National Childhood Cancer Registry (NCCR) Project

Instructions For Creating the Annual NCCR Registry File for December 2026 Submission

These instructions apply only to registries participating in the NCCR

The National Childhood Cancer Registry (NCCR) aims to build a connected data infrastructure that includes longitudinal data from multiple sources and enables secure sharing and indexing of childhood cancer data with vetted research investigators. These efforts will support childhood cancer research and provide a population-level dataset on childhood cancer patients. As a base for the infrastructure, data currently collected at targeted cancer registries is used to aggregate key information on childhood cancer patients and survivors. The centralized infrastructure is coordinated by the North American Association of Central Cancer Registries (NAACCR). This infrastructure will be integrated into the larger childhood cancer data ecosystem and will serve as a central data index and warehouse for childhood cancer data through scaled data capture from registries and by leveraging existing data sources, through linkages, representing relevant information not routinely captured by registries. The NCCR has the potential to provide real-world evidence to support data-driven clinical guidelines. This data infrastructure will also support a broad range of research questions.

As part of the NAACCR annual Call for Data, NCCR registries will create a single, standardized NCCR registry file. **IMPORTANT NOTE: Only registries that DO NOT use SEER*DMS as a primary registry database are required to create an annual NCCR submission file. All registries must have a signed *SEER*DMS System Interconnection Security and Hosting Agreement (System ISA)* in place with Information Management Services (IMS) specifically for the NCCR prior to submitting the file.**

Timeframe for File Creation: Registries will prepare the NCCR submission file as part of the annual NAACCR Call for Data process. The NCCR submission file should be created after 12-month data (cases diagnosed in 2025) have been submitted to NAACCR, NPCR and/or SEER, but **no later than December 1, 2026**. Producing the NCCR submission file immediately following the Call for Data ensures that all registry files contain comparable timeframes for follow-up and the most complete, high quality, edited data for linkage and data release. **NOTE: Unlike the Call for Data submission, the NCCR submission file contains patient identifiers and will be submitted directly to each registry's secure enclave (SEER*DMS Lite) at IMS.**

Case Selection Criteria: Cancer registries will extract NAACCR Version 26 Type C records for all state resident cases. It is essential that all Type C data items are populated, including patient identifiers. The file must include cases from as far back as possible through 2025.

IMPORTANT NOTE: This is the same XML file generated when preparing the VPR linkage file, <u>but cutoff year must be 2025</u>. NAACCR Prep will be used to limit the file to all tumors associated with patients with at least one childhood or AYA diagnosis between 1995 and 2025 (see NAACCR Prep instructions below).

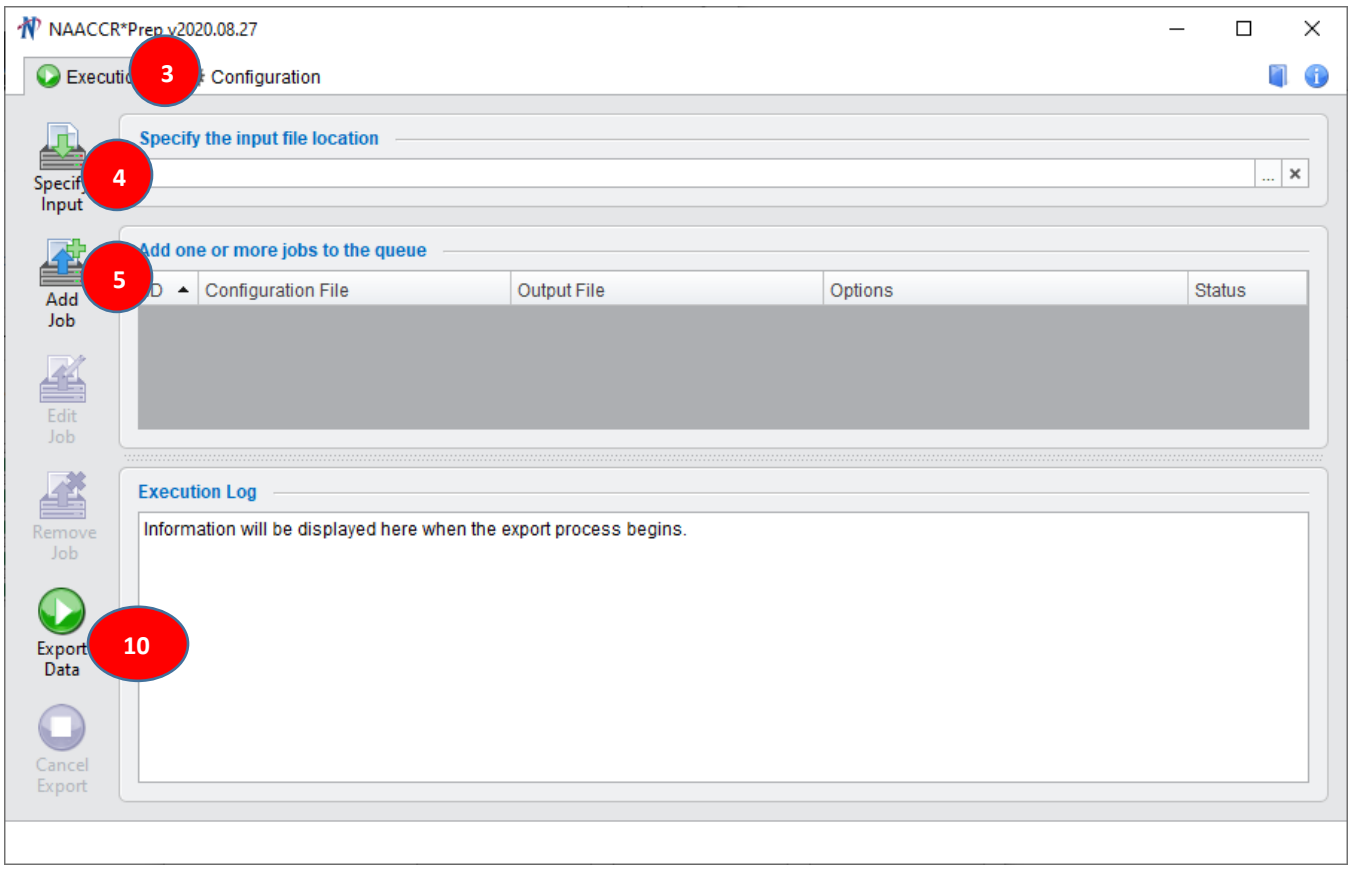
The extract should include all reportable cases routinely submitted in the NAACCR data submission (e.g., in situ, invasive, and benign brain/CNS-prior to 2004 if collected) and include VA cases, DCOs, and cases received through inter-registry data exchange.

