General Instructions for NAACCR Call for Data Deadline: Midnight Eastern Time Tuesday December 6, 2022

For questions about the NAACCR Call for Data, contact:

Recinda Sherman, MPH PhD CTR NAACCR, Inc. Phone: (217) 698-0800 ext. 6; <u>rsherman@naaccr.org</u>

All Call for Data materials are located on our website: <u>https://www.naaccr.org/call-for-data/</u>

STEP 1: Log in to NAACCR CFD System

Log-in to the Call for Data (CFD) Portal from the *Submit* Tab.

Click the long blue button "Submit Call for Data, Complete CaRI database, Access Data Assessment."

- Prior to November 1, 2022, users will only be able to access CaRI submission section, their Data Assessment section, and only view their older submissions.
- NAACCR Dec 2022 CFD Portal will open no later than November 1st, 2022.

Please ensure registry staff have proper access now. **Do not wait until you are <u>submitting your file to log in</u>**. If you have access issues, please contact Recinda Sherman <u>rsherman@naaccr.org</u>.

NOTE: Also ensure you are the Call for Data listserv to receive any updates throughout the CFD Process. Please contact Tricia Kulmacz <u>tkulmacz@naaccr.org</u> to check your status or add yourself to the CFD listerv.

STEP 2: Duplicate Assessment NEW MATCH*PRO PROTOCOL

The *Duplicate Protocol* is available on the *Documents* Tab.

The duplicate protocol is required for Certification and CiNA. The duplicate protocol must be conducted on <u>all cases</u> included in your registries' inception year to 2021, generally 1995-2021. Please refer to the *Duplicate Protocol* for detailed Match*Pro instructions on the *Documents* Tab. There is also a link to download Match*Pro and the configuration files on the *Tools* Tab.

<u>This year the duplicate protocol is patient level deduplication only.</u> Next year we will require tumor level deduplication. However, we will provide updated Match*Pro

resources to support tumor level deduplication. These updated materials will be uploaded to the NAACCR CFD website Fall 2022.

Once you have resolved as many duplicates as you can, report your Match*Pro frequency information (see page 13 of *Duplicate Protocol Instructions*, Step 19).

NOTE: You may consolidate identified duplicates and re-run Match*Pro as many times as you wish. You will be asked to attest to these counts on the General Information Form in the CFD Portal.

From Match*Pro Frequency Report:

- # of Non-Match
- # of Uncertain
- # of Match

You will also be asked the following:

- *#* of submitted cases
- I have consolidated all MATCH cases (y/n)
- If you have NOT consolidated all MATCH cases, how many are not consolidated?

Your Duplicate % will be: (# of unconsolidated MATCHS + # UNCERTAIN) divided by # of submitted cases

For questions about Match*Pro Duplicate Protocol, please contact Will Howe at <u>howew@imsweb.com</u>.

<u>STEP 3</u>: Create Submission File(s)

Create a single data file with all reportable cancer incidence cases for residents of your coverage area, who were diagnosed from 1995 through 2020. 2021 data are also being requested to be used for evaluation purposes only, including delay modeling and early assessment of the continuing impact of Covid-19 on our data. We strongly encourage you to submit the 2021 data, but this submission does not impact Certification or inclusion in CiNA products. 2021 data may be included in the submission file or submitted as a separate file as late as January 31, 2023.

We strongly recommend a full, confidential record dataset be used to create your submission file as NAACCR*Prep will remove variables not requested.

Submission Files

Registries should create a file that includes the data items listed in the excel document *Certification and CiNA Call for Data Items* available on the CFD *Documents* Tab.

A column indicates "New this year" data items, so double check they are in your initial file pull. A column also indicates "Required to derive but not submitted." These are data items that *must* be included in the initial file submitted to NAACCR*Prep, as

they are necessary to generate derived variables. However, they will be removed by NAACCR*Prep and *will not* be submitted to NAACCR for Certification or CiNA. Again, we strongly recommend a full, confidential record dataset be used to create your submission file to ensure all requested variables are included. NAACCR*Prep will remove all variables not on the *Certification and CiNA Call for Data Items* list AND remove all variables required to derive but not submit. Registries also have the choice within NAACCR*Prep to further suppress some requested variables.

