Call for Data 1995-2017 Instructional Webinar

SEPTEMBER 4, 2019

1

NAACCR

Q&A

Please submit all questions concerning the content of the webinar through the Q&A panel

- Submit questions immediately
- Questions will be addressed at the end of the presentation.

If you experience technical difficulties please call us at 217 698 0800 x 111

2

NAACCR

Presenters

Recinda Sherman, PhD, CTR
- Program Manager, Data Use & Research, NAACCR

Don Green, BS
- System Analyst, IMS

Castine Clerkin, MS, CTR
- Program Manager Virtual Pooled Registry Project

3

4

NAACCR 2019 Call for Data DX years 1995-2017

DUE TUESDAY DECEMBER 3RD, 2019

5

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Overview

General Instructions (Recinda Sherman)

NAACCRPrep (Don Green)

Edits (Recinda Sherman)

Data Use & MISC (Recinda Sherman)

CaRRI Database (Castine Clerkin)

VPR-CLS Linkage File (Castine Clerkin)

6

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INFORMATION FOR THE NAACCR CALL FOR DATA

Call for Data Letter – 09/03/19

Each year, NAACCR has a Call for Data for its certification process and to produce a new set of Cancer in North America (CINA) data products.

The NAACCR Data Use and Research and the Data Evaluation and Certification Committees invite you to submit incident cancer cases from your registry for the years 1995 through 2017 to be used for cancer statistics, surveillance, and research projects and activities. All data must be submitted using the **NAACCR Record Layout Version 18.**

CALL FOR DATA INSTRUCTIONAL WEBINAR

Webinar Coming Wednesday, Sept. 4

General Instructions

RECINDA SHERMAN, NAACCR

NAACCR

Dates

Submissions due by midnight EST December 3, 2019 (Tuesday)

Submissions accepted in Version 18, XML

https://www.naaccr.org/call-for-data/

All documents available now

All tools available on or before October 15, 2019
- NAACCRPrep, SAS programs

Call For Data Submission Site opens Nov 1, 2019

12 Month, CaRRI, VPR-CLS due by January 31, 2020

8

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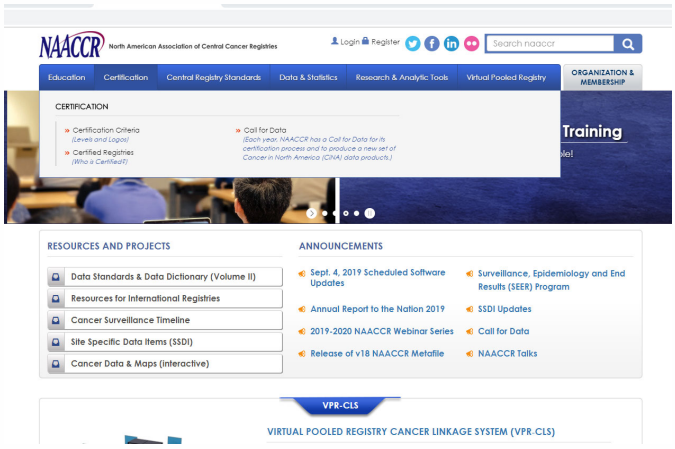
Website: https://www.naaccr.org/call-for-data/



9

CFD Documents | Data Tools (NAACCRPrep and Edits) | Submit

*The date of latest update is listed below

- General Instructions – 09/03/19
- Certification and CiNA Call for Data Items – 09/03/19
- Duplicate Protocol – 09/03/19
- Data Assurance Agreement -09/03/19
- Data Quality Criteria – 09/03/19
- Data Selection Criteria – 09/03/19
- Instructions for Pulling Virtual Pooled Registry Cancer Linkage System File – 09/03/19
- CaRRI Database Registry Instructions – 09/03/19

SUPPLEMENTAL INFORMATION

Please note that NAACCR Prep may fail if it encounters certain non-printable/special characters in your data file. If that happens, ple
Sherman rsherman@naaccr.org. She will provide you with a SAS program that will replace non-printable/special characters with spa

Resolved

- Area Based Social Measures – 09/03/19
- RUCA and URIC Data Item Description– 09/03/19
- Derived County v18 Instructions for Coding – 09/03/19
- Converting NAACCR V18 XML Files to V18 Flat Text Files – 09/03/19

10

CFD Documents | Data Tools (NAACCRPrep and Edits) | Submit

*The date of latest update is listed below

- NAACCR Prep – (Coming Soon)
- NAACCR Call for Data Edits Metafile – 09/03/2019
- EditWriter 5 and GenEDITS 5 Software – Link to External Site
- Inter-Record (IR) Edits (Coming Soon)
- NAACCR Method to Estimate Completeness Workbook 1995-2016 – 09/03/19

SAS PROGRAMS

The SAS programs listed below are included in NAACCRPrep. They have been posted to give central registry software developers the option to incorporate these programs into their software. If your software does not include these programs, please run your file through NAACCRprep prior to submission.

- NHAPIIA – (Coming Soon)
- Poverty and Census Tract Linkage SAS Program – (Coming Soon)
- Rural Urban Linkage SAS Program – (Coming Soon)
- YOST SES Index Linkage SAS Program – (Coming Soon)
- County at Diagnosis-Analysis SAS Program – (Coming Soon)

Survival

Here are the 2018 CFD "Calculate Survival Time In Months" and "Create Cause Specific And Other Death Classification" SAS programs. The programs can be run together, one after another (order doesn't matter), or independently. If run together, they should use the same cutoff setting. *Note: links below take you to the most updated programs available for download on the SEER website.*

- Calculating Survival Time in Months SAS Program – (Coming Soon)
- Cause-Specific & Other Death Classification SAS Program – (Coming Soon)

11

NAACCR

Update new personnel or positions now

Once site is open, log-in well before the due date to ensure proper representatives have access

CFD Documents | Data Tools (NAACCRPrep and Edits) | Submit

SUBMIT CALL FOR DATA FILES & CARRI INFO FOR RESEARCHERS

The submission process has changed this year! Please read the following closely.

We have developed a single site where you can login using MyNAACCR username/password and submit your CFD file, complete your electronic submission forms, and post your signed Data Assurance Agreement and consent forms.

If you have completed the Call for Data electronic submission forms in the past, you already have the permissions to use the new site. If you have not completed them in the past or if you not sure if you have completed them in the past, please contact us at info@naaccr.org. You can verify if you have a MyNAACCR account here. If you do create a new account you will then need to contact us in order to submit for your registry.

The deadline for submission is 11:59 PM eastern time on Monday, December 3, 2018.

