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Submit new Data Request

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, and a person is not required to respond to, 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 form to this address.



Use the form 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 in this form 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

Age0-19_Females_Ewing (Age0-19_Females_Ewing)

Data Sources Selected

Consolidated Tumor Case, Pharmacy

Criteria

Age: 0 - 19, Race/Ethnicity: All, Sex: Female, Years of Diagnosis: All

ICCC Major (Level 1): VIII. Malignant Bone Tumors

ICCC (Level 2): (c) Ewing tumor and related sarcomas of bone

ICCC Extended (Level 3): All

View cohort for additional criteria.

All fields are required unless otherwise in noted.

→ Your Information

Name

This field will be publicly displayed.

Johanna Goderre Jones

Institution:

This field will be publicly displayed.

NIH

Email:

johanna.goderrejones@nih.gov

→ Project Information

Project Name

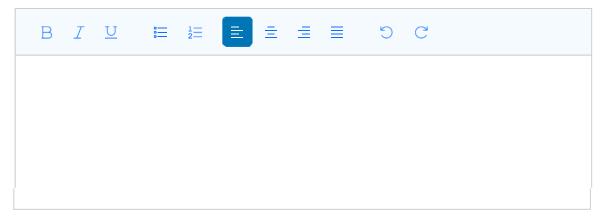
Enter a unique and descriptive project name that will be easy to identify later.

This field will be publicly displayed.

Scientific Research Aims

Briefly describe your proposed research, its aims, and its value to science or public health. (1500 characters max)

This field will be publicly displayed.



0/1500 characters

Research Relevance

Briefly describe how your research will advance a particular scientific field of inquiry. (1500 characters max)

This field will be publicly displayed.

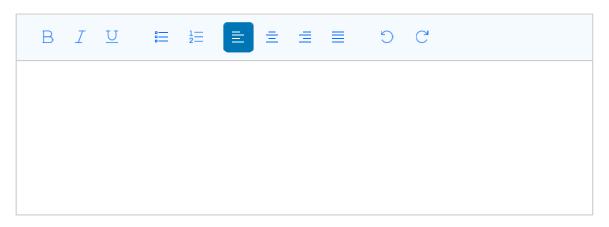


0/1500 characters

Scientific Approach and Analytic Plan

Briefly summarize your analytic plan, including key outcomes of interest. (1500 characters max)

This field will be publicly displayed.



0/1500 characters

Research Areas

This field will be publicly displayed.

- Health disparities
- Methods development
- Research focused on particular cancer diagnosis
- Social/Behavioral
- Population health
- Late-effects of cancer
- ☐ Health services
- Treatment patterns
- Epidemiology

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	Institutional Email	
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
+ Record ID	2 selected
+ Demographic	6 selected
+ Cancer Identification	13 selected
+ Stage/Prognostic Factors	42 selected
+ Treatment-1st Course	22 selected
+ Follow-up/Recurrence/Death	8 selected
+ Edit Overrides/Conversion History/System Admin	2 selected
+ Pathology	1 selected
+ Treatment-Subsequent & Other	1 selected
+ Virtual Pooled Registry (VPR)	3 selected
+ Not Categorized	1 selected

Pharmacy Elements

•	
Field name	Description
9-digit National Drug Code (NDC)	The National Drug Code is a unique 9- or 11-digit number in three segments, denoting the labeler code (manufacturer, re-packager, or distributer), product code (including strength, dosage form, and formulation), and package code (identifying package sizes and types), respectively.
☑ Drug Category	The Drug category is extracted from CanMED's SEER Rx category and classifies the drug into one of five groups: Hormonal Therapy, Chemotherapy, Ancillary Therapy, Immunotherapy, or Radiopharmaceutical.
Months from Index Cancer to Dispense Date	The difference in time from a patient's index cancer date to the first documented dispense date for each drug the patient receives. Calculating this value using the earliest documented tumor date minimizes duplicate pharmacy records for patients who have multiple tumors over many years. Please note that new data updates could potentially revise the initial diagnosis date for a patient, thus changing the months from initial diagnosis to dispense date for a particular drug.