- Data submitted must adhere to the NAACCR standard definitions and codes.
- All cases as defined in the document *Data Selection Criteria* for each diagnostic year should be included on the file, regardless of whether they are reportable in only some of the years.
- Data must be submitted in NAACCR Record Layout Version 22, XML data exchange standard. Refer to the Standards for Cancer Registries Volume II, version 22 (<u>https://www.naaccr.org/datastandards-data-dictionary/</u>) and (<u>https://www.naaccr.org/xmldata-exchange-standard/</u>) for details.
- **NEW**: New this year for the area-based variables and survival variables derived in NAACCR*Prep, there are links in the *Certification and CiNA Call for Data Items* excel spreadsheet to additional documentation.
- **NEW:** New this year we are requesting census tract for evaluation purposes only. This year's DAA has been updated with additional data security protocol information for both the standard submission as well as the census tract submission. Registries may opt to suppress the census tract fields in NAACCR*Prep.
- **NEW:** New this year we are requesting two geocoding quality fields generated by the NAACCR Geocoder (Micro Match Status & Penalty Code).
- If you are able, you may submit these variables in your main submission file. You will need to review the additional instructions *How to Include Non-Standard Data Items Instructions* available on the *Documents* Tab.
- Alternatively, you can submit these two variables as a csv file along with a patient/tumor ID. NAACCR will link the two variables to your data after submission.

STEP 4: Run NHAPIIA (US Only)

U.S. registries should run the NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm on all cases submitted. NHAPIIA is incorporated into NAACCR*Prep. *We recommend using the NAACCR*Prep utility to generate the NHAPIIA fields*.

To run NHAPIIA in NAACCR*Prep, include the NAACCR items 2230, 2240 and 2290 (first, middle and last name) in the NAACCR*Prep input file. These fields will be used

to derive the variables but will be deleted from the NAACCR*Prep output/submission file.

If NHAPIIA is run outside of NAACCR*Prep, it is recommended that registries use Option 1, the current default for NAACCR*Prep. This setting limits the Spanish surname portion of the algorithm in counties that are less than 5% Hispanic to cases coded as surname only (item 190=7) or unknown whether Hispanic (item 190=9).

As part of submission Step 9, registries enter setting they selected—if another option is used, the registry will need to provide a rationale on the General Information Submission Form. If your registry software incorporates NHIA/NAPIIA, please specify the version on the General Information Submission Form.

<u>STEP 5:</u> Run Edits

Edits Metafiles will be available on the *Tools* Tab on or before the target date of September 30, 2022.

a) Select the edit set that matches your submission

All edit errors on data items reviewed for Certification or included in CiNA submission must be reconciled prior to submission. The edits are based on the version 22 EDITS metafile releases. For questions about Edits, please contact Jim Hofferkamp at <u>jhofferkamp@naaccr.org</u>.

| Type of Submission/Type Registry | Edit Set |
|-------------------------------------|-----------------------------|
| NAACCR Certification Edits-US, 2020 | NAACCR Certification Edits |
| NAACCR CiNA-Canada, 1995-2021 | NAACCR CiNA Edits-Canada |
| NAACCR CiNA-US, 1995-2021 | NAACCR CiNA Edits-US if not |
| | submitting to NPCR |
| NAACCR CiNA-US, 1995-2021 | NAACCR CiNA Edits-US if |
| (excluding NPCR CFD Edits) | submitting to NPCR |

The edit sets use NAACCR standard definitions and are based on submission of all requested data items. **WARNING!** If you choose not to submit a data item, you may get errors because of blank fields. If you like, you can turn these edits off. Be aware that we run EDITS on your submitted files and use our results to determine Registry Certification status and fitness of the data for various uses. If the submission type requires a variable, then the variable must be 100% error-free.

Canadian registries use the Canadian Edit set regardless of which submission file type. US registries can save some time by running the NPCR edits first and then the NAACCR edits using *NAACCR CiNA-US*, *1995-2021 (excluding NPCR CFD Edits)*. Running the edits this way avoids running the same edit multiple times. Registries that do not submit to NPCR must us the Canadian or full US edits set, as applicable.

b) Run Inter-Record Edits

Run the Inter-record edits <u>after</u> running the main Edits Metafile. Please resolve all errors. Once all edits have been corrected, move on to Step 6. Registries are not required to re-run the NAACCR submission file generated by NAACCR*Prep through edits.

NOTE: There is no combined NAACCR/NPCR edit set. All materials necessary for NPCR submission will be provided by NPCR. U.S. registries submitting data to both NPCR and NAACCR will need to use different edit sets for each agency's CFD.

NOTE: Only one error free edit run is necessary. Submission of an edit summary report is not required.

NOTE: The 2021 data is for evaluation purposes and assessment of continuing Covid-19 impact on cancer reporting only. The 2021 cases should be as clean as is practical but do not need to be error-free.

<u>STEP 6:</u> Create Output File(s)

NAACCR*Prep is available on the *Tools* Tab. NAACCR*Prep and the associated materials will be available on the Call for Data page on or before the target date of October 3, 2022.

