

NCI Data Sharing: Resources and Support for Cancer Researchers

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News from NCI's Office of Data Sharing

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Researchers**

The National Cancer Institute's (NCI) Office of Data Sharing (ODS) fosters collaboration, transparency, and accessibility of cancer-related data. This maximizes its potential for scientific discovery beyond initial hypotheses and ultimately improves patient outcomes. Built upon pillars of scientific policy, process, and program, the ODS aims to enhance data sharing through the implementation of NCI/NIH data sharing policies. It facilitates the access and re-use of data generated through various NCI-funded projects to promote innovation. The ODS provides guidance and helpful resources through the [NCI Data Sharing](#) web pages and more specifically for NCI staff through a [Data Sharing Resource Hub on myNCI](#).

Data generation and reuse are major components of data sharing. NCI's intra- and extramural investigators looking to submit human subjects research data, [use the database of Genotypes and Phenotypes \(dbGaP\) to register the studies](#). Those interested in leveraging existing datasets as secondary users [submit Data Access Requests \(DARs\)](#) to gain access to controlled access datasets. Intra- and extramural investigators can also utilize the [Cancer Research Data Commons \(CRDC\)](#), a cloud-based data ecosystem that co-locates data with analysis infrastructure. These resources enable researchers to access data and leverage workflows and scalable computing power to support advanced analysis and visualization of results.

Investigators developing tools, methods, and algorithms that facilitate data generation and analysis also contribute to data sharing by making those resources widely available to the public. They can be found through [Resources for Researchers](#), the [NCI Data Catalog](#), and other program-specific pages. For example, NCI's Division of Cancer Epidemiology and Genetics (DCEG) has developed computational tools enabling users to estimate cancer risk, forecast and track mortality (including from COVID-19), which are available through [EpiSphere](#), an umbrella computational epidemiology framework. NCI's Informatics Technology for Cancer Research (ITCR) Program aids in developing tools to analyze, visualize, and interpret cancer data. The ITCR Program also offers courses and webinars to train users and developers to use these tools.

In this article, we would like to feature NCI's Comprehensive Oncology Network Evaluating Rare CNS Tumors (NCI-CONNECT) Program, which facilitates research on rare tumors and helps patients access expert care. NCI-CONNECT is a program within the Rare Tumor Patient Engagement Network (RTPEN), an initiative supported by the National Cancer Moonshot. RTPEN aims to advance research and discover new treatments for rare tumors through a collaborative network of national and international institutions that provide expertise, personalized health care, and education to patients with rare tumors. This is a natural history study, which has enrolled over 1,100 patients, provides the community with study data including clinical assessments, long-term disease observations, and biospecimens, thus supporting secondary use of data and biological samples. NCI-CONNECT has a number of studies open for adult patients with rare CNS cancers. [Explore NCI-CONNECT's Clinical Studies](#), [join NCI-CONNECT Community to connect with other patients and caregivers through the Facebook page](#), and contact NCICONNECT@mail.nih.gov or call (240) 760-6530 for any questions.

This article highlights a small number of available resources and their supporting programs. Please contact NCIOfficeofDataSharing@mail.nih.gov to have your program included in our data sharing newsletter.

Announcements

The Office of the National Coordinator for Health Information Technology (ONC) and the National Cancer Institute (NCI) are pleased to announce publication of the USCDI+ Cancer Registry draft data element list that is now available for public comment. We invite you to review and provide feedback on this important list.

The objective of the USCDI+ Cancer use case is to enhance the efficiency and timeliness of cancer registry data collection by identifying standards (e.g., FHIR, mCODE) for efficient data extraction from Electronic Health Records (EHRs) and pathology labs. This data must be interoperable across cancer clinical, public health, and research communities.

How to Provide Feedback

1. [Visit the USCDI+ platform.](#)
2. Create an account.
3. [Review the published draft cancer registry data element list.](#)
4. Submit your comments and suggestions through the provided feedback form.

Request for Information (RFI): Data Management and Sharing of Cancer Biology Research. [NOT-CA-24-062.](#)

Division of Cancer Biology/NCI is seeking input on the required resources and resulting opportunities in the development and implementation of Data and Management and Sharing (DMS) Plans for cancer biology research, please provide input by August 9th.

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

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