

Childhood Cancer Data Initiative Webinar Series

National Childhood Cancer Registry (NCCR) Update and Demonstration of Data Platform

Johanna Goderre, M.P.H.

Agenda

1. *CCDI & NCCR Background*
2. *NCCR Data Products*
3. *Demo: NCCR Data Platform*
4. *Panel Discussion: Research Opportunities Using the NCCR Data Platform*

Today's Speaker and Panelists

Speaker



Johanna Goderre, M.P.H.

- NCCR Technical Lead and Health Data Scientist, National Cancer Institute

Panelist



Kelly Getz, Ph.D., M.P.H.

- Assistant Professor of Epidemiology and Pediatrics, Perelman School of Medicine at the University of Pennsylvania and Children's Hospital of Philadelphia

Panelist



Tamara Miller, M.D., M.S.C.E.

- Pediatric Hematologist/Oncologist, Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta
- Associate Professor of Pediatrics, Emory University School of Medicine
- Clinical Consultant for the NCCR

Panelist



Rebecca Ottesen, M.S.

- Associate Director of Biostatistics, Emmes



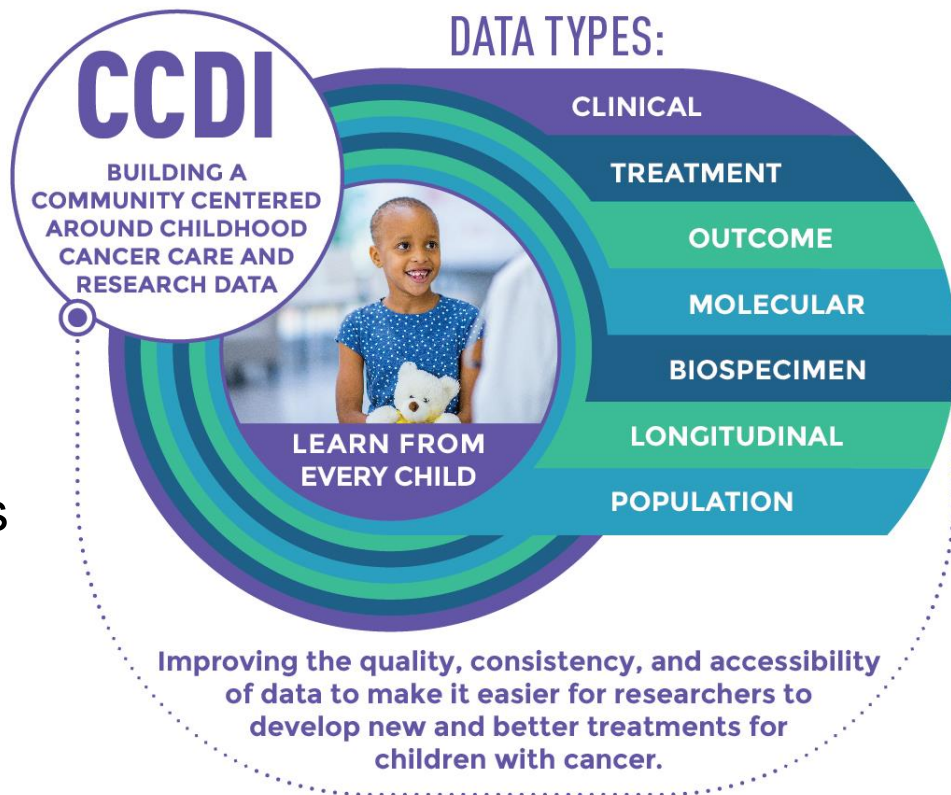
CCDI & NCCR Background

Johanna Goderre, M.P.H.

Childhood Cancer Data Initiative (CCDI)

CCDI is an effort to connect and broadly share childhood cancer clinical and research data.

Through specially designed programs and custom-built platforms and tools that enable easier access to data, CCDI aims to accelerate progress in childhood cancer research.



National Childhood Cancer Registry (NCCR)

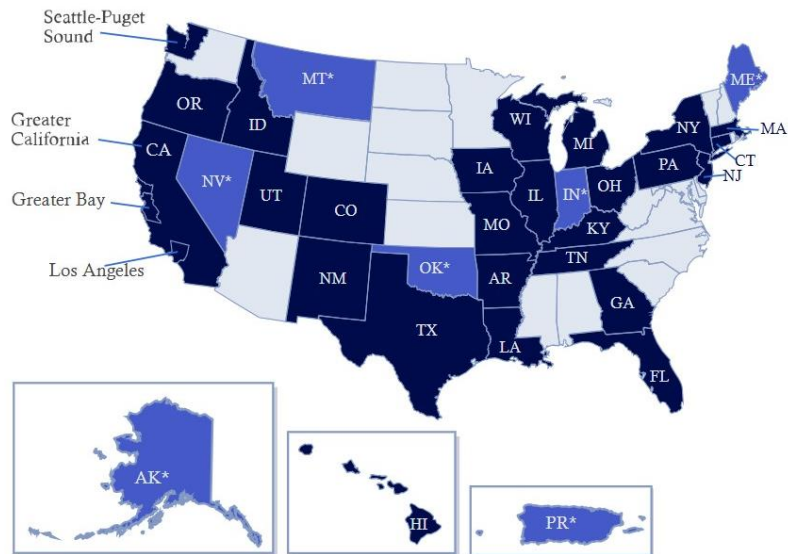
What it is:

- A rapidly growing data resource for public health statistics
- Data collected about children, adolescents, and young adults (AYAs) with first cancer under age 40, regardless of where they receive care
- **28 NCCR registries**, represent 75% of the US population and report more than 1.8 million cases since 1995
 - Plus, seven registries through the [Virtual Pooled Registry](#)

What it does:

- Enhances access to, and use of, detailed, longitudinal childhood cancer treatment and survivorship data matched to registry data
- Allows us to better understand the causes of cancer among children and AYAs and work to improve their outcomes and experiences

Map of 28 NCCR Registries



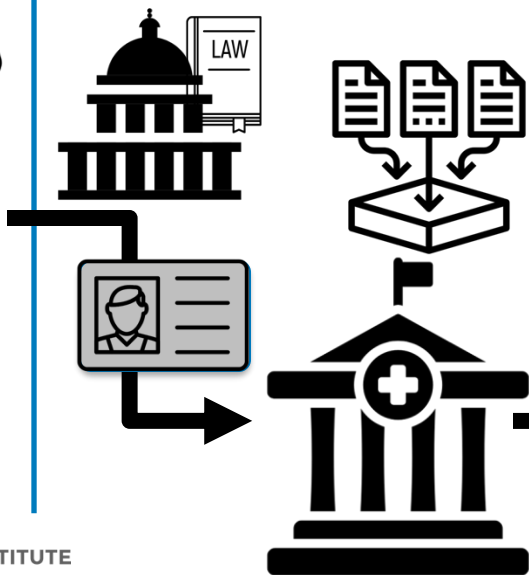
* VPR-linked Registries

Where Does NCCR Data Come From?

Healthcare treatment, payment, and operations



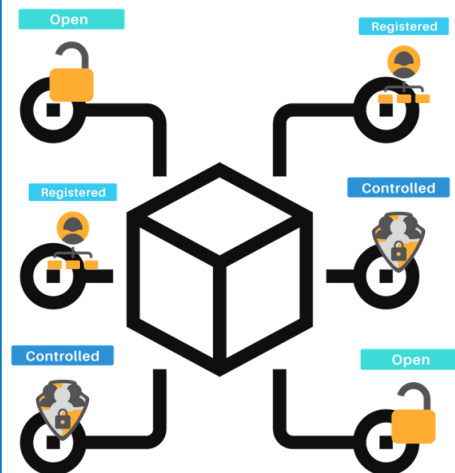
Providers comply with state-mandated public health requirements and HIPAA public health exemption to report PII and PHI to Central Cancer Registry and NCI-negotiated linkages on all cancer patients in their jurisdiction





Central Cancer Registry creates **de-identified data** and submits under appropriate agreements to NCI



NCI releases different data products to researchers and the public with appropriate authentication and authorization



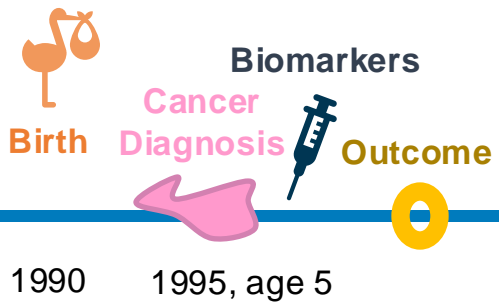
Why Is a National Data Sharing Effort Needed?

- Childhood cancer is **rare** (~16,000 new cases in the U.S. each year)

- No single institution holds enough data or sees enough patients to conduct studies large enough to understand complex causes, risk factors, treatment complications, etc.
- Especially true for ultra rare cancers (< 2 cases per 1,000,000)
- Patients **travel** for care
- Survivorship period can be **long**, and people may move, change names, etc. over their entire life
- Identify **subsequent** malignant neoplasms and **late effects** of treatment or cancer

- Share information across central cancer registries and healthcare settings and de-duplicate at a national level

