# General Instructions for NAACCR Data File Submissions

NAACCR Call for Data Deadline: Midnight Eastern Time December 1, 2016

#### For questions about the NAACCR Call for Data, contact:

Jim Hofferkamp, CTR NAACCR, Inc.

Phone: (217) 698-0800 ext 5

Fax: (217) 698-0188 jhofferkamp@naaccr.org

#### For technical questions about sending the data file, contact:

Rick Firth Information Management Services, Inc. (IMS) 6110 Executive Blvd. Suite 310 Rockville, MD 20852 Phone: (301) 628-1282

firthr@imsweb.com

#### **Location of all Call for Data Materials:**

To find the forms and instructions, go to <a href="www.naaccr.org">www.naaccr.org</a>. In the menu at the top, go to Data and Publications and then Call for Data or click on the link below.

## http://www.naaccr.org/DataandPublications/CallforData.aspx

Please read all the enclosed materials carefully. If you decide to participate in the Call for Data and/or Registry Certification, complete forms on the NAACCR website, and if you cannot submit an electronic signature, please fax or scan and email those requiring a signature to Jim Hofferkamp.

The tasks for data submission follow. If you are submitting data only for Registry Certification, you may skip the steps 3, 6 and 11 described below.

Create one data file of all reportable cancer incidence cases by December 1, 2016 for
residents of your coverage area, who were diagnosed from 1995 through 2014. In addition,
2015 data are also being requested to be used for evaluation purposes only and does not
impact certification or inclusion in CiNA products.

The list of requested data items for all uses and for a submission for Registry Certification only is available in the document *Certification and CiNA Call for Data Items*.

#### • Submission files

- U.S. registries submitting data to both NPCR and NAACCR may create a single submission file containing all data items requested for both CDC-NPCR and NAACCR for steps 2-7. NAACCR is requesting three data items not requested by CDC-NPCR. These data items are:
  - County at DX Geocode1990
  - County at DX Geocode2000
  - County at DX Geocode2010
- 2015 data may be submitted as a separate file and as late as January 31, 2017 at your option.

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- U.S. registries not submitting to NPCR should create a file including the data items listed in the document titled Certification and CiNA Call for Data Items.
- o All files should be run through NAACCRprep prior to submission.
  - In order for NAACCRprep to generate length of survival (all registries) and, for U.S. registries, derive Rural Urban Continuum Codes (Beale codes, RUC, and RUCA), Census Tract Poverty Indicator variables, the file will need to include the data items **Census Tract 2000 and 2010 variables** [NAACCR items 130 and 135]. Census Tract 2000 and 2010 variables will not be included in the output file submitted to NAACCR. See step 6.
  - In order for NAACCRPrep to generate the NAPIIA and NHIA variables, the input file must contain the following fields:
    - Name--Last (Data Item 2230)
    - Name--First (data Item 2240)
    - Name—Maiden (Data Item 2390)

These fields will not be exported to the NAACCR or NPCR submission files.

- Canadian registries should create a file including the applicable data items listed in the document titled *Certification and CiNA Call for Data Items*. This file should be run through the NAACCRprep utility prior to submission (see step 6).
- Data submitted must adhere to the NAACCR standard definitions and codes.
  - All cases as defined in the document Data Selection Criteria Based on Case
     Reportability 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 16. Refer to the Standards for Cancer Registries Volume II, version 16 for details.
  - o If your registry is still in version 15, you will need to run the conversion utility provided by NPCR for both NPCR and NAACCR. To convert from version 15 to version 16 use the NPCR utility developed for this purpose. Be sure to the appropriate edit set on the converted file. This conversion utility is downloadable at the link below:
    - http://www.cdc.gov/cancer/npcr/tools/registryplus/up\_download.htm.

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- If your registry is unable to submit a file in version 16 please contact Jim Hofferkamp ihofferkamp@naaccr.org.
- NAACCR is seeking volunteers to submit their file in an .xml format. If interested, please contact Recinda Sherman at <u>rsherman@naaccr.org</u> or 217 698 0800 x 6.
- Perform the Duplicate Assessment Protocol on 2014 cases for Registry Certification <u>and</u> on 1995 through 2014 cases for CiNA. A third duplicate protocol should be performed on 2015 cases.

The duplicate protocol is required for certification and for inclusion in any use requiring high quality data assessments. Instructions for performing this step are included in the document *Duplicate Protocol Combined Years Call for Data*.

**IMPORTANT:** If you are submitting for both CiNA and Registry Certification, you must conduct the duplicate protocol two times: once, on the 1995-2014 cases and the second time, on 2014 cases only. If you are not submitting all years, 1995-2014, for CiNA, perform the protocol on ALL the data years you are submitting. A duplicate protocol must also be performed on 2015 cases in order for evaluation of the data to take place.

