Series

The NCI Office of Data Sharing (ODS) sponsored a series of virtual Workshops (June 27, July 18 and July 24, 2024) on “*Enhancing Data Reuse in Cancer Research*” to explore attributes which describe a patient to inform cancer research across clinical, epidemiological and biological research space. Workshop participants included over 70 researchers representing several NCI funded initiatives who emphasized the need for improved access and broad sharing of high-quality data, and standardization of data and data dictionaries to facilitate reuse.

Groups discussed how best to structure and share the data for broad sharing and secondary analysis. Some specific gaps highlighted by workshop participants include lack of longitudinal data on treatment details and outcomes including measures of tumor response and survival and the need to link this information to biospecimens. Participants also highlighted the lack of detailed geographic, dietary, and nutrition data that informs research on the social and economic factors affecting health outcomes.

Groups discussed legal and administrative hurdles to access clinical trials data for research activities. Investigators highlighted an uneven distribution of resources that make data management and sharing (DMS) challenging for many institutions and advocated for the inclusion of data managers and more training for DMS activities in funding initiatives. Finally, on the topic of standardization of data and data dictionaries, Clinical Proteomic Tumor Analysis Consortium (CPTAC) and Human Tumor Atlas Network (HTAN) were mentioned as exemplars in creating standards that were subsequently adopted by the larger community. It was recommended that workshop participants form inter-consortium working groups to establish common data standards across all NCI generated data.

ODS is collating the proceedings of the workshop into a whitepaper for publication as well as identifying actionable recommendations from participants to explore opportunities in developing guidance and/or best practices on relevant patient derived data to share and mechanisms for structuring the shared data for effective downstream data reuse.

### ODS Symposium on October 15-16, 2024

To join us in person or virtually, [register for the ODS Symposium](#).

ODS will be hosting the 2<sup>nd</sup> Annual Data Sharing Symposium from October 15-16, 2024, in Bethesda, MD. The symposium will feature a plenary session, expert panels, and breakout sessions to facilitate group discussion. The panels will cover topics such as Data Sharing in a Learning Health System, Data Sharing Exemplar and Reuse, and Artificial Intelligence (AI). The breakout sessions will focus on hearing from attendees about how to tackle challenges in data sharing. The breakout sessions will be followed by a plenary session highlighting salient points discussed.

On Day 2, a plenary session will be followed by a joint session with experts from NCI's Cancer Research Data Commons (CRDC) focusing on how data analysis, visualization, and access technologies are implemented across various stages of the data sharing lifecycle. Attendees are also encouraged to participate in the hands-on live demo fair on Day 2, where they can interact with experts representing various NCI resources.

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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