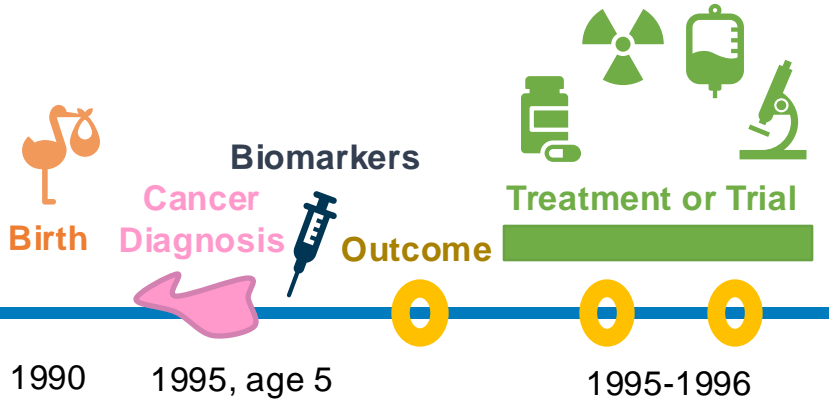


Birth

1990



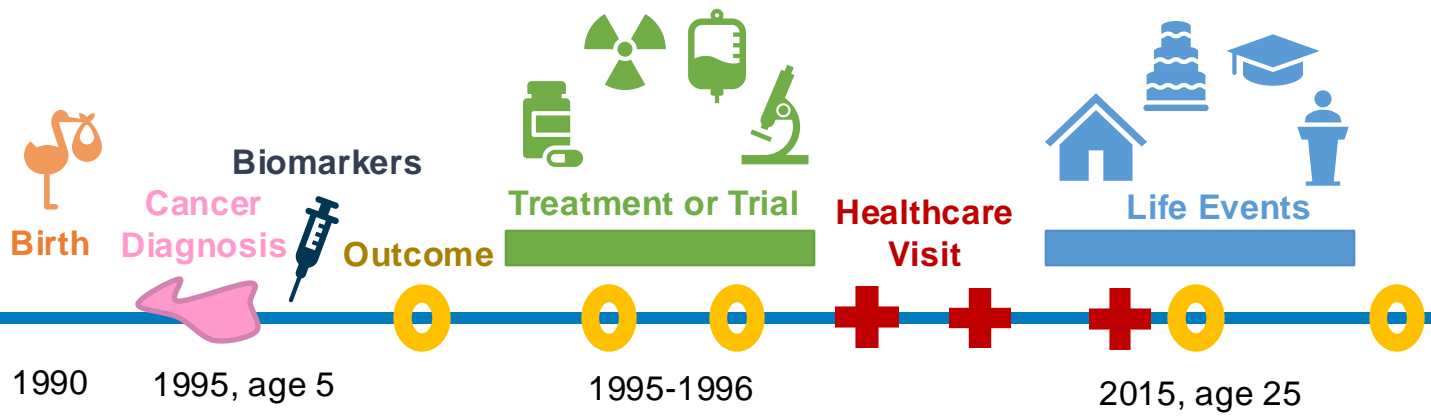
Louisiana



Louisiana



Texas



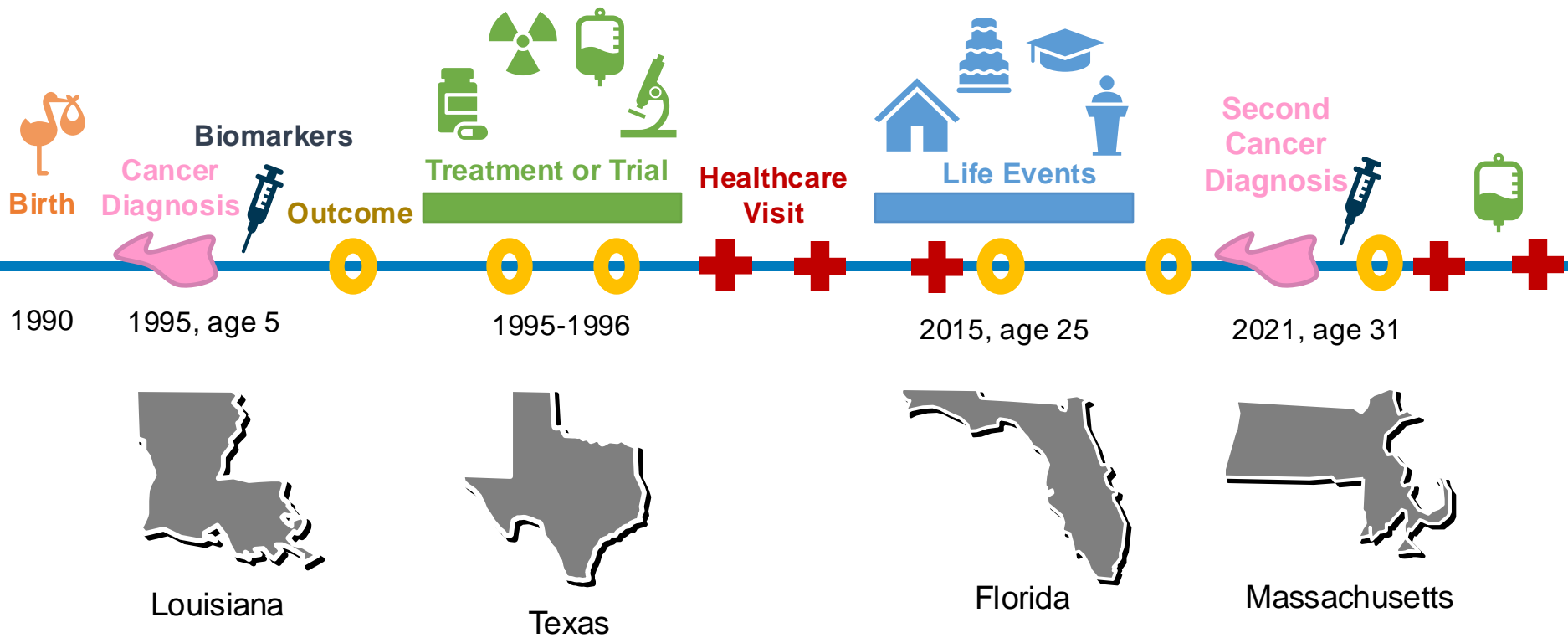
Louisiana



Texas



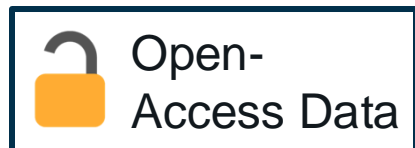
Florida



NCCR Data Products

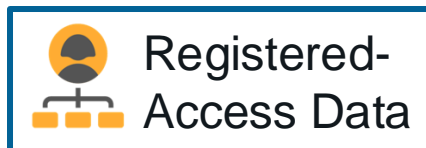
Johanna Goderre, M.P.H.

NCCR Data Products and Access Types



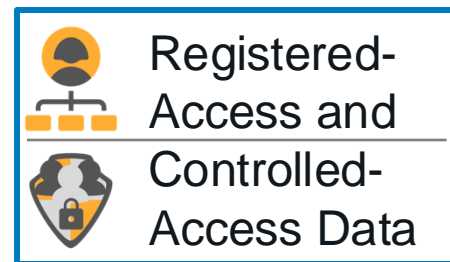
NCCR* Explorer

Quick statistics on childhood and AYA prevalence and survival available to the public and researchers



NCCR Data in
SEER* Stat

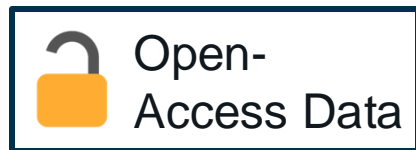
Statistics (frequencies, rates, trends, age-adjustment, survival, etc.) to study the impact of cancer on children and AYAs with a Research Plus application



NCCR Data
Platform

View descriptive statistics and analyze individual-level registry data linked to longitudinal treatment use and outcomes with a Research Plus application

NCCR*Explorer

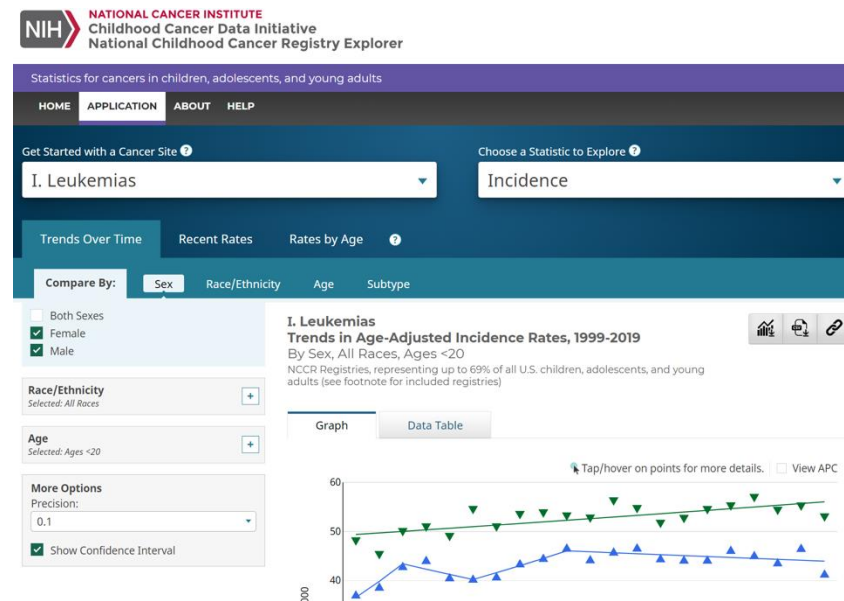


What it is:

- Interactive web application with incidence, survival, and prevalence cancer statistics
 - All 28 registries, covers 75% of the U.S. population, 1.8M+ reported cancers
 - Children and AYAs ages 0-39 from 1995-2021 represented

What it does:

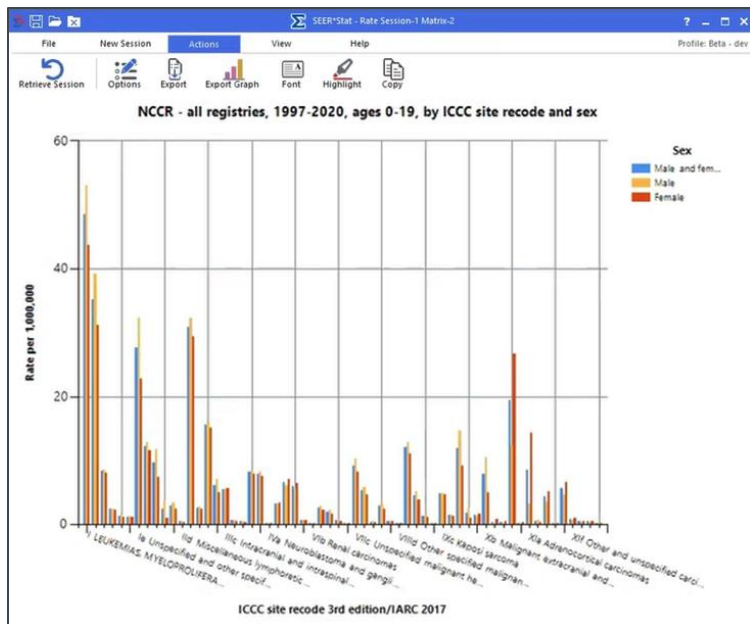
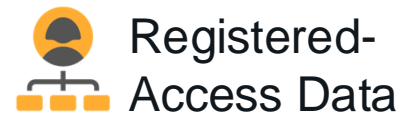
- Visualizes statistics in dynamic tables and plots based on user criteria
- Sorts data by sex, race, ethnicity, age, and cancer type



nccrexplorer.ccdi.cancer.gov

datacatalog.ccdi.cancer.gov/dataset/CCDI-NCCR%20Exp

NCCR Data in SEER*Stat



seer.cancer.gov/data-software/documentation/seerstat/nccr
datacatalog.ccdi.cancer.gov/dataset/CCDI-NCCR%20SEER*Stat

What it is:

- Database in SEER*Stat with 16 NCCR registries
- 49% of the U.S. population and more than 1.1M+ reported cancer cases
- Children and AYAs ages 0-39 from 1997-2020 represented

What it does:

- Allows user-driven queries to develop frequency, rate, survival, and prevalence childhood cancer statistics

NCCR Data Platform

Johanna Goderre, M.P.H.