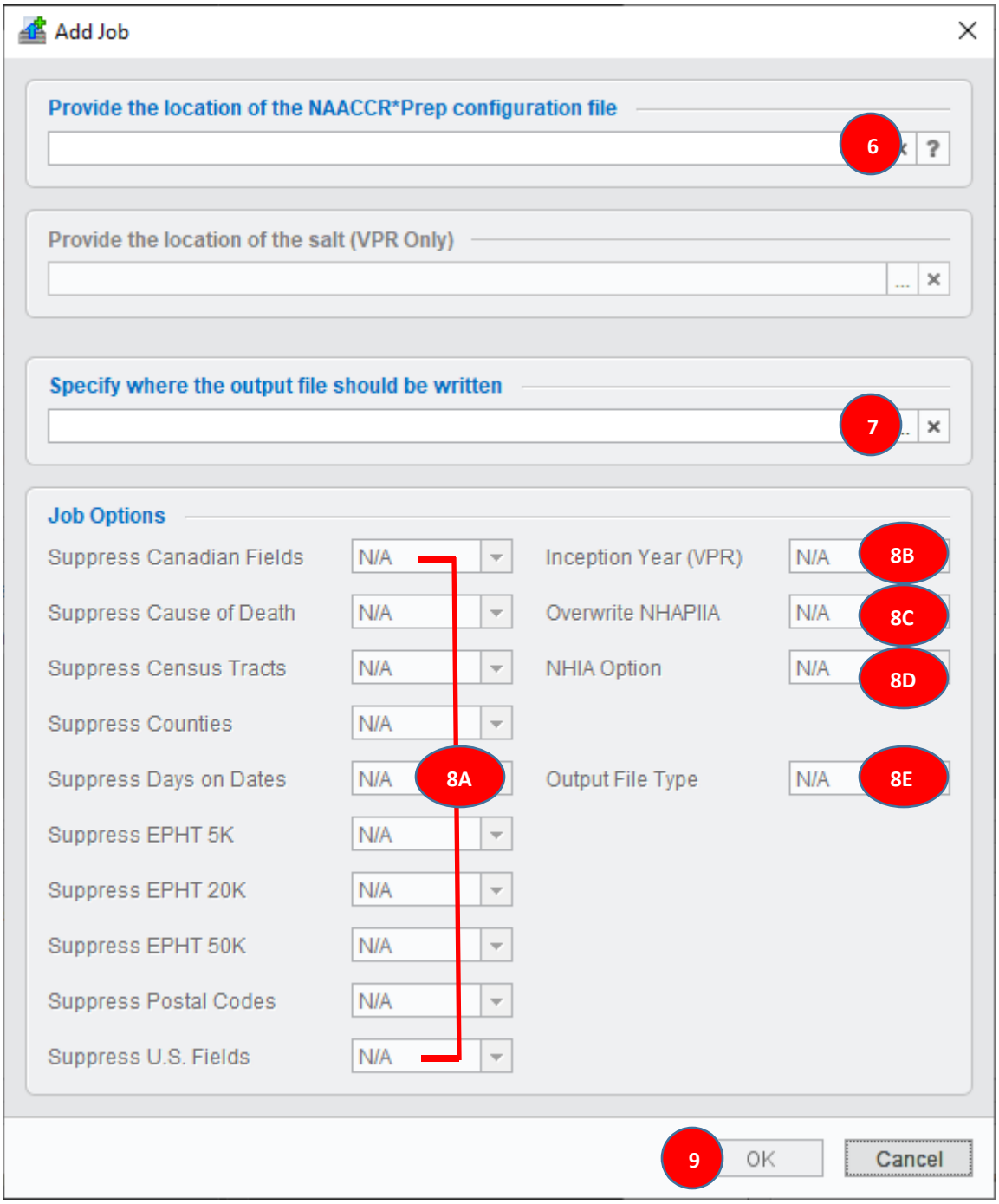
<u>NAACCR Prep:</u> There is a specific configuration file for NAACCR*Prep to create the NCCR submission file. This configuration generates additional fields as needed but does not delete the confidential information, first/last/middle name/SSN/etc, required for the NCCR. NAACCR*Prep will, however, remove the IHS Link variable after calculating a derived race recode as we are unable to share IHS Link with external partners.

