Submit new Data Request

OMB No. 0925-0775
Expiration Date: 06/30/2025

1 Complete Form — 2 Submit IRB Review — 3 Pending NCCR Review — 4 Review Complete

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 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

Total: 9 selected

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.

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 later

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://nccrdataplatform.ccdi.cancer.gov

Sign up for email updates

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

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Childhood Cancer Data Initiative
at the National Cancer Institute

Contact Us

nciappsupport@mail.nih.gov

U.S. Department of Health and Human Services
National Institutes of Health
National Cancer Institute
USA.gov

LAST BUILD 2024-07-25-1517

Data Request for: test

Your data request was successfully saved

1 Complete Form — 2 Submit IRB Review — 3 Pending NCCR Review — 4 Review Complete

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 Data Requests 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

IRB Review Information

All fields are required unless otherwise noted.

IRB Review Outcome

Approved

IRB Name

IRB Approval Number

IRB Approval Date

Upload Documentation

Please provide the IRB review outcome document.
Only Word, PDF or image files allowed with a max size of 50 MB

Upload a file

Back
Edit your data request form

Continue
Submit your request for review

Your Data Request Summary