NCCR Data Platform

What it is:

- Web application that holds childhood cancer data from population-based cancer registries and other data partners
 - 18 SEER core and 4 SEER RSR registries contributing data
 - 57% of the U.S. population; 1.5+ million reported cancers among individuals aged 0-39 at diagnosis since 1995
- Data from registries, healthcare providers, and other sources are matched for same person and consolidated for analysis

What it does:

- Provides descriptive statistics for NCCR data linked to longitudinal treatment and outcome data
- Makes deidentified data easy to search, visualize, request, and analyze in a secure cloud system



Registered- and
Controlled-Access Data

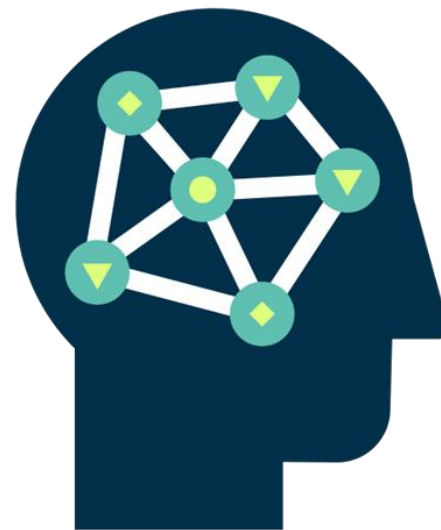


nccrdatapatform.ccdi.cancer.gov/home

[datacatalog.ccdi.cancer.gov/dataset/CCDI-NCCR Data Platform](https://datacatalog.ccdi.cancer.gov/dataset/CCDI-NCCR_Data_Platform)

The Data Platform Enables Researchers to...

- **Browse** registry and linked data collected by NCCR
- **Create** a cohort based on search criteria (e.g., cancer diagnosis, age at diagnosis)
- **View** aggregate statistics and counts
- **Submit** a data access request with IRB approval for custom, individual-level data
- **Receive** custom data sets after approval
- **Analyze** data and publish findings



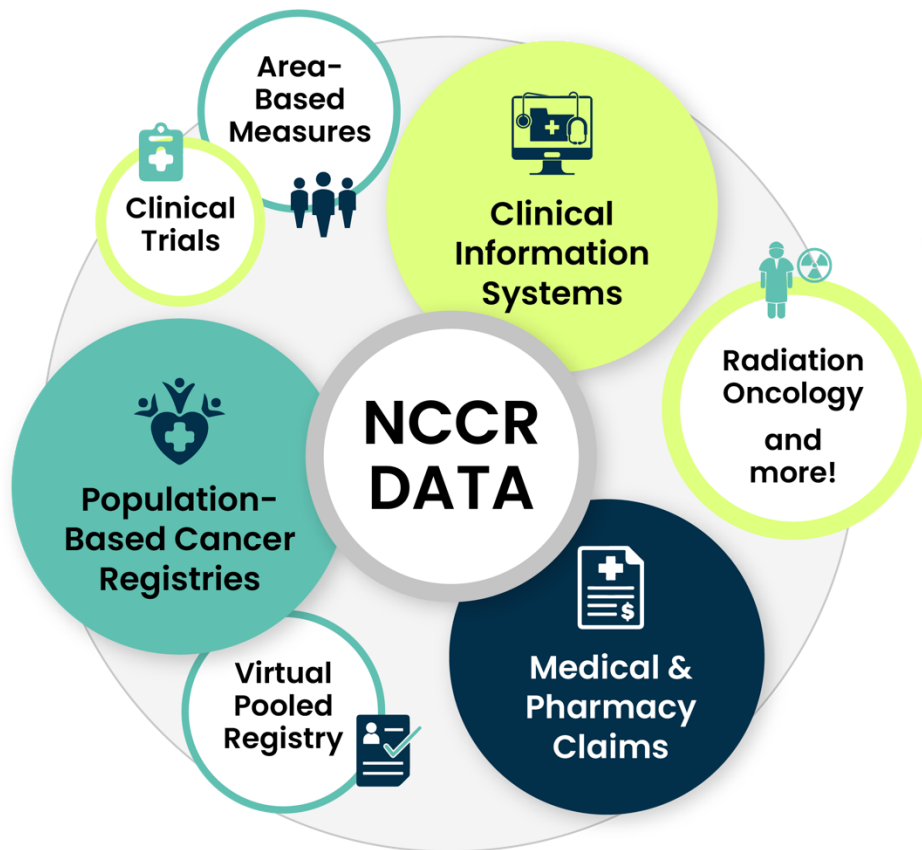
The Data Platform Enables NCI to...

- **Share** population-based registry and other linked data with authorized users **in a secure environment**
- **Manage data access requests** through the NCI Data Access Committee
- **Support interoperable use of NCCR data** with other data from CCDI

Support **secondary data sharing** to the research community to drive scientific progress that benefits children and AYAs with cancer



Data Shared through the Platform



Population-based data:

- Registry-abstracted data: 1995+, first cancer diagnosis <40 years old (1.5M+ reported cancer cases for 1.4M+ persons)
 - Area-based Measures (Yost Index, Rurality, etc.)
 - Virtual Pooled Registry

Results of data linkages:

- Children's Oncology Group (44,957 persons)
- Pediatric Proton/Photon Consortium Registry and NCI-Designated Cancer Centers:
 - Clinical Information Systems (longitudinal electronic health record, laboratory information systems, etc.) (20K+ persons from 27 healthcare facilities)
 - Radiation Oncology (treatment and outcomes) (2K+ persons with 8K+ records)
- Medical (158,721 persons with 34.7M+ records) and pharmacy claim data (137,793 persons with 5.7M+ records) from multiple data providers

Additional Protections on De-identified Data

Minimize risk of re-identifiability



No identifiers used in operational registry systems



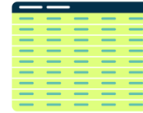
No geography



Categorical fields for variables derived from small area estimates (not exact values)



No dates → number of months from event to cancer diagnosis or year



Each data request has unique, random identifiers (identifiers for individuals cannot be merged with other data requests or resources)



Download now but transition to cloud-based analysis component to ensure additional controls, auditing, monitoring



Demo: NCCR Data Platform

Johanna Goderre, M.P.H.



Panel Discussion: Research Opportunities Using the NCCR Data Platform

Next Steps

Johanna Goderre, M.P.H.

Acknowledgments: NCCR Data Platform Development

NCI SRP

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Rachel Leffler
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Srujan Boppana
Sue Pan, M.S.

Wara Espinoza
Yashin Pan

**and CCDI leadership and
user groups!**



<https://go.nih.gov/2XLvtov>

Next Phases



Analytic Workspace

Cloud-based computing workspace for researchers to analyze data (R Studio, Jupyter Notebooks)



CCDI Interoperability

Enable search for data on other CCDI resources (dbGaP, etc.) and match at the individual-level to NCCR data

<https://ccdi.cancer.gov/explore>

<https://datacatalog.ccdi.cancer.gov>



Expand Breadth and Depth of Data

- Work with NPCR registries to contribute to Data Platform
- Refresh past linkage data
- Add new data valuable to research needs

Go to the Data Platform now!



<https://go.nih.gov/2XLvtov>

Q&A

How You Can Engage with CCDI



Learn about CCDI and subscribe to our monthly newsletter:
cancer.gov/CCDI



Access CCDI data and resources:
ccdi.cancer.gov



Questions? Email us at:
NCIChildhoodCancerDataInitiative@mail.nih.gov

Thank you for attending!



**NATIONAL
CANCER
INSTITUTE**

cancer.gov

cancer.gov/espanol

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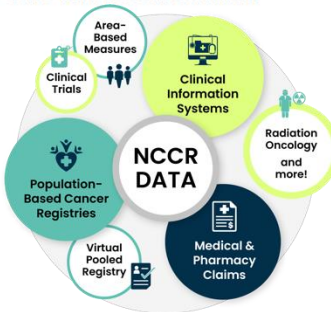
National Childhood Cancer Registry Data Platform

The NCCR Data Platform provides researchers with childhood, adolescent, and young adult cancer data to support in-depth analysis and advance scientific understanding of childhood cancer and survivorship.

About Us

Improving childhood cancer care and research data.

This secure cloud system links data records for the same person across different sources and consolidates them in one place. The NCCR Data Platform makes de-identified data easy to search, request, visualize, and analyze. The Data Platform is part of the Childhood Cancer Data Initiative Data Ecosystem and will be interoperable with other CCDI resources.

[More About Us](#) →

Contact Us

Have questions about the platform? Let's connect!

NCI provides a user guide and FAQs page to help you understand the data and features in the NCCR Data Platform. For any additional questions, please reach out to our help desk directly.

[Contact Us](#) →

Video Tutorials












NCCR Data Platform at a Glance

This tutorial is a great starting point for new users looking to understand the Data Platform, as it provides a broad overview of the platform pages, features, and workflows.

[Browse Frequently Asked Questions](#) →<https://go.nih.gov/2XLVTOV>

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NCCR Data Platform Release Notes

Year

2024 

October 25, 2024

Data Release

The following new data source was added as part of this release. Linked data sources do not represent the entire population of people diagnosed with cancer in the original catchment area.

The **Social Drivers of Health (SDOH)** data source includes area-based measures calculated from Census information, which allow researchers to gain a broader context of environmental, social, and other non-clinical factors.

Data Submission Version

2010 Census Geographic Boundaries & 2020 Census Attributes

Data Years Defined by Source

2006-2021; SEER Diagnosis Date

Data Upload Date; Release Date

10/4/2024; 10/25/2024

Data Updates

The following data sources were updated as part of this release.

Consolidated Tumor Case

Data Submission Version

November & December 2023

Data Years Defined by Source

1995-2021; SEER Diagnosis Date

Data Upload Date; Release Date

10/4/2024; 10/25/2024

Children's Oncology Group (COG)

Data Submission Version

2022 Linkage

Data Years Defined by Source

2007-2018; COG Diagnosis Date

Data Upload Date; Release Date

10/4/2024; 10/25/2024

Medical Claims Diagnosis

Data Submission Version

February 2024

Data Years Defined by Source

2000-2024; Service Date

Data Upload Date; Release Date

10/4/2024; 10/25/2024

Medical Claims Enrollment

Data Submission Version

February 2024

Data Years Defined by Source

1994-2022; Enrollment Start Date

Data Upload Date; Release Date

10/4/2024; 10/25/2024

Medical Claims Procedure

Data Submission Version

February 2024

Data Years Defined by Source

2000-2024; Service Date

Data Upload Date; Release Date

10/4/2024; 10/25/2024

- FAQs
- [Support Resources](#)
- [Release Notes](#)

Data Access Committee

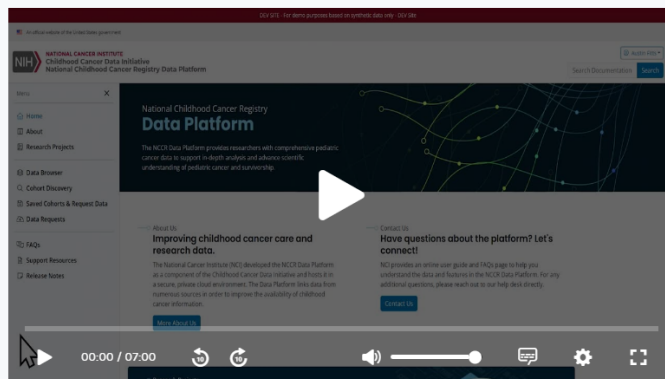
- [Quick Guide for Reviewing Data Requests:](#)
This quick guide provides members of the data access committee with instructions for evaluating their assigned data access requests.

Policies

- [NCCR Data Protection Policies](#)
This document provides an overview of the sources that submit data to the NCCR Data Platform, the policies and safeguards in place to protect the privacy and security of the data, and the framework used to control access to data.

Video Tutorials

The videos in this tutorial series provide user-friendly demonstrations to familiarize users with the features, workflows, and tasks available in the NCCR Data Platform.