The NAACCR*Prep program generates the derived variables and generates the submission file. Derived variables include the survival variables for all registries, and the area-based social measures (RUCA, URIC, poverty codes, and Yost) and NHAPIIA for U.S. Registries. The program automatically strips specific fields from your submission file after the derived fields are developed. The variables that are automatically stripped during processing include census tract codes, name fields, day of diagnosis and day of last follow up. If your state requires, you can also strip county of residence from the NAACCR file and cause of death.

For registries using NAACCR*Prep:

- The file should be free of edit errors prior to running the NAACCR*Prep utility (see steps 5).
- In order for NAACCR*Prep generate the derived fields, all the "Required to derive but not submitted" fields as indicated on *Certification and CiNA Call for Data Item* spreadsheet must be included in the input file including NAACCR items 110, 130, 364, 365, 2230, 2240, 2390. These variables *will not be included* in the output file submitted to NAACCR. All dates associated with survival will have day suppressed unless the user removes the default option.

The *Certification and CiNA Call for Data Items* spreadsheet available on *Documents* Tab has additional information about the fields generated in NAACCR*Prep: the calculated survival variables and the geographic-based measures (U.S. only), including the supplemental variables to create the YOST SES Index and minority-specific SES.

NEW: If you are unable to include the geocoding quality fields, Micro Match Status and Penalty Code in your regular submission file, you will need to provide a supplemental csv file. This file should <u>only</u> contain the linking variables

(patientID/tumor ID) and the two data quality variables. SEER*DMS users will have these variables in their registry data and will be able to include in your regular submission file. Other registries that access the NAACCR Geocoder via an API may have these variables in their registry data to include in their regular submission file. If this is the case, you will need to review the additional instructions How to Include Non-Standard Data Items Instructions available on the Documents Tab.

Registries that use the batch match, on-line version of the NAACCR Geocoder can submit a modified csv file based on the csv file output by the geocoder. Just ensure the linking variables (PatientID/TumorID) and the 2 data quality variables () are included and delete <u>all</u> other variables. This limited csv file is then your submission file.

NOTE: The two data quality variables are only generated by the NAACCR Geocoder. We **strongly encourage** all registries to use the NAACCR Geocoder to geocode their data as well as follow the geocoding recommendations included at the bottom of the *Certification and CiNA Call for Data Items* spreadsheet available on the CFD *Documents* Tab.

<u>STEP 7:</u> Name Output File(s)

Create **one** data file for your NAACCR submission. For example, if submitting 1995 through 2021 data, the output file should be labeled using the naming convention

SS9521v22.xml

where SS is the two letter postal code for your registry, followed by the years of data submitted, followed by the NAACCR version layout. For example, Vermont submitting data in NAACCR version 22 for the years 1995-2021 would create a file named V**T9521v22.xml**.

If you must submit multiple submission files, use the same naming convention. Using the Vermont example, a Certification only submission would be *VT2020v22.xml* and the 12-month data submission would be *VT2021v22.xml*.

NOTE: *NAACCR*Prep* will create a zip file for you with the proper extensions.

NEW: If you are submitting a separate CSV file with the geocoding quality variables, Micro Match Status and Penalty Code, follow the same naming convention. Using the Vermont example, a separate geocoding quality variable submission would be **VT9521v22.cvs**.

<u>STEP 8:</u> Compress Data File(s)

NAACCR*Prep outputs a zipped file. If you choose not to use NAACCR*Prep or you are submitting a separate csv file with the geocoding quality variables, you must compress the data file with 7-Zip, WinZip, PKZip, or Gzip. Gzip is the preferred method for compression. Gzip executables for Microsoft Windows and other operating systems are available for free at http://www.gzip.org/#exe.

NOTE: If you wish to review your NAACCR*Prep output file prior to submission, NAACCR*Prep can create a csv file for review or you can use the resources available on the Tools Tab under "Convert Between XML and Flat File." You can also use File*Pro to view your submission file.

STEP 9: Submit Submission File(s)

The CFD Submission Portal will be open no later than November 1, 2022 and is accessed from the *Submit* Tab.

- Click the long blue button "Submit Call for Data, Complete CaRI Database, Access Data Assessment" on the Submit Tab.
- Click "*Submit the 2022 Call for Data*" in the 2022 CFD Box **NOTE**: If the box still says 2021, it has not yet opened for the December 2022 submission.
- Click on "*File Submission Forms*" complete the form and upload your file(s).
- Once this step is complete, this section will show as checked on the dashboard.

STEP 10: Complete Submission Forms

Complete all of the electronic submission forms in the CFD Submission Portal by **December 6, 2022**.

- From within the CFD Submission Portal, click on links "*General Information*" and "*Process Verification & Vital Status Follow-Up*" and "*VPR-CLS File Log (all US registries*)" to complete the relevant forms.
- As you complete this information, these sections will show as checked on the dashboard.

