ODS Connect September 2023 Draft

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ODS Connect

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Data Sharing Champion: CCDI

The Childhood Cancer Data Initiative (CCDI) is a transformative 10-year, $50 million per year federal program launched during the 2019 President's State of the Union address, with a primary aim to advance pediatric cancer research through enhanced data generation and sharing. CCDI strives to create a Data Ecosystem connecting researchers, advocates, and care communities, facilitating systematic data collection, sharing, access, and analysis for patients aged from infancy to 39 diagnosed with a pediatric cancer. Though childhood cancers constitute only about 1% of new cancer cases, the culture of data sharing in this research community and the manageable data size enable the implementation of new data systems effectively. The Molecular Characterization Initiative (MCI, phs002790) is a key part of CCDI, offering free molecular characterization for eligible patients, aiding diagnosis, treatment planning, clinical trial eligibility, and genetic counseling. The linked molecular and clinical data from MCI support hypothesis testing across cancer types. CCDI provides a wealth of resources, including the CCDI Hub, Data Catalog housing over 250 pediatric data sets, and the National Childhood Cancer Registry (NCCR) Explorer, which offers incidence and survival statistics based on demographic factors. These resources empower researchers, clinicians, and advocates to improve childhood cancer care and outcomes, potentially benefiting all cancer patients.

Read more about CCDI or refer to our recent publication in the Journal of Clinical Oncology: https://ascopubs.org/doi/full/10.1200/JCO.22.02208

Dataset Spotlight

Each month, the scientific community highlights various cancer subtypes to raise awareness for research and funding. In September the focus is on Pediatric, Leukemia and Lymphoma, Uterine, Ovarian, Prostate, and Thyroid cancer. Learn a bit about each and see a sample list of data sets NCI offers to researchers of these cancer subtypes!

ODS Symposium

When: October 16–17, 2023

Where: NIH Clinical Center, Masur Auditorium and virtual option

Who: Open to the public, please share with your colleagues

[**Register here**](#) Registration will close October 13, 2023.

The first Annual NCI Office of Data Sharing (ODS) Symposium, a free hybrid event! Our goal in ODS is to bring together experts and stakeholders throughout the cancer research community (policymakers, scientists, clinicians, and students across government, academia, industry, and advocacy) to learn from one another and explore ways to improve implementation of new data sharing policies for the greatest public benefit.

The Symposium will include key topics of interest

- Programs that share multiple types of cancer research and care data
- Metrics and methodologies for evaluating the impact of data sharing
- Resources, obstacles, and incentives for sharing cancer research and care data

Join us for this 1.5-day event that includes learning sessions, panel discussions, 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 the [Data Sharing Resource Hub](#) on myNCI to support NCI staff needs. Please let us know if we are missing something related to data sharing.

- In keeping with our theme of honoring Childhood Cancer Awareness Month, this month we note that the ['Data Sharing Processes'](#) section of the Data Sharing Resource Hub includes a link to the [NCI Data Catalog](#) where, among many other resources, you can find a selection of data collections related to cancer research.

Meetings

Happening now:

- Trans NCI Data Management and Sharing Working Group Meeting is scheduled on Oct 11, 2023 at 10am.
- Using NCCR*Explorer and NCCR Data in SEER*Statt by CCDI is scheduled on Oct 24, 2023, 2:00 p.m. – 3pm. Register here.

Past meetings:

- Trans-NCI Data Management and Sharing Working Group meeting on Sept 20, 2023. Meeting material.
- Using the CCDI Molecular Targets Platform, Aug 21, 2023. Meeting material.
- The First Childhood Cancer Data Initiative Community Forum, by Drs. Gregory Reaman, Subhashini Jagu, Lynne Penberthy, Emily Boja, and Malcolm Smith. Sept 11, 2023.
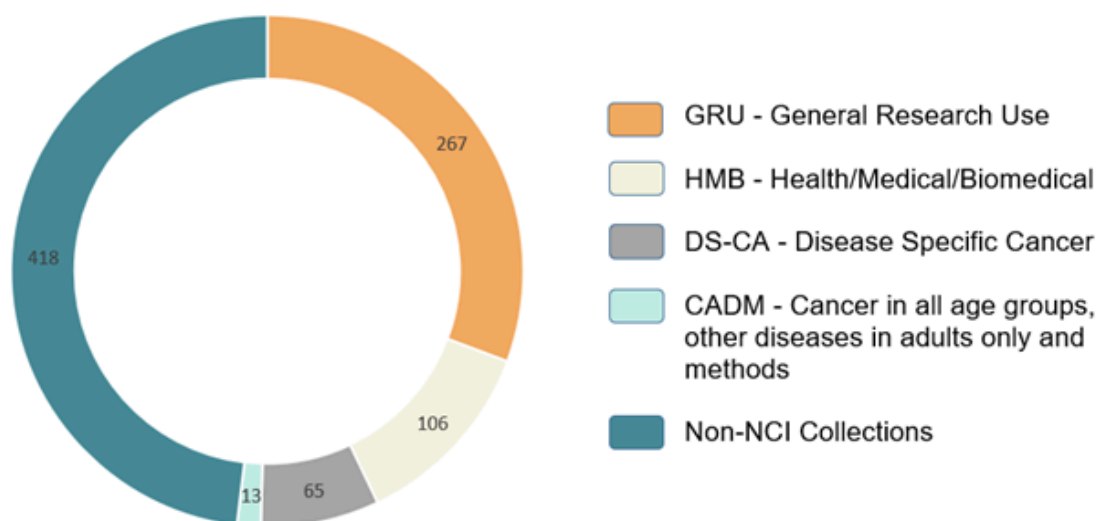
Announcement

- The CCDI has facilitated the release of rhabdomyosarcoma (RMS) imaging data. RMS is a rare and aggressive cancer that often affects children and young adults. The specimen images were collected from 403 RMS patients who participated in Children's Oncology Group (COG) trials between 1998 and 2017. These whole-slide, hematoxylin, and eosin–stained images are available through NCI's Imaging Data Commons. Access the images.
- 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. https://grants.nih.gov/grants/guide/notice-files/NOT-CA-23-093.html

Metrics

NCI dataset available through dbGaP

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

Legend:
- GRU - General Research Use
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- Non-NCI Collections

Data Access Request (DARs)
August 11th – September 11th

448
DARs Approved

1228
PI Approved

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