Video Playlist

To view a different video, choose from the list below.

- [NCCR Data Platform at a Glance](#)
This tutorial is a great starting point for new users looking to understand the Data Platform, as it provides a broad overview of the platform's pages, features, and workflows.

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Frequently Asked Questions

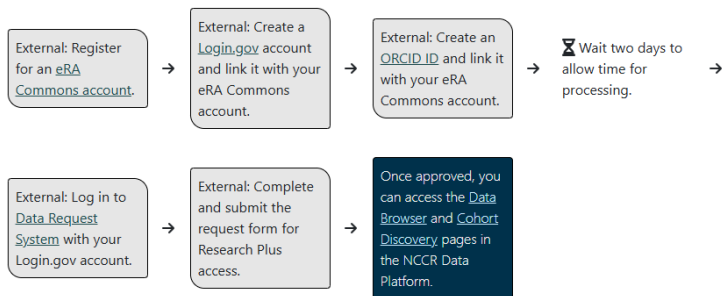
Have questions? We're here to help. If you can't find an answer, please [contact us](#).

General Inquiries

[Expand All](#)

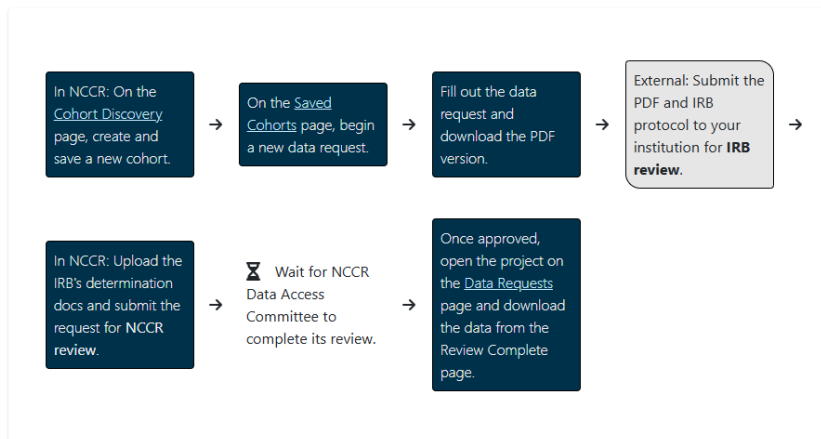
1. How do I get an account to access data in the NCCR Data Platform?

- Since the data available in the NCCR Data Platform contain sensitive information, NCI enforces several requirements to ensure that anyone requesting an account is a verified researcher or advocate and is sponsored by an institution known to the NIH. In order to view NCCR data, you will need either an HHS account or an eRA Commons account that is linked with a Login.gov account. In either case, you will also need an ORCID ID and access to SEER Research Plus. For detailed information about setting up an eRA Commons account or SEER Research Plus, see the [SEER website](#).
- In short, the procedure for setting up an account involves the following steps:
 - If you do not already have an eRA Commons or HHS account, you must first acquire an [eRA Commons account](#) (if you have an HHS account, skip to step 3).
 - Create a [Login.gov account](#) and link it with your eRA Commons account.
 - Create an [ORCID ID](#).
 - If you are a non-HHS user, you must link the ORCID ID with your eRA Commons account and allow two days to elapse while your information processes.
 - On the [Request SEER Incidence Data](#) site, select the Research Plus Login option and log in with your Login.gov or HHS account. Complete the Research Plus Request application, acknowledging the [SEER Data Agreements & Limitations](#) provided in the application:
 - SEER Research Data Use Agreement
 - SEER Treatment Data Limitations
 - Best Practices Assurance
 - National Childhood Cancer Registry (NCCR) Data Use Agreement
 - Submit the application. The SEER program will process your request within 2 business days. If approved, you will receive a SEER*Stat account with access to NCCR data. Once you receive an email indicating that your SEER*Stat account was created, you may log in to the NCCR Data Platform using your HHS or Login.gov account.



1. How do I request access to individual-level data for a cohort? —

Navigate to the [Cohort Discovery page](#) and select the data sources and parameters for your cohort. Then fill out a data request for the cohort, outlining the aims of your research. There are two review phases required before you can access the data. First, send a PDF of the data request along with IRB protocol to your institution for IRB review. Then select your request from the [Data Requests page](#), upload the IRB determination documents, and submit the request for the final NCCR approval.



2. Do collaborators on a project need to submit separate data requests? +

3. What should I do if a journal needs to review a dataset I referenced in a manuscript I submitted for publication? +

4. Do I need to submit a new data request to access updated data? +

5. Which Institutional Review Board (IRB) should I use to get approval for a data request? +

6. What exactly is the NCCR Data Access Committee evaluating when they review a data request? +

7. Will I be notified when my request is approved or rejected? +

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Data Browser

 Quickstart

NCCR links cancer data for children, adolescents, and young adults from various sources. These data sources include Consolidated Tumor Cases (CTC) from population-based registries, Children's Oncology Group (COG) study enrollment, and treatment, procedures and insurance enrollment data from medical and pharmacy claims. This interactive data browser allows you to explore the overview, data dictionary, and variable distributions for each of these sources. The data dictionary shows you detailed information about the data elements that the data source includes. The variable distributions show you the total number of unique records available in the data source, broken down by the values for each of its data elements. All NCCR data have been de-identified to protect patient privacy.

Select a Data Source

 Overview

Consolidated Tumor Case Data Source

Patient Count

1,542,685

Tumor Count

1,544,451

Years of Diagnosis

1995-2023

Overview

Data Dictionary

Variable Distributions

The Consolidated Tumor Case (CTC) data source consists of the final adjudicated data collected from population-based cancer registries, including Surveillance, Epidemiology, & End Results (SEER) registries. The CTC data available in the data platform in 2024 were submitted in December 2023 under the National Childhood Cancer Registry data submission requirements for cases diagnosed from 1995 to 2021. The records represent 57.6% of all U.S. children, adolescents, and young adults between the ages of 0 and 39 based on 2020 U.S. populations. Registries include: California (Greater Bay, Greater California, Los Angeles), Colorado, Connecticut, Georgia, Hawai'i, Idaho, Illinois, Iowa, Kentucky, Louisiana, Massachusetts, Michigan, New Jersey, New Mexico, New York, Seattle-Puget Sound, Tennessee, Texas, Utah, and Wisconsin. This data source also includes information from the NAACCR Virtual Pooled Registry linkage, which helps to identify prior and subsequent malignant neoplasms from additional central cancer registries.

Suggested Citation

Childhood Cancer Data Initiative (CCDI) National Childhood Cancer Registry (NCCR) Data Platform: An interactive data platform for NCCR cancer statistics [Internet]. National Cancer Institute; [updated: November 1, 2024; cited: November 5, 2024]. Available from <http://nccrdataplatfom.ccdi.cancer.gov>

Consolidated Tumor Case Data Source

Patient Count

1,542,685

Tumor Count

1,544,451

Years of Diagnosis

1995-2023

Overview

Data Dictionary

Variable Distributions

surv

Search

Reset

Displaying 4 results

Surv-Flag Active Followup

Description:

This flag is generated by the program that creates Surv-Mos Active Followup [1784] and describes how complete the date information is that was used to calculate survival months. This item is one of seven survival variables designed to facilitate a common approach to survival analysis by NAACCR registries.

Rationale:

Years Applicable: 1995+ The flag will enable analysts to easily select a subset of cases.

[Link to item](#)

Code	Description
0	Complete dates are available and there are 0 days of survival (i.e., date last contact = date of diagnosis)
1	Complete dates are available and there are more than 0 days of survival (i.e., date last contact > date diagnosis)
2	Incomplete dates are available and there could be zero days of follow-up (i.e., known components are equal, e.g., 2006 and 20061002)
3	Incomplete dates are available and there cannot be zero days of follow-up (i.e., any difference in known date components, e.g., 200602 and 200603)
8	Not calculated because a Death Certificate Only or Autopsy Only case
9	Unknown
Blank	Not coded

Surv-Flag Presumed Alive

Surv-Mos Active Followup

Surv-Mos Presumed Alive

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Data Browser

NCCR links cancer data for children, adolescents, and young adults from various sources. These data sources include Consolidated Tumor Cases (CTC) from population-based registries, Children's Oncology Group (COG) study enrollment, and treatment, procedures and insurance enrollment data from medical and pharmacy claims. This interactive data browser allows you to explore the overview, data dictionary, and variable distributions for each of these sources. The data dictionary shows you detailed information about the data elements that the data source includes. The variable distributions show you the total number of unique records available in the data source, broken down by the values for each of its data elements. All NCCR data have been de-identified to protect patient privacy.

Select a Data Source

Social Drivers of Health Data Source ▼

Overview | **Social Drivers of Health Data Source**

Patient Count: **1,542,685** | Years of Diagnosis: **1995-2023**

Overview | Data Dictionary | **Variable Distributions**

Type to search by field name

Search Reset

Displaying 5 results

Tumor Record Number ⓘ

Data collected for 1,543,269 cases out of 1,543,269 (100.00%)

Yost - U.S.-based Socioeconomic Status (SES) Quintile ⓘ

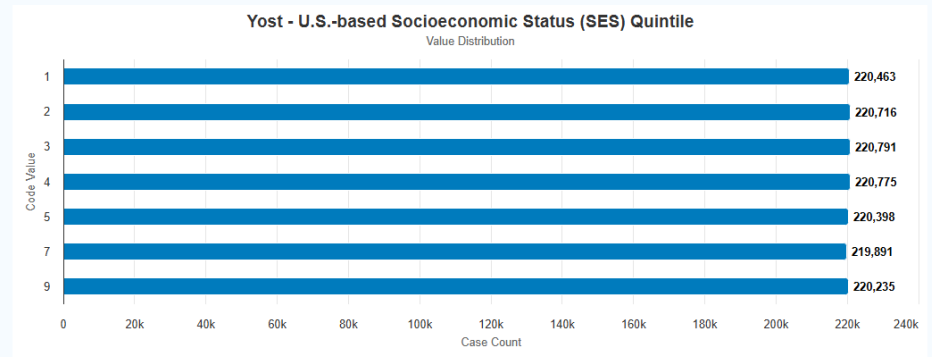
Data collected for 1,543,269 cases out of 1,543,269 (100.00%)

2010 RUCA-based Categorization C ⓘ

Data collected for 1,543,269 cases out of 1,543,269 (100.00%)

Urban Rural Indicator Codes (URIC) ⓘ

Distinct Code Values: 7



Cohort Discovery

To build a cohort of patients, choose your data sources and then select options from the provided filters. Once you save a cohort, you can include it in a data request to access more detailed information. You can also modify a saved cohort at any point until you submit a data request for it.

1 **Select Data Sources For Your Cohort**

Select the data sources to include in your cohort. Every data source you select will be included in requested datasets that use this cohort. If additional filters are available for a selected data source, a tab of filters and data visualizations will also appear for that source in the Customize Your Cohort Definition panel below.