NAACCR

Step 1: Pull Initial File

Create one data file of all reportable incident cancer cases by December 3, 2019 for residents of your coverage area diagnosed from 1995 through 2017

- Cases diagnosed 2018 are encouraged
  - Can be submitted by January 31, 2020
  - Most years strongly
  - Delay adjusted model plus assessment
- Adhere to NAACCR standard definitions and codes
  - NAACCR Record Layout v18 (will be submitted in XML)

Resources:

- Documentation
  - General Instructions, Certification & CiNA Call for Data Items, Data Selection Criteria
  - V18: https://www.naaccr.org/data-standards-data-dictionary/
  - Translation tools (v15 to v16 to v18): https://www.cdc.gov/cancer/npcr/tools/registryplus/up_download.htm

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New Data Items for this year's Call

Certification and CiNA Call for Data
- Highlighted in peach, TNM variables removed

New 2018 variables (as available)

New variables to more closely align with NPCR

New variables to assess reporting patterns/timeliness (as available)

Geographic Variables
- Details under CFD Documents, Supplemental Information

SUPPLEMENTAL INFORMATION

Please note that NAACCR Prep may fail if it encounters certain non-printable/special characters in your data file. If that happens, please contact Recinda Sherman rsherman@naaccr.org. She will provide you with a SAS program that will replace non-printable/special characters with spaces.

- Area Based Social Measures – 09/03/19
- RUCA and URIC Data Item Description– 09/03/19
- Derived County v18 Instructions for Coding – 09/03/19

NAACCR

Step 2: Duplicate Assessment

Perform the Duplicate Assessment Protocol
- This protocol must be done if you want your data to be certified or included in any analysis requiring high quality data

If you are submitting for both CiNA and Registry Certification, you must conduct the duplicate protocol multiple times:
- First time on the 1995-2017 cases (CiNA)
- Second time on 2017 cases only (Certification)
- Third time on 2018 cases only (12 Month)
- Note, if you are not submitting ALL years, 1995-2017, for CINA, perform the protocol on all the years that you are submitting i.e. 1997-2017.

Resources:
- *Duplicate Protocol*
- Note: Some registries have larger sample sizes

NAACCR

Step 3: NHAPIIA

U. S. registries should run NHAPIIA prior to submission

Recommended: Run through NAACCRPrep

- Including Name fields in the file run through NAACCRPrep will generate these codes, saving a processing step, with name fields dropped in the output file(s)
- This means edits are run before NHAPIIA which trigger a handful of inter-record edit errors for some registries
  - NAACCRPrep now handles that (all records for a patient same Hispanic Origin)

Alternative: SAS Program available on Call For Data site (on or before Oct 15, 2019)

- Please use the default option 1 when calculating NHAPIIA
- 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)
- You will be asked which option was selected

NAACCR

Step 4: Edits

Run the edit set appropriate for your submission and the NAACCR format being submitted

- Separate edit sets for NPCR and NAACCR
- Anticipate combined edit set available again next year
- Available now under Data Tools

NAACCR

Step 5: Inter-Record Edits

Run the Inter-record EDITS Utility

- This application must be run after running the intra-record edits from Step 4 but before file is run through NAACCR*Prep
- Resolve all errors and report the number of errors that could not be resolved and remain on the submitted file
  - Upload on submission site or email to Recinda Sherman rsherman@naaccr.org

Hispanic Origin edits triggered by running NHAPIIA after edits has been resolved in NAACCRPrep

NAACCR

Step 6: NAACCRPrep

Run NAACCR*Prep Utility

- Calculates
  - Survival Length, Cause-Specific & Other Cause of Death Classification
    - Uses full diagnosis date and full date of last follow-up
    - Calculates a series of fields on survival status
  - NHAPIIA codes
  - Area based social measures (county & tract level)

Able to produce submission specific output files & compresses them

- NPCR, NAACCR, VPR-CLS

Deletes User Selected Data Items

- Name fields
- Census tract, other NPCR specific items
- Exact day of diagnosis/last follow-up
  - Special circumstances: county—if you need to omit county from your dataset, contact rsherman@naaccr.org

General Instructions for NAACCR Data File Submissions

Step 7: Create Your Submission Data File
- V18, XML
- Recommended: NAACCRPrep

Step 8: Compress Your Data File
- Recommended: NAACCRPrep

Step 9: Transmit Your Data File
- Submission page will be open November 1, 2019

20

Certification

CRITICAL

Review your dataset prior to submission on all criteria
- Completeness is an *estimate*
  - NAACCR Method to Estimate Completeness Workbook 1995-2016 – 09/03/19
- All other criteria are known at time of submission
- Cut points for certification are known

Certification and CiNA inclusion criteria *Data Quality Criteria*

Contact me regarding any issues *prior* to due date rsherman@naaccr.org

21

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NAACCRPrep

DON GREEN, IMS

NAACCR PREP

Changes for 2019

NAACCR PREP

Goal: Make Creation of Submission Files Easier

- Subsets data based on the year of diagnosis
- Blanks out fields that aren't being collected
- Calculates additional fields
  - Rural Urban Continuum Codes
  - RUCA and URIC Codes
  - Census Tract Poverty Indicator
  - NHIA/NAPIIA
  - Yost Quintiles *** NEW ***
  - ACS Race-based Poverty Percentages *** NEW ***
  - **And several others…**

NAACCR PREP

Files NAACCR*Prep Can Process

- Input:
  - NAACCR V18 Fixed-Width
  - NAACCR V18 XML
- Output:
  - NAACCR V18 XML

NAACCR PREP

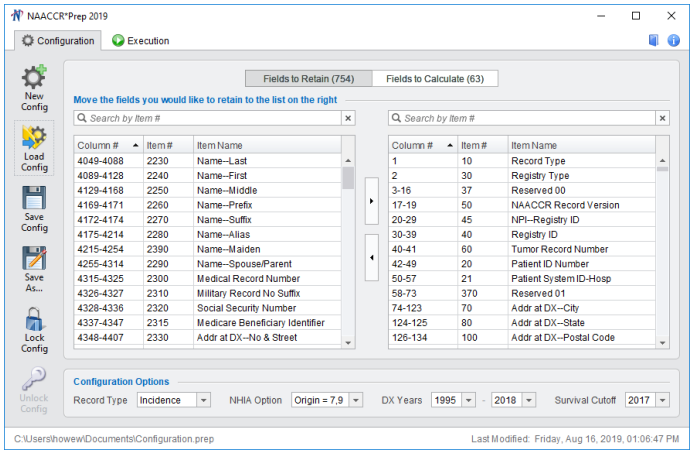
NEW for 2019

- The interface has been completely redesigned to be easier to use
- Settings are now stored in configuration files
  - NPCR and NAACCR will each have their own
- New Calculated Fields
  - Yost Quintiles
  - ACS Race-based Poverty Percentages

NAACCR PREP

The application now features a tabbed interface. Each tab is used to perform a specific task.