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# 3. U.S. registries should run the NAACCR Hispanic and Asian/Pacific Islander Identification Algorithm on all cases submitted.

The Hispanic Identification Algorithm, version 2.2 (NHIA v2.2.3) and the NAACCR Asian Pacific Islander Identification Algorithm, version 1.2 (NAPIIA v1.2.2) algorithms are combined into one SAS program, called NHAPIIA, for your convenience. Instructions for applying these algorithms are available on the NAACCR call for data <u>website</u>.

For the 2017 Call for Data, the NAACCRprep utility has been updated to generate these fields, avoiding the need for this separate step. Just include the NAACCR items 2230, 2240 and 2290 (first, middle and last name) in the NAACCRprep input file. These fields will be used by the algorithm then deleted from the NAACCRprep output file.

If you elect to run NHIA/NAPIIA outside of NAACCRprep it is recommended that registries use option 1, the current default for the SAS routine. 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). Registries selecting some other option are asked to note which option they selected and to provide a rationale for using another option. Questions asking which option you choose will be included in the electronic submission pages (see instructions #10 below). If your registry software incorporates NHIA/NAPIIA, please specify the version on the Verification Form.

4. Run the edit set appropriate for your submission and the NAACCR format being submitted. Select the intra-record edit set that matches your submission. Only one intra-record edit run is necessary. In particular, if submitting to NPCR and NAACCR, run the Combined NPCR NAACCR edits against a file with all of the data items requested by NAACCR and NPCR. Once all edits have been corrected, use NAACCRPrep to create both the NPCR and NAACCR submission files.

Type of Submission/Type Registry	Edit Set
Certification only/All	NAACCR Certification Edits
Certification & CiNA/U.S. not Submitting to NPCR	NAACCR CINA Edits
Certification & CiNA/U.S. Submitting to NPCR	Combined NPCR NAACCR Edits
Certification & CiNA/Canadian	NAACCR CiNA EDITS-Canadian

The EDITS metafiles can be downloaded from the NAACCR Call for Data website with instructions for running the EDITS and Gen EDITS Plus programs. To be included in any use of the data, you must resolve every error and report the number of errors that could not be resolved and remain on the submitted file (use the EDITS Form). The edits are based on the version 16 EDITS metafile releases.

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 specific use of the file requires a variable to be present, then the variable must be 100% error-free. Note that the 2015 data is for evaluation purposes only. The 2015 cases should be as cleaned up as is practical but does not need to be error-free.

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Submission of an edit summary report is not required.

#### 5. Run the Inter-record EDITS Utility.

This application must be run *after* running the intra-record edits described above. Please resolve all errors.

#### 6. Generate Derived Variables using the NAACCRprep utility.

The NAACCRprep program can be downloaded to run against the processed data file to generate length of survival (all registries) and, for U.S. registries, derived Rural Urban Continuum Codes (Beale codes, RUC, and RUCA), Census Tract Poverty Indicator variable, and the NHAPIIA variables. The program can be instructed to strip specific fields from your submission file after these derived fields are developed The variables that can be stripped during processing include census tract codes, name fields, NPCR variables (BCCEDP MDE Link), day of diagnosis and day of last follow up. If your state requires, you can also strip residence county from the NAACCR file..

- The SAS program developed for NAACCRprep is available for download. The processed file may also be run through SEER\*Edits in order to generate the data items. In addition, your central registry software vendor may include the algorithm in your call for data programs.
- For those registries using NAACCRprep:
  - The file should be free of edit errors prior to running the NAACCRprep utility (see steps 4 &5).
    - The output file generated by NAACCRprep does not need to be run against the GenEDITS file prior to submission. However, if a registry elects to run edits against the NAACCRprep output file, the NAACCR CiNA Edit set should be used on the file being submitted to NAACCR and the NPCR Call for Data Edits set should be run on the file being submitted to CDC-NPCR. Do not run the Combined NAACCR NPCR Edits set on the output file.

# 7. Create Your Data File.

Create *one* data file for your NAACCR submission. For example, if submitting 1995 through 2015 data, the file should be labeled using the naming convention of ss9515v16.dat

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, Montana submitting data in NAACCR version 16 for the years 1995-2013 would create a file named mt9513v16.dat. The file should have a record length of 3,339 characters.

## 8. Compress Your Data File

Compress the data file with WinZip, PKZip, or Gzip. Gzip is the preferred method for compression. Gzip executables for Microsoft Windows and other operating systems are available at <a href="http://www.gzip.org/#exe">http://www.gzip.org/#exe</a>.