Total: 9 selected

Field name	Description
✓ CanMED Major Drug Class	The Drug class is extracted from CanMED's Major Drug class and denotes the general mechanism of action or group name.
CanMED Minor Drug Class	The CanMED minor class category denotes the overall group that a particular drug is associated with, typically indicating the drugs mechanism of action or broad treatment indication.
CanMED Non- Proprietary Name	Generic name given by the FDA upon drug approval for identification irrespective of branding or proprietary naming as reported by CanMED.
CanMED Proprietary Name	Brand name assigned to a drug by the pharmaceutical company for marketing and identification as reported by CanMED.
Medication Dispense Quantity	The amount of medication that has been dispensed for each prescription. Includes unit of measure. FHIR 2.24.0.6 Quantity; 999=unknown.
Medication Dispense Duration	Identifies the number of days over which the supplied product is expected to be used, or the length of time the dispense is expected to last. Number of days; 999= unknown.

→ 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.

SEER Research Data Use Agreement

SEER Treatment Data Limitations

Best Practices Assurance

National Childhood Cancer Registry (NCCR) Data Use Agreement

Save Draft

Save this request to edit

Continue

Save and go to step two

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: July 25, 2024; cited: August 8, 2024]. Available from http://nccedataplatform.codi.cancer.gov

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Sign up for email updates

Stay updated with the latest information on the Childhood Cancer Data Initiative by signing up for our email updates.



Childhood Cancer Data Initiative

at the National Cancer Institute

Contact Us

nciappsupport@mail.nih.gov

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USA.gov

LAST BUILD 2024-07-25-1517



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Search



Data Request for: test

Your data request was successfully saved



Pending IRB Review

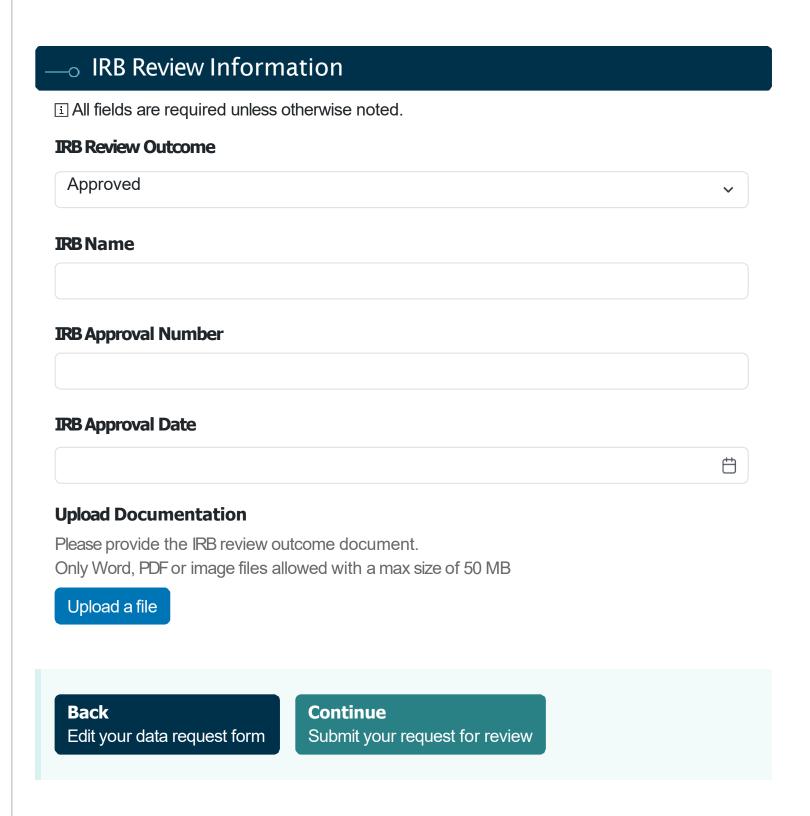
Submit this request to your Institutional Review Board (IRB) for review. After your institution's IRB reviews the request, you can submit it for approval in the NCCR Data Platform. Follow the steps below to complete the submission process.

- 1. Download a PDF copy of your data request.
- 2. Get IRB review (for example, exempt from human subjects research or expedited review).
- 3. Return here from your <u>Data Requests</u> page and submit the IRB review outcome to request NCCR review.

Your Data Request

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

Download the PDF



Your Data Request Summary