

ODS Connect October 2023

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ODS Connect

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October 2023

Data Sharing Champion: OHAM

The [Office of HIV and AIDS Malignancy](#) (OHAM) supports development of important resources that are made freely available, and programmatically oversees an HIV biorepository, [AIDS and Cancer Specimen Resource](#) (ACSR). ACSR collects and distributes specimens along with their associated clinical information. A sister initiative named [AIDS Malignancy Consortium](#) (AMC), is a large-scale consortium that has been forward-thinking about data sharing.

AMC recognized the need for a data commons (DC) to provide centralized access to large swaths of research and clinical trial data to 120 clinical and 150 global investigators before the new [Data Management and Sharing \(DMS\) Policy](#) was enacted. In addition, collaborative elements of ACSR are being integrated into the AMC DC in a large-scale effort to extend the utility of physical specimens. Plans for the AMC DC were borne out of a need to provide streamlined access to consortium members, several of whom are located outside of the United States, and these efforts are removing siloes. Developing Information Technology (IT) systems and conducting clinical trials are costly and complex, however, the AMC DC has been pushing forward balancing domestic and international policies. AMC DC hopes to complete development of this platform and ultimately contribute to our knowledge of HIV-associated cancers on a global scale.

[Read more about OHAM.](#)

Dataset Spotlight

Each month, the scientific community highlights various cancer subtypes to raise awareness for research and funding. In October the focus is on Breast and Liver cancer. [Learn a bit about each and see a sample list of data sets](#) NCI offers to researchers of these cancer subtypes!

Policy News

Update to DMS Policy: Prior Approval Requests for Revisions to an Approved Data Management and Sharing (DMS) Plan Must be Submitted Using the Prior Approval Module, released Sept 27, 2023. [NOT-OD-23-185](#)

Previous [notices related to the Final NIH Policy for Data Management and Sharing](#) are also available.

NIH Final Updated Policy Guidance for Subaward/Consortium Written Agreements, released Sept 15, 2023. [NOT-OD-23-182](#). [Open Mike blog](#), new [subaward website](#) and [FAQs](#) available now.

If you need a refresher on the January, 2023 Data Management and Sharing policy, this month we highlight recordings of the [NCI Data Management and Sharing Policy Educational Series](#), available through the [Data Sharing Policies](#) tile of the [Data Sharing Resource Hub](#).

The Office of Data Sharing has published the Hub on myNCI to support NCI staff needs. If there is something you think we should add, please let us know.

Meetings

Happening now:

- [CCDI Webinar](#): Using NCCR*Explorer and NCCR Data in SEER*Stat, Oct 24, 2023.
- Trans-NCI Data Management and Sharing Working Group meeting is scheduled on Nov 8, 2023, at 2pm.
- [CCDI Webinar](#): Navigating CCDI Hub's Explore Dashboard and Data Access, Nov 13, 2023.

Past meetings:

- The inaugural Office of Data Sharing Symposium was held October 16th and 17th: Thank you to those who were able to join us in person and online! Look for resources coming out soon and more events coming in the new year!

Announcement

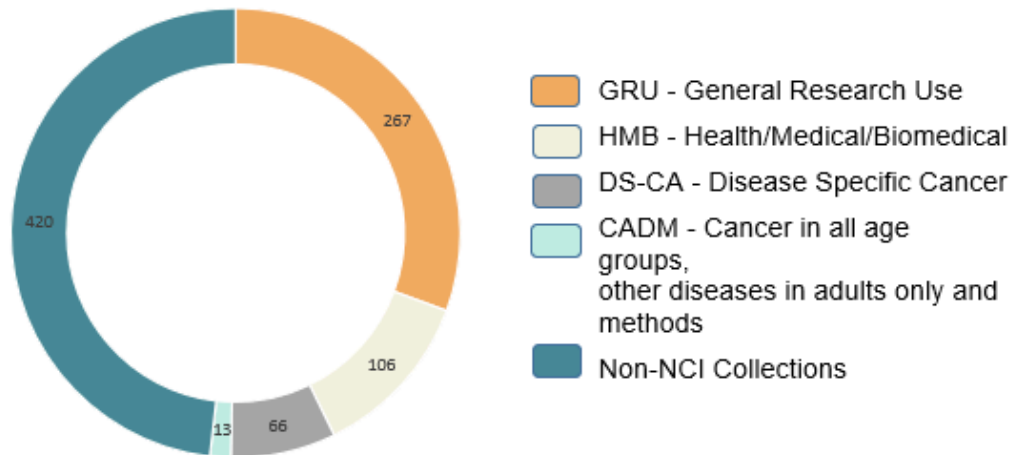


Read our latest blog “[NCI Listens: Your Feedback on Data Sharing Challenges and Opportunities](#)” which summarizes the questions asked, insights gained, and what we plan to do with feedback from our recent [RFI](#).

NCI’s Childhood Cancer Data Initiative [seeks your input](#) to identify opportunities to generate additional research molecular characterization data to accelerate scientific discovery and improve patient care through enhanced data sharing. Response Date Nov 30, 2023.

Metrics

NCI datasets available through dbGaP



Data Access Requests (DARs) September 11th – October 12th



DARs Approved



PIs Approved

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



Approved Data Requestors

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

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