Data Source		
<input type="checkbox"/>	Consolidated Tumor Case ⓘ	The Consolidated Tumor Case (CTC) data source provides the final adjudicated data from population-based cancer registries.
<input checked="" type="checkbox"/>	Children's Oncology Group	The Children's Oncology Group (COG) data source provides data for patients enrolled in studies conducted by COG member institutions.
<input checked="" type="checkbox"/>	Medical Claims ⓘ	The Medical Claims data source includes diagnosis, and procedure data extracted from claims collected by various insurers.
	Medical Claims Diagnosis ⓘ	The Medical Claims Diagnosis data source provides patient diagnosis data extracted from medical claims collected by various insurers.
	Medical Claims Enrollment ⓘ	The Medical Claims Enrollment data source provides patient enrollment data extracted from medical claims collected by various insurers.
	Medical Claims Procedure ⓘ	The Medical Claims Procedure data source provides patient procedure data extracted from medical claims collected by various insurers.
<input checked="" type="checkbox"/>	Pharmacy Claims	The Pharmacy Claims data source provides prescription data extracted from the outpatient pharmacy claims collected by various insurers.
<input checked="" type="checkbox"/>	Social Drivers of Health ⓘ	The Social Drivers of Health (SDOH) data source includes area-based measures calculated from Census information.

Customize Your Cohort Definition

2

To refine your cohort population, select options from the filters below. The data visualizations update to display the data available based on your selections. You can save your cohort at any time to preserve your selections, modify them later, or include the cohort in a data request.

Clear Filters

The data visualizations below are descriptive statistics only and are not intended to be used as inferential and predictive statistics in presentations and publications. Researchers should adhere to best practices for their analysis by conducting an appropriate statistical analysis of individual-level data accessed via the data request process and refrain from drawing any broad conclusions from the aggregate data.

Consolidated Tumor Case (CTC) Children's Oncology Group (COG) Pharmacy Claims

NCI NCCR Data Platform Aggregate Statistics for Consolidated Tumor Case (CTC) Data

Index Cancer - define if your cohort should include only the first primary tumor or all tumors

All

Min Age (Yrs)

20

Max Age (Yrs)

39

Race/Ethnicity

All

Sex

All

ICCC Major (Level 1)

I. Leukemias, Myeloproliferative And M...

ICCC (Level 2)

All

ICCC Extended (Level 3)

All

Months from Index Cancer to Diagnosis

Min Months

Enter value

Max Months

Enter value

Tumor Order

All

Number of Primaries

All

Year of Diagnosis

All

ICD-O-3 Histology/Behavior

All

Primary Site ICD-O-3

All

Combined Summary Stage

All

Surgery of Primary Site

All

Radiation Therapy

All

Chemotherapy

All

Pathology Reports Available

All

Vital Status

All

SEER Cause of Death

All

Index Cancer



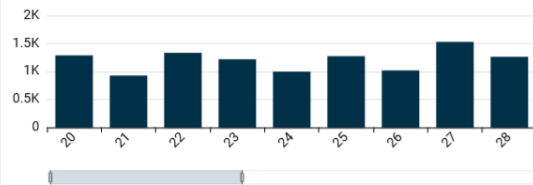
Distinct Patient Count

22,860

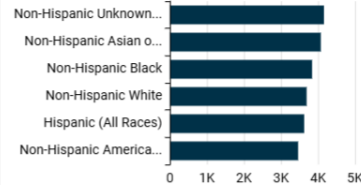
Tumor Count

22,860

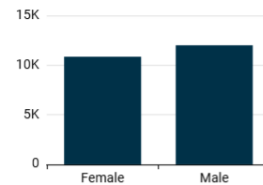
Age at Diagnosis (Yrs): 20 to 39



Race/Ethnicity



Sex



ICCC Major Category



2

Customize Your Cohort Definition

To refine your cohort population, select options from the filters below. The data visualizations update to display the data available based on your selections. You can save your cohort at any time to preserve your selections, modify them later, or include the cohort in a data request.

Clear Filters

! The data visualizations below are descriptive statistics only and are not intended to be used as inferential and predictive statistics in presentations and publications. Researchers should adhere to best practices for their analysis by conducting an appropriate statistical analysis of individual-level data accessed via the data request process and refrain from drawing any broad conclusions from the aggregate data.

Consolidated Tumor Case (CTC) Children's Oncology Group (COG) Pharmacy Claims

NCI NCCR Data Platform Aggregate Statistics for Pharmacy Claims Data

Min Months from 1st Dx to Dispense

Enter value

Max Months from 1st Dx to Dispense

Enter value

Drug Category

CHEMOTHERAPY



CanMED Major Drug Class

All

CanMED Non-proprietary Name

All

Distinct Patients

665

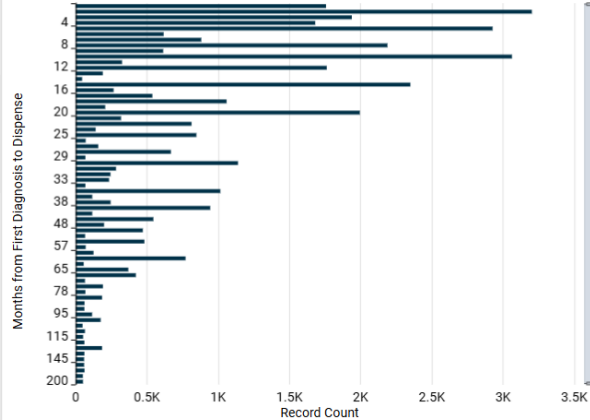
Prescription Count

40,338

Distinct Patients with Prescriptions

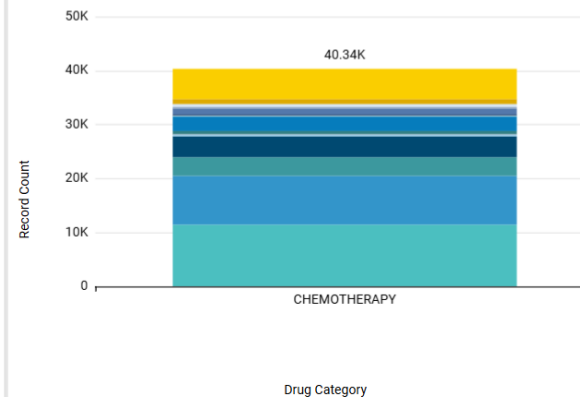
665

Months from First Diagnosis to Dispense: 1 to 200



Drug Category

Showing Drug Category and CanMED Major Drug Class



CanMED Major Drug Class



CanMED Non-proprietary Name



Save Your Cohort



- Save as new cohort
- Replace an existing cohort

test_demo

Name

test_Nov2024Demo

Description

Cancel

Save

Customize Your Cohort Definition

2

To refine your cohort population, select options from the filters below. The data visualizations update to display the data available based on your selections. You can save your cohort at any time to preserve your selections, modify them later, or include the cohort in a data request.

Clear Filters

1

The data visualizations below are descriptive statistics only and are not intended to be used as inferential and predictive statistics in presentations and publications. Researchers should adhere to best practices for their analysis by conducting an appropriate statistical analysis of individual-level data accessed via the data request process and refrain from drawing any broad conclusions from the aggregate data.

Consolidated Tumor Case (CTC) | Children's Oncology Group (COG) | Pharmacy Claims

NCI NCCR Data Platform Aggregate Statistics for Pharmacy Claims Data

Min Months from 1st Dx to Dispense

Enter value

Max Months from 1st Dx to Dispense

Enter value

Drug Category

CHEMOTHERAPY



CanMED Major Drug Class

All

CanMED Non-proprietary Name

All

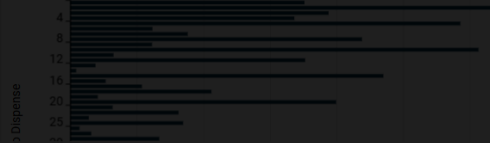
Distinct Patients

665

Prescription Count

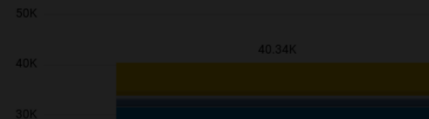
40,338

Months from First Diagnosis to Dispense: 1 to 200



Drug Category

Showing Drug Category and CanMED Major Drug Class



Save Cohort

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 Currently Viewing
test_Nov2024D

You can manage your cohorts and begin data requests for

- To modify a cohort, select its name in the Cohort column.
- To access individual-level data for your cohorts, mark the checkbox for each cohort you wish to include in a request and select **Begin Data Request**.
- To share a cohort with another NCCR user, mark the checkbox for that cohort and select **Share**.

Begin Data Request ⓘ

Share ⓘ Delete ⓘ

Select	Cohort ↑↓	Description ↑↓	Data Sources ↑↓	Total Patient Count ↑↓	Last Saved ↑↓	Requested ↑↓
<input checked="" type="checkbox"/>	test_Nov2024Demo	test_Nov2024Demo	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health	665	11/5/2024, 3:01 PM	No
<input type="checkbox"/>	test_ICCC-IXNotClassifiedXII_Nov2024	test_ICCC-IXNotClassifiedXII_Nov2024	Children's Oncology Group, Consolidated Tumor Case, Social Drivers of Health	274,477	11/5/2024, 2:44 PM	Yes
<input type="checkbox"/>	test_ChordomaNOSDediffChordoma-2017-2023_Nov2024	test_ChordomaNOSDediffChordoma-2017-2023_Nov2024	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health	577	11/5/2024, 2:28 PM	Yes
<input type="checkbox"/>	test_demo20241031	test_demo20241031	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health	17,557	10/31/2024, 2:32 PM	Yes
<input type="checkbox"/>	test_AllCa_Dx2017-2023_Alive_NoCOGENroll	test_AllCa_Dx2017-2023_Alive_NoCOGENroll	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health	180	10/28/2024, 4:15 PM	Yes
<input type="checkbox"/>	test_20241028	test_20241028	Consolidated Tumor Case	430,397	10/28/2024, 4:12 PM	No
<input type="checkbox"/>	test_demo	test_demo	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims	3,028	10/25/2024, 6:11 PM	No

Share Cohort X

You may use the link below to share your cohort with someone that also has access to the data platform. The shared cohort will provide a copy of the cohort discovery dashboard for this cohort and is based on the currently saved version. Any subsequent updates you make to this cohort will not be reflected in the shared version.












<https://nccrdatapatform-test.ccdi.cancer.gov/cohort-discovery/637efbd3-3367-43f0-b53d-c4cf4fc6ac9f?shared=1>

Cancel

Copy Link

Email Link

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Saved Cohorts & Request Data

You can manage your cohorts and begin data requests from the table below.

- To modify a cohort, select its name in the Cohort column.
- To access individual-level data for your cohorts, mark the checkbox for each cohort you wish to include in a request and select **Begin Data Request**.
- To share a cohort with another NCCR user, mark the checkbox for that cohort and select **Share**.

