ODS Connect January 2024

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Data Sharing Champion

The NCTN/NCORP Data Archive is a centralized, controlled-access database, for storing and sharing patient-level data generated from clinical trials of the National Clinical Trials Network (NCTN) and the NCI Community Oncology Research Program (NCORP). Currently, the NCTN/NCORP Data Archive has approved data of 134,537 patients from over 100 trials from NCTN groups and NCORP groups focusing on primary publication of randomized phase 2 and phase 3 trials along with selected non-primary publications of these trials. Secondary data users can request datasets including patient level, deidentified clinical dataset, a data dictionary, and limited metadata fields from one or multiple clinical trials as a registered NCTN/NCORP Data Archive user. It currently serves over 2000 registered users worldwide and has facilitated the generation of 90 publications. In the future, the NCTN/NCORP Data Archive will continue its efforts to share valuable data from cancer clinical trials, contributing significantly to NCI's pivotal role in cancer research and patient care.

Read more about the NCTN/NCORP Data Archive

Dataset Spotlight

Each month, the scientific community highlights various cancer subtypes to raise awareness for research and funding. In January the focus is on Cervical cancer. Learn more and see a sample list of data sets NCI offers to researchers of this cancer subtype!

Resources

As we welcome a new year, we remind readers that you can access last year's Office of Data Sharing monthly newsletters in the ODS Connect Archive tile of the Data Sharing Resources Hub. Happy New Year!

The Office of Data Sharing has published the Data Sharing Resource Hub on myNCI to support NCI staff needs. You can find content related to Data Sharing Dashboards, Data Sharing Policies, Data Sharing Processes and more. If there is something you think we should add, please let us know.

Meetings

Happening now:

- CCDI webinar: Navigating St. Jude's PeCan v2 & Survivorship Data Sharing Tools, January 23, 2024, 1:00 pm.
- Trans-NCI Data Management and Sharing Working Group meeting, February 12, 2024, at 10:00 am hosted by the Office of Data Sharing.
- Defining the Need for Open Data Metrics, Daniella Lowenberg, March 6, 2024, 11:00 am.

Past meetings:

- Federal Demonstration Partnership (FDP) Data Management and Sharing (DMS) Town Hall. December 14, 2023, 1:00 – 2:30 PM EST. Meeting presentation.
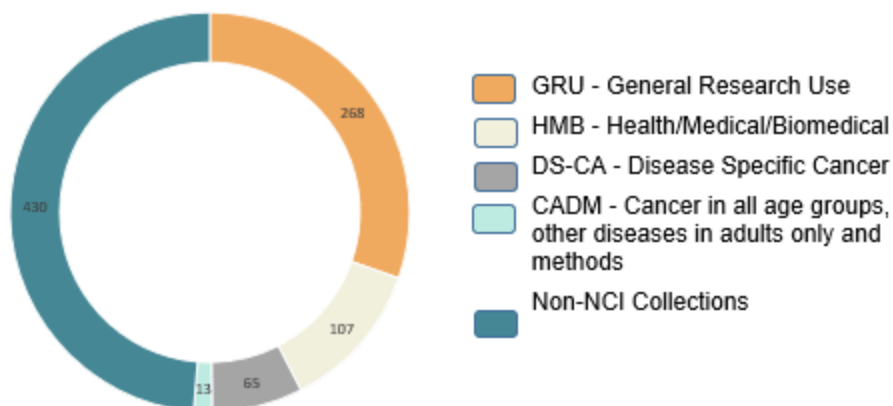
Announcement

Expert Resource Now Available to Assist with Review of Especially Challenging Data Management and Sharing Plans: A Data Management and Sharing expert panel is available to assist with complicated or challenging DMS Plans that ICs cannot resolve internally via their own resources and expertise. Included is the list of approved submitters, the SOP for submitting a request, and the request submission form.

Respond to the latest Request for Information on automated EHR data entry and extraction capabilities by February 29, 2024.

Metrics

NCI datasets available through dbGaP

- GRU - General Research Use
- HMB - Health/Medical/Biomedical
- DS-CA - Disease Specific Cancer
- CADM - Cancer in all age groups, other diseases in adults only and methods
- Non-NCI Collections

268
107
65
13
430

Data Access Requests (DARs)
December 11th – January 10th

242
DARs Approved

975
PIs Approved

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

48
Approved Data Requestors

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