The **configuration** tab is used to create and edit configuration files.



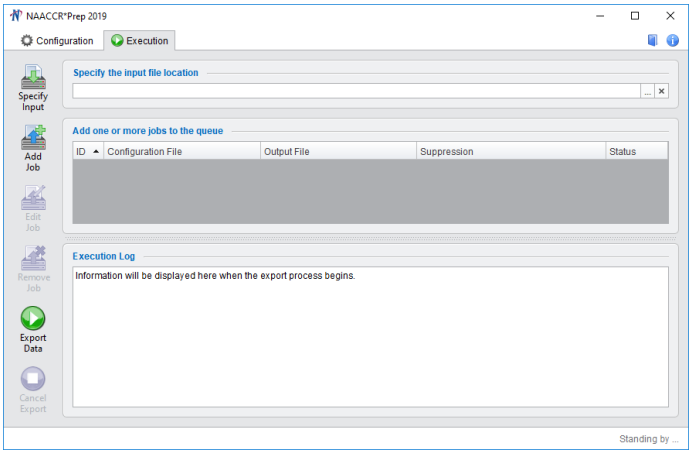
NAACCR PREP

Configuration Files

- Configuration files define
  - Which fields will ultimately end up being written to the output file
  - The record type of the file that will be created
  - The range of diagnosis years to include
- NPCR and NAACCR will create and distribute the configuration files
  - They will be downloadable from the NPCR and NAACCR websites
  - There will be configuration files for each type of submission (NAACCR CiNA & Certification, NAACCR Certification, VPR-CLS, NPCR, etc.)

NAACCR PREP

The **execution** tab is where the actual file processing will take place.



On this tab you'll:

- Provide the location of the input file you want to process
- Add jobs to a queue

Once all jobs have been added, you can execute those jobs and produce the output files.

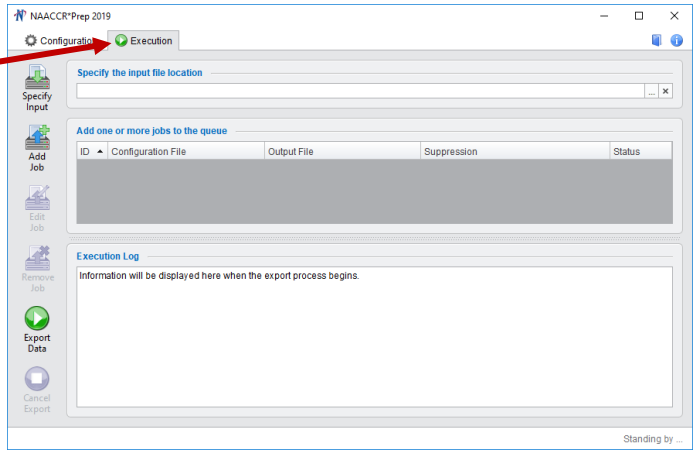
NAACCR PREP

Steps to Produce Submission Files

1. Go to the Execution tab
2. Provide the location of your input file
3. Place a job on the queue
   a. Provide the location of the configuration file
   b. Provide the name and location of your output file
   c. Set your suppression options
4. Repeat step 3 if you want to queue up another job
5. Press the Export Data button to start processing the queue

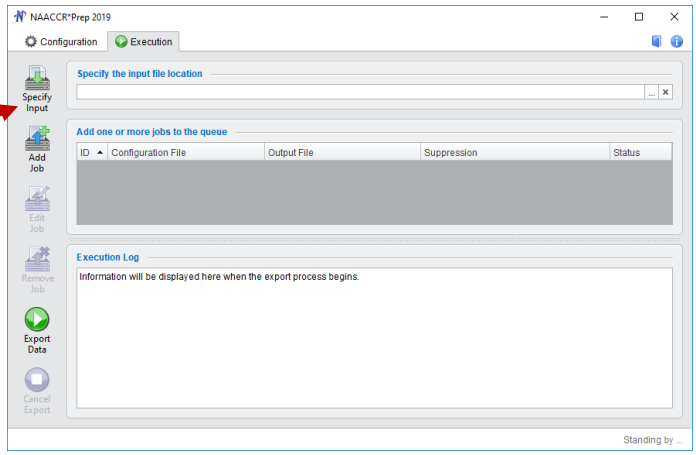
NAACCR PREP

1. Click on the Execution tab



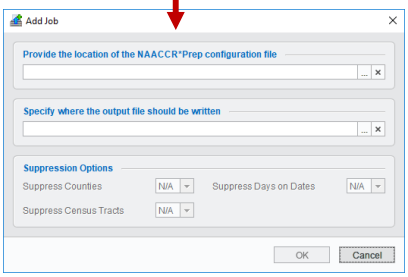
NAACCR PREP

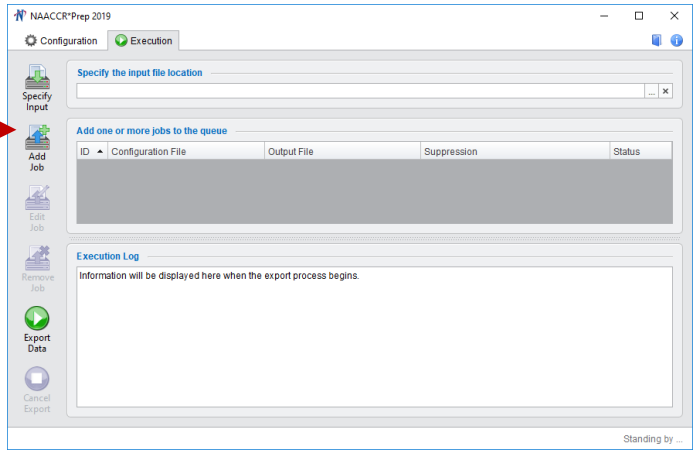
1. Click on the Execution tab
2. Provide the location of your input file.
   - Press the **Specify Input** button and browse to the location on your hard drive or network where the input file resides.
   - The input file should be a **Type-C** file (XML or fixed-width) with all of the fields populated for all of your cases, including fields like first/last/maiden name, Census tract, etc. This data is needed to produce calculated fields such as NHAPIIA, the Census tract poverty indicator, etc. The only fields that will ultimately be written to the output file will be the ones specifically requested by NAACCR and/or NPCR.