#### 9. Transmit Your Data File

The preferred method to transmit data to IMS is through the internet using a secure, 128-bit, encrypted link (<a href="https://www.naaccr-cina.org">https://www.naaccr-cina.org</a>). If you do not recall your login information, click on the "forgot your password?" link on the home page. If you have an updated e-mail address from last year and don't recall your password, or have never submitted data, please contact

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Rick Firth at (310) 628-1282 or via e-mail firthr@imsweb.com.com to have a password assigned. Be sure to include your Registry's name.

IMS can also retrieve data from your registry's FTP site using an Internet access. Contact Rick Firth to make the arrangements. You may also mail your file on a CD to Rick Firth using the mailing address information on page 1 of the "General Instructions for NAACCR Data File Submissions."

# 10. Please complete all the forms on the NAACCR website for your registry's data submission by December 1, 2016.

The submission forms can be found at

http://www.naaccr.org/Applications/CallforData/Default.aspx . The Registry Main Contact may use their MyNAACCR username and password to open and complete the forms. The main contact may assign another individual the rights to complete the forms on their behalf. A submission is only completed when the submit button is pressed for each form. The user may make changes to the form after submission until December 1, 2016. If changes need to be made after that, contact Jim Hofferkamp.

## 11. Review, sign, and fax (or email) the NAACCR Call for Data Assurances Agreement.

The agreement is available on the NAACCR website and should be sent to Jim Hofferkamp by December 1, 2016. Please note that in addition to the authorization for inclusion in CiNA, the CFD Data Assurance Agreement includes consent forms for specified secondary uses of the data (see #12 below).

## 12. Checklist of materials requiring hard copy submission.

Remember to fax or scan and email the necessary forms listed below to NAACCR, as appropriate. Signed forms must be sent to Jim Hofferkamp at fax number (217) 698-0188 or scanned and emailed to jhofferkamp@naaccr.org.

- NAACCR, Inc Call for Data Assurances Agreement
   Receipt of form authorizing use is required for inclusion in CiNA
- CiNA Public Use Dataset—Case Listing (Exporting from SEER\*Stat Allowed)—Active Consent
  Receipt of form authorizing use is required for inclusion in the new Public Use Dataset that allows
  case listing (exporting) out of SEER \*Stat. Please see <u>Appendix A. Description of \*NEW\* CiNA Public</u>
  <u>Use Dataset</u> for additional information.
- CiNA Public Use Dataset—Case Listing (Exporting from SEER\*Stat NOT Allowed)—Active Consent
  Receipt of form authorizing use is required for inclusion in the new Public Use Dataset that DOES
  NOT allow case listing (exporting) out of SEER \*Stat. Please see <u>Appendix A. Description of \*NEW\*</u>
  <u>CiNA Public Use Dataset</u> for additional information.
- ACS Facts and Figures [US Only] Active Consent for Secondary Use Receipt of form authorizing use is required for inclusion in this secondary use
- Medullary Thyroid Cancer Verification- Active Consent for Secondary Use
   Receipt of form authorizing use is required for inclusion in this secondary use
- CiNA Plus in SEER\*Stat Passive Consent for Secondary Use

  Receipt of form not authorizing use is required for exclusion from secondary use
- NCI Delay Adjustment Passive Consent for Secondary Use
   Receipt of form not authorizing use is required for exclusion from secondary use
- CiNA Deluxe File for use by ACS for routine inquiries Passive Consent for Secondary Use Receipt of form not authorizing use is required for exclusion from secondary use

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13. Review and update the revised Registry Research Information Database for your registry between November 1 and December 1, 2016.

An electronic form will be made available on the NAACCR call for data Website that will allow you to review and update information on your registry at <a href="http://www.naaccr.org/Applications/RRIDB/Default.aspx">http://www.naaccr.org/Applications/RRIDB/Default.aspx</a>

14. After other Call for Data Requirements are complete, please create your linkage file for the Virtual Pooled Registry-Cancer Linkage System (VPR-CLS) between December 1, 2016 and January 31, 2017 (U.S. Registries only). VPR-CLS is a voluntary NAACCR initiative to streamline the process of research cohort linkage among multiple cancer registries as well as deduplication among central cancer registries. The VPR-CLS file cases should match your call for data cases plus your 12 month (2015) cases. Your registry may choose to conduct linkages on a case-by-case basis. Specific instructions are included with the Call for Data materials. If you have any questions, please contact Castine Clerkin <a href="mailto:cclerkin@naaccr.org">cclerkin@naaccr.org</a>.

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