<input type="button" value="Begin Data Request"/>  <input type="button" value="Share"/>  <input type="button" value="Delete"/> 						
Select	Cohort ↑↓	Description ↑↓	Data Sources ↑↓	Total Patient Count ↑↓	Last Saved ↑↓	Requested ↑↓
<input checked="" type="checkbox"/>	test_ICCC-IXNotClassifiedXII_Nov2024	test_ICCC-IXNotClassifiedXII_Nov2024	Children's Oncology Group, Consolidated Tumor Case, Social Drivers of Health	274,477	11/5/2024, 2:33 PM	No
<input type="checkbox"/>	test_ChordomaNOSDediffChordoma-2017-2023_Nov2024	test_ChordomaNOSDediffChordoma-2017-2023_Nov2024	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health	577	11/5/2024, 2:28 PM	Yes
<input type="checkbox"/>	test_demo20241031	test_demo20241031	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health	17,557	10/31/2024, 2:32 PM	Yes
<input type="checkbox"/>	test_AllCa_Dx2017-2023_Alive_NoCOGEnroll	test_AllCa_Dx2017-2023_Alive_NoCOGEnroll	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health	180	10/28/2024, 4:15 PM	Yes
<input type="checkbox"/>	test_20241028	test_20241028	Consolidated Tumor Case	430,397	10/28/2024, 4:12 PM	No
<input type="checkbox"/>	test_demo	test_demo	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims	3,028	10/25/2024, 6:11 PM	No
<input type="checkbox"/>	Test15YoungerFemaleLeuk	Test15YoungerFemaleLeuk	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims	1,438	10/25/2024, 5:31 PM	No
<input type="checkbox"/>	test_AllCa_Dx2017-2023_Alive	test_AllCa_Dx2017-2023_Alive	Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health	291,434	10/25/2024, 4:47 PM	No

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Submit New Data Request



Use the fields below to explain why you need access to the selected data. The information you provide will be used to evaluate your request during the approval process.

If your request is approved, the fields that are marked for public display will be available to other NCCR users on the Research Projects page of this site.

Your Cohort Details

[Prev](#) Cohort 1 of 1 [Next](#)

Name

test_ICCC-IXNotClassifiedXII_Nov2024 (test_ICCC-IXNotClassifiedXII_Nov2024)

Data Sources Selected

Children's Oncology Group, Consolidated Tumor Case, Social Drivers of Health

Criteria

Age: 0 - 120, **Race/Ethnicity:** All, **Sex:** All, **Years of Diagnosis:** All

ICCC Major (Level 1): XII. Other And Unspecified Malignant Neoplasms, Not classified by SEER or in situ, IX. Soft Tissue And Other Extraosseous Sarcomas

ICCC (Level 2): All

ICCC Extended (Level 3): All

View [cohort](#) for additional criteria.

All fields are required unless otherwise noted.

Your Information

Profile information is pre-populated with information from eRA Commons. If necessary, log in to [eRA Commons](#) website to update this information.

Name

This field will be publicly displayed.

Johanna Goderre Jones

Institution:

This field will be publicly displayed.

Specify Collaborators Optional

Collaborators will need to submit a separate request form in order to access the data. However, they can use the same IRB approval if requesting access to the same cohort.

Name

Muriel Carpenter

Institutional Email

muriel@me.com

[+ Add Collaborator](#)

Data Elements Requested

Expand the categories below to choose the specific fields needed for your request.

Consolidated Tumor Case Elements

Total: 101 selected

[Select All](#) | [Clear All](#)

+ Record ID	2 selected
+ Demographic	6 selected
+ Cancer Identification	13 selected
+ Virtual Pooled Registry (VPR)	4 selected
+ Stage/Prognostic Factors	42 selected
+ Treatment-1st Course	22 selected
+ Follow-up/Recurrence/Death	8 selected
+ Edit Overrides/Conversion History/System Admin	1 selected
+ Pathology	1 selected
+ Treatment-Subsequent & Other	1 selected
+ Not Categorized	1 selected

Children's Oncology Group Elements

Total: 7 selected

[Select All](#) | [Clear All](#)

Field name	Description
<input checked="" type="checkbox"/> Reported COG Study Enrollment	Indicates whether the patient was known to be enrolled in a Children's Oncology Group (COG) study at the time of the linkage (e.g., years of diagnosis, years of specific data freezes, geographical coverage).
<input checked="" type="checkbox"/> Biobanking/Tumor Classification Study Enrollments	Number of biobanking/tumor classification studies the patient was enrolled on. Patients not found at the time of linkage will be coded as 7777 (No Data Available for Patient at Time of Linkage). These studies collect and store biological samples, such as tissue, blood, or other fluids. The goal is to use these samples to better understand the biology of cancer, improve diagnostic methods, and develop new treatments. These studies aim to categorize and/or risk-stratify cancer subtypes based on their molecular and cellular features.
<input checked="" type="checkbox"/> Registry/Epidemiology Study Enrollments	Number of registry/epidemiology studies the patient was enrolled on. Patients not found at the time of linkage will be coded as 7777 (No Data Available for Patient at Time of Linkage). These studies track and record data on patients over time to study patient health, quality of life, and/or survival outcomes.
<input checked="" type="checkbox"/> Supportive Study Enrollments	Number of supportive studies the patient was enrolled on. Patients not found at the time of linkage will be coded as 7777 (No Data Available for Patient at Time of Linkage). These studies focus on improving the health and/or quality of life patients by managing the side effects of cancer and its treatment. These studies may investigate methods to alleviate symptoms, reduce treatment-related complications, and support patients' physical, emotional, and psychosocial needs.
<input checked="" type="checkbox"/> Therapeutic-Other Trial Enrollments	Number of therapeutic-other trials the patient was enrolled on. Patients not found at the time of linkage will be coded as 7777 (No Data Available for Patient at Time of Linkage). These studies test the safety and efficacy of interventions to improve treatment response and/or survival. These are primarily interventions to reduce side effects or treat a non-cancer condition. These studies meet criteria for more than one study type.
<input checked="" type="checkbox"/> Therapeutic Frontline Trial Enrollments	Number of therapeutic frontline trials the patient was enrolled on. Patients not found at the time of linkage will be coded as 7777 (No Data Available for Patient at Time of Linkage). These studies test the effectiveness and safety of treatments that are given as the first line treatment for newly diagnosed cancers.
<input checked="" type="checkbox"/> Therapeutic Relapsed Trial Enrollments	Number of therapeutic relapsed trials the patient was enrolled on. Patients not found at the time of linkage will be coded as 7777 (No Data Available for Patient at Time of Linkage). These studies focus on treatments for cancers that have recurred or progressed after an initial cancer-directed treatment.

— Data Usage Responsibilities

By submitting your data request, you agree to use the data securely and appropriately, as previously acknowledged in the Data Use Agreement. In particular, you agree to abide by the following rules:

1. Make no attempt to re-identify individuals in the dataset.
2. Notify NCI and appropriately acknowledge the NCCR Data Platform in any publications or presentations resulting from analysis of the data.
3. Use the data only for the project specified in your data access request.
4. Collaborators must also submit a separate data access request.
5. Destroy all data upon completion of the project.

[SFER Research Data Use Agreement](#)

[SFER Treatment Data Limitations](#)

[Best Practices Assurance](#)

[National Childhood Cancer Registry \(NCCR\) Data Use Agreement](#)

Save Draft

Save this request to edit later

Continue

Save and go to step two

OMB No. 0925-0775

Expiration Date: 06/30/2025

Public reporting burden for this collection of information is estimated to average 45 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor a collection of information unless it displays a currently valid OMB control number.

Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0775).

Do not return the completed data request form to this address.

Suggested Citation

Childhood Cancer Data Initiative (CCDI) National Childhood Cancer Registry (NCCR) Data Platform: An interactive data platform for NCCR cancer statistics [Internet]. National Cancer Institute; [updated: November 1, 2024; cited: November 5, 2024]. Available from <http://nccrdatapatform.ccdi.cancer.gov>

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[Sign up](#)

NCCR Data Platform: Data Request

Document created: 11/05/2024, 02:44 PM EST

The National Childhood Cancer Registry (NCCR) is part of the Childhood Cancer Data Initiative from the US National Institutes of Health, National Cancer Institute designed to reduce data siloes and advance research resources that enhance access to and utilization of childhood cancer and survivorship data. The NCCR Data Platform is a data resource that integrates cancer registry and real-world data from hospitals, research centers, healthcare administration, and other sources. Data in this resource are originally reported to Central Cancer Registries authorized by state law to conduct public health surveillance activities or other authorized data providers. Registries and other authorized data providers de-identify data before submitting data to the NCI. The NCI and NCCR do not hold personally-identifiable information (PII). The NCCR therefore does not release PII to researchers in subsequent data requests. The NCI further protects patient privacy and confidentiality by providing limited information such as calculating intervals between dates and not releasing dates of healthcare events or treatments and by not providing any geographic information. Users of the NCCR Data Platform requesting individual-level data must agree to the Data Use Agreement and other best practices (<https://seer.cancer.gov/data/access.html>) as well as submitting an application to an Institutional Review Board for approval to conduct research. Expedited procedures will be accepted in the event a full IRB review is not permitted or deemed necessary by the Institution. If the IRB determines a request is exempt from review or not human subjects research then this documentation should be provided in the NCCR Data Platform

aute irure dolor in reprehenderit in voluptate velit esse cillum dolore eu fugiat nulla pariatur. Excepteur sint occaecat cupidatat non proident, sunt in culpa qui officia deserunt mollit anim id est laborum.

Research Relevance:

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua. Ut enim ad minim veniam, quis nostrud exercitation ullamco laboris nisi ut aliquip ex ea commodo consequat. Duis aute irure dolor in reprehenderit in voluptate velit esse cillum dolore eu fugiat nulla pariatur. Excepteur sint occaecat cupidatat non proident, sunt in culpa qui officia deserunt mollit anim id est laborum.

Scientific Approach and Analytic Plan:

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua. Ut enim ad minim veniam, quis nostrud exercitation ullamco laboris nisi ut aliquip ex ea commodo consequat. Duis aute irure dolor in reprehenderit in voluptate velit esse cillum dolore eu fugiat nulla pariatur. Excepteur sint occaecat cupidatat non proident, sunt in culpa qui officia deserunt mollit anim id est laborum.

Research Area

Methods development, Health disparities

Specify Collaborators

Collaborator Name	Collaborator Email
Muriel Carpenter	muriel@me.com

Cohort Details

test ICC-IXNotClassifiedXII Nov2024

83. RX Summ--Surg/Plnt/Seq
84. RX Summ--Surg/Rad Seq
85. RX Summ--Systemic/Sur Seq
86. RX Summ--Transplnt/Endocr
87. RX Summ--Treatment Status (2010+)
88. Scope of reg lymph nd surg (1998-2002)
89. Time from diagnosis to treatment in days recode
90. Record Number Recode
91. SEER Cause Specific COD
92. SEER Other COD
93. Surv-Flag Active Followup
94. Surv-Flag Presumed Alive
95. Surv-Mos Active Followup
96. Surv-Mos Presumed Alive
97. Vital Status Recode
98. CoC Accredited Flag
99. Path Report Flag
100. Number of Months from Diagnosis to Other Treatment
101. Number for facilities that submitted an abstract for this CTC

Data Source: Children's Oncology Group

1. Reported COG Study Enrollment
2. Biobanking/Tumor Classification Study Enrollments
3. Registry/Epidemiology Study Enrollments
4. Supportive Study Enrollments
5. Therapeutic-Other Trial Enrollments
6. Therapeutic Frontline Trial Enrollments
7. Therapeutic Relapsed Trial Enrollments

Data Source: Social Drivers of Health

1. Tumor Record Number

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Data Request for: Test_ApproveLargeDataRequest



Pending IRB Review

Submit this request to your organization's Institutional Review Board (IRB) for review. After your organization's IRB reviews the request, you can submit it for approval in the NCCR Data Platform. Follow the steps below to complete the submission process.