NAACCR PREP

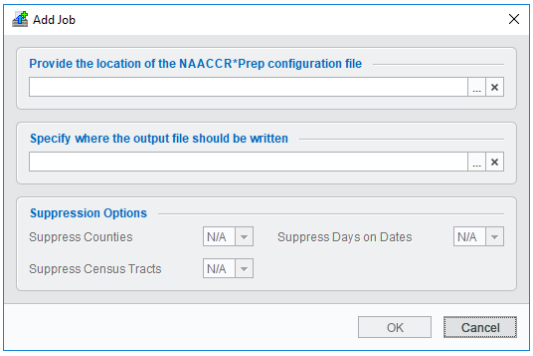
3. Place a job on the queue by pressing the **Add Job** button to display the Job dialog.





NAACCR PREP

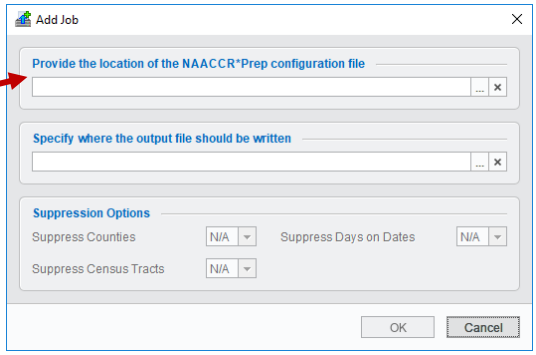
4. While viewing the Job dialog….



NAACCR PREP

4. While viewing the Job dialog….

   A. Provide the location of the NAACCR*Prep configuration file that will be used to generate the output file.



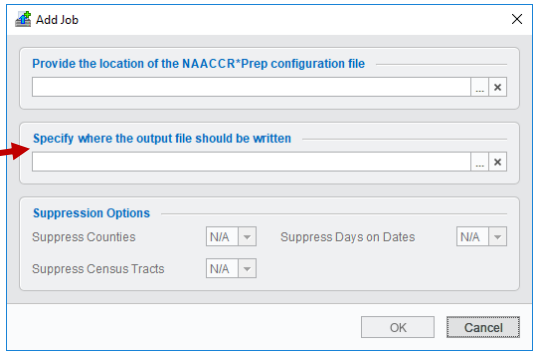
NAACCR PREP

4. While viewing the Job dialog….

   A. Provide the location of the NAACCR*Prep configuration file that will be used to generate the output file.

   B. Specify where your output file should be written.

   - NAACCR*Prep will output a **.zip** file that contains:
     - the data file (.gz)
     - a copy of the NAACCR*Prep configuration file that was selected in step 4A (.prep)
     - a copy of NAACCR*Prep's XML user-dictionary, which is required to convert between the XML and fixed-width formats should the need arise (.xml)
   - The complete zip file, **which includes all 3 files**, should be submitted to IMS (unless it is your VPR-CLS file, in which case it should remain behind your firewall and saved for later use throughout the year).



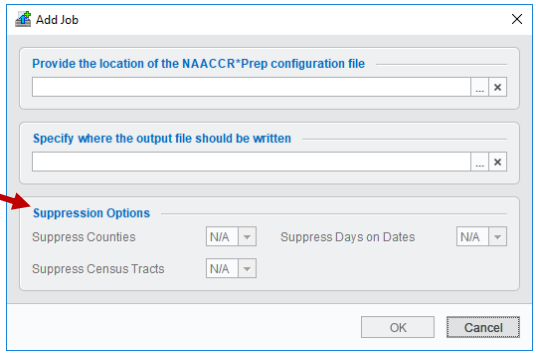
NAACCR PREP

4. While viewing the Job dialog…. (cont.)

   C. Set your suppression options.

   - You have the option to suppress certain fields even if NAACCR/NPCR have included them in the configuration file.
   - The options that will be available to you depend entirely upon the configuration file that you selected in step 4A.

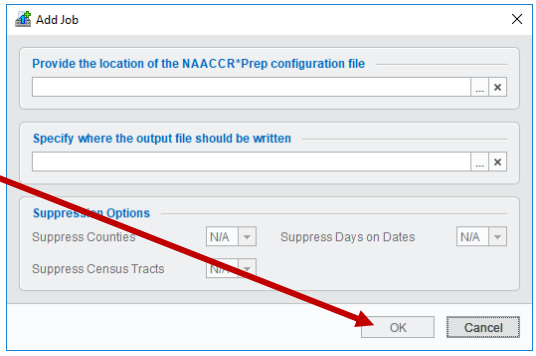
     For example, the option to suppress Census tract will only become enabled if the configuration file that you chose actually requested that Census tract be submitted, otherwise the option will remain disabled and set to N/A.
   - You may suppress the following:
     - Counties (Item Numbers 89, 90, 94, 95, 96, 97, 1840) Defaults to NO, when applicable.
     - Census Tracts (Item numbers: 110, 125, 130, 135) Defaults to YES, when applicable.
     - Days on Date Fields. Defaults to YES, when applicable.