Steps for Creating the NCCR Submission File

1. Create a <u>fully populated</u> Type C NAACCR layout file using the Case Selection Criteria listed above. This file must be created using the .XML format. This is the same XML file generated when preparing the VPR linkage file.
    a. For participating NCCR registries not on SEER*DMS or CRS Plus, the registry-defined field for tracking static tumor identifier should be placed in the Registry Defined Tumor ID field [user defined, #9701] when the VPR Linkage File is created. Note that this is a non-standard item. For more information on how to include non-standard items, please see the document "How to Include Non-Standard Data Items" on the NAACCR Call for Data web page.
2. Download NAACCR Prep and the NCCR NAACCR Prep configuration file from the NAACCR Call for Data page.
3. Open NAACCR Prep.
4. Press the button labeled "Specify Input". Browse to the Type C XML file created in Step 1, select the file, then press the "Open" button.
5. Press the button labeled "Add Job". The Add Job dialog box will appear.
6. Provide the location of the NAACCR*Prep configuration file for the NCCR.
7. Specify where the output file should be written. Use the following naming convention to identify your state and diagnosis years when entering the name for the output file: '**XX(state)19952025NCCR**'.
8. By now, several dropdown boxes should be enabled at the bottom of the dialog.
    a. A set of dropdowns on the bottom-left give you the option to suppress certain fields. Registries are encouraged to select "No" for each of these.
    b. Inception Year (VPR): This box will be disabled and can be ignored.
    c. Overwrite NHAPIIA: Choose "Yes" to allow NAACCR*Prep to recalculate any existing values for NHIA or NAPIIA or "No" to keep any existing values.
    d. NHIA Option: Choose "Option 1", "Option 2", or "All records".
    e. Output File Type: Make sure "XML" is selected
9. Press the OK button to close the dialog. The job will be added to the execution queue.

10. Press the “Export Data” button.
11. The zip file that is output by NAACCR*Prep contains several files. We are only interested in the data file. The data file has a .xml.gz extension and should be extracted from the zip file. The other files, and the zip file/container, can be discarded.
12. Review the output data file (the file with the .xml.gz extension) to verify that all Type C data items, including patient identifiers, are populated in the file. File*Pro (available on https://seer.cancer.gov/tools/filepro/) or other text editing tools can be used to view the file content.
13. Send an email to SchusslerN@imsweb.com or CoyleL@imsweb.com to receive a secure link to the IMS secure file exchange.
14. Password protect the .xml.gz file created in Step 11.
15. Upload the password protected .xml.gz file to the IMS Secure file exchange.




Add Job
Provide the location of the NAACCR*Prep configuration file
6
Provide the location of the salt (VPR Only)
Specify where the output file should be written
7
Job Options
Suppress Canadian Fields
N/A
Suppress Cause of Death
N/A
Suppress Census Tracts
N/A
Suppress Counties
N/A
Suppress Days on Dates
N/A
8A
Suppress EPHT 5K
N/A
Suppress EPHT 20K
N/A
Suppress EPHT 50K
N/A
Suppress Postal Codes
N/A
Suppress U.S. Fields
N/A
Inception Year (VPR)
N/A
8B
Overwrite NHAPIIA
N/A
8C
NHIA Option
N/A
8D
Output File Type
N/A
8E
9
OK
Cancel