1. Download a PDF copy of your data request.
2. Submit the PDF and IRB protocol to your organization for IRB review (this is done outside of the NCCR Data Platform). If the IRB determines the request should be approved, exempt, or not human subjects research, you may proceed to the next step.
3. Return here from your [Data Requests](#) page, provide the IRB review details, and upload your IRB study application (or the study protocol document) and IRB review outcome document as a single PDF or image file. Then submit your request for NCCR review. The NCCR Data Access Committee will review your request within a month.

— Your Data Request

A prepared PDF of your data request for your IRB review.

[Download the PDF](#)

— IRB Review Information

All fields are required unless otherwise noted.

IRB Review Outcome

Approved ▼

IRB Name

MyIRB

IRB Approval Number

XG591




IRB Approval Date





11/05/2024 📅


Upload Documentation




Please provide the IRB study application (or the study protocol document) and the IRB review outcome document as a single PDF or image file.

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-  Saved Cohorts & Request Data
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-  Manage Requests

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Data Requests

 Your data request was submitted successfully to the NCCR Data Access Committee for review. This may take up to a month to complete. You will receive an email once a determination has been made or if additional information is needed to complete the review. ×

You can use the table below to track the status of your data requests. Select the link in the Project Name column to submit the IRB outcome documentation for a pending request or access the custom dataset for an approved request.



Select	Project Name ↑↓	Status ↑↓	Request ID	Cohorts ↑↓	Total Patient Count ↑↓	Range of Diagnosis Years	Approval Date ↑↓
	Test_ApproveLargeDataRequest	Pending NCCR Review	...ddb92cd2471f	test_ICCC-IXNetClassifiedXII_Nov2024	274,477	1995-2023	Not Available
	Test_Nov2024_DemoApprovedDataRequest	Pending NCCR Review	...8cbcb46674c9	test_ChordomaNOSDediffChordoma-2017-2023_Nov2024	577	2017-2023	Not Available
<input type="checkbox"/>	test	Pending IRB Review	...412ddf11b30	test_demo20241031	17,557	1995-2023	Not Available
	test	Pending NCCR Review	...dc3a0e68077a	test_AllCa_Dx2017-2023_Alive_NoCOGENroll	180	2017-2023	Not Available

Suggested Citation

Childhood Cancer Data Initiative (CCDI) National Childhood Cancer Registry (NCCR) Data Platform: An interactive data platform for NCCR cancer statistics [Internet]. National Cancer Institute; [updated: November 1, 2024; cited: November 5, 2024]. Available from <http://nccrdataplatfom.ccdi.cancer.gov>

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Data Request

1

Complete Data
Request Details

Review Complete

Your data request, **Test_M**[Download CSV Data](#)

Your Data Request Summary

Your Cohort Details

Prev Cohort 1 of 1 Next

Name

test_ChordomaNOSDediffChordoma-2017-2023_Nov2024 (test_ChordomaNOSDediffChordoma-2017-2023_Nov2024)

Data Sources Selected

Children's Oncology Group, Consolidated Tumor Case, Medical Claims Diagnosis, Medical Claims Enrollment, Medical Claims Procedure, Pharmacy Claims, Social Drivers of Health

Criteria**Age:** 0 - 120, **Race/Ethnicity:** All, **Sex:** All, **Years of Diagnosis:** 2017, 2018, 2019, 2020, 2021, 2022, 2023**ICCC Major (Level 1):** All**ICCC (Level 2):** All**ICCC Extended (Level 3):** AllView [cohort](#) for additional criteria.

Data Usage Responsibilities



In order to download your approved data files, you agree to use the data securely and appropriately, as previously acknowledged in the Data Use Agreement. In particular, you agree to abide by the following rules:

1. Make no attempt to re-identify individuals in the dataset.
2. Notify NCI and appropriately acknowledge the NCCR Data Platform in any publications or presentations resulting from analysis of the data.
3. Use the data only for the project specified in your data access request.
4. Collaborators must also submit a separate data access request.
5. Destroy all data upon completion of the project.

[SEER Research Data Use Agreement](#)[SEER Treatment Data Limitations](#)[Best Practices Assurance](#)[National Childhood Cancer Registry \(NCCR\) Data Use Agreement](#)

Cancel

I agree

Name	Date modified	Type	Size
Import Scripts	11/7/2024 11:28 AM	File folder	
COG_Data_Dictionary.xlsx	11/7/2024 11:28 AM	Microsoft Excel Worksheet	
COG_test_ChordomaNOSDedi.csv	11/7/2024 11:28 AM	Microsoft Excel Comma Separat...	
CTC_Data_Dictionary.xlsx	11/7/2024 11:28 AM	Microsoft Excel Worksheet	
CTC_test_ChordomaNOSDedi.csv	11/7/2024 11:28 AM	Microsoft Excel Comma Separat...	
MCD_Data_Dictionary.xlsx	11/7/2024 11:28 AM	Microsoft Excel Worksheet	
MCD_test_ChordomaNOSDedi.csv	11/7/2024 11:28 AM	Microsoft Excel Comma Separat...	
MCE_Data_Dictionary.xlsx	11/7/2024 11:28 AM	Microsoft Excel Worksheet	
MCE_test_ChordomaNOSDedi.csv	11/7/2024 11:28 AM	Microsoft Excel Comma Separat...	
MCP_Data_Dictionary.xlsx	11/7/2024 11:28 AM	Microsoft Excel Worksheet	
MCP_test_ChordomaNOSDedi.csv	11/7/2024 11:28 AM	Microsoft Excel Comma Separat...	
PHARM_Data_Dictionary.xlsx	11/7/2024 11:28 AM	Microsoft Excel Worksheet	
PHARM_test_ChordomaNOSDedi.csv	11/7/2024 11:28 AM	Microsoft Excel Comma Separat...	
SDOH_Data_Dictionary.xlsx	11/7/2024 11:28 AM	Microsoft Excel Worksheet	
SDOH_test_ChordomaNOSDedi.csv	11/7/2024 11:28 AM	Microsoft Excel Comma Separat...	

```
/* Published: 11/05/2024 */
```

```

/***** IMPORTANT PROGRAMING NOTES *****/
/* This program example reads in unzipped NCCR DP CTC CSV file. */
/* The script provides an example of how to import your data file into SAS
/* for analysis. It is designed to guide you through the process of reading
/* your data file, ensuring that the data is correctly loaded and formatted
/* for further analysis. Follow the instructions and adapt the code as needed
/* to match your file path and data file names.
/*****

```

```
DATA test_ChordomaNOSDediffChordoma-2017-2023_Nov2024;
```

```
INFILE "CTC_test_ChordomaNOSDedi.csv"
```

```
DELIMITER = ',' MISSEVER DSD LRECL = 32767 FIRSTOBS = 2;
INPUT
```

```

    dataRequestPatientID :$21.
    cohortDefinitionRecord :$3.
    naaccrRecordVersion :$3.
    tumorRecordNumber :$2.
    sex :$1.
    ageRecodel9Groups :$2.
    ageRecode20Groups :$2.
    ageRecodeSingle85p :$2.
    ageRecodeSingle90p :$2.
    raceRecodeWBAiApiHisp :$1.
    behaviorICDO3Public :$1.
    yearOfDiagnosis :$4.
    imputedMonthOfDiagnosis :$1.
    diagnosticConfirmation :$1.
    histologicTypeIcdO3 :BEST32.
    icccMajor :$2.
    iccc2017Recode :$3.
    iccc2017ExtendedRecode :$3.
    histologyBehaviorRecodePublic :$6.
    laterality :$1.
    primarySite :$4.
    sequenceNumberCentral :$2.
    typeOfReportingSource :$1.
    indexCancer :$1.
    tumorOrder :BEST32.
    numberOfPrimaries :BEST32.
    monthsFromIndexDxToTumor :BEST32.
    brainMolecularMarkers :$2.
    breslowDepthRecode :$3.
    combinedSummaryStagePub :$1.
    csExtension :$3.
    csLymphNodes :$3.
    csLymphNodesEval :BEST32.
    csMetsAtDx :$2.

```

SAS and R import scripts to ensure analyst can read-in data correctly

```

# The script provides an example of how to import your data file into R
# for analysis. It is designed to guide you through the process of
# reading your data file, ensuring that the data is correctly loaded
# and formatted for further analysis. Follow the instructions and adapt
# the code as needed to match your file path and data file names as needed.
library(readxl)

```

```
# Load data cut CSV for CTC data.
```

```
ctc_df <- read.csv('CTC_test_ChordomaNOSDedi.csv')
```

```
dd_df <- read_excel('tmp/CTC_Data_Dictionary.xlsx', sheet='Data Dictionary')
```

```
columns_to_keep <- c('Column_Name_at_Source', 'Permissible_Values.Value', 'Permissible_Values.Description')
```

```
dd_df <- dd_df[columns_to_keep]
```

```
dd_df <- dd_df[dd_df$Column_Name_at_Source == "naaccrRecordVersion", ]
```

```
get_description <- function(code, dd_df) {
```

```
  # First, check for an exact match.
```

```
  exact_match <- dd_df[dd_df$'Permissible_Values.Value' == code, ]
```

```
  if (nrow(exact_match) > 0) {
```

```
    return(as.character(exact_match$'Permissible_Values.Description')[1])
```

```
  } else {
```

```
    # Check if the value is a range and code is within the range.
```

```
    for (row in 1:nrow(dd_df)) {
```

```
      # Split the value based on the '-' character
```

```
      range_values <- unlist(strsplit(toString(dd_df[row, 'Permissible_Values.Value']), split = '-'))
```

```
      # Check if it's a range by ensuring two values (start and end) exist.
```

```
      if (length(range_values) == 2) {
```

```
        # Convert range values and code to numeric for proper comparison
```

```
        range_start <- as.numeric(range_values[1])
```

```
        range_end <- as.numeric(range_values[2])
```

```
        numeric_code <- as.numeric(code)
```

```
        if(!is.na(numeric_code) && numeric_code >= range_start && numeric_code <= range_end) {
          return(as.character(dd_df[row, 'Permissible_Values_Description']))
        }
      }
    }
  }

```

```
  # If no match at all, return NA
```

```
  return(NA)
```

```
# Apply this function to the ctc_df
```

```
ctc_df$naaccrRecordVersionDescr <- sapply(ctc_df$naaccrRecordVersion, get_description, dd_df)
```


```
# Rename the new (merged) column.
```

```
names(ctc_df)[names(ctc_df) == 'Permissible_Values.Description'] <- 'naaccrRecordVersion'
```

```
head( ctc_df
```

```
)
```