NAACCR PREP

4. While viewing the Job dialog…. (cont.)

   D. Press the **OK** button when you are finished.

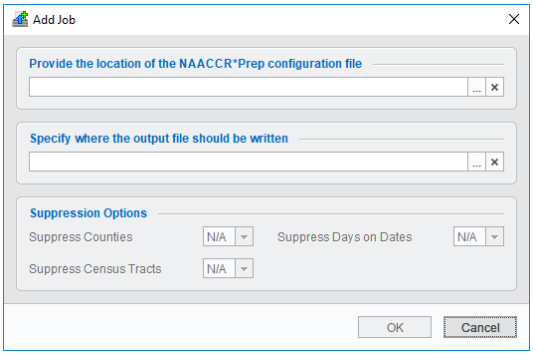


NAACCR PREP

4. While viewing the Job dialog…. (cont.)

   D. Press the **OK** button when you are finished.

5. The Job dialog will close…

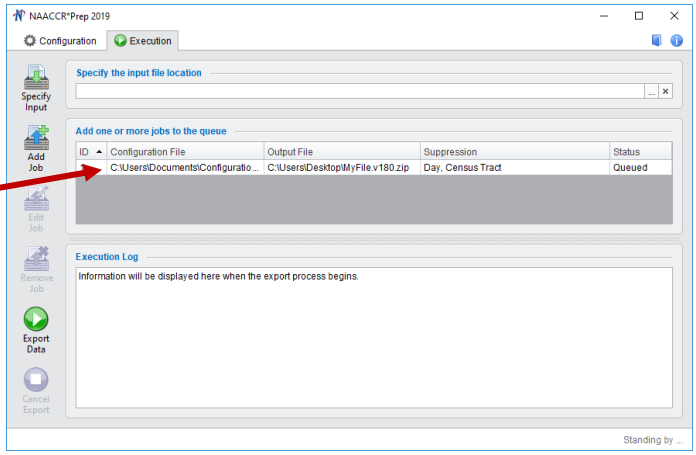


NAACCR PREP

4. While viewing the Job dialog…. (cont.)

   D. Press the **OK** button when you are finished.

5. The Job dialog will close and the job will be added to the queue.



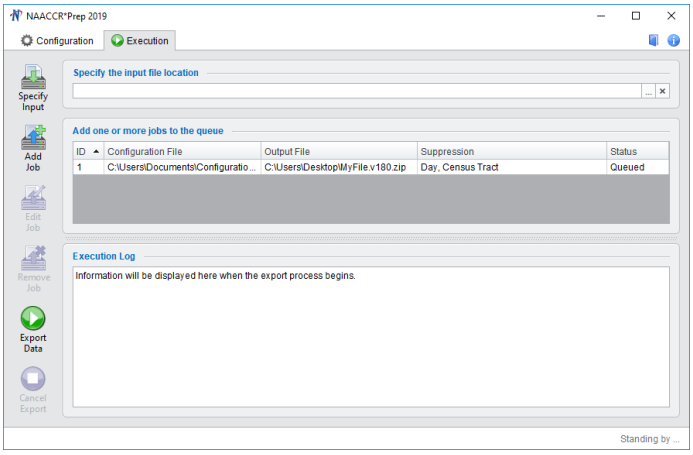
NAACCR PREP

4. While viewing the Job dialog…. (cont.)

   D. Press the **OK** button when you are finished.

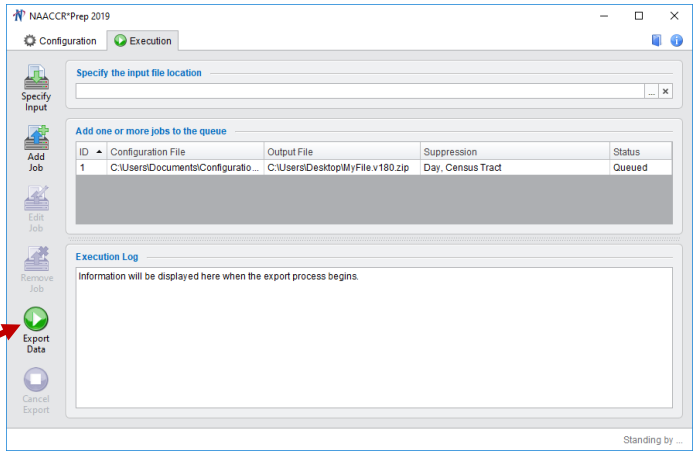
5. The Job dialog will close and the job will be added to the queue.

6. Repeat steps 3-5 for each configuration file that you have.



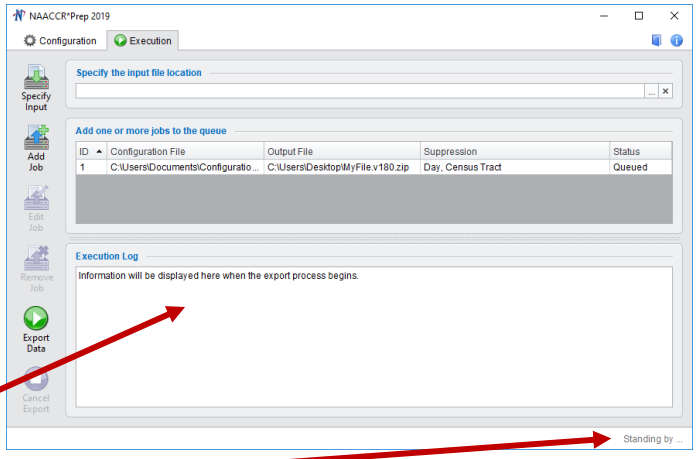
NAACCR PREP

4. While viewing the Job dialog…. (cont.)
   D. Press the **OK** button when you are finished.
5. The Job dialog will close and the job will be added to the queue.
6. Repeat steps 3-5 for each configuration file that you have.
7. Press the Export Data button to begin creating the output file(s).



NAACCR PREP

4. While viewing the Job dialog…. (cont.)
   D. Press the **OK** button when you are finished.
5. The Job dialog will close and the job will be added to the queue.
6. Repeat steps 3-5 for each configuration file that you have.
7. Press the Export Data button to begin creating the output file(s).
8. Progress will be displayed in the log and in the bottom/right-hand corner of the screen as each output file is created.



NAACCR PREP

Converting NAACCR V18 XML to V18 Flat Text

1. Not Required for NAACCR
2. Use the NAACCR XML Utility Tool
3. Software Available for Free:
   - Main Software Tools and Libraries Page:
     - https://www.naaccr.org/xml-data-exchange-standard/#Software
   - Direct Link to NAACCR XML Utility Tool:
     - https://github.com/imsweb/naaccr-xml/wiki/1:-NAACCR-XML-Utility-Tool
4. Instructions on How to Use the Tool:
   - https://www.naaccr.org/call-for-data/

44

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Edits Update

JIM HOFFERKAMP, NAACCR

45

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v18C/ v18D/ Call for Data Edits metafile

NAACCR v18C Edits Metafile

- Facilities reporting cases to central registries should be running an edits metafile based on v18C.
- Central registries should be running edits based on v18C on their consolidated records.

NAACCR v18D Edits Metafile

- Recently released (September 4 target date)
- Should replace v18C

Call for Data Edits Metafile

46

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v18C vs v18D

Question: Should central registries update to v18D before creating a submission file?

Answer: That is a registry specific decision.

- If the cases pulled for submission have passed the v18C metafile, they will pass the Call for Data Edits submission edits.
- If the cases pulled for submission have passed the v18D metafile, they will pass the Call for Data Edits submission.

Updating to v18D should have a minimal impact on 1995-2017 cases.

47

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NAACCR Call for Data Edits Metafile

The NAACCR Call for Data Edits Metafile is posted at

https://www.naaccr.org/call-for-data/#datatools

Please check this site periodically for updates to the metafile!

- If an updated metafile is posted, we will also include a spreadsheet detailing changes.

