

ODS Connect July 2023

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Data Sharing Champion

The Epidemiology and Genomics Research Program (EGRP) is featured as the first "NCI Data Sharing Champion". The EGRP has played a critical role in advocating for responsible and broad data sharing to advance scientific discovery. Two exemplars are the data from the [OncoArray/GAME-ON Initiative](#) and the [Center for Inherited Diseases Research \(CIDR\)](#). Furthermore, the EGRP provides valuable resources including the [NCI Cohort Consortium](#), and the [Cancer Epidemiology Descriptive Cohort Database \(CEDCD\)](#).

[Click here](#) to learn more about EGRP

ODS Symposium

When: October 16–17, 2023

Where: NIH Clinical Center, Masur Auditorium

Save the date for the first Annual NCI Office of Data Sharing (ODS) Symposium, a free hybrid event! The government is prioritizing broad data sharing and collaborative team science as a foundational part of all research planning and funding in this digital age

The Symposium will include key topics of interest

- Discussion of metrics and methodologies for evaluating the impact of data sharing
- Learn about exemplars in Open-data
- Hear how various NCI Programs are sharing multiple types of data
- Discussion of metrics and methodologies for evaluating the impact of data sharing

Join us for this 1.5 day event including learning sessions, panel discussion, and think tank opportunities to address how we can balance incentives across all active parties to promote meaningful data sharing and use that ultimately allows the cancer research and care community to learn from every patient so that we can successfully treat every patient.

Resources

The Office of Data Sharing has published data sharing pages on myNCI to support NCI staff needs. Please let us know if we are missing something related to data sharing ([Data Sharing Hub](#), [Data Sharing Dashboards](#), [Data Sharing Policies](#), [Data Sharing Processes](#))

- Bookmark <https://mynci.cancer.gov/topics/data-management-and-sharing-policy> for a one-stop catalog of key resources to help you navigate the new Data Management and Sharing (DMS) Policy that was implemented in January 2023

- This month's highlight is [Decision Tree for GDS and DMS Policy Harmonization](#) resource to help staff understand whether the Genomic Data Sharing (GDS) policy also applies to a study

Quick Bits

NIH's Office of Extramural Research is developing DMS FAQs that will address holding data for patent applications and how to work with Small Business Innovation Research/Small Business Technology Transfer

Refget version 2.0 (large-scale genomics workstream) has been approved. Registration for the fall Plenary Meeting on September 20 – 22 is open for all and available at: <https://www.ga4gh.org/news-events/announcements/#>

Meetings

Happening now:

- Trans-NCI Data Management and Sharing Working Group meeting is scheduled for August 9th, 2023 at 10am, which developments relating to implementing NIH 2023 DMSP and related projects will be discussed. Monthly subgroup meetings will resume after the summer.

Past meetings:

- Trans-NCI Data Management and Sharing Working Group meeting from July 12th, 2023: presentation and recording are available to WG members. [Click here](#)
- CCDI symposium from March 2023 <https://videocast.nih.gov/watch=49171>

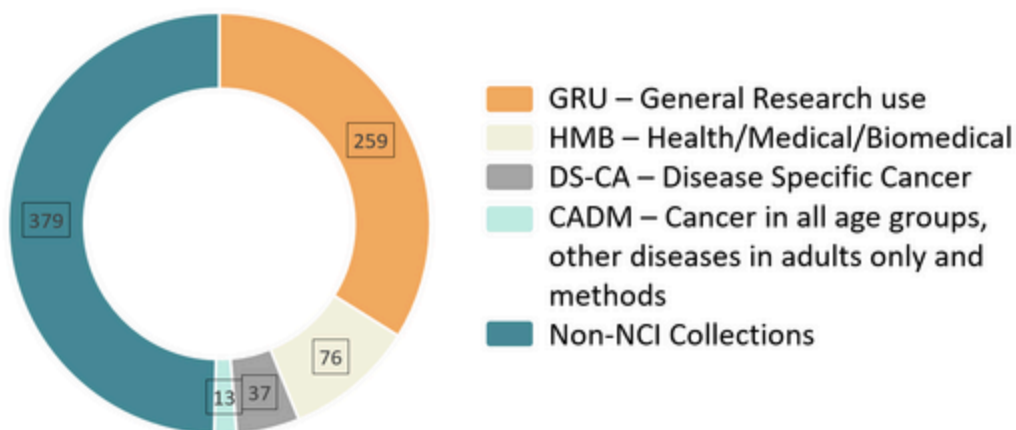
Announcements



Childhood Cancer Data Initiative: Using the Power of Data to Learn From and Improve Outcomes for Every Child and Young Adult With Pediatric Cancer is now available online <https://ascopubs.org/doi/10.1200/JCO.22.02208>

Metrics

NCI dataset available through dbGaP



Data Access Request (DARs) May 11th – June 13th 2023



Surveillance, Epidemiology, and End Results Program (Seer) Research and Research Plus Databases



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

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