Readme Information

1	
2	
3	 NATIONAL CANCER INSTITUTE
4	Childhood Cancer Data Initiative
5	National Childhood Cancer Registry Data Platform
6	National Childhood Cancer Registry (NCCR) Data Platform Data Request
7	Project Title: Test_Nov2024_DemoApprovedDataRequest
8	Approval Date: November 05, 2024
9	
10	Getting Started
11	The Consolidated Tumor Cases (CTC) data dictionary file provides important information related to the data. Please review this README file before conducting your analysis.
12	When working with CSV data cut files in excel, please turn off all automatic data conversion settings to ensure the data format is not lost. For example, leading zeros may be removed.
13	Primary Key
14	Data Request Patient ID plus Tumor Record Number
15	
16	Identifying Patients Across Cohorts
17	The data request patient IDs from this data request were generated upon approval of the request and can be linked across cohorts (if multiple cohorts were included in this request). These IDs are unique to this data request and should not be referenced outside of this dataset or combined with any other data not cited in the original data request.
18	
19	Tumor Counts
20	This dataset is associated with the patient and thus includes all available cancer records for each patient within a cohort, resulting in the potential inclusion of records that may not fit into your original cohort definition. For example, if you used Year of Diagnosis as a filter, the resulting dataset may include tumor records beyond the specified range if a patient has additional tumor records that were diagnosed outside the time span you selected. If needed, you may filter out any records that do not align with your cohort definition.
21	Data Source
22	The Consolidated Tumor Case (CTC) data source consists of the final adjudicated data collected from population-based cancer registries, including Surveillance, Epidemiology, & End Results (SEER) registries. These data were submitted in December 2023 under the National Childhood Cancer Registry submission requirements for cases diagnosed 1995-2021. The records represent 57.6% of all U.S. children, adolescents, and young adults ages 0–39 based on 2020 U.S. populations. Registries include: California (Greater Bay, Los Angeles, Greater California), Colorado, Connecticut, Georgia, Hawaii, Idaho, Illinois, Iowa, Kentucky, Louisiana, Massachusetts, Michigan, New Jersey, New Mexico, New York, Seattle-Puget Sound, Tennessee, Texas, Utah, and Wisconsin. This data source also includes information from the NAACCR Virtual Pooled Registry, which allow researchers to identify prior and subsequent malignant neoplasms from additional central cancer registries.
23	
24	Data Upload Date; Release Date
25	April 2024.
26	
27	Suggested Citations
28	Users must acknowledge the NCCR Data Platform and any applicable data sources for all oral and written presentations, disclosures, manuscripts, abstracts, books, and other publications resulting from any analysis of NCCR data. Users must not present or publish data or the results of research conducted with data in which an individual can be identified.
29	

Data Dictionary

Column_Name_at_Source	Item_Name	Item_Description	Rationale	Field_Length	Semantic_Type	Permissible
dataRequestPatientId	Data Request Patient ID	A system generated ID from each data request generated upon approval of the request and can be linked across cohorts (if multiple cohorts were included in the same request). These IDs are unique to each data request and should not be referenced outside of each dataset or combined with any other data not cited in the original data request.		21	string	
cohortDefinitionRecord	Cohort Definition Record	Indicates whether a record is included in the data cut file as part of the original cohort definition. If no, then this indicates the record represents longitudinal information for that unique person but may be associated with a different cancer diagnosis.			lookup_value	Yes
cohortDefinitionRecord	Cohort Definition Record	Indicates whether a record is included in the data cut file as part of the original cohort definition. If no, then this indicates the record represents longitudinal information for that unique person but may be associated with a different cancer diagnosis.			lookup_value	No
naaccrRecordVersion	NAACCR Record Version	This item applies only to record types I, C, A, and M. Code the NAACCR record version used to create the record. The correction record (U) has its own record version data item.	Years Applicable: 1995+ The NAACCR Layout version is necessary to communicate to the recipient of data in NAACCR form where the various items are found and how they are coded. It should be added to the record when the recorded is created.	3	lookup_value	120
naaccrRecordVersion	NAACCR Record Version	This item applies only to record types I, C, A, and M. Code the NAACCR record version used to create the record. The correction record (U) has its own record version data item.	Years Applicable: 1995+ The NAACCR Layout version is necessary to communicate to the recipient of data in NAACCR form where the various items are found and how they are coded. It should be added to the record when the recorded is created.	3	lookup_value	121
			Years Applicable: 1995+			

Synthetic data shown

A1 : fx Data Request Patient ID

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	
	Data Requ	Cohort De	naaccrRet	tumorRec	sex	ageRecod	ageRecod	ageRecod	ageRecod	raceRecod	behavior	(yearOfDia	imputedM	diagnosti	histologic	icccMajor	iccc2017R	iccc2017E	histologyE	laterality	primarySi	sequence ty	
2	8cbcb466	Yes	220	1	1	18	14	33	27	5	0	2022	1	1	8743	11	114	96	9372/3		1	C447	00
3	8cbcb466	Yes	220	1	2	02	13	37	01	9	0	2017	1	1	9080	10	103	85	9370/3		1	C569	00
4	8cbcb466	Yes	220	1	2	13	11	05	66	2	0	2020	0	1	8340	11	112	94	9372/3		0	C739	00
5	8cbcb466	Yes	220	1	1	14	99	18	15	1	1	2023	0	1	9861	01	12	5	9370/3		0	C421	00
6	8cbcb466	Yes	220	1	2	12	08	80	72	5	1	2022	0	1	8340	11	112	94	9372/3		0	C739	00
7	8cbcb466	Yes	220	1	2	02	13	37	01	9	0	2017	1	1	9080	10	103	85	9370/3		1	C569	00
8	8cbcb466	Yes	220	1	1	01	05	43	20	2	0	2017	0	1	9837	01	11	1	9372/3		0	C421	00
9	8cbcb466	Yes	220	1	2	18	18	25	85	3	2	2018	0	1	8260	11	112	94	9372/3		0	C739	00
0	8cbcb466	Yes	220	1	1	00	99	99	00	2	2	2019	1	8	8272	03	35	27	9372/3		0	C751	60
1	8cbcb466	Yes	220	1	2	18	18	25	85	3	2	2018	0	1	8260	11	112	94	9372/3		0	C739	00
2	8cbcb466	Yes	220	1	1	08	07	23	77	1	2	2017	1	1	9680	02	22	11	9370/3		0	C778	00
3	8cbcb466	Yes	220	1	2	04	11	78	14	5	2	2023	1	1	8480	10	104	91	9370/3		2	C569	01
4	8cbcb466	Yes	220	1	1	01	05	43	20	2	0	2017	0	1	9837	01	11	1	9372/3		0	C421	00
5	8cbcb466	Yes	220	1	2	12	08	80	72	4	1	2022	0	1	8340	11	112	94	9372/3		0	C739	00
6	8cbcb466	Yes	220	1	2	04	11	78	14	5	2	2023	1	1	8480	10	104	91	9370/3		2	C569	01
7	8cbcb466	Yes	220	1	2	18	18	25	85	3	2	2018	0	1	8260	11	112	94	9372/3		0	C739	00
8	8cbcb466	Yes	220	1	2	00	36	01		1	2	2023	1	1	8500	11	116	103	9370/3		2	C505	03
9	8cbcb466	Yes	220	1	1	13	03	81	76	1	2	2021	0	1	9835	01	11	1	9372/3		0	C421	01
0	8cbcb466	Yes	220	1	1	01	05	43	20	2	0	2017	0	1	9837	01	11	1	9372/3		0	C421	00
1	8cbcb466	Yes	220	1	1	08	07	23	77	1	2	2017	1	1	9680	02	22	11	9370/3		0	C778	00
2	8cbcb466	Yes	220	1	1	18	14	33	27	5	0	2022	1	1	8743	11	114	96	9372/3		1	C447	00
3	8cbcb466	Yes	220	1	1	08	07	23	77	1	2	2017	1	1	9680	02	22	11	9370/3		0	C778	00
4	8cbcb466	Yes	220	1	2	02	13	37	01	9	0	2017	1	1	9080	10	103	85	9370/3		1	C569	00
5	8cbcb466	Yes	220	1	2	16	13	45	55	1	3	2023	0	1	8500	11	116	103	9372/3		2	C506	01
6	8cbcb466	Yes	220	1	1	08	07	23	77	1	2	2017	1	1	9680	02	22	11	9370/3		0	C778	00
7	8cbcb466	Yes	220	1	1	14	99	18	15	1	1	2023	0	1	9861	01	12	5	9370/3		0	C421	00
8	8cbcb466	Yes	220	1	2	00	36	01		1	2	2023	1	1	8500	11	116	103	9370/3		2	C505	03
9	8cbcb466	Yes	220	1	1	00	99	99	00	2	2	2019	1	8	8272	03	35	27	9372/3		0	C751	60
0	8cbcb466	Yes	220	1	2	16	13	45	55	1	3	2023	0	1	8500	11	116	103	9372/3		2	C506	01
1	8cbcb466	Yes	220	1	2	00	36	01		1	2	2023	1	1	8500	11	116	103	9370/3		2	C505	03
2	8cbcb466	Yes	220	1	1	18	14	33	27	5	0	2022	1	1	8743	11	114	96	9372/3		1	C447	00
3	8cbcb466	Yes	220	1	2	04	11	78	14	5	2	2023	1	1	8480	10	104	91	9370/3		2	C569	01
4	8cbcb466	Yes	220	1	1	08	07	23	77	1	2	2017	1	1	9680	02	22	11	9370/3		0	C778	00
5	8cbcb466	Yes	220	1	2	02	01	11	18	5	3	2023	0	8	8272	03	35	27	9370/3		0	C751	60
6	8cbcb466	Yes	220	1	1	08	07	23	77	1	2	2017	1	1	9680	02	22	11	9370/3		0	C778	00
7	8cbcb466	Yes	220	1	2	16	13	45	55	1	3	2023	0	1	8500	11	116	103	9372/3		2	C506	01

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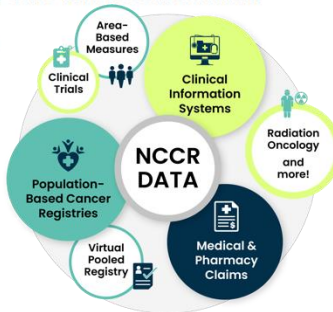
National Childhood Cancer Registry Data Platform

The NCCR Data Platform provides researchers with childhood, adolescent, and young adult cancer data to support in-depth analysis and advance scientific understanding of childhood cancer and survivorship.

About Us

Improving childhood cancer care and research data.

This secure cloud system links data records for the same person across different sources and consolidates them in one place. The NCCR Data Platform makes de-identified data easy to search, request, visualize, and analyze. The Data Platform is part of the Childhood Cancer Data Initiative Data Ecosystem and will be interoperable with other CCDI resources.

[More About Us](#) →

Contact Us

Have questions about the platform? Let's connect!

NCI provides a user guide and FAQs page to help you understand the data and features in the NCCR Data Platform. For any additional questions, please reach out to our help desk directly.

[Contact Us](#) →

Video Tutorials

NCCR Data Platform at a Glance

This tutorial is a great starting point for new users looking to understand the Data Platform, as it provides a broad overview of the platform pages, features, and workflows.

[Browse Frequently Asked Questions](#) →<https://go.nih.gov/2XLVTOV>