Send any edit issues to Jim Hofferkamp at jhofferkamp@naaccr.org

Changes to Combined NAACCR_NPCR 2018_Call_For_Data Metafile 20181018 since 20181009		
TABLES		
	IF25_3	added C739, 8343/2
EDIT SETS		
	Removed from Combined NAACCR-NPCR Edits 1995-2016	20181112-Census Tr Poverty Indictr (SEER) 20181112-Census Tr Poverty Indictr, Date of DX (NPCR) 20181112-Rural Urban Continuum 1993 (NAACCR) 20181112-Rural Urban Continuum 2003 (NAACCR) 20181112-Rural Urban Continuum 2013 (NAACCR)
	Removed from NAACCR CINA Edits-Canada	20181112-Date of Diagnosis Flag (NAACCR) 20181112-Date of Diagnosis, Date Flag (NAACCR) 20181112-Date of Last Contact (NAACCR DATEEDIT) 20181112-Date of Last Contact Flag (NAACCR) 20181027-Date of Last Contact, Date Flag (NAACCR) 20181112-Date of Last Contact, Date of Diag. (NAACCR IF19) 20181027-Follow Up Source Central, Date of DX (NPCR) 20181027-ICD Revision Number, Cause of Death (SEER IF37) Summ Stg 2000, Site, Hist ICDO3, Rpt Srce (NAACCR) Summary Stage 1977 (NAACCR) Summary Stage 1977, Summary Stage 2000 (NAACCR) Summary Stage 1977, Type of Report Source (NAACCR) Summary Stage 2000 (NAACCR) Summary Stage 2000, Over-ride CS 20 (NPCR) Summary Stage 2000, TNM M 2016 (NAACCR) 20181112-Surgery, Rad, Surg/Rad Seq (COC) 20181017-Vital Status, Cause of Death (Subm)
EDITS		
1840	Addr at DX--Postal Code (Subm)	Logic corrected to allow for trailing blanks
2106	CS Items - NPCR Required - SSF 8 (Subm) - 2016+	Schema name "Prostate" removed from edit logic requiring CS Version Input Current

48

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Software

NAACCR Call for Data Metafile was developed using EditWriter 5

- .smf format

EditWriter 5 and GenEDITS 5 are available at

- https://www.cdc.gov/cancer/npcr/tools/edits/edits50.htm

Training video on EditWriter 5 is available at

- https://www.naaccr.org/standard-data-edits/

49

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Layout required for edits

The call for data edits metafile require a v18 .txt, .txd, or .dat file

- Edits will not work with a file in the v16 layout
- Edits will not work with an .xml file

The NorthCon18 Record Converter may be used to convert a file in the v16 layout to a file in the v18 layout.

https://www.cdc.gov/cancer/npcr/tools/registryplus/up_download.htm

50

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Edit Sets

Type of Submission/Type Registry	Edit Set
Certification only (2017 cases)	NAACCR Certification Edits
Certification & CiNA/U.S	NAACCR CiNA Edits 1995-2017
NAACCR 12 Month Data 2018	NAACCR CiNA Edits 2018
Certification & CiNA/Canadian	NAACCR CiNA Edits-Canada

51

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Options for creating a submission file

Create a submission files for NAACCR

- Run the NAACCR CINA Edits 1995-2017 on your NAACCR Submission file
- Run 2018 edit sets (if applicable)

Run the Inter-Record edits

52

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Submission File

Once the file is edit free, run the file through NAACCRPrep and create an .xml NAACCR submission file.

- The .xml submission file may be sent directly to NAACCR without running any additional edits.

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Documentation & Data Use

CINA: CONSENTS, RESEARCH & DATA USE, & MORE!

54

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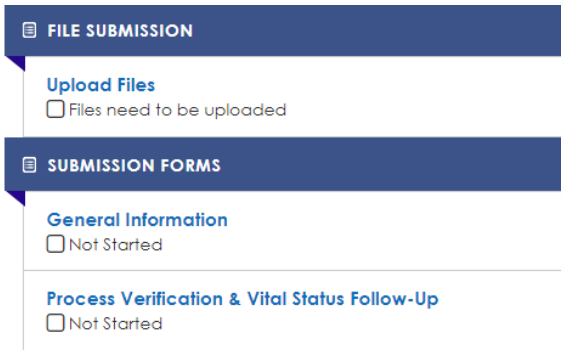
Step 10

Electronic submission forms

Opens November 1, 2019

Login early to ensure no access issues

Same system as last year



Step 11: DAA

DUA & CONSENT

Sign DUA and Consent forms

Documents need to be signed

Review and sign the NAACCR Call for Data Assurance Agreement

- Language has been updated for clarity
- Recommended: e-sign
- Alternative: download, sign, upload to site

Electronic signing through the website is preferred, but if you need or would like to sign a hardcopy and return a scanned copy you may do so by:

1. Clicking on the appropriate Sign button above
2. On the DocuSign page select **Other Actions | Print & Sign**
3. Choose the **Upload** option and click the **Continue** button
4. Click the **Download** button
5. Once signed, click the **Return Document** button and upload your scanned signed document

56

Confidential Data Assurances

NAACCR assures confidential handling of data

- Procedures, policy & IT, CoC

NAACCR will not release identifiable data

- Cell suppression for cells under 6 part of DAA & DUA (researchers)
  - Exceptions require Active Consent; MTC
- Certificate of Confidentiality

Will not release use data for purposes other than in Attachment A without express consent from registries

- CiNA Deluxe Datasets access requires RApR approval, individual registry consent, & written DCA (Attachment B)
- IRB approval no longer required (updated Common Rule) but still oversight
- CiNA Public Use Datasets access (limited file) requires written agreement

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Confidential Data Assurances

NAACCR will notify registries in the unlikely event of unauthorized access or subpoena received

Data remains property of submitting registry
- Consent can be rescinded
- Access to researchers: until research is closed (or out of compliance)
  - Public Use 1 year (automatic)
- CiNA datasets deleted after 5 years after all research is closed
  - Note: Historic data will be maintained to support the on-going production of reporting delay-factors

NAACCR requests pre-submission copy of articles and reports
- Reviewed for scientific approach and to ensure compliance with confidentiality agreement

58

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Certificate of confidentiality

CiNA data covered by a CoC from NIH
- protects the privacy of research participants enrolled in research
- prohibits disclosure in response to legal demands, such as a subpoena

Effective October 1, 2017, NIH no longer provides documentation but NIH funded research activities are automatically issues a certificate under the NIH Policy on Certificates of Confidentiality

NAACCR's coverage has been confirmed with a Human Subjects Protections Consultant from the NIH Office of Extramural Research

59

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Attachment A: Primary Uses

CiNA Monographs
- New Vol 5: Prevalence

On-line query systems
- Cancer Maps, FastStats

Annual Report to the Nation

Data requests

Data evaluation, delay adjustment

State-level data for comprehensive cancer control
- Rankings on health indicators

Create CiNA datasets
- Research datasets, Public Use

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Attachment A cont…

Section 2- Certification

Section 3- Physical & Electronic Security

Section 4- Secondary Uses Datasets
- Assurances of Proper Use

Section 5- Consent
- Active vs Passive, Rescinding Consent

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CiNA CONSENTS

	Passive Consent Process	Active Consent Process
Variable list	Standard File Standard +area-based socioeconomic variables--county or tract-based poverty or urban/rural data without County (requires specific researcher justification)	Customized Request (e.g., Single Year of Age, County Identifier, county or tract-based socioeconomic variables, such as poverty or urban/rural status, released along with a County)
Geographic Presentation	United States, Canada, North America, regional analysis	County presented individually in publication
Linked Special Geographic Variables	County-level collapsed data, i.e., Appalachian Region Y/N, CHSDA region Y/N), coded economic or other SES data at does not uniquely identify a county; data appended at the state-level is allowed	Any data linking to continuous variables or coded data that could uniquely identify county or below county, such as census tract; even if the analysis does not publish at county or tract-level