<u>STEP 11:</u> Review, sign, and submit the NAACCR Call for DUA and Consent Forms and mark COMPLETE

Review, sign, and submit the DAA and Consent Forms in the CFD Submission Portal **by December 6, 2022.**

- From within the CFD Submission Portal, click on link "*Sign DAA and Consent Forms*" to sign the forms via DocuSign. DO NOT DOWNLOAD THE VERSION AVAILABLE FOR REFERENCE ON THE DOCUMENTS TAB.
- As you complete this information, this section will show as checked on the dashboard.
- Once all the forms are signed and submitted, and all the 4 sections (*File Submission Forms, General Information, Process Verification & Vital Status Follow-Up, and Sign DAA and Consent Forms*) are checked, **please mark your** <u>call for data as COMPLETE.</u>

NOTE: Registries have the option to e-sign using the industry standard, DocuSign, or download, sign, and upload all submission documents that require a signature.

Follow the instructions on the Submission Site. If you download, sign, and upload – please indicate "Signed on paper" on so that it can be appropriately tracked.

NOTE: Occasionally, a registry needs to make a small change to the DAA. This can be done by downloading the DAA. If your registry is required to do this, please indicate the "DAA Has Modifications" so it can be appropriately tracked.

NOTE: *If you submit 2021 data after your regular submission, you may need to contact NAACCR (<u>rsherman@naaccr.org</u>) to "Unlock" your Submission.*

Checklist of materials requiring signed approval:

- ✓ NAACCR, Inc. Call for Data Assurances Agreement
- ✓ ACS Facts and Figures [US Only] Active Consent
- ✓ Medullary Thyroid Cancer [US Only] Active Consent
- ✓ CiNA Public Use Dataset—Passive Consent
- ✓ American Lung Association [US Only] Passive Consent
- ✓ Delay Adjustment—Passive Consent
- ✓ The Affordable Care Act and Cancer Stage at Diagnosis [US Only] Passive Consent

<u>STEP 12:</u> CaRI (Cancer Registry Information) Database

After other CFD requirements are complete, please log into the CFD Submission Portal on the *Submit* Tab to review, update, and/or enter the registry information for the CaRI database **by January 31, 2023**. This step is for both US and Canadian Registries.

This database captures essential information on cancer registry data. The system is populated by cancer registry staff and reviewed annually at a minimum. The data is publicly available in a queriable format here: <u>https://www.naaccr.org/caridatabase</u>. If you have any questions, please contact Recinda Sherman <u>rsherman@naaccr.org</u>.

Once logged in to the CFD Portal, click "*Enter registry information into the CaRI Database*" in the top right box. Once your entry or update is complete, click on the "*Mark as reviewed*" button. To review and create specific queries of the data, go to the public site at: <u>https://www.naaccr.org/cari-database</u>.

NOTE: Most registries input information in previous years. Those registries will only need to review and update if needed <u>**but still need**</u> to "Mark as reviewed."

<u>STEP 13:</u> Create VPR-CLS File (US Registries Only)

After all other Call for Data requirements are complete, please create your linkage file for the Virtual Pooled Registry Cancer Linkage System (VPR-CLS) **by January 31**, **2023 (U.S. Registries only).** Upload your log file created in NAACCR*Prep that is to be uploaded under the *VPR_CLS File Log* section of *Submission Forms*.

VPR-CLS is a voluntary NAACCR initiative to facilitate and streamline the process of linking research cohorts with multiple cancer registries. We ask that all registries create the VPR-CLS File at same time to ensure comparable timelines for follow-up.

While this is a voluntary step, we request **all** U.S. Registries to create this file during the Call for Data regardless of participation in the VPR-CLS to support potential, national initiatives, such as the Camp Lejeune Cancer Incidence Study which linked with all U.S. states, DC, and PR—but was not part of the VPR-CLS.

Detailed instructions for creating the VPR-CLS linkage file are on the *Documents* Tab. If you have any questions, please contact Castine Clerkin <u>cclerkin@naaccr.org</u>. Also please review the *How to Include Non-Standard Data Items Instructions* on the *Documents* Tab if you are including the "restrictedRelease" variable in your file.

NOTE: This VPR-CLS file will not leave your registry. Any linkage conducted will be behind your registry firewall.

<u>STEP 14:</u> Create National Childhood Cancer Registry (NCCR) Submission File (US, NCCR Participating Registries Only)

NCCR participating registries who are also SEER registries will have IMS submit the NCCR file on behalf of the registry. NCCR participating registries who are not SEER registries will create and submit their own submission file.

NCCR Submissions are due to the NCCR submission site **DECEMBER 6**, **2022**. Detailed instructions for creating and submitting the NCCCR file are located on the *NCCR Submission Instructions* file on the *Documents* Tab.