*"The biggest risk in **this** study is just reading the consent form!"*

62

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CiNA Datasets

Standard CiNA Deluxe Datasets
- 19 age-groups, no county identifiers
- may include special variables such as "reside in Appalachian County (Y/N)" or recodes for breast cancer subtypes (Passive Consent)

Custom CiNA Deluxe Datasets
- may contain single years of age, county identifiers
- may contain special variables that could identify a county or lower level of geography (Active Consent)

Special CiNA Datasets
- CiNA Survival, CiNA Imputed Breast Cancer Subtypes, CiNA Geographic (under development)
- Datasets developed by NAACCR Workgroups/Taskforces & evaluated for Fitness for Use prior to making available to outside researchers

Public Use Datasets
- Easy access, limited variables, non-confidential, suppression automatic
- Requires a signed DAA, no RApR review/approval

https://www.naaccr.org/cina-public-use-data-set/

63

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SECONDARY USES (ACTIVE consent)

CiNA Public Use
- https://www.naaccr.org/cina-public-use-data-set/
- CiNA Public Use Dataset 1—Active Consent (export allowed)
- CiNA Public Use Dataset 2—Active Consent (export not allowed)

ACS Facts & Figures – Active Consent, US only

Medullary Thyroid– Active Consent, US only

NAACCR Synthetic Dataset – Active Consent
- Larger, release for approved NAACCR projects

64

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SECONDARY USES (PASSIVE consent)

CiNA Plus in SEER*Stat—Passive Consent
- CiNA+ 2012-2016; matches CiNA monographs

American Lung Association—Passive Consent, US only

Delay Adjustment –Passive Consent

Affordable Care Act & Cancer Stage at DX, US only

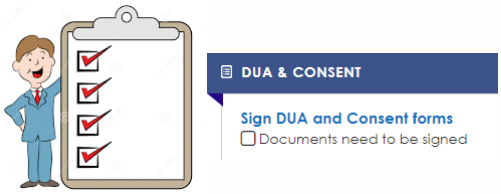
Step 12: List of materials needing signature

Checklist of materials requiring signatures

Data Assurances Agreement
- Authorized signature on page 2

9 Consent documents
- 5 for US and Canada
- 4 US Only

Sign and submit via CFD site



Electronic signing through the website is preferred, but if you need or would like to sign a hardcopy and return a scanned copy you may do so by:

1. Clicking on the appropriate Sign button above
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3. Choose the **Upload** option and click the **Continue** button
4. Click the **Download** button
5. Once signed, click the **Return Document** button and upload your scanned signed document

NAACCR Call for Data and Survival

With the aim of obtaining the most precise estimates of survival, it is necessary to use complete dates (month, day, and year components) in the calculation of the survival interval

The cancer registry community has collaborated on a survival algorithm that uses day information in the survival calculations

SEER*Stat now calculates survival using monthly intervals based on complete dates (SAS program also available)
- 7 survival time variables; 2 COD recodes (new)
- Vital Status Follow-Up Activities Form
- CiNA Survival a Primary Data Use (no consent required)
- Additional information about the algorithm and what specific values are assigned in given missing date situations is available here: http://seer.cancer.gov/survivaltime/

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What You Need to Do:

If you can, please link with NDI prior to data submission (US Only)

NDI National Death Index

Then Either

1. Provide full date of diagnosis and date of last contact to NAACCR

   Or

2. If you can't provide full dates to NAACCR, then calculate the 7 survival time variables and then strip the date components you can't send:
   1. Presumably, strip Day component only
   2. **Do not strip the year components of dates**

Recommended: Use NAACCRPrep—days on dates will automatically be suppressed

Alternative: SAS files

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7 Survival Time Variables & 2 COD Recodes

Item 1782 - SURV- DATE ACTIVE FOLLOWUP

Item 1783 - SURV- FLAG ACTIVE FOLLOWUP

Item 1784 - SURV- MOS ACTIVE FOLLOWUP

Item 1785 - SURV- DATE PRESUMED ALIVE

Item 1786 - SURV- FLAG PRESUMED ALIVE

Item 1787 - SURV-MOS PRESUMED ALIVE

Item 1788 - SURV- DATE DX RECODE

Item 1914 - SEER Cause-Specific Death Classification

Item 1915 - SEER Other Cause of Death Classification

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Interested in Calculating Survival?

Registries interested in creating their own databases for survival analysis in SEER*Stat should contact Steve Scoppa (ScoppaS@imsweb.com) for information on sorting their file before using SEER*Prep

Registries interested in performing survival analysis may wish to request access to the CiNA Deluxe survival dataset

- This will ensure that your methods and results will match those used in CiNASurvival and you will have access to national and NAACCR results for comparison
- Contact rsherman@naaccr.org

70

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ABSM—tract level Standard codes

US only, Area Based Social Measures (ABSM)

Create using NAACCRPrep (or SAS Code)

- Poverty Code Item #145, required
- RUCA & URIC Item #339, 341, 345, 346 (time dependent)
- Yost SES Index (not in Vol II) but standard variable
- Poverty Quintiles by race (avoid residual confounding)

Available in CiNA

- Poverty code, URIC, RUCA codes
- Tract-level codes NOT standardly available with county

Evaluation Stage

- Yost SES Index
- Poverty Quintiles by race

Resources: Supplemental Information

71

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Geocoding Reminders

Heavy Use = Slower Processing
- Recommend monthly or semi-annual vs annual

Multiple Runs
- Hitting cancel but in quick succession = multiple SQL runs which causes issues during writing
- Causes run to cancel or doesn't write appended information to the case
- Impacts all users using system at the time

New Features
- Review Geocoding Webinar from August 2019: https://education.naaccr.org/freewebinars

Recommended:
- Append 2010 Census data to all cases (minimum)
- Follow requirements for Poverty code (*Certification and CiNA Call for Data Items*)
- Append all Census data to all cases
  - 1990, 2000, 2010 can be appended at once

72

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Geocoding Reminder Recommendations

Recommendation 1
- Run several smaller files simultaneously
  - Will process faster than 1 large file

Recommendation 2
- CSV (Access Files more resource intensive and 2times processing time)

Recommendation 3
- Review output
- If missing variables, there was an overwrite issue
- Re-run all cases with the issue but NOT the whole file

Contact Recinda Sherman rsherman@naaccr.org with problems

73

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SAS Codes

Migrating away from providing SAS codes
- Maintaining separate, multiple codes inefficient and prone to error

Survival, NHAPIIA, and ABSM can be calculated in NAACCRPrep

--OR--

New product for researchers and registry use: FilePro
- Windows program
- Available Oct 15th, 2019 (anticipated)
- Java based, working on potential for exporting code to be modified for SAS users

74

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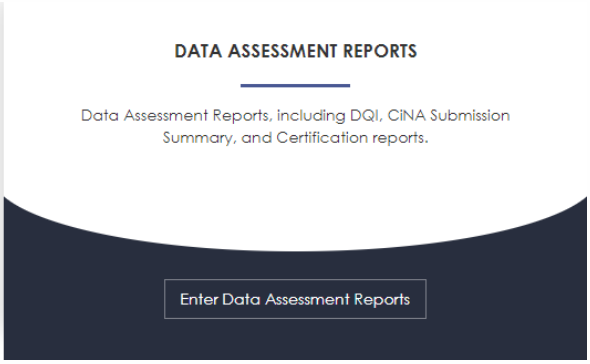
SUBMISSION SITE

https://www.naaccr.org/call-for-data/

Open Nov 1, 2019
- All materials, all submissions, CaRRI
- Electronic signatures DAA, Consents

AND….

Data Assessment Reports available now:
2016-2018 CFD Submission Years
DQI, CiNA Submission Summary, Certification
Misc – as needed
Consents to come (track projects by consent status)



Login issues? Contact rsherman@naaccr.org

75

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VPR Linkage File & CaRRI Database

CASTINE CLERKIN, NAACCR

Step 13: The CaRRI Database

- Cancer Registry Research Information (CaRRI) database
- Captures information on the following:
  - *Contact information (Registry, IRB, and VPR)*
  - *Data years available and registry participation in types of studies*
  - *IRB and registry application and review process (with URLs)*
  - *Requirements for data destruction, publication review, DUA, and progress reports*
  - *Requirements for physician and patient consent*
  - *Registry and IRB fees*
- Publically available resource for individuals interested in using registry data

76 NAACCR

Entering information in the CaRRI database

- Who should submit?
  - *All registries including Canadian provinces*
- When to enter responses?
  - *Annually, after other Call for Data requirements completed*
  - *As needed when things change throughout the year*

77 NAACCR

Entering information in the CaRRI database

- Amount of time to complete?
  - *Intensive the first year since all new, can be entered incrementally*
  - *Minimal time for annual review and update*
- How to enter data?
  - *Accessible from the NAACCR Call for Data submission site*
  - *Active users with role of 'Registry Administrator'*
  - *MyNAACCR login credentials*

78 NAACCR

NAACCR North American Association of Central Cancer Registries

Log

Home | Call for Data | CaRRI Database | CaRRI Database Search | Administration

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES DASHBOARD

Home

2017 CALL FOR DATA - CLOSED

The 2017 Call for Data is currently closed. Check back in the fall for the next year's Call for Data

You can view the previous year's Call for Data by following the link below.

Review the 2017 Call for Data

CANCER REGISTRY RESEARCHER INFORMATION DATABASE

The Cancer Registry Researcher Information Database (CaRRI Database) is designed to capture helpful information for researchers interested in using cancer registry data. The system is populated by cancer registry staff and reviewed annually at a minimum. The data is made publicly available in a searchable format.

Review the Registry Research Information Database

NORTH AMERICAN ASSOCIATION OF CENTRAL CANCER REGISTRIES - CARRI DATABASE

CaRRI Database Forms

CARRI DATABASE FORMS

General Information
Not yet updated.

RB and Registry Request Information
Not yet updated.

Data Request Process and Reporting Requirements
Not yet updated.

Consent Requirements
Not yet updated.

Fees for Requests
Not yet updated.

View Form Summary Report

Each registry is asked to enter or review their information during the annual NAACCR Call for Data, at a minimum. After you have fully reviewed all information, please let NAACCR know by **'Marking it as reviewed' with the button below**. If information changes during the year, you may update the system at any time to maintain accuracy.

For questions about the CaRRI Database, contact Recinda Sherman via email at rsherman@naaccr.org or by phone, (217) 698-0800 x6

Comments/notes

Optional notes about changes. NAACCR will be notified upon submission.

Mark as reviewed

Entering information in the CaRRI database

- Questions or feedback on the CaRRI database
  - *Send to Recinda Sherman (rsherman@naaccr.org)*
  - *NAACCR encourages feedback on the data collection process, questions, and standard responses*

81 NAACCR

Step 14: Create the VPR-CLS linkage file

- File to be used for all linkages facilitate by the Virtual Pooled Registry Cancer Linkage System (VPR-CLS)
- For US registries only
- Voluntary, but full participation requested
  - *File will be used for Camp Lejeune linkage in 2020*
- Created after all other Call for Data requirements completed and 12-month file has been submitted
- File remains at the cancer registry

82 NAACCR

VPR-CLS Goals

- Streamline linkages between research studies and multiple cancer registries
- Linkages occur behind each individual registry's firewall
- Single file created once a year to enable:
  - *Standardized, efficient cohort linkages using Match*Pro*
  - *Selection of researcher-requested data items after IRB and registry approval*
  - *Inter-registry deduplication testing*

83 NAACCR

Data Tools

- NAACCR Prep: Runs NHAPIIA algorithm without deleting first/last/middle name and calculates other variables
  - *NAACCR Prep configuration file for VPR-CLS*
- No longer using Link*Prep to standardize data items
  - *Next version of Match*Pro linkage software will include this functionality*

84 NAACCR

Instructions

- Timeframe for File Creation:
  - *By January 31, 2020*
  - *After 12-month data submitted to NAACCR, NPCR, and SEER*
- Case Selection Criteria:
  - *Reportable cases submitted to NAACCR*
  - *Cases from registry **inception year** to 2018, at a minimum*
  - *Include DCOs and cases from VA and inter-registry*
- Ability to identify and describe non-releasable cases

85 NAACCR

Basic Steps for VPR-CLS file creation

- Extract a **fully populated** Type C file (Version 18)
  - *From **registry inception year**, or older, to 2018*
  - *All data items, including patient identifiers*
- Run the file through NAACCR Prep
- Keep a copy of the file for future VPR-CLS linkages

86 NAACCR

Additional information

- Detailed instructions for creating the VPR-CLS linkage file posted on NAACCR Call for Data website
- Specific questions: Castine Clerkin (cclerkin@naaccr.org)

87

QUESTIONS

PLEASE SUBMIT ALL QUESTIONS THROUGH THE Q&A PANEL

88

THANK YOU!

89